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m! . 1	CMA Rheumatology Wait Time Benchmarks: A Data Linkage Study of Primary Care
Title	Electronic Medical Records and Administrative Data in Ontario Jessica Widdifield PhD, Sasha Bernatsky MD PhD, J. Carter Thorne MD, Claire
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Reviewer 1	Dr. Cheryl Barnabe
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General comments and author response	Widdifield and colleagues present a timely evaluation of the current situation of wait times to a rheumatologist in Ontario. Benchmarks for inflammatory conditions have been set, and the authors used linked EMR and administrative datasets to study the frequency of meeting these benchmarks. Clarifications on study methods would assist in determining the validity of the findings.
	1. EMR Data: Is pre-EMR patient data scanned into the EMR? Are there physicians who use a combination of EMR and paper charts and thus the referral letter may be missed?
	OUR RESPONSE: Pre-EMR data may be screened into the EMR but it varies by physician practice. Given that we may miss referral letters that pre-date EMR use, we do not provide a referral rate for our sample. Wait-times from 20 years ago may be different from today's practice, thus we also confined our sample from 2000 to 2013.
	2. How were re-referrals determined? Was a primary chart review necessary?
	OUR RESPONSE: The entire medical record was screened to determine if the referral identified was a re-referral. For example, if there were rheumatology consultation letters BEFORE the earliest rheumatology referral letter identified from the EMR. OR, if the rheumatology consultation letter mentioned something like "Thank you for asking me to re-assess this patient again. I had originally seen her 2 years ago" OR, if the referral letter said "Please re-asses this patient for X -You had previously seen patient X for OA in 2000, patient has a new complaint". A primary chart review was necessary to remove re-referrals and to identify dates of symptom onset, which is not captured in a structured variable field.
	Due to word count restrictions, we have not included this additional information in the manuscript.
	3. Data abstraction: Done in duplicate? Training of abstractors and inter- reader agreement?
	REVISION MADE: We have added to the methods under data abstraction: "Double data abstraction occurred on an initial 10% sample of charts, whereby each medical record was abstracted a second time by the same abstractor and once by a different abstractor. To ensure good agreement, we required kappa scores for inter and intra-rater reliability to exceed 0.85 prior to commencing full data abstraction. For all patients, an independent abstractor (JW) also performed double data abstraction related to assigning patients to diagnostic categories."
	4. Charting timing: Does the date of first encounter for the symptom always line up with the date of charting?
	OUR RESPONSE: The date of symptom onset was not the date of charting. Symptom onset may be documented in a patient visit preceding the referral date, or it may be documented within the referral letter itself, or it may appear in the rheumatology consultation letter. For example, if a patient was seen by the family physician on Mar 1 2012 and the family physician documented that the patient has had joint swelling for a duration of one month, the date of symptom onset was back-dated to Feb 1 2012.
	Results: 5A. What proportion of referrals for an individual are made to several rheumatologists?
	OUR RESPONSE: We were unable to assess interactions outside of what was documented in the clinical record (i.e. if one referral letter was faxed to multiple rheumatologists around the same time or if the primary care physician's office called around to multiple rheumatologists to determine

which one could see their patient first).

5B. How many of the rheumatologists accept new referrals?

OUR RESPONSE: As per Table 2, 87 (3%) of patients had documentation that the rheumatologist declined to see the patient. Of these declined referrals, the reason stated was that the rheumatologist was NOT accepting new patients in 10 (11.5%) patients. Privacy restrictions prevent us from contacting the individual rheumatologists directly to determine which of them were not accepting new referrals during the time frame referrals were sent to them.

6. What was the agreement between suspected/referred for diagnoses with the rheumatologists clinical diagnosis? Is there evidence that the GPs 'gamed' the system to request a consult for inflammatory arthritis merely to expedite the consultation and thus clog the system?

