

# Understanding cauda equina syndrome (UCES)

|                                        |                                                      |                                                                                                   |
|----------------------------------------|------------------------------------------------------|---------------------------------------------------------------------------------------------------|
| <b>Submission date</b><br>25/06/2018   | <b>Recruitment status</b><br>No longer recruiting    | <input type="checkbox"/> Prospectively registered<br><input checked="" type="checkbox"/> Protocol |
| <b>Registration date</b><br>31/07/2018 | <b>Overall study status</b><br>Completed             | <input type="checkbox"/> Statistical analysis plan<br><input checked="" type="checkbox"/> Results |
| <b>Last Edited</b><br>02/12/2022       | <b>Condition category</b><br>Nervous System Diseases | <input type="checkbox"/> Individual participant data                                              |

## Plain English summary of protocol

### Background and study aims

Cauda equina syndrome is a potentially devastating condition caused by compression of the cauda equina nerve roots in the spine. This can result in bowel, bladder and sexual problems and lower limb weakness, numbness, and pain. Cauda equina syndrome occurs infrequently but has serious potential medical, social, and legal consequences. This study aims to identify and describe the presentation, management, and outcomes of patients with cauda equina syndrome in the United Kingdom.

### Who can participate?

Patients over 18 years old with cauda equina syndrome

### What does the study involve?

Patients with cauda equina syndrome are identified on admission to spinal units across the UK and asked to participate. Presenting symptoms, investigation and management are recorded and participants are asked to complete questionnaires on admission, at discharge, and at six months and one year after treatment. This provides an accurate description of the number of patients, the types of symptoms, current clinical practice, adherence to national published standards of care, and patient outcomes.

### What are the possible benefits and risks of participating?

Accurate, up to date information about the presentation, management, and outcome of patients with cauda equina syndrome will inform standards of service design and delivery for this important but infrequent condition and help to identify future research priorities. There are no direct benefits to taking part in this study but the results from this study might help to improve the healthcare of patients in the future. This study will take up to 40 minutes of the participant's time over the course of the year following the initial hospital admission.

### Where is the study run from?

1. NHS Lothian
2. NHS Grampian
3. NHS Greater Glasgow & Clyde
4. NHS Tayside
5. Belfast Health and Social Care Trust
6. The Walton Centre NHS Foundation Trust

7. The Newcastle Upon Tyne Hospitals NHS Foundation Trust
8. South Tees Hospitals NHS Foundation Trust
9. Lancashire Teaching Hospitals NHS Foundation Trust
10. City Hospitals Sunderland NHS Foundation Trust
11. Salford Royal NHS Foundation Trust
12. Hull and East Yorkshire Hospitals NHS Trust
13. Leeds Teaching Hospitals NHS Trust
14. Sheffield Teaching Hospitals NHS Foundation Trust
15. Nottingham University Hospitals NHS Trust
16. Derby Hospitals NHS Foundation Trust
17. University Hospital Birmingham NHS Foundation Trust
18. University Hospitals Coventry and Warwickshire NHS Trust
19. University Hospital Southampton NHS Foundation Trust
20. Cambridge University Hospitals NHS Foundation Trust
21. Norfolk and Norwich University Hospitals NHS Foundation Trust
22. East Kent Hospitals University NHS Foundation Trust
23. Oxford University Hospitals NHS Trust
24. North Bristol NHS Trust
25. Plymouth Hospitals NHS Trust
26. Royal Devon and Exeter NHS Foundation Trust
27. Taunton and Somerset NHS Foundation Trust
28. Buckinghamshire Healthcare NHS Trust
29. Milton Keynes Hospital NHS Trust
30. Barts Health NHS Trust
31. Barking Havering and Redbridge University Hospitals NHS Trust
32. King's College Hospital NHS Foundation Trust
33. Brighton and Sussex University Hospitals NHS Trust
34. St George's Healthcare NHS Foundation Trust
35. University College London Hospitals NHS Foundation Trust
36. Imperial College Healthcare NHS Trust

When is the study starting and how long is it expected to run for?  
January 2017 to November 2020

Who is funding the study?  
British Neurosurgical Trainee Research Collaborative

Who is the main contact?  
1. Ms Julie Woodfield  
2. Dr Ingrid Hoeritzauer  
3. Mr Aimun Jamjoom  
4. Mr Patrick Statham

## Contact information

**Type(s)**  
Public

**Contact name**  
Ms Julie Woodfield

**Contact details**

Department of Clinical Neurosciences  
Western General Hospital  
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EH4 2XU

**Type(s)**

Public

**Contact name**

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**Type(s)**

Public

**Contact name**

Mr Aimun Jamjoom

**Contact details**

Neurosurgery Department  
Aberdeen Royal Infirmary  
Aberdeen  
United Kingdom  
AB25 2ZN

**Type(s)**

Scientific

**Contact name**

Mr Patrick Statham

**Contact details**

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Western General Hospital  
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EH4 2XU

**Additional identifiers****Protocol serial number**

v3

# Study information

## Scientific Title

Understanding cauda equina syndrome (UCES)

## Acronym

UCES

## Study objectives

This study aims to identify and describe the presentation and management of patients with cauda equina syndrome in the United Kingdom using trainee research collaborative networks.

