Self-Referral Adult Permission to Contact (PTC) Form

Key information for potential A3BC participants

The Australian Arthritis and Autoimmune Biobank Collaborative, or A3BC, is a large team of Australian doctors and scientists who are researching arthritis and autoimmune diseases. As you probably know, these diseases can affect the joints, bones and connective tissues, often with your own immune system attacking other parts of your body. These are very complex diseases. To achieve its aims in adults and children, the A3BC works with the Australian Rheumatology Association (ARA), Australian Paediatric Rheumatology Group (APRG), and Australian & New Zealand ChiLdhood Arthritis Risk factor Identification sTudY (ANZ CLARITY).

A large and broad amount of biological, medical, environmental and lifestyle information needs to be collected from affected patients – to allow researchers a detailed look over time at how these diseases develop and why. This ongoing patient contribution of information and blood is vital to helping researchers develop new knowledge, better treatments, improved prevention and hopefully cures for these conditions. This is what the A3BC aims to do.

Full participation in the A3BC study would involve you:

1) Completing online surveys, typically emailed every 6 - 12 months,
2) Permitting access to your medical record and health data, and
3) Donating small samples of your blood, tissue or fluids (biospecimens).

- If you prefer, you could also partially participate, for example, only donate biospecimens and/or permit health data access.
- Biospecimens are typically collected within your routine care visits to the clinic, so that additional procedures are not needed.
- Your data is securely stored and deidentified (i.e. name and address removed) for privacy if released to approved researchers.

DOCTOR & SITE

Please provide your general practitioner's (GP) or specialist's (e.g. rheumatologist) contact details below. The A3BC will need to confirm your diagnosis with them before you can consent to participate.

Name of your General Practitioner (GP):

Name of your GP's clinic:

Your GP's phone number (if known):

Name of your Specialist

Name of your Specialist's hospital or clinic:

Your Specialist's phone number (if known):

I don't have a GP or Specialist (control participants only) ☐

PRIMARY DISEASE (A3BC to confirm with Dr)

Please select the participant's primary diagnosis or select them as a control. Select only one CIRCLE below.

Rheumatoid arthritis	○	Myositis (including Dermatomyositis)	○
Psoriatic Arthritis	○	Systemic Sclerosis / Scleroderma	○
Ankylosing Spondylitis	○	Gout	○
Spondyloarthropathy (non-AS/PsA)	○	Spinal pain	○
Vasculitis - ANCA-associated Vasculitis	○	Fibromyalgia	○
Vasculitis - Giant Cell Arteritis	○	Osteoarthritis	○
Polymyalgia Rheumatica	○	Mixed Connective Tissue Disease	○
Systemic Lupus Erythematosus	○	Undifferentiated inflammatory arthritis	○
Sjogren's Syndrome	○	Undifferentiated connective tissue disease	○

Other arthritis: Write name of disease

Other auto-immune/inflammatory: Write name of disease

Other vasculitis: Write name of disease

Other crystal arthropathy: Write name of disease

CONTROL (HEALTHY, AT-RISK, RELATIVES) ○

Date of Diagnosis (select only one circle):

Date: / / If specific date unknown: Less than 12 months ○ OR More than 12 months ○

FIRST-DEGREE RELATIVES

Does the participant have any first-degree blood relatives (biological parents, brother/sister, children) who have any of the diseases listed below in the Secondary Disease section? You may know of more than one relative.

Yes ☐

No ☐

Don't know ☐

If 'Yes', select the BOX(ES) below, in the 'Relative' column (right), for the disease(s) of your relative(s).

SECONDARY DISEASE & FIRST-DEGREE RELATIVES (A3BC to confirm with Dr)

Please select the patient's main secondary diagnosis. Select only one CIRCLE below in the 'Patient' column (left). *NA = children only.*

	Patient [1]	Relative [2]		Patient [1]	Relative [2]
Rheumatoid arthritis	○	☐	Gout	○	☐
Psoriatic Arthritis	○	☐	Spinal pain	○	☐
Ankylosing Spondylitis	○	☐	Fibromyalgia	○	☐
Spondyloarthropathy (non-AS/PsA)	○	☐	Osteoarthritis	○	☐
Vasculitis - ANCA-associated	○	☐	Mixed Connective Tissue Disease	○	☐
Vasculitis - Giant Cell Arteritis	○	☐	Undifferentiated inflammatory arthritis	○	☐
Polymyalgia Rheumatica	○	☐	Undifferentiated connective tissue disease	○	☐
Systemic Lupus Erythematosus	○	☐	Juvenile Idiopathic Arthritis (unknown subtype)	*NA*	☐
Sjogren's Syndrome	○	☐	Vasculitis - Kawasaki disease	*NA*	☐
Myositis (including Dermatomyositis)	○	☐	Paediatric Myositis (incl. Juvenile Dermatomyositis)	*NA*	☐
Systemic Sclerosis / Scleroderma	○	☐	Paediatric Cutaneous Scleroderma	*NA*	☐
Other arthritis:	○ [1]	☐ [2]	Write name of disease [1]		Write name of disease [2]
Other auto-immune/inflammatory:	○ [1]	☐ [2]	Write name of disease [1]		Write name of disease [2]
Other vasculitis:	○ [1]	☐ [2]	Write name of disease [1]		Write name of disease [2]
Other crystal arthropathy:	○ [1]	☐ [2]	Write name of disease [1]		Write name of disease [2]

ADULT PARTICIPANT'S DETAILS

*Given Name**

Middle Name

Surname

*Preferred First Name (if different to *)*

Date of Birth (DD-MM-YYYY) / /

Gender: Male ☐ Female ☐ Non-binary ☐

Phone (home) ( )

Mobile Phone

Suburb / Town

State

Postcode

E-mail address (please print clearly)

PLEASE ADD AN EMAIL. Email is the preferred method of communication used by the A3BC.

CONSENT TO RELEASE CONTACT DETAILS

I hereby give my consent for my contact details to be released to the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) and Australian Rheumatology Association Database (ARAD). I also understand that my contact details will be kept secure and will not be used by other parties for any other purpose without my permission. I understand that after completing this form, a Project Co-ordinator from the A3BC-ARAD will contact my specialist or GP to verify my diagnosis I have indicated above. Once my diagnosis is verified, the Project Co-ordinator will contact me to explain the study, my involvement, and ask for consent to enter me into the A3BC-ARAD.

Please tick the box ☐ ***Today's date (DD / MM / YYYY):*** / /

If you have any concerns or questions you can talk to your specialist, A3BC Co-ordinator (email info@a3bc.org.au) or Lead A3BC Investigator Professor Lyn March on (02) 9463 1891.

OFFICE COMPLETION ONLY:

For non-A3BC GPs/specialists - Referred to nearest A3BC recruitment/collection site:

For remote participants - Mailout collection only: ☐