

TEMPLATE

Output factsheet: Tools

Version 1

Project index number and acronym	CE111 Focus IN CD
Lead partner	Municipality of Maribor
Output number and title	O.T2.2 E-learning tool for patients
Responsible partner (PP name and number)	Ludwig-Maximilian's University Medical Center KUM (PP8)
Project website	http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html
Delivery date	5/2019

Summary description of the key features of the tool (developed and/or implemented)

Background of Celiac Disease

Celiac disease (CD) is one of the most common lifelong autoimmune disorders which mostly develops in early childhood but may also be diagnosed in adults. The overall prevalence reaches 1% in the general European population. However, only 10 to 20% of affected individuals are actually being diagnosed.

The autoimmune reaction is triggered in genetically susceptible people by the protein gluten which is present in wheat, rye, barley and their hybrids, leading to an inflammatory reaction which mainly occurs in the small bowel, but can also affect other organ systems. Consequently, CD may present with a variety of symptoms not only restricted to the gastrointestinal tract. Still the only but very efficient treatment is to keep a strict lifelong gluten-free diet. This usually resolves or at least substantially improves the symptoms and also reduces the risk for long-term health consequences. However, the strict diet has an impact on the patients' daily and social life, the eating habits and the overall quality of life.

Early detection of CD patients can prevent many negative manifestations of the disease and reduce costs in the health care system. When following the available evidence-based guidelines, the diagnosis is usually straight forward. However, many patients often show a poor knowledge about their disease. The health care professionals are either not well informed about CD themselves or have not enough time to explain all aspects to the patient sufficiently, resulting in a knowledge gap with detrimental impact on the compliance of the patients. This may result in long-term health consequences and additional burden both for the patient and the health care system.

Rational and Key Features for Output D.T2.2

To improve the knowledge on CD and the self-management and quality of life, an e-learning (online course) for patients with CD has been developed within the Focus IN CD project. The e-learning is based on available evidence-based literature. The content was mainly developed and written by the expert physicians and scientific writers within the project partnership, reviewed and revised by all project partners as well as by external reviewers, comprising stakeholders from the German Celiac Disease Society (DZG) as well as CD patients who gave valuable input. The English online version was then pre-tested by several experts and patients. Finally the translations of the English version in the languages of the five Focus IN CD partner countries were implemented online and evaluated by patients and parents of children with CD.

The online course for patients includes four units (background, diagnosis, treatment, living with CD), explains the medical background in lay terms and is available in six languages (English and all languages of the Focus IN CD project partners). It offers not only written explanations illustrated by graphics but also interactive elements, explain movies, self-tests and a dictionary. Users can access the course without need to register.

Summary - Results of Report of Analysis of Usefulness

As mentioned above, we have evaluated the e-learning for patients by an extensive evaluation which comprised two questionnaires which the participants completed before and after having explored the online course (pre- and post-course).

Patients were invited to participate via the celiac societies of the respective countries.

The questionnaire comprised knowledge questions about celiac disease to identify if the use of the online course can improve the knowledge. We were able to show that - despite the majority of participants have already been diagnosed more than one year ago and were already experienced with CD - the users more often gave correct answer on the knowledge questions after having participated in the e-learning. We also identified some issues which have probably not yet been clear enough in the online course. Based on these findings we were able to improve the existing e-learning content by clarifying the explanations in relevant paragraphs.

Most importantly, the overall user satisfaction was extremely high with an average score of 8.7 on a scale from 1 to 10. The participants particularly appreciated the animation movies as well as the comprehensiveness, and understandability of the content, the illustrating graphics and the download materials. Some minor limitations have been identified only for the user friendliness and navigation which was still rated quite well but did not fully reach our expectations. However, during the evaluation we have been able to establish and move the online courses to a new and own Focus IN CD e-learning platform which was previously hosted on the Early Nutrition eAcademy platform (ENeA). This allowed us to improve the navigation and the overall user friendliness.

