

# Twitter: a viable medium for daily pain diaries in chronic orofacial pain?

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## IN BRIEF

- Demonstrates that Twitter has the potential to serve as a research platform for recruiting participants for studies.
- Highlights the potential of Twitter as an electronic location for pain diaries.
- Shows that data gathered from Twitter is easily extracted in a usable format.
- Suggests that it may be useful for researchers to explore a diverse selection of advertising locations for online studies.

**Objective** The aim of this study was to find out if Twitter could be used in a research context as a ubiquitous piece of software to record daily pain. **Design** This study was a feasibility study conducted electronically. **Setting** Our research was conducted on Twitter in 2014. **Subjects and methods** Participants were recruited via electronic advertising and consented electronically to participate. At three time-points on two non-sequential days participants were asked to record pain, mood and impact ratings on a numerical scale (0–10). Data were extracted manually. **Results** Thirty-five individuals consented to participate. Of the 24 participants providing data, 16 provided enough data to be analysed. The majority of participants were female. The mean age was 44.9 ( $\pm$  0.78) years and the most common diagnosis for participants was Trigeminal Neuralgia. Participants lived in the UK, USA, Canada and New Zealand. An increase in mean pain was reported over consecutive time periods on both days while mood and impact patterns varied between days. **Conclusion** Our study highlighted that participants can be recruited solely via social media and has ascertained the ease in which data can be collected without technical expertise. To achieve greater participation, differing advertisement strategies should be explored.

## INTRODUCTION

Orofacial pain (OFP) is an umbrella term that describes a variety of painful disorders affecting the face and mouth. OFP can be unilateral or bilateral and is relatively common.<sup>1</sup> OFP sufferers can experience a range of symptoms from mild pain and dysfunction that can resolve over time, to chronic (persisting) pain where the impact on a patient can be debilitating and affect their quality of life.<sup>2</sup>

Pain diaries are frequently used with chronic pain conditions and serve among other things to help record the chronology, intensity and impact of the pain experienced. Pain diaries can have both a diagnostic purpose, through helping clinicians and patients characterise the pain and its exacerbating factors, and a therapeutic purpose, helping guide decisions around the efficacy of trialled therapy.<sup>3,4</sup>

Increasingly, patients are moving away from paper diaries to electronic diaries due

to their ease of use.<sup>5</sup> In a research setting there is currently no standardised electronic format for chronic OFP (COFP) pain diaries meaning that they often have to be run on study-specific soft- and/or hard-ware. This may increase both the cost of research and the likelihood of lack of adherence as patients may forget to take hardware with them when they go out, thereby resulting in missing data. A universally available service, which could function effectively as a pain diary, would therefore potentially be extremely valuable to the research community.

The rapid rise of social media has provided a virtual location for patients to share information and discuss health conditions. Twitter is a freely available service in which, upon signing up, users are able to post and view messages ('tweets') of up to 140 characters in length. Users are able to 'follow' the accounts of individuals and organisations who are signed up and thus able to view other's 'tweets'. One recent phenomenon is the use of Twitter to share experiences of pain, including dental pain and migraine.<sup>6,7</sup> Examples of 'tweets' discussing COFP can also be seen within communities of people with a particular diagnosis, for example searching twitter for posts containing 'tmj' or 'temporomandibularjointdisorder' elicits examples of people with temporomandibular disorders sharing information about their condition.

Twitter has 645,750,000 registered users worldwide.<sup>8</sup> Twitter's availability and wide use has made this medium an increasingly attractive research method both in terms of gathering data<sup>9</sup> or using it as an existing source of data with which to answer existing research questions.<sup>10</sup>

Alongside emerging opportunities, the changing landscape of internet use has raised ethical questions with new issues concerning anonymity within a public forum or ensuring informed consent. While this is an evolving field there are some published guidelines available to research teams using social media for data collection for example, the British Psychological Society's (BPS) Ethical Guidelines for Internet-mediated Research<sup>11</sup> or the Association of Internet Research's (AoIR) ethical guidelines.<sup>12</sup> While these documents are by no means prescriptive, they assist researchers in considering the application of traditional ethical principles to online research.

