

Patient research:

A systematic review to uncover meaningful concepts of physical activity for patients



CORE MEASURES *of*
PHYSICAL ACTIVITY



Digital Measures Development

Access more resources: [DATAcc's Core Measures of Physical Activity](#)

Core Set of Digital Measures of Physical Activity

Project Team Approach



Meaningful Aspects of Health

Systematic Review of Qualitative Studies

Review questions: What concepts of physical activity (PA) are globally meaningful to patients and their health care providers? How is each concept meaningful to patients and their health care providers, and under what contexts? (PROSPERO [CRD42023416708](https://www.crd42023416708))



Concepts of Interest (COIs)

Modified delphi approach to identify appropriate outcomes for PA

Selected a core set of digital measures of PA, based on readiness for adoption, by reviewing:

- **Maturity of technologies and measures** related to PA concepts of interest.
- Digital measures of PA being used in **clinical trials as endpoints**.
- **Global and US recommended** physical activity measures **for clinical care** (1,2).



Outcomes to be Measured

Core Set of Digital Measures of Physical Activity

Putting Patient Perspectives at the Center: Systematic Review of Qualitative Studies



Multi-stakeholder workshop to explore gaps, enablers, and pathways forward for physical activity



Developed and registered **protocol** for systematic review, defining search strategy and eligibility criteria



Conducted **screening and full-text review** of eligible articles



Qualitative coding and thematic analysis to identify meaningful aspects of health and concepts of interest

Putting Patient Perspectives at the Center: Systematic Review of Qualitative Studies

Protocol Available



Protocol also available [here](#).



Review Questions

Primary Question

What concepts of physical activity are globally meaningful to patients and their health care providers?

Secondary Question

How is each concept meaningful to patients and their health care providers, and under what contexts?

Putting Patient Perspectives at the Center: Systematic Review of Qualitative Studies



Primary review question: What concepts of physical activity are globally meaningful to patients and their health care providers?

Secondary review question: How is each concept meaningful to patients and their health care providers, and under what contexts?

Inclusion Criteria

- ✓ Peer-reviewed research articles.
- ✓ Perspectives of populations from selected therapeutic areas, including those living with Parkinson's disease, multiple sclerosis, chronic obstructive pulmonary disease, cancer, Duchenne's muscular dystrophy, chronic heart failure, sickle cell disease, osteoarthritis, and sarcopenia.
- ✓ Perspectives of health care professionals of patients living with the diseases indicated above.
- ✓ Studies that utilize qualitative or a mixed-methods research design.
- ✓ Studies published in multiple languages.
- ✓ Systematic reviews of qualitative research.
- ✓ Research published within the last 20 years.

Exclusion Criteria

- ✗ Articles that are not peer reviewed.
- ✗ Gray literature.
- ✗ Intervention/clinical trial studies without qualitative data collected before the intervention.
- ✗ Studies that do not utilize qualitative research methods or a mixed-methods research design.
- ✗ Animal research.

Topline Findings: Systematic Review of Qualitative Research



Meaningful Aspects of Health

The aspects of physical activity that patients described as most meaningful were related to how impairments restricted participation in activities of daily living (i.e., community & leisure, self-care and domestic activities). These meaningful aspects of health were summarized as **activities dependent on ambulation, balance-dependent activities, participating in higher-intensity activities, upper limb function, and bending or changing body positions.**



Concepts of Interest for Physical Activity

For each meaningful aspect of health, we identified measurable health concepts based on the qualitative evidence.



Contextual Factors

Participants also described health concepts of PA as being influenced by disease symptoms, functional impairments (based on ICF framework), and personal and environmental factors.



Independence

Independence emerged as a theme across therapeutic areas and health concepts: patients wanted to improve or maintain function to freely take care of themselves, do chores, and move around in the community (instrumental activities of daily living (ADLs)).



Quality of Life

Quality of life was also linked to patients' physical ability to engage in **pleasurable or enjoyable activities**, such as socializing, playing sports, and volunteering in the community (ADL).

Meaningful Aspect of Health

Ambulation

Community & Leisure Activities

Walking around a shop

Walking in a garden

Walking along the beach

Interpersonal & Relationships

Walking with a friend

Walking to social events

Domestic Activities

Walking in the home to do chores

Walking up stairs

Patients described ambulation as an important aspect of physical activity, specifically to walk outside leisurely, walk to the store, and participate in social and relationship-building activities.

