



**The views and experiences of children,  
young people and parents using health  
and social care services in  
Waltham Forest**

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With special thanks to Berni Graham, Rehana Malik and all the children, young people and parents who contributed. Additional thanks to health and social care professionals and partners who participated in interviews and the shaping of recommendations.

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## Introduction

### About this piece of work

Healthwatch Waltham Forest has a statutory duty to work with children and young people and during its first 18 months (April 2013-September 2014), the organisation took part in a variety of activities including:

running information stalls at local nurseries, school and college open days and summer fairs.

- sending Healthwatch information posters to all primary and secondary schools.
- surveying approximately 50 parents in receipt of Children's Direct payments.
- running family-friendly activities at the Healthwatch Pop-Up Shop.
- meeting local parent and youth groups.

In September 2014 the Healthwatch Waltham Forest board decided to commission a broader piece of engagement work with the aim of talking to children, young people and parents about their knowledge and experience of a range of health and social care services. This was in order to:

engage children and families in Waltham Forest in the work of Healthwatch.

gain an insight and understanding of the experiences, views, comments and concerns of children and families around health and social care services in Waltham Forest, particularly focusing on Eastern European communities.

develop a network of contacts which Healthwatch Waltham Forest could use going forward.

This work was undertaken by researchers Berni Graham and Rehana Malik from January to July 2015. The following report is the result of this project.

### About Healthwatch Waltham Forest

Healthwatch Waltham Forest is a local Healthwatch organisation, established by the Health and Social Care Act 2012 to act as the local independent consumer champion for health and social care. Local Healthwatch organisations have statutory duties to:

- gather the views and experiences of patients and the public.
- make those views known to providers and commissioners.
- promote and support the involvement of local people in the commissioning and provision of local care services and how they are scrutinised.
- recommend investigation or special review of services via Healthwatch England or directly to the Care Quality Commission (CQC).
- provide information and signposting about access to services and support for making informed choices, including independent advocacy support to make an NHS complaint.
- make the views and experiences of people known to Healthwatch England, providing a steer to help it carry out its role as national champion.

More details can be found on our website [here](#).

## About Waltham Forest

Waltham Forest is a very diverse and relatively deprived borough in north-east London. Birth rates are relatively high and the proportion of children is higher than average when compared with the national picture. Just under a half of all residents are from Black, Asian and Minority Ethnic (BAME) communities and one in four people speak English as an additional language. One in four children are deemed to live in poverty and entitlement to free school meals, often used as another indicator of poverty, is higher than the London average.

Waltham Forest is known to have poor health outcomes for children and young people and high levels of need, heightened by deprivation and rates of mobility. Areas of concern for children and young people noted in official reports include high rates of infant mortality and low birth weights, low rates of breastfeeding and childhood immunisation and high levels of childhood obesity, special educational needs, mental health problems, sexually transmitted illnesses and early pregnancy. While some aspects of health have improved over recent years, numerous health concerns persist relative to other local authority areas, not least<sup>1</sup>:

- high rates of infant mortality, low birth weight and very low birth weight, still births and congenital disorders.
- low rates of continuing breastfeeding beyond 6 weeks.
- low rates of childhood immunisation.
- high levels of childhood obesity.
- poor performance on the national Childhood Wellbeing Index.
- high rates of special education needs, with and without statements.
- poor control of some chronic health conditions such as asthma.
- high incidences of mental illness and hospital admissions for mental ill health, especially among young people.
- high rates of sexually transmitted illnesses and young pregnancies.

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<sup>1</sup>Waltham Forest Joint Strategic Needs Assessment, (Refresh) May 2014, Chapter 5.  
<http://www.walthamforest.gov.uk/Documents/JSNA%202014-15.pdf>

## Executive Summary, key findings and recommendations

### Background

From January to May 2015, Healthwatch researchers Berni Graham and Rehana Malik carried out interviews and ran focus groups capturing the views of children, young people and parents from across the borough. We spoke to 362 people in total, with a particular focus on those from minority groups, and within that people from Eastern Europe. Twenty-six focus groups and three interviews with parents, children and young people took place. In addition we met with a range of health and social care professionals whose views are also featured in this report.

This study mainly used a qualitative approach to explore issues in more depth and obtain the unique perspectives and deeper understanding from people in their own terms. Those participating in focus groups and interviews were asked where they looked for health information, which services they knew of and used most and how they viewed these. Children and young people were also asked how much they were provided with information relevant to their own health and to what extent they were involved in decision-making about their care. In addition to allowing time for the topics parents, children and young people themselves identified, we probed the main concerns previously recognised in official reports and by professionals, for example breastfeeding, immunisations and mental health, in order to get input from parents, children and young people on these topic areas.

### Summary of key findings and recommendations

The work undertaken touched upon a variety of topic areas and health and social care services. Detailed findings and recommendations for each of these areas can be found in green boxes at the end of each section or subsection of the report. The number of recommendations varies in each section to allow for full consideration of the findings by commissioners and service providers.

Some common themes emerged across all topic areas and services discussed. These are summarised below:

#### **Engaging and involving children, young people and parents**

Across the specific areas discussed in this report we found ample opportunity for involving children, young people and parents in health and social care services, from creating mystery shopping teams to testing new communication materials and collecting case studies to inform staff learning. Involving those on the receiving end of services can bring new perspectives and insights to support service development in ways that meet patient needs. Services need to utilise the rich qualitative data sources already available and adopt the principles of co-production in all service design, development and commissioning. These opportunities need to be developed and embedded across child and

adolescent services in Waltham Forest to positively impact upon the ability of services to meet local needs.

### **Information, awareness and community outreach and education**

Services do not readily produce simple printed and online materials, and information is often not kept up to date or made available in a central location. In general a large proportion of the local population remain unaware of the breadth of health and social care services available to them and how to access them. Whilst this is not necessarily unusual - many people will not look for services until they have a need for them - in terms of the preventative and self-care agenda this highlights a missed opportunity and often results in a complicated journey when looking for support. Improving service information is a key aspect of empowering children, young people and families to manage their health and wellbeing effectively.

In addition, community outreach and health education can play a key role in awareness-raising and information-giving to improve appropriate uptake of services. At present conflicting or insufficient messaging around, for example, postnatal depression, tackling difficulties in breastfeeding, immunisations and boosters and mental health issues limits opportunities for self-management and care. Being unable to even access appointments and/or short appointment times with health and social care professionals means there is little room for open, informal dialogue where people can benefit from discussion and opportunities to ask questions and form their own opinions. Where different age, ethnic, cultural and community groups are concerned, it is often the trusted community network that can best deliver these messages and open up space for effective dialogue and education in a safe and protected environment. The opportunities for mainstreamed and targeted community outreach and education initiatives are underdeveloped in Waltham Forest, despite having been proven to work well across many other London boroughs.

### **Collaborative working and coordination**

New parents find it difficult to follow health and wellbeing guidance and often experience conflicting messaging from different health professionals. To avoid confusion and empower self-management and care there is a need for professionals to come together and agree and embed key messaging around, for example, breastfeeding and weaning. Existing tools such as the Waltham Forest CCG Parent's Guide booklet and NHS Choices information could be better utilised to form this basis, whilst ensuring there is room for dialogue and individual choice.

For some aspects of care, parents have to visit several locations and/or attend several different appointments. A reduction in this isolated working and more opportunities for coordinated appointments across departments would improve the patient experience for children and young people accessing care under several specialisms.

### **Specialist services, thresholds and lower levels of support, and transition from child to adult services**

The parents of children with disabilities, learning disabilities, mental health and special educational needs we spoke to reported several gaps in services for their children. Whilst provision was perhaps most available for younger age groups, this tailed off as children became older and moved into adult services, with little transition support available when it was needed. The thresholds were reported to be high for a number of services, leaving



individuals and families vulnerable and struggling to cope alone. With current financial pressures on services unlikely to ease and some thresholds and guidelines dictated nationally, local commissioning partners will need to consider how best to meet the needs of those with lower level needs to prevent escalation and more costly crisis provision. Capacity building, strategic development and commissioning of voluntary and community sector support services could assist in this area.

### **Language, acronyms, English as a second language and communication support and interpreting services**

This research work focused on engaging with children, young people and families from ethnic minority groups. As such it is unsurprising that the issue of language barriers was a common theme in our findings, from children not understanding when doctors explain things to them, to parents not being able to adequately express themselves in short appointment slots.

Across the spectrum of health and social care services there is a need to address consistent access to, and uptake of, quality interpreting services in each and every patient contact. Commissioners need to give clear guidance to providers around expectations in respect of community language leaflets, use of plain English and medical jargon, and child and young people-friendly information.

The new NHS Accessible Information Standard, which has to be in place by July 2016 across health and social care services, could be used to drive forward work in this area.

### **Access to timely professional advice and support**

Concerns around poor access to primary care and the resulting use of Whipps Cross Hospital's Emergency and Urgent Care Centre were raised frequently by the communities we spoke to. These were particularly prevalent issues for parents of babies and young children, as well as those with disabilities and a range of underlying health issues, who felt a need to be seen promptly when concerns arose and could quickly escalate. Although there are many existing and identified access issues within primary care (as well as related action plans to address these), solutions to the specific issues raised in this report around access and timely and professional advice and support for this group of patients must be sought going forward, whether that be from within or supplementary to existing primary care provision.

### **Sharing good practice and developing learning opportunities**

The people we spoke to told us about exemplary health and social care services and professionals working within the sector that really made a difference to their health and wellbeing. However, they also told us about experiences of poor customer service and approaches that were detrimental and impacted negatively on their desire to utilise the service and share vital information with professionals. Where good practice and positive patient experience exist, more effort should be made to gather case studies and audio and video recordings of children, young people and parents talking about what they liked and what worked well. Local professional learning networks should ensure a curriculum around patient and service user interaction, communication techniques and approaches, cultural sensitivities, listening to and learning from patients and reflecting and learning from professionals who consistently demonstrate good practice.

### **Strategic service development and commissioning plans**

The range of topic and service areas contained within this report provide a comprehensive overview of some of the common experiences faced by children, young people and parents in accessing health and social care services and maintaining good health and wellbeing in Waltham Forest. It is vital that these are taken into account by health and social care providers and commissioners, working in partnership to ensure existing and future action centres around the best interests and needs of our local communities.

This report has been presented to the Children's Health & Wellbeing Board, a committee of the statutory Health & Wellbeing Board, and the development of a number of the recommendations has taken place in joint partnership with supporting agencies.

Going forward it is vital that individual service area recommendations found throughout this report are mapped against existing strategies, action plans and workstreams. Where gaps do exist, these should be taken into account by those informing and influencing strategic direction.

## How we carried out this research

### This research was approached in three stages:

- i) Initially a review of existing reports and available information was undertaken in order to ascertain what was already known about local health and social care needs, identify what was less well known and prioritise the most useful issues in order to pursue these further and develop research questions<sup>2</sup>. These sources are all listed in Appendices 2 and 3, along with some of issues raised.
- ii) Qualitative interviews were conducted with key professionals from different agencies across the borough to access their expert knowledge and views.
- iii) Focus group discussions and some interviews were conducted with parents, children and young people to gather their unique perspectives. These sources are all listed in Appendix 1.

### The choice of qualitative methods

It was clear from the review of previous reports and data that a great deal of statistical information had previously been collected about the borough's population and aspects of health and social care. The current research needed to avoid reinventing the wheel and instead add new information which would be useful to Healthwatch and its partners. For this reason it aimed to go behind the statistics in order to explore some of the issues already highlighted in greater depth, and gather views and experiences as directly as possible from parents, carers, children and young people in their own words and according to their own defined priorities.

A qualitative approach was essential to achieve this. Qualitative methods, such as in-depth interviews and focus groups, use open questions and can follow through the points made which are made. The approach enables priorities to be identified and the parameters and contexts for these to be framed and explained by those being interviewed. These methods can achieve the range of subjective experiences, feelings and meanings, and priorities of those taking part. Researchers can adapt the wording and focus and pursue topics in more depth, as indicated by participants, and in turn cater for different contexts, experiences and language.

### Developing the questions to ask

Health and social care are vast topic areas, with multiple objective and subjective dimensions, and as such presented several challenges. Not least there was a need to narrow the topic down into a shortlist of discrete issues, relevant to both the public and to Healthwatch, whilst not omitting anything which might be more significant to some groups. The research also needed to provide new information and angles and gather the perspectives of those who are less often heard, not least children, young people, people new to the borough or country and those with language or other access barriers.

Interviews and focus group discussions covered physical and mental health and learning disabilities, experiences about access to services, and views on services available in the

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<sup>2</sup>Reports accessed included the local Waltham Forest Joint Strategic Needs Assessment and those produced by Ofsted, the CQC and Healthwatch Waltham Forest.

borough<sup>3</sup>. Interpreting was provided as needed. Some questions were used with all groups, with extra questions and/or different slants asked of the adult and younger groups:

- With both adults and younger participants, the research explored their awareness and use of certain health and social care services, issues around access and where and how they sought information on health.
- For both groups we sought comments on the services they used most. Within the parent groups we concentrated more on services for families with babies and young children, such as maternity services and health visitors.
- In the parent groups we explored views, experiences and practice around breastfeeding, weaning and immunisations, as these had previously been identified as areas of concern.
- With the children and young people we focused more on their awareness of how to access help or support, not least for emotional needs, as this had been flagged up by the reading and discussions with professionals. We were also interested in their sense of autonomy and involvement in their own healthcare consultations, for example how much they were asked for their views, how much understood what was going on, or how much they had a say when seeing health professionals. For the older young people we explored their awareness of contraceptive advice or services.
- As social care is a very targeted service, which the majority of people have little or no direct contact with, questions around this had to be more focused and sensitive, and were mainly posed to those who self-reported contact or who were most likely to have had direct experience of social care services. In practice this included young carers, the Children in Care Council, the Waltham Forest Parent Forum and young people with learning disabilities.

### Analysis

All interviews and group discussions were recorded with participants' consent. In addition, notes were taken by researchers and participants wrote comments on Post-it notes. These recordings and Post-it notes were analysed by the researchers by creating a matrix of the key themes and issues. This allowed comments on each topic to be systematically compared across all groups and interviewees and ensured that the main issues and priorities were accurately identified.

## Who we spoke to<sup>4</sup>

As we wanted to target minority communities and children and young people as much as possible, these were deliberately recruited. We particularly sought engagement with minority communities, with a focus on those from Eastern Europe, as these communities' access to health services is a particular concern for Healthwatch Waltham Forest. To reach these groups the two researchers worked with a series of agencies, such as community groups, religious institutions, schools, Children's Centres and others who ran groups or who could put us in contact with people who did. Sometimes we visited pre-existing groups, such as the Children in Care Council, which is run and supported by the London Borough of Waltham Forest.

We also used other groups to help us reach people. These included children's centres, a Mosque, the Roma Support Group and the Polish Saturday School. While covering the whole borough, recruitment prioritised the central and southern wards, given the higher rates of diversity and poverty in these areas and the lower age profile.

Focus groups with children and young people were mainly held in generalist settings, such as primary and secondary schools and youth services. We also targeted specialist groups such as young carers, looked-after children and young people, and young people with learning disabilities. The table below summarises the number of people who attended focus groups and those who were individually interviewed.

**Table 1: Numbers who took part in focus groups and interviews**

	Number	Number of participants
Focus groups with children and young people	18	264
Focus groups with parents	11	95
Interviews with professionals and key stakeholders	23	23
Individual interviews with young people and parents <sup>5</sup>	3	3
<b>Total</b>	<b>55</b>	<b>385</b>

<sup>4</sup> Full listings can be found in Appendix 1

<sup>5</sup> Individual interviews were conducted in just three cases for access reasons.

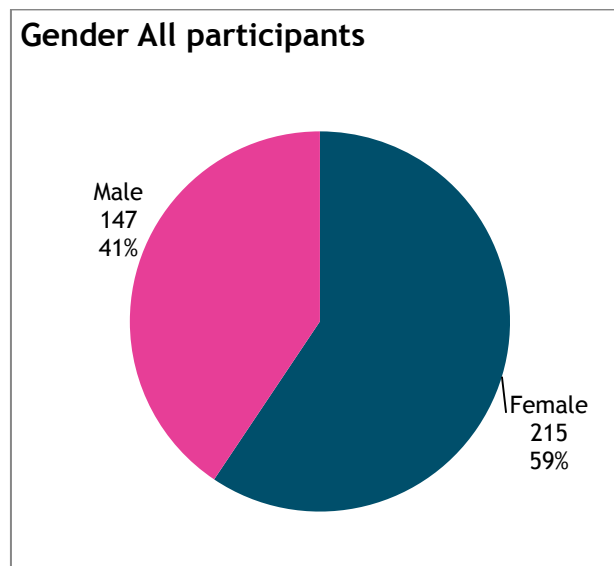
### Profile of those taking part

A total of 362 members of the public took part in focus groups and individual interviews. Of these 97 were adults and 265 children and young people.

### Gender

The adults were predominantly female, with 91 women and 6 men. Across the children and young people gender was more evenly distributed: we spoke to 124 girls and young women and 141 boys and young men.

**Fig 1: Gender of all participants**



### Ethnicity

We asked all group participants to describe their ethnic background in their own terms. Details for pupils were also provided by schools.

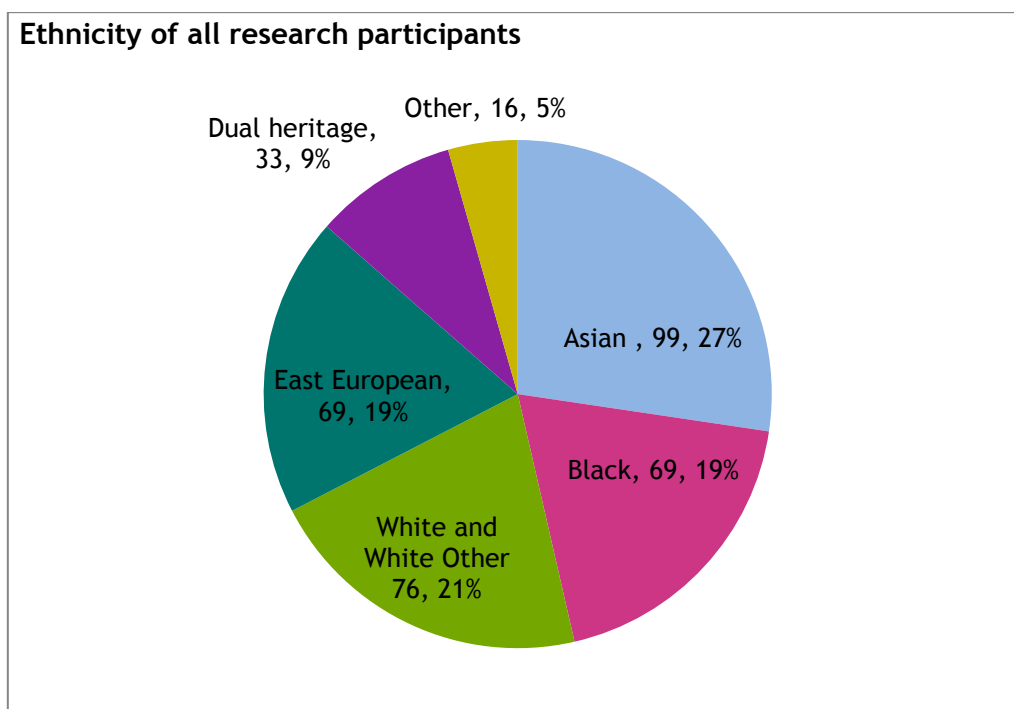
**Table 2: Numbers and percentages per classification, adults, CYP and total**

Ethnicity	Adults	CYP	Total	
	Numbers		Number	% of total
Asian	30	69	99	27
Black	11	58	69	19
White and White Other	14	62	76	21

Eastern European <sup>6</sup>	36	33	69	19
Dual heritage	1	32	33	9
Other <sup>7</sup>	5	11	16	5
Total	97	265	362	100%

While it was possible to some extent to deliberately target Eastern European parents, this was not feasible when approaching schools and youth groups. Overall we included a diverse range of backgrounds in our sample.

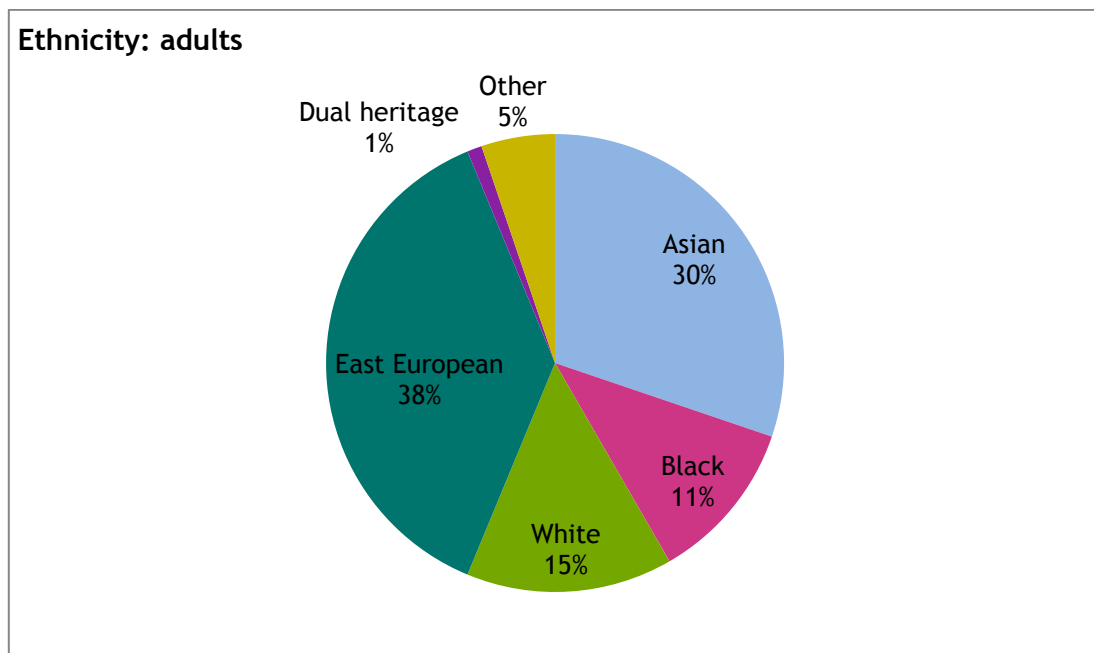
**Fig 2: Ethnicity of all participants**



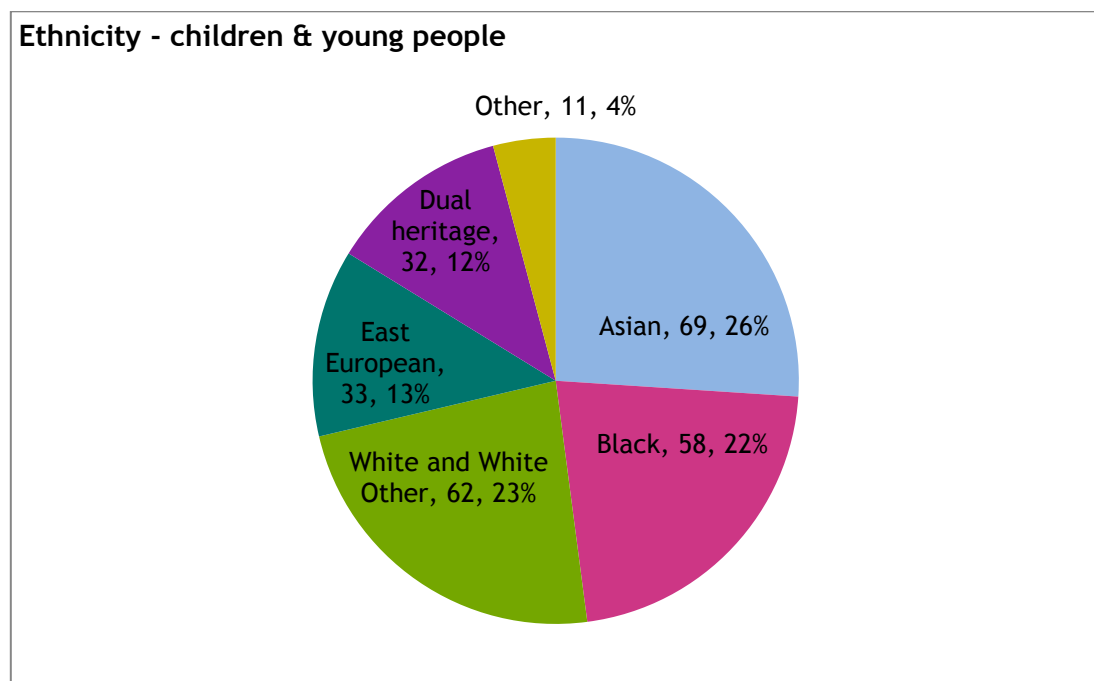
<sup>6</sup>'Eastern European' is counted separately as we wanted to ensure that we included people from this group. However, other adults from the same countries may have written 'White' or 'White Other' rather than 'Eastern European'. Children and young people were more likely to write 'British' or 'White British' if born in the UK, regardless of where their parents were from.

