

# INVOLVE



*National Institute for  
Health Research*

## Guidance on the use of social media to actively involve people in research



November 2014

# About this guidance

This guidance provides examples of ways in which different types of social media are currently being used to involve the public in research, the benefits, challenges, risks and ethics of using social media for involvement, and some top tips and things to think about. The project advisory group also compiled additional useful reading, which can be found toward the end of the guidance, including a jargon buster for social media terminology.

The examples collected to complement this guidance are listed in the text, but full details of each example – a summary of the research project; how members of the public were involved; challenges; resources used; the impact of using social media; and advice for others – are available to view and download from our website: [www.involve.nihr.ac.uk/resource-centre/examples/](http://www.involve.nihr.ac.uk/resource-centre/examples/)

## About INVOLVE

INVOLVE ([www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)) provides advice and a range of resources on patient and public involvement in research.

These include:

- invoDIRECT: a directory of research networks and organisations supporting involvement.
- resources which include briefing notes for researchers on what is public involvement and how to involve people in research; an involvement cost calculator to help with budgeting; and searchable databases including an evidence library.
- a website ([www.peopleinresearch.org/](http://www.peopleinresearch.org/)) that provides information for patients and the public about current opportunities for getting involved in research. Researchers and funders can use People in Research to advertise and invite patients and the public to get involved in their research.

### **This report should be referenced as:**

INVOLVE (2014) Guidance on the use of social media to actively involve people in research. Eastleigh: INVOLVE.

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# Contents

1. Introduction.....	4
2. Definitions.....	4
3. How the guidance was developed.....	5
4. Types of social media currently being used to involve people in research.....	5
5. Examples of using social media to involve people in research.....	6
6. Benefits and challenges of using social media.....	7
7. Managing risk.....	8
8. Ethics.....	10
9. What we don't know about using social media to involve people.....	10
10. Things to think about before using social media.....	11
11. Top tips.....	12
12. Useful reading.....	14
13. Jargon buster.....	16
14. Acknowledgements.....	19

# 1. Introduction

Social media is now well-established, but its use as a way to involve people in research is a relatively recent development. In 2014 INVOLVE ([www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)) brought a project advisory group together (see Section 14, Acknowledgements) to consider the opportunities and the challenges of using social media to involve the public in research.

The advisory group carried out a scoping exercise to look at whether there was any existing guidance and found a lot of information on the use of social media for one-way communication – for example advertising an opportunity or raising awareness of research activities. However, there was little information or guidance on the use of social media in active public involvement.

Therefore this guidance focuses on active public involvement<sup>1</sup>, by which we mean the use of social media as a way to involve people in priority setting, design or conduct of research. Although this is its focus, some of the examples also mention engagement and participation, and the guidance may also be relevant to these activities.

This guidance is aimed primarily at researchers and others facilitating public involvement in research. However it may also be of interest to members of the public involved in research and others interested in the use of social media to support public involvement.

# 2. Definitions

People have defined social media in different ways, but the definition we are using in this guidance document is: communication among people within virtual communities and networks, for example blogs, Facebook and Twitter.

This definition refers to some existing forms of social media in common use, but we are also aware that the world of social media changes quickly and that new platforms and other ways of interacting within virtual communities will be developed over time. We hope that the principles and points of learning in this guidance will be relevant to the evolving world of social media.

For definitions of other social media terms see Section 13 for our Jargon buster.

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<sup>1</sup> This guidance focuses specifically on the active involvement of people in research, using INVOLVE's definition of involvement – see [www.involve.nihr.ac.uk/find-out-more/what-is-public-involvement-in-research-2/](http://www.involve.nihr.ac.uk/find-out-more/what-is-public-involvement-in-research-2/). It does not focus on the use of social media to engage people in research or to recruit/retain participants in research.

### 3. How the guidance was developed

The project advisory group looking at the use of social media for active public involvement took a number of steps to make sure that the guidance would add to the existing information and be helpful to researchers and others considering using social media to involve people in research activities.

