



# BC KIDNEY DAYS

## Getting Youth and Young Adults ON TRAC

### Presenters:

Dr. Sandy Whitehouse

Bryn Williams

Mary Paone RN MSN

**ON TRAC**  
ONTRACBC.CA

**TRANSITIONING RESPONSIBLY  
TO ADULT CARE**



# Need for Transition Initiative

Utility and cost of a renal transplant transition clinic  
in British Columbia

## NO TRANSITIONAL CARE

n=33

3 deaths/ 7 allograft losses  
within 24 mths  
all unanticipated

## TRANSITIONAL CARE

n=12

No death or allograft loss

“We estimate that providing transition care to adolescent renal transplant recipients is at least cost neutral and may provide a cost benefit to the healthcare system...

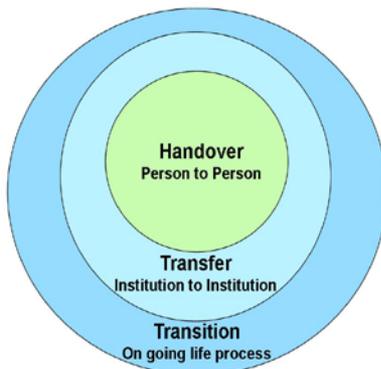
Anticipate that with reports such as ours, healthcare providers will be obliged to make transition care a priority.”

(Chanel Prestidge & Alexandra Romann & Ognjenka Djurdjev , Mina Matsuda-Abedini  
Pediatric Nephrology, 2012, 27:295–302)

# ON TRAC

## is a Province-wide Multifocal Initiative

Pediatric Transition Model



Handover: The movement of information about a patient from one caregiver to another

Transfer: The movement of a patient from one care area to another

Transition: The process of preparing for and adjusting to the changes created by a transfer.

To ensure successful **planning, preparation,** and **transfer** of youth with chronic health conditions and/or disabilities (CHC/Ds) from pediatric care to the adult care system, with **attachment** to primary care and specialist services.

Concept maps created by Sarah Cook, RN, BSN and Dr. Sandy Whitehouse, MD

**ON TRAC**  
ONTRACBC.CA

**TRANSITIONING RESPONSIBLY  
TO ADULT CARE**

Reduce. RELATE REACH REACHES Results Reason RESPECT Relief Radical Rely  
REACH resolution RESPONSIBLE. RIGHTS ROLES ROLES

# Pediatric & Adult Specialty Care

## Two Different Cultures

### PEDIATRIC

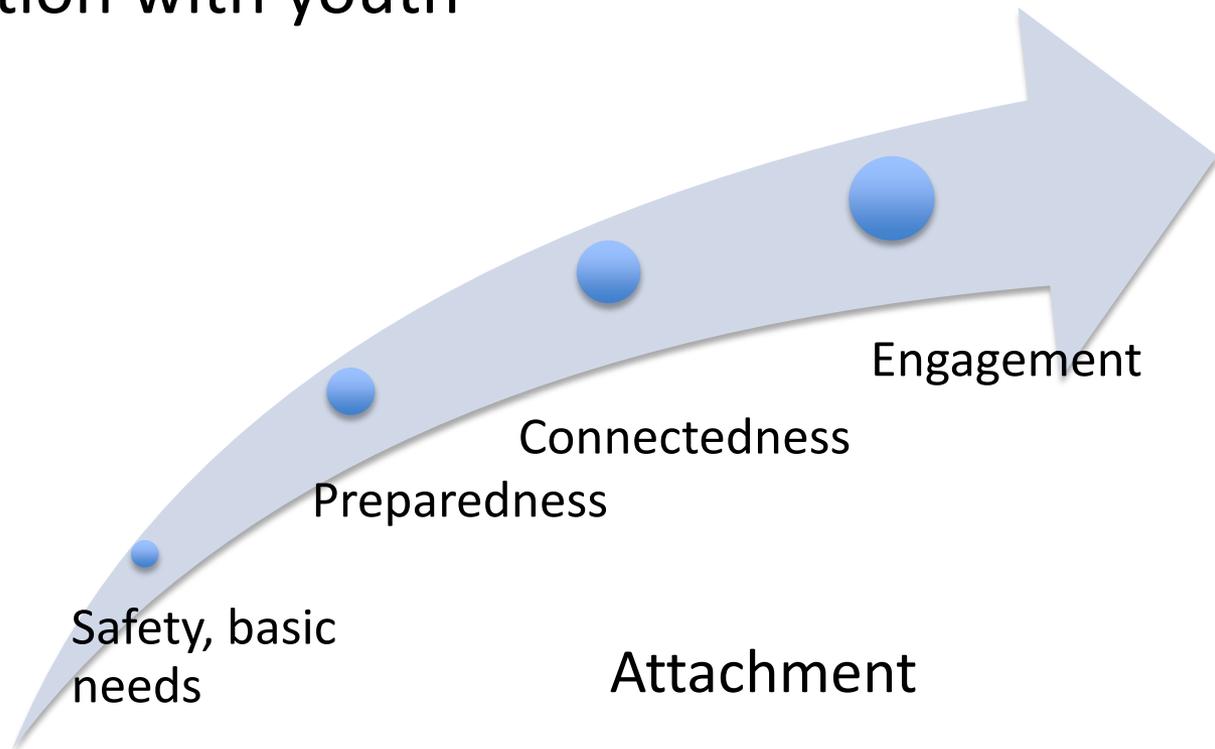
- Family focused
- Parental involvement
- Consent
- Multidisciplinary
- Developmentally oriented

