

# Social Media and Online Survey: Tools for Knowledge Management in Health Research

MARK MEROLLI, FERNANDO JOSE MARTIN SANCHEZ, KATHLEEN GRAY

Health and Biomedical Informatics Centre  
The University of Melbourne  
Level 1/202 Berkeley St, Parkville, Victoria 3010

mmerolli@student.unimelb.edu.au

## Abstract

**Intro:** This paper outlines the design, dissemination and recruitment of participants into a global online survey examining perceptions regarding the value of social media for chronic pain self-management. Building on literature supporting the use of online survey in health research design, we outline the step-by-step process involved in creating this survey and also discuss how use of social media as a distribution channel may significantly impact participant recruitment. **Methods:** We designed the online survey using Survey Monkey. After the initial survey design phase we consulted a survey expert and statistician to refine the instrument before obtaining ethics and piloting the survey. Recruitment consisted of both traditional online dissemination (i.e. emails and website posting), as well as a more active approach utilizing various social media. **Results:** 231 people with chronic pain took the survey. After applying exclusion criteria we were left with  $N = 218$  responses for analysis. Demographics and social media platform use are presented, as well as a detailed look at the survey recruitment process, contrasting traditional online recruitment with that using social media. **Conclusion:** Online surveys are a valuable study method for health research. They build on the foundations of traditional survey method but harness the power of the Internet to conduct research. Concurrently, social media provide a novel distribution channel for survey recruitment and their potential application in health research is worthy of further consideration.

*Keywords:* Online Survey, Social Media, Information-Communication Technology (ICT), Study Recruitment, Therapeutic Affordances, Chronic Disease

---

Copyright © 2014, Australian Computer Society, Inc. This paper appeared at the Australasian Workshop on Health Informatics and Knowledge Management (HIKM 2014), Auckland, New Zealand. Conferences in Research and Practice in Information Technology (CRPIT), Vol. 153. J. Warren and K. Gray, Eds. Reproduction for academic, not-for profit purposes permitted provided this text is included.

## 1 Introduction

We recently conducted a global online survey to obtain a more detailed understanding of how social media may influence health outcomes in chronic pain self-management and also, to garner individual perceptions regarding social media's underlying therapeutic value. The survey built upon findings from literature review we conducted that was published elsewhere, investigating the health outcomes and related effects of social media use in chronic disease (Merolli, Gray, Martin-Sanchez 2013). In this same review, we were able to qualitatively identify and categorise various perceived therapeutic affordances of social media that may underpin their value to chronic disease self-management. We have labelled these: Identity, flexibility, structure, narration and adaptation. Perceived affordance theory dictates that the user perceives the potential for action of how an object may be used, thus predicting and influencing how the ensuing interaction proceeds. In more recent years, information systems researchers have begun to see the potential application affordance theory may have to the study of human-computer interaction (HCI). Research continues to be published investigating how perceived affordance may be a valid model informing information and communication technology (ICT) design (Sutcliffe, Gonzalez & Binder et al. 2011, Anderson 2011, Zhao, Liu & Tang et al. 2013).

The survey presented in this paper aims to refine our understanding of therapeutic affordances so that we may look to clinically test their influence on improving health outcomes in chronic disease self-management. Studying chronic pain, this paper outlines the online survey instrument design, piloting and recruitment process, while also presenting a case for the power of social media for study recruitment purposes in health research.

### 1.1 Online survey in health research

Online surveys are relatively common for the study of Internet usage in healthcare. Examples already exist of studies employing online survey to examine Internet and social media usage patterns in chronic disease management (van Uden-Kraan, Drossaert & Taal et al. 2009, Corcoran, Haigh & Seabrook et al. 2010, Bartlett & Coulson 2011). Online survey has many advantages. Some of which include: the ability to be selective of participants, the ability to allow public access and participation, they allow participants to remain anonymous and they are convenient for the research team

in allowing responses to be stored in a readily accessible database (Eysenbach & Wyatt 2002, Daley, McDermott, McCormack Brown et al. 2003). Eysenbach and Wyatt (2002) report that many studies have been published supporting the validity and reliability of online survey by contrasting and correlating results to traditional offline approaches.

Surveying participants allows for sufficient comparison of observations to be conducted in health research. In the case of the present research, it allows for identification of trends in social media usage (i.e. how social media usage may change health outcomes). It also allows correlation to be made investigating certain relationships (such as, analysis of whether effects/outcomes are linked to the therapeutic affordances of social media) (Saks & Allsop 2007).

However, whilst online surveying may help demonstrate a link between social media, its therapeutic affordances, and health outcomes, it does not in itself provide enough evidence to insinuate a relationship. For a survey to be successful in providing meaningful descriptive data it is crucial the right questions are formulated and scrutinized. In some ways, the researcher should have a good idea of the answers to expect before beginning (Gable 1994).

