



Published in final edited form as:

Arthritis Care Res (Hoboken). 2023 January ; 75(1): 180–189. doi:10.1002/acr.24756.

Comprehension, Utility, and Acceptability of a Multi-Domain Physical Functioning Report for Systemic Lupus Erythematosus Patients and Their Providers

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Abstract

Objective: Patient-provider discussions about functioning are often outside the scope of usual care for systemic lupus erythematosus (SLE), and tools to facilitate such discussions are lacking. We assessed the comprehension, utility, and acceptability of a novel, individualized functioning report, the purpose of which is to facilitate patient-provider communication about functioning, in a predominantly Black SLE patient population.

Methods: Individualized reports (including sections with pictorial representations of participants' measured activities of daily living, falls, physical performance, perceived physical functioning, and community mobility from a previous pilot study visit) and surveys were emailed or mailed to 59 SLE patients. Ease of interpretation was dichotomized ("very easy" vs. all other responses). Utility and acceptability were assessed by items relating to usefulness for care planning and comfort with discussing the report.

Results: Among 47 (79.7%) SLE patients who completed the survey (78.7% Black, 91.5% female, mean age=49.6), reported ease of interpretation ranged from 70.2% to 85.1% across the report sections. Ease of interpretation was lower among those who were older, Black, and female and who had lower cognitive scores ($P>0.05$ for all). Most reported that physical functioning domains of the report were useful for treatment or other care planning (70.2–80.5%) and that they felt comfortable discussing the report with a healthcare provider (93.2–100%).

Conclusion: We found that a novel functioning report for SLE patients was associated with high comprehension, utility, and acceptability. Future studies can help determine how an individualized functioning report could improve patient-provider communication in the clinic setting.

Background

Systemic lupus erythematosus (SLE) patients often report reduced physical functioning.¹⁻⁵ In a recent pilot,⁶ we found that impairment was common across multiple domains of physical functioning, including physical performance, activities of daily living, falls, and community mobility, and similar to that seen in populations receiving geriatric care, regardless of age. The older SLE patient population is also rapidly expanding, due to increased life expectancy among SLE patients⁷ and a larger pool of individuals at risk of developing late-onset SLE,⁸ putting them at risk for functional impairment due to both SLE and older age. Importantly, our pilot study also revealed that Black vs. white SLE patients participating in our pilot had slower gait speed, decreased lower-body strength, more trouble with activities of daily living, and more reported falls in the prior year.⁶

Functional status has been called the “sixth vital sign” and is a strong predictor of patient outcomes, but the majority of medical records lack documentation of functional status and demonstrate poor sensitivity for detecting impairment.⁹ Unrecognized functional impairment in SLE may lead to care that is not responsive to patients’ needs,^{10,11} which may lead to poor treatment adherence and patient-physician interactions and adverse outcomes, including limited ability to participate in work and daily activities¹² and to live independently. Knowledge of functional status has the potential to identify individuals for whom resources are most needed, determine targets for intervention, and improve patient satisfaction with treatment.¹⁰ Despite this, patient-provider discussions about functioning are often outside the scope of usual care for SLE, and tools to facilitate such discussions are lacking. For Black populations with SLE, who disproportionately suffer poor outcomes generally,¹³ these gaps in care may be even more critical to address to prevent poor outcomes related to functioning, including loss of independence.

Leveraging our pilot study⁶ and other work in which we developed an app-based, patient-friendly report that provides information on functioning across these domains,¹⁴ we produced and delivered individualized reports to a predominantly Black group of SLE patients and simultaneously administered an online survey to gather feedback on the individualized report. Our aim was to describe potential comprehension, utility, and acceptability of the individualized functioning report in a predominantly Black and female SLE population.

Methods

Study Design and Population

Participants for this study were recruited from the Approaches to Positive, Patient-centered Experiences of Aging in Lupus (APPEAL) ancillary pilot study,⁶ who in turn were recruited from Georgians Organized Against Lupus (GOAL). GOAL is a large, ongoing, population-based cohort of predominantly Black patients with SLE [defined as meeting 4 of the

