

# **Stakeholder engagement in the MOSS Network 2020**

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# Contents

<b>1</b>	<b>Introduction</b>	<b>4</b>
<b>2</b>	<b>Stakeholder engagement in the MOSS Network</b>	<b>6</b>
2.1	Back and Neck Group and Musculoskeletal Group	6
2.1.1	Observations of stakeholder engagement	6
2.1.2	Stakeholder engagement activities	6
2.2	Ear, Nose, and Throat Group	9
2.2.1	Observations of stakeholder engagement	9
2.2.2	Stakeholder engagement activities	10
2.3	Eyes and Vision Group	12
2.3.1	Observations of stakeholder engagement	12
2.3.2	Stakeholder engagement activities	12
2.4	Oral Health Group	15
2.4.1	Observations of stakeholder engagement	15
2.4.2	Stakeholder engagement activities	15
2.5	Pain, Palliative, and Supportive Care Group	16
2.5.1	Observations of stakeholder engagement	16
2.5.2	Stakeholder engagement activities	17
2.6	Skin Group	19
2.6.1	Observations of stakeholder engagement	19
2.6.2	Stakeholder engagement activities	19
2.7	Wounds Group	21
2.7.1	Observations of stakeholder engagement	21
2.7.2	Stakeholder engagement activities	22
<b>3</b>	<b>Summary and themes</b>	<b>24</b>
3.1	Benefits of stakeholder engagement	24
3.2	Capacity	24
3.2.1	Stakeholder engagement requires time	24
3.2.2	Stakeholder engagement requires knowledge	25
3.2.3	Stakeholder engagement requires funding	25

3.3	Global reach	25
3.4	Authors as stakeholders	26
<b>4</b>	<b>Conclusion</b>	<b>27</b>
<b>5</b>	<b>Appendix</b>	<b>28</b>
5.1	Interview schedule	28
5.2	References	30

# 1 Introduction

Cochrane’s vision is “a world of improved health where decisions about health and health care are informed by high-quality, relevant and up-to-date synthesized research evidence”, its mission is “to promote evidence-informed health decision-making by producing high-quality, relevant, accessible systematic reviews and other synthesized research evidence”. Cochrane has an international membership consisting of

- a Central Executive Office,
- a Central Editorial Unit,
- Geographic Centres in respective countries,
- Cochrane Review Groups (CRGs) which perform systematic reviews,
- Cochrane Fields which cross the focused areas of CRGs,
- Methods Groups,
- and a Consumer Network, which provides for input from the lay public,

In 2018, CRGs were grouped into eight networks (largely by similarity of topics). Each Network has a Network team comprising of a Senior Editor, Associate Editor, and a Network Support Fellow. The objectives of the Network structure are to support review production and capacity, prioritize topic, foster collaboration, support knowledge translation, and ensure accountability and sustainability of Networks<sup>1</sup>.

The Musculoskeletal, Oral, Skin and Sensory (MOSS) Network team (Senior Editor: Peter Tugwell, Associate Editor: Jennifer Hilgart and Network Support Fellow: Roses Parker) believe stakeholder engagement is important for ensuring that the work Cochrane does is useful to our stakeholders. We therefore want to encourage stakeholder engagement throughout the MOSS Network.

A “stakeholder” is an individual or group who is responsible for, or affected by health- and healthcare-related decisions (Concannon et al., 2012, 2019). “Engagement” is defined as an “active partnership” between stakeholders and researchers in the research process (Staniszewska et al., 2017).

This report summarises interviews conducted in mid-2020 and again in early-2021 with members of each of the eight Cochrane Review Groups (CRGs) which constitute the MOSS network. The aim of these interviews was threefold:

- 1.) to understand the current stakeholder engagement work within MOSS,

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<sup>1</sup> Description taken from Cochrane Eyes and Vision United States Satellite (CEV@US) PROJECT CURRICULUM VITAE [https://www.ucdenver.edu/docs/librariesprovider64/default-document-library/cochrane-ev-cv-2020-5-27.pdf?Status=Temp&sfvrsn=febbedb9\\_2](https://www.ucdenver.edu/docs/librariesprovider64/default-document-library/cochrane-ev-cv-2020-5-27.pdf?Status=Temp&sfvrsn=febbedb9_2)

- 2.) to share examples of stakeholder engagement work within MOSS, and
- 3.) to gather information to inform the next steps in stakeholder engagement work within MOSS.

Interviews were conducted with each CRG by the Network Support Fellow (NSF) following an [interview schedule](#). CRGs described stakeholders in various ways. Examples of stakeholders included authors, consumers, journals, academic institutions, policy makers, and guideline developers.

This report begins in Section 2 by outlining the findings from these interviews in the MOSS Network. It describes the current stakeholder engagement in each of the MOSS CRGs. Section 3 summarises the key themes to come from the interviews with MOSS CRGs. This document finishes with a conclusion in Section 4 and readers should be aware of the interview schedule appendix in Section 5. This report is intended to accompany the “[Six-Step Stakeholder Engagement Framework](#)” produced by Roses Parker, NSF for the MOSS Network and Eve Tomlinson, NSF for the Cancer Network.

## 2 Stakeholder engagement in the MOSS Network

This section details stakeholder engagement work and insights gained from each of the CRGs within the MOSS Network via interviews. The NSF contacted all CRGs to ask for representatives to take part in these interviews. At least one person from the Editorial base from each CRG participated. Roles of participants included: Managing Editor, Coordinating Editor, Information Specialist, Methodologist, Systematic Reviewer and Assistant Managing Editor. From here on these will be referred to as “CRG staff”.

MOSS CRGs are diverse in their subject area and levels of resourcing resulting in a variety of styles of stakeholder engagement. The structure of these descriptions has been tailored to the activities of each CRG and whilst there is some standardisation, there are many areas of divergence.

These descriptions and opinions are examples of stakeholder engagement work and perspectives from CRGs; they are neither all-encompassing nor meant to be a “gold-standard”. The descriptions provide case studies of stakeholder engagement from a variety of subject areas and different levels of resourcing.

### 2.1 Back and Neck Group and Musculoskeletal Group

Cochrane Back & Neck (B&N) are now managed by staff from Cochrane Musculoskeletal (MSK) so the contents of this section apply to both groups who shall be herein referred to as Cochrane B&N/MSK.

#### 2.1.1 Observations of stakeholder engagement

Cochrane B&N/MSK take a focused approach to stakeholder engagement following the model of the “Evidence Ecosystem” (Ravaud et al., 2020) which suggests that putting together the community of clinical trialists, evidence synthesisers and guideline developers will provide a full cycle of evidence. This ensures evidence swiftly informs clinical practice. If these three communities are not connected, reviews may be conducted which are not taken into account by guideline developers, and trials designed which do not answer the appropriate clinical question. For this reason Cochrane B&N/MSK have focused their stakeholder engagement work on engaging guideline developers as well as clinical trial networks. They have found it surprisingly easy to connect with guideline developers who are eager to engage. This has had a consequential positive impact on dissemination. They are now trying to encourage guideline developers to share resources but have encountered more resistance here.

Much of the stakeholder work described relates to Australia, some to New Zealand, and some to Canada. Cochrane B&N/MSK express desire to expand this globally. They would like to do stakeholder engagement work in diverse settings such as lower and middle income countries (LMIC). There is evidence that LMIC are making similar “mistakes” to developed countries in terms of spending resources on treatments which do not have evidence of efficacy or have evidence of lack of efficacy. Work has been done with colleagues in Brazil, Nepal, and Mexico, and more is planned for the future. Stakeholder engagement requires CRG time and resources, reducing time available for review production, but is overall seen as positive and beneficial.

#### 2.1.2 Stakeholder engagement activities

##### Priority setting

Prioritisation is a key reason for stakeholder engagement. When Cochrane MSK was first formed they held meetings every six months with stakeholders including NHMRC, funders, policy makers, and consumers to identify high priority questions. This interaction faded as it became apparent that the stakeholders they engaged with did not know which questions should take priority.

