



A PSYCHOSOCIAL WORKSHOP TO DESIGN THE NEXT INNOVATIVE RESEARCH AGENDA

Venue:

Amphitheatre AO, at the Medical Faculty in Niš,

Bulevar Zorana Djindjica 81 Niš, Serbia

Objective:

To develop innovative psychosocial research ideas for craniofacial conditions that adhere to the objectives of the Horizon2020 call "Health, demographic change and well-being" or other relevant calls.

Participants (funded by the ESF):

<u>Name</u>	<u>Country</u>
Martin Persson	UK
Peter Mossey	UK
Nichola Rumsey	UK
Gareth Davies	France
Leva Maulina	Latvia
Inta Zepa	Latvia
Radmila Dimovska	Macedonia
Laura Linkevičienė	Lithuania
Nenad Tanaskovic	Bosnia
Predrag Knežević	Croatia
Julija Radojičić	Serbia
Zoran Pešić	Serbia
Triin Jagomägi	Estonia
Martina Drevenšek	Slovenia
Radu Lulian Spataru	Romania
Hakan Agir	Turkey
Jana Anguelova	Bulgaria
Radost Velikova	Bulgaria



Outcome:

The participants represented 11 cleft centres from the Eastern Europe together with representatives from NGO's and research institutions that facilitated the workshop.

In the morning session the participants attended the following lectures:

- Beyond ESF: Peter Mossey (appendix 4)
- Global Taskforce & Patient & Public Involvement (PPI): Nichola Rumsey (appendix 1)
- ECO & European cleft guidelines: Gareth Davies (appendix 2)
- The next innovative research agenda: Martin Persson (appendix 3)

In the afternoon, an interactive workshop was facilitated in order for the participants to evaluate their capacity to meet the criteria for European Reference Networks and discuss between themselves about the resources, capacity and potential barriers. This generated fruitful discussions that resulted in that participants could relate to the challenges and the need to collaborate together, especially if they would participate in potential European grants.

The last interactive discussion, focused upon which priorities for research grants should be considered.

- Important to include craniofacial conditions.
- The grants should be beneficial for improvement of provision of care as well as research.
- Should be used as a resource to strengthen the teams as well.
- Provide opportunity for staff members to visit other institutions on a short or long-term basis.
- Influence health care policy for cleft and craniofacial conditions.
 - This was considered paramount because some centers have limited support to provide adequate provision of care in relation to western Europe
- The centers does not have the time and/or skill to write the potential research grants or EU applications, so it is paramount that there are individuals that can support with this process.
- They all feel that given adequate resources and time via a research grant they all can contribute.



A PSYCHOSOCIAL WORKSHOP TO DESIGN THE NEXT INNOVATIVE RESEARCH AGENDA

Objective: To develop innovative psychosocial research ideas for craniofacial conditions that adhere to the objectives of the Horizon2020 call “Health, demographic change and well-being” or other relevant calls.

Venue: Amphitheatre AO, at the Medical Faculty in Niš, Bulevar Zorana Djindjica 81 Niš, Serbia Wednesday 24th of February, 2015	
09:00 – 09:30	Welcome and introduction
	Introduction - 3 min/organisation
09:30 – 09:45	Focus of the day: Martin Persson
09:45 – 10:15	Beyond ESF: Peter Mossey
10:15 – 10:45	Coffee Break
10:45 – 11:15	Global Taskforce & Patient & Public Involvement (PPI): Nichola Rumsey
11:15 – 11:45	ECO & European cleft guidelines: Gareth Davies
11:45 – 12:15	The next innovative research agenda: Martin Persson
12:15 – 13:15	Lunch
13:15 – 15:15	Criteria for European Reference Networks – Group work
15:15 – 15:45	Coffee Break
15:45 – 16:15	Group summary and discussion
16:15 – 16:45	The way forward – establish research priorities in relation to available grants
16:45 – 17:00	Wrap up: Martin Persson
Dinner for Tuesday and Wednesday evening – Julija Radojicic will provide information	

A PSYCHOSOCIAL WORKSHOP TO DESIGN THE NEXT INNOVATIVE RESEARCH AGENDA

the Medical Faculty in Niš,

Niš, Serbia

24 February 2016



Objective

- **To develop innovative psychosocial research ideas for craniofacial conditions that adhere to the objectives of the Horizon2020 call “Health, demographic change and well-being” or other relevant calls.**

EU Priorities



EU Priorities – Societal Challenges

- *Successful efforts to prevent, detect early, manage, treat and cure disease, disability, frailty and reduced functionality are underpinned by the fundamental understanding of their determinants and causes, processes and impacts, as well as factors underlying good health and well-being. Improved understanding of health and disease will demand close linkage between fundamental, clinical, epidemiological and socio-economic research.*

EU Priorities – Societal Challenges

- Successful efforts to **prevent, detect early, manage, treat** and cure disease, disability, frailty and reduced functionality are underpinned by the **fundamental understanding of their determinants and causes, processes and impacts**, as well as **factors underlying good health and well-being**. Improved understanding of health and disease will demand **close linkage between fundamental, clinical, epidemiological and socio-economic research**.

Focus

- Focus on the design for research priorities for cleft and craniofacial conditions around the EU priorities mentioned above
- Focus how we can link in psychosocial aspects into other grant applications in our field such as the Face Reader for example. This is important for all disciplines since the EU wants a multidisciplinary approach in many grant applications.
- Feasibility of EU grant applications
 - Partners resources
 - Implication for provision of care
 - Incorporation of EU priorities

Session 1

- Beyond ESF: Peter Mossey
- Global Taskforce & Patient & Public Involvement (PPI): Nichola Rumsey
- ECO & European cleft guidelines: Gareth Davies
- The next innovative research agenda: Martin Persson

Session 2

- Group Work
- The way forward – establish research priorities in relation to available grants
- Wrap up

PROMOTING PATIENT-CENTRED CARE

Global Task Force on Patient Centred Outcomes

OVERVIEW

How do we make care more patient-centred?
Moving from a Biomedical model to more
holistic care

1. Promoting the patient's voice in the process and outcomes of care (Education & training)
2. Improving understanding & knowledge.....moving towards evidence based care (GTF)

PROVIDING PATIENT-CENTRED (HOLISTIC) CARE FOR PATIENTS WITH CONGENITAL ANOMALIES

- Treatment protocols vary according to condition, however, many craniofacial conditions involve multimodal interventions spanning many years.
- Regular hospital appointments & interventions can serve as reminders of the patient's 'difference' and can cause disruption to normal routines. Patients may feel they are on a treatment 'treadmill' with little control over decisions about their care

THE BIOMEDICAL MODEL OF CARE

For the majority of health professionals, the primary aim of care is to improve or optimise the patient's quality of life. Most believe this is best achieved through striving to produce the best possible aesthetic and functional outcomes. This may lead them to be enthusiastic about the potential of repeated or new treatments.

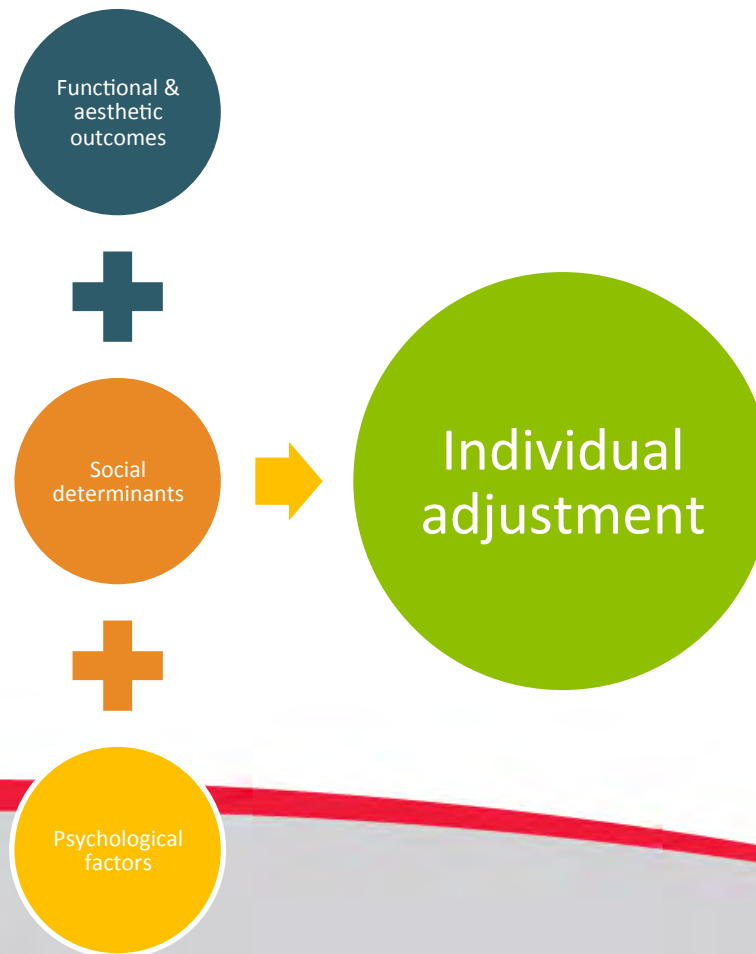
But....

Adjustment is predicted much better by psychological and social factors rather than appearance and function.

So, in order to optimise the chances of positive outcomes for the patient, care needs to become more holistic.

ALL team members can take responsibility for this shift in the ethos of care.....

BIOPSYCHOSOCIAL CARE



MAKING CARE MORE PATIENT-CENTRED

- As positive adjustment to a visible difference is better predicted by psychosocial factors than by aesthetic and functional outcomes ideally, psychological care should be available for all
- Responsibility of ALL team members
- For teams without access to specialist resource, appropriate training for all team members & referral routes for specialist intervention should be in place.

A TIERED APPROACH TO CARE

LEVEL 1 (ALL team members)

SENSITIVE EXPLORATION OF PSYCHOSOCIAL FUNCTIONING AND CONCERNS

Both patient and professional are encouraged to ask questions about psychosocial issues. Enquiring about the impact of the visible difference on the patient and 'how things are going' can normalise the challenges of looking different and can put psychosocial issues on the agenda of care.



