# Making Research Matter: Engaging Stakeholders to Improve Outcomes

Jill Chorney, PhD RPsych
Associate Professor
Dept of Anesthesia, Pain Management, Perioperative Medicine

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## Disclosure

- Platform for BALANCE provided as in-kind contribution by Velsoft
- Consulting fees from Headcan

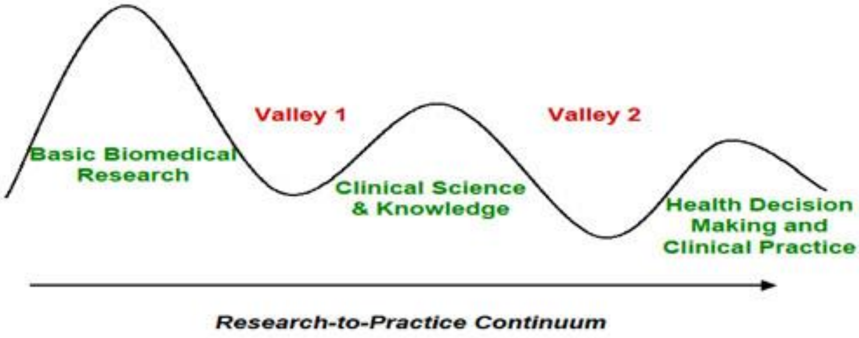
# Learning Objectives

- At the end of this presentation, attendees will be able to:
  - Identify potential benefits and drawbacks of engaging stakeholders in research
  - Describe methods to engage stakeholders in collaborative research
  - Recognize opportunities for stakeholder engagement in their own work

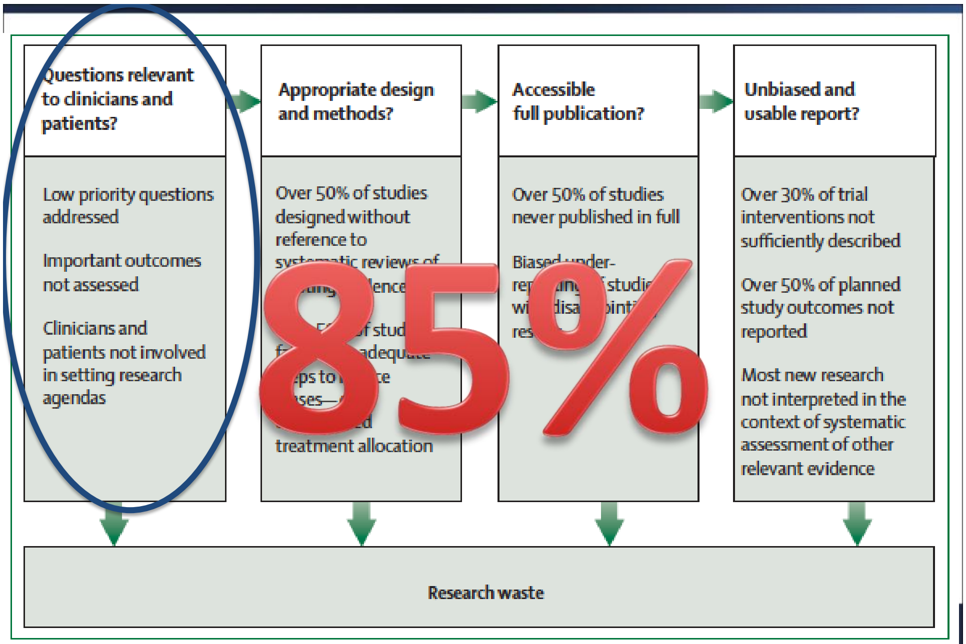
# Research Funding

> 1 million/ year

# Research to Practice Gap



# Research Waste



**Questions relevant to clinicians and patients?**

Low priority questions addressed

Important outcomes not assessed

Clinicians and patients not involved in setting research agendas

**Appropriate design and methods?**

Over 50% of studies designed without reference to systematic reviews of [illegible] ting [illegible] ence

[illegible] f stud [illegible] adequate [illegible] ps to [illegible] ce [illegible] ses— [illegible] d treatment allocation

**Accessible full publication?**

Over 50% of studies never published in full

Biased under-rep [illegible] ing [illegible] f studie wi [illegible] disa [illegible] ointi [illegible] res [illegible]

**Unbiased and usable report?**

Over 30% of trial interventions not sufficiently described

Over 50% of planned study outcomes not reported

Most new research not interpreted in the context of systematic assessment of other relevant evidence

**Research waste**

85%

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Chalmers, Glazou (2009). Avoidable waste in the production and reporting of research. Lancet, 374, 86-89

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# Genesis of a Research Study

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# The Researcher Perspective

- Motivations
  - Solving a problem
  - Understanding something
  - Improving something
  - “Checking the box”
  - Promotion, Funding, Recognition
    - Clear line of inquiry, evidence the work is feasible, impact: # of citations

