



**APPEARANCEMATTERS**

# **TOWARDS A CORE SET OF BODY IMAGE MEASURES:**

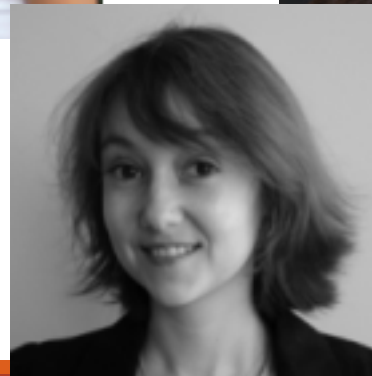
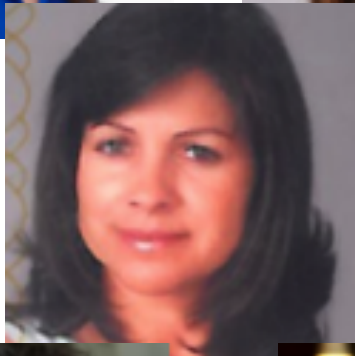
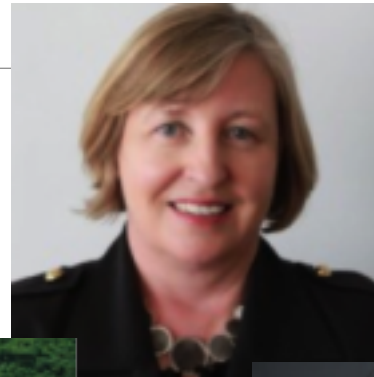
*A SYSTEMATIC REVIEW OF  
MEASUREMENT PROPERTIES OF  
COMMONLY USED QUESTIONNAIRES*

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**LJUBLJANA, APRIL 21, 2017**



# On behalf of:



# Poll:

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**(1)** Who uses measures of body image?

**(2)** Who often struggles to find the “right” measure to use?



# Background:

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- Many different measures to assess body image
- Challenging for researchers and health care providers to determine which measures to use, and to compare findings across studies



# A B O U T F A C E

May 1, 2015

Dear Dr. Thombs:



**BlondMcIndoe  
Research Foundation**

*At the forefront of  
wound healing* **Royal Patron:** HRH The Princess Royal LG, LT, GCVO

Professor Nicholas Rumsey  
Co-Director, Centre for Appearance Research,  
Dept of Health & Social Sciences,  
UWE Bristol,  
Frenchay Campus,  
Bristol.  
BS16 1QY

8<sup>th</sup> May 2015

Dear Professor Rumsey,

Thank you for inviting us, in our roles as Chief Executive and the Director of the BlondMcIndoe Research Foundation (BMRF) to participate as a Project Expert – proposed knowledge synthesis of measures related to body image for people with facial palsy. We are delighted to participate in this important project.

The BMRF has a long history of pioneering advances in scientific research and care for patients suffering from burns as well as tissue loss due to other forms of trauma. After our founders, the pioneering plastic surgeon, Sir Archibald McIndoe, the foundation laboratories are based at the Queen Victoria Hospital, Exeter. Our history can be traced back to the ground-breaking treatment of the experienced by World War II aircrew. These young men, injured by war, became the first patient support group and famously renowned as The Guinea Pig Club. The support of the club and camaraderie is evident in the remaining members of the club. The close association between the BMRF and the Queen Victoria Hospital is unique in the UK. The access to resources, facilities and clinical collaborations is unique in the UK. The BMRF has been up over 54 years of innovative research for the improved care and outcome of people with facial palsy and other body differences.

As an organisation, the BMRF is very familiar with your work into assessing people with appearance related concerns, the psychosocial needs and the impact of facial palsy on patients with disfiguring conditions. We have also met personally on several occasions at meetings of the British Burns Association, and more recently at the 'Appearance Collective' meeting held at the Royal College of Surgeons in London.

Given our long history working with the burns and trauma clinicians at QVH, our association with members of The Guinea Pig Club and our patient representatives, we understand how important body image is for people with facial and other body differences. Our research programmes are dedicated to understanding how to repair and replace damaged tissue as well as repairing deep tissue injuries caused by trauma or after surgery. We are exploring different approaches involving sprayed cells, collagen scaffolds, other biomaterials and gene therapy.

