

PROMIS®
Measuring Health Outcomes
Around the World

PROGRAM

October 23–24, 2016

Radisson Blu Scandinavia
Copenhagen, Denmark



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ORGANIZATION

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Velkommen til København

On behalf of the PROMIS Scientific Program Committee, it is our pleasure to welcome you to Copenhagen and the 2nd PROMIS Conference, ***PROMIS: Measuring Health Outcomes Around the World***. This meeting, hosted by the PHO, will explore the explosive growth of the PROMIS family of measures and their implementation across international borders. You'll hear from researchers and clinicians around the globe who are developing, translating, validating and using PROMIS in many countries.

Plenary Sessions

A highlight of this meeting is certain to be the international group of thought leaders who will share their expertise and innovative research in a series of plenary sessions. Speakers will provide updates on the use of PROMIS around the world, first-hand experiences about considerations that can arise when creating new item banks or using PROMIS measures across borders, and what we can learn from other fields. Participants will learn about the linguistically and culturally validated translations currently available, as well as ones in progress.

New Workshops Added

If you are new to PROMIS, want a refresher on IRT and computer adaptive testing, or are thinking of using Assessment Center, join the **Introduction to PROMIS Item Response Theory, and Computer Adaptive Tests** workshop Sunday morning from 9.00-10.00, just prior to the official opening of the meeting. Interested in working with the PROMIS group to help translate and validate measures in your country? **Translation of PROMIS Measures Workshop** on Monday morning (9.45 to 11.00) is a great way

to learn more about PROMIS' rigorous approach to creating universal translations. Join the workshop, **How to Work With PROMIS in Your Setting**, on Monday afternoon to hear about the range of options available to access PROMIS through systems such as Assessment Center, REDCap, EPIC and other electronic health records, and other options that optimize the online collection and scoring of health outcomes.

Explore Copenhagen

Enjoy the warm hospitality of one of Europe's most vibrant and happiest cities — Copenhagen. As time permits, hop on a bike for a cycling tour. You can explore 30 top attractions in Copenhagen that are within close proximity of the meeting hotel, Tivoli Gardens, The Little Mermaid statue, Kronborg Castle, and the one-of-a-kind Freetown Christiania, a green and car-free neighborhood. If you weren't able to secure a reservation at Noma ("the best restaurant in the world"), rest easy — there's an abundance of traditional Danish and other restaurants close by.

The PROMIS community is a vibrant network of researchers, clinicians, and others. We welcome the familiar faces that joined us last year for our inaugural conference in Philadelphia as well as those joining us for the first time in Copenhagen. We thank you for sharing your passion and commitment to state-of-the-art health outcomes measurement, and for helping us make this international meeting of PROMIS colleagues a great success.

Susan Bartlett, PhD & Caroline Terwee, PhD

Thank you to the Scientific Advisory Committee:

Jordi Alonso, MD, MPH, PhD
Susan Bartlett, PhD
Phillip Batterham, PhD
Jakob Bjorner, MD, PhD
David Cella, PhD
John Chapin, PhD
John Chaplin, PhD
Karon Cook, PhD

Helena Correia, Lic.
Christopher Forrest, MD, PhD
Richard Gershon, PhD
Wojecich Glinkowski, PhD
Sandra Nolte, PhD
Dennis Revicki, PhD
Matthias Rose, MD, PhD
Caroline Terwee, PhD

Jose (Chema) M Valderas, MD, MPH, PhD
Kevin Weinfurt, PhD

JOIN US FOR A

Social Event



Skål! [Cheers!]

*Please join us for a **dinner** reception, drinks and a relaxing opportunity to network with colleagues in a beautiful two level restaurant overlooking the harbor.*

Sunday October 24

6.30–9.00 pm

The Tower Restaurant

IDA Mødecenter, 6th & 7th floors

Kalvedbod Brygge 31

1560 København

Directions: Head west on Amager Blvd toward Klaksvigsgade (400m), and continue onto Langebro (250m). Continue on to H.C. Andersens Blvd (41m). Turn left onto Kalvedbod Brygge/02, and take the stairs down (450m). Turn left onto Bernstorffsgade (13m). Turn right onto Kalvedbod Brygge, and destination will be on the left (160m).

