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Imperial College Health Partners Rare Disease Analysis

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Imperial College Health Partners (ICHP)

- **Academic Health Science Network** (AHSN) – funded to facilitate adoption and spread of innovation across the NHS
- **Health partnership** – capability and capacity across over 400 NHS organisations across NW London

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Imperial College Health Partners (ICHP)

Our mission:

Evidence-based complex change to help our clients deliver more effective and efficient health care

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Imperial College Health Partners (ICHP)

What makes us different?

1. Our approach to innovation
2. Our people and our culture
3. Our smart use of data
4. We create connections & collaboration

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Business Intelligence Team

- Analytics
- Population Health
- Health Economics
- Visualisation
- Publication

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Effective Business Intelligence

We collect, integrate and analyse data to draw conclusions and to present **actionable information** that can be used to make informed business decisions.

We help both NHS and commercial clients develop solutions that truly make an **impact** for both individual patients and communities.

Once we understand what our clients are looking to achieve, we can help them identify the best way forward to get to the end point they are aiming for.

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Data Assets

- **NHS Digital**
  - Record level HES data* linked to Mental Health & Office National Statistics
  - Quality Outcomes Framework (QOF) indicators
  - Primary care prescribing
- **Discover/WSIC**
  - NW London integrated care data – di-identified record level data for 2.4 million patients linked across primary, secondary, mental health, social care and high cost drugs datasets

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ISPOR Best Research Paper

COMPARISON OF COSTS ASSOCIATED WITH TURP AND PROSTATIC URETHRAL LIFT FOR BENIGN PROSTATIC HYPERPLASIA

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Introduction

- Benign prostatic hyperplasia (BPH) can be associated with bothersome lower urinary tract symptoms (LUTS) that can substantially affect men's quality of life
- At least one-third of men older than 50 years are affected by BPH with bothersome LUTS[1]
- Patients with disease recalcitrant to medical treatments or who develop acute urinary symptoms (eg, acute urinary retention, urinary tract infections, haematuria, or renal insufficiency) can be considered for surgical treatment
- Transurethral resection of the prostate (TURP) is the gold standard surgical treatment, but this and less-invasive techniques that involve tissue destruction are associated with substantial comorbidities, whereas prostatic urethral lift (PUL) is minimally invasive (Figure 1)

Figure 1. Placement of PUL implants to retract obstructive prostate lobes without tissue-destructive procedures

Tissue effects of different prostate-reduction techniques versus prostatic urethral lift

- Transurethral resection of the prostate (TURP) has been the surgical gold standard since the 1970s, and improves subjective symptoms and urinary flow, but is associated with significant morbidity and long-term complications such as urinary incontinence, strictures, infections, and sexual dysfunction
- Laser-based techniques are associated with less bleeding and hospitalisation, but these still work by tissue removal or destruction, leading to similar perioperative complications and the same list of permanent complications as TURP[2,3]
- Prostatic urethral lift is a minimally invasive technique that moves the prostate lobes apart, obviating effects associated with tissue-destructive procedures

- We compared whether treatment of BPH with PUL would improve treatment-related outcomes and costs compared with monopolar or bipolar TURP.

Methods

- We were provided with derived outputs by Harvey Walsh Ltd who have licensed access to the National Health Service Hospital Episode Statistics (HES) database (Copyright NHS Digital 2018) and The Health Improvement Network (THIN) to search at the record level for hospitalisation and treatment rates for TURP in England
- The HES database holds information (ICD10 codes) on all admissions, accident and emergency visits and outpatient appointments at NHS hospitals in England
- The THIN database includes information (ICD10 and Read codes) on diagnoses, treatments, care, and visits for patients in primary care from more than 400 general practice surgeries in the UK
- To compare complications, we searched HES and THIN for each recording of 25 ICD10 codes (Table 1) that could reasonably be assumed to be directly related to non-laser TURP (procedural classifications M651 and M653) in all men who underwent this surgery for BPH in England in 2009/10, and drew on data from the literature for further information on those that were most common
- We calculated the potential annual difference in operative and postoperative costs between TURP and PUL based on the most common complication and re-treatment rates[4–10] and assuming 50% uptake for PUL