BlondMcIndoe Centre: Queen Victoria Hospital, Holtye Road,  
East Grinstead, West Sussex RH19 3DZ  
Tel: 01342 414295 Fax: 01342 414550 www.blondmcindoe.org

**Patrons:** Peter Blond Sir Ranulph Fiennes BT OBE Lord Marks of Broughton  
Aminda Redman MBE The Hon. Mrs Nicholas Wallop MBE Simon Weston OBE  
Registered charity number: 1106240 Registration number: 5204718



to participate as a Project  
related to body image for  
tant project that can help

**FacialPalsy**<sup>UK</sup>  
INFORM • SUPPORT • RESEARCH

13 May 2015

Dear Professor Thombs

I'm writing reference your proposed project for systematic review of the current measures used for facial palsy (psychological and social) for patients affected by a different appearance. As Deputy Chief Executive of Facial Palsy UK, I would like to offer my support to this project and accept your invitation to participate as a Knowledge-User. I was born with facial palsy and have over ten years' experience in supporting others affected by facial palsy.

Facial Palsy UK is a charity registered in England, Scotland and Wales, providing information and support for people affected by facial paralysis due to any cause. We raise awareness of the needs of facial palsy patients for better services, as currently this patient group is neglected, particularly in terms of psychological support. We provide adult support groups and family days for children affected by the condition, reducing isolation and helping people together who benefit from mutual support. We encourage people to talk openly about their concerns. Previously isolated and vulnerable individuals are now helping to raise awareness of their condition and offering support to others. Our future plans include Workshops: Back to work; Intimacy Issues; Mothers with Bell's palsy. It would greatly benefit us to have recommended measures for evaluation of our work and therefore have more understanding where we need to improve. Currently we are looking for measures to use to demonstrate our impact. We would also like to share and compare information with other charities working in this field across the international community, currently this is difficult.

There is a widely held misconception that facial palsy is just a cosmetic issue. The psychological impact of facial palsy is often underestimated even within the health care system. Very few clinics specialising in support for this patient group. More generalised counselling or support for patient group often reports feeling misunderstood by therapists who underestimate the social condition. I believe a defined set of measures recommended specifically for this patient group would help clinicians to better shape counselling services to improve outcomes. The role of charities such as Facial Palsy UK is extremely important that we are given the right tools to improve services and influence best practice.

Our role with the team will involve sharing our expertise and reviewing project plans to ensure we are fully involved in project meetings to educate the team about the challenges we face. We will actively participate in project meetings to meet the project goals and objectives. Professor Nick Johnson is a member of Facial Palsy UK's Medical Advisory Board and has made a valuable contribution to the charity since its launch in 2012. We look forward to working with you on this project.

Yours sincerely

Karen Johnson  
Deputy CEO

Facial Palsy UK is a company limited by guarantee in England and Wales. No. 8107184. Registered in England and Wales. No. 11481  
Registered Office: Facial Palsy UK, c/o Goldsmiths Ltd, 75 Margaret Road, London, NW6 2EG.

6<sup>th</sup> May 2015

Dear Professor Thombs

I would like to thank you for your kind invitation to join a network of collaborators working towards an assessment of the diverse range of psychometric measures in the fields of psychological and social adjustment to disfigurement in the role of Knowledge-User. In my role as Research Director of the charity Restore, as a burns surgeon and as a past burns patient, I recognize the fundamental and urgent need for this work.

At Restore, we have a range of national and international projects which focus on improving the outcome for patients who have sustained major injuries, including burns. Over twenty years ago, one of our earliest fellows noted the heterogeneity

**restore**  
Burn and Wound Research

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Mr A H N Roberts OBE BMBCh FRCS FRCSG

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Sir Ranulph Fiennes BT OBE  
Frank Lissauer  
Professor Sir Ronald Mason KCB FRB  
Gill Macdonald OBE DL  
Annette Mulholland JP DL



Changing  
the way you face  
disfigurement

12th May 2015

**Letter of support for application to the Canadian  
Institutes of Health Research**

Dear Professors Rumsey and Thombs,

I would like to thank you for your kind invitation to join a network of collaborators working towards an assessment of the diverse range of psychometric measures in the fields of psychological and social adjustment to disfigurement in the role of Knowledge-User. In my role as Chief Executive of Changing Faces which supports and represents the interests of people with facial and body disfigurements of any kind, I recognize the fundamental and urgent need for this work.