Cochrane B&N/MSK identified all musculoskeletal researchers in Australia by compiling a list of authors of all papers from major relevant journals, all recipients of funding from the Australian National Health

and Medical Research Council (NHMRC), and examining the clinical trial registry. From this they created the Australia and New Zealand Musculoskeletal Clinical Trial Network (ANZMUSC) of >320 researchers from many disciplines and backgrounds. The aim of the Network is to reduce research waste and ensure the most important research questions are addressed, including implementation questions. ANZMUSC is developing a priority setting tool. The tool will be used to prioritise questions identified by clinicians, researchers and consumers.

Cochrane B&N/MSK surveyed all Australian rheumatologists via the Australian Rheumatology Association to identify and then rank important questions relating to pharmacologic management of rheumatoid arthritis. They now have a rank order list of 34 questions, which will enable updated systematic reviews to inform the Australian guidelines. This process will be repeated for other MSK conditions starting with juvenile inflammatory arthritis.

For the Back reviews, in 2018 the editorial group reached out to guideline developers with the portfolio of reviews to identify priorities for updating and gaps for new reviews.

Cochrane B&N/MSK involve consumers in prioritisation by having two consumers provide advice to the editorial board on prioritisation processes. A wider group of consumers is involved in priority setting processes by responding to surveys and helping to rank potential titles.

In 2013 Cochrane MSK conducted a James Lind Alliance priority setting exercise for osteoarthritis reviews and health equity. Part of the process involved engaging stakeholders in two workshops (one with patients only and one with clinicians, researchers, and patients) to identify broad priority topics. Osteoarthritis patients were later engaged to rank questions. They found consumers who volunteered had above average knowledge of systematic reviews but there was a lack of understanding of health equity. They acknowledge that the global spread of participants was not even and LMIC populations were underrepresented (Jaramillo et al., 2013).

### Review production

Consumers are occasionally involved in developing protocols and author both protocols and systematic reviews. Nearly every publication receives a consumer review with the only exception being updated reviews where the clinical message has not changed. They ask consumers to focus on the plain language summary when considering a review.

A key stakeholder group is potential authors of reviews. There is some indication that authors may have stepped away from Cochrane, choosing instead to publish in other journals which authors perceive to have quicker response times and to be accessed more regularly by clinicians. The reviews published without the quality checks implemented by Cochrane may not encompass all available evidence and may not have accounted for bias in the included studies which has implications for health care decision makers interpreting this evidence. Cochrane B&N have many reviews waiting to be conducted and there is a need to “win back” review authors.

Cochrane MSK/B&N acknowledge the need to engage the next generation of researchers to ensure these potential authors publish Cochrane reviews and access evidence through Cochrane. This is challenging due to lack of systematic review experience in these potential authors and insufficient CRG resources to train them. They feel it is important to engage these authors because Cochrane provide high quality unbiased systematic reviews to inform health care decisions. In addition, Cochrane produce living reviews which are updated regularly and are particularly helpful to guideline developers.

### Dissemination

Cochrane B&N/MSK have a long history of engaging with stakeholders in knowledge translation. In a paper published in 2014 they describe knowledge translation tools tailored to patients, practitioners, policy makers, and the public/press. Several different tools exist for each group which take 1, 5, 15, or 45 minutes to assimilate (Rader et al., 2014).

There is no formal engagement of consumers in dissemination but for a set of reviews on fibromyalgia, they paired up consumer authors of these reviews with students who were adept at social media. The students mentored the consumer authors through transforming consumer relevant messaging to a social media format.

The consumer representative for Cochrane B&N is also the editor of “The Back Letter” and uses this channel to disseminate summaries of Cochrane reviews around the world. Cochrane B&N put focused effort into growing their Twitter base to 4,000+ followers who had potential to receive notification of every review published. In addition to this, the Institute for Work & Health also has a Quarterly Newsletter that is distributed widely in Canada, which featured many Cochrane B&N reviews in the “What is New” section. Cochrane B&N reviews were used to develop the ACP guidelines, and also got cited by other guidelines as well. Cochrane reviews are also cited frequently in the UpToDate LBP and MSK topics.

#### Other

##### *Policy makers*

Staff working with Cochrane B&N/MSK have many connections and positions in other academic, research, and clinical settings. Many of the connections with stakeholders stem from individual relationships. Examples include:

- Australian government: Rachelle Buchbinder sat on the Australian Pharmaceutical Benefits Advisory Committee Economic Subcommittee for nine years and now sits on the Medical Services Advisory Committee. Chris Maher advises the Australian Institute for Health and Welfare. Both Rachelle Buchbinder and Chris Maher have provided advice to the Australian Commission on Quality and Safety in Health Care, the Behavioural Economics Research Team, and the National Prescribing Service.
- Australian National Health and Medical Research Council (NHMRC): Acting on peer review committees, translation committees, and being recipients of funding via fellowships, program grants, project grants, and centres of research excellence over many years.
- Australian Commission for Safety and Quality in Healthcare: The Australian Commission contacted members of these CRGs asking them to collaborate on developing clinical care standards for back pain. In addition they will work together to develop clinical indicators which could measure routinely collected health data across the world.
- Australia and New Zealand Musculoskeletal Clinical Trial Network (ANZMUSC): Both Rachelle Buchbinder and Chris Maher are founding members of this group which, amongst other activities, has a consumer advisory group with strong links with musculoskeletal researchers across Australia and New Zealand. They have recently invited the Australian Vasculitis network to join the ANZMUSC group. Under the umbrella of ANZMUSC and Cochrane, these CRGs are leading the development of Australian Living Guidelines for musculoskeletal conditions.
- World Health Organisation (WHO): They have been approached by the Cochrane Campbell Global Ageing Partnership to work with them on the Decade of Healthy Ageing with the WHO. They have a direct link with Lorenzo Moja from the Essential Medicine List who has asked for advice on

rheumatic drugs and more recently on biologics. Providing these reports ensure Cochrane evidence is considered for policy makers worldwide. They also have indirect links with WHO through guideline developers with whom they work closely.

### Consumers

Cochrane B&N/MSK have an extensive programme of engagement with consumers. Consumers are usually recruited by word of mouth from consumer to consumer and occasionally cold contact via the Cochrane B&N/MSK website. Consumer to consumer recruitment helps as a level of trust already exists before engagement officially starts. However it does mean the demographic of the consumer group is relatively uniform as consumers tend to recruit consumers who are similar to themselves. Examples of consumer activities include providing comments on the plain language summaries, being on the advisory board for prioritisation exercises, responding to prioritisation exercises, providing peer review, and work on social media.

Cochrane B&N/MSK have found that some individuals prefer the use of the term “lived experience” over the term “consumer” or “patient”. Although individuals will often refer to themselves as “consumer” whilst working within Cochrane, and “patient” to those outside of Cochrane, they are finding that “lived experience” provides a useful mid-point and covers a wider range of people who they consider to be stakeholders.

The success of this consumer engagement work stems from developing personal relationships; spending time listening to what is happening in their lives and who they are as individuals. Having invested that time and built the relationships, these consumers are then more engaged. For a while Cochrane B&N had a consumer editor which initially worked well, but other consumers felt that they were lacking engagement from Cochrane B&N directly as they did not see the consumer editor as Cochrane B&N staff. To resolve this, Cochrane B&N intend to produce a bulletin from the group to inform consumers on their activities. A further challenge has been sending messages to consumers asking for a first come first serve response, but the timing of the message favoured particular time zones. Now the CRG alternate time zones and collate responses. They also recognise the need to help consumers understand important systematic review concepts.

*Information from this section was derived primarily from conversations with Rachelle Buchbinder (Coordinating Editor), Chris Maher (Senior Editor) and Jordi Pardo Pardo (Managing Editor).*

Cochrane Back & Neck (B&N) are now managed by staff from Cochrane Musculoskeletal (MSK) so the contents of this section apply to both groups who shall be herein referred to as Cochrane B&N/MSK.

