

# Rapid priority setting exercise on faecal incontinence for Cochrane Incontinence

Katie H Thomson ,<sup>1,2</sup> Nicole O'Connor ,<sup>2,3</sup> Kim Tuyen Dangova ,<sup>1</sup> Sean Gill ,<sup>1</sup> Sara Jackson,<sup>1</sup> Donna Z Bliss ,<sup>4</sup> Sheila A Wallace ,<sup>2,3</sup> Fiona Pearson <sup>1,2</sup>

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<sup>1</sup>NIHR Innovation Observatory, Newcastle University, Newcastle upon Tyne, UK

<sup>2</sup>Evidence Synthesis Group, Population Health Sciences Institute, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

<sup>3</sup>Cochrane Incontinence, Population Health Sciences Institute, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

<sup>4</sup>School of Nursing, University of Minnesota, Minneapolis, Minnesota, USA

## Correspondence to

Dr Katie H Thomson;  
Katie.Thomson@io.nihr.ac.uk

## ABSTRACT

**Objective** This rapid priority setting exercise aimed to identify, expand, prioritise and explore stakeholder (patients, carers and healthcare practitioners) topic uncertainties on faecal incontinence (FI).

**Design** An evidence gap map (EGM) was produced to give a visual overview of emerging trial evidence; existing systematic review-level evidence and FI stakeholder topic uncertainties derived from a survey. This EGM was used in a knowledge exchange workshop that promoted group discussions leading to the prioritisation and exploration of FI stakeholder identified topic uncertainties.

**Results** Overall, a mismatch between the existing and emerging evidence and key FI stakeholder topic uncertainties was found. The prioritised topic uncertainties identified in the workshop were as follows: psychological support; lifestyle interventions; long-term effects of living with FI; education; constipation and the cultural impact of FI. When these six prioritised topic uncertainties were explored in more depth, the following themes were identified: education; impact and burden of living with FI; psychological support; healthcare service improvements and inconsistencies; the stigma of FI; treatments and management; culturally appropriate management and technology and its accessibility.

**Conclusions** Topic uncertainties identified were broad and wide ranging even after prioritisation. More research is required to unpick the themes emerging from the in-depth discussion and explore these further to achieve a consensus on deliverable research questions.

## BACKGROUND

Faecal incontinence (FI) is the involuntary passage of faecal material through the anal canal. The prevalence of FI is estimated to range from 2% to 17% among community-dwelling individuals, rising to 40% among people aged over 65 years living in a care home.<sup>1</sup> Incontinence has a severe negative impact on quality of life and can profoundly affect an individual's health, family and sexual relationships, lifestyle choices, employment and finance.<sup>2–4</sup>

While FI associated with specific diseases has received some attention, there has been a paucity of priority setting exercises (PSEs) for FI research. Those that have been undertaken

## Key messages

### What is already known about this subject?

- ⇒ Faecal incontinence (FI) has a high prevalence in both community and residential settings.
- ⇒ Historically, there has been a lack of priority setting recommendations for FI.

### What are the new findings?

- ⇒ One hundred and fourteen reviews were identified mainly focused on drugs, surgery or the use of mechanical devices aimed at either preventing, managing, decreasing or eliminating FI.
- ⇒ Most of the late-stage clinical trials we found looked at the impact of complementary therapies, pelvic floor muscle training, electrical stimulation (non-implanted), the use of laxatives and sacral nerve stimulation on FI.
- ⇒ Prioritised topic uncertainties identified by key stakeholders were mainly focused on the patient experience more holistically, particularly psychological support and education to help individuals learn to live with the condition.

### How might it impact on clinical practice in the foreseeable future?

- ⇒ Healthcare professionals need to be more mindful of the detrimental effect FI has on a person's psychological health and wellbeing.
- ⇒ Future primary studies should aim to improve management and containment options and examine how best to support patients throughout the care pathway.
- ⇒ Cochrane Incontinence should generate questions amenable to systematic review with relevance to FI stakeholder topic uncertainties.

highlight the need for randomised controlled trials to assess effectiveness and safety of FI treatments, particularly comparative effectiveness trials.<sup>5,6</sup> The need to focus on continence literacy and communication, and the dissemination of evidence-based management interventions, has also been highlighted in commentaries.<sup>7</sup> Given the paucity of PSEs on FI, there is a need for an up-to-date assessment of the research landscape, collation of

stakeholder topic uncertainties, and the prioritisation and exploration of these.

Over the last decade, there has been an increased emphasis on the adoption of structured approaches for priority setting,<sup>8,9</sup> particularly the effective use of end user feedback to increase the likelihood of producing studies that have a positive effect on health outcomes.<sup>10,11</sup> Cochrane Incontinence (CI) commissioned this rapid PSE on FI, as there is a need for a comprehensive review of the evidence base, and stakeholder engagement to ensure priority areas are true ‘gaps’ and these topics are deemed important for patients/carers and healthcare professionals (HCPs). This rapid PSE will act as the first step in a project to identify future systematic review questions. As such, the aim of this PSE was to rapidly identify existing reviews and trial evidence on FI in partnership with stakeholders as a first step towards informing priority CI Reviews.

