

Systematic Review

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# Tools for effective patient education to manage outcome expectations in paediatric facial reanimation: a systematic review

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**How to cite this article:** Reissis D, Zubler C, Buitteir Ed, Brown S, Leckenby J, Grobbelaar A. Tools for effective patient education to manage outcome expectations in paediatric facial reanimation: a systematic review. *Plast Aesthet Res* 2024;11:52. <https://dx.doi.org/10.20517/2347-9264.2024.29>

**Received:** 26 Feb 2024 **First Decision:** 13 Aug 2024 **Revised:** 30 Sep 2024 **Accepted:** 24 Oct 2024 **Published:** 31 Oct 2024

**Academic Editor:** Nan-Ze Yu **Copy Editor:** Ting-Ting Hu **Production Editor:** Ting-Ting Hu

## Abstract

**Aim:** Informed consent for paediatric facial reanimation requires effective patient/parent education and involvement in a shared decision-making (SDM) process to help set their expectations and understanding from the outset. No article in the current literature has systematically reviewed the available tools for facilitating effective patient/parent education and the validity of informed consent in the context of paediatric facial reanimation.

**Methods:** A systematic literature review was undertaken, following the Preferred Reporting Items of Systematic Reviews and Meta-analyses (PRISMA) 2020 guidelines. MEDLINE via PubMed, Embase and Cochrane Library were searched and the results screened and reviewed in accordance with pre-defined inclusion and exclusion criteria.

**Results:** The initial search yielded 478 articles, of which only 4 fulfilled the study's inclusion criteria. One cohort



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study evaluated qualitative feedback from patients and their relatives participating in a family education and support day for paediatric facial palsy, while another article from the same group reviewed the readability of online education resources. The remaining two articles represented educational reviews focusing on treatment and patient education based on expert opinion without providing original outcome data.

**Conclusion:** There is a paucity of evidence regarding patient/parent education to support the informed consent process for children undergoing paediatric facial reanimation. There remains a need for further resources and platforms to be developed that may support children and their parents in engaging in a SDM process, setting appropriate expectations, and providing valid informed consent for their surgery.

**Keywords:** Facial reanimation, paediatric, facial palsy, informed consent, patient education

## INTRODUCTION

Paediatric facial reanimation involves complex and often multi-stage surgical treatment that begins at a young age (usually before 10 years old) and can continue into adolescence and adulthood, with life-long consequences for the children's function and appearance. Parents/those with parental responsibility and patients themselves (as much as possible) need to be able to understand, retain, and weigh up their available treatment options, encompassing both surgical, non-surgical and the option of no treatment. This information needs to be provided to an appropriate age and intellectual level and be discussed in the context of what the risks and benefits mean for them. Only then may one be able to make a fully informed decision about whether or not to consent to the surgery and set accurate expectations of what their outcomes are likely to be.

Free functioning muscle transfer (either one- or two-stage) remains the gold standard for facial reanimation in children with congenital/chronic facial paralysis. The postoperative outcomes are good but not uniform<sup>[1,2]</sup>. There is a complex interplay between functional, aesthetic, and psychosocial factors, as well as complicated concepts and terminology, to understand in order for parents and/or patients to be part of an active shared decision-making (SDM) process<sup>[3]</sup>.

Informed consent, therefore, requires effective education and involvement of parents and patients from the outset, in order to ensure both valid parental permission and child assent<sup>[4]</sup>. It is vital that parents have realistic expectations about what can be achieved with the planned interventions and believe in the philosophy of the approach used. Without such understanding, all parties are more likely to be disappointed with what may be achieved<sup>[5]</sup>. For example, the scarring associated with a two-stage facial reanimation may not be conceptually understood through discussion alone, but may prove hugely significant for a young child who is about to enter adolescence and start secondary school with the physical and psychological challenges that may be associated with for them and their peers.

Equally, encouraging more direct communication with children and young people themselves has been shown to contribute to an improved relationship in terms of satisfaction, adherence to treatment protocols, and overall improved health outcomes<sup>[6,7]</sup>. This is of particular importance in the context of facial reanimation surgery, where patient compliance and effective facial rehabilitation are key parts of the lengthy postoperative course.

Providing age-appropriate and accessible patient education to both the child and their parent is a specific challenge for those working in the field of paediatric facial reanimation surgery. The American Academy of Paediatrics (AAP) provides a framework outlining essential elements for gaining assent from paediatric

patients in medical decision making [Figure 1]<sup>[4]</sup>.

