

REPORT

COMMUNITY HEALTH SERVICES ENGAGEMENT PATIENT OUTCOMES

BACKGROUND

Tower Hamlets Clinical Commissioning Group (THCCG) decided to engage with the community in order to develop patient outcomes that will be used to select a provider of community health services and to monitor their ongoing performance.

The engagement process, detailed in full below, was managed by an independent researcher but was commissioned through three community organisations in Tower Hamlets.

This document outlines the results of the engagement.

OBJECTIVES

The purpose of the engagement process was to:

- Gather feedback from patients, carers and families about the type of outcomes they would like from community health services;
- Compile a list of any service ideas and requests that were highlighted during the process of gathering patient outcomes.

METHODOLOGY

The engagement process, managed and led by Kate Melvin, an independent researcher, took place during February and March 2015.

Recruitment of the Sample

There were three Phases of recruitment that ran concurrently. In total, 40 adults were interviewed, seven young people between the ages of 15-18 and seven families (parents and children). Respondents came from across the borough in all Phases i.e. E1, E2, E3, E14.

All respondents were selected to meet the following criteria:

- They were using a service/s provided by the Community Health Team ;
- Patients who were receiving community health services in the 'long-term' and 'short-term';
- Patients who were housebound as well as those who were not;

- To ensure a wide range of co-morbidities ;
- To ensure a wide age range;
- Both male and female.

Phase 1:- Individual Interviews

55 patients were initially selected by the Community Health Service Patient Experience Team. Following recognised research protocols, all were sent letters with an 'opt-out' slip and a stamped addressed envelope so that those patients who did not wish to take part were provided with an opportunity to withdraw. A copy of the letter is attached in Appendix I.

The research team then followed up those patients who had not 'opted-out' approximately ten days later. In total, ten withdrew from the study. Subsequently, the lead researcher, using the same criteria as above, selected fifteen patients to be interviewed. All 15 were telephoned to ensure that they were willing to be interviewed.¹

Subsequently, this list was passed over to Account3, a local community organisation, who had been commissioned by THCCG to carry out 15 interviews. During the process of interviewing, two patients on this list withdrew and two more names were passed over to Account 3.

In addition, the lead researcher carried out a further nine in-depth interviews with patients selected from the list.

Thus, a total of 24 in-depth interviews were carried out. It should be noted that there was a wide range of co-morbidities and the patients selected varied widely in terms of their levels of health and mobility.

- Services used²:
 - Community Health Team (for integrated care and generic services)
 - District Nursing
 - Physiotherapy
 - Occupational Therapy
 - Reablement
 - Specialist Community Diabetes and Education
 - Specialist Community Diabetes and Education – Dietetics

¹ This step was included since care needed to be taken, given the potential health of those included in the sample.

² This list of services also includes those that had been experienced by those participants in the focus groups. It is also important to note that the services used were self-reported and that a number of participants were not always clear as to the services they were using. Finally, it was not always possible to distinguish service provision, such as physiotherapy or occupational therapy, that took place in the secondary setting rather than in the community

- Adult Continence Service
 - Community Health team - Mental Health
 - Health Psychology - Community Health Team
 - Foot Health
 - Continuing Health Care Team
 - Community Cardio Vascular Team
 - Adult Respiratory Care and Rehabilitation
 - Cardiac Rehabilitation Service
 - Health Psychology Services
 - Advocacy
 - Interpreting Services
- Gender:
 - 13 x male
 - 11 x female
 - Ethnicity³:
 - 10 x Bangladeshi
 - 8 x White British
 - 2 x Mixed Race
 - 2 x West Indian
 - 1 x Turkish
 - 1 x Irish
 - Age Range:
 - 31-89 years
 - Involvement of carers:
 - In nine of the interviews the (informal) carer of the patient was interviewed either with or on behalf of the patient. (Please note that the demographic details listed are, in all cases, those of the patient.)
 - Employment status:
 - 8 x housebound
 - 5 x not working at time of interview
 - 11 x retired

Phase 2 – Focus Groups:

³ Ethnicity was again self-reported

The second Phase consisted of a series of focus groups which were organised and facilitated by Healthwatch. They recruited for the project through their membership. The respondents (or those for whom they 'cared') who took part in the focus groups had various medical conditions and were receiving a wide range of services including mental health provision⁴.

- 1 x focus group with 8 adults:
 - 4 x White British
 - 3 x Bangladeshi
 - 1 x Black British
 - 7 x female
 - 1 x male
 - Age range of patients between 35-80 years
 - 2 x (informal) carers
 - 3 x unemployed/4 x voluntary work

- 1 x focus group with 8 adults:
 - 8 x Bangladeshi
 - 8 x female
 - Age range of patients between 24-72 years⁵
 - 2 x (informal) carers
 - 4 x unemployed/2 x part-time working/1 x retired

Phase 3:- Interviews with Families (Parents and Children) and Young People:

THCCG additionally commissioned Headliners to carry out interviews with parents of children who were receiving service provision and, additionally, young people.

Parents: Parents and families were sourced from two Tower Hamlets schools and two focus groups were held comprising of four parents in each group.

The sample broke down as follows:

- Medical conditions – using a range of community health services:
 - Autism
 - Crohn's Disease
 - Leukaemia
 - Diabetes
 - Eczema

⁴ See above

⁵ One of carers in this group also cared for her nine year-old son who attended school

- Services Used⁶:
 - Community Children's Nursing Team
 - Children's Speech and Language Therapy
 - Specialist Children's Service - Specialist Clinics
 - Specialist Children's Service - Child Development Team
 - Autism Spectrum Disorder Assessment Services (ASDAS)

- Age range of children:
 - 4-12 years

- 1 x father; 7 x mothers

- Gender of children:
 - 7 x male
 - 1 x female

- Ethnicity:
 - 1 x African
 - 7 x Bangladeshi

Young People: Given the time framework of this project, it was not possible to source young people between the ages of 16-18 years from community health provision patient lists. Thus, they were initially sourced locally through contacts within the Specialist and Universal Children's Community Services and within Learning and Achievement, London Borough of Tower Hamlets. However, the young people who were contacted in this way were severely ill and this made recruitment difficult. Nonetheless, three young people were sourced in this way.

Locating young people who may be using community health provision for short periods provided a number of challenges but through local networking via organisations both in the statutory and non-statutory sectors such as Mile End Athletics Club, Look Ahead Supported Housing and Weavers Adventure Playground, a further five young people were sourced by the researcher leading the project.

In total, four individual, in-depth interviews and one focus group, comprising of four young people, were conducted.

The final sample for young people was, thus, as follows:

⁶ Similar to Phase 1, a number of parents were not always sure as to which services they used and again this list is self-reported

- Medical conditions:
 - Charcot-Marie-Tooth (Muscular Dystrophy)
 - Leukaemia
 - Epilepsy
 - Microcephaly
 - Range of conditions following a car accident including nerve damage
 - Range of conditions caused by intensive sport

- Services Used :
 - Community Nursing Team
 - Physiotherapy
 - Occupational Therapy
 - Community Paediatric Continence/Adult Continence Team
 - Child and Adolescent Mental Health Service (CAMHS)

- Gender:
 - 3 x males
 - 5 x females

- Age range:
 - 15-18 years

- Ethnicity:
 - 3 x Mixed Race
 - 2 x Bangladeshi
 - 2 x White British
 - 1 x Black British

Interview Process

Since there were a number of organisations that had been commissioned by THCCG to carry out the interviews, it was important that there was a level of consistency in terms of the structure of the discussion. Hence in consultation with THCCG, a Discussion Guide was developed, a copy of which can be seen in Appendix II. A copy of the outcomes to be tested can also be found in Appendix II.

The format followed that of unstructured qualitative interviews in which the guide is used as only a framework for discussion so that interviews are open-ended, flexible and responsive to what respondents have to say. Thus in essence, it is an 'aide memoire' ensuring that, on the one hand, all themes are covered but, on the other, the discussion allows for spontaneity and full exploration of the issues, providing an opportunity for respondents to

bring up issues of interest or concern to them. During the interviews the draft outcomes were shown to respondents and their opinions and views elicited.

All participants were provided with a Participant Information Sheet and asked to sign a Consent Form. This can be seen in Appendix III.

Interviews lasted between 45 minutes and 1.5 hours and were recorded with permission. Only one interviewee was reluctant to be recorded and, in this case, extensive notes were taken. All participants in this study were paid £25 as a token of thanks for their time.

Interviews were carried out by Account 3, Headliners, Kate Melvin and Nurun Nessa.

Analysis

The digital recordings of the interviews were subsequently transcribed verbatim and analysis of the data was carried out by the lead researcher.

Essentially the analysis of the transcripts and notes followed the established procedure of the National Centre for Social Research's Framework of Analysis initially developed in the 1980s⁷. This is an iterative process as follows:

- Listening to recordings and reading through transcripts/notes
- Marking and coding transcripts/notes to themes and issues and storing these to facilitate inspection and for use in support of analysis
- Development of emerging analyses
- Refinement of analysis through a debrief presentation to the client

METHODOLOGICAL NOTES

The following should be taken into account when reading the study findings.

- It should be noted that the sampling process in this study was not consistent across the three Phases. In terms of the individual interviews, the process followed established research protocols and for the interviews with families and those with young people a more direct, 'networking' approach was used. More significantly, Healthwatch advertised through their membership for participants and although this raised a number of methodological issues, in this case and for the purposes of this study, this was felt appropriate.

⁷ Ritchie, J, Lewis J, McNaughton Nicholls, C, Ormston R, (eds) *Qualitative Research Practice: A Guide for Social Science Students and Researchers, Second Edition*, Sage, 2014

- It is also unusual to have such a wide range of ages within focus groups and not normally recommended in qualitative research. However, this was inevitable given the time and budgetary constraints.
- It should be emphasised, too, that the purpose of the study was to gather patient feedback and perspectives from those within the general population who had experience of community health provision rather than from specific groups or cohorts. Efforts were made, as detailed above, to ensure there was demographic representation within this, as detailed above but the author of this report is aware that there are other specific groups in the community who may have particular perspectives on community health provision. For instance, those from the LGBT community or those who have complex disabilities and who might be labelled, 'housebound'. Such groups may well have been included in the sample by default but their specific characteristics were not part of the inclusion criteria.
- It is suggested, therefore, that if THCCG consider that there are gaps in knowledge about particular groups then further more specific research should be commissioned.
- It should be additionally noted that it was not possible to include the views of members of the Somalian community. However, it has been suggested that focus groups with this community will be able to take place at the Somalian Health Conference in April 2015.
- The research brief suggested that a division should be made between participants receiving community health services in the long-term and those receiving services in the short-term. However, this raised a number of issues. Although, at one end of the spectrum, there were patients who were clearly using provision only temporarily and, at the other, were those who clearly were in receipt on a more permanent basis, the lines were often blurred. In part, this appeared to be due to the uncertainty of the duration of health condition/s but it was also the case in a number of cases that a patient might be accessing different services for different lengths of time simultaneously. Further, a number of both adults and young people with long-term conditions may only have been using community health provision in the short-term at the time of interview but might well have used them over many years for shorter or longer periods of time. More interestingly, from the evidence and in terms of themes that emerged, the opinions and perceptions of participants did not seem to be affected by length of provision. Indeed, it was notable that emergent themes were often common across the board. Finally, as is discussed more fully in Section 1,

a number of patients believed they should be receiving services on a longer-term basis than appeared to be possible.