PHO would like to thank OBERD (www.oberd.com) for graciously underwriting this complimentary event.



PROMIS International Contacts

The PROMIS Health Organization (PHO) PROMIS International Committee is a volunteer collaboration of researchers and clinician scientists with interests in optimizing and harmonizing global use of PROMIS instruments and related resources for research, care and population monitoring. The PROMIS International Committee is part of the PHO and collaborates with the PHO Board of Directors to identify, coordinate, and promote best practices to develop, translate, validate, and utilize PROMIS instruments across countries.

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Sunday, October 23

9.00–10:30
Finland Room

Optional Workshop: An Introduction to PROMIS, Item Response Theory, and Computer Adaptive Tests

10.30–11.00
Norway Room

Official Welcome

Mongin Forrest, International Coordinator, *Danish Parliament*

Kevin Weinfurt, PhD, PHO President *Duke University, Durham, North Carolina, USA*

Meeting Orientation

Conference Chairs: Susan Bartlett, PhD *McGill University Montreal, Quebec, Canada*

Caroline Terwee, PhD *VU University Medical Center, Amsterdam, The Netherlands*

Plenary 1

11.00–12.00
Norway Room

PROMIS Updates Around The Globe

Moderator: Kevin Weinfurt, PhD *Duke University, Durham, North Carolina, USA*

Current Status of PROMIS and the PHO

David Cella, PhD *Northwestern University, Chicago, Illinois USA*

PROMIS Going Global: Challenges and Opportunities

Jordi Alonso, MD, MPH, PhD *IMIM Hospital del Mar, Pompeu Fabra University, Barcelona, Spain*

12.00–1.30

Sweden Room: Lunch & Poster Session

1.30–2.45

Concurrent Session #1

Finland Room: PROMIS on the Front Line: Assessing Quality of Care

Iceland Room: Item Bank Development and Validation

Norway Room: Translation and Cross-Cultural Validation

2.45–3.00

Break

3.00–4.15

Concurrent Session #2

Finland Room: Applications Across Clinical Populations

Iceland Room: Interpreting PROMIS Scores

Norway Room: Advanced Validation Methods

4.15–4.45

Break / Network with PROMIS National Representatives

Plenary 2

4.45–6.00
Norway Room

Details, Details, Details:

How to Implement PROMIS in Your Setting

Moderator: Dave Cella, PhD *Northwestern University, Chicago, Illinois, USA*

Implementing PROMIS CAT

Michael Bass, MS *Northwestern University, Chicago, Illinois, USA*

The Dutch-Flemish Assessment Center

Caroline Terwee, PhD *VU University Medical Center, Amsterdam, The Netherlands*

Implementation of PROMIS in Registries

John Chaplin, PhD *Inst. Clinical Sciences, Sahlgrenska Academy at University
Gothenburg, Sweden*

6:30–9.00

SOCIAL EVENT in the IDA Mødecenter Centre

Monday, October 24

8.15–8.30
Norway Room

Welcome Day 2

Plenary 3

8.30–9.30
Norway Room

How IRT & CAT Have Advanced Assessment in Other Fields

Moderator: Karon Cook, PhD *Northwestern University, Chicago, Illinois*

Open-Source Collaboration to Keep Adaptive Online Measurement In Tune and On Time: Insights From 5 Years of Concerto

Chris Gibbons, MD, Director of Health Assessment & Innovation
The Psychometrics Center, University of Cambridge, England

Learning from Educational Testing

Svend Kreiner, Professor Emeritus, Section of Biostatistics
Institute of Public Health, University of Copenhagen, Denmark

9.30–9.45

Break

9.45–11.00

Concurrent Session #3

Finland Room: Extending the Reach and Relevance of Existing PROMIS Item Banks
Iceland Room: Applications in Musculoskeletal Conditions
Norway Room: Workshop: Translation of PROMIS Measures

11.00–11.15

Break

11.15–12.30

Concurrent Session #4

Finland Room: New Developments in the PROMIS Physical Function Item Bank
Iceland Room: Data Collection Methods in Clinical Practice
Norway Room: Workshop: How to Work With PROMIS in Your Setting

12.30–2.00

Sweden Room: Lunch & Poster Session

Plenary 4

2.00–3.30
Norway Room

A Global Approach: Considerations for Expanding PROMIS Use Across Borders

Moderator: Jordi Alonso, MD, MPH, PhD *IMIM Hospital del Mar, Pompeu Fabra University, Barcelona, Spain*

Translation and Cultural Adaptation: Methodology and Challenges

Helena Correia, Lic *Northwestern University, Chicago, Illinois USA*

The Impact of Country-Specific versus General (US) Item Parameters on PROMIS CAT T-Scores

Martine Crins, MSc *Amsterdam Rehabilitation Research Center, Reade, The Netherlands*

National Reference Values: Who is the Norm?

