



## **What young people want from health-related online resources: a focus group study**

Gillian Fergie\*, Kate Hunt and Shona Hilton

*MRC/CSO, Social & Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow, UK*

*(Received 5 December 2011; final version received 25 October 2012)*

The growth of the Internet as an information source about health, particularly amongst young people, is well established. The aim of this study was to explore young people's perceptions and experiences of engaging with health-related online content, particularly through social media websites. Between February and July 2011 nine focus groups were facilitated across Scotland with young people aged between 14 and 18 years. Health-related user-generated content seems to be appreciated by young people as a useful, if not always trustworthy, source of accounts of other people's experiences. The reliability and quality of both user-generated content and official factual content about health appear to be concerns for young people, and they employ specialised strategies for negotiating both areas of the online environment. Young people's engagement with health online is a dynamic area for research. Their perceptions and experiences of health-related content seem based on their wider familiarity with the online environment and, as the online environment develops, so too do young people's strategies and conventions for accessing it.

**Keywords:** health; leisure; Internet; social media

### **Introduction**

The Internet has become established as an important source for health information. For young people, who are often associated with use of the online environment, the plethora of health information available online is wide-ranging in source and reliability. In particular user-generated content on social media websites provides instant access to other people's experiences of a variety of health issues. In this paper, we discuss the main themes in research around young people and online health information, particularly around reliability and information-seeking practices. We also discuss the conclusions of recent research on the potential of social media for health research, health information dissemination and health interventions aimed at young people. The aim of our focus group study was to contribute to this research by exploring young people's perceptions and experiences of engaging with health content online, particularly through social media, and their strategies for negotiating reliability online. Finally, we discuss the perspectives of young people in the context of related research around the use of online health resources for information and peer-support and suggest that young people's perspectives can provide useful insights for the use of social media in future health promotion and communication.

---

\*Corresponding author. Email: [g.fergie@sphsu.mrc.ac.uk](mailto:g.fergie@sphsu.mrc.ac.uk)

## Background

The most recent Oxford Internet Survey (Dutton and Blank 2011) states that 73% of people in the UK are Internet users and, of these, 71% use the Internet for health information. Qualitative research around people's engagement with health information suggests that young people identify the Internet as an important resource (Borzekowski and Rickert 2001, Skinner *et al.* 2003, Gray *et al.* 2005a, Buhi *et al.* 2009), particularly for information on sexual health and behaviours and, fitness and nutrition (Borzekowski and Rickert 2001, Skinner *et al.* 2003).

However, there has been concern about the quality and accuracy of information available online and about users' skills for appraising online health information (Nettleton *et al.* 2005). Much of the research in this area concludes that the accuracy of online health-related information varies greatly (Silberg *et al.* 1997, Purcell *et al.* 2002, Benigeri and Pluye 2003, Selman *et al.* 2006). An assessment of websites visited by young people in an observational study by Buhi *et al.* (2010) reported that websites featuring sexual health content were on the whole accurate. However, some inaccuracies occurred in the presentation of complex material, and no simple relationship was discerned between website quality and the presence of inaccurate information. Research has also explored the prospect of young people being vulnerable to misinformation on the Internet. Gray *et al.*'s (2005b) focus group study of young people in the UK and USA explored literacy in the context of engagement with online health information. While their findings highlight young people's sophisticated Internet skills, they also describe shortcomings in abilities to locate, appraise and use online health information. These studies provide useful insights into the accuracy of online health-related content and online health information-seeking practices.

Other authors have considered the Internet in terms of the opportunities it provides for interaction and its increasing prominence in young people's lives. Indeed, young people have been characterised as 'digital natives' (Tapscott 1998, Prensky 2001), a generation of Internet users who are accustomed to the online environment and its associated technologies. However, this notion has been widely critiqued (Buckingham 2006, Livingstone 2008, Holmes 2011). Holmes' (2011) recent quantitative study suggests that a third of young people with Internet access in the home do not use it regularly and that the remaining two-thirds, who are active users, can be differentiated as 'information-focused' or 'recreation-focused' users. This suggests young people's experiences of the Internet are diverse and related to specific preferences and contexts.

Despite ongoing discussion of the idea of 'digital natives' the growth of young people's use of social media websites has been well charted. Social media have become incorporated into many young people's lives; 70% of 12–15 year-olds in the UK in 2009 had profiles on social networking sites (Ofcom 2010). Young people are identified within literature around online sociability as avid users of social media websites and the opportunity to post, comment respond and 'like' have become important expressions of identity for many (boyd 2007, Thomas 2007, Papacharissi 2010). Williams and Merten (2008) emphasise the importance of considering social media as a meaningful aspect of young people's lives since it is something they invest time and effort into. Livingstone and Brake (2010) outline the need for research which explores social practices around new technologies as they become incorporated into young people's online and offline lives.

The proliferation of social media technologies has altered the ways in which health-related content is contributed and appropriated in online spaces (McNab 2009) and the increasing number of 'next generation' users (those who use mobile and multiple devices to access the Internet) (Dutton and Blank 2011) may further alter these processes. This dynamic environment has raised further concerns about the quality and accuracy of the health-related content on social media websites. A recent review of literature on online health-information reliability suggests that social media technologies undoubtedly present opportunities for public engagement with health information, but with these come challenges in ensuring information reliability (Adams 2010). Similarly, Vance *et al.* (2009) highlighted the complex web of health-related content within social media sites – ranging from personal video accounts of drug treatments on YouTube to social networks based around particular long-term medical conditions – and the challenges of interpretation such sources present. Particular attention to these issues of interpretation and reliability are, therefore, important in research on social media and health.

