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OPEN ACCESS

# 'A Procedure Without a Problem', or the face transplant that didn't happen. The Royal Free, the Royal College of Surgeons and the challenge of surgical firsts

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**ABSTRACT**

Face transplants are an innovative and unusual form of modern surgery. There have been 47 face transplants around the world to date, but none as yet in the UK. Yet in 2003, the UK was poised to undertake the first face transplant in the world. The reasons why it didn't take place are not straightforward, but largely unexplored by historians. The Royal College of Surgeons, concerned about the media attention given to face transplants and the ethical and surgical issues involved, held a working party and concluded that it could not give approval for face transplants, effectively bringing to a halt the UK's momentum in the field. This extraordinary episode in medical history has been anecdotally influential in shaping the course of British surgical history. This article explores and explains the lack of a face transplant in the UK and draws attention to the complex emotional, institutional and international issues involved. Its findings have implications beyond the theme of face transplants, into the cultural contexts and practices in which surgical innovation takes place.

**INTRODUCTION**

In 2003 the Royal College of Surgeons (RCS) of England held a meeting to discuss the controversial issue of face transplants.<sup>1</sup> The surgeon Peter Butler of London's Royal Free, had recently given a series of press interviews announcing his intention to undertake the world's first face transplant, prompting considerable media speculation and concern from charities supporting people with visible facial difference. Over a series of months, the RCS President chaired a working party that interviewed specialists from medical organisations, ethicists, potential patients and the Royal Free, in order to evaluate whether face transplants were beneficial. The working party concluded, after some debate, that there was insufficient evidence to support face transplants taking place in the UK. In a paper published in the leading medical journal *Transplantation* it called for more evidence about the philosophical, psychological, ethical and surgical impacts of face transplants.

The working party's decision effectively slowed the UK's ability to undertake a face transplant, if not bringing it to a halt entirely. Although the RCS was, and is not, a regulatory body, it carried significant international influence as an arbiter of surgical and ethical standards. To undertake a face

transplant *without* the approval of the RCS could be career ending, especially if the procedure ended badly. For Butler and his team, this was not the end of debate. They continued to move towards a face transplant, selecting patients, developing rigorous ethical and psychological protocols and securing National Health Service (NHS) ethical approvals, and raising funds, as the procedure would not be available on the NHS for reasons considered below.

In 2005, the possibility that the UK would make surgical history (as had happened so many times before, proponents argued, with reference to the development of facial surgery in World Wars I and II) was lost. The media spotlight moved to France, where in 2005 the first (partial) face transplant was undertaken on the body of Isabelle Dinoire, a woman whose lower face was chewed off by her pet Labrador while she lay unconscious from an overdose of sleeping tablets. Fifteen years later, and although there have been 47 face transplants undertaken around the world, there has still been no face transplant in the UK (Alberti and Hoyle 2021).

British research into face transplants, and the face transplant that did not happen, is critically important in understanding the contextual and contemporary issues that define whether or not surgical innovation takes place. There are numerous ways in which the RCS working party can be framed and imagined within a professional environment that is traditionally based on international competition and rivalry. These include the belief that British surgeons are, by contrast with their international counterparts, restrained by ethical inwardness and traditionalism, a belief that still carries enormous emotional and symbolic weight within the field. Equally significant, yet more nuanced considerations, include the relationships between science, surgery and the media; between personal ambition and institutional support networks; the functioning of nebulous concepts of 'risk' and 'need'; financial restraints and ethical codes of practice, all themes that governed the perception and practice of face transplants as a response to severe facial injury.

All these issues relate to, but do not fully answer the core questions of this paper, which is based on UK Research and Innovation funded research that has secured all University and NHS ethical approvals.<sup>2</sup>

Why did the RCS working party publish a paper against face transplants in the UK in 2004? And



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why—even when ethical permissions were given and, the RCS found in favour of ethically informed facial transplantation in 2006—has there still not been a face transplant in the UK? The answers to these questions are far more complex than might appear. As the oral histories used here show, they also reveal intense emotional and personal investment in surgical innovation by individual practitioners and their teams, as well as the institutional and international frameworks in which surgery takes place. Ultimately, it is less surgical ability, though that has dominated the history of the surgery (Roche *et al.* 2015, 99–103), than the institutional, emotional, political, intellectual and psychological contexts in which innovation takes place that has shaped the UK experience of face transplants.

Virtually nothing has been written about this episode in history *as history*, largely because of its status as a non-event: in the end, no face transplant took place. Nevertheless, this was a critical episode in transplant history that continues to impact on the attitudes of British teams towards undertaking a face transplant. It also contains in microcosm some of the most critical factors that determine the success or failure of medical innovation today: surgical know-how, the functioning of teams, personality and aptitude, risk, institutional support and the influence of external forces, including the media (most information can be found through the clinical and news literature of the time, for instance: McDowell 2002, 449–460). As the authors have argued about face transplants in international contexts, innovative medicine never takes place in a vacuum (Earle 2019, 7–18), and the apparent disagreement between the Royal Free and the RCS needs to be understood within a complex history of institutional practice, personal ambition, financial support and the mutable definition of patient ‘need’.

In writing the first history of face transplants in the UK, then, focusing especially on the Royal Free Hospital between 1998 and 2011, this article considers face transplants not as single acts, but as processes that intersected with institutional, personal and political contexts (Alberti 2020, 1106–07). These included NHS research policies; the centralisation of ethical processes; the restricting of organ donation and transplant; the implementation of the Human Tissue Act and the role of the British media, a double-edged sword that created public awareness of the procedure, but also engendered professional antagonism (Howard, Danielle, and Cochran 2012, 6–17; Lucassen and Kaye 2006, 690–92; Wilson 2011). This analysis extends the current historiography of recent science, building on the work of Ronald E Doel and Thomas Söderqvist and others into the multifaceted political nature of modern science, and extending these findings into the present day (Doel and Söderqvist 2006, 1012). It also highlights the ways the political includes the personal, as the desires, ambitions and rivalries of key players impacted on how surgical innovation was conceived, framed and undertaken (or not).