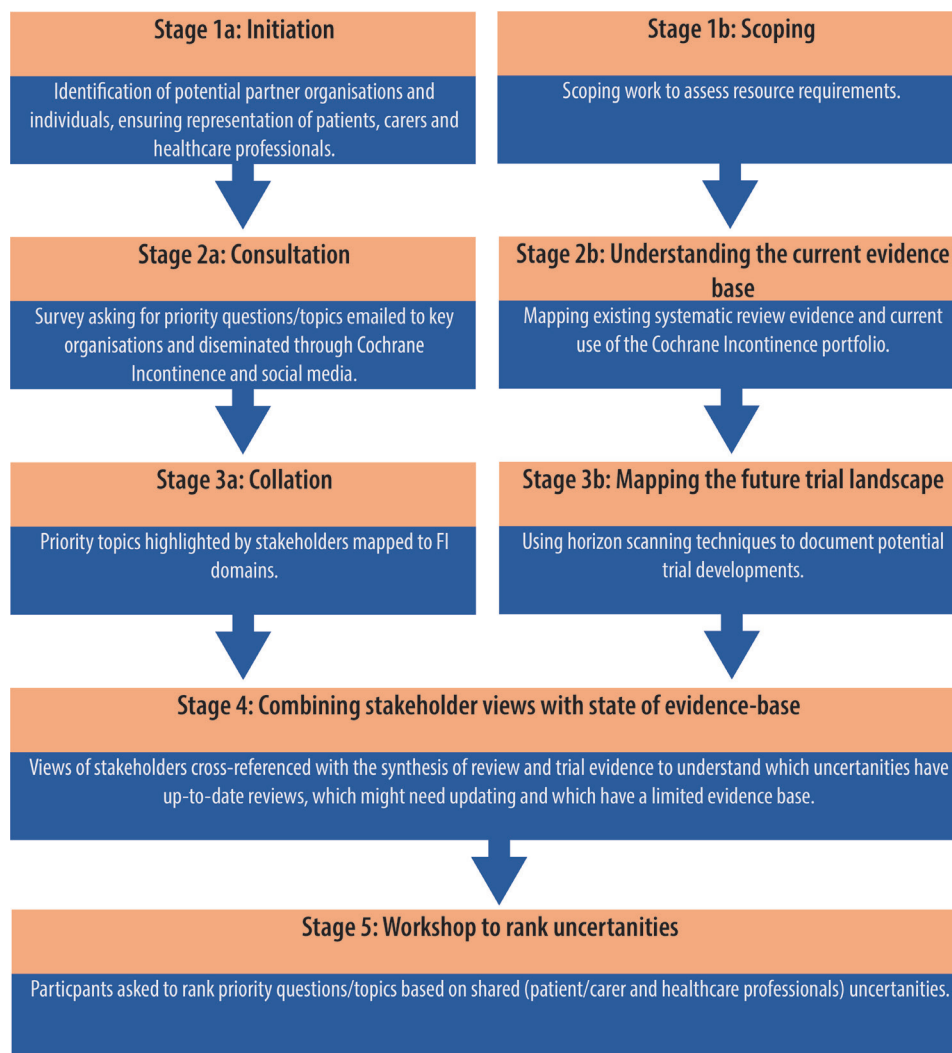
## METHODS

A brief overview of the review methods are detailed here, with more extensive description available elsewhere.<sup>12</sup> The research has been reported in line with

the REporting guideline for PRiority SETting of health research (REPRISE)<sup>13</sup> (online supplemental appendix 1). The rapid PSE process is outlined in figure 1 and the methodology is discussed below.

## Evidence synthesis methods

Three evidence synthesis approaches were conducted in parallel: usage of existing CI reviews; mapping existing non-Cochrane systematic reviews; and horizon scanning for new and emerging healthcare interventions. To assess the usage of existing CI reviews, we used data sourced from their publisher Wiley (October 2020) and assembled accession scores for all reviews within the CI portfolio that are relevant to FI (n=13). An evidence gap map (EGM), an emerging evidence synthesis method, was proposed to comprehensively assess intervention effects and outcomes in a user-friendly two-dimensional matrix framework. We constructed an EGM on interventions in FI by comprehensively summarising existing systematic reviews and meta-analyses.<sup>14,15</sup> The full-search strategy is detailed in online supplemental appendix 2. Screening was undertaken by two reviewers independently, in case



**Figure 1** The five stages of the FI prioritisation exercise process adapted from Batchelor *et al.*<sup>38</sup> FI, faecal incontinence.

of disagreement, a third reviewer was consulted. Horizon scanning for pipeline trials or those recently completed on FI was undertaken using a search performed across clinical trial registries on 11 August 2020 using the National Institute for Health Research Innovation Observatory's ScanMedicine database (scanmedicine.com) (see online supplemental appendix 3 for full search strategy details). Following deduplication and screening in duplicate, trials were included if they comprised a date of first enrolment within the last 5 years (from 2015) to highlight emerging research.

### Patient and public involvement

Stakeholder engagement comprised an online survey and a knowledge exchange workshop to help understand priority areas in FI research for patients, carers and HCPs. Snowball sampling was used for the survey. The invite was disseminated through the networks of CI (eg, mailing lists, Twitter) and other key patient and/or practitioner organisations (eg, charities, professional bodies) to allow for global reach. The workshop invite was disseminated in the same manner with participants who expressed an interest randomly selected using a ratio of two patients/carers to every HCP.

### Stakeholder engagement activities

Key stakeholder involvement was initially sought at the start of the rapid PSE using an online survey to identify the broad topic uncertainties of key FI stakeholders. The results of the survey, alongside the evidence found from the systematic reviews and horizon scanning, were mapped to topic domains based on those previously identified by the sixth International Consultation on Incontinence<sup>16</sup> (online supplemental appendix 4).

An EGM (developed using EPPI-Reviewer Web and the EPPI-Mapper app)<sup>17</sup> was used to visually present the results and was subsequently used in a half-day virtual knowledge exchange workshop. Participants were given an overview of the top 20 topic uncertainties from the FI stakeholder survey, positioned alongside existing and emerging evidence coded to the same intervention category within the EGM. Workshop activities were used to expand and subsequently rank priority topic uncertainties. Priorities were not weighted, stakeholders had the freedom to identify the importance of multiple topics or, if they wanted, a single topic depending on their perspective/experience.

Following the ranking of topics, the six highest priority topics were explored in more depth through participant-led, neutrally facilitated, group discussion (comprising 5–7 participants) in which open dialogue, equal participation and exchange of views took place. Participants were assigned to topic groups by facilitators based on their clinical expertise. Patient representatives were assigned based on their lived experience, and researchers ensured that there was an equal number of patient representatives in each group. The most pertinent points of the audio recordings for each individual

group discussion were transcribed independently by three researchers using rapid intelligent transcription. The data were then coded iteratively with the key concepts organised and then aggregated into broad themes. Handwritten notes were used to improve accuracy of the findings, and the identified themes from each discussion group were reviewed and agreed on by the research group. On review, cross-cutting commonalities were indicated between all three discussion groups. Recurring themes from the coded data were counted to develop and present a summary of the entire data.<sup>18</sup> Such techniques are becoming increasingly common for qualitative researchers interested in the rapid appraisal of findings.<sup>19</sup>

## RESULTS

### Evidence synthesis

#### Understanding current use of the existing portfolio review titles relevant to FI

The CI group has 14 systematic intervention reviews in their research portfolio focusing on FI. In [table 1](#), we present the most up-to-date systematic reviews ordered by the number of times they have been accessed between 2016 and 2019.

#### Identifying existing systematic reviews on FI

A total of 4446 records were retrieved from the 11 databases searched and downloaded to EndNote. Dededuplication resulted in 2679 unique records. At the title and abstract screening stage, 2224 records were excluded as irrelevant, meaning the full texts of 455 potentially relevant records were assessed against the review inclusion criteria (detailed in online supplemental appendix 5). However, 341 records did not meet the inclusion criteria and were excluded; reasons for exclusion are listed in online supplemental appendix 6. In total, 114 systematic reviews were included in our evidence map (online supplemental appendix 7). Reviews were dated between 1998 and 2020. The systematic review selection process is shown in [figure 2](#).