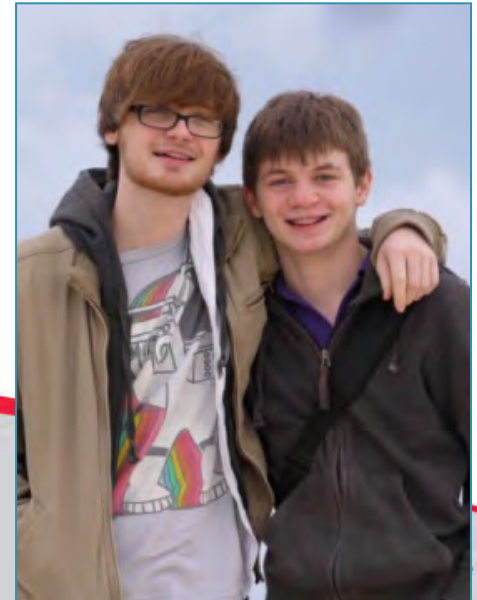
AVOID FUELLING THE 'BEAUTY MYTHS'

- Avoid an excessive focus on aesthetic outcomes
- Cut out 'appearance talk' in clinic
 - Use factual descriptors (after surgery your nose will be straighter; smaller) rather than value judgements (better looking);
- Educate yourselves (through training) & your patients/families about
 - How first impressions, friendships & relationships work
 - What makes people happy & psychologically resilient



PROVIDING PATIENT CENTRED CARE

- Adopt a 'normalising' rather than a 'pathologising' approach
 - Maintain a focus on the patient as a normal person, rather than someone defined by their condition
 - E.g. Refer to the 'patient with a cleft' rather than 'the cleft patient'



A NORMALISING APPROACH TO PROVIDING CARE

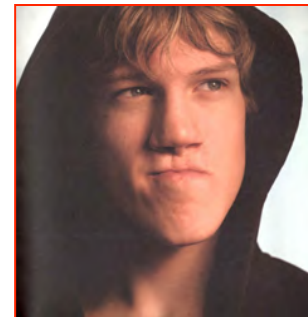
The condition will affect adjustment across the lifespan, however, so will factors affecting the whole population (including social determinants and psychological factors)

Social determinants/cultural influences

Psychosocial factors contributing to resilience or distress

Condition specific issues

LIFESPAN



LEVEL 2: ALL TEAM MEMBERS

1. GIVE APPROPRIATE ADVICE AND GUIDANCE ABOUT COMMON PROBLEMS
2. PROVIDE INFORMATION RELATING TO COMMON CHALLENGES (e.g. teasing/bullying)
 - ECO, CLAPA, Changing Faces
 - Support group websites

3. ANTICIPATE PSYCHOLOGICAL CHALLENGES & STRESS POINTS (e.g. teasing at 7/8 years; forming new friendships when changing social groups) & offer strategies to promote resilience

4. UNDERSTAND (THROUGH EDUCATION/TRAINING) FACTORS CONTRIBUTING TO RESILIENCE/POSITIVE ADJUSTMENT

- Focus on the patient's strengths as well as weaknesses
- Boost the patient's self-esteem
- Encourage parents to do the same

5. Patients may not always share the enthusiasm for multiple treatments. INVOLVE PATIENTS IN TREATMENT DECISION MAKING

6. EXPLORE CAREFULLY the

- MOTIVATION OF PATIENTS TO UNDERGO SURGERY & OTHER TREATMENT
- THEIR EXPECTATIONS OF OUTCOMES (both aesthetic & psychological). The depiction of plastic surgery in the media as ‘miraculous’ may fuel unrealistic expectations. The potential for disappointment can be high.

LEVEL 3: TEAM MEMBERS WITH RELEVANT TRAINING

- Provision of specialist advice and support, eg teaching patients social skills to deal with common problems, e.g.
 - Staring
 - Questions about the ‘difference’
 - Handling comments & questions

LEVEL 4: PSYCHOSOCIAL SPECIALISTS

SPECIALIST ASSESSMENT & INTERVENTIONS to address more complex issues, for example

- Counselling for low mood, mild anxiety or depression
- Cognitive Behaviour Therapy to tackle maladaptive thoughts, beliefs and behaviours
- Psychiatric intervention to deal with moderate or severe anxiety, depression, self-harm or Body Dysmorphic Disorder (BDD)

WHERE POSSIBLE, DEVELOP REFERRAL ROUTES TO ACCESS THIS TYPE OF PROFESSIONAL SUPPORT



2. IMPROVING KNOWLEDGE & UNDERSTANDING.....

- Adjustment is multifactorial
- To improve the quality of life of our patients, we need to know more....
- More data
 - Longitudinal data collection (audit)
 - Large samples
 - Consensus re what data to collect

AGREEING A COMMON FRAMEWORK

1. Literature review (what do we know; what don't we know?)
2. Clinical consensus re key factors
 - COST Cleft Task Group
 - UK Cleft Psychologists
 - Global Task Force
3. Patient priorities (JLA)

GLOBAL TASK FORCE

TIERED APPROACH USING COMMON FRAMEWORK:

LEVEL 1: Promote patient-centred care

LEVEL 2: Generate clinically useful patient-centred data (eg to inform treatment decision making; guide referral for specialist intervention)

LEVEL 3: Generate data for audit & research

GLOBAL TASK FORCE: TIERED APPROACH

	Cleft specific factors	Generic Psychological Constructs	Social Determinants
3	Comprehensive Standardised measures	Comprehensive Standardised Measures	Comprehensive Questions
2	One standardised measure + key questions	One standardised question & key questions	Key questions
1	Simple key questions	Simple key questions	Simple key questions

COLLABORATION.....



Development of European guidelines in the early care of babies born with clefts

Gareth Davies

Executive Director
European Cleft Organisation

Aims / Methods

- **To provide a blueprint for early cleft care agreed at a European level**
 - 2009 survey for UNICEF Bulgaria: nearly 40% parents advised to leave their babies with clefts in care. Other countries in region, similar issues
 - Not about resources but about information and referral procedures
- **Development of guidelines that could be adopted by practitioners in countries where no national protocols exist**
 - Powerful lobbying tool
- **Decision to use European Committee for Standardisation (CEN)**
 - in recent years CEN developing standards for services rather than just products
 - Healthcare initiatives: Aesthetic surgery (2014), Osteopathy services (ongoing)

Results

- **CEN instruments available**
 - European standard
 - [Technical Report](#)
 - Workshop Agreement
- **Project Committee established**
 - Vienna September 2013
 - Health professionals and patient reps from 9 countries
 - Timeframe, [scope](#) and chapter headings agreed
- **Scope**

Guidelines on the care of babies born with CLP including [referral processes](#), [establishment of feeding](#), [parental support and care pathways](#). Recommendations on all aspects of surgery, including timing and the use of pre surgical orthopaedics is excluded

Themes

- **Focus on **early** care**
 - Diagnosis (pre and post natal)
 - Referrals
 - Immediate post natal care
 - Feeding
 - Monitoring
 - Parent support
 - Information needs
- **Context of **overall** care**
 - Inclusion of long term care pathway
 - Cleft team and centre requirements
 - Record keeping and audit
 - National registers – cross border comparisons

What areas do the guidelines address?

Diagnosis – antenatal, postnatal

- Guidelines for obstetricians/midwives/paediatricians on making the diagnosis and counselling the family
- Referral pathways to appropriate cleft specialists
- Timeframe in which the diagnosis can be made and confirmed

Feeding Assessments

- Guidelines on the necessary training and qualifications for an individual to provide this service
- Guidelines on how a feeding assessment should be performed
- Guidelines on how to establish feeding

First weeks

- Guidance on directing parents to appropriate parent support groups
- Guidelines on defining the care pathway for the first months of life, prior to definitive surgery to repair the cleft lip and/or palate

Wider recommendations

- ☐ Guidelines on Facility requirements

- ☐ Guidelines on Organisation of the Cleft Service,
including clinical governance and audit

Who has been involved?

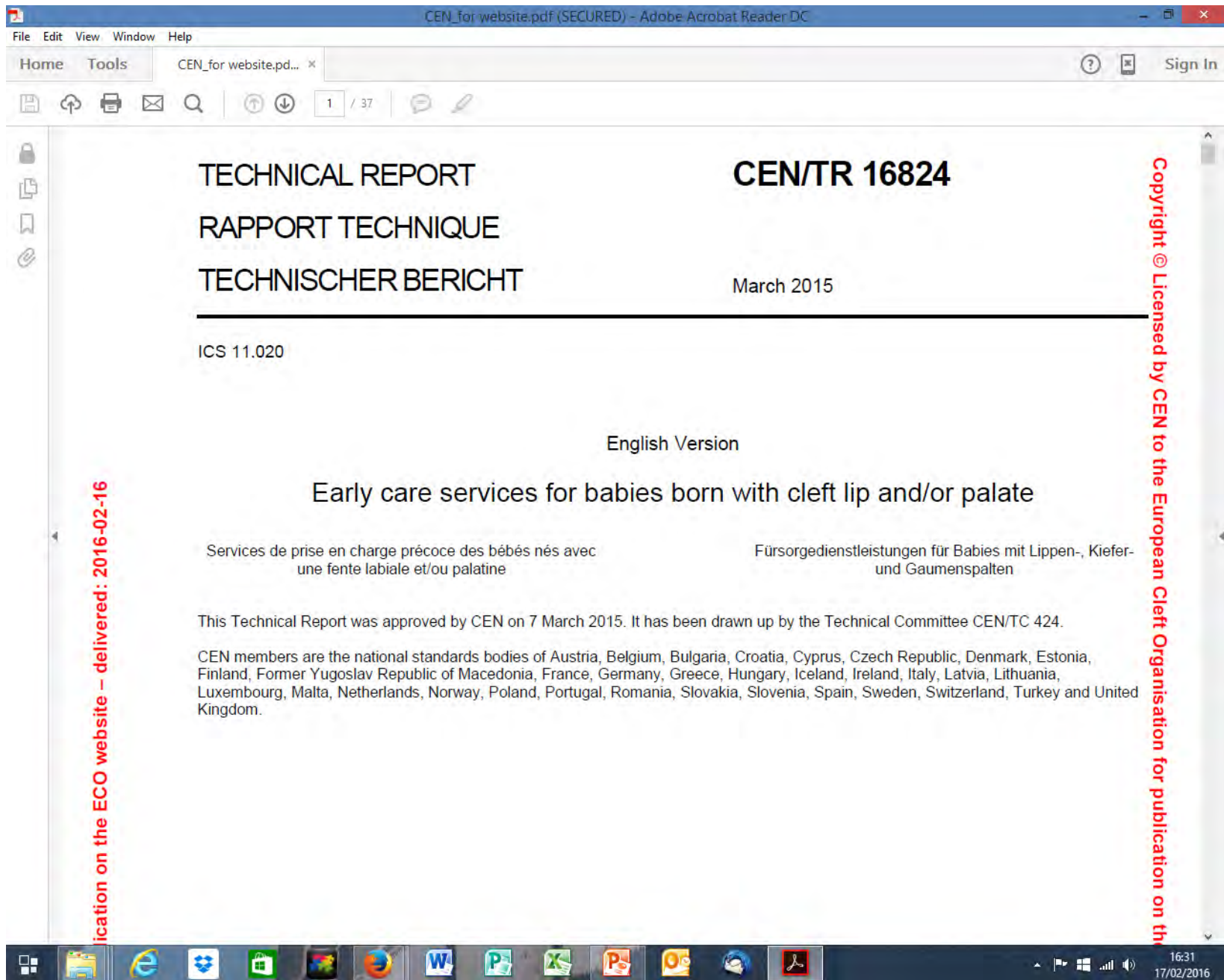
- Representation from the European Craniofacial Congress
- Representation from national cleft bodies where they exist (eg CSGB&I, AFFF, AFILAPA)
- Representation from national cleft patient associations (CLAPA UK and VAGA Belgium)
- Representation from all disciplines directly working in cleft care AND 'front line health professionals who are normally present at the birth of a baby or during the antenatal period
- 16 Countries

