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# AboutFace

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*A blueprint for sustainable face transplant  
policy & practice*

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## AboutFace

AboutFace is a major interdisciplinary research project, based at the University of York, led by Prof Fay Bound Alberti and funded by a UKRI Future Leaders Fellowship. It researches the history of face transplants and their psychosocial, cultural meanings, working with extended surgical teams, patients and families, organisations and policy makers to evaluate the impacts of face transplants on patients, practitioners, donors and families, and to explore how media representations influence policy and opinion. AboutFace also evaluates face transplants as a form of innovative surgery, and explores links between ethics, emotion, identity and facial appearance.

For more information visit: <https://aboutfaceyork.com/>

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## The Power of Numbers

The Power of Numbers is led by Ross Pow who talks and teaches internationally on how to harness the power of information to shape decision-making and performance.

Having either run or advised data-led businesses in areas such as telecoms, publishing and finance, Ross has been able to experience at first hand what works and what doesn't when it comes to getting ideas across to influence the actions of other people.

The Power of Numbers is interested in what it takes to get people to act on information – not just in terms of responding to logical, rational arguments but also how we are all affected by the psychology of human thinking and behaviour.

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# Foreword



**Professor Emmanuel Morelon**

Former President of International Society of Vascularised Composite Allotransplantation

Since the first case of facial transplantation in Amiens, France, in 2005 we have learned that facial transplantation is a therapeutic option for extensive facial injuries which are not amenable to conventional reconstructive surgery, offering patients outstanding aesthetic, functional and psychological outcomes, leading to improved social reintegration and quality of life.

However, this new field of reconstructive transplantation has not developed as it should, due to long-term uncertainty regarding chronic rejection and graft loss, complications of immunosuppression, and a high degree of mortality; 10 out of 48 patients have died, while two have been retransplanted.

This presents a new ethical challenge which can be summarized as: better life, but shorter. In this context, the blueprint outlined here should pave the way for a shift from facial transplants as an experimental procedure to a standard of care and practice and is, therefore, of utmost importance for the field.

**Professor Emmanuel Morelon**

Former President of International Society of Vascularised Composite Allotransplantation

# Introduction

Since the first face transplantation surgery was carried out in France, 17 years ago, the field of vascularised composite allotransplantation to treat ‘severe facial disfigurement’ has advanced significantly.<sup>1</sup> In that time, 48 face transplant surgeries on 46 patients in 11 different countries have been reported, as surgical operative techniques, postoperative care, and patient evaluation procedures have continued to evolve, increasingly in specialised clinics. Today, the procedure is considered a ‘viable option’ for patients suffering from severe forms of facial deficits due to injury or disease, that are not treatable by conventional reconstruction.

However, numerous question marks remain as to the clinical, social, ethical and economic sustainability of face transplants for patients, their family support networks, and clinical providers. Face transplantation is a highly complex and expensive procedure which involves considerable medical and psychological risks, and necessitates life-long follow-up care and immunosuppression for patients. Moreover, data on long-term clinical or quality of life outcomes is mostly lacking or not shared between programmes. Worse, no universal standards of care or agreed metrics of success for face transplants currently exist, something the AboutFace team, along with some of their collaborators have noted in a paper currently under review (Bound Alberti, Ridley, Herrington, Benedict, & Hall, *Under Review*).

Many of these concerns were highlighted in 2006 by the Royal College of Surgeons, whose *Facial Transplantation Working Party Report* outlined “considerable reservations” about the risks associated with the procedure and outlined a set of minimum requirements for face transplants in the United Kingdom, where the procedure is yet to be carried out.<sup>2</sup> These include complex questions regarding informed consent; the duty of care to patients and their wider support networks; the rigour of patient selection procedures; the seriousness of clinical risks, such as chronic rejection, and the challenge of long-term immunosuppression; the potential for significant psychological implications; and the problems of the largely unknown long-term outcomes for patients. The costs of face transplants and follow up care requirements and a lack of financial resources such as governmental or insurance support, threaten viability of programmes performing these procedures around the world.

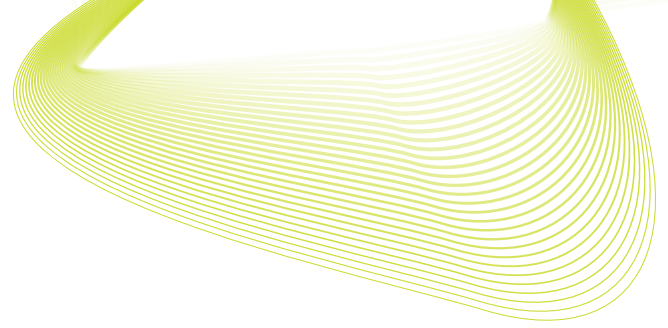
In light of these ongoing challenges, **AboutFace** at the University of York, and **The Policy Institute** at King’s College London, organised a Policy Lab to facilitate a collaborative, open dialogue on the complex clinical and non-clinical challenges for face transplants. The goal of this Lab was to discuss and build consensus around a “blueprint” for sustainable face transplants that could act as a resource for clinical teams and stakeholders around the world seeking to improve policy and practice.

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1 AboutFace opts to use facial difference and other similar terms that prioritise the perspective of the patient. However, the term ‘disfigurement’ is favoured by some disability activists because it is enshrined in law in the Equality Act 2010. Disfigurement is also used in surgical and clinical contexts, and is therefore used in this report. For more discussion about terminology, see <https://aboutfaceyork.com/about/our-values/> and <https://www.changingfaces.org.uk/for-the-media/media-guidelines-disfigurement/>

2 See: The Royal College of Surgeons of England. (2006). Facial Transplantation: Working Party Report (2006). Royal College of Surgeons. <https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/facial-transplantation-working-party-report/>

# The Policy Lab



The virtual Policy Lab was convened over three days (15-17 December 2021), where a select group of invited stakeholders and experts – representing international teams and interdisciplinary backgrounds, including leading clinicians, ethicists, psychologists, policymakers, and qualitative researchers – examined the challenges facing face transplants and the mandate for a collaborative blueprint for sustainable policy and practice.

The Lab consisted of four intensive workshops in which the Lab's 25 delegates were split into interdisciplinary breakout groups to explore **six key themes** for a proposed blueprint for face transplants policy and practice. These themes were established in advance by the Lab organisers and focused on the clinical, logistical, social, economic, and cultural challenges faced by the field, informed by the latest research in the field. The themes were introduced to Lab delegates prior to the event in a pre-Policy Lab briefing pack. Participants also received a pre-Policy Lab survey designed to capture views on these themes, establish areas of consensus and disagreement, and help advance discussions towards establishing a blueprint.



A full list of delegates, the contents of our pre-Lab survey, and the Lab schedule can be [found in our online appendix](#).

Day one broadly discussed these six themes as a whole and explored any potential gaps in the overall road map of the blueprint. Day two consisted of two intensive workshops, each of which examined three of the key themes, considering the challenges and potential opportunities within each area. The final day focused on reviewing progress and discussing next steps for progress with a proposed blueprint.

# Outcomes of the Lab

## A blueprint for sustainable face transplants

This document reports on the outcomes of the discussion in the Policy Lab, organised around six key themes, and provides a synthesis of the key recommendations that emerged from each session.

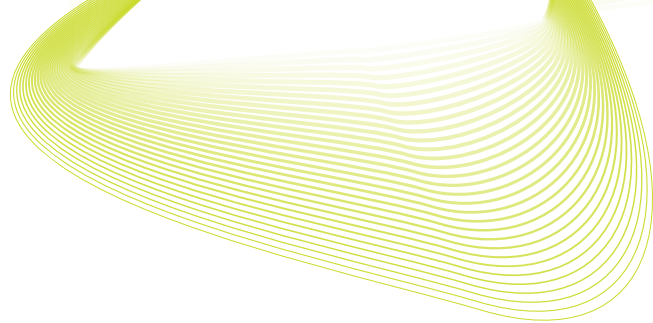
The primary outcome of the Lab is a “blueprint” which consists of a set of key processes, recommendations and considerations, for sustainable policy and practice in face transplants. The blueprint was informed by the latest clinical and qualitative research on face transplants and was developed through a deliberative process by some of the field’s leading practitioners and researchers who participated in the Policy Lab.

