

## **Example 1: The Acne Priority Setting Partnership**

**Using Twitter, YouTube and mobile phone technology to involve people in identifying research priorities**

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### **About the research**

The [Acne Priority Setting Partnership](#) (PSP) was launched in 2013 by the [Acne Academy](#) in collaboration with the [James Lind Alliance](#). The aim was to put people with acne and treatment providers at the centre of deciding priorities for acne treatment research.

### **How have people been involved?**

Mick Mullane, the Patient Learning and Engagement Manager at the National Institute for Health Research (NIHR) Clinical Research Network and Dipaka Patel, the Communications Officer, worked with colleagues at the PSP to develop multiple ways for people with acne to suggest their priorities for research. Many people who get acne are young, so it was important to use social media.

The PSP team developed a survey that people could complete using a mobile phone or a PC. They then publicised the PSP and the link to the survey via:

- a poster with a [QR code](#) that enabled people to link to the survey
- two short films that were posted on YouTube
- tweeting about the PSP, again with a link to the survey and to the YouTube films.

The first stage of the process asked people about their priorities. Responses were then grouped into themes, and a second survey asked people to vote on these. Many people completed the surveys using their mobile phones. This meant that the PSP team were able to contact respondents via text message to:

- ask further questions
- tell people about the results of the first stage of the process
- invite them to take part in the second stage
- share the results of the project as a whole.

The use of YouTube as a complement to Twitter worked particularly well, as the films were something concrete that could be tweeted about, as opposed to just a link to the website and survey.

The team considered using Facebook but decided against it, because it requires you to post more information, and they did not want to influence people's suggestions for research. In contrast Twitter only allows you to send short messages, thus reducing the risk of influencing people.

No face-to-face involvement activities were undertaken at these stages in the PSP.

### **What resources were involved?**

It took about half a day to make each of the films, working in partnership with a filmmaker. Time spent tweeting and texting was minimal, especially as software was used to schedule the tweets and texts to go out at particular times. Texting is cheaper than posting a letter, and the NIHR has a central resource for this, which made it more affordable.

### **The impact of using social media**

Analysis of the second stage of the consultation showed that more people visited the PSP survey immediately after the YouTube films were released, and after the PSP's tweets were re-tweeted by the Channel 4 programme Embarrassing Bodies, Healthwatch groups and Patient.co.uk. In all, 4,000 people responded to the first stage of the PSP, with many of these doing so via mobile phones.

### **Advice to other researchers about using social media to actively involve people in research**

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

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

**Acknowledgements:** We would like to thank Mick Mullane for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement – The Acne Priority Setting Partnership: Using Twitter, YouTube and mobile phone technology to involve people in identifying research priorities

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## **Example 2: Salford Research and Development (R+D) and National Institute for Health Research (NIHR) Greater Manchester Primary Care Patient Safety Translational Research Centre (GM PCPSTRC)**

### **Using Twitter to find people to involve in a research advisory group**

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#### **About the research**

National Institute for Health Research ([NIHR](#)) [Greater Manchester Primary Care Patient Safety Translational Research Centre](#) (GM PCPSTRC) is a partnership between the University of Manchester and Salford Royal NHS Foundation Trust. The Centre has a strong commitment to patient and public involvement. As part of this commitment it has a Research User Group, which advises on and helps to shape the research of the Centre. Philip Hammond coordinates patient and public involvement in Research and Development (R+D) at Salford Royal NHS Foundation Trust and at the GMPCPSTRC.

#### **How have people been involved?**

The Research User Group (RUG) consists of 12 members who have been recruited via a variety of traditional and non-traditional recruitment methods in order to involve a wide range of people, including people who hadn't previously been actively involved in research.

The GM PCPSTRC and the Trust each have an active Twitter account, and the decision was made to use Twitter as well as more traditional methods to recruit new members to the RUG, because Philip had already used Twitter a lot and knew it worked. He had considered using Facebook to involve people but ruled it out – the Trust had previously taken a corporate decision not to use it because of the risks attached (for more information on risks and risk management see Section 7 of the guidance).