In addition, there are further complex considerations when facilitating the decision making of children and adolescents with specific regard to consenting for surgery<sup>[8]</sup>. A consensus document published by Facial Palsy UK entitled “Recommendations for Supporting the Psychological Well-being of Children and Adults with Facial Palsy”<sup>[9]</sup> explores the concepts of consent, capacity and competence in the context of consenting for paediatric facial reanimation surgery. A child or young person can consent to treatment if they are deemed to be Gillick competent, meaning they have acquired sufficient understanding and intelligence to understand what is proposed and enable them to exercise choice in their own best interests<sup>[10]</sup>. The tools the clinician uses to facilitate this understanding should also reflect the developmental maturation of the child or young person.

The UK General Medical Council (GMC) guidance “Decision Making and Consent” (2020)<sup>[11]</sup>, which aligns with the Montgomery guidelines for valid informed consent, also states that doctors must try to find out what matters to patients, so they can share relevant information about the specific benefits and harms of proposed treatment options. In the same document, the GMC also emphasises the importance of sharing information in a way that the patient can understand.

No article in the current literature has systematically reviewed the available tools for facilitating effective parent/patient education and the validity of informed consent in the context of paediatric facial reanimation. When assessing the health literature available across various other subspecialties in plastic surgery, reviews by Chu *et al.*<sup>[12]</sup>, Murdock *et al.*<sup>[13]</sup>, Powell *et al.*<sup>[14]</sup> and Cordero *et al.*<sup>[15]</sup> all concluded that the patient education provided is consistently either of poor quality and/or exceeds the recommended readability level, whether these are provided online or as a hard copy. Lack of standardisation and regulation, particularly around medical information online, poses an additional challenge to clinicians to ensure patient and parent outcome expectations are managed<sup>[16]</sup>. New emerging technologies challenge clinicians to provide a fresh and dynamic approach to developing patient education tools for all population age groups. These tools should aim to optimize patient engagement and ultimately improve patient satisfaction and outcomes<sup>[17]</sup>.

## METHODS

A systematic literature review was undertaken, following the Preferred Reporting Items of Systematic Reviews and Meta-analyses (PRISMA) 2020 guidelines<sup>[18]</sup>. MEDLINE via PubMed (National Library of Medicine, Bethesda, Maryland), Embase, and Cochrane Library were searched on December 10, 2023. The following full-text search strategy was used: [(facial palsy) OR (facial paralysis) OR (facial paresis) OR (facial nerve palsy) OR (facial nerve paralysis) OR (facial nerve paresis) OR (facial reanimation) OR (Bell palsy) OR (moebius syndrome)] AND [(patient information) OR (patient education) OR (informed consent)] AND [(children) OR (child) OR (pediatric) OR (paediatric)]. Only publications written in English and with full-text availability were considered. No limitations for inclusion were set regarding study design, time or type of publication. After discarding duplicates, titles and abstracts of studies located by the search were screened for relevance by three study members; where there was a conflict, a senior author decided. Studies of potential importance were then reviewed in full text. Only studies providing original outcome data or recommendations regarding the patient information or education process in paediatric facial palsy patients were included. Due to the nature of this study, formal ethics application and approval by the institutional review board were not required.

Help the patient achieve a developmentally appropriate awareness of the nature of his or her condition
Tell the patient what he or she can expect with tests and treatments
Make a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy)
Solicit an expression of the patient's willingness to accept the proposed care

**Figure 1.** Practical aspects of assent by pediatric patients for medical decision making.

## RESULTS

The initial search yielded 478 articles, of which only 4 fulfilled the study's inclusion criteria [Figure 2 and Table 1]. Overall, this highlights the relative paucity of evidence regarding patient and parent/family education in paediatric facial palsy in general as well as the informed consent process for children undergoing facial reanimation surgery in particular.

In 2012, the Boston group<sup>[19]</sup> shared their treatment algorithm and expertise on facial rehabilitation in adults and children with chronic facial nerve injury. Pre- and post-surgical facial therapy sessions were employed along with focused patient education depending on whether the patient had incomplete or complete facial palsy. Patient information was provided specifically to cover all treatment options related to their underlying condition, possible stages of facial nerve recovery, the anatomy and function of facial muscles using schematics and discussion of possible complications such as synkinesis. They conclude that a well-informed, empowered and actively involved patient is the key to any successful facial rehabilitation program - "we believe that knowledge is power, and that the well-informed and fully involved patient is most likely to succeed in the facial rehabilitation process". Interestingly, they also discussed the need for education and rehabilitation goals to be tailored to the individual patient and found that those who demonstrated a "long-standing commitment" and "motivation" to a consistent and thorough treatment program were most successful.

