Online supplement for Practice Variations in the Diagnosis, Monitoring, and Treatment of Systemic Lupus Erythematosus in Canada, *The Journal of Rheumatology,* doi:10.3899/jrheum.171307

Supplementary Data 1. Survey questions.

ASSESSMENT OF EXISTING PRACTICE PATTERNS IN THE EVALUATION AND MANAGEMENT OF SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) IN CANADA

Stakeholders involved in lupus care invite you, in collaboration with the Canadian Rheumatology Association, to answer the following questionnaire to better understand the existing standard of care received by SLE patients in Canada. This should take approximately 20 minutes.

Physician / Clinic Demographics

1. What is your age group (years)?
   a. 25 – 35
   b. 36 – 45
   c. 46-55
   d. 56 – 65
   e. 66 – 75
   f. > 75

2. What is your gender?
   a. Female
   b. Male

3. In which province/territory do you practice?
   a. British Columbia
   b. Alberta
   c. Saskatchewan
   d. Manitoba
   e. Ontario
   f. Quebec
   g. New Brunswick
   h. Nova Scotia
   i. Prince Edward Island
   j. Newfoundland
   k. Yukon
   l. Northwest Territories
   m. Nunuvut

4. What town/city do you practice in? _______________

5. What is your specialty?
   a. Primary care physician
   b. Rheumatologist
   c. Pediatric Rheumatologist
   d. General Internal Medicine Specialty
   e. Nephrologist
   f. Dermatologist
   g. Other (**Specify**): _______________

6. How many years have you been in practice?
   a. Current trainee (resident or fellow)
   b. < 5 years
   c. 6-10 years
   d. 11-20 years
   e. 21 – 30 years
   f. > 30 years

7. How would you best describe your practice (choose all that apply)?
   a. Solo community practice
   b. Group community practice
   c. Academic / teaching hospital
   d. Other (**Specify**)_______________________________

8. Did you spend extra time (i.e. greater than the two year rheumatology residency) training specifically in SLE care or research during your residency and/or fellowship?
   a. Yes
   b. No

If yes, how much extra time did you spend? __________ months

9. Are you a member of the Canadian Network of Improved Outcomes in SLE (CaNIOS)?
   a. Yes
   b. No
   c. Past member

10a. Does your site currently have a dedicated lupus (SLE) clinic?
   a. Yes
   b. No

10b. If yes, do you see patients in this clinic?

a. Yes
b. No

11. Does your site collect outcome measures related to lupus in a database?
    a. Yes
    b. No

Evaluation of SLE in Clinic

12. How many patients do you follow in your practice?
    a. < 500 patients
    b. 500 - 999 patient
    c. 1000 - 2000 patients
    d. >2000 patients

13. How many SLE patients do you think you follow?
    a. < 10
    b. 11 - 50
    c. 51 - 100
    d. 101 – 200
    e. > 200

14. How many new SLE patients do you see per month?
    a. 0
    b. 1 – 3 patients
    c. 4 - 6 patients
    d. 7 – 10 patients
    e. > 10 patients

15. What initial laboratory investigations do you order (if not already performed) for an initial patient visit?

(These may be completed to confirm the diagnosis of SLE, determine prognosis, and/or ensure safety when considering future treatments?

Tests	**Always**	**Sometimes**	**Never**	**Would like to but not available**
CBC				
WBC differential				
Creatinine				
Liver enzymes,				
Urinalysis				

Urine Protein:Creatinine ratio				
24 hour urine protein				
24 hour urine creatinine				
CRP				
ESR				
Complement (C3/C4 or functional assay)				
CH50 or CH100				
ANA (antinuclear antibody)				
Double stranded DNA				
Antibodies against extractable nuclear antigens (ie. Anti-SSA, anti-Smith, etc)				
ANCA				
Anticardiolipin/ antiphospholipid antibodies				
Anti-beta 2 glycoprotein antibody				
Lupus anticoagulant/ inhibitor				
INR/PTT				
Hepatitis B/C				
HIV				
Quantitative immunoglobiulins				
Other (specify)				
Other (specify)				

16. Do you determine if your patients meet the American College of Rheumatology (ACR 1997 revised) Classification Criteria for SLE (i.e. 4 / 11 criteria) when diagnosing them with SLE in your clinic?
    a. Always
    b. Usually
    c. Sometimes
    d. Never (I do not require that my patients meet these criteria)

17. Please check ☑ the measures you utilize in evaluating SLE disease activity, damage or co-morbidity on a regular basis in your clinic?