*This blueprint provides a “gold standard” for policy and practice to which all face transplants programmes should seek to aspire. This report is aimed at practitioners, clinicians, researchers, or any stakeholder involved in the establishment or continued development of face transplant programmes, and provides a resource to inform decision making in multiple critical areas of policy and practice.*

The “Key findings” section of this report outlines in detail the Lab discussions on each of the key themes and the recommendations arising from these, which form the basis of our blueprint for sustainable policy and practice.

The final section, “Conclusion & next steps,” provides a summary overview of this blueprint as well as further details on how interested parties or stakeholders can support the widespread sharing of recommendations across international face transplant programmes.

# Key findings



## The six constituent themes

Our pre-Lab survey indicated a majority consensus among survey respondents on the make-up of a viable, collaborative blueprint for face transplant policy and practice. This was particularly clear on patient selection, support networks, and data on patient outcomes and progress, in which survey respondents indicated strong agreement on the need for cooperation and standardised approaches.

This level of agreement was also reflected in our first workshop session reviewing the six constituent themes for a blueprint and identifying potential gaps. Generally, participants agreed on the importance of the six themes. However, a range of additional points were raised – from identifying barriers to the implementation of a blueprint to concrete suggestions for policy and practice – which re-appeared in subsequent discussions.

## Centring the patient

The importance of acknowledging and incorporating the perspective of the patient emerged as a key point of consensus, informing a range of key questions and challenges.



Dry risk assessment is tricky, but we can incorporate patient narratives. What does life look like on a good day? What is a bad day? This kind of risk assessment is more intuitive.”

Chronic rejection (CR) is a fundamental concern for clinicians and patients and affects all areas of face transplant policy and practice – from clinical frameworks to public perceptions. A realistic view of the risk of CR needs to be acknowledged and integrated into ethical, shared decision-making processes with patients. This is also related to the question of what face transplants can realistically achieve for patients. Clinicians and patients together need to develop a clear understanding of how face transplants can potentially both shorten and improve life for patients. Regarding psychological assessment, participants noted the limits of psychometric testing, and the need for patients to be prepared in advance for the procedure and the realities of post-operative care. While others raised the importance of acknowledging a patient’s wider “social support network,” as well as their access to finance and other material resources, into post-operative care assessments.

Underlying all these discussions was a strong emphasis on the issue of “quality of life” and the need to develop a patient-centred understanding of that. Questions of “completeness”, “feeling whole again”, and patients’ understanding of the success of their transplant are highly subjective and varied. Any widely applicable blueprint needs to be able to incorporate these complex perspectives.

# Theme one: Patient selection & preparation

A key challenge for face transplant policy and practice is the question of patient selection. How can patient selection protocols successfully identify patients who are both clinically suitable and psychologically and socially resilient enough to manage demands of post-operative care, immunosuppression, and related challenges? What standards, protocols, or approaches can be used to improve these processes? Is international collaboration on this possible?

Our pre-Lab survey indicated that there was significant consensus on the importance of developing “universal standards” for patient selection informed by patient-centred measures, and that such a move should be supported by a widely accepted definition of “success” for face transplants.

## Developing patient selection measures

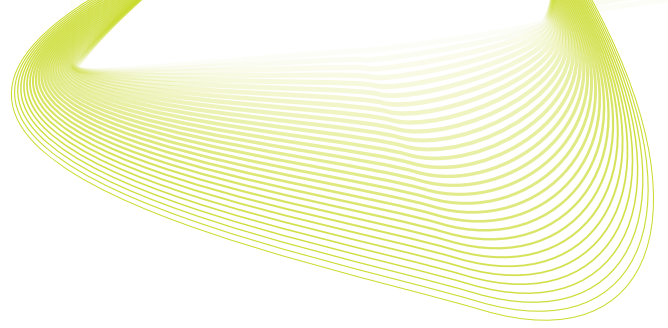
Currently, no established, standardised patient selection instruments for face transplants exist. In discussion, participants underlined that this is due, in part, to an absence of statistically meaningful datasets on face transplant outcomes, itself a result of a lack of standardised outcome measures, but also a result of the small numbers of patients involved. In this context, and until such time as more data on outcomes becomes available, qualitative insights on outcomes are required to inform assessment processes. Internationally, measures such as PROMS (Patient Reported Outcome Measures) and PREMS (Patient Reported Experience Measures) are already central to funders, and such a model might be usefully integrated in other settings to incentivise patient-centred assessments.

However, any assessment process should not be unduly restrictive of patient selection processes, which should remain centred on the singular case of each patient and their specific set of circumstances. Moreover, assessment practices and policies should remain cognisant of the particular psychological circumstances of face transplant patients. Patients’ perceptions of distress can be informed by pre-existing psychological disturbances, and this should be factored into assessment practices generally, as well as in individual assessment processes.

## A hybrid, individualised definition of “success”

Discussions made clear that any progress in face transplantation and broader VCA assessment methods would be dependent on developing a widely accepted definition of success. However, such a definition is not straightforward. While surgeons, clinical teams, or funders may have one definition of success, this might not align with that of the patient and their support network. Furthermore, for one patient, aesthetic outcomes may be paramount while, for another, other functions might be more important. Success is, therefore, a “moving target,” contingent not only on whether this is understood from a clinical or patient-centred perspective, which itself varies significantly from individual to individual, but also on patients’ individual medical and psychological circumstances. Moreover, definitions of success may be contingent on social factors, such as the expectations of family or certain cultural differences.





Understanding patient expectations, therefore, will be key to defining success. Clinical teams should consult with patients and their support network(s) to understand their singular perspective on what would constitute success. This should try to account not only for what clinical success would mean for them, but also how such an outcome is contingent on social, psychological, economic, and cultural variables. Undertaking such a process in collaboration with the patient, well in advance of the procedure, should allow for an individualised hybrid definition of success – in concert with clinical and funder measures - that helps manage expectations, assess suitability, and inform treatment prior to and after the surgery.

## **Standard processes for patient selection**

The highly individual, heterogeneous, and complex nature of face transplant presentations, treatments, patients, and expectations, means that a rigidly defined set of criteria is likely to be both unviable and undesirable for a widely accepted standard for patient assessment. As outlined above, instead, it is more practical and more appropriate for patient assessment across all contexts to adopt a standard set of processes. These processes, which should include patient-centred outcome reporting and a hybrid definition of success, can then adapt to the clinical institutional context and the circumstances of each patient. This standard set of processes (with varying outcomes) will also, therefore, allow for better comparative and collaborative understanding of patient selection trends, predictive measures of success and failure, and facilitate improved data-sharing.

## **Shared decision-making should be supported**

Implicit in the hybrid model of defining success is a consultative approach to patient assessment, which involves not only the patient themselves but also their wider family or social support network, in a decision-making process in collaboration with clinical teams and funders. This question arose under the theme of patient assessment, but is especially relevant to the next section, on patient support networks, where it will be discussed in greater length.

# Theme two: Patient support networks

Patient support networks are generally evaluated to determine whether a patient might be a good fit for a face transplant. But how is this support evaluated, and what might it need to include to ensure the true impact of becoming a face transplant patient is realised? What forms of support remain absent for patients and their wider social cluster that mitigate against face transplants being a socially and economically sustainable option?

Prior to the Lab, there was strong consensus from survey respondents on the importance of a patient's support network in securing positive outcomes for patients. There was also strong consensus that our understanding of a support network should include financial, practice, and psychosocial considerations, and that in this context, racial, gendered, and other biases should be guarded against.

