THE BUZZ!

Winter 2025

This is an update for our participants who are part of the **UK JIA Biologics Registe**r and their families.

UK JIA Biologics Register is the collective name for the **BCRD Study** and the **BSPAR Etanercept Study**. These research studies look at the long-term safety and effectiveness of treatments for Juvenile Idiopathic Arthritis.

The studies have been running at the **University of Manchester** for over 15 years; the research team continue to examine the data that is collected to answer important questions about these treatments.

Thank you for your involvement in these important studies!
Professor Kimme Hyrich, Chief Investigator

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- **Latest Research**
  - machine learning and JIA
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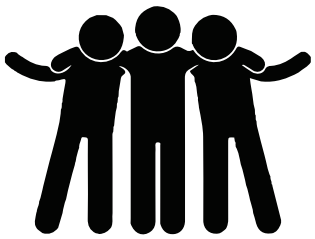
- **Quiz**: Professor in a Pickle!
- Introducing our **patient partners!**
- **Contact us!**



Over **3,500** children and young people with JIA have been recruited to these studies so far. Information about any changes to **medication**, new **illnesses** and how **joints** are affected is collected on an annual basis.

This means that there is a **lot** of information for our researchers to look at! We want to share some recent research results with you.

If you have any questions or any suggestions about what our researchers could look at next please get in touch!

LATEST RESEARCH

__Dr Stephanie Shoop-Worrall__ discusses her latest research from the CLUSTER consortium (which includes data from the UK JIA Biologics Register). This research looks at how AI can help determine which treatment will work best for children and young people with JIA .

BACKGROUND

Methotrexate (MTX) is a common first-choice treatment for young people with juvenile idiopathic arthritis (JIA).

However, it only works well for about half of them.

AIMS

1) To improve treatment decisions, CLUSTER researchers used artificial intelligence (AI) to find groups of young people who experienced different patterns in their disease and its impact after taking MTX.

2) See how these AI-based response patterns compared to traditional ways of measuring treatment 'success'.

METHOD

The researchers studied children and young people who started MTX before 2018 using data from multiple hospitals in the UK.

They tracked **key disease impacts** over a year:

- joint swelling
- how well the doctor thought the young person was
- wellbeing of the young person
- a blood marker of inflammation .

They used **AI** to group patients into six response types, based on how their condition and its impact changed over time.

WHAT WAS FOUND?

The **6** response types were:

Fast Improvers
(key impacts all got better six months after starting MTX)

Slow Improvers
(key impacts took a year to get better),

Improve-Relapse
(some improvement then worsening)

Persistent Disease
(little to no improvement)

Persistent Doctor Concern
(young person felt better, but doctors still thought the disease could be better controlled)

Persistent Parent Concern
(doctor thought disease looked well controlled, young person still had issues like pain and issues doing everyday tasks).

- Factors like **age, ethnicity**, and **initial disease severity** influenced which group patients fell into.
- Traditional scoring methods couldn't fully capture how different patients improved or relapsed over time. They also couldn't pick out young people whose disease and its impacts didn't all improve at the same rate.

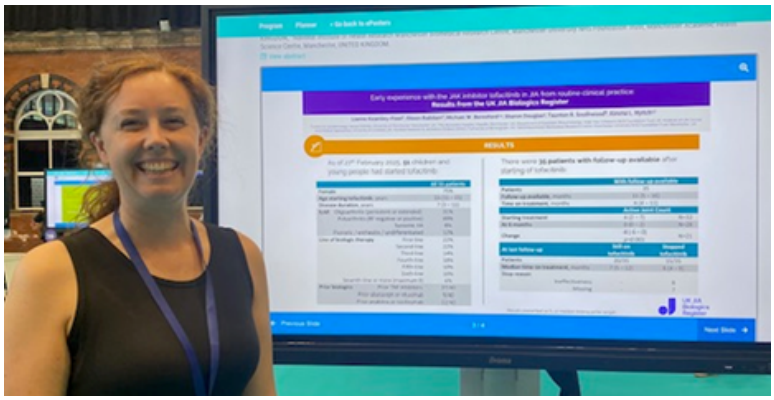
WHY THIS MATTERS

This AI-based approach shows that the standard way of judging treatment success (a simple yes/no measure) is too limited. Instead, recognizing distinct response patterns could help doctors personalize treatment plans for children with JIA.

This would make sure each young person gets the best possible care, tailored to which part of their disease and its impact are causing issues.

