Working with Patients as Full Partners in Research and Care

Susan Bartlett, Ph.D.

DISRUPT THE STATUS QUO

The Challenge

Create a healthcare system that addresses patient needs, values, and preferences

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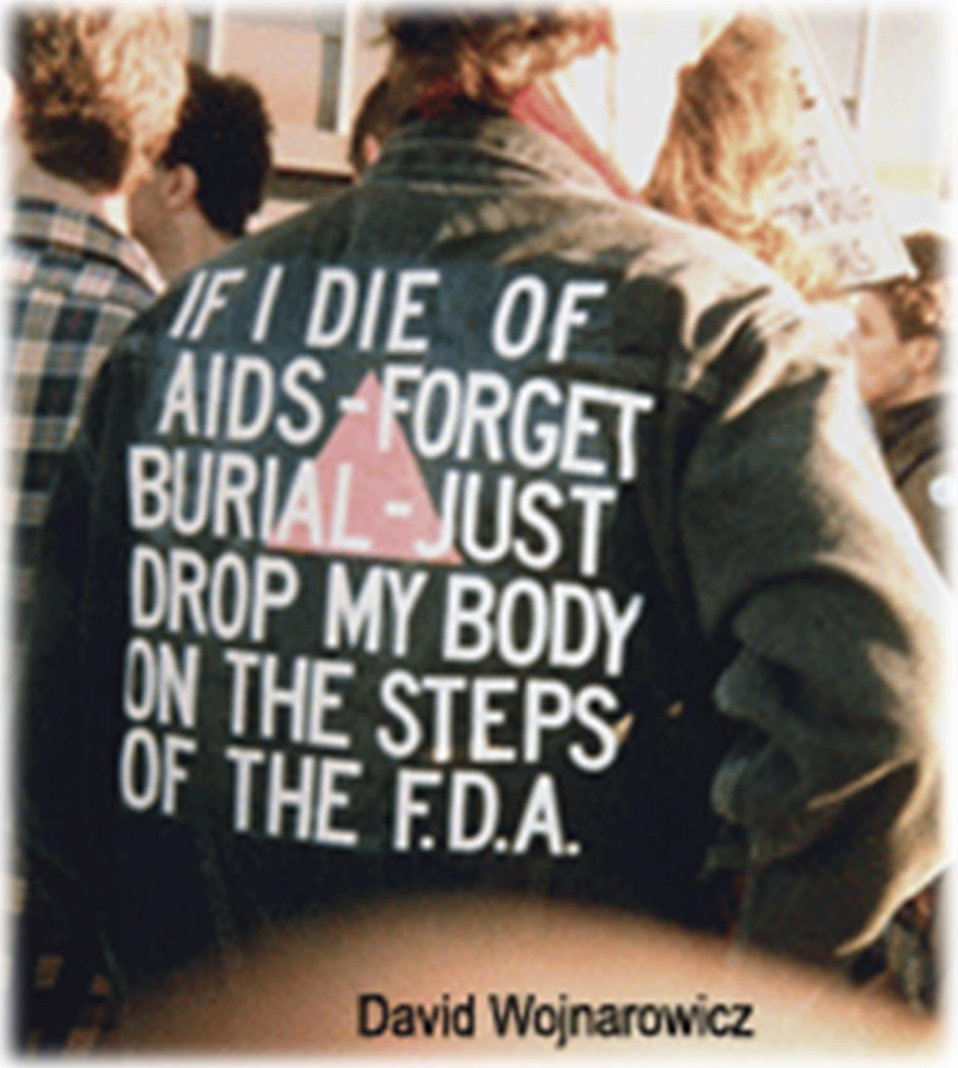
THE GOVERNMENT HAS BLOOD ON ITS HANDS

ONE AIDS DEATH EVERY 10 MINUTES


IF I DIE OF
AIDS - FORGET
BURIAL - JUST
DROP MY BODY
ON THE STEPS
OF THE F.D.A.
David Wojnarowicz

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Ask Carlo how he feels about the AIDS drug that's costing him $30,000 a year.

When medicine can save people like Carlo from going blind, obviously it's a good thing. What's not so apparent is how dramatically the same drugs increase healthcare costs.

Every year one in every four Americans with AIDS is diagnosed with CMV retinitis, a disease which untreated leads to blindness in a matter of days. But recent research has shown that Astra Pharmaceutical's prescription drug called Foscavir is effective in treating this condition.

Allowing patients like Carlo to go blind because he can't afford $30,000 a year, is one more way pharmaceutical companies destroy lives in their greedy quest for profits.

Unfortunately, a year's prescription can cost $30,000 or more. As a result, these drugs drain the nation billions in healthcare costs.

America's healthcare crisis calls for cost-saving power. And new prescription drugs are continuing to escalate in price, leaving Carlo without hope and possibly without sight.

For further information on how pharmaceutical companies are destroying lives and wasting your money, write or call The Pharmaceutical Manufacturers Association, 1100 Fifteenth Street, N.W., Box Y, Washington, D.C. 20005. 1-800-538-2692.

PHARMACEUTICALS
Taking Lives. Taking Money.

Brought to you by ACT UP The AIDS Coalition to Unleash Power

Ask Sarah how she feels about the drug that's saving her from $40,000 surgery.

PHARMACEUTICALS

PEOPLE WITH AIDS DEMAND A CURE, NOT A P.R. CAMPAIGN

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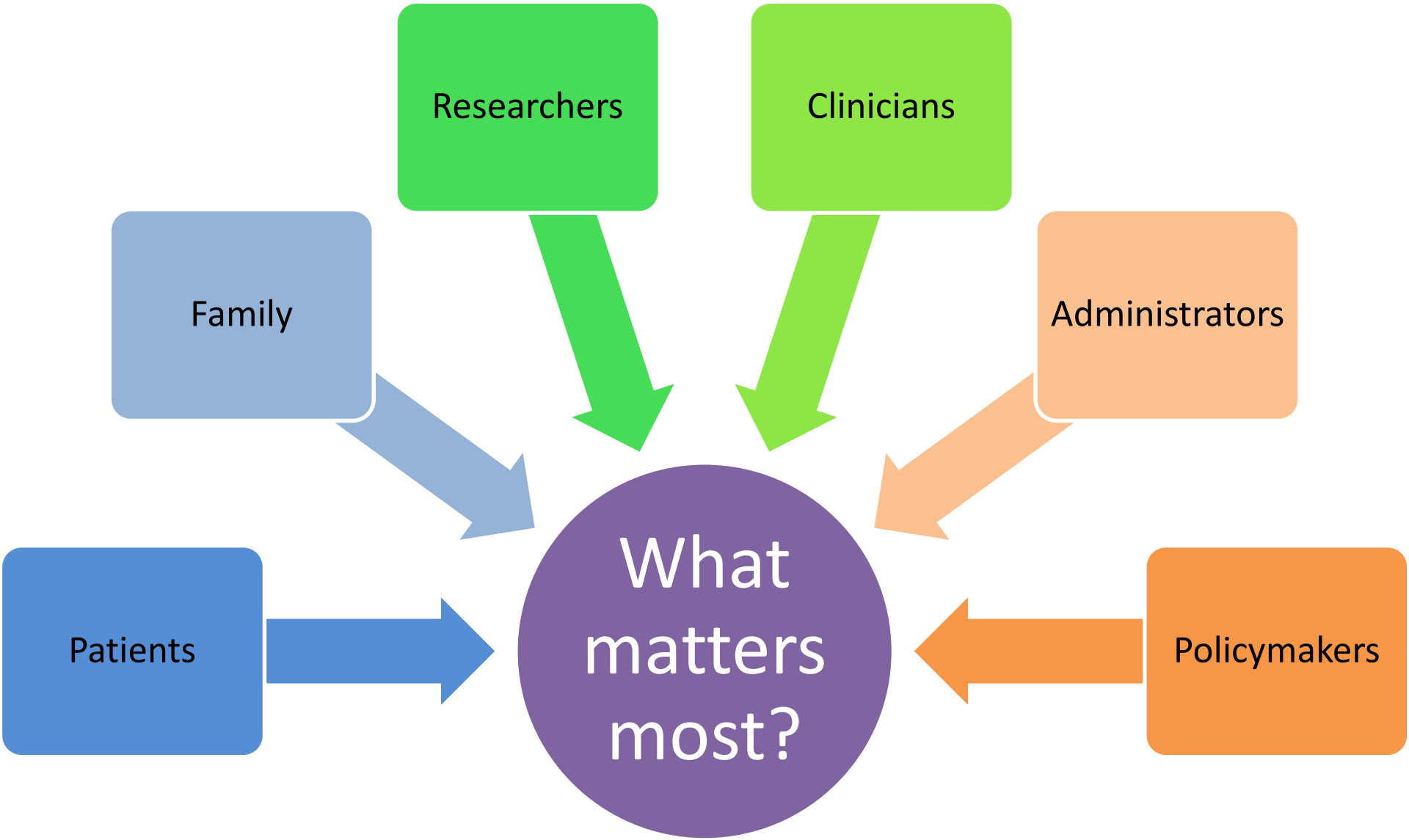
Researchers
Clinicians
Family
Administrators
Patients
What matters most?
Policymakers

Providing **care** that is respectful of, and responsive to, individual **patient** preferences, needs and values, and ensuring that **patient** values guide all clinical decisions.

