



A Shared Space &
A Space for Sharing



Information Sheet



ONLINE HEALTH FORUMS

Key messages for health professionals

● **BACKGROUND TO THE INFORMATION SHEET**

This information sheet was developed as part of the “A Shared Space and a Space for Sharing” research project, which examined how people in extreme circumstances share information and experiences through the Internet. In Sheffield, we explored how people with life-shortening, life-threatening, or long-term health conditions use online health forums to gain support. The information in this information sheet is based on findings from this study.

● **WHO WE ARE**

We are a team of researchers based at the Information School, University of Sheffield (UK). Our contact details are at the end of this information sheet.

● WHY PATIENTS CHOOSE TO ACCESS ONLINE HEALTH FORUMS

People often join forums at a time of need, typically at diagnosis, or at a later stage when they are facing difficulties or challenges. The motivation may come from a need for additional support arising from the informational and emotional demands of living with a health condition.

1. INFORMATIONAL SUPPORT

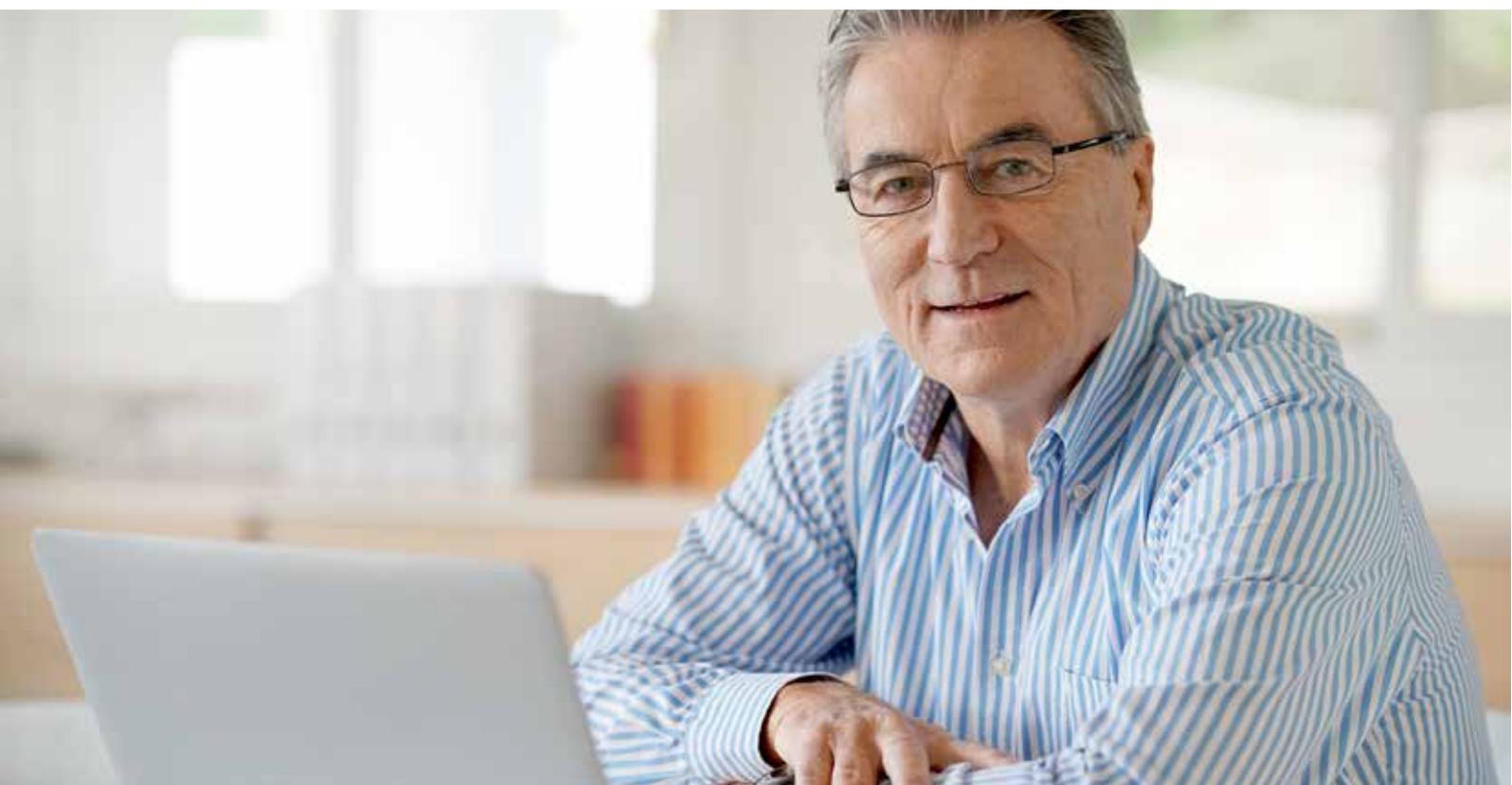
Online health forums provide a unique source of informational support because the forum users are all either living with, or affected by, a health condition. Forum posts provide a wealth of information about experiences of living with the condition, which users have shared to help and support others in the forum community.

