
  
 Improving treatment and care through representation, advocacy, education and research

## Social networking: community perspectives and issues to consider for community organisations

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## Social media technology: what is it?




Wikipedia:

- Based on Web 2.0 – “web applications that facilitate **participatory information sharing, interoperability, user-centered design and collaboration**”
- “Use of web-based and mobile technologies to turn communication into an **interactive dialogue**”
- “Allows the **creation and exchange of user-generated content**”.

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## Other popular forms

- Facebook



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## Other popular forms

- Twitter – tweets in 140 characters or less



## Why invest in social media?

### Social Networking

Australians use Social Networking sites at a rate similar to Europe's regional average, outpacing the global average by 10 reach points.



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## What type of social media?

### High Social Networking Reach in Australia is Driven by Facebook

As in many countries around the globe, Facebook is the clear Social Networking leader in Australia, both in terms of reach and usage. The average Facebook user spent about five hours on the site over the course of the month.



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## Why facebook for HFA?

- Aware that members already active there
- Could reach a younger demographic,  
Eg HFA Survey, 3.5% 18-24 yrs  
vs HFA facebook page, 18.5% 18-24 yrs

Age Group	Female (%)	Male (%)
13-17	1.4%	2%
18-24	11%	7.5%
25-34	19%	17%
35-44	14%	9.4%
45-54	5.4%	3.5%
55+	3.7%	1.5%


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## Value of social media – community

*“I believe that real benefit of using social media will be for the teen/youth section of our community, in terms of both being able to better engage that group in the bleeding disorder community and secondly (and probably more importantly) providing a support network via a medium that they will be comfortable using.*

*As a parent of a 14 year old boy with haemophilia I see social media as about the only way he will engage (willingly) in the bleeding disorder community. He is beyond/not interested in many of the other activities that our Foundation does, with the exception of the camps.”*

*Parent*



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## Value of social media – community

*“Facebook provides a way to promote haemophilia info to a younger group than the HFA web site might attract.*

*I’d like the HFA facebook page to host private groups for mothers of young children to vent or ask each other questions - lightly moderated for safety reasons – and for people with haemophilia to keep in contact and vent issues between themselves.*

*And for members to be able to post photos and comments on state activities such as Red Run, or camps that HFA may have funded. And be aware of fundraising activities.”*

*Woman carrying the haemophilia gene/parent*



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## Value of social media – community

*“Facebook is helpful for me to keep in touch with people that I don’t see that much, find things out about people and catch up with old friends.*

*I would like the HFA facebook page to provide a platform for networking between siblings, parents and other families within the haemophilia community. I would also like for my family to be able to check the facebook page to keep up-to-date with events and news.”*

*Young person affected by haemophilia*

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## Value of social media – community

*“Facebook enables those of us within the Haemophilia community to connect - where we otherwise have a limited chance to correspond....it lessens the miles between us.*

*I'd like to be able to use the HFA facebook page to ask questions.... both to medical practitioners and other mums and dads or guys affected. I would also like it to keep us updated on issues that affect us.”*

*Woman carrying the haemophilia gene/parent*

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## Benefits for community organisations


- Connection to community and supporters



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## Benefits for community organisations

- Dialogue with community; answering questions in a timely way



facebook

Haemophilia Foundation Australia

An update from the Queensland Haemophilia Centre for Queensland patients - could you pass this on to other people in Queensland with bleeding disorders. Thanks everyone for your support in getting these messages out! <http://www.haemophilia.org.au>

Haemophilia Foundation Australia - QLD Haemophilia Centre Flood Update: 17 Jan 2011 [www.haemophilia.org.au](http://www.haemophilia.org.au)

If you have Downy, please return to normal storage of haemophilia products. If you have had a power outage or still do, please make contact with the centre to discuss your individual situation.

1,192 Impressions - 0.28% Feedback

Like Comment Share January 17 at 8:58am

2 people like this.

