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Disability Experienced by People Living with HIV

Darren Brown

Chelsea and Westminster Hospital NHS Foundation Trust



@darrenabrown

Declaration of interests relating to this presentation

This presented unpublished study is funded by the National Institute for Health Research (NIHR) Masters of Research in Clinical Research. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

FUNDED BY

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for Health Research

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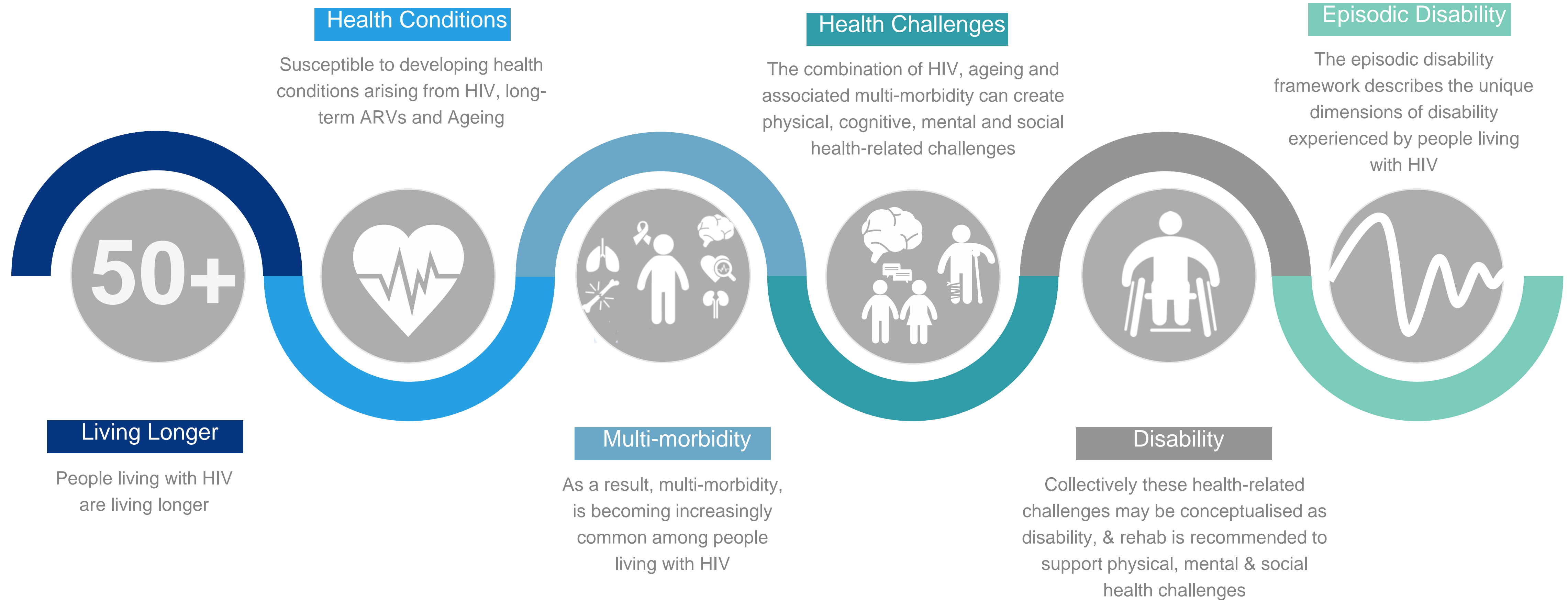
Prevalence of Disability experienced by people living with HIV in the UK

3

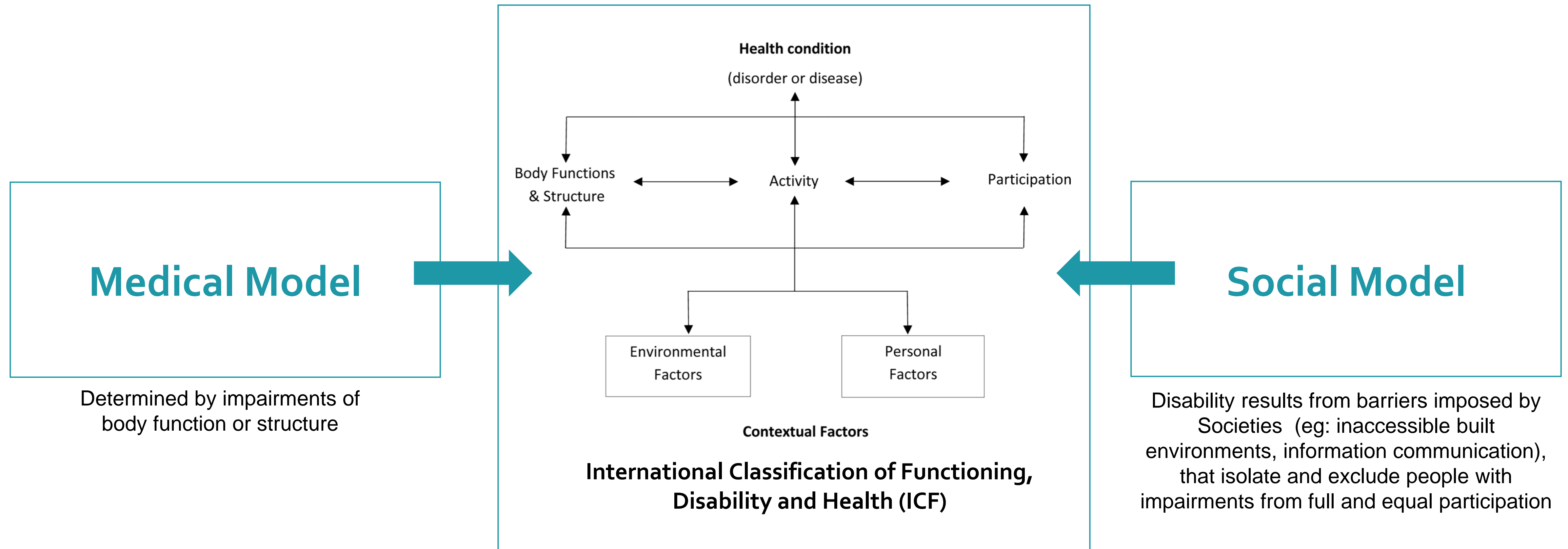
Domains of Disability experienced by people living with HIV in the UK

4

Potential risk factors of Disability experienced by people living with HIV in the UK



Defining Disability



Measuring Disability



Six Domains of Disability:

- Cognition
- Mobility
- Self-Care
- Getting Along
- Life Activities
- Participation



12-item version, self-administered

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

| In the past 30 days, how much difficulty did you have in: | | | | | | |
|---|---|------|------|----------|--------|----------------------|
| S1 | Standing for <u>long periods</u> such as <u>30 minutes</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S2 | Taking care of your <u>household responsibilities</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S3 | <u>Learning a new task</u> , for example, learning how to get to a new place? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S4 | How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S5 | How much have <u>you</u> been <u>emotionally affected</u> by your health problems? | None | Mild | Moderate | Severe | Extreme or cannot do |



