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1. INTRODUCTION

"Celiac disease is a lifelong systemic autoimmune disorder, requiring extremely meticulous dietary treatment. It affects 1-3% of population (up to 5 million in CE) of all ages. Eighty percent of people having celiac disease remain undiagnosed or misdiagnosed, and diagnostic delays reach 10 years in many regions. Undiagnosed or untreated disease is associated with a number of severe complications and comorbidities". ("Focus on Celiac Disease, Patient centred celiac disease management", Project brochure, FOCUS IN CD, page 2, 2017).

Described facts above explain why systemic and policy level solutions are required, in order to establish quality and patient centred management of celiac disease. Management of celiac disease requires many health system solutions, such as:

- Regular testing of population to identify undiagnosed patients,
- Patient-centred, interdisciplinary, continuous monitoring of quality of life of diagnosed patients across Central Europe regions.
- Support environment in the framework of society and government services, including knowledge, economic measure and psychological support.

Presented Policy recommendations include recommendations to overcome:

- Legal barriers and issues,
- Knowledge and capacity building challenges,
- Organizational and management challenges,

identified during implementation of project activities, surveying key stakeholders and testing of pilot project solutions.

As emphasized by the European health framework, **"Health 2020-a European policy framework supporting action across government and society for health and well-being" ("Health 2020)[1],** health policy must focus on policy actions and innovative responses across all levels of health systems and government sectors, to strengthen roles of public health services and health system.

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[1] Health 2020: a European policy framework supporting action across government and society for health and well-being: http://www.euro.who.int/__data/assets/pdf_file/0006/199536/Health2020-Short.pdf?ua=1

2. METHODOLOGY FOR PREPARATION DELIVERABLE

To collect inputs for policy recommendations in the framework of the project, we identified following thematic fields in the management of celiac disease, which could contribute to more patient-centred oriented approach:

- Better accessibility to existing and new knowledge and better awareness of health care professionals (doctors and other medical workers) at different levels of health care, about diagnostic and treatment of celiac disease;
- Empowering newly diagnosed patients with expert knowledge and information;
- Strengthen communication and collaboration between health, support and other institutions that are part of the social life of patients with celiac disease;
- Continuous transition of patients from paediatric care to an adult outpatient clinic and quality monitoring of adult patients;
- Inclusion of developed and tested pilot services (in the framework of our project) into an existing system.

For the above described thematic fields, policy measures are needed to improve current system solution. The individual policy measure is structured from the information bellow.

SUGGESTED POLICY MEASURE IN THE FIELD OF MANAGAMENT OF CELIAC DISEASE, WHICH COULD CONTRIBUTE TO ENHANCED PATIENT-CENTRED ORIENTED APPORACH	
Objective and background of the suggested policy measure	(2-3 sentences)
Content description of required activities	(4-5 sentences)
Expected result	(2-3 sentences)
Key stakeholders for implementation of the measure	

3. SUMMARY OF EUROPEAN HEALTH POLICY FRAMEWORK[2]

"Health 2020- a European policy framework supporting action across government and society for health and well-being" ("Health 2020), is the main policy document tackling the key challenges of healthcare in Europe.

By supporting "Health 2020", European countries agreed to follow objectives:

- To improve health for all citizens
- To reduce the health divide
- To improve leadership and participatory governance for health.

"Health 2020" policy main objective is to empower health governance. "Health 2020" policy, identified four priority areas that require policy action:

Priority 1: "Investing in health through a life-course approach and empowering people".

Priority 2:"Tackling the Region's major health challenges of non-communicable and communicable diseases"

Priority3:"Strengthening people-centred health systems, public health capacity and emergency preparedness, surveillance and response".

Priority 4:"Creating resilient communities and supportive environments".

Priority area 1. "Investing in health through a life-course approach and empowering people"

Priority area is focused on increasing long and healthy life expectancy, through all stages of life. It also emphasizes healthy and active aging, due to demographic trends in Europe, promotion of health, importance of preventive programmes and supportive environments, improving health knowledge, promoting healthy workplaces and providing healthy food.

Priority area 2. "Tackling Europe's major health challenges: noncommunicable and communicable diseases"

Priority is focused on management of noncommunicable and communicable diseases. In order to improve current state, public health actions and health care system interventions are needed. "Health 2020" especially welcomes integrated "whole of government" and "whole of society" approaches.

In the field of noncommunicable diseases efforts are oriented towards tobacco control, to reduce harmful use of alcohol, global strategy on diet.

In the field of communicable diseases efforts are oriented towards information and surveillance capacity of public health, food, to better control infectious diseases and to tackle serious viral and bacterial threats.

Priority area 3. "Strengthening people centred health systems, public health capacity and emergency preparedness, surveillance and response".

Priority stresses following health challenges: demographic, mental health, chronic diseases and conditions related to aging. All named challenges require approaches oriented towards disease prevention, more integrated services, continuous care, and support for patient's self-care.

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[2] Health 2020: a European policy framework supporting action across government and society for health and well-being: http://www.euro.who.int/__data/assets/pdf_file/0006/199536/Health2020-Short.pdf?ua=1 (pages 9- 20)

Priority area 4. Creating resilient communities and supportive environments

Fast changes related to technology use, work, energy production and urbanization effect the health of communities. In order to establish resilient communities and supportive environments a lot of work must be invested in promoting health and well-being.

Priority emphasizes interdisciplinary and inter-sectoral cooperation between the environmental and health sector to protect human health from the risks related to the polluted environment

Celiac disease is a long-term disease, which belongs in group of chronic diseases, therefore Priority area 3 "Strengthening people centred health systems, public health capacity and emergency preparedness, surveillance and response", is very important for the support of patient centred management of celiac disease in Europe and also Central Europe.

4.POLICY RECOMMENDATIONS IN THE FIELD OF MANAGAMENT OF CELIAC DISEASE

4.1 SLOVENIAN RECOMMENDATIONS

MEASURE: Accreditation of learning materials at Medical chamber of Slovenia	
Objective and background of the suggested policy measure	Currently there is insufficient awareness and knowledge about coeliac disease among HCPs. This is based on existing literature and on results of activities of Focus IN CD project. To improve the awareness and knowledge of HCPs (doctors, nurses, dietitians, students) about coeliac disease.
Content description of required activities	Authorities responsible for Continuous Medical Education (CME) should recognize all materials developed within the project. In Slovenia Medical Chamber of Slovenia accredits learning programmes. Learning programmes and materials developed should be afterward promoted through the network channels of Medical Chamber of Slovenia. UKC Maribor with other partners of the project will be responsible for regular updating of Slovene materials.
Expected result	Increased knowledge of HCPs is anticipated. This will also lead to better diagnostic yield and better follow-up of patients with coeliac disease.
Key stakeholders for implementation of the measure	Doctors – specialists of different specialities, including paediatricians, gastroenterologists, family doctors, nurses, dietitians, medical students. Students of Health care studies. Medical Chamber of Slovenia. Patients. Coeliac Disease Society.

