

Palliative and End of Life Care Report for Children and Young People in the West Midlands

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Contents

1. Introduction	4
2. Prevalence Analyses	6
2.1 Trend over time.....	6
2.2 Conditions.....	8
2.3 Geography	12
2.4 Demographic characteristics.....	16
3. Acute Hospital Utilisation.....	19
3.1 Activity.....	19
3.2 Activity characteristics	21
3.3 Costs.....	25
3.4 Activity prior to death.....	30
4. Historical and Forecast Deaths.....	33
4.1 Trends and future forecast	33
4.2 Forecast.....	35
Appendices.....	37

1. Introduction

To help support the development of comprehensive paediatric palliative care services within the West Midlands there is a requirement to understand the characteristics and levels of resource required by children and young people (CYP) (0-25 years) with life limiting conditions and/or life threatening conditions. The term life limiting condition (LLC) will be used throughout this report to include both life limiting and life threatening conditions.

The scope of this report does not attempt to explain or address the complexity of LLC and palliative end of life care for children and young people; it does however highlight a new and emerging population of significance for the NHS in England. At this juncture, a key study from Scotland¹ contains further learning for England.

In brief, people aged 0-25 span both paediatric and adult services, Clinical Commissioning Groups and Specialised and Direct Commissioning. It is much reported that there is a broad and complex age transition period in this cohort and this report therefore covers this whole period.

Much national guidance for people of all ages exists, this includes 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020'² and a commitment from Government on choice³.

More specifically in paediatric palliative medicine the 2013 NHS England Service Specification⁴ sets out population needs, context and within the specification defines aspects including: care; interventions; specialist team infrastructure; interdependencies; categorisation.

This report draws on information from a range of primary sources including Hospital Episode Statistics (HES), Secondary Users Service (SUS) and ONS population projections and death registrations to provide intelligence on the prevalence, acute utilisation and characteristics of these complex patients. Also available is a companion report commissioned by NHS England describing the status and context of palliative and end of life care services in the West Midlands, it may be helpful and provide additional context to read these two reports in conjunction.

The main chapters of the report focus on;

- **Chapter 2 – Prevalence analyses** – Identifies CYP with an LLC registered with a GP practice in the West Midlands who have been in contact with hospital services since April 2006. The chapter examines how prevalence has changed over the past decade and summarises the cohorts by demographics and condition characteristics.

¹ <http://www.cen.scot.nhs.uk/children-in-scotland-requiring-palliative-care-report-identifying-numbers-and-needs-the-chisp-study/>

² <http://endoflifecareambitions.org.uk/>

³ <https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response>

⁴ <https://www.england.nhs.uk/?s=paediatric+palliative+medicine>

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- **Chapter 3 - Acute healthcare utilisation** – Identifies and summarises all acute hospital activity in HES for the cohort including A&E, Inpatients and Outpatients. Activity is identified whether it is related to the LLC or not, and is described in terms of overall trends and demographic and condition characteristics between 2011/12 and 2015/16. The cost of activity by CCG, STP and provider is also summarised in this section. Activity in the 12 months prior to death has been examined at each point of delivery for those who died in 2015/16.
 - **Chapter 4 – Historical deaths and forecasts** - Examines the trend in deaths for all CYP in the West Midlands (0-25 years) over the past decade and compares this to deaths in our cohort. Deaths for all CYP are forecasted until 2022/23.

List of abbreviations

CYP – Children and Young People

HES – Hospital Episode Statistics

LLC – Life limiting condition/ Life threatening condition

ONS – Office of National Statistics

SUS – Secondary Users Service

List of providers included in this report

Birmingham Women's and Children's

Burton Hospitals

George Eliot

Good Hope

Heart of England

Sandwell and West Birmingham

Shrewsbury and Telford

South Warwickshire

Dudley Group

Royal Wolverhampton

University Hospitals Birmingham

University Hospitals Coventry and Warwick

University Hospitals of North Midlands

Walsall Hospital

Worcestershire Acute

Wye Valley

2. Prevalence Analyses

Prevalence can be defined as the number of individuals with a given condition at a certain point in time, as a proportion of the overall population at risk. This chapter examines hospital-based prevalence for CYP with an LLC registered with a GP in the West Midlands area. We present the characteristics of these individuals, and how prevalence has changed over time.

The hospital-based prevalence is obtained using Hospital Episode Statistics (HES) data to identify CYP who have been in contact with inpatient hospital services and have one or more LLC recorded in the diagnosis field. A cohort is determined for each financial year. The full method used for the analyses in this section can be found in Appendix 2.

2.1 Trend over time

Figure 1 – Absolute numbers of hospital-based CYP with an LLC within the West Midlands

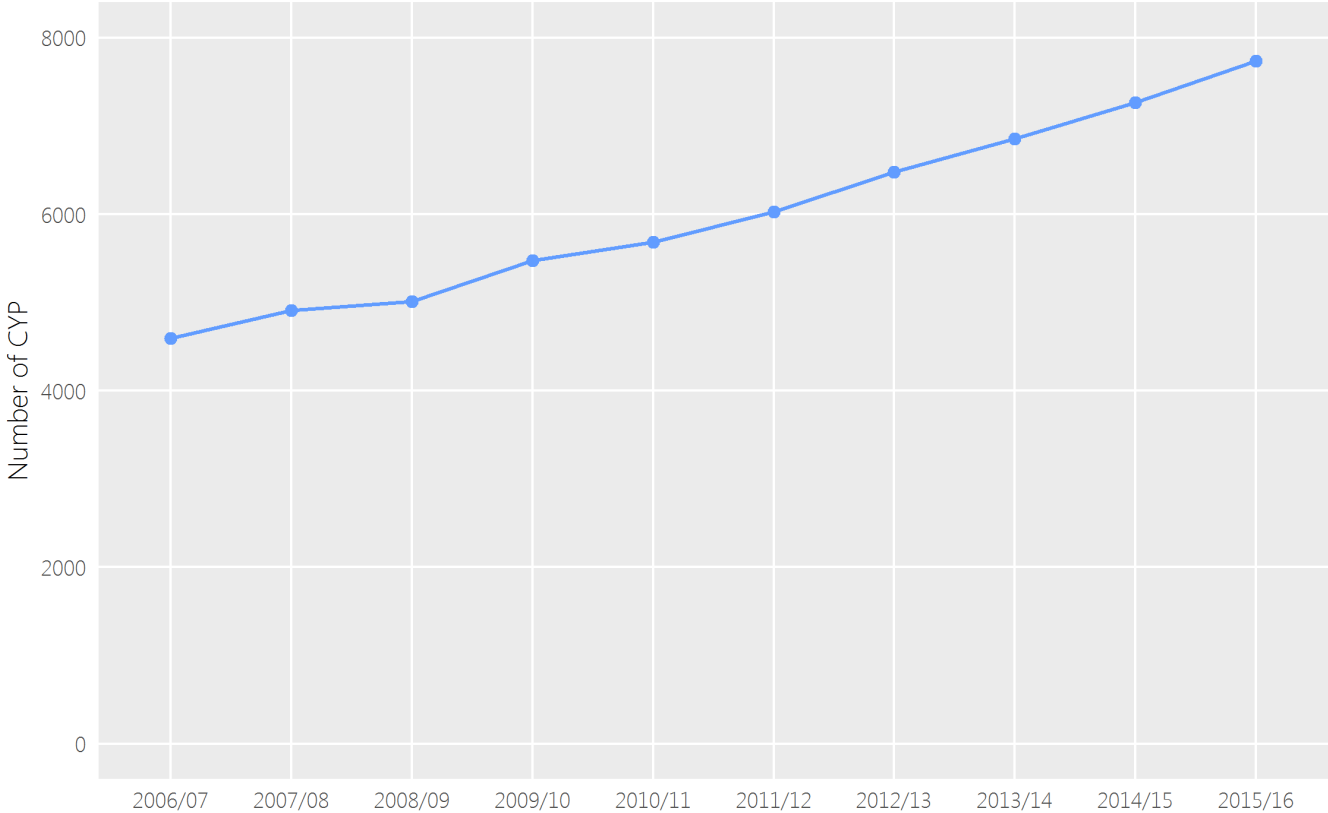
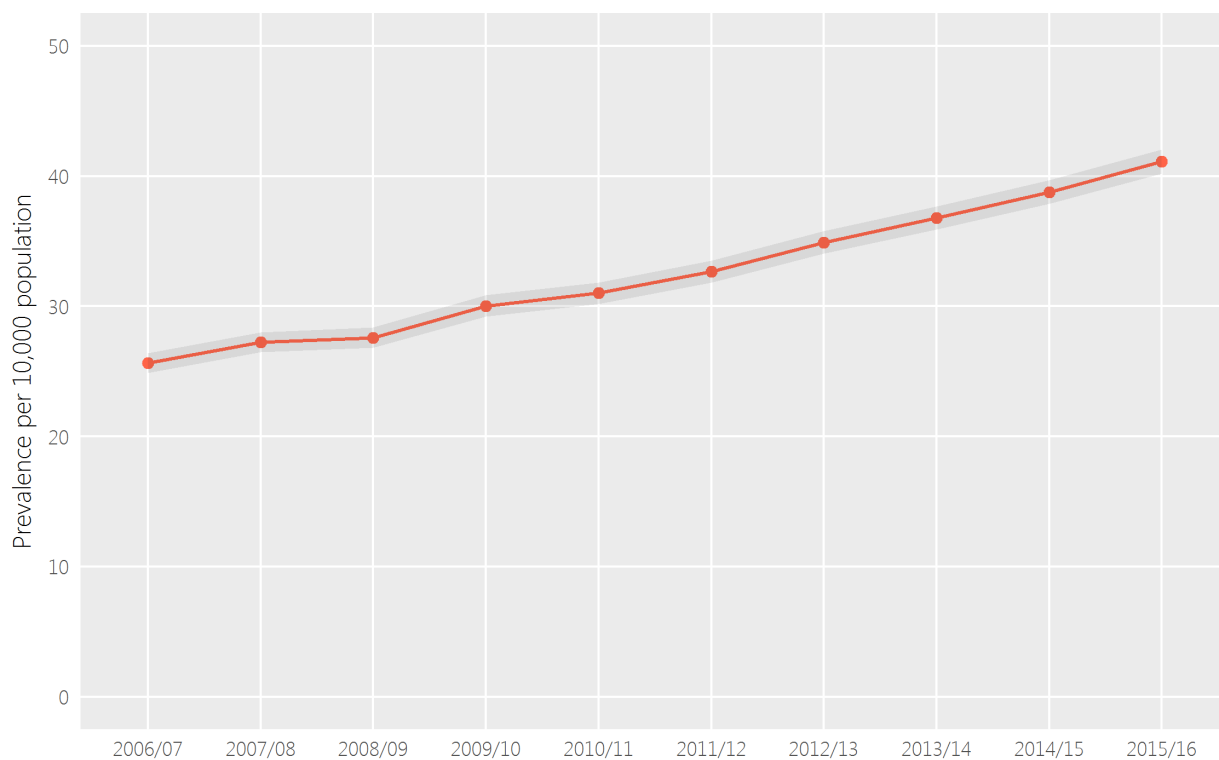


Figure 2 – Hospital-based prevalence among CYP with an LLC per 10,000 of the population within the West Midlands



Absolute numbers (figure 1) and hospital-based prevalence (figure 2) have both increased steadily year on year over the past decade. On average the yearly increase was 5.3% for absolute numbers and 4.8% for prevalence.

2.2 Conditions

Patients are identified as having an LLC if they are diagnosed with a condition found in the list Appendix 1. Patients may have more than one LLC and therefore can be identified in more than one condition group.

2.2.1 Condition summary groups

LLCs can be assigned to one of eleven individual condition groups. These eleven groups can be summarised into *Malignant* or *Non-Malignant*.

Malignant	-	Oncology
Non-Malignant	-	Circulatory, Congenital, Genitourinary, Haematology, Metabolic, Neurology, Perinatal, Respiratory, Other

Figure 3 – Hospital-based prevalence of LLCs among CYP by condition group, within the West Midlands

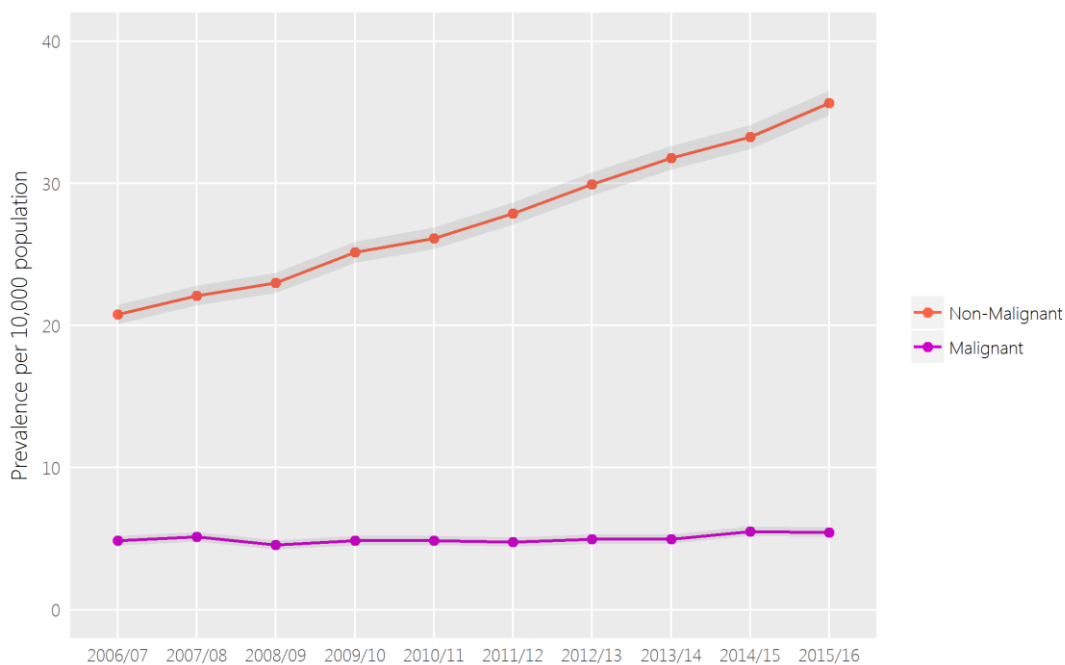


Figure 3 shows the hospital-based prevalence for each of the two summary groups. Increases in prevalence are driven by non-malignant conditions which have risen by 72% over 10 years whilst the prevalence of malignant conditions has remained stable.

2.2.2 Single and multiple conditions

Patients can fall into more than one condition group. Table 4 demonstrates that 85% of patients are assigned to a single condition group. The remaining 15% have multiple conditions, of which 12% belong to two condition groups and 3% belong to three or more groups.