<sup>7</sup>Other' comprises: North African (5), Turkish Cypriot (4), South American (2), Chinese (1), other (3) and undisclosed (1).

**Fig 3: Ethnicity of adults**



**Fig 4: Ethnicity of children and young people**

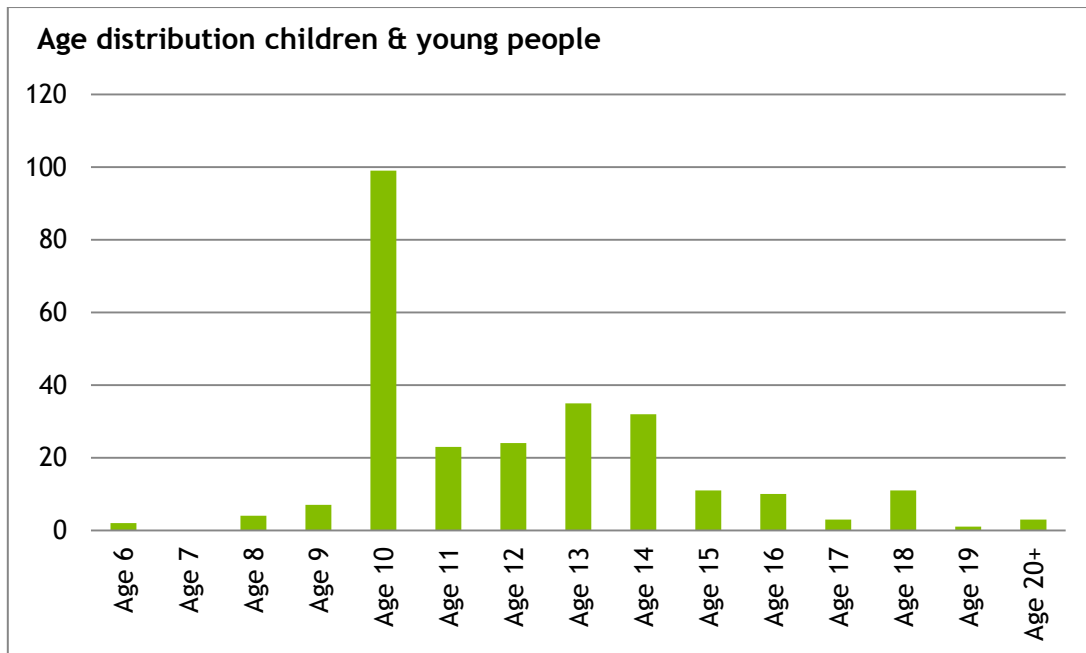


**Age of children and young people**



Although our target age was 10 to 14, we could not always control the ages of participants. Some groups catered for children older and younger than this who could not be excluded from the group simply because of our presence. The most common age range was 10-14, which accounted for 212 or just over 80% of the children and young people we spoke to. The youngest participant was six and the oldest was 24.

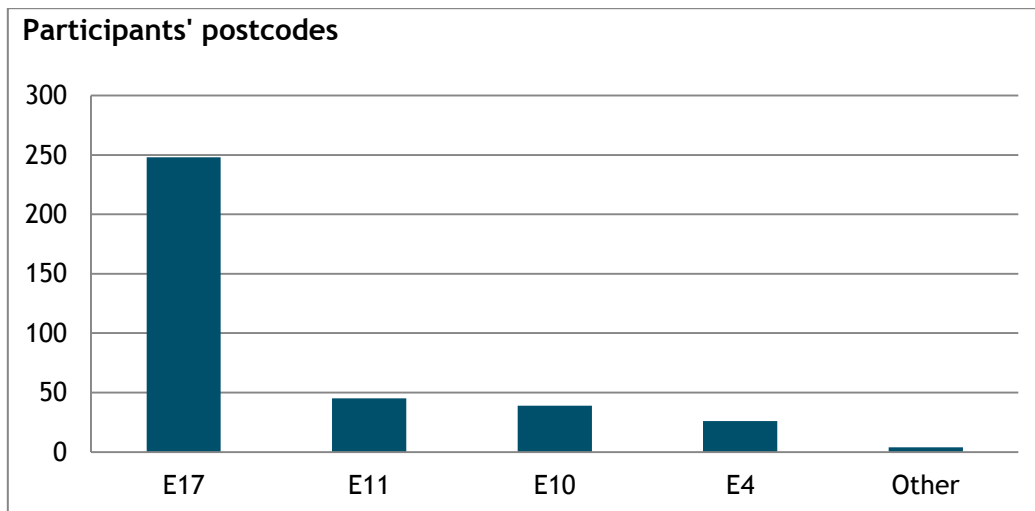
**Fig 5: Ages of children and young people**



### Where people lived

We asked all participants for their postcodes, to ensure that we had a distribution of residents across Waltham Forest. By far, E17 was the most common postcode (247), followed by E11 (44), E10 (37) and E4 (28). The data is somewhat skewed by the pupil data because for two schools the main catchment area was E17.

**Fig 6: Participants' postcodes**



## Detailed findings

The report is divided into four main sections as listed below. Each section starts with a context box providing relevant background information from existing reports, and is followed by the views of the professionals we spoke to, a summary of the questions we asked, and the views of children, young people and adults we spoke to. The main themes and issues are set out as prioritised by research participants. For example, the services in Section C are listed in the order of their significance to participants and the amount of comments each received. Where appropriate, the views of adults are presented separately from those of children and young people, unless no difference was found. Any additional considerations raised by people from specific communities are noted. Each section ends with a summary of issues identified and a list of recommendations.

As we were partly led by the topics participants wanted to raise, not every individual or group was questioned on every topic.

All views and comments that we gathered were analysed, grouped and are presented in sections as follows:

- A. Awareness and access to services, including how people get information about health matters and services, and any language issues.
- B. Children and young people's views on their input, consent, autonomy and confidentiality.
- C. Views given on specific health topics highlighted in previous reports and research, and by professionals. These were breastfeeding, weaning, immunisations and healthy eating.
- D. Opinions and experiences on individual health services, such as GPs, health visitors and mental health services, as prioritised by those in the focus groups.
- E. Issues and views given on safeguarding and social care services.

## Section A: Sourcing information, awareness and access

### Context

How people get information is a fundamental topic relevant across all ages and groups. It underpins a range of health-related issues.

Health is a vast and multi-dimensional issue, encompassing anything from health conditions and services, to accessing health information, lifestyle and more. The challenge for this piece of research was focusing on discrete areas which would be meaningful to everyone and provide useful information.

### Questions we asked

This topic underpins all other issues discussed, so it was also important to explore participants' awareness of the services available, whether they access these services and how often, and any differences across groups. Within this, the impact of language on access to services was investigated, as there are relatively high numbers of people in the borough who speak English as an additional language.

We asked parents, children and young people where they tended to look for health information, where they received health information, how they rated the different sources they used and the extent to which they used the internet to access health information. A number of questions were asked to cover the issue from different angles, in order to get a more thorough understanding and maximise the reliability of our data.

This section covers:

1. Sourcing health information: how and where adults, children and young people obtain health information, including views on using the internet and NHS 111.
2. Awareness of the health and social care services available.
3. Experience of access to services, including language issues.

### Sourcing health information

All groups reported using a range of sources to obtain information on health:

- Children and young people said they mainly relied on their parents. Other than that they said they would use the internet, ask the GP, and/or would possibly ask youth workers (if they used them) teachers and school nurses.
- Parents said that they were most likely to use in this order: family and friends, professionals, the internet and NHS 111. The most likely professionals to ask were GPs, health visitors, midwives and children's centre staff. The inclusion of the latter three groups probably reflects the fact that most of those participants who were parents had quite young children. Parents said they relied heavily on word of mouth from family and friends, both for actual advice on health concerns as well for judgment about local services:

*All life is experience and [you] get something from friends, colleagues...or if you come to the groups, this person says something or that person says something about childcare or health and friends and colleagues are great; reviews from friends - did you go there? Or how was it?* [Parent]

For all ages, obtaining accurate information was reported to be difficult. Besides wanting advice to help diagnose or treat an illness, questions for new parents and those with very young children centred on breastfeeding, weaning and sleeping. Comments on these three topics are set out more fully in later sections, while this section looks at attitudes to obtaining health information in general.

### Views on the internet as a source of health information or advice

After asking open questions about where people sought information about health matters, we asked the adults, children and young people in our groups to rate the reliability of the internet as a source of health information.

On the positive side, the internet was said to contain plenty of advice and to be very accessible. It was felt that on some topics the internet can provide more depth and provide information in an easy-to-understand way.

*There will be certain things that my doctor will say and they will be correct. However he [GP] doesn't say it in enough depth. So I have to research it to find out more. It gives me a wider understanding and explains my symptoms...So I find that it was better than what the doctor had said... but not start completely from scratch.* [Child or young person (CYP)]

*The doctor will tell you everything, but not in the terms you understand...So the internet lets you do that.* [CYP]

Examples were given of successful self-diagnosis, including one ten-year-old who diagnosed that a wound she had received on a bouncy castle was infected, would probably need antibiotics and that she should seek medical help. It was also said that the NHS Choices Symptom Checker facility asked the same questions as the doctor, which boosted confidence in it. Some young people found the internet useful on issues such as healthy eating, assistance with dieting and smaller complaints, as well as for supplementing and explaining advice from a doctor.

For parents who spoke English as an additional language, language was the determining factor when it came to seeking information. As well as consulting family and friends, adults who spoke English as an additional language - most notably those new to the country and from Eastern Europe - tended to look on the internet for information in their own language, even if they later supplemented it with information from elsewhere. For that reason, the internet was more likely to be their first port of call. This enabled people to get information in their own language, understand the parameters of an issue more fully and get more detail than would be possible if reading or speaking English, or talking to a professional. Google was used for broad searches, and some information was found on

social media, such as Facebook. Some participants were not aware of websites in their own language that are written and vetted by professionals (i.e. the equivalent of NHS Choices).

However, when we asked how they reliable they judged the internet as a source of health information, most adults, children and young people said they did not think it was that reliable. Those who reported using it appeared to be quite knowledgeable about its limitations and said it could not be universally trusted.

*The problem with the internet is that you think you're dying. The symptom checker is ok, if you know the terminology. Otherwise it's frightening.*

[CYP]

The main methods reported to test the accuracy of a website's contents was to visit several sites, compare them and look for consistency in information. Children and young people were more aware of how to identify a government site, with the ending .gov.uk.

*I will look at two or three different sites, not just one, and then will know.*

[Parent]

Few had heard of the NHS Choices website, but more were aware of its predecessor, 'NHS Direct'. Children and young people were found to be more aware of NHS Choices than their parents. Also children and young people were much more aware of the limitations of the information on the internet and provided a wide range of reasons as to why it could not be implicitly trusted, or is not suited to health problems.

*Sometimes they [doctors] do give you vague terms and big words... it helps you to use the internet to find out what these are. But if you're feeling something, you can't just go on the internet and start diagnosing yourself, maybe if you're very intellectual or you've studied medicine ... but you can't always be sure about what you find on the internet.*

[CYP]

*Not good if you don't know what specifically you're looking for... but it can be good if you know what you're looking for.*

[CYP]

*If you know what you're looking for it can save you going to the doctor or hospital. But sometimes it gives you the wrong information and you might think you have something really different.*

[CYP]

Children and young people were able to provide more drawbacks to the internet than the adults and across the groups the following list was given:

- It is necessary to know what is wrong before starting to search.
- The information can be frightening and can make people anxious that there is something very seriously wrong.
- Good advice is tailored to an individual and their symptoms. Doctors are better able to give meaningful advice.
- It is better to ask parents (in other words a close adult).
- It is easy to arrive at the wrong diagnosis. One young person said that they and their mother had followed the advice on the internet, taken the medicine advised and ended up in hospital.
- Some websites are better than others, but relative quality is very difficult for the user to determine.
- The quality and accuracy depends too much on who writes the site and their agenda.

*People can have a minor issue that they try to diagnose themselves by using the internet and they find they think they've got something worse that they've actually got and that can be bad for your health.* [CYP]

*It's so easy to find something with so some many similar symptoms... and it's something so outrageous and it's so easy to misdiagnose yourself because you are not a doctor.* [CYP]

*There is no point in the internet because you can get wrong advice.* [CYP]

*It could give you the wrong advice and it could be harmful and you could tell other people, but you might not know it, and you could tell other people and it could be dangerous for someone's life.* [CYP]

## Obtaining information from medical professionals

The majority of participants expressed a preference for getting advice from doctors. However, adults, children and young people alike reported not always being able to explain themselves to medical professionals, or understand what professionals were saying to them. Some professionals were said to be better than others at repeating or explaining the information to ensure that patients understood. Most of the comments and criticisms reported in this section relate to doctors and, within that, were mainly about general practitioners.

*They will always try to explain if they see that you don't understand and they will ask are you sure you understand and if not they will repeat. They try to explain in a different way or an easier way for us.* [Parent]

*I ask her if she can speak slowly because I cannot understand you...she said she 'was busy'...I didn't go back to her.* [Parent]

The barriers to explaining oneself or understanding what was being said were felt to stem from:

- Professionals' use of technical terms and medical jargon.
- Not having enough time within a consultation, especially with a GP, plus patients feeling very conscious of not wanting to waste the doctor's time.
- Difficulties talking about certain issues, such as women's health, mental health and other subjects that are considered sensitive.
- Language barriers. Difficulties understanding and/or being understood, were most marked for, but certainly not limited to, adults who spoke English as an additional language. This worked both ways: adults were more likely to say they did not feel they could explain themselves fully in English, while both adults and children said that at times they could not understand a doctor or nurse because their English or their diction was not clear enough. Language is covered in more detail below.
- Missing the nuances, either when trying to describe symptoms, or when doctors were giving a diagnosis or treatment options.
- Doctors speaking very quickly.
- Parents of children and young people with long-term conditions such as learning disabilities said they had to be 'expert patients' and attend consultations pre-armed with information so as to know the right questions to ask.
- For children and young people, doctors did not always take the time to explain things to them or ensure that they understood. This aspect is covered further below.

*The words are too big.*

[CYP]

## Using the NHS 111 telephone service

We were interested in finding out how much participants were aware of and used the NHS 111 telephone service to obtain information about health. On the whole, awareness of this service was very low across older and younger groups, and some thought it was the non-emergency number for the police.

Of those who knew it and had used it, it received mixed reviews. On the one hand it was considered quite useful, especially at times when the GP surgery was closed, or when participants could not leave the house (e.g. when alone with a sick child).

*111 is good because it help us and tell us where to go and it is a quick way... but they ask you a lot of questions.*

[Parent]

However, the expertise of the advisers was questioned. It was felt wise to have previously checked symptoms and have an idea of what was wrong beforehand, as otherwise 'they may frighten you'. Those who had used the service felt that too many questions were asked and were not convinced that all these questions were necessary. Those who had checked online beforehand reported being asked the very same questions as on the NHS Choices website, which further undermined their trust in the service's competency.



More fundamentally, it was considered too challenging to describe symptoms fully or correctly diagnose a problem over the phone. There was a feeling that the usual outcome of a call was advice to visit the GP or hospital.

Some of those who had used the service liked the fact that the NHS 111 operatives would commonly call an ambulance and alert A&E, as this circumvented normal waiting times in A&E. Others saw this as the only thing that NHS 111 really did and felt it was a waste of resources, especially in a non-emergency situation:

*...they are too quick to call the ambulance ...I don't think it's always needed. ...I called because my son was vomiting and there was some blood in his vomit and they said they would call an ambulance. I said I don't think it's serious enough to warrant an ambulance and I can take him in the car. They are too quick to call an ambulance... The ambulance is for a life and death situations. [Parent]*

*I called [NHS 111] for my kid because he was having a fever for hours. The GP was closed. They just want to send an ambulance. But I just wanted to know which type of medicine to give her and the ambulance came and they took her temperature and gave her paracetamol. [Parent]*

## Awareness of health and social care services

### Questions we asked

Before asking people about their experiences and views of services, it was necessary to ascertain which health and social care services participants were most aware of and, as part of that, whether their understanding of these services were broadly accurate. These questions were also considered important as we were targeting minority groups and, within those groups, adults who were more likely to have migrated to this country within recent years. Both adult and younger participants were given a set of labelled pictures, each showing individual health and social care professionals and services. The use of images was intended to help overcome potential literacy barriers. Groups were asked to divide pictures into those they knew or not and then rank those they knew according to how much they had used them recently. Brief explanations were given if professionals or services were unknown, or their role unclear. This exercise was followed by discussions about the services most known and used.

For children and young people we added a card-matching exercise. We asked them to say which professionals they would advise a friend to approach for different issues, asking: 'If a friend your age needed [what was written on each card], where would you advise them to go?' The cards covered general topics such as 'has 'flu' and 'needs vaccinations', and emotional difficulties, such as 'feeling low', 'feeling worried all the time' and 'being bullied'. These were intended to indicate where children and young people might seek support around early-stage mental health issues.

### What children, young people and parents told us

- Both adult and younger groups were most aware of general practitioners (GPs), hospitals, Accident and Emergency (A&E), specialist doctors, pharmacists, and school nurses. Parents were also aware of midwifery services and health visitors.
- Children and young people in our groups reported having a great deal of direct experience of hospital A&E departments and, to a lesser extent, of being hospital in-patients.
- Much lower and variable levels of awareness were evident around NHS 111, walk-in centres, social workers and youth workers.
- Low numbers of participants were aware of NHS Choices, the Child and Adolescent Mental Health Services (CAMHS), and some other specialist services such as psychologists, educational psychologists, physiotherapists or occupational therapists.

Across the children and young people in our groups, levels of accuracy in the understanding of different professionals' remits were quite variable, but generally low:

- When we asked who they would advise a friend to see for general health conditions, for example to deal with 'flu, children and young people usually said they would recommend the GP, youth worker, NHS 111 and maybe the school nurse, but often suggested attending hospital, calling an ambulance and seeing a specialist doctor.
- A very small minority of young people were aware that pharmacists provided free contraception, advice on contraception and some general health advice. Other suggestions given for contraceptive advice were GPs, walk-in centres and hospitals.

- For emotional and mental health needs, parents, youth workers and teachers were the most likely to be suggested, and GPs to a lesser extent. Those with experience of Child and Adolescent Mental Health Services (CAMHS), or to whom we had just explained CAMHS, would also propose it. Social workers were occasionally mentioned.
- Members of our groups were not clear on how to get in touch in social workers, CAMHS, psychologists or other mental health services.

## Understanding of health system and roles

The health system structure, names, jargon, acronyms and the distinctions across services, agencies and professionals proved confusing, especially for those who had not grown up in the UK. While participants were pleased that certain services that they were used to paying for were free - such as immunisations and GPs - certain operational distinctions took some time for people to understand.

For instance, the emphasis on GPs as the central hub for all referrals and gatekeepers to secondary or specialist care was particularly perplexing for people from Eastern Europe. It was explained that in many countries people could self-refer to see a specialist, or that frontline health care was divided into specialisms. Therefore, the primary care doctor working with children might be a paediatric specialist.

*In my country when your baby is sick, you go directly to see the paediatrician, not the GP. [parent]*

People perceived a deep reluctance to refer patients to specialists in the UK, but they were very happy with the quality of care once they saw a specialist. In some Eastern European countries it was also said to be easier to get, and indeed request, routine screening and blood tests. The restriction on these here, and their control by GPs, was not understood and was sometimes the basis of dissatisfaction.

*In my country see GP and then see specialist. [parent]*

*Until recently in Poland ... the patient decided whether to go to specialist or not, you didn't have to go through GP and usually were correct in majority of times. In Poland patients get everything to hand, not like here when you get X-ray or MRI scan you never see it. In Poland you get a CD or picture and if you ask the doctors explain everything...we're always comparing. [parent]*

*In Poland [it is] common to go to the private clinic, here I still need to have a GP referral... if I want to see someone privately I just go straight way and see them. [Parent]*

*When you ask a GP for blood test it's a big deal. [parent 1]  
They ask you 'What do you want it for?' [parent 2]*

## Experience of accessing services

### Context

Waltham Forest has a very diverse population. Just under one half, or 47%, of all residents are from Black, Asian and Minority Ethnic (BAME) communities, including 62% of children and young people. The southern and middle wards are the most diverse in the borough.

One in four people do not speak English as a main language. A small but significant number (14,250 people, or 6%) do not speak it at all. After English, the main languages spoken in the borough are Polish, Urdu, Romanian and Turkish<sup>8</sup>.

### What professionals told us

Professionals we spoke to said that all health and social care services provided interpreters if needed. However, services need advance warning that an interpreter is required in order to book one and to ensure that the right language is lined up. Even if interpreting needs have not been anticipated, services can make use of a telephone interpreting service. Professionals said that a double GP appointment was usually necessary if interpreting was required, because of the slower, three-way communication, but double appointments were reported to be difficult to secure sometimes.

Professionals also pointed out that language needs change according to the arrival of new groups into Waltham Forest, which they described as a 'very mobile borough'. For that reason the range of languages provided by staff, or translated into leaflets or other information, needed to be reviewed every few years.

The Roma Support Group Coordinator reported that amongst the Roma population in Waltham Forest, language requirements were quite complex and that numerous different first and second languages are spoken. Most Roma people in the borough were said to come from Poland or Romania. Adults were most likely to speak one of eight Romanes dialects, either alone, or alongside a national language, such as Polish or Romanian. The dialects were said to sometimes differ so substantially that it can be easier to converse in the national language. Children and young people who grew up in Britain may only be fluent in one of the Romanes dialects and English (in other words not Polish or Romanian). This means that services need to clarify the precise language and/or dialect in advance of commissioning interpreting and that adults and younger people may have different language needs.

