

# BMJ Open Establishing cross-discipline consensus on contraception, pregnancy and breast feeding-related educational messages and clinical practices to support women with rheumatoid arthritis: an Australian Delphi study

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## ABSTRACT

**Objective:** Recognising the need for a best-practice and consistent approach in providing care to women with rheumatoid arthritis (RA) in relation to (1) general health, (2) contraception, (3) conception and pregnancy, (4) breast feeding and (5) early parenting, we sought to achieve cross-discipline, clinical consensus on key messages and clinical practice behaviours in these 5 areas.

**Design:** 3-round eDelphi study. In round 1, panellists provided free-text responses to open-ended questions about care for women with RA across the 5 areas. Subsequently, panellists refined and scored the synthesised responses, presented as metathemes, themes and detailed elements. Where  $\geq 5\%$  of panellists did not support a theme in a given round, it was removed.

**Setting:** Panel of practicing Australian rheumatologists (n=22), obstetricians/obstetric medicine physicians (n=9) and pharmacists (n=5).

**Results:** 34 (94.4%) panellists participated in all 3 rounds. The panel supported 18 themes across the 5 areas (support/strongly support: 88.2–100%) underpinned by 5 metathemes. Metathemes focused on coordination in information delivery, the mode and timing of information delivery, evidence underpinning information, engagement of the right health professionals at the right time and a non-judgemental approach to infant feeding. Themes included practices for primary prevention of chronic disease and their sequelae, the importance of contraception and planning pregnancy and breast feeding, close monitoring of medications, supporting mental well-being, managing disease activity and providing practical support for early parenting.

**Conclusions:** A cross-disciplinary clinical panel highly supported key information and clinical practices in the care for women with RA across the continuum of contraception to early parenting within a whole-person, chronic disease management approach.

## Strengths and limitations of this study

- A clinical panel of rheumatologists, obstetricians and pharmacists contributed to the development of the recommendations, reflecting 'real-world', multidisciplinary clinical perspectives on best-practice care for women with rheumatoid arthritis.
- Inductive analysis of responses to open-ended questions ensured that themes were developed empirically from the expert panel.
- Very strong support was achieved for the final set of recommendations.
- The recommendations relate to clinical best-practice within a high-income economy and therefore may not be readily transferable to middle and low-income economies.

## INTRODUCTION

Rheumatoid arthritis (RA) typically occurs in women during their childbearing years,<sup>1</sup> with a prevalence that has increased over the last 15 years<sup>2</sup> and is expected to increase in coming decades.<sup>3</sup> Compounded with the prospect of living with a chronic, painful and sometimes progressive disease associated with substantial physical and mental health impacts,<sup>4</sup> young women with RA and their families face additional challenges in navigating a safe and successful pathway to parenthood.<sup>5</sup> Specifically, this pathway requires informed, collaborative decision-making and careful planning on the part of the patient and health professional(s) around RA disease activity monitoring and safe pharmacological management, physical and emotional health, and social support as they relate to contraception, conception and pregnancy, birth, breast feeding and early parenting.<sup>1 5–10</sup>

Our recent primary research investigating the information and service needs of Australian women with RA concerning pregnancy, breast feeding and early parenting identified a dearth of contemporary information available to support women to make informed decisions and implement practical coping strategies.<sup>6</sup> In particular, our data suggest that women with RA have clear pregnancy-related educational needs and seek specific information from their care providers about medicines safety during pregnancy and breast feeding, physical and emotional support services and practical coping strategies to manage pain and flares during the postnatal period.<sup>6</sup> Moreover, in a recent systematic review and editorial, we identified a lack of self-management interventions for women with RA targeted towards these issues,<sup>9 11</sup> despite European League Against Rheumatism (EULAR) recommendations that specific patient education is critical at important life and disease course stages<sup>12</sup> and published Standards of Care for RA that recommend comprehensive and individually tailored education about RA and its management.<sup>13</sup> While some consumer texts<sup>14 15</sup> and arthritis organisation web pages have been developed to address information gaps in this area, they remain limited and inadequately address some of the most important issues raised by women relating to disease management and medicines safety during pregnancy and breast feeding.<sup>5 6</sup> Consequently, treating health professionals (particularly rheumatologists) remain the primary communicators of such information, which is expected by patients<sup>6 16</sup> and entirely appropriate for the majority of cases.<sup>12</sup> Given that patients' information needs vary,<sup>6</sup> highly prescriptive guidelines are unlikely to be of use in clinical practice and do not align well with a patient-centred model of care.

Dealing with these issues is complex for health professionals, particularly in the light of limited data related to drug safety in pregnancy and breast feeding,<sup>1 17</sup> highlighting the importance of shared decision-making. Recent publications, however, provide updated evidence on medicines safety during pregnancy and breast feeding.<sup>18–20</sup> While these medications safety data and guidelines are fundamental to optimising clinical practice, they reflect only one component of care for women with RA at this important life stage. A broader counselling approach from health professionals is therefore important<sup>1 10 21</sup> and there is currently limited guidance in this area.<sup>20</sup>