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

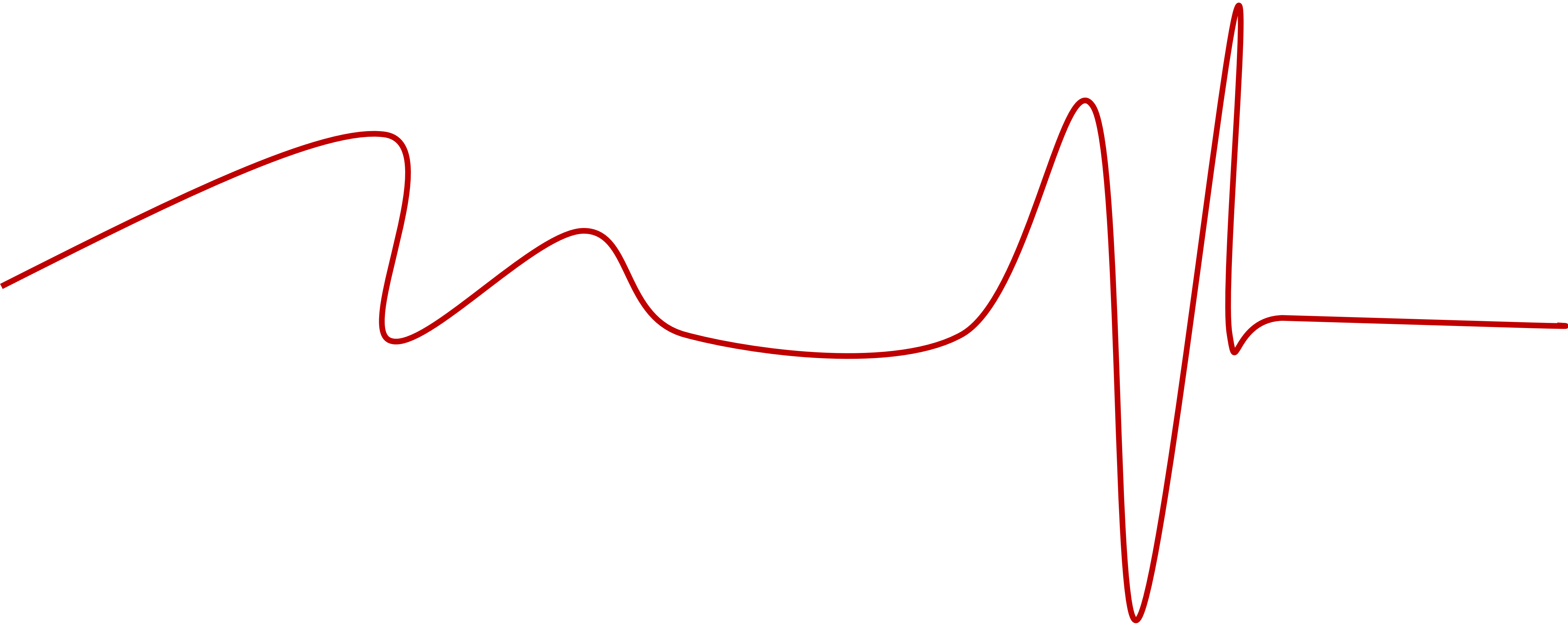
12
Self

| In the past 30 days, how much difficulty did you have in: | | | | | | |
|---|--|------|------|----------|--------|----------------------|
| S6 | <u>Concentrating</u> on doing something for <u>ten minutes</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S7 | <u>Walking a long distance</u> such as a <u>kilometre</u> [or equivalent]? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S8 | <u>Washing your whole body</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S9 | Getting <u>dressed</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S10 | <u>Dealing</u> with people <u>you do not know</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S11 | <u>Maintaining a friendship</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S12 | Your day-to-day <u>work</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |

| | | |
|----|--|-----------------------------------|
| H1 | Overall, in the past 30 days, <u>how many days</u> were these difficulties present? | Record number of days ____ |
| H2 | In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition? | Record number of days ____ |
| H3 | In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition? | Record number of days ____ |

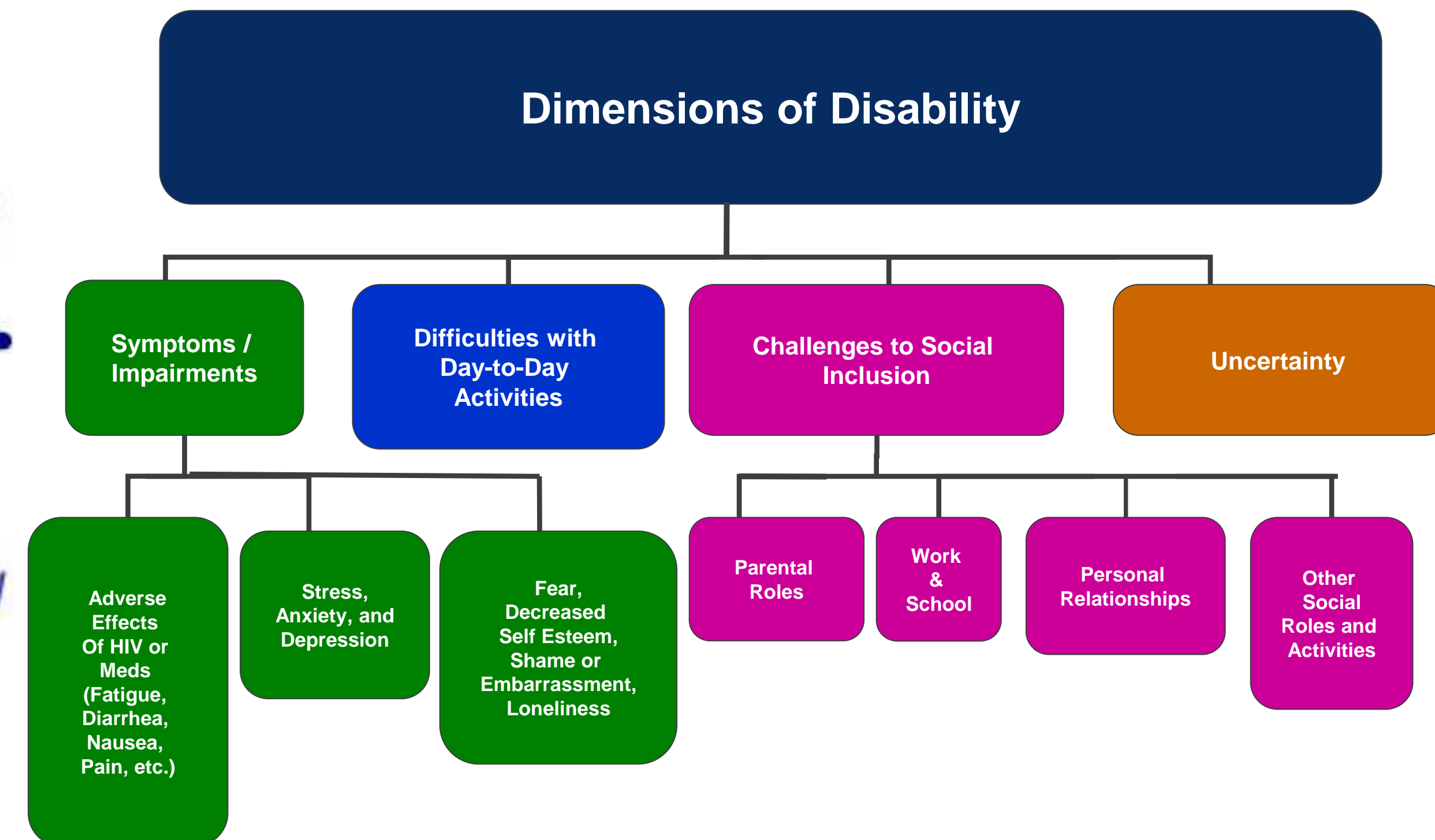
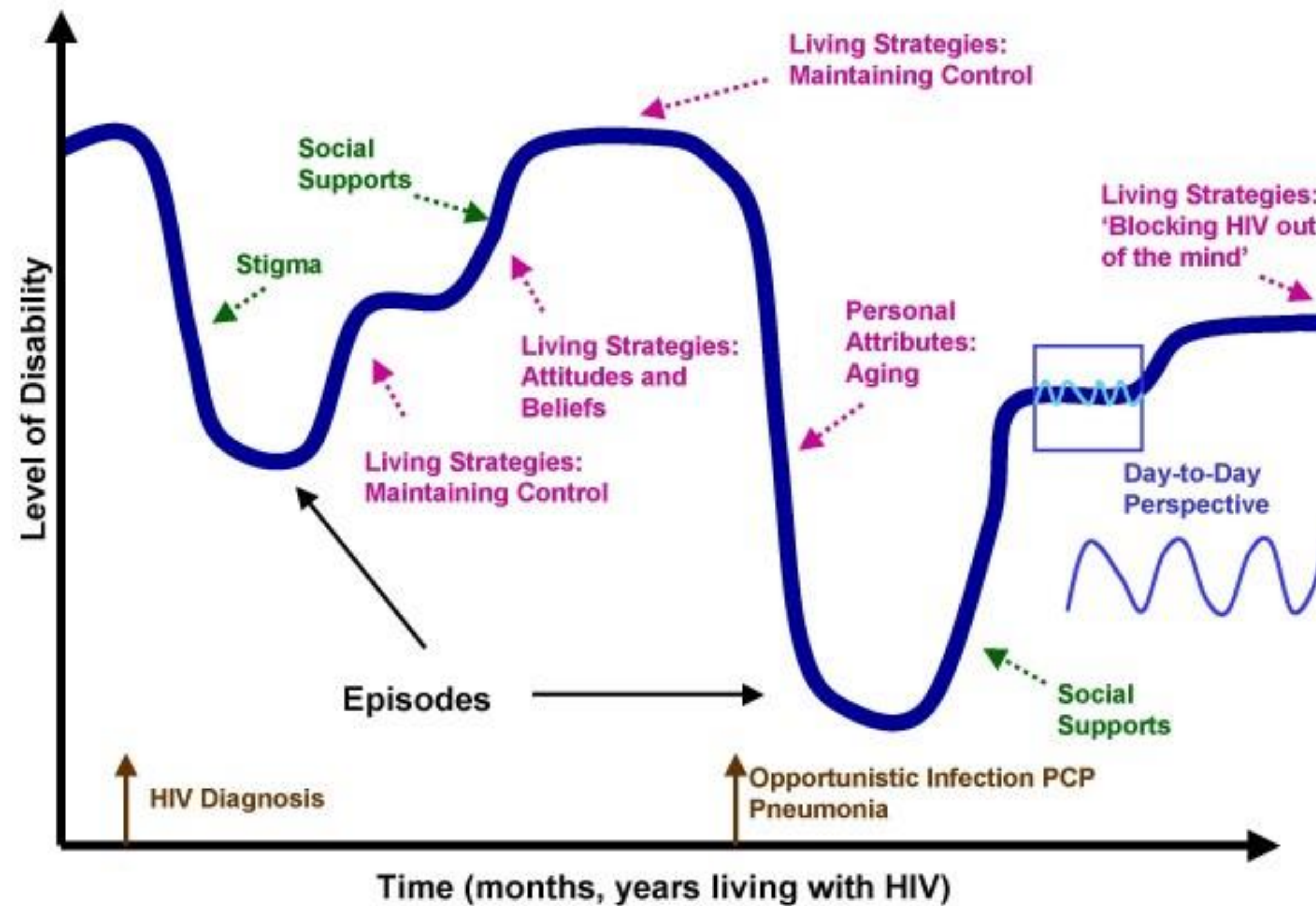
This completes the questionnaire. Thank you.

