

"My View"

Health and Social Care Experiences of Children and Young People in Barnet

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1. Introduction

Healthwatch Barnet

Healthwatch Barnet is part of a new national network, led by Healthwatch England. It was established by the Health and Social Care Act 2012 and aims to give users of health and social care services a powerful voice locally and nationally. Healthwatch Barnet is the independent voice for residents of Barnet on health and social care and was created in 2013 to emphasise the importance of people having a voice in relation to their care. This gives people the opportunity to speak up about the healthcare and social care they receive, with the aim that this data will help to influence local and national policy.

Healthwatch Barnet is part of this network, giving people a more powerful voice locally. Healthwatch Barnet creates opportunities to listen to what residents say about health and social care in the Borough; liaise with the health and social care providers to develop good quality services in Barnet; and provide information to residents about what services are available.

Healthwatch Barnet's vision is for a thriving, active community of residents, patients, volunteers and organisations that contribute to the development of quality health and social care in the Borough.

About this research

CommUNITY Barnet's dedicated Children and Young People's Team was commissioned to listen to the views of local children and young people and to learn what they had to say about their health and social care experiences. The methodology used for this research supports CommUNITY Barnet's principles around engagement

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and embedding participation across all partners working with children and young people.

Healthwatch Barnet's research was focused on children and young people aged 13-25 year living in Barnet. The team employed a mixed method methodology (surveys and focus groups) to gather positive and negative experiences, identify areas of concern and make suggestions on how services could be improved. This presented children and young people with an opportunity to have their say about local health and social care services. Using Barnet Council's objectives, defined in the Participation Strategy for Barnet Children's Trust Board, Healthwatch Barnet wanted to increase the participation of children and young people in the decision-making process and empower them to have a say in how health and social care are delivered in Barnet.

The Council's Participation Strategy aims to complement existing achievements and involve children and young people, where appropriate, in decision making and shaping services. As part of Healthwatch Barnet's commitment we wanted to ensure that children and young people are listened to and enabled to influence all issues affecting them in Barnet.

The Council's health and social care priorities for children and young people as identified in Barnet's Children and Young People's Plan (2013) and Joint Strategic Needs Assessment (JSNA) (2011) were taken into consideration throughout the research process.

Children and Young People in Barnet – key facts

According to:

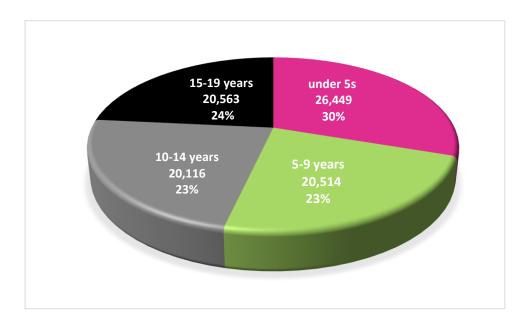
- Barnet's Children and Young People's Plan (2013)
- Joint Strategic Needs Assessment (2011)
- Joint Strategic Needs Assessment Refresh 2013/14: Children and Young People Barnet (2014)

Children and young people make up around a quarter of Barnet's total population.

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The borough's 90,464 children and young people population is the second largest in London (Barnet Council, 2013). According to the Census 2011 figures, there are:

| Age (years) | Number of children |
|-------------|--------------------|
| Under 5's | 26,449 |
| 5-9 | 20,514 |
| 10-14 | 20,116 |
| 15-19 | 20,563 |



25,700 children are educated in Barnet's primary schools and approximately 21,800 attend the borough's secondary schools. There are also a growing number of young people continuing to receive specialist services for children and young (Barnet council, 2013).

The latest JSNA figures predict that by 2025, the population of children and young people is expected to increase by 18% - this means an additional 6,000 young people will need to use a range of health, social care and educational resources.



