TEMPLATE

**Output factsheet: Pilot activities**

**Version 1**

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| **Project index number and acronym** | CE111 Focus IN CD |
| **Lead partner** | Municipality of Maribor |
| **Output number and title** | O.T3.1 Development and implementation of 10 pilot projects  **In particular: Deliverable D.T3.2.9 -** I**mplementation and testing of new service to improve transition from paediatric to adult health care** |
| **Responsible partner (PP name and number)** | Ludwig-Maximilian’s University Medical Center KUM (PP8) |
| **Project website** | <http://www.interreg-central.eu/Content.Node/Focus-IN-> CD.html |
| **Delivery date** | 5/2019 |
| **Summary description of the key features of the tool (developed and/or implemented)** | |

#### Background of Transition in Celiac Disease

Transition is defined as the process to transfer the medical care of chronically ill children and adolescents from pediatric to adult medical care.

In general, adolescence can be a challenging phase in life: the children are and should become more and more independent from their parents and learn to take care of their life themselves. However, it’s also a phase where belonging to a peer-group and the identification role models are becoming more and more important. On the other hand, unpopular duties and rules are often neglected or not followed.

If an adolescent suffers from a chronic disease like celiac disease, it becomes even more demanding. Particularly as the gluten-free diet has a major impact on social life as going out with friends usually also involves eating out. However, adolescents don’t want to be different than their peers and admitting that one has to follow a gluten-free diet is often a burden for them. Alternatively, the adolescents often do not adhere to the diet and rather prefer to suffer from symptoms than disclose their chronic condition.

This may also be a burden for the relationship between adolescent and parents, as the incompliance with the diet often causes arguments.

Parents of children with chronic disorders also often tend to be overprotective. Their child does not get the opportunity to learn how to take care of her- or himself, to assure that the meal is gluten-free and how to read food labels. They also often have no idea why and how to make and appointment for monitoring visits at their physician.

This often leads to poor knowledge and consequently incompliance and lack of monitoring visits in young and later adulthood.

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.

Another problem we aimed to tackle was the unsatisfying situation in documenting the diagnosis and follow-up. Celiac disease is a well-known and frequent topic in paediatric care, but unfortunately this is not the case in adult general practice and even not in adult gastroenterology. Often the diagnosis is questioned later on in adulthood as there is a lack of clear medical reports proofing the diagnosis of CD which the patient had received years or decades back in childhood. The German Celiac Patient Society (DZG) already had developed a Celiac Passport to document the diagnosis and the follow-up. However, the requested information was incomplete and not according to the new standards of diagnosis. Furthermore, the passport was not ideal for the patients to carry with them all the time in daily life, e.g. to show them to the service when eating out.

In order to support the adolescents with celiac disease as well as their parents in the difficult process from paediatric to adult medical care, we have developed a transition programme and an up-to-date, comprehensive Celiac Passport, including a Celiac ID card.

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

**The transition programme consists of 3 main topics.**

1. **Individual consultations at the interdisciplinary, social pediatric center (iSPZ) – preferably before and if needed also after the workshop.** Although only few of the patients participating in the Workshop aslo attended this individual consultation, we realized that it’s important for these patients with higher burden of the disease, while other patients seemed to only prefer and need the participation in a workshop with other celiacs.
2. **The transition workshop for adolescents with celiac disease and in parallel a similar but separate workshop addressed to their parents:** The workshop comprised 3 sessions on “Medical Facts”, “Gluten-free life hacks” and “Celiac Disease – psychoLOGICAL”. In between there were two breaks with gluten-free buffets which the adolescents highly appreciated and which also allowed the adolescents but also the parents to talk and exchange their experiences. Finally, the presentation of the Celiac Disease Society about their society and about support and pitfalls related to social topics (insurances; occupational choice; limitations in public financial support) received particular interest. In addition, the Focus IN CD project

and the e-learning has been presented as well as the preliminary version of the celiac passport.

1. **The development of a new, up-to-date celiac passport to document the diagnosis and the monitoring visits. This should 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. In total 10,000 passports have been printed and disseminated at relevant conferences, patient seminars and by the German Celiac Disease Society (DZG)

#### We received very positive feedback both for the Transition Workshop (average score 4.9 from adolescents and 4.8 from parents, both on a score from 1 to 5) and also for the celiac passport from pediatric gastroenterologists and from celiac patients. All 10,000 passports have already been disseminated until the end of the project and 5,000 additional passports had to be printed.

