# Mapping NHS services for people with Fibromyalgia

This survey is intended for health professionals working in the NHS who, in the last two years, have seen patients with Fibromyalgia or with signs and symptoms suggestive of Fibromyalgia (i.e. persistent widespread pain/tenderness for at least three months, with associated symptoms such as fatigue, non-restorative sleep, impaired memory/concentration and mood disorders).

This survey is being carried out by researchers from the University of Aberdeen, the University of Oxford and King's College Hospital NHS Foundation Trust to find out about NHS services for people with Fibromyalgia. It is part of a research study called PACFIND – PAtient-centred Care for Fibromyalgia: New pathway Design, funded by Versus Arthritis, which aims to improve healthcare for people with Fibromyalgia. You can find out more about the study here.

We would like to invite you to participate in this survey which should take no more than 5 minutes of your time to complete. Please feel free to forward this survey to appropriate colleagues.

Your participation is entirely voluntary and you can withdraw at any point. You are free to omit question(s). Your responses will be anonymous and the data will be stored securely at the University of Aberdeen for 10 years. After this time it will be destroyed.

If you have any questions about the survey you can contact the PACFiND team on pacfind@abdn.ac.uk

Thank you for your time.

#### **Consent to participate**

I have read and understood the information above and consent to participate in this survey\*.





Demographic information	
What is your main job in healthcare?	<ul> <li>General practitioner</li> <li>Hospital doctor</li> <li>Nurse</li> <li>Occupational therapist</li> <li>Physiotherapist</li> <li>Psychologist</li> <li>Psychiatrist</li> <li>Mental health practitioner</li> <li>Other - please specify in pop-up box below</li> </ul>
Other main job - please specify:	
In what specialty is your main job?	<ul> <li>Gastroenterology</li> <li>General Practice</li> <li>Neurology</li> <li>Pain Medicine</li> <li>Psychiatry</li> <li>Psychology</li> <li>Rehabilitation</li> <li>Rheumatology</li> <li>Other - please specify in pop-up box below</li> </ul>
Other specialty - please specify:	
What country is your main job in?	<ul> <li>England</li> <li>Northern Ireland</li> <li>Scotland</li> <li>Wales</li> </ul>
lf your main job is in England, please select your region:	<ul> <li>South East</li> <li>South West</li> <li>London</li> <li>East of England</li> <li>East Midlands</li> <li>West Midlands</li> <li>Yorkshire and the Humber</li> <li>North East</li> <li>North West</li> </ul>
lf your main job is in Northern Ireland, please select your region:	<ul> <li>Belfast</li> <li>Southern</li> <li>Northern</li> <li>Western</li> <li>South Eastern</li> </ul>
lf your main job is in Scotland, please select your region:	<ul> <li>Ayrshire and Arran</li> <li>Borders</li> <li>Dumfries and Galloway</li> <li>Fife</li> <li>Forth Valley</li> <li>Grampian</li> <li>Greater Glasgow and Clyde</li> <li>Highlands and Western Isles</li> <li>Lanarkshire</li> <li>Lothian</li> <li>Orkney and Shetland</li> <li>Tayside</li> </ul>



If your main job is in Wales, please select your region:

What is the healthcare setting for your main job?

Other healthcare setting - please specify:

Which of the following best describes the main setting from which you personally deliver healthcare for patients with Fibromyalgia, or signs and symptoms suggestive of Fibromyalgia?

In addition to this setting, do you personally deliver healthcare for patients with Fibromyalgia, or signs and symptoms suggestive of Fibromyalgia in other settings?

Please select any other setting(s) from which you personally deliver healthcare:

○ Abertawe Bro Morgannwg

- $\bigcirc$  Aneurin Bevan
- 🔾 Betsi Dadwaladr
- Cardiff and Vale
- O Cwm Taf
- O Hywel Dda
- O Powys

○ General practice

- O Primary healthcare centre
- Acute hospital
- Community hospital
- Other please specify in pop-up box below

🔿 Urban

- O Suburban
- 🔿 Rural

⊖ Yes ⊖ No

Urban
 Suburban
 Rural



#### **Diagnosing Fibromyalgia**

Do you diagnose Fibromyalgia\*?