MEASURE: Formation of National Coeliac Disease Study Group	
Objective and background of the suggested policy measure	Currently there is insufficient knowledge about coeliac disease among HCPs and other social service providers in Slovenia. This is based on the results of activities of Focus IN CD project, especially in the feedback gained in surveys. There is also a lack of institutional co-operation. To establish a National Coeliac Disease Study Group.
Content description of required activities	HCPs responsible for coeliac disease management should form a core group of the National Coeliac Disease study Group. Slovene Coeliac Disease Society representatives should be members of the group. The group should also involve nurses, psychologists and dieticians. Group should seek the involvement of experts form National Institute of Public Health, Ministry of Health and experts from Institute for Education. Group should meet annually. At annual meetings, new developments in the field of coeliac disease should be discussed. Meetings should be open for other stakeholders
Expected result	Increased knowledge of HCPs. Improved management of CD patients. Rapid exchange of knowledge and best practices. Introduction of new developments from other regions. Cooperation between centres. Improved

	doctors-patients interactions. Possibility to design epidemiological and other studies. Promotion of the development of National Coeliac Disease Registry.
Key stakeholders For implementation of the measure	Healthcare institutions. Coeliac disease society. Institute of Public Health. Ministry of Health, National Institute of Education. Health care practitioners.

MEASURE: Formation of Hospital Coeliac Disease Management Groups	
Objective and background of the suggested policy measure	Currently there is insufficient knowledge about coeliac disease among HCPs in many institutions. There is no comprehensive management protocol developed. There is also a lack of institutional co-operation. To establish a local Hospital Coeliac Disease Management Groups.
Content description of required activities	HCPs responsible for coeliac disease management in Slovene hospitals will organize local Coeliac Disease Management Groups. Groups will involve nurses, psychologists and dieticians. Group will need to be appointed by Hospital management, and should meet annually. At annual meetings, issues regarding patient management, availability of diagnostic tools, new developments in the field of coeliac disease will be discussed. Meetings will be open for other stakeholders. Members of individual groups will collaborate on national level.
Expected result	Improved management of CD patients. Rapid exchange of knowledge and best practices. Introduction of new developments from other regions. Cooperation between centres. Improved doctors-patients interactions.
Key stakeholders for implementation of the measure	Healthcare institutions. Coeliac disease society. Institute of Public Health. Ministry of Health. National Institute of Education. Health care practitioners.

MEASURE: Transition Clinics at all institutions managing children and adults with coeliac disease	
Objective and background of the suggested policy measure	Currently there is inadequate transition of patients from paediatric to adult care. To establish formal transition clinics in healthcare institutions managing children and adults with coeliac disease.
Content description of required activities	Formal transition clinics should be organised at each healthcare institution. Exact transition protocol should be designed. Passport developed within the Focus IN CD project by partner KUM should be promoted. Doctors, nurses, dietitians and psychologists should be joining the transition team. Celiac disease society personnel should be involved.
Expected result	Improved transition from paediatric to adult care will be ensured. Better compliance with gluten free diet will be achieved. Better follow-up by adult care specialists will be achieved.
Key stakeholders for implementation of the measure	Health care practitioners. Patients. Healthcare institutions. Coeliac disease society.

MEASURE: National Coeliac Disease Patient Registry	
Objective and background of the suggested policy measure	Currently there is inadequate insight in real coeliac disease patient data. To establish formal National Coeliac Disease Patient Registry.
Content description of required activities	Coeliac disease patient registry will serve as the best source of information on current situation in the disease management, diagnostic delays, changes in clinical presentation, demographics of patients, changes in prevalence of disease... It will also serve decision makers on national level to better plan institutional capacities for coeliac disease management. At the same time, it will help institutions to detect patients who could benefit from institutional incentives. It will be developed on a national level with involvement of Healthcare institutions managing children and adults with coeliac disease, Ministry of health and National Institute of Public Health.
Expected result	Improved overview of the national burden of coeliac disease, both as regards the patients and healthcare system capacities.
Key stakeholders for implementation of the measure	Health care practitioners. Patients. Healthcare institutions. Ministry of health. Institute of Public Health.

MEASURE: Formation of National Food Related Disorders Group at Institute of Education	
Objective and background of the suggested policy measure	Currently there is insufficient knowledge and management of children in Kindergartens and Schools in Slovenia. To establish a National Food Related Disorders Group at Institute of Education
Content description of required activities	Kindergarten and schools authorities responsible for healthy diet of children in these institutions should appoint members of their staff to formal Food Related Disorders Group. This group should include psychologists and social workers. They should attract healthcare institution responsible for that education institution (paediatrician, nurse) to participate in the group. Parent’s representative should join the group. Core group should be formed on national level. It should cooperate with National Coeliac Disease Study Group. Local groups should address issues in their own environment, and discuss their problems with national group on annual basis. Group should be responsible to organise Gluten Free Breakfast Day in all public education institutions.
Expected result	Increased knowledge of personnel responsible for healthy diet in schools and kindergartens. Better exchange of knowledge and best practices. Cooperation between centres. Improved patient-parent-school-kindergarten interactions. Promotion of healthy diets on national level.
Key stakeholders for implementation of the measure	Healthcare institutions. Education institutions. Health care practitioners. Teachers. National Institute of Education. Patients.

MEASURE: National Coeliac Disease Patients Log-book.	
Objective and background of the suggested policy measure	Currently patients with coeliac disease lack the awareness and knowledge about their disease. This makes them less competent in self-management of the disease. To promote the universal use of coeliac disease patients logbook.
Content description of required activities	Coeliac disease patient logbook will be designed based on the passport that was designed for better transition from paediatric to adult care. Patients will need to participate at educational activities including e-learning tools designed within Focus IN CD project. They will need to be seen by a doctor, dietitian, psychologist, and trained nurse. They will need to undergo mentorship programme provided by Society. They should also be involved in other modules organised by Coeliac Disease Society. Different levels of self-management competences will be awarded to patients.
Expected result	Higher level of self-management will enable patients with coeliac disease to experience higher quality of life, with lower risk to develop disease complications. Patients with higher level of knowledge will present less burden to the healthcare system and less burden to the society as a whole.
Key stakeholders for implementation of the measure	Patients. Coeliac disease society. Healthcare institutions. Health care practitioners.

MEASURE: Formation of Coeliac Disease Management Centre	
Objective and background of the suggested policy measure	Currently there is insufficient accessibility of HCPs with high level of expertise in coeliac disease in Slovenia. Patient management is based on preferences of individual HCPs and their institutions. No comprehensive coeliac disease management centre exist. To establish a Coeliac Disease Management Centre.
Content description of required activities	A comprehensive coeliac disease management centre, which should involve doctors, specialised in gastrointestinal diseases of children and adults, trained nurses, dietitians and possibly psychologist, should be established. Activities of this centre should be included in the national insurance reimbursement scheme. Primary care doctors should appoint patients to such centre. HCPs working in such centre should be actively involved in National Coeliac Disease Study Group.
Expected result	Improved management of CD patients in specialized coeliac centre. Rapid introduction of new developments from other regions. Cooperation between centres. Improved doctors-patients interactions. Possibility to design epidemiological and other studies.
Key stakeholders for implementation of the measure	Patients. Ministry of Health. National Health Insurance. Health care practitioners.