"I used to go walking three times a week. My friend across the street asked me to go walking. So I told her that morning, 'I can't walk as fast as you. Just go on. Don't wait on me.' Then I got to a place where I couldn't walk anymore." (CHF patient)

"I can't go shopping. Now that everything is online, I just shop online. [...] **Because, I can't walk** for most periods of time." (Patient 14, 64 years) "I try to grocery shop. [...] there are so many times when I actually have to go sit down, because I can't make it all the way through the shop." (Patient 26, 49 years) (CHF patients)

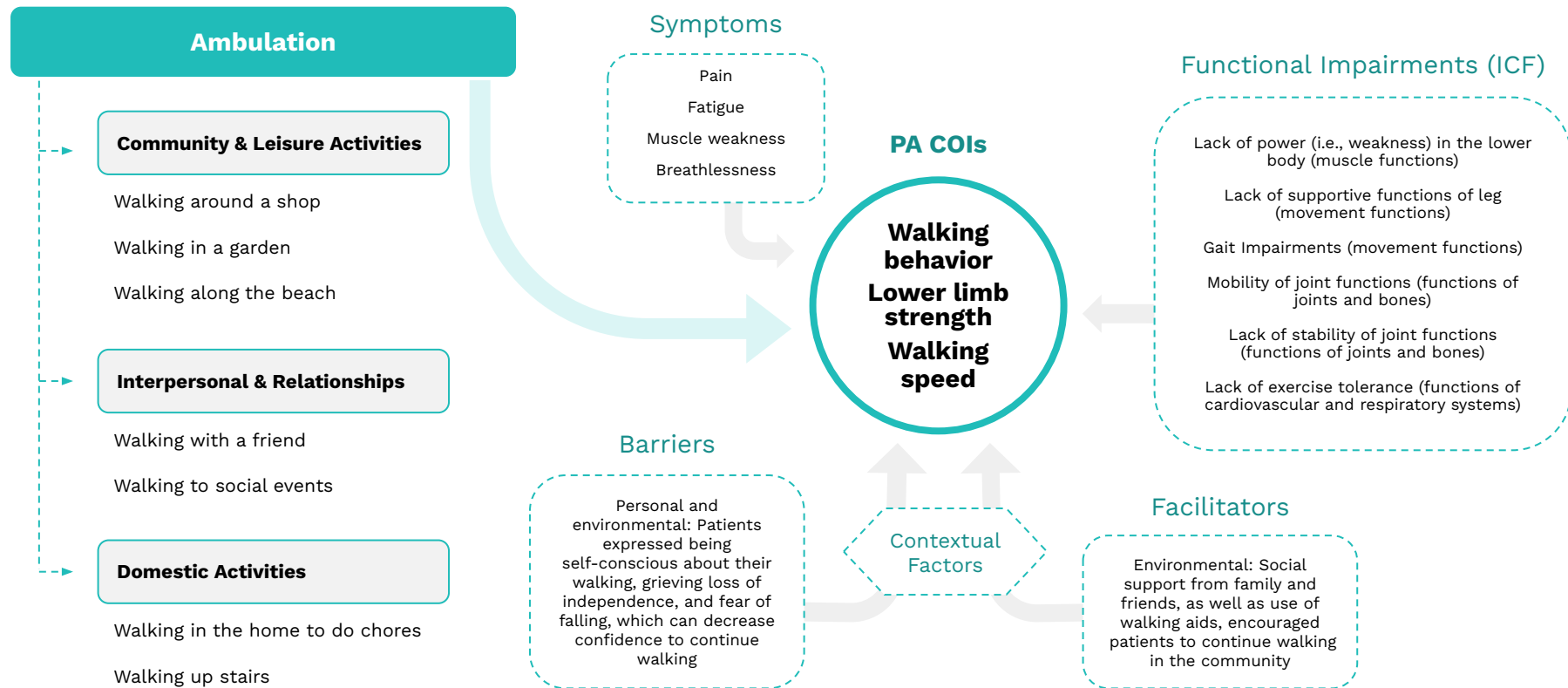
"I, you know, **could not leave, go places because I couldn't walk well** and I had to **cancel some things** that I was going to do and I **felt very self-conscious about my barely walking** and just ended up staying home. I was **concerned about tripping, falling.**" (MS patient)