## METHODOLOGIES

This article draws on a mixed methodology of semistructured oral history interviews with key figures in the UK and international face transplant surgeons, as well as archival research, primarily using media sources, the 2004 and 2006 RCS reports and responses to Freedom of Information requests made to key organisations. The authors used Standards for Reporting Quality of Research Guidelines (SRQR) in undertaking this research (O’Brien Bridget *et al.* (2014). In total 16 interviews were conducted between February and September 2020, although subsequently we lost contact with one interviewee. The sample

included eight transplant surgeons and researchers, of whom three had worked in the UK; two psychologists; three people with lived experience of facial difference; two ethicists and a Public Relations (PR) consultant. Participants were identified as significant actors in the history of UK face transplant through initial research and recruited via direct contact. Although offered anonymity, the majority of interviewees chose to be named or identified, which reflected both their desire to own their contributions and the historically public nature of face transplant debates (Moore 2012, 331–40; where anonymisation was requested, the participant number is given in lieu of a name). Interviews were conducted via Zoom or telephone due to travel limitations during the COVID-19 pandemic and were between 60 min and 120 min in length. A semistructured interview guide was adapted to the individual expertise and experiences of the interviewee and was provided in advance as part of the consent process. All were audio-recorded and subsequently transcribed using a naturalistic approach, which preserved as far as possible the authentic direct speech of the contributors (Lapadat 2000, 203–2019). Transcriptions were provided to participants for comment, amendment and additions before being analysed. All contributions were then analysed using thematic content analysis in NVivo V.12, a qualitative data analysis software, using Braun and Clarke’s reflexive approach whereby interviews were read and reread to highlight significant themes and to identify patterns of ideas, experiences and feelings (Braun and Clarke 2006).

Oral histories were undertaken in this case to access perspectives which are not otherwise available in the thousands of journal publications and media articles about face transplants. Published findings are, for the surgeons involved, the ‘official record’, but these reveal little about the impactful emotional and personal issues behind the scenes. Media articles often skew the discourse towards narratives of opposition, risk and competition, as we discuss further below. Oral history provides access to face transplants as both emotive, and emotional subjects, and as live issues, with personal, professional and emotional implications for those involved, many of whom are still active in the field (on the perils and potential of oral history, see Hoddeson 2006). This gives the research process additional significance, not only as a historical account of a distinct moment in time, or an analysis of innovative surgery, but also a commentary on the present, with potential personal and professional consequences for those involved.

This approach also aligns to history as a discipline and to medical humanities more broadly, drawing on the textual and linguistic methodologies of emotion history (Plamper 2010, 237–65). This means that we are not interested only in the emotional entanglements that influence how a particular story or position is told, or the relationships between patients and practitioners that are necessarily part of those stories. Rather it suggests that however far we have come in moving away from the ‘great man of history’ model of the past that was so commonplace prior to the rise of social, cultural and linguistic history, viewing processes and structures as though they are objective phenomena is disingenuous. Innovation is necessarily emotional, involving as it does human actors and contexts. Why face transplants happen in some places and not others is, as the authors have argued elsewhere, as much a reflection of personal characteristics (including ambition) as it is institutional, financial and technological factors (Alberti and Hoyle 2021).

As a result, we argue that the language, imagery and contexts in which face transplants have been imagined is as important as its factual chronology. History is never objective. Though

it draws on a common stock of evidence, written and verbal, choices are made about what matters and what is incidental. In oral history, choice-making occurs on several levels, from the selection of interviewees and the questions asked of them to the narrative strategies of the participants themselves. Furthermore, memory, the central theoretical component of oral history practice, is unfixed, responsive and dynamic, denying to some extent an empiricist relation between the past ‘as it happened’ and the present (Cubitt 2007, 71). Historians necessarily make arguments on the basis of assembled, sifted and sorted evidence, and this process of selection is part of the historian’s craft. Yet in oral history, historians also become instrumental in the production of the past, implicated in not only the analysis but also the creation of their source material (Frisch 1990, xv-xvi). By acknowledging this interplay between researcher and researched, between the past ‘as it was’ and the past as it is constructed in the present, the research sought to understand an episode in the history of innovative surgical procedure as it was (and is) interpreted in social, cultural and personal terms.

Over the course of our research and interviews, we discovered many different ways the story of ‘what really happened’ could be told—ways that highlight the emotional contexts in which surgery takes place, the affective relationships between patients and practitioners, the blurred lines between private and professional interests, the working environments that shaped early twenty-first century research cultures, and the ideological and institutional structures that were part of the landscape of surgical innovation. As ethical researchers, we have not included evidence that might be personally or professionally hurtful to the individuals concerned, although that means we also exclude anecdotal evidence that has widespread currency as surgical ‘gossip’ (Georganta, Panagopoulou, and Montgomery 2014, 76-81). Instead, we focus on the multiple, sometimes conflicting ways in which the story of face transplants in the UK might be told, given the professional, personal and institutional interests involved.

### TIMELINES AND INTERNATIONALISM

The origins of an innovative procedure are often uncertain, and face transplants are no different. Most leading specialists develop and hone their skills and expertise in multiple locations with different teams before they are ready to launch an innovative programme of their own. The earliest known reference to face transplant in England was made in a newspaper article in 1989, when British plastic surgeon Roy Saunders suggested that ‘it might 1 day be possible, although not for many years, to carry out whole face transplants’ (Wright 1989). Saunders was at that time a senior surgeon at Mount Vernon Hospital in north-west London and was using temporary skin grafts from dead donors in severe burns cases. His comments came in the context of publicising a fundraising appeal to support a new £7 million plastic surgery department at Mount Vernon, establishing a long-time link between face transplant and media interest. Four years later, Saunders’ former colleague James (Jim) Frame announced that he was ‘only months away from carrying the operation out’ (Halle 1993). Frame had been researching the technique since the early 1980s, first at Mount Vernon and then at the Burns unit at St. Andrews Hospital in Billericay, Essex. During an interview in May 2020, he recalled that he and Roy Saunders had almost performed a face transplant in 1987 on a patient with ‘almost a total loss of face from a deeply invasive squamous carcinoma’ but the man withdrew permission on the morning of the surgery (Frame 2020). They were aware of the immunogenic

and potential psychological challenges, insofar as these issues were understood at the time. However, given the then permissive ethical regime for surgical innovation he suggested that: ‘In the 80s - if we’d have felt that that would help the patient, we would have done it and we wouldn’t have gone through any form of approval, we wouldn’t have needed it’ (Frame 2020).

