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Improving healthcare decisions

ISPOR Special Interest Group

Are We Patient-Centered Yet? Patient Engagement and Patient-Centered Research in HEOR

Presented by ISPOR Patient-Centered Special Interest Group

Monday, 13 November 2023
11:45AM – 12:45PM

Agenda

Time	Topic	Presenter(s)
11:45	Overview of Patient-Centered Special Interest Group Speaker introductions What is patient engagement?	Jessica Roydhouse
12:00	Patient advocate perspective: patient engagement, engaging underrepresented groups and helpful resources	Omar Escontrías
12:10	Patient and public engagement in patient-reported outcome measure development and valuation studies	Jill Carlton
12:20	Discussion – Q & A	All
12:45	Forum close	All

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Introductions and Patient-Centered Special Interest Group Overview

Meet the Panelists

- Moderator
  - **Jessica Roydhouse, PhD,** Menzies Institute for Medical Research, University of Tasmania, Australia
- Panelists
  - Patient Advocate Perspective: **Omar Escontrías, DrPH,** National Health Council, USA
  - Academic Perspective: **Jill Carlton, PhD,** University of Sheffield, UK

What is an ISPOR Special Interest Group (SIG)?

A SIG is an organized member group initiated by ISPOR members and intended to:

- Focus on a specific topic area to advance the health economic and outcomes research (HEOR) science and the use of HEOR in healthcare decisions
- Monitor trends and disseminate information to SIG members or the larger ISPOR community
- Develop scientific and educational work products

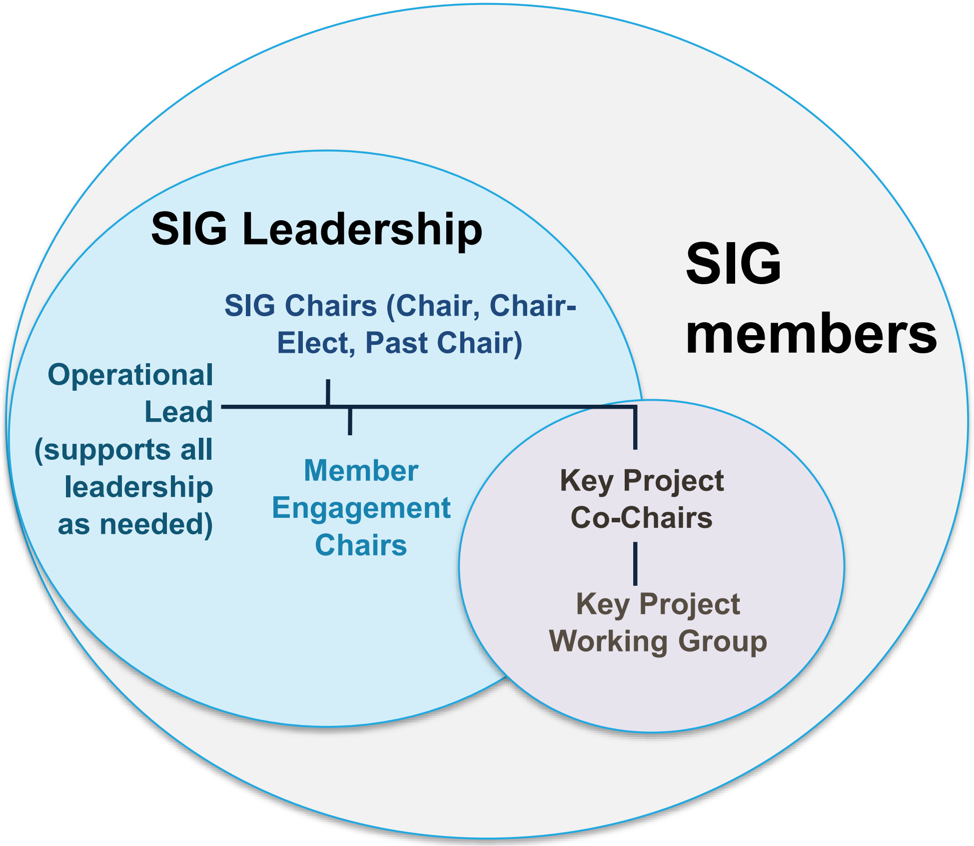
Structure of an ISPOR SIG

SIG Leadership

- Provide overall direction and leadership
- Identify topics for the SIG to address and platforms for delivery
- Work with the co-chairs to ensure the project timelines are met
- Provide updates to the SIG
- Submit yearly reports to ISPOR
- Recruit new SIG members

Member Engagement Chairs

- Develop and implement projects that encourage member participation
- Facilitate topic content dissemination
- Monitor and support the SIG community


SIG Leadership

SIG Chairs (Chair, Chair-Elect, Past Chair)

Operational Lead (supports all leadership as needed)

Member Engagement Chairs

Key Project Co-Chairs

Key Project Working Group

SIG members

Patient-Centered SIG Mission

To facilitate the involvement of patient representatives in all stages of research and decision making to improve healthcare, its delivery, and outcomes.

Patient-Centered SIG Leadership

Chair-Elect
Nan Qiao, PhD
Merck, USA

Chair
Jessica Roydhouse, PhD
University of Tasmania, AUS

Past Chair
Eleanor Perfetto, PhD
University of Maryland, USA

Operational Lead
Sam Llewellyn, BSc
Vitaccess, UK

Member Engagement Co-Chair
Angie Botto-van Bemden
Musculoskeletal Research International, USA

Member Engagement Co-Chair
Prajakta Masurkar, PhD
Amgen, USA

Patient-Centered SIG Projects: Defining Patient Engagement (2020)

Definition of Patient Engagement in Research

Webinars, VOS publication

ScienceDirect
Contents lists available at **sciencedirect.com**
Journal homepage: **www.elsevier.com/locate/jval**

ISPOR Report

Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group

Rachel L. Harrington, PhD,[1,*] Maya L. Hanna, MPH, PhD,[2] Elisabeth M. Oehrlein, MS, PhD,[3] Rob Camp, BS,[4] Russell Wheeler, BSc,[5] Clarissa Cooblall, MPH,[6] Theresa Tesoro, MSN,[6] Amie M. Scott, MPH,[7] Rainald von Gizycki, MA, PhD,[8] Francis Nguyen, PharmD,[9] Asha Hareendran, MA, PhD,[10] Donald L. Patrick, MSPH, PhD,[11] Eleanor M. Perfetto, MS, PhD[3]

[1]National Committee for Quality Assurance, Washington, DC, USA; [2]Boehringer Ingelheim Pharmaceuticals Inc., Ridgefield, CT USA; [3]National Health Council, Washington, DC, USA; [4]Community Advisory Board Programme, EURORDIS, Barcelona, Spain; [5]Leber's Hereditary Optic Neuropathy, Merusac, France; [6]Scientific & Health Policy Initiatives, ISPOR, Lawrenceville, NJ, USA; [7]Consulting, New York, NY, USA; [8]PRO RETINA Deutschland e.V., Aachen, Germany; [9]Bayer Healthcare Pharmaceuticals, Jersey City, NJ, USA; [10]Evidera, London, England, UK; [11]University of Washington, Seattle, Washington, USA

From the Patients

Defining Patient Engagement in Research

Rob Camp, BS, Community Advisory Board Programme, EURORDIS, Barcelona, Spain; Russell Wheeler, BSc, Leber's Hereditary Optic Neuropathy, Merusac, France; Rainald von Gizycki, MA, PhD, PRO RETINA Deutschland e.V., Aachen, Germany; Robert McBurney, BSc, PhD, Accelerated Cure Project for Multiple Sclerosis, Waltham, MA, USA

Patient-Centered SIG Projects – Some Current Efforts

Webinars on FDA PFDD Guidance: 2023

Jul 5, 2023

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FDA Patient-Focused Drug Development (PFDD) Guidance Webinar - Part 3

Presented by the:
ISPOR Patient-Centered Special Interest Group

2023: Survey

Measuring and evaluating quality of patient engagement activities

2023: Key Project Proposal

What is patient engagement?

ISPOR Definition, from VIH paper

“The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients’ contributions as partners, recognizing their specific experiences, values, and expertise.”

ISPOR Definition, from VIH paper

Patients: patients, families, caregivers, advocates

Researchers: people undertaking research; payors; regulators; funders

All stages: planning; conduct; dissemination

Patient contributions: provide input as experts based on the experience living with their disease

Patient engagement: active interactions; substantial and not tokenistic

Poll: Your biggest challenges in patient engagement

- Compensation for patients
- Time
- Skills
- Other

Sign up to join our Special Interest Group

ISPOR
Special Interest Group

- Scan the code and select: **Select a Special Interest Group to Join**
- Login with your email and ISPOR password
- It will bring you to a page where you can select the Patient-Centered SIG
- **You must be an ISPOR member to join a SIG**.
- Questions? Email patientsig@ISPOR.org.

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THANK YOU!

Meaningful Patient Engagement

CHARACTERISTICS OF DIRECT, MEANINGFUL PATIENT ENGAGEMENT IN UNDERSERVED COMMUNITIES

PUTTING PATIENTS FIRST®
NATIONAL
HEALTH COUNCIL

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NATIONAL HEALTH COUNCIL

National Kidney Foundation®

The LAM Foundation
A BREATH OF HOPE

LUPUS RESEARCH ALLIANCE

BRAIN INJURY ASSOCIATION OF AMERICA

Parent Project Muscular Dystrophy

Immune Deficiency Foundation

VASCULITIS FOUNDATION

Susan G. Komen®

Celiac Disease FOUNDATION®
celiac.org

CROHN'S & COLITIS FOUNDATION

LUNGEVITY
Find it. Treat it. Live.

LEUKEMIA & LYMPHOMA SOCIETY®

EPILEPSY FOUNDATION

International Rett Syndrome Foundation
www.rettsyndrome.org

American Heart Association®

American Diabetes Association®

HFA
Hemophilia Federation of America™

National Alopecia Areata Foundation

COPD FOUNDATION

FAMILY HEART FOUNDATION
Lipoprotein(a) & Familial Hypercholesterolemia

ALPHA-1 FOUNDATION

American Kidney Fund®

mg™
MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Help Us Solve The Cruel Mystery
LUPUS™
FOUNDATION OF AMERICA

THE TREVOR PROJECT

AMERICAN LIVER FOUNDATION™

Huntington's Disease Society of America

GBS|CIDP Foundation International

resolve
THE NATIONAL INFERTILITY ASSOCIATION

colorectal cancer alliance

alzheimer's association™

Arthritis Foundation℠
Champion of Yes℠

American Cancer Society®

OAC

MHA
Mental Health America

THE MARFAN FOUNDATION
Know the signs. Fight for victory.