Philip sent a range of tweets about the opportunity to join the RUG, using the Salford Royal NHS Foundation Trust R+D Team's twitter account ([@SalfordRD](#)) and engaging with the owner/operator of the GMPCPSTRC twitter account ([@gm\\_pstrc](#)). The Salford R+D account has over 700 followers, so this enables the Trust to reach a lot of people, for example, 64 tweets were sent from [@SalfordRD](#) in one week. These were mentioned four times in tweets by other people, which reached over 3,000 followers. And re-tweets reached a further 7,600 people.

Philip is also using Twitter for quick opinion gathering (e.g. what did you think of this article, what do you think our number one research priority should be?) and to alert people to opportunities for involvement.

## What resources were involved?

Using Twitter to involve people requires no additional budget and little time commitment - Philip spends between 15 and 30 minutes per day managing the Salford R+D account. He uses an application called [tweetdeck](#) to schedule tweets, so that they go out through the day rather than all at once.

## The impact of using social media

Philip received a really good number and range of applications from people who wanted to join the Research User Group. It's hard to say this was directly as a result of Twitter, but it is likely that this was the case. Three new people have now been appointed to the Research User Group, two of whom had never been actively involved in research before.

## The future

There are plans to continue to build the Twitter following at Salford R+D, and to continue to use it to engage and involve people.

## Advice to other researchers about using social media to actively involve people in research

“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. For example, if you only advertise opportunities for involvement in the Trust's membership newsletter, you will only manage to involve those people who read it and are already engaged in health services. 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.

“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.

“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

**Acknowledgements:** We would like to thank Philip Hammond for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement - Salford Research and Development (R+D) and National Institute for Health Research (NIHR) Greater Manchester Primary Care Patient Safety Translational Research Centre (GM PCPSTRC): Using Twitter to find people to involve in a research advisory group

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## **Example 3: International Centre for Mental Health Social Research**

### **Using Twitter and a blog to identify and prioritise topics for research**

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#### **About the Centre**

The [International Centre for Mental Health Social Research](#) brings together researchers from around the world to undertake a unique research programme applying social science to mental health practice. Based in the Department of Social Policy and Social Work at the University of York, the Centre's research focuses on social perspectives in mental health through the life course from childhood to old age.

#### **How have people been involved?**

The Centre is relatively new, and Martin Webber, the Centre's director, wanted to listen to people's ideas for research priorities. He wanted to reach as diverse an audience as possible, but especially people with mental health experience – those using mental health services and those working in mental health. He had already built up a Twitter following (using [@mgoat73](#)) through his professional work over the previous two years. He also has a blog which is independent of his work at the University. He decided to use Twitter and his blog to ask people for their views.

Twitter was chosen because it forms communities of interest (as people choose who to follow), and it's a medium that encourages people to express their opinions. It's also easy and efficient. Martin used Twitter and his blog (the Twitter account and the blog are linked) to tell people about the Centre, to ask them to complete a survey (using SurveyMonkey), and to seek their views about their top question for the new Centre to address.

He ruled out the use of Facebook for this exercise, as he felt it was more informal and personal. The Centre has a Facebook page but it is rarely used and Martin doesn't have time to update it.

Social media was not the only route used to listen to the priorities of people who use mental health services. Other methods were used to listen to priorities – notably by asking collaborators to seek people's views and face-to-face seminars – but these mainly reached internal audiences (e.g. academics).

#### **What were the challenges?**

Using social media means that you only reach people who are already engaged, so you might get skewed results. You exclude people who are digitally excluded. And it is hit and miss whether people will see your tweets and blog posts.

## **What resources were involved?**

The use of social media costs very little in terms of time, and nothing in terms of money. Martin spent a small amount of time setting up the survey, tweeting and blogging. He had spent about two years building up the Twitter following, but not with this project in mind.

## **The impact of using social media**

Twitter enabled Martin and his colleagues to reach a wider group of people than had been anticipated, particularly people who are plugged in to the current debates around mental health. It also led to a higher response rate for the survey than expected.

## **The future**

Martin is successfully using Twitter to seek people's views about ideas as he prepares papers for publication. This is often late at night. He is also using it to recruit people to a research study.

## **Advice to other researchers about using social media to actively involve people in research**

“Think clearly about what you want to get out of it. 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.

