NASJONAL KOMPETANSETJENESTE
for svangerskap og revmatiske sykdommer

RevNatus

Et landsdekkende kvalitetsregister for svangerskap og revmatiske sykdommer

Brukermøte 24.10.2023

Disposisjon

- Formålet med RevNatus
- Status / kvalitet
- Brukererfaring med RevNatus
- Bruk av data
- Internasjonalt samarbeid
- Publikasjoner med data fra RevNatus 2023
- Pågående prosjekter
- Elektronisk pasientrapportering – som verktøy og klinisk betydning

Formål

- sikre kvalitet og enhetlig behandling og oppfølging av pasienter med inflammatoriske revmatiske sykdommer som planlegger svangerskap eller er gravide

- bidra til økt forskningsbasert kunnskap

Overvåke

Grunnlag for økt kunnskap

Registerorganisering

registerleder: Hege Svean Koksvik

registerkoordinator: Hilde Bjørngaard

medisinsk ansvarlig: Marianne Wallenius

utviklingsansvarlig: Bente Jakobsen

Fagråd

- Leder/representant HMN: Marianne Wallenius
- Representant HV: Bjørg Tilde Fevang
- Representant HSØ: Mona Therese Thorud
- Representant HN: Synøve Kalstad
- Representant gynekologi: Sindre Grindheim

- Brukerrepresentant: Mari Skog

- Fra registeret: Hege Svean Koksvik og Hilde Bjørngaard

Status registrerte pr oktober 2023

kvinner: 2195

svangerskap: 2851
(planlagte, pågående eller gjennomførte)

Diagnose	Antall hovedskjema	Antall med registrert utfall 6 uker etter fødsel
Revmatoid artritt	656	488
Aksial spondyloartritt	616	487
Juvenil idiopatisk artritt	447	345
Systemisk lupus erythematosus	296	246
Psoriasisartritt	258	186
Polyartritt	115	80
Sjögrens syndrom	112	96
Mixed connective tissue disease	70	59
Leddsykdom assosiert med tarmsykdom	45	26
Granulomatose med polyangiit	40	35
Behçets sykdom	27	23
Myositter	24	17
Systemisk sklerose	22	14
Takayasus sykdom	19	16
Stills sykdom	8	6
Polyarteritt med lungeaffeksjon	4	4

Kvalitetsindikatorer

Minst 80 % av pasientene med SLE bruker HCQ gjennom svangerskapet

Det er en internasjonal anbefaling at kvinner med SLE skal behandles med hydroksyklorokin (HCQ) i svangerskapet, da en seponering av HCQ øker risikoen for oppbluss av sykdom.

Målet er at minst 80 % av pasientene med SLE bruker HCQ gjennom svangerskapet.

Indikatoren rapporteres på nasjonalt nivå.

2023: 10/11

CRP er tatt ved alle revmatologiske kontroller

CRP er en viktig variabel når det gjelder vurdering av sykdomsaktivitet ved inflammatorisk sykdom og bør tas ved alle kontroller.

Målet er at CRP er tatt ved alle revmatologiske kontroller (100 %). Høy måloppnåelse er satt til ≥ 90 %.

Revmatologisk enhet	2. Kompletthet CRP 2023 per 14/9-23
St. Olavs hospital	92 %
Diakonhjemmet sykehus	67 %
Universitetssykehuset Nord-Norge, Tromsø	92 %
Ålesund sjukehus	83 %
Haukeland universitetssjukehus	85 %
Oslo universitetssykehus	96 %
Martina Hansens Hospital	93 %
Haugesund SF Revmatismesykehus	88 %
Vestre Viken Drammen sykehus	87 %
Betanien Hospital	97 %
Stavanger universitetssykehus	95 %
Revmatismesykehuset Lillehammer	100 %
Nordlandssykehuset Bodø	98 %
Sykehuset Levanger	100 %
Helgelandssykehuset Mo i Rana	93 %
Sørlandet sykehus Kristiansand	53 %
Førde sentralsjukehus	88 %
Sykehuset Østfold Moss	90 %
Universitetssykehuset Nord-Norge, Harstad	100 %

Minst 80 % av pasienter med SLE står på Albyl-E i svangerskap

Kvinner med SLE skal ha Albyl-E i svangerskap som profylakse mot preeklampsi.

Målet er at 80 % av pasienter med SLE står på Albyl-E i svangerskap.

Indikatoren rapporteres på nasjonalt nivå.

2023: 10/11

Minst 80 % av alle gravide skal svare at de har mottatt rådgiving om svangerskap ved sin sykdom på hovedskjema

Alle inkluderte pasienter skal få rådgiving om svangerskap ved sin revmatiske sykdom fra sin behandler.

Målet er at minst 80 % av alle gravide skal svare at de har mottatt rådgiving om svangerskap ved sin sykdom på hovedskjema.

Kun svar på **pasientrapportering** fra enheter med > 5 skjema blir rapportert.

Revmatologisk enhet	Antall hovedskjema med selvrapportering	% svar <JA> 2022-2023
St. Olavs hospital	91	85 %
Universitetssykehuset Nord-Norge, Tromsø	48	73 %
Martina Hansens Hospital	44	77 %
Vestre Viken Drammen sykehus	37	86 %
Haugesund SF Revmatismesykehus	35	74 %
Oslo universitetssykehus	34	82 %
Diakonhjemmet sykehus	34	85 %
Stavanger universitetssykehus	32	81 %
Ålesund sjukehus	25	88 %
Nordlandssykehuset Bodø	22	59 %
Revmatismesykehuset Lillehammer	13	85 %
Sørlandet sykehus Kristiansand	11	82 %
Haukeland universitetssjukehus	11	73 %
Sykehuset Levanger	10	90 %
Helgelandssykehuset Mo i Rana	7	57 %
Sykehuset Østfold Moss		
Førde sentralsjukehus		
Universitetssykehuset Nord-Norge, Harstad		
Betanien Hospital		

stolav.no/revnatus

FOR DEG SOM SKAL REGISTRERE I REVNATUS

- Info RevNatus
- Samtykke norsk
- Samtykke engelsk
- Tips ved inklusjon i RevNatus
- Søke om tilgang til RevNatus
- Tips for bruk av SLEDAI
- Tips for bruk av BVAS/VDI
- Måling av skade med SLICC
- Klinisk verktøykasse NKRR
- Ofte stilte spørsmål
- NKSR sin hjemmeside
- NorArtritt sin hjemmeside
- NorVas sin hjemmeside
- Nasjonalt servicemiljø

FOR PASIENTER

- Samtykke norsk
- Samtykke engelsk
- Personvern
- Aktuelle koblinger

REGISTERINFORMASJON

- Formålet med RevNatus
- Godkjenning og driftansvar
- Om dataløsningen
- Kvalitetsindikatorer
- Kvalitetsforbedringsprosjekt 2023
- Variabeloversikt
- Diagnoser i RevNatus
- Fagråd RevNatus
- Årsrapporter
- Nyhetsbrev
- Brukermøte kvalitetsregistre
- RevNatus på YouTube

FORSKNING

- Prosjekter
- Søke om å bruke data fra RevNatus
- Biobank RevNatus
- Publikasjoner fra RevNatus

YouTube <Svangerskap og revmatisk sykdom>

Spilleliste som heter: RevNatus

Søke tilgang til RevNatus

Svangerskap og revmatisk sykdom

Sende ut elektronisk samtykke RevNatus

Svangerskap og revmatisk sykdom

Registrere skjema i RevNatus

Svangerskap og revmatisk sykdom

Systemic lupus erythematosus disease activity index (SLEDAI) i RevNatus

Svangerskap og revmatisk sykdom

Data fra RevNatus blir brukt!

