

Children and young people's  
health services in London



*A case for change*

London  
Strategic Clinical Networks



# IN LONDON

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1/4

of Londoners are children or young people

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3 in 10

children in London live in poverty

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23 %

of London children aged 4-5 years are overweight or obese

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# Making the case for change

Approximately a quarter of the population (2,116,223) in London are children or young people (aged up to 20 years)<sup>1</sup>. The Office of National Statistics predicts that this population will grow by 13 per cent to 2022<sup>2</sup>. Children and young people are not just young adults and have rights as highlighted by the United Nations Convention on the Rights of the Child (UNCRC), which include, “the right to be healthy, the right to be educated, the right to be treated fairly, the right to be heard and the right not to be hurt.”<sup>3</sup> Unfortunately, children and young people are not always at the heart of health service planning and policy change in London. Children and young people deserve better.

In 2013 the World Health Organization reported that although mortality rates for most of the western world had been decreasing, the opposite was the case in Britain where the rate had risen from 5.3 deaths per 1,000 births before five years of age in 2010, to 5.4 per 1,000 in 2013. When comparing this statistic to other European countries a child born in Britain is more likely to die before the age of five than in Czech Republic, Slovenia and Estonia as well as the rest of the western Europe.<sup>4</sup>

Public Health England has calculated that the average infant mortality rate (under 1 year of age) in England was 4.3 per 1,000 live births between 2010 and 2012. When comparing this rate amongst all London boroughs the range was 6.1 per 1,000 live births in Harrow to 2 per 1,000 live births in Bromley. The average directly standardised child mortality rate in England was 12.5 per 100,000 children (1-17 years old) between 2010 and 2012. Comparing this rate amongst London boroughs, the range was 20.6 per 100,000 children in Havering to 9 per 100,000 in Hillingdon.<sup>5</sup>

Whilst the average across London for mortality and other key indices, such as asthma admissions, is similar to the average for England, the variation in these outcomes is striking and extremely troubling.

Given the short distances between these London boroughs this variation shows decisively that we are not meeting the health needs of children and young people in London, as well as we could, and should be. London has some of the world's best health services for children and young people, but decidedly average health outcomes across London as a whole and some really very poor outcomes in some boroughs.

There have been a number of high profile national reports into children's services, including the National Service Framework for Children 2004<sup>6</sup>, Marmot Review 2010<sup>7</sup> and Kennedy report in 2010<sup>8</sup> that have all stressed that in order for children's services to function to meet the interests of children and young people, integrated services with health professionals working collectively are imperative.<sup>9</sup>

In his 2010 report, Professor Sir Ian Kennedy goes further,

*“If services for children and young people provided by the NHS are to improve, the barriers to collaborative working, both within the NHS and between the NHS and other agencies, must be overcome. Services must be integrated within the NHS along pathways of care. They must interact successfully and seamlessly with other public agencies. The NHS is not an island. We fail children and young people if we perpetuate a system in which they (or their parents or carers) need to knock on the right door in search of care and risk going unhelped if they get it wrong. We fail children and young people if their needs and concerns are not at the centre of everything that is done: easy rhetoric but very difficult to pull off.”<sup>10</sup>*

***“If services for children and young people provided by the NHS are to improve, the barriers to collaborative working, both within the NHS and between the NHS and other agencies, must be overcome. Services must be integrated within the NHS along pathways of care.”***

— Professor Sir Ian Kennedy



Following the Health and Social Care Act 2012<sup>11</sup>, Strategic Clinical Networks were created across the country and are a tangible opportunity to transform quality and outcomes for patients using an integrated and whole system approach. This will be achieved by working in close conjunction with commissioners to help lower unjustifiable variation in services, and to encourage innovation and collaboration.<sup>12</sup>

“Clinical networks are an NHS success story. Combining the experience of clinicians, the inputs of patients and the organisational vision of NHS staff they have supported and improved the way we deliver care to patients in distinct areas, providing true integration across primary, secondary and often tertiary care.”<sup>13</sup>

This document will set out some of the issues facing children’s health services in London, including demographics, variation, how health services have developed and commissioning. It will also set out how the Children and Young People Strategic Clinical Network will look to improve children’s health services for the entire population of children in London and those children who use London’s health services from other regions, through implementation of:

1. Children and Young People Healthcare Networks;
2. Standards covering all levels of services from community and primary care through to tertiary services;
3. Formal managed networks and care pathways for specific disease areas;
4. A single Children’s Commissioning Group across London.

This work will be led by a Clinical Director for Children and Young People, Russell Viner, Professor of Adolescent Health at the UCL Institute of Child Health. He will be supported by a Strategic Clinical Leadership Group (SCLG), encompassing clinicians and NHS managers in an advisory capacity and supported by patient, public and children and young people involvement. An expert project team based in NHS England (London region) will provide the managerial support to the work.

***This document sets out some of the issues facing children’s health services in London, and how the Children and Young People Strategic Clinical Network will look to improve these for the entire population of children using London services.***

## DEMOGRAPHICS

London contains around eight million people (2011 census), approximately 15 per cent of the 53 million people in England.<sup>14</sup> London is a very young city with more children and many fewer 'frail elderly' than other parts of England. More than two million of the London population (2,116,223, or 24.9 per cent) are aged under 20 years.<sup>15</sup>

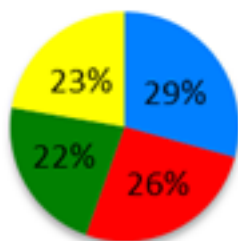
Figure 1 shows the breakdown by age (right).

The number of children and young people in London and surrounding regions is growing, and growing faster than other parts of England. The number of live births in London increased by 30,024 (29 per cent) between 2001 and 2012, as shown in Figure 2 (right). It also shows that the number of live births in East of England and the South East increased 14,481 (24 per cent) and 19,348 (22 per cent), respectively, within the same period. It is relevant to take note of this data as children from these regions access children's health services in London.

The Office of National Statistics predicts that populations in London, East of England and South East will rise by 13 per cent, 8.6 per cent and 7.8 per cent respectively over the period to mid-2022, which is faster than the projected national average population change of 7.2 per cent. Further predictions show that the population for 0-15 year olds in London will increase by 16 per cent, East of England by 11.3 per cent and South East by 9.2 per cent to mid-2022.<sup>18</sup>

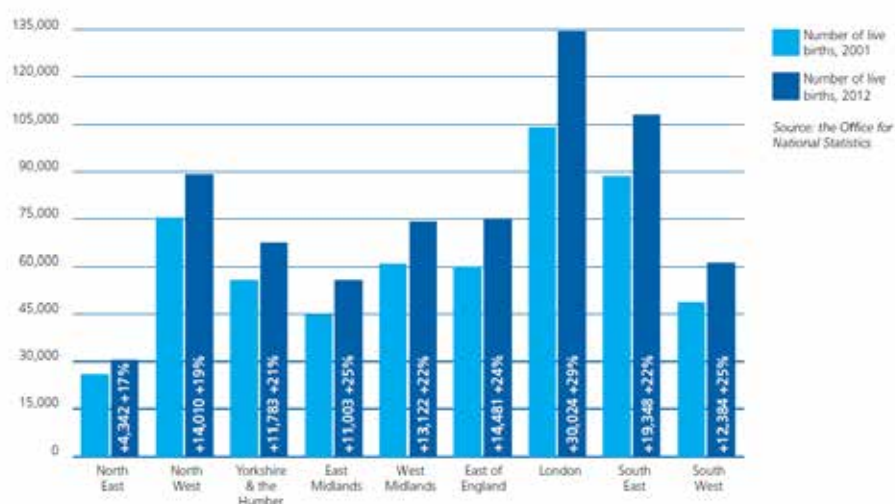
Using the data from Public Health England above, the population of 0-15 year olds in London is then estimated to increase by 262,943.

