

Name: _____ Date of birth: ___/___/___ Questionnaire completion date: ___/___/___ (TRANS-IBD # _____)

Information sheet

TRANS-IBD visit 1.

(for all patients of the TRANS-IBD study)

Patient communication during the visits of the intervention period should be coordinated according to the corresponding information sheets that were prepared based on the NASPGHAN checklist. In the control group, the information is provided by the pediatrician alone, while in the intervention group the pediatric and the adult gastroenterologist supply information together.

Basic viewpoints that should be considered by the medical team during the transitional visit:

- Encourage the patient's independency by performing some part of the examination with the parents or guardians outside of the examining room and encourage them to visit the office without parents or guardians in the future.
- Always focus on the patient instead of the parents or guardians when providing any information or explanation and offer the patient and not the parent, to choose between different options in order to increasingly involve the adolescent in decision-making.
- Encourage the patient to set specific IBD related goals including filling prescriptions, scheduling new appointments, keeping a list of medications and medical team contact information in wallet and establishing a transition plan together.
- Devote time to discuss a couple of questions with respect to the patient's medical history (including the date of the diagnosis, the affected parts of the GI tract, the previously applied medicines, the experienced side effects, previous surgeries) and with respect to the patient's actual medical treatment (names, doses, purposes, side effects of the currently taken IBD drugs and their possible interactions with other medications).
- Spend some time to discuss the effects of smoking, drug and alcohol consumption on health in general and their effect on IBD symptoms and highlight the importance of healthy lifestyle (eating habits, doing sports regularly).
- Spend some time to discuss sexuality in general (including means of contraception, possible side effects of contraceptive pill) and the effect of IBD and IBD related drugs on fertility.

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As a part of the patient education, the following topics should be discussed with the participant during the transition visit:

- Causes, nature, symptoms, course and the possible complications of IBD
- Features and the way of administration of the different IBD related medications including 5-ASA, immunosuppressants, local and systemic steroids, exclusive enteral nutrition (EEN), biological treatment, therapeutic steps according to the severity of the disease
- Specific situations and disease related complications when surgical treatment is inevitable (severe therapy-resistant disease, severe intestinal stenosis, perforation, severe gastrointestinal bleeding, fistulas, premalignant or malignant lesions)
- Names and purposes of the diagnostic tests that are done (including physical examination, blood tests, stool tests, images, endoscopies)
- Consequences of medical nonadherence, triggers that can cause IBD flare-up, and a 'to do list' when symptoms worsen

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TRANS-IBD visit 2.

(for all patients of the TRANS-IBD study)

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Basic viewpoints that should be considered by the medical team during the transitional visit:

- Encourage the patient's independency by performing some part of the examination with the parents or guardians outside of the examining room and encourage them to visit the office without parents or guardians in the future.
- Always focus on the patient instead of the parents or guardians when providing any information or explanation and offer the patient and not the parent, to choose between different options in order to increasingly involve the adolescent in decision-making.
- Encourage the patient to set specific IBD related goals including filling prescriptions, scheduling new appointments, keeping a list of medications and medical team contact information in wallet and establishing a transition plan together.
- Devote time to discuss a couple of questions with respect to the patient's medical history (including the date of the diagnosis, the affected parts of the GI tract, the previously applied medicines, the experienced side effects, previous surgeries) and with respect to the patient's actual medical treatment (names, doses, purposes, side effects of the currently taken IBD drugs and their possible interactions with other medications).
- Spend some time to discuss the effects of smoking, drug and alcohol consumption on health in general and their effect on IBD symptoms and highlight the importance of healthy lifestyle (eating habits, doing sports regularly)
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As a part of the patient education, the following topics should be discussed with the participant during the transition visit:

- The members of the health care provider medical team, their concrete roles and responsibilities during the care of the patient
- Specific platforms, sources and online pages where the patient can get more information about IBD, potential IBD patient clubs to which the patient can join
- Procedures and examinations which are covered by the insurance and those which are only available against payment
- The importance of being able to manage IBD related medical tasks independently outside home (school, work) and in healthcare (schedule own appointments, refill prescriptions, contact medical team)
- Encourage the patients to develop specific plans for self-management outside home (work/school)

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TRANS-IBD visit 3.

(for all patients of the TRANS-IBD study)

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Basic viewpoints that should be considered by the medical team during the transitional visit:

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As a part of the patient education, the following topics should be discussed with the participant during the transition visit:

- The essence of the transition process, the importance of having a well- designed transition plan, the significance of choosing the right time for transfer
- The importance of having a specific IBD centre and a medical team (medical home), which is able to manage the patient's acute IBD related problems or complications (at every day of the week and 24 hours a day) and also able to provide health care on the long term (including preventive care as well)
- Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition, remind patient that he/she has the right to make his/ her own health choices after the age of 18
- Prepare the parents for the adolescent's evolving independent status and address any anxiety they may have with respect to this issue
- Future education and working plan, and their reconciliation with IBD

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TRANS-IBD visit 4.

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As a part of the patient education, the following topics should be discussed with the participant during the transition visit:

- Differences between the child and the adult health care system
- The importance of having a good, fiduciary relationship with the future adult gastroenterologist (AGE) and the importance of having good relationship with family members, friends, schoolmates or colleagues (social network)
- Provide the patient with a final medical report document (including the patient's whole medical history) that should be taken to the AGE by the patient at transfer
- Provide information on the AGE who is willing to take the patient into adult health care
- Ensure the continuity of health care by making the first appointment with the AGE for the patient

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