- Many of the participants struggled with the wording and meaning of the outcomes that this study was designed to test. Thus, interviewers took care in interviews not only to ensure consistency of meaning but, more importantly, to allow the desired outcomes of community health service provision they received to emerge from discussions through probing rather than being presented with phrases that might otherwise have been seen in a vacuum.
- All interviews, as already noted, were transcribed verbatim but it must be emphasised that interviews were undertaken in respondents' first language and a good number of the interviews needed to be translated into English so that they could be analysed. In addition, in some interviews a translator was present.
- Although many of the themes evident during discussions cut across ages and medical conditions, it was considered more sensible to separate the findings into four sections in line with the broad parameters as suggested by THCCG. Section I covers analysis of the interviews in both Phase 1 and Phase 2 whereas Section II and III deal with analyses of the Phase 3 interviews.
- Section IV details the specific responses to the suggested 'outcomes' made by each group of participants. It also summaries the key suggestions made by participants that link in to these responses.
- All interviewees were assured of total confidentiality and every effort has been made to ensure that participants cannot be identified through any reference, direct or indirect. In line with this, quotations where possible have been annotated with brief demographic details of the respondent.
- Finally, the author would like to thank all those who helpfully supported the project in sourcing the appropriate sample with particular thanks to the Community Health Services Patient Experience Team. Most importantly, thanks should be given to all those who gave up their time to take part in this study.

MAIN FINDINGS

INTRODUCTION

The following report details the main themes that emerged from discussions with participants. As the research brief dictated, the focus of the discussions was on 'outcomes' of care rather than on the details of patient experiences and patient journeys⁸, although it was evident that 'experiences' and 'outcomes' were often inextricably linked. The following report captures and is based on many aspects of provision but it can thus only represent snapshots of experience. Given this and noting the nature of the sample, this study is merely able to report on the parameters of thought and experience but at the same time, raises important issues for provision.

It was clear that the majority of respondents welcomed an opportunity to discuss their treatment and their own desired outcomes. However, as noted earlier, many found the outcomes suggested and designed by THCCG difficult to discuss initially. Although this may have been partly due to the wording of the proposed outcomes, it was also clear that many found it challenging to make the necessary connections between these outcomes and their own provision. A further explanation also emerged from some of the interviews which indicated that participants appeared to find it hard to comment since they felt it was 'outside their field of expertise' and their predominant concern was 'getting better' and improving their everyday lives alongside the day-to-day issues, such as reliability, punctuality, respect and so on that surrounded regular health provision. In this regard, too, it was clear that many respondents appeared to be more concerned about areas of care that were covered by their (formal) carers rather than about the health provision per se.

In addition, difficulties in discussing the outcomes also seemed, in part, due to the fact that opinions appeared to be very much clouded by expectations of service provision. These may well have been based on their own previous experience, or that of others. Interestingly, younger respondents appeared to have fewer difficulties.

Almost all respondents nonetheless, agreed that the outcomes as listed would certainly achieve an optimum service, but many thought they were simply 'bland' and 'meaningless' and attempted during interviews to establish caveats or more realistic outcomes that were of greater pertinence to them.

It was interesting to note that, although the views of a number of patients were evidently based on negative experiences, it was clear that a number of respondents felt they were unable to complain to either the community health staff or any other statutory body.

⁸ There were, for example, many discussions and thoughts about other aspects of care provision such as GPs, secondary care and local authority care. Given the focus of the study, these have not been reported in this document. If further information is required, it can be sent on request

It was additionally notable that it was generally not possible to distinguish between different aspects of services within community health provision. This was not only because patients themselves were not always clear about the names of the services they received but also because it became clear that the underlying themes and patterns were frequently similar.

From the evidence, too, it appeared that patients and families did not and perhaps could not see community health provision in isolation. The majority of respondents, particularly in Phase I, discussed their health and wellbeing and their health and social care holistically. Similarly, for many respondents 'care' in their eyes came as a package and local authority care was not necessarily distinguishable from NHS provision. Even when local authority care was seen as a 'different' service, to achieve the suggested outcomes it would be necessary for all providers to be involved and to work together. It was therefore interesting and somewhat paradoxical to note that many patients additionally considered that a proportion of the 'outcomes' appeared to be beyond the remit of the NHS.

SECTION I - VIEWS FROM ADULTS

Participants interviewed in this project had a broad range of co-morbidities which included those with long-term complex conditions as well as those with seemingly lesser medical conditions. Acknowledging the severity of their conditions a number of patients and their carers found it hard to talk about their health and potential 'health' outcomes either in the present or in the future since they were clearly aware that recovery was not going to be possible.

'I don't know because he's got long term conditions and it won't get better, just to make sure he's managing himself and everything is going smoothly, or when he needs the care everything is in place, but we can't say he's going to get better anytime soon, that's the thing' (Carer of Male, 74 years, Bangladeshi)

'Nothing is going to change for me...There is always at the back of my mind, one day you might get up and walk but it is just something in you...miracles could happen...I could fall again and my neck would come back but you are just clutching at straws' (Male, 57 years, West Indian)

'I think it is impossible. They can't do nothing for me. I am ill, I will only get worse!' (Female, 41 years, White British)

As interesting were discussions that focused upon perceptions of whether patients were short-term or long-term users of community health provision. In addition to the complexities of definitions as noted in the Methodological Notes, a good number of respondents felt that the health professionals were, at times, overly keen to ensure that their medical conditions were 'short term' whereas they believed this was not necessarily the case.

'I've only got you for a certain period of time so I am going to wrap this up in this certain period. Forget about the fact that you may need an extension especially when it comes to physio...I think with physio especially it is kind of like, I've only got two months with you and I am too busy to see you' (Female, 24-72 years, Focus Group)

'Usually even if it is long term, they try and make it into a short term thing...almost like they are pushing you out' (Female, 35-80 years, Focus Group)

'It is like having a number and they can't wait to get rid of you - off the list - I have experienced it often' (Female, 35-80 years, Focus Group)

Experiences of health and social care provision varied but at the same time tended to cloud perceptions of both their present and potential care.

'So you know there's good and bad in everything. It's just that you know when you have a bad experience I suppose or certain things don't go according to plan. I'm not saying they're not doing their job properly, no they definitely are but having said that you know it's with everybody, they're overworked same as in the hospital. You've got less nurses so at the end of the day, they're trying their best but obviously the quality can't always be met' (Carer of Female, 71 years, White British)

Nonetheless, across the board, many seemed to be pleased with their present provision in terms of the actual care provided. Most, for example, acknowledged that overall the staff were extremely overstretched and when they were critical of the service, the criticisms did not tend to focus on the professionals themselves.

'I don't think they will give me accurate treatment because they don't seem to have much time and they seem to be oversubscribed always' (Female, 24-72 years, Focus Group)

On the other hand, a range of concerns and recurrent themes about aspects of provision emerged from discussions that, in turn, led to suggestions for potential outcomes of care. Notable were the difficulties a good number had seemingly encountered in accessing care, particularly local authority care, but more pertinent, were the allegedly long waits for community health provision.

'The physio for instance I've been waiting for her to come back well this was the end of January she came we're near enough now, the end of March so that's two months and I still haven't heard. She told me that she would be ordering a couple of things and I've not heard from her since. You just feel like, you're banging your head against a wall sometimes. And you have a hard enough job as it is. You haven't got the time to be contacting people. At the end of the day, more communication but when people say they're coming, to turn up or if they can't or they haven't got whatever they was going to order, just to let you know. A phone call is nothing' (Carer of Female, 71 years, White British)

'But one thing is he goes to the foot clinic, one of his feet were infected, she's been referring him to the foot clinic for some time, for about four months now, there's some kind of problem there but no one has come back to him, we've been going to the doctor and she says she's sent letters after letters. He's basically been waiting for that for some time' (Carer of Male, 74 years, Bangladeshi)

The impact was also seen to be exacerbated when a referral was slow to take place.

'After taking medication over the few years for no reason and after my community therapy, I realised that all these problems could have been resolved if I had been referred to community therapy earlier....and where your GP does not make the initial

call, you are delaying that referral that actually hinders your treatment or can have a negative impact on you' (Female, 24-72 years, Focus Group)

More concerning, perhaps, was a worry that asking for extra care may result in a loss of any present care:

'But I'm scared to ask because the minute I ask they'll come and look at my package again and they'll take everything off. That's the honest truth I'm scared to ask for that half an hour even a week because that means someone looking into your package. As soon as someone looks into your package I know what they'll do, they'll decide, right he doesn't need this no more, he doesn't need this, he doesn't need this. But actually, I do' (Male, 32 years, Bangladeshi)

The impending changes in local authority care provision was a concern for many especially since it might mean the loss of carers they knew well and 'trusted' but participants felt they were unable to discuss this problem with professionals other than those from the local authority, which would suggest a perception that provision is siloed.

'We are worried that our care will change - I mean we have to look after each other but we need the care too. We do laugh about it as if you didn't you would cry...sometimes they don't turn up and I think it will all change again' (Female, 79 years, White British)

Certainly, the loss of a 'trusted' professional was often seen as being detrimental to the patient, not least since they tended to feel they were in a vacuum and often seemed unclear as to why it had happened:

'We heard from the GP that apparently they stopped doing the service, apparently District Nurses don't come to see patients anymore, I don't know why. There wasn't any particular reason; they said they stopped doing it for now' (Male, 31 years, Bangladeshi)

There was additionally evidence of a particular need for long-term users of provision to be able to build relationships with community health staff. On the one hand, this provided comfort but, on the other, it enabled a level of trust to be built. In an ideal world, having the same familiar face was cited as being beneficial for patients including those suffering from dementia.

'So it would be helpful if there was just one person' (Carer of Female, 80+ years, Bangladeshi)

'But the only thing is, is that every time it is a new person. So you cannot get connected with somebody if one person comes and then two or three people share the job...'Cos if someone new comes they don't know the name and they don't know

that person and there is too much changing...but you can't blame them for something that is not their fault' (Carer of Female, 31 years, Bangladeshi)

In one instance, a community nurse had visited the same patient for eight years and when they left, the family were unquestionably affected:

'The knowledge of the job and the training, and also the way she spoke to people, is like she is the one who understood everything. She wouldn't judge you whatever you said but she will listen; she will try to comfort you, even when (XX) had her back done. There was a big accident in the hospital. It was a weekend when I called her, she did call me back, and she tried to comfort me, because I wasn't taking it easy. Because it wasn't something that we should take easy' (Carer of Female, 31 years, Bangladeshi)

The need for reliable and consistency of provision was also stressed:

'If the District Nurses make an appointment, they should stick to it or call to say if they couldn't come. It's the least they should do - to have the common courtesy to cancel. They will say they don't know, they might come, they might not - they don't even tell you on the day' (Female, 24-72 years, Focus Group)

'I say, come after 9 and sometimes they forget and I will be waiting for them (the District Nurses) and they don't come...I don't know if it is negligence or what but they are short staffed...They are nice and I get on very well with them but I get angry as after all these years, they forget I am here' (Male, 57 years, West Indian)

Evidently, considered as important was a need to strengthen communication and co-ordination between teams and this was identified by almost all participants as an area for improvement. Although they recognised that the few staff who visited them were overstretched, many drew attention to the frustration felt and problems caused by poor communication.