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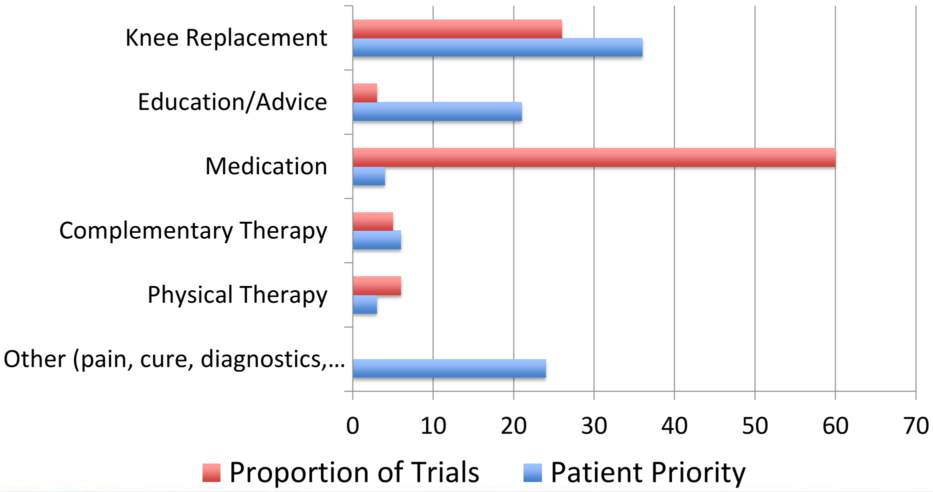
# Patient and Research Perspectives



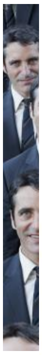
Talon, Chard, Dieppe (2000). Relation Between Agendas of the Research Community and the research consumer. Lancet, 355, 2037-40

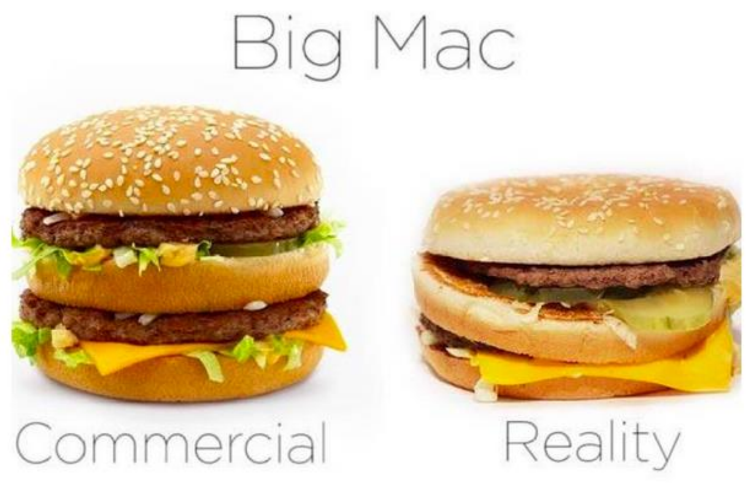
# Mismatch in outcomes too…

| Professional Priority Outcomes | Patient Priority Outcomes |
|---|---|
| Tender joint count | Less pain |
| Swollen joint count | More mobility |
| Pain | Doing everyday things |
| Physical function | No more joint damage |
| Patient rating of disease activity | Enjoy life |
| Acute phase reactant value | More independent |
| | Less fatigue |
| | Doing things you want |

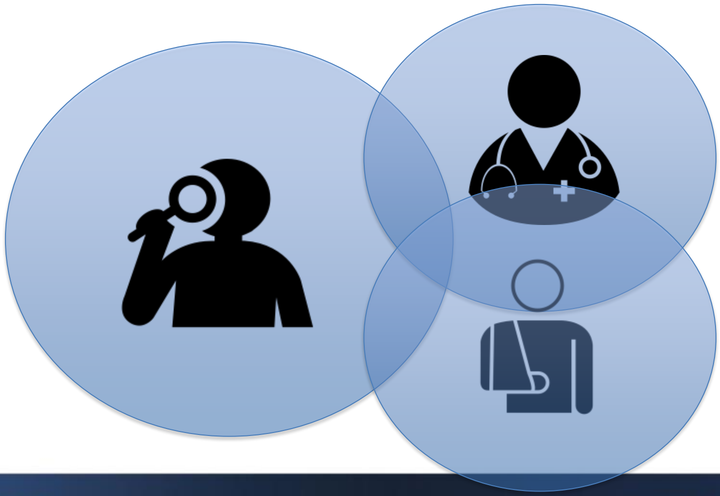
Sanderson et al., (2010) Patient perspective of measuring treatment efficacy…, Arthr Care Res, 62, 647-56

