

Primary biliary cirrhosis: data insights

HES data analysis

by Wilmington Healthcare

on behalf of Ipsen Pharmaceuticals

June 2023



Wilmington
Healthcare



Introduction





About this report

Ipsen Pharmaceuticals commissioned Wilmington Healthcare to provide insights into the landscape of primary biliary cirrhosis (PBC) – a chronic disease, also known as primary biliary cholangitis, in which bile ducts in the liver are slowly destroyed – in England.

To achieve this, Wilmington Healthcare used:

- Hospital Episode Statistics (HES) data¹ to analyse:
 - admission types: patient/outpatient, non-elective/elective
 - age/sex
 - treatment specialties
 - comorbidities
 - procedures
- Secondary Care Medicines Data (SCMD) to identify prescribing patterns for obeticholic acid (OCA).

The HES analysis covers the 5-year period including the last 5 full fiscal years (2017/2018 through 2021/2022) and uses the International Classification of Disease, 10th edition (ICD-10) code K743 for primary biliary cirrhosis.¹ Prescribing data are based on the fiscal year 2021/2022.

The report is divided into three colour-coded main sections summarising findings of particular interest. Appendices provide references, analytical methods, detailed data, and the HES.SCMD disclaimer/digital licences. The full dataset is available in a separate Excel report.

About HES data²

HES is a database containing details about admissions, A&E attendances and outpatient appointments at NHS hospitals in England. It can be used to:

- monitor trends and patterns in NHS hospital activity
- assess effective delivery of care
- support local service planning
- provide the basis for national indicators of clinical quality
- reveal health trends over time
- inform patient choice
- determine fair access to health care
- develop, monitor and evaluate government policy
- support NHS and parliamentary accountability.

The HES disclaimer/digital licence is provided in [Appendix 2](#).

About SCMD³

SCMD contains processed pharmacy stock control data in Dictionary of Medicines and Devices (DM+D) standardised format from all NHS acute, teaching, specialist, mental health and community trusts in England.

The NHS Business Services Authority (NHSBSA) hosts and publishes Secondary Care Medicines Data on behalf NHS England and Improvement (NHSE&I).



How to use this report

Use the menu below and at the top of each page to navigate between sections.

HES			Prescribing data	Appendices
Inpatient data		Outpatient data	Case study	Trusts
Patients	Spells/episodes	Treatment specialties	Age and sex	ICBs
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Time trends	Treatment specialties	Procedures		
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	MLOS			
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	Bed days			
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HES data





Inpatient data





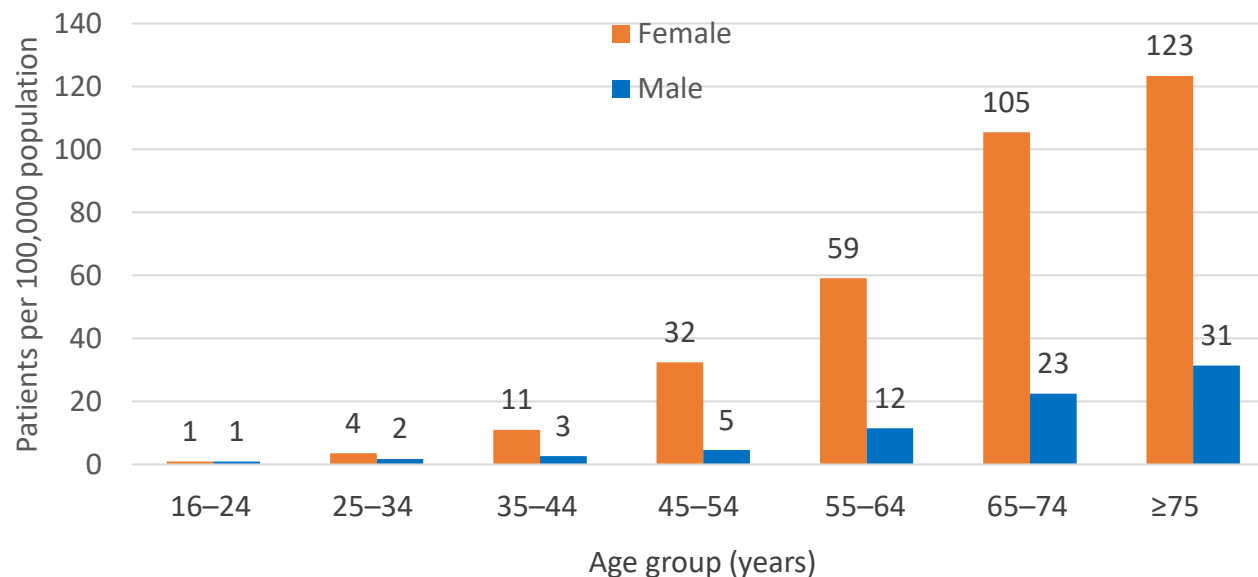
Patients



The number of patients admitted with a diagnosis of PBC increases with increasing age

- The number of patients admitted who have a diagnosis of PBC:
 - increases with increasing age
 - is higher in women than men in all age groups, except 16–24 years.
- The female to male ratio is very consistent from year to year.

Patients admitted to hospital with a diagnosis of PBC by age and sex normalised per 100,000 population,⁴*5-year total (2017/2018 to 2021/2022)



Patients admitted to hospital with a diagnosis of PBC by sex, 2017/2018 to 2021/2022

Fiscal year	Female	Male
	n (%)	n (%)
2017/2018	2,935 (84)	550 (16)
2018/2019	2,905 (84)	555 (16)
2019/2020	3,140 (85)	555 (15)
2020/2021	2,490 (84)	490 (16)
2021/2022	3,170 (85)	560 (15)

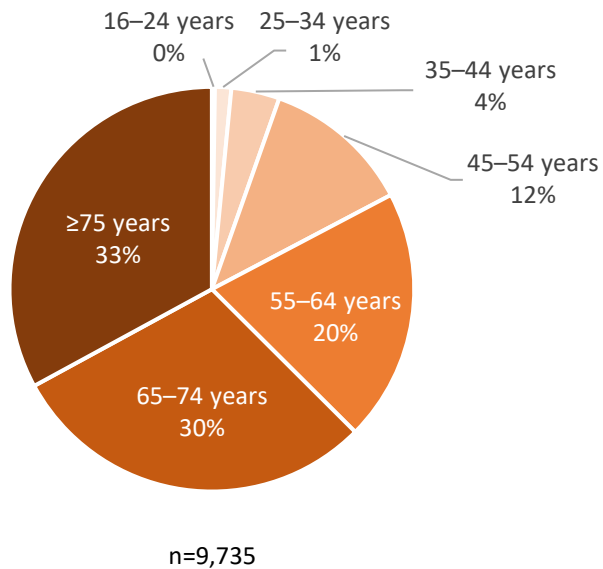
*Normalisation by age group and sex – i.e. 123 out of every 100,000 people within the female population aged ≥75 years will have PBC. Secondary care data are taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital. Copyright © 2023, NHS Digital. Re-used with the permission of NHS Digital. All rights reserved. The full HES disclaimer/digital licence is provided in [Appendix 2](#). PBC, primary biliary cirrhosis.



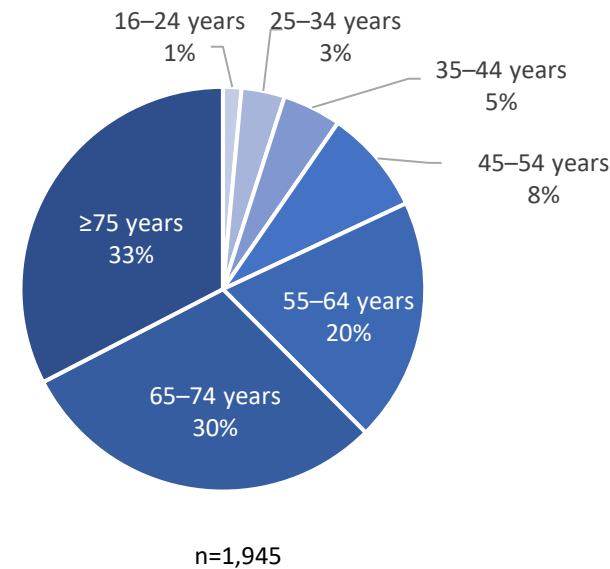
More females who have a diagnosis of PBC are admitted but the proportions for older males and females are identical

- About five times as many female patients as male patients were admitted with a diagnosis of PBC during the analysis period.
- The split between age ranges of admitted patients older than 55 years was identical for female and male patients.
- For patients younger than 55 years, female patients tended to be older than male patients.

Female patients admitted to hospital with a diagnosis of PBC split by age, 5-year total (2017/2018 to 2021/2022)



Male patients admitted to hospital with a diagnosis of PBC split by age, 5-year total (2017/2018 to 2021/2022)

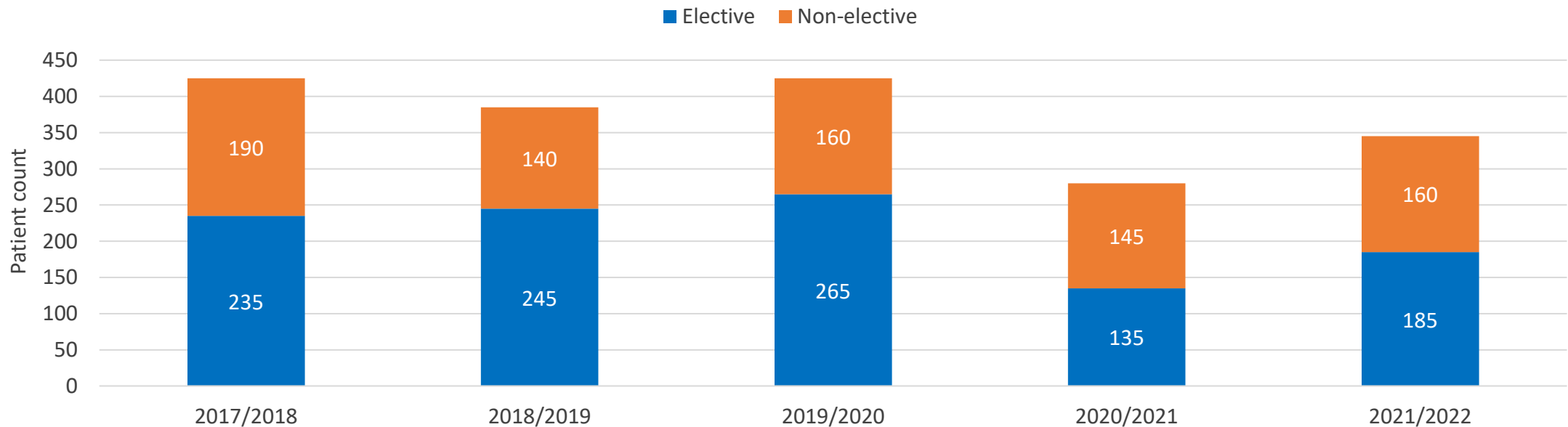




Admissions for patients with a primary diagnosis of PBC decreased overall between 2017/2018 and 2021/2022

- Between 2017/2018 and 2021/2022, elective and non-elective patient admissions in patients with a primary diagnosis of PBC decreased by 21% and 16%, respectively.
- A decrease in non-elective admissions was seen during 2018/2019.
- A pronounced decrease in elective admissions was seen during 2020–2021 at the peak of the COVID-19 pandemic; these began to recover in 2021/2022 but had not reached pre-pandemic levels.

Patients admitted to hospital with a diagnosis of PBC, 2017/2018 to 2021/2022

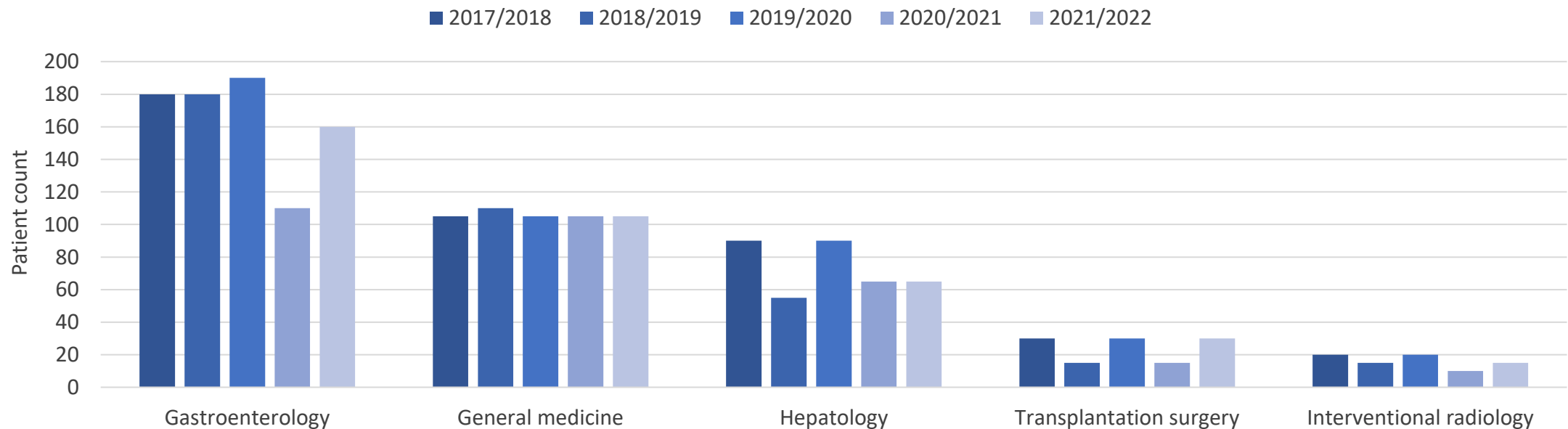




Patients admitted to hospital with a primary diagnosis of PBC are most commonly seen in gastroenterology

- Between 2017/2018 and 2021/2022, the number of patients in each speciality fluctuated.
- Numbers seen in hepatology and transplantation surgery decreased in 2018–2019.
- A pronounced decrease in patient numbers was seen during 2020–2021 at the peak of the COVID-19 pandemic and numbers have not yet fully recovered; the exception is general medicine, where numbers remained stable throughout the analysis period.

Patients admitted to hospital with a primary diagnosis of PBC by treatment speciality, 2017/2018 to 2021/2022





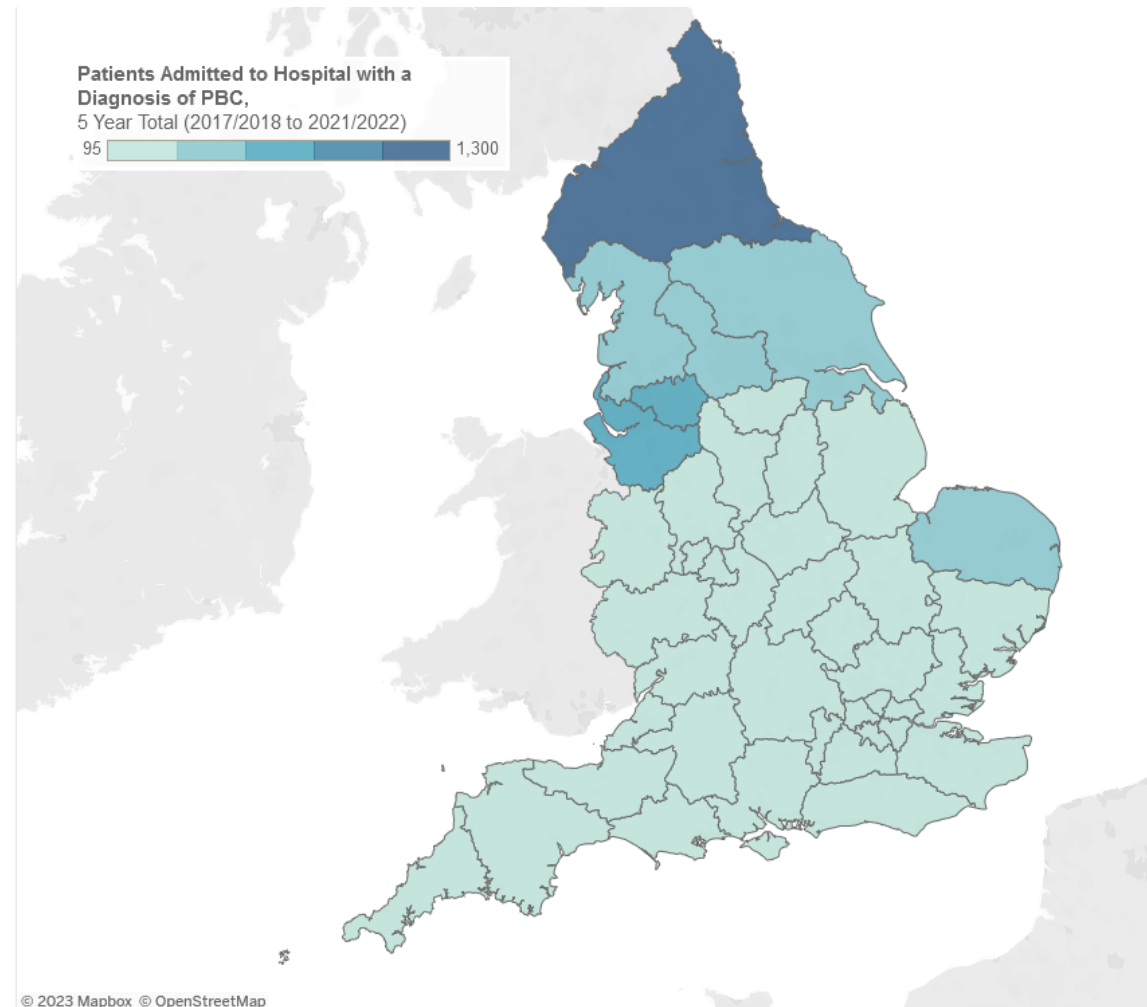
The number of patients admitted with a diagnosis of PBC varies by ICB

During 2017/2018 to 2021/2022, the highest number of patients admitted with a diagnosis of PBC was in:

- NHS North East and North Cumbria ICB (n=1,300)
- followed by:
- NHS Cheshire and Merseyside ICB (n=735)
 - NHS Greater Manchester ICB (n=580).