The advisory group:

- a. Looked at information on the use of social media already in existence
- b. Carried out its own use of social media for active public involvement by using a Google+ page to support the advisory group
- c. Consulted with the wider INVOLVE Group membership in a session at an INVOLVE meeting
- d. Put out a call for people to get in touch if they had used social media for active public involvement
- e. Carried out interviews with those who had used different types of social media across organisations and within a variety of projects
- f. Held a Twitter chat ([www.involve.nihr.ac.uk/about-involve/current-work/social-media-for-active-public-involvement/somepi/](http://www.involve.nihr.ac.uk/about-involve/current-work/social-media-for-active-public-involvement/somepi/)) in June 2014 that covered the challenges, risks, opportunities and benefits, and suggestions for what to include in guidance on the use of social media
- g. Had a discussion in July 2014 with public involvement leads from a range of National Institute for Health Research (NIHR) organisations
- h. Sought comments on the guidance in draft form from people who had sent information and/or shared their experience of using social media to involve people in research.

### 4. Types of social media currently being used to involve people in research

When we asked researchers how they were using social media to actively involve people in their work, we had a number of responses. This list is not exhaustive, but it gives some idea of the types of social media that are being used to involve people and how they are being used.

#### ■ Twitter

<https://about.twitter.com/>

To ask people for their views (e.g. on research priorities), or to invite people to get actively involved

#### ■ Facebook

[www.facebook.com](http://www.facebook.com)

To ask people for their views (e.g. on research priorities), or to communicate with and enable communication between an existing group(s)

#### ■ Blogging

To exchange information and/or views about a topic, tell people more about it, and seek their views

#### ■ Interactive websites

To create/involve a community of people in a variety of ways

## 5. Examples of using social media to involve people in research

You can read about how social media has been used to involve people in research by visiting [www.involve.nihr.ac.uk/resource-centre/examples/](http://www.involve.nihr.ac.uk/resource-centre/examples/) and downloading full details of the examples listed below, including how people were involved, the resources used, the impact of using social media and advice to others considering using social media.

- The Acne Priority Setting Partnership: Using **Twitter**, **YouTube** and **mobile phone technology** to involve people in identifying research priorities
- Salford Research and Development (R+D) and National Institute for Health Research (NIHR) Greater Manchester Primary Care Patient Safety Translational Research Centre (PCPSTRC): Using **Twitter** to find people to involve in a research advisory group
- International Centre for Mental Health Social Research: Using **Twitter** and a **blog** to identify and prioritise topics for research
- Queer Futures: Using **Facebook** to involve young people in the design and delivery of research about suicide and self-harm
- NIHR Clinical Research Network Children Specialty Rheumatology Clinical Studies Group: Using **Facebook** to ask parents and families about their priorities for research
- Children of the 90s: Using **Facebook** and **Skype** to involve young people in a long-term research project

- Cystic Fibrosis (CF) Unite: Using an **interactive website** to involve people with cystic fibrosis in discussions about research
- Greater Manchester Kidney Information Network: Exploring the impact of social media on patient information provision, networking and social support using an **interactive website**, **Twitter** and **blogs**
- West Midlands Collaboration for Leadership in Applied Health Research and Care (CLAHRC): Using an **interactive website** to involve people in dialogues about CLAHRC research.

These examples demonstrate that social media provides exciting opportunities to support active public involvement in research. When thinking about whether to use social media and what social media to use, it is most important to consider whether it is right for your study, and this will depend on your aims and the context in which you are working. What is clear from the people we interviewed is that using social media has enabled them to involve a wide range of people quickly and relatively cheaply. In most cases it cannot replace face-to-face involvement, but it can offer a really useful and exciting complement to it.

## 6. Benefits and challenges of using of social media

During the development of this guidance the following benefits and challenges for researchers and others facilitating involvement in research were identified:

### Benefits

Social media can...

- Increase the diversity and number of people who get involved in research, allowing for one-off as well as on-going involvement
- Allow people to get involved when it is convenient for them rather than restricting involvement to meeting times
- Enable people to network with each other
- Enable people to be involved who are unable or do not wish to attend face-to-face meetings/events
- Help people to keep in touch with researchers and other members of the public in between face-to-face meetings/events
- Help people to feel more comfortable expressing their opinions because they can do this anonymously
- Provide opportunities to have contact with others involved in research
- Be more accessible than other methods for involving people with certain disabilities, for example Easychirp ([www.easychirp.com/](http://www.easychirp.com/))
- Be free or relatively cheap to use
- Save time if you use an existing programme (e.g. Twitter) and already have social media skills and an established community
- Create a place where people can communicate with each other and with researchers in relative confidence – for example use closed and secret Facebook groups
- Allow people to see the whole discussion thread if using a Facebook page or blog, or if using a Twitter hashtag (#)

### Challenges

Social media can...

