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ORIGINAL ARTICLE

Factors influencing implementation of a computerized, individualized, culturally tailored lupus decision aid in lupus clinics: a qualitative semi-structured interview study

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Abstract

Objective To identify factors that might facilitate or impede the implementation of a shared decision-making in lupus electronic tool (SMILE) in clinics by assessing perspectives of clinicians, clinic champions, and patient advocacy organization leaders.

Methods We conducted a series of semi-structured telephone interviews (25–45 minutes) about facilitators and barriers of implementing the SMILE decision-aid tool with 23 lupus care providers (18 physicians, 5 champions), and leaders of two patient advocacy organizations. Interviews were audio recorded, transcribed, coded, and analyzed.

Results Physicians and clinic champions were from 18 geographically diverse US clinics. The patient advocacy leaders were from the Lupus Foundation of America and the Arthritis Foundation. Most of the clinics were rheumatology specialty (94%), at university-based academic centers (72%), located in urban areas (72%), had a specialized lupus clinic (72%), were very interested (72%) in the SMILE tool and were ready to implement it (89%). Several specific factors, composed as four themes, were identified that could either facilitate or impede the implementation of the SMILE tool: (1) patient-related theme: patient recruitment and education, and the clinic visit time; (2) clinic-related theme: staff work-load and time, and physical space to view and use the SMILE tool; (3) technology-related theme: Wi-Fi connection and iPad navigation; and (4) management-related theme: influence on the clinics' daily workflow, the need of a study champion and coordination, and leadership support.

Conclusion Physicians, staff, and patient advocacy leaders perceived the SMILE as a promising tool to facilitate patient-provider communication and quality improvement in lupus. Identification of the patient-, clinic-, technology-, and management-related barriers to the SMILE implementation will allow its integration into busy clinical practice workflow.

Key Points

- *Physicians, staff and patient advocacy leaders perceived computerized lupus decision aid to be a promising tool to facilitate shared decision-making for lupus treatment.*
- *Stakeholder identified patient-related, clinic-resource-related, technology-related and clinic-management related themes as barriers or facilitators to viewing computerized lupus decision aid during regular clinic visits.*

Keywords Barriers · Decision aid · Decision aids · Decision tool · Facilitators · Kidney disease · Lupus · Lupus nephritis · Qualitative research · Shared decision-making · Shared decision-making in lupus electronic tool · SLE

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Background

Systemic lupus erythematosus (SLE) is a complex, rare autoimmune disease that can have a seriously negative impact on all aspects of a patient's life [1, 2]. SLE affects over 300,000 individuals in the US [3]. According to a recent population-based study conducted in large patient cohorts from Georgia, the overall age-adjusted prevalence rate of SLE was up to 73/100,000 [4]. The annual direct and indirect costs associated with SLE are estimated to be $10,000–$50,000 [5]. Health-related quality of life (HRQOL) in SLE is significantly worse compared with patients with other common chronic diseases and to females in the general US population [6]. Patients with SLE have an increased mortality, with overall SLE mortality rate of 19 per 1000 person-years [7], which is 2–5 times compared with the general population [8]. In a study of patients with lupus nephritis from 1971 to 2015, the risk of end-stage renal disease in lupus nephritis increased in the late 2000s [9], which suggests the existing challenges to accepting effective current treatments for lupus by patients.

High rates of medication non-adherence ranging from 43 to 75% have been reported in SLE [10]. Poor patient adherence to SLE treatments is a predictor of poor outcomes [11–14]. Discordant patient-physician perspectives on disease, treatments, and medication adverse events are additional major factors that contribute to these poor outcomes in people with SLE [15, 16]. Previous studies identified the facilitators and barriers to shared decision-making (SDM) in lupus care [17–19]. Funded by the Patient-Centered Outcome Research Institute (PCORI), we developed a shared decision-making in lupus electronic tool (SMILE). We recently tested the SMILE in a randomized trial, individualized decision aid for diverse women with lupus nephritis (IDEA-WON) across 4 US sites, and found it to be effective in reducing decision conflict in women with lupus [20]. The SMILE is a computerized, individualized lupus decision-aid tool that can be used to educate patients, improve patient-provider communication, and assist SDM during a regular clinic visit [21].

