



EVALUATION REPORT

ONE HACKNEY & CITY

THE PATIENT EXPERIENCE

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BACKGROUND

One Hackney & City, initiated in 2014/2015, was designed to drive the transformation of local services to ensure that 'vulnerable' patients received better and more integrated care and support. Working with service providers and practitioners from across the health and social care spectrum, the programme developed a range of integrated care pathways that aimed to address fragmentation in patient services to provide greater service co-ordination and more continuous and supportive care for the most vulnerable patients in City and Hackney.

The programme is now to be developed further in order to improve service provision across the health and social care sectors. It was felt however, that it was essential to capture and understand the patient experience to-date so that lessons can be learnt and any new service specifications are built upon an understanding of the impact of this type of provision upon patients.

One Hackney and City (OHC) commissioned Hackney Healthwatch to undertake a study to build upon the two previous evaluations of the programme through discussions with patients/clients. The study would form part of a wider evaluation of OHC which will include analysis of the views of the providers, an evaluation of the voluntary sector framework and of mental health provision.

This report thus details the findings from discussions with patients/clients. A further part of the project was to film and record a number of the patients'/clients' stories. This will be carried out by Healthwatch and detailed in a further report.

OBJECTIVES

This study aimed to:

- Capture the patient experience through discussions with patients who have encountered and been registered with OHC; and
- Develop an evaluation framework so that patient experience can be 'measured' in the future.

EXECUTIVE SUMMARY

General Issues

- The sample was purposively selected from a designated list provided by OHC. It became clear that it was not homogenous either in any demographic sense or in terms of health and healthcare needs. This however, was counterbalanced by the evidently high level of social needs that underpinned the lives of almost all respondents.
- The sample was equally notable in that it differed significantly from the previous evaluation of patient experience of OHC in 2015 where health needs and difficulties with health provision were frequently a topic of discussion. In this cohort this was not the case and there appeared to be only a very small minority who reported for example, that medical and healthcare professionals visited them at home on a regular and prescribed basis. Healthcare needs were in fact rarely discussed during interviews and often only arose on probing. There was accompanying surprise when respondents were asked about co-ordination of their care for example, again a topic very much discussed previously but there did remain a sense in which respondents felt that the medical profession did not 'listen' to them.
- It was evident during interviews that it was the level and balance of health versus social needs that was the critical issue. For the majority of respondents interviewed, their social needs tended to override any other needs including health needs even though these may have been present. Even for those suffering from long-term debilitating conditions such as multiple sclerosis or Parkinson's disease although always in their mind, it merely compounded and/or was interdependent with their social problems. Mental health and emotional difficulties seemed to simply exacerbate it further.
- For most respondents there tended to be one overriding concern. For many this was housing which tended to be exacerbated by perceived difficult living conditions but a clear corollary of this was the reported isolation and loneliness. Disabilities tended to compound the difficulties. Their lives it seemed, were not so much complex as complicated and there was a belief how easy it was for the pack of cards to fall. Of note too, was the low level of expectations of help and support and most appeared to react to such offers rather than expect them in any way.
- There were a number of 'unpaid' carers in the sample and it soon became evident in the interviews that their needs were as great if not greater than those for whom they cared. Depression, loneliness, isolation and exhaustion were common reported features of this group. Duty unquestionably appeared to play an important part in these families and

relationships as well. For those that had 'paid' carers, again there were problems of time-keeping and the number of hours allocated.

- Given the nature and individual complexities of the lives of this cohort of patients and the lack of any homogeneity, it is not and would not be possible to develop an evaluation framework based on patient metrics or indeed any quantitative measurements. This could only be done on an individual basis over a period of time. The lives of those in this sample were often reported and appeared to be 'chaotic' and their memories were at best vague.

One Hackney and City

- Many of those interviewed remained unaware of the name, 'One Hackney and City' although they were aware of individuals' names that were part of the quadrant teams and connected individuals. There also remained confusion with One Support, One Housing and so on. Even though respondents may have been aware that they were referred by the GP, there was a perception that OHC was part of social services rather than the health service.
- Perceptions of the function of OHC clearly varied and this tended to be dependent upon the nature of the need of each individual patient/client. The service/s provided may also have been part of a wider package of provision of which OHC was merely a part, thus making any assessment and evaluation more complex. There did appear nonetheless, to be a difference in the perception of those who considered that OHC was a specific layer of provision offered as part of a whole package of care and those who tended to perceive it as offering a specific individual piece/s of support separate from but in some way related to 'normal' and mainstream provision.
- It was clear that OHC in responding to an individual's needs offered help with access to provision across the board when appropriate and this clearly would cut across professional and organisational boundaries. From the perspective of many of those in the latter group however, the provision appeared to be somewhat siloed.
- Respondents appeared to be clear in their own minds precisely what OHC would provide and what they could not although this was not necessarily consistent across the sample. Almost all however, were aware that OHC were unable to help with housing, a fact that caused some distress. Most interestingly equally perceived that OHC could not help with health or healthcare provision either.

- There was some evidence too that once a service had been provided, it was thought that any further provision had to be sought through 'normal' referral routes and mainstream services thus limiting the perceived role and the remit of OHC provision.
- Some interviewees considered that it would be beneficial for the specific provision offered to increase and/or to be adapted as their needs changed but in addition or possibly alternatively, for connection with OHC professionals to be continued subsequent to the initial service. When this had happened, it had been widely appreciated. A number of respondents equally underlined the importance of regular contact while they were still under the auspices of OHC.
- A further division within the sample appeared to be between those who viewed OHC as a body that enabled or facilitated faster access to mainstream provision and those who perceived them as providing a 'new' or different type of service and one that they had not encountered previously or one that they would otherwise have not been able to access. Indeed, there were calls for clarification and greater information about the role and function of OHC given its somewhat amorphous and mercurial nature.
- The majority of respondents believed that the GP had referred them but most had few expectations. The process appeared to be hazy and as a result, many reported surprise when OHC had visited or phoned. For many there had additionally been a time lapse between referral and contact and few, certainly initially, connected the two events. More pertinently, it appeared that in some cases, once the patient/client had seen OHC and then was subsequently referred back into regular service provision, the waiting times were long in contrast to the faster access that OHS had initially facilitated.
- For the vast majority, the overall support and help OHC provided was unquestionably well-received. The professionals involved were unanimously seen as being supportive, caring and kind. The only professionals who suffered criticism and then in only a minority of cases were the 'Floating support workers'. Interestingly, it was made clear that although OHC were part of the system and thus far more proficient than any 'neighbour' might be, they also managed to be perceived as standing apart from the system. This was due to their approach and level of understanding and their apparent ability to engender trust. Above all they were seen as being 'non-judgemental', taking people 'seriously' and able to enable respondents to grow in confidence, replacing isolation with safety and security.
- The list of services accessed by respondents through OHC was clearly broad. One respondent reported that they now visited the GP less often as a result and most appeared to be extremely grateful for the services they had encountered.

- As a result, there was a good deal of disquiet at the suggested closure of the service. Only two respondents had had their provision 'officially' closed but many were aware it might happen. This in part, appeared to create a feeling of helplessness and a fear of the loss of 'connection'. Despite initially not having expectations of OHC, it was evident that some respondents appeared at this point to feel they were now being let down with unfulfilled hopes both tangible and intangible.

RECOMMENDATIONS

Based on the themes that emerged from the discussions with respondents, it is suggested that the following issues are taken into account in developing any new form of provision:

- There should be clear and consistent information about the role and remit of any provision. In particular there should be clarity as to whether it is a new body of provision, a vehicle for faster access to regular and acknowledged mainstream provision or a vehicle through which alternative provision can be accessed such as the voluntary sector.
- During discussions, the tension between OHC being a 'new service' and a 'new way of working' seemed evident and appeared to be reflected in the perceptions of those interviewed. Transparency as to the nature of any new developments is likely in turn to enable greater clarity for patients/clients.
- There should be greater alignment and clear pathways between mainstream and additional provision in terms of access and transition from one to the other and timescales should be adjusted accordingly.
- Access to the voluntary sector provision should be maintained.
- Attention should be paid to recording the more intangible outcomes such as reduction in loneliness, isolation and sense of wellbeing. It seemed apparent that when this had happened it tended to remain unacknowledged unless prompted. Instead, interviewees spontaneously talked of physical or health improvements alongside any physical changes to their environment.

METHODOLOGY

Stage 1: Interviews with Patients: A qualitative research methodology was recommended for this study because of the scope it provides to engage in direct dialogue with respondents and to unpack their views.

Patients/clients were sampled and recruited using standard research protocols. It was decided that patients/clients whom had been interviewed in the previous evaluation should not be interviewed again. In part this was due to the time lapse, there would also be a strong possibility that they would no longer be registered with OHC and perhaps most importantly, it would have omitted those who been registered since 2015. A 'mixed sample' would also have meant fragmentation of the data.

In this evaluation, OHC asked each of the core teams within the Quadrants to select a number of patients. Each patient thus selected was sent a letter and an 'opt-out' slip (Appendix I), drafted by the research but agreed and signed by One Hackney & City and Healthwatch. Once those who had 'opted-out' had been removed from the list, the remaining names were passed to the researcher. Following this, patients were selected from the list. Care was taken to ensure that the sample included a wide range of demographics as well as patients/clients that had been referred or were known to different Quadrant teams.

The table below details the sample.

Please note the following:

- Ethnicity is self-reported during interview;
- 'Referrer' is as stated by OHC;
- 'Reason for referral' is also as stated by OHC;
- 'Case Closed' are those cases where the patient/client has been officially signed off by OHC;
- 'Date' is the date when OHC initially registered them;
- Where there are blanks in the table, the information is not known.

In addition:

- There were noticeably few males in the initial list provided by OHC and hence only six men were interviewed;
- Similarly on the list presented, there were only a small number of those who were classified as 'risk of admission/frequent GP usage/self-neglect';
- Two potential respondents listed had also died by the time of interview.

