



DELIVERABLE D.T4.1.2

Transnational report about tested model in
involved regions

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CONTENT

1. INTRODUCTION	2
2. PATIENT & STAKEHOLDER FEEDBACK	3
2.1. Patient survey feedback	3
2.2. Stakeholder & patient feedback about pilot projects.....	6
3. MISSION CANVAS of PATIENT CENTRED HEALTH CARE MODEL.....	10



1. INTRODUCTION

The purpose of the deliverable “D.T4.1.2 Transnational report about tested model in involved regions” is to collect inputs and suggestions from newly diagnosed celiac disease patients and stakeholders involved in pilot projects implementation, about patient centred model that partnership developed in the framework of the project implementation and testing.

The biggest challenge related to the existing management of celiac disease in Central Europe countries is, that support for patients exists, but is insufficient, partial and often neglects patient needs.

In order to develop the patient centred model, following project activities were implemented:

- analysis of current state of diagnosis, experts' knowledge and patient awareness and satisfaction,
- analysis and benchmarking of existing patient management of involved regions,
- analysis of existing financial incentives for celiac patients by regions.

All three mentioned analyses provided us information needed to develop:

1.) E-tools: e-learning tool for medical experts (doctors, nurses and dietitians) to close the knowledge gap between different expert groups, and ICT app for CD management protocol for primary care doctors to improve their diagnostic skills, and e-learning tool for CD patients to improve patient support and quality of life related to lifelong diet.

2.) Pilot services development and testing: 10 pilot services were developed and tested.

Patient centred health care model will be presented with CANVAS methodology. Instead of presenting the model with traditional Business CANVAS model, fostering primarily revenues of businesses, “Mission driven CANVAS model”¹ will be used, focusing on fulfilment of the mission= patient centred health care service model.

¹ Author: Steve Blank, information available on <https://steveblank.com/2016/02/23/the-mission-model-canvas-an-adapted-business-model-canvas-for-mission-driven-organizations/>



2. PATIENT & STAKEHOLDER FEEDBACK

In order to test, if project implemented activities had any impact on the knowledge about celiac disease among patients, we surveyed newly diagnosed patients with the identical questionnaire, as at the beginning of the project, and collected feedback from stakeholders that participated in the framework of development and implementation of 10 pilot projects.

2.1. Patient survey feedback

We surveyed 55 patients from all project participating regions, to get feedback, if awareness and knowledge during project implementation improved. We tried to identify patients, that had diagnosed confirmed during implementation of our project.

As in the framework of WPT1, the questionnaire/survey consisted of two parts:

- in the first part participants tested their knowledge of coeliac disease and the gluten free diet,
- in the second part, they provided feedback about their specific situation and shared their satisfaction with the diagnosis, medical and dietary support, the availability of gluten free products and the availability of the gluten free diet.

The results of the feedback survey can not be compared to the results in WPT1, due to too small population surveyed, but they provide valuable input for the patient centred model set-up.

FEEDBACK SUMMARY RESULTS:

CONTENT	PATIENT FEEDBACK
KNOWLEDGE ABOUT COELIAC DISEASE	Majority of patients answered that “Coeliac disease is an immune mediated disease that in the majority of cases also affects the small intestine” and that coeliac disease is a permanent/lifelong disease. All participating patients are aware that coeliac disease can occur at any age. Regarding the prevalence of coeliac disease, the answers of participating patients were still very diverse, as at the beginning of the project.
PRESENTATION OF DISEASE	Regarding the symptoms, most patients believe that disease can present with gastrointestinal symptoms or without them. Most common symptoms: abdominal pain, distended abdomen, diarrhea, weight loss, anemia.
RISKS AND COMPLICATIONS	Almost all patients stated, that first degree relatives of known coeliac patients carry a higher risk for developing coeliac disease and than other named diseases.



DIAGNOSTICS	Almost all patients answered that biopsy of small intestine is used when diagnosing coeliac disease.
TREATMENT	100% patients answered that lifelong gluten-free diet is recommended for treatment of patients with proven coeliac disease. The majority of patients correctly answered that wheat, barley, oats, rye, kamut and spelt must be excluded from the diet, because they contain gluten. They also answered that they can safely consume products that are naturally free of gluten and industrial products, that are specifically formulated for patients with coeliac disease.
FOLLOW-UP	Around 90% the participating patients believe that the follow-up of coeliac disease patients, when the control of the disease is well established, should be once a year. Around 80% patients believe that clinical picture and serological tests suggest good disease control and that the diet should be continued. Majority of patients agree that there is no need for intestinal biopsies for follow-up of coeliac disease patients after confirming the diagnosis.
DEVELOPMENT OF THE DISEASE	On average, patients reported that they went to their doctor approximately 6-7 months after the symptoms appeared. Then it took on average approximately 8 months for practitioners to perform first tests for coeliac disease and confirm the diagnosis. In almost all cases coeliac disease was confirmed with endoscopy and intestinal biopsy. Patient who did not have disease confirmed with endoscopy answered that by the doctor's opinion was not necessary or due to health risks. All patients had their diagnose confirmed by specialist gastroenterologist or pediatric gastroenterologist.
DIETETIC COUNSELLING	Approximately half patients did have counselling and half not. Patients who did not have counselling, did not know why or say it was not available. Majority of patients claimed that today they are well informed.
SPECIALIST FOLLOW-UP AND INFORMATION TRANSFER	Most patients do not see primary care physicians or specialist. They also do not use alternative medicine for these issues. In some cases specialists set-up visits for follow-up check-ups. The visit is paid by health insurance.



