Social Media Toolkit for Patient Associations

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Contents

Acknowledgements

Social media tool kit

This document aims to provide guidance on planning and developing social media for patient advocacy organisations and team members responsible for preparing and approving social media engagement.

This tool kit provides real social media examples from the public domain. However, Janssen does not accept responsibility for the examples in the content, nor is this content endorsed by Janssen.

This is a living document and should be updated regularly to incorporate the latest developments in social media.

This tool kit includes information about:
- understanding social media
- getting started
- creating a strategy
- establishing a community
- maintaining a community
- managing social media
- understanding your time commitment
- setting up social media profiles
- useful sharing and monitoring tools

Understanding social media

Social media are web based platforms that facilitate valuable conversations between organisations, communities and individuals.

Whereas information on traditional websites only flows one way – from the website to the user – social media allows for more interaction. Social media encourages and empowers engagement through sharing and commenting.

Social media provides organisations with amazing opportunities to give and receive feedback from their audiences in real time and participate meaningfully in conversations about issues around their organisational aims.

Types of social media

PLATFORM	DESCRIPTION	EXAMPLE
Social Networking	Online directories that connect people and often include multiple communication mechanisms.	Facebook Twitter
Blogs and forums	Sites that post information or opinion on various issues and are open for comments.	British Medical Journal's blog
Video sharing	Sites that allow video and other online audio visual material to be distributed, shared and streamed.	YouTube
Wikis	Online repositories of information that are open for contributing and editing.	Wikipedia

The Useful Sharing and Monitoring Tools chapter provides links to social media platforms and other relevant tools.

Getting started

Social media know-how and nous

Explore social media by using it in your personal life. It is easier to understand social media culture after spending time engaging independently of your organisation. Develop social media profiles in Facebook and Twitter, connect with others, and post pictures and experiences to generate conversations with your social networks.

Research

Before joining conversations, listen to existing conversations to find out what people are talking about and to determine how to contribute.

Research what others are doing in social media communities and evaluate best practices. Find blogs, Twitter, Facebook (pages, groups, causes), YouTube and Flickr accounts of similar interest.

Search your organisation and similar organisations, illness area, patient groups, government agencies, advocacy sites, news groups, blog comments on topic.

It is important to plan your organisation's long term communications, across all channels, not just social media, before engaging online. Social media activities should be integrated with your overall communications strategy, which is based on your organisation's aims and objectives. Your strategy will be useful to establish the purpose of your communications, your intended audiences, key messages and help schedule regular, relevant noise.

Purpose

Social media activities are amplified when integrated with an overall communications strategy. Identify specific social media goals by asking:

- Why are we engaging in social media communities?
- What will we achieve?

Your social media goals may be to:

- "**raise awareness** of how to prevent diabetes."
  By identifying and participating in relevant conversations you can spread your messages, which can reach even further if shared across your network's networks.
- "help our members **connect** and provide **support**."
  Social media is great to promote events and initiatives, bring attention to issues that affect many people, who may feel isolated, and provide support.
- "encourage **new people** to use the sexual health advice services that we provide."
  By sharing case studies, and engaging with your audience, you can highlight specific services and demonstrate how accessible they are to potential users.
- "**campaign** for fairer access to mental health treatment."
  Policy makers, the media and influential commentators often have social media accounts. It could be more direct to reach and engage with them on social media, where they are already active.

- "become the **authority** for issues surrounding HIV."
  By sharing good quality content, engaging and contributing meaningfully in conversations, your social footprint will increase and help to establish your organisation as an authority.
- "**share best practice** across the sector."
  Because online communities are bound by a common interest, it is easier to search for, interact with and build partnerships with groups across the globe.

Social media does not need to address all of your organisation's objectives. If you have limited resources, choose to do one or two things really well i.e. sharing resources and answering questions, than trying to do everything. If one thing does not work in your social media engagement, simply try something different.

