Information needs of women with rheumatoid arthritis concerning pregnancy and post-natal care

August 2015

THE UNIVERSITY OF
MELBOURNE

Arthritis
VICTORIA
inc. OSTEOPOROSIS VICTORIA

Project team

Dr Ilana Ackerman (Chief Investigator)
Senior Research Fellow, Melbourne EpiCentre
The University of Melbourne

Associate Professor Andrew Briggs (Chief Investigator)
Senior Advisor
Arthritis and Osteoporosis Victoria

Associate Professor Sharon van Doornum (Chief Investigator)
Consultant Rheumatologist, Melbourne Health

Dr Joanne Jordan (Co-Investigator)
HealthSense (Aust) Pty Ltd.

Margaret Ricardo (Project Officer)
Research and Knowledge Unit (Musculoskeletal Help Line)
Arthritis and Osteoporosis Victoria

Contents

Suggested citation:
Ackerman IN, Jordan JE, Ricardo M, van Doornum S, Briggs AM (2015): Information needs of women with rheumatoid arthritis concerning pregnancy and post-natal care. Melbourne: Arthritis and Osteoporosis Victoria.

1. Background

Rheumatoid arthritis (RA) is an autoimmune disease which affects women of reproductive age[1] and represents a sizeable economic burden in Australia[2]. Women who live with RA face a number of challenges and decisions in negotiating the journey to parenthood due to the symptoms associated with the disease, the potential for poorer pregnancy outcomes and the potential side-effects associated with medications used to manage RA[3, 4]. As some medications used to limit RA-associated joint damage are contraindicated during pregnancy and lactation, careful medical planning is required to stabilise disease activity and promote remission prior to conception[1] and to modify medication regimens. While disease activity may improve during pregnancy (although this is variable[1]), research and anecdotal evidence indicates that many women experience moderate to severe post-partum flares[5] which impact on their ability to care for their infant and themselves. Qualitative research from the United States (US) has shown that RA can impact significantly on family planning decisions, with women raising valid concerns about the impact of medications on an unborn baby, the heritability of RA and their ability to physically care for a young child[6]. The need for accurate and evidence-based information to support women with RA and their families through this important stage of their lives is clear.

While studies have identified substantial information needs among people with RA, previous research has focused primarily on issues related to treatment options and their side effects[7, 8] or the accessibility of RA information[9]. Research involving people with RA from the United Kingdom and the US has shown that the need for information was greatest among women[7, 8]. However, no studies have explored the information needs of women with RA concerning pregnancy, post-natal care and early parenting or preferred modes of information delivery, leaving an important gap in the literature.

1.1 Significance and expected benefits to the community

It is anticipated that the findings of this study will be used to plan, develop and implement new evidence-based educational materials, which will optimise the provision of information to women with RA and facilitate self-management, empowerment and health literacy. This study has a range of potential benefits to the community, from informing the development of new educational materials to improving the services provided by arthritis consumer organisations and guiding future health policy and practice in this area.

2. Methods

2.1 Aim

The overall aim of this study was to determine the information needs of women with RA concerning pregnancy and post-natal care. The specific research questions were:

1. What type of information (in terms of topics, scope and content) do women with RA seek in relation to pregnancy and post-natal care?
2. In what format and through what channels should this information be available?
3. What is the role of consumer-based arthritis organisations in this context?

A secondary research component aimed to determine the proportion of calls to the Arthritis and Osteoporosis Victoria (A&OV) Rheumatology Help Line (http://www.arthritisvic.org.au/Useful-Information/Our-Services/MSK-Help-Line) from women with RA requesting information concerning pregnancy and post-natal care over a six-month period.

2.2 Study design

This research utilised a mixed-methods study design incorporating administration of validated questionnaires and two consecutive qualitative data collection phases (semi-structured, individual telephone interviews followed by focus groups). Independent participant samples were used for each qualitative data collection phase. A two-phase design was chosen to ensure validity of the findings, minimise bias, and achieve triangulation of emergent themes[10].

2.3 Ethics approval

The study was approved by The University of Melbourne Human Research Ethics Committee (HREC).

2.4 Recruitment and sample selection

Participants for both phases of the study were recruited from the community via advertising through A&OV's media and communication channels, including the organisation's magazine, website, e-bulletin, peer-support groups, Facebook pages and Rheumatology Help Line. The study was also advertised through arthritis consumer organisations and peer support groups in other Australian states and territories, and to rheumatologists, obstetricians and maternal and child health nurses in metropolitan Melbourne. Given that people in rural and remote areas of Australia may have specific health service and information needs[11], women living in rural and remote areas were specifically recruited for this study.

To be eligible to participate, women were required to:

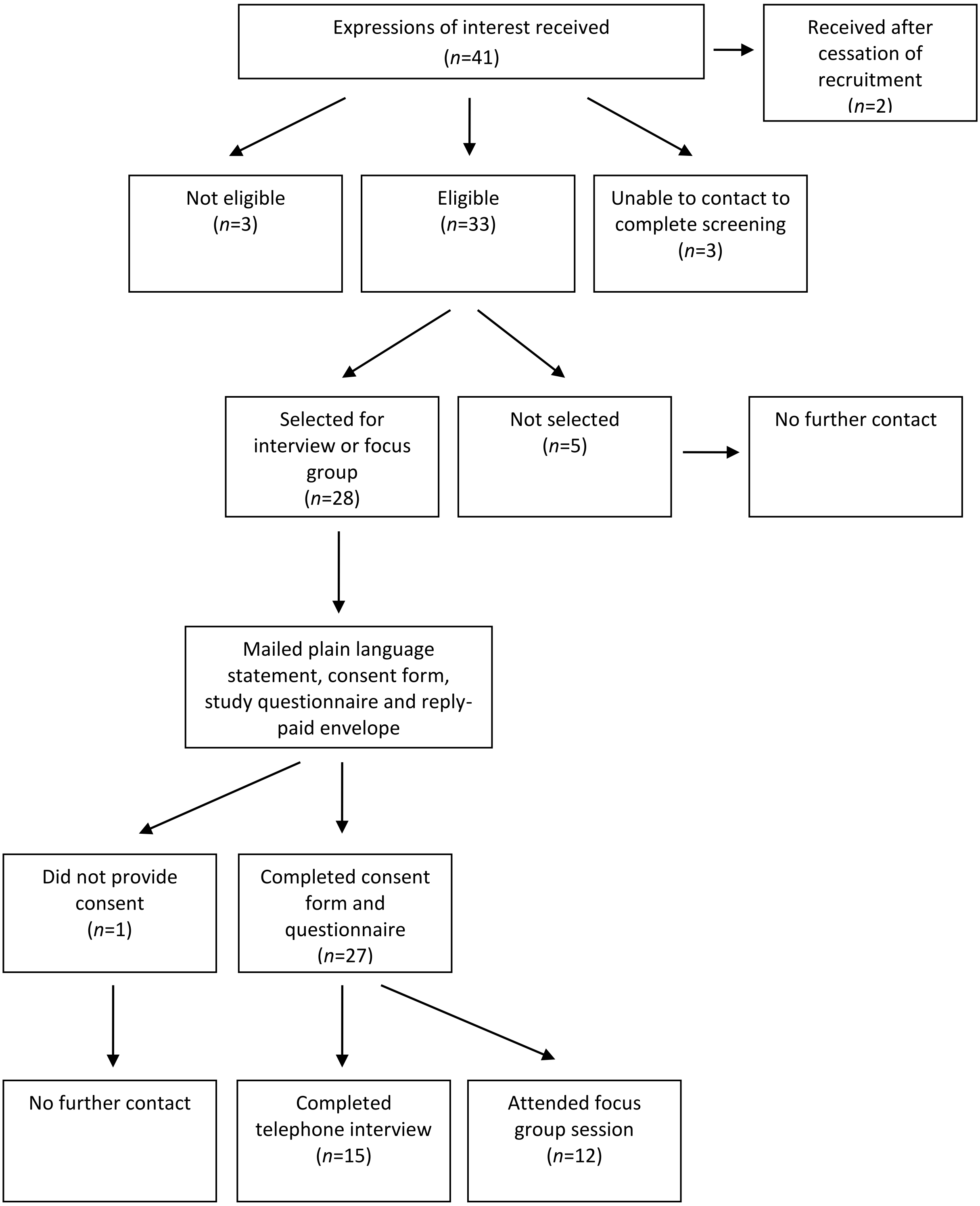
- be aged 18 to 45 years;
- have been diagnosed with RA by a rheumatologist;
- be on DMARD medication (excluding women who were pregnant or trying to conceive); and
- have been pregnant within the last 5 years, be currently pregnant, or be planning to become pregnant.