OPEN ACCESS

EULAR recommendations for a core data set for pregnancy registries in rheumatology

Yvette Meissner [1], Rebecca Fischer-Betz,[2] Laura Andreoli [3,4], Nathalie Costedoat-Chalumeau [5,6], Diederik De Cock,[7] Radboud J E M Dolhain,[8] Frauke Forger,[9] Doreen Goll,[10] Anna Molto [11,12], Catherine Nelson-Piercy,[13,14] Rebecca Özdemir,[15] Luigi Raio,[16] Sebastian Cruz Rodríguez-García [17], Savino Sciascia [18], Marianne Wallenius,[19,20] Astrid Zbinden,[9] Angela Zink,[1] Anja Strangfeld [1]

European Network of Pregnancy Registries in Rheumatology (EuNeP)

Spondyloarthritis

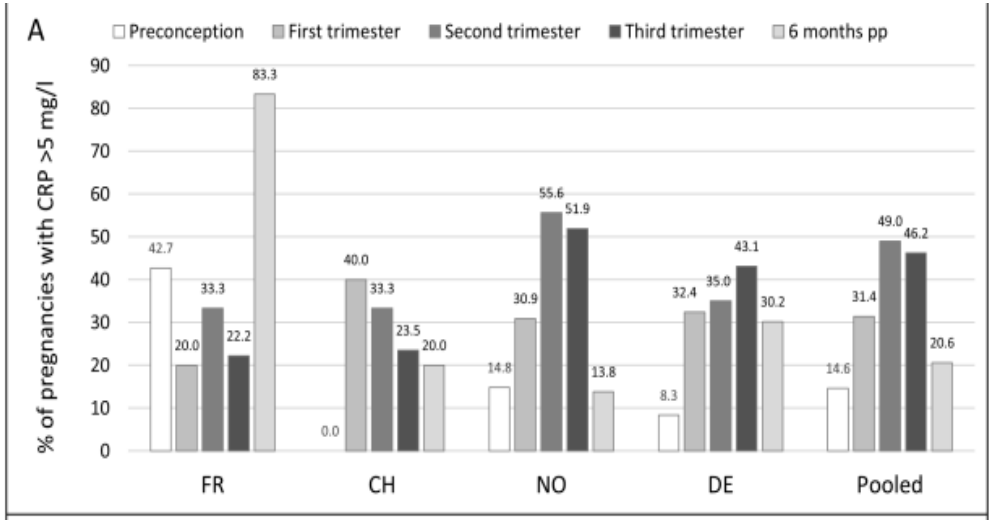
Pregnancy and neonatal outcomes in women with axial spondyloarthritis: pooled data analysis from the European Network of Pregnancy Registries in Rheumatology (EuNeP)

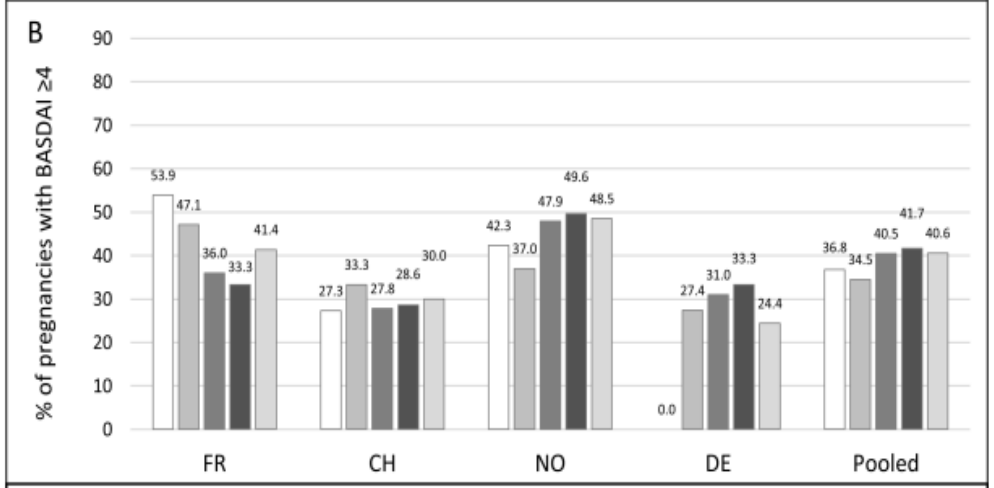
Yvette Meissner [1], Anja Strangfeld [1, 2], Anna Molto [3, 4], Frauke Forger [5], Marianne Wallenius [6, 7], Nathalie Costedoat-Chalumeau [8, 9], Hilde Bjørngaard [7], Marion Couderc [10, 11], René-Marc Flipo [12], Gaëlle Guettrot-Imbert [8], Isabell Haase [13], Bente Jakobsen [7], Hege Suorza Svean Koksvik [7], Christophe Richez [14, 15], Jérémie Sellam [16, 17], Anja Weiß [1], Astrid Zbinden [5], Rebecca Fischer-Betz [18] EuNeP collaborator group

Correspondence to Dr Yvette Meissner, Programmbereich Epidemiologie und Versorgungsforschung, Deutsches Rheuma-Forschungszentrum Berlin, Berlin, Berlin, Germany; y.meissner@drfz.de

Materiale

- 334 svangerskap hos 304 kvinner med axSpA
  - **RevNatus (No): 147 pas - 167 svangerskap**
  - Rhekiss (Ge): 81 pas – 87 svangerskap
  - RePreg (CH): 27 pas – 27 svangerskap
  - EGR» (Fr): 49 pas – 51 svangerskap