- Three major meetings of Technical Committee plus input from [national mirror committees](#)
- Involvement of national professional associations
- Total of [16 countries](#) involved at various stages, with strong representation from Eastern Europe
- Drew heavily on existing guidelines from different countries
- [Guidelines approved February 2015](#) by CEN member bodies throughout Europe
75% of voting countries (16) voted positive



Achievements

- The aim of producing a document setting out recommendations on early cleft care agreed at a European level has been successful.
- User involvement and full multidisciplinary input has helped achieve agreement.
- Compromise has been necessary, with some insisting the guidelines are not stringent enough, and others claiming we have been over-prescriptive.
- The exercise has increased the profile of clefts around Europe and has helped forge links between health professionals in different countries.
- Possible model for improving quality (and equality) of care for other congenital anomalies



CEN/TR 16824:2015 (E)

1 Scope

This Technical Report specifies recommendations for the care of babies born with cleft lip and/or cleft palate at time of diagnosis (ante- and/or postnatal) and the year following birth or diagnosis (whichever is later), including referral processes, establishment of feeding, parental support and care pathways.

Recommendations on all aspects of surgery, including timing and the use of pre surgical orthopaedics is excluded.

2 Terms and definitions

For the purpose of this document, the following terms and definitions apply.

2.1

assisted feeding

use of a soft, squeezable, bottle and/or adjusted teat and/or sipper spout to allow delivery of milk to the infant who is unable to generate suction to extract fluid independently

Note 1 to entry: It enables the infant to feed, effectively and safely, the required volume within an acceptable time frame.

Note 2 to entry: For further information on types of bottles and teats used for assisted feeding of babies born with clefts see Annex C.

2.2

cleft centre

hospital with a designated cleft team and paediatric facilities

Table 3 — Care Pathway

Antenatal	Birth to 1,5 years	1,5 to 5 years	6 to 10 years	11 to 20 years	21 years +
<p>Ultrasound diagnosis confirmed.</p> <p>Referral to cleft specialist team.</p> <p>Antenatal counselling and support.</p> <p>Provision of written information.</p> <p>Information on feeding options and presurgical infant orthopaedics (if used)</p> <p>Information about patient groups.</p>	<p>Diagnosis confirmed at birth.</p> <p>Assessment of presence of co-morbidities.</p> <p>Referral to cleft team.</p> <p>Visit by specialist advisor/nurse specializing in cleft care.</p> <p>Feeding assessment.</p> <p>Feeding plan.</p> <p>Meeting offered with parent/patient group.</p> <p>Registration on anomaly database.</p> <p>Post natal support and counselling.</p> <p>Provision of written information.</p> <p>Speech and language therapy assessment and advice.</p>	<p>ENT and audiology assessment and treatment.</p> <p>Speech and language therapy assessment and advice at 2–3 years, therapy as required.</p> <p>Psychological assessment and intervention where necessary.</p> <p>Paediatric dental care.</p> <p>Audit at 5 years.</p> <p>Possible revision surgery and velopharyngeal surgery.</p>	<p>ENT and audiology assessment/treatment.</p> <p>Speech and language therapy assessment and therapy as required.</p> <p>Paediatric dental care.</p> <p>Review of overall management.</p> <p>Audit of data set at 10 years.</p> <p>Orthodontic care and treatment.</p> <p>Secondary surgery – alveolar bone graft.</p>	<p>Orthodontic care and treatment.</p> <p>Preparation for possible orthognathic surgery.</p> <p>Psychological assessment and intervention where necessary.</p> <p>Paediatric and restorative dental care.</p> <p>Audit data set at 15 years and 20 years.</p> <p>Possible revision surgery and velopharyngeal surgery.</p>	<p>Possible orthognathic surgery.</p> <p>Psychological assessment and intervention where necessary.</p> <p>Routine dental care.</p>

CEN/TR 16824:2015 (E)

F.3 Timing of minimum records

Table F.1 — Complete Cleft Lip, Alveolus and Palate (UCLAP and BCLAP)

Timing	Models	Lateral skull radiograph	Photographs	Speech	Audiometry/tympanometry
Primary surgery	√		√		
3 years				√ ^a	√ ^a
5/6 years	√		√	√	√
10 years	√	√	√	√	√
18+ years	√	√	√	√	
^a If hard palate is closed.					

Table F.2 — Complete Palate Only (CPO)

Timing	Models	Lateral skull radiograph	Photographs	Speech	Audiometry/tympanometry
Primary surgery	√		√		
3 years				√	√
5/6 years	√			√	√
15/16 years	√	√	√	√	√

What next?

“Knowledge is nothing

.....**It is what you do with** it that has
the potential to change the world”

Implementation

- Assessment of current practices across Europe – who/where is falling short?
- How to measure and evaluate above against the guidelines
- Implementation workshop 21 March 2016 Brussels

Delegate list: Assistant to Health Minister, Republic of Serbia
Members of CEN Technical Committee 424 (who wrote the guidelines)
high level representatives of CEN, long term campaigners/researchers/
clinicians striving for equity in European cleft care, Director European
Patient Forum, Cleft NGOs, Service Directors, GPS etc from at least 13
countries

Themes

- How to get guidelines to impact upon medical training school curricula
- How to ensure governments and health ministries act on them
- How to ensure hospitals and medical directors implement them

And finally.....

Delegation to European Parliament
22 March

Thank you!



Download guidelines at
www.europeancleft.org

A PSYCHOSOCIAL WORKSHOP TO DESIGN THE NEXT INNOVATIVE RESEARCH AGENDA

the Medical Faculty in Niš,
Niš, Serbia

24 February 2016





**WHY DO I TALK ABOUT FUNDING
AND CLEFT**

Outcomes 2012 - 2015

Title and Funding source	Year
Optimising the psychosocial care for individuals with birth defects in Japan by implementing an innovative training method. Daiwa Anglo-Japanese Foundation	2015 - 2016
IHEM: Improving the long-term outcomes in children with congenital anomalies by implementing an Innovative Health Educational Module for staff in health care and NGO settings. Erasmus+ 2014 Key Action 2 (KA2), Strategic Partnerships	2015 - 2017
Be Positive: A positive psychological approach to enhancing resilience and utilising strengths in European unemployed youth. Erasmus+ 2014 Key Action 2 (KA2), Strategic Partnerships	2014 - 2016
Face Value: Optimising the psychosocial care for individuals with birth defects in Europe by implementing an innovative training method for staff in health care and NGO settings. Erasmus+ 2014 Key Action 2 (KA2), Strategic Partnerships	2014 – 2016
When Looks Get in the Way: Optimising patient outcomes through the training of health care professionals. Erasmus+ 2014 Key Action 2 (KA2), Strategic Partnerships	2014 – 2016
Mirror, mirror- VET Student's appearance concerns and the influence on completion rates in VET and on success their factors on the job market. EU Lifelong Learning program	2013 - 2015
Appearance Matters: Cooperation of Science and Technology - EU RTD Framework Programme.	2013 - 2017
Appearance Matters - optimising the outcomes for vocational guidance counselling and vocational training: EU Lifelong Learning program	2012 - 2014
Early Diagnosis Of Cancer In Primary Health Care. European Science Foundation.	2012

Total value of projects: €2,322,372

Cleft Care UK

Orthodontics & Craniofacial Research

ORIGINAL ARTICLE

M. Persson
J. R. Sandy
A. Waylen
A. K. Wills
R. Al-Ghatam
A. J. Ireland
A. J. Hall
W. Hollingworth
T. Jones
T. J. Peters
R. Preston
D. Sell
J. Smallridge
H. Worthington
A. R. Ness

A cross-sectional survey of 5-year-old children with non-syndromic unilateral cleft lip and palate: the Cleft Care UK study. Part 1: background and methodology

Authors' affiliations:

M. Persson, Centre for Appearance Research, University of the West of England, Bristol, UK
J. R. Sandy, A. Waylen, A. K. Wills, R. Al-Ghatam, A. J. Ireland, T. Jones, A. R. Ness, School of Oral and Dental Sciences, University of Bristol, Bristol, UK
R. Al-Ghatam, Dental & Maxillofacial Centre, Royal Medical Services, West Riffa, Kingdom of Bahrain
A. J. Hall, Children's Hearing Centre, University Hospitals Bristol NHS Foundation Trust, Bristol, UK
A. J. Hall, Centre for Child & Adolescent Health, School of Social & Community Medicine, University of Bristol, Bristol, UK
W. Hollingworth, School of Social & Community Medicine, University of Bristol, Bristol, UK
T. Jones, Musgrove Park Hospital, Taunton, UK

Date:

Accepted 30 August 2015
DOI: 10.1111/ocr.12104

© 2015 The Authors.
Orthodontics & Craniofacial Research
Published by John Wiley & Sons Ltd

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Persson M., Sandy J. R., Waylen A., Wills A. K., Al-Ghatam R., Ireland A. J., Hall A. J., Hollingworth W., Jones T., Peters T. J., Preston R., Sell D., Smallridge J., Worthington H., Ness A. R. A cross-sectional survey of 5-year-old children with non-syndromic unilateral cleft lip and palate: the Cleft Care UK study. Part 1: background and methodology. *Orthod Craniofac Res* 2015; **18**(Suppl. 2): 1–13. © 2015 The Authors. *Orthodontics & Craniofacial Research* Published by John Wiley & Sons Ltd

Structured Abstract

Objectives – We describe the methodology for a major study investigating the impact of reconfigured cleft care in the United Kingdom (UK) 15 years after an initial survey, detailed in the Clinical Standards Advisory Group (CSAG) report in 1998, had informed government recommendations on centralization.