OUR RESPONSE: We were unable to accurately assess if the GPs gamed the system to expedite referrals. Assessments of diagnostic agreement between providers, and diagnostic screening patterns is an area of future research. A qualitative research approach may be required to determine if GPs manipulate referral information to expedite access.

7. Was there evidence that the GPs began therapy while waiting for the consultation, or perhaps requested a phone consultation prior to the rheumatology face-to-face appointment? Perhaps the benchmark isn't relevant if treatment is initiated expeditiously. This is particularly relevant given the younger/rural demographics of the participating physicians. As well, for non-inflammatory conditions, were they seeing allied health or other specialty physicians in the interim?

OUR RESPONSE: Detailed patterns of care are not included in this report. However, overall, 40% of patients were seen by another specialist prior to referral (23% seen by allied health). DMARDs are rarely prescribed in primary care and we have ongoing assessments to provide additional insights into patterns of care for patients with rheumatic diseases.

8. Table 6 Recommend re-ordering by the No. of rheums per 100,000 rather than by LHIN number.

REVISIONS MADE: Table 6 has been modified accordingly.

Generalizability:

9. Just 168 of 8054 primary care MDs are included in this analysis. There are some demographic differences apparent but is there another reason why just the 168 were selected for participation in the study?

OUR RESPONSE: EMRALD is currently only comprised of a convenience sample of primary care physicians, but the number of participating physicians is increasing with time. At the time of study, only 168 primary care MDs were participating.

Reviewer 2

Dr. M.F. Bakker

UMC Utrecht Julius Center for Health Sciences and Primary Care, Netherlands Institution

General comments and author response

The manuscript gives a nice description of the wait times of different rheumatoid diseases in Ontario (Canada) and surrounding.

However, I do miss some more in-depth information and also comparisons to wait times in (for example) other western European countries as well as compared to the advice of ACR or EULAR guidelines.

1. Please specify the terms 'wait times varies by condition and region'. What do the authors mention by condition?

OUR RESPONSE: 'Condition' reflects 'clinical diagnoses', whereas 'region' reflects the 'geographic region' where the patient resides within the province. We have clarified this point in the abstract.

REVISIONS MADE: "Wait times varied by diagnoses and geographic region."

2. 'Wait time benchmarks were not achieved'. What are the benchmarks for the wait times?

OUR RESPONSE: We include the benchmarks for the wait-times in the

INTRODUCTION

3. Could be more concise written and I would recommend to write a bit more 'to the point'. For the reader it is (in my opinion) not totally clear what the aim of the study is after reading the introduction section.

OUR RESPONSE: We have shortened our introduction & made modifications accordingly.

4. Please give more insight in the benchmarks. It seems a bit contrary right now that first the authors write that benchmarks have been introduced for rheumatoid diseases and a couple of paragraphs later that benchmarks were not yet established for a lot of rheumatoid diseases.

OUR RESPONSE/REVISION: We have been asked by the editors to keep our introduction limited to 2 paragraphs. We have revised our introduction to stated that "The Canadian Medical Association's (CMA) Wait Times Alliance recently released consensus-based rheumatology wait time benchmarks developed and endorsed by the Canadian Rheumatology Association and Arthritis Alliance of Canada" and provide citations for both reports which describe the methodology to select the benchmarks. Below we have provided an excerpt from the reports to hopefully satisfy the reviewer's inquiry: http://www.waittimealliance.ca/wp-content/uploads/2014/05/Wait-Time-Benchmarks-for-Rheumatology-FINAL.pdf

http://www.arthritisalliance.ca/images/PDF/Final%20Background%20MOC Nov6.pdf

Methodology: The Canadian Rheumatology Association approached experts and committees to establish management guidelines for these diseases and to recommend benchmarks with the help of the best available evidence. Except where specifically mentioned, wait time was defined as "the time elapsed from when the rheumatologist received the referral to the time the patient was seen by the rheumatologist."