“Make the requirements on people as minimal as possible – e.g. only ask one or two questions.

“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.”

“People get fed up with you if you are always self-promoting, so pick different things to tweet about, tell people about interesting articles, resources etc.

“In the current university landscape there's a lot of emphasis on knowledge exchange and on impact. But you need to communicate and share what you're doing at the beginning of a project and on an ongoing basis. That engages people so that when you have the results they are already interested.”

Martin Webber, International Centre for Mental Health Social Research, University of York

**Acknowledgements:** We would like to thank Martin Webber for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement – International Centre for Mental Health Social Research: Using Twitter and a blog to identify and prioritise topics for research

## **Example 4: Queer Futures**

### **Using Facebook to involve young people in the design and delivery of research about suicide and self-harm**

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#### **About the research**

[Queer Futures](#) is a two-year study that aims to understand the experiences and perspectives of young (16-25 years old) lesbian, gay, bisexual, transsexual and queer (LGBTQ) people in order to help reduce their risk of self-harm and suicide. It is particularly interested in how gender and sexuality may influence young people's distress.

Phase 1 of the research asks 30 young LGBTQ people to talk with a researcher either online or face-to-face. In phase 2, an online questionnaire will be sent to as many young LGBTQ people around the country as possible. There will also be an online questionnaire for mental health staff.

The study is being funded by the Department of Health Policy Research Programme and aims to produce knowledge that can contribute to the government's suicide prevention strategy.

#### **How have people been involved?**

LGBTQ young people have been involved from an early stage. The research team was very keen to involve them because of the subject matter - LGBTQ suicide and self-harm is a very difficult area to research. The researchers wanted to ensure that they were asking the right questions and they needed help to recruit participants, so they set up a LGBTQ advisory group.

Initially a senior member of the research team visited two LGBTQ youth groups in different parts of the country. She talked with the youth worker and then with some young people who were interested in the project. This led to the establishment of the advisory group.

The group will meet face-to-face on three occasions, but it is predominately operating using a [secret Facebook group](#). This communication method was chosen by the young people, who also set up the Facebook group.

#### **What were the challenges?**

Young people who are active on social media are more comfortable online; it is not all young people's preferred form of communication.

You have to keep it going so that the young people don't lose interest.

## **What resources were involved?**

Use of social media in this project saved time – it would not have been possible to have the level of involvement that there has been if all interactions with the advisory group had been face-to-face.

## **The impact of using social media**

The advisory group has had a huge influence on the research, orienting the team to what's most important for LGBTQ young people. Members commented on the participant information sheet and helped to develop the Queer Futures [website](#). They helped the researchers to devise the interview schedule, and suggested developing a summary of what will be asked in the interviews.

Advisory group members used their online networks to help the researchers to recruit participants. The researchers knew there were lots of LGBTQ young people who might be prepared to take part, but were struggling to find them. The young people sent out the researchers' request to take part to their networks of LGBTQ young people, for example through [Tumblr](#). This made a big difference to the research.

## **Advice to other researchers about using social media to actively involve people in research**

“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. If we had just set up a Facebook page it wouldn't have worked – we needed to have the discussions with the young people.”

Liz McDermott, Queer Futures, Lancaster University

**Acknowledgements:** We would like to thank Liz McDermott for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement - Queer Futures: Using Facebook to involve young people in the design and delivery of research about suicide and self-harm



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## **Example 5: National Institute for Health Research (NIHR) Clinical Research Network Children Specialty Rheumatology Clinical Studies Group**

**Using Facebook to ask parents and families about their priorities for research**

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### **About the Clinical Studies Group**

The [NIHR Clinical Research Network Children Specialty Rheumatology Clinical Studies Group](#) (CSG) provides free expert advice to help researchers develop high quality research proposals.

### **How have people been involved?**

There are three consumer members of the CSG. Sharon Douglas's daughter has juvenile arthritis. This led Sharon to co-found the [Scottish Network for Arthritis in Children](#) (SNAC), where she is currently a trustee. Sharon is also a member of the CSG; she joined as a consumer representative in 2008. Her current role on the CSG is as 'Consumer Champion', which means she supports other consumers who sit on the CSG.

