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Recommendations for Supporting the Psychological Well-being of Children and Adults with **Facial Palsy**

Facial Palsy UK – Consensus Document

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Background to Consensus Document

This consensus document has been produced by an international group of Clinical Psychologists (M.H., R.M., R.R. & I.S), a Psychological Therapist (E.J.), a Counselling Psychologist (L.D.), a Child and Adolescent Psychiatrist (W.B.), Researchers (K.B., C.H.) and the Deputy CEO of Facial Palsy UK (K.J.), all of whom work with people with facial palsy (FP) and some of whom have FP themselves. This document aims to outline recommendations for the psychosocial support for this population.

The authors have drawn from evidence-based approaches for the support of people with FP, and similar conditions, to present recommendations for how mental health professionals (hereafter psychologists/ psychological therapists) can best work alongside physical health practitioners (e.g. surgeons, neurologists, facial therapists) to assess and meet the psychological needs of people with FP.

This guidance starts with an introduction to what is known about the psychological impact of FP, along with recommendations for the support of adults with FP. There is then a discussion of additional considerations for working with children, adolescents and their families. The document ends with an outline of the various ways in which psychologists/psychological therapists can support their multidisciplinary team (MDT) colleagues to understand the psychosocial impact of the condition.

Psychological support for people with FP should optimally be carried out by a professional who has specialist knowledge of the psychological impact of physical health conditions, preferably working within a multidisciplinary FP service. However, access to such services is variable in the United Kingdom (UK) and we hope that the information contained in this document will also be helpful for those mental health professionals working within general physical and mental health services who do not have experience of working with people with FP.

Although this document is written primarily for clinicians working within the UK, it has been developed by a group including UK-based and international clinicians and researchers, and as such we hope it to also be of use to a wider, international audience.

The authors welcome feedback and comments on this document and encourage interested parties to be in touch to collaborate, ahead of any future revisions of this guidance.

What is Facial Palsy?

Facial palsy is the name given to weakness of the facial muscles, typically following disrupted function of the facial nerve, which is of fundamental importance to the muscles responsible for mastication, speech, expression of emotions and the protection of the eye. More than 50 different aetiologies, among them trauma, infection, autoimmune issues, neoplasia, cerebrovascular events, and surgery (e.g. acoustic neuroma resection) have been identified as resulting in FP (Butler et al., 2019; Kim & Lee, 2020). However, in the majority of cases the exact cause of FP remains unknown (so-called idiopathic/Bell's palsy; Hohman & Hadlock, 2014).

Classification of Facial Palsy

Different classifications are used to describe FP. All of them are potentially relevant for an individual's psychological adjustment to FP. For example, the psychological adjustment process can be different between individuals with acquired and congenital FP (Bogart, 2020).

- **Congenital vs. acquired,** with most cases of FP being acquired, for example Bell's palsy. Congenital causes include genetic disorders such as hereditary myopathies and hereditary congenital FP (Verzijl et al., 2005), and may include syndromic conditions like Moebius syndrome and CHARGE syndrome, and traumatic causes like forceps delivery.

- **Isolated (e.g. Bell's palsy) vs. combined with other symptoms** (e.g. Multiple Sclerosis or Goldenhar syndrome).

- **Acute FP vs. longstanding FP.** Typically, 12 months is considered the point when an individual would transfer into the longstanding FP group. At that time facial muscles are normally less receptive to re-innervation (Butler et al., 2019).

- **Central** (resulting from damage to the facial nucleus in the pons, the motor cortex, or connections between the two – so-called upper motor neuron lesion) **vs. peripheral** (resulting from lesions of extra-temporal segments of the facial nerve – so-called lower motor neuron lesion). Central FP, for example due to a stroke, typically manifests as unilateral movement impairment opposite to the side of the lesion, predominantly affecting the lower face (Volk et al., 2019). In contrast, peripheral FP, e.g. Bell's palsy, presents as a functional loss at the same side of the lesion, usually with complete palsy (i.e. paralysis).

- **Incomplete vs. complete.** There are different methods for differentiating the severity of FP, including the Sunnybrook Facial Grading Scale (Ross, Fradet, & Nedzelski, 1996) and the House–Brackman grading system (Reitzen et al., 2009).

- **Uni- vs. bilateral,** with most cases occurring unilaterally (Kim & Lee, 2020).

Psychosocial Impact of Facial Palsy

An estimated 100,000 people in the United Kingdom are affected by FP (Facial Palsy UK, 2012). Adults with FP often report experiencing higher levels of anxiety and depression than the general population, as well as high levels of appearance-related distress, poor social well-being and low health-related quality of life (see Hotton et al., 2020a for a review).

Due to a paucity of research, there is less evidence for the psychosocial impact of FP in childhood. However, several studies have shown that children and adolescents with Moebius syndrome experience greater social difficulties than those without the condition (see Hotton et al., 2020b for a review).

Working with Adults

Psychological Assessment

Given the significant psychological difficulties experienced by many with FP (Hotton et al., 2020a), it is important that processes are in place to screen all new people presenting to health services with FP, to identify those experiencing high levels of psychological distress. Furthermore, given that the objective severity of FP often fails to predict psychosocial adjustment (e.g. Díaz-Aristizabal et al., 2019), this should occur regardless of condition severity. Finally, it is important to consider that people seeking psychological therapy may have had a negative experience of their concerns being dismissed by other health professionals without specialist knowledge of FP (Facial Palsy UK, 2019). It is therefore important that the psychologist/psychological therapist validates the individual's experience and helps them to feel listened to and supported.

People with FP identified as experiencing high levels of psychological distress should be offered a comprehensive psychological assessment, including a focus on the following:

- Appearance-related concerns
- Anxiety (with regard to prognosis and social situations)
- Low mood and any associated risk
- Difficulties adjusting to impaired facial function, including pain
- Sleep difficulties
- Social well-being, including relationships and coping with comments, questions and staring.

Clinical interview should be complimented by the use of patient-reported outcome measures (PROMS). The International Consortium for Health Outcomes Measurement (ICHOM) has produced a standardised set of outcome measures for use with the paediatric FP population (Butler et al., 2019). In areas where pre-existing standards for the use of PROMS do not yet exist, for example in the adult FP population, there are several important variables to consider prior to selecting PROMS, including: number of items; the availability of parallel proxy report; age range; administration method(s); the availability of CAT (computer assisted technology); published cohort data; reference populations and the availability of normative data. The newly developed FACE-Q | Facial Paralysis Module (Klassen et al., in press) contains a series of scales related to appearance, facial function, health-related quality of life and adverse effects, and may prove to be a useful tool for specialist FP MDTs. Potential PROMS for use with adults are summarised in Appendix A.

   Appearance-related concerns. Many people with FP experience anxiety about their facial appearance (Norris et al., 2019; Pattinson, Poole, Shorthouse, Sadiq, & Bundy, 2021), with research indicating that females and younger adults with FP may experience greatest levels of appearance-related distress (Cross, Sheard, Garrud, Nikopoloulos, & O'Donoghue, 2000). Assessment should explore individuals' self-perception of facial appearance and how this impacts on overall body image and self-esteem, as well as family and cultural narratives with regard to appearance.

Measures of facial appearance-related distress, such as those found in the FACE-Q | Facial Paralysis Module (Klassen et al., in press) can be used to assess anxiety and social avoidance in relation to appearance.

Appearance-related concerns can lead to social anxiety, typically resulting in social withdrawal, avoidance and isolation (Norris et al., 2019; Pattinson et al., 2021). A survey conducted by Facial Palsy UK (2019) highlighted that out of 319 respondents with acquired FP, 71.5 per cent reported that they liked being in photos before having FP, compared with 6.3 per cent following the onset of FP. This highlights the significant levels of avoidance that people with FP may experience in relation to photographs. Given the important social context of photographs, for example while attending events such as weddings, assessment should include detailed exploration of avoidance, the cognitions underpinning this behaviour and the extent to which these cognitions are supported by evidence from negative past encounters. Finally, the Covid-19 pandemic has led to an increase in use of video messaging for social and work-related purposes. Assessment should explore the individual's thoughts and feelings with regards to video messaging, along with any associated avoidance.

For those with acquired FP, a detailed history should explore the value placed on appearance by the individual prior to the onset of FP, as well as the person's tendency to draw social comparisons, fear negative evaluation and/or seek reassurance from others, as these factors are likely to influence their adjustment to a change in appearance.

Anxiety. Given the high prevalence of anxiety and depression in people with FP (Hotton et al., 2020a), psychologists/psychological therapists should carry out a detailed assessment of current and historic symptoms using a combination of clinical interview and relevant screening tools, such as the GAD-7 (Spitzer, Kroenke, Williams, & Löwe, 2006).

People with FP often report anxiety with regard to their prognosis (Hamlet at al.,2021) and assessment should elicit their understanding of, and adjustment to, their expected prognosis. Fears of recurrences and experience of healthcare should also be assessed as these factors may impact on their engagement with relevant treatment within healthcare services. Indeed, people with FP have reported having to 'fight' for access to treatment (Pattinson et al., 2021).

