

## **RHEUMAPS** Study

Understanding the experiences and priorities for care for people with rheumatic and musculoskeletal

conditions living in rural and urban areas

\* Required

This survey aims to understand the priorities for care for people with rheumatic and musculoskeletal conditions living in rural and urban areas. To do this, we would like to understand more about your priorities for health care. For example, how easy you find it to access care, information and support networks, and what matters to you. We will use the findings from this study to support service planning and decision making for people living in rural settings. It will also help us understand the long-term impacts of the COVID-19 pandemic on care for people with rheumatic and musculoskeletal conditions.

This survey has been approved by the School Ethics Review Board, University of Aberdeen (CERB/2021/7/2143). All information you give as part of this survey is anonymous and will be kept strictly confidential. You do not have to participate in this survey if you do not wish to do so. Please answer all the questions and use the "other" boxes to add any additional information you feel relevant. The survey will take approximately 20 mins to complete.

If you have any questions about this survey you can contact Dr Kevin Stelfox by email: <u>rheumap@abdn.ac.uk (mailto:rheumap@abdn.ac.uk)</u>, or the Chief Investigator Dr Rosemary Hollick on <u>rhollick@abdn.ac.uk (mailto:rhollick@abdn.ac.uk)</u>, or you can visit our study website:

https://www.abdn.ac.uk/iahs/research/epidemiology/mapping-rmd-study-1688.php (https://www.abdn.ac.uk/iahs/research/epidemiology/mapping-rmd-study-1688.php)

## Section 2

- 1. I consent to participate in the survey and the use of my survey responses as described above. \*
  - 🔵 Yes
  - 🔘 No
- 2. I have been diagnosed with a rheumatic and musculoskeletal condition by a health care professional? \*
  - 🔵 Yes

🔵 No

- 3. I am aged 18 years or older? \*
  - 🔿 Yes
  - 🔘 No
- 4. What is your gender \*
  - 🔵 Male
  - 🔵 Female
  - Non-binary
  - Prefer not to say
  - Self describe (please provide details below)

## 5. If you selected self describe, please provide further details

6. What is your age? \*

0 18-24

25-44

🔘 45 to 64

🔘 65 to 74

75 years or older

7. What is your postcode? (e.g. AB25 2ZD) Your postcode will only be used to tell us more information about where you live e.g. remote, rural or urban area.

- 8. Do you consider where you live to be: \*
  - O Rural
  - $\bigcirc$  Urban
  - Not sure

## About your rheumatic and musculoskeletal condition

9. From the list below please indicate the rheumatic and musculoskeletal conditions that you have been diagnosed with by a health care professional? Please select all that apply. \*

ANCA associated vasculitis
Axial spondyloarthritis (Ankylosing spondylitis)
Bechet's disease
Connective tissue diseases: e.g systemic lupus erythematosus, scleroderma, Sjogren's syndrome
Fibromyalgia
Giant cell arteritis
Gout
Inflammatory bowel disease associated arthritis
Joint hypermobility
Juvenile idiopathic arthritis
Large vessel vasculitis
Osteoarthritis
Osteogenesis imperfecta
Osteoporosis
Paget's disease
Polymyalgia rheumatica
Psoriatic arthritis
Reactive arthritis
Rheumatoid arthritis
Other rheumatic and musculoskeletal conditions (please specify below)

#### 10. If you answered "Other rheumatic and musculoskeletal conditions", please specify:

#### 11. When were you first diagnosed? \*

 $\bigcirc$  Less than a year ago

- 1-2 years
- 3-4 years ago
- 5-10 years ago
- ) 11-20 years ago
- More than 20 years ago

#### 12. Who did you receive your diagnosis from? \*

- Primary care e.g GP
- Specialist service e.g rheumatology, orthopaedics
- Complementary services e.g chiropractor, osteopath
- Other (please specify below)

#### 13. If you answered "Other", who did you receive your diagnosis from, please specify:

#### 14. How long did you wait before seeking care for your symptoms? \*

0	
O 4-11 months	

O Up to three months

- 1-2 years
- 3-4 years
- 🔵 5 or more years
- 15. What factors influenced your decision to seek medical care for your rheumatic and musculoskeletal condition? Please select all that apply. \*
  - ] My family suggested I seek medical care
  - A friend suggested I seek medical care
  - ] I was unable to work
  - I could not undertake everyday tasks such as shopping, cleaning
  - I was finding it difficult to participate in social activities e.g meeting friends or family
  - I felt that my quality of life had deteriorated
  - I was in pain
  - Other factors influencing your decision to seek medical care (please detail below)

