Online psychosocial support for young people distressed by appearance-altering conditions: A randomised control trial (RCT)

Project description

1. Relevance relative to the call for proposals

The main objective of the present application is to **evaluate and implement a new eHealth-based treatment method** for young people with appearance-related concerns due to a visible medical condition (YP Face IT), through a randomised control trial (RCT).

More specifically the study will lead to:

- Research on an underrepresented group of adolescents: those with a visible difference due to acquired or congenital medical condition. The study will increase awareness about appearance-related distress in adolescents in general, and in those with a visible difference in particular
- Cooperation and network-building across sectors in all national health regions and service levels
- Enhance the internationalisation of clinical research: The study involves close collaboration with Centre for Appearance Research (University of the West of England), who developed YP Face IT, and researchers in other countries currently piloting YP Face IT (Netherlands, Australia, USA)
- Promote user involvement: The original English version of the programme was developed in close collaboration with users. Ten patient organisations were involved in the recent piloting of the Norwegian version, and further cooperation is planned also for the current RCT
- Contribute to more equal health services for an under-served group of adolescents, irrespective of availability of health care services, ethnicity, or geographical place of residence.

2. Aspects relating to the research project

2.1. Background and status of knowledge

Appearance concerns are well-known to be "normative" and impact on psychological functioning and health during the adolescent years (Cash & Pruzinski, 2002; Grogan, 2007). One group of adolescents who are particularly vulnerable to appearance concerns are those with a condition affecting their appearance (Feragen, 2012), due to injuries (burns or accidents), treatment (cancer), skin conditions or congenital anomalies (birthmarks, acne, cleft lip and palate, craniofacial conditions). The prevalence of young people living with a visible facial difference has been calculated to be approximately 1-2% (Partridge & Julian, 2008). "Looking different" can have a profound psychological impact and contribute to low levels of selfesteem, especially during adolescence (Levine & Smolak, 2002; Rumsey & Harcourt, 2007), since "blending in" and belonging to a social group becomes especially central to psychological wellbeing during this period of life (Frisén et al., 2015). In a society with a massive emphasis on appearance and "looks", a visible difference can therefore have a profound impact on young people.

Irrespective of the cause, extent or severity of the visible difference, around a third struggle with psychosocial difficulties and appearance dissatisfaction (Rumsey & Harcourt, 2004; Rumsey & Harcourt, 2007). Research has identified potential difficulties in relation to subjective satisfaction with appearance, emotional and psychosocial difficulties, teasing, bullying, and social anxiety (Feragen & Stock, 2016; 2017; Hunt et al., 2005; Stock & Feragen, 2016), that may impact on social competence, health behaviours, academic performance, and psychological function. If not addressed, social anxiety and dissatisfaction with appearance or

over-indulgence in exercise and use of steroids, and reduced participation in society (Kanayama et al., 2006; Stice & Shaw, 2003). Appearance concerns are also known to impact on health care decision–making and could influence choices regarding aesthetic and reconstructive surgery in adulthood, an economic burden from both social and health perspectives (Stice, 2002; Rumsey & Harcourt, 2004; Williamson & Rumsey, 2016). Preventative treatment of appearance-concerns before serious problems arise therefore has health-economic consequences.

Young people with congenital or acquired visible conditions often go through extensive treatment pathways, including surgical and medical interventions aiming at diminishing a difference that may be visible to others. Nevertheless, young people with appearance concerns also need self-management skills as an alternative or addition to medical or surgical care. Research clearly demonstrates that location, size, and cause of a visible difference do not predict distress (Appearance Research Collaboration (ARC), 2009; Moss, 2005). Instead, well-being is determined by psychological factors which can be changed through psychosocial interventions, including cognitive behavioural therapy (ARC, 2009; Clarke et al., 2013; Rumsey & Harcourt, 2012). Nevertheless, evidence-based psychological interventions are scarce. Further, access to psychological treatment is limited: Norway's geographic and demographic characteristics contribute to make specialised psychological treatment difficult to reach, and there are few psychologists with clinical expertise in appearance psychology related to living with a visible difference in the local health care system.