Being **deprived of social activities**, such as entertainment, hobbies, traveling, sports and participating in parties had a negative impact on the quality of life (QOL) of some of the participants: **"That I cannot walk and exercise much, has made me feel that I lack something"** ... "It makes me upset that I am always at home"... A 69-year-old man said, **"I wish I could travel** and do sightseeing more frequently, but I cannot." (CHF patients)

"Quality of life, for me, is being able to walk on the beach and climbing stairs effortlessly and being able to walk." (OA patient)

Conceptual Model

Meaningful Aspect of Health*



*The term '**Meaningful Aspect of Health**' is synonymous with the term '**Health Concept**' used in the U.S. Food and Drug Administration (FDA) Patient-Focused Drug Development (PFDD) Guidance 3

Meaningful Aspect of Health

Balance-dependent activities

Community & Leisure Activities

Walking outside without falling
Having balance to play sports

Self-Care Activities

Getting out of bed without falling
Stability while getting dressed
Standing in the bathtub

Domestic Activities

Doing yard and house chores
Squatting to pick up groceries without falling
Going shopping

Patients describe having stability and balance as being an important factor to independently engage in community activities, do domestic chores and shopping, and take care of oneself. Patients also expressed how impaired balance while walking and fear of falling made some participants anxious and self-conscious.

"And because I feel short of breath so often, I am afraid to do certain things. I also **feel very dizzy and wobbly, which makes me feel insecure.**" (CHF patient)

"I now have one of those shower stools, then it's alright (showering). Because **I can't stand in the bathtub and shower – I'd fall down.**" (MS patient)

"I, you know, **could not leave, go places because I couldn't walk well** and I had to **cancel some things** that I was going to do and **I felt very self-conscious about my barely walking** and just ended up staying home. I was **concerned about tripping, falling.**" (MS patient)

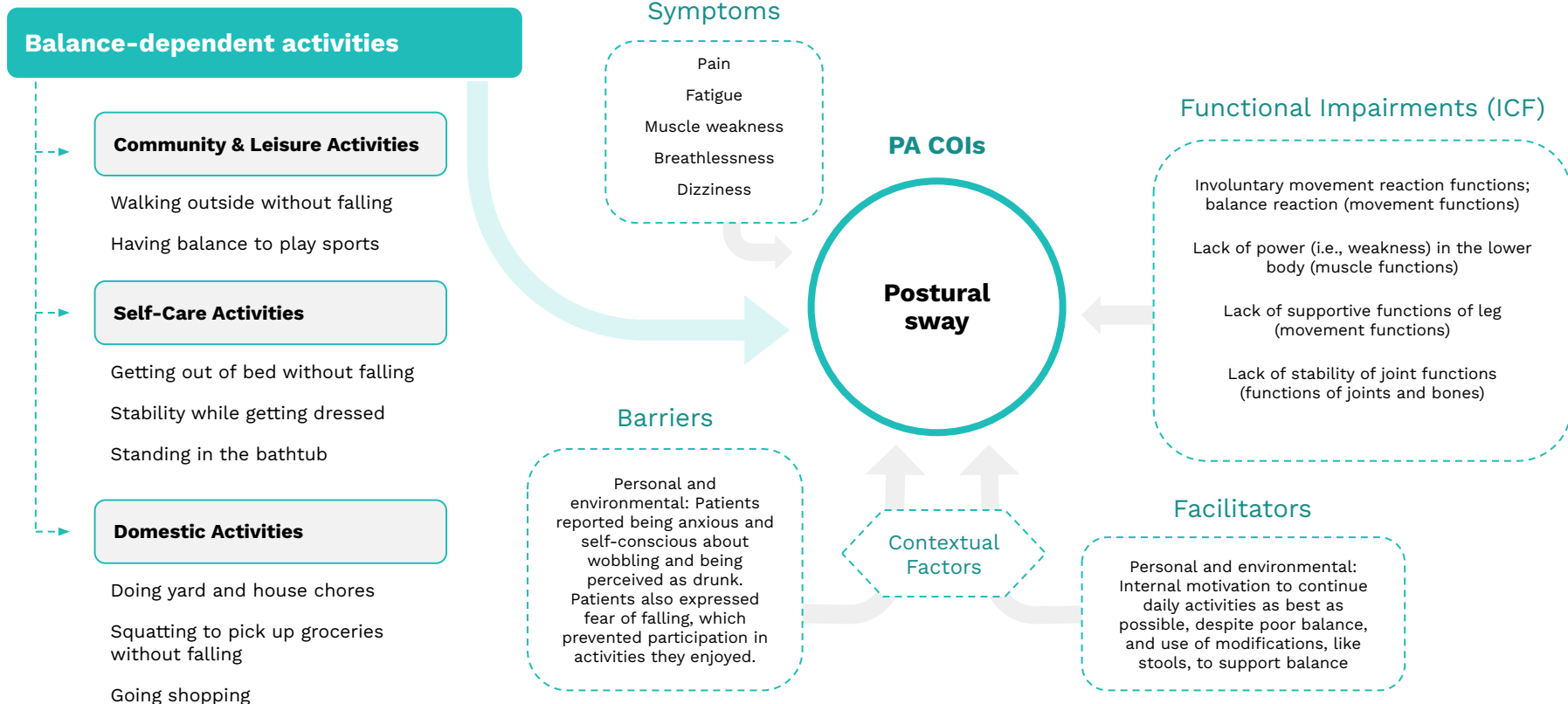
"I guess I'm a bit tentative about shopping, going out. **I'm afraid of falling again** because if you fall it makes you **a little anxious about shopping.**" (OA patient)

