THE BRITISH
PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

Original Manuscript

British Journal of Pain
2023, Vol. 0(0) 1–8

DOI: 10.1177/20494637231208095
journals.sagepub.com/home/bjp
Sage

‘I felt part of the solution’. A qualitative study about the interface between lived experience advocates, professionals and organisations in the field of persistent pain

Cameron Hartley[1] **and Chris Penlington**[1]

Abstract

Objectives: To elicit perspectives of people with persistent pain about their experiences working with pain management professionals and services as patient advocates and to consider implications for current models of involving patients in service development and research.
Design: reflexive thematic analysis from a critical realist perspective.
Methods: Online interviews were conducted individually with 10 participants who had acted as patient advocates in the field of persistent pain. Participants were recruited through purposive and snowball sampling. Data were analysed and organised into themes and are presented descriptively.
Results: The relationship between patient advocates and the organisations they help is conceptualised as ‘an unequal partnership’. Participants described positive and affirming experiences with individual health professionals and research teams (Respect). This often occurred within a context of inflexible organisational policies that presented barriers to participation including a lack of financial compensation and expectation to work to inflexible deadlines. As a result, patient advocates could experience a lack of value attributed to their experiences and voices (unmet needs from institutions).
Conclusion: People with personal experience of engaging with services for persistent pain are in a strong position to contribute to service improvement. Although this contribution is recognised as valuable, it appears to be devalued by organisational barriers. Organisational policies around payment may lead to a lack of representation of those experiencing higher levels of disadvantage. As a result, services and policy makers may be missing out on insights that could be important for service development.

Keywords

Chronic pain, qualitative research, patient advocates, thematic analysis

Persistent pain is a challenging condition for both patients and clinical staff. People accessing healthcare for chronic pain often do not find this experience to be helpful or rewarding[1] and many feel that their primary care professionals lack adequate knowledge and training in chronic pain,[2] damaging their confidence in their doctor’s ability to treat their condition.

A survey of American primary care providers found that less than half felt adequately trained to treat chronic pain.[3] Medical schools in the UK have been reported to dedicate a median of 13 h of taught content on pain medicine over 5 years, with only 4% having a dedicated pain science module.[4] Education about pain is similarly lacking in other core health professions including physiotherapy, nursing and occupational therapy.[5] Psychologists and therapists similarly lack adequate training in persistent pain.[6] The benefit of a relatively

---

[1] Newcastle University, Newcastle, UK

Corresponding author:
Chris Penlington, Newcastle University, Framlington Place, Newcastle NE2 4BW, UK.
Email: chris.penlington@newcastle.ac.uk

brief training in self-management[7] indicates the extent to which education in supporting self-management is lacking in much health and social care training, despite being recommended by the NHS long-term plan in England.[8]

People with persistent pain who find that traditional healthcare provision does not meet their needs are likely to search elsewhere for answers. However, this search can be confusing. A range of websites exist which vary in the extent to which they foster self-management support. Social media support groups are a phenomenon which can easily fall under the radar due to their often private nature, yet they have exploded in popularity with the advent of social media. A thematic analysis of people who use these support groups[9] found that they provide information, the opportunity to impart knowledge, social connection and can operate as a form of 'therapy' for those who participate.

People who have direct experience of challenges caused by pain and its management may set out to help others who are going through a similar experience. This help may be offered through various internet or social media channels directly targeted to people who want to learn to manage their pain better. Alternatively it may be directed at service providers and researchers, aimed at helping them to understand and be responsive to the needs of people who live with pain. Often such input is motivated by a wish to share what has been helpful and to prevent others having to go through experiences similar to their own when initially grappling with persistent pain.[10]

Incorporation of a 'patient voice' in research and clinical planning is increasingly recognised as important. There is evidence to suggest that research priorities between professionals and patients often significantly differ, leading to a research agenda disconnected from the needs of the patient or consumer.[11] Inclusion of advocates in the development stage[12,13] has been shown to result in outcomes closer to the needs of the patient group in question. Alongside this positive change, it is important for researchers and institutions to avoid treating patient participation as simply a 'tick-box' exercise, and particularly that advocates feel that their knowledge base is respected and validated.[14] Recent UK guidelines[15] relating to public involvement in research focus on the importance of accessibility for the public, clarity and transparency on the role the public could play in the research and provide guidance on the issue of pay. Subsequent recent guidance released by the NIHR[16] recommends payment where possible for public research involvement as best practice.