GLI GLOBAL LIVER INSTITUTE

Multiple System Atrophy
The MSA Coalition®
Support · Education · Research · Advocacy

National Foundation for Infectious Diseases®

aafa Asthma and Allergy Foundation of America

VHL Alliance

SPINA BIFIDA ASSOCIATION

OSTEOGENESIS IMPERFECTA
OI FOUNDATION
Unbreakable Spirit®

Tourette Association of America

National Eczema Association

cure SMA

American Foundation for Suicide Prevention

amputee coalition™

WomenHeart
The National Coalition for Women with Heart Disease

BEYOND CELIAC
awareness • advocacy • action

NATIONAL BLEEDING DISORDERS FOUNDATION
Formerly NHF

EVERYLIFE FOUNDATION FOR RARE DISEASES

MS®
National Multiple Sclerosis Society

Prevent Blindness

GO2 FOR LUNG CANCER

BHOF
Bone Health & Osteoporosis FOUNDATION™
Healthy Bones, Build Them for Life

NATIONAL PSORIASIS FOUNDATION®

autoimmune association

Barth Syndrome Foundation®

Pulmonary Fibrosis FOUNDATION

Mended Hearts

ALS ASSOCIATION

THE MYOSITIS ASSOCIATION

nfed
Supporting you. Supporting each other.
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Hydrocephalus Association

Solve M.E.

National Blood Clot Alliance
Stop The Clot®

NAMI
National Alliance on Mental Illness

ifopa

NORD®
National Organization for Rare Disorders

American Lung Association®

Sjögren's FOUNDATION

Patient-Centricity

Patient Centric

The NHC defines patient centered as any process, program, or decision focused on patients that play an active role as **meaningfully engaged participants**, and the central focus is on optimizing use of patient-provided information. Patient centered means doing things WITH – not FOR or TO – patients.[1,2]

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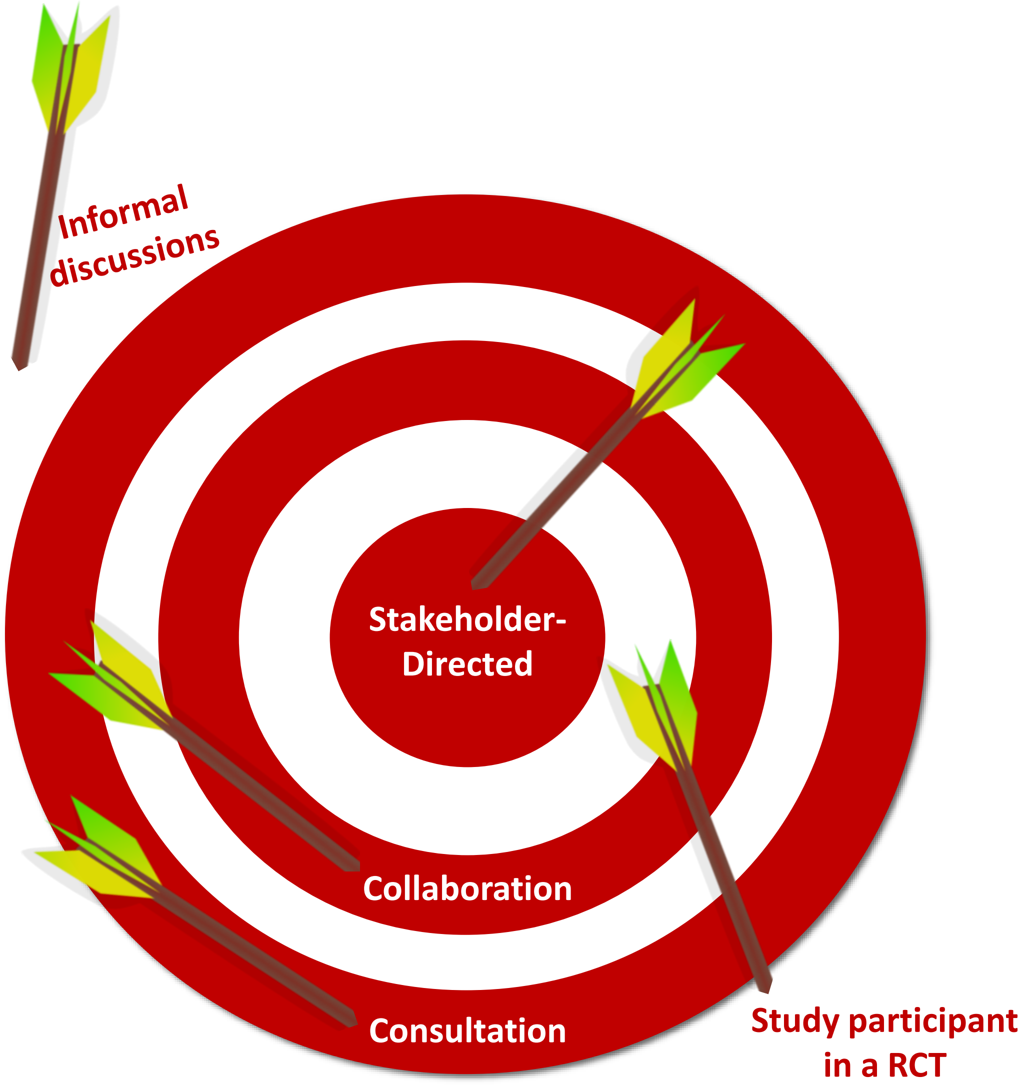
1. Glossary of Patient Engagement Terms. National Health Council. https://www.nationalhealthcouncil.org/resources/glossary-patient-engagement-terms. Published February 13, 2019. Accessed March 19, 2019.
2. What is PFCC? http://www.ipfcc.org/about/pfcc.html. Accessed June 20, 2019.
3. National Health Council. The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem. June 2019. Washington, DC. Available from: https://www.nationalhealthcouncil.org/Patient-Engagement-Rubric



- **Stakeholder-Directed**
  - Patient/Patient group led
- **Partnership**
  - Investigator/Co-investigator
- **Collaboration**
  - Advisory committee member
- **Consultation**
  - Consultant
  - Interviews
  - Focus groups
  - Surveys
- **Informal**
  - Unstructured discussions
- **Study participant**

Appropriateness of engagement method selection is context specific.

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Adapted from Forsythe, et al. JGIM, 2015 & Perfetto

Diversity in Patient Engagement

Valuing All Voices Framework

RELATIONSHIP BUILDING

Characterized by diversity and inclusion, strengthens connections and leads to better results

TRUST

Emerges when people feel safe, valued, respected and supported

SELF-AWARENESS

Seeks to understand diverse standpoints, reflects on self and acknowledges personal bias

ACCEPTANCE

Comes from deep listening and understanding that is free of judgement

COMMUNICATION AND EDUCATION

Generate an understanding of needs, expectations and results necessary to support and sustain the work

Source: Canadian Foundation for Healthcare Improvement

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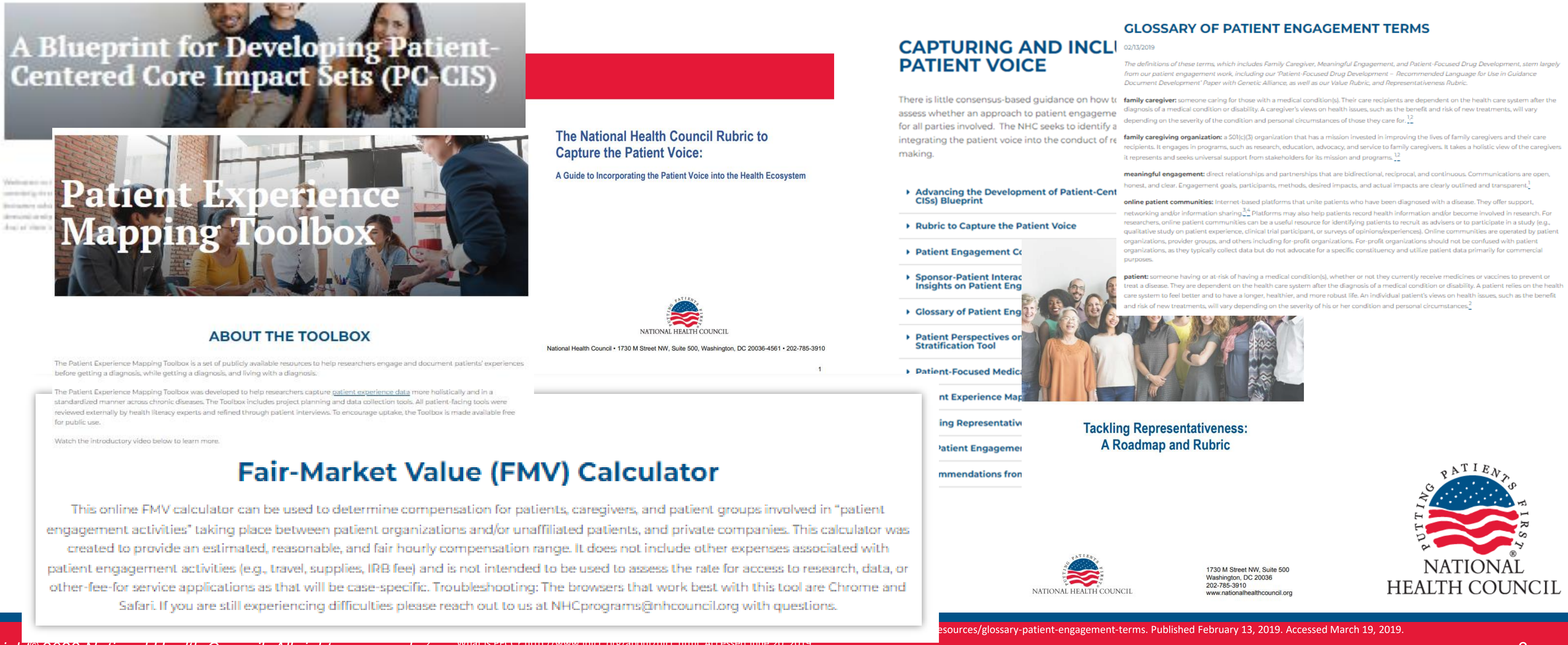
Patient Engagement



A Blueprint for Developing Patient-Centered Core Impact Sets (PC-CIS)

Patient Experience Mapping Toolbox

ABOUT THE TOOLBOX

The Patient Experience Mapping Toolbox is a set of publicly available resources to help researchers engage and document patients' experiences before getting a diagnosis, while getting a diagnosis, and living with a diagnosis.

The Patient Experience Mapping Toolbox was developed to help researchers capture patient experience data more holistically and in a standardized manner across chronic diseases. The Toolbox includes project planning and data collection tools. All patient-facing tools were reviewed externally by health literacy experts and refined through patient interviews. To encourage uptake, the Toolbox is made available free for public use.

