Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Improving continence for children and young people with neurodisability: systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

01/10/2018

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

01/10/2019

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: Yes

Review stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

Funded proposal - funding due to commence 1/10/18

Funded proposal - funding due to commence 1/10/18

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Jo Thompson Coon

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Dr Thompson Coon

7. * Named contact email.

Give the electronic mail address of the named contact.

j.thompson-coon@exeter.ac.uk

8. Named contact address

Give the full postal address for the named contact.

South Cloisters, St Luke's Campus. University of Exeter Medical School, EX1 2LU

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+44 (0)1392 724066

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Exeter

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Dr Jo Thompson Coon. University of Exeter
Mrs Morwenna Rogers. University of Exeter
Dr Anne Wright. Guy's and St Thomas' NHS Foundation Trust
Mrs Claire Lindsay. Northern Devon Healthcare NHS Trust
Mrs Davina Richardson. Bladder and Bowel UK
Mrs June Rogers. Bladder and Bowel UK
Dr Eve Hutton. Canterbury Christ Church University
Mr Nicholas Madden. Chelsea and Westminster Hospital NHS Foundation Trust
Mrs Annette Allinson. University of Exeter
Mrs Julia Melluish. University of Exeter
Dr Rob Anderson. University of Exeter
Mrs Sue Ball. University of Exeter
Professor Stuart Logan. University of Exeter
Dr Chris Morris. University of Exeter

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

NIHR HTA: 17/20/02 Improving Continence for Children and young people with neurodisability

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

1) What is the effectiveness of interventions to improve continence in children and young people with neurodisability? 2) What is the cost-effectiveness of interventions to improve continence in children and young people with neurodisability? 3) What are the factors that enhance, or hinder, the effectiveness of interventions and/or the successful implementation of interventions to improve continence in children and young people with neurodisability? 4)What are the views, experiences and perceptions of children and young people, their families, their clinicians and others involved in their care of delivering and receiving such interventions?PenCRU (Peninsula Cerebra Research Unit) is a child disability research team at the University of Exeter Medical School with several years of experience involving families with disabled children as partners in research

through our Family Faculty (www.pencru.org/getinvolved/ourfamilyfaculty). The Family Faculty are parent carers who are offered opportunities to be involved in research. Sixteen parent carers volunteered to join a project-specific working group when we began preparing this protocol. The Family Faculty public involvement working group will be involved throughout the study. Our public involvement is coordinated by a Family Involvement Coordinator. We support our Family Faculty by identifying individual learning needs and providing informal assistance and encouragement consistent with their personal motivation and time available. We also organise shared learning events and benefit from working closely with the PenCLAHRC Public Involvement Team who provide formal training where necessary. The proposed public involvement in this project will ensure i) the research is conducted in acceptable ways, ii) the research outputs are relevant and useful to families of children with neurodisability, and iii) our dissemination materials and methods are appropriate and relevant.

16. * Searches.

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.

Search methods will include extensive database searching and supplementary searching including forwards and backwards citation chasing, hand-searching of any key journals identified during the search process and additional searching on topic specific websites (if applicable). We will also look for grey literature as detailed below.

Database Searches: A search strategy will be developed by an experienced information specialist (MR) in collaboration with the co-applicants and Professional Advisory Group and PenCRU Family Faculty public involvement working group, and will be informed by the CONSULTATION phase to ensure that all relevant key terms are included. The strategy will be extensively tested in our suggested portfolio of resources. The strategy will use both controlled vocabulary (e.g. MeSH) and free-text searching. Terms will be grouped using these concepts:

- continence terms
- neurodisability terms
- children and young people

Concepts will be combined to optimize sensitivity and precision. Our searches will capture effectiveness and cost-effectiveness studies as well as qualitative literature. Scoping searches indicate that the database searches will return around 3000 studies for screening. However if the numbers returned during search design are higher than anticipated, we will apply search filters for study design.

