



Science Meeting – Scientific Report

Proposal Title: Expanding the Gateway: EUROcleftNet Directory of Resources

Application Reference N°: 5360

European Cleft Gateway

Background and work to date

Integral to the success of EUROcleftNet, it was recognised that there was a need for an updated directory of European resources and services. The data collected as part of the Eurocran project between 2001 and 2005 needs to be reviewed and expanded. Additionally, there is a need for an information 'hub' which is open and accessible to all, which will serve to:

- Inform - clinicians, researchers, users about EUROcleftNet activities, research and funding opportunities
- Signpost - clinicians and researchers to research study websites
- Direct - users and researchers to cleft centres through an updated European cleft service directory

Subsequent to a meeting of the EUROcleftNet steering committee in Manchester in December 2011, the European Cleft Organisation (ECO) proposed hosting a new portal on its website to be called the European Cleft Gateway. This would be branded differently to the European Cleft Organisation to give it a unique identity and encourage inclusivity. The Gateway was designed to become the home of new updated directory of services and resources. A key element would be a comprehensive listing of all centres wishing to participate and collaborate in research studies on prevention and treatment.

The Gateway live

The Gateway, <http://gateway.econline.org/> has been live since May 2013. The data retrieved through the [EUROcleftNet questionnaire](#) has been fully uploaded onto the site. More recently we have built in a separate service directory for cleft support groups.

Developments in 2014

A proposal was submitted to EUROcleftNet the end of 2013 to further develop the Gateway. Specifically there was a need to:

- 1) Increase the population of the database
- 2) Establishment a network of country coordinators to streamline data collection
- 3) Re-write the Googledocs online questionnaire to make it easier to upload
- 4) Enable search possibilities by the creation of import and export tools to move data to/from an Excel spreadsheet and/or Access
- 5) Use the Gateway site to further promote EUROcleftNet's activities in multi-languages
- 6) Offer the Gateway site as a home to other networks – specifically the International Cleft Taskforce established at the International Craniofacial Congress in Orlando in 2013 and also to a proposed European professional craniofacial federation

These tasks were undertaken by the European Cleft Organisation who employed a part time coordinator for 6 months to take this forward. Technical work was undertaken by a web developer, Webducate, who had been involved with the Gateway from the start

1) Increasing population of the database

This has proved to be a lengthy process and we were only able to increase population by around 27% in the six month period. This remains an ongoing process and we hope that the use of country representatives (see below) will make this more achievable. There are now nearly 100 centres fully registered on the database. We have complete listings for France and Serbia. We have no listings for Greece and we have made very little progress with Germany.

Reasons for lack of take-up have been:

- Not understanding why this project is important and why the Gateway needs to exist
- Length of online questionnaire and detailed information required. To complete the form accurately several team members need to be involved and where cleft coordinators do not exist (in most countries) the time required to complete the form may have been a deterrent
- In those countries where no cleft team data has been available in the past we have had to rely on the internet and other networks who often had little knowledge of cleft care.
- Language barriers

To further encourage population of the database we are proposing to set up a multi-language internet 'landing page' which will direct people to the Gateway and EUROCliftNet when a search is done for the word 'cleft' in any of 25 European languages (see below)

2) Country Coordinators

So far we have the following country representatives:

- Armenia (Hrachya Arshakyan)
- Cyprus/Greece (Spyros Papacharalambous)
- Bosnia & Herzegovina (Nenad Tanaskovic)
- Bulgaria (Youri Anastassov)
- Estonia (Triin Jagomagi)
- Latvia (Ieva Bagante)
- Macedonia (Slave Naumovski)
- Norway (Guvnor Semb)
- Portugal (António Bessa-Monteiro)
- Serbia (Branislav Trifunovic)
- Slovenia (Vesna Kozelj)
- Spain (Jose Lopez-Cedrun)
- Ukraine (Natalya Borchenko)

The following are willing to help but no official confirmation about being a country representative:

- Finland (Jorma Rautio)
- Denmark (Michael Wagner Olsen)
- Poland (Elzbieta Gawrych/ Michał Sobala)

3) Online Questionnaire

A new online questionnaire built into Googledocs has been written and works well. Some questions have been modified in consultation with Steering Committee members

4) Search facilities

A straightforward import/export function has now successfully been developed meaning that it is easy to transfer partial or complete data from the Gateway to an external spreadsheet or database with search facilities (Excel/Access). See attached for complete set of exported records