Audience
When building your audience on social media for the first time, start with people and organisations with whom your organisation already has a relationship with. Your network may include:
- patients
- carers and/or families
- health care providers
- partner organisations
- public health organisations
- insurance providers
- media
- pharmaceutical companies
- friends and volunteers of the organisation.

If they are difficult to find directly on social media, look at their websites and publications to see if they promote their Twitter or Facebook pages.

As you start to establish your presence and connect with others, your network will widen.

IMPORTANT! Engaging with patients online is quite sensitive and may be regulated. Understand local laws before connecting with patients. The Managing Social Media chapter provides further information.

Engaging your audience
Social media is about creating and maintaining relationships. If you are new to social media or are reaching out to a new audience, relationships will build gradually.

Contribute by:
- asking questions to start conversations
- creating and sharing your own content
- submitting guest posts to blogs and other online communities

Engage by:
- commenting on blogs and articles that are mentioned in conversations
- sharing content from other posts and conversations
- thanking contributors to encourage future participation

Messaging and tone
Create a balance between being professional and conversational to build relationships and communities, and maintain standing. By providing knowledge (not just opinion) and unique perspectives you will build your reputation as an authority.

Social media communities that are rich with a variety of updates are the most appealing and vibrant. Be creative when sharing your message so that you invite responses and ignite conversations. Vary

your message and balance it with updates from other areas of your work or news from across the sector.

Channels

While there is a plethora of social media channels, it may be better to be active on only one or two than to have inactive accounts across a large number of platforms. Choose a platform that best aligns with your audience and your organisation's communications objectives.

Content

Being in patient support and advocacy means your organisation will have lots of interesting content to contribute, which is a great start for social media.

Creatively brainstorm with colleagues to build a broad scope of ideas, themes and topics. Social media content need not be seen as a burden to collect. Your organisation already produces a lot of content; it just needs to be made ready to share. A lot of it will be driven by your organisation's yearly work plan. As content is produced, tweak it to be social media friendly.

Content may include:
- Status updates - on your own profiles and other accounts
- Comments - that you leave on blog posts or news articles
- Blog posts - from media releases and events
- Videos - from your promotional and educational resources and events
- Photographs - from events and case studies
- Presentations - from talks, conferences and training events

Communications calendar

Ensuring there are no gaps in your social media communications will maintain the audiences' interest and save your profile from becoming inactive. Develop a communications calendar based on your work plan and brainstorming to schedule regular interesting activity and content and maintain momentum. Comprehensively plan a month ahead so communications are prepared, proactive and timely.

Basic communication calendar example:

January	February	March
New Year's Treatment Resolutions	*Youth Month*	*Open Mic Month*
April	**May**	**June**
Family Focus	*Reach Out to Patients*	*Summer Symptoms*
July	**August**	**September**
Global Report Released	*Awareness Month*	*Summit Summary*
October	**November**	**December**
Study Participants Being Recruited	*Reach Out to Patients*	*Festive Season Management*

Measure and evaluate

Consider measuring and evaluating social media activities to determine if it meets your goals. For example, you could qualitatively and/or quantitatively measure:

- comments
- followers / friends
- likes
- participation
- retweets
- traffic

Consider your social media challenges and successes, and adapt from lessons learned and feedback.

Formal evaluation can be useful to:

- measure the qualitative benefits against investment
- objectively analyse if goals were achieved
- consider:
  - if it is an effective tool for external feedback and reputation management
  - if audiences were engaged meaningfully and benefited

The Useful Sharing and Monitoring Tools chapter provides a list of tools, which may help your organisation monitor and evaluate the success of your social media engagement.

Establishing a community

Communities in everyday life exist so that members can support each other. Social media communities are the same – social media is all about connecting and sharing. The more valuable your organisation's contribution to social media communities, the more connections will be made, and the more benefit to your organisation and audiences.

To advise audiences that your organisation is now on social media, include an announcement in your newsletter, social media icons on your printed material and a link on your website. Consider including a call to action like 'join our conversation'.