We take this opportunity to outline a novel research method for online survey design in health research and describe how the use of social media can influence the participant recruitment process.

## 2 Methods

Given that no matching survey design exists that has been validated in chronic disease management, our survey presents a novel approach and design. However, design components were based on best available evidence and attempted to build on the foundations of other online surveys within this domain. The survey serves two main purposes. Firstly, to refine our understanding and examine the presence of the aforementioned therapeutic affordances and their value to health intervention design and secondly, examine their potential to underpin improved health outcomes clinically via online interventions in future research.

### 2.1 The Instrument

The survey was developed and hosted on survey platform, 'Survey Monkey' (Survey Monkey is an open-access survey creation and hosting platform). It consisted of a self-administered online survey of 240 questions, obtaining participant demographics, their chronic pain and disease relevant information, current health symptom status, social media use, perceptions towards the value of various therapeutic affordances and reported effects/outcomes from social media use. There are other open-source survey platforms available to choose from and one is not limited to Survey Monkey. Another popular platform considered was 'Lime Survey'. It enables many of the same survey functionalities and processes as Survey Monkey, such as complex question logic, in-built analysis capability and the ability to

produce visuals of survey results. Both possessed appropriate functionalities to meet the complexities of our survey design, clean and user-friendly interfaces, charts/graphs, and also ability to export data to programs such as SPSS statistics software for more formal analysis. Ultimately, Survey Monkey was chosen due to the previous experiences of the study authors and comfort with the platform. This may differ for other researchers.

### 2.2 Survey Design

The online survey (available on request from the corresponding author) is broken down into four major areas (demographics, chronic pain/disease information, patient-reported health status, social media use/therapeutic affordances perception and outcomes from use). Given the complex nature of the survey and a desire to minimize survey fatigue, we used various question logic and skip options enabled by Survey Monkey to guide respondents through the survey and only elicit necessary information. We used Likert rating scales ranging from "strongly agree" to "disagree" and "not at all" to "very often" as per previous validated survey models (WHO 2002, Cella, Riley & Stone et al. 2010, Fox 2010, Fox 2011).

When ethics approval was sought, we made it clear that the survey aimed to obtain anonymous data pertaining to social media use for chronic pain management to better protect participant's privacy. In order to respect the participant's right to participate free of coercion we also made it explicitly clear that participation was voluntary, the survey did not offer medical advice, nor did it insinuate a medical relationship between patient and researcher. Before final ethics clearance was given, we were asked by the Human Research Ethics Office to avoid use of the term 'affordance' in the study title as not to confuse participants and also to copyedit the Plain Language Statement (PLS) to suit online viewing.

Before opening the survey, we sought consultation with a survey design expert and statistical consultant from the Statistical Consulting Centre (SCC) at the University of Melbourne to better understand the intricacies of survey design. Over three meetings discussions centred on sample size and statistical power, survey length, question style, eliminating bias and finally recruitment methods. Major technical and design issues to come out of these meetings included: consistency of statement/question structure, using the same number of statements for each platform, statistical power calculations, taking care to avoid use of double negatives as well as leading statements and finally, employing question skip logic to decrease survey fatigue.

Addressing survey fatigue was paramount. Our statistical consultant commented that 15-20 mins was appropriate survey length. However, he noted that on average survey participants lose focus the further they move into a survey, thus, suggested that we place the social media platforms of most interest to our research earlier in the survey. We were more interested in investigating social media platforms compared to earlier social technologies as contrasted and discussed in Merolli

et al. (2013), therefore platforms such as social network sites (SNS), blogs and wikis were placed earlier in the survey as opposed to discussion forums and chat rooms.

Statistical power and dissemination were another major focus of these meetings. Social media use to improve health outcomes in chronic disease management is still a relatively uncharted area. Previous research and informed research designs are still in their infancy. For this reason, calculating desired sample size was problematic. We referred to other online surveys created within a similar research context and there has been no specific validated sample size in any of these studies surveying social media usage in a chronic disease setting. Study methods employed varied considerably and nor was there any mention of how these studies justified their own sample sizes (Chung & Kim 2008, van Uden-Kraan et al. 2008, van Uden-Kraan et al. 2009, Bartlett & Coulson 2011, Setoyama, Yamazaki & Namayama 2011, Klemm 2012, Mo & Coulson 2012). Sample sizes ranged from N = 32 in van Uden-Kraan et al. (2008), through to N = 528 in van Uden-Kraan et al. (2009). The mean of all studies being N = 255. For the above reasons, we aimed to achieve a final sample around this range, aiming for 200-250 responses. Finally, we were warned of the inherently poor response rates to surveys. Although online surveys allow for a greater potential reach and spread of responses, data collection methods would require substantial consideration to achieve power.