Watch the introductory video below to learn more.

The National Health Council Rubric to Capture the Patient Voice:

A Guide to Incorporating the Patient Voice into the Health Ecosystem

NATIONAL HEALTH COUNCIL

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1

CAPTURING AND INCLU
PATIENT VOICE

There is little consensus-based guidance on how t
assess whether an approach to patient engageme
for all parties involved. The NHC seeks to identify a
integrating the patient voice into the conduct of re
making.

- **Advancing the Development of Patient-Cent CISs) Blueprint**
- **Rubric to Capture the Patient Voice**
- **Patient Engagement Co**
- **Sponsor-Patient Interac Insights on Patient Eng**
- **Glossary of Patient Eng**
- **Patient Perspectives on Stratification Tool**
- **Patient-Focused Medica**
- **nt Experience Map**
- **ing Representativ**
- **atient Engageme**
- **mmendations fron**

GLOSSARY OF PATIENT ENGAGEMENT TERMS

02/13/2019

The definitions of these terms, which includes Family Caregiver, Meaningful Engagement, and Patient-Focused Drug Development, stem largely from our patient engagement work, including our 'Patient-Focused Drug Development – Recommended Language for Use in Guidance Document Development' Paper with Genetic Alliance, as well as our Value Rubric, and Representativeness Rubric.

family caregiver: someone caring for those with a medical condition(s). Their care recipients are dependent on the health care system after the diagnosis of a medical condition or disability. A caregiver's views on health issues, such as the benefit and risk of new treatments, will vary depending on the severity of the condition and personal circumstances of those they care for.[1,2]

family caregiving organization: a 501(c)(3) organization that has a mission invested in improving the lives of family caregivers and their care recipients. It engages in programs, such as research, education, advocacy, and service to family caregivers. It takes a holistic view of the caregivers it represents and seeks universal support from stakeholders for its mission and programs.[1,2]

meaningful engagement: direct relationships and partnerships that are bidirectional, reciprocal, and continuous. Communications are open, honest, and clear. Engagement goals, participants, methods, desired impacts, and actual impacts are clearly outlined and transparent.[1]

online patient communities: Internet-based platforms that unite patients who have been diagnosed with a disease. They offer support, networking and/or information sharing.[3,4] Platforms may also help patients record health information and/or become involved in research. For researchers, online patient communities can be a useful resource for identifying patients to recruit as advisers or to participate in a study (e.g., qualitative study on patient experience, clinical trial participant, or surveys of opinions/experiences). Online communities are operated by patient organizations, provider groups, and others including for-profit organizations. For-profit organizations should not be confused with patient organizations, as they typically collect data but do not advocate for a specific constituency and utilize patient data primarily for commercial purposes.

patient: someone having or at-risk of having a medical condition(s), whether or not they currently receive medicines or vaccines to prevent or treat a disease. They are dependent on the health care system after the diagnosis of a medical condition or disability. A patient relies on the health care system to feel better and to have a longer, healthier, and more robust life. An individual patient's views on health issues, such as the benefit and risk of new treatments, will vary depending on the severity of his or her condition and personal circumstances.[2]

Tackling Representativeness:
A Roadmap and Rubric

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Fair-Market Value (FMV) Calculator

This online FMV calculator can be used to determine compensation for patients, caregivers, and patient groups involved in "patient engagement activities" taking place between patient organizations and/or unaffiliated patients, and private companies. This calculator was created to provide an estimated, reasonable, and fair hourly compensation range. It does not include other expenses associated with patient engagement activities (e.g., travel, supplies, IRB fee) and is not intended to be used to assess the rate for access to research, data, or other-fee-for service applications as that will be case-specific. Troubleshooting: The browsers that work best with this tool are Chrome and Safari. If you are still experiencing difficulties please reach out to us at NHCprograms@nhcouncil.org with questions.

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esources/glossary-patient-engagement-terms. Published February 13, 2019. Accessed March 19, 2019.

2. What is PFCC? http://www.ipfcc.org/about/pfcc.html. Accessed June 20, 2019.
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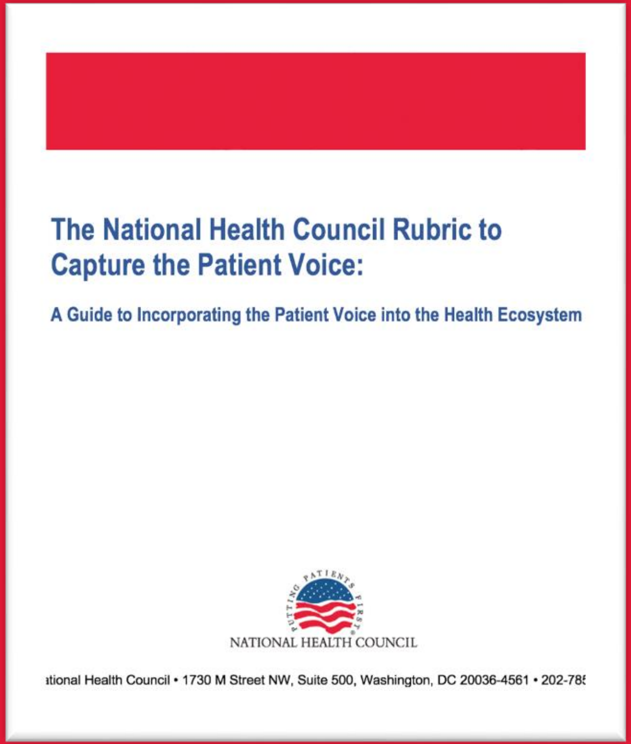
Current NHC Patient Engagement Offerings



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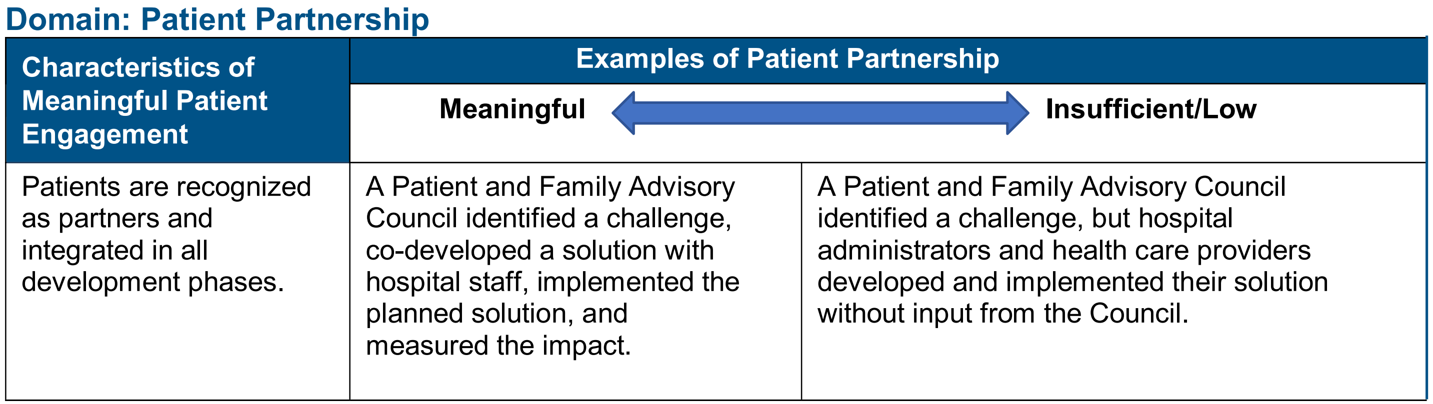
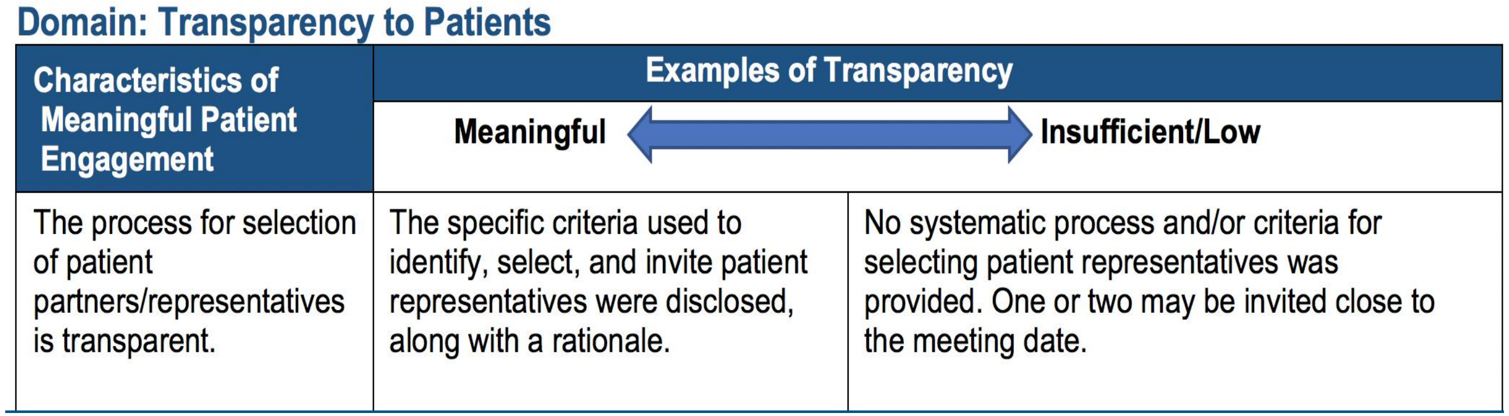


Domain: Patient Partnership

Characteristics of Meaningful Patient Engagement	Examples of Patient Partnership	
	Meaningful ↔	**Insufficient/Low**
Patients are recognized as partners and integrated in all development phases.	A Patient and Family Advisory Council identified a challenge, co-developed a solution with hospital staff, implemented the planned solution, and measured the impact.	A Patient and Family Advisory Council identified a challenge, but hospital administrators and health care providers developed and implemented their solution without input from the Council.



Domain: Transparency to Patients

Characteristics of Meaningful Patient Engagement	Examples of Transparency	
	Meaningful ↔	**Insufficient/Low**
The process for selection of patient partners/representatives is transparent.	The specific criteria used to identify, select, and invite patient representatives were disclosed, along with a rationale.	No systematic process and/or criteria for selecting patient representatives was provided. One or two may be invited close to the meeting date.

