Barriers and facilitators to physical activity for people with scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study

Running head: Barriers and facilitators

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ABSTRACT

Objective: To support physical activity among people with systemic sclerosis (SSc; scleroderma), we sought to determine the (1) prevalence and importance of barriers and (2) likelihood of using possible facilitators.

Methods: We invited 1,707 participants from an international SSc cohort to rate the (1) importance of 20 barriers (14 medical; 4 social or personal; 1 lifestyle; 1 environmental); and (2) likelihood of using 91 corresponding barrier-specific and 12 general facilitators.

Results: Among 721 respondents, 13 barriers were experienced by ≥25% of participants, including 2 (fatigue, Raynaud's) rated 'important' or 'very important' by ≥50% of participants, 7 (joint stiffness and contractures, shortness of breath, gastrointestinal problems, difficulty grasping, pain, muscle weakness and mobility limitations, low motivation) by 26-50%, and 4 by <26%. Overall, 23 (18 medical-related) of 103 facilitators were rated by ≥75% as 'likely' or 'very likely' to use among those who experienced corresponding barriers; these facilitators focused on adapting exercise (e.g., using controlled, slow movement), taking care of one's body (e.g., stretching), keeping warm (e.g., wearing gloves), and protecting skin (e.g., covering ulcers). Among those who had previously tried the facilitator, all facilitators were rated by ≥50% as 'likely' or 'very likely' to use; among those with the barrier who had not tried the facilitator, only 12 of 103 were rated by >50% as 'likely' or 'very likely'.

Conclusion: Medical-related physical activity barriers were common and considered important. Facilitators considered as most likely to be used involved adapting exercise, taking care of one's body, keeping warm, and protecting skin.

Significance and Innovations

- Based on a survey of 721 people with scleroderma, barriers to physical activity most commonly considered important involved compromised hand dexterity or condition (e.g., Raynaud's phenomenon), general symptoms (e.g., fatigue) or localized symptoms (e.g., gastrointestinal problems), and low motivation.
- Barrier-specific physical activity facilitators most likely to be used addressed adapting the exercise type or setting; using health behaviours to take care of the body; and strategies to keep warm and protect the skin.
- Generally, participants who experienced the barrier and had tried the linked facilitator were likely to use it, whereas participants who experienced the barrier and had not tried the linked facilitator were not likely to use it.
- Health care providers can use facilitators identified in this study to adapt physical activity options so that people with scleroderma can overcome barriers to physical activity.

Systemic sclerosis (SSc; scleroderma) is a rare chronic, autoimmune rheumatic disease characterized by abnormal fibrotic processes and excessive collagen production that can affect the skin, musculoskeletal system, and internal organs, including the heart, lungs, and gastrointestinal tract (1, 2). People with SSc experience significantly lower health-related quality of life in comparison to the general population (3). Disease onset typically occurs at around 50 years, and approximately 80% of people with SSc are women (4, 5).

Although regular physical activity is important to enhance health for all people (6, 7), including those with autoimmune rheumatic diseases (8), people with SSc experience a wide range of barriers that may impede engagement. Data from a large international SSc cohort demonstrated that approximately 50% of patients were physically inactive, and patients who were active rarely engaged in activities other than walking (9). That study and other studies on physical activity in SSc (10-12) have not addressed barriers or facilitators to being physically active.

For health care providers to advise SSc patients on how to be physically active, they need to be able to identify possible facilitators, or strategies, to overcome specific barriers faced by individual patients. We previously conducted a nominal group technique study to identify barriers to physical activity, along with potential facilitators, experienced by people with SSc (13). That study included only 41 people, which did not allow conclusions to be drawn about the prevalence of barriers and likelihood that people with SSc would use identified facilitators. The aim of the present study was to obtain information on the prevalence of barriers and perceived utility of facilitators to help tailor physical activity recommendations to the specific needs of people with SSc. Specific objectives were to determine (1) the prevalence and importance of

different barriers experienced in SSc, and (2) likelihood that people with SSc would use different patient-generated barrier-specific and general facilitators to support physical activity.