The ethical landscape was very different in the 1980s to that confronted by the Royal Free team in the early twenty-first century. At the same time, discussions about other forms of multicomposite transplantation were progressing. In 1991, the first conference on vascular composite allograft (VCA, then known as composite tissue allograft) was held in Washington DC and focused on the potential for limb transplantation as a treatment for veterans of the first Gulf War. In England, the hand surgeon Simon Kay, based at St. James Hospital, Leeds, was discussing the possibility of thumb and hand transplants by 1993 (Laurence 1993). However, at this time, most surgeons agreed that the immunological concerns were too significant to proceed in human patients. While temporary skin grafting could be achieved with existing immunosuppressant regimes such as ciclosporine, it was felt that high doses in the long term would be excessively toxic for life-enhancing operations. Research in the field was therefore focused on developing new immunosuppressant regimes or immunogenic tolerance. Major research programmes at Massachusetts General and Brigham and Women’s Hospital in Boston and the University of Louisville in Kentucky similarly developed interests in this area. And the world’s first successful hand transplant, performed in Lyons in 1998 (and overseen by the surgeon who would lead the first face transplant), demonstrated that the immunosuppressant treatments used in renal transplants were effective in VCA.

Subsequently an agenda for face transplants re-emerged in the international media. In an article in the British newspaper *The Guardian* in 1996, Professor John Barker, head of the Louisville research team, was cited as suggesting face transplants were the next horizon for experimental transplantation (Millar 1996). Around the same time it seems that Peter Butler, recently appointed as a consultant plastic surgeon at the Royal Free, began to consider developing face transplants in the UK. He had formerly worked with Jim Frame at Billericay (Frame 2020) and had been a Research Fellow with immunologist Andy Lee at Massachusetts General. Butler published a commentary on the possibilities of the surgery in the *Lancet* in July 2002, co-authored with his colleague Shehan Hettiaratchy, another alumnus of Mass General (Hettiaratchy and Butler 2002, 5-6). In spite of the later controversy of the procedure, the paper doesn’t appear to have gained much traction or attention outside of the plastic and reconstructive surgery field.

However, this changed when Butler and Hettiaratchy gave a paper on the same topic at the winter meeting of the British Association of Plastic Surgeons (BAPS; from 2005 the British Association of Plastic and Reconstructive Surgeons, or BAPRAS) on 27 November of the same year. Although the presentation had an innocuous title, a preview and interview with Butler in the *Guardian* sparked national media interest (Revill 2002). Reports suggested that Butler had claimed that the science was sufficiently established and that he would be prepared to perform the surgery at the Royal Free ‘within 6 months’. He acknowledged that the critical question was not how but if the surgery should proceed, stating his engagement with potential concerns at an early stage (McDowell 2002). Within a short time, the ethical complexities of the surgery had established it as the subject of contentious debate, with facial difference advocates, surgeons and ethicists on both sides. While the latter raised concerns

about immunology, informed consent and functional outcomes, the former focused on the psychological and social implications of possessing another person's face (McDowell 2002).

### MEDIA INVOLVEMENT AS A DOUBLE-EDGED SWORD?

Since the 1980s British tabloids have been widely regarded as exploitative in generating headlines, whether the subject is poverty and benefit fraud, migrants, mental health or medical experimentation, though the press escaped state regulation by setting up the Press Complaints Commission as a regulatory body (Esser 1999, 291-324; Hamilton 2003, 267-82; Torjesen 2015, 350; Vasterman 2005, 508-30). While media involvement might conceivably have lent weight to the surgical drive, by highlighting the benefits to potential patients and garnering public support, that did not happen in the case of face transplants. Instead, the potential for nuanced debate was lost in a flurry of headlines about surgical intent, with ethical complexities sidelined, and polarised positions created.

During this research, we were told informally that the British press, once alerted to the possibility of the first face transplant ever being conducted at the Royal Free, began harassing surgeons and patients, going so far as to tap private telephones and stalk vulnerable patients. Even without such intense speculation, media scrutiny would have been challenging for the Royal Free Hospital, since it had recently been involved in another media furore, when Andrew Wakefield, then a doctor at the hospital, claimed to have found a link between the measles, mumps and rubella (MMR) vaccine and autism. This controversy led to a crisis in public trust in vaccines and scandalised reporting by the British media (Fraser 2001).

There is no doubt that media coverage of Butler, a charismatic and socially well-connected surgeon, antagonised members of the medical profession who had been working in related fields for many years, as well as colleagues within the Royal Free. It was also felt as an affront to those who were personally directly affected by the coverage. James Partridge, then CEO of Changing Faces (a UK face equality charity) wrote letters requesting professional review of the procedure to a number of medical organisations (Partridge 2020). Partridge was himself caught in what Dinoire, the first face transplant recipient, described as a media 'circus' around face transplants, when tabloids speculated what he might look like as a face transplant recipient, rather than a person living with facial reconstruction (Bound Alberti 2017, 148-54; Duffy 2005; Partridge 2020). This is an example of the ways in which media involvement exacerbated the personal and professional issues involved, muddying rather than clarifying some of the ethical complexities.