According to the Child Health Profiles (2014) published by Public Health England's Child and Maternal Health Intelligence Network:

- Children in Barnet experience better health and wellbeing is generally better than the England average
- Infant mortality rate is significantly better than the England average although the child mortality rate is similar to the England average
- The absolute number of children living in households with incomes 2/3 of the England median is source of discussion locally as figures vary across sources. The rate of family homelessness is significantly higher than the England average
- A&E attendances (0-4 years) are not significantly different from those of the rest of England. Hospital admissions caused by injuries in children of ages 0-14 and 15-24 are both significantly lower than the England averages
- Hospital admissions for mental health conditions are significantly higher than the England average for the third consecutive year. Hospital admissions due to alcohol- specific conditions and substance misuse (15-24 years) is significantly lower than the England average. This is a concern for Healthwatch Barnet.
- Acute sexually transmitted infections (including chlamydia), under 18 conceptions and teenage mothers are significantly lower than the England average

2.Key findings

Services used

According to both our survey results and the outcomes from the focus groups, GP, dentist and hospital services are the health and social services most frequently used by children and young people. Overall, the majority of (78%) of the children and young people surveyed were happy or very happy with services in the Borough.

The majority of participants felt that they were treated with respect and listened to, over one third (35%) felt that their problem was not addressed when seeing a GP, dentist and/or visiting a hospital. It also emerged that almost two-fifths (38%) of children and young people felt isolated and did not have someone they could talk to about their health and social care concerns.

Two areas of general concern were waiting times to access health and social care services and alcohol and drug misuse and treatment service in Barnet Hospital.

Mental health

Quantitative and qualitative data analysis confirms that mental health is a significant concern for Barnet's children and young people. 43% of participants felt that they were not treated with respect by the adults and that 27% did not understand the information being given to them. This meant that they were unsure about the next steps of their treatment. The consequence of these feelings was that GPs and mental health professionals were viewed as untrustworthy and that children and young people children and young people would prefer to speak with their friends, family and youth workers, or consult the internet about their mental health problems. Whilst understandable, there is a risk that the advice and guidance received from these sources may not be as accurate as preferred from the point of view of technical professionals.

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The Children and Adolescent Mental Health Services (CAMHS) was identified as an area of concern by participants. Key issues highlighted included the long referral times and poor communication and correspondence.

Participants also expressed a desire that schools took on greater responsibility to support emotional well-being for children with mental health concerns – given that 38% of children and young people feel unsupported and unable to talk to someone about their mental health concerns this is something that needs to be addressed. Hospital admissions for mental health conditions are significantly higher than the England average (Child and Maternal Health Intelligence Network (2014). Concern is also growing about the number of children and young people using/misusing mood altering substances to help them to cope. The recent improvement/enforcement notices published by the Care Quality Commission about Barnet, Enfield and Haringey Mental Health NHS Trust continues to be a concern to Healthwatch Barnet (CQC, 2014).

Sexual health

Young people are significantly concerned about their sexual health on a number of different levels. According to our surveys and focus groups they would like:

- More information and awareness about sexually transmitted diseases, HIV/AIDS and avoiding/managing teenage pregnancies
- Support in attending specialist clinics offering information, advice or check-up
- To feel listened to if they actually attend such a clinic. Over 25% of those who used these services felt that their problems were not dealt with

Communication

Many participants felt that health and social care professionals needed to improve their communication with CYP.

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- A key theme to emerge from the focus groups was that they did not feel listened to and did not understand what advice and information was being said to them or what the next steps would be. There was a clear feeling that if they did not understand these things that it was highly likely that other children and young people would experience similar levels of disappointment when they access health and social care services
- Communication problems often arise because CYP are not treated age accordingly, and/or respected, and that service providers are perceived to be unwelcoming and untrustworthy
- Many of the participants did not know about the range of services available and their hours of operation

Recommendations

Providing Information, Advice & Guidance

- Review the format, design and layout of information and assess its suitability for children and young people. This should be developed in Consultation with young people (and could form the basis of further future projects). If done correctly, this could help to increase the life skills and capabilities of children and young people to improve their life outcomes
- Develop a series of bite-sized infomercials providing clear and consistent guidance on the dangers of relying solely on the internet for self-diagnosis or purchasing drugs

Communication skills

• Suggest that specialist training is commissioned to develop and improve the communications skills of health and social care professionals when dealing with children and young people

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- Remind health and social care professionals about the importance of confidentiality to young people – one of the key reasons for young people not seeking advice is concern that their requests for information, guidance and advice will be shared with their responsible adult (particularly if they are below 16 years of age)
- Encourage health and social care professionals to regularly visit school/colleges to strengthen relationships, build trust and raise awareness about available services and inform students how to access them
- Ask Healthwatch Barnet to work with CommUNITY Barnet's CYP Team to provide further guidance in this area.