Table 4 – Absolute numbers and proportion of hospital-based CYP with an LLC within the West Midlands in 2015/16

<i>Single condition group</i>		
Congenital	2,198	28%
Neurology	969	13%
Oncology	702	9%
Metabolic	582	8%
Perinatal	554	7%
Genitourinary	484	6%
Haematology	434	6%
Respiratory	409	5%
Gastrointestinal	69	1%
Circulatory	92	1%
Other	60	1%
sub-total	6,553	85%
<i>Multiple condition groups</i>		
2 diagnostic group	957	12%
3 or more diagnostic groups	224	3%
sub-total	1,181	15%
Grand total	7,734	-

For patients with multiple conditions (15% of all patients), Table 5 demonstrates the association between a particular condition (titled 'immediate condition') with any other contiguous condition. For example patients with congenital conditions make up 18% of the multiple conditions population and 9% of these patients have congenital conditions and a haematological condition, 4% have congenital conditions and an oncology condition etc.

Table 5 – Condition combinations of multiple condition patients for hospital-based CYP with an LLC within the West Midlands in 2015/16

Immediate condition	Contiguous condition										
	Congenital	Haematology	Oncology	Neurology	Genitourinary	Respiratory	Metabolic	Perinatal	Gastrointestinal	Other	Circulatory
Congenital (18%)		9%	4%	18%	18%	16%	5%	18%	5%	3%	4%
Haematology (14%)	10%		51%	4%	9%	6%	5%	1%	3%	8%	1%
Oncology (12%)	5%	60%		5%	8%	4%	3%	0%	3%	10%	1%
Neurology (11%)	28%	5%	6%		10%	23%	7%	6%	3%	6%	6%
Genitourinary (10%)	25%	11%	8%	9%		11%	9%	5%	8%	8%	4%
Respiratory (9%)	24%	8%	4%	22%	11%		9%	8%	7%	4%	4%
Metabolic (8%)	10%	9%	4%	10%	14%	12%		4%	29%	6%	1%
Perinatal (6%)	49%	1%	1%	11%	10%	14%	6%		3%	1%	3%
Gastrointestinal (6%)	12%	7%	5%	5%	15%	11%	33%	3%		6%	4%
Other (4%)	8%	19%	20%	10%	16%	8%	8%	1%	7%		2%
Circulatory (3%)	22%	5%	5%	20%	14%	14%	2%	5%	8%	5%	

2.2.3 Condition group prevalence

Single condition

Figures 4 – Hospital-based prevalence of LLCs among CYP, by single condition group within the West Midlands

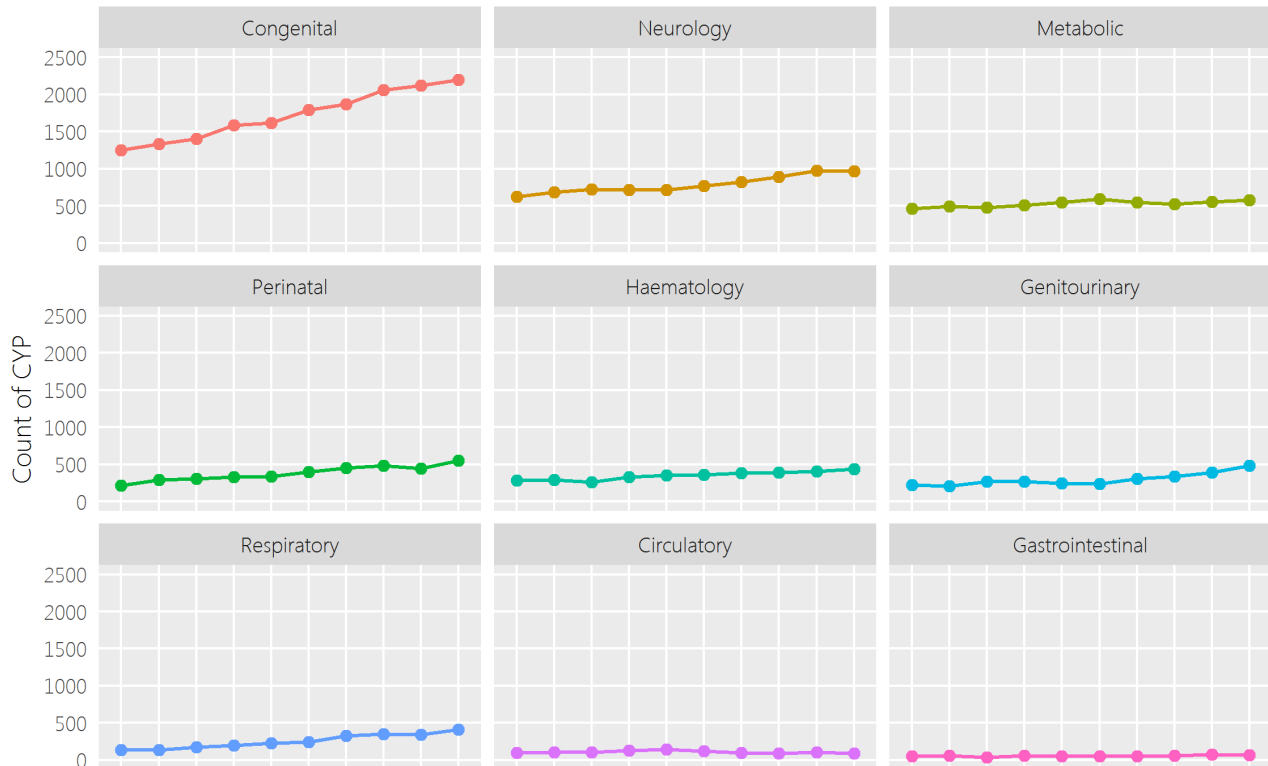


Figure 4 demonstrates hospital-based prevalence for individual condition groups where patients have only one LLC. The largest increase in prevalence is found in congenital conditions, which have doubled over the past decade.

Multiple conditions

Figure 5 – Hospital-based prevalence of CYP with multiple conditions within the West Midlands

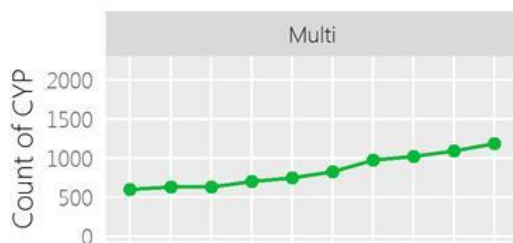


Figure 5 shows prevalence for multiple condition groups, which has more than doubled over the past decade.

2.3.2 Sustainability and Transformation Partnership (STP) areas

Figure 7 – Hospital-based prevalence of LLCs in CYP, by STP within the West Midlands

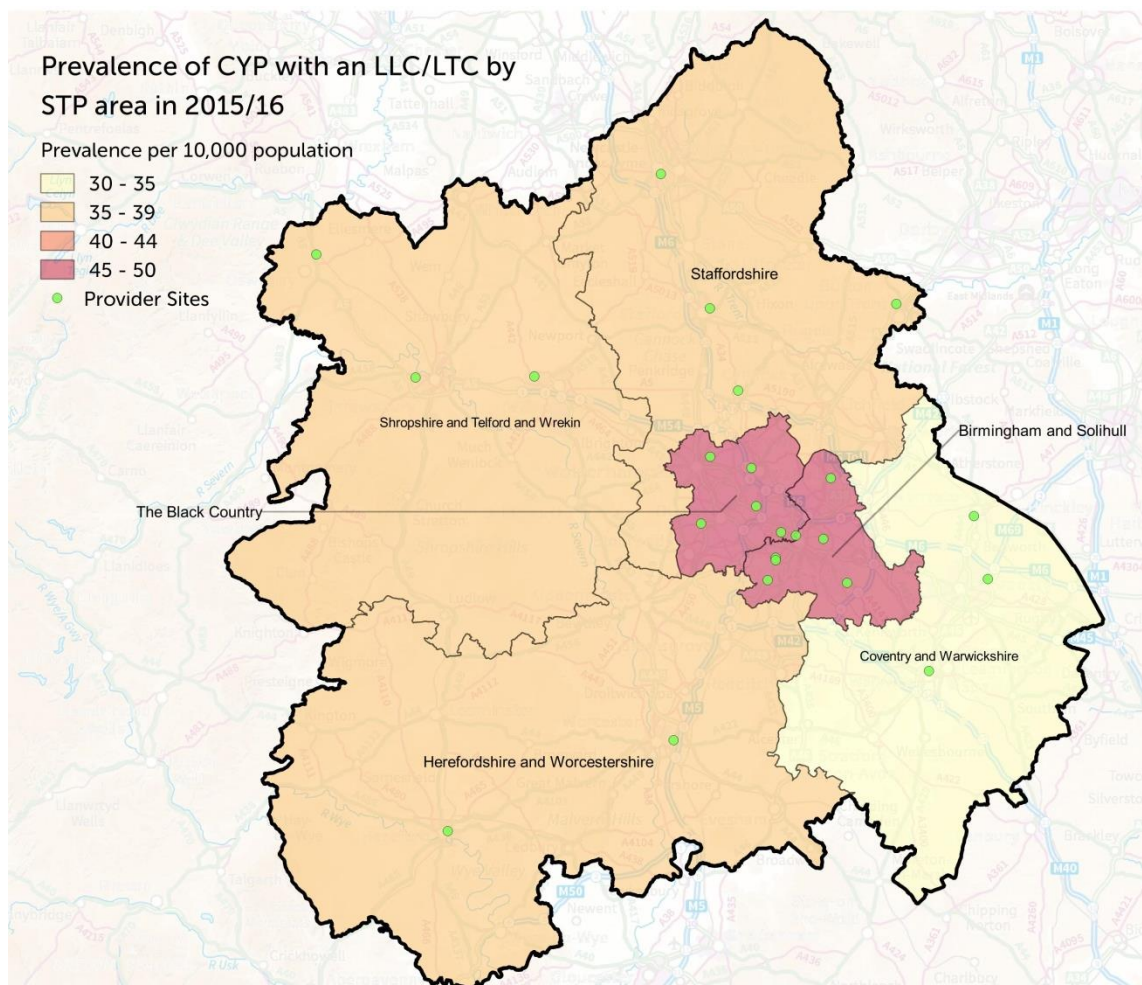
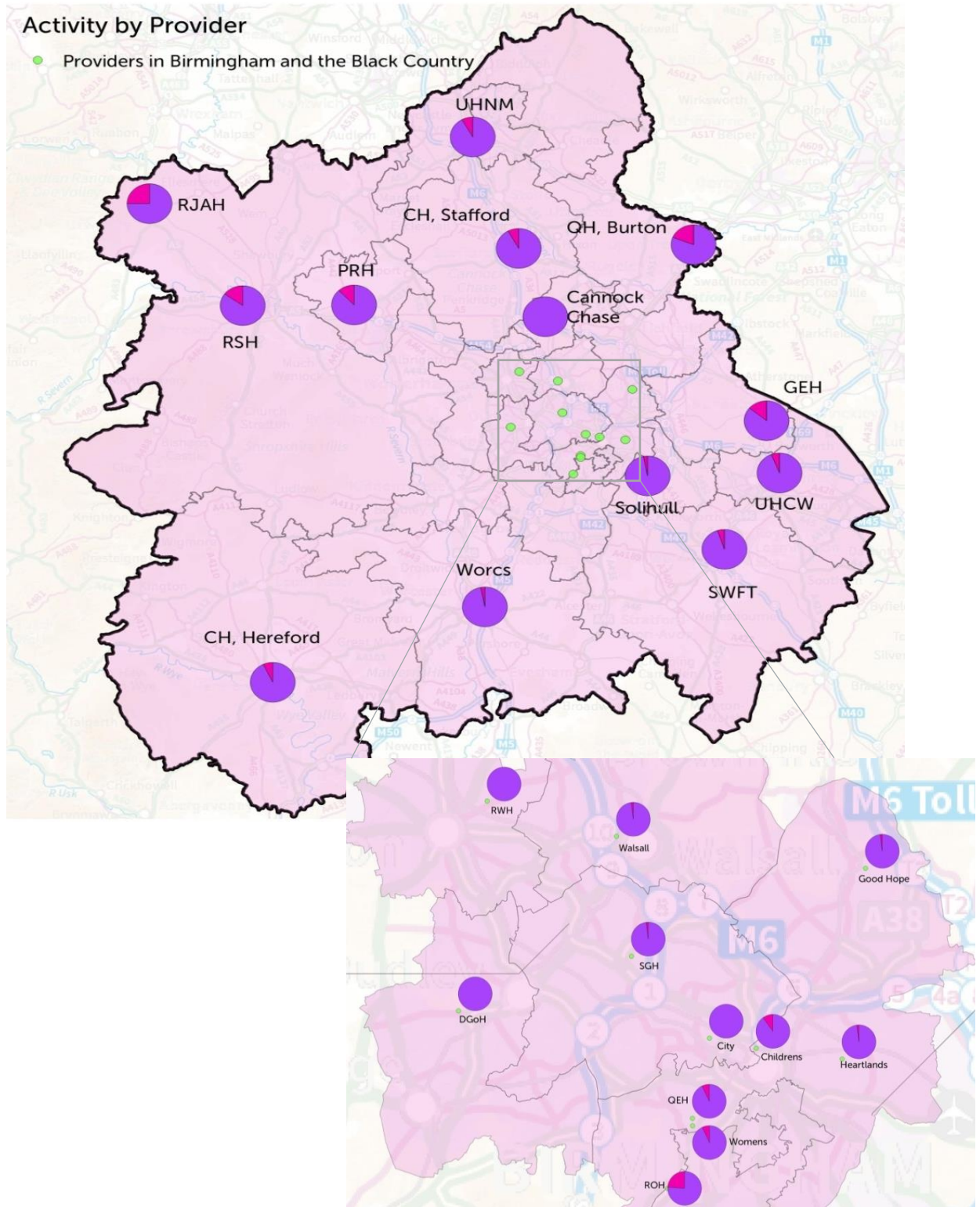


Figure 7 demonstrates in 2015/16 the STPs with the highest prevalence were Birmingham and Solihull and The Black Country, who both had between 45 and 50 CYP with an LLC per 10,000 of their population. The STP with the lowest prevalence was Coventry and Warwickshire. The remaining STPs had between 40 and 44 CYP with an LLC per 10,000 of their population (0-25 years old).

2.3.3 Acute providers

Figure 8 – Activity* of CYP with an LLC, registered inside and outside the West Midlands, by provider. Pie charts represent total activity at each provider (Pink represents patients registered outside of the West Midlands, Purple represents patients registered inside the West Midlands). *Activity is Outpatient activity only.



Whilst the main focus of the report is upon West Midlands⁶ commissioned patients, acute providers in the West Midlands also treat patients commissioned from outside the West Midlands. The pie charts in figure 8 represent the proportion commissioned within the West Midlands (purple) and outside the West Midlands (pink). Commissioning from outside the West Midlands tends to occur where providers are in closer proximity to the West Midlands border. Although certain trusts, who are more specialist (Children's, University Hospital Birmingham, Women's and Royal Orthopaedic), do see noticeable proportions from outside West Midlands.