Patients and Methods

This was a cross-sectional study in which survey results from the Scleroderma Patient-centered Intervention Network (SPIN) Physical Activity Survey were deterministically linked using participant user names (email addresses) to participant sociodemographic, medical, and patient-reported outcome measure data from the ongoing SPIN Cohort.

Participants and Procedures

We surveyed participants enrolled in the SPIN Cohort. Eligible SPIN Cohort participants must be classified as having SSc according to the 2013 ACR/EULAR criteria (14); ≥ 18 years of age; fluent in English, French, or Spanish; and able to respond to questionnaires via the Internet. Eligible individuals are invited by their attending physician or supervised nurse coordinator to participate in the SPIN Cohort, and written informed consent is obtained. The local SPIN physician or supervised nurse coordinator completes a medical data form that is submitted online to initiate participant registration. After completion of online registration, an automated welcoming email is sent to participants with instructions for activating their SPIN account and completing SPIN Cohort measures online. SPIN Cohort participants complete online outcome measures upon enrollment and subsequently every 3 months.

For the present study, in July 2019 we invited active SPIN Cohort participants to complete a survey, separately from their routine cohort assessments. We sent email invitations to all 1,707 SPIN Cohort participants who had active SPIN accounts and who complete assessments in English or French. We sent follow-up emails 2, 4, and 8 weeks later to those who had not completed the survey. In addition, we advertised the survey through an announcement presented

to SPIN Cohort participants when they logged into the SPIN Cohort portal to complete their routine online assessments. To promote participation, we informed participants that one survey respondent would be randomly selected to win a trip to the 2020 SSc World Congress in Prague, Czech Republic. The email invitation and announcements provided a link to the survey on *Qualtrics* (15). In *Qualtrics*, participants entered their SPIN username (email address) in order to access and complete the survey questions. The survey was closed in October 2019. We excluded participants who only partially completed the survey. SPIN Cohort assessment data were obtained from the most recently completed assessments prior to completing the SPIN Physical Activity Survey for participants and prior to the initial survey invitation for non-participants, without time restriction.

The SPIN Cohort was approved by the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal (#MP-05-2013-150) and by the research ethics committees of each participating centre. The present study was approved as an amendment to the SPIN Cohort by the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal.

Measures

Sociodemographic and Medical Characteristics

Medical data were provided by SPIN physicians upon enrollment in the SPIN Cohort, and included time since first non-Raynaud's phenomenon symptoms, time since SSc diagnosis, SSc subtype, degree of joint contractures for small and large joints, tendon friction rubs status, interstitial lung disease status, pulmonary arterial hypertension status, Raynaud's phenomenon status, digital ulcer status (digital pulp and anywhere else on the finger), and gastrointestinal tract involvement status (esophageal, stomach, and intestinal). For each participant, we calculated the

time from when sociodemographic and medical characteristics were obtained at entry into the SPIN Cohort to survey completion.

Physical Activity

The SPIN Cohort assessment includes an item, “Compared to other people your age, how would you rate your physical activity during the past year” (physically inactive; somewhat active; moderately active; quite active; very active), followed by the item, “Do you exercise at present?” (yes; no). Among participants who reported exercising at present, 2 additional items were administered, “On the average, how many hours per week do you exercise” and “What type(s) of exercise(s) do you do?” [walking; jogging; aerobics; swimming; other (specify)]. For the “other” option, participants could indicate more than 1 type of exercise. All exercises described by participants in the “other” option were classified based on the 2011 Compendium of Physical Activities (16).

Physical Function

We used the 4-item PROMIS Physical Function 4a v2.0 to evaluate self-reported physical activity capability. Each item is scored on a 5-point scale (1-5), where higher scores reflect better physical function over the previous 7 days. The total score is obtained by converting the sum of raw item scores into T-scores standardized from the general United States population [mean = 50, SD = 10]. The PROMIS Physical Function 4a v2.0 has been validated in SSc (17-19).