The extent to which social media have become incorporated into everyday life has begun to shape health policy. McNab (2009) draws attention to the range of opportunities that social media present to health professionals and citizens alike, including the opportunity to communicate rapidly and without media filtration. To this end, there have been a number of recent innovations in health information dissemination aimed at young people that attempt to utilise social media. In the UK, the Department of Health (DH) hosted a virtual surgery in Habbo (a social networking site for young teenagers) (NHS 2009). The DH also hosts a range of health-related Facebook pages and has utilised YouTube video-sharing facilities in the National Health Service (NHS) Internet information service NHS Choices (NHS 2011). These technologies, by design, encourage contributions from users through comment posting facilities, making them dynamic health resources featuring both official factual content and conversations and debates.

Recent research on the use of social media by young people in relation to health has tended to focus on three main areas: the visibility of young people's health-risk behaviours on social media websites; the use of social media for health interventions and support services; and, less frequently, young people's perceptions of displays of health behaviours on social media websites.

A number of articles present analyses of the health content of specific social media websites. A review of US research and national data on adolescents and social media suggested that monitoring of social media could be useful in identifying 'risk behaviours' in young people (Pujazon-Zazik and Park 2010). Griffiths and Casswell's (2010) analysis of alcohol-related user-generated content on Bebo profiles of 16–18 year-olds found that the online environment provided by social networking sites is permeated with references to alcohol, which may be contributing to the normalisation of underage drinking. Similarly, Moreno *et al.* (2010a) examined alcohol references on MySpace and suggested that explicit references to alcohol are commonplace on young people's social networking profiles and could, therefore, be influential across peer groups. They also examined sexual references across user-defined friendship groups and suggested that those young people who make references to sex on their profile are more likely to be friends with others who make similar references (Moreno *et al.* 2010b). Mental health issues have also been explored on social media websites. An analysis of blogs has been successfully used to

help identify teenagers with depression, which the authors hope could help engage teenagers suffering depression with social agencies (Goh and Huang 2009). In these studies, social media have been utilised to provide insight into young people's health behaviours particularly in relation to their social networks, made all the more visible through social networking sites.

Research has also explored the potential opportunities social media offers for health intervention. Moreno *et al.* (2009b) explored the possibility of using MySpace to contact young people advising them to reconsider their public references to sex and alcohol use and advocating sexual health testing, showing that a single message could effect a limited change in displays of some risk behaviours. The potential use of social media for outreach work concerned with sexual health has also been suggested by Ralph *et al.* (2011), who advocated for provision of services through MySpace but emphasised the importance of maintaining awareness of the dynamic nature of social media. Recent research also suggests the unique possibilities provided by social media, such as Facebook, for bringing together supportive communities. Nordqvist *et al.* (2009) have advocated the development by experienced health professionals of an online space for young people with type 1 diabetes, and Ekberg *et al.* (2010) provided guidelines on how social media can be used to facilitate effective collaborative learning amongst young people with chronic disease. These studies, around reaching and connecting young people through social media, indicate opportunities for positive uses of Internet technologies for health purposes.

Less research has focused on young people's perceptions of the presence of health-related content on social media sites. One of the few studies that has explored this area is Moreno *et al.*'s (2009a) focus group study on young people's perceptions of alcohol references on social networking sites, which suggested young people saw such references as real reflections of behaviours and an attempt to look 'cool'. While this research illustrates how young people perceive health-risk behaviours portrayed on social media, it does not provide any insight into young people's perceptions of explicitly health-related content. Indeed, the emergent research literature around young people, health and social media does not fully explore young people's engagement with explicitly health-related content. Health information dissemination that utilises social media has not as yet been comprehensively evaluated and concerns about the quality and accuracy of health information online have yet to be fully answered in relation to social media.

The development and increasing prominence of social media has created new opportunities for users, especially those in their teenage years, to contribute and engage with health-related content online. However, young people's own perspectives on these issues have not been extensively explored to date. The aim of this study, therefore, was to explore how young people engage with health issues on the Internet, particularly through social media websites. The use of the term 'engagement' attempts to capture both active and passive uses of the Internet, explicit interaction online through contributing content and observation of content without contribution. The research sought to answer the following questions:

- What are teenagers' perceptions and experiences of engaging with social media about health?
- How do young people assess the trustworthiness and reliability of health information online?

## Methodology

Qualitative methods were used. Nine focus groups were conducted with young people aged between 14 and 18 years between February and July 2011. Focus groups are particularly appropriate for generating attitudinal and experiential data and exploring points of view around a particular phenomenon (Kitzinger and Barbour 1999). The method provided an opportunity to explore the 'offline' context of young people's use of health-related social media, in particular: motivations for and barriers to accessing and contributing content; and perceptions of health-related social media and strategies for assessing online material in a social setting. The use of the method in this context, rather than interviews or participant observation, facilitated access to the processes involved in navigating online resources. The group setting prompted participants to justify and explain the series of judgements and moves they made as they browsed health content. This resonates with Bloor *et al.*'s (2001) suggestion that focus groups can encourage participants to engage in 'retrospective introspection', to attempt collectively to tease out previously taken for granted assumption (p. 6). Furthermore, Kitzinger (1994) suggests that focus groups provide unique insight into the group interactions that produce social knowledge, which was particularly useful in this case because the subject matter for discussion, social media, is increasingly important to young people's social relations (boyd 2007). Additionally, previous research on young people's perceptions of references to alcohol consumption on social networking sites successfully employed focus groups to explore young people's perspectives on issues related to health and social media websites (Moreno *et al.* 2009a). As Smithson (2000) notes particular attention needs to be paid to the impact of group dynamics on participants' contributions when using focus groups since dominant individuals may impose their opinions on others and normative rather than alternative perspectives are likely to be represented. Ethical approval was granted by the University of Glasgow College of Social Science Research Ethics Committee.