## 2.3 Survey Piloting

Between our second and final meeting with a survey and statistics consultant, we planned a pilot of the survey in order to address any usability and design issues. Once ethics clearance was received we sought input from both social media using patients and technology experts from the Department of Computing and Information Systems at the University of Melbourne. Piloting was conducted to assess survey design and whether the quantity and quality of questions/statements was satisfactory. Usability was assessed inline with the adapted work of Bevan (2009), who discussed definitions of usability in information communication technology (ICT) design and postulated a framework for its measurement in information technology applications. The assessment of usability surrounds measurement of: Attractiveness & aesthetics, suitability & appropriateness of functions, ease of use & user interface design, learnability, technical issues and safety & security of design. We had a total of five patients, and three computing and information system's staff pilot the survey. A questionnaire was embedded into the end of the beta version of the survey (a summary of questions is available on request from the corresponding author).

### 2.3.1 The Survey Domains

a) *Participant Demographics (Q. 1-8)*. The first survey domain asked participants general demographic questions (e.g. gender, age, education, employment, etc.) and were adapted from the World Health Organization's 'World Health Survey' (WHO 2002).

b) *Chronic Pain/Disease Information (Q. 9-13)*. The second domain of the survey asked about current chronic pain/disease status. Examples were: "Do you suffer from chronic pain (pain over 3 months duration)?" and "Have you been formally diagnosed with a chronic disease that has led to your pain?" and "If 'yes', what is the condition?", etc.

c) *Health Status (Q. 14-30)*. We used items from the "pain interference" item bank of the Patient Reported Outcome Measurement Information System (PROMIS) to measure Health-Related Quality of Life (HQRL) (described in Amtmann, Cook & Jensen et al. 2010). We also included one "pain behaviour" item that measured pain severity via a visual analogue rating scale. This is common amongst chronic pain studies for the measurement of pain intensity (Dworkin, Turk & Farrar et al. 2005). Selecting a Validated Patient-Reported Outcome (PRO) Measurement Tool was a crucial requisite. PROMIS - Pain Interference (PROMIS-PI) was chosen to overcome consistency issues with pre-existing pain outcome measures. Common legacy measures can be unyielding, requiring respondents to complete every item even when items provide little to no extra useful information about pain interference (Amtmann et al. 2010). PROMIS provides 'item-banks' to measure outcomes of interest. Using an 'item response theory (IRT)' model, direct comparison of scores can be made even when different items are selected, thus allowing for better across-time and different sample comparisons (Cella et al. 2010). However, perhaps most significant, allows for the development of comparable and flexible short-forms specific to a target population or study (Amtmann, et al. 2010, Gershon 2012, Witter 2012). Custom short forms can be developed for specific purposes and/or samples (Amtmann et al. 2010). We selected items from the PROMIS-PI to represent all major sub domains of pain interference: Cognitive affect, sleep, recreation/leisure activities, social life, activities of daily living (ADLs), psychosocial health and physical health.

d) *Social Media Use by Chronic Pain Sufferers (Q. 31-240)*. Given the survey's focus on understanding social media use for health self-management, this was the most comprehensive, time and labour intensive section of the survey. Participants were asked what social media they had used as part of chronic pain self-management (e.g. "In the last year, have you used Social Network Sites when you go online for information, communication or interaction about your chronic pain?"). We also asked about frequency of use, the features of the platform they used and self-reported effect use has had on their condition. The remaining questions pertained to the therapeutic affordances of social media that we put forward. Each affordance consisted of three statements designed to observe the strength and degree to which the platform in question perpetuated that affordance and nurtured changes in health status. All social media related questions were the same across all platforms to ensure reliability and consistency. As previously eluded to, given the ambiguous nature of affordances outside of academic discourse, statements designed to measure the value of therapeutic affordances were phrased in such a way as not to confuse or bias participants and therefore made no

mention of the word ‘affordance’, instead using tags such as ‘value’ and ‘prefer’.

## 2.4 Recruitment/Data Collection

A Google search was performed periodically from March 1<sup>st</sup> through to May 20<sup>th</sup>, 2013 to identify potential distribution channels. Search was limited to groups and organisations in the English language, with chronic disease or chronic pain the focus. We targeted large online health networks due to their high user bases (e.g. Patients Like Me, Daily Strength), smaller online pain support communities and global chronic disease and pain organizations (e.g. Chronic Pain Australia, Pain Research Forum UK, American Cancer Society, etc.). In addition we later searched common health online social networks and targeted active chronic pain related groups on Facebook and Twitter. Recruitment was augmented by contacting various other influencers in the field, as well as posting to active social media in health research groups on LinkedIn.

