

# BC KIDNEY DAYS

## Getting Youth and Young Adults ON TRAC

### Presenters:

Dr. Sandy Whitehouse

Bryn Williams

Mary Paone RN MSN

# 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...

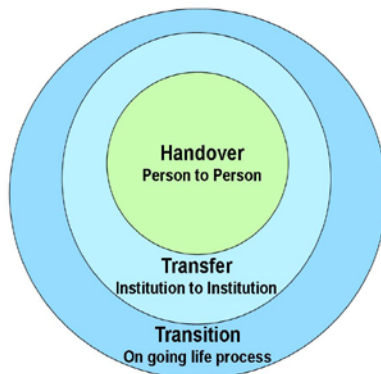
Anticipate that with reports such as ours, healthcare providers will be obliged to make transition care a priority.”

(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. **RECOMMEND** Results Reason **RESPECT** Relief Radical Rely  
RELATE **RESPONSIBLE** RIGHTS **RESOURCES** ROLES  
REACH resolution

# Pediatric & Adult Specialty Care

## Two Different Cultures

### PEDIATRIC

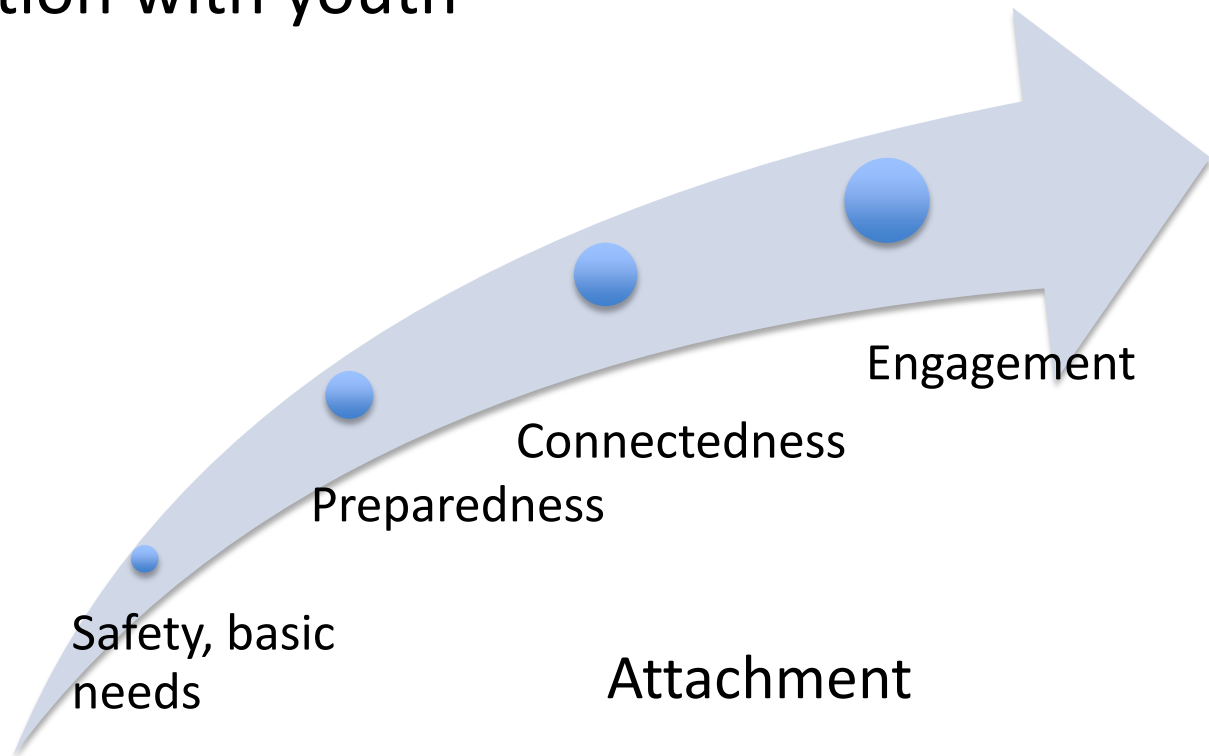
- Family focused
- Parental involvement
- Consent
- Multidisciplinary
- Developmentally oriented

