

NEWSLETTER DECEMBER 2019



Welcome to our 1st ever PACFiND newsletter, it's been a busy year here in Aberdeen, and we are all looking forward to our Christmas break. We will be off from Friday 20th December returning to the office on Monday 6th January. Here is us getting in the Christmas spirit - Marcus (PACFiND Study Coordinator), Stefanie (PhD student) and Laura (PACFiND Assistant Study Coordinator).

So what have
the team
been up to
this year....

Work Package A: Current patient experience and the healthcare they receive for fibromyalgia.

We have been interviewing people with fibromyalgia, and also looking at their healthcare pathway. These interviews will then be shared on healthtalk.org website. We plan to make a short film based on the interviews which can be used in the future training of healthcare professions.

The interviews are well underway and the huge task of transcribing and analysing them has started – well done to Stefanie who has travelled the length and breadth of Scotland completing these.

Work Package B: Organisation and delivery of care for people with fibromyalgia

We need to understand how healthcare is currently organised and delivered to people with fibromyalgia. We are currently asking healthcare professions who see patients with fibromyalgia to complete a survey about their experiences, and this is due to end at the end of the year. Currently over 1,500 people have completed this survey.

Next we are going to ask patients to complete an online survey about their experiences, and this will be available for completion in early January, more details to follow next year

We also plan to undertake a series of case studies across the UK, to identify and describe current provision of care for people with fibromyalgia and the challenges encountered in providing high quality care – We are looking to set up a PPI group in the South London area to help advise us on this – see the website for more details

Work Package C: Organisation and delivery of care for people with fibromyalgia

We will develop new models of care for people with fibromyalgia using the information gathered in work packages A and B.

We will design these along with patients, healthcare professionals and decision makers.

We will assess the benefits and costs of the current and new service, and then provide detailed information to help guide those who are setting up the new service model.

Work Package C is currently “under construction”

How to get involved

Complete an expression of interest form. This will let us know how you would like to get involved. This could be as little as receiving a newsletter such as this, to being a patient partner involved in meetings, discussing the research or, reviewing our documents. Send us email for more information

Opportunities Now Available :

We are looking to set up a patient partner group in South London (meetings will be held at Kings College Hospital NHS Foundation Trust), you would need to be located within, or close to this area to enable easy travel to meetings. For more information:

<https://www.abdn.ac.uk/iahs/research/epidemiology/patient-partners-1518.php>

Upcoming Opportunities:

In early January we will be looking for people with fibromyalgia to complete a very short survey about their healthcare experiences outside of the NHS – more details to follow on the website



Get In Touch

PACFiND Privacy Notices:

<https://www.abdn.ac.uk/iahs/research/epidemiology/privacy-notice-1601.php>

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We wish you a Merry Christmas and all the best for the New Year

With kindest regards,

PACFiND Team

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