Functional Disability

The Disability Index of the Health Assessment Questionnaire (HAQ-DI) assesses 8 disability categories over the past 7 days. Each item is rated on a 4-point scale, ranging from 0 (without any difficulty) to 3 (unable to do), where higher scores reflect greater functional

disability. The highest score from each category determines the score for that category, and the total score is the mean of the 8 category scores, ranging from 0 (no disability) to 3 (severe disability). The HAQ-DI is a valid measure of functional disability in SSc (20).

SPIN Physical Activity Survey

We developed the SPIN Physical Activity Survey (see Supplemental Appendix A) to evaluate whether possible physical activity barriers are experienced and, if so, their importance, and to evaluate possible facilitators for likelihood of use. An initial list of barriers and facilitators was generated via 9 nominal group technique interview sessions with 41 people with SSc at patient conferences in Canada, the United States, and France (13). Study investigators consolidated overlapping items, reworded unclear items, and excluded vague or unrelated items. Next, the 9-member SPIN Physical Activity Patient Advisory Team and SPIN-affiliated health care providers made recommendations to reword, exclude, or add barrier and facilitator items. The item list included 20 barriers classified into 4 categories (21);14 were health and medical barriers; 4 social and personal; 1 time, work, and lifestyle; and 1 environmental. There were 91 barrier-specific facilitators and 12 general facilitators. Patient advisors pilot tested the survey and provided feedback on usability; survey instructions were revised accordingly. The survey was then translated into French using a standard forward–backward translation process (22).

In the survey, to reduce burden, participants were asked to select up to 10 of the 20 total barriers that they have experienced and believe are important for them, to initially order selected barriers from most to least important by dragging them into position, and to rate each selected barrier on a 4-point Likert scale based on importance to them when thinking about or actually being physically active (not important; somewhat important; important; very important). We next presented participants with all barrier-specific facilitators that corresponded to their selected

barriers, and they rated the likelihood that they would use each barrier-specific facilitator to overcome the corresponding barrier (not likely; somewhat likely; likely; very likely) and indicated whether they had previously tried it. Participants similarly rated general facilitators. At the end of the survey, participants could provide suggestions for additional barriers and facilitators.

Data Analysis

We used descriptive statistics. We summarized continuous variables using medians (ranges) and categorical variables using percentages and listed additional barriers and facilitators provided by participants. To gain further insights, we stratified the analyses related to barriers by whether participants exercised or not, as well as sex. In addition, because we believe that those who tried a facilitator that helped their physical activity would be likely to use it again, we stratified the analyses based on the likelihood of using facilitators separately by those who experienced the barrier and previously tried the facilitator in comparison to those who experienced the barrier but had not tried the facilitator.

We classified barriers using the same 4 categories used to classify them in the NGT study where the list was generated (13). Also, based on consensus among investigators and the SPIN Physical Activity Patient Advisory Team, we applied descriptive labels in the text to similar barriers and facilitators in order to clearly and succinctly summarize results. All analyses were conducted with Microsoft Excel version 16.16.

Results

Participant Characteristics

Of 1,707 invited SPIN Cohort participants, 721 (42%) completed the full SPIN Physical Activity survey and were included in analyses; 70 who partially completed the survey were

excluded. The median (range) age was 59 (22 – 89), almost 90% were women, and almost half were employed full- or part-time (see Table 1). Median time since SSc diagnosis was 10.4 years, and approximately 40% had diffuse SSc. Approximately a third of participants were at least one standard deviation below the United States population mean on the PROMIS Physical Function 4a v2.0, and half had at least mild functional impairment (median HAQ-DI score = 0.6). As shown in Table 2, walking was performed by 47% of participants, and conditioning exercises by 26%.

As shown in Table 1, sociodemographic and medical characteristics of respondents were similar to non-respondents; the range of differences for categorical variables was 0% to 7%. However, there were some differences in physical activity characteristics between respondents and non-respondents. There was a 15% difference in the proportion who reported currently exercising (61% of respondents versus 46% of non-respondents), as well as differences in the proportion who performed specific types of exercises.

