

Priority setting for faecal incontinence protocol

1. BACKGROUND

Faecal incontinence (FI) is the involuntary passage of faecal material through the anal canal. The prevalence of FI is thought to range from 2-17% in community dwelling individuals and is strongly correlated with age.¹ The prevalence of FI amongst people aged over 65 years and living in care homes is 40%, of which 2.3% of individuals present with 'major incontinence' (regular soiling of bedding, clothes and furnishing).¹ Incontinence has a severe impact on quality of life and can impact individuals profoundly across a broad range of issues from health and social through to financial.^{2,3}

Cochrane Incontinence aims to prepare and maintain systematic reviews of the effectiveness of interventions for incontinence. The focus of Cochrane Incontinence's reviews are interventions designed to prevent, treat or manage incontinence and other related conditions. As part of this work, Cochrane Incontinence have commissioned a project to identify the key priorities and questions for future reviews to address within the field of FI. Developing a shared agenda, between clinicians, patients and carers will provide a fundamental step to ensure future research has the necessary relevance.

During this priority setting exercise, Cochrane Incontinence will provide funder representation and support the delivery of the project by the Evidence Synthesis Group (ESG) in collaboration with the NIHR Innovation Observatory (NIHR-IO). The ESG sits within the Population Health Sciences Institute at Newcastle University and comprises a multidisciplinary team conducting applied and methodological research to inform health and social care decision making. NIHR-IO is the national medical horizon scanning facility, funded by the NIHR and is also based at Newcastle University. Central activities, core to the remit of NIHR-IO, include advanced horizon scanning and meaningful patient involvement.

This priority setting exercise will draw on the joint expertise and collaborative relationships of the ESG and NIHR-IO which have been developed through operationalising the IMAGINE series an innovative knowledge exchange partnership which uses public insights to identify unmet needs and inform research priorities.

AIM

To identify a list of priority topics of interest to the main stakeholders within the FI field and rank them according to their relevance. In doing so, building and strengthening connections between Cochrane Incontinence and key stakeholders.

OBJECTIVES

- 1) Understand current use of the existing portfolio of Cochrane review titles relevant to FI i.e. which reviews are most/least in demand.
- 2) Identify from patients and stakeholders priorities within the field of FI.
- 3) To examine high-level evidence (volume, range and nature of systematic review publications) on FI.
- 4) To synthesise findings from objectives one to three allowing us to identify gaps and unmet need within the field of FI.
- 5) Apply horizon scanning techniques to identify new, emerging drugs, health technologies, medical devices and diagnostics that could address the potential unmet need highlighted by answering objectives one to five.
- 6) Engage with clinicians, stakeholders and patients/carers to further identify priority topics and rank according to their relevance.

