

What needs to be done to make **face transplants** more sustainable and patient-centred?

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Acknowledgements



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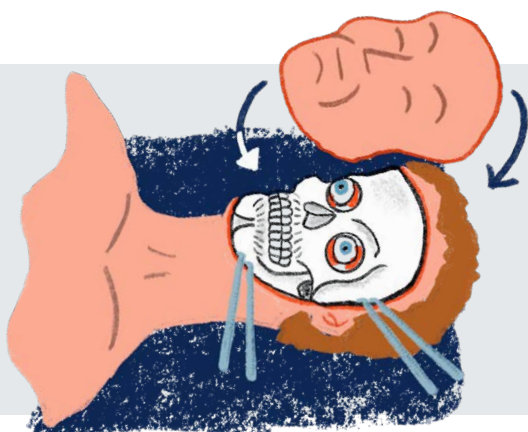
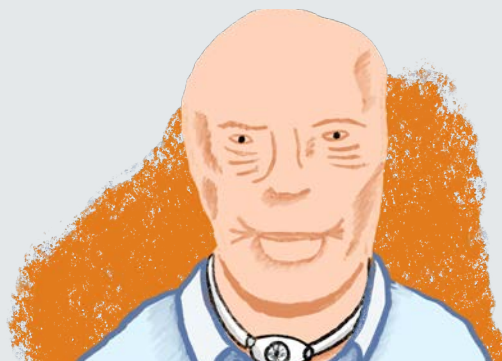
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Why face transplants?



What would happen if you lost your face?

Our faces are central to our identity, our relationships and our physical and mental health. But some people's faces have been irreversibly damaged in extreme accidents, attacks, ballistic injuries, or by medical conditions.



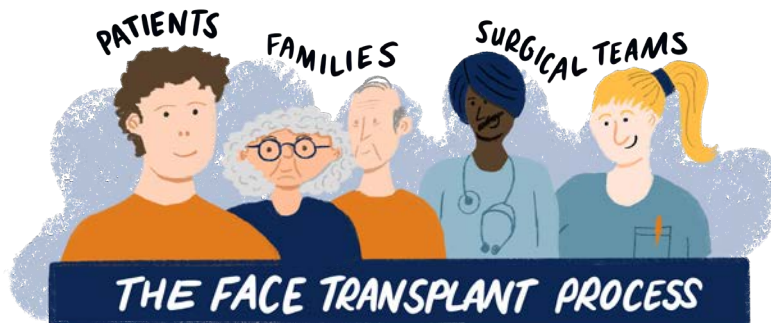
Could face transplants be the answer?

This isn't science fiction - face transplants are happening now all over the world for the over 18s. However, it isn't as simple as moving one face to another.



Fewer than 50 face transplants have taken place around the world since 2005, and none yet in the UK. Understanding their history helps us to improve medical practice.

As an experimental and innovative form of transplantation, face transplants have physical and emotional effects: on patients and families, surgical teams and society as a whole.



The research

AboutFace is a research project at the University of York that explores the impact of face transplants in history, and in the present.



This infocomic summarises findings from a virtual Policy Lab that was run over three days in December 2021, that brought together clinicians, ethicists, psychologists, policy makers, people with facial differences and qualitative researchers to explore the challenges facing face transplants.

This infocomic highlights the key themes that were discussed and the questions raised.

If face transplants are to happen, what needs to be done to make them more sustainable and patient-centred?



Patient selection & preparation



Patient selection and preparation procedures are variable around the world and need to be refined and standardised.

There is not enough communication to patients about what face transplants involve long term.



Medical professionals don't share widely enough their learnings on what helps patients.



We need:

Better standardisation of criteria around who is eligible for face transplants.