A new eHealth-based treatment method for people with a visible difference

Systematic reviews conclude that interventions based on social interaction skills training and cognitive behavioural therapy are promising (ARC, 2009; Bessell & Moss, 2007; Jenkinson, 2012), and internet-based cognitive behavioural therapy (ICBT) has been shown to be effective for treatment of mild to moderate levels of depression and anxiety (NICE, 2005; Nordgreen et al., 2017; Richardson et al., 2010; Spence et al., 2006). Still, evidence-based interventions tailored to meet specific needs among young people with a visible difference are lacking internationally (Williamson et al., 2015), and nationally. A larger RCT, informed by multiple preparatory studies in the UK and a Norwegian pilot, would provide robust evidence of the effectiveness and cost-effectiveness of a novel self-management intervention tool.

Interventions can be presented as a stepped-care model: Whereas most patients benefit from low-level interventions such as information leaflets, more vulnerable individuals require high-level interventions from specialist health care services (Rumsey & Harcourt, 2012). Therefore, the Centre for Appearance Research (CAR) in Bristol (UK) developed an online intervention for adults with a visible difference (Face IT: www.faceit.co.uk). Based on evidence of its efficacy in reducing depressive symptoms, anxiety and appearance concerns (Bessell et al., 2012; Norman & Moss, 2015), CAR further developed a similar intervention programme for adolescents (Young People's Face IT: www.ypfaceit.co.uk). YP Face IT was developed in close collaboration with young people and clinical experts, and suitability, acceptability, and feasibility has been evaluated (Williamson et al., 2015). YP Face IT was developed to support young people in need for more than information, but not requiring complex, face-to-face psychosocial interventions.

YP Face IT has recently been translated into Norwegian (Ung Face IT; www.ungfaceit.no) and been piloted (feasibility and acceptability study), through funding from the Norwegian National Advisory Unit on Rare Disorders (Feragen, 2017). The next step is a larger randomised control trial (RCT), in order to evaluate Ung Face IT's usefulness and effectiveness for young people living in Norway.

The aim of the intervention is to reduce appearance-related distress and social anxiety, thereby strengthening psychological adjustment to a congenital or acquired visible difference. The intervention provides easy access to specialist advice and support via a home computer/tablet, using illustrations, information, videos, and interactive activities, and a discussion forum for participants only (supervised by the research team). Through these tools, Ung Face IT provides advice and teaches coping skills based on

cognitive behavioural therapy and social interaction skills training, intervention approaches that have shown promise (Bessel & Moss, 2007; Norman & Moss, 2015, Jenkinson et al., 2015).

Access to care

Due to the country's geographical circumstances, many patients need to travel long-distance for specialised care in Norway. Internet-delivered care would address young people's need for psychological support, in addition to significantly reduce direct and indirect health care resources without adding health-economic costs. Ung Face IT has the potential to be an important alternative to "face-to-face" specialist interventions, and prevent the development of psychological and health-related problems in a vulnerable group of adolescents. General practitioners (GPs) have limited resources to meet the need of this group. Young people with a visible difference often do not meet the criteria for referral to specialist child and adolescent mental health services (BUP) and/or waiting lists can be long. GPs, health nurses, social workers, and local school psychologists are accessible health care providers to many young people and families. They are ideally placed to identify need and provide immediate access to support, either whilst the young person is waiting for help within secondary care, or to prevent a need for referral in the future.

YP Face IT has been demonstrated to fill a gap in current care provision (Williamson et al., 2015):

- Young people endorsed YP Face IT over face-to-face therapy since it can be accessed in privacy and they feel less embarrassed to participate
- Young people appreciated peer support from others with shared experiences
- Young people and parents welcomed not having to take time off school/work/activities while travelling to appointments
- Health professionals welcomed it because it overcomes barriers that often prevent young people from using their services
- Health professionals also reported that young people often experience a lack of access to specialised appearance-specific support services, and suggested that YP Face IT should be accessible through primary care, in order to reduce demands on limited secondary care services.

