healthwatch
Tower Hamlets

Evaluation Report
Tower Hamlets Co-ordinated Care NIS
Phase II

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1. Introduction

The Tower Hamlets Co-ordinated Care Network Incentive Scheme (NIS) was initiated in November 2013 and was designed to run in conjunction with the Tower Hamlets Integrated Care Strategy[1]. The purpose of both schemes was to change the way that patients received care and the way that their care was organised and administered. In particular, it was envisaged that the schemes would reduce the likelihood of patients' conditions deteriorating and being admitted to hospital but, more significantly, patients' experiences would echo the National Voices definition of Integrated Care: '*My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes*'[2].

Patients under the Co-ordinated Care Scheme were to receive a tailored care plan (held by the patients' GP) that would detail the health and social care needs of patients. In addition, they would be seen and cared for by an integrated community health team that would consist of staff from across the health and care spectrum including nurses, social workers and hospital consultants. The team would offer care co-ordination via a named 'care navigator', providing a single point of contact and access for patients, carers and professionals; 'rapid response' for those with acute health and support needs as well as enhanced support for people being discharged from hospital. The new service would also be underpinned by an IT system (Orion) that would allow the various organisations involved in a patient's care to share clinical information and to help them work together to respond to their needs. Each patient entering the scheme would also need to 'consent' to their information being shared as well as agreeing to participate in an evaluation.

The eligible population for the scheme was to be made up of two groups. Firstly, a 'mandatory' group of patients who would be offered the service based on particular diagnoses and other health issues such as health failure, dementia, whether they were receiving palliative care or were in a care home. Secondly, a 'discretionary' group of people, with multiple co-morbidities, would be offered the service based on the GP identifying their needs as 'high' enough and a consideration that they would benefit from this type of care.

In order to assess the efficacy of the new Co-ordinated Care Programme, Tower Hamlets Clinical Commissioning Group (THCCG) commissioned a local, independent organisation, Urban Inclusion Community, who deliver Healthwatch Tower Hamlets, to carry out an evaluation. Its main purpose was to understand the experiences of and feedback from the users of the new service over a period of time so that the programme could be both improved and tailored to their needs.

The evaluation took place in two Phases. Phase I took place between April and June and involved an exploration of the views and experiences of both patients

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[1] It is important to note that during the lifespan of this evaluation, the form and structure of Co-ordinated Care NIS was transformed so that it was aligned with the demands of the new national DES that came into being in April 2014. Thus, the patients that were part of the Co-ordinated Care NIS would now be either within Level 1 AUA (Avoiding Unplanned Admissions) or Level 2 (AUA). Please see Methodological Notes below.

[2] http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf

and providers. A full report of the findings of this Phase was presented to THCCG in July 2014.

Phase 2 took place between September and November and involved the ‘tracking’ of the 28 patients who took part in Phase 1. This report details the findings of this Phase but also incorporates the analysis of the first Phase of interviews with patients.

2. Objectives - Phase II

Thus, the aim of Phase II was to:

- Track the experiences and ‘journeys’ of the patients;
- Explore and examine a number of key themes that arose from Phase I; and
- Understand more fully what ‘better’ treatment and care would mean to individuals.

3. Methodology

During Phase II, all 28 patients were re-contacted. During the intervening period, only one patient had died. However, many remained seriously ill and, thus, unusually for such a project, interviewing took place over a period of three months.

a. Sample and Interviews

The patients were re-contacted by phone and then appointments were made.

In total, at this stage, 27 patients were interviewed as follows:

- Ethnicity[3]
    - 12 x white British
    - 11 x Bangladeshi
    - 2 x Afro-Caribbean
    - 1 x Philippine
    - 1 x Irish

- Gender
    - 11 x female
    - 16 x male

- Age range between 55-92 years

- Patients from both ‘mandatory’ and ‘discretionary’ lists[4] as of April 2014

- Patients from each of the eight practices in the locality

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[3] The ethnicity breakdown was based on self-reporting during interviews. It is also acknowledged that there were ethnic groups not included in the sample eg Somalian

[4] Although one Network provided details of which list patients were on, the other did not. GP practices and the Community Health teams also did not consistently provide this information

- Housebound patients as well as non-housebound

- Medical Issues
  - Palliative
  - Heart failure
  - Dementia
  - COPD
  - Stroke etc

As in Phase I, all patients were interviewed in their own homes apart from one patient who was interviewed in a Care Home where they resided. Four of the interviews were carried out by Agroni Research so that they could be carried out in Sylheti. The remaining interviews were carried out by Kate Melvin who was assisted by interpreters in the first Phase by Mohima Begum and, in the second, Ayesha Goni.

A number of patients additionally had 'informal' carers (that is, members of their family) present at interviews. As in the first Phase, the presence of carers was frequently invaluable in terms of offering fuller explanation and elucidating aspects of the patients' stories. It was also essential given the medical conditions of some of the sample. Full attention, however, was given to the potential complexities of the carer's perspective.

A topic guide was, as before, developed in discussion with THCCG and this provided a framework for each session and for subsequent analysis of the data. As in all qualitative research, the topic guide was only used as a framework for discussion and interviews remained flexible allowing for full spontaneity and detailed exploration of the issues. A copy of the guide can be found in Appendix I.

All participants were offered a further copy of the Participation Information Sheet. It was not necessary to ask them to sign a Consent Form again since the previous one remained valid.[5]

b. Analysis

All interviews[6] were digitally recorded with permission and subsequently transcribed verbatim. However, given the difficulties of translation and budgetary constraints, full and extensive notes, with quotations, were made from the interviews that were carried out in Sylheti.

Qualitative analysis, in the sense of identifying key themes and piecing together their relationships, was ongoing throughout this Phase. At the end of this stage of the fieldwork, once transcripts (and notes) had been prepared, a systematic working through of the data took place and final analyses took place.

There are many ways of dealing with the practical handling of qualitative data but system and transparency are critical objectives. Essentially the analysis of the transcripts and notes followed the established procedure of the National

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[5] Copies of both the Participant Information Sheet and the Consent can be found in the Appendices of the first report - Evaluation of the Co-ordinated Care NIS - Phase I.

[6] It is of note that during the first Phase, one patient did not wish to be recorded, but, in this Phase, they agreed.

Centre for Social Research's Framework of Analysis initially developed in the 1980s[7]. This is an iterative process but is based on three clear stages:

- Data management – reviewing, labelling, sorting and synthesising the data
- Descriptive accounts – identifying key themes, mapping the range of themes and developing classifications
- Explanatory accounts – building of expectations behind the patterns and themes emanating from the data

Thus, the process was as follows:

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

A verbal presentation of the findings from Phase II took place in November 2014.

4. Methodological notes

- It was notable that the majority of patients participating in this project were happy to be interviewed for a second time.

- The duration of each interview varied between 30 minutes and one hour and was dependent upon both the age of the interviewees as well as on the nature of their medical conditions.

- In the majority of cases, the situations of the interviewees had not changed between interviews. Some had been in hospital in the intervening period and the health of some had deteriorated. Only one patient, as noted above, had died.

- Similar to the interviews with patients in Phase 1, many patients found it hard to be clear about their own stories and exactly what had happened when.

- It is important to stress that this report documents the experiences of the cohort of patients in the sample. Its purpose was to track experiences and to explore areas of care which might be improved. Thus, it tends to focus on experiences that had an 'impact' rather than specifically detailing negative experiences or, as importantly, the often excellent care that patients reported.

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

- All the respondents that took part in this evaluation were registered under the Tower Hamlets Co-ordinated Care NIS but again, as with Phase I, the majority of patients were still not able to recall any details about this or any meetings they may have had with a care professional regarding any changes to their care and, specifically, a Care Plan and/or Consent.

- However, given that, by the time of the second Phase, the Co-ordinated Care NIS no longer existed in its original form, discussions tended to focus upon specific aspects of the NIS and integrated care more generally such as the notion of 'patient centred care', patients' sense of 'involvement', the concept of a 'Care Co-ordinator' as well as the purpose and design of a 'Care Plan' as envisaged in the NIS.

- Further, the time lapse between the two phases of interviews was between three and five months. Although it was possible to track specific experiences with the interviewees, it was felt that the time lapse was not significant enough to note any substantial changes in their care. However, it did mean that their views and perceptions could be explored thoroughly and it did provide an opportunity to uncover patterns in care provision.

- The interviews in Phase II built upon those carried out in Phase I in that themes that had emanated from interviews with patients were further explored. However, the exception to this were those that did not fall within the specific remit of this evaluation or it was felt by the Evaluation Steering Group that there was no need for further exploration and explanation such as discussion of the Mental Capacity Assessments. In Phase I, too, areas of provision such as 'hospital care' or 'care homes' were highlighted. In this report the underlying themes raised with specific areas of provision have now been organised thematically instead. Nonetheless, in the case of GPs, it was felt that, given their role in the Co-ordinated Care NIS and their role more generally in community care provision, they should be discussed separately.

- It was notable 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. There was, though, an accompanying assumption on the part of a number of interviewees, that the research interviewer 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 interview are made clear. It was unusual for this not to be understood to the extent that it was in this project and particularly unusual for erroneous assumptions to be aired throughout the interview even with elderly respondents.

- This, in turn, raised methodological issues for the researcher about their role as a researcher since, on occasion; it was juxtaposed uneasily with the need to respond to patients' serious concerns about their welfare.

- It was of note that in the case of four interviewees consent was given by the families to break confidentiality on the basis of the nature of the care with which they had been provided. The services concerned were one GP Practice in the South West locality and three nursing homes in the borough. To break confidentiality on these grounds is rare in such projects.

- It is difficult to capture the experiences of respondents once their ‘stories’ have been broken down into themes as in this report. In Section 8 there are extracts from six of these stories. Further 'stories' can be requested.

- In order to respect confidentiality, great care and effort has been made in this report to ensure that interviewees remain unidentifiable and quotations are annotated in line with this. The quotations are either direct quotations from patients themselves or, alternatively, from their carers/relatives as indicated. All the carers interviewed were informal carers. It is also noted when the quotation was spoken through an interpreter.

- It should be emphasised that the views and perceptions outlined in this study are purely those of the participants.

- Finally the author would also like to thank the patients who took part in this project. Many were seriously ill during the time span of this evaluation but were still willing to participate. Their stories and ‘journeys’ were often gruelling full of both emotional as well as physical pain. It was a privilege to hear these stories.

5. Executive Summary

General Issues

5.1 The patients that were interviewed in the evaluation were suffering from a range of conditions. At one end of the spectrum were those that appeared well and reported that they had had previous problems such as heart attacks, minor strokes and so on. At the other, were those who were, to all intents and purposes, bed-bound.

5.2 There was a corresponding range of perceptions and experiences of health and social care provision with those with more complex conditions tending to have more 'stories to tell'. Many too had had medical complications for some time but could recall clearly when they believed the downhill spiral had begun.

5.3 There was evidence from many respondents of a sense of loss of control of their lives which appeared to be exacerbated not just by their medical condition but also by an element of fatalism particularly with regard to the provision of their care. Among older respondents, there was also a belief that old age was not respected but more importantly and, across the cohort of patients interviewed, was a level of general anxiety and depression which a number believed could affect their physical health. This interestingly cut across those who were living with families as well as those who lived on their own.

Daily Concerns

5.4 It was striking during discussions as to the extent to which interviewees focussed upon the immediate in the sense of their day-to-day needs. This did not only concern possible care 'needs' but other concerns that they perceived to affect them on a daily basis. This ranged from fear of a loss of a partner/carer on whom they depended to worries about their inability to keep their homes 'clean' or the mal-functioning of home gadgets. Some had financial worries or were concerned about the possibility of burglaries but others were preoccupied by the need to find a solicitor or how to deal with immigration.

The Need for Support

5.5 In almost all interviews, there was a call for greater 'support' for this cohort of patients. However, the nature and level of support requested was rarely clarified. Partly, this seemed because it was an unknown and partly because it seemed that the lack of support served merely to underline the individual's plight and to highlight that support provided by present statutory provision did not seem to be consistent or systematic. Indeed, a number felt that when it was accessed, it was a matter of 'chance'.

5.6 Defining the level and nature of support needed was equally hard not simply because it could not be predicted how their medical condition/s would progress but also because it was difficult to think beyond the immediate since, in their view, they had far more pressing concerns. Nonetheless, what appeared to be critical was the need for support to enable them to articulate and communicate what they needed and at what point.

5.7 Many respondents, too, felt reluctant to or were unable to ask for help either because they did not know to whom to turn or because they did not feel able to ask. Even though some respondents were clearly determined to fight their own battles, others reported how support, in their view, had not been there when it had been needed most.

5.8 GPs, for their part, were, on the whole, perceived to be only able to deal with purely 'health' and medical issues. Some, too, were reluctant to trouble the GP for health matters as well, even if they were convinced they could 'help'. There was also a concern expressed by some that if they were seen not to be coping, complaining to the doctor might have repercussions for them and their care. However, more critically, it appeared that many of those interviewed would be reluctant to talk to any 'professionals' about personal issues.

5.9 During discussions, other and 'new' sources of support were mooted, often spontaneously, such as a specific individual who might provide a co-ordinating role or simply be a 'befriender'. A free telephone service acting as a help-line was additionally considered to be a good idea and a number requested a list of key telephone numbers in one place listing all the centres of care (including social) that they might need.

5.10 Family support was generally seen as being pivotal and many thought that without such support their relatives would have been in a far worse situation. In some cases, some families were providing all the care and support for the patient respondent. Families providing support certainly presented a stark contrast to those interviewees who did not have a family to support them. For the latter, support could be gained from a variety of sources, including (formal) carers but a number appeared very much on their own.

5.11 Crucial, too, was the evidence that showed the role that specific individuals could play in respondents' lives. This could be a social worker, a District Nurse, a GP or, for example, someone from a Day Centre or even the local library. When this support was withdrawn, often through a job change for example, it could have negative consequences for the individuals concerned.

5.12 Many of the respondents across the board believed that socialising benefitted them and the lack of social contact was hard for a number including those who were living with families as well as for those living on their own. Some interviewees accessed Day Centres but access to this type of provision could also be beset with difficulties. Others felt Centres were ‘not for them’, considering them to be ‘the end of the road’. Where experienced, Tower Hamlets Friends and Neighbours were appreciated and there was a call for more volunteers to help visit the elderly and infirm.

Perceptions of Health Care Provision

5.13 Issues in respondents’ daily lives were undoubtedly interlocked with and exacerbated by difficulties reported in medical provision. While all patients had ‘stories to tell’, many were able to recount incidents and stories which had been distressing and it appeared that such experiences, even when they were not first-hand, tended to influence both their perceptions and expectations of their health care.

5.14 The extent to which negative experiences were treated with equanimity was particularly notable with a number of respondents still regarding their care as being ‘good’, taking into consideration how busy healthcare staff were, for example. In addition, many acknowledged that they found complaining hard.

5.15 Although not a focus for discussion, awareness of service provision arose spontaneously in discussions. It was evident that it firstly depended upon previous experience but also a good many were simply unaware of services to which they might be entitled.

5.16 Many respondents, too, were beset with anxieties about their health which, in turn, fed into perceptions about provision. Although affecting the majority, it was clear that for those living on their own these daily anxieties appeared to be particularly acute.

5.17 Cutting across discussions, was a concern about how to obtain care with many respondents detailing the struggles they had or were having. Others complained about the poor administration at the London Hospital but more common were complaints either that respondents or their families did not know who was visiting them at home or professionals who said they were coming simply did not turn up. Respondents expressed distress that some professionals, such as Physiotherapy, just abruptly stopped coming without warning but almost all had noticed the long waits for service provision and appointments. Other issues mentioned were discharge difficulties, poor transport and language issues.