Provision of Health Services

- Advise Healthwatch Barnet to work with Barnet CCG to identify areas where delays in referrals could present particular risks to children and young people.
 Where appropriate, Healthwatch Barnet should be commissioned to carry out further research in this area.
- Ask Healthwatch Barnet to work with Barnet CAMHS to help to understand and identify the reasons behind the lengthy referral times for CAMHS.
- Request that Healthwatch Barnet work with Barnet CAMHS and Barnet CCG to agree a process of escalation of referrals to relevant teams
- Recommend that Barnet and Harrow Public Health Services clarify the nature of emotional/mental health support that is available to young people in schools
- Recommend that Barnet and Harrow Public Health work with CommUNITY Barnet's CYP Team to identify further ways to provide/signpost these services to young people attending local educational establishments
- Propose that Barnet CAMHS develops a learning and development programme which can support further and tertiary based teaching and pastoral staff about the referral and signposting services available in the borough. The objective of the programme would be to provide simple, clear guidance on children and young

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people's mental health, wellbeing and development to teaching staff working with CYP.

Availability of services

- Suggest that Barnet and Harrow Public Health work closer with Healthwatch Barnet to develop and advertise services which better support the health and wellbeing of local children and young people.
- Encourage all health social care providers to develop closer links with Healthwatch Barnet to better adverstise and promote their services, hours of operation and availability as they relate to children and young people.
- Ask Healthwatch Barnet to work in partnership with CommUNITY Barnet's CYP Team to test out new ideas with the wider children's voluntary and community sector
- Suggest that Harrow and Barnet Public Health work with Healthwatch Barnet to discuss the availability and accessibility of drugs & alcohol services and sexual health services in partnership with young people.

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3. What the data showed

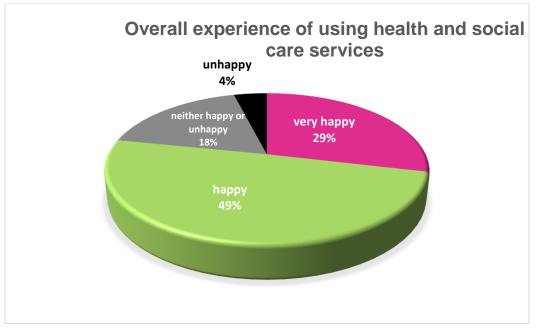
Quantitative data

This section summarises the information and data collated through the Children and Young People's Survey.

The questionnaire was designed to elicit answers to specific questions concerning CYP's current health, health and social care services most frequently used, the manner in which service users were treated, understanding of what were said to them, if they felt that their problems were dealt with, over all happiness about services and if CYP felt they had someone to talk to about their health and social care needs. A copy of the survey can be found in the annexe.

Overall experience of using health and social care services:

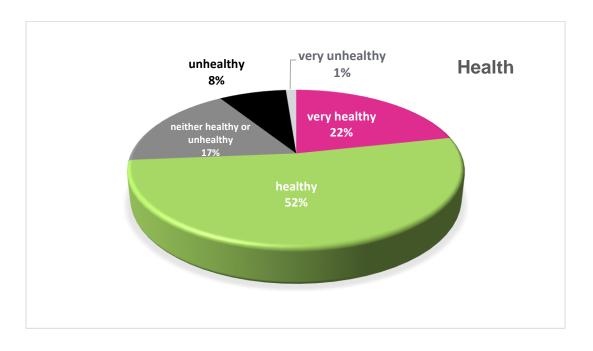
78% of children and young people feel overall happy or very happy about health and social care services.





