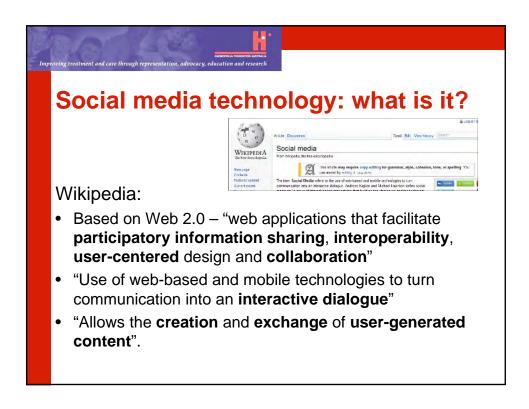
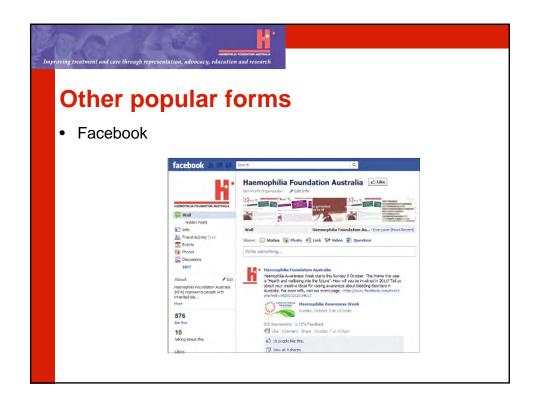


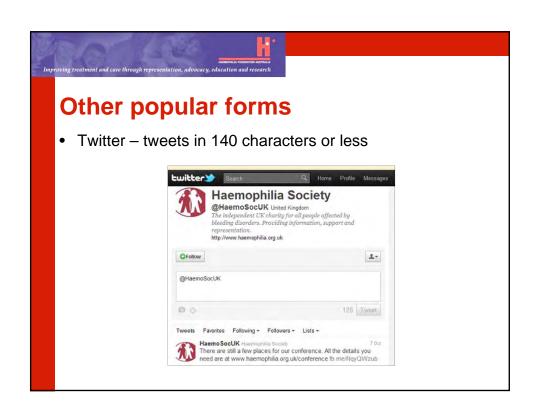
#### Social networking:

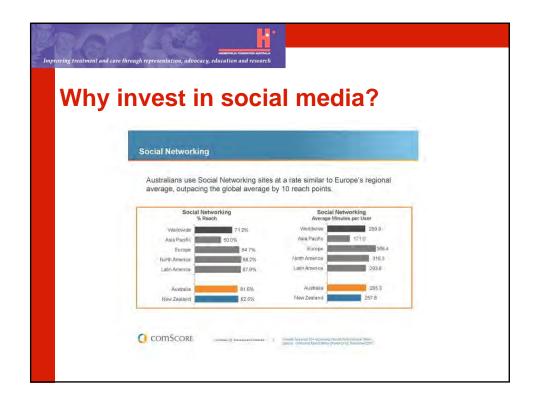
community perspectives and issues to consider for community organisations

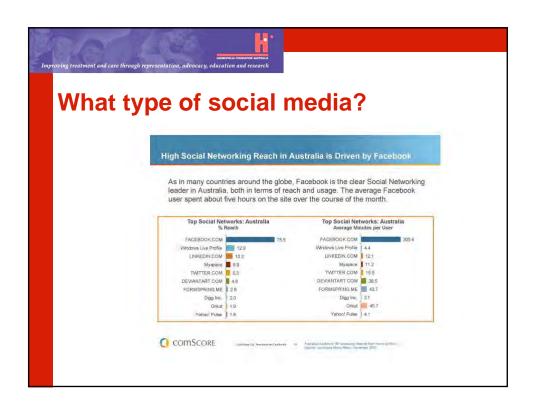
Suzanne O'Callaghan Policy Officer Haemophilia Foundation Australia







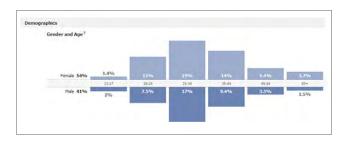






#### Why facebook for HFA?

- · 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





# 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



#### 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



### 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 upto-date with events and news."

Young person affected by haemophilia



## 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











# **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





#### **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



#### 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





### **Policies and procedures**

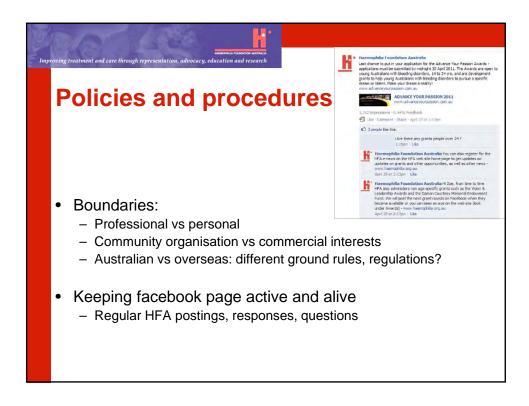
- Moderation:
  - Facebook email address emails checked daily
  - Reflects HFA policies and organisational responsibilities
  - Educational approach: explain why to individuals and facebook fans





# **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







#### 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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