Figure 1: Children and young people: Population breakdown in London<sup>16</sup>



0-4 years old	620,171
5-9 years old	554,296
10-14 years old	468,925
15-19 years old	472,831
<b>Total</b>	<b>2,116,223</b>

Figure 2: Regional variation in births<sup>17</sup>



As the population of children and young people in London and surrounding regions grow, health services in London need, not only to be able to cope with this increase, but also improve at the same time.

Population increases are not the only demographic issue that should be considered. London's children and young people are very diverse and many are deprived.

» In 2011 on average, 68.2 per cent of school children (aged 5-16 years) in London were from black and minority ethnic groups compared to 25.6 per cent in England.<sup>19</sup> In Brent, 94.5 per cent of secondary school pupils are non-white, making it the most ethnically diverse borough in England.<sup>20</sup>

- » More than 300 languages are spoken by London pupils.<sup>21</sup>
- » About 3 in 10 children in London live in poverty.<sup>22</sup>
- » One in 7 (291,000) children in London live in poor housing, and 1 in 4 (510,000) children live in overcrowded houses.<sup>23</sup>

London's population is very diverse when compared to the rest of the country. The population is younger, more ethnically distinct, transitory and growing more quickly than any other region in England.

These factors and others need to be considered when designing health services for children and young people, and a different approach is required in London.



## Variations in healthcare

The NHS has a “social duty to promote equality through the services it provides, and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.”<sup>24</sup>

NHS services are delivered to national priorities but are delivered locally. Variation exists in healthcare services due to a number of reasons. However the population of London expects that wherever they use children’s health-care services they can receive the same high standard of care across all providers. The information presented in this section suggests that there is significant variation within London’s healthcare system and services. This variation is unwarranted and is driven by the limitations within healthcare services and professionals in London rather than by patient need.<sup>25</sup> In London,

*“unwarranted variations in quality, efficiency or equity of access require urgent redress if the value of existing NHS resources is to be maximised for the benefit of children and young people.”<sup>26</sup>*

***The variation shows what is possible, what the benchmark should be and what we could be doing better.***

Examples of variation in healthcare for children in London and the wider UK are provided within this section. The variation shows what is possible, what the benchmark should be and that we could be doing better.<sup>27</sup>

## UK VARIATIONS

The examples below provide a glimpse of the unfavourable health-care variation in the UK in comparison to other countries as well as within the UK.

- » When mortality is compared to Sweden, an equivalent of 132,874 excess potential years of life are lost.<sup>28</sup>
- » The UK had the second highest mortality rate (EU15+ countries) for infants (second to Canada) and children aged 1 to 4 years old (second to Belgium) in both sexes (2005-08).<sup>29</sup>
- » Death rates for meningococcal disease, asthma, and pneumonia are higher in the UK in comparison to Sweden, France, Italy, Germany and the Netherlands.<sup>30</sup>
- » Type 1 diabetes control for those under 25 years of age in England and Wales is poor when compared to other countries, where just 16 per cent achieve HbA1c blood test levels under 7.5 per cent. In Germany and Austria, 34 per cent of young people met this standard.<sup>31</sup>
- » The amount of paediatric intensive care activity that does not map to advanced critical care varies considerably between sites in the UK, with an average of 25.3 per cent and a range of 16 to 79 per cent.<sup>32</sup>
- » Analysis by Paediatric Intensive Care Audit Network (PICANet) shows that the amount of high dependency care undertaken in paediatric intensive care units varies from 16 to 91 per cent of total bed days across England, with an average of 33 per cent.<sup>33</sup>
- » There are significant gaps between care delivered for epilepsy between providers within the UK and national

guidelines. An RCPCH Epilepsy12 audit showed that 54 per cent of children who are diagnosed as having epilepsy had no evidence of epilepsy specialist nurse input 12 months after their first paediatric assessment. When comparing units, the range was zero to 100 per cent.<sup>34</sup>

It would be unfair to suggest that the UK compares badly with other countries in all regards of healthcare provision. Injury mortality, particularly road traffic accidents, for children and young people is very low in Britain compared with other European countries, reflecting a long history of excellent public health advocacy around injuries in the UK.<sup>35</sup>

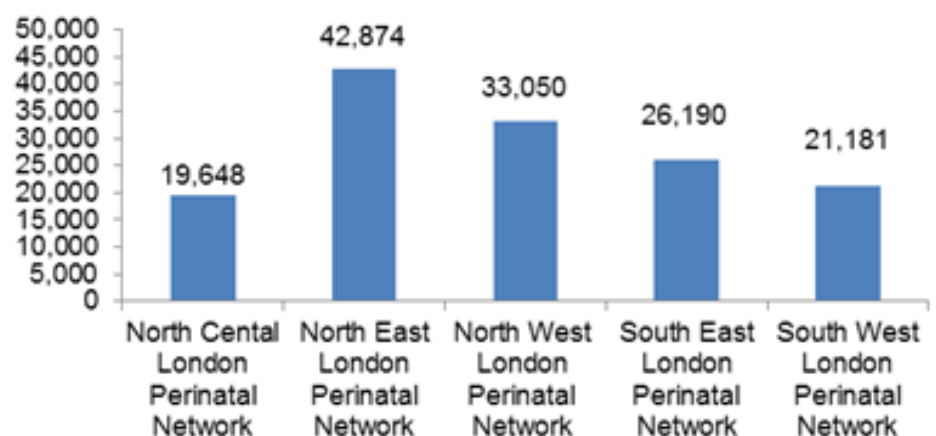
A good example is in terms of some childhood cancers where survival rates are lower in the UK<sup>36</sup>, although this is not true for all cancer mortality. There is a need to learn from these examples as there will be elements which can be transferred to other services in order to improve outcomes and experiences.

## LONDON VARIATIONS

Variation in children's population across London boroughs is considerable. Public Health England reported in 2014 that 31.8 per cent of the population in Dagenham are aged under 20 years, whilst in the City of London the figure stood at only 11.8 per cent.<sup>37</sup> This variation is no doubt due in part to the variation in the amount of live births in each London region as reported by the London Perinatal Networks for 2011/12, reported in Figure 3 (*below*).

Although there is a huge variation in the populations served by these networks, this shows that there were more than double the amount of live births in North East London Perinatal Network as compared to the North Central and the South West Perinatal Networks. Some of the variation in population may also be due to: young people coming to London for education and for work; and migration, both internal (within the UK to London) and external migration, as many migrants are young people or young families.

Figure 3: Live births 2011/12<sup>38</sup>



Variation in mortality data was briefly described in the introduction. Analysis of Child Death Panel outcome data for 2012/13 shows that, compared to the remainder of England, London has a significantly higher proportion of:

- » Modifiable causes of death in 10-14 and 15-17 year olds;
- » Modifiable causes implicated in deaths of black children;
- » Children and young people who die in Accident and Emergency and in hospital wards;
- » Children and young people who die of acute infections or acute medical or surgical problems.<sup>39</sup>

Figures 4 and 5 show graphically the variation in mortality in infants and children and young people in London. In both cases the borough titled 'England Best' shows what is possible.

