

Item Development for the Psychosocial Impact of Assistive Devices Scale for Continence (C-PIADS)

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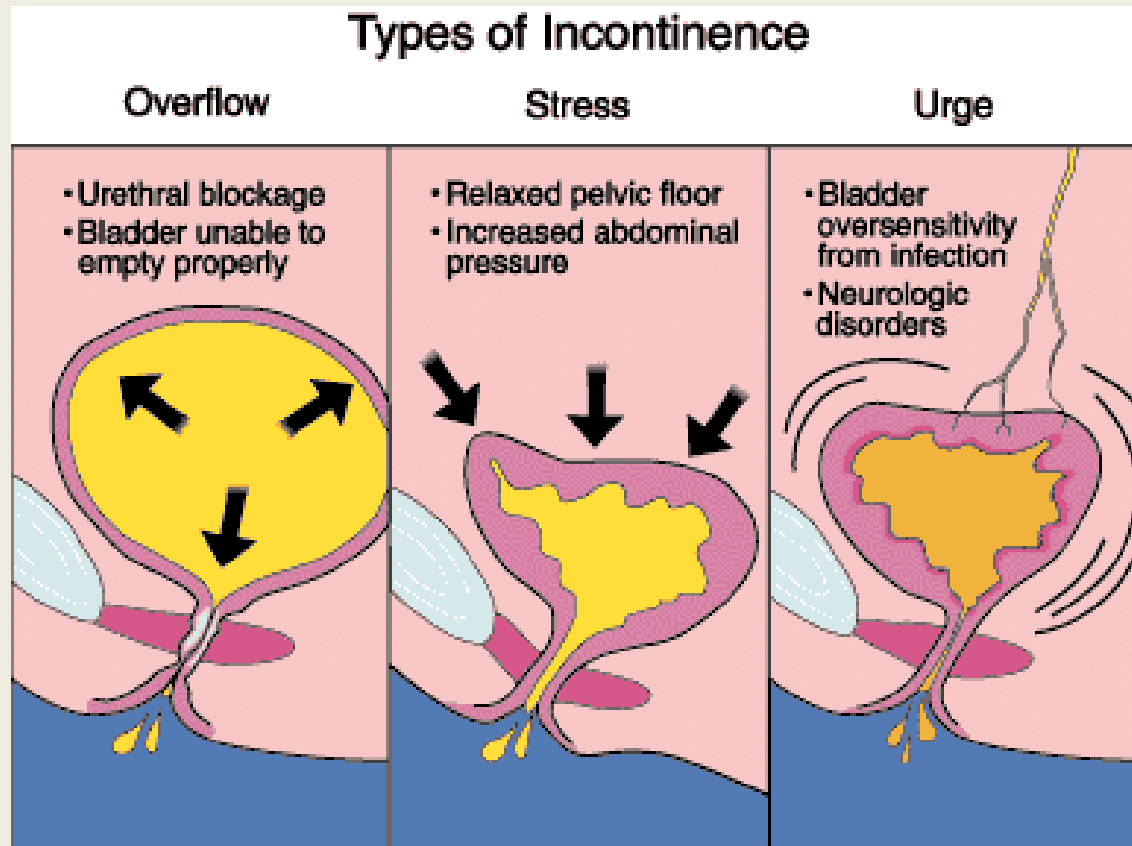