Considering that a multidisciplinary approach to care is most likely to confer optimal fetal and maternal outcomes,<sup>1</sup> cross-discipline communication is important, as is consistency in the interdisciplinary messages that are provided to women with RA.<sup>1</sup> These issues are particularly relevant in settings with limited specific healthcare resources.<sup>22</sup> The Australian healthcare system supports interdisciplinary care for people with chronic health conditions, such as RA. For most patients, care is coordinated by family physicians, and in the context of RA and

pregnancy, is delivered by rheumatologists and obstetricians, and supported by allied health practitioners and community and hospital pharmacists. Outside public tertiary hospital clinics, these health professionals are rarely colocated, so coordination of care and communication between health professionals can be fragmented.<sup>23</sup> Notably, proceedings from the American College of Rheumatology (ACR) Reproductive Health Summit suggest that interprofessional and patient–professional communication in issues relating to fertility, pregnancy and lactation need to be improved.<sup>1</sup> Further, women with RA have expressed great concern and frustration at the contradictory messages they receive from their healthcare providers relating to RA management during conception, pregnancy, breast feeding and early parenting.<sup>6</sup> Having already undertaken primary research to identify the health information and service needs of women with RA concerning pregnancy, postnatal care and early parenting<sup>6</sup> and evidence for the effectiveness of interventions to improve women's knowledge and self-management skills related to contraception, pregnancy and breast feeding,<sup>11</sup> our programme of translational research sought to develop guidance for clinicians in interprofessional care. Specifically, this study aimed to establish cross-discipline consensus on the important educational messages (ie, 'what to say') and practice behaviours (ie, 'what to do') in the management of women with RA relating to contraception, pregnancy, breast feeding and early parenting.

## MATERIALS AND METHODS

### Design

An eDelphi process, consisting of three rounds following standard protocols,<sup>24 25</sup> was used to address the research aim.

### Sampling

A multidisciplinary national clinical panel was recruited, consisting of Australian practising rheumatologists, obstetricians/obstetric medicine physicians and pharmacists. Given our earlier primary research with patients<sup>6</sup> and that the focus of this study was to develop guidance for clinicians, we did not include patients on the Delphi panel. Panellists were sampled via a range of strategies, including self-nomination, purposive sampling via personal invitation from the researchers and snowballing; consistent with standard practice and recent Delphi studies and protocols in rheumatology research.<sup>13 20 26–31</sup> The specific sampling strategies used for each discipline are summarised below:

- ▶ *Rheumatologists*: a study flyer was provided to all attendees of the 2015 Australian Rheumatology Association Annual Scientific Meeting, inviting rheumatologists who met the inclusion criteria to contact one of the investigators (SVD) to express their interest in participating. The same investigator also sent email invitations to rheumatologists in each Australian state and

territory who were known to the research team to practice clinically and/or who had an interest in pregnancy-related care.

- ▶ *Pharmacists*: pharmacists known to have a special interest in medicines safety with pregnancy or breast feeding were invited via email from one of the investigators (SVD) to participate. In addition, pharmacy departments at two tertiary women's hospitals (Victoria and South Australia) and one university (Western Australia) were contacted to nominate suitably qualified pharmacists to facilitate snowballing.
- ▶ *Obstetricians/Obstetric medicine physicians*: clinicians known to have a special interest in inflammatory arthritis, chronic disease or high-risk pregnancies were invited to participate via email from one of the investigators (SVD). Websites of obstetric medicine practices were searched to identify clinicians who advertised a special interest in high-risk pregnancies.

Across each of the three disciplines, clinicians were invited to nominate other colleagues who met the study inclusion criteria, to facilitate snowballing.

Inclusion criteria for the panellists included: current registration to practice in Australia; a minimum of 4 years consultant experience (rheumatologists, obstetricians/obstetric medicine physicians) or clinical practice

experience (pharmacists); and currently clinically active for at least 8 hours (or two clinical sessions) per week or had undertaken this level of clinical practice within the last 5 years. All potential panellists were asked to complete an online screening questionnaire that was used to confirm eligibility and collect demographic data.

### eDelphi protocol and analysis

All eDelphi rounds were administered using Qualtrics software (Provo, Utah, USA). Each round started by sending panellists an email with a unique hyperlink to access the portal.

In round 1, panellists were asked to provide free-text responses to 10 open-ended questions about important information and resources women with RA and their families needed to receive across five domains, including: (1) general health, (2) contraception, (3) conception and pregnancy, (4) breast feeding and (5) early parenting. Free-text data were analysed inductively for each question using a content analysis approach to develop a framework of key themes and detailed elements underpinning each theme within each of the five domains of interest.<sup>32</sup> Overarching metathemes (guiding principles) were also developed, representing concepts that spanned across the five domains. Data

