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Engaging Consumers with Musculoskeletal Conditions in Health Research: A User-Centred Perspective

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Abstract. Consumers are frequently involved in different kinds of health research, such as clinical trials, focus groups, and surveys. As pointed out by different studies, recruiting and involving consumers to participate in academic research can be challenging. While different research and guidelines are provided to instruct researchers to recruit participants ethically, they seldom consider the needs and expectations of consumers. In this research, we interviewed 23 consumers with musculoskeletal conditions in Australia, to understand their needs and motivations for participating in research from a user-centred perspective. Based on these data, we systematically summarise consumers' feedback into four main themes: (1) *Research as Learning Opportunity;* (2) *The Important Role of Communities and Health Professionals*; (3) *Research Transparency and Updates*; and (4) *Special Needs for People with MSK Conditions*. As a result, a few recommendations are proposed and researchers should further consider these when designing consumer-based studies. Ultimately, with a better understanding of consumers, we hope that our research can enhance consumer engagement and improve their participation in health research.

Keywords. Engagement, recruitment, consumer participation, musculoskeletal conditions, user-centred research

Introduction

Both consumer consultation and participation are crucial for all types of health research ranging from qualitative research, randomised controlled trials, and surveys among others. This is particularly true for musculoskeletal (MSK) research, which can cover a breadth of projects from developing new medications; studying the influences of MSK conditions on workplaces [1], or supporting young people's pain management with digital technologies [2]. Taking these studies as examples, many research projects now adopt research methods that heavily involve consumers. As such, consumers' participation is vital for the development of MSK research.

Recruiting participants for health research is a challenging task. When researchers conduct various investigations, a lot of effort is put into designing our research to

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collect data ethically and rigorously. However, have we considered the consumer perspective in this process? While we rely on enthusiastic volunteers to actively participate in research projects [3], we know little about what they actually look for, what they expect to gain, and what they are enthusiastic about when they explore opportunities to participate in research. In this study, we aim to investigate consumer needs and motivations to participate in academic research, so that we can adjust our research design to better fulfil their expectations. We anticipate that an improved understanding of consumers can eventually lead to a better experience and more effective recruitment for health research.

1. Related Work

Participants are a valuable component of health research [4], but their recruitment remains difficult at all times [3], [5]–[7]. Prior studies have proposed different strategies to recruit participants, such as setting up patient registers [8], [9], placing web-based advertisements [10], using social media (e.g. Facebook and Twitter) [5], [11]–[13], and adopting a dynamic consent approach [14]. Although such work is effective, it aims to increase recruitment channels rather than understanding the needs of consumers.

In addition, researchers have identified barriers that prevent different groups of people from taking part in health research. For instance, recruiting racial and ethnic minority with community networks [15], [16], understanding women's attitudes and awareness in recruitment [17], [18], and the use of technologies and social media for engaging younger cohorts [5], [11]–[13]. We anticipate that the above research can inform the recruitment methods of MSK research.

Getting the attention of potential participants relies on how people obtain information about research, and how they utilise such information. Information needs theory suggest that consumers use different approaches and channels to find relevant health information [19]–[21]. While taking part in research is not an urgent and mandatory matter for many consumers, we believe that people will have different approaches to finding and using information about academic research. This can be a starting point to understanding the underlying motivations of research participation.

2. Research Aims and Design

This study starts with the research question "What do MSK consumers need and expect to gain from participating in an academic research project?". As such, we aim to systematically investigate the motivations and decision-making process for taking part in research. The findings can help researchers to consider participants' needs in their research design, and improve the experience of being involved in academic research.

Additionally, this study looks at any special considerations required by people affected by MSK conditions, as their lives may be impacted by obstacles such as chronic pain, low mobility, losing concentration and/or an inability to work. As such, MSK consumers are likely to have different concerns than other patients.

We conducted semi-structured interviews to collect the views of consumers. The interview questions inquired about people's motivation and experience of participating in research projects, as well as their views and expectations of participating in future

MSK research (Table 1). Phone interviews were also arranged for people who could not come on-site because of time and mobility issues. The interview sessions were conducted with the presence of both the first and the second authors. All interviews were recorded and transcribed for data analysis.

Table 1. The list of interview questions.

Category	Questions
Demographic	Age / Gender / Remoteness / Work Status / Conditions
Motivation	• What makes you want to find out more about academic research? • Why is a research project of interest to you? • What do you expect to gain from participating a research project?
Getting the Information about Research	• Where do you get information about research? • How do you find the research that is relevant to you? • What websites/tools do you use to find research? • What are your search criteria?
Experience	• What is your overall experience about getting involved in a study? • What are the difficulties and challenges? • How do you think technologies can improve your participation?