## Ethics approval required

Old ethics approval format

## Ethics approval(s)

South East Scotland Research Ethics Committee 02, 01/06/2018, IRAS Project ID: 233515, REC ref: 18/SS/0047

## Primary study design

Observational

## Study design

Prospective cohort study

## Study type(s)

Diagnostic

## Health condition(s) or problem(s) studied

Cauda equina syndrome

## Interventions

Patients with cauda equina syndrome will be identified on admission to spinal units across the UK and asked to participate. Data relating to presentation, hospital admission, investigations, and follow up will be collected by the local trainee investigator who is a member of the clinical team caring for the patient. Study participants who have consented to participate will also be asked to fill out details about their patient journey to the spinal unit, their symptoms, patient reported outcome measures, and service usage. These will be collected electronically anonymously via the electronic database and linked to the patient record. Patient reported outcome measures will include visual analogue scores for back and leg pain, the Oswestry Disability Index, the neurogenic bowel dysfunction score, the short form incontinence questionnaire, and the Arizona sexual experiences scale. Participants will be asked to complete questionnaires on admission, at discharge, and at six months and one year after treatment. This will provide an accurate description of the number of patients, the types of symptoms, current clinical practice, adherence to national published standards of care, and patient outcomes.

## Intervention Type

Other

## Primary outcome(s)

The incidence of CES as measured by the number of cases of CES in the UK in all collaborating centres

### **Key secondary outcome(s)**

1. The presenting symptoms and signs in patients with CES:
    - 1.1. Back pain and leg pain measured using visual analogue scores on admission
    - 1.2. Low back pain disability measured using Oswestry Disability Index on admission
    - 1.3. Urinary bladder function measured using neurogenic bowel dysfunction score on admission
    - 1.4. Urinary incontinence measured using short form incontinence questionnaire on admission
    - 1.5. Sexual function measured using Arizona sexual experiences scale on admission
  2. The pathways of presentation to specialist spinal services for patients with CES in the UK and Ireland; the type and timing of healthcare professionals seen prior to admission with the symptoms causing admission will be assessed by patient questionnaire on admission
  3. The type and timing of imaging and other investigation of patients with CES, collected on admission
  4. The medical and surgical management of CES, including medications, type and timing of the operation, collected from routine neurosurgical notes
  5. The type and timing of investigations and surgery will be compared to the British Association of Spine Surgeons (BASS) standards of care for suspected and confirmed compressive CES issued in 2015 and the Society of British Neurological Surgeons Care Quality Statement issued in October 2015
  6. Clinical outcomes for patients with CES assessed using validated patient reported outcome measures, stratified by presentation, investigations, and management:
    - 6.1. Back pain and leg pain measured using visual analogue scores at discharge, 6 months and 1 year
    - 6.2. Low back pain disability measured using Oswestry Disability Index 6 months and 1 year
    - 6.3. Urinary bladder function measured using neurogenic bowel dysfunction score at discharge, 6 months and 1 year
    - 6.4. Urinary incontinence measured using short form incontinence questionnaire at discharge, 6 months and 1 year
    - 6.5. Sexual function measured using Arizona sexual experiences scale at discharge, 6 months and 1 year
- This data and the type and timing of clinical presentation, investigation, investigation results will be analysed and stratified within one year of study completion.
7. The ability of neurosurgical and orthopaedic surgical trainee networks to collaborate successfully on a prospective cohort study, assessed at the end of the study

### **Completion date**

30/11/2020

## **Eligibility**

### **Key inclusion criteria**

1. Over 18 years old
2. Admitted to a specialist spinal service in the UK between 1st June 2018 and 31st May 2019
3. Capacity to provide informed consent for participation in this study
4. Diagnosis of clinical CES and structural compression of the cauda equina on imaging as determined by the treating clinician. 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, etc

**Participant type(s)**

Patient

**Healthy volunteers allowed**

No

**Age group**

Adult

**Lower age limit**

18 Years

**Sex**

All

**Total final enrolment**

659

**Key exclusion criteria**

1. Patients under 18 years old
2. Patients undergoing emergent decompression for unilateral motor or sensory symptoms (eg foot drop), without clinical evidence of CES
3. Patients referred with suspected CES where the diagnosis is not confirmed, for example patients with the clinical symptoms and signs of CES without radiological evidence of cauda equina compression
4. Patients not admitted to participating spinal centres in the UK
5. Patients admitted to a participating spinal centre before 1st June 2018 or after 31st May 2019
6. Patients who are unable to provide informed consent for participation in this study