Institute of Medicine (2015)

"Listen to your patient -- he is telling you the diagnosis"

Sir William Osler

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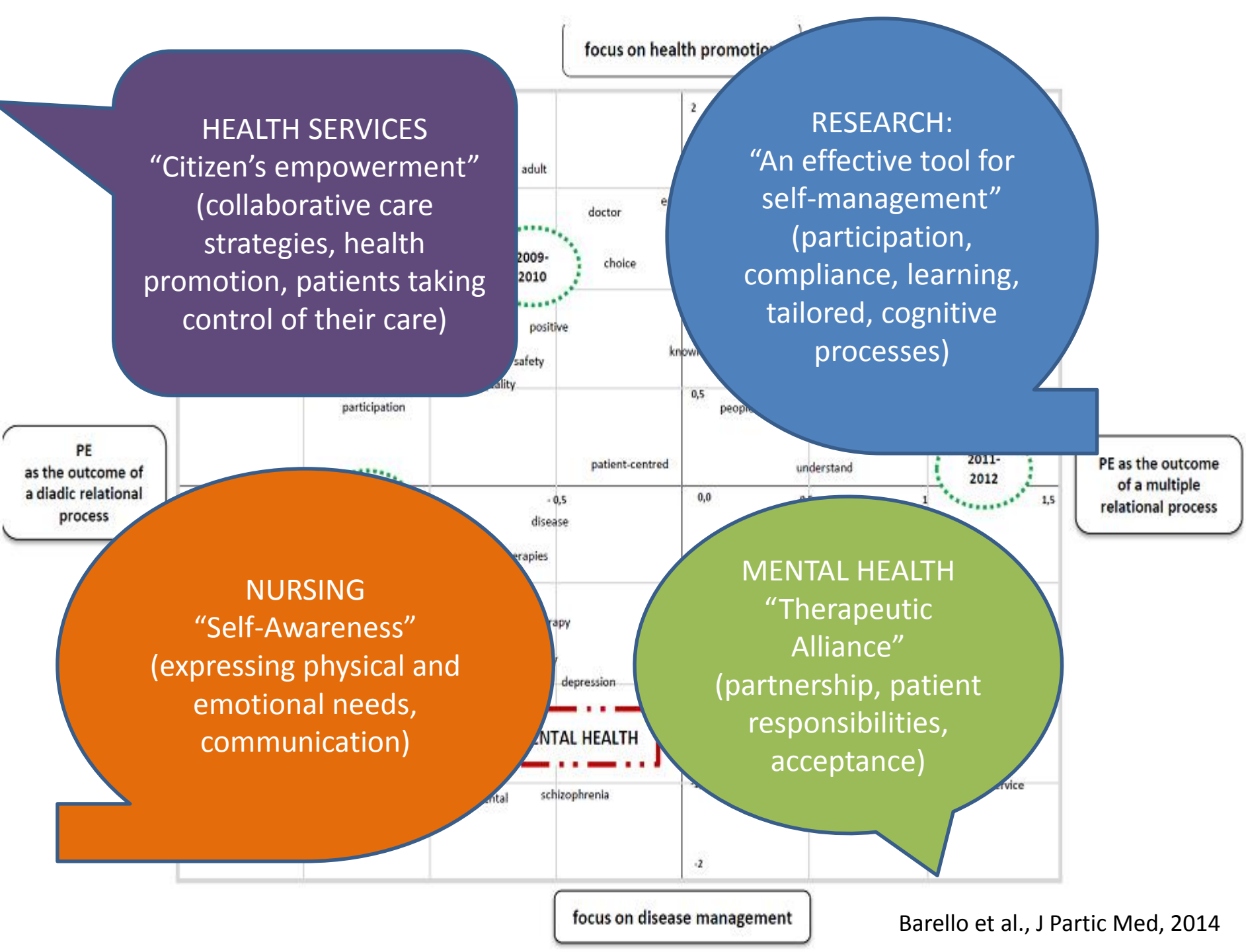
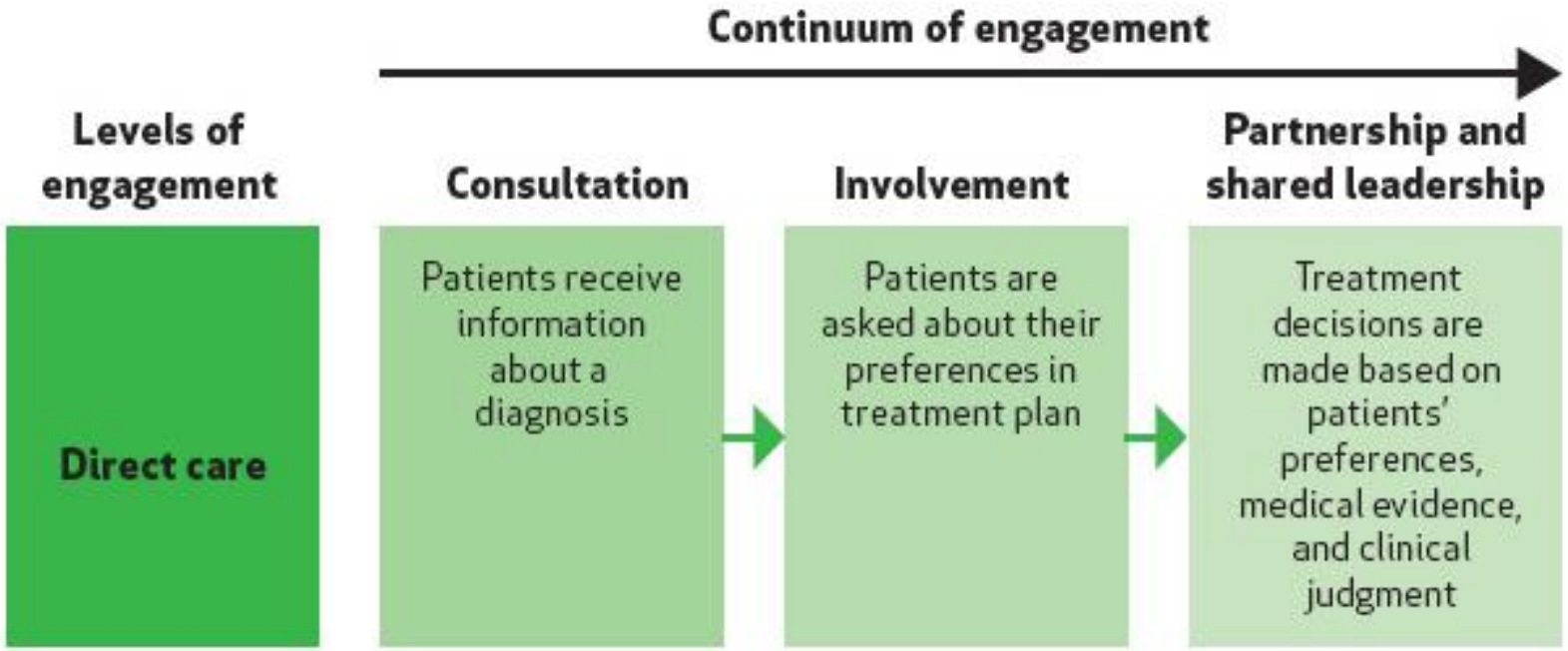