At Changing Faces, we have worked over the past 23 years to pioneer and develop and advocate for the provision of best-practice, evidence-based psycho-social interventions for this group of people. They are patients who have congenital, traumatic, oncological, ophthalmological, dermatological, rheumatological and/or neurological conditions but share a very common psycho-social experience.

We recognise that there is a great heterogeneity of objective measures for assessing outcomes and progress for these patients. Establishing which tool is best for a given patient cohort would through its usage inform studies worldwide. In so doing, it would allow health professionals to work out which interventions really work for patients.

Your proposed systematic review of all measures has the potential for being pivotal and Changing Faces would strongly support this work as it underpins all our own efforts to promote self-esteem, confidence and effective adjustment to the visual impact of these conditions.

Changing Faces would be very keen to work with the consortium to help advance this endeavour. We are delighted that the Centre for Appearance Research at The University of the West of England is involved too as Changing Faces was closely involved in the creation of this Centre.

We commend you for forging this consortium and very much support its intent.

Yours sincerely,

James Partridge OBE, DSc (Hon)  
Chief Executive

Changing Faces, The Squire Centre, 33-37 University Street, London WC1E 6JN  
Telephone: 0845 4500 275 Fax: 0845 4500 276 Email: info@changingfaces.org.uk  
www.changingfaces.org.uk

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Registered Charity No. 1011222. Charity Registered in Scotland SC039723





# ABOUT FACE

May 1, 2015

Dear Dr. Thombs:



Thank you for inviting me, in my role as the Executive Director of AboutFace, to participate as a Project Expert Knowledge User in your proposed knowledge synthesis of measures related to body image for people with facial differences. We are delighted to participate in this important project that can help improve the services of AboutFace and other organizations like ours.

Royal Patron: HRH The Princess Royal LG, LT, GCVO

Professor Michaela Rumsey is a Canadian charitable organization that provides information, support and programs for people

6<sup>th</sup> May 2015

Dear Professor Thombs

I would like to thank you for your kind invitation to join a network of collaborators working towards an assessment of the diverse range of psychometric measures in the fields of psychological and social adjustment to disfigurement in the role of Knowledge-User. In my role as Research Director of the charity Restore, as a burns surgeon and as a past burns patient, I recognize the fundamental and urgent need for this work.

At Restore, we have a range of national and international projects which focus on improving the outcome for patients who have sustained major injuries, including burns. Over twenty years ago, one of our earliest fellows noted the heterogeneity of objective measures and it is surprising that with time, only more instruments have developed with little consensus about what best measures domains such as psychological wellbeing. Establishing which tool is best for a given patient cohort would through its usage inform studies worldwide. In so doing, it would allow us to systematically review of all measures for a given condition would be pivotal and Restore would strongly support this work as it underpins our own research spheres



Burn and Wound Research

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Vice Patrons  
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Mark Gosses



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regularly. The close association between the BMRF and the Queen Victoria Hospital, in terms of access to resources, facilities and clinical collaborations is unique in the UK. Our Foundation is a charity working in this field across the international community, currently this is difficult to do. There is a widely held misconception that facial palsy is just a cosmetic issue. The psychological impact of not being able to smile in the same way as everyone else is hugely underestimated even within the healthcare community. Our role with the team will involve sharing our expertise and reviewing project plans to ensure we actively participate in project meetings to educate the team about the challenges service users face; ensuring the team has all necessary information to meet the project goals and objectives. Professor Nicola Rumsey is a member of Facial Palsy UK's Medical Advisory Board and has made a valuable contribution to the work of the charity since its launch in 2012. We look forward to working with you on this project.

As an organisation, the BMRF is very familiar with your work into assessing the needs of people with appearance related concerns, the psychosocial needs and the provision of support for patients with disfiguring conditions. We have also met personally on numerous occasions at meetings of the British Burns Association, and more recently at the 'Appearance Collective' meeting held at the Royal College of Surgeons in London.