While London overall is no different to the England average for infant mortality, there is marked variation, with most Boroughs having average or high infant mortality compared with the rest of England. The same is true for child and adolescent mortality 1-17 years.

Figure 4: Mortality rate per 1,000 live births aged under 1 year (2010-2012)<sup>40</sup>

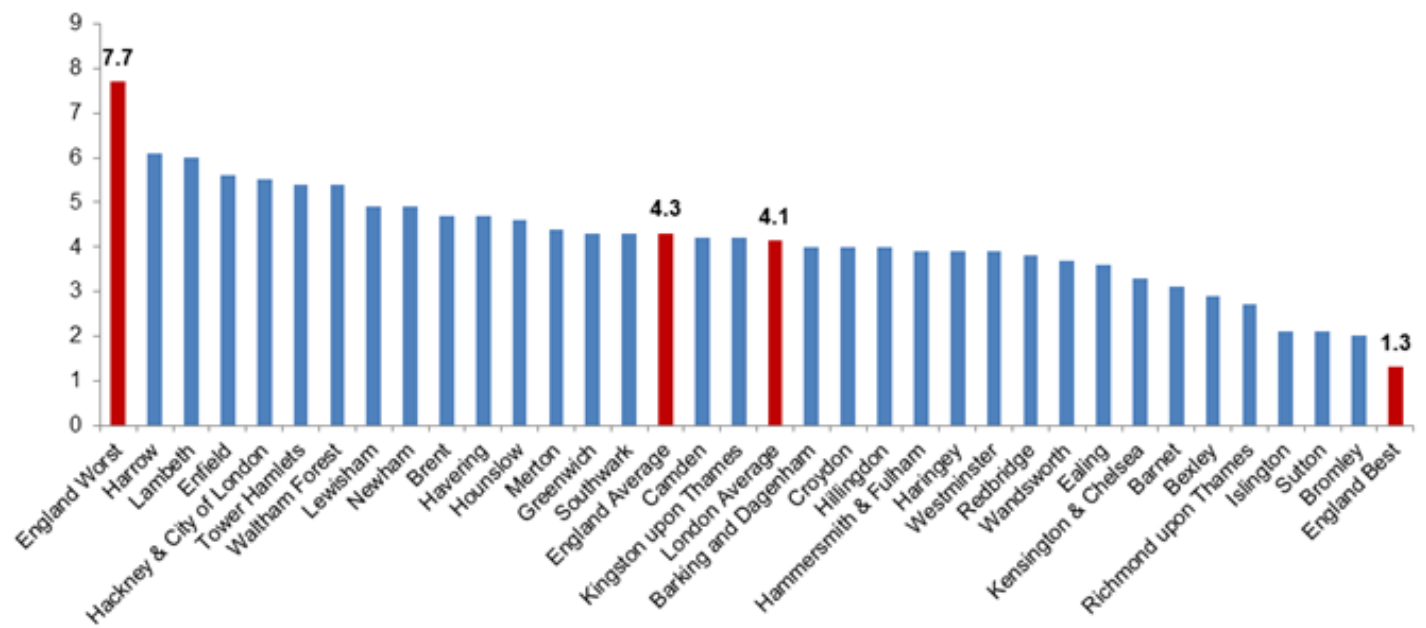
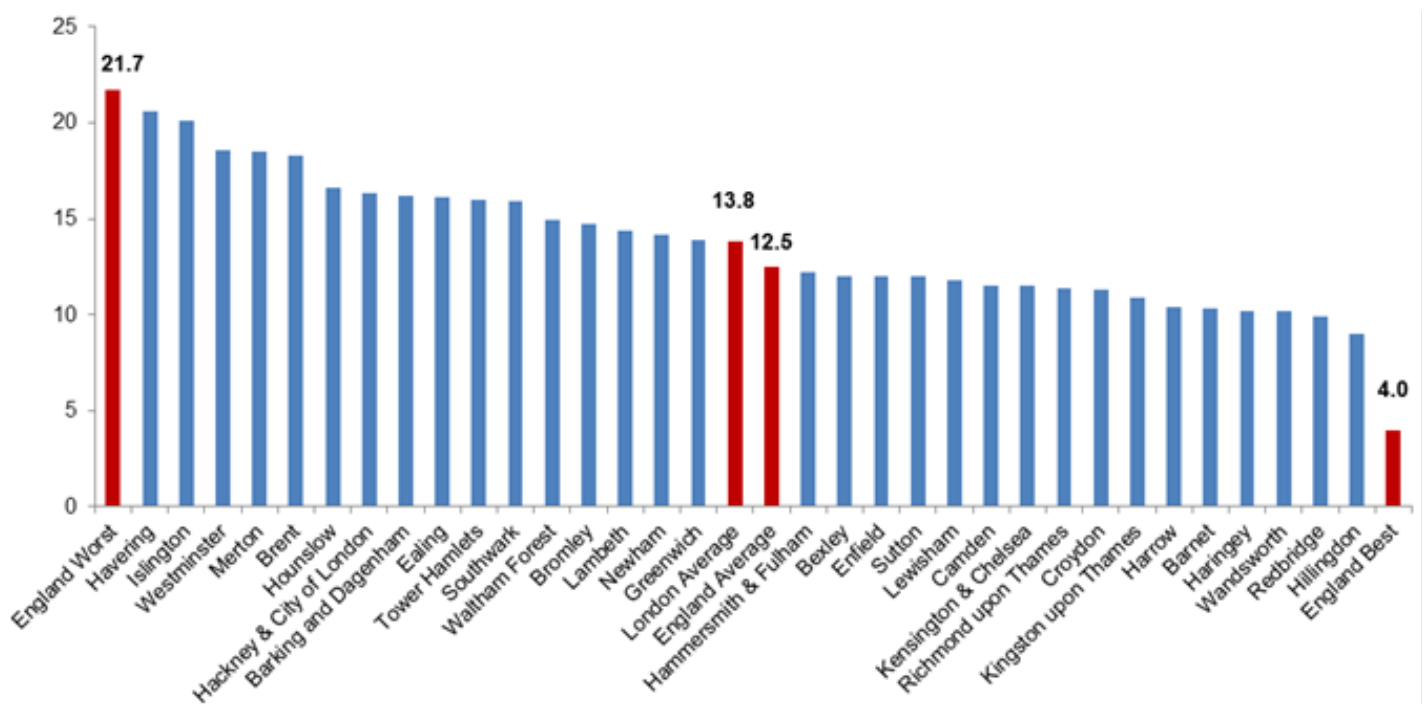


Figure 5: Directly standardised mortality rate per 100,000 children aged 1-17 years (2010-2012)<sup>41</sup>







The examples below provide an idea of other variation in London.