We propose to search the following databases:

- MEDLINE including MEDLINE in-process (via OvidSp)

- EMBASE (via OvidSp)
- PsycINFO (via OvidSp)
- Cochrane Database of Systematic Reviews (via the Cochrane Library)
- Cochrane Central Register of Controlled Trials (CENTRAL) (via the Cochrane Library)
- HTA database (via the Cochrane Library)
- CINAHL (via EBSCOhost)
- British Nursing Index (via ProQuest)
- HMIC (via OvidSp)
- SPP (via OvidSp)
- ASSIA (via ProQuest)
- Social Science Citation Index (via Web of Science)
- Conference Proceedings Citation Index (CPCI-S and CPCI-SSH) (via Web of Science)
- ProQuest Dissertations and Theses Global

Supplementary searches: The citation lists of included references and identified guidelines will be checked="checked" value="1" and forwards citation chasing (identifying where included references have been cited) will be carried out using Web of Science and Scopus. Any journals that are identified as being particularly pertinent, by frequency of identification in electronic searches and contact with topic experts through the Professional Advisory Group, will be hand-searched. Targeted searches to identify “sibling” studies (process evaluations, cost analyses and qualitative research) associated with included trials and based on trial names and first and last authors will also be conducted. Relevant systematic reviews found as part of the search will scanned for any additional studies.

Grey literature: The databases CINAHL, Web of Science Core Collection, SPP and HMIC will be searched, all of which index grey literature including conference proceedings. We will also search ProQuest Dissertations and Theses Global. In addition we will search the website OpenGrey via http://www.opengrey.eu/ and the British Library’s Explore catalogue.

Clinical Trials: ClinicalTrials.gov and ICTRP will be searched to find any additional trials.
Search results: All references identified by the database searches will be exported into EndNote X8 prior to de-duplication and screening.

Language and date restrictions: No date restrictions will be applied. Translation of non-English language qualitative papers is complex due to the risk of misinterpreting information on attitudes and experiences; therefore only papers published in English will be included.

Search write-up: The searches will be recorded using PRISMA guidelines (19). This will include the list of databases searched, recording of the date searched and the strategies used for each database. A search summary table will be produced detailing which database and method of searching found each of the included references.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Acquisition of continence is an important milestone in child development, involving planning, recognition of sensation, regulation, control, urinating and defecating in an appropriate place and cleaning afterwards. Learning to manage continence involves maturation of developmental domains including sensory perception, cognitive and social understanding and motor planning, with wide variation in the age at which this occurs. Social and environmental factors, parenting strategies and behaviours also affect toilet training.

Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and or neuromuscular system creating functional limitations. Impacts may include difficulties with movement, cognition, hearing, vision, communication, emotion, and behaviour. Sensory disturbances may impair balance, proprioception and interoception.

Children with neurodisability have a higher incidence of delayed acquisition of continence and of incontinence compared to other children. Factors that affect the ability of children with neurodisability to achieve continence include structural malformations, physiological impairments (e.g. sensation), functional limitations (e.g. movement), learning difficulties and behavioural issues. They may regress due to progressive impairment, psychological issues, development of bladder or bowel dysfunction. Incontinence affects the quality of life of the young person and that of their carers; long-term physical, psychological and financial burden can be considerable. There is also a cost for the NHS in terms of providing containment products for incontinence.

Not all children have the ability to become independent, but many can improve their continence. Assessing readiness for toilet training can be difficult. A child may display or express signs of readiness, or have capability for readiness but not express it. A variety of approaches to assessment, advice and intervention are available. Toilet training strategies are complex interventions, and build on ideas proposed in the 1960s and 1970s. Interventions to improve continence may include information/support, charts to monitor/feedback, scheduled drinks and toileting; cognitive behavioural approaches, alarms, relaxation, psychotherapy, and group-based programmes. A systematic review identified limited evidence for toilet training strategies for children with physical and learning disabilities. Medication is sometimes used as part of treatment, and medications used for managing other impairments may impact on continence. Currently there is uncertainty about which ways are most effective to assess and treat continence for children with neurodisability.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Quantitative evidence

Population: Children and young people with non-progressive neurodisability aged up to 25 years, consistent with Department of Health Special Educational Needs and Disabilities policy and Children and Families Act 2014.

