A comparison on European level between clinicians and patients' perception on Appearance

Health Care Settings:
Cleft and Craniofacial (Group 6)

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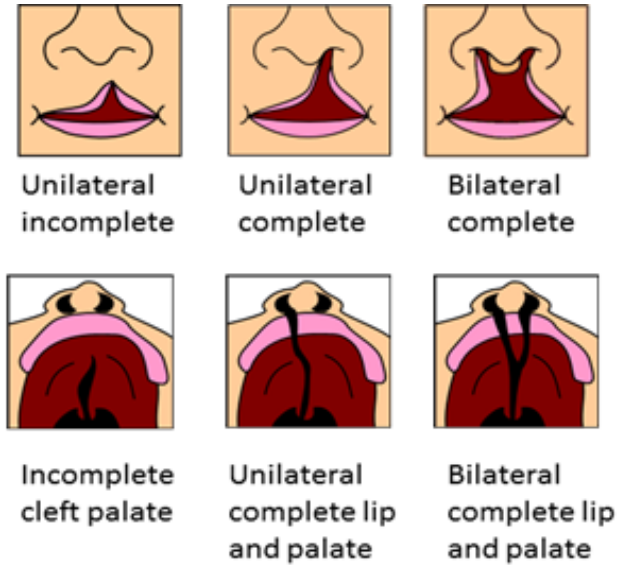
APPEARANCEMATTERS

Cleft lip and/or palate?

- One in every 700 babies is born with a cleft.



http://www.transformingfaces.org/programs/cleft-care/cleft-lip-palate/

http://www.nhs.uk/Conditions/Cleft-lip-and-palate/Pages/Introduction.aspx

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APPEARANCEMATTERS

Multidisciplinary

- Nursing
- Reconstructive (Plastic) & Maxillofacial surgery
- Speech therapy
- Orthodontics
- Audiology
- Psychology
- Genetics
- Dentistry

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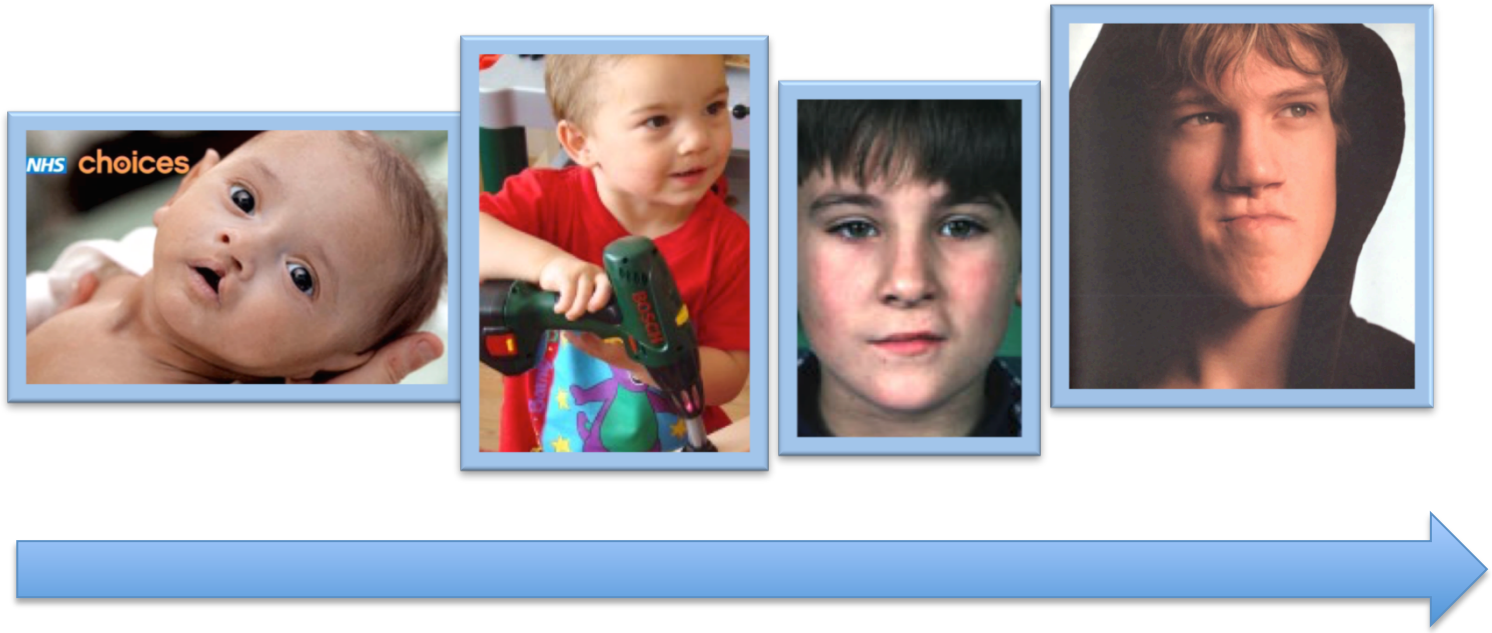
APPEARANCEMATTERS

Treatment



From birth to adulthood

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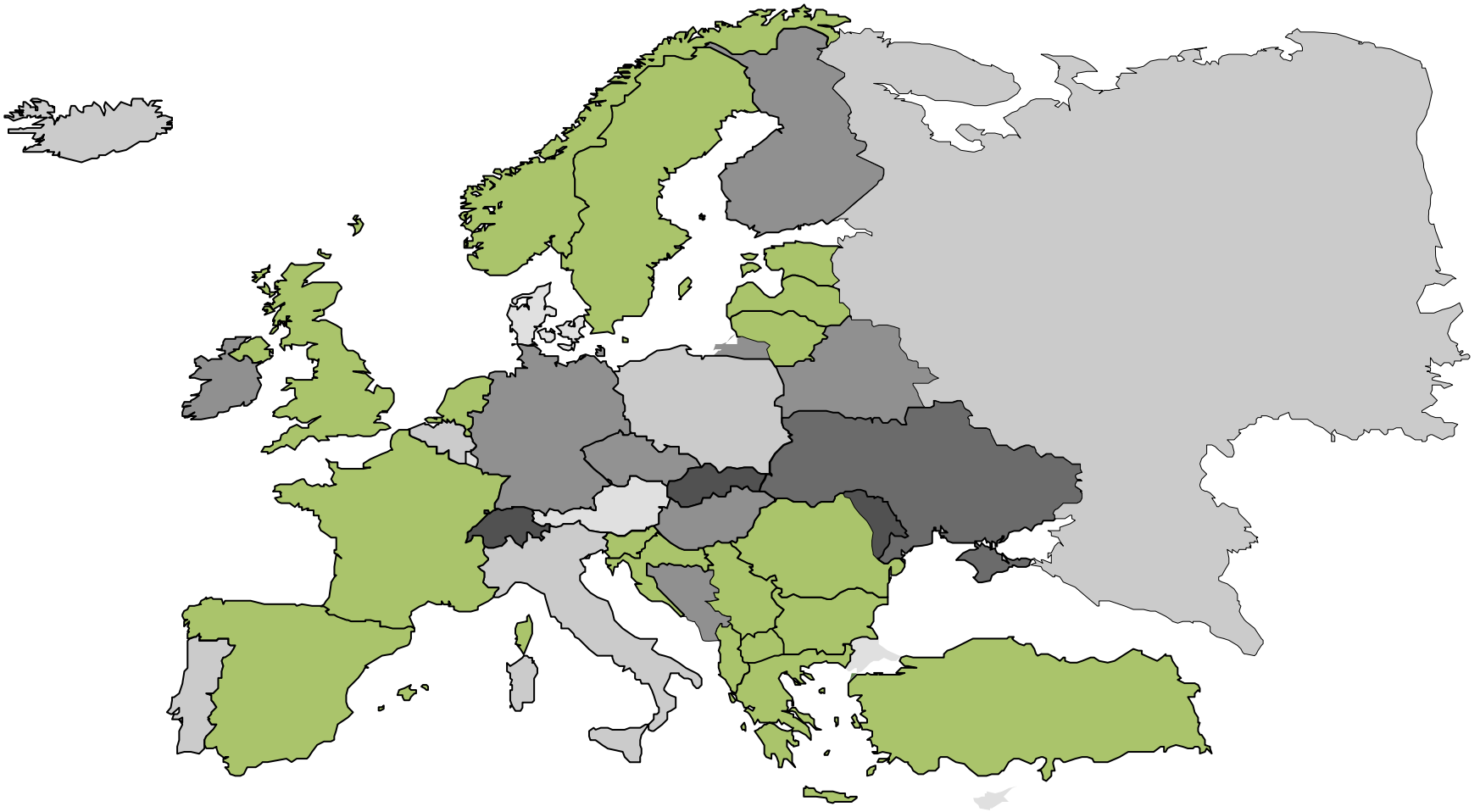
APPEARANCEMATTERS

18 Cleft teams/NGO's/Researchers



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APPEARANCEMATTERS

Objectives

- Identify what factors contribute to good adjustment in adults with cleft?
- Trial how to measure psychosocial adjustment for individuals with cleft across Europe.
- Generate collaborative grant applications
- Generate resources that can assist with psychosocial training of health care professionals and consequently enhance research collaboration.

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What factors contribute to good adjustment in adults?

How do we achieve that for our patients?

