What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally

ACCORDS Upcoming Events

January 22, 2024 AHSB 2200/2201, Zoom	**Statistical Methods for Pragmatic Research** Missing Data and Statistical Methods *Presented by:* Jun Ying, PhD
February 7, 2024 Bushnell Auditorium, Zoom	**Ethics, Challenges, & Messy Decisions in Shared Decision Making** Financial Toxicity and the Importance of Cost Discussions During Shared Decision Making *Presented by:* Mary Politi, PhD (Washington University in St. Louis)
February 26, 2024 Zoom	**Statistical Methods for Pragmatic Research** Latent Class Analysis: Assumptions and Extensions *Presented by:* Rashelle Musci, PhD (Johns Hopkins Bloomberg School of Public Health)
March 6, 2024 Bushnell Auditorium, Zoom	**Ethics, Challenges, & Messy Decisions in Shared Decision Making** Health Equity and Shared Decision Making *Presented by:* Channing Tate, PhD, MPH; Demetria Bolden, PhD, MBA; Lucinda Kohn, MD, MHS, Miria Kano, PhD
March 11, 2024 AHSB 2200/2201, Zoom	**Statistical Methods for Pragmatic Research** Pragmatic Statistical Learning: From Data to Interpretable Insights *Presented by:* Ryan Peterson, PhD

*all times 12-1pm MT unless otherwise noted

COPRH Con

Colorado Pragmatic Research in Health Conference

Innovations in Pragmatic Research Methods

From Data to Equity, Policy, and Sustainability

June 5 - 6, 2024 | 10am-3pm MT

Registration is open now at www.COPRHCon.com

ACCORDS
ADULT AND CHILD CENTER FOR OUTCOMES RESEARCH AND DELIVERY SCIENCE
UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO

Ethics, Challenges, and Messy Decisions in Shared Decision-Making

2023-2024 Seminar Series

Ellen Lipstein, MD

Who's Sharing What?

The Challenges of Adolescent Shared Decision Making

Who's sharing what?

The Challenges of Adolescent Shared Decision Making

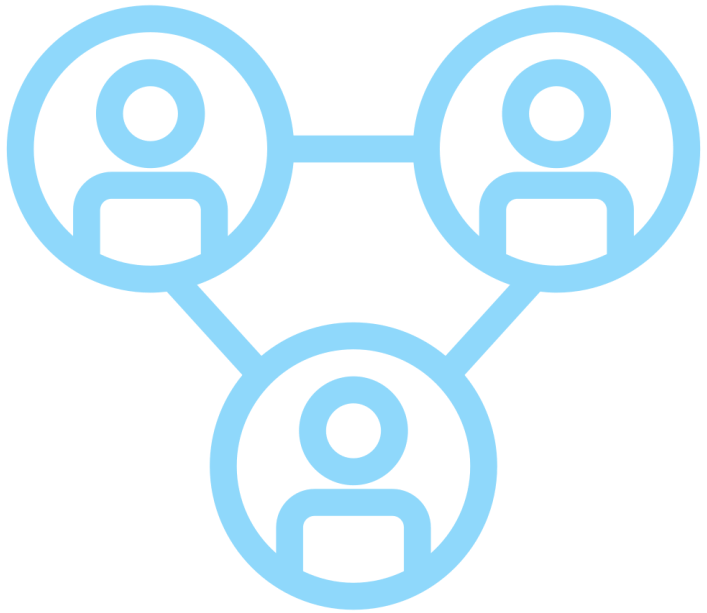
Ellen A. Lipstein, MD, MPH

Professor of Pediatrics

Conflicts of Interest

- None

Objectives



- Appreciate the nuances of shared decision making in pediatrics
- Understand the gaps in current approaches to measuring shared decision making
- Describe the challenges of developing a measure of adolescent, triadic shared decision making

Defining Shared Decision Making (SDM)

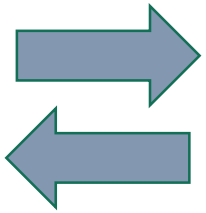
"In shared decision making, both parties share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values."

(Barry and Edgman-Levitan, 2012)

A Meeting of Experts

Healthcare provider:

- Identify problem
- Present options
- Discuss risk, benefits, uncertainties
- Provide best available evidence
- Check understanding