One of the major challenges to improving quality of care in people with lupus is the lack of effective patient education tools to improve patient knowledge of treatments for lupus. Our quality improvement/quality assurance (QA/QI) initiative aims to use the SMILE tool to facilitate SDM in SLE with a goal to optimize treatment, reduce medication and clinic appointment non-adherence, and improve disease outcomes. The short-term objective of this QA/QI initiative was to obtain provider opinions of barriers and facilitators to a future patient education implementation in their local environments. The long-term objective of this QA/QI initiative is to bring immediate improvements in the education of patients with lupus (i.e., improve health care delivery) in local settings by providing the lupus decision-aid (SMILE tool) to the patients during regular clinic visits without interrupting the clinic flow, while evaluating and learning from the local experience, and using a flexible, adaptive, and iterative design for implementation that works for each local environment.

We conducted this qualitative QA/QI project with providers, i.e., clinicians, clinic champions, and representatives from patient advocacy organizations, i.e., key stakeholders who could help us understand the barriers to local implementation of this patient educational tool. The objective of our semi-structured in-depth interviews was to identify barriers and facilitators to the implementation of SMILE in select lupus clinics, and assess their capacity, interests, and readiness to utilize the SMILE tool to educate patients with lupus during routine clinic visits.

Methods

Participants

Participants were lupus health care providers, i.e., 18 rheumatologists and 5 nurses (potential clinic champions identified by providers), and two leaders of patient advocacy organizations, i.e., the Lupus Foundation of America (LFA) and the Arthritis Foundation (AF). Provider participants were either collaborators/users of the SMILE from our previous project (providers and champions from four clinic sites) or had expressed interest in participating in our proposed project to evaluate the effectiveness and implementation strategies of our lupus decision-aid tool, in a survey. The implementation study is now funded by PCORI and is currently underway [22].

Participating rheumatologists consisted of a convenience sample of providers/clinics known to provide care to large numbers of people with lupus; all had expertise and several years/decades of experience in treating and managing people with lupus. Patient advocacy organization leaders were our key stakeholders in developing and testing the SMILE and were responsible for disseminating and implementing the tool in patient communities. As a QA/QI initiative, this project did not constitute research and therefore did not need an approval from an ethics committee. Written informed consent was not required, since this was a QA/QI initiative assessing provider opinions. Participants (healthcare providers and advocacy leaders) provided their opinions and experience and no patients were involved and no treatments were assessed. All participants provided informed verbal consent prior to the initiation of the interview, and all completed the interviews.

Semi-structured interviews

We conducted a series of semi-structured telephone interviews between November and December 2017. Each participant was

interviewed by one researcher (JS) with a semi-structured protocol. We sent the lupus decision-aid tool, SMILE, and a general outline of the interview to each participant one week prior to the interview, and confirmed the receipt. Participants were asked to review all materials prior to the interview. We asked participants for their general thoughts about facilitators and barriers to implementing our lupus decision-aid tool for their patients and health systems using a series of open-ended structured questions (Appendix). The organization/clinic characteristics, leadership's interests, and organization readiness of implementation the tool were also assessed. Probing questions were used to verify interviewer's interpretations of responses. The duration of the interviews varied between 25 and 45 minutes. Some of the questions were as follows: "What do you see as the top 3 patient barriers/facilitators to the implementation of an individualized culturally- and literacy-appropriate patient self-administered decision-aid on an iPad in your clinic? (Patients would view this while they are waiting to see their health care providers.)", "What do you see as the top 3 clinic or systems barriers/facilitators in your lupus clinic to the implementation of an individualized culturally- and literacy-appropriate patient self-administered decision-aid?" (Appendix).