### ADULT

- Client-centered
- Autonomy
- Access to information
- Referral based
- Single physician
- Long term complications

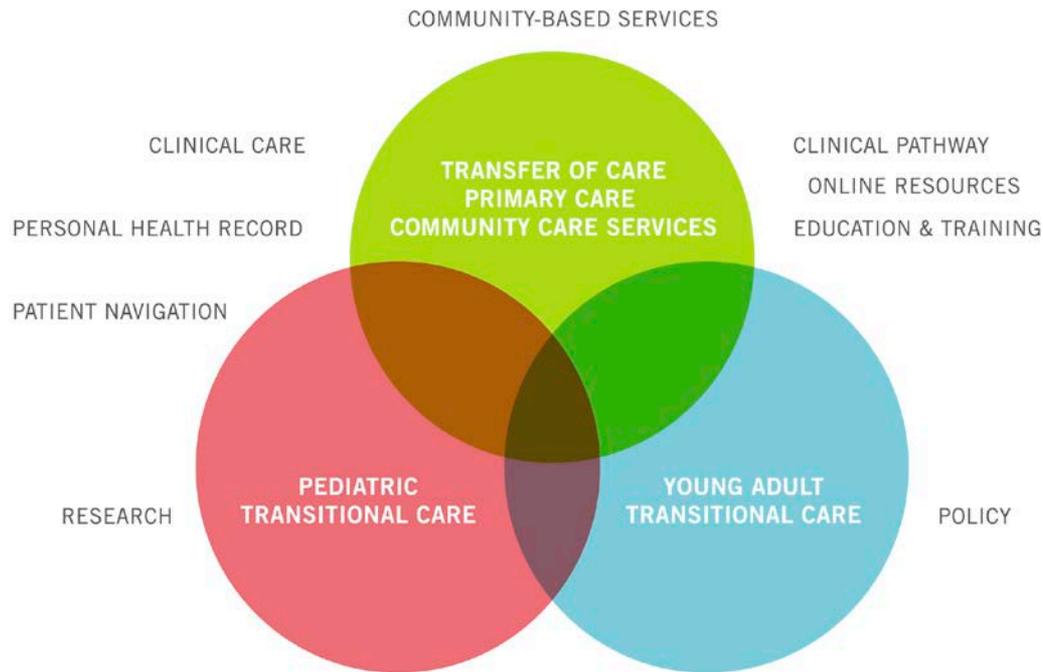
Summary:  
Improving the Transition experience

- Better communication between providers
- Better communication with youth



# Transition Model for Continuity of Care in BC

## TRANSITION SERVICE MODEL FOR BC



(ADAPTION FROM SAWYER & KENNEDY, 2008)

# Closing the Gap

## Youth Transitioning to Adult Care in BC



**A Policy Paper by BC's  
Physicians December 2012**

<https://www.bcma.org/.../1984-BCMA%20Youth%20Transitions.web>.

**All BCCH patients should  
have a Family doctor**

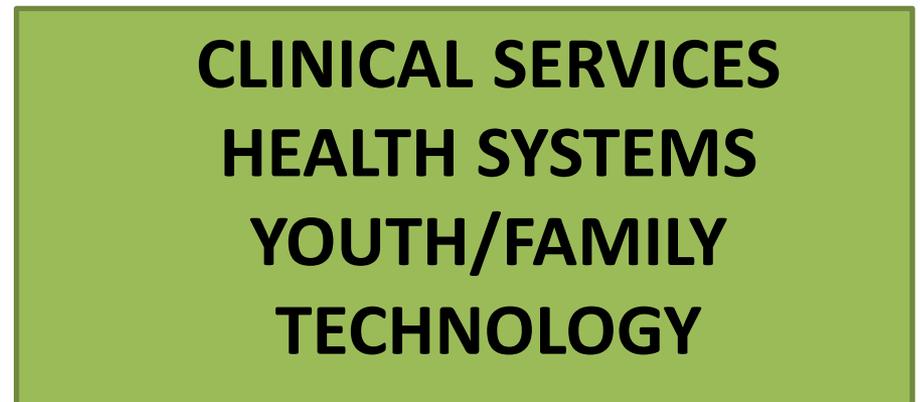
**Adult Health Care  
provider identified one  
year before discharge by  
health authority**