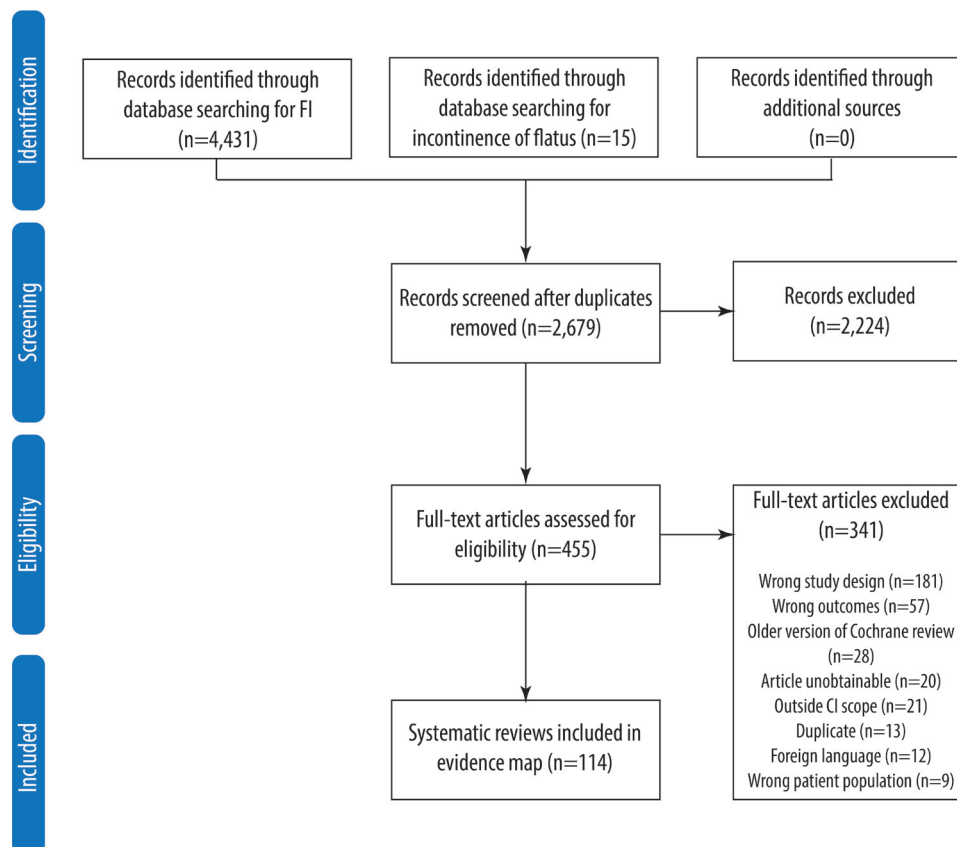
Each review was mapped to one or more of the following FI intervention domains described below:

- ▶ Forty-eight related to bowel management.
- ▶ Forty-eight focused on surgical techniques.
- ▶ Thirty-two related to bladder and bowel dysfunctions.
- ▶ Eighteen reported the impact of drug treatments.
- ▶ Twelve related to mechanical devices.
- ▶ Seven related to bowel management for neurogenic conditions.
- ▶ Six focused on interventions in particular settings.
- ▶ Five focused on interventions in particular populations.
- ▶ Four concerned other containment/non-active approaches in non-neurogenic patients.
- ▶ Three looked at models of care.
- ▶ Fourteen were termed 'other' and comprised a range of issues, including incontinence associated

**Table 1** reviews related to FI ordered by accession

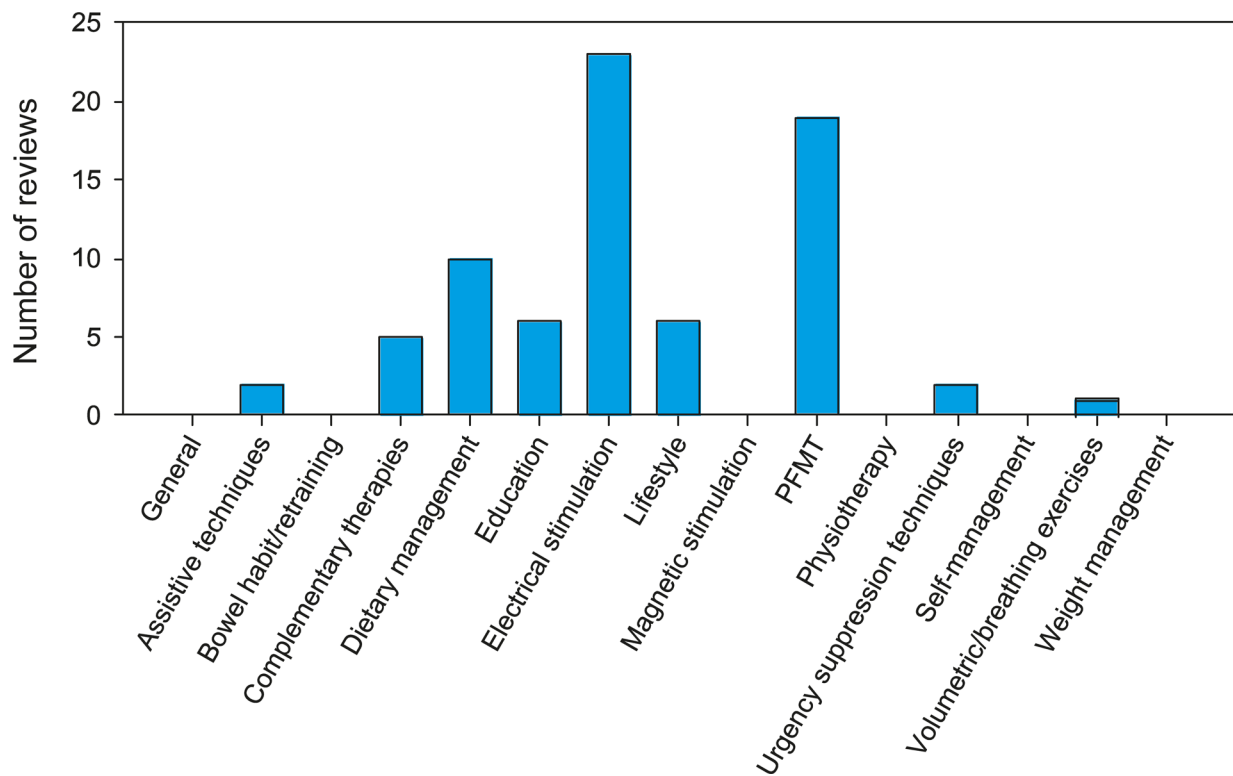
Review title	Number of times accessed 2016–2019*
Pelvic floor muscle training for prevention and treatment of urinary and FI in antenatal and postnatal women (2020) <sup>39</sup>	16274
Interventions for preventing and treating incontinence-associated dermatitis in adults (2016) <sup>40</sup>	12187
Management of FI and constipation in adults with central neurological diseases (2014) <sup>32</sup>	11804
Surgery for complete (full thickness) rectal prolapse in adults (2015) <sup>41</sup>	4697
Sacral nerve stimulation for FI and constipation in adults (2015) <sup>42</sup>	4217
Drug treatment for FI in adults (2013) <sup>43</sup>	3232
Biofeedback and/or sphincter exercises for the treatment of FI in adults (2012) <sup>44</sup>	2885
Surgery for FI in adults (2013) <sup>1</sup>	2048
Behavioural and cognitive interventions with or without other treatments for the management of FI in children (2011) <sup>45</sup>	1563
Perianal injectable bulking agents as treatment for FI in adults (2013) <sup>46</sup>	1529
Plugs for containing FI (2015) <sup>47</sup>	1312
Absorbent products for moderate-heavy urinary and/or FI in women and men (2008) <sup>48</sup>	1189
Electrical stimulation for FI in adults (2007) <sup>49</sup>	874

\*Accession data from 2016 to 2019 were used as a proxy to indicate which of the 13 review titles have been most in demand to date. Demand can be taken to be a proxy of utility for consumers (this utility may also be related to the 'currency' of the review during its time period given that the lower the order in the table, in general, the older the review).  
CI, Cochrane Incontinence; FI, faecal incontinence.