## 2.2 Ear, Nose, and Throat Group

### 2.2.1 Observations of stakeholder engagement

The Cochrane Ear, Nose, and Throat (ENT) Group identified that engaging stakeholders improves the quality and relevance of reviews as well as raising the profile of Cochrane, but was not without challenges. It was noted that engaging stakeholders in the UK was relatively easy. Even though stakeholders were engaged via email, stakeholders from other parts of the world were less likely to respond. Cochrane ENT involve consumers in prioritisation (by ranking, providing questions, and outcomes), developing protocols, providing consumer reviews, and reviewing plain language summaries.

Cochrane ENT finds it challenging to ensure the correct mix of stakeholders in their prioritisation work. It is important to balance patients and clinicians but also to get the correct mix of clinical interest within

clinicians, and disease manifestation within patients. For example, it was relatively easy to engage secondary or tertiary care physicians who dealt with balance disorders on a regular basis but harder to engage with primary care physicians for whom balance disorders was one of many areas of experience. Similarly, it was important to have a balanced mix of patient experiences and backgrounds.

It was recognised that the need to have a broad range of responses can result in an endless task and that it is challenging but important to know where to stop. Stakeholder engagement incurs a time cost including a reliance on other people's time. Knowing how to summarise feedback received by stakeholders can be challenging if ratings are mixed and there is no clear, transparent method for making sense of this information. Stakeholder engagement in prioritisation, if authentic, can produce a list of reviews which was substantially different from that which was anticipated and can potentially result in a bigger project than intended. This is both a benefit and a drawback.

### 2.2.2 Stakeholder engagement activities

#### Priority setting

##### *Balance disorders*

In 2019, Cochrane ENT commenced a prioritisation exercise investigating balance disorders. Previously this topic had been covered on an ad-hoc basis. The process aimed to produce a comprehensive suite of reviews which would be most beneficial to patients and healthcare professionals. Following a scoping exercise they identified a comprehensive list of disorders and topics that fell under the broad subject of "ENT-related balance disorders".

Three mechanisms enabled them to reach stakeholders:

1. Contact via relevant professional organisations enabled them to reach physiotherapists, doctors, and nurses interested in balance disorders.
2. Word of mouth through clinicians already involved in their work.
3. Contacting relevant patient groups found online.

Stakeholders were provided with an initial scoping document and a table listing different balance disorders. They were asked to rank a maximum of 10 disorders in order and asked specific questions around evidence availability and treatment uncertainties. The aim was to agree:

1. Which disorders and/or interventions are most important for patients, carers, and health practitioners?
2. For which disorders and which interventions is it most important to prepare new Cochrane systematic reviews, or update existing ones?
3. In those reviews, which outcomes are most important for patients, carers and health professionals? Note: there are no published core outcome sets on balance, so they asked for broad topics and narrative outcomes. They have applied for funding and are hoping to run a survey with patients to help prioritise outcomes.

The results of this process led to a prioritised list of disorders and topics which will be covered by Cochrane reviews.

##### *Otitis media with effusion (OME)*

Cochrane ENT also conducted a prioritisation exercise involving 12 professionals and one parent of a child with OME who were asked to rank 16 interventions in order of importance, based on their clinical

practice or experience. The ENT Group has a partnership with the International Society of Otitis Media who emailed their members to ask for volunteers. They also recruited lay members through Task Exchange, and a core group of clinicians was suggested by the Cochrane ENT clinical coordinator. The professional consultation group included nine otolaryngology specialists and three people with expertise in primary care or paediatrics. Each intervention was awarded a score based on its ranked position from each participant and a total score was calculated.

### Review production

In September 2020 Cochrane ENT were funded to conduct some fast-tracked living systematic reviews on the prevention and treatment of post-COVID-19 anosmia (loss/dysfunction of smell/taste). They have been working with patient groups to try to identify important outcomes that should be used in these reviews. They contacted two patient support groups, who were able to circulate surveys to their members and advertise on their webpages for rapid feedback. A preliminary survey was used to identify outcomes that were of relevance for individuals with anosmia. More than 600 responses to this survey were obtained in less than one week.

A secondary survey was then conducted to ask individuals to help prioritise the outcomes, and over 300 responses were obtained. This has proved to be a valuable way of rapidly obtaining feedback from people affected with a disorder, which will help the author team when defining critical and important outcomes for the reviews.

### Dissemination

The US journal *Otolaryngology – Head & Neck Surgery* published a quarterly “Cochrane Corner” with invited commentaries on selected review abstracts between 2007 and 2017. This feature disseminated Cochrane ENT reviews widely in the US. Cochrane ENT now has a similar Cochrane Corner in the *International Journal of Audiology* (<https://www.tandfonline.com/doi/abs/10.1080/14992027.2017.1338764>).

Cochrane ENT worked closely with NICE on two of their recent guidelines: hearing loss and tinnitus. The 2018 hearing loss guideline included a full collaboration between NICE and Cochrane ENT to complete a review of bilateral versus unilateral hearing aids. Cochrane ENT also fast-tracked a second review to inform the guideline (“Hearing aids for mild to moderate hearing loss in adults”). They then engaged extensively with NICE during 2019 on the development of the new “Tinnitus: assessment and management (NG155)” guideline (published March 2020). They carried out a prioritisation process beforehand to select topics that would be useful to the planned guideline and subsequently fast-tracked two new reviews, on betahistine and sound therapy, which were included in their entirety. Cochrane ENT is now in touch with NICE about their forthcoming otitis media with effusion (glue ear) guideline and how they can contribute.

Cochrane ENT has had a close relationship with the American Academy of Otolaryngology – Head & Neck Surgery (AAO-HNS) for many years. The AAO-HNS funds a Cochrane Scholars Program for US ENT surgeons to attend the annual Cochrane Colloquia, with 3 to 4 delegates attending each year. Cochrane ENT has now hosted nearly 50 delegates at the colloquia. They have also hosted in Oxford two “Cochrane Conclave” systematic review training events for delegations of ENT surgeons from the AAO-HNS. They organised training programmes that included introductions to Cochrane systematic reviewing, critical appraisal and meta-analysis, and presentations on putting evidence into context, evidence-based surgery and better value population health care. Cochrane ENT was a member of World Health Organisation’s World Hearing Forum for the last year. Their involvement focused on the WHO World Hearing report, which was released in Spring 2020 and which they will help disseminate.

Information from this section was derived primarily from a conversation with Katie Webster, Systematic Reviewer.

## 2.3 Eyes and Vision Group

### 2.3.1 Observations of stakeholder engagement

Cochrane Eyes and Vision (CEV) has conducted extensive stakeholder engagement work. There are several elements which have led to their success. Stakeholder engagement:

- Takes time: Their current stakeholder engagement status is a result of over 20 years of work. Stakeholder engagement “doesn’t happen overnight” and mutual trust is developed over several years.
- Requires a perception of stakeholders as true partners: It is important to develop meaningful engagement and partnership. Stakeholder engagement is not a competition with stakeholders; it is about supporting and informing each other’s work.
- Requires vision and leadership: CEV have strong stakeholder engagement following the vision and leadership of Richard Wormald and Kay Dickersin.
- Needs funding: CEV work is possible largely due to grant funding. They recognized firstly that in order to do stakeholder engagement justice, they needed funds to cover personnel and other activities. Secondly, they identified that funding bodies want to see more interconnectedness and grant applications are stronger if they include partnership. CEV@US satellite currently has funding for the equivalent of six full time personnel.