NUTS region(s) where the tool has been developed and/or implemented (relevant NUTS level)

Patients from all regions within our project area have been reached by advertisement in newsletters or on websites of patient societies, social media (mainly celiac facebook groups) medical societies, advertisement of the patient societies, presentations at conferences and via personal contact at meetings and seminars.

List of regions reached is as follows:

DE11 Stuttgart
DE12 Karlsruhe
DE13 Freiburg
DE14 Tübingen
DE21 Oberbayern
DE22 Niederbayern
DE23 Oberpfalz
DE24 Oberfranken
DE25 Mittelfranken
DE26 Unterfranken
DE27 Schwaben
DE30 Berlin
DE40 Brandenburg
DE80 Mecklenburg-Vorpommern
DED2 Dresden
DED4 Chemnitz
DED5 Leipzig
DEE0 Sachsen-Anhalt
DEG0 Thüringen
HU10 Közép-Magyarország
HU21 Közép-Dunántúl
HU22 Nyugat-Dunántúl
HU23 Dél-Dunántúl
HU31 Észak-Magyarország
HU32 Észak-Alföld
HU33 Dél-Alföld
HR03 Jadranska Hrvatska
HR04 Kontinentalna Hrvatska
ITC1 Piemonte
ITC2 Valle d'Aosta/Vallée d'Aoste
ITC3 Liguria
ITC4 Lombardia
ITH1 Provincia Autonoma Bolzano/Bozen
ITH2 Provincia Autonoma Trento
ITH3 Veneto
ITH4 Friuli-Venezia Giulia
ITH5 Emilia-Romagna
SI03 Vzhodna Slovenija
SI04 Zahodna Slovenija

In addition, we have also advertised the online course in Austria and German-speaking Switzerland.

Expected impact and benefits of the tool for the concerned territories and target groups

The e-learning for patients (online course) will allow the CD patients or parents of affected children as well as other lay people, e.g. relatives or friends, to fully inform themselves about their autoimmune disease, gain self-esteem and improve their self-management.

Consequently, not only the patients but also physicians working with CD patients highly appreciated this e-tool. This will not only allow the patients to manage their CD, be compliant with the gluten-free diet and live a healthy life despite the dietary restriction. Indirectly, the e-learning will reduce costs in the health care system as incompliant patients not adhering to the diet and not attending monitoring visits are at increased risk for long-term health consequences as osteoporosis or lymphoma.

Furthermore, with this online course we also raise the awareness for the need to test people belonging to groups with increased risk for CD. This mainly affects first degree relatives of CD patients who have a risk of 5 to 40% to develop CD. Testing is particularly important in children and adolescents to avoid negative impact of undetected CD on growth and development. By informing CD patients about the need to can then encourage to get tested for CD. The online course may improve case-finding when relatives will be screened more often.

Sustainability of the tool and its transferability to other territories and stakeholders

Already during the project duration, many stakeholders as the Association of European Coeliac Societies (AOECS) and other national CeD societies as the German Celiac Disease Society (Deutsche Zöliakie-Gesellschaft e.V. DZG, Italian CD society) have shown interest to contribute to the continuation of this output.

Furthermore, medical societies (e.g. Pediatric Gastroenterology Society in Germany GPGE, Germany Society for Digestive and Metabolic Diseases DGVS) can be involved to further finance the running costs and potential updates and improvements in the future.

Moreover, celiac experts and societies outside the Central European region, for example member of the ESPGHAN Celiac Disease Interest group are considering to collaborate with us to implement the patient course in their own language (e.g. into Spanish). This will of course substantially increase the target groups which we can reach with this tool and consequently potential additional financial support.

Furthermore, another application for an Interregional Project to involve other countries (e.g. Romania) is being planned which may also allow low-income countries to bring the e-learning in their own language.

Overall, we do not foresee major challenges to continue with the present e-learning and provide it to patients also in the future. For necessary updates in the future, we are confident to find financial support among the network of CD interest groups as well as medical societies and public funding for improved health research services.