5.18 Given that GPs were the cornerstone of the Co-ordinated Care NIS, discussions about their provision were of particular interest. In the first place, GPs tended to be perceived as the gateway to provision and often the most ‘trusted’ professional. Nonetheless, they were, at the same time, criticised for the difficulties in obtaining appointments, the rushed nature of appointments once in the consulting room and the fact patients could only bring up one problem at each visit. Some believed, too, that the GP was simply not interested in them or their concerns as reflected in their seeming refusal to visit the bedbound or seriously ill at home. It was a common suggestion that those who were seriously ill should be able to have a regular visit from the GP to ‘check up’ on them.

Co-ordinated Care

5.19 The original intention of this evaluation was to track the progress of patients who had been placed on the Tower Hamlets Co-ordinated Care NIS. As has already been noted, although this applied to all those interviewed, very few interviewees, were aware of the initiative. Interviews in the second Phase, however, proved to be more informative with a greater number of patients either acknowledging or remembering conversations they had had with their GP.

5.20 Signing of the ‘Consent Form’ tended to ‘jog’ the memories of respondents but there was confusion as to what precisely they had signed and some believed they should have been given more information at the time.

5.21 Only a minority could recollect the Care Plan and it seemed that everyone’s experience had been different not simply in terms of how they had felt about it but also, more practically, in terms of the conversations they had had with the GP. In contrast to this experience, more patients could recall the recent letter they had received at the time of the second interview informing them that they were to have a ‘named’ GP – a move which tended to be viewed very favourably by those concerned.

5.22 An explanation of the Co-ordinated Care NIS was generally well received with particular support for the idea of a Care Co-Ordinator and being able to be treated at home.

5.23 Although largely unaware of the expressions, Co-ordinated Care NIS, ‘integrated’ care or the ‘Community Health Team, by the time of the second interview, a minority said they had experienced ‘changes in their care’ for example, District Nurses visiting. For most, however, care provision had remained unchanged.

5.24 It was also evident that respondents did not perceive provision in any holistic sense but tended to envisage different professional components to be totally separate from one another. Thus, in their view, the District Nurse was totally different from the Physiotherapist or Occupational Therapist or GP. It was, therefore, difficult for the majority to envisage holistic provision.

5.25 In terms of sharing notes, the majority considered this to be a good idea. On the one hand, experience of different groups of professionals having one’s notes clearly varied but there remained an assumption that notes would be shared, particularly between GPs and hospitals. On the other, it was thought doubtful that the notes from the District Nurse or other such professionals would be shared with anyone, again reflecting the perceived 'silos' of care. Indeed, even if respondents did believe that different parts of provision shared their notes, the reality of their experiences overshadowed and remained apart from the imagined effects of the new integrated provision.

5.26 Whether or not respondents felt ‘involved in’ their care and listened to by health professionals appeared to depend partly on their understanding of the terms and partly on the extent to which they were focused on their daily existence and whether they were able to think beyond their immediate concerns.

5.27 Nonetheless, there were some interesting contradictions. Interviewees reported they were ‘involved’ in their care (or in the care of their relatives) and/or they were ‘listened’ to but their actual experience/s they reported contradicted this. Such contradictions appeared to be not simply ones of definition but equally seemed to be dependent on previous experiences with different aspects and areas of provision as well as with relationships with staff, level of family involvement and so on. They also reflected again, in part, the fact that provision was not seen holistically.

5.28 However, it is also important to point out that there were certainly those who did not feel listened to or involved in their care at all as well as those who stated they did not want any ‘more’ involvement in their care.

5.29 Opinion was divided as to whether interviewees were more concerned about co-ordination of their actual care or administrative co-ordination. Whereas some believed that it was essential that the GP should ‘know’ them and build up a relationship with them, others felt that as long as the notes were readily available, it did not matter who the GP or doctor was. For the former group, that there was now going to be a named GP was met with huge relief.

5.30 Opinion was again divided as to what was considered to be the most appropriate medium for contacting or informing patients of changes to service provision. It was argued by some that a letter was more useful since it could be read and digested but it was clear that, for others, a telephone call was much more practical.

Sub-Groups and Segmentation

5.31 The main selection criteria in this evaluation was those patients who had been included in the package of care under the Co-ordinated Care NIS. This clearly covered a broad range of people and, thus, this must be taken into account in interpreting the findings since it was not possible to analyse the data taking such factors as co-morbidity, age, gender and ethnicity into account. In this sense, therefore, this evaluation is only able to detail the parameters of prevalent views.

5.32 Nevertheless, it was evident from the study that the cohort of patients sampled was not an homogenous group. Three broad and fluid sub-groups were detected based on the evidence gained from the interviews and are explained and detailed in Section 8 of the report. It is important to note that these sub-groups, to a large extent, remain fluid and are by no means static. They have been determined on the basis of perceived service and support needs in particular as well as on expectations of service provision. It is important to note that the evidence showed that in terms of service and support needs the difference between those living on their own and those living with family was only one of emphasis. Thus those living on their own can be found in all categories.

5.33 Finally, the question that may need to be asked, in terms of assessing support needs is not, ‘What is the matter with you’ or, ‘What matters to you?’ but, instead, ‘What help do you need today?’ which may become more pertinent as patients move through different stages of care.

6. Recommendations

6.1 This study was designed to evaluate the Tower Hamlets Care Co-ordinated NIS over a period of seven months. By the end of the study period the original package of care no longer existed in its original form. However, through the analysis, it has been possible to draw out a number of recommendations that appeared to be perceived as fundamental to the introduction of new packages of care as well as to good service provision more generally.

6.2 The evaluation also identified three sub-groups within this 'high risk' category identified by the NIS. They are undoubtedly fluid with patients moving between them as their health and social support needs shift. The sub-groups, though, are defined not simply by their health needs but by their wider support needs.

New Initiatives

6.3 There is a need to explore appropriate mechanisms through which the concept of 'integrated care' can be best communicated in order to:

- Ensure clarity of the 'offer' with full explanation to patients ensuring all terminology is consistent and clearly understood
- Ensure there is clarity with regard to how patients can articulate their changing needs particularly in terms of their wider support needs;
- Ensure the package of care is clearly communicated in terms of the role of health and social care teams and key professionals - for example:
    - The role of the CHS and who they are
    - The role and potential role of the GP
    - The role of the Care Navigator/Co-ordinator
- Ensure consistency in provision of information.

6.4 There was equally a strong call for the need for 'a contact' who would be able to respond to their immediate needs. Alongside this was a need for a list of relevant contact telephone numbers so that patients felt 'supported' and not in a vacuum. This appeared particularly important when the care needs of patients changed, often dramatically, and particularly when the health of a patient suddenly deteriorates. Such contacts should also be provided alongside a clear directory of service provision, both social and health, more generally.

On-Going Evaluation

6.5 On-going evaluation was supported by the providers interviewed in Phase I. It was considered important for GPs and other health professionals to be kept informed as to how new packages of care were to be evaluated and to ensure that the appropriate evaluation tools were used. Most considered that 'tracking' of patients was an effective model but, in addition, there could be regular forums for feedback from providers themselves.

7. Main findings

7.1 General issues

7.1.1 The patients that were interviewed in the evaluation were suffering from a range of conditions. Some, for example, at the time of the interviews appeared well and reported that they had had previous problems such as heart attacks, minor strokes and so on. Within this group, there were some patients who were still working although this tended to be on a part-time basis. At the other end of the spectrum of interviewees were those who were, to all intents and purposes, bed-ridden. These patients tended to have formal carers and other medical professionals visiting them regularly. Between these two groups were others who reported that they had some level of regular care such as weekly visits from the District Nurses, Physiotherapists or Occupational Therapists or regular visits to the hospital for check-ups and so on.

7.1.2 Given the range of medical conditions within the sample, it was no surprise to find a breadth of experience of different levels and types of service provision. Indeed, to some extent, it appeared that the variation in perceptions of the service provision was dependent upon the level of care needed. Thus, those with more complex needs, demanding a high level of daily care, had more ‘stories’ to tell than, say, those who had had one coronary heart episode some years ago.

7.1.3 The majority of those interviewed also had had medical complications for some time but many could recall when they felt the downhill spiral had begun:

> *‘The onset was four years ago, August 2010, she slipped between the platform and the track at Romford and was in the London for two weeks - that was how it all started’* (Daughter of Female, White British, 80)
>
> *‘She was just 59, a friend had called for an ambulance, she had walked to an ambulance, and walked into the hospital and came out like this. She had had an aneurism they said, and had had a stroke, they put her in an induced coma and this is the result – it just happened out of the blue’* (Sister of Female, White British, 63)

‘It was when she fractured her ankle, that was when it all started and she went into hospital. When she first went into hospital she was fine and then in January they transferred her to the Mile End for physiotherapy and she got a bowel infection and bed sores and it set off the dementia and she was transferred back to the London -then she went to the home and got another bowel infection - multiple bowel infection - it sets off your dementia and that is how my mum is today’ (Daughter of Female, 75, Afro Caribbean)

7.1.4 More significant was a sense, evident in discussions, of a feeling of a loss of control of their lives which appeared to be exacerbated by an element of fatalism particularly with regard to their care.

‘Nothing would make a difference unless I had a magic wand… and what someone tells me I could get today might not be available - and you only get what is available - there may not be a health service in five years time as it is underfunded and it might be a health service you have got to pay for’ (Male, White, 83, White British)

‘The position I am in now I am all right ‘cos when you get older you see when everything is falling down - now I can cope but then I just don’t know’ (Male, White British, 82)

‘I don’t know where it goes but I have just had a thing I am supposed to wear and then I had this gadget that flashes a light that didn’t work - not sure why I bother’ (Male, White British, 86)

7.1.5 There was equally a sense in which, for some patients, the feeling of being in a vacuum' may only be round the corner:

'And he said he was thinking of discharging me and I said don’t release me because you never know something might happen if I am left alone…and so we have now decided just to see him once a year…’ (Female, Philippine, 59)

7.1.6 A number also believed that old age was simply not respected:

‘And people like me are now being told we are living too long and are a burden on the state…No one seems to support the old age pensioners…people of my age are treated like they are idiots or children and I find that most disconcerting’ (Male, White British, 83)

‘They can’t fob me off when I want to see (XXX) *but you get some Simple Simons, and they say no doctor is available, like they do to old people’* (Female, White British , 89)

‘I’m no youngster and they say they will help the pensioners but some of them they just can’t be bothered can they?’ (Female, White British, 90)

7.1.7 Alongside the sense of fatalism, it was also clear that there was a level of general anxiety and depression[8] among a good number of the respondents who took part in this study. This was especially true for those who were living on their own and who clearly felt quite isolated:

> *'Yeah, I get miserable but I can't do nothing about it, there is nobody to nag so I don't bother…I manage, I put the telly on and have a look at that and then I forget all about it and I am all right but I am not miserable all of the time'* (Female, White British, 89)
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> *'When you get old you think of years ago and that makes me miserable…and I keep saying, pull yourself together…and loneliness is a dreadful thing - if you are a bit dopey it is even worse like a dopey old age pensioner, that is a shame'*(Female, White British, 90)

7.1.8 But even those with families could be equally distressed:

> *'I panic more than anything - I wonder about this, that and the other - I just can't get shot of it…I get a bit of depression actually, I think things…'* (Male, White British, 82)
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> *'He gets so anxious so I try and come round and see him or take him for a check up to see the doctor if he is anxious - just to be reassured'* (Son of Male, Bangladeshi, 59 - reported via an interpreter)
>
> *'I ain't a peep show and when I am out there* (outside) *I am a peep show 'cos I know most of the people around here and before this happened I used to stand and speak to people…and now I can't stand out there as I can't stand up for long and I would just be a peep show…I am just sitting here, wasting away, mentally, not doing nothing, watching the telly, playing a game on the machine, that's it'* (Male, White British, 64)

7.1.9 A number also believed that depression and anxiety could certainly affect their health:

> *'I do worry, I am awake at night about worry - I worry and worry and it probably does affect my health…I keep taking my pulse to make sure…and sometimes I think it is missing a beat…I worry about everything really'* (Male, White British, 82)

7.2 Daily concerns

7.2.1 Throughout both Phase I and Phase II it was striking during almost all discussions the extent to which respondents were focussed upon the immediate in the sense of their day-to-day needs and daily issues.

7.2.2 Although the majority clearly had daily concerns about issues with their health care (as detailed below), it was the immediate concerns that were the focus of the interviews since it was these that were seemed to have a greater effect upon them.

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[8] It should also be noticed that one respondent reported that they had been 'depressed' for many years and thus, it was not simply the result of their present or recent situation.

Loss of a Partner/Carer

7.2.3 In the first place, for many, was the worry that something would happen to their partner which, in turn, would mean they would be less able to look after them.

'It is a worry, it was the leak in the bathroom and the water was running and she was mopping up and slipped and I told her not to do it and leave but I couldn't help and it could happen again' (Male, White British, 82)

'I have to take him to the hospital and that takes up the whole day and if I am not at home, if anything happened to my grandmother, she can do nothing, how would she pick him up as she is not well either…she can phone no one and doesn't know how to use a phone…she can't speak English, nothing…this is what I think every day, what is happening, are things ok …if I am at work, I have left them, are they ok, all day I think about it…' (Grandson of Male, Bangladeshi, 84)

'The other month she had a fall and we had to phone for an ambulance as I can't pick her up and my dad can't as he has got angina and has had a bypass…and if my dad has an accident and my mum is on her own….and it is my biggest concern that if my dad ended up in hospital and I couldn't come, what would happen to my mum?...I mean I really dread the long term because I don't know where to go if anything happened, who do I approach if my mum started messing herself?' (Daughter of Female, White British, 80)

'I worry about having a stroke to tell you the truth, I think I am at risk but she (my wife) *went out to feed the dog and it was pouring with rain and that step is so slippery that she fell and I couldn't lift her and I just went paralysed'* (Male, White British, 77)

Day-to-day worries

7.2.4 More surprising perhaps was the evident preoccupation of many of the respondents with day-to-day issues such as the inability to keep their homes clean or wash their curtains. Such conversations, at times, tended to dominate the discussions.

'I don't know what help I want really but as I say I just want someone to change my curtains for me' (Female, White British, 90)

'We need help with the cooking and cleaning more than anything - we asked the (people from the hospital) *to give us workers to help us but they said they could not…they offered to give us food in containers but we do not like containerised food. We want our own cooked food'* (Male, Bangladeshi, 77)

'I need a home help as they can clean the flat - it is distressing me quite a lot at the moment cos I can't keep the place as clean as my mother

> *did…I like everything to be clean…it makes me ill…a home help is all I want…does it have anything to do with the doctor?’* (Male, White British, 79)

7.2.5 Such concerns ranged from cleaning, the mal-functioning of day-to-day gadgets such as the Hoover or the intercom system. In one case, the interviewee discussed the fact that her doorbell did not work repeatedly in both interviews. For over nine months she had waited for it to be fixed.

7.2.6 One respondent during the first interview reported how she desperately wanted a cleaner as the last one that had come had not been able to clean her glass collection. She had also not been able to take down her curtains to wash them. At the time of the second interview, neither of these problems had been resolved.