'To be truthful with you, that's one thing I'm a little bit not happy about, communication because they come and do my Mum's blood pressure for instance and then another nurse will come and say we don't need to do the blood pressure because it's been OK for X amount of weeks because sometimes its weekly visits and sometimes its fortnightly visits. But I don't feel like there's any communication between them because you're either doing the blood pressure or you're not. Feedback, communication, obviously proper handovers wherever you've been and I'd even be doing home visits myself to make sure things were put in place' (Carer for Female, 71 years, White British)

'The physio man won't know what medication I'm on, my GP would know. They all need to liaise with each other and understand what someone is going through. So

like the physios not in touch with the district nurses, the district nurse's not in touch with the physio. But what it seems like, some people think too far up their head that they think that they are the authority. That they can make decisions - it doesn't matter, no sorry you don't need this, and it's wrong' (Male, 32 years, Bangladeshi)

'Inter professional communication should improve. There should be better communication between all the services instead of us repeating it all the time. We are becoming the paper and email they should be sending to each other...they need to communicate with' (Female, 24-72 years, Focus Group)

Of note, was the experience of one participant who was registered on the Tower Hamlets Integrated Care Package:

'I think it is working and better than before when it was just this particular thing they were going to focus i.e. caring for the treatment and then the other one doesn't know what the other one is doing - at least in the ICP everyone seems to know what this hand and that hand is doing and they can really focus on one direction' (Carer of Male, 76 years, Mixed Race)

But it was the impact of the lack of good communication that appeared to some to be the most stressful part:

'It does affect people. If the communication improved, the patient will be stress free and will have less pressure on them when they have to repeat themselves over and over again to the same providers' (Female, 24-72 years, Focus Group)

'I went to my own GP and the nurse I was told would flush the Hickman Line but then they don't do that there and I was told I should be going to the doctors! One says one thing and another says another thing and you are in the middle and you don't want to rock the boat as if I do I might not get seen at all' (Female, 57 years, Irish)

Discussions about 'communication' were not solely focused upon communication between professionals and, although there was a minority who believed they did not want to be 'involved' in discussions about their care, many did.

'I think it is more the Care Co-ordinator needs to be asking the patient what is needed and what is required... like the patient will be needing some support with caring and with personal care needs and I think they should be asking that' (Carer of Male, 76 years, Mixed Race)

One patient, for example, complained how she had repeatedly felt awkward about asking questions:

'More understanding of the patient and the patients' needs - sometimes you can feel you are nuisance - we will tell you what is happening don't interrupt and sometimes you say, well the hospital says, bla, bla, bla and they say, well you are not at the hospital now and this is the way we are doing it....Like you feel like you are, not pressurised, you are afraid to say anything as you will be shot down - I have been there for years at that clinic, perhaps it depends on what sort of a day they are having, I don't know....' (Female, 57 years, Irish)

Similarly, there was a sense in many discussions that 'honesty' was equally valued:

'I expected after going to physiotherapy that my illness would be reduced and I would get better...They weren't clear how long it would take. Every two weeks I went, they would tell me to do this or do that but I was expecting them to tell me what my problem is and how to treat it. They didn't...and there was not much explanation. Now the whole body is affected by pain and I am worried that I will be physically less able' (Female, 24-72 years, Focus Group)

The results of a lack of effective communication, too, could also leave patients feeling again that they were in 'no man's land':

'If it is once a week they come that is fine but after they have gone, they just leave you and that is it....the last young lady came she gave me no date when she was coming again and then an ambulance turns up and I can't go as I have not dressed but I didn't know they were coming, there was no letter and she did not tell me - I haven't seen her since' (Female, 71, West Indian)

'You don't hear again unless you ring up...I am only guessing that they go to the GP to let them know and then contact you but you don't know - no-one says anything' (Female, 35-80 years, Focus Group)

More pertinently, however, was the need for 'caring' professionals who had 'understanding'.

'At the moment, the occupational therapist is supporting me, you know I mean? She sits there, she talks to me, she is more like a friend I know than an occupational therapist, even though she is one, you know I mean? The way me and her talk to each other, we'll be laughing and cracking, like a friend, I feel comfortable. Someone just to help you and support you, someone who is kind and sensible and trustworthy. 'Cos if I cannot trust someone who is going to help me out? So I am going to have someone who is going to be there, who is trustworthy' (Male, 34 years, Bangladeshi)

'Whoever does that kind of job needs to be a caring person. Now, I am not telling them to connect people with their emotional needs, that is going to be too much for

them to carry on. Sympathise with the people with that type of condition' (Carer of Female, 89 years, White British)

'The lady from reablement did come up and when she came in...she is very kind and sweet. If she had time, she would sit here and have a chat with us, it made a difference' (Female, 89 years, White British)

There were calls for greater professional training not simply for specific areas such as dementia care but more generally:

'I would make sure they (the patient) they are happy with their services when they leave by speaking to them nicely. When they speak to you nicely it sometimes makes the ill person better - some staff don't speak to you nicely, they just want to see you for the reason you went there' (Female, 24-72 years, Bangladeshi - Focus Group)

'As long as they are caring and they treat you with respect - that is all you ask and they turn up on time' (Female, 79 years, White British)

'I think they should be more professional...I think they get too complacent...too lackadaisical about the jobs...it is agency too, here today and gone tomorrow...and then it is the attitude of, you mind your own business....like you knock on the door, will it be very long before I am seen? And then it is just, we will call you we are ready. Then there will be somebody coming round in the afternoon and they turn up in the morning - it doesn't matter if I was going out or not' (Female, 57 years, Irish)

'When I went (to the foot clinic) I came out in tears as the woman was so rude to me...I have been told to come back but somehow you are left in mid-air not knowing whether to go back or not' (Female, 35-80 years, Focus Group)

A number also drew attention the lack of respect that was awarded to those with disabilities:

'I think a lot of people don't listen to people with conditions - not those in a wheelchair people with mental conditions are capable of answering questions if they are asked' (Carer of Male, 33 years, Mixed Race)

'Once you have someone ill in a family, you are not connected with anything. And once you have a wheelchair you can't go in shops...you can't even go on public transport as, as soon as the ramp could out, none of the people like it - it interrupts other people's business' (Female, 31 years, Bangladeshi)

'I would like to make sure that people dealing with older people and people with disabilities that they had some awareness training as there is a stereotypical view...understanding the social model of disability and not continually looking in

terms of the medical condition that makes you disabled...and never judge a book by its cover' (Female, 35-80 years, Focus Group)

A particular complaint heard was that healthcare professionals were seen to 'take it for granted' that those who were receiving care at home would welcome them whenever it suited:

'Because I am disabled, it doesn't mean that I am sitting on my backside watching the telly all day...I think they do it mainly to people they know are at home because they think they are sitting at home crocheting or watching the telly' (Female, 35-80, Focus Group)

'The wrinkly cripple they expect to be at home full time and therefore they can turn up when they like as you will be there, you are not going anywhere are you and I have actually had that said to me - they don't expect you to have a life outside the house' (Female, 35-80 years, Focus Group)

Overwhelmingly evident in almost all discussions was a need for healthcare professionals to view patients holistically. Emphasising that health and social care needs were so often inextricably linked, patients found it hard to separate local authority care provision from health provision or indeed from problems such as inadequate and accessible housing. However, these aspects of life were also often seen as being 'part and parcel' of having a 'positive quality of life' or being 'socially' integrated or 'connected'. As one 48 year-old Bangladeshi male commented, the essential factor was to 'get the key to open the door'. Thus, if it was not purely a medicinal problem, then the whole situation needed to be taken into account.

'They need to address the patient's needs like if they have any other social issues, housing issues that they should provide to that patient...it is emotional support too and other advice and support the family might need' (Carer of Male, 76 years, Mixed Race)

'It is about ensuring the right team is with the patient...so if they need medicine but if they need anything else, look at everything' (Female, 48 years, Bangladeshi)

'But the way I see it, there has to be someone, not just for me, but for anyone when things get difficult...everyone needs a bit of a hand. That's what I think them people are there for, the occupational therapist, the District Nurse, the social worker any of them, all of them, it is all the same' (Male, 34 years, Bangladeshi)

Again, respondents' call for 'holistic' care tended to be based on the experience of the impact when service provision had very much been in isolation:

'We waited for the nappies and waited and it affected us all but my sister-in-law most as she is with my Mum, she has children, her children go to school - it has to be arranged before hand, how they will go to school and be picked up' (Female, 24-72 years, Focus Group)

'So when I got the help initially, I was reassured that my son would be helped but I am worried about him and he hasn't improved and I am worried that if something happens to me, what will happen to him as I do everything for him. It affects me mentally....It would mean I would have control over my situation' (Female, 24-72 years, Focus Group)

For one participant who had been in a wheelchair for nearly 40 years his experience had been particularly positive:

'I think they (community health staff) have helped me see the bigger picture. I became attached to them, you get advice and then you become like a family... like with the carers too, you develop a bond...I don't have to tell them what to do...if I am down they all say a few words to make you feel like everything is cool, all right....'
(Male, 57 years, West Indian)

Other participants or their carers drew attention to the effects of long term illness such as depression:

'I used to be up and fancy-free doing the things that I did and now I can't and it is so soul destroying...we had a (counsellor) but he disappeared, he only came once'
(Carer of Male, 76 years, Mixed Race)

'I am very, very angry about what happened and sometimes I just sit there and cry, cry, cry with my condition - I don't know how to sleep, I am going through hell and I shed tears...I am so stressed and can't be bothered to eat. What I want to do I can't...they say I should be walking better but they would never own up to their own mistakes...there is no one' (Female, 71 years, West Indian)

In particular, some patients drew attention to the need for social contact which was unquestionably viewed as something that very much contributed towards a better quality of life:

'Well she doesn't really socialise with others because she can't really come downstairs in the flat but we are in the process of sorting something out where she can but this is like nearly three years down the line so that's nearly three years wasted so how she was then would have been a bit better if she could have had a bit more quality of life but because there has been no stimulation it's just brought her within herself like she has a little conversation but not how she used to be. Well there

is really no care involved to be truthful with you, I suppose there would be if she was going to somewhere like a daycentre' (Carer of Female, 71 years, White British)

'I would love to be able to get out and about and be independent of people - not looking at the telly, not going out unless I am taken...we used to have loads of friends but they are all popping off now - they are all dying' (Female, 79 years, White British)

'I go out and meet people at the Day Centre and it breaks up the day and I play games and it takes some of the stress off and you feel good and you can at least come back in with a bit of joy' (Female, 71 years, West Indian)

'You look forward, tomorrow when I wake up, I am going to have a shower, I am going to have a tea, in the afternoon someone is going to take me out. You look forward, you are ready the whole day' (Male, 32 years, Bangladeshi)

Awareness of the need for respite care or alleviating the stress on families when they were caring for patients particularly with long term conditions was also seen as being an integral element of a good service. A number called for greater emotional support for patients and carers and the importance and the role of the family was stressed time and again.

'To be honest like I said, my family has been my support, they have always been supporting me. My family means the world to me that is the main thing' (Male, 34 years, Bangladeshi)

'Inside there is a family, children and husband, that makes good health. This gets very helpful for myself. The help of your family helps you to get better' (Female, 48 years, Bangladeshi)

Others called for greater support for informal carers and the need to consider them in any assessment of a patient's needs not least since the impact of being a carer might well affect the patient and other members of the family.

'I'd say they should have to work around us and not us work around them and I don't mean that disrespectfully. But we have a routine which is day in, day out so it has to be what is convenient for you not for them' (Carer of Female, 71 years, White British)

'They need to understand their clients and their needs and to listen to the family and parents when they say something...All those professionals think that they know more than the parents and they do all the things their way...and they should talk to the families about the services' (Carer of Female, 31 years, Bangladeshi)

Apart from anything else, the patient's family were perceived to have the greatest knowledge about the patient.

