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**BSRBR-AS: COVID-19 and musculoskeletal health
during lockdown (CONTAIN)**

**PARTICIPANT INFORMATION SHEET**

**What is the purpose of the study?**

You have previously taken part in the British Society for Rheumatology Biologics Registers in Ankylosing Spondylitis (BSRBR-AS), conducted by the Epidemiology Group at the University of Aberdeen. We are aware that during the COVID-19 pandemic there may have been changes to your everyday life and access to healthcare. In order to explore the impact of these potential changes we are undertaking an extension to the BSRBR-AS study, called CONTAIN. We want to find out about your current health and how this has changed since we previously contacted you. We are also interested in your recent experience of healthcare, and what you perceive as your current and future healthcare needs.

**Why have I been invited?**

You have been invited because you took part in BSRBR-AS conducted by the Epidemiology Group at the University of Aberdeen and agreed that we could contact you again about future studies.

**Do I have to take part?**

No, taking part in CONTAIN is completely voluntary. If you decide to take part you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will taking part involve?**

We will ask you to complete one online survey. The survey will take less than 20 minutes to complete. You will also be asked if you would like to take part in an interview, although we only need to interview a very small proportion of respondents, and you don’t have to agree to this in order to take part in the survey study.

**What will I be asked?**

You will be asked questions about yourself (including your employment), your physical and mental health, and your lifestyle (including smoking, drinking and exercise). Some of the questions will be familiar as we have asked them in your previous questionnaires, but other questions are new and will explore the issues related to the COVID-19 pandemic. We would also like you to be aware that some of these questions are considered sensitive data, such as questions on your mental health. We will also ask you at the end of the study if you would be happy to be interviewed. The interview would likely last around 60 minutes and be by telephone or computer link. It is still valuable for us, for you to complete the questionnaire, even if you don’t want to be interviewed.

**What will happen to the information I give you?**

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used**?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

**Where can you find out more about how your information is used**?

You can find out more about how we use your information:

• at www.hra.nhs.uk/information-about-patients/

• by asking one of the research team

• by sending an email to contain@abdn.ac.uk

• by ringing us on 01224 438030

• from the University Data Protection Officer, dpa@abdn.ac.uk or call 01224 272596

**What are the possible disadvantages and risks of taking part?**

Completing the online survey should only take 20 minutes of your time. Some participants may become upset or distressed when answering the questions. If you require additional support a list of useful organisations are provided at the end of the questionnaire.

**What are the possible benefits of taking part?**

There will not necessarily be any personal benefit to you in taking part. However you will be helping with our research to understand how the pandemic (and lockdown in particular) has affected the health of people with musculoskeletal symptoms and specific conditions, and to understand what are their health needs, to inform planning health care.

**What if I have a complaint?**

If you have any concerns with any aspect of this study please ask to speak to the researchers who will do their best to answer your questions – contact details are at the end of this Participant Information Sheet.

If you remain unhappy and wish to make a formal complaint, you can do this through the NHS complaints procedure. Further information about this can be obtained from:

· England: www.nhs.uk/nhsengland/complaints-and-feedback/pages/nhs-complaints.aspx

· Scotland: https://nhsnss.org/contact-us/

· Wales: www.wales.nhs.uk/ourservices/contactus/nhscomplaints

**Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. As with the main study data, no-one analysing the data will have access to your name and contact details and it is important to note that you will not be identifiable in any publications and your personal data will not be handed on to any external parties – in accordance with Data Protection legislation.

**Who is organising and funding the research?**

The study is sponsored and organised by The University of Aberdeen and is funded by a grant from Versus Arthritis and the British Society for Rheumatology.

**Who has reviewed the study?**

All research involving the NHS is reviewed by independent group of people, a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the North East – Newcastle and North Tyneside 2 Committee (formerly North-East – County Durham and Tees Valley Ethics Committee).

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|  | For further information, or if you have any questions, please contact:**Maureen Heddle (Assistant Study Coordinator)**E-mail contain@abdn.ac.ukTel: 01224 438030 |  |
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**Thank you for taking the time to read this Participant Information Sheet. It will be available online at** [www.abdn.ac.uk/iahs/research/epidemiology/pis-bsrbras-1824.php](http://www.abdn.ac.uk/iahs/research/epidemiology/pis-bsrbras-1824.php)

The NHS Health Research Authority offer independent and impartial advice on whether or not to take part in clinical research, see: [www.hra.nhs.uk/about-us/what-we-do/taking-part-or-getting-involved-research](http://www.hra.nhs.uk/about-us/what-we-do/taking-part-or-getting-involved-research).