The aims of this feasibility study were to find out if Twitter could be used in a research context as a ubiquitous piece of software to record daily pain. We wanted to find out if Twitter was a viable medium by examining:

- If data could be inputted and retrieved easily
- If awareness of the study could be raised to recruit participants via electronic advertisement only.

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**Table 1** Table to show the demographic of participants both providing data and those that did not provide data. Demographics for both data sets are similar

	Number of Participants	Mean age (years)	Females (%)	Employed (%)	Diagnoses reported	Percentage of diagnoses reported (%)	Countries involved
Participants providing data	24	45.5	92.0	70.8	Temporomandibular disorder Atypical facial pain Trigeminal neuralgia Atypical neuralgia Migraine Hemicrania continua Post-implant pain	7.4 11.1 66.7 3.7 3.7 3.7 3.7	UK USA Canada New Zealand
Participants not providing data	11	44.4	81.8	63.6	Atypical facial pain Trigeminal neuralgia	27.3 72.7	UK USA

## METHODS

We constructed our methodology with consideration of both AoIR and BPS publications.<sup>11,12</sup> Our protocol was reviewed and approved by Newcastle University's Ethics Committee.

### Phase 1 – participant recruitment

A Twitter account (@PAINDiarystudy) was created and this was advertised via regular 'tweets' to 20 Twitter-based COFP organisations (list available from authors upon request). In addition, the Facial Pain Advocacy Agency (FPA) and the Temporomandibular Joint Association (TMJA) were contacted and agreed to 'tweet' about the study to their followers on our behalf. The study was also advertised and hosted on the homepage of another COFP study (the DEEP study).

Those interested in participating were directed to the study homepage to read an electronic Patient Information Sheet (PIS) and if they wished to participate they were directed to an individualised, protected, entry portal to complete a secure electronic consent form.

As part of the consent process, participants were required to register a Twitter account name (handle) and provide sociodemographic information against this handle. Participants were advised to create a new, anonymised, handle to use in the study in order to help preserve their anonymity, although if they wished they could continue to use their existing handle. The following sociodemographic information was collected:

- Chosen Twitter handle for the study
- Age
- Gender
- Occupation
- Country
- Diagnosis.

Participants were then asked to 'follow' the study's twitter account as the contents of the study's Twitter account were locked so that only followers of the account could view other participant's 'tweets'.

### Phase 2 – active data collection and data analysis

Participants were asked to 'tweet' at three set local times (8 am, 12 pm and 10 pm) on a Wednesday and a Saturday regarding their pain. Reminder 'tweets' were sent to participants at two weeks, one week and one day before the specified study dates. These were sent directly to participants as well as generic reminders on the account. Within their pain diary 'tweet' (excluding the account name) participants were required to grade their pain, mood and impact on their day on a numerical rating scale of 0–10; 0 being the best value and 10 being the worst. Due to the 140 characters limit, participants were required to enter the initial of these descriptors: pain = P, mood = M and impact = I, followed by the relevant numerical rating. Participants were also given the option to provide a brief qualitative statement with the remaining characters of what they doing at that time and how they are feeling.

Each 'tweet' was required to follow the format:

@PAINDiarystudy.Pxx,Mxx,Ixx.  
Qualitative statement.

Data was collected for analysis by accessing the study's Twitter account archive which stores 'tweets' and copying these archives into a protected Microsoft Excel (version 14) document. This was done for data provided over both study days for all participants.

Data was coded by assigning a study number to each participant once entered into the excel document to anonymise the data. Inclusion criteria were defined as the provision of at least one-third of data inputted for each of the three entry points on both study days.

The data obtained from the 'tweets' received were analysed using simple descriptive statistics. Drop-out and completion rates were also examined, as were the singular data handler's (CP) perceptions on: logistics of the recruitment process; ease of data extraction from 'tweets'; and communication with participants.

