International Kawasaki Disease Symposium
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Lifestyle and Psychosocial Issues:

Transition to Adult Care

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TORONTO CONGENITAL CARDIAC CENTRE FOR ADULTS

SickKids The Labatt Family Heart Centre

Adrienne H Kovacs, PhD

Transition to Adult Care

FINANCIAL DISCLOSURE:

No relevant financial relationship exists

The Plan

I. Language matters: the difference between **transfer** & **transition**

II. Congenital heart disease as a model to consider the rationale and ‘best practices’ for transition

III. Putting theory into practice: practical strategies to enhance the transition process

Note: We all face transitions

Presentations at AHA 2014:

- Challenges in the Fellow-to-Faculty Transition
- Becoming an independent faculty: How to successfully transition from the early career grant to an R01

Success during these professional transitions requires preparation, education, and coordination…
not unlike patient health care transitions

Examples of Health Care Transitions

- “Healthy person” → patient
- Intensive care to the general ward
- Hospital to home (or rehabilitation facility)
- Rehabilitation facility to home
- Acute surgical pain to chronic pain
- Active treatment to palliative care
- Intervention: contemplation → procedure → outcome
- Pediatric to adult health care

Language matters:
Transfer vs. Transition

Transfer ≠ Transition

Health Care Transfer = An Event

- Movement of patients (and their medical records) from one location to another
- **Important consideration:** availability of adult providers

When to Transfer?

Flexible age of transfer

- Transition guidelines typically recommend a flexible age of transfer between 18-21 years

Mandatory age of transfer

- Present in some places (eg, in Ontario, Canada, patients transfer at the age of 18 years)

Survey of US Pediatric Cardiologists (n = 257)

PERCEIVED BARRIERS TO ACHD OR ADULT-ORIENTED CARE	%
Parent emotional attachment to pediatric provider	87
Patient emotional attachment to pediatric provider	86
Lack of qualified adult providers in specialty	76
Patient emotional/cognitive delay	76
Provider attachment to family/patient	70
Parent emotional attachment to institution	69
Patient emotional attachment to institution	65

Fernandes et al, JACC, 2012

Transfer ≠ Transition

Transition = A Process

- Preparation for (and adoption of) increasing responsibility for one's health care
- Health care management gradually shifts from the **parent** to the **patient**
- Goal: "Provide uninterrupted health care that is patient-centered, age and developmentally appropriate, flexible, and comprehensive"

Blum et al, J Adolesc Health, 1993;
Knauth et al, Cardiol Clin, 2006

When to Transition?

Begin early with patients

- Adapt to a patient's physical, developmental and psychosocial maturation
- Never to early to begin educating patients and teaching self-management skills…but ideally begins by 12 years

Engage parents

- Parents should be prepared for (and included in) transition efforts

Transition Journey

PEDIATRIC CARE

Family-focused

Parents as primary decision-makers

Focus on pediatric health and lifestyle issues

Can take
5 – 15 years

Transfer is ideally one component of transition

ADULT CARE

Patient-focused

Patients as primary decision-makers

Focus on adult health and lifestyle issues

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Transition Journey

Adolescents & young adults:

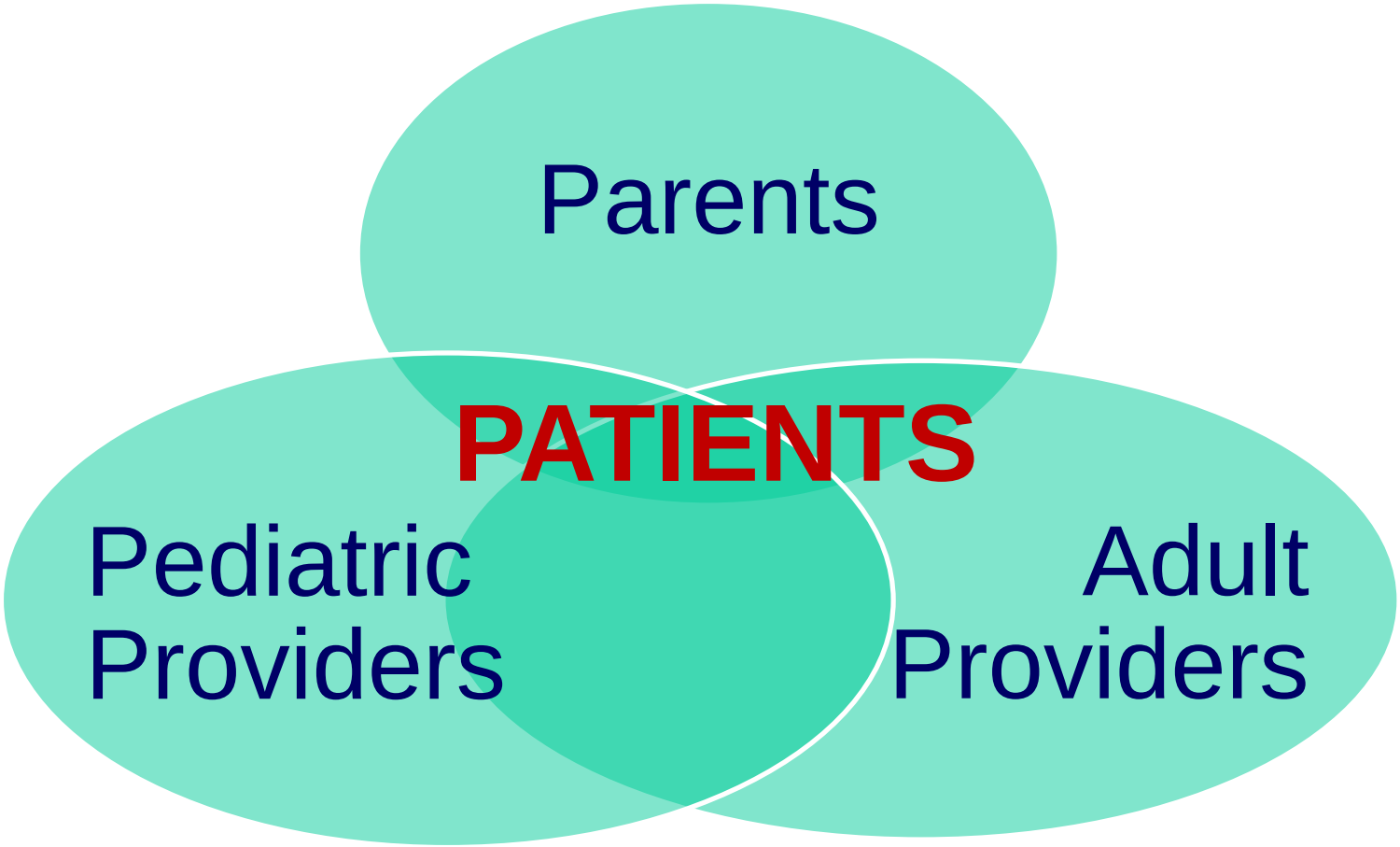
- **Taking charge:** As developmentally appropriate, teens gradually begin assuming increased responsibility for their health care management

Parents:

- **Letting go:** Gradually begin fostering increased independence and responsibility in their children

Pediatric and adult care providers

Transition Stakeholders



A Model from Congenital Heart Disease (CHD): Best Practices for Transition

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Scientific Statement from the American Heart Association (2009)

Circulation
JOURNAL OF THE AMERICAN HEART ASSOCIATION

American Heart Association®

Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues: A Scientific Statement From the American Heart Association

Craig Sable, Elyse Foster, Karen Uzark, Katherine Bjornsen, Mary M. Canobbio, Heidi M. Connolly, Thomas P. Graham, Michelle Z. Gurvitz, Adrienne Kovacs, Alison K. Meadows, Graham J. Reid, John G. Reiss, Kenneth N. Rosenbaum, Paul J. Sagerman, Arwa Saidi, Rhonda Schonberg, Sangeeta Shah, Elizabeth Tong and Roberta G. Williams

"The ultimate goal of a transition program is to optimize the quality of life (QOL), life expectancy, and future productivity of young patients."

