Interreg
CENTRAL EUROPE
Focus IN CD
European Union
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Development Fund

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

D.T3.2.9 Implementation and testing of new service to improve transition from paediatric to adult health care

Pilot project Final Report

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 adoelscents 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 adolesencts, 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.