5) Promotion of EUROcleftNet activities

The Gateway news portal is used to promote EUROcleftNet events and activities. The importance of increasing cooperation from Eastern Europe is reflected in the fact that information pertaining to short visit and exchange programmes have been translated into several East European languages. www.gateway.econline.org/news

6) and 7) Members areas

The original proposal to establish member's areas for EUROcleftNet steering committee members and provide home areas for other developing networks (the international Cleft Task force that came out of the 2013 international craniofacial congress in Orlando and a proposed European professional association) has not been fulfilled because:

- a) EUROcleftNet was keen to produce its own website and steering committee members are already communicating well through group emails
- b) The future direction of the Task Force is still under discussion and the need for a 'home' on the Gateway has not been clarified
- c) The proposal to develop a European professional craniofacial association/federation is still in its early stages and will only be taken forward at the European Craniofacial Congress in Gothenburg in June 2015.

It was subsequently felt that it would not be cost effective to go forward with these additions to the Gateway. Furthermore the benefits of establishing member's areas on websites (which can be costly to set up and difficult to monitor) are now being questioned with the development of free professional networking opportunities media such as LinkedIn.

Gateway Benefits to date

- The welcome involvement of so many clinicians and scientists from central and eastern Europe in the EUROcleftNet research conference in Plovdiv in September 2013 was due to promotion via the new Gateway mailing lists
- Thanks to contact data provided by the Gateway an international network consortium "Appearance Matters: Tackling the Physical and Psychosocial Consequences of Dissatisfaction with Appearance" (COST 1210) is now directly working with cleft teams in Bulgaria, France, the Netherlands, Slovakia, Romania, Sweden, Norway, Latvia, Estonia, Lithuania, Serbia and Israel. More are being approached and the hope is that this pooled data and expertise will lead to further collaborations and funding applications
- Two Erasmus+ grants have now been won for international training networks, using data from the Gateway to identify appropriate partners.
- Concurrent with the Gateway development, ECO has been working with the European Standards Agency (CEN) to develop a European guideline in early cleft

care. The Gateway has provided a valuable means of recruiting experts onto both the main Technical Committee and respective Mirror Committees around Europe

Budget to date

A budget showing projected versus actual figures is attached. There is an under-spend of around €3000 which we would like to request permission to put towards further promoting the Gateway to ensure it continues to be populated. See below and budget.

Proposal for multi-language landing page

To further encourage population of the database we are proposing to set up a multi-language internet 'landing page' which will direct people to the Gateway and EUROcleftNet when a search is done for the word 'cleft' in any of 25 European languages. This will serve two purposes:

- 1) It will ensure patients, clinicians and researchers are rapidly able to use the resources provided by the Gateway
- 2) There will be an option on the landing page to upload information about cleft centres that are not listed in the directory. These can then be approached directly and asked to complete the online questionnaire.

The web work will be undertaken by Envision who have currently been appointed by ECO to update their own website. We will translate the landing page into the 24 official languages of the European Commission (see below) plus Russian.

Bulgarian	French	Maltese
Croatian	German	Polish
Czech	Greek	Portuguese
Danish	Hungarian	Romanian
Dutch	Irish	Slovak
English	Italian	Slovene
Estonian	Latvian	Spanish
Finnish	Lithuanian	Swedish

We anticipate this work to be completed by December 2014.

Gateway project costs 2014 - Budget versus Actual figures

	Budget	Actual to date	
Web consultancy costs	5500	1500	
Populating resource directory			
selection/appointment of country coordinators			
ongoing dialogue with coordinators			
data extraction and inputting			
creation of Access search database			
2 days per week/6 months/80 euros per day	3840	4608*	
Adding text and data to new pages for Task Force and Professional Associations	320	0	
Reviewing and updating all existing web content (including research updates)	640	640	
ECO design, management 2 days per month/6 months/350 euros per day	4200	4200	
SUB TOTAL €	14500		
10% overall costs paid by ECO as pro bono support	Less 1450	1095	
TOTAL €	<u>13050</u>	<u>9853</u>	9853

*freelance payments were subject to 20% VAT

Request from EUROcleftNet that the remaining balance of 3197 be spent as follows;

Development of a landing page translated into majority of European languages			
webcosts (Envision)		1000	
translations (24 official EU languages + Russian) 500 words at 45 euros each		1125	
ECO supervision of above (3 days)		1050	
TOTAL		<u>3175</u>	3175
Received to date	6525		<u>1328</u>
Balance due	<u>6503</u>		
	<u>1328</u>		