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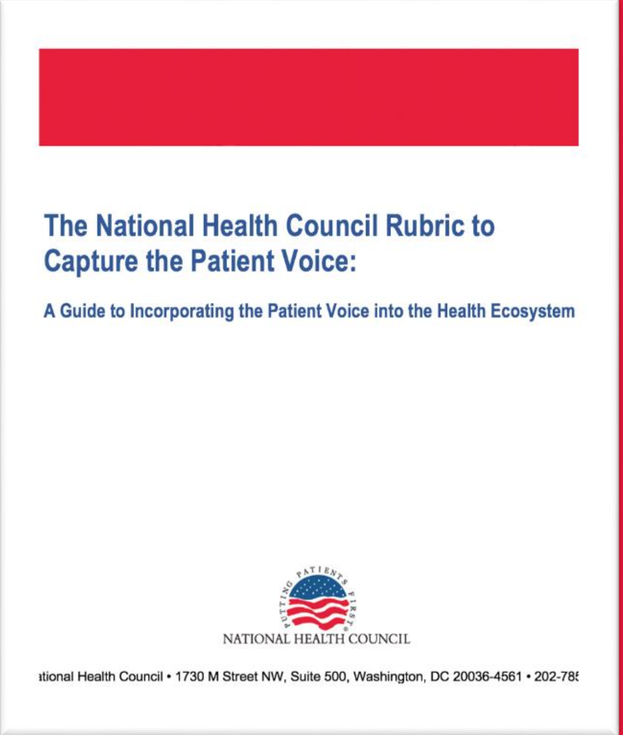
Current NHC Patient Engagement Offerings



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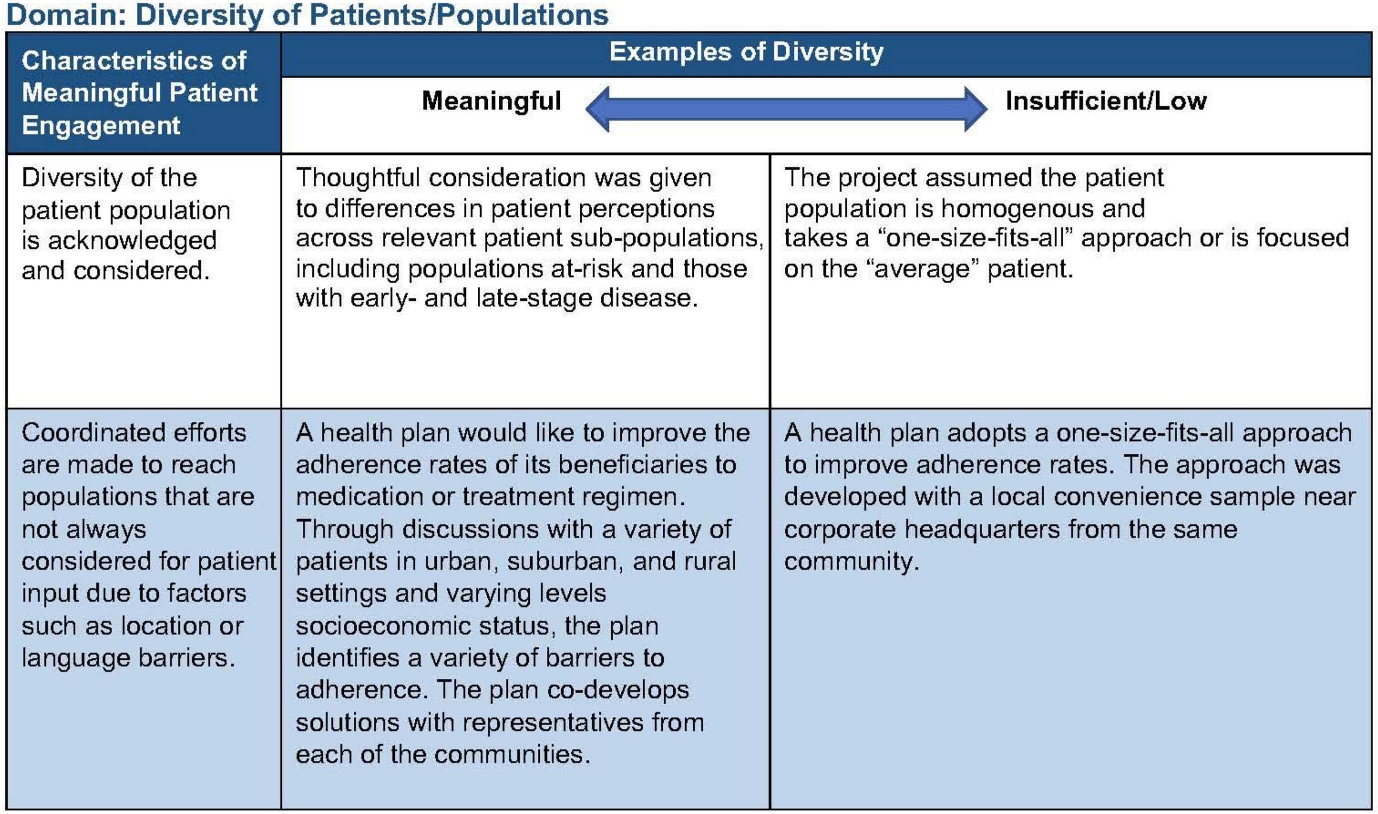

Domain: Diversity of Patients/Populations

Characteristics of Meaningful Patient Engagement	Examples of Diversity	
	Meaningful	**Insufficient/Low**
Diversity of the patient population is acknowledged and considered.	Thoughtful consideration was given to differences in patient perceptions across relevant patient sub-populations, including populations at-risk and those with early- and late-stage disease.	The project assumed the patient population is homogenous and takes a "one-size-fits-all" approach or is focused on the "average" patient.
Coordinated efforts are made to reach populations that are not always considered for patient input due to factors such as location or language barriers.	A health plan would like to improve the adherence rates of its beneficiaries to medication or treatment regimen. Through discussions with a variety of patients in urban, suburban, and rural settings and varying levels socioeconomic status, the plan identifies a variety of barriers to adherence. The plan co-develops solutions with representatives from each of the communities.	A health plan adopts a one-size-fits-all approach to improve adherence rates. The approach was developed with a local convenience sample near corporate headquarters from the same community.

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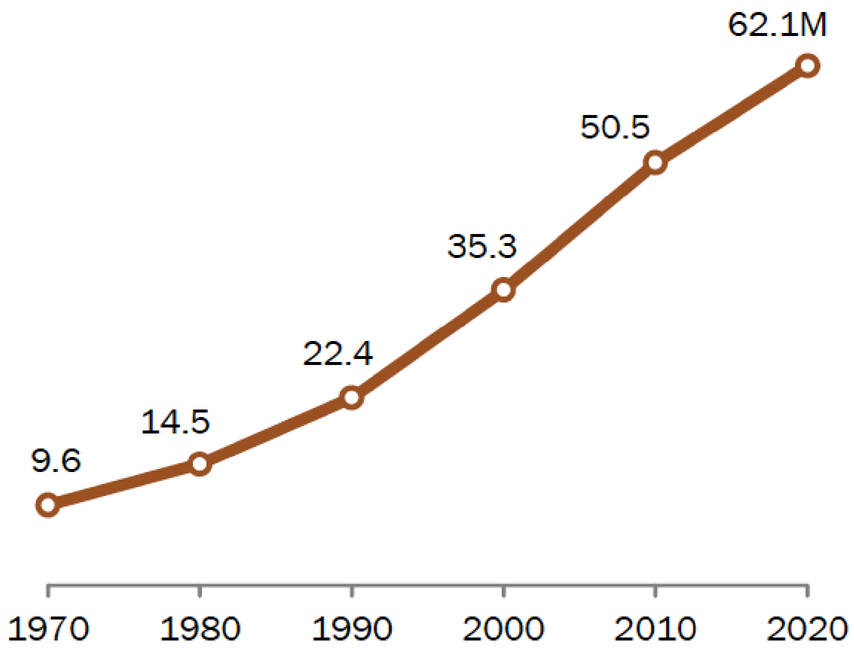
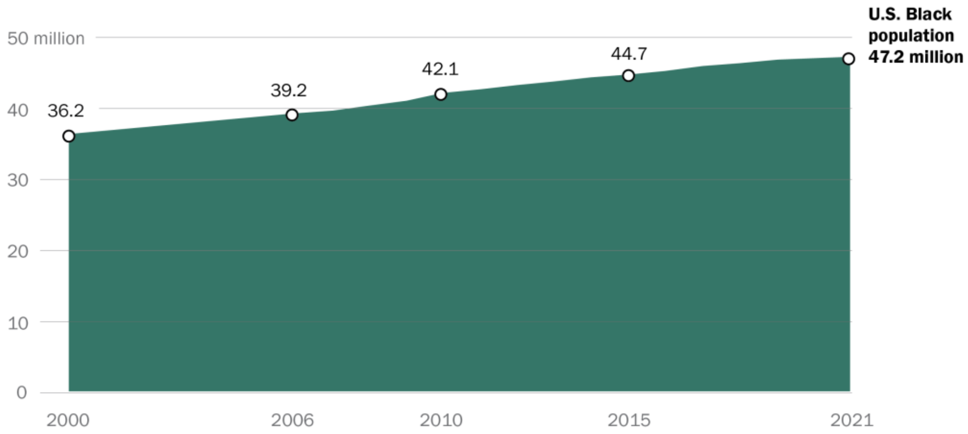
U.S. Hispanic population reached more than 62 million in 2020

In millions



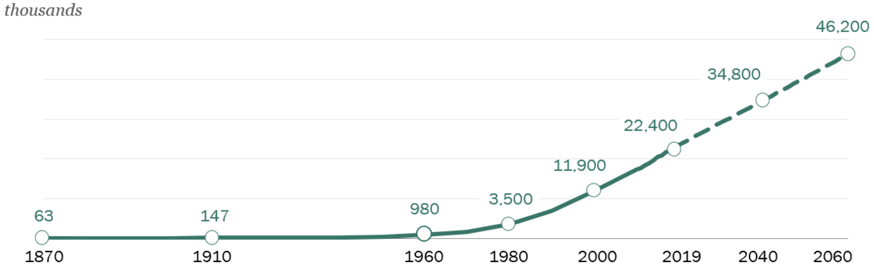
U.S. Black population has grown by 30% between 2000 and 2021

U.S. Black population growth, in millions



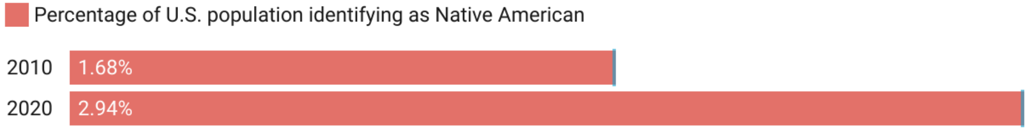
Asian population in U.S. nearly doubled between 2000 and 2019 and is projected to surpass 46 million by 2060

In thousands



More Americans identify on Census as Native American

The number of people who say they are Native American on the Census rose from 5.2 million in 2010 to 9.7 million in 2020, reflecting a trend of "racial shifting"