The lowest number of admissions (n=95) was in:

- NHS Dorset ICB.



[Click here to access interactive version of this map](#)



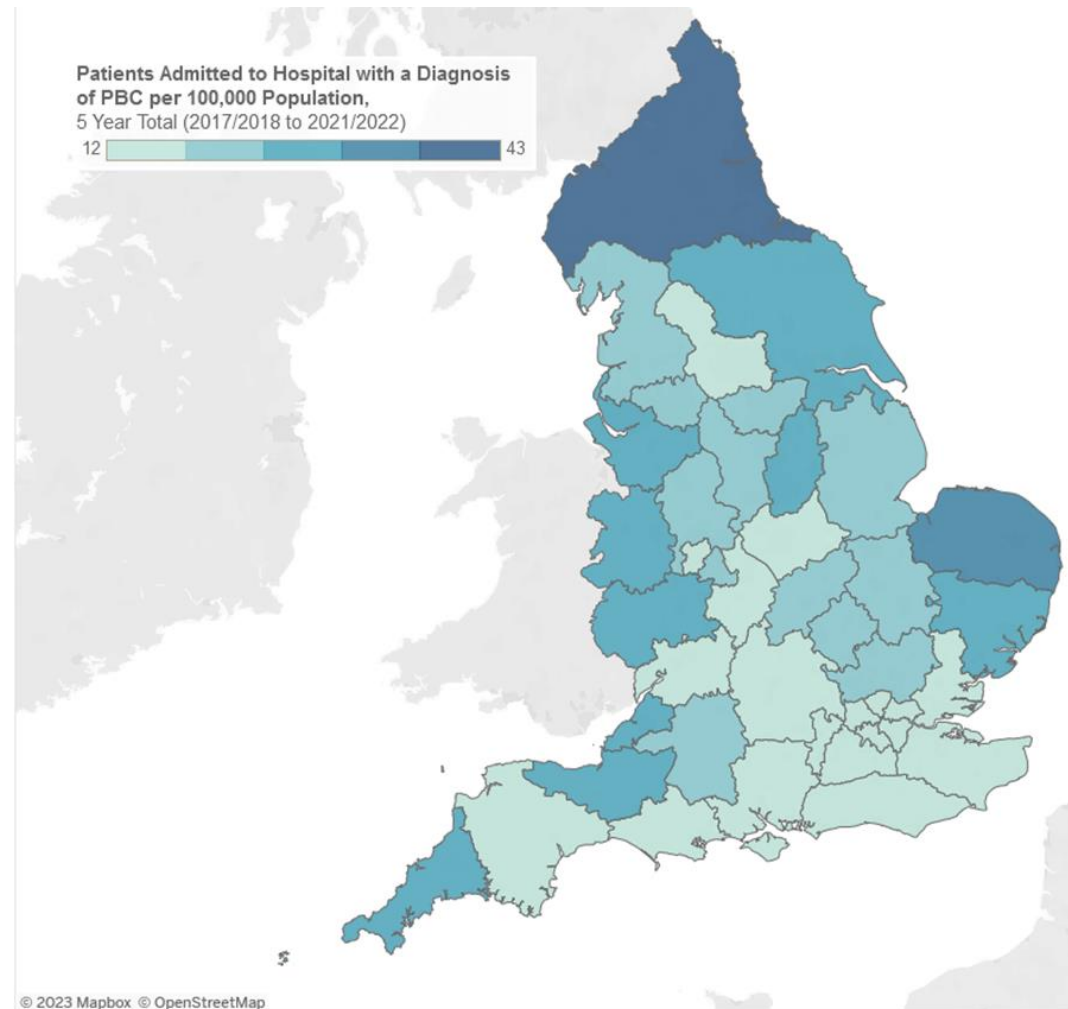
The number of patients admitted with a diagnosis of PBC per 100,000 population varies by ICB⁴

During 2017/2018 to 2021/2022, the highest number of patients admitted with a diagnosis of PBC per 100,000 population was in:

- NHS North East and North Cumbria ICB (n=43)
- followed by
- NHS Norfolk and Waveney ICB has the second highest number of admissions (n=36).

The lowest number of admissions (n=12) was in:

- NHS Dorset ICB
- NHS North Central London ICB
- NHS North East London ICB
- NHS South West London ICB.



[Click here to access interactive version of this map](#)



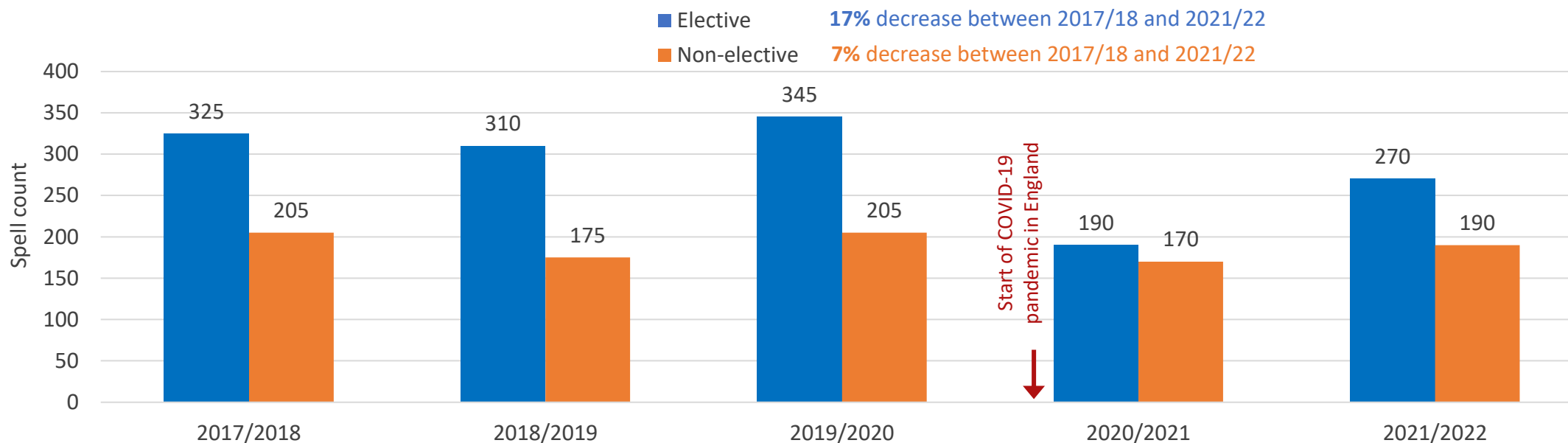
Spells/episodes



Inpatient spells with a primary diagnosis of PBC decreased between 2017/2018 and 2021/2022

- Decreases of 17% in elective and 7% in non-elective hospital inpatient spells with a primary diagnosis of PBC were seen between 2017/18 and 2021/22.
- A marked decrease in elective hospital inpatient spells for PBC was observed shortly after the COVID-19 pandemic began during 2020–21; these have increased but not yet returned to pre-pandemic levels.
- Non-elective hospital inpatient spells did not show a similar decrease during the pandemic.

Hospital inpatient spells with a primary diagnosis of PBC, 2017/2018 to 2021/2022

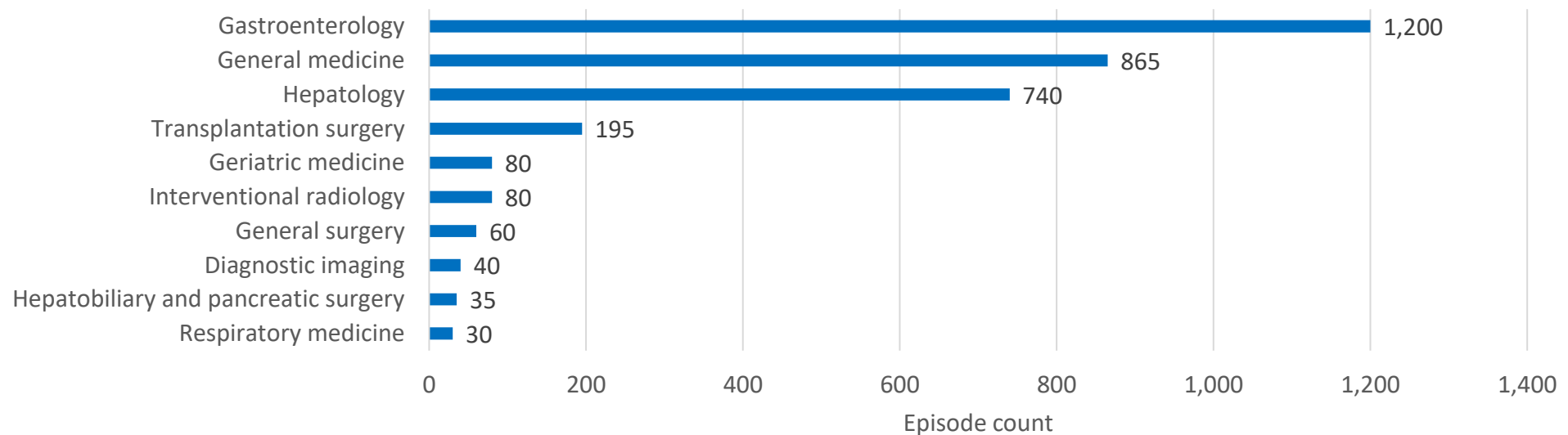




Most inpatient episodes with a primary diagnosis of PBC are seen by gastroenterology

- Most patients admitted with a primary diagnosis of PBC are seen by gastroenterology, followed by:
 - general medicine
 - hepatology.

Hospital inpatient episodes with a primary diagnosis of PBC by treatment specialty, 2017/2018 to 2021/2022

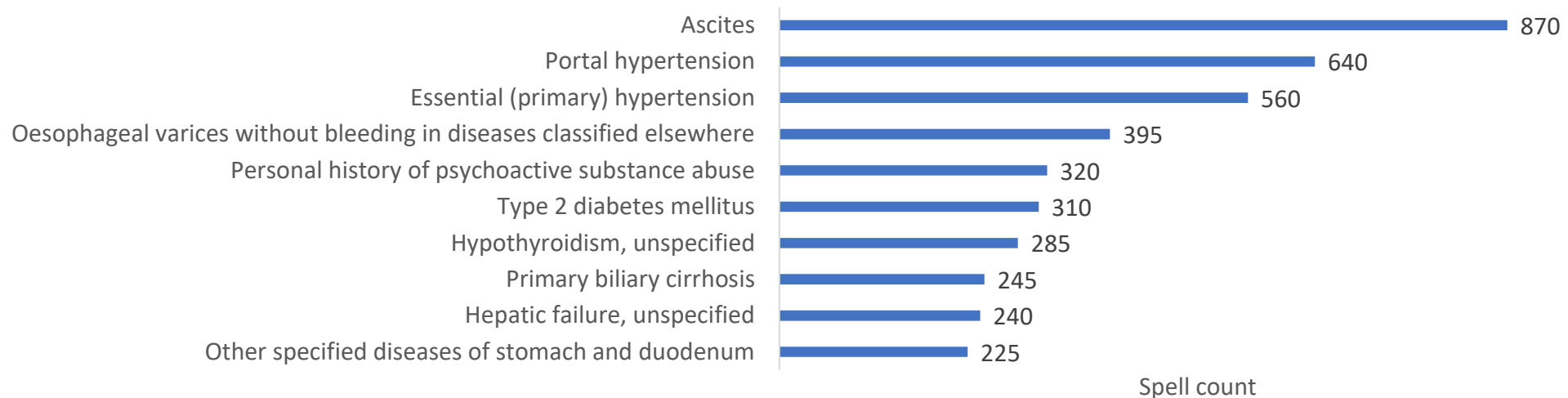




Ascites are the most common secondary diagnosis for patients with a primary diagnosis of PBC

- Ascites are the most common secondary diagnosis in patients with a primary diagnosis of PBC, followed by:
 - portal hypertension
 - essential (primary) hypertension.

Hospital Inpatient Spells with a Primary Diagnosis of PBC split by Secondary Diagnosis, 5 Year Total (2017/2018 to 2021/2022)

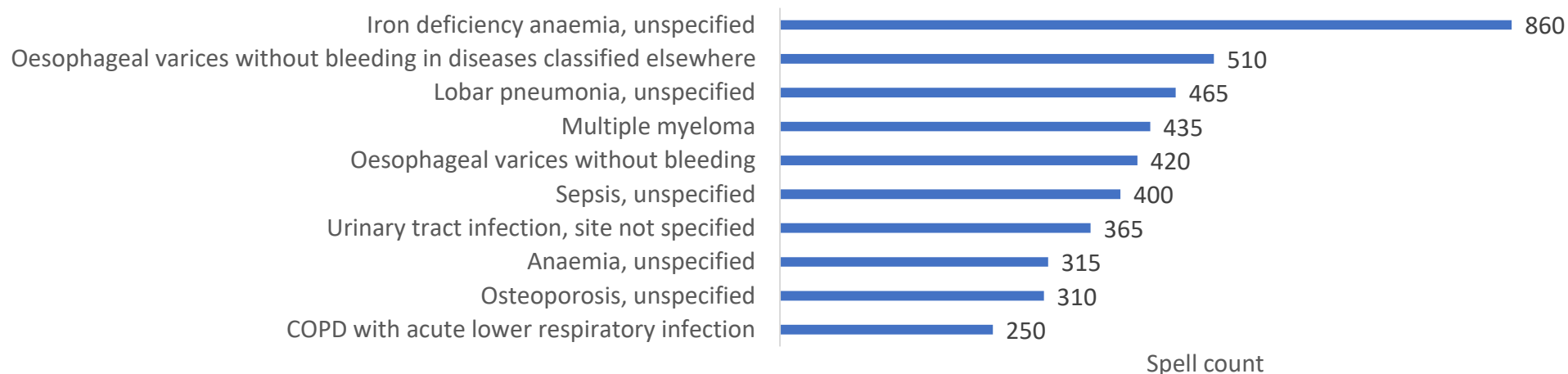




Iron deficiency anaemia is the most common primary diagnosis on admission for patients with a secondary diagnosis of PBC

- Iron deficiency anaemia is the most common primary diagnosis on admission for patients with a secondary diagnosis of PBC, followed by:
 - oesophageal varices without bleeding
 - lobar pneumonia
 - multiple myeloma.

