

Social Media Channels

In this section, you will find:

- information on various social media channels
- description of the features on these channels
- talks about issues you might face
- tells you what we have learned
- gives examples of ICISG members

Forums

A forum, also called a message board, is a space for people to talk with one another, to share what is happening to them, and to find information. People send messages (threads) to start talking or to get more information. However, a large number of forum users never send messages, but rather just read what others are saying.

Forums are places for people to share thoughts, feelings, and experiences with others. On most sites there is a place for users to share a personal profile, which gives a little more information about the person. People also can add a photo if they wish.

Features of forums

- Discussions happen in one place.
- Discussions are often grouped by topic.
- Discussions can be managed and facilitated.
- Ability to add a message can vary. In most cases you need to register in order to add content.
- Most forums are open and able to be read by anybody. Some forums may be private, where the content is only seen by those who have permission to do so.
- Conversation does not happen at the same time (unlike online chat groups) but can continue over days, weeks, months, or even years.
- Messages can be stored (archived) at least temporarily.
- Depending on how the forum is set up, posted messages may need to be approved by a moderator before others can view them.

How forums are used

Forums can be used to fill several needs:

- Patient-to-patient support
- Caregiver and family member support
- Sharing information with patients, family members, and others
- Addressing support needs of people who are socially isolated and have rare conditions
- Public sharing of expert information that might be used by a larger audience.

Issues

Privacy: One of the hardest issues on a forum is privacy. This is a challenge because people can find content on public forums via Internet search engines. It's important to remind people when they register that they might want to create a new username, otherwise, their username (and other details such as real names, e-mail addresses, home pages, telephone numbers, street addresses) can be used to identify them and link them to what they are discussing. On the other hand, even if people wish to keep their identities hidden, most want to share some personal data in connecting with others.

Conflict between users: Conflict can happen, especially when issues that are highly emotional or sensitive are being discussed. Text-based conversations, although having many advantages, can lead to misunderstandings. Not having to use one's name can lead people to talk about their experiences, opinions, and emotions in terms that can lead to heated discussion. You need guidelines for your moderators to cover such issues. These guidelines need to take into account when a moderator should step in and act. It is important for moderators not to stop people from talking. We have learned that, over time, as an online community matures it learns how to moderate itself, managing most of these issues without the moderator's help.

Medical advice from self-proclaimed "experts": Another issue is spam (unwanted messages). This is commonly automated content added by bogus users, often with embedded links to commercial web sites. Such messages are fairly easy to detect and remove; however, you will need staff to actively monitor the site.

What we have learned

- Have clear terms and conditions for users.
- Have clear policies and procedures in place to deal with misuse of the service.
- Establish clear boundaries and purpose for the service and have policies in place to deal with users overstepping these boundaries.
- All online discussions require an organizational moderator and written policies and procedures for dealing with issues.

Samples

Message board: [American Cancer Society](#)

Forum: [Cancer Council Australia](#)

Terms and conditions of use: [Cancer Council Australia](#),

Chat Rooms

Chat rooms are like forums. They are a place to "talk" on a web site, with a number of people adding text items one after the other into the same space in real time. They are much like a discussion between people in a room. Chat rooms differ from forums because conversations happen in "real time."

Features of chat rooms

- Chat rooms allow people to speak back and forth instantly, in a real-time, text-based conversation.

- People don't need to identify themselves, thus allowing them to speak more freely, ask questions, and explore issues that they might not have a chance (or feel comfortable) to do otherwise.
- Chat rooms allow people with shared interests to talk easily.
- Discussions do not remain online after posting. They do not provide a permanent source of information for users.
- Anybody can post a message.

How used

Chat rooms can be used to fill several needs:

- Patient-to-patient support.
- Sharing information with patients, family members, and others.
- Introducing and talking about specific topics of interest.
- Supporting needs of the socially isolated and those with rarer conditions through facilitated groups.
- Allowing those with speech and hearing impairments to chat more easily.