- Exclude people, as it is likely to only involve (or mainly involve) people who are already using that particular type of social media and/or have access to web-enabled technology
- Be costly and time consuming if you are designing new programmes (e.g. a new interactive website) and/or you don't already have the necessary skills and networks
- Be very public (e.g. posts on Twitter and Facebook) and sometimes be accessible even after the user has deleted them, which means that people need to be aware of what they say and how they say it
- Sometimes be fleeting (e.g. tweets need to be saved via applications such as Storify quite soon after they are posted in order not to be lost)
- Use platforms that say their users own their content, whilst at the same time reserving the right to share that content with third parties (e.g. Twitter)
- Come with technical challenges, for example if you want to create an interactive website
- Lead to having to respond to difficult issues or questions in a very public forum
- Mean that you have to monitor the social media platform and respond in a timely manner, which may require a large time commitment depending on the response
- Be controlled by organisational governance rules that limit how you use social media and what you say
- Lead to issues of safety and ethics, for example when using social media to involve children and young people and/or groups of people deemed to be 'vulnerable' (see Section 7, Managing risk and Section 8, Ethics)

## 7. Managing risk

As with any activity, it is useful to consider managing the potential risks involved before you start using social media to actively involve people. Some people we spoke to felt the use of social media for active public involvement was relatively risk free, while others felt there were a number of risks to be navigated and managed. Some of the potential risks noted in the interviews are relevant to all public involvement activity, and others are specific to the use of social media.

In the table below we summarise some of the potential risks of using social media to actively involve people in research, and suggest some ways these can be managed.

Potential risk	How might this risk be managed?
<p>People's personal information may be shared in ways that they do not like.</p>	<p>Think carefully about this before you start using social media to involve people.</p> <p>Talk to anyone you involve about privacy and anonymity.</p> <p>Do not store personal data.</p> <p>Whenever appropriate, make use of anonymity.</p> <p>Use closed groups (e.g. Facebook enables you to set up closed and secret Facebook groups), so that information is not shared publicly.</p> <p>If you plan to contact people in future, tell them this and explain how they can opt out.</p>
<p>An online discussion may not be as fluid as a face-to-face discussion and comments can be taken out of context or misconstrued.</p>	<p>Seek information via our useful reading section, elsewhere online or from colleagues to help you consider how you would deal with this situation.</p> <p>Ensure you monitor discussions and intervene where appropriate.</p>
<p>There is a risk of excluding some people.</p>	<p>Do not use social media as the only method for involving people – consider additional involvement methods that might be more inclusive for people who may not use social media.</p> <p>If you have good social media (or other) networks already, ask those you link with to help you to contact particular groups of people who may not be using social media.</p>
<p>Social media can allow people to be passionate, but can also sometimes lead to people being upset.</p>	<p>Acknowledge this when it happens.</p> <p>If it is appropriate, offer to talk with people offline or be ready to point people to sources of support.</p> <p>Include this in terms and conditions of use if you have them, and in training if you offer it.</p>