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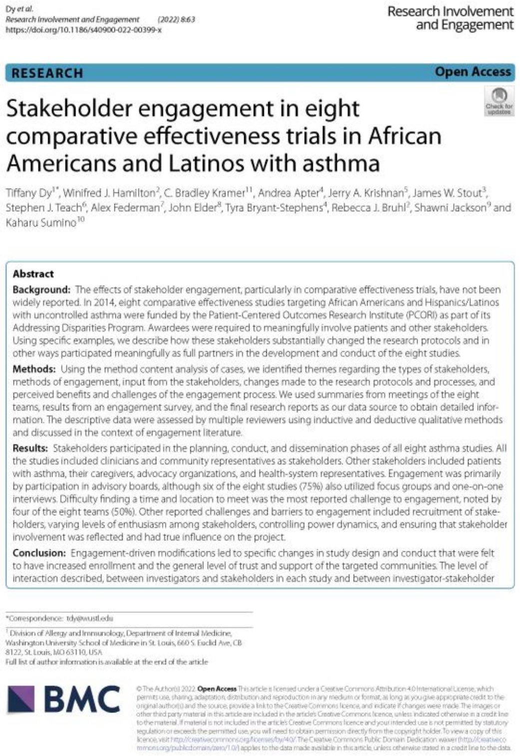

Dy *et al.*
Research Involvement and Engagement (2022) 8:63
https://doi.org/10.1186/s40900-022-00399-x

Research Involvement and Engagement

RESEARCH **Open Access**

Stakeholder engagement in eight comparative effectiveness trials in African Americans and Latinos with asthma

Tiffany Dy[1*], Winifred J. Hamilton[2], C. Bradley Kramer[11], Andrea Apter[4], Jerry A. Krishnan[5], James W. Stout[3], Stephen J. Teach[6], Alex Federman[7], John Elder[8], Tyra Bryant-Stephens[4], Rebecca J. Bruhl[2], Shawni Jackson[9] and Kaharu Sumino[10]

Abstract

Background: The effects of stakeholder engagement, particularly in comparative effectiveness trials, have not been widely reported. In 2014, eight comparative effectiveness studies targeting African Americans and Hispanics/Latinos with uncontrolled asthma were funded by the Patient-Centered Outcomes Research Institute (PCORI) as part of its Addressing Disparities Program. Awardees were required to meaningfully involve patients and other stakeholders. Using specific examples, we describe how these stakeholders substantially changed the research protocols and in other ways participated meaningfully as full partners in the development and conduct of the eight studies.

Methods: Using the method content analysis of cases, we identified themes regarding the types of stakeholders, methods of engagement, input from the stakeholders, changes made to the research protocols and processes, and perceived benefits and challenges of the engagement process. We used summaries from meetings of the eight teams, results from an engagement survey, and the final research reports as our data source to obtain detailed information. The descriptive data were assessed by multiple reviewers using inductive and deductive qualitative methods and discussed in the context of engagement literature.

Results: Stakeholders participated in the planning, conduct, and dissemination phases of all eight asthma studies. All the studies included clinicians and community representatives as stakeholders. Other stakeholders included patients with asthma, their caregivers, advocacy organizations, and health-system representatives. Engagement was primarily by participation in advisory boards, although six of the eight studies (75%) also utilized focus groups and one-on-one interviews. Difficulty finding a time and location to meet was the most reported challenge to engagement, noted by four of the eight teams (50%). Other reported challenges and barriers to engagement included recruitment of stakeholders, varying levels of enthusiasm among stakeholders, controlling power dynamics, and ensuring that stakeholder involvement was reflected and had true influence on the project.

Conclusion: Engagement-driven modifications led to specific changes in study design and conduct that were felt to have increased enrollment and the general level of trust and support of the targeted communities. The level of interaction described, between investigators and stakeholders in each study and between investigator-stakeholder

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Full list of author information is available at the end of the article

BMC

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Journal of Clinical and Translational Science

www.cambridge.org/cts

Implementation, Policy and Community Engagement Research Article

Cite this article: Sprague Martinez L, Carolan K, O'Donnell A, Diaz Y, and Freeman ER (2019) Community engagement in patient-centered outcomes research: Benefits, barriers, and measurement. *Journal of Clinical and Translational Science* **2**: 371–376. doi: 10.1017/cts.2018.341

Received: 17 August 2018
Revised: 5 November 2018
Accepted: 14 November 2018

Key words:
Delphi method; stakeholder engagement; community partnerships; patient centered outcomes research; PCORI; implementation; policy and community engagement

Address for correspondence: *L. Sprague Martinez, PhD, Boston University School of Social Work, 264 Bay State Road, Boston MA 02215, USA. Email: lsmarti@bu.edu

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Community engagement in patient-centered outcomes research: Benefits, barriers, and measurement

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Abstract

Introduction: This study employed the Delphi method, an exploratory method used for group consensus building, to determine the benefits and challenges associated with community engagement in patient-centered outcomes research. *Methods:* A series of email surveys were sent to the Patient-Centered Outcomes Research Institute (PCORI)-funded researchers ($n = 103$) in New England. Consensus was achieved through gathering themes and engaging participants in ranking their level of agreement over three rounds. In round one, participant responses were coded thematically and then tallied. In round two participants were asked to state their level of agreement with each of the themes using a Likert scale. Finally, in round three, the group was asked to rank the round two themes based on potential impact. *Results:* Results suggested the greatest benefit of community engagement is that it brings multiple perspectives to the table, with 92% ranking it as the first or second most important contribution. Time was ranked as the most significant barrier to engaging community. Strategies to overcome barriers to community engagement include engaging key stakeholders early in the research, being kind and respectful and spending time with stakeholders. The most significant finding was that no researchers reported having specific measures to evaluate community engagement. *Conclusion:* Community engagement can enhance both research relevance and methodology when researchers are engaged in meaningful collaborations. Advancing the science of community engagement will require the development of evaluation metrics to examine the multiple domains of partnership.

Introduction

The Patient-Centered Outcomes Research Institute (PCORI) was created through the Patient Protection and Affordable Care Act with the intention of elevating patient voice in research [1]. The PCORI mantra, "research done differently" translates to "funded research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information" in the provision of their care [2]. Engagement can help ensure research is culturally relevant and aligned with community priorities and can help to sustain engagement and interest among those most impacted [3]. In addition, it can promote resource sharing and co-learning between community partners and researchers, increasing their capacity [4]. Importantly, such approaches can facilitate the translation of research into policy and practice [5].

There are well-documented challenges associated with engaging communities (both residents and organizations) in research. Differences in priorities as well as a lack of transparency can lead to disagreements between researchers and community partners [6]. Communication barriers can emerge as the result of disciplinary jargon and exclusionary language on the part of the researchers [7]. Power dynamics between researchers and partners, in this case patients and providers, can complicate interactions and impede the development of trusting relationships [8]. Real barriers exist between researchers and community partners, particularly in communities of color, which have been historically exploited by academic researchers and the medical community. These barriers may accumulate to render relationship development time-intensive work [9, 10].

Similarly to our previous work exploring community engagement in the Clinical Translational Science Award (CTSA) program, to inform testimony to the Institute of Medicine [11], we employed the Delphi Method (Delphi) to determine the benefits and challenges associated with community engagement in patient-centered outcomes research (PCOR). In this instance we defined community as patients and those who work with them in the broader community. The Delphi method, specifically, was designed to be an exploratory consensus-building tool [12]. It is used by researchers and practitioners from diverse disciplinary backgrounds and is particularly useful in situations in which face-to-face meetings are not possible.

rg/10.1017/cts.2018.341 Published online by Cambridge University Press

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Increasing Patient Engagement in the African American Community through Personal Health Record Use

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Perkins, Andrea, "Increasing Patient Engagement in the African American Community through Personal Health Record Use" (2013). *Applied Research Projects*. 51. . https://doi.org/10.21007/chp.hiim.0045
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EDITORIALS

Patient engagement and cultural sensitivity as a strategy to improve health inequities: The solutions are as simple as they are complex

The SARS-COV-2 (COVID-19) pandemic has confirmed that since the 2003 Institute of Medicine Report: Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care, we have made little progress in addressing health disparities for Black Americans. The Report showed that even after adjusting for the social determinants of health such as income, comorbid illness and health insurance type, health outcomes among Blacks were still worse than Whites[1]. While there is no evidence that Blacks are genetically more predisposed to SARS -COV-2 infection, data from the CDC showed that during the first surge in April 2020, COVID-19 related hospitalization rates among Blacks were 3.3 times the rate of Whites[2].

The COVID-19 pandemic has shed a bright light on the numerous long-standing health inequities experienced by Blacks across the United States; however, the greater challenge is contrasting perception versus reality. The perception is that the impact of the COVID-19 pandemic is a result of poverty, lack of access to care, transportation challenges, social determinants of health and underlying comorbidities. But when we examine these further, other factors warrant consideration and study. Prince George's County in Maryland is one of the most affluent Black communities in the nation, yet the county had the highest death rate in the suburban Washington, D.C. area[3]. Another reality was seen in Brooklyn, New York. Brooklyn has a Black population exceeding 833,000, which is about 35% of the total population. The borough has thirteen hospitals (including one state and three public) and an extensive public transportation system. Despite this support system, this borough was among communities experiencing some of the highest COVID-19 associated deaths in New York City[4].

The current pandemic highlights the need to promote the health and well-being for the Black population. Over the years, data has shown that irrespective of diagnosis (cardiac disease, HIV, cerebrovascular disease, diabetes, glaucoma), Blacks have the worst health outcomes across several disease categories (Table 1). Consequently, we must seek solutions that address structural racism and inequities. The requisite first step to decrease health care inequities is to increase the value of the individual. It is important to recognize and address the role of cultural sensitivity across all populations. Unfortunately, the English-speaking Black population is totally left out of the current discussions devoted to improving cultural sensitivity.

The authors recognize and propose that decreased human value, and as a result the lack of patient engagement and empathy, are critical pieces missing when conscious and unconscious biases are the drivers for the current crisis. A culturally sensitive patient engagement approach designed to value the Black population overall and Black patients individually is essential.

The history of the trials and tribulations of the aging Black population is unique and must be acknowledged. Several years ago, during an encounter by one of the authors (MB) an elderly African American female stated, "All I want when I come to a hospital is for someone to be nice to me." Another elderly African American stated in a separate encounter, "I picked cotton in the South, and I paid my dues, I don't deserve to be treated in this way." These powerful quotes are saying "Do you know me, do you know my historical background, do you understand the basis of my pain and my suffering? Do you possess the level of cultural sensitivity to comprehend who I am and what issues in my life are most important to me?" In the absence of this background context, it is difficult to understand how to express empathy and engage the patient to improve the individual's health. As health care providers, very few of us have been hospitalized and the majority who have been hospitalized are women creating life through birth, whereas many of our patients are fighting for their lives.