Table 1. ICD10 codes in HES used for analysis of TURP-associated complications

General Medical Complications	D649	Anaemia
General Medical Complications	Z538	Procedure Not Carried Out for Other Reasons
General Medical Complications	Z921	Personal History of Long-Term (Current) Use of Anticoagulants
General Medical Complications	Z530	Procedure Not Carried Out Because of Contraindication
Bladder	N328	Other Specified Disorders of Bladder
Bladder	N323	Diverticulum of Bladder
Bladder	N210	Calculus in Bladder
Bladder	N320	Bladder Neck Obstruction
Bladder	N328	Other Specified Disorders of Bladder
Catheterisation	T830	Mechanical Complication of Urinary (Indwelling) Catheter
Catheterisation	Y846	Urinary Catheterisation
Haemorrhage	T810	Haemorrhage and Haematoma Complicating a Procedure
Haemorrhage	R31X	Unspecified Haematuria
Infection	N390	Urinary Tract Infection
Mental Health	F329	Depressive Episode
Micturition Problems	R32X	Unspecified Urinary Incontinence
Micturition Problems	R391	Other Difficulties with Micturition
Micturition Problems	R398	Other and Unspecified Symptoms and Signs Involving Urinary System
Micturition Problems	N359	Urethral Stricture
Micturition Problems	Z466	Fitting and Adjustment of Urinary Device
Micturition Problems	R33X	Retention of Urine
Prostate	N411	Chronic Prostatitis
Prostate	N410	Acute Prostatitis
Prostate	N428	Other Specified Disorders of the Prostate
Prostate	N419	Inflammatory Disease of the Prostate

Results

TURP

- In 2016/17, 18,362 monopolar and bipolar TURP procedures were reported in HES
- The average hospital stay is 2.7 days, and catheterisation is required for 3–5 days on average
- Although rates vary, complications of TURP include ejaculatory dysfunction, affecting at least 65% men,[7] erectile dysfunction in ~10%,[7] urethral stricture in ~4%, infection in ~4%, bleeding requiring transfusion in ~2%, and permanent urinary incontinence in ~2%
- 1–2% of patients require TURP reoperation per year[6] but around 14% of patients restart drug therapy for LUTS within 12 months, around 20% by 3 years, and around 40% by 5 years[10]
- Among all recipients of TURP for BPH in 2009/10, cumulative HES data to 2014/15 showed 70,000 post-procedure hospital spells

PUL

- The longest-term data reported for PUL are 5-year outcomes and compare the procedure with sham surgery[11]
- No hospital stays were required and catheterisation, required for 32%, was 1 day on average
- Most adverse events (mainly dysuria, discomfort, urgency, and haematuria) were mild to moderate and most resolved in 2–4 weeks without hospital treatment
- Erectile and ejaculatory function were preserved with no incident cases of sustained dysfunction reported after surgery
- The surgical re-treatment rate was 13.6% (4.3% repeat PUL, 9.3% TURP or laser ablation), but all but one of the re-treated patients had severe to very severe LUTS at baseline
- Medical treatment was restarted in just under 4% of patients at 1 year and in 11% of patients 5 years after surgery
- Based on this complication profile, we estimate that the complication rate associated with TURP could be halved with PUL and, therefore, that a saving of £27 million could be made per year

Cost calculations and estimated saving with PUL versus TURP

TURP

- Mean 2016/17 procedure cost for TURP (national schedule of reference costs) £2,869 (IQR £2,422–3,138), giving a minimum total of ~£43 million
- Complications cost to payer £109 million over 5 years for each annual cohort of patients

PUL

- Mean 2015/16 cost for PUL (calculated by The National Institute for Health and Care Excellence) £2,405[12]
- Assumptions:
  - Rate of described complications reduced by 50%
  - Uptake of PUL would be 50%