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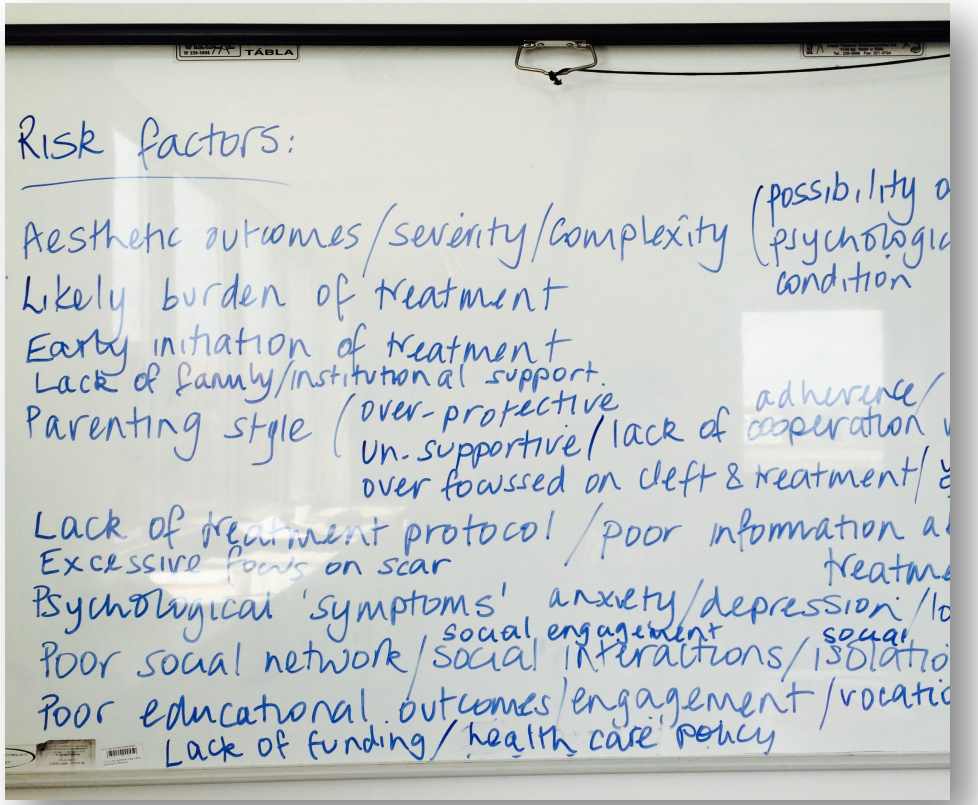
Outcomes

- A one-day group exercise to identify psychosocial variables important for positive adjustment and risk factors
- 12 European countries represented



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APPEARANCEMATTERS

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APPEARANCEMATTERS

Translation and pilot study of the Cleft Hearing Appearance and Speech Questionnaire (CHASQ)

CHASQ

- Background
- Method
- Results

Background

- Standardized treatment protocols
- Lack of corresponding protocol regarding psychological treatment
- No widely accepted Patient Reported Outcomes (PRO) measure

Background

- Results inconsistent
  - boys and girls [1-4]
  - patients and norm-population [3-7]
  - patients and their parents [1, 6, 8-12]
  - patients and clinicians/objective ratings [3, 6, 12-15]
  - different age groups [2, 7, 9, 16, 17]

- Satisfaction with appearance significantly correlates with self-reported psychosocial functioning. [3, 8, 18, 19]

Earlier research

- Lack of widely accepted instrument
- Most questionnaires used for studying PRO had been used in only one study [21, 22]
- Did not meet scientific standards of reliability, validity, and responsiveness [23]
- Difficult to compare, conclude and build on from [24]

Problems with Patient Reported Outcomes

- Parents and patients have great trust in the health care professionals
- Lack comparative knowledge of cleft treatment and outcomes
- High satisfaction with treatment due to gratefulness
- Justify their investment of emotions and effort
- May forget[9]
- Fear of more surgical interventions [1]

Even if it seems difficult...

- Include assessments of psychosocial outcomes into standard practice
- Incorporation of a psychologist or counsellor in a cleft-team [16]
  - Patients rarely discuss psychosocial issues
  - No routine psychosocial screening
  - Hardest part about having a cleft [9]
- Treatment decision is taken by the clinician through an assumption of the patients view without information on the patient's psychosocial situation

Summary

- Lack of internationally accepted outcome measure [3, 21, 24-26]

Objective

- Translate the CHASQ into seven European languages and to investigate whether the data across countries was comparable

Method

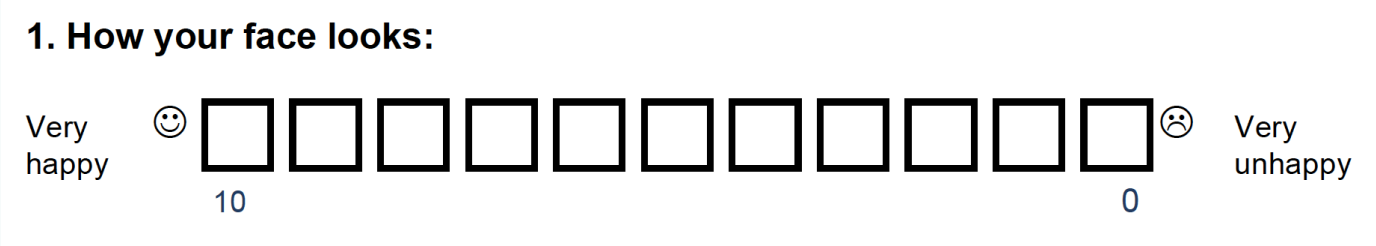
- The design of the study was decided upon in 2014 within the COST Action IS1210, Appearance Matters 'Tackling the physical and psychosocial consequences of dissatisfaction with appearance'

Method

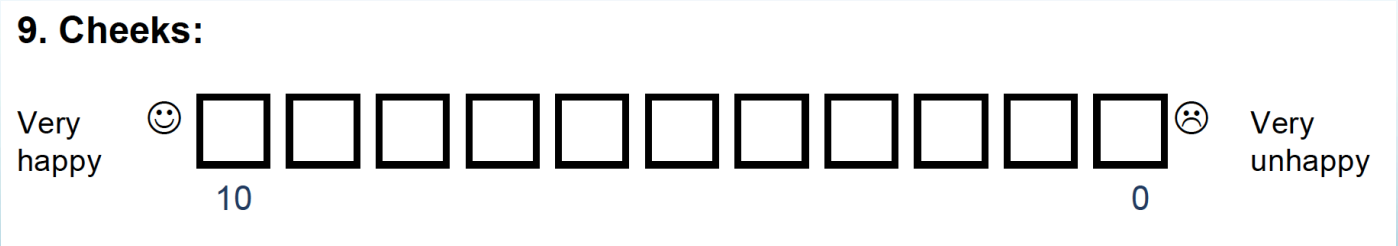
- CHASQ
  - Modified version of the Satisfaction with Appearance questionnaire (SWA) [28]
  - Designed by the Cleft Psychology Special Interest Group, Craniofacial Society of Great Britain and Ireland
    - specifically for patients with facial disfigurement
  - Good internal validity, construct validity and overall adequate psychometric properties [2, 3, 6, 13, 14, 18, 20, 27]

CHASQ

1. Questions about features typically affected by a cleft (factor 1 loading items)



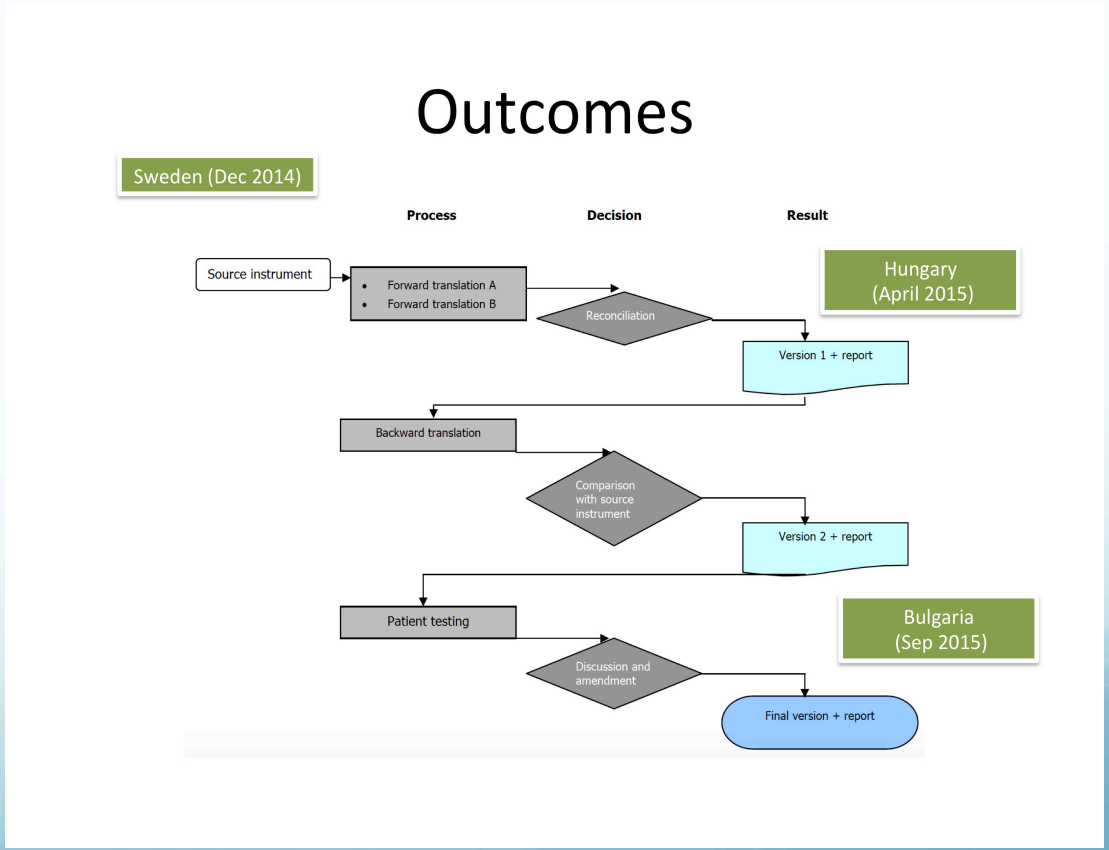
2. Questions about features not typically affected by a cleft (factor 2 loading items).