- » A boy born in Kensington and Chelsea has a life expectancy of over 84 years; for a boy born in Islington, less than five miles away, it is around 75 years.<sup>42</sup>

### Vaccination rates

- » For MMR vaccination (first dose by 2 years old) during 2012/13, there were only two London boroughs above the 92.3 per cent England average: Harrow (92.5 per cent) and Tower Hamlets (93.8 per cent). Westminster was the worst performing borough in England (77.4 per cent).<sup>43</sup>
- » During 2012/13 10 per cent of children living in London did not receive their third dose of DTaP/IPV/Hib at 12 months, and 20 per cent of children living in London did not receive their DTaP/IPV/Hib booster at 5 years. The coverage for both of these vaccinations was the lowest in England.<sup>44</sup>
- » In 2011/12, HPV uptake in London was considerably lower than in England (78.9 versus 86.8 per cent). HPV uptake varied across London with the highest uptake in Newham (90.3 per cent), which was 1.5 times higher than Barnet, the lowest (62.1 per cent).<sup>45</sup>

### Sexual health

- » In London the average acute STI diagnoses per 1,000 population aged 15 to 24 years in 2012 was

41.8, higher than the average in England of 34.4. The range in London was between 21.2 (Enfield) to 89.1 (Lambeth), the highest rate of STI diagnoses in England.<sup>46</sup>

### Mental health

- » Although the 2012/13 crude rate of emergency hospital admissions for mental health (age 0 to 17 years) for was lower in London than in England (86.6 versus 87.6 per 100,000), the variation was striking, ranging from 39.4 in Hillingdon to 228.3 in Camden.<sup>47</sup>

### Hospital admissions

- » The 2012/13 crude rate of emergency hospital admissions for asthma age 0 to 18 years was lower in London than in England (204.7 versus 221.4 per 100,000). However the range was significant from 94 in Richmond upon Thames to 388.6 in Lewisham.<sup>48</sup>
- » A&E attendances for 0 to 4 year olds in 2012/13 was significantly higher in London than England (697.5 versus 510.8 average crude rate per 1,000). With a range between 484 (Richmond upon Thames) to 1022.7 (Brent), 29 of the 32 London boroughs were above the England average.<sup>49</sup>

### Dental health

- » The percentage of 5 year olds with one or more decayed, missing or filled teeth in 2012 in London (32.9 per cent) was higher than the

England average (27.9 per cent). This has plateaued in London, where other regions have seen promising reductions. Similarly, the percentage of children with active decay for 2012 in London (28.8 per cent) was higher than the England average (24.5 per cent).<sup>50</sup>

### Obesity

- » Public Health England reports that 23 per cent of children aged 4 to 5 years in London were overweight or obese in 2012/13.<sup>51</sup> Over the same period, the average number of children aged 4 to 5 years in London classified as obese was 10.6 per cent -- worse than the England average of 9.3 per cent. The range in London was from 5.7 per cent in Richmond upon Thames, the best performing borough in England, to 13.8 per cent in both Greenwich and Southwark.<sup>52</sup>
- » Public Health England reports that nearly 40 per cent of children aged 10 to 11 living in London were overweight or obese in 2012/13.<sup>53</sup> Over the same period, the average number of children aged 10 to 11 years classified as obese in London was 22.1 per cent -- worse than the England average of 18.9 per cent. The range in London was from 12.4 per cent in Richmond upon Thames to 27.5 per cent in Newham, the worst performing borough in England.<sup>54</sup>



## ***POSITIVE VARIATIONS***

London does, however, perform favourably in comparison to the rest of England in some areas and disciplines.

For example, in London 86.4 per cent of mothers initiated breastfeeding in 2012/13 in comparison to 73.9 per cent in England. Only three boroughs had breastfeeding rates lower than the average in England (Bexley 71.1%, Havering 71.3% and Barking and Dagenham 73.7%). Haringey was the best performing borough in England, at 94.7 per cent.<sup>55</sup>

Average admissions rates for alcohol and substance misuse are lower in London than England. London averaged 29.7 per 100,000 hospital attendances (crude rate) relating to alcohol (under 18 years old) during 2010/11-2012/13, compared to the England average of 42.7. Southwark was the best performing borough in

England with a rate of 14.6, and only four boroughs (Hillingdon, Islington, Sutton and Tower Hamlets) were above the average for England, with Tower Hamlets recording a rate of 46.8.

Although performance is good in comparison to national figures, there is still considerable variation between boroughs in London.<sup>56</sup> London averaged 59.8 per 100,000 hospital attendances (directly standardised rate) relating to substance abuse compared to the England average of 75.2. Again, although this average comparison is good, the range in London was from 31.5 in Westminster to 93.7 in Barking and Dagenham.<sup>57</sup> However, it is unclear whether a low admission rate truly reflects low incidence of alcohol and substance misuse problems, or in fact represents low recognition or

poor provision of specialist services for substance misuse.

Public Health England reported that all London boroughs have improved performance on teenage pregnancy reduction and in fact Wandsworth has achieved the largest reduction with a rate now 64.1 per cent lower than its rate in 1998.<sup>58</sup> The conception rate for women aged under 18 in London (2012) was 25.9 per 1,000, lower than the England rate of 27.7 per 1,000. Although performance has improved there is still considerable variation between all London boroughs, ranging from 17.7 per 1,000 in Kensington and Chelsea to 42 per 1,000 in Lewisham.<sup>59</sup>

Where there is success relevant learning could and should be shared and transferred to other disciplines.

***Where there is success, relevant learning could -- and should -- be shared and transferred to other disciplines.***



# Integrated care

“The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population.”<sup>60</sup>

In 2012, the Secretary of State for Health initiated the development of a Children and Young People’s Health Outcomes Strategy by creating a forum compiled of individuals with a broad range of expertise and a shared commitment to improving health care for children and young people.

The Forum was asked to:

- » identify the health outcomes that matter most for children and young people;
- » consider how well these are supported by the NHS and Public Health Outcomes Frameworks and make recommendations; and
- » set out the contribution that each part of the new health system needs to make in order that these health outcomes are achieved.<sup>61</sup>

In 2013, the forum reported that in order to improve health outcomes, there is a need for integrated care tailored to the needs of children, young people and their families. They remarked that the divide between services and commissioning responsibilities are invisible and should be more integrated.

Integration for children should include partnership working between education, health and social care services.<sup>62</sup>

***There is a need for integrated care tailored to the needs of children, young people and their families.***

The manner in which children’s healthcare services have developed and are provided in London is complex, from general practice based in the community to highly specialised services in hospitals known nationally and internationally. For instance, across secondary and tertiary care, 58 sites provide inpatient services for children.<sup>63</sup>

**This section provides some understanding of this and the issues facing each level of care.**



# Primary and community care

There are currently 1,605 general practices in London.<sup>64</sup> Children represent about 25 per cent of a general practice population, but approximately 40 per cent of its workload is with young children as particularly frequent users.<sup>65</sup>

Given this proportion of their workload it is remarkable that in England 40-50% of GPs will not have had any formal training in paediatrics or child health.<sup>66</sup> As Wolfe et al explain, "Experience matters, especially in recognising rare but serious illnesses in children."<sup>67</sup>

These citations indicate more could be done to support GPs in acquiring greater knowledge of paediatric and child health. The Strategic Clinical Network, in conjunction with other partners, could support this.

