

# Experiencing Cochrane UK ‘Evidently Cochrane’ blogs: a qualitative analysis of online data to explore the value of health research blogs

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## Abstract

**Background:** Cochrane is a global independent network which produces and shares systematic reviews that summarize the best available research evidence to inform decisions about health. Cochrane UK uses blogs to share Cochrane evidence. We aimed to explore how readers use blogs and use this knowledge to make the blogs more useful.

**Methods:** We collected data in the form of comments posted on five blogs and three researchers analysed the data using thematic qualitative analysis.

**Results:** We developed seven themes that help us to understand people's use of Evidently Cochrane blogs. The categories supporting each theme, along with the source blog, are shown in Figure 1. These themes fall into three overarching concepts: (1) testament to my suffering; (2) negotiating ambiguity and uncertainty; (3) needing and finding solidarity.

**Conclusions:** Health research blogs designed to promote the uptake of research-based knowledge are also used as a space to testify suffering and find solidarity. Those utilising blogs to disseminate research findings need to consider how blog readers might utilise these spaces for unintended (albeit useful) purposes, and how they might best moderate these spaces.

## Ethics statement

Informed consent was not sought for this study. We approached the Medical Sciences Inter-divisional Research Ethics Committee, University of Oxford, our university ethics committee, to seek their advice. They were satisfied that we had followed the University of Oxford's and British Psychological Society's guidelines for internet-mediated research, and that the data analysis did not require ethical approval. They provided a letter to that effect (R67327/RE001)

## Background

Cochrane is a global independent network of researchers, professionals, patients, carers and people interested in health, producing and sharing systematic reviews that summarize the best available research evidence to inform decisions about health. It is underpinned by the need to promote the uptake of research findings into routine healthcare, and to improve health. Cochrane UK, which supports this work in the UK, shares Cochrane evidence in a variety of formats, including blogs on *Evidently Cochrane*. These blogs are updated when there is new evidence to share and so remain current. Patients, carers and others making personal health decisions are a key audience for the blogs. Some are authored by patients and others include personal or professional experiences and reflections on the evidence. The blogs allow readers to post comments, and some blogs receive a high volume long after they are published. These posted comments have the potential to give insight into what readers are looking for in the blogs, their potential value and impact, and areas where we could improve research outputs. We aimed to use qualitative research methods to explore how readers were using these blogs and to use this knowledge to make them more useful.

## Method

*Methodological approach:* A thematic analysis of online comments to evaluate the use of Cochrane UK *Evidently Cochrane* blogs. This report is guided by the published Standards for Reporting Qualitative (1) (available on request).

*Data collection:* We chose the five blogs on the *Evidently Cochrane* site that had received the most comments as of 6<sup>th</sup> November 2020. These focused on menopause, frozen shoulder, stillbirth and subsequent pregnancy, care after major stroke, and tubal flushing to increase the chance of conceiving. Four of these included the blogger's relevant personal experience and one included data from in-depth interviews with patients and family members. The blogs had all been published between 2015 and 2019. We copied all comments posted on the blogs from the date they were first published until the 6<sup>th</sup> November 2020. The issue of confidentiality when using online data poses questions. Although this data is in the public domain, we sought advice from the university ethics committee, and took the following measures to ensure confidentiality: (1) we removed overtly identifying information, such as geographical location or names; (2) we rephrased narrative, whilst taking care to retain original meaning, so that it would not be possible to return to the source data; (3) We uploaded the anonymised data to NVivo 11 (software to

facilitate qualitative analysis). We also sought permission from each blogger and invited them to take part in the analysis of the data.

*Analysis:* Data from each blog was first analysed individually. Francine Toye (FT) ‘coded’ the data, which involves reading and distilling the meaning of each unit of narrative in a few words. Where possible, FT used verbatim text to code data so as not to drift from the meaning. FT then organised the coded data into preliminary categories (NVivo ‘nodes’) and wrote a sentence which encapsulated the meaning of each category. FT is an experienced and independent qualitative researcher working within a healthcare setting, with no connection to Cochrane UK. Two co-researchers working for Cochrane UK, with good knowledge of the original data, read and commented on these categories and suggested adaptations, via online meetings. All three researchers then independently organised these categories into themes (2) that cut across the five blogs. We used Google Jamboard which allows you to move and recategorise ideas ‘live’ whilst you discuss them. The aim of discussion is not to reach consensus but to refine and distil ideas in order to encapsulate the essential meaning. At this point, all bloggers were invited to contribute to the analysis, and we incorporated their suggestions into the content and wording of the final themes. This process of collaboration contributed to the trustworthiness of the findings.

