

# TEMPLATE

## Output factsheet: Tools

Version 1

<b>Project index number and acronym</b>	CE111 Focus IN CD
<b>Lead partner</b>	Municipality of Maribor
<b>Output number and title</b>	O.T2.3 ICT-App for HCPs
<b>Responsible partner (PP name and number)</b>	Ludwig-Maximilian's University Medical Center KUM (PP8)
<b>Project website</b>	<a href="http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html">http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html</a>
<b>Delivery date</b>	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 physicians have an insufficient knowledge about celiac disease, its huge variety of symptoms and the risk groups which makes case-finding difficult. Furthermore, over-use of different, also less specific tests not helpful to diagnose CD directly leads to unnecessary expenses and also bears the risk of both false-negative and false-positive diagnoses. From previous survey we already know that false diagnoses are frequent mainly for two reasons. 1) physicians are not aware of the updated guidelines, main the potential pitfalls in the diagnostic process 2) physicians only have limited amount of time for each patient.

As CD mainly already manifests in early childhood, particularly the paediatricians are called upon to enhance case finding and to correctly diagnose this life-long disorder in affected patients. At the same time false-negative diagnoses with the consequence of an unnecessary gluten-free diet must be avoided.

## **Rational and Key Features for Output D.T2.3**

In order to support general paediatricians and pediatric gastroenterologists to identify potential patients to test for CD and diagnose them correctly, we developed an ICT-App which guides the physicians through the diagnostic process. We have decided to not develop a native app but a Web-App, as this is not only more sustainable with respect to running costs but also more easily available as doctors only have to open a website instead of downloading and updating an App from the App store.

We were able to take advantage of the most up to date diagnostic guidelines of the European Society of Pediatric Gastroenterology, Hepatology & Nutrition (ESPGHAN) to diagnose celiac disease in children which are being published in June 2019. Four of the Focus IN CD project partners are involved in this guideline group, therefore we had access to the final diagnostic algorithm finally by end of march 2019, when the new guidelines was ready to be submitted to the Journal of Pediatric Gastroenterology and Nutrition (JPGN). This diagnostic algorithm, also called "diagnostic flow scheme" or "decision tree" is the backbone of the Web-App.

Based on this algorithm, mainly PP8, PP10 and PP2 elaborated more than 50 decision pathways to cover all possible scenarios of the new diagnostic algorithm. In order to provide additional evidence-based information (e.g. what to consider when choosing a certain test and laboratory) and rationales (e.g. why and when to apply the test), we developed and provided supplementary explanations for each diagnostic step, again based on the new and were applicable the previous 2012 ESPGHAN guidelines.

All PPs and finally also external paediatricians tested the Web-App.

From the beginning of the project, we have agreed that the Web-App should not only provide the celiac guideline but that it should be possible to add other, preferably pediatric guidelines in the future in order to take advantage of synergy effects. Physicians prefer to find information on several disorders on the same platform and not to use different websites or apps for different diseases. Therefore we have planned from the beginning that the Web-App should be expandable.

#### **Summary - Results of Report of Analysis of Usefulness**

Overall the Web-App showed very positive effects and the users reported a high satisfaction, particularly related to the content and also regarding technical functionality. However, there are also some suggestions for further improvements of the layout and the app. As we have already found a non-profit society interested in further collaboration and support with respect to this app, we will be able to overcome the minor issues for improvement in the future.

In general, this Web-App will be a very useful tool to improve the patient care for celiac disease in Central Europe and save cost in the health care systems as less unnecessary diagnostic tests and false diagnoses will happen.

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

HCPs from different institutions and regions were and are being reached via several channels and media: advertisement in newsletters or on websites of 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

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

The Web-App do support physicians in the diagnosis of CD will be a very useful tool in order to improve the case-finding and the diagnosis of patients with CD by identifying those patient in whom the life-long gluten-free diet is justified, will help the patient to life a healthy life without or at least substantially improved symptoms and will also avoid long-term health consequences. On the other hand false-positive diagnoses will be reduced, preventing patients with other differential diagnoses from receiving the wrong therapy.

This will also help to reduce costs in the health care systems as the use of the Web-App will save time for the paediatricians and avoid unnecessary tests and false diagnoses.

### 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 CD societies as the German Celiac Disease Society (Deutsche Zöliakie-Gesellschaft e.V. DZG) have shown interest to contribute to the continuation of the e-tool outputs.

In particular, the European Academy of Paediatrics (EAP) has already agreed to substantially support the idea of the Web-App, also in order to include additional guidelines. This will finally increase the number of visitors as more paediatricians will visit the Web-App and will also find the celiac guideline, even if their initial intention was not celiac disease but another guideline.

In addition, a scientific grant of an external pharmaceutical company is currently in application process and may also guarantee additional funds to further improve and enlarge the Web-App and invest in advertisement.

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 Web-App for celiac disease in their own language (e.g. into Spanish). This will again increase the target groups we can reach with this tool.

When the new ESPGHAN guidelines will have been published (June 2019), we can further push the advertisement of the Web-App which will be then very attractive for the target group to use.

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

1) As four of the Focus IN CD project partners were involved in the ESPGHAN guideline group to update the existing evidence-based guidelines (Husby et al 2012), we aimed of course to build our Web-App on this most up to date evidence-based diagnostic algorithm. The guideline group consists of 18 experts in the field of pediatric celiac disease from Europe. All members of the group volunteered to fulfil this task to the best of their knowledge and efforts, without being paid. Although the group was working hard, lots of discussions and re-investigations, revisions of the manuscript and further literature research lead to a substantial delay. The initially scheduled date for the publication of these guidelines was actually October 2017, but although the project partners being members in the group tried to push the progress, the guideline will finally be published only in June 2019. Nevertheless, as four project partners were members of the group, the content of the Web-App had already been developed according to what was clear earlier, but the final content (confirmed by voting) was only available by end of March 2019. The existing e-learning content was therefore updated were needed and the output needed to be finalized short-termed.