Support groups and networking events can be another helpful resource for patients and their families coping with rare medical conditions. One study by Drs Ronald Zuker and Gregory Borschel's team in Toronto, Canada, conducted a needs assessment and evaluated the satisfaction of implementing a patient education and family support day for children living with facial palsy as part of a quality improvement project<sup>[20]</sup>. This day offered presentations from plastic surgeons focused on "smile surgery", surgical outcomes, and advances in medicine, as well as previous patients (the "personal journey" of a teenager) and families who had undergone facial palsy treatment. The programme also included educational workshops on facial palsy in general and research, as well as small group discussions on issues around coping, bullying, and therapy. The objective was to create an opportunity for patients and their families to meet, build support networks, become more educated, and interact with the healthcare team. Feedback collected anonymously from patients and their family members in the form of a post-event evaluation questionnaire documented not only a high rate of satisfaction with the event and willingness to participate again in upcoming years but also significant interest in the patient presentations and educational workshops being the most appreciated sessions, with the presentation on smile surgery receiving the highest raw score. The

**Table 1. Characteristics of the included studies**

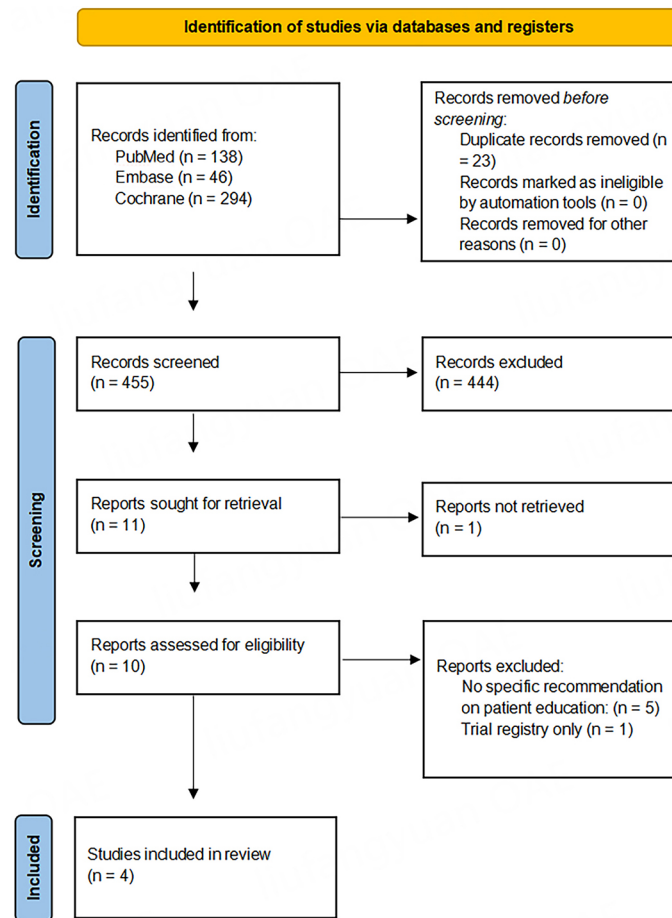
Author	Year	Focus	Study design	Number of patients	Age group	Principal outcome
Wernick Robinson <i>et al.</i> <sup>[19]</sup>	2012	Treatment algorithm and facial rehabilitation strategies for incomplete and complete facial palsy	Review	n/a	Paediatric and adult	Patient education plays a key role across all treatment categories and stages of facial nerve recovery. Personal instructions, anatomical schematics and feedback mechanisms empower patients to actively participate in the treatment of their condition.
Heinelt <i>et al.</i> <sup>[20]</sup>	2020	Quality improvement project, evaluation of a paediatric facial palsy education and family support day	Cohort study	24 children and 37 adults	Paediatric	The collected feedback suggests a high rate of satisfaction with the event and willingness to participate again in upcoming years. It also highlights a significant interest and demand for information with the patient presentations and the educational workshops being the most enjoyed sessions.
Broussard <i>et al.</i> <sup>[21]</sup>	2008	Educational article regarding recognition and anticipatory guidance in children with Moebius syndrome	Review	n/a	Paediatric	Nurses in neonatal and paediatric specialties play a key role in educating parents about the special needs of their child. They should offer them guidance on coping mechanisms, refer them to support groups and specialised webpages, and make them aware of potential treatment options such as facial reanimation surgery.
Somasundaram <i>et al.</i> <sup>[22]</sup>	2021	Readability of online education resources related to facial nerve disorders	Review	78 webpages	Paediatric and adult	Most available online education resources related to facial palsy failed to meet readability standards, creating a barrier for patients and families in their decision making.