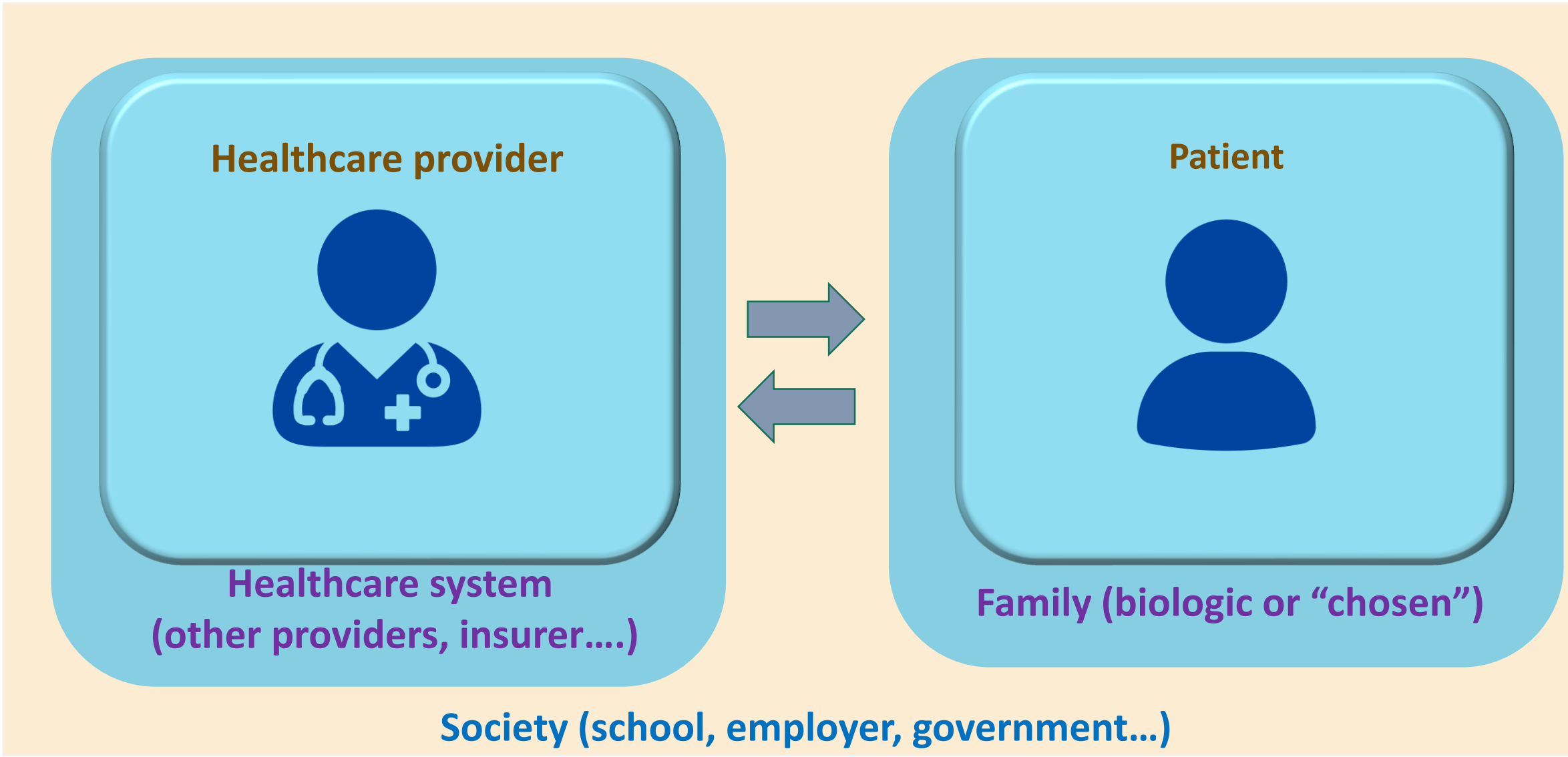


Patient:

- Knowledge and understanding about health condition, impact on self
- Clarify and voice values, preferences, and preferred style of decision making

(Tuckett et al, 1985)

A Meeting of Many Experts



What's different for kids?

a.k.a. Sharing decisions FOR vs WITH kids

Decision Making for Others

- Substituted judgement standard

"Surrogate decision makers … should use their knowledge of the patient's preferences and values to determine as best as possible what the patient would have decided herself."

- Best interest standard

"If there is not adequate evidence of the incapacitated or incompetent patient's preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being)."

(AMA Code of Medical Ethics, 2017)

Pediatric Decision Making: Consensus Recommendations

1. Parents should be presumed to have wide, but not unlimited, discretion to make health care decisions for their children.
2. Parents should protect and promote the health interests of their child, while balancing practical constraints and/or other important obligations and interests.
3. A clinician's primary responsibility is to protect and promote their pediatric patients' health interests. Clinicians' recommendations should be informed by professional judgment and the best available evidence.
4. To respect children and promote their wellbeing, clinicians and parents should inform pediatric patients of salient information and invite their perspective to the degree that doing so is developmentally appropriate.
5. In addition to state mandated reporting requirements, clinicians should seek state intervention when all less-restrictive alternatives have been exhausted and a parental decision places the child at significant risk of serious imminent harm or fails to meet the child's basic interests.
6. Clinicians and parents should collaborate in a shared decision-making process to promote the child's interests.

(Salter et al, 2023)

6. Clinicians and parents should collaborate in a shared decision-making process to promote the child's interests.

- Parents and clinicians may have different moral values, perspectives and information.
- Clinician recommendations should be informed by values of the family and available medical evidence.
- Bidirectional, substantive communication between clinician and parent, while maintaining authority of parent as decision maker.
- To the extent the pediatric patient is able, willing, and permitted to participate (Recommendation #4), the process should be flexible enough to provide the pediatric patient with salient information and include the pediatric patient in decision making in a developmentally appropriate manner.

(Salter et al, 2023)

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(Salter et al, 2023)

Open question: “Do these recommendations need to be modified…for adolescents?”

YES.

SDM with Children

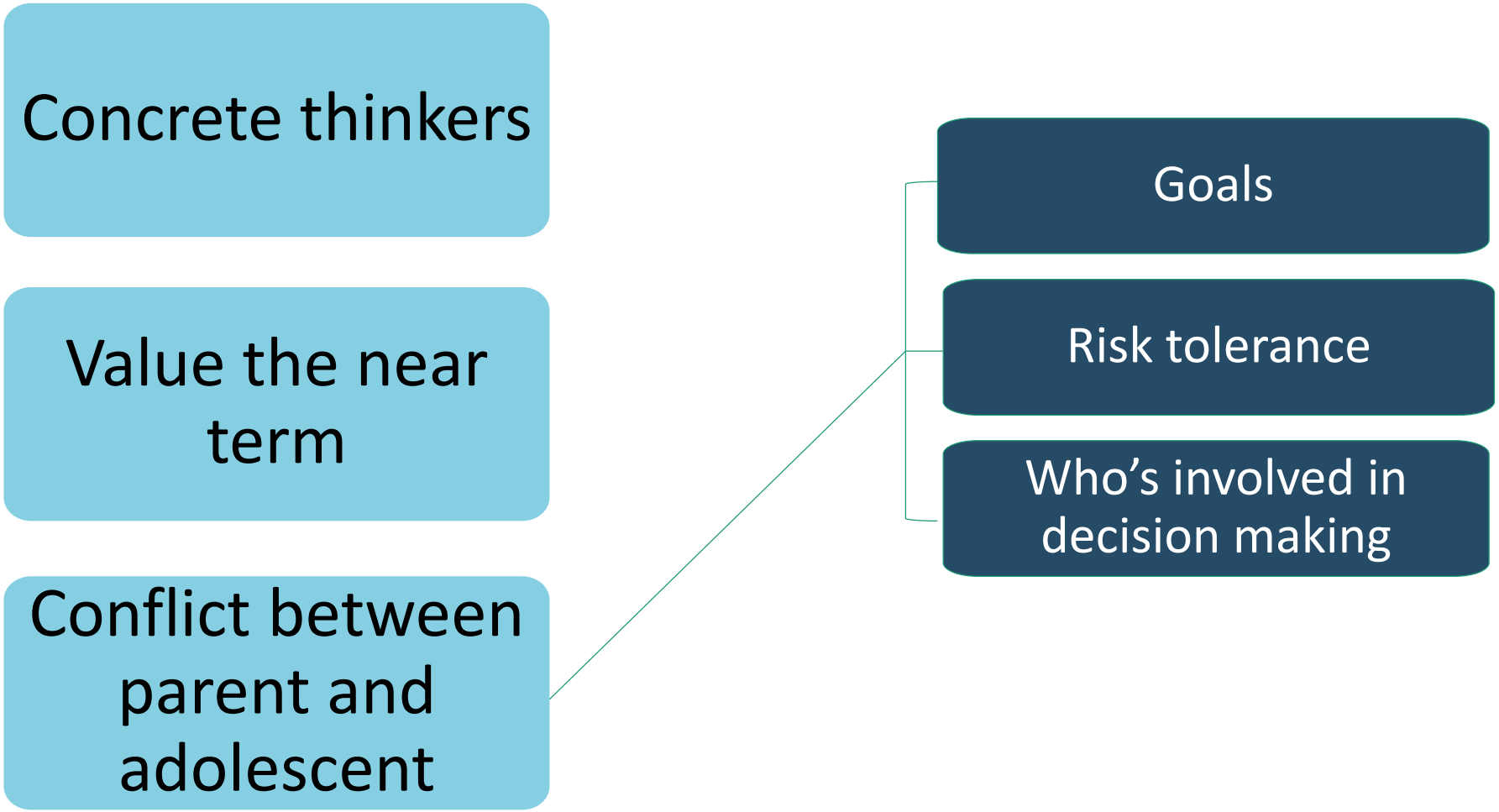
Developmentally appropriate roles for participation