"...my father was, he was training people to be **ice skating**. And I said 'oh let's go!' And **then I realised I can't go** to this because my **whole leg, it's, it's going to fall down** ... I was felt scared." (MS patient)

Having an impaired balance capacity often meant having to refrain from, or adapt, one's activities. No longer being able to perform things one previously could, led to a reduced sense of freedom and independence... **"You lose the freedom to move in the way that you would like to.** That must be the biggest freedom that you have, to be able to go where you like." (PD patient)

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Meaningful Aspect of Health

Participating in higher-intensity activities

Community & Leisure Activities

Playing sports

Enjoying the outdoors

Going on runs

Exercising for health

Traveling & exploring

Helping with chores

Keeping active

Patients described ambulation as an important aspect of physical activity, specifically to walk outside leisurely, walk to the store, and participate in social and relationship-building activities. Patients also expressed how impaired balance while walking and fear of falling prevented them from participating in social activities.

“Before this heart attacked me, I could work outside all day and not feel tired at all. I walked and ran fast. I could lift or push heavy stuff without any problem. Climbing the stairs? Not a problem at all. **I enjoyed my life outdoors very much.** Now, only walking from room to room around the office makes me tired.” (CHF patient)

“I knew I was sitting a lot because I take breaks, **I would like to sit less.**” (MS patient)