**Table 1** Baseline demographic characteristics of the expert panel

| Descriptor   | Discipline      |  |             |
|--|-----------------|--|-------------|
|  | Rheumatologists | Obstetricians/<br>obstetric physicians | Pharmacists |
| n (% panel)  | 22 (61.1)       | 9 (25.0)                               | 5 (13.9)    |
| % Female   | 68.2            | 77.8                                   | 80          |
| Location of practice; n (%)*   |                 |  |             |
| Community pharmacy   | –               | –                                      | 1 (20.0)    |
| Private practice   | 18 (81.2)       | 3 (33.3)                               | 1 (20.0)    |
| Public hospital  | 14 (63.6)       | 9 (100)                                | 5 (100)     |
| Private hospital   | 6 (27.3)        | 2 (22.2)                               | 1 (20.0)    |
| Academic appointment; n (%)  | 13 (59.1)       | 7 (77.8)                               | 2 (40.0)    |
| Number of practice locations (median (range))  | 2 (1–4)         | 1 (1–2)                                | 1           |
| Years of consultant/pharmacist experience  | 15.9 (7.6)      | 12.3 (7.4)                             | 23.6 (13.1) |
| Current number weekly clinical sessions (median (IQR))†  | 7 (3.8)         | 7 (5.5)                                | n/a         |
| Current weekly clinical hours†   | 32.8 (12.5)     | 27.5 (23.7)                            | 35.0 (12.8) |
| Usual number weekly clinical sessions in last 5 years† (median (IQR))†                         | 8 (4)           | 8 (3.5)                                | –           |
| Average weekly clinical hours in last 5 years†   | 35.7 (12.9)     | 35.5 (16.8)                            | 37.3 (11.7) |
| Special interest in inflammatory arthritis; n (%)  | n/a             | 3 (33.3)                               | 3 (60.0)    |
| Special interest in rheumatic diseases; n (%)  | n/a             | 3 (33.3)                               | 2 (40.0)    |
| Special interest in pregnancy or breast feeding; n (%)   | 17 (77.3)       | n/a                                    | 4 (80.0)    |
| Discussed contraception, pregnancy, breast feeding or early parenting in the last month; n (%) |                 |  |             |
| 0 patients   | 2 (9.1)         | n/a                                    | 0 (0)       |
| 1–3 patients   | 3 (13.6)        | n/a                                    | 1 (20.0)    |
| 4–7 patients   | 6 (27.3)        | n/a                                    | 1 (20.0)    |
| 8–10 patient   | 7 (31.8)        | n/a                                    | 0 (0)       |
| >10 patients   | 4 (18.2)        | n/a                                    | 3 (60.0)    |

Data presented as n (%) for categorical variables and mean (SD) for continuous variables unless otherwise stated.

\*Panellists could select more than one option.

†Panellists could respond to clinical hours per week and/or clinical sessions per week.

n/a, not applicable for the respondent.

were analysed independently by two analysts with clinical and patient communication expertise (AMB and JEJ, respectively). Where discrepancies were identified, these were resolved by consensus and review of the raw data.

In round 2, panellists were presented with a synthesis of the themes and elements for each domain and asked to assign their level of agreement with the information presented. Panellists were asked to rate their agreement at the key theme level, while being cognizant of the detailed elements underpinning each theme, using a three-point Likert scale: 'completely agree'; 'partly agree (modifications required)'; 'disagree'. Where panellists selected 'partly agree' or 'disagree' for a particular theme, they were asked to provide a free-text response to explain their selection. Where a theme was scored as  $\geq 5\%$  'disagree' by the panel, it was removed. Free-text data were analysed as described above and used to further refine the themes and elements. Elements were further categorised into clinical practices ('what to do') for health professionals and key messages to be disseminated ('what to say').

In round 3, panellists were presented with a final synthesis of the domain-specific themes and elements relating to clinical practices and key messages. Panellists assigned their level of support at the key theme level, while being cognizant of the detailed elements underpinning each theme, using a five-point Likert scale: 'strongly support'; 'support'; 'undecided'; 'oppose'; 'strongly oppose'. Panellists were given the opportunity to provide additional comments using free-text fields for each of the five domains. Where a key theme was scored as  $\geq 5\%$  'oppose' or 'strongly oppose' by the panel, it was removed. Free-text data were analysed as described above and used to further refine the themes and elements.

Descriptive statistics were used to characterise the panel. All members of the research team reviewed the synthesised themes and elements at each round for clarity and clinical meaningfulness. Descriptive statistics were used to analyse frequency data from rounds 2 and 3.

## RESULTS

Thirteen (35.1%) individuals self-nominated, 16 (43.2%) were purposively sampled and a further 8 (21.6%) were identified from snowballing. Of these, 36 (97.3%) were deemed eligible to participate in round 1 (1 was ineligible due to having <4 years consultant experience). Demographic characteristics of the 36 panellists are summarised in [table 1](#).

Thirty-five panellists (97.2%) participated in round 2 and 34 (94.4%) in round 3.

Analysis of free-text data from round 1 revealed 21 themes, supported by detailed elements across the five domains. At the second round, two themes exceeded the inclusion threshold of  $\geq 5\%$  disagreement and were removed. At the third round, one theme exceeded the inclusion threshold of  $\geq 5\%$  oppose or strongly oppose, leaving a final set of 18 themes supported by five

metathemes (guiding principles) with support/strongly support for key themes ranging from 88.2% to 100%.

Metathemes (guiding principles) focused on coordination in information delivery across health professionals, the mode and timing of information delivery, evidence underpinning information, engagement of the right health professionals at the right time and a non-judgemental approach to infant feeding approaches ([box 1](#)).

In the final presentation of themes and elements data for each of the five domains ([tables 2–4](#)), the elements for 'saying' and 'doing' are not intended to be linked and interpreted together within a specific table row. Rather, they should be interpreted independently and as a non-hierarchical list.

For general health approaches, panellists recommended primary prevention practices for chronic disease management, discussion around RA management and guidance on identifying trustworthy information ([table 2](#)). Across the four themes, final round scores for strongly support or support ranged from 94.1% to 100.0%.