ESTIMATED SAVING

£27 million per year over 5 years for each annual cohort of patients

Conclusions

- Durability of the treatment is similar for TURP and PUL, but the postoperative complication and medical re-treatment profiles differ
- PUL is associated with very low rate of complications, most of which are mild to moderate in severity and resolve within 2–4 weeks
- Increasing experience with PUL procedures, which is associated with increased numbers of procedures performed under local anaesthetic and rapidity of recovery, is likely to improve outcomes further (Figure 2)[13–15]
- For a similar procedural cost, PUL could reduce complications, improve quality of life, and substantially reduce post-surgical care costs compared with current standard TURP practice

	L.I.F.T. Study procedures 2011[1]	Crossover Studies procedures 2011[14]	LOCAL Study procedures 2013[2]
Local anaesthesia	97%	99%	100%
Catheter rate after void trial	68%	66%	80%
Return to normal	8.6 days	6.5 days	5.1 days

Figure 2. PUL outcomes have improved as experience with the procedure has increased

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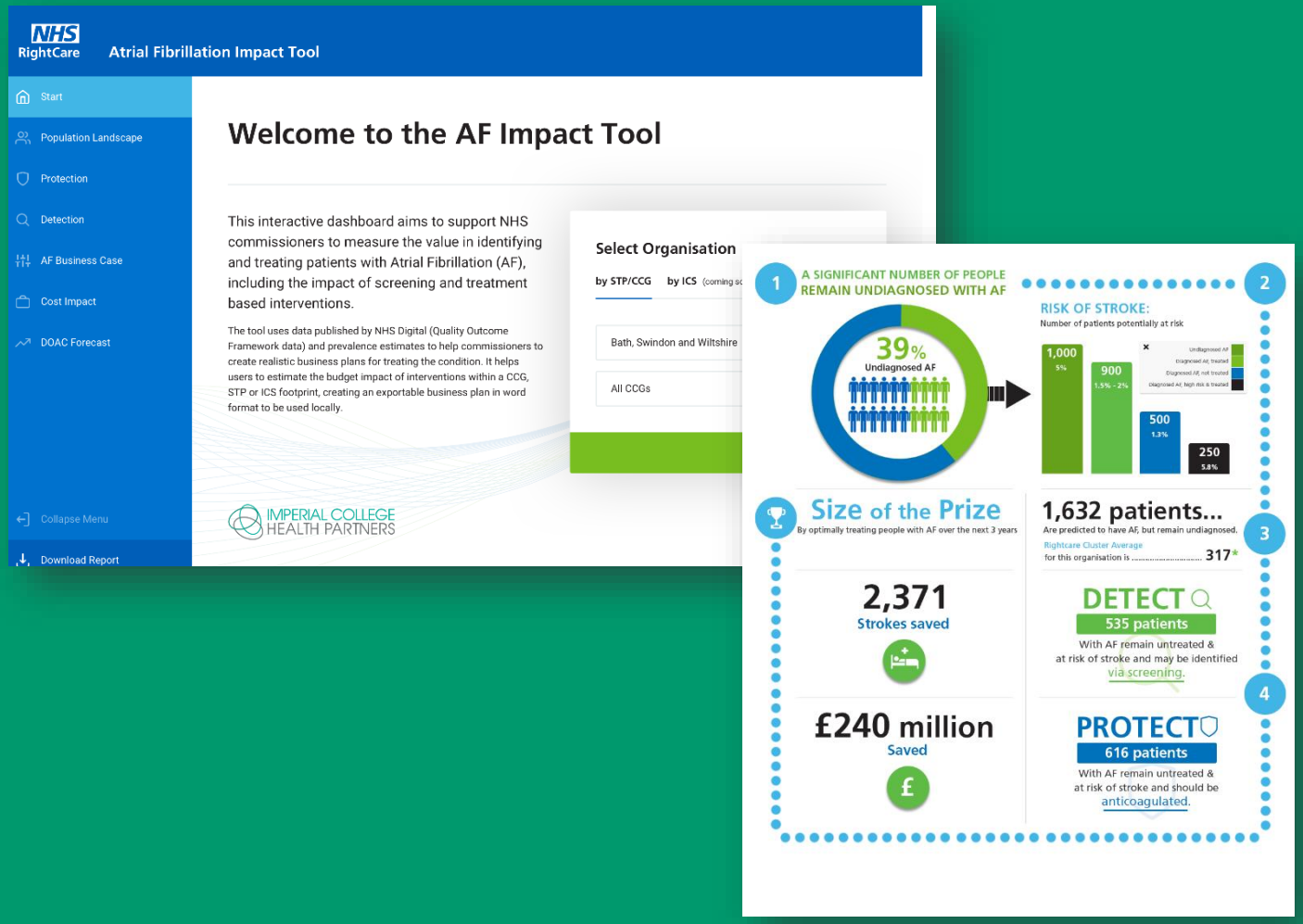
NHS Rightcare AF High Impact Tool



