Engaging consumers with musculoskeletal conditions in health research: A user-centred perspective

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This project is a joint collaboration of:
Rationale

• Growing research in the *musculoskeletal (MSK)* area for improving treatment, patient care and quality of life.

• Examples:
  • The influences of MSK conditions on workplaces;
  • Supporting young people’s pain management;

• All these research projects require consumer consultation and participation.
Motivation

• Recruiting consumers and engaging them into health research is hard.
• But, have we considered the consumer perspective in the research?
  • What do they look for?
  • What do they expect to gain?
  • What are the things they are enthusiastic about?
• This is a valuable knowledge for constructing and planning research projects.
Research Design

• Research question: “What do MSK consumers need and expect to gain from participating in an academic research project?”

• Semi-structured interviews – face-to-face & phone interviews
  • Interviews were organised through MOVE muscle, bone & joint health

• Data analysis method: Thematic Analysis
Participants

• Total: 23 Participants
  • Male: 5 (21.7%)
  • Female: 18 (78.3%)

• Average Age: 51 (SD=15.7)
  • Range: 15 – 72

• Living in:
  • Metro Area: 14 (60.9%)
  • Rural Area: 9 (39.1%)

• Work Status:
  • No work: 12 (52.2%)
  • Part-time: 5 (21.7%)
  • Full-time: 6 (26.1%)
Findings

• Responses were summarised into 4 main themes:
  1. Research as a Learning Opportunity
  2. The Important Role of Communities and Health Professionals
  3. Research Transparency and Updates
  4. Special Needs for People with MSK Conditions
1. Research as a Learning Opportunity

• “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)
2. The Important Role of Communities and Health Professionals

- “I probably don’t go about looking for something until I hear about something” (C1).

- “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)
3. Research Transparency and Updates

• “[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)

• “[I want to be] fully informed about the research... and kept up to date with the project” (C12)

• “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)

• “I think it’s a really common thing and I think it’s a big complaint of people” (C3)
4. Special Needs for People with MSK Conditions

• “I’ve got to weigh up the time and the effort involved physically and how much pain it would cost me.” (C8)

• “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)
Some Reflections

- Existing plain language statement and consent form
  - Is it “plain” enough for consumers?

- Broadly speaking, how to make the entire research process:
  - Facilitates more communication – updates/results
  - Satisfies consumer’s information needs

- The emerging of new technologies and faster networks:
  - How to better use them to meet consumer’s needs?
  - Research register / research portals
Future Work

• Interview researchers for their views on the methods and challenges of recruiting participants

• Comparative analysis: Consumers’ Needs <-> Researchers’ Thoughts
Thank you!

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