Getting better from Fibromyalgia is like a Game of Snakes and Ladders. If we can get you off the bottom line, then that’s progress. But life will continue to be full of ups and downs. We can’t undo ten years of pain in a few sessions in a clinic. Accepting little bits of progress is what we should focus on. Being able to say ‘what do we want to be able to achieve here?’ would be a good way to look at it, rather than setting goals that will fail both patients and professionals.

Reflections and plans for our area

- We’ve come to the conclusion that we shouldn’t call it Fibromyalgia. Maybe just pain or chronic fatigue. In our area, the stigma is still there.
- A year from now, I would like is to have organised a pilot project where we can take lay people who are interested in taking the programme forwards. Expert patients can work well in pain management clinics. We need to support people who have done well to be role models for other people.
- I’d really like to develop a network of people interested in moving things forward across the NHS
- We need to work better with the community and voluntary sector.

Fiona’s Top Tips for improving services

- Try and set up these kinds of support services outside of the NHS so patients get help in places they can keep on attending, and feel like that’s where their best coping strategies lie, in their community.
- Timing is key. If people get help when they are at their most ready, they can make really great progress and have a life changing experience from the help they receive.
- Early intervention is key. Find ways to help these patients as soon as possible on their journey for better outcomes combination
- Find ways to work on the negativity from some professions and help reduce the stigma by re-framing what is possible
- Sharing peer to peer experiences does help
- ‘Living Life to the Full’ is a helpful CBT resource, and we also give out the Versus Arthritis leaflets to people