Qualitative evidence

Sample: We will seek research with:

i) Children and young people with neurodisability,

ii) Their families and carers and

iii) Health care professionals providing care.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Quantitative evidence

Intervention: Assessments including identification of any underlying pathology and readiness for toilet training; interventions to improve continence including structured training programmes, products and

assistive technology, medicines and/or surgery; or care pathways/programmes involving combinations of continence assessment/monitoring and treatment/management interventions.

Qualitative evidence

Phenomenon of Interest: The factors that may enhance, or hinder the effectiveness of interventions and / or the successful implementation of interventions for improving continence in children and young people with neurodisability.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Quantitative evidence: Any control or comparator.

Qualitative evidence:Not applicable.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Quantitative evidence: As this review aims to establish whether interventions are effective or not, we will aim to include randomised controlled trials where available. However, our scoping suggests that evidence from randomised controlled trials may not be available for all the relevant interventions we have identified. We will therefore include all quantitative study designs reporting comparative data prioritising evidence from more robust study designs in the synthesis where possible. For the assessment of cost-effectiveness, we will include economic analyses and comparative cost studies of interventions meeting the inclusion criteria.

Qualitative evidence:

Design: Any recognised method of qualitative data collection and analysis, including interviews, focus groups and observational techniques. This may be stand-alone qualitative research, or reported as part of a mixed methods intervention evaluation. We will include process and outcome evaluations.

Research type: Qualitative research and process evaluations related to specific interventions aimed at improving continence in children and young people with neurodisability. We will carefully seek to identify qualitative research which is associated with the programmes included in the effectiveness review, through targeted searches for ‘sibling’ studies though will not be confined to these.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

Qualitative evidence

Location: Only studies from OECD countries will be included. Consideration will be given to the degree of transferability of findings from non-UK settings to the NHS context.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Quantitative evidence

Outcomes: Any outcome describing harms, benefits, and costs to children and young people or their parent carers or value-for-money for health services. Outcomes of interest will be discussed and agreed with the Professional Advisory Group and the PenCRU Family Faculty public involvement working group and are likely to include:

- Measures of urinary and/or faecal continence
- Night-time and/or daytime continence/dryness
- Health related quality of life
- Social functioning
- Treatment burden (on the child or young person)
- Carer burden (time, cost, psychological)

'Economic outcomes' will be collected from evaluation studies that report on the costs or resource implications of the included interventions and comparators.

Qualitative evidence

Evaluation:

i) Attitudes, experiences, perceptions and understanding of children and young people with neurodisability of receiving interventions aimed at improving continence in this group.
ii) Attitudes, experiences, perceptions and understanding of the families and carers of children and young people with neurodisability of receiving interventions aimed at improving continence in this group.
iii) Attitudes, experiences, perceptions and understanding of health care professionals involved in the care of

children and young people with neurodisability who have delivered interventions aimed at improving continence in this group.

Timing and effect measures

None.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None.

Timing and effect measures

None.

26. * Data extraction (selection and coding).

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

Quantitative evidence

Study selection: Inclusion and exclusion criteria will be applied to the title and abstract of each identified citation independently by two reviewers with disagreements being settled by discussion with a third. The full text will be obtained for papers that appear to meet the criteria and those for which a decision is not possible based on the information contained within the title and abstract alone. The full text of each paper will be assessed independently for inclusion by two reviewers. A PRISMA-style flowchart will be produced to detail the study selection process and reasons for exclusion of each full-text paper will be reported.

Data extraction: A standardised, piloted data extraction form will be used to collect data from each included paper. Data extraction will be performed by one reviewer and checked="checked" value="1" by a second, with disagreements being settled through discussion with a third.