7.2.7 A further interviewee, living on her own and immobile, explained how she was kept awake at night because one of her (formal) carers had been lent keys to the flat so that she could let herself in but had not returned them. Other, more elderly respondents, relayed how they were concerned about burglaries if they let cleaners, which they needed, into their homes:

> *‘Like it is not the point paying somebody - it is people coming here…television is worth £500 – they don’t have to nick it themselves but they can go and tell Harry and Harry can tell Bob and while I am out they can come and clean the place up’* (Male, White British, 86)
>
> *‘I am scared about living on my own. Once the flat was burgled, recently someone died and there is also a drug addict that lives next door…’* (Male, Bangladeshi, 74)

7.2.8 Whereas some were clearly concerned about their financial situation, others expressed concern about keeping warm and eating properly. During one interview, the respondent, a Bangladeshi man, aged 56, reported that his (formal) carer, on his behalf had made enquiries about increasing financial support but had been told the council had already overspent the allocated budget for him.

7.2.9 Yet others drew attention to the fact they needed help with legal matters that were of importance to them such as the need for a solicitor. One respondent asked the researcher, for example, for help with immigration officials in trying to arrange for an uncle to come to the UK to help with looking after his ill grandfather and this, clearly, was at the forefront of the family’s thoughts.

7.3 The need for support

7.3.1 While in almost all interviews there was a call for greater ‘support’ for this cohort of patients, it was not always clear precisely what form this ‘support’ should take or indeed what was actually wanted. In many cases, the issue simply appeared to underline the individual’s plight and emphasised the need for a level of support not consistently or systemically provided by present statutory provision. In essence and on the basis of this study, it appeared that it was almost a matter of ‘chance’ that patients were able to find the level of support they needed.

7.3.2 Given this, it was often not possible for the majority of interviewees to think what support they might want now or in the future or indeed other aspects of their care which may be missing that might decrease the risk of further hospital admission. One respondent when she was asked about her future care and what support she needed seemed, for example, quite taken aback when there were simply more pressing things on her mind:

> *‘She asked about what support I wanted and what help I needed and then talked about when my time came, going into a care home, bla, bla, bla. I kept wondering why she would ask me them questions…I didn’t ask her why but like at the moment, I have got to go for a cancer test on my bowel and I have just been in hospital for a week’* (Female, Afro-Caribbean, 55)

7.3.3 It was also clear from discussions that many of this cohort of patients were reluctant to ask for help and/or support either because they did not know to whom to turn and/or because they did not feel able to ask. In some cases, when perceived difficult situations were being described, the interviewer inquired whether help had been sought but the reaction was often negative. Others, too, were clearly determined to fight their battles on their own.

> *‘I can’t rely on anybody, I do everything myself, there is no one else…as long as I can get up in the morning and have my breakfast and have my inhaler I don’t worry. I will start worrying when something happens’* (Female, White British, 90)

7.3.4 But it seemed that for some interviewees support simply had not been there when it was most needed:

> *‘In the last 18 months, when it has been an absolute onslaught where I have had to fight everyone, no one has offered me anything…there were times when I thought I was having a nervous breakdown…I have not worked for a year, I have spent all my savings but she is my mum…If someone had said to me do you want to come in and sit down and offload, I would have done…I got no support’* (Daughter of Female, Afro-Caribbean, 75)
>
> *‘There is no one - I want someone but there is no one’* (Grandson of Male, Bangladeshi, 84)

‘People come here and they say do you have a social worker and we say no, we would like a person like that to talk to…I have spoken to so many people and I can’t remember who it was who I originally phoned 'cos I have spoken to that many people…and if I go on record as my mum’s carer, I would get even less help….In the end to be honest, it is guesswork, when there is a problem, I just don’t know who to phone up or who to talk to’ (Daughter of Female, White British, 80)

7.3.5 For many, too, it was clear that the GP and the GP surgery were only perceived to be able to deal with ‘health’ issues.

‘Who else would help, if there was another means of support I would use it - I don’t know anything but the GP’ (Wife of Male, Bangladeshi, 56 – reported via an interpreter)

‘She is like a lot of elderly people, the first thing they say is they are fine. And GPs are purely medical…there is I think still a stigma attached to anything mental, like stress, for a lot of people…’ (Daughter of Female, White British, 79)

‘I can’t see how saying anything (to the GP) *would help you- they can’t do anything, what could they do? Older people don’t talk about these things - it is his age…and you don’t know all the jargon they use…and it is personal isn’t it? I mean, a doctor is a doctor to look after you medically….and you might embarrass them… ’* (Wife of Male, White British, 82)

‘He (my father) *would go to the mosque when he is depressed…it would be new to his generation to go to a GP’* (Son of Male, Bangladeshi, 57)

‘I don’t find it easy at all to talk to them, not when it comes to personal things - it is just one of those things and I don’t know them’ (Male, White British,77)

‘It is only about my health that I wanted to tell him (the doctor) *not actually other things because they are my doctor’* (Female, Philippine, 59)

7.3.6 But even for 'health' there was a view expressed that it would not always be possible:

‘I do worry about his health….sometimes he has really bad days…but I don’t feel confident going to the doctor’s surgery and saying to the GP that my dad might need extra support as I know that I won’t get that extra help from the GP as it is all rushed when you go there…and if I tell him to make sure he tells the doctor about something, I know he is not going to say it because of my mum’s experience, he will think he has to go back to hospital’ (Daughter of Male, Bangladeshi, 79)

‘I mean, I come out of the hospital and I think she (the GP) *should have phoned me but she didn’t so I don’t bother with her…if they are not interested in me, I can’t be bothered with them’* (Female, White British, 89)

7.3.7 Among the older members of the sample, there additionally tended to be a resistance to 'troubling' the doctor:

'Anyway I felt I was all right… I didn't think it was bad enough to go to the doctor - I wouldn't want them around unless you know like it is at the end...I mean I won't go until I have to' (Female, White British, 79)

7.3.8 A couple of respondents, too, feared that if they told the doctor they were not coping, it might have serious repercussions for them:

'Some old people get worried they might get put away if they tell the doctor and say they can't cope so they would rather keep it to themselves instead…' (Male, White British, 82)

'I won't phone the doctor because they just send an ambulance for me and send me straight to the hospital and then I will end up in hospital and the thing is if I trouble her, I must be in trouble and I can go to the chemist…' (Female, White British, 90)

7.3.9 It was also thought by a number of the relatives/carers interviewed that this cohort of patients may be reluctant to talk about concerns, particularly personal issues, to anyone, not just health professionals:

'There are things he would not feel comfortable telling us as he wants to be independent as much as he can but we can see he needs certain things and someone maybe they can get things out of him he wouldn't tell us - maybe he will tell them about his loneliness - he needs people around but he won't say that to us' (Daughter of Male, Bangladeshi, 79)

7.3.10 During interviews, other and 'new' sources of support were discussed. In the main, respondents focused upon a person who would be able to support them when they needed support. However, it would have to be 'spelled out' that this was the role and remit of the person:

'For a certain age group it needs spelling out…not because they are slow or stupid but they come from a different era…I mean why don't they (the GPs) *mail shot their patients to say we are here for all these sorts of things… for this age group it is needed'* (Daughter of Female, White British, 80)

7.3.11 It appeared important for these respondents that any support workers involved should be 'caring', have 'listening skills' and be able to build up a trusting relationship with the patient. Compassion was seen to be critical and someone with whom they felt comfortable. Age, too, was considered to be important since anyone too young (under 40 years) was not considered old enough to understand the possible issues.

'You have to build up that trust and confidence like a priest does…but the first step is that they have to know they are open for that' (Son of Female, White British, 79)

'I think the need to build up a relationship with a person…and you need that continuity and they need to speak clear and concise English…' (Male, White British, 83)

7.3.12 Neither qualifications or profession were seen to be an issue as long as they were knowledgeable about service provision. Social workers also tended not to be too popular.

'You don't need medical training but maybe some medical knowledge and be flexible' (Male, White British, 77)

'No not a social worker - 'cos I think they are interfering and you don't meet many social workers who are nice' (Male, White British, 82)

7.3.13 Commonly suggested, for example, was the use of a free telephone service which people could phone when they needed to.

'Just on the phone even to have a talk - you might not want company' (Sister of Female, White British, 59)

'If there were resources to do that then that would be amazing…they could pick up the phone and say I need to speak to someone - is there anybody around…they could come then say at 4pm and have that kind of flexibility for those who have no-one…' (Daughter of Female, Afro-Caribbean, 75)

'I mean I would like to have someone to speak to if I wanted to - at the end of the phone…if I get depressed, especially when the sun is shining - I am the kind of person that worries about things…' (Male, White British, 64)

7.3.14 It was acknowledged that this might not only be too expensive but also might prove difficult for those with hearing and cognitive problems. Hence, a further suggestion was that it might be important to meet them first and get to know them before the telephone contact, similar to a 'buddy system'.

7.3.15 A number of interviewees and/or their families equally felt it would be helpful to have a list of telephone numbers providing relevant numbers.

'I think a phone number, or a list of all numbers you might need - if you had a phone number and if things were really bad you would phone them wouldn't you - and it could help with everything' (Male, White British, 77)

'I just need more information about who to call when like sometimes outside surgery hours, I need to call somebody else if they gave me a bit more information - so a list just in one page so I can look in there and can see where to phone' (Daughter of Male, Vietnamese, 87)[9]

Role of the Family

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[9] Sadly, this patient had died by the time of the second Phase of interviews

7.3.16 Certainly, the role of the family appeared to be pivotal in a good number of the households interviewed. A number of families, or even an individual member of a family, believed that without them, their relatives and patients would have been in a far worse situation:

'I do all the contacting…at the beginning it was all new to me but I have been mum's carer for years…I have done all the co-ordinating of absolutely everything…all the instigating, put everything in place…absolutely everything…I teach the carers…some of them are great but I have to watch them all the time…basically I had to do everything….I had to get involved (in the care) *I had no choice and I have had to scream'* (Daughter of Female, 76, Afro- Caribbean)

'If we weren't here, she would get nothing…if we didn't do the things we do for mum, I don't think we would get any extra help…we had to fight for the carer, we had to fight for the chair' (Daughter of Female, White British, 80)

'I am pretty lucky, because I have a nice wife who waits on me hand and foot and three daughters and we are lucky as we are all together - very lucky as you need that' (Male, White British, 76)

'I mean if you were on your own, you would really need somebody wouldn't you? I mean dad is lucky as he has got a big family who makes sure about his treatment and we are there, I mean we have to be there' (Daughter of Male, White British, 82)

7.3.17 On the other hand there were those who felt that they very much wanted to provide all the care themselves. In one instance, a son had taken up the role of full time care of his grandfather for the last three years who had 'late stage dementia':

'All the services he needs come out to him except for his eye check-ups at Moorfields…I am quite used to arranging stuff for him…I don't want a carer as they won't be able to do it…I have been offered but I declined…I am also quite forceful, elderly people are easier to brush off and I am up to date with his caring and they can't pull wool over my eyes and sugar coating….I am the main carer and the one who is looking after his needs and if anything the one who pushes to get things done' (Son of Male, Bangladeshi, 75)

'You could have carers but we wouldn't want that…I mean mum is quite happy to do her own washing at the moment, she doesn't want carers…as long as she is happy and we can be here…' (Son of Female, White British, 79)

'Like he was offered care but they (her parents) *didn't look into it as they felt they didn't really need it as we are all here…I mean the family is always around – God forbid anything happens to all of us'* (Daughter of Male, Bangladeshi, 68)

7.3.18 There was interestingly, in a minority of cases, a feeling evident that statutory provision assumed that family support would be available.

Contact with statutory provision was evidently problematical in one case where the respondent was reported to have had a stroke, cancer and dementia, his wife was also not well and the only daughter living at home was on dialysis.

'I worry about the future….they (the remaining siblings) *don't live at home, they have their own places, they may stay one night but I couldn't rely on them, any of them as they have their work and other commitments…I think they* (statutory provision) *may think I may have support but I am not sure'* (Wife of Male, Bangladeshi, 55 - reported via an interpreter)

7.3.19 In this regard, having family support contrasted sharply with those, within the sample, who did not have a family to support them. Among the sample were those who reported having no friends, who did not know their neighbours and who 'kept themselves to themselves'.

'I ain't got nobody, I don't know (the neighbours) *them, I don't care, I got no friends, but I can't do nothing about it, nobody seems to take an interest '* (AR)

'Most of the old neighbours have died off…new people are coming in but they keep themselves to themselves…I don't see a soul…I have never had friends, I don't believe in friends…I had one friend from school and we kept in touch till about six years ago when she went a bit funny' (Female, White British, 89)

7.3.20 In a minority of cases, respondents relied on their (formal) carers for the support that might have otherwise been provided by the family. In some of these cases it appeared that apart from carrying out their routine caring responsibilities, the care workers also seemed to be taking on the additional role of liaison between the respondents and the various care agencies.

Role of Individuals

7.3.21 As pivotal as families, in some cases, was the role of specific individuals. Evidence showed that this could be a range of professionals such as a social worker, a GP, a District Nurse or someone from a Day Care Centre who might be providing crucial support.

'The District Nurse that comes, I have got her personal number….she comes three times a week…I feel I could talk to her about anything….' (Male, White British, 64)

'I would talk to my key worker at my Day Centre…my social worker is crap…you can go to them with any problems and they try to help you out when they can…they have a lot of knowledge which is what I like about them and I trust her' (Female, Afro-Caribbean, 55)

'He (Practice Nurse) *asks me how is everything… he is so easy to talk with - before I was timid but he is very bubbly and I can tell him about everything - he listens'* (Female, Philippine, 59)

> *'I might talk about things to* (District Nurse) *I feel very comfortable with her…'* (Male, White British, 82)
>
> '(XX) *knows all about me, he knows my illnesses and he knows what I am, as it happens he is the only one…once a week he comes to see me or phones me and that is every week. He's interested in me and he is a nice person'* (Female, White British, 90)

7.3.22 When an individual had been particularly helpful, respondents tended to be able to recall the instance in great clarity as this respondent reported:

> *'To be honest with you the only person that helped me was about four, five years ago and he was from the Council - I was just getting my bare pension...he came here one day and I haven't seen him or spoken to him since'* (Male, White British, 86)

7.3.23 However, problems could be seen to arise when there were changeovers in staff. In one instance, a grandson of an interviewee relayed in his first interview how he depended totally on a social worker who had been particularly helpful. By the time of the second interview, the social worker in question had 'moved on' and thus underlined the vulnerability of the situation for the grandson.

> *'My social worker will phone if I need to do anything and any problems I can speak to him and he came to my house to see if everything was ok and he emailed the District Nurse to say to come more regularly…anything I can phone him…I can get through to his office too…'* (Grandson of Male, Bangladeshi, 84 - Phase 1 Interview)
>
> *'Ah, the social workers, they change all the time, they are not permanent…they told me that after a couple of months they move on - now I don't even know who is the social worker…there is nobody now'* (Grandson of Male, Bangladeshi, 84 - Phase 2 Interview)

Social Support

7.3.24 Many respondents across the board tended to agree that socialising was important for patients like themselves or their relatives or at least some contact with others.