Given our long history working with the burns and trauma clinicians at QVH and our association with members of The Guinea Pig Club and our patient representatives, we appreciate and understand how important body image is for people with facial and other body differences. Our research programmes are dedicated to understanding how to repair and regenerate skin structures as well as repairing deep tissue injuries caused by trauma or after surgery. We have explored different approaches involving sprayed cells, collagen scaffolds, other biomaterials and wound

Sincerely,

Karen Johnson

Deputy CEO

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# Background:

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Thus:

there is a need for clear recommendations and guidance on body image measures, in order to make the field more cohesive and increase comparability of outcome research.

# Aim of our COST team:

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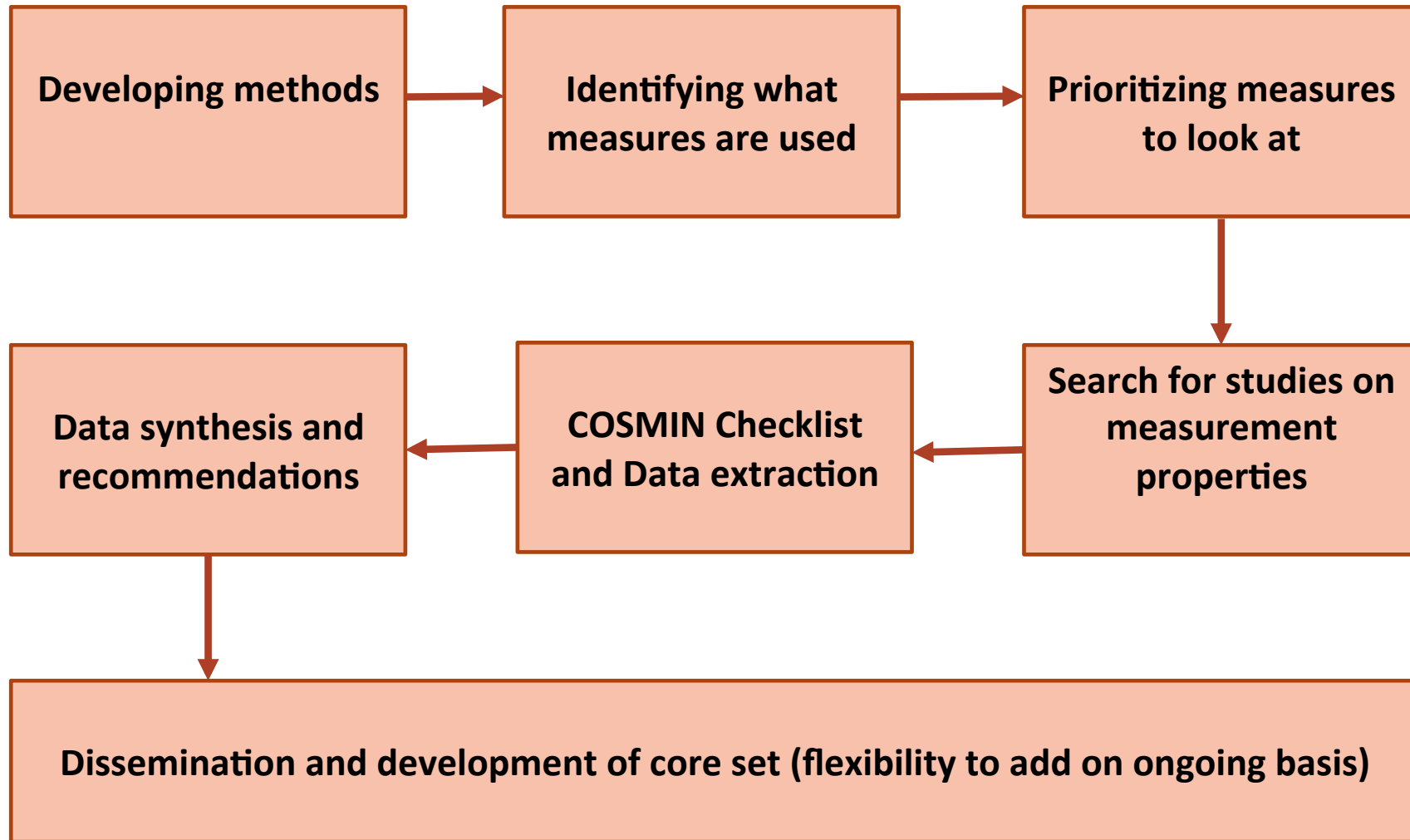
To rigorously synthesize evidence on key body image measures

*and*

work towards a recommended “core set” of measures.