Factor 1	Factor 2
Face	
Whole appearance	
Side view/profile	
Good-looking	
Nose	
Lips	
	Chin
Teeth	
	Cheeks
	Hair
	Ears
	Eyes
Speech	
	Hearing
How noticeable to others	

Translation

- Delegates translated the CHASQ into their national languages
- MAPI Guidelines [29]



Method

- The CHASQ was piloted in seven countries
  - Bulgaria
  - Estonia
  - Latvia
  - Macedonia
  - Montenegro
  - Romania
  - Sweden

Data Collection

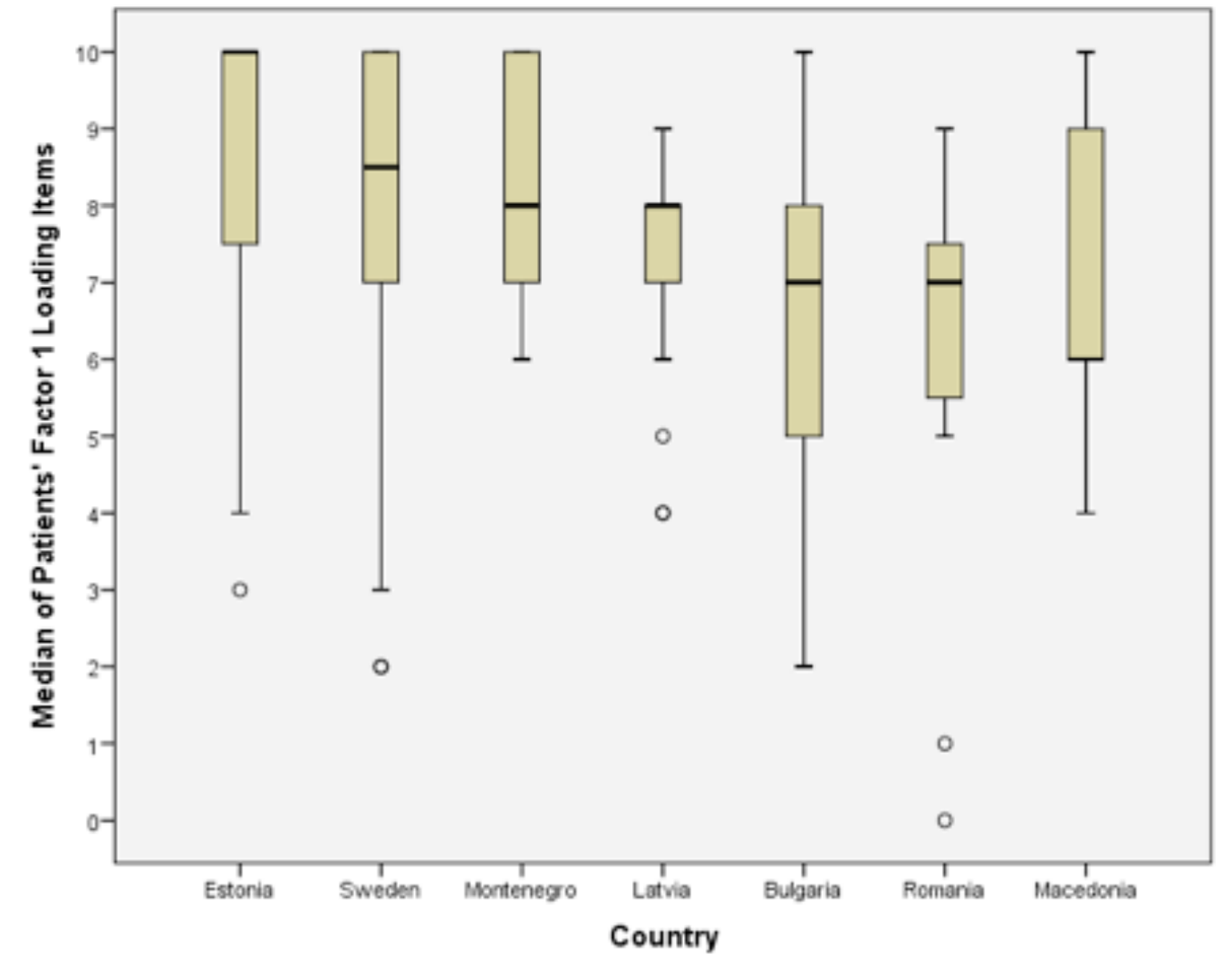
- CHASQ was administered to patients and parents at routine visits to clinics
- Clinician filled out the questionnaire directly after the visit

Results

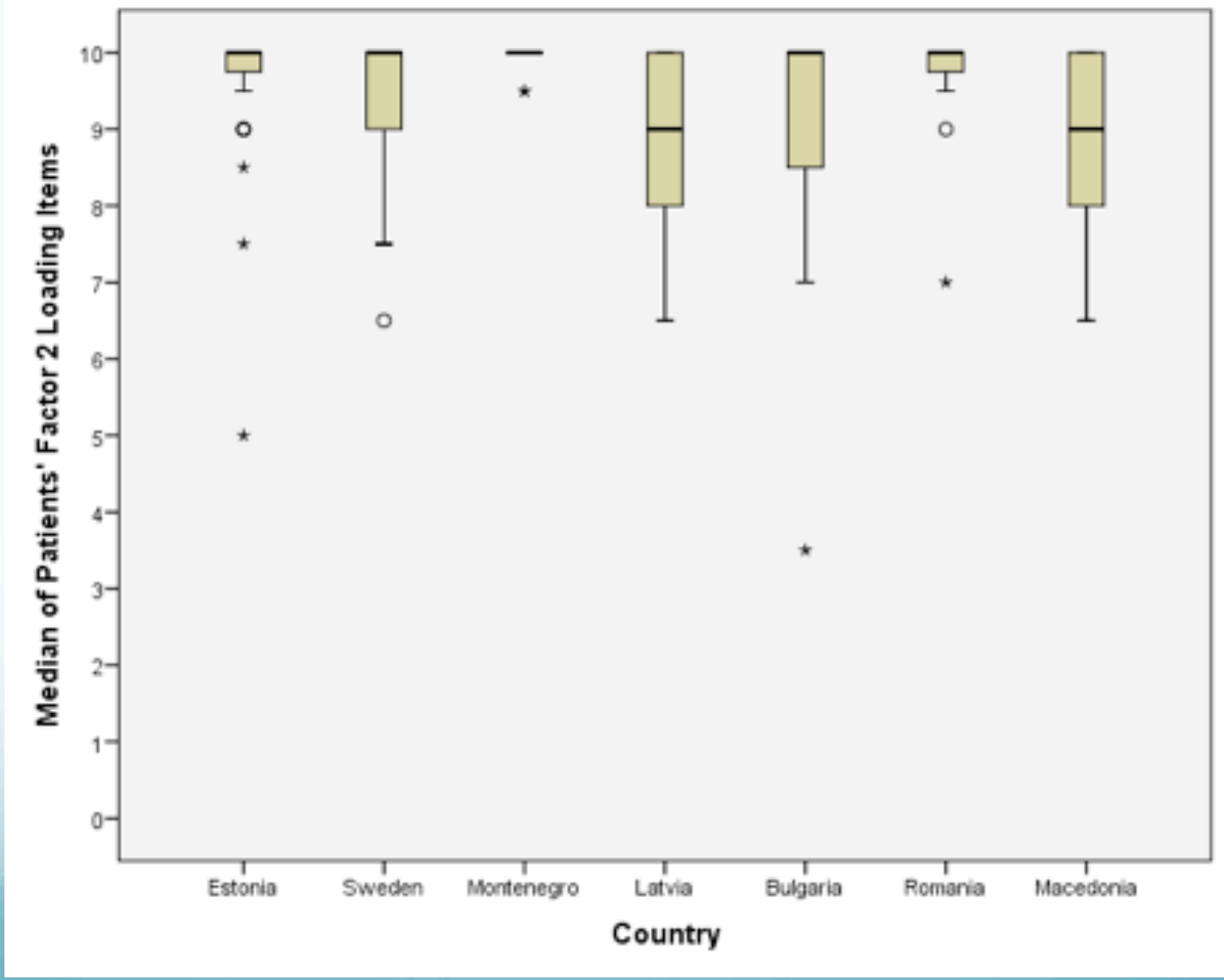
Patient factor 1 loading items

Country	Number of patients	Median	Mean
Estonia	28	10,0	8,3
Sweden	48	8,5	7,8
Montenegro	10	8,0	8,5
Latvia	17	8,0	7,1
Bulgaria	30	7,0	6,6
Romania	11	7,0	5,8
Macedonia	30	6,0	6,8

Median of patient factor 1 loading items



Median of patient factor 2 loading items



Conclusions

- Some variations in scores of the CHASQ between countries
- Translation and utilization of the same questionnaire will make international and cross-study comparison easier

Healthcare Professionals' experience of using the CHASQ

Fabio Zucchelli [a], Dr Martin Persson [a], Nick Sharratt [a], Dr Ron Strauss [b]

[a] The Centre for Appearance Research, UWE Bristol

[b] University of North Carolina, Chapel Hill

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What did we do?

