



ARAD NEWSLETTER

Australian Rheumatology Association Database

Jan 2009

Once again the ARAD project team would like to thank ALL participants for their contribution to ARAD. There are over 2,600 participants under the care of 190 rheumatologists across Australia. In particular, we would like to thank all the people who have been contributing to ARAD 'long term'. Thank-you for all your patience and support. You are helping us determine the long term benefits and safety of new biologic drugs for all Australian patients with inflammatory arthritis.

It is our duty to remind you that participation in ARAD is voluntary which means that you are free to withdraw from the project at any time (but we hope you don't because the information you give us is very important for following the effects of the treatments on your arthritis). If you no longer complete questionnaires for ARAD, thank-you for your participation so far. Should you wish to recommence, please contact your state coordinator (details overleaf) so we can update your details and get you active in ARAD again!

Early Results - Update

Ankylosing spondylitis (AS)

Some quick facts about ARAD participants with AS:

- There are ~478 people with ankylosing spondylitis in ARAD
- About 60% of these commenced biologic drugs (e.g. etanercept, infliximab, adalimumab) within 6 months of enrolling in the registry.
- They were ~45 years old (so quite young!)
- ~75% were men
- On average, there was a delay of about 5 years between their symptoms first appearing and them being told they had AS. Rheumatologists call this the 'delay in diagnosis' and it is one thing they are keen to reduce because the earlier the diagnosis usually the better a person responds to treatments such as exercises and drugs.
- About 60% of patients said that they had at least one illness in addition to their AS when they started taking a biologic drug. These were most commonly gastro-intestinal disease (29.0%), hypertension (24.7%), eye disease (17.3%) and depression (13.6%).

What we have learned from these results:

- people with AS are actually quite unwell when they commence biologics.
- these illnesses must be considered when we are trying to see if the biologics drugs are working or not.
- people with AS should take care with their general health and fitness

Stop press: Mabthera

Some participants have said they are unsure whether they have actually stopped Mabthera for good or whether they are simply 'in between' doses. This is because there is a long time between Mabthera infusions. You will know if you have **officially** stopped Mabthera when you are told by your rheumatologist that you "haven't responded to Mabthera" and you are to stop it. The date the doctor told you this becomes the date you put down in the questionnaire as the 'stop' date. If you are a responder you say that you are still on Mabthera even if you are not sure whether you will need another infusion or not.

Recent developments in ARAD

Online Web-based data entry update

This is still being developed. We still plan to run a 'dual' system. That is, participants will have the option of a paper questionnaire (like there is at the moment) or completing their questionnaire online via computer. We hope to have this up and running in 2009.

Changes to questionnaire

We have listened to your feedback and are making the following changes to the ARAD questionnaires:

1. We have simplified the 'cancer' page. Now you can simply tick 'yes/no' for any new cancers since your last questionnaire.
2. We have tried to clarify the 'medication' page. You can now indicate at the top of the page if you have started, stopped for more than 4 weeks or recommenced a biologic since your last questionnaire. If not, you can skip that page to the next question.
3. We have added a 'hospitalisation' question at the end in case the list of reasons for hospitalisation earlier was incomplete.

Frequently asked questions

Here are some answers to questions that participants frequently ask us

Q. My answers to the questions have not changed since my last questionnaire. Do you want me to keep completing the questionnaires?

A. Yes. We are looking for changes in your health. We also need to know if there has not been a change. Now, several questions can now be skipped over unless there has been a change, making it quicker to complete.

Q. I feel well. Is there any point to doing the questionnaire any more?

A. Yes. We are interested in seeing if your health gets better or worse in the future. We are also interested in seeing the effect of the treatments over a longer time because the drug trials done to test the drugs usually do not go for longer than 1 to 2 years. For these reasons we would appreciate it if you can continue to complete the questionnaires each time.

Q. I am no longer taking biologics. Do I need to complete the questionnaire?

A. Yes. The questionnaires are also for people who are no longer, or have never taken biologics. This gives us important information to compare the health of people who do and do not need to take the biologic drugs.

Q. The quality of life questions are all similar. Do I have to answer all of them?

A. Yes. Each quality of life questionnaire is measuring something slightly different and so although there are similarities between them we would appreciate you completing each one.

Q. Do I have to return the completed questionnaire promptly?

A. Yes. If everyone completes and returns the questionnaires in a timely manner we get a precise picture of how everyone's health is each 6 months. However, we know that lots of things can come up that may get in the way of doing the questionnaires and we still want that information from you so will gladly receive it at any time!

Q. I have had joint surgery recently and as a result have a lot of pain and cannot get around. Does it matter that my pain and immobility are not due to arthritis when I answer the quality of life questions?

A. No, it does not matter. The questions ask about your overall health so simply give the answer that best describes how you feel overall. If you wish you can provide further details in the 'Comments' section on the last page of the questionnaire.

Kid's corner

The number of children in ARAD is now 115! Welcome aboard!

Quirky facts

Did you know that sharks have quite poor eyesight? They make up for it with a very good sense of smell though and are also aware of movement. Although they have very sharp teeth these are really only for cutting food. They don't actually chew (they just gulp!). Thankfully there are fewer shark attacks in Australia each year than there are people hit by trams - and that is not many!

Funding and resources

We are very grateful to our funders. ARAD currently receives funding from the Australian Government National Health and Medical Research Council (NHMRC), Monash University, Cabrini Health as well as educational grants from Abbott, Wyeth, and Roche pharmaceutical companies.

Our Staff

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ARAD Scientific Advisory Committee

We would like to acknowledge and thank the members of the ARAD Scientific Advisory Committee and Management Committee:

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