If someone reaches out to you, reciprocate by returning the follow or like of an organisation or individual whose values and members are similar and appropriate. Be a valued social media participant by contributing to other organisations' or individuals' social media pages. If there is something interesting, valuable or relevant on another organisation's or individual's page, link to it.

Maintaining a community

Language

Although it may seem obvious, it is worth mentioning that attention to spelling, grammar and punctuation is essential. Being careless with language could potentially be quite damaging to your organisation's reputation. It is worth having items proofed by someone else before posting.

Translations

It is very difficult to accurately translate resources online. Facebook provides a translation button for status updates in other languages, although shared content is not translated. Google Translate is an example of a free online translation service. However, the sensitivities and nuances of languages are, of course, not easily captured in a computerised translation service, so it is commonly regarded as inaccurate. Translation remains one area of modern life that is not easily replaced by technology. For accurate translations, it is best to connect with people with foreign language skills.

Moderating

Comments from members of your network build credibility and a sense of community. However, while generally rare, comments may be inappropriate or irrelevant, or reflect negatively on an individual, and require some form of moderation. The moderation process should be objective and impartial and avoid the perception that comments are unethically censored.

Some social media sites do not allow comments to be moderated before being published so a dedicated resource for checking social media sites daily may be necessary. It is advisable to engage settings to review and approve comments before they are published, if available. This allows timely response to comments, deletion of spam and blocking of serial pests. If moderating comments, be upfront and include a notice on the site which encourages participation and a diversity of views, requests that comments are constructive and notifies the community that the organisation reserves the right to moderate.

Responding

Do not ignore difficult questions or negative comments. Consider negative comments as an opportunity to respectfully engage with the commenter to sensitively persuade a transition in their opinion. Provide links to other sources to validate arguments and justify stances. Being constructive and respectful will be more persuasive and maintain your organisation's reputation.

If a negative comment is constructive, engage publicly with the commenter to respond and resolve issues. Be appropriate and polite when disagreeing with an opinion. If the situation could become antagonistic, do not be defensive or abruptly end the conversation. Conclude politely and in a tone that reflects well on your organisation. If a negative comment is not constructive, remove it and inform the commenter why it was removed.

Managing social media

It is important to have people as the face of your organisation's profile because social media is about authentically connecting with others. Identify appropriate people to participate and represent your organisation. They should be an expert, passionate and empowered to act on feedback.

Prepare an approval protocol for publishing and a response protocol for responding to comments. Write down who in your organisation is approved and the approval process. This is important to protect the organisation and will assist in making individuals aware of their responsibilities of engaging in social media.

Because different individuals and organisations hold different values, deciding what is appropriate to endorse, by linking, liking or retweeting, is completely subjective. There is no right or wrong answer. Follow a due diligence process, consider the values of your organisation and community, delay publishing until a colleague provides a second opinion and practice good judgement. Avoid comments that may bring your organisation into disrepute. Correct any errors in judgement or mistakes quickly and visibly to maintain your community's respect.

Legalities

Individuals have been held liable for comments or content which is proprietary of or copyrighted by third parties or where defamatory, libellous or obscene. Anonymous comments may be traced back to you or your organisation's Internet Protocol (IP) address, which is a unique number.

Respect privacy and confidentiality. Do not cite or reference individuals without their written permission. If discussing a situation involving individuals, use pseudonyms or general details to ensure they cannot be identified in any way. Obtain consent of all individuals in photos, videos or other media before posting. Do not provide medical information or advice unless you are authorised to do so or unless it is already in the public domain and referenced.

Consider copyright regulations. Properly reference published content and attribute public content by disclosing its origin and linking back to the original source. If valuable content is from a subscription only online source (i.e. you have paid to access it), recommend it and include its title and source as opposed to lifting and linking it from the source.

