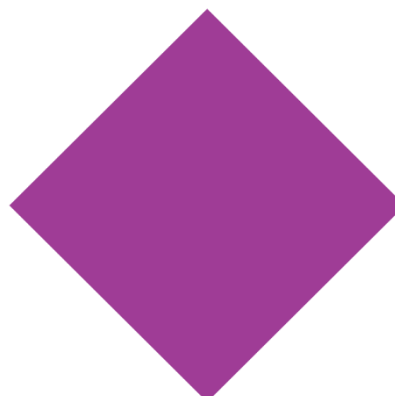




Awareness Events: Moments for sharing Cochrane evidence

Knowledge Translation

Trusted evidence.
Informed decisions.
Better health.



Overview

Cochrane currently uses awareness days, weeks and months (events) as date prompts to showcase evidence in the Cochrane Library, this could be an evidence spotlight (highlighting existing reviews on a topic) or as a date hook to launch a new special collection. This activity is not designed to endorse the awareness events per se, but to use them as an opportunity to promote evidence Cochrane has. However, this activity could be viewed as endorsing the associated messages, treatments, products, individuals or companies associated with the awareness campaign.

The aim of this overview is to look at how Cochrane uses awareness days and to set criteria to help us choose which awareness days to align ourselves with in future.

Background

A health awareness day is defined as a [“brief exposure, high visibility program designed to stimulate thinking and discussion of certain health risks and issues by large numbers of people.”](#) They are well known intervention strategies designed and adopted by public health practitioners, policymakers, and the public alike. [However, critics say intervention strategies of this type are guided by an overly simplistic theory of health promotion.](#)

The impact of awareness days is usually measured by increased knowledge, perceptions, and influencing changes in behaviour.

At the population level increased awareness, however, is not necessarily a meaningful public health outcome in and of itself. Awareness is often described as the first step in the change process, therefore, additional action is required to produce meaningful public health outcomes (e.g., behaviour change). [This and the questionable impact of awareness days is detailed in this study.](#)

Given the ubiquity of health awareness days (there are over 200 hundred listed in the US, the WHO have 100 on their lists) and ambiguity of their messages, it is possible that they bombard the public with information to the point where individuals conflate being knowledgeable about a health issue with taking action to address it – a sense of awareness day fatigue.

In January 2019, the WHO Executive looked at its support of awareness events and [the summary of the meeting can be read](#). This summary states, “Currently, no standardized methods are in place to define and measure the range of potential results generated by world days...Short-term results such as media coverage can be directly attributable to the world day; however the contribution of world days to longer term outcomes, including benefits to health, human rights and sustainable development, may be more difficult to assess.” *(Note March 2020: We know now that WHO are reviewing their use of awareness events and Emma Thompson, Cochrane’s relationship manager with the WHO is following these developments. The WHO were interested in Cochrane’s initiative and this paper has been shared with them.)*

It is important to acknowledge that awareness events could also lead to harms. Increased awareness could lead to more contacts with the healthcare system simply to confirm health, which means suboptimal resource use and opportunity costs for healthcare systems. These visits could also lead to unnecessary tests with potential for harm and overdiagnosis, ultimately leading to overtreatment. Some awareness and health promotion campaigns could also contribute to a focus on the individual and individual responsibility for health outcomes where a societal perspective is needed. This can reinforce

stigmatisation and self-blame. These concerns are a topic for the new Cochrane Field - Sustainable Healthcare.

How Cochrane uses awareness events

Special collections

Special collections pulled together for the Cochrane Library are sometimes launched on the date of an awareness event. The special collections can launch at any time, but there is increased social media traffic on an awareness day and increased social conversation about the topic, so it allows Cochrane to enter into those social conversations and present evidence on a given topic.

Examples:

<https://www.cochranelibrary.com/collections/doi/SC000037/full>

<https://www.cochranelibrary.com/collections/doi/10.1002/14651858.SC000022/full>

Evidence Spotlights

These short news items on www.cochrane.org highlight the Cochrane CRG, special collections and blogs Cochrane has on a relevant topic. They are also promoted via Cochrane.org's twitter account.