In order to explore whether the Norwegian version of the intervention can help adolescents in Norway who struggle with appearance concerns and social anxiety, Ung Face IT needs to be systematically evaluated. This will contribute towards making specialised online health care available for young people with a visible difference, addressing unmet needs in the current health care system.

2.2. Approaches, hypotheses and choice of method

A recent Norwegian pilot of Ung Face IT tested the study's acceptability and feasibility, based on a sample of 29 young people with a visible difference (Feragen, 2017). Experiences from the pilot have been used to refine the present project. A larger RCT is the next step to address the need for an online intervention tool for this group of adolescents. An RCT is the most robust design when aims are to ensure that findings are not due to extraneous effects, which might otherwise compromise the validity of conclusions. Given the need to underpin interventions with a rigorous evidence-base, an RCT will increase the likelihood of Ung Face IT being adopted by future health providers.

The study will compare an intervention group (Ung Face IT + treatment as usual, TAU) with a control group (TAU only). TAU includes a wide variation of follow-up, ranging from little or no appearance-related support for the majority, to higher-level interventions for a few. In order to be able to control for this variation, without denying participants needed support (ethical considerations), all provision of care from all levels will be registered in both groups (Health Resource Use Questionnaire, parental reports).

The pilot revealed that some parents struggled with understanding the need for a control group. Hence, in order to improve recruitment, reduce ethical considerations, and handle potential disappointment for those who are randomised to the control group, a waitlist control group design will be used. The control group will be given the opportunity to receive the intervention after 6 months (T2). When determining the effect of the intervention in this subgroup, T2 will work as a baseline measure. The current design will ensure two sets of data: 1) RCT-data comparing a control group with an intervention group (based on a 1/1 randomisation), and 2) A larger intervention sample (primary intervention group + waitlist controls who receive the intervention), for a more detailed investigation of potential factors affecting the efficacy of Ung Face IT (gender, age, ethnicity, levels of experienced appearance-related problems at baseline etc). Waitlist control groups have been criticised for potentially inflating intervention effect estimates (Cunningham et al., 2013), a risk that will be monitored by outcome measures at three time points for both groups.

Mixed methods design

Quantitative component: Block randomisation, performed by Research Support Services, Oslo University Hospital, will ensure that equal numbers from specialist and local services are allocated to each condition. The design is amenable to analysis using ANCOVA, with intervention as covariate and adjusted for baseline. The intention to treat principle will be used, such that all participants with baseline data will be included in the analyses. Missing observations for the primary outcome will be handled by multiple imputations by the primary analysis model not including the intervention covariate. The data will also be analysed with statistical models for repeated measurements, such as linear mixed models. Necessary sample size was calculated based on preliminary results from the pilot study (SD of the difference between baseline and T2 = .49) showed that n = 62 per arm will have at least 80% power for detecting anticipated effects, based on an expected improvement of .25 on the main outcome measure in the intervention group. The pilot study showed 8% attrition in the control group and 37% attrition in the intervention for appearance-related support. Motivation will therefore be discussed with the participants before acceptance into the study, which may contribute to lower attrition rates. Still, in order to secure statistical power and account for drop-out, the study aims to recruit 80 adolescents in each group (N = 160).

Qualitative component: Qualitative data will provide in-depth knowledge about aspects of psychological factors that are difficult to measure quantitatively, and capture health care providers' clinically oriented experiences. Interviews will investigate young people and their parents' experiences with the recruitment process, randomisation, retention, outcome measures, experiences of completing the programme, in addition to their evaluation of content and usefulness (intervention group). Health care providers from local and centralised settings will be interviewed about their experience with recruitment, administration, and potential implementation of Ung Face IT. Participants will be recruited until data saturation has been reached (20-30 young people and parents; 5-10 health care providers). Interviews will be digitally recorded and transcribed verbatim before thematic analysis (Braun and Clarke, 2006).

