

ACTIVITY A.T3.2 IMPLEMENTATION OF PILOT PROJECT

Pilot project Final Report

Version 1
03 2017





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.**

After all the prerequisites have been met; 1) obtaining the approval of the Ethical Hospital Committee and the Ministry of Education for the implementation of the Pilot project activity in elementary schools of our area; 2) the procurement of the rapid tests; 3) the main presentation of the Pilot project for principals of primary schools (Primorje- Gorski Kotar County, 5th May 2018)) we have been ready for implementation of testing school children on celiac disease.

The implementation of the Pilot Project has been actively started since September 2018. with intensive communication aimed at elementary schools (via mail and phone). After the agreed arrangements for holding meetings with parents, we attended professional lectures on celiac disease and related illnesses, also at the same time held presentations about the Interreg CE program and the Pilot project "Testing the school children on celiac disease".

We met (Association and Hospital, PP6 and PP4, occasionally and PP12) 55 primary schools, realized about 120 outings on the 3 micro-regions of our county (mountains area of Gorski Kotar, coast and islands). We went to each school at least twice (in some schools we went out three times because of the different timing of school tuition); at first because principals had to approve school attendance and show first interest in project implementation and the parents who had to sign approvals and the second time to carry out the testing of children themselves.

We tested a total of 1478 children with non-invasive rapid celiac test and recorded 10 IgA deficits, which were not diagnosed as a positive celiac disease patients in a further diagnostic protocol in the Hospital (anti-transglutaminase antibodies).

So, we can conclude that through the set goals of this project; discovering new patients, prevalence of disease and new recommendation for a possible new approach to disease detection, we did not find/confirmed an increased celiac prevalence rate / celiac suspect, we have not confirmed any new celiac disease patient and therefore



we can not recommend that way of testing as a new approach for CD / quick test for celiac disease as a method of detecting disease in preschool children age. We further conclude that we recorded 10 IgA deficiencies which points to the risk group of children who can develop celiac disease if they have a genetic predisposition to the disease.

As secondary conclusions, it is important to note that through this Pilot Project we have been informed in directly communication with parents about the many health issues of their children concerning food allergies and even problems related to gluten consumption, also dermatological skin changes. Almost in every class we detected children below average body weight and lower growth for which there was a possible suspect on disease (as well known CD symptoms), but this type of testing did not give positive results on that suspects.

Further we noticed that children parents (which are between 30-40 years old) have the presence of many autoimmune diseases that are mentioned in relation to celiac disease (thyroid disease, diabetes, rheumatoid arthritis ...which they shared with us after given lecture about CD).

Because of the presence of such health issues with children and parents themselves, they were positive in decision to test children on CD.

So, we can also conclude that parents as school workers were very interested in health topic, they recognized their health issues related to CD, they pointed out problems of their children and gave us big support for CD testing. We offered them a new knowledge about CD.

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

ADDED VALUE for END-USER



Short term effects	Long-term effects
1. New knowledge	1. New knowledge about celiac disease and related disorders
2. testing on CD/health check/ possibility to discover of disease and other related conditions	2. Public raising awareness
3. possibility to exchange opinion with health care professionals	3. Further cooperation with educational institutions (workshops for kitchen workers and teachers about CD and special food requests)
	4. Further cooperation with schools with related topics/related projects/prevention and health protection

- 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?**

The producer of rapid test (Biocard) declares very high sensitivity and specificity of the test so we decided to use it. We did not find any patient with CD although we expected it because every year in Pediatric department of our hospital there are at least 3-5 newly diagnosed children from Primorje-Gorski Kotar County. There are no epidemiological data on CD incidence and prevalence in Croatia. It is to be questioned are our results real picture of CD prevalence in our territory, less than in other parts of the Europe, or there is problem with rapid test. It can be concluded that new and more detailed researches need to be done. We have noticed several problems during the implementation of this pilot project but we adapted and made quick answer to situation. Implementation of CD testing was lasted five months just because we needed to go twice to every school.



On the one hand, we have the opportunity to choose the easiest way to give an information through primary school physicians (in period of systematically examining related to children for the first grade) to avoid duplicate going to schools (which has created additional effort and extended duration of the pilot project).

On the other hand, with our stay among the parents and given lectures about CD/ presentations of the Program and the Pilot Project, we have made huge raising of public awareness (parents of children, teachers, principals of the institution, as well as other public through the media that followed us: national and regional newspapers, TV and radio).

1) Primary schools in our county have classes with a small number of children enrolled in first grade so we have to go through a large number of schools what certainly slowed our work but also gave us opportunity to screen situation much better on wider area of our county.

2) Parents were motivated to participate in the project only if they were given a lecture about celiac disease and have an opportunity for discussion, so we went to each school, held a lecture, presented a project and had discussion. While information was forwarded only as a written info through the teacher, the parents response was not satisfactory or did not exist at all. It gives us conclusion about parent's need that health topic should always be presented as complete professional information (information about CD testing which was providing by principals or teachers didn't give expected results with approvals; that was the reason we asked to prolong our work).

3) Our county covers the coast, the islands and the mountainous area. Due to the equity distribution, but also as request of our partner PP12, which highlighted the opportunity for as many children from different parts of the county to get a chance to participate in this health preventive program, we decided to give extra effort to organize lectures and testing in the mountainous and island parts of county. Such kind of observation has enabled us to meet a wider social community, to different social and cultural features , as well as the ability to meet the health problems of people from different geographical areas of our county.

- 4) A medical team organization - additional efforts were needed to equip the medical team to do testing because of schools in different geographic areas of our county.



3. 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. positive and relatively fast correlation	1. a small number of children enrolled in the first grade/ which increased the number of school tours
2. interest in the subject/ prevention and health protection	2. dislocation of schools in the county/3 micro-regions/more effort in planning implementation
3. adaptability and teachers' support in preparing children to extract blood	
4. media interest for the pilot project and its results	

4. FURTHER ACTION PLAN (ACTIVITIES FOR THE FUTURE)

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

The results of the Pilot project will be present to the local authorities. Regarding to that results we will not make recommendation for mass screening using fast celiac tests because we did not prove its presence although we have proven secondary goal; IgA deficiency among the children's population. It points to the possibility of increased development of primary intestinal infections, but also of celiac disease if a person has a positive genetic predisposition to develop this disease.



We have definitely proved that cooperation with educational institutions can be achieved in the implementation of pilot projects; that parents have an interest in participating in the health prevention program of their children's health by non-invasive methods; that they are interested in health education; and that there is an interest of the public (also media) to monitor such projects and to participate in raising awareness of different needs, as celiac disease also request.

On transnational level ?

Our work and results we will present in Poland/Montenegro through our activity related to WP4.

- **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?**

We can say that this Pilot Project was of multiple benefit, although we did not confirm any celiac disease (considering that out of ten children with IgA deficiency, four of them had access to further hospitalization, no celiac disease was confirmed, the other six children so far have not responded to further processing). We will resume calls to risky patients to respond to further diagnosis, which was also presented to parents as a part of our activity in some needed cases.

This research was carried out according to the manufacturer's instructions and in our case did not prove successful in terms of certifying celiac disease, but we certainly do not exclude the possibility of further research by this method since many data showed usefulness of rapid test. Nevertheless, the most important result is in raising the awareness of the illness in the general population. It can make everyday life of the people with CD easier with more understanding for their needs, and it can be expected that people will seek medical help in different conditions that can be related to CD and actively search for CD testing.