

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.T1.1 Assessment of celiac disease management practices
Responsible partner (PP name and number)	University Medical Center Maribor - UKC MB (PP2)
Project website	http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html
Delivery date	5/2017
Summary description of the key features of the tool (developed and/or implemented)	

Delays in coeliac disease (CD) diagnosis can reach up to 10 years, and can cause important health related burden on patients' quality of life as well as on medical services. At the same time, clinical picture is changing, and these differences correlate with patient management strategies.

Many factors can influence these parameters including HCPs and patient knowledge and awareness, availability of diagnostic tools, gluten free products, governmental incentives...

To get a better understanding of these issues and to better understand patient needs, five web based surveys were designed. Used individually or in a combination these are powerful state of the art of CD management assessment tools.

We involved different target groups: individual HCPs, public authorities, health, teaching and training institutions, patient societies and individual patients - ultimate beneficiaries of the project.

Tools developed in the project:

Patient health records assessment web based survey -to assess diagnostic delays and clinical picture.

HCPs knowledge and awareness assessment web based survey.

Patient awareness and needs assessment web based survey.

Assessment questionnaire to gain information about existing financial incentives.

Management practices assessment questionnaire.

More than 4,500 participants provided valuable feedback. Data analysis show that diagnostic delay in children ranges from 13-18 months in CE (considerably better than previously assumed), and presenting symptom has shifted from diarrhoea to unspecific abdominal pain. Knowledge of HCPs is sufficient, with important gaps concerning the prevalence of CD. Patients' knowledge is also sufficient; however satisfaction with availability of health care, especially dietetic counselling, gluten free products, available information and incentives by government is low. Management practices differ in CE region based on the results and better management correlates with knowledge, awareness and availability of health care providers.

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

More than 4,500 participants of our web based surveys come from all NUTS regions of partner countries.

We actually reached participants from regions outside the program territory through extensive networks of each partner.

DE11-DEG0

HU10-HU33

HR03-HR04

ITC1-ITH4

SI03-SI04

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

By reaching more than 4,500 participants with web based tools designed in our project valuable data became available which helped us to better understand the current state of the art in coeliac disease management in Central Europe. Diagnostic delays and changes in clinical picture detected with the tools, alongside with the knowledge gaps, low awareness about some issues, and low patient satisfaction with the service provided, and especially with governmental incentives for chronically ill patients will help us in designing e-tools for HCPs and patients and will also help us to propose a patient centred disease management model.

Based on this better health care will be provided for patients through increased knowledge and capacities of individual HCPs and health care system as a whole. This will eventually lead to better quality of life of patients and will decrease the burden of the disease for individuals, their families, community and society as a whole within the CE and further.

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

All the tools developed within this task were designed based on the expertise of partners and available literature in the field of coeliac disease management. Questionnaires were originally designed in English, and comments were carefully implemented in English template before tools were translated into all partner languages.

Since the tools are web based this enables interested stakeholders to participate in any of the questionnaires even after the task is finished and after the project will end. This is very important since many different stakeholders (HCPs, ESPGHAN, AOECs, patient organisations...) have already expressed their wish to continue providing their data.

These stakeholders are however not only coming from the Central Europe. They were reached through extensive network each partner has gained previously and project has greatly benefitted with that. This means that the tools developed within the project has already reached other territories and other stakeholders.

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

During the initial state of the development of the tools a thorough literature search was done that enable partners to get better insight into the current state of the knowledge in the field of coeliac disease. This step proved to be crucial in further development of the tools.

Important step that proved valuable to partners was development of questionnaires addressing different aspects of CD management. Importance of close communication, exchange of ideas through several rounds of discussion and involvement of different stakeholders proved to be very valuable.

Selection of appropriate web tool with the help of IT experts was another important element of this process.

Without transnational co-operation, such task would be impossible. Transnational partnership enabled us to get the information of local practices and to design questionnaires applicable in different regions within CE that will easily be transferred to other interested regions.

References to relevant deliverables and web-links

If applicable, pictures or images to be provided as annex

English version serves as a template for other languages. Questionnaires in partner languages can be found uploaded under the section Annexes, File Name: WPT1 Questionnaires in partner languages - online via the web links (the complete document, consisting only of the links, exceeded max. of 1000 characters, however it follows the same structure as seen bellow. There is only a change of the last three letters indicating the language variant of the survey, e.g. ENG, CRO, GER, HUN, ITA, SLO).

Altogether 30 surveys were published in five partner languages and in English language serving as template.

Please find the complete content and analysis under the WPT1 deliverables (more than 1000 pages of questionnaires content and 600 pages of analysis).

<https://www.surveymonkey.com/r/Q1Focus-IN-CD-ENG>

<https://www.surveymonkey.com/r/Q2Focus-IN-CD-ENG>

<https://www.surveymonkey.com/r/Q3Focus-IN-CD-ENG>

<https://www.surveymonkey.com/r/Q4Focus-IN-CD-ENG>

<https://www.surveymonkey.com/r/Q5Focus-IN-CD-ENG>