BC KIDNEY DAYS

Getting Youth and Young Adults ON TRAC

Presenters:
Dr. Sandy Whitehouse
Bryn Williams
Mary Paone RN MSN
“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
ON TRAC is a Province-wide Multifocal Initiative

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.
## Pediatric & Adult Specialty Care
### Two Different Cultures

<table>
<thead>
<tr>
<th>PEDIATRIC</th>
<th>ADULT</th>
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<tbody>
<tr>
<td>Family focused</td>
<td>Client-centered</td>
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<td>Parental involvement</td>
<td>Autonomy</td>
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<td>Consent</td>
<td>Access to information</td>
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<tr>
<td>Multidisciplinary</td>
<td>Referral based</td>
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<td>Developmentally oriented</td>
<td>Single physician</td>
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<td>Long term complications</td>
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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

COMMUNITY-BASED SERVICES

TRANSFER OF CARE
PRIMARY CARE
COMMUNITY CARE SERVICES

CLINICAL PATHWAY
ONLINE RESOURCES
EDUCATION & TRAINING

CLINICAL CARE

PERSONAL HEALTH RECORD

PATIENT NAVIGATION

RESEARCH

PEDiatric TRANSITIONAL CARE

YOUNG Adult TRANSITIONAL CARE

POLICY

(ADAPTION FROM SAWYER & KENNEDY, 2008)
Closing the Gap
Youth Transitioning to Adult Care in BC

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

A Policy Paper by BC’s Physicians December 2012

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

Too challenging to succeed

Too important to ignore

Collaboration

Content

Information

Data

Too realistic to expect

Roles

Research

Rich

Regions

Growth

DATA

WORK LOAD

PROCESS

STRATEGY

TOOLS

RESOURCES

ENGAGEMENT

TOO

CHALLENGING

TO

SUCCEED
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

**SYSTEM DRIVERS**

- Policy
- Data collection
- Evaluation
- Collaboration Integration Accountability between Health Care Services
- Resources for Providers & Youth/Families
- Education / Skill Building
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).
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 ______/____/______

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
Phone
Frequency of visits
Address
For what?

Adult Specialist
Phone
Date of First Visit
Address

Recommended Tests (How often?)

Youth’s strengths and concerns on Transfer:

<table>
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<tr>
<th>Self-Advocacy</th>
<th>Early 12-14 yrs</th>
<th>Middle 15-16 yrs</th>
<th>Transfer 17-18 yrs</th>
<th>Adult Care 19-24 yrs</th>
<th>COMMENTS</th>
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<td>Comes to each visit with a question</td>
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<td>Practices meeting with practitioners on own</td>
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<td>Knows name and can describe condition</td>
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<td>Describes emergency plan – who to call for what and what to say</td>
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<td>Knows who to see for what – Family Physician vs Specialist</td>
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<td><strong>Confirms visit Family Physician at least once a year</strong></td>
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<td>Aware of possible future health and late effects of condition</td>
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<th>Independent Behaviours / Self-management</th>
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<td>Aware of possible future health and late effects of condition</td>
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<td><strong>Independent Behaviours / Self-management</strong></td>
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<td>Knows allergies to medications, food &amp; other</td>
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<td>Can name medications, how taken, reasons for them and side effects</td>
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<td>Knows when and how to fill own prescriptions</td>
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<td>Knows dietary restrictions or supplements and reasons for them</td>
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<td>Knows how to access blood/test results</td>
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<td>Knows reasons for tests and understands results</td>
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<td>Knows how, when, why getting sick</td>
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<td>Carries care card &amp; emergency numbers in wallet/purse/on phone</td>
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<td>Knows dialysis prescription, reasons for it, and when to call for adjustments (if applicable)</td>
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<td>Knows how to order/net equipment/supplies</td>
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<td>Topic</td>
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<td><strong>Condition Specific Information</strong></td>
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<td><strong>Major Events</strong></td>
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<td><strong>Medications</strong></td>
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<td>**<strong>Alerts</strong></td>
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<td><strong>Immunizations</strong></td>
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<td>****Psychosocial/Special Considerations</td>
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<td>**<strong>Overview/Plan</strong></td>
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<td><strong>Anticipatory Guidance and Recommendations for Future Care</strong></td>
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<td><strong>Transfer of Specialty Care</strong></td>
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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.
**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.

**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.

**Future Planning**
- I think about what I would like to do after high school.
- I know how my health condition might limit my career choices.
- I have a Social Insurance Number (SIN) and Fair Pharmacare.

**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).

**Grad**
- I know who my adult team (FP and adult specialist(s)) will be.
- I know how to get my medical records.
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
Explore the Tools and Resource Cards created to help you make a continuous, safe, and smooth transition to adult care.

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?
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”.