CHD: Lapses in Care

The Health, Education, and Access Research Trial (HEART-ACHD)

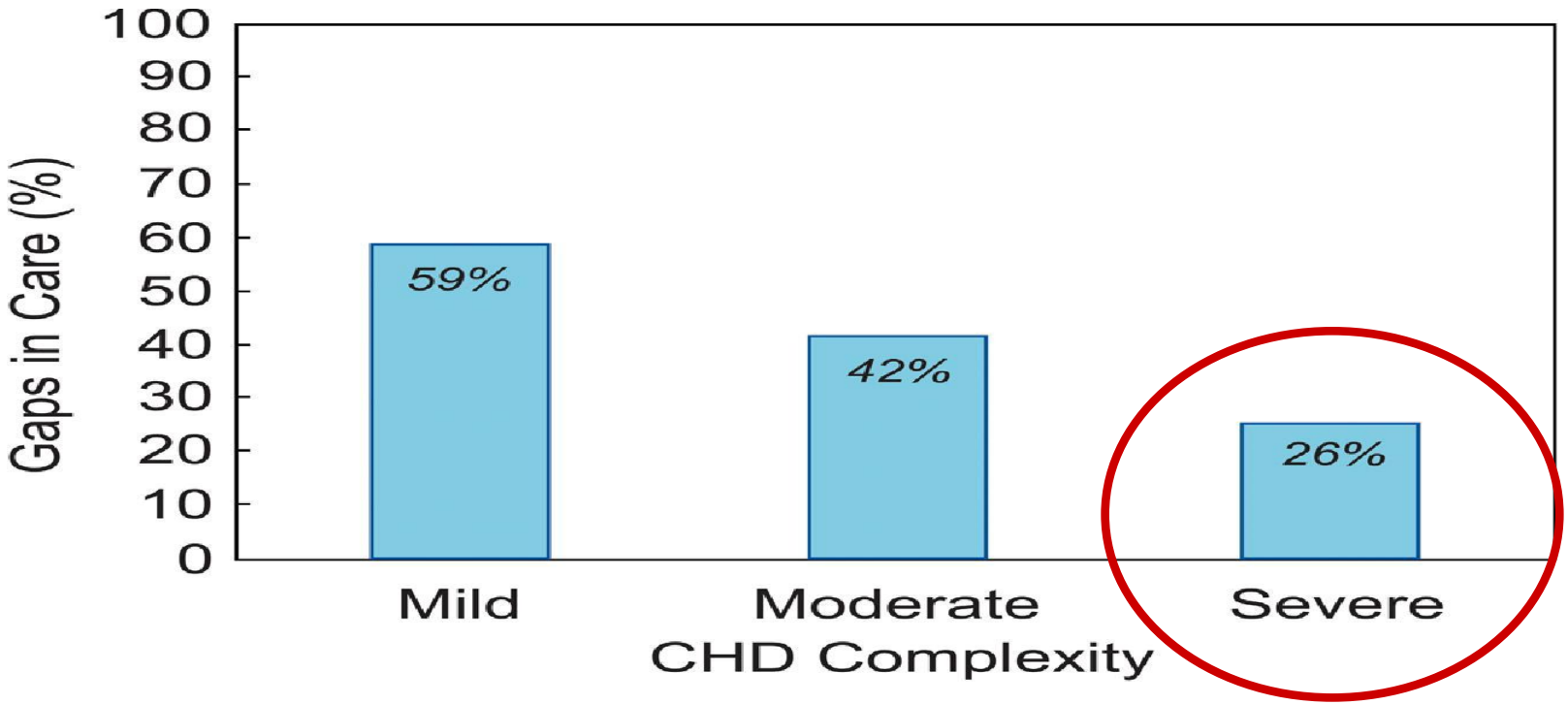
- 12 American Adult CHD centers
- 922 patients ≥ 18 years were recruited at first Adult CHD clinic appointment
- Completed surveys re. gaps/barriers to care

42% reported gaps in care of 3 years or longer

Median age at first gap = 19.9 years

Gurvitz et al, JACC, 2013

CHD: Lapses in Care



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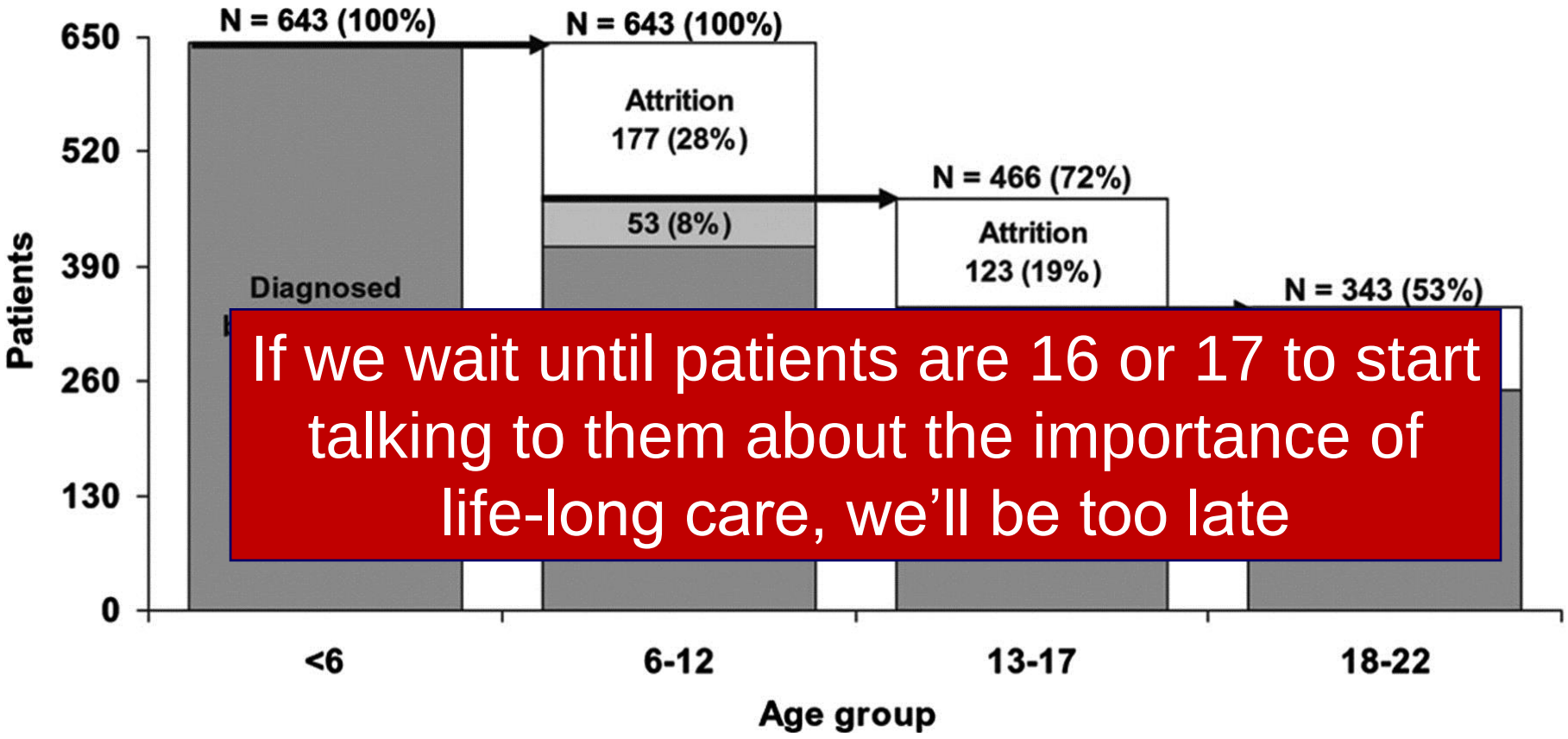
Gurvitz et al, JACC, 2013