Lesson: Dependence of external outputs which are not in the hands of project partners but which are important for the quality and timeliness of the project output is detrimental for the finalization according to the given framework of the project. However, in our case it was worth to wait and take the challenge to complete the Web-App short-termed. Otherwise a Web-App based on the old diagnostic algorithm would not have been attractive for the target group.

2) The technical development of the Web-App started with the decision to go for a Web-App instead of a native App for two reasons: 1) better sustainability as the running costs for a Web-App are much lower than for a Native App and 2) physicians prefer to easily find information on websites instead of downloading and updating App from the App stores. We experience that this was the right decision. When we invited App development companies for offers, we realized that it's difficult to take a decision without any IT background knowledge. Therefore we had involved an IT consultant working in the field of App development and finally decided on one offer, a Web-developing IT company from Munich. However, this was a short-termed external service. The WPT2 lead partner themselves had no IT expert in their team. Although the basic functionality of the App was given from the beginning, there were some misunderstandings between the WPT2 lead PP8 KUM and the IT developers respectively their project manager, making the implementation of the contents in the backend of the App quite inefficient in the beginning. However, after complaints by PP8, this improved significantly without extra costs, but it was disappointing that the IT did not put more thoughts on this earlier, without considering the needs for our purposes. Furthermore, we have pointed out in the very beginning and also during the App development process that the initial layout draft which was developed in analogy to the corporate design of the ESPGHAN,

may have to be adapted before the online implementation, as the final layout depended on the decision if ESPGHAN will collaborate with Focus IN CD for the Web-App or not. Although this was emphasized several times, this was not noticed by the IT and they have just implemented the old design, which then had to be changed again as the collaboration with ESPGHAN - at least at this moment - did not work out. This caused additional costs to change the colours, the links and the logos of the Web-App, plus further general improvements of the layout were done.

Lesson: If a project output requires substantial IT developing services, it is advisable to involve a team member who is experienced with IT development issues.

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

This output is related to deliverables D.T2.3.1 and D.T2.3.2

The Web-App for HCPs can be accessed via the following domains:

Directly via: <https://pediatric-guidelines.eu>

Or via the main e-tool start pages:

[www.celiacfacts.eu](http://www.celiacfacts.eu) (English)

[www.zoeliakie-verstehen.de](http://www.zoeliakie-verstehen.de) (German)

[www.poznam-celiakijo.com](http://www.poznam-celiakijo.com) (Slovenian)

[www.coeliakia.info](http://www.coeliakia.info) (Hungarian)

[www.sveocelijakiji.hr](http://www.sveocelijakiji.hr)

[www.celiachia-info.it](http://www.celiachia-info.it) (Italian)

## Annex: Screenshots - Examples from Web-App for HCPs



Focus IN CD

[Home](#) | [Focus in CD](#) | [EAP European Academy of Paediatrics](#) | [ESPGHAN](#) | [Child Health Foundation](#)

# Pediatric Guidelines



## Web-App Pediatric Guidelines

Welcome to the Pediatric Guidelines! We invite you to take advantage of this easy to use Web-App which takes you through the current evidence-based guidelines – free of charge and free of ads!

This Web-App was developed within the project „Focus in CD“ which has been funded by Interreg CENTRAL EUROPE in order to improve the management of patients with celiac disease.

More pediatric guidelines are planned to be published on this website for interactive use.

**Celiac disease guideline**


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English 

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Focus in CD
EAP European Academy of Paediatrics
ESPGHAN
Child Health Foundation

### About

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... celiac disease (CeD) -

- **chronic autoimmune-disease**
- triggered by the protein **gluten**
- **systemic** disorder
- **characterized by** presence of
  - CeD-specific autoantibodies
  - HLA-DQ2 and/or HLA-DQ8 haplotypes
  - small bowel mucosal lesions (enteropathy).
- **prevalence:** 1% (general population)
- only 10-20% of cases are diagnosed
- **onset:** mainly in first years of life
- **clinical presentation:** broad spectrum of non-specific signs and symptoms
- **diagnostic tools:** serology markers, histopathology, in certain cases: HLA-DQ2/-DQ8 typing
- **treatment:** strict and life-long gluten-free diet only to be initiated if diagnosis of CeD is confirmed!


For general practitioners - pediatricians


For pediatric gastroenterologists


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... this guideline +

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## What is the current situation of the patient?

Clinical suspicion or risk group for CD

Positive TGA, DGP, EMA or PoCT

TGA = Autoantibodies against tissue transglutaminase; EMA = Autoantibodies against endomyseum; DGP = Antibodies against deamidated gliadin peptides; PoCT = Point of Care Test (Rapid Test)

Patients with already reduced gluten intake
+

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Signs & Symptoms
+

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Risk groups
+

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## What was the result of the TGA-IgA testing?

TGA-IgA positive

TGA-IgA negative

Check with the laboratory if they use a calibration-curve based immunoassay which has been validated in clinical studies! If this is not the case, look for another TGA-IgA test and/or laboratory.

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## No celiac disease



If the child is symptomatic: consider other differential diagnosis. In case of severe symptoms refer to specialist.

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