Lessons learned from the development/implementation process of the tool and added value of transnational cooperation

1) The development of the contents of the patient course was initially planned to be done by involving all project partners in writing the contents. However, it became evident that this was not efficient as the different authors had not only different writing styles but also different levels of knowledge and experience in evidence-based writing. Finally, the project partners KUM and CHF collaborated and wrote a draft together. In the next step, all project partners were involved and asked to review and revise this draft. This was extremely important as the project partners have different backgrounds and expertise to review and adapt the contents and get their input which was also related to some country-specific requirements. In total there were two revisions. The input of all project partners was finally very valuable for the finalization of the e-learning.

Lesson: Writing of a draft should better be done by few selected project partners with expertise in this field and experience in medical writing. It is better to involve the project partners then in the revision of the draft and include their valuable comments and shape it according to allow its use in different health-care systems of all involved partners and maybe even beyond.

2) The e-learning was initially implemented on the Moodle e-learning platform of the Early Nutrition eAcademy (ENeA), which had already been established many years ago by the project partner Child Health Foundation. As the platform was almost free to use and hosted by the public university-related data processing center (Leibniz-Rechenzentrum LRZ, Munich), it seemed to be a good choice and sustainable due to very low running costs. However, it became evident that an e-learning Platform which is specialised on Early Nutrition, mainly addressed to experts working in this field is not the perfect setting. Furthermore, there were structural limitations on the platform e.g. not allowing us to develop our own corporate identity or improve the navigation et cetera. The start page was in English, referring to Early Nutrition Expert Topics, was clearly not ideal for patients with CD or general practitioners who would like to visit the course. Unfortunately, in 2017 the LRZ restricted the possibility to create independent Moodle platforms for separate projects within the LRZ.

In addition, the IT support to solve any technical problems (e.g. which appeared e.g. when using the H5P-Plugin to include interactive elements) was also hardly given, only one IT expert with knowledge in Moodle supported the ENeA platform, only working few hours as freelancer per month. This was not acceptable as he could not take care of our particular problems in the e-learnings for celiac disease.

Finally at a late stage of the project (Feb/March 2019) we decided to move our e-learning to an external Moodle provider and by doing so we've been already able to improve the navigation and the layout including the corporate identity.

Lesson: Implementing new e-tools on already existing IT-platforms may not always be reasonable and cost efficient. If the overlap between the topics and the target groups is not sufficiently given, it is more efficient to invest in an own platform. In addition, there are always limitations in terms of corporate identity and technical possibilities which should be taken into consideration.

References to relevant deliverables and web-links
If applicable, pictures or images to be provided as annex

This output is related to deliverables D.T2.2.1 and D.T2.2.2

The e-learning (online course) for patients can be accessed via the following domains:

www.celiacfacts.eu (Englisch)

www.zoeliakie-verstehen.de (German)

www.poznam-celiakijo.com (Slovenian)

www.coeliakia.info (Hungarian)

www.sveocelijakiji.hr

www.celiachia-info.it (Italian)

Annex: Screenshots - Examples from the e-learning for patients - new and own Focus IN CD Moodle platform



A warm welcome to Celiac Facts!

Explore our online tools to learn more about celiac disease and become an expert! We offer different tools to not only support health care professionals as physicians and dietitians but also to empower the patients or parents of a child with celiac disease!

Get familiar with the background of this autoimmune disorder, learn how to make the correct diagnosis, how to follow the gluten-free diet and how to integrate it in your daily life!

Reliable, evidence-based information with interactive elements are waiting for you – easy to use and free of costs!



Just click on one of the links to reach the different e-tools and get started!



Online Course for Patients

[Click here to get extensive and comprehensive information on celiac disease – free of cost, free of ads and without registration!](#)



Online Course for Physicians & Dietitians

[Click here to learn more about celiac disease and further improve your skills!](#)



Web-App to Diagnose Celiac Disease

COMING SOON! This Web-App is currently being developed and will be online in March 2019!