# Mismatch for Providers too





## Stakeholder Engagement to Address Mismatch



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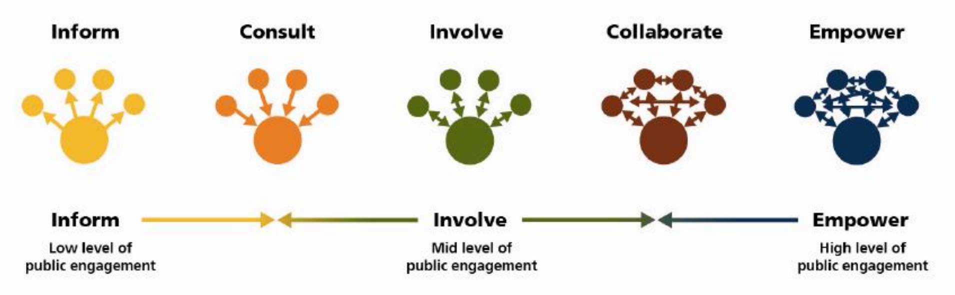
## Levels of Engagement



International Association for Public Participation (IAP2)

# Methods of Engagement

| Inform | Consult | Involve | Collaborate | Empower |
|---|---|---|---|---|
| Press release | Focus groups | Forums | Advisory councils | Stakeholder as researcher |
| Websites | Interviews | Workshops | Expert patients | Patient as project manager |
| Mail outs | Social media | Public meetings | Revolving conversation | Citizen jury |
| Fact sheets | Surveys | | Delphi | |

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Burns et al (2014). Practical resources to support patient and family engagement in healthcare decisions. BMC Health Ser Res, 14, 175

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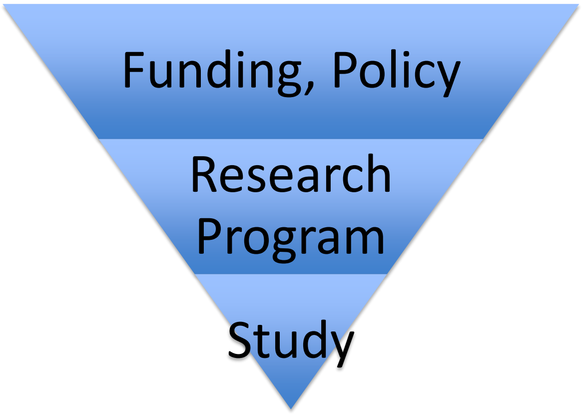
# Engagement at Different Levels



Funding, Policy

Research Program

Study

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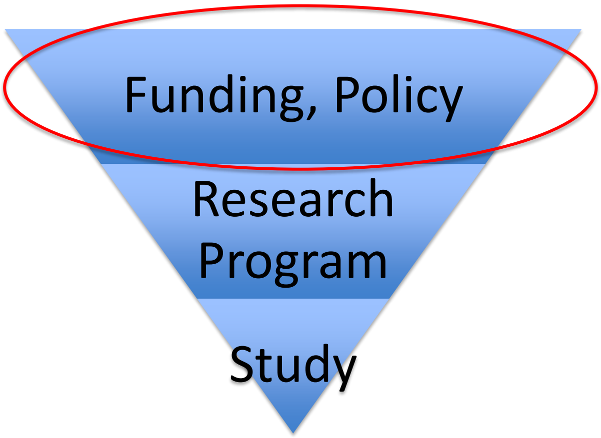
# Engagement at Different Levels



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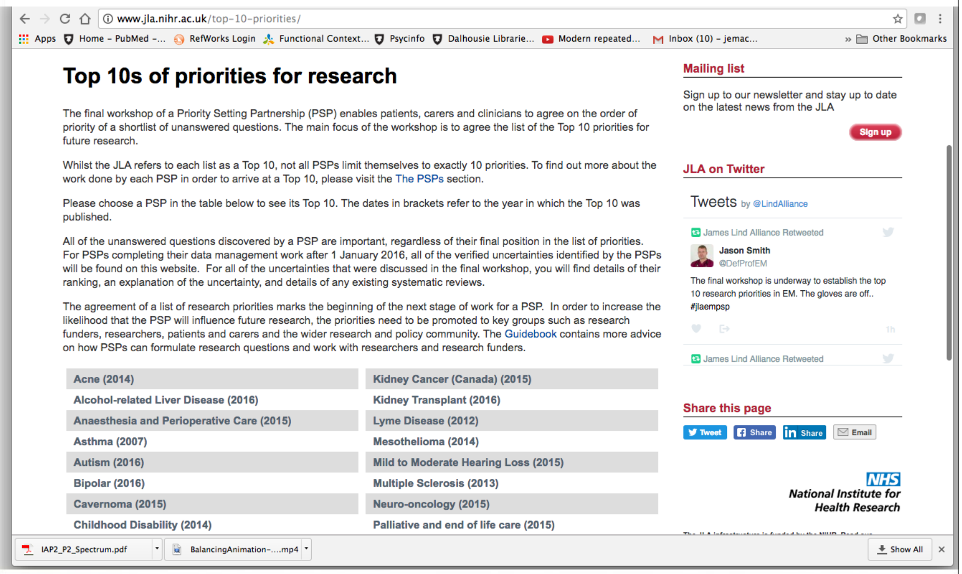
# Example of Engagement at Policy Level

James Lind Alliance

Priority Setting Partnerships



## Top 10s of priorities for research

The final workshop of a Priority Setting Partnership (PSP) enables patients, carers and clinicians to agree on the order of priority of a shortlist of unanswered questions. The main focus of the workshop is to agree the list of the Top 10 priorities for future research.