When we emailed each organization or group moderator it was made clear that our survey focussed on “pain interference” as a result of living with the condition his or her group supported (e.g. arthritis, diabetes, fibromyalgia, cancer, etc.). Formal invitation emails were sent to moderators requesting they pass study details onto members to participate in the survey. A recruitment video was also created on ‘Animoto’ to describing the study and the link was pasted into the email text (Merolli 2013). We did not offer financial incentive to participate. However, we did offer to provide preliminary survey results in appreciation of support. This is advocated by Eysenbach and Wyatt (2002), who explain that despite contributing to selection bias, is less likely to seriously skew results compared to cash incentives. The PLS and informed consent pages were embedded into the survey. By doing this, moderators were able to view the suitability of the survey to their members before agreeing to support the work. We asked that if organizations/moderators were willing to disseminate the survey amongst members and/or clinical and research colleagues, they post the survey on their websites and/or to social media accounts where appropriate. The survey was open until July 1<sup>st</sup>, 2013. If participants wished to participate, the survey link led them to the PLS, which outlined inclusion/exclusion criteria (age of eighteen years or over, have chronic pain and have used social media as part of chronic pain self-management). This in turn led to the informed consent page, which then made the actual survey available once participants clicked to agree to terms.

## 3 Results

We collected data for N = 231 individuals, of which N = 4 did not complete the mandatory first question regarding

living with chronic pain. Therefore, N = 227 people answered. N = 9 did not meet eligibility, selecting “no” to suffering chronic pain (automatic survey logic excluded these people), leaving a total of N = 218. Summary statistics for demographics of survey participants can be seen (see Table 1). Participants were predominately female. Age range varied but the biggest representation was aged forty to forty-nine. Many were married and at least high school educated. However, a large number were not working for pay due to ill health. Most indicated that they had been diagnosed with a chronic disease leading to their pain (most reported condition was fibromyalgia). Social media platforms used in self-management are listed (see Figure 1). SNS were the stand out, followed by discussion forums and blogs.

The results of this survey also highlight the wide reaching potential of the Internet to disseminate an online survey. The global spread of our results was testament to the power of the Internet to recruit from around the globe and give a truly diverse data set (see Figure 2). We were not surprised to see that the majority of respondents came from Australia given the survey’s origins (N = 128). However, we also received a respectable number of responses from the United States (N = 41) and United Kingdom (N = 23). Followed by Spain (N = 8), Canada (N = 5) and New Zealand (N = 4). Small numbers of responses (i.e. 1-2) also filtered through from Ireland, South Africa, China, Kenya, Pakistan, Burma and Taiwan.

	% of Responses
<b>Gender</b>	
Male	16
Female	84
<b>Age Range</b>	
18-29	17
30-39	22
40-49	31
50-59	21
60+	9
<b>Marital Status</b>	
Never Married	22
Currently Married/Partnered	59
Separated/Divorced/Widowed	19
<b>Level of Education</b>	
High School or Less	33
College/University Completed	42
Post-Graduate Degree Completed	25
<b>If Not Working For Pay (Reason?)</b>	
Ill Health	76
Other	24