Setting and Sample Population – This is a UK multicentre cross-sectional study of 5-year-olds born with non-syndromic unilateral cleft lip and palate. Children born between 1 April 2005 and 31 March 2007 were seen in cleft centre audit clinics.

Materials and Methods – Consent was obtained for the collection of routine clinical measures (speech recordings, hearing, photographs, models, oral health, psychosocial factors) and anthropometric measures (height, weight, head circumference). The methodology for each clinical measure followed those of the earlier survey as closely as possible.

Orthodontics & Cranio

ORIGINAL ARTICLE

J. Smallridge
A. J. Hall
R. Chorbachi
V. Parfekt
M. Persson
A. J. Ireland
A. K. Wills
A. R. Ness
J. R. Sandy

Authors' affiliations:

J. Smallridge, South Thames' Cleft Unit, Guy's and St Thomas Hospital, London, UK
J. Smallridge, Cleft Net East Cleft Network, Addenbrooke's Hospital, Cambridge, UK
A. J. Hall, Children's Hearing Centre, University Hospitals Bristol NHS Foundation Trust, Bristol, UK
A. J. Hall, School of Social and Community Medicine, University of Bristol, Bristol, UK
R. Chorbachi, North Thames Cleft Centre, Great Ormond Street Hospital for Children and Broomfield Hospital, London, UK
V. Parfekt, East of England Cleft Network, Audiology, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK
M. Persson, Centre for Appearance Research, University of the West of England, Bristol, UK
A. J. Ireland, A. K. Wills, A. R. Ness, J. R. Sandy, School of Oral and Dental Sciences, University of Bristol, Bristol, UK

Orthodontics & Craniofacial Research

ORIGINAL ARTICLE

A. R. Ness
A. K. Wills
A. Waylen
R. Al-Ghatam
T. E. M. Jones
R. Preston
A. J. Ireland
M. Persson
J. Smallridge
A. J. Hall
D. Sell
J. R. Sandy

Centralization of cleft care in the UK. Part 6: a tale of two studies

Authors' affiliations:

A. R. Ness, D. Sell, National Institute for Health Research (NIHR) Biomedical Research Unit in Nutrition, Diet and Lifestyle at the University Hospitals Bristol NHS Foundation Trust and the University of Bristol, Bristol, UK
A. R. Ness, A. K. Wills, A. Waylen, R. Al-Ghatam, T. E. M. Jones, A. J. Ireland, J. R. Sandy, School of Oral and Dental Sciences, University of Bristol, Bristol, UK
T. E. M. Jones, Musgrove Park Hospital, Taunton, UK
R. Preston, Cleft Lip and Palate Association, London, UK
M. Persson, Centre for Appearance Research, University of the West of England, Bristol, UK
J. Smallridge, South Thames' Cleft Unit, Guy's and St Thomas Hospital, London, UK
J. Smallridge, Cleft Net East Cleft Network, Addenbrooke's Hospital, Cambridge, UK
A. J. Hall, Children's Hearing Centre, University Hospitals Bristol NHS Foundation Trust, Bristol, UK

Date:

Accepted 5 September 2015
DOI: 10.1111/ocr.12111

© 2015 The Authors.

Orthodontics & Craniofacial Research

Published by John Wiley & Sons Ltd

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Clinical Standards Advisory Group (CSAG, 1998) and the Cleft Care UK (CCUK, 2013) studies.

Setting and sample population – Two UK-based cross-sectional studies of 5-year-olds born with non-syndromic unilateral cleft lip and palate undertaken 15 years apart. CSAG children were treated in a dispersed model of care with low-volume operators. CCUK children were treated in a centralized, high volume operator system.

Materials and methods – Oral health data were collected using a standardized proforma. Hearing was assessed using pure tone audiometry and middle ear status by otoscopy and tympanometry. ENT and hearing history were collected from medical notes and parental report.

Results – Oral health was assessed in 264 of 268 children (98.5%). The mean dmft was 2.3. 48% were caries free, and 44.7% had untreated car-

Ness A. R., Wills A. K., Waylen A., Al-Ghatam R., Jones T. E. M., Preston R., Ireland A. J., Persson M., Smallridge J., Hall A. J., Sell D., Sandy J. R. Centralization of cleft care in the UK. Part 6: a tale of two studies. *Orthod Craniofac Res* 2015; **18**(Suppl. 2): 56–62. © 2015 The Authors. *Orthodontics & Craniofacial Research* Published by John Wiley & Sons Ltd

Structured Abstract

Objectives – We summarize and critique the methodology and outcomes from a substantial study which has investigated the impact of reconfigured cleft care in the United Kingdom (UK) 15 years after the UK government started to implement the centralization of cleft care in response to an earlier survey in 1998, the Clinical Standards Advisory Group (CSAG). **Setting and Sample Population** – A UK multicentre cross-sectional study of 5-year-olds born with non-syndromic unilateral cleft lip and palate. Data were collected from children born in the UK with a unilateral cleft lip and palate between 1 April 2005 and 31 March 2007.

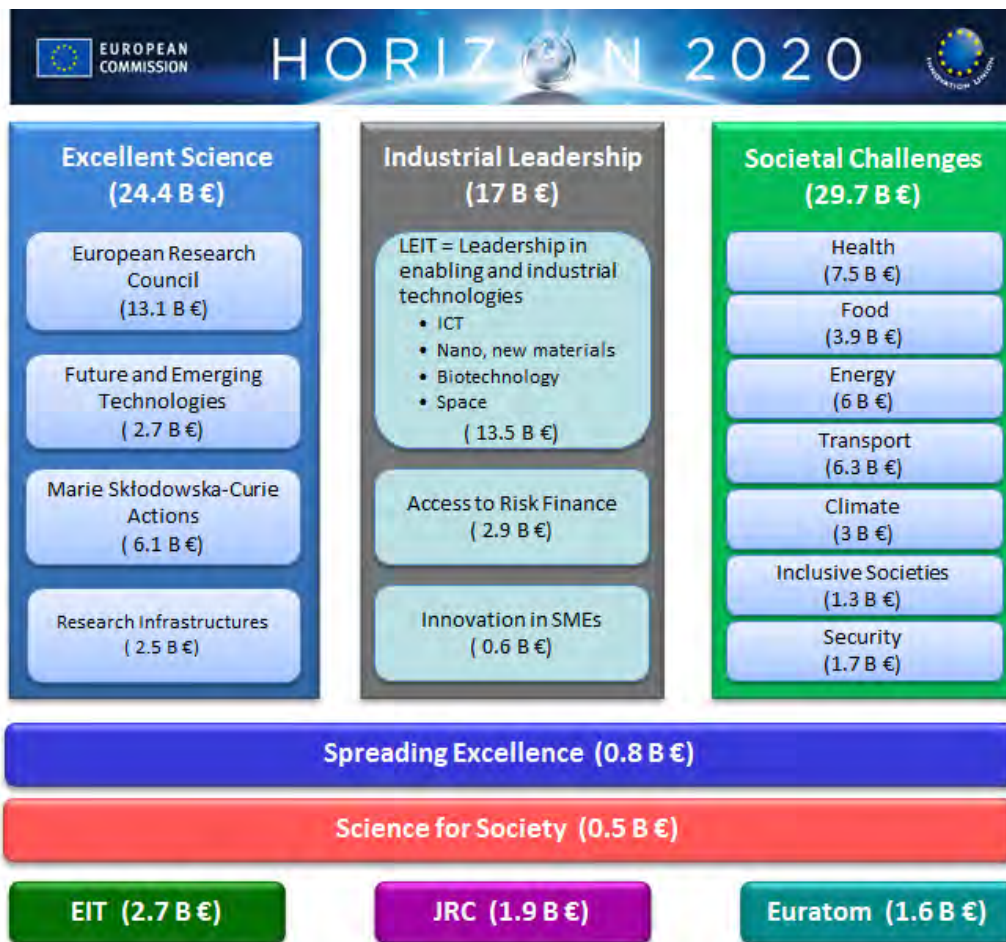
Materials and Methods – We discuss and contextualize the outcomes from speech recordings, hearing, photographs, models, oral health and psychosocial factors in the current study. We refer to the earlier survey and other relevant studies.

Results – We present arguments for centralization of cleft care in health-care systems, and we evidence this with improvements seen over a period of 15 years in the UK. We also make recommendations on how future audit and research may configure.

Conclusions – Outcomes for children with a unilateral cleft lip and palate have improved after the introduction of a centralized multidisciplinary

A vibrant image of a sun rising over the horizon of the Earth. The sun is a bright, glowing orb in the center, with numerous rays of light radiating outwards. The Earth's horizon is a curved line below the sun, showing a blue and white atmosphere. The background is a deep black space.

HORIZON 2020



Horizon 2020 – Societal Challenges

Societal Challenges

Health and Wellbeing

Food Security

Transport

Energy

Climate Action

Societies

Security

Horizon 2020 – Societal Challenges

Societal Challenges

Health and Wellbeing

Societal challenges – How have they been selected?

Selection of challenges stems directly from Europe 2020 strategy, taking into account:

- Need to focus on limited number of major challenges
- EU level nature of the challenge
- State of the economy and society in Europe and worldwide
- Europe's performance and trends in the related domains
- Need for an approach co-ordinated at EU level.

Societal challenges – Cross-cutting issues

- Focus on policy priorities without predetermining technologies or types of solutions to be developed
- Bringing together resources and knowledge across fields, technologies and disciplines
- Activities to cover cycle from research to market; focus on innovation-related activities (e.g. piloting, demonstration, demand side policies – public procurement, standards, etc.
- Social Sciences and Humanities – integral part of the activities to address all challenges.