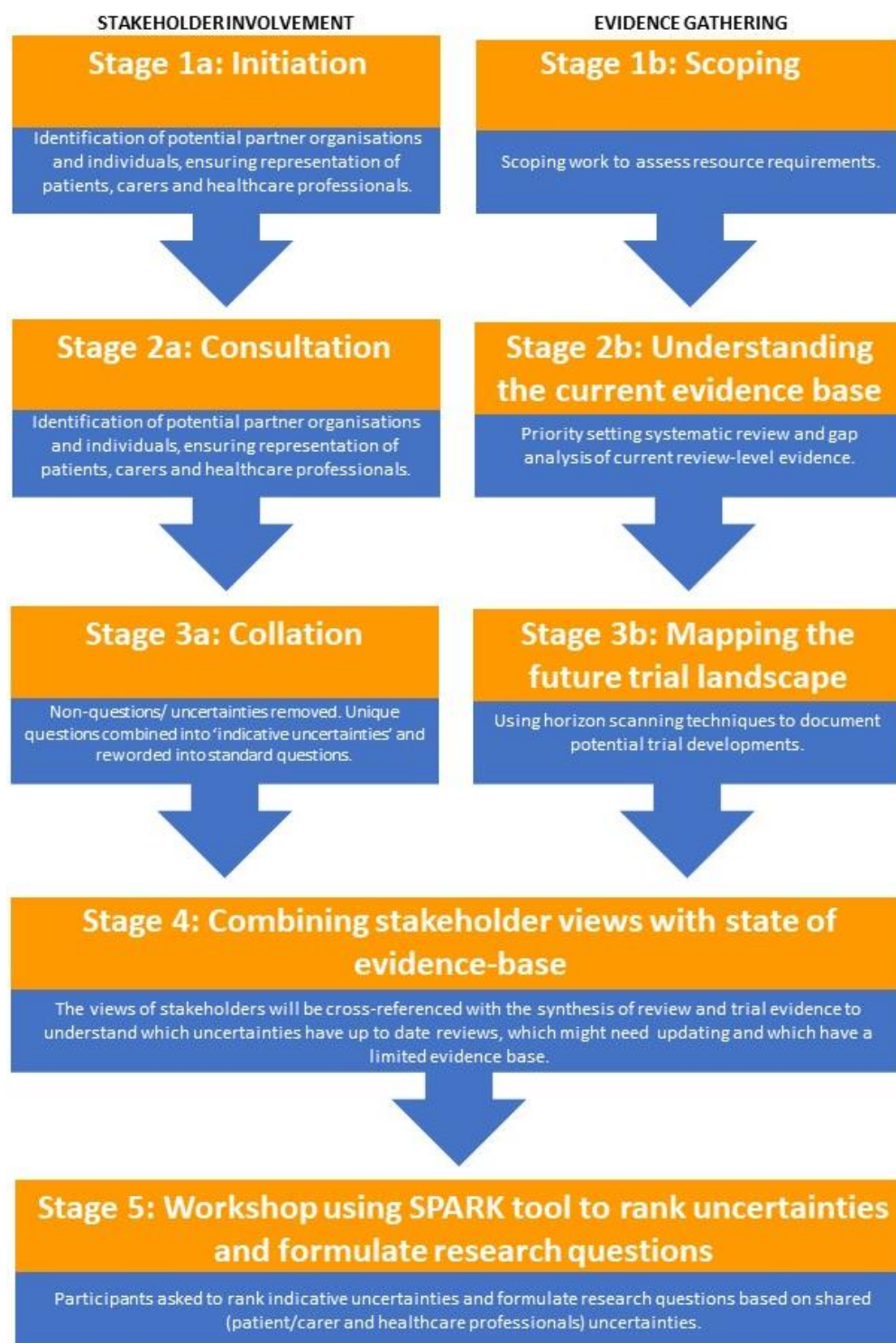
2. METHODS

Before commencing the research, we will publish, through relevant Cochrane channels, the intention to conduct a priority setting process (www.cochrane.org), to give external and internal stakeholders an opportunity to be involved (for example by facilitating connections to external stakeholders in other geographic areas, or with expertise on a specific thematic area).

The steering group, who as a team will lead the priority setting process, will be composed of the Cochrane Incontinence editorial base, plus additional panel members to add specific expertise, including an academic (Lynne Corner, UK) with expertise in the field of priority setting as well as a clinician (Donna Bliss, USA) with expertise in FI.

The methodology for this priority setting partnership (PSP) is outlined in Figure 1, and discussed in more detail below.

Figure 1 The five stages of the FI prioritisation exercise process Batchelor et al.⁴



2.1 EVIDENCE SYNTHESIS

2.1.1 Understand current use of existing portfolio review titles relevant to FI

Download information, citation data and Altmetric scores produced by Wiley will be collated for all existing review titles in the Cochrane Incontinence portfolio that are relevant to FI. This will provide a snapshot of which FI reviews have been most in demand and which have received little attention. Where data from Wiley is inaccessible the number of citations a review has in national and international guidelines, already collated by Cochrane UK, will be used as an indicator of its demand. Demand on the current Cochrane Incontinence review portfolio will be used to inform the planned public and patient involvement and engagement (PPIE) activities.

2.1.2 Evidence map to summarise existing systematic reviews on FI and to identify research gaps

Evidence mapping will be used to systematically organise and illustrate the broad field of research on FI. We will use an evidence map to characterise the depth and breadth of relevant systematic review-level data and to identify any research gaps. The search strategy will comprise of the following concepts combined using the given Boolean operators:

faecal incontinence AND systematic review

We will search:

- The Database of Abstracts of Reviews of Effects (DARE) on the Centre for Reviews and Dissemination (CRD) [website](#) (covering from the earliest record in DARE up to and including 31 December 2014 when their coverage ended).

As DARE is no longer actively updated we will perform searches of the following databases to identify eligible systematic reviews (using the systematic review filters developed by CADTH ⁵) indexed within these databases from 1 January 2015 onwards:

- MEDLINE (on Ovid) (covering 1 January 1946 to the most recent available version).
- Embase (on Ovid) (covering 1 January 1974 to the most recent available version).
- APA PsycINFO (on Ovid) (covering 1 January 1806 to the most recent available version).
- CINAHL (on EBSCOhost) (covering 1 January 1982 to the most recent available version).
- Cochrane Database of Systematic Reviews (CDSR) (covering from inception to the most recent available version).

Further details of the searches that will be performed including two example search strategies are provided in Appendix 1. Any systematic review on faecal incontinence will be included, if it meets at least four of the following five criteria, with the first three being mandatory. These criteria represent the minimum quality criteria for entry to the Database of Abstracts of Reviews of Effects (DARE) produced by the Centre for Reviews and Dissemination ⁶.

1. The inclusion/exclusion criteria were reported (any from population, intervention, comparator, outcomes, study design).
2. The search was adequate (at least one named database plus other form of searching, e.g. checking references).
3. The included studies were synthesised (narrative or statistical).
4. The quality of the included studies was assessed (ideally a systematic application of quality criteria or checklist).
5. Sufficient details about the individual included studies was presented (population, intervention, results).

Screening will be undertaken by two reviewers in a non-blinded manner. In order to identify the extent of existing systematic review-level evidence and highlight any evidence gaps, included systematic reviews will be mapped to topic domains previously identified by the 6th International Consultation on Incontinence⁷ (Appendix 2). The existing evidence, gaps identified and further research recommendations will inform the planned PPIE activities.

2.1.3 Identifying pipeline trials or those recently completed

We will search NIHRIO's 'OpenScan' database (<https://www.openscan.io/>) to identify new, emerging interventions and health technologies (drugs, medical devices or diagnostics). The search strategy will be based on the concept of faecal incontinence. Details of the search terms are given in Appendix 3. Trials identified through 'OpenScan' will be screened for relevance to FI in non-blinded duplicate.