Matthias Rose, MD, PhD *Department of Psychosomatic Medicine Charité – Universitätsmedizin Berlin, Germany*

3.30–4.00
Norway Room

A PROMISING Future

Panel Discussion: Caroline Terwee, PhD; Susan Bartlett, PhD; Jordi Alonso, MD, MPH, PhD; Matthias Rose, MD, PhD; Sandra Nolte, PhD; Jim Witter, MD, PhD, FACR; Karon Cook, PhD
Moderator: Kevin Weinfurt, PhD *Duke University, Durham, North Carolina, USA*

About PHO

Join the PHO today!

Visit www.promishealth.com and become an active member of the PHO. We need your help to advance the use of PROMIS around the world.

Yearly Membership:

\$100 per year fee for individuals

Benefits:

- Discounted registration fees to conferences
- No charge for monthly PHO member office hour & webinars
- Positive effects of associating with people who share your interests and goals



PHO's Mission

The PROMIS® Health Organization (PHO) is a 501(c)(3) charitable foundation which was founded in 2008 by a group of scientists who were funded by the United States National Institutes of Health (NIH) to develop and validate the PROMIS item banks. The PHO is a **volunteer** open society that welcome members from around the world to bring the “patient’s voice” to the forefront of research and healthcare.

Our mission is to improve health outcomes by developing, maintaining, improving, and encouraging the application of the Patient Reported Outcomes Measurement Information System (PROMIS®).

PHO's Main Goals

The four main goals of the PHO, which complement both the PHO’s mission and values, are to:

- Advance the science of health outcomes assessment,
- Disseminate standardized and validated health outcome metrics,
- Foster the development of new patient-reported health outcomes for diverse populations,
- Educate the scientific and clinical communities on the science of patient-reported outcomes.

Learn More

For more information about PROMIS and to access to the measures visit www.healthmeasures.net and navigate to explore measurement systems: PROMIS, Neuro-QOL, ASCQ-MeSM and NIH Toolbox.

Assessment CenterSM is an online data collection tool that enables researchers to create study-specific websites for capturing participant data securely online. To learn more, visit www.assessmentcenter.net.

Sunday, October 23

9.00-10.30 am
Finland Room

Optional Workshop: Introduction to PROMIS, Item Response Theory, and Computer Adaptive Tests

Nan Rothrock, PhD
Northwestern University
Chicago, Illinois USA

AND

Matthias Rose, MD, PhD
Department of Psychosomatic Medicine
Charité – Universitätsmedizin Berlin, Germany

New to PROMIS or item response theory (IRT)? Join us for an optional introductory workshop to learn about the PROMIS initiative, IRT, and computer adaptive tests (CAT). We will review terminology, and describe how IRT works, and compare IRT with classical test theory. Learn how CAT can increase precision and efficiency. We will also offer guidance about instrument selection and practical tips for using PROs in clinical research and practice settings.

PLENARY: PROMIS Updates Around the Globe

11.00-12.00 pm
Norway Room

Moderator: Kevin Weinfurt, PhD Duke University, Durham, North Carolina, USA

Current Status of PROMIS and the PROMIS Health Organization (PHO)

David Cella, PhD Northwestern University, Chicago, Illinois USA

PROMIS Going Global: Challenges & Opportunities

Jordi Alonso, MD, MPH, PhD IMIM Hospital del Mar, Pompeu Fabra University, Barcelona, Spain

1.30-2.45 pm
Finland Room

PROMIS on the Front Line: Assessing Quality of Care

Moderator: Clifton Bingham, MD, Johns Hopkins University, Baltimore, Maryland, USA