For contraception, discussing the importance of contraception and its various options were identified as important themes ([table 3](#)). Across the two themes, final

### Box 1 Metathemes (guiding principles) derived from the data that spanned all domains of interest

#### Guiding principles

1. Consistent information should be conveyed to women with rheumatoid arthritis (RA) by a range of health professionals across the care continuum in a coordinated manner, based on the expertise of the health professional and relevance to the patient (ie, it is not suggested that one health professional carries the responsibility to convey all this information)
2. The mode and format in which information is delivered; timing of information; and level of details provided by a health professional(s) should be tailored to the needs of the patient, stage of their decision-making and with consideration of their health literacy, emotional well-being and overall situation at the time
3. Information provided by health professionals should be based on the best level of evidence currently available (or best practice in the absence of clear evidence) and relevant to their disease status
4. The recommended actions are those that should be undertaken across the health professional team, in a coordinated approach if and when appropriate. It is important to recognise that not all team members will be needed at all times: some team members will have different roles at different times (eg, general practitioners and gynaecologists may take a greater role in counselling about contraception, while rheumatologists would likely take a greater role in reviewing medication profiles)
5. Information and actions are intended to support women with RA who plan to, or choose to, breast feed in a non-judgemental manner. It is acknowledged that a range of infant feeding options are available and that breast feeding may not always be possible

**Table 2** Themes and elements relating to general health information for women with rheumatoid arthritis and their families

| <b>Saying: Information that should be discussed by health professionals</b>   | <b>Doing: Actions that should be undertaken by health professionals</b>   |
|---|---|
| <p><i>General health and primary prevention practices should be discussed across health providers, inclusive of the need for appropriate physical activity, nutrition, psychological health and relevant screening practices (100%)</i></p> <p>It is important to maintain a healthy weight range through adequate and appropriate diet and physical activity</p> <p>Alcohol intake should be minimised; eg, abide to WHO safe drinking levels and consume less alcohol than currently recommended levels for otherwise healthy women</p> <p>For some mothers and their families, it is important to consider mental well-being/stress management strategies</p> <p>Safe sexual health practices, including contraception and sexually transmitted disease prevention, should be adhered to</p> | <p>Support cessation of smoking (if smoker)</p> <p>Recommend/refer for screening procedures as appropriate including: bone mineral density, cardiovascular risk factors, pap test and breast examination</p> <p>Review immunisation requirements (particularly if on immunosuppressive drugs) and ensure immunisation profile is up to date</p> <p>Referral to appropriate health professionals for further detailed information where required (eg, contraception counselling)</p>                             |
| <p><i>Specific aspects of RA management should be discussed (as appropriate to patient) relating to medication, contraception and self-management (100%)</i></p> <p>DMARDs have benefit and risk profiles across the course of the disease. Using DMARDs and other agents to manage disease activity is critical for maternal and fetal health</p> <p>It is important to use reliable contraception when taking medications that may affect the fetus</p> <p>Bone health needs to be monitored and managed in people with RA</p>  | <p>Adopt a holistic approach to management of RA (ie, medication is only one aspect of RA management)</p> <p>Review, discuss and document current medications including: side effects, interactions, contraindications, effect of medications on fertility and implantation, timing of withdrawal of medications in planning pregnancy, need for and timing related to switching medications</p> <p>Offer pregnancy test (if any chance of pregnancy) before starting medications that may affect the fetus</p> |
| <p><i>Provide guidance in relation to obtaining relevant and trustworthy information about RA (94.1%)</i></p> <p>It is important to learn about RA and its management, but the use of websites should be limited to those that are reputable/reliable</p> <p>It is important to confirm information with a specialist and to use the internet and discussion forums judiciously</p> <p>Information about the safety of RA medications, particularly in relation to pregnancy, may be inconsistent, overly conservative or potentially out of date (eg, manufacturer information) and therefore it is important to always check with a specialist</p>  | <p>Encourage patients to take the time to learn about RA to optimise their health literacy</p>  |
| <p><i>Discuss the need for family planning and relevant considerations with respect to management of RA and involve partners, where appropriate (100%)</i></p> <p>It is important to plan for pregnancy and the postpartum period (including breast feeding) with specialists prior to conception</p> <p>Have an optimistic outlook—pregnancy and breast feeding are not contraindicated in RA and can be successful</p> <p>It is important to have optimal disease control prior to pregnancy and breast feeding to improve outcomes for the mother and baby. Uncontrolled disease activity is harmful to a mother and baby, so appropriate medication management is critical</p> <p>There are medication safety issues relating to conception, pregnancy and breast feeding</p>               | <p>Establishment of an appropriate multidisciplinary team for RA management, especially as it relates to pregnancy and early parenting when required</p>  |

Four themes are listed with their supporting elements for 'saying' and 'doing'. The proportion of panellists who supported or strongly supported each theme is identified in parentheses.

DMARD, disease modifying anti-rheumatic drug; WHO, World Health Organization.