Women who met these inclusion criteria and were interested in participating were directed to register their interest with the Project Officer at A&OV, who provided more information about the study. The Project Officer also completed a telephone screening process to confirm eligibility. As shown in Figure 1, a total of 41 expressions of interest were received. Of these:

- 33 women (80%) were found to be eligible after screening
- 3 women (7%) did not meet the inclusion criteria and were excluded:
  - 2 did not have a diagnosis of RA
  - 1 was aged 56 years
- 3 women (7%) were unable to be contacted to complete the screening process
- 2 women (5%) contacted the researchers after cessation of recruitment and were therefore not considered for the study

Although sample size calculations are generally not performed for qualitative studies, it was considered *a priori* that a total sample size of approximately 20-30 participants (10-15 participants for each data collection phase) would be sufficient for achieving theme saturation[12]. For both the interview and focus group phases, maximum heterogeneity sampling was used to review the list of eligible, interested women and generate samples which encompassed a broad range of demographic characteristics. Participants were selected based on their age, area of residence (metropolitan, regional, remote) and pregnancy status (planning pregnancy, currently pregnant, had been pregnant). For pragmatic purposes, women living in Australian states and territories other than Victoria were preferentially selected for telephone interviews. Of the 33 eligible women, a total of 28 were selected to participate in the study (15 for telephone interviews and 13 for the focus groups). All potential participants were mailed a plain language statement, consent form and study questionnaire, together with a reply-paid envelope. Written informed consent was obtained from 27 women; one of the women selected for a focus group did not provide consent and therefore did not participate in the study.

Figure 1. Overview of recruitment and study procedures



2.5 Data collection

All data collection for the mixed-methods study was undertaken between November 2013 and January 2014. The Rheumatology Help Line audit included the period 1 September 2013 to 28 February 2014.

2.5.1 Questionnaires

The study questionnaire was used to collect demographic information including country of birth, primary language spoken at home, highest level of education completed, paid and unpaid work status, and years since RA diagnosis. Two validated measures were also included in the questionnaire to quantify educational needs and information preferences, and to enable comparison with published cohorts from other countries.

The Educational Needs Assessment Tool (ENAT) is a 39-item instrument which was designed to assess the educational needs of people with rheumatic diseases including RA[13]. It has been validated for cross-cultural use and comprises seven domains including managing pain, movement, feelings, the arthritis process, treatment from health professionals, self-help measures and support from others[14, 15]. The Rasch-transformed domain scores are summed to produce a total ENAT score which ranges from 0 (lowest educational needs) to 156 (highest educational needs).

The Autonomy Preference Index (API) is a validated instrument that measures health-related information-seeking and decision-making preferences[16] and has been used previously in people with RA[8]. The API consists of an Information seeking preference scale (ISPS) and a Decision making preference scale (DMPS). Consistent with an earlier study[8], only the first 6 (of 15) items of the DMPS were used for the present study as the remaining items relate to medical conditions other than RA (for example, high blood pressure and myocardial infarction). The ISPS and DMPS scores are each transformed to a 0-100 scale, where higher scores indicate stronger preferences for information-seeking or decision-making, respectively.

2.5.2 Telephone interviews

Semi-structured telephone interviews were conducted with 15 participants. The themes and prompt questions for the interviews were developed by the multidisciplinary research team and revised following independent review by a rheumatologist and two women with RA. All interviews were conducted by a musculoskeletal researcher experienced in qualitative research methods. An interview schedule was used (Appendix), although the sequence and questions were flexible depending on individual responses and the need to confirm or explore responses in more detail. Each interview covered perceived gaps in knowledge, sourcing relevant information, further information needs, preferred format and channels for accessing information, the role of consumer organisations in providing information, and dealing with the uncertainty of available information. The interviews ranged from 10-34 minutes in duration. All interview participants received a $20 gift voucher after completion of their interview.

2.5.3 Focus groups

To maximise attendance, 2 focus group sessions were planned: a face-to-face group involving women living in metropolitan Melbourne and a virtual focus group (using a teleconference facility) for those living in regional and remote areas across Australia. The use of virtual focus groups using telephone and other communication modes is becoming increasingly popular in qualitative health research and is advocated for overcoming geographic disparity while providing visual anonymity[17, 18]. Data obtained from telephone-based focus groups have been validated against data obtained from face-to-face focus groups[18]. Twelve participants took part in the focus groups (*n*=7 for the virtual group and *n*=5 for the face-to-face group). The semi-structured schedule used for the telephone interviews (Appendix) was also used for each focus group and both groups were conducted by the same researcher. Each focus group was approximately 1 hour in duration and all participants received a $50 gift voucher after the session.

2.5.4 Audit of the Rheumatology Help Line

An audit of the A&OV Rheumatology Help Line was undertaken by reviewing the records of all calls to the service's registered nurses over a 6-month period. Call volumes during this period were reviewed, as was the number of calls from women with RA who specifically requested information around planning to become pregnant, pregnancy, breastfeeding and/or early parenting.

2.6 Data analysis

Analysis of the demographic, questionnaire and Rheumatology Help Line audit data was undertaken descriptively using IBM SPSS Statistics version 22. Postcodes were used to classify geographical remoteness, according to the Australian Standard Geographical Classification - Remoteness Area system (ASGC-RA)[19]. ASGC-RA categories include major cities, inner and outer regional areas (these were combined to form a 'regional area' category), remote areas and very remote areas, based on distance to the nearest urban centre.

Interview and focus group recordings were transcribed verbatim and transcripts were sent to all participants for verification of their accuracy. The qualitative data were analysed initially by an independent, experienced data analyst. Data coding was undertaken in two stages, commencing with the interview transcripts. An inductive approach[20] was used to identify and code key themes arising from the interview transcripts until no new themes emerged. The focus group transcripts were coded using deductive methods, using the codes derived from the interview data. Where a new topic emerged from the focus group data, a corresponding theme (or subtheme) was developed inductively. Each interview and focus group transcript was then reviewed independently by a second researcher to confirm the themes identified and identify any important omissions. The findings were discussed, as was any discordance, and the themes were refined to reach consensus where necessary.