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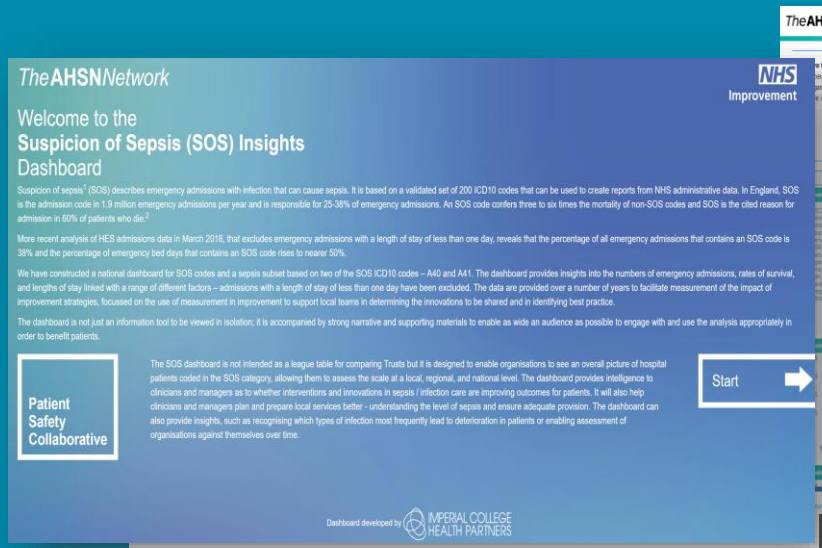
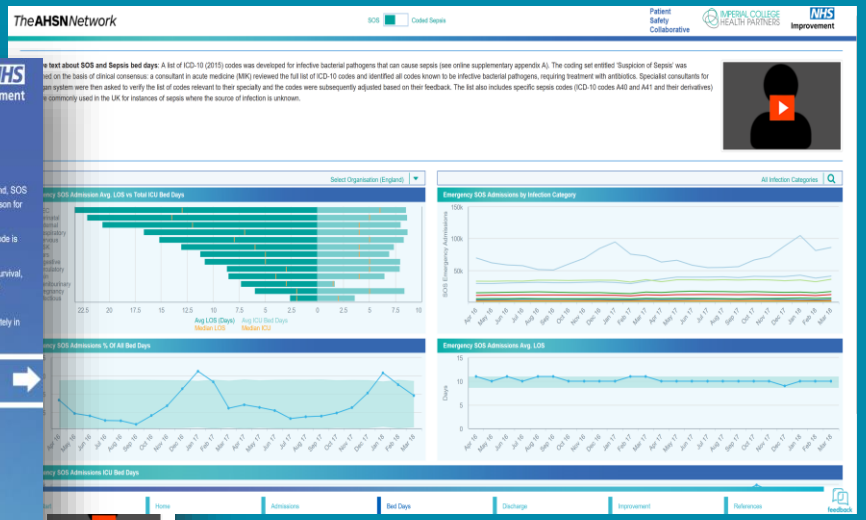
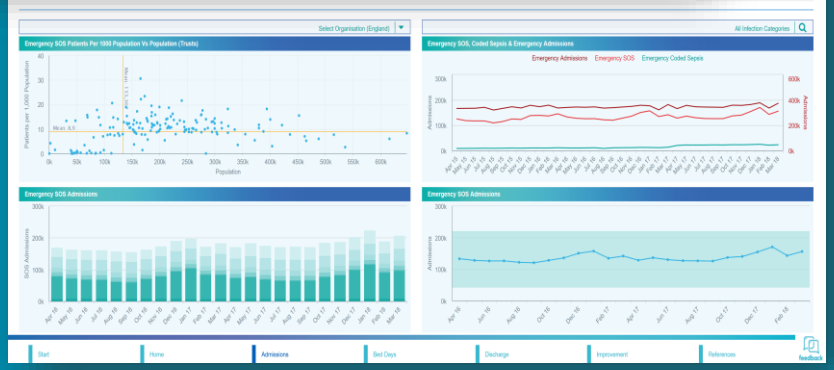
SOS Sepsis Insights