Golden rules of social media
- Understand the implicit culture and explicit rules of online communities
- Engage in social media to enhance your organisation's reputation
- Consider current and prospective community members
- Be transparent by disclosing your identity, organisation and any vested interests
- Tell your story responsibly to uphold the trust of your community; never lie or omit the truth
- Confirm that posts do not violate laws or regulations and are not related to legal matters
- Recognise that once published, there is no control over how what is written might be used
- Be aware of individual and organisational liability

When in doubt, do not post.

Understanding your time commitment

Social media is community orientated and involves pushing and reciprocating to engage within your organisation's community, and also reaching out and participating in other communities.

Social media engagement should be delegated to a role to ensure that it is maintained. If managing the social media presence becomes too cumbersome, chances are that it will become inactive. An inactive profile or community quickly loses participation, usefulness to audiences and authority as a respected resource.

Social media engagement needs to be efficient, timely and manageable. Establishing a normal pattern of use will take time and will differ across organisations. Realistically, it will be more than a few minutes per day, and, depending on your organisation's objectives, could take 20 minutes or a couple of hours per day if you are trying to encourage participation and activity. Make a commitment to update and monitor communities during office hours, Monday to Friday. This will ensure that the precedent of 24/7 activity is not expected.

It may not be possible to manage replying to all conversation threads and comments. If this is the case, reply to themes, incorporating responses to similar posts in a general summary response. Direct messages and questions should be addressed individually and promptly, which requires time.

Planning a communications calendar and messages will take time initially, but will save time on a daily basis. Drafting announcements in 140 characters, sourcing appropriate content to link and connecting with others will take time, but if incorporated with other ordinary communications, should not be too much of an additional time commitment.

Setting up social media profiles – some examples

Facebook

As of February 2012, Facebook had more than 900 million active users, making it a prime opportunity to provide patient advocacy services to a wide audience.

Before commencing, decide if a Facebook Page is the right fit to meet your goals. Research audiences to determine if they are actively present on Facebook.

Facebook pages work just like personal profiles. You can:

- make friends
- update your status

- upload videos, photos, and articles
- create events

Name the Facebook Page after your organisation. Audiences will search for a name, so ensure it is relevant and recognisable for someone to locate using search terms. It is advisable to choose one short and simple name for all social media platforms, to ensure consistency of identity to audiences and the public across different platforms.

Upload an appropriate and meaningful image for your Facebook profile photo. Consider that images convey meanings and tone faster than words, so choose wisely. Photos should complement the organisation's mission and messages. Although you can include messaging in your Facebook cover photo (such as the brand messaging in the example below), Facebook's terms and conditions state that you cannot include any calls to action, contact information, or a Facebook 'Like' or 'Share' graphic in your profile photo. For more information, visit **www.facebook.com/page_guidelines.php.**

Appropriate cover image that shows the personality of the organisation

'About' messaging is consistent with the rest of the organisation's messaging across other platforms

Good balance of different activities and content types e.g. photos, events, campaign apps

Facebook pages should be updated regularly with valuable content. Facebook posts should be interesting, link to further web content (including videos or surveys) and include a clear direction or call to action. Posts should be a balance of information about events, campaigning activities, news, tips and articles – not just produced by, or directly related to the organisation, but supporters and partner organisations too.

← Identifies source

← Calls to action

← Links to valuable content

Appropriate cover image that shows the personality of the organisation

Good balance of different activities and content types e.g. photos, events, campaign apps

Likes pages of campaigns and organisations

Activities

Facebook causes are useful in facilitating passionate supporters to champion messages to broader audiences. Successful causes engage audiences to further engage broader audiences, snowballing.

Twitter

As of March 2012, Twitter had more than 140 million active users in more than 20 languages. It is one of the top ten most visited websites on the internet.

Twitter is a micro-blogging platform, where short status updates are posted about stories, ideas, opinions, news; anything that is of interest. Anyone can see and search for tweets, whether or not they have a Twitter profile, but only those with a Twitter profile can tweet.

The twittersphere tells audiences what is happening in 140 characters or less per 'tweet'.