In addition, where research gaps have been identified (or where review-level evidence is sparse and/or old), we will identify whether any relevant trials and publications are included in the Cochrane Incontinence Specialised Register related to FI that may address these gaps. The Cochrane Incontinence Specialised Register contains trials identified from the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, MEDLINE In-Process, MEDLINE Epub Ahead of Print, [ClinicalTrials.gov](#), [WHO ICTRP](#), [Be Part of Research](#) and handsearching of journals and conference proceedings. We will search using the controlled vocabulary terms developed for use in the Register, see Appendix 4 for details.

A de-duplication of trials identified from the two sources will take place. Existing and pipeline trials will be categorised and mapped to the FI topics identified by the 6th International Consultation on Incontinence⁷ (Appendix 2) and cross-checked with existing Cochrane systematic reviews. Doing so will highlight evidence gaps and trials which are currently not included in a review (either because they are currently in progress, recently published, or are currently 'off-topic').

The existing evidence gaps and those ongoing will inform the planned PPIE activities.

2.2 Public and patient involvement and engagement (PPIE)

Public involvement will take place at two closed time-points utilising direct interaction with patients, carers and other FI stakeholders. The first time point will be at the start of the priority setting exercise using an online international survey (Qualtrics platform) to identify the broad research priorities of the patients, carers and FI stakeholders. The second time point will be at the end of the priority setting exercise using virtual workshops to build multi-stakeholder consensus, refine and rank priority topics for systematic reviews in FI.

The recruitment approach for the first PPIE event will be open and flexible and for the second will be closed with purposive quota sampling. An article to encourage stakeholder participation (survey and workshop) will be placed on the Cochrane Incontinence website and shared with the Cochrane Incontinence's consumer panel. In addition to being advertised by the Cochrane Consumer Network (consumers.cochrane.org), the survey will be linked to and disseminated through social media and elsewhere. The article will include comprehensive information about the project (introduction, aims and purpose), details of the survey and then a description about what type of participants we are looking for to take part in the workshops and what level of commitment will be required. If after reading the information potential participants will be prompted to complete an expression of interest form. The expression of interest form will be used to purposefully select a diverse and representative group. The last question in the survey will also include information about the workshop and direct people to complete an expression of interest.

The survey will focus on gathering unprompted insight whilst the workshop will focus on gathering insight prompted by the analysis and interpretation of data collected in earlier components of the priority setting exercise.

Survey (time-point one)

An online survey will be made available to organisations and individuals from the UK and elsewhere.

We will use the stakeholder analysis matrix to log the identification of various organisations, and to assess their impact and influence (see Appendix 50). The survey (shown in Appendix 6) will ask multiple stakeholder groups to suggest what they consider to be FI priority areas and why.

Once the responses have been collated they will be reviewed and discussed with the project steering group. Once the evidence synthesis component detailing existing systematic reviews priorities is finalised, the priority areas can be combined with the survey results and the assessment of the current

evidence base. The researchers and steering group will then refine this list by removing some topics or questions because:

- High quality, current systematic reviews already exist and new trials are unlikely;
- Topics are beyond scope;
- Topics are unclear or ill-defined; or
- There are duplications in the list of topics and questions collated.

Workshops (time-point two)

Following completion of the survey and the evidence synthesis components of the proposal, the researchers and Steering Group will develop a pool of topics, questions (or problems) in need of prioritisation. Workshops will then be run to select, refine and rank these priority topics that could be used to identify priority Cochrane Reviews. Workshops will use the SPARK⁸ Tool which is a validated tool for prioritising questions for systematic reviews in health policy and systems research.

Two workshops are proposed on different days, comprising 30 people in each session (split into smaller 'breakout' groups). The groups will comprise approximately 50% patients, family members or carers, 25% healthcare providers or health service managers and the remaining 25% charitable stakeholders, health policy-makers or researchers (including Cochrane Incontinence editors). The group will be carefully selected to ensure a variety of experience, age and geographical work/living base.

Expressions of interest will be reviewed by researchers for eligibility, to ensure all applicants (both individuals and representatives of organisations) are over 18 years of age and have no conflicts of interest.

All eligible participants will be formally invited to the meetings a minimum of four weeks before the first workshop is scheduled. The invitation will include a description of the minimum IT requirements needed and ask participants if accessibility arrangements are required. A 'tech session' will be run prior to the workshops in which those wanting to test connectivity and explore software functionality can do so.

Participants should be provided with an electronic version of the following (hard copies and audio files should be offered and delivered if required):

- Briefing note that describes the aims and outcomes of the day and what will be required of participants. Separate versions should be written for consumers, healthcare providers and health policy makers.
- Final schedule for all workshops (dates and times, details of each session).
- Pre-reading material – the list of priority areas identified in the survey, examples of similar workshops, pre-prepared questions or thought provoking comments.
- Housekeeping rules for the sessions and a screenshot of the basic Zoom meeting screen flagging how to mute/unmute your microphone, switch video on/off, 'raise hand'/react, send a chat message.

The schedule of the workshop will be adapted from that described in Fig. 2 of Synnot et al.⁹ see Appendix 7. Broadly speaking the workshop will be split into two parts, part A and part B, and each part will take 3 hours or less to complete. The main discussions around consensus building will entail Zoom meetings, breakout sessions, and consensus conference (using standard nominal Group Techniques or Dialogue Models). The SPARK tool will be used within the workshops. The recommended approach to use the SPARK tool, is to allow participants to complete Module 1 (see Table 2) in order to rank topics according to their relevance. Module 2 is then applied to those relevant topics in order to rank them according to the feasibility and appropriateness of conducting a systematic review to address them. Module 2 will not be complete as part of this priority setting exercise. Following completion of the exercise, the scores of the 'break-out' groups for each of the FI topics are summed, and the order of prioritisation finalised.