Whilst the JLA refers to each list as a Top 10, not all PSPs limit themselves to exactly 10 priorities. To find out more about the work done by each PSP in order to arrive at a Top 10, please visit the The PSPs section.

Please choose a PSP in the table below to see its Top 10. The dates in brackets refer to the year in which the Top 10 was published.

All of the unanswered questions discovered by a PSP are important, regardless of their final position in the list of priorities. For PSPs completing their data management work after 1 January 2016, all of the verified uncertainties identified by the PSPs will be found on this website. For all of the uncertainties that were discussed in the final workshop, you will find details of their ranking, an explanation of the uncertainty, and details of any existing systematic reviews.

The agreement of a list of research priorities marks the beginning of the next stage of work for a PSP. In order to increase the likelihood that the PSP will influence future research, the priorities need to be promoted to key groups such as research funders, researchers, patients and carers and the wider research and policy community. The Guidebook contains more advice on how PSPs can formulate research questions and work with researchers and research funders.

**Acne (2014)**
**Alcohol-related Liver Disease (2016)**
**Anaesthesia and Perioperative Care (2015)**
**Asthma (2007)**
**Autism (2016)**
**Bipolar (2016)**
**Cavernoma (2015)**
**Childhood Disability (2014)**
**Kidney Cancer (Canada) (2015)**
**Kidney Transplant (2016)**
**Lyme Disease (2012)**
**Mesothelioma (2014)**
**Mild to Moderate Hearing Loss (2015)**
**Multiple Sclerosis (2013)**
**Neuro-oncology (2015)**
**Palliative and end of life care (2015)**

**Mailing list**

Sign up to our newsletter and stay up to date on the latest news from the JLA

**JLA on Twitter**

Tweets by @LindAlliance

James Lind Alliance Retweeted

**Jason Smith** @DefProfEM

The final workshop is underway to establish the top 10 research priorities in EM. The gloves are off.. #jlaempsp

1h

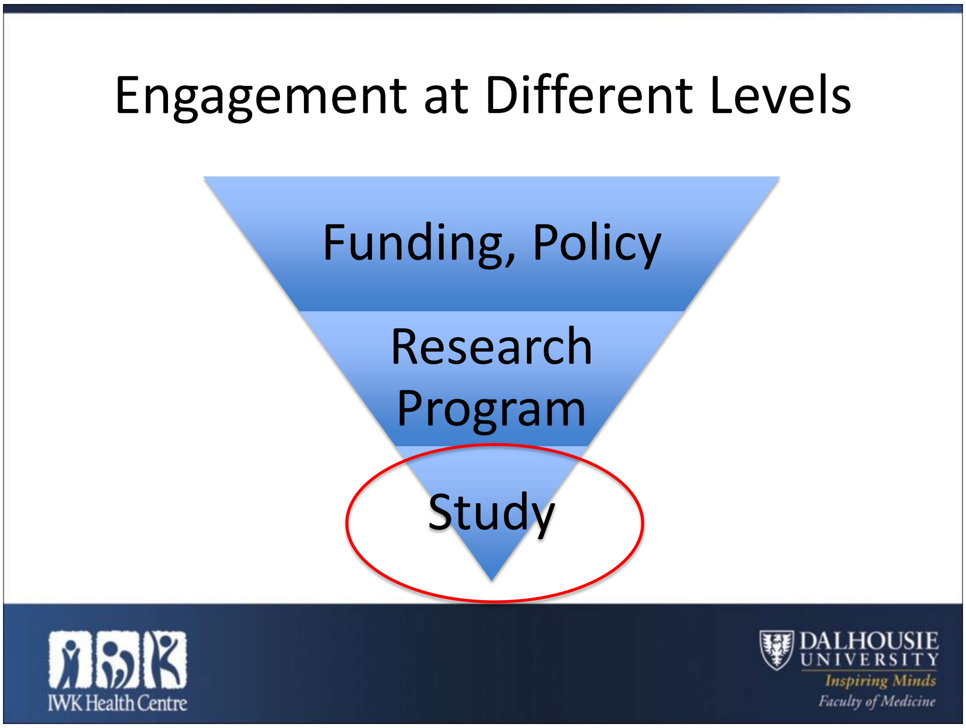
James Lind Alliance Retweeted

**Share this page**

National Institute for Health Research

# JLA: Depression

1. What are the most effective ways to **prevent occurrence and recurrence** of depression?
2. What are the **best early interventions** (treatments and therapies) for depression? And **how early should they be used** in order to result in the best patient outcomes?
3. What are the best ways to **train healthcare professionals** to recognise and understand depression?
4. What is the **impact on a child** of having a parent with depression and can a parent **prevent their child** from also developing depression?
5. What are the best ways to inform people with depression about **treatment options** and their effectiveness in order to **empower** them and help them **self-manage**?



