

DELIVERABLE D.T3.2.2

Mentoring service for newly diagnosed
patients

Version 1
2/2019





INTRODUCTION

»Mentoring service for newly diagnosed celiac disease patients«

Pilot activity »Mentoring service for newly diagnosed patients« is being developed by the lead partner Municipality of Maribor, in the cooperation with Slovenian Celiac Disease Society and Slovenian partners. The main aim is to support newly diagnosed patients in the first year after getting the diagnose. First steps will not be easy. Patients are faced with information overload, but a coeliac diagnosis isn't the worst thing although it can feel like the end of your world.

We developed, implemented and tested a new social service »Mentoring newly diagnosed patients«. Experienced celiac disease patients are helping/mentoring newly diagnosed patients to better cope with the disease when doing the first steps into new life with chronic disease. They are faced with new circumstances, have to change their way of life, their eating habits, their social life is going to change and much more.

Experienced patients are giving new patients information about coeliac disease, guidance about how to live your life gluten-free, how to change their lifestyle, where to find necessary information and answers to your questions about gluten free diet, about eating out, cooking and travelling gluten-free. They meet, communicate per phone or e-mail, finding the individual ways to help the patient.

The main aim of our pilot activity was to develop a sustainable service, which will be further developed and offered as a new social service to newly diagnosed patient by celiac societies. The second goal is to transfer this service with specific modifications to other chronic diseases and to other environments.

In the framework of development, implementation and testing of pilot services, 'LEADERS living lab methodology' was used.

Deliverable "Mentoring service for newly diagnosed patients" was prepared on the basis of SUPPORTING TOOLS (templates):

- Report about pilot project ideas & established stakeholder groups
- Pilot Status report
- Pilot final report



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

Pilot project Start-up description template: “MENTORING SERVICE FOR NEWLY DIAGNOSED PATIENTS”

Version 1
07 2017



1. Pilot Background

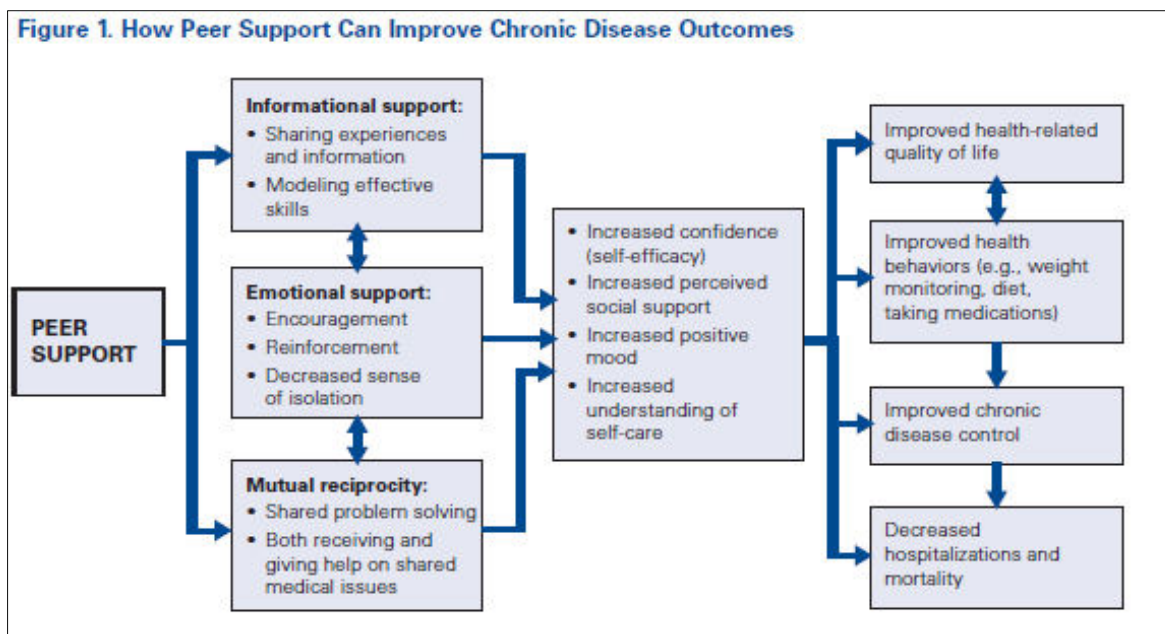
Please describe here the background of your pilot in terms of ideas, preliminary actions, plans defined earlier and methods already chosen, etc. Some of the aspects you can tell about are as follows:

- *How did the project idea surface?*
 - A diagnosis of life long disorder can mean shock and disbelief. The challenge of chronic disease will be with people for the rest of their lives.
 - People living with chronic disease need more than medical treatment from their health care providers. They need support in sustaining self-care that enables them to live as healthily as possible. Peer support does not compete or replace the role of others, it complements and enhances health care delivery.
 - Similar to other health systems in EU, also Slovenian health system is faced with severe resources constraints, therefore peer support interventions are necessary, to provide more holistic health approach. Enhancing effectiveness and humanizing care is an important feature of peer support.
 - Arguments that support peer mentoring: 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, employers... lack of financial resources makes it difficult to follow health care provider's recommendations. Chronic diseases are seldom confined to physical problems. Social and emotional measures are very important.
 - Peer support mentoring embodies widely recognized patient-centred principles (basing decisions on the perspective of the whole person) - 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.
 - We have found some literature and studies about peer mentoring of chronic patients, but they usually refer to Diabetes, Chronic Obstructive Pulmonary Disease and some other severe diseases, there is no evidence about being carried out in other diseases, which also need peer support and there is no evidence about being carried out in Central Europe. The society is changing, patients' needs are changing and well developed peer support could also go hand in hand with a public health care sector, reduce problems, costs etc. 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.

- 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.



Source: “Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success”, California healthcare foundation, Prepared by: Michele Heisler, M.D., M.P.A., December 2006

- Are there preliminary works that the project is based on? What are they?
 - Preparation of adequate mentoring material
 - Recruiting experts that will prepare tutors for mentoring



- Finding suitable peer mentors for all age generations

- *What is the knowledge base behind the project (studies, methods, statistical data etc.)?*

Studies and articles related to different chronic disease mentoring/tutoring

- “Building Peer support programs to manage chronic disease: Seven models for success” California healthcare foundation, Prepared by:
 - Michele Heisler, M.D., M.P.A., December 2006
- Clinical trial of community nurse mentoring to improve self-management in patients with chronic pulmonary disease, International Journal of COPD 2012:7407-413
- Chronic Disease Self-management Support (a practical approach to working with people with chronic disease (toolkit)), November 2008
- Global Evidence for Peer Support - humanizing health care, prepared by: Edwin B. Fisher, Peers to progress, 2014
- Support for patients with celiac disease: A literature review; UEG journal (United European gastroenterology journal); Ludvigsson, Card and others, 2014
- Contribution of Peer support to Health, Health Care and Prevention: Papers from Peers to Progress: Annals of family medicine, 2015
- Patient perspective on peer support for adults with type 1 diabetes: a need for diabetes-specific social capital, Joenesen and others, published online, 2016
- Potential impact of Peer Mentoring on Treatment Choice in patients with chronic kidney disease, Ghahramani, Archives of Iranian Medicine, 2015
- Volunteer, lay tutors experiences of the chronic disease self-management course: being valued and adding value, Barlow, Bancroft, Turner, Health education research, 2004
- Effect on Exacerbation on Quality of life in Patients with Chronic Obstructive Pulmonary Disease, Seemungal, Donaldson and others, American Journal of respiratory and Critical Care Medicine, 1998
- Daily life experiences, symptoms and well-being in women with coeliac disease, A patient education intervention, Lisa Ring Jacobsson, Linköping Studies in Health Sciences, Thesis No. 119, Linköping 2011

- *What methods will you / do you plan to use (to motivate stakeholders, to involve lead users, to develop ICT infrastructure, to communicate online etc.)?*

- Developing an educative programme for mentors to pick up the skills and knowledge necessary to provide effective support - volunteers, who will be trained at tutor trainings, to gain knowledge about many different aspects of chronic CD, experts included: celiac society experts, doctors,



dietitians, psychologists, content included: facts about CD, dietary requirements, food supply and preparation, complications, how to provide psychological supports, presentation skills, dealing with challenging participants, administrative and managerial tasks, legal matters ...

