Understanding cauda equina syndrome (UCES)

Submission date	Recruitment status No longer recruiting	Prospectively registered		
25/06/2018		[X] Protocol		
Registration date	Overall study status Completed	Statistical analysis plan		
31/07/2018		[X] Results		
Last Edited	Condition category	Individual participant data		
02/12/2022	Nervous System Diseases			

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

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Additional identifiers

Protocol serial number

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

Study design

Prospective cohort study

Primary study design

Observational

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 vear
- 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

Αll

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

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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

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Study participating centre

The Newcastle Upon Tyne Hospitals NHS Foundation Trust

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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

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Study participating centre Salford Royal NHS Foundation Trust

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Study participating centre Hull and East Yorkshire Hospitals NHS Trust

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Study participating centre

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Study participating centre Cambridge University Hospitals NHS Foundation Trust

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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

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Study participating centre Oxford University Hospitals NHS Trust

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Study participating centre Buckinghamshire Healthcare NHS Trust

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Study participating centre Barts Health NHS Trust

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Study participating centre Barking Havering and Redbridge University Hospitals NHS Trust

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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?
Results article		17/11/2022	02/12 /2022	Yes	No
Protocol article	protocol	14/12/2018	10/12 /2020	Yes	No
HRA research summary			28/06 /2023	No	No
Other publications	Demographics of Scotland wide data	31/10/2022	02/12 /2022	Yes	No
Participant information sheet	Participant information sheet	11/11/2025	11/11 /2025	No	Yes