3. Results

3.1 Participant characteristics

Participants were aged between 22 and 41 years, and the median (interquartile range (IQR)) age was 32 (31-36) years. The median (IQR) time since diagnosis of RA was 5 (2-13) years and time since diagnosis ranged from less than 1 year (diagnosed in 2013) to 21 years. Of the 27 participants, 25 (93%) reported they were currently under the care of a rheumatologist. Eighteen participants (67%) had been pregnant in the last 5 years, 5 (19%) were pregnant at the time of the study, and 18 (67%) were considering pregnancy (including subsequent pregnancy) in the next 5 years.

The geographical distribution of the sample was broad, as shown in Figure 2. According to the ASGC-RA classification, participants lived in major cities (*n*=13, 48%), regional areas (*n*=12, 44%) and remote areas (*n*=2, 7%).

Figure 2. Geographical distribution of the study participants

The majority of participants were born in Australia (*n*=24, 89%) and all participants nominated English as the primary language spoken at home. Nineteen participants (74%) had completed a university degree, while 7 (26%) had a trade or technical education and 1 participant (4%) had completed year 11-12 of secondary education. Sixty-seven per cent of the sample (*n*=18) were in paid work, 8 (30%) were not in paid work due to parenting responsibilities and 1 participant (4%) had stopped work due to her RA. The average (median) hours of paid work undertaken per week was 18.5 (range 2-45 hours). While 10 participants (37%) reported doing unpaid work (including parenting, household tasks and volunteer work), 2 (7%) were unable to undertake unpaid work due to their RA and 15 (56%) reported they did not do unpaid work for other reasons.

3.2 Questionnaire data

The mean (SD) total ENAT score was 97.2 (30.8), indicating that, on average, participants reported high educational needs. The ENAT domain scores are presented in Table 1 and demonstrate that the greatest information needs (represented by the highest mean domain scores) were in relation to the arthritis disease process, treatments from health professionals and self-help measures. The mean domain and total scores were similar to those reported for a subgroup of females with RA from a recent Austrian study[21].

Table 1. Educational Needs Assessment Tool domain scores

Domain	Mean (SD)	Range
Managing pain	14.2 (4.8)	0.0-24.0
Movement	11.0 (4.5)	3.1-20.0
Feelings	10.7 (4.3)	0.0-16.0
Disease process	19.2 (5.7)	8.9-28.0
Treatments from health professionals	17.5 (7.0)	2.2-28.0
Self-help measures	16.0 (6.2)	5.0-24.0
Support from others	8.7 (3.9)	3.0-16.0
Total score†	97.2 (30.8)	27.3-156.0

Data represent Rasch-transformed scores;

†Total ENAT scores range from 0 (lowest educational needs) to 156 (highest educational needs)

Analysis of the Autonomy Preference Index data showed that the mean (SD) score for the DMPS was 68.4 (8.2), with scores ranging from 50.0 to 83.3. The mean score for the ISPS was very high (89.8, SD 5.6) and similar to average scores reported for a community-based study involving people with RA in the United Kingdom[8]. In the present study, ISPS scores ranged from 77.5 to 100, indicating a high level of need for information among participants which was greater than the need for involvement in treatment decision making.

3.3 Interview and focus group data

Six key themes consistently emerged from the interview and focus group data, as summarised in Table 2. Analysis of the focus group data reinforced the themes identified from the interview data, with some additional subthemes emerging from the focus groups.

Table 2. Key themes identified

Theme	Description
1. Lack of specific information regarding the pregnancy and post-natal periods	• Perceived lack of consumer-focused written information relating specifically to RA and pregnancy, the post-natal period and early parenting • Perception that the needs of younger people with arthritis are not well addressed
2. Information needs are dependent on the individual situation	• Difficulty of knowing what specific information will be needed given the variability in how RA symptoms can be affected by pregnancy • Information needs vary according to maternal stage and educational or professional background
3. Rheumatologist as the primary information source	• Expressed trust in rheumatologists who provide individuals with most of the information relating to RA and pregnancy

4. Identified information gaps	• Four main subthemes were identified in relation to information gaps:
	  • RA drug toxicity
	  • physical and emotional support services
	  • practical tips and strategies to assist in coping with daily challenges
	  • RA-related information for family, friends and the workplace

5. Accessible information through electronic formats	• Clear preference for written information which can be made available via electronic formats and updated regularly to maintain relevance and alignment with evidence
6. Arthritis consumer organisations as a resource hub	Arthritis consumer organisations should: • collate and provide access to up-to-date, evidence-based information • provide a referral system to support services and facilitate peer support groups • provide RA-related education and training to upskill health professionals

Each key theme and related subtheme are described in detail in the following sections, with pertinent quotes from individual participants provided to illustrate each theme.

Key theme 1: Lack of specific information regarding pregnancy and RA

There was general consensus among participants regarding a dearth of consumer-focused, written information specifically relating to pregnancy and post-natal issues in RA. Several participants referred to a published book which detailed personal experiences of pregnancy with RA as their only resource. Information from reputable organisations was perceived to focus on medications and associated risks, although participants indicated that the available information was not extensive. Some participants also expressed an interest in obtaining information about the hereditability of RA, or the risk of passing RA onto their children. Focus group participants reinforced that information specifically relating to pregnancy, post-natal and early parenting issues was difficult to find.

> *"I searched worldwide to try and find a resource or resources that that could help me through the process. So I looked on the internet, I looked at websites of reputable arthritis organisations around the world. I spoke with my rheumatologist, my obstetrician, with a specialist in 'high-risk' pregnancies, from my Arthritis Foundation, etc….and also, yeah, all the books that I had on my own bookshelf, but unfortunately found very, very little...and if there was something written that was only sort of, one or two lines about, you know, coming off your medication to fall pregnant."*
>
> *"...I mean I know everyone's condition and circumstances are different, but I think because it is such as specific area, rheumatoid arthritis and pregnancy, I didn't find there was a lot. Basically other than the book by Susie Edward May, like I haven't stumbled across anything that really sort of reflects my experience…"*
>
> *"...there was nothing to guide women through that process, so, you know, you're planning to become pregnant and planning to have a family but there was nothing to actually tell me how to go about that and how other women had done it and succeeded."*
>
> *"I also find that it's hard to find the information. Even when I was looking at getting pregnant and all of that kind of thing I just found that internet searching and libraries and all of that kind of thing just didn't...there just wasn't much and it was all very repetitive. The information was all sort of much of a muchness. It was really hard to find stuff out, and I find that it's all...you know, it's a bit like pulling teeth, it's not really offered to you as such."*

A number of women highlighted a specific need for information about post-partum flares and how to manage after the birth of their child.

> *"The risk of post-partum flare is probably the one that needs to be covered a bit more."*
>
> *"...but I think it's the post-birth stuff where my knowledge is probably lacking, where I've got a seven month old at the moment, and it's just been a...probably a pretty rough slog caring for and finding...finding the right information and the right knowledge I guess, post-birth and parenting."*

> *"As far as early parenting and rheumatoid arthritis I have no information at all and would have really loved some because that's what I'm struggling with at the moment…just, you know, the physical…physical side of it, of care, of actually caring for a baby."*

> *"...but it's the early parenting information that was the big gap and, yeah, like other people have been saying, the device and the tips and the tricks that might get you through a day with less pain and discomfort, that's where the big gap has been. I haven't been very successful in finding a lot of information about that."*

Interviewees and focus group participants also highlighted the broader community's perception of arthritis as a condition affecting older people. Consequently, they considered that information specific to the needs of younger women (such as managing a pregnancy with RA) was not being appropriately addressed.