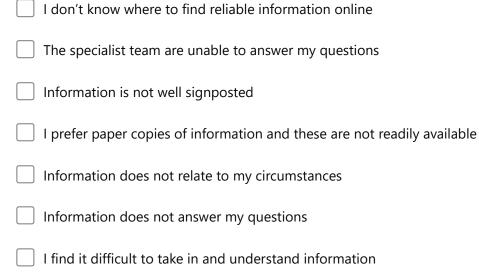
16. If you answered "Other", please detail the other factors that influenced your decision to seek medical care:

- 17. Did you delay seeking care after your symptoms first appeared? \*
  - 🔵 Yes
  - 🔵 No
- 18. What influenced your decision to delay seeking medical care? Please select all that apply. \*
  - I thought I would have to wait a long time to see a health care professional
  - ] I consciously put off seeking medical care
  - ] I did not want to travel to the hospital
  - I did not think there was any treatment for my symptoms
  - I did not want to waste health care professionals time
  - I looked for a diagnosis online rather than see an health care professional
  - ] I did not believe it was a serious issue
  - I chose to manage symptoms myself
  - ] I thought it was just old age
  - I was frightened of what might be wrong
  - Other (please detail below)

19. If you answered "Other", please detail other factors influencing your decision to delay seeking medical care:

# Information and support for your rheumatic and musculoskeletal condition

20. What problems, if any, have you experienced accessing information? Please select all that apply. \*



- I didn't know where to look for information
- I didn't require access to any further information
  - No difficulties accessing information

#### 21. If you have any other issues accessing information please specify

22. Over the last 12 months have you accessed any of the following to find out information about your condition and care? \*

	Often	Occasionally	Never
Charity Website e.g.Versus Arthritis	$\bigcirc$	$\bigcirc$	$\bigcirc$
General web searches using topical words (rheumatoid, fatigue, pain etc)	$\bigcirc$	$\bigcirc$	$\bigcirc$
NHS web pages e.g NHS inform	$\bigcirc$	$\bigcirc$	$\bigcirc$
NHS 24 MSK help line	$\bigcirc$	$\bigcirc$	$\bigcirc$
NHS 24	$\bigcirc$	$\bigcirc$	$\bigcirc$
МЅК Арр	$\bigcirc$	$\bigcirc$	$\bigcirc$
Pain concern	$\bigcirc$	$\bigcirc$	$\bigcirc$
Rheumatology /orthopaedic service in person (Clinic appointment)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Rheumatology / orthopaedic services help line/email	$\bigcirc$	$\bigcirc$	$\bigcirc$
Local support groups	$\bigcirc$	$\bigcirc$	$\bigcirc$
Government web pages	$\bigcirc$	$\bigcirc$	$\bigcirc$
Local council office	$\bigcirc$	$\bigcirc$	$\bigcirc$
News channels (e.g BBC, ITV)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Friends	$\bigcirc$	$\bigcirc$	$\bigcirc$
Family	$\bigcirc$	$\bigcirc$	$\bigcirc$
Social media	$\bigcirc$	$\bigcirc$	$\bigcirc$
University/Research websites	$\bigcirc$	$\bigcirc$	$\bigcirc$

	Often	Occasionally	Never
NICE (National Institute for health and Care Excellence)	$\bigcirc$	$\bigcirc$	$\bigcirc$

23. If there are any other resources that you have accessed in the past 12 months please specify

- 24. Does the information you access from the above sources help you to manage your condition? \*
  - 🔘 Yes
  - 🔵 No

#### 25. Please tell us how you think the information provided could be improved.

## Access to rheumatic and musculoskeletal services

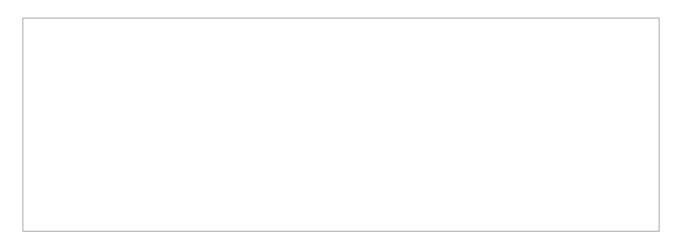
26. Please indicate if you had any difficulties BEFORE THE PANDEMIC, attending the following services? \*