'And I must say, don't get me wrong, because I'm so actively involved in my mum's care no one can pull the wool over my eyes do you know what I mean' (Carer of Female, 80+ years, Bangladeshi)

'Whoever works in that field they need to understand their clients and their needs. Also to listen to their families when they say something. 'Cos in this, I can guarantee you they don't listen to the parents. All those professionals think that they know more than the parents, and they do all the things, their way' (Carer of Female, 57 years, Bangladeshi)

A further concern of many, especially carers, was the sometimes long wait for aids and equipment echoed in a number of discussions:

'Even these days, if you ask them for something which the District nurse should order, you have to keep on asking and asking and asking before you get the thing. And it is not a nice experience if you have to keep asking them. Like last time I waited all year for (the) sleeping system. I don't like asking people continuously for one thing' (Carer of Female, 31 years, Bangladeshi)

'With the occupational therapist, I'm not too pleased with them because last year sometime, I asked for a ramp outside and small ramp inside, because there is a lady that comes round on Tuesday, when the weather's nice she takes out mum on the wheelchair. Tomorrow we've got an appointment at the clinic for her Warfarin test and it's difficult to get her out in the wheelchair, now I received a letter from the grant had gotten through and it's just down to the workshop and when they're going to do it but no news' (Carer of Female, 81 years, Turkish)

'Another thing that comes to mind when it comes to the district nurses, because mum has a delivery of pads every three months and last time the company had delivered the regular size and we said look we want large, she says we just deliver, you have to speak to the district nurses and they have to phone us and request the large ones. I've rang them a couple of times but I've got no feedback, it's been two weeks, what they've done with the delivery, and no one gets back to you' (Care of Female, 89 years, White British)

Information about and access to appropriate health and social care provision was seen by many to be a necessary prerequisite for good quality provision but some felt they only heard about provision through 'word of mouth'. One respondent thought there should be a department specifically set up to enable improvement of the service.

'There should be, not a complaints department, a liaison department where everyone can openly and honestly say things and they can take information in and bring about changes. I know there are complaints services and I don't know how and if they are doing much but there is something like that where everyone can put their complaints in or suggestions in' (Male, 74 years, Bangladeshi)

'I didn't know these services existed. I didn't even know the carers existed. A lot of people are not aware. All they think is when I'm ill I'm going to hospital, I'm going to stay there, when I come out that's it and if my family can't look after me, I have to go to a care home. That's what many people got in their heads but you can live independently. You can. I've seen myself and it takes time. These services are there but not many people know about it' (Male, 32 years, Bangladeshi)

'I do think that for carers they should be able to find out about the Carers' Centre...it is free and you can have lunch and meet others there...I mean, I didn't even know about it until two months ago and I have been a carer for 20 years' (Carer of Male, 33, Mixed Race)

Finally, language difficulties were also cited as a particular barrier for those whose first language was not English.

'They are there when you need them; the only difficulty will be for someone who can't speak English, that is why I would recommend them to have the right person they can trust, or someone there to help them if they cannot speak English' (Male, 34 years, Bangladeshi)

'The staff are rude to my response when I ask for an interpreter...even phone lines can be used for interpreting...just be nice...try to help the patients' (Female, 24-72 years, Focus Group)

SECTION II - VIEWS FROM PARENTS

In discussions with parents of children who were receiving community health services, the majority of those interviewed spoke highly of a number of aspects of the community health provision they had encountered. However, in so doing not only did they make clear which were the key aspects of provision that were important but also drew attention to areas where provision was considered to be lacking and, thus, where 'outcomes' should be focused.

In the first place, it appeared that any past negative experience that parents had encountered seemed to dominate both subsequent experiences as well as their views on provision. In one instance, one respondent argued that they were now simply unwilling to allow their child to be treated by the London Hospital again and, instead, insisted on being treated at Great Ormond Street Hospital.

'Because he has experienced, the worst experience he has ever had in this lifetime with the London Hospital...they said they treated him like an animal' (Group Discussion, Parent, spoken through a translator)

It seemed that the 'start' of their journey into provision was critical and some parents complained about not simply slow diagnosis but that they had to carry out their own research as well.

'But when we moved here we waited a long time (for Speech and Language Therapy)...the waiting list is just hilarious. The diagnosing process is such a long , long wait...I had to do my own research online and help my child' (Focus Group, Parent)

A strong call was also heard across the focus groups with parents for greater understanding and support when diagnoses are given:

'As parents, we don't understand because we especially need to understand what is going on in his body, (and) there should be more medical help available...there is not much. There is the diagnosis. They just say, your child is autistic, challenging behaviour, and then they have to go time to time to the doctor but I think they need more specialist help and more explanation' (Focus Group, Parent)

'And being in denial on top of that...Because no one wants to face the reality of what ever diagnosis you are going to get...' (Focus Group, Parent)

For one mother, the understanding and support that had been shown to her was clearly very much appreciated:

'What made my experience goodis for them to be a people's person...because when you are dealing with an illness like Crohn's, it is a very hard, difficult time and you need someone to be understanding and open and warm... (instead of) being too technical and too professional and too by-the-book and things like that. You know throwing too many big words at somebody in a situation that they are finding very difficult, it is not a good thing because it is just confusing and rings alarm bells. Because we are humans, we are people, we have feelings and we don't want you to come across robotic. And I think that's where people tend to shy away from going to medical professionals and things like that because they don't want to deal with that kind of disconnection' (Focus Group, Parent)

There was, though, a balance between explaining things clearly and not treating parents as if they were 'stupid'.

'They understood that this is so new to us...we don't know anything about it so they have to basically treat us as if we are not stupid but children basically. So you have to explain it as clear and as simplified as possible so that an individual can grasp it ...I have never felt as if, you know, that I am looked at as if I am dense or my race had something to do with it. They've always been super, super nice and basically did everything beyond their means and that is the honest truth' (Focus Group, Parent)

Others talked about needing support and help with the ensuing 'stigma' post diagnosis.

'There is always a stigma about special needs...they (the professionals) don't see that...you are faced with the reality which is a completely different thing...Just tell us what is going in reality rather than hoping and expecting too much and then you face, Oh your child is not 100% accepted in the community'(Focus Group, Parent)

For a number, too, greater support was felt to be needed long after the diagnosis stage. A particular emphasis was placed on the need for 'emotional' support.

'We parents, we need that emotional support...They (health professionals) understand what I am trying to say. They know our feelings' (Focus Group, Parent)

'They (health professionals) came home and they supported me. Basically, they were like a safe net for me because....my emotional was really below zero. It is very difficult to see your child is having a problem and you always compare....at the early stage of diagnosing your child, parents need more support because if we are not happy I can't make my child happy and I cannot cater for his needs. I am talking about the psychological health for the parents...that is the first thing before the child' (Focus Group, Parent)

Attention, for example, was drawn to the plight of parents living with a child with complex needs:

'It is such hard work with him all day and night, 24 hours. If she had somebody helping around her, because she is a single mum, then she can have a little rest...Because at the end of the day is her time - she has to be with him but she needs a life as well' (Focus Group, Parent, spoken through a translator)

'These people are suffering outside of the clinic and every experience they have should be the best because they want to come out feeling as if they are doing something good and they have done the best for their child and I don't think they are feeling like that' (Focus Group, Parent)

Others commented upon the need for a 'personal' approach at all times:

'What I would want them to find important is knowing, first and foremost, this isn't a patient, no this is a person, not a person with cancer...simple things like when you go for your appointments, you greet them, you say, how are you, do you want a cup of tea? That instantly eases the anxiety or whatever the emotion you might be feeling....because every appointment, even it is a just a routine appointment, you never know what they can turn round and say to you...always a nice tone, even though you are delivering a negative thing...what will make a good community nurse or any professional individual is to basically have the patience, have the love...you need to have that people person, that patience..., what other ways can I get that child to do what I want them to do and make it more fun...' (Focus Group, Parent)

The importance of 'listening' to parents about their children was thought to be integral to this. A number complained not just about their local GP who did not listen in their view but other more specialised staff as well.

'I think they should listen more to the patients. I am sure they have loads of people to see but then they need to sit down and think, what is that we are doing? Is there anything that we are helping? Like the other day, my community nurse all she did was take a list of what the doctor said that I saw on Tuesday. What was the point of that? She is not doing anything to help me....If they (GPs/nurses) are disregarding you for it, then I feel quite like...hang on a minute don't patronise me thinking that, I have looked after my child all this time. I've brought him to this place because of that I feel he is not emotionally or he is not physically or mentally healthy...if you patronise me, I am emotionally unhealthy' (Focus Group, Parent)

'(Listening) is very, very important...especially for the professionals so they understand what you are going through, they help you with your child...' (Focus Group, Parent)

'But what about the core of treating people with respect? Talking to them, listening to them. You are not going to get someone being physically, mentally, or emotionally healthy, if you are not going to talk to them, if you are not going to see what the parents have gone through' (Focus Group, Parent)

There was, too, a minority voice that was concerned that there was a duplication of service provision:

'I just don't like explaining the same thing three times a week and there was nothing she (the community nurse) could give me that would help my child. It was a waste of time for her and waste of time for me - even now she is coming every week and I just think what is the point?' (Focus Group, Parent)

There also seemed to be a view that although services were seen to be good there was a belief that there were not always enough of them and even though the referral process appeared to be straightforward, the waiting times both for appointments and waiting to be seen were sometimes unacceptably long.

'The services are all right, excellent in my opinion...but they are giving diagnosis but they are still not catering enough for these children. Like there isn't enough special needs schools' (Focus Group, Parent)

'The long waiting list. I think that is the most...everybody says the waiting list' (Focus Group, Parent)

'I've noticed appointment wise, they give you an appointment and you know a patient takes about an hour why give appointments like ten minutes?' (Focus Group, Parent)

And this could be particularly difficult for families with children with complex needs.

'We were waiting with my young son three hours for an appointment to see an allergist. One problem is when the temperature in the room gets really warm, they get really flared up. He got really irritated...he was tired and he was hungry...' (Focus Group, Parent)

'Especially if you've got an ill child...that is the worst. I'm physically drained trying to entertain this child. He's physically and mentally crying...it is just not good...' (Focus Group, Parent)

The need for access to appropriate information at appropriate times was also an issue that emerged from discussions. Whereas some suggested that there should be information in the local newspaper about conditions such as autism to inform parents, particularly if they were new to the country, others argued that there could be a range of media to provide

parents with information, such as DVDs. More generally, there was additionally a call for training for parents about such conditions.

'More training for parents about autism. How to communicate with the child, it is the most important thing because they go to school for only three hours so the parents are the main teacher' (Focus Group, Parent)

Parents should also be informed about access to groups they might attend for support not least since isolation and other difficulties faced by parents with children with medical conditions might just be alleviated:

'You just have to be vigilant and be aware of your surroundings because you have to take that responsibility yourself - that information is not going to just come on your lap...and advertising more of groups...when you have been recently diagnosed with whatever it is...so that when you are going through the drama you can go and be with someone that you can relate to...' (Focus Group, Parent)

'I think the only thing that could be added is maybe more groups where families can meet other families...kids could meet up with kids like themselves' (Focus Group, Parent)

'And they have got a complex situation...and then you are opening up doors to other disabilities like depression...so not only are you dealing with a person with Crohn's you are now also dealing with the parent or the supporting person with a depression because they don't know what they are entitled to or because they have either got a language barrier and they don't have the family support for instance. So what I really recommend that we have these groups that these parents can go to and with people they can relate to' (Focus Group, Parent)

Finally, the language barrier was seen by many to be a large issue for parents and appeared to have a number of significant implications:

'A lot of the problems are because of communication...I think the next generation will be fine but obviously the generation before that, English is still their second language and it is very difficult to convey what they are trying to say and that is where the problem is. Both parties are frustrated' (Focus Group, Parent)

'Every time he asks for an interpreter, he feels that they never support him and his family as in what he is trying to convey. Half of it is they won't discuss what he is feeling - it is always interpreted, trying to explain the medical side' (Focus Group, Parent, spoken through a translator)

SECTION III - VIEWS FROM YOUNG PEOPLE

The young people interviewed in this study had a wide range of medical conditions that included those with life-long conditions as well as those who had suffered a sports injury. As such, their experience of community health provision was substantially different. It was particularly noticeable, for instance, that for those who had spent long periods of their lives in and out of hospital, the experience could affect, either positively or negatively, their perceptions of all provision. However, it was equally evident there were a number of clear themes that emerged from discussions that cut across medical conditions either temporary or permanent. Reactions to the proposed 'outcomes' were, in turn, based upon these themes.