11 criteria defined by the American College of Rheumatology (ACR), or 3 ACR criteria with a final diagnosis of SLE by a board-certified rheumatologist¹⁵] from metropolitan Atlanta, Georgia.¹⁶ The aims of the APPEAL pilot ($n=60$) were to provide preliminary estimates of the prevalence of impairment across multiple physical and cognitive functioning domains in SLE and demonstrate the feasibility of performing these measurements in SLE.⁶ Functioning data for the APPEAL pilot were obtained from a series of performance tests and questionnaires administered during study visits (10/16–4/17). Details of how each domain was measured in the pilot can be found in Plantinga *et al.*⁶ Briefly, basic and instrumental ADLs were assessed using the Katz¹⁷ and Lawton¹⁸ instruments, respectively; falls (12-month history and fear of falling) were assessed by recall and via the Falls Efficacy Scale (FES)¹⁹; self-reported physical functioning was assessed via the Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Functioning-Short Form 12a²⁰; physical performance was assessed by the Short Physical Performance Battery (SPPB)²¹; and community mobility was assessed using the University of Alabama at Birmingham (UAB) Study of Aging Life Space Assessment.²²

In another previous study, our team developed a comprehensive, individualized, patient-friendly report for patients receiving dialysis,¹⁴ which included pictorial representations of five domains of patient-specific levels of functioning [activities of daily living (ADLs), falls, self-reported physical functioning, physical performance, and community mobility]. The report was modified as needed to reflect the instruments used in the APPEAL pilot and also to address the target SLE patient population. Each domain was included in a separate section on the report with descriptive, patient-friendly titles for ADLs (“What Can You Do?”), falls (“Do You Fall?”), self-reported physical functioning (“How Do You Think You Are Doing?”), physical performance (“How Do You Move?”), and community mobility (“How Far Do You Go?”; Supplementary Figure).

Using the existing APPEAL pilot data, we generated a report for each participant based on their measured function. These individualized reports were then delivered via email (PDF) or mail (paper) to the 59 eligible individuals who had participated in the APPEAL pilot study and were still alive, along with a link to an online survey or paper survey. Of these, 47 (79.7%) consented and completed a survey ($n=42$ online; $n=5$ paper) about the comprehension, utility, and acceptability of their individualized report (see Supplement for complete survey). Participants were oriented to each section of the report (each section representing one domain of functioning, *e.g.*, ADLs or “What Can You Do?”) and instructed to respond to survey items only about that section throughout. Participants were given no other information beyond that contained in the report and survey. Data were collected in 4/19–9/19 and managed in REDCap.²³ The Emory University Institutional Review Board approved the study protocol (Protocol No. 104581), and all participants provided informed consent prior to completing the survey.

Study Variables

Comprehension of the report.—For each section of the report, participants were asked “How easy was it to understand your results on (section of report)?” assessed on a Likert scale, scored 1–5, with higher scores representing greater difficulty with interpretation

Results

Participant Characteristics

Table 1 shows that overall mean age of the participants was 49.6 years; 91.5% of the participants were female, and 78.7% were Black. Participants were highly educated (59.6% with a college degree), and 93.6% spoke English as their primary language. Participants reported performing an average of 5.3 (maximum, 6) and 6.9 (maximum, 8) basic and instrumental activities of daily living independently and without difficulty. Nearly half (44.7%) of the participants reported falling at least once in the past year, and 10.6% had a fear of falling during daily tasks. Both self-reported physical functioning (t-score, 40.3) and overall fluid cognition scores (adjusted t-score, 40.9) were, on average, about 1 SD below the general population (with 42.6% being < 40). The mean overall physical performance score was 8.9 (maximum, 12.0), and the mean life space assessment score, assessing community mobility, was 52.5 (maximum, 120).

Comprehension of the Report

Most participants described the sections of the report as easy to understand (70.2–85.1% very easy, Figure 1; 88.4–93.6% very or somewhat easy). Few (0.0–4.2%) respondents described these sections as very or somewhat difficult to understand (Figure 1). Although no differences were statistically significant, there were patterns of lower reported ease of interpretation among participants of Black vs. other race (*e.g.*, 64.9% vs. 90.0% finding the activities of daily living section to be very easy to understand); female vs. male sex (*e.g.*, 67.4% vs. 100% finding the activities of daily living section to be very easy to understand); and lower vs. higher cognitive functioning scores (*e.g.*, 75.0% vs. 92.6% finding the falls section to be very easy to understand; Table 2). In general, ease of understanding did not differ by older vs. younger age. Across sections, some participants reported difficulty with scales, scoring, numbers, and charts (8.5–12.8%), but few reported difficulties in understanding wording or the use of color (Table 3). No participants noted reasons for difficulty in free-text responses that were not already in the options provided. Additionally, 85.1% of respondents reported that the information on the back of the report (which included basic information about the measures; a list of potential types of providers the participant might wish to consult if they had concerns about their functioning; and contact information for the study team in the event of questions; see Supplementary Figure) was “very” or “somewhat” easy to understand.