Hospital inpatient spells with a secondary diagnosis of PBC split by primary diagnosis on admission, 5 Year Total (2017/2018 to 2021/2022)

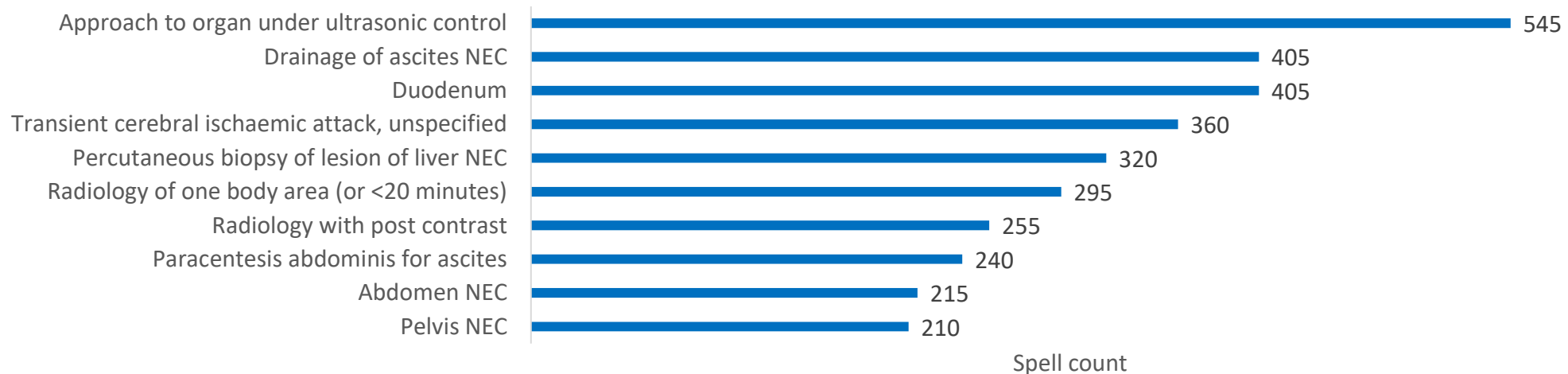




Approach to organ under ultrasonic control is the most common inpatient procedure in patients with a primary diagnosis of PBC

- Approach to organ under ultrasonic control is the most common inpatient procedure in patients with a primary diagnosis of PBC, followed by:
 - drainage of ascites
 - duodenum.

Hospital inpatient spells with a primary diagnosis of PBC by procedure, 5-year total (2017/2018 to 2021/2022)

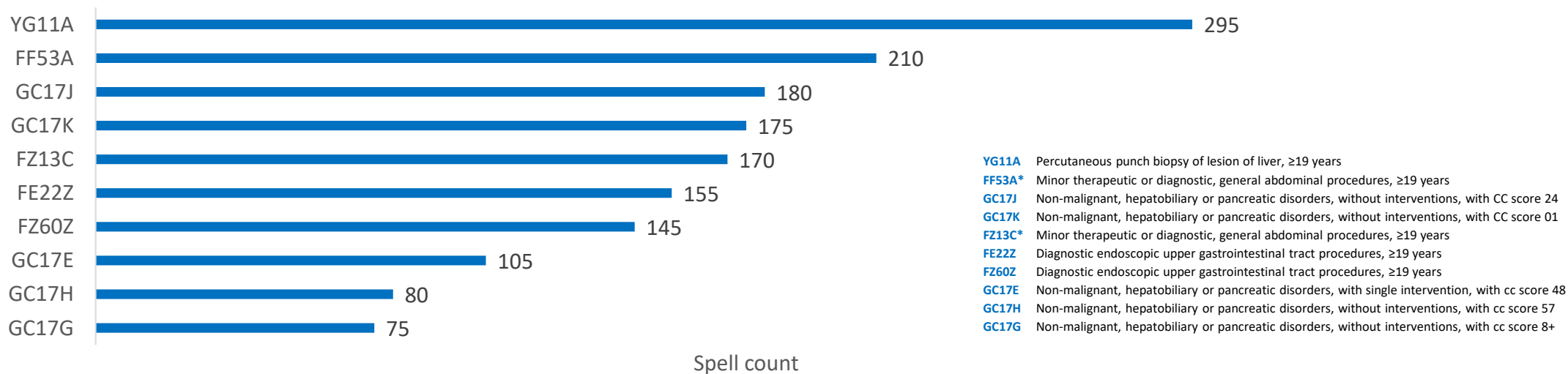




Percutaneous punch biopsy of liver lesion is the most common HRG code in patients with a primary diagnosis of PBC

- Percutaneous punch biopsy of liver lesion is the most common HRG code in patients with a primary diagnosis of PBC, followed by:
 - minor therapeutic or diagnostic, general abdominal procedures, ≥19 years
 - non-malignant, hepatobiliary or pancreatic disorders, without interventions, with CC score 24
 - non-malignant, hepatobiliary or pancreatic disorders, without interventions, with CC score 01.

Hospital inpatient spells with a primary diagnosis of PBC split by HRG code, 5-year total (2017/2018 to 2021/2022)



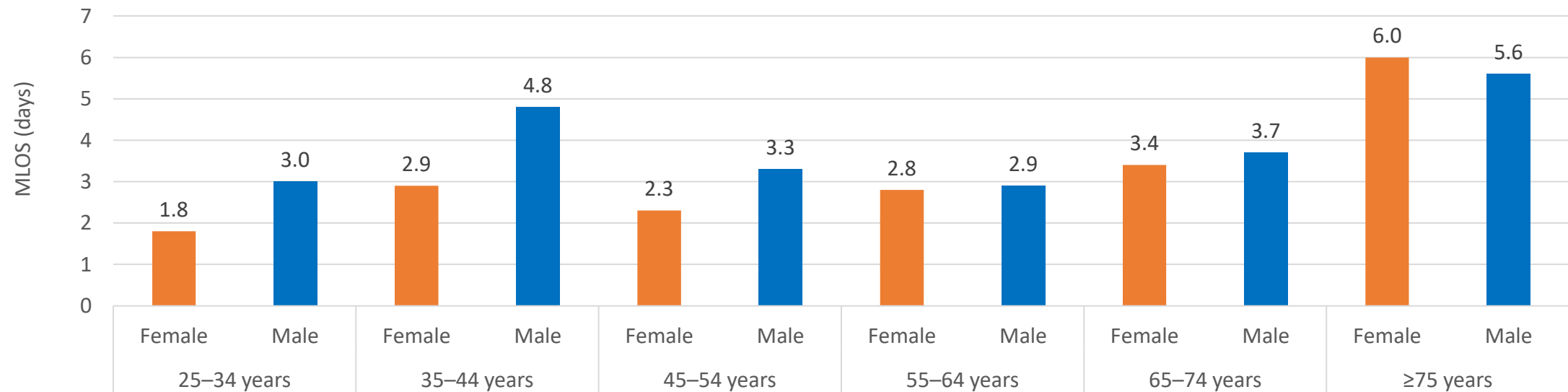
*FF53A and FZ13C have the same description because the coding changed in 2018/2019.



MLOS for inpatient spells fluctuates with age but is typically higher for men who have a diagnosis of PBC than women

- MLOS for hospital inpatient spells fluctuates across the age ranges:
 - It is typically longer for men than women, particularly in patients aged 35–44 years
 - but longer for women than men in patients aged ≥ 75 years.

MLOS of hospital inpatient spells with a diagnosis of PBC by age and sex, 5-year total (2017/2018 to 2021/2022)



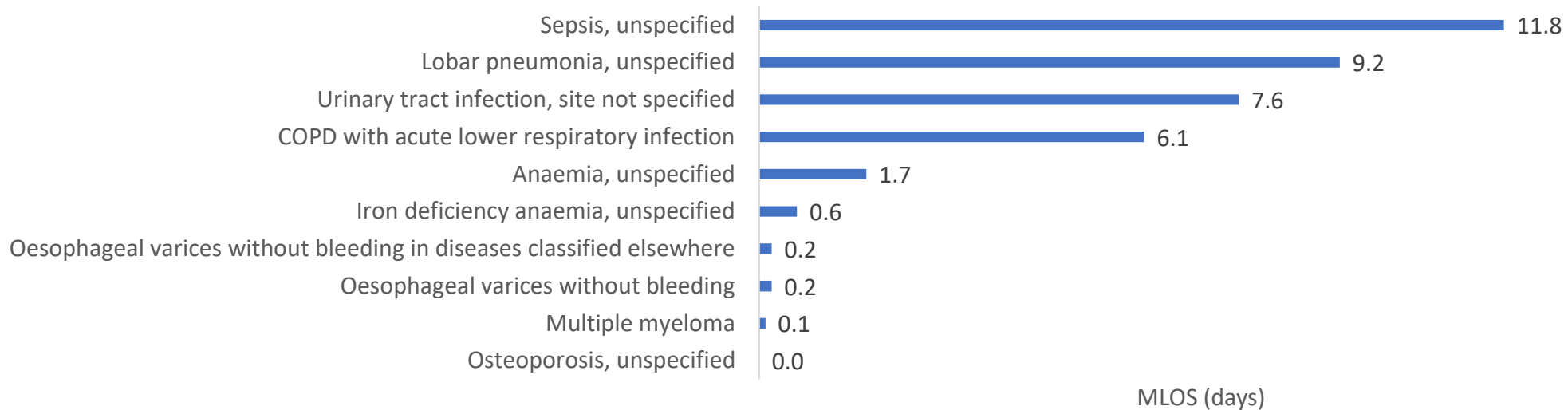


MLOS for hospital inpatient spells with a secondary diagnosis of PBC on admission by primary diagnosis is longest for sepsis

MLOS for hospital inpatient spells with a primary diagnosis of PBC by secondary diagnosis is longest for sepsis, followed by:

- lobar pneumonia
- urinary tract infection.

MLOS of hospital inpatient spells with a secondary diagnosis of PBC by primary diagnosis on admission, 5-year total (2017/2018 to 2021/2022)



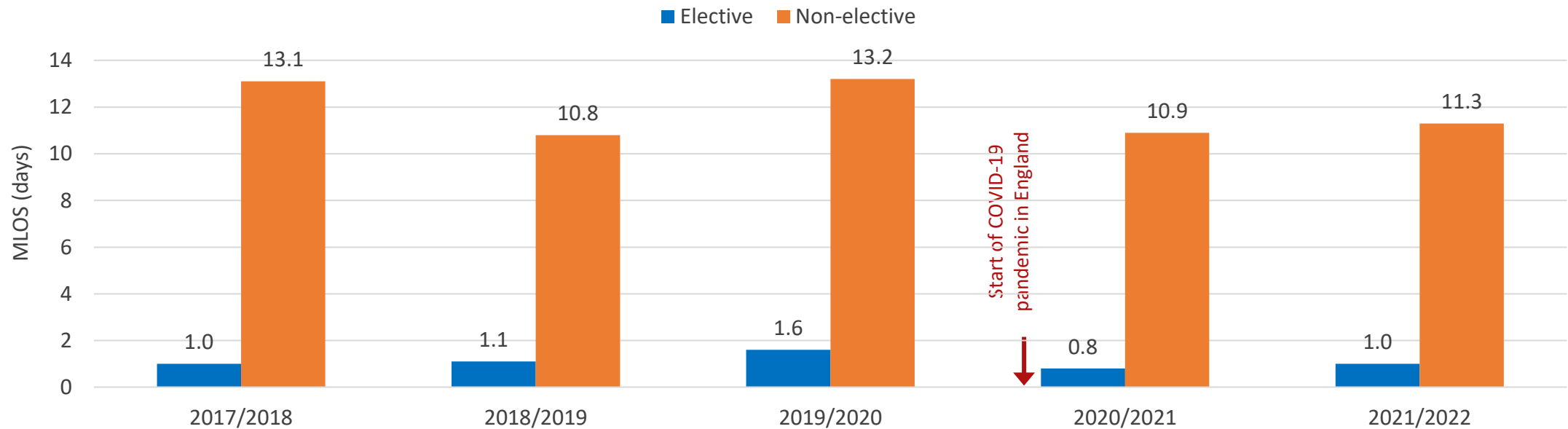
Source data in appendix



MLOS is shorter for elective than non-elective inpatient spells with a primary diagnosis of PBC

- MLOS for elective hospital inpatient spells was relatively stable during the analysis period (between 0.8 and 1.0 days).
- MLOS for non-elective hospital inpatient spells fluctuated throughout the analysis period (between 10.9 and 13.2 days).

MLOS of hospital inpatient spells with a primary diagnosis of PBC, 2017/2018 to 2021/2022





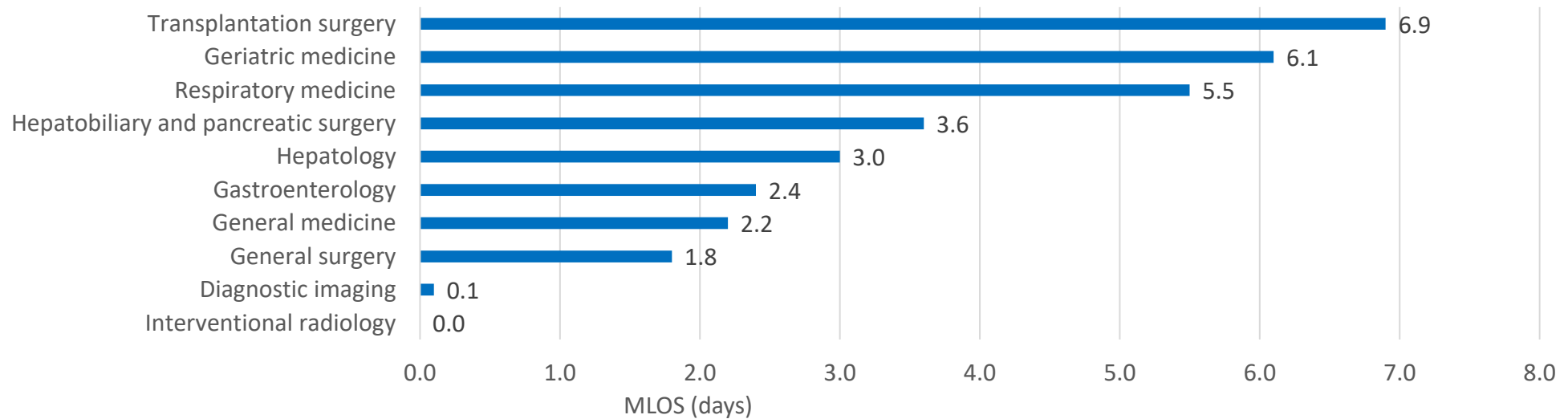
MLOE for patients with a primary diagnosis of PBC is longest for transplantation surgery

MLOE for inpatient episodes with a primary diagnosis of PBC is longest for transplantation surgery, followed by:

- geriatric medicine
- respiratory medicine.

MLOE describes the mean length of an episode within an overall spell.

MLOE for inpatient episodes with a primary diagnosis of PBC by treatment specialty, 2017/2018 to 2021/2022



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MLOE, mean length of episode; PBC, primary biliary cirrhosis.

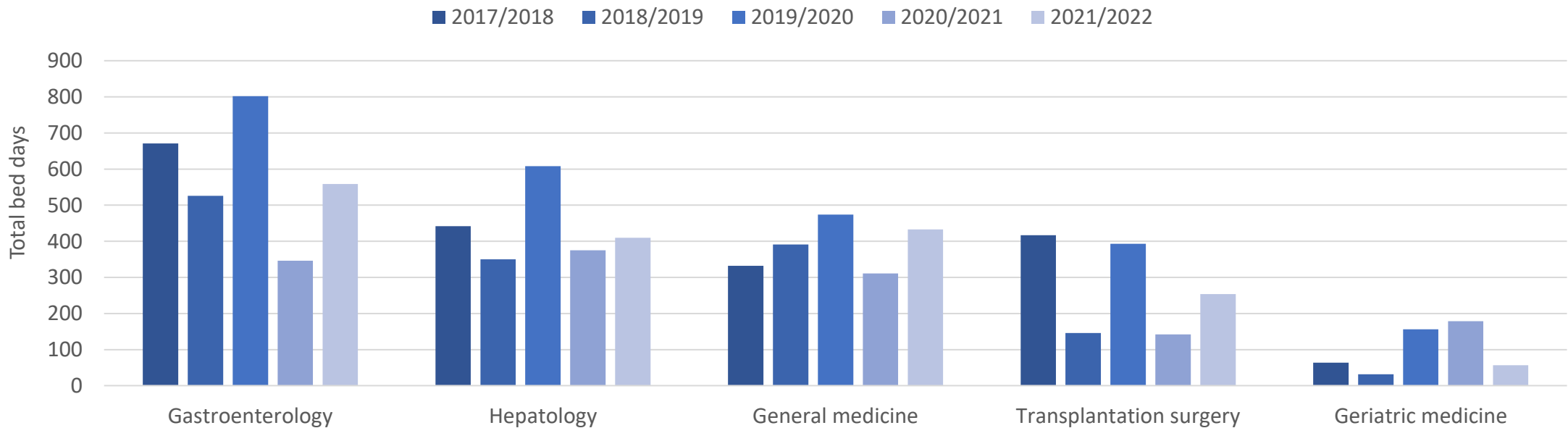


Bed days

Bed days for inpatient episodes with a primary diagnosis of PBC are highest for gastroenterology

- Bed days for inpatient episodes with a primary diagnosis of PBC are highest for gastroenterology, followed by hepatology, general medicine and transplantation surgery.
- Bed days decreased during 2020–2021 at the peak of the COVID-19 pandemic for these four specialties and have since increased but not returned to pre-pandemic levels.
- Bed days increased during the pandemic for geriatric medicine but decreased again in 2021/2022.