**Table 3** Themes and elements relating to specific contraception information for women with rheumatoid arthritis and their families

| <b>Saying: Information that should be discussed by health professionals</b>  | <b>Doing: Actions that should be undertaken by health professionals</b>  |
|--|--|
| <p><i>Discuss need for, and importance of, contraception (100%)</i><br/>It is important to use contraception as a strategy to plan pregnancies and ensure good control of RA prior to conception, for optimal outcomes</p> <p>There are possible sequelae if one falls pregnant while on treatment</p>   | <p>Explore the patient's current relationship situation—whether in a relationship, current sexual activity status, plans for children (soon/never) and if currently using contraception (including what type)</p> <p>Determine need for contraception based on review of current medications (especially for Methotrexate and Leflunomide); disease activity and/or washout periods of medication</p> <p>Develop plan of potential options if unplanned pregnancy occurs, particularly if on medications which may affect the fetus, including where to seek expert advice</p> |
| <p><i>Outline different contraception options available including discussion of advantages and disadvantages based on patient need (97.1%)</i><br/>There are different contraceptive methods available (eg, barrier, hormonal, IUDs, diaphragms) and these options should be discussed in detail with your general practitioner in the first instance</p> <p>There are pros and cons of different contraception options relating to efficacy, convenience, cost, risks (eg, infection concerns with IUDs and comorbidities or medical history) and physical ability of the patient to insert devices correctly. In most cases, the general practitioner or gynaecologist is the most appropriate practitioner to discuss this information. Where more disease-specific clinical decisions are required, engagement of rheumatologists may be indicated</p> | <p>Provide written information regarding contraception options (where appropriate)</p>   |
| <p>Two themes are listed with their supporting elements for 'saying' and 'doing'. The proportion of panellists who supported or strongly supported each theme is identified in parentheses.<br/>IUD, intra-uterine device.</p>   |  |

round scores for strongly support or support ranged from 97.1% to 100.0%.

For conception and pregnancy, medication reviews, discussion about maternal and fetal health and preconception care, maintaining optimism, health and disease monitoring and practical considerations related to being pregnant with RA were deemed important (table 4). Across the six themes, final round scores for strongly support or support ranged from 94.1% to 100.0%.

Similarly, medication reviews and discussion concerning maternal and fetal health were considered important for breast feeding (table 5). For both of the two themes, final round scores for strongly support or support were 100.0%.

For early parenting, discussing impacts of RA, medication reviews and whole-person management were considered important (table 6). Across the four themes, final round scores for strongly support or support ranged from 88.2% to 100.0%.

## DISCUSSION

While clinical practice guidelines, drug surveillance data from registries, databanks and electronic medical

records are critical to informing clinicians' decisions about safe and appropriate RA management decisions,<sup>33</sup> these resources do not necessarily bridge the 'know-do' gap for clinicians or empower patients to engage in shared decision-making.<sup>34</sup> Supporting clinicians with clinician-centred, practical guidance (eg, guidance on 'what to say' and 'what to do') on how to practically implement evidence into routine clinical practice is therefore important,<sup>34</sup> particularly in diseases like RA where evidence-practice gaps exist.<sup>35 36</sup> To the best of our knowledge, this is the first study that has addressed this issue as it relates to cross-discipline management of RA in the context of contraception, pregnancy, breast feeding and early parenting. While recent publications provide excellent contemporary evidence on concerning the safety and effectiveness of pharmacological management in the perinatal and postnatal periods,<sup>18-20</sup> they do not consider a broader approach to management, particularly as it relates to implementing a person-centred model of care at the level of the clinical encounter. Consensus-based recommendations, supported by metathemes, have been developed to guide information delivery and clinical practices in a model of person-centred care for RA. Importantly, this study

**Table 4** Themes and elements relating to specific conception and pregnancy information for women with rheumatoid arthritis and their families

| <b>Saying: Information that should be discussed by health professionals</b>  | <b>Doing: Actions that should be undertaken by health professionals</b>   |
|--|---|
| <p><i>Review of current medications in relation to safety during conception and pregnancy (100%)</i></p> <p>Prior to conception and pregnancy, review current medication(s) and discuss:</p> <ul style="list-style-type: none"> <li>▶ Medications vary with respect to their safety during pregnancy and risks related to fertility, ovulation, conception and miscarriage</li> <li>▶ Some medicines used in RA care may have effects on fertility, conception and pregnancy process, for example, regular NSAIDs may impair fertility and associated risks with fetus</li> <li>▶ It is important to time conception</li> </ul> <p>Where current medication(s) is (are) contraindicated for conception/pregnancy the following should be discussed with the patient:</p> <ul style="list-style-type: none"> <li>▶ There are safe medication options pre, during (including delivery) and postpregnancy (including breast feeding)</li> <li>▶ Timing is important in relation to ceasing or switching of current medications and allowing for washout periods prior to conception</li> <li>▶ There is a need for close supervision/monitoring by a rheumatologist when discontinuing current medications prior to pregnancy, including considering potential need for disease stabilisation on new treatment prior to conception and pregnancy</li> </ul> | <p>Provide guidance as to where to obtain reliable information about safety of medicines in pregnancy</p>   |
| <p><i>Discuss impact of RA pathology on pregnancy and pregnancy on RA (100%)</i></p> <p>There are different scenarios regarding RA disease activity during pregnancy (eg, possible remission/low disease activity)</p> <p>Conception may take longer compared with women who do not have RA</p> <p>There is a need to balance disease control with maternal and fetal health and safety</p> <p>RA may affect pregnancy and pregnancy may affect RA, and there are possible adverse outcomes where risks are identified (eg, prematurity)</p> <p>There are significant risks associated with active or uncontrolled RA for the mother and baby, especially irreversible joint damage and functional impairment</p> <p>Pregnancy may change a patient's health outlook in the future</p> <p>The size of the baby may be smaller than women without RA and may also be delivered pre-term</p>   | <p>Discuss: RA-related pain management options during pregnancy</p>   |
| <p><i>Discuss important elements of preconception care relevant to patient (97.1%)</i></p> <p>It is important to achieve optimal disease control prior to considering pregnancy—planning conception is preferable after patients achieve and maintain low disease activity</p> <p>There is a critical need for a planned pregnancy rather than an unplanned pregnancy</p> <p>History of previous attempts to conceive/pregnancies or pregnancy-related complications (eg, miscarriage) and other relevant patient history (such as smoking/illicit drug use history, family history of hereditary issues) may affect pregnancy</p> <p>Weight management and appropriate exercise are very important</p>  | <p>Encourage and facilitate early discussions with all health practitioners involved in care about family planning to allow for adequate preparation</p> <p>Review prenatal nutrition, including need for dietary/vitamin supplements (ie, folic acid, calcium, vitamin D, iodine, iron)</p> <p>Undertake relevant health checks such as immunisation status (eg, rubella, varicella, pertussis), sexually transmitted disease screening, pap test, screening for other autoimmune disorders that may impact on pregnancy</p> <p>Consider the need for review of diabetes or impaired glucose tolerance if risk factors are present (eg, on steroid medication or overweight/obese)</p> |

