



# **'YOUNIQUE VOICES'**

A study of health and wellbeing: experiences, views and expectations of seldom heard and marginalised groups in Rochdale Borough

**FINAL REPORT** 

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# Younique Voices. A study of health and wellbeing: experiences, views and expectations of seldom heard and marginalised groups in Rochdale Borough

# **FINAL REPORT**

June 2009

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All study Advisory Group members are thanked for sharing their ideas and expertise.

Members of the Young People's Advisory Group were critical to the success of this study and they are thanked for coming along to the meetings and for helping us to get our approach right for young people in the Borough.

All participants are thanked for giving up their time to help us gain a better understanding of their perspectives of health and wellbeing.

We are grateful to The Patient Experience Committee for showing an interest in our work.

#### **Preface**

Ensuring that the patient voice is at the centre of the modern NHS is a key theme running through the Lord Darzi review (Better Health for All) and is also reflected in the NHS NW vision "Healthier Horizons" published in June 2008. In addition, World Class Commissioning – the new way in which PCTs are assessed as being effective organisations - requires evidence to be provided of how local people have been engaged in designing and improving services and particularly targets "seldom heard" groups.

"Ticking boxes" is not enough – as the leader of the local NHS we need to demonstrate that we involve, engage and listen to the people we provide healthcare for.

There are many groups in the Borough that historically have not had a voice and we wanted to undertake a piece of work with a target group which could provide us with real opinion and feedback. It was recognised early in the process that a focus was needed if a meaningful piece of work was to be undertaken within the time and financial constraints for the project.

NHS Heywood, Middleton and Rochdale, working together with other local partners, recognised that an often marginalised group were those in the age bracket 16 to 25 years – in other words, those in transition between children's and adult's services. This group also cuts across a wide range of other seldom heard groups (e.g. people with disability, Black and Minority Ethnic groups, travellers etc).

The aim of this study was to talk directly to as many people in this age group as possible so that we could find out what their experiences and expectations of the NHS were.

We hope this study is the beginning of a journey and not the end. Too often, research sits on a shelf gathering dust. Instead we wanted a "live" report which we could use to help us design services which young people need and to open up networks for an ongoing dialogue so that this particular marginalised groups could influence what we do in the future for their own benefit.

Chris Wright Head of Corporate Services NHS Heywood, Middleton and Rochdale

#### **General Introduction**

This Final Report presents the findings from a 15 month study which was commissioned to explore the health and wellbeing experiences of seldom heard and marginalised people in Rochdale Borough. Following negotiation with study advisors, the particular focus of the study became young people between the ages of 16 and 25 years. The report begins by outlining the background and specific study aims and objectives of the project. This is followed by a brief overview of the wider context in which the project is situated. Details of the study design and processes undertaken to gather and analyse data, and validate findings are given. We also share some reflection about our learning along the way in terms of accessing seldom heard groups. Lastly the findings and key messages from the study are presented.

# **Background to the Study**

The project commissioners are keen to 'give voice' to people from seldom heard or marginalised groups regarding the health and wellbeing services available to them locally. Almost by definition these groups are traditionally difficult to access, and so relatively little is known about their views in relation to such issues as perceptions of local health care; understanding of range and availability of services; services they would like to access; factors preventing or discouraging them from using existing services. NHS Heywood, Middleton and Rochdale has demonstrated a commitment to seeking the views of people from seldom heard or marginalised groups regarding by funding this external research study as part of its ongoing commitment to involving, engaging and listening to all people who use local health and wellbeing services.

The defining characteristics of 'seldom heard' and/or 'marginalised' may be applied to a wide range of people and groups. A Study Advisory Group met in the early development of the project to identify people and groups which could be of specific interest to this project. Through a process of discussion and negotiation it was agreed that the project would focus on young people between 16 and 25 years. Particular characteristics of young people that might lead to them being considered seldom heard or marginalised were also identified and helped to inform the study design. The Study Advisory Group helped develop and agree the aims and objectives given below.

## Aim and Objectives of the Study

The broad aim of the study was to:

a) Gain insight into the views of seldom heard and marginalised young people (aged 16-25 years) concerning health and wellbeing services in Rochdale Borough.

The *objectives* of the study were to:

- a) Identify and target seldom heard and marginalised groups whose views are to be elicited:
- b) Develop meaningful engagement of representatives of the participant groups in the study processes (user involvement);

- c) Develop effective collaborative working with the project funders and stakeholders;
- d) Using a participatory approach, agree the questions of most concern to ask study participants (most concern to NHS Heywood, Middleton and Rochdale, their key partners and participants);
- e) Devise means of access and investigation to elicit experiences, views and expectations of participants with regard to local health and wellbeing activities;
- f) Widely disseminate findings locally and nationally.

## Context

Lay knowledge is now considered to be a key component of the development of health policy at a local, regional and national level (Popay and Williams, 1998). The effective use of lay knowledge can often result in improved representation and a sense of ownership at local level with increased levels of involvement of all members of the community. More recently, the inclusion of the voices of children and young people in health service provision and development has become increasingly important (WHO 2002; Department of Health 2004; HM Government 2005; Department for Education and Skills 2004). There is particular interest in young people's views about health needs and access to primary care. However, whilst young people in the 11 to 16 years age group tend to receive specific research attention, there is a paucity of work focusing on the age group who are at the centre of this study - those aged between 16 and 25 years who are in transition between children's and adult's services. It is recognised that there is huge diversity within this age range across the borough of Rochdale, and further that many within this age range may be considered "seldom heard" or marginalised.

Representation and access to health care services remains an issue of concern for marginalised groups (Fazil *et al* 2006) particularly in the primary care arena (Wright *et al* 2004). There are a number of reasons suggested to account for lack of representation and restricted access to or use of services. For example, some communities may hold belief systems that require them to access alternative/traditional practitioners of health care within their own communities, in preference to mainstream or 'conventional' NHS services. For some cultural groups health beliefs may be expressed in different ways, for example in some South Asian communities it may be appropriate to express one's emotional distress through bodily symptoms (Fenton & Sadiq-Sangster 1996; Holland & Hogg 2001).

Consultation may be useful as it may uncover 'hidden' voices or opinions that are not often heard, so enabling wider representation and the development of responsive services. However it should be noted consultation may provide information that is contrary to the existing professional consensus. Work by Whitley and Prince (2005) investigating health in an inner city area of London note that the value and the quality of information derived from investigating the opinions of members of the public within neighbourhoods and community groups was at odds with that of conventional professional wisdom.

Issues around who is categorised as 'seldom heard' or 'marginalised', and the reasons for such designation, need to be treated sensitively. For example, broad uncritical use of the term 'minority ethnic' population for research or analytical purposes fails to recognise the complexity of ethnic background. This complexity has to include not only reference to ethnic origin, but also to gender, religion and even social class in order to enrich our understanding of society (Ahmed *et al* 2001).

There are other perhaps less obvious 'seldom heard' people who can be further marginalised by their lack of visibility, for example homeless people, travellers, asylum seekers and people who are housebound. Homeless people for example may face discrimination as they may be perceived as undeserving, whilst refugees and asylum seekers may be excluded from or unfamiliar with systems of health care provision.

Previous research (Doherty *et al* 2004) suggests that the following broad terms might be useful when discussing 'hard to reach' groups:

- Minorities Traditionally under represented, marginalised, disadvantaged and socially excluded.
- Service Resistant The overlooked, the invisible, and those unable to articulate their needs.
- Slipping through the Net The over targeted and disaffected, 'known' families, and those who are wary, suspicious or distrustful.

Issues around consultation and the engagement of so called 'hard to reach' groups are well documented as being challenging and it is widely recognised that studies are in need of creative, interesting approaches if they are to be successful. Yet a well designed study, if handled with sensitivity and innovation, stands to be very rewarding for commissioners and participants alike. Benoit *et al* (2005) note that research on 'hard to reach' populations presents challenges to researchers but often yields valuable and worthwhile results. The Scottish Executive (2002) provides guidance on targeting 'hard to reach' groups through a number of strategies such as 'grass roots' consultations for example using local developments workers and outreach services as gateways to reaching other groups/communities.

## **Design of the Study**

## Project management

The study has been undertaken by researchers from the Salford Centre for Nursing, Midwifery and Collaborative Research at the University of Salford. The project was co-led by Dr Tracey Williamson (Research Fellow - Older People/User Involvement) and Julia Ryan (Senior Lecturer - Nursing). The day-to-day conduct of the study was undertaken by Dr Christine Hogg (Senior Lecturer - Mental Health Nursing) and Dr Debbie Fallon (Senior Lecturer - Child Health). From NHS Heywood, Middleton and Rochdale, Chris Wright was Authorised Officer and Zoe O'Neill was Contract Manager.

#### **Advisory Group**

A multi-agency Study Advisory Group was set up at the study outset and expanded to a membership of over twenty staff from across health and social care services in Rochdale Borough including statutory and voluntary sectors. The Advisory Group met seven times over the course of the study and was instrumental in fine-tuning the study focus. Advisors also played a key role in informing the evolving study design, advising on potential means of accessing potential participants and supporting the study generally with their ideas and encouragement. Appendix one provides a list of members.

# Young People's Advisory Group

Both the research team and study commissioners were committed to meaningful user involvement in the research process as is good practice. The research team have particular expertise around service user involvement/public engagement. A Young People's Advisory Group was set up early on in the study drawing on good practice principles. This comprised a fluid and diverse membership of 10 young people representing the seldom heard or marginalised. This group met three times and was helpful in informing the design of the research including for example developing the interview guide; advising on the interview information sheet; devising the study name 'Younique Voices'; locating potential participants and developing a publicity flier with appeal to young people. Members of the Young People's Advisory Group were rewarded for their involvement with a £10 voucher per meeting and a £15 voucher for the study validation event described below. Another means of valuing advisor's contribution was to award a 'Certificate of Involvement' for inclusion in the young person's CV and/or personal development portfolio.

#### **Data Collection Methods**

A flexible study design was proposed that would be tailored in response to feedback from commissioners, members of both study Advisory Groups and participants. The data collection methods used included individual face-to-face interviews and focus group interviews. The latter proved to be greatly preferred by participants who especially like airing their views in a group format with their peers. An interview guide (see Appendix Two) was developed based on topics of interest identified by both Advisory Groups. This was then adjusted several times during the study in the light of participant responses and further Advisory Group feedback.

## Sample

The population being targeted was young people aged 16-25 years who may be considered 'seldom heard'. Characteristics which were identified by the Advisory Groups as being relevant included young parents, young carers, young people with disability, homeless young people, young refugees and asylum seekers, young people from black and minority ethnic groups and young gay, lesbian, bisexual and transgender people. In agreement with study advisors we sought a 'maximum diversity' sample as a means of involving a broad cross section of the young person's community, rather than seeking more readily accessible groups. Table 1 provides an overview of the key characteristics of the sample. By nature of being seldom heard, a number of challenges in accessing these groups and so a three months study extension was granted to allow us sufficient time to engage participants with as wide range of characteristics as possible. The sample were accessed in schools, community centres, and various outreach locations across the borough, but in order to maintain anonymity for individuals who participated, the specific locations have not been included in the report.

#### Data collection and analysis

Access to potential participants was negotiated with local staff and arrangements made for convenient dates and times for interview. Issues related to gaining access to potential participants are discussed in the section entitled 'Reflection on research with marginalised groups'. Written informed consent was gained immediately prior to each interview. All interviews were digitally recorded with participants' permission. Participants were rewarded for their involvement with a £10 gift voucher.

Thematic data analyses were conducted using a framework drawn from the detailed interview guide and followed analysis principles set out by Miles and Huberman (1994).

Participant group	Number	Age range	Gender	Type of interview
Young Asian Men's Group	12	16-19 yrs	Male	Focus group
Young Asian Women's Group	11	16-19 yrs	Female	Focus group
Young Parents Group	4	16-24 yrs	Female	Focus group
Youth Empowerment Group	8	16-22 yrs	Female & Male	Focus group
Homeless Services	1	22 yrs	Female & Male	Individual
Homeless young people	9	16-25 yrs	Female & Male	Focus
Travelling community	2	17 and 24 yrs	Female	Joint
Divert Group	14	16-20 yrs	Male	Focus group
Youth Bank	5	16-18 yrs	Female & Male	Focus group
Refugees and asylum seekers	14	16-24 yrs	Female & Male	Focus groups(2)
Physically disabled young people	2	16 and 17 yrs	Male	Joint
Total	82			

**Table One: Characteristics of the sample** 

#### Verification of findings

Two core means of validating findings were undertaken. Firstly, members of the research team met for a verification workshop at which they compared their individual analyses of data collected up to November 2008. This both identified key thematic elements in the data collected at that point and identified areas on which to focus attention data collection during the remainder of the study. At this point the sample strategy was reviewed and adapted to maintain the principle of maximum diversity. This workshop also reinforced the accuracy of the interpretations of the research team member leading the analysis work (CH).

Secondly, a process of findings verification was combined with an end of project celebration event to which members of the Young People's Advisory Group and all interview participants were invited. This verification event comprised two core activities. Firstly, participants were asked to join in an exercise where gaps in the data or points in need of clarification were put to them so that they could explain what the issues were. For example, drug and alcohol use were little raised during interviews and reasons for this were explored. Secondly, participants were given an overview of study findings and asked to say whether

they felt these were an accurate reflection of the views of themselves and their peers. They were asked to identify any surprising findings, inaccuracies or omissions. Participants in the validation event were offered a £15 gift voucher in recognition of their contribution to the project. The event was attended by 13 individuals, most of who came from refugee and asylum group communities. It is recognised that this group may not have fully represented the diversity of the wider sample. However, those who attended offered useful insights into the data findings and validated these as being a representative reflection of the views of young people (see Appendix Three).

#### Limitations

Accessing seldom heard and marginalised groups for research purposes can be challenging, as was identified earlier. Whilst the voices of a number of 'seldom heard' young people are represented in this study, there are limitations within the sample. A larger study may have enabled the inclusion of young carers, young fathers, young sex workers or those in receipt of mental health services. It should be noted that although ethical approval for access to young people who use mental health services was granted by Pennine Care Trust gate-keeping processes prevented participation by this group within the available timeframe. It is difficult therefore to identify the extent to which this group are included in the study, but it is likely that some young people in the sample group have used such services.

# **Ethics and Research Governance approvals**

The need for NHS Local Research Ethics Committee (LREC) was discussed with the Chair of Trafford LREC who advised it was not necessary. Research Governance approval was similarly not required by ReGrouP who is responsible for such approvals in Greater Manchester. Both forums defined the study as service development. Ethical approval was gained from both Pennine Care Ethics Committee and the University of Salford Research Governance and Ethics Committee. All aspects of the study were conducted to recognised high ethical standards.

## **Reflection on Research with Marginalised Groups**

As a research team we anticipated that there may be a number of challenges within the study. The fact that the target population had been identified to us by advisors as 'seldom heard and marginalised' highlighted both the need for a flexible approach, and the importance of identifying key learning points. We therefore ensured a process of reflection was built into the project plan and issues from these reflections are shared here for others to appreciate and learn from.

As a study with an emergent co-operative design – that is, a research process which is not known at the outset and is tailored through discussions with advisors – we determined our target populations and explored means of accessing them as the study progressed. As a range of young people were to be included, we knew that no single approach was going to be possible with all, and we relied on the advice of the Advisory Groups to guide us.