> *'Fresh air is good for you, it keeps your mind fresh. But I have been imprisoned in my own house. For me nothing more to do in a day than going to bedroom to sleep, living room for sitting and watching TV and kitchen for eating'* (Male, Bangladeshi, 56)
>
> *'I think sometimes just someone being there to talk to - sometimes elderly people just like company, reminiscing and it is just someone being there'* (Son of Male, Bangladeshi, 75)

> *'I think* (social activities) *keep them happy and their body will then be happy - it does help the health physically as well as mentally'* (Daughter of Male, Bangladeshi, 68)

7.3.25 The lack of social contact was evidently an issue for many cutting across whether they lived with their family or on their own and equally their co-morbidities. Some spontaneously mentioned that they would like more visitors and that they had no one to visit them:

> *'There is nobody I know that would come and visit me…it would be nice to have that'* (Female, White British, 90)

7.3.26 Frequently heard, too, was the complaint that interviewees could no longer 'get out':

> *'I was so depressed because I couldn't get up and I couldn't get out…I hobble to the door and I can get in the car but my son has to put the wheelchair in the car when he comes'* (Female, White British, 92)
>
> *'I like socialising but I don't like these old clubs that the old people go to - just because really….they are not my type…I have got the radio and the telly and I can sit and read...but what have I got to look forward to? I can't get out like I used to, if I could I would, I used to love going out, shopping you would meet someone to talk to - them days are gone, there is no one to talk to now'* (Female, White British, 90)
>
> *'I used to enjoy meeting other Bengali women at the centre* (Sonali Gardens) *and chatting with them...but now I am wheelchair bound and cannot go (*following the housing association's refusal to install a lift) (Female, Bangladeshi, 76)

7.3.27 Although a minority of the respondents already accessed Day Care Centres, some would have clearly liked to but this again appeared to be beset with difficulties:

> *'My dad is quite lonely but he won't say that - he says he needs to go to these centres but he is quite independent and the GP has seen him and just said he doesn't need it and said it would just take him a couple of months to get over it* (the death of his wife)' (Daughter of Male, Bangladeshi, 79)
>
> *'There are no services….there are no clubs for me…there was only one and that is not open anymore, The Dockers' Club…strangely the councillor* (to whom he had spoken) *did not believe me'* (Male, White British, 83)

7.3.28 Some respondents also commented they were not aware how to access the Centres. The daughter of one respondent very much wanted her father to access a Day Centre but having been offered once, they had not been offered again and she was unsure what to do.

> *'No one has contacted us - I thought they would have done. He used to go and it was nice but now no one calls him and he needs a group for his age'* (Daughter of Male, Bangladeshi, 68)

7.3.29 For others, Day Centres were clearly not the answer:

> *'We were offered befrienders by the Mile End. She said no to that and then she said no to a club - it is not for her and the meetings are at the wrong times and in the wrong places* (for Alzheimer's) (Daughter of Female, White British, 80)
>
> *'I used to go to the* (Beaumont Centre) *but I don't like it no more…they weren't all that - they had a little clique and I wasn't in their clique so I couldn't be bothered and then the management changed over it was no good not like it used to be'* (Female, White British, 90)

7.3.30 There was also the feeling, expressed by some, that Day Centres were somehow 'the end of the road':

> *'I think my parents felt, when they were told about it, that they were getting ready for them to pass away - it was sort of a joke but I am not sure…'* (Daughter of Male, Bangladeshi, 68)
>
> *'I have told him he needs to go to a Day Centre but he feels it is like for people right at the end'* (Daughter of Male, Bangladeshi, 79)

7.3.31 A couple of respondents also were visited by Tower Hamlets Friends and Neighbours. This tended to be a service well-liked although in two cases the befriender had simply disappeared with some lack of clarity as to why.

> *'I had a befriender and they came and then they just disappeared - no idea why'* (Female, Afro-Caribbean, 55)
>
> *'My mum was ok with the fella that came and then all of a sudden, he cancelled one day, he had a meeting and then he didn't come back and we didn't hear anything and that was nearly two years ago'* (Daughter of Female, White British, 79)

7.3.32 Others called for more volunteers but it was felt that there should be some level of consistency and that they should be of an appropriate age:

> *'It would be marvellous to have volunteers just to come and sit with her but they had volunteers here* (in the Care Home) *and they sent up an Asian girl of 16 and a boy of 18 and they just sat there…18 is just too young'* (Sister of Female, White British, 59)
>
> *'Somebody should go round there and say do you want your shopping done or do you want to go out and then someone could say there is a club two days a week'* (Male, White British, 82)

7.4 Perceptions of health care provision

General Issues

7.4.1 Issues in respondents' daily lives were undoubtedly interlocked with and exacerbated by difficulties reported in medical provision. While all patients had 'stories to tell', many were able to recount incidents and stories which had been distressing and it appeared that such experiences, even when they were not first-hand, tended to influence both their perceptions and expectations of their health care.

7.4.2 For one family, for example, their experience of their mother's illness had clearly been difficult and, as a result, the whole family appeared to be living on a 'knife-edge'.

> *'We had a very bad experience with my mum, the doctor wouldn't refer her and then she had stomach cancer in the late stages, and I don't feel confident about going to the doctor's surgery and it is a worry as he is not well'* (Daughter of Male, Bangladeshi, 79)
>
> *'My wife went into A&E, and we waited two and a half hours for an ambulance and then she was suddenly moved into the surgical ward and other patients just watched her die from 10am to 4pm – with no screens round and no privacy…..'* (Male, White British, 83)

7.4.3 Nonetheless discussions abounded with respondents' stories of their own care many of which they considered to be unacceptable. Indeed, in four cases the researcher broke confidentiality with permission from the respondents to report the provider of care to the THCCG – three incidents concerned events that took place in care homes in the Borough and one case concerned a GP surgery. In the case of the latter, although only one family agreed to break confidentiality, there were other cases of 'poor treatment' provided by the same surgery.[10]

7.4.4 However, the extent to which such experiences were treated with equanimity by a number of patients was startling and often they would still regard their care as being 'good'.

> *'My daughter suffers from dialysis and she visited her father and he had soiled himself and the nurses ask her if she could change him as they had actually changed him three or four times…she was offended and he was* (that) *they had done this…but the staff were busy and the care is good in hospital'* (Wife of Male, Bangladeshi, 56 – reported via an interpreter)
>
> *'Maybe they assume things and just put things in practice without really discussing as with my Dad he can't really communicate so they have to go through me for consent and they have to involve me basically – maybe with certain elderly people, they just do it but when he has been to hospital twice they put it down as DNR- it was their decision, the*

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[10] Details of these cases can be provided on request.

consultant or his underling - the first time I was a bit shocked - because of the way his condition is, it is not really…..it won't really improve his quality of life if they did resuscitate - because I was there and I know a bit of first aid, I said, whatever as it is quite a lengthy process to get it changed. It is quite bad, as I had assumed that they would try their best whatever the circumstances to resuscitate but I think it is a matter of finance probably - it is cheaper not to resuscitate - because the way he is frail, resuscitating and doing all that, it does more damage - I am assuming that as they don't really have the time to come and explain - that is what I have noticed in hospital - they don't really have the staff or the time to sit down with you but that is quite a big decision. The first time I wanted to challenge it, but the process I read up about is quite long… it is too long - the process is quite complicated to get the decision reversed' (Son of Male, Bangladeshi, 75)

'I could never fault the London - I have always had good treatment…. and all people make mistakes and the doctors and nurses are only doing their best…but when I came home, nothing was set up - I had to wait weeks for the rehab and no one came round…the time the Physio came I didn't need them as I was up and walking…and the nurse didn't come…. Recently, I went for treatment for piles and I had a scan and the consultant said I needed treatment and then I get a letter saying I am being discharged and now I have to raise a new appointment but they always treat me well and they are busy…they are not good with record keeping' (Female, White British, 79)

7.4.5 It was also clear that many found complaining difficult. There was some evidence that this was culturally related but more generally it appeared to be a generational issue.

'I don't think people like my dad and his generation and our community would complain' (Daughter of Male, Bangladeshi, 68)

'I don't like complaining because I think if I complain, they might lose their job and you get known as the people who are always complaining' (Male, White British, 82)

'I think my Dad is very polite and some people from his generation would be very polite and don't want to make a fuss about what has happened' (Daughter of Male, White British, 82)

7.4.6 In spite of the abundance of difficult experiences and the general consensus that care was somewhat 'patchy' across the spectrum of provision, there were certainly patients within the sample who had, in their view, only ever had good care. In particular, this tended to be the case for those interviewees who had not been in hospital or had not had an 'episode' of illness in recent times.

'He gets a good service and he gets quite a lot - he is quite happy, the GP always comes when asked, people come in and give him a new chair - if things go wrong, I phone them and they come' (Daughter of Male, Vietnamese, 87)

Awareness of Service Provision

7.4.7 The level of awareness of service provision was not a focus of the interviews. However, it did come up spontaneously and it was evident that it varied hugely. For many, it was dependent on previous experience - again, either their own or that of others.

7.4.8 It was notable, however, that many were either not aware of services to which they are entitled but were also unsure whom to ask.

> *'I don't know whether he is entitled to anything and my mum doesn't really either - I have no idea who we might ask either'* (Son of Male, Bangladeshi, 59)
>
> *'There is a lot of things you don't know about - a lot of services like the attendance allowance - apparently my mum and dad could have had it for years but nobody told them and they don't know what to do'* (Son of Female, White British, 79)

7.4.9 In one case, a respondent's grandson sought help from a social worker since his grandfather had fallen five times following discharge from hospital. After a good deal of 'phoning around', a social worker to whom he had spoken on the telephone finally told him to return to the hospital:

> *'I went there and they* (the ward staff) *said the social worker was meant to do it and they were not supposed to tell you to come back to us…then I spoke to Physiotherapy at the hospital and I was there for three hours but I did have a conversation and they are now going to give me a bed, a folding bed so I can put those barriers up so he can't get up from his bed with his dementia'* (Grandson of Male, Bangladeshi, 84)

Health anxieties

7.4.10 Clearly, for many, daily health anxieties fed into their perceptions of provision but, for those on their own, evidence showed that such concerns appeared to be especially acute:

> *'I worry about dying and I will be on my own. I am always afraid I will get pneumonia…I worry as I can't go up the stairs, one step at a time and I am struggling to breathe…I can't go to my niece's any more…I tell you too, I am afraid of clots…that preys on my mind but I am always afraid...you get a clot and it goes to your heart straight away and you are gone'* (Female, White British, 89)
>
> *'I want to move myself. But I get tired and I cannot do things on my own. There is always a danger that I might lose balance and fall and hurt myself'* (Male, Bangladeshi, 56)

7.4.11 Although many of those with families appeared more reassured, they too worried about their future health:

'I think I can handle everything at the moment, I mean I have the family but in the future I worry about what help I will get…when I came out of the Chest Hospital, I got nothing at all' (Male, White British, 82)

Specific Issues in Healthcare Provision[11]

7.4.12 It became apparent during discussions that there were a number of views about aspects of provision that were common to many of the sample cutting across morbidities, age and ethnicity.

7.4.13 In the first place, a key concern for many was how to obtain care. Whereas there were examples of how respondents were concerned about finding healthcare professionals such as a community dentist, a recurring issue in discussions were the difficulties involved in home care and the need for additional help. In the first example below, it should be noted that this issue had been resolved by the time of the second interview but it had taken a number of months.

'It has been going on since January to get another person here at night….we have met the social services, my mum's social worker and the manager of the care agency all saying she needs two people here at night…and we have been fighting for an answer, and then five weeks ago we were told it had gone to Panel but it was refused' (Female, Afro-Caribbean, 75)

'Originally we had been given a carer once a day to put her stockings on but as my mum's diagnosis got worse, we have asked for extra help because the stockings are too strong for my dad to remove as he has medical conditions as well - it took us six months, maybe longer of trying to get extra care and we only got it because everyone kept saying your mum was assessed last year, she doesn't need to be assessed again but things change rapidly….and it was only when I said I was no longer coming up here that they agreed she actually needed care in the evening - it almost took a year' (Daughter of Female, White British, 81)

7.4.14 A further notable issue was the administration of the hospitals in the area (both the Royal London and Barts) with reports of how notes were lost or there were simply no records of the patients.

'Over the last six months, I have been very, very dubious about the NHS - I have been getting phone calls from the London hospital, they told me to go to the new department on the 13th floor and I went there with my sister and it took all day and they said they had no report for me. They don't know their left hand from their right hand. I was there all day and stopped over one night and I had to go down to the third floor and have

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[11] As noted in the Methodological Notes, there were many reports of what was considered to be excellent provision. This section highlights issues which appeared to be common across the board and which were frequently brought up spontaneously. The author is also aware that such issues have been previously reported in a number of documents published by Healthwatch Tower Hamlets. Hence they are only briefly mentioned here.

tests and I didn't get to a bed there until 7 o'clock…' (Male, White British, 86)

'The last time I went, we checked in at reception -the woman said, who is it for and she (my daughter) *said for me mum and she said, where is your mum and she said she is sitting down and she said is her name James and she said, it is not James, it is Winifred and she said I have got down here James - it might be your dad then and she said, no. They were looking everywhere and they could not find any papers of me at all - don't tell me I am going home now when we have paid all this fare money up here - and you are going to tell me to go home without seeing a doctor and she said you can't see a doctor because we have got nothing about you….then the doctor came out and he said, come in and said I have worked here all these years and I have never seen anything like it, he said, you don't exist - you don't exist you are not on the computer you are not anywhere, nothing at all of me there. He didn't know, never ever seen anything like it - nothing on the screen anywhere - he said I will send you for a blood test but I don't think they will do it - and she said no, we can't do it as somebody else might get your blood - then I was asked if I had changed my sex! Fancy asking me that question!- My daughter said my mum is not 60 and she has not changed her sex - her names is (XXX) - he said I am ever so sorry but I can't even examine you - I can't examine you today as we have got no sign of you at all and all I can say is, come back again next year - but I had chronic leukaemia in its early stages'* (Female, White British, 79)

7.4.15 Two patients also reported how they had been taken off the patient list at their surgery, which they had attended since they had been children, because they had not been to the surgery for some time.

7.4.16 As common were discussions how patients were confronted daily with different professionals visiting them and at times they were simply unsure of who they were.

'I don't mind them all coming here but I have had so many people coming in one after the other - my domestic, my nurse, my occupational therapist and I had no time for myself…I would have wanted them spaced out really' (Female, Afro-Caribbean, 55)

'I don't know who the people were - they might have been from social services as they put me walk-in shower in but they might have been healthcare visitors….' (Male, White British, 83)

'Last week a Bengali man came and about two weeks ago an English woman came with a Bengali man from the London Hospital…I don't who they were' (Female, Bangladeshi, 74)

7.4.17 In some cases, particularly where there were two members of the household receiving regular interventions, there was a concern that all the care professionals came on the same day at the same time which simply added to the general malaise.

7.4.18 Evidence showed that a good deal more frequent and more concerning for patients, however, tended to be professionals who say they were coming and simply did not. This often seemed to cause some distress and worry.

> *'The doctor told him someone was coming round and they would bring someone who spoke English and just nobody has turned up…'* (Daughter of Male, Bangladeshi, 68)
>
> *'I mean I get letters to say they* (OT and Physiotherapy) *are going to help me but they are all talk and no one does anything'* (Female, White British, 90)
>
> *'At the moment, my mum is quite well considering but it would be nice if they did what they said they were going to do - last year they wrapped her legs because her legs were so bad and you have to wrap them in bandages and they were meant to change them every day and we were at the hospital so I had to ask my other sister to come down to let the District Nurse in but she didn't turn up and didn't phone so that was three people they are putting out and I think they didn't come for a weekend and we are told to phone them at the weekend to come and then we get told by the District Nurse that my mum is not a priority for a weekend call so it goes round in circles'* (Daughter of Female, White British, 80)
>
> *'Like she was meant to be putting this thing on his finger and doing his blood pressure and making sure he was ok….and to make sure he had all the equipment that he needed and it was after he came out of hospital….and then someone came round and she said she would be round the next day and then we phoned up and she is not in for a week and then she said she will be there on the Monday and never showed up and then she said Wednesday and never showed up and then Friday and then we couldn't get in touch with her…and it was about two weeks latter* (XX) came round' (Wife of Male, White British, 82)

7.4.19 In one case, the respondent had been given 'stockings' to wear daily but they had been the wrong size;

> *'A nurse rang me and measured me legs, they are meant to take the swelling down but I can't get a pair of shoes on. They are not doing me any good these socks. The nurse did phone me and I said they were still swollen and she said they should have gone down by now and she said she would come and see me but she's not been* (a month later)' (Female, White British, 89)

At the time of the second interview, the respondent reported the nurse had returned about three weeks after the first interview. Unfortunately, she was not able to put the new stockings on either as they were now too tight. She was once again waiting for the nurse to phone her back.

