

DELIVERABLE D.T3.2.9

PP8 KUM - Implementation and testing of
new service to improve transition from
paediatric to adult health care

Version 1
02 2019





INTRODUCTION

Implementation and testing of new service to improve transition from paediatric to adult health care

This pilot project has been developed by the project partner Klinikum der Universität München (PP8 KUM), mainly in cooperation with its collaborating interdisciplinary social pediatric center (iSPZ), supported by the German Celiac Disease Society (DZG).

The main aim of the project was to develop a strategy to prepare adolescents with celiac disease to take care of their gluten-free diet and their health independently of their parents, to realize and take over their own responsibility for the management of their disease. Furthermore, it was important to make them aware that they in case of non-compliance, they may risk severe long-term complications but on the other hand can live a healthy life if they stick to the gluten-free diet as the still nowadays only available but efficient therapy. As this means a substantial, psychosocial burden for many patients particularly in adolescence when they do not want to be different from their peers and “belong” to a group, it was also an important issue to take care of the psychosocial aspects of the disease and the life-long, strict diet.

In addition, parents of children with a chronic disease tend to be over-protective and hinder the process of becoming a self-reliant, responsible personality.

Therefore we aimed to also involve the parents and raise the awareness that it's necessary to allow their children learning their own way and making their own mistakes, but supporting them in becoming self-reliant.

To do so, we could build on existing experience from other transition programmes but also our experience in treating patients with celiac disease and being involved in many celiac projects, knowing about all aspects and problems that patients and particularly adolescents may face.

We planned a celiac transition programme comprising three steps:

- 1) Individual consultations at the interdisciplinary, social pediatric center (iSPZ) - preferably before and if needed also after the workshop.
- 2) The transition workshop for adolescents with celiac disease and in parallel a similar but separate workshop addressed to their parents
- 3) The development of a new, up-to-date celiac passport to document the and the monitoring visits in order to allow the young patients to be prepared for the future when seeing other doctors which may not be so familiar with celiac disease and in order to avoid any doubts about the initial diagnosis. This passport is also meant to be disseminated in the whole German project area.

To disseminate our outputs, we are collaborating with the German Celiac Disease Society (DZG) and with the German Pediatric Gastroenterology and Nutrition society (GPGE).



DELIVERABLE D.T3.1.1 REPORT ABOUT PILOT PROJECT IDEAS & ESTABLISHED STAKEHOLDER GROUPS

Pilot project Start-up description template

Version 1
02 2017



1. Pilot Background

Please describe here the background of your pilot in terms of ideas, preliminary actions, plans defined earlier and methods already chosen, etc. Some of the aspects you can tell about are as follows:

Project: „Implementation and testing of new service to improve transition from paediatric to adult health care”

- Transition from childhood to adulthood means that we have to consider the physical, mental and psychosocial development of the growing adolescent
 - In this sensitive phase, the focus has to be set both on the adolescent patient and the family
 - Adolescents need to gradually take over responsibility
 - Challenges in adolescence:
 - Desired affiliation to peer group may decrease compliance
 - Overprotection of parents may hinder autonomy
 - Emotional and physical changes
- It is known that the transition from pediatric to adult care is often a challenge for the adolescent patients. Many of them are lost and do not consult a doctor after having left pediatric care. This may result in long-term health consequences if the compliance to the diet is not monitored and dietary mistakes are undetected, leading to co-morbidities as e.g. osteoporosis and bone fractures later in life.
- For some the diagnostic process is even repeated as the original documents of their diagnosis are not taken into consideration.

Preliminary works and basis of the project

- Celiac disease passport of the German Celiac Disease Society: this is already a good basis but we will have to adapt several issues and find a format for the paper-print that will be sustainable (similar to vaccination passport but even more durable)
- Already existing transition programmes which have been developed respectively adapted for other diseases will serve as a basis for our celiac transition programme



Our objectives - we aim to...

