#### **Care Without Borders** Mapping Health Cooperation Across the UK

Andrew Mooney



Health Commission Report

### Foreword by Dr Zubir Ahmed

Dr Zubir Ahmed is a transplant and vascular surgeon working in Glasgow, and is also standing as the Labour candidate for the Glasgow South West seat at next year's General Election.

The trajectory of medical science is heavily weighted toward ever increasingly complex and personalised treatments. Small scale healthcare institutions and smaller nations such as Scotland, face a unique challenge in delivering deliver these treatments on an equitable and high quality basis. This paper assesses succinctly the impact of delivering certain such services administrated at a UK level.

As a member of the transplantation community in the UK I am pleased that this paper adumbrates the success and wisdom in particular of delivering organ transplantation through the pooling of resources across the 4 UK nations. Common regulatory and legal frameworks, working practices, cultures and mobility of staff between nations has made co-operation possible but not always natural within the UK NHS.

The paper demonstrates the utility and equity of access trans nation NHS cooperation can bring for Scottish patients in undeniable statistical form. Scottish patients are net beneficiaries from solid organ transplants as well as access to specialist care in relation to rare diseases.

It is therefore imperative for all of us working in healthcare to use research such as this as a stepping stone to deepen the UK level NHS cooperative spirit. In the era of digital healthcare such cooperation has the potential to better utilize (in real time) the capacity of our common NHS to deliver better patient outcomes whether you live in Lothian or Lincoln.



#### About the Author

Andrew is a recent graduate from the University of Cambridge, where he studied a Masters in Population Health Sciences.

Prior to this, he worked in a variety of analytical roles both within the NHS and private sector.

During his time at the NHS, he developed numerous data products currently used by clinicians across the country.

He also holds a Masters in Mathematics and Physics from the University of Glasgow.

#### Introduction

In our previous paper, "Closing the Gap", we outlined the myriad ways that the local environment, both physical and social, impacts on health and health inequalities. Access to local health services, work, housing, and air quality all determine the quality of good health.

Local healthcare is vital. In most cases, the local GP or hospital will be where someone is treated. But through genetic chance, the opportunity for some citizens to rely on local health provision alone is denied.

The Scottish Government currently estimates around 400,000 Scots live with a rare disease<sup>1</sup>. These conditions are more likely to be life-limiting or life-threatening, with a greater likelihood of requiring specialised care. Rare diseases disproportionately affect children, with more than 30% of children with a rare disease dying before their fifth birthday.

To give everyone access to the best available care, no matter their local provision of healthcare, NHS Scotland operates national networks of high-quality specialist services. These national networks, including specific ones for inherited metabolic disorders and inherited cardiac conditions, allow patients and their families access to the full range of clinical expertise when these may not be available in their NHS board or region. They bring together health and other professionals, patients, carers, families, and voluntary groups, to deliver a range of treatments tailored specifically to that cohort<sup>2</sup>.

This cooperation ensures that all Scots have equitable access to the best clinical expertise in Scotland. However, in some extremely rare cases, NHS Scotland is not able to offer life-enhancing treatment. With incredibly complex research methods required to discover new medicines, alongside highly advanced technologies for treatment, the cost to deliver therapeutics continues to rise. As these therapeutics are delivered to a small number of patients, they may not be cost-effective. One way of delivering for citizens, whilst not leading to runaway costs, is through greater cooperation across the United Kingdom.

In this paper, we will discuss some of the benefits from pooling and sharing health treatments and services across the United Kingdom.



## Highly Specialised Services

Across Scotland, the NHS provide more than 85 designated specialist services. These include specialised treatment for advanced heart failure, spinal injuries, and organ transplants<sup>3</sup>.

