

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19

Supplimentary Matereials

Supplementary Materials 1: ECCE training schools

First training school

Location: University of Malta, Valletta. Date: March 2019

Over 50 participants attended this training school, including 20 local healthcare trainees and clinically active professionals. Various disciplines, including public health specialists, dentists, orthodontists, speech and language pathologists, psychologists and obstetricians, were represented. Over the three days, international experts covered the areas of psychological and intimacy issues, as well as parent involvement in research priorities, and public health. In depth training was provided on social research methods and how these can be tailored to reach and engage socially disadvantaged and hard-to-reach populations in order to study sensitive and ethically challenging topics. To provide more understanding on the patient and family perspective, there was a poignant session on a patient experience and public engagement, followed by the provision of guidelines and practical exercises used by ECO to train parents of children with clefts to support new parents.

Second Training School

Location: Pühajärve Conference Centre, Estonia. Date: October 2020

The second training school, which, due to a COVID-19 postponement, has been moved to October 2020, will be held in Estonia. This three-day school will be dealing with equality of care within the context of multidisciplinary teamwork, organisational structures and the implementation of change. Following an introduction to multidisciplinary workplaces, there will be a seminar followed by a workshop on healthcare and gender with training in the Health Innovation, Implementation and Impact (HI3) concept^[35]. During the last day, there will be a lecture on global



© The Author(s) 2018. Open Access This article is licensed under a Creative Commons Attribution 4.0 International License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, sharing, adaptation, distribution and reproduction in any medium or

format, for any purpose, even commercially, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

29 perspectives from different cultural settings in multidisciplinary team workings. In
30 conclusion, there will be a session on the multidisciplinary care and person-centred care
31 in relation to understanding and managing the patient and the family perspective.

32

33

34

35 Supplementary Materials 2: ECCE conferences*36 First conference*

37 Location: Niš, Serbia. Date: September 2018

38 The first Action conference took place in an ITC-in the city of Niš in Serbia. The event
39 attracted 200 participants from 28 countries with a diverse range of speakers covering
40 all aspects of the Action, including healthcare access issues for those denied settled
41 status (refugees and immigrants). Another keynote speaker from Thailand spoke
42 passionately about ensuring every cleft patient should be able to fulfil their potential
43 and how his team at the Tawanchai Centre provides support well beyond medical care
44 to ensure patients reach their full educational and employment capabilities.

45

46 Second conference

47 Location: Kristianstad, Sweden. Date: December 2019

48 The Action's mid-term conference took place in Kristianstad, Sweden with 85 attendees
49 from 25 countries. The speakers included the hosts of the 2021 and 2025 World Cleft
50 Congresses (Scotland and Japan) who presented global perspectives on cleft care. There
51 was also an opportunity to hear from a public health specialist from Poland who spoke
52 about how person-centred care can be effectively delivered by health systems (a major
53 theme within the Action). The importance of this theme was also brought up by another
54 speaker who spoke about the psychosocial factors that can bring about enhanced patient
55 resilience.

56

57

58

59 Supplementary Materials 3: ECCE STSMs60 *Example STSMs*

61 One of the earliest STSMs performed under the auspices of this Action involved a
62 research active surgeon based in Bulgaria visiting another research active surgeon in
63 Spain who is the coordinator of a multidisciplinary cleft team. Somewhat unusually,
64 one of the primary goals of this STSM was for the applicant to share details of a patient
65 centred, patient accessible, electronic medical records system used by the applicant and
66 colleagues in their work in Bulgaria and which helps facilitate information sharing
67 between cleft specialists and patients' local medical teams.

68

69 The STSM was conducted in this manner as introducing this system (or similar) into a
70 new healthcare setting would require the coordination of many people. During the
71 course of the STSM, the system was introduced to medical specialists, hospital
72 directors, patient group representatives, IT specialists and other members of the
73 hospital management and infrastructure. Its suitability for the local context alongside
74 technical and legal issues were considered and the benefits it may afford in facilitating
75 follow-up and multidisciplinary care to harder to reach and vulnerable patients noted.
76 Whether or not the specific system is eventually adapted to the Spanish context, the
77 STSM afforded the hosts the opportunity to learn about and consider the suitability of a
78 new system of data management and communication and may impact upon future
79 processes and decisions within the local, host cleft team.

80

81 Other STSMs with an applied focus have allowed the applicants to learn about the
82 structure, organisation and operation of multidisciplinary teams in institutions based in
83 other members of the Action and consider how they may apply this learning within
84 their own professional context. For example, a psychologist working within a Croatian
85 speech and language rehabilitation centre spent time at a Swedish university hospital to
86 explore best practice and patient care within cleft and craniofacial specialities. In
87 addition to applying the learning to the applicant's organisation, where greater
88 standardisation and quality control of procedures will result as well as the possible
89 introduction of new diagnostic instruments and therapy tools, future research

90 collaborations focussed upon the equalisation of standards of care between the parties
91 have also been proposed.

92

93 Similarly, a dual academic-clinician obstetrician and gynaecologist based in Malta
94 conducted an STSM at a cleft and craniofacial clinic in Israel (a cooperating member in
95 COST Actions). As Maltese cleft care often does not incorporate coordinated,
96 multidisciplinary care, and there is no national protocol for the treatment of cleft,
97 understanding how these elements of the healthcare system operate in Israel was the
98 primary goal of this STSM. In addition, the applicant had the chance to observe,
99 discuss and appreciate social determinants of health, health inequalities and the access
100 to care afforded to vulnerable or disadvantaged groups and is implementing the
101 understandings gained within the local services with which they are involved.

102 The ECCE Action has also supported STSMs between research institutes based in
103 Switzerland and in Italy with applicants occupying positions from PhD student to full
104 professor. This has involved collaborative fundamental research including investigating
105 the potential impact of specific genetic mutations upon the expression or severity of
106 cleft, the role of Notch1-expressing cells in vascularisation and cleft formation and the
107 possibility of combining angiogenetic molecules with osteo-inductive molecules
108 towards an innovative cleft treatment.

109

110 These collaborative efforts are ongoing. It is the hope of the members of the Action that
111 breakthroughs in pure research related to our understanding of and treatments for cleft
112 can, when eventually used and applied in an equitable manner, help redress health
113 inequalities. This highlights an important consequence of the ECCE Action, the
114 opportunity for those from a variety of professional backgrounds, at different stages of
115 their career, and in a large number of member states, to consider these issues together
116 and contemplate how their own work may, now or in the future, be utilised in order to
117 reduce inequalities in cleft and craniofacial care.