Attrition Begins Early



If we wait until patients are 16 or 17 to start talking to them about the importance of life-long care, we'll be too late

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Mackie et al, Circulation, 2009

Lapses in Care: Patient Explanations

Feeling well (but know about need for follow-up)
Being unaware that follow-up was required
Told that cardiac follow-up was not required
Discharged from pediatric hospital without identified follow-up medical facility
Complete absence from medical care
Lack of insurance
Fearful of receiving bad news

Yeung et al, Int J Cardiol, 2008;
Gurvitz et al, JACC, 2013

Lapses in Care: Consequences

Upon eventual presentation, patients with lapses in care are more likely to:

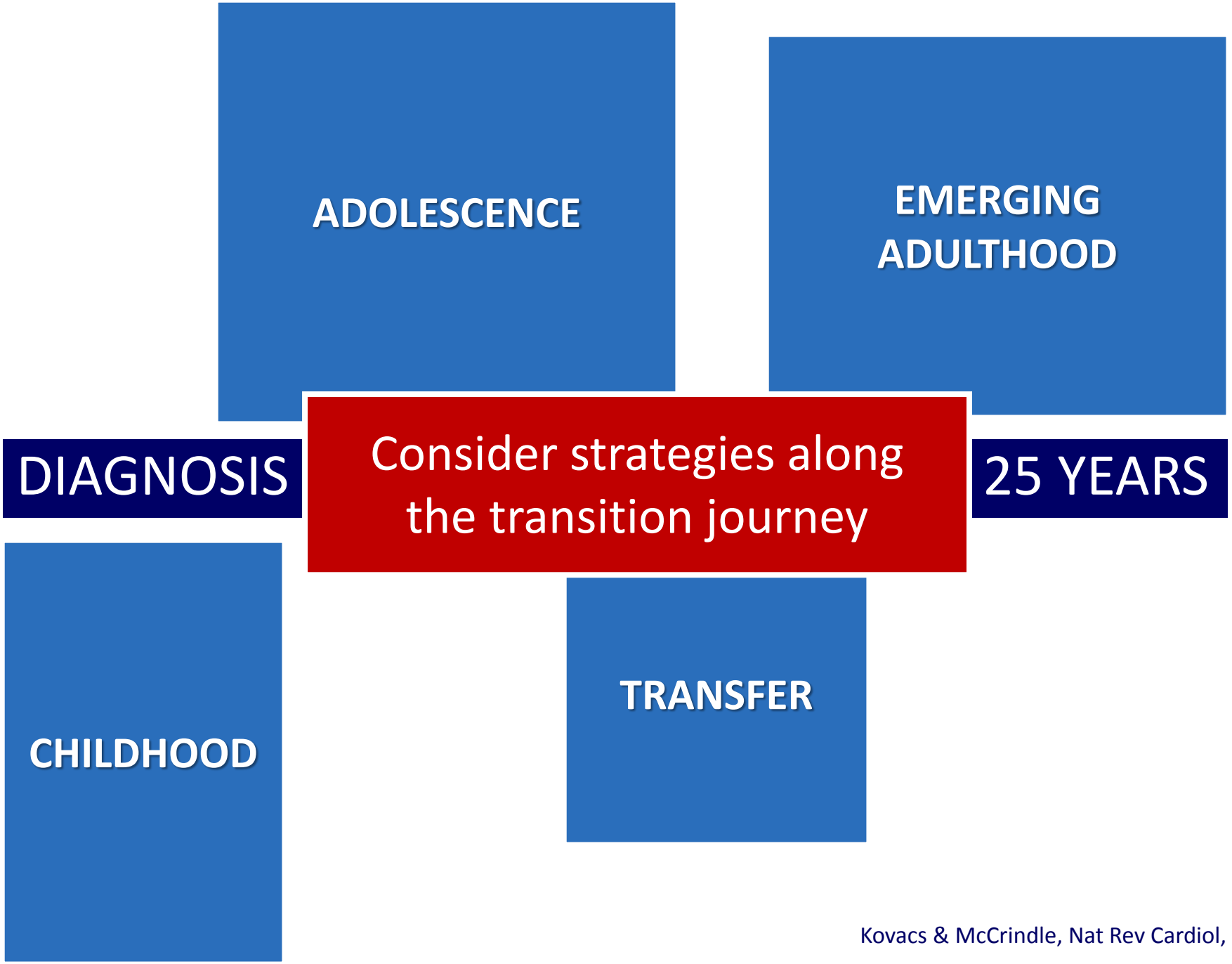
- Be symptomatic
- Not have an appropriate medication regimen
- Not have received optimal medical care
- Receive additional diagnoses
- Require additional diagnostic testing
- Require urgent cardiac intervention

De Bono et al, Int J Cardiol, Iversen et al, Cardiol Young, 2007, Yeung et al, Int J Cardiol, 2008; Wray et al, Heart 2013