Abstract Number & Title	Presenting Author
(59) Using PROsetta Stone to Translate PROMIS Depression Scores for Meaningful Use in Orthopaedic Trauma	Amanda Spraggs-Hughes, MA
(37) Impact of PROMIS on Patient Satisfaction	Marsha Jensen, BSN, RN
(38) The Use of PROMIS CAT Post-Surgical Scores In Assessing “Value” in ACL Reconstruction Surgery.	Owen Papuga, PhD
(57) Insurance Status and Patient Outcomes in the Orthopaedic Outpatient Settings	Christopher McAndrew, MD, MSc

Sunday, October 23

1.30–2.45 pm

Item Bank Development and Validation

Iceland Room

Moderator: Wojeich Glinkowski, MD, PhD *Medical University of Warsaw, Poland*

Abstract Number & Title	Presenting Author
(40) Development and Content Validation of a PROMIS Measure for Medication Adherence	<i>Rob J Fredericksen, PhD, MPH</i>
(24) Development and Psychometric Evaluation of the Pediatric Oral Health Item Banks	<i>Christopher B. Forrest, MD, PhD</i>
(72) Validation of PROMIS Emotional Distress Short Forms in a Cervical Cancer Survivor Population	<i>Lari Wenzel, PhD</i>
(67) Variability of PROMIS Domains Across Orthopedic Conditions	<i>Agnes Dardas, BA</i>

1.30–2.45 pm

Translation and Cross-Cultural Validation

Norway Room

Moderator: Helena Correia, Lic *Northwestern University, Chicago, Illinois, USA*

Abstract Number & Title	Presenting Author
(9) Danish Translation of the PROMIS Item Bank for Physical Functioning – Results from Cognitive Testing	<i>Christina W. Schnohr, MSc, PhD</i>
(19) Translation of the Concept of Fatigue in PROMIS Measures	<i>Benjamin Arnold, MA</i>
(14) German Translation of Six Item Banks from PROMIS	<i>Fionna Klasen, PhD</i>
(25) Progress in the Cultural Adaptation of Four PROMIS Pediatric Item Banks for Use in Sweden	<i>John Chaplin, PhD</i>

Sunday, October 23

3.00–4.15 pm

Applications Across Clinical Populations

Finland Room

Moderator: Kevin Weinfurt, PhD *Duke University, Durham, North Carolina, USA*

Abstract Number & Title	Presenting Author
(50) Chinese-American Rheumatology Patients Using Traditional Chinese Medicine Have Worse PROMIS Health Status Scores	<i>Kai Sun, MD</i>
(22) Functional Impact of Congenital Hand Differences: Results from the Congenital Upper Limb Differences (CoULD) Registry	<i>Patricia Connell, MPH</i>
(15) The Ability to Capture Sexual Dysfunction in Young Cancer Patients Using Items of the SexFS	<i>Lena Wettergren, PhD</i>
(44) Correlation of PROMIS Upper Extremity, Pain Interference and Depression Scores with SST and ASES Scores	<i>Aaron M. Chamberlain, MD, MSc</i>

3.00–4.15 pm

Interpreting PROMIS Scores

Iceland Room

Moderator: Christopher Forrest, MD, PhD *Children's Hospital of Philadelphia, Pennsylvania, USA*

Abstract Number & Title	Presenting Author
(70) Comparing IRT Pattern Scoring and IRT Summed Score Conversion Tables for PROMIS Short Forms	<i>Eisuke Segawa, PhD</i>
(66) Floor Effect of Depression on Patients with Orthopedic Conditions	<i>Ryan Calfee, MD MSc</i>
(82) The Clinical Spectrum of PROMIS Physical Function Scores Over Time in Patients with Operative Lumbar Pathology	<i>Ashley Neese, BS</i>
(71) Differences in PROMIS Responses in People with RA Recruited Online vs. an Academic Medical Center	<i>Susan Bartlett, PhD</i>

