Title: #WhyWeDoResearch: using social media effectively and positively as a tool to engage public, patients and healthcare staff in research

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Author Biographies

Emma Yhnell

Emma is a Health and Care Research Wales Fellow at Cardiff University. In 2016 she was awarded a fellowship to translate her work on cognitive training into the Huntington’s disease (HD) patient clinic. She became involved in the #WhyWeDoResearch campaign after volunteering to host a Tweetchat as part of the 2017 Tweetfest. Her passions are public engagement and developing novel ways of engaging patients and the public in research.

Hazel A Smith

Hazel, prior to being elected as Vice-Chair for the IRNN (@Irish_RNN) in February 2018, was selected as the Communications Officer for the Irish Research Nurses Network (IRNN) in January 2015. The IRNN became #WhyWeDoResearch collaborators in May 2015. Hazel, in her role as Communications Officer and as Research Coordinator (Clinical Midwifery Manger II), has hosted #WhyWeDoResearch tweetchats and written #WhyWeDoResearch blogs. Hazel’s research passions are maternal and child health and social epidemiology.

Kay Walker

Kay got involved in #WhyWeDoResearch in 2016 to give the patient voice to debates, and help clinicians think of things that the patient/general public want to know. She is also a researcher so finds it interesting to hear what new research is being done and what new techniques are being used. Patients can interact with clinicians and researchers to ensure the research is being done in areas that are important to them.
The campaign is important for research staff to see their hard work is paying off and having an impact on the general public and that care is being improved.

**Claire Whitehouse**

Claire’s professional role involves complete oversight of all research and the Clinical Research Nursing Teams. After qualifying in 2005 she worked in critical care prior to moving in to the research arena in 2010. Claire developed #WhyWeDoResearch in 2014 and has led the campaign ever since. She has a MSc in Nursing Studies, is a member of the International Association of Clinical Research Nurses (@IACRN) and is a three times Florence Nightingale Foundation Scholar (@FNightingaleF). Her passions are patient care; supporting capacity and capability of staff and patients to engage in research.

**Abstract**

The #WhyWeDoResearch campaign was set up in 2014 and was originally planned to run, locally, for 12 days in December. Within four days the campaign was being utilised nationally at other Trusts and Charities. By the New Year 2015 the campaign had become international and had reached Australia and Canada. The intended audience for the campaign is broad and includes: patients, the general public, all staff working in healthcare and/or research including (but not limited to) NHS, commercial companies, charities and schools. The campaign is a community where patients, staff and public alike can share their voice on an equal playing field.
Each year to coincide with International Clinical Trials Day (ICTD) on 20th May, a #WhyWeDoResearch ‘Tweetfest’ is hosted. This includes a number of ‘Tweetchats’ at set timepoints throughout the ‘Tweetfest’. Tweetchats are hosted by ‘experts’ in particular disease or other areas. Patients and patient groups are included in this group of experts. This article uses the #WhyWeDoResearch campaign to demonstrate how social media can be utilised to raise research awareness across the globe.

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Background

The #WhyWeDoResearch (http://whywedoresearch.weebly.com/) campaign was set up as a way of introducing the James Paget University Hospital NHS Foundation Trust (@JPUHResearch) team to the local population through the Twitter social media platform in December 2014. It was a Christmas campaign sharing photographs of staff members holding a placard describing why they were involved in research (Figure 1). The hashtag was used nationally by Trusts and charities within four days and had reached international audiences within three weeks, with researchers from Australia, Spain and Canada tweeting their own #WhyWeDoResearch quotes and photographs.
Figure 1 – Representative images from the #WhyWeDoResearch campaign.

A. An expectant mother stating that she takes part in research to keep mum’s and babies safe. B. A school child proudly holding his placard stating that we do research so that people’s lives can be saved.

#WhyWeDoResearch has since become the most utilised research Twitter community globally providing an open and equal playing field for staff, patients and the public to discuss, share and learn about research.