**Table 1: Participant Demographics**

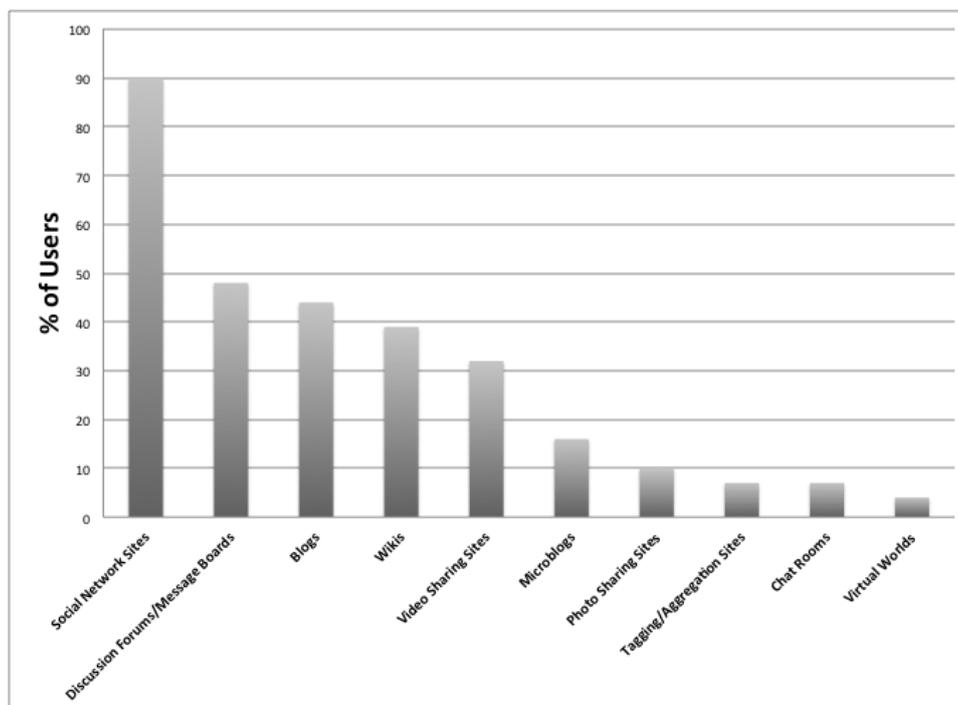


Figure 1: Social Media Platforms Used by Participants

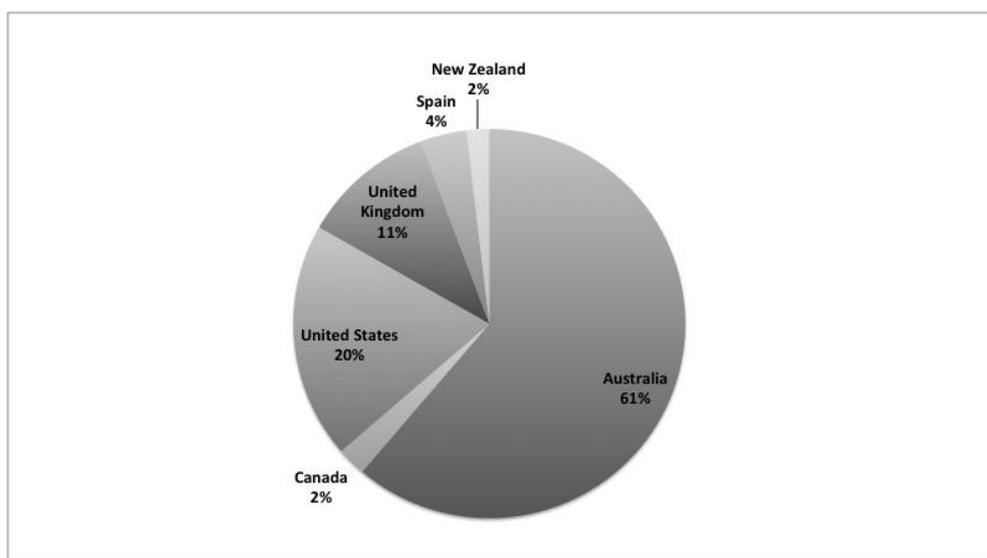


Figure 2: Global Spread of Survey Responses

### 3.1 Examining Modes of Dissemination

The survey was opened on May 24<sup>th</sup>. At this time emails were sent to various chronic disease and pain organizations asking for support to disseminate the survey to group members. We posted a recruitment blog via our departmental website (HaBIC 2013), posted the study to our Facebook page and Twitter account, as well as to Scoop.it. Figure 3 represents the progress of survey responses collected over time. From what can be seen in the figure, response to our survey was initially quite slow. We calculated that in the first week of recruitment, we received only N = 29 responses. Week 1-2 represent a

focus on more traditional means of online recruitment whereby no active sharing of the study was taking place. For example, we posted the study to organisations/moderators, posted it to our blog and posted to our Facebook page. All of which give initial limited visibility but fail to a) hone in on our target audience (patients) and, b) generate interest enough to share the survey. From the beginning of week 2 through to early week 3 we saw a steady increase in the number of weekly responses, more than doubling and peaking at N = 72. At this time we were able to observe several factors that we believe contributed to the increased response rate: a) the survey started to appear on various chronic disease/pain

website news feeds, Facebook pages and Twitter accounts and, b) we altered our recruitment effort by contacting online support groups on Facebook directly, rather than continuing to rely heavily on email and, c) we began to receive emails, notifications and tweets from people who had shared the survey via their own social networks and other platforms. Further progress from week 3 through to week 5 (to when the survey closed on July 1<sup>st</sup>) showed a

steady stream of responses to continue to come in with week 4 bringing N = 54 responses, before one final peak of N = 66 just before close. In the final week of recruitment, we made one last attempt to recruit participants by posting to social media in healthcare special groups on LinkedIn.