Episodes of Wellness and Illness



Episodic Disability

@KellyOBrien25



Episodic Disability

@KellyOBrien25

Open Access

Research

BMJ Open Measuring disability experienced by adults living with HIV: assessing construct validity of the HIV Disability Questionnaire using confirmatory factor analysis

Kelly K O'Brien,^{1,2,3} Patricia Solomon,² Ahmed M Bayoumi^{3,4,5}

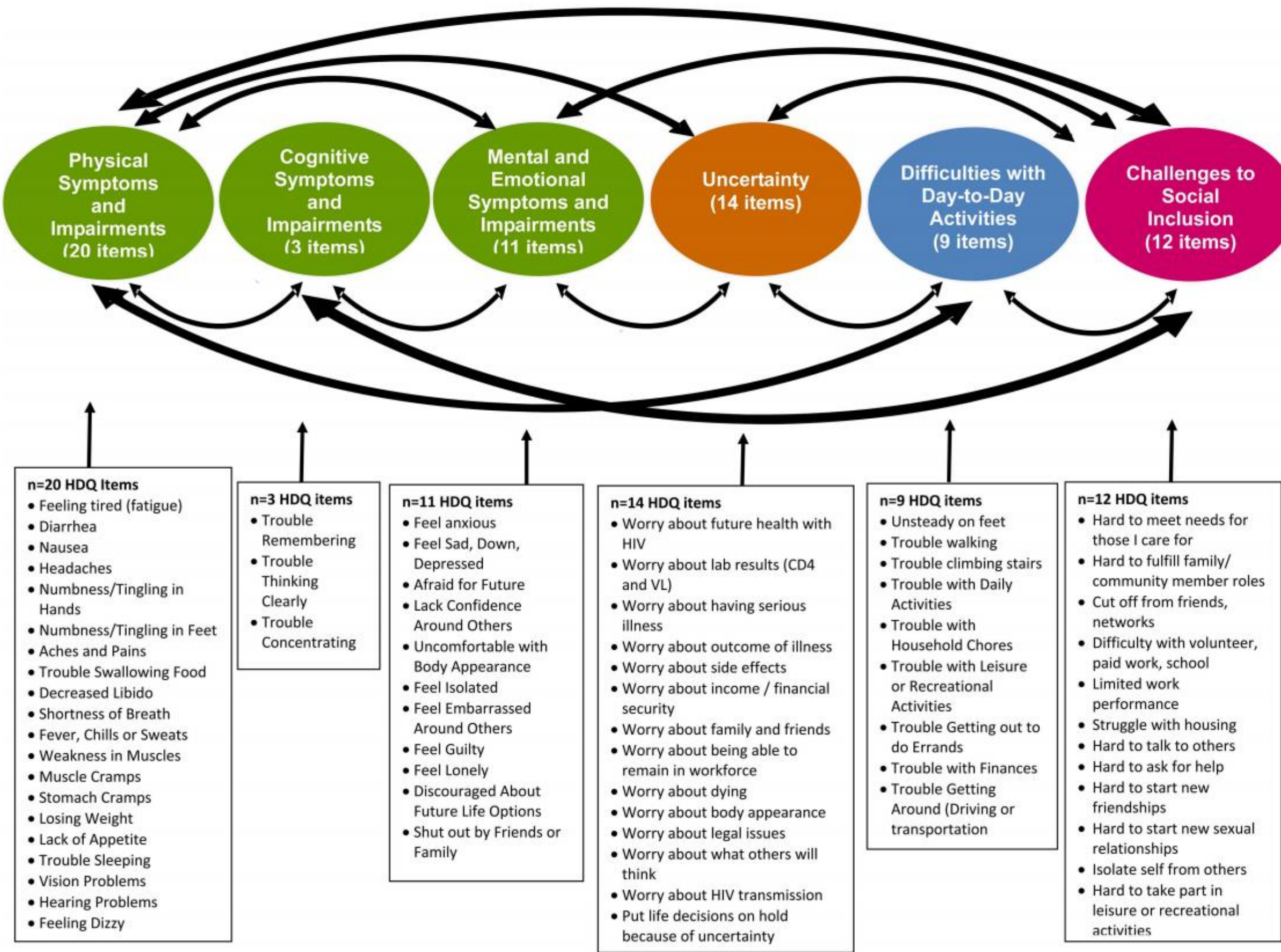
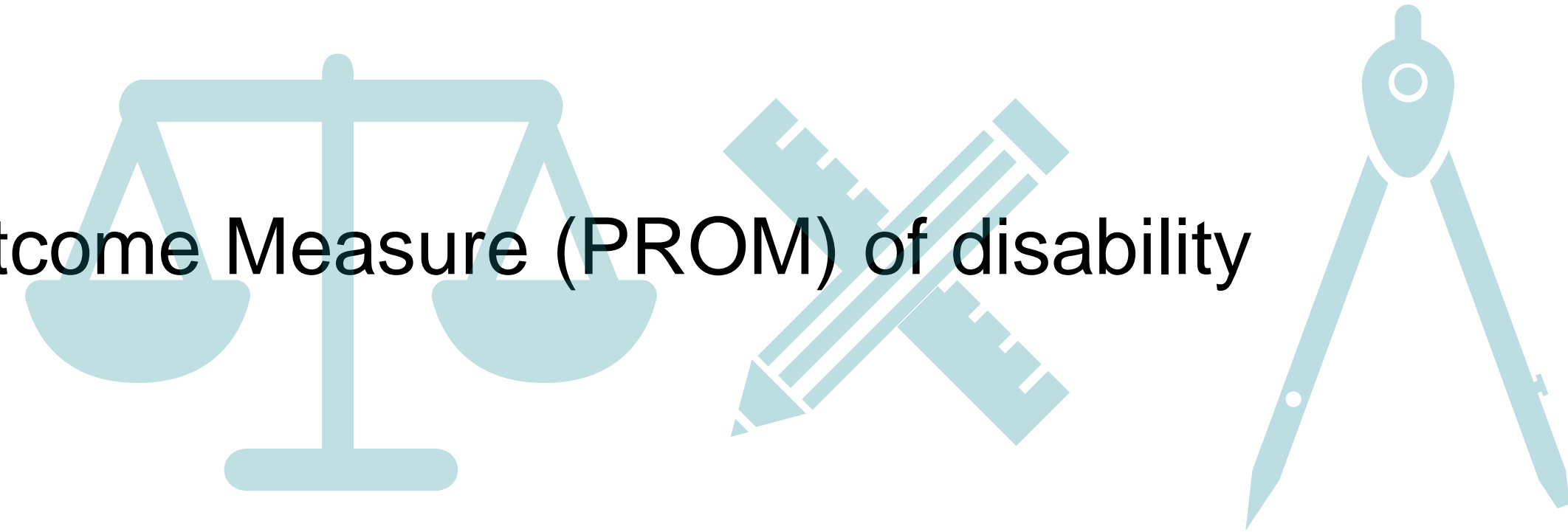


Figure 1 A priori measurement model for confirmatory factor analysis of the HIV Disability Questionnaire.

| Statement | Check the box that describes how you are feeling <u>today</u> . | | | | | Has this challenge fluctuated (or changed) <u>over the past week</u> ? | |
|---|---|--------------------------|--------------------------|--------------------------|--------------------------|--|--------------------------|
| | Not at all | Slightly | Moderately | Very | Extremely | Yes | No |
| I feel too fatigued or tired to do my usual activities. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | (0) | (1) | (2) | (3) | (4) | (1) | (0) |

HIV Disability Questionnaire

HDQ is the sole HIV-specific Patient Reported Outcome Measure (PROM) of disability



The HDQ has demonstrated validity and reliability when used with people living with HIV in Canada¹, Ireland², USA³, and the UK⁴



The disability domain “*Uncertainty of Worrying about the Future*” is the most present and severe domain of disability experienced by people living with HIV in Canada¹, Ireland², USA³ and UK⁴.