- ...raise the overall knowledge about CeD among young patients (pre-/pubertal age)
- ...promote self-empowerment of the patients already in early adolescence
- ...allow a smooth transition with detailed documented diagnosis to adult care
- ...improve overall adherence during adolescence
- ...reduce unnecessary long-term burden for patients and costs for health care system by avoiding uncontrolled CeD

Available knowledge - literature and references

- Ludvigsson JF, et al. Transition from childhood to adulthood in coeliac disease: the Prague consensus report. Gut 2016;65:1242-1251
- Barnea L. et al. Pediatric Celiac Disease Patients Who Are Lost to Follow-Up Have a Poorly Controlled Disease Digestion 2014;90:248-253
- O'Leary C et al. Celiac disease and the transition from childhood to adulthood - a 28yrs follow-up. Am J Gastroenterol 2004;99:2437-2441
- <http://www.transitionsmedizin.de>
- <https://www.kompetenznetz-patientenschulung.de/modus-transitionsschulung/>

Anticipated methods:

- Close cooperation with stakeholder (discuss planned measures, involve their experience and input in the development of the measures)
- Develop / adapt the celiac disease passport with all diagnostic data of celiac disease
- Develop a transition work-shop which is addressed to the adolescent patients. Our work-shop will be based on already tested transition programmes (e.g. ModuS Transitions Schulung) which have already been used for years in other diseases
- Evaluate the measures and adapt them if necessary, also in cooperation with the stakeholders
- Provide a final transition programme which may be used in other pediatric GI settings.



2. Pilot Objectives

Please describe here the objectives of your pilot in terms of what the pilot project plans to achieve at the project's end and by what means. Some of the aspects you can tell about are as follows:

- **What are the main outputs of the pilot project (service, process, new management approach, new knowledge...)**
 - Develop a detailed programme:
 - Identify major issues and challenges of transition into adulthood: close contact and discussions with all stakeholders (see below)
 - Adaption and implementation of the „celiac passport“ in our clinical practice to provide a summary document of the diagnosis including all relevant laboratory values and other medical data
 - Establish a structured transition of patients to adult care also in cooperation with our adult gastroenterology unit:
 - Develop and perform a work-shop for adolescents with CeD
 - Discussions: what are your experiences, expectations, feelings, worries?
 - Educational parts: general health aspects, diet, long-term effects if diet is not followed, potential co-morbidities (need for screening)
 - Legal issues
 - Reliable sources of information
 - Emphasize and enhance self-empowerment (responsibility and organization)
 - Evaluate all conducted measures and implement them in our clinical practice.
- **What is the approach that makes the project viable and sustainable?**
 - Disseminate our transition programme:
 - to other pediatric GI units (cross-regional impact; mainly by involving GPGE)
 - directly to the target group by other stakeholders (DZG, GPGE, Deutsche Gesellschaft für Transitionsmedizin, Kompetenznetz Patientenschulung, health insurances)
- **What kind of problems are you anticipating and what are your "plan B"-s if something doesn't turn out as you counted in certain situations?**

Due to logistic and personnel challenges, the currently planned collaboration with our adult gastroenterology unit may not run as smoothly as necessary, particularly as the chief of the department is changing. In this case we may have to involve the general practitioners of the participating children, but to a lesser extent as we now aim to involve the adult gastroenterology unit.



■ Any other aspects you find important?

Our main aim is to provide the adolescent patients all tools they need to live their life with celiac disease very well, reducing restrictions in their daily life but to “teach” them how important the dietary compliance is.

To do say, we focus on self-empowerment and raising awareness that they can learn to be their own advocates and that they need to handle their disease independent from their parents.

In order to keep them interested and involved, we aim to do all this in a playful and interactive way in order to raise their attention and interest in this important topic.

3. Partnership

Please describe your stakeholders and their roles in the pilot project. Insert rows according to your needs.