Physical Activity Barriers

There were 172 (24%) participants who experienced and selected 10 barriers for rating and 549 (76%) who selected fewer than 10; the median number of barriers selected was 7. As shown in Figure 1, there were 4 barriers, all health and medical barriers, that were experienced and selected for rating by ≥ 50% of 721 total participants, including Raynaud's phenomenon, fatigue, joint stiffness and contractures, and difficulty grasping objects. Of these, fatigue (58%) and Raynaud's phenomenon (57%) were selected for rating and classified as 'important' or 'very important' by ≥ 50% of total participants. Joint stiffness and contractures was selected and rated as 'important' or 'very important' by 49%, shortness of breath by 38%, gastrointestinal problems by 36%, both difficulty grasping objects and pain by 33%, muscle weakness and difficulty with

mobility by 29%, and lack of motivation and difficulty committing to exercise by 26%. See Supplemental Appendix B for summary of initial sorted rankings of barriers, rather than ratings, of importance.

Supplemental Appendices C and D illustrate the distribution of barrier ratings separately for participants who did (N = 433) and did not (N = 282) report presently engaging in exercise, respectively. Importance of barriers tended to be rated higher by those who did not exercise; the 3 largest differences in the percent rating barriers as 'important' or 'very important' were for lack of motivation (21% difference), fatigue (14% difference), and difficulty grasping objects (11% difference).

Supplemental Appendices E and F illustrate the distribution of barrier ratings for males (N = 81) and females (N = 640), respectively. Overall, the distributions of barrier ratings for males and females were generally similar; the two barriers with the largest differences were gastrointestinal problems (12%) and Raynaud's (10%), which both had a higher percentage of females rating the barrier as 'important' or 'very important'.

[Insert figure 1 here]

Physical Activity Facilitators

Overall, of 103 facilitators rated by participants who had experienced the linked barrier, 23 (22%) were rated as 'likely' or 'very likely' to use by ≥ 75% of participants and an additional 58 (56%) facilitators were by ≥ 50%. The full list of barriers, their facilitators, and participant ratings is available in Supplemental Appendix G. It is also accessible online as an interactive spreadsheet (https://osf.io/2mxj5/) that facilitates sorting and identifying facilitators for different barriers. Table 3 presents the 12 health and medical barriers that were experienced and selected for rating by ≥ 25% of total participants and a selection of corresponding barrier-specific

facilitators that were commonly rated as ‘likely’ or ‘very likely’ to use among those who tried them. The most common facilitators overall and among those presented in Table 3 involved strategies for adapting exercise type, conduct or setting (e.g., using controlled, slow movement); changing health behaviours to take care of the body (e.g., stretching); keeping warm (e.g., wearing gloves); and protecting the skin (e.g., covering ulcers). Supplemental Appendix H presents additional barrier and facilitator suggestions to those presented in our survey that were provided by survey respondents and were substantively different from those included in the survey.

The majority (62/103; 60%) of facilitators had been tried by ≥ 50% of participants who rated them. Among those who tried facilitators, 103/103 facilitators were rated by ≥ 50% as ‘likely’ or ‘very likely’ to use and 65/103 facilitators were rated by ≥ 80% as ‘likely’ or ‘very likely’ to use. In contrast, only 12/103 facilitators were rated as ‘likely’ or ‘very likely’ to use by ≥ 50% of participants who had not tried them previously.

Discussion

The main results of our study include prevalence of barriers to physical activity among over 700 people with SSc, along with their ratings of the importance of each barrier and of the likelihood that they would use corresponding and more general facilitators of physical activity. The most common barriers to physical activity were Raynaud’s phenomenon and fatigue, followed by compromised hand dexterity and challenges related to respiratory, gastrointestinal and skin pathologies. Among the 103 barrier-specific and general facilitators in the survey, for participants who had tried each of them, at least 50% of participants said they would be ‘likely’ or ‘very likely’ to use them to facilitate physical activity. Health care providers can use our interactive Excel spreadsheet (https://osf.io/2mxj5/) to review physical activity barriers and

identify patient-generated facilitators to address them and support physical activity among individuals with SSc.