1) O'Brien K,K., Solomon P, Bayoumi AM. Measuring disability experienced by adults living with HIV: assessing construct validity of the HIV Disability Questionnaire using confirmatory factor analysis. BMJ Open 2014 09/01;4(8):e005456-e005456.

2) O'Brien K,K., Solomon P, Bergin C, O'Dea S, Stratford P, Iku N, et al. Reliability and validity of a new HIV-specific questionnaire with adults living with HIV in Canada and Ireland: the HIV Disability Questionnaire (HDQ). Health Qual Life Outcomes 2015 08/12;13:124-124.

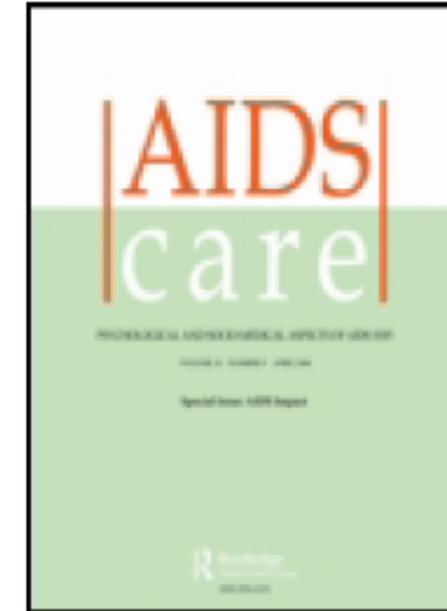
3) O'Brien KK, Kietrys D, Galantino ML, Parrott JS, Davis T, Levin T, Tran Q, Solomon P. Reliability and Validity of the HIV Disability Questionnaire (HDQ) with Adults Living with HIV in the United States. 26th Annual Canadian Conference on HIV/AIDS (CAHR Conference). Montreal, Quebec. April 6-9, 2017. 2017.

Ageing and Uncertainty

@solomon_patty



Chelsea and Westminster Hospital **NHS**
NHS Foundation Trust



AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV

Publication details, including instructions for authors and subscription information:
<http://www.tandfonline.com/loi/caic20>

Aging with HIV and disability: The role of uncertainty

Patricia Solomon^a, Kelly O'Brien^b, Seanne Wilkins^a & Nicole Gervais^a

^a School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada

^b Department of Physical Therapy, University of Toronto, Toronto, Ontario, Canada
Published online: 26 Jun 2013.

Uncertainty related to Aging with HIV

Sources of
Health
Challenges

Who will
care for
me?

Appropriate
Long Term
Housing

Transition
to
Retirement

Episodic
Nature of HIV

Health care providers'
knowledge & skills

Financial
Uncertainty

Ageing and Uncertainty

@solomon_patty



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Trajectories of Episodic Disability in People Aging with HIV: A Longitudinal Qualitative Study

Patricia Solomon, PhD¹, Kelly Kathleen O'Brien, PhD²,
Stephanie Nixon, PhD², Lori Letts, PhD¹, Larry Baxter³,
and Nicole Gervais, MA¹

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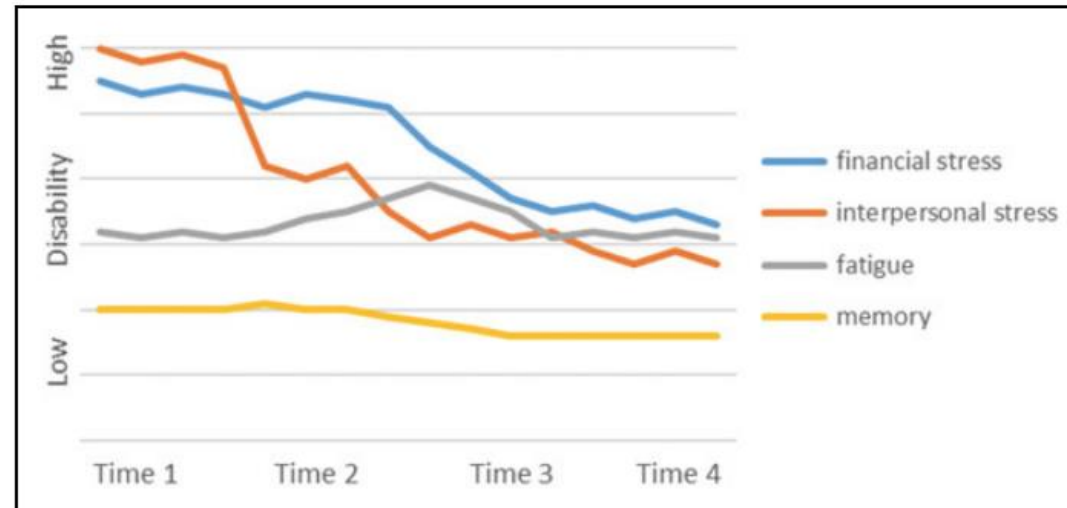


Figure 1. Participant A. Example of decreasing disability over time.

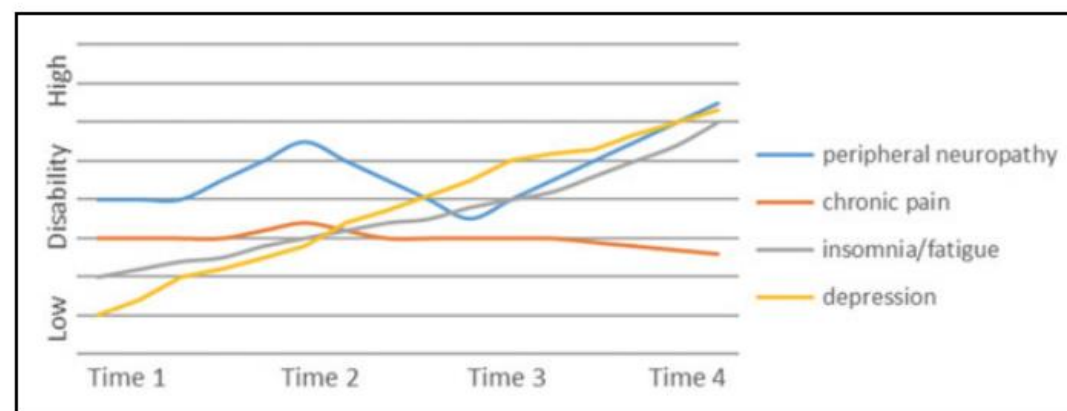


Figure 2. Participant B. Example of increasing disability over time.

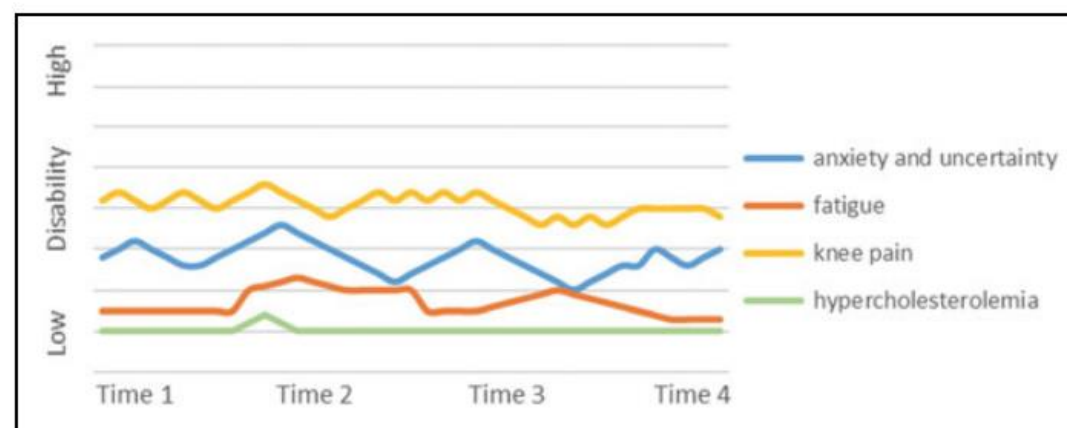


Figure 3. Participant C. Example of stable over time.

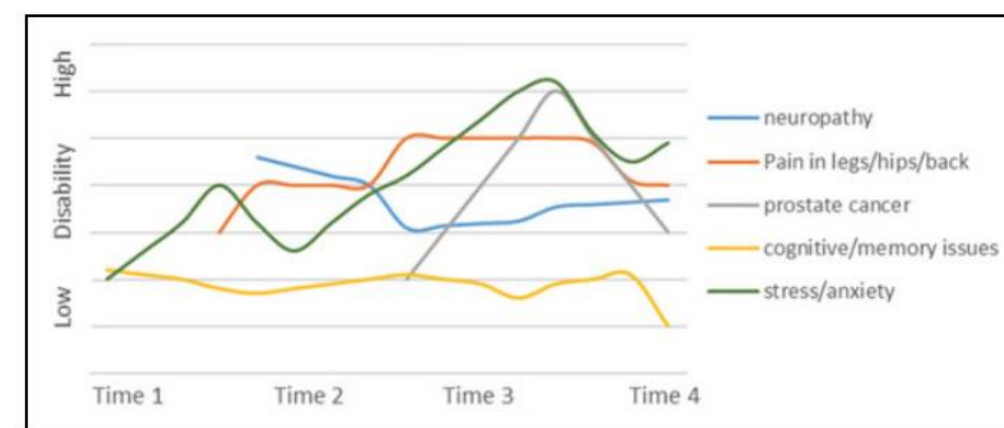


Figure 4. Participant D. Example of significant fluctuations in disability over time.



