**Supplementary Material:**

|  |  |  |
| --- | --- | --- |
| **Table S1 - Importance of transition**  |  |  |
|   | # Of respondents (total n=77)  | Percentage |
| Importance of transition: |   |   |
| Very important | 48 | 62.3% |
| Moderately important (but important enough) | 27 | 35.1% |
| Little importance  | 2 | 2.6% |

|  |  |  |
| --- | --- | --- |
| **Table S2 - Age to begin and complete transition** |  |  |
|  | # Of respondents  | Percentage |
| Age to begin transition (n=76): |   |   |
| 12 | 2 | 2.6% |
| 13 | 3 | 3.9% |
| 14 | 1 | 1.3% |
| 15 | 14 | 18.2% |
| 16 | 31 | 40.1% |
| 17 | 5 | 6.6% |
| 18 | 20 | 26.3% |
| Mean Age  | 16 (16.2) SD = 1.46 |   |
| Age to complete transition (n=75) |   |   |
| 16 | 8 | 10.1% |
| 17 | 15 | 20 % |
| 18 | 12 | 16% |
| 19 | 35 | 46.7 % |
| 20 | 5 | 6.7% |
| Mean Age | 18 (18.2) SD = 1.16 |   |

|  |  |  |
| --- | --- | --- |
| **Table S3 - Factors important for successful transition**  |  |  |
|   | # Of respondents | Mean score (+/- SD)  |
| Patient's general knowledge of IBD including potential complications | 76 | 4.6 (0.72) |
| Patient's knowledge of his personal condition  | 76 | 4.6 (0.68) |
| Patient's knowing current treatment and previous treatments  | 76 | 4.7 (0.57) |
| Patient is in charge of preparing and taking their medication | 76 | 4.7 (0.56) |
| Patient knows the indication of his medication  | 76 | 4.3 (0.70) |
| Patient understands the impact of tobacco, alcohol and drugs on their condition | 76 | 4.5 (0.72) |
| Patient participates in the discussion during his RDV and communicates directly with the MD | 76 | 4.7 (0.70) |
| Patient goes alone to RDV  | 76 | 3.5 (1.06) |
| Patient makes his own RDV | 76 | 3.7 (0.96) |
| Patient can recognize when his disease is active and know who to contact  | 76 | 4.8 (0.43) |
| Patient will call a HCP himself if things are not going well | 76 | 4.3 (0.65) |
| Patient knows his insurance coverage situation  | 76 | 3.2 (1.03) |
| Patient knows the name of his GP and pharmacy | 76 | 4.0 (1.01) |
| Patient is able to talk about the impact of their illness on their personal life | 76 | 4.1 (0.75) |
| Patient is able to undergo a colonoscopy under sedation  | 74 | 4.2 (0.85) |
| Note: Linkert scale used (1 - not important, 4 - very important but not essential 5 - very important and essential) |  |
| RDV = appointment, SD - standard deviation |  |  |

|  |  |
| --- | --- |
| **Table S4 - Tools which could facilitate transition** |  |
|   | # Of Respondents (n=76) | Percentage  |
| Transition Program | 59 | 77.63% |
| Education Day (Patient/Family) | 36 | 47.37% |
| Education Day (Physicians) | 12 | 15.79% |
| Education Day (Residents) | 14 | 18.42% |
| Education Day (Nurses) | 14 | 18.42% |
| Transition Clinic | 25 | 32.89% |
| Chart Summary  | 58 | 76.32% |
| Copy of visit to referring MD | 24 | 31.58% |
| Internet Site | 20 | 26.32% |
| Brochures | 16 | 21.05% |
| Support Groups | 17 | 22.37% |
| Health Passport  | 26 | 34.21% |
| Check list pre RDV with adult GI | 41 | 53.95% |
| Readiness checklist | 31 | 40.79% |
| RDV = Rendez-vous = Visit  |  |  |