<b>Potential risk</b>	<b>How might this risk be managed?</b>
<p>There is the danger that people won't always behave well online, for example by posting inappropriate comments.</p>	<p>This is also possible if you involve people in other ways, but it is always worth considering this possibility ahead of time and thinking about ways of handling this behaviour.</p> <p>Ensure that someone checks the Facebook page, Twitter feed or other type of social media often enough to respond (e.g. remove a post) in a timely manner and minimise upset.</p>
<p>You could expose yourself, your study or your organisation to potential criticism.</p>	<p>For an interactive website or Facebook page, agree terms and conditions for use of the site that people sign up to as part of the enrolment process. These can outline what is expected in terms of courtesy, and explain that defamatory posts will be deleted and that people can be barred as a last resort.</p> <p>But remember that criticism can be useful and help you to improve your research.</p>
<p>People might talk about medical issues. Not everyone with a similar medical condition is treated in the same way, and this can worry some people.</p>	<p>If this is likely to be an issue in your research, ensure you work with health professionals who have experience in the field you are researching.</p> <p>Be clear that your role is as a researcher and do not offer clinical advice.</p> <p>Make it clear in the information you provide that not everyone with certain medical issues is treated in the same way.</p>
<p>Some people want to know more than others about their condition.</p>	<p>If the discussion is likely to include progress or prognosis of a condition, warn people when they get involved that this information may be discussed.</p> <p>If you can, include warnings on pages or posts if there is discussion about the progress or prognosis of a condition.</p>
<p>Even if you delete a post, there may be a trail.</p>	<p>Be aware that, although it is unlikely someone will try to find a deleted post, you are communicating in a public sphere.</p>

Perhaps the most important message from the people we interviewed about managing risks was that you need to use your common sense.

## 8. Ethics

As with any other involvement method, if you use social media to actively involve people, you need to consider the ethical issues it might raise. Make sure that you:

- Are clear about whether you plan to use social media to actively involve people or to recruit them as participants or as ‘subjects’ of the research. Ethics committee approval is not needed if you are involving people in the design or conduct of research but is needed if they will be participants of your research. See Section 12, Useful reading for the INVOLVE publication on research ethics committee review.
- Check any guidance produced by your institution about the use of social media. Some professional bodies and regulators also have guidance on this – see Section 12, Useful reading for the links to these.
- Familiarise yourself with some of the ethical issues relating to the use of social media – see Section 12, Useful reading for the NHS Employers website, which has relevant information.

## 9. What we don’t know about using social media to involve people

Because the use of social media to actively involve people in research is relatively new, many people are still finding their way. This guidance should give you an idea about how social media is being used to involve people, and what kinds of things to consider if using social media. However, we know that social media is a rapidly changing world and new types of social media will continue to be developed and evolve over time.

This guidance is the first step in helping people to navigate this new type of interaction, and we will look to renew it over time. If you are using social media to actively involve people in research, especially if you are using a type of social media not mentioned in this guidance, please contact us at [socialmedia@invo.org.uk](mailto:socialmedia@invo.org.uk) and tell us your story.

## 10. Things to think about before using social media

- Are you clear about your short and long term aims in using social media to involve people in research?
- Have you considered the people you wish to involve and what type of social media might work best to involve them?
- Are there people that use of this type of social media might exclude, and do you have other ways to involve them in your research?
- Does your organisation have governance in place to deal with the use of social media? If not, do you need to establish governance arrangements?
- Do you have someone with technical know-how able who can help you with any technological questions?
- Have you considered potential risks and discussed with your colleagues how to manage problems if they do arise?
- Do you have someone who is committed to spending time updating posts, checking for unacceptable/offensive posts and/or responding to queries?

## 11. Top tips

Here are some top tips from researchers and others who shared their experience of using social media to involve patients and members of the public in research:

### 1. Keep it simple

“Keep it simple. It’s important not to bombard people with lots of posts, and to be clear about what you’re asking. Don’t over-burden people, and don’t ask things too often.”

Makaela Jacobs-Pearson, Avon Longitudinal Study of Parents and Children (ALSPAC)

“Try to do it as simply and as easily as possible, and with as few resources as you can. Don’t invest lots of money as there are often cheaper ways to do it.”

Jo Sartori, West Midlands Collaboration for Leadership in Applied Health Research and Care (CLAHRC)

### 2. Start slowly and build relationships

“If you’re new to Twitter, lurk and listen. Don’t expect instant gratification. Watch what people are saying, then start with a few re-tweets. The more things you have to say, the more followers you will accrue.”

Philip Hammond, Patient and Public Involvement Coordinator, Salford R+D and NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (PCPSTRC)

“Social media is an easy way to connect with people. Start by finding charities that are relevant and build a relationship of trust. Involve them from the start – at the ideas stage.”

Sharon Douglas, Scottish Network for Arthritis in Children (SNAC) Trustee, NIHR Clinical Studies Group (CSG) Consumer Champion

### 3. Make it interesting

“Make sure the messages you send are engaging. Don’t just send hollow tweets... Use things like YouTube films to stimulate people’s interest. And make sure you feed back to people – otherwise you risk them not engaging with you in future.”