Like with Facebook, before commencing, decide if a Twitter account is the right fit to meet your goals. Research audiences to determine if they are actively present on Twitter.

Twitter profiles require a name and image. It is advisable to choose one short and simple name and small and simple image for all platforms, to ensure consistency of identity to audiences and the public. Profile names should be as brief as possible because audiences may wish to reference your organisation's name in their tweets.

Upload an appropriate and meaningful profile image that complements the organisation's mission and messages. Twitter images are very small. It is recommended to choose an easy to identify image, with little detail, that fits the provided space.

IFPA @PsoriasisIFPA   12 Oct
Wave for #WorldArthritisDay! worldarthritisday.org @ArthritisDay
Expand

Mayo Clinic @MayoClinic   11 Oct
Join #WorldArthritisDay chat Fri 12:30pET. Get answers to your #arthritis, #osteoarthritis & #rheumatology questions. mayocl.in/SSfpLi
Retweeted by IFPA
Expand

IFPA @PsoriasisIFPA   12 Oct
Up to 42% of people with #psoriasis also suffer from #PsoriaticArthritis. It's #WorldArthritisDay- spread awareness and caring today!
Expand

IFPA @PsoriasisIFPA   12 Oct
Health News – Research reveals how immune cells can be altered to help fight inflammatory diseases shar.es/5UXvc
Expand

IFPA @PsoriasisIFPA   11 Oct
#WPD12 World #Psoriasis Day 2012: focus on getting psoriasis on the global health agenda! View campaign pics here: bit.ly/SNt0YR.
Expand

Twitter pages have flexible designs. Page backgrounds and colours can be customised by importing images and changing colours palettes. Ensure the look and feel follows your organisation's branding for consistency across platforms.

Tweets must be concise and contain clear messages.

Tweets cannot have more than 140 letters, punctuation marks or spaces otherwise text cuts off, clipping key words. This is 140 characters!
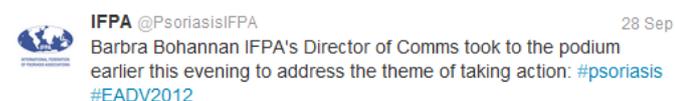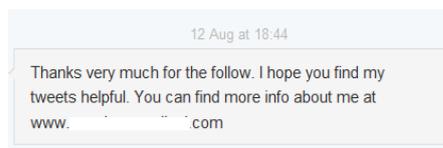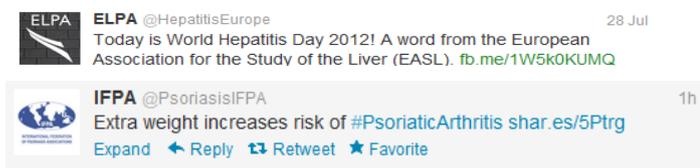
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Every day, Twitter is used by not for profit organisations to reach millions of people and gain support for initiatives, which without Twitter, might have gone unnoticed. Organisations use Twitter to regularly update audiences and provide valuable content. Use Twitter to:

- make announcements

- link to pictures, videos or webpages with latest information, anecdotes and resources

- retweet, which is the equivalent of forwarding an email. It repeats someone else's message to your followers in recognition of the post's value

- @reply, which is a message between two users and visible to anyone searching Twitter, following the poster of @reply and in your organisation's Twitter profile page

- direct message, which is a private message between users and is not visible to others, the internet or searchable

- group information around a specific theme, subject, campaign or event using a #hashtag

ELPA @HepatitisEurope   28 Jul
Today is World Hepatitis Day 2012! A word from the European Association for the Study of the Liver (EASL). fb.me/1W5k0KUMQ

IFPA @PsoriasisIFPA   1h
Extra weight increases risk of #PsoriaticArthritis shar.es/5Ptrg
Expand   ← Reply   ⇄ Retweet   ★ Favorite

