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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

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**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