### ADULT

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

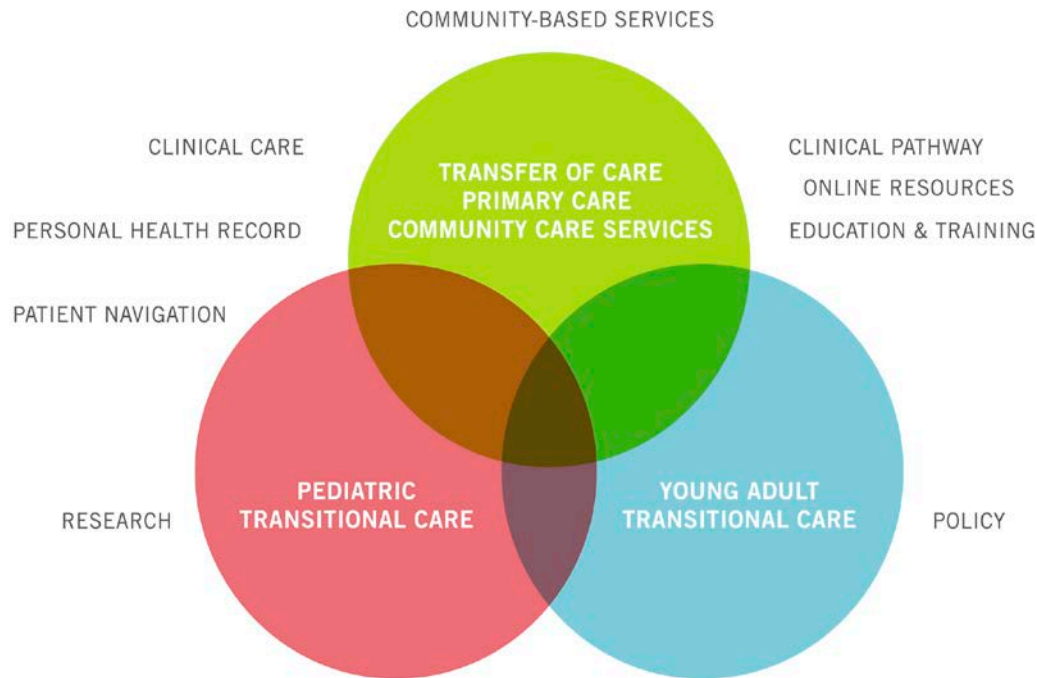
Summary:  
Improving the Transition experience