Number of total pregnancies with live birth

	51	26	165	86	328

Number of pregnancies with missing information on CRP | BASDAI

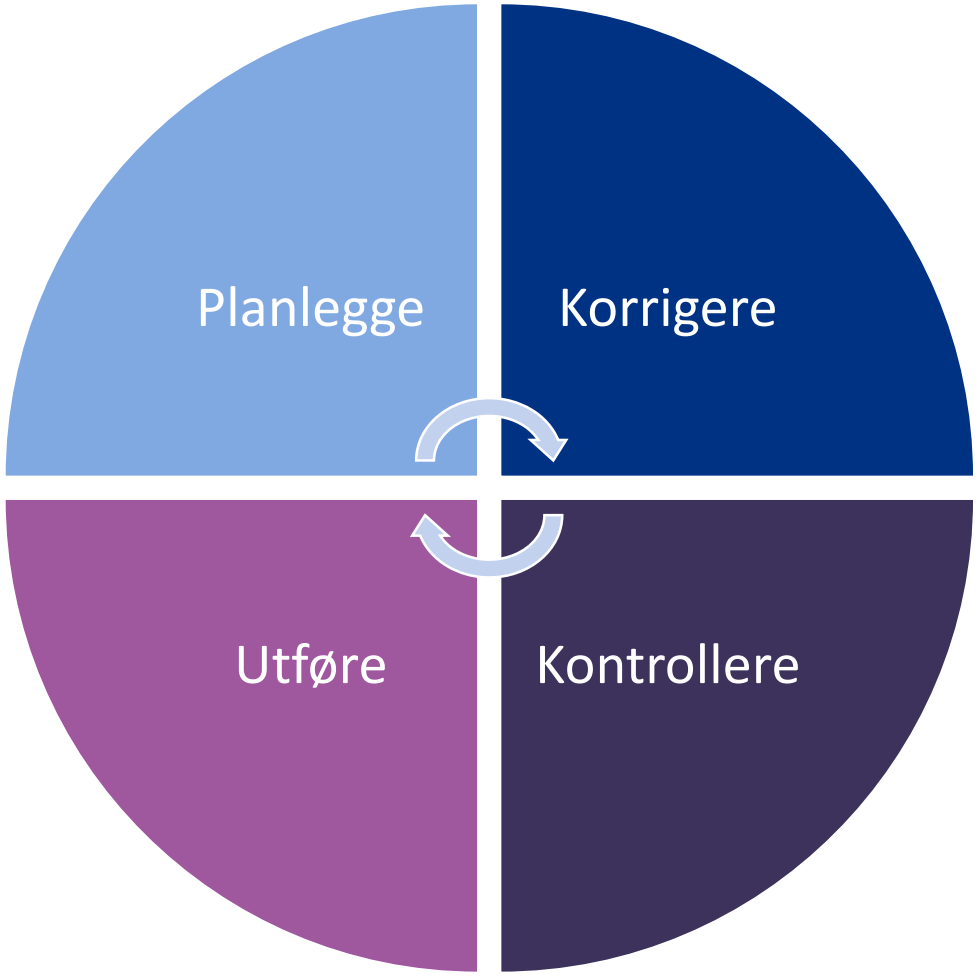
Preconception	44 | 38	46 | 34	42 | 26	42 | 27	45 | 22
First trimester	17 | 15	21 | 20	11 | 8	9 | 5	21 | 16
Second trimester	111 | 113	55 | 73	23 | 46	30 | 44	49 | 62
Third trimester	74 | 75	15 | 24	46 | 28	35 | 29	43 | 41
6 months pp	246 | 241	137 | 151	122 | 108	116 | 105	158 | 141

Obs missing data!

- Må være et mål å få til så komplette registreringer som mulig

Kvalitetsforbedringsarbeid

- Årlige fokusområder
- Deming´s sirkel



Langley, Nolan, Nolan, Norman, Provost: The Improvement Guide, New York; Jossey Bass, 1996.

2021 - 2022

Systematic improvement of completeness on data in data in the quality register RevNatus

H. Bjørngaard[1], B. Jakobsen[1], H.S. Koksvik[1]
[1]St. Olavs hospital, Norwegian National Advisory Unit on Pregnancy and Rheumatic Diseases, Trondheim, Norway

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PURPOSE

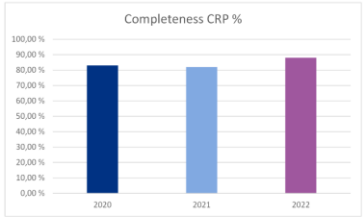
The objective of this study is to determine the effect of a systematic quality improvement project in the the nationwide quality register RevNatus that aims to improve the completeness of the variable <CRP>.

METHODS

The Figure present the project using Demings`s circle.

RESULTS

The table shows completeness of the variable <CRP> in the period 2020 – 2022.



CONCLUSION

We saw an improvement in completeness of CRP after running a systematic quality improvement project over three years. This leads to higher quality of the data describing women's disease activity in the course of pregnancy.
The principles of Deming's circle as a method was well suited for this work.

Corresponding author: hilde.bjorngaard@stolav.no

NORWEGIAN NATIONAL ADVISORY UNIT on Pregnancy and Rheumatic Diseases

Improving quality of diagnostic data in data in RevNatus 2020 - 2022

H. Bjørngaard[1], B. Jakobsen[1], H.S. Koksvik[1]
[1]St. Olavs hospital, Norwegian National Advisory Unit on Pregnancy and Rheumatic Diseases, Trondheim, Norway

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PURPOSE

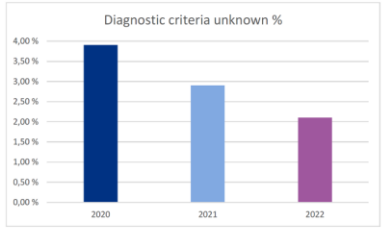
The objective of this study is to determine the effect of a systematic quality improvement project in the nationwide quality register RevNatus to reduce the number of <UNKNOWN> answers on classification- and diagnostic criteria.

METHODS

The Figure present the project using Demings´s circle.

RESULTS

The table shows the presentage of <UNKNOWN> on the variable diagnostic- and classification criteria in the period 2020 – 2022.



CONCLUSION

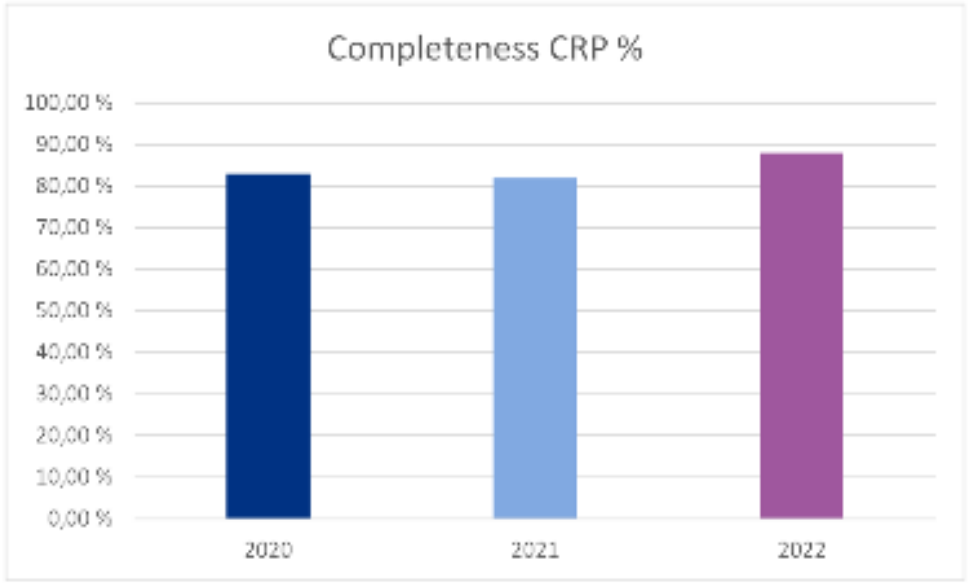
We saw a reduced use of <UNKNOWN> on the variable classification – and diagnosis criteria over 3 years. The principles of Deming's circle as a method was well suited for this work.

Corresponding author: hilde.bjorngaard@stolav.no

NORWEGIAN NATIONAL ADVISORY UNIT on Pregnancy and Rheumatic Diseases

2021 - 2022

Systematic improvement of completeness on data in data in the quality register RevNatus