**Transition resources for  
individual Pediatric  
programs**

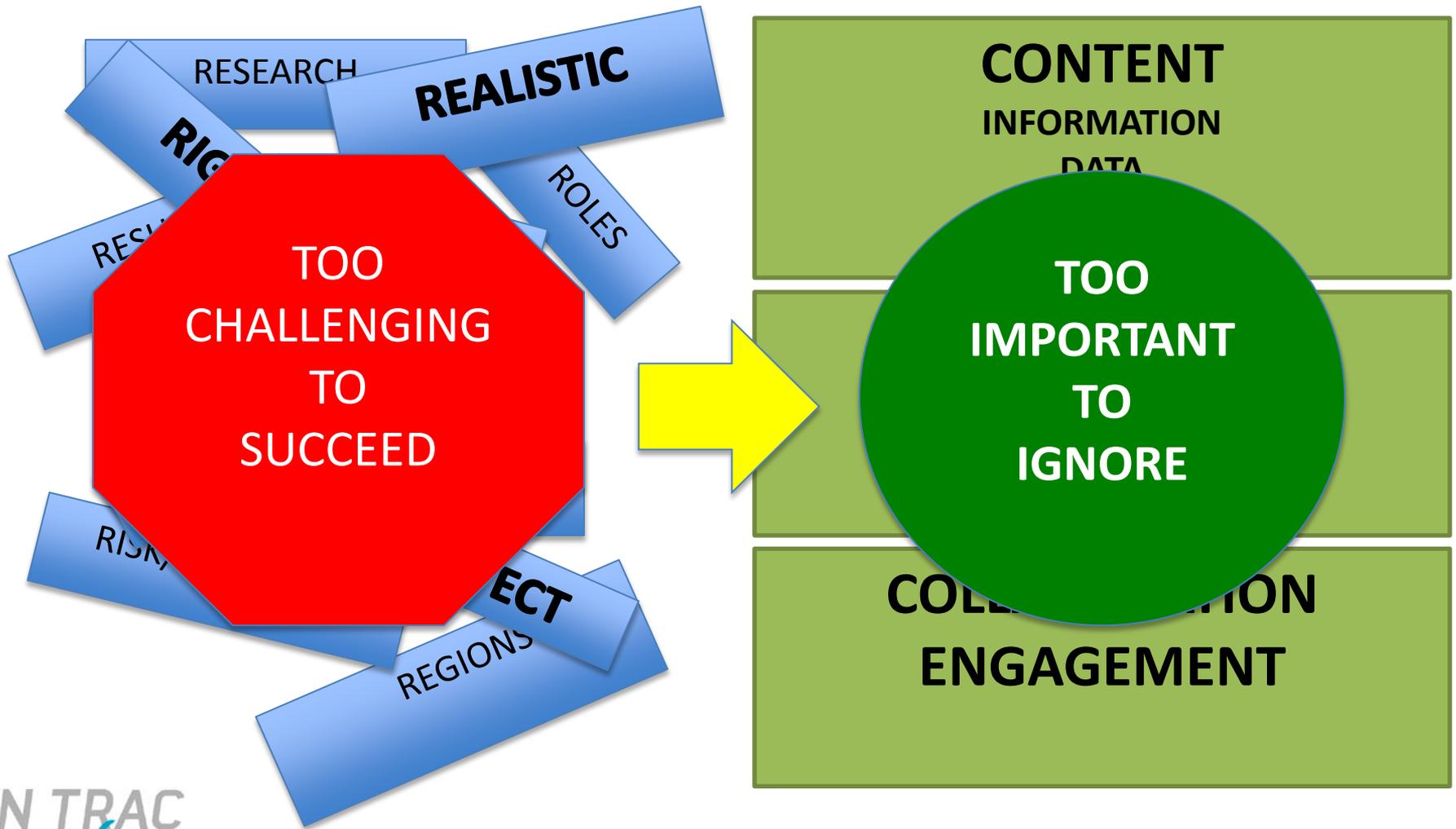
**Collaborative processes  
across Pediatric Divisions**

**Data collection/outcome**

# On TRAC: Transitioning **RESPONSIBLY** to Adult Care



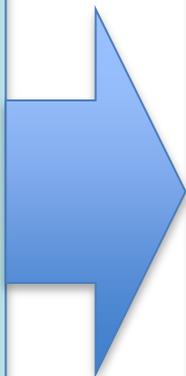
# On TRAC: Transitioning **RESPONSIBLY** to Adult Care



# Approach to Transitions System Change and Evaluation

## SYSTEM DRIVERS

1. Policy
2. Data collection
3. Evaluation
4. Collaboration  
Integration  
Accountability  
between Health  
Care Services
5. Resources for  
Providers &  
Youth/Families
6. Education / Skill  
Building