In this speculative climate, the RCS convened a working party on facial transplantation, under the chairmanship of Professor Peter Morris, then President of the College. From interviews it is apparent that it was not only Partridge that sought a professional review from the RCS, but also BAPS (G01\_008 2020). The party was comprised of a panel of medical and psychological experts: Sir Peter was a specialist in transplant immunology, and the other members of the group were equally renowned: J Andrew Bradley, a professor of surgery at the University of Cambridge, also a specialist in immunology and transplantation; Michael J Earley, a facial reconstructive surgeon; Martin P Milling, a consultant plastic surgeon specialising in burns injuries, based at Morrision Hospital in Swansea; Professor Len Doyal, an internationally respected medical ethicist and Professor Nichola Rumsey, a psychologist who cofounded the Centre for Appearance Research in Bristol in 1990. The group met three times between

April and September 2003, and interviewed Peter Butler about his research and intentions (G06\_003 2020; G06\_007 2020). In November they issued a report which confirmed Butler's suggestion that any face transplant 'must be preceded by careful and open debate' (Morris et al. 2004, 330-8, 330).

It is important to note that each of the parties involved, whether representing the RCS or the Royal Free, believed that they were acting in accordance with the best interests of the patient, though the former also had an eye on the reputation of the profession as a whole. In his discussions with the media and published articles, Butler did not downplay the potential psychological, ethical and surgical hazards of the procedure. In fact, one could argue that the most innovative work done by the Royal Free team in this area was their consideration, through the work of Alex Clarke, of the psychosocial and emotional aspects of face transplants. Until very recently, psychosocial issues have been neglected by facial transplant surgeons in favour of surgical ones (Alberti and Hoyle 2021). It is quite probable that under different circumstances—a decade earlier, say, when ethical protocols were less stringent, or even in the 2000s, without intense media attention—that Butler and his team would have carried out the face transplant. Once it had been brought to the attention of the Royal College, however, the working party felt bound to investigate whether they could approve the procedure. And they did not approve it, finally, setting out the main areas of resistance, including:

- ▶ Immunological challenges, including the significant potential for acute and chronic rejection, and the side effects and life-shortening impacts of immunosuppression.
- ▶ The psychosocial challenges associated with solid organ donation, which would be heightened by the central role of the face in communication, emotions and identity.
- ▶ The paradoxical nature of the ideal transplant patient, who would have to be desperate enough to require the procedure yet resilient enough not to need it.
- ▶ The impact on the recipients' family and the family of the donor.
- ▶ The potential for societal misconceptions about people with severe facial differences, in particular that they could not live fulfilling and happy lives (Morris et al. 2004, 331-5).

The most critical pillar of the RCS's argument against face transplant was the issue of informed consent. If there had been no such procedure before, and the outcomes were uncertain, how could consent be secured? (G06\_007 2020).<sup>3</sup>

It is difficult to imagine, given these challenges, combined with the weight of media interest (which typically followed innovation transplantation, raising the stakes should anything go wrong); the relatively recent Wakefield scandal over the MMR vaccine; the professional reputation of the College and the public and professional scrutiny that would fall on the first face transplant patient in the UK, that the RCS could have acted differently (Nathoo 2009). There were inevitably personal and professional conflicts involved, as there would be with any innovative procedure, but these contexts were critical. So, too, was the oppositional framework in which the debates took place.

The publication of the RCS report in *Transplantation* in 2004 coincided with a series of public events, including at the Royal Society of Medicine, which featured proponents for and opponents against the procedure. It is typical for moments in medicine to be entangled with their proponents; the gendered 'great man' school of science and medicine in which innovation is depicted as the work of a single genius. And there is no doubt that charismatic individuals were at the forefront of debates. John Barker from Louisville presented the 'for' position at a debate at the

Science Museum, at which Peter Morris, Nichola Rumsey and James Partridge also spoke (Parker 2003).

By this time, face transplants were the subject of international controversy. Shortly after the publication of the RCS report, an ethical committee in France refused an application for five experimental face transplants that was submitted by Paris-based surgeon Laurent Lantieri (). A team based at Louisville in Kentucky, led by Barker, and another at the Cleveland Clinic in Ohio, led, unusually for these procedures, by a woman, Maria Siemionow, were also actively developing ethics applications. Between 2002 and 2005 dozens of papers were published in the scientific literature, culminating in a special issue of the *American Journal of Bioethics* (Special Issue 2004).

In the UK, the RCS report may have reaffirmed Butler's commitment to the psychological and sociological dimensions of face transplants. Prior to the BAPS paper, Butler had recruited clinical psychologist Alex Clarke, to support the non-surgical side of programme development. Clarke had joined the plastic and reconstructive department at the Royal Free in 2002, originally to provide broad support to patients and surgeons. She became closely involved with the development of face transplants because of her pre-existing interests in facial difference (Clarke 2020). Butler also consulted the British ethicist Professor Richard Ashcroft, who advised the Royal Free team on the complex medical ethics involved (Ashcroft 2020).

Ultimately the first face transplant was not conducted by any of the teams who had publicly declared their intentions, but as noted above, in France. Dinoire, a 38-year-old woman, received a transplant of the lower part of her face, including nose and lips, on 27 November 2005. The surgery was a collaboration between transplant specialists at Lyons, led by Jean-Michel Dubernard, who had led the team that undertook the world's first hand transplant, and plastic and reconstructive surgeons at Amiens, led by Bernard Devauchelle. One of Dinoire's leading surgeons suggested that the Amiens team had been preparing to do such a transplant for years, and that they had protocols in place in anticipation of a suitable patient. In contrast to what had happened in the UK, they noted, they did not want to alert the media or colleagues of their intentions until after the surgery had taken place (Lengelé 2020). However, against the wishes of the French team, news of the procedure was leaked to a British tabloid, and by the first week of December, Dinoire's story had become global news (G06\_004 2020). This is an important moment in the international history of face transplants, partly because the media furore that emerged, and that was damaging to Dinoire as a patient, has supported the presumption that the French team was ill-prepared for the public impact of the surgery. This is not the first time that media involvement has been critical of the course of modern surgery, as Ayesha Nathoo has explored in the history of heart transplants, which helped transform transplantation from a patient/practitioner to a 'public' concern (Nathoo 2009). In a similar fashion, media discussion of face transplants raised the stakes on surgical outcomes and put pressure on an already fraught series of professional relationships. On a practical level, the announcement shifted the focus of UK media debate from 'if' to 'when' a face transplant might take place, since what was a theoretical concept became a reality.