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Rare Disease Case Study

- Despite this global prioritisation, very few comprehensive **impact analyses** have been conducted at the population-level to evaluate the **healthcare burden** of Rare Disease (RD),
- More specifically the **time period prior to diagnosis**; and their contribution to overall healthcare resource utilisation and healthcare costs
- A commercial partner commissioned ICHP to ascertain the burden of RD to the NHS

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Rare Disease Case Study

RD's are an increasingly recognised **health priority** due to their impact, severity and burden on the patient, their family and the health system

People with rare diseases tend to have **multiple health problems and complex care needs** requiring access to a wide range of health services

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Rare Disease Case Study

- Differential diagnosis for a RD often relies on the availability of an accessible/reliable laboratory or genetic test and/or access to an appropriately experienced clinician.
- This means that the prolonged journey to medical diagnosis can involve **serial referrals** to several specialists alongside a plethora of, often invasive, tests.
- This **diagnostic delay** can reach up to 30 years for some conditions

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Rare Disease Case Study

- How can we understand the **burden** of RD's compared to the rest of the patient population using current data assets?
- Phase one: **10-year HES data linked at the record level**
- Phase two: **NW London integrated dataset Discover/WSIC**

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Rare Disease Case Study

Caveats

- ICD-10 codes believed to only account for approximately 5% of known RD
- **Orphanet** offers a more comprehensive coding system and have been used to inform the updated ICD-11 but this has not yet been widely implemented across routine data collection systems in the NHS
- Subset for analysis

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Rare Disease Case Study

Phase one:

Preliminary investigation into the potential cost and resource impact of RD on the NHS, with a focus on the **time period up to diagnosis**, using the reported real-world hospital dataset Hospital Episode Statistics(HES), provided by NHS Digital in England over a 10-year period

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Rare Disease Case Study

Method:

- One ICD10 code per RD analysis of a total of **426 RD codes** crossing a range of body systems and clinical specialty
- This approach ensured that only accurately diagnosed and reported RD's were included in the dataset

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Rare Disease Case Study

- Aggregated statistical reports from HES tracked records of all ages diagnosed with one of these **426 specific RD diagnostic codes over a 12-month 2017/18**
- HES identification numbers enables **10-year retrospective longitudinal analysis** across the hospital system (IP, OP & AE) and ensured no ‘double counting’ in the analysis
- Comparator was the **total remaining hospital population**

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Rare Disease Case Study

In the last 10 years, **2,197,501** patients were linked to one of the 426 RD ICD-10 codes, comprising 3.2% of the overall inpatient / outpatient hospital population.

In terms of **new diagnoses** during 2017/18, this totaled **258,235 patients**, or 0.94% of the overall inpatient / outpatient hospital population;. .
38,155 patients were 10 years old or younger