Table 2: The 22 items included in the SPARK tool

Module 1 <i>(relevance of question to policy makers and stakeholders)</i>	Module 2 <i>(Appropriateness and feasibility for systematic review teams)</i>
1. Addressing this question responds to a problem that is of large burden	1. The question can be translated into an answerable systematic review question

2. Addressing this question responds to a problem that is persistent	2. There are no available or adequate systematic reviews on this question
3. Addressing this question responds to the needs of the population	3. Primary studies are available for inclusion in the systematic review
4. Addressing this question responds to the needs of decision-makers	4. There is adequate human capacity to undertake the systematic review
5. Addressing this question responds to national health priorities	5. There is adequate operation/management capacity to undertake the systematic review
6. Addressing this question is a moral obligation	6. The systematic review is feasible within the expected timeframe
7. Addressing this question is expected to positively impact equity in health	7. Conducting the systematic review contributes to sustainable capacity to conduct future reviews
8. Addressing this question is expected to positively impact population health	8. Conducting the systematic review is a social responsibility
9. Addressing this question is expected to positively impact patient experience of care	9. Conducting the systematic review does not raise any ethical concerns
10. Addressing this question is expected to positively impact healthcare expenditures	
11. Addressing this question is expected to positively impact the overall development of the country	
12. Using the research evidence for this question is critical to inform decision-making	
13. Using the research evidence for this question is expected to be supported by political actors	

The lead facilitator and co-facilitators (which include project researchers and engagement officers) should be identified and briefed in advance of the meeting. Facilitators should ideally have good subject knowledge and overview of the therapeutic landscape. Facilitators should be experienced and feel confident guiding and managing group discussion making sure all participants have an opportunity to contribute. We will aim to host with a facilitator to attendee ratio of 1:7.

Participants will be informed that the workshops are being recorded and transcribed, they will have the option of not having video switched on. The automated Zoom transcription facility will be utilised.

As far as possible workshops will be undertaken using Zoom and its integral features; recording, transcription, multiple choice voting, chat, whiteboard, breakout rooms. If deemed necessary, a minimum of the following software (or similar) will be used in addition to Zoom to improve facilitation:

- Visual whiteboards platforms (Stormboard (allows thread development and voting) MURAL, Miro, Jamboard etc.).
- Voting, Q&A and evaluation ([Vevox](#), Mentimeter (hides votes to reduce social normalisation) or Sli.do)
- Online group facilitation (groupmap, teamretro)

2.3 DISSEMINATION

To disseminate the findings of the priority setting exercise, comprehensively document the research evidence and patient and clinician insights used to identify, refine and rank the priority topics we will ensure both the process and results of the priority setting exercise are promoted.

A project plan will be registered with Cochrane ([Cochrane.org](#)) and a summary listed on the '[Current Priority Setting Activities](#)' page. The full project plan along with other key information such as the stakeholder advert, survey results and workshop results will be made available. A report will be produced detailing the findings from the evidence synthesis component of the exercise, in addition to results from the PPIE. These will be shared online utilising the normal engagement and dissemination pathways of Cochrane Incontinence and NIHR-IO (Twitter, newsletter, website and academic publication).

Stakeholders will be contacted at two time-points following the completion of the formal priority setting exercise. Firstly, to inform them of the conclusions of the priority setting exercise, and secondly to notify them of the subsequent reviews when they have been conducted.

Academic publications will be produced detailing the priority setting exercise findings and will be submitted to a relevant journal (e.g. Journal of Clinical Epidemiology or Health Research Policy and Systems). In addition, a conference presentation will be given at a relevant conference, such as the Cochrane Colloquium 2022. In addition, the priority Cochrane systematic reviews will be promoted on publication, including dissemination by the Cochrane KT dissemination brief.

Appendix 1 MEDLINE and Embase search strategies to identify systematic reviews on FI

Topic related search terms will be used and combined with 'AND' with the search filters for identifying systematic reviews developed by CADTH (Strings attached: CADTH database search filters [Internet]. Ottawa: CADTH; 2016. [cited 2020 05 20]. Available from: [/resources/finding-evidence](#))

Drafts of the strategies that will be run in MEDLINE and Embase are given below. Terms will be added to these strategies to cover incontinence of flatus.

MEDLINE

Ovid MEDLINE(R), Epub Ahead of Print, In-Process & Other Non-Indexed Citations, and Daily (covering 1 January 1946 to the most recent available version) will be searched using the following search terms:

