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Aims

- To design a Smartphone Application (App) for the daily assessment of pain intensity and pain impact
- To assess validity of data collection using the App in primary care patients receiving new analgesics

Plain English Summary

When patients are receiving treatment from their local medical practitioner or other local medical service, information on daily changes in pain and other symptoms (sometimes called symptom trajectories) can be very important, for example to monitor the severity of symptoms, obtain information about the possible cause of symptoms or to assess responses to treatments. However early changes in pain are rarely assessed in clinical practice where follow-up of patients is often planned several weeks or even months after the first consultation or start of treatment. If symptom changes are assessed this is often carried out using paper diaries, which are cumbersome, often poorly completed and information might be outdated by the time it reaches the practitioner. In this project we will develop a Smartphone application (called Pain Recorder) which can be used by patients with painful musculoskeletal conditions to record daily information on the severity of pain and impact on daily life. Pain recorder has been developed in collaboration with the Keele Research Users' Group (RUG). The research team wanted advice on 1) collecting data that was relevant to patients 2) appearance of Pain Recorder 3) functions and ease of use.

Method of PPI

Keele's Research Users' Group (RUG) has nearly 60 members. We invited a sample of members to participate in this project and 8 members formed an advisory group. There was a range of experience of using Smartphones in the group (none to daily users). The advisory group met twice. The aim of the first meeting was to gain advice on 8 specific aspects of Pain Recorder development. An innovative method (TurningPoint technology) was used to facilitate discussion. Hand held voting keyboards were used to determine the importance (ranking) of issues that the group had raised within the 8 aspects. Meeting 2 focused on testing Pain Recorder using GoTab tablets.

Patient and public involvement in the design and testing of a Smartphone Application to assess short term pain trajectories in primary care patients with musculoskeletal conditions (Pain Recorder)

Key Impacts

Pain Recorder Item	PPI Impact
Content of the introductory page of Pain Recorder	Important areas to include: Reason for the research, who the research group is, contact name and number for researcher, emphasis on confidentiality, what outcomes Pain Recorder intends to measure (level of pain in a day, medication use etc), indication of time required each time Pain Recorder is used, what options are available to the user.
Contact information required	Age and gender are important, but add occupation and level of activity.
Measurement of pain and interference	Preference for scoring pain on a visual analogue scale and not using a question on "bothersomeness". Acknowledgment that impact of pain on activity is important to capture. App developers agreed to investigate the inclusion of a validated measure for impact of pain on activity. Add an "access diary" button on each page to enable people to record other things.
Frequency of pain and interference measurement	At least twice a day and suggestion that users can record pain at night.
Medication use	Preference for clicking to record medication taken that day as prescribed (or not) instead of recording each time medication is taken.
Recording of side effects	Suggestion of a question to record side effects of new medications "Have you noticed anything different with respect to your health since you started your new medication and the last time you recorded your pain level?"
Mental health	No agreement on whether this should be included or not. Phrase "mental health" seen as too emotive. Could wellbeing or mood be used?
Data flow	User should be able to choose how to progress from one page to the next by sweeping or clicking next. Need for a back button. Lock important questions so that progress cannot be made until these are answered. One question per page preferred. Key pad preferred to a slider for entry of numerical data.
Other	Help button required on each page, diary for patients to record experiences.

Table 1: Impact of PPI on Pain Recorder Development

Outputs

To date PPI has occurred in 65 studies at the Institute of Primary Care and Health Sciences, some of which have been written up for publication. For example:

- Grime J, Dudley B. Developing written information on osteoarthritis for patients: facilitating user involvement by exposure to qualitative research. *Health Expect.* 2011 Nov 10. doi: 10.1111/j.1369-7625.2011.00741.x. [Epub ahead of print]
- Strauss V, Carter P, Ong BN, Bedson J, Jordan KP, Jinks C, in collaboration with the Arthritis Research UK Research Users' Group. Public priorities for joint pain research: results from a general population survey. *Rheumatology (Oxford).* 2012 Nov;51(11):2075-82. doi: 10.1093/rheumatology/kes179. Epub 2012 Aug 11.
- Carter P, Beech R, Coxon D, Thomas MJ, Jinks C (2013): Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research, *Contemporary Social Science: Journal of the Academy of Social Sciences*, DOI:10.1080/21582041.2013.767468
- Goberman-Hill R, Jinks C, Dziedzic K, Barbosa Bouças S, Hislop K, Rhodes C, Adams J. Designing devices and placebos: involving service users in trial design. *Health Expect.* 2013 Jan 14. doi: 10.1111/hex.12043. [Epub ahead of print]

PPI at the Institute of Primary Care and Health Sciences

This poster presents one example of PPI in Keele projects funded by the SPCR. Other SPCR funded research teams have worked together with patients to:

- Design a question to ask about public priorities for joint pain research.
- Discuss recruitment, patient materials (questionnaires, interview guides, letters and information sheets) and potential drugs to use in studies on gout.
- Design a mixed method study to investigate cost and consequences of PPI in primary care research.
- Understand pathways that lead to unplanned hospital admission in order to inform study design.

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School for Primary Care Research

The National Institute for Health Research School for Primary Care Research (NIHR SPCR) is a collaboration between the Universities of Birmingham, Bristol, Keele, Manchester, Nottingham, Oxford, Southampton and UCL.

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