## Avoiding a “top-down” approach to patient support

In discussions, there was broad agreement that support networks were a key component in ensuring the success of face transplants, particularly as regards the long-term post-operative care and resources required by patients. If the support network's attitude towards face transplants is negative, it was argued, it can be more difficult for the transplant candidate to proceed towards the operation and adapt to the transplant. And a lack of support can also be a risk factor for anxiety, depression and even suicide after the transplant. However, understanding what constitutes a “support network” is not simple nor easily standardised.



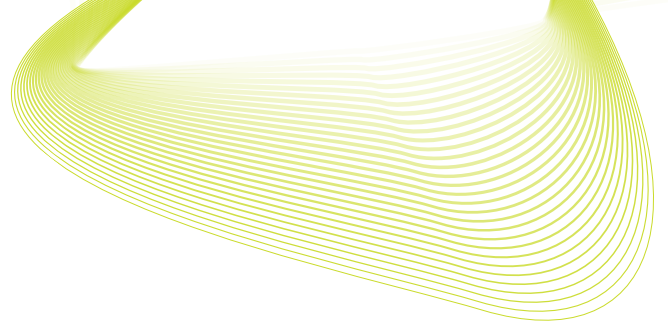
Top-down assessments are made by research institutions, siloed with their own interests - this is inadequate at best. Who is checking biases? We need to understand that these decisions this will affect an entire family.”

Wider social and support networks differ significantly from patient to patient and should be evaluated case by case. Moreover, a patient's network should be understood qualitatively, in relation to economic means, psychosocial, and practical support, and be sensitive to cultural context.

A key point here, raised in discussion, is that decisions made by clinical teams and institutions can sometimes be made in a “top-down” manner, decision makers failing to appreciate the perspective of the patient's wider social and family support. To understand more precisely what constitutes a support network for each patient, institutional and ethical decision-making processes, need to adopt a “bottom-up” approach. This should involve consulting both the patient – as already noted in Theme one – as well as that patient's wider support cluster, prior to and after the surgery, to understand the nature and level of support available and the kinds of care required – as well as the impact the surgery and long-term care will have on the patient's family or wider support network.

## Encouraging open conversations

Two related questions dominated the discussion of support networks: how to assess the negative impacts of becoming a lifelong patient against the benefits of a face transplant, and how the associated assessment can be communicated clearly with a patient? Some participants reflected on the difficulties of ensuring prospective patients fully appreciate the risks of face transplant surgery and long-term care. On the one hand, patients are subject to their own biases and limitations, and are



sometimes at a point of desperation, making realistic conversations around risk challenging. On the other hand, some patients are likely to be life-long patients with or without transplantation, meaning the potential benefits to quality of life, in the absence of chronic rejection, should be clearly communicated. In all cases, no easy answer is available and conversations around the complex assessment of risks and benefits take time.

To address this complexity, conversations with patients should involve all members of the wider clinical team and their support network and take place as early as possible in the process. This will facilitate a shared decision-making process and help to prepare the patient and their support network as early as possible as to the clinical, psychological, economic, and practical challenges that are likely to be involved.

Crucially, these conversations should also integrate open, narrative-based, qualitative discussion to help the patient and their supports to visualise the realities of their care and all potential outcomes. We need to understand how the patient sees their life with a transplant, and how their network of family or other carers will be able to provide support. Patients, their families, and clinicians, therefore, can proceed together in dialogue – whether choosing to proceed with a face transplant or another treatment – with the risks, benefits, and complexities explored in advance in a way that all stakeholders can accept.

## **Investing resources in patient support**

In addition to the question of a patient’s support network, participants highlighted the importance of practical and economic resources to ensure the long-term success of a face transplant. More than solid organ transplant recipients, face transplant patients need significant amounts of resources, particularly care resources, after surgery. Whether the patient can pay for this care long-term, or whether their family can take on these burdens of care is an important factor to consider when evaluating risks for patient success or their risk of non-adherence to post-operative immunosuppression.

However, filtering access to face transplants based on socio-economic resources risks creating structural biases that exclude people suffering from relative socio-economic deprivation, as well as on the gendered, ethnic, racial lines with which it frequently intersects. Recognising that the questions of economic resources and health inequality are common to all contexts, participants nevertheless provided several suggestions to address the general question of access to resources and the related issue of structural bias.

First, providers should consider the practical questions of pre- and post-surgical care: patients should be able to access clinics, meet clinicians, and receive support within a reasonable geographical limit. Secondly, providers should invest concrete resources and capacity to prepare patients and their ‘social cluster’ in advance of the procedure. This would amount to a form of social and psychological “pre-habilitation” to match post-operative rehabilitation processes, ensuring patients, families, and others are prepared for the costs – economic or otherwise – of the procedure in the longer term.

Another suggestion is to develop national and international support networks between patients and their wider networks so that patients can communicate with

peers and share experiences from others in similar circumstances. Finally, clinicians and providers should understand and remain mindful of the unconscious forms of bias and the intersectional forms of inequality that may determine the success of a face transplant for a patient and their support network.

The wider question of developing sustainable economic models for face transplants is a related but distinct issue which is explored in greater detail in Theme six.

# Theme three: Clinical frameworks



Developing best practice and policy for clinical frameworks will be key to the ongoing success and sustainability for face transplants, both in a purely clinical context and in relation to wider psychosocial, economic, and cultural domains. What are the greatest clinical challenges facing the field of face transplant practice, including chronic rejection, risks of immunosuppression, donor availability, and long-term clinical outcomes? How do these relate to questions around patient selection, support, and other non-clinical considerations? How do systems of donor recruitment and selection differ internationally with impacts on the sustainability of face transplant programmes? And how might these challenges be overcome by more consistent and collaborative reporting?

Respondents to our pre-Lab survey indicated a degree of polarisation on the question of whether international collaboration and international standard clinical frameworks were critical for addressing clinical challenges. Moreover, our survey indicated some disagreement as to whether face transplants should be viewed as entirely clinically unique or considered alongside other forms of transplant. However, while discussions in this section reflected the complexity of these questions, participants did agree on a range of concrete points to inform a blueprint for clinically sustainable face transplants.

## Overcoming institutional challenges

Discussions on clinical frameworks – as with the blueprint’s other key themes – made clear the need for clinical multidisciplinary teams to foster a long-term “transplantation culture”. Face transplant procedures are not a “one-off” event, but a long-term process, with multiple points of clinical contact and care prior to and after the surgery itself.

This culture should be embedded across clinical teams in which a multidisciplinary set of expertise are available to ensure the patient receives the necessary medical and psychological care. However, participants discussed several fundamental institutional challenges for teams looking to set-up and develop this kind of long-term transplantation culture.

A shortage of qualified and experienced psychologists and psychiatrists hampered attempts at developing face transplant programmes. Similarly, the breadth of experience required for clinicians is not always readily available, while data on patients itself is limited due to the low number of cases within teams. If there is some agreement among clinical teams that many of the basic clinical challenges of face transplants are surmountable, or at least their risks understood, participants also noted the ‘massive team effort and coordination’ and needed to develop a face transplant programme with a long-term outlook.

Aside from the question of funding models, which is explored further in Theme six, participants suggested that improved peer-to-peer collaboration – between teams across different contexts – would improve capacity in teams. This could be achieved, participants suggested, via easily established informal networks, on a case-by-case basis. However, this kind of initiative will be best supported by the development

of formalised modes of collaboration and data-sharing that help teams standardise processes and share learning, data, and experience.

