HPoP, Patient Focus Group Topic Guide

Part A. Background

(20 mins)

1. Welcome/Introduction/ground rules/aims

2. Past experience of physiotherapy

- · What did it include?
- Education/ advice given? exercises given?
- What you expected or hoped for? What useful/ less useful?
- How many treatment sessions? How long? What period?

Part B: Physiotherapy treatment views

(30 mins)

1. Education & Advice

discuss is the education/advice physiotherapists give

- What need to know about?
- · Importance of education/advice on
 - How to protect your joints.
 - How to pace activities.
 - How to set realistic goals
- Format of education/advice? verbal/paper/other?

2. Exercise & Activity

exercise & physical activities - often main focus of physiotherapy

- · What sorts of exercises important to teach?
 - Very specific exercises for each joint?
 - More general exercise/activity (walking, gardening)
- how and when to progress exercise and activities?
 Format of exercise/activity info? verbally/demonstration/
- Format of exercise/activity info? verbally/demonstration, paper or other format?

3. Support and engagement

ways of supporting & motivating you to stay active and manage your condition effectively:

- · How could physiotherapists support and motivate you?
- . How could you be encouraged to stay active in the long term?
- What would help you to be able to manage your condition more effectively in the long term?

Part C: Intervention design

(20 mins)

1. How to measure success

measuring how successful (or unsuccessful physiotherapy has been):

- . What would need to change for you to say that physiotherapy has helped?
- What would you expect physiotherapy to help with?
- What would you not expect physiotherapy to help with?

2. Training for physiotherapists

the training of physiotherapists in managing joint hypermobility

· What do you think physiotherapists could be taught to do better?

3. The later trial

A major problem for the later study is deciding what to compare the new physiotherapy intervention against. We <u>think</u> that physiotherapy works but there is actually no convincing evidence that it does.

It is therefore planned to give half of the people in the study the new physiotherapy intervention & the other half will only receive general advice and existing booklets from Arthritis Research UK & the Hypermobility Syndrome Association. It will be randomly decided which treatment people receive. Only by doing that will we know if physiotherapy works (& by how much).

- Do you think it is reasonable to only offer advice and information booklets to half of the patients?
- Would it prevent you from signing up to the study?
- Do you have any other thoughts about the later study?

Final thoughts

Thank you all so much for your discussion. Do you have any final points that you would like to discuss or that you feel you didn't have the opportunity to say?