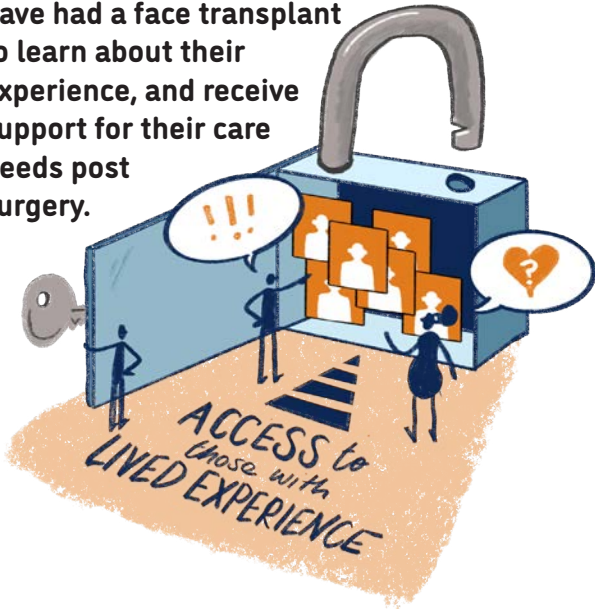


To hold medical professionals accountable, so they share best practice for better patient care.



Patient support

Patients deserve access to people who have had a face transplant to learn about their experience, and receive support for their care needs post surgery.



Patients should be understood as individuals, recognising their particular needs and the support networks around them, instead of adopting a 'one size fits all' approach.



We need:

To recognise that face transplants involve long term care - medical professionals and patients need to consider how those care needs will be met by family and friends.



To secure financial, social and emotional support for patients in the short and long term.



Clinical frameworks

There needs to be consensus between medical professionals AND patients as to what good care looks like.



To establish an international agreement of a standard of best practice.



We need:

A transparency of governance that includes better data sharing between medical professionals and centring the patient at the heart of care and decision-making

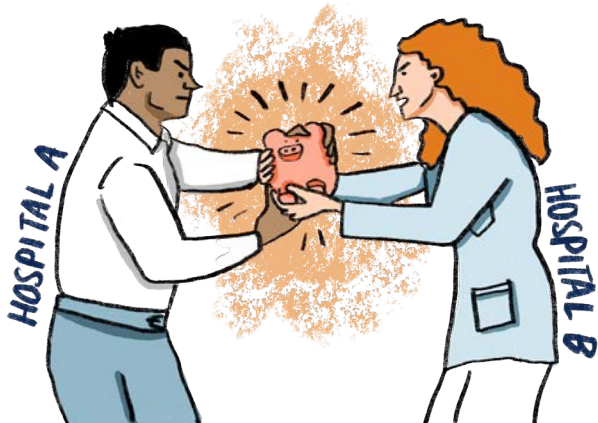


To talk openly about what happens when face transplants go wrong, and the long term needs of those who have them.



Data on patient outcomes & progress

In many countries, hospitals compete for funding. That means that sharing negative outcomes isn't always desirable.

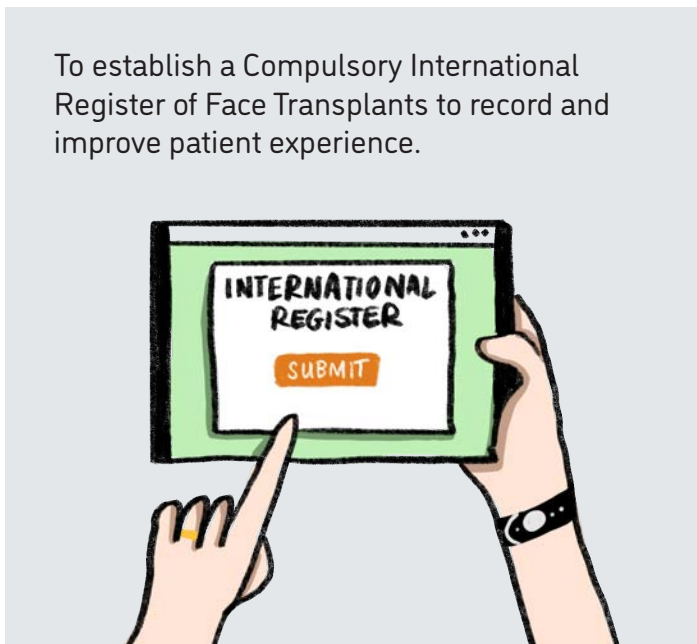


It also means that there is no way to standardise care or comparatively measure patient outcomes.

