

NEWSLETTER DECEMBER 2020



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

We hope this newsletter finds you safe and well. We would like to wish everyone a very merry Christmas and a much happier 2021!

The coronavirus pandemic has certainly dominated 2020 but the PACFiND team have been working hard, finding new ways to work, and have had an extremely busy year. Some study highlights are detailed below, we hope you enjoy the read.

Work Package A: Current patient experience of healthcare for fibromyalgia

Stefanie has finished interviewing. Overall, 31 people with fibromyalgia shared their experiences with us in person, via phone and online video (due to the pandemic). Analysis of the interview data is underway. The findings will be available on the healthtalk website in the new year: <https://www.healthtalk.org/>

Stefanie won several prizes in 2020. One was the prestigious British Federation of Women Graduates (BFWG) Johnstone & Florence Stoney Prize (read more here: <https://bfgw.org.uk/bfgw2/student-earns-prestigious-award/>). She has used these opportunities to increase awareness about fibromyalgia in society and our research undertaken to improve healthcare delivery. As she puts it: "This is a shared success based on everyone's input who has been involved in one or another way in the project".

Stefanie would like to thank all the people who participated and/or supported our research in various ways throughout the work package A (such as sharing their own experiences and providing feedback)!

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

This year we have been busy analysing the results from two surveys that we conducted to find out how healthcare is organised and delivered for people with fibromyalgia in the UK. Over 1700 healthcare professionals and 500 people with fibromyalgia responded to the surveys. We plan to produce a short video to tell people about the findings.

In November, Teresa Finlay (pictured right), a researcher at the University of Oxford joined the team.

Our plans for 2021 include visiting services in England, Scotland and Wales, and doing library-based research to find out what is working well for people with fibromyalgia and how to bring about better care.



Work Package C: A new model of care for people with fibromyalgia

We are currently planning and testing a survey to determine the healthcare preferences of people with fibromyalgia. This will be carried out next year, firstly among people who responded to an earlier survey. We will then distribute the survey to more participants through social media.

Publications

The first scientific paper* from the PACFiND project was published in the journal PAIN in August.

The next publication is in preparation. It will give results from the survey about healthcare currently received by people with fibromyalgia.

*Doehl, S., Macfarlane, G. J., & Hollick, R. J. (2020). "No one wants to look after the fibro patient". Understanding models, and patient perspectives, of care for fibromyalgia: reviews of current evidence. *Pain*, 161(8), 1716-1725.

Patient Partner Activities

We would like to thank all the patient partners who have signed up to help with the PACFiND project through the year.

The PACFiND South London Patient Partner group has held some very successful meetings to discuss the organisation of healthcare for people with fibromyalgia. And we are currently conducting "think aloud" sessions with patient partners to test out the survey questions which will determine preferences for care. This survey will be conducted next year.



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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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