**Sondage TRACC**

**TRACC: Transition des patients atteints de Crohn et Colite Ulcéreuse**

Notre Priorité: Une transition réussie

**Identification:**

* Êtes-vous: Gastroentérologue Adulte □

 Pédiatrique □

 Résident en gastroentérologie : Adulte □

 Pédiatrie □

 Résident en médecine interne □

 Infirmière MII □ Membre REQUIEM □

* Votre milieu de pratique est:

 Centre hospitalier université □ Centre hospitalier □ Clinique uniquement □

* Faîtes vous partie du réseau TRACC? Oui □ Non □

 (Avez-vous accepté que votre nom figure sur le tableau TRACC? dernière révision été 2013)

* Vous travaillez depuis < 5 ans □

 5-10ans □

 > 10 ans □

 N/A □

**Questionnaire:**

1. Quel est l'importance d'une structure standardisée pour la transition des soins en MII du milieu pédiatrique à adulte?

 Très important □

 Modérément (Assez) important □

 Peu important □

 Pas important □

1. Pensez-vous que la transition a un impact futur sur la maladie du patient? (rémission, réactivation, visite à l'urgence)

 Oui □ Non □

1. Selon vous, quel est l'âge approprié pour initier la transition et pour le transfert des patients avec MII?

Initiation de la transition

 12ans □ 13ans □ 15ans □ 16ans □ 18ans □

 Compléter le transfert

 16ans □ 17ans □ 19ans □ 20ans □

1. Actuellement, pensez-vous que les patients référés ont eu une préparation adéquate pré transition? Oui □ Non □
2. Si selon vous la préparation des patients est inadéquate, identifiez les domaines?

 Connaissances □ Maturité □ Indépendance (défendre ses intérêts) □ Autres \_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Selon vous, quelle est l'importance des facteurs cités ci-bas pour une transition réussie?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 1pas important | 2 légèrement important | 3modérément important | 4très important mais pas essentiel | 5très important et essentiel |
| 6\_1. Patient connaît de façon générale ce qu'est une MII incluant les complications potentielles |  |  |  |  |  |
| 6\_2. Patient connaît sa condition personnelle (site de l'atteinte, date du dx, chx ant., manifestations extra articulaires) |  |  |  |  |  |
| 6\_3. Patient connaît son traitement et ses traitements antérieurs de même que les effets secondaires (capable de nommer sa médication: actuelle, passée & effets secondaires) |  |  |  |  |  |
| 6\_4. Patient en charge de préparer et prendre sa médication |  |  |  |  |  |
| 6\_5. Patient connaît les indications de sa médication |  |  |  |  |  |
| 6\_6. Patient comprend l'impact du tabac, de l'alcool et des drogues sur sa condition |  |  |  |  |  |
| 6\_7. Patient participe à la discussion durant son RDV et communique directement avec le médecin |  |  |  |  |  |
| 6\_8. Patient va à son RDV seul |  |  |  |  |  |
| 6\_9. Patient prend son RDV seul |  |  |  |  |  |
| 6\_10. Patient peut reconnaître lorsque la maladie se réactive et sait avec qui communiquer |  |  |  |  |  |
| 6\_11. Patient appelle lui-même l'infirmière MII ou le médecin si ne va pas bien |  |  |  |  |  |
| 6\_12. Patient connaît sa couverture d'assurance médicaments |  |  |  |  |  |
| 6\_13. Patient connaît le nom de son médecin de famille et sa pharmacie |  |  |  |  |  |
| 6\_14. Patient capable de parler de l'impact de sa maladie sur sa vie sexuelle, santé globale et vie sociale |  |  |  |  |  |
| 6\_15. Patient capable de subir une coloscopie sous sédation |  |  |  |  |  |

1. Recevez-vous assez d'informations pré 1er RDV transition de la part du gastroentérologue pédiatrique? Oui □ Non □
2. Préférez-vous recevoir le résumé : Au moment de la 1ère visite □ Avant la 1ère visite □
3. De quelle façon préférez-vous recevoir le résumé?

