healthwatch
Tower Hamlets

Evaluation Report
Tower Hamlets Co-ordinated Care NIS
Phase I

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BACKGROUND

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. 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*'[1].

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.

However, given the main thrust of the Programme was primarily a cultural shift towards partnership patient centred working in a holistic way, it was decided that it would also be important to hold discussions with service providers so that there was a greater understanding of the complexities of implementing the programme into local social and health care provision.

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

OBJECTIVES

The purpose of the evaluation was thus to:

- Explore the views of patients and track their ‘journeys’ and experiences of the Co-ordinated Care NIS;
- Explore the views and perceptions of service providers of the new package;
- Make recommendations for improvements to the Programme.

METHODOLOGY

The evaluation was designed in two Phases and would take place over a period of six months. Phase I was carried out between April and June and included:

Stage 1 – Contextual review
Stage 2 – Interviews with providers and patients
Stage 3 – Analysis and interim presentation and report

It was initially suggested that Phase II would continue to track the patients who formed the sample in Stage 2 of Phase I to assess and evaluate their on-going experience of the Co-ordinated Care NIS. Although early discussions with THCCG suggested that this second Phase should consist of simply tracking experiences, following the Interim Presentation, it was felt that a more productive way forward would be to hold discussions with the same patients in order to:

- Track their experiences and ‘journeys’; and
- To concentrate discussions around a number of key themes emanating from Phase I.
- Fuller details of the suggested themes are listed in Section 3.
- This report details the findings of Phase I of the evaluation.

a) Stage 1:- Contextual Review

A brief literature review2 took place which provided an overview of the secondary literature available both nationally and locally. The purpose of the review was to place the evaluation in context and to ensure the evaluation team had a broad grasp of the relevant issues. This involved sourcing national data (for example the work of National Voices, the King’s Fund and the Nuffield Trust), regional data and information from WELC as well as local data including details of the rationale for the new packages of care.

During this Stage, the evaluation team also attended the locality Integrated Care Board monthly meeting.

b) Stage 2:- Interviews with Providers and Patients

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[2] It is important to note that this ‘review’ was not comprehensive and did not explore the on-going research presently taking place nationally and internationally

Following discussions with THCCG, it was considered that there would be a number of benefits for the evaluation to take place within one locality, covering two networks. Firstly, this would enable a level of thoroughness that would have been harder to achieve within the time and budget over the whole borough and, secondly, it would provide an opportunity to unpick and delve into the factors underpinning the development of the pilot and how they related to each other. The south west locality was chosen on the basis that it was the locality in which the Orion system was being piloted.

Providers - Sampling and Recruitment

A broad spectrum of providers was selected to take part in the evaluation to ensure that those actually delivering the Programme were involved as well as the management teams. The final sample[3] [4]included:

- Practices – Eight Practices in Network 3 and Network 4 involving:
  9 x GP – salaried
  13 x GP - partner
  2 x GP trainees
  2 x Registrar
  1 x Phlebotomist
  2 x Lead Nurse/Network Nurse
  6 x Practice Nurse
  3 x Assistant Practitioner/Nurse Practitioner
  2 x Health Care Assistants
  2 x Reception Manager/Administrator
  1 x Practice Manager

- Community Teams covering Network 3 and Network 4:
  Interim Community Services Manager
  Interim Team Manager for Longer Term Support
  1 x Locality Lead Manager
  1 x Lead Community Nurse/Lead District Nurse
  2 x Care Co-Ordinator/Lead Care Navigator
  4 x District Nurse/Community Nurse
  1 x Community Mental Health Nurse
  2 x Physiotherapists
  1 x OT
  1 x Community Geriatrician
  1 x Social Worker

- Network Teams:
  2 x Network Managers
  1 x Assistant Network Manager/Network Co-Ordinator
  3 x Administrators

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[3] It is important to note that due to the remit of the evaluation those working within the Single Point of Access/Out-Of-Hours team/s were not included

[4] Please note that the titles of respondents are self-reported and are those given during interviews

A letter (Appendix I), introducing the researcher and explaining the need and purpose of the evaluation, was sent to all potential provider participants. Following this, interviews were arranged.

Providers were interviewed in their place of work and in the following contexts:
8 x focus groups with GP practices
8 x focus groups with Community Health Teams
2 x focus groups with Network teams
1 x focus group with representatives from the social work team
1 x face-to-face interview with the Consultant Geriatrician
1 x face-to-face interview with the Interim Community Services Manager

Patients - Sampling and Recruitment

Patients were selected in two stages. In the first instance, the two Network Teams were asked to select patients who were registered as being part of the Care Co-ordinated NIS. It was requested that the sample should include:

- A range of co-morbidities
- A range of ethnicity/gender/age
- Patients across all practices within the two Networks
- Patients from both the 'mandatory' and 'discretionary' lists

Network 4 selected approximately 35 patients on the basis of their records ensuring the above criteria. A letter was sent to these patients (Appendix II) which provided an opportunity for potential participants to opt-out. Once those who had opted-out (six patients) had been removed from the list the contact details of the remaining patients were passed to the evaluation team.

Network 3 made a decision to invite patients to participate by telephone, gaining permission to pass over contact details to the evaluation team. Following this, the patients who were selected and who had agreed were sent the letter as above and subsequently their contact details were passed to the evaluation team.

Although this selection process provided the evaluation team with a broad range of patients fitting the desired criteria, it became clear that there was an inherent difficulty in selecting patients from the 'mandatory' list. If a patient, for example, had had at some point a heart attack, they would have been selected to be part of the Programme but would not necessarily have any recent or on-going contact with the health or social care services. This was an issue brought up by GP practices, as is detailed below but, by definition, it meant that it might be difficult to 'track' their journeys and experiences. In the second phase of recruitment, therefore, it was decided that GP practices and the Community Health Team would be asked to select patients in their care who had a Care Plan, who had 'consented' and who had regular health or social care interventions. On this basis a further ten patients were selected and interviewed.

In total, at this stage, 28 patients were interviewed as follows:

- Ethnicity[5]
    - 12 x white British
    - 11 x Bangladeshi
    - 2 x Afro-Caribbean
    - 1 x Philippine
    - 1 x Vietnamese
    - 1 x Irish

- Gender
    - 11 x female
    - 17 x male
- Age range between 55-92 years
- Patients from both ‘mandatory’ and ‘discretionary’ lists[6]
- Patients from each of the eight practices in the locality
- Housebound patients as well as non-housebound
- Medical Issues (both ‘mandatory’ and ‘discretionary’)
    - Palliative
    - Heart failure
    - Dementia
    - COPD
    - Stroke etc

Following the verbal presentation of the findings detailed in this report, a further seven patients were identified from lists given by service providers. It will be discussed with the THCCG whether these will be included in the Phase II sample, thus bringing the total sample in the evaluation to 35, as detailed in the original research brief. However, although the need for details of patient experiences and ‘journeys’ has been emphasised, it is also clear that in terms of themes emanating from this cohort of patients, ‘data saturation’ has been reached.

At the same time as this evaluation took place, there were two further projects running concurrently in Tower Hamlets. Whereas the first of these was a specific short-term project exploring the needs of the ‘housebound’, the second is on-going and is run by the Patient Experience Team, Barts Community Health Service. All patients taking part in this evaluation were asked whether they had been approached by either of these two projects and in all cases they had not.

Interviews

Interviews with providers took place in April and May 2014 and patients were interviewed face-to-face in their own homes between April and June. Carers were often present during the interviews with patients and in some cases the interview was held with the carer and not the patient on the basis that the patient was not able to hold a discussion due to their medical condition. The

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[5] 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

[6] 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

perspective of carers during the interviews was invaluable not simply in terms of clarifying issues but also in terms of understanding the carer 'experience' and 'journey'. The evaluation team, however, were aware that the role of the carer could often be ambiguous.

The majority of interviews were carried out by Kate Melvin and assisted by Mohima Begum. Four interviews were carried out by Agroni Research, a local research agency that specialises in working with BAME communities and who were able to offer a Sylheti speaking interviewer.

Qualitative data collection is flexible, open-ended and responsive to what respondents have to say. Thus, questions are not formulated in advance and coverage of a theme will often vary a great deal between people because of the differing perspectives and experiences they bring to bear. Nonetheless, it is usual to sketch out a rough ground plan to be covered.

Topic guides were thus developed in discussion with THCCG which provided a framework for each session and for subsequent analysis of the data. It should be noted that the guides were only a framework for discussion and interviews remained flexible allowing for full spontaneity and detailed exploration of the issues. Individual guides were developed for both service providers and patients as seen in Appendix III and IV.