- Recruiting 10-15 newly diagnosed celiac disease patients. The report will be prepared until the end of December 2018.
- Peer training will be organized in September or early October, accompanied programme: gluten free cooking course (youngsters and adults), grocery shopping, lectures,....).
- 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; the evidence booklet will be prepared by the pilot project.
- Patient will be reviewed monthly from October 2017 and every two months during the summer months for a total follow-up of 12 months (until October 2018).
- Pilot project will develop mentoring protocol and methods, a complete service including variety of services, which will be offered by mentors: e.g. telephone interviews, telephone based peer support, peer visits, self-management training, self-support groups, web and e-mail based programmes, assistance in daily management, social and emotional support (expression of reassurance acceptance, through sharing the activities, discussions and common interests), linkage to clinical care and community resources, awareness rising and education for patient families, relatives and friends, employers, teachers, kitchen staff, nannies, kindergarten and schools nurses,...
- Self-management will be delivered by volunteers (mentors, tutors, peers) 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 to which others often cannot relate.
- Mentoring, particularly by trained peers, has the potential of reinforcing self-management skills and activities and has been used as an approach to enhance managing and decision making in chronic conditions. We will focus on patients with celiac disease as a model for the study of the impact of peer mentoring. It could be an effective model to provide individualized patient - centred information, decision and self-management support for patients with chronic conditions.
- The model could be upgraded and improved tailored to target group needs in other regions and for other chronic diseases.



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...)*
 - Mentoring service for newly diagnosed celiac disease patients, for different generation groups (children, young people and elderly; peer support will be developed and implemented.
 - New celiac society service including specific tools and strategies will be a useful framework to be used (and modified up to their needs) 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.
 - Promoting of peer support for those with celiac disease and other health challenges around the world.
- *What is the approach that makes the project viable and sustainable?*
 - The need for the service was expressed by future end users, patients of Slovenian celiac disease society, who would like to set-up a long-term approach for regular education of peer-to-peer mentoring among their members and offer a new societies' service to newly diagnosed CD patients, who are, when being diagnosed completely lost and faced with new circumstances, new challenges, they often cannot manage.
 - After the project closure the Slovenian celiac society will still implement education and support for which they have been trained. Partner hospital will provide in-kind assistance, we will prepare recommendations for local society to remain committed to this initiative. In some settings, the goal for sustainability may not be the whole adaption of a programme, but of its key features in routine practice. A model for effective and humanizing peer support has to be flexible and adaptable to individuals, varied settings, populations and health care systems.
- *What kind of problems are you anticipating and what is your "plan B"-s if something doesn't turn out as you counted in certain situations?*
 - Celiac 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



- Will the pilot have cross-regional impacts? Which are they?
 - We invited the partnership to participate, we got positive responses from: PP2 University medical center Maribor, PP3 E-Zavod, PP6 Association of celiac patients Primorsko-goranska County, PP8 Ludwig-Maximilian's University Medical center, PP9 Hungarian celiac society and PP12 Primorje - Gorski kotar county.
 - Pilot activities and achievements will be 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.

- Any other aspects you find important?
 - Acceptance, equality, women inclusion, sample, inclusion of food experts
 - Family involvement
 - There is a clear evidence that patients with CD are less likely to dine out in restaurants or at friends' houses as a result of concerns regarding cross-contamination or inadvertent exposure to gluten.
 - Further development - e-health innovations - smartphones, automated systems, social media platforms can extend peer support.
 - Policy
 - Global evidence for peer support, page 4
 - Expanded peer support programme
 - Contribution and benefits of peer support
 - Peer support goals, challenges, results
 - Contribution and benefits of peer support



- Grocery shopping, gluten free work shops
- eHealth peer support, researches, comprehensive programs, financial modelling (page 31), quality assurance, certification, ...
- How to integrate peer support into public health care system?
- A celiac disease diagnosis may be related to personal resources, for example there is an immediate financial burden associated with purchasing gluten free products, particularly in countries where no financial support is provided to CD patients. Other possible negative influences may be a significant delay between the beginning of symptoms and diagnosis, type of symptoms, as well as the degree of family support.



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>
1. Slovenian Celiac Society	NGO	Co-creation, design and implementation of pilot project's main activities	To implement and test the mentoring programme, evaluation of benefits and restrains
2. Medical experts (specialists gastroenterologists, phycologists, nurses)	Healthcare professionals	Presenters at mentoring trainings and will also have monitoring and support role during mentoring process	Monitoring and evaluation of newly diagnosed patients
3. Nutritionist / dietitians	Healthcare professionals	Presenters at mentoring trainings and will also have monitoring and support role during mentoring process	Monitoring and evaluation of newly diagnosed patients
4. Promotion team, responsible for design and making of video tutorials	Students of Master degree studies of Media communications (Faculty of Electrical Engineering and Computer Science at the University of Maribor (UM FER))	Responsible for design, filming and editing of 2 tutorial videos (Gluten free kitchen and Gluten free bread backing).	Gaining new practical experience and knowledge