Measure	Always	Sometimes	Never	Would like to but need infrastructure (personnel, and IT)
SLEDAI (any version)				
BILAG (any version)				
SLICC / ACR damage index				
SLAM				
MD global assessment of disease activity				
Patient global assessment of disease activity				
Charlson Co-morbidity Index				
BMD (with chronic steroids)				
Swollen Joint Count				
Tender Joint Count				
Other (specify)				
Other (specify)				

18. Please check ☑ the tests you utilize to monitor SLE disease activity over time?

Tests	**Always**	**Sometimes**	**Never**	**Would like to but limited to no availability**
CBC				
WBC differential				
Creatinine				
Liver enzymes,				
Urinalysis				
Urine Protein:Creatinine ratio				
24 hour urine protein				
24 hour urine creatinine				
CRP				
ESR				
Complement (C3/C4 or functional assay)				
CH50 or CH100				
ANA (antinuclear antibody)				
Double stranded DNA				
Antibodies against extractable nuclear antigens (ie. Anti-SSA, anti-Smith, etc)				
ANCA				
Anticardiolipin/ antiphospholipid antibodies				
Anti-beta 2 glycoprotein antibody				
Lupus anticoagulant/ inhibitor				
INR/PTT				

Hepatitis B/C				
HIV				
Quantitative immunoglobiulins				
Other (specify)				
Other (specify)				

19a. Please check ☑ whether you screen your SLE patients for the following traditional cardiovascular (CV) risk factors at any point in their care:

Traditional CV Risk Factor	Yes	No	Sometimes
Fasting lipids			
HbA1C / fasting glucose			
Blood Pressure			
Weight			
BMI			
Family history of cardiovascular disease			
Framingham or other CV risk score			

19b. If you do not routinely screen SLE patients for any of the CV risk factors listed in question 19a, is it because (choose **all** that apply) :

a. Responsibility lies with primary care
b. Too busy managing immediate SLE concerns
c. Not familiar with management of these factors
d. Other (Specify): ___________________________________

20. Please rank the most common clinical manifestations of SLE in your practice from most common (1) to least common (11):

a. Cutaneous including mucocutaneous
b. Musculoskeletal
c. Renal
d. Pulmonary
e. Cardiac
f. CNS
g. Hematologic – thrombocytopenia (bleeding)
h. Hematologic – leukopenia (infections)
h. Gastrointestinal
i. Fatigue
j. Fibromyalgia-type pains

21. What is the most common cause of death (if any) in your SLE practice?
    a. Infection
    b. Cardiovascular disease
    c. SLE-related disease
    d. Other comorbidities
    e. Other (Specify):___________________________

22. In a SLE patient stable for more than one year with minimally or no active disease, how frequently do you monitor the patient's disease activity with laboratory studies EXCLUDING monitoring for drug AEs (adverse events)?
    a. Every month
    b. Every 2-3 months
    c. Every 3-4 months
    d. Every 6 months
    e. Once a year
    f. I never formally request laboratory monitoring
    g. Other (Specify): ___________________

Pharmacotherapy of SLE

23. For non-renal SLE, are you using any of the following medications in your practice?

Medication	**Yes**	**No**	**If yes, what percentage of patients do you treat with this agent as first-line?**
Hydroxychloroquine			
Chloroquine			
Quinacrine			
Oral steroids			
NSAIDs (serositis/ arthralgia/arthritis)			
Sulfasalazine			
Methotrexate			
Azathioprine			
Mycophenolate mofetil			
Thalidomide			
Cyclophosphamide			

TNF inhibitors			
Rituximab			
Belimumab			
Leflunomide			
TNF Inhibitor			
Abatacept			
IVIG			
IV steroids			
Other:			