During the interviews all participants were provided with a Participation Information Sheet and Consent Form. The Form for providers is shown in Appendix V and was adapted for patients.

As is the norm in social research, the general public are offered a financial token of thanks for their participation. Thus all patients were given £20 during this Phase of the evaluation with the promise of a further £20 in the second Phase. It is of note that a number of participants found it difficult to accept the incentive.

c) Stage 3:- Analysis and Interim Presentation

All interviews, bar one,[7] 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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[7] This particular respondent refused to be recorded on the basis that her 'friend' had been recorded and the recording had been aired on Bengali TV

Centre for Social Research's Framework of Analysis initially developed in the 1980s[8] [9]. 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 I took place in June 2014.

METHODOLOGICAL NOTES

The following should be noted and taken into account when reading this report.

- The majority of service providers were very willing to be interviewed and there was high attendance during the interviews[10]. Similarly, there appeared to be little difficulty in the recruitment of patients.
- Following an explanation at the start of each discussion of the process of the evaluation including the reason for choosing the south west locality, it was only a minority of providers who spontaneously raised concerns. This was either on the basis that 'all projects' were carried out in this one locality or, more significantly, it was felt it may lead to a certain amount of 'bias' given the connections between the THCCG and certain GPs in the locality. It was of note, therefore, that the views expressed in this evaluation were particularly wide-ranging and the evaluation team did not consider 'bias' in this context to have been an issue.
- As has been noted above, Phase I of this evaluation was carried out over a period of three months which had a number of implications.
- The eight GP practices, for example, participating in this evaluation were at different stages in the implementation of this new Programme. Thus, whereas, for example, some practices had been signing up patients to the Programme since the end of 2013, others had only recently begun the process at the time of the interviews and it was apparent that this may have played a part in their views and perceptions of the Programme.

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[8] 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
[9] This process has now been formalised within Nvivo.
[10] In social research, arranging interviews with GPs is considered to be notoriously difficult

- Hence, care has been taken in interpreting and analysing the views of different provider teams and/or surgeries across the locality since experiences of the Programme were not necessarily comparable.
- In detailing and exploring patients' stories, it is important to emphasise that many patients were confused about dates and times of events or simply were unable to remember. Hence, stories often appeared 'muddled'. All effort was made to clarify experiences not simply for a level of accuracy but, more importantly, so that the underlying themes and patterns could be extracted and explored.
- It appeared, for example, particularly difficult for patients to 'remember' the Care Plan and the 'Consent Form'. Although it was assumed, through their records held by the Network Teams, that every patient had been through this process, many reported that they had no knowledge of it during the interview. This may well have been because they were unable to remember or possibly that they may have 'consented' and their Care Plans written some time before being interviewed.
- Carers, often elderly and sometimes 'patients' themselves, were also not always able to provide clarity on whether a Care Plan had been drawn up or if they had 'consented' possibly because they may not have been told or they may not have been present at the GP appointment. A number of GPs, for instance, reported that they actually wrote (or completed the template) patients' Care Plans after the consultation with the patient. As will be detailed later in the report, it appeared that it may equally have depended on how and in what way the GP had approached the process of inviting patients to the Programme.
- Given that the majority of the patients had little or no recollection of the Co-ordinated Care Programme, interviews concentrated on their life in general, their experiences of service provision, their concerns, how and in what way their lives could be improved and so on.
- Thus, this report details the main themes that have emanated from these interviews but it will be noted that the findings from patients are less detailed than those of providers. Since the second Phase and resultant report will track the full experiences of patients over a period of time, it was felt that, at this stage, a summary of the patient findings would be appropriate. It was for this reason that there are also no quotations from patients in this report. The final report following the second Phase of the evaluation, will detail patients' experiences of their care and of the Co-ordinated Care NIS but in addition, will concentrate on the further exploration of these themes.
- On occasions during interviews, there was evidence of care that prompted concern and such cases will be listed in the final report following Phase II. In social research, further action may be taken once the research team has gained additional consent from the patient to break confidentiality. Alternatively the research team may give the patients or their carers details of where and how to complain.[11]

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[11] http://www.esrc.ac.uk/about-esrc/information/research-ethics.aspx
http://the-sra.org.uk/research-ethics/ethics-guidelines/

- In order to respect confidentiality, great care and effort has been made in this report to ensure that interviewees remain anonymous and quotations are annotated in line with this. In the annotations, therefore, distinctions have not been made, for example, between levels of staff or between specific professions within a team. Thus, quotations are annotated as ‘Network Teams’, ‘GP Practice’ or ‘Community Health Team’.
- It should be emphasised that the views and perceptions outlined in this study are purely those of the participants.
- Finally it is acknowledged with thanks that providers gave up considerable time to support this project.
- The author would also like to thank the patients who took part in this project. Many were seriously ill at the time of interview but were still willing to participate.

1. SUMMARY OF FINDINGS - PROVIDERS

1.1 Initial Perceptions

1.1.1 The majority of providers appeared to welcome the idea of discussing integrated care and the Co-ordinated Care NIS although there was a general consensus that it was too early to carry out an evaluation

1.1.2 Overwhelmingly across all discussions with providers ‘integrated care’ was perceived as being a good idea. Working together with community services benefited the patient, met a practice need and was perceived to be a marked improvement on its forerunner, the Virtual Ward. Care would generally be less fragmented particularly for those on the Co-ordinated Care NIS since patients would only be part of one package of care. Ultimately, many thought that it might also mean that the providers’ workload would become less, time in the long run would be saved and services would become more accessible for the patient. However it was emphasised that, although a good idea in principle, it was too early to assess whether these hopes were or would be realised.

1.2 The Context

1.2.1 Concerns, therefore, about either integrated care generally or the Co-ordinated Care NIS specifically concentrated not on whether it should be implemented but how and in what way.

1.2.2 Underpinning discussions were a number of themes that appeared to underlay and, at times, cloud perceptions and opinions about the Co-ordinated Care NIS. In the first place, although it was apparent that providers had a vision of ‘integrated care’, it was clear that it was not ‘shared vision’ either conceptually or practically. Interviewees at all levels and from all professions noted that ‘integrated care’ meant different things to different people in terms of what it was and how it should be implemented.

1.2.3 For some it was an unachievable dream but others were able to cite examples where it was beginning to work and how it had improved over time. There were services, such as mental health and social services, that were perceived to be more 'separate' but it was thought that there were organisational and governance protocols that hindered greater integration. A further obstacle was that a number of those working in the community considered that the present structure and form of 'integrated care' was still based on a medical model.

1.2.4 More critically, it was argued by many, that there were differing levels of commitment particularly within the GP community which others felt was compounded by a lack of understanding not simply of different professionals' roles but more specifically their roles with respect to the implementation of 'integrated care'.

1.2.5 This situation seemed, at times, to be exacerbated by the way in which practices were implementing the programme as well as by the practicalities and demands of their day-to-day work.

1.2.6 Secondly, there was overwhelming evidence of an underlying confusion between the Tower Hamlets 'Integrated Care Package' and the Co-ordinated Care NIS that permeated almost all discussions and at all professional levels. One surgery that was interviewed twice reported that even after a further meeting where this was discussed they remained confused. It was difficult, at times, to pinpoint precisely where the confusion lay but, in general, it appeared to be in understanding the distinctive features of each initiative and where they overlapped. Respondents drew attention to the confusing terminology – for example, the difference between 'integrated' and 'co-ordinated' or between a Crisis Plan and a Care Plan and so on.

1.2.7 Some argued that they felt that the THCCG were equally unsure but all agreed that it was essential for it to be clarified. The problem was not necessarily that the actual care for the patient would be any different but that it was important because of the protocols, pathways and the governance involved.

1.2.8 At an operational level, some members of the Community Health Team reported they simply had no idea why some patients were being referred to the Co-ordinated Care NIS or, for example, whether the Care Plan was an actual referral. Other members of the team were confused as to why they should, as GPs had instructed them, keep patients on their lists when they were not 'active'.

1.2.9 There was confusion among GPs as to who was or who was not a Care Co-Ordinator, Case Manager or a Care Navigator, whether the Community Health Team would include professionals such as social workers and, although part of a very small minority, there were some GPs who were simply not aware of the Programme at all.

1.2.10 Those that were aware, at the time of the interviews, of the new DES believed the confusion could only get worse. Clear communication was called for possibly in the form of a workshop with clear descriptions of the potential pathway/s.

1.2.11 A further significant dimension that appeared to feed into this scenario was an acknowledged lack of clarity as to the purpose of the NIS which in turn seemed to influence how providers, especially GPs, approached its implementation. At one end of the spectrum was a belief that the Co-ordinated Care NIS was merely the next evolutionary phase and a natural sequel to the Virtual Ward. In this way, it was argued that the Programme should be seen as a vehicle to progress the process of integration, to break down further ‘silo’ working or to enable the building of relationships across professional boundaries. Within this strand of thought was a voice that it was essential that, this time, the change was given time to settle.