Although this was the first study to evaluate patient-generated physical activity barriers and possible facilitators to overcome them in a large SSc sample, results are consistent with findings from previous studies. A previous study with the SPIN Cohort (n = 752) found that presently reported exercise was associated with fatigue, pain, degree of skin thickening, and functional disability (9), all of which were identified by participants in the present study as barriers. Facilitators rated widely as likely to be used for such barriers were often related to adapting the exercise form (e.g., use controlled, slow movements for pain), conduct (e.g., take rest breaks for fatigue, pain, and muscle weakness and difficulty with mobility), and equipment (e.g., use wrist weights for difficulty grasping objects). Consistent with the shortness of breath barrier, lung involvement (23) and pulmonary hypertension (24) have been found to be associated with reduced aerobic capacity in 2 small exercise studies (n = 46 and 18 SSc patients). Two of our barrier-specific facilitators (‘take rest breaks while exercising’ and ‘lower the intensity of exercise to not experience shortness of breath’) directly address reduced aerobic capacity.

Barriers outside the medical category were generally less common than medical barriers. The most common was ‘lack of motivation’, which was rated ‘important’ or ‘very important’ by 26% of total participants, followed by ‘finding time available to schedule exercise’ (16%) and ‘feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others’ (12%). While motivation- and time-related barriers have been reported as important barriers to physical activity in the general population (25, 26), the barrier about feeling embarrassed or discouraged seems to more directly reflect the unique experiences of people with

SSc, particularly psychosocial consequences due to concerns about visible changes to one's appearance (27).

Sub-group analyses revealed that a substantially larger proportion of inactive than active participants had rated 2 health and medical barriers (fatigue, difficulty grasping objects) and 1 social and personal barrier (lack of motivation) as 'important' or 'very important'. These 3 barriers could be targeted when developing general interventions to promote physical activity in SSc patients.

All facilitators were rated by at least half of participants who tried them as 'likely' or 'very likely' to use. Some facilitators commonly rated as likely to be used are consistent with widely recommended strategies, such as for warming in Raynaud's phenomenon (28), and identifying enjoyable activities for people who have difficulty with motivation or exercise adherence (29). On the other hand, there were novel barrier-specific facilitators widely perceived as likely to be used that, to our knowledge, have not been reported in the literature but could be helpful for health care providers promoting physical activity to individuals with SSc. Many novel facilitators addressed adapting the exercise, either by adapting the exercise conduct, type, or setting, including 'use adapted exercise equipment' (barriers of difficulty grasping objects and joint stiffness and contractures), and 'participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising' (barrier of fear of injury or extended recovery time). Importantly, individuals with SSc should consult a qualified clinician about how to exercise safely.

In general, participants who tried facilitators rated them favourably as 'likely' or 'very likely' to use in comparison to those who had not tried them. This suggests some challenges may exist when proposing new facilitators to SSc patients. Communication skills and strategy may be

very important. A widely used intervention to support physical activity in the general population, Active Living Every Day (ALED) (30), uses a social modelling component when exposing individuals to new facilitators. This involves sharing the personal experiences of people who describe how they overcame specific barriers to leading a more active lifestyle. We expect that such social modelling would be a potentially effective strategy to promote physical activity in SSc, especially for those patients who had not tried a proposed facilitator.

Our findings suggest barriers that could be targeted to facilitate physical activity. Strategies to treat fatigue in rheumatoid arthritis include exercise, cognitive behavioural therapy, and self-management programs (31); SPIN is currently testing a SSc self-management program (SPIN-SELF) (32). Strategies to reduce the effects of Raynaud's include keeping a diary and identifying activities that trigger attacks; keeping the body and hands warm (e.g., layered clothing, gloves); and avoiding smoking (33). Limitations in mobility, which are common in the hands (34), may be addressed through hand stretches and exercises, and SPIN has developed the SPIN-HAND Program, which is available online, free-of-charge (35). Social support is a strong predictor of exercise intention and stage of behaviour change for exercise (36). Many people with SSc attend support groups (37), and the SPIN-SELF Program also contains a group component.

