

## Response to: 'Correspondence on 'EULAR recommendations for a core data set for pregnancy registries in rheumatology' by De Cock *et al*

We are pleased to see that so shortly after publication already the first evaluation of the "EULAR recommendations for a core data set for pregnancy registries in rheumatology"<sup>1</sup> was performed in daily rheumatological practice.

De Cock *et al* have analysed data on pregnant women with rheumatoid arthritis (RA) available in their rheumatology clinic and were able to evaluate 30 pregnancies in 21 women.<sup>2</sup> As would be expected from careful clinical documentation that is not specifically designed to collect data on pregnancies, the data on general clinical parameters and therapies were very complete, but on events during and after pregnancy (especially those that are more likely to occur in rheumatic diseases other than RA) were often missing. However, it is encouraging that a considerable part of what we have proposed is apparently already collected in clinical routine.

When it comes specifically to the course of pregnancy and fetal outcome, there is no way around a targeted prospective data collection. It was the intention of the Task Force, of which the first author of this correspondence was a member, to standardise such prospective registries.

There seems to be a misunderstanding in the correspondence regarding the 28-day period after delivery. Perhaps this was not communicated clearly enough in the recommendations. The Task Force did not suggest that a visit to a rheumatologist had necessarily to take place during this period, but that events occurring during this period, that is, in the neonatal phase, should be documented. Of course, this information can also be collected and documented at a later time, when the woman visits the rheumatology practice for the first time after delivery. The Task Force considered it a minimum requirement to record all deaths and malformations recognisable during the neonatal period. This means that the doctor will at least query events in this phase during the first visit. It is desirable to document child development prospectively over a longer period of time, for example, until the second birthday. However, since this poses additional work load, the Task Force did not define this as a minimum standard but recommended to extend the observation beyond the time frame of 4 weeks in order to assess long-term outcomes concerning child development.

Overall, de Cock's analysis confirms the Task Force's approach of proposing a feasible set of variables that can be well integrated into clinical routine, and we are grateful for the analysis.

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