Can online social medium forums offer an easier strategy to implement patient and public involvement?

Sirs,

Patient and Public Involvement (PPI) is an important component in research to promote active patient involvement as studies are planned, carried out and presented. This ensures that the research is important, applicable and beneficial to patients and that studies are conducted using methodology that is relevant to the patient (1). Clinical trials in the UK have experienced a surge in PPI activity as part of grant applications (1). PPI is usually conducted by meetings and interviews, but as this is often difficult to organise and time consuming, difficulties are met in recruiting and retaining volunteers (2). This is particularly the case in systemic sclerosis (SSc), a rare and complex immune-mediated disease, where patients are treated at specialist tertiary centres (3). To facilitate PPI in the planning and design of our randomised controlled trial looking at a new surgical technique in SSc patients, we utilised social media as an alternative platform for communication and obtaining data, to see if it provided an effective method as a PPI vehicle. We aimed to understand if a trial evaluating this new intervention was relevant from the patient's perspective.

The Mouth Handicap in Systemic Sclerosis (MHISS) questionnaire (Table I) was distributed online to establish from the patient's perspective the most important symptom a new intervention should improve and the most appropriate methodology to assess the symptom. The questionnaire was distributed by a patient through a closed dedicated Facebook group for SSc patients. Twenty patients completed the survey within seven days. Feedback was also collected specifically for the use of online forums compared to face-to-face meetings (Table I). This demonstrated preference for online platforms due to time and cost-savings. We found online platforms were common places by which patients research, discuss and share opinions on their disease, and was therefore a comfortable and familiar setting to give feedback. Patients felt more inclined to fill out the form because it was distributed by a patient, and felt no concerns regarding privacy or confidentiality. The researchers felt online forums were beneficial in allowing feedback to be mobilised to a greater diverse population of volunteers in a short space of time. Lastly, researchers felt they needed no additional training to use potential online social platforms than traditional techniques to interview patients for research purposes.

Table I. Online questionnaires included the Mouth Handicap in Systemic Sclerosis (MHISS) questionnaire where patients were asked to grade each question as 10 being the worst affected and 1 the least. Feedback was also collected regarding the use of online forums compared to face-to-face meetings.

Mouth Handicap in Systemic Sclerosis (MHISS)		
Q1	I have difficulties opening my mouth	0 1 2 3 4 5 6 7 8 9 10
Q2	I have to avoid certain drinks (sparkling, alcohol, acidic)	0 1 2 3 4 5 6 7 8 9 10
Q3	I have difficulties chewing	0 1 2 3 4 5 6 7 8 9 10
Q4	My dentist has difficulties taking care of my teeth	0 1 2 3 4 5 6 7 8 9 10
Q5	My dentition has become altered	0 1 2 3 4 5 6 7 8 9 10
Q6	My lips are retracted and/or my cheeks are sunken	0 1 2 3 4 5 6 7 8 9 10
Q7	My mouth is dry	0 1 2 3 4 5 6 7 8 9 10
Q8	My meals consist of what I can eat and not what I would like to eat	0 1 2 3 4 5 6 7 8 9 10
Q9	I have difficulties speaking clearly	0 1 2 3 4 5 6 7 8 9 10
Q10	I have trouble with the way my face looks	0 1 2 3 4 5 6 7 8 9 10
Questions to the Patient:		
Q1	Would you consider joining online forums to discuss research studies?	Yes No
Q2	Do you feel comfortable using online forums to discuss your symptoms?	Yes No
Q3	Would you prefer face to face meetings or online forums to discuss your symptoms?	Yes No
Q4	If you prefer online forums to face to face meetings can you explain why in your own words……..	
Q5	Do you have any concerns about privacy if the online forum is anonymised?	Yes No
Q6	Please explain why you think online forums would be useful or not useful in your own words……	
Questions to the Researcher:		
Q1	Would you consider online forums better at collecting data from patients with rare diseases than face to face meetings?	Yes No
Q2	Please explain why you think online forums would be useful or not useful in your own words……	

No specific guidelines exist on optimal tools to conduct PPI and it remains an evolving practice (2). Participation in social medium has increased over the last decade across all ages and professions, and has shown to provide well-being (4). Difficulties in finding 'the right PPI' volunteer due to time, travel and financial constraints can be potentially overcome with the use of social media forums to approach more volunteers (2, 5). However, drawbacks to using questionnaires via online forum include not being able to discuss topics outside the closed range of questions (6). Alternatively, interviews would allow volunteers to lead the communication (6). A range of PPI models may overcome such difficulties (6). The main limitation of using social media platforms is the fear of breaching patient privacy (4). With appropriate training and education, researchers can use this online platform to enhance their research impact (4).

In conclusion, online social medium forums allow for patients to interact with research in way that is accessible, familiar and cost effective. Social media allows researchers to complete PPI in a time effective manner with minimal training. Integrating online platforms and PPI forums can offer an effective technique to allow good quality PPI to support and further clinical research, particularly in the context of rare diseases such as SSc. Use of social media platforms allowed effective PPI in informing the planning and design process of our randomised controlled trial.

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