3. The project plan, project management, organisation and cooperation **3.1. Sample and procedure:**

The aim is to recruit approximately 160 young people with any appearance-altering condition, injury, or treatment side-effect, who also self-identify as experiencing appearance-related distress, teasing or bullying. Participants will be informed about the study through health care services, user organisations, and the media. The research team will be responsible for inclusion and follow-up of all interested participants.

Inclusion criteria:

 Age 12-17 with an appearance-altering condition, and experiencing appearance-related distress, teasing, or bullying

- Access to a home computer/tablet and internet
- Reading level > 12 years of age. Audio recordings for all written text available on the website for those who may struggle with reading
- Normal/corrected-to-normal vision

Exclusion criteria:

- Severe clinical depression, psychosis, eating disorder (alternative support necessary)
- Post-traumatic stress disorder (PTSD) or within 12 months of traumatic injury (alternative support necessary)
- Learning disability that would impede understanding of the programme's content
- Currently receiving psychological face-to-face interventions

3.2. Recruitment and collaboration with health care services:

A research assistant will be mainly responsible for information about the study, recruitment, screening of participants, and follow-up (Year 1 and 2; see Budget in electronic grant application for details). This is expected to strengthen the study's feasibility and treatment fidelity, and hence reduce drop-out.

Specialist care: Contacts with clinics at Oslo University Hospital (Division of Neurosciences and Division of Head, Neck, and Reconstructive surgery) and centres under the administration of the Norwegian National Advisory Unit on Rare Disorders are already in place (pilot study). Specialists involved in the treatment of young people with a condition affecting appearance from all health regions will be asked to inform patients about the study. Patient lists will be used to send information and flyers will be distributed in relevant clinics. The pilot indicated a 10% participation rate when using patient lists from specialised services for recruitment. We therefore believe it is realistic to recruit 60 young people through specialist services. Collaborations will capitalise on national research expertise and promote national net-work building.

Local health care: Information will be sent to GPs, municipal psychologists, and care providers in school settings (social workers, nurses, psychologists). The pilot study suggested that school workers, health nurses, and local psychologists felt the project addressed unmet needs. The research team will follow-up participants, reducing local involvement (time cost). However, in order to evaluate the feasibility of primary care staff undertaking the responsibility of supervising young people enrolled in the programme, 20% of the participating local health services will allocate this role to an "administrator" (GP, psychologist, or nurse) who will receive training in this task. This will facilitate networks for future implementation and collaboration. The research team will still review all participants, irrespective of local "administrators". As an incentive to recruit and participate, local care providers will be offered courses about appearance and body-image distress in adolescents in general, and how to address such concerns, based on existing programmes that have been developed by Dove self-esteem projects (www.dove.com/uk/home.html), in collaboration with Centre for Appearance Research. Subsequently, local administrators will be asked for their experience, time spent on the task and potential concerns, so that local administration can be evaluated as a model. Given the number of young people in contact with local services with visible medical conditions such as those already described, in addition to more common conditions such as eczema, acne, and psoriasis, we expect to recruit 60 young people through local services. Collaborations will promote national net-working and create awareness about appearance- concerns in local settings.

Patient organisations: Approximately 10 patient organisations were involved in the pilot, and have confirmed their wish to support a larger RCT. Other relevant patient organisations and Youth Councils at Oslo and Haukeland University Hospitals will also be contacted. Young people were recruited through patient organisations into the pilot, and we expect to recruit an additional 20 for the larger RCT study.

Posters, websites, media and social media: Posters will be displayed in participating services and posted on patient organisation's websites and social media, in addition to through traditional media. We believe the study will recruit approximately 20 young people by using websites, media, and social media.