### 2.3.2 Stakeholder engagement activities

#### Priority setting

CEV have engaged with the following organisations during priority setting:

- James Lind Alliance: Members of Cochrane Eyes and Vision were involved in the James Lind Alliance Sight Loss and Vision Priority Setting Partnership which is published (Rowe et al., 2014).
- American Society of Retina Specialists: survey membership to help prioritise questions and identify evidence gaps.
- American Glaucoma Society: helped in prioritising systematic reviews.
- Asia Pacific Glaucoma Society: helped in prioritising systematic reviews.
- The Macular Disease Society (UK) helped to identify people with age-related macular degeneration for a consumer panel. The contributors provided input on plain language summaries as well as giving direction on the appropriateness and measurement of outcomes (Twamley et al., 2011).
- In the US, consumers formed a patient panel for a specific eye condition, and discussed outcome and questions to help prioritise questions to be addressed by CEV systematic reviews (Saldanha et al., 2018). For each question, specific patient groups are approached. This ensures that the questions asked and the outcomes assessed are patient-important. CEV has supported a consumer to attend a Cochrane Colloquium and host a workshop.

#### Review production

CEV@US has partnered with clinical centres which they accredit as *Cochrane Eyes and Vision Centres for Evidence-based Vision Care*. This designation results from providing collaborative educational programmes, co-hosting workshops, publishing Cochrane Reviews, and mentoring of individuals in

evidence-based care (<https://eyes.cochrane.org/cev-centers-evidence-based-medicine>). To become a Centre, an institution must: (1) complete five or more CEV reviews or have three or more first authors of CEV reviews; and (2) keep its systematic reviews up to date.

CEV@US is working on criteria for maintaining a Centre status. This means each Center has highly skilled investigators who work to provide the best patient care worldwide. They provide conduits for dissemination and ensure evidence is used in their own practice. They are partners in education in Cochrane methodology and evidence. These partnerships help them prioritise their reviews and produce recommendations for practice. Each partnership developed leads to increase the likelihood of interest from other professional societies which further increases the profile of CEV.

Current CEV Centres for Evidence-based Vision Care are:

- Wilmer Eye Institute at Johns Hopkins
- Byers Eye Institute at Stanford
- Stein Eye Institute at UCLA
- Ohio State College of Optometry
- Montefiore Medical Center, Department of Ophthalmology and Vision Sciences
- G.B. Bietti Foundation
- University of Florence

Centres in progress:

- Department of Ophthalmology, Mayo Clinic
- Division of Optometry and Visual Science, City, University of London
- University of Alabama at Birmingham, School of Optometry
- Department of Ophthalmology, Brown University
- Department of Ophthalmology, University of Colorado Anschutz

In 2011, CEV@US began partnering with relevant journals to increase the quality of systematic reviews published outside *The Cochrane Library*. This partnership began with *Ophthalmology* and now includes ten major eye journals. CEV@US appointed a methodologist to serve on the board of journals they partner with as a quality check. Their grant permits them to pay methodologists a small amount as recognition of their expertise, time, and commitment. This payment is in recognition that to do stakeholder engagement you have to have paid personnel, it is to ensure they are equipping their stakeholders with what they need to engage. In addition, several journals (*Ophthalmology*, *American Journal of Ophthalmology*, *JAMA Ophthalmology*, and *BMC Ophthalmology*) link to CEV online peer review course “Translating Critical Review of a Manuscript into Meaningful Peer Review”.

### Dissemination

CEV provide reviews for every single guideline produced by the listed guideline panels. CEV reviews have underpinned 121 clinical practice guidelines in the US and internationally (as of December 2020). Partnerships involve working to produce the right reviews, involving a methodologist to ensure evidence is translated appropriately, sitting in guideline meetings, and explaining summaries of evidence.

CEV have partnerships with:

- The American Academy of Ophthalmology: updating 19/23 “preferred practice patterns”.
- National Institute for Health and Care Excellence (NICE): In 2017, this involved prioritising reviews and updates to support the development of guidelines on macular degeneration and cataract.

- Royal College of Ophthalmologists and College of Optometrists: ensuring evidence based guidelines to draw on Cochrane Reviews.
- WHO: ongoing collaboration to identify evidence for the Package of Eye Care Interventions.
- American Academy of Optometry: help to reach the status of a “**Cochrane Eyes and Vision Centres for Evidence-based Vision Care**”. Partnering with them to educate members about Cochrane and Cochrane reviews.
- American Optometric Association: offer annual workshops on systematic review methodology
- European Glaucoma Society: invited CEV to partner with them for guideline development.

Partnership with clinical trial networks to expedite the synthesis of primary research and to ensure systematic reviews are used to inform trial designs. CEV have partnerships with:

- Diabetic Retinopathy Clinical Research Network (DRCR.net)
- Paediatric Eye Disease Investigator Group (PEDIG)

CEV use numerous strategies to work with stakeholders in dissemination. They have presented educational workshops at conferences hosted by Association for Research in Vision and Ophthalmology, AAO, American Academy of Optometry, American Glaucoma Society, DRCR.net, Pediatric Eye Disease Investigator Group (PEDIG), Guidelines International Network (G-I-N), and Association of Vision Science Librarians. Authors are encouraged to present their work at professional and speciality society meetings and so are important partners in dissemination. With help from the National Medical Association, CEV reach underserved populations with their research.

CEV has partnered with two clinical decision-support applications which are used widely by clinicians: DynaMed® and UpToDate®. DynaMed® is accessed by more than one million providers and identifies which Cochrane reviews are useful for recommendations. UpToDate® is also accessed by millions of clinicians and includes articles by prominent subject leaders. CEV have received “Letters of Support” from DynaMed® and UpToDate® which demonstrates that CEV reviews have impact.

CEV commissions regular Cochrane Corner type articles for Eye which is the journal of the Royal College of Ophthalmologists in the UK. These provide a clinical commentary on selected Cochrane reviews.

## Other

### *Consumers*

CEV try to work with consumers who can represent an average patient rather than just his or her own experience. They recognise that an individual’s own experience is important but they look for individuals who are able to represent the patient population. CEV have partnered with several consumer organisations (Dry Eye Zone, MD Support, Tear and Film Society) Consumers are involved in prioritisation, developing protocols, being authors on systematic reviews, providing peer reviews, advising on the writing of plain language summaries, and engaging with social media.

### *CEV@US Project CV*

[https://eyes.cochrane.org/sites/eyes.cochrane.org/files/public/uploads/cev\\_cv\\_30.12.20\\_0.pdf](https://eyes.cochrane.org/sites/eyes.cochrane.org/files/public/uploads/cev_cv_30.12.20_0.pdf)

*Information from this section was derived primarily from a conversation with Jenny Evans, Co-ordinating Editor CEV UK, and Tianjing Li, Co-ordinating Editor and Director, CEV@ US Satellite.*

## 2.4 Oral Health Group

### 2.4.1 Observations of stakeholder engagement

The Oral Health Group (OHG) has extensive stakeholder engagement work which has proved especially beneficial in responding to the Covid19 pandemic. There was urgency which united everyone to work together for the same challenge. As a whole community there is the realisation that projects can be completed quickly when everyone works together.

Engaging stakeholders can be challenging because although most of the population visit the dentist regularly, for most review topics, there is no specific patient or consumer group or charity. Despite this, OHG have a clear understanding of the Oral Health “ecosystem”, their position within it, and how to engage their stakeholders. As a result of stakeholder engagement work, Cochrane’s reputation within Oral Health is such that doors are open to the OHG throughout the world. The challenge for the OHG is to work out what to ask for and what to offer their stakeholders given their finite resources.

The OHG historically had a consumer who would look over protocols, provided peer review, and helped to write the Plain Language Summary. This consumer has now moved on and there is no formal process in place. They engage with the Macular Disease Society who help identify patients to sit on a panel providing input on plain language summaries and looking at appropriateness and measurement of outcome.

### 2.4.2 Stakeholder engagement activities

#### Priority setting

At the outset, the OHG decided to involve stakeholders in their prioritisation work as much as possible. They began with an open survey which received 164 respondents evenly divided between clinicians and consumers. The global spread of responses was diverse with India being the biggest contributor. From these responses approximately 200 questions were collated into themes, combined with what was already known about priorities from other work, and put into a survey sent to an expert panel. This panel of about 40 people consisted of policy makers, guideline developers, consumers, general dentists, dental surgeons, and orthodontists. Recruitment to this panel was conducted through using existing authors and their networks, task exchange, and GEEOH. The priority titles are now established so the OHG will now turn attention to the challenging task of recruiting authors who have both the capability to do the work and the time to complete it within set deadlines.