The tenacity, patience and time required to explore and gain access to potential participants cannot be overstated. There are a number of factors which need to considered, For example, gaining formal ethical and governance approval can be challenging, particularly if the sample groups are perceived to be at risk or vulnerable, as young people often are.

We anticipated the possibility of travelling down 'blind alleys' before finding a successful route to reach the intended participants. For example attempts to access young people with mental health needs via MIND did not come to fruition since MIND informed us that they tended to provide services for men in the over 35 years age group. The research team were also aware that gatekeepers could either help or hinder contact with potential participants and acknowledged that some staff might not wish to take part in or assist with the study, or that they had other priorities that may take precedence over the needs of this study.

The main difficulty experienced with gatekeepers was the lack of staff response to repeated contact attempts from the research team. One example of this was young people using a service which would have included some of the most marginalised people such as young sex workers. Unfortunately, access could not be negotiated via local gatekeepers within the timescale afforded by this project despite repeated attempts and the securing of appropriate ethical approval. Another example was the two occasions when staff in services expressed reluctance to pass on contacts or publicise the study stating that their particular client group are 'over consulted and 'over researched'. On only one occasion did staff appear to be openly unwelcoming. A staff member said they felt that projects like this were 'pointless, as people here get access to everything anyway but didn't take it up'.

In contrast, there were other staff who were actively engaged in passing information on to potential participants, finding recruits for our study and encouraging young people to take part, urging that it was their chance to be heard. Access to young people in the travelling community, those who are homeless, refugees and asylum seekers and young people with disabilities was greatly facilitated by helpful staff. In particular the Youth Service, SureStart, school staff, and housing workers working with the travelling community were very active in assisting us to recruit participants. In some cases staff expressed pride that the young people they worked with were taking part in the study, and would take photographs and so forth for their own use with the group. Many staff also provided contextual information which proved invaluable in gaining an understanding of the specific issues that would face us in approaching certain groups. For example, we received very helpful advice and information from housing workers regarding the participation of young people from the travelling communities.

A valuable learning point was that face to face contact with both staff and participants was better received than other forms of communication Meeting with the staff in person and spending time explaining the project was very effective in building a rapport and alleviating any concerns about the project. For example, our lead researcher gained an impression that sometimes people felt a little intimidated by the title or focus of the study. Such concerns were addressed in face to face meetings as described above. Establishing a good relationship with the staff who acted as gatekeeper was essential, as this person was central to contacting potential participants and organising interviews. However, this was a resource-intensive and time-consuming activity; it was common that several trips were needed to arrange one interview.

On reflection, the *marginalisation* aspect of the project proved more of a challenge than the *seldom heard* one. Once participants had been identified to us, usually through local workers or service leads, we found them relatively straightforward to *hear*. What proved difficult was finding the existing groups and services and securing the input of a staff member to assist us.

A reliance on focus groups as the main data collection method posed its own challenges, in particular because the number of participants was often not known until the start of the interview. The flexible approach necessitated by this study meant that we collected data 'where the action was' - in settings such as buses, schools and children's centres where the daily business continued around us. This meant that at times the data collection activity was lively and somewhat chaotic and it is possible that the inclusive nature of our approach resulted in some loss of quality in data collection.

We learnt that the offer of a payment (£10 voucher) was a great incentive and often we were faced with more people presenting for the interview than we had anticipated. However, it was inappropriate to turn people away and so again there may have been some loss of quality in data collection, however this was offset by the positive and inclusive nature of our approach.

The participants were thanked for giving up their valued time with a £10 gift voucher. Many of the community workers/service staff agreed that this would be appreciated particularly by participants who were struggling financially, for example those living in hostels. One salient experience for us was at the end of one interview, when three young women were clearly delighted and spent about 15 minutes writing messages to each other on the gift cards. This illustrates the emotional aspects of researching seldom heard and marginalised groups. For example interviews with participants from a hostel left our team with a profound sense of sadness, whereas the interview with people who were asylum seekers was much more upbeat and optimistic.

At each of the interviews we offered refreshments and this was always well received. We offered healthy foods such as fruit and vegetable snack foods as well as some chocolate and biscuits. This seemed to not only break the ice but also gave the message that we valued the participants and their opinions. The participants also talked about the food we gave them, often discussing their preference for health foods and so on. Interestingly, the healthy options were often consumed eagerly and chocolates left untouched.

In any future study of this kind, time and funding permitting we would seek to use multimethods data collection, making more use of individual interviews and perhaps photographs or vignettes (short stories) as prompts for the discussions. We acknowledge it was ambitious to attempt to keep participants focused for what could be a long time (in excess of fifty minutes) and in an activity that could remind some of their school years, despite best efforts to be informal.

A central issue that we reflected on that has major implications for this study is how disparate and diverse young people are. This was highlighted to us in an early Young People's Advisory Group meeting. The participants in this group came from very diverse social and cultural backgrounds, had differing life experiences and had a wide range of views and opinions. For example, in one group meeting the participants stressed their view of how different 16 year olds are to 25 year olds and likened them to 'chalk and cheese'. As a 24 year old with two children, a mortgage and a husband, one participant felt unable to relate to the 16 year old A- level student or young traveller. These differences manifested themselves at some points during the meetings, when the group dynamic prompted us to use our group management skills to the full. The group facilitation skills of the research team proved invaluable in ensuring each group members had a voice. Contact with the

Young People's Advisory Group throughout the project reminded us that categorising everyone together under the label of 'young adults' was inappropriate.

The support and direction of both Advisory Groups was essential and highly valued, in particular because of their familiarity with local issues. It proved to be very helpful to have stakeholders from across health and social care settings as members of the Study Advisory Group. It may have been that different Advisory Group membership could have enabled access to young people who may be relatively underrepresented in our sample (such young people using mental health services and young carers). The Young People's Advisory Group was central in the development of the study design and their ideas, suggestions and feedback were honest and constructive. We adapted significant parts of the interview schedule on their advice and made adjustments to wording used when at times we were using language that was too formal or ambiguous. Other useful advice concerned how best to engage with young people, issues around the differences amongst an age group of 16 to 25 years, and the need for a study name which they then devised: 'Younique Voices'.

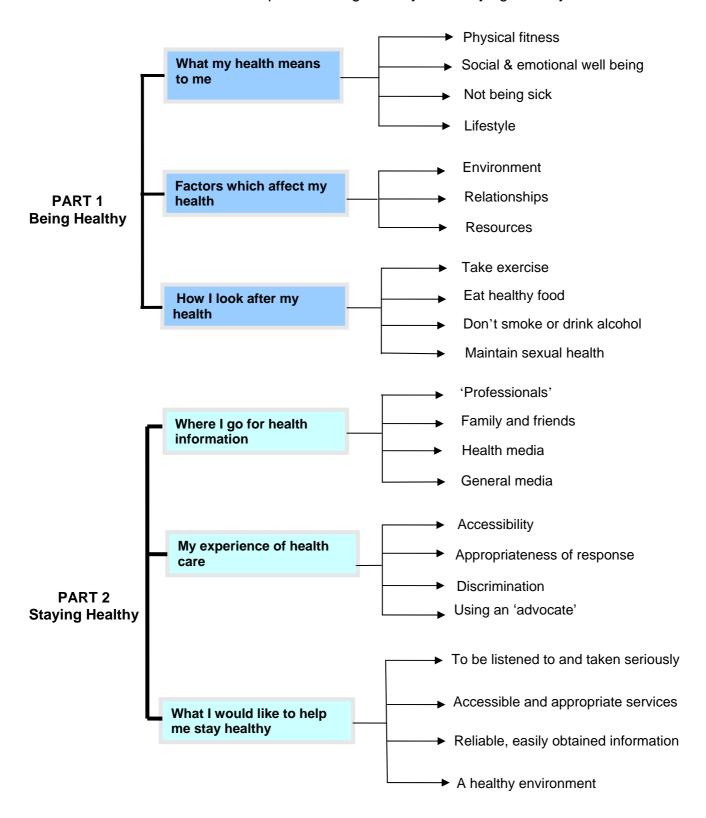
The intended participant groups we didn't access should be noted. In some cases we do not know the extent to which characteristics were present in the sample. We gathered limited personal details about participants and so do not know about their sexual orientation, health status, or caring responsibilities for example. In other cases there a clear gap in the sample. With respect to the traveller community there is general consensus amongst both community workers and members of the community themselves that 'the men won't talk' and we were strongly advised not to try and access this group. Despite being prepared to offer reward for involvement, and choice in the time and place interview, we did not recruit any male participants from the traveller community. This issue of men's voices in the travelling community being unheard has been reaffirmed in other projects and there seems to be a suggestion that women carry the health knowledge and responsibility for health in these communities (Acton et al 1998, Parry et al 2004). Of concern is that such young men may be considered vulnerable to a range of mental and physical health problems. These young men perhaps marginalise themselves by their actions and nonactions, but they remain a classic seldom heard group. In retrospect the gender and age of the researchers - female and older than them - may have hampered recruitment.

Stereotypical views that young people are difficult to reach and focused on the 'here and now' (as opposed to long term concerns over health issues) were not supported by this study. The groups of people we interviewed all appeared to be interested in health and in particular fitness and many had strong opinions that they were keen to share. Some of the discussions that took place were not dissimilar to the seminars that we have experienced in teaching nursing and health sciences. They also seemed to enjoy the inclusivity of the project and the fact that someone was listening to them.

This has been a challenging and stimulating project that has raised some unexpected and significant issues for us and one that had yielded some rich data. We have gained a lot of insights into working with marginalised young adults in a research context. We gained a sense that there are many young people in the Borough who would welcome future working with local health services and others to improve their health and wellbeing further.

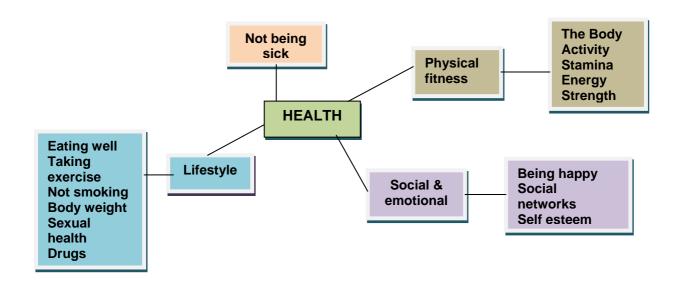
# **Findings**

This section is divided into two parts – being Healthy and Staying Healthy.



# PART 1

# A. What My Health Means to Me



# **Physical fitness**

When asked about the meaning of 'health', physical fitness was commonly identified by the majority of participants. Physical activity was the factor most often identified as part of a healthy lifestyle. Value was placed on being 'strong and happy', 'fit and active', 'being in good condition' and 'able to last longer and have stamina'. Typical responses include:

'It's how you feel in your body. It's like fitness and things'

(Travelling community)

'Yes it's important... exercise - all of us go to the gym... We all play football' (Young Asian men's group)

# Social and emotional wellbeing

As well as physical health factors, participants widely recognised that health and wellbeing also comprised social and emotional factors. Social and emotional well being included 'having self esteem, 'not getting depressed and being fit and well' and 'having a good group of friends'. Being unhealthy was described by one young parent as when '...someone is scruffy and down in the dumps'.

Perceptions of the effect of physical environment on health are discussed below; however some participants made a direct link between physical environment and mental wellbeing, for example:

'If you're living somewhere that's not nice... yeah, mentally, it's going to have a bit of an effect on you.'

(Divert Group)

# Not being sick

Another common definition of health given by participants was the absence of disease and not being sick. This was sometimes described in a general way such as:

'Well health is like when you're not sick and you are full of energy. You're healthy and you're not sick.'

(Travelling community)

or specific illness, for example 'They've not got cancer'
(Divert group)

This was also seen as related to bodily function:

*'Everything working properly in your body.'* (Youth Empowerment Group)

# Lifestyle

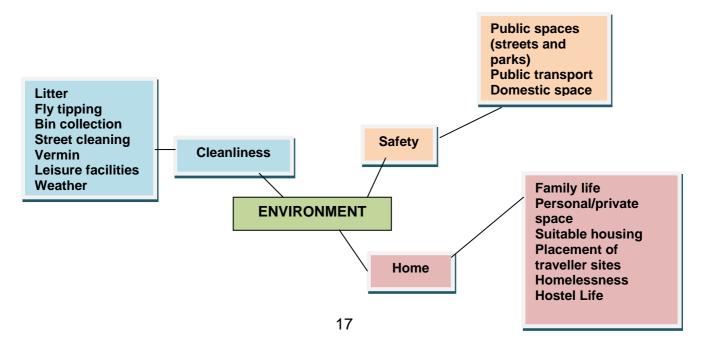
Health was also recognised as being about lifestyle and lifestyle choices. Healthy lifestyles were seen to include physical activity and did not involve 'being lazy and standing around'. Participants felt that healthy food came second only to exercise as a key component of a healthy lifestyle. As one participant said 'healthy food keeps you young and fresh'. Further components of a healthy lifestyle suggested by participants were avoidance of smoking and ensuring sexual health. Drugs and alcohol were seen as unhealthy choices.

It was evident that most participants demonstrated an awareness of the interlinked aspects of health and healthy living, as is illustrated by the quote below:

'Being mentally healthy is important because it affects your physical health... let's say if you are depressed you don't want to do anything you don't want to go out and exercise and so it will affect your physical health as well...'

(Young Asian women's group)

# B. Factors Which Affect My Health



#### **Environment**

Many participant groups and individuals independently brought up environmental issues as having the potential to negatively affect their health. Comments were made concerning the physical environment relating to both public and private spaces. Three key issues were raised: safety, environmental cleanliness, and the home.

# Safety

There existed a common fear amongst many participants of violence, crime and the need for personal safety and security. This is illustrated by a lengthy discussion in the focus group with Youth Bank which included the following:

'It's quite violent, not a good area to live in really.'

'But Heywood and Middleton do it all the time. They are always fighting. What was that lad on the bus the other day saying? He was going to get people from Heywood. I was scared at the time because he was threatening me.'

'I don't feel safe on the bus. Because the 163 goes ... I have to get it at 7.10 am in the morning, when it is still dark. And I have to walk to the top end of this road, all the way up, and then get on the bus which goes through all the Middleton Estates and you do sit on the bus sometimes and think, I'm scared.'

Being on foot in local neighbourhoods was noted as a particular risk especially when having used a bus and walking the remainder of the journey home. A female Youth Bank participant talking about getting home from the bus stop and said:

'Just because it is so dark and it is like a field with bushes round it. I don't want to walk past that at night. And a derelict building, you have to walk past that as well. I don't want to walk past that. I don't go out really at weekends or anything.'

For one participant much depended on how well the young person knows (or is known) in the neighbourhood:

'I personally feel safe on my estate because I have lived there all my life, but I can walk five minutes from my estate and feel completely like.... scared.'

(Youth Bank)

This same participant goes on to add:

'I think it depends on where you are known, where you feel safe. Because I can go to my friend's house and go on her estate and be absolutely scared to death. And they both have equally bad reputations, but to be on my estate and walk around on my own and not feel at all threatened.'

Fears about safety were also linked to participant's health behaviour, for instance exercise. The Youth Bank group talked extensively about the wish to exercise being countered by safety issues. The example of jogging was given:

'Yeah... because it is winter... If I wanted to go down there and I would like to go jogging in Queen's Park, but because it is dark, it is not lit, it is unsafe to go there, because there are so many trees and stuff like that. So you would have to wait until the summer to do it anyway.'