Depression. People with FP have been shown to experience significantly higher levels of depression than those without the condition (Pouwels, Beurskens, Kleiss, & Ingels, 2016; Nellis et al., 2017). Difficulties smiling, or excessive or reduced eye closure may affect a person's ability to provide important social cues or affect the emotional states of others, which in turn can result in fewer positive social interactions and lower mood (Bogart, Briegel & Cole, 2014).

Depression may also be a direct consequence of impaired facial expression of emotion on mood (Nellis, Ishii, Boahene, & Byrne, 2018), with reduced ability to express positive emotions being believed to lead to a reduction in the experience of positive emotions (e.g. Lewis, 2012). Furthermore, anxiety related to social situations can result in social isolation and lower mood. Measures such as the PHQ-9 (Kroenke, Spitzer, & Williams, 2001) can be used to assess mood.

Assessment should also include comprehensive exploration of current or past risk (e.g. thoughts about self-harm or suicide) and those individuals identified as experiencing high levels of current risk should be referred to mental health services for relevant support, and their General Practitioner (GP) should be informed of any risk issues.

Facial function. Some studies have found associations between perceived facial function, particularly difficulties with smiling, and psychological distress (e.g. VanSwearingen, Cohn, & Bajaj-Luthra, 1999; Díaz-Aristizabal et al., 2019).

Clinical interviews should explore experiences of factors such as pain, discomfort and synkinesis, as well as difficulties with eating, drinking and speech. The Facial Clinimetric Evaluation Scale (FaCE; Kahn et al., 2001) or Facial Disability Inventory (FDI; VanSwearingen, & Brach, 1996) both provide a measure of perceived facial function; however neither measure explores the experience of symptoms such as visual disturbance or synkinesis and are best administered and interpreted alongside other members of the FP MDT, such as surgeons and facial therapists. The FACE-Q | Facial Paralysis Module is a more recent tool which can also be used to assess self-reported facial function, including with regards to eye function.

Sleep. Risk of sleep problems is increased for individuals with FP (Pattinson et al., 2021), especially among those with Moebius syndrome (Parkes, 1999). Sleep problems may be a secondary effect of FP due to structures and functions impacted by the palsy itself, such as lack of eye closure or nasal airway problems or may be a manifestation of the psychological stressors associated with FP, including depression or anxiety. Some individuals with FP following a viral infection, such as those with Ramsay Hunt syndrome, may also experience post-viral fatigue over an extended time period. There are a variety of measures available to identify and monitor sleep difficulties, as outlined in Appendix A.

Social well-being. The difficulties described so far can all lead to a reduction in social well-being. Furthermore, people with FP often report experiences of receiving unwanted comments, questions and staring (Norris et al., 2019; Pattinson et al., 2021).

Social functioning can be assessed using the FaCE, FDI, or FACE-Q | Facial Paralysis Module, all of which include scales of social function and were developed for the FP population. More generic measures, such as the SF-36 – Short Form 36 Health Survey Questionnaire (Ware Jr & Sherbourne, 1992), allow for comparison with the general population and may be helpful for research purposes.

Careful consideration should be given to the impact of FP on an individual's close relationships. Some people with FP report difficulties with online dating and concerns about having their photographs on dating apps, and social media more widely. People with FP may experience difficulties with kissing and other intimate acts, highlighting the benefit of psychological assessment taking into account the impact of FP on romantic relationships. Furthermore, partners may find themselves taking on a new role as carer within the relationship, which may change the dynamics within a partnership or affect the development of new ones. Assessment should also identify the impact of FP in the workplace, including workplace discrimination. Further information and advice for employers and employees can be found at www.facialpalsy.org.uk/support/work.

Relevant history. Finally, assessment should involve comprehensive discussion about previous significant life events or traumas, as well as an exploration of resilience and protective factors. In particular, the onset of Bell's palsy during pregnancy is associated with additional challenges for both the individual and their family (Hussain, Nduka, Moth, & Malhotra, 2017) and psychologists/psychological therapists may wish to liaise with other professionals involved, such as midwives, GPs and health visitors.

Psychological Interventions

Many psychological interventions are effective in reducing psychological distress and promoting resilience in individuals with physical health conditions. However, there is a paucity of research focusing on the effectiveness of psychological interventions for people with FP. Where evidence is not available for the FP population, recommendations have been made based on clinical experience and evidence in similar populations. The following recommendations are not to be viewed as an exhaustive list of interventions, but rather a summary of potential options available to the psychologist/psychological therapist.

Psychoeducation. Psychoeducation is an evidence-based therapeutic intervention for people with FP and their families which provides information, education, resources and support in an empathetic and supportive manner (Rahmani, 2016). This may help people with FP to collect and to comprehend all the information that is necessary to make treatment-related decisions, as well as understand the emotional and social implications of these decisions.

It can be helpful to educate people with FP about the important role that the face plays in communication and, for those with acquired FP, to normalise the psychological impact of a change in facial function. It is also important to explain the responses of others (e.g. staring or asking curious questions) and to provide coping strategies such as explaining, reassuring or distracting with positive self-talk. The goal of psychoeducation is not to completely alleviate the distress caused by FP, but rather to give the person a better road map towards functioning in an optimal way.

Social Skills Training. Evidence shows that effective social skills can reduce others' bias toward people with FP (Blakeney et al., 2005; Bogart, Tickle-Degnen, & Ambady, 2014; Rumsey, Bull, & Gahagan, 1986). Although evidence comes from children and young people, a pilot social skills intervention, 'Getting Social with Facial Paralysis', was conducted with teenagers with Moebius syndrome and included group-based discussion and activities on social challenges and resilience, alternative expression, eye contact, and disclosure decisions (Michael et al., 2015). Subsequent increases were observed in expressive behaviour, interaction partners' expressive behaviour, and observer-rated rapport.

Although the face is a major communication channel, people with FP can be encouraged to increase their use of alternative expression (i.e. posture, gesture, prosody, laughter, and language). Indeed, people with congenital FP have been found to use more alternative expression than those with acquired FP, perhaps because of greater opportunity for adaptation (Bogart, Tickle-Degnen, & Ambady, 2012), which can lead to more positive responses from strangers in social interactions (Bogart et al., 2014). In addition, some people with FP are self-conscious of the way they speak, and as a result, may speak quietly or quickly (Michael et al., 2015). These individuals may benefit from increasing their confidence, patience and persistence around being understood. For example, they could adopt strategies such as repeating themselves, or writing down their message. Similarly, some may avoid eye contact due to self-consciousness about their appearance; this can be practised.

Research has found that some people with FP may be uncertain about when and if they should disclose and educate about FP (Hamlet at al.,2021). There is little public awareness of FP, and people with FP are often aware that others may notice their condition – creating preoccupation in both parties (Bogart & Tickle-Degnen, 2015). A person with FP may opt to explain their condition to others who may play an important role in their life, such as a friend, romantic partner, or employer. Discussing FP can be

stressful, and practising a few short explanations with a psychologist/psychological therapist can be helpful.

Cognitive Behavioural Therapy (CBT). CBT is widely used with people experiencing distress due to a visible difference (Clarke et al., 2013; Harcourt et al., 2018). CBT supports the individual to understand the link between their thoughts, feelings and behaviours, and to identify the ways in which unhelpful thoughts and behaviours can have a negative impact on their emotional well-being. CBT has a strong evidence base for the effective management of chronic health conditions, such as those resulting in pain or a reduction in physical function (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012).

CBT for appearance-related distress typically focuses on reducing behavioural avoidance, such as avoidance of social situations, along with teaching anxiety management techniques. A further aim of CBT is to support the person to challenge their negative thoughts about themselves, FP and associated symptoms, with the view to them becoming better able to generate alternative, more helpful ways of thinking about their condition. The book 'CBT for Appearance Anxiety' by Clarke et al. (2013) provides a useful introduction to this approach.

Third-wave cognitive therapies

Mindfulness and compassion-focused approaches. Mindfulness has been defined as *"paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally."* (Kabat-Zinn, 1994, p.15). It is cultivated through practising periods of 'focused attention', or meditations; using the body, breath, sounds and sensations of the present moment as an 'anchor'.

Although there is a lack of research into the effectiveness of Mindfulness training for people with FP, a meta-analytic review by Hofmann et al. (2010) of studies in which participants with a range of psychological and/or physical health difficulties received Mindfulness-based Therapies, such as Mindfulness-based Stress Reduction and Mindfulness-based Cognitive Therapy, demonstrated a reduction in negative psychological states, such as stress, anxiety, and depression.

Cultivating Mindfulness can nurture the ability to disengage from negative ruminations and loosen the grip of negative self-judgement, giving respite from the self-criticism so commonly experienced by people who have FP. However, it is important to note that studies with individuals with a visible difference have shown that higher rates of 'observing or mindful noticing', one of the five key facets of Mindfulness (Baer et al., 2006), is related to greater impairment in quality of life (Montgomery et al., 2016) and a higher level of appearance anxiety (Shepherd et al., 2019), suggesting that increased focus on internal and external sensations may be unhelpful for those with FP.

Therefore, based on this finding, it may be helpful to focus more on increasing awareness, acceptance and self-compassion, rather than focusing on 'observing', for those with FP, which may, unhelpfully, result in an increase in focus on the facial difference.