Courriel □ Fax □ Poste régulière □

1. Quels éléments clés devraient figurer dans le résumé de dossier? Cochez tous les éléments que vous jugez importants.

10\_1. Date du diagnostic\_\_\_\_\_ 10\_2. Chirurgie(s) antérieure(s)\_\_\_\_\_\_ 10\_3.Site de l'atteinte\_\_\_\_\_\_

10\_4. Histoire familiale\_\_\_\_\_\_ 10\_5. Autres diagnostics\_\_\_\_\_\_ 10\_6. Histoire sociale\_\_\_\_\_\_

10\_7. Allergies\_\_\_\_\_\_ 10\_8. Investigations antérieures\_\_\_\_\_\_ 10\_9. Liste Rx & effects secondaires\_\_\_\_\_ 10\_10. Immunisations\_\_\_\_\_\_ 10\_11. Le degré de scolarisation\_\_\_\_\_\_

10\_12. Voudriez-vous  d'autres renseignements et si oui lequels? \_\_\_\_\_\_\_\_\_\_\_

1. Parmi les outils listés ci-bas, lesquels jugez-vous prioritaires pour améliorer la transition et que vous aimeriez que le réseau TRACC mette en place?

 11\_1. Programme de transition □

 11\_2. Journée éducation: Patient/Famille □

 M.D. □

 Résidents □

 Infirmières □

 11\_3. Cliniques de transition □

 11\_4. Résumé de dossier type □

 11\_5. Copie de la rencontre au M.D. référant □

 11\_6. Contact téléphonique avec le patient: Pré 1ère visite □

 Post 1ère visite □

 11\_7. Modifier la durée du RDV: Dernier en pédiatrie □

 Premier en adulte □

 11\_8. Élaborer des plans de transition individuels □

 11\_9. Site internet □

 11\_10. Brochures □

 11\_11. Projets de recherche spécifiques à la transition □

 11\_12. Groupes de support □

 11\_13. Passeport santé □

 11\_14. 'Check-lists' pré RDV en adulte □

 11\_15. 'Check-lists' pour préparer les patients (readiness checklists) □

 11\_16. Quel est l'outil le plus important à développer selon vous? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 11\_17. Autres suggestions d'outils? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Trouvez-vous votre formation adéquate pour prendre en charge cette clientèle?

 Oui □ Non □

1. Désireriez-vous une formation spécifique pour la transition? Oui □ Non □

 Sous forme: D'ateliers □ Conférences □

1. Avez-vous suffisamment de ressources dans votre milieu pour accueillir cette clientèle (administratif/infirmière)?

Oui □ Non □

1. Listez les 3 obstacles principaux à une transition réussie au Québec.

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

1. Est-ce que les patients viennent à leur 1ère rencontre avec leurs parents? Oui □ Non □
2. Acceptez-vous la présence des parents lors de la 1ère rencontre? Oui □ Non □
3. Acceptez-vous la présence des parents lors du suivi? Oui □ Non □
4. What is the importance of a standardized framework for the transition of care from the paediatric IBD domain to the adult world

 Very important □4

 Moderately important □3

 Of little importance □2

 Not important □1

1. Do you think that the transition has a future impact on the patient's disease? Yes □ No □
2. What do you think is the appropriate age to initiate the transition and complete the transfer of care in patients with IBD?

Initiation of the transition: 12 □ 13 □ 15 □ 16 □ 18 □

Complete the transfer: 16 □ 17 □ 19 □ 20 □

1. Currently, do you think that patients referred are adequately prepared pre transition? Yes □ No □
2. If you think preparation is inadequate identify the areas?