To address the issue of health inequities, it is important to understand that the solutions are as simple as they are complex. If we successfully solve the "simple" we may prevent problems escalating to "complex." This concept evolved from empathetic and non-judgmental conversations conducted by one of the authors (MB) over a 10-year

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https://doi.org/10.1016/j.jnma.2022.09.005

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Patient Engagement of Diverse Constituencies

- Requires a humble and vulnerable approach.
- Not one-size-fits-all.
- Language and cultural barriers must be accounted for.
- At every stage of the development of the activity, every effort should be made to ensure diverse representation of the patients.
- Patient engagement activities should attempt to represent the proportion of the population impacted by a disease.
  - Acknowledgement that engagement may be impeded by systemic and structural barriers, including the social drivers of health.

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Thank you!

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Patient and public engagement (PPIE) in patient-reported outcome measure (PRO) development and valuation studies

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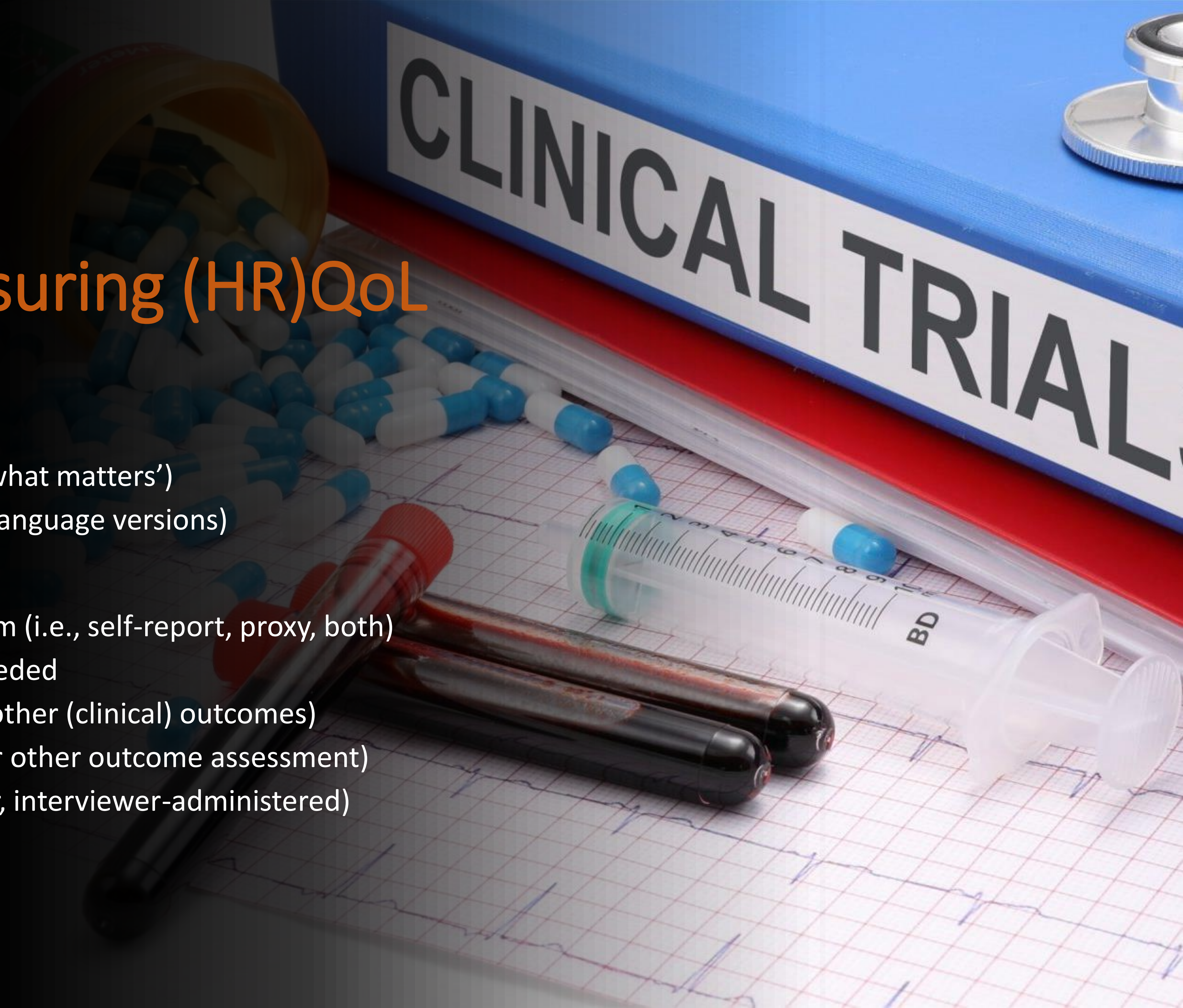
PPIE in trials: measuring (HR)QoL



- PRO selection
  - Content validity (i.e., ‘measuring what matters’)
  - Acceptability (i.e., length of PRO, language versions)
- Administration
  - Who best to collect responses from (i.e., self-report, proxy, both)
  - What additional information is needed
  - Where it is issued (i.e., as part of other (clinical) outcomes)
  - When to issue (i.e., before or after other outcome assessment)
  - How it is issued (i.e., online, paper, interviewer-administered) and how often

PPIE in trials: measuring (HR)QoL

- PRO selection
  - Content validity (i.e., ‘measuring what matters’)
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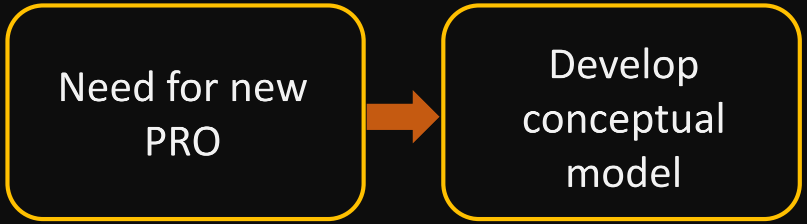
MAXIMISE DATA QUALITY