Background



Continence problems

- Stress
- Urge
- Mixed
- Voiding difficulties



Prevalence in women

Worldwide

Systematic review, *V.A. Minassian, H.P. Drutz, A. Al-Badr, 2003*

- 26.7 %
- Increases with age

Europe

Self-reported questionnaire, *Hunskar et al., 2004*

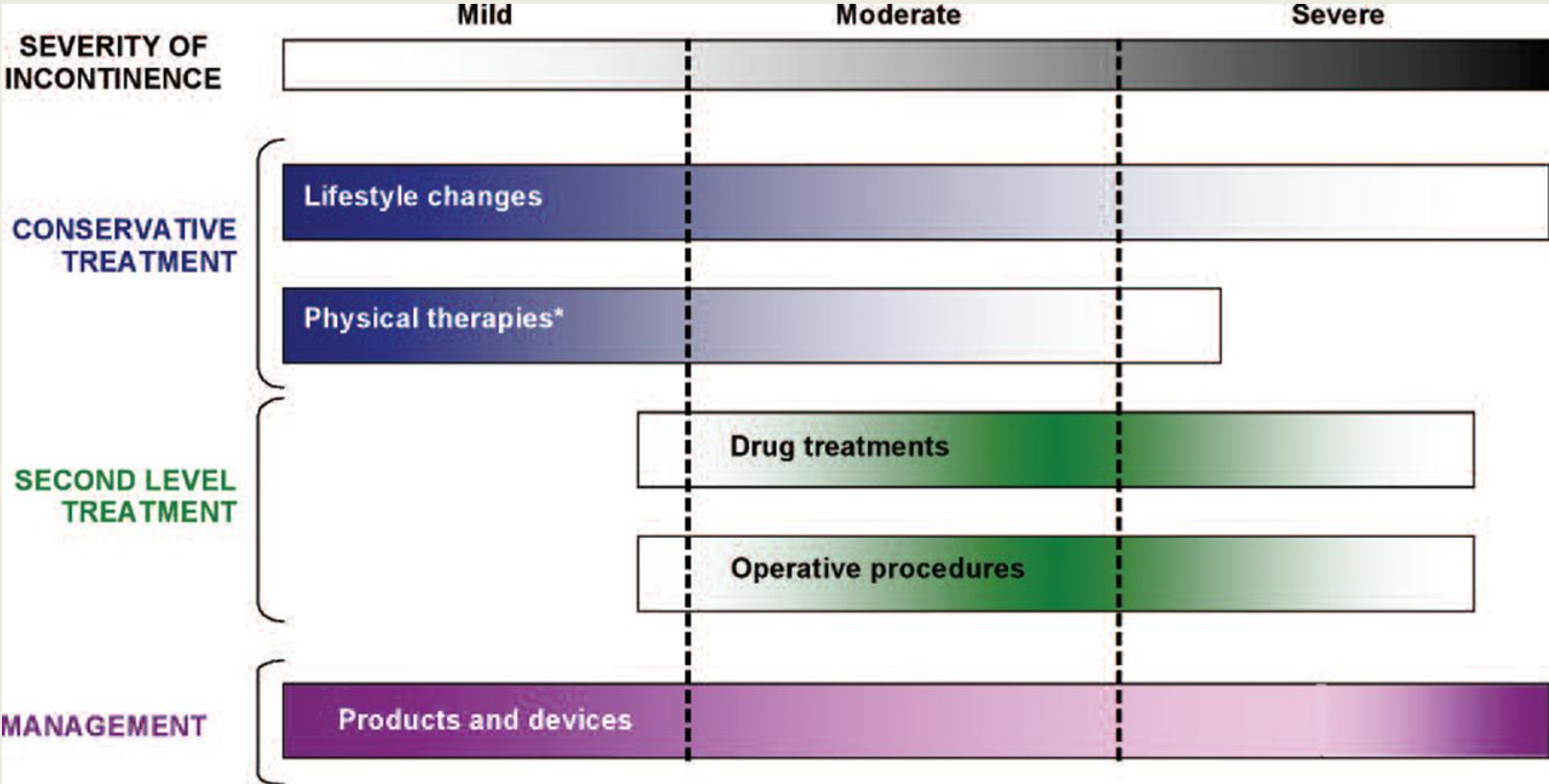
- 35% reported involuntary loss of urine in the preceding 30 days
- Spain 23%; France 44%; Germany 41%; UK 42%.
- Pads were used by 50% of the women