## **Centring the patient in clinical frameworks**

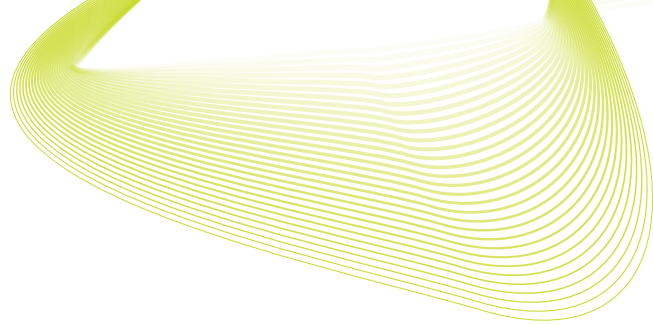
How and in what ways are the viability of face transplant procedures measured against more traditional forms of facial reconstruction, or even other forms of solid organ transplant? This question generated significant discussion among participants. Face transplants, it was argued, are highly specialised procedures and the unique circumstances of each patient and surgery should be attended to carefully. Unlike other forms of vascularised composite allotransplantation (including hand and penis transplant), faces may have lower threshold expectation of survival, providing only facial coverage and sensation. The primary goal of face transplant is not merely survival but enhancing quality of life and the unique quality of the face as an organ has implications for patients' identity and sense of self. Moreover, face transplant patients are a highly heterogeneous group, with varying indications, some of whom may have complex psychological or experience of trauma or be turning to face transplants after undergoing multiple other procedures.

What, then, might consist in a standard clinical framework to understand viability, in the absence of a universal understanding of patients and outcomes? Using generic measures, derived from other procedures, is a starting point, but face transplant programmes should collect standard but specific measures, grounded in the experience of the patient, which apply to this particular group to understand what matters to them – which in turn influences the clinical approach.

## **Common standards of care for post-operative therapies**

Although work in the field of face transplants has been progressing on the question of standards of care— such as technical considerations and definitions of success – participants underlined that there is still significant room for further development. However, it is not immediately clear what set of standards of care would be widely, if not universally acceptable, across numerous clinical, social, regulatory, and economic contexts. For example, in the United States there is sometimes a lack of funding to sustain long-term post-operative care, such as the case of co-payments for medications. In that context, how viable is it to create a broadly acceptable international standard of care?

Key to addressing this kind of challenge is understanding the potential differences in the practical viability of some standards in some contexts, and the varying levels of likely take-up, while continuing to pursue a “gold-standard” of care to which all programmes can aspire. The blueprint that this document sets out will help clinical teams think about what is needed for a successful programme, at a provider level as well as for regulators and funders, so these stakeholders can assess existing and proposed programmes in terms of effectiveness. A robust and open international network committed to sharing, publishing, and peer review will also aid in creating this standard of care internationally.



## Predictors of success, failure, and other clinical outcomes

Lab participants explored how clinical teams could work predictively rather than in a reactive manner, by improving our understanding of likely patient outcomes. With that in mind, to improve clinical outcomes and patient selection, clinical teams, policymakers, and funders should contribute to and support research that investigates predictors of success. This will allow face transplant programmes to understand in advance what kinds of patients are likely to respond well to surgery and to inform clinical choices before and after the surgery, rather than responding reactively to clinical problems. To do this, however, clinical teams need to be open about failures as well as successes, while collecting additional data on specific outcomes – such as genetic data and other biomarkers, as well as psychological assessments and social outcomes. Moreover, that data will have to be shared across borders, between teams in different contexts, to develop a sample size large enough with which to make informed conclusions.



What do we do if this fails? What are our exit strategies? Funders say it is great to be pushing boundaries but what happens if it fails – and we lose not just graft but other elements of the larger face transplant?”

## Contingency plans for chronic rejection and graft loss

In discussing clinical frameworks for face transplants, and the potential for a standard approach or set of processes, the risk of serious clinical risks – such as chronic rejection and graft loss – and outcomes which could be considered a “failure” were raised several times. It was underlined that no standard set of processes or guidance exists for dealing with failure in face transplant procedures or care. In that context, it was noted that while funders and other stakeholders are enthusiastic about pushing the boundaries of surgical possibility and procedures, it is not clear how to respond when an experimental treatment results in undesirable outcomes, such as losing elements of the graft or even bone, in the case of larger face transplant procedures. Clinical frameworks for face transplants, therefore, need to integrate contingency planning and “exit strategies” – providing patients with a set of options for a range of eventualities, including chronic rejection, and not just the best-case scenario. As was stressed in discussions on Themes one and two, early, open, and realistic consultation with patients and their support network would provide the opportunity to communicate these risks with patients and develop a series of plans for all reasonable outcomes. This will not only contribute to ethically transparent shared decision-making, but also to improved outcomes, by securing “buy in” from patients and families.

## Implementing complete transparency of governance

One of the key points under consideration under this theme was governance. While the singularity of face transplant procedures and clinical frameworks was acknowledged, participants explored whether examples of governance from other, comparative procedures could provide an example in this field. Have other blueprints been produced that have positively influenced policy and, through that, on medical outcomes for other clinical areas?

Face transplant programmes should look to other transplant programmes, or other comparable procedures, such as gender reassignment surgery, especially where outcomes relate to quality of life rather than survival, to develop frameworks for

governance. Most importantly, clinical frameworks require complete transparency, including international and national forms of regulation (such as formalised data-sharing agreements), oversight of dunging, and ethical decision making at the level of the provider.



# Theme four: Data on patient progress and outcomes



It is widely recognised that there is insufficient data on face transplants from the perspective of patient progress and outcomes. This is in part a result of the relatively small numbers of procedures carried out globally but is also caused by a lack of open data-sharing between clinical teams. How can better forms of data-sharing be fostered to create a common evidence base and potentiate learning? What standard term of reference would be acceptable to help create such an evidence base? What metrics or terms of reference are required to track and evaluate patient outcomes over short-, medium-, and long-term timescales?

Prior to the Lab, respondents to our survey broadly agreed that better data collection and sharing processes were desirable for face transplants, helping to support standardised metrics for patient outcomes and progress. Building on these areas of consensus, discussion in the Lab workshops evinced wide agreement that improved data collection and sharing was critical to improvements in all areas of policy and practice, from patient assessment and support networks, to improved clinical approaches, and funding models. However, as the following sections show, such consensus did not avoid realism on the barriers to implementing these suggestions.

## **Standard measurement tools, databases, and outcome sets**

Much of the discussion of this Lab focused on two key principles for policy and practice: collaboration and standardisation. Already outlined in this document are suggestions to standardise outcome measures, definitions of success, processes for patient selection, standards of care, and research into predictive measures and to do so in a collaborative manner. Additionally, these standards, measures, and tools should be developed in close consultation with patients and their support networks and sharing them among clinical teams in different contexts. In discussions around data collection, participants underlined the very same principles.

While it was pointed out that data on face transplants does exist from the past decade, there are no current studies reporting short- or long-term outcomes for face transplantation that combine clinical and qualitative researchers. Other forms of research, it was argued, can be influenced by methodological bias, and fail to present a clear picture of what face transplants are like for patients. In that context, it was agreed that standard measurement tools, databases, and outcome sets should be developed for use across all settings, combining generic metrics with as many measures specific to face transplants as possible.

In addition to clinical metrics and psychological assessment, this should include the development of a widely acceptable understanding of Quality of Life, which accounts for the patient's reported outcomes and experience (PROMS and PREMS) as well as other non-clinical markers such as social reintegration or return to work. Such forms of assessment and measurement should be developed in close consultation with patients, charities, and support networks to ensure they remain grounded in their experiences and priorities.

## **Widening the net of data collection and reporting**

While much discussion in this workshop focused on the question of what can be measured or reported on when a patient undergoes a face transplant, it was emphasised that comparatively little is known about what happens to patients who decide not to proceed with the surgery. To put it another way, we need to understand the natural history of not doing anything to establish comparatively the full range of outcomes for people living in various ways with facial difference.

