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)

Coeliac disease (CD) is a lifelong disease affecting 1% of general population in developed world with major effect on health-related quality of life. The only known treatment is extremely strict gluten free diet with additional negative psychosocial effect. Early detection can prevent many negative manifestations of the disease.

However, based on the available data, delays in CD diagnosis still reach up to 10 years. This has important impact on both individuals' well-being as well as on health care services. This can to some extent be attributed to changes in clinical picture of the disease in last decades, but other important factors including health care professionals' (HCP) and patients' knowledge and awareness, availability of diagnostic tools and gluten free products, as well as governmental incentives, also play an important role.

To get the better understanding of changes in clinical picture and current diagnostic delays in the CE region and to assess patient needs, specific web based surveys were designed during the Focus IN CD project. Used individually or in a combination these are powerful state of the art of CD management assessment tools based on which further project activities such as the development of e-tools, pilot services and finally proposal of a patient centred management model will be designed.

Different target groups were involved during this activity, such as health care institutions, individual HCPs, public authorities, teaching and training institutions, patient societies and individual patients – who are the ultimate beneficiaries of the project.

Five web based assessment tools were developed during the project with the interdisciplinary input of all participants as well as some external experts. These are: *Patient health records assessment web based survey*, *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* and *Management practices assessment questionnaire*.

More than 4,500 participants (HCPs, patients, coeliac disease patient organisations, public authorities and teaching institutions) were involved in assessment of the current state of the art in CD management during the first half of 2017. Based on the data assessed by different questionnaires it was shown that diagnostic delays in children in CE region range from 13-18 months, which is considerably better than previously assumed, and that presenting symptom has shifted from diarrhoea to unspecific abdominal pain. It can also be assumed that HCPs knowledge of is sufficient, with important gaps especially concerning the prevalence of CD. Patients' knowledge is also satisfactory, however their satisfaction with availability of health care services, especially with dietetic counselling, availability of gluten free products, and governmental incentives is low. We also found that management practices differ in CE region and better management correlates directly with the higher knowledge, and awareness and better 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.

Participants in regions were reached thorugh web based survey. HCPs from different institutions and regions were actively contributing their patient data, they were involved in the HCPs knowledge and awareness assessment, and current CD management practices survey. Patients and public and educational institutions provided data for patient awareness and existing incentives surveys.

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

By reaching more than 4,500 different participants with web based tools designed within Focus IN CD 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. New insight into the changes in clinical picture will allow us to better stress these changes in e-tools for HCPs and for patients. Better knowledge about the real diagnostic delays within the regions and differences will help in focusing on the regions where these gaps are longer. Despite the data are better than reported data from other regions, there is still a gap of more than one year, which can and must be further decreased with educating HCPs. The data will also be presented at educational events for future HCPs with long lasting effect on health system in CE region. Shortage of governmental incentives in some regions will help patients united in patient organisations as well as HCPs to approach their authorities in their efforts to improve their deprivileged status. The data will also be presented to stakeholders outside the region who will be able to use it in their regions.

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 - European Society for Paediatric Gastroenterology, Hepatology and Nutrition, AOECS – Association Of European Coeliac Societies, patient organisations…) have already expressed their wish to continue providing their data.

Members of ESPGHAN Coeliac Disease Special interest group coming from each European region and also from regions outside Europe have expressed their interest in participating in both CD management survey as well as in HCPs knowledge survey and in providing patient data. Patient organisations from Europe united in AOECS will be involved in distributing surveys among the members of their national and regional societies within Europe.

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.

All web surveys will remain active on the web portal and will be easily adopted according to individual needs of interested stakeholders. PP2 will serve as a contact point after the project.

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. Lesson: extensive search of available literature in different data bases is crucial initial state of designing questions to be addressed during the surveys. Expert opinion and individual experience are important, but not fully sufficient.

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.

Lesson: Open communication of partners with different backgrounds and with different expertise is crucial for development of appropriate questions addressing all aspects of problems related to CD disease management.

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

Lesson: Many web tools are available, and expert analysis of their functionality by IT personnel is important in selecting appropriate tool for defined purpose.

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.

Lesson: Transnational co-operation is the most effective way to design tools which can assess management practices in different regions and later to harmonise them and exchange examples of good practice from one region to another regardless of financial/political/cultural/language… differences.

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

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).

Questionnaires can be found, and used online at Focus IN CD web page. They can also be found on the PP2-UKC MB web page.

All questionnaires can be found online via the following links

Patient health records assessment web based survey.

https://www.surveymonkey.com/r/Q1Focus-IN-CD-CRO-EU
https://www.surveymonkey.com/r/Q1Focus-IN-CD-GER-EU
https://www.surveymonkey.com/r/Q1Focus-IN-CD-HUN-EU
https://www.surveymonkey.com/r/Q1Focus-IN-CD-ITA-EU
https://www.surveymonkey.com/r/Q1Focus-IN-CD-SLO-EU

HCPs knowledge and awareness assessment web based survey.

https://www.surveymonkey.com/r/Q2Focus-IN-CD-CRO-EU
https://www.surveymonkey.com/r/Q2Focus-IN-CD-GER-EU
https://www.surveymonkey.com/r/Q2Focus-IN-CD-HUN-EU
https://www.surveymonkey.com/r/Q2Focus-IN-CD-ITA-EU
https://www.surveymonkey.com/r/Q2Focus-IN-CD-SLO-EU

Patient awareness and needs assessment web based survey.

https://www.surveymonkey.com/r/Q3Focus-IN-CD-CRO-EU
https://www.surveymonkey.com/r/Q3Focus-IN-CD-GER-EU
https://www.surveymonkey.com/r/Q3Focus-IN-CD-HUN-EU
https://www.surveymonkey.com/r/Q3Focus-IN-CD-ITA-EU
https://www.surveymonkey.com/r/Q3Focus-IN-CD-SLO-EU

Assessment questionnaire to gain information about existing financial incentives.

https://www.surveymonkey.com/r/Q4Focus-IN-CD-CRO-EU
https://www.surveymonkey.com/r/Q4Focus-IN-CD-HUN-EU
https://www.surveymonkey.com/r/Q4Focus-IN-CD-ITA-EU
https://www.surveymonkey.com/r/Q4Focus-IN-CD-SLO-EU

Management practices assessment questionnaire.

https://www.surveymonkey.com/r/Q5Focus-IN-CD-CRO-EU
https://www.surveymonkey.com/r/Q5Focus-IN-CD-GER-EU
https://www.surveymonkey.com/r/Q5Focus-IN-CD-HUN-EU
https://www.surveymonkey.com/r/Q5Focus-IN-CD-ITA-EU
https://www.surveymonkey.com/r/Q5Focus-IN-CD-SLO-EU

English templates of all questionnaires.
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