- People share knowledge about the health condition and experience of living with it, for example, the symptoms, and experiences of treatments, support services, and everyday life.
- People share practical solutions to the problems that they face while living with the health condition, such as sharing coping strategies, side effects of treatment and practical advice.

This information can be particularly helpful for people who are recently diagnosed, or have reached a new stage in the condition, and are uncertain about what will happen in the future. Forums can help to alleviate some of this uncertainty and fear, as others share their experiences of what happened to them, and how they coped. This can be very reassuring. This peer-to-peer support may be perceived as particularly meaningful and helpful because it comes directly from people who have shared similar experiences.

The information that forum users provide for each other has several advantages:

- Other people on the forum can answer questions that no one else can answer because of their direct experience of living with the health condition.
- People may feel more inclined to ask other people on the forum for information than health professionals, especially when time with health professionals is limited.
- The varied experiences shared on the forum can help people in their decision making about their health, or everyday life.
- Forum users can search for answers to their questions within the conversations held on the forum (the repository of posts) or, if they are not able to find the answer, they can post asking for help and forum members will reply.
- Online health forums can be positive spaces where peers help each other to deal with the challenges of living with a health condition. People find it inspiring and heartening to read through other peoples' accounts of how they live and cope with the condition.
- People who have a positive attitude and determination may become role models for others, demonstrating through their posts a way to live with resilience and hope.



KEY MESSAGES FOR HEALTH PROFESSIONALS

2. EMOTIONAL SUPPORT

People often need emotional support to help them cope with living with a serious health condition. Sometimes they may need help additional to that provided by health professionals. Emotional support can be important for people diagnosed with a life-threatening or rare health condition, or for people without a support network of friends and family. Health forums provide accessible peer-to-peer support 24/7:

- **A unique understanding of the emotional burden of ill-health** - Forum users share a unique understanding of the emotional burden of living with a specific health condition, having both experienced and felt the emotional impacts. People may feel better able to share their feelings with others who understand their situation more directly.
- **Emotional support at times of crisis, e.g. after diagnosis** - Forums provide an emotional outlet to express fears at times of distress. Other users offer comfort, reassurance, coping strategies, and perspectives gained from experience of living with the condition.
- **Venting** - Sharing feelings on a forum can have therapeutic benefits, as people unburden their fears in posts shared with others who are able to offer empathy and understanding. People may feel more able to express fears online than face to face. This may be especially valuable for people who choose not to share their fears with family/friends to protect them.
- **The need to know you are not alone** - Living with a health condition can be very isolating, even for people with support from friends and family. Participants in our study drew comfort from knowing they were part of an online community of people living with the same health condition and this made them feel less alone.
- **A place to go to at times of need, and a place to be** - Forums provide a space to go to find solace, or just 'to be'. People in our study valued being able to turn to the forum if they received bad news or something went wrong, knowing that their story would be met with caring and understanding. The posts are not just about ill-health; there are many conversations about everyday life, good news, and humour.

3. FRIENDSHIP AND COMPANIONSHIP

Forums can provide a source of companionship or friendship. People can develop friendships based on shared experiences of the health condition, or they may find other connections which draw them to a person or group. We found that people were drawn to others with whom they felt an affinity or were similar. Some forums set up spaces to bring together groups of people sharing the same experience, e.g., Breast Cancer Care has monthly groups for people starting chemotherapy at the same time. Online friendships provide supportive relationships for sharing both good and bad experiences.

DIFFERING LEVELS OF ENGAGEMENT

People interact with online health forums in individual ways. Some people only wish to access informational support, whereas others seek emotional support and friendship. Some users are very active users of the forum, posting regularly, whereas others may never actively participate, preferring to read the posts and gain support that way. Everyone is different and people decide on their own level of engagement with the forum, based on what they feel comfortable with.