Participants were asked if there were any running clubs they could join, but they could not identify any that they felt were suitable. Whilst some young people were worried about their safety when out on their own; they also had concerns about being together and looking like a 'gang'. They felt other peoples' reactions included thinking they were 'gangs looking for a fight' and that they were more likely to be stopped and questioned by police or Police Community Support Officers.

'Even with a group you don't feel safe. You would rather be sat at home'

Some of the fear expressed was related to the use of alcohol on the streets and how this might lead to street violence. On the whole alcohol was seen as easy to get hold of.

According to another participant, this fear and concern for safety and security extends into the home.

'Watching Crimewatch scares you. I saw that last night, I had nightmares... I'm on the ground floor in a one bedroomed flat... anyone could get in... when that little kid got took out of the bath! Oh my god!'

(Young parent)

#### Environmental cleanliness

In a number of interviews participants raised concerns about cleanliness and hygiene in public spaces. Litter and the presence of vermin were identified as adversely affecting the environment and impacting on health and wellbeing. Participants in one focus group raised this issue and went on to say:

'Yeah yeah (all agree) it does. We got rats in the park, they come from the street and the rivers. There's loads of problems with junk and people lighting fires. A lot of people don't know how to use skips so they just throw things in the river. It's full of rubbish old sofas, washing machines, that sort of thing.'

'Yeah people don't know how to use bins around here.'

'Yeah in our street people throw nappies in the street out of the window and... Like spitting and (urinating) in the street.'

(Young Asian Men's Group)

Participants affirmed that they believed dirty and infested environments affected their health, noting that behaviours such as spitting and urinating in public places were antisocial behaviour.

'Yes they just wee on the stairs and they leave their drinks ... the following day it smells so bad... I get headaches actually when it smells so much' (Refugee and asylum seeker group)

Vermin were especially a problem for the young people living in the travelling community as the commentary below indicates

'All the rats... Sometimes if you walk out with no shoes on, sometimes we have to go out to the shed for toilets and showers and sometimes you do just forget and you run out... but you don't know what's been on the ground. Then kids drop sweets and pick them up. All kids do don't they?'

'Where we are at the minute, there's a tip here, and a tip there and there's an awful... oh it absolutely stinks. And some... it is really bad in the heat, the smell is that bad.'

When asked how they felt that this affected their health, these participants gave the following reply:

'Even when you're eating you don't feel like eating because of the smell and everything, it's very bad. You try and make sure everything's extra clean. Me, personally I use quite a lot of bleach. I know people say you're not supposed to wash with bleach. I used to walk around in the kitchen and I wanted to bleach everything, the surfaces, the cups, the plates and you're not allowed. The only thing you're allowed in an industrial kitchen is bleach for the floors, you are allowed to bleach the floors... but I bleach everything. Especially in the summer, there's an awful lot of flies come here and you end up with an awful lot of bites, in the summer, don't you, from that tip. A lot of bites. You cannot leave food out, like now (winter). In the summer, you just couldn't leave that because it can get unbelievable, flies as well. (We are) surrounded where we're living (with refuse tips). The one that causes the smell is this one at the back but I don't know what kind of waste they're putting in. We did try and petition against it but it's gone ahead anyway. So in general, you're getting everybody's rubbish. It is a nice place to live, like I said, but two tips are enough.'

It is interesting to note the final comment in the above transcript, despite the problems described, the site is still a 'nice place to live'. Participants were asked about their use of resources to help promote and maintain health. Some participants commented on what they saw as the poor state of some leisure facilities in the area:

'You know that £20 million new sports centre they've had built? Where's ours? We've got Rochdale swimming baths, it's horrible, it's dirty and I don't want to go in there. The water's brown.' (Homeless young people group)

Another environmental issue identified as affecting young people's health was air quality and pollution, for example:

'Well it's like the pollution in the air it affects you...allergies and things.'

(Refugee and asylum seeker group)

On the other hand a refugee and asylum seeker group participant made the following observation indicating that some perspectives may be comparative to previous experience.

'It's clean here compared to the country I come from. Like there they don't clean every week but here they clean every week. The place is clean.'

#### Home

Participants highlighted several issues concerning their home environments, other than those mentioned above. The extent to which the home environment might affect health was explored in the interviews. The young parents raised a number of issues:

'It's hard work really. Living in a second floor one-bedroomed flat... it just depresses you ... I mean you get home with your shopping and you can't even get it all up the stairs... It's depressing...you have no room for anything... you have to share a bedroom with your kids... you have to share every little bit of your space...'

One parent shared how she believed it was unhealthy for her to be required to carry her wheelie bin up the stairs to her flat.

'Yeah that is it though...'cos it smells... it's a health hazard. It is a health hazard because I have to drag my bin up and down the stairs. Yeah ... you're not allowed to leave your bin downstairs outside the door... you've got to take them up to your front door. I have to drag my bin down a flight of stairs and all.'

This participant goes on to say:

'Yeah... It's alright getting it up the stairs but getting it down is hard. It's the same with a newborn baby in a pram... my friend... I'm alright... we're in the same flats but she's upstairs and mine's downstairs so...'

Interviewer: But what if you weren't able to take your wheelie bin out? What if you physically couldn't do it?

'You'd have a house full of rubbish. Sometimes you physically can't when it's quite heavy ... I have to go and knock on a neighbours.'

Interviewer: You're only small and all aren't you?

'I just kind of let it go down the stairs...'

Similarly, a participant with physical disabilities made the connection between their health and housing and said that the family had been trying to get a new house to replace their existing terrace for years.

'Well, like, oh it's difficult. I just about manage but it is difficult 'cos I've got a staircase and I'm sort of, if I can put it this way, half kneeling, half walking up the stairs using the hand rail. So that's just the way it is. I know this is because of money, and the CC, the credit crunch. We can't quite get enough money. My mum and dad can't get enough money to give it quite at the moment. So we're having to save up now. So hopefully everything will be sorted.'

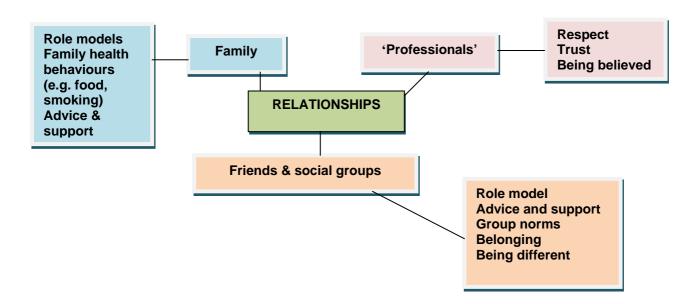
For other participants, home was a hostel. These participants explained how whilst 'home' is an important factor influencing health, there are important issues when there is a lack of 'home'. The interviews with homeless young people revealed that living in a hostel and being homeless was perceived by them as being particularly stressful and affected their mental well being.

'Yes. I weren't ill (with depression) before I came here. It has got worse since I've been here.'

Another homeless participant added:

'The same with me. It's stress...and it's just being homeless and everything getting on top of you isn't it? The rules.'

# Relationships



Many young people noted the influence that other people had on their health. In particular friends and family were identified as important influences.

## Family

Family members were described as being strong role models. This might mean encouraging healthy choices or alternatively that relatives could display unhealthy behaviours which were potentially influential on the participant. These were commonly described as relating to food, smoking and exercise as is illustrated below:

'My mum and... like... before her,... through our family diabetes runs, as it mostly does in Asian families. High blood pressure and all that sort of stuff, but my mum is like, she got used to it, because she had it at a young age she realised the problems and she had to cut back straight away so she has influenced that on us now, because she got it at a young age, she said I don't want you to catch it at a young age neither.' (Youth Empowerment Group)

'My mum and dad give me unhealthy food I know that!'

(Young Asian Women's Group)

As well as dietary influences, participants raised family member's smoking too.

'It's not just that it's like if you have an unhealthy family it makes you more determined... like my dad he smokes and he is really unhealthy because of that... and my mum like she is early unhealthy as well and it makes you more determined... 'cos you don't want to end up like that... 'cos they're only young but they look a lot older...' (Young Asian Women's Group)

The Youth Empowerment Group participants had a discussion around the family organizing informal, intergenerational health promoting activities which they described in a positive manner.

'We get the family out as well. My mum picks up my auntie and they go walks then everyone in the estate joins us... 60 kids run along with skipping ropes and basketballs and bikes.'

#### **Friends**

Friends and social groups can be supportive to change but also the group norms can be very powerful.

'I think if you were going to give up smoking, and your friends knew it was something that you had your heart set on, I think if you really did feel like you were going to lapse, so I think they are there to talk to you and stop you doing what you don't want to do.'

(Youth Bank)

Friends support or otherwise with healthy food choices was raised by several participants:

'If your friends are like healthy and eat healthy foods then you go along with it' (Young Asian Women's Group)

'Yeah sometimes like you get some food and you start talking about it like healthy foods and exercise and that... and like if you all go out and want to eat at the same place... they go to the chippy and you say I want to grab a salad... and you feel like erm oh... well I might as well go along with the crowd.'

(Young Asian Women's Group)

Peer pressure was described as having negative consequences at times:

'Well if there is a group of you and all your friends are drinking and you have said you are not drinking, you get called lightweight... so...you end up drinking and getting drunk and having fights, getting arrested...'

(Youth Bank)

This peer pressure was most raised in relation to drinking alcohol, taking drugs, smoking and eating. When asked directly, young people told us that that drugs and alcohol were considered easy to get hold of 'if you know the right people'.

Over all there was a general issue for participants of fitting in with group norms whether they are displayed through family or friends.

'Well it is. It is true because it might affect the way that ... people around you, and they are all going out to eat or whatever, unhealthy and then you'll join in rather than just making your own dinners. Sometimes decisions are just sort of made for you or maybe the atmosphere, someone's smoking and you are just sat there.'

(Youth Empowerment)

One participant indicated a shift in behaviour having reached a particular age.

'Once you have reached a certain age, obviously you start pushing your parents to one side, and your friends become more important.'

#### **Professionals**

This section brings together some of the findings about the relationships between young people and 'professionals'. We use the umbrella term 'professionals' here to signify the broad spectrum of health and social care workers and volunteers that young people may come across in relation to their health and wellbeing.

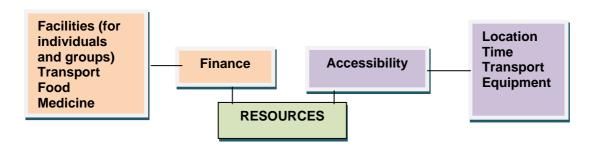
Young people expressed some ambivalence regarding their relationships with professionals. Community type workers were generally described most positively. This was because they were perceived as being more in touch with the young people and more understanding of their lives. However, relationships with other professionals tended to be seen in a less favourable light. This was particularly evident in discussions regarding experiences with GP services, some of which is described in more detail below.

Some people felt that their choices were compromised due to the perceptions of their needs by other people. This was expressed clearly by young homeless people:

'We don't get treated as we should get treated. We get treated like kids. It's a lack of respect. Sometimes they send you to places where they think it's helping you but at the same time it's degrading you... I think you should be able to choose. They make people go... you think I don't need to go there (Early Break) but they are making you go there or you get kicked out.'

'It feels like prison. Nobody, the staff, don't trust you. It's like prison.'

#### Resources



There are a number of key factors identified in these findings as impacting on the young person's health and these are discussed further in the report. However, there are important issues which are described as influencing the extent to which such resources are utilised to both maintain and enhance health and wellbeing. These are accessibility and finance.

## Accessibility

Access to leisure activities that promoted health were seen as very important by almost all participants. Participants most commonly discussed barriers to accessing facilities for exercise. A number of problems were identified by participants and included:

- Suitability of the environment in terms of litter and safety e.g. to go out walking or jogging;
- The cost of gym facilities;
- The availability of gyms;
- The age-appropriateness of gyms;
- The perceived poor state of some facilities e.g. swimming baths;
- Access in terms of location;
- Expensive public transport especially at weekends.

Individuals often described a number of barriers to their accessing existing facilities. For some who did not have the benefit of car use, or have local/neighbourhood facilities, both the financial cost and the time needed to use public transport were seen as prohibitive. This was especially the case for those not in employment. The following extracts are typical of comments made. One female participant from Youth Bank spoke of accessing gym facilities from Heywood:

'The one at Rochdale at Alder Hill you would have to get the 469 (bus), but where you live, it would be like going from one end of Heywood all the way to the other. Just to get on a bus, to get off and have to walk through for ten minutes to get to it anyway. But it is like, if we get a college pass for the bus, you can get on for 70 pence but that is to and from college. At the weekend we are still expected to pay adult fare (which is) £4.'

The group at Youth Bank discussed the age-appropriateness of some facilities and resources, expressing the opinion that they would like what they saw as age-appropriate provision:

Interviewer: So if you had dedicated time, what age group would be good for you?

'We wouldn't want to go to the gym and there is a load of 12 year olds screaming and messing about.'

Interviewer: So would you say 16 to 18 or just 16 and over so that you might be in with adults as well...?

'We have the Friday Night Project haven't we which is for the younger ones, so may be on a Thursday night or, well obviously not a Thursday night for us because... Maybe Saturday morning, or another night? One night in the week, just that one/ two hours for 16s to maybe 19s? Just to get that gym in, because we have got college as well.'

Another consistent finding across interviews was that many participants did not know the specific details of what resources or facilities were available either in Rochdale Borough, or in their immediate locality. This included how to access resources and the associated costs including any concessions. The group discussions indicated that individuals had differing degrees of knowledge, and further than they often had conflicting understanding.

#### **Finance**

It became evident in the early interviews that finance (or rather the lack of finance) was seen as a major factor influencing health: in particular accessing resources that help to maintain or enhances one's health and wellbeing. This was discussed further with the Advisory Groups, and as a consequence the question of money and its importance in the health for young people was specifically addressed in the later interviews. Whilst money wasn't viewed as always being necessary for good health, it was nonetheless recognised as important.

'If you have a problem with your body then money can't take it away'.

(Refugee and asylum seeker group)

'Money is very important to your health. It affects everything, like if you don't have money you can't do anything in life.'

(Refugee and asylum seeker group)

Money was seen as needed for access to some leisure and fitness facilities.

"...and swimming for 16s and under, does that include us or not? Because we are in college we have got to pay for swimming. We have got to pay for the gym. You have to pay if you want to use the Astroturf, kick about for a few hours and then you end up getting kicked off by the older lads..."

(Youth Bank: female)

Conversely, one participant in the Youth Empowerment Group commented that money was '...not much of issue as you can go for a run for free.' This fits with the popularity of walking and jogging as cheap or 'free' activities. However as is pointed out elsewhere in the report this is set against barriers such as fear of crime or the physical state of the neighbourhood.

Overall, leisure facilities such as gyms were considered too expensive. Participants commented that it is often assumed that those over 16 years of age are working and so are classed as adults and charged admission prices at the adult rate. Cost of gyms was

described by participants as between £20 and £27 per month. Many participants were still at college and did not have incomes comparable to their working peers. Some expressed difficulty finding employment, including part time or temporary employment. Generally low income and the cost of facilities and public transport, especially at weekends, were seen as particular barriers to exercise.