General practice is under pressure to meet and adapt to the challenges, especially in London. Many of these issues relate to the demographics in London. For instance, due to the transitory nature of the population, there is an approximate 30 per cent annual turnover of general practice lists, which makes consistency and continuity of care more difficult.<sup>68</sup>

There are other issues as detailed below:

- » Community children's nursing teams have developed reactively to local need but with no national or regional planning, leading to fragmentation across London.<sup>69</sup>

- » GP accessibility varies across London. Less than half of patients get to see a GP by the next working day, many surgeries are not open outside of normal working hours and some still close for a half day during the week, and using satisfaction indicators 22 London boroughs score poorly for seeing their GP of choice, which are amongst the bottom 30 boroughs in England.<sup>70</sup>
- » There is a shortage of GPs nationally, and it is predicted that 16,000 more will be required by 2021.<sup>71</sup>

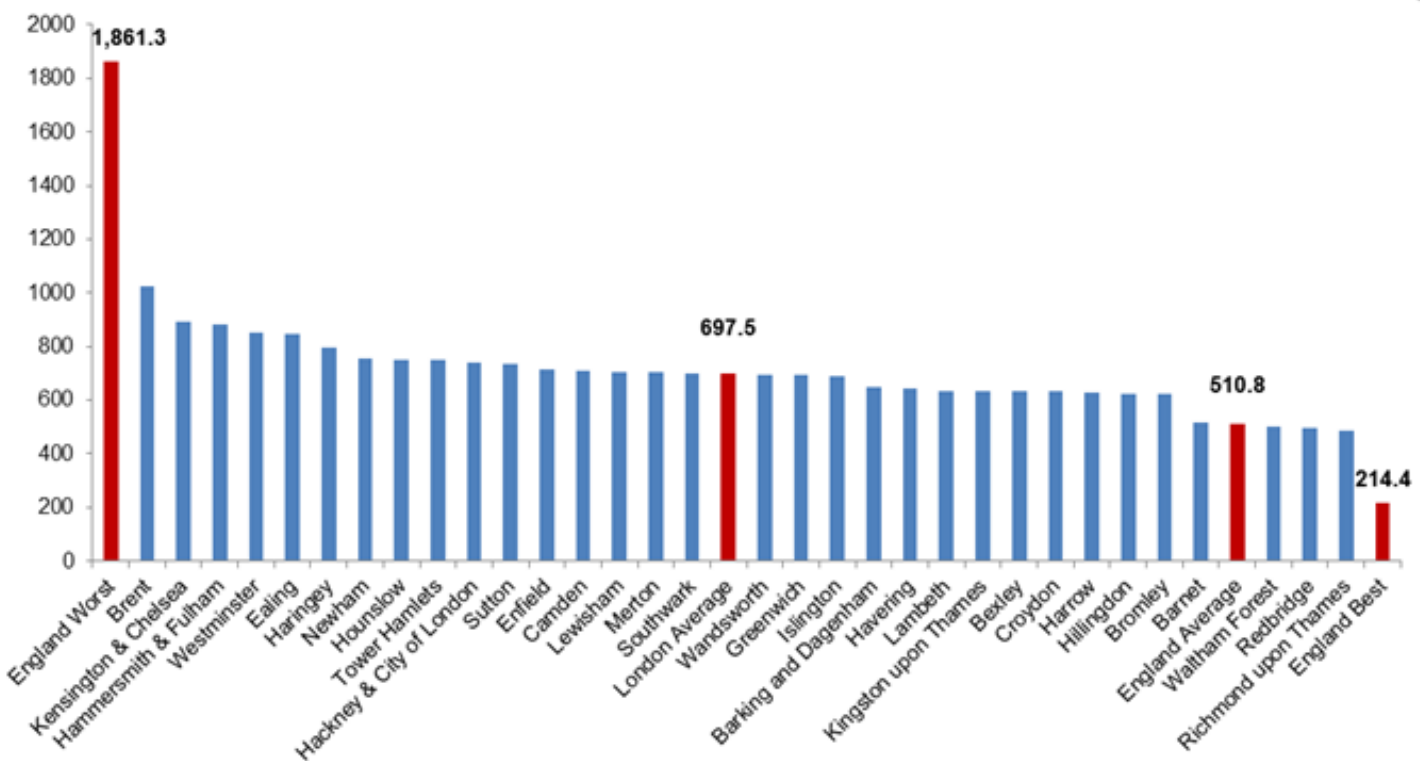
In relation to specific diseases or conditions improvements in primary and community care provision are required to resolve the following issues:

- » Two-thirds of hospital admissions for asthma could be averted, with improved preventative care, incorporating asthma plans, education and risk reduction.<sup>72</sup>
- » Emergency admission rates for diabetes, asthma and epilepsy show a threefold to fivefold variation across boroughs in London.<sup>73</sup>
- » Cancer referrals (all ages) are lower in London than England in accordance with guidelines.<sup>74</sup>

Ultimately, parents of children who are faced with the option with seeing an on-call GP they don't know, or going to an Accident and Emergency department, often choose the latter, even though many of these cases can be dealt with in the community.<sup>75</sup> Provision of primary and community care is changing within London, through practice networks, unifications and alliances in an attempt to improve care.

Figure 6 (*below*) shows the variation within each London borough of A&E attendances for children aged 0 to 4 years old, and how much the difference there is between the London average and national average.

Figure 6: 2011/12 Crude rate of A&E attendances age 0 to 4 years (per 1,000)<sup>77</sup>





# Secondary care

There is an increasing over reliance on secondary care services, especially Accident and Emergency. Between 1999 and 2010 there was a 28 per cent increase in emergency admissions for children under 15 years old.

In London secondary care is provided in 26 sites (not trusts) for inpatient medicine and 25 sites for surgery.<sup>78</sup> As detailed within the previous section there is an increasing over reliance on secondary care services, especially A&E. Between 1999 and 2010 there was a 28 per cent increase in emergency admissions for children under 15 from 63 to 81 per 1,000 children -- equating to 700,000 cases each year. Admissions for less than one day had also doubled.<sup>79,80</sup>

Presentation to A&E or admittance to hospital, for children and young people with problems that could easily be treated within the community, is becoming an all too common experience. On the other hand out patient appointments are provided, more often than not, in a hospital setting when they could be provided closer to home in most instances.<sup>81</sup>

A 2008 study found that only 25 per cent of children and young people admitted to A&E with non major conditions, should have been treated by an A&E clinician, and that 87 per cent of the same category of patients could have presented at a different entry point.<sup>82</sup> Another study found that 36 per cent of referrals to paediatricians were potentially preventable; in most circumstances they

were children with minor problems<sup>83</sup> and thought to be due to a lack of knowledge or confidence by some GPs.<sup>84</sup>

There has also been a shift in the amount of children's surgery that is performed in a secondary care setting. It is estimated that in 1994/95 approximately 72 per cent of children's surgery was provided nationally in local hospitals. This dropped to 60 per cent a decade later. Such a decrease makes it difficult for surgeons and anaesthetists to maintain their skills. In some cases, too, they are not prepared to, due to the lack of critical mass, perform surgery on children they once would have done. A knock-on effect of this is that secondary care hospitals have problems recruiting and retaining staff, and tertiary care centres have seen an increase in referrals for routine surgical procedures. Surgeons in secondary care settings see skills gradually diminish due to less exposure to surgical cases.<sup>86</sup>

In London, HES data from 2009/10 showed that 42 per cent of secondary care centres operated on less than 51 paediatric elective surgery, and only six sites operated on more than 100 cases.<sup>87</sup> Formal network arrangements to support paediatric services and surgery in secondary care, in terms of provision of facilities, staff and training, would help stabilise changes witnessed in recent years.