Utility of the Report

About two-thirds to three-quarters (63.8–74.5%) described the sections of the report as useful for treatment or care planning (Figure 2). Again, no differences across participant characteristics were statistically significant, but there were patterns of lower reported usefulness of the report sections among younger participants (*e.g.*, 59.1% vs. 76.0% finding the activities of daily living section to be useful for planning) and higher vs. lower cognitive functioning scores (*e.g.*, 59.3% vs. 70.0% finding the falls section to be useful for care planning; Table 2). In general, ease of understanding did not differ by sex, and the patterns were inconsistent for race: Black vs. other participants reported higher usefulness of the physical performance section (78.4% vs. 60.0%) and lower usefulness of the self-report

physical functioning section (70.3% vs. 90.0%). Overall, participants reported that the individualized report would be useful for improving patient-provider communication (48.9–63.8%), working on improving functioning (31.9–46.8%), setting treatment goals (29.8–42.6%), and obtaining needed referrals and services (19.2–27.7%; Table 3); participants did not provide free-text responses to this item for any section. Most (95.7%) of respondents reported that the information on the back of the report (see Supplementary Figure) was “very” or “somewhat” helpful. In free-text responses, a few participants noted that it would be helpful to “include suggestions on areas to focus on” and to include “pain,” “mental cognition,” and “exercise plans” on the report as well.

Acceptability of the Report

Most participants indicated comfort with discussing the report sections with their providers (93.6–100%; Figure 3). As with ease of understanding and usefulness for care planning, there were no statistically significant differences by participant characteristics. While comfort was less frequently reported by participants of younger age and other race, differences were small and not statistically significant (Table 2). Participants most frequently reported rheumatologists (61.7–68.7%) and primary care providers (40.4–55.3%) as individuals with whom they would be comfortable discussing the various report sections (Table 3). Participants were more likely to list physical therapists (14.9%–17.0%) and other healthcare providers (12.8–17.0%) than social workers (6.4–10.6%), occupational therapists (6.4–8.5%), and mental health professionals (2.1–8.5%) as individuals with whom they would be comfortable discussing the report. Neurologists, nephrologists, palliative care providers, and orthopedists were listed by participants among other healthcare providers. Some participants also indicated they would be comfortable discussing the report with non-providers: for example, spouses (10.6–14.9%), children (10.6–14.9%), other relatives (12.8–17.0%), and friends (4.3–12.8%; Table 3). Among those who noted “other,” “caregivers,” “gym” or “personal trainer,” and “orthopedist and podiatrist” were listed in free-text responses. Finally, 87.2% reported interest in receiving a real-time individualized report during a clinical appointment and 89.1% expressed willingness to arrive early for an appointment to complete the needed assessments, respectively. At least half of participants (53.6%) would be willing to repeat the measurements to receive a report every 3 months; 78.7% and 93.6% would be willing to complete the assessments every 6 months and annually, respectively.

Discussion

In this exploration of an individualized physical functioning report for individuals with SLE, we found that the comprehension, utility, and acceptability of the reports by the participants receiving them were high. Most participants reporting the sections of the report to be easy to understand (with about three-quarters reporting “very easy”), although we found that some groups (particularly participants who were Black, female, or who had lower fluid cognition scores) were less likely to report ease of understanding across sections of the report; however, no differences were statistically significant. About two-thirds to three-quarters of participants reported that the various sections of the report were useful for care planning, although younger participants and participants with higher cognitive functioning were less

likely to indicate the report's usefulness for these tasks. Nearly all participants found the report to be acceptable, as measured by reported comfort in discussing the report with their providers and willingness to have functioning assessed frequently and in real-time.

