

Social Media, Research and NHS Campaigning, and Ethics

As a distraction from my usual EoL/MCA/CPR stuff, I've recently been pondering something that I stumbled across on Twitter – Sarah Russell [@learnhospice](#) and Bridget Johnston [@BridgetJohnst](#) had tweeted about the use of social media for academic research (it would be end-of-life research, in all probability). This set me thinking, about how social media could be used for health research, and as a tool by those of us who are trying to get the NHS to change its behaviour (Kate Masters [@katemasters67](#) Kate Allatt [@KateAllatt](#) Lindsey Briggs [@LindseyBriggs](#) Celia Kitzinger [@KitzingerCelia](#) Jenny Kitzinger [@JennyKitzinger](#) John Clarke [@C7RKY](#) etc, and also people who are perhaps not 'campaigning' but who do object to some NHS behaviour, such as Mike Ashworth [@MikeAlphaOne](#)), and also about the 'ethical issues involved'. Wasim Ahmed [@was3210](#) has joined the Twitter discussion about social media and ethics.

Before I get into that, I will point out that I will be concentrating on Twitter, and that I only joined Twitter about a year ago at the suggestion of Mark Taubert [@DrMarkTaubert](#).

What I am thinking of, as 'social media'.

For the first few years of my own 'involvement', I tended to interact by means of e-mails in the main. I learnt – because after a while you find yourself re-typing the same stuff – to publish material online: in places such as the Dignity in Care discussion forum, or as responses to pieces published on BMJ or Marie Curie.

I discount e-mails from 'social media' - they are 'private'. And I separate other 'platforms' according to the questions 'can everyone see what is published without paying' and 'can readers easily publish responses to what they can read'. The BMJ has a mixture of subscription and free-to-access articles, although all responses are open-access, whatever the status of the original article. Anybody can read and download material on/from the Dignity in Care website, but to post articles and comments, you need to join the group (joining is free and simple).

Put at its simplest, the things I think of as social media are a mixture of 'notice boards' and 'discussion boards', with the added complication of some pay-walls, and some 'groups' which are 'exclusive'.

A diversion into my own thoughts about Twitter.

David Oliver [@mancunianmedic](#) recently described the uses of Twitter, in a short tweet: good for finding new contacts and trawling for expert opinion, good at sometimes drawing your attention to things you had not previously

thought about, and good for 'overall positions' but not great for 'explaining detailed argument' is probably what David and I both think.

After I'd joined Twitter, I noticed people on Twitter who I had already exchanged e-mails with (Hugh Constant @HughConstant1 Glyn Elwyn @glynelwyn Rowan Harwood @RowanHarwood Lucy Series @TheSmallPlaces Juliet Spiller @JASpiller Catherine Calderwood @CathCalderwood1 and others) and I found new and interesting people from Twitter (Elin Roddy @elinlowri Linda Dykes @mmbangor Trisha Elliott @Trisha_the_doc Ken Spearpoint @K_G_Spearpoint Jules Cavalier @Jules_Cavalier Gordon Caldwell @doctorcaldwell and many more).

I also notice that Twitter isn't - despite it being a 'rather chaotic jumble' - a 'chaotic and jumbled presentation of 'everything on Twitter': instead, it shows me 'a chaotic and jumbled presentation of **a part of** Twitter'.

Research and Ethics.

It is obvious that Twitter, because of the breadth of its membership, has enormous potential for research and campaigning. But, I pose two questions:

- 1) If Twitter is to be used for academic health research, can the 'traditional' ethical principles be applied;
- 2) Must 'lay NHS campaigners' also consider 'ethics'.

Bridget and Sarah pointed to a few papers about the ethical considerations of research via social media. One investigated the use of social media as 'a recruiting board' for participants in more-traditional subsequent research projects: issues such as 'the 'net knows what you have clicked on' and the implications of that, were explored. Another was about the use of existing tweets in research - about 'using what you can see on Twitter' for research.

But personally, I am more interested in 'Twitter discussions of posted questions' - asking for opinions about an issue.

In 'traditional' health research, papers are published after a research project, with the patients' identities being hidden, and with quite a lot of 'editing' of what participants actually said - and 'ethical approval' is obtained at the project design stage. If you ask a question on Twitter, you get to see - and 'the world gets to see' - who is answering, and the unedited answer. And you do not control who answers - in a 'traditional research project' steps would be taken to try and avoid recruiting participants whose mental health might suffer if they participated: how could you do that, if 'asking the question on Twitter and analysing the responses' was the nature of the research project?

I recently stumbled on a 'furious Twitter attack' on David Oliver - he had tweeted, to it appeared to me two other doctors, the 'gripe' that there exists a group of people, who persistently attack any doctor identified as working in

end-of-life or palliative care with the accusation that they are 'murderers and 'death doctors'' (my phrasing - you get the gist). David used the word 'trolled' and he was being 'lynched' on Twitter - and while tweeting 'you are a troll' to someone you know has got mental health issues is clearly something doctors and nurses should not do, David was discussing something which doctors are naturally annoyed by, in a tweet to other doctors. Out of interest - at least to me - I had not until recently, realised how aggressively this 'palliative equals murder' belief is being pushed: it is Twitter which has made me aware.

So, if the ethics of research on Twitter which involves asking questions are complicated by the question of 'will the participants be damaged by participating', what are the problems of 'passively-trawling Twitter'?