3.3. Measures:

Self-report: Young people will complete measures of social and emotional functioning, and health-related well-being. Measures have been chosen based on good psychometric properties and use in appearance-related research. All necessary permissions for use are granted. Measures are completed on a secure online IT system approved by the hospital (TSD) at T1 (baseline), T2 and T3. Adolescents will be incentivised to complete measures at T2 and T3 with a voucher (200,- NOK), which seemed to motivate the participants positively during the pilot. Young people need 20-30 minutes to complete the questionnaires. Measures are:

- Primary outcome measure: Body Esteem Scale (BES)
- Secondary outcome measures:
 - Social Anxiety Scale (SAS)
 - Perceived Stigmatisation Questionnaire (PSQ)
 - Life Engagement Scale (LES)
 - o Self-Perception Profile for Adolescents (SPPA)
 - o **EQ-5D-5L**

Parental report: Parents (one per participant) complete the Health Resource Use Questionnaire, some open-ended questions about their child's adjustment to appearance-related challenges, and their perceptions of the usefulness of Ung Face IT (intervention group).

Health economic cost-effectiveness: As mentioned, the Health Resource Use Questionnaire will be used for calculations of health economic cost-effectiveness. Parental reports of family's use of health care services such as GPs, social services, nurses, psychologists/psychiatrists, other local or centralised health care providers, or contact with charities (peer support), in addition to reports about days off school, will be compared in the intervention group and the control group. Health economic calculations will also be completed for the waitlist control group, comparing their reports of health care use during the control condition and the intervention, for those choosing to undergo the intervention after 6 months.

	2019			2020				2021				2022			
	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Ethical approval and contract set-ups															
Steering Committee meetings															
Information and Recruitment															
Questionnaires T1 (baseline)															
Intervention delivery															
Questionnaires T2 (13 weeks)															
Questionnaires T3 (6 months)															
Qualitative interviews															
Qualitative analyses															
Evaluation/Health cost analysis															
Quantitative analyses															
Work on five publications															
Dissemination to national care services															
Implementation of Ung Face IT															

3.4. Project plan - Main activities and milestones (see also electronic grant application):

3.5. Project management and local expertise:

The project manager has highly relevant and long national and international research experience (CV in electronic grant application), coordinates and supervises all research activities at Centre for Rare Disorders, and supervises several external PhD-projects; among those, two are clinical intervention studies.

Centre for Rare Disorders has previously collaborated on several projects with Faculty of Psychology, Oslo University, and more recently with Faculty of Psychology in Bergen. Dr Tine Nordgreen, Department of Clinical Psychology (University of Bergen) and Division of Psychiatry (Haukeland University Hospital), has relevant and important experience with internet-based interventions and will be a central member of the research group. Close collaboration with Centre for Appearance Research, who developed YP Face IT, will also secure competence about online interventions. Master and clinical psychology students who may be interested in collaborations will also be involved in the project. Statistician Are Hugo Pripp (Centre of Biostatistics and Epidemiology, Research Support Services) and Clinical Trial Unit (CTU), both Oslo University Hospital, will be involved in data management, analyses and health economic calculations.

Budget: See electronic grant application.

4. Key perspectives and compliance with strategic documents

4.1. Relevance and benefit to society:

The project's relevance and benefit to society includes:

- Cost- effective healthcare as an alternative to less available clinical face-to-face appointments
- Increases access to care for an under-served but psychologically vulnerable population
- Evidence for a new preventative eHealth-based intervention at a national and international level
- Reduces time off school/work/ activities for a vulnerable group of adolescents and their parents compared to traditional interventions
- Promotes life engagement and participation in society, and prevents the development of emotional problems and other negative health behaviours in a group of adolescents at psychosocial risk
- Increases knowledge about an under-researched group of adolescents
- Sector Examines health-economic advantages, an under-researched issue within the health sector

4.2. Relevance and benefit:

Relevance and benefit for adolescents living with a visible difference:

- Reduced appearance-related distress and social anxiety, and improved psychological well-being
- Empowerment of adolescents at risk by providing self-help coping strategies
- Enjoyable, interactive and engaging for young people, by using multiple media
- Readily accessible eHealth intervention tool: no need to travel to face-to-face appointments and no need to miss school. Readily available 24 hours a day, 7 days a week and from almost anywhere.
- Equal access to specialised health care irrespective of ethnicity or geographical place of residence