Name	Specialization Area	Role in Project	Motivation / Benefits
<i>If you plan to include a certain type of stakeholder but you don't yet know the specific organization, write "[TBD]" (to be determined) in this column.</i>	<i>Healthcare professional / patient / presentative of NGO / policy maker...</i>	<i>Participating in development phase / participating in testing, communication, evaluation etc.</i>	<i>What is the main motivation of the organization to participate in the pilot project? What will be their anticipated benefits?</i>
Stakeholders (planned): <ul style="list-style-type: none"> • <i>Social pediatric center (collaborator of KUM / Dr. of Hauner children's hospital)</i> • <i>Adult gastroenterology unit of KUM</i> • <i>German CeD society (DZG)</i> • <i>German PedGI society (GPGE)</i> • <i>German Society for transition medicine (DGfTM)</i> • <i>Public health insurances (for dissemination)</i> 			



4. Business Model Canvas

Please summarize your project plan and approach model described above in this table. Write bullet points in each cell of the table

Key pilot Partners	Key Activities	Value Proposition of the pilot (what is the benefit ?)	End-user (patient) Relationships	End-user (patient) Segments
<ul style="list-style-type: none"> • <i>Social pediatric center (collaborator of KUM / Dr. of Hauner children's hospital)</i> • <i>Adult gastroenterology unit of KUM</i> • <i>German CeD society (DZG)</i> • <i>German PedGI society (GPGE)</i> • <i>German Society for transition medicine (DGfTM) and Kompetenznetz Patientenschulungen</i> 	<ol style="list-style-type: none"> 1. Gathering data 2. Model/method 3. Promotion and raising awareness 4. Evaluation 5. Testing 	<ul style="list-style-type: none"> - The existing celiac disease passport which was developed by the German Celiac disease Society (DZG) will be adapted and implemented to be used in clinical practice. This will allow the diagnosed children to always have a proof of their diagnosis and to avoid any additional and unnecessary gluten challenges or uncertainties about their diagnosis. It will serve as reliable document for later treatment in adult care. - The transition work-shop will invite (pre)pubertal celiac disease patients and “teach” them in a playful and interactive way about their disease and all aspects as compliance with the diet but also socioeconomic and sociopsychological issues as job choice, rights and how to deal with the stigmata of gluten-free diet 	<p>Self-service, support and self-empowerment; development of independence from parents</p> <p>Co-creation process with end-users: the participants in the transition programme and also their parents will be asked for their evaluation and input</p>	<p>(pre)pubertal patients with celiac disease</p>
	<p>Key Resources</p> <ol style="list-style-type: none"> 1. Human 2. Financial 		<p>Communication channels ?</p> <ul style="list-style-type: none"> - personal contact - social media - work-shop - train the caring physicians (indirect communication) to support self-empowerment and independence of the young patients 	



<p>Cost Structure</p> <p>Pilot development coordination costs:</p> <p>We currently estimate costs of about 70 to 75,000 Eur</p> <p>Maintenance costs / later after the project will end</p> <ul style="list-style-type: none"> - Approximately 2000 Eur/Year for external services (gluten-free catering at work-shops; printing of materials etc.) - Approximately 8000 Eur/Year for staff costs (all together about 1.5 person months (6 weeks), involving doctor (1week), psychologist (2weeks), nurse (1 week), organization staff (2 weeks) - In total approximately 10.000 Eur / year 	<p>Revenue Streams</p> <p>This will depend on stakeholder's capacities.</p>
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5. Preliminary work plan

Please give a time plan of how you plan to proceed with your pilot project. Define the main stages and milestones of the workflow. Insert rows according to your needs.

Phase Title & Description	Participating Stakeholders	Milestones	Planned Date
<i>Give the title and/or short description of the phase (identification process, focus group meeting, survey, testing... etc.).</i>	<i>According to the Partnership table above. You can write "All" if all of the stakeholders participate in the Phase.</i>	<i>Describe the milestone that you plan to achieve at the end of the phase</i>	<i>Planned date of milestone</i>
Preparation phase - contact and discussion with stakeholders, gathering information and planning of the details of the transition programme	all	Final and detailed programme for this transition pilot	May 2018
Adaption of the "celiac passport" of the DZG, evaluation of the new passport and implementation in our clinical practice	Celiac disease society (DZG) German PedGI society (GPGE)	Use of new "celiac passport" in clinical practice	July 2018
Conduction of transition work-shop with children with celiac disease including an evaluation (survey before and after)	Social pediatric center (iSPZ) Adult gastroenterology unit of KUM	Transition work-shop successfully completed	Sept 2018
Analysis of evaluation of the transition programme and adaption if necessary	Social pediatric center (iSPZ) Adult gastroenterology unit of KUM	Data analysis, interpretation and final transition programme	Nov 2018
Reporting of pilot outcome	None	Report of deliverable D.T3.2.9	Dec 2018