There is evidence that short-term self-compassion exercises may lead to improved emotional regulation and activation of the parasympathetic response (Kirschner et al., 2019), which may have an important positive impact in reducing the basal tone of the muscles of the face and neck. This may be valuable in preparing the way for daily massage and stretching exercises to be more effective. Indeed, Robinson and Baiungo (2018) recommended the use of Mindfulness to help relieve facial tension, as part of a neuromuscular retraining programme.

Acceptance and Commitment Therapy (ACT). ACT is a therapeutic approach which incorporates Mindfulness principles and has a growing literature base in relation to appearance-

related distress and associated factors such as social anxiety, body image dissatisfaction and shame (Zucchelli, Donnelly, Williamson, & Hooper, 2018). In addition, ACT has an evidence base in managing pain (McCracken & Vowles, 2014) and it may be that this approach could also be useful in managing physical sensations associated with FP such as pain, numbness and tingling.

Key concepts within ACT which may be useful in supporting people experiencing FP may include developing mindful acceptance or being willing to experience discomfort such as frustration, shame and pain in a way which enables them to 'let go of the struggle' with these difficult thoughts, feelings and sensations and to be more present. As with Mindfulness-based approaches, self-compassion underlies ACT concepts. In acquired FP, such as Bell's palsy where stress may be attributed to the cause, or in situations when surgery has not had the desired outcome, this self-compassionate perspective can help acknowledge difficult thoughts and feelings and enable a person to accommodate these in order to carry out meaningful/valuable behaviour.

Using an ACT approach to explore what is important to a person may also support medical treatment. For example, there may be psychological barriers to maintaining a facial therapy exercise programme which are maintained by avoidance. An ACT approach may enable a person to identify what their motivation is for the exercises, as well as help them to accommodate some of the difficult feelings which they may be trying to escape by avoiding exercises.

Dialectical Behavioural Therapy. Individuals living with FP may be at risk of experiencing emotion regulation difficulties, for example, heightened feelings or expressions of anger, frustration or emotional numbness (Davies, Jenkinson, & Halewood, 2020). These difficulties may be a reaction to loss, illness and trauma and/or difficulties communicating via facial expression, hence leaving the individual feeling misunderstood and invalidated by others.

While to date there does not exist an evidence-based intervention for building emotion regulation skills in this population, Dialectical Behavioural Therapy (DBT; Linehan, 1993) is an evidence-based psychotherapeutic approach utilised in the general mental health population, which integrates theory and skills from CBT and ACT, to support individuals to develop a 'wise mind' (a state of mind which balances emotions against reason/rationality), in order to regulate emotions and to interact effectively with others and express oneself in an effective way. The DBT approach consists of four modules which aim to build these emotion regulation skills and these are: mindfulness skills, distress tolerance skills, emotion regulation skills and interpersonal skills. This group-based intervention was originally developed for adults who experience emotion regulation difficulties and has since been adapted to meet the needs of children who experience such difficulties.

It is recommended that psychologists/psychological therapists working within the area of FP consider how this approach could be adapted to build emotion regulation skills in adults and children with FP and subsequent research could be conducted to assess clinical effectiveness and build an evidence base for this population.

Metacognitive Therapy (MCT) is a therapeutic approach based on the self-regulatory executive function model proposed by Wells & Matthews (1996). According to this specific theory, psychosocial difficulties are primarily caused by the so-called cognitive attentional syndrome (CAS) which comprises persistent negative thinking (i.e. rumination and worry), threat monitoring, thought control strategies, avoidance and reassurance seeking (Wells, 2009). CAS is driven by dysfunctional positive and/or metacognitive beliefs, i.e. beliefs about cognition (e.g. positive: worry helps to stay

prepared; negative: uncontrollability and dangerousness of certain thoughts; Wells, 2009). Thus, MCT mainly focuses on changing how people think rather than what they are thinking about.

Although there is no evidence for the effectiveness of MCT in people with FP, MCT has been found to be efficacious in many psychological difficulties in the general population, especially anxiety disorders and major depression (Normann & Morina, 2018). People living with an acquired or congenital FP may be at risk of experiencing persistent negative thinking (e.g. "Why did all this happen to me? Why can't I just be normal?"), resulting in psychological distress, e.g. feelings of frustration, sadness and anxiety. Thus, they could benefit from specific MCT techniques, such as attention training, situational attention refocusing and detached mindfulness.

Therefore, it is recommended that psychologists/psychological therapists working within the area of facial palsy consider how MCT could be adapted to change unhelpful metacognitive beliefs and reduce CAS symptoms in subjects living with FP. Moreover, research is needed to assess clinical effectiveness and build an evidence base for this population.

Family/Systemic Therapy. Systemic approaches focus on the impact of FP on the person with FP and their family system (see Campbell, 2003, for a discussion about its application with those with physical health conditions). Changes to family roles, including family members transitioning to 'caring' roles, can be particularly challenging. It can therefore be helpful to work with the whole family to help develop perspective taking and build on relational resources to identify ways in which family members can support and nurture each other.

Concerns about appearance and difficulties kissing, as well as pain and/or fatigue, can impact negatively on romantic relationships. It can be beneficial to work with couples in order to identify resources and strategies for adjusting positively to this change in a relationship or for addressing issues as they come up in new relationships.

Peer Support. There is evidence for the value of peer support for adults with congenital FP, with repeated conference attendance at a biennial Moebius Syndrome Foundation conference associated with improved stigma, social comfort, companionship support, emotional support, informational support, and knowledge in adults with Moebius syndrome (Bogart & Hemmesch, 2016).

In Facial Palsy UK's 2019 survey of 421 adults with facial palsy in the UK, 162 had attended a Facial Palsy UK support group. When compared with a range of psychotherapies and peer support options engaged with, Facial Palsy UK Support Groups received the most positive feedback (91% overall). A further survey of 117 adults with facial palsy in June 2020 investigated views on more peer support options, finding face-to-face support (62.4%) and Facebook groups (59%) to be the most popular. Online support can prove difficult for patients who struggle with appearing on video, but 42.7% said they would access online support groups with video conferencing. A survey of 72 patients attending Facial Palsy UK support groups via Zoom in November and December 2020 found 98.6% would recommend this support to others. Patients reported reduced feelings of isolation, greater acceptance of their situation, increased motivation to continue facial therapy exercises, benefits of information sharing, and feeling more in control of their recovery.

Eye Movement Desensitisation and Reprocessing Therapy (EMDR). For some the experience of acquiring FP can be a traumatic experience. EMDR is an integrative treatment, which involves supporting an individual to address trauma (Shapiro & Maxfield, 2002). Psychological trauma occurs when the brain's threat system is overwhelmed, as can occur at the onset of FP, and subsequently in situations of stress and negative self-appraisal.

Although never formally evaluated for use with individuals with FP, EMDR is a phased therapeutic approach which has the potential to help individuals to address distress associated with the condition. Bilateral stimulation, (such as with eye movements, body tapping or alternating tones) facilitates the processing and allows the brain to re-store information adaptively. Accommodations should be made for the lack of lateral eye movement found in people with Moebius syndrome. Also, synkinesis affecting the muscles around the eye may be exacerbated by repeated eye movements, therefore effective alternatives (tapping or tones) should be considered. Typically, after treatment the details of trauma will lose their intensity, thereby reducing anxiety, distress and intrusive memories associated with a traumatic experience.

Pre-surgical Assessment, Supporting Decision-Making and Managing Expectations about Potential Surgical Treatment

Surgery for people with FP can aim for functional and/or aesthetic outcomes. For example, facial reanimation surgery may involve muscle, cartilage or nerve grafts in order to be able to produce improved facial movements as well as a more symmetrical appearance. It is important to note that for some people with FP the primary motivation for surgery can be appearance, which may differ from the aims of the surgical team (Bradbury, Simons & Sanders, 2006; Jenkinson & Wickwar, 2016).

In a social context where there is a growing importance of appearance, and popularity of cosmetic surgery (British Association of Aesthetic Plastic Surgeons, 2019) and where potential surgical options are available, it is important that people with FP are supported in making decisions about surgery and throughout the process of intervention. This is because those who have unrealistic expectations for aesthetic surgery can be left dissatisfied (Brunton et al., 2014), whilst those whose expectations are met demonstrate satisfaction, improved body image, and quality of life (Ching et al., 2003).

Having a psychologist/psychological therapist embedded within the team can help people with FP to feel that psychological support is a supportive and beneficial part of their care, rather than psychologists/psychological therapists being seen as 'gate-keepers' for surgery.

There is a lack of research on the surgical decision-making process with people with FP, and the following guidance has been developed by drawing on literature relating to cosmetic and reconstructive plastic surgeries (e.g. Clarke, Lester, Withey, & Butler, 2005; Clarke et al., 2013) and risk-reducing mastectomies (Donnelly et al., 2018), as well as the clinical experiences of the current authors working with those with FP.

Individuals making the decision about undergoing surgery may have a lot of information to make sense of and also have their own emotional reactions to the different options.

The role of psychologists/psychological therapists working with people considering surgical intervention for facial palsy may therefore include:

- Assessment in relation to the psychological suitability for surgery.
- Supporting the decision making process, managing expectations and promoting shared decision making.
- Supporting the individual and the MDT regarding psychological well-being/mental health factors which may have an influence on how the team manage the process of surgery.