Relevance and benefit for parents:

- Reduced worry about their child's distress
- Knowledge that the child is being supported without the need to miss school/college and without parents having to take time off work to attend psychological treatment in local or secondary care

Relevance and benefit for patient organisations:

Intervention tool that can be recommended to parents and young people in need of support

Relevance and benefit for local and centralised health care:

- Access to specialist advice from home (eHealth) that can be offered to those in need
- Health care services can offer immediate support, rather than waiting for referral to specialist care and specialist face-to-face interventions
- Potential to reduce the burden on specialist care resources
- Cost- effective healthcare compared to clinical face-to-face appointments

4.3. Ethical perspectives:

YP Face IT was designed for use with minimal additional input from health professionals. Nevertheless, appearance can be a sensitive topic for young people, and the first trials in the UK tested whether an unguided YP Face IT was safe for participants. No safeguarding issues were registered. Safeguarding routines will still be set in place. Data entered by the young person (diary entries, outcome measures, assignments) are saved and protected by high data protection security, and are reviewed weekly online by the researcher, checking for signs of abuse, self-harm, or psychological distress. Potential concerns can be discussed with the project manager (clinical psychologist with specialised experience in the treatment of appearance-related concerns). Participants in need of follow-up other than Ung Face IT will be referred to relevant health care services who will respond following usual protocols. Parental guidelines for supporting their child have also been developed, and are distributed to participating parents.

The young people allocated to the control group will not have immediate access to an intervention we believe could be helpful. Waitlist controls will however receive treatment as usual, which means the project does not deny them any care. After 6 months, participants will be offered the intervention, which means all participants will be given the opportunity to try Ung Face IT.

Online data entry and storage of Ung Face IT has hyper-secure online data protection (VeriSign[®]) and complies with University of the West of England and OUS data processing agreements regarding storage, sharing, and accessibility of data. Ethical approval was granted for the pilot study (similar design and method), and we therefore expect ethical approval for the present project to be granted. No adverse incidents occurred during the UK studies or the Norwegian pilot.

5. Dissemination and communication of results (See also electronic grant application)

Communication of results: Results will be presented at relevant national and international conferences, such as the Norwegian national psychology conference (2019-2022), Appearance Matters 9 and 10 (UK, 2020; 2022), European and International Cleft and Craniofacial Congress (Ütrecht, 2019; Edinburgh, 2021), in addition to other relevant international conferences.

Papers will be submitted to peer-reviewed international and national journals aimed at researchers and clinicians seeking evidence-based supportive care for young people affected by a different appearance. Potentially relevant journals could be *Psychology, Health & Medicine, Health Psychology Open, Journal of Health psychology, Body Image* or other similar peer-reviewed international journals.

The project will lead to at least five publications. This will be possible through collaborations with master or clinical psychology students, in collaboration with Faculty of Psychology (Bergen and Oslo), and international collaborations with partners from CAR (see CV for previous successful collaborations). Ongoing piloting of local versions of YP Face IT in Australia, the US, and the Netherlands is also expected to lead to potential international publications. Planned international publications are:

 The efficacy of an online intervention for adolescents with appearance-related distress in Norway (Ung Face IT): A randomised control trial

- The efficacy of an online intervention programme: An investigation of background factors facilitating or reducing the impact of Ung Face IT
- Adolescents' and parents' experiences of the need for a self-management tool for appearancerelated distress: A qualitative study
- An evaluation of the administration of Ung Face IT through specialised and local health care providers: Experiences of health professionals and future recommendations
- International experiences with YP Face IT: Combining data across countries (UK, Norway, Netherlands, potentially also USA and Australia)
- To talk or not to talk about appearance-related distress: Qualitatively investigated cultural differences when living with appearance-altering conditions

Dissemination and implementation of Ung Face IT: Collaboration with communication advisors at Centre for Rare Disorder will ensure that information about the project and results will be disseminated via popular media and social media. Based on evidence for the beneficial effect of the intervention, as all preliminary findings from the UK suggest, findings will be disseminated and Ung Face IT implemented into local and specialised health care services across the country. Funding is sought at the end of the project period for 9 months (Year 4), in order to implement Ung Face IT in local systems, general health care services within the country's four health care regions, and within specialised health care services. In order to reach local clinicians in touch with young people with potential appearance-related distress, findings will be disseminated via primary care journals, GP practices, and patient organisations, in addition to social media and other web-based information channels.