I think - the ethical danger of 'drawing false conclusions' is one. Linda Dykes recently tweeted about the need for 'a DNACPR' if you want to have a peaceful natural death, but if you were simply collecting tweets containing 'DNACPR' you would totally miss the complexity of the problem: Linda, Celia Kitzinger and I moved into a discussion of the difference between a 'DNACPR' and an ADRT refusing CPR, the law and how on-the-ground-behaviour doesn't seem to correctly reflect our law, and whether we should be telling patients 'in reality you actually need to do this ..' or whether we should be telling healthcare professionals 'you can't carry on doing what you are doing - your behaviour isn't what the law requires'. To add further complexity, while Celia, Linda and I understood what we were discussing, it isn't at all clear to me that most readers of that Twitter thread would have understood it.

My own Campaigning; my 'ethical worries'; and that National Conversation about Dying and Death.

Moving on to 'lay campaigners and ethics', I will now write 'for myself'. And, more widely than just 'social media'.

I once - early during my 'campaigning career' - sent an e-mail to a nurse who had published a review of various papers pertaining to end-of-life: the nurse had quoted from many of the papers ['Jones says 'whatever'''] but she had done so entirely uncritically. I sent her an e-mail, with my usual type of comment [I know Jones says 'whatever' but clearly Jones is wrong because ...]. She wasn't expecting such an e-mail - she said something like 'If I'd known I would get e-mails like that one, I wouldn't have published!'.

Bridget and Sarah both agree with me - 'Totally acceptable to email a published author' from Bridget - that it is okay to send comments to anyone who publishes. But - **I had made an incorrect assumption**. I had assumed, that the nurse who had written the review article, 'was an end-of-life expert' - it turned out (and once I became aware of my mistake, and apologised, we 'got on fine') that she has written the paper at the suggestion of her Masters supervisor. I think, she was one of many experienced nurses who had not entered nursing with a first degree, and who at the time (ca 2010/11) were studying for masters degrees. And although she knew much more about end-of-life nursing than I did (not difficult - as I know very little about that), it wasn't

'the nursing' I was picking-apart in my comments about those papers. I was upset, that I had 'upset her' - so I try to not repeat that mistake.

I **do not** have similar qualms, about pointing out their mistakes 'to people who really should know better' - if you are claiming to be publishing 'as an authority' then you should be 'up for robust debate'. In reality, it is often impossible to get 'experts' to engage in 'robust public debate'. I found it so frustrating that the ReSPECT 'team' refused to discuss various issues, that I resorted to sending an e-mail to the two people at the top of ReSPECT and promptly publishing it as a BMJ rapid response: that was very close 'in academic terms' to brawling, but it did provoke a reply from ReSPECT. I think it might have also annoyed ReSPECT - **but I am unapologetic**, because 'discussing ReSPECT **should be** a part of that 'National Conversation about Dying and Death'' which the Neuberger Review called for. In fact, you cannot get ReSPECT to debate the correctness of its 'positions' - you usually 'get pointed at ReSPECTs FAQs' [and - yes - 'I'm using 'you' for 'I' there].

There are conversations about 'dying and death' - 'action day events' on the topic, etc. But the discussions are in my experience 'partial': you can talk about 'bereavement', you can talk about 'care during dying', you can talk about 'planning', etc. But if you are at such a 'dying and death' event, and you ask end-of-life nurses who are present about the legal rules for decision-making during end-of-life - in other words, if you ask them what their understanding of the Mental Capacity Act is, and how do they gather their understanding of the law - then in my experience 'they will probably not be happy'.

The 'ethics' of asking nurses about their legal understanding, is interesting. Loosely:

'Is it legitimate to want to know what front-line nurses believe the MCA says/means?' is a question to which the answer must be 'yes';

'How good an understanding of the MCA should front-line nurses possess?' is a question which involves understanding how well the MCA is taught, and how difficult it is to comprehend;

Is it 'ethical' to establish that a front-line nurse has been taught a flawed-understanding of the law by his employer/professor/guidance/protocols, to then explain why that understanding 'must clearly be flawed', and thereby to put the nurse 'in the position of knowing that if I agree with my 'boss' I'll be doing something legally dubious'? ***This one is 'ethically troublesome' - it isn't acceptable to not challenge legally-poor behaviour, we service users are often interacting with 'relatively-junior' HCPs, but is it fair to put relatively-junior HCPs 'between a rock and a hard place'?***

It surely doesn't take very long, before NHS Campaigners such as Kate Masters and myself, come to realise that we simply cannot influence directly all of the clinicians towards the bottom of the 'clinical pyramid': so, we need to persuade those, often very busy, senior doctors and nurses who teach and influence their less-senior colleagues. Which, of course, means that we need to engage with those senior clinicians.

My own preferred method of engagement, is by e-mail – so, I will now give a few tips on how to find the necessary e-mail address, focusing on what you can search for on the internet using a Search Engine:

First search for the person's name, and 'job title', with 'e-mail address' in your search question;

Search the 'staff profiles' at their organisation (hospital, employer, etc) and the person's e-mail address might be there;

Search for academic papers and similar, which the person has published (these will often contain their contact e-mail address);

Try asking the employer/organisation via contact forms/addresses 'could I please have an e-mail address for' the person;

Make an 'educated guess' at the person's e-mail address, by analogy with addresses for other people who are at the same organisation and which you have been able to find.

NOW - a closing 'ethical question'.

I have just argued, that laymen such as myself, need to engage with and influence senior nurses and doctors, if we are to successfully alter 'NHS behaviour'. I have also mentioned – at the time 'in passing' but with this ethical issue in mind – that those senior clinicians are typically very busy (and I'm not implying that other less-senior clinicians are not very busy also: I've already explained, that engaging with those less-senior clinicians is perhaps ethically dubious):

so, is it 'ethical' for me to have published that list of tips for how to find the e-mail addresses of senior clinicians?

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