Interreg
CENTRAL EUROPE
Focus IN CD

European Union
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Development Fund

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

D.T3.2.2 Mentoring service for newly diagnosed patients - 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.**

We implemented and tested the mentoring service, we addressed lack of sufficient knowledge (dietary treatment, risk factors for CD, complications), lack of self-confidence or skills to manage the condition well, lack of support from family and friends.

Celiac disease is a lifelong disorder, requiring a dietary treatment, it is associated with a number of complications and comorbidities, patients with CD perceive their disease and its treatment as a burden. Peer support mentoring embodies widely recognized patient-centred principles – patient choice and empowerment, through such a programme, which is adaptive to the needs of patients, they are able to navigate their health and their lives. Peer support creates a secure environment that situates patients at the centre of their health care. Well-designed peer support empowers patients to improve management of their health and at the same time provide opportunities for patients to help others facing similar challenges. Case studies also acknowledge that peer support is successful because of non-hierarchical and reciprocal relationship created through sharing of experiences and knowledge with others who are facing similar challenges. The society is changing, patients' needs are changing and well-developed peer support goes hand in hand with a public health care sector, reduces problems, costs etc. Celiac (chronic) disease is a public health issue that could be addressed by increasing the ability of individuals to better manage their condition and its consequences on a daily basis.

We recruited 10 newly diagnosed celiac disease patients and 5 mentors - experienced coeliac disease patients. Self-management is delivered by volunteers (mentors) who themselves have a celiac disease or are active celiac society members (chronic disease), volunteering in the context of chronic disease management is receiving increased attention. Patients with the same chronic disease or having the disease in the family share knowledge and experience, provide individualized patient – centred information, decision and self-management support for patients with chronic conditions.

We developed an educative programme for mentors to pick up the skills and knowledge necessary to provide effective support.

The first education event for mentors and new patients was organized in October 2017 with a comprehensive programme. Professionals gave lectures about the facts of celiac disease (doc. dr. Jernej Dolinšek, dr. med), about a gluten-free diet (mag. Aja Kocuvan Mijatov), about a psychosocial aspect of living with chronic disease (Jernej, Vidmar, univ. dipl. psih.) and about the rights of chronic patients and financial incentives available to chronic patients (Simona Ornik). Cooperation is crucial, Inflammatory bowel disease society President Ms. Mateja Saje, presented a very well-organized educational concept of their society.

A video tutorial »How to rearrange gluten-free kitchen« was prepared and presented.

The second part of the education event was devoted to train new patients how to cook gluten free and about the specifics of food preparation. They have prepared bread and got some basic tips from the experienced gluten free cook Majda Jurše. More than 20 participants attended the basic gluten free work shop.

The third part of the start-up self-management event »A gluten-free shopping« was organized on Thursday, 26. 10. 2017.

If you have been diagnosed with coeliac disease and are making the shift to a gluten-free diet your grocery shopping experience is going to change. The best advice comes from experienced coeliac disease patients.

Simona Ornik was training new patients to learn tips and tricks how to find safe gluten-free products, which products are naturally gluten-free, which may contain hidden gluten, how to organize your shopping, where you have to be careful, and much more.

The most important part of gluten-free shopping for those following a strict gluten-free diet is reading and decoding the labels (the ingredients).

We reached following target groups: 58 individuals, 3 societies and 1 s. p., we reached 67 participants.

We established mentor-new patient pairs, they started to cooperate in December 2017 (testing ended in December 2018). Mentor-patient pairs were in contact, testing the new service. First education event for mentors was organized in Maribor (at University Medical centre Maribor).

Second education event was devoted to mentors, who are helping new diagnosed CD patients to better cope with chronic disease diagnose (it was organized in Maribor), in frame of our pilot project on 3rd February 2018, under the professional guidance of psychologist Jernej Vidmar. Mentors presented their first mentoring experiences. Mentors gained new knowledge and shared the experiences during the workshops and presentations. Main topics: living with chronic disease, good practices exchange, how to improve patient self-management, how to foster patient cooperation, mentorship supervision.

We prepared a programme and a methodology how to organize cooperation among mentors and patients. They are regularly in contact (in vivo, per telephone, per E-mail).

The second gluten free shopping event in the frame of our pilot activity »Mentoring service for newly diagnosed patients« (gluten-free shopping for newly diagnosed patients) was organized in Maribor on 15th February 2018.