- 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

## **ROLES**

RESEARCH

## **RIGHTS**

RESULTS

## **REALISTIC**

RECORDS

## **RELATIONSHIPS**

RESOURCES

## **RESPECT**

RISK/RESILIENCE

## **RESISTANCE**

REGIONS

RANGE

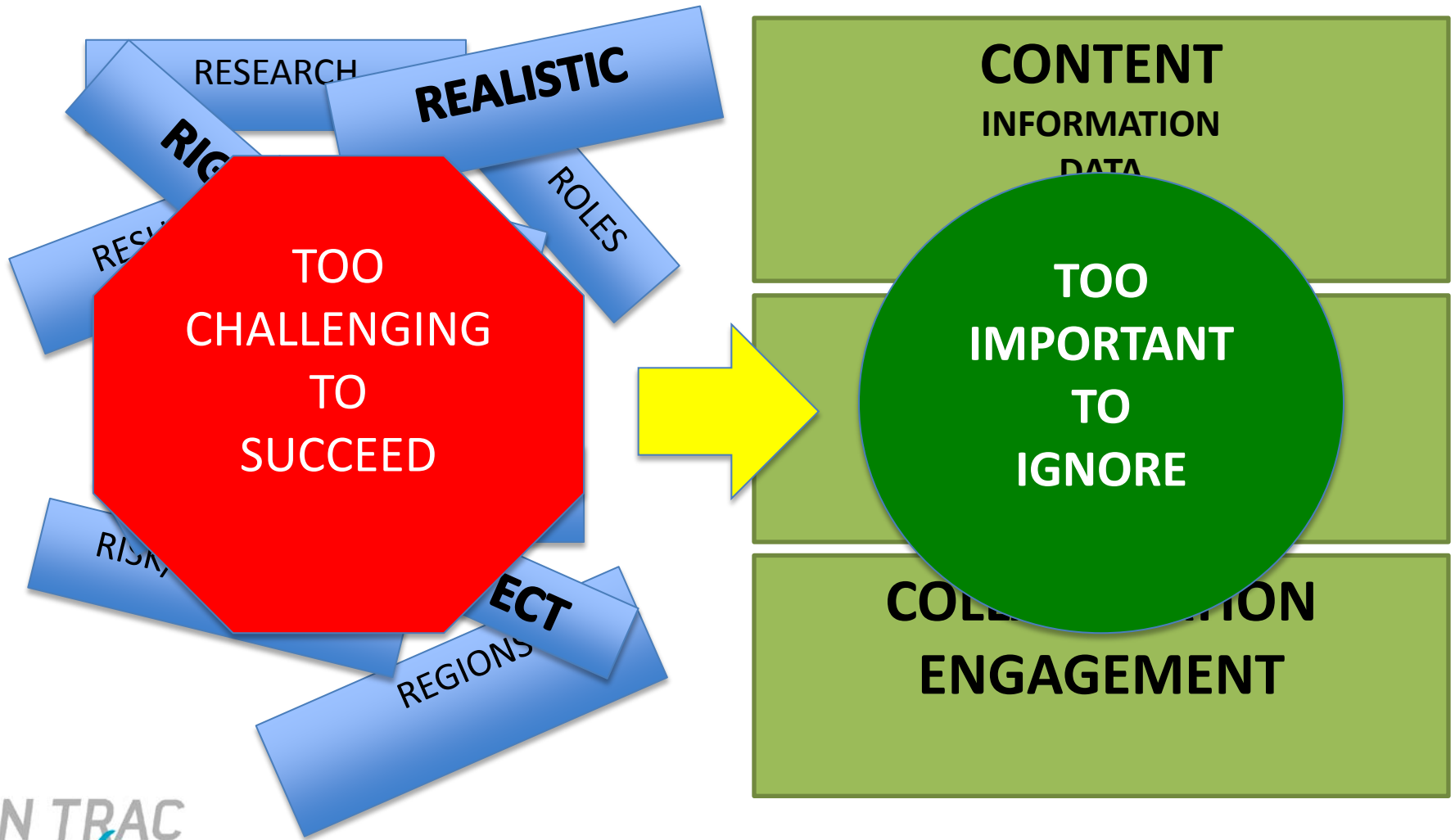
**CONTENT  
PROCESS**

**ENGAGEMENT  
COLLABORATION**

**CLINICAL SERVICES  
HEALTH SYSTEMS  
YOUTH/FAMILY  
TECHNOLOGY**



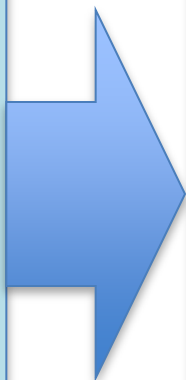
# On TRAC: Transitioning **RESPONSIBLY** to Adult Care