24. What percentage of your SLE patients are on antimalarial medications (i.e. chloroquine, hydroxychloroquine)?

a. 0-10%
b. 11- 20%
c. 21-40%
d. 41-60%
e. 61-80%
f. 81 – 100%

25. Please check ☑ what screening (if any) you complete for patients on antimalarials? (Choose **all** that apply).

Test	Baseline	Ongoing screening
Ophthalmology referral		
Optometry referral		
ERG (electroretinogram)		
Visual Field Testing		
Other (specify):		

26. How frequently do your SLE patients on antimalarial therapy typically receive ophthalmology/ optometry checks? (Choose **all** that apply).

a. Every 6-12 months
b. Every 13-24 months
c. Every 25-36 months
d. > Every 36 months
e. Dictated by type of antimalarial (chloroquine vs hydroxychloroquine)
f. Determined by ophthalmologist/optometrist
g. Never

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27. To your knowledge, what is the percentage of SLE patients in your practice who have discontinued their antimalarial due to related retinopathy?

a. 0-1%
b. 2-5%
c. 6-10%
d. 11-20%
e. 21-30%
f. >30%
g. Other:____________

28. Which of the following newer medications for SLE (label, and off-label) are available in your province through non-group, non-private insurance?

Medication	Yes	No	I do not know
Belimumab			
Rituximab			
Mycophenolate mofetil			
Abatacept			

29. Regarding the use of rituximab in SLE treatment, have you found it clinically beneficial on an individual patient basis for any of the following SLE manifestations:

SLE manifestation	Yes	No	Sometimes	I do not know
Cytopenias				
Arthritis				
Cutaneous lupus				
Serositis				
CNS				
Vasculitis				
Interstitial Lung Disease				
Class 3/4 lupus nephritis				
Gastrointestinal				
Other (Specify)				

30. If you have an SLE patient with renal involvement, who routinely treats the patient for their nephritis? (Select **all** that apply).

a. Nephrologist
b. Rheumatologist
c. Immunologist
d. General Internist
e. Other (specify):__________________

31. In addition to high dose steroids, please rank the agents used for induction for class 3/4 nephritis from most (1) to least commonly used (5), or please leave blank if never used.

Medication	Ranking
Cyclophosphamide po	
Cyclophosphamide IV	
Mycophenolate mofetil	
Imuran	
Rituximab	

32. If induction for lupus nephritis fails, what is your second line choice? Rank from most (1) to least commonly used (6) or please leave blank if never used.

Medication	Ranking
Mycophenolate mofetil	
Cyclophosphamide po	
Cyclophosphamide IV	
Imuran	
Rituximab	
IV methylprednisolone pulse	

33. What percentage of your SLE patients requires at least a minimum low dose prednisone indefinitely?

a. 0-5%
b. 6-10%
c. 11-20%
d. 21-40%
e. 41-60%
f. 61-80%
g. 81-100%
h. I have no idea

34. In a stable SLE patient with low disease activity but requiring less than 10 mg of oral daily steroid, do you adjust the immunosuppression to facilitate steroid taper and discontinuation?

a. Yes
b. No
c. Sometimes
d. Other (Specify):_______________

35a. Have you utilized belimumab in the treatment of active SLE patients?

a. Yes
b. No
c. Sometimes
d. Other (Specify):_______________

35b. If yes, please check ☑ the SLE manifestations where you found belimumab useful.

SLE manifestation	**Yes**	**No**	**Sometimes**	**I do not know**
Cytopenias				
Arthritis				
Cutaneous lupus				
Serositis				
CNS				
Vasculitis				
Interstitial Lung Disease				
Class 3/4 lupus nephritis				
Gastrointestinal				
Other (Specify)				

36. In patients requiring IV cyclophosphamide, how often do you use the following precautions (if at all)?

	Always	**Sometimes**	**Never**
PCJ (PCP) prophylaxis			
MESNA			
IV prehydration			
Sperm banking for male patient using cyclophosphamide			
Freezing ovarian section			
Use of OCP (oral contraceptive pills) in premenopausal			

woman for ovarian protection			
Gonadotropin releasing hormone in female patients			
Other (Specify)			

37. If a patient has achieved and maintained remission for their SLE on a steroid sparing agent (other than antimalarials) for a prolonged period of time (eg. >2 years), do you recommend eventual discontinuation of their immunosuppression? (Select **all** that apply).