Qualitative evidence

Study selection: References obtained through the search strategies will be uploaded into reference management software (Endnote X7). Assessment for inclusion will be undertaken initially at title and/or abstract level by two researchers independently. Where the research methods used or type of initiative evaluated are not clear from the abstract, assessment will be based upon reading of the full paper. The full text of any potentially includable papers will be obtained. Any disagreement or uncertainty will be resolved through discussion with a third member of the review team.

Data extraction: Details of the studies' methods and findings will be extracted into a pre-designed and piloted data extraction form. The extraction of data will be conducted by two reviewers independently, and reconciled by discussion. Involvement of more than one reviewer in the extraction of qualitative research allows for alternative readings of the findings to be explored. To facilitate analysis and synthesis, included papers will be uploaded into NVIVO for coding.

27. * Risk of bias (quality) assessment.

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

Quantitative evidence

Quality assessment: We will use the EPHPP tool to critically appraise all included papers that assess the effectiveness of interventions as this allows critical appraisal of different quantitative study designs according to the same metric. Cost-effectiveness papers (economic evaluations) will be critically assessed using the CHEC checklist. Quality assessment will be performed independently by two reviewers, with recourse to a third in case of disagreement. Where insufficient detail is provided in the published paper to adequately assess the risk of bias, authors will be contacted and asked to provide additional information.

Qualitative evidence

Quality appraisal: We will use the Wallace checklist for quality assessment. The checklist will be supplemented by critical reading of each study. The quality of studies will be independently quality assessed by two reviewers. Any disagreement will be resolved by consensus and if necessary a third reviewer will be consulted. We also anticipate, however, that the value of each study will be judged through its contribution to the synthesis.

28. * Strategy for data synthesis.

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a quantitative synthesis will be used if the included studies are sufficiently homogenous.

Quantitative evidence

Data synthesis: Data will be tabulated and discussed narratively in the first instance. Data tables for the effectiveness studies will include details of the intervention type and content, the setting and the provider, sample characteristics of the included population and the type of outcomes measured. Studies will be grouped by comparator, by intervention and/or by co-morbidity if appropriate.

The methods and findings from included economic evaluations will be summarised in a tabular format, noting

the type of evaluation carried out, the setting and perspective. Details of the sources of data and structural approaches of any decision analytic models used to synthesise data for the economic evaluations will be noted. Findings will be synthesised in a narrative review (i.e. we will not quantitatively synthesise summary measures of inputs to economic evaluation) which will pay particular regard to issues relating to generalisability of findings to the UK.
If data allow, meta-analysis will be used to estimate summary measures of effect on relevant outcomes, based on data from intention to treat analyses in contributing studies. Further, if data allow, we will explore the impact of study quality factors (e.g. control for potential confounding factors) using meta-regression and will explore sub-group analyses by common intervention and delivery components. If meta-analysis is conducted it will be carried out using random effects models, using Review Manager and STATA software. Heterogeneity will be explored through consideration of the study populations, methods and interventions by visualisation of results and, in statistical terms, by the ?² test for heterogeneity and I² statistic and, where possible, using meta-regression.

Qualitative evidence

Synthesis: Precise methods of synthesis will be determined in response to the nature of the findings in identified studies. Preliminary analysis will involve reading and re-reading the findings of included papers, in order to consolidate understandings of the themes and concepts and their relations within and between studies. A structured summary for each paper will be produced which will aid discussion of the emerging synthesis amongst the review team. Key findings, quotes and concepts will be coded in NVIVO to aid analysis. We will initially code deductively, using our logic model to guide synthesis. However we will also be open to new ideas and concepts and will code inductively to accommodate these.

Assuming sufficient conceptual data are available, we will undertake a meta-ethnography. The aim of meta-ethnography is to identify where similar themes and concepts from different papers refer to the same concepts (congruent synthesis) or identify opposing findings (refutational synthesis); this process is referred to as ‘translation’. Study concepts may also be linked to create a ‘line of argument’, developing ideas across more than one study. The context of the findings will also be considered in relation to the methods used to collect them and any theories that either drive the research or are produced by it. Such elements may help to explain similarities and differences between study reports. This may be particularly useful in identifying where experiences are generic, and where they are condition specific.