Total bed days in hospital inpatient episodes with a primary diagnosis of PBC by treatment specialty, 2017/2018 to 2021/2022



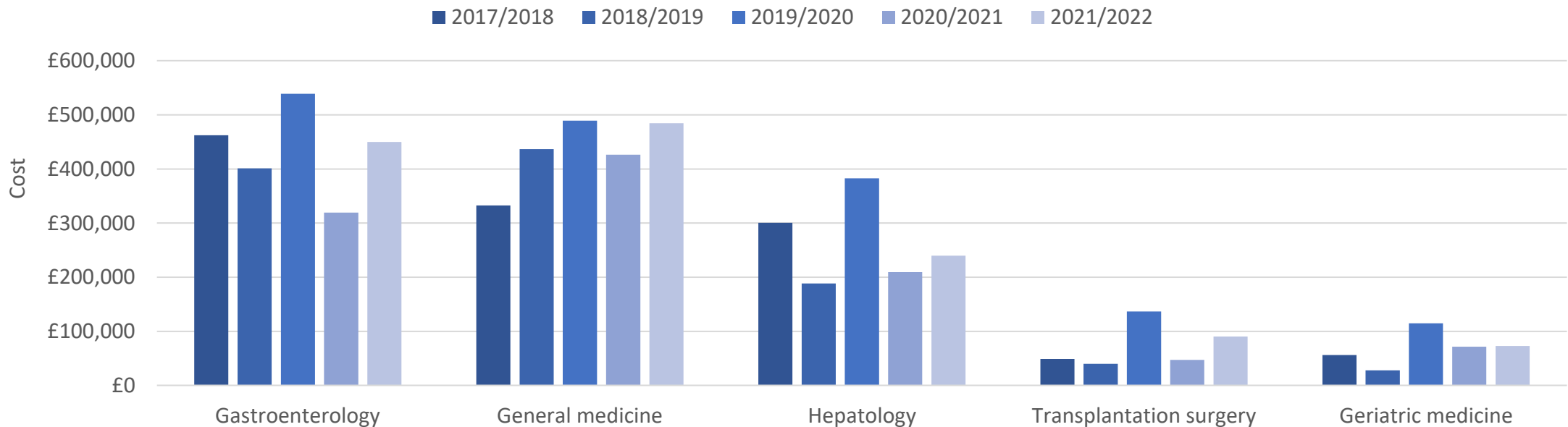
Inpatient data



Cost of hospital inpatient spells with a primary diagnosis of PBC is highest for gastroenterology and general medicine*

- Cost of hospital inpatient spells with a primary diagnosis of PBC is highest for gastroenterology, general medicine and hepatology.*
- Costs fluctuated across the analysis period but decreased for all specialties during 2020/2021 during the peak of the COVID-19 pandemic and have not yet returned to pre-pandemic levels.

Cost of hospital inpatient spells with a primary diagnosis of PBC by treatment specialty, 2017/2018 to 2021/2022



*Other specialties in the spell might be driving costs, and some patients may be counted twice if they are seen by more than one specialty within a spell. Secondary care data are taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital. Copyright © 2023, NHS Digital. Re-used with the permission of NHS Digital. All rights reserved. The full HES disclaimer/digital licence is provided in [Appendix 2](#). PBC, primary biliary cirrhosis.

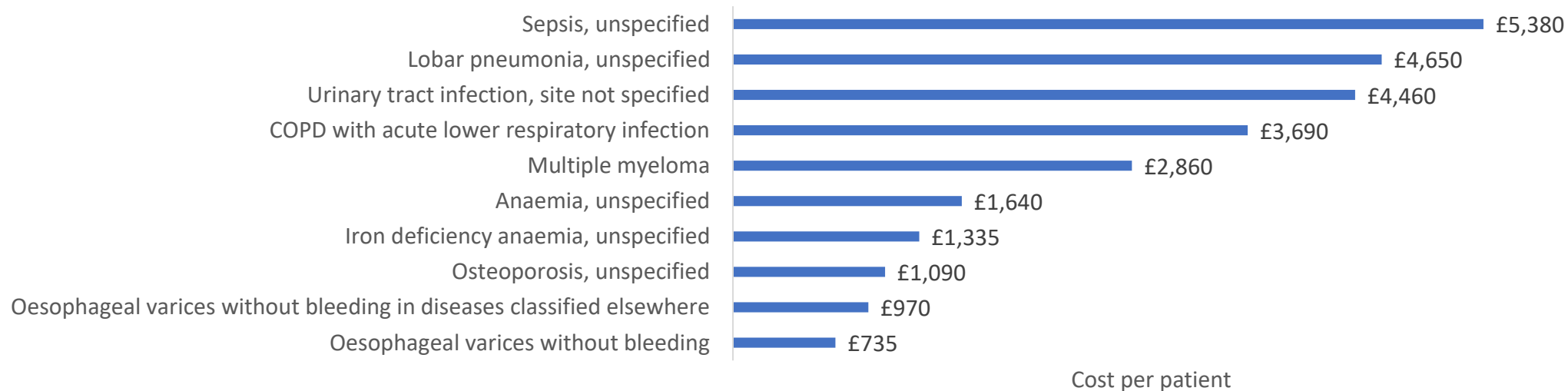


Sepsis is the most costly primary diagnosis per patient for patients admitted with a secondary diagnosis of PBC

Sepsis is the most costly primary diagnosis per patient on admission for patients with a secondary diagnosis of PBC, followed by:

- lobar pneumonia
- urinary tract infection.

Cost per patient for hospital inpatient spells with a secondary diagnosis of PBC split by primary diagnosis on admission, 5-year total (2017/2018 to 2021/2022)



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COPD, chronic obstructive pulmonary disease; PBC, primary biliary cirrhosis.

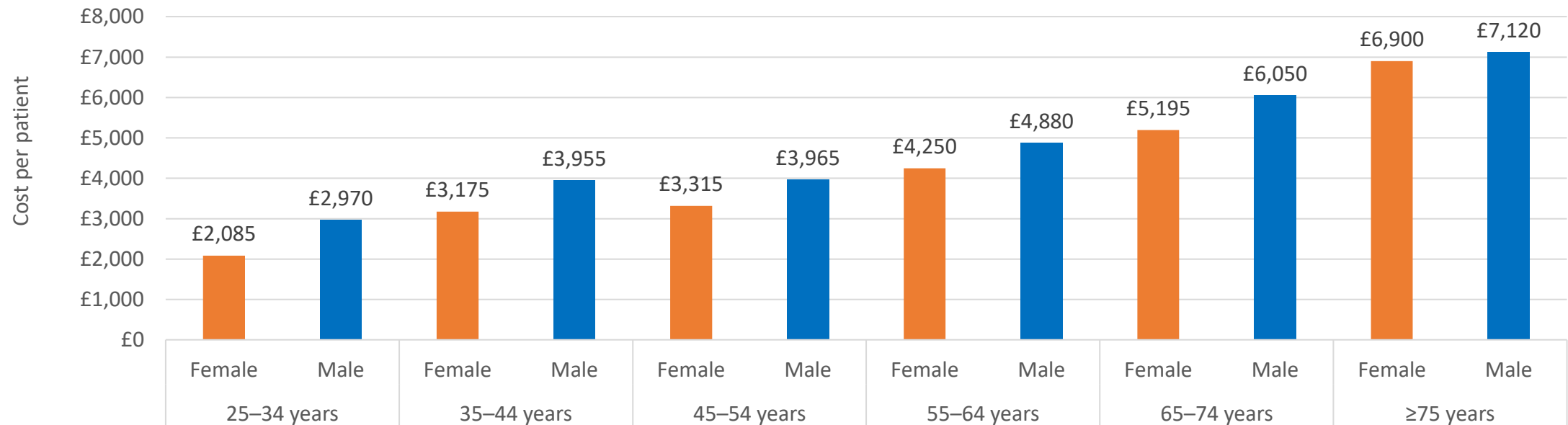
Source data
in appendix



Per-patient costs of inpatient spells in patients with a diagnosis of PBC are higher for men than women

- Per-patient costs of inpatient spells in patients with a diagnosis of PBC:
 - are slightly higher for men than women in all age groups
 - broadly increase with increasing age.

Cost per patient of hospital inpatient spells with a diagnosis of PBC by age and sex, 5-year total (2017/2018 to 2021/2022)



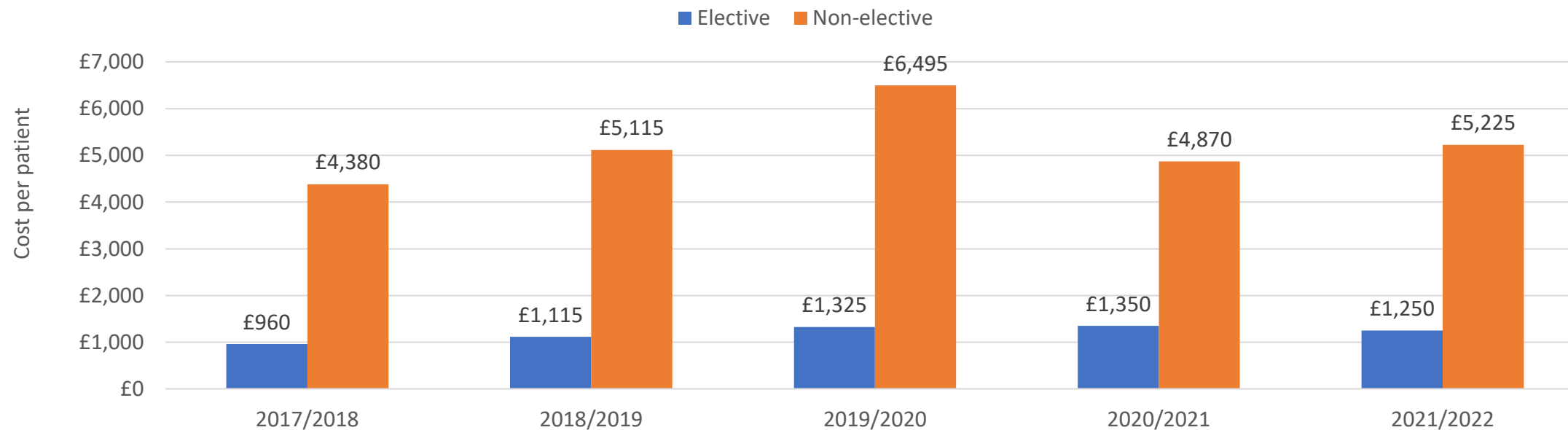
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Per-patient costs are lower for elective inpatient spells with a primary diagnosis of PBC than for non-elective inpatient spells

- Per-patient costs for non-elective spells increased over the analysis period overall.
- A decrease in per-patient costs for non-elective spells was observed in 2020–2021 during the pandemic; costs did not return to pre-pandemic levels in 2021/2022.
- Costs for elective spells fluctuated but remained broadly the same during the analysis period.

Cost per patient of hospital inpatient spells with a diagnosis of PBC, 2017/2018 to 2021/2022





Outpatient data





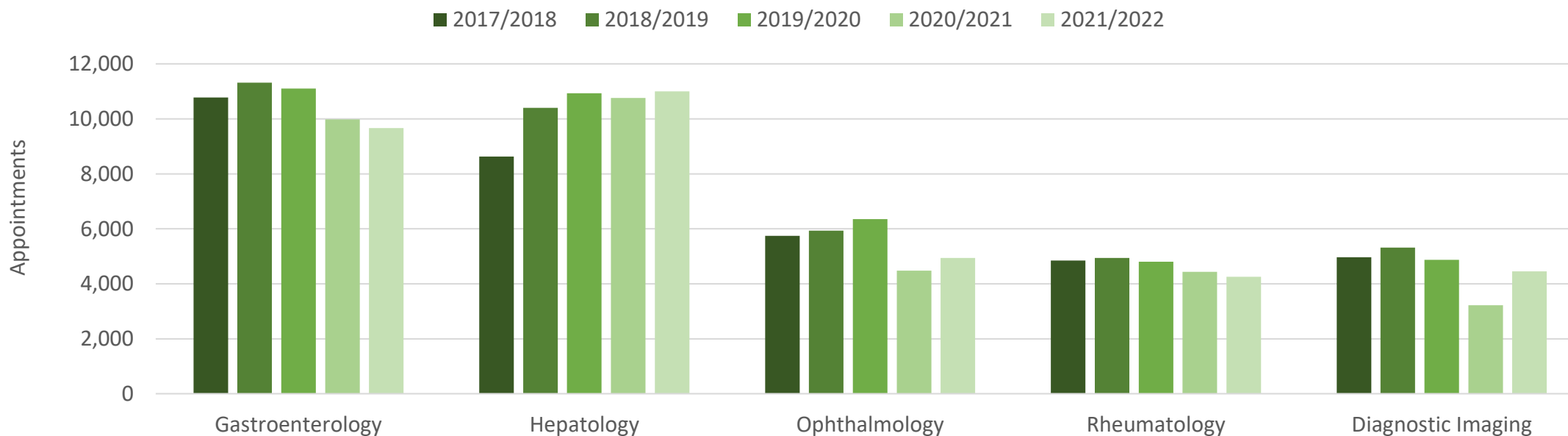
Treatment specialties

Patients who have a diagnosis of PBC are most often seen as outpatients by gastroenterology and hepatology

The top 5 specialties in terms of outpatient appointments attended by patients diagnosed with PBC were gastroenterology, hepatology, ophthalmology, rheumatology and diagnostic imaging.

- The number of appointments fluctuated over the analysis period for all top 5 specialties but was most consistent for rheumatology.
- The number of appointments decreased in 2020–2021 during the COVID-19 pandemic for all five specialties and had not recovered during 2021–2022 for gastroenterology or rheumatology.

Outpatient appointments for patients diagnosed with PBC by treatment specialty, 2017/2018 to 2021/2022



Outpatient data

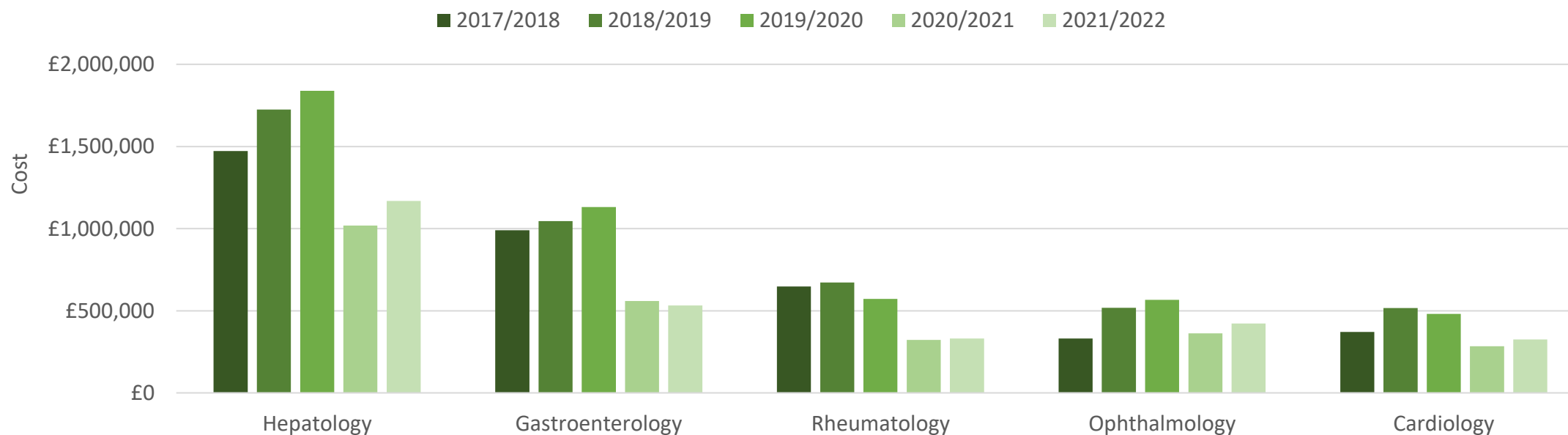


Cost

Cost of outpatient appointments for patients diagnosed with PBC are highest for hepatology and gastroenterology

- The top 5 specialties in terms of cost of outpatient appointments attended by patients diagnosed with PBC were hepatology, gastroenterology, rheumatology, ophthalmology and cardiology.
- Costs decreased for all specialties in 2020–2021 during the COVID-19 pandemic; costs for none of these specialties have recovered to pre-pandemic levels.