Societal Challenges - Health

Objective: improve lifelong health and wellbeing

Three key areas:

- Prevention – through increasing understanding of relationships in all areas relating to health: genetic, environmental, socio-economic factors, healthy approach to aging
- Disease – to understand the development processes & process of disease & its spread in order to stimulate innovative drugs and therapies
- Health and Social Care – to improve sustainability & efficiency of care provision, plus management & effects of emerging health threats (e.g. epidemics)

Societal Challenges - Health

Delivered through:

- Long-term studies of large populations to collect and process data
- Developing and supporting data and biological infrastructures
- Supporting and developing appropriate tools and technologies
- Development of research findings into practical & marketable products and services, including regulation

- Horizon 2020
- Pillar: Societal Challenges
- Work Programme Year: H2020-2016-2017
- Work Programme Part: [Health, demographic change and well-being](#)
- Call : [H2020-SC1-2016-201](#)
- Scope: Proposals should develop population-oriented primary prevention interventions to promote mental well-being of young people and assess them for their effectiveness. The interventions should build on but may go beyond existing state-of-the art knowledge on biological, psychological and social determinants of mental well-being such as societal, cultural, work life, lifestyle, epidemiological, economic and environmental perspectives. The proposals should aim at increasing resilience and mitigating the impact of biological, psychosocial and environmental risk factors. The target group should include young up to 25 years (or a subgroup there of), which is an age limit often used as many severe disorders start in this period.
- Grant awarded: between EUR 2 and 4 million
- Process: Identify partners that can contribute to the scope of the proposal and be able to submit the necessary documentation for the 1st stage of the proposal.

Marie Skłodowska-Curie Actions



Research networks (ITN): support for Innovative Training Networks

- ITNs support competitively **selected joint research training** and/or doctoral programmes, implemented by European partnerships of universities, research institutions, and non-academic organisations.
- The research training programmes provide experience outside academia, hence developing innovation and employability skills.

International and inter-sectoral cooperation through the Research and Innovation Staff Exchanges (RISE)

- RISE supports short-term mobility of research and innovation staff at all career levels, from the most junior (post-graduate) to the most senior (management), including also administrative and technical staff.
- It is open to partnerships of universities, research institutions, and non-academic organisations both within and beyond Europe.



EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY



Erasmus+



FACE VALUE

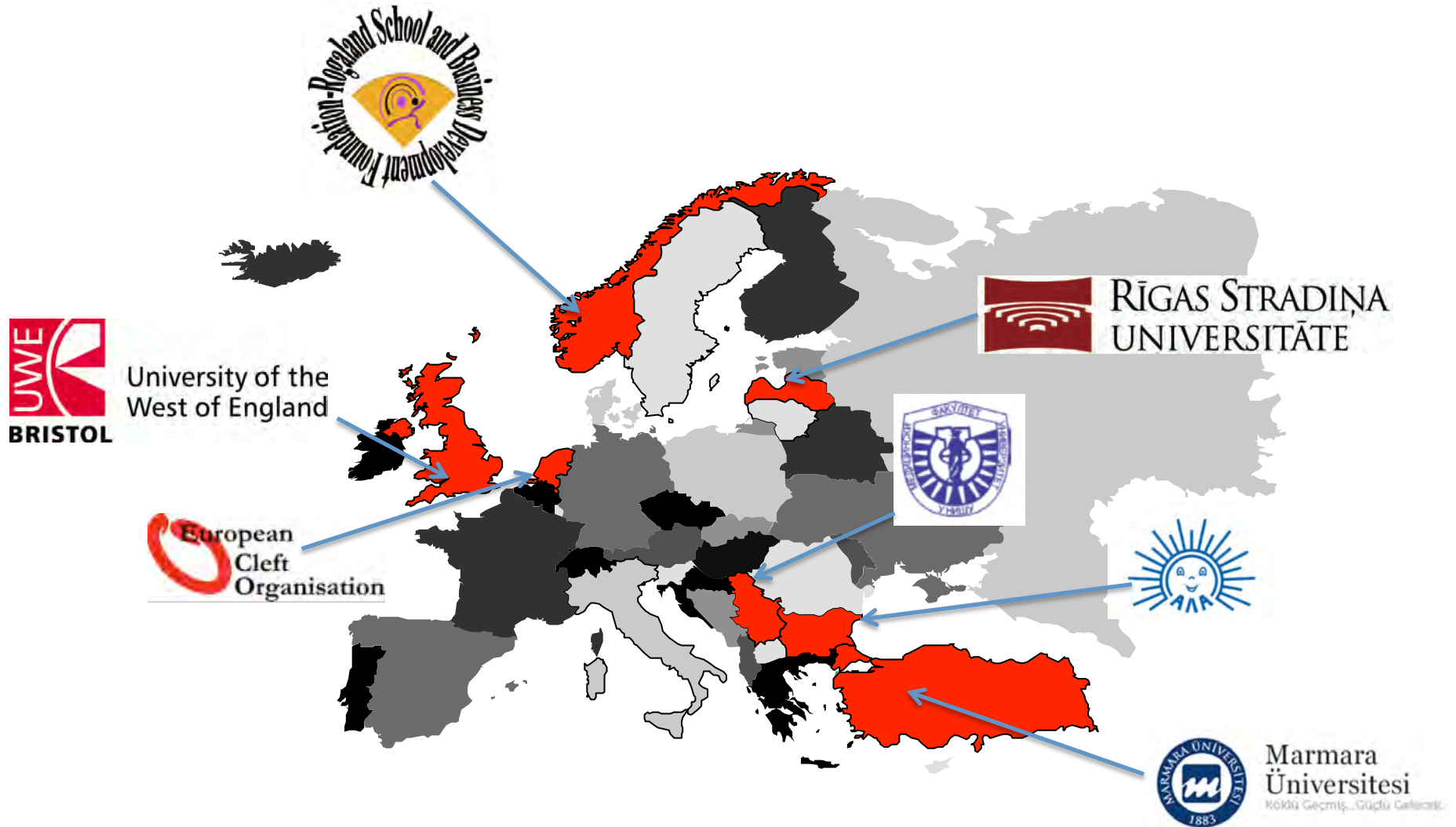
Optimising the psychosocial care for individuals with birth defects in Europe by implementing an innovative training method for staff in health care and NGO setting



Erasmus+

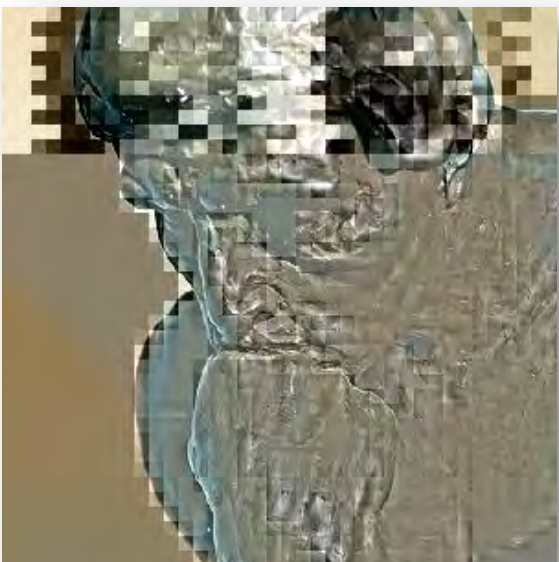
This project has been funded with support from the European Commission. 2014-1-UK01-KA202-001615. This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

7 Partners





EURORDIS
Rare Diseases Europe



Make it easy on the evaluator



- **30-seconds-rule**

- Why bother? (*what is the problem? “EU gap”*)
- Is it a European problem?
(*beyond national level?*)
- Solution already available? (*state of the art*)
- Why now? (*what happens if we do not fund this?*)
- Why you? (*are you the best people/consortium?*)

Make it easy on the evaluator

Objectives (and proposal in general) should meet the 4 C's:

Credibility

The idea is convincing and achievable
“it has to make sense”

Communication

Clear description of what will be done

Concrete

Very specific, not general concepts
“who will do what, when, and how?”

Consistency

High quality documentation (proof read)
Written by consortium, but edited



Thank you!

A PSYCHOSOCIAL WORKSHOP TO DESIGN THE NEXT INNOVATIVE RESEARCH AGENDA

the Medical Faculty in Niš,
Niš, Serbia

24 February 2016



Networks

- **General** Criteria and Conditions to be fulfilled:
 1. Highly Specialised Healthcare
 2. Governance and Coordination
 3. Patient Care
 4. Multidisciplinary Approach
 5. Good Practice, Outcome Measures, and Quality Control

Networks

6. Contribution to Research
7. Continuous Education, Training, and Development
8. Networking and Collaboration

Healthcare Providers

- **General** Criteria and Conditions to be fulfilled :
 1. Patient Empowerment and Patient-Centred Care
 2. Organisation, Management, and Business Continuity
 3. Research, Education and Training
 4. Expertise, Information Systems, and e - Health Tools
 5. Quality and Safety

Healthcare Providers

- **Specific** Criteria and Conditions to be fulfilled:
 1. Competence, Experience and Outcomes of Care
 2. Human Resources
 3. Organisation of Patient Care
 4. Facilities and Equipment

On a scale of 1 to 10 (where 1= not good and 10 = Best)

	1	2	3	4	5	6	7	8	9	10
Highly Specialised Healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Governance and Coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multidisciplinary Approach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Good Practice, Outcome Measures, and Quality Control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribution to Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Continuous Education, Training, and Development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Networking and Collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Empowerment and Patient-Centred Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organisation, Management, and Business Continuity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research, Education and Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expertise, Information Systems, and e - Health Tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

On a scale of 1 to 10 (where 1= not good and 10 = Best)

	1	2	3	4	5	6	7	8	9	10
Quality and Safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Competence, Experience and Outcomes of Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human Resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organisation of Patient Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Facilities and Equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you for your time

EUROCleftNet



“Pragmatic research Collaboration beyond ESF”

- **NIS, Serbia**
- *24th February 2016*

ESF Network expiry !