Across the board, the young people agreed that in terms of the community health provision they had encountered, the staff had been helpful and nice - a feature that was particularly important:

'I would say the people who came to see me were really friendly and I just enjoyed having them around and taking care of me - that is what makes things really important - you are interacting with other people especially when you are vulnerable and you don't want somebody who is going to treat you in a bad way, who is going to be friendly who is understanding what you are going through and tries to support you so think for me I had a pretty good experience working with them' (Male, 18 years, Bangladeshi)

'The actual people, when they do come, when you finally get to see them, yes, they're really, really nice. They are really nice. But apart from that, obviously I don't really see them that much' (Female, 16 years, White British)

Part of being considered 'nice' and 'good' certainly meant an expected level of understanding and care. For the young people interviewed who had had sports injuries an understanding of their plight was a particular issue.

'I was at my high point at 13/14 and I got hip problems and then I had to drop athletics as I was doing my GCSEs...it is kind of still disappointing seeing people who compete against nationals as I used to race against them and we were at the same standard' (Female, 18 years, Mixed Race)

But, for others too, the sense of being cared for seemed very important.

'They were really understanding and we had loads of conversations and I had one District Nurse and we had loads of laughs together - he would say, it doesn't matter how it happened and we all go through tough times and even when he wasn't supposed to come to see me, I found out he was only coming to see me as he felt

sorry for me and he cared about me so that was really actually touching - he wasn't supposed to but he said that he didn't want me - I told him I could look after myself and I had no idea he was supposed to stop working with me about three weeks ago and he told me he was actually doing it out of his own good will - but it is good to know there is good people out there' (Male, 18 years, Bangladeshi)

'Hire the right people - so if you are going to have someone cold and ruthless who doesn't pay attention to little details and doesn't care about people in general you are going to have a bad time - I feel sorry for the patient when that happens and I do think that it happens' (Female, 18 years, Mixed Race)

What also appeared to be key for the majority, was a greater, more holistic understanding of the individual. Again, for those with sports injuries, their future was very pertinent but this was naturally an issue for almost all respondents.

'They never really mention how it might affect you... they could say, what about for this muscle in the next year because that might happen or this might happen... they don't seem to think about your life at all really' ((Female, 18 years, Black British)

'No, just make sure that you actually do take the whole situation and health of how the person is feeling - they have a life, a family' (Female, 15 years, White British)

Consideration of the family was also critical.

'It would be nice to even be offered things...like they go sometimes, has she been to respite, and I am like no-one has ever asked me...you know just sometimes to be asked for certain things - that is all' (Mother of Female, 16 years, White British)

Nonetheless, a fear was expressed that if too much was asked for, the young person might well be taken into care:

'Well do you know what then, if you can't cope with cooking, seeing to your kids then, we'll take them, we'll put them in foster care then if that's the case, if you can't cope. Even when I felt really... like over Christmas, I was really bad and I'd just had enough and that, even like sometimes when I was getting upset and that, you know when you just think sometimes I'm too scared to say, I can't cope, thinking that they will go, well we'll take the kids off you then' (Mother of Female, 16 years, White British)

For young people, too, education was a focus. A number of the interviewees had had to withdraw from key examinations but for some the enforced lack of education could be devastating:

'I want to know what is causing the pain and what can be done so it doesn't happen again and having the injuries is constantly kind of straining on the training and on my school work and stuff so I want to sort it out rather than going back and forth'
(Female, 18 years, Mixed Race)

'Basically I missed the whole of Year 5 due to being ill. I have missed a big part of my education and I am still trying to catch up on it all now...They could have sent work to home but they didn't. I feel like the school has given up on my education so I have given up on myself' (Female, 15 years, White British)

'When I have had hours of chemo I simply can't do anything...it is like, finish' (Male, 17 years, Bangladeshi)

Clear, honest and respectful communication was felt by many to be a key component of a good service.

'There's things I don't like about nurses is like their age difference... not between them and you, but how they would treat a little child and then to me. But they'll still treat me like I'm that little child - you should be truthful and not so blinded' (Female, 15 years, White British)

'I would say they should communicate, keep the patient informed as to what is going on behind the scenes at things they might not be able to control - they should be made aware of things - so if they have certain things in place, the patient should be made aware of any potential delays or complications that might happen - they might say ignorance is bliss but maybe they have a right to know' (Male, 18 years, Bangladeshi)

'It can be the more information the patient has the more reassured they feel - that is one of the biggest things they should be pushing towards, reassuring the patient that everything is going to be OK instead of raising panic and that might just make things worse. Even if it is as bad as it can be, they should try and ease the patient's pain'
(Male, 18 years, Mixed Race)

Part of the dialogue with community health professionals should, it was argued, also be two-way:

'I mean, no physio has ever said to me, do you think this is working for you - is my treatment good for you?' (Male, 18 years, Mixed Race)

'It was not as clear as I would have liked it to be...They used long works and stuff. I could (ask) but I just felt I was a burden, 'cos they know what they are doing so I might as well let them...' (Female, 15 years, Mixed Race)

'I mean the whole thing about questioning the professional about what they are doing right and what they are doing wrong keeps you quiet in a sense...you tell them where it is hurting but you feel it is a bit worse and aching more and you don't want to have to say your methods are bad as that is rude' (Female, 18 years, Black British)

However, whereas a minority complained of the high turnover of staff, others felt that reliability and consistency was an issue.

'It wasn't that they were not helpful, they just took their time to get back to me ...wasting my time, telling me this and that and didn't get back to me for two months. It just pissed me off as then I had to wait even longer and now I have to miss out on this season as well' (Male, 18 years, Mixed Race)

'I must admit (XX) is the only one that we've seen that's been her nurse for a certain amount... every time we only see them for say, once a year, not even that really. (XX) is the only one that does chase things up and then she does get back to me. Everyone else never gets back...They are murder to get in touch with' (Female, 16 years, White British)

'I think it is probably hard but if you had the same physio then you don't have to explain yourself again and again and you can build up a relationship' (Female, 18 years, Black British)

One respondent complained that they had not received the equipment/aids at home they had been promised but more common was a sense that being let down in this way could have far more subtle repercussions for individuals with chronic medical conditions:

'Obviously, if everyone followed through what they say to you, because whenever I see them, they all promise me, oh yes, we'll do this for you, we'll do that, and then once they've gone out that door or once we've walked out that hospital after what they've said they're going to do, what they are not going to do. I know obviously it's not as if they just see one patient all the time. I know they see hundreds of patients, but they just literally forget about everything, and then they tell you how important it is for her to do this, and how important it is for her to have this machine and use the machine, and all that and then no-one even phones up to just check up whether she's using it. Trying to get in touch with them lot, it is hard to try and track them down, even when you leave messages' (Mother of Female, 16 years, White British)

There was also a call from those who had had sports injuries that the community health team should have, for example, physiotherapists who were specialists so that they understood sports injuries.

'The NHS physio just gave me bad options - they suggested fusing the bone which would have reduced my flexibility - my specialist said that would have been the worst option' (Male, 18 years, Mixed Race)

SECTION IV - SPECIFIC RESPONSES TO SUGGESTED OUTCOMES

SPECIFIC RESPONSES TO SUGGESTED OUTCOMES	FURTHER KEY SUGGESTIONS TO SUPPORT OUTCOMES
<p>A: Adults</p> <p>It was unquestionably challenging for many participants to make connections between their own experiences and the suggested outcomes. <i>'I mean what do we know about things like this...it is a load of old toffee...we are old and all we need is a little bit of care and that is it'</i> (Female, 79 years, White British). <i>'At my age, what are they going to achieve for me?'</i> (Female, 57, Irish) Interviewers were also asked who had written them</p> <p>In part, this appeared to be because of the wording and the seemingly 'meaningless' and bland phrases. <i>'You couldn't disagree with any of this could you? I would like it to say, a good quality of life, but this is what you expect the service to be offering isn't it?'</i> (35-80 years, Focus Group) <i>'It is just an overarching statement of intention for all the services they deliver - you couldn't disagree with any of it, you might want to tweak it a bit - of course you want to be cared for in a safe environment, of course you want to feel supported if you are a carer...'</i> (Female, 31-89, Focus Group). It was also argued that the bullet points were very <i>'ambiguous'</i> and down to interpretation. <i>'They don't actually tell me anything and I am not sure what they are getting at'</i> (Female, 74 years, White British)</p> <p>While a number felt it was simply impossible to disagree with any of them, others argued that they were <i>'on the right lines'</i>. However, efforts were made in discussions to provide some substance to them and to link them with their own experiences of care and <i>'reality'</i>. Clearly, most agreed if these <i>'outcomes'</i> were met, the patients would benefit enormously</p>	<p>Key throughout was the importance of treating each patient holistically ensuring that their health and social care needs are seen as a whole.</p> <p>The more holistic view of the patient and their needs should be applied in all spheres - for instance, centres where those with physical disabilities could do something of interest to them rather than simply sitting indoors - <i>'something to make the brain expand'</i></p> <p>A key additional outcome was thought to be: To ensure patients and their views are respected at all times and to avoid the following complaint: <i>'You are like a number - you are actually like something that is going along on the conveyor belt - not seen just passed along, somebody not looking, keep going, keep going, God help older people...You are not a number and you should not be scolded for what you are saying'</i> (Female, 57 years, Irish). In particular, appropriate respect should be awarded to those with disabilities</p> <p>Families and carers must be considered as part of the provision of care and, in particular, more support (including emotional) should be given to (informal) carers</p> <p>Consistency of staff was considered to be important and if there were to be staff changes, then patients should be informed in a timely manner. Many expressed the need to build relationships with community health staff to provide <i>'comfort'</i> for example but it also enabled trust to be built up - this was seen as particularly</p>

Further, it was evident that responses to the 'outcomes' clearly depended upon the health of the patient. Many, for example, only appeared to think about 'outcomes' in the immediate term since their main concern was to 'get better' and 'get on with their lives'.

There was also a majority view that although many of the outcomes were appropriate they should not be and were not within the remit of healthcare professionals.

Some also could only conceptualise the outcomes within a medical and healthcare context and did not consider that the remit of CHS provision should venture beyond this

There was additionally a query as to what was meant by the generic term 'CHS' in terms of who and which professionals were going to help people have a positive quality of life or increase their independence and so on

Some drew attention to the changes in the NHS and were seemingly confused by the new integrated healthcare teams and which service was delivering which provision. *'It is a muddle and we don't make the best use of the services as we don't know where they are coming from and they don't seem to work together but they are meant to be in the new integrated team'* (Female, 35-80 years, Focus Group). This appeared to affect their perceptions of the outcomes in that they were unsure about which 'team' would be doing 'what'.

It should also be noted that a number of participants were, at the time of interview, particularly concerned about the future of their care, particularly that provided by the local authority, and the impending changes to care provision and this tended to cloud their view of both expectations and 'outcomes' of care.

important for patients with dementia.

Involvement of patients in decision making when appropriate but patients should be aware of what is happening at all times

Staff should work together with patient's families and carers more consistently and effectively to produce a high level of 'co-production' with staff and patients, meeting, talking and communicating to come to an agreement about care. Staff should also be given training in this process.