Aim

- Gain HCP perspective on CHASQ's clinical usefulness as part of international validation process.

Method

- Online/paper survey
- Focus group
- Participants: COST Cleft & Craniofacial Task Group members using CHASQ
- 16 HCPs* working in cleft care across 10 countries

Analysis

- Thematic analysis

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Themes

Clinical utility

Effect on HCPs

Implementing in practice

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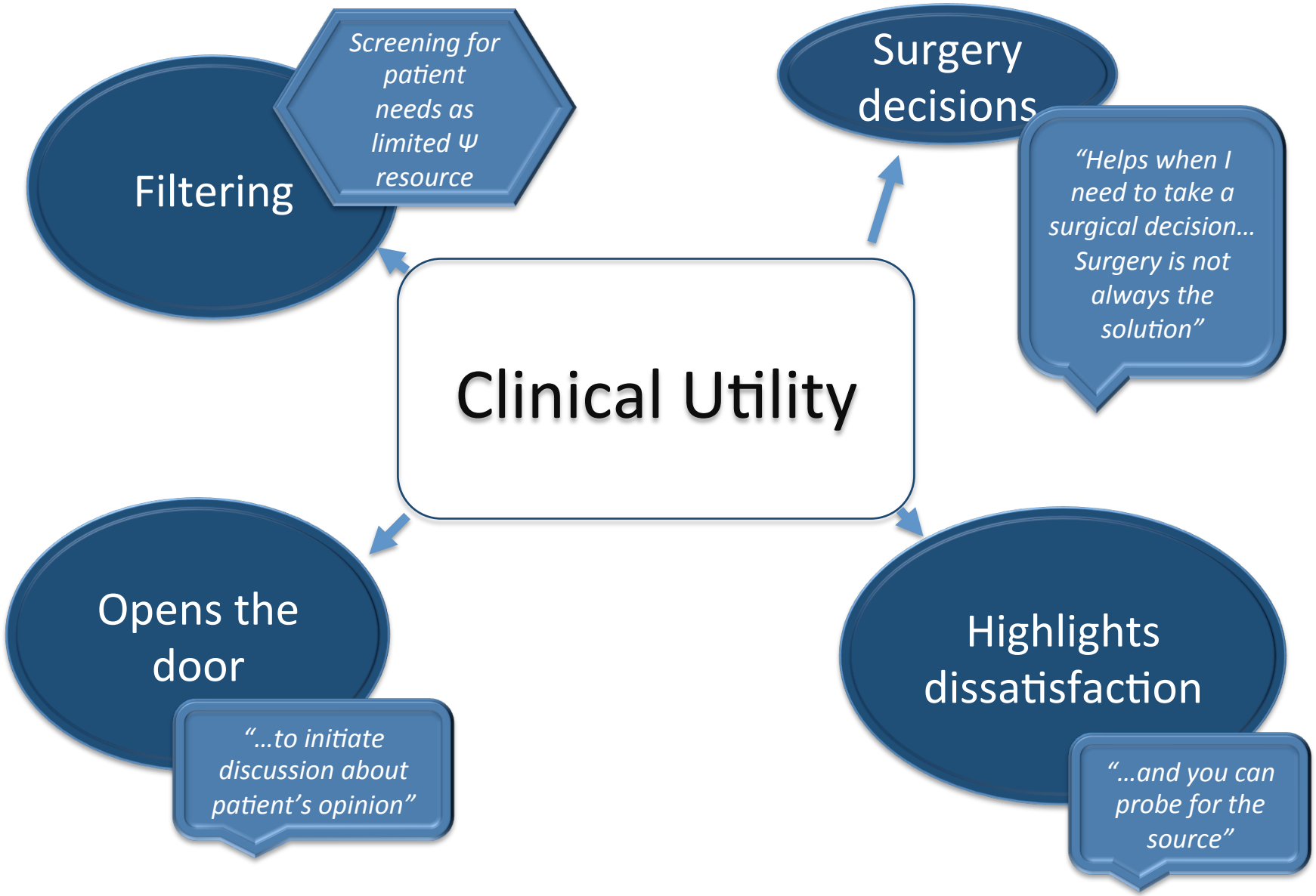

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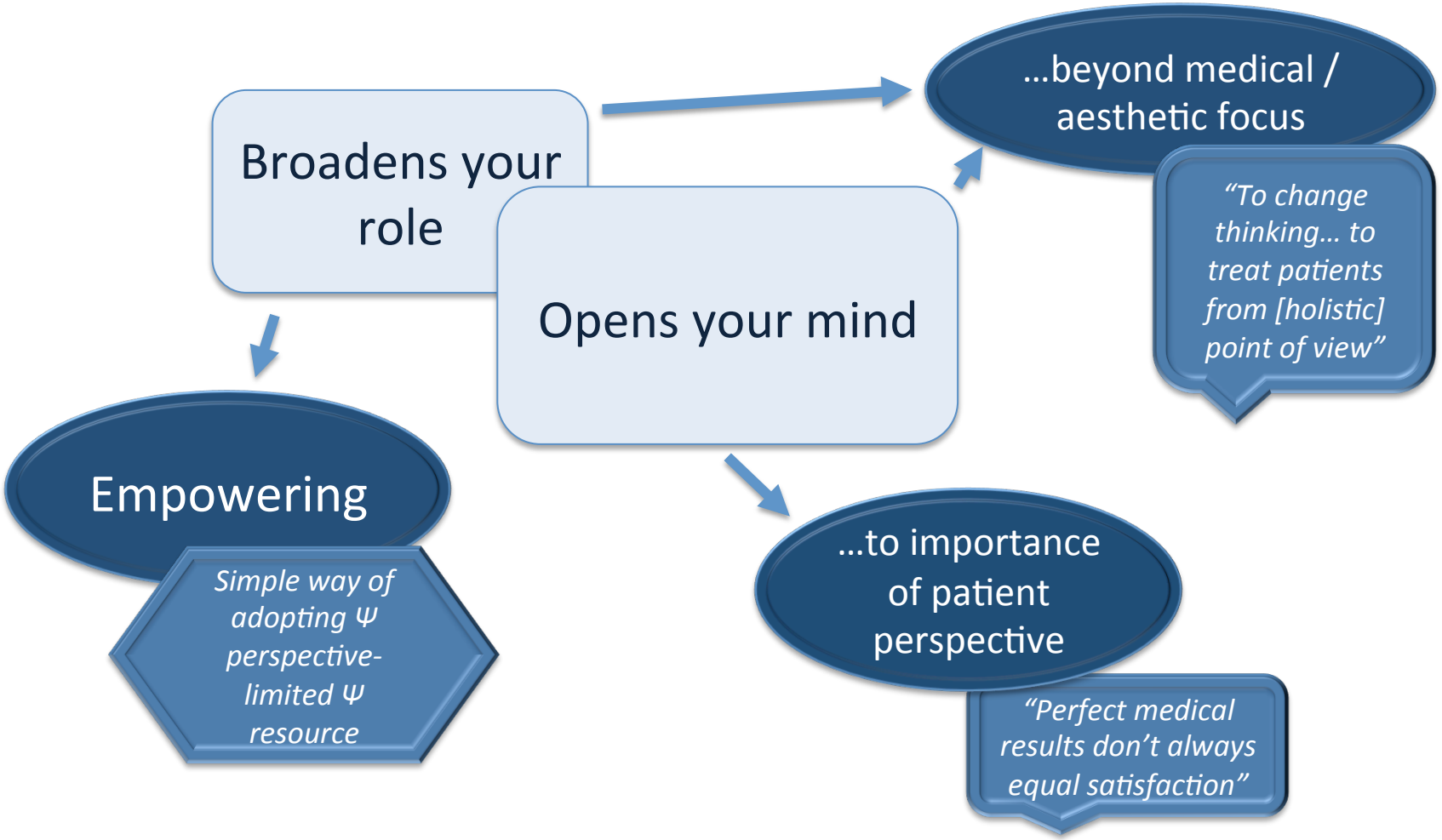
Effect on HCPs