# 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

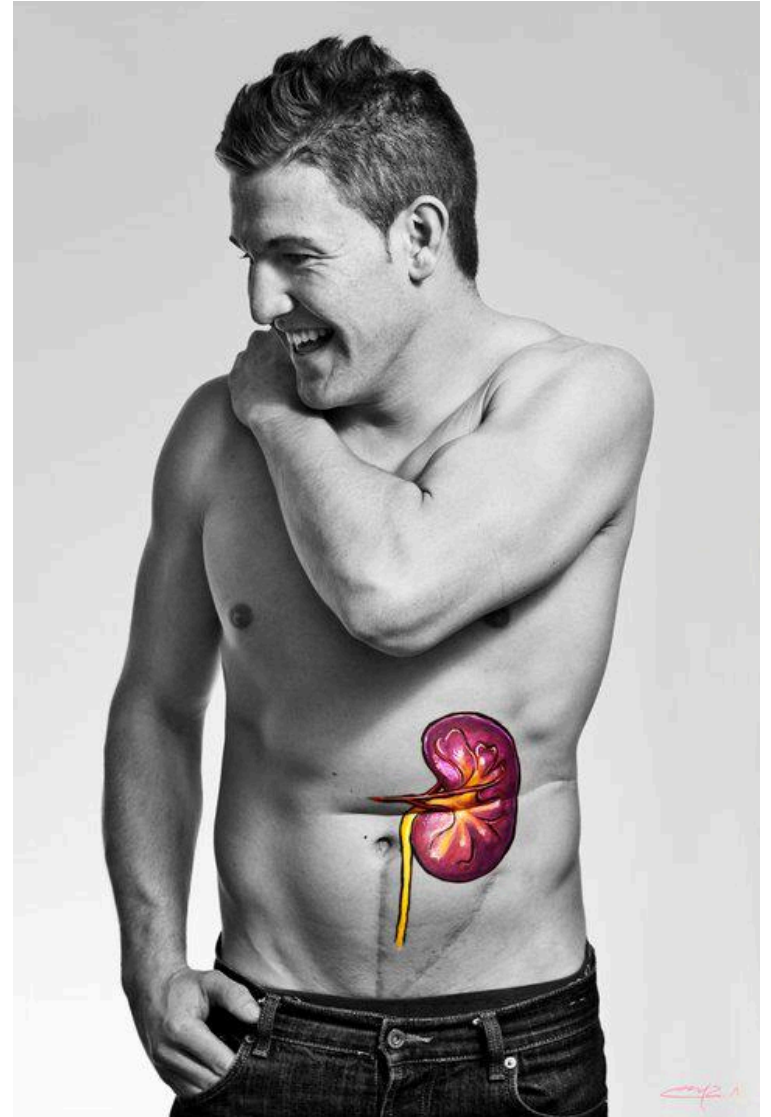
## HEALTH SYSTEMS

- **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

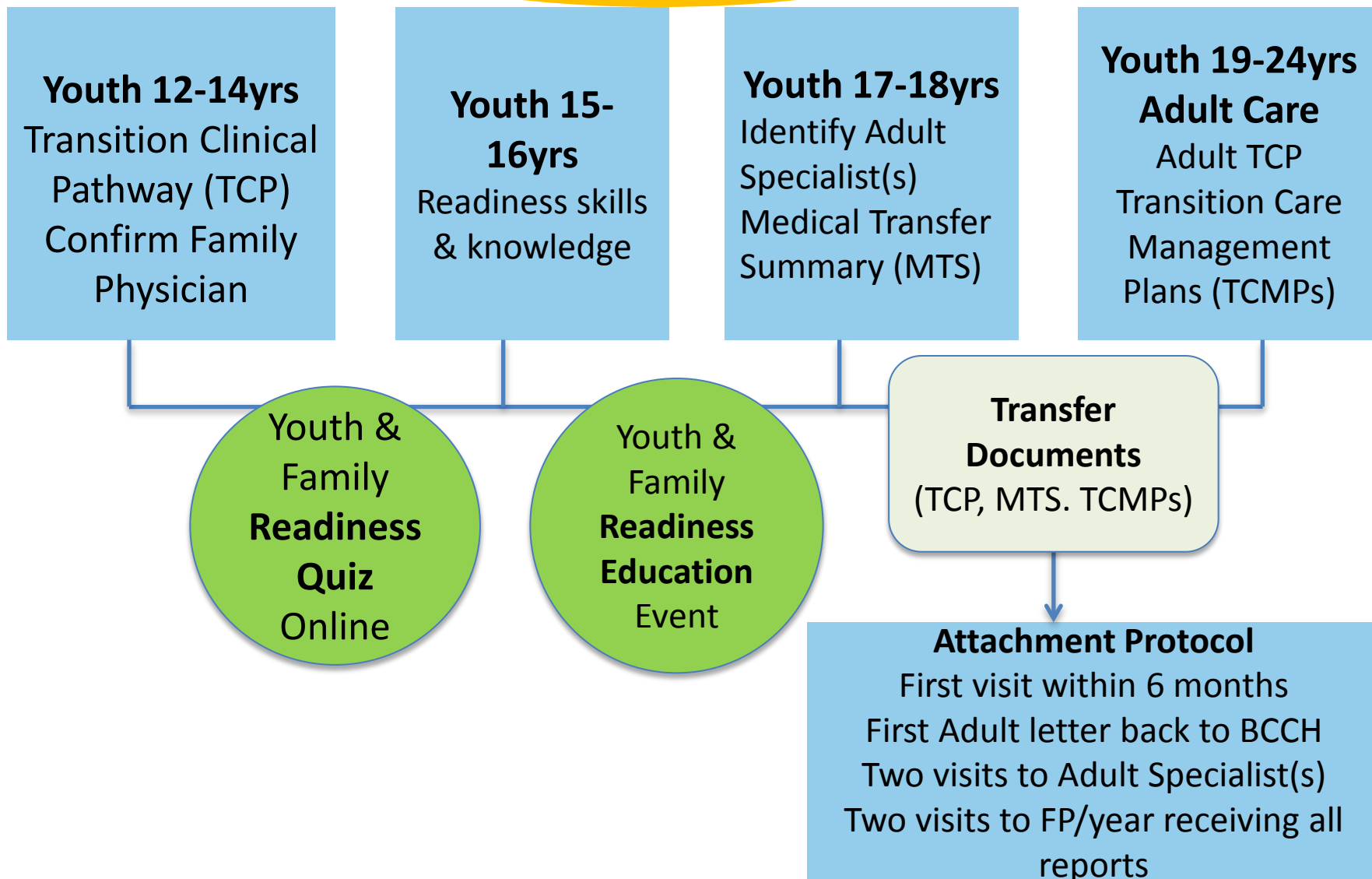
- Patient-centred
- Primary Care by Family Physician (FP) – confirmed by 14 years of age
- Identify Adult Specialist(s) one year prior to transfer
- Focus on self/co-management skills & education.
- Documentation meeting condition-specific /patient-focused requirements.

## 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**





# 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 \_\_\_\_/\_\_\_\_/\_\_\_\_  
DD MM YYYY

DATE LAST CLINIC VISIT \_\_\_\_/\_\_\_\_/\_\_\_\_  
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

These people have been sent the following attachments:

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:**


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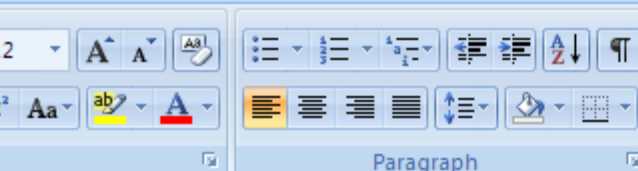
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ON TRAC Transition Clinical Pathway (Simple) **RENAL/DIALYSIS/TRANSPLANT JUNE 2014** DRAFT

<b>Self-Advocacy</b>	<b>Early</b> 12-14 yrs	<b>Middle</b> 15-16 yrs	<b>Transfer</b> 17-18 yrs	<b>Adult</b> Care 19-24 yrs	<b>COMMENTS</b>
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>					



AaBbCcL

Emphasis

AaBbC

Heading 1

AaBbCcI

Normal

AaBbCcI

Strong

AaBbCcI

Subtitle

AaBbC

Title

AaBbCcI

No Spacing

AaBbCcL

Subtle Emphasis

AaBbC

Intense

Styles

	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"/>	
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Describes emergency plan – who to call for what and what to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
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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"/>	