For a small number of patients, highly specialised treatment cannot be provided in Scotland. In these circumstances, assuming treatment is available elsewhere, funding can be provided by National Services Division (NSD). Almost all these treatments are delivered by NHS England. NHS Scotland has a service agreement with NHS England, allowing Scottish patients access highly specialised services provided on a UK basis<sup>4</sup>. However, not all specialist services are covered in this agreement. When required, NSD can finance treatment through shared funding on behalf of NHS boards.

Funding for treatment is authorised if patients are referred by NHS Scotland specialists, treatment is provided by the NHS (i.e. not private) and in England (i.e. not abroad), and the specialised service is not available elsewhere in Scotland4. In some incredibly rare circumstances, NSD will consider funding referrals to internationally recognised specialist services.

We submitted a freedom of information request to NSD to understand the level of need for highly specialised treatment in England. Between financial years 2015/16 and 2021/22, NSD approved 4,160 treatments in England, averaging just under 600 referrals each year. These referrals are broken down by year in Figure 1, with the last two years impacted by the pandemic. In comparison, over the same period, an average of just over 111,400 patients in Scotland required elective treatment in Scotland. This suggests that each year, around 1 in 200 (0.5%) patients requiring elective procedures need to access healthcare outside of Scotland.





Accepted Referrals to Highly Specialised Treatment in England, by Financial Year

#### Figure 1. OSF analysis of a National Services Division FOI

In FY 2021/22, 61% of all NSD approved referrals were from just five highly specialised services. These are presented in Figure 2. Rather than an isolated incidence, these five treatments regularly appear in the top five, with gender reassignment surgery continuously the most approved referral for the past seven years.

#### Top Five Approved Referrals in Financial Year 2021/22



Figure 2. OSF analysis of a National Services Division FOI

Most of the highly specialised services listed in Figure 2 require incredibly expensive equipment. With advances in medical technologies, more conditions are likely to be treatable, but at much higher costs. Proton beam therapy (PBT) is a perfect example of this.





PBT uses a dose of high energy protons to precisely target a tumour, reducing the damage to surrounding healthy tissue. This is important for tumours close to critical parts of the body, such as the spinal cord. The therapy in Figure 2 relates to low intensity ophthalmology, provided by the Clatterbridge Cancer Centre in Liverpool. Whilst low intensity beams are useful for eye tumours, to treat tumours deep within the body, a higher intensity beam is required. Since 2008, NHS England have financed patients to receive high intensity proton beam therapy abroad (predominantly in Germany and the USA). With year-on-year increases in treatment applications, particularly for children, the UK Government decided on funding the construction of two centres, one in Manchester (opened in 2018) and the other in London (opened in 2021)<sup>5</sup>. At a cost of over £250 million, it demonstrated a sizeable national commitment to providing PBT domestically. With fewer than 18 patients in Scotland requiring high intensity PBT each year (it does not feature in the top five treatments in 2021/22), it would be unjustifiable to spend such vast sums for such a small number of cases. Instead, through cooperation with NHS England, Scottish patients benefit from the collective pooling of resources, gaining access to these expensive medical technologies.

#### **Other Care Services**

Whilst NSD is the primary funder of cross-border referrals, the NHS boards themselves may directly fund treatment in England. We submitted FOIs to all NHS boards in Scotland to determine the total number of patients who used elective NHS services in other parts of the UK. We specifically requested data on elective treatments since emergency care (such as from A&E) will likely arise from individuals temporarily living in other parts of the UK – such as on holiday. Whilst all A&E services in the UK allows equitable and free access, it is not a direct opportunity of health cooperation.

The responses to our FOIs were mixed. Two boards did not provide information due to no data available, whilst one board reported that their data management

system would require having to review each patient record. Despite these setbacks, we have used the data made available to us to make an estimate on demand. Between FY 2015/16 and 2021/22, we estimate that around 10,500 individuals, 1,500 individuals each year, used non-Scottish NHS services for planned activity.

With around 600 referrals each year, highly specialised services will account for around 40% of this planned activity. The other 60% is comprised of many differing circumstances.