Continued

Table 4 Continued

| <b>Saying: Information that should be discussed by health professionals</b>   | <b>Doing: Actions that should be undertaken by health professionals</b>   |
|---|---|
| <p>It is important to manage comorbid conditions, such as diabetes and hypertension</p> <p>Some women may need to avoid conception during a flare</p> <p>RA disease activity may or may not improve with pregnancy and there is a likelihood of postpartum flares</p>   |   |
| <i>Importance of maintaining optimistic outlook and providing positive messages (97.1%)</i>   |   |
| <p>Pregnancy and breast feeding success rates are near normal in women with mild to moderate RA nowadays (where appropriate for the patient's clinical status)</p> <p>RA is not a barrier to pregnancy</p> <p>Strategies to address anxiety, stress and depression (if relevant) are important, such as mindfulness meditation</p>  |   |
| <i>Need for close monitoring of a patient prior to and during pregnancy, where indicated (94.1%)</i>  |   |
| <p>It is importance to have a healthcare team with expertise in autoimmune disorders for some women with RA</p> <p>Some women require closer monitoring of their pregnancy and this is usually proportional to disease activity, comorbidities and maternal history</p> <p>It is important to develop a pregnancy plan, which includes different options for management of RA and support for different scenarios</p> <p>Vaginal delivery may not always be possible, depending on condition of the patient's hips. There are other possible options for delivery and positions</p> | <p>Determine the need for high-level obstetric care during a pregnancy (where indicated), including the need for anaesthetic input</p> <p>Assess the requirements for any extra treatment or monitoring prior to, or during, pregnancy</p>  |
| <i>Outline practical considerations and planning requirements for the patient in relation to pregnancy and postdelivery (94.1%)</i>   |   |
| <p>Support networks are important during and after pregnancy (particularly in relation to postnatal flares)</p> <p>There are different pain management options for RA disease if medications are withdrawn during pregnancy</p> <p>It is important to establish a skilled, general practitioner-led multidisciplinary team</p> <p>In some situations, clinical psychologists play an important role</p>   | <p>Develop a plan as to how to manage a pregnancy based on physical function</p> <p>Develop a plan for equipment and services required to care for an infant</p> <p>Develop a postpartum management plan for medicines and physical therapies</p> <p>Assess the need for physiotherapy and occupational therapy assessment/review and support in terms of managing physical tasks associated with caring for a baby</p> |
| <p>There is a need for contraception after delivery if taking medications that may be harmful to the fetus</p>  | <p>Assess physical ability to manage pregnancy, motherhood and family life</p> <p>Explore patient's wishes regarding a birth plan</p> <p>Explore patient's breast feeding wishes and potential considerations for immediately after birth (eg, initial attachment, establishing lactation) and during postnatal period (eg, ability to hold baby and feed comfortably)</p>  |

Six themes are listed with their supporting elements for 'saying' and 'doing'. The proportion of panellists who supported or strongly supported each theme is identified in parentheses.

NSAID, non-steroidal anti-inflammatory drug.

complements the eumusc.net standards of care for RA<sup>13</sup> and EULAR overarching principles for antirheumatic drug use before, during and after pregnancy<sup>20</sup> by operationalising these standards and principles in the context of contraception, pregnancy, breast feeding and early parenting.

The themes and elements identified across the five domains reasonably balance clinical practice behaviours

and recommendations for the delivery of health information across health professionals with support for self-management, shared decision-making and recognition of non-physical impacts of pregnancy and early parenting on a background of RA. We suggest these components and this balance are reflective of best practice in a person-centred model of care for a chronic disease, such as RA.<sup>37</sup> The consensus clinical recommendations also