No	Ethnicity	Age	M/F	Area	Referrer	Reason	Case Closed	Date
1.	White British	44	M	N4	GP	Mental Health		May 2016
2	Afro/Caribbean	50	F	N4	GP	Multiple Long Term Health Conditions	X	August 2016
3.	Black British	49	M	N4	GP	Social Isolation		February 2016
4.	Mauritian	81	M	E5	GP	Multiple Long Term Health Conditions		September 2016
5.	Black British	53	F	E9	Social Work			August 2015
6.	Jamaican	59	F	N16	GP	Social Isolation		Oct 2016
7.	White	74	F	E8	Social Work			Feb 2016
8.	Jewish	30	F	N16	Bikur Cholim	Mental Health		Dec 2015
9.	Black	39	F	N1				July 2016
10.	Afro-Caribbean	55	F	E9	Physiotherapy	Social Isolation		
11.	White	60	F	E2	GP	Multiple Long Term Health Conditions		
12.	White	60	M	E8	GP	Social Isolation		June 2016
13.	Turkish	56	F	E5	GP	Social Isolation		
14.	Jewish	81	M	E5	Bikur Cholim	Multiple Long Term Health Conditions		November 2015
15.	White	43	M	E5	GP	Risk of Admission/GP usage/Self-neglect		June 2016
16.	Turkish	68	F	N4		Multiple Long Term Health Conditions	X	August 2016
17.	Pakistani	81	F	E8	Social Work			March 2016

The researcher subsequently contacted the patient/carers to arrange an interview but on initial contact, interviewees were provided with a further chance to 'opt-out'. All interviews were held at the respondents' homes.

Care was taken to ensure that all interviews took into account language, age and other factors that might impede or enable the discussions. In seven cases, 'unpaid' carers, often family members, were present during the interviews. In these cases, the carer tended to either act as a support and/or provided interpreting facilities. Although the role of the carer can be ambiguous, in these particular cases, all the patients/clients concerned spoke some English and it was felt that this was not an issue.

During the interviews, each respondent was provided with a Participant Information Sheet and Consent Form (Appendix II) and was offered £25 as a token of thanks for their time.

Discussions were based on a topic guide (Appendix III) that consisted of a number of key of key themes but it should be stressed that this guide purely acted as an 'aide-memoire' and interviews were open-ended, flexible and responsive to what respondents had to say, thus allowing for spontaneity and full exploration of their experiences. This guide also built upon the guide that was used during interviews with patients in 2015.

Interviews took place in January and February 2017 and lasted between 30 minutes and one hour. All were digitally recorded with permission. Recordings were subsequently transcribed verbatim in order to make it easier for the researcher to access raw data and improve the transparency of the analysis process. The analysis of the transcripts will follow the established procedure of the National Centre for Social Research's Framework of Analysis developed in the 1980s^{1 2}.

The findings from this study were discussed with OHC in early March 2017. Importantly, developing metrics of patient experience was discussed in some depth. Given the nature of the cohort as detailed in the following report, it was suggested that it was simply not possible to develop quantitative measures.

[Stage 2 - Filming of Patients:](#) During the above interviews, each respondent was asked whether they would agree to be filmed by Healthwatch. In total, seven agreed, six refused and four remained unclear.

METHODOLOGICAL NOTES

- Given the often seemingly complex nature of patients' lives, it was notable how enthusiastic the majority were about being interviewed and there was only one refusal. Many however found it hard to accept the incentive offered.
- Across the sample, there was a wide range of co-morbidities. A good number had both physical and mental health conditions that ranged across the spectrum but

¹ . 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.

² This process has now been formalised in Nvivo

included long-term conditions such as multiple sclerosis, cerebellar ataxia, kidney failure, Parkinson's disease, COPD as well as issues of anxiety, dementia, substance misuse and so on. More significantly, many additionally had a range of social problems including acknowledged isolation and loneliness. It is important to note that all conditions were self-reported during interview although not all participants were able to articulate precisely the nature of their co-morbidities.

- Similar to the 2015 evaluation, it is important to emphasise that many respondents were confused about dates and times of events or simply were unable to remember. Hence, their 'stories' often appeared confused. All effort was made to clarify experiences not simply for a level of accuracy but, more importantly, so that the underlying themes and patterns could be extracted and explored.
- Although all those patients interviewed were registered with 'One Hackney' and many had been for some time, there remained a number who reported they had never heard of the term. On probing however, it was evident that they were aware of individuals who were clearly linked to OHC.
- It was notable that views and experiences appeared to be largely independent of the ethnicity of the patient/client as well as whether or not they were living on their own. The interviews varied in length usually because of the evident difficulties that some patients/clients appeared to have in terms of both their physical, mental and emotional health. It was also not uncommon for the interviews to be disrupted at times due to health issues.
- It was evident that for many of those interviewed, their main anxieties were focussed upon their immediate needs, such as benefits, level of care provided to them, social support and so on. As in the previous evaluation, there was though, an accompanying assumption on the part of a number of interviewees that the researcher could help in some way with such issues. Normally explanations about the purpose of the interview happen at the start of the interview when the parameters of the role of the interviewer are made clear. It remains unusual for this not to be understood to the extent that it was and this can be attributed to the nature of the cohort.
- It is difficult to capture the experiences of respondents once their 'stories' have been broken down into themes as in this report. Case Studies as detailed below go some way to rectify this but in this instance, they are relatively short given the concerns about breaking confidentiality. The sample was not homogenous in any sense apart from the fact all respondents appeared to have complicated lives and interviewees through their stories may be too easily identifiable.

- All participants were reassured of confidentiality and care has been taken in terms of annotations of the quotations to ensure this.
- The author would like to thank all those who took part in this evaluation. Many were often extremely distressed during the interviews but were still willing to continue to participate.

MAIN FINDINGS

A: GENERAL ISSUES

1: Nature of the Sample

The patients/client selected to take part in this evaluation were chosen from the allocated list as detailed above but at the same time efforts were made to ensure that there was a cross-sample of those who had different demographic characteristics and those who had been referred to OHC for a range of reasons. The sample selected, similar to the list provided by OHC, was not homogenous in terms of demographics and it was apparent that there was equally a wide variation in terms of health need/s. However, this lack of homogeneity tended to be counterbalanced by the underpinning similarities of the evidently high level of social needs.

It had been assumed nonetheless, that the sample would be similar in nature to that of the 2015 evaluation. It was of note therefore that compared with interviews in the previous evaluation health and health care were not spontaneously discussed. In this cohort for example, there also appeared to be only a very small minority who reported that medical professionals visited their homes on a regular and prescribed basis. Indeed, difficulties with healthcare provision, so much a focus of the previous evaluation, were hardly discussed and rarely emerged without prompting. It was only in the minority of cases that there were suggestions of late or misdiagnosis, lack of accessibility to provision particularly GPs, contradictory information, perceptions of poor care co-ordination and so on.

'I was explaining problems I had with my stomach to my Crohn's consultant ...and my consultant more or less accused me of not taking medication for it... but I was taking it and it took me six months to persuade them to do a colonoscopy and it showed ulceration of the lining of the bowel and it was not responding to treatment...no apologies nothing' (Male, aged 60)

'They thought I had MS for years and now they just say sorry - I just had a one off attack and when I was pregnant, they made me have a termination' (Female, aged 73)

Respondents however appeared to be surprised when asked about their experience of co-ordination of their care and none of those asked reported any problems. Nevertheless, being 'listened to' remained an issue for some.

'You can still go to hospital and some doctors, they just tap on the computer or the table and don't look at you or look down at you or you say something they don't like to hear' (Male, aged 60)

2. Complicated Lives

It became evident during interviews that it was the level and balance of health versus social needs that was the critical issue rather than the level of health or social needs per se. In this way, those who reported spontaneously that their issues were mainly health related, even if they did not require any healthcare at home, tended to be those where the social issues did not seem or were not reported to be quite so overriding. On the other hand, for the vast majority of respondents, there were clearly vast social issues that took precedence over their health problems even though even the latter were often present. Notably too, in some cases, respondents were suffering from debilitating and progressive conditions such as multiple sclerosis, cerebellar ataxia or Parkinson's disease which although forever present, tended to appear to compound or be interdependent upon the social problems. Moreover, it was evident that difficulties such as substance misuse, emotional and/or mental health difficulties frequently simply blended into this melting pot.

Further, for almost all respondents there tended to be one overriding focus of concern. For many this was housing, a factor that very much featured in the previous evaluations.

'It is shit...the area is shit...and all the same shit in hostels...drugs, alcohol, prostitution...the back end of Hackney..they told me I need to get out of here because it is as rough as fuck ...(this hostel) is a shit hole, really bad, really bad'' (Male, aged 44)

'I have lived for ten years...I have had terrible experiences, I can't get down the stairs or up the stairs, my scooter has been vandalised down at the bottom...I have been stabbed and slashed, people are on drugs and drink...I have not even got a cooker and not even a heater...the noise is the ventilator...I can't get into the shower because I can't hold the hose up as I have only one hand...' (Male, aged 43)

'It is a one-bedroomed flat and I am hoping to be moved...the ground floor and the first floor are temporary accommodation so when someone is cooking or burning toast, the fire alarm goes off...my children are suffering from sleep deprivation, the school has concerns...If the lift is not working, the ambulance have concerns about how they would get me out of the property. Obviously I am on the fifth floor, so when the lift breaks down....I just stay here and there was a time when there was no lift for twelve days 'cos the council were waiting for parts and my children didn't go to school so that was quite upsetting. I mean I wasn't planning for the lift not to work but Tesco's were not willing to come up to the fifth floor to make the delivery and so the school went out to do my shopping' (Female, aged 39)

A good number of those interviewed too were living in very difficult conditions with other compounding factors and importantly, they appeared to be fully aware of their poor environment:

'I live on my own. Before I was in another dive, another hovel. This is having a real detrimental effect on my health as I have very severe COPD. I am at the top of the list but am still waiting to be moved...I have damp and the man who came round from the housing said it was damp as there is no ventilation in the flat and no fresh air coming. The windows open but they all need fixing and they said my pneumonia was caused by this flat. The electricity goes off because the box is loose - I am on a concentrator and that is run by electricity and that is not safe and someone from Hackney Housing told me it was dangerous to use. Water drips down into the girls below from the shower but they broke the electricity when they came to fix it'
(Female, aged 53)

'They put me in a bath but I can't get into it as it is too high so they want to put in a shower that I can sit in and use as a wet room but I am waiting to hear about it as I have to let them know what my money is...I can't have a bath - I just take a bowl upstairs and splash with water - I can't remember when I was immersed in water...I only have my hair washed every eight weeks...(the geriatrician) said it was quite dirty in here and said I smoke a lot because all the walls are yellow... about every three weeks (sister) comes in and cleans the floors to make sure they are not slippery'
(Female, aged 74)

'I have a friend who comes to my shopping, cleaning, everything, my laundry...I have no family here - he comes every two weeks for one hour...if he does the cleaning one day then next time he does my shopping...he is illegal in this country and he does things fast...but I can't see anyway, so I don't know...' (Male, aged 49)

Although housing and related issues were recurrent themes, a second common strand underpinning almost all interviews was a sense of isolation that some respondents described in simply graphic detail. Most for example, rarely had visitors.