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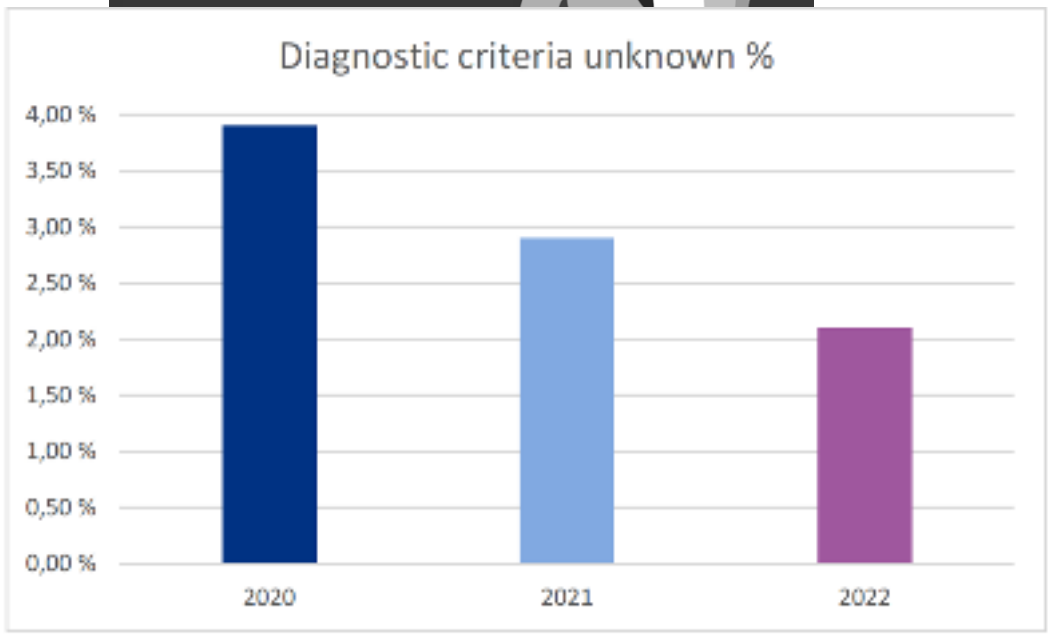
NORWEGIAN NATIONAL ADVISORY UNIT
on Pregnancy and Rheumatic Diseases

Improving quality of diagnostic data in data in RevNatus 2020 - 2022



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Corresponding author: hilde.bjorngaard@stolav.no

NORWEGIAN NATIONAL ADVISORY UNIT
on Pregnancy and Rheumatic Diseases

Kvalitetsforbedring 2023

- Fokus på missing data og forlengelse av kvalitetsindikator (CRP)
  - Kompletthet på målt sykdomsaktivitet med **ASDAS-CRP** ved aksial spondyloartritt (SpA)
  - Kompletthet på målt sykdomsaktivitet med **SLEDAI** ved SLE

Revmatologisk enhet	ASDAS 2023 Per 14/9-23	ASDAS 2022	SLEDAI 2023 Per 14/9-23	SLEDAI 2022
St. Olavs hospital	75 % ↓	80 %	100 %	100 %
Diakonhjemmet sykehus	63 % ↑	54 %	Ingen SLE	Ingen SLE
Universitetssykehuset Nord-Norge, Tromsø	57 % ↓	63 %	92 % ↑	54 %
Ålesund sjukehus	46 % ↓	68 %	60 % ↑	0 %
Haukeland universitetssjukehus	71 % ↑	63 %	71 % ↑	14 %
Oslo universitetssykehus	Ingen SpA	Ingen SpA	100 % ↑	77 %
Martina Hansens Hospital	38 % ↓	67 %	< 5	20 %
Haugesund SF Revmatismesykehus	67 % ↓	76 %	< 5	67 %
Vestre Viken Drammen sykehus	83 % ↑	32 %	< 5	60 %
Betanien Hospital	82 % ↓	85 %	100 % ↑	63 %
Stavanger universitetssykehus	< 5	64 %	< 5	15 %
Revmatismesykehuset Lillehammer	83 % ↑	36 %	83 % ↑	75 %
Nordlandssykehuset Bodø	71 % ↓	80 %	90 % ↑	36 %
Sykehuset Levanger	< 5	25 %	< 5	100 %
Helgelandssykehuset Mo i Rana	< 5	86 %	< 5	Ingen SLE
Sørlandet sykehus Kristiansand	< 5	100 %	< 5	Ingen SLE
Førde sentralsjukehus	< 5	50 %	< 5	100 %
Sykehuset Østfold Moss	Ingen SpA	100 %	Ingen SLE	50 %
Universitetssykehuset Nord-Norge, Harstad	Ingen SpA	Ingen SpA	Ingen SLE	Ingen SLE

↓ nedgang i 2023 ↑ bedring i 2023

Takket være fantastisk innsats med registering av data blir de også brukt!

Clinical science

A population-based study of caesarean section in women with juvenile idiopathic arthritis

Carina Götestam Skorpen [1,2,*], **Stian Lydersen** [3], **Kjell Å. Salvesen** [4,5], **Marianne Wallenius** [1,6]

[1]Department of Neuromedicine and Movement Science, Norwegian University of Science and Technology, Trondheim, Norway
[2]Department of Rheumatology Ålesund, Helse More og Romsdal HF, Ålesund, Norway
[3]Department of Mental Health, Regional Center for Child and Youth Mental Health and Child Welfare, Norwegian University of Science and Technology, Trondheim, Norway
[4]Department of Clinical and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway
[5]Department of Obstetrics and Gynecology, St Olavs Hospital, Trondheim University Hospital, Trondheim, Norway
[6]Norwegian National Advisory Unit on Pregnancy and Rheumatic Diseases, Department of Rheumatology, St Olavs Hospital, Trondheim University Hospital, Trondheim, Norway

*Correspondence to: Carina Götestam Skorpen, Department of Rheumatology Ålesund, Helse More og Romsdal HF, Postboks 1600, 6026 Ålesund, Norway. E-mail: carina.skorpen@ntnu.no

Abstract

Objectives: The literature on delivery methods in women with JIA is limited. Active inflammation is a risk factor for caesarean section (CS) in other arthritic diseases. A CS entails a higher risk for complications than vaginal delivery and restricted physical activity in the first weeks after birth. Our objective was to explore a possible association of inflammatory active disease and the proportion of CS in women with JIA.

Methods: Data from the Norwegian nationwide observational register RevNatus were linked with data from the Medical Birth Registry of Norway (MBRN). Cases comprised singleton births in women with JIA ($n = 196$) included in RevNatus from 2010 to 2019. Singleton births registered in the MBRN during the same period of time, excluding births in mothers with rheumatic inflammatory diseases, served as population controls ($n = 575\,798$).

Results: CS was more frequent in women with JIA (20.4%) and in the subgroup of women with inflammatory active JIA (30.0%) than in population controls (15.6%). Women with active JIA had a risk for elective CS similar to population controls [risk difference 2.3% (95% CI −2.5, 12.9)] and a higher risk for emergency CS [risk difference 14.0% (95% CI 4.3, 27.4)] compared with population controls.

Conclusion: Women with active JIA had a higher risk for emergency CS, but not elective CS, compared with population controls.