MEASURE: Ensuring routine follow-up for adult patients with coeliac disease	
Objective and background of the suggested policy measure	Currently there is insufficient accessibility of HCPs with high level of expertise in coeliac disease in management of adult patients in Slovenia. Patient management is based on preferences of individual HCPs and their institutions. Regular follow-up visits are not scheduled. To ensure routine follow-up of adult patients with coeliac disease.
Content description of required activities	Health care institutions managing adult patients with gastrointestinal disorders should enable enough personnel for regular follow-up visits of coeliac disease patients. Preferably once a year. National Health Insurance should reimburse these visits. Focused laboratory work-up should be performed at these follow-ups based on international management guidelines.
Expected result	Improved management of adult CD patients. Improved doctors-patients interactions. Early preventive and curative measures.
Key stakeholders for implementation of the measure	Patients. Ministry of Health. National Health Insurance. Health care institutions. Health care practitioners.

MEASURE: Promoting routine dietetic counselling for coeliac disease patients	
Objective and background of the suggested policy measure	Currently there is insufficient accessibility of dietitians with high level of expertise in coeliac disease in Slovenia. Dietetic counselling is based on preferences of individual service providers and regional accessibility of dietitians. To promote routine dietetic counselling for coeliac disease patients.
Content description of required activities	A network of dietitians skilled in coeliac disease patient counselling should be established. National Health Insurance should reimburse dietetic counselling. Dietitians should be specifically trained to provide disease specific service. They should be involved in reginal Coeliac Disease Groups.
Expected result	Improved management of CD patients.
Key stakeholders for implementation of the measure	Patients. National Health Insurance. Health care practitioners. Dietitians.

4.2 CROATION RECOMMENDATIONS

MEASURE: Complete medical basic care	
Objective and background of the suggested policy measure	In Croatian's hospital system there is no complete medical care for CD patients basic on gastroenterologist +dietitian + psychologist. After diagnosis, rare hospitals provide nutrition counselling for the parents of the underage children. Adult patients are fully counselled about the gf diet in CD societies. They take a great responsibility in managing the patients. It is important to note that the people who lead societies have minimal professional knowledge about nutrition. Their work is based on experience gained through the long-term implementation of a restrictive gf diet which is definitely not enough because CD patients mostly have other serious health issues related to CD.
Content description of required activities	After the diagnosis is made the patient needs a professional nutritionist / dietitian-specializing in gluten-free diet because the diet is the only cure for disease and psychologist- who need strengthen and advise the patient for living with a life-threatening illness and how to use self-discipline and self-evaluation tools, to overcome everyday "hard steps".
Expected result	Improved management of CD patients. Empowering the patient with expert guidance for a better understanding of CD, in order to provide more adequate patient self-care so that reduce further health disturbance and development of complications of CD disease and ultimately a reduction in health costs.
Key stakeholders for implementation of the measure	Gastroenterologists. Dieticians. Psychologists. Patients.

MEASURE: Regular education of hospital kitchen staff on gluten free food requirements	
Objective and background of the suggested policy measure	In the hospital's kitchen there is insufficient professional knowledge of gluten free diet requirements. There are frequent failures that are rarely related to the wrong choice of foods and more often is related to meal contamination. Patients express their dissatisfaction with the Patient Societies and through the Facebook patient support group.
Content description of required activities	Dieticians and kitchen staff need to improve their knowledge of preparation safe gluten free meal through Focus in CD created web tools for patients as well as specific instructions that ensure an uninfected meal.
Expected result	Improved management of CD patients. Avoiding insecure hospital treatment which directly disrupts the health of patients suffering from celiac disease. Avoiding possible lawsuits.
Key stakeholders for implementation of the measure	CD Society. Public Health Institution. Dietitians. Kitchen staff.

MEASURE: Long-life basic social rights	
Objective and background of the suggested policy measure	Ensuring basic social rights (finance, material, immaterial) for patients suffering from celiac disease since it is a life-threatening illness whose only remedy is the implementation of a strictly long-life gluten free diet. Such diet requires increased cash outflows. Most patients are unable to respond to such requests and this is one of the reasons for not carrying out a gluten free diet and direct disturbance of health due to economic inability
Content description of required activities	The relevant institutions should make their rulings through their statutes to ensure the material and immaterial rights of patients suffering from celiac disease and the financial rights that would directly affect the quality of life, maintenance of the patient's health and the dignity of living with lifelong disease. It is important to note that such rights need to be provided for children and adults (they must not be discriminatory).
Expected result	Increase the quality of life. Settling the increased basic living expenses of food and ensuring a strict gluten-free diet which is the only cure for CD. Treating the increased health cost cause patients suffering from celiac disease most often suffer from several other autoimmune chronic diseases.
Key stakeholders for implementation of the measure	Health Insurance Institutions, Social Welfare Institutions, CD societies, Ministry of Health

MEASURE: Safe gluten-free food for kindergartens, schools and student restaurants	
Objective and background of the suggested policy measure	There is no adequate care in Croatia through pre-school and school education, and in furtherance of ensuring safe gluten free meals for children suffering from celiac disease. This violates their basic right to education, and such a system is completely discriminatory and encourages the segregation of persons with special needs. This violates the basic principle of equality and freedom and health treatment cause of those special needs. Nutrition in kindergartens and schools is usually arranged on an individual parent-educational Institution basis. Contracts are very often signed to protect the institution of possible lawsuits of parents for damaging the health of their children suffering from celiac disease because they are not able to provide them adequate gluten free nutrition. Students also do not have adequate nutrition in student restaurants.
Content description of required activities	Nutrition in kindergartens, schools and student restaurants is a part of the state system, it is participated and also need to be ensure for those who suffer from celiac disease equally as l other health children(with no such special need) and youth have. For staff education in named institutions (kitchen staff, waiters in student restaurants, teachers and kindergarten educators...), a web tool for patients and additional professional guidance and support from experts from the Public Health Institute and Associations is recommended.
Expected result	Increasing the quality of life of an affected person. Better disease management. Reduced costs of patient treatment. Reduced costs of the health system. Respect for the fundamental human rights prescribed by the UN Convention
Key stakeholders for implementation of the	Educational institutions, Public Health Institution, CD society, Ministry of Education

measure	

MEASURE: Reducing the value of added tax for gluten-free products	
Objective and background of the suggested policy measure	In Croatia, the value added tax is 25%, what in the beginning leads us to an unequal position with the Central European countries. Gluten-free products are themselves more expensive at start-up, and the pursuit of gluten-free diet requires higher start-up costs. Such a high tax definitely endangers the process of treating the patient and conducting adequate long-life care providing by every patient.
Content description of required activities	The Ministry of Finance should make a special decision on the taxation of food as a cure. The tax should definitely be reduced and a specific rules should focus on the specific category of beneficiaries/users.
Expected result	Improved management of CD patients. Better quality of life.
Key stakeholders for implementation of the measure	Ministry of Finance, Ministry of Health, CD Society.