Increasing capacity to participate in decision making

Key skill for transition to adult care setting

(Lipstein et al, 2012)

Developmental Challenges to SDM with Adolescents



Examples of Adolescent vs Parent Focus

GOALS

Adolescents:

- physical changes
- decreased gender dysphoria
- happiness

Parents:

- child's happiness and self-confidence
- greater focus on long-term

RISKS

Adolescents:

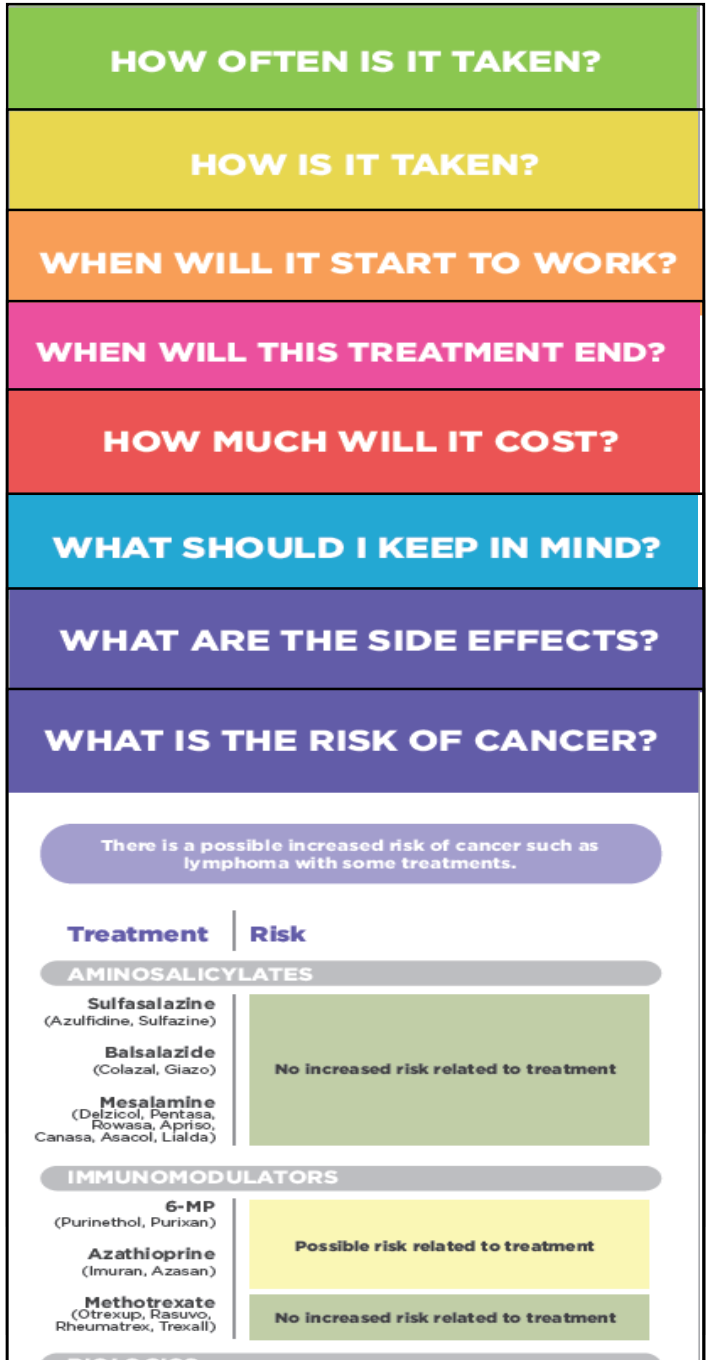
- Fear of needles
- acne

Parents:

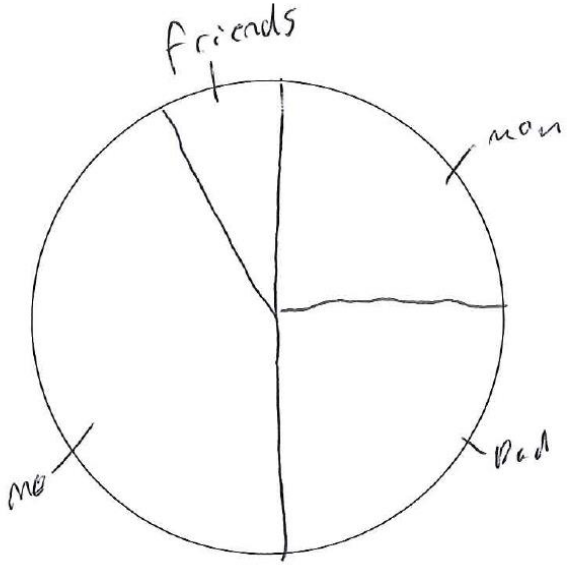
- infertility
- liver disease
- impact on relationship with less supportive community members

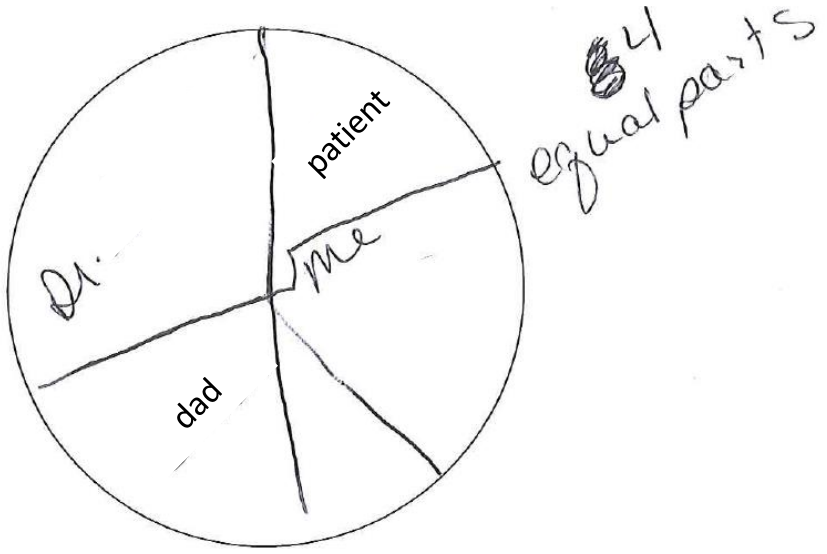
(Daley et al, 2019)

IBD Medication Choice Cards



Who's the Decision Maker?