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Celiac Facts for Patients

Introduction

Unit 1 Understanding Celiac Disease Unit 2 Diagnosing Celiac Disease Unit 3 Treatment of Celiac Disease Unit 4 Living with Celiac Disease

Welcome to the Online Course "Celiac Facts for Patients"

You may have accessed this e-learning because you (or your child) have been diagnosed by celiac disease. Or maybe a close relative, friend or colleague told you about her or his celiac condition recently. The following units of this e-module aim at giving you the most important information on celiac disease, including its diagnosis, treatment and impacts on daily life. The better one knows about the disease, the easier it will become to keep the gluten-free diet and to accept it. Moreover, it is very important not to only rely on healthcare professionals, but to be actively involved when it comes to the prevention of long-term health consequences and monitoring of celiac disease. Always keep in mind: as long as you keep the gluten-free diet, you can live a healthy life!

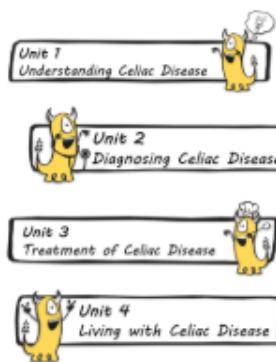
This video gives you a first overview of the topics that will be covered in more detail in the following units:



Useful hint: you may also show this video to your family, friends and colleagues when talking about your celiac disease for the first time.
The video may also be useful to explain celiac disease to your child.

And now - let's get started

This module contains four separate units which can be worked through in your preferred order. For the best understanding of the topic, we recommend to follow the units in the proposed sequence.



Please click here to see an overview of the contents of this online course

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Celiac Facts for Patients

Introduction

Unit 1
Understanding Celiac Disease

Unit 2
Diagnosing Celiac Disease

Unit 3
Treatment of Celiac Disease

Unit 4
Living with Celiac Disease

Test knowledge

Lesson 1 - Basics

Lesson 2 - Why Getting it?

Lesson 3 - What Happens?

Lesson 4 - Different Faces

Test MDW Knowledge

Unit 1 - Understanding Celiac Disease

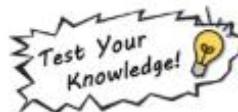
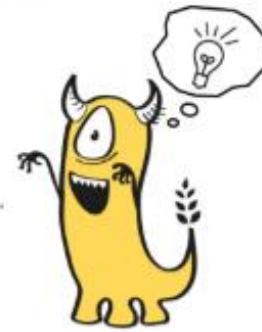
(Do you know what gluten is and why it's so common in our food?
Why does gluten cause celiac disease?)

(How many people actually have celiac disease?)

(What are the reasons that some people get celiac disease and others do not, although they all consume gluten?)

(And why is the gluten-free diet still the only truly effective treatment?)

(How and why those questions will be explored and answered in the following Unit 1. If you are new in the celiac world, you'll learn about all important basics here. But even if you are already experienced, there may be some interesting additional information for you, allowing you to re-examine and to understand the whole story and relation between gluten, genes and environment even better. Click on the links below to explore the lessons and self-assessments. Let's begin... let's get started!)



Lesson 1
Celiac Disease - The Basics

Lesson 2
Why Do Some People Get Celiac Disease?

Lesson 3
What Happens in the Gut?

Lesson 4
The Different Faces of Celiac Disease



Overview of the contents and learning aims of Unit 1

Dictionary, References & Legal Notice

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Celiac Facts for Patients

Introduction	Unit 1 Understanding Celiac Disease	Unit 2 Diagnosing Celiac Disease	Unit 3 Treatment of Celiac Disease	Unit 4 Living with Celiac Disease
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Test Knowledge Lesson 1 - Glutenfree Diet Lesson 2 - Food Labels Lesson 3 - Healthy and Glutenfree?

Quiz - Glutenfree Shopping

Request to Cook

Glutenfree Shopping

Quiz - Glutenfree Shopping



Drag all foods which are ALWAYS SAFE to eat (without need to check any ingredient list) into the shopping trolley. You can retry as many times as you wish.