Both co-ordinating editors have been involved in the James Lind Alliance Oral Health Priority Setting Partnership but the questions produced are generally too broad to be used for the OHG own reviews hence their own priority setting process.

#### Review production

Stemming from an impromptu conversation at a Cochrane Colloquia regarding the evidence of duplication of systematic reviews in the oral health field, the OHG set up the Global Alliance (GA) of funding partners (<https://oralhealth.cochrane.org/partnerships-alliances>). This has recently developed into the Global Evidence Ecosystem for Oral Health (GEEOH) which aims to “to reduce research waste, avoid duplication of effort, and close the loop between new evidence and improved care by involving international organisations with responsibility and contributions at different stages of the ecosystem”. This group includes amongst others, the WHO, International Federation of Dentists (FDI) (worldwide), International Association for Dental Research (IADR), specialist groups worldwide, guideline producers, and publishers. Further information can be found online: <https://oralhealth.cochrane.org/about-us/partnerships-and-funders/global-evidence-ecosystem-oral-health-geeoh>. The GEEOH is working to

realise the potential of working differently together the benefits of which have become clearly apparent as a consequence of the Covid19 pandemic.

### Dissemination

The COVID-19 Dental Services Evidence Review (CoDER) Working Group which includes the Health Services group in Aberdeen, the Scottish Dental Clinical Effectiveness Programme, and Cochrane OHG, collaborated to rapidly (over 10 days) collate guidance documents on the reopening of dental practices (<https://www.nature.com/articles/s41415-020-1660-1>). Through this collaboration Cochrane's position within the Oral Health field as an agent to share information has been emphasized. The OHG webpage was redesigned as a repository for information and Cochrane's Knowledge Translation department supported dissemination of this review which was accessed 45,000 times in May. It is used by the WHO, and chief dental officers from governments around the world. They are provided with weekly updates by chief dental officers from the US, Canada, Australia and New Zealand. This project was supported by the GEEOH team who enabled them to access international guidance. Cochrane OHG note that it has been hard to engage with the WHO and engagement varies depending on who is in the position of director which changes regularly.

They have now been approached by the International Federation of Dentistry and asked to extend their work to incorporate particular concern for lower and middle income countries. At point of interview, the first minister in Scotland was waiting for guidance from this group to be published prior to making dentistry decisions. Within the UK, the OHG are part of a group of all dental officers, presidents of the hygiene and therapy associations, dental nurses, practice managers, orthodontists, paediatric dentists, aerobiology specialists, virologist, national physical laboratories and the British Dental Association responding to Covid19. They are now looking at guidelines on introducing the drill in post-Covid19 dental settings.

The creation of GEEOH laid the foundations and principles for collaboration which were enacted in practice when the Covid19 crisis occurred.

*Information from this section was derived primarily from a conversation with Jan Clarkson (Co-ordinating Editor) and Anne Littlewood (Information Specialist).*

## **2.5 Pain, Palliative, and Supportive Care Group**

### **2.5.1 Observations of stakeholder engagement**

The Pain, Palliative, and Supportive Care Group (PaPaS) has an international pool of editors to assist in stakeholder engagement which includes heavy coverage in the UK, one editor in Belgium, Germany, USA, Canada and Australia. PaPaS are aware this means they lack balanced global coverage. Cochrane UK provides annual data on review citations in national and international guidelines, and PaPaS Reviews are highly cited across the broad scope of topics (2019 unofficial equivalent impact factor 11.446).

PaPaS covers four broad topics: acute pain, chronic pain, palliative and supportive care, and headache/migraine. There are challenges engaging effectively with people affected by the conditions within their scope. Despite these challenges, PaPaS has established stakeholder engagement work in dissemination and consumer peer review, and has plans to continue to improve and innovate in this area. The Group is also focusing on priority setting, and continuing to ensure their reviews are relevant and useful to all stakeholders.

## 2.5.2 Stakeholder engagement activities

### Priority Setting

In 2019, PaPaS embarked on a priority setting exercise with the aim of identifying the priorities in each topic area within their scope. For each topic, a steering group is recruited from the editorial team to include members with clinical and methods expertise. The steering groups are responsible for: assessing the current status of PaPaS reviews and “gap mapping” across the portfolio; providing expertise with regards the current evidence base and any ongoing trials or new interventions; advising of any existing priority setting work; and making connections with additional expertise via their own networks. External stakeholder engagement as part of priority setting involves gathering feedback from relevant stakeholders on the list of potential priority Cochrane Reviews identified by the steering group, as well as providing further comments about their own priorities if not on the list. Full details of this process are described on their website: <https://papas.cochrane.org/resources/prioritisation/priority-setting-project>.

### Review production

A key stakeholder for the PaPaS Group is review author teams. The main route of communication is through email (e.g. regular newsletters) and Archie tasks. While there are a few well-established author teams that can produce a series of several timely reviews to a high standard (such as neuropathic pain and fibromyalgia; TENS, and psychological interventions), retaining authors who complete subsequent reviews after their first publication remains a challenge. An author’s competing priorities such as clinical work or career progression may be contributing factors to the high turnover rate, but the sheer volume of work required to complete a full review, alongside all the often-changing Cochrane guidance and requirements, is likely the biggest factor.

Every PaPaS protocol, review and update receives peer review by a consumer. Usually these individuals are recruited through Task Exchange by advertising for someone with “lived experience” of the review topic. Often there are several volunteers to choose from who are keen to contribute. PaPaS appreciates the swift feedback provided by consumers which is also often highly valued by the author teams. In addition, consumers have expressed appreciation at being able to see the impact they can have, since PaPaS routinely sends the collated peer review comments and author responses to all peer reviewers along with the final publication.

Members of the PaPaS core editorial board have established and led a special interest group in systematic reviews and evidence synthesis methods for many years within the International Association for the Study of Pain (IASP). This group was recently relaunched as the Methodology, Evidence Synthesis, and Implementation SIG (MESISIG) and is chaired by Prof Eccleston (former PaPaS Co-Ed to October 2020). The goals of the group are to:

- foster a widespread interest in the production and science of systematic reviews and meta-analysis of the highest quality for pain management;
- provide a forum for dissemination of skills and reviews, providing assistance in the work of "discovering" relevant publications, quality control and scoring, and extracting data, to assist in maintaining the high profile of pain research and management in the wide context of health care.

Through this group, PaPaS is working to drive improvements in the quality of evidence synthesis in the field of pain and to share innovative methods and best practice.

### Dissemination

PaPaS has a successful social media presence and uses online platforms to engage with stakeholders at many different levels. Some examples of social media stakeholder engagement include:

1. Partnering with Hospice UK and the “Dying Matters” coalition around the annual Dying Matters week in May. This was initiated in 2015 following several successful discussions, and has led to annual engagement around the Awareness Week. PaPaS creates and shares topical blog posts and blogshots of relevant reviews.
2. Using a wider “catch all” strategy of Tweets and Blogshots, for example for all new publications, to raise awareness and reach a broad audience, e.g. clinicians, patients, and researchers.
3. Tagging specific charities or organisations with Tweets. For example they worked closely with authors and Cochrane’s KT team to launch a large dissemination plan to share findings in children’s chronic pain. They helped to co-ordinate and disseminate articles, blogs, newsletters, videos, and a social media experience campaign to help raise awareness of the importance of evidence production in children’s pain.
4. PaPaS has sought to engage principal investigators by tailoring the “Implications for Research” section of their reviews. Authors are encouraged to specify the exact requirements (such as PICO and time points) for future research so that funders and researchers designing trials can ensure their research fills the necessary gaps.
5. Since 2019, PaPaS policy is to ensure that every review and update has a Dissemination Plan in place before publication; new protocols are also disseminated via Social Media for information.
6. The PaPaS Peer Review Checklist includes a section for the reviewer to suggest any relevant stakeholders to include in the Dissemination Plan, and this section often provides excellent suggestions.