n/a: Not applicable.

authors discussed the importance of providing emotional support to parents and psychosocial support to children. It was also clear that connecting patients/families with older patients who had the procedure may “help with the decision-making process both through discussion and seeing the outcome in person”.

Broussard and Borazjani published their recommendations on the approach to children with Moebius syndrome in an educational article focused on nurses who work in neonatal and paediatric specialties<sup>[21]</sup>. They point out the importance of educating and guiding parents regarding the individual needs of their child, with a focus on providing “comfort, support, and information” from the time of diagnosis and throughout their treatment journey. They also discuss useful coping mechanisms and the benefit of drawing attention to potential treatment options such as facial reanimation “smile surgery”. Additionally, they suggest a list of patient support groups and webpages that parents should be referred to for further information, including the Moebius Syndrome Foundation, as well as attendance of an annual International Conference in the United States which families can attend and meet “successful adults and teens with Moebius syndrome or other facial and physical differences who provide excellent role models for the children who attend”. Given the nursing focus of this article, they do not discuss the specifics of surgery and postoperative outcomes, although the recommendations for supporting these families provide a useful framework for taking a more holistic approach to developing educational tools for children and their parents in order to improve patient engagement, understanding of their condition, and subsequent patient satisfaction and outcomes.

In view of the fact that increasing numbers of patients rely on the internet for medical information, Somasundaram *et al.*, again from the Toronto group, conducted a review of online education resources related to facial nerve disorders published by medical institutions, health systems, professional organizations,



**Figure 2.** PRISMA flow diagram of eligible studies. After screening and applying exclusion criteria, 4 articles from the initial 478 items were included in this systematic review. PRISMA: Preferred Reporting Items of Systematic Reviews and Meta-analyses.

and governments<sup>[22]</sup>. The readability of 78 such webpages was evaluated based on the Flesch-Kincaid grade level and Flesch reading ease scores. They found that most of the available online education resources related to facial nerve disorders failed to meet readability standards, with mean Flesch-Kincaid grade levels above 6.0 (the minimum recommended standard of grade 6 (in Canada and the USA) reading level) and mean Flesch reading ease scores below 80.0. They discussed that this creates a barrier for patients and families in their decision making that relies on adequate comprehension of the medical condition. The authors conclude that “patient education is an essential component of medical and surgical care” and so online resources should be “written at the recommended reading level to ensure that patients seeking information related to facial paralysis can better understand this information”. This is particularly important in the context of reported high rates of low health literacy and the numerous complex management options and terminology associated with facial reanimation surgery.

### Literature review across all surgical specialties

Given the limited specific literature on patient education in paediatric facial palsy, a further scoping review of the literature was conducted, focusing on studies that evaluated the SDM process for surgery in general. These consistently show that patient engagement in surgical decision making was preferential and leads to improved outcomes.

One article identified that 54% of adult patients preferred shared decision making and 75% of surgeons preferred SDM<sup>[23]</sup>. The most common factors for patients favouring SDM included younger age, female gender, and higher education. For surgeons, the most common factors for favouring SDM included multiple treatment options, limited evidence for a given treatment plan, and impact on patient lifestyle.

A more recent article aimed to identify tools for use during SDM, assess their suitability, and characterise domains that future tools should measure<sup>[24]</sup>. They found that risk calculators were the most common, with communication tools being the least common. Existing tools to aid in the surgical SDM process were generally more related to short-term prognosis rather than patient-centred domains such as long-term prognosis, patient goals and expectations.