'We don't have friends...we see no-one...no-one comes here, we are alone' ('Unpaid' Carer of Male, aged 81)

'I know my next door neighbour but I don't see anyone...I was very lonely, it just gets so lonely when you don't have anyone around to talk to...I can talk on the computer but it is not really the same as having a human interaction...the only person I would see would be the person who delivered my food but that would only be here for a few seconds and they drop it in the kitchen for me but on the whole I didn't see anybody, not a single person...nobody' (Female, aged 61)

'I only get out at weekends...I go out with my daughter and she is like my crutch....'
(Female, aged 50)

'It is boring on my own and I am not really a TV person...I listen to the radio and then I watch the shopping channels...All I do is sit there....I am really fed up as I can't do the things that I used to do and I want to get out and I can't...it is SO boring, sitting and doing the same thing every day, over and over, it is so boring...sometimes I get really angry and I get really tearful as it is so boring... it is always the same old, the same old same old, it is not fair' (Female, aged 55)

Although individual situations could be made worse for example by the evidently prevalent low level of literacy³, those with physical difficulties were often especially and explicitly depressed by their situation.

'I have a carer when I press the bell but however nice they are, it is not the same as doing it yourself and you have to get used to that but you never do' (Female, aged 30)

'Sometimes I can walk and sometimes I can't - depends on whether it is a good day or not but when I got the brain tumour, I couldn't even walk across this room, my legs were like jelly and I am so isolated...if I want to go out I need someone with me as now I risk falling...so if I fall, I am on my own...even to the corner shop I can't do it on my own' (Female, aged 61)

Others described how they were embarrassed to see their friends because of the disabilities or of how they suffered indignities, for example finding help when going to the toilet.

'I don't go to church now as my eyes were getting bad, I feel really sad and I was like in the wheelchair and they were all like feeling sorry for me...and I asked this one girl to wheel me to the toilet and she said she was busy and she wasn't so I got really cross...and I used to go the rehab gym and they are threatening to close it and we had to fight for that...and all these things I need to do and used to do and I don't want to just sit in the house and waste away' (Female aged 55)

It appeared that their lives were not so much complex but complicated not least by the ease with which everything could be thrown into disarray. In a number of interviews, respondents broke down simply due to recounting either past or present experiences.

'I have got to the point where I hate being let down by people and it really affects me so I just do things myself...I try to keep the home tidy and try to look after myself. I don't like to rely on people and it is just very, very frustrating and it gets me really, really annoyed. It is lonely' (Female, 50)

Alongside the ever present social needs, equally common was appeared to be a lack of expectations of any kind. Expectations of actual help and support were unquestionably low

³ It was clear that a good number of respondents had a low level of functional literacy and for instance, both the Participant Information Sheet and the Consent Form needed to be read to them.

and respondents tended to be simply reactive to such offers rather than possessing any sense of entitlement. It was clear that for most life was very much a day at a time.

'Yes, it is a day at a time, you never know what the next day can bring it is getting worse' ('Unpaid' Carer of Male, aged 84)

'You never know what is around the corner and if something else happens - you just never know what you are going to need tomorrow - there is always something - so if it not there, you might need it again in the future or something' (Male, aged 60)

3. Carers

As already noted, in a number of interviews, 'unpaid' carers were present. In some cases, they acted as interpreters but in others it quickly became evident that support was needed not necessarily just for the patient/client but instead, for the carers themselves. In these cases, it was difficult at times to maintain the focus upon the patient/client since continually attention was drawn back to the carer.

'I asked for help for me...but also for my mother. I was at that time really depressed because I didn't have and I still don't have a life...we are always there staying with mum and taking care of her...it was about me and my depression' ('Unpaid' Carer of Female, aged 68)

'It is a bit unfair on me...I don't any receive any allowance or anything...I do it because it is my sister...I have been doing for three years...if there are any forms, I have to fill it in...if there is anything that needs posting, it is me and if she needs a stamp, it is me...I mean I will have to go out again in a minute to get the milk' ('Unpaid' Carer of Female, aged 74)

'I told the GP I cannot cope as I go to bed at 2am and 3am to look after him and then to get up as he has to be changed and so I said I just can't cope and how I have lost my memory' ('Unpaid' Carer of Female, aged 81)

In one case, a carer explicitly drew attention to the belief that there was a strong sense of duty involved and it was their responsibility to care for their relative.

'I do the cooking for my parents and there is no time to sit down to relax...I do everything, she can't do baths, the ironing, the cooking, she can't do nothing. I do it all...I do the shopping and I am still working at 12pm at night...I am so very, very tired but this is my job and I accept it' ('Unpaid' Carer of Female, aged 82)

In a further case, there was a respondent who had failing eye sight among other conditions and was reliant on her son who was quite evidently not particularly reliable:

'I want my son to phone my social worker as he has all the details...I keep asking him to get in touch with her but he keeps forgetting but he is young and I don't like to ask...he was supposed to come last night but he did not and he said, mum, I have got my life and I just said I was really, really sorry' (Female, aged 55)

For those in the sample who had been allocated 'paid' carers, there were again problems. These tended to be focussed upon the numbers of hours and their general time-keeping:

'They came at 10.30 today but they were meant to come at 10 but yesterday, they came at 1.30pm and then some days they don't come and I have appointments...and then they put it in the books they have been but I know they haven't' (Male, aged 43)

'We have two hours a day but it is a help but not at all enough because it does not give my mother a chance to do anything or to have a life and he needs more help...he can't do nothing, he needs to be dressed and he needs to have an activity and two hours is definitely not enough...she has no sleep as he is up at 3am and she wakes too and gets upset' ('Unpaid' Carer of Male, aged 81)

B: ONE HACKNEY AND CITY

1. Knowledge of One Hackney and City

For many of those interviewed, there was a good deal of confusion as to the name 'One Hackney and City'. There was confusion such as the difference between One Hackney, One Support, One Housing, Hackney One and so on. One respondent was quite adamant that OHC had changed their name to 'Navigators' and most were unaware of terminology such as 'Care Co-Ordinators' or indeed, 'Navigators'. Although all respondents were clearly registered with OHC, only a few unequivocally said they knew what it was. Most did not but on probing it became evident that the support workers to whom they referred during interviews were those from across the OHC teams within the quadrants. Thus, respondents referred to 'Gareth', 'Ruth', 'Shah', 'Louise', 'Virginia' and so on.

More interesting was that across the board, there was little awareness of whether OHC was part of health or social care or even as one respondent believed, a charity. Most of those interviewed believed it was part of social services even though as in most cases they had been referred by the GP. In the end, information like this seemed unimportant.

'When you need help, you need help, and when help is there you are happy, you don't need to know where it comes from....I don't think they are from health though. Do they help you with your healthcare?' ('Unpaid carer' of Male, aged 81)

2. Perception of the Role and Function of One Hackney and City

During discussions, it was clear that respondents viewed OCH in different paradigms revealing a number of interesting tensions. It was hard to pinpoint for example, the function the provision provided since it was dependent upon the individual patient/client and their individual needs. Further the provision may also have been part of a far wider set of provision of which OHC was merely a part. For this reason alone, it was difficult to draw out the specific service/s OHC offered and to assess it with any precision.

There did seem however, to be a difference in the perception of those who viewed OHC as a specific layer of provision offered as part of the whole package of care and those who tended to perceive it as specific individual piece/s of support separate from but in some way related to 'normal' care. The difference in perception tended to have developed on the basis of experience rather than dependent on anything they had been told.

In the former group were those who considered that OHC would responsive to almost any request and it seemed that it provided an over-arching support. One respondent for example, was an elderly man, cared for by his wife who had had a range of support from OHC. This had included arranging for a befriender, access to someone who could help fill in necessary forms, provision of Dial-A-Ride, organising an advocate for helping with the housing, equipment/aids in the house and so on.

'We had no expectations, he was telling us and asking us what our problems were and what we needed, they were very, very caring and supportive...you are confined indoors with a sick person, it is not easy...and now the shopping is done and he is eating better. The help has always been accessible - you just have to tell them where you need help and they are very approachable and you can talk to them and be open to them' ('Unpaid' Carer of Male, aged 81)

In another instance, the following respondent had been offered psychiatric support, access to the Alcohol Dependency Unit, a befriender, voluntary work as well as attempts to fast track his access to CBT.

'I don't know what I couldn't ask them - they have done everything I have asked for and done everything they could really. And they have now given me numbers for Crisis and the Samaritans - I have all these numbers to ring up if do get fucked up - and I can ring them for anything too...I think they put pressure on the CBT people for me and now I have got that after a whole year- there is finally light at the end of the tunnel and I wouldn't have got that without them' (Male, aged 44)

In the same way one woman believed that their provision cut across almost all other provision available.