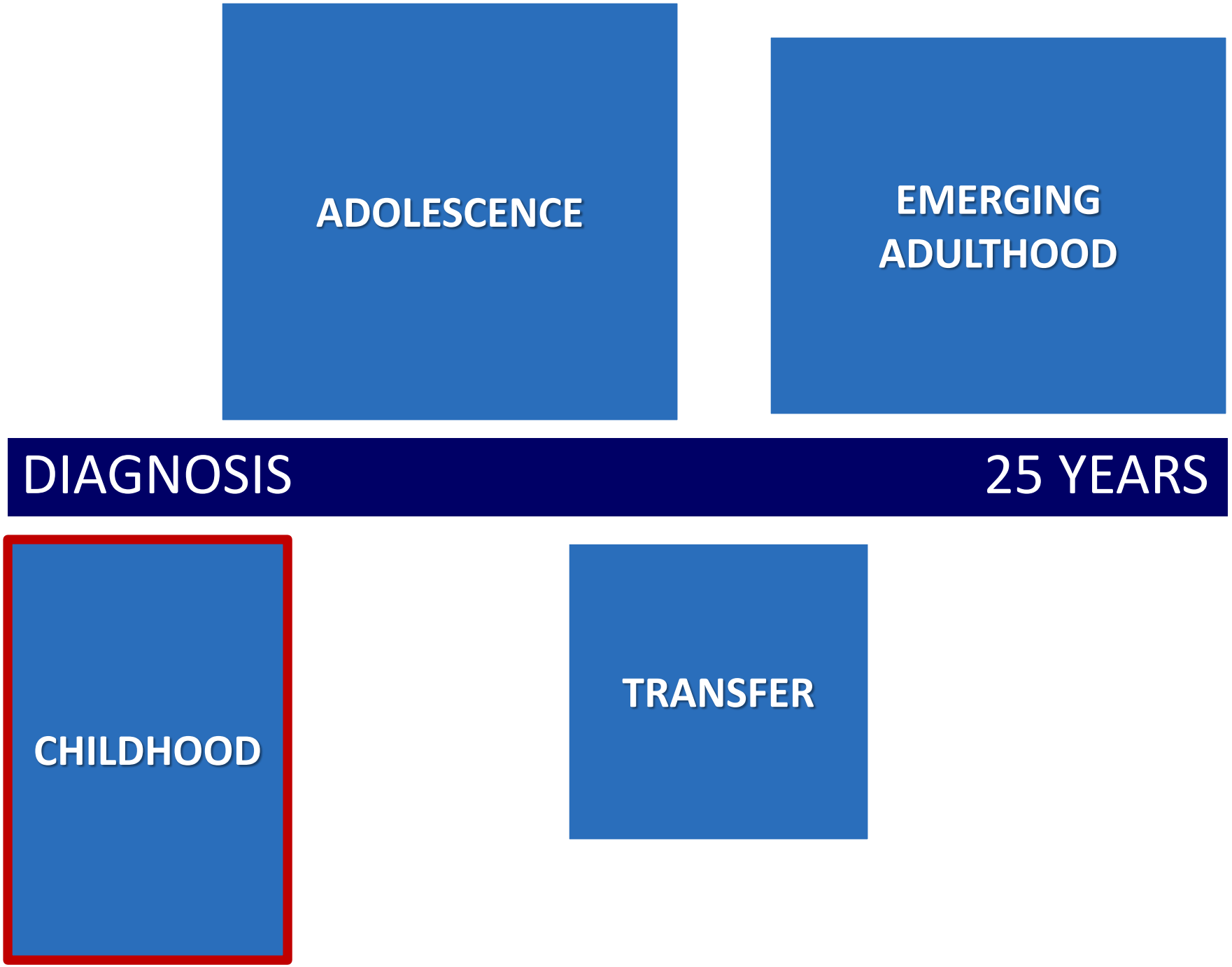
Putting Theory into Practice:
Practical Strategies

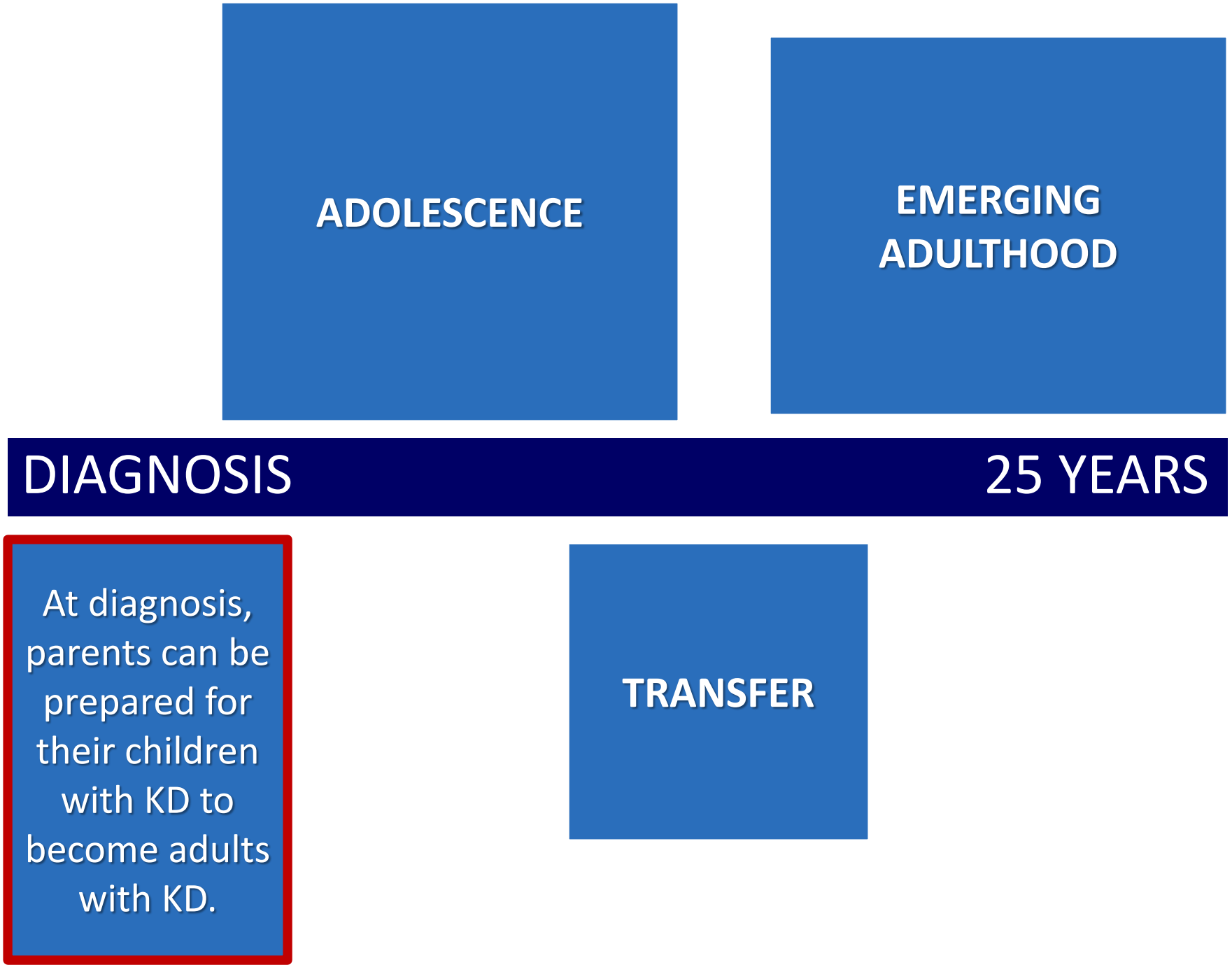
Identify a Transition Team:
Transition 'Champions'

- **Consider a transition coordinator who is the primary contact for patients, family and staff**
  - Ideal, but certainly not sufficient
  - More important for multiple staff to be knowledgeable and committed to enhancing transition
- **Engage <u>all</u> staff in the transition team**
  - Physicians, nurses, allied health professionals
  - Administrative staff



Kovacs & McCrindle, Nat Rev Cardiol, 2014


ADOLESCENCE
EMERGING ADULTHOOD
DIAGNOSIS
25 YEARS
CHILDHOOD
TRANSFER


ADOLESCENCE
EMERGING ADULTHOOD
DIAGNOSIS
25 YEARS
At diagnosis, parents can be prepared for their children with KD to become adults with KD.
TRANSFER

Talking with Parents

Provide honest medical information

- Focus on current needs but allow them to prepare for the future (including eventual transfer of care)

Acknowledge broader impact of KD

- Do not limit discussions to medical implications of KD
- Discuss potential impact on lives of child and family
- Support parents' celebration of their child's achievements

Some General Communication Tips…

INSTEAD OF

Do you have any questions or concerns?