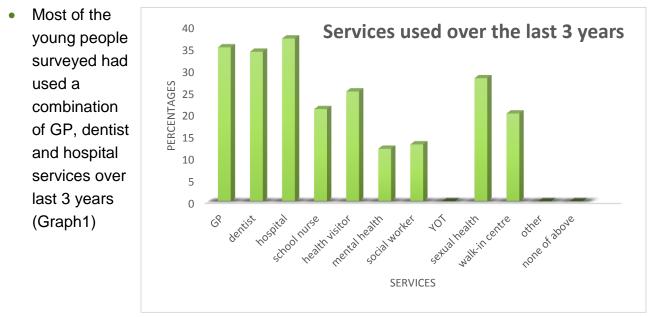
Self-awareness of 'healthiness' of participants:

• 74% of children and young people perceived themselves to be feeling either healthy or very healthy currently over the last year



 The concepts 'healthy' and 'unhealthy' were not defined in the questionnaire. The analysis represents the subjective opinions of what participants believe to 'healthy' and 'unhealthy'. Currently there is little research about what children and young people believe is 'healthy' and could be an area that could be explored n further research

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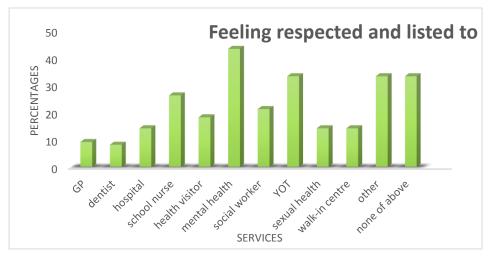


Which services were most used by children and young people:

(Graph 1)

Not feeling respected and listened to:

 Participants recorded 57 instances where children and young people believed that they had not been treated with respect or listened to if they had used one or more health and social care services (Graph 2).

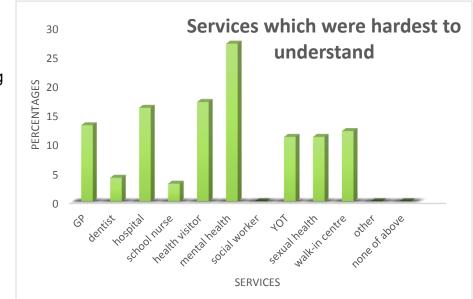


Graph 2

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Which services felt the hardest to understand:

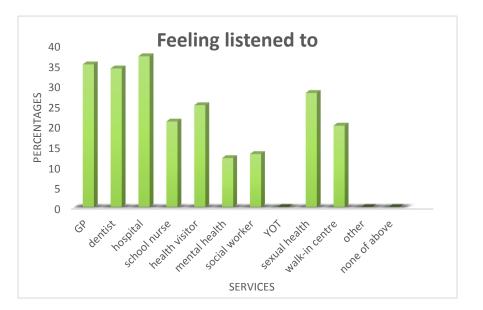
 Participants recorded 37 instances where children and young people struggled to understand information received from health and social care services



(Graph 3)

Feeling listened to:

 Participants recorded 93 instances where CYP that felt their problem was not dealt with when using one or more health and social care services. Percentages according to services used are shown below.



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Feeling alone:

 38% of respondents revealed that they did not have someone to talk to about their health and social care concerns



Qualitative data

This section analyses the qualitative data gathered through the open-ended sections from the questionnaire and the focus groups.

In both the open-ended sections of the questionnaire and the focus groups discussion focused on:

- health and social care services most regularly used
- service user satisfaction
- concerns
- suggested improvements.

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Service user satisfaction

• Children and young people feel stereotyped by their age and felt they were not treated age - appropriately.

"Felt that my health concerns were brushed off due to being young or fit and health"

and

"they do not know how to speak to young people"

 Several participants believe they are not respected and listened to, and not treated like individuals. Other participants felt respected, treated well and listened to. There were also participants that felt they were treated well due to their parents/carers being with them, but were worried that this would change as they grow older and had less parental support. Participants relied heavily on their parent/carers to help them explain procedures and to reassure them when visiting GPs and hospitals but wanted to feel more in control.