'I used to have a psychologist and used to have sessions every two weeks but she went to America and (XX) is now going to find whether there has been a

replacement...and they have chased up the community nurse...and because of her I am now registered with Dial-A-Ride and I have a Freedom Pass...and I have a bath seat and in the toilet I have got a toilet frame to help me and when I cook, I have a high stool...she is really pushing things for me and will organise my transport now to take me to the appointments and is chasing my appointments too with my consultant...It has been amazing...I mean things have started to move as everything had been so stagnant...' (Female, aged 50)

'I would probably call them for anything - I mean I have done and even if they are not there, they have called me back to see what the problem is' (Female, aged 60)

In contrast, were those in the latter group who appeared to think that OHC was more of a reactive and related service who were only able to offer one particular part of provision such as befrienders, access to support, access to equipment and so on.

'I went to One Hackney for emotional support, I spoke to Bikur Cholim and asked for a therapist and One Hackney subsidised this for me...I didn't meet anyone from One Hackney and I know nothing else about them at all - do they do anything else?' (Female, aged 30)

'The social worker I had really pushed because I had waited years for the council to do the kitchen and bathroom and she really pushed it...I have a befriender but that was through the GP and then there is (XX), I think he is One Hackney and he rings me a lot and asks how things are going and he told me what he did and what he didn't do but I want to ring the social worker as I want to go to a club and the social worker does that' (Female, aged 55)

'What they did provide for me was very good and straight away - I found them marvellous ...I have someone too who rings me and he is from One Hackney - he can't help with the carer as he has to go through social services but he does ask me what I need in the house and he gave me his number' ('Unpaid Carer' for Male, aged 81)

This all may well have been because they had not and appeared unlikely to ask for other support but it also confirmed that although OHC provided a team of support cutting across professional and organisational boundaries, from the perspective of these interviewees, it appeared that provision remained relatively siloed:

'I would go to my GP for more support but I would feel embarrassed. I don't want to as I also do not have the time...One Hackney only provide the carer' ('Unpaid' Carer for Female, aged 68)

'I mean if I was feeling low or something, I would phone my nurse...I would feel comfortable talking to (XX from OHC) as I clicked with her straight away ...but that is

not her role - her role is helping you with things like taxis, Dial-A-Ride, practical things - I mean I wouldn't burden her with psychological things as that is not her role'
(Female, aged 50)

In one case, the social worker, believed to be from OHC had been very clear as to her role but interestingly in contrast, the mental health practitioner in the same case had been particularly supportive and had evidently provided an alternative source of support and help.

'I think (OH) are from the council as (XX) is from the council and I know the mental health lady is from them too and I have been able to access OT and the fire brigade and the alarm, and psychotherapy but when I asked for help about the forms she said she does not do forms and she would put me through to another gentleman who does benefits but I kept calling and calling and he was apparently on holiday and it was over a month and out of panic I just went straight to Family Mosaic and they opened up my case again...and once I asked her to do some shopping, I said I didn't know if she could do it and she said that was not her remit and she was not supposed to do that for me so I called the school' (Female, aged 39)

Indeed, depending on their own individual experience, almost all respondents were very clear as to what individuals within OHC did or did not do but this of course, was not necessarily consistent across the sample. Nonetheless almost all were aware that OHC were unable to help with housing, a fact that caused some consternation especially for those who were in dire need of new accommodation.

'I wish they could help me with the housing - it is not their fault I know but it would help - I have to continue to do it and to do the bidding but we are both ill and I am tired' ('Unpaid' Carer of Male, aged 81)

Most too, particularly those in the latter group above also did not think that OHC had anything to do or could help in any way with health provision.

'And (XX) has helped a lot channelling the right people but they just don't do health or appointments and things like that' ('Unpaid' Carer of Male, aged 81)

More interesting was some evidence that once a service had been provided, any further provision had to be sought through normal referral routes and mainstream services thus limiting both the role and the remit of OHC provision. Two families who had received care for their relatives for example, felt very strongly that it was not enough and it had not changed their own life as carers to any significant degree.

'My life has not changed...I don't want to ask for more help as I don't want to put myself forward...it is not enough help as three hours during the day. Nothing changes,

I have to be here all the evening, at night, I don't go out ever...and it may be the wrong information but I heard from people that they wouldn't give night care anymore...' ('Unpaid' Carer of Female, aged 68)

'I have been back to Bikur Cholim to say it was not enough but they told me I had to call up social services and they have to come and assess me....and they have told me I have to go to a clinic (for psychiatric support)' ('Unpaid' Carer of Male, aged 81)

And for some who had a particular quest, the service provided although excellent, was seen to be somewhat restrictive:

'They have not told me what they can or can't do and I am happy doing the voluntary work and going out and happy I am going to college and I have learnt things but what I want to learn is more English and get a job and I want more' (Male, aged 49)

Further, a number of interviewees also felt that it would be hugely beneficial not simply for the provision to be on-going as their needs might develop and change but for the connection itself with the OHC professionals to continue on a regular basis. It was evident that this had clearly happened in some cases and a good many respondents reported that they had had regular contact with particular individuals even when a particular provision had ended.

'I can still contact them as they have given me their mobile numbers but I still think it would be better if they did it in blocks, see you for a month, come back in three months time and see you again - 'cos that means you still think you are parked, in contact' (Male, aged 43)

'I do think they should keep in touch just for anything they have put us forward for or whatever and we haven't heard feedback - they need to keep us informed about what is happening, or really if there is anything else' (Female, aged 50)

For a minority too, there was a feeling that the role should include more regular contact while they were still under the auspices of OHC.

'I think it could be more involved like telling me what is happening, what is going on, where are we with this and where are we with that...I have not even got a cooker...and then last Friday, I was waiting on a call (from the befriender) but nothing so I don't even know what is happening' (Male, aged 44)

'I think (XX) is really, really nice....and she helped me get my kitchen and bathroom done ...I think she has left me now but I don't know and maybe they just think I am ok now' (Female, aged 55)

A second paradigm cutting across the above underlined a further division between those who viewed OHC as merely but importantly, a body that could facilitate and enable faster

access to provision and those who saw them as providing a particular service that they either had not encountered previously or one they would not otherwise have been able to access.

'I was very thankful for what they did and helped me with...and otherwise I would have been just stuck in here...they gave me some services and I know now where to go and I can phone up MIND or go to the Volunteer Centre...I think it has really provided faster services for me and even though it is another person to talk to so you don't feel isolated and you know they are going to come and see you' (Male, aged 44)

'It is definitely quicker than social services, they just ignore you and then let you down...they are not helpful. One Hackney is so much more on the ball...they are there to help and they come straight away - they don't push you off and they have a bit more push as they are a company...they don't really offer anything different just faster services really' ('Unpaid Carer' of Male, aged 81)

In terms of those within the second category, the main 'new' services provided were befriending, access to Hackney Volunteer Centre, St Mary's Garden, college or help with applying for Taxi Cards or Dial-A-Ride and other such provision. In these cases, OHC were considered to be the signpost:

'I think I see them as pointing you in the right direction to help you get the help to make your recoveries or get back in the community' (Male, aged 44)

'She (OHC) will always offer a helping hand and if she can't help she will point you in the right direction or tell you who could help you or put you in touch with someone who could help you- they put things in motion'

In two such cases respondents had turned to Bikur Cholim directly when they were in need of help and in their view this had enabled them to bypass all other referral routes.

In this sense, the role and function of OHC appeared somewhat amorphous and mercurial and led some to report that they would have liked greater clarity and more information.

'Maybe they did say but it would probably help me if I had got a bit more of a definition of what her role was - they should definitely have a list or a leaflet or something to let the person they are dealing with what they can do for them and what they can't' (Female, aged 50)

'If they had some information that could help me, I think they would give it to me but information would be useful about everything' (Female, aged 60)

'I think I see them just for support...I don't see them as helping me emotionally but it would be useful to know what they did do and what they didn't do' (Male, aged 44)

3. Referral Process

For most too, the referral process was hazy. After prompting, the majority believed their GP had referred them but others thought it might have been the Homerton Hospital. Either way most appeared to have had few expectations

'I had no expectations, not really, I just asked for someone to talk to really because I don't get out...my bones ache and my muscles don't respond to me...' (Female, aged 60)

'It was the GP but I can't remember what they said and I am not sure really, I cannot remember when the doctor first referred me - I can just about remember what I did yesterday and then the GP kept on emailing my consultant and then she one day said she was going to put me forward to these One Hackney people and they came and they have been absolutely amazing' (Female, aged 50)

For the majority of those interviewed, there was a varying time gap between when they thought they had been referred and when someone came to see or telephoned them. Few in the first instance connected the two events.

'I told the GP that I can't cope any more - I can't change, I can't do nothing, I can't wash, nothing - there is nothing I can do - I can't cook, I can't do nothing, nothing, nothing and I was crying in his office and he put a fax and a text through whatever and the next week I got a letter from the nurse - she is from Hackney Wick, not One Hackney' (Male, aged 44)

'I didn't know they were coming, no-one told me. This bloke phoned me and said they would come and visit you, bla, bla, bla and I thought what the fuck is this and they are arrived and they were as good as gold...but I have no idea why they came and where from but do they work for the NHS?' (Male, aged 44)

There were a small number of examples of respondents reporting that someone had been but never came back but in the majority of cases this had not been the case. In one incident, the respondent reported they thought they had been offered gym classes but these had never been followed up and in another, they thought the fact that the person who originally came never returned was possibly due to the fact they had been admitted to hospital.

'Did they get me the duckboard and shower? And the name, (X), rings a bell...I think they asked about the shower and meals on wheels...Do they wear white uniform with green piping? They was going to put grab rails in but then I had an episode and you know what might have happened, I had gone into hospital as I couldn't breathe and they take me in...I think they said they would follow it up - I must get back in contact with them... can I Google them? It was a long time ago now though and there was no

follow up - I am still battling with my illness and everything so I put them to the back of my mind' (Female, aged 53)

Two respondents reported that someone had come whom they assumed to be from One Hackney but that this first approach simply had not worked out. Instead, in both cases they were re-visited reaping reportedly good results as one explained.

'I don't know who the first people were but they sounded really positive...and it was a girl with her assistant and then another person made an appointment to come and see me and to be honest with you, nothing, she came, she saw me and something made me think nothing is going to happen here...and then she sat down to talk and I had to sign to say I was happy with the service but I thought you haven't done anything yet so how could I sign the form...and then they sent me a letter to say I haven't used their services...and then (XX) appeared last year after these other people signed me off...I was surprised...but she has been amazing and not let me down and I have faith in her' (Female, aged 50)

More relevantly, it appeared in a few cases that once the patient/client had seen OHC and then subsequently had been referred into a particular and regular service, the waiting times were long.