More important was a request that patients should be asked what their needs were rather than assumptions being made. *'I think they should ask what we want...Then you could ask for the rails you need and ask for a social worker - I need one and I wouldn't ask for one - my old one has moved...they should have replaced her but they haven't'* (Female, 41 years, White British)

Certainly a call was made for patients to be consulted and not to feel awkward about asking questions about which some patients complained. Critical was that patients must feel listened to and understood

Acknowledgement was needed of the impact of poor communication on patients, families and carers

In one Focus Group, the introduction of Care Plans was seen by many as an excellent idea in that it was viewed as a 'step by step' guide to the full condition of the patient. It would help other professionals visiting, would militate against mistakes being made since everyone would know what had been done previously and would provide the patient and their family/carer with a level of security in terms of knowledge. Potentially, it might also contribute to a higher level of independence among patients since they would be more 'in control of their care'. Nonetheless, there was a danger, as one participant had experienced, that it might be inaccurate and it should, as a result, be updated annually.

1. Parents, their families and carers have a positive quality of life

As noted above, a number of participants felt that although the key elements 'were there', it needed further explanation. Crucially, it was asked by some as to which service would give you a positive quality of life in terms of the way in which it is delivered, the amount that is delivered and the quality

The words, '*better*' or '*good*' might be more appropriate

Everything flowing nicely and smoothly was a phrase that echoed the views of a number. Alternatives mooted were, '*return to normality*', '*gain my independence*', '*make my last 20 or 30 years happier*'

There should be more explicit emphasis on the 'whole picture' to cover housing and other social needs

Others stressed the importance of getting out more

The practicalities of everyday life should also be included here - such as the need for equipment and aids

But for a good number, achieving the outcome simply did not seem possible. '*To go back to work, there is only so many films you can watch in the evening, day after day*' (Male, 51 years, White British). '*I have had MS for quite some time, if only I could go back to normal, it would mean the world to me*' (Male, 34 years, Bangladeshi). '*I don't think she is going to improve that much now...I have taken a lot of independence away from her as I do everything for her...I don't expect miracles*' (Carer for Female, 89 years, White British). '*For him to be as comfortable as possible having all the medication when he needs it...so if everything is there to support him*

Greater co-ordination and communication between different teams and professionals was called for

Need to communicate with patients at all times including explaining why there were long waits for provision and, for example, for equipment.

In addition, patients should be informed if a particular service is to be stopped with explanations as to why and appropriate reassurance given.

Need to give patients more time at each visit but, at the same time, provide patients with the opportunity to decide on their care and who visits where appropriate. Timings of visits, if possible, should fit around patients

Care professionals should aim to visit at appropriate times that suits the patient

Staff need '*professionalism*' training and also training in specialist areas such as dementia.

Need for improved and easier access to information about day care provision/centres and, for instance, befrienders. Counselling should also be offered

For the majority, '**good**' CHS would mean '*caring*' for the patient and so that '*I know where they are, what they are and how to contact them*', in addition to the issues above. Other words used were, '*understanding*', '*honesty*', '*transparency*', '*clarity*', '*trust*', '*compassion*'

Staff should also be consistently aware of any language issues for patients

when he needs it that is something good' (Carer, of Male, 74 years, Bangladeshi)

Patients and their families are able to achieve increased independence:
There was general agreement that this would be great. The more elderly, in particular, felt that it would be wonderful to be less dependent on others

One respondent commented that patients may be able to increase their independence but that they may feel quite isolated as a result and this effect should be taken into consideration

As part of this process, the health service should refer patients on to services which would enable them to have greater independence rather than doing it directly e.g. To community centres/befrienders etc

Critical here, too, was the question of choice - i.e. If requested by patient

Patients and their families are socially connected: The word, '*better*' should be inserted i.e. '*better connected*'. There should be an emphasis on families here and not just individuals

Although, many considered this phrase to be rather '*nonsensical*', the importance of socialising was emphasised across discussions. '*If someone pays a social visit if they are Bengali speaking that would be great*'(Carer of Male, 74, Bangladeshi). '*He needs to be in a place, people coming, people talking, somewhere he can have a social life, people can visit and he can go out*' (Carer of Male, 83 years, Bangladeshi)

Carers feel supported and are able to look after themselves Most argued that carers should be unquestionably be included more in this set of outcomes

Finally, a number of patients believed they would benefit from a map of service provision and how the new integrated care teams (including the role of the Care Navigator) operated

2. Patients and their families fulfil their potential:

Again, the bullet points were seen as being far too general and 'waffley' and, once more, it was questioned as to whether this was the remit of health service. *'I think the remit of the health service for me in this particular context is to help patients and their families and their carers to be as independent as possible'* (Female, 54 years, White British)

Respondents emphasised how this, for many families, was simply inappropriate. *'I didn't get that outcome because my child didn't improve. They are not able to fulfil his potential and I feel helpless'* (Female, 24-72 years, Focus Group)

Others simply asked what it meant

Some suggested it might mean 'helping themselves' and not relying on others but here again others believed it had to include independence which was the ultimate goal

Hence, also a suggestion that this could mean achieving 'independence' thus duplicating other outcomes. In this sense, it was thought it could also mean 'fulfilling potential' in terms of their care i.e. carrying out your own self-care

This made some within the sample relatively wistful, particularly the elderly: *'We can't do anything on our own now and we never go out together, it would be great'* (Female, 79 years, White British)

Patients and their families are able to contribute to society: This was difficult for the majority. Many simply did not understand what it meant and were baffled as to how they were expected to contribute. *'We should contribute to society but I don't think the health service needs to tell us that. I think it is rather weird'* (Male, 60, White British). But more often people felt that, if you were not 100% fit and healthy, then your time would be

spent looking after yourself, not others. Apart from anything else, participants questioned who would have the time to do it. As one participant said: *'What does that mean? To give? But lots can't do that can they? Sometimes people in a wheelchair, people are not inclined to listen to them anyway - what could they do?'* (Carer of Male, 33 years, Mixed Race)
'What are you going to do? Nurse the other patients?' (Female, 57 years, Irish)

Patients and their families are able to build positive relationships:

Frequently the response to this was, with whom? Themselves? Some asked the question as to who in the health service was going to build positive relationships

Patients and their families are able to look after other people: Clearly only if they are able bodied but most also argued that they probably were taken up with their own problems

'That would all be very nice but it seems to be odd to have an overarching statement to say patients and their families are able to look after other people - of course you want to but I don't really see it as the province of the health service' (Female, 54 years, White British)

3. Patients and their families have a longer, healthier life

'Well this is motherhood and apple pie, jolly good' (Male, 60 years, White British)

This was clearly hard for many with their present conditions. Some made light of it by hoping that it did not mean 'hastening' the progression of a terminal condition

Some did suggest, however, that if it was not possible to give patients a longer, healthier life, it might be possible to give them a 'good quality of death' and this should be added

Many thought it was meaningless too in the sense that anything could happen in the future and it could not be guaranteed

Overriding these positions, however, was also a view that what it should mean was that the patient's illness has been treated and life had been prolonged for as long as possible

In one case, an interviewee felt that his life could become '*healthier*' if he went out more but he simply felt unable to: '*I know I am locked in my own place as I haven't got the gall or the determination to get on with life as normal - it is six years now and I need to do something and I can't - I am scared*' (Male, 60 years, White British)

Carers should be also be unquestionably included. This was only because, as main carers, they need to know what is happening with care but additionally because of the effect full time caring can have - '*Because the carer has to look after their health as they are the person who is looking after their sons or their daughters who needs their help so it is the carer who needs to be the healthier one*' (Carer of Male, 33 years, Mixed Race) '*I think we have been neglected as we don't get involved yet I am the one who does all the care, I have to take control of it and they don't think about the effect it is having on me*' (Female, 35, Bangladeshi)

A number added that consideration should be given to the appropriate level of need for respite care

4. Patients are safe from harm

'Utopia isn't it? Accountability - there doesn't seem to be that, it is very loose - there is not anything that you can use as an anchor point - another statement that is disingenuous to put it nicely' (Female, 35-80 years, Focus Group)

Some queried as to what this meant - safe from what? Equally there was confusion as to who in the NHS and which team was responsible for what e.g. Dangers in the home, dangers outside the home and so on

Others drew attention to possible violence or racism and felt reassured by knowing they had good friends or neighbours

Families and carers should also be included in this outcome in terms of the support structures needed to keep people safe

Many responded by talking about the aids and equipment they have in their homes

Patients are treated and live in a safe environment: Some considered that this would depend on the patient and the level of their cognitive function. Certainly if there was a history of harm that had been sustained in the home then there should be an assessment but the whole set-up should be considered including the input of the family and carer.

Patients know how to keep themselves safe: This was thought, by some, to be somewhat foolish since it was not possible for anybody to check up on how safe patients' homes were. However, it was thought of as being very much appropriate for those with cognitive difficulties or learning difficulties. Hence, the wording should/could be changed to *'know how to keep themselves safe with the appropriate support'*. Healthcare staff, it was thought, should be aware of the extent to which patients are able to look after themselves

It was suggested by one group that the words, 'from physical and mental abuse' should be added

It should also possibly be made clear that some patients, particularly those with mental health issues may see themselves as mistakenly being 'unsafe' and this should be taken into account

Patients know who to contact if they feel unsafe and feel confident they would get the right support and response: It was evident that this was important to most and the vast majority appeared to know who they would contact if need be. A number, too, had panic alarms. However, it was pointed out that there was a section of people who would not want to 'trouble' anybody particularly the elderly and health professionals should be aware of this.

Staff feel confident that services are clinically safe and guard against neglect: There was undeniable confusion among many as to what this meant. Some, for example, thought it might mean that the community should be safe from staff. *'Whose neglect? Is it the staff guard against their own neglect or care of the family's neglect or neglect of yourself or your neglect of any people who they may be responsible for?'* (Male, 88 years, White British). Some also argued the NHS were simply 'covering themselves for anything they have done wrong'

For some of those who interpreted it as the neglect of patients, it was argued that it was not maintained, *'all of the time'*. Participants drew attention to cases where patients had not been listened to and their conditions had deteriorated. One interviewee suggested that the phrase should read, *'Guard against their own neglect'*!

For others, there was some confusion as there was an assumption that staff would guard against 'neglect' anyway

There was also the view that it would not be possible for the health professionals to ensure there was no neglect - they could not, for example, turn the gas or taps off

5. Patients can return to their preferred way of living as rapidly as possible and stay there

Although this originally was a draft outcome for those receiving community health provision in the short term, the sub-headings were considered relevant to all

However, many believed it was simply not relevant to them in their own situation.

A further concern was that the services were often only too keen to send patients back 'into the community', often, in their view, too soon and there should be a caveat to prevent this

In particular, patients complained that even if they were long-term users of provision, they were made to feel they should be short-term users and this included those with long term conditions such as Multiple Sclerosis or Cerebral Palsy. *'After care is missing too - if you do improve that is all well and good but if you regress, it is about having that reassurance about having after care - the bridge to normal living'* (Carer of Male, 44 years, Bangladeshi)

Across the board, interviewees complained of services being stopped seemingly abruptly since the community health teams considered them to be 'better'. *'I would like to see a bullet point that says CHS assist more*

proactively in helping people maintain their independence so they don't just finish with you but they somehow have reviews and you have an opportunity to say, I would like a bit more help with this' (Female, 35-80 years. Focus Group)

Patients understand the care they will receive and are involved in developing it: Some participants immediately responded that they thought they would simply not be able to understand the care but would, at the same time, expect to be involved in 'decision making'.