MEASURE: Institutional support for gluten-free food producers	
Objective and background of the suggested policy measure	In Croatia there are small number of gluten free producers. The market offer is largely based on foreign industrial gluten free products. Domestic industry still does not show enough interest in product testing for the presence of gluten and their labelling (certification).
Content description of required activities	It is necessary to inform the manufacturer about the new gluten free market requirements based on the fact related to number of people with CD but also non-celiac gluten intolerance and gluten allergy in the country, but also in Europe and the world (given that we are a well-known tourist destination). Systematic education and information for small food producers. Connecting large industries and small agricultural holdings to achieve co-operation on the basis of the production of non-contaminated gluten free cereals. Encourage manufacturers to test food products and label them with a cross-wheat class and control them to meet the safety and quality criteria of gluten-free products.
Expected result	Increase of gluten free domestic market. Domestic production progress. Better offer, better quality of life for patients
Key stakeholders for implementation of the measure	Chamber of Commerce, Ministry of Agriculture, Ministry of Health, associations, small and large food producers in Croatia

MEASURE: Preventive program / Screening of CD	
Objective and background of the suggested policy measure	World and European data talk about celiac disease as a major public health problem of today that affects 1-3% of the general population. Disease is less detected through classical / well-recognizable symptoms. Asymptomatic image of celiac disease makes it difficult to diagnose (in adults 6-10 years delay, in children up to 2 years delay). The disease develops and promotes

	the illness of many other autoimmune diseases. Disease is defined as multiorgan (because inadequate treatment and late detection affects the entire organic system), although it is primarily related to the small intestine.
Content description of required activities	We should certainly think in the context of early detection and prevention of many complications of the disease. We need to keep in mind the concealed disease symptoms complicating the diagnosis. It is necessary to consider a further research / pilot project that would be make with a non-invasive method of testing children on celiac with rapid test ,at period of enrolment in first grade of primary school to contribute to early detection of the disease.
Expected result	Early detection of CD and prevention of other health issues. Reducing of health system costs (diagnostic delay ; facts based on Focus in CD research)
Key stakeholders for implementation of the measure	Ministry of Health, Public Health Institution, Primary care physicians

MEASURE: Regular education for health care professionals about CD	
Objective and background of the suggested policy measure	In Croatia there is insufficient knowledge of celiac disease as a multi-organ disease and the special requirements of a patient suffering from celiac disease and its treatment therefore requires their systematic education.
Content description of required activities	The health care professionals which needed to be covered by education range from primary practice of family doctors, specialists (special for illnesses related to celiac disease), nurses, nutritionists / dietitians. Education should be based on web tools created through the Focus in CD project.
Expected result	Improving of knowledge about CD. Better treatment and understanding of patients.
Key stakeholders for implementation of the measure	Better health care conditions as a part of CD management for health care professionals.

4.3 GERMAN RECOMMENDATIONS

MEASURE: Updated guidelines for the Diagnosis of Celiac Disease in Adult Patients and Improved Training Activities for Adult Gastroenterologists.	
Objective and background of the suggested policy measure	For pediatric gastroenterologists, celiac disease is a well-known and relevant entity in their daily work and usually they have a rather good knowledge how to diagnose and treat it. However, gastroenterologists working in adult care are often not well informed about the correct diagnostic steps because celiac disease is not one of their focus of interest. Consequently, it is difficult to raise awareness about the potential problems and pitfalls in celiac disease diagnosis (serology, histopathology) and dietary management. Furthermore, the current guidelines for diagnosing celiac disease in adult patients are already outdated (DGVS 2014) and need to be revised.
Content description of required activities	Improved training strategies and activities of adult gastroenterologists should be developed, **taking advantage of the already available e-tools** of the Focus IN CD project together with leading celiac experts in Germany and in collaboration with the German Society for Gastroenterology, Digestive and Metabolic Disorders (DGVS) and the German Celiac Disease Patient Society (DZG). DGVS and DZG should actively promote the e-learning and the Web-App for physicians. In addition, the newly developed celiac passport (pilot project of PP8 KUM – transition programme D.T3.2.9) will be actively disseminated among all pediatric and adult gastroenterologists by the DZG and if successful, DZG already agreed on printing more passports on their own cost. Furthermore, DGVS will be encouraged to update the guidelines for the diagnosis of celiac disease in adult patients based on the new European Pediatric Guidelines which are being published by mid of 2019.
Expected result	A strategy for gastroenterologists working in adult health care can only be successful if it’s driven by other well-accepted gastroenterologists working in this field, therefore such a strategy will finally lead to knowledge improve and therefore improved management, identification and diagnosis of adult patients with celiac disease.
Key stakeholders for implementation of the measure	Celiac disease experts working and doing research in adult celiac patients (University Hospital Charité Berlin, University Hospital Mainz) DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheitengen e.V.) DZG (Deutsche Zöliakie-Gesellschaft e.V.)

MEASURE: National Celiac Disease Registry	
Objective and background of the suggested policy measure	Although Celiac Disease is a chronic autoimmune disease and frequent in the general population with a prevalence of 1%, only approximately 80 to 90% have not been diagnosed and in those, the diagnosis is often delayed for years. Little is known about its true management in clinical practice, correct diagnosis, follow-up monitoring and potential long-term health consequences due to delayed diagnosis and/or lack of compliance with the gluten-free diet. A structured, nation-wide

	registry for celiac disease could give substantial in important insights and relevant statistical data as basis for further improvement of the patient management. Particularly the identification of the rare but often fatal refractory disease can only be studied in a nation-wide setting.
Content description of required activities	Main steps in the preparation and development of a national CD registry have already been taken by the German Celiac Disease Society (DZG) and its scientific committee (Sibylle Koletzko is one of the team). However, there is still a lack of funding for this long-term ambiguous project. Therefore the identification of sources for ongoing financial support as well as the definition of a sustainable setting to establish and keep the registry with high quality for reasonable costs are important.
Expected result	The National Celiac Disease Registry will provide important data and insights in the current and future management of celiac disease and will help to identify pitfalls and problems in practice which will need to be tackled.
Key stakeholders for implementation of the measure	DZG (Deutsche Zöliakie-Gesellschaft e.V.) Kompetenznetz Darmerkrankungen e.V. DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheiten e.V.) GPGE (Deutsche Gesellschaft für Pädiatrische Gastroenterologie und Ernährung)