Communication with users (See also mandatory attachment in electronic grant application)

The development of YP Face IT in the UK actively involved several young people with a range of conditions that affect appearance, and their views have guided the decision to develop the online intervention programme, involving the young people also when designing the intervention itself. As mentioned, many Norwegian patient organisations have already given their support to the testing Ung Face IT. During the pilot study, nine Norwegian patient organisations represented the following medical conditions: Cleft lip and palate, craniofacial conditions, ectodermal dysplasia, ichthyosis, epidermolysis bullosa, dysmelia, neurofibromatosis, albinism, and psoriasis). All patient organisations will be represented in the project's Steering Committee, in order to involve users in the evaluations of findings, project experiences, and discussions regarding the future need for implementation, and facilitating communication with users.

The study will qualitatively investigate young people's views on the Norwegian version of the programme and whether changes should be made. Participants' perception will be sought for Ung Face IT's content, design, outcome measures, and experienced helpfulness. Parents will be interviewed about the recruitment process, level of support needed during the completion of the intervention, their experience of being in the control group, and their thoughts regarding the outcome measures (content and time taken to complete). Health care providers from centralised as well as primary care settings, in addition to Youth Councils at Oslo and Haukeland University Hospital, will be involved in discussions and decisions about support needs and the implementation of Ung Face IT.

References

- Appearance Research Collaboration (2009). Identifying factors and processes contributing to successful adjustment to disfiguring conditions. Final report, Centre for Appearance Research, University of the West of England, Bristol, UK.
- Bessell A, Brough V, Clarke A, Harcourt D, Moss T, Rumsey N. (2012). Evaluation of the effectiveness of Face IT, a computer-based psychosocial intervention for disfigurement-related distress. *Psychology, Health and Medicine*, 5:565–577.
- Bessell A, Moss TP. (2007). Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: A systematic review of the empirical literature. *Body Image*, 4:227-38.
- Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77–101.

Cash, T.F., & Pruzinsky, T. (2002). Future challenges for body image theory, research, and clinical, practice. In T.F. Cash & T. Pruzinsky (Eds.), *Body images: A handbook of theory, research, and clinical practice* (p. 509-516). NY: Guilford Press.

Clarke A, Thompson AR, Jenkinson E, Rumsey N, Newell R. (2013). CBT for appearance anxiety: Psychosocial interventions for anxiety due to visible difference. ISBN: 978-1-118-52343-8. Wiley-Blackwell.

Cunningham JA, Kypri K, McCambridge J (2013). Exploratory randomized controlled trial evaluating the impact of a waiting list control design. *BMC Medical Research Methodology*, 13: 150.

Feragen KJB. (2012). Experiences of people living with visible differences: Congenital conditions. In: Rumsey N, Harcourt D (Eds). Oxford Handbook of Psychology of Appearance (p. 353–371). Oxford, UK: Oxford University Press.

Feragen (2017). Sluttrapport Ung Face IT [Report of feasibility and acceptability study for Ung Face IT]. NKSD.

Feragen, KB, Stock, NM. (2017). Psychological adjustment to craniofacial conditions: A review of the literature. *Psychology and Health*, 32, 253-288.

- Feragen KB, Stock NM. (2016). A longitudinal study of 340 young people with or without a visible difference: The impact of teasing on self-perceptions of appearance and depressive symptoms. *Body Image*, 16:133-42.
- Frisén A, Lunde C, & Berg AI. (2015). Developmental patterns in body esteem from late childhood to young adulthood: A growth curve analysis. *European Journal of Developmental Psychology*, 12: 99-115.