'About two or three months ago I had a call from Occupational Therapy from the council and I asked who he was and he said that (OHC) had made the referral but he did apologise for taking several months to get around...he got adaptations in the bathroom...it took a long time' (Female, 39)

'So I was referred to MIND and they thought they could offer me two services but they couldn't so I had to wait a long time for another referral to go out...' (Male, aged 44)

4. Services Received

Whatever the difficulties in some cases, for almost all of those interviewed, the overall support and help One Hackney provided was overwhelming well-received. The professionals involved were seen as 'wicked', 'kind', 'caring', 'supportive' and so forth. There were simply no negative comments about any of the professionals involved apart from the lack of regular access to the 'Floating Support Workers' but this was only reported in two cases. In particular, it was made explicit by some that although OHC were part of the system and thus far more proficient and helpful than any neighbour might be, they also managed through their approach and level of understanding to stand apart, thus engendering trust.

'I know she cared as you can see in people's eyes if they care - you can see she cares for me seriously...they are good people...I mean I hate social workers and I hate the

system but even if they are part of the system, I can still trust them, definitely' (Male, aged 44)

'Like they are on the same level...they didn't have airs and graces and like putting on a voice - it made me feel comfortable' ('Unpaid' Carer of Female, aged 74)

'They are so lovely and very good and made her very happy...She is confident they are trustworthy and now she feels more confident and much more safer. The trust is so important and she feels comfortable with them' ('Unpaid' Carer/Interpreter for Female, aged 57)

More importantly, they were seen as 'good people' and although the provision might well depend on the vagaries of individuals, complaints were hard to come by. Apart from anything else they were seen to 'take you seriously' and were not judgemental:

'They have really helped me and they are such good people...they do everything they can to help - not condescending, not saying you can't flipping do this, you are not capable' (Male, aged 43)

'I have met some really lovely people through itand that is an achievement I think. They care for you and when you know there is somebody trying to fight your corner and doing whatever they can to help you, even something small it is a token, a good gesture...they understand you and they don't judge you for your mental health problems or for your physical problems or whatever you are going through - they just judge you for you and value you as a person' (Male, aged 44)

As critical seemed to be the engendering of a level of confidence which appeared to go hand in hand with a sense of replacing isolation with safety and security:

'You build up that relationship with (XX) and you feel you have someone to talk to about your problems even if it is just another person but you don't feel so isolated as you know you can talk to them and you know they are going to come and see you...they have helped me as I have had to deal with other people again so it has given me confidence' (Male, aged 60)

'They do make you feel a bit more confident because you know that they do care and you know that they are there if you call them...They are there when you need them...I am independent and you only use them when you need them...perhaps it's a bit more secure, more safe but definitely a bit more confidence' (Male, aged 44)

'I wouldn't say it is more confidence but what they have done is put things in care for me - so if I was to have a fall then someone would come out to me, I wouldn't say confident...maybe safer' (Female, aged 39)

The vast majority revealed during interview the broad range of support that had been offered and accepted. This included:

- Access to psychotherapy
- Access to occupational therapy
- Chasing up appointments and particular professionals such as community nurses
- Chasing up the council for repairs and renovations
- Access to appropriate equipment such as bathroom aids, alarms etc
- Access to support for 'form filling' for benefits, Freedom Passes etc
- Access to 'home helps'
- Access to Hackney Volunteer Centre
- Access to charities such as MIND
- Access to befriending services

In a minority of cases nonetheless, it was clear there had been a level of 'disengagement' with usually part of the provision offered. One respondent for example, had refused to use the equipment such as the walking frame that had been offered and another and been unable to engage with the psychotherapy services that had visited him at home.

Finally, there was one respondent who believed that they now visited the GP less often as a result of the OHC intervention:

'We do go to the GP less in the sense that I have some help with the cleaner and the carer comes round so I am not as sick as before - I used to go more often because of my health and for him because I could not look after him' ('Unpaid' Carer of Male, aged 81)

5. Closure

Across the board there was tremendous disappointment as to the impending closure of the provision. Only two respondents had had their provision 'officially' closed but many, although not all, were aware it would happen. Some interviewees were clearly distraught at the thought, reminding them of their personal complicated lives. A number too, broke down during interview at this point:

'(If they stopped coming...)I would be really sad, really, really sad' (Female, aged 55)

'I hear they are closing....I am very upset about it as they were very helpful - let's see without them what it is going to be...They haven't said anything to me yet...My parents will feel the same as me - they will feel lost - who will they turn to? How quickly will they get a response if they need something? I don't know' ('Unpaid Carer' of Male, aged 84)

'She will be so down...The first time in her life, she has got someone to help and if they close down, she can't deal with nothing, she doesn't have someone behind her and she trusts One Hackney so much and she says she will have no-one to trust' ('Unpaid' Carer/Interpreter of Female, aged 57)

'I would feel helpless, they have been helpful and you don't know where to turn if they close, you just don't know where to go...helpless, hopeless' ('Unpaid Carer, of Male, aged 81)

'I will feel upset - I will miss so much that relationship and contact as (XX) has been always there if I need her...I will feel really, really gutted...it has been that feeling of hope' (Female, aged 50)

'You get depressed regarding closure. Closure is a bad word for someone who is depressed - it means finished, it means it is all over' (Male, aged 44)

Where respondents had been contacted on a regular basis, there was particular consternation.

'I can phone (XX) but it is not the same as for people like me, we need people to phone us, to check up to see and to see what has happened' (Female, aged 60)

'I think they have helped me but I would like them not to have discharged me and stayed with me longer...that would have been like even if it was once every two months you had a catch up or something like that - just for a twelve month period...just to check on you...to see how your progress grows through those stages... and flag up things not going right...' (Male, aged 43)

As noted above, most interviewees argued that they had not had particular or specific expectations of OHC. It was notable nonetheless that there was not simply disappointment about closure but also a belief that expectations had somehow not been fulfilled. It was almost as if once contact had been made in some cases, OHC had created unanticipated expectations.

'(XX) was going to get the taxi card and Dial-A-Ride and the bus pass was from the Stroke Unit but I have not even heard back from them... I have not got nothing - I have been out of hospital for a year in June and still now Freedom Pass' (Male, aged 44)

'I've met other people who have seen One Hackney and I think some people might have far too bigger expectations...I can understand it if you are like me you want things sorted when things are wrong but things just can't be sorted can they? Not for people like us' (Male, aged 49)

'Like I didn't know what they were going to do but I did say I would go to an exercise class...but she never replied back to me...I am not that bothered but I do think they could get back to me - I think I expected them too' (Female, aged 53)

CASE STUDIES

The following case studies are purely based on the discussions held.

GENERAL

CASE STUDY 1

XX is 44 years lives alone and rents one room in a privately owned house. He has a number of debilitating after effects from a stroke and additionally is diabetic and has a heart condition. He explained that he has no heating and no cooker, just a microwave and only eats pre-packaged food. He has a shower in his room but he is unable to use it as he only has use of one hand and thus unable to hold the hose. He is unable to sleep on the bed and instead has to sleep in a reclining chair. It takes him a long time due to his condition to go up and down stairs and is also fearful in case he falls since at 17.5 stone, neighbours *'are not going to be able to carry me up and down and I don't want to depend on them'*. He is not happy being *'dependent'* on anyone. He explained how there had been a good deal of trouble in the house and he had his door kicked in and he has also been *'stabbed and slashed'*. His mobility scooter has been vandalised and is no longer in use. He was once a scaffolder but since his stroke he has been unable to work. He has friends but given his condition, he can no longer visit them as he is unable to get there. He has no family in London.

He has carers but they come at different times of the day and sometimes simply do not turn up. More recently he broke his shoulder while at St Leonard's hospital where he was attending physiotherapy. He reported he has been allocated gym classes but the hospital have failed to let him know any details about when and where they are.

The GP referred him to OHC since he *'was not coping. I told the GP I can't do nothing, I can't wash, nothing, I can't cook, there is nothing I can do, nothing, nothing, nothing'*. The following week he received a letter from *'a nurse'* and also met a *'co-ordinator'*. Through OHC, he has been told that he was now on the housing list of a charity and that he was to be rehoused at the *'end of December, January at the latest and I am still here'*. OHC also organised for him to have the carers from social services. He has been allocated a befriender but so far has only been able to meet him once, partly through miscommunication. One of the OHC team gave him a *'hot plate thing - it is my only source of heat but it is breaking down now'*. He was referred to the Stroke Project but a year later still has not received his *'Taxi Card'* or his *'Freedom Pass'*. He has also been allocated a *'Floating Support Workers'* but he only sees him once a month. When he confronted this worker, he was simply told, *'I have 29 other clients to see'*. He commented that the worker always waits until one day short of the prescribed 30 days and then telephones.

He feels OHC *'helped him'* and the people he met were *'nice', 'understanding'* and gave him *'a good service'*. *'They are a sympathetic ear but I want action'* and he would have liked

more contact and to be kept informed more regularly about progress on his concerns. He will *'miss it'* when it shuts and would like to maintain regular contact.

CASE STUDY 2

XX is 55 years and suffers from a debilitating disease. She finds it hard to walk and is losing her sight. One of her three sons does live with her but he is out a good deal and *'she doesn't like to bother him'*. She has lived in the flat for 30 years. Her son does her shopping for her on-line. Her benefits had been stopped at one time but that is now rectified. Recently her condition was made worse following the dislocation of her shoulder. She has also been run over twice. She very occasionally goes to church and her children take her in her wheelchair when she needs to go to the GP.