# Steps towards developing a core set



# Step 1: what measures?

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**Differences in terminology and concepts related to appearance, e.g.:**

- \*Body image
- \*Appearance self esteem
- \*Appearance satisfaction
- \*Body esteem
- \*Fear of negative evaluation
- \* ...



# Step 1: definition

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*Contains a measure that generates a total score or subscale scores that assess an evaluative component of body image*

*defined as: an individual making some kind of cognitive or affective evaluation of their body or appearance with a positive or negative valence.*

# Step 1: what measures?

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## Identifying commonly used measures:

- PsycINFO, CINAHL Plus, and MEDLINE databases
- Published articles describing research on body image between August 2011 and August 2014
- Extracted the names of the body image measures used from full-text

# Quiz:

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**How many different body image measures were used between Aug 2011 and Aug 2014?**

- 1) Less than 60
- 2) Between 60 and 120
- 3) More than 120

# Step 1: outcomes

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- Search revealed **> 400 studies**
- Using in aggregate **>150 measures**
- Of which **56** met our definition





# Step 2: Prioritizing


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- Consensus expert meeting
- Prioritized measures based on:  
the extent that they are used in research,  
clinically, and in program evaluation, and/or are  
important theoretically



# Step 2: Outcomes

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- Body Appreciation Scale (BAS)
  - Body Shape Questionnaire (BSQ)
  - Body Esteem Scale (BES)
  - Eating Disorder Inventory (EDI)
  - Multidimensional Body-Self Relations Questionnaire (MBRSQ)
  - Body Image States Scale (BISS)
  - Drive for Muscularity Scale (DMS)
  - Eating Disorder Examination Questionnaire (EDE-Q)
  - Centre for Appearance Research Valence of Appearance scale (CARVAL)
- 

# Step 3: Systematic reviews

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Aim: to synthesize, critically appraise, and compare the evidence on the measurement properties of nine commonly used body image measures.



# Step 3: Systematic reviews

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- For each measure separately:
  - Identify papers on measurement properties
- CINAHL Plus, EMBASE, ERIC, PsycINFO, Scopus, Web of Science databases
- Search terms: variations of the name of the measure in the title/abstract (e.g., Body Shape Questionnaire, BSQ-Short Form, BSQ, BSQ-SF)


# Step 3: In- and exclusion

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- 2 reviewers independently:
  - Title/abstract screening
  - Full-text screening
- Inclusion: papers that examined measurement properties (either as the focus of the article or in a designated section of the article)

# Step 2: Outcomes

---

- Body Appreciation Scale (BAS)
  - Body Shape Questionnaire (BSQ)
  - Body Esteem Scale (BES)
  - Eating Disorder Inventory (EDI)
  - Multidimensional Body-Self Relations Questionnaire (MBRSQ)
  - Body Image States Scale (BISS)
  - Drive for Muscularity Scale (DMS)
  - Eating Disorder Examination Questionnaire (EDE-Q)
  - Centre for Appearance Research Valence of Appearance scale (CARVAL)
- 



# Step 3: In- and exclusion

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Body Appreciation Scale (BAS)	<i>Pending</i>
Body Shape Questionnaire (BSQ)	<i>Pending</i>
Body Esteem Scale (BES)	<i>Pending</i> , <20
Eating Disorder Inventory (EDI)	>90
Multidimensional Body-Self Relations Questionnaire (MBRSQ)	12
Body Image States Scale (BISS)	2
Drive for Muscularity Scale (DMS)	<i>Pending</i>
Eating Disorder Examination Questionnaire (EDE-Q)	<i>Pending</i>
Centre for Appearance Research Valence of Appearance scale (CARVAL and CARSAL)	2

# Step 3: COSMIN checklist

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- Consensus-Based Standards for the Selection of Health Status Measurement Instruments (COSMIN) method: tool increasingly accepted as the gold standard for evidence synthesis of the performance of patient-reported outcome measures
- Can be used to determine if a study on measurement properties meets the standards for good methodological quality.