1. meta-analysis.pt.
2. meta-analysis/ or systematic review/ or meta-analysis as topic/ or "meta analysis (topic)"/ or "systematic review (topic)"/ or exp technology assessment, biomedical/
3. ((systematic* adj3 (review* or overview*)) or (methodologic* adj3 (review* or overview*))).ti,ab,kw.
4. ((quantitative adj3 (review* or overview* or syntheses*) or (research adj3 (integrati* or overview*))).ti,ab,kw.
5. ((integrative adj3 (review* or overview*)) or (collaborative adj3 (review* or overview*)) or (pool* adj3 analy*))).ti,ab,kw.
6. (data syntheses* or data extraction* or data abstraction*).ti,ab,kw.
7. (handsearch* or hand search*).ti,ab,kw.
8. (mantel haenszel or peto or der simonian or dersimonian or fixed effect* or latin square*).ti,ab,kw.
9. (met analy* or metanaly* or technology assessment* or HTA or HTAs or technology overview* or technology appraisal*).ti,ab,kw.
10. (meta regression* or metaregression*).ti,ab,kw.
11. (meta-analy* or metaanaly* or systematic review* or biomedical technology assessment* or biomedical technology assessment*).mp,hw.
12. (medline or cochrane or pubmed or medlars or embase or cinahl).ti,ab,hw.
13. (cochrane or (health adj2 technology assessment) or evidence report).jw.
14. (comparative adj3 (efficacy or effectiveness)).ti,ab,kw.
15. (outcomes research or relative effectiveness).ti,ab,kw.
16. ((indirect or indirect treatment or mixed-treatment) adj comparison*).ti,ab,kw.
17. or/1-16
18. (defecation adj2 disorder\$).tw.
19. (defaecation adj2 disorder\$).tw.
20. (stool\$ adj25 (incontinen\$ or continen\$)).tw.
21. fecal incontinence/
22. encopre\$.tw.
23. encopresis/
24. (leak\$ adj2 (fecal or faecal or feces or faeces or stool\$ or motion\$)).tw.
25. (soil\$ adj2 (faeces or feces or fecal or faecal)).tw.
26. (bowel\$ adj25 manag\$).tw.
27. ((fecal or faecal or feces or faeces or stool\$) adj2 (urge\$ or frequen\$)).tw.
28. (sphincter adj2 hypotoni\$).tw.
29. soiling.tw.
30. (bowel\$ adj2 control\$).tw.
31. (pelvic adj2 dyssynerg\$).tw.
32. ((feces or faeces or fecal or faecal) adj2 (seep\$ or leak\$ or loss)).tw.
33. ((stool\$ or motion\$) adj2 (seep\$ or leak\$)).tw.
34. ((defecat\$ or defaecat\$) adj2 (urge\$ or frequent\$)).tw.
35. (bowel adj2 program\$).tw.
36. ((neurogen\$ or neuropath\$) adj2 bowel\$).tw.
37. ((fecal or faecal or feces or faeces or stool* or anal or anus or bowel or alvi) adj25 (incontinen\$ or continen\$)).tw.
38. or/18-37
39. 17 and 38

Embase

Embase (on Ovid) (covering 1 January 1974 to the most recent available version) will be searched using the following search terms:

1. meta-analysis.pt.
2. meta-analysis/ or systematic review/ or meta-analysis as topic/ or "meta analysis (topic)"/ or "systematic review (topic)"/ or exp technology assessment, biomedical/
3. ((systematic* adj3 (review* or overview*)) or (methodologic* adj3 (review* or overview*))).ti,ab,kw.
4. ((quantitative adj3 (review* or overview* or syntheses*)) or (research adj3 (integrati* or overview*))).ti,ab,kw.
5. ((integrative adj3 (review* or overview*)) or (collaborative adj3 (review* or overview*)) or (pool* adj3 analy*)).ti,ab,kw.
6. (data syntheses* or data extraction* or data abstraction*).ti,ab,kw.
7. (handsearch* or hand search*).ti,ab,kw.
8. (mantel haenszel or peto or der simonian or dersimonian or fixed effect* or latin square*).ti,ab,kw.
9. (met analy* or metanaly* or technology assessment* or HTA or HTAs or technology overview* or technology appraisal*).ti,ab,kw.
10. (meta regression* or metaregression*).ti,ab,kw.
11. (meta-analy* or metaanaly* or systematic review* or biomedical technology assessment* or biomedical technology assessment*).mp,hw.
12. (medline or cochrane or pubmed or medlars or embase or cinahl).ti,ab,hw.
13. (cochrane or (health adj2 technology assessment) or evidence report).jw.
14. (comparative adj3 (efficacy or effectiveness)).ti,ab,kw.
15. (outcomes research or relative effectiveness).ti,ab,kw.
16. ((indirect or indirect treatment or mixed-treatment) adj comparison*).ti,ab,kw.
17. or/1-16
18. (defecation adj2 disorder\$).tw.
19. (defaecation adj2 disorder\$).tw.
20. (stool\$ adj25 (incontinen\$ or continen\$)).tw.
21. fecal incontinence/
22. encopre\$.tw.
23. encopresis/
24. (leak\$ adj2 (fecal or faecal or feces or faeces or stool\$ or motion\$)).tw.
25. (soil\$ adj2 (faeces or feces or fecal or faecal)).tw.
26. (bowel\$ adj25 manag\$).tw.
27. ((fecal or faecal or feces or faeces or stool\$) adj2 (urge\$ or frequen\$)).tw.
28. (sphincter adj2 hypotoni\$).tw.
29. soiling.tw.
30. (bowel\$ adj2 control\$).tw.
31. (pelvic adj2 dyssynerg\$).tw.
32. ((feces or faeces or fecal or faecal) adj2 (seep\$ or leak\$ or loss)).tw.
33. ((stool\$ or motion\$) adj2 (seep\$ or leak\$)).tw.
34. ((defecat\$ or defaecat\$) adj2 (urge\$ or frequent\$)).tw.
35. (bowel adj2 program\$).tw.
36. ((neurogen\$ or neuropath\$) adj2 bowel\$).tw.
37. feces incontinence/
38. ((fecal or faecal or feces or faeces or stool* or anal or anus or bowel or alvi) adj25 (incontinen\$ or continen\$)).tw.
39. defecation disorder/
40. defecation urgency/
41. or/18-40
42. 17 and 41