Barello et al., J Partic Med, 2014

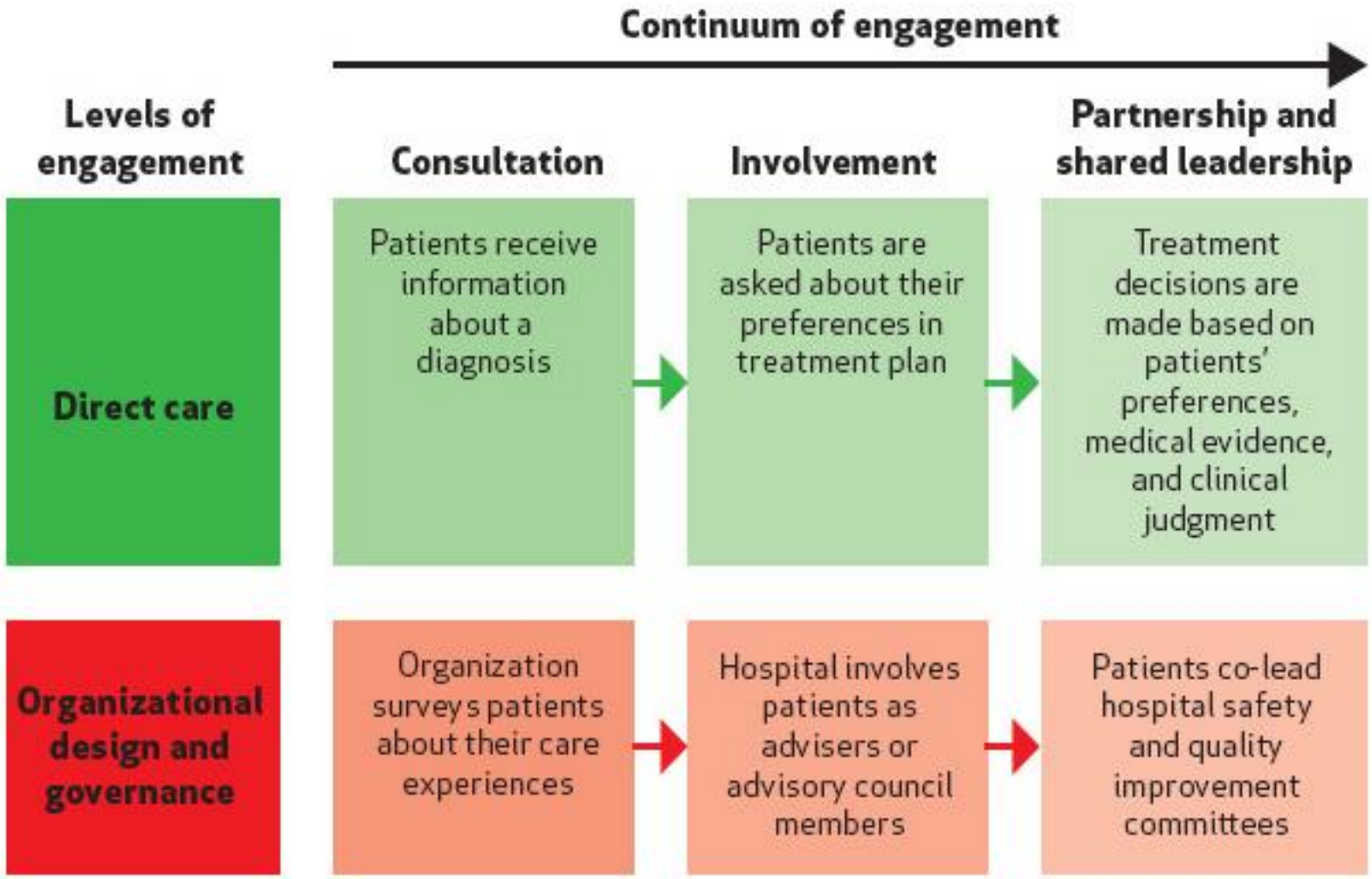
Patient engagement occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research as well as in summarizing, distributing, sharing, and applying it's resulting knowledge

CIHR IRSC

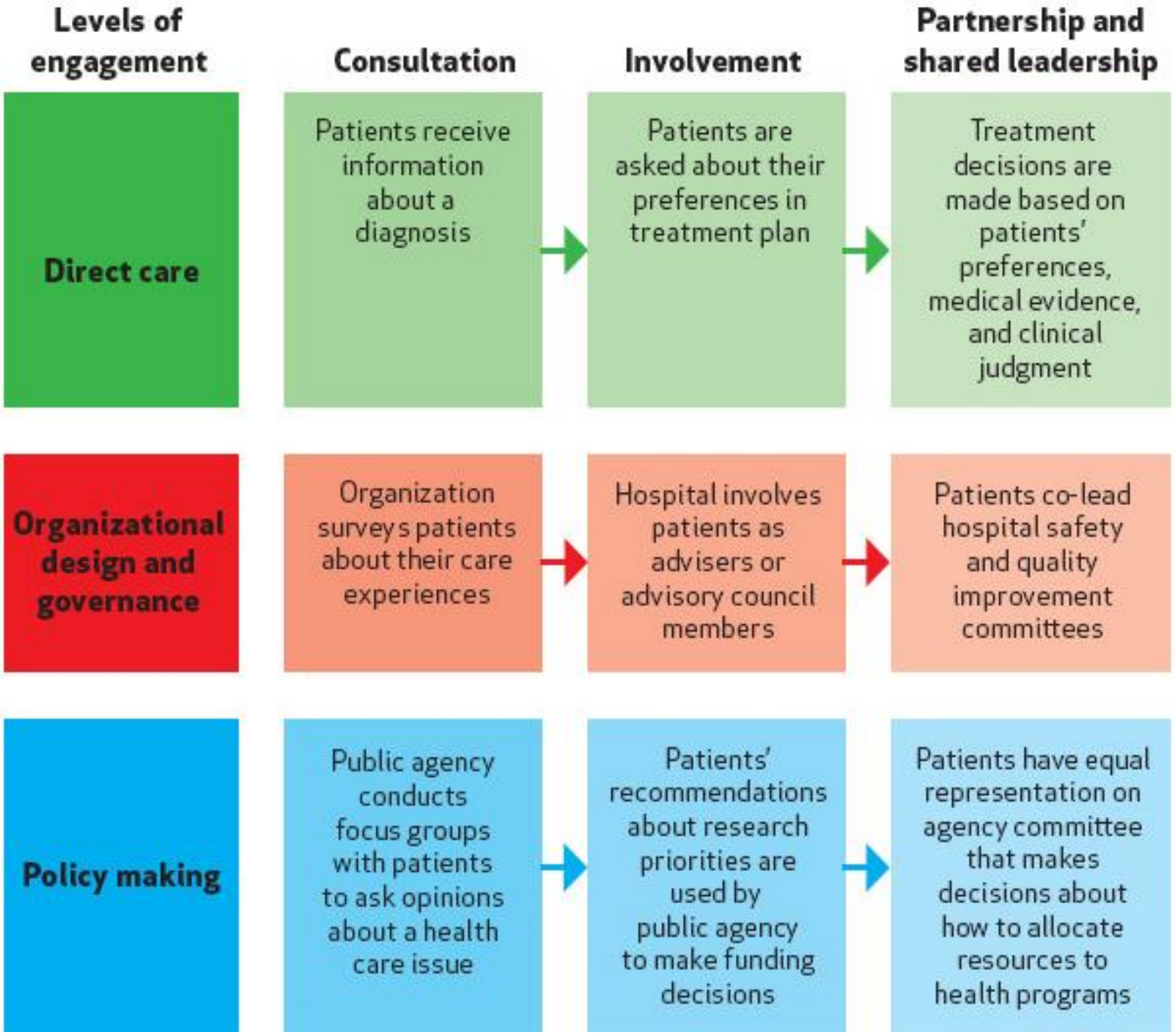
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada



Carmen et al *Health Affairs*, 2013



Carmen et al *Health Affairs*, 2013


Levels of engagement
Consultation
Involvement
Partnership and shared leadership
Direct care
Patients receive information about a diagnosis
Patients are asked about their preferences in treatment plan
Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment
Organizational design and governance
Organization surveys patients about their care experiences
Hospital involves patients as advisers or advisory council members
Patients co-lead hospital safety and quality improvement committees
Policy making
Public agency conducts focus groups with patients to ask opinions about a health care issue
Patients' recommendations about research priorities are used by public agency to make funding decisions
Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Taking Patient-Centeredness Seriously

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Patient Engagement → Patient-Driven Research → Dissemination

Understanding the choices patients face

Aligning research questions and methods with patient needs

Providing patients and providers with information for better decisions

Research Should Engage Stakeholders at Every Step

- Planning the study
- Conducting the study
- Disseminating study results
- PCORI Engagement Principles

PCORI Engagement Rubric

A four-part rubric developed to help guide applicants, reviewers, awardees, and program officers on ways to engage patients and families in conducting research

http://www.pcori.org/assets/2014/02/PCORI-Patient-and-Family-Engagement-Rubric.pdf

pcori
Patient-Centered Outcomes Research Institute

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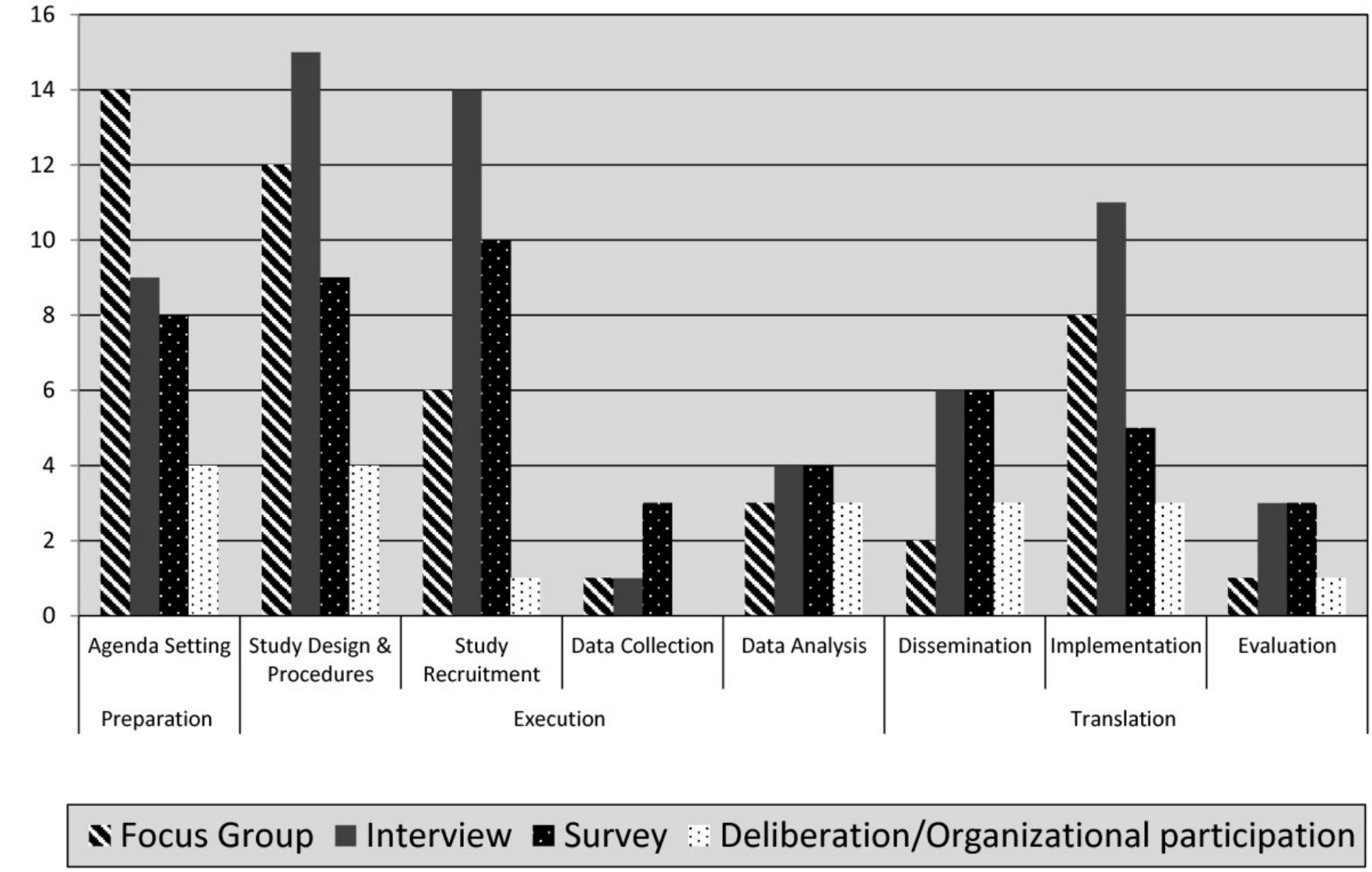

Domecq et al., BMC Health Serv Res 2014

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SPOR principles to ensure relevance:

- Patients need to be involved in all aspects
- Decision-makers and clinicians need to be involved throughout the entire research process
- Funding is based on a 1:1 with non-federal partners
- Requires a multi-disciplinary approach;
- SPOR is *outcome driven* and incorporates *performance measurement and evaluation* as integral components