She no longer goes to the hospital as there is nothing they can do for her. She has had physiotherapy but would like it again. She did have a social worker and would like to get in touch with them again as she wants to go to a club or a day centre. She is waiting for her son to telephone them but he *'keeps forgetting'*. The social worker who was *'really nice'* did organise for her kitchen and bathroom to be re-done since she had been waiting for years,

She described how lonely and fed up she is. She feels embarrassed about her disabilities and has few friends now. She has a befriender whom she believes was referred by her GP and would be *'really sad if they stopped coming...as it is someone to talk to'* and does not *'want to sit in the house and waste away'*. She also talked about another person whom was also believed to be from the surgery who is connected to the befrienders. This person still phones her regularly and she would be upset if he no longer contacted her since *'he makes sure things are going ok and sees if she is unhappy'*. She does not think that he or the befriender would be able to help with finding a club or day centre to go to.

She was unaware of the name of 'One Hackney'.

CASE STUDY 3

A personal friend and 'carer' was present throughout the interview and acted as an interpreter.

XX is 57 years and has lived in her flat for 30 years. She has a particularly debilitating long-term condition and is now going blind. She takes morphine regularly. She also has no functional literacy in either her first language or English. She lives on her own following the death of her husband and does not have children. She reported how she had had ten pregnancies but all had died at birth. She has to attend a specific clinic at two different hospitals regularly but otherwise rarely goes out although she does have an electric car. The GP will visit her at home if necessary.

She reported that she believed that the Homerton Hospital referred her to OHC. Two months later a man phoned and subsequently visited. They arranged for someone to check

the safety of the house and also for a younger befriender. OHC have also helped her to sort out her letters which she could not read and latterly her various appointments. She also believes that her kitchen was re-done because of OHC and that her window frames will be renovated as well. Through the interpreter she commented, *'For the first time, she has got someone to help and if they close down, she can't deal with nothing...she trusts Hackney so much'*. She was demonstrably very upset at the closure.

CASE STUDY 4

XX is 30 years and has a neurological condition. She lives with her husband in sheltered accommodation who also is disabled. They have carers, organised by the care home, on a regular basis throughout the day. She attends various hospitals using hospital transport on a regular basis. She also does have a part-time job working for a charity.

She turned to Bikur Cholim for *'emotional help'* and they referred her to OHC. She believes that OHC subsidised the fees for the therapist she was allocated. She said she did not meet anyone from OHC and only met an intermediary from Bikur Cholim. She had no information about OHC and was unaware of their role or their remit.

CASE STUDY 5

XX is 43 years and has lived in his flat on his own for 14 years. He has no internet and was recently disconnected from the gas supply and now has no cooker. He does have a microwave. He once had a managerial job but had a heart attack and was subsequently knocked down by a car. He also has Crohn's Disease and reported he suffered from PTSD and anxiety. He remains on a ten month waiting list for CBT but adds that he is reluctant to go out because of his fear of noise, fast cars and so on. His condition rendered him unable to go out even to buy food. He would spend weeks on his own.

His GP referred him to OHC since it was felt he had too much to manage with the Crohn's Disease and a recent diagnosis of *'severe depression and severe anxiety'*. He had to wait at least four weeks *'before I heard from them and she had to keep chasing them up for me'*. When OHC came, he was in the first instance referred to MIND in the anticipation he would be allocated a Welfare Rights Advisor and a Support Worker. However, he was only able to have the former but not the latter. He had waited eight weeks for referral to MIND. He then waited a further six weeks for a referral to Family Mosaic for a Support Worker. He was unable to be referred for counselling at home because of the uncertainty of the future of OHC who also did not want to take him off the waiting list for CBT at St Leonard's. He has additionally been referred to Hackney Volunteer Centre and has been put on the Step Up Programme which he believes has been hugely beneficial. He now additionally has a befriender as well as a mentor to help him look for volunteering work when he is ready.

He feels OHC have done a good deal for him including improving his confidence and they are *'lovely people'*. They have also kept him informed and would always return telephone calls

immediately. He feels that without them he would still *'have been stuck in here'*. The befriending was particularly beneficial in that he could go out and talk to someone *'about how he was feeling...and you have someone to talk to about your problems and you don't feel so isolated'*. Although disappointed about the closure of OHC, he remains involved with the Hackney Volunteer Centre and the benefits it provides.

The only criticism he has is of the 'Floating Support Worker' who is *'disorganised sometimes'*. He also drew attention to the long waiting times in the various referrals, the initial miscommunication and the lack of information about precisely the services that MIND could provide.

CASE STUDY 6

XX is 53 years and has lived in the country for 33 years. She has lived in her present flat, with her partner for about 15 years. She has cancer and now has a colostomy bag. No healthcare staff visit her at home apart from a District Nurse who came once when she was discharged from hospital. She has check-ups at the hospital every two months. She is unable to work or receive benefits as she *'does not have the right papers'*.

She had not heard of OHC but commented that at one time *'a girl came but never came back'*. Apparently she talked about *'my health and stress but she never came back'*. She was offered exercise classes but she was never told any more about them. She reported that she was *'not bothered. I am never really bothered'*

CASE STUDY 7

XX is 49 years and lives on his own. He has been in the UK for 23 years and is blind. He has a friend who is an illegal immigrant who comes to help him every two weeks in order to do either his cleaning or shopping. He also reports he has someone whom he believed was from an organisation called 'Charity World' who comes every two weeks for an hour.

He is unaware of OHC but does know the name of one of the workers who he says put him in touch with a woman who took him to the Homerton to do *'clay work'*. He also says that he went to Victoria Park to do some gardening. He now goes to college, about which he is very pleased since it has improved his English. He believes that these people have been a huge help and keep in contact with him. Now however, he wants more and needs to improve his English further so he can find a job and feels that he would like them to provide him with more options rather than the voluntary work he has so far done.

CASE STUDY 8

XX is 53 years and has lived in the present flat for three years. One of her sons is presently living with her. She reports that she has *'severe'* COPD, asthma and depression. She is on oxygen that is delivered regularly to the flat but no healthcare professionals visit. The chemist delivers all her prescriptions. She has no help with her depression which often

results in hospital admissions since when she is depressed, she does not eat and her *'body starts shutting down'*. She says she is unable to cook on her gas cooker because of her oxygen. Her sister comes occasionally to help. She refers to her living conditions as, *'hovel that is having a real detriment'* to her health conditions. She is presently unable to get up and down the stairs so she remains alone in the flat and never goes out. There is no ventilation in the flat and no fresh air coming in. All the windows need mending and the electricity has recently been declared unsafe by Hackney Homes but nothing has yet been done. She has a carer for one hour a day whom she likes and whom she thinks was organised by the respiratory nurse in hospital. She reported she has been classified as *'Grade A'* and has all the appropriate medical evidence but is still waiting to be moved by the council. She has little faith in her GP who does not come and see her even when she has to take her *'Rescue Pack'*.

She has slight recollection of OHC but cannot really remember. Her initial thought was that they were the *'housing people'*. She later remembers that someone did come about two years ago to visit but that they may have been in a uniform. At the time she was given a duckboard for the bath and they fitted a shower both of which were done *'in nanoseconds'*. They were going to put in grab rails, offer her a perching stool and also provide her with Meals on Wheels but then she was admitted to hospital. She noted how nice they were and *'really respectful'*. It does bother her however, that they never came back and never contacted her again as *'they were the only people to help her and make her life a little bit easier'*.

CASE STUDY 9

XX is 50 years and lives with her partner and daughter in a flat. She suffers from a progressive long-term debilitating condition. She only gets out at weekends when she has support from her daughter. Her partner is often not there as he works long hours. As her illness progresses she is able to do less and less including cooking. She is becoming more and more frustrated with her condition. She is under the UCH and the National Hospital for Neurology and Neurosurgery, Queen's Square. She is also under the Homerton Hospital in which she has little faith not least because her community nurse has been totally unreliable and has not been seen since December.

She recalled how her first encounter with OHC had not been positive. She cannot remember when her GP referred her but someone did come and see her last year and told her about what help she would be able to receive including help with housing and with benefits. She discovered however that she was not entitled to a number of the benefits they offered. Someone else subsequently came and asked her to sign a form to say that she was happy with the services she had received. She told them she should not sign the form because she had not received any services but she did anyway. She was then sent a letter to say she had been taken *'off the books'*. Some length of time later, another woman came who has subsequently worked out extremely well. She is now registered with Dial-A-Ride

and a taxi service added to which the woman visits regularly for a chat. The woman has also chased up the community nurse and arranged for the psychologist to visit her at home. XX would however, like more information about the services that could be provided, perhaps in the form of a leaflet. She is aware however that it is not the woman's role to help with emotional problems but is confident that if the woman is unable to help, she will be able to point her in the right direction.

XX stated that she will be upset when the service closes as she feels that she has been able to *'just pick up the phone, or email her and she always replies. I will miss that relationship and contact with her as she is always there when I need her...she is one in a million'*. She believes that the experience has made her more confident and that although she would not necessarily have been any worse off without the woman's help, *'she has just been amazing in helping me to apply for things and get things that would help me'*. She adds that she may be *'lost without her'*.

CASE STUDY 10

XX aged 60, lives alone in a flat and has had now had cancer three times. The most recent was a brain tumour which affected her walking, balance as well as her cognitive facilities. Her three sons live out of the country but she speaks to them regularly on Skype. She has a friend who comes to clean for her. She is regularly in and out of hospital.

Her GP referred her to OHC and to the befriending agency *'because I was so isolated and did not have anyone coming here. I would go weeks without seeing anyone...I said I was very lonely'*. She recalls how sometimes she could go for a month without seeing anyone and has only one friend from school. The man who subsequently came has organised for a taxi-card and she is now registered with Dial-A- Ride. He also came along with someone else from OHC and now has been allocated a befriender. The process was quick and everyone has been very helpful. She has been assessed by social services but they have told her that she does not need any care which she does not think is appropriate. They have nonetheless, put rails in the bathroom and given her a zimmer frame. She has been offered therapy but feels she does not need it at the moment. She also now has an alarm on her if she were to fall.

