

Healthcare resource utilisation (HCRU) by patients with Duchenne Muscular Dystrophy (DMD) using UK patient level data

J. ROBERTS¹, D. HICKEY¹, S. SHARER¹, B. RICHARDSON¹, and R. SELBY²
¹ Carnall Farrar, 1 Lyric Square, London W6 0NB, United Kingdom
² ITF Pharma UK, 27 Old Gloucester Street, London WC1N 3AX, United Kingdom

INTRODUCTION

- DMD is a severe X-linked neuromuscular disorder primarily affecting males, with a prevalence of 2.8 per 100,000. It manifests in early childhood, causing progressive muscle weakness and loss of mobility between ages 8 and 14. Most patients require ventilation support by age 20 and face severe respiratory and cardiac complications, often leading to death in their mid-twenties.^{1, 2, 3}
- While there is no cure, treatments focus on managing symptoms, slowing progression, and enhancing quality of life. As treatments advance, understanding the healthcare burden and associated costs of DMD is important.

OBJECTIVES

This study aimed to identify the HCRU and costs of patients with DMD by age range to determine the burden associated with the condition as it progresses until death.

METHOD

- Using five years of NHS Hospital Episode Statistics (HES) data, the ICD-10 code of G71.0 identified an initial cohort of patients likely to have DMD.
- The cohort was refined based on clinical expert input and DMD-specific criteria to exclude patients with other muscular dystrophies, those over 20 without ambulation issues, and those over 30 without ventilation support recorded in the HES dataset in the past 5 years, resulting in a final cohort of 1,937 individuals for analysis.
- This analysis evaluated HCRU in inpatient, outpatient, and emergency care settings. Deaths in HES data were identified by discharge due to death or a transfer to a hospice within the past five years.

RESULTS

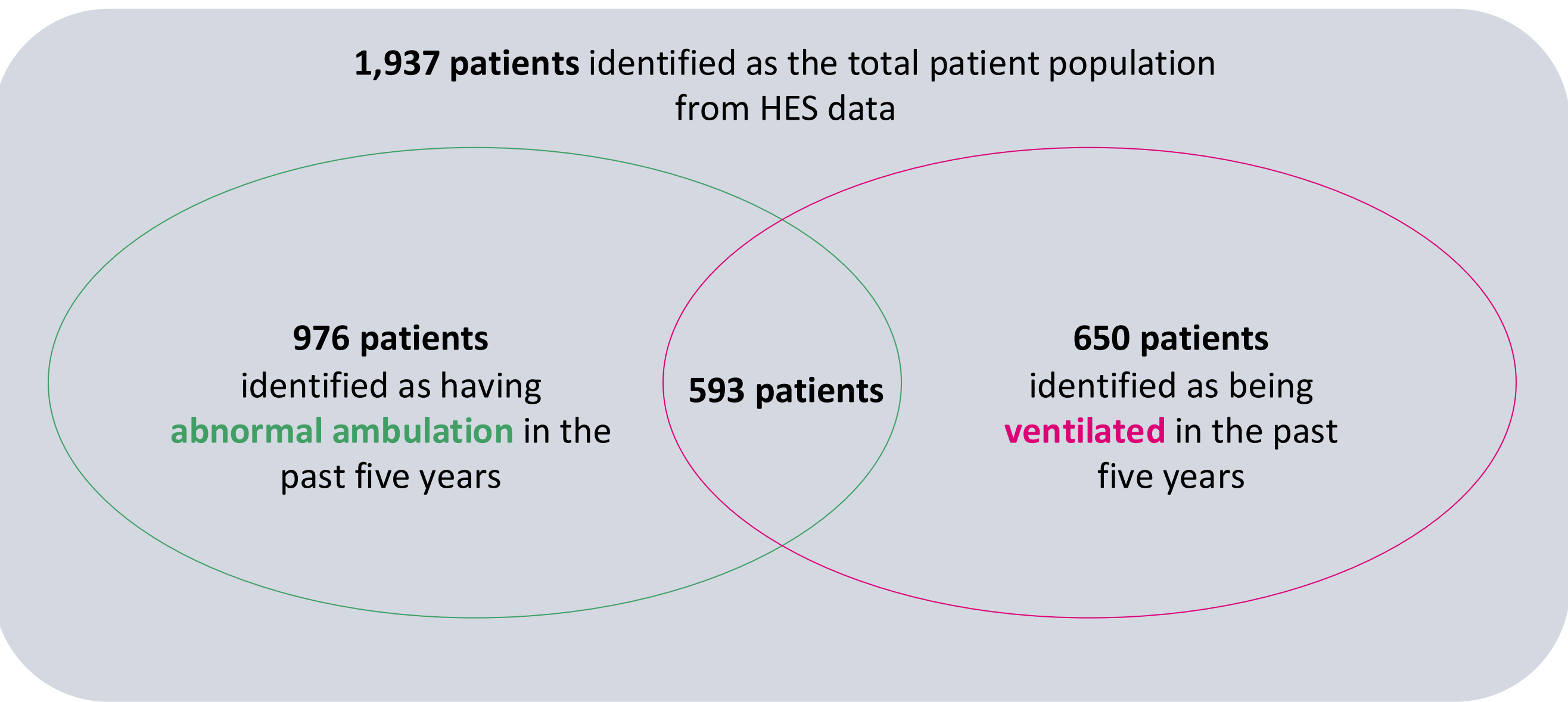
- The mean age of the 1,937-patient cohort was 17 years, and the mean age of death was 28 years.
- The data reflected current published literature regarding disease progression, with abnormal ambulation developing in children aged 6-15 years and ventilation support needed for those aged 11-20 years. Of the entire cohort, over 50% (976) had significant mobility issues and over a third (650) required ventilation.
- Over 75% of healthcare activity was through outpatient appointments, with an average annual cost of £1,325 per person across all age groups.
- For patients below 20 years, the average annual cost for elective admissions was £1,538 per person, while for those over 20, it was £987 per person.
- Non-elective average annual admission costs were more than 2.5 times higher per person for individuals over 20 years (£1,692) compared to those under 20 years (£658).