1.2.12 At the other end of the spectrum was the argument that its real purpose and benefit would be in identifying patients that might have previously ‘slipped through the net’ as well as providing an opportunity to catch problems early. Linked to this was a further view that the main purpose of the NIS was as a point of reference and reflection giving GPs a chance to think about their patients with greater care and prompting them to ensure appropriate on-going treatment for their patients.

1.2.13 Some additionally considered that the NIS could be useful as a means of engendering a more pro-active mind-set among GPs particularly since the Care Plan theoretically prompted a different level of conversation that GPs would not otherwise have necessarily held with their patients. However, it was suggested that the Programme was likely to make the system as a whole more proactive rather than GPs themselves.

1.3 Issues in Implementation

Set-up

1.3.1 In terms of the set-up of the NIS, there was a consensus that it all happened in a rush with constant reiterations. Most common was a complaint that communication had been poor.

1.3.2 It was also evident, for example, that there was no uniform way in which it was being approached by surgeries. To some extent this might, in the initial stages, have been dependent on the fact that the two Networks were approaching it differently in terms of the ‘selection’ of patients but it was also clear that there was a wide variation among GPs themselves as to how they considered it should be tackled and implemented.

Specific Issues for Providers

1.3.3 Although providers were enamoured by the concept, there remained an element of scepticism about how the Co-ordinated Care NIS would work in practice. Unanimously, providers questioned the level of resources available in terms of finance, staffing and training. GPs emphasised their heavy workloads but the most common concern focused upon the staff shortages within Community Health Services. Many within these services predicted a greater workload within a rapidly changing service which was being constantly transformed without any apparent and concurrent organisational development. In turn, this situation affected the GPs and their workload as well as feeding into the difficulties of implementing Co-ordinated care.

1.3.4 It was only a minority who thought that professionals' workload would be effectively reduced in practice. The feeling of pressure and in some cases, resentment was also evident among some GPs alongside a belief that the Co-ordinated Care NIS remained an 'add-on' to their normal service.

The Patient Group

1.3.5 Spontaneously respondents agreed that the Co-ordinated Care NIS was capturing the appropriate cohort of patients in that it was designed to improve the care of those patients who may otherwise have been missed. Most GPs, however, argued that they were the patients they would be seeing anyway on a regular basis. There was also a concern expressed that the Programme by default selected those who may have had an episode in the past but now were not necessarily 'active' and thus questioned their inclusion.

Potential Impact

1.3.6 Though the Programme might in theory pick up patients and crises early, providing a faster service, they were also patients who might deteriorate fast and it simply was not possible to look into a 'crystal ball' and prevent, for example, hospital admission.

1.3.7 A minority argued that this was an opportunity to interact with patients differently and this had already been evidenced. In contrast, however, were the majority who considered that given they knew these patients well in any case, they would not be spending any longer with them than they would do as a matter of routine although they might reflect more closely on their care.

1.3.8 There was greater agreement in terms of an anticipation that patients would be seen and would be able to access services more quickly. However, a number of providers, particularly in the Community Health Team, felt that where this had happened, it was due to the integrated teams rather than the Co-ordinated Care Programme per se.

1.3.9 In reality, many thought it would be unlikely that there would be a great change in terms of patient experience. What change there might be, would also probably go unnoticed. Of note, was a group of GPs spread across all practices who argued that care would be no different for their patients since they already provided ‘holistic care’. As a result, there was a potential danger that the NIS had the potential of becoming another tick-box exercise.

1.4 Specific Features

The Multi-Disciplinary Team

1.4.1 The majority of providers believed that the appropriate professions were in the multi-disciplinary teams. It was argued, nonetheless, that the team could potentially be enlarged to include the London Ambulance Service, opticians, pharmacists, and so on. Including social workers and the consultant geriatrician was seen as a huge bonus although the former were perceived by a number to be an ‘add-on’ and some GPs appeared unaware of their existence in the team.

1.4.2 There was greater debate about Care Navigators with many not being sure whether or not they had been appointed, their correct title or the remit of their role. Nonetheless, the concept of a Care Navigator was widely applauded and some considered that to a large extent the new roles would be pivotal to the ‘effectiveness’ of the Programme.

1.4.3 Most considered it too soon to assess the effectiveness of the Multi-Disciplinary Team meetings. Whether surgeries held regular Multi-Disciplinary Team meetings was not only variable but attendance was often considered to be poor. Where they had been implemented, there appeared to be a difficulty, in some cases, in terms of how they were conducted. There was often not enough time to discuss all the patients and, as a result, they ran the risk of becoming a ‘tick-box’ activity.

1.4.4 Secondly, there were a number of examples of how Community Health Team members had felt unwanted or superfluous at the meetings, again emphasising the lack of integrated working and difficulties within their relationships with practice staff. On the other hand, it was noted that it was both useful and helpful to be able to put names to those faces within different professional groups.

1.4.5 The Community Health Team also noted that as a team they held their own meetings every day to discuss their referrals, ‘prioritise’ their work load and ‘screen’ patients.

The Care Plan

1.4.6 The Care Plan was discussed at some length in almost all interviews with providers. Few denied that it was potentially a useful document but criticism abounded in terms of its concept, purpose and form.

1.4.7 Though the benefits of having an overarching Care Plan were acknowledged, it was firstly objected to on the basis of terminology and whether it was a ‘plan’, a ‘referral’ or an ‘assessment’ since there were implications for each.

1.4.8 Secondly, if it were designed for an integrated care approach, then all professionals should be involved in its compilation and it should not be the responsibility of one professional group. As it was, professionals, particularly in the community setting, argued they might use it for generic background information but would continue to do their own specialist care plan for patients as well as individual professional assessments. This would both run the risk of duplication of information and the need for patients to repeat their stories.

1.4.9 The most common concern was that it should be a live document and as such it constantly needed to be up-dated. The fear was, as expressed by some, it would sit on a patient's notes and would soon become 'buried' by other information or that it would simply not be read by other professionals. Either way, it would mean that patients would again have to answer more questions.

1.4.10 Given the length of the form, again raising concerns, GPs were completing them in different ways including when the patient was not present. Most GPs, too, felt that it was possible simply to leave questions blank if they did not seem appropriate, particularly taking into account that they knew many of the patients well.

1.4.11 Indeed, the Plan was thought to run the risk of becoming another 'tick box' exercise if questions were pursued remorselessly. While acknowledging, for example, the usefulness of the questions about end of life care, there was also thought to be a time and place to ask them. Asking at the 'wrong time' might simply mean ticking the box.

1.4.12 Similarly the questions that centred upon 'wellbeing' were also not always asked and often for the same reasons. Whereas some GPs felt that 'wellbeing' was generally discussed in the natural flow of conversations with their patients, other providers felt that it was hard to define and wrong to push such questions purely for the sake of this document.

1.4.13 There was additionally a criticism that the questions were based very much on a medical and not a social model of care.

1.4.14 Finally, a question was raised as to whether the Care Plan was needed at all particularly if there were regular multi-disciplinary meetings held and if the Orion system was working effectively.

Consent

1.4.15 The issue of the 'consent' arose spontaneously in many discussions. It was firstly acknowledged that it was a prerequisite for inclusion into the Programme and necessary both for a patient's care and to share information across professional boundaries. However, again there was variation in how it was being asked since it was sometimes verbal and sometimes written.

1.4.16 Most respondents reported that patients were surprised at being asked since it was assumed that documentation would be or should be shared anyway and thus it was a question that could seem out of place within a consultation. Although there were few reported ‘refusals’, many drew attention to the fact that patients often confused it with the recent media attention on patient records more generally.

1.4.17 Opinion though was divided. Whereas some argued that it focused the mind and it was good to have it crystallised and not implied, others, from all professional groups, expressed an uneasiness arguing that there was a lack of clarity about how the information would be used and by whom. It also felt by these providers that some patients would probably sign anything if asked to and were often not aware of what they were signing. Potentially, it was suggested that it could undermine the trust that had built up between GPs and patients. At times, too, the unease appeared to be compounded by the fact that they were, as GPs, being incentivised.

Single Point of Access

1.4.18 The majority of providers felt that the Single Point of Access was working well and effectively. A minority, however, reported that the service did not seem to operate outside ‘working hours’ and there was a concern aired by members of the Community Health Team that, in their view, those working within the Single Point of Access did not always seem to be clear exactly what to refer and when. There was also a debate across discussions as to who was able to telephone the service, whether it was patients as well as providers.