The PaPaS Managing Editor (ME) is a registered stakeholder with the National Institute for Health and Care Excellence (NICE) in the UK. NICE produces evidence-based guidance and advice for health, public health and social care practitioners, and the ME is signed up to receive notification of new or updated guidelines entering the consultation phase. The PaPaS editorial board will provide feedback which the ME collates and submits to NICE. PaPaS editors have worked with bodies such as NICE to develop clinical guidelines. For example PaPaS Co-Ed Neil O’Connell was on the guideline development group for the 2016 NICE guideline on the management of low back pain and sciatica and was an expert advisor to the Quality Standards. In 2020, PaPaS received a NICE Priority Review grant to work with an author team to produce an updated review on interventions for malignant pleural effusions.

Editor Winfried Hauser is a member of the steering committee of the update of the European League Against Rheumatism (EULAR) recommendations on the management of fibromyalgia, and is also the head of the steering committee of the German interdisciplinary guidelines on fibromyalgia syndrome.

In 2019, PaPaS published an overview review in the PAIN Journal on the efficacy of pharmacological interventions for children with chronic pain and cancer-related pain (Eccleston et al., 2019). The overview summarises the evidence from 23 systematic reviews, including several PaPaS reviews from their NIHR Programme Grant (<https://papas.cochrane.org/nihr-programme-grant-2014-17>). This work also builds on a policy workshop the group held in 2018 focussing on this topic (<https://bit.ly/2RGOGcK>). All of this work led to engagement with the World Health Organization (WHO) where members of PaPaS were successful in being competitively selected to produce the evidence-based summaries to inform the updated guidelines on chronic pain in children, published in December 2020 (<https://www.who.int/publications/i/item/9789240017870>). This work also led to a Lancet Child and

Adolescent Health Commission on transformative goals for paediatric pain which is anticipated to set policy, research, clinical, and funding policy for the next 5-10 years (<https://www.thelancet.com/commission/paediatric-pain>).

*Information from this section was derived primarily from a conversation with Anna Erskine (Managing Editor) and Kerry Harding (Assistant Managing Editor).*

## 2.6 Skin Group

### 2.6.1 Observations of stakeholder engagement

Up to 25% of the population globally has a skin condition. Reviews conducted by Cochrane Skin (CS) gain a lot of interest from the media and popular press, which means there is great potential for wide stakeholder engagement.

They recognise that stakeholder engagement can be time and resource intensive, drawing resources away from systematic review production. However, it ensures they are not an “ivory tower” of systematic review production, unaware of the reality, but instead are engaged and able to improve healthcare decision making around the globe. Stakeholder engagement is valued and highly important. CS has a “longstanding tradition” of engaging consumers and has branched out by undertaking a wide range of stakeholder engagement activities. CS stakeholder engagement covers areas of their work including prioritisation, review co-production, dissemination, collaboration, and international meetings. They have recently appointed a Consumer Editor, to encourage participation and facilitate consumer involvement.

### 2.6.2 Stakeholder engagement activities

#### Priority setting

To assist with prioritisation work, CS examined James Lind Alliance Priority Setting Partnerships top 10 for relevant areas. They engaged with professional societies and guideline developers, consumers, and patient organisations. These groups help CS to decide where to put resources.

For their 2020 prioritisation process they contacted UK, US, and European guideline developers and professional societies, including National Institute for Health and Care Excellence (NICE), British Association of Dermatologists (BAD), American Academy of Dermatology (AAD), European Academy of Dermatology and Venereology, European Dermatology Foundation and the Primary Care Dermatology Society. They received suggestions from dermatologists and researchers across the world. Relevant AAD and NICE guidelines were scoped to identify priorities for research already summarised there. They also looked at relevant Priority Setting Partnership top ten uncertainties. The results have been fed back to all stakeholders who took part, and expressions of interest in authoring the prioritised titles received.

As part of their 2020 prioritisation process, they contacted patients and patient groups to ask for their suggestions for reviews of importance to patients. This led to 25% of the contribution to their prioritisation work coming from individual consumers or consumer groups. The following organisations were contacted:

- Vitiligo Society
- Psoriasis Association
- Psoriasis and Psoriatic Arthritis Alliance (PAPAA)
- Acción Psoriasis
- SPIN (Skin Inflammation & Psoriasis International Network)
- Alopecia UK
- Hidradenitis Suppurativa Trust

- National Eczema Society
- L'Association Française de l'Eczéma
- National Eczema Associations (US and Australia)
- Nottingham support group for carers of children with eczema
- Skin cancer awareness
- Melanoma UK
- DEBRA (Epidermolysis Bullosa)
- Hyperhidrosis Support Group
- Ichthyosis Support Group
- Association for Lichen Sclerosus and Vulval Health
- UK Lichen Planus

### Review production

In addition to the work on prioritisation, CS aim for all review teams to include a consumer co-author, who ensures that review questions are relevant to people requiring and accessing healthcare, and that areas of high importance to consumers are given priority. They aim to have every review and protocol peer reviewed by a consumer. In one instance a consumer led a review. In the past, consumers have been involved in writing the plain language summary.

### Dissemination

Cochrane Skin have been building a closer relationship with the American Academy of Dermatology's (AAD) guideline developers and have now been appointed as preferred providers of AAD systematic reviews to inform their guideline development process going forwards. In 2020, the AAD have commissioned CS to produce a number of data deliverables for their Phototherapy for Atopic Dermatitis Project, based on the production of a Cochrane Review. AAD presented at the virtual CS meeting in March 2020 and have attended CS virtual editorial meetings.

Cochrane Skin remains alert to NICE's plans for developing/updating guidelines and register as stakeholders on those that are relevant. In 2019 they shared drafts of two acne reviews to inform the NICE acne management guideline, and in response to the NICE announcement that their guideline "Skin tumours including Melanoma: assessment and management" was due for updating, they contacted NICE in October to highlight the DTA reviews CS published late last year on diagnosis of skin cancer. These were passed to the guideline developers, for consideration in the scoping phase.

They maintain a relationship with the British Association of Dermatologists, regularly updating each other about relevant review and guideline progress.

### *Collaboration with the Centre of Evidence Based Dermatology*

Cochrane Skin sits within the Centre of Evidence Based Dermatology (CEBD), which has multiple avenues (social media posts, email newsletters, educational events) for promoting CS reviews to the dermatology community across the world. As part of the CEBD they have links with a patient panel, a pool of existing consumers for specific skin conditions.

Cochrane Skin reviews can be used to inform the development and design of new intervention trials (often funded by the NHS) within the CEBD, and to synthesise the outcomes of such trials. For example, an individual participant data meta-analysis of skin care interventions for preventing eczema is being undertaken within CS, and this capitalises on the Barrier Enhancement for Eczema Prevention intervention trial that is co-ordinated from the Centre.

### *International Meetings*

Cochrane Skin advocates for global knowledge translation via satellites in France and Colombia. Examples of this include a talk given by the Director of the French Satellite in May to approximately 200 dermatologists, where she discussed three CS reviews from the past year. And with the French Society of Dermatology, the French Satellite produces systematic review summaries for French-speaking dermatologists distributed by newsletter.

Robert Dellavalle (CS Joint Co-ordinating editor) is also raising the profile of Cochrane and CS internationally. He delivered a CS evidence-based dermatology 3-hour seminar at the 2019 American Academy of Dermatology annual meeting in Washington DC and presented to the Taiwanese EBM Society in August 2019. He was a methodologist on a guideline for HIV skin disease with the World Health Organisation.

Cochrane Skin prepared virtual posters on various Cochrane themes for the World Dermatology Congress in Milan 2019. CS always aim to have consumer input at their Annual Meeting, by regularly offering travel bursaries, and always inviting a patient to present at each meeting to ensure their voice is represented.