**Date of first enrolment**

01/06/2018

**Date of final enrolment**

30/11/2019

**Locations****Countries of recruitment**

United Kingdom

England

Northern Ireland

Scotland

**Study participating centre**

**NHS Lothian**

Western General Hospital  
Edinburgh  
United Kingdom  
EH4 2XU

**Study participating centre****NHS Grampian**

Aberdeen Royal Infirmary  
Department of Neurosurgery  
Forrester Hill  
Aberdeen  
United Kingdom  
AB9 2ZB

**Study participating centre****NHS Greater Glasgow & Clyde**

Institute of Neurological Sciences  
University Department of Neurosurgery  
Southern General Hospital NHS Trust  
Glasgow  
United Kingdom  
G51 4TF

**Study participating centre****NHS Tayside**

Ninewells Hospital And Medical School  
Dept of Neurosurgery  
South Block Level 6  
Dundee  
United Kingdom  
DD1 9SY

**Study participating centre****Belfast Health and Social Care Trust**

Royal Victoria Hospital  
Department of Neurosurgery  
Grosvenor Road  
Belfast  
United Kingdom  
BT12 6BA

**Study participating centre**

**The Walton Centre NHS Foundation Trust**

Lower Lane  
Fazakerley  
Liverpool  
United Kingdom  
L9 7LJ

**Study participating centre**

**The Newcastle Upon Tyne Hospitals NHS Foundation Trust**

Royal Victoria Infirmary  
Department of Neurosurgery  
Queen Victoria Road  
Newcastle upon Tyne  
United Kingdom  
NE1 4LP

**Study participating centre**

**South Tees Hospitals NHS Foundation Trust**

James Cook University Hospital  
Department of Neurosurgery  
Marton Road  
Middlesbrough  
United Kingdom  
TS4 3BW

**Study participating centre**

**Lancashire Teaching Hospitals NHS Foundation Trust**

Royal Preston Hospital  
Department of Neurosurgery  
Sharoe Green Lane North  
Fulwood  
Preston  
United Kingdom  
PR2 4HT

**Study participating centre**

**City Hospitals Sunderland NHS Foundation Trust**

Sunderland Royal Hospital  
Sunderland  
United Kingdom  
SR4 7TP

**Study participating centre**  
**Salford Royal NHS Foundation Trust**  
Hope Hospital  
Department of Neurosurgery  
Stott Lane  
Salford  
United Kingdom  
M6 8HD

**Study participating centre**  
**Hull and East Yorkshire Hospitals NHS Trust**  
Hull Royal Infirmary  
Department of Neurosurgery  
Anlaby Road  
Hull  
United Kingdom  
HU3 2KZ

**Study participating centre**  
**Leeds Teaching Hospitals NHS Trust**  
The General Infirmary at Leeds  
Department of Neurosurgery  
Great George Street  
Leeds  
United Kingdom  
LS1 3EX

**Study participating centre**  
**Sheffield Teaching Hospitals NHS Foundation Trust**  
Royal Hallamshire Hospital  
Department of Neurosurgery  
Glossop Road  
Sheffield  
United Kingdom  
S10 2JF

**Study participating centre**  
**Nottingham University Hospitals NHS Trust**  
Queen's Medical Centre  
Department of Neurosurgery  
C Floor, West Block

University Hospital  
Clifton Boulevard  
Nottingham  
United Kingdom  
NG7 2UH

**Study participating centre**  
**Derby Hospitals NHS Foundation Trust**  
Royal Derby Hospital  
Uttoxeter Road  
Derby  
United Kingdom  
DE22 3NE

**Study participating centre**  
**University Hospital Birmingham NHS Foundation Trust**  
Queen Elizabeth Neuroscience Centre  
Department of Neurosurgery  
The Queen Elizabeth Hospital  
Birmingham  
United Kingdom  
B15 2TH

**Study participating centre**  
**University Hospitals Coventry and Warwickshire NHS Trust**  
Walsgrave Hospital  
Department of Neurosurgery  
Clifford Bridge Road  
Walsgrave  
Coventry  
United Kingdom  
CV2 2DX

**Study participating centre**  
**University Hospital Southampton NHS Foundation Trust**  
Wessex Neurological Centre  
Department of Neurosurgery  
Southampton General Hospital  
Tremona Road  
Southampton  
United Kingdom  
SO16 6YD

**Study participating centre**

**Cambridge University Hospitals NHS Foundation Trust**

Addenbrooke's Hospital,  
Neurosurgery Unit  
Hills Road  
Cambridge  
United Kingdom  
CB2 2QQ