7.4.20 The difficulties for healthcare professionals arranging to see patients were also highlighted in the case of one interviewee whose family complained that the District Nurse did not phone to give an estimated time of arrival. If the respondent's husband was out, the interviewee was unable to reach the buzzer to let her in. This had meant that the interviewee had not been seen by the District Nurses for some time. By the time of the second interview, however, following an episode in hospital and a new care package, this issue had now been resolved.

7.4.21 In addition, patients were often somewhat surprised when some service provision appeared to end abruptly such as physiotherapy. It seemed, however, it was less that the provision had stopped but more that they had not been told it was going to stop.

'This fella comes from the Mile End and does my exercises…I have a lot of faith in him… he gets on with me….(But during the second interview he reported:) *They phoned me and said they would still come but nothing happened and they say they are going to come and they don't come and they have stopped it… they thought I was well enough I suppose but they didn't say so'* (Male, White British, 86)

'I mean you get used to it…they are nice but they keep moving on and my time is up - you get used to one person and then they move on to another hospital, another place…they don't always tell you though' (Female, Afro-Caribbean, 55)

7.4.22 Stories also abounded about the long waits for appointments, particularly hospital appointments, but even once the appointments were in place, there was then the wait to be seen:

'I have to go all the way to St Thomas' from here which is long way and I can't climb a lot of stairs - I have been waiting two years to have this done - carpal tunnel - …it says on it, 'URGENT' and that was in 2013' (Male, White British, 77)

'It is his eye appointments that I dread as it such a long wait, like three or four hours…' (Daughter of Male, Bangladeshi, 79)

'You wait two or three weeks for an appointment (with the GP) *and then that problem might go and then you cancel the appointment because there is no point going as you feel you couldn't explain it when the problem actually happened or you go and you are rushed and you then forget why you are there'* (Daughter of Male, Bangladeshi, 79)

7.4.23 It was, however, the wait for items such as incontinence pads and catheter bags that appeared to cause particular distress both for patient and their families. In one case, the family after six months still had not received the correct sized 'pads' for the patient and they had been referred backwards and forwards between the GP and District Nursing for a considerable length of time. In the meantime, the patient's wife, not well herself, was constantly washing sheets and cleaning.

7.4.24 As common was the wait for items such as catheter bags or incontinence pads as well as equipment and aids such as walk-in showers. One respondent described her situation, that had spread over a year, as follows:

> *'When I came out of hospital, my social worker said, would you like a walk-in shower? She was nice and then I got a different social worker, they had six meetings here and then she made an arrangement for the meeting and had gone on holiday and then we got a letter saying your time was up since when you applied for it so now we have to reapply for it'* (Female, White British, 92)

7.4.25 There was also the issue of the location of appointments. A number of patients bemoaned the closure of the London Chest Hospital not least since it presented complications for them in terms of travel and how they would get to Barts, for example.

> *'I am supposed to go for a check up at the chest hospital and they look like they are closing it up - and they are going to transfer to Barts, what transport have they laid on for me to go to Barts….I am not a young fella, I am 86 years of age'* (Male, White British, 86)

7.4.26 One patient further relayed how confused he had become with the vagaries of how the hearing clinic was run on the Isle of Dogs, whether he needed to go back there or to the London hospital and so on.

7.4.27 A number of respondents also had had problems on discharge. On the one hand were those who had been discharged and, to their surprise, had not been visited by anyone. It is notable that the following incident was spontaneously brought up in both interviews with the following respondent:

> *'I haven't had any help from the hospitals when I came out of the operation - I don't know whether it was my fault or not. You know like a little bit of help to see if you are all right - I had had a by-pass. I was told to do this, that and the other but I never had any home visits - nobody came'* (Male, White British, 82)

7.4.28 On the other, were those whose discharge had been continually delayed as the care package had not been put into place.

> *'The point I wanted to make is that if they are going to discharge a patient to make sure that everything that patient requires in their home is there. If they want patients back at their home to be looked after at home by their family, then everything should be there for them - instead of that you have to go back and fight for it - they tell you, oh yes they are putting it in place. Last Wednesday she came out of hospital and we haven't seen anybody since then - we knew the carer but we had to fight to see if the carer was in place…they seem to do everything five minutes before you are walking out the door - everything seems to be very lax'* (Daughter of Female, White British, 80)

7.4.29 Transport was often cited as being a problem with long waits. Cost was also seen to be an issue but it was the lack of co-ordination of information that appeared to be especially upsetting:

> *'The problem is they don't know the history of my wife - first of all, she can't get into a car so they have to send an ambulance with a hydraulic*

> *as she can't lift her legs - the system has changed where they have stopped using ambulances and they send minicabs so that is no use as she can't get in them'* (Husband of Female, White British, 80)
>
> *'Today the transport didn't turn up - she had to be ready from 9am this morning but this happens all the time'* (Son of Female, White British, 79)

7.4.30 Finally, difficulties in language were equally mentioned with a number of respondents reporting how they were unable to understand both healthcare professionals and (formal) carers.

GP Provision

7.4.31 Although aspects of hospital provision were discussed as noted above, far more attention was awarded to GP provision. Given that GP provision was the cornerstone of the Co-ordinated Care NIS, the following issues were of particular significance.

7.4.32 GPs were clearly expected to be and frequently seen as the referral point and 'gateway' to further care, either social or health.

> *'I imagine, if you tell a doctor like or the doctor knows you can't manage, I think he can put you on to social services, and send help around for you'* (Female, White British, 89)
>
> *'The doctor is the best person I reckon as they sort of help you and refer you on and to the welfare people…handy really when you get older and you then occasionally get a few people visiting you to see if you are all right'* (Male, White British, 82)
>
> *'The GP is my first point of contact for all the services'* (Female, Bangladeshi, 76)

7.4.33 In part, too, support from the GP was seen as critical for many of those interviewed. For a good number, they were certainly the most 'trusted' professional:

> *'I think it is because it is more personal there, they know you'* (Daughter of Male, Bangladeshi, 68)
>
> *'I am very satisfied with my doctor, I trust them and go to them for all my care'* (Male, Bangladeshi, 77)

7.4.34 However, a minority also commented that they were simply generalists and not experts.

> *'I think the GP has been helpful - they are not experts are they the GPs? Not on heart trouble or kidneys - but they do their best - they test you but I would always phone the hospital'* (Male, White British 77)

7.4.35 Obtaining an appointment at the GPs was seen to be a difficult and long-drawn out process for many of the respondents. One patient reported how he had held on for 35 minutes to even speak to the receptionist at the surgery. For many it was certainly hard to obtain an appointment on the same day.

> *'Sometimes I have to wait a day, sometimes two weeks but I get one in the end'* (Male, White British, 77)
>
> *'I left my GP because every time I phoned up I couldn't get an appointment for a month…and then you get one and sit there for three hours'* (Male, White British 82)

7.4.36 Once an appointment was made there were complaints that the GP would only talk about one problem.

> *'GPs don't tend to like you asking about more than one thing because they just want to stick to one kind of issue and that is it…so you have to make use of it, so if something cropped up, and you mention it they say, no, no, no, you are only here for this and you can only talk about this as I think they have this time frame they have to finish the appointment or something -so you make another appointment and that will be after two or three weeks and that problem might go and then you cancel the appointment because there is no point attending the appointment as you feel you couldn't explain it when the problem actually happened if you know what I mean'* (Daughter of Male, Bangladeshi, 79)
>
> *'They try and get rid of you as soon as you open the door - after you have discussed that one problem, that is it, allocated time gone - and you could have waited three to four weeks for the appointment'* (Wife of Male, Bangladeshi, 56 - reported via an interpreter)

7.4.37 Others complained they perceived that the GP was simply not interested in them and that they 'brushed them off' all the time:

> *'They give you ten minutes and that is it…and all the time they talk to their computer, that is the truth…even for reviews and you go to tell them something and they say they have not got the time, sometimes you could scream at them but they just sit there … and as soon as you walk in that door they go, oh I know what is wrong with him…so they spend even less time with you. They haven't got time to give you advice…and they just want to prescribe things and I want to discuss it so you know about the side effects'* (Male, White British, 77)
>
> *'I mean I walked briskly into his surgery and he decided there was virtually nothing wrong with me, never examined me or anything…they just have a preconceived condition and their own idea of what is wrong and then they want you to go'* (Male, White British, 83)

7.4.38 A good number of respondents, also, reported how difficult it was to speak to their GP when they needed to.

> *'I would have liked him just to ring (XX) and talk to him - I know they are busy and I don't need preferential treatment but they know he is not going to be able to get there so if the doctor could have just taken five minutes to talk about the pain and the tablets that are making him nauseas…but we still get the same co-codamol and everything*

> *else…luckily the pain is better and not too bad but all the time he could get another ulcer at any time so we are going to start all over again and then what are we going to do?'* (Wife of Male, White British, 64)
>
> *'The GPs don't come, that is the problem, last time I phoned to check in and they said we need to make an appointment to come…it can take two or three days to speak to a GP too, so now I just go to the hospital. He* (grandfather) *has not seen a GP for two years…he can't walk and is in bed'* (Grandson of Male, Bangladeshi, 84)

7.4.39 There was also an assumption on the part of many that the GP is supposed to come and visit if there is a need for them to do so.

> *'It is just they* (GP) *are supposed to go to elderly people's houses once a week or once a month, something like that but they don't - that is a big problem - they can obviously see them as they are always at home but they don't come'* (Grandson of Male, Bangladesh, 84)
>
> *'I don't think they come and visit people in their houses any more - they used to at one time. You have to be really ill for them to come so nine times out of ten you have to go down there to the surgery and it shouldn't be like that'* (Male, White British, 82)

7.4.40 For a number of patients this tended to be particularly distressing. One woman reported how she did not like contacting the GP as she did not think the GP wanted to see her husband, who was terminally ill and bed-ridden, particularly when it was 'out of hours'

> *'I don't think they like coming out in the evening and I find it difficult to ask them….I feel they are not going to come because they don't want to come and I know they won't come'* (Wife of Male, Bangladeshi, 56 - reported via an interpreter)

7.4.41 A number thought it would be very beneficial if regular visits were made to patients with co-morbidities like themselves not least to catch problems early:

> *'If somebody was going to come and see my mum, I would like to see a check up every six months - it shouldn't have to wait until there is a red light before you read the notes - I don't know if I am asking too much - I wouldn't want someone to come in and they don't know her from Adam and they would have to start again'* (Daughter of Female, Afro-Caribbean, 75)
>
> *'I think the GPs should keep a better check on elderly patients to make sure that people are getting the proper care 'cos if they know what is wrong with them they can see if they are being looked after - I know they are busy but there must be lots of people like me who are on their own'* (Female, White British, 79)
>
> *'I mean I think they should arrange to see people when they don't see them to knock on their doors to see if they were all right…like you read it in the paper, they have found a body after three weeks'* (Male, White British, 77)

7.4.42 Nonetheless some respondents did speak very highly of their GP surgery commenting how responsive they were when and if they phoned and how, in their experience, they would always visit if need be. The following quotation is taken from an interview where the patient had a particularly good relationship with their GP:

> *'I know for a fact that if I phone my doctor up and say I have got a problem, she will tell me to come down, if I can get there, but she knows everything about you and asks about you - she is helpful and you can have a little chat with her, she is very, very helpful and she wouldn't give you any medication that would damage your health and she sort of listens to you and examines you…she insists on pulling up a chair to have a chat…with previous doctors you are just in and out of the surgery'* (Male, White British, 82)

7.5 'Co-ordinated care'

The Co-ordinated Care NIS

7.5.1 The original intention of this evaluation was to track the progress of patients who had been placed on the Tower Hamlets Co-Ordinated Care NIS. As has already been noted, although this applied to all those interviewed, very few interviewees certainly in the first Phase of interviewing, were aware of the initiative. Interviews in the second Phase, however, proved to be more revealing with a greater number of patients either acknowledging or remembering conversations they had had with their GP or papers they had signed which indicated their involvement.

7.5.2 A number of respondents during the first Phase and rather more during the second Phase, did have some vague recollection of either someone coming round or telephoning to ask questions but nothing further had happened. There was some surprise and slight annoyance when they were not contacted again as the following indicated[12].

> *'Someone did phone me when I was at work and the doctor said he would contact me to arrange a meeting to see my granddad but that is all I know and they never phoned me again but I think the social worker will tell me about it I suppose'* (Grandson of Male, Bangladeshi, 84)
>
> *'I got a letter, a plan and there was a man who came and he said he would come back but I haven't seen him…he said something about caring but not sure really'* (Daughter of Male, Vietnamese, 87)
>
> *'About five weeks ago, we received a form to fill out but not too sure what it was for…then the doctor told him to bring someone with him next time he went but then he said someone would come but nobody has*

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[12] It is interesting to compare this section and the perceptions of respondents with those of the experiences of the Primary and Community Health staff, detailed in the report: Evaluation of the Tower Hamlets Co-Ordinated Care NIS – Phase One

> *turned up - I think I thought they would'* (Daughter of Male, Bangladeshi, 68)

> *'I did sign it* (in the end) *but have not heard anything back…'* (Daughter of Female, Afro-Caribbean, 75)

7.5.3 During the first Phase a few interviewees said that they had received a Consent Form which they had planned to send off when they had signed it. One, for example, explained during the first Phase why he had at the time not sent it off. By the time of the second interview, it had still not been chased up:

> *'I think they phoned me and gave me a letter but it was only one page document - it was just time, I was supposed to fill it in….*(Phase II:) *I lost it in the end - I thought they would probably send it again but they haven't and nothing has been mentioned'* (Son of Male, Bangladeshi, 57)

7.5.4 Indeed, for those that did recollect being asked to sign the Consent Form there was a view expressed that more information should have been given. Some, too, were sceptical:

> *'The nurse came out and I did have a phone call from the GP about sharing the notes and that was fine as it then saves me the hassle of dragging his medication with him all the time and regurgitating everything again to them but I wasn't given any information and some literature would have helped or even a copy of what she took down'* (Son of Male, Bangladeshi, 75)
>
> *'It is a good thing for everyone to have our notes but I don't expect anything to change'* (Daughter of Male, Bangladeshi, 68)
>
> *'I don't have to do anything about it if I don't want anyone to know my records but I am too old to worry about things like that…I mean it's helpful but it is not going to make any difference, just the hospital or whoever knows about me health'* (Female, White British, 89)

7.5.5 Only a minority could recollect the Care Plan and it seemed that everyone's experience was different. It had certainly been a mixed experience for this man who, at 82, was still working part-time:

> *'I signed the Consent – that came through the post and then I saw the doctor and she asked me like where I wanted to die - I thought that was jumping the gun you know asking me before it happened…but I think it was for the Government wasn't it? She said something about being happy but she did ask me about my depression in the same appointment and it all sort of came together…I asked her if I could have something to calm me down and she recommended these tablets…it was the first time I had mentioned it'* (Male, White British, 82)

7.5.6 This was in contrast to a respondent who also suffered from anxiety as reported in the interview but who felt it simply was not the place at the doctor's surgery to mention it. Nonetheless, he seemed content with the discussion about his Care Plan although it was only unexpectedly half an hour and not longer and he did not feel confident his records would be shared as a result.