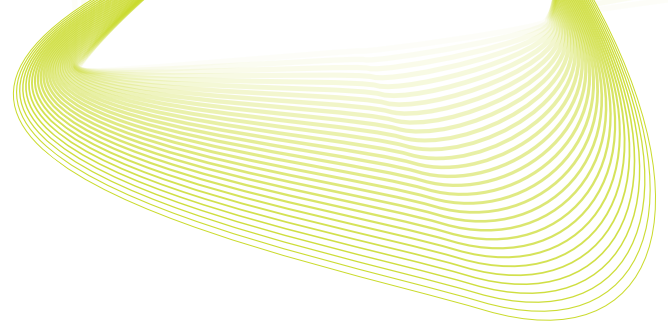
To ensure this data is captured, it was proposed that patients should be enrolled on a face transplant programme at the point of referral and their outcomes tracked even after the point that surgery is not pursued. Following up with enrolled patients at specified intervals would effectively constitute a long-term study that would provide valuable data with which to understand both the benefits and risks of conducting versus not conducting the surgery. Moreover, including families and support networks in this study would provide information not only on patients that undertake the surgery but also of the wider impact of being referred and, more widely still, of severe facial difference.

## **Overcoming barriers to data-sharing and collaboration**

While there was general consensus on the importance of developing standard, widely acceptable data collection measures, procedures, and practices, discussants sought to underline some of the barriers that could limit the implementation of such guidelines. Firstly, practically speaking, it might be challenging to integrate widely expanded, qualitative, and collaborative data reporting protocols into existing and complex face transplant workflows in different contexts. There may also be challenges around data ownership and protection, ensuring data can be easily shared, while remaining protective of the patient's privacy. Moreover, it was acknowledged that completion rates for PROMS and PREMS are not always reliable.

To integrate new data collection and sharing practices, clinical and research teams will have to remain mindful of the trade-off between data quality and ease of completion and collection. Another challenge is the logistical complexity of accessing patients regularly over a long period of time. For patients that may have complex clinical and psychological challenges, reporting to clinics or researchers beyond standard clinical touchpoints is likely to be a challenge. This underlines a previous point made in Theme two that patients should be able to access clinical and care resources within a reasonable geographical limit.

Another challenge is the necessity of collecting and sharing data on negative outcomes of face transplants. As participants of the Lab pointed out, such data is critical in learning lessons and sharing best practices across different teams, however, it is not always easy to gain access to such information. The culture of face transplantation is competitive, with the value of open collaboration at times exceeded by the interests of individuals and institutions, who are also keenly aware of the need for positive public perception of face transplantations. Sharing negative data that might appear to reflect poorly on teams or clinicians, then, is not always a simple proposition.



## **A compulsory international registry**

To support face transplant programmes in implementing a range of new data collection policies, metrics, and sharing protocols, a robust set of regulations or clear incentive structure is required. In discussions in this Lab, while acknowledging some of the inherent difficulties in enforcing any regulatory or compulsory data sharing policies, the preferred instrument is a compulsory international data registry for all face transplant procedures, to which any trusted programme must sign on.

Going beyond a voluntary mechanism for data-sharing would ensure negative or challenging results are shared and the centralised nature of the registry would allow for the implementation of standardised metrics. The key incentive of such a mechanism is that adherence to the policies and regulations of this registry would represent a “gold-standard” of data transparency, collection, and collaboration, helping also to embed the key qualitative and patient-centred metrics that constitute this proposed registry within the workflows of existing face transplant programmes.

# Theme five: Public image & perception

Media and wider representation of face transplants can offer a sensational or inaccurate view of the procedure and its outcomes, embedding unrealistic expectations among the public regarding face transplants and reproducing problematic ideas about visible facial difference. How best to create an environment where the psychosocial, medical, and environmental complexities of face transplants and facial injuries or medical conditions are widely explored? How can stakeholders, clinical teams, or policymakers better communicate these complexities for the benefit of patients, families, and potential donors, as well as for people with facial disfigurement more widely?

Responses to the survey undertaken prior to the Lab indicated relative consensus on the importance of media narratives and public relations to the continued success of face transplants for patients and clinical teams. However, discussions in our Lab workshop – initially, at least – reflected the wider view that such questions are subordinate to issues of greater urgency, such as clinical challenges and patient selection procedures. The Lab nevertheless produced a useful exploration of a range of complex questions and reflected some of the challenges and opportunities relating to media and public perception, the results of which are outlined below.

## Differentiate between media genres and channels



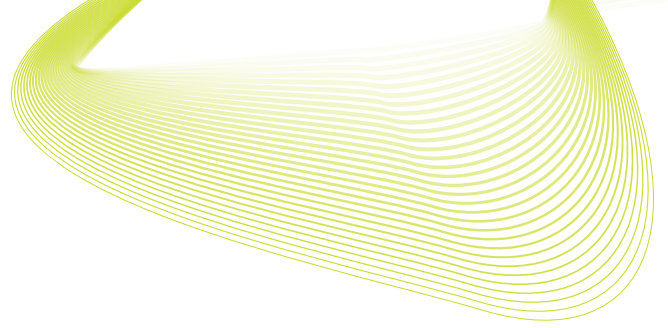
Many of our patients do develop independent relationships with the media - they have been interviewed and often feel a degree of motivation to advocate for the field”

How can clinical teams, institutions, patients, and their families be supported to have good relations with media outlets and nourish a positive public perception of face transplants? Discussions in this workshop demonstrate that this is not a simple question: the media landscape is a highly complex ecology with a multitude of actors, interests, drivers, and narrative forms. Today, “media” is also a contested term, which may involve both traditional media like newspapers and television, as well as new media forms like social media or internet forums, and even fictional forms, all of which may influence public attitudes towards face transplants and the expectations and experiences of patients and their support networks.

To begin, all stakeholders - clinical teams, researchers, patients, and support networks - need to develop an awareness of key distinctions between media forms, in order to better navigate this complex field. Stakeholders should seek to understand, first of all, the basic differences between genres of media – particularly in news media where certain styles of reporting will tend to focus on particular types of narrative. Clinical teams should be aware of trusted outlets and reporters.

Patients and families should also, where possible, seek to understand the risks of engaging with certain media forms, especially on social media where an entirely unregulated environment can encourage highly damaging narratives and unrealistic expectations. Indeed, in the current news environment, clinical teams and institutions should be aware of the capacity for patients to share their narratives independently and advocate for face transplants.

In order to build this capacity for media awareness, institutional and clinical communications teams, media centres, and/or public relations teams should work in consultation with clinical teams and patients. This will provide dedicated media teams with an understanding of the full complexity of face transplants which, in turn,



can be leveraged to support clinical teams and patients in understanding the media sphere, its benefits, and potential risks.

## **Refocus from medical competency to patient experience**

Dealing with questions of public perception also implies a range of highly challenging conceptual questions such as what constitutes normality and the pervasion of wider ideological and attitudinal biases in relation to facial difference and “otherness”. That said, participants in our Lab did identify some common themes. These included a persistent focus on sensational aesthetic outcomes, the before and after comparison, and medical and surgical skill, as well as a general absence of a nuanced or longer-term view of transplantation, which might include an acknowledgement of immunosuppression or functional outcomes.

As outlined in the previous point, it is not simple to just change these attitudes, given the complexity of the media sphere. Nor is it possible – or desirable – to try and control media narratives. Instead, stakeholders should be encouraged to acknowledge the narratives that do dominate the media sphere and public perceptions and to try – where possible – to shift narratives away from simplistic, outcome-focused, sensational framings towards a more patient-centred narrative that includes the nuances already mentioned.

This might involve encouraging media engagement with clinical experts at an earlier stage of the process, encouraging wider involvement in media relations beyond the patient, and becoming cognisant of language use, particularly in relation to questions of “deformity”, “abnormality”, visible difference and “disfigurement”. At the very least, stakeholders remaining vigilant and cognisant of these tendencies and narratives in media reporting – as well as having an understanding of the different kinds of media outlets – will help offset the inherent risks. It will also encourage positive narrative reporting on face transplants, refocusing media attention on the longer-term stories of patients and face transplants as broader social and historical phenomena.