Research into peer support workers has identified issues that may have relevance to the field of chronic pain patient advocacy. A qualitative study with peer outreach workers for people who use drugs[17] noted that meaningful inclusion and avoidance of tokenism provided useful skills, allowing a degree of CV building and improved quality of life. A lack of salaried roles available to peer support workers, with a lack of compensation while working alongside salaried support workers in this study, led to a perception that lived experience time and expertise were not valued. In a set of recommendations for supporting peer researchers based on experiences in community HIV/AIDS research in Canada, two key features raised were the degree of emotional labour inherent to this work and the weight of pushing for meaningful involvement.[18] In their recommendations, they also raise the somewhat contentious issue of financial compensation. Support in these environments can come from other advocates, with a strong sense of community being noted, and non-peer allies within organisations supporting and raising up advocates.[19] Such issues of emotional labour, meaningful participation and financial renumeration may be equally relevant in the field of persistent pain. There are no published studies to our knowledge that explore in detail the perspectives of chronic pain advocates themselves. This research therefore aims to explore the experiences of people who take on this role in relation to the staff and organisations they hope to influence and support.

Methods

This study was granted ethical approval by Newcastle University Faculty of Medical Science Ethics Committee. University ethics was appropriate for this research as participants were recruited through public forums and did not need to be NHS patients or to represent the views of NHS patients to take part. Potential participants were sent an information sheet with details of the study. Participants signed a consent form before taking part in the study and were given the option to withdraw their data within a month of interview. The lived experience advocate who took part in a pilot interview (see below) received a £25 voucher for their time, and all other participants were offered a £10 voucher.

Pilot Interview

A pilot interview was conducted with an experienced chronic pain patient advocate in order to agree and refine a suitable topic guide, with discussion centring around several key areas:

- The variety of contexts that advocacy can take place in.
- Challenges in achieving genuine co-production.
- Financial renumeration and how its introduction can increase diversity in advocacy.
- Managing advocacy work with chronic pain.
- The increasing formalisation of chronic pain advocacy.

Data from the pilot interview were used to inform the interview process and were not included in the results.

Participants

Inclusion criteria were adults over 18 who were currently or formerly active in chronic pain advocacy in a substantial way. This advocacy needed to be based on lived experience. Participants needed to be able to take part in an online interview for up to an hour in English. Ten participants were recruited through purposive and snowball sampling, not including the pilot interview.

When considering sample size, the concept of data saturation has been criticised for the assumption that saturation is necessary or even possible.[20] Adequacy of sample size was determined by an alternative rubric, information power[21] that considered the breadth of the topic, richness of interview data, research question and diversity of the sample in addition to practical constraints. The rich data generated in the interviews, which had an average duration of 48 minutes, was an important factor in determining the size of the sample. Initial participants were known to the research team through links on social media and professionally. The first participant was known to the second author through being leaders of 'Footsteps Festival', an online series of events curated by volunteers with lived or professional experience of pain to support people with self-management of pain. She was invited in a conversation to take part. The remainder responded to twitter posts by the second author which were subsequently shared widely. Participants who were interviewed put forward additional names of people who might be willing to take part. Four males and six females were interviewed with an average age of 47.2 (range 25 to 71). All participants were white and had made contributions in academic (3) and health settings (5), to charitable organisations (7) and through their own independent creation of resources for patients (10). For confidentiality reasons and due to participants' profiles being in the public domain, individual details of participants' age and gender and other identifiable demographics are not provided.

Interviews

Interviews were loosely structured and followed a semi-structured topic guide, asking about personal experiences with pain, route into advocacy and experiences as a pain advocate. They took place online over Zoom and were recorded and transcribed. Once transcription was completed, transcripts were checked and anonymised and interview recordings were deleted. Each participant was ascribed a random letter in place of their name.