# Engagement at Different Levels

Funding, Policy

Research Program

Study

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Premedication Protocol

Passport

Fast Track Admission

**Where to start????**

Avoid Surgery altogether

Characterization, predictors, outcome measurement

System and Family Costs

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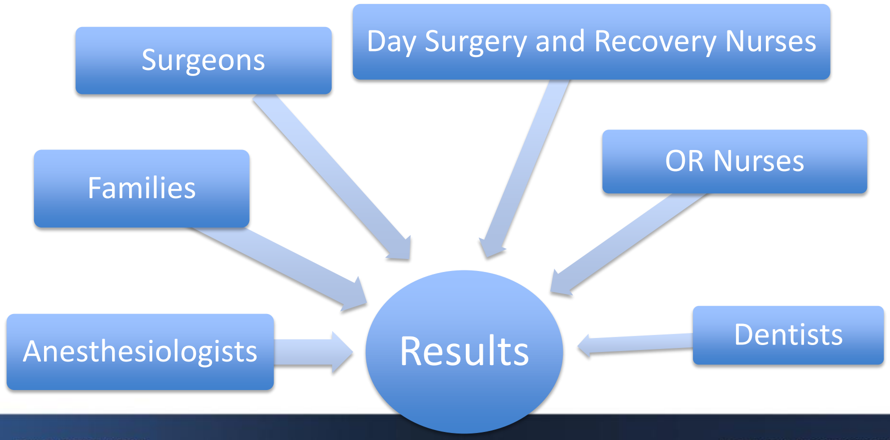
# Needs Assessment

- Aim: To guide a cohort study characterizing distress and predictors
  - What does distress look like in this group?
  - What factors contribute to distress?
  - What factors can reduce distress?
- Literature review (commentaries!)

# Stakeholder Interviews



# Results

- Child distress important, but so much more!
  - Child directed strategies (e.g., sensory, emotional, communicative), but needed to be tailored
  - Even when everything “done right,” still unpredictable
- Parent factors
  - Work done before day of surgery
  - Important resource but stressed themselves
  - Just want providers to “try their best”

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# Results

- Healthcare provider unease
  - Lack of training
  - Anticipatory worry (even if things going well)
- System-level issues
  - Lack of coordination; Differences in approaches
  - Power imbalances and difficulty communicating with one another

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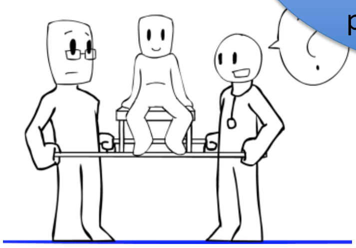
# Now what?!?



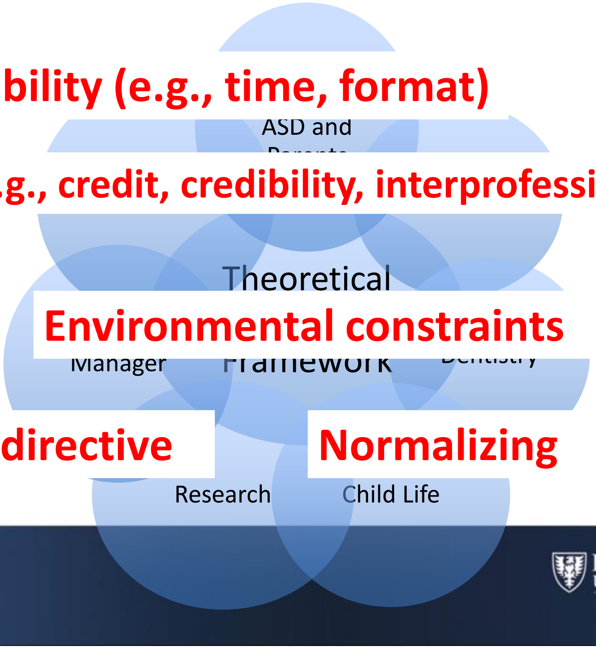
We don't want more description or validation of measures.
Do something to help us now!
We want a program for healthcare providers

↔ Stakeholders

# What is our target?

- Delivery of High Quality Family Centered Care
  - Tailoring care to each child's sensory, emotional, and communication needs
  - Partnering with families-but not relying on them too much
  - Acknowledging difficult emotions and express empathy
  - Coordinate care through respectful inter-professional communication

# Change HCP behavior, really?!?



**Feasibility (e.g., time, format)**

**Buy in (e.g., credit, credibility, interprofessional)**

**Environmental constraints**

**Non-directive**

**Normalizing**

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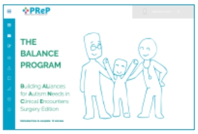
# BALANCE

**7 Online modules:**

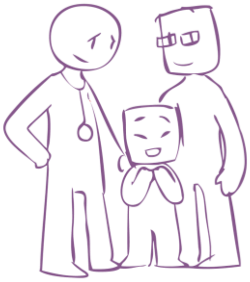
1) Introduction
2) Family Centred Care
3) Focus on the Child
4) Focus on the Family
5) Focus on the Provider
6) Focus on the System
7) Putting BALANCE into practice