The RCS' recommendation did not stop developments at the Royal Free; rather, the team was apparently spurred on by surgical reports from France (Devauchelle *et al.* 2006, 203-209). In June 2006 the Royal Free Hospital and Medical School Local Research Ethics Committee met to discuss an application for a series of four face transplants on patients with pan-facial

burns (Royal Free and Medical School Local Research Ethics Committee).

The proposal was the culmination of 4 years of intense effort on behalf of Butler and his team. Ethical permission was received by the Royal Free on 30 October 2006, (Royal Free Hampstead NHS Trust, 20 October 2020) triggering a patient selection and screening process which Butler and his colleague, Clarke, had developed in anticipation (Clarke and Butler 2004, 315-26). A series of practical challenges followed ethical approval, however, which shows the importance of evolving ethical legislation.

An unexpected complexity for the Royal Free team came about in July 2007 when it became clear that the Human Tissue Authority (HTA) regarded faces as tissues rather than organs. While in France and the USA faces were defined as organs for the purposes of transplantation, a case needed to be made in the UK for that usage. Butler's 'abiding fear' as stated in notes acquired from the HTA under a Freedom of Interest request, was that the details of the procedure would be requested under the Freedom of Information Act of 2000 (FOI) and that the 'at risk' status would be revealed. (Surname *et al.*) For the future of face transplants in this country, he wanted the whole procedure to be seen as 'squeaky clean' (Human Tissue Authority, 10 Sep 2020). If seen as tissue, the 24 hours needed to undertake medical tests prior to transplantation would render the donation unusable for face transplants, a point that Butler made convincingly to the HTA, who accordingly gave consent for the face to be regarded as an organ. There were further, practical steps needed: Specialist Nurses in Organ Donation (SNODs) had to be trained in soliciting facial donations, which was a concern to NHS Blood and Transplant, who feared general donor rates might be negatively impacted by requests for faces.

The RCS working group reconvened in light of events in France, and its findings were published shortly after Butler's team received ethical permission from the Royal Free board. The second RCS working party report gave cautious support for facial transplantation, on the proviso that a number of ethical and psychosocial conditions were met in advance. If it had been difficult for the RCS to give support at the first meeting, it would have been difficult to reject face transplants entirely at the second, since proof of concept had been demonstrated in the case of Dinoire. So, setting out the precise ethical terms in which face transplants might be possible was an important intervention that had international influence (G01\_008 2020; G06\_007 2020). The second Report of the Working Party was also published in the journal *Transplantation* (Morris *et al.* 2007).

While members of the working party saw the document as critical to the safe conduct of the procedure, Butler's team felt that it set out requirements they had already met—or met to an extent that was possible before a procedure took place (Clarke 2020). The Royal Free's face transplant programme did not go live until early 2010. During this time 4 patients appear to have been seriously screened for the procedure—although upwards of 50 approached or were referred to the team for consideration—and only 2 patients were placed on the waiting list for a donor match. The difficulty in identifying patients reflected the narrow criteria set out in the ethics application: individuals needed to have full facial burn injuries (Alberti and Hoyle 2021). As Clarke (2020) has since observed, this injury profile was problematic, not least because this was not a random section of the general population, and patients in this category might have higher rates of mental health problems. In 2011, the programme was indefinitely placed on hold when Peter Butler took an extended period of leave. Shortly afterwards Alex Clarke retired, and the research nurse who had supported the project moved on. Although Butler

did return to work at the Royal Free, the programme was never started again, and the focus of his work shifted to tissue regeneration. The Royal Free website continued, until the summer of 2020, to suggest that ‘the Royal Free is able to provide full face transplants’ (Royal Free Hospital). It now offers a more general historical and ethical account of the procedure, though also states that ‘the UK face transplant team...hopes to perform a full-face transplant in the near future’ (Royal Free Hospital). It is likely that this reflects the slowness of NHS website updates, rather than any ongoing capacity or ambition in the original transplant team. By contrast, there are several sites across the UK that now have the capability of undertaking face transplants, though for reasons of finance and risk, no hospital trust has committed to it publicly.

### FRAMING FAILURE: WHY LANGUAGE MATTERS

The self-expressed ‘failure’ of the Royal Free to perform a face transplant was not unique among early developers of the procedure. John Barker’s team at Louisville similarly never undertook a face transplant, despite considerable preparatory work, and never received institutional ethical approval. However, the period during which Butler’s programme was active (2010–2011) was the peak of face transplant activity around the world—more than half the world’s transplants to date were performed between 2009 and 2013 (Alberti and Hoyle 2021). As many of our interviewees observed, the fact that a face transplant did not happen in the UK is at odds with the history of the UK as a country with a reputation for pioneering plastic and reconstructive work.

Why, then, did a face transplant not happen in the UK, even when the RCS gave its consent?

And why has there still been no face transplant, more than 15 years on? Historically, the face transplant programme at the Royal Free was in development for over decade, but by 2011 was dormant and while two other UK teams, in Glasgow and Newcastle, subsequently publicised their intention to undertake a transplant, neither has done so. Ostensibly, Glasgow and Newcastle were hampered by available funding with the NHS refusing to fund procedures that are seen as life-enhancing, rather than life-saving (and NHS Scotland additionally identified a lack of potential patients.) (Puttick 2016). Yet the Royal Free attracted a reasonable level of funding through the charity Butler established while the programme was at its peak (Coombes 2008, 18-9).

In contrast to the trajectory of face transplants, hand transplants, another form of VCA with a similarly complex ethical and emotional history, is well established in the UK. Led by the surgeon Professor Simon Kay, who first mooted upper limb VCA 20 years earlier, the team performed the first ever hand transplant in the UK in Leeds in 2012 (Leeds, along with Oxford, secured NHS financial support for the procedure) (Clark *et al.* 2020, 28-33). And there have been other VCA developments. The first abdominal wall transplant took place at Oxford in 2013; the first womb transplant was scheduled to take place in 2020, though it has been temporarily paused by the COVID-19 pandemic (G01\_006 2020).