Where do we go from here ?:

- EuroCleftNet and its legacy
- Measure the impact ?
- Future Cleft Networking in healthcare and research in Europe
- Addressing inequalities
- The patients view of issues in Psychology
- Objective facial measurement

EUROCleftNet (2011-2016)

Address two of the major questions in cleft care:

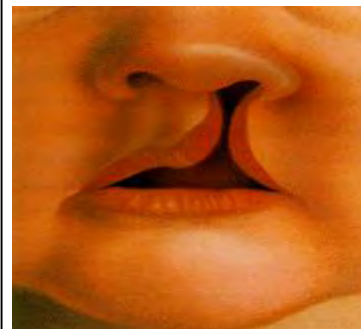
1. Improve treatment / quality of care (e.g. through inter-centre studies)

2. Aetiology & Prevention using post GWAS genomic research

Aspiration:

Utilise world-leading EU expertise in multi-disciplinary treatment, robust data on phenotyping (incl. 3D / 4D imaging), statistical approaches, high throughput genome wide techniques, triad DNA biobank

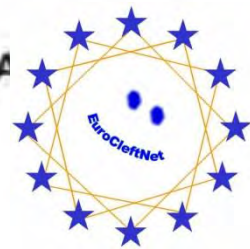
Encompass the diversity of the European populations (with a special emphasis on eastern Europe and translational approaches)



EUROCleftNet Successes



APPEARA

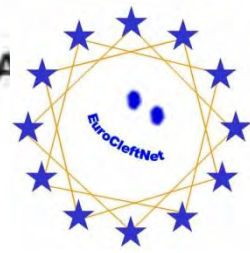


- Pan European directory of resources created through the Gateway project; and this underpinned the recruitment for the EUROCleftNet conference in Bulgaria
- Engagement with colleagues in Eastern Europe regarding involvement in collaborative European research on OFC
- Addressing inequalities in cleft lip and palate care through improving collaboration and research capacity in Eastern Europe
- Engagement with MEPs in October 2012 at a parliamentary session dedicated to presentation of orofacial clefting issues across Europe; and a subsequent session planned for 22nd March 2016

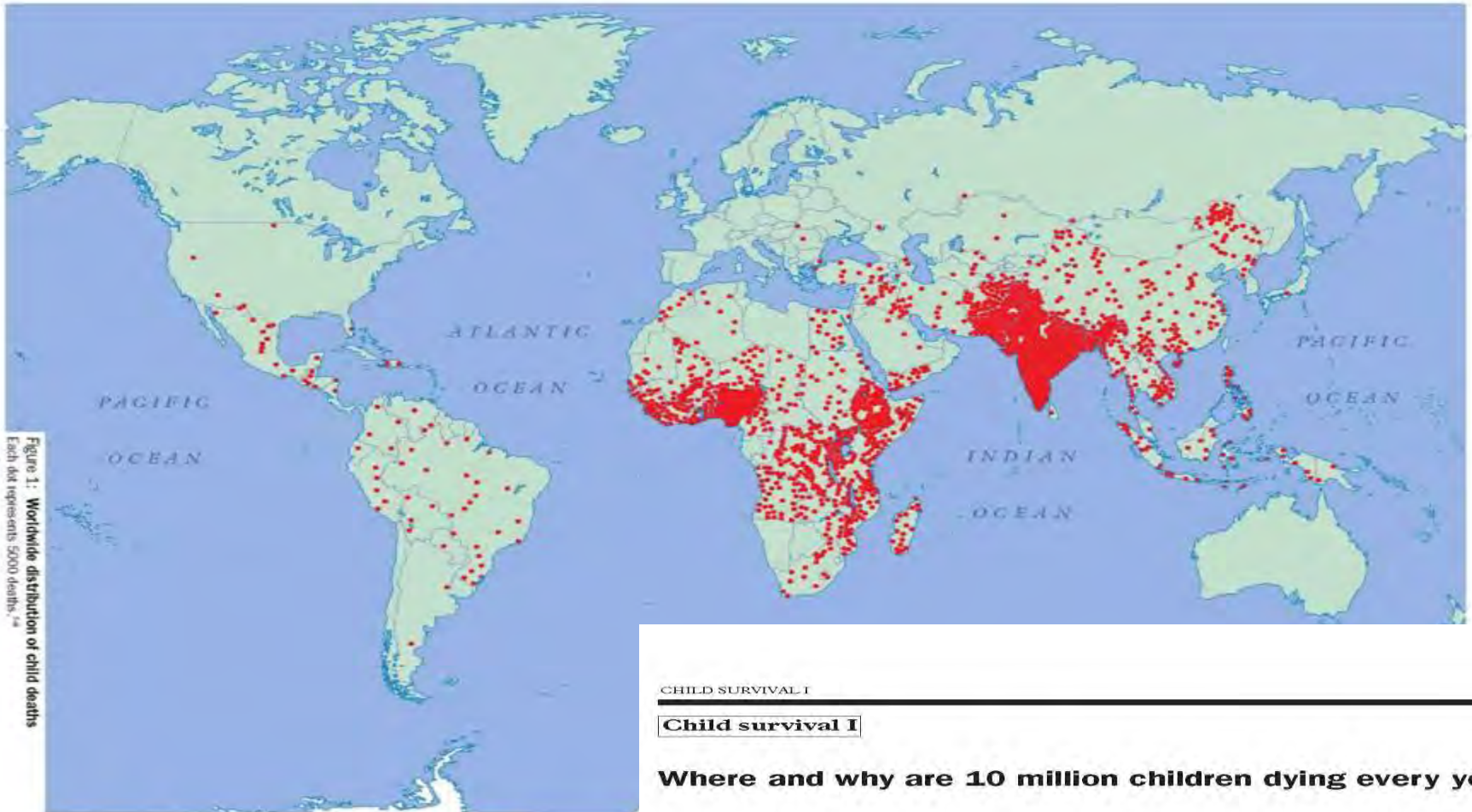
EUROCleftNet Successes II



APPEARA



- Use of the Gateway project to improve the communication and dialogue between cleft researchers across Europe
- Translation of information and research protocols into other languages (7 languages) to facilitate understanding of the Network, and encourage research
- Links with other organisations: the European Cleft Organisation (ECO), CEN Standards Agency in Brussels, EUROCAT, COST, and global bodies such as WHO, the International Clearinghouse for Birth Defects surveillance and research (ICBDSR) and engagement with the IADR Global Oral Health Inequalities Research Network (GOHIRN)
- On-going EuroCleftNet short visits and exchanges dealing with a range of OFC research issues, producing quality publications, encouraging early career researchers and building research capacity.

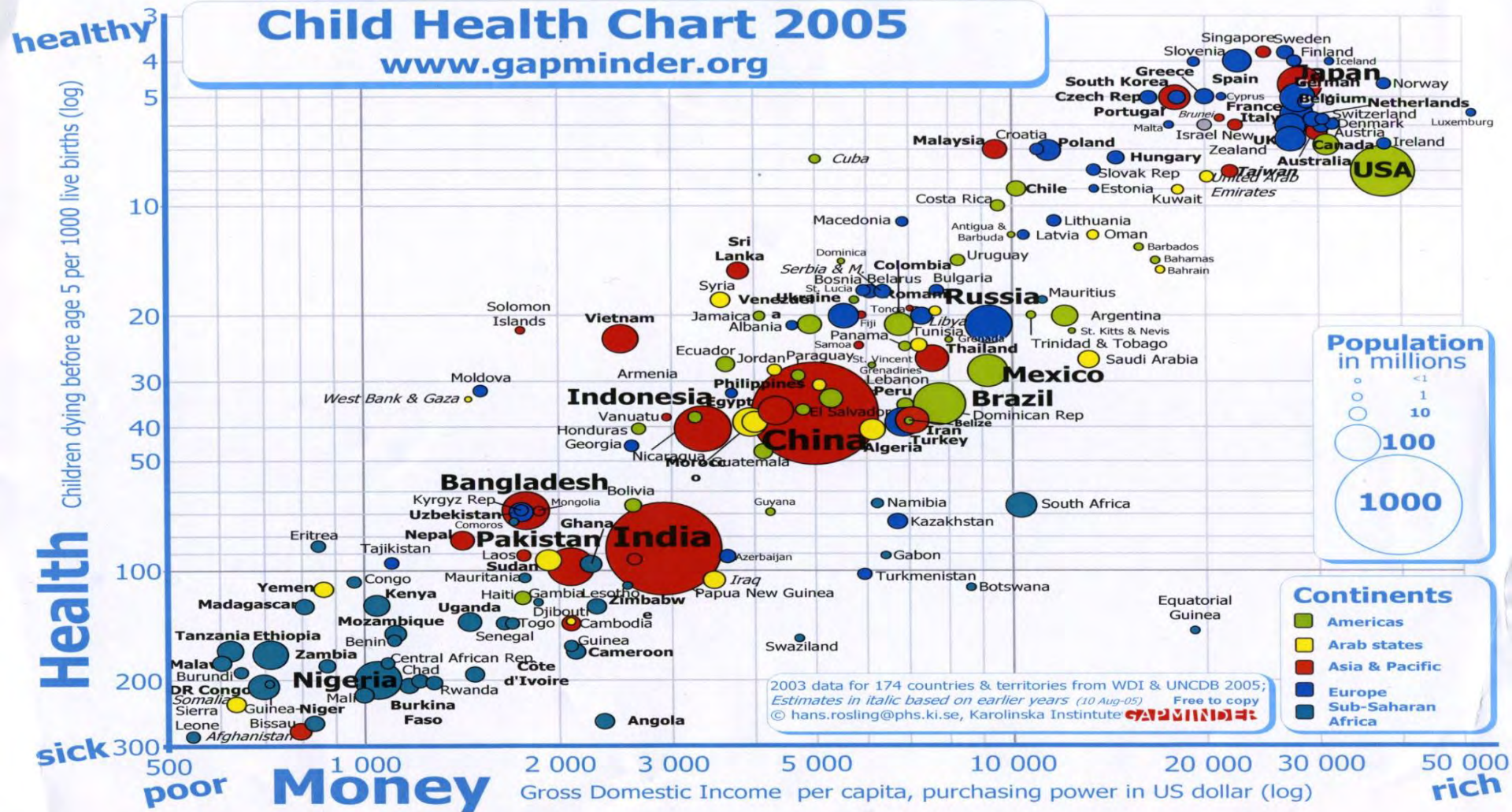


CHILD SURVIVAL I

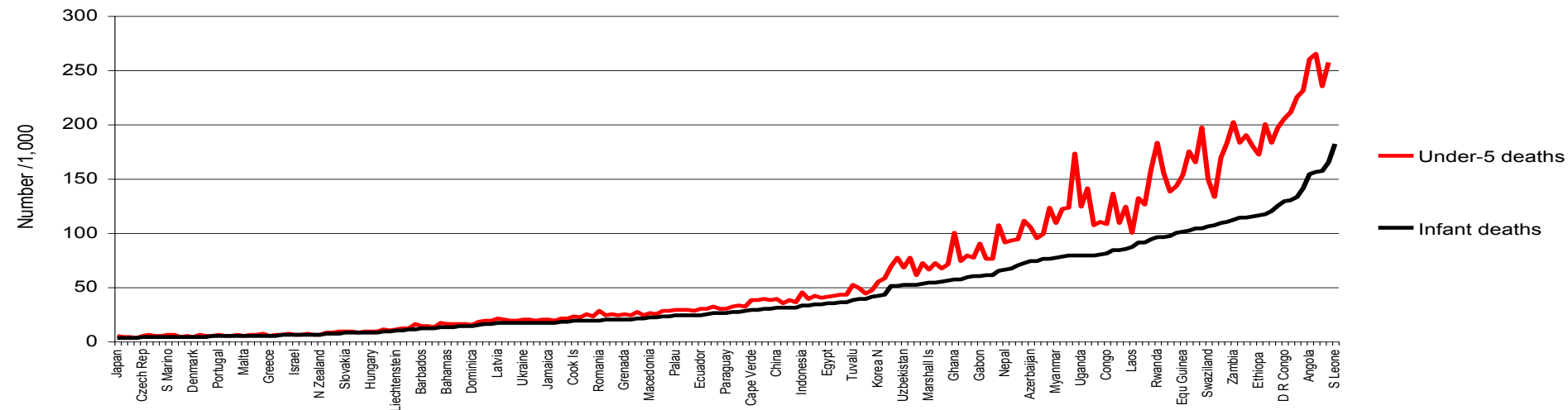
Child survival I

Where and why are 10 million children dying every year?