## RESULTS

Our feasibility study recruited a heterogeneous group of people with a range of COFP diagnoses. Initially 81 individuals expressed interested in participating in the study; either by following our Twitter account (n = 62) or sending us an email asking about the study (n = 19).

Of the 81 individuals expressing interest, 35 gave consent to participate in the study. Of those 35 consenting to participate, 24 provided data on one or both study days and 11 participants did not provide any data (Table 1). Table 1 demonstrates that the demographic is similar for those providing data and for those who did not provide data. Both groups have a high proportion of female participants and the mean age is also similar at approximately 45 years old. Furthermore the most common disorder reported by all participants was Trigeminal Neuralgia.

Of the 24 participants providing data, 16 participants provided enough data to be analysed in the study (at least one-third of data provided for each time point). The patterns of pain, mood and impact of these participants are demonstrated in Figures 1–3.

A general increase in mean pain was reported over the three time periods on both study days (Fig. 1). There is a greater increase in mean pain on Saturday compared to Wednesday. Mood ratings (Fig. 2) on the first study day are very similar over the three time-points compared to the second day where there is an increase from morning to lunch. Impact ratings (Fig. 3) show an increase on Wednesday over the course of the three time-points compared to Saturday, where there is a decrease between morning and lunch; impact ratings increase following this.

## DISCUSSION

Our study is novel in that we tested the viability of using Twitter as a research platform by actively recruiting participants suffering from COFP. Due to the low number of participants completing the study we do not

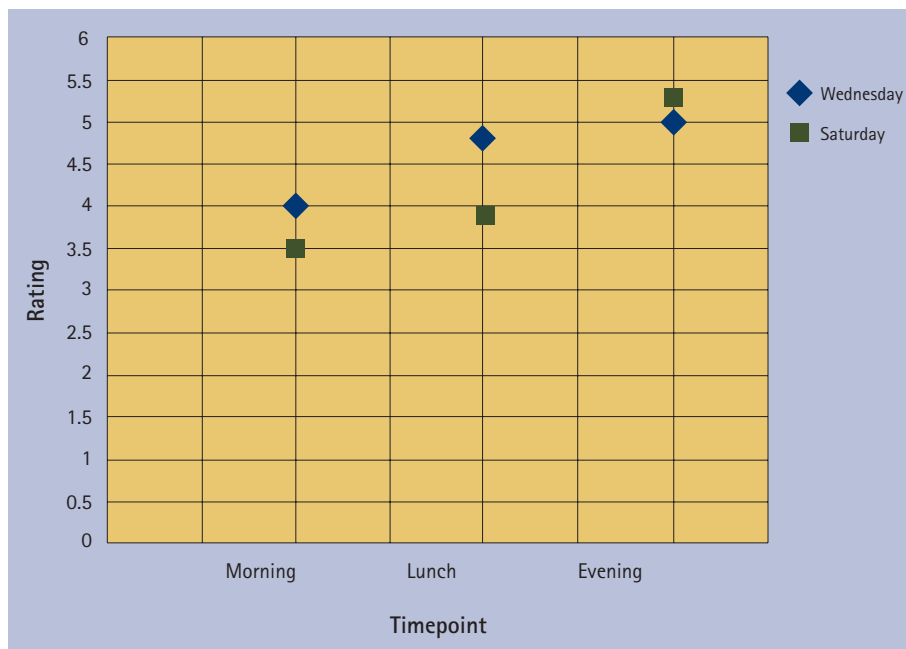


Fig. 1 Comparison of mean pain ratings between both study days across three time points