MEASURE: National Dissemination and Use of the Celiac Disease Patient Passport	
Objective and background of the suggested policy measure	Patients are often only told about the diagnosis of celiac disease but it lacks written reports which are handed out to the patient and document details on the diagnostic measures and outcomes for her- or himself. As celiac disease is a lifelong condition, patients usually visit different doctors during their lifetime - either related to the follow-up of celiac disease or other due to other health problems. Years later, other doctors or the patient her-/himself may question if the diagnosis was made correctly but cannot proof it without having access to the previous medical records. Furthermore, the monitoring of celiac disease is also an important measure but often neglected and the patient does not get written reports on the serology results, thus does not have a good understanding of the own disease management. In addition, an official document confirming that a patient truly suffers from celiac disease and needs a gluten-free diet may help the patients to raise awareness that they truly have to avoid even traces of gluten (e.g. ordering food in a restaurant or when seeking medical care). Within the Focus IN CD project, an update of the previous celiac passport of the German Celiac Disease Society was developed and disseminated mostly to pediatric gastroenterologists. The passport does not only allow the correct and complete confirmation of the diagnosis and the monitoring but also to gives basic information to health care professionals less experienced with celiac disease. Moreover, the passport includes a “Celiac ID card” to be signed by the doctor, which the patient can carry with her/him every time and show it e.g. in the restaurant.
Content description of required activities	The celiac passport should be disseminated to all physicians diagnosing celiac disease in Germany, not only comprising pediatric gastroenterologists but also physicians working in adult care in gastroenterology. To do so, the German Celiac

	Society could disseminate the passport upon request but the relevant medical societies need to advertise and recommend the use of the passport to their members.
Expected result	A national launch of the celiac Passport can help to improve the correct steps of the diagnosis and the monitoring, to document all medical outcomes correctly and completely and to provide the patient a tool for their own self-management in order to improve the compliance with the diet and the monitoring visits.
Key stakeholders for implementation of the measure	DZG (Deutsche Zöliakie-Gesellschaft e.V.) DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheiten e.V.) GPGE (Deutsche Gesellschaft für Pädiatrische Gastroenterologie und Ernährung) Gastroenterologists working in adult and pediatric care

MEASURE: Transition Programme for Adolescents with Celiac Disease	
Objective and background of the suggested policy measure	In the challenging phase of puberty, adolescents wish to identify themselves with their peers and therefore feel stigmatized by the gluten-free diet. This frequently leads to non-compliance. Furthermore, adolescent should also learn to take care of their own responsibility (including appointments for medical check-ups etc.) but are often over-protected by their parents, resulting in insufficient self-management when becoming adult. Although a transition programme has already been suggested for celiac disease (*Ludvigsson et al. Gut. 2016 Aug;65(8):1242-51*), it has up to now not yet been implemented in the clinical practice of German Pediatric Gastroenterology Units.
Content description of required activities	Based on the Focus IN CD pilot project developed by PP8 KUM, a strategy for transition of adolescents with celiac disease into adult healthcare can be developed in collaboration with the German Celiac Disease Society (DZG) and the German Society for Pediatric Gastroenterology and Nutrition (GPGE). All materials of the pilot project's transition workshop as well as the newly developed Celiac Passport will be comprised and further promoted and offered to all German Pediatric Gastroenterologists.
Expected result	To offer materials for the transition workshop as well as the already well accepted new Celiac Passport will help to support adolescents with celiac disease to accept their condition. This will improve the compliance and the further medical follow-up and reduce the risk for long-term health consequences.
Key stakeholders for implementation of the measure	DZG (Deutsche Zöliakie-Gesellschaft e.V.) DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheiten e.V.) GPGE (Deutsche Gesellschaft für Pädiatrische Gastroenterologie und Ernährung) Pediatric Gastroenterology Centers Local Social Pediatric Centers

Training of dietitians and nutritionists for dietary counselling of celiac patients	
Objective and background of the	The gluten-free diet is still the only and life-long, but very effective therapy to treat celiac disease. Nevertheless, patients need to stick to a strict diet; even

suggested policy measure	traces of gluten have to be avoided. This setting substantially affects the patient's eating habits, the daily life routine and social life (e.g. eating out at with family, friends, colleagues, when travelling etc.). Consequently, an extensive and comprehensive dietary counselling is of utmost importance, also considering the individual situation of the patient. However, not all dietitians and nutritionist are experienced with the gluten-free diet. Patients can try to find a dietitian with good knowledge in celiac disease and gluten-free diet themselves, but usually only part of the costs are reimbursed by the health insurance. Furthermore, some public health insurances in Germany only offer dietary counselling of their own dietitians and do not reimburse any external dietary counselling. However, dietitians from the health insurances are often not well trained in the gluten-free diet, leading to insufficient counselling of patients who are often frustrated and do not feel self-confident in managing their gluten-free treatment.
Content description of required activities	In collaboration with relevant societies of dietitians and nutritionists as well as with the German Celiac Disease Society (DZG), a training programme for dietitians and nutritionist should be developed to improve the knowledge about celiac disease and the gluten-free diet. In addition, the public health insurances should be involved here and attention must be drawn to the fact that the dietary counselling is a central part of the therapy. Furthermore, the online course on celiac disease for physicians & dietitians, developed within the Focus IN CD project, should be promoted as this is an easy and free to use tool, which already exists.
Expected result	Improved quality of dietary counselling will be supportive for newly diagnosed celiac disease patients and may improve the compliance to the gluten-free diet.
Key stakeholders for implementation of the measure	DZG (Deutsche Zöliakie-Gesellschaft e.V.) VDD (Verband der Diätassistenten - Deutscher Bundesverband e.V.) VDÖ (Berufsverband Ökotrophologie) DGEM (Deutsche Gesellschaft für Ernährungsmedizin) Public health insurances in Germany (e.g. AOK, TK and others)DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheiten e.V.)

MEASURE: Nation-wide Celiac Disease Campaign	
Objective and background of the suggested policy measure	Many patients with celiac disease are still facing several problems in daily life, particularly when eating outside and in social situations (e.g. eating out with family, colleagues, friends). Current gluten-free dietetic trends for life style and not medical reasons are popular with detrimental effects for celiac patients as they feel stigmatized and their social environment often does not take their problem seriously to stick to a strict gluten-free. Even the majority of professionals working in the gastronomy (kitchen staff, service) is indeed not aware of the true consequences of gluten contamination and the burden for celiac patients.
Content description of required activities	The German Celiac Disease Patient Society (DZG) should be encouraged and supported to enhance their activities in the social marketing of celiac disease to raise the awareness and inform the public but also professionals working in medical care and in gastronomy about facts of celiac disease. New innovative marketing strategies should be investigated. Collaboration with other Societies (German Society of Nutritional Medicine DGEM, Germany Society of Nutrition DGE; German Society for Gastroenterology, Digestive and Metabolic Disorders (DGVS), German Society for Pediatric Gastroenterology and

	Nutrition (GPGE)) are important for the campaign and synergies with food allergy campaigns may be reasonable and more effective, e.g. the collaboration with the German Society for Allergology and Clinical Immunology (DGAKI). Involvement of the German Association of Hotel and Catering Industry, with whom DZG has already been collaborating earlier, is reasonable to reach the target groups.
Expected result	A better awareness and knowledge about facts on celiac disease in the general population and among professionals working in fields related to celiac patients (medical care; hotel and catering industry) will lead to a better acceptance and therefore can improve the dietary compliance of the affected patients and their overall quality of life.
Key stakeholders for implementation of the measure	DZG (Deutsche Zöliakie-Gesellschaft e.V.) DGEM (Deutsche Gesellschaft für Ernährungsmedizin e.V.) DGE (Deutsche Gesellschaft für Ernährung) DGVS (Deutsche Gesellschaft für Gastroenterologie, Verdauungs- und Stoffwechselkrankheiten e.V.) GPGE (Deutsche Gesellschaft für Pädiatrische Gastroenterologie und Ernährung) Kompetenznetz Darmerkrankungen e.V. DEHOGA (Deutsche Hotel- und Gaststättenverband e.V.)