PReP

THE BALANCE PROGRAM

Building ALliances for Autism Needs in Clinical Encounters: Surgery Edition



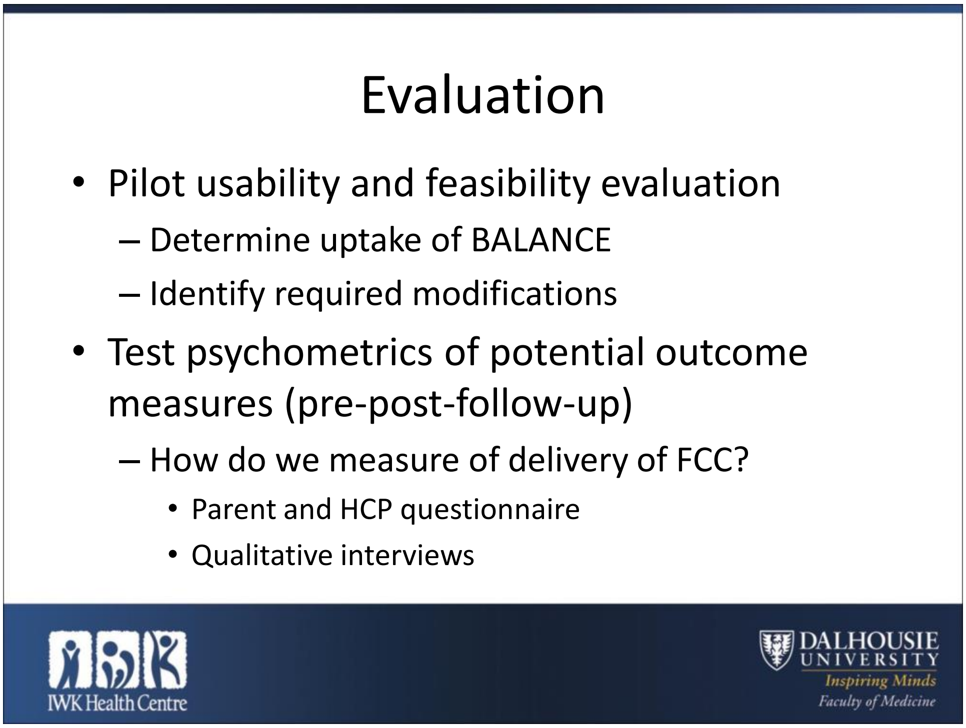
**Toolkits:**

PReP

Take a SEC Resource

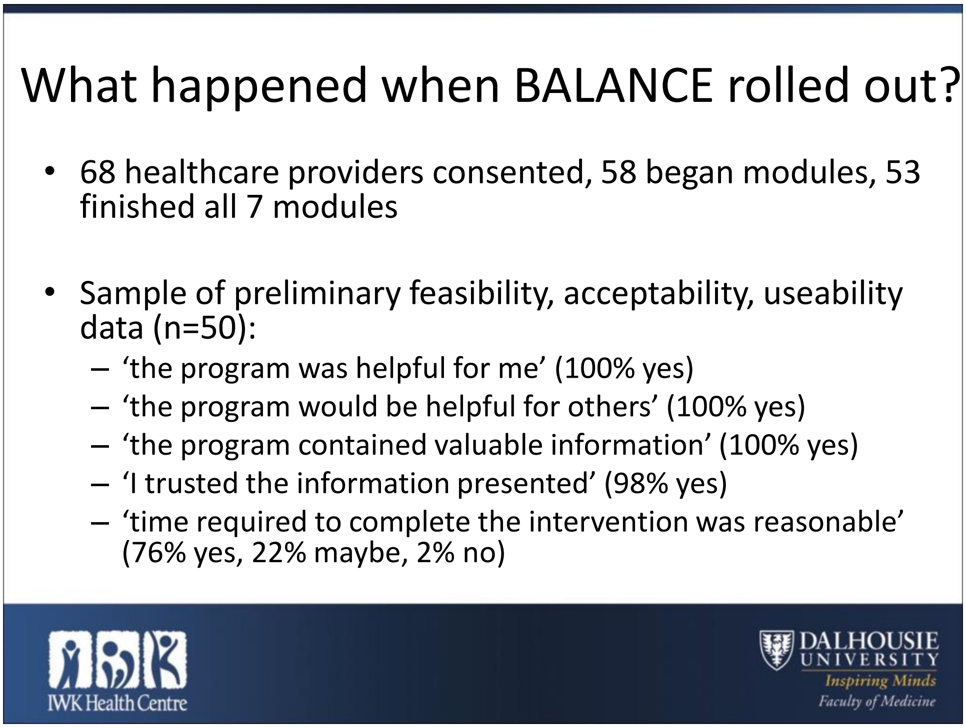
| | ASSESSMENT | APPROACH |
|---|---|---|
| SENSORY | | |
| EMOTIONAL | | |
| COMMUNICATION | | |