Table 6. Percentage of Outpatient Activity for CYP with an LLC by provider

Provider Name (Map Label)	Patients registered Outside the West Midlands	Patients registered Inside the West Midlands
Birmingham Children's Hospital (Childrens)	10%	90%
Birmingham Womens Hospital (Womens)	7%	93%
Cannock Chase Hospital (Cannock Chase)	0%	100%
City Hospital (City)	0%	100%
County Hospital (CH, Stafford)	8%	92%
George Eliot Hospital (GEH)	14%	86%
Good Hope Hospital (Good Hope)	2%	98%
Heartlands Hospital (Heartlands)	2%	98%
Manor Hospital (Walsall)	2%	98%
New Cross Hospital (RWH)	0%	100%
Queen Elizabeth Hospital Birmingham (QEH)	7%	93%
Queen's Hospital Burton Upon Trent (QH, Burton)	19%	81%
Robert Jones and Agnes Hunt Orthopaedic Hospital (RJAH)	25%	75%
Royal Shrewsbury Hospital (RSH)	15%	85%
Russells Hall Hospital (DGoH)	0%	100%
Sandwell District General Hospital (SGH)	2%	98%
Solihull Hospital (Solihull)	3%	97%
The County Hospital Wye Valley NHS Trust (CH, Hereford)	7%	93%
The Princess Royal Hospital (PRH)	12%	88%
The Royal Orthopaedic Hospital (ROH)	24%	76%
University Hospital Coventry (UHCW)	6%	94%
University Hospitals of North Midlands (UHNM)	8%	92%
Warwick Hospital (SWFT)	5%	95%
Worcestershire Royal Hospital (Worcs)	3%	97%

⁶<https://www.england.nhs.uk/wp-content/uploads/2014/05/who-pays.pdf>

2.4 Demographic characteristics

Figure 9 – Hospital-based prevalence of LLCs among CYP by age group, within the West Midlands

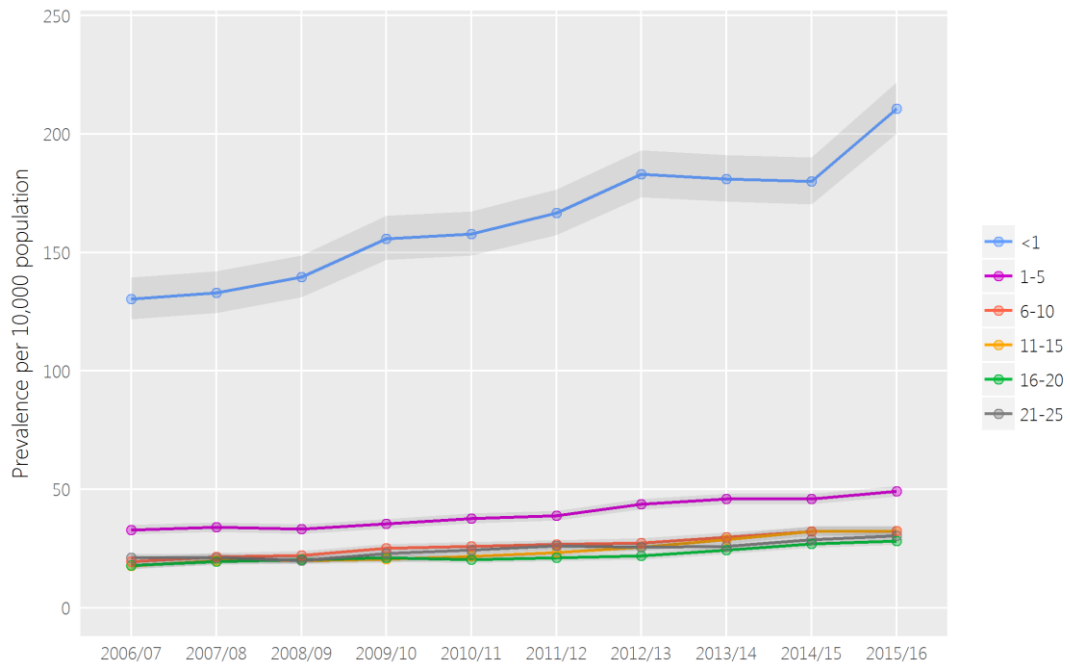


Figure 10 – Hospital-based prevalence of LLCs among CYP by gender, within the West Midlands

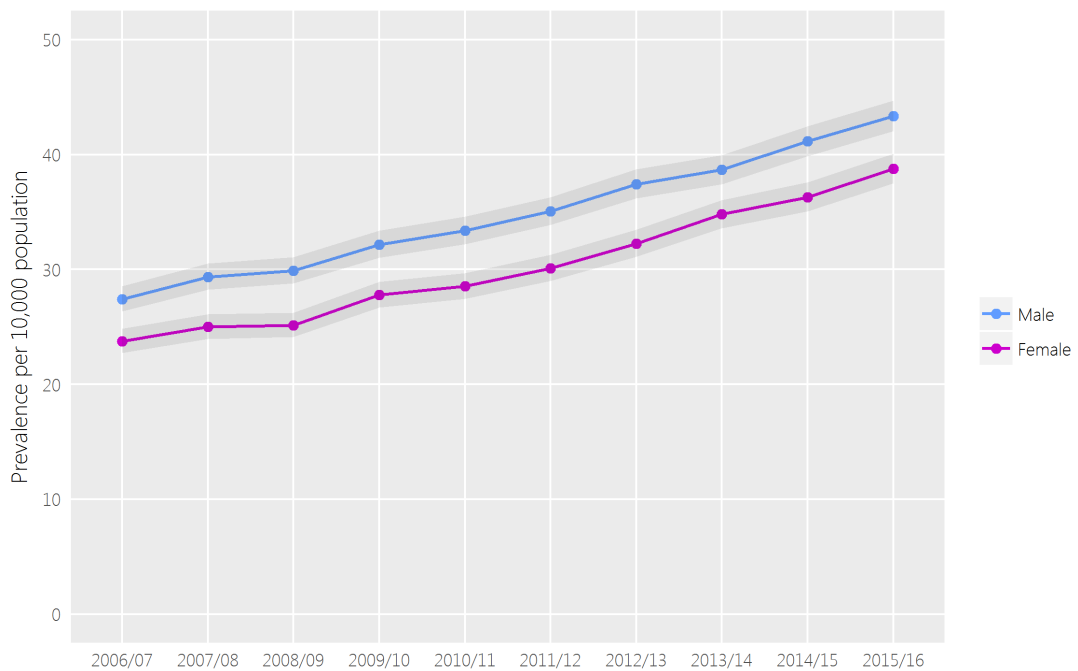


Figure 11 – Hospital-based prevalence of LLCs among CYP by ethnicity, within the West Midlands

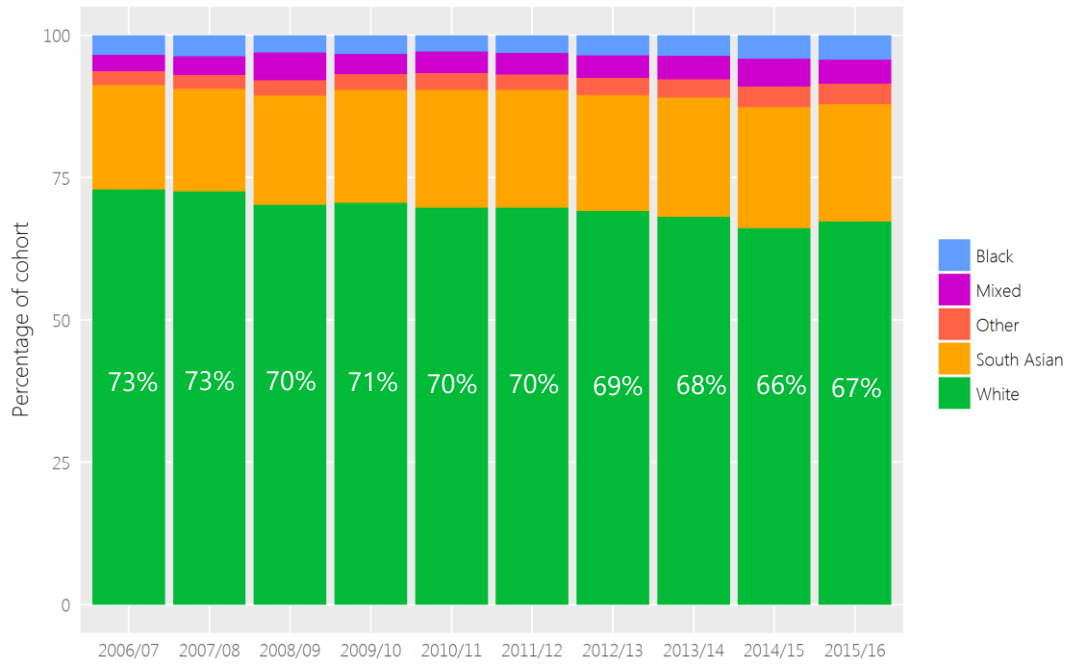
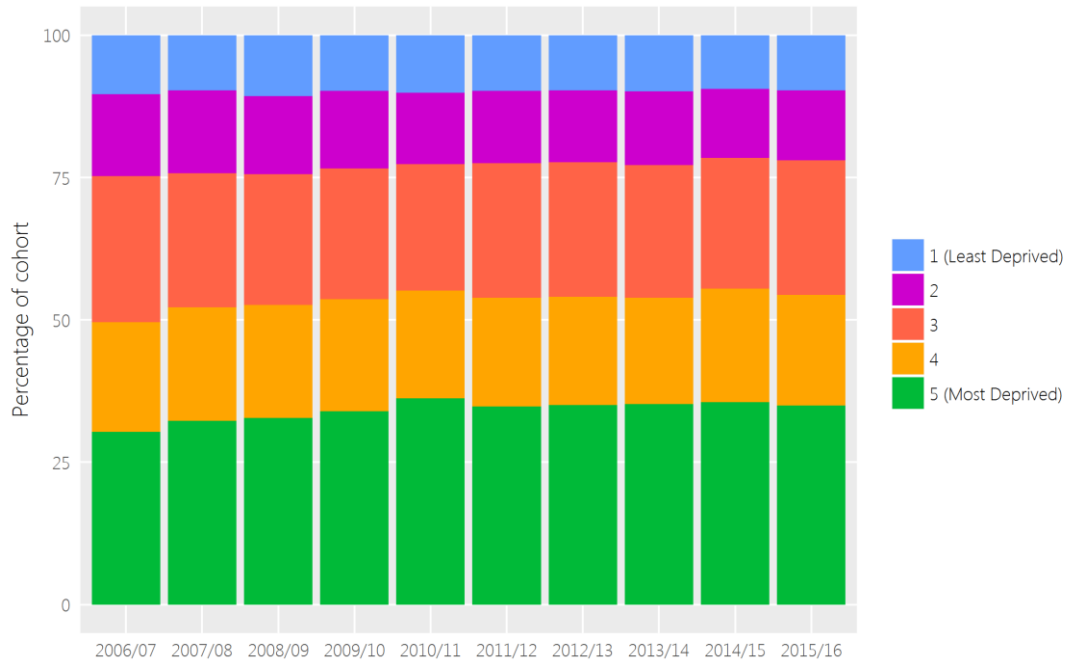


Figure 12 – Hospital-based prevalence of LLCs among CYP by index of multiple deprivation, within the West Midlands



Age

Prevalence is highest in the <1 year old age group and generally decreases with age. These very young patients are also the age group with the largest increase in prevalence (figure 9). On average an increase of 4.9% per year.

Ethnicity

The largest single ethnic group are those patients who classify themselves as 'white' (figure 11), although as a proportion this has decreased over the past decade. Corresponding increases are across the remaining ethnic categories.

Gender

Gender prevalence (figure 10) is higher for males than females in all years. Both genders show the same year on year increase over the past decade.

Deprivation

Nearly a third of patients live in the most deprived quintile (figure 12). The most deprived quintile should typically represent only 20% of the population.

Portrait of the West Midlands

Demographic characteristics of the cohort can be put into context by examining the overall population of the West Midlands. The portrait of the region produced by the Office for National Statistics⁷ says "...the West Midlands had the highest proportion of children aged under 16 of the nine English regions, 19.4 per cent compared with an England average of 18.7 per cent" and in terms of ethnic make-up "The West Midlands has the largest non-White population outside of London, according to experimental population estimates for mid-2009. According to the estimates, 14 per cent of the population of the West Midlands were classed as non-White, only second behind London at 30 per cent."

⁷<https://www.ons.gov.uk/ons/rel/regional-trends/regional-trends/regional-trends--july-2011-edition/portrait-of-the-west-midlands.pdf>

3. Acute Hospital Utilisation

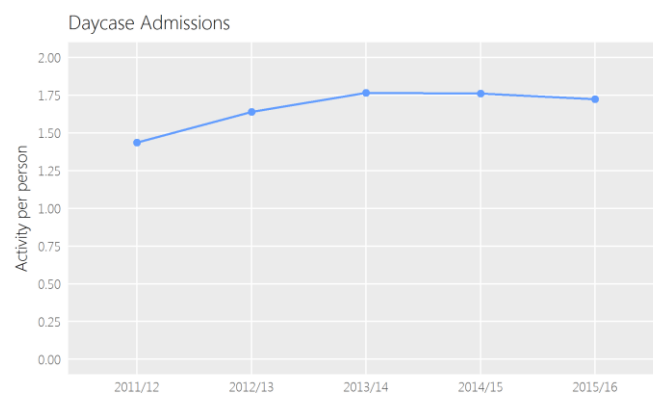
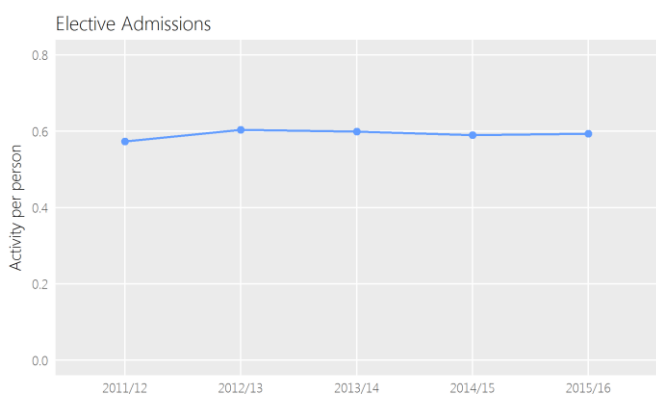
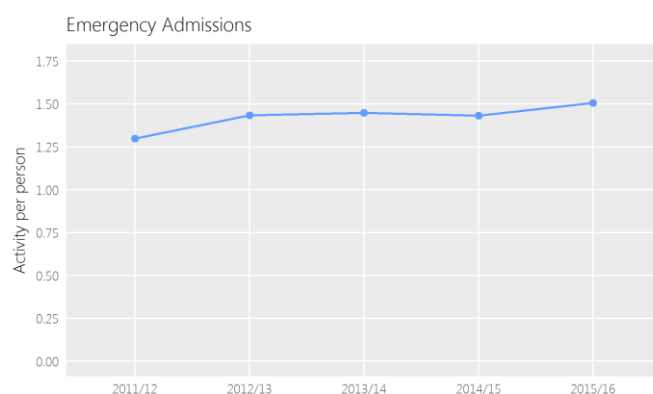
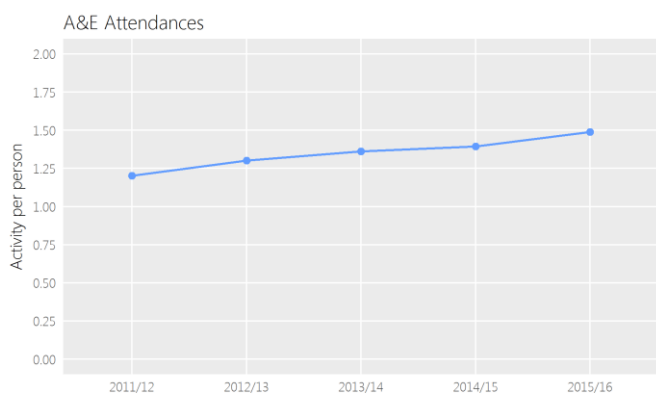
The identification of patients for the hospital-based prevalence analyses in chapter 2 is at a patient level, therefore this allows patient level linkage across other Hospital Episode Statistics (HES) datasets. Consequently, this section considers all acute hospital activity recorded for CYP with an LLC.