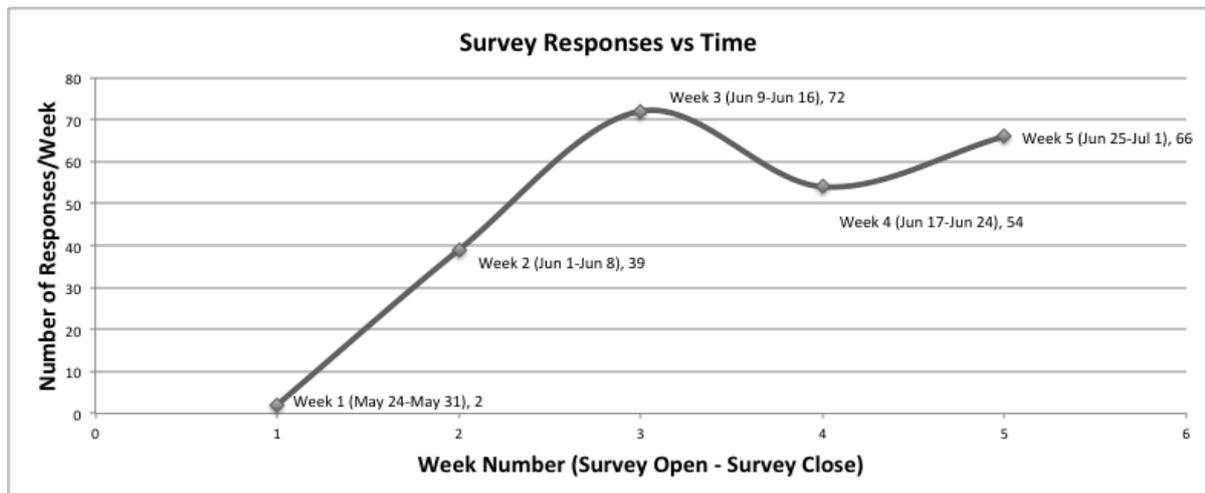


Figure 3: Survey Responses vs. Time

## 4 Discussion

### 4.1 Considerations For Conducting Online Surveys in Health Research

Eysenbach and Wyatt (2002) provide instances where online survey may be highly suitable in health research. For instance, when target participants are already enthusiastic Internet users (as was the case in our own inclusion criteria) and when a global spread of responses is desired (see Figure 2). Online survey is also advocated in survey design to keep costs down and also when the survey is complex in nature, requiring branching and question logic to guide respondents through (Daley et al. 2003). This same complexity was present in the present survey and as previously discussed supports our choice to use Survey Monkey. Eysenbach and Wyatt (2002) also state that the power of online survey is recognised when large amounts of data need to be collected and analysed in a timely fashion. This is particularly relevant to our study, with N = 231 responses to 240 questions. We were able to feed results directly into statistics software, SPSS.

However, Eysenbach and Wyatt (2002) highlight a few particularly salient precautions when considering the appropriateness of online surveys for health research. Online surveys are well recognised in qualitative research. However, for quantitative purposes researchers need to take into consideration potential bias that comes with the online survey method. Often the target group

(i.e. chronic disease sufferers) is underrepresented on the Internet, thus leading to selection bias (Eysenbach & Wyatt 2002, Daley et al. 2003). This fact has previously been described in chronic disease and Internet research published elsewhere (Fox 2010). Self-selection bias is also discussed, whereby participants are more likely to respond to a survey when the study area is of direct interest, potentially creating a skewed sample.

### 4.2 Opportunities For Social Media In Survey Recruitment

Results presented showing progress of our survey recruitment highlight two similar, yet contrasting modes of online participant recruitment. Week 1 of survey recruitment represents a traditional (Web 1.0) online recruitment style, where despite posting to a variety of media, visibility was inherently low with minimal spread or call for people to be actively involved (Close, Smaldone & Fennoy et al. 2013). This mode of recruitment included: Email, blog posts and the survey website itself on Survey Monkey. From week 2 and beyond, recruitment style shifted and relied much more heavily on the power of social media to generate activity and sharing, as well as active participation by the public in the recruitment process. Close et al. (2013) suggest that this is because along with greater numbers using social media comes increased visibility and potential for communication. We recognised a much more consistent inflow of survey responses at this point as the survey worked its way across the social web and essentially became part of the digital conversation, rather than laying

in waiting for people to stumble across it. We saw one such instance, where the survey was posted to the Facebook page of a chronic pain clinical research team. It was commented on, liked and shared by a handful of members to their own pages, some of which we then further shared by other people in extended networks. All this occurred over a matter of hours.

Close et al. (2013) introduce the term 'snowballing' to describe this type of study recruitment via social media, as we have described above. This highlights the spread of study information across online social networks, thus increasing reach, visibility and ultimately participant numbers. Furthermore, Close et al. also suggests that increased visibility across multiple social media augments traditional online recruitment advertisements. In our case, advertising of the survey on our departmental website, the survey website itself and the emails that were sent, were augmented by blogging, Facebook, Twitter and LinkedIn efforts. This represents a layering of the recruitment message and ultimately has each medium supporting the other and, optimizes the likelihood that recruitment will be successful. Layering also has potential to improve trust between researchers, the research institution and potential participants. In providing multiple channels for exposure, our supporters and participants were given the opportunity to digest and ponder participation in our survey in more depth, creating sense of autonomy and ownership over their eventual participation.

On the other hand, Close et al. (2013) also indicate that care must be taken when using social media for study recruitment purposes because often the presence of clinical researchers may be a sensitive issue to online patient communities gathered around a specific disease. If online community members sense the call for research participation does not reflect the goals of the community, mistrust develops and forms a barrier to recruitment and participation. In order to avoid this and limit any potential negative affects on these patient communities we deliberately did not contact individual patients directly, nor did we unscrupulously and pervasively post recruitment messages in any communities without invitation. All study advertising on social accounts that were not our own was done by the disease organisations' own staff or group moderators.