Consult



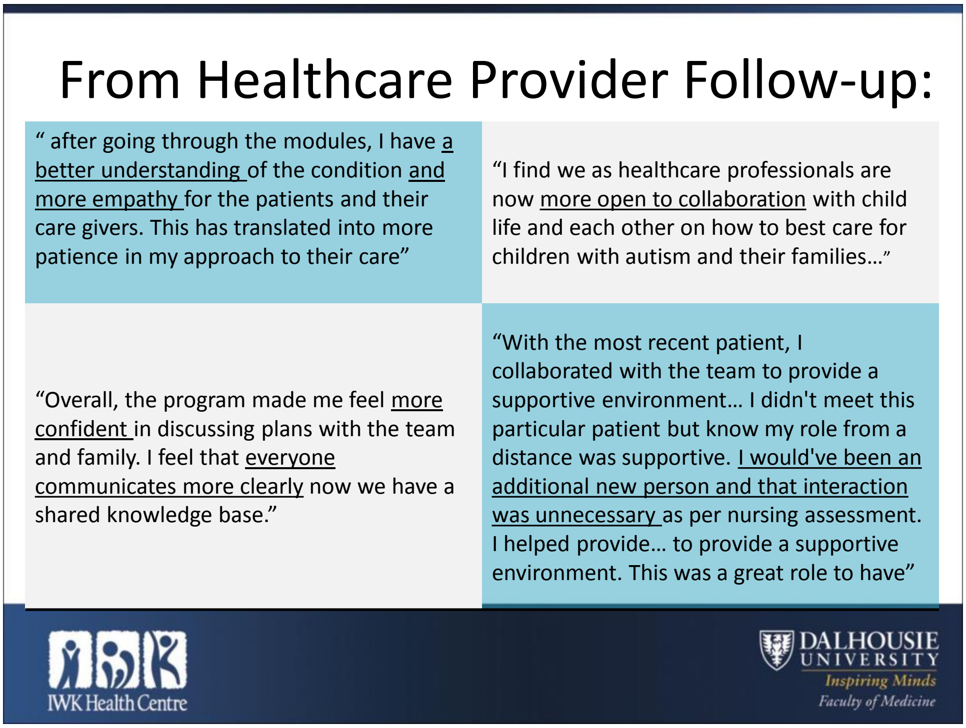
# Evaluation

- Pilot usability and feasibility evaluation
  - Determine uptake of BALANCE
  - Identify required modifications
- Test psychometrics of potential outcome measures (pre-post-follow-up)
  - How do we measure of delivery of FCC?
    - Parent and HCP questionnaire
    - Qualitative interviews



# What happened when BALANCE rolled out?

- 68 healthcare providers consented, 58 began modules, 53 finished all 7 modules
- Sample of preliminary feasibility, acceptability, useability data (n=50):
  - ‘the program was helpful for me’ (100% yes)
  - ‘the program would be helpful for others’ (100% yes)
  - ‘the program contained valuable information’ (100% yes)
  - ‘I trusted the information presented’ (98% yes)
  - ‘time required to complete the intervention was reasonable’ (76% yes, 22% maybe, 2% no)



# From Healthcare Provider Follow-up:

“ after going through the modules, I have a better understanding of the condition and more empathy for the patients and their care givers. This has translated into more patience in my approach to their care”

“I find we as healthcare professionals are now more open to collaboration with child life and each other on how to best care for children with autism and their families…”

“Overall, the program made me feel more confident in discussing plans with the team and family. I feel that everyone communicates more clearly now we have a shared knowledge base.”

“With the most recent patient, I collaborated with the team to provide a supportive environment… I didn't meet this particular patient but know my role from a distance was supportive. I would've been an additional new person and that interaction was unnecessary as per nursing assessment. I helped provide… to provide a supportive environment. This was a great role to have”

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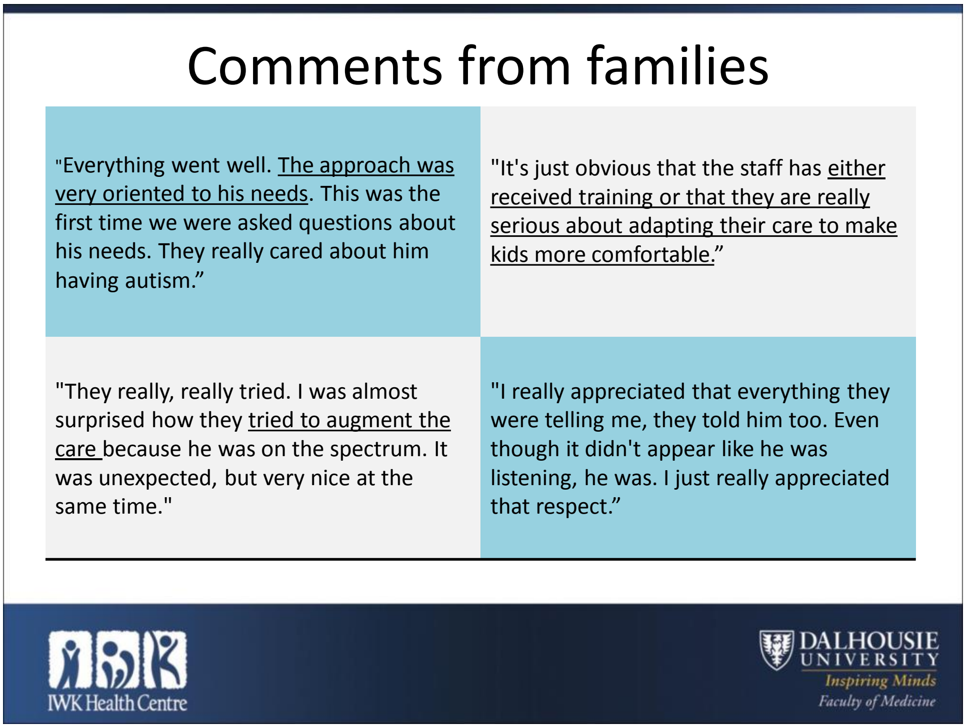