<p>INFORMATION ABOUT COELIAC DISEASE</p>	<p>The majority of participating patients stated, that they got the most information about coeliac disease from coeliac disease society, specialist, dietitian and other patients. Patients were mostly satisfied with the information they receive from society, specialist or dietitian. For additional information sources, they are using internet, but less other sources. In most cases, patients were satisfied with the information provided.</p>
<p>FOLLOW-UP VISITS</p>	<p>Half participating patients believe they should be seen primary care physician once a year. Majority also believe they should be seen by paediatric gastroenterologist or adult gastroenterologist once a year. Patients answers related to visiting dietitian were quite diverse, some think, it is necessary if needed, some once per year and some more than two times per year. The same situation repeats with dietitian counselling, answers are diverse. The longest visits are at psychologists and at alternative medicine and the shortest at family doctor. Patients would like to have longer visit time at different specialists.</p>
<p>SATISFACTION WITH THE SERVICE</p>	<p>Patients were more satisfied with services of paediatric gastroenterologist and gastroenterologist, but less with primary physician, dietitian and psychologist. Satisfaction with the availability of the service is for majority of patients on average level, they are more satisfied with access to society services and the lowest with receiving psychologist's help. Patients are happy with availability of gluten-free food in specialized stores and disappointment with availability of food in restaurants, schools and with the price of the products.</p>
<p>GOVERNMENTAL INCENTIVES</p>	<p>Patients are aware about financial incentives related to care and food and about incentives related to employment rights. Patients mostly suggested financial incentives related to needed government support.</p>
<p>SUPPORT FOR ISSUES RELATED TO COELIAC DISEASE</p>	<p>Patients were the most satisfied with support provided by paediatric gastroenterologist and gastroenterologist and less with family physician, nurse and dietitian. Patients were also happy about support provided by family and friends and less with school and government.</p>



2.2. Stakeholder & patient feedback about pilot projects

In the framework of thematic work package 3, ten innovative pilot project services were developed and tested in order to improve existing services or medical treatment of celiac disease patients. In the pilot projects, besides pilot stakeholders, patients had a role of end-user, service beneficiary and in some pilot projects, patients were also co-creators of the final solutions, with providing their knowledge and experience.

In the table below, we summarized concrete suggestions and feedback about new tested services and their value for the improvement of the existing support model.

PILOT PROJECT	FEEDBACK/SUGGESTIONS/ADVICE
Mentoring service for newly diagnosed patients	<ul style="list-style-type: none"> ▪ it would be very wise to involve mentors (experienced patients) of different age groups of both genders, to address different groups of patients ▪ education programs for mentors and patients has to be standardised ▪ supporting publications (brochure for mentors) and documents (e.g. patient pass) have to be prepared ▪ mentor - patient communication has to be tailored to patient needs (different types) ▪ procedures has to be standardised (from the doctor to the society, welcoming and first information,...).
Testing for celiac disease antibodies in school children	<ul style="list-style-type: none"> ▪ For pilot project all work documentation need to be prepared "on time" (Ministry of Health approval, Ethical Hospital Committee approval, parent's approval, documentation for public procurement...). ▪ To choose highly sensible rapid test and prove them in cooperation with producer to get valuable instruction. ▪ To cooperate with Public Health Institution and School Medicine to help in organizing implementation of testing: to choose the right time and place of testing (as a part of general medical check before starting the school year for example).
Implementation and testing of new service to improve transition from paediatric to adult health care	<p>Organization of Workshop for teenage patients:</p> <ul style="list-style-type: none"> ▪ Assure that your SPZ is taking care of the administration and the necessary tasks to be able to get re-imburement from the health insurance. Otherwise ask the CD society for support.