# Step 3: COSMIN checklist



# Steps to complete

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- Finish systematic reviews
- Synthesize evidence
- Formulate recommendations for:
  - Use of measures
  - Additional studies needed
- Disseminate
- Add reviews of other measures (ongoing basis)



# Conclusion

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- Our work will help address the need for more consistency in the assessment of body image in research and intervention evaluation, which has been emphasized as a priority by researchers, as well as non-government organizations (NGOs) and health care professionals.
- We will be able to provide clear recommendations on research that remains to be conducted on these measures.
- Results will be disseminated through the COST Appearance Matters Network and targeted to key NGOs and health care professionals.





*\*Take  
home message*

- Think twice before developing new measures!
- Focus on carefully conducting validation studies that may be lacking for some commonly used measures





## Systematic review to develop a core set of body image measures: a study of the COST Appearance Matters Network

Linda Kwakkenbos<sup>1</sup>, Barbara Dooley<sup>2</sup>, Maria Piedade Brandão<sup>3</sup>, Ann Frisen<sup>4</sup>, Amanda Fitzgerald<sup>2</sup>, Johanna Kling<sup>4</sup>, Rachel Rodgers<sup>5</sup>, Anabela Silva<sup>3</sup>, Phillippa Diedrichs<sup>6</sup>, Chris Jarrett<sup>6</sup>, Brett Thombs<sup>1</sup>, Lisa Jewett<sup>1</sup>, Diana Harcourt<sup>6</sup>, Nichola Rumsey<sup>6</sup>

<sup>1</sup>Jewish General Hospital and McGill University; <sup>2</sup>University College Dublin; <sup>3</sup>University of Aveiro; <sup>4</sup>University of Gothenburg; <sup>5</sup>Northeastern University; <sup>6</sup>Centre for Appearance Research and University of the West of England

### Background

- Many different measures have been developed to assess body image, making it challenging for researchers and health care providers to determine which measures to use, and to compare findings across studies.
- Thus, there is a need for clear recommendations and guidelines for assessing body image, in order to make the field more cohesive and increase the comparability of outcome research.
- The Consensus-Based Standards for the Selection of Health Status Measurement Instruments (COSMIN) method is a relatively new tool that is increasingly accepted as the gold standard for evidence synthesis of the performance of patient-reported outcome measures.

### Objective

To apply the COSMIN methodology to rigorously synthesize evidence on key body image measures and work towards a recommended "core set" of measures

### Methods

- We searched the PsycINFO, CINAHL Plus, and MEDLINE databases for published research articles related to body image between August 2011 and August 2014.
- Team members extracted the names of the measures used to assess body image, defined for our purposes as a cognitive or affective evaluation of one's body or appearance with a positive or negative valence.
- Our international team of experts then prioritized measures based on the extent that they are used in research, clinical settings, and/or are important theoretically.
- A search for each measure separately was conducted to identify published studies on measurement properties.

### Findings

- Over 400 studies were identified that had used, in aggregate, more than 150 body image measures.
- Based on priority rankings, the following measures were selected as the top priority measures for evidence synthesis:
  - Body Appreciation Scale;
  - Body Shape Questionnaire;
  - Body Esteem Scale;
  - Eating Disorder Inventory;
  - Multidimensional Body-Self Relations Questionnaire;
  - Body Image States Scale;
  - Drive for Muscularity Scale;
  - Eating Disorder Examination Questionnaire;
  - Centre for Appearance Research Valence of Appearance scale.
- The next step will involve 9 systematic reviews of the measurement properties of these measures and synthesis of results.



### Conclusions

- Our work will help address the need for more consistency in the assessment of body image in research and clinical practice, which has been emphasized as a priority by researchers, as well as non-government organizations (NGOs) and health care professionals.
- In addition, we will be able to provide clear recommendations for increasing the empirical support for the measures proposed within the final core set.
- Results will be disseminated through the COST Appearance Matters Network and targeted to key NGOs and health care professionals.



APPEARANCEMATTERS



COST is supported by  
the EU Framework  
Program Horizon 2020

# Thank you!

- Barbara Dooley
- Maria Piedade Brandão
- Ann Frisen
- Amanda Fitzgerald
- Johanna Kling
- Rachel Rodgers
- Anabela Silva
- Phillippa Diedrichs
- Chris Jarrett
- Brett Thombs
- Lisa Jewett
- Diana Harcourt
- Nichola Rumsey



KwakkenbosL@gmail.com