There are limited data on the SDM process for paediatric surgical procedures and the preferences that patients and/or their parents may have when making decisions and providing informed consent to undergo surgery<sup>[25]</sup>. One single-centre randomised control trial was published, which tested different types of educational material to reduce children's preoperative anxiety and worries<sup>[26]</sup>. The study participants were randomised into one of three groups: an experimental group, which received educational materials with information about surgery and hospitalisation (a board game, a video, or a booklet); a comparison group, which received entertaining material with the same format types; and a control group, which did not receive any material. The study found that children who received educational materials were less worried about surgery than children in the other two comparison groups; however, these differences were not statistically significant.

Adams *et al.* published their experience in delivering a perioperative patient education program designed to provide increased information to paediatric patients and their parents regarding the surgical process and expectations for their postoperative recovery<sup>[27]</sup>. They found reduced levels of anxiety in their patients and parents and a generally improved patient-clinician relationship. The study focussed predominantly on the immediate postoperative period and did not explore any long-term impact of their patient education program on engagement in post-surgical rehabilitation, but did explore the positive impact of setting patient/parent expectations prior to undergoing surgery.

### **Existing recommendations and online resources for paediatric facial palsy**

Facial Palsy UK has produced a consensus document, which contains many recommendations for supporting the psychological well-being of children and adults with facial palsy<sup>[9]</sup>. This further highlights the current scarcity of research with regards to the SDM process for facial reanimation surgery, and it is noted that the guidance itself draws largely on literature from alternative reconstructive surgeries such as breast reconstruction following mastectomy.

The Wessex Facial Nerve Centre in the UK has a series of informative descriptions of treatments online for facial reanimation, but these are non-specific to the paediatric population, nor do they provide sufficient detail for an informed decision to be made as part of the informed consent process<sup>[28]</sup>. The Oxford Facial Palsy Clinic also has a webpage dedicated to facial palsy with specific sections for adult and paediatric rehabilitation exercises and a separate patient information booklet<sup>[29,30]</sup>. However, the exercises described on the website are for reference following surgery and not designed to be used as a point of education prior to consenting to treatment.

Similarly, the Facial Palsy Institute based in Beverly Hills, California, has an extensive resource bank on their website featuring descriptions of facial palsy pathophysiology, treatments, and patient testimonials<sup>[31]</sup>.

These include various techniques for facial reanimation to allow prospective patients or parents to review prior to consulting with their surgeon. The website is well designed but does not include educational materials on possible complications, recovery times or rehabilitation programmes often required for patients and their parents to make fully informed decisions about treatment options.

Finally, when a search is made for “paediatric facial reanimation” or “paediatric facial reanimation patient education” on YouTube, the search returns a wide range of videos with varied lengths, quality and levels of detail from various institutions, as well as individual practitioners and patients themselves. Several short animations of surgical techniques have been developed by groups such as the Cleveland Clinic<sup>[32]</sup>, as well as a range of educational videos on facial palsy in general from Facial Palsy UK in collaboration with Queen Victoria Hospital, East Grinstead<sup>[33]</sup>. There are also a wide range of patient testimonials from individual patients and those associated with institutes such as Loyola Medicine<sup>[34]</sup> and Johns Hopkins<sup>[35]</sup>. Additionally, there are a variety of detailed presentations aimed at clinician education, including lectures from UCLA Health<sup>[36]</sup>, Stanford Health Care<sup>[37]</sup>, and UT Southwestern Medical Centre<sup>[38]</sup>, as well as some good-quality narrated operative videos which are informative for clinicians performing facial reanimation surgery themselves, such as a series created by Dr Ronald Zuker for the Washington University in St Louis teaching channel<sup>[39]</sup> and a short video from Dr Jon Paul Pepper for the JAMA Network<sup>[40]</sup>, alongside occasional educational video recordings for clinicians from PRS Journal Grand Rounds<sup>[41]</sup> and other educational sources. While these are a potentially useful resource for clinicians and some patients, these videos require careful selection and may cause more anxiety and confusion for patients, especially paediatric patients and their parents, if viewed in the perioperative period. Our search has not identified any videos produced for paediatric patients or their parents that aim to educate them about the relevant details of their facial reanimation surgery and the recovery and rehabilitation process in order to facilitate a valid informed consent discussion and SDM process with individual patients and their parents.

## DISCUSSION

Active patient and/or parent engagement in a SDM process for surgery is not only a matter of respecting their autonomy but also a strategy that can lead to more effective and satisfactory clinical and patient-reported outcomes. Information and communication tools that can enable and enhance patient/parents’ understanding of what they are likely to experience from their perspective, may help to set their expectations at the appropriate level from the outset and subsequently support involvement and compliance with their treatment journey.