Cost of outpatient appointments for patients diagnosed with PBC by treatment specialty, 2017/2018 to 2021/2022

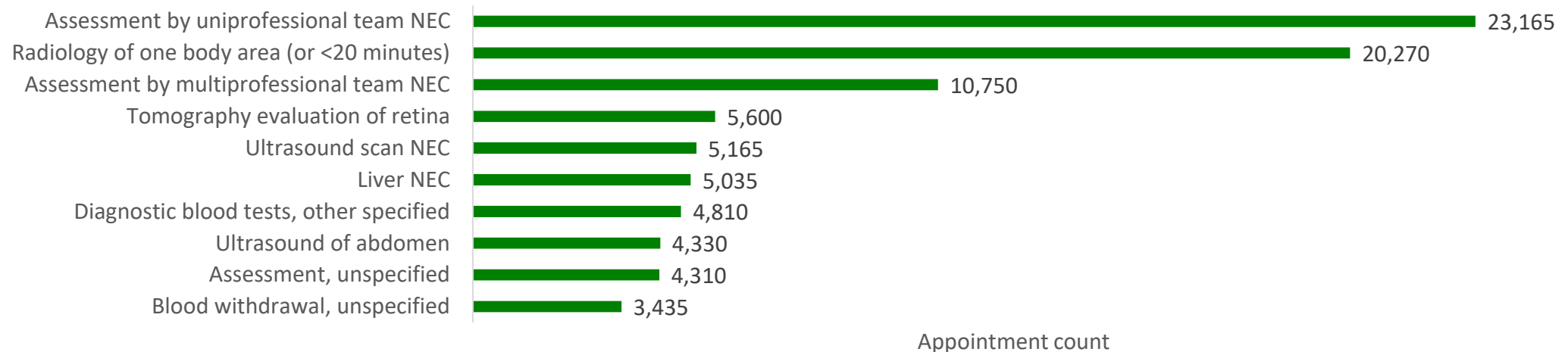




Assessment by a uniprofessional team is the most common outpatient procedure for patients with a diagnosis of PBC

- Assessment by a uniprofessional team is the most common procedure within outpatient appointments for patients with a diagnosis of PBC, followed by:
 - radiology of one body area (or <20 minutes)
 - assessment by a multiprofessional team.

Outpatient appointments for patients diagnosed with PBC split by procedure, 5-year total (2017/2018 to 2021/2022)

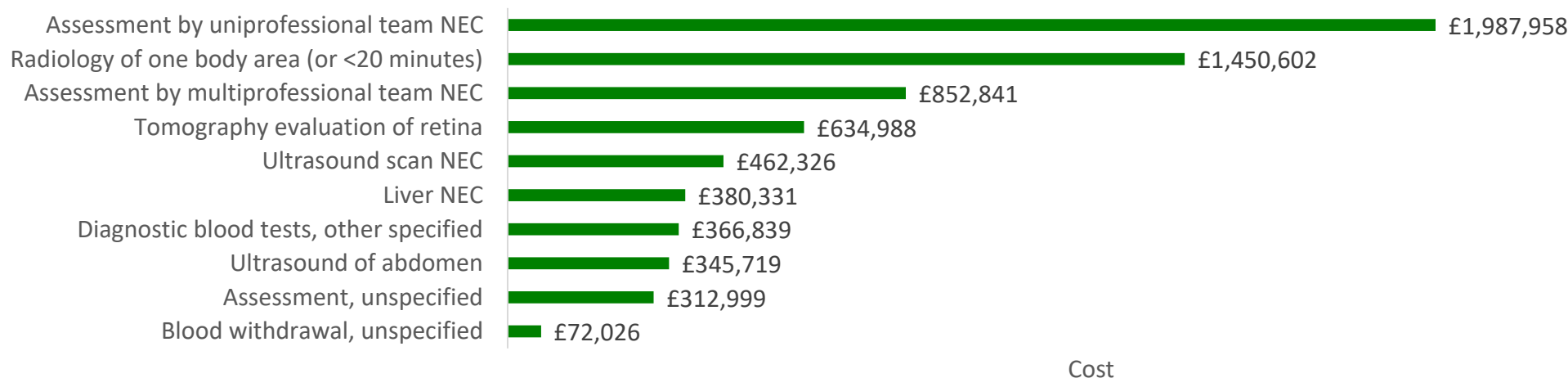




Assessment by a uniprofessional team is the most costly outpatient procedure for patients with a diagnosis of PBC*

- Assessment by a uniprofessional team is the most costly outpatient procedure for patients with a diagnosis of PBC,* followed by:
 - radiology of one body area (or <20 minutes)
 - assessment by a multiprofessional team.

Total cost of outpatient appointments for patients diagnosed with PBC split by operation, 5-year total (2017/2018 to 2021/2022)



*Other procedures within the appointment may drive overall costs.

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Case study

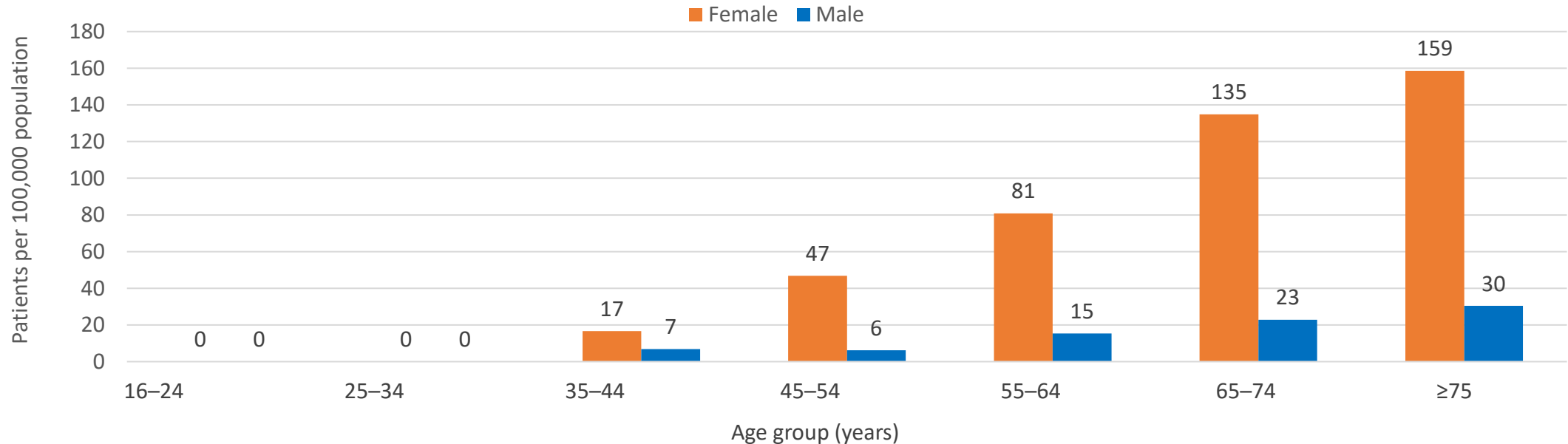




NHS Cheshire and Merseyside ICB

- In line with the [national analysis](#), admissions with a diagnosis of PBC increase with increasing age and are higher in women than men.
- In NHS Cheshire and Merseyside ICB, no patients aged 16–24 years or 25–34 years were admitted with a diagnosis of PBC.

Patients admitted to hospital with a diagnosis of PBC by age and sex – normalised per 100,000 population,⁴
5-year total (2017/2018 to 2021/2022), Cheshire and Merseyside ICB

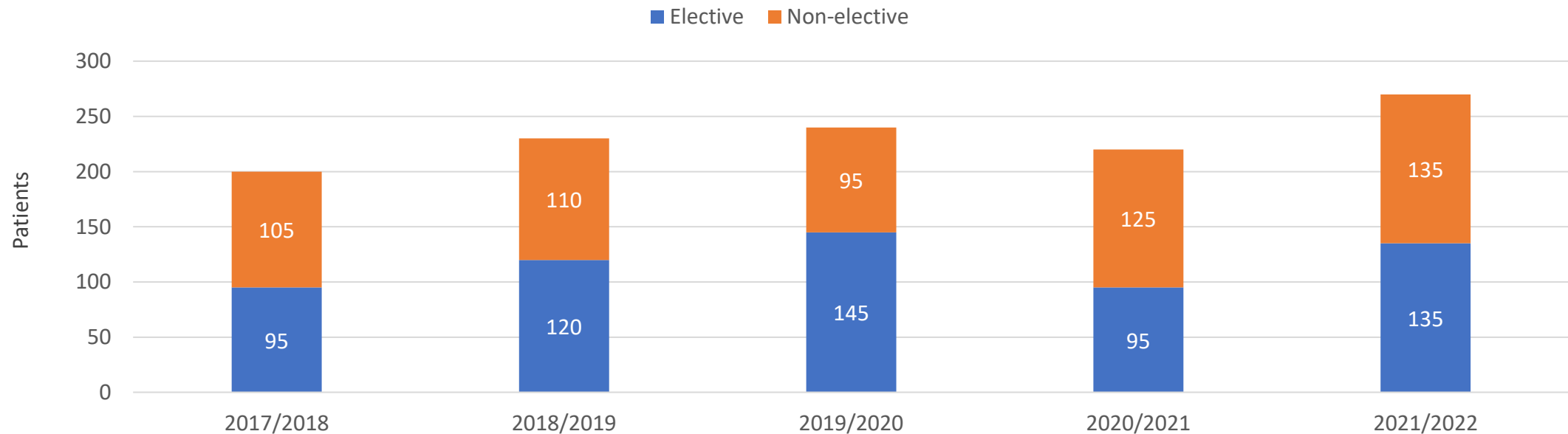




NHS Cheshire and Merseyside ICB

- In contrast with the [national analysis](#), the number of patients admitted with a diagnosis of PBC increased overall during the analysis period
- Although numbers of patients admitted electively decreased during the COVID-19 pandemic, the number of patients admitted non-electively increased, which could suggest that patients who did not attend electively subsequently required non-elective admissions.
- Elective admissions have almost returned to pre-pandemic levels, while non-elective admissions remain higher than pre-pandemic.

Patients admitted to hospital with a diagnosis of PBC, Cheshire and Merseyside ICB, 2017/2018 to 2021/2022

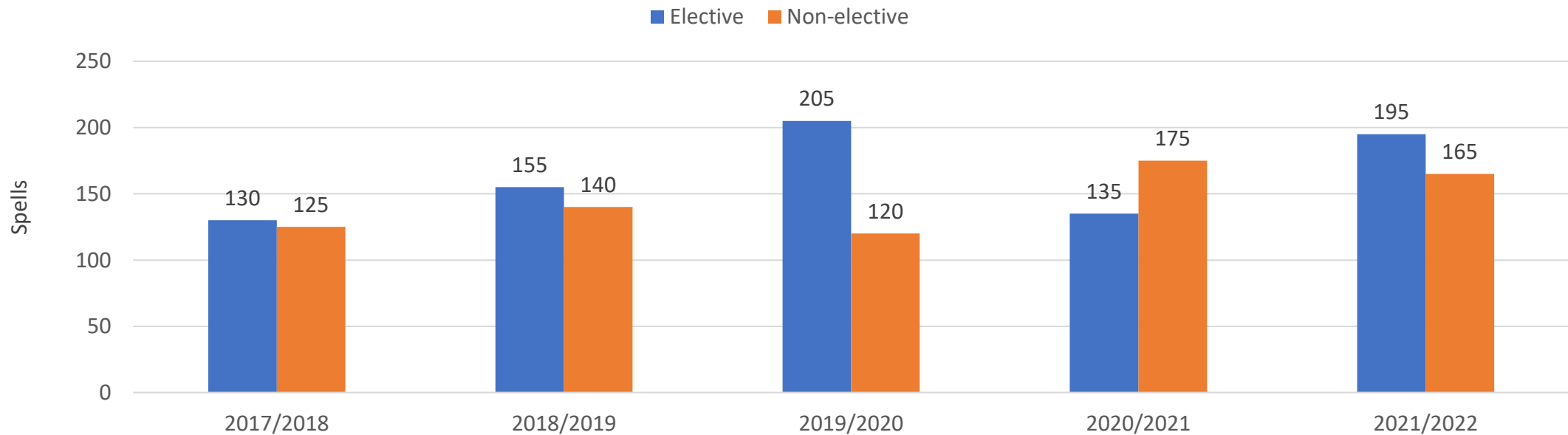




NHS Cheshire and Merseyside ICB

- In contrast with the [national analysis](#), inpatient spells with a diagnosis of PBC increased during the analysis period.
- Also in contrast with the [national analysis](#), although elective spells decreased during the COVID-19 pandemic, non-elective spells increased, which could suggest that patients who did not attend electively subsequently required non-elective admissions.
- Elective spells have almost returned to pre-pandemic levels, while non-elective admissions remain higher than pre-pandemic.

Hospital inpatient spells with a diagnosis of PBC, 2017/2018 to 2021/2022, Cheshire and Merseyside ICB

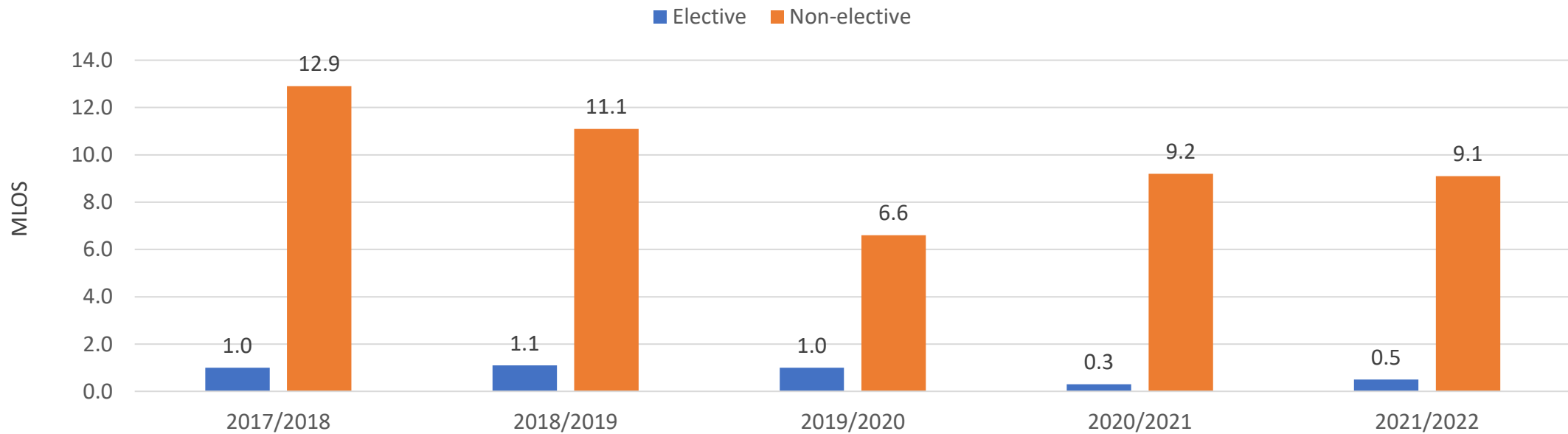




NHS Cheshire and Merseyside ICB

- A pronounced decrease in MLOS for non-elective inpatient spells was seen during the analysis period, while MLOS for elective spells decreased but to a lesser extent.
- MLOS for elective spells was lowest during 2020/2021 at the peak of the COVID-19 pandemic, while MLOS for non-elective spells increased during 2020/2021 compared with the previous year; this increase persisted in 2021/2022.