Appendix 2 Faecal incontinence topics

- **Bowel management** including: lifestyle, education, complementary therapies, bowel habit/retraining, self-management, complementary therapies, psychological/behavioural/urgency suppression techniques, pelvic floor muscle training (PFMT)/biofeedback/sphincter exercises and electrical stimulation (non-implanted, transcutaneous and percutaneous). Including for example:
 - Lifestyle – overlaps with self-management includes:
 - ❖ Weight loss
 - ❖ Smoking cessation
 - ❖ Dietary fibre supplements
 - ❖ Modifications in diet/food, fluid/cafeine/alcohol and eating patterns
 - ❖ FODMAP diets
 - ❖ Physical activity/exercise
 - ❖ Containment (absorbent products)
 - ❖ Use of apps and maps of toilet locations
 - Bowel habit/retraining and bowel training
 - Education (patients and healthcare providers) including:
 - ❖ Self-management
 - ❖ Incontinence literacy – regarding diagnosis, treatment plan, self-management
 - ❖ Use of technologies/apps for education and self-management
 - Complementary therapies including:
 - ❖ Probiotics
 - ❖ Prebiotics
 - ❖ Herbal supplements
 - ❖ Acupuncture
 - ❖ Other complementary therapies as defined by the Cochrane Complementary Medicine that do not fall into any of our other categories – a full list is available at: <https://cam.cochrane.org/operational-definition-complementary-medicine>
- **Bowel management for neurological conditions** including:
 - Bowel programmes/bowel care
 - Assistive techniques – transanal irrigation, abdominal crede/massage, manual/digital stimulation of anus
 - Devices – anal plugs, anal inserts, vaginal-bowel devices
 - Physical therapies
 - Surgery
- **Drugs** including: anti-diarrhoeal agents, stool-forming agents, suppositories and enemas.
- **Surgery** including: injectable bulking agents, sphincter repair, sacral nerve stimulation (implanted), sphincteroplasty, post anal repair, antegrade irrigation, muscle transposition, artificial anal sphincter, magnetic sphincter formation, slings, stem cells, radiofrequency and colostomy.
- **Models of care:** General practitioner (GP)/family practitioner versus continence nurse advisor; nurse-run clinics/services.
- **Mechanical devices:** anal plugs, inserts, vaginal-bowel devices, absorbent products (such as pads, pants or bedpans), commodes, rectal catheters (only used for critically-ill patients), anal pouch, rectal trumpet ('off label' use). Any new devices eg intra-rectal diversion devices.
- **Other containment/non-active/other in non-neurogenic patients** including: trans-anal irrigation and scheduling toileting/toileting programmes for FI (in any setting eg in long-term care/nursing home settings).
- **Other interventions that may be important in particular settings** including:
 - Receiving timely assistance with toileting, toilet access/environment, privacy when toileting are topics for long-term care/nursing homes
 - Patient/carer/consumer concerns regarding odour and sounds (as well as soiling) during loss of faeces and/or flatus. Associated products may include underwear, pants, pads and set pads/pillows containing charcoal as a filter/absorber and over the counter (OTC) products such as gas reducers, as well as lifestyle interventions such as diet modifications to avoid gas producing foods.

Appendix 3 Search terms for pipeline trials on FI

(fecal incontinence) OR (defecation disorder) OR (encopresis) OR (soiling) OR (stool incontinence) OR (incontinent of stools) OR (leaking faeces) OR (faecal leakage) OR (stool leakage) OR (leakage of motions) OR (faecal soiling) OR (faecal urgency) OR (stool urgency) OR (faecal frequency) OR (hypotonic sphincter) OR (hypotonic anal sphincter) OR (pelvic dyssynergia) OR (faecal leakage) OR (faecal seepage) OR (faecal loss) OR (stool seepage) OR (leaking stools) OR (seepage of motions) OR (leaking of motions) OR (urgent defaecation) OR (frequent defaecation) OR (neurogenic bowel) OR (faecal continence) OR (stool continence) OR (anal continence) OR (anus continence) OR (bowel continence) OR (alvi continence) OR (alvi incontinence) OR (defecation urgency) OR (incontinence of wind) OR (incontinence of flatus)

Search limits:

Enrolment year >2015

Registries limited to: Brazil, Peru, USA, EU, AUSNZ, UK, India, Japan, South Korea, Thailand, and Sri Lanka

Appendix 4 Cochrane Incontinence Specialised Register search terms

The terms that we will use to search the Cochrane Incontinence Specialised Register are given below:
(design.cct* OR design.rct*) AND topic.faecal*

(All searches will be of the keyword field of EndNote X8.2).

Appendix 5 Patient and professional networks

Stakeholder name	Contact person <i>Phone, email, website, address</i>	Impact <i>How much does the project impact them? (Low, medium, high)</i>	Influence <i>How much influence do they have over the project? (Low, medium, high)</i>	What is the importance of the stakeholder?	How could the stakeholder contribute to the project?	How could the stakeholder block the project?	Strategy for engaging the stakeholder?

Source: <http://www.tools4dev.org/resources/stakeholder-analysis-matrix-template/>

Appendix 6 Survey and Expression of Interest Form

Survey:

Thank you for your interest in responding to this survey as part of the Cochrane Incontinence faecal incontinence priority setting exercise.