In addition, it was highlighted that those who were middle-aged or older were commonly not literate. Therefore providing written translated information was said not to be a useful alternative. Older people from this community in particular did not use the internet and we were told that even when information was being provided verbally, this needed to be done in short, easily-remembered chunks and repetition was essential, as everything

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<sup>8</sup>From the London Borough of Waltham Forest Joint Strategic Needs Assessment, May 2014

relied on memory. In other words, telling someone all the information at once was likely to be confusing and counter-productive.

### Questions we asked

We asked all participants how much they felt they were understood by health professionals and how much they understood what professionals said to them. We asked people to give their positive and negative experiences and views on the services they had used most recently.

As Healthwatch was particularly interested in the experiences of minority communities, and especially people from Eastern Europe in accessing services. We probed this area extensively and also probed if language presented any barriers, and the extent to which interpreting facilities addressed any such barriers.

### What parents, children and young people told us

Responses were analysed thematically and are presented according to how frequently issues were raised by participants and the priority they gave these. Points made by focus group participants fell into two main themes, each with sub-themes:

- Language barriers
  - Interpreting
  - Family members interpreting
- Getting GP appointments
  - Difficulties in getting GP appointments
  - Emergency and same-day appointments
  - Attending A&E instead of a GP
  - Awareness of, and access to, NHS walk-in centres
  - GP consulting periods
  - Uncomfortable waiting areas in GP surgeries and A&E
  - GP receptionists

These are discussed in the sections below.

### Language barriers raised by focus group participants who speak English as a second language

Language barriers were identified by many participants. Difficulties in making appointments were reported by some, but not all, of those people from Eastern Europe as well as those from Asian, African and other backgrounds. Problems were aggravated if both patients and GP receptionists spoke English as an additional language. Difficulties were experienced in making appointments, especially over the phone, for example to get a same-day appointment. Because of this many preferred to attend the surgery in person to make appointments, although this was not always feasible and could create other difficulties. For example, some receptionists were reported to not like people turning up in groups, although for Roma people this was often essential so that other family members could interpret.

Even if an appointment was obtained, language posed a barrier within consultations with professionals. However, many found GPs very helpful when it came to explaining things and said that they would rephrase and repeat as necessary and arrange interpreting or use the telephone interpreting service.

*They will always try to explain if they see that you don't understand and they will ask are you sure you understand and if not they will repeat. They try to explain in a different way or an easier way for us. [parent]*

*At my medical centre (Forest) there is a Polish doctor as well and in some cases they might ask for his help to interpret. [parent]*

Adults felt problems mainly arose if they were not proficient enough in English to explain themselves, but adults, children and young people who were fluent also complained about not being able to understand doctors, especially if they also spoke English as an additional language, had a strong accent or spoke quickly.

## Interpreting

Some of the parents we spoke to had not realised that they could ask for an interpreter.

Although some doctors used the telephone interpreting service routinely, there were also numerous complaints about professionals not arranging any interpreting. This meant that the patient felt they could not explain their symptoms, ask questions, be understood or understand what they were being told.

*Last week I had (my first) appointment with the midwife and she came without an interpreter I don't speak very well English. I speak Arabic and French. [parent]*

In one case language barriers had contributed to a serious misunderstanding, which could have resulted in their child being removed into care, as the mother could not understand or provide information:

*... GP said 'you burn him... I call health visitor because you don't look after your child'... I feel very upset and feel like crying... I rang my husband...they tell him your wife she cannot speak English... I did not tell them anything like this. Thirteen other people have to see my baby to confirm this is not a burn...I was afraid. Then they say it is an allergy and not a burn. [parent]*

## Family members interpreting

The mothers we spoke to said they commonly relied on family members or friends to accompany them and interpret. They reported that this could often result in the doctor speaking mainly, or solely, to the interpreter. Using children as interpreters was also found to be common and some of the children said they did the interpreting if they were at the doctor's with their parents, both for their own issues, or for their parents.

*...my children interpret: I understand but can't speak and explain myself fully [parent]*

However, parents said they did not like using children as interpreters for several reasons:

- If the appointment was in the daytime (and often no evening appointments were available) it meant keeping a child off school.
- Parents were also reluctant to talk about certain health issues through a child.

Professionals concurred with this and said that many parents found it difficult to discuss certain issues with a professional in any case, particularly gynaecological and mental health issues, and would avoid discussing these in front of their children. One example was highlighted of a Roma woman who could only use her son to interpret and found it difficult to talk about her symptoms for cultural and other reasons, and was especially reluctant to discuss them via a boy. Eventually she was admitted to hospital as an emergency, diagnosed with cervical cancer and died two weeks later.

In our groups, the following was recounted by one Asian woman, via another group member who translated:

*...They cannot understand me and I can't speak English. I need to see a female doctor ... I already told them that I cannot explain my problem to them, but they did not offer anything, an interpreter or anything... Everyone is busy ...I don't know who to take. ...The [female] doctor is not available in the evenings... (when children could go with her). [parent]*

In the end another woman in our group offered to go with her.

The level of English proficiency required by patients was said to be much more demanding and more technical than what was needed in other circumstances, even for those who were quite fluent. Many adults who spoke English fluently, but as an additional language, said they often did research in advance of an appointment, looked up words and used Google Translate to help them prepare what to say.

*It depends. If it's something simple like 'flu, I can explain myself. But if it is something big... I will prepare beforehand at home and bring the dictionary. Sometimes I understand all but not always the medical words... [parent]*

Even if they aware that interpreting could be provided, those who were reasonably proficient in English said they tended to save this for something they felt was 'serious'.

## GP Appointments

Problems getting GP appointments were raised spontaneously in every focus group held, and there was clear anger and frustration. The findings for this report echo some of those raised in the 2013 and 2014 Healthwatch Waltham Forest reports on GP services in the borough<sup>9</sup>, while looking in more depth at the concerns of families, children and young people.

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<sup>9</sup><http://www.healthwatchwalthamforest.co.uk/reports>

The problems highlighted included: difficulties getting appointments and the use of A&E as an alternative; being expected to wait a long time to see the GP, even if you have an appointment; short consulting periods; uncomfortable waiting areas and the attitudes of some receptionists.

### Difficulties in getting GP appointments

Those we spoke to described different appointment systems being used across GP practices in the borough. The ease of making an appointment was considered to be a matter of luck, being dependent on the process in place at a particular GP practice. It was commonly said that GP appointments were only available a number of weeks in advance. People felt this was pointless because usually they would be fully recovered by then.

Some surgeries were said to operate a same-day policy, on a first-come, first-served basis. While having the opportunity to see a doctor on the same day was greatly appreciated, the number of appointments was limited and the process for accessing them was difficult. In most cases, patients had to ring the surgery, usually during a limited time-window. Phone lines were said to be constantly engaged. Participants said that usually by the time they got through, all the appointment slots were gone and a recorded message would advise them to try again in the afternoon, or the next day, which they found very frustrating. The limited periods during which patients could call were further criticised when the appointments were for young people, as the window for the calls clashed with school hours.

For those without good English, visiting the surgery in person to book an appointment was preferable as they often could not understand what was being said over the phone.

At some surgeries people could queue in person and - as long as they arrived very early and were able to wait for an hour or more - could get an emergency appointment that day. However, parents said that waiting quietly in the reception area 'for hours' for the emergency appointments was very challenging for children, and even harder for those children and young people with behavioural problems.

At some practices appointments can be booked online, but this was not felt to guarantee any greater access, as again it was said that appointment slots were quickly filled. In addition, not everyone we spoke to was able to access online booking and some did not like this method. Younger people were happier with online booking in principle, although no luckier in practice.

Those who managed to get appointments were angry that if they arrived a few minutes late, they were told they were too late to see the doctor and had to rebook. But if they arrived on time or early, they normally had to wait a very long time, regardless of their appointment time. Patients viewed this as grossly unfair.

*... if you're five mins late for appointment - lose it, then told to come again later, then told to come next day and so on - that's very difficult to do if you have children. [parent]*



While certain GPs offered telephone consultations, this was not found to be the norm.

*If I go with my child, but don't have an appointment, or can't make an appointment, the doctor will phone you back and talk to you. [parent]*

On the other hand, not everyone liked telephone consultations, especially if speaking or understanding English was an issue.

## Emergency and same-day appointments

Parents wanted to be able to get an appointment on the day when they considered their own or their child's condition to be critical. They stressed that this was essential with babies and children, as health problems can be difficult to diagnose at home and can escalate very quickly.

While some local GPs were praised for always creating a time to see a sick child, even if all the appointment times were officially taken, this approach was not universal. Parents sometimes said that they had learned to always tell the receptionist that it was an 'emergency' in order to get seen by the doctor and avoid waiting weeks for an appointment.

*Appointments take a long time - takes two weeks at least...very busy...But if I go with my child and [say it's an] emergency they will see me now... not two weeks [parent]*

## Attending A&E instead of a GP

People regularly told us they went to A&E, for example for a high temperature or 'flu, as a direct result of not being able to get a GP appointment. And by all accounts they did not mind the waiting time at A&E, as long as their child was attended to.

*The main problem is getting an appointment. They always say to you it will be a week's time. If you're really ill, go to the A&E. [parent]*

*Same for me, rather than calling the GP, 'cos I know what the answer will be, I'm taking him straightaway to the A&E. Basically if a high temperature or vomiting, I will go to Homerton...They will check him properly and straight away and will give him Nurofen [parent]*

*If you're really ill, just go to A&E. ...I go to A&E for 'flu, high temperature. A&E will triage and prioritise, wait ... 3 hours, always 3 hours ... [parent]*

These findings confirm those found by Healthwatch Waltham Forest in autumn 2014<sup>10</sup>. Roughly one in five said that they were attending A&E instead of going to see a GP.

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<sup>10</sup>500 people attending Whipps Cross A&E were surveyed. This included responses from, and on behalf of, 129 children and young people aged up to 18. HWWF October 2014

## Awareness of, and access to, NHS walk-in centres

Only a minority of participants in every focus group said they were aware of NHS walk-in centres. Therefore in each group we had to explain what these were and where they were located in the borough. Some of those who attended Whipps Cross Hospital in an emergency may have attended the walk-in centre rather than A&E, but were largely unaware of the distinction. Those who reported using walk-in centres were very happy that they were open at times when their GP was closed and that they did not require a prior appointment. However, people generally preferred to see their own GPs, not only because they knew each other, but also for a sense of continuity.

Waiting times in walk-in centres were found to vary and unsurprisingly people were happier if the wait was shorter in general and shorter than those experienced at their GP's surgery:

*I walked in and got help. Waiting time was shorter than at my GP. [parent]*

*If I don't have an appointment with the GP I go to the walk-in Centre. It's in Leyton. I'd prefer to see my doctor but have to use - not a choice. Last time waited an hour which is fine. [parent]*

## GP consulting periods

The length of appointments and the system of only allowing one issue to be discussed per consultation was widely criticised. Young and old felt they could not explain themselves fully in the allocated time, especially if it was a difficult, emotional, embarrassing or complicated issue. They said they often felt that the doctor was rushing them.

*... then he can't wait to get you out... you walk in there with an emergency appointment and then you're out in 5 mins. [parent]*

It was also felt that the allotted ten minutes was much too short for those with language barriers and/or if interpreting was being provided.

## Uncomfortable waiting areas in GP surgeries and A&E

Being expected to wait for a long time, either in GP surgeries or in hospital A&E departments, was said to be difficult for children and young people. This was additionally problematic for anyone with behavioural problems. GP waiting areas were often criticised for being dirty, airless and boring. One mother praised her GP surgery for allowing them to wait outside in the car until it was her child's appointment time. That way they did not get distressed or disruptive in the waiting area. However, another parent said their surgery had unrealistic expectations that she should be able to keep her autistic child silent while they waited:

*You have to be really quiet. Don't allow mobile phones, or anything ... I know that, but they expect you to sit there for an hour. Can't say a word - if say a word, [they] ask you to leave ... Even if you have an appointment you wait an hour. I've told them my daughter has autism. They just ignore that. But you still have to wait an hour. [Child is]...not really disruptive, but will ask 'what does that say?' the receptionist is rude and tells us to stay quiet... Nothing for children whatever. [parent]*

Some adults, children and young people we spoke to criticised the fact that there was usually nothing for children or young people to do and that in most surgeries electronic devices, mobile phones or even talking were forbidden. Participants said that, at best, waiting areas might have 'old women's magazines' and some broken play equipment, usually designed for very young children. Notably the children and young people were extremely critical of the level of hygiene in most waiting areas and toilets. They reported that this, combined with the smell and waiting for a long time among a lot of sick adults, was very off-putting.

### **GP receptionists**

While attracting praise when helpful and friendly, receptionists were more likely to be criticised by those we spoke to for being unfriendly, uninformative, impatient or abrupt. Other complaints included receptionists asking personal questions, trying to discuss medical issues with patients and, apparently, attempting to diagnose patients rather than letting them see a doctor.

Summary findings	Recommendations
<b>Sourcing information and access and awareness of services</b>	
<p>Awareness of the NHS Choices website and NHS 111 is relatively low.</p>	<p>Health Visiting leaflets to highlight NHS 111 and NHS Choices.</p> <p>Promotion of NHS Choices and NHS 111 services within the maternity unit and appropriate hospital departments, e.g. A&amp;E and Acorn Ward.</p> <p>Outreach and health education sessions at Children's Centres to promote awareness of services and the CCG <i>A Parent's Guide to Child Health and Common Illnesses</i> health booklet.</p>
<p>Little is known about services for children's health and for young people with mental health difficulties.</p>	<p>Services to work collectively to develop and deliver a rolling programme of outreach and awareness-raising around services, as well as building better relationships and partnerships with children's centres, nurseries, primary and secondary schools to deliver these.</p> <p>Ensure an increase in school nursing contracts, establishing drop-in clinics at all secondary schools to inform young people about what is available for them.</p>
<p>Awareness of mental health services is low across all groups.</p>	<p>Providers of mental health services to develop improved communications and outreach education programme(s), and build better relationships and partnerships with local groups, community networks, schools and colleges.</p>
<p>Young people have very low awareness of free contraceptive services.</p>	<p>Providers to evaluate current uptake of C-Card and broaden outreach programmes and links with schools and colleges and other local groups and networks.</p> <p>Information to be made available in all GP surgeries and pharmacies and other services that young people access.</p>
<p>The split between primary and secondary health care professionals, and especially the central coordinating role of GPs, is somewhat perplexing to people from Eastern Europe.</p>	<p>Key partners to collectively develop and deliver targeted outreach and health education sessions within these communities to increase awareness of, and access to, health services.</p> <ul style="list-style-type: none"> <li>- Recruit community development officers with appropriate languages.</li> <li>- Link sessions with immunisations awareness.</li> <li>- Link sessions with public health commissioning.</li> </ul> <p>Audit uptake of interpreting services by different providers and ensure improved access and use.</p>

Summary findings	Recommendations
Awareness and use of NHS walk-in Centres is variable, but generally low.	<p>Review publicity and marketing of Oliver Road Walk-in Centre.</p> <ul style="list-style-type: none"> <li>- Link to GP Extended Hours advertising</li> </ul> <p>Consider opportunities for baby/child/family health services at the location.</p>
The NHS 111 telephone service is mainly relied upon to avoid queuing at A&E.	<p>Work with local, regional and national partners to deliver awareness-raising about NHS 111 and other local services available to families with babies and young children.</p> <p>Feedback findings of this report into commissioning of urgent care services and NHS 111.</p>
A range of information sources and avenues must be used simultaneously to target information at children, young people and parents.	<p>Map current sources and avenues used by health and social care services to inform parents and families of local services.</p> <ul style="list-style-type: none"> <li>- Consider how to better use technology and link in with the GP texting scheme, for example.</li> <li>- Consider use of community languages for key information materials.</li> </ul>
Obtaining accurate, reliable and consistent health information can be difficult.	<p>Key health professionals, partners and parents to jointly develop and agree key messages, starting with breastfeeding and weaning guidance.</p> <ul style="list-style-type: none"> <li>- Utilise existing CCG Parent's Guide booklet and confirm cross-sector commitment to key messages.</li> <li>- Link to NHS Choices information.</li> <li>- Link to Council and CCG website information/messaging.</li> <li>- Distribute messages via local parent Facebook and Twitter groups.</li> </ul>
Information needs of Roma communities centre around verbal communications.	<p>Commission targeted work to understand and find solutions to address the communication needs of Roma communities.</p> <ul style="list-style-type: none"> <li>- Recruit community outreach officer(s).</li> <li>- Health and social care partners to consider Big Lottery Reaching Communities application.</li> </ul>
Children and young people with long-term conditions have to become their own experts in order to get the information and advice they need.	<p>Adopt the principle of co-production and involve children and young people in the development of current pathways.</p>

Summary findings	Recommendations
<p>The internet is often the first port of call for health information and advice where English is a second language - websites available in first language are commonly used.</p>	<p>Consider the need to make the current CCG Parent's Guide booklet available in community languages.</p> <ul style="list-style-type: none"> <li>- Develop a programme of outreach and distribution to in-reach into communities.</li> </ul>
<p>Time-limited appointments when visiting the GP and language barriers (both on the patient side, but also on the GP/professional side) prevent children, young people and families getting information directly from health professionals (their preferred method).</p>	<p>Audit uptake of interpreting services by different GP practices and develop actions to ensure improved access and use.</p> <p>Standardise local procedures for booking double appointment slots where interpretation needs are present.</p>
<p>Language barriers create problems in making GP appointments, especially over the telephone, but also during consultation. However, some GPs handle this difficulty well and to the satisfaction of the patient.</p>	<p>Audit uptake of interpreting services by different GP practices and develop actions to ensure improved access and use.</p> <p>Enlist high-performing practices in sharing good practice across the sector.</p>
<p>Interpreting is not routinely arranged by GPs or other professionals.</p>	<p>Audit uptake of interpreting services by different GP practices and develop actions to ensure improved access and use.</p>
<p>Using family members, including children, as interpreters is common, but not desirable.</p>	<p>Audit uptake of interpreting services by different GP practices and develop actions to ensure improved access and use.</p>

Summary findings	Recommendations
Interpreting needs of Roma patients may be difficult to anticipate as many different dialects are spoken - the interpretation needs of Roma communities are not currently being adequately met.	Commission targeted work to understand and find solutions to address the communication needs of Roma communities.
Medical and technical language is inaccessible to most children and young people and some parents, even for those fluent in English.	Establish a patient communications testing group to review new leaflets/materials, etc. Work with schools to develop better understanding of medical and health-related terms and phrases.
There are changing language needs in the borough.	Review staff languages, community language leaflets and information, and interpreting services every 2-3 years.

Summary findings	Recommendations
<b>GPs</b>	<b>Overall, feed findings and recommendations into the Primary Care Commissioning Committee and Primary Care Strategy Action Plan.</b>
Access to GP appointments is the largest single issue identified by the children, young people and parents we spoke to: difficulties in making appointments; getting through on the telephone; being expected to wait several weeks on some occasions and the lack of emergency appointments were identified as issues.	Review findings against current Primary Care Strategy Action Plan. Report issues identified by parents, children and young people to Primary Care Commissioning Committee.
Appointment systems and availability vary widely across GP practices in Waltham Forest and there is a lack of standard practice.	Audit normal and 'urgent' appointment booking procedures at all GP practices. - Seek to develop a consistent approach.
Same-day appointments are greatly in demand - parents feel it is essential to have access to emergency appointments for sick children.	Review availability of same-day health services for parents with babies and young children, including access to telephone or drop-in support.
Parents have learned to tell the receptionist it is an	Audit normal and 'urgent' appointment booking procedures at all GP practices.

Summary findings	Recommendations
emergency in order to be seen that day.	
Participants commonly reported going to A&E with infections and high temperatures because of not being able to see a GP.	Audit normal and 'urgent' appointment booking procedures at all GP practices.  Review availability of same-day health services for parents with babies and young children, including access to telephone or drop-in support.
The ten-minute and single issue limit on GP consultations is an issue for patients and is widely criticised. People with English as an additional language are particularly disadvantaged by this time limit.	Standardise local procedures for booking double appointment slots where interpretation needs and or other needs are present.
Receptionists sometimes attracted negative comments for how they communicated and for a perceived lack of respect for confidentiality.	Implement customer service training for all practice staff.  Ensure receptionists have the opportunity to feed back and influence practice, customer service and information governance improvement plans.
Access to telephone appointments, whilst appreciated, is not preferred by those who have difficulties in speaking or understanding English.	Review communications and awareness-training available to practice staff answering phones.  Audit uptake of interpreting services by different GP practices.
GP waiting areas were described as being unsuitable for children and young people. It is common for there to be nothing for children and young people to do whilst waiting in surgeries/hospitals for appointments. Signage prohibiting use of electronic devices, mobile phones and even talking exacerbates patients' comfort when waiting.	Undertake mystery shopping of GP, hospital and other health service waiting areas with a group of children, parents and young people.
Excluding issues around the appointments system and GP access in general, participants were generally very complimentary of the care they received from GPs.	Develop case studies to share examples of good practice.
GPs' manner, communication and the information given to patients are areas for improvement.	Review training offer available to all practice staff.
Confidence in GPs is undermined when they look up information on the internet during consultations. This issue was particularly reported by patients from Eastern Europe.	Share feedback with GPs through educational sessions and gather feedback on why the practice takes place. - Incorporate feedback from GPs into awareness and outreach education sessions with communities.



Summary findings	Recommendations
Common advice to take paracetamol and the limitations of antibiotics in treating many infections is not widely understood and leads to dissatisfaction with GP consultations - antibiotics are viewed as an indicator of having a thorough examination.	Gather feedback from GPs and develop educational information about these practices for dissemination across communities and embedding within community outreach/education programmes.
Patients' experience a reluctance to refer to specialists/tests which can be a basis for dissatisfaction.	Audit levels of referrals to establish whether reducing referrals is a reality.
GPs' knowledge and understanding of learning disabilities and special educational needs, requires improvement, as do their skills in dealing with this client group.	Parents with specialist knowledge to be supported to develop awareness-raising training for GPs.

## Section B: Children and young people's input, consent, autonomy and confidentiality

### Context

Several pieces of legislation and official policy guidance spell out children's and young people's rights vis-a-vis health services<sup>11</sup>. These include their rights to have services meet their needs, to be informed and consulted on matters that affect them, to have their confidentiality and privacy respected and to be asked for their explicit consent for treatment.

### Questions we asked

This issue was mainly only discussed with children and young people. In this research we were interested in finding out from children and young people how much they were involved in discussions about their care and to what extent their views about, and consent for, treatment were sought by health professionals. To this end we asked the children and young people in our groups to indicate how much they agreed or disagreed with each of a series of statements. We then followed up this by asking for explanations and examples.