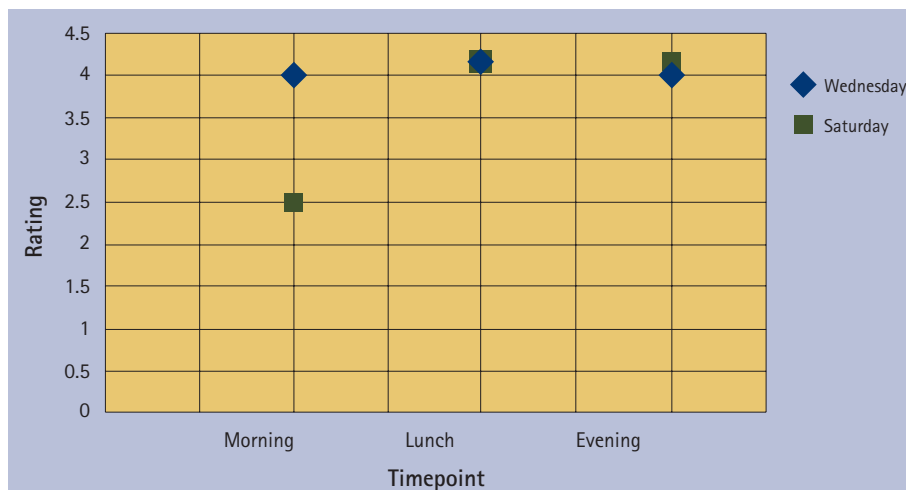


Fig. 2 Comparison of mean mood ratings between both study days across three time points

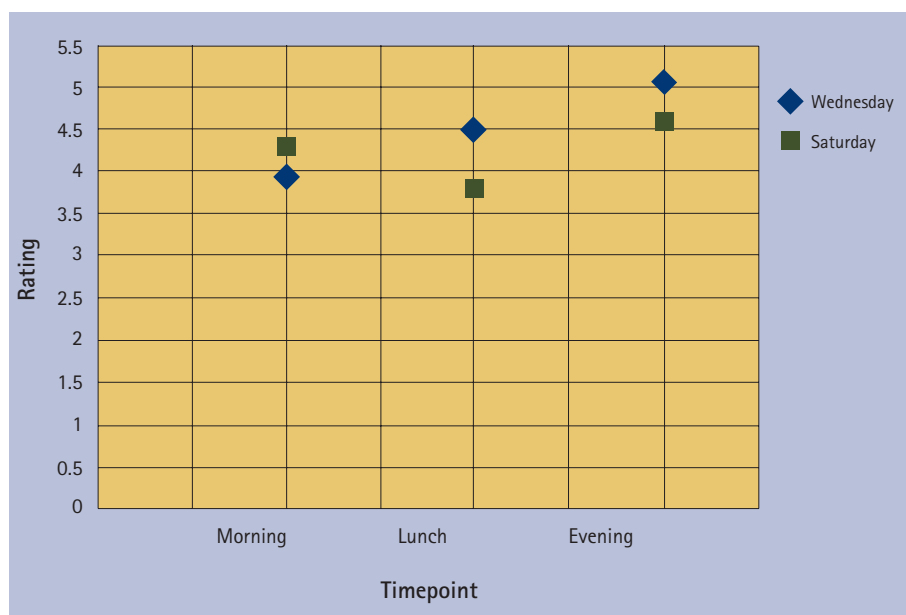


Fig. 3 Comparison of mean impact ratings between both study days across three time points

have a large enough sample size to employ inferential statistics on the data collected. However, in line with our primary aim, we have been able to test the viability of using Twitter as a platform for research.

During this feasibility study we faced several challenges. One of our objectives was to advertise our study via the internet alone to determine the feasibility of this. We originally advertised via Newcastle University's DEEP website as this is visited by COFP sufferers. The disadvantage to this was that a proportion of visitors to this website may have already been enrolled in the DEEP study and therefore may not have wished to participate in another study. We also advertised via Twitter itself by 'tweeting' about our study to various COFP Twitter groups, encouraging their follower base to register an interest in our study. The TMJA and FPA were also involved in advertising our study, and although their combined follower base is over 3,500, it is not possible to know how engaged the individuals who 'follow' them are with the social media site. In contrast, the study's Twitter handle achieved a modest following which highlights the value of study promotion in collaboration with organisations with existing followers. Our Twitter study was only advertised for five weeks before the study start date which may have had a negative effect on recruitment, although it could also be argued that a longer recruitment period could result in the increased likelihood of people forgetting about the study.