As prevalence has risen over the years it is likely that activity volumes will also have risen. This chapter therefore considers activity on a per person basis rather than as total volumes. This allows a more genuine comparison of activity changes between financial years.

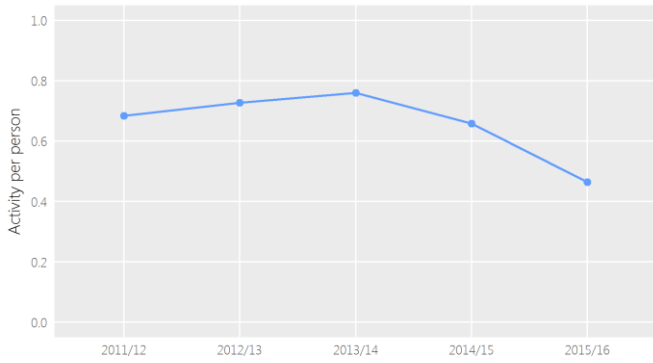
Details of the quantitative analyses in this section can be found in appendix 2.

3.1 Activity

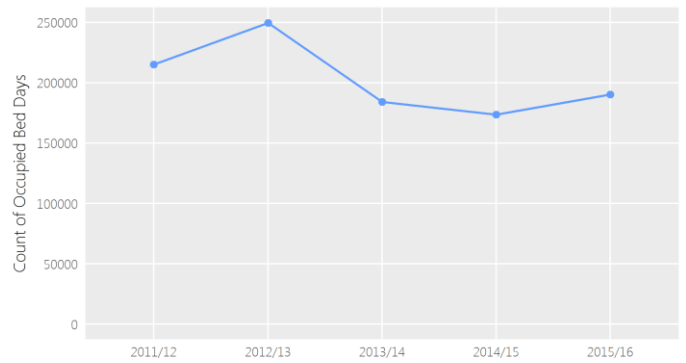
Figures 13-21 – Acute hospital activity per person for West Midlands commissioned CYP with an LLC



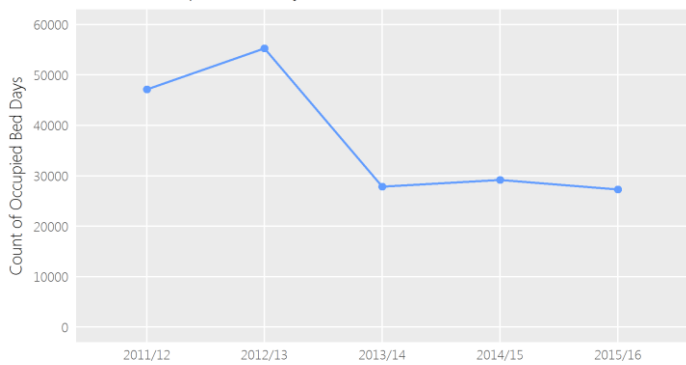
Regular Day/Night Admissions



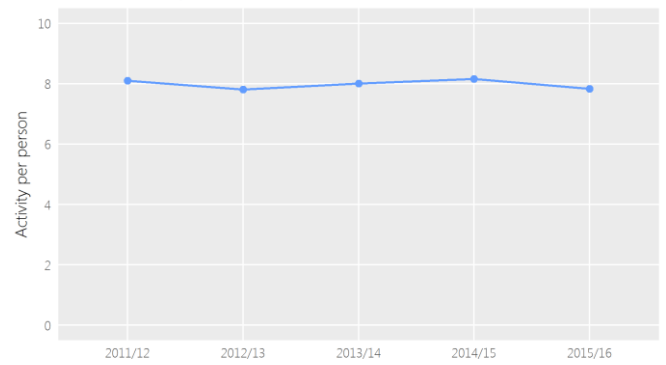
Emergency Occupied Bed Days



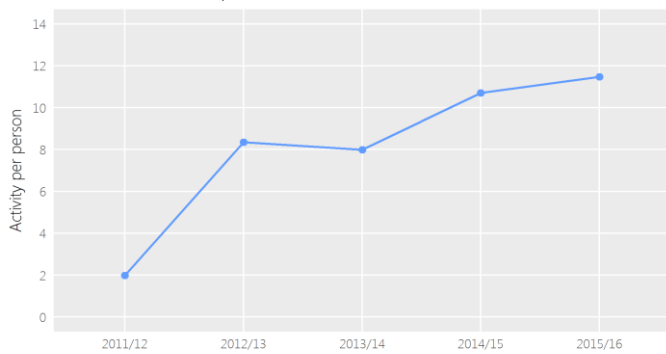
Elective Occupied Bed Days



Consultant Outpatient Attendances



Non-Consultant Outpatient Attendances

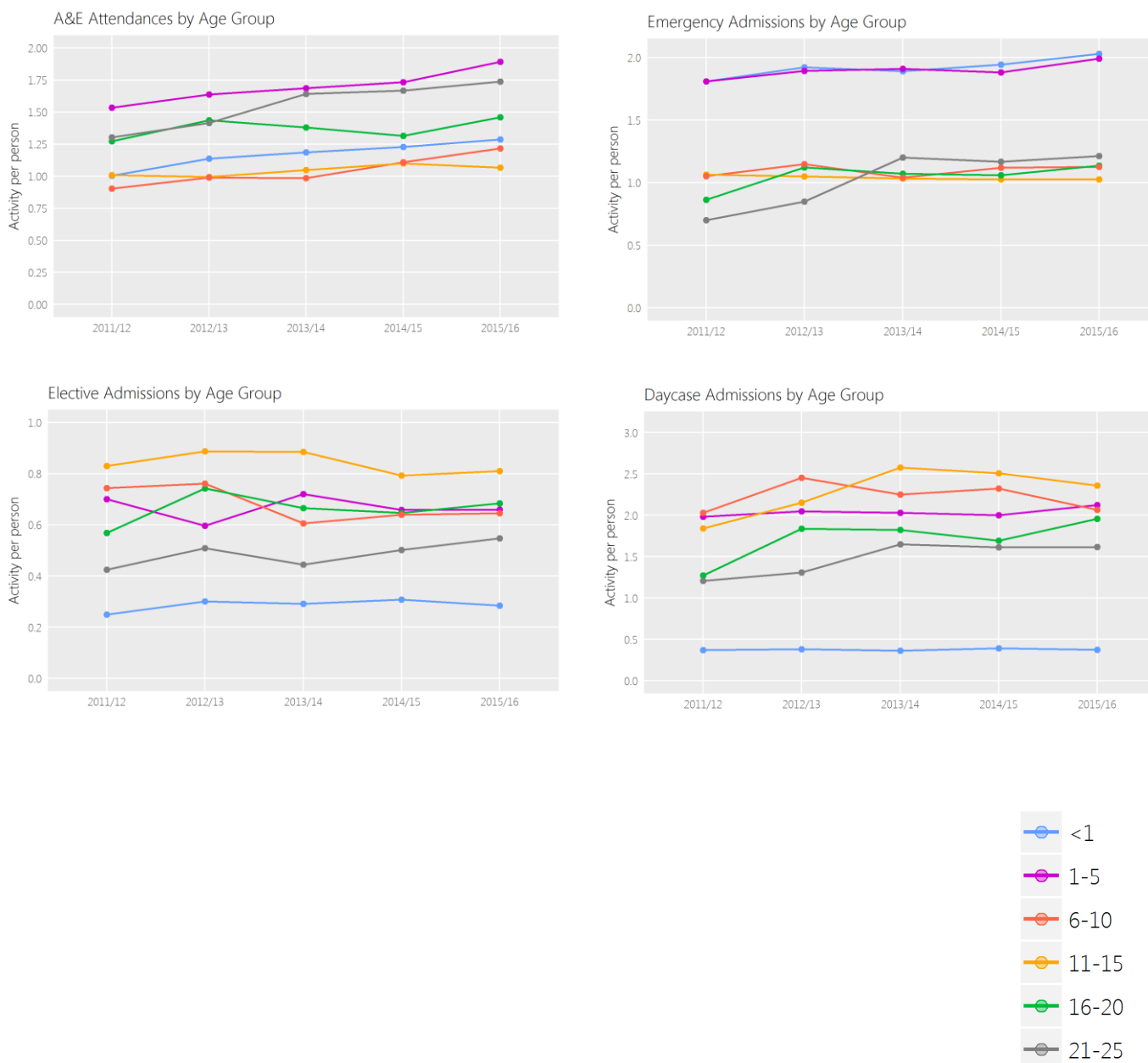


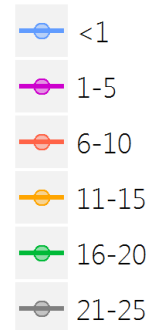
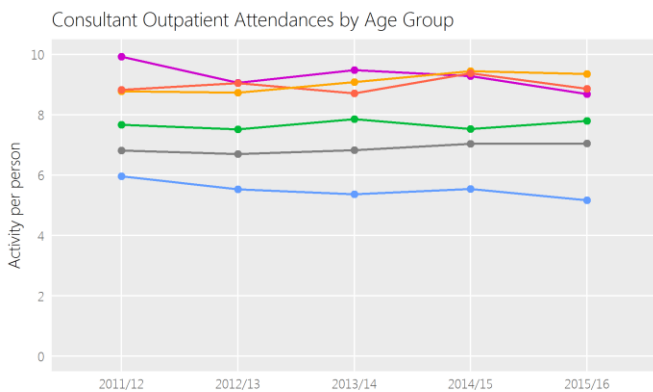
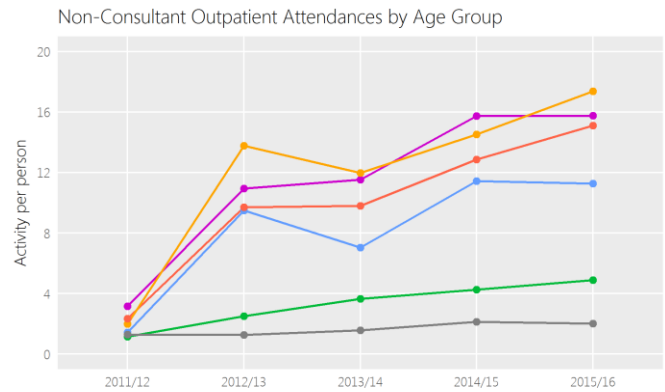
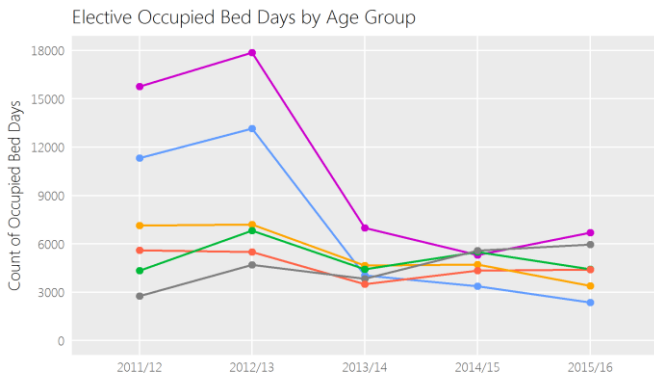
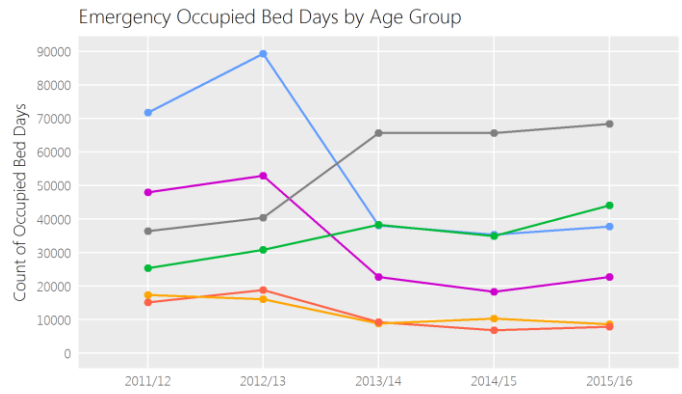
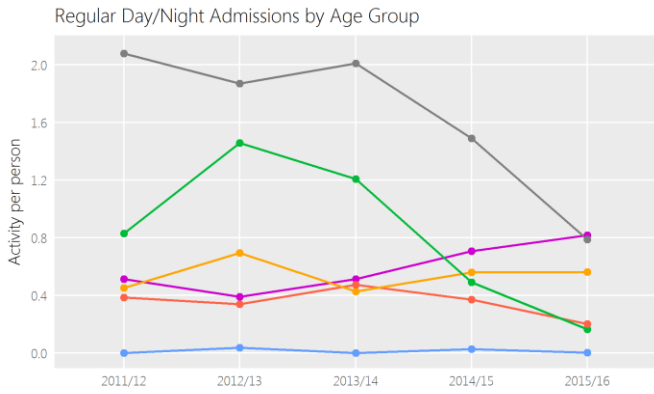
3.2 Activity characteristics

3.2.1 Age Group

The picture varies for each activity setting dependent upon age group. Generally younger patients, those under 1 year and the 1-5 age groups, tend to dominate in the unplanned areas of care – A&E attendances and emergency admissions. Older ages tend to dominate in the planned care areas such as elective and daycase admissions, outpatient appointments and regular day/night admissions.

Figures 22 - 30 – Acute hospital activity per person, for West Midlands commissioned CYP with an LLC by age group.