MTSMasterRenalDIATransAug2014 [Read-Only] [Compatibility Mode] - Microsoft Word

Table Tools

Design Layout

References Mailings Review View

Page Setup Page Background Paragraph Arrange

Watermark Page Color Borders

Indent Left: 0 cm Right: 0 cm

Spacing Before: 0 pt After: 0 pt

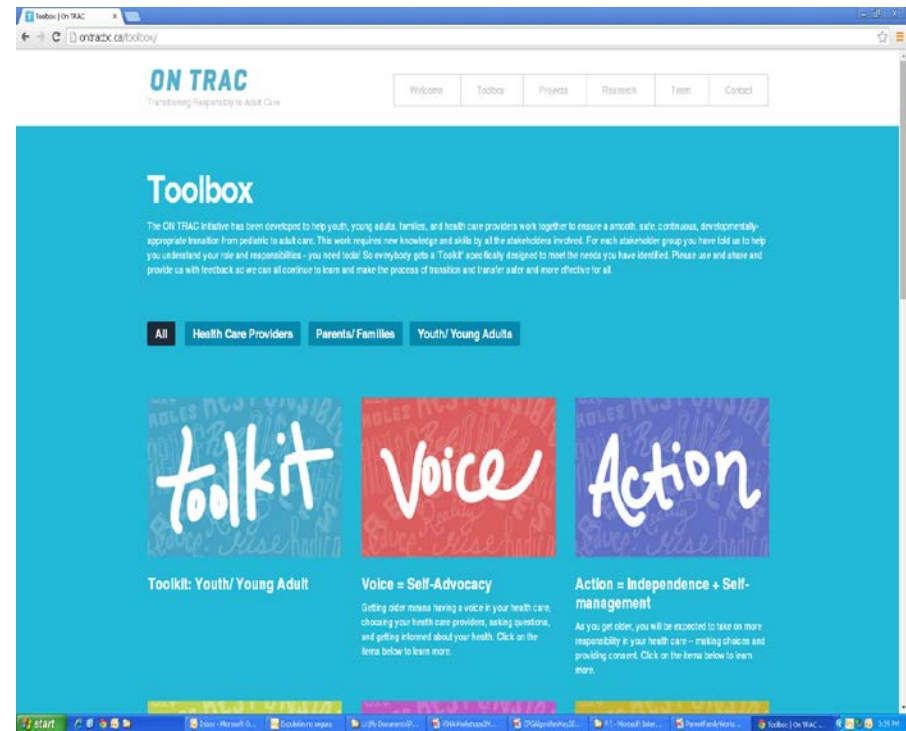
Position Wrap Text Bring Forward Send Backward Selection Pane

Topic	Content
Condition Specific Information	<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>
Major Events	<ul style="list-style-type: none"> <li>Birth History</li> <li>Date, event, outcome and plan</li> </ul>
Medications	<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>
Results	<ul style="list-style-type: none"> <li>Most recent lab work and imaging with important trends</li> </ul>
**Alerts	<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>
Immunizations	<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>
**Psychosocial/ Special Considerations	<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>
**Overview/Plan	<ul style="list-style-type: none"> <li>Flag restrictions: activity/ work</li> <li>Youth strengths/concerns for discharge/transfer</li> </ul>
Anticipatory Guidance and Recommendations for Future Care	<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>
Transfer of Specialty Care	<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.





# YOUTH QUIZ

## I AM #ONTRAC

PUT A SYMBOL IN EACH BOX TO COMPLETE THE QUIZ



GOT IT!



NEEDS WORK

## connections

My family supports me in managing my health

I talk to my friend(s) about my problems or worries

I keep myself safe by telling someone if I am being bullied in person and/or online

I talk to others if feeling sad, depressed, anxious, hopeless or difficulty sleeping

I participate in clubs, groups, sports or activities

## Voice

I ask health care providers questions about my health at my visits

I meet with my health care providers on my own

I can describe my health condition to others

When my symptoms are getting worse I contact the clinic for help

I have a family doctor

I can get to my clinic appointments on my own

I know what my long-term health problems might be

I know what patient confidentiality means

I understand the risks and benefits of health care treatments before consenting

## Action

I know the side effects of the medications I take

I know the names of my medications

I know what each of my medications are for

I take my medications on my own

I know how to fill my own medication(s) prescriptions

I visit my family doctor when I need to (for example: to have check-ups, get birth control, or if I have the flu)