7.5.7 A further respondent, who recalled the Consent Form and the Care Plan in the first interview, was however unsure of either its purpose or its function. He was given a copy of his Care Plan but was unsure whether he should take it with him to hospital or not.

> *'I mean, I don't know whether I am supposed to take it when I go to the hospital – but it lists my health problems and tells them I can make decisions for myself…I assume the point of it is that I get better care than I do sometimes when I go into hospital – I mean it is only a care plan for when I am an in-patient. Common sense says take it when I go but what worries me is that when I have taken things in before, the doctor in A&E takes it and says I will fetch it back shortly like the discharge letter…and then I never see it again!'* (Male, White British, 83)

7.5.8 One patient additionally queried its purpose and her main concern appeared to be the length of time she would be taking up in the surgery:

> *'I had a letter and then an appointment - she* (GP) *talked to me about if I want to share my health problems so that other people can learn about it or share… she asked me my worst problem and I said the psoriasis as it may go on my face…it was a longer appointment and I kept apologising to her as it was keeping the other patients waiting…she has given me a copy but my care is just the same….'* (Female, Philippine, 59)

7.5.9 In contrast to this, was a patient who felt that they had simply been rushed in and out of the surgery and felt rather let down by the process. For this family, the GP also did not appear to ask the most important question for them:

> *'She* (GP) *said it was a new thing, NHS has brought it up…everyone is working together so they know what is going on…I mean I thought it would be a good thing as it takes so long to get all this information and you have to repeat everything….but I am not too sure if it is like that because the GP seemed very rushed and she just wanted to get the questions answered quickly…it was rushed and I don't know if I had all the information - I was told it would be an hour but we only took half an hour….when we next went into hospital, everyone was too busy to even explain about it…They did ask questions about what would make my dad happy but he just said walking to the mosque but I don't think that is the case…and I think I thought we would get the question he needed that would ask us what kind of help do you think your father needs or something like that but it wasn't anything like that'* (Daughter of Male, Bangladeshi, 79)

7.5.10 In one interview, a family member described how his mother had been telephoned by the GP and asked the questions on the Care Plan but that she had been very confused.

> *'There was a letter about a named GP and we have to phone up about that to find out what it is about but there was another one about her*

> *history and then they rang up and asked a few questions…they asked about DNR, do not resuscitate and she was confused and she mentioned it to me. She said 'yes' but I then explained it to her and she said 'no' and I don't think it is right to ask someone that, like my mother, over the phone - they said they would send a form but it could be disturbing for some and they should have sent a letter first and then done it face to face and then you have time to think and know what questions to ask…but I don't think anything will change'* (Son of Female, White British, 79)

7.5.11 More interesting perhaps was the reaction to the letter that was sent out by surgeries, at the time of the Phase 2 interviews, informing patients that they were now to have a 'named GP'. For many respondents, it was not possible to disentangle the effects of the NIS from that of the letter:

> *'There was one time somebody called from the GP asking me how I am and I had a letter stating the name of my GP….they call me once or twice a week now asking me if I'm all right and how is the treatment and they ask me if I have seen the specialist…'* (Female, Philippine, 59)
>
> *'The letter said basically he would have a named GP and whatever problem he had he could see that GP…I thought it was positive…I mean we had that Care Plan but it is still rushed and we saw a locum last time and he had not read it…at least now I can say we have got this letter and we have to see him but I suppose it depends if we get an appointment!* (Daughter of Male, Bangladeshi, 79)
>
> *'We did sign that thing about a year ago and the hospital did have our notes but now we have a letter which gives us an allocated doctor so it means that if my mum goes into the hospital, you can actually give a designated GP's name…'* (Daughter of Female, White British, 80)

7.5.12 Once an explanation of the outline of the Co-ordinated Care NIS was given, however, a number of interviewees responded favourably. In particular and noting the nature of support required, as detailed above, the idea of the Care Co-ordinator was particularly well received – with provisos:

> *'Of course it would have helped to have had a Care Co-ordinator - I never had anybody straight to tell me what had happened to* (XX) *but I would have to meet them first to know I could trust them'* (Sister of Female, White British, 59)
>
> *'I have not heard anyone pick up the phone and say, hi, how is it all going - can we come and see you, do you have any questions, anything we can do…The person could be the first point of contact, and they are the person they feel most comfortable with and then that person can pass on information to the GP and it is a GP issue…it shouldn't be the District Nurse , it shouldn't be the befriender...it could be the social worker ….it could have helped me about the home making decisions with the professionals…and they could negotiate on your behalf – the main point of contact'* (Daughter of Female, Afro-Caribbean, 75)

'It would be a good idea but you have to see them now and again and you have got to get on obviously and trust them…the rest is trial and error really isn't it…' (Male, White British, 77)

7.5.13 Treating respondents at home was also welcomed:

'When they did the Care Plan, they said they would come and do this stuff at home and I was a lot happier as if he needed antibiotics again or intravenously they could come here and do it – I never want to leave him again as (in hospital) *when he calls them* (the nurses) *they don't respond. I saw the bed bound calling for help and no one would attend to them'* (Son of Male, Bangladeshi, 75)

'They explained I could be treated at home as well and I wouldn't want to go into a home - it will be wonderful providing you have got people…I would be much happier in my own home than I would be in any hospital' (Male, White British, 82)

Community Health Team

7.5.14 The Community Health Team was initiated as a central feature of the Co-ordinated Care NIS and of integrated care provision. Experience of this was thus a focal point in discussions.

7.5.15 Although unsure of either the term, ' Community Health Team' or the 'Co-ordinated Care NIS', there was some evidence that there had been a change in provision over the time span of the interviews, for a minority of the interviewees . However, the majority perceived their care to have remained unchanged.

'I have had miraculously in the three weeks, visits from the District Nurses, they just knock on the door and say, hello, how is your dad doing, we have just come to have a look? Have you got notes here but I tell them they have never given us notes…I was shocked at having three visits, I think someone must be cracking the whip somewhere…probably had an audit' (Son of Male, Bangladeshi, 75)

'Well, I was surprised as they had all my notes, everything, and they just had everything there!' (Male, White British, 82)

'I think I have been treated better because they seem to show more interest – I do think that – like they ask you now' (Female, Afro-Caribbean, 55)

7.5.16 And some remained rather pessimistic:

'I don't know of its use - all my allergies are not on it - I have had to write those out on the computer…and I still don't know what to do with the Care Plan…in theory all ideas are good like this but in practice they never seem to work because there does not seem to be much co-ordination between them - there is all these different cogs in the wheel and all it needs is one of them not to do their job' (Male, White British,83)

7.5.17 In particular, it seemed that respondents did not see their care provision in any holistic sense but, instead, in silos. Thus, although there was a very small minority that knew the term, ‘Community Health Team’, almost all those interviewed believed that the components of the team were totally separate from one another.

> *‘No I wouldn’t ask the District Nurse* (to chase up the Physio) *because they are not the same thing, the same department, it is all different and I know ‘cos of before…I mean there is no communication between this room and that room even in the hospital…they all need to get their act together’* (Son of Female, White British, 80)
>
> *‘The District Nurse can do nothing because District Nursing is under the GP, GP is above the District Nurse…and the Occupational Therapist is something different and nothing to do with the GP’* (Grandson of Male, Bangladeshi, 84)
>
> *‘If the GP comes, I would expect him to have a rough idea of her history but not the Occupational Therapist and Physio, they are totally different - they just move her around’* (Daughter of Female, Afro-Caribbean, 75)
>
> *‘I just want a home help but I don’t think home helps are anything to do with the GP are they?’* (Male, White British, 77)

7.5.18 Even for those who were aware they were on the NIS, they felt little would change in this regard:

> *I know they* (District Nurses) *will say that I have to go through the GP to get the Speech and Language Therapists - and that is what I have previously done’* (Son of Male, Bangladeshi, 75)

The Sharing of Notes

7.5.19 As part of the NIS, all patients were asked to sign a Consent Form so that their notes could be shared across provision. The issue of sharing of notes was discussed with those who were conscious they had signed a Consent Form as well with those who had poor, if any, recollection of this.

7.5.20 A good number of respondents assumed that this was happening anyway and certainly had had the experience of the hospital and GP sharing information.

> *‘I imagine they do I meant they must do…but they are not going to have a row about me are they the doctors?’* (Male, White British, 77)

7.5.21 Although there were some respondents who clearly had had difficulties with communication between hospital and their GP, there was also a sizeable group who were simply not sure as to the extent to which notes were shared.

'They probably should, but I have no idea if they do - I have been to the hospital and a lot of times they have never had the notes from the last appointment' (Male, White British, 82)

'I assume it is shared but when I went to the Physio at Mile End, they didn't say they had my information and they didn't, I know…I think (the Out Of Hours) *should be able to have a computer where they could actively look up your record - I don't know if they do either '* (Male, White British, 83)

7.5.22 On the basis that, in their perception, the health service was comprised of separate teams, some respondents were quite adamant that although GPs and hospitals may share results and information, this did not happen with other branches of the NHS and care provision:

'She (District Nurse) *wouldn't share my notes would she? They are here, she writes them here and they stay here – they don't go nowhere else…'* (Male, White British, 64)

'There seems to be liaison with the hospital and the GP but Social Services? I suppose they should (share) *but then they know what the requirements are and it is something totally different'* (Son of Female, White British, 79)

7.5.23 A smaller number also simply believed that somewhere, somehow there simply had to be a central bank of notes.

'I haven't noticed any co-ordination but I am assuming there is a central system that has got all his details on there that they do access 'cos I have noticed they ask for his date of birth and stuff and so I assume they look up the notes - there must be a central system somehow' (Son of Male, Bangladeshi, 75)

7.5.24 Whether or not respondents believed that different parts of provision shared notes also tended to reflect the reality of their experience which overshadowed and remained separate from the intended effects of the new integrated provision.

Involvement in Care

7.5.25 One of the key aspects of 'integrated care' was to ensure that the patients were 'involved' in their care and they felt that health professionals 'listened' to them. This was very much a discussion point in the interviews and it seemed respondents' views were largely dependent on firstly what they understood by the terms, 'involvement' and 'being listened to' and, secondly, the extent to which they were focused on their day-to-day existence and whether they were able to think beyond their immediate concerns.

7.5.26 Undoubtedly, some respondents felt that they were 'involved' and healthcare staff seemed to be interested in them.

'They are interested in him and the doctor does discuss things, she will advise him - like it wouldn't be a quick visit and they involve him…' (Daughter of Male, Bangladeshi, 68)

'I think they listen and they always go through all the side effects and involve us in the decisions' (Son, of Male, Bangladeshi, 59)

'They (the hospital) *listen and the GP also talks kindly and she will listen - she won't be cold and sits there and listens and gives you the eye to eye and asks him kindly'* (Daughter of Male, Bangladeshi, 68)

'Oh yes, they do (listen) *because sometimes when I go to see him* (doctor) *he asks how I feel and I tell him and the heart specialist does that… and they always listen when I tell them about the side effects'* (Female, Philippine, 59)

7.5.27 Those families who had very much taken control of the care of relatives, as discussed earlier, tended to believe they were fully involved but it seemed involvement in decisions was almost by chance rather than by design. For example, the following quotation is taken from an interview where the son cared for his father full-time. He very much felt involved in the care but did not know why 'DNR' has been put on his father's records without any consultation[13]. The same contradiction is also inherent in the second quotation below.

'They have to involve me for consent for everything as my dad can't communicate and they do involve me……..(but) *no-one discussed it* (DNR) *with me…it was just what the consultant had decided - I was kind of shocked really…'* (Son of Male, Bangladeshi, 75)

''Yes they do make decisions with me and they (the hospital and the GP) *do speak to me every time…but the GP doesn't listen ever to whatever I say so I go to the hospital…'* (Grandson of Male, Bangladeshi, 84)

7.5.28 More interesting and more common were those cases where respondents felt they were listened to and involved but the stories and experiences they reported appeared to be ones where this had clearly not been the case. In the first example below, the family had been waiting for incontinence pads for over five months and by the time of the second interview they still had not been delivered. They were also having difficulties in seeing or speaking to their GP and had repeatedly asked for assistance. Nonetheless the patient's wife, not well herself, felt 'involved'.

'I feel involved in any decisions made and when they discuss things like Health Plans or little things like day care or Day Centres and I am quite happy about that' (Wife of Male, Bangladeshi, 56 - reported via an interpreter)

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[13] This case is also referred to earlier

7.5.29 In a further case, one patient, who had a number of co-morbidities and was wheelchair bound, felt she was ‘listened to’ and ‘involved’ but was unsure, for instance, why she was given Botox for her legs, unsure why she had been given the wrong medication (and was thus hospitalised) and was ‘put to sleep’, when she had to go to hospital for her teeth, without being informed. Interestingly, when asked whether she would like to be more involved and what this might mean, she replied:

> *‘I don’t know how, I really can’t tell you - I would like to be more involved but I don’t know how - I would like to have more of a say but I don’t know in what respect’* (Female, Afro-Caribbean, 55)

7.5.30 However, some families felt not only did they not listen but they were not involved either.

> *‘No, they are not interested…it is a last resort place here…they die off like flies* (Care Home), *they don’t involve me, not at all, they don’t tell you anything if she is upset or if she has wet herself - I mean she had bruises down her shins and they didn’t say…they tell you the bare necessities, they don’t want you involved and they shut you out of everything and they don’t want to know’* (Sister of Female, White British, 59)
>
> *‘It depends what you call involved…so that someone would actually tell me what the problem is in the first place and then what they are going to do about rectifying it…but I am not the only patient in the hospital and they are under a lot of pressure so they haven’t got time to explain things…’* (Male, White British, 83)
>
> *‘’If we weren’t here she would get nothing….I know my mum doesn’t feel in control of her care, but we try to be…but family meetings are arranged around their* (the hospital professionals) *workload and not us…nothing is discussed with us until afterwards - but until you query something, nobody actually talks to you and when you say something and they don’t like it, it gets their backs up’* (Daughter of Female, White British, 80)

7.5.31 But there were clearly a group of respondents who did not want to be involved any more than they had to be:

> *‘They have to listen to what they tell you but I didn’t want to go to hospital but I had to…but involved in the decisions? They make the decisions and they just tell me what they plan to do…I can go to the hospital and they will explain everything to me but I don’t really want to know…I just don’t feel up to going into all of that - I take it they know what they are doing’* (Male, White British, 77)
>
> *‘Put it this way, when I go to the doctor’s I want to get in and out as quickly as I can…I don’t ask questions, I don’t want to know…I don’t know this new doctor and he asked me lots of questions and I just wanted to walk out’* (Male, White British, 64)

7.5.32 The contradictions and perceptions highlighted above appeared to reflect not simply different definitions[14] but also it appeared views were clearly affected both by patient expectations and perceptions of provision. As noted above, this was, in turn, partly dependent on previous experience as well as perceptions of particular services, relationships with staff, level of family involvement and so on. Evidence also indicated, however, it was in part, again, due to the fact that the interviewees tended to perceive and experience provision in silos and not holistically.