Geography is a factor. NHS Borders had over four times as many interactions with planned procedures with the rest of the UK than NHS Tayside, despite being around one quarter the size in population. Due to geographical proximity, NHS Borders have an agreement in place with three English health trusts, Northumbria Healthcare, Cumbria Healthcare and NHS Newcastle, to cover both elective and emergency activity for Borders patients.

Compassion is a factor. Individuals who require haemodialysis due to poor kidney function are required to undergo the procedure three times a week – usually in hospital. This severely limits travel. To allow patients the option of respite, agreements with other hospitals can be arranged to continue the treatment when on holiday.

Specialist advice is a factor. Clinicians in Scotland may wish to query their patient's diagnosis with a specialist in England. These situations arise when confronted with incredibly rare diseases, where a second opinion is valued, or to request advice for future management of the condition.

Moving home is a factor. When an individual moves whilst in the middle of a treatment episode, the Scottish health board where that individual now resides may query some of the patient history from the former hospital. This also extends to queries regarding funding for any follow-up care.

6

All these reasons, and perhaps others not mentioned, are not just Scottish issues. Individuals living in other parts of the UK require the use of elective treatment in Scotland too. Patients living near the border have access to NHS Borders services thanks to their service agreement; patients receiving haemodialysis may wish to have a respite holiday in Scotland and need to use a local hospital for treatment; Scotland is home to world class medical research, with clinicians in other parts of the UK seeking second opinion or advice on their own patient's care; and with individuals moving to other parts of the UK for further education, work, lifestyle or retirement, maintaining links with their Scottish health board is needed for any transition in care delivery.

We submitted FOIs to all NHS Scotland boards to determine the demand from other UK patients to Scottish NHS services. We received less responses than the previous request, but from the six (of fourteen) boards which were able to provide information, a total of 9,706 individuals in the rest of the UK used elective treatment and outpatient services in Scotland between 2015/16 and 2021/22. These figures are likely to undercount the true extent of citizens in other parts of the UK who receive treatment in Scotland.

Through our FOI requests, we did not find any evidence that patients from other parts of the UK receive specialist treatment in Scotland. However, with strengths in specialised heart surgery, precision medicine and medical imaging, Scotland has the skills and technologies needed to support individuals living in other parts of the UK.

The Imaging Centre of Excellence (ICE) at the Queen Elizabeth University Hospital in Glasgow is an exemplar. Equipped with a 7 Tesla MRI scanner, the joint largest MRI scanner by magnetic strength in the UK, clinicians are able to take very high-resolution images of inside the body. Research has shown 7T MRI scanners are able to detect subtle abnormalities, providing clinicians with a stronger case to whether to operate compared with more conventional MRI scanners<sup>6</sup>. Used in this way, the Glasgow centre could help support clinicians around the UK determine if patients with complex neurological conditions should be operated on.



### "

We estimate that around 1,500 individuals each year, used non-Scottish NHS services for planned activity.

# **Transplant Services**

# "

With low volumes and the need for a biological match, the probability of receiving an organ is relatively small. To increase the number of positive matches, the UK operates a nationwide organ sharing programme.

Alongside specialist services, organ transplantation is shared across the United Kingdom. Solid organ transplantation is a treatment available for patients with end-stage organ failure of the kidneys, liver, pancreas, heart, and lung.

Transplantation involves removing an organ from a donor and placed in the body of a recipient. It is an incredibly complicated procedure, with a high degree of risk. The donated organ must closely biologically match the recipient patient to ensure the body does not reject the organ. If the body rejects the organ (between 10 to 15 in every 100 kidney transplants<sup>7</sup>), it could lead to a transplant failure and the immediate removal of the organ from the recipient. This is one reason why some patients do not wish to opt for transplant treatment. However, studies have shown that patients who opt for a transplant tend to have a better quality of life afterwards<sup>8</sup>.