Several years ago the CSG consumers wanted to know more about parents' priorities for research. Sharon and her colleague, Katherine Venter, tried to access parents' and families' views by approaching a number of arthritis charities, but got very little response. They were keen to reach parents and families they hadn't managed to reach through the charities. So they decided to post questions on two Facebook groups that are used by parents and families of children with juvenile idiopathic arthritis in the UK. These groups currently have over 1,000 members between them and are seen as a lifeline by the parents and families who use them. Researchers cannot join the groups, but they can ask to access them.

Sharon was a member of one of the Facebook groups so was able to put up a post herself. She had a good relationship with the administrator of the other group who endorsed the post. The post asked: "What are your top three concerns about your child's condition and care?"

### **What were the challenges?**

There were very few challenges. People need to know you and trust you before you can ask questions about your child's condition and care, so the fact that Sharon was a parent was important – it meant that the question was posted by a parent to other parents and families, so it didn't feel challenging in any way.

## **What resources were involved?**

There were almost no resources involved. Using Facebook was quick, easy and also more effective than using emails as you can see all of the discussion.

## **The impact of using social media**

Sharon received 40 replies from Facebook. Facebook groups have grown hugely in the last two years, and are now an important tool to support and connect families.

In total the CSG consumers received 200 replies, which identified 600 concerns. These mainly related to uncertainty about the progress of the disease and the side effects of treatments. The responses gave Sharon and Katherine the confidence to know that they were advocating for research that was important to parents and families.

Social media, and particularly Facebook, has also enabled parents and families to discuss research that is taking place. This wasn't possible previously.

## **The future**

Sharon and SNAC are now using Twitter and Facebook to facilitate discussions about research with parents and families (and researchers). They are also using social media to provide information surrounding access to studies, and to inform people about results of research.

## **Advice to other researchers about using social media to actively involve people in research**

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

“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.

“Be clear why you want to use social media as part of your research – is it to involve people, to recruit them or to disseminate results? Social media can enable you to link with people more closely and to get better answers to your questions.

“Social media can inform and engage people in research if it's done well - and people need to be aware of research before they can get involved.”

Sharon Douglas, SNAC Trustee, NIHR CSG Consumer Champion

**Acknowledgements:** We would like to thank Sharon Douglas for agreeing to share her experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement - National Institute for Health Research (NIHR) Clinical Research Network Children Specialty Rheumatology Clinical Studies Group: Using Facebook to ask parents and families about their priorities for research

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## **Example 6: Children of the 90s**

### **Using Facebook and Skype to involve young people in a long-term research project**

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#### **About the research**

The Children of the 90s study, also known as the Avon Longitudinal Study of Parents and Children (ALSPAC), is a long-term health research project based in Bristol. More than 14,000 mothers enrolled during pregnancy in 1991 and 1992, and the health and development of their children has been followed in great detail ever since. In recent years, the project has expanded to include the fathers, siblings, children and grandparents of the original children (now aged 21 to 23), making it a unique four-generational study.

#### **How have people been involved?**

There is an advisory panel made up of young participants in the study. It was set up when the study participants were teenagers. The panel meets face-to-face at least six times per year to advise on various aspects of the study, for example to review documents related to new research projects before they are submitted to an ethics committee. Social media is used to complement this face-to-face involvement.

#### **Facebook**

It was agreed that a [secret Facebook group](#) would be the best way for panel members to communicate with each other and with the ALSPAC participation team and researchers outside meetings.

Facebook was seen as an easy way for panel members to get in touch with the participation team, because they are using it anyway. It also offered a place to communicate securely.

Facebook is used to arrange meetings and to continue discussing issues that are raised during meetings. The Facebook group enables members to continue the discussion and allows the researchers to see how the discussion develops.

#### **Skype**

The panel uses Skype to enable young people who no longer live near Bristol (where the study is based) to join meetings. Around five young people currently call into meetings via Skype.

#### **What are the challenges?**

With the Facebook group, the main challenge has been ensuring that members see messages and posts as not everyone looks at the page regularly. So Makaela (a

member of the ALSPAC participation team) sends an email to panel members if she wants to ensure that they see a post. It can also be a challenge to keep things clear, and to ensure that the most relevant posts are at the top of the page; however this can now be overcome by 'pinning' important posts to the top of the page.