> *"I picked up a brochure from my mother which was about...a brochure for carers of people with arthritis, and just so she could get some understanding, but the picture on the front was a really, old wrinkly hand and it was all kind of twisted, and I thought oh, that's not a good perception. People don't…and when you tell them you have arthritis they really don't understand because they think it's still, yeah, it's still an old people's thing."*

> *"I think in general probably being a young woman with arthritis is not well covered...in terms of, you know, whether you want to be a professional young woman, or whether you are thinking about pregnancy or, you know, combining the two, or whatever that may be."*

Some participants expressed a need for accessible information regarding obstetricians who have a special interest or experience in dealing with women with RA.

> *"...one of the things that I've been struggling with is to get references or details of gynaecologists, obstetricians who have dealt with women who have had rheumatoid arthritis and help them with the deliveries and the pregnancies."*

> *"Personally, yeah, I mean I would love to know if there are any obstetricians that know a little bit more about RA than most."*

Key theme 2: Information needs dependent on individual situation

Telephone interviewees and focus group participants talked about the difficulty of knowing what specific information they needed because they were often uncertain as to how their RA might be affected during pregnancy and following the birth of their baby. Additionally, information needs varied depending on the particular life stage (i.e. planning to conceive, pregnancy or post-natal stage) and their educational or professional background. In particular, participants with a health professional or research background had a clearer understanding of what information they needed and appeared to be more successful in sourcing information. One participant advocated for documenting different pregnancy scenarios and making these available as case studies to provide reference for medical specialists and patients.

> *"I guess in terms of pregnancy and what to expect and I guess it is hard because everyone is so different, but because when I was first diagnosed I'd already had my first daughter I didn't know what to expect to then be pregnant and have rheumatoid arthritis, so I guess I was a little bit anxious you could say...yeah about what would happen and if I would go into remission."*

> *"And there's also a lot of unknown, like lots of the other women are saying about you might go into remission, you might not but no-one knows. You just have to wait and see. There's just so much sort of wait and see and unknown."*

> *"I think my knowledge on post-natal care is pretty minimal, probably almost next to zero only because I choose to only consciously think about one step at a time. And as I'm trying to conceive now, it's more about well what…the first step is, what medications should or shouldn't I be taking right now. And I haven't really thought about anything further than that."*

> *"There's a lot of things that are lacking and it's true because everyone's situation is different…it's a bit difficult to explain it but I wish sometimes we could document all these…I know it would probably be a lot for clinicians and rheumatologists just to document different situations and kind of store them up so that we can kind of refer to them as separate case studies."*

Key theme 3: Rheumatologist as the primary information source

The majority of telephone interviewees cited their rheumatologist as their primary information source, particularly in relation to treatment decisions. These participants spoke more about trusting their rheumatologist's judgment rather than wanting to know or understand detailed information relating to RA medications. Participants also sourced information from the internet, including online forums and social media. Consistent with telephone interviewees, focus group participants also expressed trust in their rheumatologist, but were likely to actively seek additional sources of information (primarily from the internet) in order to make informed treatment decisions.

> *"Well I don't really, I mean, I really get all my information from my rheumatologist and it's just specific to my care, I wouldn't say there's much information out there at all really."*

> *"I was probably guided by my rheumatologist first and foremost because I really do trust him. And he, and I guess one of the reasons why I trust him is because he is very up-to-date with the latest research and he goes to conferences and comes back and draws me diagrams and tells me the information and gives me, you know, information to read and I just, I feel like he's constantly open with me and constantly educating me about the new…about the changes in treatments."*

> *"Look I trust in my rheumatologist. Sometimes it's, look and I have read up and it scared me a little bit with information, so sometimes I think it's best if I just leave…I don't investigate too much, I just trust in my rheumatologist and if she says it's safe, it's safe."*

> *"I think we all pay our rheumatologist good money and they're the ones that should be on top of the research, quite frankly."*

> *"I suppose all the information I got is like from my rheumatologist but also I have a medical background so I sort of wanted to do as much research as I could and I guess the internet is the best source that I have. So I suppose I'd just look up questions I have when I get them in terms of like what issues taking medication might have for my baby, like my unborn baby, or with breastfeeding and...with having flare-ups, what's going to happen when I take prednisolone when I'm breastfeeding or trying to conceive or whatever."*

> *"...with the rheumatologist...I trust him so I trust him as a sort of a sounding board and a jumping off point into other sources of information, in terms of medications and things like that."*

> *"You know what's available, you pretty much know what your rheumatologist is going to tell you. I guess you just get as much information as you can yourself. I've been guided by my rheumatologist, I've got an amazing relationship, a very long-term relationship with my rheumatologist. He guides me but I really do follow my nose...I get as much information as I can and just kind of put it all together and hope for the best."*

Key theme 4.1: Identified information gap - drug toxicity

Irrespective of pregnancy stage, of greatest concern to most participants was the need for more information regarding the safety and toxicity of RA medications and the possible effects on their unborn or breastfed baby. Many telephone interviewees cited a need for more information on the use of RA medications around conception, pregnancy and breastfeeding, and some desired information about 'safe' medications, alternative therapies or lifestyle options.

> *"Certainly some more information about…well, some information full-stop about breastfeeding, that's a huge issue…it would have been useful to have some definitive information about what was safe and what wasn't..."*

> *"I think primarily your drug interactions and how it affects your baby and through your breast milk. I mean that's, I think that's one of the most pressing needs and also the post-partum flare."*

> *"I think in terms of medication, that's one thing I struggled with my second pregnancy...in terms of what safe levels of medication there were in terms of pregnancy and also with breastfeeding. I was very determined to breastfeed, but I was worried that if I was to have a post-birth flare, would I be able to manage that without a safe level of medication for breastfeeding?"*

> *"Yeah, I wanted to know more information on ways without just using medication and I haven't…no-one would actually give me much information on that. I wanted to know, after, like I've looked up a few things and they say maybe gluten free and things like that, so I wanted more information on that and still now my current rheumatologist won't give me that*

> *information either. Just, I just want to know if there's a healthier way than filling my body with drugs for the rest of my life. Cause I'm only thirty."*

A distinguishing feature of the focus group discussions was the need for more decision-making support, primarily from rheumatologists, when selecting medication options during pregnancy or when breastfeeding. Participants appreciated that this was a complex area given the varying needs of each individual, but wanted to better understand the possible range of scenarios and treatment options, the potential side effects of medications, the potential effects of not taking medications (in terms of future joint damage) and different ways of managing post-partum flares.

> *"So I feel as though the rheumatologists really need to kind of take on a bit more decision-making and look at the patient on a case-to-case basis and really look at everything, the long term, look at the past history as well and look into the long term history especially if it's women in terms of getting pregnant."*
>
> *It's that balancing the risk and risk management and you feel like it's your own health and it's your baby's health and no-one else is taking that decision for you, they kind of are backing off a fair bit and saying we've given you the information but it's up to you."*

Participants also expressed frustration at the inconsistent advice received from rheumatologists and pharmacists, in particular, about RA medications, and the lack of knowledge about RA and its management among midwives, maternal and child health nurses and in some cases, obstetricians. This resulted in the patient having to be the 'go between' when dealing with different health professionals, which further complicated treatment decision-making.

