
Example 7: Cystic Fibrosis (CF) Unite

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

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

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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