## STANDARDIZE CLINICAL DOCUMENTATION

Standard  
Templates for  
Preparation &  
Transfer

- **Transition  
Clinical  
Pathway**
- **Medical  
Transfer  
Summary**
- **Transition Care  
Management  
Plans**

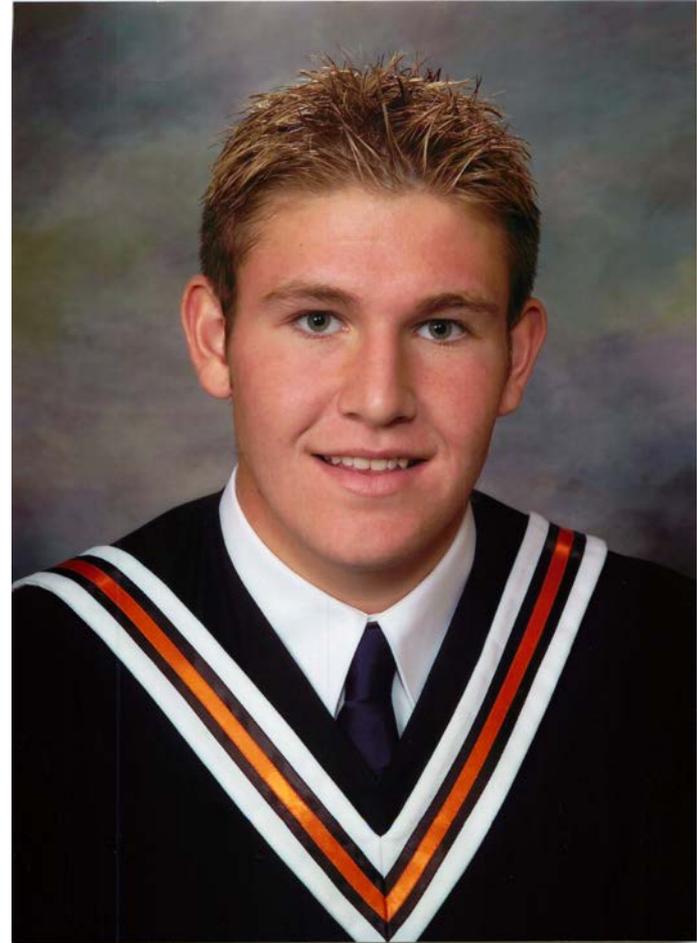
## COMMUNITY and YOUTH ENGAGEMENT

- Youth/Family  
Workshops
- Youth Advisory  
Committees
- Online  
Resources
- Phone apps  
and tools
- Mentorship