Pre-surgical Assessment

Psychological assessments can be a way of promoting the best outcome for the person with FP, as well as informing the surgical process. Assessment should be carried out by a clinician with specialist knowledge of FP and associated procedures. Following assessment, the psychologist/psychological therapist is able to advise whether the individual is likely to be satisfied by surgery.

Clarke et al. (2005) have provided a framework for the psychological assessment of individuals attempting to access surgery, which helps to identify which individuals might have unrealistic expectations and therefore potentially benefit from psychological, rather than surgical, treatment. Clarke et al. (2005) outline five psychological indicators for surgery:

1. Appearance-related distress, above normal discontent, assessed by standardised measures.

2. Specific concern and worry about the noticeability of a defined feature, without the presence of any external motivators for change, current stressful life events or psychiatric difficulties.

3. Appearance concerns having a direct impact on behavioural function (e.g. change in sexual function, impact on employment).

4. Realistic expectations of the procedure and its outcome, and the patient is able to use specific terms to describe the procedure and associated risks.

5. The patient is an active participant in the decision-making and treatment process.

These guidelines suggest that as part of the assessment, there should be a screen for body dysmorphic disorder and also exploration of other mental health issues which may influence decision making or satisfaction with post-operative outcomes. Considering that difficulty making decisions is a core feature of depression (Leykin et al, 2011), people with FP (who may be at higher risk of depression) may benefit from greater support, as well as a longer 'cooling-off' period before proceeding with invasive surgery. Similarly, there is evidence which suggests that people who experience depression may be more likely to be dissatisfied with surgery for FP (Bradbury et al., 2006).

Offering assessment and support regarding decision making means there is an opportunity to identify areas where a person may need more information or further clarification. It also may be an opportunity to explore how proactive a person has been in relation to seeking out relevant information, attending appointments and also any relevant behaviour change, such as engaging in facial therapy exercises and lifestyle factors which can influence surgery, such as reducing smoking.

Decision-Making Process and Managing Expectations

The decision-making process for a person with FP can also be facilitated by a psychologist/psychological therapist by clarifying their aims and objectives for surgery, providing information about procedures, as well as providing people seeking surgery with the opportunity to work on any underlying psychological issues.

Many people may have had to wait a lengthy period of time before seeing a FP specialist. For some, this can mean they have built up expectations in the hope that surgical options may 'fix' symptoms. Pre-surgical assessment should ensure that individuals understand the physical outcomes of the proposed surgery and that they are clear and specific about these, rather than having a more generalised goal such as "to look more attractive".

Evidence highlights that some people with a visible difference report that they want to look as they did prior to the onset of their condition (Estcourt et al., 2008) and similar expectations may occur in people

who have had an onset of conditions such as acquired FP. People with congenital conditions may expect to look as they think they would look without the condition. Discussing realistic expectations, including clear physical outcomes and ensuring that people have awareness of scarring, is therefore very important.

Assessment should also explore the person's understanding of the procedure, risks and possible complications. It can be useful to explore how they anticipate they would cope in relation to potential risks and complications, as well as their feelings regarding scarring.

Individuals can feel that family, friends and the surgical team have an opinion or a vested interest in what decision they make and therefore the psychologist/psychological therapist can offer a non-judgemental space to explore the options and to weigh up the pros and cons specific to their individual context, and how the options may or may not align with their own values.

Promoting Post-Surgery Recovery and Support for the Surgical Process

Research shows that surgery for FP can be a stressful experience, regardless of satisfaction with the outcome (Bradbury et al., 2006). It is vital that people are adequately prepared and supported through the surgical process.

Prior to surgery, psychological therapy offers opportunities to build skills to promote resilience whilst undergoing surgery. This may be supporting the person to plan and problem-solve practical issues and also to develop a plan for coping whilst in hospital. It may also include psychoeducation about understandable responses to stressful situations and teaching people stress management skills.

Considerations for Working with Children and Adolescents

Psychological Assessment

Similar to the assessment process in adults with FP, clinical interviews for children and adolescents should be complemented by the use of well-evaluated parent/teacher-reported questionnaires as well as self-reported outcome measures. Additionally, standardised intelligence or developmental tests can be administered. Especially for younger children, observational schedules and instruments for the evaluation of parent-child interactions can be indicated.

Outcome Measures. The International Consortium for Health Outcomes Measurement (ICHOM) has published a recommended standard patient-centred outcome measure set for paediatric facial palsy (Butler et al., 2019), which covers domains such as function, appearance, and psychosocial outcomes. Of note to psychologists/psychological therapists, recommendations included the PROMIS Global Health-Paediatric and PROMIS Peer Relationships. PROMIS Global Health has two items relating to mental health, which could be used as a general screening tool. Peer Relationships is an 8-item scale assessing peer acceptance and social support. PROMIS scales are scored using published T scores and are normed to the United States population such that a score of 50 represents the population norm. Although the ICHOM measurements are ideal for efficient general assessment, professionals working with children with FP should engage in more thorough screening for anxiety, depression, social anxiety, and body image concerns. A list of potential measures can be found in Appendix B.

Relevant history. In addition to the proposals for adults with FP (see above), family and school environment are of particular interest. Furthermore, referral for special genetic assessment and counselling should be considered for those individuals with congenital FP. It is also important to check

the child's understanding of their diagnosis. In the context of a degenerative condition associated with FP (e.g. facioscapulohumeral muscular dystrophy), it is important to identify what the child understands about their diagnosis and prognosis, and whether the family needs support to explain this to the child.

Assessment can also help identify whether the child has additional learning or developmental needs which need to be taken into account, and whether the child is currently undergoing other active medical treatment (e.g. radiotherapy for cancer/ tumour), as well as understanding whether discussing their facial difference is a priority for the child at the time of assessment.

Psychological Interventions

Many psychological interventions are effective in reducing psychological distress and promoting resilience in children and adolescents with physical health conditions. However, effectiveness studies on the prevention and treatment of psychological stress and psychiatric disorders in young people with FP are almost completely missing. Where evidence is not available for the FP population, recommendations have been made based on clinical experience and evidence in similar populations. The following recommendations are not to be viewed as an exhaustive list of interventions, but rather a summary of potential options available to the psychologist/psychological therapist.

Psychoeducation. Psychoeducation as described in the adults section is an important therapeutic intervention for older children and adolescents as well as their caregivers and families. It is important that any information provided takes into account age, emotional and cognitive development. Parents of children with congenital FP with a genetic or syndromic background can often feel guilt or responsibility for their child's disabilities. In such instances, psychoeducation with parents should be carried out in a sensitive way. If parents have concerns about the hereditary aspects of their child's condition, a referral to a clinical geneticist may be indicated.

Social Skills Training. There is some evidence that social skills training might be effective in children and adolescents with FP. An exploratory study with a pilot social skills intervention, 'Getting Social with Facial Paralysis', was conducted with teenagers with Moebius syndrome and included group-based discussion and activities on social challenges and resilience, alternative expression, eye contact, and disclosure decisions (Michael et al., 2015). Subsequent increases were observed in expressive behaviour, interaction partners' expressive behaviour, and observer-rated rapport. Similarly, Hotton et al. (2019) designed a single-session workshop for children with FP and their parents. This focused on developing children's skills in talking about their FP with others, as well as increasing their parents' confidence in supporting their child with concerns related to facial difference.

Parent-Child Relationship Interventions. The parent-child relationship is a complex, dynamic and unique dyadic system which is developed and changed through daily reciprocal interactions in different domains (e.g. Briegel, Greuel, Stroth, & Heinrichs, 2019). There is a strong body of research findings which suggest that the parent-child relationship plays a central role in children's physical, social, emotional and cognitive development in childhood and beyond (Fonagy et al., 2004; Bornstein & Cheah, 2006), and that this is facilitated through parent-child face-to-face interaction (Beebe, 2010; Beebe & Lachmann, 2013).

These interactions can be significantly complicated due to FP, especially for children with congenital bilateral FP which can result in a so-called mask-like facies. In the absence of any facial clues parents may feel uncertain about the emotional state of their young child. Moreover, parent-child interaction can be less rewarding for parents as the child is not able to smile at them. This might cause parental

feelings of discomfort, sadness or anger (especially when the parent feels rejected by the child) with a subsequent impact on parental reactions towards the child. This may result in reciprocal interactional problems in the form of a vicious circle.

Despite a variety of psychotherapeutic interventions for children up to the age of 12 years, to date there have been no studies on the effectiveness of interventions focusing on parent-child relationships when a child has FP. However, parent-management trainings such as Positive Parenting Program (PPP; Sanders et al., 2014) or Incredible Years (Webster-Stratton & Hammond, 1997), as well as parent-child psychotherapies like Parent-Child Interaction Therapy (PCIT) and Parent Infant Psychotherapy have been found to be effective in this age group in the general population (e.g. Mingebach et al., 2018).