## Tertiary care

There are 24 NHS providers who provide specialist services for children in London.<sup>88</sup> This makes achievement of delivery of co-dependent services on one site almost impossible as detailed within the framework of critical interdependencies.<sup>89</sup>

A survey in 2009 concluded that tertiary care services in London were fragmented and that due to this fragmentation patients from the same borough can be treated at up to four different providers for some specialised services.<sup>90</sup> The recent service specification work undertaken by specialised services nationally shows that 54 per cent of those 24 providers only provide one or two specialised services for children, whereas 29 per cent of those providers have 10 or more specialised services.<sup>91</sup>

There are some reasons for this fragmentation, already described within the demographics section. Approximately 1.7 million children in Kent, Surrey, Sussex and East of England also access specialised services in London. This is significant, considering those services also tend to children living in London.<sup>92</sup> Children from all over the UK access some specialised and highly specialised services in London. For example, the only provider in the UK to provide complex tracheal surgery is Great Ormond Street Hospital. It was estimated that even though the wider population is not clearly defined, that specialised services in London would serve between 8 and 17 million children.<sup>93</sup>

This fragmentation does, however, cause some problems. There has been a lack of planning and coordination of specialised services in London, which has meant that service provision, in some instances, is variable. This, together with the lack of critical mass in some areas, means that quality and sustainability is at risk.<sup>94</sup>

The survey in 2009<sup>90</sup> also found that only three of the providers providing specialised services were meeting interdependency requirements when considering 'absolute dependency, requiring co-location'. These gaps affect the safety and sustainability of services. It is possible that some of these areas, or elements of services, could be provided in conjunction with other providers, which points to formal networking.

***Approximately 1.7 million children in Kent, Surrey, Sussex and East of England access specialised services in London, in addition to children living in London.***



# Serious incidents

Serious incidents are a useful barometer of where a system is failing to provide care of the required standard. In 2010 a national framework for serious incidents in the NHS was developed by the National Patient Safety Agency.

The national framework described the following<sup>95</sup>:

- » An overview of the definitions of serious incidents requiring investigation
- » Categories and examples of incidents that should be notified to the relevant authorities/bodies
- » Links to national bodies
- » Associated guidance where appropriate

The Children and Young People SCN team undertook an analysis of serious incidents in 2013. The patient safety team within NHS England provided a list of all serious incidents involving children that had been reported to them. The Clinical Director and SCN Lead analysed these to determine which could be attributable to system failures. Over a five year period (2008-2013) there were 86 serious incidents identified as being caused by system level factors. It was concluded that in some of these incidents no failure was identified. However, others showed similar themes including consent issues, recognition of how sick the child was, knowledge/expertise and training of staff, documentation issues, lack of review by senior clinician, workload, service delivery problems and issues with transfer to tertiary centres.<sup>96</sup>

An underlying issue within these themes is a lack of communication within organisations and to the patients and their families. The 2012 Paediatric Emergency Services patient survey found that a lack of communication and information relating to treatment was a real issue for patients, families and carers. Fifty-seven per cent of respondents stated that the level of information provided about their child's condition was very poor, poor or satisfactory. Overall nearly a quarter of children, their families and carers rated their experiences of emergency care in London as very poor or poor.<sup>97</sup>

A 2008 review of child deaths reported that 'identifiable failure in the child's direct care' was found in 26 per cent of deaths, and that there were potential avoidable circumstances in 43 per cent of deaths.<sup>98</sup> Errors or inadequacies included deficient children's training, supervision and the recognition and management of the severely ill child.<sup>99,100</sup>

If there are similar themes related to children's deaths over the course of a number of years, it means that health professionals are not learning from previous experiences, or there are limiting factors affecting services. NHS Trusts in London should be using these examples to improve their services.





## Commissioning children's health services

Following the Health and Social Care Act 2012<sup>101</sup> the landscape of commissioning health services for children and young people in London changed dramatically. Clinical Commissioning Groups (CCGs) were established made up of GPs, nurses, the public and hospital doctors.

The aim of CCGs is to improve health services for the populations they serve by selecting and purchasing services from a range of organisations.

There are 32 CCGs in London. NHS England commissions specialised services, primary care services and offender health care regionally. Public Health England commissions public health services.<sup>102,103,104</sup> School nurse commissioning moved into boroughs in 2013, and health visitor commissioning will transfer to local authorities in 2015.

Cohesive commissioning of children's health services in London provides a particular challenge as functions are split across such a diverse number of commissioning organisations. In order to improve children's health services in London, it is important that these different organisations are working together collaboratively and see an overall picture of children's services, not just the area for which they have commissioning responsibility.

***There are 32 CCGs in London.  
Made up of GPs, nurses, the public and hospital doctors, CCGs aim to improve health services for the populations they serve by selecting and purchasing services from a range of organisations.***



## Staffing provision and shortages

A skilled workforce is essential to the provision of a safe effective service giving good experience for children, young people and their families.

Staff shortages are reported across all levels of children and young people's health services in London, which means we are not able to provide a safe and sustainable, 24-hour service across the current configuration.<sup>105</sup>

Trained children's nurses are critical to the delivery of skilled, child-focussed healthcare. Insufficient numbers of nurses are training to be children's nurses.<sup>106</sup> This is likely to lead, in time, to nursing personnel across London unlikely to understand the needs of all children and their families. There is also an issue of inconsistency in relation to children's training in nursing. For example, for registered nurses not specialising in children's care, there is no ability to access even an abridged version of a children's training module. Also, children's training overseas is not recognised in the UK, thus requiring nurses from overseas to be supervised, even though they may be hugely experienced children's nurses in their own countries.<sup>107</sup> This makes recruiting nurses from other nursing disciplines and from overseas more difficult.

There are also limited training opportunities for nurses to become nurse practitioners or advanced practitioners. Nurses who have progressed along these lines provide a valuable, effective, cost efficient and experienced 24-hour workforce for children, and can be utilised in the hospital and in the community.<sup>108</sup>

There are specific problems in sub-specialties of children's nursing. There are problems recruiting to community children's nursing posts across London. In addition there are minimal training opportunities for community nurse specialists.<sup>109</sup> In hospital settings it has been reported that already almost half of London's accident and emergency departments do not have a paediatric trained nurse on duty at all times.<sup>110</sup>

The Royal College of Child Health and Paediatrics in 2011 reported that there is disparity between the number of paediatricians being trained, the number of funded consultant positions and the required number to staff acute hospitals legally and safely.<sup>111</sup> Following an increased demand for physiotherapy, occupational therapy, speech and language therapy in children's services in emergency and community surroundings, shortages in skilled specialists have been reported. As a result some organisations have created specialist rotations in both of these surroundings, facilitating employees to acquire an extensive range of skills, and NHS trusts to grow a workforce fit for purpose.<sup>112</sup> This could be worth exploring further and rolling out more widely if evidence suggests it is adding value.

A survey in 2011, found that 83 per cent of hospitals provided a paediatric orthopaedic trauma surgery service in London but the surgery is carried out by paediatric trained orthopaedic surgeons in just 3 per cent of hospitals in London. The survey also reported variation in the number of adult orthopaedic surgeons that are paediatric trained and are confident to undertake paediatric cases, as well as variation in the amount of cases that are reviewed within four hours of admission, especially out of hours and at the weekend.<sup>113</sup>

The inability of smaller hospitals to train and recruit staff with appropriate paediatric skills and also maintain skills as a result of centralisation of services or specialties has led to clinicians, once confident in dealing with children in an emergency or surgical situation, now not being able to provide this expertise. There are numerous examples of this across disciplines, including general surgery, anaesthesia and ear, nose and throat surgery. This has led to increases in referrals to tertiary centres for procedures that were previously provided in local settings. It was reported in 2013 that although there had been a 50 per cent increase in the consultant paediatric workforce in London over a 10 year period, it showed that children's services are struggling to preserve important services, especially out of hours.<sup>114</sup>

Some examples are provided below.