Orion

1.4.19 At the time of the interviews, there was some confusion as to whether the Orion system was up and running. A number of providers said they were able to see some notes but not all. There were also queries as to the extent of the notes that would be available across levels of provision and across organisations. Many held a level of scepticism as to whether the new system would meet all expectations and a level of surprise, on the part of a number, that the Programme was implemented before it had been completely installed.

1.4.20 Nonetheless, the majority considered it would be a huge bonus if it worked and that it could potentially act as a mechanism through which the Co-ordinated Care Package could be ultimately judged.

Mental Capacity Assessment

1.4.21 This issue did not raise any particular issues or concerns within practices. The new training available was generally welcomed and it was acknowledged that practice in this area needed to be tightened. It was unclear to most at the time of the interviews as to whether new procedures would involve more time and/or work.

1.5 Evaluation

1.5.1 Questions were also raised during interviews about how the Co-ordinated Care NIS was going to be evaluated and whether there were outcome measurements. While some argued that it would be difficult to have measurable outcomes given there were so many variables with different patients, others feared that hospital admissions were to be the likely mechanism. It was pointed out that, for this group of patients, hospital admissions could not and should not be the only indicator. Alternatively, the key indicator should be 'better health' more generally as seen from the perspective of patients. There was, finally, a minority, who believed there should be measurements in place already.

2. SUMMARY OF FINDINGS - PATIENTS

2.1 General Themes

2.1.1 Many of the patients interviewed were elderly and frail with multiple morbidities and clearly found it hard to recollect accurately what had happened when and where. However, the vast majority welcomed the chance to detail their experiences.

2.1.2 Undoubtedly many patients were also confused about which professionals they saw when and why but it appeared that more significant was a sense that they felt they had lost 'control' of their 'information' and the history of their own medical problems.

2.1.3 Interestingly, just as services were perceived to operate in 'silos', the majority of patients appeared to think in 'silos' and even though they would have liked different professionals to communicate about them, it was not thought either likely or possible. Similarly, although patients felt 'listened to', it appeared that this was on specific issues within specific services and did not appear to detract from an overall sense of a loss of 'control'.

2.1.4 Although a number of patients described situations that would seem to an outsider to be untenable and unacceptable, there were few complaints and instead was a general acceptance of the seeming inequities of care.

2.1.5 Further it appeared from the evidence that the issue was not necessarily a question of whether patients felt the service had failed them or not. Rather, it seemed there was a need to improve communication to enable patients to understand what was happening to them and what had happened in the past at the same time as enabling patients to articulate their needs. Presently, help and support appeared to be and was perceived to be on a 'one size fits all' basis.

2.1.6 Their actual health appeared to be far less of a concern to the patients interviewed than the future, what would happen to them and how they would manage. In addition, their greatest concerns when asked were those concerning their day-to-day life such as transport, housing, aids in the house, cleaning etc. Above all, concerns about their 'informal' carers, such as partners particularly, were overriding.

2.1.7 The most commonly expressed demands were for a list of useful telephone numbers for different services but more importantly for someone to 'talk to' when patients felt the need. A number of those interviewed, presently relied on a trusted professional which might be the GP, a Community Nurse or a Social Worker.

2.2 Service Provision

2.2.1 Experiences of service provision varied enormously and were often influenced by those of a close relative.

2.2.2 Complaints tended to focus upon waiting times for appointments across service provision but also upon the unreliability of professionals who had not done what they said they were going to, causing not simply medical difficulties but, more significantly, difficulties to their lives and the lives of their families.

2.2.3 Hospital provision came under fire, particularly for the perceived lack of support following discharge but there was s greater concentration on Care Homes. They were perceived by those who had experienced them to be the 'beginning of the end' and there were a number of individual stories of particularly worrying care.

2.3 The Co-ordinated Care NIS

2.3.1 Similar to providers, the concept of Co-ordinated Care was welcomed but the experience to-date had not yet met up to expectations. Only a few recollected talking to their GP about it and a number were clearly confusing it with other care plans with which they may have been involved. Likewise, few recalled the Consent Form, sometimes confusing it with national Summary Care Records. Those that did recall it either reported that they had been sent it and it was 'somewhere' in the home or that they had only been asked verbally.

2.3.2 For the few that did remember, the process and being asked to be included in the Programme was met with a mixed reaction. On the one hand were those who reported that the session with the GP had been rushed and, on the other, were those who felt slightly taken back by some of the questions. However, one patient, for example, was able to bring up his feeling of depression for the first time.

2.3.3 Finally, it appeared evident that how the NIS was explained to them was pivotal in terms of whether they remembered it or not.

3. MAIN FINDINGS - PROVIDERS

3.0 The majority of providers appeared to welcome an opportunity to discuss the Co-ordinated Care package and to air their views. There was, nonetheless, a view that the evaluation was being carried out 'too early' particularly since it became clear that provider teams appeared to be at different stages in the implementation of the Programme. Discussions with providers thus focused upon general perceptions of the Programme as well as upon both the facilitators and barriers encountered in its implementation.

3.1 Initial Perceptions

3.1.1 Perceptions about the actual concept of integrated care and the Co-ordinated NIS specifically were on the whole hugely positive. Across the board and in all discussions with providers there was evidence of undeniable enthusiasm.

'I think it is a very good thing for the patient and also a very good thing for the GPs as well - it is more involvement from all services together under one roof - you have got dieticians, speech therapists and so on - you used to be more disintegrated'
(GP Practice)

'I think it is a great idea, makes perfect sense, if we can get it to work. I think this is exactly what we should be doing and I think it is sustainable…I mean if we had come up with a sort of pie in the sky, how would we best like to be looking after our complex patients, this would be it - this is really a great idea'
(GP Practice)

3.1.2 For those who saw it as the next step in the evolutionary process of provision of care in the community, it was a marked improvement on the previous attempt.

'For complex patients, I think this is what we should be doing - I think it has got various teething problems but I think this is a billion times better than the Virtual Ward which I thought was total nonsense'
(GP Practice)

3.1.3 A number of GPs argued that working alongside community services could only be beneficial to the patient as well as meeting a practice need.

'The Co-ordinated Care has been used as a platform to improve the resources for the community and the hope is it will optimise the resources. I imagine that the overall care may be more efficient and maybe more preventative and therefore there will be fewer problems and maybe they will be able to cope therefore with the numbers'
(GP Practice)

'These developments meet very much a practice identified need of patients with multiple conditions trying to make their journey a bit easier and by teaming up with the community health teams it may be

> *more feasible to do everything in one go, complementing the practice development need really'*
> *(GP Practice)*

3.1.4 Certainly, it was argued by some GPs that the care would by definition be less fragmented and this would especially be the case on this specific Programme since those patients who were included would no longer be part of a whole gamut of different NIS'.

> *'I thought it was a good idea actually as this fragmentation of everything into NIS' does mean that you sometimes concentrate on the detail rather than on the whole….in principle I think it will help us to concentrate on the patients who need to be seen and understand and make sure at all times we are up to speed with what is happening to them'*
> *(GP Practice)*
>
> *'So previously they would have been under all these different NIS', now they are under just this, the overarching one which will be good for the patient and good for the clinicians and they don't need to come back all the time for everything now'*
> *(GP Practice)*

3.1.5 Care would also, it was argued, be less fragmented because the services were working together which again would benefit the patients.

> 'I have been wholly for this as the teams are meeting and talking to each other and everyone will know what is going on and the hospital too'
> (GP Practice)
>
> 'From my point of view it is everyone keeping an eye out on what might be needed…that is how it should be, that is the way care should be - we know that'
> (GP Practice)

3.1.6 Many of the above points were also echoed in discussions with the Community Health Team.

> *'I would hope that care is more joined so patients are not repeatedly being asked the same questions again and again and again and that when they ring up and talk to someone the left hand knows what the right hand is doing - and they can feel there is some co-ordination and I would hope too that they feel they are being listened to more about what is important for them rather than what is important for us'*
> *(Community Health Team)*
>
> 'Hopefully the social worker and the community nurses or therapists will all go out together so there is a Co-ordinated approach…and you are not on the telephone all the time trying to get information (and) the feedback is there when you get back to the office'
> (Community Health Team)

3.1.7 Additionally, in the long-run it was thought by many that theoretically it would potentially save time and work for clinicians and provide more accessible services for the patient.

> *'It saves people an awful lot of work if you can go armed with some information when you make contact with the patient - it will be a quicker assessment and you don't have to go searching to find out who else is involved…'*
> (Community Health Team)
>
> *'If it works and they are looked after properly, they will see the care they need and they can access it or it has been accessed and arranged or it can be organised sooner rather than later'*
> (GP Practice)

3.1.8 However, there was also a view echoed across providers that although a good idea in principle it was too early to talk about the overall benefits given that it was still in its infancy.