Mick Mullane, Patient Learning and Engagement Manager, NIHR Clinical Research Network

“Be warm and positive and engaging and enthusiastic. Don’t assume that just because you’ve got a good title or a catchy tweet this will come across to people.”

Martin Webber, International Centre for Mental Health Social Research

### 4. Allow plenty of time and be flexible in your approach

“Social media isn’t a quick fix. It’s resource intensive. It can be as brilliant as it can be a complete failure. You need to understand why you’re using it. Do your research about whether the people you want to involve are using social media.”

Liz McDermott, Queer Futures, Lancaster University

“You need to invest time in this. Don’t be afraid of social media. There are risks as well as benefits, but the benefits outweigh the risks.”

Matt Hurley, Cystic Fibrosis (CF) Unite

“You need time – once you start working on a project like this it’s not a 9-5 job. You need to be working when people are active and posting – usually this is in the evenings. And to sustain a site like this you need a local base.”

Cristina Vasilica, graduate student, University of Salford

“It’s useful to have a second pair of eyes to look at things when you’re doing things like Twitter. You need to be prepared to contact people when they are around – to tweet and respond to tweets in the evenings. And you need to get the topics right.”

Matt Hurley, CF Unite

## 5. Set limits and establish ground rules

“As a researcher you need to be clear what your role is and you need to understand how it will change over time. You need to know how to start and stop a discussion and when to intervene.”

Cristina Vasilica, graduate student,  
University of Salford

“You need everyone (researchers and members of the public) to sign up to terms and conditions before they can take part.”

Jo Sartori, West Midlands CLAHRC

“It’s important to maintain a focus and boundaries – be aware of the target audience and, if concentrating on research, be clear not to give clinical advice.”

Matt Hurley, CF Unite

## 6. Be responsive

“Think about your target audience and select the social media that this group is most likely to use. Use more than one form of social media if possible.”

Martin Webber, International Centre for Mental Health Social Research

“It’s a relatively new method, but it’s becoming more important. It enables you to reach a wider range of people. But if you ask people for their views via social media (or in any other way), ensure you act on them.”

Philip Hammond, Patient and Public Involvement Coordinator, Salford R+D and NIHR Greater Manchester PCPSTRC

## 7. Use social media alongside other forms of involvement

“Social media is most effective when it’s combined with other forms of communication, so it should be used alongside face-to-face meetings and other means of communication.”

Makaela Jacobs-Pearson, ALSPAC

“As with any form of public involvement, there is no single method that will suit everyone. You need to have a portfolio of techniques to involve a range of people, and social media is one of these... Social media enables you to reach a wider range of people including those sometimes referred to as ‘hard-to-reach’ – it doesn’t replace existing methods.”

Philip Hammond, Patient and Public Involvement Coordinator, Salford R+D and NIHR Greater Manchester PCPSTRC

“Social media should be viewed as an additional tool to involve the patient and public in all aspects of research.”

Sharon Douglas, SNAC Trustee, NIHR CSG Consumer Champion

## 12. Useful reading

### Guidance about using social media

ESOMAR (2011) ESOMAR guideline on social media research  
[www.esomar.org/uploads/public/knowledge-and-standards/codes-and-guidelines/ESOMAR-Guideline-on-Social-Media-Research.pdf](http://www.esomar.org/uploads/public/knowledge-and-standards/codes-and-guidelines/ESOMAR-Guideline-on-Social-Media-Research.pdf)  
ESOMAR is the world organisation for encouraging, advancing and elevating market research worldwide. This guideline covers the collection of social media data for market, opinion or social research purposes.

Gray, C. (2011) Social media: A guide for researchers  
[www.rin.ac.uk/our-work/communicating-and-disseminating-research/social-media-guide-researchers](http://www.rin.ac.uk/our-work/communicating-and-disseminating-research/social-media-guide-researchers)  
This guide has been produced by the International Centre for Guidance Studies, and aims to provide the information needed to make an informed decision about using social media and select from the range of tools that are available.