Robert E Black, Saul S Morris, Jennifer Bryce

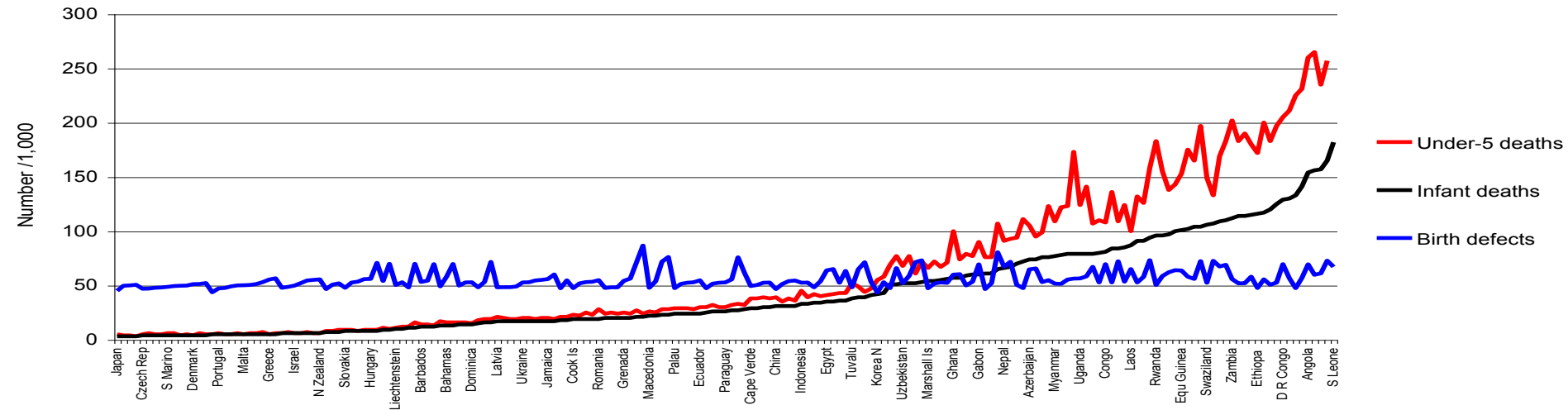


Childhood mortality rates



WHO - Brussels October 2012

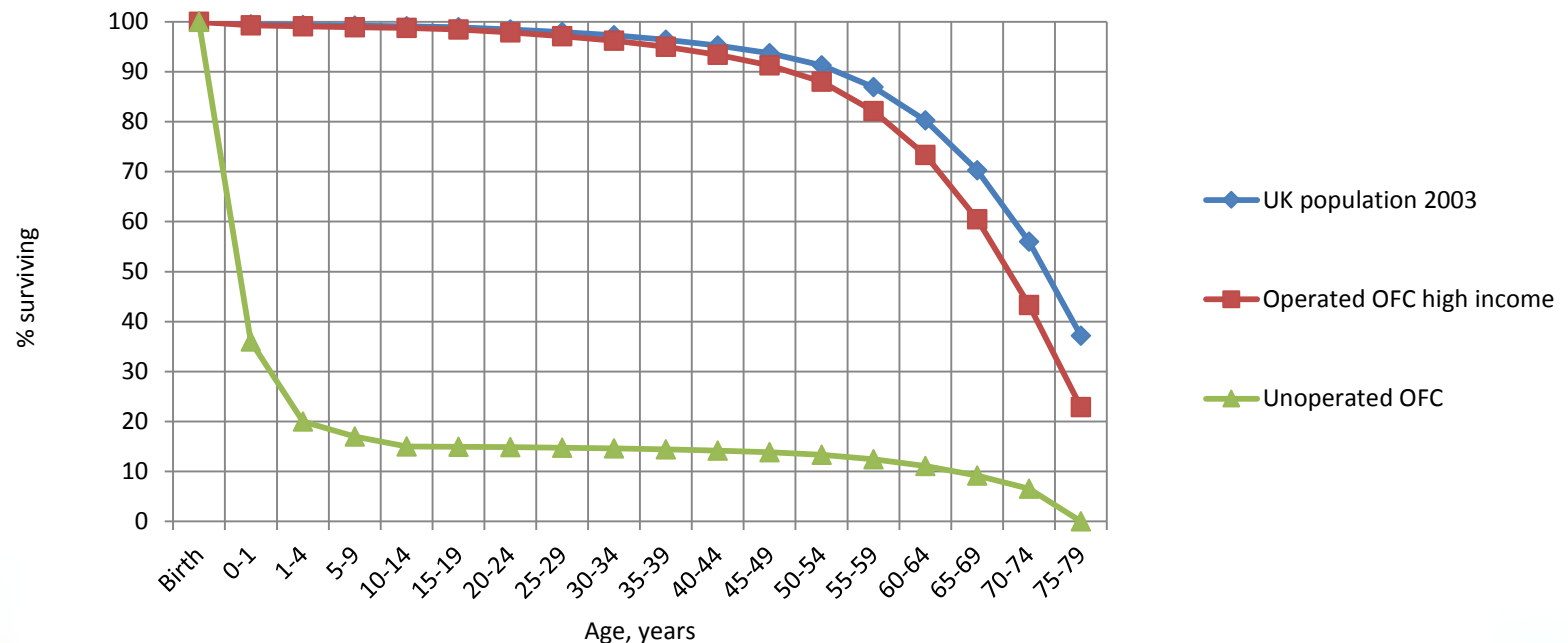
Birth defects and childhood mortality



WHO - Brussels October 2012

Oro facial clefts – outcomes

Rates for excess neonatal, infant and under-5 mortality due to isolated orofacial clefts, and mean age at death derived from the survival curves



WHO - Brussels October 2012

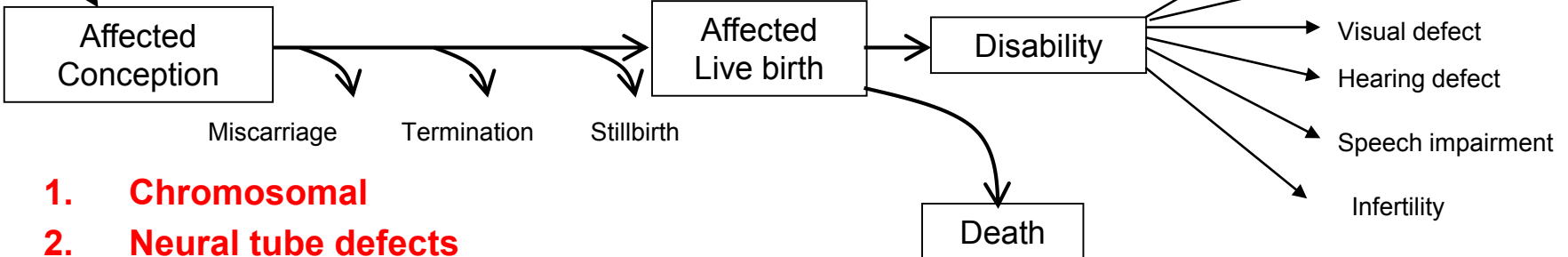
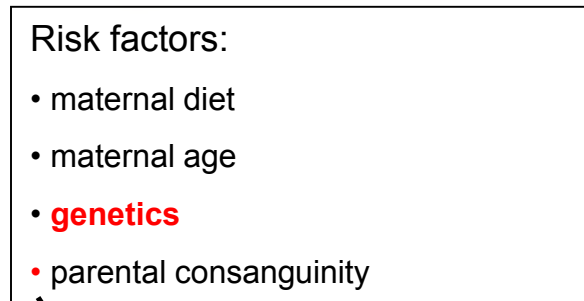
Smile Train data

Has the world done anything about it ?



GBD generic schematic for congenital abnormalities (2010)

Mean age at death



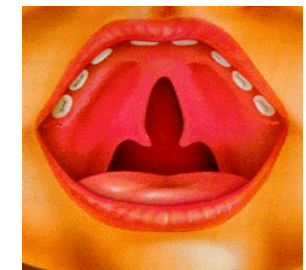
1. **Chromosomal**
2. **Neural tube defects**
3. **Congenital heart disease**
4. **Orofacial clefts**
5. **Structural GU and GI**
6. **“Other”**

WHO - Brussels October 2012



Residual morbidity

- Residual morbidity and effective cure / OFC rehabilitation is possible – requires good primary surgery and multi-disciplinary approach.
- Involves cleft surgeons, specialist nurses, speech and language therapy, orthodontics, audiology, maxillofacial surgery, psychology and genetics.
- Estimate of the residual disability related to communication problems (speech, hearing)
- Aesthetic impairment, stigma / psychology and social disadvantage or exclusion
- **Residual disability will vary according to CLEFT TYPE and ACCESS TO CARE using the WHO metrics to quantify DALYs and YLDs**
- Respiratory function unknown



The inequality of residual disability....

Congenital disorders interfere with normal social, physical and intellectual development.

What is the proportion of affected individuals who achieve each of these goals?

- **Access to appropriate education:** 95% in the developed, and 20% in the developing world
- **Ability to live independently:** 95% in the developed, and 50% in the developing world
- **Ability to work:** 95% in the developed, and 50% in the developing world
- **Sexual development and functioning:** 95% in the developed, and 60% in the developing world
- **Ability to build a family:** 95% in the developed, and 50% in the developing world
- In fact, the **social impact** of congenital disorders increases with age much more than their **clinical effect**.
- **Variation according to low or high income settings**

The reality of Cleft lip and palate in India



- Born with a severe UCLP in rural India
- Survived infancy and childhood with her cleft
- Did not attend school, or go outside her home

Pinki from India: Wimbeldon 2013



- All children should be given the opportunity to reach their full potential

What are our plans for the future?