ADVISING PATIENTS ON HOW TO CHOOSE AN ONLINE HEALTH FORUM

Online health forums can offer a valuable source of support, but patients may not either be aware of the existence of the forums, or they may not know how to access the best forum for their needs. Health professionals can play a valuable role, both in raising greater awareness of the value of forums for patients, and offering them advice about choosing a suitable forum. A search for a health forum should be guided by two key considerations – relevance, and safety.

1. RELEVANCE

Our study found that people gained better support from forums which were most relevant to their needs and circumstances.

- **Support and advice relevant to the health condition** – It is better to find a forum that supports a specific health condition, or that offer spaces within a forum to support people with a specific diagnosis, or stage of treatment. This makes the support more meaningful and relevant. Many well-known and reputable health charities provide health forums as part of their online support.
- **Shared circumstances** – Some people find it valuable to access support from forum spaces that mirror their own circumstances, e.g., forums may have boards for younger people with families. This may be helpful for people who are not typical of the people in the forum (e.g. the Breast Cancer Care forum has a board for men living with the condition).
- **Shared context** – It is better to find a forum hosted within the person's own country to ensure that information shared about treatments and health services is relevant to their needs.

People may need to try out a few forums before they find the right one for their needs.



ONLINE HEALTH FORUMS

2. SAFETY

There are two key concerns around safety that patients should be aware of. Firstly, the risks around information sharing on the Internet, and secondly concerns around whether the health information provided by the forum can be trusted.

a. Safe sharing practices

Patients can reduce their risks in sharing online by joining health forums hosted by a reputable charity that are moderated. Moderators oversee the safe running of the forum. Their role is to check posts to ensure that users are following safe sharing rules, treating others with respect and that factual information shared is accurate. Moderators also welcome new users and sign-post them to sources of help.

Patients can reduce risks by following safe sharing practices: -

- **Not sharing information which would identify them as an individual, or anyone they refer to (such as friends, family, or health professionals)** e.g. do not share names and address.
- **Being aware that some forums are open for anyone on the internet to read.** There are good reasons why forums are open to anyone to read, as this enables more people to gain support - but people need to read the terms and conditions to find out if this is the case.
- **Taking things a step at a time.** It is advisable to spend some time reading through the forum to assess usefulness and get a sense of the community, and people within it. People in our study used their instincts to decide whether they felt comfortable in the forum, and whether they felt that the people in the community were trustworthy.
- **Private spaces.** Some conversations take place off the forum, such as, in emails or users may set up their own closed or separate Facebook groups. These offer the opportunity to converse in private spaces about issues that users might not wish to share on the wider forum; however, there are some risks to sharing in private spaces (see Trustworthiness of information below) and these tend not to be moderated by professionals.
- **Medical advice.** Online health forums are a valuable resource for people to share experiences (e.g. of medications and treatments), but it is not appropriate to offer medical advice to others. Forum user guidelines may state that medical advice should not be shared, and advise users to seek advice from a health professional if they have any health concerns.

b. Trustworthiness of information

There are some risks around users posting factually inaccurate health information. The information posted on moderated forums is likely to be more trustworthy than in forums where no one is overseeing the postings. Moderators may screen posts to correct misinformation. Participants in our study were aware that posts may include factually incorrect health information, and did not necessarily accept information shared at face value. Forum users may correct misinformation themselves to protect others. In private spaces, such as email and unofficial Facebook groups, no one formally checks the accuracy of posts.

POTENTIAL RISKS

There are some risks to taking part in online health forums, but the participants who took part in our study felt that the benefits far outweighed the risks.

- **Health forums are anonymous spaces and there is a risk that people online may not be who they say they are** e.g. we found a rare example of someone trying to sell things.
- **There is a small risk of being upset by the actions of other forum users.**
Users may share in an insensitive way e.g. talking about sensitive topics without considering the feeling of others.
Users may disagree with each other from time to time, and, in very rare instances, an argument may break out.
- **Sorrow for others.** It can be very upsetting if a friend on the forum become very ill, or dies. This can be a reminder of a person's own vulnerabilities.
- **The amount of support available at any one time will depend on how many other users are logged onto the forum at any one time.** There may be times when no users are available to help, especially if it is a small forum or group, or it is in the early hours of the morning.
- **Treat with caution any medical advice offered by forum users.** Users in our study gave some examples of posts offering medical advice; however, forum moderators are likely to intervene and question, or remove, these posts.

SEE ALSO

Online Health Forums: Key messages for people living with health conditions seeking support (www.space4sharingstudy.org).



For further information about our project or for more copies of this information sheet please contact:

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