### What children and young people told us

Children and young people we spoke to reported that their experience of being given information and their understanding of what they were told varied substantially. What we gleaned was not a very encouraging picture and involvement did not necessarily increase with age, as illustrated by the ages of those quoted (given in brackets after quotes). These issues are discussed in more detail in the following sections:

1. Involvement in health discussions and decisions
2. Asking children and young people for consent
3. Privacy and confidentiality

### Involvement in health discussions and decisions<sup>12</sup>

Being informed of the considerations to do with a condition and its potential treatment is one aspect of informed consent, which underpins most medical treatment in this country. In general the children and young people we saw said they attended GP and other health professional appointments with their parents or carers, apart from appointments with school nurses, which they usually attended without their parents. While being accompanied by their parents was tapering off for those in their late teens, it had not completely stopped for everyone at sixteen. In order to ascertain how much children and young people were consulted on their health issues or potential treatment, we asked how

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<sup>11</sup>For example: *The UN Convention on the Rights of the Child (1989), Article 24*, sets out children and young people's right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health, *The NHS Constitution 2009* and the *Department of Health Quality Criteria for Young People Friendly Health Services 2011*. See references in the Appendix.

<sup>12</sup>Findings on involvement in social care decisions are provided in the section on Safeguarding below.

much they agreed or disagreed with the statement: 'When I am at the doctor (or other medical professional), they always tell me information, not just my mum or dad, or the adult I go with'

Overwhelmingly, the children and young people we spoke to disagreed with this statement. In other words, they felt that medical professionals did not routinely speak to them directly, explain things to them or ask their opinions, but they felt this should happen more. In this section we provide ages to accompany quotes from children and young people as it might help the reader judge the context and appropriateness.

*Sometimes they mainly talk to your parents and don't talk to you. [aged 14]*

*I think children should have a right, it shouldn't just be the parents. [aged 10]*

*It would be better if they listened to the person who had the accident, not to the parents. [aged 11]*

Most children gave examples of doctors talking solely or mainly to the adults and not talking to the child or young person. A few cases were recounted of children being asked to leave the room while the doctor talked to their parents.

*Say if you broke your arm, they look at them [parents] and squeeze your arm and say to you 'does it hurt?' and you say 'yes' and then they say to them [parents] that you've got a sore arm, do this to him. [aged 15]*

*They say '[name] can you go out of the room please, I need to talk to your parents.'* [aged 10]

*I said to them 'can you explain it?' and they said 'get out of the room or I'll give you an injection'. [aged 11]*

Children and young people also said that even when a doctor does talk to them, in practice it can be hard to understand what is being said:

*They talk to me, but they don't explain it well. [aged 11]*

*Most of the time I don't get what they're saying ... it's their accent they use scientific words and then I ask them to explain it and they just use more scientific words. [14 years old]*

*Most of the times when they tell you what's wrong with you, I just nod my head and get my mum to tell me after. [aged 12]*

In addition, when we asked the younger groups what they would prefer, they said they wanted doctors to explain things both to them and to their parents. Some gave positive examples of doctors managing to communicate effectively with both adults and children. The younger people felt that having parents there could be helpful because parents could pick up something that they would otherwise have missed.

*I understand half of it and parents understand the rest. [aged 12]*

*If I don't really understand what the doctor is telling me my parent will usually tell me what I don't understand and then usually in the end I will understand... They explain it more to parents, then to me. [aged 14]*

*They talk to me and tell me how I can do something to make it stop and then they talk to my mum as well and tell her what I can do. [aged 13]*

Another point made was that even if a young person visits a doctor alone, they may not be given a full explanation. For this reason young people felt it can be simpler to go with parents in the first place:

*If you go on your own they don't tell you anything - so better to go with your parents or carers. Then they tell you the whole story. [aged 14]*

Children and young people said they often felt too shy with doctors, especially if it was someone they did not know (which is quite likely if they see different doctors each time), or a doctor of the opposite sex. This was explored further in one group of young people who indicated that both young women and young men were more likely to feel awkward with a male doctor. Having a parent to do the talking in those cases was seen as helpful, as it took the pressure off the young person.

While wanting doctors to talk to them directly, children and young people were also attuned to being patronised and what they perceived as lip-service:

*Sometimes when they are talking to me, they are really talking to my parent. [aged 13]*

*I don't like it when they say to you that everything is going to be alright when something has happened to you. 'Cos when I was in hospital they had to do something to me. They said everything was going to be alright and that it wasn't going to hurt... they were lying to me, because it did hurt. [aged 11]*

We also found many examples of good practice where children and young people were explicitly consulted and their views taken on board, including for quite serious operations and procedures.

*When I had my operation the doctors were talking to me and asking me what I wanted to do. I just told them what I wanted and after that they talked to my parents. [aged 11]*

*When I was vomiting a lot and I had to go to hospital, they gave me a choice either to take tablets or to take a little recipe, to take each night... every day. I had a choice between them two. My mum and dad said 'take the tablets', but because I don't like tablets I chose the recipe. [aged 11]*

Children and young people felt that hospital staff and staff in A&E departments were much better than GPs at speaking directly to them and getting their story directly from them, rather than using the parent as proxy. This could entail having to explicitly tell parents to be quiet. As the quote below illustrates, important pieces of information might be missed by not asking the child or young person directly.

*They [GP] talk to the parents a lot. They'll ask the parent the issue. Definitely, in comparison, if you go to A&E they always ask you. They want to know about you, and they usually tell the parents to be quiet. They usually say 'sorry can you please be quiet 'cos I want to hear how the child explains it'. It's mainly to do with safety, I think, especially with broken arms and fractures. They ...want to know it wasn't the parent. And I think that that's a lot better when they ask you. 'Cos at the [GP] when they ask, the parents will say 'Oh this has happened and this has happened'. But you might not say certain things to your parent. Then it won't be completely accurate. So they might miss something and misdiagnose.*  
[aged 15]

Where appropriate, we followed up this topic by asking young people how much they thought this tendency to mainly talk to the parents was down to the doctor or to their parents taking over. The answers indicate that it could be both.

*Sometimes your mum brings you in when they notice something. Then they'll be talking to your mum. And will ask you have you noticed this? But if for example I go in and say look doctor 'I've had this problem and this problem', then they'll be talking to me. But if my mum says 'oh my daughter has this blah, blah', they'll talk to her.* [aged 16]

*As soon as my mum starts talking she'll just talk... then they talk to me. But whenever they're asking questions they just go straight to my mum and not me.*  
[aged 17]

As mentioned earlier, we also met a number of children and young people who were the main interpreters in their families, so they did all the talking to health professionals and had to explain what had been discussed back to the parents. Thus they acted as the main gatekeepers of information and, in contrast to their peers, knew everything that the doctor decided to say.

## Asking children and young people for consent

### Context

In the UK, the 16<sup>th</sup> birthday is normally the point at which a young person is considered able to understand the implications of, and consent to, their own medical treatment, with or without their parents' agreement, unless they are deemed to be intellectually 'incapable'. Earlier than this, children can consent, or not, to treatment in their own right if they are judged to have the understanding and capacity to understand what is involved<sup>13</sup>.

### What professionals told us

Perceived inconsistencies around consent emerged from our discussions with professionals. One professional compared the case of a teenager under 16 who received a pregnancy test, a hospital ultra-sound and information and advice around their pregnancy, without their parents being informed. In contrast, another young person of the same age who was self-harming was refused mental health support, without parental consent. As the young person wanted to keep this issue a secret from their parents, no treatment was provided.

### Questions we asked

We asked the degree to which children were asked their views and given a say, alongside their experience of adults speaking for them.

### What children and young people told us

In group discussions we found that children and young people were generally unaware of their rights in relation to consent or of more explicit rights when they turned 16. There was also an underlying view that doctors and/or parents know best.

*My mum is experienced and knows all the medicine and she knows most of them it will help. So when the doctors recommend she knows if it will help. I don't know if the doctor is right but if my mum tells me [it's ok]. [aged 13]*

Children and young people appreciated being given some, even limited, choice about treatment:

*When I did go to the hospital because I had to get an operation and the doctors said you can either get the operation or live with bad hearing for the rest of my life. [aged 11]*

*When I was having my operation they gave me two choices: they said we can either do it now or you can think about it and come back tomorrow and do it. [aged 10]*

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<sup>13</sup>This is often referred to as 'Gillick competency'

*When I went to the doctor I had something wrong with my thumb and they said if you do it right now your thumb will feel much better, or if you don't do it, it will keep on getting purple and things will go wrong. [aged 11]*

Conversely those who felt their views or feelings were ignored or overruled were quite unhappy:

*They don't really ask what medicine you want or what will work; they just say that you have to have it. [aged 14]*

*When I had my operation they put me to sleep. I went to sleep in my clothes and then I woke in the hospital clothes... I didn't like that someone had undressed me and stuff. [aged 11]*

Even where young people had some inkling that they could have some say, there was a tendency to feel that they themselves lacked adequate information and that they did not know how to question the doctor's knowledge or disagree effectively, without appearing rude.

One young person said they did not like being prescribed a lot of medication, were worried about becoming addicted to it, but did not feel they could refuse it. Another had found that, despite knowing they had a right to refuse a certain medicine, this was difficult to translate into practice:

*Every time they ask me about a medicine, and I say 'no, not really', but they say 'you have to have it, you just have to have it'. [aged 15]*

Additional consent problems emerged in relation to looked-after children and young people who reported other difficulties in exercising their rights. Examples were recounted where the GP did not know if the young people's vaccinations were up to date as their medical records were either not updated or unavailable. Rather than consulting the local authority or social worker - who count as their Corporate Parent - and despite the young people's wishes to the contrary, they decided to vaccinate because the young people concerned could not give precise dates for earlier treatment. In a similar situation one young person succeeded in not getting the injection by showing their BCG scar.

## **Privacy and confidentiality**

Privacy and confidentiality were raised as significant issues by the older children and young people we spoke to and they said that this was a major deterrent to talking to, or being open with, professionals such as doctors. They also reported that this could mean they clammed up when their parents were present.

*Sometimes if parents are there at the same time, sometimes you don't want to talk. [CYP]*

One reason given was their embarrassment in relation to certain topics in front of their parents:

*Won't be comfortable talking about personal issues and stuff. If it's headaches and really vague stuff, I'd be ok talking to them. [CYP]*

*I'm not comfortable with certain issues and not a confident person anyway. So this barrier would be so hard to talk about... I can't do it. [CYP]*

While some young people volunteered that anything to do with puberty or sexual health would be too difficult to raise with a doctor, we judged that the group settings were similarly not safe enough environments to probe too much into which topics were most embarrassing. As this issue became more evident over several groups, in later sessions we asked young people to write on Post-its what they felt to be the easiest and most difficult subjects. They wrote that the most sensitive topics to talk about were: genital problems, sexual health, alcohol and mental health.

In addition, they said that even if they could broach a difficult subject with a doctor, they did not like the idea that this would be in their records and that the doctor would remember this the next time they met. This presents a contradiction with the general desire to have continuity of doctors.

*Because I see the same GP, I wouldn't want to say something that was a little bit too personal, because ...it's going to be written down and next time I'm here he's going to remember it. If it was someone different, a stranger, I'd probably not mind. [CYP]*

*There's some things you wouldn't really want to ask them as it comes across that they are judging you sort of thing... Sometimes you feel if you were to ask them a stupid question they'll think 'She's just a stupid little girl that doesn't know anything.' [CYP]*

Talking with a doctor of the opposite sex about male or female problems or having a physical examination heightened embarrassment:

*I wouldn't feel as comfortable, especially if it obviously involves checking your body parts. [CYP]*

*Say I was worried I had an STI, I wouldn't feel comfortable having a male doctor checking. [CYP]*

*I wouldn't ask my doctor - like say if I did have a question about sexual health or a question that's specific about being a woman... I wouldn't feel as comfortable about asking my doctor because he's a man. If it was a woman I'd feel a lot more comfortable. [CYP]*

Besides the topics themselves, another significant barrier was their fear that confidentiality and privacy might be broken, especially with parents.



*Say I go to the doctors on my own one time and I might have an STI, but then I go to the doctor's for something else for a completely different issue with my mum and your records are there. They might start telling her. [CYP]*

*Sometimes they'll say it's all in confidence, but ... they don't keep in confidence because you're under age. [CYP]*

Some of the young people we met reported that such breaches had previously happened to them. One young person recounted how everything they had said in privacy in a treatment session had been related back to their parents, against their wishes and understanding. Another young person said this prevented them from sharing information with doctors:

*Because of ... serious experience of them, I don't really bother telling them much because they're not going to do much about it anyway. [CYP]*

Disrespect for their confidentiality and privacy were also raised in connection with other professionals and settings, for example schools and social workers.

*But say if you had a problem and you told your social worker. She would just tell others... my one told my teacher. Can't keep things private. [CYP]*

Examples were given of school teachers making announcements to the whole class when calling one child out to see their social worker.

*...the teacher announced in class that my social worker was coming. [CYP]*

Besides breaching confidentiality, this increased this child's risk of being bullied.

Summary findings	Recommendations
<b>Children and young people's involvement, autonomy, consent and confidentiality</b>	
A great deal of good practice exists in the borough where children and young people are consulted and their views taken on board in regards to their health and treatment.	Develop case studies to assist in disseminating and sharing good practice.
A&E staff and hospital staff are reported to be better at talking and listening directly to children and young people than GPs.	Develop case studies to assist in disseminating and sharing good practice.
Children and young people are not normally informed of what is going on - health issues and treatment are discussed between, and decided by, parents and the doctors, typically without the young person's involvement. Even when doctors talk directly to young people, they do not necessarily explain everything as much as is needed. Children and young people value explanation to both themselves and their parents.	Review local implementation of the national 'You're Welcome' standards from 2009.
Children and young people do not realise what rights they have in regard to being informed or consent.	Review local implementation of the national 'You're Welcome' standards from 2009.
Children and young people value being allowed some choice and time to consider issues regarding their health and care, even if in practice the consent is out of their control.	Gather case studies for use in training and educational sessions for GPs.
Children and Young People find certain topics quite difficult to raise with doctors, including those around mental health, sexual health and alcohol, and worries around confidentiality aggravate this.	Work with young people to understand features/approaches that make them feel more at ease.
Both young men and young women feel more awkward in talking about their health issues with male GPs.	<p>Work with young people to understand features/approaches that make them feel more at ease.</p> <p>Ensure young people are aware of options to request a GP of the same/opposite sex, depending on their preference.</p>
Children and young people do not trust professionals to respect their confidentiality and privacy, and some breaches of these were reported.	<p>Work with young people to develop materials that clearly explain rights around confidentiality and instances where these might be overridden, as well as how to make a complaint.</p> <ul style="list-style-type: none"> <li>- Incorporate awareness and understanding into school/college PSHE (personal, social and health education) sessions.</li> </ul>

Summary findings	Recommendations
<p>Looked-after children and young people we spoke to reported additional difficulties in being able to exercise their rights.</p>	<p>Work with looked-after young people to develop materials that clearly explain rights around confidentiality and instances where these might be overridden, as well as how to make a complaint.</p> <p>Embed into discussions with looked-after children during key contact points.</p>
<p>Medical language and jargon inhibits children and young people from being able to be involved in decisions about their care.</p>	<p>Establish a children and young people communications testing group to review new leaflets/materials, etc.</p> <p>Work with schools to develop better understanding of medical and health-related terms and phrases.</p>
<p>Professionals reported a lack of parity of esteem for children and young people around consent and confidentiality issues when dealing with physical health matters and mental health matters.</p>	<p>Joint working group/meeting to establish how widespread this issue is.</p>

## Section C. Views on specific health topics

Some specific health topics have been raised in partner reports and previous discussions with Waltham Forest Public Health team and other partners. These topics were explored in the discussion groups to help gain a deeper understanding and guide any policy or practice development in these areas. The subjects pursued more deeply were:

1. Breastfeeding
2. Weaning
3. Healthy diet and weight
4. Immunisations

For each topic, contextual details and concerns are provided along with relevant observations and background from professionals. The views of parents, children and young people are then given.

### Breastfeeding

#### Context

UK official policy and guidance is to encourage women to breastfeed for at least the baby's first six months. In Waltham Forest the proportion of women who try to breastfeed is higher than the average for London and England, although rates have fluctuated over recent years. There are also notable variations in the numbers who breastfeed across different wards and ethnic groups: White British and Irish women and Black African Caribbean women were noted to have the least likelihood of initiating breastfeeding<sup>14</sup>.

In Waltham Forest, roughly one quarter of those who start breastfeeding do not continue beyond six weeks and the Waltham Forest Public Health Department estimated that only four in ten mothers in the borough are likely to breastfeed for at least six months<sup>15</sup>.

#### Questions we asked

Female participants who were parents were asked about breastfeeding in order to provide additional context to the statistics. As the existing data showed that more women started than continued breastfeeding, we were particularly keen to understand what factors may have contributed to them ceasing to breastfeed. While stressing that we did not have any views on the matter, we asked women what influenced their decisions around breastfeeding and how much they agreed or disagreed with the statement: 'I found breastfeeding my baby up to six months easy.'

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<sup>14</sup>Waltham Forest Joint Strategic Needs Assessment, 2014, p133

<sup>15</sup>Paper for the Best Start in Life Board 19<sup>th</sup> Feb 2015: *Increasing the rate of exclusive breastfeeding and improving early nutrition in Waltham Forest: a concise review* LB Borough Waltham Forest, Public Health

We followed up their responses by probing any issues encountered - if they had needed any information or support where they had got this from and what they felt about the support and advice given.

### What professionals told us

The professionals we spoke to offered their own anecdotal observations around breastfeeding. They observed that breastfeeding rates were increasing across the board; that on the whole women from some Eastern European countries had a stronger tendency towards breastfeeding than White British women; that rates varied a great deal across Asian women; and that commencement and continuation rates among White British women were heavily influenced by class and education.

They also reported that breastfeeding and issues arising from that can be very individual and so cannot be addressed by a checklist approach. That said, the common factors undermining the commencement or continuation of breastfeeding included:

- Custom and practice among families and handed down to new mothers.
- Family and peer influences and pressures.
- Conflicting information from professionals and a variation in the message about the challenge of breastfeeding. It was reported that post-natal ward staff tended to suggest introducing a bottle as soon as any problem with breastfeeding emerged. The implication from the professionals interviewed was that this was too quick, without enough guidance being provided on waiting or the sometimes naturally slow process of initial breastfeeding, and without any analysis of the problems or providing more support to breastfeed.
- For younger mothers, the availability of support and fitting breastfeeding in with education, social life, training and work pressures was very challenging.
- The demand to return to work as soon as possible after the higher rate of maternity pay ceases (at six weeks) encouraged women to start introducing bottle feeding so that the child can be more easily looked after by others.
- Individual complications and issues for a baby child and/or its mother.
- Lack of individual advice and support. It was reported that up until 2011 Waltham Forest used to train groups of local mothers to work as Breastfeeding Champions. The professionals interviewed felt this to be a good service in terms of reaching more mothers, offering peer advice and bridging the divide between professionals and mothers.

### What women told us

Women in our focus groups generally reported feeling very positive about breastfeeding and had heard the message that breastfeeding was good. They reported intending to, or having started to, breastfeed. A minority said they had not intended to breastfeed, for example because they 'just didn't like it'.

Indeed breastfeeding was seen as so much the norm and the officially-approved practice that to not breastfeed was felt to attract negative judgement and criticism:

*You have to breastfeed. Otherwise they look at you like you are not normal.  
[parent]*

*Made to feel bad if you haven't breast fed. [parent]*

The mosque group we spoke to provided insights in the context of Islamic attitudes to breastfeeding, saying that breastfeeding was now officially condoned as Islamic, in contrast to some years ago when the official line on breastfeeding was more equivocal, or it was not so clearly supported. This had encouraged some of the women we met to breastfeed their more recent children, whereas they had not attempted to when their older ones were born.

*That time they didn't really push you that much to breastfeed anyway and we didn't think really either that it was that good or that it was Islamically that good either. And then afterwards we knew that Islamically it was good to breastfeed the children to two years ... it was not Islamic back then, but now know that it is Islamic. .. to two years... not just coming from midwives but coming from the mosque as well. [parent]*

The women we discussed this with reported breastfeeding for periods ranging from one day to three years. There was little awareness of the official guidance to continue breastfeeding for at least six months. The reasons given for stopping earlier than six months were varied, but fell into the following main areas:

- concerns about the adequacy of breast milk.
- encountering difficulties when trying to breastfeed.
- external factors creating additional challenges.
- lack of adequate and timely advice and support.

### Concerns about the adequacy of breast milk

Many women said that they had not had enough breast milk when they tried to breastfeed. Others were worried about the nutritional value of breast milk and said that it was easier to ensure babies were getting enough nutrition and gaining weight when they are bottle fed. In some cases it was felt that their babies had preferred bottle-feeding.

*I didn't have enough [milk] for my baby. [parent]*

*She didn't like the breast milk. Only two months, then started the bottle and she preferred that. [parent]*

### Encountering difficulties

Across these discussions, women recounted many specific challenges, such as difficulty positioning the baby, severe pain - including cracked nipples, infections such as mastitis and their babies having allergic reactions to something within the breast milk, typically eggs and/or dairy products.

These difficulties were exacerbated by expectations and assumptions around breastfeeding. Several participants recalled being totally surprised and unprepared for any difficulties, as they felt that they had been led to expect it to be easy and

straightforward. The element of surprise had in itself made these challenges harder to cope with.

*Thing is it is hard. Before the child is born they tell you it's easy, it's not easy... so that's the pressure, it's actually hard and then there's not really as much support as there used to be... there's not enough. [parent]*

*They never tell you that the first four weeks, engorgement, is really painful. [parent]*

A sense of failure, mixed with disappointment and guilt, were also evident, for example at having to 'give up early'. Overcoming the challenges encountered often required immense determination on the part of mothers, in the face of pain and other difficulties.

### **Additional external factors and challenges**

Sometimes physical health and/or mental health problems - typically post-natal depression or having to stay in hospital - interfered with women's ability to breastfeed:

*I tried it, but I got the depression. I had lots of milk but I just couldn't do it. [parent]*

*When my baby was born I had some heart problems and I stayed in hospital and that's why. I tried but I couldn't. [parent]*

*I spent two weeks in hospital and I was very upset... I didn't have power or anything I was crying and didn't want to speak to nobody... I just wanted to go home and I think because of that and the stress I didn't have any milk. [Parent]*

Lone parents said that breastfeeding added additional pressures for them and limited their abilities to engage others in childcare.

*... it's ok, but it's really hard, because she refuses to drink from the bottle. So it's just me, so when she goes to other people she just cries. It's just me. [parent]*

### **Inadequate advice and support**

It was said that more advice and support was needed and that this advice and support needed to be available as soon as problems emerged. It was also said that women need to know when and who to ask.

*It's just about position, but no-one told me. [Parent]*

*...they support if you asked them, if you ask them, but you have to ask them. [Parent]*

Data from the focus groups and from interviews indicate that more support is needed at critical junctures, but that women were not always aware of the support available or how to how to access this. Several women said that the lack of support affected their ability to start or continue breastfeeding. One mother gave a distressing account of having no input

in the hospital (Whittington) and felt that it might have made a difference to her, but she did later manage to breastfeed through the help of a breastfeeding counsellor.

*... I was just by myself with baby and no one told me anything ...they left me there until I came home and went to children's centre... nothing. Nobody said anything about breastfeeding. They just left me there until they came to discharge me. [Parent]*

As well as views amongst the professionals, there were also indications from women that there are inconsistent messages from professionals. For instance, it was said to be common in the post-natal wards to encourage mothers to give a bottle if their baby was crying or having initial difficulties latching on.