PRO development research

Need for new PRO

PRO development research



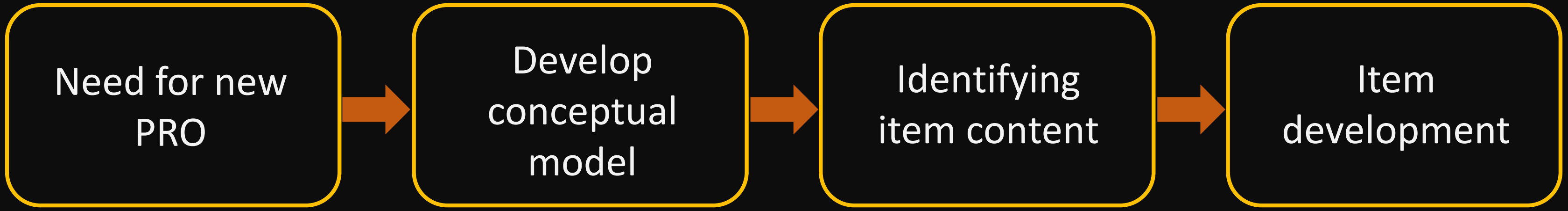
Need for new PRO

Develop conceptual model

PRO development research

Need for new PRO → Develop conceptual model → Identifying item content

PRO development research



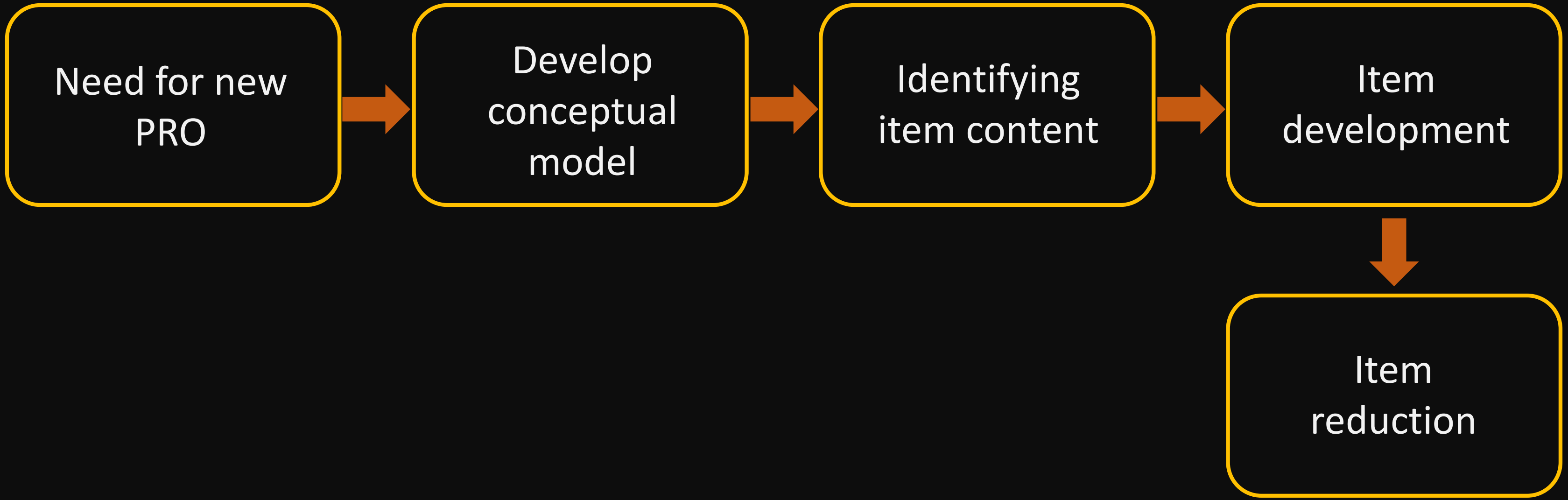
Need for new PRO

Develop conceptual model

Identifying item content

Item development

PRO development research



Need for new PRO

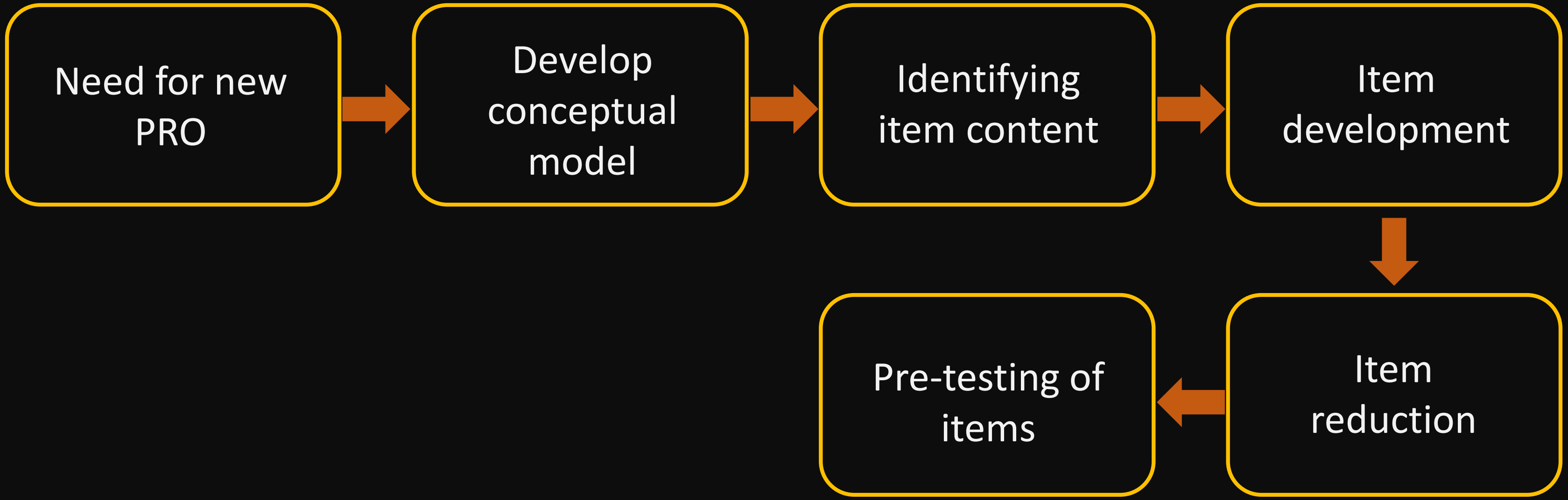
Develop conceptual model

Identifying item content

Item development

Item reduction

PRO development research



Need for new PRO

Develop conceptual model

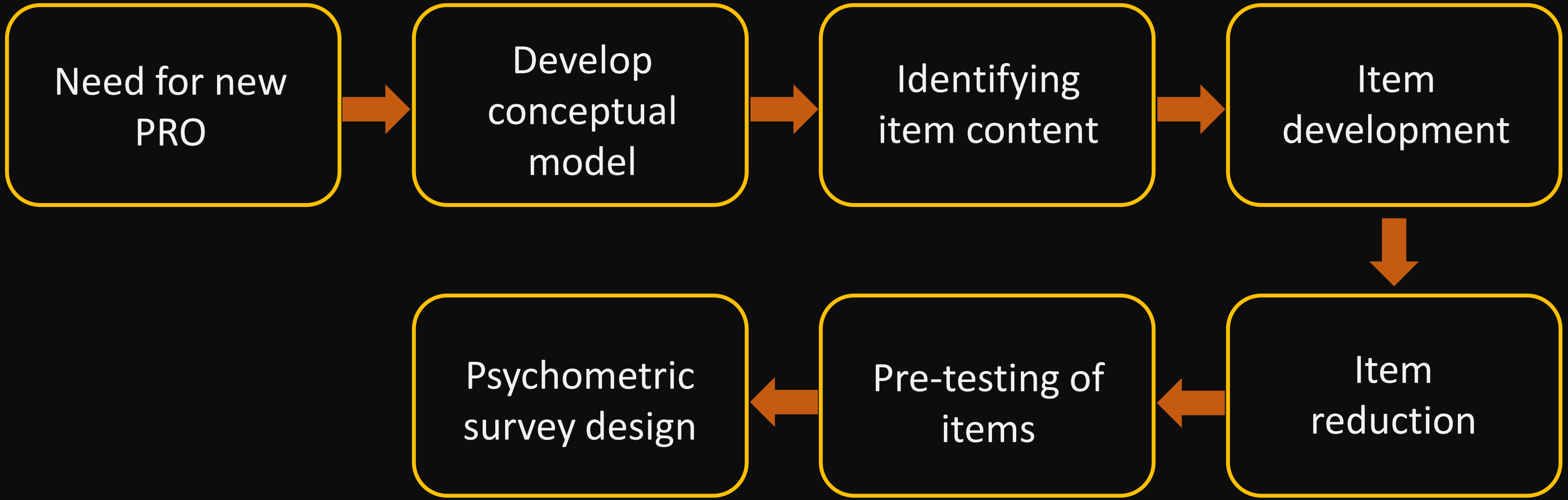
Identifying item content

Item development

Item reduction

Pre-testing of items

PRO development research



Need for new PRO

Develop conceptual model

Identifying item content

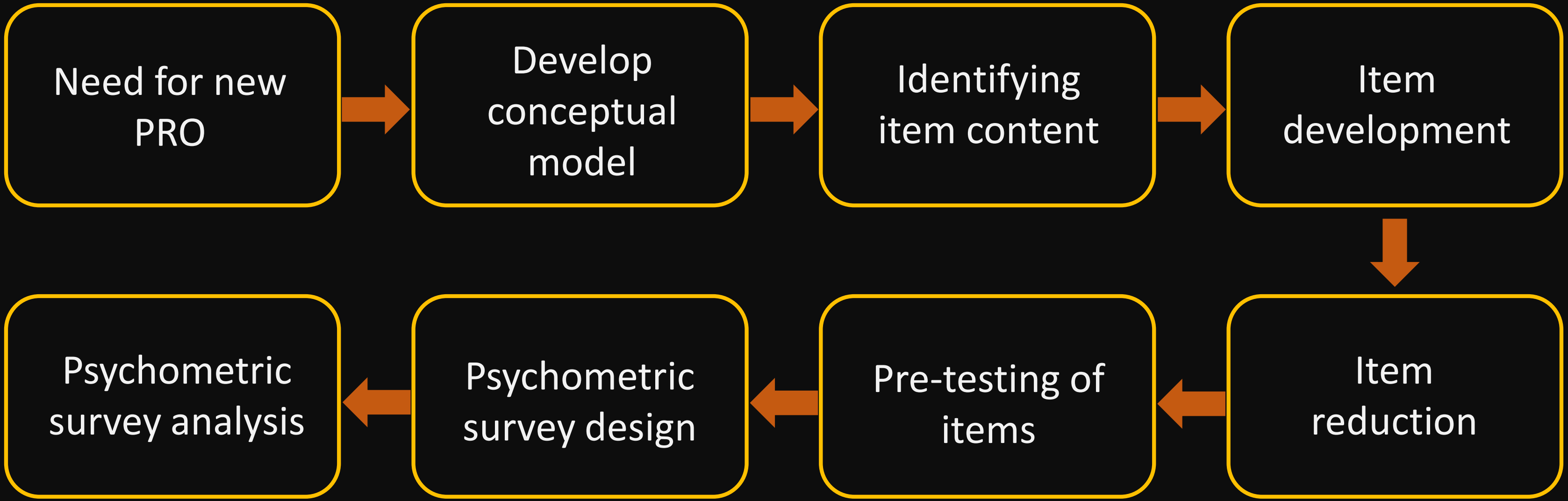
Item development

Item reduction

Pre-testing of items

Psychometric survey design

PRO development research



Need for new PRO

Develop conceptual model

Identifying item content

Item development

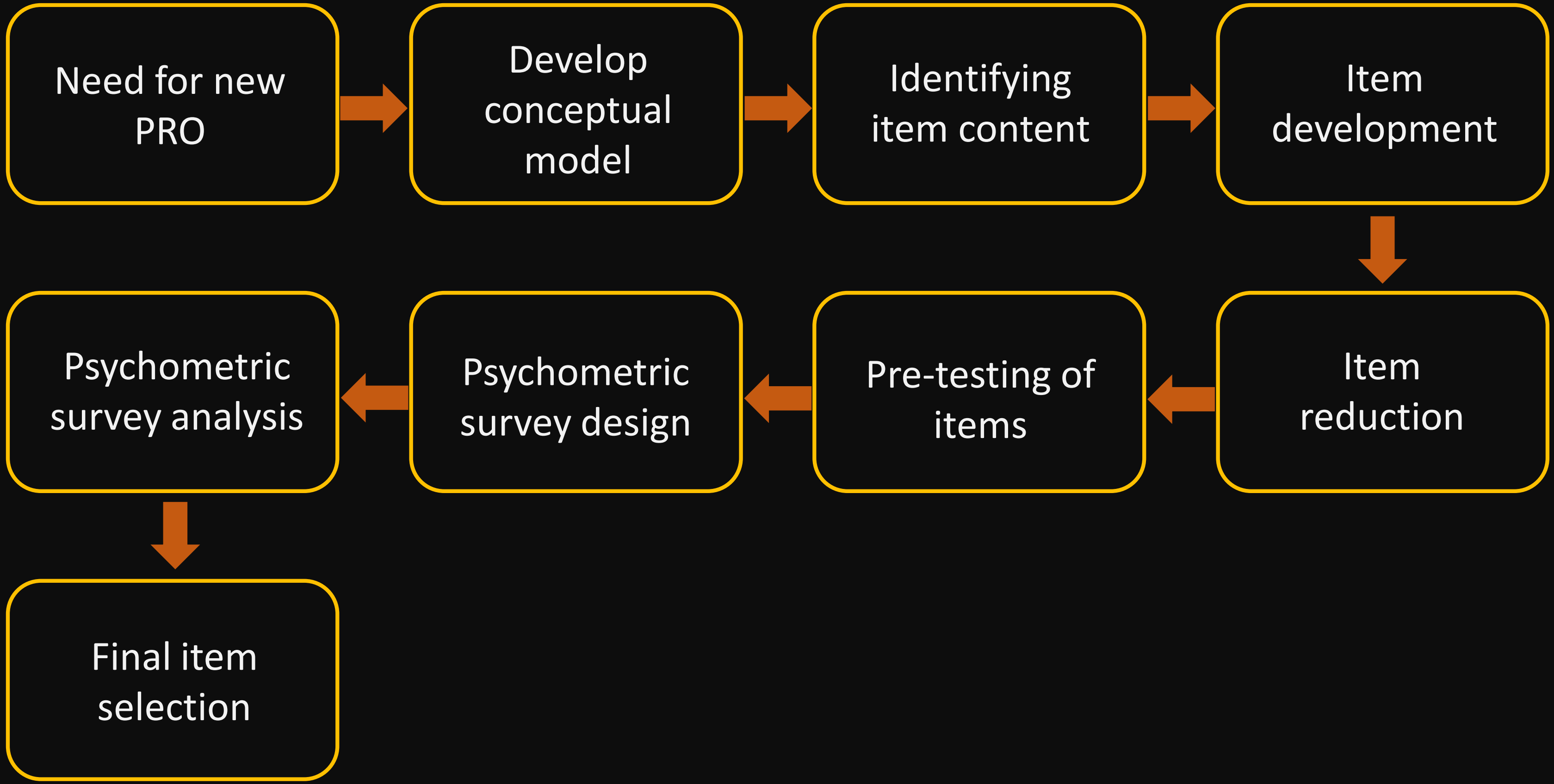
Item reduction

Pre-testing of items

Psychometric survey design

Psychometric survey analysis

PRO development research



Need for new PRO

Develop conceptual model

Identifying item content

Item development

Item reduction

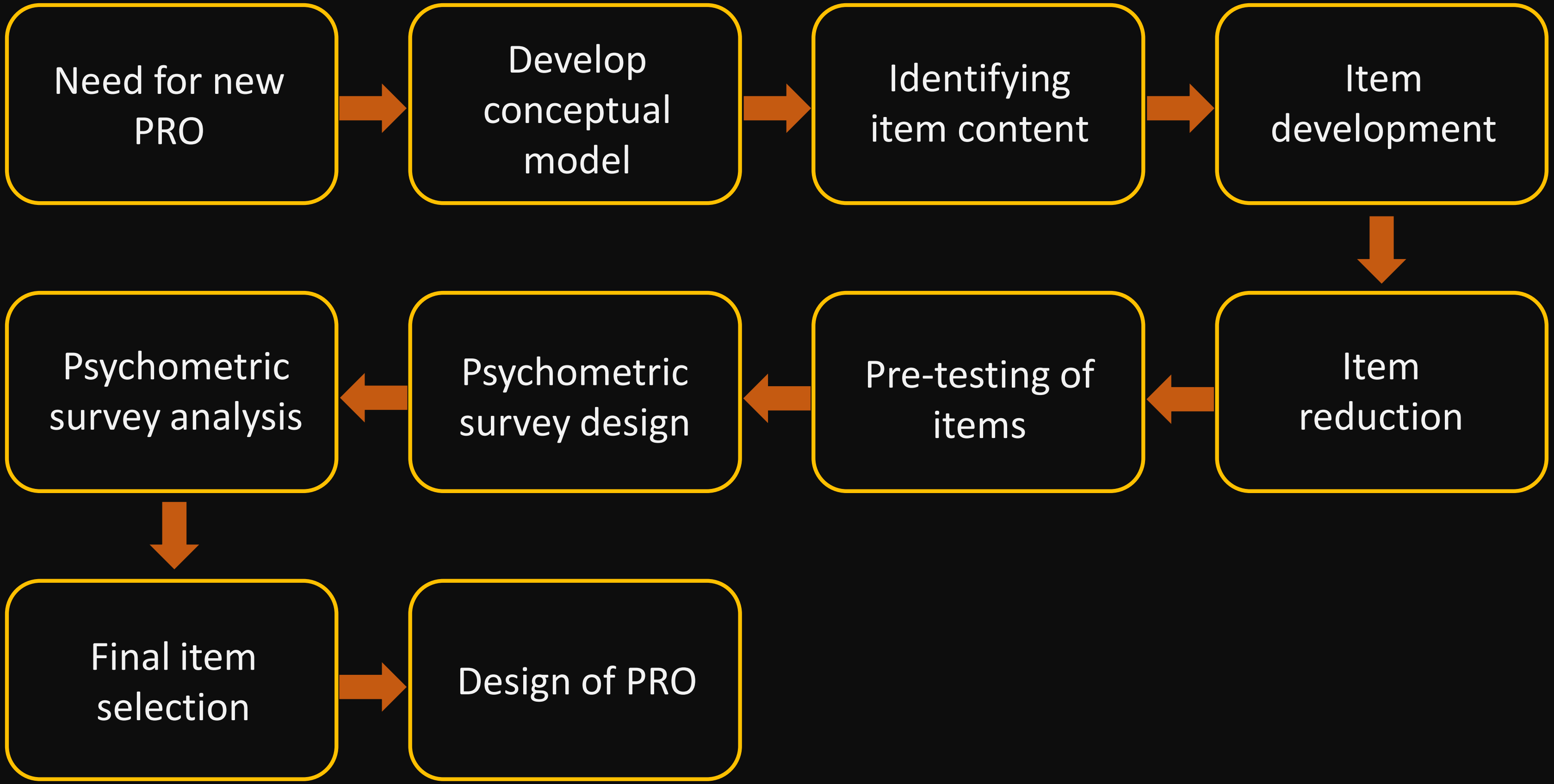
Pre-testing of items

Psychometric survey design

Psychometric survey analysis

Final item selection

PRO development research



Need for new PRO

Develop conceptual model

Identifying item content

Item development

Item reduction

Pre-testing of items

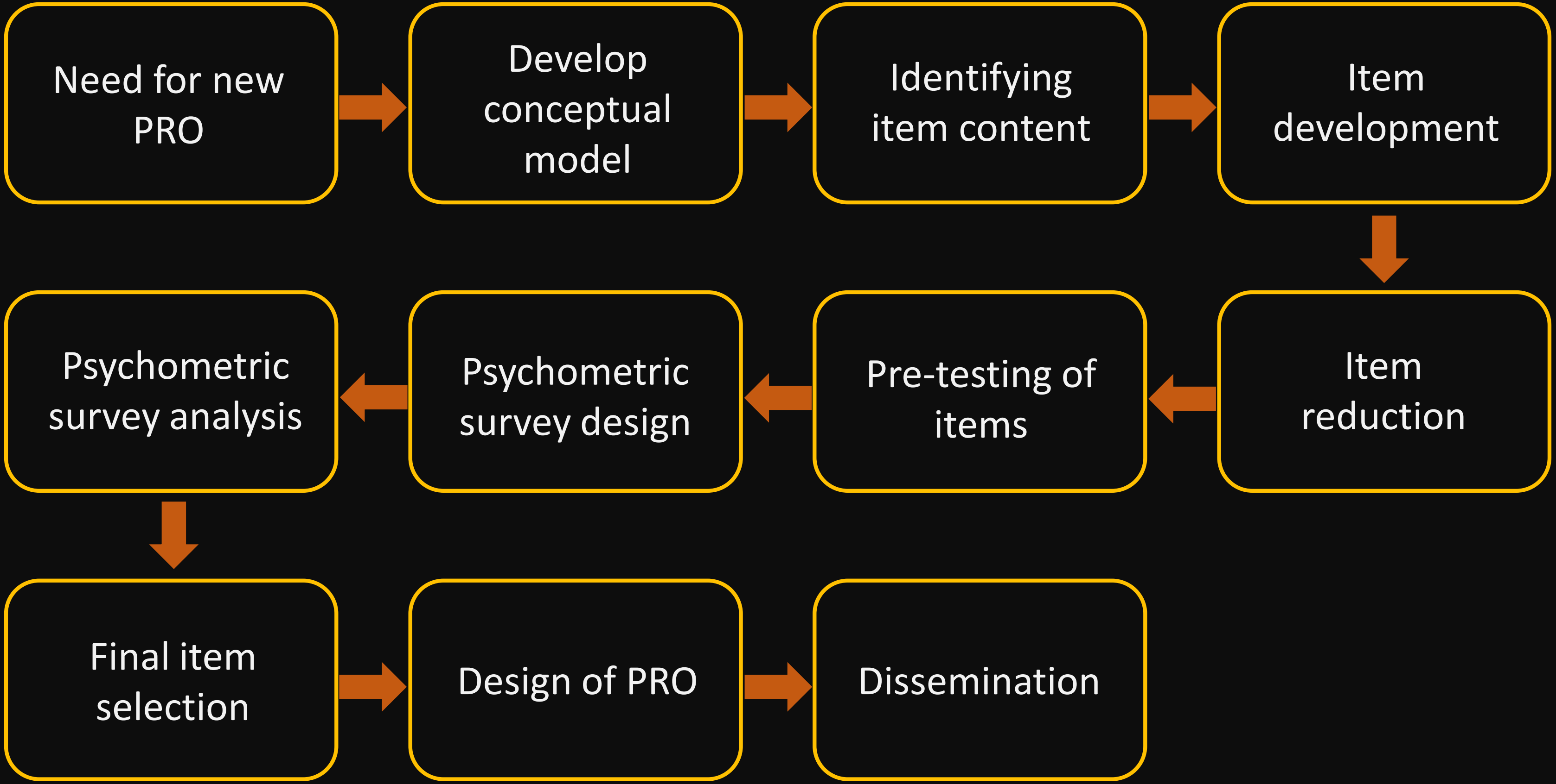
Psychometric survey design

Psychometric survey analysis

Final item selection

Design of PRO

PRO development research



Need for new PRO

Develop conceptual model

Identifying item content

Item development

Item reduction

Pre-testing of items

Psychometric survey design

Psychometric survey analysis

Final item selection

Design of PRO

Dissemination

PRO development research