### *Sample selection, recruitment and group facilitation*

A 'purposive' sample of young people, aged between 14 and 18 years, was recruited (Table 1). Purposive sampling involves identifying individuals or groups whose contributions could most usefully address the research questions and provide insight into the phenomenon of interest (Denzin and Lincoln 2005). In this case, older teenagers were of particular interest since they are more likely to have concerns about their own health (Macfarlane *et al.* 1987, Jacobson *et al.* 2000) and most are likely to be registered on social networking sites (Ofcom 2010). In order to represent a range of views, a diverse sample was sought through recruitment of both boys and girls from a range of social economic (largely urban) areas across Scotland.

In order to recruit young people, 'gatekeepers' (i.e. adults who could facilitate access to particular groups of young people) were contacted by email. These included university course conveners and various community youth group leaders. The researcher then used snowballing through participants and professional networks and posted recruitment information on a number of Scottish youth organisations' social media websites to identify further potential participants. Young people or gatekeepers who responded to the recruitment information or introductory email were then provided with information sheets and response forms to distribute to interested groups.

Table 1. Characteristics of focus groups.

Focus group	SIMD rank (2009) (1 most deprived, 5 least deprived) <sup>a</sup>	Participants <sup>b</sup>	Type of area	Age range	Setting	Gender
1	3	University students – Tanya, Jane, Stephen	Urban	17–18 yrs	University building	Mixed
2	3	University students – Elaina, Sonia, Peter, Anya	Urban	18 yrs	University building	Mixed
3	5	School pupils – Claire, Jennifer, Siobhan, Diana	Urban	14–15 yrs	Parent's house	All female
4	5	School pupils – Amy, Becky, Catherine, Denise	Urban	14–15 yrs	Parent's house	All female
5	5	School pupils – Alice, Sally, Fiona, Natalie	Urban	15–16 yrs	Parent's house	All female
6	1	School pupils – Jack, Anthony, Barbara, Tim, Sarah	Urban	16 yrs	Youth Centre	Mixed
7	5	School pupils – Alison, Bea, Cara, Davina	Urban	14–15 yrs	Community leader's house	All female
8	4	School pupils – Ollie, Rhea	Rural	14–17 yrs	Community Centre	Mixed
9	4	School pupils – Joseph, Donald, Sam, Ethan	Urban	15–16 yrs	Local library	All male

<sup>a</sup>Scottish index of multiple deprivation rank quintile, based on participants' postcodes, if these differed the mean is shown.

<sup>b</sup>Pseudonyms have been used to conceal the participants' identities.

Morrow and Richards (1996) suggest that decisions around ethical issues in research involving young people should give consideration to the context of the research, the subject matter and the role of participants in the research. They also caution against treating young people as one homogenous group. In accordance with this guidance, two different consent procedures were developed. Participant response forms included an individual consent form for the young person and, for prospective participants under 16 years old, a parental consent form so parents could opt-in at the response stage if their child was keen to participate. Using the response forms participants were invited to contact the researcher for further information and suggest a date, time and place for the focus group. Following the return of response forms and having had an opportunity to ask questions about the research all participants provided written consent prior to data collection. This approach to recruitment means it is impossible to estimate participant response rates since it is unclear how many young people were approached but not interested.

Focus groups were facilitated in locations convenient to participants, including community centres, private houses and university buildings. Private, comfortable spaces were chosen in an attempt to create an intimate but spacious and undisturbed setting, as recommended for focus group facilitation (Kitzinger and Barbour 1999). All groups were facilitated by the same researcher (GF). During the focus groups no gatekeepers who had made the focus group possible were present in the room in which the focus group was conducted, although they may have been on the same premises. All focus groups consisted of friendship groups of between two and five participants in an attempt to maximise each individual's opportunity to participate fully in the group activities and discussion (Green and Hart 1999). However, despite these measures some participants may have felt more comfortable contributing to the discussion than others. Attempting to create a friendly environment and encouraging contribution in a non-confrontational manner was useful in addressing potential unease felt by participants.

The first half of the focus group was activity focused. Kitzinger and Barbour (1999) suggest interactive activities and stimuli can be useful for focusing discussion on key issues and allowing participants to develop their own vocabulary for discussing these issues without the researcher imposing particular terminology or ideas. Participants were provided with access to individual laptops to look at examples of health-related content on social media websites, including YouTube pages featuring video and text and Facebook groups featuring text and images. Participants were asked to discuss their perceptions of the site, its content and the strategies they might employ for assessing its reliability and usefulness. The discussion was then widened, using a topic guide which was based around the central research questions and informed by the literature. Questions were framed to place the participants in the position of expert in an attempt to address the potential power imbalance in the researcher-participant relationship, which is particularly important in research with young people (Morrow and Richards 1996). These prompted discussion of personal experiences of engaging with health-related content on the Internet, motivations for engagement, and perceived advantages and disadvantages of using social media to find out about health issues. Additions to the topic guide were made as the fieldwork progressed, introducing issues raised by participants in previous groups. The focus groups lasted between 45 and 75 minutes.

### ***Data analysis***

The focus groups were audio-recorded with participants' permission, fully transcribed and checked against the recordings. Thematic analysis of the transcripts was used to unpick participants' meaning-making and the social context in which these meanings were produced (Braun and Clarke 2006) as well as to generate useful insights for future research and policy around social media and health. This involved data reduction (reducing complex data to broad themes) and data interpretation (constructing meanings from the contributions of others) (Marshall and Rossman 1995). The importance of group interaction to focus group data encourages analyses that 'code the moving picture as well as the snapshots', that is, analyses which maintain the integrity of the story of the focus group and do not fracture participants' interactions (Catterall and Maclaran 1997). All transcripts were read closely and the entire text annotated on paper. Simultaneously, a mind-map of

emergent codes was developed. To ensure a systematic approach to coding a constant comparison method was employed (see Charmaz 2006). The transcripts were then revisited and excerpts collated by theme. Throughout data analysis, attention was paid to areas of consensus and disagreement, as well as to any unique or unusual perspectives (Frankland and Bloor 1999).