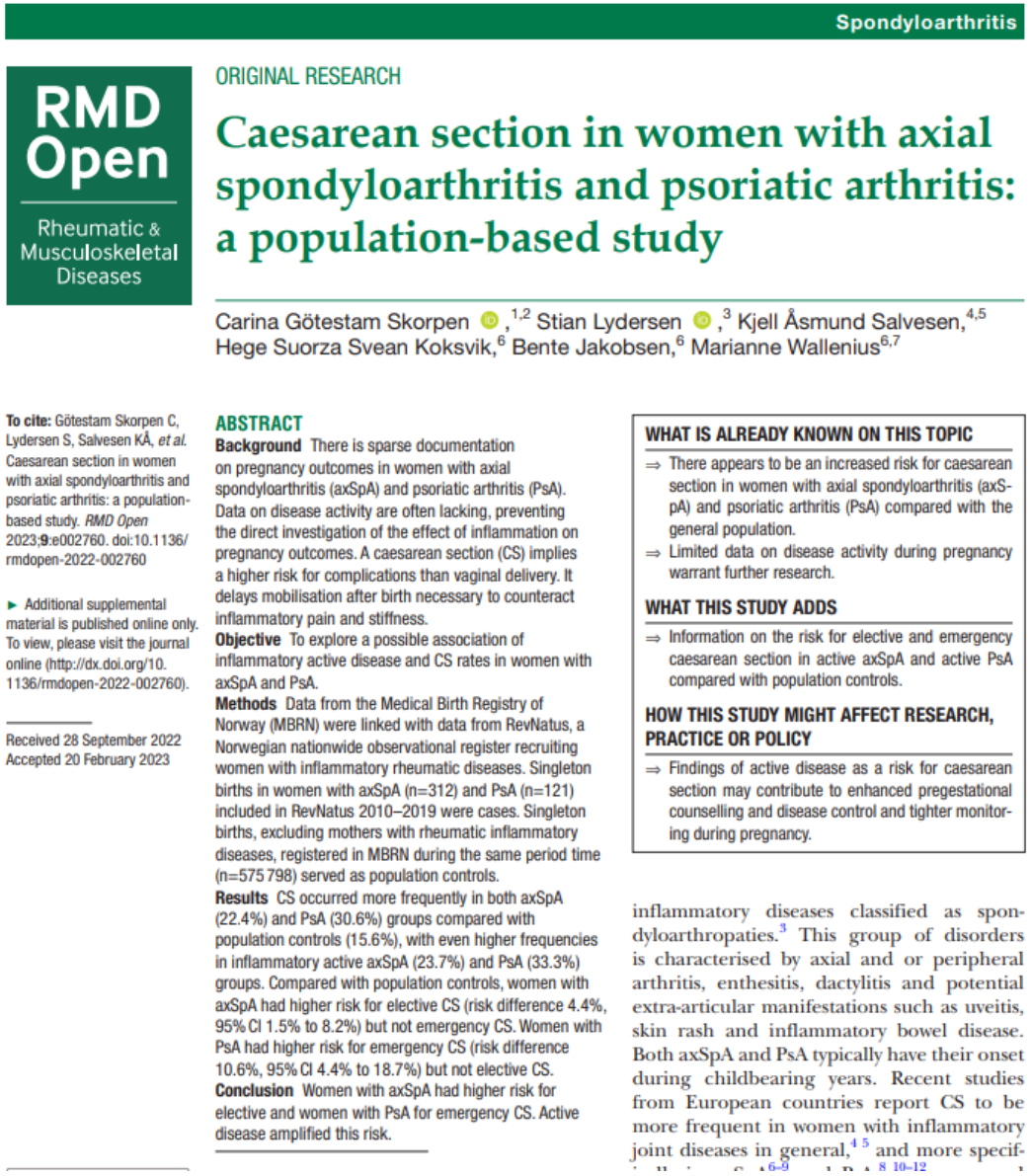
Lay Summary

What does this mean for patients?

Vaginal birth is the preferred choice of delivery. However, a caesarean section (CS) may be a necessary intervention to prevent potential harm to the mother or baby. The reasons for considering a CS include underlying risk factors of the mother, earlier births and psychosocial factors. In women with JIA, active disease, joint damage, medication and health-related quality of life may be additional factors. We compared CS in women with JIA and healthy controls to see if it was more frequent in women with JIA. We found that CS overall was more frequent in women with active JIA than in healthy controls, but was not increased in women with inactive JIA. Women with active JIA had a higher risk for emergency CS compared with healthy controls. The risk for elective CS in women with active JIA was similar to that of healthy controls. Women with JIA who are planning pregnancy or are pregnant are advised to contact their rheumatologist for tighter follow-up, with a goal of well-controlled disease during pregnancy.

Keywords: pregnancy and rheumatic disease, JIA, epidemiology, inflammation

- Data fra RevNatus og Medisinsk fødselsregister
- Undersøkt forekomst av keisersnitt ved JIA
- Konklusjon:
  - aktiv sykdom øker risikoen for akutte keisersnitt, men ikke elektive keisersnitt sammenlignet med friske kontroller



Spondyloarthritis

RMD Open
Rheumatic & Musculoskeletal Diseases

ORIGINAL RESEARCH

Caesarean section in women with axial spondyloarthritis and psoriatic arthritis: a population-based study

Carina Götestam Skorpen ,[1,2] Stian Lydersen ,[3] Kjell Åsmund Salvesen,[4,5] Hege Suorza Svean Koksvik,[6] Bente Jakobsen,[6] Marianne Wallenius[6,7]

To cite: Götestam Skorpen C, Lydersen S, Salvesen KÅ, *et al*. Caesarean section in women with axial spondyloarthritis and psoriatic arthritis: a population-based study. *RMD Open* 2023;**9**:e002760. doi:10.1136/rmdopen-2022-002760

► Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/rmdopen-2022-002760).

Received 28 September 2022
Accepted 20 February 2023

ABSTRACT

Background There is sparse documentation on pregnancy outcomes in women with axial spondyloarthritis (axSpA) and psoriatic arthritis (PsA). Data on disease activity are often lacking, preventing the direct investigation of the effect of inflammation on pregnancy outcomes. A caesarean section (CS) implies a higher risk for complications than vaginal delivery. It delays mobilisation after birth necessary to counteract inflammatory pain and stiffness.

Objective To explore a possible association of inflammatory active disease and CS rates in women with axSpA and PsA.

Methods Data from the Medical Birth Registry of Norway (MBRN) were linked with data from RevNatus, a Norwegian nationwide observational register recruiting women with inflammatory rheumatic diseases. Singleton births in women with axSpA (n=312) and PsA (n=121) included in RevNatus 2010–2019 were cases. Singleton births, excluding mothers with rheumatic inflammatory diseases, registered in MBRN during the same period time (n=575 798) served as population controls.

Results CS occurred more frequently in both axSpA (22.4%) and PsA (30.6%) groups compared with population controls (15.6%), with even higher frequencies in inflammatory active axSpA (23.7%) and PsA (33.3%) groups. Compared with population controls, women with axSpA had higher risk for elective CS (risk difference 4.4%, 95% CI 1.5% to 8.2%) but not emergency CS. Women with PsA had higher risk for emergency CS (risk difference 10.6%, 95% CI 4.4% to 18.7%) but not elective CS.

Conclusion Women with axSpA had higher risk for elective and women with PsA for emergency CS. Active disease amplified this risk.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There appears to be an increased risk for caesarean section in women with axial spondyloarthritis (axSpA) and psoriatic arthritis (PsA) compared with the general population.

⇒ Limited data on disease activity during pregnancy warrant further research.

WHAT THIS STUDY ADDS

⇒ Information on the risk for elective and emergency caesarean section in active axSpA and active PsA compared with population controls.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Findings of active disease as a risk for caesarean section may contribute to enhanced pregestational counselling and disease control and tighter monitoring during pregnancy.

inflammatory diseases classified as spondyloarthropaties.[3] This group of disorders is characterised by axial and or peripheral arthritis, enthesitis, dactylitis and potential extra-articular manifestations such as uveitis, skin rash and inflammatory bowel disease. Both axSpA and PsA typically have their onset during childbearing years. Recent studies from European countries report CS to be more frequent in women with inflammatory joint diseases in general,[4 5] and more specif-

- Data fra RevNatus og Medisinsk fødselsregister
- Undersøkt forekomst av keisersnitt ved axSpA og PsA
- Konklusjon:
  - axSpA gir høyere risiko for planlagte keisersnitt
  - PsA gir høyere risiko for akutte keisersnitt
  - aktiv sykdom øker risikoen keisersnitt

Bjerkaas Hanssen *et al.*
International Breastfeeding Journal (2023) 18:37
https://doi.org/10.1186/s13006-023-00576-y

International Breastfeeding Journal

RESEARCH Open Access

Breastfeeding in women with systemic lupus erythematosus: results from a Norwegian quality register

Maylinn Bjerkaas Hanssen[1*], Agnete Malm Gulati[2,3], Hege Koksvik[4] and Marianne Wallenius[1,4*]

Abstract

Background Knowledge on breastfeeding among women with systemic lupus erythematosus (SLE) is sparse. We wanted to identify the frequency of breastfeeding in SLE, and to compare breastfeeding women with SLE to non-breastfeeding women to examine possible differences in disease characteristics and self-reported health data between the groups.