5. National institute of public health (NIZJ)	National health institutions	The representatives of Institute will be invited to a meeting, when the pilot partnership will have evaluation of pilot results, to discuss and propose future guidelines related to patients with life-long diseases.	Gaining information about newly tested practices
6. Ministry of health of Republic of Slovenia	Policy maker	The representatives of Institute will be invited to a meeting, when the pilot partnership will have evaluation of pilot results, to discuss and propose future guidelines related to patients with life-long diseases.	Gaining information about newly tested practices
7. Other Slovenian health societies that are active in support of life-long chronic diseases	NGOs	Pilot partners would like to set-up and enhance cooperation with other NGOs, present the results of pilot project, exchange experience	Exchange of experience and knowledge between NGOs.



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"> Project partners (LPMOM PP2 UKC MB and PP3 E-ZAVOD) Slovenian Celiac society (SDC) Medical experts (specialists gastroenterologists, phycologists) Nutritionist / dietitians Promotion team Institute of public health (NIJZ) Ministry of health of Republic of Slovenia Other Slovenian health societies that are active in support of life-long chronic diseases 	<ol style="list-style-type: none"> Preparation of training programme and materials Candidates for mentors (method for the selection of mentors, criteria,), promotion of programme and recruiting Promotion activities: <ul style="list-style-type: none"> Gluten free kitchen video tutorial Gluten free bread backing video tutorial E-brochure for newly diagnosed patients Implementation of training <ul style="list-style-type: none"> Training for mentors Education event for newly diagnosed patients, gluten free workshop and gluten free shopping trip Testing of mentoring programme: <ul style="list-style-type: none"> Recruiting of new patient and mentoring Choose type of communication 	<p>(what is the benefit?)</p> <ul style="list-style-type: none"> Developed one new mentoring program Implementation of one training program for mentors Establish mentoring protocols/used methods (telephone interviews, telephone based peer support, peer visits, self-management training, self-support groups, web and e-mail based programmes, assistance in daily management, social and emotional support, awareness raising, education for patient families, relatives, friends, employers, teacher...) Inclusion of 10-15 newly diagnosed celiac disease patients in mentoring program Implementation of one mentoring program (from 	<p>Two co-creation process in relation to:</p> <ul style="list-style-type: none"> Existing mentors will train new mentors New mentor will guide new patients 	<p>At least 10 (max 15) new patients</p> <ul style="list-style-type: none"> Teenager Men Families with children Elderly



	<p>• Take notes, following and supporting the patients, feed-back</p> <p>6. Evaluation of the programme (questionnaire)</p>	<p>January to October 2017 - 10 months)</p>		
	<p>Key Resources</p> <p>1. Human</p> <ul style="list-style-type: none"> Society (SDC) members, project partners, health experts <p>2. Financial</p> <ul style="list-style-type: none"> LP MOM - staff cost 16.100 €, external on WP C 5.500 € E-ZAVOD: staff cost 14.690 €, external 5.000 € 	<ul style="list-style-type: none"> diary writing by patients (problems, questions, problems solving, feeling, benefits of peer support...) - 10-15 diaries monthly reviewing of new patients (number of reviews: 10 patients x 10 months) 	<p>Communication channels?</p> <ul style="list-style-type: none"> personal contact ICT tools (survey, diary...) social media (invitation of new mentors) working group workshops fieldtrip 	
<p>Cost Structure</p> <p>Pilot development coordination costs: distribution of working hours</p> <p>Maintenance costs / later after the project will end (mentors, external experts - only human resources)</p>		<p>Revenue Streams</p> <p>Not planned</p>		



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>
1.Preparation of training programme and materials	Project partners, celiac society, medical experts	The content and templates for training and testing mentoring will be prepared	End of August 2017
2.Selection of candidates for mentors	Celiac society	Upon invitation of Celiac society, candidates will be interviewed and selected for training	1.week of September 2017
3. Preparation of promotional activities	Project partners, celiac society, promotion team	1.Gluten free kitchen video tutorial 2. Gluten free bread backing video tutorial 3. E-brochure for newly diagnosed patients	1. End of Septemeber 2017 2.&3. End of October/November 2017
4. Implementation of training	Project partners, celiac society, medical experts	Whole day workshop, including: introduction lecture, GF diet, legal framework, psychological aspect	End of September or 1 st week of October 2017
5. Testing of mentoring programme	Project partners, celiac society, medical experts	Experts will monitor the process and interactions during the mentoring	From October 2017 to October 2018
6. Evaluation of the programme	Project partners, celiac society,	Preparation of questioner for	From November to December 2018



	medical experts	involved stakeholders and preparation of report	
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ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