## **Media relations toolkits**

As numerous participants pointed out, it is relatively easy to suggest that key stakeholders remain cognisant of dominant narrative trends and the distinction between different forms of media. It is less easy, however, to put in place robust, standard, and practical mechanisms that ensure all stakeholders can access this knowledge and implement best practices. Media narratives are difficult to manage and providing consistent messaging requires high levels of organisation. Developing universal standards for communications and reporting – whether they apply to media outlets, patients, or clinicians – will also prove difficult given the difference in media contexts and regulation internationally, not to mention the complexity of media ecologies within individual national contexts.

Nevertheless, participants believed it is important that all the key stakeholders involved in a face transplant should be provided with the resources to support them in making good decisions with regards to media and public relations. For patients and their families, institutions should provide a toolkit to support them in dealing with

the inevitable interest from media outlets, as well as to manage potential intrusions into their privacy. For those that wish to speak to media outlets independently, face transplants programmes can at least provide a set of suggestions and best practices to follow, based on the key points raised above.

Similarly, members of clinical teams should be provided communications support and resources to help them navigate the complex media field and to avoid some of the pitfalls of media engagement outlined above. In exchange, clinical teams should provide input into a communications toolkit for institutional communications and PR professionals who may require more detailed, nuanced briefings on the nature of face transplants, to help steer narratives away from the sensational, aesthetics-focused narratives that dominate media attention.

# Theme six: Financial sustainability



The financial and economic aspects of face transplants are often overlooked in favour of questions around surgical viability and the procedure's perceived functional and aesthetic outcomes. However, it is imperative to understand how we can create financially sustainable face transplant programmes that are both viable within given health systems, in a range of different contexts, while also supporting patients and their families in the long-term.

Prior to the Lab, respondents to our pre-Lab survey indicated strong consensus on the need to integrate social, psychological, and other “externalities” to the cost assessment of face transplants. However, less clear was the question of whether a standardised or universal approach to cost-benefit assessments for face transplants was desirable or viable. The discussions that expanded on these questions were complex and sought to bridge gaps between the differences in financial circumstances across different economic and medical jurisdictions, without obscuring the specificities of each.

## Long-term clinical support

A critical component of this blueprint has been to emphasise the extended nature of face transplantation care, which goes far beyond the surgical procedure itself to involve a wider multi-disciplinary team and the patient's support network over a long-term post-operative period. As such, this longer-term perspective means that face transplants, to be sustainable for patients, families, and their clinical support team, will require significant ongoing resource to be effective. As well as the costs of long-term care, psychological or psychiatric support, immunosuppressants, and potential future additional surgeries, patients are likely to incur significant additional costs such as housing or travel costs, or other forms of rehabilitative support.

Each of these issues was underlined by participants, who also agreed that such costs are necessary to ensure the sustainability of a face transplant for a patient. The challenge here is to communicate to funders, whether private or public, that the costs associated with long-term and holistic care for face transplant patients are also offset by significant benefits. Lab participants discussed the potential longer-term savings and social benefits this kind of provision can provide. In all cases, however, best practice as part of a gold standard of care should ensure as a matter of principle that providers offer all necessary financial support to guarantee the necessary long-term clinical provision for patients.

## Improved cost-benefit analyses

Currently, there is no international or standard process for calculating the monetary costs of face transplants. As one participant pointed out, there is a general lack of transparency in relation to precisely how these costs are assessed. This is a key issue for the financial and clinical sustainability of face transplants, which require significant funding to continue – which in turn requires robust and transparent cost benefit analyses for funders, whether private or public. As the previous sections have shown, the challenge of developing a purely quantitative financial cost benefit analysis of face transplants, moreover, will be significant: as a life-enhancing

procedure, its benefits are more readily captured by qualitative or even narrative measures, rather than by monetised costings. Certainly, as some argued in this workshop, face transplants may provide significant savings in the longer-term (event cost versus process cost) by reducing repeat clinical visits and providing social and economic value. However, as a number of participants in this Lab pointed out, to the extent that such a costing is possible, it may nevertheless not provide a simple answer to the question of whether face transplants represent value for money.

How can we develop a form of cost-benefit analysis to ensure funders can confidently and fully fund face transplants? The answer to this lies in the distinction between analysis and decision: while the analysis may be largely monetary and quantitative in nature, the final decision on whether to fund – and to what extent – will likely take into account qualitative elements. The expansion of our costing models, therefore, must be willing to make a compelling argument in relation to the duty of care we owe to patients and the ultimate effectiveness of face transplant as an option – as opposed to other treatments. As such, cost-benefit analyses will be enhanced by improved data collection and sharing, as well as standard and more accurate procedures for patient selection.

## **Improved patient support resources and funding**

This discussion acknowledged that the problem of health inequalities - whether on socio economic, gender, or ethnic/racial lines - is a widespread one, and not confined to the field of face transplants. However, given the singular nature of face transplants, discussions sought to draw out the issues of health inequality relevant to this procedure, in relation to patient selection, as well as donor availability.

Participants pointed out how health inequalities are particularly likely in private health systems, where funding for face transplants may be constrained by insurance plans and patients' access to financial support in the long-term. There are clear implications here for equality of access for people without significant socio-economic means, which are also likely to intersect with other forms of inequality (gender, race/ethnicity, sexuality). However, in the UK, where healthcare is nationalised, a face transplant has yet to be carried out, due in part to the rigorous standards for care recommended by the Royal College of Surgeons. This suggests that equality of access is also partly contingent on ensuring that clinical teams are able to satisfy public funders' and regulators' requirements with regards the clinical, psychological, and ethical sustainability of face transplants, so that patients in both public and private systems have access to face transplants.

In addition to the fundamental question of access, health inequalities are especially likely to affect patients in the longer-term, due to the lifelong clinical, pharmaceutical, psychological, and rehabilitative care required for patients after the procedure itself. As a starting point, funding for face transplants should integrate these costs, to ensure that socio-economic and intersecting forms of inequality do not affect the outcomes of face transplants. Funders should also seek to take into account wider questions of social capital, geographic location, and cultural context, to ensure patients that need additional support - such as travel or housing costs or access to support networks - can access the necessary funds, if required.



# Overcoming barriers to implementation



This section addresses three barriers to the implementation of the blueprint recommendations outlined in this report's six component themes. These are issues that were raised repeatedly across discussions in the Lab and are key cross-cutting challenges in all areas of face transplant policy and practice.

## International differences

The institutional, regulatory, practical, and policy space of face transplants is a highly fragmented one which varies across national contexts. Individual countries and face transplant programmes have different clinical, social, and economic needs and constraints, including the recruitment of donors, which will shape how they understand the risks and benefits, as well as any potential direction their policies and practices will take. Moreover, individual teams and programmes will have their own set of interests and priorities, themselves shaped by the cultural, social, economic, and clinical circumstances of their individual context. These factors have significant implications for the development and implementation of any standardised or widely accepted set of practices and policies, including those set out in this report. The recommendations outlined in this blueprint have been formulated with precisely this challenge in mind. Having been developed collaboratively between multiple international stakeholders in our Lab, the blueprint provides a set of standard processes and considerations, designed to be adaptable to the specific context of any face transplant programme.

Furthermore, while the institutional field of face transplants may seem internationally fragmented, its global nature provides us with a diverse and international network of practice from which to draw lessons. This is also a key resource to support the development of face transplant programmes in new international settings.

## Funding and resources

Face transplantation is a costly medical procedure requiring significant long-term funding to ensure positive outcomes for patients beyond the procedure itself. It is also dependent on being able to attract suitable donors. Whether a face transplant programme is based in a jurisdiction with nationalised healthcare funding, or within a private or semi-private health system, access to adequate funding for face transplant programmes continues to be a challenge.