Data analyses

All interviews were audio recorded and transcribed. Transcripts were examined line-by-line, double-coded, and analyzed using NVIVO 11.0 Pro [23] by authors (HQ and XH). Coding was compared iteratively and the inconsistencies were discussed resulting in inter-coder agreements of 78%. A thematic analysis and constant comparative method were used to identify the main categories and themes [24]. Descriptive statistics for participant and organization characteristics were analyzed using IBM SPSS (version 25; Armonk, NY: IBM Corp.).

Results

Participant and organization characteristics are provided in Table 1. There were 18 rheumatologists and 5 clinic champions (allied health care providers) from 18 clinics, and 2 patient advocacy organization leaders. Male (52%) and female (48%) participants are equally represented. The median year of practice/service was 14 years (interquartile range, 8 to 23).

Most of clinics were rheumatology only (94%), were affiliated with a university (72%), located in urban areas (72%), had a dedicated lupus clinic (72%), were very interested (72%) in the lupus decision-aid tool, and indicated the readiness of their clinic to implement it in their practice (89%).

The data obtained from the responses were categorized in four themes, including patient-related, clinic-related, technology-related, and management-related factors. All factors identified in those themes would either facilitate or impede the implementation of a quality initiative to implement patient viewing of the lupus decision-aid tool during regular clinic visits to facilitate information regarding lupus and its treatments and a SDM regarding lupus treatments. Identified patient level and system/clinic level barriers and facilitators are summarized in Table 2**.** The word frequency of interviewees' responses is shown in Fig. 1.

Patient-related theme

The most important concern for the interviewees was the time needed to use the decision-aid tool, and challenges with patient engagement, including the way to identify patients prior to their clinic visit and getting patient consent. Participants' views differed regarding the best patient engagement process. They thought patient engagement process could either be a facilitator or a barrier to the implementation of the lupus decision-aid tool. The reasons for this concern was that patient interests and preferences, health literacy, and the time availability to view the decision aid are variable, and the same process may be viewed as positive by one patient and negative by another patient.

The first factor was the time needed to allow the patient to view the tool before discussing it with their physician. Almost each participant (92%) mentioned the time issue. Participants worried that "visits may become longer—MD1, MD11 and MD15" if patients used the tool. Patients on average have "30-minute visit usually—they may have to wait an extra 10-20 (minute) for these visits—MD13." They said the "total time patients spend in the clinic is more like 30-40 minutes: (there are) challenges in getting them to complete this—MD1." Some participants said that patients in their clinic "are already completing two forms: lupus-PRO (lupus-patient reported outcomes) and MD-HAQ (Multidimensional Health Assessment Questionnaire)—MD6," patients would need extra time to view the tool and complete surveys. "These are socially disadvantaged patients, for the most part, they are going to have issues with that, so they will come in late, they will be rushed, distracted in that regard, sometimes, not all the time, but they do have a lot of down time for sure, or they usually will—MD9."

According to the participants, the majority of the patients would be interested in viewing the tool, "patient is very interested in information that is new and up-to-date and as a resource, and patient population is usually pretty good about wanting to receive information regarding their disease process—champion 2." Also, some participants mentioned, "I think if patients were given something to do as they waited as opposed to just staring at the four walls they would like it and feel that they were actively participating in taking care of themselves and their healthcare—patient advocacy leader 1."

Table 1 Interviewee ($n = 25$) and clinic ($n = 18$) characteristics

		N	%
Interviewee type	Physician	18	72
	Clinic champion	5	20
	Patient advocacy organization leader	2	8
Interviewee gender	Male	12	52
	Female	13	48
Location	Northeast	2	8
	Southeast	9	36
	Midwest	8	32
	Southwest	2	8
	West	4	16
Years of practice/service	Median = 14.0 (Inter-quartile range, 8–23)		
Practice setting	Urban	15	72.2
	Suburban	3	27.8
Practice type	Rheumatology only	17	94.4
	Rheumatology-nephrology	1	5.6
Have a lupus clinic	Yes	13	72.2
	No	5	27.8
Practice ownership	University	13	72.2
	Private	5	27.8
Academic	Yes	13	72.2
	No	5	27.8
Leadership's interest	Very interested	13	72.2
	Interested	5	27.8
Readiness of practice	Ready	16	88.9
	Not sure/might be ready in the next few months	2	11.1
Lupus patients seen in 1 year	< 50	3	16.7
	50–99	5	27.8
	100–149	5	27.8
	150–199	2	11.1
	450–499	1	5.6
	Missing	2	11.1