Four Phenotypes of Episodic Disability



Acceptance and optimism are hallmarks of those whose phenotypes were stable or improved over time



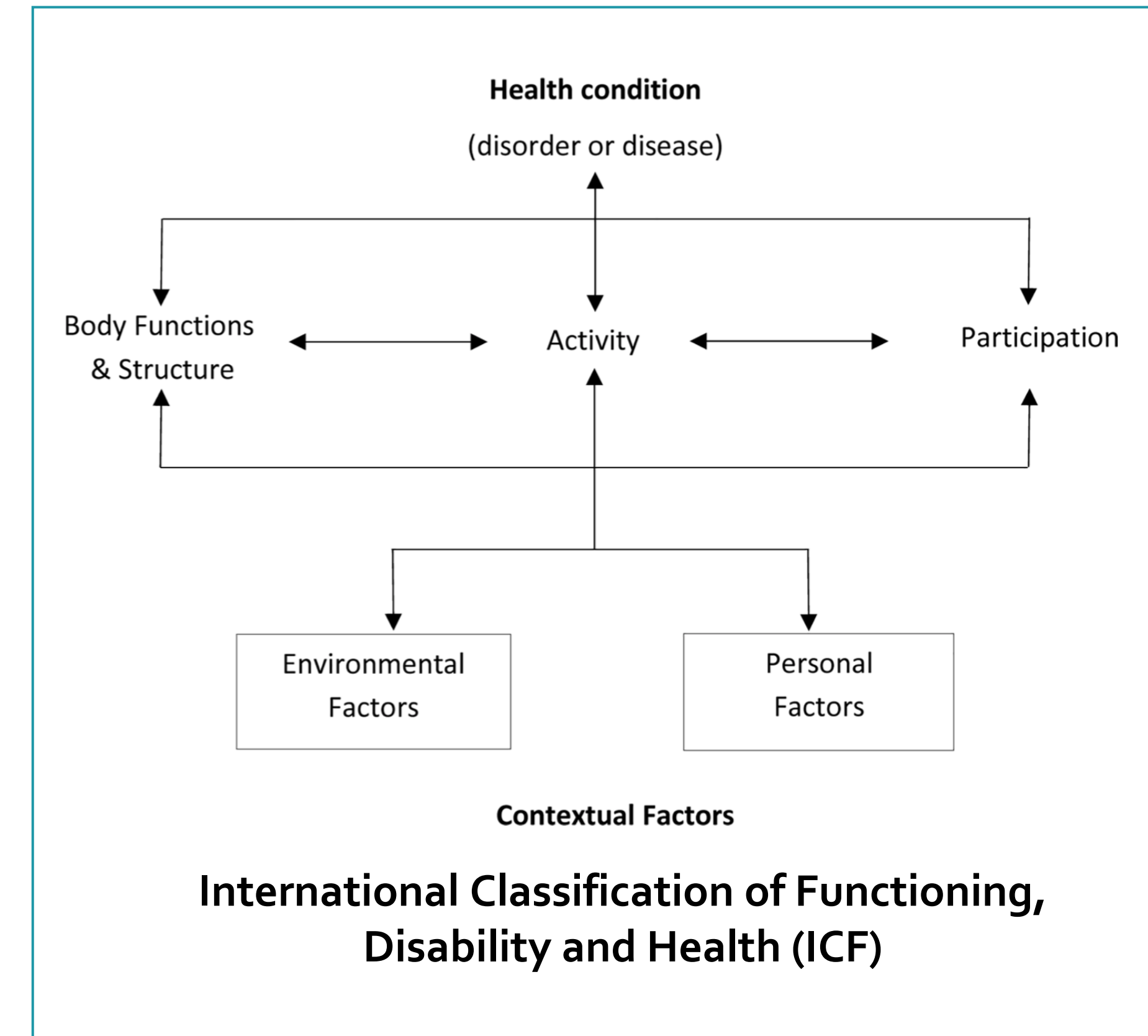
Understanding a persons episodic trajectory may help to tailor interventions to promote stability, mitigate upwards trajectory and increase time between episodes of disability

www.ncbi.nlm.nih.gov/pubmed/29464973

Prevalence of Disability



- High prevalence of PLHIV experiencing “disability” ¹
- However most literature focuses on health conditions and impairments ²
- Impairments alone are **NOT** an adequate proxy for disability ³
 - Not multi-dimensional
 - Do not consider interactions between health and context



1) Banks *et al.* (2015) 'The relationship between HIV and prevalence of disabilities in sub-Saharan Africa: systematic review (FA)', *Tropical Medicine & International Health*, 20(4), pp. 411-429.

2) Hanass-Hancock *et al.* (2013) 'HIV-related disability in HIV hyper-endemic countries: a scoping review', *World Journal of AIDS*, 3(03), pp. 257.

3) Mont, D. (2007) *Measuring disability prevalence (English)*. SP discussion paper ; no. 706. Washington, DC: World Bank. Available at: <http://documents.worldbank.org/curated/en/578731468323969519/Measuring-disability-prevalence>

Prevalence of Disability



No Studies aiming to measure prevalence of functional disability among PLHIV

WHODAS criteria
presence of functional
limitations/disability:

35.5% prevalence (n=1042) ¹

51.9% prevalence (n=1044) ²

Disability is driven by different factors in different parts of the world.
Therefore, measuring prevalence of self-reported functional disability,
will provide info about the extent of disability and the changing needs of
PLHIV in the UK, reflecting the long-term nature of HIV care.

1) Hanass-Hancock *et al.* (2015) 'Disability and living with HIV: baseline from a cohort of people on long term ART in South Africa', *PloS One*, 10(12), pp. e0143936.

2) Myezwa *et al.* (2018) 'Disability and health outcomes—from a cohort of people on long-term antiretroviral therapy', *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 15(1), pp. 50-59.

“Prevalence, domains and risk factors of disability experienced by people living with HIV during routine outpatient HIV care in London, UK: a cross-sectional self-report study”

Research Objectives:

- Measure prevalence of disability
- Report types of disability experienced
- Evaluate potential risk factors of disability



- London ½ PLHIV population
- Routine care = representative
- No UK data: observational & exploratory, no sample size calc.
- Aimed to recruit 200

Disability measured using UK Equality Act 2010, WHODAS, & HDQ

Sample Characteristics

(n=201)

| | |
|--------------------------|----------|
| Taking ART | 100% |
| Viral Suppression | 97% |
| Median duration with HIV | 11 years |
| Diagnosed Late | 52% |

| | |
|-------------------------------------|-------------|
| Male | 87% |
| Gay/Lesbian | 79% |
| White Ethnicity | 72% |
| Mean Age | 47 years |
| Age Range | 22-85 years |
| Aged ≥50 years | 41% |
| Median Concurrent Health Conditions | 2 |
| Self-Rated Health Status: | |
| - Very Good | 39% |
| - Good | 37% |

| | |
|--|-------|
| Economically Active: | (67%) |
| - self-employed | 21% |
| - full-time employed | 39% |
| - part-time employed | 7% |
| Housing: | |
| - owner occupied | 37% |
| - private rent | 36% |
| - social housing | 23% |
| - homeless | 2% |
| Educational Qualifications: | (92%) |
| - Degree level or above | 58% |
| Living alone | 44% |
| No adaptations @ home to help with day-to-day activities | 85% |
| Transportation Modes: | |
| - Tube | 41% |
| - Bus | 30% |
| - Walking | 24.4% |
| Do not receive or provide care | 72% |
| Not accessed Rehabilitation in past 12 months | 65% |

- Representative of people living with HIV in the UK
- Not representative of people living with HIV in the UK
- No comparable UK data



Prevalence of Disability

39.5% CI [0.33-0.46] — **70.5%** CI [0.64-0.77]

UK Equality Act 2010

(n=201)

- Census style questions (limited)
- May represent more severe challenges that requires complex rehabilitation
- Higher than UK general population
UK 21%, London 14%