Money was widely seen as being linked with good food. 'Healthy' food was generally perceived as more expensive for example:

'Yes, like if you've got money you can buy healthy food. Yes, like vegetables.' (Refugee and asylum seeker group)

'Sometimes it's like, the people were saying like, the healthy food is more expensive to buy than junk food so they'll probably just tend not to eat them. Because why pay more for something when you can just pay less and get more for your portion?'

(Youth Empowerment Group)

Money was recognised by some participants as needed for treatment of ill health

'If you don't have money like you can't buy medicine and things.'

(Refugee and asylum seeker group)

Young people described many ways in which low income and lack of financial resource impacted on their health and wellbeing. Access to dentistry was noted in a number of interviews, whilst one young woman discussed the expense of wearing spectacles:

'Even though I'm a full time student I have to pay £150 at a time for my glasses because my lenses are that strong. And it is not fair because I end up being blind. So I am stuck in that situation where I have to wear glasses all my life. The next time I go back my eyes have got worse which means my lenses are stronger which means they cost you more which means the prices are going up. And my mum and myself, I cannot afford it and it is not fair, because then other people will come in with designer glasses.'

(Youth Bank)

Money and the effects of a lack of it were also linked to mental wellbeing. An example given by a member of the refugee and asylum seeker group was:

Well if you don't have money sometimes it can cause most parents depression and stress and that affects other people who are living in the family. Because when the parents don't have money and they've got stress they take it out on their kids.'

(Refugee and asylum seeker group)

# C. <u>How I Look After My Health</u>

#### Take exercise

Participants identified a range of exercise activities which they said they used to promote their health and wellbeing. These included:

- Walking
- Jogging
- Football
- Gym
- Swimming
- Cycling
- Dancing

In addition to going to the gym, walking was often mentioned as being a valued exercise activity, especially where a suitable environment exists.

'It is quite easy from our back door, our back garden... has got loads of hills, so everyone's like, 'Do you want to go for a walk?' Whereas if (it is) full of litter it doesn't promote you enough to say 'I want to get out there and do something'.'

(Youth Empowerment Group)

The importance and value of walking was particularly noted by participants in the young parents groups, the travelling community, Youth Bank and Youth Empowerment Group.

Dancing was a preferred activity identified by many female participants, although places to dance were seen as limited. One exception was described by a Youth Bank participant.

'And it is like there is nothing for dancing or anything, just something as a hobby. And if it is, it costs a bomb. Like you come home from college and you have had one of them days, and all you want to do is like, you could just go and dance somewhere. We go to see one of our friends who are in a band, and it is called the Back Door Project. We only go when there is a band there because it is in Middleton... And when we go, you can just go and dance about'.

Some of the physically disabled participants we talked to had tailored exercise activities they performed to help manage their disability.

'I walk around the house on crutches nowadays because I've got sore legs. So I've started to do more exercise. But when my legs are better I do exercises on my arms and my legs and my back. But at the moment I can't [...].and I'm going into hospital to get treated. So up until then I'll just wait and take it easy, and walk around as best as I can.'

At the time of interview, these participants reported that opportunities for them to participate in team exercise such as football and basketball were being pursued.

The Youth Empowerment Group had an interesting discussion regarding gender and exercise. There was a broad agreement that women were more aware of the need for a healthy lifestyle, but this was likely to be influenced by media images and so motivated by

concerns about body shape and self-image. Men's interest in fitness, particularly the gym and team sports was a 'hang out thing'.

# Eat healthy food

A number of eating habits were described by participants. The importance of eating good food was seen as important and most participants were aware this involved aiming to eat 5 fruit and vegetables a day and drinking plenty of water.

Good food was generally seen as an important aspect of keeping healthy and 'fast food' was generally seen as 'bad' and a threat to health. Some participants stated that there were too many takeaway shops selling 'unhealthy' foods in their local area:

'Yeah if you like live round loads of take-aways, you just like go to the chippy. Like at college if there's loads of chippys you use them everyday. It's quicker than to get a sandwich' (Young Asian women's group)

Boredom was seen by some as a factor affecting eating habits, for example:

'It makes me binge eat because it's a rubbish street. Yeah, it's dead boring right. I eat when I'm bored'. (Divert Group)

A related issue is the control of body weight. For many of the young people we interviewed weight maintenance was an important issue and one which concerned them. One female participant commented, 'When I am old I don't want to go big'. Diet was usually described as the most important factor in controlling body weight, with some female participants noting calorie counting as important. Body weight was also linked to self esteem and mental health:

'Yeah and your self esteem, because if you feel fat and you feel depressed you don't want to do anything...' (Young Asian women's group)

#### Don't smoke or drink alcohol

The participants in this study appeared to be well aware of the negative effects of smoking and drinking alcohol on health and well being. As was noted previously, the influence of other people on health behaviour was noted. For example, a Youth Empowerment group participant noted, 'If you start smoking your children start smoking'. Some participants were also concerned about the effects of passive smoking and a perceived lack of choice:

'Sometimes decisions are just sort of made for you, or maybe the atmosphere, someone's smoking and you are just sat there'. (Youth Bank)

At the verification event a discussion took place about why, when the harmful effects are well known, young people smoke. There was a consensus within this group that smoking was perceived as a 'cool' thing to do: smoking was linked to image. The recognised reality amongst participants was that tobacco is a strong addiction and so despite knowing the harm it can do to health, participants said cigarettes were simply too hard to give up.

An alternative perspective on smoking was given by two of the young parents who smoked. They said that smoking helped them to manage stress in their lives:

Interviewer: You made a conscious decision to stop drinking when you got pregnant but you didn't give up smoking. What was the difference for you?

Participant 1: 'I couldn't stop smoking. It was too difficult, I need a smoke.'

Participant 2: 'I think you either smoke or drink but not both.'

Interviewer: Where did you get that idea from?

Participant 2: 'That's just how it goes. You've got to have something haven't you to calm you down and that? When you get stressed and stuff like that.'

Interviewer: How do you feel about that? Are you happy about the decisions you made? Or do you wish you had changed them?

Participant 1: 'I wish I could stop smoking me, I do. But I just know it wouldn't happen. I've had like loads of smokers' packs, but I just know I couldn't... I'd like to.'

Similarly, alcohol was seen as having a negative effect on both health and other aspects of healthy lifestyle, for example, commenting on someone who drinks alcohol, 'You can't play football, he runs out of breath every time' (Divert Group).

It is interesting to note at this point that, whilst cigarettes and alcohol were discussed, the use of drugs and their impact was health was not raised by young people in these interviews.

#### Maintain sexual health

Sexual health was considered an important issue and was discussed by many of the participants. The availability of contraception and sexual health services was discussed, and it should be noted that, as with other resources and services, the level of knowledge amongst participants was variable and sometimes conflicting. Indeed, some participants in a number of different interviews said that they where unaware of where or how to access sexual health services. This was followed up during the validation event, where over half of those attending said that did not know about some or all of the local resources and service where they could access free and confidential sexual advice and treatment, condoms or emergency contraception.

Issues of access to services was again identified: this is exemplified in the following extracts from the Youth Bank interview

'But it is like I was saying with the contraception-wise, and the morning after pill. You can't get it from the chemist anymore like you used to be able to, and go and sit upstairs and speak to a qualified doctor. It is like you have to go to Rochdale, the one on the big hill. And it is like why should we have to travel when we just want that little bit of help? It is not fair, because you do really need to be offered more. Because it is like that they have posters up there for the elderly, 'Come and have a free check', 'Come and have this check'. There is nothing anyway saying 'Come and have a chat with your

(Youth Bank)

doctor about contraception.'

and

'It is like I know the clinic in Heywood, the family planning thing whatever it is. It is used to be a well women centre I know that. I think it was a Thursday night, but because of the time, if it is for teenagers, because of where it is as well, it is not in a nice place where that clinic is. And it is like, I don't know, I wouldn't want to go, because I feel like really intimidated because I'm embarrassed by the people there'. (Youth Bank)

The gender and age of the health-care workers seemed important for some participants. The Young Asian Men's Group agreed that they would find it difficult to seek advice or support in maintaining their sexual health from other males:

'Yeah, but if you go to a guy now and say 'Hey look man I've got this wrong with me' you might feel ashamed, because you could imagine him laughing.'

(Young Asian men's group)

Whilst some female participants said they would prefer to rather see a female about 'female problems':

'There is only a male doctor but it is about woman things. I don't want to go in and say I'm having a period this week, and a period that week. You don't want to be saying things like that, because you feel embarrassed. You feel like you can talk to women more.'

(Youth Bank)

Some participants also raised the issue of the age of health workers, specifically in relation to sexual health care - for example:

Interviewer: What services would you like?

'A clinic in this area, run by young people of the area. Our age group. I don't want to come to someone of your age (late forties). I want someone of my own age group.'

An interesting issue that arose in one group interview was participant's views about seeking sexual health advice from who they perceived to be members of their local community. The rest of the group agreed with this comment:

'OK, it would be OK to talk to a white lady, but an Asian lady? I'd feel ashamed. Well the ladies who work there... they are from this area...'

Interviewer: Is that a problem??

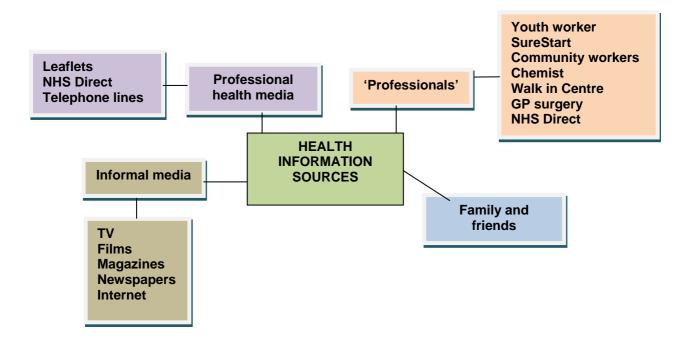
'At the sexual health clinic the women are all from this area. Yeah they might know your parents. Asian ladies right, they are good at talking...' (all group in agreement)

(Young Asian men's group)

## PART 2

# **Staying Healthy**

# A. Where I Go for Health Information and Advice



#### **Professionals**

As was stated before, the term 'professional' is being used as an umbrella term which includes workers in health, social care, community and voluntary agencies. In terms of which professionals young people would go to for health *information and advice*, participants gave a strong overall impression that their 'first port of call' for information would be the 'community worker' type of role holder. For *treatment*, the GP was commonly given as the first resource used.

# Youth and Community Workers

As stated above, when asked who they would go to if they needed health and advice, a majority of participants identified a Youth or Community worker. This is exemplified by the number of young parents who demonstrated high regard for their SureStart worker and the extent of support and advice given:

Interviewer: Do you think there should be an information service that addresses your information requirements in relation to your needs? As young parents do you think you need something special?

'You can always get whatever you need from X' (SureStart Worker). 'Yeah, we just ring X"

'If I need anything, well I've just got a job and I ring X straight away "What do I do?" She helps you with everything...'

Interviewer: OK, so how would somebody else get to find out about X then?

'I tell everyone about her. I always say 'Yeah I'll ask my worker'. Like my little sister and all that, everyone that asks me about anything'.

The broad range of services impacting on health and wellbeing offered by SureStart was seen as invaluable by those using the service. As one participant said:

'Everywhere you go there is something on SureStart, telling you about it. I mean it's probably been the best thing for years isn't it really? SureStart now, it's the best thing for our kind of people.'

(Young parent)

Where participants were in contact with Youth Workers, these were spoken of very highly and rated as important in providing information in an accessible manner for example: 'Yes, yes, he is understanding and he knows about things. We know him and he won't go round telling.' Such positive comments arose amongst the refugee participants about their community workers and case workers and also workers with the young Asian groups.

# Doctors and other health personnel

Whilst doctors and medical services were often mentioned as sources of health and wellbeing treatment and sometimes health information and advice, medical services in general and GP services in particular were not always perceived as helpful. Concerns raised by participants included doctors not being up-to-date, not understanding young people's issues or not listening to young people. In a number of interviews there was a notable element of frustration for example:

'Well no one has a clue what goes on. Do these doctors have to answer to someone? Someone above them or what? It seems like they just do what they like. They've no one above their heads. They don't check you properly, they just can't wait to get you out of the room. They just sign that prescription and hand it to you, or just give you Paracetamol and hand it to you.'

(Young Asian men's group)

The gender of doctors was viewed by some as important, particularly if the health issue is sensitive. Female doctors were preferred by both males and females. Some participants commented that they felt some doctors were too old to understand young people and hence were not their preferred source for health information. It is important to note that a repeated issue amongst participants concerned the issue of trust. Young people wanted to trust the professional competence of the doctor, trust that confidences would be kept and trust that they are being listened to:

'Well they'll help you but they won't take the time to talk to you about it. Like they'll tell you what medicine you need but they won't talk to you about how to be healthy and that. You need that relationship with your GP, and if you can't trust them right?'

(Young Asian women's group)

Some college attending participants identified college health workers (rather than teachers) as a source of health care advice and support, whilst Divert Group participants suggested going to a first aider for their health problems. However, it should be noted that there were

few, if any references to other members of the primary care team as sources of health information, advice or treatment.

#### Chemists/Pharmacist

A significant number of participants in a number of different interviews identified chemists and pharmacists a helpful and reliable source of health advice and information:

'Yes. If I have ever had any problems I have gone in and asked to speak to a pharmacist. You can just go in and ask. Sometimes they are as good as a doctor.'

(Young Asian men's group)

'I had a cold sore before and I went to the chemist and said I had a cold sore. But it wasn't a cold sore, I don't know what it was but it got real big... and they told me to go to the doctors because it was an infection in my mouth, and I thought it was a cold sore.'

(Travelling community)

## Family and friends

For all participants, family and friends were considered useful sources of advice and information. Friends were an especially popular choice for health information. Whilst mothers were the most commonly identified family members, fathers, siblings and cousins also featured as sources of help. Some participants mentioned the value of home/traditional remedies which could be sourced through family and friends e.g. for stomach upset or sore throat. Others would more likely go to close friends than family for sensitive issues such as pregnancy or sexually transmitted diseases. People who have had similar experiences, such as older friends where identified as sources of helpful information:

They are 'like a lot more mature than you and they have been through it and they can help you. They can guide you through, like don't do this, don't do that, and give you good examples.'

(Youth Bank)

## Professional health media

Leaflets were viewed very positively by many participants as a means of communication with young people concerning health and wellbeing matters. Participants stressed they needed to be located in accessible places where young people meet:

'Yes and look at the leaflets we have here (in youth centre).'

Interviewer. So are they important then?

'Yes we read them and put them back or sometimes we take them home.'

Interviewer. Which ones of these have you read?

'Oh the ones on smoking and on drugs.'

(Young Asian men's group)

Participants were asked to identify characteristics which would make leaflets appealing to young people. Key characteristics were identified as a relevant topic, an attractive format and not too wordy. Recent local campaigns using leaflets aimed at the general population (not specifically at young people) include 'Speak Up, Choose Well' and 'Heart of Local

Health'. Some participants said that they had noticed these campaign leaflets, but interestingly few had read them. In future campaigns, participants said that they would prefer relevant information to be sent to them personally, as opposed to general 'household' addressed post. For participants living with parents, such general household post is often viewed as being for their parents and which they would then not look at it.