Others argued that a more appropriate outcome might be for patients to be 'in control' of their care rather than being 'involved' to negate the feeling, for example' of being 'shunted around'. Good, consistent information was thought would alleviate this (and Care Plans might contribute towards this)

Essentially, liaison with the patient, carer and family was considered to be a prerequisite of care at all times

Patients feel the service is right for their individual needs: There was some lack of clarity as to why this phrase was included at all on the assumption it should be automatic

6. Patients regain and maintain their independence

Again originally an outcome for those receiving community health provision in the short term but viewed as relevant for all. However, comments here were similar to those given under Outcome 1 above.

Seen as clearly critical (see above) but here an important caveat was that the health professionals do not always know the full condition of the patient and his circumstances. Hence stories abounded about contradictory advice. For instance being told to go to the bathroom and shower on their own without considering the slippery floor etc

<p>Some perceived that the balance between being 'independent' at the same time as needing to rely on care professionals was complex. Certainly some patients appeared to feel overwhelmed by the level of care they needed and endless professionals visiting. The aim it was thought should be to both involve the patient and discuss the balance with them</p> <p>There was also considered to be a danger that helping someone become too independent might mean a loss of necessary support <i>'I have had to fight for everything...Maybe because I am too independent...you ask but you don't get so you just get on with it but you are frightened of a knock back and I do such a good job, I am now left to get on with it basically'</i> (Carer of Female, 71 years, White British)</p> <p>Also, it was pointed out, sometimes patients have no choice and can only manage with service support which should be maintained</p> <p>There was also a view that present service provision tended to make patients less independent and 'housebound' since they perpetually have to wait in for healthcare professionals since you never knew when they were coming</p> <p>Patients actively manage and sustain their own recovery: Again some difficulties and concerns with the meaning of this - whether it would result in less care and provision. It would be important to ensure that those who needed the appropriate level of support still were able to have it but, on the other hand, it was considered by some to be important that patients are encouraged to sustain and manage their own and to feel they would be able to manage</p>	
<p>B. Parents and Children</p>	
<p>Generally, responses to the outcomes were positive but there was concern as to how they would translate into reality. In particular it was</p>	<p>Clear process needed for diagnosis. Diagnosis to be delivered with clarity, understanding and appropriate support</p>

thought outcomes should reflect a holistic approach to the care of the child which should encompass the whole family including carers.

1. Children, siblings, families and carers are physically, mentally and emotionally healthy

Seen as being key:

Important to involve and respect the family since parents understand their children the best

Essential to listen to the parent and the child

Professionals should have a level of understanding to be able to communicate comprehensively and sensitively with the parent and child

Families should be given the appropriate support to enable them to support the child and have a clear understanding of the situation and what to expect - particularly for those more vulnerable parents who might have English as a second language

Clear explanations of process and procedures to be given at all times

2. Children, siblings and families are safe from harm

Some considered this to be remit of Social Services and not the NHS and there was general confusion as to which services should be the first contact point

Appointments with health professionals should be positive and fun and

Faster referral process should be initiated

Support need for parents and families throughout their 'journey' e.g. listening to parents, dealing with stigma, access to emotional support including provision of groups and other support networks

Clear communication needed at all times - e.g. straightforward language and simplified medical terms

Further staff training to ensure a more 'personal' (and non patronising) approach is adhered to at all times. This should include an understanding of a holistic view of the child and family's life

Access to information regarding medical conditions for parents including possible use of DVDs as well as more common media

Clear signposting to information and also support mechanisms such as groups

Initiation of a straightforward complaints procedure

Staff should be aware of potential language barriers for patients and families

<p>not traumatic in any way</p> <p>For children accessing ASDAS, 'safe from harm' can be very literally viewed and might mean support is needed in everyday issues such as crossing the road or coming to the appointment</p> <p>Parents should feel they are able to ask for help if they need it - including psychological support</p> <p>3. Children fulfil their potential</p> <p>There was some lack of clarity about what this meant</p> <p>There should be good links between health professionals and school so that education can be continued and supported throughout treatment</p> <p>Health professionals should be fully versed in the conditions so that they are able to understand and support the child and family accordingly</p> <p>Clear explanations of process and procedures to be given at all times</p>	
<p>C: YOUNG PEOPLE</p>	
<p>For many of those interviewed, there was a strong feeling that the outcomes did not relate specifically to them as individuals. For one young person with a generative disease, for example, there was a feeling that they were all totally irrelevant. For this reason, a number were discussed</p>	<p>A higher level of understanding and care seemed to be needed for young people</p>

only in passing and not all are listed below. There was also a view that they were 'mere guidelines' that should be followed rather than determinable outcomes.

1. Patients, their families and carers have a positive quality of life:

Should be 'better' not 'positive' since 'positive' is being 'overly optimistic and exaggerating about what is really happening and is misleading'

Interpreted by some as that 'quality of life' is good as long as people are well looked after by their family and others who care and love them

Patients and their families are able to achieve increased

independence: `This was thought to be hard for those young people with complex needs. Although ostensibly encouraged, one mother argued, given the demands of her family situation, that it was quicker for her to do everything for her daughter

Parents and their families are socially connected: Most thought it was important to encourage social confidence in those who have complex needs. *'I want to develop my confidence so I can actually be able to talk to people and actually make friends...the youth group makes me feel safe...and makes me feel better'* (Female, 15 years, White British)

2. Patients and their families and carers fulfil their potential:

It was evidently important to consider the whole young person and take into account all aspects of their life e.g. pressure/s on the family, education, training etc

The ability for staff to be honest, respectful and to communicate clearly was seen as essential by most.

It was also seen as essential for staff to communicate with young people allowing for a two way conversation

Also key was reliability of provision with consistency of staff being paramount

It was equally important for young people to receive the appropriate amount of aids/equipment in their home so that their lives can be improved

The CHS team should have a greater number of specialist staff who might cater for particular types of health problems

A number of participants questioned what this meant seeing it as a 'strange' way to word it. There was equally derision at the phrases, 'contribute to society', 'build positive relationships' and 'look after other people' e.g. *'Look after other people? That is expecting a lot from the patient - first is being able to look after yourself!'* (Male, 18 years, Bangladeshi)

Education was considered important across all discussions and the difficulties highlighted for young people who have to take time out of school for health reasons

For one respondent, continuing with his apprenticeship was key

3. Patients and their families have a longer, healthier life

This was considered to be the 'whole point', to make sure people either live longer or, importantly, prevent any further deterioration

4. Patients are safe from harm

Some considered this to mean getting to know nurses well so patients feel more comfortable

Patients know who to contact if they feel unsafe and feel confident they could get the right support and response: This was seen as important and the majority of participants were confident that this was the case

Staff feel confident that services are clinically safe and guard against neglect: Again seen as being important but some confusion as to what it meant. One participant felt that 'neglect' was more likely due to the

lack of co-ordination between and within different services

5. Patients can return to their preferred way of living as rapidly as possible and stay there

It was felt by some this was very much dependent on the person -
'They may not feel motivated or inclined to push themselves...they might be incapacitated or don't have the energy or physical strength to do some of those things' (Female, 18 years, Black British)

Patients understand the care they will receive and are involved in developing it: Opinion was divided between those who did not wish to have any involvement as there was nothing that would change and the doctors knew best and those who felt more comfortable discussing their health with service providers

6. Patients regain and maintain their independence

Considered to be very important

APPENDIX I



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Dear Patient/Carer

We are writing to you to ask you if you would be willing to take part in a small study to help us improve our local NHS services. This will involve a discussion either on a one-to-one basis or within a group with other patients similar to you. All those taking part in this study will receive £25 cash as a token of thanks for their time.

In Tower Hamlets we are always seeking to improve the health and social care provided for patients and in this particular study we want to hear your views on the services that are provided by the Community Health Teams. We understand that you are or that you have, at some point, received services from one or more of the professionals who work within this team which hosts a number of different services including the District Nurses, Physiotherapists, Occupational Therapists, Diabetes and Rehabilitation services to name but a few.

The interviews will be carried out by independent researchers and all discussions will be entirely confidential and should take no longer than one hour. It is normal practice in such a study that the meetings are recorded so that all views and opinions are accurately captured. The recordings will be kept secure and used only by the study team and after the evaluation is complete, they will be destroyed. There will be a report generated from this study but the report will contain no names or any other references which could potentially identify you.


The name of the independent researcher leading this study is Kate Melvin and she can be contacted for any further information and to answer any questions you might have about the study. Her email address is katemelvin2@gmail.com or she can be telephoned on: 07748 762 986.

In order to understand more fully how patients are experiencing community health service provision or how they may have experienced it in the past, it is very important we hear your views and opinions about services. However, if you do not wish to take part in this evaluation, please fill in the attached slip and return it in the stamped addressed envelope. You may also telephone 020 8223 8735 and leave a message indicating that you do not want to take part.

We are very grateful for your time and support in this project and we would like to emphasise that your decision about whether or not to take part will in no way affect any future care you might need. Nearly 100 patients who receive care and support from the community health team are being sent this letter but only the study team will be aware of the names of those who finally take part. Neither the CCG, Barts Health nor the primary and healthcare teams will be aware of the names of people selected for interview during this evaluation.

Many thanks indeed for your support.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'WJ', written over a horizontal line.

Bill Jenks
CCG Engagement Manager

COMMUNITY HEALTH SERVICES - PATIENT EXPERIENCE

I DO NOT WISH TO BE CONTACTED by the study team. I understand that I am under no obligation to take part and that my decision will not affect any future health or social care I might need.

Signed

Please could you fill in the following so that we can take your name off our list.

Surname

First name:

Address:

APPENDIX II

DISCUSSION GUIDE FOR FOCUS GROUPS WITH PATIENTS/CARERS/YOUNG PEOPLE

Notes:

This is the Discussion Guide for use with patients/users/carers of Community Health Services.

The format follows that of unstructured qualitative interviews in which the guide is used as only a framework for discussion so that interviews are open-ended, flexible and responsive to what respondents have to say, thus allowing for spontaneity and full exploration of the issues. It sets out key issues to be raised, some possible lines of questioning and areas to probe. Probing will be continuous throughout the discussions even when probes per se are not listed below. The order in which issues are raised will tend to vary and questions will rarely be asked in the way they appear on the guide.

Introduction to Discussions

As an independent organisation, XXX has been asked to speak to people in Tower Hamlets who have seen and been treated by health professionals who work within Community Health Service provision. The purpose of the discussions is to understand people's perceptions and opinions about Community Health Services and to explore the outcomes they want from the services they receive. This is so that when the services are recommissioned they can be improved in order that they might work more effectively for patients themselves. It is therefore important that we understand what you think so that those who provide these services know what matters to patients.