> *'It is a very good concept but early days…it is difficult to comment on something that hasn't actually happened. The nurses are here of course but that is because we have always worked with them…and palliative care, so it is the same faces we are working with, not new faces'*
> (GP Practice)
>
> *'I think, in principle, it is good as it all about co-ordinating the care but there is a lot of paperwork and there is a lot of work around and I don't think we have ironed out or really tested out how effective it is - we are not at that point yet since we have only got as far as consenting patients…it sounds good because it means we are reviewing the patients that are at high risk on a regular basis and doing it as a MDT but, in reality, how is that going to work and we have not gone far enough to see what the benefits are and what the outcomes are for patients'*
> (Community Health Team)

3.2 The Context

3.2.1 Given that conceptually, integrated care generally and the Co-ordinated Care NIS specifically were largely applauded in discussions, the issue was clearly not whether it should be implemented but how and in what way.

> *'My perception is that we work more closely together providing seamless care - in rhetoric that has always been said and I think in practice how it happens is the big challenge'*
> (Community Health Team)

3.2.2 However, underlying discussions about the implementation of the Programme, were a number of key themes that tended to underpin and, in some cases, cloud resultant perceptions of the Programme.

A Shared Vision

3.2.3 It was apparent from the interviews that although the majority of providers had a vision of ‘integrated’ care, it was not necessarily perceived as being shared together either conceptually or practically.

3.2.4 In the first place it was argued by some that the definition of ‘integrated’ care had changed over time.

> ‘It is not new and it has been around for ages and there are all these different levels of integration - so if you talk about integration about five years ago, the focus would have been with the local authority - then as time has moved on, it has changed and it is integration with primary care practices and our teams - at this moment in time it is about with all the services’
> (Community Health Team)

3.2.5 Whereas most agreed that in reality it meant something different to different people, some went further and simply thought it was unachievable.

3.2.6 However, at the same time it was believed that there were areas where health professionals were already working closely together:

> *‘In primary care, is there a joint vision? I don’t think you will ever get a single vision in anything in health but I definitely get the feeling that some practices have signed up to it more than others’*
> (Community Health Team)
>
> *‘It may mean something different to different people but, to be fair, some of the community staff, we work closely with them and they are inclined to the same sort of view and as far as the District Nurses go, they work with us well but the other health professionals, we don’t necessarily work that closely with them - I mean like the Physios or the OT’*
> (GP Practice)

And that this had definitely improved over time.

> *‘We can see a lot of difference - I personally have seen a lot of difference and a lot of positive changes to providing care in the community…I mean we all work for the patient so I personally feel that the vibes are very positive compared to where we were before’*
> (GP Practice)
>
> *‘To a certain extent we were doing all this already but I think it is identifying a larger group of patients where we would now probably start having to have those kinds of conversations with them so it is helpful in that way’*
> (GP Practice)
>
> *‘To be honest I have never had much interaction with the local authority and social services but from the community health services point of view, we have always had quite a close working relationship with them and over the years that has been reinforced and it is getting better….there are some services that historically haven’t been that good*

> *at integrating and getting involved but the community health service team I work with are good, very good'*
> (GP Practice)

3.2.7 Certainly, some believed that the experience of the Virtual Ward had enabled such developments since it was felt that there were more practice leads 'around the table' and greater involvement from the District Nursing Team.

3.2.8 Some services, though, such as mental health and social services were perceived to be more out on a limb than others:

> *'So we have never had very good co-ordination even in terms of safeguarding children ….and very little comes back to us except in fairly crisis situations so I think really it wouldn't be right to say we have got a shared vision - we imagine they have got a vision similar to ours but it is not a shared vision'*
> (GP Practice)
>
> *'We haven't built up the service with the mental health team nor with the local authority and there are still barriers there…we have a social worker in our locality which is great but some of the social workers you get from the longer term team, you ask them about certain issues you think they need to be supporting and they will say it is a health issue - surely we should be together, working together to try to meet the needs of the patients'*
> (Community Health Team)

3.2.9 One member of the broader Community Health Team drew attention to the fact that it was not so much that the 'footsoldiers' and those on the ground were not 'working together' but that difficulties arose both in terms of decision making and in terms of organisational procedures. For instance social workers aligned to Community Health Teams still had to work within the parameters of local authority governance and policy guidelines.

> *'People do work together but frequently, people find stumbling blocks when it comes back into the organisation. So I think we are increasingly getting to the shared vision - we are having teaching sessions for our senior nurses and therapists and part of that is talking about the shared vision, their understanding and the contextual vision of the organisation - the work has started'*
> (Community Health Team)
>
> *'There is a vision but whether that vision is understood by the staff, I am not convinced. Whether every bit of the organisation does its own bit because of its obligation or its governance or whatever does matter but increasingly I find that we are working more closely with other partners…'*
> (Community Health Team)

3.2.10 A further factor that was seen to work against greater integration of services across provider organisations was that the notion of integrated care remained a medical model.

> *'To make it work, in the model that is currently up and running, we would all have to working around the patient and I don't think we are at the moment….and we would have to working to the same model. The fact is it is GPs leading the practice meeting, identifying the patients and saying you, you and you need to be involved in this patient or it needs this. It is of course a medical model…..and the agenda, too, for the ICB meetings is medical'*
> (Community Health Team)

3.2.11 More relevantly perhaps and particularly within the broader Community Health Team, there was an element of dissatisfaction that not all providers seemed equally committed to the shared vision[12].

> 'Everybody is talking about something different and I don't think everybody understands what it is that we are supposed to be doing - everybody understands the concept of integrated care and if it is working properly, it should be absolutely brilliant because we work as an integrated team anyway - but it is becoming more and more complex and the way the information is fed down to you, it is either a passing comment like, Orion - oh, incidentally, Orion goes live on Monday - that was it!'
> (Community Health Team)
>
> 'I think the GP's world is about how soon can I hand this person over - I think that is national. Whether the GPs are committed to this new way of working, I am not convinced. In one locality we can't find a GP to chair the (MDT) meeting and it is telling isn't it that if the GPs are at the forefront of all of this both in terms of commissioning the services but also in making the integrated NIS work, then they should be sitting there leading it - I just haven't seen that high level of participation by GPs yet'
> (Community Health Team)
>
> 'I have to say most conversations I have with GPs they say, great you are involved and you can manage all this then! That's not helpful - it is literally a case of well you can manage it all…There is one GP I am thinking of whenever there is an issue with a patient that he can't deal with any more, he will send me an email and just expect me to come up with all the answers because that is what we do in the community and we solve the problems for them - certainly not all GPs but quite a few of them - I suppose it is not so much telling us what to do but more of an expectation that someone in the community will come up with something because we always do'
> (Community Health Team)

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[12] There were also examples given during interviews where the Community Health Teams had felt that at times they had been given inappropriate clinical responsibility by GP. For example, one community nurse was asked to catheterise a patient but felt it might have been a medical risk and, given the GP would not visit, the patient was admitted to hospital. Fuller details of such incidents reported can be provided on request.

3.2.12 Some GPs also commented that they believed that not all their colleagues were on board even in theory and this was essential if a shared vision was to be achieved.

'Ideally we would like it to be as integrated as possibly but I am not sure all my clinician colleagues would agree with that. Some of them think it is extra work that we are doing and is it going to lead to anything and is it going to improve patient care - but I think it is a good thing'
(GP Practice)

'I think it is has the potential to work but it also has the potential to fail if there isn't the effort made…there has to be ongoing effort from all the parties'
(GP Practice)

'So one person's involvement or lack of it can disturb all the other stakeholders and then it is not integrated any more is it?'
(GP Practice)

3.2.13 But the difficulties between different sections of the health sector were also observed by others:

'GPs have never been particularly good at referring into the community health services in some ways as there is I think a view that the community health service is not going to deliver so there is a barrier before we even start…and there is very much a them and us situation with primary and secondary care and working at it at the top level down will hopefully start to see some integration and a sense of shared working but it is going to take a long time'
(Network Team)

3.2.14 It was additionally considered by some that the situation was made worse by a lack of understanding of different professionals' roles and responsibilities.

'I think there are elements of knowing what each other does but I have heard different things like a GP complaining at the ICB meeting about what they considered to be a delay in getting a therapist involved but what they were actually asking for was a wheelchair assessment so they had referred to the Single Point of Access but if the GP had been more aware of what the Single Point of Access does, what is out of scope of the Community Health Team and so on'
(Community Health Team)
'I think there is on occasions a lack of full understanding of who does what within teams and where the boundaries lie'
(Community Health Team)

3.2.15 Further, whereas some argued that fortunately in each practice there was a lead who fully understood the concept and the Programme, others argued that this could actually work to its detriment, a view that was undoubtedly reflected within other provider groups.