Canada

Enrolled in a trial related to heart disease, *Brown J et al., 1999*

- 56% of older women

Treatment Options and role of Assistive Devices



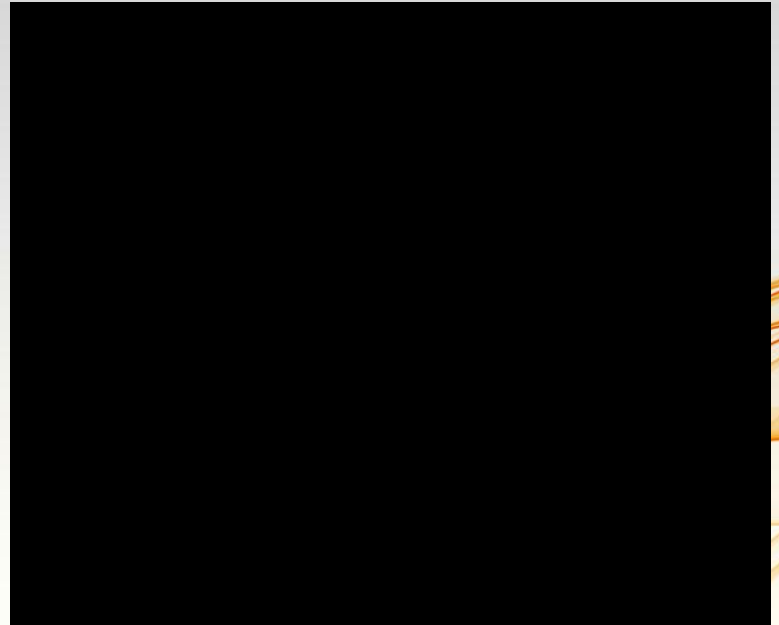
Assistive devices for incontinence



Products for urinary retention

Products for urinary incontinence

Psychosocial effects of incontinence



Measuring impact: PIADS tool

Psychosocial Impact of Assistive Devices Scale (PIADS) Today's Date: _____
month/day/year

Client Name: _____ male female
(last name, then first name)

Diagnosis: _____ Date of Birth: _____
month/day/year

The form is being filled out at (choose one) 1. home 2. a clinic 3. other (describe): _____
 The form is being filled out by (choose one) 1. the client, without any help 2. the client, with help from the caregiver (e.g., client showed or told caregiver what answers to give) 3. the caregiver on behalf of the client, without any direction from the client 4. other (describe): _____

Each word or phrase below describes how using an assistive device may affect a user. Some might seem unusual but it is important that you answer every one of the 26 items. So, for each word or phrase, put an "X" in the appropriate box to show how you are affected by using the _____ (device name).

	Decreases	-3	-2	-1	0	1	2	3	Increases
1) competence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) happiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) independence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) adequacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) confusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) efficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) productivity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) frustration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) usefulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) self-confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) skillfulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) well-being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) capability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) sense of power	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) sense of control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) embarrassment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) willingness to take chances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) ability to participate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24) eagerness to try new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25) ability to adapt to the activities of daily living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26) ability to take advantage of opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Score +3 to +1 positive impact
 Score 0 no difference
 Score -1 to -3 negative impact

Competence: reflecting perceived functional capability, independence and performance

Competence (+)	Ability to do well the important things you need to do in life
Independence (+)	Not dependent on, or not always needing help from, someone or something
Adequacy (+)	Capable of handling life situations, and handling little crises
Efficiency (+)	Effective management of day to day tasks
Productivity (+)	Able to get more things done in a day
Usefulness (+)	Helpful to yourself and others; can get things done
Expertise (+)	Knowledge in a particular area or occupation
Skillfulness (+)	Able to show your expertise; perform tasks well
Capability (+)	Feeling more capable; able to cope
Quality of Life (+)	How good your life is
Performance (+)	Able to demonstrate your skills
Confusion (-)	Unable to think clearly, act decisively

Adaptability: reflecting inclination or motivation to participate socially and take risks

Well-being (+)

Feeling well; optimistic about your life and future

Willingness to Take Chances (+)

Willing to take some risks; willing to take on new challenges

Ability to Participate (+)

Ability to join in activities with other people

Eagerness to Try New Things (+)

Feeling adventuresome and open to new experiences

Ability to Adapt to the Activities of Daily Living (+)

Ability to cope with change; ability to make basic tasks more manageable

Ability to take advantage of opportunities (+)

Ability to act quickly and confidently when there is a chance to improve something in your life

Self-esteem

Happiness (+)

Gladness, pleasure; satisfaction with life

Self-Esteem (+)

How you feel about yourself, and like yourself as a person

Security (+)

Feeling safe rather than feeling vulnerable or insecure

Self-Confidence (+)

Self-reliance; trust in yourself and your abilities

Sense of Power (+)

Sense of inner strength; feeling that you have significant influence over your life

Sense of Control (+)

Sense of being able to do what you want in your environment

Frustration (-)

Being upset about lack of progress in achieving your desires; feeling disappointed

Embarrassment (-)

