Clinical research benefits go viral via Twitter

In this article...

- The world of clinical research is poorly understood
- A Twitter campaign communicated why people were involved
- Researchers and patients all over the world have joined in

The world of clinical research is often poorly understood and can appear mysterious to patients, the public and healthcare staff. Much research takes place out of the public eye and only receives attention when the media announces the latest breakthrough or, in very rare cases, adverse outcomes.

The term clinical research is often poorly understood. A Twitter campaign communicated why people were involved. Researchers and patients all over the world have joined in.

Research community
In December 2014 we invited the core research team at the James Paget University Hospital to pose for a photograph holding a placard explaining in simple terms why they did research. This was posted on the trust research department’s Twitter account (@JPUHResearch) using the hashtag #WhyWeDoResearch.

The hashtag generated responses from outside the trust and what began as a simple way to introduce the research team to their clinical colleagues, patients and the local public gained momentum and attracted national and international attention through the force of social media.

Other research teams working in the NHS, in industry and in charities throughout England, the UK and finally internationally began to post their own reasons for being involved in clinical research. Patient participants, the most important members of the research team, have also joined in, tweeting their reasons for joining research projects.

Press releases supporting and publicising the hashtag were sent out from James Paget (2015) and also from Blackpool Teaching Hospitals (2015), which was keen to be involved in the campaign.

We also created and posted a YouTube video in January 2015, which received more than 400 views in its first week. At the time of writing it has received just under 1,100 views (Bit.ly/JPHresearch). The hashtag has now been championed in nine other countries including Australia and the US. An idea expressed their passion for research to the healthcare community and general public. This article demonstrates how a social media campaign helped to change this.

5 key points

1. The term clinical research is often poorly understood
2. A Twitter community has enabled staff and patients to share their interest in clinical research
3. Clinical researchers place patients’ needs and wellbeing at the centre of their research
4. Social media platforms such as Twitter allow for rapid and global connectivity
5. Online communities offer opportunities to collaborate, share problems and develop solutions
that began in a single research department in Norfolk with 20 core staff members had become a global campaign.

With more than 5,000 tweets carrying the #WhyWeDoResearch hashtag, and more than 5 million impressions on Twitter within the first three months, researchers and patients around the UK and the world have found a simple way to voice their enthusiasm and excitement for this important work.

Others can read the simple, inspiring statements posted by colleagues and fellow research participants. Among the #WhyWeDoResearch-tagged tweets were:

- To ensure babies get the very best care;
- To make a difference to patient care and treatment;
- To save lives;
- The high-quality care we provide now
  is because of research in the past;
- To inform treatments and medications
  of the future;
- To give people with dementia an
  enhanced care experience;
- Because without it we can't get to the
  core of the problem;
- Why not?

A simple analysis of the reasons given, based on the frequency of words used in these tweets, is shown in the form of a “word cloud” (above). There are few surprises in the reasons given for why people take part in clinical research: what predominates is the word “patient”.

Clinical research is ultimately about people and improving the quality of patients’ lives. Researchers who have been involved in this campaign are clearly demonstrating that they hold their patients’ wellbeing and needs at the very centre of their work. Positive and highly active verbs also figure prominently: terms such as “improve”, “share” and “collaborate”, as well as those expressing the sentiments that underpin the job of research, such as “enthusiasm”, “passion” and “pride”.

Reflection
The success of this campaign has been unexpected and merits some reflection. Social media platforms such as Twitter allow for rapid and global connectivity and can serve as a remarkable vehicle for communication as well as education (Choo et al, 2014). In this example, there has been a snowballing of activity that started with a small and localised beginning and grew in only a few months into an international campaign that deserves recognition.

However, #WhyWeDoResearch is not about gaining influence or promoting behavioural change. Neither is it a mere sales or marketing strategy. It focuses on opportunity and inspiration. The #WhyWeDoResearch format is a simple means to begin a conversation with a question. It asks “Why do you do research?” and enables those who rarely have a voice to share their reasons publicly. The answers, posted as photos on Twitter, have provided the second element of the campaign: inspiration.

Health professionals, support staff and those who participate in research as volunteers have given short statements – often simple, sometimes profound – that they are willing to declare to the world. These include “To save our daughter’s life” and “Because the possibilities are endless, we just don’t know what all the possibilities are yet!”

These tweets have revealed a community purpose. Those involved in research may have already known that it existed. The use of social media to build and maintain community has received attention (Gruzd and Haythornthwaite, 2013) and will continue to do so. With #WhyWeDoResearch, the ability to join the conversation and take part in this community is probably one of the reasons for the campaign’s success.

Conclusion
By asking those involved in research why they do what they do, and giving them a simple means to express that answer, the #WhyWeDoResearch campaign has shone a light on the world of clinical research. Now, anyone can see the motivation behind the work.

They can also see that clinical research involves a large, diverse team of health professionals and patients across the world who share a common purpose – to advance knowledge in order to improve patient care. They can see the pride and enthusiasm in the faces and in the words of those who have added their voices.

The #WhyWeDoResearch “word cloud” was a clear demonstration of tweeters’ priorities

The #WhyWeDoResearch campaign continues to grow. There are now calls from trusts around the UK and groups in other countries to build on its success. As the online community grows, it gives us the opportunity to develop collaborations, to share problems and to develop solutions together rather than in isolation. This is particularly welcome for the researchers who work in isolation or in small teams.

References

Benefits of social media for nurses and service users
Bit.ly/NTSoMeBenefits