"Experience is positive if you are with a parent or carer"

- It was reported that dentists were considerably clearer at explaining the procedures in a calm and reassuring manner and that parents did not have to be relied upon as heavily when using dentistry services
- Several participants felt some health and social care service providers could to be impolite, unwelcoming and in one case even aggressive because they were not adults. Some participants did not feel treated well.

"counsellors (were) disrespectful, impolite and I fell that I was not taken seriously"

 Participants felt that they did not receive enough information from professionals and that communication (between service user and services provider and Page 17 of 30 different professionals within the service provider) needs improvement. Several participants did not understand what was said to them.

"They need to really improve communication between nurses and doctors"

"There needs to be better communication between workers and patients"

• It also emerged that participants have a particular lack of understanding about the availability and accessibility of mental health services.

"I do not know where to go if/when mental health problems arise"

"I use the internet for information ... there is nothing in Barnet"

Trust was a common theme that was brought up in the case studies.

Several participants did not trust professionals with their problems, and there
were concerns about confidentiality. There were concerns that information would
be passed on to other institutions. These issues were especially frequent when
discussing mental health, sexual health and substance abuse issues.

"I feel uncomfortable going to clinics for sexual health, drug and mental health problems"

"I have confidentiality concerns around mental health"

• Disturbingly, many of the participants commented that they could not trust either their GPs or mental health and would rather speak to friends, youth workers and/or family members for support, advice and information.

I do not trust GPs with mental health problems ...family and friends are easier to trust when it comes to mental health issues"

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- Friends were seen as the most important source of support.
- Access to health services was cited as a particular concern for the groups.
 Comments were raised about waiting to get an appointment with GPs, waiting in the reception of service providers and the waiting time after a referral.

"It takes a long time to get problems sorted. All referrals are a waste of time. Waiting for answers is an endless waiting game"

• Worryingly, some participants felt uncomfortable about approaching health and social care services in the future based on their recent negative experiences.

Concerns

- Mental health and emotional wellbeing is an area of serious concern to children and young people. GPs and mental health professionals were perceived to be untrustworthy and in most instances children and young people would prefer not to approach them to discuss issues of concern relating to mental health and emotional wellbeing. Participating children and young people believed that the information they disclosed about themselves would not be kept confidential and they did not want information to be shared across institutions. This perception has repercussions for the health and social care integration programme currently under development and raises the importance of health commissioners to ensure that their patient and resident engagement programmes include a clear workstream focusing on children on young people.
- This perception is further borne out by the lack of understanding of what services are available and very often participants would not know where to go if/when

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problems arise but also a sense of disappointment when services do not follow through.

"Lack of follow up by mental health services and general lack of support for families experiencing mental health issues"

- Stress and depression were the mental health conditions were the most discussed topics followed by substance abuse and eating disorders.
- In many of the focus groups, children and young people discussed possible links between alcohol and substance abuse with mental health/stress/sexual health problems. It was suggested that some children and young people used alcohol and drugs to 'escape' from their mental health/stress and/or sexual health problems. Alcohol and drugs were often used as an alternative response to health and social care services who were not trusted and were deemed to be 'inaccessible'. Mental health, sexual problems and substance abuse are believed to be 'linked in a vicious circle'.
- Concerns were raised over referral times to CAMHS, and it was felt that correspondence received from CAMHS was extremely poor leaving service users feeling neglected and abandoned
- It was also felt that there are not enough done within schools to support emotional wellbeing, and there was a lack of knowledge about who to speak to when help was needed.
- Considerable concern was expressed by older (16-18) participants about drug and alcohol misuse (including smoking) in the borough often as a coping strategy for dealing with mental health problems, stress and sexual problems.

"Drugs and alcohol, there not enough help. Like, if you drink a lot, the health services just don't take it seriously and it could be that there are actual problems and that is related to stress"

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 Sexual health is an area of significant concern with children and young people in the Borough. Concern was especially high amongst female participants. Participants were worried that they do not know enough about sexually transmitted diseases (STDs) and HIV/AIDS, and are concerned about teenage pregnancy. They felt they needed more information and awareness about the issues. Some participants did not feel comfortable with going to clinics. Those who are willing to use clinics feel unsure of how to locate them. Suggestions have been made to open more sexual health clinics.