Finally, results from Fenner, Garland & Moore et al. (2012) show strong predictors of participation in online studies are dictated by various participant demographics. These include: Older age, being female, a higher level of education and coming from a higher socioeconomic status group. We too have found similar demographic profiles of online health seeking people and this description of the more typical health seeking social media user has previously been reported (Fox 2010, Merolli et al 2013). Particular studies have focussed their efforts on the effect of various demographics on study participation, particularly as related to gender (Mo, Malik & Coulson 2009). Despite being beyond the scope of the present study, it is worthy to highlight the potential impact of gender on study recruitment and survey results. Although we were not able to verify the male/female membership ratio of the participating organisations,

results (see Table 1) indicate that females were the more active survey participants, thus creating a skew of survey findings to the female population. We are currently investigating whether gender played a role in the patient-reported health outcomes obtained in the survey, which we hope to present at a later date. However, we do believe that the present study is reasonably representative of the current online health seeking landscape as described in Mo et al. (2009). Mo et al. present inconsistencies among reports of gender difference in online health communication but one suggestion is that regardless of gender, online patient communities may encourage a greater number of individuals to participate in health self-management with less stigma attached. However, salient to our study, when gender is considered females appear to be more likely to seek health information online and be active participants health research.

Finally, in a similar fashion to Eysenbach and Wyatt's (2002) description of online survey, Close et al. (2013) report that a pivotal limitation of online recruitment in general is the bias negatively effecting socioeconomically disadvantaged groups and culturally diverse minorities with lack of Internet access. This again raises the question of access, whereby those who may have the most to benefit from social media may be under-represented in studies.

## 5 Conclusion

This study has highlighted the potential for application of online survey in health research and presents several design considerations. It has also depicted a case that outlines and endorses the possible value of social media to study recruitment. Results, while partly anecdotal, suggest that the wide reach of social media for communication may be ideal for study recruitment. This needs further investigation and may provide a means to deal with the inherent poor response rate that surveys suffer from. Further research is warranted.

## 6 References

- Amtmann, D., K. F. Cook, M. P. Jensen, W. H. Chen, S. Choi, D. Revicki, D. Cella, N. Rothrock, F. Keefe, L. Callahan and J. S. Lai. (2010): 'Development of a PROMIS item bank to measure pain interference'. *Pain* 150(1): 173-182.
- Anderson, C. (2011): 'Health Information Systems Affordances: How the Materiality of Information Technology Enables and Constrains the Work Practices of Clinicians', *Computer Information Systems Dissertations*, Georgia State University, USA. PhD thesis: 141.
- Bartlett, Y. K. and N. S. Coulson. (2011): 'An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication', *Patient Educ Couns* 83(1): 113-119.
- Bevan, N. (2009): Extending Quality in Use to Provide a Framework for Usability Measurement, *Human Centered*