In contrast, several women praised the extensive support they had received from hospital and community midwives, health visitors and specialist breastfeeding support workers. Often the help required was described as relatively 'simple' tips, such as adjustments to positioning, but this help needed to be individual to the woman and baby in question. Individualised advice was said to have had a significant impact and to have made the difference between women stopping or continuing breastfeeding, despite the problems encountered.

*I had great support from the health visitor. I went to the hospital. I said I had no milk and they were so helpful, midwife...in North Middlesex, she was great. [parent]*

*There used to be breastfeeding clinics at Parkside for my first baby...but shut about two years ago...it was really helpful. [parent]*

The expertise of an experienced breastfeeding adviser had proved crucial in several cases. In one example they had quickly diagnosed a tongue-tie which was interfering with breastfeeding.

*Worth her weight in gold, that lady [specialist breastfeeding support worker]. [parent]*

*I had twins and I got support she came to visit me at home and it was great...the specialist midwife from Whipps Cross. Excellent... helped a lot. [parent]*

*Got help from specialist breastfeeding midwife who came round to my house, she was very helpful. [parent]*

*[The Children's Centre Breastfeeding support worker] is really good. She helped me through the whole [problem] and teething 'cos I couldn't get to grips with it. She's lovely. [parent]*

On the other hand, there was a perception across focus groups that they were judged negatively if they did not breastfeed. Their comments indicated that, rather than explaining the reasons why they were not breastfeeding or asking for help, they hid any doubts, questions, negative feelings and difficulties about breastfeeding from



professionals to avoid the criticism they presumed this would attract. As a result this may also have meant that they did not get support when they needed it.

*I started to breastfeed my first but I found that I couldn't. But when I decided to bottle feed I was looked at like 'God, what are you doing....?' It made me feel that I should try harder, but there was no support. If you still wanted to, you need support. I was told afterwards, they told me I could have had some support.  
[parent]*

Summary findings	Recommendations
<b>Breastfeeding</b>	<p><b>Overall, feed findings and recommendations into Breastfeeding Strategy action plans(s).</b></p> <ul style="list-style-type: none"> <li>- <b>Link in with Children’s Centres and Health Visiting and Local Authority commissioning of.</b></li> </ul>
<p>Women in focus groups were generally very positive about breastfeeding and, on the whole if not universally, viewed it as better for babies.</p>	<p>Gather video clips of personal journeys and experiences to share more widely with pregnant and new mothers.</p>
<p>While most mothers had tried to breastfeed, they reported experiencing numerous challenges. Rates of starting and persevering with breastfeeding were found to vary by individual, according to their determination and the availability and timing of any support and advice. Reasons for not starting at all, or stopping before six months, included: concerns that their baby was not getting enough nutrition; difficulties such as pain and infections; illness and hospital admissions; the baby being allergic to something in the breast milk; and not getting the right advice at the right time.</p> <p>Breastfeeding problems often come as a shock to new mothers, who feel they have been led to believe it is straightforward and easy.</p>	<p>Gather video clips of personal journeys and experiences to share more widely with pregnant and new mothers. Ensure these reflect the reality and full spectrum of experiences.</p> <p>Review the breastfeeding support offer for women and advice provision prior to birth.</p> <ul style="list-style-type: none"> <li>- Link into Breastfeeding Strategy action plans.</li> <li>- Link into plans for dedicated infant feeding support worker.</li> </ul> <p>Develop peer to peer support networks for parents.</p>
<p>Women were not very aware of the guidance to continue breastfeeding up to at least six months.</p>	<p>Consider within Breastfeeding Strategy action plans.</p> <p>Develop peer to peer support networks for parents to disseminate messages.</p>
<p>Women get inconsistent messages from relevant professionals on breastfeeding.</p>	<p>Key health professionals, partners and parents to jointly develop and agree key messages.</p> <ul style="list-style-type: none"> <li>- Utilise existing CCG Parent’s Guide booklet and confirm cross-sector commitment to key message.</li> <li>- Link to NHS Choices information.</li> </ul>

Summary findings	Recommendations
Breastfeeding issues can be very individual and so a checklist approach is unsuitable.	Distribute messages via local parent Facebook and Twitter groups. Review the breastfeeding support offer for women and advice provision prior to birth.
Recent Islamic support for breastfeeding has impacted on Muslim women's uptake of breastfeeding.	Develop relationships with local mosques to better understand religious messaging around reproduction, pregnancy, birth, breastfeeding and other children and young people health issues.
Some women hide the fact that they are not breastfeeding to avoid the presumed criticism that will follow. This results in them not getting appropriate support.	Gather experiences and case studies to inform staff training around approaches and techniques for interaction. Embed into staff inductions, training and personal development plans.

## Weaning

### Context

The World Health Organisation (WHO), the Department of Health (DH) and other official bodies and guidance advise that weaning should not commence until the baby is six months old. However, the Department of Health has acknowledged that this advice is not normally followed by parents for a variety of reasons, not least conflicting information and guidance<sup>16</sup>.

### What professionals told us

Professionals we interviewed were concerned that weaning was often started earlier than the recommended six months in Waltham Forest, a concern echoed by the Best Start in Life Board meeting on 15<sup>th</sup> Feb 2015<sup>17</sup>. Professionals attributed this in part to the conflicting information received by parents. For example, packaging on weaning foods, such as jars and baby rice, commonly states that these are suitable from the age of four months. The novelty, convenience and wide range of baby food on sale was said to be more influential among some immigrant communities. Besides the concerns about undeveloped digestion systems, much of the processed food which is marketed as suitable for weaning contains relatively high levels of salt and sugar, which is believed to affect the child's developing palate.

### Questions we asked

Qualitative focus groups offered an ideal opportunity to explore parents' views about weaning and the main influences affecting their decision-making around timing. In the focus groups we asked parents if they felt they knew 'how to get good information about weaning'. As a follow-up question, we probed when they had started weaning, while strongly emphasising that we did not have particular views on this and that there were no right or wrong answers, in order to encourage openness.

### What parents told us

Parents gave the following main reasons for starting weaning earlier than six months:

- Distrust of the standard, official line, which was aggravated when parents noted that there were inconsistencies across professionals.
- The view that individual children are ready at different times.
- No known or perceived harm in starting sooner.
- Concerns that their baby was not getting enough nutrition from milk alone.
- Custom and practice within a family.

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<sup>16</sup>Breastfeeding and Introducing Solid Foods. A Consumer Insight Summary, DH, April 2010

<sup>17</sup>Public Health Waltham Forest, 19<sup>th</sup> February 2015, *Paper for the Best Start in Life Board: Increasing the rate of exclusive breastfeeding and improving early nutrition in Waltham Forest: a concise review*

## Conflict between official guidance and other sources of information

Interestingly, nearly all the parents we discussed this issue with said they knew that six months was the official guideline for weaning to begin. However, it was clear that they were not passive recipients of information. Rather they actively sought out information and advice from a range of sources. Parents expressed frustration at receiving conflicting information from professionals, including GPs and health visitors. One parent said that their GP had told them to start weaning at four months, while their health visitor told them to wait until six months. Another mother was told by the GP to start 'when you feel the baby is ready' and a nurse had said to another parent 'ask your mother'. Such inconsistencies, and what these parents saw as changing trends, undermined trust in professional advice and official information concerning weaning.

*Confusing. It used to be 3 months, then they changed it to 6 months. [parent]*

Conflicting information on packaging and elsewhere increased the confusion. In addition, there was said to be misinformation around, for example, the view that babies were ready for weaning when 'they put their hands in their mouth'. A belief commonly expressed in the focus groups, and which conflicted with official guidance, was that weaning should be child-led: 'she let me know'. A few mothers said that they had taken the child beginning to chew as indicative that they were ready for solid food. There was a strong feeling that individual children are ready at different ages and that the standard guidance was therefore wrong, as it is not felt to take these differences into account. One parent felt that, because their child had been born prematurely, they had not been ready at six months, so she had delayed weaning for another few weeks. On the other hand, another mother said that she had started introducing solids at four months for each of her children and that by six months they were on two to three meals a day.

In one discussion, a diverse group of parents all said they knew and followed the six-month guidance, and indicated that they would not dream of starting weaning any sooner. However, when this was pursued further, it emerged that this is not necessarily the case in practice, as illustrated by the following discourse among parents within the group:

*...six months is better for baby. [parent]*

*..it's not a question of what's the right thing... it's what is better for children.  
[parent]*

*Information is confusing, for our last child we started at 4 months. She was ok with that... 'Cos if she wants, why stop her? [parent]*

*We started at 5. [parent]*

*We started at 4 months - but then the health visitor told me off. [parent]*

*They don't know if it's a good thing or bad thing they don't really ... mixed signals, you have to try, you don't know if you're doing the right thing at 3 months, 4 months, or 6 months or even after a year. [parent]*

*Look at Google. [parent]*

*GP not that good with information, they tell you everything is 'normal'.  
Sometimes we feel like no point going to the GP. [parent]*

*Health visitors are saying six months. [parent]*

*Everybody thinks different ...I don't think it makes any difference if they start at  
4 or 6 months, it cannot harm them. [parent]*

Issues around being judged negatively emerged around weaning as it had with breastfeeding, with parents similarly reluctant to discuss their real views and reservations openly for fear of expected condemnation. By all accounts, there was an inclination to simply tell the professionals what they wanted to hear and follow other counsel at home.

One mother (in a different group) had changed practice between her two older children and her most recent baby: she attributed her older children's constipation to them being weaned at four months and so had waited until six months for her youngest.

Summary findings	Recommendations
<b>Weaning</b>	
<p>Parents are generally aware of the guidance to wait until the baby is six months old before starting to wean. However, they do not really trust this guidance to be correct.</p>	<p>Develop peer to peer support networks for parents to disseminate messages.</p>
<p>Advice on weaning was seen as inconsistent and at times conflicting, particularly in relation to advice from health visitors versus GPs.</p> <p>The advice of professionals was crucial. However, lack of discussion or implied negative judgement tended to make parents defensive and secretive. Parents wanted more explanation, including the evidence behind the six-month recommendation, without judgemental overtones.</p>	<p>Key health professionals, partners and parents to jointly develop and agree key messages, starting with breastfeeding and weaning guidance.</p> <ul style="list-style-type: none"> <li>- Utilise existing CCG Parent’s Guide booklet and confirm joint commitment to professional messages.</li> <li>- Link to NHS Choices information.</li> </ul> <p>Distribute messages via local parent Facebook and Twitter groups.</p> <p>Open up opportunities for informal dialogue around weaning to take place, for example within Children’s Centres.</p>
<p>Some weaning before 6 months takes place as a result of information on baby food labels.</p>	<p>Ensure discussion with parents around conflicting advice is embedded into key contact points and appointments.</p>
<p>Professionals are concerned about the prevalence of weaning before 6 months.</p>	

## Healthy diet and weight

### Context

Official reports show that rates of childhood obesity in Waltham Forest are higher than national averages: 10.4% of children aged four to five are judged to be obese and 22.6% of those aged 10 to 11. The rates of 'low' and 'very low' birth weights are also high<sup>18</sup>. These figures have remained relatively constant over recent years, and are on par with some other London boroughs<sup>19</sup>.

Recorded rates of Type 1 and Type 2 diabetes are high in Waltham Forest. They are higher still among BAME communities and are expected to rise further. In addition, many cases go undiagnosed. Control and management and arrangements for young people's transition to adults' diabetic services are reported to be below optimum<sup>20</sup>.

### What professionals told us

As well as shortages of health visitors as noted later in the report, professionals said that it has been difficult to recruit school nurses in the borough, who would help monitor and advise children and young people on healthy weight and diet. Children being overweight was seen as one aspect of neglect, but at the same time there were inadequate staff resources to deal with this.

### Questions we asked

As diet and weight can be sensitive topics, encompassing a wide range of issues, we approached the subject by first asking parents how much they agreed or disagreed with the statement 'It is easy to ensure that children eat healthily.' We then followed up the points raised.

### What parents and young people told us

Overall, parents answered this question with a very clear 'no', and felt that more professional advice on nutrition was needed across the borough. There was a demand for more detailed information, as well as a service in the borough for support with healthy eating and weight. No one we spoke to was aware that there was a community dietetic service, or knew how to get a referral to this service. Parents felt they did not really know how to effectively make changes around their children's diet and eating habits.

However, it was notable that this did not necessarily mean they always accepted professionals' opinions. Mothers resented being told that their babies were overweight. They disputed whether a baby could be judged to be overweight, and expected that any excess weight would 'fall off' once their children started walking. Official views about healthy weight levels were seen by some as just another trend, which might be subject to change again in the future, and another way to criticise parents.

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<sup>18</sup> *Child Health Profile, Waltham Forest, Public Health England, March 2014* - [www.chimat.org.uk](http://www.chimat.org.uk)

<sup>19</sup> Waltham Forest Joint Strategic Needs Assessment, (Refresh) May 2014, p100-5.

<http://www.walthamforest.gov.uk/Documents/JSNA%202014-15.pdf>

<sup>20</sup> Waltham Forest Joint Strategic Needs Assessment, (Refresh) May 2014, p100-5.



Parents felt that not enough information was given to children in school about healthy eating and that schools should do more in this area. One group of Polish parents contrasted British and Polish schools and described the latter as providing more health input in general, such as around diet, posture and exercise, as well as regular health screening to help identify any problems early.

A focus group was conducted with a health group set up by one school for young women who had weight problems. The strongest message from the young women was that they felt they got no help, guidance or support from GPs on the issue of diet and weight, and that advice when sought from GPs was superficial and derogatory. This was illustrated by some of their comments:

*They're too rude and even when you ask them what can I do to lose weight they say 'just run around'. [young person]*

*Avoid going 'cos afraid the GP is going to say the same thing about weight. [young person]*

In addition, they felt that if they attended a GP for any other ailment, the doctor would ascribe everything to their weight:

*If you say your arm is hurting they would say it is because you are overweight - whether it is or not. Like I had hurt my arm and I went to one GP and they said it was because of my weight. So I went to another and they said it was because you have sprained it. [young person]*

This group found the support provided by the school nurse and through their special project was really helpful as it guided them and gave useful suggestions, such as keeping a food diary and calorie counting. They trusted the school nurse on this issue and found her approachable and reliable, which was key. The camaraderie in this group also helped.

Summary findings	Recommendations
<b>Healthy diet and weight</b>	
Good advice about healthy diet, nutrition and weight was said to be difficult to get in Waltham Forest - there is a demand for more detailed information and somewhere/somebody to see to obtain this.	Work with parents, children and young people to review the local offer and opportunities for improvement.
Awareness of the community dietetics service was non-existent.	Improve basic information leaflets and communications around the service and consider development of outreach and educational sessions for parents.
Parents need help to effectively change children's eating habits and diet.	Work with parents, children and young people to review the local offer and opportunities for improvement.
Parents do not agree with assessments about babies being 'overweight', feeling it too soon to judge.	Incorporate awareness-raising around healthy weight guidance into outreach/educational sessions for parents.
Parents feel schools could play a greater role in giving information and teaching about healthy eating, diet and exercise.	Work with nurseries and schools to gather good practice examples and utilise appropriate forums to distribute these and develop best practice and toolkits for lessons. - Utilise and link in with the Healthy Schools Programme.
A support group in one school provides a useful model of how to assist young people around healthy diet and weight issues.	
Guidance and support from GPs around weight, when sought, was reported to be lacking and insensitive.	Gather experiences and case studies to inform staff training around approaches and techniques for interaction. Embed into staff inductions and personal development plans.

## Immunisations

### Context

Rates of childhood immunisations in the borough (81 to 89.9% in 2012/13, varying with the type of immunisation): are lower than the English average and the WHO's target of 95%. These rates have decreased somewhat since 2012. Immunisation rates are known to decrease with age and to be lower among poorer families<sup>21</sup>.

This has implications for individuals, in terms of their susceptibility to these illnesses in the future, but also to public health if not enough people are immunised and diseases spread across groups, such as in a school. Ofsted<sup>22</sup> found that there was a lack of overview for looked-after children and young people, especially around vaccinations.

### What professionals told us

Professionals reported that the following factors contributed to the low immunisation rates in the borough:

- The degree of transience within and in and out of Waltham Forest. These high levels of mobility were said to be linked to housing, especially the lack of long-term rental contracts in the private sector.
- Transience in the patient population resulting in difficulties in keeping patient details and records up to date. This compounds existing data control difficulties with GPs' call and recall processes for immunisation appointments.
- People who have migrated from other countries with their children may be used to a different system in terms of the type of inoculations or timing, and may also lack the official records to evidence which immunisations their children previously received.
- Remembering names and dates and providing proof of the precise timings of all immunisations previously received was said to be particularly challenging for immigrant groups. Roma people said they found this especially difficult as they often did not have the written records or sufficient language skills.

### Questions we asked

We explored attitudes to immunisations in our focus groups with parents. We were keen to ascertain if attitudes or practice varied across different groups, and whether there was any resistance to immunisations, especially following the high profile scare in the 1990s around the measles, mumps and rubella (MMR) injections (based on now-discredited research).

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<sup>21</sup>LB Waltham Forest , *Joint Strategic Needs Assessment, 2014 (p134)*,

<sup>22</sup>Ofsted, Jan 2015, 'Single Inspection of LA Children's Services and Review of the Local Safeguarding Children's Board'

## What parents told us

In general parents were found to be positive towards immunisations.

*When I was a child, I got the injections and now I'm still alive. [parent]*

*Yes, are happy and we have the Red Book and they advise what time and what injections you need and write when. [parent]*

*And when I see the GP they ask what date I had the injections for my son. [parent]*

However, some reservations also emerged. Most notably, a small minority of parents had hesitations about MMR, because of the allegations made about a link between it and autism.

*It depends which ones...MMR. In the past ... everyone had MMR but now because of information about autism and mental problems and after that, now I'm confused, I'm scared... about MMR.*

While fears about MMR were not found to be universal, it was nonetheless a significant barrier, if only for a minority. Notably, it was the only vaccination that any parents made any issue about and more clarification and assurance was desired.

*... we didn't know what to do... some medical doctors say you shouldn't do that because it doesn't help the child... so we didn't but we're still not sure. [parent]*

*...because my child has some autism and my wife thinks it's after the vaccination. I think it's not true... but someone needs to explain and the GP just says your [other child] does not have their vaccination yet... I think someone should explain and provide some proof that this is wrong...the doctor have their heads down in the computer and don't care. [parent]*

*I heard some doctors said that shouldn't do that because of danger to child, so then we didn't. [parent]*

Interestingly, in the same groups other parents would voice contrasting views, stating that they were quite happy with the MMR vaccine and that the negative claims had been totally discredited.

*I just heard the stories from my neighbour: that children got changed after the vaccinations .... I haven't seen it personally. I'm not sure, I'm not really sure about it, but I heard the stories and it's like, you know, making me think about it. [parent]*

*..it's the anti-vaccination movement...believe the rubbish that it's all a plot... but the guy who had all these theories has been discredited. [parent]*

Our sample was small, and those voicing concerns were a minority within that. It is, however, noteworthy that such doubts persist around MMR, and had prevented some

parents from getting their children vaccinated. In our groups any such reluctance was more apparent across Eastern European and younger parents.

## General understanding

There was also some doubt about the efficacy of vaccines, due in part to the news about the failure of the 'flu vaccine given in autumn 2014. When this was further explored, there was an evident lack of understanding of the notion of herd immunity (when a large percentage of a population has become immune to an infection, thereby providing a measure of protection for individuals who are not). In other words, immunisation was perceived as an individual matter, rather than a community or public health concern.

The parents we spoke to were less aware that booster doses of the childhood vaccinations were provided, for example, at five years old or at the start of secondary school.

## Practical challenges

There was some confusion over which vaccines to get, when each was due, and whether to go to the health visitor or the GP to obtain them. One mother had received confusing and conflicting information and directions about where to go and when, compounded by language barriers:

*With my first injections for my baby...I had problems. I went to the Forest Centre and I'm still waiting 3 months for the first injection for my baby. I asked the GP and they said 'we don't do it in the GP ...and the first injection you have to do it in the Forest Medical Centre'. And then I was waiting for appointment and then they told me they we don't do it now at this time.... and then when I go to the GP they asked me 'why did you not do this injection for baby?' [parent]*

Some parents said they just had not got around to it and possibly had not realised its importance or the expectations:

*...missed the appointment and ...something like that ...and the health visitor explained and I plan to do it next week. [parent]*

Language problems and getting used to different systems were common barriers to getting vaccinations. Parents from Eastern Europe were very pleased that childhood vaccinations are provided free in the UK, as in many countries these cost money. However, parents said they sometimes found it hard to understand which vaccines were for what and what the names meant:

*In Poland it's the same injections, but you have to pay for them and it's very expensive. When I moved here ...the GP said to me that [the baby is] needing the injections and she tried to explain to me... She tried to explain in an easy way what the injections are for...but at first just gave me the names....If she just says the name how can I know what the name of the injection means! ... BCG...then she explain and then slowly, slowly I got it. [parent]*

Those who had moved to the UK after their child was born reported difficulties in providing evidence of what immunisations their children had already received in their country of birth. This often required a trip back to visit previous doctors in their country of origin, resulting in additional delays to immunisation.

Another difference in practice which was reported by several Eastern European parents was their perception that vaccines were given here even if the child had a cold or 'flu. They said this was different to the practice they were accustomed to and were afraid that it might have negative health consequences for their children, as their immunity would be low.

Summary findings	Recommendations
<b>Immunisations</b>	
<p>Parents are very positive about immunisations. However, awareness of booster doses and when these were needed is low.</p>	<p>Review communications and information about immunisations and boosters.</p>
<p>Practical challenges to getting immunisations include: not being sure where to get immunisations; which ones were due when; and providing evidence of vaccinations.</p>	<p>Review use of flagging systems and call-up process for immunisations and boosters.</p> <p>Consider opportunities to centralise immunisation/booster sites so parents do not have to go to different places for different injections.</p>
<p>Reservations around immunisations are mainly centred on the MMR vaccination and are more apparent in groups of Eastern European and young parents.</p>	<p>Train community health trainers to deliver key messages to communities with a low uptake of immunisations and boosters.</p>
<p>Reservations are growing around the 'flu vaccine.</p>	
<p>The call and recall systems used by GPs, high mobility within and in and out of the borough and low contact by health visitors contributes to people falling through the net.</p>	<p>Review communications and information about immunisations and boosters.</p> <p>Review contact points within the system and use of flagging systems and call-up process for immunisations and boosters.</p>
<p>The notion of 'herd immunity' is not widely understood and immunisation is perceived as an individual matter.</p>	<p>Embed discussion into key contact points, communications and information about immunisations and boosters.</p> <p>Train community health trainers to deliver key messages to communities with a low uptake of immunisations and boosters.</p>
<p>Language barriers and different systems in the UK to the country of origin affect rates of immunisation and boosters.</p>	<p>Train community health trainers to deliver key messages to communities with low uptake of immunisations and boosters.</p>

## Section D: Views on individual services

### Questions we asked

Rather than set up separate focus groups to discuss different services, we asked each group to identify the health and/or social care service participants knew of, and which they had used most. We then asked for positive and negative views on those most used, both by asking participants to write comments on Post-it notes and by discussing the three or four most commonly-used services within the group.