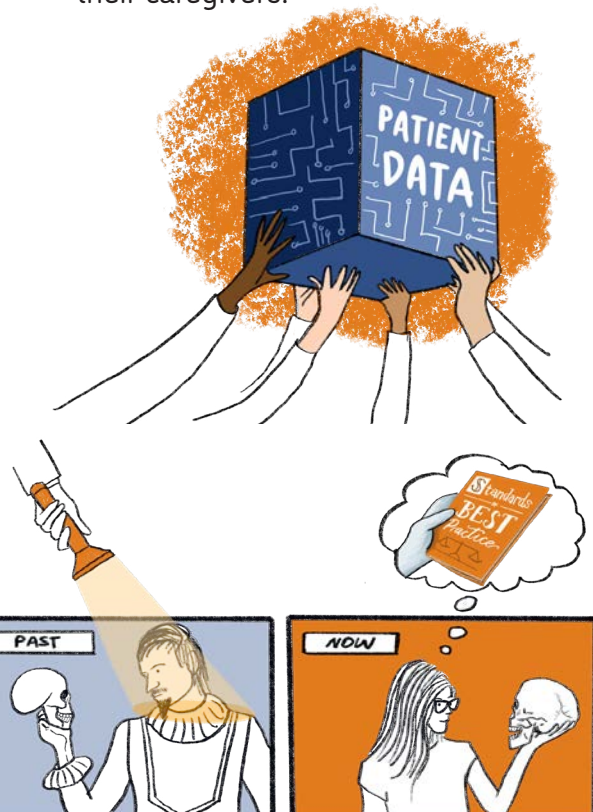


We need:

To establish a Compulsory International Register of Face Transplants to record and improve patient experience.



Improve the quality of the data that is shared, like face transplant outcomes and quality of life post surgery, AS DEFINED BY PATIENTS and their caregivers.



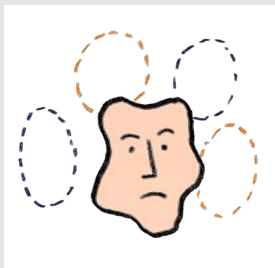
To understand the past to ensure best practice in the present and to shape the future.

Public image & perception

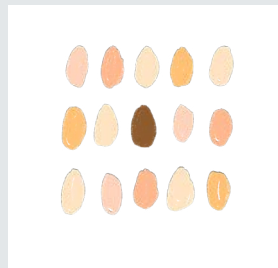
Face transplants are often viewed as science fiction, with surgeries cloaked in drama. There is no awareness of the patients behind the procedure and their journey post transplant.



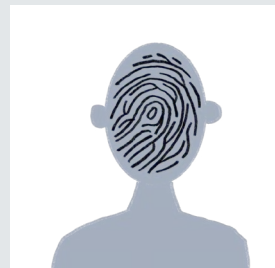
This can also be said for the issue of face donation - the media make donors sound like 'life giving heroes', but don't consider other issues like:



The lack of face donors



Ethnic inequalities around faces available for transplant



The ethics of giving a face and personal identity



The ongoing and challenging journey of the patient post transplant

We need:

Media toolkits to help clinicians and patients navigate the media, to protect them and their privacy post surgery.



To raise awareness of the realities and inequalities around face transplants.

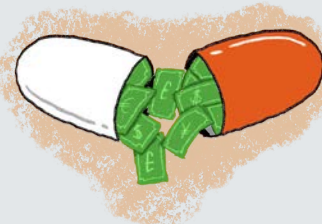


Financial sustainability

The cost of a face transplant is variable around the world, and so are funding structures.



Financial costs are lifelong, and include surgical procedures and long-term medical expenses and medications.

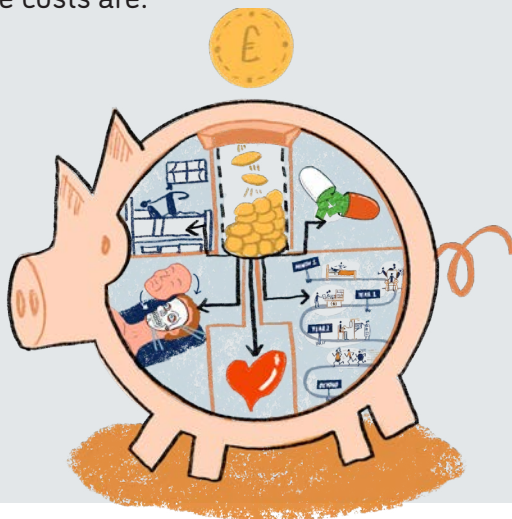


Long-term lifestyle costs on patients and their caregivers is rarely considered in making surgical decisions.

