

Happy February 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

OR find us on Facebook, Twitter, or via the website yourrheum.org

Research Round Up

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

Continuous data monitoring event: Your Rheum in partnership with Eli Lilly - on 8th December last year Your Rheum held a workshop in central Manchester, which was all about using electronic devices (e.g. fitbits and Apple watches) to track information such as heart rate and sleeping patterns. The event was in partnership with Eli Lilly (a drug company), who are interested in knowing what young people think about using this type of data (also called continuous monitoring), in drug clinical trials in Juvenile Arthritis. The day was fantastic, eight young people attended and discussed what they liked and didn't like about this type of data collection and what the key features would be of ideal devices. As well they raised important questions about data governance (e.g. where will the information be stored and who has access to it). Findings from the workshop have been summarised and submitted to an international rheumatology conference (EULAR) as an abstract. Well done Imogen Bolger (member of Your Rheum) who is a co-author on the abstract. Good luck with the abstract guys.

Exploring educational challenges in young people with Juvenile Idiopathic Arthritis – Researchers at the University of Bath and University of Stirling, worked with Your Rheum towards the end of last year. They developed an online activity for Your Rheum members to get involved in, which was helping them with their research funding preparation. Abbie and Line, members of the research team, are wanting to explore the challenges young people with JIA might face in education. The team wanted to gain important feedback about whether they are asking the right research question and whether the description of the study makes sense. Your Rheum's insight on this topic has helped to inform a funding grant application which Abbie and Line submitted in November 2018 to Bath Institute for Rheumatic Diseases. Fingers crossed this important research is funded and we look forward to hearing all about it.

NOTICE Board

- ❖ Next Your Rheum Meeting **13th April, 1-4pm, Edinburgh**. Contact your.rheum@manchester.ac.uk if you want to come along.
- ❖ World Young Rheumatic Diseases Day (**WORD Day**), **18th March** is an annual event to spread the WORD that children and young people get rheumatic diseases too. <https://www.pres.eu/activities/word-day/about-the-word-day.html> Twitter: @WORDday2019
- ❖ Your Rheum has joined the GenerationR Alliance <https://generationr.org.uk/about/>, they are a network of young persons advisory groups from across the UK, who like Your Rheum, are involved in paediatric (children's) health research.



SPOTLIGHT

Member of BANNAR



- Name:** Wendy Thomson
- Least favourite food:** Anchovies
- 3 words to describe Your Rheum:** Insightful, supportive, fun
- Best holiday:** African safari
- Would you rather be a big hamster or a tiny Elephant?** Neither, but if I have to choose a big hamster

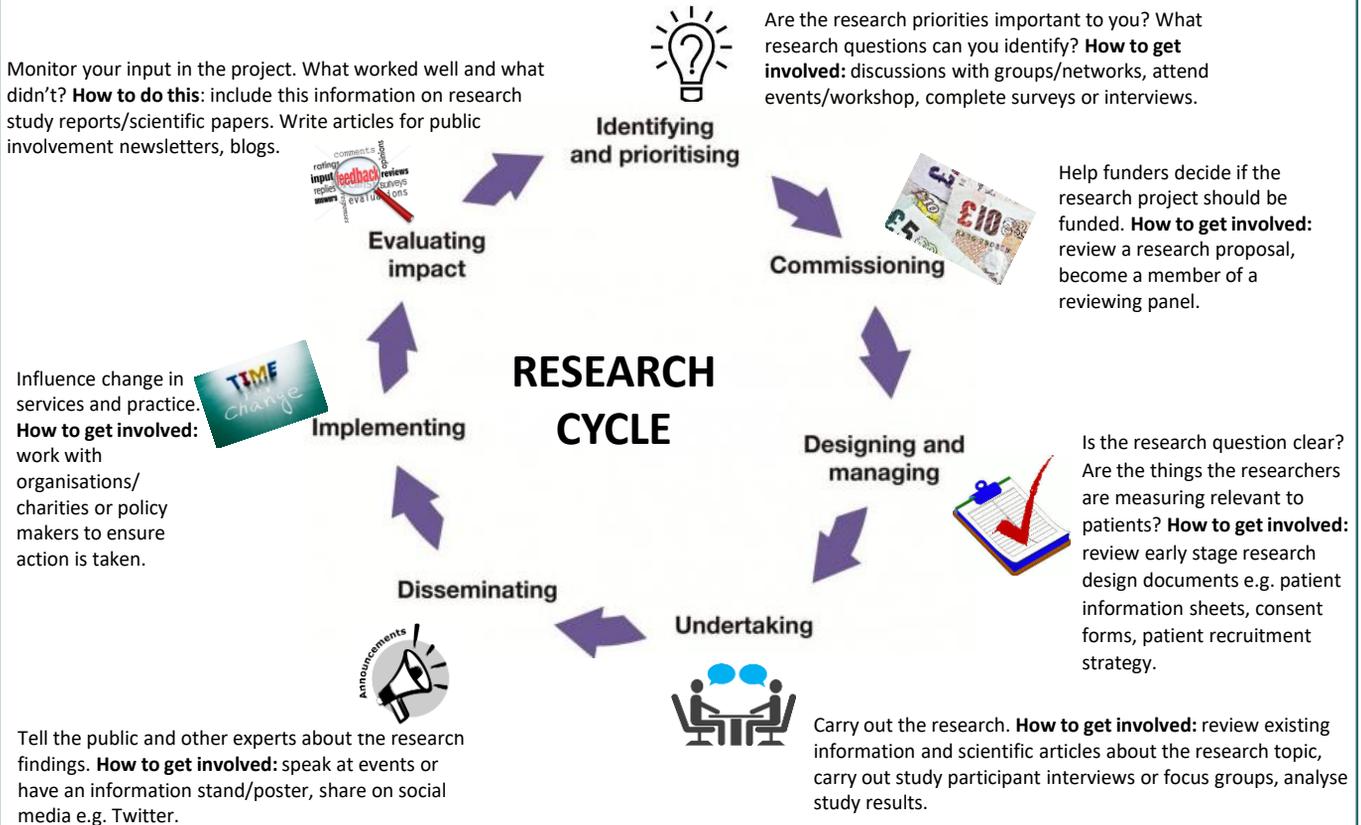
Send Laura a short message or quote for the WORD Day travelling message board - this is your opportunity to tell the public what you want them to know about living with a rheumatic condition.
Deadline 10th March
laura.lunt@Manchester.ac.uk



★ Get Rid Of The Jargon ★

Continuous data monitoring: a term used to describe the collection of information such as heart rate, blood pressure, sleeping pattern using devices such as fitbits and Apple smart watches. Information is collected over a certain time period (for example, once a day for two weeks).

Research cycle: the National Institute for Health Research (NIHR) have explained (below) the different stages you (patients/public) can get involved in research.



Library

National young person advisory groups / networks relating to health and wellbeing

- **British Youth Council** (*aims to empower young people aged 25 and under to influence and inform the decisions that affect their lives. BYC also run NHS England Youth Forum which aims to give a voice to young people to express their thoughts on the health issues that matter most to them*)

<https://www.byc.org.uk>

- **The Association for Young People's Health (AYPH)** (*is the UK's leading independent voice for youth health. Who work to improve the health and wellbeing of 10-24 year olds*)

<http://www.youngpeopleshealth.org.uk/resources>

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/>

- **National Children's Bureau** *Jack and Tina - share their experiences of transition and examine what data tells us about the needs of these young people. This animation was developed by Young Research Advisors on behalf of the Children's Policy Research Unit at UCL.*

https://www.youtube.com/watch?v=u_NG0Vb3tec