> *'(GPs) tend to work in silos and if one GP says in a practice, I think it is a load of rubbish then others might follow suit so you tend to find that you have got some leaders who are really for it and a lot that will just follow because the key leader has said so but there is very little sharing unless they come to MDT meetings….sometimes I think none of the GPs actually want to get on board unless they know it will work and the plan is still being set in motion so it does seem as if we are trying to paddle uphill at the moment'*
> (Network Team)
>
> *'The thing is everybody wants to be captain of their own boat and when it comes to working as a team, the GPs, the social services, the district nurses, the specialist therapies, they are all used to driving their own car'*
> (GP Practice)

3.2.16 It was evident from the interviews that this was not the experience of all providers and, for example, some members of the Community Health Teams spoke very highly of certain GPs and their commitment. But it was equally clear that the practicalities of their day-to-day work could also work against the implementation of any shared vision.

> *'You can't answer for everyone else, that is the problem - of course patient centred care should be at the centre of everyone's agenda but everyone has got their own agendas, their own timescales, their own workload to manage'*
> (GP Practice)
>
> *'Theoretically everything is possible but in practical life, there are lots of variables and one person's involvement can disturb all the other stakeholders if he or she is not communicating properly or not sharing'*
> (Network Team)

Confusion

3.2.17 Across all discussions and certainly across all professions there was a concern that there was confusion between the 'integrated care' package and the Co-ordinated Care Programme. In some interviews, this dominated the discussion and clouded almost all issues raised. In the first place, it was thought by some that the terminology was interchangeable thus rendering the two packages at times indistinguishable in name but not in form or structure.

3.2.18 Even taking into consideration the time span of this evaluation, the confusion was still apparent. One GP practice, for example, had helpfully given up their time on two occasions to take part in this evaluation. In-between the two meetings, it was reported that a 'PLT' meeting had taken place to discuss the Co-ordinated Care NIS. However, the GPs in this practice who had attended did not seem to be any clearer:

> *'We had a meeting last Tuesday about the Co-ordinated Care and integrated care but everybody is confused still - and there was widespread confusion even among the consultants'*

(GP Practice)

3.2.19 But it was clear that this practice was by no means alone:

'It has been explained many times – I think I understand it at the time, then it is simply a blur. It seems there is an overlap and the services almost seem to be the same'
(GP Practice)

'I think it is a great idea, makes perfect sense, if we can get it to work - it is extremely complicated and confusing and complex and I think we are really struggling to get our heads around it - there's two things, integrated care and there is the Co-ordinated Care NIS and I think are all a little bit like - ah, ah, - not entirely sure who is in this one and who is in that one - I don't know why it is so difficult to get our heads around it but it is and that has been the case since the inception, everybody is struggling with that'
(GP Practice)

'Generally it is mayhem, there are two terms bounced around in frequent meetings that nobody seems to clarify what they mean – everybody seems to have their own understanding of it and it makes it very difficult for us…but it does not alter the standard of care we are providing'
(Community Health Team)

3.2.20 One GP practice believed that it appeared the THCCG were not necessarily any clearer themselves

'Obviously, it sounds like they are making it up as they go along…., I think the Co-ordinated Care started on a separate footing, separate from integrated care or the idea about integrated care and they have suddenly realised there is too much cross-over and people are getting their wires crossed'
(GP Practice)

3.2.21 Whereas some argued it was the 'overlap' of patients or the numbers that had to be consented that had been the cause of the lack of understanding, others believed it was the actual wording and the difference was simply a matter of paperwork. As one GP commented, they 'sort of melded together' and in terms of making decisions and treatment it would make no difference.

3.2.22 At another level, however, it was considered essential that the confusion subsided not least because of the administration, governance and the protocols involved both within and across organisations but also because of the patient pathway.

'I have to admit that I keep muddling myself up and have to keep checking before I see patients to make sure I am doing the right Care Plan and one patient, they were on the integrated care pathway, but I went and did the Co-ordinated Care pathway – the structure is different, the information is slightly different but I suppose they could have been on both'

(GP Practice)

'There is a bit of confusion as we don't know which patients are in which plan and which programme and we haven't had any explicit explanation about how to go ahead with all of these plans'
(GP Practice)

3.2.23 In other teams, the situation seemed the same. One member of the wider Community Health Team, for example, argued that given the overlap and confusion, it was unlikely that the two packages would be separated when patients were admitted to Barts Health. From the hospital's perspective it would not matter which package they were on since the primary aim was for the patient to return home and to prevent readmission.

3.2.24 Nurses and therapists in the Community Health Team also believed that although patients would not necessarily be treated any differently, they needed to know the correct pathway and the reason why the patients were being referred.

'Most of (the nurses) need to understand how it is going to fit in with what they are doing at the moment. They understand integrated care but they still do not get the clear definition of what integrated care means sitting with the GP. There is going to be an increase in case work and they need to understand why this is happening…I mean I don't know….I don't fully understand it myself…and so often I just switch off'
(Community Health Team)

3.2.25 For the Community Health Team, it seemed it was not simply a question of not understanding the difference between the two packages of care but also their respective roles and responsibilities with regard to each package of care. A number of community nurses reported that they were receiving lists of patients either direct from practices or via the Single Point of Access but they were unsure what they were supposed to do with them and whether the patients on the list were actual referrals or not. Those from the local authority also raised concerns about lists of people they had been sent but little indication of which group they were in.

'(XX Practice) seem to have a better understanding but for us certainly at (XX Practice)it is like getting blood out of a stone to get the GPs to do their part, the consent part, we are getting lists coming through constantly and I don't know what to do with them'
(Community Health Team)

'Maybe we are just not understanding it or it hasn't been explained to us in the right way….and this is where we are confused because we go to the meetings and we keep getting lists of numbers and for us to phone patients'
(Community Health Team)

3.2.26 Others drew attention to the fact they were being asked to gain 'consent' from patients or to compile the Care Plan and were not sure whether this was their role or not.

> *'We are asked to go and see patients to get consent. Some GPs are asking us to do the Care Plans or give them the Care Plans that we have already got in place. They have asked us to see any copies of the Care Plans - we haven't done that and I said I wasn't doing it - it is a long drawn out process for them and they are not used to working so hard so they want us to do it'*
> (Community Health Team)
>
> *'We have what is called an integrated care pathway which means some of those patients we do need to see but what they are trying to do is put all of them on there and we will have this massive SOS list basically. Basically, this is where we haven't fathomed it out - it is what we do with all of those patients that aren't active and who don't need us, where do they sit, what do we do with them?'*
> (Community Health Team)

3.2.27 Some members of the team reported that they had been asked, for example, to keep such patients on the list who were not considered 'active' just in case they became 'active' and they could then be seen by the Community Health Team quickly. The confusion remained, however, as to whether they could be taken off their list.

3.2.28 It was of note that this confusion also seemed to feed into the difficulties of working together with a shared purpose and seemed to compound the sometimes negative relationship between the two groups of professionals thus appearing to influence perceptions about the Programme itself.

> *'To a certain degree we feel the Co-ordinated Care NIS is theirs - it is their responsibility, they are being paid to deliver on it. It is to their benefit and it also means they get a response from another team - the patient is seen quickly without too much effort on their part'*
> (Community Health Team)

3.2.29 Confusion was additionally evident with regard to specific areas within the Co-ordinated Care Programme. The following extract is taken from a discussion with GPs in one practice but such conversations were not unique:

> *'The Case Manager relies a lot on the Care Co-Ordinator which is the GP for decisions…'*
>
> *'Sorry, but I thought the Case Managers were now Care Co-ordinators…'*
>
> *'No, we are the Care Co-ordinators, you are the Care Co-Ordinator for a group of patients …'*
>
> *'But (XXX) is a Case Manager, the social worker but why isn't she the Care Co-Ordinator then?'*

Another surgery thought that some practices had their own Care Navigators but was not clear why this might be the case when others did not.

3.2.30 As interesting was the case in a further practice where there was confusion about who was actually in the multi-disciplinary integrated care team and doubted that it would include a social worker. Other interviewees were unsure, for example, whether the patient could or did telephone the Single Point of Access directly or whether that was the role of the GP.

3.2.31 It was suggested across interviews that there was a need for clear communication to ensure that everyone was signed up to the same Programme and understood it equally. Clearly, at the time of the interviews, this was not the case and was underlined by the fact that in one GP Practice there were GPs who simply did not know about the NIS at all.