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

CIHR IRSC

Canadian Institutes of Health Research

Instituts de recherche en santé du Canada

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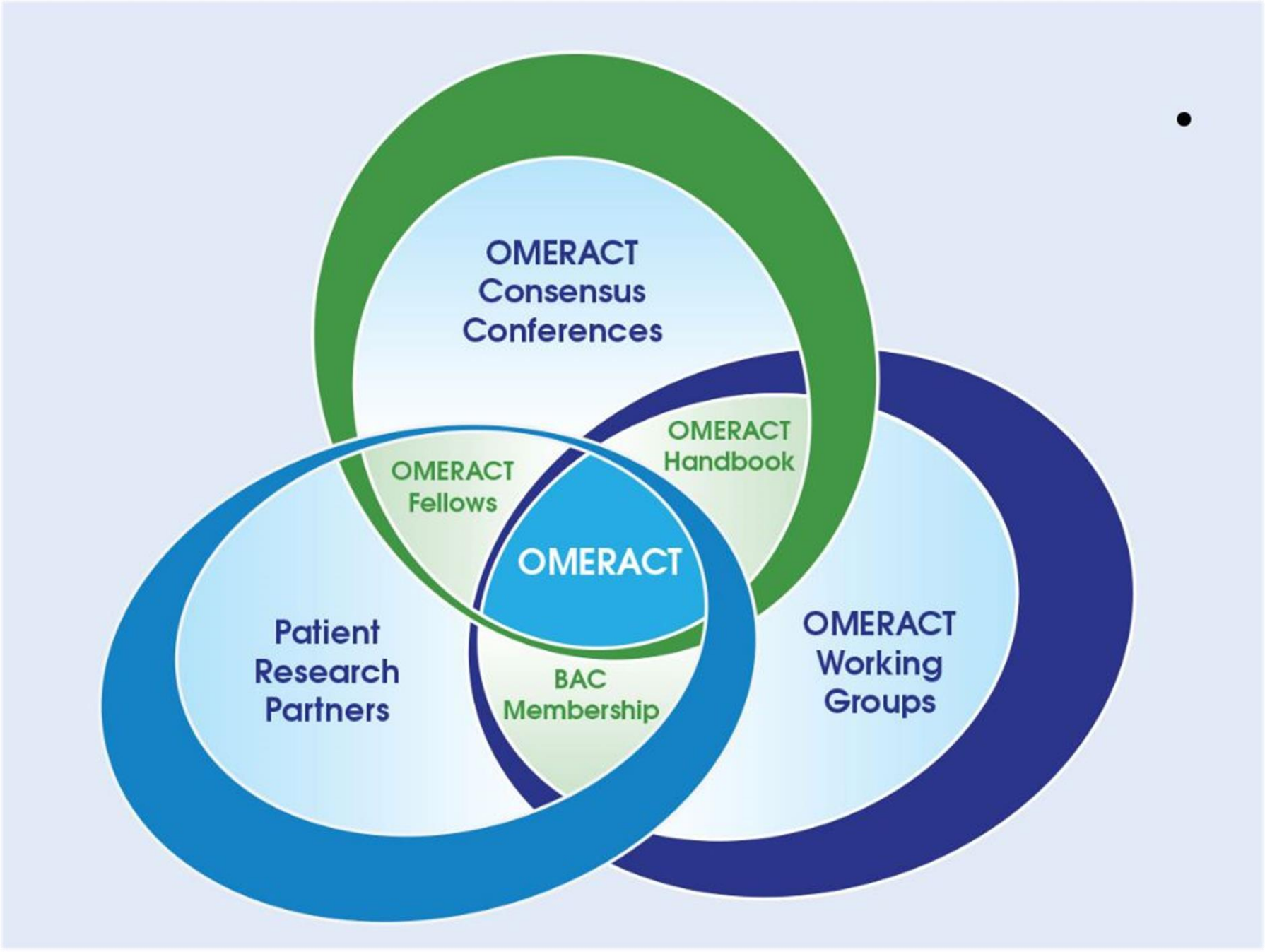
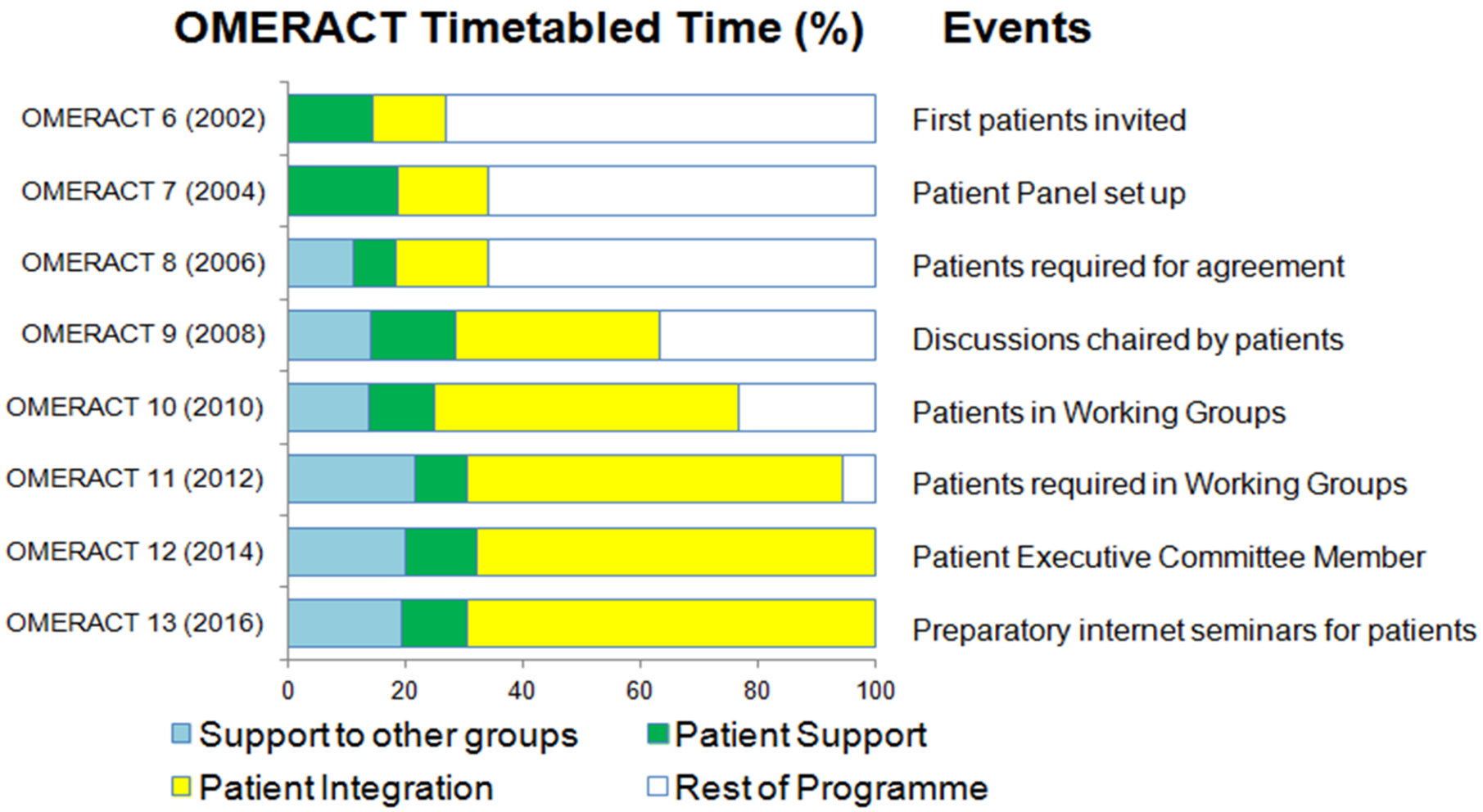
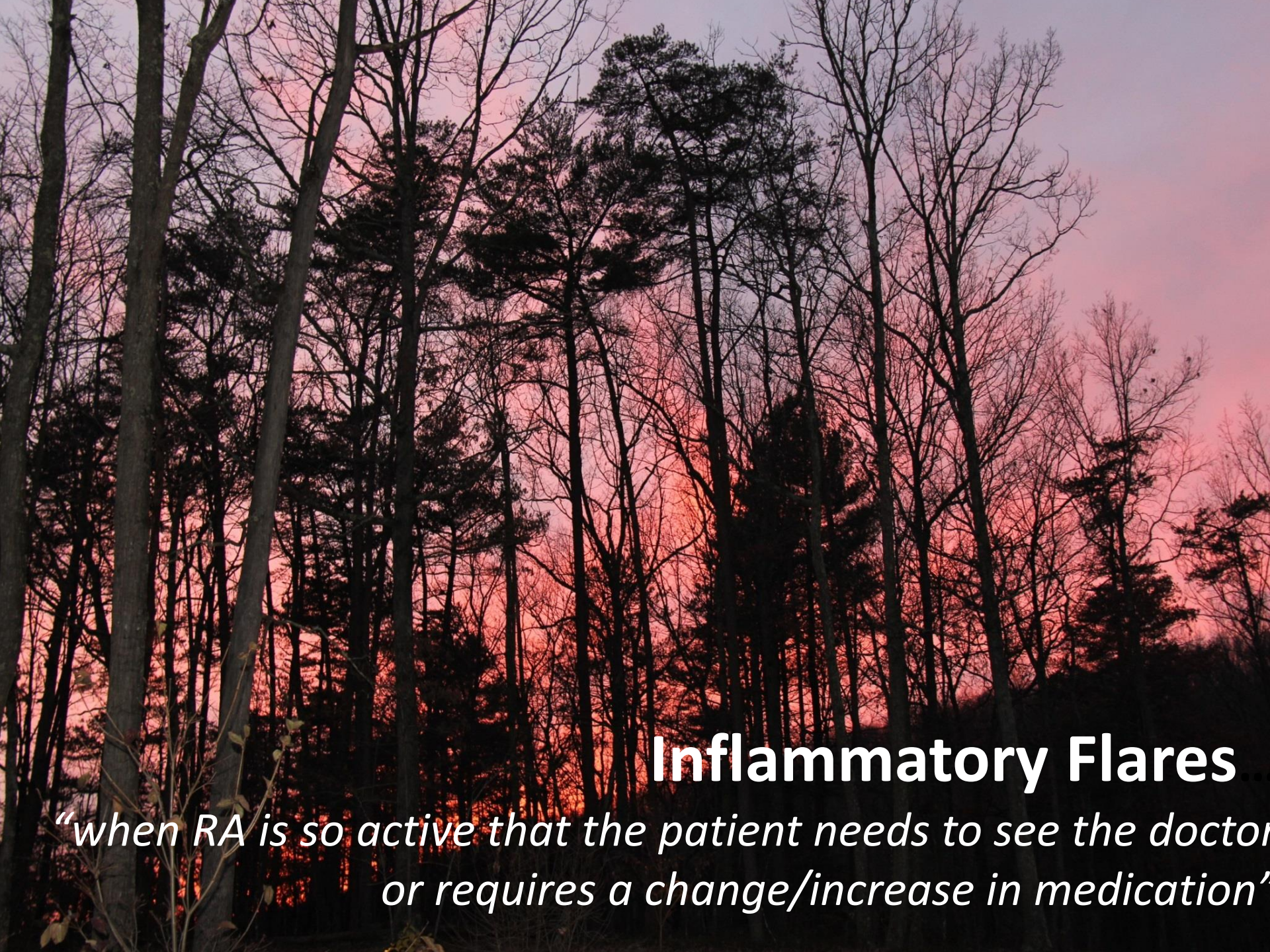