If findings are more descriptive, we will conduct a thematic synthesis. Where the evidence base consists of a

mixture of more and less conceptual analyses, it may be necessary to thematically analyse the more descriptive papers first, before incorporating these into a meta-ethnography. This approach has been successfully used by members of the team in a previous, complex qualitative synthesis. In this previous review, we found that initial synthesis of similar viewpoints (for example, children and young people; parents) was helpful, prior to juxtaposing these experiences and perceptions in an overarching synthesis. We plan to take a similar approach here. Ongoing discussions within the broader team and consultation with our Professional Advisory Group and Family Faculty public involvement working group will ensure that we develop a coherent picture of the body of relevant research.

Overarching synthesis

In order to bring together the findings of the strands of the review, we will seek to understand differences in the effectiveness findings in terms of the findings of the qualitative evidence review. This process, used by the team in two recent projects, will allow us to map out the conjectured links between the interventions and anticipated outcomes, heterogeneity in the findings, gaps in the evidence and factors that seem to enhance or limit intervention success. In our previous complex reviews use of diagrammatical representation of the study findings has proved invaluable as a communication aid and in facilitating discussion between stakeholders from differing perspectives. We will produce a complete and transparent report of the systematic review with reference to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist.

29. * Analysis of subgroups or subsets.

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence or co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

None.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
Yes

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis

No

Intervention
No

Meta-analysis
Yes

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
Yes

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system

No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is an English language summary.

32. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

This review forms part of a larger project. Outputs from the project will be a description of NHS approaches to the assessment and treatment of continence in children with neurodisability, and a synthesis of published evidence for assessment and interventions to improve their continence, and recommendations for research and practice. Thus the findings will substantially inform decisions about the direction and feasibility of further

evaluative research to appraise interventions in this area. In the process of conducting the study we will bring awareness to this sometimes neglected topic, and highlight its importance and the impact it has on families and health services.

Our dissemination strategy aims to reach all those involved in the clinical care of children with neurodisability, families with disabled children, relevant third sector organisations and charities, academics and NHS commissioners. We aim to raise awareness of the study from the early stages and share our findings expediently. We will work with our Professional Advisory Group and Family Faculty public involvement working group to identify the key messages, key audiences for those messages and how we plan to reach them. We will also work with them to guide our choice of approach and dissemination product for specific organisations/audiences and to ensure that popular internet information sources and social media are included.

We propose a dedicated dissemination event to announce our findings to which we will invite participants from the survey and other stakeholders. This event will be supplemented by:

- Websites and online media – members of our team are affiliated with various organisations that use websites to disseminate information and are perceived as reliable sources, e.g. Paediatric Continence Forum, PenCLAHRC, PenCRU, University of Exeter Medical School and others.
- Plain language summaries – We will co-create a series of tailored plain language summaries with members of our Family Faculty public involvement working group and Professional Advisory Group. We will offer to share the summaries to relevant organisations where we anticipate that they will form the basis of contributions to newsletters or websites. We will also seek to use them as a basis for creative communication products.
- Open access peer reviewed academic papers – We will seek to publish the findings in higher impact clinical journals focusing on health services, childhood disability or urology where most appropriate to the aspects of the study being reported. We will also seek opportunities for items in more discipline-specific publications such as for allied health professions.
- Conference presentations. We will offer presentations of our findings to academic meetings and any public-facing conferences including the British Academy of Childhood Disability, European Academy of Childhood Disability.
- We will target our findings through CLAHRC networks and with partner NHS organisations and the South West Academic Health Science Network (AHSN) to reach clinicians and service commissioners; also professional societies and special interest groups. We will use our links with charities to reach public and other audiences such as Bladder and Bowel UK, Cerebra, Council for Disabled Children, Contact, National Network of Parent Carer Forums, Include Me TOO and condition-specific charities.

Do you intend to publish the review on completion?

No

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

neurodisability; children; continence

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.