Rheumatoid arthritis: The Arthritis Alliance of Canada is working on establishing models of care for inflammatory arthritis and helped establish the benchmarks for rheumatoid arthritis. A scoping review was conducted to gather existing quality indicators. However, there are gaps in the literature, and certain quality indicators and their performance measures do not exist. This is especially noted in the area of system-level performance measures (e.g., tracking number of rheumatologists, wait times, access to allied health care).

The results of the scoping review and preliminary set of measures were presented and input was obtained from members of the working group. Revisions to the measures were made and circulated for open comment. Final benchmarks were set on the basis of these discussions. Psoriatic arthritis: Wait-time benchmarks for psoriatic arthritis were

Psoriatic arthritis: Wait-time benchmarks for psoriatic arthritis were established by consensus among experts in the field including members of the Spondyloarthritis Research Consortium of Canada (SPARCC) and other interested parties.

Axial spondyloarthritis: SPARCC is leading the spondyloarthritis research efforts and is currently developing updated treatment guidelines for the management of axial spondyloarthritis including ankylosing spondylitis. Following a literature review, results relevant to wait-time benchmarks were presented to the SPARCC guidelines committee. MRI imaging has become an integral part of axial spondyloarthritis assessment and has helped decrease the delay in diagnosis. Availability of MRI is integral to the process of decreasing wait times for patients with axial spondyloarthritis and this is reflected in the established benchmarks. Following initial comments, a second round of discussion was conducted on the written document before the wait-time benchmarks were finalized.

METHODS

 $5.\ \mbox{Please}$ define the characteristics that were assessed for the EMRALD vs. Ontario Primary Care physicians.

OUR RESPONSE: Under data sources, we defined how we obtain these characteristics: "The Ontario Health Insurance Plan (OHIP) Corporate Provider Database (CPDB) is used to determine physician demographics, training and practice location, defined using the Ontario Medical Association's Rurality Index of Ontario(33). Physician group affiliations were identified in the Client Agency Program Enrolment (CAPE) database of patient enrollments with primary care groups." We have listed these characteristics under the "analyses" section for the results reported in Table 1.

REVISIONS MADE: In the methods under analyses, we now state: "To determine generalizability of our results, we assessed the characteristics of EMRALD

study physicians in comparison to all Ontario primary care physicians in terms of demographics (sex, age, practice location), medical training location, primary care model, and practice duration."

6. Why do the authors provide means (sd) as well as medians (IQR) for the different wait times? It should be one or the other, not both, please choose the right ones (depending on (non)normal distribution)

REVISIONS MADE: We have removed means (SD) from the manuscript and now only report the medians (IQRs) in Table 4.

7. In the statistical analysis three different types of wait times were described. I think this gives a nice overview where the biggest delay might be. However, throughout the manuscript (introduction/discussion) this is not further addressed. I suggest to incorporate this more throughout the manuscript.

REVISIONS MADE: We have stressed the different types of wait times analyzed more thoroughly throughout.

- Abstract: "The duration of each phase of the care pathway (symptom onset to primary care to referral to rheumatologist consultation) was determined and compared with established benchmarks."
- Intro: "We evaluated wait times overall, and for different diagnostic categories for each component of the care pathway (from symptom onset to see a primary care physician, time for the primary care physician to request a referral, and then the wait to see a rheumatologist) and by geographic region."
- Methods: "The wait time was determined overall and for each diagnostic category for each component of the care pathway: 1) symptom onset until the date of the first primary care visit related to the complaint; 2) first primary care visit related to the complaint until the date of referral to a rheumatologist; and 3) date the referral was sent to the date of the first rheumatologist visit."
- Results: "Wait times from symptom onset to rheumatologist also varied amongst different types of systemic inflammatory rheumatic diseases (Table 5) and for different phases of the care pathway (time from symptom onset to see a primary care physician, the time for the primary care physician to request a referral, and then the wait to see a rheumatologist). The total delay was longest for patients with crystal arthropathies and spondylitis. The longest delay consistently occurred prior to referral."
- Discussion: "We conducted a novel data linkage study to address the total wait to see a rheumatologist faced by patients, including the time from symptom onset to see a primary care physician, the time for the primary care physician to request a referral, and then the wait to see a specialist." ... "There is also ample evidence from international studies that support our findings that the majority of the delay occurs prior to referral"...