**Figure 2** PRISMA flow diagram of the literature assessment process. FI, faecal incontinence; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.





**Figure 3** Graph showing systematic review evidence for bowel management. PFMT, Pelvic Floor Muscle Training.

dermatitis, financial support, psychological support and quality of life.

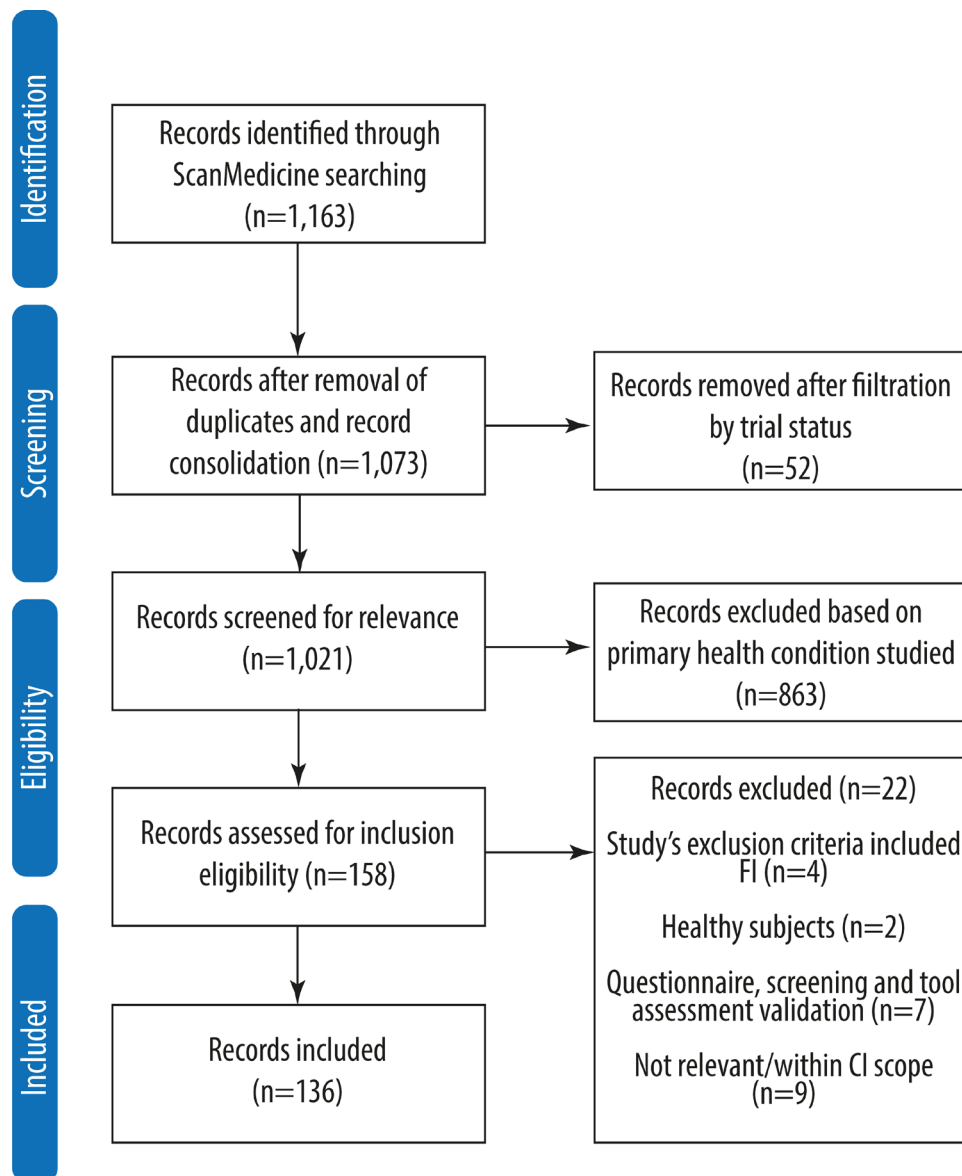
The three most reviewed areas in the bowel management domain are ‘electrical stimulation’ (n=23), ‘pelvic floor muscle training/biofeedback/sphincter exercises’ (n=19) and dietary management (n=10) (figure 3). Three reviews in the ‘electrical stimulation’ section focused on FI in people who have spinal cord injury.<sup>20–22</sup> The majority investigated the application of electrical stimulation in adults (ca. 90%). The reviews on ‘pelvic floor muscle training/biofeedback/sphincter exercises’ were targeted at a range of patient groups, including those diagnosed with dementia,<sup>23</sup> women who were pregnant (or post-partum),<sup>24 25</sup> patients who had undergone low anterior rectal resection<sup>26</sup> and adults more generally. The systematic reviews included in the dietary management category covered a variety of interventions such as probiotics in children<sup>27 28</sup> or the role of fibre in adults.<sup>29</sup> Others compared dietary management to a range of other conservative bowel management strategies.<sup>30 31</sup> We found no systematic reviews relating to other areas pertaining to bowel management, such as ‘weight management’, ‘physiotherapy’, ‘bowel habit/retraining’ or ‘magnetic stimulation’.

The surgery domain had 25 separate interventional areas; the number of systematic reviews in most of these areas ranged from none to seven. Sacral nerve stimulation (SNS) was the most evidenced intervention (n=17), followed by injectable bulking agents (n=10). Another popular domain was comorbid bladder and bowel dysfunction. The majority of these (n=20) related to

constipation. We only included reviews that examined constipation when FI was also explicitly stated as present, recognising the cyclic nature of FI and constipation. The majority of these papers focused specifically on children, older adults or those with central neurological diseases.<sup>32</sup> A range of studies looked at drug treatments, particularly laxatives, enemas and antidiarrhoeal medication. Most of these systematic reviews compared treatments for FI, which encompassed drug, surgical and bowel management options. Interestingly, only one paper<sup>31</sup> used a network meta-analysis to numerically compare alternative treatments.