What about Victoria?  
9:54am · Like

Haemophilia Foundation Australia Thanks Helen - that was a good question. We followed it up with the Haemophilia Centres in Victoria and grabbed the Victorian alert on Facebook the next week. Just to let you know your concerns make a difference!  
February 21 at 4:05pm · Like

Haemophilia Foundation Australia Watch out for personal stories about the floods and cyclones in Queensland from people with bleeding disorders and the Haemophilia Centre staff in the next issue of National Haemophilia - due out in late March.  
February 21 at 4:06pm · Like

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## Benefits for community organisations

- Opportunity to promote events, activities and resources



facebook

Haemophilia Foundation Australia

Have you wondered what it would be like to be an Olympic champion with haemophilia? Download the latest Youth Focus to hear Alex Consett talk about training for the 2012 Olympic Games in London and get tips for cycling. Alex is a champion UK cyclist who has severe haemophilia A. Other great stories - see on social, date about life choices and leaving school. <http://www.haemophilia.org.au/Documents/Item/2621>

Wall Photos

1,527 Impressions - 0.59% Feedback

Like Comment Share March 23 at 2:27pm

5 people like this.

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## Benefits for community organisations

- Engaging community members in programs



The screenshot shows two Facebook posts from the Haemophilia Foundation Australia. The top post is dated Sunday, October 9 at 12:00pm and has 856 Impressions and 1.75% Feedback. It features a postcard for Haemophilia Awareness Week with the theme 'Health and wellbeing into the future'. The bottom post is dated Sunday, October 9, 2011 at 12:00pm and has 175 Impressions and 2.86% Feedback. Both posts show engagement metrics like likes and shares.

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## Risks for community organisations


Interactivity creates community dialogue, but also potential risks:

- Protecting the privacy of community members
  - Feels intimate, but is very public
- Potential for inaccurate or unsafe advice
- Cyberbullying, offensive or inappropriate behaviour
- Advertising, commercial gain, misrepresentation




The illustration shows a person wearing a yellow hard hat and a high-visibility vest, holding a large red octagonal sign with the word 'STOP' in white. A single orange traffic cone is positioned on the ground next to the person.




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## Considerations



- Capacity of the organisation to manage risks productively
  - Risk to community member safety
  - Risk to the organisational reputation
- Capacity of the organisation to keep its social networking presence active and alive
- Organisational guidelines: policies and procedures


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## What has HFA done?

Established HFA facebook page in April 2009

- Capacity decision: facebook page rather than group
- Organisational reputation: reliable, responsible, careful of the safety of its community members
- Policies and procedures to reflect this
  - Developed before page set up



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## Policies and procedures

- Moderation:
  - Facebook email address – emails checked daily
  - Reflects HFA policies and organisational responsibilities
  - Educational approach: explain why to individuals and facebook fans

 **Haemophilia Foundation Australia**

We have noticed market research companies posting on this page to recruit Australian participants and have removed them. Medicines, consumer research and privacy are regulated in Australia by various bodies. For more info go to [www.haemophilia.org.au/bleedingdisorders/cid/10/parent/1/pid/10/t/bleedingdisorders/title/participating-in-research](http://www.haemophilia.org.au/bleedingdisorders/cid/10/parent/1/pid/10/t/bleedingdisorders/title/participating-in-research). Contact HFA for our research procedure – [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)


1,114 Impressions · 0.09% Feedback

Like · Comment · Share · April 21 at 10:58am

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## Policies and procedures

- Response to queries
  - Reflects HFA expertise; no medical advice given; may direct to another organisation
  - Discussed with Executive Director, HFA team
  - More informal, personal
  - Sample responses kept on record for reference
- Protecting privacy
  - Ground rules: a person can disclose that they have a bleeding disorder, but no one else can disclose for them



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## Policies and procedures

- Boundaries:
  - Professional vs personal
  - Community organisation vs commercial interests
  - Australian vs overseas: different ground rules, regulations?
- Keeping facebook page active and alive
  - Regular HFA postings, responses, questions




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## Where to next?

- Capacity to manage private groups?
  - Risks?
- Ongoing development of social media technology





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## Web 3.0

Many experts: Web 3.0 browser = personal assistant.

- Personalisation: "As you search the Web, the browser learns what you are interested in. Eventually you might be able to ask your browser open questions like "where should I go for lunch?" Your browser would consult its records of what you like and dislike, take into account your current location and then suggest a list of restaurants."  
<http://computer.howstuffworks.com/web-30.htm>
- Could community organisations use this technology to deliver more personalised information to community members?



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