The recommendations set out in this blueprint seek to improve practices and policies regarding cost-benefit analyses, to ensure both private and public funding systems appreciate the potential longer-term value of face transplants. However, our aim here is not to make the argument for face transplants on the basis of a monetised cost-benefit analysis. However much added value such an analysis might provide, it is likely that face transplants will continue to be costly, and an acknowledgement of this fact is critical to making realistic and accurate proposals to funders as to the wider benefits of face transplants for patients and their future sustainability for health systems. This process of understanding the benefits as well as the costs will be further enhanced by the implementation of qualitative reporting processes we propose in this blueprint.

## Data-sharing and collection

This blueprint has made a number of key recommendations to ensure that data-sharing and improved data reporting practices are adopted by new and existing face transplant programmes, a move that our Lab showed would support the sustainability of face transplants across a wide range of domains, including patient assessment, clinical standards and frameworks, as well as funding models and economic analyses. However, as numerous participants in our Lab pointed out, in addition to being internationally diffuse, the field of face transplant surgery has historically been highly competitive – rather than collaborative – where decisions are made according to the individual priorities of institutions, teams, or clinicians. For better data-sharing and collection practices to be adopted, a culture shift will be required. The establishment of any mechanism for better data practices demands willingness, significant coordination, and capacity from stakeholders – and this will depend on a change in the wider culture.

The Lab and this report may represent the first indications of a shift in culture, towards a collaborative ethic in face transplant policy and practice. Our Lab attracted 25 participants from contexts across Europe and North America and took part in open, collaborative discussions on a variety of nominally difficult questions, including data sharing. As our report makes clear, there is significant appetite to improve data-sharing practices; the establishment of formal structures – such as a centralised, mandatory data repository - to meet this demand represents a realistic logical next step.

# Conclusion & next steps



The purpose of this Policy Lab was to convene a multidisciplinary and international expert group on face transplants and to work towards the development of a blueprint for sustainable face transplants policy and practice. It was our aim to create recommendations which would be widely acceptable and applicable in a range of contexts.

The blueprint we have developed in collaboration with Lab participants includes six component parts, an overview of which is outlined in the table on the next page.

- 1. Patient selection and expectations:** creating a standardised multi-perspective, patient-centred, and holistic procedure for managing patient selection and their expectations;
- 2. Patient support:** encouraging a “bottom-up” approach to patient support and enabling patient discussions on clinical approach to take place earlier;
- 3. Clinical framework:** creating standardised, transparent, and flexible metrics of success, common standards of care, and modes of governance;
- 4. Data on patient progress & outcomes:** developing a range of data and reporting procedures, including internationally shared metrics, and accounting for long-term and/or negative outcomes;
- 5. Public image & perception:** creating toolkits to support practitioners and teams in dealing with media interactions, to ensure better public understanding of the procedure’s complexity;
- 6. Financial sustainability:** ensuring long-term financial support and addressing funding inequalities through establishment of improved understanding of outcomes.

# Possible components for a “Blueprint”

Patient selection & expectations	Patient support	Clinical framework
<p>Understand fully the <b>lives and perspectives of patients</b> (views on QoL and success, visual narratives, hopes and fears, natural life course, description of good and bad, ethics, values, required support, etc)</p>	<p>Fostering a <b>“bottom up” approach to determining patient support</b> that starts with understanding the individual, their situation and needs, rather than prescribing this “top down”</p>	<p>Taking a <b>“transplantation culture”</b> across the whole multi-disciplinary team that recognises the necessary long-term commitment required to support face transplant patients</p>
<p>Achieving a <b>multi-perspective agreement on success</b>, combining input from the “social cluster” (with the patient at the centre of this), the “clinical cluster” and the “funding cluster”</p>	<p>Encouraging <b>conversations to happen earlier</b> with face transplants presented as a last resort when other options have been exhausted</p>	<p>Ensuring programmes follow a high quality <b>standardised process</b> that is protective of the patient and that can be flexibly adapted as per cultural setting requirements</p>
<p>Using a <b>standardised approach to patient selection and assessment</b> including setting reasonable expectations based on a realistic approach to risks and benefits (patients, clinicians, families, etc)</p>	<p>Enabling <b>patients to speak with each other</b> (eg establish global network)</p>	<p>Researching <b>predictors of successful clinical care</b> (eg genetic biomarkers, trauma and its implications as key part of aetiology, etc)</p>
<p>Supporting <b>shared decision-making</b> (eg informed with capacity, stable, committed, etc)</p>	<p>Investing resources where the situation allows to <b>prepare patients in advance</b> of the procedure (eg social and psychological pre-rehabilitation, etc)</p>	<p>Agreeing <b>common standards of care</b> for therapists</p>
		<p>Contending with <b>chronic rejection</b> and graft loss (salvage/exit strategies, etc)</p>
		<p>Having complete <b>transparency of governance</b> (national regulation, oversight of funding programmes, ethical decision-making at provider level, etc)</p>



# Beyond the Lab

The recommendations outlined in this report, summarised in the table above, represent a blueprint for a “gold standard” of policy and practice for sustainable face transplants internationally.

We recognise that clinical teams and face transplant programmes in different contexts will have different priorities, practical barriers, and needs for support. For precisely this reason, we strongly propose that the gold standard of policy and practice here represents a goal to which all face transplants programmes should aspire. The recommendations we propose are based on the most up-to-date knowledge and research on face transplants drawn from multi-disciplinary experts and were developed through discussion and deliberation in over three days in our Policy Lab.

What can you do to support the take-up and implementation of this blueprint for a gold standard in face transplant policy and practice? We ask that if you have read this blueprint and support its recommendations to share it widely across your professional network, to colleagues, collaborators, clinicians, patient groups, or any other interested stakeholders. To build momentum, it is crucial for this blueprint to reach as many interested parties as possible.

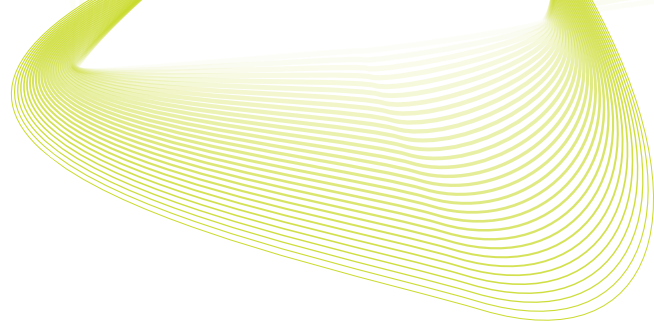
As AboutFace at the University of York continues its research into face transplants, it will continue to explore the themes outlined in this document, and work with interested stakeholders on developing the suggestions outlined here into policy impact. In particular, AboutFace will be examining, in consultation with collaborators, how this blueprint can be applied across different contexts, to ensure implementation of its recommendations remains sensitive to the requirements of individual clinical teams and, crucially, patients.

**If you feel like you can contribute to this work or have questions, thoughts, or queries about the blueprint more generally, we would like to hear from you. All correspondence can be sent to: [fay.boundalberti@york.ac.uk](mailto:fay.boundalberti@york.ac.uk)**

**Further information on AboutFace and its research can be found here at: <https://aboutfaceyork.com/>**

**To read further details of the Lab, including delegate list, schedule, and survey questions, [click here](#).**

# Afterword



**Vijay Gorantla**

Professor of Surgery, Ophthalmology  
and Bioengineering at the Wake Forest  
School of Medicine

With close to 50 face transplants to date, and as more are attempted across the world, there is an imminent need to address program standards, patient support, public perception, and progress metrics with the goal of increasing generalisability of outcomes after these complex procedures.

The Policy Lab is a first attempt to build a blueprint for collaborative consensus on policy development for clinical practice, standards of assessment, and advocacy of VCA with a patient-centred approach.

Experts from across the world examined issues related to standards for safety, efficacy, feasibility, privacy, confidentiality, and equitability, as well as patient, donor, family, and societal barriers to VCA, including limitations to access and affordability questions.