Different services and professionals attracted different amounts and types of comments. In this section we present the views on services which were said to be used most and which people had the most to say about. These were:

- GPs
- Midwives
- Health visiting
- Mental health services for children and young people
- Disability services for children and young people
- Pharmacies
- Local hospital services, including A&E
- Dentists

### GPs

#### Context

There are 45 GP practices in Waltham Forest and the average registered number of patients on each GP's list is 6,531<sup>23</sup>. At the time of writing it was said that GP practices in the borough will shortly be organised into 'hubs'. There is one NHS Walk-in Centre, located in Oliver Road. However, on the NHS Choices website the Urgent Care Centre at Whipps Cross Hospital is also listed as an NHS Walk-in Centre .

#### What professionals told us

As Healthwatch has already written a number of reports around GP services and access issues, this topic was not identified as a priority for this piece of work. As such, professional input was not sought on this issue. However, discussion emerged quite spontaneously within most groups, as outlined below and in previous sections.

#### What parents told us

On the whole, the quality of GP care and diagnoses attracted far fewer comments than the appointments system, which is covered in previous sections, although the difficulties in securing appointments tended to colour people's overall views. Individual surgeries and

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<sup>23</sup>Great Expectations: A blueprint for GP services in Waltham Forest, January 2014  
[https://www.walthamforest.gov.uk/Documents/SCRPAN\\_GP\\_PanelFinal\\_2014.pdf](https://www.walthamforest.gov.uk/Documents/SCRPAN_GP_PanelFinal_2014.pdf)



GPs received mixed reviews, with experiences varying from practice to practice as well as between individual doctors within a surgery.

*I love mine. [parent]*

*I find them brilliant. [parent]*

*Once you get in through the door and past the receptionist they might say 'Oh why didn't you come earlier?' [parent]*

Relationship factors, including continuity, communication, and the doctor's manner emerged as being nearly as important to patients as the clinical care received. Many GPs were described as caring, excellent, making accurate diagnoses and arranging necessary care quickly, while others were criticised for being abrupt, rushing and not apparently listening.

*She is very nice. Whenever I tell her my health problems she listens carefully and discusses with me and then prescribes me medicine. [parent]*

*I find them brilliant...I can get same day appointments...see the same doctor all the time, have seen the same one for years... will notice if something is wrong. [parent]*

*Some are good and some are not. Some are caring and some are not. [parent]*

*That's the key. If you find that someone is caring it makes all the difference. If you find that someone is not caring it makes a massive difference the other way. [parent]*

*... when baby was 6 or 7 months and had a temperature, and I took her to the GP and he said 'You're a bad mother: why didn't you take her to the A&E?' [parent]*

One Roma family reported considerable rudeness and poor clinical care at one practice. In their experience, interpreting was often not arranged, making it difficult for the patient to know what was going on. On one occasion a woman knew she was being told to go to the chemist but did not understand what for. Sometimes no notes were taken during her consultations, which meant that on subsequent visits there was no record of what had previously been discussed or prescribed. This woman said that on another occasion the doctor had laughed at her when she said she had depression and gave her a leaflet about making a self-referral, which was too hard for her to do because of language barriers. On another occasion the doctor had said 'You won't be able to get benefits much longer', which the patient found very hurtful and an unreasonable comment to make.

Another woman complained that her doctor told her she should continue trying to conceive rather than adopt, although this had hitherto proved impossible.

It was evident from discussions across many groups that parents wanted GPs to provide more details during consultations and that they felt disappointed and fobbed off if the GP told that everything was 'fine'. This perception also made them question the diagnostic abilities of doctors:

*'normal'... everything is 'normal'! [parent]*

A common expectation was to have antibiotics. Indeed antibiotics were somehow used as the indicator of having had a thorough examination, getting good treatment or being a good doctor. In contrast, being advised to take paracetamol was criticised.

*My impression is that we are going to GP just to be told 'we cannot give antibiotic, just take paracetamol'. They prescribe paracetamol for everything - 'flu or a knife stuck in your heart...paracetamol. I had a shoulder problem and was told to take paracetamol. I now see a physiotherapist privately. [parent]*

Parents from Eastern Europe said they doubted a doctor's clinical competence when they observed them looking up information on the internet or in the British Formulary in order to decide on which medicine to prescribe. They felt that the doctor should know this information already.

*...they are not professional: they are checking how to treat you on Google. [parent]*

*Whenever they prescribe for you, they're opening the big book to see what medicines to give you... this was quite shocking to me... would not have seen a Polish doctor doing that and that makes you quite scared that they don't know what they're doing. [parent]*

In addition, they felt that on the whole, Polish people were usually well informed about health matters and self-care and tended to use home remedies, such as hot lemon, ginger, honey, garlic and paracetamol for colds and 'flu in any case. This is why when they attended the GP they wanted to get something stronger than this and felt aggrieved to be told to take hot lemon and paracetamol.

The parents we spoke to whose children had learning disabilities were quite critical of GPs' knowledge and understanding of learning disabilities. While some of their needs were quite specialist, these young people still experienced the normal range of childhood illnesses. It was felt that GPs lacked the skills to deal with children who had learning disabilities, or knowledge of how that might interact with another condition. For example, it was said that GPs did not understand the greater need for a 'flu jab, or did not appreciate the behavioural aspects. In one case a young person's behaviour was criticised, but when the parent said that this was because of the child's autism, the doctor said 'But she does not look autistic.'

These parents felt that GPs 'don't always know what to do. So the parent or carer has to be the expert'. As a result the more experienced parents said they had to visit the doctor, forearmed with knowledge about the likely diagnoses, treatment and referral options, but to an extent resented this situation:

*You should not need to have to be [the expert]. [parent]*

Some parents complained about an apparent contradiction in health information. They had followed the advice given in public health posters, i.e. to visit the GP after their child had

been coughing for two weeks. However, the doctor told them they should not have bothered.

See section A for recommendations around GP services

## Midwifery services

### Context

Roughly three-quarters of births in Waltham Forest take place at Whipps Cross Hospital, with Homerton Hospital in Hackney catering for most of the remainder. Over recent years maternity care in Waltham Forest, and in Whipps Cross Hospital in particular, has been under great scrutiny. The CQC has produced three reports on Whipps Cross maternity facilities<sup>24</sup>, highlighting several areas for improvement.

In terms of ongoing evaluation and assessment of maternity services, the Friends and Family Test<sup>25</sup> is used and a number of consultations have been undertaken to gather feedback from patients. These are all expected to be collated for the Midwifery Liaison Standing Committee, which was in the process of being re-launched at the time of this study and which Healthwatch Waltham Forest has a seat on.

### What professionals told us

Numerous specific concerns were voiced about pregnant women in minority groups. Birth weights were lower among BAME (Black, Asian and minority ethnic) parents. Black African and Asian mothers were reported to be less likely to take Vitamin D supplements during pregnancy. Low Vitamin D can cause problems later on in life, and a special initiative had been launched to address this. Minority groups were also said to engage with midwives later in their pregnancy than their White counterparts, which may be problematic if additional scans or treatment are required. BAME women were also said to be less likely to participate in ante-natal classes, which was partly attributed to conflicts with working hours and with language barriers, especially for those from Eastern Europe and South Asia. Expectant BAME mothers tended to have low rates of vaccinations themselves and whooping cough and 'flu were of particular concern. Language barriers also affected access to midwifery services and ensuring a shared understanding, although interpreting was thought to be on offer. Data on the rates of these issues for different groups was not available.

### What parents told us

Most of the comments made related to Whipps Cross Hospital and the Homerton Hospital, depending on where participants' babies had been born.

Issues relating to breastfeeding are covered in previous sections.

<sup>24</sup>Care Quality Commission, Jan 2014, *Whipps Cross University Hospital Quality Report*; <http://www.cqc.org.uk/location/R1HKH>

<sup>25</sup>This is a short questionnaire, asking patients if they would recommend a service to their friends and family.

Parents had variable experiences of midwifery at local hospitals. Many women we spoke to valued the support that midwives provided and found it invaluable, but would have liked to have seen them more often. One person who had had several children felt that services had deteriorated since becoming less community-based and more centred in the hospital:

*...I think there's a difference: between when I had my 17 year old and when I had my nine year old. I did find a difference in the antenatal care. I did find it's got worse as time has gone on... [For the oldest] I was given a local midwife where I could see her locally. Whereas for my nine year old my GP referred me to the hospital... everything was done at the hospital. Whereas when I had my seventeen year old I had the midwives more local and there was a lot more care. [parent]*

*In the past the midwife would come to visit you at home after the birth. [parent]*

Many participants had accounts of bad experiences in Whipps Cross maternity unit, but most took place some years ago. Those with both recent and past experience felt that the maternity services had improved, especially since Barts Health NHS Trust took over. Nonetheless, any negative experiences were vividly remembered. It was generally felt that expectant mothers would try to avoid Whipps Cross because of its reputation. Several women across different focus groups recounted bad experiences of care when they had miscarried. Others reported insensitive treatment. For example, having to attend a general ultrasound clinic to confirm that a foetus had miscarried, and so being around expectant parents who were (happily) being told the gender of their baby.

However, other mothers praised the care they had had at Whipps Cross maternity unit, including the specialist care they received because of being at 'high risk'.

Summary findings	Recommendations
<b>Midwifery</b>	<b>Overall, feed findings and recommendations into Transforming Services Together (TST) Maternity and Newborn workstream.</b>
Women want to see midwives more often - they find the support invaluable.	Feed into the development of Transforming Services Together (TST) Maternity and Newborn workstream. Clarify the current midwife service offer and how it should be experienced by women.
Whipps Cross maternity services have a poor reputation locally.	Promote progress against CQC findings and warning notices and the Improvement Plan.  Gather positive case studies for use in communications and local publicity.  Undertake open discussion forums in the community with pregnant couples to provide reassurance about the service. - Link with Maternity Services Liaison Committee work.
Care when women have miscarried was reported to be lacking and, at times, taking place in insensitive environments.	Review complaints and feedback information to ascertain whether this is a live or historic issue. - Link with Maternity Services Liaison Committee work.

## Health visiting

### Context

Health visitors are often the main health contact for those with young children and can be the main, or only, professional contact before children start nursery or school. Besides providing advice on child development, infant feeding and weight, they also provide general advice, screening and referrals for parents. For example, they may be the first to recognise signs of post-natal depression or other mental health problems. Despite an ongoing recruitment drive, at the time of these interviews the staff quota in Waltham Forest was at approximately 60% of capacity (60 health visitors out of a target of 101). One of the more significant recruitment challenges reported was that the pay rates were those which applied in an outer London borough, although the work demands were more akin to those of an inner London borough.

### What professionals told us

Professionals reported that the number of health visitors in the borough has been well under par for some time and that this impacted on service delivery. Limited staff numbers were said to have resulted in services being targeted towards those with the most serious needs, while for those with more general needs and concerns, access was more restricted. The average caseload per health visitor was said to be 700, instead of the usual target of 240.

High rates of post-natal depression, domestic violence and safeguarding were among the many problems said to prevail in the borough. It was reported that approximately 60 safeguarding referrals per week were made by Whipps Cross Hospital A&E. To add to these challenges, the degree of mobility across, into and out of the borough, made it difficult and time-consuming for health visitors to keep track of families, who often moved without notifying any professionals. Indeed there was a view that some 'don't want to be found', including those in highest need and where there were safeguarding concerns.

Professionals reported that health visiting had been more accessible when the service had been based in children's centres. They felt that this not only facilitated access in terms of location and timing, but also made the advice less formal and more relaxed. As a result it was easier for parents to assimilate. Concerns were voiced about the passing of health visiting services to the local authority in autumn 2015, particularly that the expertise, standards and competencies normally expected of health visiting might be 'diluted' if cheaper, less qualified staff were employed instead in order to reach targets.

### Questions we asked

We asked parents to describe what kind of support they had from health visitors, what they valued and where they felt improvements could be made.

### What parents told us

Parents reported valuing the health visiting service and finding it very useful:

*Good start-up information. [parent]*

*Kind and approachable. [parent]*

*I find them more helpful than the GP at the moment I think, because they are more helpful with the creams to use and advice... The GP just offers paracetamol [all laugh] and I think they are useful ...and definitely you don't have to wait for them. .. you just see them... For the kids, they are more available and more practical and helpful. For adults the GPs might be better. [parent]*

However, as with midwives, parents also said they would like health visiting to be more accessible and to be able to contact health visitors and/or see them more often. The number of times our group members had seen health visitors ranged substantially from just once to twice a week and ongoing. In our sample, parents often reported finding it difficult to get hold of a health visitor, and at best sometimes managed to talk to one over the phone. Not everyone was aware that they could drop in to the weekly clinics held by health visitors at different venues around the borough, without a formal appointment.

*Informative at first visit - but no other visit. [parent]*

*Not enough visits - only one. [parent]*

*Saw her just two times. Nobody contacted me about the 12 months check-up. [parent]*

*Had to chase BCG [immunisation]. [parent]*

One woman had developed an infection after a caesarean section, and had to be re-admitted to hospital as a result. She was convinced that this might not have happened if she had seen the health visitor sooner. A lack of continuity was reported, in that parents reported seeing a different professional each time, which was felt not to be ideal.

Advice from health visitors around breastfeeding, weaning, infant feeding and childhood illnesses was considered particularly important. In addition, parents felt they needed answers to health concerns about babies and young children very quickly, as their condition could deteriorate so rapidly.

As outlined in the section on weaning, the way in which health professionals spoke to parents was seen as nearly as important as what they said. Many found health visitors too critical. In addition, not everyone agreed with the advice provided. Some felt that the approach could be too dogmatic and would have preferred more discussion. Parents reported that one consequence of the service being stretched was that they could easily avoid seeing the health visitor, with the advantage of avoiding the expected negative judgement.

Experience and competence was not seen as consistent but to vary from one professional to another:

*...when son was two months old, he stopped sucking milk ... didn't know why... [the health visitor at] clinic said 'maybe try this' .... Then I took him to the GP and the GP said 'if he doesn't eat just leave him'. But he was a very skinny baby and a premature as well, and I was worried. Then another day I went to see the health visitor and saw a different one and she was very good and she referred me to a hospital paediatric specialist and she diagnosed reflux ...and slowly, slowly, he began to improve. [parent]*



Summary findings	Recommendations
<b>Health visiting</b>	<b>Overall, feed findings and recommendations into recommissioning of service.</b>
Parents want more access to health visitors - they value the service and find it useful.	Review health visiting offer within the development of a new service model.
It can be difficult to access a health visitor - parents reported wanting rapid answers to health concerns due to a worry about quick deterioration when babies/children are ill.	Develop specialist community health services/access lines for parents to prevent default option of attending A&E with urgent concerns about babies and young children.
Parents are not always aware of the availability of drop-in baby clinics.	Improve information and communications about clinics and health visiting services.
It was reported to be easy for parents who were a priority to avoid contact due to the service being overstretched. This was aggravated by high rates of movement.	Ensure progress against recruitment targets and plans to address shortfall.  Review risk management plans within the context of current staff shortages.
Women report a lack of continuity and seeing different health visitors.	Review Health Visiting offer within the development of a new service model.
Parents prefer dialogue with health visitors and report some of the approaches as being too dogmatic.	Gather experiences and case studies to inform staff training around approaches and techniques for interaction. Embed into staff inductions, training and personal development plans.
The health visiting offer is unknown and women's contact with the service is variable.	Review communications around the health visiting offer within the development of a new service model.

## Mental health services for parents, children and young people

### Context

Prevalence of mental ill-health among parents, children and young people in Waltham Forest is relatively high<sup>26</sup>. It is reported that:

- Approximately 20% of women giving birth each year (1000) have some degree of mental health problem over the period just before and/or after giving birth.
- Rates of emergency admissions and hospital stays for a mental health condition for those aged 17 or under are higher than the London average.
- Rates of admissions for self-harm for those aged 0-18 are higher than the London average; Waltham Forest is ranked the 5<sup>th</sup> highest in London.
- Known risk factors for children and young people include: growing up in poverty; coming from a minority ethnic background; having parents with mental health problems; being in care and being in the criminal justice system.
- The Waltham Forest Joint Strategic Needs Assessment (JNSA) estimated that 5,000 children and young people had a specific mental health disorder in any given year. A review in February 2015 put the figure at approximately 12% to 19.5%, or roughly 5,615 Waltham Forest children and young people in 2012<sup>27</sup>. (NB: These numbers cover all children and young people with behavioural problems, including those with learning disabilities.)
- The 2015 review also highlighted numerous shortcomings in current services for children and young people, especially low rates of referrals, inadequate provision for those with early-stage or less-severe problems and poor services for those in the care system<sup>28</sup>.

### What professionals told us

Professionals identified postnatal depression for mothers as a major issue in the borough. They also said that local services were especially lacking when it came to early enough identification, referrals and provision. Referrals by health visitors and midwives into mental health support services for pregnant women and new mothers were said to be fewer than desirable.

Professionals noted cultural variations in the self-reporting of mental health problems by adults. Concepts of, and terms for mental ill health do not exist in every culture and language, and speaking about mental ill health is often considered taboo, even if the words existed. As a result, difficulties may be experienced or described as physical ailments. In Waltham Forest currently this was described as being particularly an issue among the Roma community.

<sup>26</sup>Waltham Forest Joint Strategic Needs Assessment, 2014, pp125-144, based on a range of studies

<sup>27</sup>Stuart Collins, CAMHS Tier 1 and Tier 2 Review, Feb 2015, Waltham Forest. See summary in Appendix 5

<sup>28</sup>Stuart Collins, CAMHS Tier 1 and Tier 2 Review, Feb 2015, Waltham Forest

To meet the needs among new mothers, it was reported that the North East London Foundation Trust (NELFT) were going to train mental health champions. Champions will be members of the public. In the area of post-natal depression they will be other pregnant women or new mothers who will be trained to help provide awareness and support around particular issues.

Language barriers were particularly apparent within talking therapies. A three-way consultation via an interpreter was felt to be detrimental to the therapeutic process, particularly for people who are not used to talking about such matters. In addition, if the interpreter comes from a patient's own community, they can be especially reluctant to discuss difficult issues and may fear that confidentiality will not be maintained.

Professionals we spoke to, including several school staff, felt that the threshold used to assess whether children and young people qualified for help was set too high. In other words it was said to be extremely difficult for children and young people with mental health problems, such as anxiety or self-harm, to get support or treatment via the Child and Adolescent Mental Health Services (CAMHS). Even where children and young people did qualify for treatment, complaints were made about the long waiting times.

### Questions we asked

After this research started, we discovered that Waltham Forest had commissioned reviews of CAMHS services<sup>29</sup>. These are summarised in Appendix 5. As a result, some re-organisation of CAMHS services in the borough was expected, but was still to be confirmed at the time of writing. Rather than re-invent the wheel, we asked professionals what, if any, gaps in knowledge still existed. Professionals suggested we ask where children and young people sought help for early stage and for less severe mental health needs.

As mental health is a very sensitive topic to discuss within a group setting, and only a minority were likely to have had direct experience of mental health services, we had to be careful in our questioning. We approached this in several ways:

- i) Psychological and mental health services were included in the cards for participants to sort, to indicate if they were aware of these services and if they had used them recently.
- ii) If someone mentioned that they had used one of these we asked their views of the service and left it to them to decide how much to say. We deliberately avoided asking people why they had attended.
- iii) To find out where children and young people went for emotional or psychological advice or support, we developed a set of cards about seeking general health information and included some mental health issues on these. They were asked where they would suggest a friend of their age got help for any of the needs on these cards. As well as advice on very general topics like 'has 'flu', the issues included: 'is feeling worried all the time'; 'is being bullied' and 'is feeling low' (see Appendix 7). In this exercise, the options for where the friend could get help included teachers and parents, as well as a range of professionals.

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<sup>29</sup>At the time of discussion with professionals, this was expected to report in mid-April 2015.

### What parents, children and young people told us

On the whole, parents, children and young people in our groups did not know what the acronym CAMHS stood for. There was a similar lack of knowledge about the role of an Educational Psychologist. When we explained what specific services were provided by CAMHS and the Educational Psychologists, participants were still generally unaware that these services existed. A young person who had used the Improving Access to Psychological Therapies service (IAPT), was unclear what the distinction was between this service and others, or what the abbreviation stood for, but had nonetheless found the service helpful.

In the card-matching exercise, described above, parents and teachers were the most likely to be identified as people to go to with emotional problems, while those who had social workers or used youth facilities also suggested talking to them. On the whole, those who reported having used CAMHS said they found it helpful and liked the people involved.

### Emergencies

The lack of emergency mental health provision in the area was criticised by the young people we spoke to. A number of young people across different groups complained about long waits at Whipps Cross Hospital A&E. A couple described waiting hours with a young friend who had tried to commit suicide. Another young person recounted waiting four hours there whilst suffering high anxiety and panic.

Thorpe Coombe Hospital was described as a 'horrible building', as well as understaffed. Those familiar with it were happy that it was expected to close shortly, but said they had had no information about what replacement provision was planned. Parents felt that the co-location of mental health services with drug and alcohol services in Thorpe Coombe Hospital was inappropriate and also frightening for children and young people attending the same venue who would encounter service users.

### Confidentiality

Young people were particularly concerned with professional respect for their confidentiality and privacy in relation to mental health issues and services. One young woman who had found CAMHS useful when she was a teenager had stopped attending for this reason.

*They were good but...It was fine except they wouldn't keep things private, they didn't... they literally told everything I was saying to them they were saying to my mum...I was 12-13 at time. I lost trust. I stopped going for this reason. [CYP]*

### Learning disabilities and special educational needs (SEN)

Parents of children and young people with learning disabilities and/or SEN, who used CAMHS services, because behavioural problems come under CAMHS in the borough, had numerous complaints. They felt that:

- Behavioural problems associated with learning disabilities should not be confused with other mental health issues, as each required a different approach.

- For some young people their learning disability means talking therapies are inappropriate, as they cannot conceptualise or discuss issues in the way required by such treatments.
- Young people aged 18 who have learning disabilities are expected to use the adult mental health services. Parents complained about the poor transitional arrangements, communication and lack of adequate local facilities.

### Language barriers

Parents identified a range of specific barriers caused by not being able to speak English. These ranged from getting the appropriate referrals from GPs or making a self-referral to expressing emotional or mental health needs:

*Doctor just laughed ... Then he just gave a leaflet and said 'just deal with it'.  
[parent]*

In the case quoted above a family member had to be asked to help make the necessary contacts and the woman received a few weeks of therapy. However, treatment stopped because she missed two appointments. The patient then had to enlist someone else to ring on her behalf to find out what was happening and try to reinstate her on the waiting list.