So, it is not the nature of VCA per se that is the issue. Arguably, the moment for face transplants in the UK (and indeed globally) has passed, given the international issues involved in funding and outcome analysis, with the drive towards innovation having moved towards tissue regeneration (Alberti and Hoyle 2021). There are financial reasons, including a lack of NHS funding as discussed above. And it is also the case that the

risks attached to face transplants—ethical, psychological, immunological—remain substantial. There is insufficient evidence of positive longitudinal outcomes and the risks would be borne by institutions and trusts as well as surgeons and patients. The potential for reputational damage is high.

Much of the history of medical innovation, notably in the fields of facial reconstruction and transplantation, concerns the development of skills and technologies, of ‘skin flaps’ and immunosuppressants. Another strand of enquiry focuses on the social and cultural contexts, the ethical reasons why, in the case of face transplants, parts of the body might carry specific emotional load. But there’s another, equally significant aspect of innovation to consider, which is context. Whether or not a new technology is taken up and adapted depends not only on surgical expertise, funding and ethical approvals, but also timing, personalities and the emotional climate in which the surgery takes place.

To this end, there was a ‘perfect storm’ of circumstance that converged in the early 2000s to inhibit face transplants in the UK. Relevant factors include sensationalist media coverage; the past experience and reputation of the Royal Free (especially in relation to the Wakefield scandal); a limited number of potential patients; the concerns of the RCS, whose then President was an internationally-respected expert in transplantation; the interests of facial difference charities, who were far more influential in the UK than they were internationally; international rivalry and competition; and the individual personalities involved.

It is too simplistic to view this episode in history as some kind of face-off between old and the new, between the quest for innovation versus British traditionalism, or surgical ambition versus professional stagnation, though that is how the story of face transplants in the UK has been framed anecdotally. Certainly, the traditions of institutions like the RCS, whose emphasis was on appropriate codes of conduct rather than legal regulation, gave the episode a characteristically British flavour, but the College was not against face transplants per se; rather it identified the criteria that needed to be met. Indeed, members of the working party were subsequently in contact with surgeons in the USA, including Maria Siemionow, about best practice in the field (G01\_008 2020).

The relationship between UK face transplant researchers and their international counterparts seems uneasy in retrospect. From a UK perspective, the ‘face race’ perspective favoured by the media championed the work of underdogs like Butler, perceived as following in the footsteps of Harold Gillies and Archibald McIndoe as pioneers of facial surgery (Bamji 2017; Geomelas *et al.* 2011, 363-8). From an international perspective, however, the British lead was less convincing. There are specific axes of collaboration at work in international research, and it was common for the US and French pioneers of face transplants to work together. There were rivalries, of course, and some of these have cast long shadows. But oral history descriptions of the team and work culture at the Royal Free contrasted significantly to those of international face transplant teams. In the USA, for instance, John Barker and Moshe Kon talked about an enthusiastic and collaborative culture at Louisville, as well as frequently name-checking colleagues and talking about the interdependence of large, collaborative teams. The same is true of Emmanuel Morelon and Benoît Lengelé from the Amiens/Lyon team. By contrast, the British experience was one of isolation and separateness. Alex Clarke described how ‘it could feel at times as if it was just Peter and me’, with it being difficult to get other individuals consistently involved.

The problems in maintaining a team at the Royal Free, and the centrality of Peter Butler as a lone figure, may have been

partly due to the NHS setting. There were few resources available for the face transplant programme over and above regular staffing, and Clarke described what a toll this took on the people involved, as a ‘labour of love’ with no reward. Forming and holding together a strong coherent team in these circumstances appears to have been almost impossible and might explain why no one could be named as a key team member or natural successor to Butler. This was a critical difference between the UK and US experiences, where an ‘open chequebook’ at Louisville and competition between private institutions meant that there were opportunities that were unavailable in the UK, even in a research hospital. Yet it doesn’t necessarily explain why the Amiens/Lyon team avoided these limitations.

### A LABOUR OF LOVE

Medical firsts can be impactful in many ways, and the history of science is littered with stories of inclusion and exclusion in the narrative of progress (Hopwood 2009, 146). For the Royal Free, the world’s first face transplant was the kind of innovation that could bring international research kudos. On the other hand, it also opened them up to significant institutional challenges and exposed the Trust to risk. Funding remained a problem. A lack of NHS resources could have been ameliorated by external grant funding, which interviewees described as impossible to secure because the work was too experimental. By contrast, US, French and Turkish teams were all able to secure funding, although in the US case this was primarily due to the support of the Department of Defense. Without research grants, Butler’s work was reliant on the unpaid labour of research students and medical students, who appear to have been important research resources. As Clarke put it ‘it was a real case of hand to mouth... how can we do that with no money?’ (Clarke 2020). Butler also established The Face Trust to raise money for the programme. (Charity Commission for England and Wales)

The lack of financial and institutional backing led to the importance of the programme being conceived as a form of moral action, which went above and beyond the requirements of standard medical practice. The personal and emotional investment of those involved in trying to establish a face transplant programme, in the belief that it was for the good of patients, was profound, and took a considerable emotional toll on some of the lead participants. Others described the sense of meaning and purpose the project had for them, in giving the best possible quality of life to patients. It was a gamble, to be sure, but wasn’t it better than what was currently on offer?

A different emotional perspective was held by James Partridge, founder of Changing Faces and Face Equality International, who talked about the personal cost of the media discussion of face transplants, especially the use and alteration of his image without permission, rather than any aversion to face transplants per se (Partridge 2020). However, special emphasis has been placed on the negative personal impact that the programme took on Peter Butler himself, in raising funds, caring for patients and trying to pioneer a new form of surgery within an NHS framework. In Clarke’s words: ‘it took a huge personal toll on him... it was tough on him...and disappointing’. Butler was open about the toll the work took on his health, and his then wife Annabel Heseltine wrote about the personal and professional ambitions involved (Heseltine 2008).