## Findings

We collected narrative data from 463 comments from the five blogs (58,929 words). We developed seven themes that help us to understand people’s use of *Evidently Cochrane* blogs. The categories supporting each theme, along with the source blog are shown in Figure 1. These themes fall into three overarching concepts: (1) Testament to my suffering; (2) Negotiating ambiguity and uncertainty; (3) Needing and finding solidarity (Figure 1). The extracts below, which illustrate the themes, are not verbatim quotes from individuals. Rather, they are rewritten narratives that capture the essence of multiple comments. This allows us to protect the anonymity of the people who have posted comments.

### Negotiating ambiguity and uncertainty

Three themes suggested that the blogs are spaces where participants (people leaving comments) negotiated uncertainty and ambiguity. The first theme, ‘the agony and ambiguity of making and living with difficult decisions’ describes the daily torment of living with ambiguous decisions and ambiguous outcomes. For example, those whose relatives were living with the consequences of a major stroke simultaneously described wanting the end to come, but not wanting the end to come

*(I have said my goodbyes over and over)*. They described the agonising decision to switch to end-of-life care *(Ending care is an agonising decision, even if it is right)* and the need to make judgements about quality of life above physical survival *(It is quality of life that is important, not length of life)*:

*I have said my goodbyes over and over: stroke*: I am living on a roller-coaster. Is this the end? I have said goodbye over and over. I am not ready for the end, but at the same time I want the end to come. I prayed that they would recover but recover for what? I don't want to seem negative, but I want to know if this is the end.

*Ending care is an agonising decision, even if it is right: stroke*: The decision to end treatment was horrible. It was the toughest decision that we had ever made, and we live with this decision. It breaks my heart. We keep questioning ourselves. My mind is screaming that I made the choice to let them die. I may question my decision for the rest of my life.

*It is quality of life that is important, not length of life: stroke*: They would not want to live like this. Living like this was their biggest fear. It makes me shudder to think of it. Surviving is not living. There would be no quality of life for them or us. It looks like I am wishing them gone and I am not. I don't want them to suffer anymore.

Those who had experienced stillbirth described the difficult decision to spend time with their baby, and some regretted not doing this *(I am so glad that I decided to spend time with my baby)*. They also described the difficult decision of trying for another child *(I am scared to think of another baby, yet scared not to)*:

*I am so glad that I decided to spend time with my baby: stillbirth*: I made the decision to spend some time with my baby. They cleaned my baby and brought them to me. My baby was beautiful. The moment felt like forever. I am so grateful for those precious moments. I was afraid to hold my baby and I regret this.

*I am scared to think of another baby, yet scared not to: stillbirth*: I am crippled by fear for another pregnancy. I am haunted by my worries. I know that worst can happen. I am worried about leaving it too long. I feel guilty for wanting another baby. I am not looking for a replacement. The longing to be a mother fills my mind.

The second theme, 'Why did this happen and could something different have been done?' describes a retrospective questioning to try and make sense of ambiguity. Those experiencing stillbirth asked what could possibly have gone wrong *(I need to find out what could have gone*

*wrong*) and described their own guilt (*what if it was something that I did*). Some looked for explanations beyond themselves (*was it because no one listened to me*):

*I need to find out what could have gone wrong: stillbirth:* It was an ordinary uncomplicated pregnancy, so what went wrong? Why did this happen? I am still trying to process it. I am full of unanswered questions. The doctors just said it can just happen. I might have to accommodate never knowing.

*What if it was something that I did: stillbirth:* Was it something I did or didn't do? I waited too long to check. Perhaps it was because I was stressed. I should have insisted that they checked me over. I let my baby down. I blame myself. It is breaking my heart. I live with guilt.

*Was it because no one listened to me? stillbirth:* I realised something was terribly wrong. If only they had listened to me. They could have saved my baby. They dismissed it. No one was listening. I wish I could turn back time and demand attention. They kept saying don't worry, this is normal.

Similarly, those who had lost relatives following stroke looked retrospectively for answers (*I have been left with so many questions*):

*I have been left with so many questions: stroke:* I have so many questions. I can't understand what is happening. I would like some advice if anyone has been through this. We still don't know what happened to them. I am still puzzled. I want to understand if I did the right thing.