# Comments from families

"Everything went well. The approach was very oriented to his needs. This was the first time we were asked questions about his needs. They really cared about him having autism.”

"It's just obvious that the staff has either received training or that they are really serious about adapting their care to make kids more comfortable.”

"They really, really tried. I was almost surprised how they tried to augment the care because he was on the spectrum. It was unexpected, but very nice at the same time."

"I really appreciated that everything they were telling me, they told him too. Even though it didn't appear like he was listening, he was. I just really appreciated that respect.”

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# Reflections

- MANY benefits to collaborating with families and healthcare providers
  - Increased buy-in (recruitment far exceeded expectations; comments on value of work)
  - Increased trust
  - Empowerment – staff and families
  - Increased clinical utility and uptake

# Reflections

- Challenges of collaboration
  - Building relationships is HARD and time consuming work; time is often hard to account for and quantify (e.g., 641 email threads)
  - Especially challenging to reach under-represented groups in flexible ways

# Reflections

- Consider how you might respond if…
  - Participants priorities pose research challenges
    - No outcome measures available! How do I get a grant for this?!?
  - If 'sub-groups' of collaborators have different perspectives and motivations
    - Risk of tokenism

# What seemed to work well?

- Open collaborative stance
- Flexibility

# It’s not just research…

Image: Karlsruhe Institute of Technology

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# Resources

- Maritime SPOR Support Unit
  - Training and consultation in patient engagement
- James Lind Alliance
  - Priority setting partnerships
  - Guidance on methodology

# Acknowledgements

Collaborators
- Patients and Families

- Anesthesiologists, Nurses, Child Life Specialists, Surgeons, Dentists, Administrators

Trainees
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- Emma Cameron
- Michelle Lehmann

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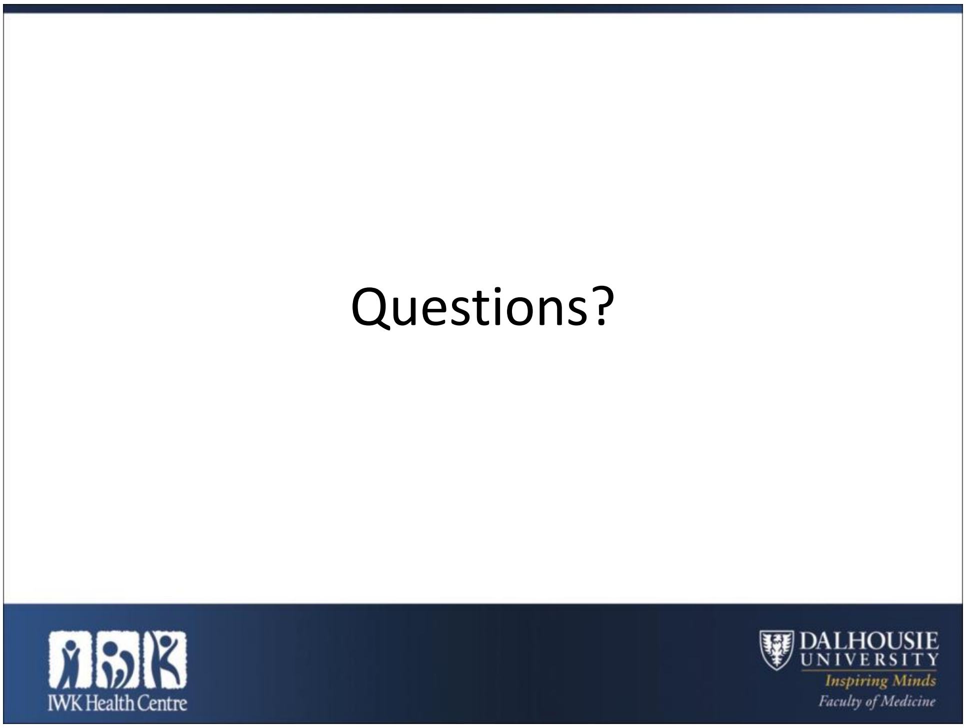
- Sharon Amey, Karen Archibald, Gil Ungar

Funding:
- IWK TRIC
- Dept of Anesethia…



# Questions?