



Third edition October 2019

Editors - Beth Dillon and Laura Lunt



Happy autumn readers and a very warm welcome to all of you who are new to Your Rheum & YOURR News!

- ❖ If you have news items you want covered or stories / resources / events / photos to share, get in touch and we can include them in the next edition of YOURR News
- ❖ We are also always looking for new Your Rheum members - if you know of a young person aged 11-24, living with a rheumatic condition and interested in research, get in touch with us.

Contact us using [your.rheum@manchester.ac.uk](mailto:your.rheum@manchester.ac.uk)  
OR find us on Facebook, Twitter, or via the website [yourrheum.org](http://yourrheum.org)

## Research Round Up

Here are some highlights of the work Your Rheum has been involved in since April...

**Chronic Pain** – We welcomed researchers Line and Jay to the last Your Rheum meeting, up in sunny Edinburgh. The group worked really hard at decorating cupcakes (it's a messy job but someone has to do it). Sounds like madness? The research team wanted members of Your Rheum to help them design a research priority setting activity for children and young people living with chronic pain. We were able to decorate the cakes exactly how we wanted and later explain what each piece of decoration represented about our lives and living with a rheumatic condition. From doing all of this, Line and Jay were able to see if the activity was easy to do, fun and explore hidden messages important to young people, without us realising. We hope the chronic pain workshop in Bath goes well guys, keep us posted on how the cakes go down.

**Patterns of disease (CLUSTER study)** – We also welcomed Stevie to the meeting. Stevie brought, which looked complicated at first, graphs from her study results, as she needed a hand understanding these results and what they really mean. Stevie's graphs showed information from children and young people with JIA, over a period of time. This information was put into a computer and using clever maths, the computer was able to predict patterns. For example, pain experienced over time and swelling over time. These aspects of disease were sometimes low then high, or constantly high. The group were able to draw on big pieces of paper their own experiences over time and talk about them. This helped Stevie understand if her results were similar or familiar to young people, or if the computer got it completely wrong. It was really interesting to hear many people in the group could see their own experience off disease in at least one graph.

## NOTICE Board

- ❖ Versus Arthritis are recruiting for a new Young Person's Panel. Are you aged 18-25, interested in helping Versus Arthritis, living with arthritis or a related condition? Link for more details on how to apply <https://www.versusarthritis.org/get-involved/volunteer/#young-people-versus-arthritis-advisory-panel>
- ❖ **HAPPY BIRTHDAY Your Rheum!**  
3 years old this month. Help us celebrate at the next meeting, details below.
- ❖ Next Your Rheum Meeting **9<sup>th</sup> November, 1-4pm, Cardiff.** Contact [your.rheum@manchester.ac.uk](mailto:your.rheum@manchester.ac.uk) if you want to come along.



## SPOTLIGHT

### Member of Your Rheum



- Name:** Adam Agowun
- Least favourite food:** I'm a human vacuum. I eat everything. But if I had to pick, pizza
- 3 words to describe Your Rheum:** Vital, reassuring, and fun!!!
- Best holiday:** If we're talking about where I've been, then New York. If we're talking about other destinations, Italy
- Would you rather be a big hamster or a tiny Elephant?** I've got the ears of an elephant already so let's go with hamster

**ONE STEP AT A TIME** launched this year with one mission, to increase support for children and young people with disabilities and/or any long term health conditions. For more info go to:

**Facebook:**  
[https://www.facebook.com/One-Step-At-A-Time-2303564063199616/?modal=admin\\_todo\\_tour](https://www.facebook.com/One-Step-At-A-Time-2303564063199616/?modal=admin_todo_tour)

**Blog:**  
[https://onestepatatime.family.blog/2019/06/24/introducing-us/?fbclid=IwAR2WmuvGQr29xm6rFXCYCMBaEuenSHv-v9WqplLi9Okdf\\_afM3ULhZCnmT3A](https://onestepatatime.family.blog/2019/06/24/introducing-us/?fbclid=IwAR2WmuvGQr29xm6rFXCYCMBaEuenSHv-v9WqplLi9Okdf_afM3ULhZCnmT3A)