About the survey

Cochrane Incontinence publishes systematic reviews about any aspect of incontinence management, treatment, rehabilitation or prevention. Systematic reviews summarise existing evidence on specific research topics to inform clinical practice and policy questions. Cochrane Incontinence aim to dedicate their resources to covering topics with the highest priority and impact. To support this, a priority-setting exercise is currently being undertaken, to help determine topics for systematic reviews on faecal incontinence over the next five years. This survey is part of the priority setting exercise.

The survey aims to identify what research questions you would like to see answered about faecal incontinence. Your suggestions will be combined with those put forward by other survey respondents and then prioritised during a series of online workshops. The survey contains ten questions and should take 5 to 10 minutes to complete. All data collected will be kept confidential and will only accessible to members of the priority setting project team. Data will be held securely by Newcastle University.

If you have a colleague or contact whom you feel should complete the survey, please feel free to share the survey link with them. If you have any questions please contact the priority setting project team at: nihrvoice@io.nihr.ac.uk

The survey will be open until 31st of August 2020 or until no new topics are being identified by individual contributors.

The results of this faecal incontinence priority setting exercise will be shared by December 2020 on the following websites:

[NIHR Innovation Observatory](#)

[Cochrane Incontinence](#)

[Cochrane Community: Current Cochrane Priority Setting Projects](#)

By continuing past this point and submitting information you are agreeing to the use of data collected by Newcastle University by the faecal incontinence priority setting project team. Please indicate whether you are happy with this.

Yes
No

Are you 18 years of age or over?

Yes
No

I am answering the survey from the perspective of a:

Individual patient or consumer
Patient group or consumer group (please specify)
Caregiver or family member of a patient
Clinician or healthcare professional
Clinical society, association or professional organisation (please specify)
Guideline developer (please specify)
Policy or decision-maker (please specify)
Researcher

Please give any conflicts of interest below that maybe relevant to the proposed work. If none, list 'none'.

What faecal incontinence topic(s) or question(s) would you like Cochrane Incontinence to prioritise over the next five years?

Please place them in order of importance with 1 being most important.

1.
2.
3.
4.
5.

Why do you think these topic(s) or question(s) are important?

.....

Would you consider being involved in developing a review on faecal incontinence for Cochrane Incontinence? Involvement could include, for example, securing funding to complete the work, being involved as a review author or acting as a peer reviewer. If you would consider being involved, please tick 'yes' and indicate how.

No

Yes

Workshops for the Prioritisation of Cochrane Incontinence Systematic Reviews on Faecal Incontinence

Following the collation of information collected in this survey we will be organising two online workshops to refine priority areas and build consensus. The workshops will be around 3 hours long and will involve presentations from the prioritisation project team, Q&A sessions with the prioritisation project team and large and small group discussions between attendees. The exact dates are to be confirmed but they are expected to take place in late September/early October 2020.

Would you be interested in taking part in the online workshops?

No

Yes

If you answered yes (to either being involved in a future Cochrane Incontinence review, or to take part in the workshop), please provide your email address below and someone will be in contact. This will only be used to provide more information about the priority setting project, or to provide information regarding future Cochrane Incontinence reviews.

.....

Expression of interest form:

Thank you for your interest in taking part in our online workshops for the Cochrane Incontinence faecal incontinence priority setting exercise.

This expression of interest form contains eight questions and should take no more than 5 minutes to complete. All data collected will be kept confidential and will only be accessible to members of the priority setting project team. Data will be held securely by Newcastle University.

If you have any questions please contact the priority setting project team at: nihrvoice@io.nihr.ac.uk

The results of this faecal incontinence priority setting exercise will be shared by December 2020 on the following websites:

NIHR Innovation Observatory

Cochrane Incontinence

Cochrane Community: Current Cochrane Priority Setting Projects

By continuing past this point and submitting information you are agreeing to the use of data collected by Newcastle University by the faecal incontinence priority setting project team. Please indicate whether you are happy with this.

Yes

No

Are you 18 years of age or over?

Yes

No

Online workshops for the Cochrane Incontinence faecal incontinence priority setting exercise

We will be organising two online workshops to refine and build consensus upon faecal incontinence priority areas identified by a survey. The online workshops will be around 3 hours long and will involve presentations from the priority setting project team, large and small group discussions between attendees and Q&A sessions with the project team. The exact online workshop dates are to be confirmed but are expected to take place in late September/early October 2020.

Would you be interested in taking part in the online workshops?

Yes

No

As there are only 30 spaces available within the online workshops, we may unfortunately not be able to invite everyone who expresses an interest in joining. To ensure we have a diverse range of opinions expressed in the online workshops, we will invite attendees based on a predefined sampling quota. To facilitate this please complete the following demographic questions.

Are you:

Male

Female

Other as given below

.....

Prefer not to say

I would take part in the online workshops from the perspective of a:

Individual patient or consumer

Patient group or consumer group (please specify)

Caregiver or family member of a patient

Clinician or healthcare professional

Clinical society, association or professional organisation (please specify)

Guideline developer (please specify)

Policy or decision-maker (please specify)

Researcher

Please give any conflicts of interest below that maybe relevant to the proposed work. If none, list 'none'.

.....

Would you consider being involved in developing a review on faecal incontinence for Cochrane Incontinence?

Involvement could include, for example, securing funding to complete the work, being involved as a review author or acting as a peer reviewer. If you would consider being involved, please tick 'yes' and indicate how.