**Table 5** Themes and elements relating to specific breast feeding information for women with rheumatoid arthritis and their families

| <b>Saying: Information that should be discussed by health professionals</b>   | <b>Doing: Actions that should be undertaken by health professionals</b>  |
|---|--|
| <p><i>Discussion of breastfeeding considerations for patient that take into account their disease activity, medication, physical function and social support network (100%)</i></p> <p>Breast feeding is important and highly possible with RA when planned appropriately</p> <p>There are potential challenges associated with RA and breast feeding (eg, postnatal flares, being able to hold the baby comfortably for a prolonged period of time and fatigue)</p> <p>There are many benefits associated with breast feeding to the baby and mother</p> <p>Good disease control is important to optimise duration of breast feeding</p> <p>There is a need to balance medication for disease control to maintain a healthy mother with the importance of breast feeding</p> <p>There is often a need for support and help in assisting with breast feeding, caring for the baby and getting adequate rest</p> | <p><i>into account their disease activity, medication, physical function and other comorbidities (eg, osteoporosis) including:</i></p> <ul style="list-style-type: none"> <li>▶ Patient beliefs and wishes</li> <li>▶ Risks/benefits</li> <li>▶ Duration</li> <li>▶ Plan for different options depending on disease control (including postnatal flares)</li> </ul> <p>Refer to local lactation consultant or direct to local breastfeeding support organisations (eg, breast feeding associations) for further information and support if required</p>  |
| <p><i>Review of RA medication in relation to safety during breast feeding once pregnancy has been established (100%)</i></p> <p>Some medications can be safely continued while breast feeding (eg, most biologics) and some that are contraindicated (eg, Methotrexate)</p> <p>Timing breast feeding around drug administration to minimise exposure to the baby can be important, especially where medication has a short half-life</p> <p>Breast feeding may need to be stopped if disease activity cannot be brought under control</p> <p>There are different medication options that can assist with establishing lactation (where problems are experienced) that are also safe with RA medication</p>  | <p>Provide guidance concerning misinformation about drugs, eg, awareness of no official rating system for safety of drugs in lactation unlike in pregnancy, and need to consult beyond product information provided by pharmaceutical companies (ie, consult with health professionals)</p> <p>Identify/refer to credible sources for obtaining information about medication in lactation</p> <p>Provide information relating to expressing breast milk, storage and feeding to assist with management of medication regimes</p> <p>Develop an individualised breast feeding plan based on identified risk factors (eg, diabetes, non-vaginal birth, ability to hold infant comfortably) prior to birth. Review and modify the plan regularly, particularly in the early postpartum period until breast feeding is established</p> |
| <p>It is imperative to review breastfeeding practices if medications change</p>   |  |
| <p>Two themes are listed with their supporting elements for 'saying' and 'doing'. The proportion of panellists who supported or strongly supported each theme is identified in parentheses.</p>   |  |

align with the findings of a recent review around managing pregnancy in women with rheumatological disease,<sup>38</sup> and extend beyond the physical implications of RA. Although a previous small study reported no mental health impact of pregnancy in a group of women with RA compared with controls, as assessed by the SF-36,<sup>39</sup> panellists in our study recognised the potential for psychological health to be impacted. The metathemes acknowledge that these recommendations should be considered in the context of a person's health literacy and disease status, which are critical for informed decision-making and capacity to engage in

cocare.<sup>40</sup> Importantly, many of the themes and elements were oriented towards empowering women, through tailored education, to make decisions (eg, about breast feeding) in collaboration with their health professionals and maintaining a positive outlook to pregnancy and early parenting. In this context, an important theme that emerged was the risk of relying on web-based materials for information about medicines safety related to pregnancy and breast feeding and disease control. Panellists were unequivocal in recommending that women seek professional advice from their healthcare team and consult appropriately qualified organisations,

**Table 6** Themes and elements relating to specific early parenting information for women with rheumatoid arthritis and their families

| <b>Saying: Information that should be discussed by health professionals</b>  | <b>Doing: Actions that should be undertaken by health professionals</b>  |
|--|--|
| <p><i>Discuss potential impacts of RA in early parenting (91.2%)</i><br/>Possible impacts of RA include greater fatigue, pain levels, joint deformities and musculoskeletal dysfunction/mobility impairment. These may impact on one's ability to undertake specific tasks when caring for a baby<br/>There is a possibility of RA flares during the postnatal period. It is important to contact your rheumatologist early to discuss management options if flares occur<br/>Sleep deprivation increases the risk of higher disease activity and pain<br/>Physical limitations may impact parenting of children<br/>It is important to learn pacing and balance activity with rest<br/>Consider the long-term risks and challenges associated with early parenting in the context of having RA<br/>With good planning and consideration, women with RA are able to have a similar experience to other parents who do not live with RA</p> |  |
| <p><i>Review RA medication options during the postpartum period (100.0%)</i><br/>There are substantial benefits in achieving good disease control for mother and baby postpartum and this may need to be a primary aim<br/>It is important to continue treatment compliance even though your normal routine will be altered</p>  | <p>Provide treatment options/develop a plan to manage flares if they arise (eg, ability to safely use NSAIDs, Prednisolone, Plaquenil and Salazopyrin if breast feeding)<br/>Review medication options after breast feeding has ceased<br/><br/>Discuss the potential impact/safety of RA medications on the baby, for example, anti-TNF medications given in pregnancy</p>  |
| <p><i>Discuss physical and psychological support needs during early parenting (88.2%)</i><br/>There is often a need for support networks, given the challenges associated with early parenting such as sleep deprivation and physical impairments. Mothers groups and RA peer support groups may be useful options to consider</p>   | <p>Refer to occupational therapy/physiotherapy for assistance with physical tasks associated with caring for baby<br/><br/>Direct to local arthritis organisation for further information and support<br/>Develop an action plan for support including when to seek help and who to contact<br/>Discuss practical advice about caring for an infant (eg, accessing a cot, pushing a pram, changing nappies) and the importance of occupational therapy and physiotherapy support</p> |
| <p><i>Importance of maintaining well-being and disease control (94.1%)</i><br/>It is important to maintain a healthy lifestyle, for example, healthy diet, safe exercise, alcohol and smoking restrictions/modifications</p>   | <p>Discuss the childhood vaccination schedule and relevant safety considerations including:<br/> <ul style="list-style-type: none"> <li>▶ Some childhood vaccinations are live and care needs to be taken if on standard or biological DMARDs</li> <li>▶ Vaccinations required/contraindicated based on RA drugs transmitted to baby</li> </ul>           Refer to appropriate specialists for further information, for example, paediatricians or neonatal medicine specialists</p> |
| <p>Good disease control is important for bone health</p>   |  |