4.4 ITALIAN RECOMMENDATIONS

MEASURE: Application of innovative immunological assay in the diagnosis of all clinical forms of celiac disease	
Objective and background of the suggested policy measure	To date, guidelines and diagnostic practices capable of identifying and adequately treating symptomatic subjects with atypical celiac disease are missing. The aim of the measure is focus to the improvement of the knowledge concerning the various clinical forms of celiac disease and the use of innovative diagnostic tools to identify and diagnose all these clinical conditions.
Content description of required activities	Develop the use of innovative immunological techniques on intestinal biopsies able to diagnose celiac disease even in atypical conditions in which this condition occurs. Establish the use these diagnostic methods in daily clinical practice and evaluate the specificity and sensitivity of these methods versus standard procedures.
Expected result	Good levels of diagnostic specificity and sensitivity of immunological tests (> 90%). This should lead to a diagnostic improvement and a rational treatment (gluten-free diet) of these patients that will have to be followed to monitor the clinical advantage of the gluten-free diet. Discuss the results obtained during national and international scientific meetings. Publish results in scientific journals.
Key stakeholders for implementation of the measure	Family paediatricians, general physicians, gastroenterologists, dietitians. Patients and Italian Celiac Society.

MEASURE: Guideline for the diagnosis of celiac disease in new at CD-risk groups: subjects with severe food allergy.	
Objective and background of the suggested policy measure	It is unclear whether subjects with food allergy constitute a group at risk for celiac disease. The aim is to verify the real prevalence of celiac disease among children with severe food allergy and propose an active CD-screening in these patients.
Content description of required activities	Children with severe food allergy, a positive history for a severe allergic reaction defined according to Clark's criteria. Measure the specific CD-antibodies and in case of positivity propose the endoscopic investigation to formalize the diagnosis of celiac disease. Follow the children for at least a year during the gluten-free diet.
Expected result	To include at least 150 children with severe allergy and produce robust prevalence data to consider this clinical condition at risk of celiac disease and provide rational guidance for CD-screening.
Key stakeholders for implementation of the measure	Family paediatricians, general physicians, gastroenterologists, expert for allergies.

4.5 HUNGARIAN RECOMMENDATIONS

MEASURE: Screening of first degree relatives of coeliac disease patients	
Objective and background of the suggested policy measure	Since coeliac disease has a strong genetic background, family members of diagnosed patients have elevated risk for the disease. This risk is on average 10%, but depending on the number of inherited risk alleles, it may go up to 40% in the children of coeliac patients. Undiagnosed subclinical disease or silent small bowel damage may lead to complications, such as osteopenia, chronic iron deficiency, compromised physical and mental fitness, underachievement of academic degrees. Currently family members have insufficient knowledge, referrals are occasional and dependent on volunteering. Costs of the investigations are often not incorporated in the insurance scheme. Both under and over investigations occur. No there is no regular measure dealing with family members and it is unclear which health sector should provide this service. To establish open access family screening in the Coeliac Disease Management Centre.
Content description of required activities	In a comprehensive coeliac disease management centre motivation for screening is raised by appropriate information on this condition, serology tools provided and persons found positive enrolled in the diagnostic process. Genetic test (HLA-DQ typing) is provided in contradictory cases or when clinically necessary. Interpretation of results is done in expert way. For young family members (below the age of 9 years) there is a predefined scheme for follow-up (3, 6 and preferably at 9 years of age). Activities of this screening service should be included in the national insurance reimbursement scheme. Primary care doctors should refer family members to such centre.
Expected result	Increase of CD diagnoses and better patient health outcome with improved quality of life. Reduction of medical and social costs associated with long-term undiagnosed disease.
Key stakeholders for implementation of the measure	Patients and their relatives. Ministry of Health. National Health Insurance. Health care practitioners.

MEASURE: Gluten-free safe food in restaurants and hospitality services	
Objective and background of the suggested policy measure	The only well-known and effective treatment of coeliac disease is the lifelong and strict gluten-free diet. This means that the patient mustn’t eat more than 10 mg of gluten/day (Carlo Catassi et al: A prospective, double-blind, placebo-controlled trial to establish a safe gluten threshold for patients with celiac disease (Am J Clin Nutr 2007;85:160-6). This is a really small amount and the patients usually are worried about the consequences of the unintended diet faults and they are afraid to go eating out of their home. That is the reason why they limit visiting restaurants and travelling in their country and abroad – consequently their quality of life is worse than it could be.

	The aim is to train restaurants (hotels, hospital kitchens and the public catering providers), so as the owner and the staffs know what does it require for a coeliac patient as a safe gluten-free meal.
Content description of required activities	It was necessary to develop a training material which booklet contains relevant information about the disease, the rules of the gluten-free diet and the food which is safe, prohibited or must-be-checked before serving it to gluten-intolerant customers. One detailed chapter with basic advises for using gluten-free ingredients to safe and savoury gluten-free meals. Training of restaurants (hotels) is the following step. It is useful to involve in the training also the students of secondary schools where the further chefs, cooks, waiters, conditioners are learning. The system is based on volunteers' active participation, because the restaurants' staff changes and food quality must be inspected regularly.
Expected result	For coeliac patients the safe 'gluten-free restaurant network' will increase the quality of life and decrease their psychosocial burdens. They could be again active members of their social network and can go out for program where eating is an essential part without fear and worry. Better disease management. Reduced costs of patient treatment. Reduced costs of the health system. Respect for the fundamental human rights prescribed by the UN Convention Possibility to join the AOECS 'Eating Out Gluten-free' program to be part of a really wide European network.
Key stakeholders for implementation of the measure	Coeliac patients and their relatives. Volunteers of the program. Coeliac Society members. Owners and staffs of restaurants. Secondary and high schools for restauration and hospitality. Food safety authorities and controllers Dietitians and other health care professionals. Public and private providers.

MEASURE: Reducing the value of added tax for gluten-free products	
Objective and background of the suggested policy measure	In Hungary, the general value added tax for food is 5/18/27%. Unfortunately the gluten-free specialized products are not in the preferential 5% category, their customers are charged by 18 (cereal based products) and 27% (any others) and these charges are high, compared to the 5% of the pharmaceutical products. Other UE-member states the food have lower VAT %, e.g.: Malta and UK: 0%, Italy: 4/5/10%, Austria: 10%. https://ec.europa.eu/taxation_customs/sites/taxation/files/resources/documents/taxation/vat/how_vat_works/rates/vat_rates_en.pdf On the other side, the compensation of coeliac patients is very limited. Only for children available for parents a higher family allowance until generally 18 years old/ special cases 21 year of age. Adulthood is limited the support as only those who are subject of personal tax, so they can reduce their charges - by the general preferential rule for all chronic ill patients - every month by 5% of the state minimal salary. Besides these 2 groups there are big vulnerable groups of diagnosed coeliac patients - ones who are older than 18 year and are students of universities or colleges, the unemployed persons and the biggest group is the retired persons, who has no other incomes as their pension.