Some participants said they had made some use of telephone help lines and liked these because 'they are confidential and you can go home and ring them'. Arguably these also gave the young person using them a degree of personal control. More specifically, the telephone service provided by NHS Direct was not identified as a resource by all participants. Those who did not have English as a first language did value the availability of interpreters offered by NHS Direct, and the service had been used by some young parents and one participant from the travelling community.

There were few comments about the 'Life Channel' in GP waiting rooms. The Divert Group participants were familiar with it, but considered it boring and said they would prefer to have information on matters of interest to them for example, football injuries.

When asked what they understood by the term Primary Care Trust (PCT), participants demonstrated a range of misunderstanding and none knew accurately what it meant:

- 'Is it a trust for young people?'
- 'Is it a trust or the area?'
- 'Is it for doctors and walk-ins and that?'
- 'Primary school?'

#### General media

#### Television.

A range of general media were highlighted by participants as successful in reaching them with health information. Commonly cited by participants as most effective were soap operas such as EastEnders or Coronation Street where a storyline was followed and insights gained into a real-life condition or issue. Television was further noted for advertisements such as drink driving campaigns. A smaller number of participants said they gained health information from programmes on cable/satellite channels.

#### Radio.

Three radio stations in particular were considered by participants are being effective at reaching young people with health information. These were Galaxy, followed by Key 103 and then Crescent Radio, Asian Sound (the latter especially at Ramadan).

#### Magazines and newspapers.

National newspapers were not seen as useful unlike the local ones which were very highly valued as sources of relevant and useful information. By far the most popular were the Metro free newspaper (available widely on buses, Town Centre etc) and the Rochdale Observer. Various national glossy magazines were viewed as useful for women.

#### Internet.

Using the internet was seen as a bonus to add to the sources above, or to get immediate information:

'Yes. I mean I'm not one that will probably look on the Internet. Some people are into self-diagnosis and things like that and people are then using the Internet more and more to sort of work out what's wrong with me'.

(Youth Empowerment Group)

Interestingly, most young people recognise that the Internet needs to be used carefully for health information and advice. Comments include:

- 'There are a lot of unreliable sources.'
- 'Random people just put it on with blogs and don't they sometimes?'
- 'You need a good source.'
- 'Too much information.'

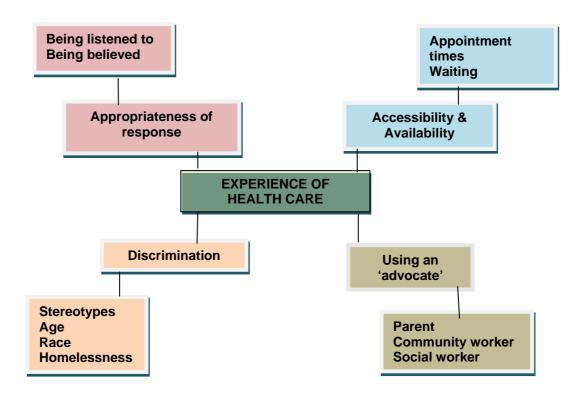
One participant felt that the Internet was especially helpful for males who might not want to discuss health issues face to face:

'I think lots would probably go on, like, the Internet and stuff because guys tend to like, leave it... hide it. They hide it away'

(Youth Empowerment Group: male)

It was also noted that the Internet was not considered accessible to some young people including homeless people, refugees and travellers. This can be illustrated as, when asked, only one out of fourteen refugee participants had Internet access at home whilst one other said they may use the library for access if required. Whilst some of the required technology might be available in public spaces such as libraries, these settings were not considered welcoming of certain people using their facilities e.g. travellers. There was also the privacy issue, considering what people might need to view in a public space.

### **B. My Experience of Healthcare**



## **Accessibility**

The accessibility of health care services was a noted theme throughout most of the interviews. As GP services were the primary source of help in getting treatment, issues concerning appointments with them were raised frequently by participants.

## Waiting to get an appointment with GPs and others.

Problems in getting GP appointments were mentioned by the majority of participants, and within all groups represented. Examples include:

'If you get the doctor's phone number, try and ring it and make an appointment you'll be there 'til next week. And when you do get through, you've got to wait a week anyway. You'll be dead. Sometimes if you ring in the morning they have an appointment that day. I rung at 9 o'clock this morning. I was up at half eight and dead on 9 o'clock I tried to ring and now you've got to press a button, press number one if you want to make an appointment. 'Sorry we are unable to take your call' or whatever. And when you do get through, it is next week.'

'If you don't have an appointment, the doctor is always busy. There are so many people all the time, you can't find somewhere to sit. In the surgery, a lot of people just sitting and a long time to wait. That's if you don't have an appointment.'

(Refugee and asylum seeker group)

'The doctor's surgery, this one round here, you ask for an appointment and they say come back next week. They take the phone off the hook. You can never ever get an appointment with them. Me right, I haven't been to the doctors for years, if there is something wrong with me I'll just go to the chemists and ask them like what do they recommend. I've given up with these doctors, they're just a waste of time'. (Young Asian men's group)

When asked what he would like this participant went on to say:

'Well these doctors over here they have got too many people. We need more doctors in this area. There's only two doctors round here. It's too overcrowded, you are always waiting for an appointment. It's too much of a long process'

Another example was given by a young parent:

'I went to the doctor on Tuesday with the baby, she [the receptionist] said I've got no appointments so I said well you'll have to send the doctor out then. Then she was like 'we'll fit you in'. Anyway they did and he's got bronchiolitis!'

The extracts above highlight a number of concerns raised by participants about the facilities in the GP surgeries. These were further identified in both individual and group interviews and typical comments include:

• 'Too much waiting around one you get in there and its boring'

- 'Too small'
- 'nowhere to sit'
- 'claustrophobic', 'overcrowded'
- 'Receptionists are grumpy'

A smaller number of participants viewed GP services in a more positive light: GP services:

'In Africa you need to go there for ages, you have to have money and wait in a queue. Here everything is organised you can phone them, tell them the time that you'll be there and they'll do what they are supposed to do. To me I find everything positive compared to where I was before... It's really nice everyone is really positive. My doctor is Dr X. He's friendly and he talks to me...' (Refugee and asylum seeker group)

Where services are easily accessible, these were rated highly. There was much discussion in some groups about health care provision in a local supermarket, for example:

Participant. 'There's Sainsbury's now... our doctors are at Sainsbury's now'

Group. 'Really?', 'Are they?', 'For if you haven't got time?'

Participant. 'Yeah, he does the practice down there. He was the very first one, it was on the news and everything. But like I've taken my mum to an appointment there, you know straight from work. It's a good thing if you work nine to five. He does Saturdays there and Sunday evenings like 'til nine o'clock. So you know if you phone for different things but you don't want to take the day off work, that's what it's for.'

(Young parents)

Waiting times for other appointments where commented on by some, for example to access Speech and Language Therapy Services:

'You know who I think I'm waiting for a letter from? The speech therapist. Stuff like that, they take ages. A three year waiting list, he needs to go now, by then it's too late'. (Young parents)

Young people with physical disabilities expressed concerns regarding their transition from Children's to Adult services. These concerns included clarity on processes for accessing services, the location of service provision and the development of relationships with unfamiliar staff.

#### Walk-in-centres.

Walk-in centres, one-stop type services and some specialist services were viewed as both accessible and appropriate for meeting some health needs. A number of participants described personal experience of the Rochdale and Bury walk-in-centres. These were described as useful and helpful places where staff listened. This was particularly the view of participants from the travelling community, Divert Group, homeless groups, Youth Empowerment Group and young parents.

'When you travel and whatever, the first place you always look for when you do go somewhere is the doctor's or walk-in centre. You know that a doctor won't see you if you're not on the list, but a walk-in centre will.'

Interviewer. Right okay.

'I think the walk-in centre is brilliant, it was definitely. Even if my brothers or their children come here and they get sick and they're staying here, you can't take them to our doctors because the doctors won't see them. So if you can't take them home and they're sick, you can bring them to a walk-in centre and they can be better by the time they go home. Sometimes when you do go some places, like... going back a couple of years ago... when my little brother was ill, he was only three, and we were in a different place and the doctor refused to see him because he was a gypsy. So we then had to go to a different town, 20 or 30 miles to a different town, because there were no walk-in centres at that time.'

The experiences participants describe in walk-in centres were generally positive, for example.

'They just bandaged it. It was better than the doctors. Like they saw me straight away. It was quick wasn't it? And they were alright, they were talking with me asking me what happened and that. Yeah they were alright, they wrapped it up. They asked me questions like how can we make it better and that.'

(Male Asian participant)

The few negative comments about walk-in centres pertained to being 'batted back' to other services, or the walk-in centres not being an easy distance to travel to from Heywood. Again, there were very different levels of knowledge regarding walk-in centres amongst the participants. There was a widespread view amongst participants that people needed to know what exactly the walk-in centres can deal with and exactly what services they provide.

For some participants, more specialist services were identified as the most accessible and helpful. For example:

'Well I'd go to Triple H's surgery, obviously because Triple H... and I do know some of the staff, take it onto a personal level. And once you go the staff get to know you and get to understand you more, and that's not because they're listening more, it's because they're having more interaction with you, and if they have more interaction with you they're going to know what the facts are and they're also going to know how to treat you. They know personally how to treat you because everyone's different.'

Interviewer. So for you then, in that service, Triple H, are they different then?

'They're different because... they're not the good things... free parking anywhere or silly things like that. It doesn't happen with Triple H because it's like a drop-in centre and you can see a doctor whenever you want. It's only shop hours but then again if you're there they'll sit and they'll wait after two

and they'll see you after two o'clock. But you can see the nurse there and she's a very nice lady'.

#### Dental services.

Dental services were generally viewed as inadequate and were frequently mentioned by a number of the groups and individuals interviewed. The lack of availability of NHS dentists and the high cost of private dentists were highlighted.

'I got a real problem tooth and as it happened I needed a filling, but then things happened in my family life and I ended up losing my dentist. And it took me two years to get a dentist. Because you are looking everywhere for an NHS dentist.'

(Youth Bank)

'Well one thing that is missing in this area is the dentist...yeah (all in agreement). The ones that are private they charge a bomb and the ones that are NHS they are full. Mine's in Bury now. (Young Asian men's group)

A female refugee participant gave the example of how she had needed to carry on treatment previously begun by an orthodontist but could not get a referral to one without being registered with a dentist, and she couldn't get registered with a dentist. The availability of appointment times at dentists was problematic for some of those participants registered with a dentist:

'So then I've got a dentist and everything. For the last three weeks I missed exactly the same lesson each week because of the time. Because every time I go he would go, "Oh right you need to come back next week for me". I had a tooth taken out, and then he went "I need you to come back this week, for five minutes, just to see if it is healing". So I came back and I missed an hour and half lesson for that because he had no other time to fit me in for five minutes. So I missed an hour and half lesson, because it is in Bury, the dentist.'

#### **Appropriateness of response**

In terms of the response young people received from statutory health services, especially GPs, participants highlighted two key areas of concern: having a sense of not being believed and not being listened to. These appear to result in a notable degree of frustration and a lack of faith in some health care providers:

'I personally think that if there was something wrong with me, maybe the doctor I've got? I wouldn't trust him.'

(Youth Empowerment Group)

A significant number of participants felt they were not believed or taken seriously and that this impacted on the response from and relationships with health care providers. One young woman related how distressed she was when, having had anaemia in the past, she recognised the signs and went to her GP practice, where the response from a nurse was, 'well so what? If you're feeling weary just have a little rest'. Other participants felt GPs did not take sufficient time in talking to them and hearing what they had to say. A discussion with participants at Youth Bank included the following

'Well they'll help you but they won't take the time to talk to you about it. Like they'll tell you what medicine you need, but they won't talk to you about how to be healthy and that. You need that relationship with your GP and if you can't trust them right...'

'Well I've got eczema and I've like had it since I was little. I want to get transferred to a skin specialist, but they've never helped me to find out what the big problem is and what I can do to help it go. They just go "here's some cream".'

Interviewer: So you feel you don't have enough time at the GPs?

'And I hate it like when you are talking they are shouting "What the hell you been...". And then you tell them something and they go "No, no you lying..."

Interviewer: So are you saying then that you don't feel that people listen to you? (general murmurs and nods of agreement)

One participant expressed a sense of being viewed differently to others:

'I've been through the NHS several numbers of times and I've just been treated without respect and I've been told to leave when I've been needing most help and now, because no-one's listening to me, now I'm in a situation like I am now.'

(Homeless group)

Contrastingly there were some experiences of not feeling as if one was treated differently and being actively made to feel welcome. The friendliness of health staff was particularly highlighted by two refugee and asylum seeker group participants.

'Yes they are nice... when I went they asked me questions and gave me some time.'

'Mmm yes, they seem to like their job. They asked me questions and gave me time to answer. Yes, they were nice.'

Of note is the sense we gained from participants that experiences they had and attitudes they formed in relation to health and health services in their youth stood to have a long term impact into later life.

'I don't think I'm being listened to. I think if something did happen to me I wouldn't, you know, know like I said, I wouldn't trust them, and if they did tell me there was something wrong with me, I don't know where to go and what to do.'

(Youth Empowerment Group)

#### **Discrimination**

Participants shared a range of accounts that they viewed as positive and negative experiences. However, there appeared to be some who had expectations or experiences of what they considered to be poor treatment. When explored further, this was most

commonly attributed to an element of discrimination against them based on age, race or social attributes or a combination of these. This could be very overt, for example

'They [health professionals] think 'cos you like Paki that you're just going [e.g. to the GP] to get things for free.' (Young Asian women's group)

Age and being young was picked out by some participants as a factor that they felt influenced the quality of service they experience. They thought that some health professionals held the view that young people do not get ill. This is an example from an interview with the Youth Empowerment Group:

Interviewer: I mean going back to what you were saying before, do you think it is something to do with your age or is it just...?

'I think it is probably because of my age sort of thing. Oh, I don't know what it is but I... when I was meeting that nurse I think it was to do with the age and with my sister being obese they just saying, 'Oh she's young, she'll grow up, she'll be alright'. Well I just hope she does but I don't know do I?'

'They've just got it in their heads that they think that young people are totally fit and they can't get ill and only old people... the older generation are the ones who are constantly sick.'

'It doesn't matter how old you are, what you are, they should listen to you. They should act on it and then they should provide you with the evidence and say to you "well you're wrong" or "you're right".

Other participants perceived different forms of discrimination:

'People look down on me when they hear 'homeless', they always think junky, roots through the bins, you know, drinks alcohol to go to sleep at night, and that isn't the case. So I do think I've been let down.' (Homeless group)

This was affirmed by a male homeless participant from a hostel:

Interviewer: Do you think people treat you differently because you are homeless?

'Yes they do a bit... they think it is all full of smack heads and druggies... weirdoes and alcoholics. When you go into hospital and you have to book in and you know that you've got there at least before three other people, and they all go before you.'

One male participant from a hostel described his frustration at not being able to manage his own care:

'Nobody will understand. I have to go to the anti-coag clinic every week. I can't go anywhere or move anywhere because I have to come back here (hostel). You can get these special machines now, they're probably about £200 or something, you can take your own reading but they won't give me

one. I want my own machine, so I wouldn't have to wait a whole week to go and check if I'm alright, I could just check myself at the time that I want to check and see if I'm alright.'