In the data analysis stage, we used thematic analysis [22] to iteratively process the transcriptions. Such methodology involves reading transcripts, categorising codes into themes and refining the list of themes iteratively along the analysis. Meanwhile, the number of participants connected to each theme is tracked for verifying the generality of themes. The first author was responsible for the data analysis.

For this study, participants were recruited through a national consumer organisation, *MOVE muscle, bone & joint health*, which supports people with MSK conditions. Recruitment continued until we reached data saturation [23], [24]. Interviewees did not receive incentives for participating in the study. This study was approved by the human research ethics committee of the University of Melbourne.

3. Participants

We interviewed 23 participants in this study. Their average age was 51 (*SD*=15.7, range 15 to 72). Our sample included a diverse group of consumers with MSK conditions (Table 2). The majority of which were female; lived in metro areas, and were not working. About half our participants reported that they had taken part in academic research before. An overview of participants can be found in Table 2.

Table 2. The composition of the participants (N=23).

Gender		Remoteness		Work Status	
Male	5 (21.7%)	Metro	14 (60.9%)	No work	12 (52.2%)
Female	18 (78.3%)	Rural	9 (39.1%)	Part-time	5 (21.7%)
				Full-time	6 (26.1%)

4. Results

Four themes emerged from our interviews with MSK consumers: (1) Research as a Learning Opportunity; (2) The Important Role of Communities and Health Professionals; (3) Research Transparency and Updates, and (4) Special Needs for People with MSK Conditions. Selected quotes from the interviews are shown in italics with participant identifiers listed next to them.

4.1. Research as a Learning Opportunity

In addition, not every consumer has adequate health literacy and access to information sources to learn more about their issues, and researchers are often seen as the frontier of science for them. Participants were enthusiastic about taking part in research, and inquire about late-breaking remedies and treatments that may be available to them in the near future. They saw it as a learning opportunity to gain new knowledge and learn more about management and treatments options. Below are some representative quotes:

"For me it is the possibility of new information on effective treatments becoming available to me and I do a lot of my own looking around but – or just trying to keep on top of new developments I guess." (C4)

"Research is one of the things that people want to know about because it gives them a sense as a set of hope[s] that things might be different for them in the future." (C5)

4.2. The Important Role of Communities and Health Professionals

Many interviewees highlighted that they will not search for information about research projects, e.g. *"I probably don't go about looking for something until I hear about something"* (C1). Also suggested by participants, it is essential for someone to inform them about eligible studies, in where community groups and health professionals play an important role. A large portion of our participants described that they were introduced or referred to the research projects via support groups, rheumatologists, physiotherapists and general practitioners (GPs).

There is a trust factor involved in the role of communities and health professionals. Our participants were reluctant to participate in pharmaceutical and marketing research, and were concerned about finding genuine research from other channels (e.g. Google), e.g. "*I'd probably go by word of mouth and ask other people or other clinicians or something like that rather than just go randomly onto Google*" (C3). Participants were more confident about research referred to them by e-mail newsletters and Facebook pages of patient support groups which they found to be more relevant and reputable compared to other sources.

4.3. Research Transparency and Updates

Research participants demanded clearer information about the study and what was required of them. Particularly in light of their condition; as one participant said: *"[researchers need to] be explicit about what they expect from participants. Because, as I said, there's a lot of anxiety with a lot of people with chronic illness about how much they have to give to anything energy wise…"* (C5).

Consumers also wanted feedback regarding the progress of a study and the final results, e.g. *"[I want to be] fully informed about the research… and kept up to date with the project*" (C12). Some consumers that had participated in research had stated they were dissatisfied that they had not received any communication regarding the progress or final results of the research, e.g. "*In the end, I didn't ever get to hear any results back. I've got obviously, thanked for my participation, but it was disappointing that I never heard anything back*" (C21). Another interviewee who was a member of a patient support groups added: "*I think it's a really common thing and I think it's a big complaint of people*" (C3).

4.4. Special Needs for People with MSK Conditions

In our conversations with consumers, we found out that people with MSK conditions needed extra considerations for involving them into any studies. For example, many of them had low mobility, which limited their capacity to travel to researchers. This was particularly a problem for people living in rural areas, *e.g. "I've got to weigh up the time and the effort involved physically and how much pain it would cost me."* (C8)

The way in which people wanted to engage in research also differed with older people, preferring physical contact and the opportunity to build a social connection with the researchers. As pointed out by an interviewee: *"I think for some of the older – older people prefer to have a face to face conversation. They like to talk to people, they like that option of being able to have a chat."* (C4)

5. Discussion

The results of this study have revealed four themes that impact on the recruitment and participation of consumers in MSK research.