(Daley, et al, 2019)

Case example: Control Preferences Scale

A. I prefer to make the decision about which treatment I will receive.
B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.
C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously consider my opinion.
E. I prefer to leave all decisions regarding treatment to my doctor.

(Degner and Sloane, 1992)

Case example: **Control Preferences Scale – Pediatric**

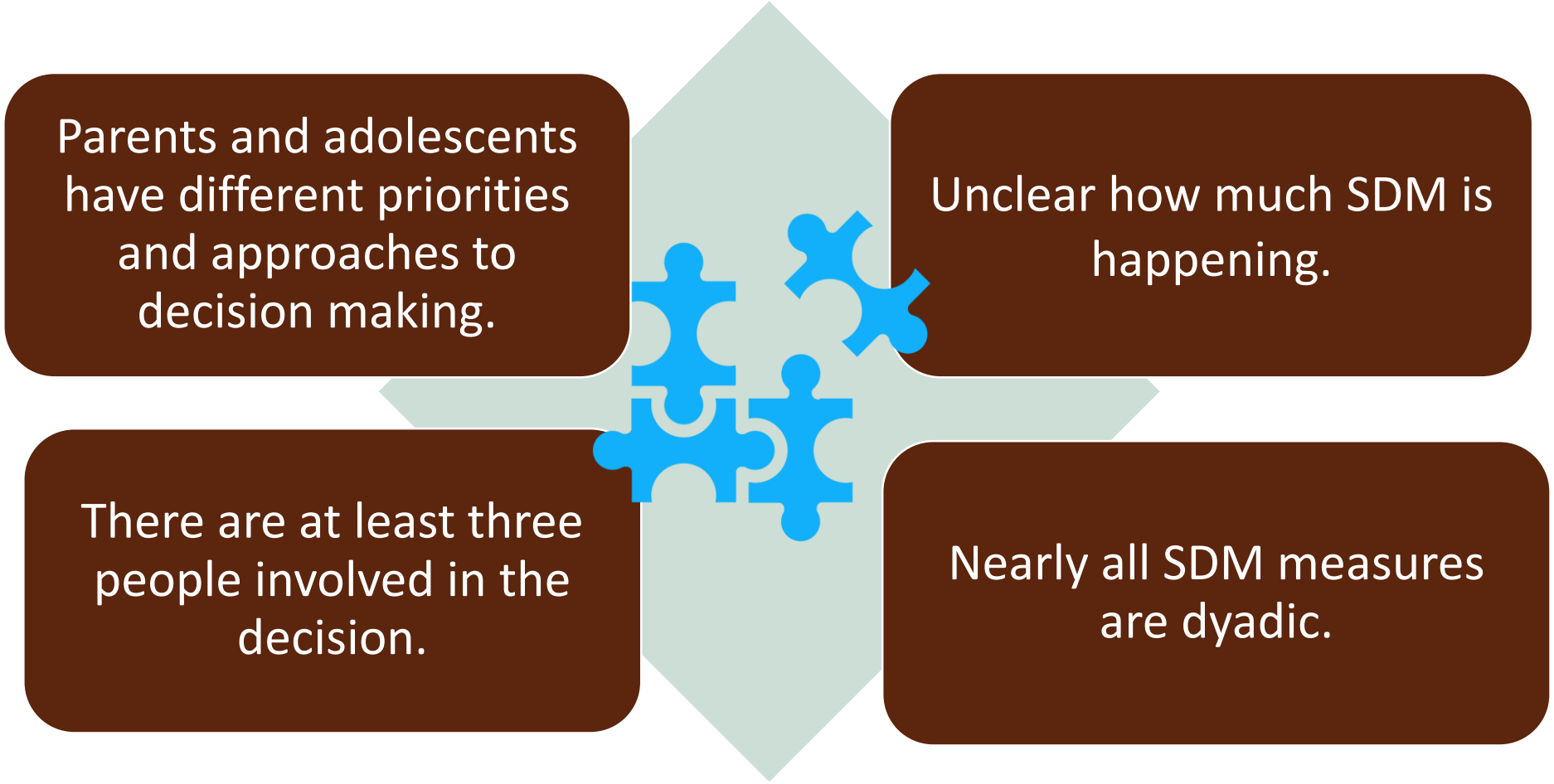
A. I prefer to make the decision about which treatment my child will receive.
B. I prefer to make the final decision about my child's treatment after seriously considering my doctor's opinion.
C. I prefer that my doctor and I share responsibility for deciding which treatment is best for my child .
D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously consider my opinion.
E. I prefer to leave all decisions regarding treatment to my doctor.

(Pyke-Grimm et al, 1999)

Case example: Adapting control preferences scale for the adolescent (item B)

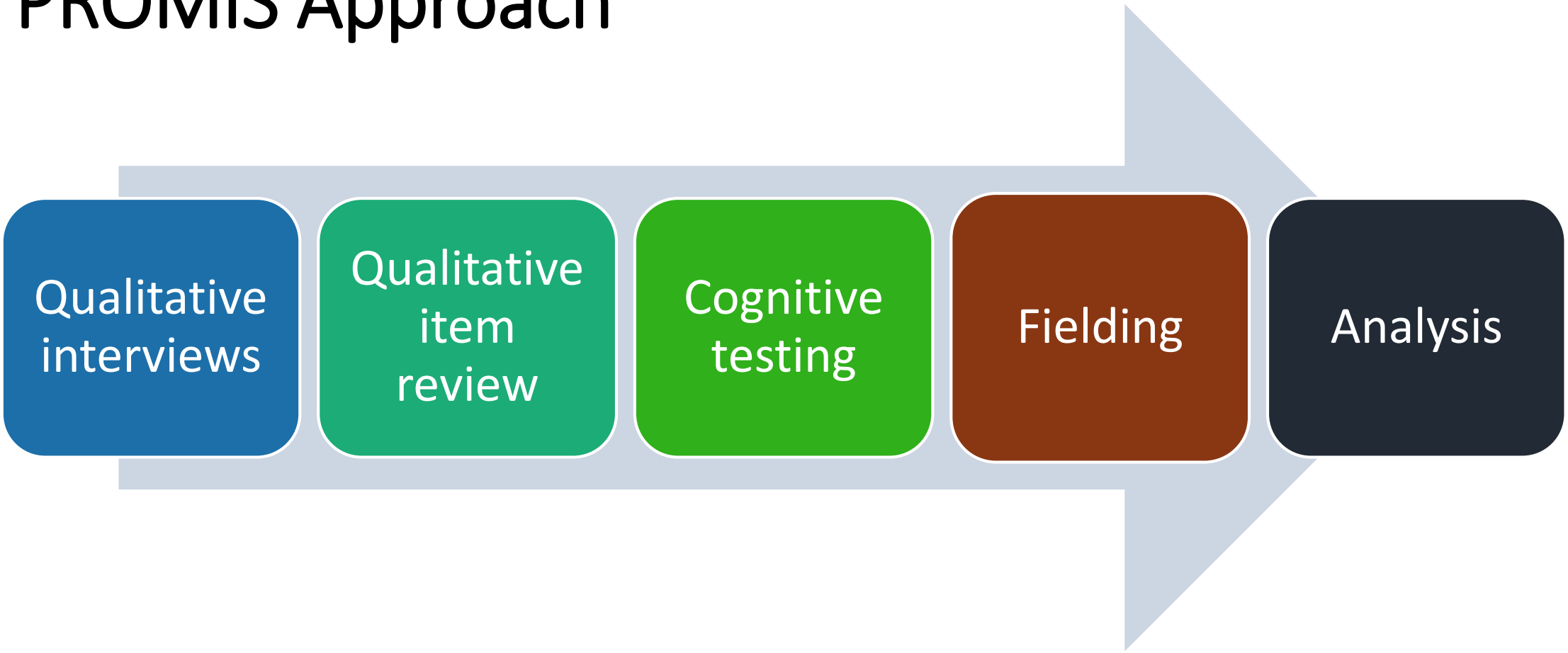
- I prefer to make the final decision about my treatment after seriously considering my doctor's and my parent's opinion.
- I prefer to make the final decision about my treatment after seriously considering my parent's opinion.
- I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