It was difficult to ensure that participant interest in the study was maintained, and attempting to do so involved monitoring and updating of our Twitter account multiple times daily which was labour intensive. We posted generic reminders to our followers ensuring we were reminding them of our study dates and including statements about the general purpose of our study. This had limited success as compared to 81 people originally showing an interest in the study only 16 (20%) people provided enough sufficient data for the study.

A recently published online survey of 182 cancer survivors which used both on- and off-line locations for advertising describes promotion of the survey on over 35 online locations in addition to using social media.<sup>13</sup> This highlights that it may be necessary to advertise in a large number of locations to achieve a reasonable sample size compared to our study where our electronic advertising was limited.

This feasibility study highlighted the ease at which data can be extracted from Twitter and thereby, possibly, from other social media sites. We simply copied data

provided by participants directly from Twitter and pasted this into a coded, secure Excel document. As Twitter is a 'public' forum, all 'tweets' are publicly available and therefore freely accessible as demonstrated by a similar Twitter study that did not actively recruit participants.<sup>9</sup> Although there are various software which claim to be able to extract data from social media, this study demonstrates that there is not a direct need for specific, specialised programmes to anonymise or analyse data.

Data gathered solely from the internet can attract criticism for obtaining non-probability-based samples and underrepresentation of specific groups without internet access.<sup>14</sup> In addition, while social media continues to be used globally, historically some countries have restricted the use of specific sites including Twitter. These issues notwithstanding, as internet access continues to widen it is likely that this method may become more representative. Our study's sample was a relatively young, predominately female sample with a high proportion of those suffering from Trigeminal Neuralgia. This may reflect the group of Twitter users exposed to the study advert.

While a considerable advantage of Twitter is its large and near-global user-base, a range of social media platforms exist and different sites with differing formats may

offer researchers different opportunities and challenges.

## CONCLUSION

To our knowledge, this is one of the first studies to use Twitter to actively recruit patients and gather primary data about pain in the form of a diary. Our study was successful in highlighting that participants can be recruited solely via social media however to achieve greater participation the time between beginning to advertise the study to the start date of the study and increased advertising should be explored. It may be the case that an extremely large potential readership is required in order to achieve a modest sample size. Most importantly, this study has ascertained the ease in which data can be inputted and extracted from a freely available social media site without requiring any technical expertise in Twitter.

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## COMMENTARY

Twitter, love it or hate it, one has to accept that social networking is here to stay and it is an active form of communication for many people. However, can such mediums be used in a research context? The authors of this article have set out to answer this question. Participants were recruited and consented by digital advertising. They were then asked to provide a pain diary and once again this was all completed electronically. It reminds me of the rock band Queen, whose early sleeve notes stated 'no Synthesisers were used', so I guess the phrase 'no paper was used in this study' could be applied.

Tweeting is seen as shouting in social networking parlance whilst Facebook would be regarded as a quieter conversation with friends. The authors were able to lock the account so that only followers could view other participants' 'tweets'. This provided

privacy, allowing the researchers and participants the freedom to participate in the study without the world interfering. Twitter was not designed primarily for research and so the constraint of 140 characters in a 'tweet' was overcome by abbreviations and some clever methods of conveying the information.

The demographics revealed a high proportion of female participants and the mean age was 45, revealing the type of population this research reached. The study did show the viability of using Twitter as a research platform; however, the recruitment of participants was low and maintaining interest in the study proved difficult. If these weaknesses can be overcome then there is much potential in the medium. The authors mention the possibility of using other social media sites in a similar manner to how Twitter was used in this study to recruit more participants.

It is a novel approach and shows that such social media platforms have many advantages. The main reason why it is an important contribution to the literature is that the researchers have shown how easy such a study can be set up. The data can be quickly captured and accessed. All this can be done without the need of technical expertise in Twitter. So, if you have enjoyed the paper then access the twitter account @PAINDiarystudy.

And summarising the final work in not more than 140 characters ready for tweeting:

@Paindiarystudy #advertise #recruit #participants #Input #Extract #data #easily @Twitter #publish @The\_BDJ #research @NewcastleSoDs

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