Paediatric facial reanimation surgery is a complex and potentially multi-stage treatment process that requires patient/parent understanding of new concepts such as nerve recovery, scarring and cortical re-training, as well as the likelihood of undergoing multiple surgeries followed by a lengthy facial rehabilitation programme. While most surgeons performing these procedures will have a good personal understanding of the relevant guidelines and legalities related to paediatric informed consent, few currently have access to useful and age-appropriate resources to help set patient/parent expectations and engage them in a fully informed consent decision-making process.

While there is no substitute for spending time talking with patients/parents to build rapport, explain the relevant concepts, and explore their understanding and questions, the literature also tells us that most patients will forget up to 90% of the information relayed to them in a clinical setting, retaining only 10%-15% on average<sup>[42,43]</sup>. Moreover, if written information resources are provided, these are often not read, and if they are, they are most commonly of inappropriate reading age and generally associated with up to 50% information retention for patients<sup>[44,45]</sup>. There is consequently a clear need for improved patient/ parent

information resources, which may improve both their understanding and expectations of surgery, as well as facilitate a valid informed consent process and enable better postoperative satisfaction.

There now exists a range of technologies that may provide options for supporting patients/parents in this regard, with the use of video becoming especially widespread and available on personal devices through the internet and social media. Newer technologies such as virtual reality and augmented reality may also have a role in engaging patients, although these are still in their infancy with regards to medical education research and need further testing before more reliable and widespread use<sup>[46]</sup>.

The authors are therefore currently exploring the use of a specific animated patient/parent information video to help improve preoperative understanding and set expectations for “second-stage facial reanimation surgery”. Quantifying the impact of these videos using a knowledge quiz and feedback questionnaires for both patients and parents is also a key component of the project and findings will be reported as a multi-centre cohort trial in due course. Importantly, this will be used to enhance the informed consent process for paediatric facial reanimation surgery, rather than replace the patient-doctor discussion, and will aim to provide a universal video resource that may be appropriate for patients and doctors from a range of different countries, resource levels, and consent requirements.

Given the paucity of evidence, there is a need for further studies investigating effective strategies for patient/parent education and methods of optimising the informed consent process for paediatric patients. These may utilise patient-reported outcome measure questionnaires, which can be tailored to a paediatric population in parts, to provide both subjective and objective outcomes that can be evaluated systematically. Such resources may also help to provide context for parents to focus on the most important issues for them and address their main priorities for treatment in discussion with their surgical team. The issue of high literacy level affecting current patient information sheets, online resources, and questionnaires should also be an area of active effort to address in the future.

### **Limitations of the current study**

While this study identifies a significant gap in the literature regarding patient/parent education and informed consent for paediatric facial reanimation, there are several limitations. These are primarily associated with the limited sample size, as only four articles met the inclusion criteria. Equally, these studies are reviews or evaluations of educational initiatives rather than original research based on objective outcome data. This demonstrates the lack of high-quality studies available to support current recommendations for improving the informed consent process for paediatric patients and their families.

There do exist some useful online resources and guidance from medical bodies such as the AAP (in the USA) and GMC (in the UK); however, it is clear that further research in conjunction with a focus on standardisation, outcome reporting, and the use of simple technology such as videos, may pave the way for more holistic and evidence-based management of paediatric facial reanimation patients in the near future.

In conclusion, There is a lack of useful and appropriate resources available to support patients/parents who are undergoing paediatric facial reanimation surgery and postoperative rehabilitation. The current evidence in the literature is limited and of low quality, being supplemented in practice by non-validated online resources of inappropriate literacy level. There is, therefore, an important need for further tools and educational platforms to be developed that may support all patients, especially children and their parents, to engage in a SDM process and be able to provide valid informed consent for their surgery. Providing simple information videos that are validated and can be watched by families in their own time may be one potential

option to help improve patient education and set realistic expectations for their treatment journey from the outset.

## DECLARATIONS

### Authors' contributions

Made substantial contributions to the conception, design, writing, and final approval of the manuscript: Reissis D, Zubler C, de Buitelir E, Brown S, Leckenby J, Grobbelaar A

### Availability of data and materials

Not applicable.

### Financial support and sponsorship

None.

### Conflicts of interest

Not applicable.

### Ethical approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

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