Parent-Infant Psychotherapy. Parent-infant psychotherapy is a dyadic psychodynamic intervention, grounded within psychoanalytic theory, attachment theory and findings from infancy research, which aims to address difficulties that occur within the parent-infant relationship during the pre-verbal period (Baradon, Biseo, Broughton, James, & Joyce, 2016). Parent-infant psychotherapy aims to identify unconscious, unhelpful relational patterns that occur within the dyadic system and to teach the parent new ways of relating with the infant which improves the parent-infant relationship (Baradon et al., 2016).

Davies, Jenkinson, & Halewood (2020) have suggested that infants with congenital FP and their caregivers might benefit from this type of pre-verbal intervention in order to facilitate the development of an alternative embodied (non-verbal) communication system to promote effective non-verbal dialogue between the dyad and to encourage the development of a secure attachment relationship and a secure sense of self within the infant.

Parent-Child Interaction Therapy (PCIT). PCIT is a manualised therapy which aims to help parents develop an authoritative parenting style by combining play therapy and behavioural therapy approaches (Eyberg, 1988). The treatment consists of two phases: the child-directed interaction (CDI) to help parents learn skills to strengthen their relationship with their child and to increase parental warmth, and the parent-directed interaction (PDI) to help parents learn a clearly structured and consistent approach to discipline. Parents are regularly coached in vivo by the therapist while interacting with their child. PCIT is an evidence-based intervention for children aged 2-6 years with behavioural difficulties. Moreover, recent research has also shown positive effects in children with internalising disorders such as depression (Luby et al., 2012), and in autism spectrum disorders (Ginn et al., 2015). Thus, PCIT can be seen as a promising trans-diagnostic intervention for those children with FP aged 2-6 years who are experiencing behavioural difficulties.

For older children and adolescents, the theoretical background of interventions may be similar to what has been already described in the adults section (see above). However, design and implementation of the interventions are typically adapted to the subject's age and developmental level.

Surgery

While surgical decompression of the facial nerve within the labyrinthine segment is not recommended for the paediatric population, nerve grafts and muscle transfer techniques are an option (Barr et al., 2011). There are several additional considerations when facilitating the decision making of children and adolescents with regard to surgery (Bradbury, Kay, Tighe, & Hewison, 1994). It is important to assess parental beliefs about surgery and determine the extent to which these mirror the child's. Where parental attitudes differ from the child's it is important to determine whether the child is competent to make a

decision and whether the child's motivation to undergo surgery is intrinsic or extrinsic. Furthermore, it is important to consider the developmental stage of the child and especially their ability to consider both the short-term and long-term consequences of their decision. Finally, it is important to support the young person to develop strategies to discuss any future changes in facial appearance with their peers.

There is ethical debate about surgical intervention for children when they are unable to consent to surgery, often based on concerns of parents and worry about problems the child may encounter (Clarke et al., 2013). Parents can feel a sense of responsibility or a moral obligation to pursue surgery which is 'normalising' (Nelson, Caress, Glenny & Kirk, 2012).

Consent, Capacity and Competence

Aspinall (2010) highlights the importance of focusing on the child's perspective and involving children and adolescents in their care and decisions, as well as considering the child's family and social context, when considering surgical interventions.

A child or young person being competent to consent to treatment means that they have acquired sufficient understanding and intelligence to understand what is proposed and enable them to exercise a choice in their own best interests. This is often known as Gillick competence (Gillick v West Norfolk & Wisbech Area Health Authority and Department of Health & Social Security, 1985).

The capacity to consent depends on a young person's ability to understand and weigh up options to make a decision and does not depend on age (General Medical Council, 2018). At 16 a young person in the UK is presumed to have the capacity to consent unless there is significant evidence to suggest otherwise (Mental Capacity Act, 2005). A child under 16 may be viewed has having competence to consent, depending on their maturity and ability to understand what is involved (General Medical Council, 2018). The GMC advises that clinicians must decide whether a young person is able to understand the nature, purpose and possible consequences of investigations or proposed treatments, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others can they consent to that investigation or treatment. Psychologists/psychological therapists should work with their MDT colleagues to ensure that all practical support possible has been provided in the communication of information before deciding whether or not a child or young person has the capacity to consent.

If a child lacks capacity to consent, parents can consent on their behalf. Note that the legal framework for parental responsibility and the treatment of 16- and 17-year-olds who lack the capacity to consent differs in different parts of the UK. (See General Medical Council website for further details).

Parents cannot override the competent consent of a young person to treatment that the FP MDT considers is in their best interests. Where a competent child under 16 refuses a specific treatment which is in their best interests, but the parents support the recommendation for treatment, there are recommendations as to what clinicians should do and evidence to manage this (General Medical Council, 2018). However, ultimately the decision rests with the competent child. The legal framework varies across the UK and further advice should be sought in this event.

Family and Social Support

As with any chronic health condition, it is not just the child who may be affected by the impact of FP, but also parents, siblings and wider family or social systems. It is therefore important that the systems

around a child or adolescent are supported to facilitate development in the context of experiencing a visible difference.

Parental well-being and support. Literature in other areas of visible difference, such as cleft lip and palate, highlight that parental adjustment can impact a child's psychosocial adjustment and self-esteem (Masnari et al., 2012). Parents of children who have a visible difference may have concerns about stigma and how others may perceive or behave towards their child at different ages (Nelson et al., 2012).

Parents with young children with FP understandably worry about the future. An explanation of how children's awareness of facial difference develops can help parents understand when to provide an age-appropriate explanation at specific times. For example, children don't always start primary school knowing they look different. Questions from other children early on are typically curious and not intended to offend, and it is helpful for parents to be aware of this. Information should be provided to parents for how to talk about their child's visible difference in a way which supports the development of healthy self-esteem and a positive body image, for example by talking to their child about their appearance in a way which is accepting, open and confident. It is helpful to encourage parents to display photographs of their child to reinforce the message that their appearance is accepted and normal for them. Resources on websites including Facial Palsy UK (www.facialpalsy.org.uk) and Changing Faces (www.changingfaces. org.uk) have specific pages for parents of children of different ages and include information about managing mental health, social communication, coping with other people, and building knowledge and confidence.

The underlying condition may have an impact on developmental needs and consequently result in increased demands on parents including regular medical appointments. For about 30% of children and adolescents with Moebius syndrome, disability-related problems with the child's healthcare and therapies at least once every week were reported by their mothers, and disability-related problems were significantly positively correlated with maternal stress (Briegel, 2018). Similarly, positive correlations between parental stress and child adjustment problems have been found in several studies on children and adolescents with Moebius syndrome, (Briegel et al., 2007; Briegel et al., 2010; Briegel et al., 2019).

Parents should be encouraged to engage in coping strategies, including drawing on social support from friends and family, as this has been shown to be associated with reduced negative family impact, lower psychological distress, and better adjustment (Baker, Owens, Stern, & Willmot, 2009.) Parents should also be signposted to opportunities to engage with peer support opportunities hosted by not-for-profit organisations, such as Facial Palsy UK and the Moebius Syndrome Foundation.

Peer support. All forms of FP are considered rare disorders, making it difficult to find others who share one's experience. For parents, repeated attendance was correlated with greater rare disease self-efficacy and knowledge, as well as lower anxiety and depression. Companionship and informational support were the most noted benefits of attending a conference, while being surrounded by others who share one's condition was a destigmatising and normalising experience (Bogart et al., 2017).

Meeting other children with FP can be a very positive experience, as children get the opportunity to see the smiles on other children's faces and it can reassure them about their own appearance and help to normalise visible difference. Hotton et al. (2019) designed a single-session workshop for children with FP and their parents. This focused on developing children's skills in talking about their FP with others, as well as increasing their parents' confidence in supporting their child with concerns related to facial

difference. After a one-off meeting with other children with FP, over one third reported feeling happier about discussing their face with others.

Facial Palsy UK's Family Days are a relaxing and fun day for children affected by FP, their siblings and parental guardians. The aim of these days is to reduce isolation for children affected by FP and their parents, in a non-medical environment. Volunteers include adults who were born with FP and often a health professional with a special interest in the condition. As well as the benefits outlined previously for children meeting others with FP, children meet happy well-adjusted adult volunteers with FP who they can relate to. Parents are also reassured by talking to these volunteers about their experiences of growing up with the condition. It can also be beneficial to children to meet surgeons in a non-medical setting, as well as giving parents an opportunity to ask informal questions. Further information about the Family Days can be found on the Facial Palsy UK website.

School support. Children with facial differences may be more likely to experience stigmatising behaviours such as staring, teasing, startled reactions, and expressions of pity (Rumsey & Harcourt, 2005; Masnari, 2012). Schools and youth clubs should be signposted to relevant resources and the websites of charities for guidance and support for teachers and schools. For example, the Changing Faces website includes teacher guides for supporting children and young people of different ages 3-16, classroom resources for talking about visible difference and promoting an inclusive culture, as well as ideas for managing bullying.

The Facial Palsy UK website has a Starting School form which can help inform teachers about an individual child's specific situation including how their child prefers to answer questions about FP. Facial Palsy UK has also published a book When Teddy Lost His Smile which parents and children with FP find helpful to educate and normalise the condition.

Psychologists/psychological therapists involved with family care should liaise with schools as part of gathering assessment information regarding the child or young person's educational functioning, and their social and emotional functioning at school. Liaising with school staff to provide more general education to teachers and support staff about promoting inclusion, developing self-esteem and managing issues such as bullying may be particularly useful, as well as being part of any meetings where a psychological perspective regarding any current difficulties may be beneficial.