However, some other participants doubted that "can all patients understand this decision-aid?—MD5." Many of them thought that patient "understanding the tool" (8 physicians) was very important to implement the tool and "helping navigating technology" (9 physicians) and "educating patients with the tool" would facilitate the patient engagement and implementation of the tool.

The third concern was about patient literacy. "Numeracy issues—MD17," "technology literacy—MD1," and "sometimes the literacy level of some (of) our patients that can be a little questionable—champion 5." Participants were also concerned about language barriers, "only African American and Caucasian patients who can understand English will be able to enroll—MD11." "They are going to have to be able to read the basic language—MD8." Some participants suggested that the front-desk staff or research coordinators should make sure they explain right to each patient.

Clinic-related theme

The second theme from the responses related to the clinic flow, time added to the clinic staff, and the space needed for the patients to view the lupus decision-aid tool. Eleven interviewees (44%) thought that clinic flow is a major concern; especially those institutions that have several clinic sites with different set ups. "Will this interfere with the patient flow?—MD15" "I think the only thing that we ever had difficulty is if they (patients) go in the room ahead of the doctor and that kind of interrupts flow but I think education, if we, if our staff up front knows, the more they know about it the better they can advocate for it—champion 4." One participant said, "Well, in

Table 2 Perceived facilitators and barriers to effective implementation of the decision-aid tool

	Facilitators	Barriers
Patient level	Patient interest in viewing the tool and getting knowledge about their disease	• Time to review the tool • Understanding the tool • Navigating technology, iPad, Wi-Fi, • Extra waiting time for visit • Pre-identify patients • Concern about participate in a research study • Preferences of obtaining information • Sick patients • Language barrier • Age, very young or very old • Literacy and numeracy issues
System of clinic level	• Very interested in participation • Have an experienced team • Buy-in from clinicians • Have a study/clinic champion and/or a pharmacist • Have a lupus clinic • Adequate staff funding • Project with Academic credit are preferred in our set-up • Satisfy local and national CME • Motivation from the research team • Buy-in from the administration	• Slow down patient flow • Extend visit time for patients • Limited space • Pre-identify patients and patient recruitment • Extra staff burden for the front-desk staff • Lack of a clinician champion • Lack of experience with the decision aid use • Get the iPad to the patient quickly • Busy front desk • Busy clinic • Supportive nurse manager • Incentivize the recruitment • Funding for staff personnel • Lack of staff personnel • Patient privacy • Variability on the patients • Nurse rotation • Separation of clinics • Front desk nurse forgetting about the tool • IRB issues • Technology related to iPad use

an academic center where you have to account for your time, and they want to improve the patient flow, there is no way this can get done in the traditional visit, especially if you are talking about sick people or people who just have a lot of issues and you are in a teaching clinic—MD9." "Clinical administrators may not be used to research, they are focused on patient flow—MD18." "Personnel for making procedure changes: They are in a hurry to get patients in and out: if anyone sits in the room for longer, it's a problem—MD6."

In terms of provider time, some participants said, "Nurse practitioner and the remaining PAs (physician assistants), who see(s) lupus patients will be very challenged to do anything other than patient care – study coordinator needs to (be) full time, if this is implemented as part of a research study." "At least 50% time FTE (full time equivalent)—MD3." They thought "clinic staff is very busy and over-committed—MD15" and concerned about the "Time for clinician: Lupus clinic is always supervised by attendings but patients are seen by fellows, they have a lot of down-time. 1-2 hours. Plenty of down-time—MD2." Some participants thought time was not a problem for their clinic. "We have a survey 30-40 pages that patients complete, so time is not an issue—MD4."