Sunday, October 23

3.00–4.15 pm

Advanced Validation Methods

Norway Room

Moderator: Karon Cook, PhD *Northwestern University, Chicago, Illinois, USA*

Abstract Number & Title	Presenting Author
(48) Construct Validity and Differential Item Functioning of Spanish PROMIS Depression, Anxiety and Anger	<i>Gemma Vilagut, MSc</i>
(49) Determining When Multidimensionality Impacts Total Scale and Subscale Scores: Application of Confirmatory Bifactor Modeling to Osteoarthritis of the Knee (OAK) Patient Responses to the KOOS	<i>Michael A. Kallen, PhD</i>
(47) Multidimensional Higher-Order Factor Structure and Diagnostic Accuracy of PROMIS Mental Health Domain	<i>Carlos G. Forero, PhD</i>
(2) Longitudinal Measurement Invariance of the Dutch Flemish PROMIS Item Banks for Anxiety and Depression	<i>Gerard Flens, MSc</i>

PLENARY: Details, Details, Details: Implementing PROMIS in Your Part of the World

4.45-6.00 pm

Norway Room

Moderator: David Cella, PhD *Northwestern University, Chicago, Illinois, USA*

Implementing PROMIS CAT

Michael Bass, MS *Northwestern University, Chicago, Illinois, USA*

The Dutch-Flemish Assessment Center

Caroline Terwee, PhD *VU University Medical Center, Amsterdam, The Netherlands*

Implementing PROMIS in Registries

John Chaplin, PhD *Inst. Clinical Sciences, Sahlgrenska Academy at University Gothenburg, Sweden*

PLENARY: How IRT & CAT Have Advanced Assessment in Other Fields

8.30-9.30 am
Iceland Room

Moderator: Karon Cook, PhD *Northwestern University, Chicago, Illinois, USA*

Open-Source Collaboration to Keep Adaptive Online Measurement in Tune and On Time: Insights from 5 Years of CONCERTO

Chris Gibbons, MD *Director of Health Assessment and Innovation, The Psychometrics Center, University of Cambridge, England*

Learnings from Educational Testing

Svend Kreiner, Professor Emeritus *Section of Biostatistics, Institute of Public Health, University of Copenhagen, Denmark*

9.45 – 11.00 am **Extending the Reach and Relevance of Existing PROMIS Item Banks**

Finland Room

Moderator: Jordi Alonso, MD, MPH, PhD *Health Services Research Unit, Hospital del Mar Medical Research Institut (IMIM) Barcelona, Spain*

Abstract Number & Title	Presenting Author
(36) Creating Condition-Specific PROMIS® Assessments: An Overview of the Gap Analysis Method	<i>Susan Yount, PhD</i>
(5) Development of a Dutch-Flemish PROMIS® Physical Functioning Short Form for Geriatric Rehabilitation	<i>Ewout B. Smit, MD</i>
(55) PROMIS Physical Function: Application to a Complex Rare Disease Population - Tenosynovial Giant Cell Tumor (TGCT)	<i>Heather L. Gelhorn, PhD</i>
(11) Development of a Patient-Reported Outcome Instrument For Patients with Lumbar Radicular Pain - STUDY PROTOCOL	<i>Charlotte Ibsen, MHSc</i>

9.45 – 11.00 am **Applications in Musculoskeletal Conditions**

Iceland Room

Moderator: James Witter, MD, PhD *Medical Officer/Rheumatic Diseases Clinical Program Division of Skin and Rheumatic Diseases NIAMS, NIH, DHHS, Bethesda, Maryland, USA*

Abstract Number & Title	Presenting Author
(62) Validity and Reliability of PROMIS in Systemic Lupus Erythematosus (SLE)	<i>Shanthini Kasturi, MD</i>
(58) PROMIS Physical Function, Pain Interference, and Depression: Assessing Outcomes in an Orthopaedic Trauma Setting	<i>Christopher McAndrew, MD, MSc</i>
(16) Responsiveness of the DF-PROMIS-PB and the DF-PROMIS-PI Item Banks in Patients Presenting in Musculoskeletal Practice	<i>Wouter Schuller, MD</i>
(73) PROMIS-29 Health Profile and Related Short Forms Capture the Experiences of People Living with Rheumatoid Arthritis	<i>Susan Bartlett, PhD</i>

Monday, October 24

9.45-11.00 am

WORKSHOP: Translation of PROMIS Measures

Norway Room

Helena Correia, Lic

*Northwestern University
Chicago, Illinois, USA*

AND

Caroline Terwee, PhD

*VU University Medical Center, Amsterdam
The Netherlands*

This workshop will focus on introducing the state-of-art translation methodology adopted by PROMIS, covering topics such as universal approach, equivalence, harmonization across languages, and cognitive debriefing. We will also outline how PROMIS's organization of items into item banks affects translations from both a conceptual and a pragmatic perspective. The session will include a practical translation exercise, discussion of translation issues and examples of recommended solutions. This workshop is appropriate for researchers and clinicians with little experience with translation and anyone who wants to better understand the rigorous PROMIS translation methodology.