Overview of the Challenge



So, we’re developing a measure.

PROMIS Approach



Interview Components

Decision making experience

Defining shared decision making

Clarify components of shared decision making

- Decision clarity
- Evidence exchange
- Preference and value engagement

Teen

Goals:

- know the options
- understand the scientific evidence
- understand what's important to the teen and parent

Doctor

Parent

Participants

Adolescents (12-17 years) with chronic condition who made a decision at last appointment

Parents of such adolescents

Pediatric clinicians caring for adolescents with chronic conditions

Parent and Adolescent Demographics

	Adolescents (n=16)	Parents (n=21)
Age, median (IQR)	14 (13-14.3)	44 (40-46)
Gender, n(%)		
Male	10 (62.5)	2 (9.5)
Female	6 (37.5)	19 (90.5)
Race, n(%)		
White/ Caucasian	7 (43.8)	12 (57.1)
Black/African American	8 (50)	9 (42.9)
Other	3 (18.8)	2 (9.6)
Ethnicity, n(%)		
Hispanic	1 (6.3)	1 (4.8)
Highest Level of Education		
High School Graduate/GED		6 (28.6)
Some college		7 (23.3)
Bachelor's degree or higher		8 (38.1)

Clinician Demographics (n=21)

	n (%)
Gender	
Male	9 (42.9)
Female	12 (57.1)
Race	
White/ Caucasian	16 (76.2)
Other	7 (23.8)
Ethnicity	
Non-Hispanic	21 (100)
Year Clinical training was Completed	
< 2000	6(28.6)
2000 -2009	5(23.8)
2010-2019	8(38.1)
>2019	2(9.5)
Clinical Specialty	
Adolescent Medicine	4 (19)
Endocrinology	4 (19)
Gastroenterology	4 (19)
General Pediatrics	4 (19)
Pulmonology	4 (19)
Rheumatology	1 (4.8)

Adolescent perspective

Role defined by what they've done in past and by perception of what they should do

"When I was younger, all I had to do was sit there and my parents would make my decisions for me. But now that I'm getting older, I got to make my own decisions..."

Challenged by the need to understand complex health information

"[I know I understand] once I'm able to explain it fully."

Adolescent perspective

Recognize their evolving understanding	*"…school, like science classes obviously have provided some more medical knowledge for me. I've had things, you know, explained to me by doctors and my mom, so, yeah, it's changed a lot."*
Important that parents and providers value their experience and input	*"I'd try to get her to feel like she's in my shoes to understand why I'm saying that."*
Need to find shared values	*"It should matter what's going to work best for the child. Because the ultimate goal is for the kid to get better. And I guess if there's a conflict with the parents, if that can come into consideration. But the main focus should be of the child feeling better."*

Parent perspective

Importance of gathering and understanding information

"It's really important as a parent to educate yourself as much as you can…so that you can ask the best questions."

Have to be forward thinking

"Her health and her long-term effects are what's most important…is this going to have long-term permanent effects when she's an adult?"

Parent perspective

Control

- *“I want him a part of that process...because he’s 17 now, I also like that to be more of like a collaborative thing and where he’s making those decisions too and not just being told.”*
- *“Ultimately, because [the adolescent] is not an adult, it has to be up to the doctor and the parent.”*