MLOS of hospital inpatient spells with a diagnosis of PBC, 2017/2018 to 2021/2022, Cheshire and Merseyside ICB





Prescribing data

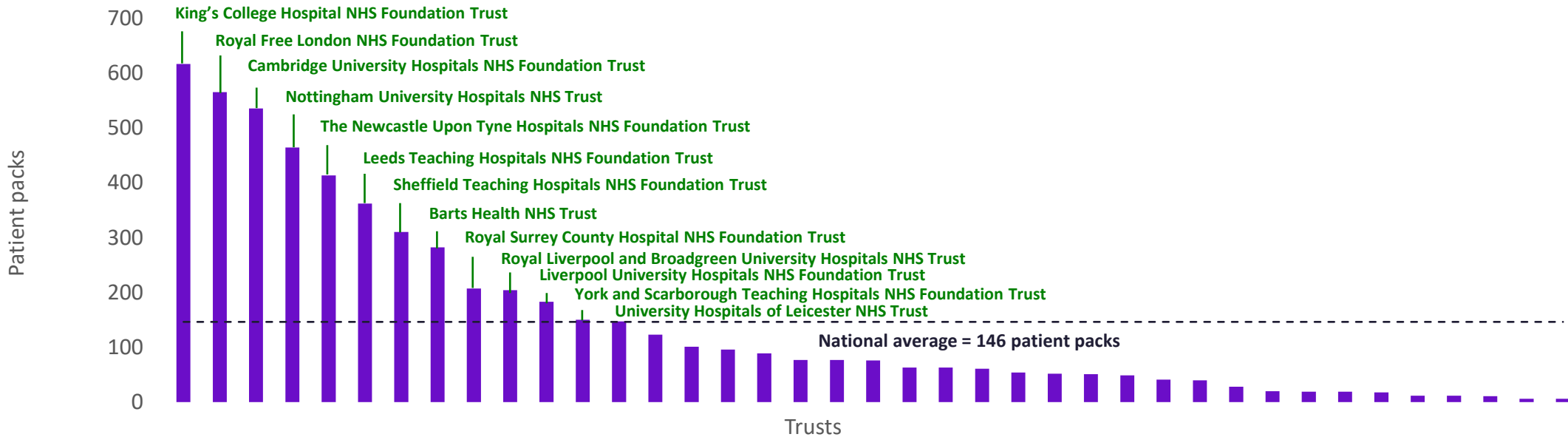




The national average of patient packs of OCA prescribed in 2021/22 by trust was 146

- 13 trusts prescribed above the national average.
- 26 prescribed below the national average.
- The remaining trusts did not prescribe any OCA during the analysis period.

Prescribing of OCA in secondary care medicines data by trust, 2021/2022



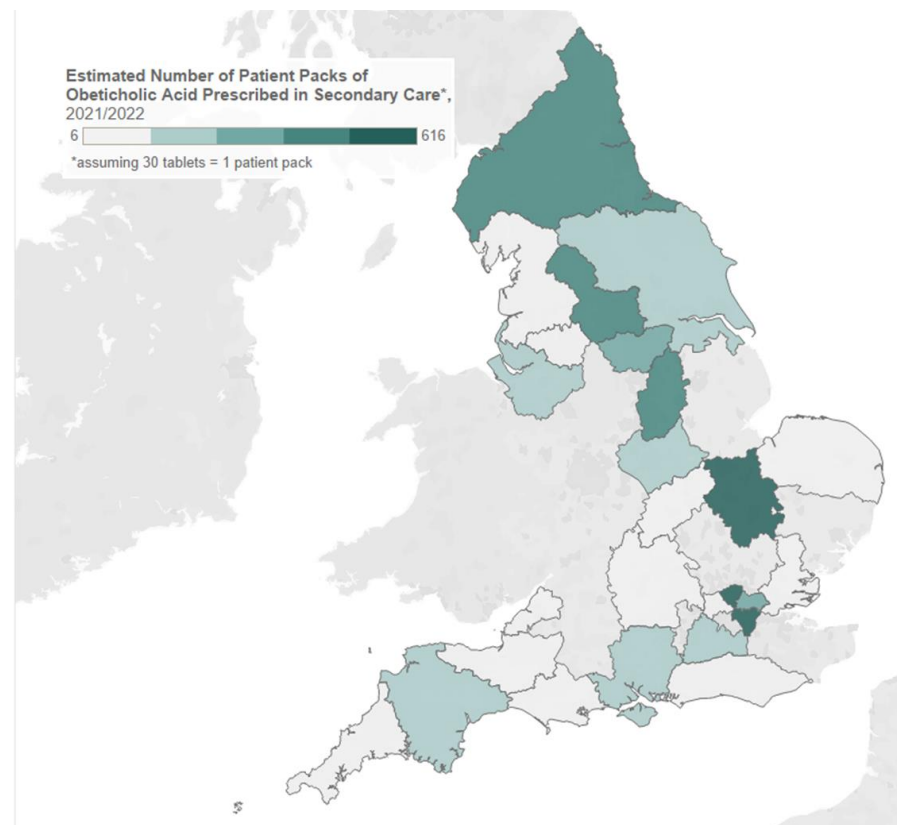
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OCA, obeticholic acid; PBC, primary biliary cirrhosis.



The national average of patient packs of OCA prescribed in secondary care by ICB in 2021/22 was 206

10 ICBs prescribed above the national average.

- NHS South East London ICB (n=616 patient packs)
- NHS North Central London ICB (n=565)
- NHS Cambridgeshire and Peterborough ICB (n=535)
- NHS North East and North Cumbria ICB (n=474)
- NHS Nottingham and Nottinghamshire ICB (n=464)
- NHS West Yorkshire ICB (n=425)
- NHS South Yorkshire ICB (n=310)
- NHS North East London ICB (n=282)
- NHS Humber and North Yorkshire ICB (n=227)
- NHS Surrey Heartlands ICB (n=207)



16 ICBs did not prescribe any OCA:

- NHS Bath and North East Somerset, Swindon and Wiltshire ICB
- NHS Bedfordshire, Luton and Milton Keynes ICB
- NHS Birmingham and Solihull ICB
- NHS Black Country ICB
- NHS Coventry and Warwickshire ICB
- NHS Derby and Derbyshire ICB
- NHS Frimley ICB
- NHS Gloucestershire ICB
- NHS Herefordshire and Worcestershire ICB
- NHS Hertfordshire and West Essex ICB
- NHS Kent and Medway ICB
- NHS Lincolnshire ICB
- NHS Shropshire, Telford and Wrekin ICB
- NHS South West London ICB
- NHS Staffordshire and Stoke-on-Trent ICB
- NHS Suffolk and North East Essex ICB.

[Click here to access interactive version of this map](#)



Appendices





Appendix 1: References

1. NHS Digital. *Hospital Episode Statistics*. Secondary care data are taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital. Copyright © 2023, NHS Digital. Re-used with the permission of NHS Digital. All rights reserved.
2. NHS Digital. *Hospital Episode Statistics (HES): about the HES database*. Available at: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics> (accessed 9 May 2023).
3. NHS. *Secondary Care Medicines Data (SCMD)*. Available at: <https://opendata.nhsbsa.net/dataset/secondary-care-medicines-data> (accessed 11 May 2023).
4. Office for National Statistics. *Mid-2020 population estimates for 2021 clinical commissioning groups (CCGs) in England by single year of age and sex*. Available at: <https://www.ons.gov.uk/file?uri=%2Fpeoplepopulationandcommunity%2Fpopulationandmigration%2Fpopulationestimates%2Fdatasets%2Fclinicalcommissioninggroups%2Fmidyearpopulationestimates%2Fmid2020sape23dt6a/sape23dt6amid2020ccg2021estimatesunformatted.xlsx> (accessed 18 May 2023).



Appendix 2: HES disclaimer/digital licence (1)

1. Secondary care data are taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital, the new trading name for the Health and Social Care Information Centre (HSCIC) Copyright © 2023, the Health and Social Care Information Centre. Re-used with the permission of the Health and Social Care Information Centre. All rights reserved.
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 - 2.1 One of the basic principles for the release and use of HES data is to protect the privacy and confidentiality of individuals. All users of HES data must consider the risk of identifying individuals in their analyses prior to publication/release.
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 - 2.1.2 On no account should an attempt be made to decipher the process of creating anonymised data items.
 - 2.2 You should be on the alert for any rare and unintentional breach of confidence, such as responding to a query relating to a news item that may add more information to that already in the public domain. If you recognise an individual while carrying out any analysis you must exercise professionalism and respect their confidentiality.
 - 2.3 If you believe this identification could easily be made by others you should alert a member of the Wilmington Healthcare team using the contact details below. While appropriate handling of an accidental recognition is acceptable, the consequences of deliberately breaching confidentiality could be severe.
 - 2.4 HES data must only be used exclusively for the provision of outputs to assist health and social care organisations.
 - 2.5 HES data must not be used principally for commercial activities. The same aggregated HES data outputs must be made available, if requested, to all health and social care organisations, irrespective of their value to the company.
 - 2.6 HES data must not be used for, including (but not limited to), the following activities:
 - 2.6.1 Relating HES data outputs to the use of commercially available products. An example being the prescribing of pharmaceutical products
 - 2.6.2 Any analysis of the impact of commercially available products. An example being pharmaceutical products
 - 2.6.3 Targeting and marketing activity.
 - 2.7 HES data must be accessed, processed and used within England or Wales only. HES data outputs must not be shared outside of England or Wales without the prior written consent of Wilmington Healthcare.
 - 2.8 If HES data are subject to a request under the Freedom of Information Act, then Wilmington Healthcare and NHS Digital must be consulted and must approve any response before a response is provided.



Appendix 2: HES disclaimer/digital licence (2)

3. 2022/23 HES data are provisional and may be incomplete or contain errors for which no adjustments have yet been made. Counts produced from provisional data are likely to be lower than those generated for the same period in the final dataset. This shortfall will be most pronounced in the final month of the latest period, e.g. September from the April to September extract. It is also probable that clinical data are not complete, which may in particular affect the last two months of any given period. There may also be errors due to coding inconsistencies that have not yet been investigated and corrected.
4. ICD-10 codes, terms and text © World Health Organization, 1992-2023.
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10. You can contact Wilmington Healthcare by telephoning 0845 121 3686, by e-mailing client.services@wilmingtonhealthcare.com or by visiting www.wilmingtonhealthcare.com.



Appendix 3: HES analysis methods

Last 5 fiscal years (2017/2018 – 2021/2022)
and full 5-year period

ICD-10 code	ICD-10 description	3 character ICD-10	Group description
K743	Primary biliary cirrhosis	K74	Primary biliary cirrhosis

Topic	Description
IP split by admission type	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) split by admission type, primary biliary cirrhosis position for organisation types ICB, trust and national, covering periods mentioned above.
IP split by age band and sex	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) split by primary biliary cirrhosis position, age band, sex for organisation types ICB, trust and national, covering periods mentioned above.
IP by age and sex (normalised)	Inpatient patient counts with a diagnosis of primary biliary cirrhosis (K74.3) split by primary biliary cirrhosis position, age band, sex for organisation types at national level only for the full 5 year period. Patient counts are presented as normalised values per 100,000 population for each age band and sex using data from ONS Mid-2020 Population Estimates. ⁴
IP split by treatment speciality	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient, episodes, episode bed days, episode MLOS) with a diagnosis of primary biliary cirrhosis (K74.3) split by primary biliary cirrhosis position, treatment specialty for organisation types ICB, trust and national, covering periods mentioned above.
IP top 10 comorbidity (first episode)	Inpatient primary diagnosis comorbidity in the first episode of a spell (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) in the secondary position split by primary diagnosis code, primary diagnosis description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on spell count.
IP split by top 10 comorbidity a	Inpatient comorbidity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) in the secondary position split by primary diagnosis code, primary diagnosis description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on spell count.
IP split by top 10 comorbidity b	Inpatient comorbidity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) in the primary position split by secondary diagnosis code, secondary diagnosis description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on spell count.
IP split by top 10 operations	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) displaying the top 10 operations split by diagnosis position, operation code, operation description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on spell count.
IP split by HRG	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) split by primary biliary cirrhosis position, HRG for organisation types ICB, trust and national, covering periods mentioned above. All data where both patients and spells are suppressed has been removed.
IP split by all operations	Inpatient activity (patients, spells, bed days, MLOS, cost, cost per patient) with a diagnosis of primary biliary cirrhosis (K74.3) displaying all operations split by diagnosis position, operation code, operation description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on spell count.
OP split by treatment speciality	Outpatient activity (patients, appointments, cost) for tracked inpatients that have a diagnosis of primary biliary cirrhosis (K74.3) split by treatment specialty for organisation types ICB, trust and national, covering periods mentioned above.
OP split by top 10 operations	Outpatient activity (patients, appointments, cost) for tracked inpatients that have a diagnosis of primary biliary cirrhosis (K74.3) displaying the top 10 operations split by operation code, operation description for organisation types ICB, trust and national, covering periods mentioned above. Top 10 is based on appointment count.
Rounding and suppression	Values for patients, admissions, spells above 7 have been rounded to the nearest 5. Values for patients, admissions, spells between 1 and 7 inclusive have been suppressed and are represented by *. Cost per patient has been rounded to the nearest 5; due to this totals may not sum across columns/rows. Cost per patient is suppressed where patients are suppressed; MLOS is suppressed where spells are suppressed.

HES, Hospital Episode Statistics; HRG, healthcare resource group; ICB, integrated care board; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th edition; IP, inpatient; MLOS, mean length of stay; ONS, Office for National Statistics; OP, outpatient.



Appendix 4: HES dataset (1) Inpatient data

Inpatient admissions with PBC as a diagnosis in any position by patient count and patients per 100,000 population, national

Sex	Patient count (5-year period)							Patients per 100,000 population						
	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	≥75 years	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	≥75 years
Female	25	135	400	1,230	2,090	3,065	3,410	1	4	11	32	59	105	123
Male	30	70	95	170	395	605	660	1	2	3	5	12	23	31

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.
HES, Hospital Episode Statistics; PBC, primary biliary cirrhosis.



Appendix 4: HES dataset (2) Inpatient data

Inpatient admissions with PBC as a diagnosis in any position split by age and sex, national

Fiscal year	Female								Male							
	≤15 years	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	≥75 years	≤15 years	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	≥75 years
2017/2018	0	10	40	115	385	595	900	915	0	10	10	15	50	115	160	185
2018/2019	0	0	40	105	360	640	880	900	0	0	20	20	40	115	175	190
2019/2020	0	10	35	110	355	625	985	1,045	0	0	25	25	40	100	180	180
2020/2021	0	0	30	85	250	480	705	955	0	10	15	30	35	80	160	155
2021/2022	0	0	40	130	315	630	925	1,145	0	10	20	20	35	105	170	200
5-year period	10	25	135	400	1,230	2,090	3,065	3,410	10	30	70	95	170	395	605	660

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; MLOS, mean length of stay; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (3) Inpatient data

Inpatient admissions with a primary diagnosis of PBC split by elective and non-elective admissions, national

Fiscal year	Elective admissions						Non-elective admissions						MLOS difference*
	Patients	Spells	Cost (£)	Cost per patient (£)	Bed days	MLOS	Patients	Spells	Cost (£)	Cost per patient (£)	Bed days	MLOS	
2017/2018	235	325	227,708	960	340	1	190	205	823,002	4,380	2,713	13.1	12.1
2018/2019	245	310	272,624	1,115	328	1.1	140	175	710,862	5,115	1,860	10.8	9.7
2019/2020	265	345	350,319	1,325	538	1.6	160	205	1,039,003	6,495	2,698	13.2	11.6
2020/2021	135	190	184,945	1,350	145	0.8	145	170	696,686	4,870	1,871	10.9	10.1
2021/2022	185	270	232,329	1,250	262	1	160	190	835,861	5,225	2,126	11.3	10.3
% change	-21	-17	2	30	-23	0	-16	-7	2	19	-22	-14	

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*Difference between non-elective and elective MLOS.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; MLOS, mean length of stay; PBC, primary biliary cirrhosis.