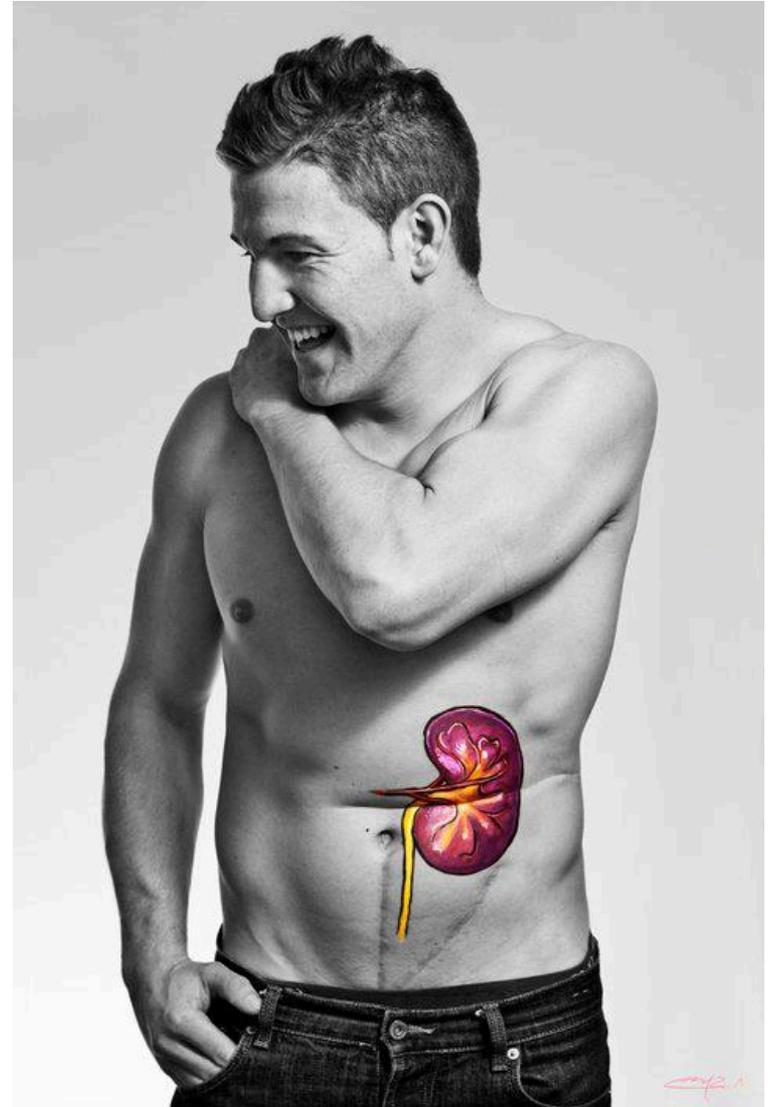
## HEALTH SYSTEMS

- **Physician  
Attachment -  
Most Responsible  
Physician**
- **Reimbursement**
- **Referral  
Networks-  
Divisions of Family  
Practice**
- **Physician  
Education &  
Support**
- Organization of  
Care for Continuity

# Bryn's Transition Journey



# His Message...



# Alignment of Clinical Guidelines

## BC Children's Transition Clinical Practice Guidelines

- Patient-centred
- Primary Care by Family Physician (FP) – confirmed by 14 years of age
- Identify Adult Specialist(s) one year prior to transfer
- Focus on self/co-management skills & education.
- Documentation meeting condition-specific /patient-focused requirements.

## Best Practices for Kidney Care: BC Guidelines April 2014

- Patient –centred
- Focus on Self/Co-management skills.
- Referral from FP/ Medical Home.
- Increased frequencies of visits if unstable.
- Shared care management/ documentation/ education (across disciplines).

**ON TRAC**  
Transition Timeline

**Youth with CHC/Ds**  
**12-24yrs**

**Youth 12-14yrs**  
Transition Clinical  
Pathway (TCP)  
Confirm Family  
Physician

**Youth 15-16yrs**  
Readiness skills  
& knowledge

**Youth 17-18yrs**  
Identify Adult  
Specialist(s)  
Medical Transfer  
Summary (MTS)

**Youth 19-24yrs**  
**Adult Care**  
Adult TCP  
Transition Care  
Management  
Plans (TCMPs)

Youth &  
Family  
**Readiness  
Quiz**  
Online

Youth &  
Family  
**Readiness  
Education  
Event**

**Transfer  
Documents**  
(TCP, MTS, TCMPs)

**Attachment Protocol**  
First visit within 6 months  
First Adult letter back to BCCH  
Two visits to Adult Specialist(s)  
Two visits to FP/year receiving all  
reports

# Transition Clinical Tools

## Standardized Documentation

### Transition Clinical Pathway (TCP)

#### Simple/ Complex (12-24 years)

Initiated at 12 years of age in clinical setting

Identify/revisit FP by 14 years of age.

Identify Adult Specialist by 16 years. Self-care skills, knowledge and behavior development.

### Youth / Family Readiness Checklists

At home, school, community – online (pre-visit).

### Medical Transfer Summary (MTS)

Comprehensive summary of last clinic visit

Includes 'anticipatory guidance'

Copy to Adult and FP and Youth.

### Transition Care Management Plans (TCMPs)

Shared model of specialty care between FP, pediatric and adult specialists – decreasing differences between pediatric and adult care provision –evidenced based practice.





### ON TRAC TRANSITION CLINICAL PATHWAY (SIMPLE)

DATE INITIATED \_\_\_\_/\_\_\_\_/\_\_\_\_ DATE LAST CLINIC VISIT \_\_\_\_/\_\_\_\_/\_\_\_\_  
 DD MM YYYY DD MM YYYY

Preferred Name: \_\_\_\_\_

Date of Birth \_\_\_\_\_ PHN# \_\_\_\_\_

Clinic (Initiated): \_\_\_\_\_

Diagnosis(s)

Primary \_\_\_\_\_

Secondary \_\_\_\_\_

Youth Email \_\_\_\_\_

Youth Cell# \_\_\_\_\_

Mailing Address: \_\_\_\_\_

#### Contacts

Preferred Contact \_\_\_\_\_

Phone \_\_\_\_\_

Emergency Contact (if Different) \_\_\_\_\_

Phone \_\_\_\_\_

Planned Post Secondary Work \_\_\_\_\_

School \_\_\_\_\_

Location/ City \_\_\_\_\_

#### Special Considerations

First Nations Status: Yes \_\_\_\_\_ No \_\_\_\_\_

Financial/ Medication Assistance: Yes \_\_\_\_\_ No \_\_\_\_\_

Contact: \_\_\_\_\_

MSP \_\_\_\_\_ Fair Pharmacare \_\_\_\_\_ Not Insured Health Benefits (NIHB) \_\_\_\_\_