	A lot of difficulty	Some difficulty	No difficulty	Not available	Not applicable to me
Primary care e.g GP practice, community nurses	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Specialist services e.g. rheumatology, orthopaedics	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Physiotherapy services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Occupational Therapy	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Podiatry services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Community Pharmacy	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Social care e.g social work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

27. Please indicate if you CURRENTLY have any difficulties attending the following services? \*

	A lot of difficulty	Some difficulty	No difficulty	Not available	Not applicable to me
Primary care e.g GP practice, community nurses	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Specialist services e.g. rheumatology, orthopaedics	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Physiotherapy services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Occupational Therapy	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Podiatry services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Community Pharmacy	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Social care e.g social work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

28. Are there any services that you would find helpful that you do not currently have access to? Please specify



## 29. Do any of the following TRAVEL issues create difficulties for you attending health services: \*

	Always a problem	Sometimes a problem	Neutral	Not usually a problem	Never a problem	Not applicable to me
Lack of public transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Cost of public transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Timing of public transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Lack of disabled access on public transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Cost of personal transport (e.g petrol)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Lack of access to private transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Complexity of journey e.g multiple modes of transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Accommodation e.g. cost and availability	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Parking	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Lack of patient / hospital transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Journey time	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

30. Do any of the following WORK issues create difficulties for you attending health services: \*

	Always a problem	Sometimes a problem	Neutral	Not usually a problem	Never a problem	Not applicable to me
Permission from employer to get time off work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
My roles and responsibilities at work prohibit taking time off	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l can only attend before or after work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Difficulty in taking time off work due to loss of earnings	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
My employer is not aware of my health condition	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

## 31. Do any of the following create difficulties for you attending HEALTH SERVICES \*

	Always a problem	Sometimes a problem	Neutral	Not usually a problem	Never a problem	Not applicable to me
Services not available at convenient times	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Services are not available locally	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Services are not available in my health board or trust	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Services are available but I don't know how to access them	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
The time taken to attend the appointment is not worth it	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Appointment times offered are not convenient	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

## 32. I find the following create difficulties for me attending health services \*

	Always a problem	Sometimes a problem	Neutral	Not usually a problem	Never a problem	Not applicable to me
Caring responsibilities e.g. children, other family member or friend	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Additional care costs	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Support to attend services e.g. patient transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
I need to ask someone to take time off work to accompany me to my appointment.	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Dependant on friends or family for transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Dependant on availability of my carer to take me	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Cost incurred by others (friends or family) for my transport	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Time taken to travel to the services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

33. Currently, how important are the following in helping you access services to manage your condition? \*

	Very Important	Important	Neutral	Unimportant	Very Unimportant
Help from friends and family to access services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Public transport to and from services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Availability of local specialist health care services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Seeing the same health care staff who know me and my condition	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Care provision for dependants or others, to allow me to attend services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Employer understanding of the need to attend services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Flexible opening times for the services to avoid normal working hours	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

34. If you have any further comments about your priorities for help to access services, please describe them below.

## Employment

35. Please select one category that best describes your current employment status. \*

- O Working full time in a paid job, as an employee
- O Working full time self-employed
- Working part time in a paid job, as an employee
- Working part time self-employed
- Doing unpaid work full time in the home, e.g.housework, carer
- Unemployed but seeking work
- Unemployed because of ill health / disability (and not seeking work)
- Retired
- Retired early because of ill health / disability
- 🔵 Volunteer
- 🔵 Student
- 36. What is your occupation? \*

37. In what sector do you work (e.g. farming, shipyard, car factory, shoe shop, hospital, insurance office)

- 38. What size is the organization/ company that you work for ? Or if you are a selfemployed/ business owner, how many do you employ? Please select one. \*
  - 1 person (myself)
  - Micro ( 2 to 9 people)
  - Small (10 to 49 people)
  - Medium (50 to 249 people)
  - C Large (250 people or more)
- 39. Do any of the following create difficulties for commuting to and from work BECAUSE OF YOUR RHEUMATIC AND MUSCULOSKELETAL CONDITION? \*

	Always a problem	Sometimes a problem	Not usually a problem	Never a problem	Not able to do	Not applicable
Using public transport (e.g. bus/train)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Using private transport (car)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Walking	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Cycling	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Parking availability	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

#### 40. If there are any other difficulties in accessing your work, please specify

41. Thinking about the demands of your work. Please indicate which best represents your views on the following statements: \*