There are limitations to take into account in interpreting results of the present study. First, the results may not be generalizable to people who do not speak English or French, reside outside of North America and Europe, or do not have access to a device with Internet. Second, a higher proportion of respondents (61%) reported currently exercising in comparison to SPIN Cohort non-respondents (46%). Third, participants were presented with 20 possible barriers, but in order to reduce respondent burden, we only allowed them to select up to 10 barriers which

they had experienced. Almost 25% of participants selected 10 barriers and might have experienced and selected additional barriers, if that had been permitted, although these would have been of lesser importance to the participant than the ones they selected. Fourth, although participants were asked to select the barriers for rating that they experienced and feel are important, some participants rated at least one of their selections as 'not important'. Fifth, although participants rated the importance of barriers and likelihood of using facilitators, the survey did not elicit explanations for why they rated barriers and facilitators as they did. Such explanations might help to fine-tune guidance to better address physical activity difficulties experienced by individuals with SSc. Sixth, although our measure of physical activity behaviour was modelled after part of an existing validated questionnaire (38, 39), we did not administer a validated measure of physical activity behaviour, which would have allowed us to better characterize participants and to compare their physical activity behaviour with other samples. This was an effort to reduce respondent burden because there were constraints on the number of items that we were able to add to a pre-existing cohort assessment. One area of future research could include comparing general levels of physical activity behaviour in SSc patients to the published norms in the general population.

In summary, medical-related barriers to activity were most commonly experienced and considered important; Raynaud's phenomenon and fatigue were the most commonly experienced. Facilitators widely considered likely to be used addressed adapting exercise type or setting, using health behaviours to take care of the body, and using clothing or materials to protect the skin or to keep warm. Participants who had tried facilitators were generally more likely to use them again compared to participants who had never tried them. Our online interactive Excel file (https://osf.io/2mxj5/) allows health care providers to easily identify

relevant facilitators for common barriers to physical activity experienced by individuals with SSc.

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Table 1. Participant sociodemographic and medical characteristics. Percentages refer to the percent of data recorded.

Variable	**SPIN Cohort respondents (N = 721)**	**SPIN Cohort non-respondents (N = 986)**
Sociodemographic variables		
Age in years, *median (range)*	59 (22 to 89)	57 (21 to 91)
Women, *n (%)*	640 (89%)	865 (88%)
White race/ethnicity, *n (%)*	603 (85%)[a]	717 (79%)[b]
Years of education completed,[c] *median (range)*	16 (3 to 27)[d]	15 (0 to 28)[e]
Employed full- or part-time, *n (%)*	323 (46%)[d]	369 (41%)[f]
Married or living as married, *n (%)*	455 (64%)[d]	547 (61%)[f]
Geographic region, *n (%)*		
North America	429 (60%)	584 (59%)
Europe	292 (40%)	401 (41%)
Australia	0 (0%)	1 (0%)
English survey language, *n (%)*	447 (62%)	649 (69%)[g]
Medical variables		
Time in years since baseline assessment when medical data were recorded, *median (range)*	3.1 (0.4 to 5.8)	3.1 (0.4 to 6.7)
Time in years since first non-Raynaud's phenomenon symptom, *median (range)*	12.3 (0.4 to 47.3)[h]	11.3 (1.6 to 58.8)[i]