Analytic Procedure

A critical realist[22] orientation was taken, assuming that participants were well placed to describe their experiences but that these will have been constructed differently by different individuals depending on many interlinked factors. Thematic analysis[23] was used to guide the analytic process. Each transcript was read several times, and then semantic-level codes were produced by the first author to describe the essence of each meaning-level unit. The semantic approach to coding was judged to be appropriate due to the lack of previous qualitative research on the topic, in order to capture the experience of chronic pain advocates as they described it.

Codes were assembled into larger meaning units and discussed in depth at regular supervisory meetings. Consistent with reflexive thematic analysis, sub-themes were further refined and combined into higher-order themes over a series of reflexive meetings of both authors. Following well-established recommendations,[23] coded extracts were reviewed by the second author to check internal consistency within the themes, and candidate themes were then reviewed against the entire dataset to ensure an accurate representation. During this process themes were modified, combined and subsumed.

Participants were invited to a group discussion session to discuss the results of the research. Five of the ten participants attended this session and engaged in detailed discussion. All expressed agreement with the representation of results that were presented.

Results

Analysis of results overall generated a description of a journey undertaken by participants.[10] This involved first having their own challenging experiences with persistent pain, where their experiences with medical services were frequently less than ideal, followed by the gaining of new knowledge that helped them and a wish to help others by sharing their experiences. This brought several participants in contact with organisations where they largely experienced respect from individual clinicians and researchers but also encountered organisational challenges and unmet needs. The final stage reflected the personal growth and learning through advocacy described by many of the participants. This journey, which is not necessarily linear, has previously been described overall.[10] The purpose of this article is to describe in detail the experiences and views of advocates with regard to their contact with professionals and organisations.

An unequal partnership

The overarching theme of 'an unequal partnership' speaks to experiences of lived experience advocates that have interfaced with professionals and organisations. Participants spoke of a range of experiences within this space. Many reported positive experiences in which they recognised that they had been impactful, often in relation to individual healthcare staff or researchers. These experiences affirmed their efforts to contribute to improving services and, in some cases, came as a pleasant surprise after previously difficult healthcare interactions. On the other hand, participants frequently encountered barriers to their advocacy from organisations. In some cases, their contributions appeared to be less valued than those of doctors and researchers. In others, the need for their input was perhaps highlighted by the poor fit between their need to manage their symptoms and the demands of working to typically inflexible organisational demands.

Respect

Most participants reported positive experiences of being well received by clinical and research staff they had encountered in their capacity as patient advocates.

Here, M discusses his experience as a part of a team of professionals in a debrief after presenting to policymakers:

> So we all had a meeting in a pub. And, you know, everybody was including me, I'm a friend [...]. I'm not just, you know, "he's a patient, what's your view" sort of thing. I'm one of them [...]. And there's no, you know, hierarchy (Participant M, lines 318–320).

The excerpt demonstrates inclusion, with M feeling an integrated and valued part of the team. He contrasts this sense of inclusion to the tokenism that he may initially have been expecting. This sense of inclusion is furthered when credit is given for the outcomes of consultation, as described by J here in relation to contributions to a published booklet.

> I've been really lucky in the pathways and papers and programmes and that, that I've been involved with, I feel like I have had a really valuable input. And you can see where I've contributed. [The] most recent thing was a booklet [...] on managing pain after your surgery. [...] they've put a thank you to me as well, which was a nice little touch (Participant J, lines 277–281).

The collaborations J has experienced have allowed her to identify the change she is affecting, facilitating a process that incorporates lived experience and turns it into concrete action. It provides a discernible result of the desire to use one's experiences for good, representing an achievement of this wish. Importantly, J is also credited for her contribution. This is an important part of recognising the value of lived experience and is in keeping with the recognition that would be expected by an academic or clinician for their work.