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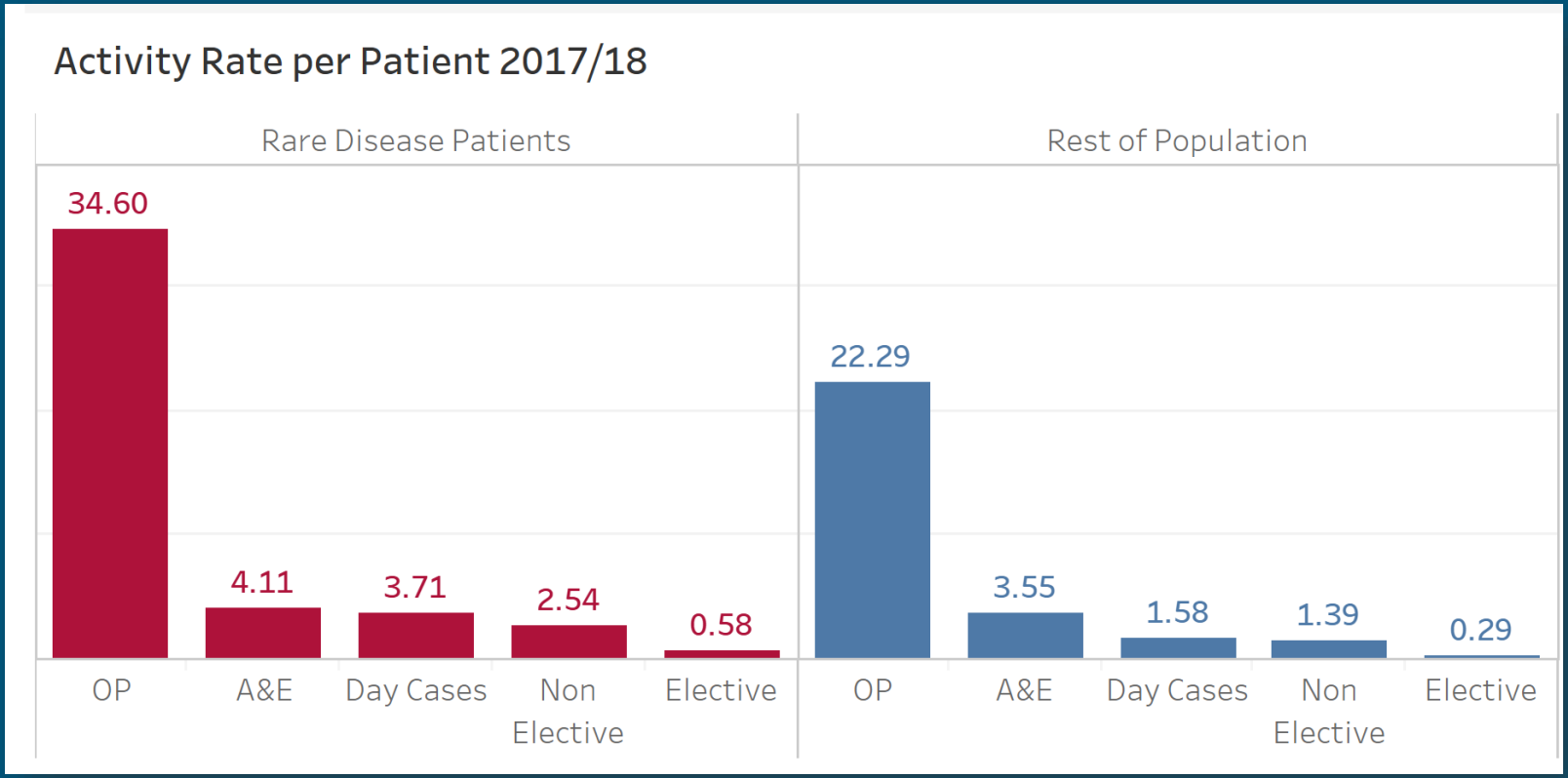