\*Symptoms are: persistent widespread pain/tenderness with associated symptoms such as fatigue, non-restorative sleep, impaired memory/concentration and mood disorders.

What age groups do you diagnose?

What screening/assessment tool(s)/technique(s) do you use to diagnose Fibromyalgia? Please tick all that apply.

If you use other screening/assessment tools/technique(s) - please specify:

Do you refer to other providers to make a diagnosis of Fibromyalgia?

To which providers do you refer? Please tick all that apply.

Please specify which other provider(s) you refer patients to:

Which of these providers that you refer patients to for a diagnosis are located in your healthcare setting? Please tick all that apply.

Please specify which of the other provider(s) that you refer patients to for a diagnosis are located in your healthcare setting:

С	)	Yes
(	)	No

 $\bigcirc$  Adults ( $\geq$ 18 years)

Adolescents (13 to 17 years)

Adults AND Adolescents

□ Widespread Pain Index

Symptom Severity Scale

Tender Point examination

Clinical opinion

🗌 None

Other - please specify in pop-up box below

Ο	Yes
$\sim$	

Ŏ No

General practitioner

Occupational therapist

Physician in pain medicine

Physiotherapist

Psychologist

Psychiatrist

□ Gastroenterologist

🗌 Neurologist

Rheumatologist

Other - please specify in pop-up box below

None

General practitioner

Occupational therapist

Physician in pain medicine

🗌 Physiotherapist

🗌 Psychologist

Psychiatrist

Gastroenterologist

🗌 Neurologist

Rheumatologist

 $\hfill\square$  Other - please specify in pop-up box below

🗌 Don't know



#### Treatment/management of patients with Fibromyalgia

⊖ Yes

 $\bigcirc$  No

Do you personally provide treatment/management\* for patients with Fibromyalgia?

\*Treatment/management is considered any intervention that aims to combat Fibromyalgia or alleviate signs and symptoms suggestive of Fibromyalgia.



#### **Treatment/management interventions**

What treatment/management interventions do you personally provide for patients with Fibromyalgia? Please tick all that apply.

- □ Information leaflet
- Education (e.g. about sleep hygiene, exercise or mental health)
- Structured land-based exercise (e.g. physiotherapist-led fitness class)
- Structured water-based exercise (e.g. hydrotherapy)
- □ A medicines prescription
- A recommendation for a medicine or an over the counter medicine
- Manual therapies (e.g. massage, manipulation)
- Acupuncture
- Psychological therapies (e.g. CBT, counselling)
- A multicomponent programme (e.g. a pain management programme)
- Other please specify in pop-up box below

Please specify what other treatment/management interventions you provide:



Multicomponent programmes	
What intervention(s) are delivered within your multicomponent programme? Please tick all that apply.	<ul> <li>Exercise therapy</li> <li>Meditative movement (e.g. Tai Chi, Yoga)</li> <li>Psychological Therapy (e.g. CBT)</li> <li>Sleep hygiene / management</li> <li>Education and advice</li> <li>Other - please specify in pop-up box below</li> </ul>
Please specify what other multicomponent intervention(s) you provide:	
How is your multicomponent programme delivered? Please tick all that apply.	<ul> <li>One to one face-to-face sessions</li> <li>Group-based face-to-face sessions</li> <li>Telephone sessions/support</li> <li>Online sessions/support</li> <li>Other - please specify in pop-up box below</li> </ul>
Please specify what other way(s) your multicomponent programme is delivered:	
What is the overall length of your multicomponent programme? Please enter a number of weeks.	
How many sessions are there within your multicomponent programme?	
What is the length of each session? Please enter a number of minutes.	
Where is your multicomponent programme delivered? Please tick all that apply.	<ul> <li>General practice surgery</li> <li>Hospital setting</li> <li>Home</li> <li>Leisure centre</li> <li>Community venue (e.g. community centre)</li> <li>Other - please specify in pop-up box below</li> </ul>
Please specify the other location(s) where your multicomponent programme is delivered:	
Which healthcare workers deliver this multicomponent programme? Please tick all that apply.	<ul> <li>Doctors</li> <li>Psychologists</li> <li>Nurses</li> <li>Physiotherapists</li> <li>Occupational Therapists</li> <li>Mental health practitioners</li> <li>Pharmacists</li> <li>Assistant practitioners, e.g. physiotherapy assistant</li> <li>Other - please specify in pop-up box below</li> </ul>
Please specify which other healthcare workers deliver this multicomponent programme?	