A number of participants recognised that to change the experience of chronic pain patients, education must be delivered to healthcare professionals as well as patients. Here, R discusses the response from doctors after presenting at a conference:

> That really encouraged me that they were genuinely interested, they weren't just doing it, [as a] tick box exercise. [...] these people were genuinely interested in what they could do, and asking questions about their specific bit of research or medical practice. [...] it blew my mind, because that's the first time I felt part of the solution rather than this abrasive voice trying to so you know, give a different perspective (Participant R, lines 219–226).

The genuine engagement from the doctors in this scenario allowed this transition to a collaborative relationship, changing R's view of himself from somebody shouting into the wind, to being part of a process of iterative change.

While we will discuss the more challenging situations experienced in terms of accessibility and inclusion in the next sub-theme, our participants did describe experiences where individuals and organisations supported them in making their voices heard, as we see with J discussing her first time speaking at a conference:

> Initially, it was absolutely terrifying. [ ] I arrived in this room. There was nobody in there, I was the first one to arrive and I was horrified. I thought 'I can't do this'. And then one of the ladies who was chairing the event arrived and told me that she was thrilled to bits because our event was the most booked up event of the whole thing. And she felt it was because there was a patient advocate speaking.

J's impact is directly linked here to her status as a patient advocate, providing validation and particularly confirmation of her belonging in that space.

Overall, this sub-theme captures the impact of professionals' respect for lived experience and how it allows advocates to become influential agents of change when given the space they need. Despite feeling positive and impactful with individual professionals, participants described other, more frustrating experiences and barriers to their engagement with organisations.

Unmet needs from institutions

All participants carried out some of their work voluntarily, many setting up their own groups, platforms or other initiatives to help others. However, it was also a common experience for them to be asked to give their time and expertise for free by organisations, even when this was to fit a different agenda. R discusses his experience when helping to film a promotional video for a charity:

> when you see these charity ads, TV adverts or radio adverts, the amount of times I've been asked to travel down to London to film or record something free of charge, only to find that the lighting and the editing team and the film crew and the professional actors beside me are all getting paid [...], that smarts a bit. Because the whole point of this is this patient experience that we want to raise awareness of (Participant R, lines 251–257).

The contrast in approach between R and those he is working with to produce the same piece of media is indicative to him of how this organisation values his time, versus those who he is working with. This represents a devaluing of his contribution to the video despite it being as important, if not more so, as that of the other individuals involved. He also points out the hypocrisy in producing a video centred on the patient experience, while simultaneously devaluing that experience. This stands in contrast to how professionals are renumerated for their time and expertise. Here, S compares the perceived value of lived experience to clinical expertise:

> I've got 20 years experience with pain. There is no way if I went to speak at some conference somewhere about that, that I would be paid at the same rate as a consultant with 20 years experience. There's no way that that would happen. Yeah, why is my time less valuable? (Participant V, lines 318 – 320).

In a separate interview, W suggests that if their input were to be paid it may be given more weight:

> it's one of those things where I think if you're being paid, I think there are certain professionals who will take you more seriously, but it also opens the door to [...] as a group of people, [...] how can we then be trained in various ways [...] and then we can maybe do our job better? (Participant W, lines 192–196).

Here, W also raises the point that renumeration for their role aids in a degree of professionalisation for advocates themselves, allowing them to develop their role and utilise their experience in a more effective way to achieve the change they desire. This could lead to a greater recognition of the role of a lived experience advocate as part of a multi-disciplinary team, breaking down the barriers between advocate and clinician.

Additionally, as L points out, expecting advocates to give significant time without payment risks perpetuating inequality as it excludes people who are less financially secure from contributing their views.

> you know, an awful lot of people have been in either similar positions to me or they've been retired. So they've got retirement income, they've basically not needed to be paid. And yeah, that will inevitably exclude quite an important constituency, won't it? (Participant L, lines 319 to 321).

Even when organisations did pay, participants described difficulties. In the UK, the benefits system makes it difficult for many to accept payments, as these may be deducted from advocates' state welfare payments. Payment was frequently delayed and often in the form of vouchers, which did not always meet the needs or preferences of participants. Typically in the UK, people receiving some benefits are granted a small weekly allowance of 'permitted work' for which payment can be received before having an impact on benefits. One suggestion therefore could be to provide payment in a way that had the least impact on benefit payments.