Knowledge □ : Maturity □ : Independence □ : Others \_\_\_\_\_\_\_\_\_\_\_\_

1. What do you think is the importance of the below mentioned factors for a successful transition?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 1Not important | 2 Slightly important | 3Moderately important | 4Very important, but not essential | 5Very important and essential  |
| 6\_1. Patient knows generally what IBD is including potential complications |  |  |  |  |  |
| 6\_2. Patient knows his personal condition (site of the breach , the date of dx, previous surgeries…, Extra articular manifestations ) |  |  |  |  |  |
| 6\_3. Patient knows his current and previous treatments as well as side effects ( able to name his medication : present , past & side effects) |  |  |  |  |  |
| 6\_4. Patient is in charge of preparing and taking their medications |  |  |  |  |  |
| 6\_5. Patient known the indication for his medication |  |  |  |  |  |
| 6\_6. Patient knows the impact cigarettes, drugs and alcohol have on their condition |  |  |  |  |  |
| 6\_7. Patient participe à la discussion durant son RDV et communique directement avec le médecin |  |  |  |  |  |
| 6\_8. Patient goes to visit themselves |  |  |  |  |  |
| 6\_9. Patient arranges follow up themselves |  |  |  |  |  |
| 6\_10. Patient can recognize when the disease reactivates and know who to contact |  |  |  |  |  |
| 6\_11. Patient calls himself the nurse or doctor if his IBD symptoms are not well |  |  |  |  |  |
| 6\_12. Patient knows his prescription drug insurance coverage |  |  |  |  |  |
| 6\_13. Patient knows the name of his family doctor and pharmacy |  |  |  |  |  |
| 6\_14. Patient able to talk about the impact of their illness on their sex life , overall health and social life |  |  |  |  |  |
| 6\_15. Patient able to have a colonoscopy under sedation |  |  |  |  |  |

1. Are you getting enough pre 1st first transition visit information from the pediatric gastroenterologist Yes □ No □
2. When would you rather get the information / summary: At the 1st visit □  Before the 1st visit □
3. How would you prefer to obtain the summary? E-mail □ Fax □ Regular mail □
4. What key elements should be included in the summary file? Check all that you think are important:

10\_1. Date of diagnosis \_\_\_\_ 10\_2. Previous surgery(ies) \_\_\_\_ 10\_3.Affected site \_\_\_\_

10\_4. Family history \_\_\_\_ 10\_5. Other diagnosis \_\_\_\_ 10\_6. Social history \_\_\_\_

10\_7. Allergies \_\_\_\_ 10\_8. Previous investigations \_\_\_\_ 10\_9. List of treatments and their secondary effects \_\_\_\_

10\_10. Immunizations ­ \_\_\_\_ 10\_11. Level of education \_\_\_\_

10\_12. Would you like more information, if so specify?

1. Among the tools listed below, which do you think are the priorities for improving the transition and which ones would you like the TRACC network to set up?

 11\_1. Transition program □

 11\_2. Day of education  for: Patient /Family □ , M.D. □ , Residents □, Nurses □

 11\_3. Transition clinic □

 11\_4. Chart summary □

 11\_5. Copie de la rencontre au M.D. référant □

 11\_6. Telephone contact with the patient

Pre 1st visit □ : Post 1st visit □

 11\_7. Modify the time of the appointment :

Last peds visit □ , First adult visit □

 11\_8. Develop individual transition plans □

 11\_9. Internet site □

11\_10. Brochures □

 11\_11. Research projects specific to transition in IBD □

 11\_12. Support groups □

 11\_13. Health passport □

 11\_14. 'Check-lists' pre 1st adult GI visit □

 11\_15. 'Check-lists' to prepare the patient (readiness checklists □

 11\_16 In your opinion which of these tools is the most important to develop / implement?

11\_17. Other suggestions?

1. Do you find your training adequate to support this clientele? Yes □ No □
2. Would you want specific training focusing on this transition? Yes □ No □

Which form of tarining: Wokshops □ Conferences □

1. Do you have enough resources in your community to welcome this client? Yes □ No □
2. List the three main obstacles to a successful transition in Quebec:
3. Do patients come to their first meeting with their parents? Yes □ No □
4. Do you accept the presence of parents at the first meeting? Yes □ No □
5. Do you accept the presence of parents at follow-up? Yes □ No □