Jones, C. (2011) Ethical issues in online research. British Educational Research Association on-line resource. Available at <https://www.bera.ac.uk/researchers-resources/publications/ethical-issues-in-online-research>. These guidelines contain advice on ethics and social media in research.

Mollett, A., Moran, D. and Dunleavy, P. (2011) Using Twitter in university research, teaching and impact activities: A guide for academics and researchers. LSE Public Policy Group  
[http://blogs.lse.ac.uk/impactofsocialsciences/files/2011/11/Published-Twitter\\_Guide\\_Sept\\_2011.pdf](http://blogs.lse.ac.uk/impactofsocialsciences/files/2011/11/Published-Twitter_Guide_Sept_2011.pdf)

NatCen Social Research and SAGE New Social Media, new social science?  
<http://nsmnss.blogspot.co.uk/>  
Should social science researchers embrace social media and, if so, what are the implications for methods and practice? This network, led by NatCen Social Research and SAGE, is for people using or seeking to use social media in social science research who want to explore the implications of that question.

Potter, N. (2014) Twitter: Becoming a networked researcher  
[www.slideshare.net/UniofYorkLibrary/twitter-for-researchers-22963915](http://www.slideshare.net/UniofYorkLibrary/twitter-for-researchers-22963915)  
A guide to why Twitter is relevant in the research environment, how it can be useful and how to tweet successfully.

Smee, H. (2008) Web 2.0 as a social sciences research tool. London: British Library.  
[www.bl.uk/reshelp/bldept/socsci/socint/web2/web2.pdf](http://www.bl.uk/reshelp/bldept/socsci/socint/web2/web2.pdf)

White, C. (2012) Using social media to engage, listen and learn  
[www.networks.nhs.uk/nhs-networks/smart-guides/documents/Using-social-media-to-engage-listen-and-learn.pdf/view](http://www.networks.nhs.uk/nhs-networks/smart-guides/documents/Using-social-media-to-engage-listen-and-learn.pdf/view)  
Although this guide is aimed at Clinical Commissioning Groups, it is useful for anyone who wants to understand more about what social media is, and how it can be used to engage with patients and the public.

## Articles about how social media has been used to involve people

Ryan G. (2013) Online social networks for patient involvement and recruitment in clinical research. *Nurse Researcher*. 21, 1, 35-39. Abstract available at [www.ncbi.nlm.nih.gov/pubmed/24004430](http://www.ncbi.nlm.nih.gov/pubmed/24004430)

Wicks, P. (2014) Could digital patient communities be the launch pad for patient-centric trial design? *Trials*. 15: 172. [www.trialsjournal.com/content/15/1/172](http://www.trialsjournal.com/content/15/1/172) Article about how some patients are becoming increasingly involved in clinical trials through the use of social media.

Woolfall, K., Young, B., Frith, L., Appleton, R., Iyer, A., Messahel, S., Hickey, H. and Gamble, C. (2014) Doing challenging research studies in a patient-centred way: a qualitative study to inform a randomised controlled trial in the paediatric emergency care setting. *BMJ Open*. 4: e005045 <http://bmjopen.bmj.com/content/4/5/e005045.full> This paper describes the experience of researchers who used Facebook to find parents who then helped to design the patient information sheet and other aspects of a proposed trial.

## Other useful links

Family Care Research  
<http://familycareresearch.wordpress.com/about/>  
A website set up and run by a group of patients, relatives and staff affiliated to East Lancashire Hospitals Trust, which aims to communicate with other members of the public and local communities about research and involve them in the design and development of research studies.

Greater Manchester Kidney Information Network  
<http://gmkin.org.uk/>  
One of the examples featured in this guidance

INVOLVE (2009) Patient and public involvement in research and research ethics committee review. Eastleigh: INVOLVE.  
[www.involve.nihr.ac.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review/](http://www.involve.nihr.ac.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review/)

NHS Employers Social media guidelines  
[www.nhsemployers.org/your-workforce/need-to-know/social-media-and-the-nhs/social-media-guidelines](http://www.nhsemployers.org/your-workforce/need-to-know/social-media-and-the-nhs/social-media-guidelines)  
Links to various regulators and professional bodies' social media guidelines.

