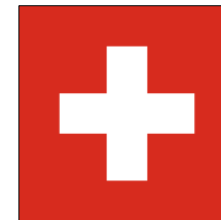


Supporting People with an Altered Appearance

The work of the
Clinical Interventions Task Group

Members of the Task Group

- Kristin Billaud-Feragen
- Luis Joaquin Garcia-Lopez
- Claire Hamlet
- Diana Harcourt
- Ornella Masnari
- Jose Mendes
- Francesca Nobile
- Jolanda Okkersse
- Anna Pittermann
- Saskia Spillekom-vanKoulik
- Nicola Stock
- Heidi Williamson





A challenge at the outset

A group that works in:

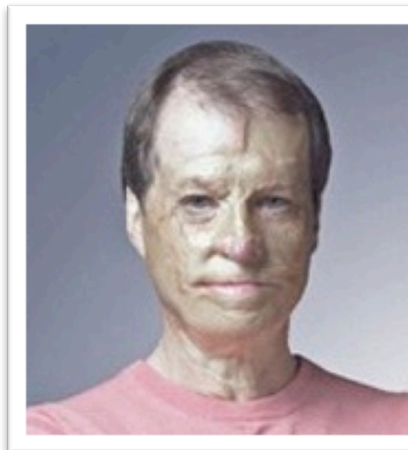
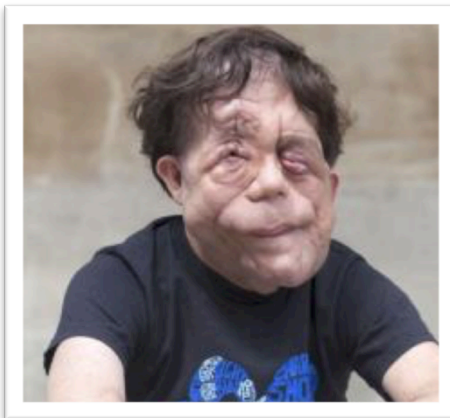
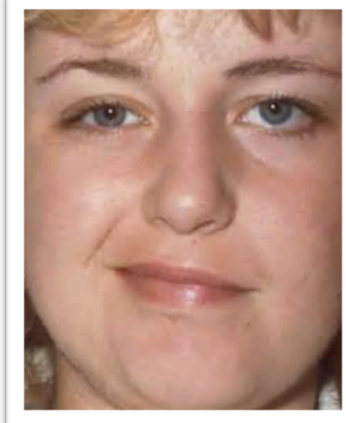
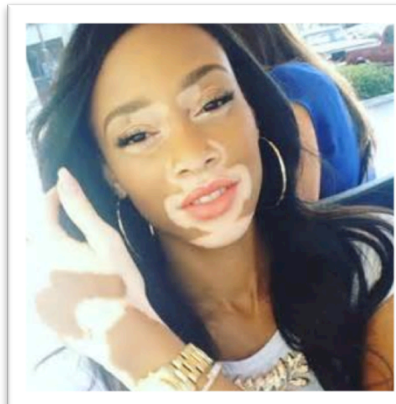
- different languages
 - different conditions
 - different systems of care
-
- What do we have in common?

A challenge at the outset

A group that works in:

- different languages
 - different conditions
 - different systems of care
-
- What do we have in common?
 - Wanting to improve care in some way

Visible difference/altered appearance (disfigurement)



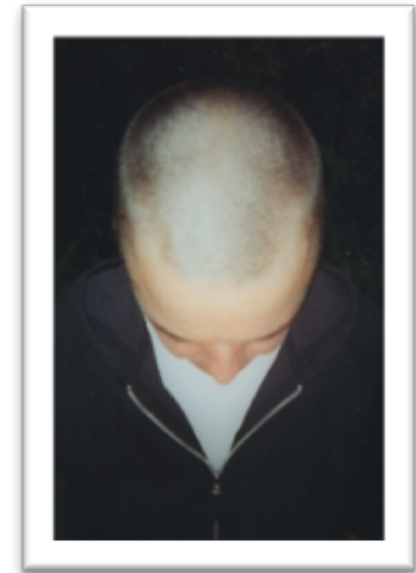
Common challenges:

- reactions of other people
- ‘loss of social anonymity’
- discrimination by society, work, school, family
- physical impact: scarring, contracture
- treatments



Possible psychosocial impact:

- depression
- anxiety
- anger/aggression
- shame
- social avoidance
- pre-occupation with appearance
- avoiding intimacy
- impact on academic achievement & career aspirations



Interventions & support

- specialist support can be difficult to access
- CBT & Social Skills Training dominate
- limited evaluation

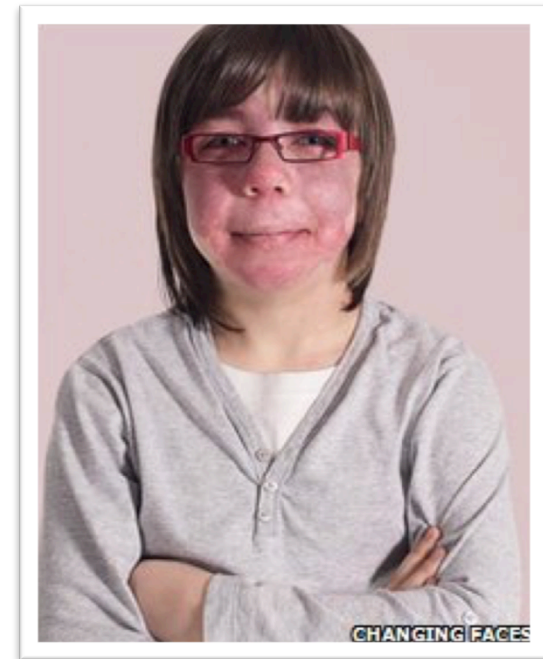
*(Jenkinson et al, 2015; Bessell & Moss, 2007;
Norman & Moss, 2005; Muftin & Thompson, 2013)*

- “A pressing need to develop & evaluate interventions to improve outcomes”

(Attoe & Pounds-Cornish, 2015)

Our aims

- To use **research & 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
- to explore the **transferability** & **feasibility** of existing psychosocial **interventions** into **new European settings**
- to conduct a literature **review** of **pre-surgical screening** for appearance-altering procedure
- to **collate resources** for clinicians in this field
- to support **networking** to facilitate longer-term collaborations.

Question: What do we know already
about the provision of psychosocial
support in Europe?

Question: What do we know already
about the provision of psychosocial
support in Europe?

Answer: Very little

Q: What do **psychosocial specialists** working in this field offer patients & their families considered to need support?

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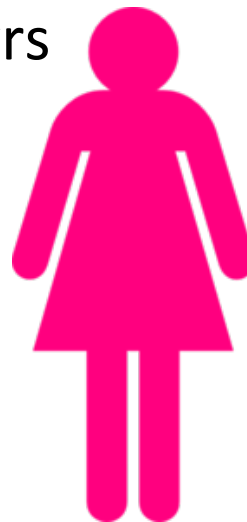
A: We don't know

The Provision of Specialist Psychosocial Support for People with Visible Differences: A European Survey

- Who is providing it, in what context, & how is it accessed?
- How are clients' needs identified?
- What interventions & approaches are used?

Respondents

- N = 116
- 15 countries
- Mean age = 42.5 yrs



102
(87.9%)