Cochrane Skin has held two virtual two-day annual skin group meetings in March 2000 and March 2021 funded by an NIH conference grant. The grant funds the organization, dissemination and evaluation of the 2020 annual meeting of the Cochrane Collaboration Skin Group in Aurora, Colorado, in March 2020, where leading US dermatologists met to discuss collaborative comparative-effectiveness research.

Cochrane Skin only publishes a review once the authors provide a dissemination strategy specifying targeted stakeholders and their intended messaging.

Upon publication of a review, they sometimes contact the NIHR Dissemination Centre, who may wish to consider turning CS research into an “Alert”. Alerts constitute a short summary of health research presented in plain English and are used to promote the research. In 2019, the DTA review “Dermoscopy, with and without visual inspection, for diagnosing melanoma in adults” was chosen. Prior to this, two older Alerts have also used CS reviews.

For each review published, they notify DynaMed, which covers all Cochrane reviews and summarises them in its topics. DynaMed works in partnership with Evidence Alerts, an Internet service that notifies physicians and researchers about newly-published clinical studies, produced by McMaster University.

Cochrane UK’s Knowledge Broker, Selena Ryan-Vig, disseminates all of Cochrane Skin’s reviews to relevant organisations, and although these are mostly UK-based organisations, she also contacts some more generalised global health organisations when the reviews may be of interest to them.

*Information from this section was derived primarily from a conversation with Robert Dellavalle, Joint Co-ordinating Editor and Helen Scott (Assistant Managing Editor) and supplemented by written information provided by Laura Prescott (Managing Editor).*

## **2.7 Wounds Group**

### **2.7.1 Observations of stakeholder engagement**

Cochrane Wounds consider stakeholder engagement to be the essence of who they are, the “bread and butter” of everything they do. Nicky Cullum states “it’s everything to me, what my career has been about”. Stakeholder engagement is not a project for Cochrane Wounds; rather it is an ongoing, continuous, everyday activity.

Effective stakeholder engagement involves putting effort into identifying key stakeholders and time into building relationships. It is important relationships are built on trust and an accurate understanding of each other's roles. As a collaborator, be clear on what is brought to the table, what is offered to the stakeholder, and how their job will be made easier. When it is obvious that something substantial is being offered, relationships can be built more quickly. Cochrane Wounds understand that stakeholder engagement requires resources but they could not imagine functioning without it.

### 2.7.2 Stakeholder engagement activities

#### Priority setting

Cochrane Wounds conducted a James Lind Priority Setting Partnership for Pressure Ulcers which generated 12 priority questions and they continue to be guided by those priorities to ensure reviews and updates respond to service-user demand. To date, the majority of the uncertainties identified in this exercise now have a new or updated corresponding Cochrane Review.

Wound care related products are frequently offered for evaluation and Cochrane Wounds support NICE in ensuring the evidence for costs and effects is considered as fully as possible. Their involvement in this process is another way they prioritise topics for systematic review

Cochrane Wounds has a close collaborative relationship with Manchester University NHS Foundation Trust (MFT); Nicky Cullum is Honorary Professor of Nursing, Jo Dumville (who is non-clinical) holds an honorary contract with the Trust. This has led to the founding of the Manchester Wound Care Group, chaired by the Chief Nurse of MFT, Professor Cheryl Lenney. This multidisciplinary group is developing a wound care strategy for Manchester and these close clinical links will identify priorities for research (including systematic reviews) and practice.

The close involvement of Nicky Cullum and Jo Dumville in the English National Wound Care Strategy Programme enables them to identify priority topics relevant to pressure ulcers, lower limb ulcers, and surgical wounds where systematic reviews are needed

The Wounds Research Group at the University of Manchester led, until September 2019, the Wound Care Research Programme of the NIHR CLAHRC Greater Manchester (GM). This Programme worked closely with stakeholders in the health system of GM to increase the volume, quality and responsiveness of wounds research in GM. Cochrane Wounds conducted a comprehensive analysis of the management of more than 2000 people with complex wounds in GM to identify treatments being used in practice and unintended variations in practice (which are signals of uncertainty). The CLAHRC work also included a formal prioritisation process with NHS stakeholders that yielded 158 "raw" uncertainties in wound care (Gray et al., 2017). These 158 uncertainties were further prioritised to a final 25 identified as high priority for decision makers. All these data are used to prioritise updates and new reviews and the Wounds group published an analysis of the extent to which systematic reviews are meeting the needs of decision-makers in wound care.

#### Dissemination

Cochrane Wounds is embedded within the Wounds Research Group at the University of Manchester and from there they collaborate on an ongoing basis with stakeholders including NICE, Manchester University NHS Foundation Trust (MFT), NHS England National Wound Care Strategy Programme, CLAHRC Wounds, and James Lind Priority Setting Partnership. NICE, MFT, and NHS England National Wound Care Strategy are key stakeholders for dissemination of reviews.

These partnerships stem from Nicky Cullum's long term relationships including being on the first NICE appraisals committee in 1999, being involved in the NIHR before it was even known as the NIHR, and being in the first Cochrane meeting. Partnerships also stem from a clear focus on evidence availability and an understanding of issues in practice. Cochrane Wounds feels that this extensive stakeholder engagement gives them the ability to do reviews people most want and need. This is evidenced by good download statistics and a high impact factor.

Some of Cochrane Wounds' specific collaborations are described below:

- NICE
  - o Cochrane Wounds receives draft guidelines and other guidance for comment; consequently they ensure Cochrane evidence is properly reflected and that Cochrane reviews exist for key decision points identified by NICE.
  - o Jo Dumville and Nicky Cullum are wounds advisors to NICE on their Medical Technologies Evaluation Programme, wherein new devices with promise are evaluated and guidance is produced and published.
- NIHR
  - o Collaboration with the NIHR enabled the group to understand research gaps nationally, influence the research agenda, benefit from subsequent funding, and eventually see policy changing and care become more effective as a result of their engagement.
- Academic Health Science Networks
  - o These networks are responsible for deploying innovation in the system and receive instruction from NHS England. Cochrane Wounds supports one of these networks by providing evidence on innovations being rolled out.

## Other

### *Consumers*

Consumers are frequently, though not always involved in prioritisation, developing protocols, being authors on systematic reviews, providing peer reviews, advising on the writing of plain language summaries, and engaging with social media. Cochrane Wounds has two specific challenges in relation to stakeholder engagement with consumers. Firstly, there are no patient groups or charities specifically for Wounds. Where patient groups do exist for conditions like diabetes, the consumers in these groups often would rather not think about wounds as it is an unwanted consequence. Secondly, most patients who experience wounds are elderly, frail, immobile, and have underlying conditions but consumers who engage are mostly young physically disabled wheelchair users. Whilst Cochrane Wounds appreciates engagement with these consumers, they recognise that these patients are not typical.

*Information from this section was derived primarily from a conversation with Nicky Cullum, Joint Co-ordinating Editor.*

## 3 Summary and themes

Readers will find real-life examples of stakeholder engagement in a variety of settings. Some CRGs have extensive resource and others have very little but all CRGs value stakeholder engagement and have found ways to make use of their capacity.

### 3.1 Benefits of stakeholder engagement

In the MOSS Network, CRGs work hard to ensure stakeholders are engaged in their work. The extent, and shape of engagement varies between CRGs but all CRGs recognise the value that stakeholder engagement brings. CRGs identified broad and specific benefits of stakeholder engagement:

*“Whatever topic you’re talking about in healthcare if you’re not tapped into the system, if you don’t know what the issues in the system are, then you can’t do the things that are important. It’s obvious.”*  
– Nicky Cullum, Wounds

*“...now we could go anywhere, people would open the door to Cochrane in dentistry anywhere, at any level”*  
– Jan Clarkson, Oral Health

*“By doing this and involving people and getting the right questions to start with, we know that we’re addressing the important topics and answering the questions that people want the answers to, getting it right at the beginning”*  
– Anna Erskine, PaPaS

### 3.2 Capacity

*“People to do the work... stakeholders are going to want something, and we’ll be in a position where we won’t be able to give it to them”*  
– Jan Clarkson, Oral Health

*“It depends on each group’s funding...who’s going to actually do it... we all know it’s a good thing to do but to do it well you need dedicated time and effort”*  
– Tianjing Li, Eyes and Vision

MOSS CRGs are unanimous in emphasising their desire to do stakeholder engagement but all describe a tension between completing high quality systematic reviews in a timely manner, and doing stakeholder engagement. Lack of capacity in CRGs manifest in three interlinking areas: lack of time, lack of funding, and lack of knowledge.