Clinician perspective - roles

Clinician

- Guide
- Facilitator/coach
- Educator

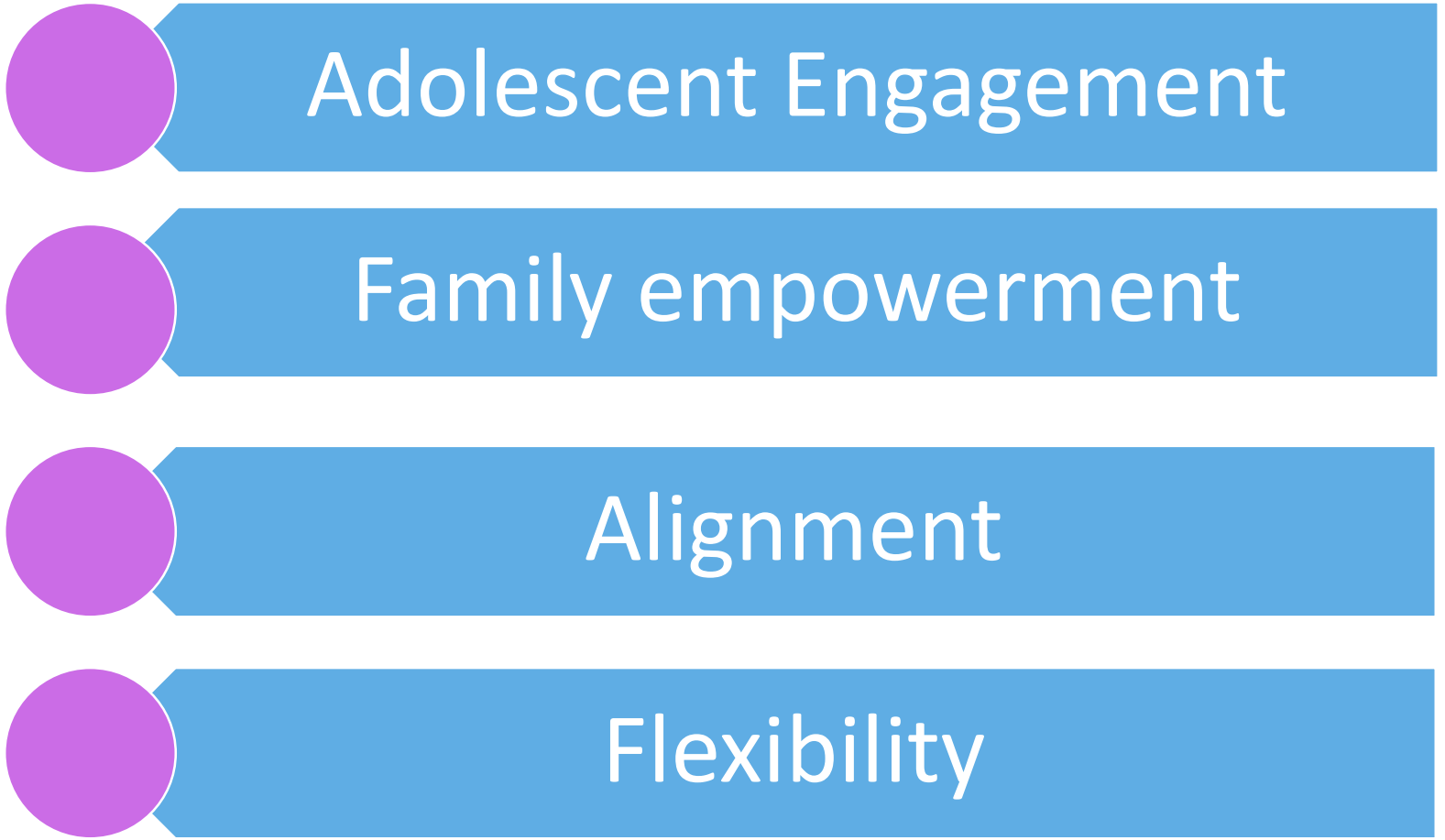
Adolescent

- Deliverer of information
- Learner

Parent

- Deliverer of information
- Facilitator/advocate
- Authority

Clinician Perspective – Adolescent SDM Essentials



Model
(sneak peak)

Prerequisites	Core components	Supported by
• Collaboration • Trust	• Information exchange • Values Engagement • Preference Engagement • Confirmation of decision	• Flexibility • Mutual engagement • Alignment

“Philosophy” behind the measure

- Focus on the triangle, not the octagon.
- Decision making is a continuum.
- Our goal is to measure the process, not judge it.
- Limit the length.

Going from interviews to items

Review data for potential item “bits”

- “the information that my doctor gives me is sufficient to be able to make a decision.”
- “explain to the doctor why you feel like this is important to you”
- “I ask questions with my doctor.”
- “They give him the opportunity to ask and respond”

Development of potential items

Item Development Example

My doctor gave me information about the options.

My doctor gave me information about each option.

My doctor shared information with me about each option.

My doctor presented information about each option.

Another Example

Did you share what option you prefer with your parent?

I shared the option I prefer with my parent.

I told my parent which option I prefer.

I told my parent what I liked.

Early challenges

- Who is eligible for measure?
- Is teamness part of SDM?
- What to call the decision?
- What to call the treatment?