TRY

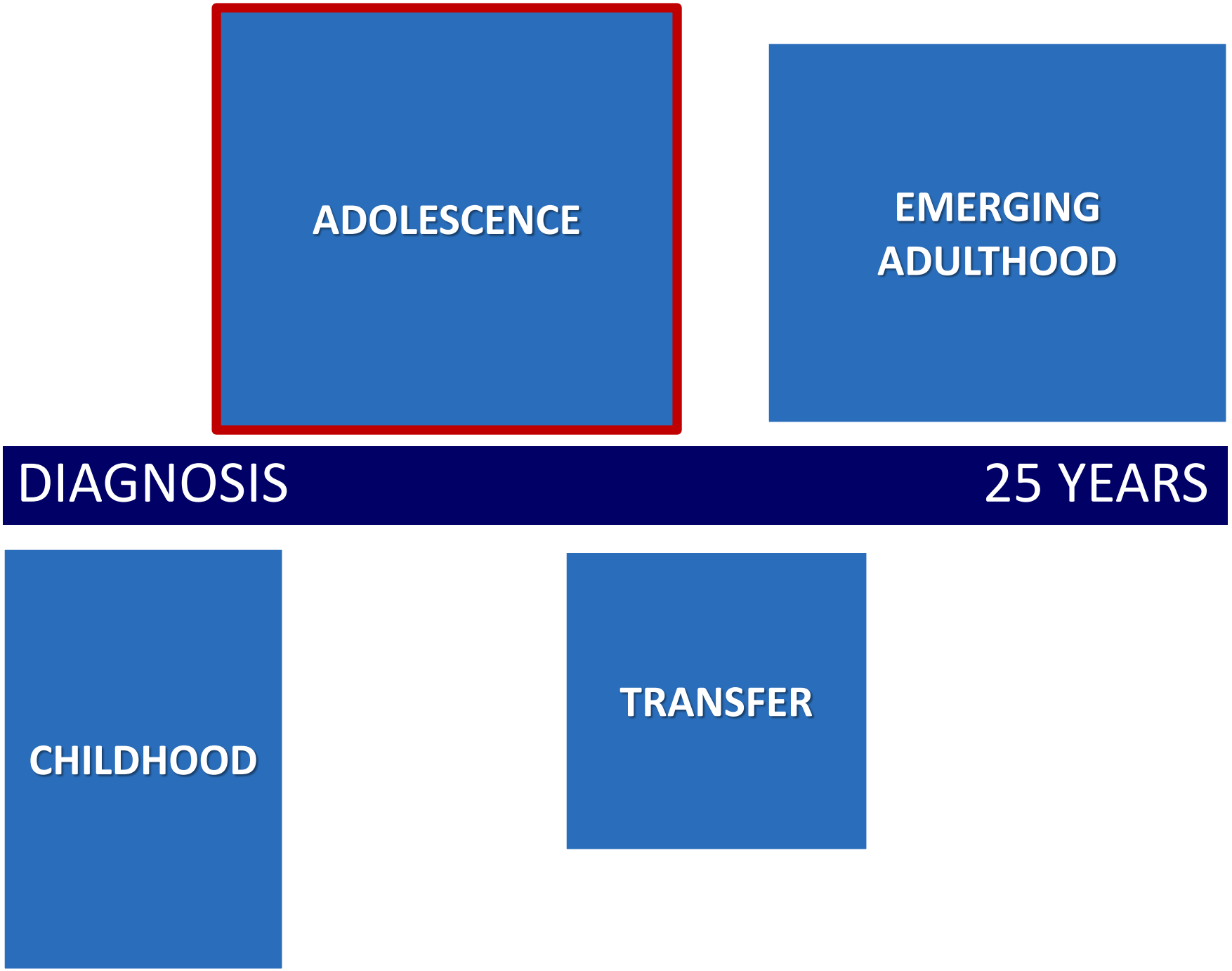
What are your questions and concerns?

INSTEAD OF

Do you understand the information I'm giving you?

TRY

Am I explaining this clearly?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Beginning by 12-13 years, patients should be helped to gradually develop the knowledge and self-management skills to eventually assume responsibility for their health care management.

EMERGING ADULTHOOD

DIAGNOSIS 25 YEARS

CHILDHOOD

TRANSFER

Working with Adolescents

Adolescence

- Significant cognitive, emotional, and sexual development
- ‘Identity formation’ is a key feature
- Sense of personal uniqueness
- Sense of invulnerability (the personal fable: that won’t happen to me)
- The time when we begin to transition patients to take increased responsibility for their health care management is also the time when they are most likely to consider themselves invulnerable

Kaufman, Prog Transplant, 2006

Encourage normal socialization

Social factors contribute to psych adjustment

- Speak to patients and parents to ensure that patients are not being inappropriately limited from participation in school and social activities
- Actively encourage social skills development

Encourage age-appropriate independence

- As developmentally appropriate, most teens can transition toward assuming greater responsibility for their health care and general decision-making

Make a Public Commitment

Patients and Parents:

When patients become teenagers, it is our standard practice for them to speak with their cardiologist on their own for part of the visit.

!

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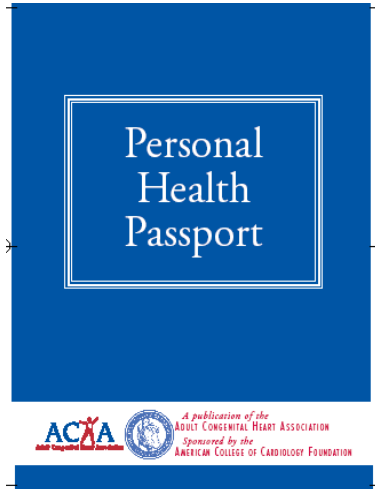
Health Passports

- **Portable health summary**
- **Created with health provider**
  - Educates patient
  - Prepares patient to meet new providers (including in emergency situations)



www.sickkids.ca/myhealthpassport

Patient (& Family) Education

- Name & description of KD and other health conditions
- Names of (and ages at) previous interventions
- Name, dose & purpose of medications

Consider a curriculum or checklist in the medical chart

- Long term health expectations
- Importance of life long specialized health care
- Healthy lifestyle guidelines (eg, exercise)

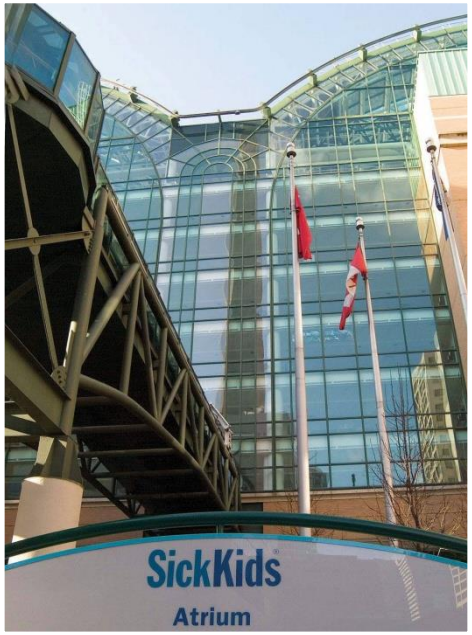
Kovacs & McCrindle, Nat Rev Cardiol, 2014