RESULTS

8. Most referrals seem to be in between 2005-2013, almost none were included between 2000-2004: can this difference/change be explained?

OUR RESPONSE: The adoption of EMRs in Ontario has lagged other countries. The difference largely reflects the average duration of EMR use in our sample.

- Of the 2430 referrals, 2417 (99.5%) occurred between 2005 and 2014. There was an increasing number of referrals each year which is largely a function of increasing data added to EMRALD. [The average duration of EMR use in EMRALD is 5 years (range 2-25)]. Our study was not designed to assess referral rates and whether they are increasing over time.
- 9. How is the percentage referred patients compared to what is "regular" seen? So for example is the ratio female/male and are the ages of the different types of the rheumatic diseases in comparison to the "guidelines" / conform the numbers of Canada?

OUR RESPONSE: We have not -and are not aware of other Canadian studies who have - quantified the patients by diagnoses under ongoing rheumatology care. Given that 1 in 3 referrals were for a systemic rheumatic diseases, we suspect these are the individuals who remain under rheumatology care. Thus, 2/3rds of referrals are likely discharged back to primary care and raise questions about appropriateness of referrals. However, there are no guidelines to define what constitutes an appropriate rheumatology referral. Future research is needed in this area.

10. Is the percentage of the occurrence of the different types of rheumatoid diseases of this investigation in comparison to what is seen in literature? Or might some kind of selection bias be introduced?

OUR RESPONSE: No, the occurrence of different conditions in our sample does not necessarily reflect the occurrence of these conditions in the population. For example, gout is more prevalent in the population than represented in our sample largely because gout may be diagnosed and managed in primary care (without a referral).

11. Was there any difference between the centers/physicians? The authors already state there were some differences in wait times between the physicians. Is it possible to give more insight whether some physicians referred many more patients of one of the subtypes compared to the other subtypes compared to other physicians? This might be explain the differences in wait times as well.

OUR RESPONSE: Privacy restrictions prevent us from providing this data as we can only report on the aggregate level.

DISCUSSION

12. What is the expectation of the difference in the wait times found? Could this be solved?

OUR RESPONSE: We address some explanations of what may be driving the excessive wait times and potential solutions in the $3 \, \mathrm{rd}$ paragraph of the discussion.

"In Canada, both rheumatologists and primary care physicians identify long wait times as a barrier ... We believe our findings represent a call to action on the need for increasing awareness amongst patients, physicians and policy-makers ...and to prioritize planning of healthcare services, medical education and research. The relative shortage of rheumatologists especially in rural areas ...suggests a need for innovative models of care. Rheumatology referrals are often not done in a standardized or consistent way and wait times vary by individual rheumatologist. ...This suggests a need for better ways to systematically track and report waits at the level of specialists. Finally, given the substantial delay in patients seeking medical attention and the delay of primary care physicians requesting referrals, increasing patient awareness and medical education are acutely needed."

13. How are these wait times in comparison to the literature / guidelines / other (western) countries? Please provide more details.

REVISIONS MADE: We have expanded on making international comparisons in our discussion: "There is also ample evidence from international studies that support our findings that the majority of the delay occurs prior to referral. However, the total delay to rheumatology consultation may be substantially longer in Ontario than in other countries. For example, the median delay from symptom onset to assessment by a rheumatologist for RA patients across 10 European centres was only 24 weeks, in contrast to our 47 weeks (327 days) in our sample. Taken together, this suggests delays attributed to the awareness and care-seeking behavior of patients, as well as opportunities to improve screening in primary care in Ontario.