- Need for new PRO
- Develop conceptual model
- Identifying item content
- Item development
- Item reduction
- Pre-testing of items
- Psychometric survey design
- Psychometric survey analysis
- Final item selection
- Design of PRO
- Dissemination

https://doi.org/10.1186/s41687-019-0172-8

Valuation

- Method may be fixed
  - Time trade-off (TTO)
    - Face-to-face vs. online
  - Discrete choice experiment (DCE)
- Who’s preferences
  - Patient
  - General population

Valuation

- Method may be fixed
  - Time trade-off (TTO)
    - Face-to-face vs. online
  - Discrete choice experiment (DCE)
- Who's preferences
  - Patient
  - General population
- Reimbursement
- Scheduling (venue, time)

Challenges to meaningful PPIE

- Finding the ‘right’ people
  - May not be easy to identify or convince!
- Bringing people up-to-speed
  - (i.e., knowledge of what HRQoL is, how it can be measured, how it can be used, understanding of PROs and PBMs)
- Some things can’t be changed, particularly in valuation studies
  - Can be frustrating to PPIE members
  - Potential to damage relationships
- Time and resources

Are we striving for the impossible?

- PPIE → better research
- Reporting standards have helped in transparency
- Best practice guidance helps ‘us’ in thinking about what could be done
- BUT
- If we don’t do *everything,* do we leave ourselves open to criticism?
- Are some PPIE activities more important than others?

What could we do to change things?

- Generic resources to explain different concepts
  - HRQoL
  - PROs / PBMs
  - Valuation etc…..!
- Resources available in different formats to suit different
  - Languages
  - Ages
  - Learning needs (i.e., video/text/cartoon etc.)

What could we do to change things?

- Generic resources to explain different concepts
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  - Valuation etc…..!
- Resources available in different formats to suit different
  - Languages
  - Ages
  - Learning needs (i.e., video/text/cartoon etc.)
- Reflection on ‘best practice’, ‘acceptable’, and ‘insufficient’
  - How these are described and documented in research