> *"I've seen two rheumatologists...and received different information about how the drugs that I've been suggested to start taking would affect a pregnancy and breastfeeding. So then I find it really hard to make a decision on what actually is the right thing to do."*
>
> *"It's always a problem when it comes to the medication. I had to spell my medication out several times to my midwife and to my GP and they just…there's just this lack…there's no connection between the arthritis and the post-natal care and so I think they need to probably educate themselves a bit more."*
>
> *"But what I find frustrating too is when you actually go into your pharmacy to get your medication and then the pharmacist disagrees with what your doctor says, and you have to argue with them to get your pills, and, you know, and it's really...you have to always put this argument in your mind, and to everyone else around you that you're not...you know, you don't want to harm your baby but you also need to be able to move, you know, and...and it's an inner struggle as well as a struggle with everybody else that knows what you're taking, or, you know, and between doctors like...like rheumatologists have different opinions on what's safe and what's not, so it's really...yeah, frustrating would be the top word I think."*

Key theme 4.2: Identified information gap - physical and emotional support services

Of the interviewees who had children, most highlighted that the debilitating effects of RA made it physically challenging to care for themselves and a new baby, particularly during a post-partum flare. Consequently, knowledge of available physical support services during this period was considered to be important.

> *"There was pretty much no support for me after I'd had my baby. And I was flaring both, both times and I was flaring very, very badly. I had post-birth flares with both of my children and there were…and even though my, my doctors were saying "Yes, you're eligible for HACC services, Home and Community Care Services", once I, when I rang them and told them my age and my disability and where I lived, they promptly told me "No, you're not eligible, we have nothing for you." So I was very much isolated, I had no, no support in the home and I couldn't, I mean I couldn't pick my babies up, I was in agony, I could hardly walk…and I managed to get Red Cross, a wonderful woman from Red Cross who came to me four hours a week and she would, you know, hold the baby while I could care for my toddler or hold the baby, or you know, she'd make my…she'd chop my dinner up or, you know, she did, she helped me."*

> *"But I guess my biggest gap was what our council might have offered too in terms of things like home help and things like that, I've found that really...I've had a lot of phone calls and been sent from one department to another and trying to find out what might be on offer here in my town to help me out."*

> *"What I would have liked was to have my community health nurse, cause I was involved in the public and private systems and nobody could help me, to have them educated, and it doesn't necessarily have to be just women with RA, but a mother who's got chronic health issues to actually have someone come to the house, you know, through an OT program or the community health nurse, and say "Right" and spend the day with you or come on a regular basis and say "Look, this is how we can help you."*

The majority of participants reported feeling isolated and uncertain of what to expect during the pregnancy and post-natal stages. They perceived that emotional support services and information about how to access established support groups for pregnant women with RA would be beneficial. These groups were considered to be an important source of emotional support by allowing women to share their experiences and learn about helpful tips for managing RA from the conception to post-natal stages. Several interviewees cited online forums as their preferred way to access such support, as these overcame geographic barriers for those who lived in regional and rural areas and were easiest for individuals who were not well enough to travel. Focus group participants also emphasised the importance of emotional support from peers for managing challenging phases such as post-partum flares and making difficult decisions such as ceasing breastfeeding in order to re-commence RA medications.

> *"I would have liked to have connected with other women who were pregnant and...I would have liked to have either connected with or read about other women's experiences…and while the rheumatologist is fantastic, it would have been nice to also have some support in terms of mentally dealing with that...both from women who have also doing it themselves, you know, going through it themselves, but also even having, you know, access to therapy or a counsellor*

> *or someone that had knowledge in this area who could have actually supported me through that process cause it's a very emotional time, yeah."*

> *"I guess one of the other things that, you know, post-birth is, you know, especially with my first child when I was a first-time parent and I would go and, you know, I went and joined a mothers' group and, you know, all the other women were sort of sitting around, kind of complaining cause they didn't get enough sleep and I would kind of, I kinda didn't feel like there was any point in me trying to explain or complain about the fact that, you know, I couldn't even lift my baby, or that I was in so much pain. Because I just, you know, they wouldn't understand...that isolation and so, you know, it kind of would have been nice at that stage when I was a brand-new mother to connect with other brand new mothers who had, who had RA..."*

> *"I've been so alone with it and dealt with it so alone that it would be so wonderful to get an awareness out there and get those support groups happening."*

> *"I know if there were even volunteers on some phone line or something you could ring, but, you know, I can remember going to the maternal health centre and telling them that...you know, with the pain was just getting too bad and I was going to have to go onto these drugs again and I'd have to stop breastfeeding, and we had a very young maternal health nurse at the time and she said "Well, you just have to decide whether you're going to be selfish and choose yourself over your child", you know that's a hard decision, and yeah, if you had a support person that you could sort of lean on, I think that would be really helpful."*

> *"…I think it's very much, just stop your medication or come off it over three months or six months and then just off you go, have a baby and I just think that there's a lot more that needs to be done to support women through that process because it's not just about stopping medication, it's about taking a crutch away from them that actually allows them to function, and helping women feel supported and feel like they have a level of confidence in that process and beyond that into pregnancy."*

Key theme 4.3: Identified information gap - practical tips and strategies

Participants consistently expressed the need for information about practical tips and strategies to assist them during the pregnancy and post-natal periods. While there was some interest in learning about the latest research information, there was a clear preference for pragmatic information from peers to enable them to cope with the day-to-day challenges of RA, particularly when caring for a young baby. Focus group participants also perceived a need for information regarding assistive devices that could facilitate daily activities, such as using a baby car seat.

> *"I guess just the day-to-day nitty-gritty strategies on how to manage your pain, how to conserve energy, just the little things along the way like right down to the basics like sharing other women's experiences of how they bath and feed. Like I learnt with my second baby I didn't buy those jumpsuits with the press studs...yeah, I bought her little dresses and more little leggings and t-shirts and, cause I think what it…people think all the little stuff doesn't matter, but over the course of the day it adds up."*

> *"I think where I'm sort of struggling a bit is just kind of handy sort of things to help me with my baby, you know, picking up a baby off the floor, getting a baby out of the car seat. So not so much knowledge as, you know, I know how to get a baby out of a car seat, but how do I get a baby out of a car seat...I know like in terms of devices there's lots of, you know, devices for, say, handicapped people, you know, people...and there are organisations in the States like there's an engineering volunteer organisation that will retro-fit your...you know, whatever, your car seat, your highchair, whatever. But there seems to be nothing that I can find in Australia to kind of do that."*

> *"Something just as simple as being shown the best way to hold your baby, especially when feeding them, and because I found, especially in that first week after I had my little girl, my shoulders locked up and I couldn't...I was in excruciating pain and it was just from holding her in that position for so long. Something that simple would have really made a big difference."*

> *"I think it's more finding other people who've maybe done what you…what you need to do, and getting the little tips and hints off people who've walked in your shoes before you."*

> *"...from my perspective I feel like I can get information about research and all of that from my rheumatologist, so it's the practical things that I find that I just can't find."*

> *"So I prefer more practical information because having an 18 month old and you wake up and you can't bend your knees, you need something that's going to help you get through the next couple of hours rather than looking at the research."*

Key theme 4.4: Identified information gap - information for family, friends and workplaces

A new theme to emerge from the focus group discussions was the need for information to be made available for family, friends and work colleagues, in order to improve their understanding of RA and the challenges faced during pregnancy and early parenting.