## Findings

The total sample comprised 34 young people, 24 girls and 10 boys. Two main themes are examined in detail below: perceptions of health-related content on social media websites and the evaluation of health-related content online.

### *Perceptions of health-related content on social media websites: 'can't always trust it' but 'you can relate to it more'*

Most participants expressed familiarity with using the Internet to find information about health and many had encountered health-related content on social media websites. They expressed one major disadvantage and a number of advantages of engaging with health content through these websites. The perceived disadvantage of health-related content on social media websites related to concerns about reliability. For example, in FG 7 when asked about negative aspects of accessing health information on social media websites, the participants said:

Bea: [You] can't always trust the information that you find.

Alison: And if you do trust it, [...] you could do more harm than good.

Cara: Yeah. (FG 7)

Similarly, another group responded:

Ollie: I don't know [...] people could just say anything.

Rhea: Yeah.

Ollie: Like... there's nothing to prove that it's true. (FG 8)

This concern with information reliability was referred to across all groups and seemed to shape young people's perceptions of the online environment and their experiences of engaging with health-related content online. Their accounts of concerns about the source and reliability of information posted on social media websites suggests a cautious and knowledgeable approach to the online environment.

While caution about reliability of information was commonplace, some aspects of health-related content on social media websites were viewed favourably. Some young people described positive experiences of engaging with health-related user-generated content. Tanya described an instance where she had drawn on another user's health-related contributions:

That's where the personal thing sort of comes in, rather than the NHS sites, [...] when I was looking up Accutane stuff, I knew what [...] the possible side-effects were but I had no idea how likely it was that someone would have those or [...] if it would happen to me so it was helpful to see how many or just [...] to read people's things, like 'oh it was fine' or 'really bad'. (Tanya, FG 1)



Tanya's experience, of being prescribed a treatment that she was unsure about and seeking reassurance online through the accounts of other people, suggests the value she attached to engaging online with other users' experiences. Through contributing and engaging with other young people's accounts on easily accessible social media websites, experiential knowledge around health might be shared widely and usefully.

While the participants stressed the likelihood of unreliable information within user-generated content, they saw social media as valuable for providing access to real individuals' accounts, which could be relevant and helpful in their own lives. For instance, during FG 9, participants outlined their first impressions of some health-related content on YouTube:

Donald: I think that's good because if someone is going through the same thing then they can look at them and whatever they've used to help [...] or cure whatever it is [and], it will help them as well.

GF: Mhmm . . .

Joseph: It's quite good, it's quite visual, with the video as well, it's not just someone typing something into a site and then you are reading it, you're actually seeing the person that's there, hearing their voice and their experience, so you can relate to it more I suppose. (FG 9)

In this case, and in other discussions, the idea of user-generated content about health being 'relatable' was important to participants. They viewed the opportunity to access other people's personal experiences as a particularly useful resource, which was most easily accessed through social media websites. Summing this idea up, the participants in FG 2 reached a consensus about the value of social media as complementary to factual information from official websites:

Peter: Social media is most likely to have personal opinions I think and the more informative like official sites they would have dry facts about the illness or any other problem you might have, so you kind of should look at both, to have the facts and then see how other people react to that, I think that's a great combination.

Anya: It's true. (FG 2)

Similar conclusions were reached in most focus groups, i.e., that social media provided a platform for engaging with other users' personal experiences and opinions which otherwise might not be accessible, and while no participants suggested this type of content should be entirely trusted, they appreciated its value as a resource. Cautiously approaching user-generated content as a source of information and comparing it with other trusted sources of information reflects the differences participants identify between the two types of resource and perhaps, their complementary nature.

Another important feature of social media raised and discussed by many of the participants, related to the idea of sharing personal experience, was the opportunity it provided for peer-support. When asked about useful aspects of health-related content on social media websites, Denise stated:

There [are] a lot of things [online] for people who are different [...], people can tell them they are not alone and that there is nothing to be ashamed of and that they can get help and things. (Denise, FG 4)

During this focus group, participants were keen to suggest that the online environment, and social media websites in particular, offers a useful place for people who are suffering to access support. Similarly, during FG 2, participants constructed a related point together:

Sonia: Just knowing that you are not alone, that is good, psychological[ly].

Elaina: Because I think [...] sometimes it is easier to communicate through the Internet, especially if you have something like serious, it is sometimes easier to talk with people you don't actually know than people who are close to you.

GF: Because of the anonymity?

Elaina: Yeah, and . . .

Peter: And sometimes a person that has the same illness will be more understanding and more supportive than somebody who doesn't have because he doesn't know what it's like to have the illness. (FG 2)

The opportunity for connecting with other people in a similar situation was another positive use of social media which participants thought might be valuable in terms of health. Indeed, social media were seen as a facilitator for making connections and creating supportive communities around particular health issues.

Anonymity was another perceived advantage of using online facilities for addressing particular health-related issues. This was often related to the issue of using the Internet for sensitive and 'embarrassing' health issues. When asked about perceptions of a question and answer forum contributed to by medical professionals, participants of FG 5 commented:

Alice: Young people don't really want to ask their doctors [in person] about this stuff.

Fiona: Yeah, they'd rather do it anonymously, because they might feel a bit embarrassed because their doctor is much older than them. (FG 5)

The importance of the Internet being a hassle-free, anonymous source of information was important to many of the participants.