Pilot Status Report 1
Mentoring newly diagnosed celiac disease
patients (LP MOM)

Version 1
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:

- Mentoring service for newly diagnosed celiac disease patients
- New celiac society service to support other chronic patient groups
- Added value to the lives of patients
- Promoting of peer support

The approach that makes the project viable and sustainable:

- The need for the service was expressed by future end users
- After the project closure the Slovenian celiac society will still implement education and support for which they have been trained.

We anticipated following problems:

- Celiac 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

- 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?

The test sample will be a bit smaller at the end of testing period, because of different reasons: smaller celiac society CELIAC from Novo mesto and their mentor-patient pairs gave



up after first education event, due to lack of experience, lack of knowledge, lack of staff (volunteers) and some organizational problems.

Other pairs, members of Slovenian Celiac Society, are working together from the beginning of the testing phase and will probably be working until the end of it. Two pairs changed, two mentors got new patients in the first months of the implementation, due to non-activity of some patients (psychological aspects of the first phase after being diagnosed, personal reasons).

Although, celiac society members, who represent the main pilot supporting pillar, are volunteers, who's amount of time they can devote to patients is limited, they are very enthusiastic and willing to help new patients. Slovenian celiac society (project manager: Simona Ornik and Aja Mijatov, dietitian) mobilized experienced patients in larger number than expected.

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**

Pilot activity »Mentoring newly diagnosed patients« is being developed by the lead partner Municipality of Maribor, in the cooperation with Slovenian Celiac Disease Society and Slovenian partners. The main aim is to support newly diagnosed patients in the first year after getting the diagnose. First steps will not be easy. Patients are faced with information overload, but a coeliac diagnosis isn't the worst thing although it can feel like the end of your world.

We are developed and implemented a new social service »Mentoring newly diagnosed patients«, which is now in the testing phase. Experienced celiac disease patients are helping/mentoring newly diagnosed patients to better cope with the disease when doing the first steps into new life with chronic disease. They are faced with new circumstances, have to change their way of life, their eating habits, their social life is going to change and much more.

Experienced patients will give new patients information about coeliac disease, guidance about how to live your life gluten-free, how to change their lifestyle, where to find necessary information and answers to your questions about gluten free diet, about eating out, cooking and travelling gluten-free. They will meet, communicate per phone or e-mail, finding the individual ways to help the patient.

The main aim of our pilot activity is to develop a sustainable service, which will be further develop and offered as a new social service to newly diagnosed patient by celiac societies. The second goal is to transfer this service with specific modifications to other chronic diseases.



We have organized several, in the pilot project involved, project partner meetings: 20.6.2017, 12.7.2017, 24.8.2017, 5.9.2017, 25.9.2017, 26.9.2017, 17.10.2017, 15.11.2017, 17.11.2017, 7. 12. 2016, 15.2.2017, 22.3.2017, 28.3.2017, 11.4.2017, 17.1.2018, 8.3.2018, 15.3.2018 and 24.5.2018.

We have had 8 organizational meetings in the period until the end of May 2018.

At the meetings we discussed the main issues, first steps of the project development, prepared a concept, collected available literature, researched the environment and services available, decided about the methodology which will be used and contacted the patients to present their needs and wishes, we developed the concept of tutoring service, education and communication channels, we involved target groups interested in a field of social innovation. We talked about the promotion and promotion material upon patient needs. Some concrete steps were done in March: the call for mentors will be published, the concept of the educational event will be designed. The four templates have been prepared. We discussed the methods we will use to reach the main goals. Some other draft templates were prepared (follow up of patients, etc).

We involved 3 NGO's, (Slovenian celiac society was involved in the development of pilot activities, IBD society (Društvo KRONČEK) and CELIAC (society of celiac disease patients from Novo mesto).

A lot of documents were prepared upon the methodology based on knowledge from the CenraLab project.

We organized some stakeholder meetings and prepared a concept of the educational event for mentors and newly diagnosed patients, which took place in October 2017. We have studied available literature and prepared the first document to support the pilot methodology (pilot start-up description document), build on available knowledge from Central Lab project.