Examples:

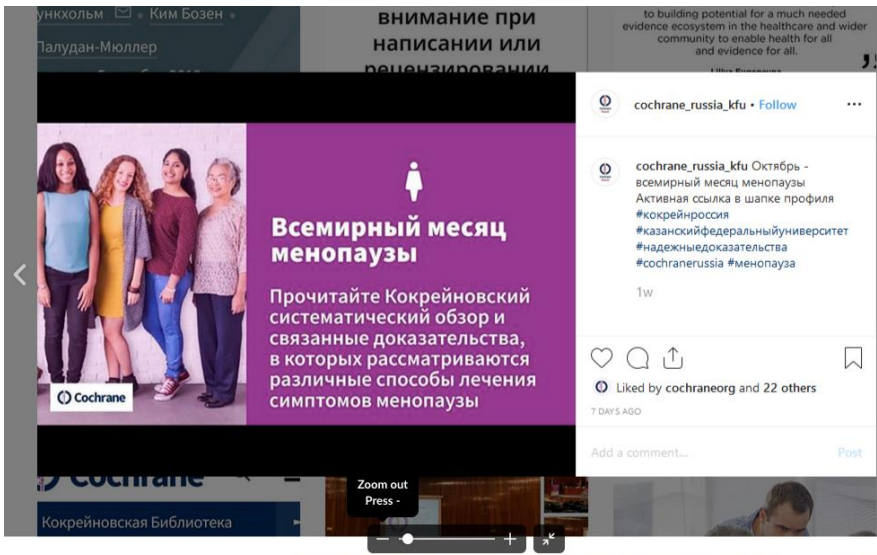
<https://www.cochrane.org/news/world-mental-health-day>

<https://www.cochrane.org/news/stoptober>

<https://www.cochrane.org/news/breast-cancer-awareness-month>

Cochrane Groups

Cochrane CRGs and geographical centres also take advantage of awareness days, this activity is driven by their needs, and is not an initiative led by the KTD.



Cochrane Russia use awareness days to increase engagement on social media.



Joining health awareness campaigns on Twitter by using trending #hashtags is an effective way to disseminate Cochrane evidence to a bigger audience

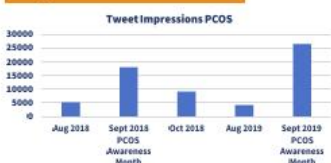
Objective

To disseminate Cochrane evidence to a wider audience through social media (Twitter) using hashtag awareness campaigns

Background

Knowledge translation (KT) is an integral part of Cochrane's mission to promote evidence-informed health decision-making. Cochrane Gynaecology and Fertility Group (CGF) has implemented several KT initiatives aiming at communicating evidence to a wider audience. Here we discuss how health awareness campaigns focusing on polycystic ovary syndrome (PCOS) and endometriosis in particular can be used to facilitate evidence communication and dissemination on Twitter.

Key Results



Methods

- In September 2018 and 2019, and in March 2019 we joined two international health awareness campaigns on Twitter using specific hashtags (#PCOS, #PCOSAwarenessMonth, #Endometriosis, and #EndometriosisAwarenessMonth).
- The tweets contained summarised results from reviews on PCOS and endometriosis published by CGF, as well as links to the reviews on the Cochrane Library.
- We also created web pages on our own group website so we could track page visits directly.
- We used Twitter Analytics to analyse the impact of the campaigns by measuring the number of tweet impressions (how many times a tweet is seen) and user engagement (retweets, likes, click links). We used Google Analytics to measure page visits and assess visitors' location.