#### 3.2.1 Stakeholder engagement requires time

*“This kind of activity does take time; in my view... it takes vision and leadership from the institutions of participating organisations. It doesn’t happen overnight.”*

– Tianjing Li, *Eyes and Vision*

CRGs recognised that stakeholder engagement takes time to research stakeholders, build rapport with individuals and organisations, take on additional collaborative projects, and ultimately develop a collaborative relationship built on trust. They emphasised that lack of time was the key barrier to stakeholder engagement.

Despite this, one CRG felt they had identified some “quick wins” in terms of stakeholder engagement by widely distributing surveys for prioritisation exercises. In addition, one CRG pointed out that if you have something good to offer your stakeholder, it might not take as long to build the relationship and collaboration can develop swiftly.

### 3.2.2 Stakeholder engagement requires knowledge

*“I can see that there are a lot of people that we perhaps could engage with that we don’t, and part of that is that it’s hard to find the right person to engage with”*

– Katie Webster, ENT

CRGs expressed feeling unsure how to work out who their stakeholder were. There were many potential stakeholders but knowing about them and choosing which to reach out to is difficult. Some CRGs identified stakeholders by systematic means such as reaching out to every clinician in a field. Some CRGs used Twitter to help identify stakeholders.

Once identified, some CRGs were unsure how to contact stakeholders. Although cold-contacting stakeholders had been successful at times, at other times it produced no response. Attending conferences and colloquia meant that CRG staff could be well connected and reduced the need for cold contacting. Sometimes the success of interaction with stakeholders depended on the individual person in post at a particular organisation such as the WHO.

Once contact had been made, CRGs also expressed lack of the right language to articulate how to build a relationship and potential models for that relationship.

### 3.2.3 Stakeholder engagement requires funding

*“If you’re not properly funded its taking away the essential work that you are funded to do”*

– Tianjing Li, *Eyes and Vision*

Most CRGs did not have specific funding for stakeholder engagement so carried it out in voluntary time. They were aware of a tension between unfunded stakeholder engagement work and funded production of systematic reviews. Some CRGs attributed successful stakeholder engagement work to big funding grants. Other CRGs had not been able to increase stakeholder engagement work due to unsuccessful funding applications. Some CRGs recognised funders themselves as stakeholders with whose help they could engage more widely.

## 3.3 Global reach

*“We have to guard against being too UK centric...we’re very keen to develop our knowledge and understanding of wound issues in lower and middle income countries... I don’t want to be too parochial about it, I think it’s really important that we’re not.”*

*– Nicky Cullum, Wounds*

CRGs share a common challenge that their stakeholder engagement was often focused in specific geographic areas. They tried to combat this by having a spread of editors globally. One CRG had reviewed evidence in particular lower and middle income countries. Another CRG had deliberately tried to contact stakeholders who themselves had global reach (such as the WHO). One CRG planned to have social media champions in different countries around the world to help disseminate their evidence more globally.

### 3.4 Authors as stakeholders

*“The consequence is they don’t do a review with us, they go and do a review on their own, that gets published, in essence it could be rubbish, but as guideline developers then you’ve got to spend your time sorting all that out”*

*– Jan Clarkson, Oral Health*

*“I was just as guilty of doing reviews outside of Cochrane but I’ve seen the consequences of that, there’s a whole raft of reviews that are horrible, and now people are relying on those to make decisions so we have to get back to making Cochrane work because we need a reliable source of evidence”*

*– Chris Maher, Back and Neck / Musculoskeletal*

A common theme among CRGs was the need to engage authors as stakeholders. This ties in with the lack of time as much time was spent either doing reviews or heavily supporting authors who are not adequately trained or not able to work to the deadlines required. CRGs recognised the disadvantages to healthcare decisions in every area if systematic reviews were sub-standard as is the risk with reviews conducted outside of Cochrane. This incurs heavy workload for guideline developers, policy makers, clinicians, and patients trying to understand the evidence. It also led to duplication of research.

There was an indication that authors had moved away from doing systematic reviews with Cochrane due to how hard the work was and the increasing complexity of methods. It was also thought that authors were put off by how long the review could take and delays in publication.

## 4 Conclusion

This report provides examples of CRGs stakeholder engagement activities and observations gathered from interviews with each of the eight CRGs in the MOSS Network. It describes a project undertaken with three objectives:

- 1.) to understand the current stakeholder engagement work within MOSS,
- 2.) to share examples of stakeholder engagement work within MOSS, and
- 3.) to gather information to inform the next steps in stakeholder engagement work within MOSS.

Section 2 of this report describes stakeholder engagement work conducted in every MOSS CRG. Each CRG is different in its capacity, funding, and current connections with stakeholders. The CRGs face different challenges in engaging stakeholders and yet each CRG has conducted extensive and significant stakeholder engagement work. This benefits the CRG and ultimately patients and clinicians when making health decisions. Reading Section 2 and the resultant themes in Section 3 meets objectives one and two of the project, as it enables readers to understand current stakeholder engagement and its publication facilitates the sharing of this work.

The information gathered from CRG interviews will be used to inform next steps in stakeholder engagement work within MOSS, in line with objective three of the project. This project has already led to the development of a six step stakeholder engagement process in collaboration with the NSF from the Cancer Network ([here](#)).

It is hoped that CRGs, Fields, Geographic Centres, departments, organisations, and entities within and beyond Cochrane will find the examples detailed in this report, and the accompanying six step stakeholder engagement process, useful if considering engaging stakeholders for mutually beneficial purposes.

## 5 Appendix

### 5.1 Interview schedule

Ensuring we have equal understanding of concepts

1. What is your understanding of the meaning of the phrase “stakeholder engagement” as it relates to your work?
  - a. Who would you consider to be “stakeholders” for your CRG?
  - b. Below is a list of potential stakeholders. Can you comment on the extent to which you feel they are relevant stakeholders for your CRG?
    - Patients
    - Public
    - Providers
    - Purchasers
    - Payers of health services
    - Policy makers
    - Product makers
    - Principal investigators
    - Payers of research
    - Press and other media

Understanding current CRG stakeholder engagement → a report which details the status quo with regard to stakeholder engagement within MOSS.

2. Have you done any stakeholder engagement work as a CRG?
  - a. If so, could you describe this work?
  - b. Who were your stakeholders?
  - c. What went well?
  - d. What could be improved?
3. Do you plan to do any stakeholder engagement work as a CRG?
  - a. If so, could you describe this work?
  - b. If not,
    - i. What are the barriers?
    - ii. In an ideal world, what would you do, and how would you do it?
      1. Who would be your stakeholders?
    - iii. Taking a more pragmatic approach, what would you do and how would you do it?
      1. Who would be your stakeholders?

Understanding needs of CRGs with regards to stakeholder engagement → Ideas for future stakeholder engagement either as a network or for CRGs.

4. What do you think are the potential benefits of doing stakeholder engagement work?
5. What do you think are the potential drawbacks of doing stakeholder engagement work?
6. Which specific characteristics of your CRG affect stakeholder engagement?

- a. How?
7. Which specific characteristics of MOSS affect stakeholder engagement?
  - a. How?
8. What do you think could be learned from collaborating as a network in stakeholder engagement?
9. How do you think the Network Team could support you in stakeholder engagement work?

**Closing the conversation**

10. Interviewer to reflect back the main points of the conversation to check understanding.
11. Any other comments?
12. Describe next steps (see “outputs”) below.

## 5.2 References

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