Appendix 4: HES dataset (4) Inpatient data

Patients admitted as an inpatient with a primary diagnosis of PBC by treatment specialty, national

Treatment specialty	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Gastroenterology	755	180	180	190	110	160
General medicine	500	105	110	105	105	105
Hepatology	335	90	55	90	65	65
Transplantation surgery	110	30	15	30	15	30
Interventional radiology	75	20	15	20	10	15
Geriatric medicine	60	10	0	20	15	10
General surgery	55	15	15	10	0	10
Diagnostic imaging	40	0	15	10	0	0
Respiratory medicine	25	10	0	0	0	0
Hepatobiliary and pancreatic surgery	25	10	0	0	0	0

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page 11

Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

A&E, accident and emergency; HES, Hospital Episode Statistics; MLOS, mean length of stay; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (5) Inpatient data

All, elective and non-elective admissions with a diagnosis of PBC in any position, ICBs, 5-year total (1)

Organisation name	Patients			Spells			Spells (%)		Total population	Patients per 100,000 population
	All	Elective	Non-elective	All	Elective	Non-elective	Elective	Non-elective		
NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE ICB	190	120	120	535	320	215	60	40	929,964	20
NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES ICB	200	135	120	555	325	235	59	42	959,098	21
NHS BIRMINGHAM AND SOLIHULL ICB	240	125	160	550	280	270	51	49	1,179,731	20
NHS BLACK COUNTRY ICB	240	130	155	560	305	255	54	46	1,380,809	17
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE ICB	250	140	160	515	235	280	46	54	969,256	26
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST ICB	280	165	175	575	290	285	50	50	1,723,447	16
NHS CAMBRIDGESHIRE AND PETERBOROUGH ICB	205	135	110	470	255	210	54	45	896,725	23
NHS CHESHIRE AND MERSEYSIDE ICB	735	445	445	1,540	820	720	53	47	2,503,902	29
NHS CORNWALL AND THE ISLES OF SCILLY ICB	145	100	70	275	175	105	64	38	575,525	25
NHS COVENTRY AND WARWICKSHIRE ICB	135	85	75	370	235	130	64	35	963,173	14
NHS DERBY AND DERBYSHIRE ICB	240	120	170	455	220	235	48	52	1,030,393	23
NHS DEVON ICB	220	135	140	555	305	250	55	45	1,209,773	18
NHS DORSET ICB	95	50	60	175	80	95	46	54	776,780	12
NHS FRIMLEY ICB	100	70	55	230	150	85	65	37	746,739	13
NHS GLOUCESTERSHIRE ICB	115	70	70	305	180	120	59	39	640,650	18
NHS GREATER MANCHESTER ICB	580	385	345	1,610	940	670	58	42	2,881,890	20
NHS HAMPSHIRE AND ISLE OF WIGHT ICB	310	175	205	895	510	385	57	43	1,831,473	17
NHS HEREFORDSHIRE AND WORCESTERSHIRE ICB	195	125	105	455	285	165	63	36	791,685	25
NHS HERTFORDSHIRE AND WEST ESSEX ICB	285	175	175	730	400	330	55	45	1,488,061	19
NHS HUMBER AND NORTH YORKSHIRE ICB	480	295	320	1,370	715	660	52	48	1,708,723	28
NHS KENT AND MEDWAY ICB	320	215	175	710	410	300	58	42	1,868,199	17
NHS LANCASHIRE AND SOUTH CUMBRIA ICB	340	205	210	1,155	825	330	71%	29	1,701,655	20
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND ICB	165	85	120	425	205	220	48	52	1,107,597	15
NHS LINCOLNSHIRE ICB	175	105	105	440	240	200	55	45	766,333	23

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Appendix 4: HES dataset (6) Inpatient data

All, elective and non-elective admissions with a diagnosis of PBC in any position, ICBs, 5-year total (2)

Organisation name	Patients			Spells			Spells (%)		Total population	Patients per 100,000 population
	All	Elective	Non-elective	All	Elective	Non-elective	Elective	Non-elective		
NHS MID AND SOUTH ESSEX ICB	195	120	120	490	270	220	55	45	1,199,296	16
NHS NORFOLK AND WAVENEY ICB	375	265	220	1250	790	455	63	36	1,032,661	36
NHS NORTH CENTRAL LONDON ICB	190	130	100	400	230	170	58	43	1,526,582	12
NHS NORTH EAST AND NORTH CUMBRIA ICB	1300	815	795	3480	2030	1450	58	42	3,000,432	43
NHS NORTH EAST LONDON ICB	235	145	150	735	455	280	62	38	2,036,470	12
NHS NORTH WEST LONDON ICB	315	200	175	845	500	345	59	41	2,111,469	15
NHS NORTHAMPTONSHIRE ICB	140	80	95	335	170	165	51	49	740,111	19
NHS NOTTINGHAM AND NOTTINGHAMSHIRE ICB	290	170	185	720	355	365	49	51	1,052,195	28
NHS SHROPSHIRE, TELFORD AND WREKIN ICB	140	95	80	465	305	160	66	34	506,737	28
NHS SOMERSET ICB	145	95	95	455	275	180	60	40	563,851	26
NHS SOUTH EAST LONDON ICB	290	180	165	660	365	295	55	45	1,818,226	16
NHS SOUTH WEST LONDON ICB	180	105	115	475	280	200	59	42	1,509,741	12
NHS SOUTH YORKSHIRE ICB	330	200	210	835	450	385	54	46	1,533,334	22
NHS STAFFORDSHIRE AND STOKE-ON-TRENT ICB	265	170	150	675	370	305	55	45	1,139,794	23
NHS SUFFOLK AND NORTH EAST ESSEX ICB	255	160	160	635	335	300	53	47	987,177	26
NHS SURREY HEARTLANDS ICB	160	105	110	390	200	190	51	49	1,052,425	15
NHS SUSSEX ICB	290	155	185	590	295	295	50	50	1,711,539	17
NHS WEST YORKSHIRE ICB	440	250	300	1170	620	545	53	47	2,396,517	18

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (7) Inpatient data

Top 10 treatment specialities for inpatient episodes with a primary diagnosis of PBC, national

Treatment specialty	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Gastroenterology	1,200	250	265	275	155	255
General medicine	865	160	195	175	165	170
Hepatology	740	195	85	190	140	130
Transplantation surgery	195	50	25	55	30	40
Geriatric medicine	80	10	10	25	20	15
Interventional radiology	80	20	15	20	10	20
General surgery	60	15	15	15	10	10
Diagnostic imaging	40	0	15	10	0	0
Hepatobiliary and pancreatic surgery	35	10	0	0	10	0
Respiratory medicine	30	10	10	0	0	0

Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; PBC, primary biliary cirrhosis.

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Appendix 4: HES dataset (8) Inpatient data

Hospital inpatient spells with a primary diagnosis of PBC by secondary diagnosis, national

Secondary diagnosis code	Secondary diagnosis description	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
K318	Other specified diseases of stomach and duodenum	225	NA†	50	55	NA†	50
K729	Hepatic failure, unspecified	240	55	45	NA†	NA†	45
K743	Primary biliary cirrhosis	245	NA†	50	60	NA†	55
E039	Hypothyroidism, unspecified	285	80	50	70	45	NA†
E119	Type 2 diabetes mellitus	310	60	60	65	65	60
Z864	Personal history of psychoactive substance abuse	320	NA†	55	75	70	75
I982	Oesophageal varices without bleeding in diseases classified elsewhere	395	110	65	100	45	70
I10X	Essential (primary) hypertension	560	110	100	110	115	125
K766	Portal hypertension	640	120	125	175	85	135
R18X	Ascites	870	195	150	200	155	165

Green shading shows highest costs in each row.

†Not in the top 10 for that year

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

COPD, chronic obstructive pulmonary disease; HES, Hospital Episode Statistics; NA, not in the top 10 for that year; PBC, primary biliary cirrhosis.

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Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (9) Inpatient data

Hospital inpatient spells with a secondary diagnosis of PBC by primary diagnosis, national

Primary diagnosis code	Primary diagnosis description	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
D509	Iron deficiency anaemia, unspecified	860	160	170	145	140	240
I982	Oesophageal varices without bleeding*	510	115	110	115	60	105
J181	Lobar pneumonia, unspecified	465	95	120	110	65	80
C900	Multiple myeloma	435	NA†	95	135	90	85
I859	Oesophageal varices without bleeding	420	75	85	90	65	105
A419	Sepsis, unspecified	400	110	95	80	55	NA†
N390	Urinary tract infection, site not specified	365	55	80	85	65	85
D649	Anaemia, unspecified	315	65	60	NA†	60	65
M819	Osteoporosis, unspecified	310	NA†	55	65	70	90
J440	COPD with acute lower respiratory infection	250	NA†	65	NA†	NA†	NA†

Green shading shows highest costs in each row.

†Not in the top 10 for that year

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

COPD, chronic obstructive pulmonary disease; HES, Hospital Episode Statistics; NA, not in the top 10 for that year; PBC, primary biliary cirrhosis.

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Appendix 4: HES dataset (10) **Inpatient data**

Top 10 procedures, where PBC was the primary diagnosis, by spells, national, 5-year totals

Procedure code	Procedure description	Patients	Spells
Y532	Approach to organ under ultrasonic control	495	545
Z274	Duodenum	375	405
G459	Transient cerebral ischaemic attack, unspecified	335	360
J132	Percutaneous biopsy of lesion of liver NEC	310	320
Y981	Radiology of one body area (or <20 minutes)	270	295
Y973	Radiology with post contrast	235	255
T462	Drainage of ascites NEC	230	405
Z926	Abdomen NEC	205	215
O161	Pelvis NEC	195	210
T461	Paracentesis abdominis for ascites	90	240

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; MLOS, mean length of stay; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (11) **Inpatient data**

Top 10 inpatient HRGs, where PBC was the primary diagnosis, by patients and spells, national, 5-year totals

Procedure code	Procedure description	Patients (n)	Spells (n)
YG11A	Percutaneous punch biopsy of lesion of liver, 19 years and over	290	295
GC17J	Non-malignant, hepatobiliary or pancreatic disorders, without interventions, with CC score 24	155	180
FE22Z	Diagnostic endoscopic upper gastrointestinal tract procedures, 19 years and over	150	155
GC17K	Non-malignant, hepatobiliary or pancreatic disorders, without Interventions, with CC score 01	150	175
FZ60Z	Diagnostic endoscopic upper gastrointestinal tract procedures, 19 years and over	140	145
GC17E	Non-malignant, hepatobiliary or pancreatic disorders, with single intervention, with CC score 48	100	105
GC17G	Non-malignant, hepatobiliary or pancreatic disorders, without interventions, with CC score 8+	75	75
GC17H	Non-malignant, hepatobiliary or pancreatic disorders, without interventions, with CC score 57	75	80
FF53A	Minor therapeutic or diagnostic, general abdominal procedures, 19 years and over	65	210
FZ13C	Minor therapeutic or diagnostic, general abdominal procedures, 19 years and over	60	170

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page 20

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

CC, comorbidity and complication; HES, Hospital Episode Statistics; ICB, integrated care board; MLOS, mean length of stay; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (12) Inpatient data

MLOS for hospital inpatient spells with a diagnosis of PBC in any position by age and sex, national

Fiscal year	25–34 years		35–44 years		45–54 years		55–64 years		65–74 years		≥75 years	
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male
2017/2018	1.9	1.3	3.1	5.2	3.0	3.5	2.8	3.1	3.7	4.3	6.6	4.4
2018/2019	1.5	4.4	3.2	1.3	1.9	2.3	2.6	2.8	3.3	4.0	5.8	6.1
2019/2020	1.8	2.6	3.7	4.2	2.0	2.5	2.8	3.1	3.5	3.1	5.9	5.9
2020/2021	1.2	0.9	2.5	9.8	2.4	4.3	3.3	3.2	3.5	3.6	5.8	5.8
2021/2022	2.5	4.9	2.2	1.8	2.3	3.3	2.5	2.4	3.1	3.7	6.1	5.8
5-year period	1.8	3.0	2.9	4.8	2.3	3.3	2.8	2.9	3.4	3.7	6.0	5.6

Chart on
page 21

Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

COPD, chronic obstructive pulmonary disease; HES, Hospital Episode Statistics; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (13) Inpatient data

Hospital inpatient spells in patients with a secondary diagnosis of PBC on admission by primary diagnosis, national

Primary diagnosis code	Primary diagnosis description	Patients (n)	Spells (n)	Cost (£)	Cost per patient (£)	Bed days (n)	MLOS (days)
D509	Iron deficiency anaemia, unspecified	425	860	566,325	1,335	493	0.6
J181	Lobar pneumonia, unspecified	425	465	1,980,684	4,650	4,297	9.2
A419	Sepsis, unspecified	360	400	1,946,741	5,380	4,711	11.8
I982	Oesophageal varices without bleeding in diseases classified elsewhere	315	510	302,840	970	124	0.2
N390	Urinary tract infection, site not specified	315	365	1,396,389	4,460	2,743	7.6
I859	Oesophageal varices without bleeding	310	420	227,560	735	69	0.2
D649	Anaemia, unspecified	230	315	377,570	1,640	545	1.7
J440	COPD with acute lower respiratory infection	195	250	716,200	3,690	1,532	6.1
M819	Osteoporosis, unspecified	185	310	200,685	1,090	0	0.0
C900	Multiple myeloma	25	435	65,780	2,860	43	0.1

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page 22

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page 27

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

COPD, chronic obstructive pulmonary disease; HES, Hospital Episode Statistics; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (14) Inpatient data

Top 10 inpatient treatment specialties, where patient has a primary diagnosis of PBC, by MLOE, national

Treatment specialty	MLOE (days)					
	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Transplantation surgery	6.9	8.5	6.1	7.0	5.1	6.4
Geriatric medicine	6.1	5.3	3.6	6.2	9.9	3.6
Respiratory medicine	5.5	4.3	6.0	0.0	0.0	0.0
Hepatobiliary and pancreatic surgery	3.6	5.1	0.0	0.0	3.4	0.0
Hepatology	3.0	2.3	4.2	3.2	2.7	3.1
Gastroenterology	2.4	2.7	2.0	2.9	2.3	2.2
General medicine	2.2	2.1	2.0	2.7	1.9	2.6
General surgery	1.8	2.1	0.9	3.1	1.0	1.6
Diagnostic imaging	0.1	0.0	0.1	0.0	0.0	0.0
Interventional radiology	0.0	0.0	0.0	0.1	0.0	0.0

MLOE describes the mean length of an episode within an overall spell.