#### Transfer Information Checklist

<i>These people have been sent the following attachments:</i>	FP	ADULT SS
Medical Transfer Summary		
Relevant Recent Lab Reports and Flow sheets Urinalysis, ACR or proteinuria		
Radiology reports e.g. nGFR, Renal U/S		
Biopsy reports (if available)		
ECHOs, ECG		
All relevant Consult Letters		
Psychology Assessment		
Psycho-educational Assessment		
Social Work Assessment		
Nutritional Report		

#### Consents

I agree for this information to be passed onto my (indicate who gets reports)

Family Physician \_\_\_ Adults Specialist(s) \_\_\_

Mother \_\_\_ Father \_\_\_ Other \_\_\_\_\_

Youth Signature \_\_\_\_\_ Date \_\_\_\_\_

I agree to be contacted about my transition experience up to five years after leaving BC's Children's Hospital

**Adult Health Care Team & Recommendations**

**Family Physician** \_\_\_\_\_ Address \_\_\_\_\_

Phone \_\_\_\_\_ Frequency of visits \_\_\_\_\_ For what? \_\_\_\_\_

**Adult Specialist** \_\_\_\_\_ Address \_\_\_\_\_

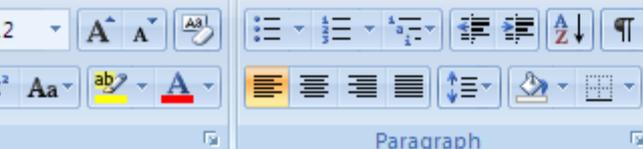
Phone \_\_\_\_\_ Date of First Visit \_\_\_\_\_

**Recommended Tests** (How often?) \_\_\_\_\_

**Youth's strengths and concerns on Transfer:**

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Self-Advocacy	Early	Middle	Transfer	Adult Care	COMMENTS
	12-14 yrs	15-16 yrs	17-18 yrs	19-24 yrs	
Comes to each visit with a question	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Practices meeting with practitioners on own		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows name and can describe condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Describes emergency plan – who to call for what and what to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows who to see for what – Family Physician vs Specialist			<input type="checkbox"/>	<input type="checkbox"/>	
<b>Confirms and visit Family Physician at least once a year</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Aware of possible future health and late effects of condition			<input type="checkbox"/>	<input type="checkbox"/>	
<b>Independent Behaviours / Self-management</b>					

*AaBbCcI*

Emphasis

**AaBbC**

Heading 1

AaBbCcI

Normal

**AaBbCcI**

Strong

AaBbCcI

Subtitle

**AaBbC**

Title

AaBbCcI

No Spaci...

*AaBbCcI*

Subtle Em...

**AaBbC**

Intense

	12-14 yrs	15-16 yrs	17-18 yrs	19-24 yrs	
Comes to each visit with a question	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Practices meeting with practitioners on own		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows name and can describe condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Describes emergency plan – who to call for what and what to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows who to see for what – Family Physician vs Specialist			<input type="checkbox"/>	<input type="checkbox"/>	
Confirms and visit Family Physician at least once a year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Aware of possible future health and late effects of condition			<input type="checkbox"/>	<input type="checkbox"/>	
<b>Independent Behaviours / Self-management</b>					
Knows allergies to medications, food & other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Can name medications, how taken, reasons for them and side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows when and how to fill own prescriptions		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows dietary restrictions or supplements and reasons for them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows how to access blood/test results			<input type="checkbox"/>	<input type="checkbox"/>	
Knows reasons for tests and understands results			<input type="checkbox"/>	<input type="checkbox"/>	
Knows how, when, why getting sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Carries care card & emergency numbers in wallet/purse/on phone		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows dialysis prescription, reasons for it, and when to call for adjustments (if applicable)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Knows how to order/get equipment/ supplies		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Styles

MTSMASSTERRenalDIATransAug2014 [Read-Only] [Compatibility Mode] - Microsoft Word

File Layout    References    Mailings    Review    View    **Table Tools**    Design    Layout

Page Setup    Page Background    Paragraph    Arrange

Breaks    Line Numbers    Hyphenation    Watermark    Page Color    Page Borders    Indent    Spacing    Position    Wrap Text    Bring Forward    Send Backward    Selection Pane