NUTS region(s) where the tool has been developed and/or implemented (relevant NUTS level)

List of regions reached is as follows:

**DE11** Stuttgart **DE12** Karlsruhe **DE13** Freiburg **DE14** Tübingen **DE21** Oberbayern **DE22** Niederbayern **DE23** Oberpfalz **DE24** Oberfranken **DE25** Mittelfranken **DE26** Unterfranken **DE27** Schwaben **DE30** Berlin

**DE40** Brandenburg

**DE80** Mecklenburg-Vorpommern

**DED2** Dresden **DED4** Chemnitz **DED5** Leipzig

**DEE0** Sachsen-Anhalt

**DEG0** Thüringen

and other German regions outside Interreg CENRAL EUROPE as well as Austria

**Expected impact and benefits of the tool for the concerned territories and target groups**

The transition workshop was well-accepted by the target groups and we presented it at the German Pediatric Gastroenterology Conference in Munich (March 2019) to a broad number of pediatric gastroenterologists who all appreciated this idea. Many other hospitals and pediatric gastroenterology centers already showed interest to implement our pilot project in their own practice. Furthermore, the celiac passport gained high interest, the first edition with 10,000 passports has been disseminated already until end of April and we reprinted 5,000 additional pieces.

The children and adolescents with celiac disease will substantially benefit from the awareness that becoming an adult with this chronic disorder, requiring a life- long restricted diet, is not so easy. The transition workshop will be a starting signal for them to take over responsibility and for their parents to gradually commit the responsibility to their child. This will improve the compliance to the gluten-free diet and the overall quality of live. Furthermore, the workshop often for the first time enabled them to exchange themselves with peers in the same situation and to learn that they often have to face the same problems, which is usually a relief and reduces the own burden of disease.

The documentation of the diagnosis and the monitoring will furthermore improve the disease management for the patient but also help to reduce unnecessary cost for the health care system as double-testing’s or gluten-challenges to confirm the diagnosis will be avoided in most of the cases.

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| **Sustainability of the tool and its transferability to other territories and stakeholders** |
| In our own hospital, we will be able to continue with the transition programme in collaboration with the interdisciplinary Social Pediatric Center (iSPZ), based on the already developed workshop contents. As the costs for the gluten-free catering were less than anticipated, we are confident that iSPZ will be able to cover the catering from own budgets in the future. However, the organization of the workshop itself will be demanding and staff from PP8 KUM will need to be involved. This may be supported by budgets form the German CD society (DZG).  During the project duration we have already presented our pilot project at several occasions and gained high interest. Other pediatric gastroenterology centers, e.g. the Pediatric Gastroenteroloy at University Hospital Charité Berlin or University Hospital Leipzig showed interest to implement our pilot project in their setting. |
| Lessons learned from the development/implementation process of the tool and added value of transnational cooperation |
| 1. **Collaboration with German Society for Transition Medicine (DGfTM):** Initially we planned to collaborate with the DGfTM and we also participated in their Transition Conference and Workshop to prepare for this collaboration. However, the colleagues from our associated interdisciplinary Social Pediatric Center (iSPZ) then reported disappointing experiences in a previous collaboration with respect to transition of patients with Chronic Inflammatory Bowel Disease (IBD). It seemed that the DGfTM did not really shape the programme to the relevant needs of the IBD patients and the outcome of their evaluation was poor. Therefore, we finally decided to completely develop the transition programme with our own staff in order to better focus on the needs of adolescents with celiac disease. Consequently we had to shift the majority of the external pilot project budget to staff costs. However, it paid out as we also could involve a colleague from our team with background in social education.   **Lesson:** collaboration with societies can be an advantage, but it’s wise to first get some experience and assure that the ideas and aims are the same.   1. **Individual consultations of adolescents with CD at the interdisciplinary Social Pediatric Center (iSPZ):** in parallel to the transition programme for patients with IBD, we planned to offer individual visits at the iSPZ. However, it became obvious that there were not enough free time slots available and we had to postpone the transition workshop for this reason. However, only 2 of the 14 patients which signed in for the workshop finally attended an individual consultation before and only 1 patient after the workshop. The majority of patients replied they are not interested in an individual appointment. However, for the few patients attending the iSPZ visit, the disease burden was particularly high and it seems reasonable to still offer this opportunity in the future for this kind of patients.   **Lesson:** Not all patients may need individual special consultation visits and in addition the availability of such special care consultations may be limited. |

**References to relevant deliverables and web-links**

**If applicable, pictures or images to be provided as annex**

**This output is related to deliverable D.T3.2.9 Implementation and testing of new service to improve transition from paediatric to adult health care**

**The deliverable and the output are published here:** [**https://www.interreg-central.eu/Content.Node/Implementation-and-testing-of-new-service-to-improve-tran.html**](https://www.interreg-central.eu/Content.Node/Implementation-and-testing-of-new-service-to-improve-tran.html)