While our results suggest that the report is easy to understand overall, there are several issues to consider in the comprehension of the report. It is possible that participants overestimate their comprehension of the report or do not wish to admit where they fail to understand the report; further, these phenomena may differ by participant characteristics and partially explain some of the patterns of comprehension we reported. These patterns also suggest that some groups (Black and female patients and those with lower cognitive functioning) may benefit more from targeted education along with the delivery of the report, together with changes to increase ease of comprehension for all users of the report. Some participants did note that numeric elements of the report (such as numbers, scales, and charts) were more difficult to understand than the wording and color gradations ("red=bad, green=good"). This is consistent with the qualitative feedback on a hypothetical cognitive functioning report that we recently gathered in this population.²⁵ It may also reflect issues with low health numeracy, which may be more prevalent than low health literacy in SLE.²⁶ Furthermore, this information provides additional targets for improvement of the report and for individualized education with respect to the delivery of a functioning report. It is important to note, however, that, although participants indicated remembering assessments that were reflected on their individualized reports >80% of the time, at least 2.5 years had passed since their assessment. This report is ultimately designed to be delivered in real time and in a setting with a care provider, who could also be trained and provide education and feedback to the participant, both of which could help increase comprehension.

Overall, most, but not all, participants found the various report sections to be useful for care planning, suggesting the individualized report has utility. While participants were not asked about specific aspects of care planning in the survey, examples of what might be discussed include: starting stopping medications, or tapering medications (including over-the-counter medications); designing an individualized exercise plan that takes SLE activity and burden into account; and scheduling preventive care and needed referrals and follow-up visits. Participants who were younger and had higher cognitive functioning were less likely to find the report useful, which may reflect a lack of understanding that functioning is a result of multiple factors including, but not limited to, age, regardless of the measures being traditionally "geriatric." Additionally, patients who found the report less useful may be less likely to consider functioning as part of overall health or critical to their medical and self-care planning. In fact, while 49–64% thought the report could improve communication between patient and provider, fewer thought the report could help them set care goals (30–43%) or obtain needed health referrals and services (19–28%).

The individualized report had high acceptability for use in the clinical setting, in that the vast majority of participants were comfortable with discussing the report with care providers, with no substantial differences in this comfort by participant characteristics. Among the specific providers with whom the participants would feel comfortable discussing the report, rheumatologists were most frequently identified, suggesting that many patients would like rheumatologists to be aware of their functioning by these various measures as part of

their overall health. Importantly, participants infrequently noted they would be comfortable discussing the report with some providers who could use functioning information to help improve patients' day-to-day functioning, such as occupational therapists²⁷; this may highlight a gap in SLE patient understanding of the potential resources available to maximize function and improve quality of life.

This survey suggests potentially high comprehension, utility, and acceptability of the report among SLE patients, but the perspectives of SLE providers, which were not collected in this pilot study, are important for the use of this report in future pragmatic studies and/or in the clinic. While comprehension of the measures is likely to be higher amongst care providers, certain numeric aspects of the report will likely be novel and require some training to increase provider comfort with explaining the report to patients; it is also possible that the report will be less well-accepted by providers than by patients, or that some or all aspects of the report will not be considered useful or intervenable enough to overcome the limitations (primarily, lack of time), as reported in our dialysis study.¹⁴ In our recent qualitative study of a hypothetical cognitive report, providers noted that functioning reports may be difficult to address for sole SLE providers without the resources available at a large practice or academic setting.²⁸ Future studies to assess the effectiveness of the report should include provider feedback and consider providing mechanisms of multidisciplinary team support. Reports that include additional important measures of disability (such as the Stanford Health Assessment Questionnaire Disability Index²⁹) and health-related quality of life (Functional Assessment of Chronic Illness Therapy³⁰) could also be explored.

This study has other limitations beyond those noted above. The sample size is small and from a single region, which limits generalizability. Importantly, the associated lack of power also limits our ability to uncover patterns by important participant characteristics such as race and gender and to explore patterns across multiple response levels (vs. dichotomized responses), both of which could help further guide implementation. Participants' reports reflected functioning from the pilot study, which may not reflect participants' current functioning; it is possible that gaps between prior and current functioning affected how participants reported comprehension, utility, and acceptability. Although images and colors were used in the report in addition to words, it is important to note that other cohorts who are less educated or less likely to speak English as a primary language may have reported more difficulty with comprehension. While free-text responses revealed some additional information about barriers to report utility, it is possible that participants have other barriers to using the report, such as the perceived costs of potential provider suggestions, referrals, or services. The repetitive nature of the questions across the sections of the report may have resulted in similar intra-individual answers, although there was variation across sections, suggesting participants did consider sections individually. Finally, while our report covers multiple domains of functioning, it is not a complete picture of functioning, which would also include cognitive functioning. However, we are only in the early phases of developing such a report^{25,28} and have not yet enabled the generation of reports directly from the cognitive data.