Feeling awkward or ashamed

- The psychosocial impact of assistive devices can be reliably assessed in a standardized way across diverse populations of device users
- The PIADS is capable of predicting device retention and abandonment.
- Patterns of psychosocial impact vary across populations of device users.
- Devices associated with stigma produce predictable patterns of psychosocial response.
- The psychosocial impact of assistive devices is dissociable from the effects of illness and disabling condition.
- The overall agreement between user self-report and caregiver report of device impact on the user is surprisingly good.
- The PIADS is sensitive to clinically and functionally important variables associated with the user's condition and device capabilities

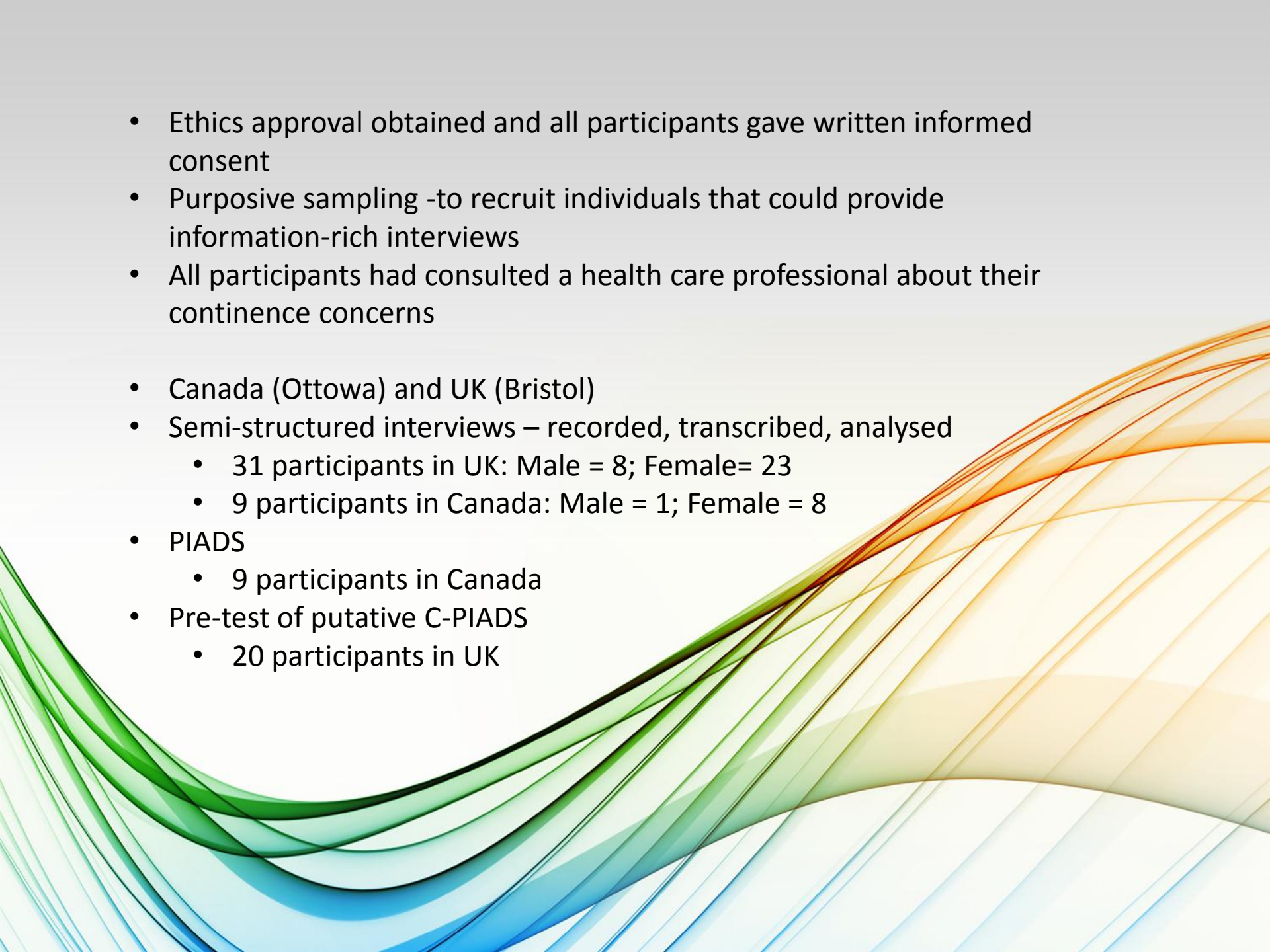
H. Day, J. Jutai and K.A. Campbell, Development of a Scale to Measure the Psychosocial Impact of Assistive Devices: Lessons Learned and the Road Ahead. *Disability & Rehabilitation* **24** (2002) 31-37

H. Day, J. Jutai, J., W. Woolrich and G. Strong, G. (2001). The Stability of Impact of Assistive Devices. *Disability & Rehabilitation* **23** (2001) 400-404.