Methods Prospective data on women with SLE from RevNatus, a consent-based Norwegian nationwide quality register was used for this study. Data were collected during January 2016 to September 2021. We used data registered at inclusion when planning pregnancy or in 1st trimester, and 6 weeks, 6 and 12 months after delivery. Breastfeeding and non-breastfeeding patients were compared according to demographic, serological and obstetric data as well as disease activity, medication, self-reported pain, and fatigue.

Results A total of 114 pregnancies in 101 SLE women were included in the analysis. A majority of the women (78%) breastfed six weeks postpartum. Six and 12 months after delivery, breastfeeding rates were 54% and 30% respectively. Six weeks postpartum, non-breastfeeding women showed higher prevalence of emergency caesarean delivery ($p=0.038$), preeclampsia ($p=0.056$) and lower educational level ($p=0.046$) compared to breastfeeding women. 12 months after delivery, we observed a higher frequency of multiparity among breastfeeding women ($p=0.017$) compared to non-breastfeeding. Overall, we found low disease activity in both groups at all registrations in the follow-up, and disease activity did not differ between the groups. More than 70% of both breastfeeding and non-breastfeeding women used hydroxychloroquine (HCQ).

Conclusions Breastfeeding rate in women with SLE was high six weeks postpartum. Multiparous women breastfed longer than primiparas. Disease activity, use of HCQ, and self-reported health data were comparable between the groups. Our data indicate that health professionals should encourage women with SLE to breastfeed.

- Undersøkt andel av kvinner med SLE som ammer sammenlignet med ikke-ammende, og sett på om demografiske variabler, sykdomskarakteristika eller medikamentell behandling har påvirket ammefrekvensen
- Konklusjon:
  - Amme-raten var sammenlignbar mellom SLE-kvinner og den generelle norske befolkningen

Low serum lipocalin-2 in pregnant women with systemic lupus erythematosus

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Abstract

Objective

Systemic lupus erythematosus (SLE) pregnancies are considered high-risk due to risk of disease flare and pregnancy complications. A more in-depth understanding of the immunological alterations in SLE patients during pregnancy and identification of predictive biomarkers may help to achieve stable disease and to avoid pregnancy complications. Lipocalin-2 (LCN2) has been implicated as a potential biomarker for rheumatic diseases and preeclampsia, but remains unexplored in SLE pregnancies.

Methods

We measured LCN2 levels in serum samples from SLE pregnancies (n=25) at seven different time points. Samples were taken preconception, in each trimester, at 6 weeks, 6 months and 12 months postpartum. Serum LCN2 levels were compared to samples from rheumatoid arthritis (RA) (n=27) and healthy (n=18) pregnancies at each time point using t-test, and for all time points using a linear mixed effects model. In addition, we investigated the association between LCN2 levels and disease activity, CRP, kidney function, BMI, treatment regimen and adverse pregnancy outcome for SLE and RA patients.

Results

We found significantly lower serum LCN2 levels throughout pregnancy in SLE patients with quiescent disease compared to RA and healthy pregnancies. We did not find an association between serum LCN2 and disease activity or adverse pregnancy outcome in SLE pregnancies.

Conclusion

In a population of SLE women with low disease activity we have not found evidence that serum LCN2 levels predict disease activity or adverse pregnancy outcomes. Further studies are needed to elucidate a possible biological role of low LCN2 levels in SLE pregnancies.

- Kliniske data fra RevNatus og prøver fra RevNatus biobank
- Konklusjon:
  - Fant ingen sammenheng mellom serum LCN2 nivåer og sykdomsaktivitet eller uønskede svangerskapsutfall hos kvinner med SLE

Abstrakter på internasjonale kongresser

EULAR og RheumaPreg 2023

Mixed connective tissue disease and course of pregnancy - Results from the nationwide pregnancy register RevNatus

POS1561

Hege Svean Koksvik [1], Bente Jakobsen [1], Hilde Bjørngaard [1], Tina Therese Pedersen [1,2] and Marianne Wallenius [1,3]

Introduction

- Mixed connective tissue disease (MCTD) is a complex and multisystemic disorder of unknown etiology
- Commonly diagnosed in women of reproductive age

Objective

- Describe the course of pregnancy in patients with MCTD

Methods

- Prospectively collected data on pregnancy outcome in women with MCTD
- Through the nationwide Norwegian registry on pregnancy and rheumatic diseases (RevNatus) from 2016-2022
- All women were diagnosed with ICD-10 code M35.1
- **48 pregnancies** in 38 women were recorded. One woman had twin birth

Results

- Mean maternal age at 1.st trimester was 31 yrs
- Mean disease duration was 7 yrs
- Median gestational age at delivery was 37 w
- Two pregnancies were not planned
- 69 % of the women were in clinical remission at inclusion

	At enrollment (N=48)	1. trimester (N=37)	2.trimester (N=35)	3.trimester (N=39)	delivery (N=48)	6 weeks post partum (N=48)
CRP in mg/l mean (SD)	5 (8)	4 (10)	7 (9)	3 (2)		3 (4)
CRP >5mg/l n (%)	8 (17)	4 (11)	12 (35)	3 (8)		2 (5)
Patient global (VAS 0-100), mean (SD)	30 (28)	32 (32)	29 (27)	40 (28)		22 (22)
Patient pain (VAS 0-100), mean (SD)	21 (21)	19 (22)	22 (23)	25 (22)		19 (22)
Patient fatigue (VAS 0-100), mean (SD)	46 (28)	53 (31)	49 (31)	45 (27)		34 (24)
Use of hydroxychloroquine n (%)	32 (67)	30 (79)	26 (74)	30 (77)		31 (65)
Miscarriages < week 12, n					4	
Birth weight (gram) of singelton, mean					2995	
Birth weight (gram) of singelton born at term, mean					3265	
Preeclampsia n (%)					8 (17)	
HELLP n (%)					4 (8)	
Vaginal delivery n (%)					22 (46)	
Caesarean section planned, n (%)					8 (17)	
Caesarean section acute, n (%)					12 (26)	

Conclusions

- Most patients with MCTD in this cohort had a favorable course and outcome of pregnancy
- Four patients were diagnosed with **HELLP** syndrome
- We observed an increased rate of **preeclampsia** compared to the frequency reported in the Norwegian birth registry (NFR) (17% vs 4%)
- We found **lower mean birth weight** compared to NFR (2995 gram vs 3480 gram)
- **Hydroxychloroquine** was used by a majority of the women throughout pregnancy, and might have contributed to the favorable course and outcome
- Analysis on the association to specific risk factors predicting adverse pregnancy outcomes should be done in the future

NORWEGIAN NATIONAL ADVISORY UNIT
on Pregnancy and Rheumatic Diseases

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NORWEGIAN NATIONAL ADVISORY UNIT
on Pregnancy and Rheumatic Diseases

Behçet's disease and course of pregnancy- results from the nationwide pregnancy register RevNatus