Issues

Terms and conditions: Before you launch a chat room, you will need to set clear boundaries for anyone who will be taking part. Set up rules and decide what will happen to those who do not follow them.

Moderating discussions: You will need to decide whether or not to moderate the discussions. Moderating lets you try to stop any incorrect information from being posted. It also allows you to find people who are breaking the rules you have set up. If you moderate the site, however, be careful when editing content. Do not remove messages or ban members from the site without a good reason.

You need to consider:

- Whether you wish to moderate, and why.
- What policies and procedures you will need for your moderators.
- The amount of time and resources it will take to moderate.
- The amount of time and resources you will need to take part in online discussions.
- How you will deal with postings that you feel are not acceptable.
- What your liability will be if users post inaccurate information or harmful advice.
- How you will deal with people who wish to remove a posting for privacy reasons.
- The role of self-policing and how long you will wait to allow self-policing to happen.
- How you would respond if your organization were criticized on a public forum you support or manage.

What we have learned

- It has been useful to set up different facilitated support groups for specific users (advanced cancer patients, caregivers, bereavement), site-specific users (breast, pancreatic, lung, brain cancers, etc.), or different age groups (younger adults).
- All online discussions require an organizational moderator (or facilitator, if operating as part of an online support group).

- Before you intercede (wrong information, advertising, spam), allow time for self-monitoring among the users.
- It is worth considering hosting topic-based live chat events involving guest experts as a way of providing information and support. Transcripts from these events may be published online as a document that can be downloaded.
- If you are going to have one-to-one dialogue in text, make sure you understand the amount of time and resources that will be required.

Samples

Cancer Chat: [Cancer Research UK](#)

Cancer Survivors Network: [American Cancer Society](#)

House rules: [Cancer Chat \(Cancer Research UK\)](#)

Terms and conditions of use: [Cancer Chat \(Cancer Research UK\)](#)

Blogs

A blog (which is short for “web log”) is a name for an online journal or diary. Simple to set up and regularly updated, blogs are self-published by people or institutions who provide entries (posts, blogposts) on any subject. Blog entries are presented in reverse chronological order (newest first). Although bloggers don’t talk directly with one another, each of them talks with many others, forming an interlinked network. Blogs are less expensive to host and manage than traditional Web sites; however, they still take time and other resources.

Features of blogs

Blogs express the views of the writer, be it a doctor, nurse, pharmacist, communications specialist, advocate, patient or a loved one, or anybody else.

- They can include any type of content, from video to podcasts to text and photos.
- They usually consist of opinions and experiences.
- People can comment or respond to blog entries.
- Material in blogs can be stored (archived).

How used

Blogs can be used to fill several needs.

For organizations:

- Getting real-time feedback from audiences.
- Commenting on or explaining information in the media, making it easy for journalists to find the latest, most accurate information.
- Engaging with the public, promoting your services, establishing expertise in a subject area
- Introducing and addressing specific topics of interest by speaking directly to your audience and leading the conversation.
- Keeping audiences up to date on current issues in health or medical care
- Personalizing your service.
- During a crisis, shaping the conversation about it.

For people affected by cancer:

- Providing a way for the sharing of narrative, support, and practical strategies (therapeutic for both the writer and readers).

Issues

Whom the blog represents: It needs to be clear which content is written by the organization and which is contributed by other users. Content appearing in any blog that is published under an organization's name must express the views of the organization. So it is important that the purpose of the blog and its place in your communications program are clear. Although your organization may not yet have written social media policies, you need to set up lines of authority and approval for what is going to appear in your blog. It also is useful to think through the top five things that can go wrong and develop the policies and training that would be needed should something happen.