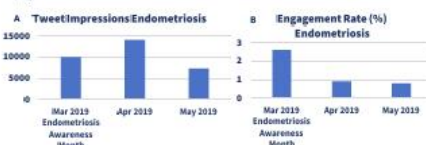


Figure 1. PCOS Awareness Month. During #PCOSAwarenessMonth we posted 23 tweets in September 2018 and 25 tweets in September 2019. In 2018, the PCOS tweets received 15,000 impressions. In 2019, the PCOS tweets received 25,000 impressions. Thus, the #PCOSAwarenessMonth tweets earned 3 to 5 times more impressions compared to other months before and after the campaigns. The engagement rate (number of engagements divided by number of impressions) was 0.8% in September 2018 and 1.7% in September 2019 (data not shown). An engagement rate above 0.3% is considered high on Twitter.

Figure 2. Endometriosis Awareness Month. During the annual #EndometriosisAwarenessMonth campaign in March 2019 we shared 20 tweets. The tweets earned 10,000 impressions in total (A). Moreover, the tweets received a very high engagement rate of 2.6% (B). For example, if a tweet with 800 impressions has an engagement of 2.5%, this means it has received 40 user engagements (this includes retweets, likes, click links, and profile clicks). Importantly, these Twitter metrics are based on data collected through our own account only and do not take into account the impressions and engagement earned through retweets from other accounts.

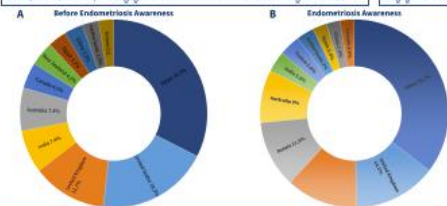


Figure 3. Geographical distribution of website visitors. We also created a web page dedicated to #EndometriosisAwarenessMonth on our group's website. The page contained a collection of all endometriosis titles in our portfolio with review summaries and links to the Cochrane Library. The chart on the left represents the geographical distribution of our website visitors in the month prior to the post dedicated to endometriosis which we use as a reference (A). Using Google Analytics we measured a marked increase in website visits related to #EndometriosisAwarenessMonth. Compared to the month before, our website received a 56% increase in visits due to posts linking to the page on endometriosis. In addition, we saw a shift in visitors' demographics demonstrating an increase in diversity as well (B).



Disseminating Cochrane evidence to a wider audience through social media

Kostova EB¹, Nazeis M², Vercoe M², Showell M², Farquhar C², van Wely M¹

¹Amsterdam UMC, University of Amsterdam, The Netherlands
²The University of Auckland, New Zealand



The Cochrane Gynaecology and Fertility Group prepared this poster at the 2019 Colloquium. The group used Polycystic Ovary Syndrome Day to push out blogshots and related Cochrane reviews. <https://www.cochrane.org/news/polycystic-ovary-syndrome-awareness-month>

The group has done some research on using the awareness day as a 'hook' to disseminate their evidence more widely—showing the value these awareness days can have to a review group.

How they are selected and by whom

Currently the awareness events are selected by the KTD, Editorial Unit or the relevant CRG or geographic centre for support. The KTD use the WHO list, input from CRGs or Wiley to make their selection.

The Cochrane UK centre, by way of example, check:

- Legitimacy, through an online search. They check the nature of the campaign, its goals and whether these align with Cochrane's and Cochrane UK's. They would also avoid those which were championed, visibly, by industry. (Although, it is noted that this can be hard to establish because of the practice of astroturfing.)
- UK-relevancy (e.g. link to NHS priority topics or relate to established campaigns supported by organisations such as Public Health England e.g. 'Stoptober').
- It has an existing, established audience (e.g. annual campaigns such as 'Antibiotic Awareness Week').
- It is associated with/supported by charities that we know Cochrane Groups already have links with (e.g. Asthma UK, given their links with Cochrane Airways), particularly UK-based charities.

- We have relevant, up-to-date existing content for (e.g. blogs or blogshots) or ones where there are relevant, recent reviews for which we could create new content

However currently there is not a list or any guidance on the criteria for selecting an awareness day.

Concerns

Concerns have been raised within Cochrane and by [Wiser Healthcare](#) that Cochrane should look carefully at the awareness days it uses as date hooks, explaining that whilst Cochrane is using the awareness days to promote its own evidence, in doing this it is suggesting that awareness days are a successful health intervention and is not taking into account the role of these days in driving over diagnosis and over treatment.