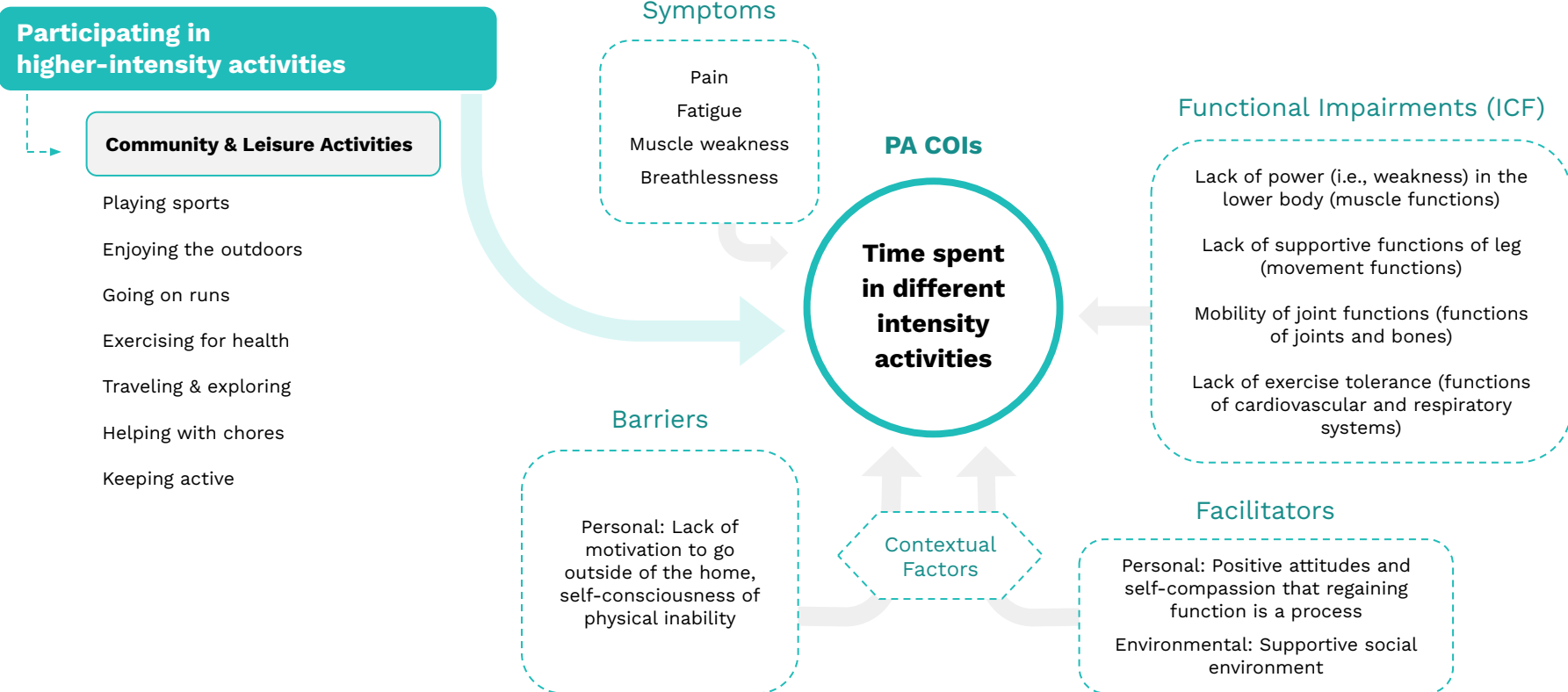
[About social activities] **“There are a lot of things I’ve had to give up,** you know. Well **playing football...** Can’t walk along the corridor, never mind run. And as I said, when you go out with **your wife and she’s carrying two big bags** and you’re walking along there with nothing, **people must say to themselves, ‘Oh look at that man his wife carrying the bags and he’s got nothing,’** but at the end of the day they dinnae ken [don’t know] what’s happening inside you!” (COPD patient)

Being deprived of social activities, such as entertainment, hobbies, traveling, sports and participating in parties had a negative impact on the QOL of some of the participants: **“That I cannot walk and exercise much, has made me feel that I lack something.”** ... and **“It makes me upset that I am always at home.”** A 69- year-old man said: “I wish I could travel and do sightseeing more frequently, but I cannot.” (CHF patient)

“Before, I liked to run once a week. I’ve stopped now because my knees felt uncomfortable and **now I do not exercise at all.**” (OA patient)

Conceptual Model

Meaningful Aspect of Health*



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Meaningful Aspect of Health

Activities needing upper limb function

Community & Leisure Activities

Playing upper body-dependent sports
Volunteering
Lifting a paintbrush

Self-Care Activities

Lifting a hairbrush
Washing one's hair
Lifting eating utensils

Domestic Activities

Putting dishes in the cupboard
Carrying a laundry basket
Pushing around a vacuum

Impairments in arm mobility and strength were related to limitations in instrumental activities of daily living, including ability to care for oneself and do household chores. Patients also had to give up participation in sports and activities of leisure requiring arm function.