Although there are research ethics requirements (e.g. [25]) to specify how human participants should be informed about a study; it is often hard to verify whether the information adequately engages consumers to maximise recruitment. For example, how do we know whether a plain language statement is appropriate for consumers and adequately addresses the issue of health literacy of the intended participants. To address this, consumer organisations can play a role by connecting researchers with consumers so they can review recruitment material to ensure key messages are engaging and easy to understand.

The results highlight the importance of the communications between researchers and consumers, that is often neglected by researchers [14]. The interviews suggest that consumer participants do not often receive updates and final results from the researchers, which deviate from their expectations of learning new knowledge and reduce the research transparency. A brief message sent via email or SMS can greatly improve these problems. Sending regular updates about research projects not only provides information to consumers, but also keeps the social connection with consumers, shows their contribution useful, and makes them feel respected in the research process.

Consumers tend to have passive information-seeking behaviour in terms of looking for research information [21], [26]. Past studies have proposed that patient registers can effectively recruit participants [8], [9]. We believe that such registers can be further upgraded to one-stop research portals which can promote research studies; and provide recruitment opportunities, notifications and project updates to consumers. This can fulfil their needs of getting information and feedback at their convenience, and can eventually help them to acquire knowledge from the study. Projects advertised in these portals from reputable institutions or organisations can be spread around and can be shared in social networks thus addressing the issue of trust.

Finally, with the growing momentum of faster internet networks, researchers can consider using technologies to collect data. For example, mobile apps can be used to log user activities and could be an alternative to conducting diary studies; or skype can be used to explain the research to people in a more natural way. On the other hand, researchers can use infographics, visualisations and videos to convey the rationale, process and important facts of a study to consumers. All these approaches can make research easier to understand and to reach a broader group of people. Meanwhile, the use of technologies can enable MSK patients with above-mentioned special needs to participate and to engage in research.

6. Conclusion

Through a user-centred lens, we present four major types of needs that MSK consumers look for when they consider participating in academic research. These findings are consistent with the existing literature on recruiting participants for health research. Our findings lead to a better understanding of human participants and offer an opportunity to reflect on the design of health research. Moreover, we argue that the use of technologies can assist in addressing consumers' needs. For future work, we will continue to analyse the data and develop our findings to the broader domain of health research. Additionally, more research can be conducted for consumers in regional areas and the younger cohort of patients, as they might have different needs and expectations from research activities.

The limitations of this study include the generalisability of study participants, with more women and older people sampled. However, this can be partly explained by the fact that more women and older people suffer from MSK problems [27]. Additionally, the recruitment of this study was conducted with a single consumer organisation, which might affect the diversity of the sample.

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References

[1] J. Oakman, N. Kinsman, and A. M. Briggs, "Working with Persistent Pain: An Exploration of Strategies Utilised to Stay Productive at Work," *J. Occup. Rehabil.*, vol. 27, no. 1, pp. 4–14, 2017.

[2] H. Slater, J. E. Jordan, J. Chua, R. Schütze, J. D. Wark, and A. M. Briggs, "Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study," *BMJ Open*, vol. 6, no. 12, Dec. 2016.

[3] P. Bower *et al.*, "Improving recruitment to health research in primary care," *Fam. Pract.* , Jan. 2009.

[4] S. Polgar and S. A. Thomas, *Introduction to Research in the Health Sciences*, 5th ed. Philadelphia, PA: Churchill Livingstone Elsevier, 2008.

[5] Y. Fenner *et al.*, "Web-based recruiting for health research using a social networking site: an exploratory study.," *J. Med. Internet Res.*, vol. 14, no. 1, 2012.

[6] M. X. Patel, V. Doku, and L. Tennakoon, "Challenges in recruitment of research participants," *Adv. Psychiatr. Treat.*, vol. 9, no. 3, pp. 229–238, 2003.

[7] B. G. O. Sully, S. A. Julious, and J. Nicholl, "A reinvestigation of recruitment to randomised, controlled, multicenter trials: a review of trials funded by two UK funding agencies," *Trials*, vol. 14, no. 1, p. 166, 2013.

[8] L. C. Lovato, K. Hill, S. Hertert, D. B. Hunninghake, and J. L. Probstfield, "Recruitment for controlled clinical trials: Literature summary and annotated bibliography," *Control. Clin. Trials*, vol. 18, no. 4, pp. 328–352, Aug. 1997.