CONCLUSION

This latest HES study of DMD aligns with current literature^{1,4} on the reported costs of acute care settings, indicating that costs remain unchanged despite the availability of new treatments for DMD.

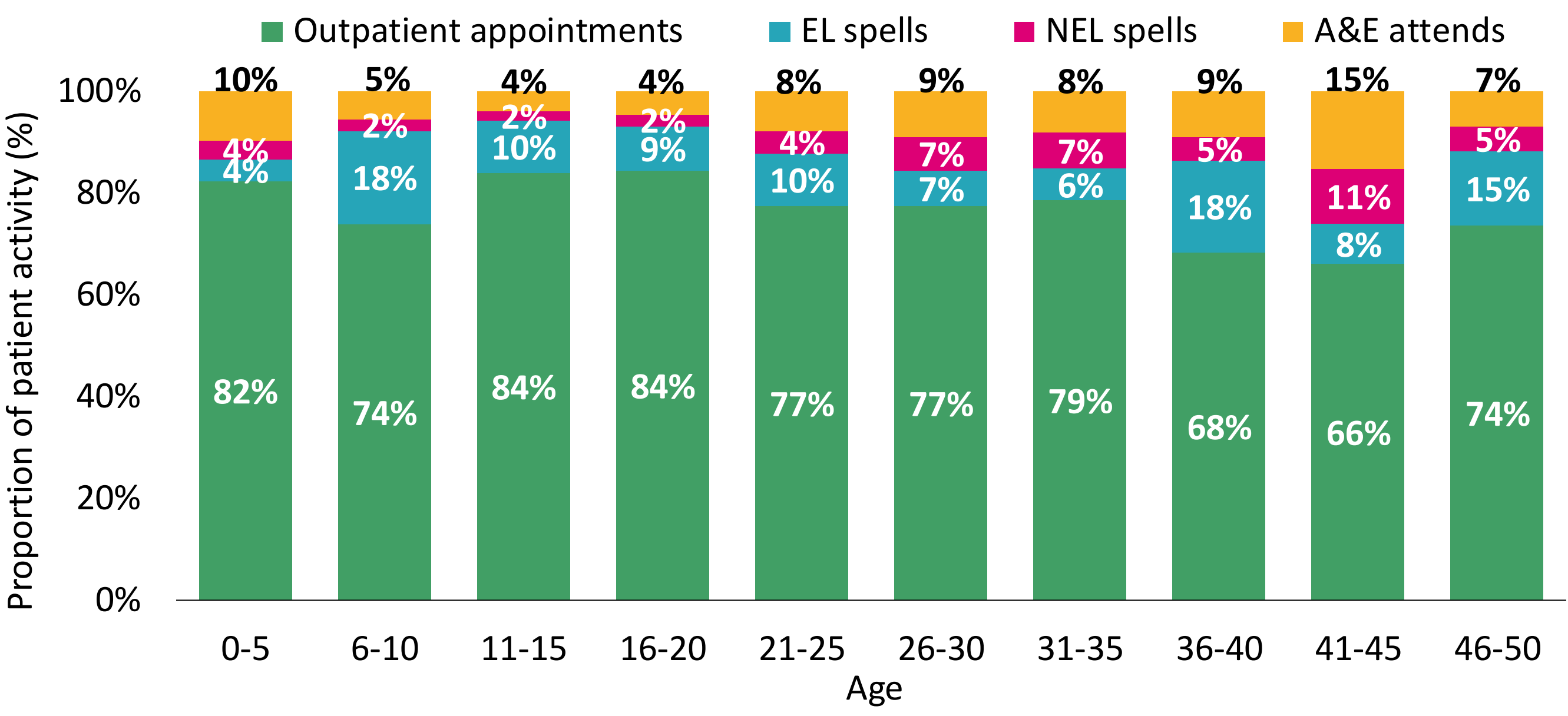
Identified patients with both ambulation and ventilation needs