Tweetchats and Tweetfest

#WhyWeDoResearch Tweetchats are held approximately monthly; with a specific ‘Tweetfest’ covering International Clinical Trials Day annually (schedules for the 2016 and 2017 Tweetfests are shown below in Figures 2 and 3). A Tweetchat is an hour-long live discussion whereby anyone can join at a pre-determined time and date using the hashtag #WhyWeDoResearch. Tweetchats are designed to engage the audience and followers about specific research topics, to share learning and experiences, and raise awareness of research opportunities about a particular topic. Tweetchats are hosted by #WhyWeDoResearch originator @ClaireW_UK and/or guest hosts who are either working in a research area, or are a patient with a particular research interest in a disease or process.
Figure 2 – Tweetfest 2016 schedules from the UK and Australia.

A. The 2016 UK Tweetfest schedule. The times, dates, titles and presenters of the chats were all included in the schedule as well as on the website and this was advertised prior to the event. B. The Australian event was hosted by @AusNurseEd and ran through several days in May.
**Figure 3 – Tweetfest 2017 schedule.**

The 2017 UK Tweetfest schedule. For the two week Tweetfest the times, dates, titles and presenters of the chats were all included in the schedule as well as on the website and this was advertised prior to the event. Tweetchats included a range of topics and were hosted over lunchtimes, evenings and weekends to maximise participation.
Tweetchat hosts are provided with a toolkit of materials which allows them to develop a title and set questions to be launched via Twitter every 10-15 minutes within the hour. Tweetchats have two or more hosts to manage the scale of participation, and to support those hosting for the first time. In 2016 #WhyWeDoResearch ran the world’s first research ‘Tweetfest’ which included 19 Tweetchats over one week. In 2017 this increased to 29 Tweetchats over two weeks with 51 hosts. Tweetchats were hosted by patients and/or patient groups and support was provided by @ClaireW_UK and @smithhazelann.

Week one of the 2017 Tweetfest dedicated every evening to patient and public Tweetchats; others were interspersed throughout the day to match the patient’s preferences. Some patients contacted the organiser directly to request a hosting position and others were approached having shown interest in the campaign previously (or having hosted Tweetchats before). Patient hosts chose their own Tweetchat titles and subjects which were reviewed in line with all others to ensure no duplication of content. Hosts were further supported in design of questions to build confidence if they were unsure on the approach and to allow for open discussion.

**Limitations**

*Social media as a stand-alone tool*

Not all members of the public or indeed healthcare staff, are active on social media platforms. This may be due to lack of access in relation to technology, issues with confidence in using technology and particularly in relation to using social media platforms. Therefore, although Twitter was the social media platform used in this campaign it should not be used as a stand-alone tool for raising research awareness.
To account for this #WhyWeDoResearch campaign followers also host events at their healthcare organisations or in local communities. Previous examples of such events have included stalls with ‘pop-up' photo booths (Figure 4); the public, patients and staff may engage in photos or share their experiences at these stands.

Figure 4 - Engaging with the #WhyWeDoResearch campaign locally.

A. Research team showing their support for the #WhyWeDoResearch campaign using their #WhyWeDoResearch placards. B. A #WhyWeDoResearch stall with a ‘pop-up’ photo booth.
Some organisations have hosted live ‘twitter walls’ within their hospitals where Tweetchats are linked to a television screen in lobby’s and communication teams enter feedback to questions in real-time on the patient’s / public’s behalf.

#WhyWeDoResearch also host monthly guest blogs which are written by patients and staff sharing their experiences of research. On the #WhyWeDoResearch website there is an option to comment on and the discuss the guest blogs. This provides another forum for the public, patients and staff to engage with each other.

*Global inclusivity*

In ensuring the #WhyWeDoResearch campaign was inclusive to the global community throughout Tweetfest, different time-zones posed a potential problem. Strategies employed to combat this included:

a) Where possible scheduling Tweetchats towards the afternoon and evening Greenwich Mean Time (GMT) timezone which equated to Eastern Standard Time (EST) morning and lunchtimes (with others fitting in between).

b) Inviting people to host Tweetchats from their own country and at a time which was most suited to their followers. The same hashtag was used throughout and this further allows people to catch up at a later more convenient time if they would like to.