Co-ordination of Care

7.5.33 A further topic of discussion was the extent to which patients were concerned about co-ordination of medical care or, alternatively, co-ordination of administrative care. Here opinion was divided but there was a sizeable proportion of respondents who felt there was a need for the medical professional, usually a GP, to 'know them'.

'It has to be that doctor as he knows him and knows all about him' (Daughter of Male, Bangladeshi, 68)

'I could see another doctor, but I don't want to I like him and I know him' (Female, White British, 90)

'I just want someone who knows me inside out…that personal contact and they know about me' (Female, Afro-Caribbean, 55)

'You want the same doctor, so you can converse with them better and they know you and what is wrong with you' (Male, White British, 82)

'And the locums don't read the notes because they are only allocated ten minutes to see you' (Daughter of Female, White British, 80)

7.5.34 Whereas a further minority were not sure, others clearly felt that as long as the doctor had the notes, it actually did not matter whether it was the same person.

'I don't see the same doctor every time…if you want to see (XX) *you have to wait two weeks and everyone wants to see him…so any doctor, it doesn't matter so as long as it all comes up on screen'* (Male, White British, 77)

'Well, what could I do? You can't do anything to make sure you always see the same person - I don't mind as long as they do things correctly and have the notes' (Female, Philippine, 59)

'To him, it is the same, simply whoever fixes him' (Son of Male, Bangladeshi, 57)

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[14] One respondent, for example, considered that involvement meant 'self-care' and another believed it meant simply receiving information.

7.5.35 Nevertheless, for one patient, there would only be relief if they saw a doctor at all and the family of another patient, who had been diagnosed with dementia for ten years, simply felt exasperated:

'It doesn't matter as long as they treat people nicely - he can't go to a doctor so as long as they come and see him which they don't and everything thing is checked, that is ok…' (Grandson of Male, Bangladesh, 84)

'My last trip to the doctor when I went there he asked me what my dad's illness was so I don't think he had even looked at the notes - it isn't the first time, I am so used to it and it really doesn't bother me any more' (Son of Male, Bangladeshi, 75)

7.5.36 There was also the argument, expressed by some, that seeing the same doctor was not always a good thing.

'What I am saying is, I think a doctor can get used to you and see you too often…so they spend even less time with you and just bang out a prescription'
(Male, White British, 77)

7.5.37 Nonetheless for those respondents who had received the letter informing them they were to have a named GP, as noted above, there was clearly a good deal of enthusiasm:

'Because of that letter, if I call I can at least say, (XX) *we have got this letter and we will see him and then you won't have to see the locum'*
(Daughter of Male, Bangladeshi, 79)

Communication

7.5.38 Opinion was divided as to the most appropriate medium for contacting or informing patients of changes to service provision. It was argued by some that a letter was more useful since it could be read and subsequently digested.

'A letter so then I can sit and read it and take it all in and over the phone I will forget what you said five minutes later' (Sister of Female, White British, 59)

'If they wrote to you, you can sit and read it over and over again and then it comes to you' (Female, White British, 89)

'Letter is better then I can read it and tell him - phone calls you can't really talk for long can you? (Daughter, of Male, Bangladeshi, 79)

'I would prefer letters - with a letter you can bleeding keep it' (Male, White British, 82)

7.5.39 For others, the telephone was far easier and more practical.

‘Phone is better, as I am the main carer, I give my number to everyone, housing, the GP and the hospital, I have to speak on behalf of everything’ (Grandson of Male, Bangladeshi, 84)

‘I think letters they don’t always understand it – you need phone calls with a Sylhetti speaking person…’ (Daughter of Male, Bangladeshi, 68)

7.5.40 Finally, a minority of respondents spontaneously suggested that face-to-face contact was always preferable.

8. Sub-groups/segmentation

8.1 The evidence showed that this cohort of patients, although all of whom had been considered appropriate for inclusion in the Co-ordinated Care NIS, were not a homogenous group. Based on the findings, three sub-groups have emerged. Although whether they lived alone or with family/carers, ethnicity, age and gender may all well be important issues, it appeared that where the lines were most clearly drawn was on the basis of the service and support needs of patients. Levels of health literacy, though not focused upon in this evaluation, may also be a determining factor.

8.2 The segmentation has therefore been developed on the respondents’ perceived needs and expectations of service provision. The sub-groups are broad and all could be sub-divided. Importantly, these are ‘fluid’ and not ‘static’ groups and patients can move between one sub-group to another as their health improves or deteriorates or as their support needs change. They can also overlap and certain aspects of a service are important to all three sub-groups – see Figure 1. Importantly, these groups are not based on their behaviour as might normally be the issue in a segmentation process but, alternatively, are based on the level of health and social care provision that is required as well as, importantly, upon the level of support that is needed beyond the remit of statutory provision. It is important to note that the evidence showed that in terms of service and support needs the difference between those living on their own and those living with family was one of emphasis. Thus those living on their own can be found in all categories.

Sub-Group 1 - Past Problem - Presently Independent

8.3 This group may have had an acute health problem (such as a heart attack) in the past but now appear to attend only regular check-ups and reported assessments at the hospital and possibly at the GP surgery as well. They may have a range of co-morbidities such as coronary heart disease, high blood pressure, kidney problems, COPD, diabetes, early stages of dementia etc and may have had periods of being in and out of hospital. Presently, they appear ‘stable’. Their experiences of health provision in terms of their own satisfaction will have varied but, at this stage, they are perfectly happy with their care. They may have periods when they have seen different members of the Community Health Team such as Physiotherapists or Occupational Therapists and they may well express a concern about what happens if they are 'discharged' from a service since they may be fearful that they may have a recurrence.

Within this group will be those living alone and those with partners and/or family. They will vary in their need/desire to go to social clubs and some will categorically refuse. They will be mainly unsure about service provision and benefits/services to which they may be entitled but, more importantly, they may well be asking for services such as home helps, cleaners, people to shop for them etc. Given their health, they might also express a range of anxieties related to their present and future health and may feel relatively unsupported in this – they may, for example, feel their GP is largely unsupportive. For those that live with their partners/family, there are particular concerns about what might happen to the partner. For those on their own, they tend to feel particularly ‘alone’. They are relatively sceptical about the level of care they might receive, particularly in terms of co-ordination of care. In a sense, they appear to be ‘waiting for the next time’.

Examples:

***Respondent A – White British, Male, 77**: Respondent has reported heart and kidney problems, arthritis, is diabetic and is now losing his sight. He is divorced, lives on his own, rarely sees his children and has one friend who lives on the outskirts of London. At the time of the first interview, he had just come out of hospital for his heart and feels they ‘did a good job’. He has also had eye operations which were not ‘nice experiences’. He does not like going to hospital as ‘nobody likes going to hospital’, although he seemed positive about his recent admission. He attends the GP surgery regularly for check-ups. He has faith in the doctors, trusts them and feels they ‘have to listen what you tell them’. But also states, ‘they make the decisions and they just tell me what they plan to do…*(but) *I don’t want to go to the hospital and know too much…They obviously have to tell me what they plan. I take it they know what they are doing – the less I know the better’*

He is clearly anxious about his health and regularly goes to the GP. ‘I have asked to see the GP – there are a few things what I want to ask them but I can’t remember what they are now’. He tends to see the same doctor but would not mind seeing a different one.

At the time of the second interview, he was having difficulty breathing in the mornings and sometimes throughout the day. He was also waiting for results from a kidney check-up. He had asked the doctor about his breathing but they, ‘haven’t said anything at all…that is why I going (again) *on Wednesday’*

In both interviews, he was particularly distressed about the state of his flat and he wanted a home help or a cleaner and someone to do his ironing. ‘All I can think of at the moment is a home help – it would take me weeks to do that ironing – that is all I can think of’. He has asked his friend but also worries about someone coming who is trustworthy. He has not asked his GP whom he likes but, ‘I don’t find it easy to talk to them – not when it comes to personal things – I don’t know them’

He has no recollection of the Co-Ordinated Care NIS and says he did not sign anything, 'I won't sign anything when I don't understand what I am signing for'. He supported the idea of a Care-Co-Ordinator but felt it might take time to build up trust.

Example 2 - Bangladeshi, Male, 79: *Respondent is diabetic, has had a number of heart attacks, kidney problems and additionally has 'pain on walking'. Lives with his daughter who is the main carer, his son-in-law and their child. At the time of the first interview, their main concern was the difficulties they have in obtaining an appointment with the doctor. The previous week they had been sent to the out-of-hours by the receptionist but, due to the long queue, had gone to A&E. Recently, the respondent had only needed a blood pressure check and that had taken a week. The daughter said they have been badly affected by the experience of her mother (the respondent's wife) whose cancer was not diagnosed until too late. They question everything as a result and the daughter notes that the GP does not want to provide that 'extra' help they might need and they always feel rushed in their appointments. The family worry about health since he also has swollen legs and they worry about diabetes. The GP, in their view, just tends to 'prescribe you something and that is it... and you just come out of the room and it is like…go, go away and you think, why did I go and sometimes GPs make you forget why you went'*

The respondent is able to go to the mosque but the family feel that although he might seem independent, he has 'bad days' but tends not to say anything as is reluctant, due to the experience with his wife, to go to the GP or to the hospital. The family feel he needs some other support as well, possibly a Day Centre or a befriender. The GP has said that he will not refer because he is 'quite independent'. The family would like a central telephone number to phone for different types of support, 'because you always think at the GP surgery it is all about health in terms of medical well being but what about the other things he might need, emotional and things like that and other support he might need' .

Sub-Group 2 - Present Problem/s - Reliant on Intermittent/Care

8.4 Sub-Group 2 also have varying levels of support from the health and social care system and are likely to have a range of co-morbidities including dementia. At one end of the spectrum will be those who will have permanent and regular care in the form of formal carers (as well as possibly informal ie relatives/partners). They have tended to feel they have had to 'struggle' for the care that they have or feel they should have had and often feel in a 'vacuum' without knowing which way to turn. As a result, the families feel they are relied upon for everything.

At the other end of the spectrum, are those who do not have regular carers but who do have regular interventions such as District Nurses and therapists and have done for some time. They may well have developed 'trusted' relationships with key members of the statutory sector and rely on these for support. However, they do not necessarily like asking for help or talking to professionals.

The groups within this segment are united by the fact they seem aware that they will probably not improve in the long-term. They may attend Day Centres on a regular basis. They tend to be particularly anxious about the future and are often frustrated about their situation feeling a loss of control over their lives. They may well need other forms of support such as social and emotional support or merely help with issues in their lives such as finding a solicitor. They may also report depression or high anxiety. There is often an issue with obtaining the right ‘aids’ and equipment. They have experience of a wide range of professionals and feel they would benefit from a greater level of ‘co-ordination’ and a contact point.

Examples

Example 1 - Female, White British, 80: *Reported to have corrosion of the spine, angina, lymphedema and early onset Alzheimer’s. The respondent lives with her husband, also with serious heart problems but has family nearby and daughters regularly visit. At the time of the first interview, the respondent found it hard to walk and was supposed to have a District Nurse visiting to check the lymphedema but they did not give prior warning and the respondent was not able to get to the buzzer. This had happened on a few occasions. The family had asked repeatedly for the District Nurses to pre-warn the family when they were visiting. The family have also had repeated problems in accessing carers. They finally managed to have two carers to help with the stockings for the lymphedema as father was not strong enough to lift her and one carer could not manage. It took six months to arrange for the second carer. The family feel that they ‘go round in circles’ with their mother’s care. There was also a concern that when she falls, the husband may be out or alternatively something might happen to the husband and she would be left on her own. She does not want to go to Day Centres or have a befriender. There was a health mentor who just stopped coming - they don’t know why. A Physiotherapist was also coming but this was stopped, rather to the annoyance of the family, as the respondent could not remember the exercises due the Alzheimer's.*

By the time of the second interview, the respondent had just returned from hospital having had two falls at home. She was a patient in the London Hospital for two days and then transferred to the Mile End. They felt the treatment in the Mile End Hospital was dire with a lack of co-ordination, poor nursing and the staff had also not read the notes that the respondent had Alzheimer’s which had deteriorated due to the fall and to a chest infection. The discharge was delayed twice and once because the family were suddenly told on the day of discharge that they had to organise all the care themselves. Finally sorted out, the family is now happy with the package of care they have. For support, they now rely on the care agency, London Care who have been very helpful. Neither the respondent nor her husband would feel comfortable about talking about anything other than health with their GP even though they spoke highly of them.

Example 2 - Male, White British, 64: *Respondent has reported blood pressure issues, heart issues and presently ulcerated legs and lymphedema. He lives with his wife but their children and families call in regularly. He is only able to walk with difficulty. The District Nurse comes regularly often three times a week to tend to the leg. At the time of the first interview, he had not seen the GP for six months. He likes the GP but it is almost impossible to speak to them as they have repeatedly tried to do. His wife is particularly concerned about pain relief and if the pain suddenly gets worse. They are both concerned if something were to happen to his wife but equally concerned what would happen if he fell as she could not lift him and feels she would have to phone the fire brigade. This concern is so great that, as result, he hardly stands up. They had a problem with Occupational Therapy who could not fit rails upstairs as it was not possible to fit them to plywood. Thus, the wife has to do his bathing. They also worry about him 'smelling' and his personal hygiene.*

He acknowledged that he is 'depressed' and feels he is wasting away. He would like someone to talk to but it would be important to meet them first. He feels it would not be possible to talk to his GP and would not want to in any case. He is reluctant to ask the GP for anything and never wants to stay long in an appointment and discuss his health.

At the time of the second interview, the situation had not improved and the legs still were not better. Until they were, he was not able to have any physiotherapy. He is also conscious he is very overweight but cannot do anything about it until he is mobile. His depression and anxiety had also not abated. He feels he is in a Catch 22 situation. He has, however, built up a close relationship with his District Nurse who visits regularly and reliably and he now has 'her phone number'. He is also, in his own words, reliant on his wife but, for instance, was reluctant to call her his 'carer'. He stated that he found it particularly hard to ask for help.

Sub-Group 3 - Permanent/Palliative Care

8.5 This group tended to have 'serious' health issues, were possibly bed/wheelchair bound and were generally unable to speak for themselves. This group can again be subdivided by the nature of the support they receive. The first group are those who are looked after almost totally by relatives although they may have formal carers as well. The relatives organise all their care and 'fight' for everything they have. They can be seen to operate in parallel to the statutory system, occasionally linking in where necessary. The carers are likely to need some level of support themselves which tends to be rarely forthcoming.

This is in contrast to the second group who, although dependent in every way on their family, are to a far greater extent dependent upon statutory provision which is regularly seen to fail them. In this study, for this second group, care was seen to be unco-ordinated and chaotic. Again there was reluctance to ask for help unless at crisis point and a reluctance to complain.

Those within this segment as a whole appear to be less likely to have ‘trusted’ relationships and also appear less likely to, or less likely to want to, have access to social clubs. The focus appears to be on the decline of the respondent and the implications of this and, particularly in the second group, there is a need for greater external support, including emotional, with co-ordination of care and support for the carers.