What we have learned

- Successful blogs have a written purpose, with a distinct focus and goals.
- You need to update your blog at least once a week.
- An authentic voice and solid writing skills add to a successful blog.
- It takes time and work to have solid readership and steady traffic.
- Depending on your objectives and how often you update your blog, you can spend 3-4 hours each week or 2 hours a day to prepare your blog and do blog-related work.
- You should, at the beginning, put in place a method for tracking results and measuring success.
- A blog is like a soapbox, with both its pros and cons. You need to be your own censor. Understand that anyone can (and, in time, will) read your blog.
- Be open to both positive and negative posts on your blog. Answer in a professional and businesslike manner.
- You need to be clear about who will be responsible for monitoring and responding to comments and what (if any) criteria there are for removal of material (e.g., spam or offensive language). Generally, comments should remain as an archive of the conversation.

Samples

Dr. Len's blog: [American Cancer Society](#)

Science Update blog: [Cancer Research UK](#)

Terms and conditions (for posting on blog): [Cancer Research UK](#)

Social Networking Web sites (Facebook, MySpace, etc.)

A social networking web site is an online community that brings together people who have similar interests. Large sites, which host several communities, offer a place where people engage with one another online and share content. Some, like Facebook, started out as a "special interest" community (supporting a neighborhood network only), before taking on a wider audience. Others have narrower audiences and limit access. There are also some activity-centered or affiliation-focused sites that are limited by audiences and tend to be smaller.

There are several different kinds of communities, geared to specific groups of people, interests, or content, including:

- Facebook: An online community for people to connect or reconnect with others; enables people to share videos, pictures, and information about themselves; one of the most-used, fastest-growing social networks
- Flickr: An online site for storing, sharing, and commenting on photos
- LinkedIn: A professional online community used to network with fellow professionals; an online resume-sharing site
- MySpace: A site where people can meet others with similar interests and create online communities by sharing videos, photos, and personal information
- You Tube: An online site for uploading and discussing videos; videos from YouTube can be added to other social media sites such as blogs or social networks

Features of social networking sites

- They vary in their features and user base.
- Most are now organized around people rather than interests.
- Most contain visible profiles that display a list of friends who are also users of the site.
- Profiles are unique pages, created after each user provides descriptive material.
- They can include photos and other materials added by users.
- The site can control who views material. Some are visible to anybody, others require a registered account for viewing.
- Users are asked to identify others to connect to others (“friends”).
- Users are encouraged to share small updates (“statuses”) about what is happening for them in daily life. These updates are then provided to others (often “friends”) as a “feed.”
- Most allow users to choose how visible their information is to their “friends” as well as other users.

How used

Social networking sites can be used to fill several needs:

- Promoting other services and health initiatives
- Helping people who share interests or activities connect with each other.
- Addressing the needs of a specific audience, such as the socially isolated or those with rare conditions.
- Encouraging a sense of community, promoting community services and resources
- Reporting on research findings.
- Hosting discussions on cancer topics, including talking about the organization, with the general public.
- Using patients and their stories to change the way people think about cancer.
- Promoting events and services, attracting people to specific campaigns.
- Bringing together like-minded people for social and political movements. Facebook (and Twitter) has shown a value in social and political movements, playing a key role in keeping people connected. Social networking sites provide a platform for planning events and sharing news and videos of ongoing events in real time.

Issues

Privacy: A major issue is privacy and what role you have in protecting the confidentiality of a user's private and sensitive information.

Medical advice: The giving of medical advice is another challenge when managing these sites. You need to plan how you will control people from misusing the site.

What we have learned

- Post clear guidelines and restrictions.
- Understand the privacy issues.
- Consult with your organization's legal department to lessen liability.
- Don't be afraid to challenge information that is inappropriate. If you can show other users why the information is incorrect, they can help moderate the site by reacting to misinformation and myths, using the examples you have given them.
- Do not be afraid to remove inappropriate material and information.

Samples

Facebook:

[American Cancer Society](#)

[Cancer Council Australia](#)

[Canadian Cancer Society](#)

[Cancer Research UK](#)

[Danish Cancer Society](#)

[Institute National du Cancer, France](#)

[German Cancer Research Center](#)

You Tube:

[American Cancer Society](#)

[Cancer Council Australia](#)

[Canadian Cancer Society](#)

[Cancer Research UK](#)

LinkedIn:

[American Cancer Society](#)

Flickr:

[Canadian Cancer Society](#)

Twitter

Twitter is a microblog, where users post updates ([tweets](#)) of no more than 140 characters. It allows people to follow others with similar interests or information they want to learn about, becoming part of each other's Twitter conversation. Users also can "retweet" (retransmit) other people's messages to their own followers.