[9] J. Hewison and A. Haines, "Overcoming barriers to recruitment in health research," *BMJ Br. Med. J.*, vol. 333, no. 7562, pp. 300–302, Aug. 2006.

[10] J. S. Gordon, L. Akers, H. H. Severson, B. G. Danaher, and S. M. Boles, "Successful Participant Recruitment Strategies for an Online Smokeless Tobacco Cessation Program," *Nicotine Tob. Res.*, vol. 8, no. Suppl_1, p. S35, 2006.

[11] A. O'Connor, L. Jackson, L. Goldsmith, and H. Skirton, "Can I get a retweet please? Health research recruitment and the Twittersphere.," *J. Adv. Nurs.*, vol. 70, no. 3, pp. 599–609, Mar. 2014.

[12] S. Close, A. Smaldone, I. Fennoy, N. Reame, and M. Grey, "Using Information Technology and Social Networking for Recruitment of Research Participants: Experience From an Exploratory Study of Pediatric Klinefelter Syndrome," *J. Med. Internet Res.*, vol. 15, no. 3, p. e48, Mar. 2013.

[13] D. E. Ramo and J. J. Prochaska, "Broad Reach and Targeted Recruitment Using Facebook for an Online Survey of Young Adult Substance Use," *J. Med. Internet Res.*, vol. 14, no. 1, p. e28, Feb. 2012.

[14] J. Kaye, E. A. Whitley, D. Lund, M. Morrison, H. Teare, and K. Melham, "Dynamic consent: a patient interface for twenty-first century research networks," *Eur J Hum Genet*, vol. 23, no. 2, pp. 141–146, Feb. 2015.

[15] A. K. Yancey, A. N. Ortega, and S. K. Kumanyika, "Effective Recruitment and Retention of Minority Research Participants," *Annu. Rev. Public Heal.*, vol. 27, pp. 1–28, 2006.

[16] S. Couzos, T. Lea, R. Murray, and M. Culbong, "'We are Not Just Participants—We are in Charge': The NACCHO Ear Trial and the Process for Aboriginal Community-controlled Health Research," *Ethn. Health*, vol. 10, no. 2, pp. 91–111, May 2005.

[17] B. A. Brown, H. L. Long, N. Milliken, J. . Jackson, and M. . Moskowitz, "What's to know about study recruitment? We asked recruiters," *Women's Heal. Issues*, vol. 12, no. 3, pp. 116–121, May 2002.

[18] B. A. Brown, H. L. Long, H. Gould, T. Weitz, and N. Milliken, "A Conceptual Model for the Recruitment of Diverse Women into Research Studies," *J. Womens. Health Gend. Based. Med.*, vol. 9, no. 6, pp. 625–632, Jul. 2000.

[19] P. C.-I. Pang, S. Chang, K. Verspoor, and J. Pearce, "Designing Health Websites Based on Users' Online Information Seeking Behaviours: A Mixed-method Observational Study," *J. Med. Internet Res.*, vol. 18, no. 6, p. e145, 2016.

[20] K. Lee, K. Hoti, J. D. Hughes, and L. M. Emmerton, "Consumer Use of 'Dr Google': A Survey on Health Information-Seeking Behaviors and Navigational Needs," *J. Med. Internet Res.*, vol. 17, no. 12, p. e288, Dec. 2015.

[21] P. C.-I. Pang, S. Chang, J. Pearce, and K. Verspoor, "Online Health Information Seeking Behaviour: Understanding Different Search Approaches," in *Proceedings of the 18th Pacific Asia Conference on Information Systems (PACIS 2014)*, 2014.

[22] V. Braun and V. Clarke, "Using thematic analysis in psychology," *Qual. Res. Psychol.*, vol. 3, no. 2, pp. 77–101, 2006.

[23] P. I. Fusch and L. R. Ness, "Are we there yet? Data saturation in qualitative research," *Qual. Rep.*, vol. 20, no. 9, pp. 1408–1416, 2015.

[24] M. Mason, "Sample Size and Saturation in PhD Studies Using Qualitative Interviews," *Forum Qual. Soc. Res.*, vol. 11, no. 3, 2010.

[25] National Health and Medical Research Council, “National Statement on Ethical Conduct in Human Research,” 2015.
[26] P. C.-I. Pang, K. Verspoor, S. Chang, and J. Pearce, “Conceptualising health information seeking behaviours and exploratory search: result of a qualitative study,” *Health Technol. (Berl).*, vol. 5, no. 1, pp. 45–55, 2015.
[27] Arthritis and Osteoporosis Victoria, “A problem worth solving,” Elsternwick, VIC, Australia, 2013.