Despite these limitations, our results suggest that our individualized functioning report is easy to understand, useful, and acceptable to a majority Black and female group of SLE

patients. The exploratory data reported here on this novel resource can support future studies that further explore patient and provider assessment of functioning reports; develop and provide targeted, relevant educational materials for both patients and providers; improve upon report presentation and delivery; and determine whether the delivery of a similar report can help improve patient-provider communication, facilitate shared decision-making, and, ultimately, improve patient-centered outcomes in SLE.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

We thank the participants of the APPEAL pilot study. This work was accepted at the canceled American Geriatrics Society 2020 Annual Scientific Meeting, originally scheduled for May 7–9, 2020, in Long Beach, California.

Financial Support:

This work was supported by the Department of Defense Congressionally Directed Medical Research Programs (CDMRP) Lupus Research Program (Award No. W81XWH-18-1-0619, to L.C.P.). The APPEAL pilot was supported in part by PHS Grant UL1TR000454 from the Clinical and Translational Science Award Program, National Institutes of Health, National Center for Advancing Translational Sciences Emory University. The GOAL cohort is currently supported by the Centers for Disease Control and Prevention (CDC) Grant U01DP006488 (to S.S.L. and C.D.). REDCap is supported by UL1TR000424. The funders had no role in the design of the study or collection, analysis, and interpretation of data or in writing the manuscript.

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Significance and Innovations

- To address not only the comprehensive measurement of functioning but also patient-provider communication about related preferences and goals in SLE care, we created a novel, app-based, patient-friendly functioning report, including sections addressing multiple domains of functioning (activities of daily living, falls, physical performance, perceived physical functioning, and community mobility)
- In general, we found that comprehension (patient-perceived ease of interpretation=70.2–85.1%), utility (usefulness for care planning=70.2–80.5%), and acceptability (comfort with discussing the report with providers=93.2–100%) were high across all report sections, among the majority Black and female group of SLE patients who received individualized reports
- Results from this descriptive pilot study can help improve individualized functioning reports for SLE and inform studies to determine how patient-provider communication in clinical encounters may be improved with such reports

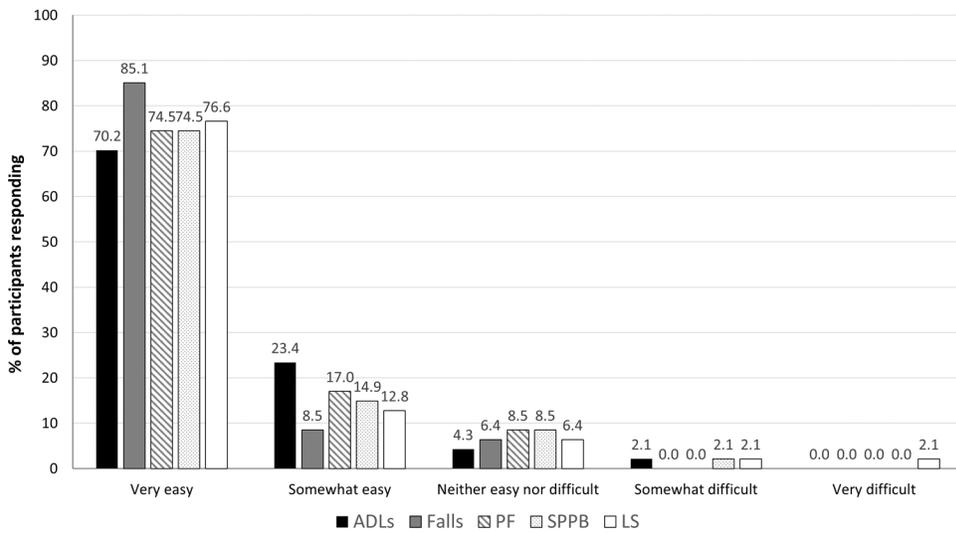


Figure 1. Ease of interpretation of report, by sections of the individualized report. ADLs, activities of daily living; PF, physical functioning (self-reported); SPPB, short physical performance battery; LS, life-space score.