"I just **wanted to be able to get more of a range with this arm** because it meant the **end of my golf**—if I couldn't swing it all the way up." ... "Obviously, **I gave up playing tennis**. I gave up playing volleyball. I can't do any of my upper extremity sports. I still ski; I just don't pole-plant anymore." (Breast cancer patient)

Upper limb impairments were described as loss of mobility and/or strength in arms, hands, and/or fingers. Some responses provided explicit examples of how loss of arm, hand, or finger function impacted day-to-day life. "**The arm weakness is a real problem for me because I cannot reach for a lot of things that I would like to reach**. It can get **frustrating** to have somebody help me every time I need to get something." (DMD patient)

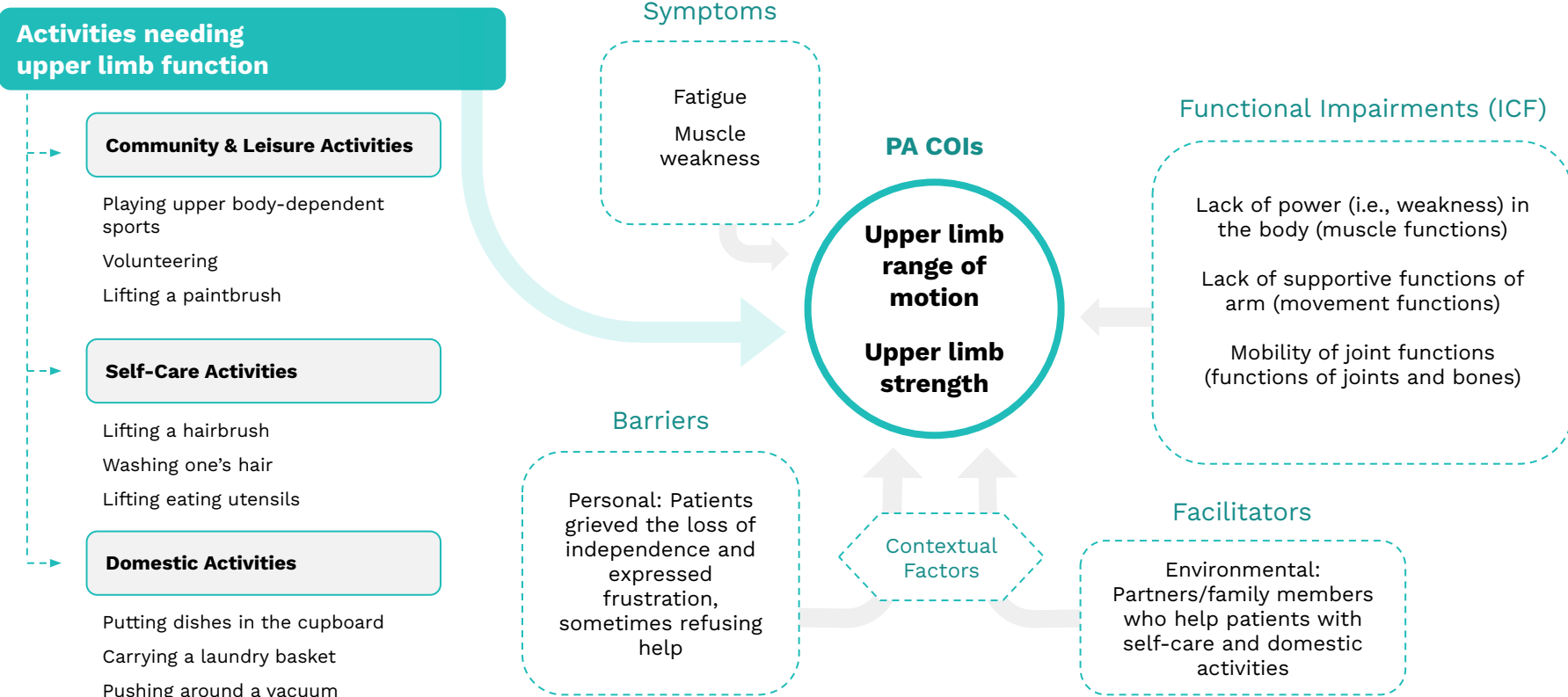
"I **don't volunteer in the library anymore because I can't pick up heavy books and put them up on the shelf**. Well, I dabbled in needlework and things like that. If I work too long, then my hands cramp up." (Sarcopenia patient)

"I also notice that **my arms get really, really tired** and—well, all of me gets tired, like **I can't wash my hair** without taking breaks because **my arms get tired**." (MS patient)