> there are ways I think they could maybe do it, like instead of paying 150 In one go, they spread it over a few months (Participant F, lines 576 – 577).

The final point of analysis is the lack of fit between the needs of people living with pain and the way in which they were sometimes asked to work by organisations. Some participants reported needing to maintain boundaries in order to continue to function well, and several examples were given where an organisation, perhaps wanting to learn more about how it could meet the needs of its users, was not able to meet the needs of advocates with similar issues.

In addition to the need to pace and spread work out, F talks of the emotional impact of speaking about traumatic experiences which is often unrecognised.

> But so I'm getting paid the, you know, two hours I spent doing this, but I don't get paid for the three days where I'm recovering from it, because it was such took so much energy and hard work to just contain that emotion, and the trauma of it (Participant F, lines 411–413).

In the following excerpt, N describes attending a conference to give a presentation. Travel and accommodation were paid for by the organisers, but she struggled to recover from a 20 h journey in time to present the following day.

> I don't, they, they didn't make allowances in a way because they should have allowed us an extra day before we got there to sort of rest and recover, which we didn't have, particularly those of us who had to come a long way (Participant N, lines 242–245).

Participants routinely described having to spread meetings and deadlines in order to pace themselves and avoid taking on too much. In contrast, they described pressure to meet tight deadlines and attend long meetings with few breaks by health and research organisations that requested their help. Navigating this complex set of circumstances had been a challenging aspect of the role and one that participants had navigated without support from the organisations they engaged with.

Discussion

Findings from this study illustrate the enthusiastic participation in support, clinical and research activities by people with lived experience of persistent pain, and it is heartening to acknowledge the openness and enthusiasm with which their contributions are received, by at least some professionals. The positive attitudes described by participants towards incorporating a lived experience voice are mirrored by good practice guidelines.[15,16]

The significant barriers that patient advocates encountered were similar to those that have been reported in qualitative studies of lived experience advocates in other settings. Issues of emotional labour, fair compensation and the need to support meaningful involvement which have been highlighted as important in other areas[17,18] were highly relevant also to the participants of this study. The current study extends these findings to the field of persistent pain and also adds new perspectives. The first of these is that current models of reimbursement for advocacy or representation work may contribute to inequalities since those from the most disadvantaged groups are unlikely to be able to afford to spend time engaged in the work given current reimbursement practices. The suggestion made by one participant to 'spread out' payments for work to fit in with the 'permitted hours' allowed by benefit payments, rather than paying a single lump sum, could help to remediate this issue. The work involved from an organisational point of view to enable this change might be seen as a good indication of the importance placed on inclusion and representation by organisations.

The second is that organisations who wish to incorporate meaningful input from lived experience voices need to carefully assess the conditions under which this input can be achieved. In many cases, expecting lived experience advocates to work under conditions of high pressure and tight deadlines expected of professionally employed staff will limit their ability to participate and to make a meaningful contribution.

The lack of adjustment to usual working practices to accommodate participants perhaps speaks to the pressing need for their perspective and input. Inclusion is not limited to simply having advocates at the table but facilitating an environment where they can provide their expertise and produce a more focused and relevant end product.

The contrast between feeling respected and valued at an individual professional level but less so within institutional culture is interesting, as professionals frequently work within and for organisations. As such, many will have encountered organisational 'red tape' when trying to provide payment to patient representatives and may have become resigned to the difficulties in doing so. People who work with patients in a helping capacity may have a need to feel as though they are fair, open and good people.[24] To some degree, this could lead to a degree of blindness to their own contributions to inequity. Potentially, this narrative could apply to individuals working within the field of pain, especially if they have previously been overwhelmed by their organisation's (or state) bureaucracy with regards to sourcing and making appropriate payment. It would seem to be important for organisations using patient representatives in pain to review and update their payment policies and procedures to improve this process.