> *"Just something that I think would be really helpful is also some information that you can give to your close…your partner, support people like your parents or your siblings or whatever, because I think a lot of women, especially as new mums, find it hard to reach out for help or support. But if there was something that you could actually just go, oh yeah, this is what my rheumatologist gave me to give to you and it said something like, yeah, this is what they're actually…this is what she's going through and this is the ways…these here are some of the ways that you can help or this is some of the ways that this person needs some help, that would be really beneficial."*

> *"And also, I would agree that a brochure or something you can give to your workplace is a great idea, but also something to give to your family, like your partner or your parents or your friends, because you are relying on them for support a lot, and something that will help them understand what you're going through and what to expect, perhaps."*

Consistent with comments regarding the community's perception of arthritis as an ‘old person’s disease’, it was also considered that provision of specific information about RA and pregnancy could assist in counteracting the perception and garnering workplace support.

> *“But work were really not good at understanding what was happening to me, so as I got increasingly sorer and slower, it...so it would have been good if there was information about how to inform your workplace because as we’ve talked about before they do perceive this as only an old person’s thing, but, you know, how could such a young person really be crippled up and, you know “Take a couple of Panadol and you’ll be fine.” So for me, yeah, it was to have some way of informing work, or some sort of brochure or information that you could give to your boss so they could be a little more understanding would have been good.”*

Key theme 5: Accessible information through electronic formats

While participants agreed that written information was preferable, there was variation regarding how this information should be delivered. Some participants expressed a strong preference for written information to be available in electronic formats (e.g. via email or an online source) so that it could be easily stored and retrieved when needed, while others preferred to receive information packs from a health professional (e.g. general practitioner or maternal and child health nurse) or arthritis consumer organisation, or to access information via social media. Focus group participants emphasised the need for regular review of materials to ensure that information and contact details remained relevant and up-to-date.

> *“I think you also need information written down to be able to take home and then go through it yourself…and I think it needs to be available online for people who are not mobile enough to go and access it themselves. I think it needs, I actually think it needs to be...provided in a variety of ways.”*

> *“Yes, I would think maybe a PDF document or somewhere where you can go and download itself for when you’ve got time and when you’re ready and you go and find that information.”*

> *“Yeah, probably either a…like something sent in the mail or probably in an email which makes it a little bit easier to access. Yeah, instead of sort of having to look things up or do searches it’d be nice if it was already there for me.”*

> *“I mean I find, you know, like the Facebook pages etc really kind of helpful cause you can go on there and you can, you know, filter through it yourself and read what you want to and what you don't want to and...you know, it's your choice to contribute if you want to. So I find them helpful.”*

> *“I like reading, so internet books help me. Videos are great, I've seen some video blogs through Arthritis Queensland…that's another really good way. Yeah, online forums help me a lot too…”*

> *“I think online is a really great way to do it, you can update those details quickly, you know, if phone numbers change or other people come on-board, you know, those details can be updated online and it can be a current source of information.”*

Key theme 6: Arthritis consumer organisations as a resource hub

While many telephone interviewees had contacted their local arthritis consumer organisation, some indicated that they had not been able to obtain the information they desired. Interviewees identified three main roles for arthritis consumer organisations, and these were reinforced by the focus group discussions:

1. to be a central resource service which collates and provides accessible, up-to-date, evidence-based information from local and international sources;
2. to provide a referral system for directing consumers to relevant physical and emotional support services, including facilitating peer support groups; and
3. as a provider of disease-specific education and training for health professionals encountered during the pregnancy and post-natal periods (e.g. midwives, maternal and child health nurses, community health nurses and other allied health professionals).

> *"I think they have an imperative role. Again, you know, I think while a rheumatologist can provide information…about the medications that the person, the woman, should be on and obviously, you know, monitor and guide her through that medication process, I think we need to be realistic and rheumatologists don't have time to go through all the other components that need to be addressed. So I think consumer organisations need to take on a huge role and get lots and lots of knowledge about it and they need to be, it needs to be, an area that there are courses run all the time, the information sessions run all the time, the written information sent out, there's telephone counselling where someone can ring and talk, you know, talk about the issues. I think it needs to become one of those areas that is a standard part of the service that they offer, cause I think it's really, really important."*
>
> *"…would hope that they would be a source for all the information that you would want...yeah, I would hope that they would be the main go-to kind of source."*
>
> *"I guess, them sifting through the research and the evidence and providing, you know, the links or the research. Like I guess to save me doing all that kind of work and sifting through what's relevant and what's not, probably them doing it and probably more like I like to read more about Australian based research as well."*
>
> *"but I think Arthritis Victoria is in one of those pretty privileged positions where they'd actually get all this information from all these people and other doctors, etc, and they're probably in the best-placed position to then share that information amongst those who need it the most."*
>
> *"Facilitating groups. Disseminating information and pointing me in direction of other sources…and other groups that would help."*
>
> *"...if they have a list of doctors specialising in that area and just general tips, you know, and how to prepare yourself pre- and post-pregnancy and not that it's not available at other places, but I just would have more trust in the information that comes on their website, perhaps compared to other online resources."*
>
> *"Yeah, well I think what it boils down to is that, and I know these things aren't easy, is that the various arthritis organisations would have a plan that maybe they would roll out to educate*

> *various community health nurses or, you know, have a program that well, let's say in any district one midwife or whatever educated in it, and then so for example, I would ring Arthritis Queensland and say "Well this is my situation", instead of being told "Well, there's nothing we can really send you or do", be told "Oh, yes, you know, and this is…this person in your area is trained in this or…" I don't know. It sounds complicated, but then other times I think it is quite simplistic really.*
>
> *"Well I think educate the allied health professionals and be a referral system. I mean you can only do so much, but I think if there can be an education program, educate the allied health professionals so then I can ring up and you can then refer me to someone in the community."*

Participants from regional and rural areas preferred information to be made available online to ensure it was accessible to all individuals.

> *"...but when you initially first, say, get pregnant and you go to your regular GP, you know, they won't...they don't have anything, so even...I don't know, even if it's something that they can say well ring your local arthritis group in your capital city and they'll have everything for you there...yeah, and in a big booklet of contacts and phone numbers, and...you know, so that you can ring someone to talk to someone if you need to as well as information about all the practical tips and information about medication, and online groups, you know. I'm not sure exactly the best way to get it out there to every single person, but me being in a remote area, online is probably the best thing for me."*
>
> *"I think if it's available from all of the arthritis state organisations such as Arthritis Victoria, that would be good, and all of the rheumatologists that we have. But at the moment, I'm not even seeing a rheumatologist at the moment because I live in a really remote rural area and I would have to travel for about two thousand miles to get there...so perhaps on their websites as well."*