- » Provision of paediatric imaging in combination with comprehensive services, varies across London especially in relation to the availability of consultant reporting for some radiology within the standard one hour, at the weekend and out of hours.<sup>115</sup>
- » Approximately one-third of hospitals in London met the Royal College of Surgeons recommendation that children's surgical cases are operated within 24 hours of admission.<sup>116</sup>
- » More than 50 per cent of hospitals in London reported that they are able to provide a paediatric emergency service supported by an anaesthetist with paediatric training. Furthermore, a Royal College of Surgeons survey of general paediatric surgical provision in 2008 found that 77 per cent of hospitals in London do not have a specific on-call paediatric anaesthetic rota, and 35 per cent of the remaining hospitals have an anaesthetist with paediatric training always on call.<sup>117</sup>
- » The Royal College of Paediatrics and Child Health reported in 2011 that a quarter of hospitals in London are not able to meet their standard of having one medical handover, led by paediatric consultants, during every 24-hour period, meaning clinically significant information can be lost.<sup>118</sup>

These examples point to the need to balance paediatric skills within local services and integrated networks which can provide more specialist skills.

*These examples point to the need to balance paediatric skills within local services and integrated networks which can provide more specialist skills.*





## Gaining their views

“The NHS aspires to put patients at the heart of everything it does...Patients have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.”<sup>119</sup>

It has long been recognised that patients and other stakeholders can provide great insight into what works well and what can be improved within NHS services. Children and young people are among key NHS stakeholders and their interests should be at the centre of any decisions about health services. Developing a culture of participation will be key to addressing this.

“Participation encourages integration and inclusion, lets youth feel valued and ultimately leads to progress. It is right and should not be tokenistic, where services merely ask youth for their views just so they fit in with a trend.... include the views of children and young people wherever possible – the benefits are clear.”<sup>120</sup>

Through the establishment of NHS England there is an opportunity to allow service change to be delivered around the experiences of children and young people. The strategy *No decision about me without me*<sup>121</sup> ensures that children and young people will have the opportunity to be involved in health service design and delivery.<sup>122</sup>

Furthermore, through the Department of Health *You're Welcome* criteria<sup>123</sup>, which provided an overview for providers and commissioners to progress children and young people health services, with a number of standards covering the spectrum of integrated services. Unfortunately, the implementation of these criteria and standards is left to local discretion. The Royal College of Paediatrics and Child Health in 2011 reported that 81 per cent of commissioners

recommended that local services implement these criteria and standards, and 64 per cent of commissioners engaged with children and young people in reviewing their experiences.<sup>124</sup>

Following on from this, a Patient Experience Network (PEN)<sup>125</sup> report concluded that even though many NHS organisations had grasped the importance of patient experience and planted this within their cultures, there is still variation, even within particular organisations, and that work was still required to implement this within cultures. A PEN survey showed that less than half the respondents had a precise strategy to improve patient experience to include engaging directly with children and young people. Most engagement, in terms of children and young people services is with parents and carers rather than with these groups themselves. For example, children and young people represented less than 20 per cent of the respondents to the GOSH patient experience survey. Parents and carers have rather differing opinions and experiences to their children. The report provides an overview of recommendations and priorities to improve patient engagement.<sup>126</sup>

The provision of meaningful patient experience opportunities for children and young people ensures their needs are at the heart of work in designing services. There is an opportunity to learn from organisations or services that are doing this well, to improve the whole patient pathway across London.



# Networks

Clinical networks over the years have combined clinical expertise and experience with the input of patients to improve the way the NHS has delivered patient care across distinct areas and across the entire patient pathway.

In 2012, upon introducing Strategic Clinical Networks as one of the improvement vehicles for NHS England, Professor Sir Bruce Keogh, NHS England Medical Director, and Jane Cummings, NHS England Chief Nursing Officer, declared, “Clinical networks are an NHS success story.”

**This section will provide an overview of successful clinical networks and explain how the Children and Young People Strategic Clinical Network for London will attempt to improve health service and outcomes for children and young people.**

Clinical networks over the years have combined clinical expertise and experience with the input of patients to improve the way the NHS has delivered patient care across distinct areas and across the entire patient pathway. The Way Forward stated that strategic clinical networks across the country will facilitate major healthcare change, where a whole system approach is required to deliver real change in outcomes and quality for patients.<sup>127</sup>

The aims of Strategic Clinical Networks include:

- » Reducing unwarranted variation in health and well-being services;
- » Encouraging innovation in how services are provided now and in the future;
- » Providing clinical advice and leadership to support their decision making and strategic planning;
- » Involving patients and the public in strategic healthcare decisions.<sup>128</sup>

## NETWORK BEST PRACTICE

A successful network will aim to be defined by certain principles. Examples include collaboration, shared protocols and clinical guidelines agreed by all providers, communication and linkages between different disciplines over multiple sites and shared education development. Some clinical networks have been in existence for a while with varied formality. It is important to ensure that the benefits of clinical networks are maintained.

Stroke and cancer networks are commonly used as exemplary examples of clinical networks. Stroke networks have allowed services to adjust and have led to improved experience and outcomes for patients. Cancer networks have improved standards of care, facilitated easier and faster access and allowed best practice to be shared.<sup>129</sup>

Although cancer networks have made progress since they started more than a decade ago, diagnosing cancer earlier, ensuring better treatment, providing better information to patients and improving intelligence, there is still much more to do to ensure the NHS provides the best care possible for patients across London and wider. The NHS Outcomes Framework 2013/14 reported that cancer is the highest cause of death (21 per cent) for children aged 1 to 14 years old, compared with deaths as a result of accidents and external causes (18 per cent).<sup>130</sup>

One of the successes of the cancer network is peer review, allowing professionals to review other services, against national measures and assess clinical care and treatment, identifying and sharing good practice.

In 2013 NHS Improving Quality reported nationally that in 2012/13<sup>131</sup>:

- » 646 (52 per cent) of the multidisciplinary teams scored more than 90 per cent against the peer review measures, compared with 28 per cent in 2011/12 and 34 per cent in 2010/11;
- » 277 network site specific groups achieved more than 90 per cent compliance with the measures;
- » 323 chemotherapy services, 166 radiotherapy services and 37 acute oncology services achieved more than 90 per cent compliance with the measures;
- » 169 children's and teenage and young adults' services achieved compliance with more than 90 per cent of the measures.

Another successful example are the major trauma networks. These networks have been especially effective at linking providers across the system. Defined roles and protocols ensure patients are taken to the most suitable hospital for the injuries they display. Some patients will self present to an inappropriate setting. Collaboration across the network ensures rapid and unfettered access to specialist major trauma care in the specialised major trauma centres where required.



During the first year of major trauma networks being established in London, results showed that an additional 58 people who were expected to die of their injuries survived. Following this successful pilot, major trauma networks were rolled out nationally in 2012. The Trauma Audit and Research Network (TARN) have reported that major trauma networks have continued to improve patient outcomes since their inception, as an additional 40 people who were expected to die of their injuries across all London trusts survived between January 2011 and December 2013 (data is unavailable for two trusts).<sup>133</sup>

The London Neonatal Operational Delivery Networks (ODNs), although in their infancy, have already begun to show great value, including improved productivity and communication. Review and formalisation of network pathways has led to an improved understanding of capacity flows, identified areas for audit and improved outcomes. Within a three month period the amount of women being treated rose by 3 per cent. The networks have improved communication between all neonatal stakeholder allowing operational issues are identified and acted upon quickly, improving safety and outcomes. This has also enabled London-wide mortality and morbidity reviews to take place to facilitate shared learning and potential ideas for future research.<sup>134</sup>

Following the [Connecting care children's health](#) another network was established in London. Three boroughs in London -- Hammersmith and Fulham, Westminster, and Kensington and Chelsea -- experienced high levels of unscheduled paediatric care use in 2011/12, so much so that up to 50 per cent of children who were seen in a secondary setting could have been seen and treated within a general practice or community setting, including patients who were referred from primary care.