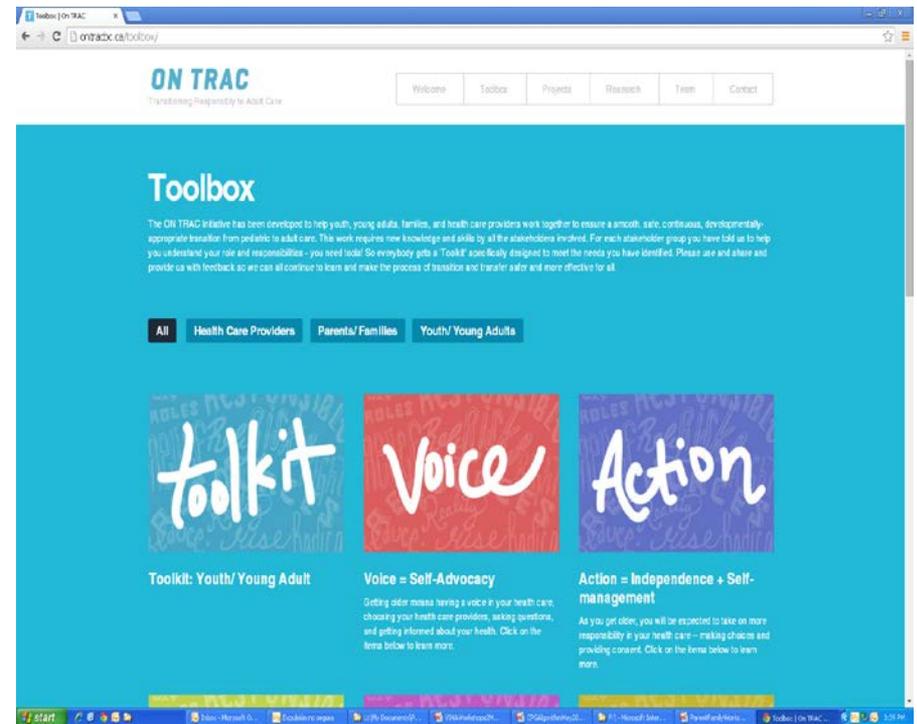
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Topic	Content
<b>Condition Specific Information</b>	<ul style="list-style-type: none"> <li>• Primary Renal Diagnosis and other diagnoses               <ul style="list-style-type: none"> <li>○ Date of diagnosis and significant investigations</li> <li>○ Renal Biopsy (if applicable)</li> <li>○ GFR Category (CKD Stage), Level of Albuminuria</li> <li>○ Co-morbidities (Renal and Non-renal)</li> <li>○ Dietary Restrictions or Supplements</li> <li>○ Dialysis Prescription (if applicable)</li> </ul> </li> <li>• Preferred Treatment Modality</li> </ul>
<b>Major Events</b>	<ul style="list-style-type: none"> <li>• Birth History</li> <li>• Date, event, outcome and plan</li> </ul>
<b>Medications</b>	<ul style="list-style-type: none"> <li>• Name, dose, rationale, plan</li> <li>• Previous medications</li> <li>• Rationale for changing medication protocols</li> <li>• Indications and contraindications for medications</li> <li>• Specific drug interactions and alerts</li> </ul>
<b>Results</b>	<ul style="list-style-type: none"> <li>• Most recent lab work and imaging with important trends</li> </ul>
<b>**Alerts</b>	<ul style="list-style-type: none"> <li>• Allergies, clinical warnings, other risks in ongoing care</li> <li>• Red Flag condition specific and unresolved transition related issues</li> </ul>
<b>Immunizations</b>	<ul style="list-style-type: none"> <li>• Flag any condition-specific immunizations protocols and alerts</li> <li>• Rationale for non-completion of recommended schedule</li> <li>• What future immunizations are required</li> </ul>
<b>**Psychosocial/ Special Considerations</b>	<ul style="list-style-type: none"> <li>• Psychosocial information pertaining to success of primary/specialist care, eg.) cognitive level, communication strategies/barriers, family dynamics and compliance, finances and travel issues (outside lower mainland)</li> <li>• Need for an interpreter</li> </ul>
<b>**Overview/Plan</b>	<ul style="list-style-type: none"> <li>• Flag restrictions: activity/ work</li> <li>• Youth strengths/concerns for discharge/transfer</li> </ul>
<b>Anticipatory Guidance and Recommendations for Future Care</b>	<ul style="list-style-type: none"> <li>• Condition-specific and potential complications/ late effects</li> <li>• Monitoring of medications and suggested tests and lab work</li> <li>• Specialty-specific directions from Ministry of Health Guidelines: Chronic Kidney Disease: Identification, Evaluation and Management of Patients (<a href="http://www.bcguidelines.ca">www.bcguidelines.ca</a>)</li> </ul>
<b>Transfer of Specialty Care</b>	<ul style="list-style-type: none"> <li>• Timing when Specialist(s) will take over care – urgency of referral and type of follow-up- requesting a confirmation letter for the</li> </ul>

# Youth Readiness Quiz to Online Youth Toolkit



- Youth-driven readiness indicators.
- Indicators /domains correspond with the TCP.
- Each indicator (skill or knowledge) links to Resource cards with activities, tips, and links to services and resources.
- Can be used by all stakeholders at anytime – at home, school, or clinical settings.





Getting older means having a voice in your health care, choosing your health care providers, asking questions, and getting informed about your health.

Click on the items below to learn more.

Asking questions.

Talking with health care providers.

Describing my health condition.