Summary findings	Recommendations
<p><b>Mental health services for parents, children and young people</b></p> <p>Some professionals view the eligibility threshold for children and young people to receive mental health support in Waltham Forest to be too high.</p>	<p><b>Overall, ensure findings and recommendations are addressed within the Waltham Forest Mental Health CAMHS Transformation Plan.</b></p> <p>Review threshold criteria across mental health services.</p> <p>Report issue to commissioning partners and Health and Wellbeing Board.</p> <p>Ensure local opportunities for strategic commissioning of low-level mental health support and coping strategies are embedded within the strategic direction of, for example, voluntary and community sector services and the Healthy Schools Programme.</p>
<p>Professionals report postnatal depression as being a major issue in the borough.</p>	<p>Ensure the issue is being addressed through appropriate embedding within key contact points and services for new mothers and their families.</p> <p>Consider commissioning of a specialist service to address parent awareness of postnatal depression, diagnosis of and support provision.</p>
<p>Professionals report gaps existing around early identification and intervention.</p>	<p>Ensure local opportunities for strategic commissioning of low-level mental health support and coping strategies are embedded within the strategic direction of, for example, voluntary and community sector services and the Healthy Schools Programme.</p>
<p>Children, young people and parents do not know what CAMHS stands for and are unaware of the CAMHS services available.</p>	<p>Develop awareness-raising campaign and community outreach and education programme.</p> <p>Ensure all services have clear information, online material and leaflets and that there is a programme for regular distribution and promotion of these.</p>
<p>There is a lack of emergency mental health provision for children and young people in crisis.</p>	<p>Ensure issue and actions addressed within the Waltham Forest Mental Health CAMHS Transformation Plan.</p> <p>Local partners to work nationally to address.</p>

Summary findings	Recommendations
On the whole, children and young people do not know where to go for help, but said they would tend to speak to parents and teachers and other professionals, such as youth workers, if they already had contact with these.	Embed discussions about mental health and support and information avenues into PSHE and other educational settings.
There are barriers to accessing and self-referring to talking therapies, particularly concerning language and learning disabilities.	Ensure this issue and actions are addressed within Waltham Forest Mental Health CAMHS Transformation Plan.
Children and young people are concerned about the confidentiality of treatment.	Review local implementation of the national 'You're Welcome' standards from 2009.
Some young people with learning disabilities need different services to those traditionally provided - talking therapies is described as being inappropriate by some parents.	Review service offer available to this patient group.
Parents feel there are gaps in transitional arrangements - both communications and a lack of local facilities available.	Ensure this issue and actions addressed within the Waltham Forest Mental Health CAMHS Transformation Plan.
Co-location of CAMHS services alongside drug and alcohol services on the Thorpe Coombe Hospital site is felt to be inappropriate and at times frightening.	Ensure children and young people are involved in Thorpe Coombe Hospital relocation site development plans currently underway and their voices can influence new service location and features.

## Disability Services for children and young people

### Context

Disability and long-term impairment affect a significant number of people in Waltham Forest. Learning disabilities and congenital problems are of particular concern in the borough. An estimated 4,500 people have learning disabilities, many of whom are children and young people. Rates are predicted to rise, as risk factors including poverty and rates of special education needs were reported to be high. Rates of 'moderate' learning difficulties are relatively high in Waltham Forest compared to London as a whole<sup>30</sup>.

Part of the 'Local Offer' under the Children and Families Act 2014 involves ensuring that children and young people with additional needs get one combined assessment covering all their health, social care and educational needs. At the time of this piece of work, the new Local Offer was still being developed and the timetable for its implementation was unclear.

### What professionals told us

Professionals we spoke to reported high rates of special educational needs, especially in relation to speech and language problems. Professionals said that among Asian families, a learning disability can carry additional stigma. Most relevant professionals and the support groups we spoke to were largely unaware of what was available under the Local Offer or of how this was progressing. Concerns were voiced that the timing of the new assessment and review procedures might be too tight in practice. No one we spoke to was sure when the new provisions under the Local Offer would be fully operational and the Council website was still being developed<sup>31</sup>.

### Questions we asked

We held a focus group discussion session with the Waltham Forest Parent Forum, which represents the needs of carers of disabled children, young people and young adults. We also interviewed staff from an Asian carers' group and met a group of disabled young people. All groups were asked the same questions around the same topic and service areas as previously discussed in this report, but with more emphasis on how this affected them as children or young people with disabilities and/or carers of children and young people with disabilities. They were also asked to describe any particular issues they had with local health and social care services.

### What parents, children and young people told us

Many of the issues raised by focus group participants are covered in other sections. For example, difficulties in getting GP appointments affect this group as much as anyone else, while access problems and being expected to wait quietly in GP surgeries presented additional challenges. Parents made specific suggestions about appointments, for example

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<sup>30</sup>Waltham forest Joint Strategic Needs Assessment, 2014, p140;

<sup>31</sup><http://walthamforest.childrensservicedirectory.org.uk/kb5/walthamforest/fsd/localoffer.page>



being offered the chance to talk to GPs over the phone rather than having to attend the surgery in person. They also felt that hospital departments should coordinate better so that disabled children and young people could have all their required tests and appointments on one day, in order to minimise the associated disruption and challenges.

Those who had had contact with the Special Educational Needs and Disability Information and Advice Service (SENDIASS) praised it extensively, especially the advice and help provided in negotiating services and appealing to get special educational needs support at school. It was also felt that the service needed to be expanded and more staff employed.

Parents reported having to be ‘experts’ in their child’s condition and to an extent coordinate the various professionals’ involvement. They wanted more courses for parents, especially on managing challenging behaviour and dealing with emotional issues. At present, these are not provided by the council or health bodies. It was also felt that services should be reconfigured to offer ongoing support, and not just crisis management.

### **Transition and services as adults**

A major issue said to face parents was the expectation to continue providing the same levels of care to their grown-up children, especially those with learning disabilities, as well as managing the variable transition to adulthood. Parents worried about how care needs would be met into the future and how to avoid vulnerable adults being taken advantage of. Other concerns were raised about the transition to adult hospital services once young people turned 18, which particularly impacted on those with long-term conditions. Up to the age of 18, children and young people with serious or long-term conditions can get most of their specialist needs met by Great Ormond Street Hospital. After that, specialist in-patient or out-patient care tends to be provided by a number of different hospitals around London. The lack of oversight and continuity, as well as the associated travel, were said to be very demanding for those with long-term conditions and their carers, and worse again for young people with learning disabilities.

These findings echo previous work undertaken by Healthwatch Waltham Forest in July 2014<sup>32</sup>.

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<sup>32</sup>HWWF; *Talking to the parents and carers of children and young people with disabilities and special educational needs, July 2014; and CCG response 6<sup>th</sup> October 2014*

Summary findings	Recommendations
<b>Disability services for children and young people, including those with Special Educational Needs (SEN)</b>	<b>Overall, feed findings and recommendations into the SEND Joint Commissioning Group.</b>
Children and young people with disabilities experience difficulties in accessing GP appointments and will resort to using A&E instead (similarly to the rest of the population).	Audit normal and 'urgent' appointment booking procedures at all GP practices.  Review availability of same-day health services for children and young people with disabilities, including telephone or drop-in support.
Being expected to physically wait for a long time in a GP surgery for an appointment can impact negatively on children with learning disabilities and special educational needs' ability to be assessed and treated effectively.	Adopt good practice examples from elsewhere where parents are given buzzers and are able to walk around the block and be called when their appointment is almost ready to be called.
The 'Local Offer' of new provisions under the most recent legislation is relatively unknown. People who are aware are unsure how the new 'Local Offer' will relate to existing information, advice, representation and other services.	Deliver a series of small talks/information sessions/discussion forums within community settings to supplement wider conferences previously delivered.
Carers are concerned about the transition to adult services, including hospital care, and how young people's continuing needs would be met as adults.	Review use of key contact points for discussion and the transition service offer itself across different pathways.
Professionals report high special educational needs in the borough in relation to speech and language needs.	Review referral rates to the Speech and Language Therapy (SALT) service, the level of provision available in the borough and community outreach and awareness-raising.
Parents want coordinated hospital appointments to reduce anxiety and minimise disruptions.	Work with parents to review opportunities for cross-department coordination and video conferencing for children accessing several hospital services.
The SENDIASS service is highly valued, but under-resourced.	Review local offer and resourcing.
Parents want more courses on managing challenging behaviour and dealing with emotional issues.	Review current level of provision.  Support development of voluntary and community sector to deliver.
Parents desire ongoing support, not just crisis management.	Work with parents to review the current offer and improve support provision within health and social care services.

## Pharmacies

### Context

Chemists play an important role within primary health care, giving health and contraceptive advice, advising on non-prescription drugs and providing a convenient and regularly-accessed service for many seeking support for ad hoc health concerns and in managing long-term health conditions. Within this piece of work we investigated awareness of their role in health care with children, young people and parents to supplement any findings of the Healthwatch consultation in 2014<sup>33</sup>

### What professionals told us

Professionals were not asked any detailed views on pharmacies.

### Questions we asked

General attitudes towards high street pharmacies were explored with parents, children and young people, as well as young people's awareness of the contraceptive advice service.

### What parents, children and young people told us

Pharmacies emerged as one of the most heavily-used services in our groups. Everyone we spoke to was generally positive about pharmacists. They were said to be more accessible than GPs because they were open longer hours and appointments were not necessary. Adults and young people described them as very helpful and knowledgeable about medicines and appreciated that they could provide a certain amount of health and medical advice and so might reduce or remove the need to see the doctor. Pharmacists were described as a common first point of call instead of a GP, and their advice was clearly trusted. Some were praised for their helpfulness, for example delivering medicine to the home to save parents with sick children from having to visit the pharmacy, or getting GPs to fax over prescriptions.

*Chemist is good. They guide you for using medicines and give some advice for some ...which are available without prescription. [parent]*

*They can help us before see the doctor. [parent]*

Alongside these positive elements, some downsides were reported. These included:

- Their remit is limited. Therefore they might have to recommend visiting the GP in any case for a more thorough assessment, or because they believed that a drug only available on prescription was needed.

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<sup>33</sup>Healthwatch Waltham Forest; *The future of pharmacy services: Views and experiences of users in Waltham Forest*; April 2014

- It was reported that few pharmacies in the borough were open out of hours or on a 24-hour basis, not even those sited within 24-hour supermarkets.
- Across our groups, young people's awareness of the availability of free contraception from chemists was found to be extremely low.
- People entitled to free prescriptions might prefer to get a prescription for a medicine, even though it was available over-the-counter, to help save money.

Summary findings	Recommendations
<b>Pharmacies</b>	<b>Overall, feed into North East London Local Pharmaceutical Committee</b>
People are very positive about the pharmacies in the borough. They are appreciated for being helpful and able to provide advice or medication and avoid the need for a GP appointment.	Promote availability of pharmacy services through outreach activity.
Few pharmacies were said to be open out of hours, or on a 24 hour basis, and generally people do not know which ones are.	Ensure clarity and centralisation of this information. - Distribute via community outreach and awareness- raising sessions.
Young people were not generally aware of the availability of free contraception through chemists.	Broaden awareness-raising, outreach and educational programmes and links with schools and colleges and other local groups and networks.

## Local hospital services

### Context

The local hospital Whipps Cross has, in recent years, been the subject of increasing scrutiny. Most recently the CQC inspection report published in March 2015 issued several enforcement and compliance actions. Inspectors rated urgent and emergency services, medical care, surgery, end of life care, outpatients and services for children and young people as ‘Inadequate’ and the critical care and maternity and gynaecology services were rated as ‘Requiring Improvement’<sup>34</sup>.

There continue to be extensive efforts by local and national partners, including Healthwatch Waltham Forest and Waltham Forest CCG, to hold Barts Health NHS Trust to account and support the Trust to improve.

### What professionals told us

Professionals were not asked any detailed views on hospital services.

### Questions we asked

As so much had already been reported around Whipps Cross Hospital and its services, we tried to avoid talking about Whipps Cross Hospital with parents, as it was not felt that much could be added. We did gather views and experiences from children and young people, as these had not been so widely explored. However, both parent and younger groups were quite keen to talk about their experiences at the hospital and did so spontaneously, giving both positive and negative experiences.

### What parents, children and young people told us

#### Accident and emergency (A&E) at Whipps Cross Hospital

The A&E at Whipps Cross was mainly criticised for long waits and a poor physical environment, but parents were content with the treatment received.

*I've been to hospital A&E a couple of times with my child. Went to A&E after he had big fall, frightening. Called ambulance and went to Whipps Cross and times when they were good. They give really good care, because that was serious. ...Also other he was ill, high temperature, but we were waiting for hours. The doctors always check him properly but the waiting for three hours. [parent]*

*The doctors always check him properly, but it's the waiting... You need to have your patience to wait, always 3 hours. [parent]*

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<sup>34</sup><http://www.cqc.org.uk/location/R1HKH>  
<http://www.cqc.org.uk/content/chief-inspector-hospitals-calls-improvements-whipps-cross-university-hospital-rated>

Old and young alike complained about the triage system and a lack of information and communication while waiting. Perceptions were that the triage system was not fair, nor based on a sound medical judgement of need:

*At the hospital the people who give you the cards... they need to be trained to diagnose it. A lot of time I've seen people severely bleeding and they're sitting there waiting and a lot of the time they don't listen properly to see what it is and they don't understand the severity of the problem. They're not quick enough to know you need to go straight to paediatrics ... They're not trained enough to know... even if you've been given the right card you could still wait and your condition could deteriorate and you have to keep going in to say it's got worse and they don't check. [CYP]*

Provision of interpreting at A&E was said to vary. While A&E staff were reported to be more prepared to use interpreters than GPs, people often took other family members or friends along with them in case there was no interpreting service provided. This is likely to impact on numbers in the waiting areas.

As mentioned in previous sections, not being able to see a GP either out of hours or without an appointment had a direct impact on A&E attendance and this was highlighted by parents:

*Very difficult to get appointment for young child when ill, and so we have to go to A&E with it, for example recently with high temperature and for an asthma attack. Usually we would be at A&E for several hours and given a special inhaler and then allowed to go home. Usually have to wait a long time. [parent]*

## Children and young people's views on hospitals

It was notable how many children and young people had direct experience of attending A&E and/or being in-patients.

Children and young people found the children's sections of the A&E waiting area dismal and boring. A few who had been to other hospitals, such as the Royal London and Great Ormond Street, recounted the fun they had had while waiting, or being in-patients there, and described a range of activities for different ages to get absorbed in, and that this had distracted them. There was said to be little or nothing for older children or young people to do in the Whipps Cross A&E waiting area. Meanwhile the children's ward (Acorn ward) was described as 'drab' by both children and parents.

The children and young people we spoke to people described hospitals as extremely frightening environments. They particularly disliked having to wait alongside ill 'old people', or those who had 'lots of tubes going in and out'.

*The waiting area in Whipps X, hospitals are very scary anyway, especially as a child, you feel more nervous when you see people sitting in front of you or beside you and they're vomiting and they've got severe problems and it's a scary thing. [CYP]*

*When you're going down the hall, it's just all silent and you see people passing you ... and they're all in the wheel chairs with plastic tubes going up the noses... scary. [CYP]*

*I don't like when you walk into some big room ... you see loads of people with loads of tubes connected to them and you walk around there are lots of older people. It's a bit scary. [CYP]*

Hygiene, especially the apparent lack of it, really troubled children and young people. One young person observed an adult vomiting blood into a bag in the A&E waiting area, and said this was not cleared away but was left on the floor for too long.

*You're sitting there and there's germs everywhere...Everyone is coughing and contaminating everything. Maybe if they separate people out into different categories. [CYP]*

Not being fully informed about what was happening to them added to children's fear:

*When they put you to sleep and they do all sorts of stuff - I don't like not knowing what they're doing. [CYP]*

*You don't know what happened. Like they put you to sleep and they do the operation and when you wake up and you don't know what has happened...they've done something to your leg ... They haven't explained. [CYP]*



Summary findings	Recommendations
<b>Hospitals</b>	
<p>Parents, children and young people are unhappy about the long waits in A&amp;E at Whipps Cross. However they are content with the treatment received.</p>	<p>Extensive work is already in place to address the waiting issue.</p> <p>Finalise and disseminate leaflet to be given out to patients in Emergency and Urgent Care Centre waiting areas to inform them of the process and why waits take place.</p> <p>Work collaboratively with partners to develop and deliver community outreach and education programmes around health education and the variety of local services parents and young people can access.</p>
<p>Parents, children and young people are not confident in the triage system and a lack of communication and information whilst waiting exacerbates this (and overall patient experience).</p>	<p>Finalise and disseminate leaflet to be given out to patients in Emergency and Urgent Care Centre waiting areas to inform them of the process and why waits take place.</p>
<p>A proportion of the A&amp;E demand comes from people unable to see a GP.</p>	<p>Target promotion of GP Extended Hours pilot to nurseries, children's centres and parent Facebook and Twitter networks.</p> <p>Ensure demand issues from parents with young families are addressed within Primary Care Action Plan and Urgent Care commissioning going forward.</p> <p>Work collaboratively with partners to develop and deliver community outreach and education programmes around health education and the variety of local services parents and young people can access.</p>
<p>Provision of interpreting is variable at A&amp;E (although better than at GP surgeries).</p>	<p>Audit use of interpreting service and seek feedback from staff to inform future improvement.</p>
<p>The waiting areas are felt to be unfriendly to children and young people, boring and unhygienic.</p>	<p>Undertake mystery shopping of GP, hospital and other health service waiting areas with a group of children, parents and young people.</p>
<p>Children and young people want more information about their treatment.</p>	<p>Ensure child and young people-friendly literature is available and conversations are had with the child as well as the parent.</p>
<p>The transition to adult hospital care is challenging for young people with several long-term conditions, as it requires attending numerous different hospitals.</p>	<p>Promote use of video conferencing where it is available and investigate other examples of practice that could reduce the number of hospital visits for young people.</p>

## Dentists

### Context

The 2012 official statistics show that Waltham Forest compares unfavourably with English local authorities on average, but is on a par with London as a whole. However, Waltham Forest has higher rates of tooth decay and extractions than Redbridge, which is counted as its statistical neighbour<sup>3536</sup>.

The next large-scale study of five-year-olds by Public Health England is due in 2016.

### What professionals told us

Professionals we spoke to reported that because children often required multiple tooth extractions, these needed to be done in hospital under a general anaesthetic. As a result, there were long waiting lists, which resulted in children commonly getting repeated doses of antibiotics to address infections in the meantime. This was reported to be a national problem and not only particular to Waltham Forest. Another point made was that to date no analysis has been done to identify or address different needs or issues among different ethnic groups and communities. However, it was expected that this data would be collected in the future.

### Questions we asked

We asked adults and children in our groups if they had been to a dentist within the past year and, if not, if they were registered with a dentist. We also specifically asked children what they liked and did not like about visiting the dentist.

### What parents, children and young people told us

Overall, children and young people reported having and attending a dentist more than the adults we spoke to, but it was not universal in either case. A minority of our parents said they had not managed to register with a dentist and some were not aware of how to do so. Consistent with the statistical reports referred to above, children and young people had extensive experience of fillings and extractions.

It was unsurprising that children told us they did not like extractions, drills, injections, pain, or being scolded, but the more unanticipated dislikes were the banana-flavoured varnish and overhearing the sound of other people getting their teeth drilled. In several groups, children and young people expressed concerns about the hygiene of equipment and the risk of cross-contamination: they were very anxious to know whether dentists cleaned their tools in-between patients.

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<sup>35</sup>Dental Health of Five Year-Old Children; Public Health England, 2014  
<http://www.nwph.net/dentalhealth/5yearoldprofiles/London/Waltham%20Forest%20LA%20Dental%20Profile%2005yr%202012.pdf>

<sup>36</sup>Waltham Forest Joint Strategic Needs Assessment 2014

Children liked being given stickers, lollypops, a picture to look at on the ceiling and being praised. One practice was praised by parents for being able to provide treatment to people who were highly anxious about different aspects of dentistry.

Summary findings	Recommendations
<b>Dentists</b>	
Children and young people find some noises frightening in dental surgeries and some are concerned about the hygiene of dental equipment.	<p>Work with children’s centres and schools to deliver fun and informative sessions around visits to the dentist and what to expect.</p> <ul style="list-style-type: none"> <li>- Ensure future of oral health champions in all Children’s Centres is secured.</li> <li>- Upskill Children’s Centre staff.</li> <li>- Build regular audits/checks/screening into universal offer through Children’s Centres.</li> </ul>
Children and young people like being rewarded and having some visual distractions during treatment.	Develop learning opportunities for local dentists to share best practice and techniques.
One local dentist was praised for being able to reassure and treat people with anxieties and difficulties with dentistry.	Expand Comely Bank community dentist and outreach service and develop opportunities to share best practice.

## Section E: Safeguarding children and looked-after children and young people

### Context

Local authorities are obliged under various pieces of legislation and official policy to safeguard children and young people in their area. Over recent years, Ofsted, which inspects and reports on local authority safeguarding, has criticised Waltham Forest's general provisions and its care for children and young people looked after by the council<sup>37</sup>. The most recent Ofsted report, published in January 2015<sup>38</sup>, concluded that all areas 'Required Improvement' although it noted that staff were trying hard. Previous Ofsted reports in 2011 and 2013 had also recognised a need for improvements. Problems identified by Ofsted included:

- Poor coordination of services for vulnerable children and young people, including those missing from residential children's homes.
- Poor care planning and placements.
- High staff turnover.
- Low levels of contact with young people who have left care.
- Poor outcomes on various fronts for looked-after children and young people.
- Lack of involvement of children and young people and a low emphasis given to this. In particular Ofsted found that looked-after children and young people were not being consulted about their care plans on an individual level, nor involved at a strategic level.

Over recent years, social care services in the borough have undergone major restructuring. Generic youth work provision has been largely scaled back and many voluntary and community services have ceased to exist, or diminished in scale and services over recent years. Indeed several stopped operating over the course of this study. Prior to 2015, Waltham Forest had 17 children's centres. These were reduced to six in early 2015 and further reductions were expected from April 2015. Children's Centres provided primary care health and social care and in the past used to host midwifery and health visitor clinics.

### What professionals told us

#### Neglect and thresholds for intervention

Professionals reported that child neglect was one of the major problems facing social services in the borough. Many factors were said to contribute to this, not least high rates

<sup>37</sup><http://reports.ofsted.gov.uk/local-authorities/waltham-forest>

<sup>38</sup>'Single Inspection of LA Children's Services and Review of the LSCB' Jan 2015

[http://reports.ofsted.gov.uk/sites/default/files/documents/local\\_authority\\_reports/waltham\\_forest/054\\_Single%20inspection%20of%20LA%20children%27s%20services%20and%20review%20of%20the%20LSCB%20as%20pdf.pdf](http://reports.ofsted.gov.uk/sites/default/files/documents/local_authority_reports/waltham_forest/054_Single%20inspection%20of%20LA%20children%27s%20services%20and%20review%20of%20the%20LSCB%20as%20pdf.pdf)

of parental mental health problems, substance misuse and domestic violence. These were often combined with housing deprivation, especially over-crowding, with many families sharing the same flat or house in short-term, insecure, tenancies with high rents. Poor housing was said to contribute to high rates of movement into and within the borough.

The factors contributing to neglect were said to be evenly spread across all the communities in the borough. The exception was housing, which was perceived to affect newer communities and BAME groups in particular. Concerns about trafficking were also expressed, but no details were provided. The high mobility, combined with a mistrust of statutory services and sometimes immigration concerns, presented challenges for professionals such as health visitors in trying to maintain contact with families. It also meant families could quite easily escape the notice of social services if they wished. In addition, social work services are felt to be so targeted that only those with serious safeguarding concerns could qualify. This was said to aggravate any existing potential stigma. Although professionals were worried about 'neglect' across all communities in the borough, most families were assessed as being under the threshold at which social services would get involved.