Hege Svean Koksvik
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Head of Unit

Mixed connective tissue disease and course of pregnancy – Results from the nationwide pregnancy register RevNatus

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BACKGROUND

- Mixed connective tissue disease (MCTD) is a complex and multisystemic disorder of unknown etiology
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- Describe the course of pregnancy in patients with MCTD

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- Prospectively collected data on pregnancy outcome in women with MCTD through the nationwide Norwegian registry on pregnancy and rheumatic diseases (RevNatus) from 2016-2022
- All women were diagnosed with ICD-10 code M35.1
- 48 pregnancies in 38 women were recorded
  One woman had twin birth

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- Two pregnancies were not planned
- 69 % of the women were in clinical remission at inclusion

	At enrolment (N = 48)	1st trimester (N = 37)	2nd trimester (N = 35)	3rd trimester (N = 39)	delivery (N = 48)	6 weeks postpartum (N = 48)
CRP in mg/l mean (SD)	5 (8)	4 (10)	7 (9)	3 (2)		3 (4)
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Patient pain (VAS 0-100), mean (SD)	21 (21)	19 (22)	22 (23)	25 (22)		19 (22)
Patient fatigue (VAS 0-100), mean (SD)	46 (28)	53 (31)	49 (31)	45 (27)		34 (24)
Use of hydroxychloroquine, n (%)	32 (67)	30 (79)	26 (74)	30 (77)		31 (65)
Miscarriages < week 12, n					4	
Birth weight (gram) of singleton, mean					2995	
Birth weight (gram) of singleton born at term, mean					3265	
Preeclampsia n (%)					8 (17)	
HELLP n (%)					4 (8)	
Vaginal delivery n (%)					22 (46)	
Caesarean section planned, n (%)					8 (17)	
Caesarean section acute, n (%)					12 (26)	

CONCLUSION

- Most patients with MCTD in this cohort had a favorable course and outcome of pregnancy
- Four patients were diagnosed with HELLP syndrome
- We observed an increased rate of preeclampsia compared to the frequency reported in the Norwegian birth registry (NFR) (17% vs 4%)
- We found lower mean birth weight compared to NFR (2995 gram vs 3480 gram)
- Hydroxychloroquine was used by a majority of the women throughout pregnancy, and might have contributed to the favorable course and outcome
- Analysis on the association to specific risk factors predicting adverse pregnancy outcomes should be done in the future

Pregnancy course in a cohort of women with myositis - Results from RevNatus

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BACKGROUND

Myositis is a rare autoimmune disease characterized by proximal and symmetrical muscle weakness and inflammatory infiltrates on muscle biopsy, and may affect women in reproductive age. Active disease before and during pregnancy has been associated with preterm birth and infant small for gestational age (GA).

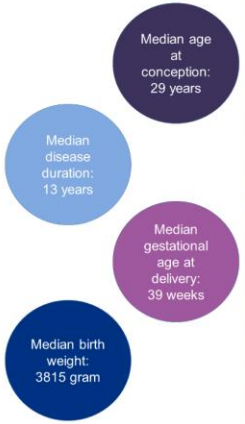
OBJECTIVE

Describe the course of pregnancy in patients with myositis.

METHODS

We prospectively collected data on pregnancy in women with myositis in the nationwide Norwegian quality registry RevNatus from 2016-2023. women were diagnosed with ICD-10 codes: M33.0 (n=8), M33.1 (n=3), M33.2 (n=1), M33.9 (n=4). 16 pregnancies in twelve women were included.

RESULTS



Patient #	Pregnancy #	Maternal age at conception	Disease duration (years)	Medication during pregnancy	Disease activity 2nd trimester	Gestational age at delivery	Infant birth weight (gram)	Delivery mode
A	1	29	25	none	remission	38	3355	standard vaginal delivery
B	2	34	7	azathioprine	persistent disease	39	3725	standard vaginal delivery
B	3	40	14	azathioprine	remission	41	3965	standard vaginal delivery
C	4	29	15	azathioprine				spontaneous abortion week 7
C	5	30	16	azathioprine	remission	37	4010	operational vaginal delivery
C	6	31	17	azathioprine	remission	37	4570	standard vaginal delivery
D	7	35	3	ciclosporin + prednisolone 5mg	persistent disease	40	3000	standard vaginal delivery
E	8	28	13	none	remission	37	2765	operational vaginal delivery
F	9	25	10	azathioprine + hydroxychloroquine	remission	41	4085	standard vaginal delivery
F	10	27	12	azathioprine + hydroxychloroquine	remission	41	3815	standard vaginal delivery
G	11	36	13	prednisolone 5mg				spontaneous abortion > week 12
H	12	43	5	azathioprine prednisolone 5mg	remission	37	3140	elective sectio
I	13	36	26	none	remission	41	4750	acute sectio
J	14	32	15	hydroxychloroquine	remission	27		stillbirth
K	15	26	13	none	remission	39	3420	standard vaginal delivery
L	16	25	4	none	remission	39	4192	standard vaginal delivery

CONCLUSION

We did not observe disease flare during pregnancy.
One pregnancy ended in early spontaneous abortion, one in late spontaneous abortion and one in stillbirth.
Data are sparse, and larger cohorts are necessary to evaluate possible risk factors.

Changes in the use of TNF-inhibitors before, during and after pregnancy from 2006 - 2022 in women with juvenile idiopathic arthritis

H. Bjørngaard[1], H.S. Koksvik[1], B. Jakobsen[1], M. Wallenius[1,2]

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BACKGROUND

The EULAR points to consider (2016), American College of Rheumatology (ACR) (2020) and British Society of Rheumatology (BSR) (2022) guidelines state increasing knowledge about use of TNF-inhibitors during pregnancy and lactation.

PURPOSE

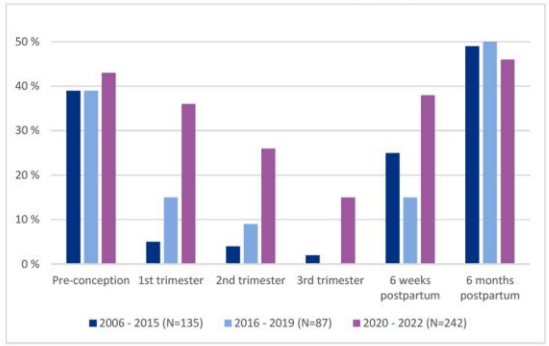
The objective of the current study was to examine time trends in the use of TNF-inhibitors before conception, during pregnancy, 6 weeks and 6 months postpartum, in women with juvenile idiopathic arthritis (JIA).

METHODS

Data on women diagnosed with JIA included in the nationwide Norwegian quality register RevNatus from 2006 - 2022 were analyzed. Prospectively, the register collects information about the use of medications including TNF-inhibitors at visits preconception, each trimester and 6 weeks and 6 months postpartum.

RESULTS

The figure summarize our results and shows the percentage of women using TNF-inhibitors preconception, during pregnancy and postpartum.



CONCLUSION

Since the introduction of international guidelines treatment with TNF-inhibitors during pregnancy and postpartum have increased in women with JIA.

Exercise in the course of pregnancy in women with axial spondyloarthritis

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PURPOSE

The objective of this study is to describe the level of physical activity (PA) before, during and after pregnancy for women with axial spondyloarhritis (SpA) (M45, M46.8, M46.9), using data from the Norwegian nationwide quality register RevNatus.