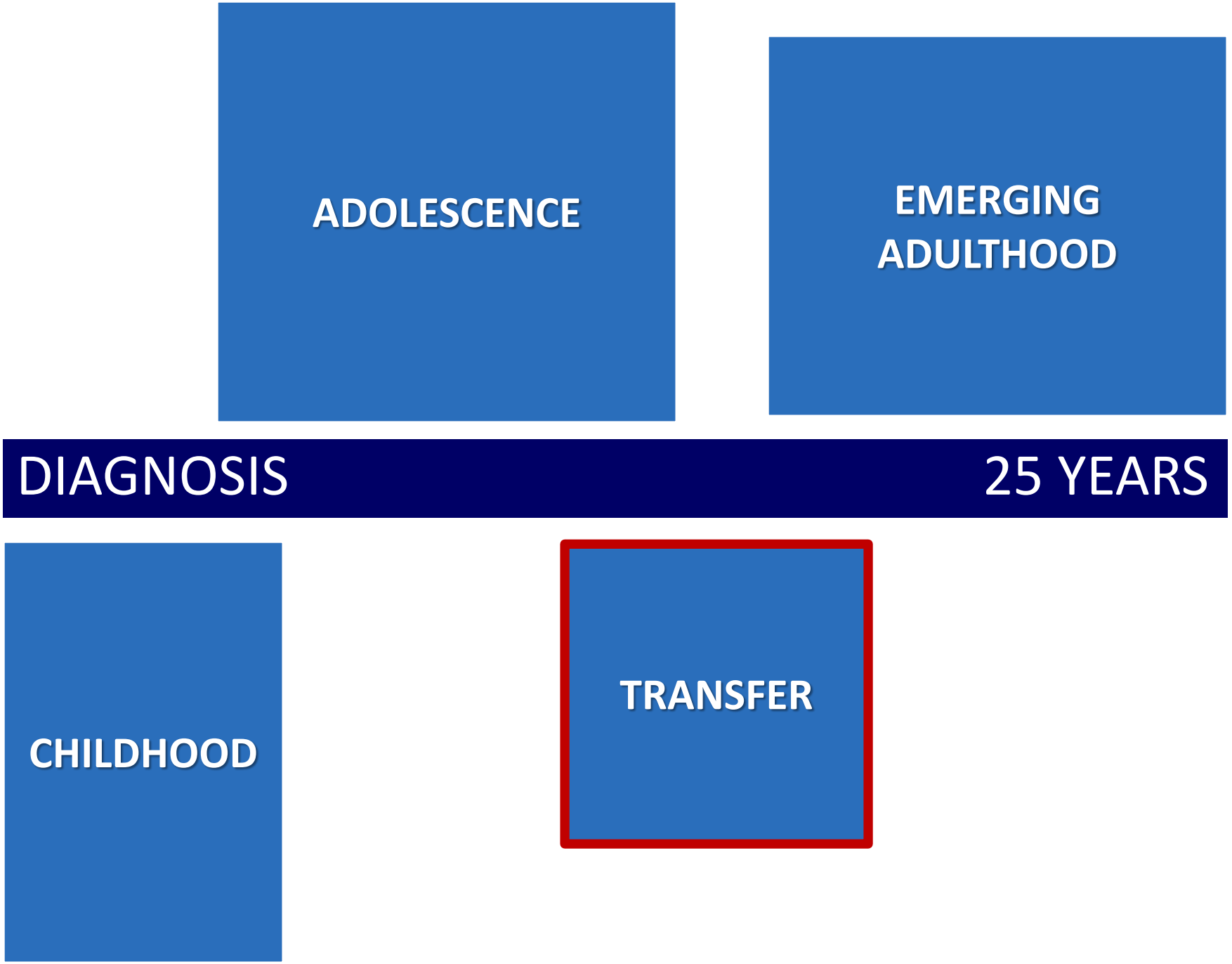
Self-Management Skills

- Speak independently with health providers
- Contact health providers
- Maintain health records & portable health summary
- Schedule & attend medical appointments
- Adhere to medication regimen; request refills
- Know when & how to access mental health services
- Know when & how to access emergency care
- Understand health insurance matters

Kovacs & McCrindle, Nat Rev Cardiol, 2014

Family & Patient Education Events

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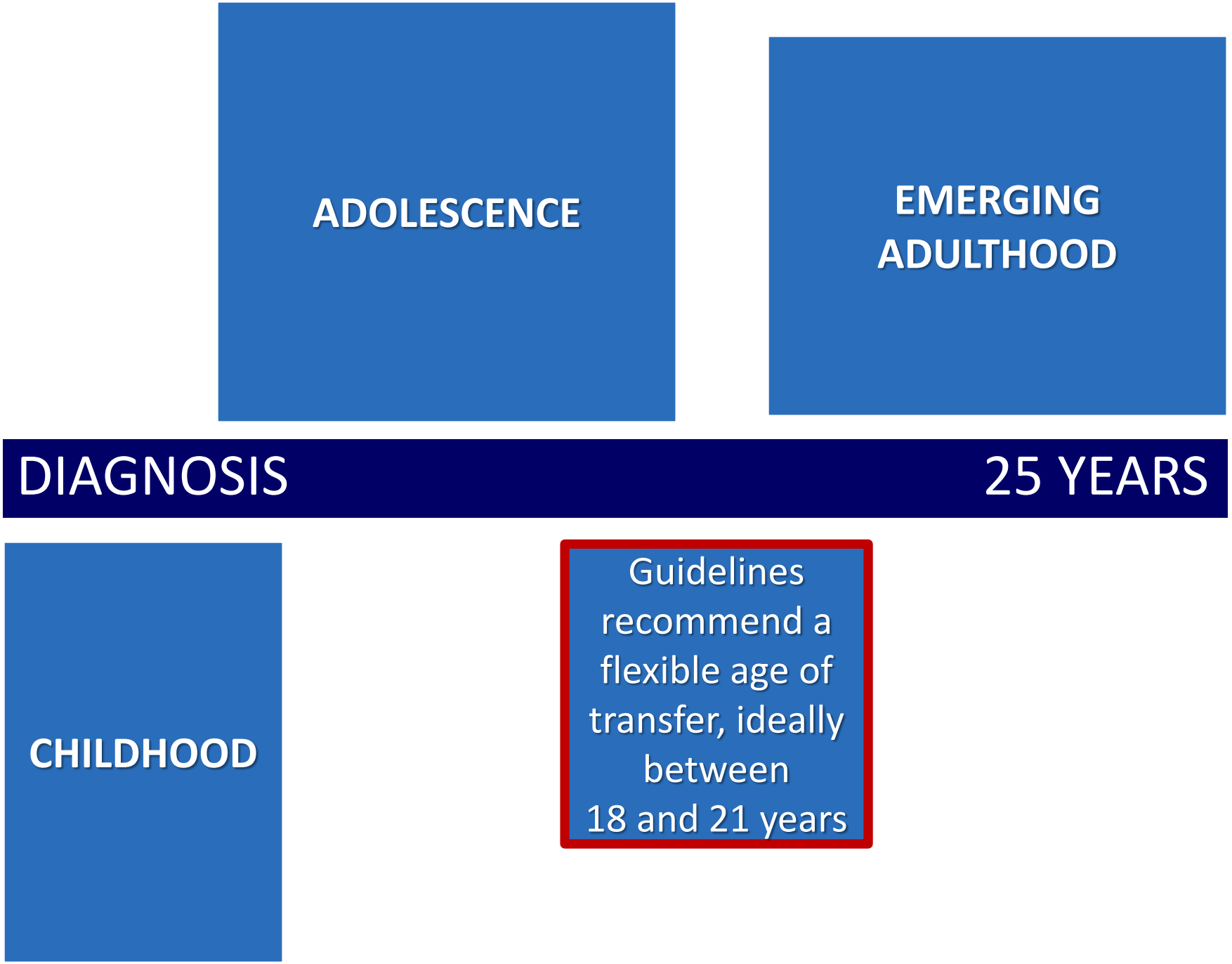
ADOLESCENCE
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Guidelines recommend a flexible age of transfer, ideally between 18 and 21 years