Issues such as poor school attendance, poor diet and weight problems in children were commonly cited as signs of parental neglect among the professionals we spoke to. However, there were found to be other, especially cultural, dimensions to these concerns. For example the Roma Support Group explained how what might look like neglect here could be somewhat attributed to differences in understanding and expectations. Aspects of diet perceived as neglect could, on the other hand, also signify a community adjusting to the availability and relative cheapness of sweet foods and the convenience of fast food in this country. In terms of schooling, older members of the Roma community who were new to this country were unlikely to have attended school themselves and may not place the same importance on formal education as might others in the UK. In addition, in many participants' countries of origin the school starting age is much later, at six or seven. It was said that children were particularly cherished in the Roma community and so the idea of leaving young children in childcare is quite alien, and as families provide a lot of support to new mothers there is less perceived need to use drop-in and play services. Furthermore 'play' does not have the same perceived developmental and educational purpose as is now accredited to it by early years' professionals. Last but not least, as literacy levels are low, much written information is ineffective for this community.

### **Using children's centres**

Professionals felt that the best way to establish and maintain contact with families was to encourage trust in professionals, especially through offering universal and generic frontline services, or locating key personnel within children's centres,. Children's centres in Waltham Forest were popular and by all accounts well used, despite recent reorganisation and fears of further reductions. In recent years midwifery and health visitor services were moved away from community-based centres, which was felt to have made it more difficult for these services to engage with a wide range of women, including those on the verge of children in need status. There was some evidence of services moving back and some specialist groups and clinics were being held in some children's centres to

improve access. Other services are also being developed in response to emerging need, including food banks.

### Services for young carers

It was felt that young carers often go unnoticed and unsupported in schools and health and social care services. Being a young carer is known to have serious negative short-term and long-term impacts for those involved, including poor educational outcomes and poor mental and physical health. Many good examples of support for young carers were found in Waltham Forest, including the young carers' clubs run and supported by Early Help Service and support in some schools. However, this support was limited and in the main young carers received support only where there were additional concerns about the family, not simply because of their caring responsibilities.

Some school-based identification and support was found, but it was said that this was far from universal. Anecdotally, one secondary school was reported to say that they had no young carers on their roll. When we asked young carers if their GPs knew they were carers, most said 'no', or that they did not know if their doctors were aware or not. Not all wanted their GPs to know and preferred this aspect of their lives to be kept private. Their reasons could not be probed further in the limited time available, but this will have implications for provision of coordinated support through the health system.

### Questions we asked

Social workers were included in the list of professionals discussed with groups and were one of the professionals that participants could identify knowing or having worked with. We were aware of the potential stigma attached to social services involvement, so follow-up with those who mentioned them was sensitive, focusing more on the help received than the cause of the involvement.

### What parents, children and young people told us

The diverse range of services provided in Children's Centres (including professional advice, drop-in play and food banks) was appreciated by the parents we spoke to and accessed well by parents and children from the diverse local populations. Parents felt the staff in Children's Centres were more approachable for advice, for example on breastfeeding and weaning. This was partly attributed to the fact that they spent more time developing trust and so relationships were established in which the information and advice given was more accepted. In addition, the particular expertise of some of the staff, for example breastfeeding support workers, was acknowledged and appreciated by other professionals as well as by parents.

Reported contact with social workers was higher in certain focus groups, such as the groups of young carers, disabled young people, children in care and the Parent Forum. It was also mentioned by a small number of parents, children and young people in other groups. Social services support for disabled children and young people was said to be mainly limited to emergency needs or processing applications for respite breaks.

Children and young people who had social workers in their lives, including those in the care system, gave varied feedback. Some made it clear that they resented having social work involvement, while others felt they had benefitted from this, liked their social workers and had developed a good relationship with them.

Decisions such as removing children from the family into care were not necessarily understood and contributed to negative attitudes about the profession:

*...they keep twisting everyone's words around ... and they'll lie to you. For example they said ...that they would give us contact and phone contact... years ago and it still hasn't happened. [CYP]*

On the other hand, getting emotional help was appreciated, such as advice on coping with difficult emotions and frustrations, as was practical advice on effective communication and dealing with bullying:

*... And when I said to her I've got a problem at school, 'cos I was always getting bullied all the time at school, she was helpful, 'cos she told me don't react to them because it's fun for them to pick on that person 'cos they react all the time So once I listened to her and stopped reacting, it helped...it stopped. [CYP]*

Being able to speak to a social worker when they need to was important:

*My social worker she's alright. But say you have a problem, she keeps her phone on voice mail all the time... So if I call my social worker she wouldn't answer. [CYP]*

The looked-after children and young people we met were used to social workers changing every year and had come to accept this as the norm. They appreciated rules and promises being adhered to, and being given a say in major decision-making, such as where to live, foster care placements and moving on to independent living. They also wanted confidentiality to be more respected across the board, for example for their status as a child in care to be kept private. Children and young people said they would like more time to prepare for social worker visits and to be able to meet with them alone. It was not clear if this only applied to their personal social worker or to their Independent Reviewing Officer as well.



Summary findings	Recommendations
<b>Safeguarding, neglect and looked-after children and young people</b>	
Children and young people involved with social services want social workers to be available and responsive when they are needed. They want to be able to trust social workers and other professionals, for example to maintain confidentiality about their status.	Build on existing work and incentives to retain staff and ensure consistency in the relationship between key workers and children and young people in order that trust can be built.
Cultural nuances around child rearing affect perceptions of 'neglect'.	Use internal learning opportunities to challenge assumptions and 'norms' and develop understanding around different cultural nuances.
Although 'neglect' is a major concern across all communities, this usually does not qualify for intervention.	Review thresholds and service offer available at lower levels of 'neglect'.
Some young carers attend support groups and enjoy these. However, group support was mainly only available to those with high-end needs or where there were additional parenting concerns.	Review thresholds and service offer available at lower levels of 'neglect'
Certain schools offer special support to young carers, but this is not universal and the presence of young carers is not always identified by schools.	Share good practice across the school network and investigate appropriate mechanisms to flag up and support young carers.

## Conclusion

Health and social care in Waltham Forest presents multiples challenges. Not only are needs relatively high, diverse, complex and liable to change with changing populations, but services were also found to vary in quality, delivery and accessibility. These issues have also been compounded by major structural reorganisations and public sector cuts in recent years.

There is inadequate capacity evident in GP, health visitor and mental health services for parents, children and young people, which arguably undermines the local population's ability to access appropriate care. In addition, the findings of our focus groups indicate that problems with access to GPs have a direct impact on the numbers using emergency services, such as A&E, which are already more likely to be under pressure in a deprived area. Relatively high rates of mental health problems among children and young people have been identified and these are predicted to rise. However, not only was existing provision lacking, but there was a significant question mark over how rising needs would be met over coming years.

Public knowledge of services and basic health issues was found to be low across the board, as was knowledge of where to source reliable information. For such a diverse population, language poses a significant barrier to accessing services in a meaningful manner and interpreting was not always used or requested by patients. In addition, the technical language in medical conversations and the speed of GP consultations added additional challenges to mutual understanding.

While the language difficulties found were most striking amongst the Roma population in Waltham Forest and, to a lesser extent among people from Eastern Europe and Southern Asia, other barriers were also evident, not least differing expectations and understanding of health and social care services and systems.

Respect for children's rights appeared variable and lacking, especially in terms of providing information about important matters which directly affect them, such as their own medical treatment, enabling informed consent and protecting confidentiality. Children and young people were largely unaware of any rights but eager to find out more. Many of the comments made about GP and hospital waiting areas and the expectations on children and young people to sit quietly for long periods of time, without entertainment, indicate that little attention is paid to the comfort and reassurance of young patients.

Last but not least, these and other findings, for example around infant feeding, point to a need for professionals to have a dialogue with their patients or clients around relevant issues and to be more willing to share the evidence which underpins their advice. Our participants were keen to know about health, how to look after their own health and do the best for their children. They did not enjoy feeling that they are being lectured to or judged and knew they could politely ignore official advice if they did not agree with it and instead seek advice elsewhere that fitted their beliefs. Dialogue is imperative.

This report highlights a range of experiences, views, concerns and priorities of children and families in relation to health and social care services in Waltham Forest. While certain

aspects affect some communities more than others, most of the issues are shared across people from all backgrounds.

## Glossary and abbreviations used

Acronym/phrase	Explanation
<b>A&amp;E</b>	Accident and Emergency Department in a hospital
<b>BAME</b>	Black, Asian and minority ethnic groups
<b>British Formulary</b>	A pharmaceutical reference book that contains a wide spectrum of information and advice on prescribing and pharmacology, along with specific facts and details about many medicines available on the NHS.
<b>CYP</b>	Children and Young People. This covers everyone under the age of 19. However, for certain services, such as when disabled, ill long-term or looked after, services can continue until the age of 25, in which case the term 'young people' would also continue to apply.
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CCG</b>	Clinical Commissioning Group (set up by Health & Social Care Act 2012)
<b>CQC</b>	Care Quality Commission
<b>DH</b>	Department of Health
<b>ESOL</b>	English for Speakers of Other Languages
<b>FFT</b>	Friends and Family Test - a feedback tool used in the NHS to gather opinions from patients on their experiences of services
<b>JSNA</b>	Joint Strategic Needs Assessment
<b>LA</b>	Local Authority
<b>LACYP</b>	Looked-after children and young people
<b>LBWF</b>	London Borough of Waltham Forest
<b>LCSB</b>	Local Children's Safeguarding Board
<b>'Local Offer'</b>	This is the new term for the coordination and delivery of services from April 2015 for disabled children and young people, those with additional educational needs and those with long-term conditions. Under the new legislation and guidance, health, social care and education bodies are expected to work together and children are entitled to a single joint education health and care assessment.
<b>NELFT</b>	North East London Foundation Trust - the main provider of Mental Health and Community Health services
<b>SEN</b>	Special Educational Needs
<b>SENDIASS</b>	Special Educational Needs Disability Information Advice and Support Service -a confidential service that listens and supports parents of children with special educational needs.
<b>Tier 1,2,3 (CAMHS)</b>	Tier 1 - CAMHS at this level are provided by practitioners who are not mental health specialists working in universal services. This includes GPs, health visitors, school nurses, teachers, social workers, youth justice workers and voluntary agencies. Tier 2 - Practitioners at this level tend to be CAMHS specialists working in community and primary care settings in a multidisciplinary way. This can include primary mental health workers, psychologists and counsellors working in GP practices, paediatric clinics, schools and youth services.

Acronym/phrase	Explanation
	Tier 3 - This is usually a multidisciplinary team or service working in a community mental health clinic or child psychiatry outpatient service, providing a specialised service for children and young people with more severe, complex and persistent disorders. Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, community psychiatric nurses, child psychotherapists, occupational therapists, art, music and drama therapists.
<b>WHO</b>	World Health Organization

## Appendices

### Appendix 1 - Details of Focus groups and interviews

	Target group	Number of groups
<b>Children's Centres</b>		
– Chingford Children's Centre	Parents and carers with pre-school children, including fathers	5
– Walthamstow East Children's Centre		
– Walthamstow West Children's Centre		
– Leytonstone Children's Centre		
– Chingford E4 Stay and play		
<b>Primary schools</b>	Children aged 5 - 11	4
– Chapel End Primary School		
– Davies Lane Primary School		
<b>Secondary Schools</b>	Young people aged 11 - 16	4
– Rushcroft Secondary School		
– Willowfield Secondary School		
<b>Youth groups</b>	Young people aged 11 +	4
– Waltham Forest Young Advisers		
– Worth Unlimited		
– Youth Club, Asian Centre		
<b>Disability group</b>	Children and young people	1
– Early Help Learning Disability Group		
<b>Looked-after children and young people</b>		1
– Children in Care Council		
<b>Carers' groups</b>	Adult carers	4
– Waltham Forest Parent Forum		
– Young Carers Group, Outset Centre, E17		
<b>Religious centres</b>	Adults	1
– Noor Ul Islam mosque		
<b>Polish families</b>		
– Polish Saturday School, E17 - Adults	Adults	1
– Polish Saturday School E17 - Children 8-14 years	Children (8 - 14)	1
<b>Roma group</b>	Adults	1
– Roma Support Group		
<b>ESOL Groups</b>		
– ESOL Group held in Higham Hill Library, run by ELATT	Adults	2
– E17 ESOL language class, run at the Mill, Coppermill Lane		
<b>Total</b>		<b>29</b>

## Interviews and discussion conducted with individuals

Name and position	Organisation
Linzi Roberts-Egan Deputy Chief Executive, Children and Families	London Borough of Waltham Forest
Mary Neilson Public Health Strategist - Health in Schools	London Borough of Waltham Forest
Amy Coates Public Health consultant	London Borough of Waltham Forest
Kirsty Partridge, Stuart Collins, Louise Harvey CAMHS and Manager CAMHS 722 Service,	NELFT
Emma Goodman Psychologist Perinatal service	NELFT
Margaret Burke Early Help under 11	London Borough of Waltham Forest
Denise Humphrey Group Manager, Early Help 11 Plus	London Borough of Waltham Forest
Debbie Freeland SEND Information and Advice Service	London Borough of Waltham Forest
Mary Marsh Targeted Services and Health visiting,	NELFT
Felipe Castro Cordona Consultant Midwife	Barts Health NHS Trust
Anna Jones Designated Nurse Safeguarding children	Waltham Forest CCG
Korkor Ceasar Designated Nurse for Looked After Children	Waltham Forest CCG
Kristy Leach Service Lead, Family Nurse Partnership	NELFT
Katie Lewis Specialist Children's Community Nursing	Wood Street Health Centre, NELFT
Anna Rinaldi Manager, Leytonstone Children's Centre	London Borough of Waltham Forest
Carol Lee and Raymond Wood Managers, Chingford Children's Centre	London Borough of Waltham Forest
Marjorie Aissani Senior Outreach Worker - Plus Breastfeeding support, Leytonstone Children's Centre	London Borough of Waltham Forest
Sajida Ahmed Coordinator	Waltham Forest Asian Mothers Group
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- *Talking to the parents and carers of children and young people with disabilities and special educational needs, July 2014; and CCG response 6<sup>th</sup> October 2014*
- *The future of pharmacy services: Views and experiences of users in Waltham Forest; April 2014*
- *Accessing GP Services in Waltham Forest: What people want, December 2013*

## Appendix 3 - Waltham Forest Population Profile, Joint Strategic Needs Assessment

The local authority's analysis of the latest Census and other data indicates that Waltham Forest has a growing, young and diverse population<sup>39</sup>. Most notably for this report:

- One third of households have dependent children, birth rates are relatively high and the population is younger than national or London averages. An estimated 67,303 children and young people live in the borough, and almost one in three (31%) are under the age of four.
- Waltham Forest has a very diverse population. Just less than one half, 47%, of all residents are from Black, Asian and minority ethnic (BAME) communities. Within this, roughly one fifth are from Asian backgrounds (21%); 17% are Black British, African or Caribbean; 5% are of dual heritage and 4% are from 'other' backgrounds. Among children and young people the rates of diversity are higher: over six in ten, 62%, are from BAME communities. The southern and middle wards are the most diverse in the borough. Records on applications for new National Insurance numbers indicate that recently most migrants come from Pakistan, Lithuania, Poland, Romania and Bulgaria.
- One in four people, 26%, do not speak English as a main language. A small but significant number (14,250 people, or 6%) do not speak it at all. Besides English, Polish, Urdu, Romanian and Turkish are the main languages spoken in the borough.
- Relative and absolute deprivation have grown in the borough and one in four children are deemed to live in poverty (16,800 - 25%). Entitlement to free school meals is higher than the London average.

### Previously recorded health issues

Several recent reports have highlighted specific health concerns for families, children and young people in Waltham Forest. For example, the JSNA 2014 reported that while some health indicators had improved over recent years, Waltham Forest ranked low, at 324 out of 354 local authority areas on the 2009 Childhood Wellbeing Index (where 1 is the highest). Numerous specific concerns affecting families, children and young people persist, not least:

- Relatively high rates of infant mortality, low birth weight, still births, and congenital and genetic disorders.
- Low rates of maintaining breastfeeding beyond 6 weeks.
- Low rates of childhood immunisation.
- High rates of special education needs.
- Poor control of some chronic health conditions, such as asthma.
- High levels of childhood obesity.
- Among young people, high incidences of mental illness and hospital admissions for mental ill health, sexually transmitted illnesses and young pregnancy.

A number of relevant reports and recent initiatives were referenced for this study and formed the basis of some of the questions developed. For example a meta-analysis<sup>40</sup> conducted on data gathered in Waltham Forest, Tower Hamlets and Newham found that:

<sup>39</sup>Waltham Forest Joint Strategic Needs Assessment, (Refresh) May 2014.  
<http://www.walthamforest.gov.uk/Documents/JSNA%202014-15.pdf>

- The high rates of child deprivation, not least poverty, homelessness and poor nutrition contributed to a high demand for health services.
- Births are increasingly complex for various reasons.
- Higher than average rates of childhood obesity contribute to the early onset of other long-term conditions.
- Worse than average mental health among children and young people.
- There is a need for well-developed prevention, public health and screening services.

The professionals we spoke to highlighted some additional concerns, including:

- That JSNA data is by nature a bit historic and it is hard to collate accurate and up to date for inclusion.
- High rates of domestic violence, drug and alcohol misuse in families.
- Sexual health among young people and a high abortion rate.
- Difficulties filling school nurse and health visitor posts.

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<sup>40</sup>*Transforming Services Changing Lives, Case for Change* (NHS England, Dec 2014)

## Appendix 4 - Summary of statutory documents relating to rights for children and young people vis-a-vis health services and care

### **The NHS Constitution**

<http://www.gov.uk/government/publications/the-nhs-constitution-for-england>

The Constitution brings together the existing legal rights and responsibilities of patients, the public and staff in relation to any service that is funded by the NHS and applies to all parts of the NHS. The constitution along with some of the other documents listed below states that the NHS has to take account of local needs in commissioning services, including the needs of children and young people, who have a right to timely access to services - as laid out in the Handbook that accompanies the Constitution.

### ***You're Welcome - Quality Criteria for young people friendly health services. Last published 2011***

<http://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

The *You're Welcome* quality criteria provide a set of standards for delivering young person-friendly health services for 14-19 year-olds in England. Although not mandatory, health services are expected to use them to assess how well their provision meets the needs of young people. Quality assurance was provided by the Department of Health until 2010 when this was devolved to local health agencies.

### ***Children and Young People's Manifesto for Health and Wellbeing 2013***

<http://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>

The Chief Medical Officer's report, *Prevention Pays - Our Children Deserve Better*, included a chapter on the voices of children and young people. 'A *Children and Young People's Manifesto for Health and Wellbeing*' forms the conclusion of the chapter based on a literature review and input from children and young people.

### ***Better health outcomes for children and young people Pledge***

<http://www.gov.uk/government/publications/national-pledge-to-improve-children-s-health-and-reduce-child-deaths>

The Pledge sets out a pledge of five shared ambitions and five commitments to improve health outcomes for children and young people. A wide range of NHS bodies have signed up to the pledge.

A summary of all these documents, how they inter-relate and the rights therein has been produced by the Council for Disabled Children and is available here:

<http://www.councilfordisabledchildren.org.uk/resources/children-and-young-people-s-health-rights-in-england-shared-messages>

## Appendix 5 - Review of Child and Adolescent Mental Health Services in LB Waltham Forest, 2015

A review of Tier 1 and 2 CAMHS, which reported in February 2015, demonstrated that incidence of mental ill-health amongst the young population of Waltham Forest was both high and predicted to increase. Prevalence was estimated to range from 19.5% of children aged 2-5 (or over 3000 children); 12% of 5 to 16-year-olds; and 15% among 16 to 19-year-olds. Known risk factors for children and young people developing mental health difficulties included: growing up in poverty; being from a minority ethnic background; having parents with mental health problems; having learning disabilities and being in the care or criminal justice systems. The table below shows the estimates for the need for different levels of intervention among children and young people.

Estimated Tier 1-4 needs for children and young people in Waltham Forest (Feb 2015)

	Tier 1	Tier 2	Tier 3	Tier 4
2012	9425	4400	1165	50
2019	10720	5005	1325	55

Shortcomings with current commissioning and provision were outlined, not least:

- Inadequate provision for children under 5.
- A skewing of services toward the high end needs at Tier 3, such as hospital treatment, with inadequate provision for those with Tier 1 and 2 needs such as counseling.
- Inadequate services and support for looked-after children and young people, which were worse if they placed out of borough.
- A lack of outcome measurement.

A discussion at the CAMHS Partnership Board meeting in February 2015 indicated that schools were under-referring into Tier 2 CAMHS services. Waltham Forest Young Advisers had provided some input to the Tier 1 and 2 reviews, and suggested that mental health should be included in the school curriculum as well as in extra-curricular activities and that support should be made much more accessible. The recommendations made by that review have been formally approved.

In 2014 NELFT conducted a survey with families ( $n=188$ ) to ascertain why people often did not attend their CAMHS appointments<sup>41</sup>. The main reasons found were: appointments coinciding with school hours; administration, such as not getting the appointment letter or being unaware of the referral; parents or children not understanding what the appointment was for; not wanting the service; and not finding it useful.

<sup>41</sup>DNAs in Waltham forest CAMHS, Sam Illaie, Feb 2015

Appendix 6 - Extract from Ofsted Report 2015

**Page 9 of Inspection of local authority services for children in need of help and protection, children looked after and care leavers and review of the Local Safeguarding Children Board, Ofsted Report, Jan 2015**

<http://reports.ofsted.gov.uk/local-authorities/waltham-forest>

- Ofsted last inspected Waltham Forest's services for children in care in 2011 and found them to be inadequate. The council had not given enough priority to helping children in care and care leavers. Many children and young people were not getting the help and support that they and their families needed.
- Ofsted last inspected Waltham Forest's services to keep children safe in 2013. At that time, services were improving but some children and families were not being helped effectively. Many social workers and managers were temporary and did not stay long. This meant that they did not always know the children well.
- The recent inspection found that some of these problems remain, so the help, protection and care that many children get are still not good enough. There have been signs of some improvement, particularly in the last six months, but it now needs to happen more quickly.
- Adults are not doing enough to talk to and listen to the views of children and young people. For example, social workers are not always visiting children at home or in their placements as often as they should. Some children who go missing are not spoken to on their return to find out what is happening in their lives. The service has lost touch with some care leavers, who may be vulnerable or may not know what help they are entitled to. This means that some young people might not get the help they need.
- Managers and local politicians now better understand how well the service is helping, protecting and caring for vulnerable children and young people. They are determined to make sure that children are consistently kept safe and helped to have happy and successful lives.
- Managers and frontline staff are working hard to improve services and to respond to concerns about children, including improving help for young people who go missing or who are at risk of being sexually exploited. They know that they need to do more to ensure that young people always get the help that they need.
- Children and young people should be much more involved in planning and monitoring services, as this will help to make sure that services are child-friendly and are effective. A fantastic group of children in care and care leavers has been elected by their peers to the Waltham Forest Children in Care Council. These young people know what it is like to be in care, so they could really help the council to improve services. But to do so, they must be given a higher profile and allowed to influence big decisions made by managers and politicians.