Time in years since systemic sclerosis diagnosis, *median (range)*	10.4 (0.4 to 43.8)[j]	9.8 (0.8 to 58.8)[k]
Diffuse systemic sclerosis subtype, *n (%)*	279 (39%)[l]	409 (42%)[m]
Body mass index, *median (range)*	24.0 (14.7 to 60.7)	24.6 (13.0 to 64.4)
Raynaud's phenomenon, *n (%)*	695 (98%)[n]	963 (98%)[m]
Digital ulcers (distal pulp), *n (%)*	238 (34%)[o]	364 (38%)[p]
Digital ulcers (anywhere else on the finger), *n (%)*	101 (15%)[q]	184 (19%)[r]
Current or past tendon friction rubs, *n (%)*	154 (25%)[s]	210 (24%)[t]
Moderate or severe contractures of small joints, *n (%)*	172 (26%)[u]	253 (27%)[v]
Moderate or severe contractures of large joints, *n (%)*	79 (12%)[w]	136 (15%)[x]
Any gastrointestinal involvement, *n (%)*	621 (87%)[y]	873 (89%)[z]
Interstitial lung disease, *n (%)*	228 (33%)[aa]	346 (36%)[ab]
Pulmonary arterial hypertension, *n (%)*	45 (7%)[ac]	80 (9%)[ad]
Physical function domain score of the Patient Reported Outcomes Measurement Information System (PROMIS-29) profile version 2.0, *median (range)*	43.4 (22.9 to 56.9)[ae]	41.8 (22.9 to 56.9)[af]
Total score of the Disability Index of the Health Assessment Questionnaire (HAQ-DI), *median (range)*	0.6 (0.0 to 3.0)[ag]	0.6 (0.0 to 3.0)[ah]

Due to missing data: [a] N = 714; [b] N = 912; [d] N = 708; [e] N = 900; [f] N = 903; [g] N = 935; [h] N = 666; [i] N = 899; [j] N = 697; [k] N = 939; [l] N = 713; [m] N = 979; [n] N = 711; [o] N = 703; [p] N = 970; [q] N = 692; [r] N = 944; [s] N = 618; [t] N = 865; [u] N = 673; [v] N = 934; [w] N = 657; [x] N = 918; [y] N = 706; [z] N = 983; [aa] N = 692; [ab] N = 974; [ac] N = 691; [ad] N = 937;[ae] N = 705; [af] N = 876; [ag] N = 701; [ah] N = 862.

[c] Years of education completed beginning from elementary/primary school and including all levels of formal education.

582

Table 2. Participant physical activity characteristics. Percentages refer to the percent of data recorded.

Variable	SPIN Cohort respondents (N = 715 due to missing values)	SPIN Cohort non-respondents (N = 933)
Participants' perception of their physical activity level in the past year compared to other people their age, *n (%)*		
Physically inactive	85 (12%)	155 (17%)[a]
Somewhat active	199 (28%)	316 (34%)[a]
Moderately active	233 (33%)	270 (29%)[a]
Quite active	148 (21%)	115 (12%)[a]
Very active	50 (7%)	66 (7%)[a]
Currently exercise, *n (%)*	433 (61%)	421 (46%)[b]
Average hours per week of exercise (among participants who currently exercise), *median (range)*	4 (1 to 15)[c]	4 (1 to 15)[d]
Types of exercises performed, *n (%)*		
Walking	333 (47%)	328 (35%)
Jogging	24 (3%)	25 (3%)
Aerobics	75 (11%)	64 (7%)
Swimming	59 (8%)	41 (4%)
Other	275 (39%)	209 (22%)

Categories of "other" exercises (selected participant examples in parentheses),[e] *n (%)*		
Bicycling (biking, cycling, spinning)	42 (6%)	29 (3%)
Conditioning (elliptical, gym, Pilates, stretching, tai chi, weight lifting, yoga)	183 (26%)	152 (16%)
Lawn and garden (gardening, landscaping, yard work)	16 (2%)	9 (1%)
Sports (badminton, racquetball, bowling, golf)	25 (4%)	26 (3%)
Walking (Nordic walking)	13 (2%)	9 (1%)
Water activities (aquatic classes, kayaking, pool exercises)	14 (2%)	7 (1%)
Other categories[f]	52 (7%)	12 (1%)

Due to missing data: [a] N = 922; [b] N = 921.
[c] N = 433 who reported currently exercising and their average hours per week of exercise.
[d] N = 418 who reported currently exercising and their average hours per week of exercise.
[e] Participants could indicate > 1 exercise and each exercise was classified into one category.
[f] Other categories of activities performed by ≤ 2% of participants were dancing, fishing and hunting, home activity, miscellaneous, music playing, and winter activities.