The third theme, 'trying to decide what now' describes participants seeking and offering experiential knowledge to help negotiate ambiguity: an exchange of experiential knowledge. Those with frozen shoulder reached out for answers (*I hope you don't mind me asking*) and exchanged information, understanding that this knowledge could be anecdotal (*have you tried this out?*):

*I hope you don't mind me asking: frozen shoulder:* Please can anyone offer any experience on this? Has anyone else had this? I would be interested to know from my fellow sufferers if this will make any difference. I am trying to decide what to do.

*Have you tried this out? frozen shoulder:* I just wanted to add my experience and ideas. I have a few suggestions. It might help or it might not. It's worth a try. It may be anecdotal, but...

Similarly, those experiencing menopause sought (*has anyone else had this problem?*) and exchanged information and experience (*I have tried this...*):

*Has anyone else had this problem? Menopause:* I've been scouring the internet. Has anyone else had this? Is this common? Is this normal? Is hormone replacement the answer? Can someone recommend pain relief? Has anyone out there got any suggestions? Advice would be appreciated.

*I have tried this...: menopause:* Herbal remedies. Yoga. Meditation. Exercise. I keep crackers handy for nausea, avoid oily, sour or spicy food. Drink lots of water. Cut back on coffee. Anti-depressants. Hormone Replacement Therapy. Stay positive. Do things you enjoy. Make space for you. Say no. Find the right doctor.

Those considering tubal flushing also reached out for experiential knowledge in the face of ambiguity (*please help, I don't know what to do next*):

*Please help I don't know what to do next: tubal flushing:* Please, I really need help. Is there anything I can do to help me get pregnant? Will tubal flushing work? I have read so many stories with different outcomes. What should I do next? Can I get pregnant? Can I unblock my tubes? What did you do? Did it work for you? I am so confused.

## Testament to my suffering

Two themes suggest that the blog is used as a space where participants can safely give voice to their suffering. There was a sense that people felt compelled to write their story and that writing this down gave some relief. The first theme, 'heartbreak, despair and desperation in the face of physical and emotional suffering'. Those with frozen shoulder used the blog to describe the physical and mental toll of living with this condition:

*This is so physically and emotionally draining: frozen shoulder:* This pain is horrible. My arm is useless. Sudden or unexpected movements are excruciating. I try to keep my arm still. I can't sleep. Normal things become a monumental task. I can't get my clothes on, I can't even flush the loo. I cry every day. It is so emotional. I don't enjoy anything. It has a physical and mental hold on me. It is the hardest thing that I have had to deal with. It is exhausting. I want to start living again.

Those with a family member after a stroke described being torn apart by seeing their loved ones suffer:

*It is heart-breaking to watch them suffer: stroke:* I feel desperate. It is cruel and heart-breaking to watch my loved one suffer. They don't react or understand. They can't eat or speak. They have no

control of their bladder or bowel. They would hate this. They cry when I visit. I can't do anything to help. I feel crushed. They don't even know me. It tears me apart. I wouldn't wish my experience on my worst enemy. It is so sad.

Those experiencing menopause described living at the '*point of utter despair*':

Menopause It is ruining my life. I feel like garbage. Pain. Aching. Bloating. Dizziness. Nausea. Extreme hot flashes and sweats. Palpitations. Bad hair. Dry skin. Weight gain. Irregular cycles. Bladder problems. I never know what I am going to be feeling like. Fear. Despair. Dread. Terror. Panic. Rage. Sadness. Mental fog. It is exhausting. It is all consuming. It is torture. I have no motivation. No energy. Cannot sleep. No sex drive. I cry all the time. I am moody. I lash out. I feel useless.

And those considering tubal flushing described the desperation of not conceiving:

*I am so desperate to have a baby: tubal flushing:* We have been trying to have a baby for so long. It is so disappointing. I am depressed every month when my period starts. I go to the bathroom over and over to see if it has started. I am desperate. I want a baby so badly. It's so draining. I have cried my eyes out. I am too scared to do a pregnancy test. I have taken so many. I was devastated when I found that my tubes were blocked. I left in tears. My biological clock is ticking.

The second theme 'profound and life altering grief' added further support for the blog as a space to testify suffering. Those who have lost a relative following a stroke described living with a broken heart:

*I am heartbroken to have lost them: stroke:* How I miss them. I cherish the last words we spoke. My heart is breaking. This is the saddest day of my life. I feel helpless. I will miss them so much. I feel alone without them. I just want them to be alive. I can hardly breathe with horror and sadness. I wish I could have them back.