> *'We do need to get our communications right and there are still people who say they have never heard about any of this - they simply don't hear or read or perhaps follow what has been communicated'*
> (Community Health Team)

3.2.32 The situation was, it was thought by a number, going to be further compounded by the introduction of the new national DES. This was only spontaneously brought up in a few discussions and there were calls for clear distinctions to be made between the three packages. Apart from anything else it was thought that it would be impossible to see how the Programme was working while there remained such confusion.

3.2.33 Various solutions were put forward to rectify this overarching confusion. The most common suggestion from both the Community Health Teams and GPs was for a workshop. What was needed, it was thought, was an 'idiot's guide' to the process, how to do it from a practical point of view.

> *'Even if they give me like a dummy, dumb sheet or even pictorial - for half an hour, an hour, this is how it works…giving clear definitions and clear guidelines as to what is expected'*
> (Community Health Team)
>
> *'I think if they could use like a dummy patient and come to each surgery and use that system to demonstrate one step at a time and you physically seeing it, it would make it so much easier and then at least you know what you are doing - you have seen it before'*
> (GP Practice)

The Purpose

3.2.34 It was apparent that part of the confusion also appeared to emanate from a lack of understanding of the purpose of the Co-ordinated Care NIS. This, in turn, seemed to influence how providers approached the implementation of the Programme.

3.2.35 It was not that there was a debate running across interviews as to what the purpose might be but, instead, it was clear that respondents had, in the main, already made assumptions. At one end of the spectrum was a belief that the Programme was simply the next evolutionary step following on from the Virtual Ward.

> *'Before this came along, we had the community Virtual Ward….and that sort of died a death and then this came along as a replacement to it with additions'*
> *(Community Health Teams)*
>
> *'I think the Virtual Ward has been sort of part of the integrated care now….and there was Co-Ordinate My Care before that - it is really the new name for what we had before'*
> *(GP Practice)*

3.2.36 It was commented upon by some in this group that the Programme would further enable the integration of services through for example, the breaking down of 'silo' working, but this time they hoped the Programme would be given enough time to settle before it was changed again.

> *'We welcome this yet another attempt to integrate services which has been an aim for a long time - we went through the virtual wards and - it would be nice if it stays like that because they keep changing things that aim for the same outcome'*
> (GP Practice)
>
> *'What is different? I think they have just reinvented the wheel and they are just calling it a different name - it was care in the community in the past wasn't it?'*
> (GP Practice)

3.2.37 At the other end of the spectrum were those who highlighted that the key aim of the Programme was to 'pick up' those patients who otherwise might have been missed but who were 'at risk' as well as providing an opportunity to reflect upon the care that was being offered and what could be offered.

> *'It is not clear what they are trying to do with this - it was not set out at the beginning adequately what are you trying to achieve by doing this - what was the expectations out of it, what is the process and what are the aims and as far as I can see, from our point of view, it is about reviewing a patient's care, seeing what is involved and documenting it, having thought about it'*
> (GP Practice)
>
> *'I think what this was trying to do was to pick up those people that you can't assess in a normal tick boxey way and say this is a standard of good quality care for this person…so I suppose a reference point for the patient but also a point of reflection, an opportunity to discuss overall care but I am not sure it was necessarily set up with these aims - I am*

> *not sure I know what the main aims are and have no idea if we are meeting them'*
> (GP Practice)

3.2.38 The Programme would also thus provide a prompt for the on-going treatment of those with long term conditions.

> *'I think that is the main aim so making sure that patients are followed up and you increase dosage of medications and things like that which, if you don't, could precipitate an admission into hospital so I think to monitor patients' conditions to see if there is any early deterioration or warning signs'*
> (GP Practice)

3.2.39 But in addition to this was a suggestion, spontaneously put forward by a number, that this Programme would be a vehicle for engendering preventative care, further enabling GPs to shift their mind-set to thinking more pro-actively. It was thought that the Care Plan, for example, prompted different conversations that GPs would not otherwise have had:

> *'I think it is already shifted the thinking of GPs, I mean just doing the Care Plan with the family and doing it together…I suppose the meetings you have with all the people going through everything'*
> (GP Practice)

3.2.40 Some likened it to the Falls Service or specific diseases where the pathways prompted forward thinking but equally acknowledged that this was still relatively 'siloed' and it remained hard to bring all the tracks of care together.

3.2.41 Even though others were less sanguine, believing that if a GP does not want to be shift his mindset then this will not be the catalyst, there was still a suggestion that the care package might prompt them to think about the patient in a way that they might not have had time for previously.

> *'I think it is unlikely but it might have triggered a bit more pro-activity for some GPs who might think, I haven't got time to do this, I haven't got time to do that…it might make them think what else do I need to do for that patient and what I am not doing or what am I missing'*
> (GP Practice)

3.2.42 However there was also a view put forward that given the NIS was a package that was part of a wider move aimed at shifting the nature of care, it was more likely to make the system as a whole more proactive rather than the individuals within it.

3.3 Issues in Implementation

Set-Up

3.3.1 During the interviews there were a number of issues brought up that had arisen during the set-up of Programme that were seen to have influenced its later development.

3.3.2 In the first place, interviewees commented that it was set up not only in a rush but that the format and, for example, the outline of the Care Plan, had been repeatedly changed.

'I think the care package when it was launched has been very muddley and there have been lots of iterations and lots of queries regarding pay and there has been lots of, this is how we are going to do it, oh no, we are going to do it slightly differently, oh we are going to change it again'
(Network Team)

3.3.3 More common was a complaint that the communication had been poor in spite of the training that had been offered. A minority voiced criticisms of the training itself and felt it should be done in-house and within working hours. There were also those in GP practices who said that they had had no training at all.

'I mean the training I went to is like the people who did the training were not aware of what they were training us about – it was just a waste of time'
(GP Practice)

3.3.4 Importantly, it became clear that each surgery was and had been approaching it differently. In some, there was one clinical lead who was 'selecting' the patients (as noted in 3.2.15) but over a period of time other GPs would be carrying out this function as well. In one Network, on the other hand, the Network team were undertaking this function on behalf of their GPs. From the interviews and from the process of the selection of patients for the final sample, it was also noted that different practices were at different stages in the development of the Programme – a further factor which might well have influenced their perceptions of the Programme. At the time of the interviews, there were some, for instance, who had only completed Care Plans for a handful of patients.

Specific Issues for Providers

3.3.5 Although supportive in principle, an element of scepticism remained among all provider groups about how the Co-ordinated Care NIS would work in practice.

'I still don't know how it is going to work - if a Physio spots there is an ulcer on a leg, they should contact the district nurse or if the Physio finds out they have not had a 'flu jab at home, then they can arrange for that to happen – that is how it should be'
(GP Practice)

'There is a lot of positive thought by the CCG and GPs and it sounds like what we all want and what the patient needs – whether it will happen or not and whether it will work and whether the teams will

cope, only time will show…I mean if it works like we hope, then it is wonderful, if that is what they are endeavouring to do, then that is really wonderful'
(GP Practice)

3.3.6 A number of providers, cutting across organisational and professional boundaries, suggested that there were further factors working against the implementation of integrated care, that were related to primary care provision more generally. Across provider groups and in the majority of interviews was a call for adequate resourcing in terms of finance, staff and training. Again, respondents argued that although the intention was good, the means of implementing the programme had simply not been there.

'Give the resources, the right resources, give the GPs time to do their work without being bombarded - that is what we need, we need time and we need resources, we need staff and we need training'
(GP Practice)

'It is one of those projects with the best of meaning introduced without the support, back up and training of the staff. I can see the objectives and they are honourable and good but will it work? Doubtful as you need training, resources, money and time….'
(GP Practice)

3.3.7 Above all, respondents referred over and over to the staff shortages within the Community Health Team and the difficulty of recruitment. This was on top of staff at all levels leaving, staff on maternity leave and so on

'Certainly in our network there is a problem with District Nursing staff because they have got staff off on maternity leave, retirement and sick leave. We have got the geriatrician and, most of the other people are there. Nursing generally is an issue and the Community Health Service has got a real recruitment problem'
(Network Team)

3.3.8 Although this was a concern for GPs, it was a key focus in discussions with the Community Health Team at all levels. One of the resultant implications, it was succinctly noted by more than one respondent, of staff leaving, for example, was not simply the loss or the lack of organisational memory. As if not more significant was the increase in the workload and, particularly with extra responsibilities such as 'Rapid Response', the resultant pressure on staff.