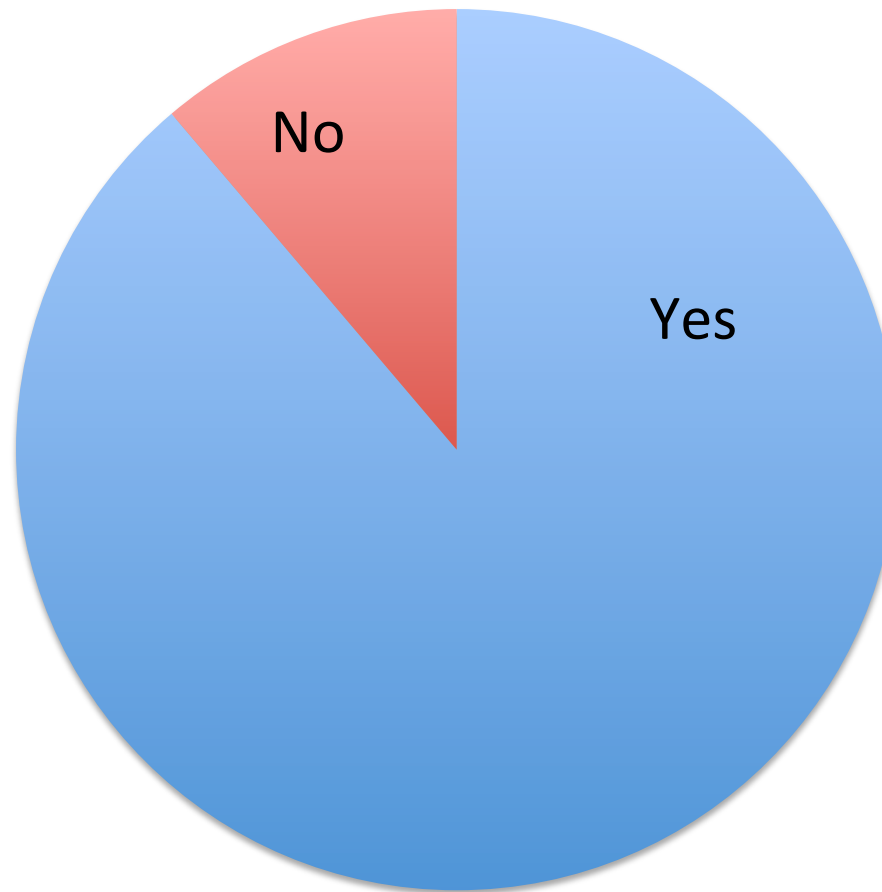


14
(12%)