She is disappointed that the service is coming to an end but she has been given a contact number and has been told she can telephone whenever she needs to. She is concerned that the man may get another job and will no longer have time for her. *'He was different and always willing to talk and listen and I didn't feel put down when as if I was doing something wrong when I was talking to him. I felt confident and felt like he was helping me even if he couldn't do anything, just to listen to me. I could talk to him'*. In general, she has only had positive experiences with OHC. They were never *'condescending'* and she thinks they have inspired confidence in her *'because you know they do care and they are there if you call*

them'. She has been told however, that the befriender will continue. She argues that information would be useful as to the full remit of their services.

CASE STUDY 11

XX is aged 30 and lives on the fifth floor flat with her two small children. It is only a one-bedroomed flat and she has to sleep in the sitting room. She has lived there for three years, having fled from domestic violence and sexual abuse. She has been diagnosed as bi-polar and personality disorder and also has osteoporosis. She is awaiting an operation presently. Beneath her in the block is temporary accommodation and the fire alarm frequently rings which means the whole family are suffering from sleep deprivation. Recently the lift broke down and she and the children had to stay in the flat for twelve days before it was mended. Tesco's would not carry the on-line shopping up the stairs so she had to ask the school to help with some provisions even though the children were not able to attend school during that time. In particular, the ambulance service has been concerned that they would not be able to carry her from the flat if the lift was not working.

She is not clear who or what OHC is but is aware of and deals with one of the social workers from one of the quadrant teams. She believes that it was the GP who had referred her to social services. Previous to this a man had called but XX felt that they did not seem to have the right verification details. She recalls that the GP referred her because of concern that her daughter was doing too much of the caring for her mother. The second person from social services who came was a woman who when she first arrived, brought with her a mental health worker. They initially said they would try and enable her to move flats but then said that was beyond their remit. She was then referred to another gentleman to help her fill in the appropriate forms for the housing. He however, has been very hard to reach and she kept calling him. In the end, the mental health worker suggested that she helped but then XX decided to go straight to Family Mosaic who had previously helped her when had an issue of domestic violence. Through the mental health worker, she is now receiving psychotherapy. She has though, been given an alarm and now the fire brigade come and check to see if she is all right when they are called to the block. She was also referred to occupational therapy who after a three month wait have been to assess the flat for adaptations.

Finally, she had applied to the Learning Trust for help with her children but the social worker has told her the application has been rejected, although she has not sent the letter to her. The school and Children's Services are now dealing with this as the social worker was not able to help and did not provide a copy of the letter.

XX feels OHC are *'good - on a scale of 10, I would say seven'* but believes the communication could be better. It was hard to reach the social worker and XX had sometimes to go through the mental health worker to reach them. The service was fast, good and they were *'very on the ball'*. She also believed it reduced her anxiety simply *'that someone is out there thinking*

of you and wanting to help you'. She did feel though, that she should not have had to chase them repeatedly and believes that the social worker should have *'pushed a bit more'* for help to get the children to and from school.

She has not been told officially that the provision has ended and her worker from Family Mosaic has advised her that she should presume it is still available.

CASE STUDY 12

XX is 44 years and lives in one room in a hostel. He suffers from PTSD and has recently been discharged from *'mental hospital'*. He hates the hostel as he describes it as *'shit - drugs, alcohol, prostitution'*. He is concerned he will be made homeless.

He had no idea he had been referred to OHC until *'this bloke phoned me and said he would come and visit'*. They arrived and *'were as good as gold'*. They said they would try and arrange housing and will provide other services too. Since then he has had access to the Alcohol Dependency Unit, WDP and psychiatric help. He has additionally been allocated a befriender. The mental health worker who subsequently came, *'was wicked, very caring, doing her job absolutely perfectly'*. He has now additionally been referred to One Support. He also has to appeal against the latest benefits ruling that said he was *'not crazy enough'*. More recently he has been given telephone numbers for the Samaritans and Crisis if he were to need them.

He believes that OHC have done everything in their power to help him and would not be able to do anything else. *'They have kind of given me confidence - just to get out more and stuff - they have done 100% right'*. Genuinely believing that they cared for him (*'I know she cared as you can see in people's eyes they care'*), he is looking forward to the befriender as it, *'just gives you a bit of a fucking lift - just to be a bit more social - gets you out'*. He trusts OHC implicitly even though they are part of the system he despises. Finally, because of the psychiatric help, *'he now feels there is light at the end of the tunnel'*. Although he has nothing but praise for OHC, he suggested that they should come and see you on a regular basis, perhaps every three months. He added at the end of the interview that *'closure'* was a difficult word for someone with depression.

THOSE WITH CARERS:

CASE STUDY 13

XX is 68 years and has a progressive and debilitating long-term condition. She lives with her husband and two of her three daughters periodically stay there. The family have been in this country for over 20 years. A third daughter, YY, is there almost permanently in order to look after her every evening/night. YY was present during the interview since she was able to interpret for her mother who was only able to speak a very little. YY reported that she had been to the GP and broke down during the consultation because of the pressure she was

under in trying to cope with her mother. At that time she felt she was *'mentally sick'*. Her father is also elderly but was reported to manage relatively well. YY works in the day but is tied to the flat with her parents every evening and night. Her husband also lives there but he also works much of the time. YY is rarely, if ever, able to go out. The GP referred the family to OHC and *'social services'* subsequently visited, the forms were completed and her mother was allocated a carer but only for three hours during the day. This, of course, does not affect YY and feels that *'nothing changes in my life'*. YY understands from her friends that it will not be possible to have *'night carers'*. YY was also referred by the GP to a psychologist but she found that this was no help either since sessions were only offered when she was working. She did attend once but it was not possible to have any more time off work. During the interview she reported that she remained depressed and was particularly sad since she wanted children. She was very distressed during the interview. This has been made worse by the state of her mother, who *'hates herself'* and no longer wishes to see anyone outside the immediate family due to her condition. Her mother has also refused to use some of the equipment they have been given. Recently for some unknown reason the Disability Living Allowance has been stopped and they now have to reapply. YY had *'heard of One Hackney'* but was unsure what they did. She did think that the social worker who came had come because of One Hackney.

CASE STUDY 14

XX is 84 years, *'old and frail'*, has a leaking heart valve and *'heart failure'*. He rarely gets out of bed and finds it harder and harder to do anything. He is unable to wash or clean his teeth. He was also reported by his family to have OCD which is on-going and becoming harder to manage. He and his wife have only been in the country six years but already had a daughter, YY, living here who managed to find them the flat. XX and his wife live on their own but YY is there almost permanently. She herself, has ten children of her own and finds it very hard to manage everything. XX's wife is also old and frail. XX has few friends but occasionally he manages to go to the synagogue.

YY called Bikur Cholim, OHC visited and then social services came. XX was allocated two hours a day care only which was seen to be a help but it is *'not at all enough because it does not give my mother a chance to go out and have a life'*. She has asked Bikur Cholim for more help but they have told her she has to call back social services and become reassessed. At the moment she believes that they are not entitled to any more help or care. She has been told that he is able to be left on his own but the family feel this is not the case particularly if he were to fall.

In addition to the carers, XX was also allocated a psychologist but he did not want to continue with this and it stopped. YY also mentioned that a different person came, ZZ, whom she thinks was from OHC, who offered to look into whether XX was entitled to any additional support such as Disability Living Allowance. ZZ believes he is unable to help with the carer as that is not their role.

YY believes that OHC were '*marvellous and they came straight away, they don't make you wait*'. She believes that they were '*on the ball, very good and very nice*'. She also believed that OHC '*are not in charge as everything has to go back to social services but they have a bit more push*' than she would, '*because they are a company and a somebody*.' She has no contact with them now but she does have ZZ's number whom she can call if need be. She was upset to hear they were closing as '*they were very helpful*'.

CASE STUDY 15

XX is 81 years and lives in a flat with her husband. She was reported to have a range of conditions including diabetes, arthritis and high blood pressure. Her eye sight has all but disappeared and she finds it hard walking. Her husband has had a stroke and also has dementia. According to the daughter, their flat is small and living conditions are difficult. The interview was carried out in her daughter's flat who does everything for her, including the cooking, ironing and personal care. She has looked after her parents for 16 years and has five children herself. She argued she accepted her responsibility as a daughter but finds it hard and '*cries in front of her GP*'.

She had heard the name 'One Hackney and City' but had no idea of who they were or anything about them. She reported that she did see someone about the care for her parents about three months ago but she could not remember much about it. She thought that someone was going to come to interview her again but it had been a long wait.

CASE STUDY 16

XX is 81 years, married and lives with his wife (aged 79 years) in a flat. They came to this country in the 1960s and have lived in their present flat for 22 years. He has a number of conditions including high blood pressure, diabetes, and prostate cancer. They have Attendance Allowance and with this they pay for a cleaner whom their son found. His wife was severely distressed and is also not well. She told the GP that she could not cope with the stress and strain and as a result, they were referred to OHC. She believes though, that OHC have changed their name to 'Navigators'.

She reported that she had been unaware that they had been referred until a man came round who '*knows the right channels and get things done what needs to be done*'. It was through him that they received Attendance Allowance and also became registered with Dial-A-Ride. Her husband has now been allocated a befriender who will be able to take him out. She is distressed however, that they are unable to help with housing and enabling them to move to a ground floor flat. Nonetheless she was clearly distressed the organisation was closing down and comments that she will feel '*helpless*' since they have been very supportive and helpful. She also believes that she and her husband now go to the GP less often as she is better supported at home. '*I don't know how to thank them - I want to be thankful to them and to the doctor*'.

CASE STUDY 17

XX is 74 years old and lives on her own in a maisonette with her dog. When she was younger, XX was misdiagnosed and as a result had to have a termination. She has one son who rarely visits. Her husband died three years ago. Up until a year ago, she was seeing a physiotherapist and a dietician. She spends her days *'jiving and listening to Elvis'*. She apparently refuses to go out and will not join any clubs.

Her sister lives next door and does much of the caring for her. Her sister detailed the stress she was under and how she had to do everything for XX including all the cleaning and for example, ensuring the floors are not slippery. They have not been able to access any care as XX has a private pension. Her sister completed the relevant forms but they were never received and now they are still waiting for new forms.