### Referring to other providers for treatment/management

Do you refer patients with Fibromyalgia to other providers for treatment/management?

To which providers do you refer for treatment/management? Please tick all that apply.

- ⊖ Yes
- ⊖ No
- General practitioner
- Psychologist
- Nurse
- Physiotherapist
- Assistant practitioner, e.g. physiotherapy assistant, health trainer
- Occupational Therapist
- Mental health practitioner
- 🗌 Pharmacist
- 🗌 Physician in pain medicine
- Psýchiatrist
- Rheumatologist
- □ Other please specify in pop-up box below

Which other provider(s) do you refer to for treatment/management? Please specify.

Which of these providers that you refer to for treatment/management are located in your healthcare setting? Please tick all that apply

None
General practitioner
Psychologist

- Nurse
- Physiotherapist
- Assistant practitioner, e.g. physiotherapy assistant, health trainer
- Occupational Therapist
- Mental health practitioner
- Pharmacist
- Physician in pain medicine
- Psychiatrist
- □ Rheumatologist
- Other please specify in pop-up box below
- Don't know

Please specify which of the other provider(s) that you refer patients to for treatment/management are located in your healthcare setting:



#### Signposting

Do you direct or signpost patients with Fibromyalgia to other services or interventions?

What services or interventions do you signpost patients with Fibromyalgia to? Please tick all that apply.

What other services or interventions do you signpost patients with Fibromyalgia to? Please specify:

⊖ Yes ⊖ No

Self-help book(s) / leaflets

On-line resources

□ Support group(s) and or workshops

Other - please specify in pop-up box below



#### Gaps in service provision

In your opinion, are there gaps in your local healthcare services for patients with Fibromyalgia?

What do you consider is the most important unmet need for the care of patients with Fibromyalgia in your locality?

- ⊖ Yes
- O No
- O Don't know
- Lack of available services (e.g. physiotherapy, multicomponent programmes)
- Limited transport availability between patient and provider
- Long wait times to appointments
- Lack of health professional's knowledge and skills in assessment, treatment/management of patients with Fibromyalgia
- C Lack of adequate time during appointments
- Restrictive service delivery policies
- Funding issues (e.g. underfunding, high treatment costs)
- Continuity of relations between provider and patient
- Lack of access to shared patient medical records
- Limited communication and coordination between providers
- Other (please specify)
- Please specify what other most important unmet need exists in your locality:

Please select other important unmet needs for the care of patients with Fibromyalgia in your locality

- Lack of available services (e.g. physiotherapy, multicomponent programmes)
- Limited transport availability between patient and provider
- □ Long wait times to appointments
- Lack of health professional's knowledge and skills in assessment, treatment/management of patients with Fibromyalgia
- Lack of adequate time during appointments
- □ Restrictive service delivery policies
- Funding issues (e.g. underfunding, high treatment costs)
- Continuity of relations between provider and patient
- Lack of access to shared patient medical records
- Limited communication and coordination between providers
- Other please specify in pop-up box below

Please specify what other important unmet needs there are in your locality:

If you have any further comments about service gaps in your locality, we would be grateful if you would include them here.



#### **Other comments**

If you have any other comments about any aspect of this survey we would be grateful if you would include them here.



#### **Contact details**

It would be most helpful if you would provide the address of your service / practice. This will help us to identify potential case study sites for future research associated with PACFiND.

Postcode of service/practice:



## Thank you

Thank you for completing this survey. Please remember to press the submit button below!