.....and who should determine that agenda

James Lind top 12 priorities for OFC research

1. **Type and timing of psychological intervention**
2. **Education, employment and personal outcomes**
3. Best protocol for primary cleft repair
4. When should speech therapy begin?
5. Best treatment for glue ear
6. Use of stem cells for palate repair?
7. What interventions for better educational outcomes?
8. Impact on maternal / child attachment
9. Best management for cleft operation
10. Genetic and environmental cause?
11. Can we improve pre-natal diagnosis?
12. Best way to prevent tooth decay in children with CLP





The James Lind Alliance

Tackling treatment uncertainties together

[Home](#) | [Contact](#) | [Sitemap](#)

About JLA

Partnerships

Affiliates

Research Priorities:
top 10s

JLA Method

Research

Publications

Events

Newsletters

Notice Board

Get Involved

Links

Glossary

The JLA Guidebook

Add to Favorites

[Follow @lindalliance](#)

[Show all page content](#)

[Search our website](#)

Research Priorities: top 10s

This page lists the top 10 research priorities, shared by patients, carers and clinicians, for each completed JLA Priority Setting Partnership.

+ [ASTHMA PRIORITY SETTING PARTNERSHIP TOP 10](#)

- [CLEFT LIP & PALATE PRIORITY SETTING PARTNERSHIP TOP 12](#)

1. What types of psychological intervention (individual therapy, community or school based) and at what time (from diagnosis to adulthood) are most helpful for patients with a cleft of the lip and/or palate and their families?
2. What are the educational, employment and personal (eg relationships) outcomes for individuals with a cleft of the lip and/or palate during childhood, adolescence and in the long term?
3. What is the best protocol for primary repair of both the lip and palate, including technique/timing and sequence?



We seem to agree that.....



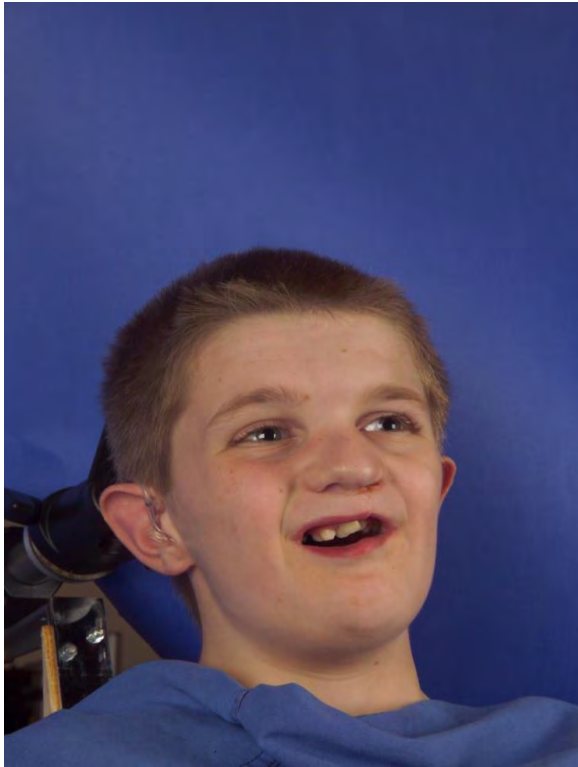
APPEARANCEMATTERS

COST Action no. IS1210

**Action Title: Appearance Matters: Tackling the
Physical and Psychosocial Consequences of
Dissatisfaction with Appearance**

...but can we measure it ?

Is he happy ?



....And can we detect more objectively the reason if he is not ?

Measurement of facial disfigurement

- Remains a major problem – aesthetics of CLP traditionally use subjective criteria – at mercy of skills and perhaps attitudes of assessors
- Can we be more objective about assessment of facial deformity ?
- This can influence surgical decisions
- Parents consistently report more disappointment with child's facial appearance than their children (Strauss, 1988, Noar, 1991)

Research on self perception

- In CLP there is apparently little or no correlation between features of facial disfigurement and patient (or parental) perception
- Is this predictable ? Is it feature specific ? Is there a threshold ? Is it a surgically correctible feature ?
- Is this different between parent, patient and surgeon ?

Can we produce an objective measurement system ?

- Would there be value in a system that grades severity of facial disfigurement, and based on anatomical regions ?
- Something that could be used on any craniofacial deformity ?
- Could be a useful tool for detecting and measuring asymmetry
- Can this be utilised as a clinically useful research tool



Can we improve the measurement of patient, parent
(and surgeon) perception

- The challenge of psychometric testing is to identify ways in which subjective experiences of patients can be made more objective.
- How can we improve identification of those who are concerned about their facial appearance, and identify which aspects are of most concern
- Is there a role for non-invasive eye-tracking studies ?

Eye tracking ?

- Assumption – eyes will focus on features of interest or concern ?
- Could be used to identify which aspects of a cleft disfigured face the public tend to focus on ?
- Could be used to identify which aspects of a cleft disfigured face the patient focuses on ?
- Could inform the debate around asymmetry ?
- Could inform the question of whether facial animation is important in aesthetics ?
- Results may help inform surgery ?



1 / 379



172 / 299



1 / 379



184 / 379

Where do we go from here ?

- The future research agenda in Europe should:
- (a) seek to engage all European centres in cleft & CFA research and ensure standardised data collection
- (b) identify the best interventions for treatment of infants, children and adults with OFC (incl psychological)
- (c) devise the best ways to get research findings into practice, policy and health systems
- (a) improve the methodology for dealing with the scandal of health inequalities
- (d) Eurocleft has successfully led to changes in OFC healthcare legislation in some participating countries
..lets build in that success



ERN – Rare Diseases: Rationale

- [Directive 2011/24/EU](#) The main rationale is “added value” of the European Reference Networks (ERN) in identification of centres of expertise to facilitate improvements in access to diagnosis and delivery of high-quality, accessible and cost-effective healthcare in the case of patients who have a medical condition requiring a particular concentration of expertise or resources, particularly in medical domains where expertise is rare (see [Recital 54 of the Directive](#)).
- European Reference Networks could also be focal points for medical training and research, information dissemination and evaluation, especially for rare diseases.





General aspects regarding ERNs

- ERNs are a mechanism of cooperation between healthcare providers of highly specialised services all over Europe
- ERNs should improve access to diagnosis, treatment and provision of high-quality healthcare
- ERNs should act as hubs for medical training, research and dissemination of information
- Healthcare providers will benefit from an improvement in knowledge, international recognition and leadership in their area of expertise
- ERNs will be built around thematic groups; so that every RD is covered.
- Healthcare providers are expected to collaborate amongst themselves in a dedicated field of expertise in order to establish a Network.
- The Members of a network will work in accordance with the legislation of their Member State.



LOGY



APPEARANCEMATTERS

Target groups – opportunities in CFA ?

- Patient organizations (e.g. ALA), health professionals' organizations (e.g. ECO) and healthcare provider's organizations (e.g. NHS)
- Healthcare providers and centres of expertise, academic and public health and healthcare specialized institutions
- Public authorities and government-appointed bodies involved in the definition of criteria of reference centres (e.g. WHO CCs)
- Reference networks of centres providing highly specialized healthcare for rare diseases (ECO ??)

Rare Diseases Task Force





Opportunities in the CFA field ?

- A CFA ERN can act as a focal point for HP training and research, helping to establish European standards of care and improved dissemination of awareness / knowledge about CFA.
- ERNs profile and recognition in their particular domain will improve access to care, attract the best expertise and reduce inequality
- While ERNs facilitate the cross-border health care it is expected that e-Health solutions and pooling of resources will decrease the burden of travelling for the patients.
- The Networks and their members will be in a good position to apply for more research funding and further develop and accelerate basic and translational research
- This collaboration will help with the adoption and spread of innovations in medical science and health technologies.



ECPCA and ERN: Schipol 11th Jan 2016

- **Austria** (Innsbruck – Prof Michael Rasse) Michael.rasse@i-med.ac.at
- **Bulgaria** (Plovdiv – Prof Youri Anassasov) yanastassov@gmail.com
- **France** (Necker – Prof Arnaud Picard) arnaud.picard@aphp.fr
- **Germany** (Tuebingen – Professor Marcos Tatagiba) marcos.tatagiba@med.uni-tuebingen.de and / or Leipzig – Prof Alexander Hemprich) alexander.hemprich@medizin.uni-leipzig.de
- **Italy** (Milano – Professor Brusati, roberto.brusati@unimi.it and / or Monza – Prof Alberto Bozzetti) alberto.bozzetti@unimib.it
- **Netherlands** (2 centres: Utrecht and Erasmus MC) Corstiaan Breugem to provide information
- **Norway** (Oslo) Bill Shaw & Gunvor Semb to provide information
- **Sweden** (Gothenburg – Hans Mark) hans.mark@vgregion.se
- **UK** (Great Ormond Street – David Dunaway / Greg James) Gregory.james@gosh.nhs.uk

ERN – fully inclusive across EU

- Member States with no Member of a given Network may decide to designate healthcare providers with a special link to a given Network, following a transparent and explicit procedure.
- Those providers might be designated as Associated National Centres focusing in the provision of healthcare or as Collaborative National Centres focusing in the production of knowledge and tools to improve the quality of care.



Projected timetable

- 2nd half 2015 Call for selection of independent bodies to evaluate ERN
- January-May 2016 Call for Networks
- 2nd half 2016 Establishment of ERN
- End of 2016 Network is operational
- 2020 Evaluation



**Future research strategy: Evidence based care
(WHO consensus report, 2002)**

- trials of surgical methods for the **surgical repair** of different orofacial cleft subtypes, not just unilateral clefts;
- trials of surgical methods for the correction of **velopharyngeal insufficiency**;
- trials of the use of prophylactic ventilation tubes (**grommets**) for middle-ear disease in patients with cleft palate;
- trials of adjunctive procedures in cleft care, especially those that place an increased burden on the patient, family or medical services, such as **presurgical orthopaedics**, primary dentition **orthodontics** and **maxillary protraction**;
- trials of methods for management of perioperative **pain, swelling and infection**; and nursing;
- trials of methods to optimize **feeding** before and after surgery;
- trials addressing the special circumstances of **care in the developing world** in respect of surgical, anaesthetic and nursing care;
- trials of different modalities of **speech therapy**, orthodontic treatment and counselling.

Lets heed the recommendations of the 63rd WHA. The knowledge & technology to improve the care & prevention of BD in developing countries is available. Networking, internationally and nationally, is needed to harness its capability.



Oral Health
2010 IA



Acknowledgements

- To all those who have contributed to the successes of EUROcleftNet
- To all those who continue to work on behalf of children and adults born with OFC, particularly those who do this in difficult circumstances
- To Julija Radojicic and her team in Nis (and Belgrade) who have organised this conference