Further complicating transplantation is the low volume of available organs. Most transplanted organs are provided by deceased donors. These donors will have most likely had a fatal injury to the brain, such as from a stroke, and died whilst under medical supervision. Medical intervention is required to artificially maintain sources of breathing, which in turn maintains the heartbeat. This means that the organ can continue functioning as normal until its extraction. For these reasons, the number of potential deceased donors is incredibly small.

With low volumes and the need for a biological match, the probability of receiving an organ is relatively small. To increase the number of positive matches, the UK operates a nationwide organ sharing programme.



We have made a series of data requests to NHS Blood and Transplant (NHSBT) to understand the level of cross-border sharing of transplanted organs. Between financial years 2015/16 and 2021/22, Scottish patients donated a total of 1,810 organs and were the recipients of 2,118 organs.

Whilst these results suggest Scotland is a net recipient of organ transplants, the true extent of this is unknown. In some circumstances, patients with complex medical requirements may be referred to a specialist centre which is better equipped to support that condition. This means a Scottish patient may be registered through an English transplant site. One example of this is lung transplants. Over the period we have data for, Scotland was a net donor, with 77 lungs transferred to England, and no transplants carried out in Scotland. However, no Scottish hospital currently performs this organ transplant – Newcastle is the closest site – meaning any Scottish residents in need of a lung transplant would be registered to a site in England. Whilst sites in Glasgow and Edinburgh are highly equipped to perform kidney, liver, heart and pancreas transplants, we have been informed that there may be rare circumstances where patients are instead treated in England, particularly for paediatric surgery.

Figure 3 visualises the cross-border flow of all transplanted organs between FY 2015/16 and 2021/22. The graph on the left displays the destination of donated Scottish organs, and on the right, the origin of recipient organs.



Figure 3. OSF analysis of an NHS Blood and Transplant data request. Some numbers are suppressed (\*) due to small values and a risk of identification.

What is most striking from these graphs are the high volumes of flow between Scotland and England. 63% of Scottish donated organs were sent to a recipient in England. Similarly, 63% of Scottish recipient organs originated from English donors. This high level of flow will likely be

10

due to the centralised list system. NHSBT manages the organ transplant lists, with oversight from a national committee<sup>9</sup>. Once added to the list, patients will be algorithmically prioritised for a deceased donor organ from a set of nationally agreed criteria. These include compatibility of blood group with the donor, time spent on the waiting list and the probability of another match in the future.

The need for urgent action will also cause high levels of cross-border flow. Once organs are removed from a deceased donor, they no longer receive oxygenated blood, resulting in the tissues and cells beginning to break down. If they break down too much, the organ will cease to function properly, if at all. Each organ has a specific timeframe, with hearts lasting 4-6 hours outside of the body, to kidneys lasting 24-36 hours outside of the body<sup>10</sup>. Every minute matters. When a deceased donor is identified, specialist surgeons from the National Organ Retrieval Service travel to the donor's hospital to remove their organs. These are then rapidly transported to the recipient's hospital. This national effort, carried out daily, improves the likelihood of successful transplants across the whole country.

Over the period, we have seen cross-border cooperation increase. Figure 4 visualises the total number of transplanted organs in Scotland, alongside the proportion of transplanted organs whose donor is resident in Scotland. From a peak of 45% in 2016/17, the proportion of Scottish donor to Scottish recipient has gradually reduced, dropping to 19% in 2021/22. In that year, 4 in 5 organs received by Scottish patients came from donors outside of Scotland. It is important to re-emphasise that a similar figure, 77%, of Scottish donated organs were received by individuals living in other parts of the UK. Reduced volumes in the past two years due to the pandemic may also impact on percentages, but the general direction of travel pre-dates this.





Figure 4. OSF analysis of an NHS Blood and Transplant data request.