Features of Twitter

- Anybody can follow anybody else on Twitter.
- Twitter has more information and is less social than other social networks.
- Your Twitter page is a snapshot of your organization. Its format and design should be integrated.
- The limitation of 140 characters per tweet means text is short and simple.
- You need to include valid material in your tweets.
- You can limit your Twitter posts only to those you wish to communicate with.
- Twitter's limit on text provides less room for liability issues.

How used

Twitter can be used to fill several needs:

- Bringing attention to your other services and events.
- Driving people to other sources of information.
- Giving basic useful information or news items. The length of text limits its usefulness for giving detailed information.
- Engaging people to build a network for collaborative or creative opportunities.
- Sharing information with journalists and contributing to discussions in the media.
- Reaching target audiences for fundraising events.
- Bringing together like-minded people for social and political movements. Twitter has shown a value in social and political movements, playing a pivotal role in keeping people connected. Twitter sites provide a platform for planning events and sharing news and videos of ongoing events in real time.
- During a crisis, Twitter can move information quickly and efficiently around social networks.

Issues

Short life: Tweets on a particular topic rarely last longer than a week, with most topics only “trending” once, and then phasing out.

Lack of interest: Since entry is free, most people who sign up in Twitter are just following others. It is challenging to come up with material that will be interesting and useful to a large, diverse audience.

What we have learned

- Much of the information on Twitter is repeated. It can be a re-evaluation, re-interpretation, or misinterpretation of the original tweet.
- Make sure you have a specific strategy and rationale for your tweeting. A good plan avoids problems later.
- Twitter can reach out to a wide group but you will need to interact with your audience to develop a relationship. Having conversations with followers takes time but helps build relationships.
- Create simple, basic guidelines, especially if more than one person is sending out information.

Samples

American Cancer Society

Cancer Council Australia

Canadian Cancer Society

Cancer Research UK

Apps

App is short for application. An app is software designed to help users carry out an activity or specific function on a computer or handheld device. Apps range from Web browsers and games to specialized programs such as digital recorders, online chat, or music players. Their popularity has grown with apps built specially for iPhones and other smartphones. There are over 750,000 developers around the world building apps that now number well over a million.

Features of apps

- They can require a password for access; data stored in some systems can be encrypted for security.
- Information is available wherever the person is, without needing to be in an office or at a computer to access it.
- Apps can combine reference texts into a single device with Web access to get the latest, most up-to-date information.

How used

Apps can be used to fill several health-related needs:

- Promoting services and events
- Locating community services for people affected by cancer
- Alerting users to news and events
- Driving people to other sources of information
- Checking for health care data, community services
- Helping people build more healthy habits, like losing weight, using sunscreen, or stopping smoking
- Assisting patients to control chronic illnesses, such as by recording food intake, exercise, and blood sugar levels for diabetics
- Providing information to health professionals, such as drug references and clinical images
- Sharing electronic records with patients and allowing them to carry medical histories with them

Issues

For iPhone and other smartphone apps:

- They require rigorous testing.
- They can encounter unforeseen crashes, bugs, and technical difficulties.
- They are judged by public ratings and reviews.
- iPhone apps need to be approved by Apple. This process does not have a set time frame and there is no guarantee an app will be approved. (Android apps don't need to go through this approval process.)

- In most cases an external developer will need to be engaged to develop the app.

What we have learned

- Market research is crucial in planning and designing the app (e.g., predevelopment surveys, focus groups).
- You need to develop a detailed project plan and ensure you engage an experienced developer.
- Set aside at least 1 month for testing. Test on a number of different devices in a number of different locations.
- Allow at least a month for approval processes where required.

Samples

Cancer Council Victoria and VicHealth

Cancer Research UK