LATEST RESEARCH

Co-Lead of the UK JIA Biologics Register, ***Dr Lianne Kearsley-Fleet****, presented her work on tofacitinib at the British Society for Rheumatolgy conference 2025 in Manchester.*



Early experience with tofacitinib (a new treatment in JIA) from routine clinical practice

Within the UK JIA Biologics Register, we have over 50 children and young people who have started the JAK inhibitor, tofacitinib.

These children tend to start this advanced therapy at a slightly older age, having had their JIA for longer and previously tried at least one other biologic therapy.

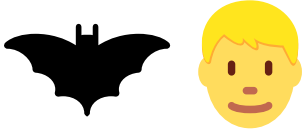
For those children who had information available 6 months after starting tofacitinib, the number of joints they had with active arthritis appeared to reduce, and over half the children were still on therapy at their last clinic appointment.

Our data suggests that tofacitinib could be a very effective treatment for JIA even after multiple prior biologic therapies.

PROFESSOR IN A PICKLE!

Professor Kimme needs to figure out the names of these films but she only has emoji clues. Can you help her?

Answers at the bottom of the page!

1 

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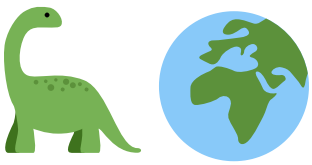
6 

1. Batman, 2. Elf, 3. Wicked, 4. Frozen, 5. Minecraft, 6. Jurassic World

REPRESENT!

The UK JIA Biologics Register has a **Steering Committee,** which includes doctors, researchers and patient partners. These patient partners ensure that people with experience of JIA are represented in the research.

The steering committee meets twice a year to make sure that the research is being carried out well, and discusses any questions that might need to be answered using the data.

Let's meet our patient partners!

Debbie Wilson was diagnosed with JIA as a child, and her daughter has also been diagnosed. She has been a member of the steering group for several years and wants to ensure that the voices of patients and parents are represented in the research that help shapes treatment and improved care for anyone living with this disease. Debbie is also proud to represent the community supported by her charity Inflammatory Arthritis UK.

"Many important questions about JIA remain unanswered - why do some children respond well to treatment while others do not? What are the long-term effects of being on medication for years? it's been inspiring to witness the dedication and passion of researchers working to improve the lives of children and adults with JIA. My hope is that future research will move us closer to removing the trial-and-error approach to treatment. For families, watching a child suffer through medications that didn't work is heart breaking. Anything that brings us closer to more precise, effective treatment would be an incredible step forward"

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Peter Foxton joined the National Rheumatoid Arthritis Society (NRAS) charity as CEO in the summer of 2024. Having been involved in healthcare charities for many years, he understands the importance of this type of research and listening to and involving patients in the development of treatments and care pathways.

"Before I joined NRAS, like much of the general population, I had no knowledge of the impact of inflammatory arthritis on young people and their families.
I hope by joining the committee I can represent those people as well as support the register by offering access to our community. I hope that greater understanding of how treatments work and research that includes people with lived experience will ultimately lead to improved patient care and better outcomes for young people with JIA!"

REPRESENT!

Dr Lucy Peacock is a a Senior Research Fellow working at the University of Cambridge. She was diagnosed with JIA at the age of three, and in recent years diagnosed with an additional inflammation-related condition: ulcerative colitis. She switched to biologics just before starting university and said this change in treatment had life-altering effects at a crucial time in her life, granting her the confidence to live and work independently.

"I have no doubt that healthcare is best informed by the perspectives of those most affected by it: patients and their families. Steering Committees like this one help ensure that real patient needs – not just assumptions – are being heard. If by sharing my journey, insights and challenges I can contribute to improving care for future patients, then I feel that it is my duty to do so.

I really enjoy how mutual learning happens in our meetings. Not only do medical professionals and researchers better understand my patient experience, but I have gained insight into medical research that I would not otherwise experience. In particular, I have appreciated the opportunity to provide feedback on academic journal articles.

I want JIA researchers to continue to be responsive to patients' stories, recognising that 'success' is more than just clinical outcomes. As someone who transitioned to biologic treatment in 2008, I have a personal hope that JIA research is forward-looking, prioritising how to better understand long-term and adulthood outcomes for those who have experienced biologics over a significant number of years".

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CONTACT THE TEAM

It is so important for us to hear the voices of people affected by JIA and find out what is important to you.

*We would **LOVE** to hear from you if you have any questions you would like to see answered, or any other suggestions for our research!*

Please contact the Study Coordinators if you have any questions :

Katy (right)
Katy.Mowbray@manchester.ac.uk
Emily (left)
Emily.Sutton@manchester.ac.uk

https://sites.manchester.ac.uk/bcrdbspar/for-participants/