METHODS

Data from 393 women with SpA enrolled in RevNatus from february 2016 - february 2023 are included.
Available data on self-reported level of PA, pain and fatigue on a visual analogue scale (VAS) 0-100, the bath ankylosing spondylitis disease activity index (BASDAI) score and body mass index (BMI) from seven time points before, during and after pregnancy are collected and presented. Level of excecise was defined as: Regular exercisers $\geq$ 3 times a week, irregular exercisers $\leq$ 2 times a week, non-exercisers $\leq$ 3 times a month.

RESULTS

CONCLUSION

A large proportion (28 - 68 %) were non-exercisers and they reported higher levels of pain at all seven time-points compared to the regular and irregular exercisers. PA should be an integral part of standard care throughout the course of disease for people with SpA and healthcare providers should take responsibility for promoting it and make necessary referrals to ensure that people with SpA receive appropriate PA-interventions.

Pågående prosjekter som bruker data fra RevNatus

- Tryggere svangerskap ved revmatisk sykdom - betydningen av immunregulering og østrogen
(pågående PhD-prosjekt)
- Revmatoid artritt og risiko ved sykdomsaktivitet i svangerskap
(pågående PhD-prosjekt)
- How does inflammation affect outcome of pregnancy in women with SpA, PsA and JIA?
(pågående post-doc prosjekt)
- Health related quality of life in mothers with a chronic inflammatory rheumatic disease 1999-2019 - 20 years perspective (pågående forskningsprosjekt)
- "Juvenile idiopathic arthritis and breastfeeding" (pågående studentprosjekt)
- "Axial spondyloarthritis and breastfeeding" (pågående studentprosjekt)
- "Helserelatert livskvalitet hos kvinner med Sjøgrens syndrom - i svangerskap og barseltid, jordmors rolle" (pågående studentprosjekt)

Elektronisk pasientrapportering

– som verktøy og klinisk betydning

NASJONAL KOMPETANSETJENESTE
for svangerskap og revmatiske sykdommer

GULL: Pasientrapporterte data er det nye gullet, skriver f.v: Cecilie Delphin Amdal, Trond-Eirik Strand og Kristin Bjordal.

Pasientrapporterte data i klinikk og registre; bedre for alle parter

Pasientrapporterte data er det nye gullet.

Trond-Eirik Strand
MD, PHD, SPES. RÅDGIVER KVALITET OG SAMHANDLING, OSLO UNIVERSITETSSYKEHUS HF, PROFESSOR II,, UIT

Cecilie Delphin Amdal
MD, PHD, LEDER PROMINET, AVD. FORSKNINGSSTØTTE FOR KLINISKE STUDIER, OUS HF OG REG. FORSKNINGSSTØTTE, HELSE SØR-ØST, OVERLEGE, AVD. FOR KREFTBEHANDL., OUS HF

Kristin Bjordal
MD, PHD, VIRKSOMHETSLEDER FOR FORSKNINGSSTØTTE OG FORSKNINGSLEDER I OSLO SYKEHUSSERVICE (OSS),OUS HF, PROFESSOR II, UIO

PUBLISERT Mandag 09. oktober 2023 - 09:01

PASIENTRAPPORTERTE DATA er det nye gullet sies det og kanskje det viktigste verktøyet i utviklingen av konseptet «pasientens helsetjeneste». Det er en utfordring at vi mangler felles system for innhenting og bruk av pasientrapporterte data i klinisk praksis. Det er også avgjørende å etablere løsninger som sikrer at slike data overføres til kvalitetsregistre.

Systematisk innhenting og bruk av pasientrapporterte data i klinisk praksis vil kunne gi bedre pasientbehandling, støtte kvalitetsarbeid og forskning og bidra til bedre utnyttelse av ressursene.

Hvorfor pasientrapporterte data?

- Gir økt kunnskap om pasientens opplevelse av sykdom, helse, funksjon og livskvalitet
- Kan gi informasjon om effekten av behandling
- Pasientrapporterte data i den revmatologiske kontrollen
  - kan sendes ut elektronisk så man har svar før konsultasjonen starter
  - øker kunnskap, øker kvaliteten på kontrollen, også på telefon- og videokonsultasjoner

Sykdomsaktivitet og sykdomsbyrde

- Pasientens rapportering om helse, funksjon og sykdomsbyrde inngår i standardiserte mål på sykdomsaktivitet
  - Eks ASDAS –CRP, som kombinerer pasientens subjektive symptom med objektive mål (CRP)

Pasientrapportering i RevNatus

- Tilgjengelig for alle uten ekstra kostnad
- ePROM forenkler innhenting av pasientrapporterte data til RevNatus
  - pasienten får lenke på SMS og logger inn via helsenorge.no
  - løsningen ivaretar personvernet
  - pasienten får tilgang til egne rapporterte data
    - mulighet til selvrefleksjon – hvordan har jeg det, og hvorfor har jeg det sånn?

Revmatologisk kontroll
Fysisk vs avstandsoppfølging 2023

- Av 1504 revmatologiske kontroller det siste året har **37 %** blitt gjennomført som telefon- eller videokonsultasjon

- Viktig med gode verktøy for å få vurdert inflammatorisk sykdom for best mulig helse
  - Elektronisk selvrapportering - ePROM

Utvidet pasientrapporteringen i 2022

- Flere data hentes fra pasientenes ePROM inn i RevNatus
  - Svangerskapsutfall registreres av pasienten selv

- Fortsatt frivillig – tips til hvordan vi skal få pasientene til å svare?

Elektronisk samtykke er tatt i bruk av alle enheter

ePROM har engelsk versjon

NASJONALT KOMPETANSENETTVERK
for svangerskap og revmatiske sykdommer

stolav.no/nksr

nksr.no

nksr@stolav.no

Følg oss på Instagram og Facebook

«svangerskapogrevmatisksykdom»

E-læringskurs

svangerskap og revmatiske sykdommer

"VEILEDER I SVANGERSKAP OG REVMATISKE SYKDOMMER" KOMMER I EGEN PASIENTVERSJON!

NASJONAL KOMPETANSETJENESTE
for svangerskap og revmatiske sykdommer

GRUPPEOPPGAVE RevNatus:
«Har du fått rådgivning om svangerskap ved din diagnose?»

- Pasientene besvarer denne via elektronisk selvrapportering.
  - Dersom de har svart «nei» når de blir inkludert i registeret får de også spørsmålet ved neste besøk (når de har blitt gravid).

- Som kvalitetsindikator ønsker vi at denne skal være besvart med «JA» hos > 80% av pasientene.

- Oppgave til diskusjon: «Hvordan kan vi ved vår avdeling sikre at aktuelle pasienter får rådgivning om svangerskap».

Revmatologisk enhet	Antall hovedskjema med selvrapportering	% svar <JA> 2022-2023
St. Olavs hospital	91	85 %
Universitetssykehuset Nord-Norge, Tromsø	48	73 %
Martina Hansens Hospital	44	77 %
Vestre Viken Drammen sykehus	37	86 %
Haugesund SF Revmatismesykehus	35	74 %
Oslo universitetssykehus	34	82 %
Diakonhjemmet sykehus	34	85 %
Stavanger universitetssykehus	32	81 %
Ålesund sjukehus	25	88 %
Nordlandssykehuset Bodø	22	59 %
Revmatismesykehuset Lillehammer	13	85 %
Sørlandet sykehus Kristiansand	11	82 %
Haukeland universitetssjukehus	11	73 %
Sykehuset Levanger	10	90 %
Helgelandssykehuset Mo i Rana	7	57 %
Sykehuset Østfold Moss		
Førde sentralsjukehus		
Universitetssykehuset Nord-Norge, Harstad		
Betanien Hospital		