### Using an 'advocate'

The main strategy used to manage the challenges of not being believed or listened to, was the use of an intermediary or someone to act in the role of advocate for the young person. This was often a family member, and usually their mother:

Interviewer: So going on from there... Do you think your age plays any part in the way people see you or...?

'Ah right. I went to the doctors once and this... the doctor goes to me, "What's wrong with you?" He said, "Yes, you've either got this, you've either got that or you're faking it." I was like, 'Oh my god you're not really saying that to me. You think I've come in faking it? I was like, 'Oh god. Because that was the time when I went in by myself, f and from then on I take my mum with me all the time.'

(Female Youth Empowerment Group)

Other participants also stated that being accompanied by a parent or parents intervening helped them. An example from one young person who was trying to get an appointment to fit in with college attendance:

'And they go "We have got no appointments today, can you come tomorrow at 2.00pm?" and I will go "No, because I am at college", and they go "Well surely, you can take time off?" and it is like well no, because you can't take time off college.'

Interviewer: Well you don't want to?

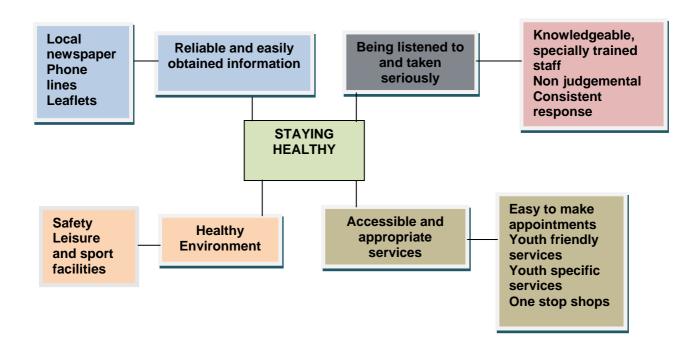
'Yes. So then I will start getting annoyed then and then my mum will have to come. And [....] and my mum will talk it through with them, and it will still take her, I will say a good 10 or 15 minutes before they will even try and find you an appointment that is after college time.' (Youth Bank)

For others, community workers had occasionally acted as intermediaries.

'They like to help... like my social worker took me to the doctor's, and she showed me where to go' (Refugee and asylum seeker group)

Having experienced poor service or a situation that might warrant a complaint, participants were asked where they would go to do this. Almost all participants made it clear that they would not know where to go: answers offered included contacting the NHS, asking for a complaint form and consulting a solicitor. Only one participant had heard of the Patient Advice and Liaison Service (PALS) but did not know what it did. .

### C. What I Would Like to help Me Stay Healthy



## Being listened to and taken seriously

Participants were asked about ways in which they could be supported to better manage their health and stay healthy. A popular response was for services that 'take young people seriously and concentrate on what young people are saying'. A number of suggestions were made as to how this might happen.

Participants said they wanted a consistent service with personnel who knew them as individuals, were well trained, understood issues of concern to young people and would take them seriously. Alongside this was there was a clear expressed preference for some specialist services for young people:

'It would be good to have a special doctor for young people. They know about things that happen to people our age. Like you could have specialists for people our age. Like a specialist in young people's health. Yes that would be good.'

(Youth Empowerment Group)

Another popular suggestion was for services provided and run by young people:

'I'd like services run by young people of the area. Of our age group

Interviewer: Why?

'You mix well with own age group. I don't want to come to someone of your age, I want someone of my own age group.' (Young Asian men's group)

Alternatively the Triple H service was a suggested good model. This service was described as easy to access, but importantly the staff were described as seen as easy to talk to, that they listened and were non-judgmental in their response.

## Having services that are accessible and appropriate

A range of suggestions were made by participants for more accessible and appropriate services. These include:

- Appointments which are easy to book be telephone
- · Same day appointments if ill
- NHS dental care
- Easy to get to services good, cheap public transport links
- 'General services' that are youth friendly e.g. anti-coagulant clinics
- Some services that are specifically youth focused:
  - Drugs services for young people
  - Discrete services e.g. for sexual health
  - A one-stop-shop for different health issues not just sexual health: maybe in town centre or at college. Other things young people might want advice on e.g. eating weight control, alcohol
  - One-stop family health clinics for young parents
  - Walk in general clinic at school/college
- Facilities in surgeries, clinics waiting areas to include:
  - Play stations in GPs
  - Less waiting
  - TV
  - A 'little room for the kids'
- Services that are not too far from home, more local or in a town centre.

An underlying view, relevant to the provision of appropriate services was the need for knowledgeable staff. An example of was concern regarding the regular updating of medical staff:

'I think that the thing I heard on the news like, as in upgrading the license or certificate every year, I think that's great because I know myself that he has recently passed his test and he's qualified and he knows what he's doing and they should be taken off if he doesn't know what he's doing.'

(Youth Empowerment Group)

The notion of accessibility is wider than the physical proximity and availability of services. For example, in an earlier discussion around sexual health services, a male Asian participant raised a concern that older Asian female staff might not respect confidentiality, a concern supported by fellow interviewees. The issue here is not the integrity of individual workers or actual organisation of services, but it is rather the perception of the young person and the ultimate importance that he or she has a sense of security in the confidentiality of the service.

## Reliable and easily obtained information

There was a clear desire amongst the participants for reliable and easily obtained information on a range of health services and resources for health maintenance. In particular, there were three main types of information identified:

 Information on health service provision e.g. what walk-in-centres are and what they provide, how to access dental services, sexual health services;

- Information on resources to maintain health e.g. what exercise facilities are available and how to access them;
- Direction towards further sources of reliable information e.g. Internet health sites for young people.

Participants were asked to describe what might help them get information that they and their peers would find useful. Resources identified included:

- A billboard listing services for young people in town centre;
- A local 'Dear Doctor' newsletter agony aunt or uncle style;
- Leaflets with an appealing appearance and contents tailored for young people;
- Leaflets in places where they are easy to pick up such as youth clubs, community centres and local shops;
- Enhanced role of youth workers as information providers;
- Local newspapers;
- Use of celebrities as role models or presenting health information;
- Phone lines
  - Confidential and that have 'personal control'; 'you can go home and ring them.'

## A healthy environment

A number of suggestions were made by participants as to how environments can be made healthier.

#### Social, leisure and home

- · More and cheaper leisure facilities;
- Gyms with affordable crèche facilities;
- Better access to sports facilities for everyone especially young disabled people;
- Services specifically for 16 plus groups:
- Inexpensive group activities e.g. running groups, dancing;
- More facilities like the Friday Night Project a youth club with free activities.

'I think if we had more things like the Friday Night Project. If we had more stuff like that running as well, I think you would find more people mixing. Because when you go on the Friday Night, there is literally people who... I would mix with people who I probably wouldn't even speak to on the street.'

(Youth Bank)

#### Safety

- The presence of Police Community Support Officers/Police to enhance security in public spaces for example getting rid of gangs;
- More street lights:
- Dealing with abandoned houses.

#### Environmental cleanliness

- To enforce the no litter rule;
- Rethink about location of refuse tips next to traveller sites.

#### **Discussion**

This section will consider the findings and where relevant relate them to key policy documents or literature.

Participants demonstrated a complex view of what being healthy means which we considered to be at odds with stereotypical ideas about younger people's understanding of health and wellbeing. Unlike Lawton (2002), who suggests that young people are not 'future oriented' with regards to health promotion messages, we found participants did recognise that action taken now impacted on their future health. Generally they showed a good appreciation of different dimensions of health including mental and physical aspects as well as social and environmental. These views fit with lay models of 'health' derived from other age groups, including feelings of happiness and the importance of social relationships. Participants understood well that a healthy lifestyle contributed greatly to health and that efforts to maintain a healthy lifestyle needed to start from a young age. Several participants viewed health as an absence of disease and showed some awareness that some diseases were often preventable such as diabetes. Participants were well aware of the factors that could discourage a healthy lifestyle such as diet and alcohol but also recognised the influence of peers, family and the media in encouraging unhealthy behaviours.

There is a stereotype that young people's lives are problematic and that they are primarily chequered by 'risky behaviours' (Brooks & Magnusson 2006). Similarly there is often a focus on the notion that young people as 'troublemakers' who need extra intervention to ensure that their health and well being is maximised (Wills *et al* 2008). However the participants in 'Younique Voices' refute these stereotypes and present young people as having a sound understanding of the need for good health and also the motivation to take care of one's health.

Interestingly, the impact of environmental issues on health and wellbeing were highlighted very strongly amongst participants. A large number of environmental hazards were discussed that either acted as barriers to young people carrying out health-promoting activities or were directly unhealthy in themselves e.g. vermin. Participants had made it clear that they believed their health and wellbeing was at times related to feelings of happiness and we discovered things that made them unhappy included litter, wasteland, dirty rivers and so on. Anti-social behaviour by some people in their neighbourhoods such as abandoning alcoholic drinks and depositing urine in public spaces were little tolerated. We heard of the challenging conditions that some participants and their families experienced due to living immediately next to refuse tips and resultant 'plagues' of flies and rats. The only participants who were not overly concerned about environmental issues were refugee and asylum seekers some of whom found this country cleaner than previous countries of residence. These environmental issues are clearly of public health concern and demonstrate a need for close inter-agency working.

Whilst the media is replete with sensational stories of gangs, 'hoodies' and knife crime, the view given by participants was that these are real concerns to them that affect them on a daily basis. Almost all participants agreed that they experienced regular situations in which they felt their safety was compromised, requiring them to use avoidance tactics. Their fears commonly related to walking in their local neighbourhoods past derelict buildings or waste land and avoiding other youths who they felt were 'looking for trouble'. Importantly, this avoidance of perceived danger impacted significantly as it stopped many participants from fully undertaking the health promoting /maintaining activities they wished to e.g. jogging.

Furthermore, home environmental issues featured heavily in our findings. Different issues faced participants depending on the type of home they had e.g. a hostel or a rented flat. Some issues were health and safety related such as carrying heavy refuse bins up and down stairs whilst others concerned the constraining environments in some hostels where residents felt mistrusted and stifled by rules. Others lived in cramped housing conditions such as the young parent who shared her only bedroom with her two children. In all cases these participants shared stress-inducing feelings of being undermined and undervalued as people.

In terms of relationships, participants widely recognised the influence of family on health and wellbeing in terms of the role-modelling or the bad influence they could exert. Views generally pertained to family's influence on diet, smoking and exercise. Similarly friends had an important role to play and group norms were strong factors affecting participant's behaviour. Thus it was sometimes easier to 'go with the flow' than avoid what the peer group or majority was doing e.g. drinking alcohol or eating fast food.

Relationships with professionals were not as conducive as they could be to supporting young people to optimise their health and wellbeing. This perception presented large numbers of participants with significant challenge as often they needed to engage with health professionals yet poor relationships hampered these interactions.

Whilst, as discussed above, the environment was seen as a resource for maintaining health and wellbeing, two more issues in relation to resources were also strongly articulated. These were the accessibility of resources and their financing. Resources such as gyms and other leisure facilities featured highly and barriers to accessing these related commonly to admission cost, age-appropriateness of some facilities and cost of transport. This finding concerning transport fits with the You're Welcome (Department of Health 2007) criteria that indicate where there is a choice about service location, the service should be accessible by public transport. However, the criteria also suggest that young people should be able to use the service outside school or college hours, or that the service is provided on or very close to a school or college site. In our study, cost of public transport was a particular irritation for those young people who are not in employment but the high cost of gyms and transport especially concerned others also. Participants also recognised that not all health promoting activities required money .e.g. running, yet this is where other factors discussed earlier come into play such as feeling sufficiently safe to go jogging. The lack of some resources e.g. absence of running clubs and dance facilities was another key concern, yet it may be considered that some of these activities are fairly low-cost.

Overall, the strength of social and family norms on health has been indicated. Our findings suggest caution is needed to avoid viewing young people outside of the wider context: that is, individualising 'health' as the young person's personal responsibility when many of what they describe as key factors are (at least perceived as being) out of their control. These findings concur with those of Lawton (2002), and Wills *et al* (2008) who suggest that young people's attitudes to weight and health were grounded in their familial experiences. This suggests that we cannot see young people as a unitary group in isolation but that we need to see them in the context of their social and cultural environment. Whilst in this study, we found that young people's relationships with family and friends may be difficult to influence, the relationships forged with them by some professionals clearly militate against their use and experience of health resources and could usefully be addressed.

A wide range of activities were highlighted by participants as their preferred means of exercise. Some participants indicated a lack of provision for some of their choices such as dancing, activities that integrate people with physical disability with able bodied people and football for women. The negative influence of widely available fast food outlets, smoking and drinking alcohol and concern for body weight/shape also featured prominently in the findings. The acknowledgement of smoking being used for stress management was perhaps unsurprising when hearing about issues that caused stress in participant's lives. What was encouraging was that although a minority of participants viewed smoking as 'cool', most saw it as detrimental to health. There may exist the opportunity to explore ways of working with those others who saw smoking as a 'necessary evil' but would like to give up if the right approach could be found.

Healthy eating messages appear to have been heard by the young people in this study: the 5 a day message being particularly well understood. Current intensive focus on weight and obesity in childhood and young adulthood is understandable, yet account needs to be taken of real world young people inhabit and the competing pressures in their lives. For example, the desire for healthy food and the importance that participants in this study placed on healthy diets is at odds with the wide availability of fast food outlets in the Borough. These outlets were seen by them as harming their health in two ways: through increased litter in the environment and by providing them with choices that were convenient but unhealthy.

Sexual health was a particular concern across participant groups. What was striking was both a lack of knowledge across the board of what services are available, where, when and to whom. There where also misconceptions about services, for example regarding the gender of staff at sexual health clinics. During interviews there was a significant exchange of information between participants about sexual health services suggesting clear opportunity to better promote what is available to young people. If the You're Welcome (Department of Health 2007) criteria were being followed successfully then it would be hoped that participants would have had an awareness of a range of sexual health services available to them including:

- Opportunistic chlamydia screening and treatment of young men and young women, with referral pathways for partner notification;
- Accurate information about the full range of hormonal, reversible and long-acting methods of contraception;
- Free condoms (with information and guidance on correct use);
- Emergency hormonal contraception;
- Free and confidential pregnancy testing and the opportunity to obtain accurate and unbiased information about pregnancy options and non-directive support;
- Referral for NHS abortion services:
- Referral for antenatal care.

Many participants were extremely complimentary about community and youth workers and services such as Triple H and SureStart. These approaches are clearly highly valued by the young people we spoke to and seen as key sources of health information and advice or signposts to such information. Doctors commonly came first for actual treatment although pharmacists were also seen as key sources of both treatment and information. GPs were the most frequent professional to be criticised by participants as not meeting their needs, often because participants felt they were not listened to nor understood. Family and friends

featured to a lesser extent. The rare reference to the role nurses and other caring/therapy professionals was also notable.

A range of useful insights was gained into what health media were effective in reaching young people. Of note was the wide popularity and large audiences reached by some of these e.g. the Metro free paper, Galaxy and Key 103 Radio stations. The common belief that young people would mostly use the Internet for seeking health information was challenged by our findings and it was encouraging that participants appreciated that not all online sources of information were reliable. Participants were generally using the Internet to seek treatment information rather than general information and advice and so needed to locate a route for getting that treatment. As participants came from marginalised groups it is not surprising that many did not have home access to the Internet. The concerns they expressed were less about access (as they knew about computers in libraries being available and so on) and more about not feeling welcome to use publicly available computers (e.g. traveller participants) or finding the amount of information through the Internet overwhelming and often irrelevant. It was notable that recent local health campaigns including leaflet drops had not reached many participants primarily because the young people viewed the leaflets as being aimed at an older population, or found them visually unappealing.

