# **Preconception & Inflammatory Arthritis**

A co-produced Realist Synthesis of methods supporting family planning discussions and preconception care for women with inflammatory arthritis









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**Background:** Chronic conditions add extra complications to family planning considerations, with additional physical challenges, potentially teratogenic medicine managing their condition, and queries over heredity to name a few. Patients with inflammatory arthritis (IA) want support to have 'better' conversations with their healthcare team regarding their family planning<sup>1</sup> To understand the context of existing support for women with IA and their healthcare team, in family planning conversations, a realist literature synthesis of the literature was conducted<sup>2</sup>

#### Methods:

- . Collaborative working between academic and patient reviewers
- . Realist methodology: what works, for whom, in what circumstances
- . Iterative literature search to firstly understand the research area, next generate initial theories for understanding what works for whom, in what circumstances.
- . These initial theories were shared with patients and practitioners to ensure they represented a realistic clinic/patient experience
- . Theories then tested against the wider literature (including academic and grey literature and charity resources (webpages and information leaflets).

### **Results:**

26 realist 'initial' theories were identified under three core themes: training and education, modelling behaviours, and recording data.

These theories are formulated in **C**ontext-**M**echanism-**O**utcome (CMO) format, demonstrating the highly relevant nature to this patient population, and how these theories can be applied in practice. The three key CMO theories are:

## Contexts

- 1.Family planning conversations are inconsistent, in their delivery, content, frequency, and patient recall of them
- 2. <u>Limited time & lots of information</u> in each appointment
- 3. Uncertainty of how their arthritis will affect planning/ raising children means some women feel unable to proceed with a pregnancy

# Mechanisms

- A physical tool, held by the patient, which is:
  - Summarising each family planning conversation
  - a helpful reminder for the patient of what was said in them,
  - a place to record questions for staff, and the answers
  - reminds staff to repeat conversations, at drug/ relationship change
- brought to appointments in secondary care and/or annual primary care reviews
- Modelling behaviour (peer-run support lines, online & face-to-face groups, public media campaigns (e.g. Versus Arthritis) that show 'women like them' having a family whilst having similar health challenges with children

# Outcomes

- Improve patients recall of safe family planning,
- · reduce unplanned pregnancies
- reduce time needed for family planning conversations
- avoid repetition, and identify relevant changes
- prompt for regularly revisiting these discussions
- can provide reassurance about starting or growing a family

Conclusion: There are simple, cost-effective methods which could greatly improve Shared Decision Making in appointments, reduce decisional conflict, anxiety over choices; and increase knowledge, self-management, and satisfaction in patients' own family planning choices. The results from this research suggests that includes a physical tool, a paper booklet, which includes a Decision Aid (basic information, possible benefits and challenges for each option, space to support women to weigh up this information and make decisions). Due to the demonstrated need to revisit these conversations over time, there must be space for this document to expand (add additional pages) over time. More research into how this tool would best be formatted, and how we support different clinical settings to use this tool, needs to be conducted.

**Next Steps:** This synthesis will be combined with analysis from staff focus groups and patient interviews, to help coproduce an inexpensive intervention to support staff and patients make informed family planning choices they are happy with; and how to best use this intervention in different primary and secondary care settings.

References: 1. Phillips, R., Pell, B., Grant, A. *et al.* Identifying the unmet information and support needs of women with autoimmune rheumatic diseases during pregnancy planning, pregnancy and early parenting: mixed-methods study. *BMC Rheumatol* **2**, 21 (2018). https://doi.org/10.1186/s41927-018-0029-4. 2. FAMILIAR Study literature review protocol: https://www.crd.york.ac.uk/PROSPERO/display\_record.php?RecordID=138550.