All of the participants of this study continued to be actively involved in at least one form of patient advocacy at the time of interview. Regardless of compensation and organisational culture that could present barriers, they remained highly engaged and motivated to contribute. A strong motivation for doing so came from their wish to harness their own personal experiences to help others,[10] to protect others from pitfalls they had encountered and also to share insights and learning that had helped. This passion and desire to help made them strong allies to others with persistent pain and could also leave them somewhat vulnerable to working with minimal recognition at times.

The experience of advocates in providing a valuable service which may or may not be financially compensated is not equitable with paid work and therefore excludes less privileged voices who are not in a position to work for minimal income. Something of a liminal space appears to exist, where patient advocates are neither truly patient nor worker. They make a valued contribution but are liable to have their voices drowned out amidst powerful professional and organisational viewpoints.[25] One alternative to this position is to develop and advertise professional lived experience roles which have shown promise in other contexts.[17,26] Lived experience roles relevant to pain and other long-term conditions have recently been advertised in the NHS and may offer at least a partial solution to the above challenges. To date we have typically seen such roles advertised as full-time positions, offering not only the advantage of security of employment and access to appropriate training and resources but also disadvantages if not supported by more flexible options of limiting the pool of people who can contribute to important conversations.

A limitation to this study is the method of recruitment, which may have introduced bias as participants were known to the senior author personally or through social media or were recommended by other participants. However, recruitment resulted in a mixed gender sample incorporating varied forms of pain advocacy. Further research with patient advocates may be useful, perhaps using quantitative measures to find out how frequently organisations pay for patient representation, in what form and at what rates and to collect the opinions of a larger group of patients about whether this is appropriate and sufficient and to confirm whether other issues raised by the participants are widely experienced.

The study includes previously unexplored detail about the experiences of lived experience advocates in their contact with professionals and organisations. It builds on previously reported findings of the strong motivation and potential benefits to patients, organisations and lived experience advocates themselves of this type of role.[10] It also adds to what is currently known and poses some important questions for professionals and organisations who wish to incorporate the views of people with lived experience of pain. Further research is needed into how patient advocates and representatives of organisations can meaningfully work together in a way that meets the needs of each. Qualitative work into the experience of representatives of health, academic and charitable organisations around their experience of engaging the service of patient advocates would also be beneficial. Given the emotionally challenging nature of this work, further work should also explore supervision and support arrangements for these roles.

Conclusion

Advocating as a lived experience representative for people living with pain is an important role that is highly valued by some professionals in healthcare and research. Currently, although doing so can be rewarding, it also comes with both emotional and financial costs that limit its' potential and most likely exclude some more disadvantaged voices from being heard. Further research could explore how widespread these barriers are and consider whether organisational factors could be changed in order to enable advocates to feel like equals in these environments.

Acknowledgements

The authors with thanks to Mark Agathangelou for his guidance and assistance in understanding the role of a lived experience advocate.

Author contribution

CH and CP developed the study protocol. CH conducted and transcribed the interviews and carried out the initial analysis. Both authors revised the analysis. Both authors wrote the paper, reviewed and edited the manuscript and approved the final version of the manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Faculty of Medical Sciences, Newcastle University.

Ethical approval

Ethical approval was sought and obtained from Newcastle University Ethics Committee Ref: 15,165/2021.

Informed consent

Written (online) informed consent was obtained from all subjects before the study.

Guarantor

CP.