The Policy Lab recommendations will help develop guidelines that define success/failure and validate new therapeutic approaches, increase quality of standardized evidence for patient-centric, clinical decision making, provide objective cost-value analysis for reimbursement, and inform health policy for approval and adoption of a face transplantation as a standard of care, safe, effective, and ethical therapeutic option.

# About the authors



## **Fay Bound Alberti**

Fay is the project PI and in 2019 became one of the first UK Research and Innovation Future Fellows for the AboutFace project. She is a Professor in History at York, and was the co-founder of the Centre for the History of Emotions at Queen Mary, University of London.

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## **Dr Vijay Gorantla**

Vijay is Professor of Surgery, Ophthalmology and Bioengineering at the Wake Forest School of Medicine. Dr. Gorantla is currently the President of the International Society of Vascularized Composite Allotransplantation and a founding member and board member of the American Society for Reconstructive Transplantation.

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## **Professor Emmanuel Morelon**

Emmanuel is the former President of International Society of Vascularised Composite Allotransplantation.

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## **Dr Sarah Hall**

Sarah is Public Engagement and Events Officer for the AboutFace project. She is an experienced events manager with significant experience in the Higher Education sector, and is interested in engaging with creative methods for disseminating academic research to different audiences.

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## **Ross Pow**

Ross is the director of Power of Numbers. He works with a wide range of clients in commerce, technology, education and research to harness the power of information to shape decision-making and performance.

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## **Dr Niall Sreenan**

Dr Niall Sreenan is a Research Associate at the Policy Institute at King's. He works across a variety of policy areas but is particularly focused on arts, culture, higher education, and research policy.

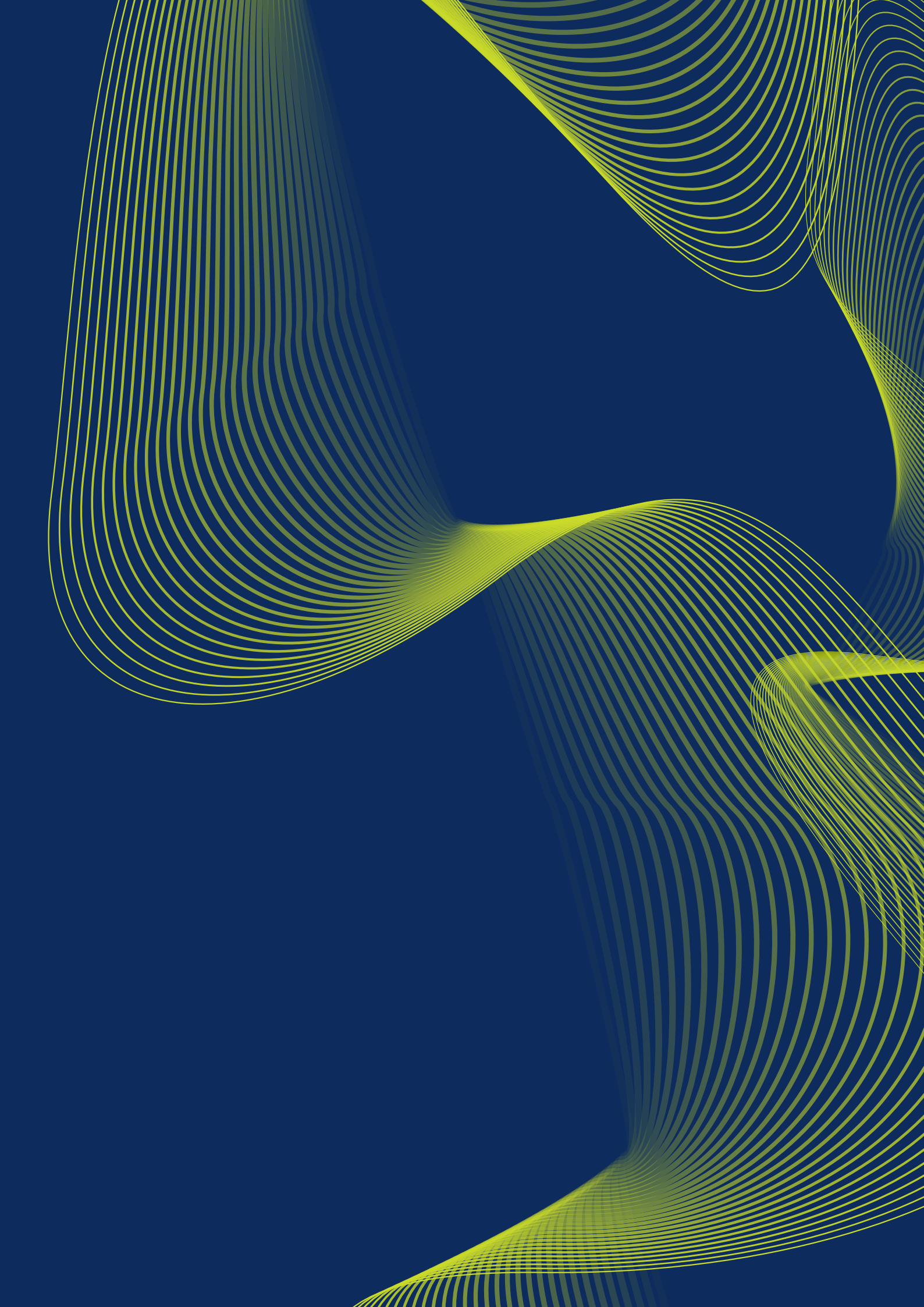
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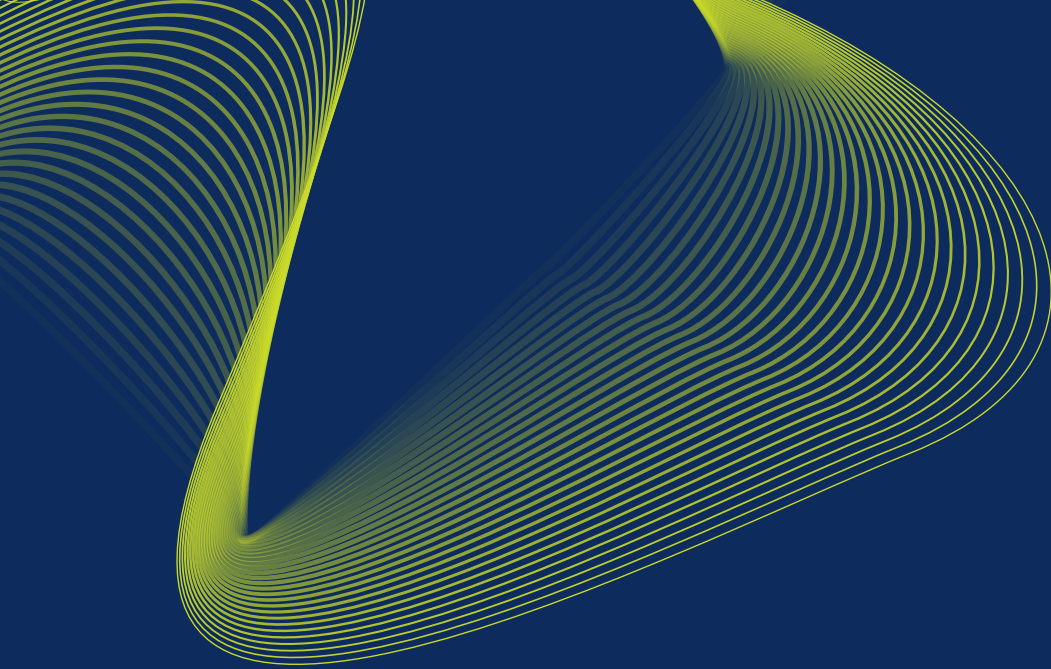


## **Dr Matthew Ridley**

Matthew is Postdoctoral Research Associate on the AboutFace project. He is a Chartered member of the British Psychological Society, a member of the International Network on Personal Meaning, and a member of the European Network for Positive Psychology.







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