The most common organ transplanted across the period were kidneys. From 2015/16 to 2021/22, Scottish residents donated 1,107 kidneys and were the recipients of 1,220 kidneys. Figure 5 visualises the cross-border flow of all kidneys between FY 2015/16 and 2021/22.

Like the total number of organs transplanted, the level of kidney transplant integration between the home nations has increased over the period. In 2016/17, 52% of kidneys transplanted were from a Scottish donor-recipient pair, with this reducing down to 21% by 2021/22.



Figure 5. OSF analysis of an NHS Blood and Transplant data request. Some numbers are suppressed (\*) due to small values and a risk of identification.

Following kidneys, livers were the second most common organ transplanted in Scotland. Scottish residents donated 454 livers between 2015/16 and 2021/22 and were the recipients of 600 livers. This was followed by the pancreas (87 Scottish donations, 199 Scottish recipients) and heart (68 Scottish donations, 97 Scottish recipients).

Across all organ transplantations, we see a high level of cross-border flow between Scotland and England. This high level of cooperation ensures that the maximum number of organs are delivered to the best patient match, increasing the success rate of transplants and quality of life for recipients.

# "

Medical advancements come at a cost. Healthcare is becoming increasingly specialised and a high financial barrier to treat. It is therefore vital, that as we look toward the rest of the 21st Century, the UK continues to cooperate in delivering health services.

NIN

### Future Opportunities

We have seen rapid acceleration in health research and medical breakthroughs. Over the past 65 years, we have witnessed the first modern hip replacement, the first kidney transplant, the first cloned mammal and the sequencing of the human genome. Many diseases previously thought to be untreatable are now potentially curable. However, medical advancements come at a cost. Healthcare is becoming increasingly specialised and a high financial barrier to treat. It is therefore vital, that as we look toward the rest of the 21st Century, the UK continues to cooperate in delivering health services.

One major advance in health is regenerative medicine. Regenerative medicine can help repair or replace damaged or diseased human cells or tissues to restore normal function. Treatment could involve either transplanting stem cells or tissue, to stimulate a repair process in the body; use cells as delivery vehicles for therapeutic agents; or use biomaterials to support tissue regeneration<sup>11</sup>. An example of regenerative medicine is heart disease. By growing heart muscle cells in a lab, they can be implanted into a patient's heart muscles, to help repair the injured heart.

Specialised centres across the United Kingdom are developing advanced therapeutics for regenerative medicine and its overlapping, but independent field, cell and gene therapy. These centres are fast becoming national, and international, hubs attracting a high concentration of expertise. In 2022, researchers and clinicians based at Great Ormand Street Hospital performed the world's first use of base-edited cells to treat previously incurable leukaemia. This treatment, delivered to a 13-year-old girl from the East Midlands, used new base-editing technology to edit T-cells which would hunt down and kill cancerous T-cells within the body. Whilst still recovering, the signs are currently positive that the leukaemia is undetectable in the patient<sup>12</sup>.

Medical breakthroughs such as base-editing technology will likely form part of future health provision. As shown by this world's first treatment, researchers clustered in one city can provide life-enhancing treatments to patients living in other parts of the UK. With greater specialisation and agglomeration of expertise in fewer sites, alongside the high costs of medical technology, continued health cooperation across the United Kingdom is vital. This will ensure that an individual who could benefit from medical breakthroughs, such as children with previously incurable leukaemia, have access to treatment – no matter where they live in the UK.







# "

With greater specialisation and agglomeration of expertise in fewer sites, alongside the high costs of medical technology, continued health cooperation across the United Kingdom is vital. This will ensure that an individual who could benefit from medical breakthroughs...have access to treatment – no matter where they live in the UK.

#### Conclusion

From accessing specialised health technologies and expertise, to sharing organs suitable for transplantation, Scots gain from working cooperatively with the rest of the UK.