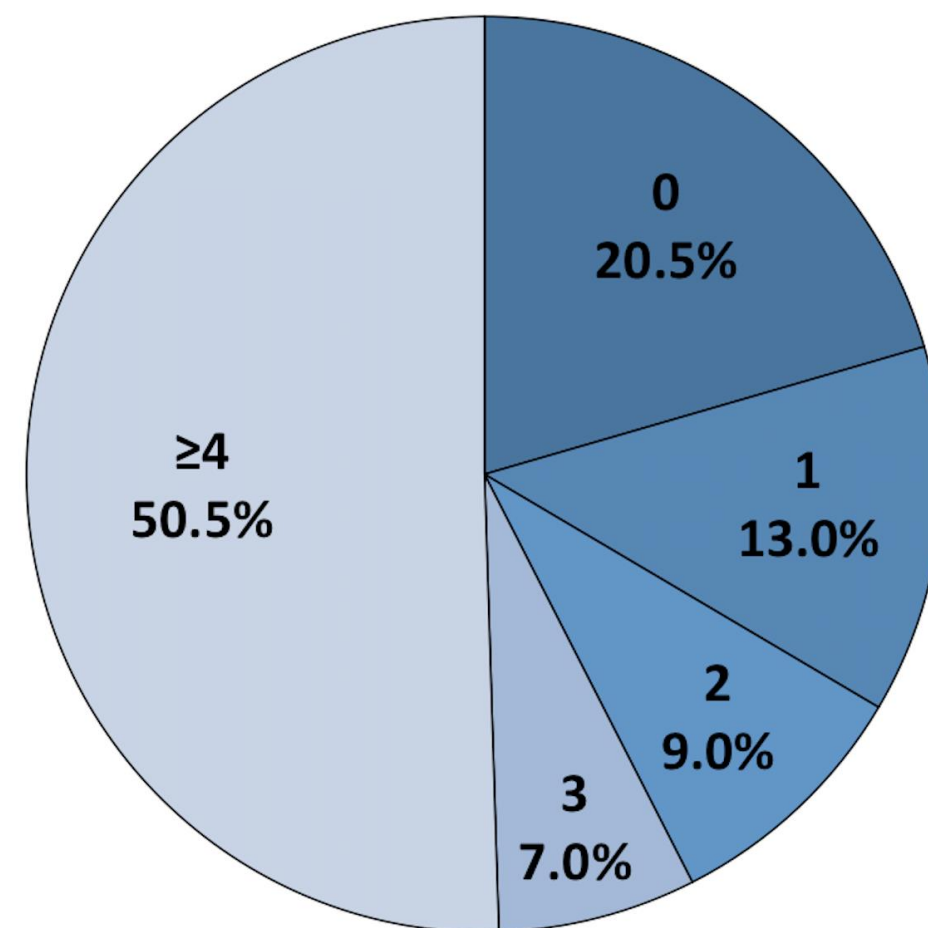
WHODAS presence of activity limitations/disability

(n=200)

- Survey style questions (more detailed)
- May represent moderate challenges that requires therapeutic interventions
- Higher than PLHIV in South Africa
KwaZulu Natal 35.5% & Guateng 51.9%

Reported Disability WHODAS

(n=200)



% scoring ≥1 activity limitation

Mild Difficulty 37%

Moderate Difficulty 34%

Different to:
South Africa

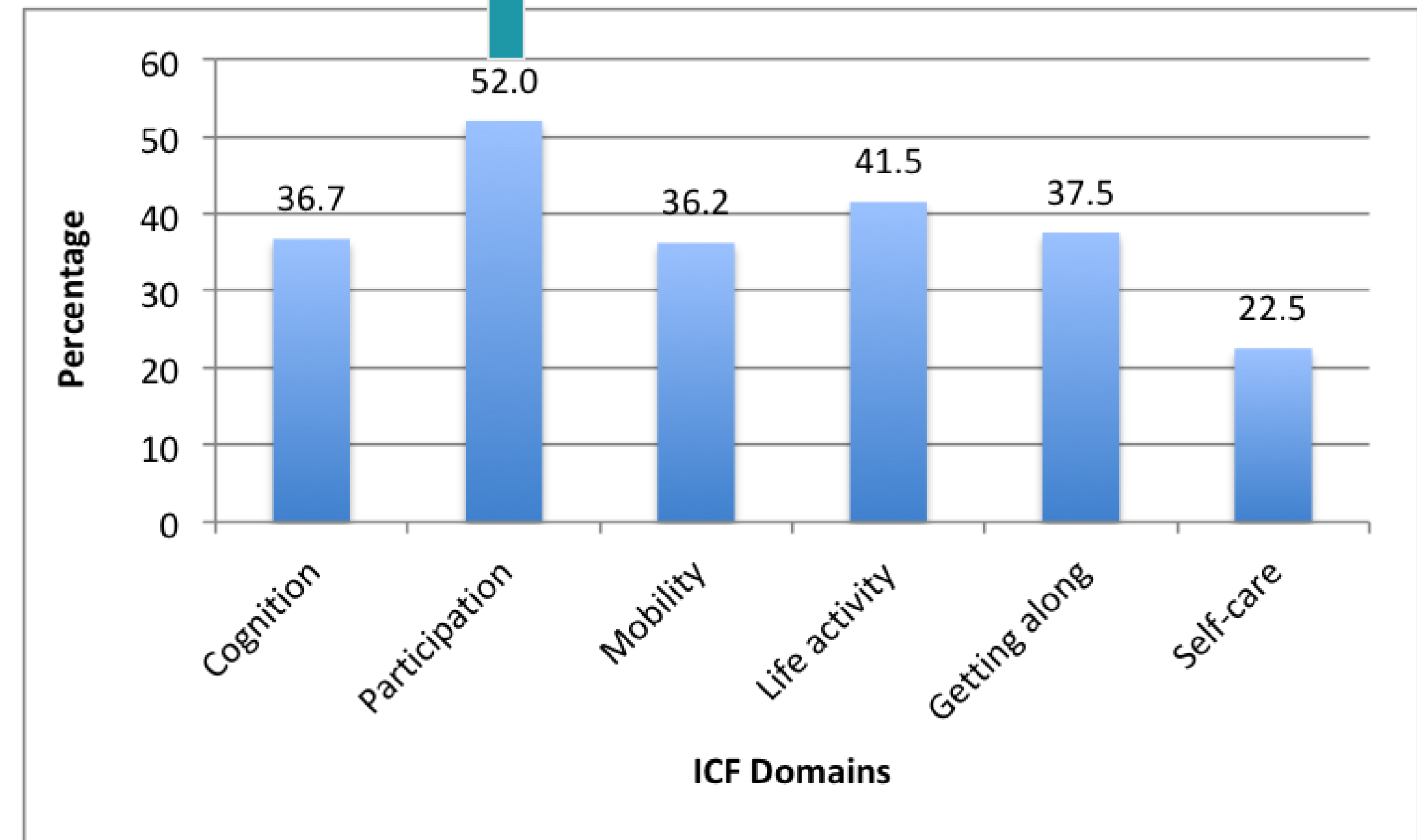


Also observed in:

South Africa



Canada



Reported Disability HDQ

(n=200)



Cognitive

Uncertainty

Physical

Uncertainty

Uncertainty

Physical

Median HDQ Scores

| HDQ Disability Dimension | HDQ Presence Score (IQR) | HDQ Severity Score (IQR) | HDQ Episodic Score (IQR) |
|--|--------------------------|--------------------------|--------------------------|
| Physical symptoms and impairments | 30.0 (15.0-53.8) | 11.3 (5.0-26.3) | 20.0 (10.0-40.0) |
| Cognitive symptoms and impairments | 33.3 (0.0-100.0) | 8.3 (0.0-25.0) | 0.0 (0.0-66.7) |
| Mental and emotional health symptoms and impairments | 45.5 (18.2-72.7) | 13.6 (4.5-34.1) | 18.2 (0.0-54.5) |
| Uncertainty or worry about the future | 57.1 (28.6-78.6) | 23.2 (10.7-38.9) | 7.1 (0.0-42.9) |
| Difficulties with day-to-day activities | 11.1 (0.0-44.4) | 2.8 (0.0-16.7) | 0.0 (0.0-22.2) |
| Challenges to taking part in social and community life | 33.3 (8.3-58.3) | 14.6 (4.2-29.2) | 0.0 (0.0-25.0) |
| HDQ Total | 36.2 (21.7-59.4) | 13.4 (6.3-28.8) | 17.4 (5.8-36.2) |