### Horizon scanning for pipeline trials and emerging evidence on FI

A total of 1163 records were identified through searching ScanMedicine. After duplicates were removed and filtered by clinical trial status, trial registry and enrolment year, 1021 records were screened for relevancy and 863 studies were excluded based on FI not being the primary health condition studied (and, therefore, outside the scope of CI). The remaining 158 records were investigated in detail by assessing trials’ primary end points and inclusion or exclusion criteria, and a further 22 studies were deemed irrelevant (see online supplemental appendix 8 for a full list of trial exclusions). In total, 136 trials were included in the final data extraction and mapping process (online supplemental appendix 7). Figure 4 shows the horizon scanning selection process flow diagram.



**Figure 4** Horizon scanning of clinical trials and selection process flow diagram.

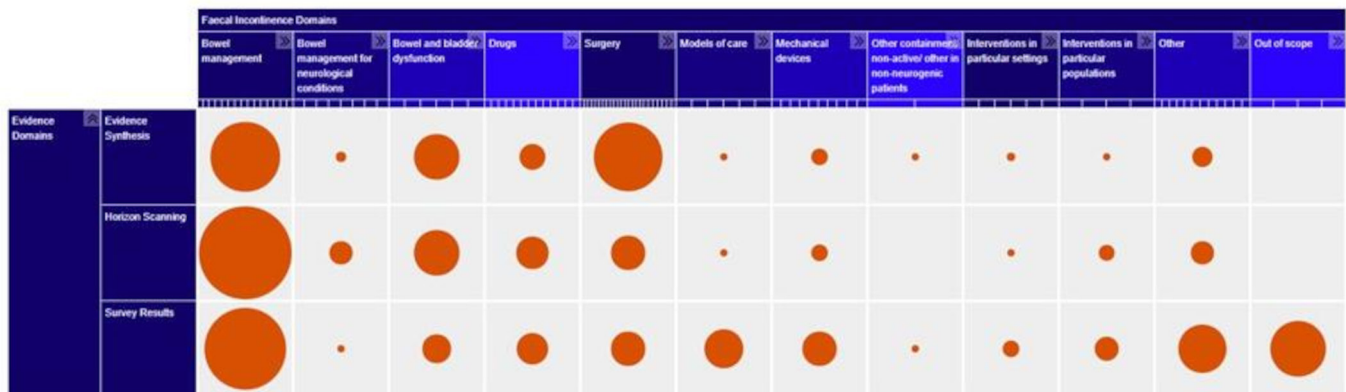
Included clinical trials were mapped to one or more FI domains:

- ▶ Sixty-five clinical trials related to bowel management.
- ▶ Thirty-two related to comorbid bladder and bowel dysfunctions.
- ▶ Twenty-four trials focused on surgical techniques.
- ▶ Twenty-three trials reported the impact of drug treatments.
- ▶ Sixteen related to bowel management for neurogenic conditions.
- ▶ Twelve trials focused on mechanical devices.
- ▶ Eleven trials focused on interventions in particular populations (eg, postmenopausal, diabetic)
- ▶ Three trials investigated interventions in particular settings.
- ▶ One trial looked at a model of care.
- ▶ Sixteen trial records were termed 'other' and comprised a range of issues, including incontinence

associated dermatitis, financial support, psychological support and quality of life.

A full breakdown of the trials identified is reported elsewhere.<sup>33</sup> In summary, most trials focused on bowel management strategies (including those for patients with neurogenic bowel) (n=81), followed by strategies related to comorbid bladder and bowel dysfunction (n=32), particularly for constipation. Drug treatments (n=23), surgical techniques (n=24) and mechanical devices (n=12) were also highlighted in the ongoing research. There was limited evidence found for new drugs in the development pipeline (n=2). However, 11 trials evaluated the effectiveness of existing repurposed drugs.

The evidence map is displayed in [figure 5](#), and an interactive version is found at <https://bit.ly/2XqQcGw>. Broadly speaking, the results of the horizon scan mirrored the evidence from the systematic reviews.



**Figure 5** Evidence map showing volume of evidence synthesis, horizon scanning and survey results (<https://bit.ly/2XqQcGw>).

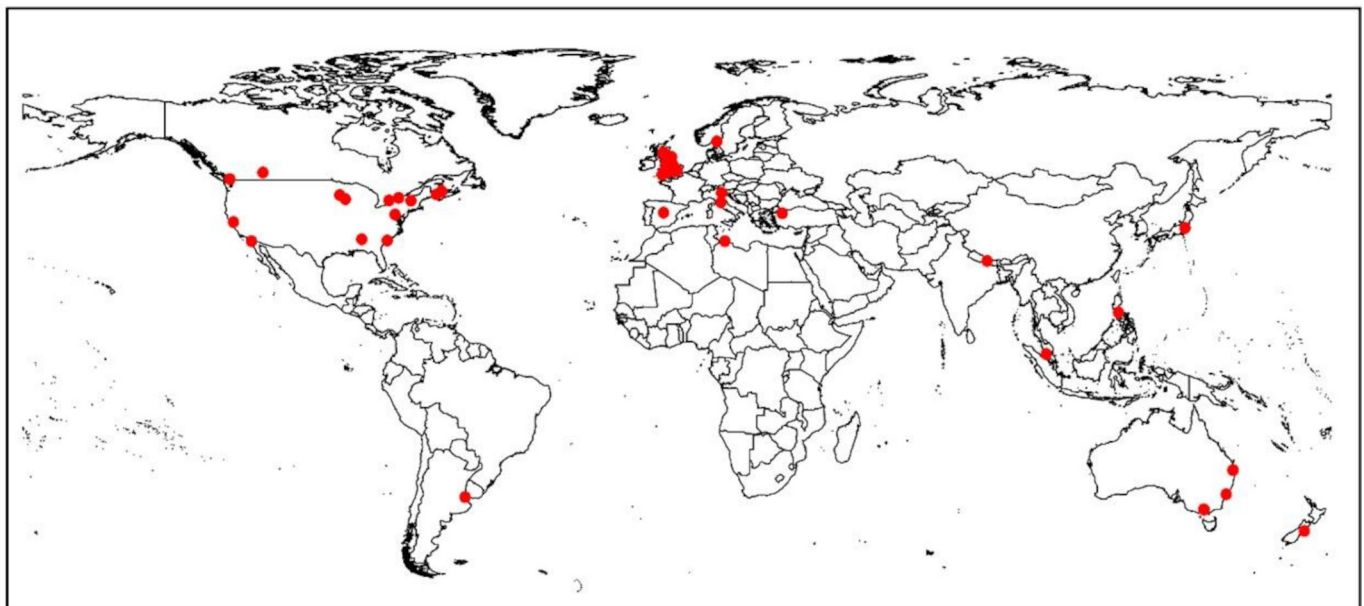
### Survey responses

Sixty-eight participants took part in the survey, and 268 indicative topic uncertainties were proposed. The majority of the survey respondents ( $n=32$ ) were from the UK, followed by USA ( $n=8$ ), Australia and Canada ( $n=6$ ) (figure 6). The only countries for whom the participants were not drawn from high-income economies were Argentina, Libya, Malaysia and Turkey (upper middle income) and Nepal and the Philippines (lower middle income). The majority of respondents answered from a single perspective (78%); most were individual patients or consumers ( $n=19$ ) or HCPs ( $n=19$ ). However, 22% of respondents identified with multiple roles.

