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Understanding cauda equina syndrome (UCES)

Submission date	Recruitment status	[_] Prospectively registered
25/06/2018	No longer recruiting	[X] Protocol
Registration date	**Overall study status**	[_] Statistical analysis plan
31/07/2018	Completed	[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

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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

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 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
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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
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BT12 6BA

Study participating centre
The Walton Centre NHS Foundation Trust
Lower Lane
Fazakerley
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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
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NE1 4LP

Study participating centre
South Tees Hospitals NHS Foundation Trust
James Cook University Hospital
Department of Neurosurgery
Marton Road
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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
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Department of Neurosurgery
Stott Lane
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Study participating centre
Hull and East Yorkshire Hospitals NHS Trust
Hull Royal Infirmary
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Leeds Teaching Hospitals NHS Trust
The General Infirmary at Leeds
Department of Neurosurgery
Great George Street
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LS1 3EX

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Sheffield Teaching Hospitals NHS Foundation Trust
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Nottingham University Hospitals NHS Trust
Queen's Medical Centre
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Derby Hospitals NHS Foundation Trust
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Study participating centre
University Hospital Birmingham NHS Foundation Trust
Queen Elizabeth Neuroscience Centre
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The Queen Elizabeth Hospital
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B15 2TH

Study participating centre
University Hospitals Coventry and Warwickshire NHS Trust
Walsgrave Hospital
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University Hospital Southampton NHS Foundation Trust
Wessex Neurological Centre
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Study participating centre
Cambridge University Hospitals NHS Foundation Trust
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Norfolk and Norwich University Hospitals NHS Foundation Trust
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Oxford University Hospitals NHS Trust
Oxford Radcliffe NHS Trust
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North Bristol NHS Trust
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Plymouth Hospitals NHS Trust
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Charing Cross Hospital, Fulham Palace Road
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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