Sibling well-being and support. There is limited research in relation to evidence-based support or interventions for siblings of children with facial palsy. However, there is evidence that siblings of children with a long-term condition or a visible difference can experience positive gains as well as experience negative psychosocial effects (Phillips & Rumsey, 2008). Facial Palsy UK (2020) highlight that siblings may experience:

- Protectiveness for their sibling with facial palsy.
- Other people making unkind comments about their sibling's face.
- Jealousy if more attention is paid to their sibling.
- Resentment – if there are lots of hospital appointments which they also have to attend, or which take their parents away from home.
- Confusion – if they don't understand facial palsy and any related problems.

Siblings may observe their sibling being teased or stigmatised (Lehna, 2013) or being asked questions from other children or teachers; they should be modelled to and supported by parents as to how to

respond to questions or attention, and also to deflect comments and say that they do not wish to talk about it.

Common concerns are that hospital visits change how the family spends time together or that siblings may worry about their brother or sister. Stock et al. (2016) highlighted that siblings of children with a visible difference (e.g. a cleft lip and/or palate) may experience distress over the child's surgical treatment and it has been suggested that experience of anxiety can stem from a lack of understanding about the treatment. If a child with FP is receiving treatment or surgical intervention parents may need support to be able explain things to siblings and prepare them for the process and outcomes of surgery. Maintaining routines as much as possible in the context of multiple hospital visits and keeping siblings informed as to what to expect are likely to be protective for siblings and should be encouraged by the MDT.

Families can be signposted to not-for-profit organisations, such as Changing Faces, which provide information about helping siblings to learn about their brother or sister's visible difference and how to respond to others. Family days which are run by organisations such as Facial Palsy UK, may also be a good opportunity for siblings to access peer support.

Young Adults and Transition

Appearance becomes more of a focus in adolescence alongside increased comparison to others, as young people explore and develop their own identity. Young people's concerns about appearance can impact on social and emotional development. Detailed information about the perspectives of young people and guidance for improving transitional care are provided in Clarke et al. 2013, chapter 8. Clarke et al. (2013) highlight the importance of promoting adjustment through psychosocial interventions including social support from peers, parents and school, as well as the role of CBT. It is important that developmentally appropriate topics, such as dating and appearance ideals, are discussed with young people in order to give them permission to acknowledge potential difficulties.

Promoting shared decision making for young people can be promoted by psychological therapists within the team. Clinicians should consider guidelines on communication, capacity and consent as applicable in their country whilst encouraging young people to engage in their health care and be active in shared decision making. It is encouraged that 16 year olds and older should be written to directly in language that they can make sense of (Academy of Medical Royal Colleges, 2018).

Multi-disciplinary Team Working

Communication of Diagnosis, Treatment and Recovery

Evidence from surveys (Facial Palsy UK, 2019) and qualitative research (Hamlet at al.,2021) has shown the significant psychological impact of poor communication surrounding a FP diagnosis and associated treatment. Indeed, some people with FP in the UK have reported not feeling listened to or treated with compassion by health professionals, including by their GP (Hamlet at al.,2021).

Psychologists/psychological therapists working within multi-disciplinary FP services can work alongside their colleagues to provide a compassionate response to people accessing their service and to validate their concerns with regard to both the functional and aesthetic aspects of their condition. Furthermore, psychologists/psychological therapists can work with their MDT colleagues to ensure that

the team use respectful language. For example, terms like 'fixing' or 'correcting' when used in the context of surgery can be potentially unhelpful, as they can create feelings of inadequacy in the person with FP.

It is important that people with FP are told explicitly about their diagnosis and that relevant treatment is outlined in a clear, unambiguous manner. There is often a degree of uncertainty with regard to the likely prognosis or recovery for certain conditions associated with FP and it is important that clinicians are open and clear about this. Information about the potential for recovery from acquired FP should be repeated consistently by all members of the FP MDT. There are several evidence-based communication skills training models, such as SPIKES (Baile et al., 2000), which provide structure for breaking bad news.

More widely, psychologists/psychological therapists should work alongside MDT colleagues to form links with local GPs. A survey carried out by Facial Palsy UK (2019) highlighted how more than one third of respondents with FP reported not thinking that their GP took their concerns seriously. FP MDTs should consider ways of supporting the continuing professional development of GPs by offering teaching or training on the physical and psychological impact of FP, and associated treatment options, as well as ensuring that local GPs are aware of when and how to refer to a specialist FP MDT.

Psychologically Informed Stepped Care

The PLISSIT model of stepped care for interventions to promote psychosocial adjustment in appearance concern has been proposed by Clarke et al. (2013) and suggests that all health professionals should be able to deliver level 1, 'permission' and level 2 'limited information' interventions. This may include having an awareness of the impact of language, and being able to explore psychosocial concerns as well as supporting people to be able to respond to others' questions about their facial appearance. Others involved in care should also be able to provide signposting to relevant organisations and resources, such as Facial Palsy UK, Changing Faces and Face IT (Bessell et al., 2012).

Skilling up the MDT in understanding and supporting the psychological impact of FP may help the team to offer a stepped-care approach and ensure that all people with FP experience psychologically informed care. Psychologists/psychological therapists may offer clinical supervision to specialists in relevant settings and offer teaching so that other clinicians can develop skills in communicating about diagnosis and treatment as well as increasing their understanding of the common psychological difficulties in relation to FP and the management of these. The MDT should be skilled up to be able to normalise the emotional responses to the onset of FP and acknowledging the loss often associated with the condition.

Integrating Psychologists/Psychological Therapists Within the MDT

It can be useful for psychologists/psychological therapists to sit in MDT clinics or for all people with FP to be seen by a psychologist as part of their initial MDT appointment. Offering this means that psychology is introduced as a core part of the team and promotes values of holistic person-centred care. It also offers an opportunity for some brief screening of psychological well-being which can be helpful for the team.

Delivering joined-up care can provide opportunities to deliver treatment in psychologically informed ways which can promote engagement and help those with FP to manage emotional difficulties which may arise during treatment. For example, psychologist/psychological therapists may collaborate with facial therapists and the individual with FP to develop a graded exercise programme.

Facial therapists occasionally experience that some people with FP have difficulties with regard to adherence to facial exercise. When it comes to children and adolescents with FP it can be complicated to balance many developmental and contextual factors, while simultaneously following the young person's own agenda.

Psychologists/psychological therapists may support their facial therapy colleagues to further develop their engagement skills, by sharing approaches such as Motivational Interviewing. This is a gentle and respectful method of communication with others about their difficulties with change and the possibilities to engage in different behaviour (Naar-King, Suarez, 2011). This combined with clear goals, variation in exercises, the use of digital tools and regular praise and reward can help to maximise the effectiveness of facial therapy.

Some Examples of Models of MDT Working

Queen Victoria Hospital – East Grinstead, UK

All new patients attend an MDT Clinic where they initially meet with a member of the Psychological Therapy Team before then going into a consultation with the consultant and specialist physiotherapist. Prior to the appointment, all patients are sent questionnaires which ask about the functional, social and emotional impact of facial palsy, as well as general psychological distress.

This initial appointment allows psychology to be introduced as part of the team, explain the different roles of psychology, normalise emotional responses and enable the individual or family to be aware of the support which is available to them throughout their process. It is hoped that this reduces stigma which can be associated with help-seeking and also encourages patients to be proactive as they have already met with a clinician. This appointment allows a brief social and emotional history, including a screen for any mental health difficulties which could impact on the person's decision making or ability to cope, as well as being able to identify protective factors.

Relevant information is shared, with patient consent, with the consultant and physiotherapist, and a plan is agreed with the individual regarding further psychological support. Should the person not feel that any support is relevant at this time, they are provided with a leaflet with the department's contact details, and informed that they can contact them in the future and also signposts useful websites and apps (Facial Palsy UK, Changing Faces, MyLife Meditation).

John Radcliffe Hospital – Oxford, UK

Prior to their first appointment with the service, all new patients are invited to complete a pack of questionnaires, covering a variety of topics, including medical history, self-reported facial function, emotional well-being, appearance-related concerns, and work and social adjustment.

Patients then attend an MDT clinic, where they simultaneously meet with a consultant plastic and reconstructive surgeon, consultant oculoplastic surgeon, facial therapist and clinical psychologist.

The purpose of this initial appointment is for the patient to have an opportunity to share the history of the FP, including their journey to the service. The service aims to work collaboratively with the patient to develop a treatment plan, which can include a combination of Botox treatment, surgery, facial therapy and/or psychological support.

The service has recently developed a series of self-guided psychological therapy resources, funded by the Vocational Training Charitable Trust Foundation, which are currently being evaluated in a trial, with a view to them being widely available to patients and professionals from 2021.

Evaluation and Research

The collection of routine outcome data does not only facilitate the evaluation of the effectiveness of individual courses of psychological support, but also provides opportunity for larger scale evaluation of the effectiveness of psychological interventions for people with FP, something currently lacking from the literature (Hotton et al., 2020a).