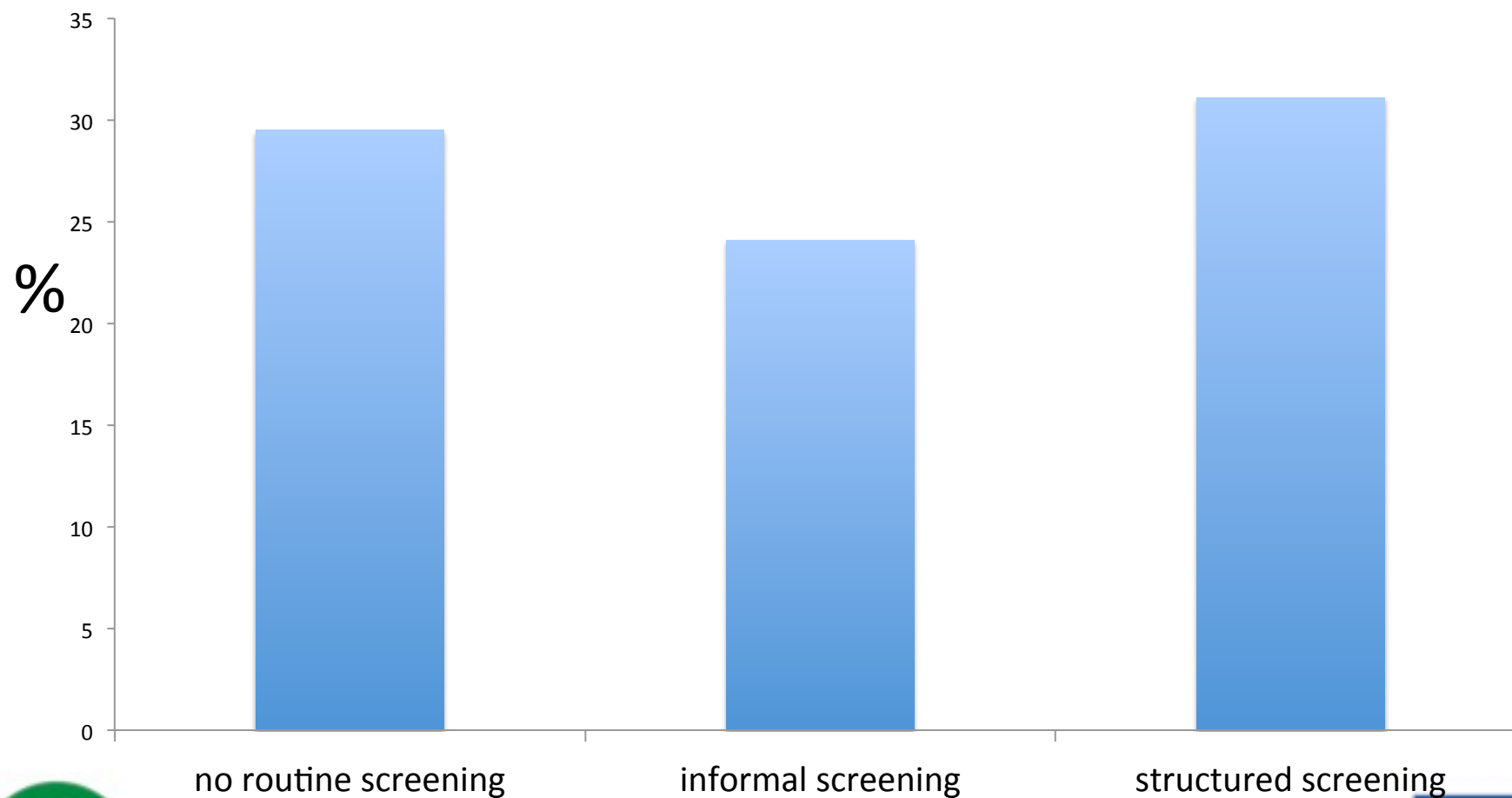
Work setting

- cleft lip/palate (31%)
 - cancer (27.6%)
 - burns (25%)
-
- hospital inpatient (65.5%)
 - outpatient (73.3%)

Multi-disciplinary team?



How are clients' needs identified?



Most common reasons for referral:

- low self-esteem/confidence (83.5%)
- body image/appearance concerns (81.7%)
- social anxiety/avoidance (76.2%)
- experiencing or worrying about teasing, bullying or staring (72.6%)
- depression/low mood (72.6%)

What interventions & approaches are used?

- Cognitive Behaviour Therapy (CBT; 60.3%)
- Psychoeducation (51.7%)
- Mindfulness (40.5%)

Mode of intervention delivery

- few (16.3%) used online or remote interventions
- the majority (78.6%) of these used telephone based counselling

How could support be improved in your country?

- increased awareness of psychosocial issues
- increased access to support
- more psychosocial specialists
- standardised psychological care



Limitations

- although responses from participants in 15 countries, most were from UK
- anecdotally, v few psychosocial specialists in some countries
- sample precludes analysis by condition or country



Looking ahead:

- opportunities to:
 - consider the use of a wider range of interventional approaches
 - explore possibility of wider use of online intervention





YP Face IT: A Norwegian feasibility and acceptability study

Kristin Billaud Feragen,
Clin.psychologist, PhD, Centre for Rare Disorders, Oslo University Hospital,
Norway.



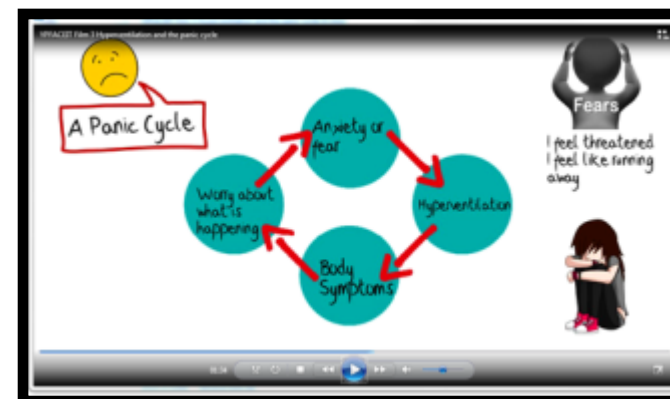
- 7 weekly sessions + booster
- Videos, quizzes, audio, forum
- Completed at home +/- parental support
- Supervision from HP

www.yppfaceit.co.uk



Social skills training





CBT



Who is YP Face IT for?