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

Pilot status report 1

PP8 KUM - Implementation and testing of
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08 2018





1. Pilot Status According to Objectives defined in D.T3.1.1

- Short description, if pilot development activities are implemented according to objectives set-up in the framework of D.T3.1.1

Pilot development activities are implemented according to objectives set-up in the framework. The main outputs of the pilot project remain the same and are:

- 1) individual consultations of adolescent celiac patients at the interdisciplinary social-pediatric center (iSPZ) before and after the transition workshop
- 2) Workshop for adolescents and in parallel (separate room) their parents:
- 3) Celiac passport for definite documentation of the diagnosis and the follow-up/monitoring of celiac disease.

We anticipated following problems:

- In contrast to what has been promised, there were only very few free time slots for individual consultations (output 1) for of the adolescent patients at our collaborating iSPZ until the end of this year, due to limitation of staff.
- Therefore we decided to postpone the date of the workshop (output 2) until beginning of 2019 in order to be able to invite more participants and to allow them to get an appointment of the individual consultation at iSPZ before the workshop
- Regarding the development of the new celiac passport, we are still waiting for the finalisation of the new Celiac guidelines which are still being updated but were supposed to be published already end of 2017.

- *Did the development process contribute to any additional new objectives?*
No, we anticipated all objectives.

- *Did the team discover that any of initially set-up objective would not be reachable and please explain reasons/circumstances?*

We are currently in doubt if all adolescents will be able to get an individual appointment at the iSPZ due to the limited time slots and the problems that the adolescent patients are also very busy with school tasks etc. However, we are confident that we will be able



to get appointments for those adolescents who are really in need of getting an individual consultation.

2. Activities implemented so far

- Please provide short description of activities implemented so far and explain the progress in developing and testing of pilot solution
 - 1) Literature research: as reported earlier, we have done literature research and participated in a transition conference (Nov 2017)
 - 2) Preparations - Meetings with the iSPZ and external service providers:
 - a. Meeting 1: on 04.05.2018 PP8 KUM (KW and SK) with iSPZ (Dr. Kathrin Krohn) and discussed that we will need to involve a pediatric gastroenterologist, a dietitian with experience in CD and a psychologist with experience in chronically ill children. Furthermore, we discussed several options how to conduct the workshop and the administrative issues. We also discussed to involve the German CD society (DZG) actively in the workshop. In this meeting, we first discussed to split the workshop into 2 sessions of each 2-3 hours only, if possible on Saturdays.
 - b. Meeting 2: on 12.06.2018 PP8 KUM (KW and SK) met the stakeholder from KUM adult gastroenterology (PD Dr. Helga Török) and iSPZ (Dr. Kathrin Krohn). We discussed that active participation of KUM adult gastroenterology is not necessary, but that they will keep them up to date and refer our young adult patients to them in case there are severe problems related to celiac disease which a general physician cannot manage. Furthermore, we discussed the best strategy for the workshop and that the optimal time is a Friday afternoon as the patients usually do not have to attend school. It was also discussed again to schedule the workshop on a Saturday but we realized that administrative staff must be available to register the patients at the iSPZ and they are not willing to come into office on Saturdays. Furthermore, we realized that the willingness of the participants to come to 2 different occasions is probably low or it's difficult to organize, therefore we agreed to do the workshop at one date and 3,5 to 4 hours in total. In addition, we decided that for the pilot workshop we will register up to 15 patients and - if they wish to participate - also their parents who will get separate workshop classes in parallel to their children. We have also agreed that we will identify and include adolescent patients with celiac disease mainly between 14 and 17 yrs of age (exclusions may be made for 12 or 13 yr olds, depending on their individual situation)
 - c. Meeting 3 - scheduled: in Sept 2018, the project coordinator of PP8 (KW) will travel to Stuttgart to present and discuss the whole project and also particularly the pilot project with the German Celiac Disease society in person.
 - 3) Preparations - Staff and external services
 - a. We were investigating on potential experts for hiring as external service provider which will prepare the content of the different parts of the workshop: 1) a dietitian 2) a pediatric gastroenterologist working at iSPZ 3) a psychologist preferably working at iSPZ
 - b. We invited one of our physicians in training who has just been starting to work in our pediatric gastroenterology division to work few hours per week for the project (in addition



to her clinical job). Her main tasks will be to identify potential participants for the transition programme, to invite them to participate and explain the programme, to keep track who has already decided on the participation and submitted all necessary administrative documents and to support the PP8 Focus IN CD coordinator (KW) in revising any materials related to the pilot project