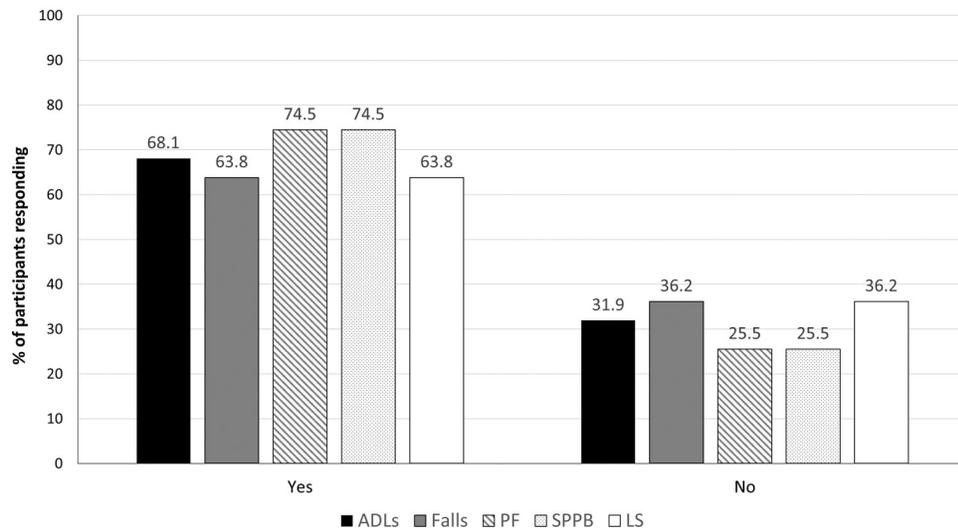


Figure 2. Usefulness of report for care planning, by sections of the individualized report. ADLs, activities of daily living; PF, physical functioning (self-reported); SPPB, short physical performance battery; LS, life-space score.

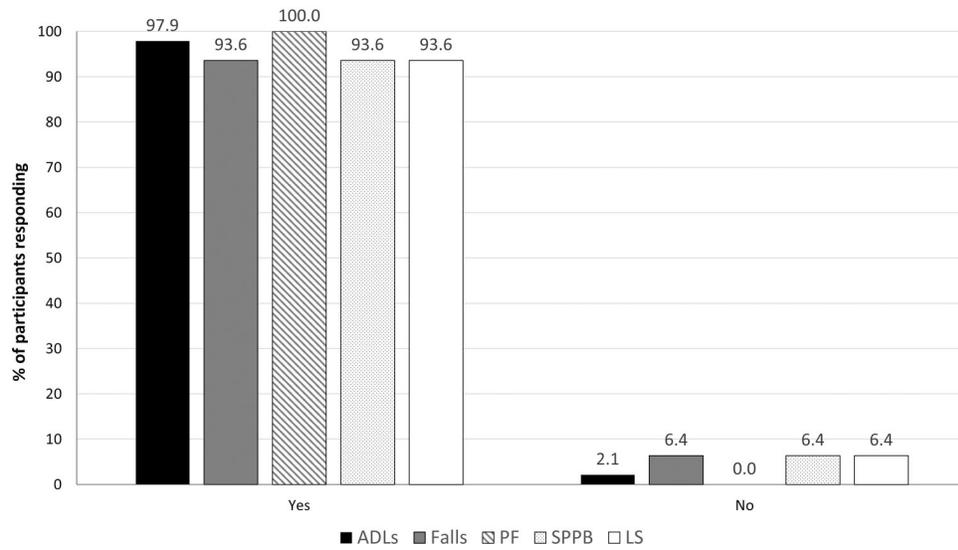


Figure 3. Comfort in discussion of report with healthcare provider(s), by sections of the individualized report. ADLs, activities of daily living; PF, physical functioning (self-reported); SPPB, short physical performance battery; LS, life-space score.

Table 1.

Characteristics of individuals with systemic lupus erythematosus who participated in survey (4/19–9/19) regarding individualized physical functioning reports.

Characteristic	Mean (SD) or <i>n</i> (%)
<i>N</i>	47
Age at survey, mean (SD)	49.6 (12.3)
Sex	
Male	4 (8.5%)
Female	43 (91.5%)
Race, <i>n</i> (%)	
Black	37 (78.7%)
White	7 (14.9%)
Other	3 (6.4%)
Education, <i>n</i> (%)	
Less than high school	2 (4.3%)
High school graduate/some college	17 (36.2%)
College graduate	28 (59.6%)
Primary language spoken, <i>n</i> (%)	
English	44 (93.6%)
Spanish	3 (6.4%)
Physical functioning as presented on individualized report*	
No. basic activities of daily living performed with no difficulty, mean (SD)	5.3 (1.1)
No. instrumental activities of daily living performed with no difficulty, mean (SD)	6.9 (1.3)
1 fall in the past year, <i>n</i> (%)	21 (44.7%)
Fear of falling, <i>n</i> (%)	5 (10.6%)
Self-reported physical functioning t-score, mean (SD)	40.3 (9.4)
Short Physical Performance Battery score, mean (SD)	8.9 (2.4)
Life Space Assessment (community mobility) score, mean (SD)	52.5 (35.0)
Overall fluid cognition adjusted t-score, ** mean (SD)	40.9 (12.5)
Lower cognitive function, ** <i>n</i> (%)	20 (42.6%)