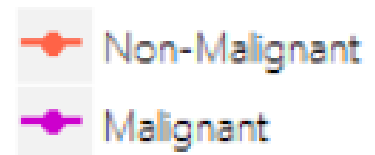
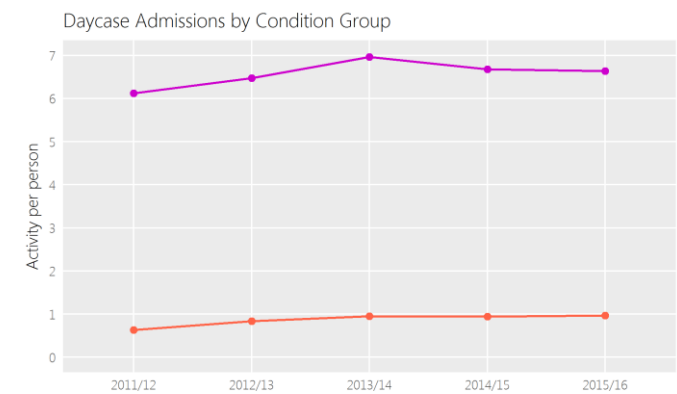
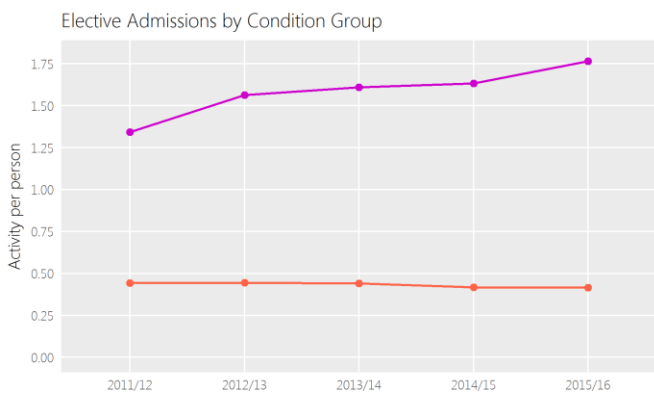
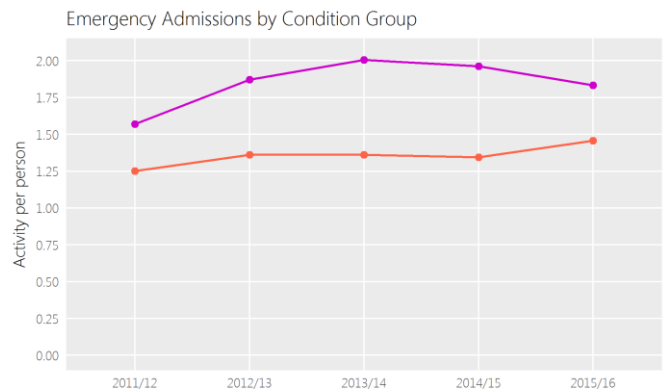
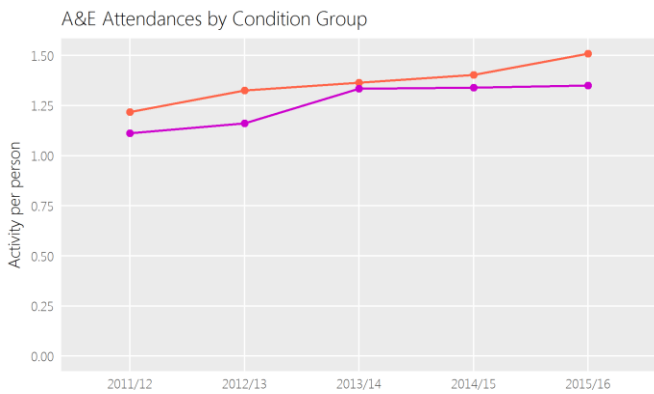




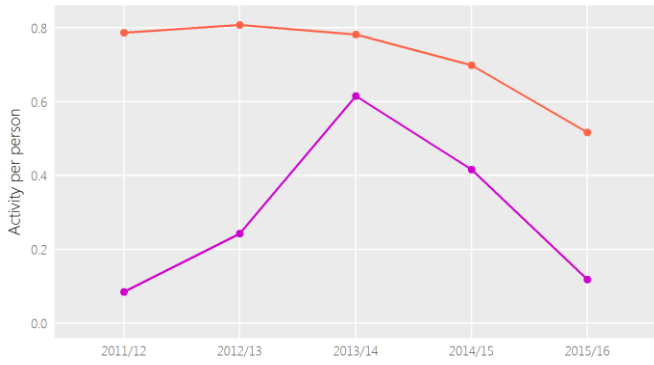
3.2.2 Condition summary groups

In the area of planned admissions (elective and daycase admissions) by far the largest volume is within malignant conditions. This is as expected perhaps, given the treatment regimens for those with a malignant condition.

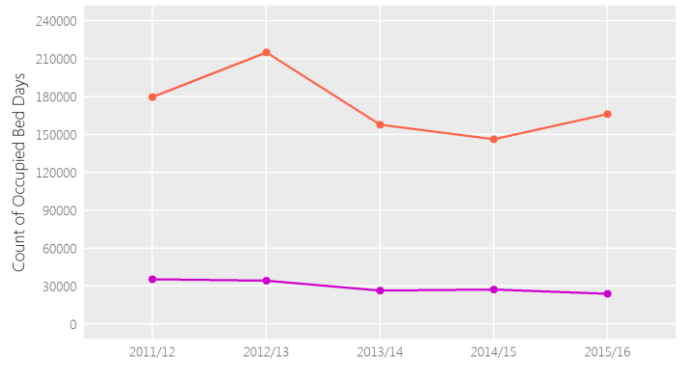
Figures 31-39 – Acute hospital activity per person for West Midlands commissioned CYP with an LLC by condition summary group



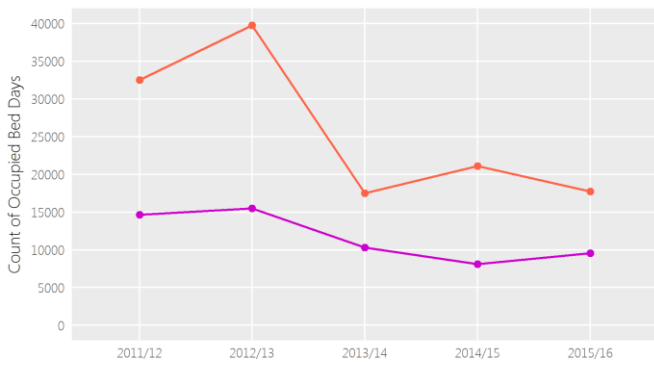
Regular Day/Night Admissions by Condition Group



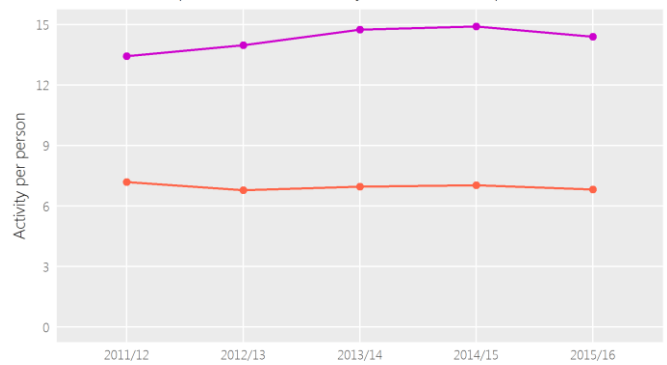
Emergency Occupied Bed Days by Condition Group



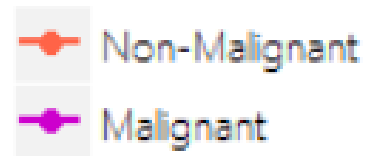
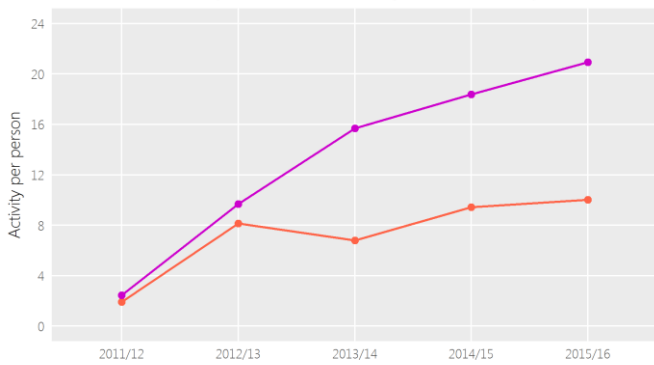
Elective Occupied Bed Days by Condition Group



Consultant Outpatient Attendances by Condition Group



Non-Consultant Outpatient Attendances by Condition Group



3.3 Costs

Fully costing acute care is not possible from national Hospital Episode Statistics (HES) datasets. The Secondary User Service (SUS) does provide fully priced patient level datasets however these are limited to the West Midlands commissioners only.

In theory this should make little difference as the scope of this report is already limited to West Midlands, however, in practice when using multiple data sources, it is likely that discrepancies will exist between them.

3.3.1 Describing NHS tariffs⁸

In brief, activity *within* scope of national rules can have a 'national tariff', a mandated price which a commissioner is required to pay, or a 'local tariff' where providers and commissioners agree a price.

Activity *outside* national rules is paid for by local arrangement (not necessarily the same as 'local tariff'). For example many drugs are outside national rules, as are some devices. Local arrangements may also include block contracts - where a fixed amount is paid per year to provide a service regardless of the actual numbers – this is often the case in areas such as patient transport.

Overall it is difficult to ascertain an accurate picture of spend across multiple providers. This section is therefore limited to costs *within* scope of national rules and uses the most accurate and readily accessible information.

⁸<https://www.gov.uk/government/publications/simple-guide-to-payment-by-results>

3.3.2 NHS tariffs across financial years

Further complications exist in that rules, prices, inclusions and exclusions change between financial years, which make comparison across years a difficult exercise. Reasons for changes can either be due to;

i) Policy⁹;

"The role of the payment system as a tool for effecting change rests on the power of payment approaches and price signals to influence behaviour"

ii) Long term strategy;

"The main function of prices in the payment system is to provide signals to guide the decisions of providers and commissioners"

Or iii) Other adjustments for changes in costs which providers have little control over such as improvements in efficiency, inflation, changes in cost of the Clinical Negligence Scheme for Trusts (CNST) and changes in capital costs (i.e. changes associated with depreciation and PFI payments).

⁹<https://www.gov.uk/government/publications/national-tariff-payment-system-2014-to-2015>

3.3.4 Costs

Figures 40-46 – Acute hospital activity costs within scope for West Midlands commissioned CYP with an LLC



3.3.5 Financial Summaries

Clinical commissioning groups

Table 7 – Acute hospital activity costs within scope, by clinical commissioning group, for West Midlands commissioned CYP with an LLC in 2015/16

	<i>Emergency care</i>		<i>Planned inpatient care</i>		<i>Outpatient care</i>		<i>Regular day/night</i>	
	total	avg. per activity	total	avg. per activity	total	avg. per activity	total	avg. per activity
BIRMINGHAM SOUTH AND CENTRAL	£2,179,333	£1,197	£1,625,647	£1,890	£712,540	£141	£30,282	£704
CANNOCK CHASE	£501,047	£1,576	£323,934	£1,543	£161,362	£137	£0	-
COVENTRY AND RUGBY	£2,184,896	£1,160	£2,364,048	£2,207	£672,779	£140	£29,601	£722
DUDLEY	£1,605,149	£1,340	£1,333,385	£1,916	£625,340	£130	£39,590	£720
EAST STAFFORDSHIRE	£611,338	£1,393	£517,903	£2,000	£166,493	£143	£1,651	£550
HEREFORDSHIRE	£683,926	£1,305	£698,963	£2,774	£218,329	£116	£2,781	£309
NORTH STAFFORDSHIRE	£1,056,120	£1,565	£1,032,893	£2,188	£229,461	£132	£167,661	£702
WARWICKSHIRE NORTH	£882,886	£1,101	£514,333	£1,948	£269,326	£143	£16,043	£594
REDDITCH AND BROMSGROVE	£577,800	£1,290	£633,644	£2,674	£219,555	£143	£137,567	£720
SANDWELL & WEST BIRMINGHAM	£3,555,303	£1,298	£3,303,563	£1,837	£1,426,429	£141	£407,189	£717
SHROPSHIRE	£984,486	£1,494	£1,098,566	£2,746	£419,396	£154	£155,480	£707
SOLIHULL	£897,522	£1,116	£1,141,134	£2,220	£371,059	£122	£0	-
SE STAFFS & SEISDON PEN.	£749,521	£1,177	£643,783	£1,850	£265,929	£132	£0	-
SOUTH WARWICKSHIRE	£816,310	£1,235	£1,323,440	£2,746	£292,540	£144	£14,970	£680
SOUTH WORCESTERSHIRE	£945,524	£1,261	£1,079,845	£2,686	£337,456	£143	£121,470	£741
STAFFORD AND SURROUNDS	£666,618	£1,642	£564,181	£2,008	£157,932	£130	£0	-
STOKE ON TRENT	£1,688,049	£1,628	£1,679,294	£1,813	£369,166	£136	£2,231	£446
TELFORD AND WREKIN	£838,572	£1,364	£815,111	£2,008	£367,933	£156	£115,632	£714
WALSALL	£1,429,195	£1,520	£1,390,161	£2,679	£568,524	£151	£35,123	£639
WOLVERHAMPTON	£1,876,981	£1,487	£1,503,667	£1,573	£496,464	£137	£0	-
WYRE FOREST	£439,100	£1,861	£315,614	£1,960	£136,700	£148	£722	£722
BIRMINGHAM CROSSCITY	£4,922,974	£1,266	£4,396,818	£2,040	£1,680,237	£136	£406,301	£722
All West Midlands commissioners	£30,092,650	-	£28,299,927	-	£10,164,950	-	£1,684,294	-

Total spend for all types of activity: £70,241,821

Sustainability and Transformation Partnerships

Table 8 – Acute hospital activity costs within scope, by sustainability and transformation partnership area, for West Midlands commissioned CYP with an LLC in 2015/16

	<i>Emergency care</i>		<i>Planned inpatient care</i>		<i>Outpatient care</i>		<i>Regular day/night</i>	
	total	avg. per activity	total	avg. per activity	total	avg. per activity	total	avg. per activity
Birmingham and Solihull	£7,999,829	£1,228	£7,163,599	£2,030	£2,763,836	£135	£436,583	£704
Coventry and Warwickshire	£3,884,092	£1,160	£4,201,821	£2,313	£1,234,645	£142	£60,614	-
Herefordshire and Worcestershire	£2,646,350	£1,352	£2,728,066	£2,593	£912,040	£136	£262,540	£722
Shropshire and Telford and Wrekin	£1,823,058	£1,431	£1,913,677	£2,374	£787,329	£155	£271,112	£720
Staffordshire	£5,272,693	£1,501	£4,761,988	£1,908	£1,350,343	£135	£171,543	£550
The Black Country	£8,466,628	£1,379	£7,530,776	£1,897	£3,116,757	£139	£481,902	£309
All West Midlands commissioners	£30,092,650	-	£28,299,927	-	£10,164,950	-	£1,684,294	-

Total spend for all types of activity: £70,241,821

Providers

The majority of the West Midlands commissioned patients will have activity taking place at providers in the West Midlands. Table n shows the costs for West Midlands commissioned patients within relevant providers.