The immediate cessation of the face transplant programme at the Royal Free exposed the institution’s structural weaknesses, particularly after Clarke and other team members left and retired. In this context, the NHS research ecology had an impact

on innovation at the level of the individual, with the desire to innovate and develop new ways of working unsupported by existing resources. Jim Frame told a similar story about his own trajectory in the NHS: as the institution became more prescriptive and bureaucratic from the 1990s, his ability to exercise a free hand in experimental treatments was limited (Frame 2020). This perspective aligns with the development of stricter ethical protocols in the early 2000s, which some felt stifled innovation, and shut down productive risks that lead to progress (Ashcroft 2020). This is not the first time that the idea of surgical ‘risk’ in innovation has been explored publicly (Frampton 2018). But from the 1970s, as Duncan Wilson has shown, there was more focus on ethics and accountability in medicine than ever before, as it was widely accepted that ‘doctors and scientists could not solve ethical problems on their own’ (Wilson 2014, 2). That did not, however, mean that surgeons were against using the media as a way to address public concerns, and even critique regulatory frameworks by the back door. It might have been perceived, as a Public Relations strategy, that attracting media attention, and highlighting the ‘need’ for face transplants as a matter of public interest, could shift the dial on political opinion and securing financial support.

In the British context, this was a gamble. Whereas the USA celebrates ‘Rockstar surgeons’, and advertises them as such at international conferences, British culture is far less forgiving towards innovators (Face Ahead). For the RCS and other interested parties, the intense media focus on Butler and his ambitions might have seemed insensitive and ego-driven, regardless of the intent. It was also reminiscent of other controversial leaders in the transplant field (such as Christiana Barnard, associated with the first successful heart transplant in 1967) (Myers, Lu-Myers, and Ghaferi 2018, 363). Innovative procedures always involve a degree of personal charisma and ambition, and it is unrealistic to think that these emotional qualities can be removed from the drive to discover and trial new techniques. Moreover, the desire to innovate is not always antithetical to the best interests of patients.

It is clear from our interviews that whatever the reasons the RCS was initially opposed to the practice of face transplants, including whether they were clinically viable rather than simply a theoretical concept, the narrative of opposition (between innovators and traditionalists, and between ‘great men’ in surgery) is influential, and not just in the UK. Perhaps because surgical innovation is usually conceived in gendered terms of competition and one-upmanship, and because there are multiple competing interests, this oppositional narrative has not only been anecdotally or professionally important—it has also influenced surgical practice (Liang, Dornan, and Nestel 2019, 541-9). Thus, while ethics boards were designed to temper and moderate ambition in pursuit of an objective balance of risk and safety, the reality was rather more subjective (Doyal 1997, 314, 1107). The Royal Free Ethics committee was seen as helping Butler’s team to circumvent the RCS. From an insider perspective, the reported attempts by the RCS to put obstacles in the way of the procedure encouraged the committee to approve the research, if only to assert their independence. This may be connected to ideas about the ‘changing of the guard’, and a shift from the influence of the RCS towards a more centrally administrated ethics procedure. As Thomas Schlich has observed of ethics around transplantation before 1930, it was the ‘benevolent paternalism’ of the doctor that decided what was right; the patient’s ‘freedom of choice’ was yet to come (Schlich 2013).

This is certainly how the ethicist Richard Ashcroft framed the RCS’ intervention, viewing face transplants as situated in the



tricky period of this shift, when the procedure was available for scrutiny from both sides. Thus, the RCS was figured by some respondents as outdated, unreasonable and illogical—like ‘King Cnut turning back the tide’—but by others as reasonable, logical and acting in the interest of patients.

Oppositional frameworks continue to shape perceptions of early face transplant history. Proponents of the procedure at the Royal Free and their supporters characterise Butler as a brilliant surgeon who was wronged by history, whose desire and drive to make a difference was met with resistance and hostility (G06\_004 2020). Accusations of phone tapping by the media, bullying by senior colleagues and professional bodies, and a lack of personal and institutional support illustrate an unhappy and unjust situation in which the UK drags its ethical feet and prevents medical innovation. The patient is depicted as the loser in the long run.

And yet the patient is also at the heart of the alternative narrative, with charities supporting people with facial difference and the RCS guarding against individual ambition in defence of public good. This ‘for and against’ opposition was exacerbated by media reporting, which fed off the sense of controversy. It was also encouraged by the way the debate was framed. Clarke described how every public event about face transplant was designed as a debate, with the rehearsal of the same tired arguments. In this way opposition and controversy nourished each other, making communication and negotiation between the ‘two sides’ very difficult (Clarke 2020).

This combative dynamic is heavily gendered. It is notable that the relationship between the two women who were centrally involved in the process, psychologists Clarke (who worked with Butler at the Royal Free) and Rumsey (who sat on the RCS working party), was not oppositional but described as actively constructive, despite them being on ‘different sides’ of the committee table and the process. What is also lost in the oppositional narrative, in its focus on the ethics of face transplants and the work of leading surgeons, is the experience and views of extended team members—nurses, immunologists, prosthetists and transplantation specialists—and the patients themselves.

### Patients and donors

One thing all interviewees agreed on is that Butler really wanted to help his patients. However, the signifier of ‘patient’ seems to mean two things throughout the interviews. There are the actual patients, who are seen and screened by team, and the notional ‘patient’ who was constructed through the course of the long ethical debate. The notional patient is the motivating factor—Butler spoke of these regularly and emotively in the media. This individual had severe functional and psychosocial problems as a result of their facial difference; their life would be transformed by a face transplant. It is possible to speak of this ‘patient’ generically, or with reference to past patients who have inspired the notion. They are the individuals who appear, for example, in the arguments to the ethics committees and the *American Journal of Bioethics* special issue (Special Issue 2004, 4). These patients are straightforward to talk about, because they are hypothetical. Speaking of Butler’s presentations to French meetings prior to 2005, Lengelé called them ‘concepts’, that prefigured the potential recipient in unhelpful ways. This may be the beginning of the ‘ideal patient’ that Samuel Taylor Alexander described, one constructed to justify the need for face transplant (Taylor Alexander 2014, 27-50).