Using Skype at meetings can also be a challenge. The free version of Skype only allows one person to join on a video link, so the audio-only format is used. That means that people joining by Skype can't see what's going on at the meetings and don't know when they can contribute vocally. The participation team, researchers and panel members have got round this by having a verbal discussion amongst people who are actually in the room, with those joining by Skype typing in their comments. The Skype messages appear on a large screen in the meeting room so that everyone can see them. The chair is then responsible for ensuring that the points are brought in to the discussion. There is 'Skype time' as part of each agenda item to ensure this can take place.

### **What resources are involved?**

The Facebook group is free and has saved time in arranging meetings and continuing discussions. It's also more effective than using emails as you can see all of the discussion.

It has taken time to get used to Skype contributions at meetings but this is now working well.

### **The impact of using social media**

Social media has been really beneficial in enabling people who no longer live in Bristol to remain involved. It has saved time and enabled the participation team, researchers and the advisory panel to work more effectively. It makes the research more accessible to those who are actively involved and means people can contribute if they can't attend a meeting and see first-hand what's being said. Previously, the emphasis was on discussion in meetings but now the discussion can continue over a longer period if needed. This gives people more time to reflect and is particularly useful if the panel are discussing more controversial research methods or proposals.

### **The future**

ALSPAC plans to use Twitter (@CO90s), YouTube (<http://www.youtube.com/user/children90s>), SoundCloud (<https://soundcloud.com/children-of-the-90s>) and Imgur (<http://co90s.imgur.com/>) to involve and engage young people in the future. At the moment YouTube and Twitter are used to engage participants – alerting them to new publications, and giving them access to talks and podcasts whilst Imgur is a useful tool to disseminate research findings in an accessible manner.

### **Advice to other researchers about using social media to actively involve people in research**

“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.

“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.

“The Children of the 90s study is growing and increasingly young people are using social media to interact with us. So if you’re trying to communicate with participants, it’s a good avenue to use.”

Makaela Jacobs-Pearson, ALSPAC

**Acknowledgements:** We would like to thank Makaela Jacobs-Pearson for agreeing to share her experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement - Children of the 90s: Using Facebook and Skype to involve young people in a long-term research project

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## **Example 7: Cystic Fibrosis (CF) Unite**

### **Using an interactive website to involve people with cystic fibrosis in discussions about research**

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#### **About Cystic Fibrosis (CF) Unite**

Matt Hurley was undertaking some research about lung infection in cystic fibrosis (CF). He wanted to listen to the views of people with CF, but he knew he couldn't physically bring them together in a room to do this. People with CF can't meet each other face-to-face as there is too high a risk of cross-infection. So he began to think about how he could bring people with CF and researchers together online. This is how [CFUnite](#) began.

Matt put together a panel of people with CF, parents of children with CF and researchers, and together they obtained a Wellcome Trust grant. This enabled them to develop CFUnite: an interactive website that aims to increase collaboration and discussion between people with CF, parents of children with CF, researchers and clinicians about CF research. The primary goal is to hold online events where researchers present their work so that people affected by CF can have an input.

#### **How have people been involved?**

Some events have been very successful. For example, an event about Kalydeco, a potential new drug for CF, was 'attended' by around 90 people. But several thousand people then watched the event at a later date. Other events have attracted smaller numbers, perhaps because of the subject matter and the time that the events have taken place.

#### **What are the challenges?**

One of the challenges has been promoting the site. Matt used Facebook and Twitter, but found it hard to convey what CFUnite is about in 140 characters. A group called [CF Aware](#), which aims to raise awareness of CF, gave advice on using Twitter successfully and re-tweeted all CFUnite tweets. This was very helpful.

Another challenge is lack of time – Matt works full time as a doctor and is now in a clinical role, so needs to involve more people in the running of CFUnite.

Whilst some researchers are very enthusiastic to contribute and share their work (evidenced by a well written piece, with a timely response), others are less so (either no response, declining to contribute due to 'lack of time', or a very poorly written submission).

There have also been some technical challenges, but they are getting easier to overcome as the technology develops.