	Not at all	A little	Somewhat	Quite a bit	A great deal
Do you have control over your work schedule (That is, the order in which you do your work, the pace at which you work, being able to take short breaks when you need to)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Is your job flexible? (That is, being able to start and finish at different times)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Do you receive help from colleagues in carrying out your work?	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Is your job physically demanding (e.g. using tools and equipment with force, bending, lifting, walking, standing for longer periods etc.)?	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Is your job mentally demanding? (e.g. requires a lot of your attention, concentration)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
In the past 6 months, do you think your condition and its treatment has resulted in you being less productive at work?	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

42. What work-related support services are you aware of, or have accessed in connection to your rheumatic and musculoskeletal condition? Please select all that apply. \*

	Aware	Accessed	Not Aware
Occupational health in your workplace	$\bigcirc$	$\bigcirc$	$\bigcirc$
Human Resources in your workplace	$\bigcirc$	$\bigcirc$	$\bigcirc$
"Access to Work" Employment support programme	$\bigcirc$	$\bigcirc$	$\bigcirc$
Fit for Work (website or telephone support)	$\bigcirc$	$\bigcirc$	$\bigcirc$
The Sutton Trust	$\bigcirc$	$\bigcirc$	$\bigcirc$
Disability Employment Advisor/ Job Centre	$\bigcirc$	$\bigcirc$	$\bigcirc$
Received work advice or work rehabilitation from an NHS therapist	$\bigcirc$	$\bigcirc$	$\bigcirc$
Received work advice or rehabilitation from any other occupational health practitioner	$\bigcirc$	$\bigcirc$	$\bigcirc$

43. Are there any other work-related support services that you are aware of, or have accessed in connection to your rheumatic and musculoskeletal condition?

44. Please use this space to tell us anything else about your rheumatic and musculoskeletal condition and your work that we have not asked.

45. Did you retire early or have to give up work due to your MSK condition? \*

🔵 Yes

🔵 No

## 46. Please give further details of your reasons for leaving employment

#### Service delivery

47. We would like to know about your priorities for delivery of rheumatic and musculoskeletal services.

Please place the following statements in order of importance, where 1 is most important and 4 least important. In order to answer this question you need to make at least one change in the order of priorities (using up and down arrows to change priority), even if you change it back again before submitting the question. \*

Seeing the same members of the care team

On demand appointments when I need them

Access to multi-disciplinary rheumatic and musculoskeletal care services at one location (even if travel is required)

Access to care provision locally (in my local town or village)

48. Do you have any issues getting your medicine(s)? e.g delivery \*

🔵 Yes

🔵 No

49. Please describe any issues that you have getting your medicine(s)

50. Do you have access to any of the following? Please select all that apply. \*

A land line

ſ

A mobile phone

Internet access at home

Internet access in public building such as library

I do not have access to any of the above

51. With regards to virtual (video) and telephone appointments, please indicate your response to the following statements: \*

	Always	Sometimes	Neutral	Not often	Never
My mobile phone reception is good enough to be able to have a telephone appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
My Internet connection/broadband speed is good enough to be able to have a virtual (video) appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l feel my condition can be well managed via phone appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l feel my condition can be well managed via video appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l save time by having a video or telephone appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l feel my condition can be well managed by an in person appointment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
I would like a mixture of virtual (video), phone or in person appointments depending on my needs	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
l require assistance or support to access virtual(video) appointments	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

52. With regards to services please state how much you agree or disagree with the following statements in relation to your rheumatic and musculoskeletal condition? \*

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Seeing the same staff for my care means I have consistency in my treatment	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
I would prefer access to less frequent but more locally available services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
I would prefer access to more frequent services even if they were further away	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Frequently changing staff gives me less confidence in my care	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Frequently changing staff gives a fresh perspective to my care	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

53. If you have any other comments about your rheumatic and musculoskeletal services, please detail these below.

## Goals and priorities for your rheumatic and musculoskeletal care

54. Apart from your Rheumatology team (including: consultant, rheumatology nurse, occupational health and physiotherapy) what other services are a priority for your rheumatic and musculoskeletal care?