*Funding and input*

The campaign is completely voluntary with no current funding. The input in terms of time required from the organisers was high level to support first time hosts. However, the benefits far outweighed the limitations and are discussed below.
Benefits

Reach

The #WhyWeDoResearch campaign has demonstrated global impact and engagement. The hashtag has had over 400 million impressions to date. An ‘impression’ on Twitter measures the total number of times a tweet has been viewed or acted upon.

More than 45,000 individual social media accounts have participated in the campaign and these span 23 countries. The 2017 Tweetfest reached over 50 million impressions in two weeks. Each Tweetchat, both patient and staff led, throughout the 2017 Tweetfest achieved over one million impressions within their dedicated chat hour (statistics were kindly supported through @wegizmos). This demonstrates huge impact and engagement, thus highlighting the reach and power that positive social media use can have on research.

Feedback from 2017 Tweetfest hosts

Hosts provided feedback about their experience of leading Tweetchats via a survey monkey questionnaire. Of the hosts that replied eighty percent had participated in a Tweetchat prior to Tweetfest and fifty per cent had hosted a Tweetchat prior to the event; therefore, twenty per cent of people had neither participated or hosted before. Qualitative data collected from staff and patient hosts demonstrates the clear impact of the campaign (examples are provided in Figure 5).
Figure 5 – Qualitative feedback collected from Tweetchat hosts.

A. Qualitative feedback from staff chat hosts

1. “Increasing skills and knowledge of using social media (SoMe) as a professional tool”.
2. “Increased awareness of research within our organisation”.
3. “A great way to connect with other professions, and especially wonderful to be able to speak directly with patient followers at the same time”.
4. “The numbers involved was staggering and it made me truly feel part of a community”.
5. “We have had more people asking about research at our site as a result of this experience”.
6. “The volume of followers meant pressure to respond however I have been able to take that learning in to my clinical role”.
7. “Our site recruited to one of our studies within one of the chats”.

B. Qualitative feedback from patient chat hosts

1. “Realising that the staff are human and this campaign is more of a community where things really are on a level playing field for open discussion was wonderful.”
2. “Patients are really valued in this campaign, it’s the only of its kind to be so welcoming and open, count me in for next year.”
3. “It was daunting hosting a tweetchat for the first time but we were supported in the development and during the chat; we learnt technical skills as well as organisational skills and understanding of how much work this takes behind the scenes”.
4. “I’ve joined three studies since getting involved in tweetfest as I found out about them whilst engaging in the chats”.
5. “We found out about research courses that are open to us as patients as well as to the staff, four of us joined, completed them and thoroughly enjoyed it”.
6. “I’ve told my family about the campaign; people share opportunities to participate in research using the hashtag and every now and again we fill the criteria so sign ourselves up”.
7. “Hectic but brilliant, so wonderful to have co-hosts and feel supported”, “the organisers and everyone involved really care for patients and our voices, that’s the essence of the whole thing”.
8. “We found some patient followers had their own agendas however as patient hosts we were able to confirm that the chat was a general conversation; this made a big difference as their defences were instantly down and they contributed beautifully”.
Networking

All hosts fed back that their communities (personal and professional) had increased as a direct result of participating in the Tweetfest. Feedback from staff included an increase in patients asking about research opportunities in the months following Tweetfest. There were multiple reports of collaboration in research studies or sharing of studies already open at sites to enable more opportunities for patients to join in various areas across the globe. International discussions meant that assumptions or different working practices were challenged in a professional way, and learning ensued from this.

Patient hosts reported either an increase in their own followers or increases in communication with others with the same disease / research interest. All reported a consequent and immediate positive increase in their personal support networks and some enrolled as ambassadors for charities in specific disease areas as a result of their experience in the #WhyWeDoResearch campaign.

Conclusion

Social media has become a valuable platform for sharing voices and engaging healthcare staff and patients in research, though it should not be used as a stand-alone tool. There are many aspects to the #WhyWeDoResearch campaign and community and in this paper, we have chosen to highlight the benefits of #WhyWeDoResearch Tweetchats in generating open discussion between patients, public and staff.
Patients are experts in their own right and engaging and informing them in research was the primary motivation for establishing the campaign, not forgetting that at various times in life, we are all patients.

The #WhyWeDoResearch campaign provides an example of how social media has been used effectively and positively as a tool to engage the public, patients and healthcare staff in research.

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