Another big concern for the clinic was the space to apply the tool, 48% participants talked about the space issue. Participants said, "Finding space: there is no extra room, it will be done in the waiting room—MD8." They were concerned about patient confidentiality and privacy and hoped that there is a "space to review materials that is quiet—MD16." Some participants said they have a very crowded clinic, "limited exam rooms—MD12", or "shared space with other (non-rheumatology) clinics—MD9." They also thought "coordinators not getting enough space- reminding how important it is to let coordinators to have space—MD18."

Besides the time and space, other resource constraints were considered. Several participants (20%) shared that there was a "lack of iPads in the clinic." Others concerns included "We have very limited resources, with anyone committing time to this study: We don't have any pharmacist in the clinic—

Fig. 1 Perceptions about implementation of lupus decision-aid tool. This figure shows the word frequency of interviewees' responses, with those words/ issues that were mentioned most often showing most prominently in the figure

MD6." They also thought that they need training materials for both patients and clinical staff, because "nurses are always rotating, so are the front desk people- our study coordinators—MD5". "It would be nice to have enough knowledge so all the folks are involved and understand what the reason behind it and then move forward—champion 2." The "resource for guiding the patient through the process—MD17" is also important. Moreover, the participants reported that having an experienced team was the facilitator for the decision-aid tool implementation from one of the sites that participated in the previous study of this tool—"We have a team that is functional and works well together and with your (Dr. Singh) team—MD1."

Technology-related theme

The third theme was technology support, including Wi-Fi connection and iPad utilization. They anticipated that both staff and patients need "technical help with the iPad." The research team should "come and train our team—MD15" and show staff and patients how to navigate the tool in the iPad. At the same time, Wi-Fi connection was also an issue for some clinics, but not for others. One participant said, "There is the main hospital Wi-Fi which is probably not 100% reliable but probably reliable over 85% of the time—MD3."

Management-related theme

Participants highlighted that attention should be paid to the effects of the lupus decision-aid tool adoption on the clinic routine operation management. Some interviewees worried "Will this interfere with the patient flow in the clinic?—MD15" They thought, "If it slows down (clinic) flow- it may be an issue—MD1." As a solution to this concern, participants suggested, it might be helpful to "have a different check-in desk" to identify the patients, whereas some others suggested that physicians should identify eligible patients before the patient visit for a research study of the implementation of this tool.

Most of the participants agreed that a study champion would be very helpful for the decision-aid tool implementation, including "Get the iPad to the patient quickly—MD5." "We have a couple of long-term coordinators who have a rapport with the clinic staff—MD18." "Clinic champion- I can envision one person, nurse aid- barrier is she is asked to do other things- nurse manager would be supportive—MD10." "We have a champion related to lupus education, who has been working with us, so this might be good—MD1."

In addition, the leadership support was also very important. Most interviewees (72%) reported that their leadership was very interested in the quality initiative program (Table 1). "I

think being a part of PCORI, division chief is very supportive—MD1." "Department of medicine is interested, and they are supportive—MD10." One patient advocacy leader indicated, "We have a social network –we need to do that and help in the widespread implementation beyond the clinic-that's the only way to get it to every patient with lupus."

Other themes

More than half of the interviewees mentioned the IRB issue. Some participants were concerned about questionnaire fatigue because of ongoing data collection for other studies, including other quality improvement initiatives. "Main competition is that patients are asked to participate in a lot of studies—MD16." One interviewee mentioned that it would be helpful to monitor the iPads after they are given to patients. Participants also pointed out that it would be helpful if this project can involve fellows. Two participants were concerned about patient privacy.