Four themes are listed with their supporting elements for 'saying' and 'doing'. The proportion of panellists who supported or strongly supported each theme is identified in parentheses.

DMARD, disease modifying anti-rheumatic drug; NSAID, non-steroidal anti-inflammatory drug; TNF, tumour necrosis factor.

such as arthritis consumer organisations and breast feeding organisations, for more information. Notably, while internet searching is important to consumers in this context,<sup>6 41</sup> data from recent studies examining website quality as it relates to chronic pain suggest it is highly variable.<sup>42 43</sup>

Panellists provided the most detailed responses for Theme 3—Conception and Pregnancy. In addition to supporting women in conception and pregnancy within a chronic disease model of care through education, practical skills and situation planning, the most significant clinical issues raised related to the critical need for pregnancy planning due to the possible teratogenic effects of disease-modifying agents and achieving disease control to ensure maternal and fetal health and safety. These issues are consistent with those raised in recent reviews on this topic, confirming face validity of the recommendations<sup>20 22 38</sup> and reflect the priorities of women with RA.<sup>6</sup> We suggest, therefore, that our findings, while intentionally clinician-centred, align well with the primary research we conducted with women with RA that formed the basis for the current study.<sup>6</sup>

Panellists considered that assessment of indications and contraindications for various contraceptive options related predominantly to care provided by general practitioners or gynaecologists and this theme was, therefore, not included in the final set. Notably, a recent systematic review<sup>44</sup> and guidelines<sup>45</sup> have been published on the issue of contraception in RA, which provides some guidance to clinicians.

While recommendations have been developed concerning the management of RA at this important life stage,<sup>18–20 38 44 45</sup> there is a lack of RA-specific guidelines for clinicians, largely attributed to a lack of definitive clinical trials data concerning drug toxicity and safety during pregnancy and breast feeding, particularly as they relate to the newer disease-modifying agents.<sup>10</sup> A recent review highlights this issue to be particularly relevant in the Middle East.<sup>22</sup> Variability in practice is, therefore, unsurprising,<sup>46</sup> resulting in uncertainty and dissatisfaction for patients.<sup>6 47</sup> Our data offer some practical strategies for health professionals as a means to facilitate consistency in an approach to management and a prompt for cross-discipline care, which has previously been identified as inadequate,<sup>47</sup> despite being recommended.<sup>38</sup> For women with RA and their families, we support the use of the RA Standards of Care Checklist as a means to ensure RA care, as it relates to contraception, pregnancy, breast feeding and early parenting, is optimised.<sup>13</sup>

Our study has a number of important strengths: we recruited a large expert sample relative to other comparable studies in arthritis care,<sup>12 13 20 27 30 31</sup> our sample was cross-disciplinary with a spread of practice locations across the country, our response rate remained very high across all three rounds, and we achieved a high level of support for the final set of themes. Our sample was purposely weighted towards rheumatologists to reflect the discipline

most usually involved across the continuum of care from contraception through to early parenting. Importantly, however, the findings do not relate solely to rheumatologist-delivered care, but rather all clinicians involved in a woman's care and reflect a best-practice approach. It would be unreasonable to expect a single clinician or clinical discipline to adopt all the recommendations. The transferability of our recommendations may be limited in some aspects since we sampled only Australian clinicians and therefore, the cross-cultural relevance and meaningful transferability to other health systems (eg, those in low and middle-income economies or rural settings) should be explored in future work.<sup>22 48</sup> Australians living in urban settings enjoy a health system that supports access to coordinated care from multiple health professionals. In rural Australia and in other nations, this is rarely accessible and therefore the recommendation to establish multidisciplinary care teams may not be feasible in a real-world setting in these contexts, particularly at the primary care level. Multidisciplinary team care may, in some settings, be more appropriately established at the tertiary hospital level where access to medical specialists and upskilled allied health providers is more achievable. Although we did not include patients in our sample, the foci for the Delphi were directly informed by previous empirical, consumer-based research, consistent with the approach adopted by Hawker *et al.*<sup>30</sup> The results from this study and our recent systematic review<sup>11</sup> point to the opportunity to develop and evaluate targeted educational interventions for this group of consumers.

## CONCLUSION

Coordinated, multidisciplinary care for women with RA concerning contraception, pregnancy, breast feeding and early parenting is important. Although clinical guidelines provide necessary information on 'what care' should be provided, guidance on 'how' to provide the care is rarely described. Cross-discipline recommendations for care delivery include: counselling and practices relating to primary prevention of chronic disease and their sequelae, supporting women to actively use contraception and to plan pregnancy and breast feeding, close monitoring of medications, supporting mental well-being, managing disease activity and providing practical support for early parenting. A chronic disease model of care should underpin these practices.

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