a. Yes
b. No
c. I do not know
d. Depend on the agent(s) used
e. Depends on the extent of SLE disease/damage overall
f. Other (Specify):___________________

38. Do you consider discontinuation of antimalarials in stable SLE patients who have been on the medication for a prolonged period of time (eg. > 2 years) and continue in remission? (Select **all** that apply).

a. Yes
b. No
c. I do not know
d. Other:___________________

39. Please check ☑ the agents you would consider as first line for the following SLE manifestations: (Please check all that apply)

SLE Manifestation	Antimalarial	Azathioprine	Mycophenolate mofetil	Cyclophosphamide	Methotrexate	Rituximab	Belimumab
Arthritis							
Active lupus skin disease							
CNS lupus							
Class ¾ Nephritis							
Class 5 Nephritis							
Pulmonary hemorrhage							

40. Do you routinely review and recommend vaccinations (e.g. flu and pneumovax) for your SLE patients prior to starting therapy?

a. Yes
b. No
c. Sometimes
d. Other (Specify):________________________

41. Do you review and recommend vaccinations (e.g. flu and pneumovax) for your SLE patients on a regular basis (not related to initiation or maintenance of treatments)?

a. Yes
b. No
c. Sometimes
d. Other (Specify):________________________________

42. Will you withhold SLE therapy post-vaccination for a period of time?

a. Yes
b. No
c. Sometimes
a. Other (Specify):____________________________________

43. Please check ☑ whether you use any of the following for your SLE patients on prolonged periods (i.e. > 1 month) of steroids at any dose?

Medication	**Yes**	**No**	**Sometimes**
Calcium (in conjunction with dietary intake for total 1 - 1.5 g daily)			
Vitamin D 1000 – 2000 IU daily			
Bisphosphonates			

Pregnancy in SLE

(please skip if this is not applicable to your practice and go to the next section, "Optimizing Patient Care")

44. How frequently do you see your stable pregnant SLE patients? (Select **all** that apply)

a. Weekly
b. Monthly
c. Every trimester
d. As needed
e. Other (Specify):_______________________

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45. Please check ☑ whether you request your SLE patients to stop the following medications when they are attempting conception or are pregnant?

Medication	**Yes**	**No**	**Sometimes**	**Other (Specify)**
Hydroxychloroquine				
Chloroquine				
Azathioprine				

46. Please check ☑ whether you ask your SLE patients to stop (or not reinitiate) the following medications when they are breastfeeding?

Medication	**Yes**	**No**	**Sometimes**	**Other (Specify)**
Hydroxychloroquine				
Chloroquine				
Azathioprine				

47. Do you recommend that your female SLE patients planning pregnancy ensure disease quiescence for at least 6 months prior to conception attempts?

a. Yes
b. No
c. Sometimes
d. Never
e. Other (Specify)____________________

48. Please check ☑ whether you advise patients with SLE (no antiphospholipid syndrome) to use the following forms of contraception?

Method	**Always**	**Sometimes**	**Never**
Low dose estrogen			
Moderate dose estrogen			
High-dose estrogen			
Progesterone only			

IUD			
Mirena			
Abstinence			
Rhythm method			
Other (Specify)			

49. Please check ☑ whether you advise SLE patients with known antiphospholipid syndrome to use the following forms of contraception?

Method	**Always**	**Sometimes**	**Never**
Low dose estrogen			
Moderate dose estrogen			
High-dose estrogen			
Progesterone only			
IUD			
Mirena			
Abstinence			
Rhythm method			
Other (Specify)			

50. Do you believe that oral contraceptives with estrogen trigger lupus flares?

a. Yes
b. No
c. I do not know

51. What percentage of your patients with SLE have secondary antiphospholipid antibody syndrome?

a. 0-20%
b. 21-40%
c. > 60%
d. I have no idea

52. Which physician primarily manages the anticoagulation of these patients?

a. Rheumatologist
b. Hematologist

c. General Internist
d. Other (Specify) ________________________

53. How long do you require an SLE patient to have discontinued a bisphosphonate before conception is recommended?

a. 3 – 6 months
b. 6 – 12 months
c. 12- 18 months
d. 18 – 24 months
e. > 24 months
f. I do not use bisphosphonates in childbearing women
g. Other (Specify):_____________________________