Discussion

In summary, results from this formative evaluation as part of a QA/QI initiative can help us understand how clinicians, clinic champions, and patient advocacy leaders perceived the facilitators and barriers to implementation of our shared decision-making lupus decision-aid tool, SMILE, at both the health system/clinic level and the patient level. Overall, the participants were very positive about the implementation of this tool, viewed it as a quality improvement tool and expressed high interest in implementing this tool in their clinics.

First of all, participants were very positive about patient recruitment and engagement. They thought that most patients would want to learn more about their disease. This is consistent with findings in previous studies [19]. At the patient level, patient identification, time needed in the clinic to view the lupus decision-aid tool, and patient knowledge about the use of the tool and iPad were the main concerns. Some participants thought the application of the tool might increase patient visit time by about 20–30 min. Some participants reported patients would like to view the tool in the waiting area before they see their doctors compared with doing nothing. Patient literacy level, language (English or Spanish only), current lupus activity, and barriers of using the iPad and the tool were also concerns. The lupus decision-aid tool is at grade 4 to 5 English reading level. Identifying barriers and facilitators with different stakeholders will help effectively implement this decision-aid tool in the clinical practice settings because different types of stakeholders' perspectives toward concerns, preferences, and priorities may differ [25].

The main concerns were the perceived staff burden and the need/availability of space and time to apply the tool in the clinic. About 72% participants reported that their hospital was urban, university owned, academic, and had a lupus clinic. These lupus clinics are usually very busy half or full-day clinics that provide care to a large number of lupus patients. Participants worried that the tool might increase the staff burden because of a busy clinic and overworked front-desk staff. This finding is similar to those from a recent study conducted with 153 Canadian rheumatologists [26]. Participants all agreed that a study champion would be very helpful for this implementation study, which is consistent with findings of other studies of implementation of decision aid for diabetes, or cancer [27, 28]. Some suggested that a separate registration desk at check-in might be needed to provide patient education and support in clinical encounters.

Wi-Fi connection and iPad navigation were among the most frequently mentioned technology barriers. Specific areas of the clinic may have Wi-Fi drop zones. Training for clinic staff and detailed instructions seemed to be vital for a successful tool implementation to counter these barriers. A more user-friendly interface for patient users will likely help facilitate the implementation of this tool. An improvement in the quality of Wi-Fi connection in clinic waiting areas is expected over time and therefore this barrier is likely to diminish or resolve over time. Patients and providers depend on Wi-Fi for multiple patient care services including electronic medical record (EMR), that is, now standard in most clinics in the USA.

A majority of the participants thought that their leadership would be very supportive to this project. Almost all (89%) reported practice readiness to implement the tool in their practice. About one-third of the participants reported that they have an experienced team and several had experienced study coordinators who could help the implementation of the tool.

This qualitative study identified several concrete steps to ensure smooth execution of the next-stage implementation project. These include, but are not limited to, the following. Solutions and planning for lupus decision-aid implementation will be site-specific depending on its unique barriers and strengths, which will be identified with detailed interviewing of key clinic team members at each site. We plan to identify at least one clinic champion at each site, who will help troubleshoot implementation challenges in the busy clinic, work with the study coordinator in the clinic, and help to explain the decision-aid implementation study to patients in the regular clinics. Patients will then be able to provide informed consent, view the lupus decision-aid tool (SMILE), and complete study surveys and audio-record patient-physician conversations using the iPad, utilizing the waiting periods during the regular clinic visits. We will provide training to study coordinators, clinic companions, and the front-desk staff about the tool and iPad, so that they can troubleshoot software/hardware issues and avoid any

frustration for the clinic team or the patient. These trainings will be available as web-links, to allow for staff turnover and training of new clinic team members. As needed, various clinic team members will help patients navigate the tool using the iPad. The clinic study teams will work with patients in waiting area spaces with privacy and/or clinic room/areas that ensure patient privacy.