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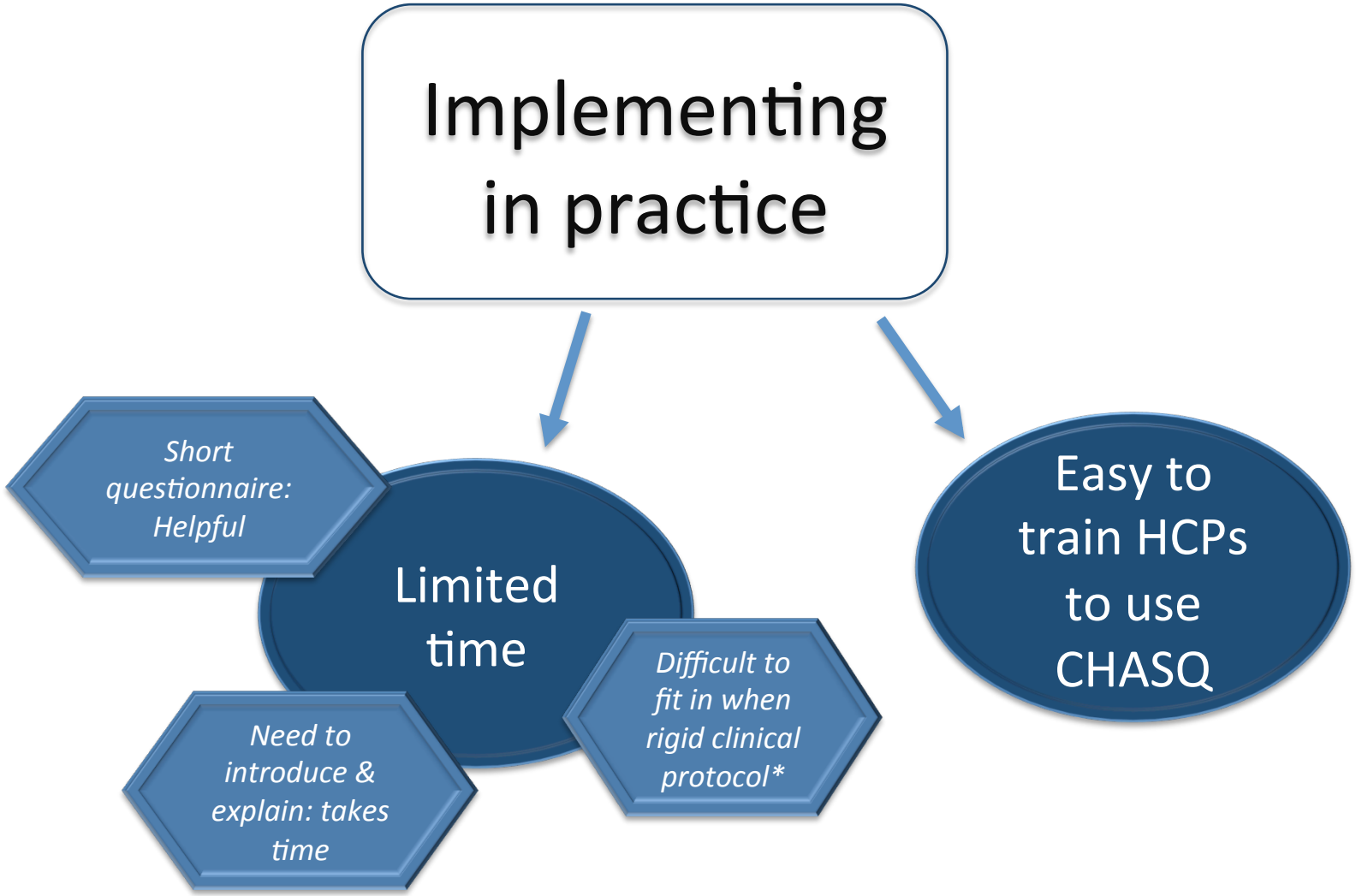

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COST involvement & CHASQ

- Involvement in COST Task Group increased psychosocial awareness through meetings, networking and training…

- Piloting the CHASQ has provided a means of actually start psychosocial conversations with patients.

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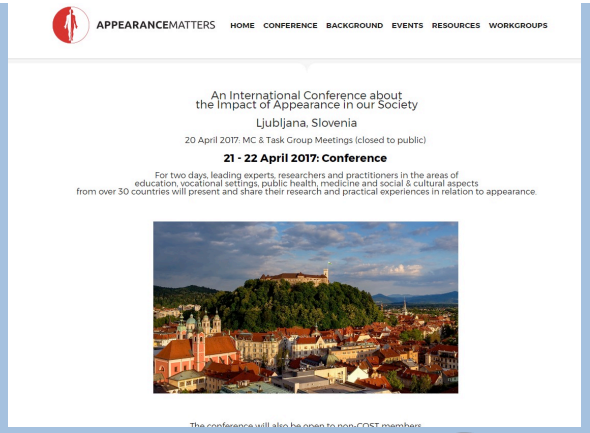


The CHASQ included in the Electronic Medical Record for Facial Anomalies

Y. Anastassov,

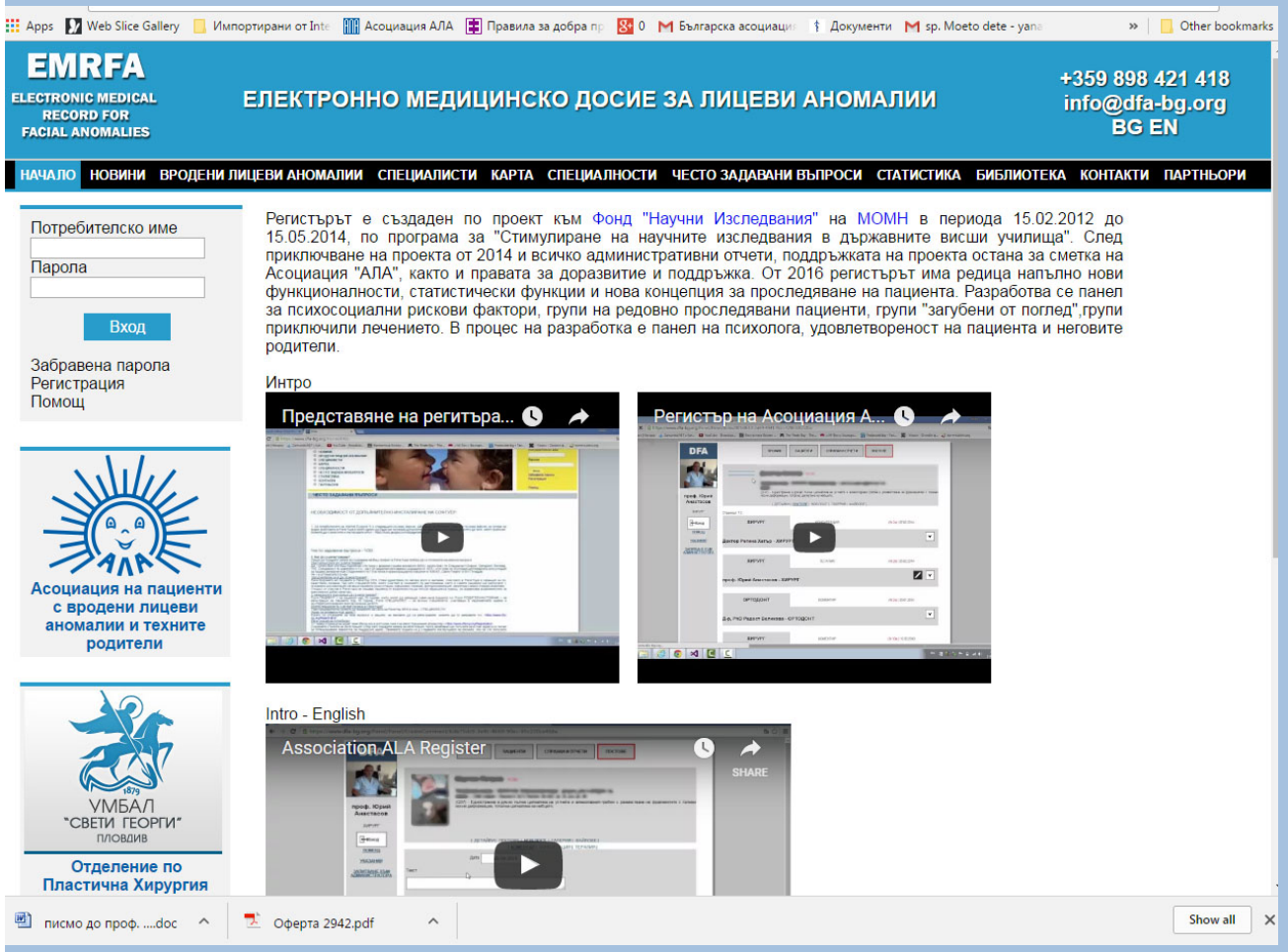
K.Gigov, R.Khater, R.Velikova, M.Kazakova,
N.Hashova, M.Bojinov, S.Karakoleva ,
At.Gulev, P.Tcarvulanova

EMRFA
ELECTRONIC MEDICAL RECORD FOR FACIAL ANOMALIES

Medical University of Plovdiv

In 2010 – A project funded by the Ministry of Education, University of Plovdiv and parternership with ALA

Start in Septembre 2013



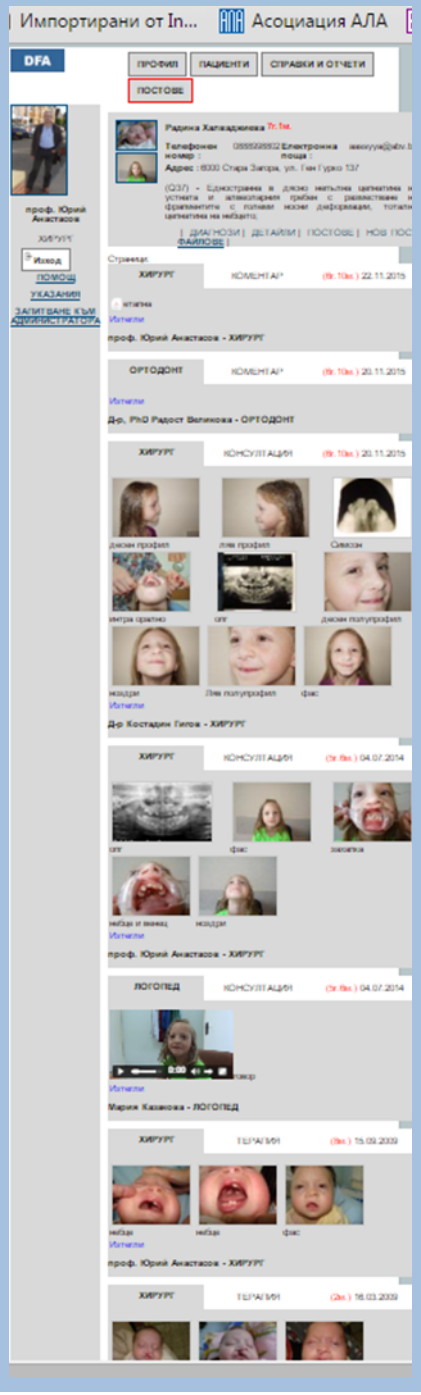
How it works ?