FY 2023-24, Number of patients



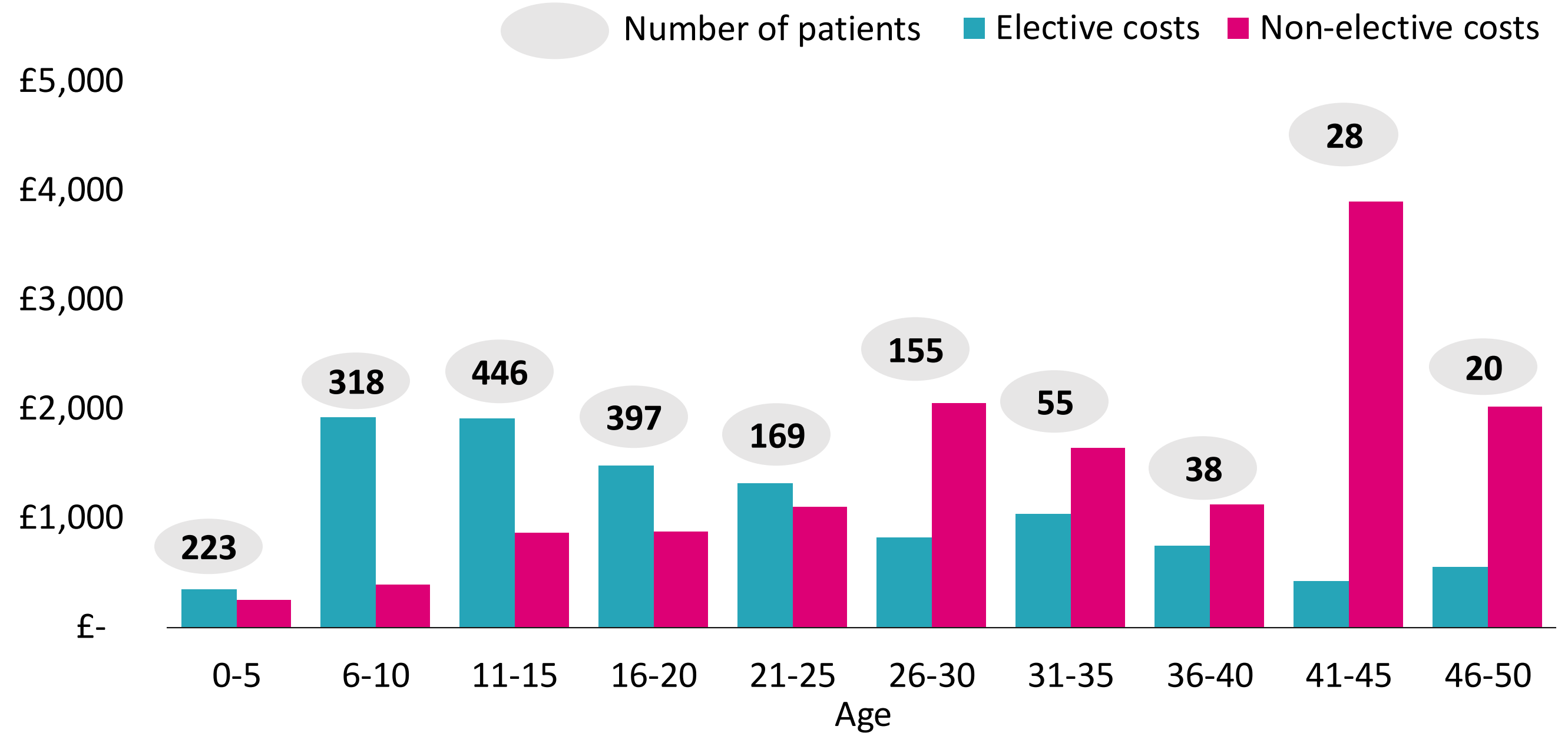
Proportion of acute and outpatient activity in each age group

FY 2023-24, Acute activity as a proportion of the total DMD cohort activity

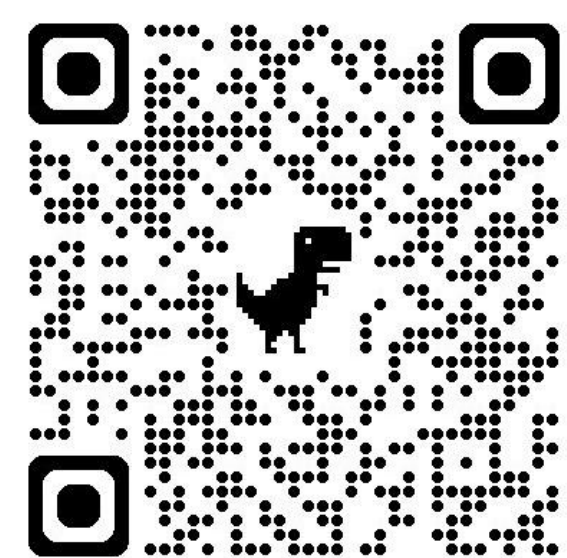


Average annual elective and non-elective inpatient costs

FY 2023-24, £ per person per year



CONTACT DETAILS



Carnall Farrar
T: + 44 (0)20 3770 7535 E: LifeSciences@carnallfarrar.com

Jacqueline Roberts (Corresponding Author)
T: +44 (0)7301 205088 E: Jacqueline.Roberts@carnallfarrar.com



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