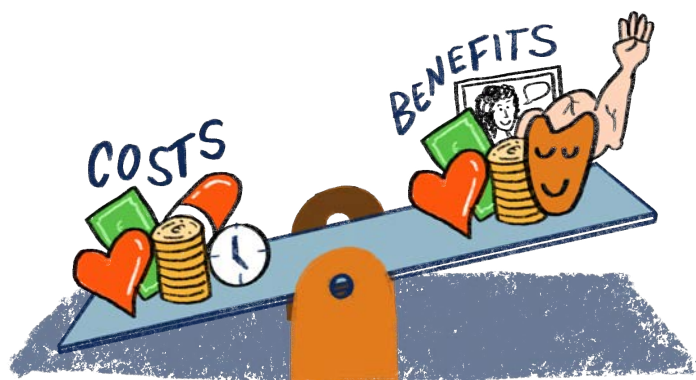


We need:

Financial transparency in how much the procedure costs, and what the ongoing care costs are.



Cost benefit analyses of whether a face transplant is truly worth it financially and emotionally for the patient.



To improve funding for face transplant patients.

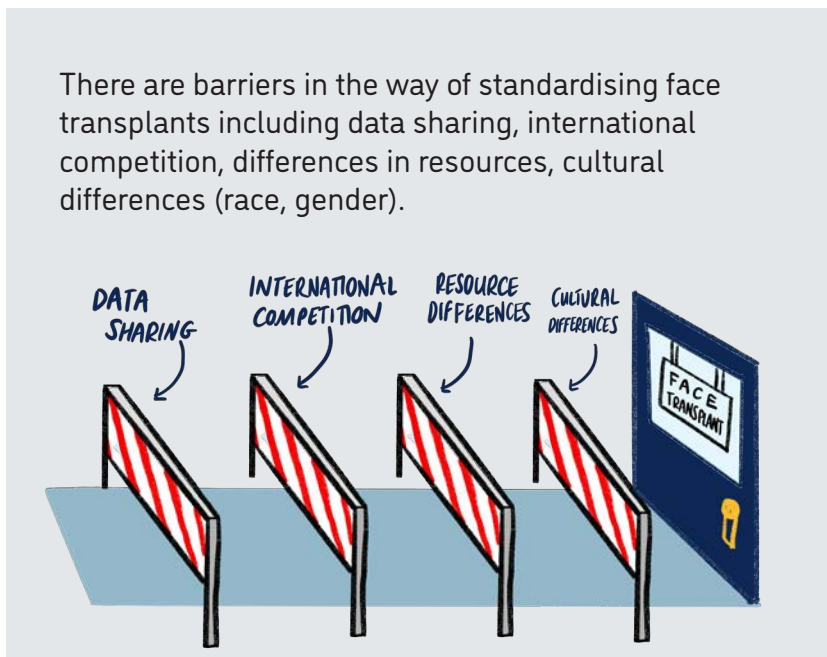


Where do we go next?

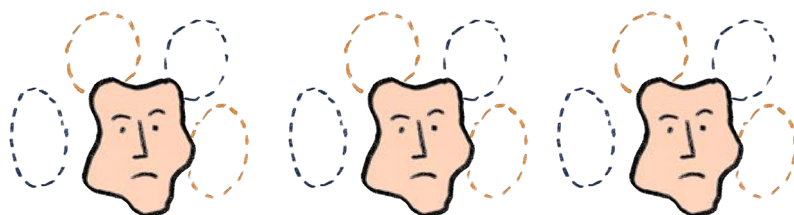
We have international agreement on what needs to change and why.



There are barriers in the way of standardising face transplants including data sharing, international competition, differences in resources, cultural differences (race, gender).



There are also not enough donated faces to go around.



WHERE DO WE GO FROM HERE?

We believe the patient's experience matters, and that sharing experiences is crucial to understanding face transplants.



We believe that a public conversation about the future of face transplants needs to take place if we want to improve patient experience and donation. We also believe that understanding the history of face transplants can improve medical practice in the future.

We want to hear from you. To tell us what you think and find out more, visit: aboutfaceyork.com



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