Most participants reported reduced strength, particularly in the arms: "My physical strength is gone. I used to be able to lift pretty heavy stuff, and now, it's like, **lifting a hairbrush... I'm so tired that it's... difficult**." (Breast cancer patient)

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Meaningful Aspect of Health

Bending/Change in body position

Self-Care Activities

Dressing oneself
Cleaning legs/feet

Domestic Activities

Loading the dishwasher
Making the bed
Picking things up

Impairments related to bending and changing body positions limited patients' ability to independently complete instrumental activities of daily living, including self-care and domestic activities

"[I fear] getting down [to] where I can't live by myself..." "The vacuum cleaner de-winded me; sweeping is just as bad. **I can't bend over** ... I can't raise my arms up or I lose my air, so I'm just really a helpless person." (COPD patient)

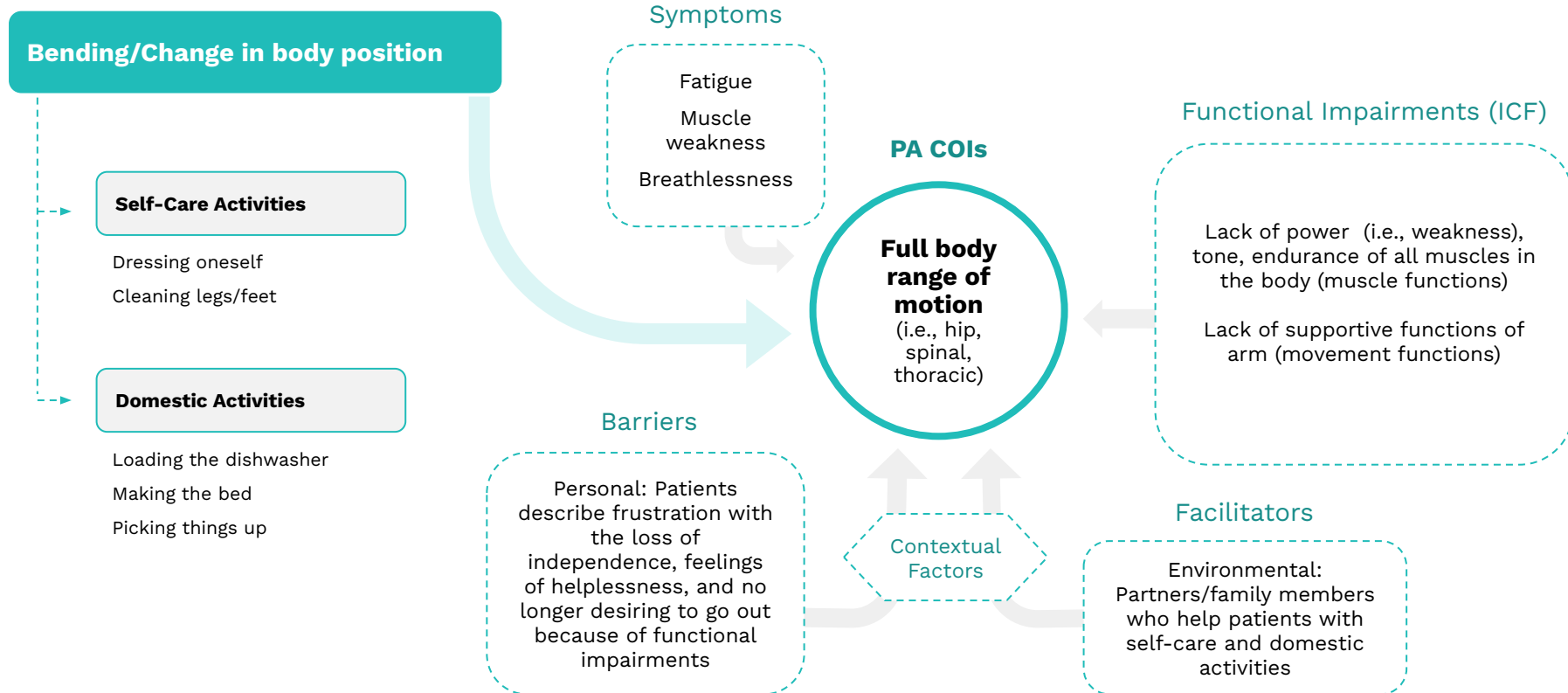
Seemingly easy activities, like washing one's hair (with arms lifted) or bending down to the floor, caused breathlessness and fatigue. **"It's hard to bend over** like this [down toward the floor]; my entire body quite simply gives out ... and I get short of breath, and have **difficulties, when I bend over like this.**" (CHF patient)