### **What resources were involved?**

CFUnite received a Wellcome Trust People Award of £29,000 to help to develop the site. This covered two years and has been made to last a little longer than that. It takes about two days per week to run the site properly. The main tasks are:

- identifying and contacting researchers to ask them to share their work
- editing any plain English summaries of research
- publicising and supporting events.

### **The impact of using social media**

The site has reached a lot of people and the momentum is growing.

### **The future**

CFUnite plans to continue to run events, but also to build the involvement of the advisory panel in the project.

### **Advice to other researchers about using social media to actively involve people in research**

“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, which is not when researchers are usually at work. And you need to get the topics right.

“You have to be honest and not tokenistic. If your involvement is tokenistic, people will disengage.

“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.

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, CFUnite

**Acknowledgements:** We would like to thank Matt Hurley for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement – Cystic Fibrosis (CF) Unite: Using an interactive website to involve people with cystic fibrosis in discussions about research

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## **Example 8: 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**

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### **About Greater Manchester Kidney Information Network (GMKIN)**

Cristina Vasilica is undertaking a PhD project to explore the impact of social media on patient information provision, networking and social support. She is supervised by Professor Paula Ormandy. Cristina's research has two key aims: to develop a sustainable interactive social hub in partnership with people with renal disease to offer information and support, and to follow 18 patients in depth to explore their experience of using social media.

The website is called the [Greater Manchester Kidney Information Network](#) (GMKIN). The aims of the site are to provide links to existing information rather than duplicating what is already available, and to enable networking and support.

### **How have people been involved?**

To develop GMKIN, Cristina began by talking face-to-face and on Facebook with some kidney patients in the Greater Manchester area. She then ran two focus groups for kidney patients to ask for their views.

A variety of people write blogs for the site, including patients who are pre-dialysis or on dialysis, transplant patients, and health professionals. Cristina uses Twitter to alert people to the GMKIN site and to raise awareness of GMKIN. Twitter chats are now being planned. There is an advisory board for the project (which includes kidney patients) and a young adult group.

Cristina has also worked in partnership with kidney patients to develop a closed Facebook group to offer support and networking. She tried using a forum on the website to complement the Facebook group, but found Facebook was more effective, because it has been designed for networking and many people are already familiar with it.

The target audience for the website and Facebook group is anyone affected by kidney disease in Greater Manchester. GMKIN now has members across the world, although the focus remains Greater Manchester.

After 10 months, the GMKIN website now has 96 blogs and 301 comments on these blogs. The site has been visited by over 3,000 people, who spend an average of just over 3.5 minutes looking at the site. The Facebook group has 146 active members and the Twitter account has 203 followers, with 903 tweets, 118 re-tweets and 52 tweets favourited.



The website, Twitter feed and Facebook page are now mainly run by kidney patients, with Cristina providing support. She has also offered training to enable people to use social media and to manage the website, Twitter feed and the Facebook group.

### **What are the challenges?**

The main challenge for Cristina has been to distinguish between her roles as researcher, community manager and digital manager. As she is studying the impact of social media, her strategy has been to intervene as little as possible, and to keep a log about what happens when she does intervene. This has helped her to consider and manage any ethical issues, and to highlight the impact her intervention has on the community. For example, Cristina noticed that there had been very few posts on the Facebook page after a period of a few days when most posts had been about fairly dry research. So she posted a photo of her garden, which had tomatoes growing in it. This led to a lot of posts about her garden, then about diet and then about potassium.

### **What resources are involved?**

This project has taken a lot of time, but not very much money. It cost between £3,000 and £4,000 to develop the website and about £150 per year for hosting.

The patients who run the website, Facebook group and Twitter feed give their time free of charge. The total cost of moderation (health personnel) is estimated at £2,970 per year, and takes about 3.5 hours per week. The community manager (role undertaken by researcher) spent four months developing the platform and content and five hours per day for the first six months, then 2.5 hours per day for the following six months. This time was spent on community management of Facebook and Twitter.

Comprehensive training of patients and health care staff in championing website moderation was essential in influencing sustainability and safety operating guidance. Medical advice posted on the website is moderated by healthcare professionals, whereas general support is overseen by patient moderators.