This will be a fairly informal session that is anticipated to last no more than an hour. In order to obtain an accurate record, I would like your permission to record the discussion. **However, your name will not be revealed and all discussions will remain entirely confidential. The tape and the resultant transcript will be accessible only to the study team and it will be ensured that your views will not be linked with your name or any other details when the research is reported.**

Description/questions	Comments	Approx. time (mins)
<u>1. General background information</u> Introductory questions: Can you tell me a little bit about yourself?	<i>Warm - Up: Aim to detail</i>	5 mins

(PROBE: Age, family details, employment status etc)	<i>briefly demographics of respondents</i>	
<p><u>2. General attitudes towards health and health professionals</u></p> <p>Tell me about your health:</p> <p>What are their main health issues? Which, if any, health issues are they mainly concerned about?</p> <ul style="list-style-type: none"> • Is it a longstanding problem? • Or is it a recent issue? <p>Tell me a bit about the health services you use at the moment?</p> <ul style="list-style-type: none"> • Which services? • How long have you used them for? <p>(Probe for brief details)</p>	<p><i>Listen to see if they mention anything in regard to provision they might have received and from which service</i></p> <p><i>Try and gauge what the main concerns are (ie they may be different from why they are having community health provision)</i></p> <p><i>Pay attention here to good things/bad things they might have experienced so that they can be reminded of what they said here when talking about outcomes later.</i></p> <p><i>Try not to let them get bogged down with the details of this – looking for general overview at this stage and whether any services are differentiated in this initial discussion BUT note which are the community health services and which are not</i></p>	5 mins
<p><u>3. Community Health Service Experiences</u></p> <p>What are their first experiences of the Community Health Services that they have used?:</p> <ul style="list-style-type: none"> • Can they remember what their hopes were when 		15 mins

<p>they started to see (XXX service)?</p> <ul style="list-style-type: none"> ○ What were their expectations? ○ What had they been told? ○ By whom? ○ Has the information been consistent? <p>Probe for expectations about</p> <ul style="list-style-type: none"> ○ Their health ○ Their future health ○ Their lifestyle ○ The frequency of care ○ Length of time under service ○ Support received - what support? From whom? For what? ○ Anything else? ○ Etc <ul style="list-style-type: none"> ● What are your biggest concerns about your care so far? <ul style="list-style-type: none"> ○ Why? In what way? ● How could these be alleviated? <ul style="list-style-type: none"> ○ In what way? ○ By whom? ● What has been good about the (<i>particular</i>) service? ● And what has been not so good? <ul style="list-style-type: none"> ○ In what way? ○ Why? ○ Probe: <ul style="list-style-type: none"> ▪ Professionals ▪ Co-Ordination of Care ▪ Administrative Co-Ordination ▪ Adequate levels of information ▪ Support offered - What support did they want? At what level? Who from? ● What do they think are the key issues that might have made it better? <ul style="list-style-type: none"> ○ How? In what way? ○ For which service? 	<p><i>If in a group context, it will be important to be clear to which service people are referring. The aim would be to facilitate a discussion at this point not so much about individual services but what are the key underpinning issues about expectations etc?</i></p> <p><i>Aim of this section. too, is to explore aspects of the 'patient journey', looking at what went well and why and what, in their view, went badly and why</i></p> <p><i>Also important to try and distinguish between different services if appropriate and relevant</i></p> <p><i>The key issue here is to discover if they had expectations and, if so, what they were.</i></p> <p><i>Also distinguish if possible between expectations about their health, those about provision and those about lifestyle and whether these expectations differ depending on the individual service. How do they rate such expectations? How paramount are health expectations - can they be separated from those concerning lifestyle, work, leisure and so on.</i></p> <p><i>Important to try and explore the range of</i></p>	
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<ul style="list-style-type: none"> ○ Why might it differ across different services? ● In their view, what makes some services, which they have experienced, better than others? <ul style="list-style-type: none"> ○ The healthcare staff ○ Level of co-ordination ○ Administration ○ Etc ● Have your expectations been met? <ul style="list-style-type: none"> ○ If yes, in what way? ○ If not, why not? ● To what extent, do you think that your expectations were realistic? <ul style="list-style-type: none"> ○ If not, why not? ○ If yes, what went wrong? ○ What, in their view could be done about this? 	<p><i>experiences so that a sense of what is important to people and what is note can be obtained</i></p> <p><i>Key too is what support do people need and what is the nature of that support?</i></p> <p><i>It is also important to gauge the extent to which they feel 'safe' with their care and encouraged by the progress of care</i></p> <p><i>Also remember to refer back to the earlier discussion and pick up on any inconsistencies and contradictions</i></p>	
<p><u>4. Outcomes of Care</u></p> <ul style="list-style-type: none"> ● Have their expectations been met? <ul style="list-style-type: none"> ○ If yes, how? In what way? ○ If no, why not? ○ What do they think has been the problem? ● What would be the best outcome of your treatment for you? <ul style="list-style-type: none"> ○ In terms of your health? ○ In terms of your lifestyle? ○ In terms of your life more generally? ● To what extent do you think that the health professionals you are seeing are working towards the same outcomes as you? 	<p><i>Here, it is important to ensure that there is an understanding of what <u>they</u> mean by 'outcome'</i></p>	<p>30 mins</p>

<ul style="list-style-type: none"> ○ If yes, can you explain in more depth? ○ If no, why not? ○ What do you think the differences are? ● What do you think the barriers are for other patients in talking about 'outcomes'? ● Do think that other people achieve the outcomes they want? <ul style="list-style-type: none"> ○ If not, why not? ○ If yes, why? ● What would a 'positive quality of life' mean to you? <ul style="list-style-type: none"> ○ What difference would it make to your life? How? In what way? ● And a 'return to their preferred way of living' <ul style="list-style-type: none"> ○ What difference would it make to your life? How? In what way? ● And 'fulfilling their potential'? <ul style="list-style-type: none"> ○ What difference would it make to your life? How? In what way? ● And 'a longer healthier life' <ul style="list-style-type: none"> ○ What difference would it make to your life? How? In what way? ● And 'safe from harm'? <ul style="list-style-type: none"> ○ What difference would it make to your life? How? In what way? ● And 'regain their independence' <ul style="list-style-type: none"> ○ And 'maintain it'? ○ What difference would it make to your life? How? In what way? ● What are the key ingredients in your view, for successful outcomes? 	<p><i>Explain again the purpose of the interview and try to get the respondents to think what these phrases could mean to them?</i></p> <p><i>You may need to probe but it might be better to let them really think what it would mean to them</i></p>	
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<u>SHOW OUTCOMES AND DISCUSS</u>		
<p><u>5. Conclusions</u></p> <ul style="list-style-type: none"> • If you were in charge of health professionals in the community, what would you want them to do? • How could patients be supported more effectively? <ul style="list-style-type: none"> ○ In what way? ○ What would this mean in practice? • What do you think patients like themselves want from their care but do not receive? • How could this be achieved? • If you were designing 'outcomes', what would you put? 		10 mins

THANK AND CLOSE

Draft outcomes for people who use community health services to help manage long-term and short-term illnesses

Patients, their families and carers have a positive quality of life

- Patients and their families are able to achieve increased independence
- Patients and their families are socially connected
- Patients and their families are cared for in a safe environment
- Carers feel supported and are able to look after themselves

Patients and their families and carers fulfil their potential

- Patients and their families are able to contribute to society
- Patients and their families are able to build positive relationships
- Patients and their families are able to look after other people

Patients and their families have a longer, healthier life

- Patients' disease progression is slowed, where appropriate

Patients are safe from harm

- Patients are treated and live in a safe environment
- Patients know how to keep themselves safe
- Patients know who to contact if they feel unsafe and feel confident they would get the right support and response
- Staff feel confident that services are clinically safe and guard against neglect

Patients can return to their preferred way of living as rapidly as possible and stay there

- Patients understand the care they will receive and are involved in developing it
- Patients feel the service is right for their individual needs

Patients regain and maintain their independence

- Patients feel able to manage their condition with the support of community health services
- Patients actively manage and sustain their own recovery

Draft outcomes for people who use early years and children's community health services

Children, siblings, families and carers are physically, mentally and emotionally healthy

- Children and their families and carers make informed choices
- Children and their families and carers understand and follow healthy lifestyle guidance
- Children feel able to live with their condition
- Children, siblings, families and carers have a positive quality of life
- Children are a healthy weight, are well nourished and are active

Children, siblings and families are safe from harm

- Children are treated and live in a safe environment
- Children know how to keep themselves safe
- Children know who to contact if they feel unsafe and feel confident they would get the right support and response
- Staff feel confident that services are clinically safe and guard against neglect

Children fulfil their potential

- Children have the best start in life
- Children are equipped with resilience now and for the future
- Children develop a positive relationship with others
- Children have self-awareness and personal interests
- Children gain and maintain their own independence
- Children are prepared for adulthood

APPENDIX III

Participant Information Sheet

Patients/Carers

February 2015

Community Health Services Study

We are very pleased that you have agreed to take part in the above study. This information sheet explains why this study is being carried out and what it will involve. We would be grateful if you could read the following information carefully. Please contact us if anything is unclear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to understand the views, opinions and experiences of those patients who have received service/s provided by the Community Health Team in Tower Hamlets.

Who is organising and funding the study?

The study is being funded by the Tower Hamlets Clinical Commissioning Group (THCCG)

Why have I been invited?

You have been asked to participate on the basis that you have received services provided by the Community Health Team.

Do I have to take part?

Participation in this study is entirely voluntary. If you are happy to take part, you will be given this information sheet to keep and be asked to sign a separate consent form in line with ethics requirements. You are still free to withdraw at any time and without giving a reason.

What will the research involve for me, if I take part?

Involvement in the study will mean that you will either take part in a one-to-one discussion or, alternatively, join a discussion group with others who have received the services.

All interviews will be fairly informal and will take the form of a discussion. There will be a loose topic guide that will outline a number of areas to talk about but it will be designed so that discussions are open-ended, flexible and responsive to what you might have to say, thus allowing for spontaneity and full exploration of the issues from your perspective.

The main themes in the topic guide will focus upon your experiences of the services you have received from the Community Health team but, in particular, will focus upon what outcomes you expected and/or what you would like.

Interviews will be recorded, if permission is granted, and then transcribed by the study team. All recordings and the transcriptions will be anonymised and any information that could lead to participants being identified will be removed.

What are the possible risks and disadvantages of taking part?

There is a possible disadvantage in spending time to take part in the interviews.

What are the possible benefits of taking part?

Those taking part would be contributing to a study which we hope will prove of benefit to health and social care provision. It is important that the THCCG understands the views and experiences of patients so that services can be improved.

Will my taking part in the study be kept confidential?

The lead evaluator will follow ethical practice. All data from interviews will be treated as entirely confidential by the study team. The participation of all those taking part will also be entirely confidential. THCCG will not be aware at any time of who has taken part in this study.

All data from interviews will only be available to the study team. It will be securely stored and will be treated as confidential at all times. All interview transcripts will have any personal identifying information removed before analysis and will be destroyed as soon as the project is complete. Quotations from the interviews will be used in the final report but participants in the study will remain, at all times, unidentifiable. Thus all references to where you or your family might live or work, for example, will be deleted.

What will happen to the results of the study?

The data will be analysed and written up and will be made available to THCCG as a final report. Participants will not be identified and THCCG will **not** have access to interview transcripts. On completion, the data will be securely destroyed and not used for any other purpose.

The report will be disseminated by the THCCG to interested parties and may be considered for publication. All those taking part in the study will be sent a copy of the final report. At all times, you, as a participant, will remain anonymous and unidentifiable.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time and your data will be destroyed immediately.

What if there is a problem or you wish provide any feedback, please contact:

Zoe Hooper

Communications Manager
NEL Commissioning Support Unit
Third Floor
Clifton House
75-77 Worship Street
London EC2A 2DU

Email: Zoe.Hooper@nelcsu.nhs.uk

You will be given a copy of the information sheet and signed consent form to keep.

Alternatively you may wish to contact the independent organization, **Healthwatch** whose contact details are below.

Healthwatch Tower Hamlets

Room 12, Block 1 (Trust Offices)
Mile End Hospital
Bancroft Road
London E1 4DG

Office number: 020 8223 8922

Freephone number: 0800 145 5343

Email: info@healthwatchtowerhamlets.co.uk

Thank you again for considering taking part in this study and taking the time to read this information.

CONSENT FORM

This consent form should be completed by all participants in this project and returned to the address below. Please keep a copy for your records. Many thanks for your cooperation in this.

Title of Project: Community Health Services - Engagement

Name of Lead Evaluator: Kate Melvin

Name of Interviewer:

Please initial box

For Participating Patients/Carers

1. I confirm that I have read and understand the information sheet, dated February 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I agree to take part in the above study.

I am the patient/carer:

Name

Date

Signature

Please complete and sign this form and return it to the interviewer at the time of the interview.