ECPC @cancereu   20 Sep
RT @LILT_Bologna Smokers who start at 15 are 3x more likely to die from cancer than those starting 10yrs later corriere.it/salute/sportel… #smoking
● View conversation

IFPA @PsoriasisIFPA   29 Sep
@mylou1977 Thanks again for your support :) #EADV2012
● View conversation   ← Reply   ⇄ Retweet   ★ Favorite

12 Aug at 18:44
Thanks very much for the follow. I hope you find my tweets helpful. You can find more info about me at www._____.com

IFPA @PsoriasisIFPA   28 Sep
Barbra Bohannan IFPA's Director of Comms took to the podium earlier this evening to address the theme of taking action: #psoriasis #EADV2012

Google+

Google+, also known as Google Plus and G+, is Google Inc's multilingual social networking site. Established in June 2011, it already has more than 250 million registered users.

The advantage that Google+ has over other social networks is that any engagement over a piece of content that happens in Google+ results in increased visibility in the search engine ranking within Google. This is especially important as the first step for those seeking more information on a particular subject is a Google search. Therefore, using Google Inc will be likely to increase the rank of your content, acting as an automatic search engine optimisation. Ensuring that your content is ranked as highly as possible on Google, means that people are more likely to connect with your organisation.

With a Google+ Page, organisations can share information and anecdotes, photos and videos, ask questions. Communication and engagement can be tailored for your organisation's different audiences using Google+ Circles, which segments groups of people with distinct communication needs and interests. For instance your organisation might establish a circle for volunteers and a separate circle for patients, or even separate circles for different countries, ensuring that content is relevant to each circle.

Google+ Hangouts easily facilitates live, high quality video conversations with up to nine users with a simple click of the mouse. Just send the date and time to invitees and click to connect.

Most people already have a Google account to one of Google's many services e.g. Gmail, YouTube, Google Calendar, so can set up their Google+ page using their existing account. Anyone with a personal profile on Google+ can create a not for profit Google+ Page for their organisation. If no one in your organisation has a personal profile, creating a Google account is very straightforward. Your organisation can have a maximum of 20 Google+ Pages, but remember, fewer, more regularly updated social media platforms have more impact than more, inactive pages.

If your organisation includes a +1 button on its website, your audience can endorse or recommend your organisation or posts, which then appear on your website, Google+ Page and in Google searches.