In a letter of concern sent to Cochrane from Wiser Healthcare they explain, “Overdiagnosis and overtreatment are important and widespread problems in modern health systems, and disease awareness campaigns unfortunately can contribute to them by encouraging healthy people to have tests that they don’t need and which may harm them (2). In general, campaigns which promote disease awareness to well citizens may result in individuals overestimating (or underestimating) their true disease risk, raise anxiety unnecessarily, and encourage uninformed testing which can turn healthy people into patients without benefiting them. Regrettably, breast cancer has been a prime target for disease awareness raising. Sometimes promotions may be well intended, but sometimes they are undertaken by companies with undeclared financial interests (3), and sometimes by charities whose promotional activities mislead rather than enlighten (4). Breast Cancer Awareness Month (Pink October, Octobre Rose) was recently criticised by an independent civil and scientific inquiry in France, which found the promotional information was misleading and exaggerated. (5) These activities are also known as “pink washing” which has been a focus of strong criticism (6). In summary, campaigns to encourage breast cancer awareness have not demonstrated benefits (according to a Cochrane systematic review, (7)), may carry risks as outlined above, and are contested.”

Concerns have also been flagged within the Cochrane community:

Dr Minna Johanssen, new Director of the Cochrane Sustainable Health Field explains with reference to [PCOS Awareness day](#), “Incidence of PCOS (Polycystic Ovary Syndrome) has risen sharply with little evidence of any benefit for many of the women diagnosed, as accounted for in this paper:<https://www.bmj.com/content/358/bmj.j3694>. Although there is also potential for under diagnosis, the increased awareness of this condition has likely contributed to substantial overdiagnosis (over 20% of women in fertile age may fit the new criteria for the diagnosis, and these criteria could hardly be considered evidence-based). Although this is of course only anecdotal, this is something me and many of my GP colleagues experience, as women with no hyperandrogenic or other symptoms, nor a wish to become pregnant, now turn to us with a request to "check if they have polycystic ovaries".

We have collated this additional feedback:

- Addressing these campaigns in the form of tagged tweets and topic specific linked text on Cochrane web pages could be perceived as support for the awareness day campaign, even if intended to simply promote evidence around a topic. It is implied Cochrane endorses awareness day campaigns.
- Some campaigns themselves are problematic. Raising public awareness about diseases is not necessarily a good thing. It may increase unnecessary worry and concern; increase GP visits that are a waste of resources; increase testing that may lead to overdiagnosis; and increase overtreatment that can lead to harms, some of which can be serious.

- Breast cancer awareness month was one of the first awareness campaigns to be established. This initiative has subsequently been commercialised and then criticised - <https://www.vox.com/the-goods/2018/10/17/17989624/pinkwashing-breast-cancer-awareness-products-profit><https://www.vox.com/the-goods/2018/10/17/17989624/pinkwashing-breast-cancer-awareness-products-profit>.
- Breast cancer awareness month is often used to promote breast cancer screening, which is not supported by the Cochrane review on this subject. Breast cancer screening is a multi-billion dollar private enterprise in the US and elsewhere. Unless we actively counter some of the themes in these awareness campaigns, we will be perceived as supporting them – simply linking to the review will not do. Most people do not interact with the tweets or websites enough to catch the full meaning.
- Another example of a problematic campaign is “Movember” which is used to promote Prostate Cancer Screening, which goes against UK guidance. If Cochrane sent out messages about the reviews linked to prostate cancer, it is likely many would fail to look at the detail and would assume an endorsement of the awareness month
- The Alzheimer’s awareness campaign is an example of a particularly problematic pharma-endorsed campaign with the agenda to promote use of Alzheimer drugs, which probably have little or no benefit but certain harms. <https://www.worldalzmonth.org/>. There is extensive pharma presence and huge financial interests involved in these campaigns. The idea from pharma is to get more people tested for Alzheimers (which is a disease without an objective confirmatory tests). This will lead to more diagnoses (some of which are wrongly applied, with enormous negative personal consequences) which in turn will increase sales of Alzheimer’s drugs that have little or no benefit.
- It is unreliable to use the WHO as a source of endorsement/quality as it promotes quite a few interventions that are problematic. For years, neuroaminidase inhibitors (Tamiflu etc) were on their Essential Medicines list. Cochrane should not trust the Blue Stamp of another organisation
- Cochrane has a new Sustainable Health Field, and it could be perceived by others that we do not live up to our own policy and values by supporting the practice of communicating about awareness campaigns. We need to consider awareness days within the context of overdiagnosis, overtreatment and prioritisation of the use of resources within healthcare.