Conclusion

Physicians and staff perceived SMILE, the lupus decision-aid tool for SDM, as promising for improving patient-provider communication and quality improvement. Important questions were raised, patient-, clinic-, technology-, and management-related barriers were identified, and solutions regarding how to overcome those barriers were also identified. Facilitators for the integration of the tool and resultant information into their daily practice workflow were suggested. Additional research investigating how to best implement our lupus decision-aid tool (SMILE) across difference clinic site settings (private vs. academic; rural vs. suburban vs. urban; solo vs. group practices; general rheumatology vs. specialized lupus vs. rheumatology-renal clinics) will be conducted prior to the widespread adoption of the QA/QI initiative to maximize its benefits to patients and healthcare teams while minimizing workflow disruptions.

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Compliance with ethical standards

Ethical approval and consent to participate This was a quality assurance/quality improvement (QA/QI) initiative that did not require any ethics committee approval.

Consent for publication Not required.

Potential conflict of interest JAS has received consultant fees from Crealta/Horizon, Medisys, Fidia, UBM LLC, Medscape, WebMD, Clinical Care options, Clearview healthcare partners, Putnam associates, Spherix, the National Institutes of Health and the American College of Rheumatology. JAS owns stock options in Amarin pharmaceuticals and Viking therapeutics. JAS is a member of the executive of OMERACT, an organization that develops outcome measures in rheumatology and receives arms-length funding from 36 companies. JAS serves on the FDA Arthritis Advisory Committee. JAS is a member of the Veterans Affairs Rheumatology Field Advisory Committee. JAS is the editor and the Director of the UAB Cochrane Musculoskeletal Group Satellite Center on Network Meta-analysis. JAS previously served as a member of the following committees: member, the American College of Rheumatology's (ACR) Annual Meeting Planning Committee (AMPC) and Quality of Care Committees, the Chair of the ACR Meet-the-Professor, Workshop and Study Group Subcommittee and the co-chair of the ACR Criteria and Response Criteria subcommittee. Other authors have no conflicts to declare. The funding agencies played no role in project design, collection, analysis, interpretation of data, writing of the manuscript, or in the decision to submit the paper for publication. They accept no responsibility for the contents.

Disclaimer The views, presented in this article are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Abbreviations SLE, systemic lupus erythematosus; HRQOL, health-related quality of life; SDM, shared decision-making; PCORI, Patient-Centered Outcome Research Institute; QA/QI, quality improvement/quality assurance; SES, socioeconomic status; CER, comparative effectiveness research; SD, standard deviation; ACR, American College of Rheumatology; UAB, University of Alabama at Birmingham; IDEA-WON, individualized decision aid for diverse women with lupus nephritis; SMILE, shared decision-making in lupus electronic tool; LFA, Lupus Foundation of America; AF, Arthritis Foundation

Appendix. Interview questions

1. What do you see as the top 3 patient barriers to the implementation of an individualized culturally- and literacy-appropriate patient self-administered decision-aid on an iPad in your clinic? Patients would view this while they are waiting to see the health care provider.

2. What do you see as the top 3 clinic or systems barriers to the implementation of a culturally- and literacy-appropriate patient self-administered lupus decision-aid on an iPad in your lupus clinic? Patients would view this while they are waiting to see the health care provider.

3. Which of these key clinic barriers do you see a clinic champion (i.e., nurse/manager) sorting out for the decision-aid implementation project?

4. Which of these key clinic barriers do you see a UAB study team sorting out for the decision-aid implementation project?

5. Are there any other critical barriers outside of these barriers that clinic nurse or UAB team can address that would make the implementation project fail?

6. How interested is the leadership in this quality initiative?

7. How ready is the practice to implement this quality initiative? Are there any competing priorities (EHR installation or leadership changes)?

8. Is your practice urban/sub-urban? Is it rheumatology-nephrology or only rheumatology? Is it like private practice or academic? How many patients could you enroll in a 1.5-2 year period?

9. What do you see as the top 3 clinic or systems facilitators in your lupus clinic to implementing a culturally- and literacy-appropriate patient self-administered lupus decision-aid?

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