IQR: Inter-Quartile Range

Results



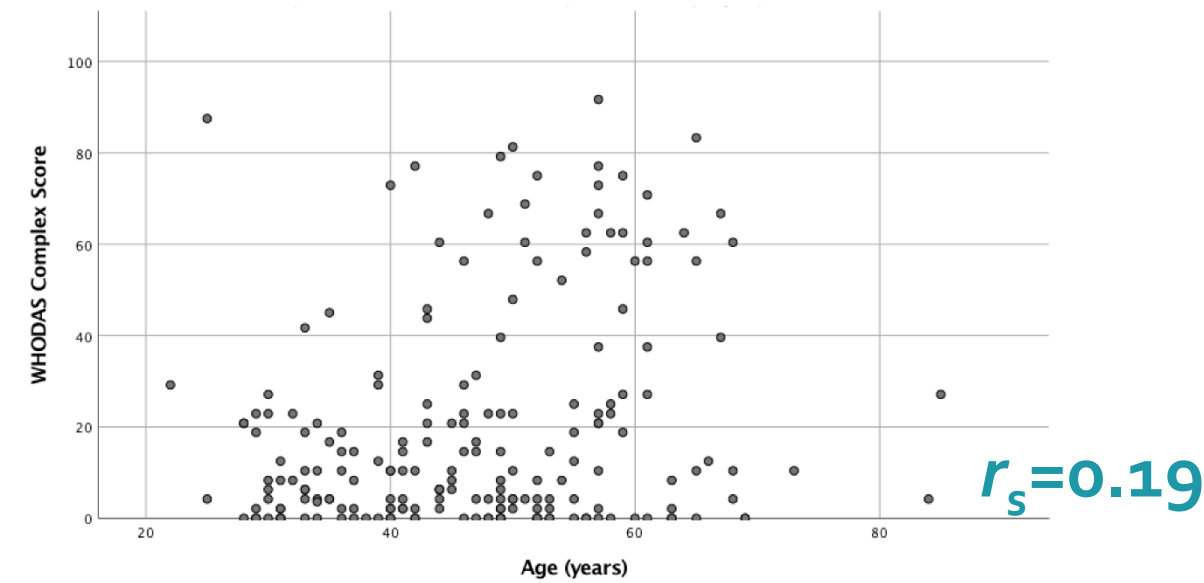
Associations with Age

(n=200)

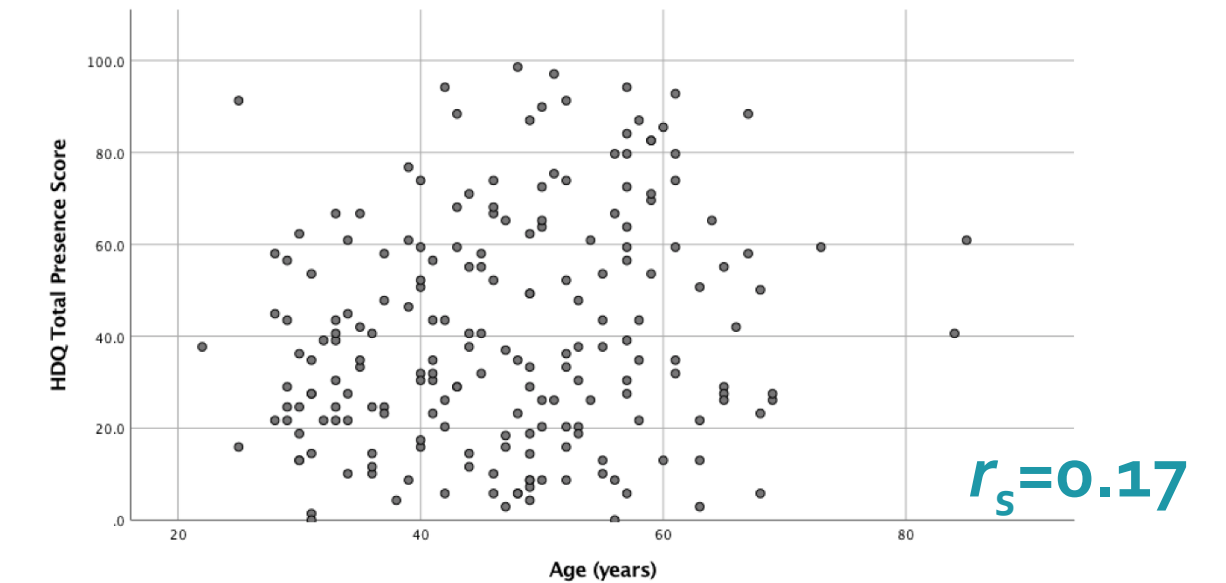
Correlation Analysis

Clinical Significance:
Overall disability could be experienced
across the life-course

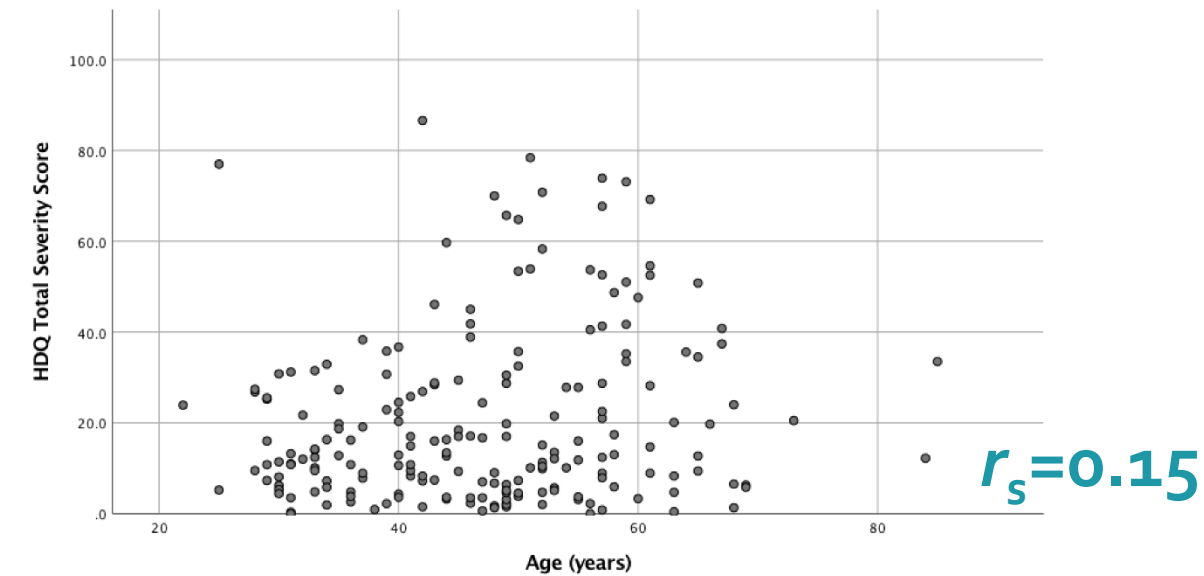
WHODAS - Overall Disability



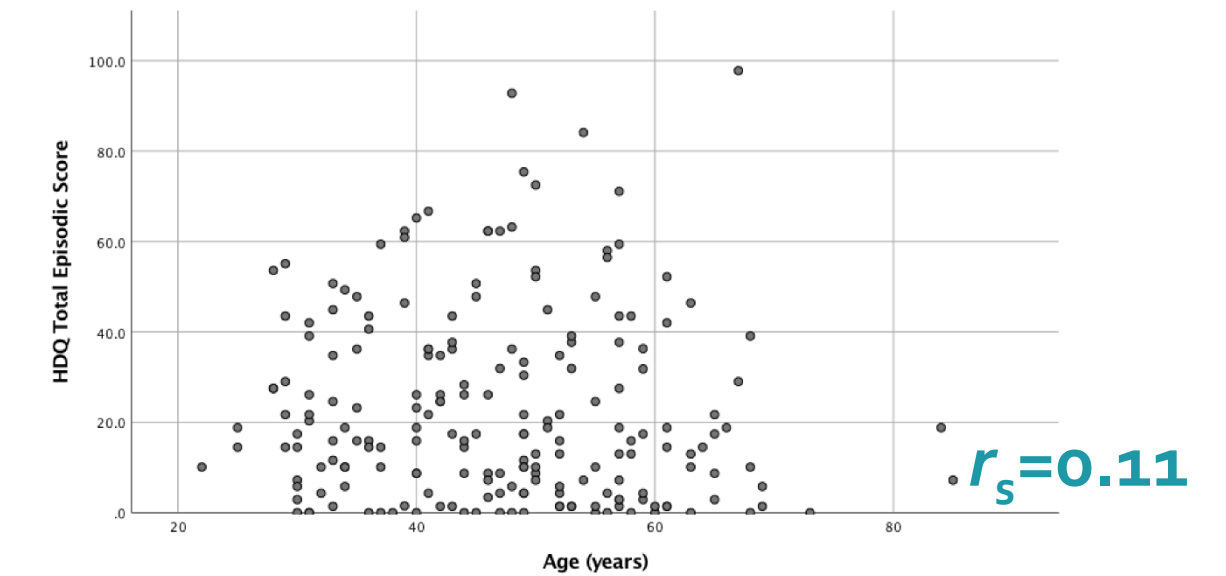
HDQ - Presence of Disability



HDQ - Severity of Disability



HDQ - Episodic Disability



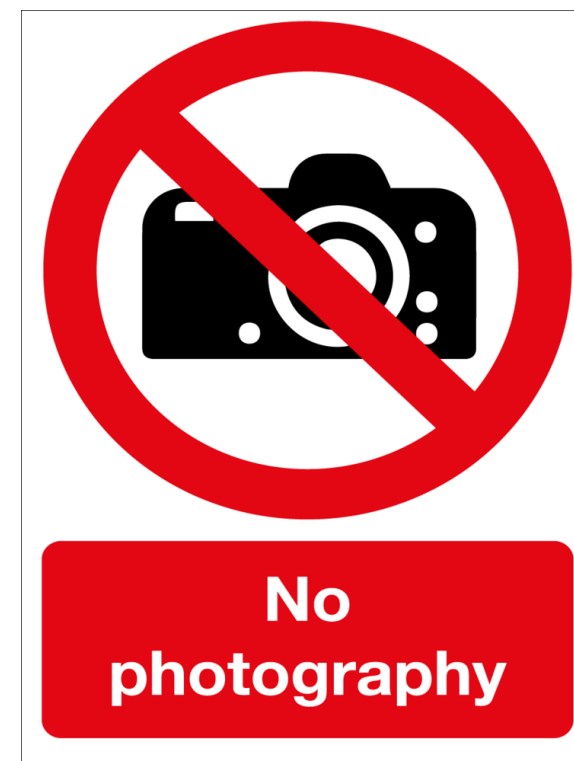
Spearman's Rank Correlation Coefficient
No statistically significant linear or monotonic associations
Coefficients closer to zero



