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| **Task Group – Clinical Interventions (group 12)** | | |
| **Group coordinator(s):** | | |
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| **Overall Aims and Objectives of Task Group** | | |
| Aims:  To use research and clinical expertise to improve the provision of psychosocial support for people with appearance-altering conditions and appearance-related concerns across Europe.  Objectives:   * To conduct a survey of the current provision of psychosocial support for people affected by visible difference across Europe in order to establish current care provision and inform plans for future research. * To establish research collaborations to explore the transferability and feasibility of existing psychosocial interventions into new European settings. * To conduct a literature review of pre-surgical screening of children and young people undergoing an appearance-altering procedure. * To collate resources that could be of use to clinicians working in this field. * To support networking that will facilitate longer-term collaborations in the future. | | |

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| **Activities of Task Group** |
| We have:   * Developed a strong group membership that has held regular meetings via Skype (*Diana Harcourt, Ornella Masnari, Francesca Nobile, Kristin Billaud Feragen, Jolanda Okkerse, Heidi Williamson, Luis Joaquin Garcia-Lopez, Jose Mendes, Anna Pitterman, Saskia Spillekom-vanKoulil, Claire Hamlet, Nicola Stock)* * Conducted several meetings (face-to-face and Skype) to establish new research collaborations (*Diana Harcourt, Ornella Masnari, Francesca Nobile, Kristin Billaud Feragen, Jolanda Okkerse, Heidi Williamson, Luis Joaquin Garcia-Lopez, Jose Mendes, Anna Pitterman, Saskia Spillekom-vanKoulil, Claire Hamlet, Nicola Stock)* * Completed two online pan-European surveys of psychosocial specialists regarding the provision of psychosocial support for people affected by visible difference. One survey (n = 116) targeted those who considered their work to specialise in visible difference/appearance, the other targeted those who saw clients with appearance-related concerns but did not consider themselves to be specialists in this particular field (*Diana Harcourt, Ornella Masnari, Francesca Nobile, Kristin Billaud Feragen, Jolanda Okkerse, Heidi Williamson, Luis Joaquin Garcia-Lopez, Jose Mendes, Anna Pitterman, Saskia Spillekom-vanKoulil, Claire Hamlet, Nicola Stock)* * Successfully acquired funding to translate the YP Face IT intervention for young people affected by visible difference into Norwegian, and started a feasibility study of its use in Norway *(Heidi Williamson & Kristin Billaud Feragen).* * Explored the potential utility of YP Face IT in the Netherlands and developed applications for funding to translate it into Dutch and test its feasibility (*Heidi Williamson, Jolanda Okkerse &Saskia* *Spillekom-vanKoulil* ) * Started to investigate the use of the PEGASUS intervention in Norway *(Diana Harcourt & Kristin Billaud-Feragen)* * Examined the potential use of the RoFCAR screening tool in Italy *(Francesca Nobile with members of the Centre for Appearance Research)* * Conducted a review of existing literature regarding pre-surgical screening of young people and children *(Ornella Masnari, Francesca Nobile, Kristin Billaud Feragen, Jolanda Okkerse, Heidi Williamson, Diana Harcourt).* * Examined the literature regarding the use of mirrors in therapeutic settings (*Jose Mendes)* * Supported one STSM visit (*Francesca Nobile visited the Centre for Appearance Research in November 2016).* * Started to collate resources (e.g. papers, measures) that could be of use to clinicians working in this field *(all members)* * Established a small network of researchers/clinicians in this field who intend to maintain contact and continue to develop future collaborations. |

OUTCOMES, ACTIVITIES & ACHIEVEMENTS RESULTING

FROM TASK GROUP ACTIVITIES

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| **Publications** (include only those with at least 3 authors from 3 different COST Countries) |
| In progress:  The Provision of Specialist Psychosocial Support for People with Visible Differences: A European Survey *(working title*), for submission to *Body Image.* |

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| **NETWORKING** |
| **Added value of the Networking** (within the TASK GROUP) |
| We have been able to share knowledge with one another and have established new collaborations that will continue beyond the COST action and, hopefully, lead to further research in the future. |

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| **Please describe any other outputs and achievements that have resulted from Task Group activities, or that are still in progress, highlighting in particular on those relevant to the aims of COST** (“COST enables break-through scientific developments leading to new concepts and products and thereby contributes to strengthen Europe’s research and innovation capacities.”) |
| A literature review of pre-surgical screening for children and young people is in progress, and will be submitted to a peer-reviewed journal (*led by Ornella Masnari*) |

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| **Impacts** | | |
| Please describe the impacts that have resulted, or might result from the Action in future | | |
| **Description of the impact** | **Type of impact1** | **Timing of impact2** |
| Access to the YP Face IT intervention in Norway, the Netherlands and Switzerland | Scientific | Foreseen within 2 years |
| Use of the PEGASUS intervention in Norway, Italy and Switzerland / Adaptation for use in Pediatric Settings | Scientific | Foreseen within 2 years |
| Use of the ROFCAR screening tool in Italy | Scientific | Foreseen within 2 years |
| **Establishing a model for presurgical screening in children and young people before appearance altering surgery.** | **Scientific** | Foreseen within 2 years |
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Scientific/ Technological, Economic, Societal

2 Achieved/ Foreseen within 2 years/ Foreseen 2-5 years/ Foreseen 5-10 years/ Foreseen 10+ years

DISSEMINATION & EXPLOITATION OF TASK GROUP ACTIVITIES

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| **Add description here** (Add more rows if needed) | | | | | |
| **Item/ activity** | **Country** | **Target Audience** | **Number** | **Result** | **Hyperlink** (if available) |
| ***Below are examples of some activities,***  ***Please delete before starting*** | | | | | |
| Seminar on the PEGASUS intervention to support patient decision making (May 2016) | Norway | Clinicians at the Centre for Rare Diseases, Oslo | 20 | Discussions about possible future use of the intervention and research |  |
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Were there any challenges that were encountered in your task group? What solutions were used to overcome these challenges?

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| We share our interest and enthusiasm for research and clinical practice that supports people living with a visible difference of any sort. However, we work in different specialities (e.g. cleft, craniofacial, burns, plastic and reconstructive surgery), speak different languages, and work in different countries under differing systems of care. In addition, the amount of time that members of the group spend on research differs markedly, with some having this as the prime focus of their work whilst others are primarily clinicians who do not have any time allocated to research. Whilst this variation added a very interesting element to our work, it was very difficult to find a way of pooling our relevant expertise effectively to carry out tasks that were feasible given the lack of heterogeneity amongst the group and the lack of resources available. Working in a wide range of specialties was particularly challenging and meant that we looked for projects that were broad and relevant to a variety of conditions, rather than having a niche focus which may have enabled us to be more specific, targeted and focussed.  All members of the core group were generous with their time, expertise and support, which they gave for free. Without this positive attitude and engagement we would not have been able to carry out any of the tasks outlined above. We were also fortunate that a researcher at the Centre for Appearance Research, Claire Hamlet, was able to join the group and was available to conduct the analysis of our online survey data.  Meeting face-to-face was limited to the COST group meetings, but it was not possible for all group members to be present due to their work commitments and/or lack of financial support for their attendance. We therefore had regular virtual meetings and after trying a range of programmes for group conference calls (with varying degrees of success/frustration) found that Skype was the best option, although this was still problematic in that not everyone was able to access it (particularly when trying to access it in a hospital setting). We have tried to keep everyone in the group updated with minutes of meetings, especially for those who have been unable to join meetings in person. |

THANK YOU VERY MUCH FOR completing this and for ALL YOUR HARD WORK!