Social Research Association (2014) Social media in social research  
<https://storify.com/commutiny/thesra-socialmedia-socialresearch-conference-m>  
Storify about talk on use of social media in social research, which was given at the Annual Social Media in Social Research conference in 2014



## 13. Jargon buster

Term	Explanation
Blog	A website or web page that contains information or promotes discussion and consists of discrete entries (also called posts) written over a period of time. The most recent post usually appears first.
Closed Facebook group	<p>When a Facebook group is closed, only those who have been invited into a group can see the content and information shared within it. Others will still be able to see that the group exists and who its members are, but they will not be able to see any posts or information within the closed group unless they are invited. Only the creator of the group and anyone they make an administrator has the power to invite someone to a group.</p> <p>For more information see <a href="http://facebook.about.com/od/PagesGroups/ss/Everything-You-Need-To-Know-About-Facebook-Groups.htm">http://facebook.about.com/od/PagesGroups/ss/Everything-You-Need-To-Know-About-Facebook-Groups.htm</a></p>
Engagement	Where information and knowledge about research is provided and disseminated, for example science festivals, open days, media coverage.
Facebook	An online social networking service. After registering to use the site, users can create a personal profile, add other users as friends, exchange messages, post status updates and photos, and receive notifications when others update their profiles. Users can also join interest groups, which can be open, closed or secret.
Follower	Twitter users may subscribe to other users' tweets – this is known as 'following' and subscribers are known as 'followers'.
Google+ page	A Google+ page is similar to a Facebook page, in that it enables people to set up profiles, or 'pages', to post and share information.
Hashtag	On Twitter, a hashtag (#) is a way to bring together information about a topic. For example you can have a hashtag for a conference or an interest group.



Term	Explanation
Interactive website	A website that encourages people to interact with it, rather than just offering information or selling products. For example it might invite contributions (e.g. stories, photos, films), comments and blogs; hold online events and discussions; and include open or closed discussion forums.
Participation	Taking part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.
Podcast	A programme (e.g. a talk or a piece of music) made available in digital format for automatic download over the internet.
Profile	Personal information about a specific social media user that is established online – a digital identity.
Public involvement	<p>INVOLVE defines public involvement in research as research being carried out <b>‘with’</b> or <b>‘by’</b> members of the public rather than <b>‘to’</b>, <b>‘about’</b> or <b>‘for’</b> them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants.</p> <p>When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.</p>
QR code	A machine-readable label that consists of square dots arranged in a square grid on a white background. The label can be read by the camera on a telephone and when a photograph is taken it will take you to an internet site with more information.
Re-tweet	Re-tweeting is passing on someone else’s tweet. It means a lot more people will see the tweet.

Term	Explanation
Secret Facebook group	Nobody on Facebook can see a secret group other than those in the group. This group will not appear anywhere on a person's profile, and only those within the group can see who the members are and what is posted. For more information see <a href="http://facebook.about.com/od/PagesGroups/ss/Everything-You-Need-To-Know-About-Facebook-Groups.htm">http://facebook.about.com/od/PagesGroups/ss/Everything-You-Need-To-Know-About-Facebook-Groups.htm</a>
Skype	A messaging service which enables users to communicate with people by voice, video and instant messaging over the internet.
Social media	Interaction among people within virtual communities and networks, for example blogs, Facebook and Twitter.
Social networking service	A platform to build social networks among people who share interests, activities or connections. Twitter and Facebook are examples of social networking services.
Storify	A social networking service that lets the user create stories or timelines using social media such as Twitter and Facebook.
Tweet	Messages sent out on Twitter are called tweets. Your tweets are seen by others who follow you, and you see the tweets of people you follow. Your tweets can also be seen by anyone who looks at your profile.
Twitter	A social networking service that allows users to exchange public messages of 140 characters or less, known as tweets.

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The authors of this resource are Marisha Palm of the INVOLVE Coordinating Centre and Bec Hanley of TwoCan Associates.

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# INVOLVE

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If you would like to know more about what we do, please contact us:

## INVOLVE

Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD

Web: [www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)  
Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: 023 8065 1088  
Twitter: @NIHRINVOLVE

If you need a copy of this publication in another format please contact us at INVOLVE.

Email: **[admin@invo.org.uk](mailto:admin@invo.org.uk)**  
Telephone: **023 8065 1088**

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