Another positive perspective on user-generated content was vocalised by Diana (FG 4), who suggested that other users offer alternative views on health issues that are not bound to conform to official accounts: 'like in schools and in PSE [Personal and Social Education classes], they have certain things that they *have* to say, and they are very persuasive, they don't talk about the subject as a whole'. A number of further contributions in other groups reflected this search for alternative viewpoints on the Internet. Perhaps, user-generated sources of health-related content, posted on social media websites, offer opinions and opportunities for engagement beyond 'official sources' which may be appreciated by some young people.

### ***Evaluation of health-related content online: 'I think you check everything'***

Another important theme was the complex process of evaluation that most of the participants engaged in as they negotiated the online environment. During FG 2 Sonia summarised this process 'I think you check everything I mean maybe you don't see yourself checking it but you still notice the design, the style everything, how it's written, what is written, who did that work'. Throughout the focus groups the young people discussed numerous methods of evaluating online content about health. Their varied strategies, which were often complex and sometimes sub-conscious, seemed

grounded in their wider day-to-day Internet use. The need for evaluation of health content seems driven, in the most part, by the over-riding concern with the reliability of health information online, discussed above. During discussions all groups agreed a distinction between factual, informative websites and social media websites. The former was seen to offer information and the latter opportunities for interaction, particularly with other users. The strategies which young people discussed using to evaluate the reliability of 'factual' and social media websites differed accordingly.

#### *Evaluating reliability of factual websites*

Checking URLs, logos and organisations' information pages were all common practice when evaluating factual websites. For example, during FG 5 the participants concluded a particular website was 'official' and, therefore, trusted because of the logos it featured:

Sally: Yeah but it's an official website, look at the bottom, it's got like the wee YoungScot card sign [...]

Fiona: Not like on Facebook and YouTube where people can just make up anything [...]

Similarly, Sam (FG 9) commented that 'NHS, [...] YoungScot, [...] the British Medical Journal' were recognisable and respected logos to look out for. In another group the participants reached a consensus about judging websites by their URL, when deciding which search hits to prioritise:

Siobhan: You look at the URL to see it...

Jennifer: So if it's like www dot NHS...

Siobhan: You'd be more...

Claire: Or dot org...

Jennifer: You'd be more inclined to click on that [...] (FG 3)

Similarly, Stephen (FG 1) suggested 'you can always tell with the URL, usually if they're government website, NHS website, they've always got the dot something, it's a good sign to be sure'. These extracts suggest the importance of locating known hallmarks of quality, such as logos or recognisable URLs, for the participants. They expressed confidence in recognised approved sources of information and were grateful for prominent indicators of this.

Another major indicator of quality of information in factual websites identified by participants was the presentation and visual appearance of the websites. In all groups a so-called professional look was considered of the utmost importance in assessing the reliability of information contained within the website. For example, during FG 8, participants discussed what they would look for in a reliable factual health website:

Ollie: [...] if it's like well done and stuff like that [...]

Rhea: [...] cos it's like plain and quite simple [...] it looks more professional. (FG 8)

In this exchange Ollie and Rhea were comparing two websites' logos and concluded that the one which looked most professional was the more trustworthy website.

Barbara (FG 6) also related the appearance of websites to the legitimacy of the website creators and the reliability of the featured information:

[. . .] see if you click on it and it looks like an official website and it's got like info and like news feeds and stuff like that, like it actually tells you [who] made the website, yes, but see if it's just like a page that comes up with [hundreds] of writing, big pink flashy things, telling you you've won a trip to Benidorm, I don't think I'd trust that. (Barbara, FG 6)

A related indicator of reliability and quality of information mentioned during focus groups was the language used. Language, which was formal in register, serious in tone and spelled correctly was an important marker of trustworthy information for all participants. When asked what made a website good for providing health information for young people, some discussed language above all else:

Ethan: Be formal.

Sam: Mmm, not overly, I don't think it needs to be formal . . .

Joseph: Happy medium.

Sam: It just needs to be in proper English.

Joseph: Yeah I suppose. (FG 9)

Although there was some debate over how formal language on health-related websites should be, as evident in the extract from FG 9, attempts to make websites appeal to young people were generally disliked. Using abbreviations such as '2' for 'to' was mentioned in a number of groups as cringe-worthy. Sally (FG 5) elaborated:

Sally: It's trying to like make something really uncool, cool.

Natalie: Wait, it's trying to what?

Sally: It's like electric violins, something really uncool trying to make it cool, duh, it doesn't work. (FG 5)

Similarly, in FG 8, discussion turned to the choice of abbreviated language:

Ollie: It's kind of like they are trying to . . .

Rhea: Get down with the kids. (FG 8)

Language that attempted to imitate peer-to-peer communication was not welcomed on formal health information websites. On this issue, evaluating websites extended beyond reliability and became about credibility. Credibility seems to be an important issue in ensuring users engage with health websites; websites deemed not credible could be dismissed without further attention, regardless of the information they present.

### *Evaluating reliability on social media websites*

Young people evaluated the opinions and personal experiences featured on social media websites by very different criteria. In online spaces where users were the primary contributors, the content that they posted was judged according to some of the unique features of social media – such as the number of views; 'likes' and 'dislikes' facilities and user-ratings. For instance, during one group, participants discussed the 'likes' and 'dislikes' of a YouTube clip:

Sam: I'm just looking at the 'likes' cos I always find that's useful, this has 92 'likes' but 180 'dislikes', you know sometimes that can be a bit useful, just to let you see . . .

GF: So would that put you off watching something like that?

Joseph: Yeah.

Donald: Yes.

Sam: If there's more 'dislikes' than 'likes' especially. (FG 9)

Similarly Tanya (FG 1) explained: 'on Facebook [. . .], reliability could be determined by how many people "like" the page, cos that would mean that it's been around for a while and [. . .] it's a popularity sort of thing'. These interactive rating features of social media, which young people were familiar with, were being used as markers of quality for health-related content just as they are used more commonly for day-to-day purposes.