- Design*. M. Kurosu, Springer Berlin Heidelberg 5619: 13-22.
- Cella, D., W. Riley, A. Stone, N. Rothrock, B. Reeve, S. Yount, D. Amtmann, R. Bode, D. Buysse, S. Choi, K. Cook, R. DeVellis, D. DeWalt, J. F. Fries, R. Gershon, E. A. Hahn, J.-S. Lai, P. Pilkonis, D. Revicki, M. Rose, K. Weinfurt and R. Hays. (2010): 'The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008', *Journal of clinical epidemiology* 63(11): 1179-1194.
- Chung, D. S. and S. Kim. (2008): 'Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes', *Journal of the American Society for Information Science & Technology* 59(2): 297-306.
- Close, S., A. Smaldone, I. Fennoy, N. Reame and M. Grey. (2013): 'Using information technology and social networking for recruitment of research participants: experience from an exploratory study of pediatric Klinefelter syndrome', *J Med Internet Res* 15(3): e48.
- Corcoran, T. B., F. Haigh, A. Seabrook and S. A. Schug. (2010): 'A survey of patients' use of the internet for chronic pain-related information', *Pain Med* 11(4): 512-517.
- Daley, E. M., R. J. McDermott, K. R. McCormack Brown and M. J. Kittleson. (2003): 'Conducting web-based survey research: a lesson in internet designs', *Am J Health Behav* 27(2): 116-124.
- Dworkin, R. H., D. C. Turk, J. T. Farrar, J. A. Haythornthwaite, M. P. Jensen, N. P. Katz, R. D. Kerns, G. Stucki, R. R. Allen, N. Bellamy, D. B. Carr, J. Chandler, P. Cowan, R. Dionne, B. S. Galer, S. Hertz, A. R. Jadad, L. D. Kramer, D. C. Manning, S. Martin, C. G. McCormick, M. P. McDermott, P. McGrath, S. Quessy, B. A. Rappaport, W. Robbins, J. P. Robinson, M. Rothman, M. A. Royal, L. Simon, J. W. Stauffer, W. Stein, J. Tollett, J. Wernicke and J. Witter. (2005): 'Core outcome measures for chronic pain clinical trials: IMMPACT recommendations', *Pain* 113(1-2): 9-19.
- Eysenbach, G. and J. Wyatt. (2002): 'Using the Internet for surveys and health research', *J Med Internet Res* 4(2): E13.
- Fenner, Y., S. M. Garland, E. E. Moore, Y. Jayasinghe, A. Fletcher, S. N. Tabrizi, B. Gunasekaran and J. D. Wark. (2012): 'Web-based recruiting for health research using a social networking site: an exploratory study', *J Med Internet Res* 14(1): e20.
- Fox, S. (2010): 'Chronic Disease and the Internet', *Pew Internet & American Life Project*. Washington D.C., Pew Research Centre: 35.
- Fox, S. (2011): 'The Social Life of Health Information', *Pew Internet & American Life Project*. Washington D.C., Pew Research Centre
- Gable, G.G. (1994): 'Integrating case study and survey research methods: an example in information systems', *European Journal of Information Systems* 3(2): 112-126.
- Gershon, R. (2012): 'PROMIS and CTS', *National Institutes of Health*: 22. MD, USA.
- HaBIC. (2013): 'Social Media use for Chronic Pain Management: An Online Survey', <http://hbiru.wordpress.com/2013/05/24/social-media-use-for-chronic-pain-management-an-online-survey/>. Retrieved May 23<sup>rd</sup>, 2013
- Klemm, P. (2012): 'Effects of online support group format (moderated vs peer-led) on depressive symptoms and extent of participation in women with breast cancer', *Comput Inform Nurs* 30(1): 9-18.
- Merolli, M. (2013). 'An analysis of social media use by people with chronic pain', <http://animoto.com/play/EY5Vh6FUHKmeZrqLAIUNQ Q>. Retrieved May 17<sup>th</sup>, 2013
- Merolli, M., K. Gray and F. Martin-Sanchez. (2013): 'Health Outcomes and Related Effects of Using Social Media in Chronic Disease Management: A Literature Review and Analysis of Affordances', *Journal of Biomedical Informatics* (in press).
- Mo, P. K. H. and N. S. Coulson. (2012): 'Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS', *Psychology & Health* 27(4): 445-459.
- Mo, P. K. H., Malik, S. H. and N. S. Coulson. (2009): 'Gender differences in computer-mediated communication: A systematic literature review of online health-related support groups', *Patient Educ Couns* 75(1): 16-24
- Saks, M. and J. Allsop (2007). 'Quantitative Survey Methods in Health Research'. In *Researching Health: Qualitative, Quantitative and Mixed Methods*. 174-196. SAGE, Los Angeles.
- Setoyama, Y., Y. Yamazaki and K. Namayama (2011). 'Benefits of Peer Support in Online Japanese Breast Cancer Communities: Differences Between Lurkers and Posters.' *J Med Internet Res* 13(4).
- Sutcliffe, A. G., V. Gonzalez, J. Binder and G. Nevarez. (2011): 'Social Mediating Technologies: Social Affordances and Functionalities', *International Journal of Human-Computer Interaction* 27(11): 1037-1065.
- van Uden-Kraan, C. F., C. H. Drossaert, E. Taal, E. R. Seydel and M. A. van de Laar. (2009): 'Participation in online patient support groups endorses patients' empowerment', *Patient Educ Couns* 74(1): 61-69.
- van Uden-Kraan, C. F., C. H. Drossaert, E. Taal, B. R. Shaw, E. R. Seydel and M. A. van de Laar. (2008): 'Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia' *Qual Health Res* 18(3): 405-417.
- van Uden-Kraan, C. F., C. H. Drossaert, E. Taal, W. M. Smit, H. J. Moens, S. Siesling, E. R. Seydel and M. A. van de Laar. (2009): 'Health-related Internet use by patients with somatic diseases: frequency of use and characteristics of users', *Inform Health Soc Care* 34(1): 18-29.
- WHO. (2002): 'World Health Survey', *World Health Organization, Evidence and Information for Policy*.

<http://www.who.int/healthinfo/survey/instruments/en/index.html>. Geneva, Switzerland, World Health Organisation.

Retrieved March 5<sup>th</sup>, 2013.

Witter, J. (2012): 'NIH and PROMIS', *ACR 2012: Clinical Highlights*. National Institutes of Health: 56. MD, USA,

Zhao, Y., J. Liu, J. Tang and Q. Zhu. (2013): 'Conceptualizing perceived affordances in social media interaction design', *Aslib Proceedings: New Information Perspectives* 65(3): 289-303.