* Measured in 2016–2017 during the pilot study. Reported are the mean number of basic (maximum: 6) and instrumental (maximum: 8) activities of daily living^{17,18} for which participants reported no difficulty. Fear of falling assessed via the Falls Efficacy Scale¹⁹ (scale, 0–100), which measures confidence in performing a range of activities of daily living without falling; a score of 70 or above indicates that an individual has a fear of falling. Self-reported physical functioning assessed via the PROMIS Physical Functioning Short Form 12a,²⁰ and raw scores were scaled to t-scores, such that 50 = average score for a general adult population and 10 = 1 SD; higher scores = better self-reported physical functioning. Short Physical Performance Battery²¹ scores (scale, 0–12) include assessments of balance, lower body strength, and gait speed; higher scores = better physical performance. The UAB Study of Aging Life Space Assessment²² (scale, 0–120) captures community mobility and social participation; higher scores = greater life-space mobility.

** Overall NIH Toolbox fluid cognition score²⁴ measures the capacity to reason and solve novel problems. Raw scores were scaled to adjusted t-scores, such that 50 = average score for the adult population of the same age, race, sex, and educational attainment; and 10 = 1 SD. Higher scores = better fluid cognition. Lower cognitive function defined as t-score < 40.

Table 2.

Self-reported ease of interpretation, usefulness of discussion, and comfort in discussion, across sections of report, overall and by patient characteristic*

Characteristic	Section of report				
	Activities of daily living	Falls	Self-reported physical functioning	Physical performance	Community mobility
Ease of interpretation**					
By age					
<50 years	68.2%	81.8%	77.3%	81.8%	77.3%
50 years	72.0%	88.0%	72.0%	68.0%	76.0%
<i>P</i>	>0.9	0.7	0.7	0.3	>0.9
By race					
Black	64.9%	83.8%	73.0%	70.3%	75.7%
Other	90.0%	90.0%	80.0%	90.0%	80.0%
<i>P</i>	0.2	>0.9	>0.9	0.4	>0.9
By sex					
Female	67.4%	83.7%	74.4%	72.1%	74.4%
Male	100%	100%	75.0%	100%	100%
<i>P</i>	0.3	>0.9	>0.9	0.6	0.6
Cognitive Functioning***					
Lower	60.0%	75.0%	65.0%	65.0%	70.0%
Higher	77.8%	92.6%	81.5%	81.5%	81.5%
<i>P</i>	0.2	0.1	0.3	0.3	0.5
Usefulness for treatment/care planning**					
By age					
<50 years	59.1%	59.1%	68.2%	72.7%	59.1%
50 years	76.0%	68.0%	80.0%	76.0%	68.0%
<i>P</i>	0.3	0.6	0.5	>0.9	0.6
By race					
Black	70.3%	62.2%	70.3%	78.4%	64.9%
Other	60.0%	70.0%	90.0%	60.0%	60.0%
<i>P</i>	0.7	0.7	0.4	0.3	>0.9
By sex					
Female	67.5%	62.8%	74.4%	74.4%	65.1%
Male	75.0%	75.0%	75.0%	75.0%	50.0%
<i>P</i>	>0.9	>0.9	>0.9	>0.9	0.6
Cognitive Functioning***					
Lower	65.0%	70.0%	85.0%	80.0%	70.0%
Higher	70.4%	59.3%	66.7%	70.4%	59.3%
<i>P</i>	0.8	0.5	0.2	0.5	0.5
Comfort with discussion**					
By age					