Perhaps unsurprisingly in discussions with participants about services, issues around access featured prominently. The making of GP appointments at a time and on a day that was suitable was frequently mentioned as problematic. Again other primary care studies of 16 to 18 years olds people's experiences (Kari *et al* 1997; Klein *et al* 1997) also found that young people wanted easier access for appointments with their GP and that they often found the GP to be unsympathetic or felt embarrassment when discussing intimate issues.

Modest numbers of participants had good experiences to share concerning access for example the appeal of supermarket-based medical services. Less mentioned were the lack of appointments to access Speech and Language Therapy Services and transition to adult services which reflect the mix of participants in this study as these latter issues were only experienced by a minority of them. Walk-in centres were highly valued as accessible as no appointment was necessary and waiting times were generally considered to be acceptable. Whilst limitations existed as to what conditions could be treated there, there was a preference for this type of service although there was some acknowledgement of inconvenience when being referred on from there to another service. The nationally recognised difficulty in getting registered with a dentist was also highlighted as a negative experience.

In terms of the appropriateness of the response participants felt they received in the various services, a focus on negative experiences was evident in relation to GP practices. Examples pertained to widely shared perceptions of not being believed or listened to or being actively discriminated against for being young. Whilst arguably, it is some people's nature to focus on the negative, and GPs especially can be considered to be on the 'front-line' of health services and so targets for criticism, the participants in this study were generally able to illustrate their views with recent examples. It was a common collective perception that young people were all too often treated with disrespect and commonly mistrusted. These findings resonate with a study by the Participation Education Group (1997) of 187 young people (91% were aged 11-18 years) which reported that young

people would like to be believed when they are ill and have their confidentiality and privacy respected.

There were a small number of examples of positive experiences expressed by participants concerning health service staff attitudes towards them. Employment of an advocate – often the young person's mother and occasionally a community worker - was a strategy frequently employed by participants to support them in navigating what they perceived as unhelpful services. This is interesting in relation to the You're Welcome (Department of Health 2007) criteria which indicate that there should be opportunities for young people to make appointments and attend consultations without the involvement of a parent or carer. Although this was possible, in many incidences the participants in our study identified that in order to be taken seriously they had to co-opt a parent to advocate for them with the gatekeepers to the service.

Despite the seeming dissatisfaction with many health care experiences, the majority of participants did not know where and how to complain and therefore did not. Instead our findings suggest participants often 'voted with their feet' and would try to avoid future engagement with health care services following a bad experience.

A very strong message from these findings is that young people, perhaps like any other age group, simply want to be listened to and taken seriously. There was a considerable preference for young adult specific services including one-stop-shops and drop-in centres where a range of conditions can be managed. Participants wanted staff in these services to be sensitive to their needs and for their anonymity and confidence to be maintained. Where services are not young person specific, they are to be 'age-proof' and appropriate across the life course; that is to 'treat everyone the same'. Services that integrate people with physical disability and those who are able bodied were preferred by those participants with a disability. The You're Welcome (Department of Health 2007) criteria concur that health services should be easily accessible by people with any form of physical disability or sensory impairment, and be provided in accordance with the Disability Discrimination Act 2005.

A wish for accessible services with good transport links were a strong feature of our findings. Opportunities were considered as being missed to make waiting areas such as in GP surgeries more interesting and for them to be sources of information that young people are interested in. A range of measures were suggested to promote a healthier local environment in participant's neighbourhoods e.g. extra policing and management of derelict buildings. Similarly a range of potential sources for health information and advice were suggested including town centre billboard adverts of services aimed at young people and leaflets.

In terms of publicity, the You're Welcome (Department of Health 2007) document suggests useful components to leaflets that every health service for young people should provide explaining:

- What the service offers;
- How to access the service;
- What will happen when they access the service;
- How the service is linked to other services:
- How to access other services and get appropriate onward referral;

- How to make suggestions or complaints about the service;
- Who else has access to any information that the young person shares with the service, and the circumstances under which information will be disclosed.

Whilst some locally distributed general publicity leaflets had been shown to participants in our study (Speak Up, Choose Well and Heart of Local Health), none reflected the above guidance regarding content and were little read or valued by the few participants who were aware of them. As noted earlier, these campaigns were not aimed specifically at young adult and perhaps as a consequence did not have a great impact on participants we spoke to.

At this point it may be useful to consider the update to the "You're Welcome" quality criteria published in March 2007 by the Department of Health. This is a document that outlines key principles and guidance to enable both NHS and non-NHS health service providers to become 'young people friendly'. The criteria have been endorsed by the Royal College of Nursing, The National Youth Agency and Brook. The criteria support the implementation of Standard 4 of the *National Service Framework for Children, Young People and Maternity Services* and build on the Royal College of General Practitioners' initiative *Getting it Right for Teenagers in Your Practice,* which has been supported by the Teenage Pregnancy Unit Department for Education and Skills) and the Department of Health. The criteria pertain to all young people under the age of 20 years.

#### The document considers issues of:

- Accessibility
- Publicity
- Confidentiality and consent
- The environment
- Staff training, skills, attitudes and values
- Joined-up working
- Monitoring and evaluation, and involvement of young people
- Health issues for adolescents
- Sexual and reproductive health services
- Child and adolescent mental health services (CAMHs)

Apart from the last one (CAMHs), these criteria were brought up independently by participants in our study to varying degrees which adds weight to the findings as being valuable to focus on in the Borough.

#### Conclusions

This study did not aim to generalise the findings across the wider young adult population of the Borough. Instead, what is presented is a range of views from a diverse target population demonstrating patterns of agreement where they exist.

Clearly, young people aged between 16 and 25 years are not a homogenous group. Heterogeneity may be viewed as age-related; certainly some participants between 16 and 18 years of age viewed themselves as very different to people aged 19 and 25 years. However such differences were generally related to factors such as college attendance, employment status or commitments such as children rather than age per se. In addition the remit of the project, to listen to the voices of range of young people who might be considered marginalised or seldom heard, necessitated a sample which included a range of relevant characteristics. The findings for this study must therefore be taken within this context of a diverse and heterogeneous sample.

A number of the factors identified in this study as influencing health of young people are beyond the control of the individual. Environmental and public health issues indicate the need to utilise a whole systems response to improving health and wellbeing. Barriers to the utilisation of existing facilities/services are identified in this study, together with suggestions from young people regarding how these might be removed or reduced.

The knowledge and understanding of available services and resources to support health and wellbeing was very variable amongst the study participants, with some people appearing to have very limited awareness of what is available. This suggests the need for enhancing and developing current information giving media and mechanisms targeting young people. Young people have a potentially important contribution to make towards the design and development of these media so as to make them fit for purpose.

Highly positive experiences cited by participants related in particular to youth and community workers and those working in initiatives such as SureStart, Triple H and walk-incentres. The high value placed on these personnel and services should be noted by commissioners. Less positive were the perceptions by many participants that they were not always taken seriously (trusted, believed) by a range of health workers but especially GPs and GP practice staff. This suggests there is work to be done on exploring attitudes to young people and rooting out ageism amongst local health providers where it exists.

In conclusion, participants in this study had a good understanding of factors that affect their health and an interest in maintaining and maximising their health and wellbeing. They were keen to share their thoughts, ideas, experience and expectations. This draws a distinction between understandings of marginalisation and being seldom heard. Once the research team had gained access and secured participation it was relatively easy to listen to what participants had to say. The challenge is in response. The enthusiasm of participants in this study suggests that there are opportunities to further engage young people in initiatives optimise both their individual health and that of their communities

### **Key issues for consideration**

- Age-proofing 'general' services: examining current services to ensure accessibility
  and appropriateness of provision for young people. This could include health
  services and those services identified by young people as supporting their health
  and wellbeing such as leisure and sports facilities. This would ensure that 'generalist'
  services are young person friendly. A useful strategy is to employ young people as
  'mystery shoppers' in health and wellbeing service provider environments e.g. GP
  waiting rooms, walk-in-centres.
- Specialist 'young person' services. In particular consideration of a 'one stop shop' approach to general health focused services for young people. This may include physical, mental and sexual health services and an information resource. A well advertised, high visibility service close to schools and colleges and with opening times to reflect the daily lives of young people and to include health, social care and information on resources such as leisure services
- A health and wellbeing information campaign aimed at the 16 to 25 year old age group. This could use the information channels identified in this study to ensure a wide audience, including marginalised and seldom heard young people. This may include using bespoke leaflets, the Metro newspaper and billboards as key media, but also use the valuable connections that community workers have with young people. This could increase knowledge of local services and resources and also raise awareness national health information sources e.g. (http://www.ruthinking.co.uk/). RU Clear (http://www.ruclear.nhs.uk/) and Brook (http://www.brook.org.uk/). Initiatives such as the development of information and communications media would be enhanced by the genuine involvement of young people in the process.
- Dignity and respect in care. The policy initiatives relating to the promotion of dignity
  and respect in care apply to young people. Equality and diversity audit should
  consider the impact of age discrimination based on youth and take account of
  marginalised young people who may be at risk due to a number of factors. Equality
  and diversity training should also recognise age discrimination based on youth and
  promote dignity and respect for all service users regardless of age.
- Opportunities for exercise and physical activity. Virtually all participants valued physical activity as part of a healthy lifestyle. The accessibility of leisure facilities to all young people, including those who are marginalised and socially excluded could be usefully reviewed, including new approaches to making facilities and resources accessible and affordable to all young people. This may include consideration of low cost gym/leisure centre membership, specific time slots, and safe and reliable transport options. Two relatively low cost activities valued by young people in this study were walking and dance: a well being initiative aimed at marginalised younger people and focused on street dance classes and/or walking and jogging clubs could be developed. Such resources could provide a mechanism for engaging young people in other health-promoting activities.

- Participation and engagement of young people in developing and delivering services. Commissioners and service providers could consider the wider use of innovative strategies to listen to the voice of all young people and enable wider participation and involvement. Mechanisms for listening to the voice of young people need to take into account issues of marginalisation, and use alternative strategies to listen to different voices. The role of community workers in enabling participation and engagement needs to be recognised and may have the potential to be developed further. The desire of young people to have some health and wellbeing workers of a similar age group could be further investigated, including the role of volunteer/peer health trainers.
- Healthy environments: consideration of inter-agency action focused on making environments healthier for young people. This could include promoting safer streets; the management of disused land; vermin management; safer waste management arrangements.
- Investigations of the views of other seldom heard groups within the diverse population of Rochdale Borough for example young people with mental health problems, migrants and those with learning disabilities.
- Review progress against the Department of Health (2007) "You're Welcome" quality criteria for young person friendly health

#### **Next steps**

As an investigation of young people's health and wellbeing experiences, it is beyond the scope of this study to make explicit recommendations as opposed to the more general issues identified above. These suggestions have largely come from the participants themselves. However, what is not said can also be of most. For example, there was little discussion of drug use in these interviews: participants appeared more concerned about cigarette smoking and alcohol intake. Focused research on specific health issues such as this might be useful in the future. A second observation that might bear further investigation is the relative invisibility of much of the health workforce, for example nurses working in primary and secondary care.

Whilst we have tried to emphasis strong views that are common across participant groups, we wish to stress our conclusion that young people are not a homogenous group. In the future it may be that in depth studies are needed with very specific groups/populations. This study also asked broad questions regarding experience of health and health services. It may be valuable to consider more in-depth study of particular services highlighted in this study such as GP services.

We gained an impression from many participants they would welcome further involvement in the development of health services for young people. Participants will be sent summaries of the study report (with full report also available) at their request in summer 2009. There will also be dissemination of study findings to some of the groups who participated in the study.

What remains is for the commissioners of this study and other stakeholders to discuss the key issues identified and agree a way forward that reflects local concerns, priorities and funding situation. There are some important findings that are relevant both to the development of responsive personalised health and car services, and the development of workforce that is able to deliver such services.

## **Appendices**

Appendix 1 Membership of the Advisory Group

Samina Arfan, David Bayliss Katie Beaumont Jeremy Bentham Phil Burton Nicola Crosby **Denise Dawson** Mary Drummond Glynn Hodkinson Karen Hurley Michelle Loughlin Zoe O'Neill Julie Parrish Javed Reyman Jan Reynolds Chris Spankie Chris Wright

#### Appendix 2- Interview Guide

### Health & Wellbeing Study INTERVIEW GUIDE version 1 18/6/08

## General views of health and well being

- 1. What does the term 'health' mean to you? E.g. physical fitness, free of illness, able to do day-to-day tasks, don't think about it
- 2. What factors do you think affect your health? E.g. positive/negative environment, peer pressure, health literature, money, how brought up

Some people in the study up to now have indicated that money – and perhaps lack of it affects their health. What are your ideas about that?

Other people have told us that they feel that the environment around them is very important for their health – in terms of the overall cleanliness and things like litter is important to how they are feeling.

Do you have any opinions on that?

- 3. What do you do personally to look after your health? E.g. Don't unless ill, guit smoking, diets
- 4. How do you feel about it? (your response to Q3)
- 5. If you need help or guidance about a health issue, where do you go? E.g. friends, family, internet, magazines, PCT sources, school nurse, clinics
  - a. Which sources are the most used and why?
  - b. How effective/useful are these?
  - c. How accessible/ suitable are they to you and other young people?
- 6. When was the last time you had a health need and how was it addressed? E.g. self-help, clinic, GP, family advice, peer advice. If they used a service:
  - a. How did you know about the service?
  - b. What was your overall experience like of using the service (from first contact through to aftercare if relevant) and how might this have been improved? E.g. location, staff confidentiality, environment
  - c. Do you feel that the service met your health needs?
  - d. If needs not addressed, why not? (e.g. unsuitable opening hours)
  - e. What needs were unmet and how might they have been met?
  - f. Did you express concern about your needs not being met and to whom?
  - g. If the service was not positive why do you think you were treated like that?
- 7. Do you currently have any health needs/concerns and how are you thinking of dealing with them? E.g. Won't address them, see GP, NHS Direct, ask family/peers, specific service
- 8. If you had a concern/complaint about a health service, where would you go?
- 9. Have you heard of PALS (Patient Advice and Liaison Service)?
- 10. Do you think there should be a service which would address your information requirements in relation to your needs? E.g. go down, phone up

11. How would participants wish to access such a service?

## <u>Understanding and experience of locally provided health and related services</u>

- 12. Describe to me how you think health care is provided locally? E.g. where, by who, how?
- 13. Who do you view as being health care providers? E.g. doctors, nurses, voluntary agencies
- 14. What do you know about local services available to you and anyone you care for?
  - a. General services
  - b. Young people specific services
  - c. How would you find out about local services?
- 15. What knowledge and experience do you have of accessing health related services locally?
  - a. For yourself
  - b. For someone you care for/know
  - C
- 16. What do you understand by the term 'PCT' or 'Primary Care Trust'? E.g. explain the term and establish degree of appreciation/understanding
  - i. What do you think the PCT does?
  - ii. Which services are provided by the PCT and how?
  - iii. Relationship with other service providers/commissioners

Do you have any suggestions about what facilities there should be for young people and health in your area? E.g. leisure facilities.