Table 2 summarises the most frequently identified topic uncertainties from the survey. Patients primarily wanted to know the treatment options that would be most beneficial to help their own FI, but many also had a desire to understand the causes or mechanisms, which may help to

alleviate FI and its symptoms. Also, the patients emphasised the importance of support (in addition to treatment options) to help with the psychological consequences of living with FI. The carers who completed the survey were most concerned with treatment options particularly for children, for whom constipation was a primary concern. They too emphasised the importance of support for and awareness of FI, both from HCPs and also in their daily lives. Clinicians were understandably concerned with the management and treatment of FI, particularly the relative effectiveness of one treatment option over another.

Topics listed in red denote areas that are not directly relevant to CI (whose scope centres on intervention reviews). For the purposes of the workshop activities, these topics were excluded. However, both mechanisms/causes and prevalence were often more broadly discussed in dialogue centred on educational research, a topic that was included in workshop activities.



**Figure 6** Location of survey respondents.

**Table 2** The 23 most frequently cited topic uncertainties derived from the survey\*

1. Mechanisms and causes (n=31)	13. Evidence-based practice (n=11)
2. Psychological support (n=24)	14. Faecal Incontinence in children (n=11)
3. Education (patients, carers, healthcare providers) (n=23)	15. Pregnant/post-partum women (n=11)
4. Drugs (general) (n=21)	16. Lifestyle (n=9)
5. (Self) Managing condition† (n=20)	17. Physiotherapy‡ (n=9)
6. PFMT/biofeedback/sphincter exercises (n=20)	18. Prevalence (n=9)
7. Bowel management (general) (n=19)	19. Electrical stimulation (n=7)
8. Surgery (general) (n=19)	20. General models of care (n=7)
9. Dietary management (n=15)	21. SNS (n=7)
10. Psychological/behavioural/urgency suppression techniques (n=14)	22. Improvements to physical environments (n=6)
11. Clinical pathway to diagnosis (n=13)	23. New devices§ (intra-rectal diversion devices) (n=6)
12. Constipation (including in children) (n=12)	

\*Categories were based on survey responses, sometimes responses were not very detailed and broad categorisations had to be used. To reflect the detail in the responses, we chose the most precise category based on the description in the response, for example, if respondents specifically mentioned electrical stimulation this would be the category chosen whereas if 'physiotherapy' was mentioned with no further description then the 'physiotherapy' (not otherwise specified) category was used. †Patients/carers wanted the tools to be able to self-manage the condition on a day-to-day basis. ‡Not otherwise specified. §Respondents wanted new devices to be invented to help divert faeces non-surgically to help with day-to-day management of the condition for example, an intra-rectal diversion device). PFMT, Pelvic Floor Muscle Training; SNS, sacral nerve stimulation.

## Synthesis across evidence streams

### Cochrane portfolio

The CI group has 14 systematic reviews in their research portfolio that focus on FI (table 1). Broadly speaking, the topics of some of the most accessed reviews were also noted as priority topics by people who completed the online survey. For example, reviews relating to pelvic floor muscle training, biofeedback and sphincter exercises are among the most accessed reviews and rank as the 5th priority area (20 people mentioned this). Survey respondents identified many new or emerging topics providing useful insight into potential topic areas for future reviews on FI. Psychological support (mentioned by 24 people), education (mentioned by 23 people) and lifestyle modifications (mentioned nine times) rank as the 1st, 2nd and 10th areas that should be given priority status. Topics

covering the prevention, management and treatment of FI in specific groups were highlighted within the survey, for example, for overweight people (mentioned by two people), patients with cancer (mentioned by two people), people with diabetes (mentioned by two people) and postmenopausal women (mentioned by four people). At present, there are no published reviews on these topics within the CI review portfolio for these population groups. Research on FI in children was important to survey respondents (mentioned by 36 people). There is a review within the portfolio that was carried out to understand the effectiveness of behavioural and cognitive interventions in the management of FI in children, which is the 9th most accessed review (of 14 reviews). However, it was last updated in 2011 and, as with other older reviews, is less likely to now be cited.

### Systematic review evidence

The 114 reviews that were identified covered a broad range of topics. There are FI priority areas considered important by survey respondents, where there is limited or no evidence available (as indicated by the number of completed systematic reviews), for example, psychological support (mentioned by 24 people), diagnostics (mentioned by 13 people) and physiotherapy (mentioned by nine people). There are many systematic reviews that aim to understand the role of electrical stimulation (24 systematic reviews) and SNS (17 reviews) and while some survey respondents identified this as an important priority area, other areas were considered more important.

Many of the survey respondents talked much more generally about the treatment or management of FI. In these circumstances, we took treatment to mean either the use of drugs, surgery or mechanical devices aimed at managing, decreasing, eliminating or preventing FI. Other survey respondents highlighted the importance of evidence-based treatments used to inform decisions for the management of patients with FI. Most of the review-level evidence is on key treatments. Interventions to support patients with the psychological effects of living with FI and educational interventions for clinicians to improve recognition of the daily struggles, which patients and their carers face, were scant in the review-level evidence.

### Pipeline trials and emerging evidence

The results of the horizon scanning mirrored the evidence from systematic reviews. The majority of trials looked at the impact of complementary therapies of FI, pelvic floor muscle training, electrical stimulation (non-implanted) and the use of laxatives and SNS (implanted).<sup>33</sup> There was some emerging evidence for pipeline drugs (currently in development) and the use of repurposed drugs and new surgical techniques and procedures to treat FI.<sup>33</sup> There was also trial evidence that looked specifically at quality of life, which was highlighted as an important area of concern by the survey participants. Also, some



**Table 3** Top 10 priority areas as ranked by workshop participants when asked to allocate 100 points to the topics most important to them

Ranking*	Priority area
1	Psychological support
1	Lifestyle
1	Long-term effects of living with FI
1	Education
5	Constipation
5	Cultural impact
5	Psychological/behavioural/urgency suppression techniques
5	Training
5	PFMT
5	Physiotherapy

\*The ranking was undertaken using Mentimeter. Stakeholders had '100 points' to allocate across any of the priority areas the reviews/trial evidence had highlighted. The topics listed were equally popular with stakeholders and as such have the same ranking.

FI, faecal incontinence; PFMT, Pelvic Floor Muscle Training.

trials focused on the management of FI for patients with cancer, which was also raised by some of the survey respondents as a priority area.<sup>33</sup>

### Priorities from knowledge exchange workshop

Twenty-one participants from seven countries took part in the knowledge exchange workshop, including 11 HCPs and 10 patients, consumers or care givers. The responses given within the workshop were formed after insight sharing, in which the evidence outlined above was discussed. The online voting for priority topic uncertainties was very close, the top 10 responses from workshop participants are included in [table 3](#).