11.15-12.30 pm

New Developments in the Physical Function Item Bank

Finland Room

Moderator: Muirne Paap, PhD, CEMO University of Oslo, Norway

Abstract Number & Title	Presenting Author
(69) An Upper Extremity Physical Functioning Item Bank	<i>Aaron J. Kaat, PhD</i>
(68) Patient-Reported Musculoskeletal Function: Comparing PROMIS Upper-Extremity to PROMIS General Physical Function Scores	<i>Ryan Calfee, MD, MSc</i>
(34) Reducing Ceiling Effects in PROMIS Physical Function Measures by Using an Extended Response Scale	<i>Gregor Liegl, Mag</i>
(79) Descriptive, Psychometric, and Feasibility Summaries of PROMIS Physical Function Instruments for the TOIMIA Database	<i>Kaisa Kokko, MSc, PT</i>

11.15-12.30pm

Data Collection Methods in Clinical Practice

Iceland Room

Moderator: Dennis Revicki, PhD Evidera, Bethesda, Maryland, USA

Abstract Number & Title	Presenting Author
(10) AO Patient Outcomes Center : A Novel Software to Implement PROMIS in Orthopedic Surgeons' Clinical Routine	<i>Alexander Joeris, MD MSc</i>
(75) Treatments Should Target Physical Function, Mood, and Fatigue to Enhance Participation in People with Rheumatoid Arthritis	<i>Clifton Bingham, MD</i>
(6) Integrating PROMIS Short Forms to a Patient-Driven Mobile ICanFunction Assessment Tool (mICF)	<i>Heidi Anttila, Ph.D., PT</i>
(31) Using a Multi-Modal, Longitudinal Collection Strategy to Collect PROMIS Scales Across a Healthcare Delivery System	<i>Randi Zegman, BA</i>

Monday, October 24

11.15 -12.30 pm

WORKSHOP: How to Work with PROMIS in Your Setting

Norway Room

Nan Rothrock, PhD

Northwestern University

Chicago, Illinois, USA

AND

Michael Bass, MS

Northwestern University

Chicago, Illinois, USA

Learn more about implementing PROMIS in your setting. Common and unique features between CAT, off-the-shelf and custom short forms (SFs) will be outlined. Data collection tools that are readily available and can be used to administer PROMIS will be reviewed, and guidance will be offered on selecting tools that meet your needs. We will troubleshoot common implementation challenges and highlight successful examples from research and clinical settings.

PLENARY:

A Global Approach: Considerations for Expanding PROMIS Use Across Borders

2.00-3.30 pm

Norway Room

Moderator: Jordi Alonso, MD, MPH, PhD *IMIM Hospital del Mar, Pompeu Fabra University, Barcelona, Spain*

Translation & Cultural Adaptation: Methodology & Challenges

Helena Correia, BA *Northwestern University, Chicago, Illinois, USA*

The Impact of country-Specific Versus General (US) Item Parameters on PROMIS CAT T-Scores

Martine Crins, MSc *Amsterdam Rehabilitation Research Center, Reade, The Netherlands*

National Reference Values - Who is the Norm?

Matthias Rose, MD, PhD *Department of Psychosomatic Medicine Charité – Universitätsmedizin Berlin, Germany*

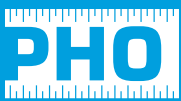
3.30-4.00 pm

PANEL DISCUSSION: A PROMISing Future

Norway Room

Caroline Terwee, PhD; Susan Bartlett, PhD; Jordi Alonso, MD, MPH, PhD; Matthias Rose, MD, PhD; Sandra Nolte, PhD; Jim Witter, MD, PhD; Karon Cook, PhD

Moderator: Kevin Weinfurt, PhD *Duke University, Durham, North Carolina, USA*



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