	<ul style="list-style-type: none"> ■ You need a really good and enthusiastic team (dietitian, paediatric gastroenterologist, psychologist with some experience / knowledge in CD or willing to learn about the patient's situation). ■ In addition, the gluten-free buffets were also very important for the patients as this facilitated the exchange between the so far foreign adolescents and parents and also was a very positive event for them ("I just can eat whatever I like!", "Somebody cares that I do get really good AND gluten-free food.") but do not underestimate the efforts to organize such a buffet. ■ You should try to make the sessions as interactive as possible and create a good, relaxed and trustful atmosphere. <p>Celiac passport: inform your assistant doctors about the importance and usefulness of the celiac passport and make clear that it is actually not so much extra work to complete it. Use it yourself.</p>
<p>Improvement of diagnostics with testing 3 methods to improve CD practice</p>	<ul style="list-style-type: none"> ■ Since CD diagnosis and follow up needs blood sampling, parents of children with CD are very interested in finding non-invasive way how to diagnose and control their children. Stool sampling is easy to perform and repeat and without need for forcing children to do aggressive approach.
<p>Detecting and managing CD patient within a cohort of super allergic population</p>	<p>Patients are satisfied as by using the new diagnostic procedure developed in the pilot we have help them to partially solve their health problems.</p> <p>The close collaboration within the stakeholders, the regional allergological group, the centre for research in autoimmunity (in Novara -Italy) and PP5 and PP7 has created a scientific network with wider connections (national and internationals) that will help in disseminating out the outcomes and guidelines produced.</p> <p>All partners would like to participate in the activity after the end of the project and include it in the standard diagnostic procedure.</p> <p>Suggestions:</p> <ul style="list-style-type: none"> ■ procedures have to be standardised ■ supporting publications (Scientific papers) and documents (e.g. guideless) have to be prepared



	<ul style="list-style-type: none"> it would be very wise to involve patients of different age/genders/ethnic origin to validate the discovery.
<p>Improvement of early diagnostics, testing method 'IGA T-TG' deposits in tissue sample</p>	<ul style="list-style-type: none"> Patients with unclear clinical picture and with unclear laboratory results of standard diagnostic tests expressed high satisfaction with improved diagnostic possibility. HCPs aware of diagnostic challenges expressed satisfaction with introduction of new method in the region. <p>Implementation suggestions:</p> <ul style="list-style-type: none"> Suitable equipment should be purchased in advance. Exact location of equipment should be determined at an early stage. Estimation of the number of samples likely to be tested in one year should be determined in order to determine needed workload. Early training of the technique at the centre with substantial experience. Agreement between all laboratories needed to be involved in the development of the method.
<p>Simulator testing to improve endoscopist practice in field of CD</p>	<p>Stakeholders involved in the pilot development and implementation expressed high level of satisfaction with the service.</p> <p>One comments that was shared by several participants was concerning relatively short individual exposure at group training sessions.</p> <p>Implementation suggestions:</p> <ul style="list-style-type: none"> Carefully analyse current settings at your institution. Designate specific training time. Develop written and video materials early. Allow only limited number of participants at single training session. Match participants with small or moderate differences in expertise. Train the trainers during the training sessions.
<p>Improvement of diagnostic of atypical CD patients</p>	<p>The results obtained during the project have been enthusiastic, as they have shown that many unsolved clinical cases can be solved, thanks to the innovative procedures implemented.</p> <p>All the participants showed interest in the continuation of the project objectives, through the organization of prospective study projects which are the ideal continuation of the present project, which has now been completed.</p>



<p>Testing of real life environment use of gluten free offer in restaurants</p>	<p>Based on a feedback from trainers and trained restaurants: they are really satisfied and would like to participate in the activity after the end of the project. New trainers and trained restaurants will be recruited. They would like to continue developing the project.</p> <p>Suggestions:</p> <ul style="list-style-type: none"> ▪ it would be very wise to involve trainers (experienced patients) of different parts of the country, , to have more trained restaurant in the countryside! ▪ education programs have to be standardised ▪ supporting publications and documents have to be prepared ▪ trainers - restaurant communication has to be tailored to the trained person's needs (different types).
<p>Evaluation and follow up of family members of CD patients</p>	<p>Involved stakeholders (family members, parents) were happy to receive free serology test results (especially HLA-DQ genetic results) and when serology results were positive, they mostly collaborated in further diagnostic activities and treatment by a gluten-free diet.</p> <p>Implementation suggestions:</p> <ul style="list-style-type: none"> ▪ For the family testing, an efficient recruitment strategy should be followed. ▪ The recruitment/information sessions are very important also for getting the appropriate samples preferably from each first degree relative (father, mother, sibs) and to avoid false interpretation of genetic results ▪ We suggest that screening at age 3, 6 and 9 years are the most decisive time points and most positives can be found just with this simple protocol.



3. MISSION CANVAS of PATIENT CENTRED HEALTH CARE MODEL

Patient centred health care model will be presented with CANVAS methodology, using celiac disease as an example use case.