4) First steps

- a. We already got oral confirmation by the external service providers = referents for the workshop.
- b. As mentioned above, our initial plan was to schedule the workshop at end of October 2018 or beginning of Nov 2018. However, finally we decided to better postpone the date this until beginning of 2019 in order to allow the participants to get an individual consultation at the iSPZ before the workshop and to be able to invite more patients in person when they are coming for their regular monitoring visit (instead of calling them by phone). Due to schedule difficulties of all referents and organizers of the workshop, finally the 8th of Feb was identified as next possible date.
- c. In the following, we developed a flyer which will be available and distributed to all patients in our own inpatient clinic, at the iSPZ, by other pediatric gastroenterologist in private practice in Munich and surroundings and by the South-Bavarian CD society.
- d. Furthermore, we started to develop a first concept of the new and more extensive celiac disease passport. However, as the new Celiac Guidelines of the ESPGHAN working group is still not ready, we were not able to make substantial progress here, but already got some ideas how to improve its content and layout. We have already discussed the update of the celiac passport with the scientific advisor of the German CD society (Sofia Beisel) via phone and she was very supportive and told us that she considers it likely that DZG will support this, including revising our drafts and by disseminating the passports as soon as they are printed. However, we will have to wait for an official approval by the advisory board of the DZG.



3. Changes in stakeholder's partnership

No new stakeholder involved

STAKEHOLDERS NO LONGER PARTICIPATING

Name	Reason for leaving / not involving as planned
<p>German Society for transition medicine (DGfTM)</p>	<p>After internal discussions, we realized that it does not seem reasonable and to involve DGfTM as the previous experience of iSPZ with a collaboration was unfortunately not really helpful as their solutions were not tailored according to the relevant patient group /disease.</p>
<p>Public health insurances (for dissemination)</p>	<p>At this stage, as the future costs for continuing with the pilot project after the end of our project (= after 31st May 2019), we decided that it's not relevant to involve public health insurances but we of course plan to disseminate our outputs also to them.</p>

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

Pilot project Final Report

Version 1
03 2017





1. RESULTS ACHIEVED ACCORDINGLY TO OBJECTIVES

- Please review the objectives you have set up in your D.T3.1.1 description, in the Status report Phase 1 and describe activities and results achieved by your pilot. Give an overview of the processes that are part of your pilot project.

Our Pilot project “Transition from adolescence to adulthood” comprises 3 topics:

1) individual consultations of adolescent celiac patients at the interdisciplinary social-pediatric center (iSPZ) before and after the transition workshop (2):

- a. activities: we aimed to invite adolescent celiac patients of our pediatric gastroenterology outpatient clinic to participate in a transition programme and to consult the iSPZ for individual, medical, psychosocial and dietary advice (according to individual needs).
- b. Results: although many patients were interested to participate in the workshop, only few with a higher burden of the disease were acutally interested to also make an appointment for the individual consultation at the iSPZ. However, although only few patients were interested, it was not so easy to find appropriate time slots in a timely manner (also see 3. Deviations and problems). However, finally 4 of in total 22

2) Workshop for adolescents and in parallel (separate room) their parents:

- a. Activity: in order to prepare the adolescents with celiac disease to become independent of their parents and take care of their health and gluten-free diet on their own, we prepared a workshop with parallel sessions for both the adolescents and the parents. The workshop should allow and enhance the exchange among the adolescents, to share their experience, fears and problems. A gluten-free buffet was therefore planned to guarantee social exchange in an informal, relaxed atmosphere. The same applies for the parents who are often concerned if their children do not keep the diet as strictly as they should.
- b. Results: in total 26 adolescents with celiac disease were identified to be potentially eligible to participate (at least 12 years to maximum 17 years of age, no other interfering co-morbidities), thereof 13 refused to participate (6 due to scheduling conflict, 7 due to lack of interest or unknown reasons). In total 13 teenagers and 15 parents registered for the workshop, thereof 2 teenagers were not able to join due to illness at the day of the workshop,



finally including 11 teenagers in the workshop. The parallel sessions for adolescents and parents were given in 2 separate rooms to keep the target groups together, but for both included 3 main topics: “Gluten-free life-hacks” (given by nutritionist Sandra Fleissner), “Medical Facts” (pediatric gastroenterologist Dr. Andrea Sustmann) and “celiac disease psychoLOGICAL” (psychotherapist Lisa Bohata). The mode of presentation and content was adapted according to the needs of adolescents respectively parents. Both groups participated very well in the interactive presentations where they were asked to join, report their experience, opinion and ideas and to ask their questions. In between, gluten-free buffets were offered very successfully and there was a very good social interaction between the participants (e.g. talking about their diagnosis, school life etc.). In order to motivate the adolescents to take care of their daily gluten-free diet and to try new gluten-free pseudo-cereals, we distributed simple but nice recipes and packages with the corresponding (pseudo-)cereal to try the gluten-free cooking at home. Finally, the German Celiac Society presented their youth organisation with a movie (Ulla Hirschmann) and pointed out important issues with respect to insurances and job choice (Sofia Beisel) both to adolescents and parents altogether. As a closing session, the Focus IN CD coordinator (K. Werkstetter) presented this and the other project outcomes and the Interreg funding programme. The evaluation of the workshop (feedback questionnaires) revealed an overall average satisfaction (scale of 1 = not at all satisfied to 5= very satisfied) of 4.5 for adolescents and 4.6 for parents. All would recommend the participation in the workshop.

3) Celiac passport

- a. Activity: to develop a new celiac passport to definitively document the diagnosis and the follow-up/monitoring of celiac disease.
- b. Results: based on the previous, basic version of the celiac passport of the German Celiac Disease Society (DZG), we have elaborated an updated and more extensive version and asked the DZG and medical experts working in the field of adult and pediatric celiac disease for their critical revision. We have finally developed a new version and organized the logistics for printing. Dissemination will start among our own patients as well as e.g. among paediatricians attending the German Pediatric Gastroenterology Congress (end of March 2019) and also among adult gastroenterologists, supported by the DZG which will also



provide this passport to all their members as well as to non-member patients if requested.

2. ADDED VALUE OF THE DEVELOPED & TESTED PILOT SOLUTION IN YOUR REGIONAL ENVIRONMENT

- Please describe shortly, what is the gained added value for the end-user of pilot service solution

ADDED VALUE for END-USER	
Short term effects	Long-term effects
1. Increased knowledge and self-capability to deal with celiac disease among the adolescents which have participated and support of the participating parents to allow their children to become independent and self-responsible with their celiac disease	1. Repeat of the workshop in our own institution and alerting HCPs and stakeholders to the need for a transition programme for adolescents with celiac disease (and their parents) as an important tool to increase the self-capability and responsibility of the adolescents, leading to improved compliance with the diet and reduction of long-term health consequences
2. Participation in the workshop and support with the celiac passport (critical review / revision) by representatives of the German Celiac Disease Society (DZG) leads to enhanced dissemination of our transition project and the passport	2. Long-term use of the celiac passport - availability for all celiac patients in Germany (regardless if they are members of the DZG or not) and dissemination e.g. planned at the German Pediatric Gastroenterology Conference, end of March 2019
3. Our patients (not only those participating in the transition workshop, but also others) will immediately benefit from the use of the passport which we will complete and sign as soon as the printed version will be available (approximately until end of March 2019).	3. Spreading the idea of the workshop and the celiac passport all over Germany, the Focus IN CD partner countries and maybe even other European countries, potentially considering to establish similar workshops and taking-over the passport

3. DEVIATION AND PROBLEMS ENCONTERED

- In case your outcomes are different from the planned, please give an explanation of the reasons and formulate your modified results achieved. Was your planned model working



or did you had to make modifications, if yes, describe ? Did you had any problems in you pilot implementation? If yes, which was the solution adopted?