Voluntari participation, personnel data are protected. The patient or his/her représentatives chose the specialilists at home – nurse, ENT, speech therapist or orthodontist. Each specialist has a different pannel for the diagnose, the actual outcome and a plan for treatment and filters

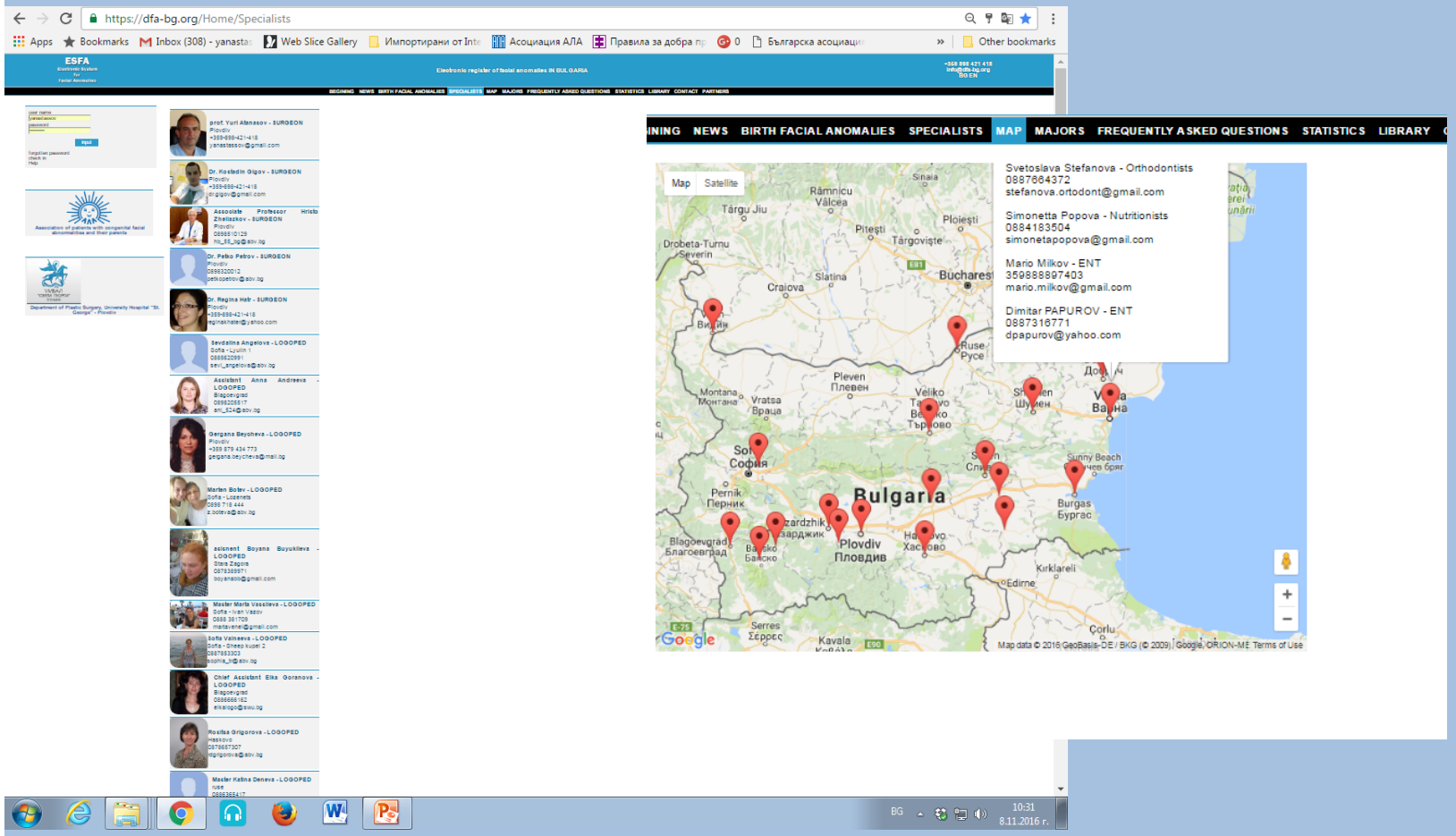
Each post can be a text, videos, pictures and PDF

Reminders at 3, 5, 8, 12, 14, 16 years of ages

Sending a mail to all participants when a new post is done



Selection of a specialist by the parents or the patient



download

prof. Yuri Atanasov - SURGEON

SURGEON CONSULTATION (5g.0m.) 28/02/2014


cigarette butt


profile


occlusion

download

prof. Yuri Atanasov - SURGEON

LOGOPED CONSULTATION (5g.0m.) 28/02/2014

speech

00061 (2) .webmhd.webm

download

Maria Kazakova - LOGOPED

SURGEON CONSULTATION (3g.0m.) 02.03.2012


nostrils


cigarette butt


profile

download

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Psychosocial factors – risk groups

Until 2 risk factors – low risk or regular

From 3 to 5 risk factors – medium risk – to be evaluated by the psychologist

From 6 to 12 risk factors – high risk - to be evaluated by the psychologist

Table N 1 – Psychosocial risk factors (particular for Bulgaria)

Name and surname of the patient ……..;

Presence of other severe pathologies :
yes .....no …..comments.

Lives in Institution .....- yes /high risk /, no;

Lives in Institutions social residence – yes, no;

Measures for protection
yes .....no . if yes select :

Lives with family members –names and comments …

Foster family names and comments

Other .....comments ……

I Parents

Biological yes – no

Numerous family more than 3 childs : yes ....no ;

Other children in Institutions yes...no

Names of the Father ..... -

Studies – without studies ---primary school ---, secondary,.... superior .....

Permanent work, part time ; unemployement –

Sickness of the Father yes .....no

Comments.....
.....

Names of the Mother ..... -

Studies – without studies ---primary school ---, secondary,.... superior .....

Permanent work, part time ; unemployement –

Sickness of the Mother yes .....no

Comments.....
.....

II. Divorced or deceased parents

Divorced -yes .....no

Deceased Parents

Mother yes ... no

Father yes ... no

Who is taking care of the child – names ....., comments

The rights of the parents are refused yes .....no

III. Family Income

- less than 1000 lev per month

Comments .....

Distance of the home to a Departmental city

-0-30 km

-30-100km

-More than 100 км

Comments.....

The house where lives the child is :

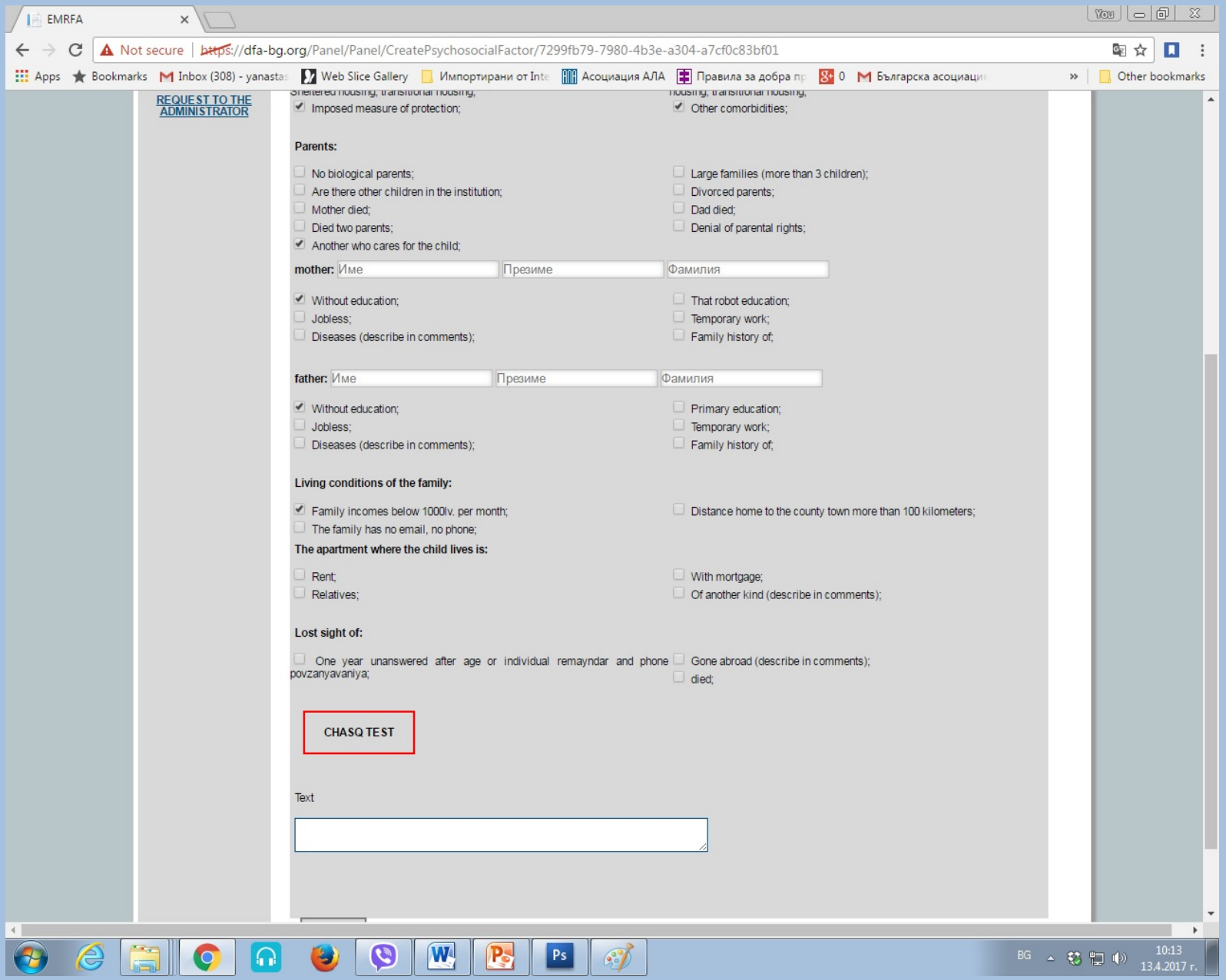
Own property ,rent,mortgage , belong to family members, other ...