She and her sister were unaware of OHC but were aware of a social worker (who is one of the quadrant teams). This social worker organised for someone else to come round who will be putting in a shower for XX since at the moment she is unable to *'immerse herself in water'* and only washes with a bowl of water. She has her hair washed once every eight weeks. A stair lift did arrive recently but on installation they discovered that it gets stuck at the top of the stairs so it will have to be replaced. Her sister explained that she is unsure why the social worker came but that it could be a result of telling the doctor how worried and stressed she was. She added that *'all of the people we have seen have really thoroughly done their job...and it is nice to have people who are on the same level...and didn't have airs and graces'*. Ideally she added that she would like to be her sister's befriender and have someone else to do all the other roles she has to fulfil.

APPENDIX I



January 2017

Dear Patient and Carer

As part of an initiative to improve health and social care for patients, One Hackney and City was set up to provide a specific programme of care that aimed to change the way patients received care and the way their care is organised and administered. The programme has now been running for two years and has worked with many local patients.

In order that any future new services offered to patients are built upon the successes and lessons learned from any new programme of care, it is important that the views, opinions and experiences of those patients who have received services provided by One Hackney and City are both heard and understood. Healthwatch Hackney, an independent organisation that aims to provide a voice for patients and the public, has therefore been asked to capture the stories and experiences of patients who have received their services.

We are aware that you have been part of this new programme of care and we would now very much like to invite you to take part in this project.

- Being involved in this study will involve a discussion with an independent researcher who works alongside Healthwatch Hackney.
- The discussion might last between 45 minutes and one hour but the length will very much depend on how you feel at the time.
- All those taking part will receive £25 as a token of thanks for their time.
- The researcher is **totally** independent and all discussions will be entirely confidential. There will be a report but no names will be given and people will not be able to be identified by any other references – such as where they live, what they do for a living or details of their household.
- As is normal practice in such a study, the meetings will be recorded so that all views and opinions are accurately captured. The recordings will be kept secure and used only by the study team. After the project is complete, they will be destroyed.

The name of the researcher leading this project is Kate Melvin and she can be contacted for any further information and to answer any questions you might

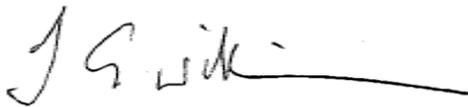
have about the evaluation. She can be reached by telephone on 07748 762 986 or by email on katemelvin2@gmail.com.

However, if you do not wish to take part in this project, please fill in the attached slip and return it in the stamped addressed envelope provided.

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. Your name, alongside 40 others, has been selected randomly from the list of patients who receive services provided by One Hackney and City but **only** the researcher will be aware of the names of those who finally take part. Neither the commissioners of the study nor the primary and healthcare teams will be aware of the names of those patients selected for interview during this project.

Many thanks indeed for your support

Yours faithfully

A handwritten signature in black ink, appearing to read 'Jon Williams', with a long horizontal line extending to the right.

Jon Williams
Director, Healthwatch Hackney
Programme Director

Jennifer Walker
One Hackney

ONE HACKNEY AND CITY - 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

Participant Information Sheet

January 2017

One Hackney and City - Patient Experience

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 services as part of One Hackney and City, an initiative that was designed to improve health and social care services. The project will aim to capture patients' stories but will, as a result, also make recommendations for future service improvements.

Who is organising and funding the study?

The study is being funded by One Hackney and City.

Why have I been invited?

You have been asked to participate on the basis that you have received services as part of One Hackney and City provision

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 an independent evaluator will hold a discussions with you

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 of discussion 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 your recent health and social care, whether your care has changed in any way. It will also ask for your views on how the service could be improved or what could or should be done differently.

Interviews will be recorded, if permission is granted, and then transcribed by the lead evaluator. 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 services. It is important that One Hackney and City understands the views and experiences of patients so that services can be improved.

You will be given £25 as a token of thanks for your time.

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 researcher. The participation of all those taking part will also be entirely confidential. One Hackney and City 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 lead evaluator. 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 every effort will be made to ensure that any references to any participant omitted so that they will remain, at all times, unidentifiable.

What will happen to the results of the study?

The data will be analysed and written up and will be made available to One Hackney as a final report. Participants will not be identified and One Hackney and City 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 One Hackney and City 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.

If you wish to provide any feedback, please contact:

Jennifer Walker

One Hackney and City Programme Director

Email: Jennifer.walker9@nhs.net

APPENDIX III

DRAFT DISCUSSION GUIDE - PATIENTS

ONE HACKNEY AND CITY - CAPTURING PATIENT EXPERIENCE

Notes:

This is the guide for use in the discussions with patients. It is not expected that individual interviews will last more than one hour and in many cases will be probably anything between 30-50 minutes.

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 seldom be asked in the way they appear on the guide.

All patients taking part will receive £25.

Introduction to Discussions

One Hackney and City have commissioned Healthwatch to 'capture' patient experience of the service they have provided over the last two years. The purpose of this is to try to understand more clearly the experiences of patients over a period of time.

Becoming involved in this study will mean that the way these new services are provided to patients will be influenced and improved by your experiences, opinions and ideas.

All sessions and conversations will be fairly informal and are unlikely to last no more than an hour. If at any time you are feeling tired then please say and we can continue at another time that suits you.

In order to obtain an accurate record, I would like your permission to record the discussion. The tape and the resultant transcript will be accessible only to the study team and every effort will be made to make sure that your views cannot be linked with your name when the research is reported.

At end of the discussion you will be asked whether you would be happy for Healthwatch to return in order to record your experiences on film/video. You will be under no obligation to do this but they would be very grateful if you were to agree. Details of this will be discussed further during this interview.

1. General background information

Introductory questions:

- Brief life details
 - Age, marital status,
 - Details of home life
 - Who lives with them
 - Family details etc
 - General lifestyle questions:
 - Whether they manage to 'get out'
 - Nature of social activities etc
 - If not, how they manage on their own etc

2. General Health Issues

- Can they talk a little bit about your health?
- Do they have any particular conditions?
 - For how long have they had them?
- Which health professionals do they see regularly?
 - GPs/CHTs /hospital doctors etc
 - How often?
- Do they see other services as well?
 - Therapists etc
 - Eg social workers/befrienders etc
- Over the last few years what have been the main concerns about the health care they have received?
 - Eg, delayed appointments/waiting times/discharge from hospital/duplication of provision/repeating their stories etc
 - Is there anything in particular that has made them concerned?
 - If so, what?
 - At the time of (each instance) what would have made it better for them?
 - How? In what way?
- And what have been their main concerns about their social care they have received (*if appropriate*) **Repeat as above**

3. One Hackney and City

- Are they aware they are registered with One Hackney and City?
 - If so, when did they become aware?
 - (If not, have they ever heard the expression? Who from?)
- When were they referred to One Hackney and City?
- Are they aware of why they were referred?
- How did they feel about this?
 - Can they explain their feelings about it?
- At the time of referral, were they aware what One Hackney and City did?
 - What?
 - Can they remember who told them?
 - And now?
 - How and in what way has their perception changed?
 - Why?
- To what extent were they aware of the services that were being offered to them?
 - What were they?
- Were they aware of them previous to this? What information were they given?
 - Who by?
 - Did they believe the information given was accurate?
 - Did they want more information? Or less? Why?
 - How should it be given to them? Eg email/face-to-face/telephone etc

3. Experience of One Hackney and City

- At that time, did they have any expectations of One Hackney and City?
 - If yes, what?
 - If not, why not?
- Have these expectations been met?
 - If yes, how? In what way?
 - If no, why not?

- In their view have there been any changes in their lives since they have been registered with One Hackney and City?
 - If so, what? **Probe for details/examples**
 - How and in what way?
- To what extent do they believe their life and lifestyle has now changed?
 - How? In what way?
 - Why?
- Are they able to pinpoint when these changes occurred?
 - Was it a slow process?
 - Or the result of a number of steps? By whom?
 - Is it possible to measure such improvements? If so, how?
- Are they aware of which services over the past XXX they have received have come from One Hackney and City?
 - Which?
 - Have more people being visiting them? If so, who?
 - Has it mattered? If so, how? Why? In what way?
- And what have been the good things about the services they have received from One Hackney and City?
 - Quicker access to services? If so, which?
 - Quicker access to support? If so, what?
 - Support generally? If so, what?
 - Access to different services? If so, what?
 - Greater co-ordination of care?
 - Etc
- In their view, to what extent this has been due to One Hackney and City?
 - How? In what way?
- To what extent do they feel able to ask One Hackney and City for support?
 - If yes, Whom did they ask?
 - What for?
 - If no, what have been the barriers?

- Which professionals do they now see?
 - How and in what way has this changed since they have been registered with One Hackney and City?
- Have they, in their view, had any negative experiences with One Hackney and City?
 - If yes, what? **Probe for details**
 - With whom?
 - Why do they think that happened?
- What are their main health concerns now?
 - How and in what way has this changed since they have been registered with One Hackney and City?
- And their main social care concerns?
 - How has this changed since they have been registered with One Hackney and City?
- To whom do they now look for support?
 - What sort of support?
 - Why?
 - How and in what way has this changed since they have been registered with One Hackney and City?
- Have they noticed anything else that is different about the way in which their health and social care is delivered to them now?
 - **Probe for details**
 - Eg More contact with professionals
 - Spending more time with their GP
 - Better response from professionals
 - More likely to know who to contact if need be
 - More involvement in decisions about their care
 - Better/different types of information
 - Greater co-ordination of care
 - Being 'listened to' by professionals - which? How?
 - How do they feel about that?
 - Why and in what way does it seem different?
- And have they noticed any difference in 'what' health and social care staff talk to them about?
 - If so, what?
- And in how they talk to them?

- In what way?
- To what extent is One Hackney and City different from simply a 'good neighbour'?
 - What does this mean?
 - Why? How? In what way?

5. Conclusions

- Overall, how do they feel about their experience of One Hackney and City?
 - What other changes would they like to make?
- How would they describe it to someone else?
- What changes would they like to make to the service?
 - Why?
 - How? In what way?
- In their view, how could One Hackney and City tell whether the service they provide has been good?
- And bad?
- Would they like to make any recommendations to those that design the services at this moment?
 - If so, what?

THANK AND CLOSE