	Gluten-free foods are more expensive because of technical and food safety reasons than the staple counterparts. Moreover, coeliac disease has no pills or any other medicaments which are usually and naturally reimbursed as for other lifelong chronic ill patients are systematically done. These two facts mean significant inequalities and lower quality of life of coeliac patients - so the present system must be changed and they must have the same conditions as other patients. There are some techniques or controllable way for their compensation, like 5% VAT for the quality and controlled gluten-free foods or refunding the higher VAT for those coeliacs who are active partners of their disease management. Elaborating a European-wide guideline for such a supportive system would have less costs for the healthcare system (the coeliac patients follow the strict diet, are regularly checked the complications of the not-perfect treatment, higher adherence and co-operation with the healthcare system, more healthy nutrition, etc.) and less risk of serious illnesses and hospital care.
Content description of required activities	The government must evaluate the financial impact of a VAT-correct and controllable refunding solution as they accept that gluten-free specialized foods are equal for coeliac patients with other chronic illness patients' medicaments.
Expected result	Better compliance and improved management of CD patients. Less burden of national healthcare, more healthy workforce and better quality of life of coeliacs.
Key stakeholders for implementation of the measure	European Commission, DG Santé. In Hungary: Prime Minister's Office, Ministry of Human Capacities, Ministry of Finance, Coeliac patients societies, association of food producers. Gluten-fee products' manufacturers and retailers.

MEASURE: Transition Programme from the paediatric to adult coeliac disease management	
Objective and background of the suggested policy measure	In the challenging phase of puberty, adolescents wish to identify themselves with their peers and therefore feel stigmatized and limited social life because of their gluten-free diet. That's mostly the reason of non-compliance and deny question the right diagnosis. Some young people wants to control their health and medical condition, others fight with the parents' strict control – the right solution for both groups is the independent and responsible self-care and self-management. Although a transition programme has already been suggested for celiac disease (*Ludvigsson et al. Gut. 2016 Aug;65(8):1242-51*), it has up to now not yet been implemented in the clinical practice in Hungary, both pediatric and adult gastroenterologists' practices.
Content description of required activities	Based on the Focus IN CD pilot project developed by PP8 KUM, a strategy for transition of adolescents with celiac disease into adult healthcare can be developed in collaboration with the coeliac patients' associations and the responsible medical bodies. As the proposed by German project partners, such a Celiac Passport could be localized and elaborated also in Hungary with the close co-operation with the German Coeliac Society (DZG), KUM and other European Professional organizations (ESSCD, ESPGHAN, European Gastro, etc.)
Expected result	A Celiac Passport will help to support coeliac adolescents to accept their condition. This will improve the compliance and the further medical follow-up and reduce the risk for long-term health consequences.

Key stakeholders for implementation of the measure	Coeliac patients‘ associations Coeliac Medical Centres in Hungary Association of Paediatric gastroenterologists Hungarian Gastro Association Ministry of Human Capacities DZG (Deutsche Zöliakie-Gesellschaft e.V.) Association of European Coeliac Societies (AOECS)

5. CENTRAL EUROPE's POLICY RECOMMENDATIONS TO IMPROVE MANAGEMENT OF CELIAC DISEASE

5.1 Recommendations to improve existing legal frameworks

By striving to ensure legal solutions, which contribute to the improvement of quality of life of specific disadvantage group, in our case celiac disease patients, governments signal how good they are aware of life situations of their citizens.

Together with engaged project stakeholders, we identified following recommendations to improve existing legal frameworks:

MEASURE 1: Long-life basic social rights

Ensuring basic social rights (finance, material, immaterial) for patients suffering from celiac disease since it is a life-threatening illness whose only remedy is the implementation of a strictly long-life gluten free diet. Such diet requires increased cash outflows. Most patients are unable to respond to such requests and this is one of the reasons for not carrying out a gluten free diet and direct disturbance of health due to economic inability.

MEASURE 2: Reducing the value of added tax for gluten-free products

Gluten-free products are more expensive than other food products, and the pursuit of gluten-free diet requires higher food costs. Governments should reconsider to make a special decision on the taxation of gluten free food as a cure.

5.2 Recommendations to improve knowledge capacities

Knowledge, research and discoveries in the medicine are changing rapidly, as conditions in our society, therefore keeping up with new knowledge and protocols is essential. Through implementation of the project, knowledge gaps were identified. In order to improve current situation, following measures are proposed:

MEASURE 1: Accreditation of learning materials at national Medical chambers

To improve the awareness and knowledge of HCPs (doctors, nurses, dietitians, students) about coeliac disease, authorities responsible for Continuous Medical Education (CME), should recognize learning programmes and materials developed in the project as relevant and provide accreditation.

MEASURE 2: Formation of National Coeliac Disease Study Groups

There is a lack of institutional co-operation, in order to change that, National Coeliac Disease Study Groups should be established. HCPs responsible for coeliac disease management should form a core group of the National Coeliac Disease study Group. Group should seek the involvement of experts from National Institute of Public Health, Ministry of Health and experts from Institute for Education.

MEASURE 3: Formation of Hospital Coeliac Disease Management Groups

HCPs responsible for coeliac disease management in hospitals should organize local Coeliac Disease Management Groups. At annual meetings, issues regarding patient management, availability of diagnostic tools, new developments in the field of coeliac disease should be discussed.

MEASURE 4: Formation of National Food Related Disorders Groups

Currently there is insufficient knowledge and management of children in Kindergartens and Schools. Kindergarten and schools authorities responsible for healthy diet of children in these institutions should appoint members of their staff to formal Food Related Disorders Group. Besides including HCPs, this group should include psychologists and social workers in order to solve different issues in local environments efficiently.

MEASURE 5: National Coeliac Disease Patients Log-book.

Patients with coeliac disease lack the awareness and knowledge about their disease. This makes them less competent in self-management of the disease. To improve skills, a patient logbook will be designed based on the passport, patients will need to participate at educational activities including e-learning tools, will need to be seen by a doctor, dietitian, psychologist, and trained nurse. They will need to undergo mentorship programme provided by Society.

MEASURE 6: Institutional support for gluten-free food producers

In most of CE markets offer is largely based on foreign industrial gluten free products. Domestic industry still does not show enough interest in product testing for the presence of gluten and their labelling (certification).It is necessary to inform the manufacturer about the new gluten free market requirements Systematic education and information for small food producers is necessary.