#### Scenarios:

If you had a health issue concerning the following where would you seek info/advice etc (and views of these, same as above) – pregnancy/family planning, diabetes, smoking, heart disease, alcohol intake.

Do we need this now that we have the definite scenario below? I was thinking two definite scenarios to replace this question.

## Experience and views regarding alternative communication strategies in relation to locally provided health related services

In general what information sources are participants aware of/have they made use of?

- o Where/how did you access information concerning local services?
- What media were used and what is your view of these? E.g. leaflets, text, video clips, adverts
  - How useful/helpful was it?
  - How could it be improved?

Say the health services wanted to get a specific message through to young people about a particular health issue – say for example binge drinking.

What would be the best way for them to get that message through to young people in this area?

Would you notice/make use of health related info from the following routes and why?

Internet

Supermarket

TV
Local radio
Local newspaper
Magazines
School/college teachers
Notice board.
Friends
Parents/Family
Workmates

Any others?

## Appendix 3 - Feedback from Celebration and Findings Validation Event

## NHS HMR Younique Voices Celebration and Findings Validation Event March 3<sup>rd</sup> 2009

Following feedback from the study advisory Group and observations by the research team, a set of further questions were put to the participants at the event as a means of checking out gaps in the data. Once each question was put to the participants, they wrote any comments they had on post-it notes and displayed these around the room. These are presented below:

**TRANSPORT** i.e. how does this affect your use of health related services/leisure services in the Borough?

- If it is near the home is better then because usually most people go by walk. The transport is too expensive so when I go to gym I go by walk
- Walk-in-centre is quite far, ask mum to drop me off. Doctor's is quite close –OK.
   Leisure centre just up the road from my house but don't like walking dangerous (gangs). Dentist in Littleborough very far, usually late to appointments end up charging us
- Transport doesn't affect it. No problems go by car and doctor's and dentist are close by
- Local so it is easy to walk there. Like walk-in-centre. Can also walk to leisure facilities such as the gym
- Good about it is that I don't have to get a bus or anything, just 10 mins walk. Dentist
  though is far and getting a bus will request knowing of the time of the bus that could
  be very earlier or later than your appointment and taxis cost a lot
- My mum would take me by car so I have no problem with getting to the health centre but sometimes my mum's car might break down. Sometimes when you try to get your dental care it takes you a long time
- If someone has to get the bus they might be late for their appointment and because of traffic so it should be placed somewhere it is more to get to. Also expensive
- Good about is that I don't have to get a bus because just 10 mins away
- I think they should put maybe a free NHS bus coz sometime when you've an
  appointment you are late because of the bus. Get a main bus that only takes you to
  the place you need to go
- Yes it's cheap. I don't care
- It help some people who are using bus like go to school
- If the transport was easier and cheaper it will effect on people using for health centre and leisure centre because some will be a big problem to go to one of them

**ALCOHOL & DRUGS** i.e. little raised at interview – why? Is it an issue that affects you or young adults?

- Yes the alcohol and drugs affect the health and wellbeing. Now the teenager take a
  lot of drugs and drink a lot of alcohol which is not good for them and for the society
  because most teenagers become homelessness and poor from drugs and alcohol
- Is a BIG ISSUE!!! People think it's normal nowadays! It's easily available people smoke weed publicly -hate the smell and strong passive. Smoking more common

- Alcohol & drugs affect us even though we don't take it because people tend to go violence
- YES
- Alcohol is an issue (BIG ISSUE!). Children are not wise enough to know the dangers. All kids experiment. However when addicted do not know how to avoid/leave alcohol
- It does affect the people who take them as well as the people around. They could be told through TV and shows how drugs and alcohol are bad for our health
- Alcohol and drugs actually its decrease the health and also who the person used drugs or alcohol make problems and crimes
- I think they should be counselling groups to teach more about use of alcohol and drugs to the young people
- Yes it does affect your health in a negative way. Young people feel as though it helps them as they think it drowns their sorrows but it doesn't. they think it looks good
- Yeah they slow you down, make your heart work more when you're working out.
   Make you lazier. Make people turn ugly
- No!! Only drunk people on street are dangerous and look scary and drugs people are also dangerous
- Alcohol and drugs affect us even though we don't take it because people tend to go violent and would also tempt you to take them when you are at their age. Smoking also affect when someone smokes and you breathe the smoke in

**GYMS** i.e. should they be for specific groups or do sessions for specific groups and ideal cost?

- Yeah good for fitness. Yeah because we don't pay much
- Gyms should be free because some other people can't afford it
- Young people should get free gym services. If not have a certain time for young people to get free specific time. Near my house. 50% discount £1.50
- They should have special leisure for teenagers and I think is too expensive. So they
  must have gym facilities for teenagers. I like to be cheaper or make good sale for
  teenagers like £10 per month which encourage teenagers to go and visit gym
- I think maybe they should have groups maybe like for young, old or disabled people and they should be at least free
- Leisure centre cheaper for students!!! Have ladies only, but for young girls don't like it when there's a lot of old people. Keep us informed on new things and offers
- They should have special for teenagers. They should be free. They should be modern and good
- Everybody should be together so they feel they are equal
- Gyms should be free for people who are on benefits and maybe cheaper for all.
   Available for teens after school times
- Dance facilities *nb:* very popular with the girls
- Everybody else or be in a group. Feel are equal
- Should pay about £2-4. should be separate girls and boys

WHAT MAKES A GP APPROACHABLE? i.e. why open up to some not others and why are some better?

- It would be easier if the doctor would be able to see you as soon which they do according to my opinion. My doctor is the best. He gave me a prescription for gym that was worth discount after checking my BMI
- They are friendly helpful and kind
- I have never been in hospital in this country but my GP he good and him talking to me
- Some GPs are better because they are patient
- A doctor that only sees to less people so he can always check you up when you're not well. Make sure they have time to talk to you
- Aaarghh!! Hate 'em! Can't communicate with them. Good GP = listen to what you have to say, let you feel confident to tell you what's wrong. Gives you a lot of time – tell you what's common to people your age
- You get along the GPs when they're of the same sex and when they are older than you, that makes them good GPs
- Hate them. Disrespectful. They aren't approachable. Can't communicate with them. Not serious/professional. Make you feel low about your illness
- New health centre. Good treatment for people
- New health centre in Town. A bigger health centre

# **LOCATION OF HEALTH SERVICES** i.e. does location matter, where is best and how best provided?

- Prefer it a little way away from home, not too far (so local people that know don't go blabbin' to others) but somewhere safe... not isolated
- Somewhere near to where I live so that I go to my appointment in time, because if you have to get the bus you might be late because of traffic
- I don't mind travelling if it concerns my health I mean its life!!! But if it is near that would be better
- I prefer in town centre
- Near Falinge flats
- I think it good if it is in your area. You don't to worry if you have a problem and if it too far you have to get bus and if you get bus sometimes you can be late
- Prefer it nearby but not as noticeable
- I think they should put more local health centres in the local area coz sometimes you get late becoz of traffic
- More local so if you're in survival danger then you can reach their fast enough. No because my mum can take me
- Location doesn't matter as long as we get friendly and reliable advice from those who are professional
- I prefer in Rochdale centre because it is near my home and all people to go to Rochdale centre so it is good for all the people

## LOCAL HEALTH CAMPAIGNS/LITERATURE i.e. aware of them, seen leaflets, read leaflets?

- Yes we do read them because it is important and its giving us information
- I don't about them, I know a little bit

- Sometimes if it looks attractive and it relates to me. Short but sends the message out.
- Well the leaflets of NHS look good and they help to know more about NHS
- I read the information if it concerns what I want to know, but if its small writings I don't really bother because it looks boring, but of its big writing and good styles of fonts, then it will be interesting
- Yes we do get leaflets through the post and I read them sometimes
- I didn't have anything about it e.g. I didn't have a leaflet, advert, card, form, letter or any other facilities
- Yes they get posted through my door. Yes I do read them. Gives you tips on your health. Tell you where your services are. More standing out
- I know about them a bit. I show some leaflets. I read them.

## **WALK IN CENTRES** i.e. appeal to males and females, know services they provide, how know?

- I think we need more information about the walking centre; I didn't use it and I don't know what they provide there
- Walking centres are useful. I would like to know what other services they do provide whereas I had just went in there with my mum when I wasn't feeling well. I didn't actually know what they were going to provide
- We need more information about walking centres because some other people don't know what walking centre is!
- Want to know more about walking centre because I don't know it and have never used it before
- I think they should give more information about walking centres because many people does not know more
- Yes we want to know what a walking centre is all about
- I need more information about walking centre because now it is the first tie I heard this name. I don't know the difference between GP and walking centre
- Walking centre is good for everyone
- Yes because we should be able to know what the service provides. Sometimes you
  feel uncomfortable with a male GP. When I went to the walk-in-centre I had to wait 1
  hour to be seen for a minor problem. But sometimes it depends how much people
  work there. Also they don't check you proper and just tell you to have paracetamol
  (GPs)
- Walk-in-centre Not really confidential need more privacy because they ask what's wrong sometimes it's embarrassing. Sometimes when you're finally seen to over an hour, tell you to book appointment with GP! Not fair ②. In some cases really helpful but hate waiting BORING!! should make something to do so waiting is fun ③

**ONE STOP SHOP** i.e. would you like one for young people, what would it be like, where locate?

- I like the idea. I like to be in town centre. I prefer to everything that we need to use
- Great idea! © Would like one specifically for young people. Would like it local Rochdale. Have people who treat you properly - helpful instead of stubborn. Have it more confidential – so others don't hear about why you're there

- Yes it is a good idea. Should be located where it is not as noticeable. Should be accessed to everyone even young people
- Yes it's a good idea for one stop shop dentists and doctor. Go in one place and noone knows what you're going in for
- Go in one place and no-one knows what you go in for! Have it not far from where you live. Have one of them.
- Yes it would be more confidential, placed in somewhere quiet
- I like idea of one stop shop, it good to help people. I like hospital
- I like idea of one stop shop. I like it to have in the town centre. I like to have inside it everything that about health
- Yes because everything is altogether so you can get different treatments in the same building. Near your house. It will have all the things you need for health
- That's a good idea. More people will use it. No-one will be shy/embarrassed to use it. Would be nice if located next to the Infirmary hospital.

**TELEVISION** i.e. what can be taken from TV to help reach young people with health info, what make TVs in GP surgeries more appealing, where locate them?

- Advertise things for health the ones that don't tell you what to do but give you advice on what to buy. Waiting areas.
- Dancing on ice, news
- X-Factor, posters and examples of magazines
- X-Factor, Britain's Got Talent, posters and newspapers
- TV shows like Waterloo Road or EastEnders or Coronation Street, the ones that give info on things which happen in real life (e.g. Frank adverts) – scare you and also is an eye opener
- Through hip hop, dance and drama
- Catchy adverts talking about health. Someone good looking talking about health. Someone famous.
- Advert, health message like "stop smoking"
- They should be putting them at the notice board and they should put information to stop
- X-Factor, Britain's Got Talent, posters and magazines
- The drugs which have a negative effect on you so it stops some people from having them and shows the consequences
- Catchy, colourful, slogans, music (hip hop) famous people, someone good looking (catchy)
- Hip hop to represent health, scary advert that makes you think about your health, advising, the consequences that you may have if you don't take the precautions
- Adverts, news, health adverts in waiting area
- Soaps EastEnders

#### **INTERNET SITES FOR YOUNG PEOPLE** i.e. know any, visit any, which?

• Don't know any. Yes I would. So sometimes of there is a minor problem I can check it up myself and see if I could help myself get better. Will like to know some.

- When I have searched on the internet in relation to health I have found the NHS is useful. I don't know of any others but I would like to. Otherwise I would just go on Google.
- I don't know of any. I would like to know one because its useful to us young at our age
- Smoke free, NHS, Blood pressure, BMI, peak flow
- NHS can give you information
- We would like more internet sites where young people can get information from because some sites are boring to find information from
- No I don't know any site
- No I don't know any websites in the internet about health. I need more information about it.
- The NHS website I think they are good and they help to know more about the NHS
- Internet Google search illnesses usually complicated info hard to understand or too long can't be bothered reading it. Usually ask family what's wrong.
- Google search (use it now and then) but don't use it much. Ask family.

## **PROJECT FINDINGS** i.e. how get these to you and your peers?

- Message booklets/magazine, leaflet, get letter about meeting and attend
- Through leaflets, radio
- Email, letters, phone call, advertisement, leaflet, talk to you about, Facebook, come in to groups
- The best way is by leaflet, advert, letter, website internet, radio advert, some people talk about it (I prefer this one)
- Through someone coming to talk to young people in the community
- Through TV and adverts, through magazines, newspapers, posters, leaflets
- In think the best way is checking NHS websites service or searching projects
- Post, email, TV, phone, personal letter
- I think the team should become to the community or come to the area to talk to us and give more encouragement to young people
- You can ask your parent, I think that the best way because they can give you ideas
- Include a leaflet and put word searches and comic writing on it. A letter sent by your name

#### References

Acton T; Cattrey S; Dunn S; and Vinson P (1998) Gendered health policies and a womens' movement: the gypsy case. *Health and Place*, 4(1), 45-54.

Ahmed S; Hussain M; and Vournas G (2001) Consultation with 'hidden' and hard to reach groups, Consulting Hard to Reach Groups, LARIA seminar, 2001.

Calnan M and Gabe J (2001) From consumerism to partnership? Britain's National Health Service at the turn of the century. *International Journal of Health Services*, 31 (1), 119-131.

Fazil and Quishom (2007) An exploration of the explanatory models of illness amongst Pushtuun communities living in the UK who are high attenders in general practice. *Diversity in Health and Social Care* 3 (3), 171-181.

Fenton S and Sadiq-Sangster (1996) Culture relativism and the expression of mental distress South Asian women in Britain. *Sociology of Health and Illness*, 18, 66-85.

Gibbon M (2002) Doing a Doctorate Using a Participatory Action Research Framework in the Context of Community Health. *Qualitative Health Research*, 12 (4), 546-558.

Griffiths S (2002) Addressing the Health Needs of Rough Sleepers: A Paper to the Homelessness Directorate. London: Stationery Office.

Holland K and Hogg C (2001) Cultural Awareness in Nursing and health care-An Introductory Text. Arnold Publications, London.

Miles MB and Huberman AM (1994) *An Expanded Sourcebook. Qualitative Data Analysis.* Second Edition. Sage Publications. London.

National Co-ordinating Centre for NHS Service Delivery and Organisation (2000). *National Listening Exercise: Report of the findings.* NCCSDO. London.

Parry G; Van Cleemput P; Peters J; Walters S; Thomas K; and Cooper C (2007) Health Status of Gypsy and Travellers in England. *Journal of Epidemiology Community Health*, 61, 198-204.

Popay J and Williams G (Eds) (1998) Researching people's health. Routledge, London.

Scottish Executive (2002) Good practice Guidance Consultation with Equalities Group. www.scotland .gov.uk

Whitley and Prince (2005) Are inner cities bad for your health? Comparisons of residents and third parties' perception of the urban neighbourhood of Gospel oak. Sociology of Health and Illness, 27 (1), 44-56.

Wright N Tompkins C Oldham N Kay D (2004) Homelessness and health: what can be done in general practice? *Journal of the Royal Society of Medicine*, 97, 170-173.