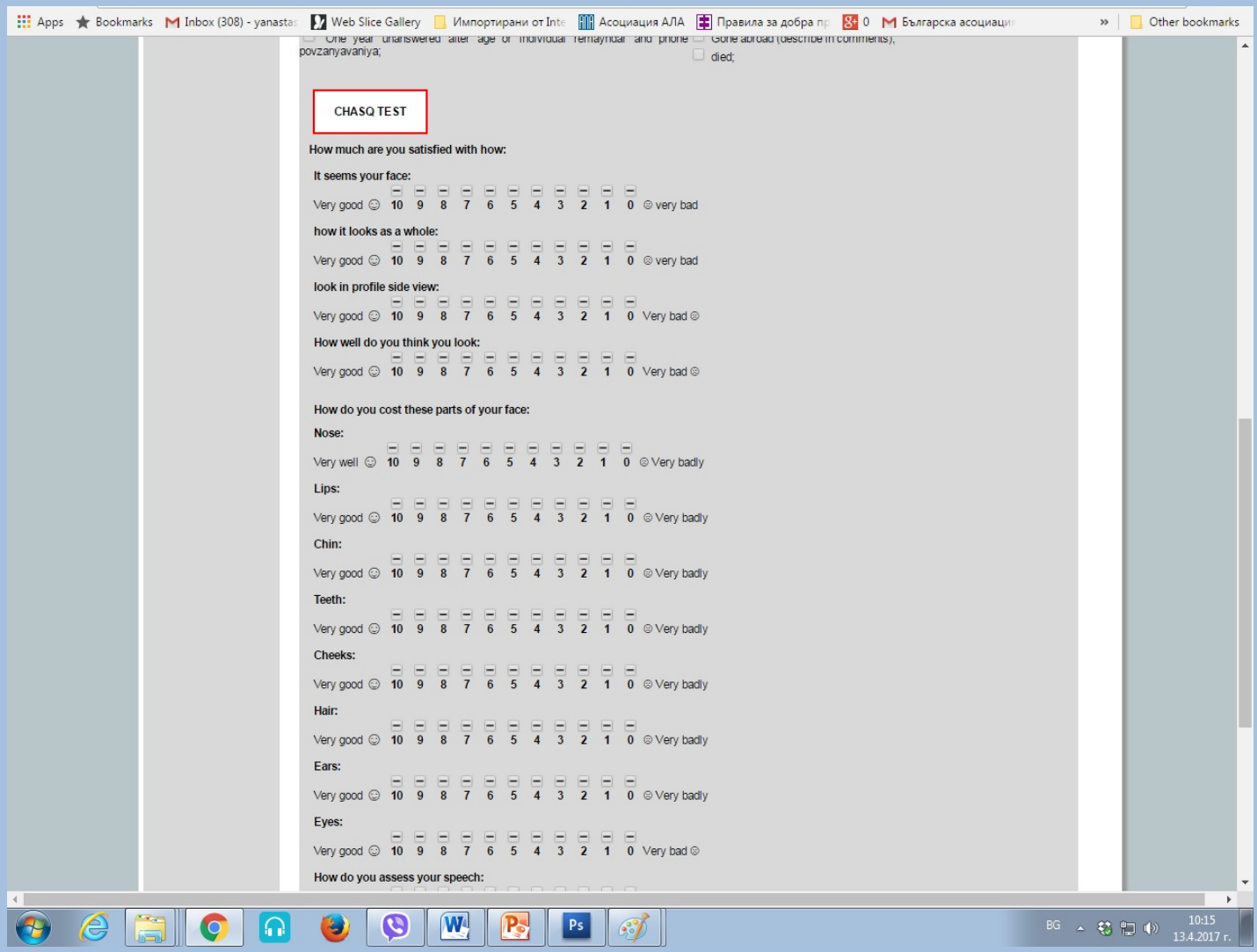
Comments…….

Particularities of the familial relationships – if signals .

Comments ……

The patient or the family does not have electronic address or phone number


EMRFA
Not secure
https://dfa-bg.org/Panel/Panel/CreatePsychosocialFactor/7299fb79-7980-4b3e-a304-a7cf0c83bf01
Apps
Bookmarks
Inbox (308) - yanastas
Web Slice Gallery
Импортирани от Inte
Асоциация АЛА
Правила за добра пр
Българска асоциаци
Other bookmarks
REQUEST TO THE ADMINISTRATOR
Sheltered housing, transitional housing,
Imposed measure of protection;
housing, transitional housing,
Other comorbidities;
Parents:
No biological parents;
Are there other children in the institution;
Mother died;
Died two parents;
Another who cares for the child;
Large families (more than 3 children);
Divorced parents;
Dad died;
Denial of parental rights;
mother: Име Презиме Фамилия
Without education;
Jobless;
Diseases (describe in comments);
That robot education;
Temporary work;
Family history of;
father: Име Презиме Фамилия
Without education;
Jobless;
Diseases (describe in comments);
Primary education;
Temporary work;
Family history of;
Living conditions of the family:
Family incomes below 1000lv. per month;
The family has no email, no phone;
Distance home to the county town more than 100 kilometers;
The apartment where the child lives is:
Rent;
Relatives;
With mortgage;
Of another kind (describe in comments);
Lost sight of:
One year unanswered after age or individual remayndar and phone povzanyavaniya;
Gone abroad (describe in comments);
died;
CHASQ TEST
Text
BG
10:13
13.4.2017 г.


Apps
Bookmarks
Inbox (308) - yanastas
Web Slice Gallery
Импортирани от Inte
Асоциация АЛА
Правила за добра пр
0
Българска асоциаци
Other bookmarks
povzanyavaniya;
died;
CHASQ TEST
How much are you satisfied with how:
It seems your face:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ very bad
how it looks as a whole:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ very bad
look in profile side view:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 Very bad ☹
How well do you think you look:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 Very bad ☹
How do you cost these parts of your face:
Nose:
Very well ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Lips:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Chin:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Teeth:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Cheeks:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Hair:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Ears:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 ☹ Very badly
Eyes:
Very good ☺ 10 9 8 7 6 5 4 3 2 1 0 Very bad ☹
How do you assess your speech:
BG
10:15
13.4.2017 г.

prof. Yuriy Anastasov

SURGEON

exit

AID

INSTRUCTIONS

REQUEST TO THE ADMINISTRATOR

Nasko Nikolaev Banchev 7 m.

Phone number : 0896385851 **Email :** mariakaz@mail.bg
Address : 7573 Babuk Str. Vitosha 23

(Q37) - Unilateral left complete cleft lip and the alveolar crest with dislocation of the fragments with large nose deformities, total cleft palate;

| diagnosis | DETAILS | **POSTS** | NEW POST | GALLERY | FILES |

pages:

PSYCHOLOGIST

PSYCHOSOCIAL FACTORS (5m.) 02.28.2017

Psychosocial factors - HIGH RISK

Child - patient:

Temporarily placed in a specialized institution - orphanage or DDLRG; Imposed measure of protection;
Other comorbidities;

Parents:

Another who cares for the child;

mother:

Without education;

father:

Without education;

Living conditions of the family:

Family incomes below 1000lv. per month;

PARENT / GUARDIAN

Guardian / Custodian: Zhelya Bancheva

CONTENT

The child was placed in an orphanage Ruse and the first meeting with him and his grandmother carer for the child and visited him in the institution at the end of 2016. The operation was postponed because of established heart murmur. For the second time in the ward and again is not operated. The child is at risk given that the judgment of relatives to apply for reintegration is related operations. The grandmother was consulted about opportunities to take action on reintegration, despite the delay in surgery. One major problem is that lack their own home to parents. Also extended family working abroad, making it difficult relationship with the child and more frequent visits.