Given the potentially differential impact of FP according to aetiology, it is recommended that any research investigating the psychosocial impact of FP aims to include sufficiently large and representative samples to allow comparison across aetiologies, particularly between those that are acquired and those that are congenital in nature. It is also advisable that researchers record information about duration, severity and laterality of FP, so as to identify the role of these factors in psychosocial adjustment (Hotton et al., 2020a), as well as to carry out longitudinal studies in order to observe how the psychosocial impact of FP changes over time and in line with recovery (where applicable).

There is a need for research into the effectiveness of psychological interventions for people with distress related to FP. Given the difficulties accessing psychological therapy reported by people with FP, such research should evaluate a range of delivery methods, including individual therapy, therapy groups and self-guided psychological therapy.

As is the case with research focusing on other conditions affecting the head and neck, such as craniofacial conditions (Stock, Feragen, Moss, & Rumsey, 2018), future research would benefit from consensus and consistency with regard to which constructs are measured, and which measures are used to do so. We recommend the constructs and measures included in this document as a potential starting point. Furthermore, there is a concerning paucity of research into psychosocial impact of FP in children and adolescents (Hotton et al., 2020b), despite this being identified as a key research priority (Hamlet et al., 2018), and this is an important area for future research.

Finally, a focus on strengths and resilience, as well as difficulties, will further help our knowledge of how best to promote well-being in this population. Not all people with FP will experience high levels of distress, and there is much to be learnt about the factors which contribute to resilience for those living with FP. The authors hope that continued research in this area, along with greater provision of psychological support for individuals with FP, will help to minimise the significant impact that this condition can have on psychosocial well-being.

Help Facial Palsy UK by providing feedback about this guide.

Take the survey: https://survey.alchemer.com/s3/6180719/Psychological-Wellbeing

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APPENDIX A

Psychosocial Measures for Adults
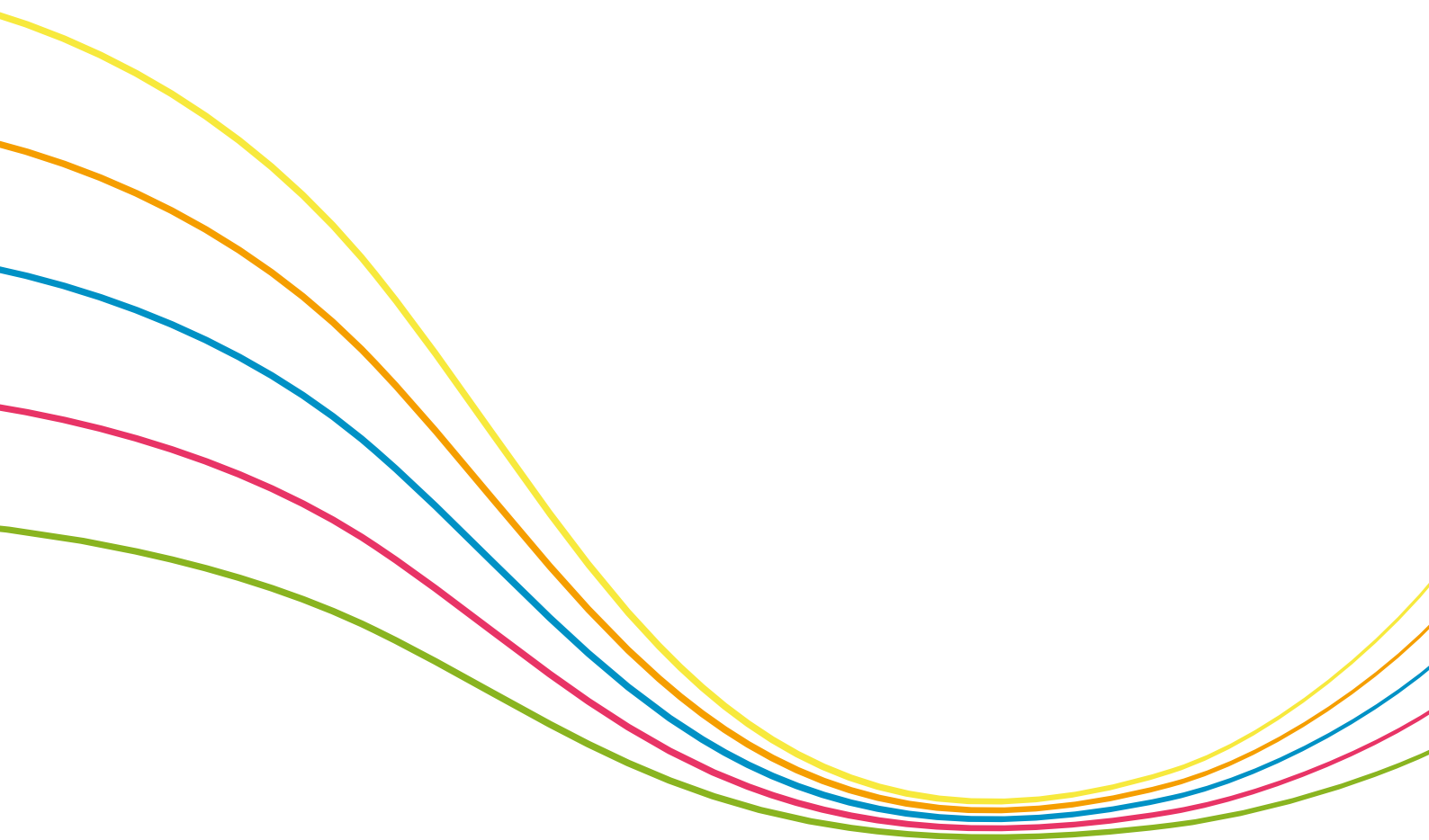
Appendix A: Psychosocial Measures for Adults

Domain	Measure (Reference)	No. of Items	Age Range	Method of Administration	Published FP Cohort Data?	Further Information
Depression	PHQ-9 (Kroenke, Spitzer & Williams, 2001)	9	18+	Self-administered	No	https://www.phqscreeners.com/
	PROMIS-Depression (Cella et al., 2010)	(various lengths)	18+	Self-administered; Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	HADS- Depression Snaith & Zigmond (2000)	7	17+	Self-administered	Various – see Hotton et al. (2020) for a review	www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale-hads/
Psychological Distress	CORE-10 (Barkham et al., 2013)	10	17+	Self-administered, web-based available	No	https://www.coresystemtrust.org.uk/instruments/
Trauma	Impact of Events Scale - Revised (Weiss, 2007)	22	18+	Self-administered	No	https://eprovide.mapi-trust.org/instruments/impact-of-event-scale-revised#member_access_content
Anxiety	GAD-7 (Spitzer et al., 2006)	7	12+	Self-administered	No	https://www.phqscreeners.com/
	HADS-Anxiety Snaith & Zigmond 2000)	7	17+	Self-administered	Various – see Hotton et al. (2020) for a review	. https://www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale-hads/
	PROMIS-Anxiety (Cella et al., 2010)	(various lengths)	18+	Self-administered; Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	Brief Fear of Negative Evaluation (Leary, 1983)	12	18+	Self-administered	No	https://sites.duke.edu/leary/home/for-researchers/
	Fear of Negative Appearance Evaluation (Thomas et al.,1998)	8	18+	Self-administered	No	https://www.sciencedirect.com/science/article/pii/S1471015303000552?casa_token=Y3-ThEz97SQAAAAA:l1UDARSysKqj7aTR3sPOvUG1_BfxBgM-hq7mqsqwT-CRTuG77mWt55upOyTfpegUq_GgAxL8yg
	Liebowitz Social Anxiety Scale (Liebowitz et al., 1985; Mennin et al., 2002; Rytwinski et al., 2009)	24	18+	Self-administered; clinician rated versions	No	Copyrighted and may not be reproduced without the permission of the copyright holder, Michael R Liebowitz