Furthermore, some participants mentioned that they considered other users' behaviours and interaction, in order to make judgements about the credibility of user-generated content. In some of the focus groups, the regulatory nature of social media was mentioned as a means of overcoming issues of reliability. For instance, Stephen (FG 1) described the possibility of habitual users of a forum exposing users who post misinformation (trolls):

See if you see like someone's posted thousands of times, and then a troll's posted twice, usually that thousands person says "stop trolling!" or something and you think I can trust you user132 or something, which sounds kinda dumb in retrospect but at the time you do think "oh I can trust them". (Stephen, FG 1)

This idea was echoed during FG 9:

There is always a group of people who want to make it correct, and want to help people [. . .], and you know even on forums you'll see that, somebody says something ridiculous or incorrect there will be a lot of people just bouncing quickly off, saying that's wrong. (Sam, FG 9)

While a user's contribution cannot always be trusted to be factually accurate, some participants were keen to suggest the regulatory function that a group of users together could provide to create some kind of quality control over contributions.

## Discussion

The findings of this study suggest that young people are active and enthusiastic consumers of health-related content online. The participants' discussions around engaging with both health-related user-generated content and factual informative websites reflected an explicit concern with the source and reliability of information, which has much in common with the dominant reliability discourse in the wider research literature (Conrad and Stults 2010). The participants' descriptions of strategies for assessing reliability were presented as a means of cautiously negotiating this potentially risky environment. This echoes the findings of Nettleton *et al.*'s (2005) study of everyday engagement with health information online which suggests that this kind of risk-aware response to the online environment serves to re-establish hierarchies of medical knowledge. Discourses of reliability in the accounts of the

young people, therefore, perhaps reflect a wider concern in society with maintaining medical information quality and reproducing expert knowledge on the Internet.

The generally cautious approach to health-related content online exhibited by these young people suggests they employ transferable skills rooted in everyday Internet use to assessments of the sites they encounter whilst using the Internet for health-related purposes. Both Buhi *et al.* (2009) and Gray *et al.* (2005b) emphasise the need for educating young people on engaging with online content about health. The accounts and discussions of the young people in this study provided an insight into how this might best be tailored. Throughout the study, young people provided a number of examples of the evaluation strategies they employ as they approach and process online content about health. Perhaps, education in this area could draw on examples and activities related to these everyday social media websites.

Despite a cautious approach to online health information, participants saw distinct value in health-related user-generated content online. A study of users' changing online practice suggests the importance of information being from an expert reliable source for users to determine trustworthiness (Sillence *et al.* 2007). However, participants in the current study seemed also to value user-generated content for gaining useful insights from first-hand accounts they relate to. Related research indicates that while health professionals are useful for providing medical facts, friends and family are often drawn upon for psycho-social information and suggests that the Internet could provide both (Gray *et al.* 2005a). Perhaps, then, social media provide a wider volume of peer information than friends and family can, offering a degree of anonymity if desired, and so meet the needs of young people for psycho-social health information.

Related to the importance of the Internet for providing peer support and experiential information, participants' discussions often centred on the importance of shared experience and interaction. There has been much research interest in the formation and use of Internet support groups (also known as electronic support groups) around particular illnesses and health issues (Conrad and Stults 2010). A number of qualitative studies suggest that people find specific and sustained health-related support online (Broom 2005, Fox *et al.* 2005, Bar-Lev 2008, Barker 2008). Supportive communities provide important public spaces for expression of thoughts and emotions about illness and for some users can offer safe spaces in which to express alternative accounts of their experience and identity (Broom 2005, Bar-Lev 2008). Furthermore, in some cases online support groups, through facilitating the sharing of experiences, enable the emergence of informed or expert patients (Fox *et al.* 2005). Indeed, some groups even go on to develop wider objectives, such as challenging medical expertise (Barker 2008). While discussions in this study did not suggest that young people encountered such sustained and transformative experiences of support on social media websites, they did suggest the value of social media for finding advice that is easy to relate to and sharing experiences. Indeed, user-generated content may be an easily accessible means of gaining access to some level of support on, or a range of experiences of, health issues. Similarly, while none of the groups discussed actively contributing content to social media websites, a recent review of health blogging practices suggests that blog technology could facilitate positive new ways for users to document and manage their personal health experiences (Adams 2010).

While the focus groups generated rich data, this study had a number of limitations. Although the sample included groups from different backgrounds

recruited from across Scotland, the sample was small, ethnically homogenous (reflecting the populations from which they were drawn) and included more girls than boys. Therefore, there could be some groups to whom these findings are not directly relevant. Since young people's Internet use seems to be increasingly divergent (Holmes 2011), these could include: those who have not been exposed to the Internet at home or in school; those who choose not to engage online and those who engage primarily as information-focused users. Furthermore, the participants were approached by gatekeepers and only interested, potential participants made themselves known to the researcher, so response rates cannot be calculated. Additionally, criticism of focus group research suggests the public nature of discussion dictates that only socially acceptable views may be aired and individuals who hold views which do not conform may not wish to raise them (Wilkinson 1998).

This study has some potential implications for future research, as well as some insights into current and future health information dissemination policy. In terms of policy, it seems important to recognise young people's perceptions and experiences of engaging with social media which have been utilised by official health organisations, and to continue to develop these resources so that they are distinct and less open to exploitation by commercial groups. Furthermore, although social media are online spaces where young people are active, they might not always be the best places for factual information provision. This study suggests that the value of social media is in facilitating peer-to-peer interaction about health, opening up opportunities for sharing personal experiences and exchanging views. However, information that is entirely factual is perhaps best hosted on static websites that are well designed, appear professional and do not patronise or utilise inappropriately youthful language. The findings also suggest that young people might usefully contribute to the development of guidelines for engaging with health-related content and could provide insights for the future development of online information resources about health.