Search and Ripples make it easy to monitor what is being said about your organisation on Google+.
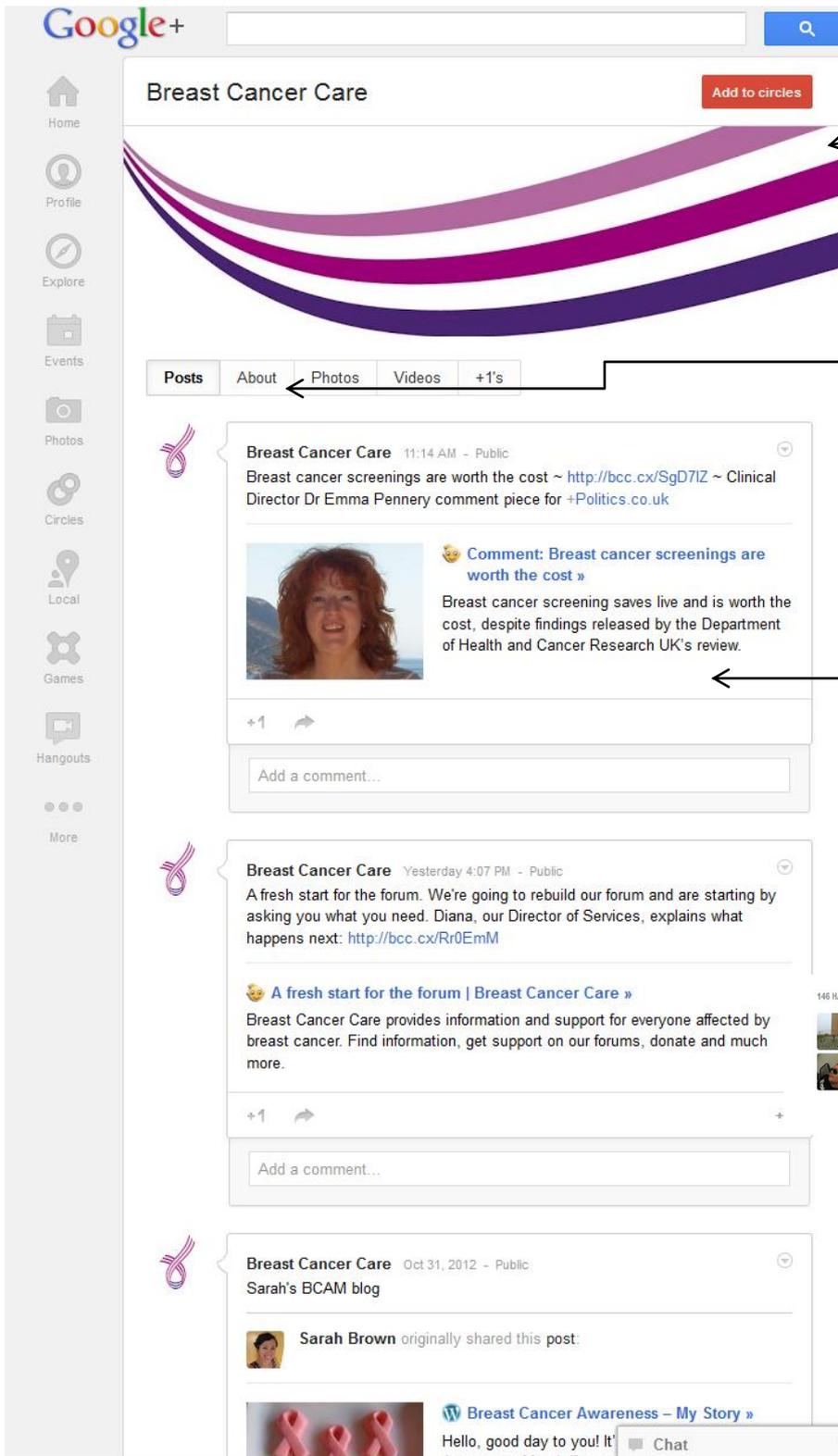
Appropriate cover image and logo that shows the personality of the organisation

'About' messaging is consistent with the rest of the organisation's messaging across other platforms

Good balance of different activities and content types e.g. photos, events, campaign

Links to pages of circle connections

Glossary of terms

Facebook

Friend	People / organisations that you have connected with on Facebook
Like	Used on your content by other people / organisations to endorse content instead of leaving a comment
Message	Is a private message between the sender and recipient and is not publicly visible and can be sent to multiple recipients
Posts	Content that you load and comments that you make on a Facebook page
Profile	Your Facebook page with your content
Profile picture	The main photo of your Facebook page
Status	Is a description on your Facebook page of what you are currently doing
Tag	Links your content to other people / organisations on Facebook i.e. in photographs
Wall	Post and share content with others on your wall, which is located on your profile page. Depending on your security settings, other people / organisations can also post and share content on your wall

Twitter

@	Precedes a Twitter username and links to that person's / organisation's Twitter profile. It is used when people want to reply to or mention another Twitter user
# (Hashtag)	Precedes a key word or topic in a tweet. Twitter collates all words or topics tagged with the hash symbol (#) in search results
DM	Is a direct message, which is private between a sender and recipient and is not publicly visible
Follow	Connect to people / organisations on Twitter to receive their tweets in your profile's timeline
Follower	A person / organisation who has connected to your Twitter account and receives your tweets in their timeline
Profile	Your Twitter page with your content and tweets
Retweet	Forward and share a person's / organisation's tweet with your followers
Timeline	A list of immediate and chronological tweets from people / organisations you follow
Tweet	Posting a public message on Twitter