OMERACT
Consensus
Conferences
OMERACT
Handbook
OMERACT
Fellows
OMERACT
Patient
Research
Partners
BAC
Membership
OMERACT
Working
Groups


OMERACT Timetabled Time (%)
Events
OMERACT 6 (2002)
OMERACT 7 (2004)
OMERACT 8 (2006)
OMERACT 9 (2008)
OMERACT 10 (2010)
OMERACT 11 (2012)
OMERACT 12 (2014)
OMERACT 13 (2016)
First patients invited
Patient Panel set up
Patients required for agreement
Discussions chaired by patients
Patients in Working Groups
Patients required in Working Groups
Patient Executive Committee Member
Preparatory internet seminars for patients
0
20
40
60
80
100
Support to other groups
Patient Support
Patient Integration
Rest of Programme



Inflammatory Flares…

"when RA is so active that the patient needs to see the doctor
or requires a change/increase in medication"

“Not everything
that counts
can be counted,
and not everything
that can be counted
really counts.”

Sign in Einstein’s office

N=67

Ear piercing…ear-shattering pain. It goes from just aching, a dull background ache to an ear-shattering pain.

Maybe that's the difference for me that it [pain] doesn't let up. It just is unrelenting.

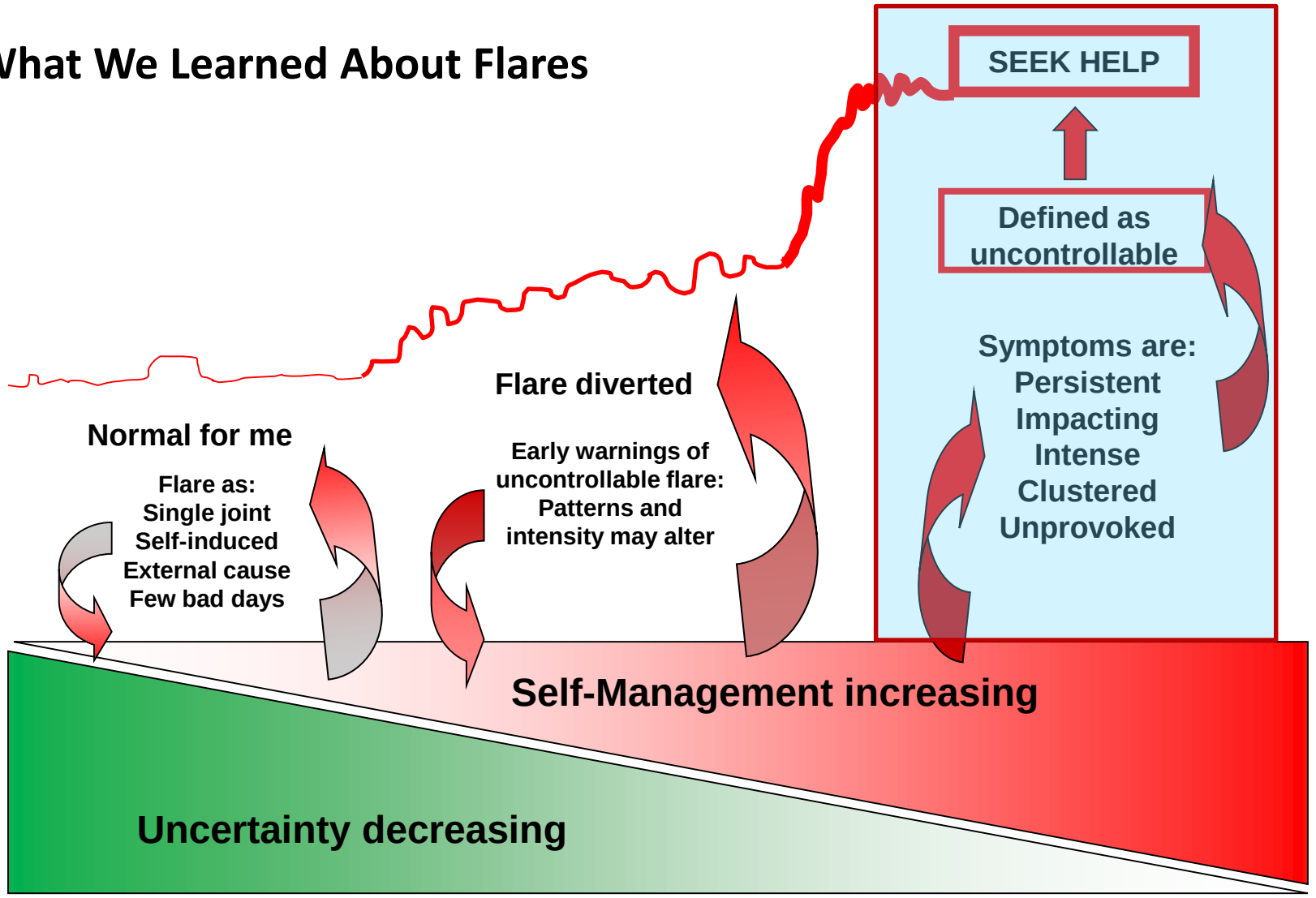
I need 2 hours in the early mornings to get going… The simplest things like washing or cleaning, combing my hair -- all very tiring and stressful.

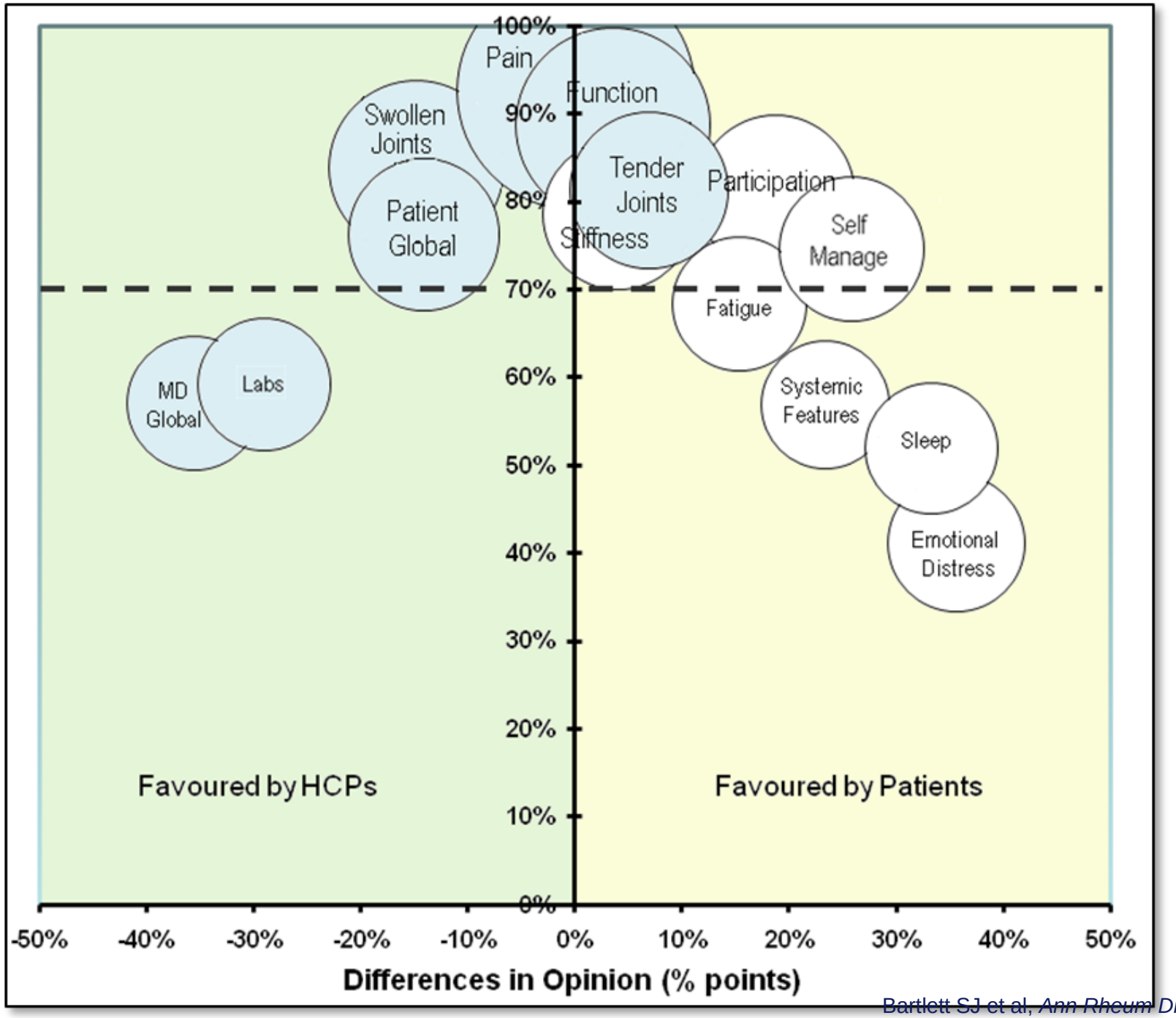
"I'm just like an animal. [I want to] go get in a cage somewhere until it goes away, and then I'll come back out."