We prepared the draft programme of the event, contacted lecturers, organized some stakeholder meetings etc. In December started the testing year.

1st pilot project event

Educational pilot project event in a frame of »Mentoring service for newly diagnosed patients« was held on 21st October 2017 in Maribor in organization and cooperation of Municipality of Maribor, Slovenian celiac society, University medical centre Maribor and E-zavod from Ptuj.

Almost 60 newly diagnosed patients and mentors attended the event which took place at "Izobraževalni center Piramida Maribor".

We presented the Focus IN CD project, comprehensive celiac disease management model, which is one the main aims of the project. Our 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 by »FERI«.

PR

Press release was prepared, TV, Radio and newspapers reported about the event.

A video tutorial

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

It is available in Slovenian and English versions (<https://youtu.be/bsSCimU7sw4>. <https://youtu.be/Za0-NuxMH5Q> PR was prepared).

A basic gluten free workshop

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.

1st gluten free shopping workshop

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.

When buying products, patients have to read carefully the declaration and ingredients, and compare the translation with the original label.

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.

Mentor - new patient pairs



We established mentor-new patient pairs, they started to cooperate in December. Mentor-patient pairs are in contact, testing the new service. The work is going on, interesting results will be presented at our next event in November 2018.

We have organized several in the pilot project involved project partner meetings and prepared a supporting pilot documentation.

2nd pilot project event

First education event for mentors was organized in Maribor (at University Medical centre Maribor).

An education event devoted to mentors, who are helping new diagnosed CD patients to better cope with chronic disease diagnose, 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.

Simona Ornik, experienced CD mentor and society member organized a guided tour through the grocery store to help new patients to find safe gluten-free products, she informed them 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.

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).

2nd glutenfree shopping workshop

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 15 February 2018.

Simona Ornik, experienced CD mentor and society member organized a guided tour through the grocery store to help new patients to find safe gluten-free products. The most important part of gluten-free shopping for those following a strict gluten-free diet is reading and decoding the labels (the ingredients). She provided patients with some tips.

Mentor meetings

30st May 2018 - a meeting with mentors took place in Maribor (Hotel Betnava) to share experience and to make plans for the activities during the summer.

Participants were Simona Ornik and mentors Barbara Krajnc and Polona Vidovič. Simona and Majda Zorko, who excused herself being not able to join the meeting, have had a phone meeting and have discussed the same issues: implementation of service, problems, solutions, needs and wishes.



4th June 2018 - a meeting with mentor Živo Kuliš Plavc was held in Ljubljana (Križanke).

Topics: mentoring new patients and the main problems patients and mentors are facing.

Patients:

- dietary compliance
- accidental dietary violations
- how to deal with complications
- how to relieve the pain
- job - gluten free eating at work
- governmental incentives - how to arrange the situation
- legislation and parental (guardian) incentives

Mentors:

- suggestions for the improvement of monitoring documentation (outlook and visual appearance of the document, which supports the mentor when communicating with the patient)
- some patients exposed their everyday problems with the gluten free diet, despite of mentor support, they ask for their help (assistance) very rarely
- how to motivate them to cooperate

Sustainability: all activities will hopefully lead to a new social innovation service, offered permanently by celiac societies.

Transferability and cooperation: our partner societies from Budapest and Rijeka will join us at later stage to transfer the new service to Croatia and Hungary. We invited the partnership to participate, we got positive responses from: PP2 University medical center Maribor, PP3 E-Zavod, PP6 Association of celiac patients Primorsko-goranska County, PP8 Ludwig-Maximilian's University Medical center, PP9 Hungarian celiac society and PP12 Primorje - Gorski kotar county. Pilot activities and achievements will be transferred to other regions and countries through our participation at transnational events (D.C.6.2): AO ECS, 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.

Plans: we will meet again in September and organize a third pilot event in November to gain feed-back from mentors and patients and to support them. We are planning to develop supporting documents (mentoring pass). A workshop will be organized, some relevant professionals invited.



3. Changes in stakeholder's partnership

STAKEHOLDERS NO LONGER PARTICIPATING

Name	Reason for leaving
CELIAC society from Novomesto	- lack of experience, lack of knowledge, lack of staff (volunteers), organizational problems.

NEW STAKEHOLDERS

Name	Specialization Area	Role in Pilot Project	Motivation / Benefits
-	-	-	-

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

Mentoring service for newly diagnosed
patients - Final Report

Version 1
02 2019





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.