### **The impact of using social media**

GMKIN has grown very quickly because it has a local base. It continues to grow – for example every week between two and five kidney patients join the Facebook group.

The website is now mainly run by patients. Feedback on the information that has been generated has been very positive. Another success has been the way relationships have started to form between members of the Facebook group. Cristina's research has demonstrated how social media can have a positive impact on patients' quality of life, self-worth and self-advocacy. Those who get involved in GMKIN have moved from low activity (e.g. not using Twitter at all) to using it and enjoying it.

## **Advice to other researchers about using social media to actively involve people in research**

“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.

“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

**Acknowledgements:** We would like to thank Cristina Vasilica for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement – 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

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## **Example 9: Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West Midlands**

### **Using an interactive website to involve people in dialogues about CLAHRC research**

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#### **About the CLAHRC online platform**

The Patient and Public Involvement (PPI) Programme at the [Collaboration for Leadership in Applied Health Research and Care \(CLAHRC\) West Midlands](#) involves members of the public as PPI advisors. This is a formal role that can be time consuming, and to become involved in this way people have to complete an application form and be interviewed. If successful they are then asked to sit on, for example, a research management group or steering group. The CLAHRC wanted to develop a way to involve a broader range of people, who could choose how much or how little to be involved depending on the time they had available.

They are therefore developing an online forum called 'CLAHRC Voices West Midlands'. The aim is to enable online collaboration between the CLAHRC and members of the public with an interest in/experience of health-related research and service improvement. Everyone who signs up to the platform (it is a closed, by invitation only, group) is asked in which of the CLAHRC strands of work they are interested. This enables them to take part in online discussions about research.

It is envisaged that the platform will facilitate two-way dialogue, feedback and polls and will enable researchers to better communicate the impact of PPI in research.

The platform is initially being developed for the use of CLAHRC West Midlands to:

- enable platform users to create their own profile with specific interests to ensure contact is user-controlled, filtered and targeted
- contact platform users for feedback via polls, questionnaires, and discussion forums
- identify platform users or groups to become more intensely involved in specific projects that interest them
- disseminate information to request feedback, advertise learning opportunities, share information, post regular blogs and podcasts, and so on
- test out CLAHRC-developed public engagement with science tools
- develop public facing dissemination materials, including plain English summaries.

It is hoped that the platform will reach a wide range of people, which in turn should free up resources to reach seldom-heard groups. The platform will go live after a period of testing by CLAHRC staff and service users. Once fully developed and piloted, it has the potential to be used by other organisations in the West Midlands and possibly nationally.

One member of research staff from each of the CLAHRC research themes is now being trained to use the platform. They will moderate information related to their theme, and will have editing rights, be able to create events and initiate discussions. Success of the platform will depend upon regular engagement by staff from each of the four service themes to set up projects and activities on the platform workspace. The fifth section on the platform 'Open Forum' will be managed by the PPI team and will serve to look at wider issues in the local health and social care landscape.

### **What were the challenges?**

CLAHRC West Midlands was originally working to design and set up their own online platform by working with a local community engagement organisation. A period of testing by citizens, patients and service users as well as CLAHRC academics and individuals from service partners was carried out. This informed decisions regarding what content and features to include and helped to ensure that the platform was user-friendly. After the introduction of the National Institute for Health Research (NIHR) Google Hub, it was agreed that CLAHRC Voices West Midlands will be situated on the Hub, which is a new collaboration workspace that is being made available for everyone working in NIHR initiatives.

Another challenge is resources; it will take time to moderate the platform and to make it interesting, so that people want to get involved. It may also be a challenge to get researchers to use the platform.

### **The impact of using social media**

It's too early to say what impact the platform will have. It will be evaluated as part of the CLAHRC West Midlands Implementation Science theme.

### **Advice to other researchers about using social media to actively involve people in research**

"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.

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

"Researchers need to be trained in the use of social media as it's not a skill everyone has."

Jo Sartori, CLAHRC West Midlands

**Acknowledgements:** We would like to thank Jo Sartori for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement: Collaboration for Leadership in Applied Health Research (CLAHRC) West Midlands: Using an interactive website to involve people in dialogues about CLAHRC research