> *"More advertisements of clinics, like I don't know where they are. They don't tell you these things"*

"There are not enough sexual clinics"

 Concerns have been raised about Barnet Hospital. Several participants had negative experiences when they attended clinics and were worried about infection and even death. They felt that patients are not treated well at the hospital.

"Never go to Barnet General – they don't treat you well"

Suggested improvements

- Younger (12-16) participants suggested that more should be done to raise awareness and educate children and young people about the health and social care issues affecting them. They felt that when information was provided, it was not communicated in the most effective manner. They suggested information should be presented in a more interesting and digestible manner, e.g. personal stories are preferred to statistics and graphs.
- More should be done to train professionals to understand the health and social care concerns about children and young people and the importance of effective communication.

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- Communication and signposting training for youth workers should also be considered. Children and young people felt there is a lack of gentleness and compassion when they access services and that professionals need to listen more carefully. Professionals are not trusted and it was suggested that something should be done to remedy this.
- Children and young people like to see more interaction between them and health and social care professionals to break down barriers and promote understanding and trust. This could be done by visiting school/college assemblies. Informal face to face interaction is believed to be an effective tool to build relationships and explaining what services are available and how to access them. The police and fire departments had very successful engagements in this manner.
- Participants felt the need for more of the following services:
 - Mental health services in schools/colleges/universities
 - Sexual health clinics
 - Walk-in centres
 - Drug and alcohol support
 - Smoking cessation support
 - Illness prevention in schools
- Participants thought they need a place where they can speak openly about health and social issues affecting them. They said that if these places already exist, they have not heard about them.
- Services and how to access them should be better advertised, sexual health clinics in particular.

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4. Methodology

Data collection techniques and the motivation for using them

The research was conducted using a mixed method methodology, based on both quantitative and qualitative research designs. Focus groups were conducted concurrently with surveys as complementary components of a unified research design. Survey questionnaire and focus group discussion guidelines were designed in advance to yield independent quantitative and qualitative research perspectives on the CYP's experiences. The survey questionnaire and the discussion guidelines were jointly designed before the results of either component were known. Survey data and transcribed texts were then analysed together.

When focus groups and surveys are concurrently designed and implemented, they provide asymmetrical but independent observations of the study population that strengthen the ability to draw conclusions as well as confidence in the conclusions themselves. The focus groups and surveys examined different dimensions of the same experiences, and the results of these independent analyses also confirmed each other. Outputs from both measures combined provided deeper insights into the nature of the children and young people's experiences than would be possible using either methodological approach alone.

The justification for integrating focus groups and survey methods might best be described in the gains to the validity of conclusions from any one study and the identification of new areas of concern about health and social care service delivery in Barnet. The focus group component in this integrated design reinforces internal validity, or the extent to which conclusions from the analysis can be said to be true of the cohort. The survey research component strengthens external validity or representativeness that are the inherent weakness of small-scale, in-depth qualitative studies.

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The goal of the mixed method research design is the mutual enhancement of the analysis and understanding of each component by the other, also known as triangulation between qualitative and quantitative data.

Benefits of mixed methods research:

Focus groups and surveys were combined to triangulate participating children and young people's experiences in order to mutually corroborate the findings.

- The mixture of focus groups and surveys created an offset of the weaknesses of the methods to draw on the strengths of both. This created a more complete and comprehensive account of our participants' experiences
- The survey provided an account of experiences, but the focus group provided a sense of how the experiences are processed.
- Focus groups were used to help explain findings generated by the survey.
- Employing both focus groups and surveys strengthened the credibility and integrity of our findings
- Focus groups provide contextual understanding of broad relationships among variables uncovered through the surveys
- Focus groups can be used to illustrate quantitative findings in a more effective manner.
- Focus groups improve the usefulness of the findings for practitioners and decision makers.