As explained in the Introduction chapter, CANVAS methodology also develops continuously and instead using CANVAS business methodology, which is revenue driven, we will use “MISSION DRIVEN CANVAS”² methodology published by Steve Blank, oriented towards improving solutions in the field of public good, “Where the goal is not to earn money, but to mobilize resources and budget to solve particular problem and create value for beneficiaries”.

For public institutions “traditional” CANVAS business methodology does not fit, therefore Steve Blank adjusted the Mission Model CANVAS:


- Customer Segments is changed to Beneficiaries
- Cost Structure is changed to Mission Cost/Budget
- Channel is changed to Deployment
- Customer Relationships is changed to Buy-in/Support.

Mission driven CANVAS is also adjusted in measuring the achievements. The mission achievement is the value created for all beneficiaries, the greater good, according to Blanks adaptation.

Patient surveys feed back, along with results from testing of project e-tools and pilot services will be translated into the Mission model CANVAS, identifying key partners, activities, resources, support, channels and mission required to set-up “Patient centred health care model”.

² Author: Steve Blank, available: <https://steveblank.com/2016/02/23/the-mission-model-canvas-an-adapted-business-model-canvas-for-mission-driven-organizations/>

MISSION DRIVEN CANVAS FOR PATIENT CENTRED HEALTH CARE MODEL

<p>KEY PARTNERS</p> <ul style="list-style-type: none"> ▪ healthcare professionals and health institutions ▪ Institutions responsible for health policy development, national health programme's implementation (preventive and monitoring) ▪ NGO's & societies ▪ education institutions, schools and kindergartens ▪ government 	<p>KEY ACTIVITIES</p> <p><u>1.SET-UP OF SYSTEMIC KNOWLEDGE AND CAPACITY BUILDING OF KEY PARTNERS & PATIENTS</u></p> <ul style="list-style-type: none"> -accreditation of project e-tools materials at national Medical chambers to ensure quality and sustainable education of HCPs and patients -formation of hospital & national food related disorders groups, -national coeliac disease patients "Log-book", -institutional support for gluten-free food producers, -updated guidelines for the diagnosis of celiac disease -guideline for the diagnosis of celiac disease among coeliac disease-risk groups. <p><u>2.ORGANIZATIONAL & MANAGEMENT SOLUTIONS</u></p> <ul style="list-style-type: none"> -transition clinics at all institutions managing children and adults with coeliac disease, -national coeliac disease patient registries, -ensuring routine follow-up for adult patients with coeliac disease, -promoting routine dietetic counselling for coeliac disease patients, -preventive program / screening of CD, -national dissemination and use of the celiac disease "patient passport", -regular screening of first degree relatives of coeliac disease -patients gluten-free safe food in restaurants and hospitality services. <p><u>3.LEGAL FRAMEWORK</u></p> <ul style="list-style-type: none"> -ensuring basic social rights (finance, material, immaterial) for all patients, regardless age, -reducing the value of added tax for gluten-free products. 	<p>VALUE PROPOSITION</p> <ul style="list-style-type: none"> ▪ Lifelong comprehensive support to celiac disease patients from diagnostic of disease to regular monitoring visits provided by HCPs, dietitian, psychologist, NGOs and system of regular education. <ul style="list-style-type: none"> ▪ Proper health system organization and government support. ▪ Continuous raising awareness and knowledge about the disease. 	<p>SUPPORT</p> <ul style="list-style-type: none"> ▪ Consultation meetings ▪ Consultation groups ▪ HCPs trainings & conferences ▪ Awareness campaigns ▪ Preventive healthcare policy measures provided by government programmes 	<p>BENEFICIARIES</p> <p>Celiac disease patients and their families</p>
<p>KEY RESOURCES</p> <ol style="list-style-type: none"> 1.Human 2. Financial 3. Re-organization of specific activities, processes and protocols 	<p><u>3.LEGAL FRAMEWORK</u></p> <ul style="list-style-type: none"> -ensuring basic social rights (finance, material, immaterial) for all patients, regardless age, -reducing the value of added tax for gluten-free products. 	<p>MISSION BUDGET OR COST (COST STRUCTURE)</p> <ul style="list-style-type: none"> ▪ Costs of health institutions and Institutions responsible for health policy development, national health programme's implementation (preventive and monitoring) ▪ Costs of government health programmes and social support, financed by ministry ▪ Other sources (national and EU projects) 	<p>DEPLOYMENT (=CHANNELS)</p> <ul style="list-style-type: none"> ▪ Personal meetings ▪ E-learning and use of e-tools/apps ▪ Experimental projects ▪ Research papers ▪ NGO's information and awareness events 	<p>MISSION ACHIEVEMENT (OR „FULFILMENT“ OR „IMPACT“) FACTORS (OR CRITERIA)</p> <ul style="list-style-type: none"> ▪ Number of satisfied patients leading quality and healthy lifestyle. ▪ Number of satisfied key PROFESIONAL & VOLUNTEERING partners building patient centred health care model.