With advanced medical treatments becoming ever more expensive, and delivered to a small number of people, pooling resources across the United Kingdom to deliver services through a couple of centres of excellence ensures we all benefit from medical breakthroughs. This is seen to great effect with high intensity proton beam therapy, where the purchasing of the equipment for Scottish patients alone would incur unjustifiably high costs. It is imperative this cooperation in delivering highly specialised treatment to everyone in the UK, no matter where they live, continues to be provided.

With incredibly low probabilities of successful organ donor matches, pooling organ donation across the United Kingdom can result in many more transplant successes. Time is limited, but the geography of the UK means it is possible for a kidney donated in Glasgow to be given to a patient in Cardiff, leading to a higher transplant success rate and improved quality of life for recipients.

These examples show the benefit of health cooperation across the United Kingdom, where maximising our economies of scale helps improve lives.



#### References

1 Scottish Government. Illnesses and Long-Term Conditions. Scottish Government. 2022. (Available from: <u>https://www.gov.scot/policies/illnesses-and-long-term-conditions/rare-diseases/</u>) [cited 10 March 2023].

2 National Services Scotland. What are National Networks? National Services Scotland. 2020. (Available from: <u>https://www.nss.nhs.scot/specialist-healthcare/national-networks/what-are-national-networks/</u>) [cited 10 March 2023].

**3** National Services Scotland. About Specialist Services. National Services Scotland. 2022. (Available from: <u>https://www.nss.nhs.scot/specialist-healthcare/specialist-services/about-specialist-services/</u>) [cited 10 March 2023].

**4** National Services Scotland. Specialist Services UK. National Services Scotland. 2022. (Available from: <u>https://www.nss.nhs.scot/specialist-healthcare/specialist-services/specialist-services-uk/</u>) [cited 10 March 2023].

**5** NHS England. Proton Beam Therapy. NHS England. 2021. (Available from: <u>https://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt/</u>) [cited 10 March 2023].

6 Mayo Clinic. 7-Tesla MRI: Pioneering use for patient care. Mayo Clinic. 2018. (Available from: <u>https://www.mayoclinic.org/medical-professionals/</u> neurology-neurosurgery/news/7-tesla-mri-pioneering-use-for-patient-care/MAC-20449573) [cited 10 March 2023].

**7** NHS Blood and Transplant. Early Risks of a Kidney Transplant. NHSBT. (Available from: <u>https://www.nhsbt.nhs.uk/organ-transplantation/kidney/benefits-and-risks-of-a-kidney-transplant/risks-of-a-kidney-transplant/early-risks-of-a-kidney-transplant/</u>] [cited 10 March 2023].

8 Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, Klarenbach S, Gill J. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. Am J Transplant 11(10) pp. 2093-2109. 2011

**9** NHS Blood and Transplant. How Does the Offering System Work? NHSBT. (Available from: <u>https://www.nhsbt.nhs.uk/organ-transplantation/kidney/receiving-a-kidney/how-does-the-offering-system-work/</u>) [cited 10 March 2023].

**10** LifeSource. How long can an organ be outside the body before transplant. LifeSource. 2022. (Available from: <u>https://www.life-source.org/latest/</u><u>how-long-can-an-organ-be-outside-the-body-before-transplant/</u>) [cited 10 March 2023].

**11** UK Research and Innovation. Regenerative Medicine. UKRI. 2022. (Available from: <u>https://www.ukri.org/what-we-offer/browse-our-areas-of-investment-and-support/regenerative-medicine/</u>) [cited 10 March 2023].

**12** UK Research and Innovation. World-first use of base-edited cells to treat "incurable" leukaemia. UKRI. 2022. (Available from: <u>https://www.ukri.org/news/world-first-use-of-base-edited-cells-to-treat-incurable-leukaemia/</u>) [cited 10 March 2023].

Our Scottish Future believes that good government in Scotland and across the United Kingdom has to be based on the values of cooperation, empathy, solidarity and reciprocity.

Our Scottish Future | www.ourscottishfuture.org | info@ourscottishfuture.org