"All I do is lie down, and get up to go to the toilet, and it takes me half an hour to get to the toilet.

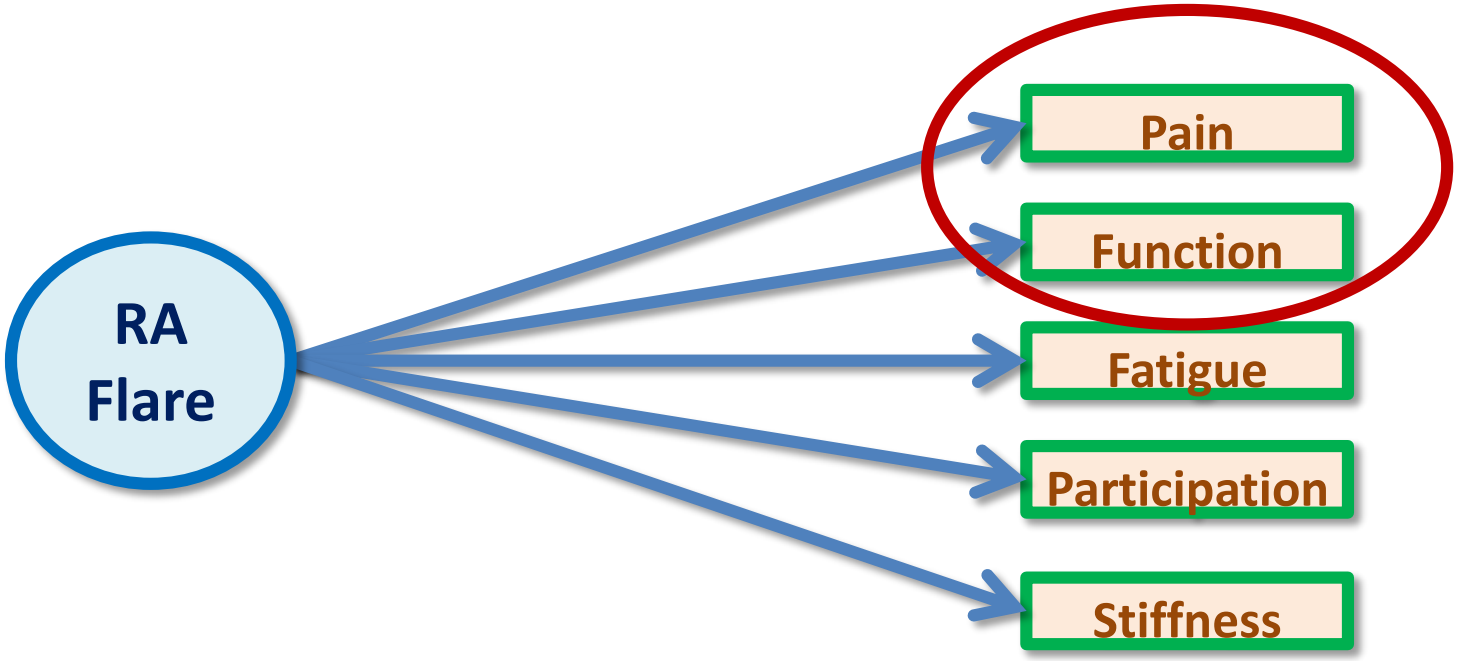
"When…my doctor says '*Why are you in here today?,'* I say '***Because I can't function like this. I'm hurting, I want to kill myself.***"