Health-related quality of life	PROMIS Global Health (Hays et al.,2009)	10	18+	Self-administered	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	FACE-Q | Facial Paralysis Module – Health-related quality of life scales (Klassen et al., in press)	10	8+	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
	SF-36 (Hays, Sherbourne & Mazel, 1993; Hays, Sherbourne & Mazel, 1995)	36	18+	Self-administered	Various – see Hotton et al. (2020) for a review	https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/survey-instrument.html
Sleep	PROMIS-Sleep disturbance (Yu et al., 2012)	8	18+	Self-administered; Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	PROMIS- Sleep-related impairment (Yu et al., 2012).	8	18+	Self-administered; Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	Insomnia Severity Index (Bastien, Vallières & Morin, 2001)	7	18+	Three versions: Self-administered; Clinician; and Significant others	No	https://mapi-trust.org/questionnaires/isi/#conditions
	Epworth Sleepiness Scale (Johns, 1991).	8	18+	Self-administered	No	https://eprovide.mapi-trust.org/instruments/epworth-sleepiness-scale
	Sleep Condition Indicator (Espie et al., 2014)	8	18+	Self-administered	No	https://www.sleepio.com/sleep-condition-indicator/
Social well-being	FACE-Q | Facial Paralysis Module - Social (Klassen et al., in press)	10	8+	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
	Perceived Stigmatization Scale (Lawrence et al., 2006)	21	8+	Self-administered	Yes (Bogart & Hemmesch, 2016)	https://doi.org/10.1037/1040-3590.18.1.106
	Social interaction anxiety Scales-6 (Peters et al., 2012)	6	18+	Self-administered	No	https://doi.org/10.1037/a0024544

| Appearance	FACE-Q | Facial Paralysis Module – Appearance Distress (Klassen et al., in press)	10	8+	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
	Body Esteem Scale-Appearance Subscale (Mendelson, Mendelson, & White, 2001).	10	12+	Self-administered	No	https://psycnet.apa.org/record/2001-03031-006
	Derriford Appearance Scale- DAS24 (Carr, Moss & Harris, 2005)	24 or 59	18+	Self-administered	No	http://www.derriford.info/
	Appearance Anxiety Inventory (BDD) (Veale et al., 2014)	10	18+	Self-administered	No	https://novopsych.com.au/assessments/appearance-anxiety-inventory-aai/
	Social Appearance Anxiety Scale (Hart et al.,2008)	16	18+	Self-administered	No	https://journals.sagepub.com/doi/abs/10.1177/1073191107306673?casa_token=_G72mthiJTMAAAAA:W939pfEiL_yX7Em4-kP3UipE8tlzXob9glAuiO7cYh3Mbo4JuTRXBrwYJ-XW0bFoOpvURgNXOKVN

Note: BDD – Body Dysmorphic Disorder; CORE – Clinical Outcomes in Routine Evaluation; HADS – Hospital Anxiety and Depression Scale; PHQ-9 – Patient Health Questionnaire; PROMIS – Patient-Reported Outcomes Measurement Information System

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APPENDIX B

Psychosocial Measures for Children
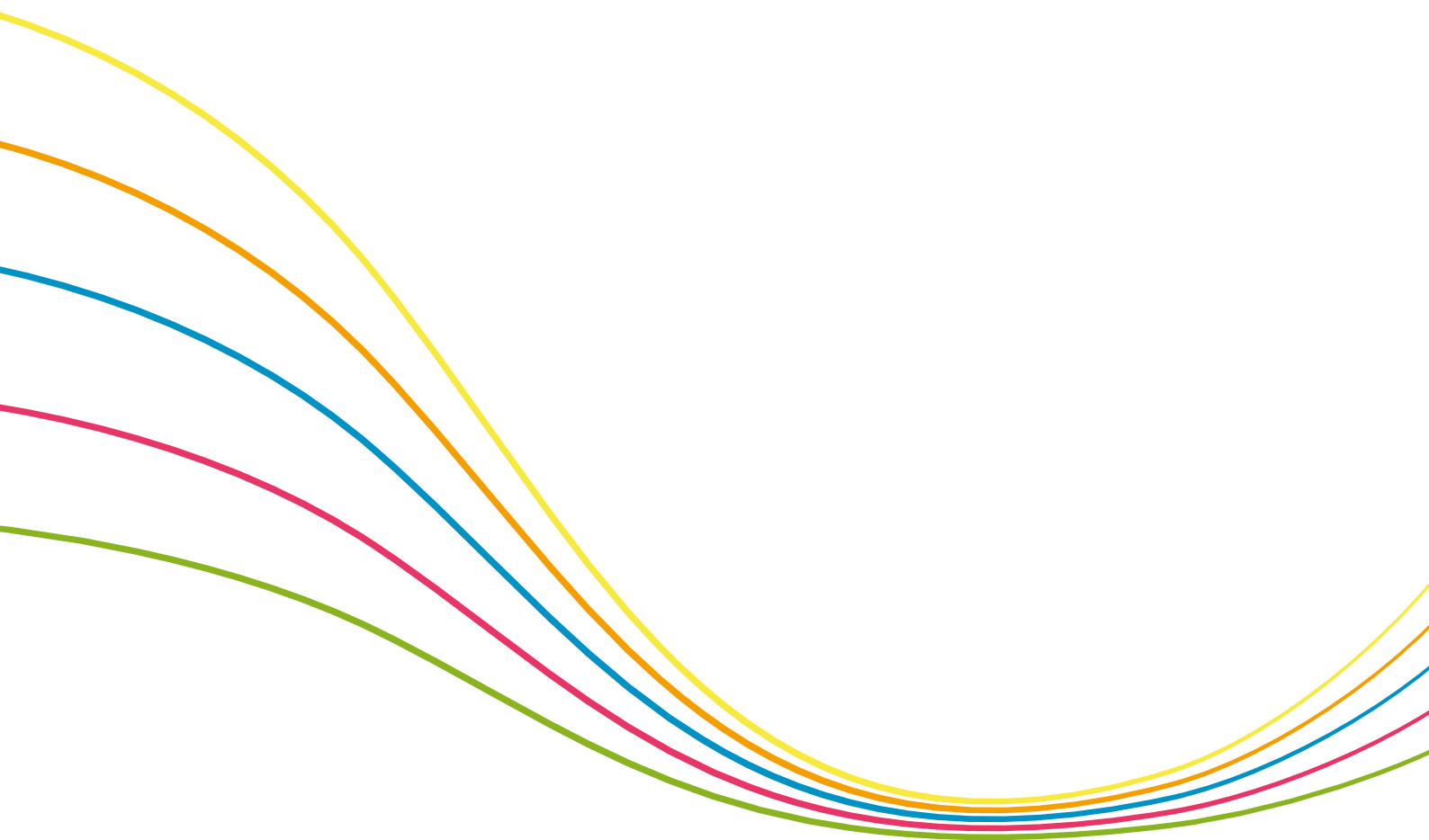
Appendix B: Psychosocial Measures for Children

Domain	Measure	No. of Items	Age Range	Method of Administration	Published FP Cohort Data?	Further Information
Depression	PROMIS – Depressive Symptoms	14	5–17	Self-administered (8–17; Parent-proxy (5–17); Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	Child Depression Inventory, 2nd ed. (Kovacs, 2010)	28	7–17	Self-administered; Parent and teacher-proxy also available	No	https://www.annarbor.co.uk/index.php?main_page=index&cPath=556_579
	RCADS (Chorpita, Moffitt & Gray, 2005)	47	8–18	Self-administered; Parent-proxy also available	No	https://www.childfirst.ucla.edu/resources/
Trauma	CRIES-8 (Perrin, Meiser-Stedman & Smith, 2005)	8	8+ years	Self-administered	No	https://www.corc.uk.net/media/1268/cries_selfreported.pdf
Anxiety	PROMIS – Anxiety	8–15 (various forms)	5–17	Self-administered (8–17; Parent-proxy (5–17); Computer Adaptive Test available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	Revised Children's Manifest Scale (RCMAS-2) (Reynolds & Richman, 2008)	49	6–19	Self-administered	No	https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildMentalHealth/RCMAS-2/RCMAS-2.aspx
	RCADS (Chorpita, Moffitt & Gray, 2005)	47	8–18	Self-administered; Parent-proxy also available	No	https://www.childfirst.ucla.edu/resources/
	Social Anxiety Scale for Children – Revised (SASC-R) (La Greca & Stone, 1993)	22	7–18	Self-administered	No	https://www.tandfonline.com/doi/abs/10.1207/S15374424JCCP2201_2
Sleep	Brief Infant Sleep Questionnaire–Revised Short Form (Mindell et al., 2019)	20	0–3	Parent-proxy	No	https://www.babysleep.com/bisq/
	PROMIS Sleep Disturbance (Forrest et al., 2018)	4 and 8 item versions	5–7 (parent proxy) 8–17 (self-administered)	Self-administered; Parent-proxy also available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures)
	PROMIS Sleep-Related Impairment (Forrest et al., 2018)	4 and 8 item versions	5–7 (parent proxy) 8–17 (self-administered)	Self-administered; Parent-proxy also available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures)

Social well-being	FACE-Q | Facial Paralysis Module – Social (Klassen et al., in press)	10	8 and up	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
	Perceived Stigmatization Scale (Lawrence et al., 2010)	21	8 and up	Self-administered	Yes (Bogart & Hemmesch, 2016)	https://psycnet.apa.org/doiLanding?doi=10.1037%2Fa0021674 https://psycnet.apa.org/record/2015-46874-001
	PROMIS Paediatric Social Relationships –Short Form (DeWalt, 2013)	8	8–17	Self-administered	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
Health-Related Quality of Life	PROMIS Paediatric (Forrest et al., 2014)	7	5–17 8–17	Self-administered; Parent-proxy also available	No	https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
	FACE-Q | Facial Paralysis Module – Health-related quality of life scales (Klassen et al., in press)	10	8 and up	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
Appearance	FACE-Q | Facial Paralysis Module – Appearance Distress (Klassen et al., in press)	10	8 and up	Self-administered	Yes (Klassen et al., in press)	http://qportfolio.org/face-q/
	Body Esteem Scale – Appearance Subscale (Mendelson, Mendelson & White, 2001)	10	12+	Self-administered	No	https://psycnet.apa.org/record/2001-03031-006

Note: CRIES – Child Revised Impact of Events Scale; PROMIS – Patient-Reported Outcomes Measurement Information System; RCADS – Revised Child and Adolescent Depression Scale

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