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Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; MLOE, mean length of episode; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (15) Inpatient data

Top 10 inpatient treatment specialties by bed-days in episode, where patient has a primary diagnosis of PBC, England

Treatment specialty	Bed days in episode					
	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Gastroenterology	2,904	671	526	802	346	559
Hepatology	2,185	442	350	608	375	410
General medicine	1,941	332	391	474	311	433
Transplantation surgery	1,352	417	146	393	142	254
Geriatric medicine	488	64	32	156	179	57
Respiratory medicine	164	43	54	31	5	31
Hepatobiliary and pancreatic surgery	119	46	4	10	31	28
General surgery	106	30	15	40	8	13
Diagnostic imaging	2	0	1	0	1	0
Interventional radiology	1	0	0	1	0	0

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page 25

Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts
are available in the Excel report



Appendix 4: HES dataset (16) Inpatient data

Top 10 inpatient treatment specialties by cost, where patient has a primary diagnosis of PBC, England

Treatment specialty	Cost (£)					
	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Gastroenterology	2,171,739	462,427	401,361	538,881	319,337	449,733
General medicine	2,169,905	332,505	436,738	489,455	426,585	484,622
Hepatology	1,321,194	300,683	188,615	382,646	209,551	239,699
Transplantation surgery	363,442	48,794	40,060	136,812	47,340	90,435
Geriatric medicine	343,663	56,211	28,121	114,761	71,685	72,885
Respiratory medicine	141,601	39,851	40,814	20,974	21,167	18,795
General surgery	104,542	13,287	15,066	18,873	20,752	36,564
Hepatobiliary and pancreatic surgery	99,268	18,618	20,537	17,770	42,343	0
Interventional radiology	51,030	3,218	11,044	14,540	7,996	14,231
Diagnostic imaging	30,773	965	15,153	6,063	6,296	2,296

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Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; OCA, obeticholic acid; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (18) **Inpatient data**

Cost per patient of hospital inpatient spells with a diagnosis of PBC by age and sex, national

Fiscal year	Cost (£)											
	25–34 years		35–44 years		45–54 years		55–64 years		65–74 years		≥75 years	
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male
2017/2018	845	835	2,210	2,885	2,570	2,310	2,725	3,495	3,465	3,850	4,310	4,325
2018/2019	1,330	3,185	2,235	1,705	2,440	2,370	2,835	3,345	3,315	4,300	4,490	5,240
2019/2020	2,145	2,495	2,395	2,745	2,175	2,985	3,510	5,040	3,740	4,750	5,015	5,495
2020/2021	1,200	1,140	3,020	4,325	2,575	6,015	3,220	3,750	3,895	4,195	4,955	4,395
2021/2022	2,250	3,455	2,135	4,030	2,540	3,240	2,720	3,220	3,730	4,475	4,885	6,010
5-year period	2,085	2,970	3,175	3,955	3,315	3,965	4,250	4,880	5,195	6,050	6,900	7,120

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Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

COPD, chronic obstructive pulmonary disease; HES, Hospital Episode Statistics; NA, not in the top 10 for that year; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (19) **Outpatient data**

Top 20 treatment specialties, where patient has had a diagnosis of PBC, by appointments and estimated backlog due to COVID-19, national

Treatment specialty	Appointments						Estimated backlog due to COVID-19			
	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	Pre-COVID-19 annual average	COVID annual average	Annual backlog	Total backlog
Gastroenterology	52,830	10,775	11,315	11,100	9,980	9,665	11,208	9,823	1,385	2,770
Hepatology	51,730	8,635	10,405	10,930	10,760	11,005	10,668	10,883	-215	-430
Ophthalmology	27,460	5,745	5,935	6,350	4,480	4,945	6,143	4,713	1,430	2,860
Rheumatology	23,290	4,850	4,940	4,805	4,435	4,260	4,873	4,348	525	1,050
Diagnostic imaging	22,840	4,965	5,320	4,875	3,220	4,455	5,098	3,838	1,260	2,520
Trauma and orthopaedics	19,715	4,385	4,235	4,380	3,125	3,595	4,308	3,360	948	1,895
Cardiology	18,580	3,670	4,105	4,030	3,240	3,535	4,068	3,388	680	1,360
Respiratory medicine	14,855	2,855	3,135	3,340	2,725	2,800	3,238	2,763	475	950
Clinical haematology	14,380	2,780	2,930	2,945	2,825	2,905	2,938	2,865	73	145
Dermatology	13,040	2,840	3,090	2,790	2,040	2,280	2,940	2,160	780	1,560
Physiotherapy	11,805	2,895	2,900	2,915	1,270	1,825	2,908	1,548	1,360	2,720
General surgery	9,485	1,890	1,880	1,785	1,855	2,080	1,833	1,968	-135	-270
Clinical oncology	9,160	1,520	1,815	1,565	2,110	2,150	1,690	2,130	-440	-880
Medical oncology	9,145	1,375	1,700	1,925	1,840	2,305	1,813	2,073	-260	-520
General medicine	7,975	1,655	1,725	1,735	1,380	1,480	1,730	1,430	300	600
Nephrology	7,950	1,575	1,625	1,580	1,585	1,590	1,603	1,588	15	30
Urology	7,945	1,530	1,605	1,740	1,515	1,555	1,673	1,535	138	275
Transplantation surgery	7,440	1,115	1,360	1,665	1,550	1,745	1,513	1,648	-135	-270
Gynaecology	7,435	1,545	1,595	1,560	1,255	1,480	1,578	1,368	210	420
ENT	7,400	1,650	1,650	1,700	1,130	1,275	1,675	1,203	473	945

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Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

ENT, ear, nose and throat; HES, Hospital Episode Statistics; MLOS, mean length of stay; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.



Appendix 4: HES dataset (20) **Outpatient data**

Top 20 treatment specialties, where patient has had a diagnosis of PBC, by cost, England

Treatment speciality	Cost (£)					
	5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
Hepatology	7,225,795	1,472,288	1,725,666	1,839,616	1,019,631	1,168,594
Gastroenterology	4,262,707	990,683	1,046,883	1,131,705	560,491	532,944
Rheumatology	2,548,158	648,004	672,373	572,876	323,184	331,720
Ophthalmology	2,202,028	331,528	517,965	567,067	362,760	422,709
Cardiology	1,979,599	370,790	517,504	481,704	283,874	325,726
Trauma and orthopaedics	1,773,727	380,756	389,957	431,186	254,983	316,845
Respiratory medicine	1,639,815	318,381	396,166	425,414	246,462	253,392
Clinical haematology	1,638,556	363,681	382,399	414,260	249,494	228,722
Dermatology	1,056,464	151,461	279,687	271,060	154,027	200,228
General medicine	1,043,692	214,964	241,492	238,121	164,517	184,597
Nephrology	958,804	215,258	227,352	215,102	149,037	152,055
Medical oncology	952,359	147,064	183,472	251,170	155,279	215,375
General surgery	945,627	190,428	208,500	208,933	159,190	178,576
Clinical oncology	882,575	138,752	157,903	189,407	196,075	200,437
Gynaecology	881,531	121,864	212,920	214,469	143,972	188,306
Urology	795,032	105,276	190,832	215,672	130,968	152,283
Ear, nose and throat (ENT)	587,836	89,116	152,261	161,474	77,358	107,627
Diabetic medicine	560,109	136,939	142,533	133,128	67,650	79,860
Geriatric medicine	531,593	124,568	121,547	143,155	58,665	83,658
Breast surgery	511,957	101,307	116,245	114,357	80,163	99,886

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Green shading shows highest costs in each row.

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; MLOS, mean length of stay; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.



Appendix 4: HES dataset (21) **Outpatient data**

Top 10 procedures, where patient has had a diagnosis of PBC, by appointments, England

Operation code	Operation description	Appointments					
		5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
X621	Assessment by uniprofessional team NEC	23,165	4,280	4,650	5,165	4,290	4,775
Y981	Radiology of one body area (or <20 minutes)	20,270	4,270	4,575	4,375	3,050	3,995
X622	Assessment by multiprofessional team NEC	10,750	2,160	2,650	2,495	1,550	1,900
C873	Tomography evaluation of retina	5,600	1,145	1,270	1,315	825	1,040
U216	Ultrasound scan NEC	5,165	1,165	1,125	1,055	745	1,070
Z301	Liver NEC	5,035	925	1,010	1,145	790	1,170
U328	Diagnostic blood tests, other specified	4,810	1,050	1,360	1,300	NA†	745
U082	Ultrasound of abdomen	4,330	885	985	960	735	770
X629	Assessment, unspecified	4,310	795	840	895	690	1,095
X369	Blood withdrawal, unspecified	3,435	645	810	820	NA†	NA†

Green shading shows highest costs in each row.

†Not in the top 10 for that year;

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; NA, not in the top 10 for that year; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.

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Appendix 4: HES dataset (22) Outpatient data

Top 10 procedures, where patient has had a diagnosis of PBC, by cost, England

Operation code	Operation description	Cost (£)					
		5-year period	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022
X621	Assessment by uniprofessional team NEC	1,987,958	386,512	490,882	519,351	283,573	307,640
X622	Assessment by multiprofessional team NEC	1,450,602	271,844	390,173	372,374	188,479	227,732
Y981	Radiology of one body area (or <20 minutes)	852,841	111,046	161,074	226,507	160,277	193,938
U328	Diagnostic blood tests, other specified	634,988	129,906	176,077	185,435	NA†	100,948
C873	Tomography evaluation of retina	462,326	NA†	127,978	136,902	86,362	111,085
Z301	Liver NEC	380,331	47,141	63,445	92,795	76,246	100,704
X629	Assessment, unspecified	366,839	96,102	102,342	98,023	22,820	47,552
X369	Blood withdrawal, unspecified	345,719	62,308	82,685	99,619	NA†	NA†
U216	Ultrasound scan NEC	312,999	54,892	60,701	61,963	63,251	72,193
U082	Ultrasound of abdomen	72,026	14,375	22,091	19,697	5,740	10,123

Green shading shows highest costs in each row.

†Not in the top 10 for that year;

Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; NA, not in the top 10 for that year; NEC, not elsewhere classified; PBC, primary biliary cirrhosis.

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Appendix 4: HES dataset (23) NHS Cheshire and Merseyside ICB case study

Inpatient admissions for patients with PBC as a diagnosis in any position by patient count and patients per 100,00 population,

Sex	Patient count (5-year period)							Population by age band							Patients per 100,000 population						
	16-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	≥75 years	16-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	≥75 years	16-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	≥75 years
Female	25	135	400	1,230	2,090	3,065	3,410	128,711	159,977	150,183	170,707	173,026	140,833	132,409	1	4	11	32	59	105	123
Male	30	70	95	170	395	605	660	131,502	160,987	145,358	161,362	162,533	130,826	98,442	1	2	3	5	12	23	31

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 4: HES dataset (24) NHS Cheshire and Merseyside ICB case study

Inpatient admissions for patients with PBC as a diagnosis in any position by admission type

Fiscal year	Elective admissions						Non-elective admissions					
	Patients	Spells	Cost (£)	Cost per patient (£)	Bed days	MLOS	Patients	Spells	Cost (£)	Cost per patient (£)	Bed days	MLOS
2017/2018	95	130	180,178	1,860	138	1.0	105	125	494,302	4,665	1,595	12.9
2018/2019	120	155	202,391	1,675	164	1.1	110	140	482,505	4,425	1,541	11.1
2019/2020	145	205	295,484	2,040	195	1.0	95	120	381,621	4,060	798	6.6
2020/2021	95	135	138,986	1,435	34	0.3	125	175	604,079	4,755	1,603	9.2
2021/2022	135	195	188,147	1,395	92	0.5	135	165	578,887	4,290	1,476	9.1

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Values for patients, admissions and spells above 7 have been rounded to the nearest 5. Values for patients, admissions and spells between 1 and 7 inclusive have been suppressed and are represented by *.

HES, Hospital Episode Statistics; ICB, integrated care board; MLOS, mean length of stay; PBC, primary biliary cirrhosis.

Full data for England, ICBs and trusts are available in the Excel report



Appendix 5: SCMD disclaimer/digital licence

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Appendix 6: Prescribing analysis methods

- OCA is presented as a 30-tablet pack in two doses – 5 mg and 10 mg – both doses are flat priced per pack.
- The total quantity of tablets and total cost was used to calculate the number of packs of OCA.
- This was used to estimate the numbers of patients on OCA per annum.
- These calculations were performed at national, ICB and trust level.



Appendix 7: Prescribing dataset (1)

Patient packs of OCA by trust, 2021–2022

Organisation name	Tablets	Cost (£)	Patient packs
BARTS HEALTH NHS TRUST	8,460	672,299	282
BASILDON AND THURROCK UNIVERSITY HOSPITALS NHS FT	1,200	95,362	40
BRADFORD TEACHING HOSPITALS NHS FT	1,896	150,671	63
CAMBRIDGE UNIVERSITY HOSPITALS NHS FT	16,050	1,275,461	535
CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FT	570	45,297	19
DORSET COUNTY HOSPITAL NHS FT	600	47,681	20
EAST LANCASHIRE HOSPITALS NHS TRUST	1,890	150,195	63
HAMPSHIRE HOSPITALS NHS FT	180	14,304	6
HULL UNIVERSITY TEACHING HOSPITALS NHS TRUST	2,310	183,571	77
IMPERIAL COLLEGE HEALTHCARE NHS TRUST	2,310	183,571	77
KING'S COLLEGE HOSPITAL NHS FT	18,480	1,468,569	616
LEEDS TEACHING HOSPITALS NHS TRUST	10,845	861,830	362
LIVERPOOL UNIVERSITY HOSPITALS NHS FT	5,490	436,279	183
MANCHESTER UNIVERSITY NHS FT	542	43,072	18
MID AND SOUTH ESSEX NHS FT	1,230	97,746	41
NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS FT	2,670	212,180	89
NORTHAMPTON GENERAL HOSPITAL NHS TRUST	180	14,304	6
NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	13,920	1,106,195	464
OXFORD UNIVERSITY HOSPITALS NHS FT	570	45,297	19
PORTSMOUTH HOSPITALS UNIVERSITY NATIONAL HEALTH SERVICE TRUST	2,880	228,868	96

Organisation name	Tablets	Cost (£)	Patient packs
ROYAL CORNWALL HOSPITALS NHS TRUST	1,484	117,931	49
ROYAL DEVON UNIVERSITY HEALTHCARE NHS FT	3,028	240,629	101
ROYAL FREE LONDON NHS FT	16,956	1,347,459	565
ROYAL LIVERPOOL AND BROADGREEN UNIVERSITY HOSPITALS NHS TRUST	6,120	486,344	204
ROYAL SURREY COUNTY HOSPITAL NHS FT	6,222	494,450	207
SHEFFIELD TEACHING HOSPITALS NHS FT	9,300	739,052	310
SOMERSET NHS FT	360	28,608	12
SOUTH TYNESIDE AND SUNDERLAND NHS FT	1,830	145,426	61
TAUNTON AND SOMERSET NHS FT	330	26,224	11
THE NEWCASTLE UPON TYNE HOSPITALS NHS FT	12,390	984,609	413
THE ROYAL BOURNEMOUTH AND CHRISTCHURCH HOSPITALS NHS FT	2,280	181,187	76
TORBAY AND SOUTH DEVON NHS FT	360	28,608	12
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FT	1,530	121,586	51
UNIVERSITY HOSPITALS BRISTOL AND WESTON NHS FT	3,690	293,237	123
UNIVERSITY HOSPITALS DORSET NHS FT	1,560	123,970	52
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	4,398	349,500	147
UNIVERSITY HOSPITALS PLYMOUTH NHS TRUST	1,620	128,738	54
UNIVERSITY HOSPITALS SUSSEX NHS FT	840	66,753	28
YORK AND SCARBOROUGH TEACHING HOSPITALS NHS FT	4,507	358,162	150

National average 146 patient packs

All other trusts did not prescribe any OCA

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Appendix 7: Prescribing dataset (2)

Patient packs of OCA by ICB, 2021–2022

Organisation name	Tablets	Cost (£)	Patient packs
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE ICB	3,690	293,237	123
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST ICB	570	45,297	19
NHS CAMBRIDGESHIRE AND PETERBOROUGH INTEGRATED CARE ICB	16,050	1,275,461	535
NHS CHESHIRE AND MERSEYSIDE ICB	5,490	436,279	183
NHS CORNWALL AND THE ISLES OF SCILLY ICB	1,484	117,931	49
NHS DEVON ICB	5,008	397,976	167
NHS DORSET ICB	2,160	171,651	72
NHS GREATER MANCHESTER ICB	542	43,072	18
NHS HAMPSHIRE AND ISLE OF WIGHT ICB	4,590	364,758	153
NHS HUMBER AND NORTH YORKSHIRE ICB	6,817	541,733	227
NHS LANCASHIRE AND SOUTH CUMBRIA ICB	1,890	150,195	63
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND ICB	4,398	349,500	147

Organisation name	Tablets	Cost (£)	Patient packs
NHS MID AND SOUTH ESSEX ICB	1,230	97,746	41
NHS NORFOLK AND WAVENEY ICB	2,670	212,180	89
NHS NORTH CENTRAL LONDON ICB	16,956	1,347,459	565
NHS NORTH EAST AND NORTH CUMBRIA ICB	14,220	1,130,035	474
NHS NORTH EAST LONDON ICB	8,460	672,299	282
NHS NORTH WEST LONDON ICB	2,310	183,571	77
NHS NORTHAMPTONSHIRE ICB	180	14,304	6
NHS NOTTINGHAM AND NOTTINGHAMSHIRE ICB	13,920	1,106,195	464
NHS SOMERSET ICB	360	28,608	12
NHS SOUTH EAST LONDON ICB	18,480	1,468,569	616
NHS SOUTH YORKSHIRE ICB	9,300	739,052	310
NHS SURREY HEARTLANDS ICB	6,222	494,450	207
NHS SUSSEX ICB	840	66,753	28
NHS WEST YORKSHIRE ICB	12,741	1,012,502	425

National average 206 patient packs

All other ICBs did not prescribe any OCA

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