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# ★ Get Rid Of The Jargon ★

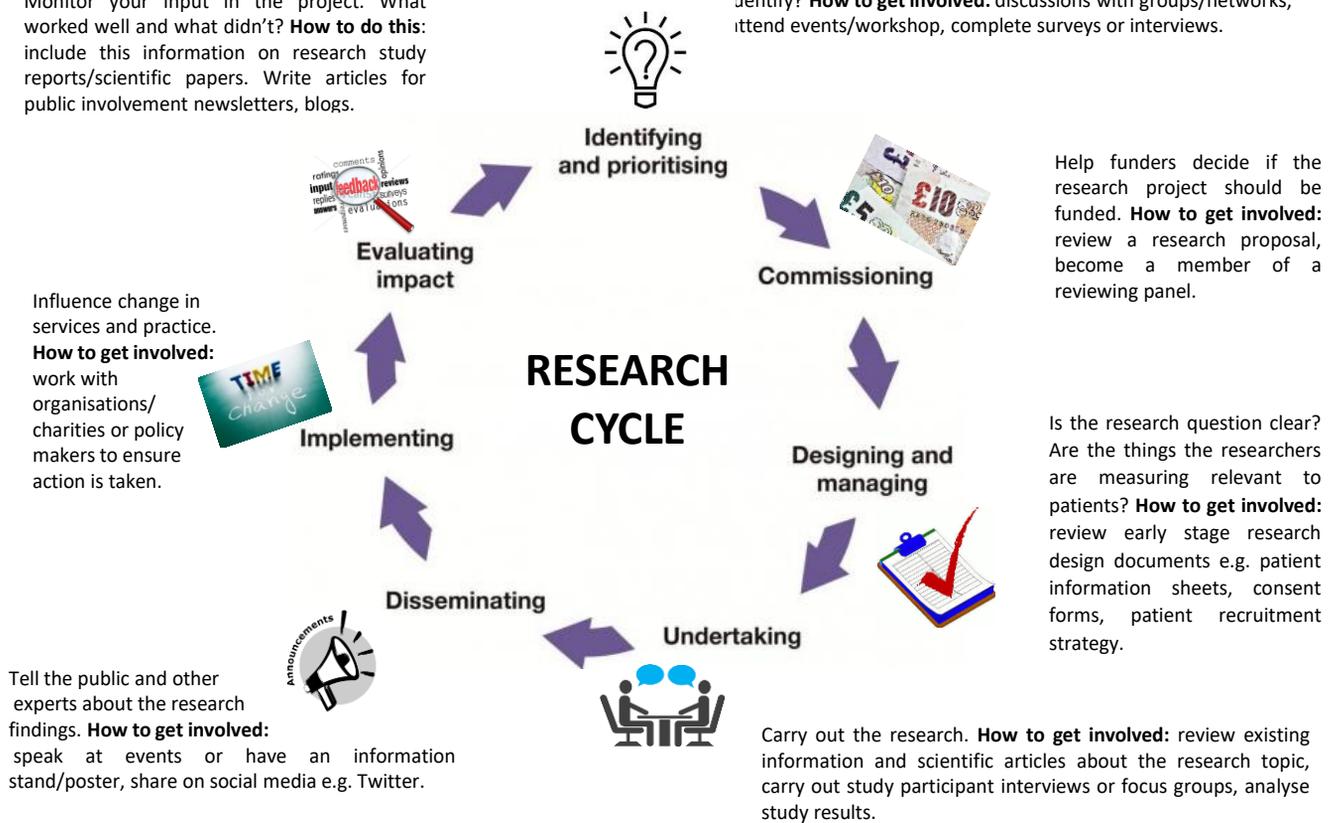
**TNF:** Stands for Tumour necrosis factor and is what is called a cell signalling protein or cytokine. Basically this means it is a cell which communicates with other cells in all the various bodily processes. When it increases however it causes inflammation as occurs in arthritis. Drugs like etanercept or adalimumab are called anti-TNF biologic drugs, they block the action of TNF thereby reducing and/or preventing inflammation.

**ESR:** Stands for erythrocyte sedimentation rate. It is a type of blood test that measures how quickly erythrocytes (red blood cells) settle at the bottom of a test tube that contains a blood sample. Normally, red blood cells settle relatively slowly. A faster-than-normal rate may indicate inflammation in the body as happens in arthritis or lupus but also in infections.

**CRP:** Stands for C reactive protein and is a protein produced by the liver. The test is similar to ESR but will return to normal much quicker than ESR so is particularly useful to monitor infections. It is interesting in lupus as it is usually normal in lupus but the ESR increases when lupus is active. This is unlike in arthritis when BOTH the ESR and CRP generally go up when there is a lot of joint inflammation.

Monitor your input in the project. What worked well and what didn't? **How to do this:** include this information on research study reports/scientific papers. Write articles for public involvement newsletters, blogs.

Research priorities important to you? What research questions can you identify? **How to get involved:** discussions with groups/networks, attend events/workshop, complete surveys or interviews.



## Library

### UK Youth Parliament

- Have your say! Make Your Mark Ballot which will decide on what is debated on the green benches of the House of Commons by members of the Youth Parliament.

<http://www.ukyouthparliament.org.uk/makeyourmark/>

### Interactive resources

- GenerationR** (National Network (GenerationR Alliance) of Young People's Advisory Group's (YPAGs) based across the UK) have a number of interactive resources to help explain aspects of research and how to get involved.

<https://generationr.org.uk/games-quizzes-more/>