Work was undertaken to understand why this was happening and three factors were identified<sup>135</sup>:

- » Access to same-day GP appointments or urgent consultation
- » Parental capability to 'self-care' with the right support
- » Parental confidence in the GP paediatric expertise

A model was introduced to enhance networks between primary care, secondary care and local authority settings, leading to better communication between children, families, schools, and NHS services in terms of diagnosis and education. It did this mainly through joint outreach clinics and multidisciplinary team meetings, and open telephone access.<sup>136</sup>

Initial findings from the pilot<sup>137</sup> showed that:

- » 74 per cent of parents said that they would be more likely to see their GP for child health related issues, 98 per cent of parents would recommend the outreach clinics to their friends.
- » Two per cent *Did Not Attend* rate.
- » Increased confidence in diagnosis in primary care, reduced referrals
- » Sustained decrease in 2011-13 admissions for asthma
- » Reduced hospital admissions for paediatric diabetes and improved HbA1c (glycosylated haemoglobin) levels.
- » Development of an information app for children and young people with sickle cell.

These examples, and other networks, prove just what can be achieved if networks are developed, nurtured and allowed to flourish. Collaboration across a health system brings about tangible benefits in making the system and the experience of patients more effective.



# London CYP SCN: The solution

The Children and Young People Strategic Clinical Network in London has set a programme of work, agreed by the Strategic Clinical Leadership Group, with the aim of improving health services for children and young people.

This document has highlighted a number of issues facing health services in London and for children and young people themselves. The Children and Young People Strategic Clinical Network in London has set a programme of work, agreed by the Strategic Clinical Leadership Group, with the aim of improving health services for children and young people.

The work programme includes creating and implementing Children and Young People Healthcare Networks, overarching standards covering all levels of an integrated service, formal managed networks and care pathways for specific disease areas and a single Children's Commissioning Group across London.

The work will also involve those, at the heart of all this, children and young people, their families and carers.

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## *CHILDREN AND YOUNG PEOPLE'S HEALTHCARE NETWORKS*

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There is strong evidence that when different elements of the health system work in conjunction it leads to more effective delivery of healthcare. A fundamental element of the work of the Strategic Clinical Network will be to join up different settings of care by establishing networks of providers and commissioners of healthcare services for children and young people. There is a proposal to establish population based healthcare networks bringing together Academic Health Science Networks (AHSNs), NHS England Area Teams and the Local Education and Training Boards (LETBs) of Health Education England (HEE), which will formally link providers of out of hospital and in hospital care with other related NHS organisations. These networks will ensure healthcare delivery for children and young people is based on effective needs analysis, and enable linkage of all elements of the healthcare system. A number of potential configurations are being explored based on CCG Strategic Planning Group areas.



By working collaboratively the networks will be able to have an overarching view of service provision across the network and will be able to address specific issues by:

- » Enabling strategic linkage of all organisations responsible for delivery of healthcare to children;
- » Facilitating co-operation between providers at senior clinical and managerial level;
- » Looking at where pathways have been effectively delivered and implementing lessons learnt from these areas;
- » Driving improvements to reduce variation in quality of service provision across London;
- » Implementation of the standards for children's care across pathways as agreed by the Children and Young People Strategic Clinical Network;
- » Acting as vehicles for commissioners to be involved in commissioning of local pathways and for undertaking quality assurance functions;
- » Enabling effective communication between whole pathways of care and other parts of the system for example Local Education and Training Boards (LETBs), Academic Health Science Networks (AHSNs);
- » Driving improvements on education, training and workforce development;
- » Liaising with public health, social care, Healthwatch England, voluntary sector and non-health organisations.

## ***Overarching standards covering all levels of integrated services***

Many professional associations and NHS organisations have developed numerous standards which cover elements of children's services or pathways. Unfortunately these standards are all located in different organisations. The Children's SCN will gather all of these standards together in one cohesive document to enable commissioners to see all the standards in one place and to commission against them, and for providers to deliver services against them.

## ***Formal managed networks and care pathways for specific disease areas***

Disease or discipline-specific pathway groups have been established with the aim of implementing agreed pathways of care and formal managed networks. These groups include asthma, diabetes, renal, oncology, cardiology, critical care, surgery, gastroenterology and neonatal.

## ***A single Children's Commissioning Group across London***

As already stated, commissioning of services for children and young people is undertaken by many different NHS organisations. The aim is to set up one group who oversees all commissioning of children and young people services in London, bringing together representatives from clinical commissioning groups, specialised commissioning, primary care services and Public Health England. This group will make sure priorities for children and young people health services are aligned across all levels of commissioning, working together as one to improve these services.

## ***Patient and public engagement***

There is a varied model of patient and public engagement proposed to make sure all stakeholders are represented and have the opportunity to provide their views on the work of the Children's SCN. Overarching voluntary sector organisations sit on the SCLG, including Children England, National Children's Bureau and The Association of Young People's Health. A number of specific events will be held for parents, carers, children and voluntary sector organisations to test out specific proposals. The SCN will also engage with existing patient forums, for instance the Clinical Senate Patient Forum.



# Conclusion

London has world class services for children and young people but decidedly average overall outcomes and unacceptable variation in outcomes between boroughs. Children and young people suffer and even die in the gaps between our generally excellent services.

*“We must harness the power of clinical networks, to pool resources and clinical expertise, to improve quality and to optimise health outcomes for children and young people. Above all, we must see the existing magnitude of unwarranted variations in healthcare for children and young people”<sup>138</sup>*

The Children and Young People Strategic Clinical Network has a real opportunity to improve health services for children and young people and to propel London to the forefront of international standards.

It aims to do this by bringing together the many different elements of children's healthcare services, from community, primary, secondary and tertiary care, to commissioners, public health and other organisations inside and outside the NHS. It also has the opportunity to improve the issues around the variable provision of children's healthcare highlighted within this document.

The evidence is clear that change needs to happen. Commissioners, providers and clinical staff must work collaboratively to support pan London networks which cover the whole children's pathway from home to world class treatment.

***The evidence is clear that change needs to happen.***

***Commissioners, providers and clinical staff must work collaboratively to support London networks which cover the whole children's pathway from home to world class treatment.***

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## About the Strategic Clinical Networks

The London Strategic Clinical Networks bring stakeholders -- providers, commissioners and patients -- together to create alignment around programmes of transformational work that will improve care.

The networks play a key role in the new commissioning system by providing clinical advice and leadership to support local decision making. Working across the boundaries of commissioning and provision, they provide a vehicle for improvement where a single organisation, team or solution could not.

Established in 2013, the networks serve in key areas of major healthcare challenge where a whole system, integrated approach is required: Cardiovascular (including cardiac, stroke, renal and diabetes); Maternity and Children's Services; and Mental Health, Dementia and Neuroscience.