Sylvia Karakoleva - Psychology

Out of sight

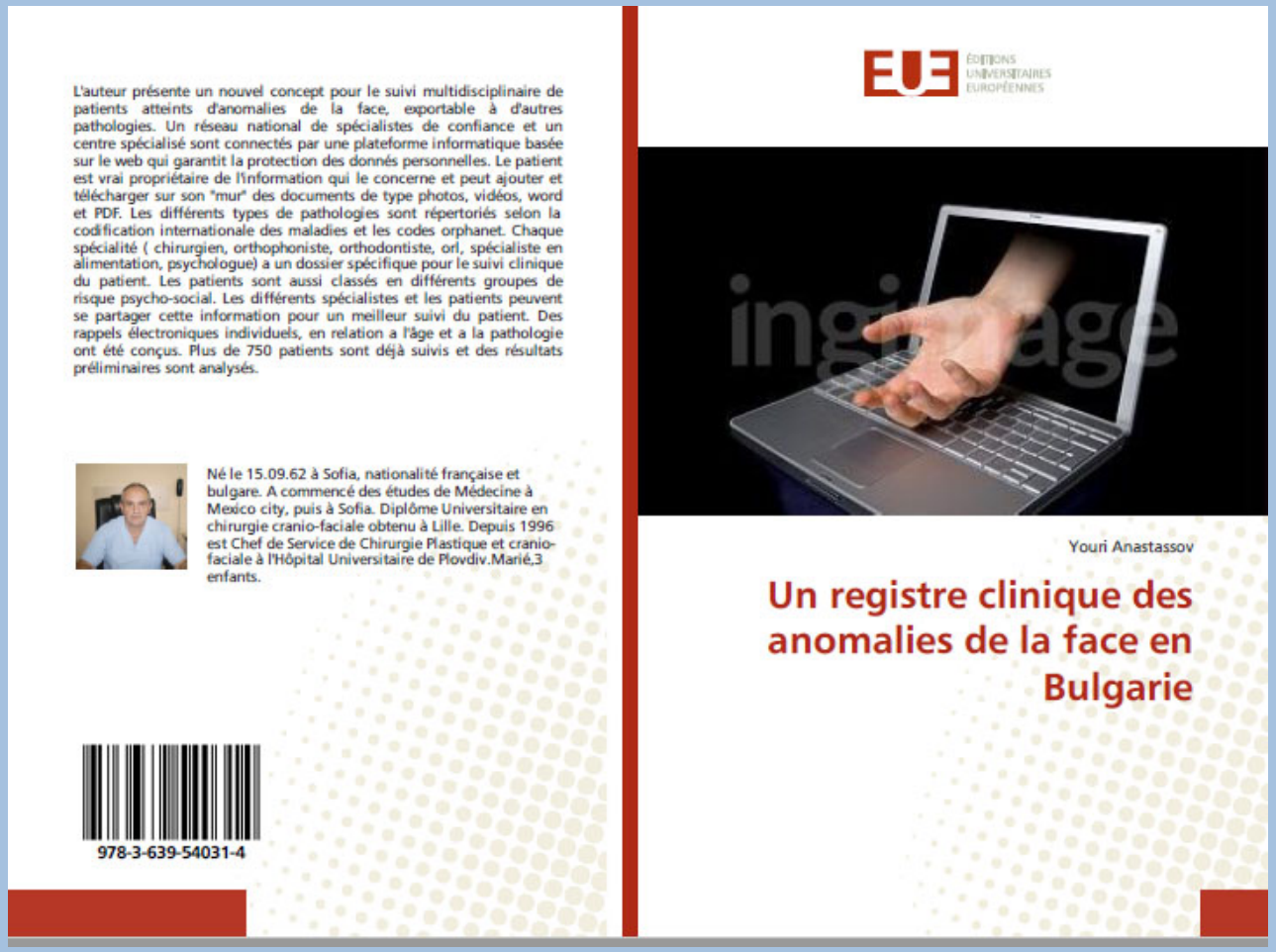
When the patient is not coming to the clinics at fixed ages (1, 3, 5, 8, 10, 12, 14, 18 , 21 years) and after an individual reminder for more than 1 year, an automatic reminder is send to the family and the Administrator.

Then phone calls are done by the responsible of the Team. 1 year after - the patient is classified as out of sight if there is no written consultation for 1 year in the register and also become part of the high risk group of patients

Originality of the EMR

- Clinical data using the EUROCLEFT standards for documentation
- Consecutif cases, life time follow up
- Participation of the patient
- Control of the Centre on the work performed near the home of the patient
- Statistics, research, epidemiology
- The Chasq test are included in our EMR
- The Team members filter the patients at risk and the system direct them to the psychologist

A book has been edited in 2016



L'auteur présente un nouvel concept pour le suivi multidisciplinaire de patients atteints d'anomalies de la face, exportable à d'autres pathologies. Un réseau national de spécialistes de confiance et un centre spécialisé sont connectés par une plateforme informatique basée sur le web qui garantit la protection des donnés personnelles. Le patient est vrai propriétaire de l'information qui le concerne et peut ajouter et télécharger sur son "mur" des documents de type photos, vidéos, word et PDF. Les différents types de pathologies sont répertoriés selon la codification internationale des maladies et les codes orphanet. Chaque spécialité (chirurgien, orthophoniste, orthodontiste, orl, spécialiste en alimentation, psychologue) a un dossier spécifique pour le suivi clinique du patient. Les patients sont aussi classés en différents groupes de risque psycho-social. Les différents spécialistes et les patients peuvent se partager cette information pour un meilleur suivi du patient. Des rappels électroniques individuels, en relation a l'âge et a la pathologie ont été conçus. Plus de 750 patients sont déjà suivis et des résultats préliminaires sont analysés.

Né le 15.09.62 à Sofia, nationalité française et bulgare. A commencé des études de Médecine à Mexico city, puis à Sofia. Diplôme Universitaire en chirurgie cranio-faciale obtenu à Lille. Depuis 1996 est Chef de Service de Chirurgie Plastique et cranio-faciale à l'Hôpital Universitaire de Plovdiv.Marié,3 enfants.

978-3-639-54031-4

ÉDITIONS UNIVERSITAIRES EUROPÉENNES

Youri Anastassov

Un registre clinique des anomalies de la face en Bulgarie

Collaborative Grants

FACE VALUE

IHEM | Innovative Health Educational Module

cost EUROPEAN COOPERATION IN SCIENCE & TECHNOLOGY

COST is supported by the EU Framework Programme Horizon 2020

APPEARANCEMATTERS

Training resources

- Psychosocial training for Health Care Professionals (HCP)
- Developed open resource training material in 5 languages
- Trained 324 HCP in Europe

FACE VALUE

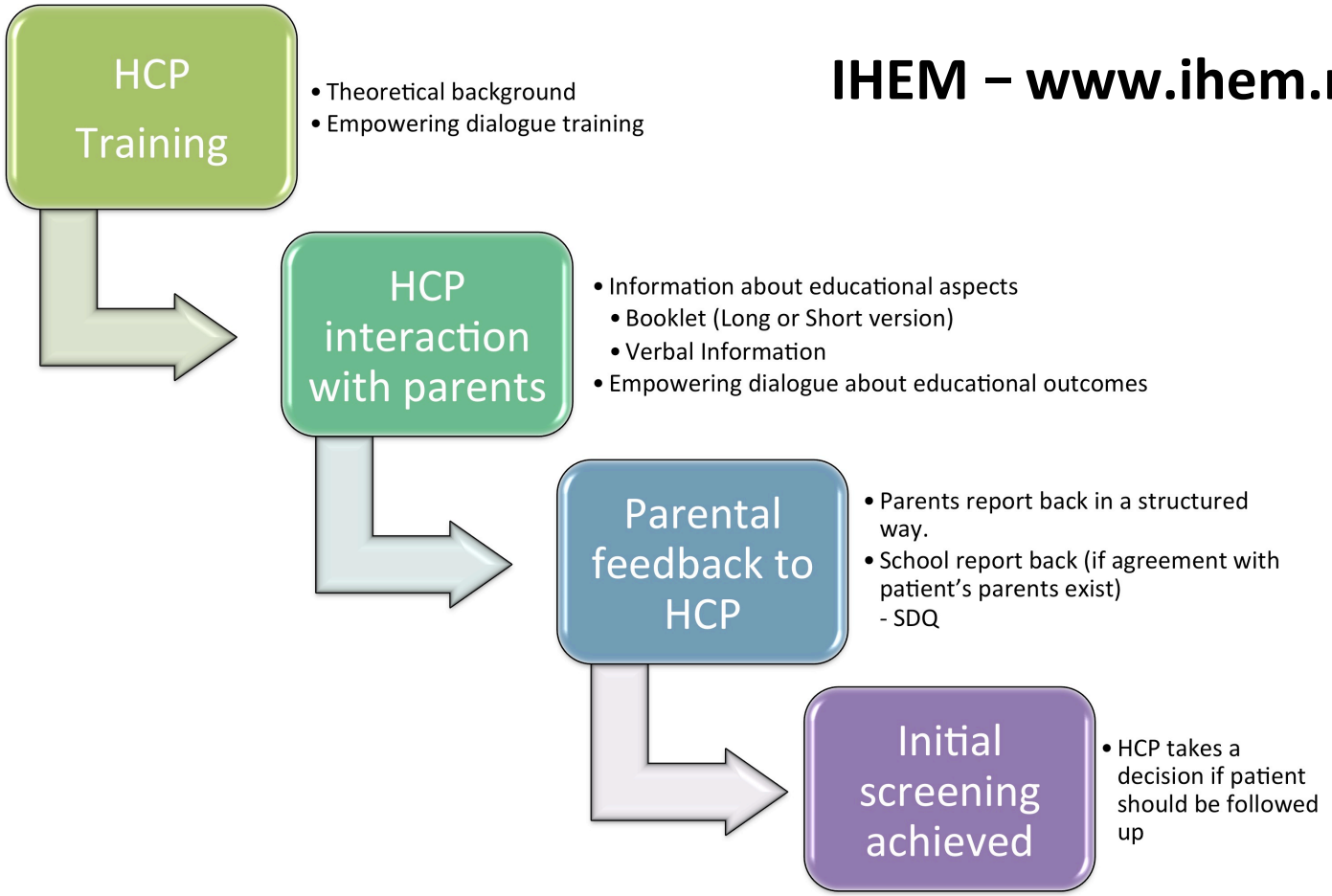
http://www.facevalue.cc

cost EUROPEAN COOPERATION IN SCIENCE & TECHNOLOGY

COST is supported by the EU Framework Programme Horizon 2020

APPEARANCEMATTERS

Training resources



IHEM – www.ihem.no

HCP = Health Care Professionals

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Future

- Submitted 5 new grant applications
  - COST
- Networking
- Improved care

cost EUROPEAN COOPERATION IN SCIENCE & TECHNOLOGY

COST is supported by the EU Framework Programme Horizon 2020

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Thank you!

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