template

Output factsheet: Pilot actions

Version 1

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| Project index number and acronym | Focus IN CD 111 |
| **Lead partner** | Municipality of Maribor |
| Output number and title | Output O.T3.1.1  Development and implementation of 10 pilot projects |
| **Responsible partner (PP name and number)** | IRCCS Burlo Garofolo PP7 |
| **Project website** | https://www.interreg-central.eu/Content.Node/Focus-IN-CD.html |
| **Delivery date** | 5/2019 |

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| Summary description of the pilot action explaining its experimental nature and demonstration character |
| »Mentoring service for newly diagnosed celiac disease patients«  Pilot activity »Mentoring service for newly diagnosed patients« was developed by the Municipality of Maribor, in cooperation with Slovene Celiac Disease Society and Slovene partners UKC Maribor (PP2) and E-Zavod (PP3). The main aim was to support newly diagnosed patients in the first year after being diagnosed. First steps are never 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 helped/mentored newly diagnosed patients to better cope with the disease when taking their first steps into new life with chronic disease. Patients 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 gluten-free life, how to change their lifestyle, where to find necessary information and answers to their questions about gluten free diet, about eating out, cooking and travelling gluten-free. They met in person, and communicated via telephone or e-mail, to find individual ways to help the patient. One of the first activities was to prepare a video tutorial “How to arrange a safe gluten-free kitchen. Then we established 10 mentor-patient pairs.  We prepared some supporting publication: “Living with celiac disease” booklet, a sticker with basic instructions, picture book for young patients… During the implementation year, education events for mentors and patients were organized. Some pairs were very active, the others less, in general patients were independent after being mentored for one year. Their self-management improved. 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 was to transfer this service with specific modifications to other chronic diseases and to other regions. |

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| NUTS region(s) concerned by the pilot action (relevant NUTS level) |
| SI03 Vzhodna Slovenija  SI04 Zahodna Slovenija  HU10 Közep-Magyarorszag  HR03 Jadranska Hrvatska  HR04 Kontinentalna Hrvatska  DE21 Oberbayern |

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| Expected impact and benefits of the pilot action for the concerned territory and target groups |
| |  |  | | --- | --- | | 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 | | |

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| Sustainability of the pilot action results and transferability to other territories and stakeholders |
| Sustainability: all activities led to a new social innovation service - mentoring service for newly diagnosed celiac disease patients, which will be offered permanently by celiac societies. Trained mentors are educated and well-motivated. We have, based on available knowledge, prepared a new application, the activities will help us to ensure sustainability of the results.  Transferability: upon exchange of needs of participating regions and other regions, the main aim was to transfer best solutions among project partners of participating regions and outside the regions.  Regional Celiac disease society from Novo mesto (CELIAC) has started to implement upon the experiences of Slovene celiac society. The pilot activity was presented to celiac society CeliVita from Zagreb (CRO), knowledge was transferred to other EU countries and Russia and Belarus.  We invited the partnership to participate, so partner societies from Budapest and Rijeka will transfer the new service to Croatia, Germany and Hungary.  Pilot activities and achievements were transferred to other regions and countries through our participation at transnational events: AOECS (EU patient society), ESPGHAN, UEG (EU professionals society) through project communication channels as well as through digital activities. We will continue to promote new developed service through our networks. |

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| Lessons learned from the implementation of the pilot action and added value of transnational cooperation |
| 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.  |  |  | | --- | --- | | 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 |  | |

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| References to relevant deliverables and web-links  If applicable, pictures or images to be provided as annex |
| WPT3 Pilot activity deliverables:  D.T3.1.1 Report about pilot project ideas and established stakeholders’ groups  D.T3.2.1 Preparation of common pilot methodology  D.T3.2.2 Pilot activity: Mentoring service for newly diagnosed patients  ALL DELIVERABLES CAN BE FOUND AT PROJECT WEBSITE: <https://www.interreg-central.eu/Content.Node/Mentoring-service-for-newly-diagnosed-celiac-disease-pati.html>  <https://www.facebook.com/focusincd/>  <https://www.interreg-central.eu/Content.Node/Focus-IN-CD.html>  <https://twitter.com/Focus_in_CD>  Pictures are added as annex:”Pilot implementation pictures\_LP MOM”. |