## **Conclusion**

While active contributions to online resources might be limited for many young people, they seem enthusiastic in their engagement with the diversity of health information available online. Health-related user-generated content seems to be appreciated by young people, as a useful, if not always trustworthy, resource for accounts of health experiences. Reliability and quality of both user-generated content and official factual content were concerns for young people, which is in keeping with broader discourses about reliability and the Internet. The various strategies they employ for negotiating this environment are particular to the type of website, with social media websites and fact-based websites being judged according to different criteria and different markers of reliability. Young people who regularly use social media technologies appear to have developed strategies for online engagement and appraisal which they apply to health-related content.

The dynamic nature of social media and of the online environment more broadly means that research, although always providing valuable insight, can rapidly become less relevant to contemporary realities by the time it has been published. Further research could usefully focus on these shifting areas of online activity, keeping abreast of young people's online practices.

## Acknowledgements

Thanks to all the young people who participated in the research. The study was funded by the UK Medical Research Council as part of a 1 + 3 research studentship, MC\_A540\_5TK70 at the MRC/CSO Social and Public Health Sciences Unit. The funding body had no role in study design; data collection; data analysis; writing of the report or the decision to submit the manuscript for publication.

## References

- Adams, S.A., 2010. Revisiting the online health information reliability debate in the wake of “web 2.0”: an inter-disciplinary literature and website review. *International journal of medical informatics*, 79 (6), 391–400.
- Barker, K.K., 2008. Electronic support groups, patient-consumers, and medicalization: the case of contested illness. *Journal of health and social behavior*, 49 (1), 20–36.
- Bar-Lev, S., 2008. ‘We are here to give you emotional support’: performing emotions in an online HIV/AIDS support group. *Qualitative health research*, 18 (4), 509–521.
- Benigeri, M. and Pluye, P., 2003. Shortcomings of health information on the Internet. *Health promotion international*, 18 (4), 381–386.
- Bloor, M., et al., 2001. *Focus groups in social research*. London: Sage.
- Borzekowski, D.L.G. and Rickert, V.I., 2001. Adolescent cybersurfing for health information: a new resource that crosses barriers. *Archives of pediatrics and adolescent medicine*, 155 (7), 813–817.
- boyd, d., 2007. Why youth [heart] social network sites: the role of networked publics in teenage social life. In: D. Buckingham, ed. *Youth, identity, and digital media*. The John D. and Catherine T. MacArthur Foundation series on digital media and learning. Cambridge, MA: The MIT Press, 119–142.
- Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3 (2), 77–101.
- Broom, A., 2005. The eMale: prostate cancer, masculinity and online support as a challenge to medical expertise. *Journal of sociology*, 41 (1), 87–104.
- Buckingham, D., 2006. Is there a digital generation? In: D. Buckingham and R. Willett, eds. *Digital generations: children, young people and new media*. Mahwah: Lawrence Erlbaum Associates, 1–13.
- Buhi, E.R., et al., 2009. An observational study of how young people search for online sexual health information. *Journal of American college health*, 58 (2), 101–111.
- Buhi, E.R., et al., 2010. Quality and accuracy of sexual health information web sites visited by young people. *Journal of adolescent health*, 47 (2), 206–208.
- Catterall, M., and Maclaran, P. 1997. Focus group data and qualitative analysis programs: coding the moving picture as well as the snapshots. *Sociological research online* [online], 2 (1). Available from: <http://www.socresonline.org.uk/2/1/6.html> [Accessed 2 November 2011].
- Charmaz, K., 2006. *Constructing grounded theory: a practical guide through qualitative analysis*. Thousand Oaks: Sage.
- Conrad, P. and Stults, C., 2010. The internet and the experience of illness. In: C.E. Bird, P. Conrad, and A.M. Fremont, eds. *Handbook of medical sociology*. 6th ed. Nashville: Vanderbilt University Press.
- Denzin, N. and Lincoln, Y., 2005. *The Sage handbook of qualitative research*. 3rd ed. Thousand Oaks: Sage.
- Dutton, W.H. and Blank, G., 2011. *Next generation users: the internet in Britain*. University of Oxford: Oxford Internet Institute.
- Ekberg, J., et al., 2010. Web 2.0 systems supporting childhood chronic disease management: design guidelines based on information behaviour and social learning theories. *Journal of medical systems*, 34 (2), 107–117.
- Fox, N.J., Ward, K.J., and O’Rourke, A.J., 2005. The ‘expert patient’: empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social science and medicine*, 60 (6), 1299–1309.