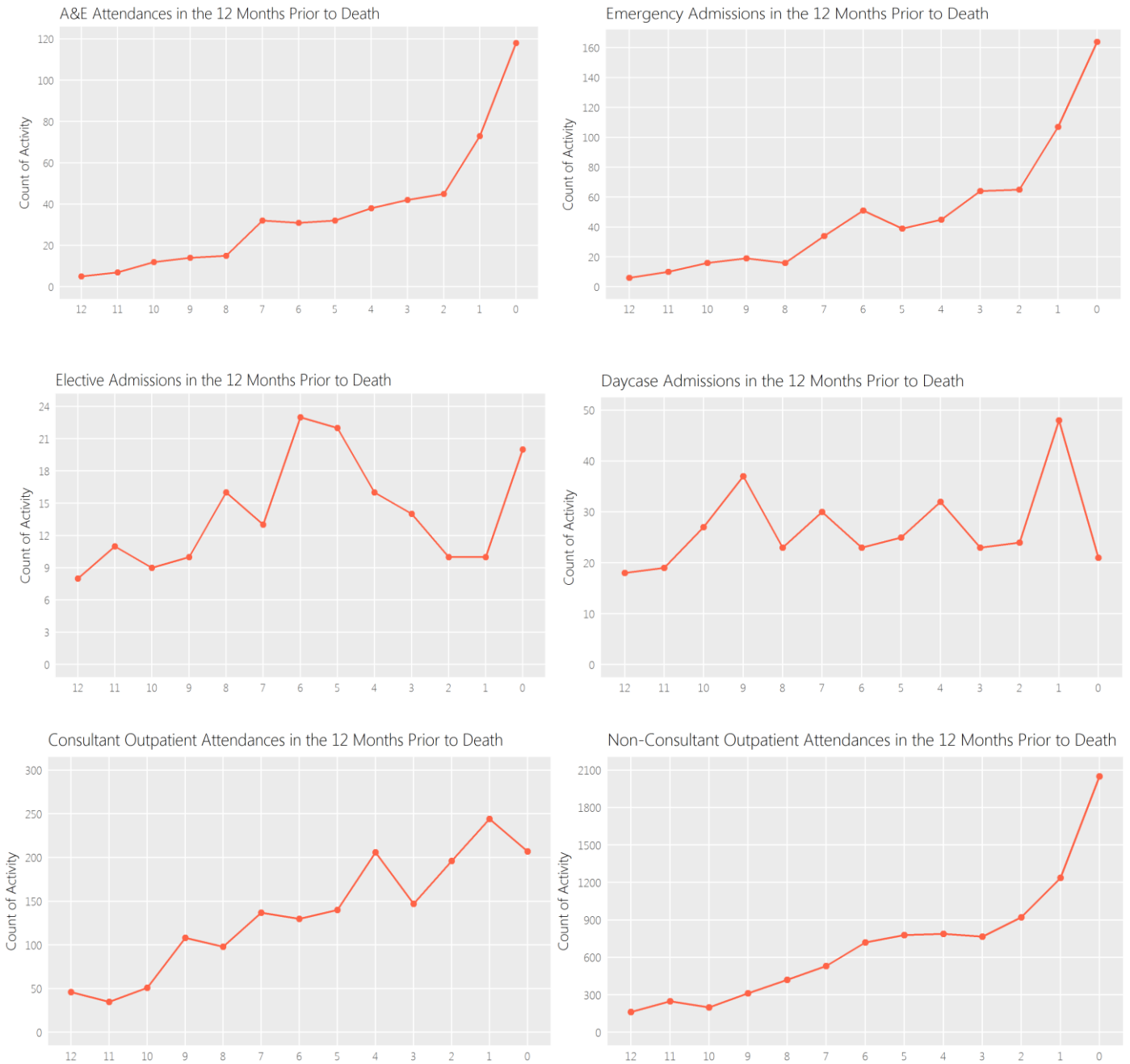
Table 9 – Acute hospital activity costs within scope, by provider, for CYP with an LLC in 2015/16

	<i>Emergency care</i>		<i>Planned inpatient care</i>		<i>Outpatient care</i>		<i>Regular day/night</i>		
	total	avg. per activity	total	avg. per activity	total	avg. per activity	total	avg. per activity	
BIRMINGHAM WOMEN'S AND CHILDREN'S	£13,859,328	£2,131	£16,784,820	£2,791	£5,260,453	£152	£1,637,469	£725	
UNIVERSITY HOSPITALS OF NORTH MIDLANDS	£2,739,228	£1,326	£2,039,847	£1,494	£524,946	£125	£8,173	£409	
UNIVERSITY HOSPITALS BIRMINGHAM	£1,540,619	£1,531	£1,842,670	£1,064	£716,653	£123	£12,787	£412	
UNIVERSITY HOSPITALS COVENTRY & WARWICKSHIRE	£1,388,809	£732	£795,389	£1,076	£447,191	£133	£0	-	
HEART OF ENGLAND	£1,608,301	£684	£395,207	£800	£404,707	£102	£0	-	
THE ROYAL WOLVERHAMPTON	£1,353,881	£955	£532,575	£847	£317,127	£115	£0	-	
SANDWELL AND WEST BIRMINGHAM HOSPITALS	£929,175	£742	£381,679	£682	£564,426	£126	£0	-	
THE ROYAL ORTHOPAEDIC HOSPITAL	£46,189	£3,849	£1,843,790	£4,116	£97,482	£105	£0	-	
SHREWSBURY AND TELFORD HOSPITAL	£1,005,298	£945	£482,904	£1,626	£392,707	£155	£0	-	
WORCESTERSHIRE ACUTE HOSPITALS	£908,635	£775	£115,105	£1,096	£183,418	£129	£0	-	
THE DUDLEY GROUP	£768,287	£737	£139,989	£833	£231,674	£96	£0	-	
WALSALL HEALTHCARE	£439,478	£779	£54,844	£1,055	£160,000	£159	£404	£404	
WYE VALLEY	£374,001	£787	£108,773	£1,066	£101,096	£94	£2,781	£309	
ROBERT JONES & AGNES HUNT ORTHOPAEDIC HOSPITAL	£3,780	£1,890	£244,773	£2,205	£203,833	£235	£10,484	£499	
SOUTH WARWICKSHIRE	£336,338	£749	£38,992	£1,300	£69,456	£116	£0	-	
BURTON HOSPITALS	£322,215	£663	£31,989	£744	£51,444	£108	£0	-	
GEORGE ELIOT HOSPITAL	£131,648	£320	£3,363	£561	£49,717	£145	£12,196	£469	
BIRMINGHAM WOMEN'S	£9,678	£1,075	£6,848	£978	£88,201	£154	£0	-	
All West Midlands providers	£27,764,888		£25,843,557		£9,864,531		£1,684,294		
Total spend for all types of activity:								£65,157,270	

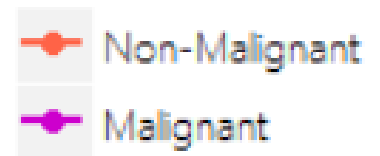
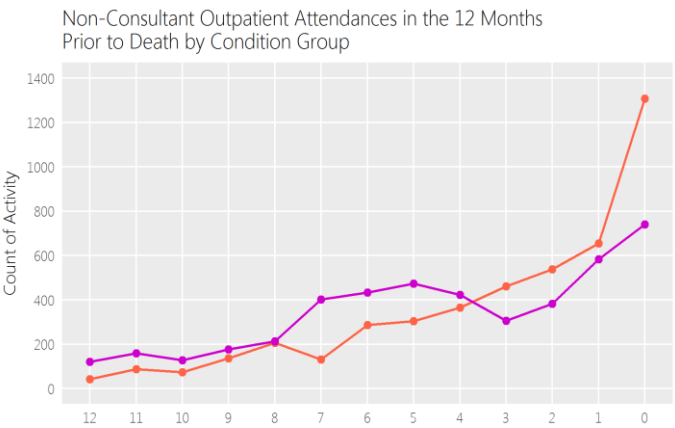
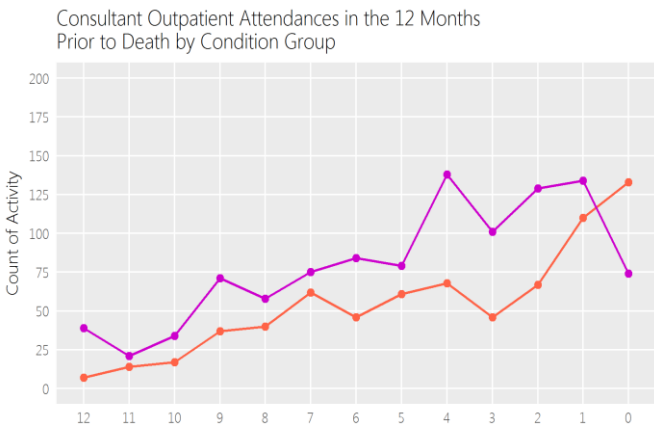
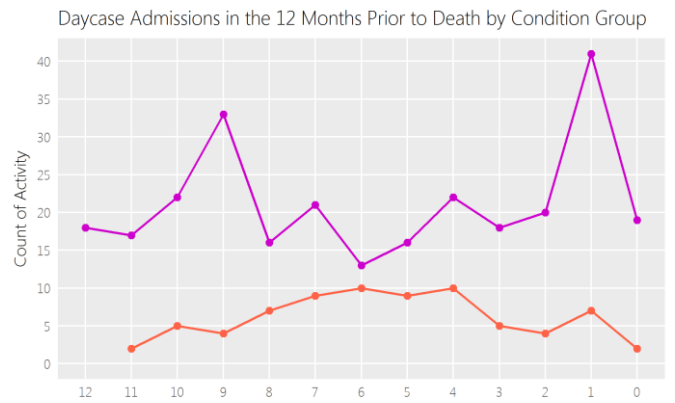
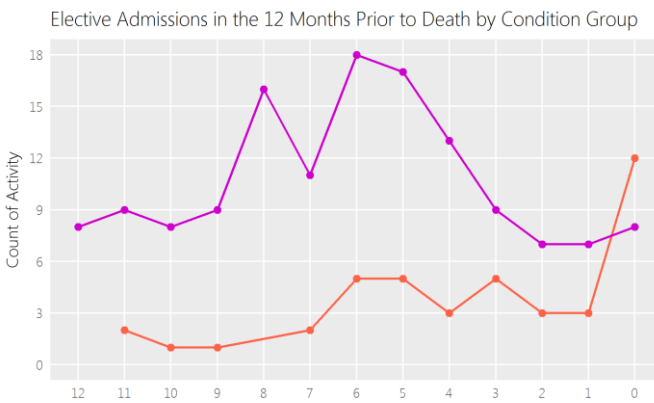
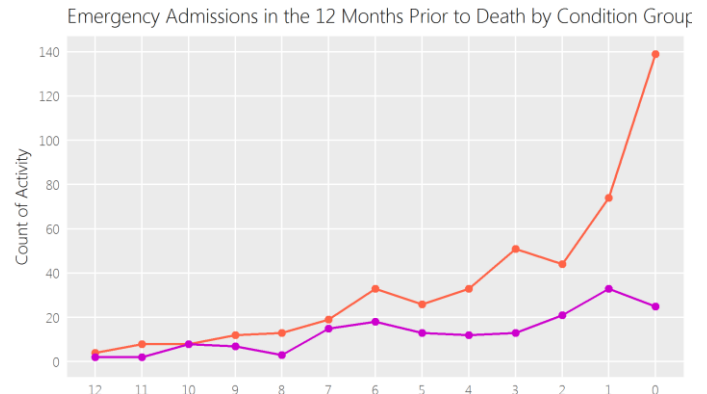
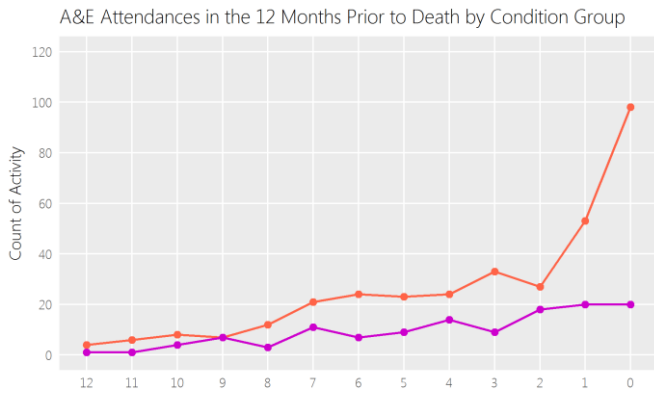
3.4 Activity prior to death

The association between acute healthcare utilisation and proximity to death can be explored by linking Hospital Episode Statistics (HES) to data on death registrations.

Figures 47-52 – Acute hospital activity per person for West Midlands commissioned CYP with an LLC who died in 2015/16

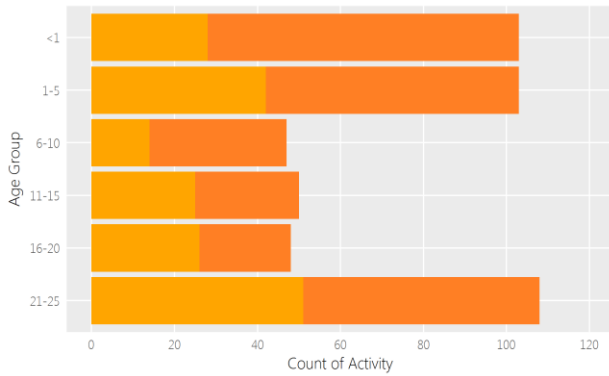


Figures 53-58 - Acute hospital activity per person for West Midlands commissioned CYP with an LLC who died in 2015/16 by condition group

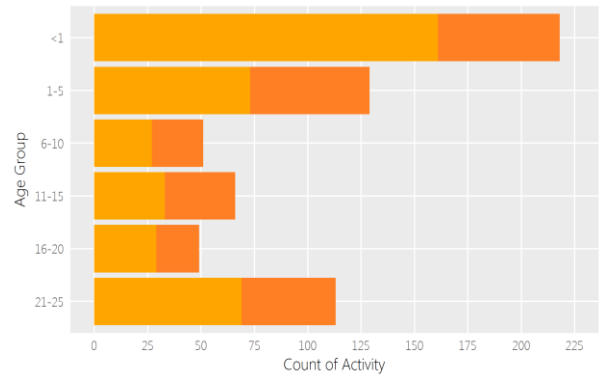


Figures 59-64 – Acute hospital activity for West Midlands commissioned CYP with an LLC who died in 2015/16 by age group

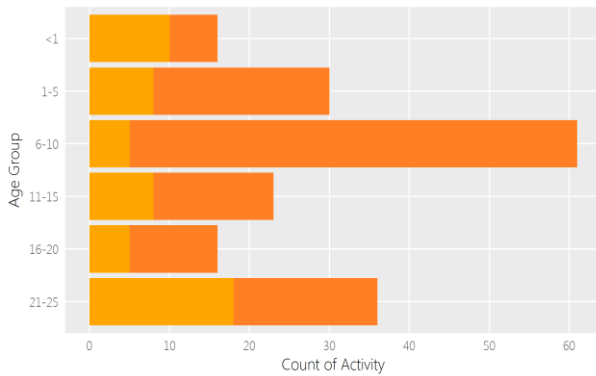
A&E Attendances Prior to Death by Age Group