## Sexual Health

I know how to prevent sexual health risks such as pregnancy and sexually transmitted infections (STIs)

I know how my condition might affect my sexual health

## Safety

I participate in activities/exercise to stay healthy

I know how my health condition affects my physical activities

I know how alcohol, drugs, and tobacco can affect my medications

I know if I have any driving restrictions

## Grad

I know who my adult team (FP and adult specialist(s)) will be

I know how to get my medical records

## MY NOTES & QUESTIONS

**ON TRAC**  
ONTRACBC.CA

TRANSITIONING RESPONSIBLY  
TO ADULT CARE



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

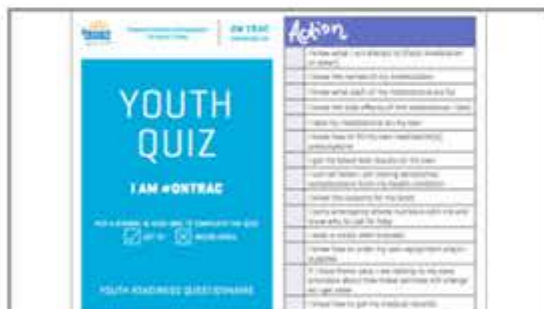
Projects

Research +

## Youth Toolbox

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

## Tools



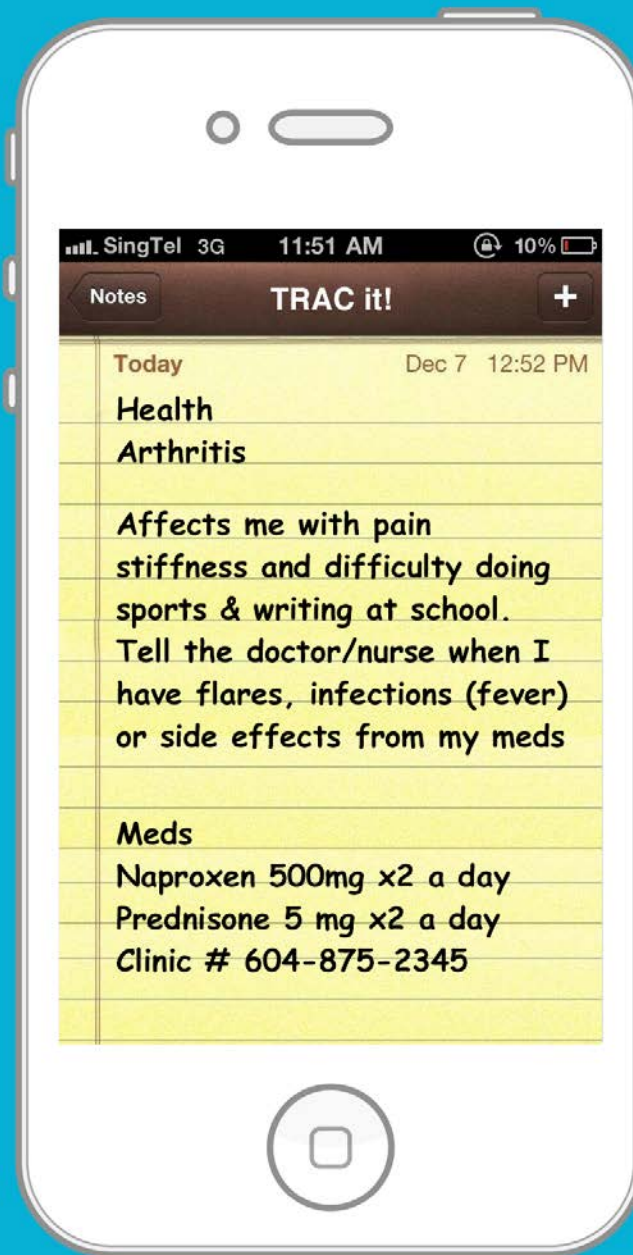


# Youth Strategy - Just TRAC It!

- 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”.