ORCID iD

Chris Penlington https://orcid.org/0000-0002-2695-7041

References

1. Devan H, Perry MA, van Hattem A, et al. Do pain management websites foster self-management support for people with persistent pain? A scoping review. *Patient Educ Couns* 2019; 102: 1590–1601.
2. Kress H-G, Aldington D, Alon E, et al. A holistic approach to chronic pain management that involves all stakeholders: Change is needed. *Curr Med Res Opin* 2015; 31: 1743–1754.
3. RobertJamison NP, Anne Sheehan KBA, Elizabeth Scanlan NP, et al. Beliefs and attitudes about opioid prescribing and chronic pain management: Survey of primary care providers. *J Opioid Manag* 2014; 10: 375–382.
4. Shipton EE, Bate F, Garrick R, et al. Systematic review of pain medicine content, teaching, and assessment in medical school curricula internationally. *Pain Ther* 2018; 7: 139–161.
5. Thompson K, Johnson MI, Milligan J, et al. Twenty-five years of pain education research—what have we learned? Findings from a comprehensive scoping review of research into pre-registration pain education for health professionals. *PAIN* 2018; 159: 2146.
6. Darnall BD, Carr DB and Schatman ME. Pain psychology and the biopsychosocial model of pain treatment: Ethical imperatives and social responsibility. *Pain Med* 2017; 18: 1413–1415.
7. Corline A, Cole F, Trewern L, et al. Power to the people, to the people": Training for social prescribers improves support of persistent pain. *Br J Pain* 2023; 17: 281–292.
8. NHS Digital. *The NHS long-term plan*, 2019, https://www.longtermplan.nhs.uk/ (accessed 19 July 2022).
9. Merolli M, Gray K and Martin-Sanchez F. Therapeutic affordances of social media: Emergent themes from a global online survey of people with chronic pain. *J Med Internet Res* 2014; 16: e3494.
10. Hartley C and Penlington C. I will fight for people to not have the experience I've had". A thematic analysis of the experiences and perspectives of chronic pain lived experience advocates. Qual Health Res. 2023; 33(11): 995–1004
11. Tallon D, Chard J and Dieppe P. Relation between agendas of the research community and the research consumer. *The Lancet* 2000; 355: 2037–2040.
12. O'Connell D and Mosconi P. An active role for patients in clinical research? *Drug Dev Res* 2006; 67: 188–192.
13. Nicklin J, Cramp F, Kirwan J, et al. Collaboration with patients in the design of patient-reported outcome measures: Capturing the experience of fatigue in rheumatoid arthritis. *Arthritis Care Res* 2010; 62: 1552–1558.
14. Abma TA, Nierse CJ and Widdershoven GAM. Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qual Health Res* 2009; 19: 401–415.
15. UK Standards for Public Involvement, https://sites.google.com/nihr.ac.uk/pi-standards/home (accessed February 17, 2023).
16. Health and Care Research Wales, Health Research Authority and NIHR. *Payment for Public Involvement in Health and Care Research: a guide for organisations on determining the most appropriate payment approach*, 2022, https://www.nihr.ac.uk/documents/payment-for-public-involvement-in-health-and-care-research-a-guide-for-organisations-on-determining-the-most-appropriate-payment-approach/30838#how-to-cite-this-guidance (2022, accessed February 17, 2023).
17. Kennedy MC, Boyd J, Mayer S, et al. Peer worker involvement in low-threshold supervised consumption facilities in the context of an overdose epidemic in Vancouver, Canada. *Soc Sci Med* 2019; 225: 60–68.
18. Ibáñez-Carrasco F, Watson JR and Tavares J. Supporting peer researchers: recommendations from our lived experience/expertise in community-based research in Canada. *Harm Reduct J* 2019; 16: 55.
19. Mancini MA and Lawson HA. Facilitating positive emotional labor in peer-providers of mental health services. *Adm Soc Work* 2009; 33: 3–22.
20. Braun V and Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health* 2021; 13: 201–216.
21. Malterud K, Siersma VD and Guassora AD. Sample size in qualitative interview studies: Guided by information power. *Qual Health Res* 2016; 26: 1753–1760.
22. Bhaskar R. Critical realism and the ontology of persons. *J Crit Realism* 2020; 19: 113–120.
23. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
24. Sucharov M. Politics, Race, and class in the analytic space: The healing power of therapeutic advocacy. *Int J Psychoanal Self Psychol* 2013; 8: 29–45.
25. Feige S and Choubak M. *Compensating People with lived experience: best Practices from the literature*. Guelph, ON: Community Engaged Scholarship Institute., 2019.
26. Oborn E, Barrett M, Gibson S, et al. Knowledge and expertise in care practices: The role of the peer worker in mental health teams. *Sociol Health Illn* 2019; 41: 1305–1322.