Parent Concerns during Transition

Most parents want what's best for their kids!

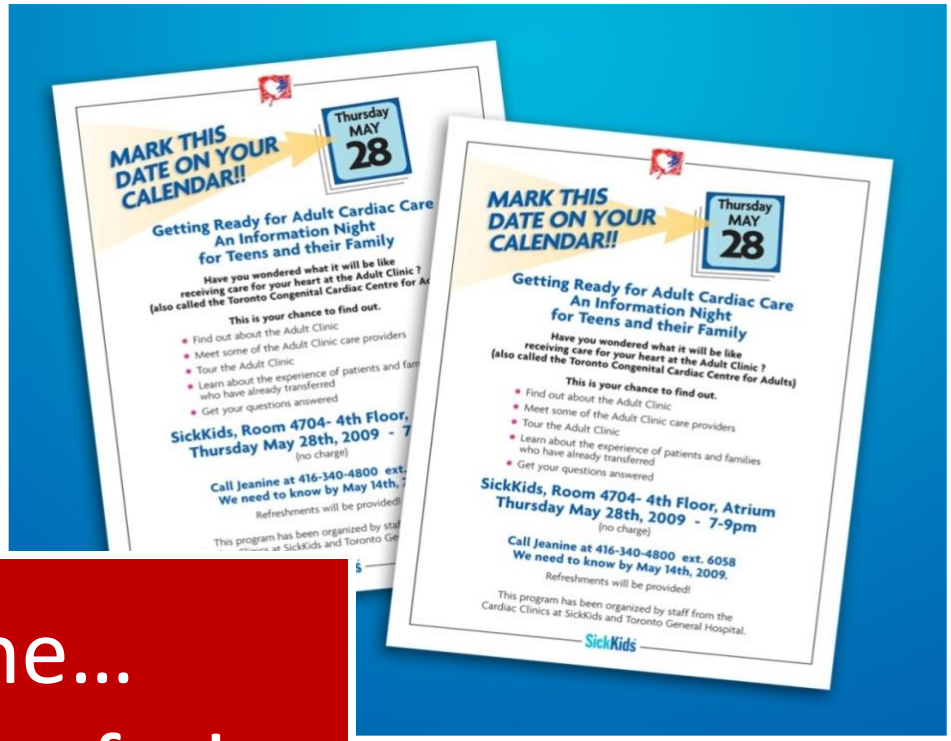
- Less than half think their child would be ready to take complete responsibility at 18 years of age
- It can be scary for many parents to let go
- Parental over-involvement is understandable and not uncommon, but can impede children gaining knowledge and self-management skills
- It is important to fully explain the rationale for and challenges and benefits of transition

Clarizia et al, Can J Cardiol, 2009;
Kovacs & McCrindle, Nat Rev Cardiol, 2014

Preparation for Transfer: Clinic Posters

Preparation for Transfer: Transfer Events/Tours

- For patients and families
- Pediatric and adult providers in attendance
- Adult clinic orientation & tour
- Meet and greet session (including graduate families)



Set the tone…
Celebrate transfer!

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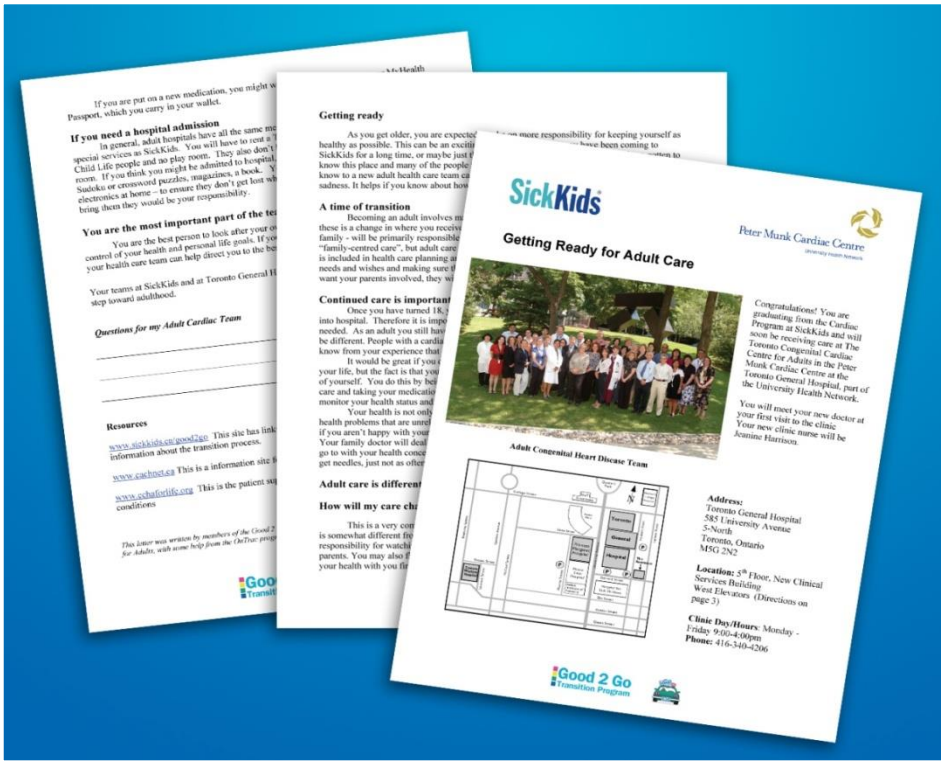
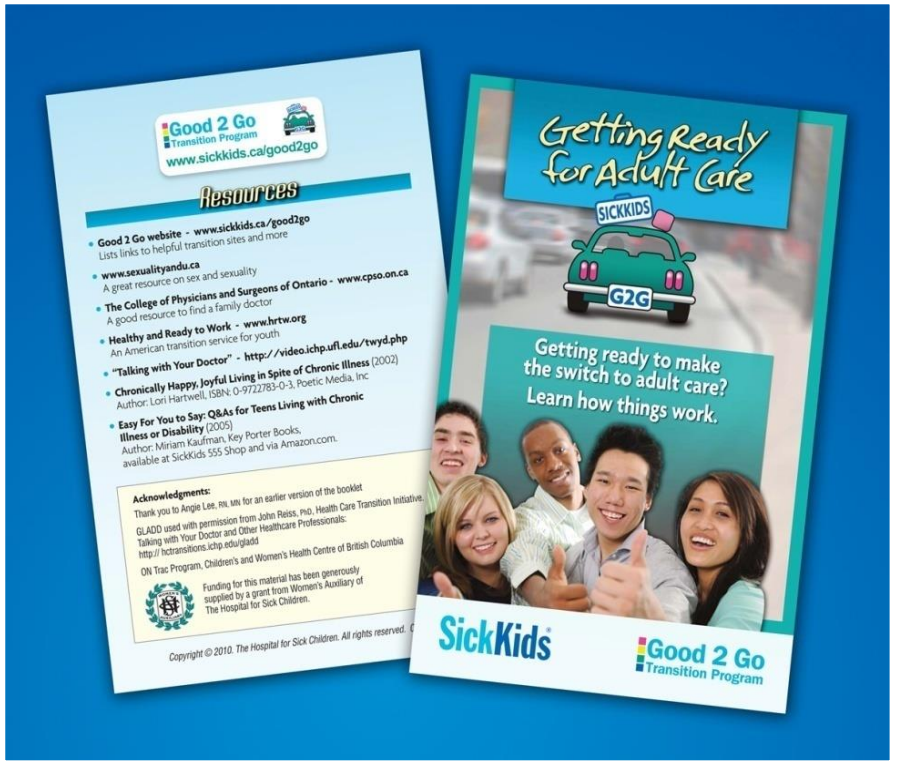
Coordinated Transfer of Care:
Transfer Documents for Patients & Family