Characteristic	Section of report				
	Activities of daily living	Falls	Self-reported physical functioning	Physical performance	Community mobility
<50 years	100%	95.5%	100%	95.5%	90.9%
50 years	96.0%	92.0%	100%	92.0%	96.0%
<i>P</i>	<i>>0.9</i>	<i>>0.9</i>	—	<i>>0.9</i>	<i>0.6</i>
By race					
Black	97.3%	94.6%	100%	94.6%	94.6%
Other	100%	90.0%	100%	90.0%	90.0%
<i>P</i>	<i>>0.9</i>	<i>0.5</i>	—	<i>0.5</i>	<i>0.5</i>
By sex					
Female	97.7%	93.0%	100%	93.0%	93.0%
Male	100%	100%	100%	100%	100%
<i>P</i>	<i>>0.9</i>	<i>>0.9</i>	—	<i>>0.9</i>	<i>>0.9</i>
Cognitive Functioning ^{***}					
Lower	95.0%	96.3%	100%	90.0%	90.0%
Higher	100%	90.0%	100%	96.3%	96.3%
<i>P</i>	<i>0.4</i>	<i>0.6</i>	—	<i>0.6</i>	<i>0.6</i>

* Comparisons by two-sided Fisher's exact test.

** Ease of interpretation dichotomized as very easy vs. all other responses; usefulness of and comfort with discussion defined as yes vs. no.

*** Higher vs. lower cognitive functioning was defined as an adjusted fluid cognition t-score of ≥ 40 vs. <40 .

Table 3.

Summary of other feedback on individualized report sections, by section of report.

Survey item	Section of report				
	Activities of daily living	Falls	Self-reported physical functioning	Physical performance	Community mobility
Recall measurement during pilot	41 (87.2%)	39 (82.3%)	43 (91.5%)	43 (91.5%)	42 (89.4%)
Difficulty with: *					
Scale	4 (8.5%)	—	5 (10.6%)	6 (12.8%)	—
Scoring	3 (6.4%)	—	6 (12.8%)	6 (12.8%)	—
Colors	0 (0.0%)	—	0 (0.0%)	0 (0.0%)	1 (2.1%)
Wording	2 (4.3%)	2 (4.3%)	1 (2.1%)	—	2(4.3%)
Numbers	—	5 (10.6%)	—	—	—
Picture	—	—	—	0 (0.0%)	1 (2.1%)
Chart	—	—	—	—	8 (17.0%)
Other	5 (10.6%)	1 (2.1%)	3 (6.4%)	4 (8.5%)	2 (4.3%)
Comfortable discussing report with: *					
Rheumatologist	32 (68.1%)	29 (61.7%)	34 (72.3%)	32 (68.1%)	29 (61.7%)
Primary care provider	25 (53.2%)	19 (40.4%)	26 (55.3%)	21 (44.7%)	19 (40.4%)
Social worker	5 (10.6%)	4 (8.5%)	5 (10.6%)	3 (6.4%)	4 (8.5%)
Physical therapist	7 (14.9%)	7 (14.9%)	7 (14.9%)	7 (14.9%)	8 (17.0%)
Occupational therapist	3 (6.4%)	4 (8.5%)	4 (8.5%)	3 (6.4%)	3 (6.4%)
Mental health provider	4 (8.5%)	2 (4.3%)	1 (2.1%)	2 (4.3%)	3 (6.4%)
Other provider	6 (12.8%)	7 (14.9%)	8 (17.0%)	8 (17.0%)	7 (14.9%)
Spouse	7 (14.9%)	7 (14.9%)	7 (14.9%)	5 (10.6%)	6 (12.8%)
Child	7 (14.9%)	5 (10.6%)	7 (14.9%)	6 (12.8%)	6 (12.8%)
Other relative	8 (17.0%)	9 (19.2%)	9 (19.2%)	6 (12.8%)	7 (14.9%)
Friend	6 (12.8%)	4 (8.5%)	4 (8.5%)	2 (4.3%)	4 (8.5%)
Spiritual advisor	2 (4.3%)	1 (2.1%)	1 (2.1%)	1 (2.1%)	2 (4.3%)
Employer	2 (4.3%)	1 (2.1%)	2 (4.3%)	1 (2.1%)	2 (4.3%)
Other	2 (4.3%)	0 (0.0%)	1 (2.1%)	1 (2.1%)	2 (4.3%)
Purpose in discussing reports: *					
Improve communication with provider	28 (59.6%)	23 (48.9%)	30 (63.8%)	29 (61.7%)	27 (57.5%)
Obtain needed referrals and services	9 (19.2%)	11 (23.4%)	13 (27.7%)	10 (21.3%)	11 (23.4%)
Work on improving functioning	17 (36.2%)	15 (31.9%)	22 (46.8%)	22 (46.8%)	19 (40.4%)
Set treatment goals	16 (34.0%)	14 (29.8%)	16 (34.0%)	20 (42.6%)	16 (34.0%)

* Responses were not exclusive and may total >100%.