We have successfully reached all 3 intended outcomes of our pilot. However, we had to face some challenges, which we however were all able to solve. In brief:

- *Individual consultations of adolescents with celiac disease in our interdisciplinary, social pediatric center (iSPZ): our plan was to first have individual consultation for almost each participant in the transition programme and then conduct the workshop for all adolescents (and in parallel the parents). However, due to very limited capacities of the iSPZ medical staff (not enough time-slots left to give an appointment to celiac adolescents for an individual transition consultation within few weeks), we had to postpone the transition workshop in order to arrange the individual consultations beforehand. However, it turned out that only one third of the patients interested to participate in the transition programme also aimed to attend an individual consultation. The others were more interested to only participate in the workshop. Nevertheless, we were able to at least arrange the individual consultation at the iSPZ for those adolescents with the most severe problems (regarding psychological aspects), but this was already quite a challenge.*
- *Transition workshop: as explained above already, we had to postpone the transition workshop from Nov 2018 to Feb 2019 for two reasons: 1) there were not enough time-slots for individual consultation at the iSPZ for those patients in need and 2) it was difficult to find a date where all involved experts (physician, psychologist, dietitian, Focus IN CD organisation team, iSPZ availability) were available on a Friday afternoon. Soon I turned out that Friday afternoon is the only reasonable day / timeslot to conduct such a workshop as we have to consider that the adolescents have to attend school but are not willing or able to attend a workshop during school holidays. Weekends are not possible due to need for iSPZ administration.*
- *Celiac passport: no major problems, but some delays due to consultations / revisions of external experts which we have invited to give us their feedback on our drafts of the passport.*



4. LESSON LEARNED RELATED TO CO-CREATION OF PILOT SOLUTIONS WITH ENGAGED STAKEHOLDERS

- Please describe what were the benefits and setbacks related to co-creation of pilot project with stakeholders.

LESSONS LEARNED	
Benefits	Setbacks
1. Collaboration with German CD society (DZG) was extremely supportive and became closer as before the project, substantial advantage for disseminating our outcomes.	1. Delays due to limited capacities of iSPZ (too few time-slots to get individual consultation appointment in a timely manner)
2. Staff of iSPZ is already well trained and collaboration between KUM / Dr. von Hauner pediatric Gastroenterology and iSPZ is working very well	2. Location was bound to the rooms of the iSPZ (two rooms needed, one for adolescents, one for parents) and their administrative staff (no workshops possible on a Saturday, only weekdays)
3. Celiac passport: very positive feedback from experts in celiac disease care, but also important hints and suggestions to further improve it and also ideas for dissemination	3. In order to organise a really successful workshop, high personal enthusiasm of the staff already during the preparation is absolutely necessary, it will be possible to keep this alive if the iSPZ is willing to spend part of their budget which they can get from health insurances to conduct such workshops in the same quality, also assuring a gluten-free buffet

5. FURTHER ACTION PLAN (ACTIVITIES FOR THE FUTURE)

- What are your further activities of the pilot project development,
 - > On the local level ? - We aim to repeat the celiac workshop once or twice a year and to identify celiac adolescents with high burden of the disease and/or diet to offer the possibility for individual consultations at the iSPZ
 - > On transnational level? We aim to present our transition workshop to colleagues working in the same field and to increase awareness about the need to prepare adolescents to take care of their celiac disease and get informed.
- How did you plan to ensure sustainability to your pilot? Have you plan any action for the maintenance/follow up/development of the actions implemented, after the project ends?



- **Celiac Workshop:** we have discussed earlier (and will continue discussing) that the iSPZ will take over the main parts of the organisation of the workshop in the future. iSPZ was not able to cover staff costs to prepare the content of the workshop, however, for the conduction of the already existing workshop they are able to obtain budget from the public (not private) health insurances and will therefore be able to continue with the workshops. Individual consultations are anyhow covered by health insurances if there is need for interdisciplinary setting (e.g. psychological consultation).
- **Celiac passport:** we are disseminating the passports until the end of the project and supported by the DZG, we are planning to conduct an simple and anonymous evaluation (online questionnaire) in about 1-2 years. If the passport is successful, the DZG agreed to cover the costs for further printings in the future.