Unexpected outcome of the focus groups

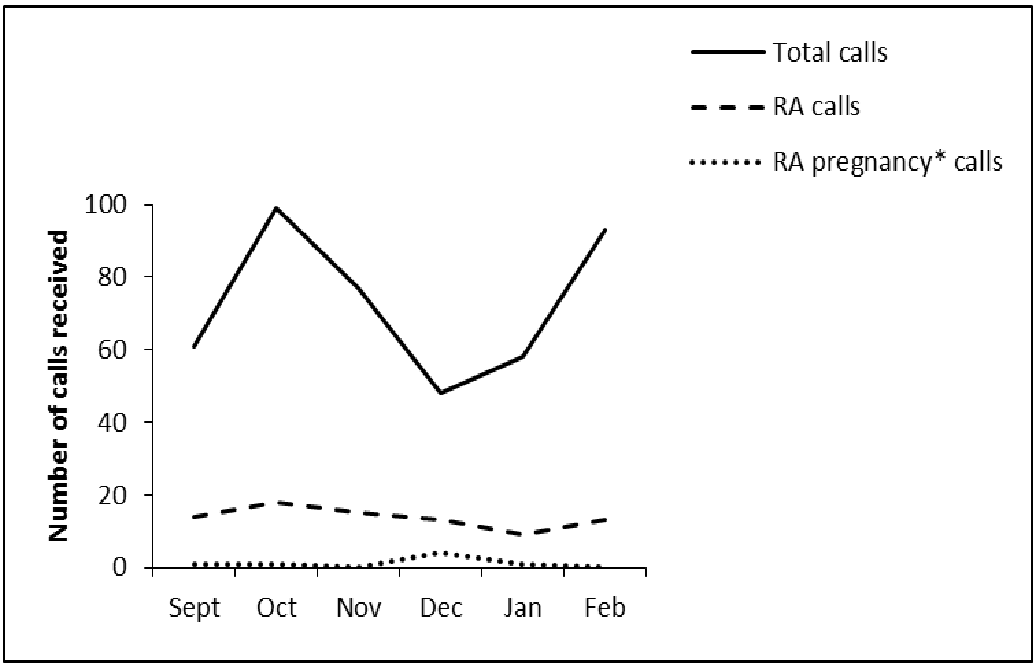
There was also a positive and unexpected outcome of the focus groups. At the end of the virtual focus group session, participants requested that the group's contact details be made available so that they could form their own support group for women with RA focusing on pregnancy and post-natal concerns. All of the participants in this focus group considered this to be worthwhile given their previously unsuccessful attempts to find women in similar situations, and the perceived lack of available support. Following this request, the researchers sought further approval from The University of Melbourne HREC who permitted the sharing of given names and email addresses among focus group participants provided that specific additional consent was obtained. Four of 5 participants (80%) in the virtual focus group and 6 out of 7 participants in the face-to-face group (86%) consented to sharing their contact details, and these two groups were left to contact each other without any further involvement or oversight from the researchers.

3.4 Rheumatology Help Line data

In total, 436 calls were made to the A&OV Rheumatology Help Line between 1 September 2013 and 28 February 2014. Of these, 82 calls (19%) were from men and women with RA. However, only a very small proportion of calls (7 calls, <2% of total calls to the Rheumatology Help Line) were from women with RA in regard to maternal issues including pregnancy planning, pregnancy, breastfeeding and/or early parenting.

Figure 3 illustrates the number of total calls per month during the audit period, the number of calls received from people with RA and the number of calls from women with RA that covered pregnancy and related issues.

Figure 3. Calls to Rheumatology Help Line from September 2013 to February 2014



*Denotes calls relating to pregnancy planning, pregnancy, breastfeeding and/or early parenting

4. Recommendations for translation into policy and practice

Based on the key themes that emerged from this research, a comprehensive list of recommendations for translating the findings into policy and practice has been developed. These recommendations are designed to address the major knowledge and service gaps identified, and are pertinent to arthritis consumer organisations such as A&OV.

Recommendation 1:

- Raise awareness of RA (within the general community and among allied health professionals) as a form of arthritis which affects younger women of reproductive age and use appropriate images in publications and online materials to reflect this demographic

Recommendation 2:

- Develop a central, online resource hub comprising:
  - up-to-date, evidence-based information on medication safety for the conception, pregnancy and breastfeeding stages
  - practical tips and strategies for managing activities of daily living with a young baby including bathing, nappy-changing, dressing, lifting and feeding tasks
  - information on specific aids and appliances to facilitate activities of daily living during the post-natal period, including modifications of baby car seats and other assistive equipment
  - detailed information on RA for partners, family members and friends including disease features, associated impairments, specific challenges during the pregnancy and post-natal periods, and suggestions for supporting women with RA
  - detailed information on RA for employers and work colleagues including information as above, but with a particular focus on supporting women with RA in the workplace
  - a list of obstetricians with specific experience or a special interest in planning and managing pregnancies in women with RA; this resource should be informed by a clinical practice survey of obstetricians or a collaborative initiative with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists
  - a list of available support services for women with RA including relevant home help services, emotional support/counselling services, medication safety information services and government financial support options
  - resources for clinicians (for example, physiotherapists and health professionals who may encounter women during the pregnancy and post-natal stages, such as midwives and maternal and child health nurses)
- All educational materials should be regularly reviewed and revised to ensure that information and contact details remain current

Recommendation 3:

- Offer a variety of information formats to comprehensively meet the needs of women with RA encompassing:
  - online educational materials (as described in Recommendation 2)

  - seminars/workshops incorporating specialist health professionals and women with RA who can share first-hand experiences and demonstrate practical strategies
  - written educational materials (that can be mailed or emailed)
  - telephone counselling services staffed by trained health professionals

Recommendation 4:

- Facilitate online support groups or initiate mentoring/'buddy' programs to enable women with RA to share their personal experiences in dealing with conception, pregnancy and postnatal issues. The specific role of arthritis consumer organisations could be limited to initiating these support services (by providing an appropriate platform for finding appropriate peers), with interested women scheduling subsequent face-to-face or telephone discussions without further oversight from the organisation
  - consider the development of 'outreach' programs to support women with RA during the early parenting period; this type of program could include home visits by trained health professionals and/or consumer representatives with RA

Recommendation 5:

- Promote the role of arthritis consumer organisations and their existing and new services (including the Rheumatology Help Line) to obstetricians, rheumatologists, general practitioners, maternal and child health nurses, midwives and community health nurses, and provide links to the online resource hub (described in Recommendation 2)

Recommendation 6:

- Develop disease-specific training programs and related materials to upskill health professionals who encounter women with RA during the pregnancy and post-natal periods, including allied health professionals, midwives and maternal and child health nurses

5. Summary of findings

This study has clearly demonstrated that Australian women with RA struggle to find contemporary, high-quality, detailed and accessible information on pregnancy planning, pregnancy and early parenting in relation to their chronic disease. Although most participants trusted their rheumatologist as their primary information source, particularly for medication decision-making, there was consistent demand for more information about the safety of RA medications. Women also considered that clear information for family, friends and workplaces was imperative for improving understanding about the challenges faced during pregnancy and after the birth of their baby. Access to physical and emotional support services during the pregnancy and post-natal phases, and knowledge of practical strategies to facilitate caring for young infants were also highlighted as key information needs. The importance of learning from other women's personal experiences was a consistent theme, with access to peer support groups favoured by many. Participants considered that arthritis consumer organisations should act as a central resource hub for collating and disseminating up-to-date, evidence-based RA information, and that these organisations should direct individuals to appropriate support services, as well as provide focused training to health professionals commonly encountered by women during this important life stage. For women living in rural and remote areas, access to online materials was viewed as particularly important.