By contrast, actual patients were problematic, for a whole range of reasons. Fundamentally, it was challenging to identify

a patient who fit the face transplant criteria—someone who had the right functional indication and the right psychological profile. In addition, an individual needed a strong support network; the ability to commit consistently to a strict medication regime; and a geographical location within a reasonable distance of the Royal Free. The UK team had even further restricted their pool of potential applicants by applying for ethics clearance for full-facial burns, which would only require a ‘skin envelope’ transplant rather than the transplant of bone, muscles, tongue and teeth. This may have been an attempt to make the proposition palatable to an ethics committee, and to avoid questions about recipient/donor likeness. However, this patient pool wasn’t conducive to the other criteria for transplant. Clarke explained that patients with full-facial burns were problematic because it was a rare injury. And while the team’s ideal candidate would have been a veteran, as someone likely to have severe injuries and a robust attitude, they found this cohort to be least likely to want a transplant and most well-adjusted to their facial change. The paradox of the face transplant patient was that the people most likely to cope with one were those who had the least need for it. After all those years of fitting for ethical clearance they ended up with ‘a procedure without a problem’, as Clarke put it.

This problem isn’t specific to the UK, but rather a challenge that has been observed frequently in the literature on face transplants. Globally, face transplant units have identified extremely small numbers of potential candidates. There are also international differences in the perception of need. Face transplants have become associated with ballistic injuries and workplace accidents that are not perceived to be as common in Europe and the UK as elsewhere. America is often cited as being different in this respect. However, as of 2018 there were only two people on the waiting list in the whole of the USA. This suggests that patient need is always projected ‘elsewhere’.

The lack of patients exacerbated another problem, moreover, namely a lack of donors. The donation issues that emerge in the interviews are emotional, cultural, organisational and practical. Culturally the UK already had low rates of organ donation. Understandably NHS Blood and Transplant, the responsible body, didn’t want to jeopardise this any further by requesting families to donate something as personal and significant as a face. While Butler and Clarke did research with donating families to develop protocols to approach facial donation, their conclusions didn’t trickle down to the ground level. Local SNODs were originally hesitant, though supportive of the team. In other places, SNODs have expressed resistance to face donation, for fear that raising the question could put potential donors off. Removing a face is also slow and laborious and could impede the life-saving removal of solid organs. Clarke described how few calls they ever received offering a donor. Once one then takes into account the practical problem of physical and immunological compatibility (human leucocyte antigen) with a small recipient pool, potential donors could be reduced to zero.

### THE UNKNOWNNS OF FACE TRANSPLANT SURGERY

Whenever surgeons embark on a novel procedure there are unknownns. In the case of face transplants, surgeons knew that recipients would need immunosuppression; they knew to expect rejection but didn’t know what it would look like, and they knew to expect nerve recovery, but they didn’t know how good it would be; they didn’t know how high morbidity would be, or how few patients would have the indication for transplant. Some knowledge is always unknowable. But in the early 2000s, face transplant surgeons found themselves in the intractable situation

of being asked to know everything, with absolute certainty, before proceeding. The problem being, as Delaporte has argued, that this certainty cannot be generated, and no new knowledge created, except by doing the uncertain thing. Following this equation, the extent to which a system allows for uncertainty and risk is a predictor of how innovative it will be. The face transplant case study offers a way to investigate the innovative capacity of overlapping systems of influence in the UK in the early 2000s, namely the NHS, professional associations like the RCS, the media and the public.

Concepts of what is knowable and what is unknowable are relevant to this case study more broadly, in theoretical and methodological ways. Oral history begs questions about the extent to which memory and forgetting, story-telling and narrative conventions, shape what we are able to know about the past through the testimonies of our witnesses. At the same time, approaching this research from a constructivist humanities perspective means that our ways of knowing, and the knowledge that we produce, is outside of the paradigm of surgery as a subject of study. In a world where competition for funding and prestige is fierce, nobody is used to talking about how the game is played, only about the papers that are published.

As a subject of interdisciplinary, contemporary history, the face transplant that didn't happen in the UK forces us to confront questions about how we 'do' history, as well as the narrow confines of the subject. All forms of innovative and experimental medicine are necessarily contested and controversial, at least at the time of their discovery. Nothing that has taken place in the field of facial transplantation since the findings of the RCS working party has given the lie to the uncertainty and scepticism raised. Many of the issues around immunosuppressants, donation and rejection continue to be debated, and ethical uncertainties remain. Moreover, there is a general lack of comparative international data on outcomes, and continued uncertainty about who constitutes an ideal patient, and whether consent can ever truly be secured. The UK experience, ultimately, provides a microcosm of the issues involved in any kind of experimental surgery, drawing attention to the political, social, economic, emotional and practical issues involved in surgical innovation, and the patient/practitioner relationship. The themes raised about the choice of patient, and the balancing of risk versus opportunity, moreover, continues to be central to medical ethics, and medical practice. It is not only at the edge of innovation that the conundrum of the 'ideal' versus the 'real' patient exists (Vincent and Amalberti 2016, 13-25).

### Patient and public involvement

It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research.

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### NOTES

1. A face transplant is a type of VCA, in which multiple tissues (including skin, fat, muscle, nerves, bone, teeth and hair) are transferred from a dead donor to a recipient. Other examples include hand and upper limb, womb, penis and abdominal wall. With the exception of womb and abdominal wall VCAs are used primarily in plastic and reconstructive surgery; all are life-enhancing rather than life-saving. Like all transplants, face transplants come with significant medical risks. Recipients require a strict regime of immunosuppressant drugs to stop their bodies rejecting the graft. This medication has multiple side effects, including increased risks of infections, cancer and renal failure.
2. Integrated Research Application System (IRAS) reference number 275650: AboutFace, approval granted March 2020.
3. Informed consent is a complex but critical subject that will be discussed in-depth by the authors in a follow-up article.

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