- 12-17 years
- Appearance-altering condition
- Related distress, teasing / bullying (self-report)



- Clinical depression
- Eating disorder
- PTSD
- Psychosis
- Learning disability

More Information

YP Face IT video



<https://www.youtube.com/watch?v=a3FWTYsHtQU>

Setting up the Norwegian study

- Contracts between UWE and the Centre for Rare Disorders
- Funding: Norwegian National Advisory Unit on Rare Disorders (NKSD)
- Ethical approval
- Translation to Norwegian

UNG FACE IT

Nettbasert støtte for ungdom som har fått utseendet påvirket av sykdom eller skader.

[Hjem](#) | [om oss](#) | [kapitler](#) | [forum](#) | [spørreskjemaer](#) | [teamet](#) | [foreldre](#) | [helsepersonell](#) | [kontakt](#) | [lenker](#)

[Admin Area](#)

Logg ut
Krifer

Kapittel 1

Vanlige
utfordringer

Kapittel 2

Bli sosialt
tryggere

Kapittel 3

Ikke vær redd,
involvér deg

Kapittel 4

Tenk, føl,
gjør det

Kapittel 5

Smarte
mål

Kapittel 6

Vekk med
angst

Kapittel 7

Din fremgang

Kapittel 8

UNG Face
IT-spørsmål

UNG Face IT skal være til hjelp. Vi vil gjerne høre fra deg.

Kontakt forskningsansvarlig og psykolog Kristin J Billaud Feragen på Senter for sjeldne diagnoser (Oslo Universitetssykehus) | Telefon: 23 07 53 40 | E-Post: krifer@ous-hf.no

Study outline



- Need for UNG Face IT in Norway?
- Qualitative and quantitative data
- Acceptability & feasibility of:
 - Therapeutic content and presentation
 - Questionnaires (social anxiety, body esteem, perceived stigmatisation, social skills)
 - Recruitment **via secondary care**
 - Study design (RCT)

Progress so far



- 240 YP registered with a **craniofacial** or a **skin** condition sent information
- **22 recruited**
- 13 patient organisations (33 contacted) disseminated information
- Ethical approval for recruitment from other specialised treatment units
- Interviews of the first wave of participants completed

Sub-study



- New development
- Requests for UNG Face IT for young adults with appearance-altering conditions associated with developmental delay.
- Additional support from parents / health care providers
- Well-received: 2 recruits so far

Personal reflection



- First translation of YP Face IT: full template now available
- Administrative challenges (contracts, ethics, data protection ...)
- Recruitment and project management is time consuming: funding essential



Personal reflection



- Meaningful and needed
- Study design successful
- Motivated parents, YP less so!
- Overcoming cultural norms: is talking about appearance concerns less acceptable in Norway?



Next steps:

UNG
FACE IT

- **Funding**
- **Effectiveness** – does UNG Face IT work?
- **Recruitment:**
 - Other Rare Disorders Centres / patient organisations / treatment teams at Oslo University Hospital
 - Local health professionals (General Practitioners, school psychologists & nurses etc)
- **Implementation:**
 - Local and specialised health services





For more information contact:

[Kristin: krifer@ous-hf.no](mailto:krifer@ous-hf.no) or Heidi3.williamson@uwe.ac.uk

Further activity & collaborations within the group:

- grant application for YP Face IT in the Netherlands
- literature review of surgical decision making for children & young people in progress
- use of mirrors
- feasibility of the PEGASUS intervention to support shared decision making in craniofacial conditions

A surgeon's view

Luca Siliprandi

Plastic Aesthetic & Reconstructive Surgeon, Clinica Cittagiardino
Medical Director

Francesca Nobile, Clinical psychologist & Psychotherapist



Thank you