- Frankland, J. and Bloor, M., 1999. Some issues arising in the systematic analysis of focus group materials. In: J. Kitzinger and R. Barbour, eds. *Developing focus group research: politics, theory and practice*. London: Sage, 144–155.
- Goh, T.T. and Huang, Y.P., 2009. Monitoring youth depression risk in Web 2.0. *VINE*, 39 (3), 192–202.
- Gray, N., et al., 2005a. Health information-seeking behaviour in adolescence: the place of the internet. *Social science and medicine*, 60 (7), 1467–1478.
- Gray, N.J., et al., 2005b. The Internet: a window on adolescent health literacy. *Journal of adolescent health*, 37 (3), 243.
- Green, J. and Hart, L., 1999. The impact of context on data. In: J. Kitzinger and R. Barbour, eds. *Developing focus group research: politics, theory and practice*. London: Sage, 21–35.
- Griffiths, R. and Casswell, S., 2010. Intoxigenic digital spaces? Youth, social networking sites and alcohol marketing. *Drug and alcohol review*, 29 (5), 525–530.
- Holmes, J., 2011. Cyberkids or divided generations? Characterising young people's internet use in the UK with generic, continuum or typological models. *New media and society*, 13 (7), 1104–1122.
- Jacobson, L.D., et al., 2000. Teenagers' views on general practice consultations and other medical advice. *Family practice*, 17 (2), 156–158.
- Kitzinger, J., 1994. The methodology of focus groups: the importance of interaction between research participants. *Sociology of health and illness*, 16 (1), 103–121.
- Kitzinger, J. and Barbour, R., 1999. Introduction: the challenge and promise of focus groups. In: J. Kitzinger and R. Barbour, eds. *Developing focus group research: politics, theory and practice*. London: Sage, 1–20.
- Livingstone, S., 2008. Internet literacy: young people's negotiation of new online opportunities. In: T. Mcpherson, ed. *Digital youth, innovation and the unexpected*. The John D. and Catherine T. MacArthur Foundation Series on Digital Media and Learning. Cambridge: MIT Press, 101–122.
- Livingstone, S. and Brake, D.R., 2010. On the rapid rise of social networking sites: new findings and policy implications. *Children and society*, 24 (1), 75–83.
- Macfarlane, A., et al., 1987. Teenagers and their health. *Archives of disease in childhood*, 62 (11), 1125–1129.
- Marshall, C. and Rossman, G., 1995. *Designing qualitative research*. 2nd ed. Thousand Oaks: Sage.
- Moreno, M.A., et al., 2009a. Real use or “real cool”: adolescents speak out about displayed alcohol references on social networking websites. *Journal of adolescent health*, 45 (4), 420–422.
- Moreno, M.A., et al., 2009b. Reducing at-risk adolescents' display of risk behavior on a social networking Web site: a randomized controlled pilot intervention trial. *Archives of pediatrics and adolescent medicine*, 163 (1), 35–41.
- Moreno, M.A., et al., 2010a. A content analysis of displayed alcohol references on a social networking web site. *Journal of adolescent health*, 47 (2), 168–75.
- Moreno, M.A., et al., 2010b. An evaluation of the distribution of sexual references among “Top 8” MySpace friends. *Journal of adolescent health*, 47 (4), 418–420.
- Morrow, V. and Richards, M., 1996. The ethics of social research with children: an overview. *Children and society*, 10 (2), 90–105.
- McNab, C., 2009. What social media offers to health professionals and citizens. *Bulletin of the world health organization*, 87, 566.
- Nettleton, S., Burrows, R., and O'Malley, L., 2005. The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence. *Sociology of health and illness*, 27 (7), 972–992.
- NHS, 2009. *News Direct Archive* [online]. Available from: <http://www.nhsdirect.nhs.uk/commissioners/newsdirect/newsdirectarchive/newsdirect2009/newsdirect-july2009/teamwin-sinnovationaward> [Accessed 22 January 2012].
- NHS, 2011. *NHS Choices* [online]. Available from: <http://www.youtube.com/user/NHSChoices?blend=1&ob=5> [Accessed 22 January 2012].
- Nordqvist, C., et al., 2009. Health professionals' attitudes towards using a Web 2.0 portal for child and adolescent diabetes care: qualitative study. *Journal of medical internet research*, 11 (2), e12.

- Ofcom, 2010. *UK Children's Media Literacy* [online]. Available from: <http://stakeholders.ofcom.org.uk/binaries/research/media-literacy/ukchildrensm11.pdf> [Accessed 22 January 2012].
- Papacharissi, Z., 2010. *A private sphere: democracy in a digital age*. Cambridge: Polity Press.
- Prensky, M., 2001. Digital natives, digital immigrants. *On the horizon*, 9 (5), 1–6.
- Pujazon-Zazik, M. and Park, M.J., 2010. To tweet, or not to tweet: gender differences and potential positive and negative health outcomes of adolescents' social internet use. *American journal of mens health*, 4 (1), 77–85.
- Purcell, G.P., Wilson, P., and Delamothe, T., 2002. The quality of health information on the internet. *British medical journal*, 324, 557–558.
- Ralph, L., et al., 2011. Finding teens in TheirSpace: using social networking sites to connect youth to sexual health services. *Sexuality research and social policy*, 8 (1), 38–49.
- Selman, T., Prakash, T., and Khan, K., 2006. Quality of health information for cervical cancer treatment on the internet. *BMC women's health*, 20 (6), 9.
- Silberg, W.M., Lundberg, G.D., and Musacchio, R.A., 1997. Assessing, controlling, and assuring the quality of medical information on the Internet: caveat lector et viewer – let the reader and viewer beware. *Journal of the American medical association*, 277 (15), 1244–1245.
- Sillence, E., et al., 2007. Going online for health advice: changes in usage and trust practices over the last five years. *Interacting with computers*, 19 (3), 397–406.
- Skinner, H., et al., 2003. How adolescents use technology for health information: implications for health professionals from focus group studies. *Journal of medical internet research*, 5 (4), e32.
- Smithson, J., 2000. Using and analysing focus groups: limitations and possibilities. *International journal of social research methodology*, 3 (2), 103–119.
- Tapscott, D., 1998. *Growing up digital: the rise of the net generation*. London: McGraw-Hill.
- Thomas, A., 2007. *Youth online: identity and literacy in the digital age*. New York: Peter Lang Publishing.
- Vance, K., Howe, W., and Dellavalle, R.P., 2009. Social internet sites as a source of public health information. *Dermatologic clinics*, 27 (2), 133–136.
- Wilkinson, S., 1998. Focus groups in feminist research: power, interaction, and the co-construction of meaning. *Women's studies international forum*, 21 (1), 111–125.
- Williams, A.L. and Merten, M.J., 2008. A review of online social networking profiles by adolescents: implications for future research and intervention. *Adolescence*, 43 (170), 253–74.