Survey

Self-completion survey questionnaires were employed to gather quantitative data about CYP's experiences. 85 participants were recruited to complete our questionnaire and take part in our CYP survey. Information about the CYP survey were publicised and promoted through:

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- Healthwatch Barnet newsletter
- Community Barnet newsletter
- CYP newsletter
- CYP network meetings
- Facebook and Twitter
- Community Barnet's charity partners
 - Advocacy in Barnet
 - Barnet Age UK
 - Carers Trust
 - Barnet Centre for Independent Living
 - Citizen Advise Bureau
 - Barnet Mencap
 - Home Start
 - Jewish Care
 - Mind in Barnet

Prospective participants were invited to visit a website where the questionnaire could be found and completed online. The web-based questionnaire included 1 open question and 5 closed questions. Each of the closed questions allowed for an open-ended section for additional comments. The questionnaire further collected the participants' demographic backgrounds. The questionnaire targeted children and young people aged between the ages of 13 and 25 years, both male and female, and from most of the Borough's geographical areas. The questionnaire further represented the research population's diverse ethnicity, and occupational and socio-economic status.

The benefit of using this mode of survey administration is that it allows for visual aids, gives participants the opportunity to consult others for information, minimizes the impact of interviewers 'characteristics and minimizes the impact of the social desirability effect.

Focus groups

A total of 97 participants, aged 12-18, were recruited to participate in 10 focus groups held in 6 different locations within the geographical boundaries of Barnet.

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- Barnet College: High Barnet
- Queen Elizabeth's Girls School: Hendon
- Hendon School: Hendon
- Whitefields School: Cricklewood
- Burnt OakYouth Club: Burnt Oak
- Fairplay Barnet: Hendon

Of the 10 focus groups conducted, 70% were in educational establishments (schools, colleges) and 30% in youth groups/clubs. The focus groups were set up with the permission and in conjunction with schools/colleges and youth groups/clubs. We spoke to same and mixed sex groups with a composition that was representative of the Borough's diverse ethnic, religious and socio-economic backgrounds. The focus groups were facilitated by experienced members of CommUNITY Barnet's Children and young People's Team.

A uniform set of focus group guidelines was used for all sessions. Guidelines were decided in advance. Emphasis was placed on the questioning of particular and fairly tightly defined topics in the sessions. Topics included health and social care services used, service user satisfaction, concerns and suggested improvements. The facilitator maintained a relatively high level of control over the discussion, introducing general issues from the guidelines for discussion and probing or interjecting to make sure the groups covered all the essential points. The accent was upon interaction for the group and the joint construction of meaning. Considerable latitude was maintained to permit free discussion of issues, unsolicited opinions and unanticipated responses. Sessions were transcribed by the facilitator.

The benefit of using focus groups are that children and young people can be interviewed in a relatively unstructured way about their experiences; the technique allowed Healthwatch Barnet to develop an understanding about why the participants feel the way they do; the participants had the opportunity to bring to the fore issues in relation to health and social care that they deem to be important and significant.

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Thematic Analysis

The transcription of the sessions were analysed using thematic analysis. Thematic analysis is a research method often employed to identify, analyse and report on patterns in qualitative data. Patterns, referred to as themes and subthemes, are the product of thorough reading and re-reading of the transcriptions that make up the data. This method organises and describes a data set in rich detail.

The benefits of using thematic analysis is that it was flexible, summarised key features of a large body of focus group transcriptions, offered a 'rich description' of our children and young people's experiences, generated unanticipated insights and was useful for producing qualitative analysis for informing development.

5. Ethics

Ethical issues were taken very seriously as they relate directly to the integrity of this piece of research and to Healthwatch in general. The research was guided by and conducted according to the requirements of the *Research Ethics Framework* (REF) as published by the *Economic and Social Research Council* (ESRC) in 2005. The REF lays down six principals of ethical research which was followed by Healthwatch throughout the research process:

- Research should be designed, reviewed and undertaken to ensure integrity, quality and transparency.
- Research staff and participants must normally be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.
- The confidentiality of information supplied by research participants and the anonymity of respondents must be respected.
- Research participants must take part voluntarily, free from any coercion.
- Harm to research participants and researchers must be avoided in all instances.
- The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

The research adhered to the professional codes of practice, legal requirements and compliance with the Data Protection Act 1998 (DPA).

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6. Appendices

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7. References

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