Google+

+1	Clicking the +1 button publicly shows that you like or recommend people's / organisation's content. It also improves the ranking of that content in Google search results
Circles	Catalogues your Google+ connections into groups so that you can share relevant content with specific audiences
Hangout	Is a video chat and collaboration feature with multiple audiences

Useful sharing and monitoring tools

Social networking
Facebook	facebook.com
Twitter	twitter.com
LinkedIn	linkedin.com
Google+	plus.google.com

Media-specific social sharing
While these services exist to host rich media – i.e. photos, videos – they also have communities.

Video
YouTube	youtube.com
Vimeo	vimeo.com

Photo
Flickr	flickr.com
Instagram	instagr.am
Teleportd	teleportd.com
Pinterest	pinterest.com

Audio
Audioboo	audioboo.fm
Soundcloud	soundcloud.com

Blogging platforms
Wordpress	wordpress.org
Blogger	blogger.com
Tumblr	tumblr.com

Sharing buttons
Although it is possible to embed or install these buttons individually on your website, some platforms have these buttons built in – you simply need to enable in your administrative panel.

Facebook 'Like' button	developers.facebook.com/docs/reference/plugins/like
Twitter buttons	twitter.com/about/resources/buttons
Google +1 button	google.com/intl/en/webmasters/+1/button/index.html
LinkedIn button	developer.linkedin.com/plugins/share-button
AddThis & ShareThis	addthis.com & sharethis.com
allows you to select sharing options for multiple platforms in one button	

Monitoring tools

The following tools are free (and/or have free versions of their accounts). Before you sign up, consider what you want to measure and ensure that the tool you select can do this.

Twitter Counter	twittercounter.com
Samepoint	samepoint.com
HowSociable?	howsociable.com
Addictomatic	addictomatic.com
bit.ly	bitly.com
monitor links you share on Twitter	
Storify	storify.com
collate social mentions and publish as one story	
Netvibes	netvibes.com
uses RSS to keep track of social media and news feeds	

Useful Google campaign tools

Google Analytics	google.com/analytics
add to your website for comprehensive onsite traffic and visitor flow	
Google Ad Planner	google.com/adplanner
identify websites your target audience will visit	
Keyword Tool – Google Adwords	adwords.google.com/select/KeywordToolExternal
shows related keywords and search terms people are using to find your content	

Other useful free tools

Tweriod	tweriod.com
identifies optimal times to tweet	
Buffer	bufferapp.com
distributes tweets and posts at optimal times	
Twilert	twilert.com
like Google Alerts for Twitter – good for monitoring your key words	
Scribd	scribd.com
share PDFs on Facebook	
Mr Unfollowr	twitter.com/unfollowr
tells who is unfollowing you on Twitter	
Manage Flitter	manageflitter.com
identifies accounts that are inactive or do not follow you back	
Aviary	aviary.com
capture a picture of the screen, edit and add comments, useful for Twitter	

Social media: you can do it!

Not for profit organisations all over the world use social media every day to reach millions of people and gain support for their initiatives, which may otherwise have gone unnoticed. There are so many innovative examples of how social media benefits people, communities and organisations. The potential uses of social media by patient advocacy organisations to successfully reach and engage with audiences feel infinite.

To successfully engage in social media, it needs to fit it into your organisation's communication objectives and planned activities. Do one or two things really well, rather than overreaching and being overwhelmed. Build a community and enhance your reputation by reaching out and developing relationships. Be a valuable contributor by adapting quality content already produced by your organisation so it is social media ready and linking to and referencing quality content already published by others. Be aware of sensitivities and your responsibilities and adhere to regulations. Monitor and adapt what you do online; if something does not work, consider what could work better.

Patient advocacy groups can make an enormous difference by engaging in social media. This tool kit was designed to help patient advocacy organisations be energised and proactively engage in and manage social media.

janssen