Optimizing Patient Care

54. Do you feel that a dedicated, multidisciplinary care team including health workers (i.e. Nurse practitioner, social worker, psychologist, etc) would improve the care of your SLE patients?

a. Yes
b. No
c. Maybe
d. Other (Specify):_______________________

55. Do you feel that the family physician (primary care physician) plays a pivotal role in the optimal care of your SLE patients?

a. Yes
b. No
c. Maybe
d. Other (Specify):___________________

56. Do you think a web-based support for consumers (patients) would be useful for SLE patients?

a. Yes
b. No
c. It depends
d. Other (Specify):_______________________

57. Do you feel that a lupus health passport (a type of electronic medical record adapted to SLE) would assist you in the management of your SLE patients?

a. Yes
b. No
c. It depends
d. Other (Specify):____________________

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58. Do you currently collaborate closely with other specialties in the management of your difficult, multi-system SLE patients?

    a. Yes
    b. No
    c. Sometimes
    d. Other (Specify):________________________

59. Do you feel that combined clinics with two or more specialties are useful in managing certain SLE patients (e.g. Nephrology-Rheumatology)?

    a. Yes
    b. No
    c. Sometimes
    d. I do not know
    e. Other (Specify):___________________

60. Does your practice incorporate EMR tools (electronic medical records) in the evaluation of your SLE patients?

    a. Yes
    b. No
    c. Other (Specify):__________________________

Thank you for your participation.
Please provide any additional comments below.

Supplementary Data 2. Members of the Canadian Systemic Lupus Erythematosus Working Group.

Name (alphabetical order)	**Degree**	**Position**	**Area of expertise**
Alabdurubalnabi, Zainab	MD, FRCPC	Trainee	Rheumatology resident, University of British Columbia
Avina-Zubieta, Antonio	MD, FRCPC	Associate Professor of Medicine, Division of Rheumatology, University of British Columbia	Clinical epidemiology; interest in lupus research and managing complex lupus patients
Baril Dionne, Alexandra	MD	Medicine Resident, Programme de rhumatologie, Universite de Montreal	Internal Medicine Resident involved in conducting the systematic literature review for osteoporosis/osteonecrosis
Barr, Susan	MD, MSc, FRCPC	Associate Professor of Medicine, Division of Rheumatology, Department of Medicine, University of Calgary	Expertise in managing complex lupus patients; interest in lupus research; member of CaNIOS
Bergeron, Louise		Canadian Arthritis Patient Alliance representative (CAPA)	SLE Patient advocate
Bernatsky, Sasha	MD, PhD, FRCPC	Professor of Medicine, McGill University	Research focus on malignancy in systemic lupus and clinical epidemiology; manages complex lupus patients as part of McGill Lupus Clinic
Bouree-Tessier, Josiane	MD, MSc, FRCPC	Clinical Professor,	Research focus in connective tissue

		Division of Rheumatology, Universite de Montreal	diseases, particularly on cardiac manifestations of SLE
Clarke, Ann	MD, MSc, FRCPC	Professor, Cumming School of Medicine, University of Calgary	SLE cohorts, chronic atopic diseases (eg. peanut allergy)
Dutz, Jan	MD, FRCPC	Professor & Department Head, Division of Dermatology, University of British Columbia	Cutaneous manifestations of autoimmunity
Ensworth, Stephanie	MD, FRCPC	Clinical Assistant Professor, Division of Rheumatology, University of British Columbia	Expertise in the management of complex SLE patients
Fifi-Mah, Aurore	MD, FRCPC	Clinical Assistant Professor, South Health Campus, Rheumatology Clinic, University of Calgary	Expertise in the management of complex SLE patients
Gladman, Dafna	MD, FRCPC	Professor of Medicine, Senior Scientist, University Health Network, University of Toronto	Prognosis, genetic and therapeutic studies in the rheumatic diseases including psoriatic arthritis, systemic lupus erythematosus, rheumatoid arthritis; created the Toronto Lupus Cohort
Haaland, Derek	MD, MSc, FRCPC	Medical Director and CEO, The Waterside Clinic, Assistant Clinical Professor, McMaster University	Rheumatologist and immunologist; management of complex SLE patients
Hanly, John G	MD, FRCPC	Professor, Division of Rheumatology, Department of Medicine,	Major research foci in pathogenic mechanisms and clinical outcomes in SLE, especially impact of