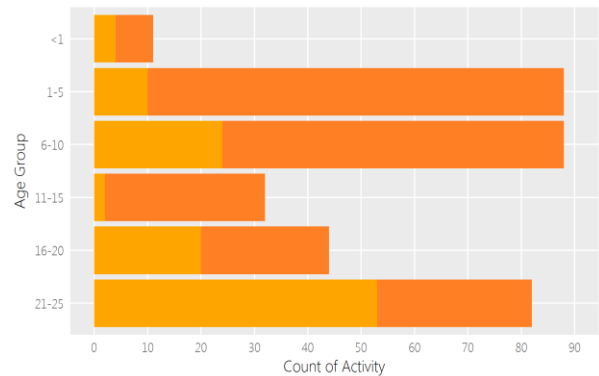
Emergency Admissions Prior to Death by Age Group



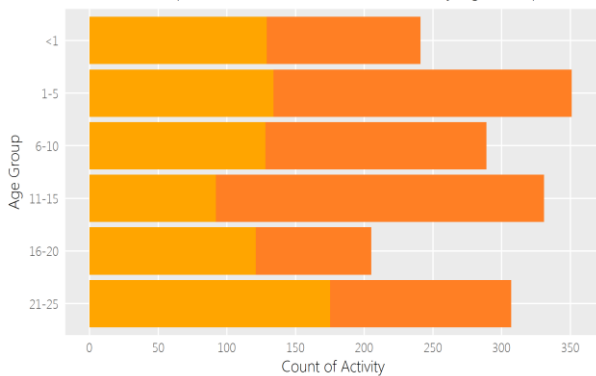
Elective Admissions Prior to Death by Age Group



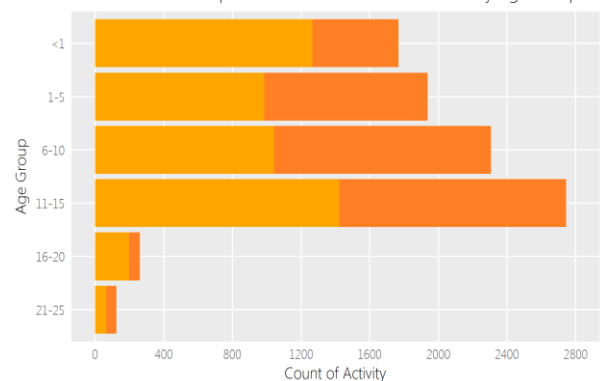
Daycase Admissions Prior to Death by Age Group



Consultant Outpatient Attendances Prior to Death by Age Group



Non-Consultant Outpatient Attendances Prior to Death by Age Group



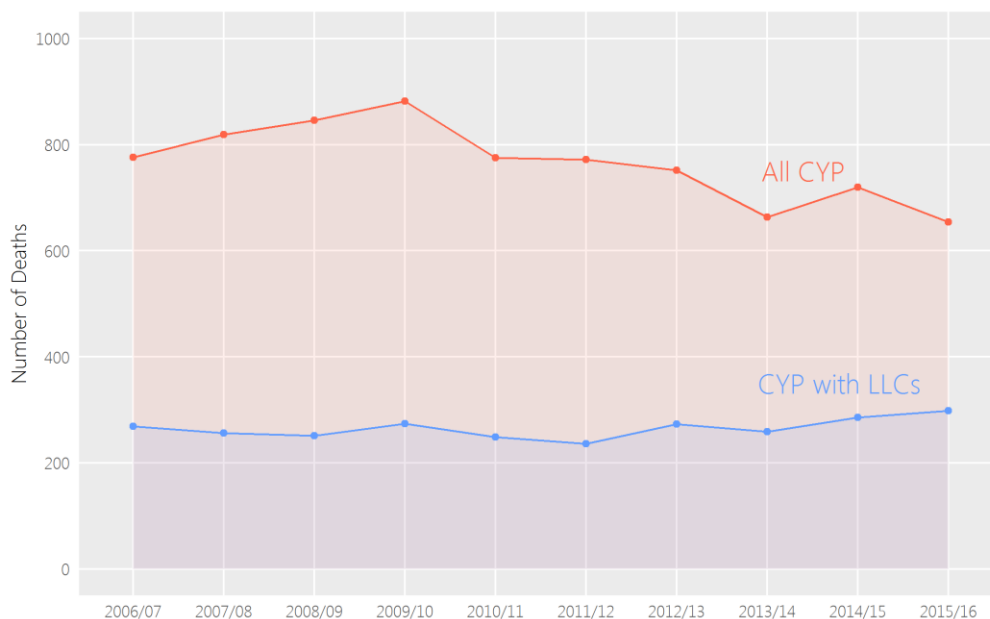
Proximity to Death
 0-3 months
 4-12 months

4. Historical and Forecasted Deaths

4.1 Trends and forecasts

4.1.1 Trends

Figure 65 – Number of deaths among CYP and CYP with LLCs in the West Midlands

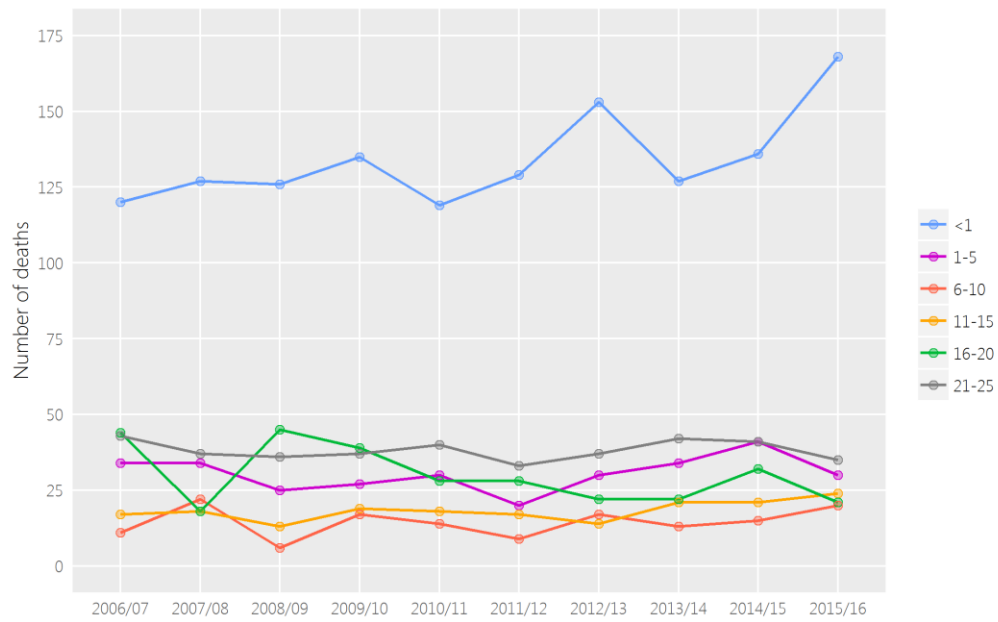


Numbers of deaths for *all* CYP in the West Midlands have been declining since 2009/10, except in 2014/15, where there was an increase on the previous year (figure 65).

Numbers of deaths for the CYP living with a LLC /LTC has been relatively stable, with a slight increase from 269 to 298 between 2006/7 and 2015/6. Deaths of CYP with an LLC have represented between 31% and 46% of all deaths in CYP in the West Midlands in the last decade. More recently deaths of CYP with an LLC represent a greater proportion of all deaths in CYP.

.1.2 Age group

Figure 66 – Number of deaths, by age group, among CYP with LLC in the West Midlands



Although number of deaths for CYP living with a LLC or LTC has been relatively stable a breakdown by age group indicates that numbers have increased in those under 1 year old.

4.2 Forecast

Forecasted death figures for *all* CYP (using the ONS 2014-based Subnational Population Projections which forecast deaths by single year of age, gender, and local authority) shows decreasing numbers of deaths for the upcoming decade.

Figure 67 – Number of deaths among CYP in the West Midlands

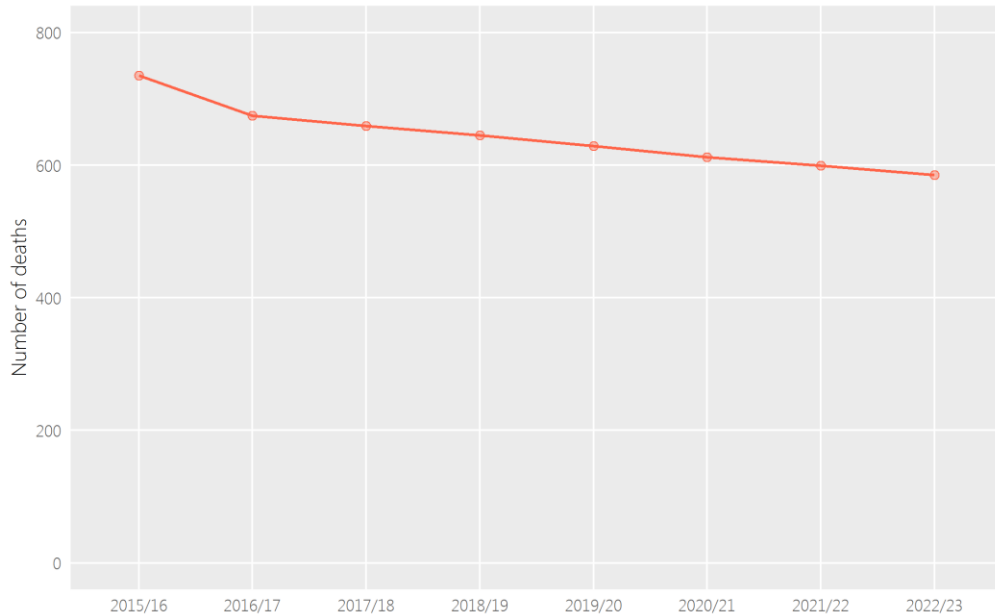


Figure 68 – Number of deaths, by age group, among CYP in the West Midlands by age group

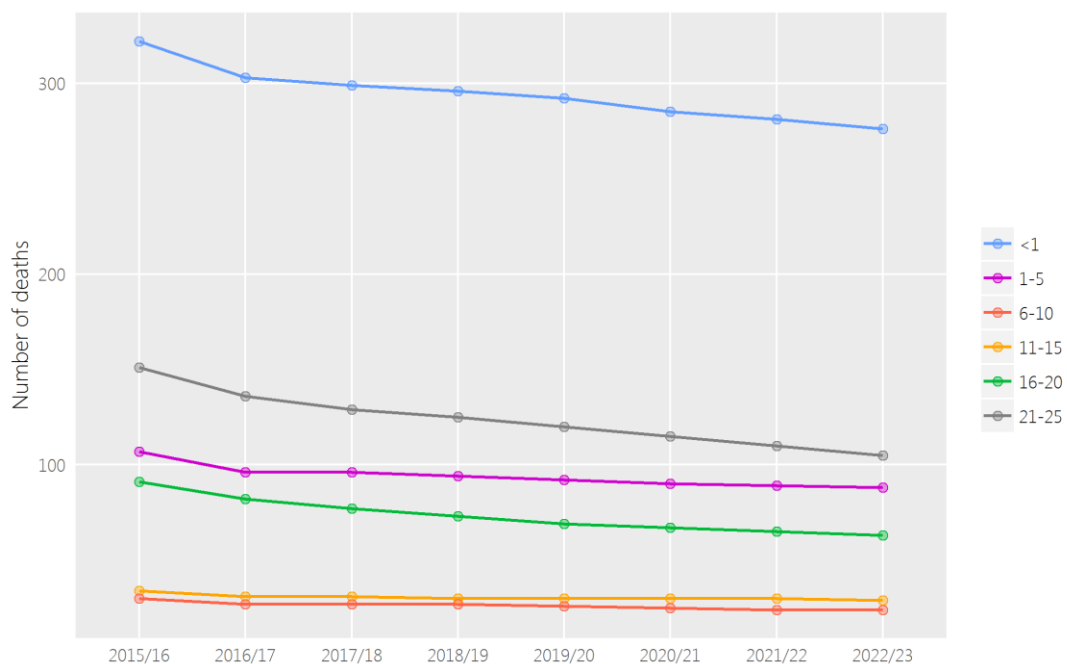
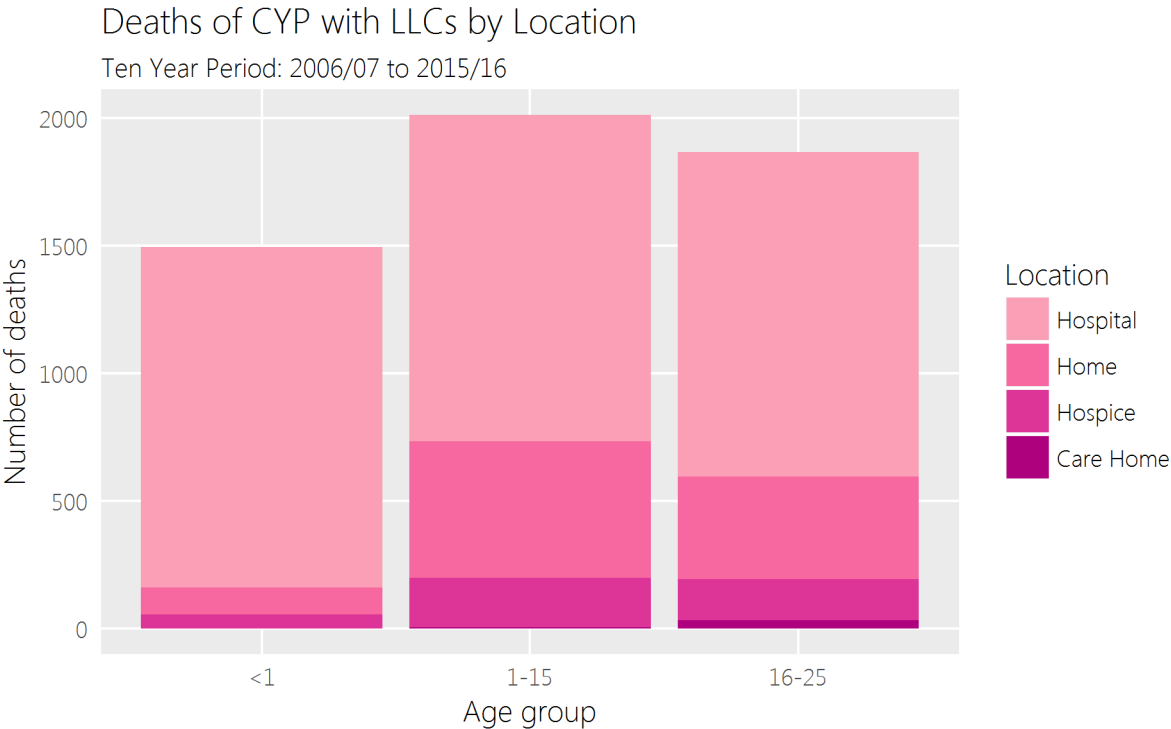


Figure 69 – Deaths of CYP with LLCs by location of deaths for the entire 10 year period.