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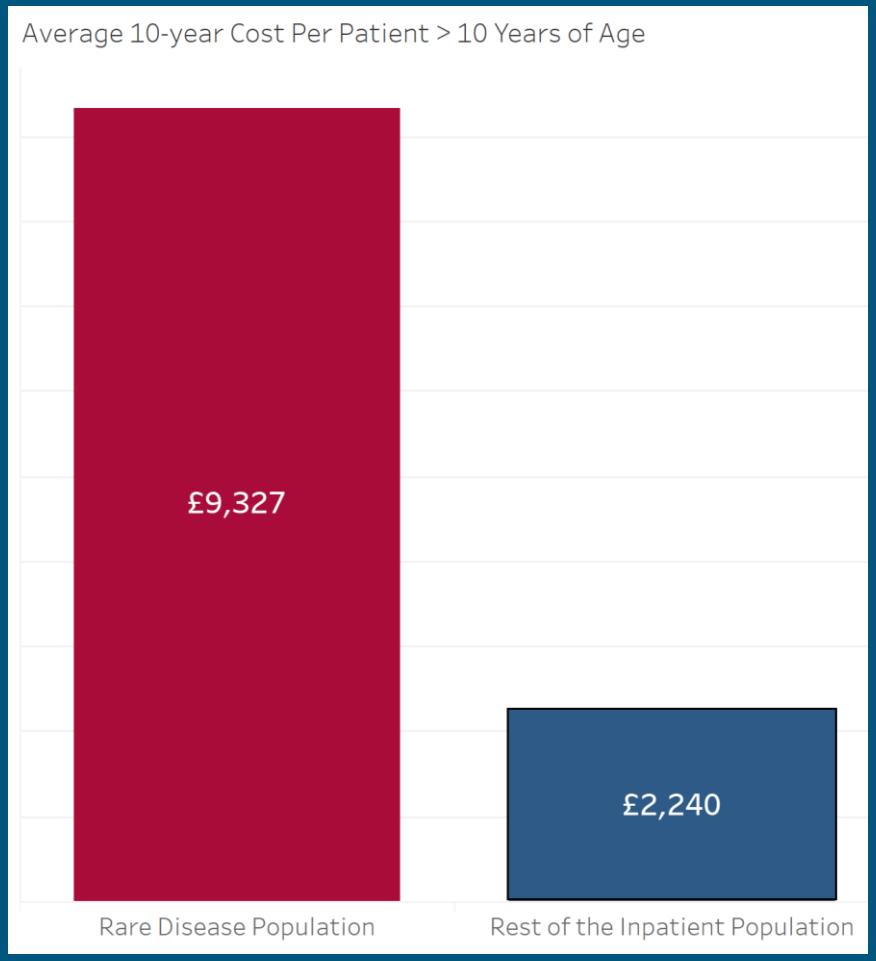

For patients 10 years old and younger the average patient cost* 416% higher compared to the rest of the patient population

**Costs – NHS tariff costs, excludes high cost drugs*

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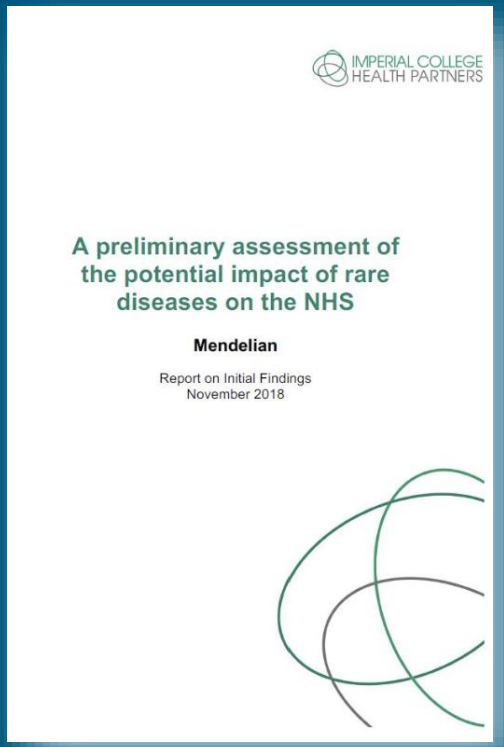
Rare Disease Case Study

Link to full report:

https://imperialcollegehealthpartners.com/a-preliminary-assessment-of-the-potential-impact-of-rare-diseases-on-the-nhs/



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Rare Disease Case Study

Next steps:

Extend the patient journey using the **integrated dataset** for NW London, including primary care and social care activity comprising GP, community nurse and prescribed medications

High cost drugs are also included in this integrated data set and so evaluations of these drugs is possible


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Any Questions?
Thank you!