"To grab dishes out of the dishwasher, if I keep on doing the bending and standing motion (that's hard)." Participants further explained that reduced ability to squat limits picking up items such as groceries, and the combination of squatting and picking up items may result in balance issues. (Lung cancer patient)

"It would be important to be able to get up on your own and be able to move around in your home/car, or at least to be able to turn around on your own in bed." (DMD patient)

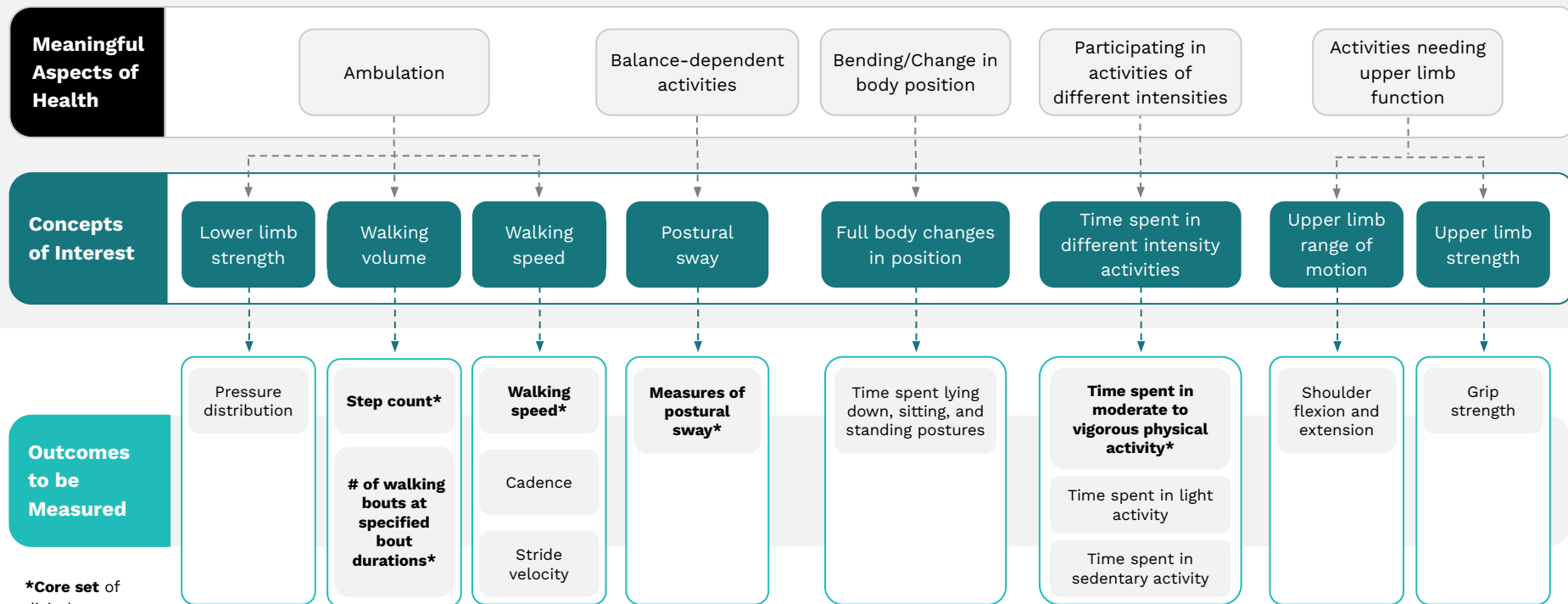
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Conceptual Model: Digital Measurement of Physical Activity



*Core set of digital measures of physical activity

Note: while outcomes outside of the core measure set were identified as meaningful during a modified delphi exercise among a multi-stakeholder group of experts, the core set represent measures with a greater readiness for clinical use (e.g., as digital endpoints or recommended by global/US health authorities) and technological/measure maturity (e.g., V3 studies published)