Please place the following statements in order of importance, where 1 is most important and 5 is least important. In order to answer this question you need to make at least one change in the order of priorities (using up and down arrows to change priority), even if you change it back again before submitting the question. \*

Mental Health services

Complimentary services e,g osteopathy

Chronic pain services

Sexual health services e.g family planning

Sports and exercise medicine services

55. How important is it to you that your care enables you to:  $^{\star}$ 

	Very Important	Important	Somewhat Important	Somewhat Unimportant t	Very Jnimportan t	Not applicable to me
Stay in work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Go back to work	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Better manage pain	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Better manage fatigue	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Remain physically active	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Be able to socialise with friends and family	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Be able to look after children/grandchildren	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Remain engaged in hobbies and interests	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Enjoy physical relationships	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Care for an older relative	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

56. Do the services you currently access for your rheumatic and musculoskeletal condition enable you to meet your own priorities? \*

◯ Yes

🔘 No

57. Please tell us why the services you currently access do / do not help meet your priorities?

58. If there is anything else you'd like to tell us about your care priorities please tell us below.

59. With regards to the impact of COVID -19 on care for your condition please state how much you agree with the following statements. \*

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
COVID-19 has changed my priorities for care	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
COVID -19 has changed the way I have received care	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
There have been positive changes to my care due to COVID-19	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
There have been negative changes to my care due to COVID-19	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
I feel COVID-19 has changed the priorities of those who provide my care	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

60. Please give details of any changes to your care provision that came into place due to COVID 19 that you would like to continue after the pandemic?

## Access to Research

The following section is asking about your views on research in general and not this specific project.

61. Have you ever had the opportunity to take part in any research related to your rheumatic and musculoskeletal condition in the past? \*

- 🔿 No
- 62. Please tell us any reasons for not previously taking part in research. Please select all that apply \*



- ] Time commitment
- Difficulty attending study appointments
- No interest in research
- I lived too far away to be recruited
- My health board / trust wasn't involved in the study
- I didn't meet the inclusion criteria for the study
- I only wanted to take part in some aspects of the study
- I didn't get paid for taking part
- The study was too confusing
- ] My friends and family discouraged me from taking part
- Someone on my health care team discouraged me from taking part
- Not previously seen or heard of any opportunites
- Other (please detail below)

## 63. Please tell us any other reasons for not previously taking part in research.

## 64. Would you consider taking part in other research in the future? \*

◯ Yes

🔘 No

◯ Unsure

## 65. If you were to take part in other research would you be: \*

	Yes	No
Willing to travel to take part in the research (travel expenses reimbursed)	$\bigcirc$	$\bigcirc$
Willing to take part in research by telephone or video call if appropriate	$\bigcirc$	$\bigcirc$
Willing to become involved in the design of the research as a Patient Partner	$\bigcirc$	$\bigcirc$

66	. How would you like to be informed/find out more about research opportunities in
	the future?
	Diasco mark all that apply *

appointments

Please mark all that apply \*

As part of my usual heathcare
Social media

Charity e.g Versus Arthritis

Support groups

Prefer to find out information on my own



Other (please detail below)

67. Please detail any other ways you like to be informed/find out more about research opportunities in the future?

68. Is there anything else that you would like to comment on that we have not covered in the survey?

## Finally before you go

We may wish to contact you and invite you to take part in more study activities such as workshops or sharing our findings. At the moment, you are only asked to provide consent for us to contact you again. If you agree, we will send you further details at a later date. You will be free to decide if you wish to take part or not. You are free to change your mind and withdraw your consent at any time.

# 69. Please indicate whether you consent or not to us contacting you by ticking the relevant box below \*

I do not give consent to be contacted again

 $\bigcirc$  I give consent to receive further information about this research study

 $\bigcirc$  I give consent to receive further information about this, and other research studies

## Please provide contact details

Please note that this information below will be separated from the rest of the survey to ensure your answers remain anonymous. Thank you again for your help.

You can also click on the link below to see details of our Privacy Policy, this notice explains how the University of Aberdeen handles your personal information.

https://tinyurl.com/4rbmmc83 (https://tinyurl.com/4rbmmc83)

70. Full name \*

#### 71. Postal Address (optional)

## 72. Email \*

## 73. Telephone Number (optional)

## Thank you for completing the survey

If you have any questions about this survey you can contact Dr Kevin Stelfox by email: <u>rheumap@abdn.ac.uk (mailto:rheumap@abdn.ac.uk)</u>, or the Chief Investigator Dr Rosemary Hollick on <u>rhollick@abdn.ac.uk (mailto:rhollick@abdn.ac.uk)</u>, or you can visit our study website:

https://www.abdn.ac.uk/iahs/research/epidemiology/mapping-rmd-study-1688.php (https://www.abdn.ac.uk/iahs/research/epidemiology/mapping-rmd-study-1688.php)

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