Method



- Ethics approval obtained and all participants gave written informed consent
 - Purposive sampling -to recruit individuals that could provide information-rich interviews
 - All participants had consulted a health care professional about their continence concerns

 - Canada (Ottawa) and UK (Bristol)
 - Semi-structured interviews – recorded, transcribed, analysed
 - 31 participants in UK: Male = 8; Female= 23
 - 9 participants in Canada: Male = 1; Female = 8
 - PIADS
 - 9 participants in Canada
 - Pre-test of putative C-PIADS
 - 20 participants in UK
- 

Semi-structured interviews

What technologies (i.e., devices and strategies) are used for continence management?

What daily difficulties are encountered with continence management?

What is the impact on daily life and significant other people?

What are the most liked and disliked features of the technologies being used?

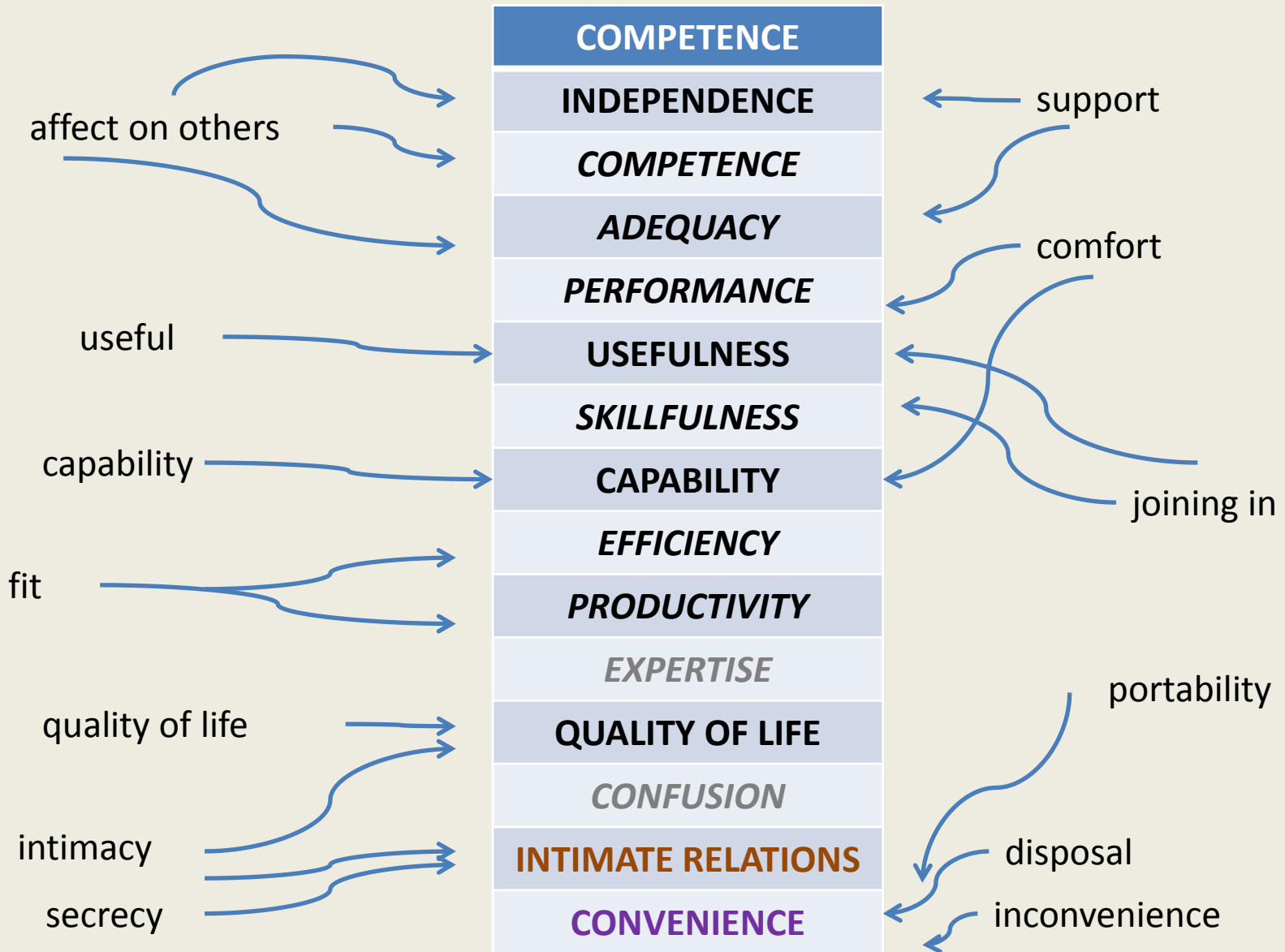
What barriers are there to obtaining desired continence management solutions?