### Prioritised topic uncertainties discussed within small groups

The six highest-ranking topic uncertainties listed in [table 3](#) were discussed further during the workshop by three separate small groups of ~7 people. These participant-led discussions were intended to explore in more depth patients lived experiences and to allow participants to discuss prioritised topic uncertainties in their own words. Discussions were broad but primarily centred around the unmet needs of people with FI and how these issues could be addressed. As such, eight key themes emerged from the discussions ([table 4](#)), the five most discussed cross-cutting themes are reported below.

#### Theme 1: education

Across the six priority topic uncertainties, participants described education as having a significant role in preventing, diagnosing and managing FI. It was commented on 39 times and 10 of those times while calling for preventative interventions targeted towards

young children, their teachers, parents and health visitors to help them address lifestyle issues among children before they reach adulthood. Participants referred to successful preventative early years bowel health education programmes offered in schools in various countries. In addition, participants called for studies to assess the barriers that are preventing the uptake of existing best practice education among primary care providers.

#### Theme 2: impact and burden of living with FI

The impact and burden of living with FI was mentioned 26 times. Participants strongly felt that if the financial, emotional and social impact of FI were better evidenced by research, it would give impetus to decision-makers to prioritise treatment and management within healthcare settings.

#### Theme 3: healthcare service improvements and inconsistencies

Twenty times various issues relating to healthcare provision at both the organisational level and at the HCP level were discussed. Participants called for a more standardised approach to implementing care pathways (where these exist) resulting in faster referrals and access to specialists with FI knowledge. The idea of a specialised centre through which you could try different treatments, see a range of HCPs, including those with psychological training, and talk to others in a similar position appealed to all workshop participants.

#### Theme 4: psychological support

The need for psychological support was indicated 19 times. Participants expressed a desire to see the introduction of psychological support integrated into a multi-disciplinary care provision model. One surgeon noted that he often has returning patients not because they want surgery but because they need someone to talk to, alluding to the need for emotional support by appropriately trained professionals.

#### Theme 5: stigma

Highlighted 19 times, there was strong agreement among all groups that efforts should be undertaken to normalise discussions about bowel health and conditions like FI. The desirable effect would be to increase general awareness and understanding while lessening embarrassment from those who suffer.

## DISCUSSION AND CONCLUSION

### Key findings

This project aimed to rapidly identify existing FI systematic reviews, trial evidence and prioritised stakeholder identified topic uncertainties. The objective of the workshop was to bring together FI stakeholders to exchange knowledge and experience before expanding and prioritising the topic uncertainties identified through the survey. The project was commissioned as a first step towards generating priority FI systematic review questions for delivery by CI. To our knowledge, this is the first

**Table 4** Key themes identified from stakeholder workshop

Theme	Number of occurrences	Illustrative quotes
Education (of healthcare professionals, patients, parents and carers)	39	<p>“There are so many clinicians I came across that just label it IBS it seems easy to call it IBS I had to say to my GPs I have no IBS symptoms at all other than urgency, I have nothing, I’ve never suffered with it, and they’d just look at me and say oh I don’t know then.”—Person with FI</p> <p>“Primary physicians are not screening for urinary incontinence (or FI), and therefore the patients aren’t even getting the questions asked of them about whether FI is a problem. This may be because of poor education in medical schools, if not now, 30 years ago and therefore there are problems even opening the conversation with patients or where to send people, particularly in rural communities or for diagnostic tests in low-income countries, or in areas which require insurance for treatment plans.”—HCP</p> <p>“It is common for parents of young children who are soiling to be told it is a toilet training issue when it is not at all, and it needs to be identified and recognised from that really early age.” - Parent of a child with constipation and FI</p>
Impact and burden of living with FI	26	<p>Prioritisation in healthcare systems: “If you can’t show the impact it has in dollars and cents it is probably not going to get much prioritisation, that’s what we have to build on.”— HCP</p> <p>“(It impacts) all aspects of life, social life, how you can get out and be physically active, how to remain an active member of the community, whether you can engage in hobbies that you like, the financial side of things (increases cost of living) etc.”—Person with FI</p>
Psychological support	20	<p>“I became so stressed and distressed I felt I couldn’t live with this anymore. I went back to the doctor and said how I actually felt and from then on got a referral... even so there has been absolutely no form of psychological support of any sort from anybody.”—Person with FI</p> <p>“It’s really quite difficult because we don’t have training in psychology and counselling skills only very few bowel tertiary centres in [city in UK] actually employ a psychologist as part of the team.”—HCP</p> <p>“We had to pretend someone had a different condition to get them psychological support.”—HCP</p>
Healthcare service improvements and inconsistencies	19	<p>“The typical GP appointment is only 10 minutes if you don’t get straight in there and explain just how difficult this is, just how much you struggle then you just get a box of loperamide... Having more time whether that’s through specialist areas or a much quicker referral.”—Person with FI</p> <p>“One of the most common issues was that when patients came in [to hospital], they were automatically given pads and then the incontinence was cited later as the main reason why people were going to care homes when it wasn’t the reason they were admitted in the first place.”—Physiotherapist</p>
Stigma	19	<p>“Bowel dysfunction taboo subject in nearly all cultures, like what urinary incontinence was 10 or 12 years ago. Need to educate people and talk about it and open up the discussion...”—HCP</p> <p>“You are not expected to be a functional adult walking about and not be able to control yourself.”—Person with FI</p>
Treatments and management	17	<p>“When you use medication at what point and at what stage do you use it? For example, at what stage do we use psyllium over loperamide? The evidence for recommendations is lacking in these types of questions.”—HCP</p> <p>The need for a personalised approach: “Different people benefit from different treatments. It’s unhelpful to say there are no treatments. Most people can get some improvement in some aspects (eg, lifestyle, drugs, psychological support, nerve stimulation, PFMT).”—HCP</p>
Cultural management	9	<p>Better education about the body and the bowel: People didn’t have the language to express their problems, or to describe what was going on, they didn’t feel in the past that had ever really been properly listened to and so they weren’t confident to talk about their problem.”—HCP</p> <p>“What management aspects constitute ‘lifestyle’ in mid to low-income countries? We have to think about religious practices such as time spent praying, quality of toilets and how this leads to toileting practices that causes chronic constipation with overflow.”—HCP</p>
Technology and accessibility (apps, products, facilities, communication platforms)	5	<p>Improvements are needed in containment technology: “Pads for urinary incontinence have improved (more absorbency etc.), but management products for FI are still limited. Could technology be improved?”—HCP</p> <p>“Planning a journey, particularly in an unfamiliar place, as it’s important to know the location of toilets etc. Need to plan ahead (sister who has Parkinson’s has a card saying, ‘just can’t wait’ which she is supposed to give to shops etc. when she is desperate).” The patient also has a radar key which has been a “godsend in lockdown” when toilets have been closed in lockdown.—Person with FI</p>

FI, faecal incontinence; HCP, healthcare professional.