Examples

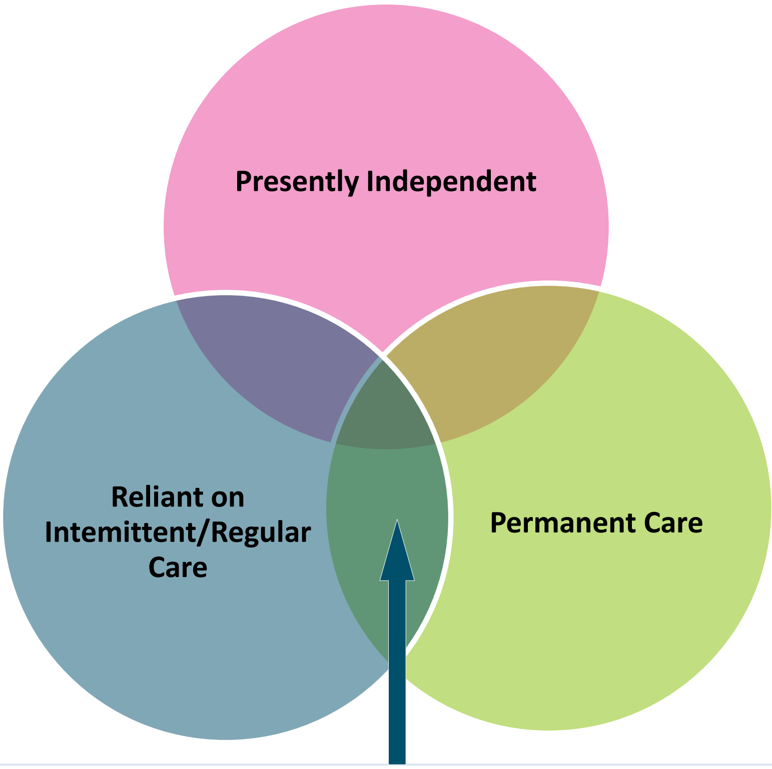
Example 1: Female, Afro-Caribbean, 75: *Respondent is bed-bound with reported heart problems, vascular dementia and diabetes. She lives on her own with two carers who come four times a day. She is also permanently cared for by her daughter who organises all her care since otherwise it would not be done. The problems initially started with a fractured ankle and early signs of dementia. She was given a clean bill of health but is ‘too scared to get up’. Following the fracture, she was sent to the Mile End Hospital for rehabilitation. She developed bad bed sores and a bad bowel infection and was sent back to the London. She was then sent to a Care Home where she remained for five weeks. There she was given sleeping tablets without family consultation and developed chronic bed sores, a severe necrotic pressure sore and a double bowel infection which in turn antagonised the dementia. When discovered, she returned to the London and is now cared for at home. Her daughter is constantly by her side and, in her view, has had inadequate support. She has organised and initiated all the care including dieticians, physiotherapy, someone to cut her nails and ‘teaches’ the carers when they are new. She believes to have someone to co-ordinate the care would have been a tremendous help. She herself has had to work part-time as she cannot concentrate because of the pressure but nobody at any time has offered her any support. She feels her mother is isolated with no stimulation and thus her mental state is deteriorating. She is concerned about this but unsure where to turn.*

Example 2: Male, Bangladeshi, 84 *– Respondent is bed-bound with reported heart disease, hypertension, gall bladder problems, haemotoma and dementia. He lives with his wife and grandson with no other relatives close-by. He is looked after totally by his grandson, who works night shifts in a restaurant. The GP never comes out and has not seen his grandfather for two years. ‘The GP is rubbish and they don’t care, you die, you die, they don’t care…how am I supposed to take him for a flu jab, he can’t even walk’. Even when he had an infection for which he needed antibiotics, it took three or four days just to speak to a doctor to get medicine for him. The District Nurse comes once a week and carers come four times a day. There is a perennial problem of the catheter becoming blocked causing infections. This has often and still does mean regular trips to A&E and periods in hospital. The grandson feels the District Nurse should come more than once a week as it could become blocked at any time. By the time of the second interview, the situation had not changed and although the District Nurses are coming regularly (but in his view not regularly enough), he is still waiting for a supply of catheter bags.*

The second interview took place just after the respondent had again been in hospital. He had fallen out of bed five times since coming out *and the grandson had rung up the social worker to try to find a different bed. The social worker, whom he did not know, told him he had to go back to the ward to ask for support which he subsequently did and finally a Physiotherapist at the hospital arranged for him to have a new bed.*

The grandson reported in the first interview that he relied on his allocated social worker who was very helpful in all ways but by the time of the second interview, the social worker had 'moved on' - hence why he had had difficulties with the bed. He also mentioned a District Nurse who had been helpful but she only worked part-time and thus he was not able to see her regularly.

The grandson is constantly concerned about his grandfather particularly if anything were to happen when he was not there. The grandmother speaks no English and is unable to use a telephone. He said he would have to change his shifts as he was so concerned. He also asked the researcher to help him with immigration as he would like his uncle to come over to support him with the care of his grandfather



All segments appeared to need and want a level of co-ordination of care, support in the short-term in terms of immediate needs, either health or social and support in the longer-term in terms of a level of reassurance and framework for care. All also appeared to need an understanding of what services (statutory or voluntary) were available and how the services worked eg the role and remit of each professional individually and as a team - thus acting together and not simply acting. This, in turn, for example, might create a level of understanding that the GP may be able to consider 'wellbeing' as well as health. The question that may need to be answered is not, 'What is the matter with you' or, 'What matters to you?' but, instead, 'What help do you need today?' which may become more pertinent as patients move through different stages of care.

APPENDIX 1

DISCUSSION GUIDE - PHASE 2
TOWER HAMLETS CO-ORDINATED CARE NIS- EVALUATION

Introduction

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.

Please note that the guide below will be adapted to each individual. For example, there were patients who remembered the Consent Form but had no idea about the Care Plan and so on. References will also be made throughout the interviews to previous discussions.

Introduction to Discussions

As you may remember, the Tower Hamlets CCG has commissioned an independent evaluation of the Co-ordinated Care NIS. In the first Phase, discussions were held with GPs, practice staff and Community Health Teams, but the evaluation remained patient focused. The purpose of this second phase is to track your patient experience as well as to talk more in-depth about some of the issues that the evaluation uncovered in the first Phase.

The CCG wants to make sure that the voice of patients is at the heart of what it does as a NHS organisation and wants services to be based on the needs of the local community and focus on the priorities of patients. They believe that patients have the right to be involved in the planning, review and decisions about the health and care services they use.

Getting involved in this evaluation will mean that the way these new services are provided to patients will be influenced and improved by your experiences, opinions and ideas and therefore you will be part of making sure these services are right for you and for other people like you who are also using them.

Again, all sessions and conversations will be fairly informal session 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.

Description/questions

1. Update

- Could you possibly detail what has happened to you over the past few months since I met you previously? ***(NB: Any particular appointments will be followed up here as well as, for example, an update on appointments they were expecting)***
- How has your health been more generally over the last few months?
  - What concerns have you had about your health recently?
    - Was there anything that prompted them? If so what?
    - Were they dealt with? How? By whom?

- Have you been to hospital during the last few months?
  - If so, why? What happened? ***Probe for details***
    - Did you notice any difference in your treatment? If so, what?
    - How did the discharge process work for you?

- Have there been any (other) health changes in your life?
  - If so what? ***Probe for details***

- And in other aspects of your life?
  - If so what? ***Probe for details***

2 Co-ordinated Care Programme - For those who were not aware previously

- Are you now aware of the Co-ordinated Care Programme?
  - If yes, how did you become aware?
    - How was it introduced to you? In what way?
    - Do you feel you received enough information?
      - If no, what sort of information would you have liked?
      - How would you have liked to receive it?

  - If no, are you able to recall if anybody has mentioned to you over the last few months that your care will be changing?
    - If so, how and in what way were you told it would change?
  - Can you remember if you ‘consented’ to this new Programme of care – it might have meant signing a Consent Form or being asked to ‘consent’ verbally?
    - What did you understand by ‘consenting’ to the programme?
    - Did you need more information?
    - Who would you have liked to give you this information?
    - How would you have liked this information? Eg on paper/verbally etc
    - Up to now, to what extent, if at all, has it changed the nature of your relationship with your GP? How? In what way?

- To what extent do you think you have been involved in the planning of your care?
  - What does ‘being involved’ in your care meant to you? Why?
  - Would you like to be more involved? If yes, how, in what way?
  - If no, why not?
  - What would make it hard for you to be involved?

  - And what would make it easy?

- And what has been your experience with your Care Plan?
  - Do you remember when your Care Plan was carried out?
  - How was your care plan developed?
  - Who by?
    - Does it matter who does it? Why? Why not?
  - To what extent were you involved with it? Did you want to be more involved? In what way? Why? Why not?
  - Do you know how you might use your Care Plan?
  - Or how it might be used by health or social care professionals?

- Are you aware of which professionals were involved in the development of your Care Plan?
  - If so, which?
  - Should they have been?
  - Who would you have liked involved? Why?

- Are you aware if you have a Care Co-Ordinator attached to your Plan?
  - If so, are you aware of what they do?
  - What might you like them to do? Why?
  - How would that help you?

- ***If relevant and if appropriate:*** *Can you recall whether a Mental Capacity Assessment has taken place recently?*
  - *If so, who carried out the assessment?*
  - *How did you feel about it?*
  - *What could have been made easier, if anything?*

- What did you understand about the changes in your care under this new programme?
  - What were you told would happen?

    When?

    Which aspects of your care?

    ***Probe fo**r*:
    - Well being
    - Discussions about their future

- What are your own expectations?
  - ***Probe for details***

- What would you like to happen?
  - Why?
  - In what way?
  - Which aspects of your care?

- Did you have any reservations?
  - If yes, what?
  - Why?
  - Have you discussed your reservations with anyone?
    - Who? What did they say?

        - If not, why not?

3. Experiences of the Co-ordinated Care Programme

- What have been your experiences of the Programme to-date?
    - ***Probe for details***
- In your view, have your relationships with health care professionals changed in any way? Have you noticed any changes since we last spoke?
    - If yes, with which professionals? How? In what way?
    - Has it been positive? If not, why not?
    - If relationships have not changed, were you expecting them to? Why?
- Do you feel in any way you are more involved with their care than previously?
    - In what way? How?
- To what extent do you think you your 'involvement' affected your care?
    - How? In what way?
- Do you wish to be more involved ***(refer back to earlier)***?
    - If yes, why?
    - If no, why not?
- Why do you think some people and patients are more involved than others in their care?
    - What makes 'involvement' happen in your view?
    - And why do you think some people or patients want greater involvement?
- To what extent do you think your carer should be involved in your care?
    - And in the actual planning of your care?
    - And informal/formal carers ***(depending on their own situation)***
    - Why? Why not?
    - In their view, what might be the difficulties?
    - And in their own experience?
- What do understand by the term, 'patient centred care'?
    - What might it mean to you?
    - What would you like it to mean?
- Have you seen any 'new' health or social care professionals over the last few months (e.g. occupational therapy/physio/community nurses/social workers etc)
    - If yes, was there anything different in your experience this time compared to experiences previously? If so, what?
    - Were you aware of who they were?
        - What they did?
        - Why they had come to see you?
        - Did it matter?
    - Were you given a 'new' assessment?
        - How did you feel about this?
        - Was it different from previous assessments? How? In what way?
- In your view, it is important that the same professionals come and see you?
    - If yes, why? In what way?
    - If not, why not?
    - To what extent does it matter whether they know about all your details and medical history?
- Do healthcare professionals come at the same time?
    - And social care professionals?

  - Is this a good idea for you?
  - If yes, why? What difference does it make?
  - If no, why not?
- Are you aware of the Community Health Team?
  - And what they do?
- Have you noticed anything else that is different about the way in which care is delivered to you now?
  - ***Probe for details - these may be prompted if they are not brought up spontaneously***
    - Eg, more contact with professionals
    - Spending more time with your GP
    - Better response from professionals
    - More likely to know who to contact if need be
    - Having more regular reviews
    - More involvement in decisions about their care
    - Changes in reviews for their prescriptions
    - Better information which is explained now
- How do you feel about that?
- Why and in what way does it seem different?
- And have you noticed any difference in 'what' they talk to you about?
  - Eg 'Well being'
    - Did they talk to you about this when discussing your Care Plan?
    - Do you think they should have done? Why? Why not?
    - Is it important? Why? Why not?
    - Is it the job of your GP? If not, whose job is it to talk about this? Why?
  - Social care
  - The future
    - Did they talk to you about this when discussing your Care Plan?
    - If yes, how did the GP approach it? How did it feel for you?
    - Do you think they should have done? Why? Why not?
    - How should it be approached?
    - Is it important? Why? Why not?
    - Is it the job of your GP? If not, whose job is it to talk about this? Why?
    - Should they also ask about Power of Attorney?
    - Should your family be involved? Why? Why not?
  - Issues within the care plan?
- Do you feel more able to discuss these things with your GP?
  - If yes, why?

4. Specific Issues

- Is there anything that is of particular concern to you at the moment?
  - If so what? ***(Probe for all areas of life)***
  - Have you discussed it with anyone?
    - What did they say?
    - How do you feel about it?
  - If not, why not?
- In your view, do you think different health professionals talk to each other about a person's care? (***refer to above)***
  - And different medical departments or hospitals?

- Do you think they share your notes?
    - Why? Why not?
    - Should they?
- And do you think health professionals are aware what their colleagues may have done?
- If you were not happy with a health professional who might you discuss it with?
    - Why?
- If you were concerned about a health issue, who would you wish to discuss it with?
    - GP/Community Nurse/Social worker?
    - Why?
    - How would like to contact them to talk about it? Phone/face-to-face/GP surgery etc
    - Have you discussed issues with them in the past? What happened?
- And if you were concerned about a non-health issue such as housing, legal, cleaning etc?
    - Would it be the same person?
    - Why? Why not?
    - Who would you like to ask? Why?
    - And how would you like to contact them to talk about it? Phone/face-to-face/GP surgery etc
- Is it easy for you to talk about a non-health issue with a health professional?
    - If easy, why?
    - If not easy, why? In what way?
- To what extent is it difficult to talk to the same people about health and other issues?
    - Why?
    - What might make it easier? In what way?
- What qualities does a person need so that you feel able to talk to them about health issues?
    - Ability to listen
    - Non-judgemental
    - Helpful
    - Flexible about timings
    - Gender/age
    - Etc
- And other issues?
    - If it is different, why?
    - What makes it different? The subject? Or merely because it is unusual?
- And how do you prefer to talk to them?
    - By telephone
    - Face-to-face etc
- In their view, what are the main issues that make life better for people like themselves?
    - Getting out more
    - Seeing more people
    - Having someone to talk to when they want
    - Or merely choosing what they might like to do
- How do they think this could best be achieved?

  - By having more ‘help’ – what sort?
  - By having greater access to clubs/societies/befrienders?
  - By having a person they could talk about it with? If so, who would be the best person? Why?

5. Conclusions

- Overall, how do they feel about the care so far?
  - What other changes would you like to make?
- To what extent do you think that this (Co-ordinated Care NIS) type of care may further enable you to live the life you want?
  - If yes, in what way? How?
  - If no, (or partly), what else would you like to happen? ***Probe for details***
  - Do you think it is likely it will happen?
- For you, what is the best way to tell you about changes to your care?
  - By letter/email/telephone/person
  - Who would you like to tell you? Why?
  - And who else would you like told – eg family/friend etc
- And what is the best way to tell you about other services?
  - GP/health professional/social worker/family/friend
  - And who would be the most trustworthy? Why?
  - And who else would you like told – eg family/friend etc
  - By letter/email/telephone/person
- Would you like to make any recommendations to Tower Hamlets Clinical Commissioning Group/those that design the services at this moment?
  - What?
- And what advice would you like to give to those that are designing this programme of care?

THANK AND CLOSE