Next steps

- Narrow number of items
- Cognitive interviews
- Survey fielding

Future Directions

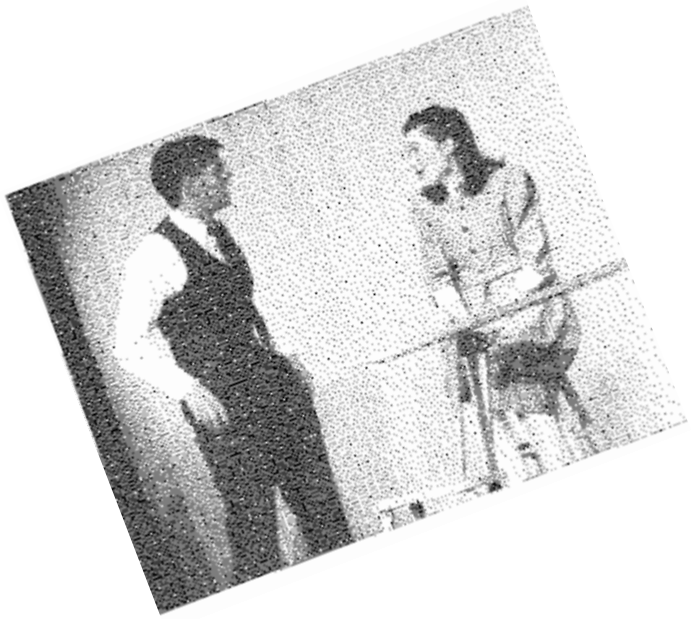
Physician measure

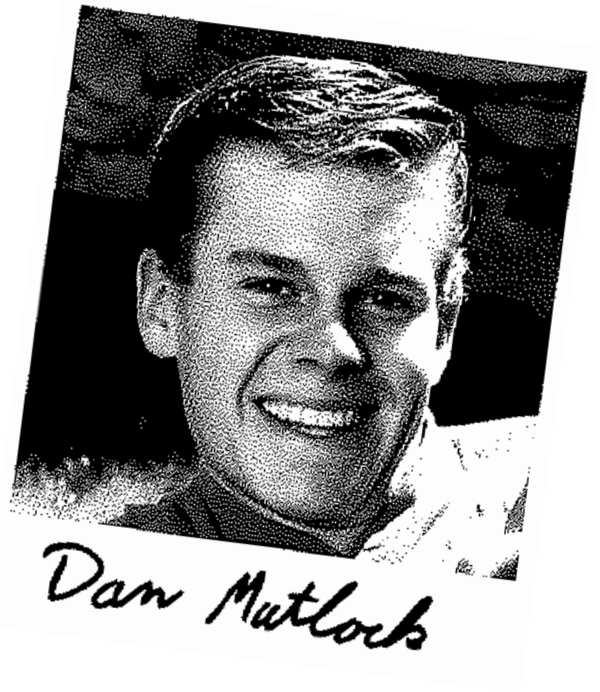
How to score

Actually improving SDM

Acknowledgements

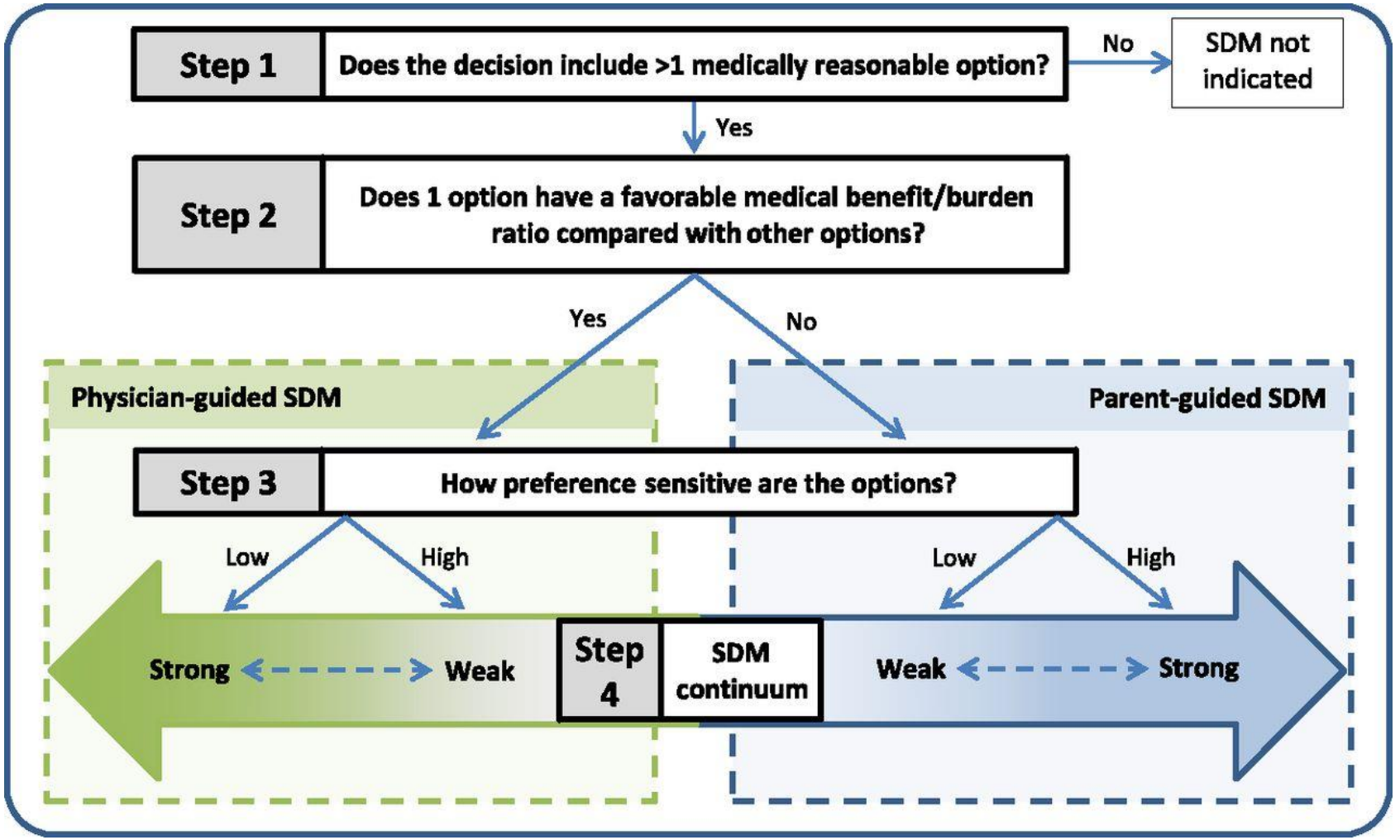
Disclosure





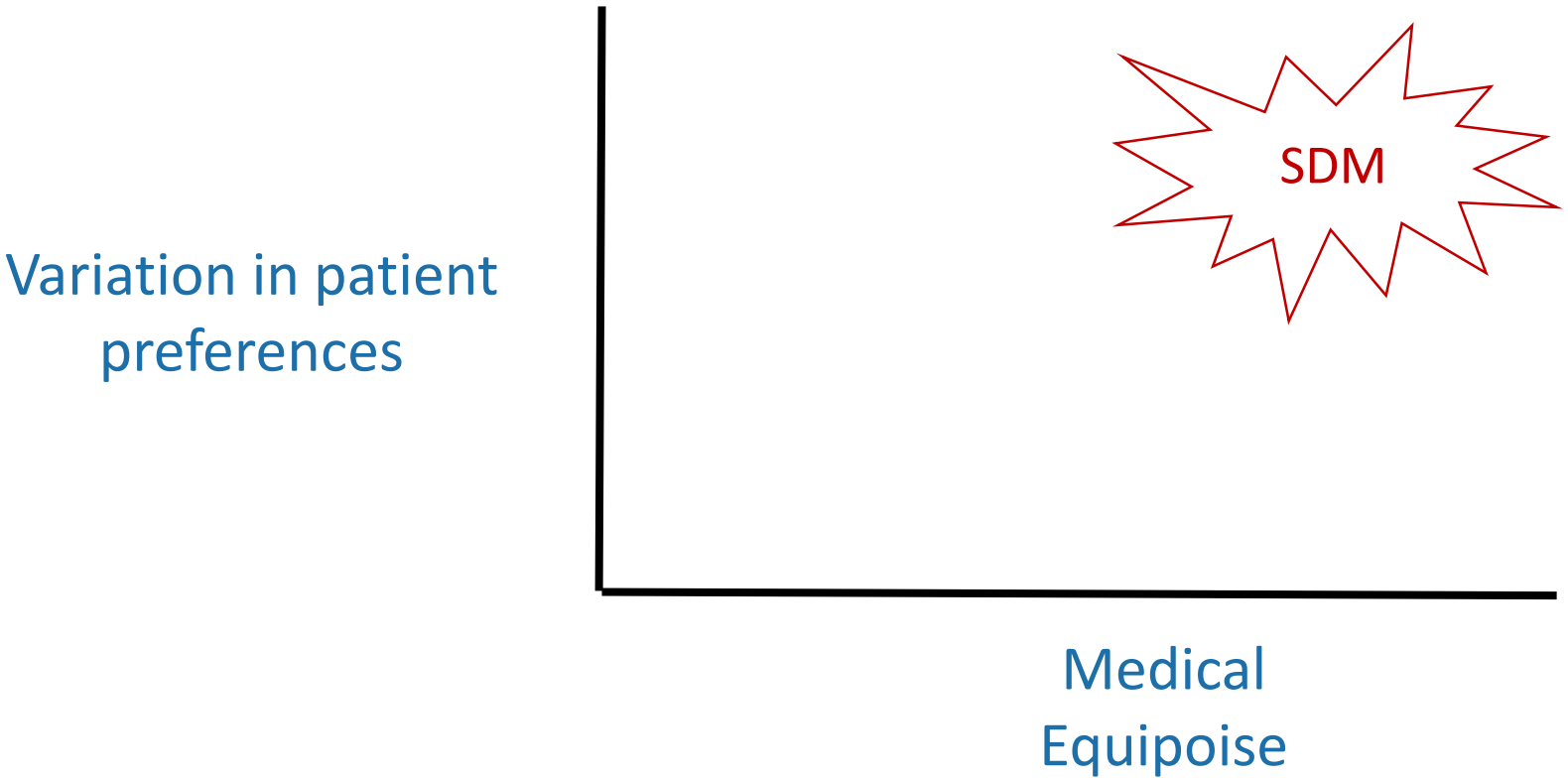
Thank you.