We organized several mentor meetings. Topics: mentoring new patients and the main problems patients and mentors are facing.

Patients will have to complete the “dairy” about their problems, questions, about how they solved the problems, about their feelings, benefits of peer support, which will be prepared during the first pilot preparation phase. The draft template will be prepared.

Mentors/tutors/peers will complete the evidence about their work done; we have planned to prepare the evidence booklet, some kind of mentor-patient pass by the pilot project, but this task was not realized because of lack of interest.

Patients were reviewed regularly, until December 2018.

We developed mentoring protocol and methods, a complete service, which is be offered by mentors: e.g. telephone interviews, telephone-based peer support, peer visits, self-management training (WPT2 e-tools and Focus IN CD publications), assistance in daily management, social and emotional support, linkage to clinical care and community resources, awareness rising and education for patient families, (could in future be extended to relatives and friends, employers, teachers, kitchen staff, nannies, kindergarten and schools nurses,… The type of communication and interaction varied from patient to patient.

CLOSING event “Mentoring newly diagnosed celiac disease patients – mentors conference« in the frame of our pilot activity took place on Saturday, 24. November in Hotel Maribor.

During the conference the 15 attending mentors (mainly mentors and some new interested CD members) were able to improve their knowledge, share their experiences, and get support in developing high-quality service for new patients.

The conference entailed many talks and lectures, among which were a Lecture by Nada Polajžer, who talked about self-respect and self-esteem of patients with a chronic disease. Lead partner representative presented the project results. Jernej Dolinšek explained the importance of HCPs knowledge and talked about diagnostic guidelines as well as problems that can arise with lack of this knowledge. New relevant scientific information from this field was presented.

Živa Kuliš talked about supplements and things we should know before purchasing them. She especially focused on probiotics as patients seek them very often and it is therefore crucial for mentors to have knowledge of them.

Anja Prislan presented the draft idea of our comprehensive patient centered celiac disease management model, which was followed by the discussion with mentors who were asked for comments on the model.

We also organized a workshop, led by Aja Mijatov, with a basic idea of exchanging experiences, opinions, comments, problems and suggestions among mentors. It included preparing a supporting monitoring document that will be designed right after the layout is confirmed by mentors, who will actively cooperate in the process.

All in all, the service proved itself to be very useful and mentoring is spreading in other parts of Slovenia as well.

Our hopes are that Slovenian Celiac Association will keep using the service even after the project is finished.

Together with Slovenian Celiac Society we organised a meeting for adult patients with celiac disease that took place on 20th December 2018 in Gostilnica in Picerija Pobreški hram in Maribor. The patients were welcomed by the president of Slovenian Celiac Society, Domen Fras, who gave the introductory speech. We presented Focus in CD project and its results as well as the new e-tool that is to be launched in January and a speech by Simona Ornik focusing on the information and results of »Mentoring newly diagnosed patients«.

Next gluten-free workshop was organized on 31st January 2019 in cooperation of Slovenian celiac society and Focus IN CD project. Young celiac disease patients have learned how to shop gluten-free. Trying to follow a strict gluten-free diet can be overwhelming, and your first few gluten-free shopping’s will be challenging; however, it will become easier over time. If you have just started eating gluten-free, you will be glad to learn tips and tricks on how to find safe gluten-free products, which products are naturally gluten-free, which may contain hidden gluten, how to organize your shopping, where you have to be careful, and much more. The publication was presented: https://www.interreg-central.eu/Content.Node/Focus-on-CD-brochure-for-patients-ENG-9-16.4.2018.pdf. The most important part of gluten-free shopping for those following a strict gluten-free diet is reading and decoding the labels (the ingredients). We have provided young celiac disease patients with some tips. The best advice comes from experienced coeliac disease patients and their family members. The workshop was led by Simona Ornik.

We prepared thematic promotion material (aprons, cutting boards, kitchen towels) and publications for patients: e-brochure for newly diagnosed patients (also a printed version), a sticker for restaurants and households, a thematic picture book for children.

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

New celiac society service including specific tools - Mentoring service for newly diagnosed celiac disease patients, for different generation groups and modified up to their needs (children, young people and elderly; peer support was developed and implemented, to support other chronic patient groups.

Added value to the lives of patients – to raise a quality of life of chronic patients and tutors – adding value to the lives of others, along with increased confidence, that they are doing something positive for others will be the key benefits of being a volunteer tutor.