Appendices

Appendix 1:

List of diagnosis codes taken from ChiSP Study¹⁰

NEUROLOGY	HAEMATOLOGY	ONCOLOGY	METABOLIC	RESPIRATORY	CIRCULATORY	GASTROINTESTINAL	GENITOURINARY	PERINATAL	CONGENITAL	OTHER	
A17	B20-B24	C00-C97	E31.0	E84	I21	K55.0	N17	P10.1	Q00.0	Q44.2	H11.1
A81.0	D56.1	D33	E34.8	J84.1	I27.0	K55.9	N18	P11.2	Q01	Q44.7	H49.8
A81.1	D61.0	D43	E70.2	J96	I42	K72	N19	P21.0	Q03.1	Q60.1	H35.5
F84.2	D61.9	D44.4	E71	J98.4	I61.3	K74	N25.8	P28.5	Q03.9	Q60.6	M31.3
G10	D70	D48	E72		I81	K76.5		P29.0	Q04.0	Q61.4	M32.1
G11.1	D76.1		E74			K86.8		P29.3	Q04.2	Q61.9	M89.5
G11.3	D81		E75					P35.0	Q04.3	Q64.2	T86.0
G12	D82.1		E76					P35.1	Q04.4	Q74.3	T86.2
Q20	D83		E77					P35.8	Q04.6	Q75.0	Z51.5
Q23.0	D89.1		E79.1					P37.1	Q04.9	Q77.2	
Q23.8			E83.0					P52.4	Q07.0	Q77.3	
G31.8			E88.0					P52.5	Q20.0	Q77.4	
G31.9			E88.1					P52.9	Q20.3	Q78.0	
G35								P83.2	Q20.4	Q78.5	
G40.4								P91.2	Q20.6	Q79.2	
G40.5								P91.6	Q20.8	Q79.3	
G60.0								P96.0	Q21.3	Q80.4	
G60.1									Q23.2	Q81	
G70.2									Q21.8	Q82.1	
G70.9									Q22.0	Q82.4	
G71.0									Q22.1	Q85.8	
G71.1									Q22.4	Q86.0	
G71.2									Q22.5	Q87.0	
G71.3									Q22.6	Q87.1	
G80.0									Q23.0	Q87.2	
G80.8									Q23.4	Q87.8	
G82.3									Q23.9	Q91	
G82.4									Q25.4	Q92.0	
G82.5									Q25.6	Q92.1	
G93.4									Q26.2	Q92.4	
G93.6									Q26.4	Q92.7	
G93.7									Q26.8	Q92.8	
									Q28.2	Q93.2	
									Q32.1	Q93.3	
									Q33.6	Q93.4	
									Q39.6	Q93.5	
									Q41.0	Q93.8	
									Q41.9	Q95.2	
									Q43.7		

¹⁰ Fraser, L.K., Jarvis, S.W., Moran, N.E., Aldridge, J., Parslow, R.C. & Beresford, B.A. (2015) *Children in Scotland Requiring Palliative Care: identifying numbers and needs (The ChiSP Study)*. University of York.

Appendix 2

Method

Defining the cohort

HES Inpatient tables were queried for each financial year from 2006/07 to 2015/16. A previously developed list of ICD-10 codes¹¹ was used to identify patients with a life-limiting condition (LLC) or a life-threatening condition (LTC). For each financial year in the analysis, a cohort of CYP with these conditions was identified on the following criteria:

- Patient had at least one inpatient episode within the financial year
- Had a minimum of one diagnosis code from the aforementioned list recorded in one of the 20 diagnosis fields
- Was under the age of 26
- Was registered with a GP practice in the 6 STPs within the West Midlands;
 1. Birmingham & Solihull
 2. Coventry & Warwickshire
 3. Herefordshire & Worcestershire
 4. Shropshire & Telford & Wrekin
 5. Staffordshire
 6. The Black Country

Stillborn children were removed from this analysis.

Prevalence figures were produced using ONS population estimates for the years 2006 to 2015.

Hospital Activity

To understand Healthcare utilisation and total activity, we queried HES Accident and Emergency, Inpatient (IP), and Outpatient tables between 2011/12 and 2015/16. Each person in our inpatient cohort has a unique encrypted patient ID. The encrypted ID field was used to identify patients from our cohort who used another hospital service. Inpatient data was split into daycase, elective, non-elective (emergency) and regular day/night attenders using the admission method field. Outpatient attendances were split into consultant-led and non-consultant-led using the main speciality code.

Deaths for patients in the cohort were identified by matching unique HES episode identifiers to the same field in the ONS Mortality data set, providing the year of death. Location of death was determined from an establishment code also given in this data set.

¹¹ Fraser, L.K., Miller, M., Hain, R., Norman, P., Aldridge, J., McKinney, P.A. & Parslow, R.C. (2012) Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, 129 (4), e923-e929. DOI: [10.1542/peds.2011-2846](https://doi.org/10.1542/peds.2011-2846)

Data

Data manipulation and data visualisations was conducted in MS SQL Server 2012 and R Studio 3.4.0

Maps

QGIS version 2.8.9 was used to produce maps. STP and CCG populations for all 0-25 year olds were obtained from ONS Population Estimates. Prevalence was then calculated for these geographic areas and plotted on the map using shape files obtained from the ONS Open Geography portal¹². Data was obtained from SQL to inform the provider maps, activity was split between patients commissioned outside and inside the West Midlands but constrained to providers within the West Midlands as demonstrated on the map.

¹² <http://geoportal.statistics.gov.uk/>

Appendix 3

Appendix 3. Activity count for each point of delivery by CCG

Financial Year	Birmingham CrossCity	Birmingham South & Central	Cannock Chase	Coventry & Rugby	Dudley	East Staffordshire	Herefordshire	North Staffordshire	Redditch & Bromsgrove	Sandwell & West Birmingham	Shropshire	Solihull	South East Staffordshire & Seisdon Peninsula	South Warwickshire	South Worcestershire	Stafford & Surrounds	Stoke on Trent	Telford & Wrekin	Walsall	Warwickshire North	Wolverhampton	Wyre Forest
A & E																						
2011/12	1,328	680	71	866	341	146	160	127	143	1,050	127	257	222	189	168	26	230	145	373	254	249	62
2012/13	1,453	859	104	849	355	231	129	152	228	1,306	135	301	233	192	191	44	254	118	486	279	387	123
2013/14	1,851	905	91	954	434	167	173	169	198	1,311	149	325	228	244	211	37	315	175	519	357	274	114
2014/15	2,047	968	103	938	498	245	109	122	197	1,369	161	413	245	263	228	96	327	157	435	353	578	109
2015/16	2,226	1,180	175	1,031	562	213	198	226	210	1,606	225	429	343	266	352	156	384	194	492	424	467	114
Day Cases																						
2011/12	1,219	605	201	660	372	166	185	261	115	884	320	338	271	279	311	168	680	122	429	252	633	99
2012/13	1,412	874	231	873	512	224	248	437	219	1,228	425	347	271	264	406	170	781	161	426	328	594	126
2013/14	1,929	918	173	1,110	589	326	300	425	228	1,535	314	383	290	403	372	235	681	197	473	276	709	131
2014/15	1,956	847	166	825	687	285	283	492	214	1,705	231	351	383	553	313	330	961	274	543	312	791	196
2015/16	2,174	898	189	849	669	232	215	478	158	1,807	315	569	413	471	337	275	897	342	451	200	1,122	149
Elective Admissions																						
2011/12	460	176	38	291	121	84	382	93	77	326	168	93	109	119	94	51	199	77	158	160	125	45
2012/13	366	217	65	275	139	120	607	158	81	396	195	109	83	123	118	66	246	83	129	149	123	46
2013/14	501	162	34	370	198	130	551	157	89	389	193	122	80	110	121	87	210	113	136	93	149	75
2014/15	540	206	70	301	242	119	404	164	93	454	203	124	127	126	118	85	224	153	144	113	193	68
2015/16	711	194	57	361	204	87	276	166	98	452	203	154	146	188	135	103	277	165	199	113	217	61

Financial Year	Birmingham CrossCity	Birmingham South & Central	Cannock Chase	Coventry & Rugby	Dudley	East Staffordshire	Herefordshire	North Staffordshire	Redditch & Bromsgrove	Sandwell & West Birmingham	Shropshire	Solihull	South East Staffordshire & Seisdon Peninsula	South Warwickshire	South Worcestershire	Stafford & Surrounds	Stoke on Trent	Telford & Wrekin	Walsall	Wanwickshire North	Wolverhampton	Wyre Forest
Emergency Admissions																						
2011/12	1,074	422	72	650	373	225	256	233	142	915	311	192	194	287	304	70	657	200	379	166	499	102
2012/13	1,112	581	119	666	431	213	339	353	247	1,183	365	280	201	242	421	106	682	214	430	169	689	175
2013/14	1,395	571	91	735	487	276	336	335	238	1,116	410	286	193	333	397	98	688	327	459	267	562	149
2014/15	1,431	642	134	700	549	338	357	278	232	1,212	354	351	226	346	331	197	651	310	435	224	755	178
2015/16	1,710	706	188	755	678	241	329	435	235	1,163	470	369	322	336	472	243	731	409	530	282	834	140
Regular Day Cases																						
2011/12	831	488	0	179	208	0	1	93	193	850	426	0	2	47	47	2	93	234	211	14	46	1
2012/13	905	704	0	232	0	0	110	1	276	1,321	551	1	0	129	67	69	3	164	47	20	107	1
2013/14	1,117	597	0	277	289	0	108	8	43	1,116	812	5	0	61	51	4		158	156	7	239	95
2014/15	1,497	195	29	101	550	21	7	128	81	716	394	1	154	6	135	0	5	227	229	47	192	65
2015/16	860	52	110	44	249	7	11	226	201	635	295	5	5	23	224	0	6	324	123	27	50	108
Consultant Outpatient Attendances																						
2011/12	6,614	3,087	704	3,853	2,282	897	1,329	1,310	986	7,111	2,158	1,484	1,382	1,591	1,760	629	2,521	1,602	2,634	1,330	2,579	553
2012/13	6,488	3,113	810	4,448	2,323	918	1,613	1,509	1,117	7,157	2,510	1,621	1,236	1,366	1,781	617	2,556	1,509	2,379	1,393	2,863	750
2013/14	7,774	3,692	810	5,111	2,566	912	1,716	1,505	1,036	8,128	2,564	1,766	1,187	1,699	1,783	656	2,313	1,893	2,507	1,374	2,914	670
2014/15	9,074	4,297	942	4,675	3,109	1,258	1,683	1,321	1,208	7,902	2,244	1,964	1,538	2,044	1,829	830	2,114	1,835	3,040	1,499	3,558	885
2015/16	9,435	3,793	897	4,353	3,099	951	1,897	1,479	1,183	8,066	2,762	2,259	1,626	1,908	2,292	950	2,417	2,328	3,126	1,570	3,172	786
Non-Consultant Outpatient Attendances																						
2011/12	1,765	936	206	241	1,459	324	376	554	145	1,146	430	389	279	598	344	136	982	312	662	197	288	122
2012/13	9,207	4,656	973	1,810	4,145	1,590	1,097	653	1,417	8,672	1,468	3,964	1,108	1,104	2,413	649	1,154	915	3,086	859	1,976	765
2013/14	9,721	5,623	632	3,244	3,864	1,118	1,139	742	1,437	7,497	1,731	2,962	1,508	1,558	2,366	587	1,154	670	3,457	749	1,707	857
2014/15	1,524	7,978	1,049	3,074	5,903	1,866	1,568	1,048	1,952	9,791	1,961	3,134	1,945	2,020	2,156	655	1,398	1,219	4,862	1,374	4,979	1,676
2015/16	1,896	9,938	783	3,964	5,814	1,181	1,291	1,577	1,722	1,129	2,034	4,154	2,801	1,892	2,361	1,270	1,464	1,939	4,809	2,039	5,556	1,436

Appendix 4. Activity count for each point of delivery by STP

Financial Year	Birmingham & Solihull	Coventry & Warwickshire	Herefordshire & Worcestershire	Shropshire & Telford & Wrekin	Staffordshire	The Black Country
A & E						
2011/12	2,265	1,309	533	272	822	2,013
2012/13	2,613	1,320	671	253	1,018	2,534
2013/14	3,081	1,555	696	324	1,007	2,538
2014/15	3,428	1,554	643	318	1,138	2,880
2015/16	3,835	1,721	874	419	1,497	3,127
Day Case						
2011/12	2,162	1,191	710	442	1,747	2,318
2012/13	2,633	1,465	999	586	2,114	2,760
2013/14	3,230	1,789	1,031	511	2,130	3,306
2014/15	3,154	1,690	1,006	505	2,617	3,726
2015/16	3,641	1,520	859	657	2,484	4,049
Elective Admissions						
2011/12	729	570	598	245	574	730
2012/13	692	547	852	278	738	787
2013/14	785	573	836	306	698	872
2014/15	870	540	683	356	789	1,033
2015/16	1,059	662	570	368	836	1,072
Emergency Admissions						
2011/12	1,688	1,103	804	511	1,451	2,166
2012/13	1,973	1,077	1,182	579	1,674	2,733
2013/14	2,252	1,335	1,120	737	1,681	2,624
2014/15	2,424	1,270	1,098	664	1,824	2,951
2015/16	2,785	1,373	1,176	879	2,160	3,205

Financial Year	Birmingham & Solihull	Coventry & Warwickshire	Herefordshire & Worcestershire	Shropshire & Telford & Wrekin	Staffordshire	The Black Country
Regular Day Cases						
2011/12	1,319	240	242	660	190	1,315
2012/13	1,610	381	454	715	73	1,475
2013/14	1,719	345	297	970	12	1,800
2014/15	1,693	154	288	621	337	1,687
2015/16	917	94	544	619	354	1,057
Consultant Outpatient Attendances						
2011/12	11,185	6,774	4,628	3,760	7,443	14,606
2012/13	11,222	7,207	5,261	4,019	7,646	14,722
2013/14	13,232	8,184	5,205	4,457	7,383	16,115
2014/15	15,335	8,218	5,605	4,079	8,003	17,609
2015/16	15,487	7,831	6,158	5,090	8,320	17,463
Non-Consultant Attendances						
2011/12	3,090	1,036	987	742	2,481	3,555
2012/13	17,827	3,773	5,692	2,383	6,127	17,879
2013/14	18,306	5,551	5,799	2,401	5,741	16,525
2014/15	26,361	6,468	7,352	3,180	7,961	25,535
2015/16	33,052	7,895	6,810	3,973	9,076	27,473

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Midland and Lancashire

Commissioning Support Unit