		Department of Pathology, Dalhousie University	SLE on the brain and other parts of nervous system
Hiraki, Linda	MD, PhD, FRCPC	Clinician Scientist, The Hospital for Sick Children, University of Toronto	Masters and Doctor of Science in Epidemiology; focus on Genetic and Genome Biology at Sick Kids
Hussein, Sara	MD,	University de Montreal	Rheumatology Resident
Keeling, Stephanie	MD, MSc, FRCPC	University of Alberta	Clinical research and trials in SLE
Legault, Kimberly J.	MD, MSc, FRCPC	Assistant Professor, Division of Rheumatology, Department of Medicine, McMaster University	Research focus in lupus, antiphospholipid antibody syndrome.
Levy, Deborah	MD, MSc, FRCPC	Assistant Professor of Medicine, Pediatric Rheumatology, Hospital for Sick Children, University of Toronto	Outcomes in pediatric SLE, especially cognitive impairment
Lim, Lily	MD, PhD Candidate, FRCPC	Assistant Professor, Division of Rheumatology, University of Manitoba	Pediatric rheumatologist with interest in SLE, specifically prognosis; recent work evaluating disease trajectories in pediatric SLE
McDonald, Emily	MD, FRCPC	Assistant Professor of Medicine, General Internal Medicine, McGill University	Attending physician at McGill University Health Center, interest in pregnancy
Matsos, Mark	MD, FRCPC	Associate Professor of Medicine, Division of Rheumatology,	Expert in the management of complex SLE patients; clinical trials and research in SLE

		McMaster University	
Medina-Rosas, Jorge	MD	Junior Researcher, Rheumatology, University of the Sabana, Columbia	Geoff Carr Lupus Fellowship; research in SLE; management of complex SLE patients
Peschken, Christine	MD, MSc, FRCPC	Associate Professor of Medicine and Community Health Sciences, University of Manitoba; Chair of CaNIOS (Canadian Network of Improved Outcomes in SLE)	Health disparities & vulnerable populations with SLE
Pineau, Christian	MD, FRCPC	Assistant Professor, Division of Rheumatology, McGill University	Co-Director of Lupus and Vasculitis clinic; expert management of complex SLE patients
Pope, Janet	MD, FRCPC	Professor, Division of Rheumatology, Department of Medicine, Department of Epidemiology & Biostatistics, Schulich Medicine & Dentisry, University of Western Ontario	Expertise in scleroderma and lupus; involved in recent ACR/EULAR guidelines for scleroderma
Reynolds, Jennifer	MD, FRCPC	Clinical Assistant Professor, Lupus Clinic, University of British Columbia	Expertise in lupus managing patients in Vancouver's Lupus Clinic; member of CaNIOS
Silverman, Earl	MD, FRCPC	Professor of Paediatrics, Division of Rheumatology, SickKids Hospital, Editor-	Director of the Paediatric Lupus Clinic; multiple roles; major interest in outcomes in paediatric SLE and the etiology of neonatal lupus

		in-Chief Journal of Rheumatology	
Suitner, Manon	MD	Universite de Montreal	Internal Medicine Resident involved in systematic literature reviews for osteoporosis/osteonecrosis
Touma, Zahi	MD, PhD, FACP, FRCPC	Assistant Professor of Medicine, Department of Medicine, University of Toronto	Expertise in lupus research including patient-reported outcome measures, cognitive impairment.
Tselios, Konstantinos	MD, PhD	Division of Rheumatology, University of Toronto	PhD thesis on immune regulation in SLE; expert management of complex SLE patients
Urowitz, Murray	MD FRCPC	Professor of Medicine, Director, Centre for Prognosis Studies in Rheumatic Diseases, Senior Scientist, University of Toronto	Established the University of Toronto Lupus Clinic and Lupus Database Research Program; extensive lupus research experience
Vinet, Evelyne	MD, PhD, FRCPC	Assistant Professor, Division of Rheumatology & Division of Clinical Epidemiology, McGill University	Interest in clinical epidemiology of peripartum issues in rheumatic diseases including SLE and rheumatoid arthritis