Potential new items for C-PIADS

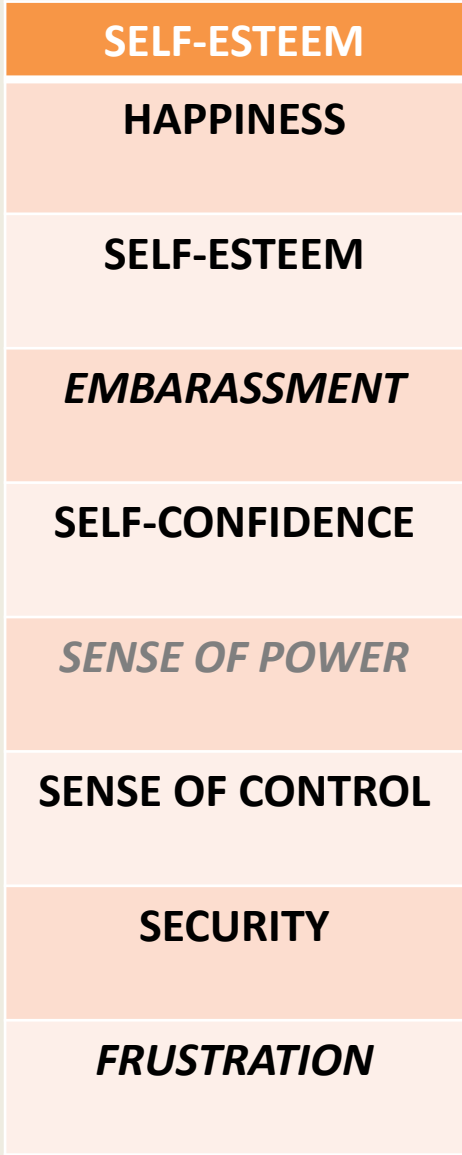
Self-consciousness	Level of self-awareness and that others may observe your actions and state
Fear of being 'outed'	Fear and anxieties associated with others discovering your condition or symptoms
Social acceptance	Fears that other make negative judgements about you
Secrecy	Actively hiding your condition from others
Isolation	Withdrawing oneself from social activities
Revealing to others	Disclosure of information about your condition to others
Social participation	Engaging in social events and activities
Intimate relations	Romantic and physical relationships

Findings









confiding
isolated
secret
denial
visible
Self-conscious
"just in case"
Interrupted sleep

Arrows from these terms point to the central stack: "confiding" points to the top SELF-ESTEEM; "isolated" points to the second SELF-ESTEEM; "secret" points to the third SELF-ESTEEM; "denial" points to EMBARRASSMENT; "visible" points to SELF-CONFIDENCE; "Self-conscious" points to SENSE OF POWER; "just in case" points to SENSE OF CONTROL; "Interrupted sleep" points to SECURITY.

cruelty of others
embarrassment
leakage
smell
"feel dirty"
ownership
feel safe
inconvenient

Arrows from these terms point to the central stack: "cruelty of others" points to the top SELF-ESTEEM; "embarrassment" points to the second SELF-ESTEEM; "leakage" points to EMBARRASSMENT; "smell" points to SELF-CONFIDENCE; "feel dirty" points to SENSE OF POWER; "ownership" points to SENSE OF CONTROL; "feel safe" points to SECURITY; "inconvenient" points to FRUSTRATION.

NEW ITEMS?