Those who had experienced stillbirth describe the theft of motherhood: I have been left with empty arms and heart, I am heartbroken and irreparably altered by loss, and I cannot believe that this has happened to me:

*I left the hospital with empty arms: stillbirth:* I left with empty arms. A mother should never lose a child. I became a mum that day but had no baby. It is so painful to lose a baby. The best day of my life became my worst. My arms are empty. I have milk and no baby. My breasts are a constant reminder of my loss.



*I am living with the loss of a child: stillbirth:* I am living alongside grief. I am empty. I am lost. I am devastated. Forever heart broken. Words cannot express this sadness. There is no comfort. I miss my baby every day. I am overwhelmed with emotions: sadness, rage, guilt, jealousy, helplessness. It is always on my mind. I live by the moment. I have good and bad days.

*All I could hear was my own heartbeat: stillbirth:* All I could hear was my own heartbeat. My baby was motionless. 'Nothing' they said. Utter disbelief. Only yesterday, it was beating. I will always remember the sound of my own heart. I was so shocked. My heart sank. That was it; my baby was gone.

Those experiencing menopause described grieving for the person that they had once been:

*It has stolen the person I was or would be: menopause:* this is not me. I can't hold down a job or relationship. My life as I knew it is over. It has destroyed my self-esteem and confidence. I am trapped in an alien body. I don't recognise myself. It has stolen my future and ruined my life. I have become moody, unhappy and unpleasant. I want to be me again.

## Needing and finding solidarity

The final two themes suggest that the blog filled a human need to share suffering and find solidarity. The first, 'we are in the same boat sharing our suffering' describes the value of finding community. Those considering tubal flushing shared their journey (*I want to share my experiences*) and described a sense of camaraderie: I am in the same boat: your story is my story: your success is my success: we stand united (*you could be writing about me*) and encouraged others to 'keep believing it will happen':

*I want to share my sharing my experiences: tubal flushing:* I'm going through the same thing as you. I had my test today. My tubes are blocked. IVF failed. I had an ectopic pregnancy. I tied my tubes a few years ago. I have endometriosis. I have heavy periods. I have irregular periods. I had a miscarriage.

*You could be writing about me: tubal flushing:* I am going through this. I feel your pain. we are in the same boat. are you pregnant yet? I will keep you posted. Any update yet? This sounds like my story. I feel for you.

*Keep believing it will happen: tubal flushing:* Best of luck to us all. I pray we all conceive. Don't give up trying. There is always hope. Don't stop believing. Don't give up. My tubes are open. I finally got pregnant.

Similarly, those with frozen shoulder described the relief of feeling that they were 'in the same boat' as someone else:

*I am in the same boat: frozen shoulder:* it is good to know that I am not the only one going through this. Good luck to all. Reading this makes me feel that I am not alone, or crazy. I am in a similar boat. It will get better: that's the good news. I hear you. Wishing you all well. I hope we both get through.

Those with relatives following a stroke described the value of sharing human stories and offered thanks and condolences (*thanks for sharing your stories*, and *condolences to you all*). They also encouraged and supported others who were making difficult decisions (*you made the right decision*) and encouraged them not to lose heart (*don't give up, miracles can happen*):

*Thanks for sharing your stories: stroke:* I wanted to share my story. Thanks for reading and replying. Thank you for sharing; it helps me know that here are others in the same boat. Your prayers and thoughts are getting me through this. I hope this reaches someone who is suffering.

*Condolences to you all: stroke:* I am in tears reading your stories. I am so sorry for your loss. I will pray you get through it. I wish you strength.

*You made the right decision: stroke:* You have made the right decision. You are doing all that you can. You are there for them. Do not blame yourself or feel guilty. No 'what-ifs. I hope that someone would do the same for me. They would thank you. You did what they wanted. They were well loved.

Those who had experienced stillbirth described connection through stories and found solace and hope in sharing (*connected by the loss of a baby*):

*Connected by the loss of a baby: stillbirth:* I feel your suffering. We are in the same club. I don't want to be in this club, but this club sustains me. Your story is my story. It helps me to know that there are others who understand my story. I feel like I belong here. I feel I am not alone. I am so grateful. It was like you read my mind. We are connected through pain and grief. This story has given me some hope.