### Tips & Links

- [TRAC it!](#): Ask your health care providers for the name and spelling of your condition – write it in the Notes app on your phone.
- Search out the definition of your condition at [HealthLink BC](#).
- Create your own [MyHealth Passport!](#)

### Activities

**What I Need To Know About My Health Condition**

# ON TRAC

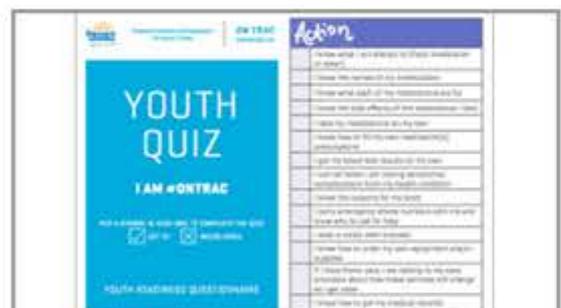
Transitioning Responsibly to Adult Care

Welcome	Toolbox	Projects	Research +
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## Youth Toolbox

Explore the Tools and Resource Cards created to help you make a continuous, safe, and sm

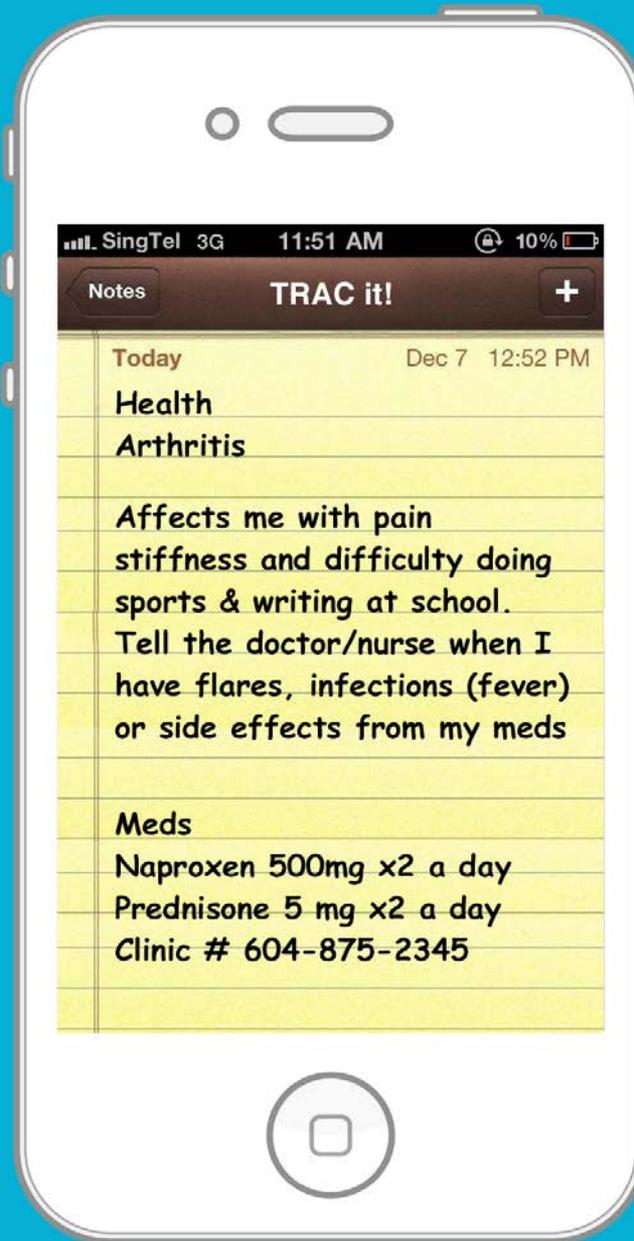
### Tools



# Youth Strategy - Just TRAC It!

- Powered by PiC YAC at BCCH
- Mobile health intervention
- 90% of youth use a phone
- Come to clinic – TURN YOUR PHONE ON!
- FREE – no app necessary
- Notes app – condition, medications, allergies, NB items to remember, questions
- Calendar app – book own appointments/ alarms
- Contact app – physician, nurse, Pharmacy, other?





SingTel 3G 11:51 AM 10%

Notes TRAC it! +

Today Dec 7 12:52 PM

Health  
Arthritis

Affects me with pain  
stiffness and difficulty doing  
sports & writing at school.  
Tell the doctor/nurse when I  
have flares, infections (fever)  
or side effects from my meds

Meds  
Naproxen 500mg x2 a day  
Prednisone 5 mg x2 a day  
Clinic # 604-875-2345

# “Come to clinic and Turn your Phones On!”



- 1) Please take a moment to turn your phones on.
- 2) Go to [www.ontracbc.ca](http://www.ontracbc.ca)
- 3) Click on Youth Toolkit
- 4) Save using icon at base of phone and “Add to Home Screen”.