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Table 3. The 12 medical barriers experienced and selected for rating by ≥ 25% of participants, and a subset of corresponding novel and common facilitators (n = 721 total participants). See interactive Excel file (https://osf.io/2mxj5/) for the full list.

Barrier and (%) N who experienced and selected for rating	Facilitators	Tried facilitator and 'likely' or 'very likely' to use it,[a] % *(N)*
Raynaud's phenomenon 78% (564)	• Dress to stay warm (keep your core warm and cover areas of the body that become cold – e.g., wear a warm hat, gloves, or mittens)	93% (501 of 539)
	• Exercise in an area with a temperature that is comfortable for you	90% (451 of 502)
	• Wear heated or non-heated warm gloves or mittens and socks	92% (452 of 494)
	• Insert warmers (i.e., liners, or electric or chemical warmers) in gloves or mittens or socks	86% (334 of 387)
Fatigue	• Take rest breaks while exercising (e.g., between activities)	83% (333 of 403)

71% (508)		
	• Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk)	82% (235 of 286)
	• Get enough sleep and plan to take a nap during the day	80% (273 of 342)
Joint stiffness and contractures 60% (434)	• Do daily gentle stretching and exercises that move your joints through their maximum range of motion	82% (256 of 312)
	• Use controlled, slow movements that are comfortable for you	85% (263 of 309)
Difficulty grasping objects 51% (365)	• Use adapted exercise equipment (e.g., weights with a larger handle, or wrist weights)	82% (108 of 132)
Shortness of breath 47% (338)	• Lower the intensity of the exercise to not experience shortness of breath	86% (251 of 291)
Gastrointestinal problems 46% (334)	• If you have acid reflux, modify exercise positions to keep your body upright (e.g., do push-ups against the	89% (148 of 166)

	wall instead of push-ups against the ground)	
Pain 42% (300)	• Modify exercise so it does not cause pain (e.g., use lighter weights or walk slower)	87% (223 of 256)
Itching or dryness of skin 40% (289)	• Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks)	89% (223 of 251)
Muscle weakness and difficulty with mobility 36% (258)	• If you have difficulty with balance, place a hand against an immovable object (e.g., wall or pole) for support, or exercise while sitting on an immovable chair or seat	88% (151 of 172)
	• If you have difficulty with balance, use assistive devices (e.g., hiking poles)	81% (77 of 95)
Difficulty with bowel and bladder control 28% (205)	• Wear a pad or underwear designed for bowel and bladder control issues	90% (132 of 146)
Ulcers or sores on hands or feet 27% (195)	• Apply non-adhesive bandages to cover and protect ulcers or sores	92% (140 of 153)

	• Wear appropriate clothing to cover and protect ulcers or sores (e.g., gloves or mittens)	90% (148 of 165)
	• If you have foot ulcers or sores, put pads in shoes or wear specialized soles or shoes (e.g., open toe shoes)	87% (65 of 75)
Activities involving water may worsen condition of hands or skin on other areas of the body 26% (188)	• Wear a wet suit, gloves, or socks designed for water exercises to stay warm	72% (33 of 46)

[a] We present the percentage and number of participants who rated the facilitator as 'likely' or 'very likely' to use among those who experienced the barrier and had tried the facilitator. Participants rated on a 4-point Likert scale the likelihood that they would use each barrier-specific facilitator to overcome the corresponding barrier to be physically active (not likely; somewhat likely; likely; very likely).

584

Figure 1. Distribution of ratings for barriers (n = 721 total participants). Participants only rated up to a maximum of 10 barriers which they experienced and selected for rating. Using a 4-point Likert scale, they rated each of their selected barriers based on how important it is to them personally when thinking about or actually being physically active (not important; somewhat important; important; very important). Because 172 participants rated the maximum of 10 barriers, it is possible that they experienced other barriers as well. Percentages refer to the percent of 721 participants who rated the adjacent barrier as ‘important’ or ‘very important’.