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Coordinated Transfer of Care:
Clinical Documentation – Closing the Loop

Pediatric Program:

- Provide letter to patients with information about adult care setting
- Provide comprehensive health summary to adult team

Adult Program:

- Send welcome letter to patients
- Copy the pediatric program on the initial visit letter

Coordinated Transfer of Care:
Transfer/Transition Clinics

Options:

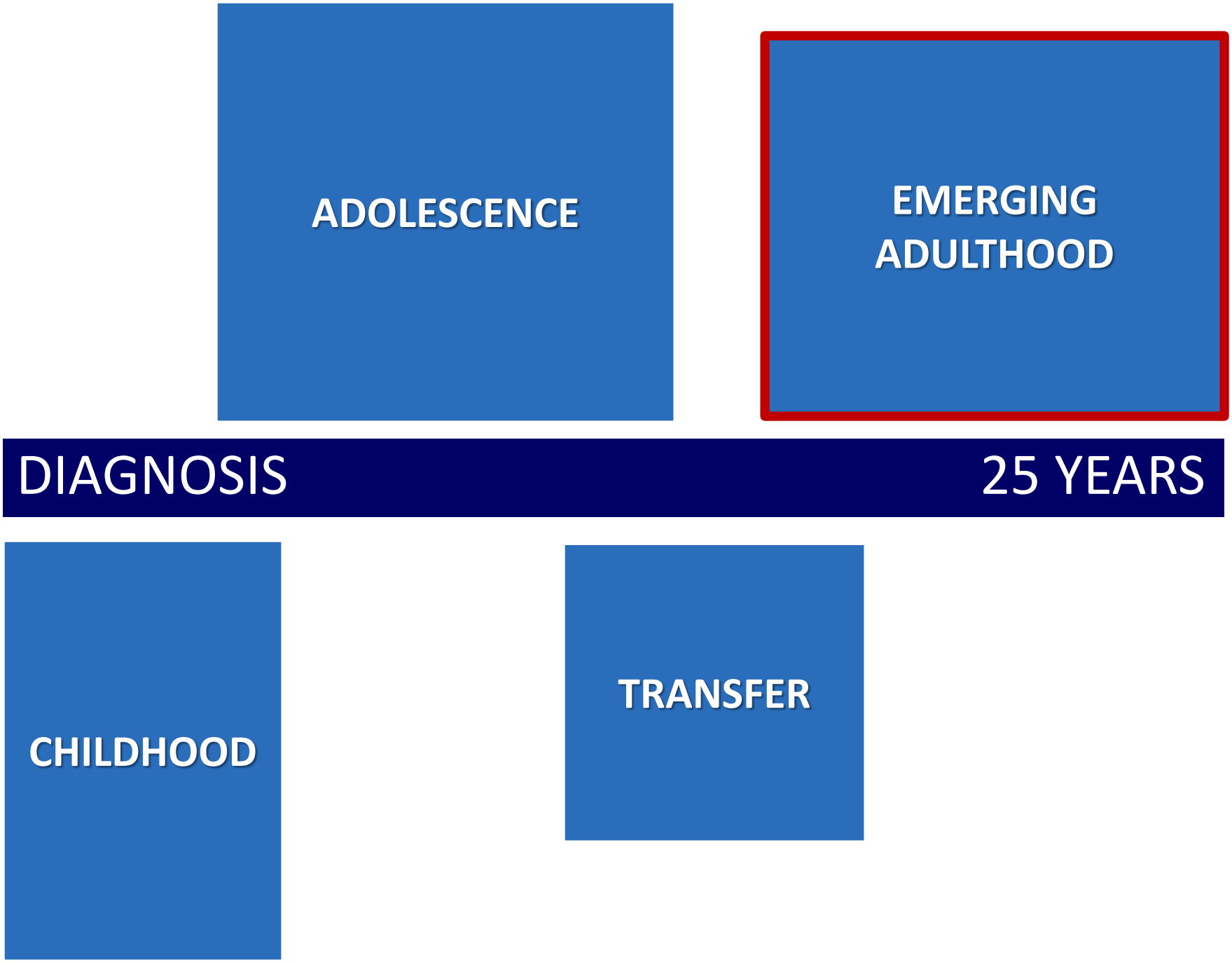
- Joint clinic attended by pediatric and adult providers
- Clinic in the pediatric setting to focus on education and preparation for transfer
- Clinic in the adult setting to focus on education and adult care expectations

Considerations: personnel & reimbursement

Coordinated Transfer of Care:
But what if there is no Adult KD program?

Consider 'Internal' Transfer

- Within a pediatric cardiology practice or program, consider 'transferring' patients to an adolescent and young adult clinic
- Could have assigned days in which adolescent and young adult patients are scheduled
- Develop links with providers with expertise in management of adult comorbidities


ADOLESCENCE
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ADOLESCENCE

Between 18-25 years, knowledge and self-management skills continue to develop. Focus on decision-making & responsibility becomes prominent.

DIAGNOSIS 25 YEARS

CHILDHOOD

TRANSFER

Conclusions

The Goal: Patients Retained in Care

- Lapses of care may occur in the pediatric setting, but appear most common around the age of transfer
- Multiple factors contribute to lapsed care
- Consequences can be serious

The Goal: Educated and Responsible Patients

- Transition is an extended process (diagnosis–25 yrs), though a major push should begin at 12-13 yrs
- Patient needs: education & self-management skills

Both goals benefit from close collaboration between pediatric and adult providers

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Thank you

Questions?

Comments?