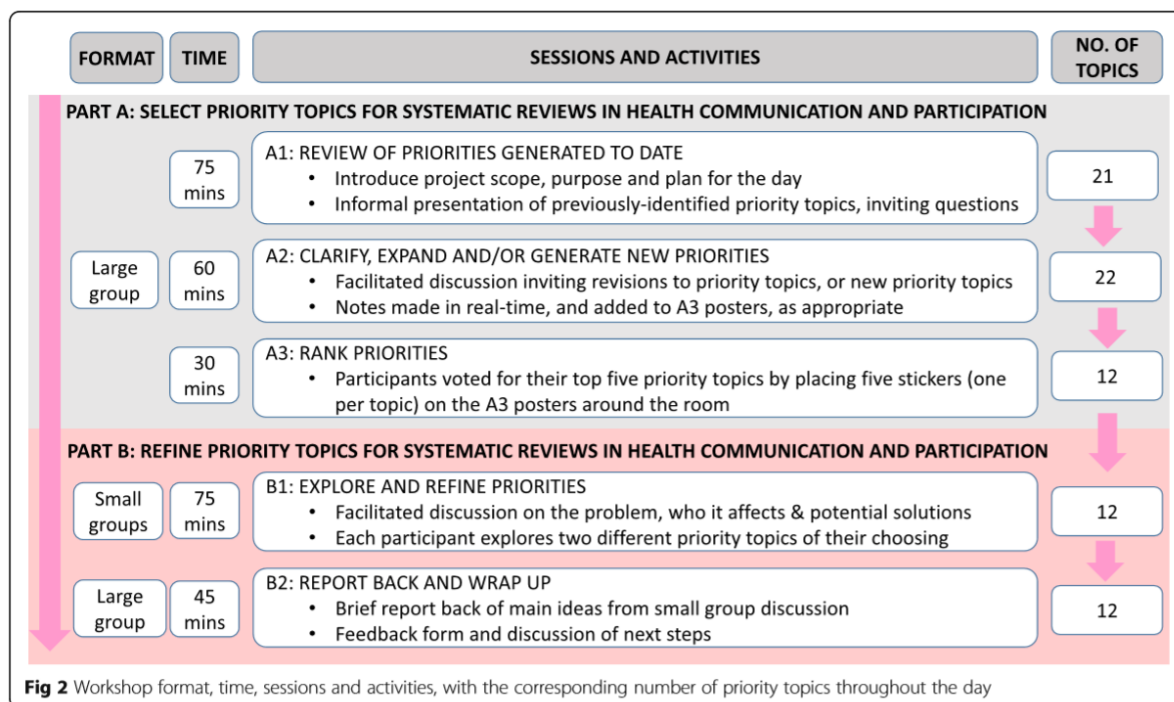
No

Yes

If you would like to take part in the online workshops or be involved in developing a review, **please provide your email address below** and someone will be in contact. Your e-mail address will only be used to provide more information about the priority setting exercise online workshops, or to provide information regarding future Cochrane Incontinence reviews.

.....

Appendix 7 Basis of the workshop format (from Synnot et al. ⁹)



References

- 1 Brown SR, Wadhawan H, Nelson RL. Surgery for faecal incontinence in adults. *Cochrane Database of Systematic Reviews*. 2013;Issue 7(Art. No.: CD001757). Available from: <https://doi.org/10.1002/14651858.CD001757.pub4>.
- 2 Perry S, Shaw C, McGrother C, Mathews RJ, Assassa RP, Dallosso H, et al. Prevalence of faecal incontinence in adults aged 40 years or more living in the community. *Gut*. 2002(50):480-4. Available from: <http://dx.doi.org/10.1136/gut.50.4.480>.
- 3 Rockwood TH, Church JM, Fleshman JW, Kane RL, Mavrantonis C, Thorson AG, et al. Fecal incontinence quality of life scale. *Diseases of the Colon & Rectum*. 2000;43:9-16. Available from: <https://link.springer.com/article/10.1007/BF02237236>.
- 4 Batchelor JM, Ridd MJ, Clarke T, Ahmed A, Cox M, Crowe S, et al. The Eczema Priority Setting Partnership: a collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. *British Journal of Dermatology*. 2013;168(3):577-82. Available from: <https://doi.org/10.1111/bjd.12040>.
- 5 CADTH. *CADTH database search filters*. Ottawa: CADTH; 2016. Available from: <https://www.cadth.ca/resources/finding-evidence>.
- 6 NHS Centre for Reviews and Dissemination. *Effectiveness Matters: The Database of Abstracts of Reviews of Effects (DARE)*. 2002. Available from: <https://www.york.ac.uk/media/crd/em62.pdf>.
- 7 Abrams P, Cardozo L, Wagg A, Wein A, (Eds). Incontinence: 6th International Consultation on Incontinence. Bristol, UK: ICI-ICS. International Continence Society 2017.
- 8 Akl EA, Fadlallah R, Ghandour L, Kdouh O, Langlois E, Lavis JN, et al. The SPARK Tool to prioritise questions for systematic reviews in health policy and systems research: development and initial validation. *Health Research Policy and Systems*. 2017;15(1):77. Available from: <https://doi.org/10.1186/s12961-017-0242-4>.
- 9 Synnot AJ, Tong A, Bragge P, Lowe D, Nunn JS, O'Sullivan M, et al. Selecting, refining and identifying priority Cochrane Reviews in health communication and participation in partnership with consumers and other stakeholders. *Health Research Policy and Systems*. 2019;17(1):45. Available from: <https://doi.org/10.1186/s12961-019-0444-z>.