This research has generated detailed information about knowledge and service gaps that can now be translated into policy and practice. The findings show a pressing need to develop accessible, consumer-focused information and support services for women with RA, and highlight the importance of providing specific training for health professionals regarding RA and its management during pregnancy and beyond. Based on these findings, a detailed set of recommendations has been compiled to assist arthritis consumer organisations such as A&OV in meeting the specific needs of this group.

6. Acknowledgments

This research was supported by grant funding awarded to A&OV by the Angior Family Foundation, with in-kind support provided by A&OV.

Dr Ackerman is supported by a National Health and Medical Research Council Public Health (Australian) Early Career Fellowship (#520004).

The research team would like to thank the study participants for their contribution to this study and Ms Franca Marine (Arthritis Australia) for assistance with recruitment.

7. References

1. Ostensen M, Forger F. Management of RA medications in pregnant patients. *Nature Reviews Rheumatology* 2009;5:382-390.
2. Arthritis and Osteoporosis Victoria. A problem worth solving: The rising cost of musculoskeletal conditions in Australia. Elsternwick: Arthritis and Osteoporosis Victoria; 2013.
3. Chambers CD, Tutuncu ZN, Johnson D, Jones KL. Human pregnancy safety for agents used to treat rheumatoid arthritis: adequacy of available information and strategies for developing post-marketing data. *Arthritis Research and Therapy* 2006;8:215.
4. Signore C, Spong CY, Krotoski D, Shinowara NL, Blackwell SC. Pregnancy in women with physical disabilities. *Obstetrics and Gynecology* 2011;117:935-947.
5. de Man YA, Dolhain RJEM, van de Geijn FE, Willemsen SP, Hazes JMW. Disease activity of rheumatoid arthritis during pregnancy: Results from a nationwide prospective study. *Arthritis Care and Research* 2008;59:1241-1248.
6. Katz PP. Childbearing decisions and family size among women with rheumatoid arthritis. *Arthritis Care and Research* 2006;55:217-223.
7. Fraenkel L, Bogardus S, Concato J, Felson D. Preference for disclosure of information among patients with rheumatoid arthritis. *Arthritis and Rheumatism* 2001;45:136-139.
8. Neame R, Hammond A, Deighton C. Need for information and for involvement in decision making among patients with rheumatoid arthritis: A questionnaire survey. *Arthritis Care and Research* 2005;53:249-255.
9. Tammaru M, Polluste K, Lember M. The sources of disease-related information for Estonia's rheumatoid arthritis patients: a qualitative study. *Journal of Clinical Nursing* 2010;19:1343-1351.
10. Mays N, Pope C. Rigour and qualitative research. *British Medical Journal* 1995;311:109-112.
11. Briggs A, Slater H, Bunzli S, Jordan J, Davies S, Smith A. Consumers' experiences of back pain in rural Western Australia: Access to information and services, and self-management behaviours. *BMC Health Services Research* 2012;12:357.
12. Sandelowski M. Sample size in qualitative research. *Research in Nursing and Health* 1995;18:179-83.
13. Hardware B, Anne Lacey E, Shewan J. Towards the development of a tool to assess educational needs in patients with arthritis. *Clinical Effectiveness in Nursing* 2004;8:111-7.
14. Ndosi M, Tennant A, Bergsten U, Kukkurainen M, Machado P, de la Torre-Aboki J, et al. Cross-cultural validation of the Educational Needs Assessment Tool in RA in 7 European countries. *BMC Musculoskeletal Disorders* 2011;12:110.
15. Ndosi M, Bremander A, Hamnes B, Horton M, Kukkurainen ML, Machado P, et al. Validation of the educational needs assessment tool as a generic instrument for rheumatic diseases in seven European countries. *Annals of the Rheumatic Diseases* 2013.
16. Ende J, Kazis L, Ash A, Moskowitz M. Measuring patients' desire for autonomy. *Journal of General Internal Medicine* 1989;4:23-30.
17. Cooper CP, Jorgensen CM, Merritt TL. Telephone focus groups: An emerging method in public health research. *Journal of Women's Health* 2003;12:945-51.

18. Frazier LM, Miller VA, Horbelt DV, Delmore JE, Miller BE, Paschal AM. Comparison of focus groups on cancer and employment conducted face to face or by telephone. *Qualitative Health Research* 2010;20:617-27.

19. Australian Government Department of Health. Australian Standard Geographical Classification - Remoteness Area (ASGC-RA). Available from: http://www.doctorconnect.gov.au/internet/otd/Publishing.nsf/Content/ra-intro; accessed 24 February 2014

20. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation* 2006;27:237-46.

21. Dragoi R, Ndosi M, Sadlonova M, Hill J, Duer M, Graninger W, et al. Patient education, disease activity and physical function: can we be more targeted? A cross sectional study among people with rheumatoid arthritis, psoriatic arthritis and hand osteoarthritis. *Arthritis Research and Therapy* 2013;15:R156.

Appendix

Telephone interview and focus group schedule

1. Perceived gaps in individual knowledge

   Suggested prompts:

   - Can you tell me about your current level of knowledge about pregnancy, postnatal care and early parenting, in relation to your RA?
   - Do you think there are any gaps in your current knowledge about RA in relation to pregnancy, postnatal care and early parenting?

2. Finding information about pregnancy, postnatal care and early parenting, in relation to RA

   Suggested prompts:

   - How have you tried to find information about pregnancy, postnatal care and early parenting, in relation to your RA?
   - How successful have you been in finding information about pregnancy, postnatal care and early parenting, in relation to your RA?
   - Can you tell me about areas that you think are currently covered well, either by your doctor or other information sources?
   - Can you tell me about areas that you think are not covered well, either by your doctor or other information sources?

3. Further information needs

   Suggested prompts:

   - Thinking about your RA and pregnancy, can you give some specific examples of what information would be helpful for you?
   - Thinking about your RA and postnatal care, can you give some specific examples of what information would be helpful for you?
   - Thinking about your RA and early parenting, can you give some specific examples of what information would be helpful for you?
   - Overall, what would be more helpful to you - information about the latest research evidence or information about practical strategies and tips? Can you explain your decision?

4. Preferred format and channels for accessing information

   Suggested prompts:

   - How would you prefer information about pregnancy, postnatal care and early parenting, in relation to your RA, to be provided to you?
   - In what format would you prefer this information to be made available?

5. Role of consumer organisations in providing information

   Suggested prompt:

   - What do you see as the role of consumer organisations, such as Arthritis and Osteoporosis Victoria, in providing information about pregnancy, postnatal care and early parenting in relation to your RA?

6. Dealing with uncertainty of information

   Suggested prompts

   - How do you deal with the lack of good evidence relating to the safety of some rheumatoid arthritis medications, with regard to pregnancy and breastfeeding?
   - How do you decide which information to trust or use to make your treatment decisions?

Arthritis
VICTORIA
inc. OSTEOPOROSIS VICTORIA

ARTHRITIS AND OSTEOPOROSIS VICTORIA
ABN: 26 811 336 442
263-265 Kooyong Road, Elsternwick, Victoria, 3185
P.O. Box 130, Caulfield South, Victoria, 3162
Tel: 03 8531 8000
Fax: 03 9530 0228
Email: afv@arthritisvic.org.au
www.arthritisvic.org.au