What We Learned About Flares





Bartlett SJ et al, *Ann Rheum Dis* 2012

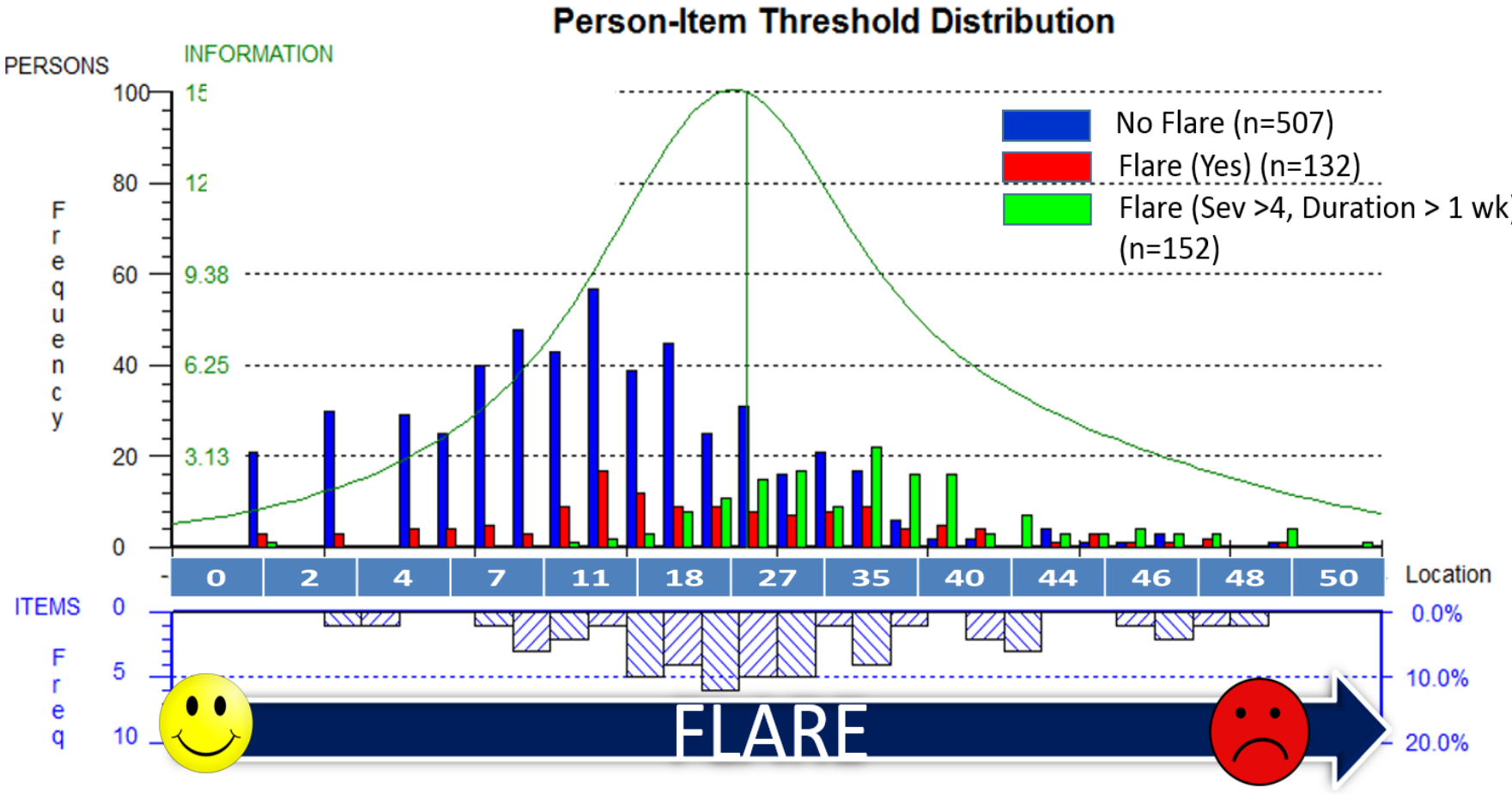


3 Modified Delphi's

- Patients: 148 in 11 countries
- Providers: 177 in 19 countries
- Combined: 125 pts and 108 HCPs in 23 countries

“Flares are common in RA and are often preceded by treatment reductions…

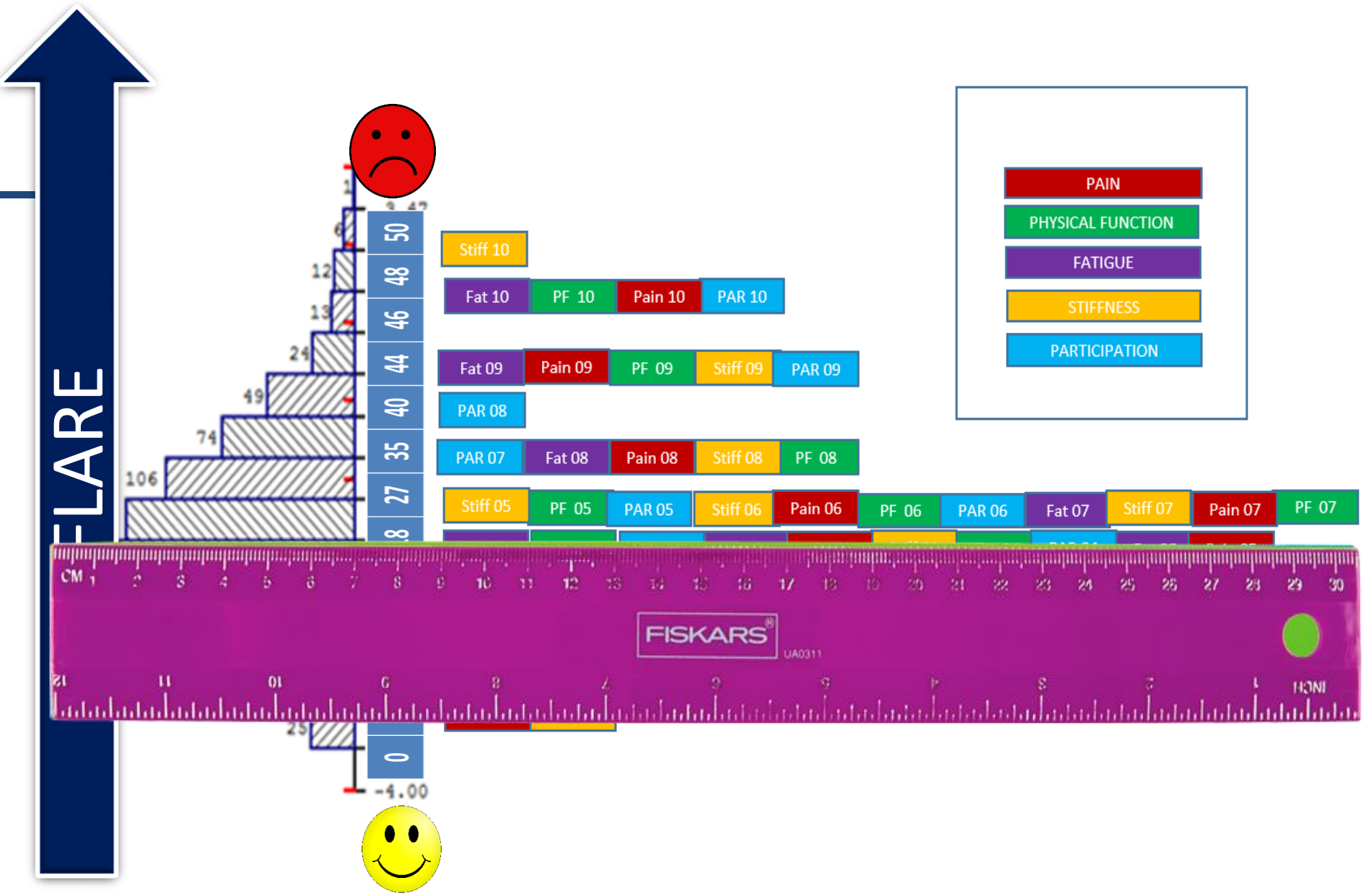
RA-FQ can discriminate between patients with/without flare and has strong evidence of construct and consequential validity.”



Canada (n=896), France (n=138), and Netherlands (n=178)

Coming Full Circle

- Scores ranged from 10-42 out of 50
- Items meaningful?
- Score make sense?
- Is this truly fit for purpose?


FLARE
50
48
46
44
40
35
27
8
0
-4.00
106
74
49
24
13
12
6
Stiff 10
Fat 10
PF 10
Pain 10
PAR 10
Fat 09
Pain 09
PF 09
Stiff 09
PAR 09
PAR 08
PAR 07
Fat 08
Pain 08
Stiff 08
PF 08
Stiff 05
PF 05
PAR 05
Stiff 06
Pain 06
PF 06
PAR 06
Fat 07
Stiff 07
Pain 07
PF 07
PAIN
PHYSICAL FUNCTION
FATIGUE
STIFFNESS
PARTICIPATION
FISKARS

"It's empowering to know my score."

"I'm thinking I'm way to the edge, and I don't even know it…there is utility in [knowing] it."

"I know we're talking about clinical trials here….[but] we who have this disease are always looking for ways we can minimize our time on the edge."

"It validates…you know when you go and they say you are fine, but I don't feel fine."

Working with our PRPs

- Members of the Steering Committee
- Analyzing focus group data
- Developing items and reviewing wording
- Interpreting the results
- Presenting findings at international meetings
- Authoring publications

- Thinking creatively to get into patients' hands

Translate knowledge to action

npr

Creaky Joints

Bringing arthritis to its knees since 1999.

IMHA Research Ambassadors

- Sharing knowledge about research
- Contribute new perspective
- Review plain language abstracts, documents
- Discuss new initiatives or projects

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- Ask new questions
- Engage new partners
- Design studies differently
- Translate knowledge to action

شكراً جزيلاً
ngiyabonga
рахмат
danke
謝謝
teşekkür ederim
Баярлалаа
mersi
barka
welalin
tack
mahalo
tapadh leat
спасибо
faafetai lava
vinaka
спасибі
blagodaram
dank je
misaotra
matondo
paldies
grazzi
thank you
gracias
хвала
kiitos
dankie
nandri
dhanyavad
bedankt
hvala
mauruuru
köszönöm
asante
manana
obrigada
tenki
enkosi
bayarlalaa
gràçie
dankon
aċiū
akun
djiere dieuf
mochchakkeram
murakoze
dziękuję
дякую
mamnun
chnorakaloutioun
gratias ago
gràcies
sulpáy
go raibh maith agat
chokrane
sobodi
dēkuji
obrigado
sagolun
sukriya
kop khun krap
taiku
arigatô
takk
dakujem
trugarez
mèsi
ありがとう
tanemirt
grazie
najis tuke
terima kasih
rahmet
shukriya
mercê
мерси
didi madloba
kam sah hamnida
rahmat
diolch
dhanyavadagalu
তোমাকে ধন্যবাদ
감사합니다
xièxie
ευχαριστώ
merci