ADDED VALUE for END-USER	
Short term effects and long-term effects	
1. new celiac disease service puts the patient in the center, gives him support, helps him to better cope with the disease in the first year, to better manage their condition, to gain knowledge and skills, to reduce problems, risks, diet compliance, psychological disorders, complications…. 2. improvement of CD society service - standardised education protocol offers CD society a tool to improve their services 3. better quality of life of chronic celiac disease patients	

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 anticipated some problems listed below:

- Celiac disease society members who represent the main pilot supporting pillar, are volunteers, amount of time that peer supporters can devote to patients is limited, time lack problems may occur
- non-participation, indifference or mistrust of individual patients may occur
- some patient may not be willing to expose their problems or could have other concerns
- financial problems may influence sustainability of new developed service (model) use

Two problems were identified during the implementation of our mentoring service:

- some patient were not be willing to expose their problems or could have other concerns (some new celiac disease patients were not willing to speak about their problems and were not prepared to take part in the mentoring activity (some of them needed some time after the diagnose, they usually contacted mentors later after some time), some patients were completely satisfied with the information obtained at the internet, although in the reality internet does not always offer relevant information),

- financial problems may influence sustainability of new developed service (model) use in the future (we did not realize problems, connected with the lack of time of volunteers, who are the main pilot supporting pillar, but with the general society problem, lack of financial resources,

but did not influence the implementation very much. We successfully managed all these risks.

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. experienced celiac disease patient's knowledge input	1. number of risks associated with co-creation
2. interaction between society members, and the three Slovenian project partners (hospital (UKC MB), local authority (MOM) and E-Zavod.	2. no guarantee that the service will be sustainable
3. co-creation of new service – new patient participation in new service development	3.
4. better quality of service	

5. FURTHER ACTION PLAN (ACTIVITIES FOR THE FUTURE)

- What are your further activities of the pilot project development?
    - On the local level?
    - On transnational level?

- 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?
- Sustainability: all activities will hopefully be led to a new social innovation service, offered permanently by Slovenian celiac society. Trained mentors are educated and well-motivated.
- We will, based on available knowledge, plan activities to ensure sustainability of the results in new applications.
- Second CD society from Novo mesto (CELIAC) will start to implement mentoring service upon the experiences of Slovenian celiac society.
- Transferability and cooperation: our partner societies from Budapest and Rijeka will transfer the new service to Croatia and Hungary. We invited the partnership to participate, we got positive responses from partner societies and hospitals: PP2 University medical center Maribor, PP3 E-Zavod, PP6 Association of celiac patients Primorsko-goranska County, PP8 Ludwig-Maximillian's University Medical center, PP9 Hungarian celiac society and PP12 Primorje – Gorski kotar county. Pilot activities and achievements were transferred to other regions and countries through our participation at transnational events (D.C.6.2): AOECS, ESPGHAN, UEG and other events and project communication channels. New services e. g. "Peer support to newly diagnosed CD patients" will be introduced to other target groups, regions and can be transferred to other chronic diseases and tailored to their needs.
- Deliverable D.T3.3.1 "Transnational transferability plan of pilot solutions" - Upon exchange of needs of participating regions, transnational transferability plan will be prepared to transfer best solutions among project participating regions.
- Deliverable D.T3.3.2 "Pilot project recommendations for transfer to other users/regions" - Based on a feedback from pilot stakeholder group and end users, pilot project recommendations will present development process, experience and results related to pilot projects to other possible users within the consortium and within the region. We will visit our neighbouring – not participating country Austria, where a workshop with our target groups, HCPs and patients, will be organized. We will transfer the pilot achievements and promote e-tools.

Tasks for future:

to establish self-support groups, web and e-mail-based programmes,

the model could be upgraded and improved tailored to target group needs in other regions and for other chronic diseases,

promoting of mentor support for those with celiac disease,

education and motivation of mentors,

suggestions for the improvement of monitoring documentation (outlook and visual appearance of the document, which supports the mentor when communicating with the patient, developing a kind of supporting documents (mentoring pass),

to prepare a new patient standardised transition doctor – society protocol

to prepare a first year after diagnose comprehensive program (education event twice a year, mentor education events once a year, mentor support, workshops (gluten free cooking and shopping….)

to ensure funds for the successful permanent implementation.