Grogan S. (2007). Body Image: Understanding body dissatisfaction in men, women and children. Taylor & Francis.

Kanayama G, James SB, Harrison H, Pope G. (2006). Body image and attitudes towards male roles in anabolic-androgenic steroid users. *The American Journal of Psychiatry*, 163:697-703.

- Hunt O, Burden D, Hepper P, Johnston C. (2005). The psychosocial effects of cleft lip and palate: A systematic review. *European Journal of Orthodontics*. 27:274–285.
- Jenkinson E. (2012). Therapeutic interventions: Evidence of effectiveness. In Rumsey, N. & Harcourt, D. (Eds). *The Oxford Handbook* of the Psychology of Apearance. (p. 679-692). London: Oxford University Press.

Jenkinson E, Williamson H, Byron-Daniel J and Moss TP (2015). A systematic review of psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury or treatment effects. *Journal of Pediatric Psychology*. 40:1017-1033

Levine MP, Smolak L. (2002). Body image development during adolescence. In TF Cash & T Pruzinsky (Eds), *Body image. A handbook of theory, research, and clinical practice* (p. 74-82). New York: Guilford Press.

Moss TP. (2005). The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment. *Body Image*, 2:151-159.

National Institute for Health and Clinical Excellence, NICE (2005). Final appraisal determination: Computerised cognitive behaviour therapy for depression and anxiety (review). *Clinical Psychology*, 74, 614-621.

- Nordgreen T, Gjestad R, Andersson G, Carlbring P, Havik OE (2018). The implementation of guided Internet-based cognitive behaviour therapy for panic disorder in a routine-care setting: effectiveness and implementation efforts. *Cognitive Behavioral Therapy*,47:62-75.
- Norman A, Moss T. (2015). Psychosocial interventions for adults with visible differences: A systematic review. Peer Journal, 3:e870.

Partridge J, & Julian D. (2008). The incidence and prevalence of disfigurement. London: Changing Faces.

Richardson et al. (2010) Computerised Cognitive Behavioural Therapy for the prevention and treatment of depression and anxiety in children and adolescents: A systematic review. *Clinical Child and Family Psychology Review*, 13, 275-290.

Rumsey N, Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image*, 1, 83-97.

Rumsey N, Harcourt D. (2007). Visible difference amongst children and adolescents: Issues and interventions. *Dev Neurorehabil*, 10:113-23.

Rumsey N, Harcourt, D. (2012). The psychology of appearance: The future. In Rumsey, N. & Harcourt, D (Eds). *The Oxford Handbook* of the Psychology of Apearance. (p. 679-692). London: Oxford University Press.

- Spence, S. H., Holmes, J. M., March, S., & Lipp, O. V. (2006). The feasibility and outcome of clinic plus internet delivery of cognitivebehaviour therapy for childhood anxiety. *Journal of Consulting Clinical psychology*, 74:614-21.
- Stock NM, Feragen KB. (2016). Psychological adjustment to cleft lip and/or palate: A narrative review of the literature. *Psychology and Health*, 15:1-37.
- Stice E.(2002). Risk and maintenance factors for eating pathology: A meta-analytic review. Psychological Bulletin, 128:825-48.

Stice E, Shaw H. (2003). Prospective relations of body image, eating, and affective disturbances to smoking onset in adolescent girls: How Virginia slims. Journal of Consulting and Clinical Psychology,71:129–135.

Williamson H, Griffiths C, Harcourt D. (2015). Developing young person's Face IT: Online psychological support for adolescents struggling with conditions or injuries affecting their appearance. *Health Psychology Open*, July-December: 1-12.

Williamson H, Rumsey N. (2016). The perspectives of health professionals on the psychosocial impact of an altered appearance among adolescents treated for cancer and how to improve appearance-related care. *Journal of Psychosocial Oncology*, 35:47-60.