Criteria for selection

Many campaigns don’t promote specific interventions or diagnostic tests very openly - it is sometimes difficult to see which campaigns may end up promoting overdiagnosis and overtreatment - even if one follows the criteria and suggested questions:

- Are there Cochrane Reviews on the relevant awareness event? Do they support or contrast with the messaging of the awareness event?
- Does the awareness event encourage over diagnosis/treatment/wasted resource? (Which may lead to drugs and device companies selling more products?)
- Does the intervention the awareness day recommends have known harms? Do we have a Cochrane review to support this?
- Has the awareness day been ‘hijacked’ to have commercial benefit?
- [Is it on the WHO list?](#)
- Does the day appear to be championed or sponsored by industry?
- [Is the day of global \(or national\) relevance? Does it support global/national health priorities \(such as obesity, mental health, antibiotic resistance\)?](#)

- Does the event have an established audience/social media following which can benefit Cochrane? (Or will the event be lifted by Cochrane's involvement (this isn't ideal.))
- Is the day led by an organisation or charity Cochrane already has existing links with?
- Can we consider it evidence based/robust?

Constraints and considerations

CRGs and geographical Centres may decide to pick an awareness event, this is paper is given as guidance to help make these decisions.

Recommendations

1. Some of these awareness days go against Cochrane evidence. So, as well as using some awareness days as date hooks to present Cochrane evidence, we also look at some as opportunities to champion evidence that goes against their key messages. (Raising awareness that Alzheimer's drugs have little or no benefit; that breast screening causes serious harms for little or no benefit and that informed choice should be promoted, etc.) Cochrane actively "corrects" some of these messages based on our evidence, mitigating risk that we are simply seen to support these awareness days. We could work with the Sustainable Health Field and advocacy team to identify some of events where we seek to build campaigns to counter public messaging which goes against the evidence in Cochrane reviews.
2. Cochrane seeks to develop its own awareness events which speak to the goals of the Advocacy Strategy – an Evidence Week which promotes the use of evidence/transparency in trials. Or piggy backs on dates which exist in the calendar to promote these goals. These events should be given top tier status and support from KTD with co-ordinated editorials, video, op-eds.
3. The KTD holds a list of events it has used to do Evidence Spotlights. We have reviewed this list in light of the criteria and picked ten KTD will support. In turn this guidance allows us to give better support to editorial colleagues on good events to launch special collections.
4. Cochrane Groups using awareness events can use this criteria and guidance when electing to use an awareness campaign to promote Cochrane evidence. This could be done by sharing the criteria with them and advising considered use of awareness days.
5. The criteria for selecting an awareness day is shared with CRGs/MEs through the comms digest

Top awareness events – selected by KTD for central support (split by disease/advocacy/organisational opportunities)

Disease events:

Salt Awareness Week: March

World Immunisation Week: March (need to check we have reviews)

World No Tobacco: May

World Asthma Day: May

Dementia Awareness Week: May (also same content works for [World Alzheimer's Day](#) in Sept)

World Breastfeeding week: August

World Mental Health Day: October

World Menopause Month: October

World Aids Day: December

Advocacy opportunities:

March for Science: April

International Clinical Trials Day: May

World Evidence Based Medicine Day: October

World Antibiotics Week: November

Organisational opportunities:

International Women's Day: March (celebrate female contribution and achievement)

International Translation Day: September (celebrate global community of contributors)

World Volunteer Day: December (celebrate Cochrane contributors)