



**VERSUS  
ARTHRITIS**



# PACFiND Newsletter

*December 2021*



## PACFiND Newsletter: December 2021

Welcome to our PACFiND Christmas newsletter. Thank you for continued interest in the project.

If you do not want to receive further communications, please reply to this email with "STOP" and we will remove your details from our database.

In this newsletter we will tell you more about new members of the team, what research we have done, and what research is planned.

Thank you for taking the time to read this email, and if you would like to contact us, please email [pacfind@abdn.ac.uk](mailto:pacfind@abdn.ac.uk) with any comments or feedback you may have.

## New Members of the Team



### **Dr Caroline Cupit**

is a Research Fellow working based at the University of Oxford working on “Case Studies”.

Caroline started work on PACFiND in July. She is a social scientist. She holds degrees from Universities of Reading and Leicester and a doctorate from the University of Leicester. Caroline has experience using interview methods to study the organisation of healthcare settings. She will interview healthcare professionals in Wales to explore the best way to deliver care for fibromyalgia.



### **Dr Ka-Kin Lam**

is as Research Fellow based at the University of Aberdeen working on “Data Linkage”.

Ka-Kin started work on PACFiND in May. He is a data analyst and has a degree and a doctorate from the University of Leicester. He will be analysing data from healthcare record to learn about the healthcare journey of people with fibromyalgia.

## The PACFiND Work Packages

The PACFiND project is divided into separate work packages. Each focusses on a different aspect of healthcare for people with fibromyalgia. Work Package A looks at **patients' experiences** of healthcare. Work Package B looks at the **organisation and delivery of healthcare**. And Work Package C looks at developing a **new model of healthcare** for people with fibromyalgia.

### Work Package A: Current patient experience of healthcare for fibromyalgia

There are three parts to this work package: a survey, patient interviews, and analysis of healthcare records.

We have completed the survey and the results were published in June. The publication was in the journal Arthritis Care & Research (<https://doi.org/10.1002/acr.24723>).

Over 400 people who had reported pain completed this questionnaire. We looked at differences between people who had a fibromyalgia diagnosis, people who had fibromyalgia symptoms but no diagnosis, and people who had chronic pain but not fibromyalgia.

We found that people with a fibromyalgia diagnosis were more likely to be female. We also found they reported more negative experiences with healthcare than those without a diagnosis. It took people on average three years to get a diagnosis of fibromyalgia. This diagnosis happened most often in a hospital department (especially rheumatology).

People in with fibromyalgia symptoms were affected similarly by their symptoms whether they had a diagnosis or not. This was especially in their ability to function in daily life and at work. The impact of symptoms in these groups was much greater than in people with chronic pain.



We have prepared the interviews with patients ready for publishing on the healthtalk website. They should be available here very soon: <https://healthtalk.org/fibromyalgia>

We have received access to the medical records of fibromyalgia patients who took part in our questionnaire survey and gave us permission to do so. We'll be analysing those in the next year.

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

There are two parts to this work package: surveys to map healthcare services for fibromyalgia across the UK, and in-depth case studies of services for fibromyalgia.

The surveys to map healthcare services were completed before the start of the COVID-19 pandemic.

Over 1500 healthcare professionals across the UK told us about what services for fibromyalgia they provided in their part of the NHS. Over 500 patients with fibromyalgia took part to tell us about their use of healthcare outside of the NHS.

The results of these surveys have now been analysed and are being prepared for publication. You can watch a short video about the surveys here:

<https://youtu.be/VaVizmPqJGM>

The case studies for fibromyalgia healthcare services have been delayed due to COVID, but we'll be starting up again soon. Ten sites across the UK will be chosen for in-depth interviews with the people providing fibromyalgia care. This work will be ongoing throughout 2022.

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

Work Package C has two parts. Firstly, we will estimate the benefits and costs of different types of healthcare. Secondly, we will hold a series of workshops to look at different ways healthcare can be provided.

These workshops will be attended by patients, healthcare professionals, and researchers.

To estimate the costs and benefits of healthcare for fibromyalgia, we are conducting a survey to find out what kind of healthcare people with fibromyalgia prefer.

The pilot of this survey was already completed, with 41 participants. We are running the full survey online in January 2022. Everybody in the UK with a diagnosis of fibromyalgia is eligible to take part. When the survey is open, we may contact you to request your participation. The workshops looking at different ways of providing healthcare are due to begin toward the end of 2022.

## Get Involved with the Epidemiology Group



PACFiND is one of a number of studies coordinated by the University of Aberdeen Epidemiology group. Our group recognises that collaborating with patients, carers, and individuals with relevant experience positively impacts on all stages of research. Patient and public involvement in our work helps identify the most relevant research priorities, allows for better design management and undertaking of research projects and improves the interpretation and dissemination of our findings.

Would you like to receive updates or get involved further with the Epidemiology group? Please visit our Patient and Public Involvement page [here](#), or to get involved please complete our Expression of Interest Form [here](#)

**Thank  
You**

Thank you for taking the time to read this newsletter!

Please email any feedback to [pacfind@abdn.ac.uk](mailto:pacfind@abdn.ac.uk)

Kind regards,

**The PACFiND Investigators**

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