**Study participating centre**

**Norfolk and Norwich University Hospitals NHS Foundation Trust**

Colney Ln  
Norwich  
United Kingdom  
NR4 7UY

**Study participating centre**

**East Kent Hospitals University NHS Foundation Trust**

Kent and Canterbury Hospital  
Ethelbert Road  
Canterbury  
United Kingdom  
CT1 3NG

**Study participating centre**

**Oxford University Hospitals NHS Trust**

Oxford Radcliffe NHS Trust  
Department of Neurosurgery  
Level 3, West Wing  
John Radcliffe Hospital  
Headley Way  
Headington  
Oxford  
United Kingdom  
OX3 9DU

**Study participating centre**

**North Bristol NHS Trust**

Southmead Hospital  
Ground Floor Academic Centre  
Level 2, Gate 6, Brunel building

Southmead Hospital  
Bristol  
United Kingdom  
BS10 5NB

**Study participating centre**  
**Plymouth Hospitals NHS Trust**  
University Hospitals Plymouth NHS Trust  
Department of Neurosurgery  
Derriford Road  
Plymouth  
United Kingdom  
PL6 8DH

**Study participating centre**  
**Royal Devon and Exeter NHS Foundation Trust**  
North Devon District Hospital  
United Kingdom  
EX31 4JB

**Study participating centre**  
**Taunton and Somerset NHS Foundation Trust**  
Musgrove Park Hospital, Parkfield Drive  
Taunton  
United Kingdom  
TA1 5DA

**Study participating centre**  
**Buckinghamshire Healthcare NHS Trust**  
Stoke Mandeville Hospital  
Mandeville Rd  
Aylesbury  
United Kingdom  
HP21 8AL

**Study participating centre**  
**Milton Keynes Hospital NHS Trust**  
Milton Keynes University Hospital NHS Foundation Trust  
Standing Way  
Eaglestone  
Milton Keynes

United Kingdom  
MK6 5LD

**Study participating centre**

**Barts Health NHS Trust**

St Bartholomew's and Royal London Hospital  
Department of Neurosurgery  
Whitechapel  
London  
United Kingdom  
E1 1BB

**Study participating centre**

**Barking Havering and Redbridge University Hospitals NHS Trust**

Essex Neurosciences Centre  
Department of Neurosurgery  
Second floor, Admin Block  
Queen's Hospital  
Rom Valley Way  
Romford  
United Kingdom  
RM7 0AG

**Study participating centre**

**King's College Hospital NHS Foundation Trust**

King's College Hospital  
Department of Neurosurgery  
Denmark Road  
London  
United Kingdom  
SE5 9RS

**Study participating centre**

**Brighton and Sussex University Hospitals NHS Trust**

Hurstwood Park Neurological Centre  
Department of Neurosurgery  
The Princess Royal Hospital  
Haywards Heath  
West Sussex  
United Kingdom  
RH17 7RS

**Study participating centre****St George's Healthcare NHS Foundation Trust**

Atkinson Morely Wing  
Department of Neurosurgery  
St George's Hospital  
Blackshaw Road  
Tooting  
London  
United Kingdom  
SW17 0QT

**Study participating centre****University College London Hospitals NHS Foundation Trust**

The National Hospital for Neurology & Neurosurgery  
Victor Horsley Department of Neurosurgery  
Queen Square  
London  
United Kingdom  
WC1N 3BG

**Study participating centre****Imperial College Healthcare NHS Trust**

Charing Cross Hospital, Fulham Palace Road  
London  
United Kingdom  
W6 8RF

**Sponsor information****Organisation**

NHS Lothian

**ROR**

<https://ror.org/03q82t418>

**Funder(s)****Funder type**

Research organisation

## Funder Name

British Neurosurgical Trainee Research Collaborative

## Results and Publications

### Individual participant data (IPD) sharing plan

Following the initial analysis and publication, study data will be made available to those who submit successful peer-reviewed proposals for use of the data to the steering committee via the BNTRC (British Neurosurgical Trainee Research Collaborative).

### IPD sharing plan summary

Available on request

### Study outputs

| Output type                          | Details                            | Date created | Date added | Peer reviewed? | Patient-facing? |
|--------------------------------------|------------------------------------|--------------|------------|----------------|-----------------|
| <a href="#">Results article</a>      | protocol                           | 17/11/2022   | 02/12/2022 | Yes            | No              |
| <a href="#">Protocol article</a>     |                                    | 14/12/2018   | 10/12/2020 | Yes            | No              |
| <a href="#">HRA research summary</a> | Demographics of Scotland wide data |              | 28/06/2023 | No             | No              |
| <a href="#">Other publications</a>   |                                    | 31/10/2022   | 02/12/2022 | Yes            | No              |