(n=200)

Disability Risk Factors HDQ

Multivariate Associations
Generalised Linear Models
HDQ Severity Scores
Bio-psychosocial characteristics



| Risk Factor |
|--------------------|
| Age |
| Gender Identity |
| Sexual Orientation |
| Ethnicity |
| Late HIV Diagnosis |
| Employment |
| Housing Situation |
| Education |
| Care and Support |
| Benefits |
| Rehabilitation |

Disability Risk Factors - “Physical Symptoms and Impairments”

(n=200)

Multivariate Associations



| | Risk Factor | Characteristic | |
|---|--------------------------|------------------------------|---|
| | Age | | |
| → | Gender Identity | Female | ← |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| → | Housing Situation | No fixed abode/other | ← |
| | Education | | |
| | Care and Support | | |
| → | Benefits | Receives benefits | ← |
| → | Rehabilitation | No rehab in past year | ← |



Disability Risk Factors – “Cognitive Symptoms and Impairments”

(n=200)

Multivariate Associations



| | Risk Factor | Characteristic | |
|---|-----------------------|------------------------------|---|
| | Age | | |
| | Gender Identity | | |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| | Housing Situation | | |
| | Education | | |
| | Care and Support | | |
| → | Benefits | Receives benefits | ← |
| → | Rehabilitation | No rehab in past year | ← |



(n=200)

Multivariate Associations



Disability Risk Factors - “Mental and Emotional Health Symptoms and Impairments”

| | Risk Factor | Characteristic | |
|---|--------------------|----------------------|---|
| → | Age | <50 years | ← |
| → | Gender Identity | Female | ← |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| → | Housing Situation | No fixed abode/other | ← |
| | Education | | |
| | Care and Support | | |
| → | Benefits | Receives benefits | ← |
| | Rehabilitation | | |



Disability Risk Factors – “Uncertainty or Worry about the Future”

(n=200)

Multivariate Associations



| | Risk Factor | Characteristic | |
|---|--------------------|-----------------------|---|
| → | Age | <50 years | ← |
| → | Gender Identity | Female | ← |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| → | Housing Situation | No fixed abode/other | ← |
| | Education | | |
| | Care and Support | | |
| | Benefits | | |
| → | Rehabilitation | No rehab in past year | ← |

Disability Risk Factors – “Difficulties with Day-to-Day Activities”

(n=200)

Multivariate Associations



| | Risk Factor | Characteristic | |
|---|-----------------------|------------------------------|---|
| | Age | | |
| | Gender Identity | | |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| | Housing Situation | | |
| | Education | | |
| | Care and Support | | |
| → | Benefits | Receives benefits | ← |
| → | Rehabilitation | No rehab in past year | ← |



Disability Risk Factors – “Challenges to Taking Part in Social and Community Life”

(n=200)

Multivariate Associations



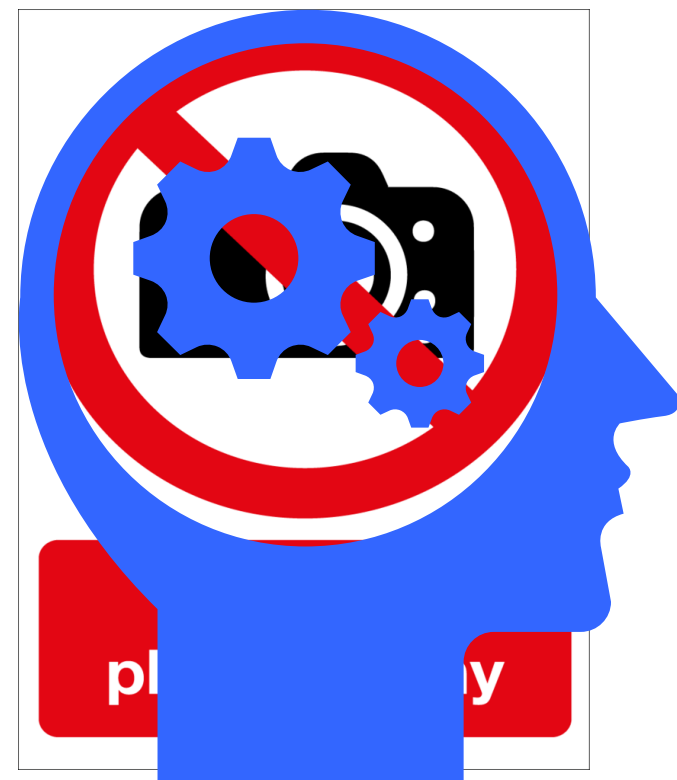
| | Risk Factor | Characteristic | |
|---|--------------------|-----------------------|---|
| → | Age | <50 years | ← |
| → | Gender Identity | Female | ← |
| | Sexual Orientation | | |
| | Ethnicity | | |
| | Late HIV Diagnosis | | |
| → | Employment | Economic inactivity | ← |
| → | Housing Situation | No fixed abode/other | ← |
| | Education | | |
| | Care and Support | | |
| → | Benefits | Receives benefits | ← |
| → | Rehabilitation | No rehab in past year | ← |



Disability Risk Factors

(n=200)

Multivariate Associations



HDQ Domains
of Disability

Economic Inactivity



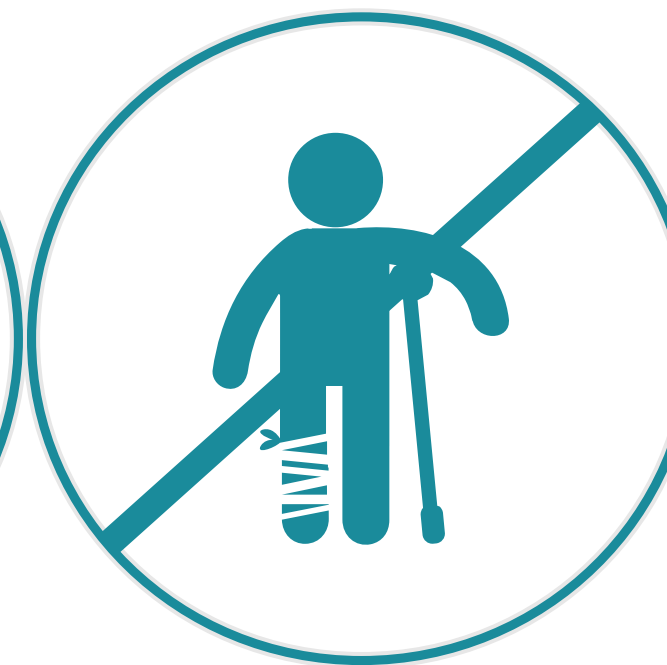
PHYSICAL
COGNITIVE
MENTAL
UNCERTAINTY
ACTIVITIES
PARTICIPATION

Received Benefits



PHYSICAL
COGNITIVE
MENTAL
ACTIVITIES
PARTICIPATION

No Rehab 12 months



PHYSICAL
COGNITIVE
UNCERTAINTY
ACTIVITIES
PARTICIPATION

No fixed abode



PHYSICAL
MENTAL
UNCERTAINTY
PARTICIPATION

Female



PHYSICAL
MENTAL
UNCERTAINTY
PARTICIPATION

Aged <50 years



MENTAL
UNCERTAINTY
PARTICIPATION

Conclusions

- Disability is multi-dimensional and episodic
- Different PROMs exist to measure disability
- The HDQ is the sole HIV specific disability measurement tool
- Uncertainty most present and severe domain across high income settings
- High prevalence of severe (40%) and moderate (71%) threshold disability in London, UK
- Uncertainty most present and severe, with physical most episodic disability domains
- Overall disability is not associated with age
- Disability risk factors vary by disability domains
- Economic inactivity, receiving benefits, and no rehab in past year, are risk factors present across the most number of disability domains

Any Questions?

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