SELF-CONSCIOUSNESS

FEAR OF BEING 'OUTED'

SOCIAL ACCEPTANCE

SECRECY

ISOLATATION

REVEALING TO OTHERS

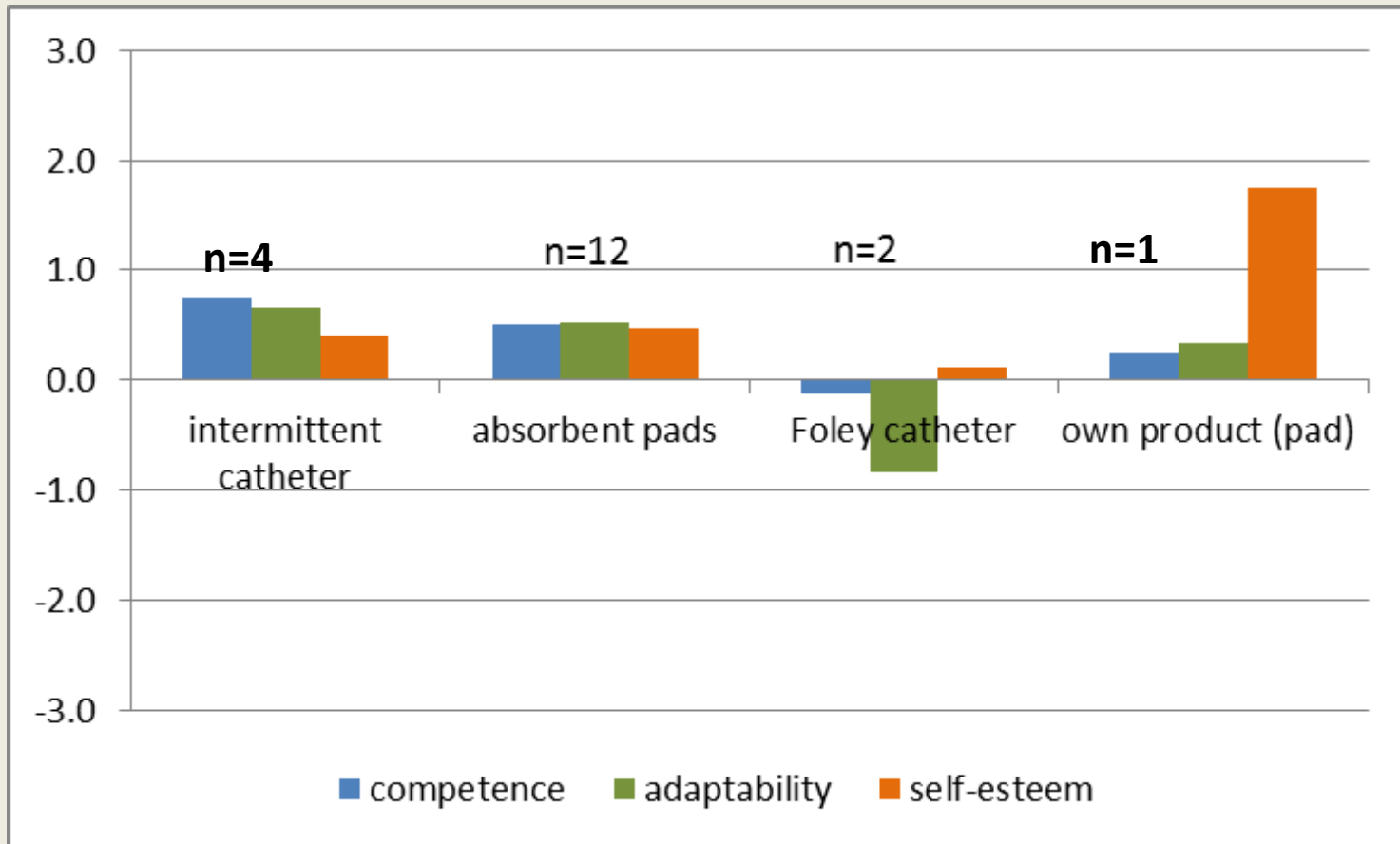
SOCIAL PARTICIPATION

INTIMATE RELATIONS

CONVENIENCE

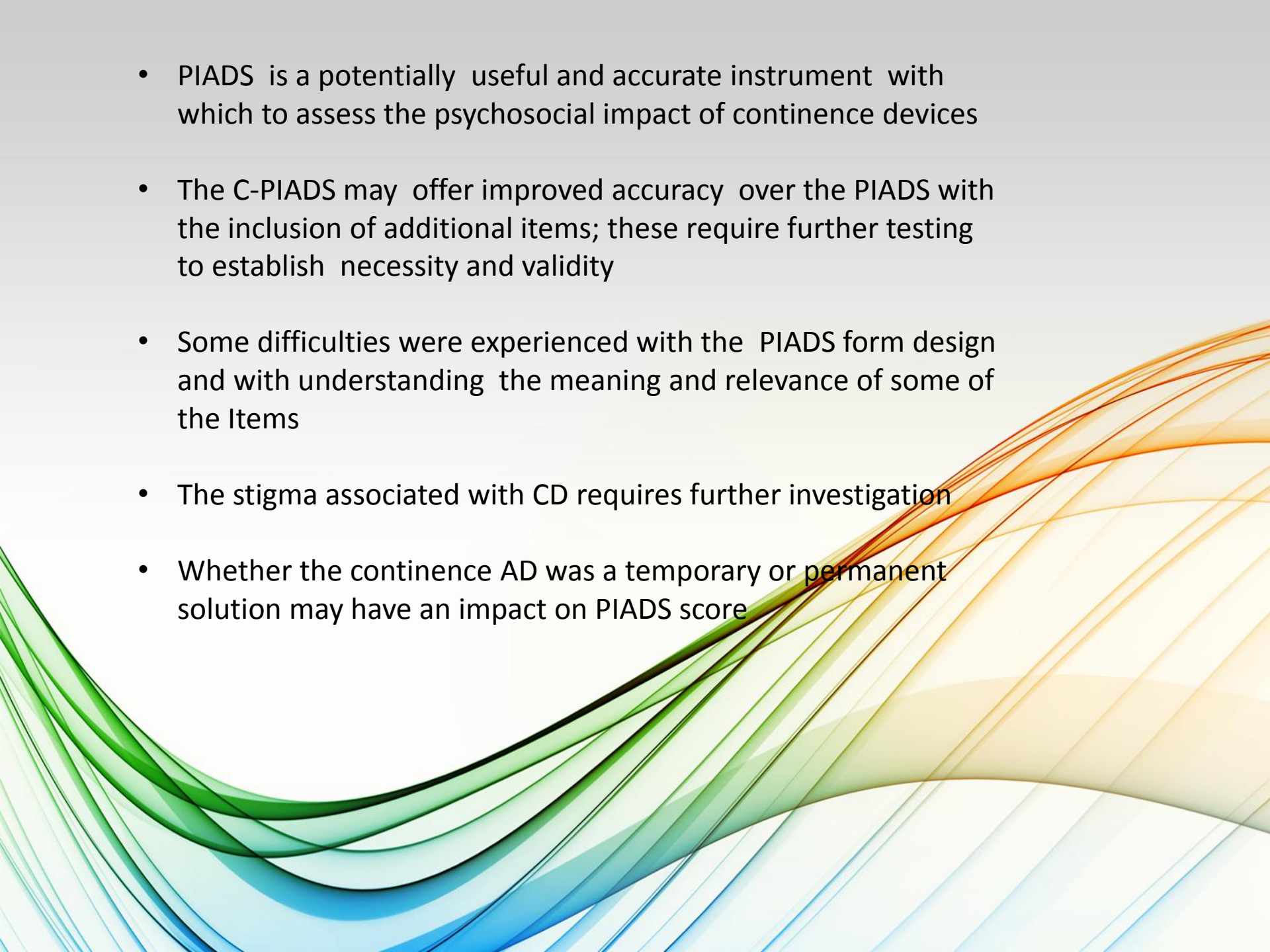
KNOWLEDGE

PIADS for cohort of 20 UK participants



Conclusions



- PIADS is a potentially useful and accurate instrument with which to assess the psychosocial impact of continence devices
 - The C-PIADS may offer improved accuracy over the PIADS with the inclusion of additional items; these require further testing to establish necessity and validity
 - Some difficulties were experienced with the PIADS form design and with understanding the meaning and relevance of some of the Items
 - The stigma associated with CD requires further investigation
 - Whether the continence AD was a temporary or permanent solution may have an impact on PIADS score
- 

Thank You for Listening

Co-authors

Canada

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