Similarly, those experiencing menopause describes relief from knowing that others are in the same boat (*it is therapy to feel that I am not alone*). With this came heartfelt encouragement to others living the same experience (*bless you all*):

*It is therapy to feel that I am not alone: menopause:* I could have written those identical words. It is like therapy to hear your words. You are describing me. I don't feel alone reading this. I want to connect with others who are going through this. I thought it was all in my head. I felt I was on an island on my own before. I feel normal now. Thanks for being brave and sharing

This need for solidarity was highlighted by a second theme, *feeling like and outsider: stigmatised, isolated and alone*. Those experiencing menopause described this experience as 'living alone on an island'. They did not talk about their experience for fear of judgement and the blog provided a safe space to share and to feel connected. There was an edge of hostility towards those that had not had the same experience (*some of you are lucky enough to breeze through it*)

*I am living alone on an island: menopause:* I pull away from other people. I am alone on an island. No one to turn to. Menopause is silent. We don't talk about it because we don't want to be criticised. People think you are crazy. It is hard to explain to someone who has not experienced this. It is horrible to feel alone

*Some of you are lucky enough to breeze through it: menopause:* I have suffered all my life with women's problems. I hate those women who just sail through it. Why do I have to endure this, and others don't have to?

## Discussion

We aimed to explore the use of *Evidently Cochrane* blogs through a qualitative analysis of the five blogs with the most comments. Our findings indicate three uses: to provide a space where participants negotiate ambiguity and uncertainty; as a testament of suffering; to fill a need for solidarity through shared suffering.

Many people now search the internet to find information about their health issues (3) and it is an established route to health information (4). Our findings suggest that people access blogs in order to negotiate uncertainty, and this is clearly aligned with the *raison d'être* of Cochrane (trusted evidence; informed decisions; better health). However, our findings also resonate with research indicating that the internet can also be used as a space to be heard and to create a sense of solidarity and support (5). Charon (6) and Frank (7, 8) advocate the importance of giving voice to

suffering through narrative and this may be a useful way to allow this to happen in a safe space. Those providing internet spaces to disseminate research need to consider that exposure to internet space is not always benign (4, 9). For example, internet use can lead to unrealistic expectations, give false information, or even create hostility. There is also the danger that people come to rely on the online community at the expense of face-to-face contact. Our aims were pragmatic and motivated by a desire to improve what Cochrane UK offers its readers.

Our findings have prompted Cochrane UK to make some changes. First, they have revised the guide to blogging for *Evidently Cochrane* (<https://www.evidentlycochrane.net/a-guide-to-blogging-for-evidently-cochrane/>). For example, the revised guide asks bloggers to signpost sources of information and support for readers who can feel alone in negotiating ambiguity and uncertainty. Although *Evidently Cochrane* blogs do not make treatment recommendations, the revised guide now encourages bloggers to make suggestions that might help readers to consider their treatment choices or facilitate discussion with healthcare providers. Second, the editors of *Evidently Cochrane* are reflecting on, and discussing, their policy for moderating online comments. The duty to protect the community from abusive comments remains paramount. At the same time our findings indicate the value of allowing readers to respond freely to each other's shared experiences. At times, this may mean that readers will recommend treatments that are not supported by evidence. This raises a potential dilemma for implementation science which not only aims to facilitate the uptake of interventions supported by best evidence, but also to *de-implement* those with no proven clinical benefit: the dilemma being, that to remove the facility for readers to comment and make suggestions freely can take with it the benefits of providing a community space. The Editors of *Evidently Cochrane* have now revised the disclaimer in the blogs to clarify that they do not fact check comments or endorse treatments mentioned by readers. Future research to explore how best to help internet users think critically about treatment claims would be useful.

## Limitations

It is likely that different blogs are utilised in different ways depending on their purpose and content. We used data from the five blogs with the most comments and further research exploring the use of other *Evidently Cochrane* blogs would help us to further understand their value. Qualitative research is an interpretive methodology and, as such, it is likely that different researchers would make different interpretations. In order to challenge interpretations we used a collaborative approach to improve rigour, incorporating the suggestions of three researchers and

the original 'bloggers'. We could be criticised for reconstructing verbatim narrative and 'sacrificing authenticity for the sake of confidentiality' (10). We sought ethical advice and made the decision to illustrate themes with reconstructed narrative. An underlying principle of research on human subjects is that you cannot carry out observational research, without consent, unless those observed are expecting to be observed (11). This is a grey area as the internet blurs the boundary between public and private, and there is no consensus on ethical guidelines for internet research (12, 13).

## Conclusions

Qualitative research methods can help us to understand the potential impact of research. Health research blogs designed to promote the uptake of research-based knowledge are also used as a space to testify suffering and find solidarity. This creates a potential dilemma for implementation science: those utilising blogs to disseminate research findings need to consider how blog readers utilise these spaces for unintended (albeit useful) purposes, and how they might best moderate these spaces.

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Figure 1: Organisation of codes into seven themes, and three categories