MEASURE 7: Updated guidelines for the Diagnosis of Celiac Disease in Adult Patients and Improved Training Activities for Adult Gastroenterologists

For paediatric gastroenterologists, celiac disease is a well-known and relevant entity in their daily work and usually they have a rather good knowledge how to diagnose and treat it. However, gastroenterologists working in adult care are often not well informed about the correct diagnostic steps because celiac disease is not one of their focus of interest. Improved training strategies and activities of adult gastroenterologists should be developed, taking advantage of the already available e-tools of the Focus IN CD.

MEASURE 8: Application of innovative immunological assay in the diagnosis of all clinical forms of celiac disease

To date, guidelines and diagnostic practices capable of identifying and adequately treating symptomatic subjects with atypical celiac disease are missing. The aim of the measure is focus to the improvement of the knowledge concerning the various clinical forms of celiac disease and the use of innovative diagnostic tools to identify and diagnose all these clinical conditions.

MEASURE 9: Guideline for the diagnosis of celiac disease in new at CD-risk groups: subjects with severe food allergy

It is unclear whether subjects with food allergy constitute a group at risk for celiac disease. The aim is to verify the real prevalence of celiac disease among children with severe food allergy and propose an active CD-screening in these patients.

MEASURE 10 Gluten-free safe food in restaurants and hospitality services

The only well-known and effective treatment of coeliac disease is the lifelong and strict gluten-free diet. The aim of the measure is to train restaurants (hotels, hospital kitchens and the public catering providers), so as the owner and the staffs know what does it require for a coeliac patient as a safe gluten-free meal.

5.3 Recommendation to improve organizational & management solutions

Organizational and management solutions in the national health systems a lot of times present barrier for quality and efficient treatment of long-time diseases, like celiac disease. With following measures, management of celiac disease patients can be enhanced:

MEASURE 1: Transition Clinics at all institutions managing children and adults with coeliac disease

Currently there is inadequate transition of patients from paediatric to adult care. Formal transition clinics should be organised at each healthcare institution. Exact transition protocol should be designed. Doctors, nurses, dietitians and psychologists should be joining the transition team.

MEASURE 2: National Coeliac Disease Patient Registries

To overcome the inadequate celiac disease patient data, national Coeliac Disease Patient Registries should be set-up. Coeliac disease patient registry can serve as the best source of information on current situation in the disease management, diagnostic delays, changes in clinical presentation, demographics of patients, changes in prevalence of disease... It will also serve decision makers on national level to better plan institutional capacities for coeliac disease management. At the same time, it will help institutions to detect patients who could benefit from institutional incentives.

MEASURE 3: Formation of Coeliac Disease Management Centres

There is an insufficient accessibility of HCPs with high level of expertise in coeliac disease. A comprehensive coeliac disease management centres, which should involve doctors, specialised in gastrointestinal diseases of children and adults, trained nurses, dietitians and possibly psychologist, should be established. Activities of centres should be included in the national insurance reimbursement scheme.

MEASURE 4: Ensuring routine follow-up for adult patients with coeliac disease

Health care institutions managing adult patients with gastrointestinal disorders should enable enough personnel for regular follow-up visits of coeliac disease patients. Preferably once a year. National Health Insurances should reimburse these visits. Focused laboratory work-up should be performed at these follow-ups based on international management guidelines.

MEASURE 5: Promoting routine dietetic counselling for coeliac disease patients

A network of dietitians skilled in coeliac disease patient counselling should be established. National Health Insurances should reimburse dietetic counselling. Dietitians should be specifically trained to provide disease specific service. They should be involved in reginal Coeliac Disease Groups.

MEASURE 6: Preventive program / Screening of CD

World and European data talk about celiac disease as a major public health problem of today that affects 1-3% of the general population. Disease is less detected through classical / well-recognizable symptoms. Asymptomatic image of celiac disease makes it difficult to diagnose. We should certainly think in the context of early detection and prevention of many complications of the disease, by establishing Preventive program / Screening of CD. Early detection of CD and prevention of other health issues. With this measure, health system costs could be reduced.

MEASURE 7: National Dissemination and Use of the Celiac Disease Patient Passport

Patients are often only told about the diagnosis of celiac disease, written reports which are handed out to the patient usually lack. Celiac disease is a lifelong condition, patients usually visit different doctors during their lifetime. Years later, other doctors or the patient her-/himself may question if the diagnosis was made correctly but cannot proof it without having access to the previous medical records. Furthermore, the monitoring of celiac disease is also an important measure but often neglected and the patient does not get written reports on the serology results, thus does not have a good understanding of the own disease management. All these facts describe, why a Celiac Disease Patient Passport would be necessary. In addition, an official document confirming that a patient truly suffers from celiac disease and needs a gluten-free diet may help the patients to raise awareness that they truly have to avoid even traces of gluten (e.g. ordering food in a restaurant or when seeking medical care).

MEASURE 8: Screening of first degree relatives of coeliac disease patients

Since coeliac disease has a strong genetic background, family members of diagnosed patients have elevated risk for the disease, therefore to establish open access family screening in the Coeliac Disease Management Centre would be recommended. Expected result, the increase of CD diagnoses and better patient health outcome with improved quality of life, reduction of medical and social costs associated with long-term undiagnosed disease.

6. CONCLUSIONS

Presented policy recommendations provide key innovative solutions and services, some of them also tested in the framework of the project, how to improve management of coeliac disease in Central Europe countries, by offering quality health services to patients and also to reduce costs, by introducing and focusing more on preventive systemic measures in the future.

Although in the provided document, each partner country, firstly introduced and emphasized specific policy recommendations, Central Europe area health systems are faced with similar knowledge, legal, organizational & management challenges in the field of supporting celiac disease patients.

Overview of the provided policy recommendations revealed, that a lot of work in the future should be still focused on knowledge and capacity building of all relevant stakeholders (health professionals, patients, policy stakeholders), since nine policy recommendations were identified through implementation of different project activities, in the field of needed knowledge improvement:

- accreditation of e- learning materials developed in the framework of FOCUS IN CD project at national Medical chambers, to reach more health professionals and improve knowledge
- formation of national coeliac disease study groups and hospital coeliac disease management groups,
- formation of 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 in adult patients and improved,
- training activities for adult gastroenterologists,
- application of innovative immunological assay in the diagnosis of all clinical forms of celiac disease and
- guideline for the diagnosis of celiac disease among coeliac disease-risk groups.

Besides knowledge deficit about coeliac disease, among key players, a lot of management and organizational gaps exist, which have negative effect on long-term quality of life of celiac disease patients. To overcome these barriers following organizational & management solutions, were suggested:

- transition clinics at all institutions managing children and adults with coeliac disease,
- national coeliac disease patient registries,
- formation of coeliac disease management centres,
- 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”,
- screening of first degree relatives of coeliac disease patients
- gluten-free safe food in restaurants and hospitality services.

All suggested recommendations could minimize health complications of coeliac disease patients in long-term period of time, therefore are crucial to be taken into consideration.

To ensure quality of life of coeliac disease patients, also legal framework conditions are relevant. Two policy recommendation are suggested:

- ensuring basic social rights (finance, material, immaterial),
- reducing the value of added tax for gluten-free products.