Process of SDM for Children

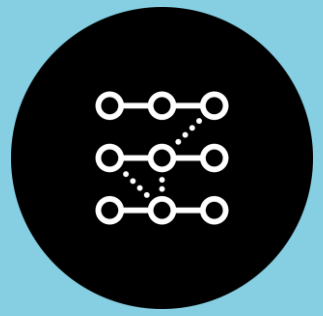


(Opel, 2018)

What types of decisions are appropriate for SDM in pediatrics?



SDM in Chronic Conditions



Multiple touchpoints

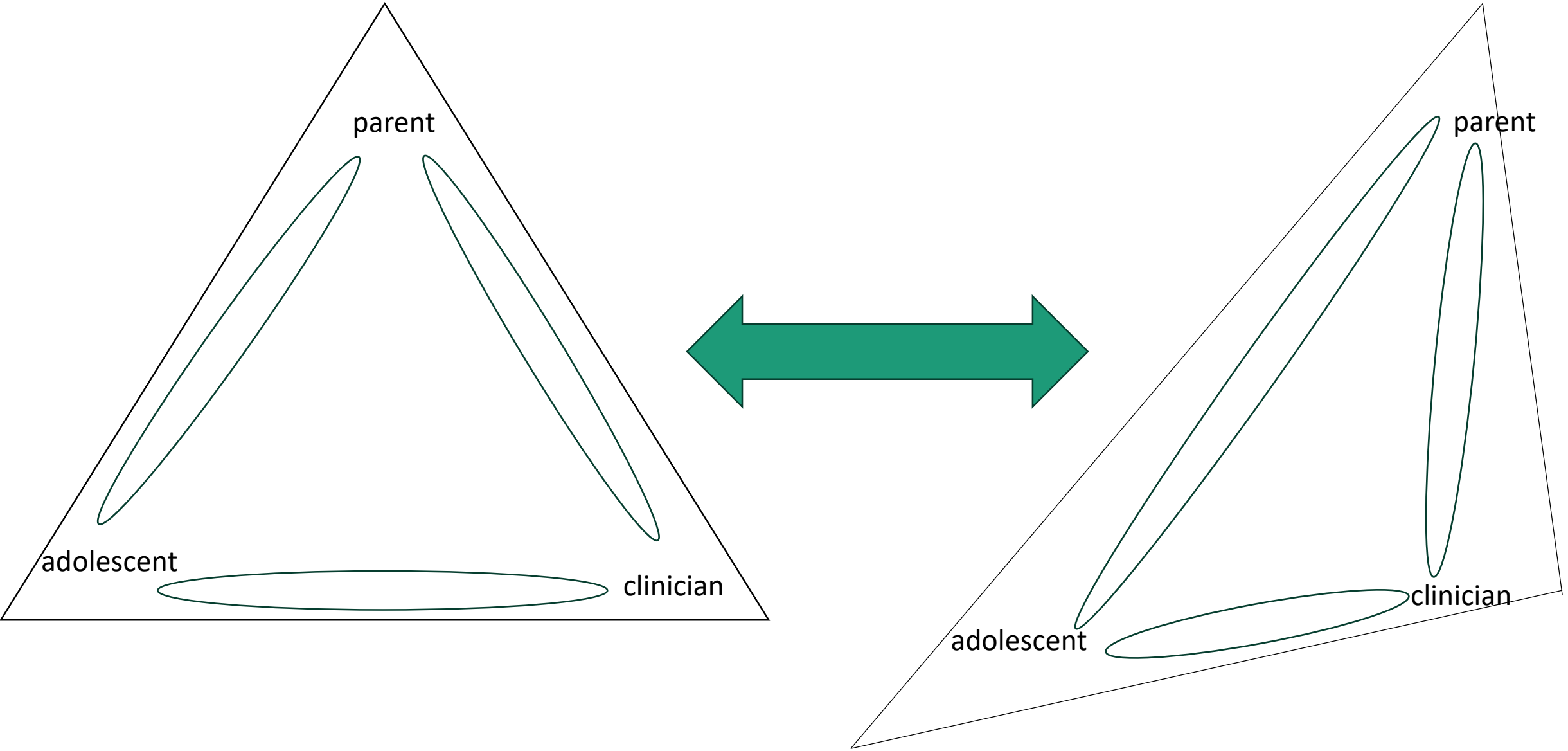
Opportunity to gain skills

Natural to revisit decisions

Multiple providers

Co-morbidities

(Lipstein, et al 2015)


parent
adolescent
clinician
parent
clinician
adolescent

Essential “needs” for aSDM

- FLEXIBILITY
  - Decision roles are not static
    - Push and pull between parent and adolescent role but final decision rests with parent
  - How much to involve kid varies by age, maturity, decision, family structure, experience
  - Timeline
    - Decision making doesn’t all happen at once
    - Loop back as needed
- FAMILY EMPOWERMENT
  - Doesn’t really matter what MD wants
  - Parent and kid need to be engaged
  - Who’s involved, who’s in charge and who may defer or be excluded depends on the decision
- ENGAGE ADOLESCENT
  - Read their non-verbals
  - Invite them into the conversation (eye contact, direction questions)
  - Talk 1:1
  - Make them feel it’s a discussion with them
- ALIGNMENT
  - Part of physician role is helping with values and preference alignment between parent and kid

Unique aspects of components of aSDM

- Info exchange
  - Open to questions, likely need to repeat/rephrase
  - Need input from adolescent
  - Address questions to each
- Values engagement
  - Need to hear all voices
  - Find kid's motivation
  - Encourage outside discussion
  - Find alignment
- Preference engagement
  - Find alignment
  - Weight of kid preferences varies with decision
  - Push-pull of how and when to engage kid

doctor

Guide
- Present info
- [Make recs]
- Determine urgency
- Navigate health system

Facilitator/coach
- Facil adol role in decision
- Ensure neither parent nor kid overly defers
- Translate between parent and kid
- Find common ground
- Keeping conversation open

Educator
- Ensure understanding
- Synthesize data

Learner???
- Open to info brought by family
- Collect data to form diagnosis
- Learn goals/context

adol

Deliverer of information
- Concerns
- Symptoms
- Opinions

Learner
- Learn about health
- Learn to participate in decision making

parent

Deliverer of information
- Concerns
- Symptoms
- Opinions

Facilitator/ Advocate
- Connect kid and doctor
- Paint big picture for kid

Authority
- Financial and legal authority