PSE in FI research to include input from members of the public who have the condition of interest. Through a variety of methods, we were able to comprehensively understand the nature of FI research in 2020, when the exercise took place. We found 114 relevant systematic reviews, most of which related to bowel management strategies, surgical techniques, drug treatments and bladder and bowel dysfunctions. The horizon scanning results broadly mirrored the existing evidence from reviews, showing some emerging evidence for pipeline drugs currently in development (n=2), the use of repurposed drugs (n=11), new devices, surgical techniques and procedures to treat FI. In comparison to the existing evidence from reviews and the horizon scanning results, the 68 participants who were involved in the survey and those subsequently involved in the workshop prioritised psychological support and education above drugs, surgical techniques and bowel management strategies. The evidence synthesis and horizon scanning suggested that these are important gaps for which there is limited existing, and emerging evidence.

The overview of existing research has also more fundamentally emphasised major knowledge gaps on disease epidemiology and pathogenesis, which may necessitate future primary clinical research on FI. From the onset of this rapid PSE, we specifically did not screen for reviews on the mechanisms or causes of FI or on FI prevalence as these topics are outside of the scope of CI who focus on intervention effectiveness. However, mechanisms or causes of FI were often highlighted as priority areas by survey respondents (n=31) as well as understanding FI prevalence (n=9). Survey results suggest the need for a greater understanding of the distribution and determinants of FI among different populations. Such topics are beyond the scope of CI but would make valuable future systematic reviews.

Systematic reviews, including those developed by Cochrane, have traditionally focused on clinical interventions. It is, therefore, unsurprising that the Cochrane portfolio did not match the perspectives of stakeholders who were more focused on psychological support, education and models of care. Increasingly, Cochrane is incorporating non-clinical interventions into their portfolio (eg, behavioural and educational interventions for nocturnal enuresis in children<sup>34</sup>), particularly so with the Cochrane 'Effective Practice and Organisation of Care' group undertaking reviews to guide health system decision-making. It is important for Cochrane to be responsive to the priorities identified by their stakeholders. We combined different evidence streams to identify gaps, which the patients/carers and HCPs subsequently expanded and ranked their research priorities. Identifying topics for which no Cochrane reviews are available highlights the importance of looking beyond Cochrane. Primary studies for some of these topics are available,<sup>35</sup> and, for others, more research is needed, and future funding calls can be used to prioritise primary studies.

## Strengths and limitations

Undertaken as a rapid project, it was not possible to complete a multiround consensus building or prioritisation method. Rather, an EGM was produced giving an overview of available FI systematic review and trial evidence (within scope of CI) in parallel to a survey identifying FI stakeholder topic uncertainties. Evidence gaps and redundancies were identified and highlighted in a knowledge exchange workshop with key FI stakeholders during which topic uncertainties identified through survey were prioritised. This project was funded by CI, and as such was targeted at mapping the evidence on FI within the scope of evidence covered by CI and where FI was the primary focus of the intervention. FI prevention, in particular, is researched by other Cochrane groups (eg, Pregnancy and Childbirth, Gut). Our resulting EGM is, therefore, a pragmatic overview of the evidence base related to FI intervention research of immediate relevance to CI and to the wider FI stakeholder audience.

With regards to the EGM, we believe that our methodological approach was robust. Our searches were broad and wide-ranging. In addition, screening and charting were undertaken in duplicate, either blinded or fully checked by a second reviewer. We did, however, restrict to papers published in English, or to those which could easily be translated. We also did not complete formal critical appraisal of the systematic reviews.

The horizon scanning techniques used to identify pipeline trials and emerging evidence offer an up-to-date insight into the novel and emerging health technologies to address the unmet need of FI. The process provides the background for the development of future technologies, thereby potentially gaining lead-time for planning, adaptation and implementation strategies. The horizon scanning search was comprehensive and covered 11 registries. A review of the trial evidence was completed simultaneously with the stakeholder survey. The stakeholder views, however, were focused on predominantly education/psychological interventions, for which trial evidence was sparse. A more comprehensive review of primary studies or the funding landscape may have been more illuminating given the subsequent interest in non-clinical interventions, however, these were beyond the scope of this rapid PSE. Finally, the survey was completed by 68 participants, a number which is lower than other Cochrane stakeholder surveys (eg, 147 for Cochrane Airways<sup>36</sup>), however, given the tightly focused remit (on FI specifically), this is perhaps not unexpected. Snowball sampling was used for the survey and workshop. Although the invite was disseminated through networks and organisations with global reach, most participants that responded were from the Global North. Given this, it is likely survey responses (and ultimately workshop participants) were focused predominantly on issues related to high-income countries.

As is to be expected, due to the neutral facilitation of group discussion, several of the emerging themes identified relate to the burden and stigma of the condition



and unmet clinical need rather than research priorities. These themes are, however, illuminating, and it is imperative they are shared with the wider community of FI stakeholders. Themes highlight key topics of importance to the workshop attendees such as psychological support. CI plan to take the prioritised topics and identified themes into subsequent multistakeholder workshops to derive questions amenable to systematic review.

The global COVID-19 pandemic brought unexpected benefits with regards to the workshop organisation and delivery. The potential challenges of social distancing, limited movement and suspended daily activities were turned to an advantage. Moving online, it was possible to attract a wide variety of stakeholders, 53% of whom were from outside the UK, which gave rise to valuable heterogeneous discussion bringing in experiences from using or providing services within different healthcare systems and models of care.

## Implications

The information collected during this priority-setting exercise, particularly in the group discussions, provides a broad understanding of the topic uncertainties that key FI stakeholders thought were important. Due to the nature of the topics identified, we were unable to ascertain specific questions from survey results and subsequent group discussions. A second phase of research would be necessary to explore these topic uncertainties to achieve a consensus of deliverable research questions.<sup>37</sup>

**Twitter** Katie H Thomson @katiehthomson

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**Ethics approval** This study involves human participants but was not approved by Stakeholder engagement comprised an online survey and a knowledge exchange workshop to help understand priority areas in FI research for patients, carers and HCPs. The host institution required no ethical approval for this PSE. Participants

instead gave informed consent at each stage. Participants gave informed consent to participate in the study before taking part.

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## ORCID iDs

Katie H Thomson <http://orcid.org/0000-0002-9614-728X>  
 Nicole O'Connor <http://orcid.org/0000-0002-6654-7178>  
 Kim Tuyen Dangova <http://orcid.org/0000-0003-2055-2286>  
 Sean Gill <http://orcid.org/0000-0001-5281-4725>  
 Donna Z Bliss <http://orcid.org/0000-0002-9972-3377>  
 Sheila A Wallace <http://orcid.org/0000-0003-2853-3653>  
 Fiona Pearson <http://orcid.org/0000-0003-1626-0862>

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