'The thing is they are having to review patients as they are having to do the Care Plans for them and also part of the NIS says that they have to be reviewed every six months to one year and they (the GPs) are being paid for that and they have got additional work and that will have an knock on effect for us as they will say, this patient has come to light, perhaps it would be really good to have the Community Health Team involved who know about them - that is my feeling and that is what is going to happen, there is going to be an increasing work load…definitely'

(Community Health Team)

'The more you add, the more you tip people over the edge, it is about re-prioritising the work load and relook at what we stop doing and at what is important'
(Community Health Team)

3.3.9 But it equally had a ripple effect on patients.

'And discharges are poor, absolutely appalling in some cases with no referrals and then we get a call to say my husband or wife has been at home for a week and no one has seen them so we end up with it'
(Community Health Team)

3.3.10 Nonetheless, most felt this had to be seen within the context of the huge transformation that had taken place within Barts Health.

'I have been really quite overwhelmed by the amount of change that I see the staff in the Barts Trust being subjected to in the community over the last six months- there has been a huge amount of top down, this is going to be reorganised, people are going to have re-apply for their jobs, people are going to be down-graded, which I think is totally the wrong way to go about bringing change in such a massive organisation - I just think I don't know how you are ever going to get the commitment of staff and the understanding and the co-operation unless people are clear about why these things are happening'
(Community Health Team)

3.3.11 Other members of the Community Health Team additionally highlighted the 'de-skilling' of staff that had occurred following the demise of the community matrons

'Most of the nurses that we have now in the Community Health Teams don't have the level of skills that the nurses in the Virtual Ward had. What should have happened is more integration within the nursing teams because what happened was the best community nurses were picked to be community matrons and that was to the detriment of the community teams. They (the nurses) have got the skills but if we are looking at the level of preventing hospital admissions at the level they are talking of, they don't'
(Community Health Team)

3.3.12 Others bemoaned the lack of any apparent organisational development or staff structuring or re-structuring and asked for investment in a staff development programme within 'protected learning times'.

'They are talking about integration and how well we are all going to work together but if you haven't got the staff you can't deliver the service and that is one of the biggest risks….there wasn't any transparent organisational development support built into the transformation….I still think that hasn't been recognised'
(Community Health Team)

3.3.13 But the lack of staff was also thought to be an issue for other professionals as well:

'As I said, at the moment it is under control and it is manageable but when we do get the influx of more referrals we will need to be looking at staff resource issues. When we talk about the locality, we have eight GP surgeries and maybe a future plan might be two social workers so one social worker to cover four or three surgeries depending on how big the surgery is'
(Community Health Team)

'You could almost do for a small multi-disciplinary team around the patient at each GP practice because obviously how can the team manage and spread themselves across eight or nine practices with so few therapists and so few social workers'
(Community Health Team)

3.3.14 It was equally apparent that this was clearly linked to other concerns from GPs that the Community Health Team was, at times, hard to contact.

'Then once we get a number you try to call, the phone is not working you don't know who is where and if you really need to speak to someone, it is impossible…if you asked me now to phone the district nurse it would take a couple of hours'
(GP Practice)

3.3.15 For some GPs the issue was that, given the shortage of staff in the community, there did not seem to adequate support to provide the services that identifying additional patients on the Care Co-ordinated NIS demanded.

'We are trying to be proactive and pre-empt things and identify more suitable patients for the case load, but there needs to be that back up support and the moment we are struggling and a lot of it is falling back to the GP which I think Is not ideal as the whole point is, yes we are involved in the patient's care but it doesn't mean that everything has to be done by us because there are not enough support service in the community – it is an on-going thing and will get worse if we don't get District Nurses and allied health professionals involved in the community teams'
(GP Practice)

3.3.16 It was frequently pointed out during interviews, that the Care-ordinated NIS was yet another piece of work to add to GPs' ever increasingly responsibilities. Most GPs remarked upon the extra workload, including the paperwork it demanded and it was only a minority who still appeared to think that, in reality in the long run, it would be reduced through the co-ordination of care and the support of the multi-disciplinary team.

3.3.17 Some argued, too, they were doing it simply because they 'had to', balancing the fine dividing line between pressure and resentment.

‘You are trying to give better care for less money and as GPs we are going to end up doing a lot of work for not any good reward …’
(GP Practice)

‘It is something we have to do - on top of an already very stretched service - it is another add-on and the amount of work involved is huge…I certainly feel a bit resentful but I am not sure that is the right word but I certainly feel the pressure’
(GP Practice)

3.3.18 Many GPs argued that the type of care offered as part of the NIS should be part of their ‘normal service’ but there were only a few that thought that, in time, this would be the case.

‘I think GPs are seeing it as an add-on and it is an add-on writing out the Care Plan and it is an add-on getting them to sign the form because those are not what we normally would have done’
(GP Practice)

‘I think at the moment it is all still being seen as separate as it is still quite new but I think when we get more familiar with it and more sort of engrained in how to do things and what to do and when to do them, it will be become second nature’
(GP Practice)

3.3.19 One GP suggested that in order to prevent the Programme becoming and remaining a tick box exercise, it may be useful to have regular updates, in bullet point form, of how it was progressing so that its relevance was maintained.

The Patient Group

3.3.20 Whether or not the patients within Co-ordinated Care NIS were the ‘right’ category of patients was not an issue that had initially been addressed by the evaluation study team but it was one that arose spontaneously. Whatever the intended purpose of the NIS, as discussed above, the majority of respondents believed not only was it the right category of patients but it also enabled them as medical professionals to ‘pick up’ patients that otherwise might not have come to their attention.

‘It will help us to concentrate on the patients who need to be seen and make sure that at all times we are up to speed with what is happening to them and I think there are a lot of people living alone and are at risk of being neglected and the Co-ordinated Care could be very helpful picking up the most vulnerable’
(GP Practice)

‘It has helped me identify certain patients who may become at risk who I might not have thought about and I think I am more active that way - so I will get the Community Health Team to go in and assess conditions at home’
(GP Practice)

3.3.21 However, some GPs argued that it meant they were therefore seeing more patients:

> *'We are now seeing patients that really should be in intensive care almost but they are in primary care and part of it is respecting the patient's wish not to go into hospital and they can be very ill. We have heart patients that you have to check on a weekly basis for example and it is very demanding for primary care to provide this'*
> (GP Practice)

3.3.22 Others responded by believing that the chances were the majority of the patients on the Programme were ones they saw regularly anyway and, if not, it was a bonus to catch patients 'early' before a crisis. A further group, nonetheless, pointed out that they were not convinced that the 'right' patients were being selected particularly if they had not had an episode of illness for many years[13].

> *'Generally I think they are those with multiple morbidities or a high risk of admission but some on my list are mandatory but I am not doing anything with them because they are ok and I have questioned whether they actually do need to be on there. Sometimes I wish I had not put them on the list as I don't know what to do with them and they are not sure why they are being dragged into the surgery - I am not sure whether I can take them off the list'*
> (GP Practice)
>
> *'If a box pops up on my screen saying this person is in the Co-ordinated Care NIS and they need a Care Plan and they need to be consented I will do it but sometimes it pops up for patients and you just think I have no idea why this patient is in the NIS and it does not make any sense at all but I don't know how to remove them'*
> (GP Practice)

3.3.23 A further debate linked to this issue was aired by a number of GPs. They argued that, given the nature of many of this targeted group of patients, the process of the pathway and, in particular, the Care Plan, would make little difference to their relationship with them on the basis that essentially the patients were likely to do whatever the doctor told them.

> *'If we were to ask ten patients, I would probably say three or four definitely know what we are talking about but then some of them would be like, you do whatever you want Doctor because you do whatever you need to do, if it is going to help me with my care and if it is going to help the hospital, if I have to go to hospital then you do what you need to do'*
> (GP Practice)

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[13] This was certainly the case in terms of selection of the patients for interview in this evaluation. Please see Methodology Section

Potential Impact[14]

3.3.24 Certainly it was thought by a large number of GPs that under this Programme they would be more aware and knowledgeable about their patients, problems would be picked up sooner and it might lead to fewer hospital admissions.

> *'You will have an awareness of who is on this and you know they will be more at risk so it gives you that awareness. The problems will be picked up sooner, and the GPs will know more. Patients will probably notice that things are getting done and they work - the whole idea is that treatment is effective and that it works and it is not delayed'*
> (GP Practice)
>
> *'It will provide a focus - otherwise it is very easy to get lost as a clinician when you are trying to sort of do things for patients and I just think it is a slightly different way of looking at things and a slightly different way of organising the clinical information that you have got and we are seeing patients that we wouldn't necessarily see unless things had gone wrong or there had been a bit of a crisis'*
> (GP Practice)

3.3.25 But it still would not, as some pointed out, be possible to look into a 'crystal ball' particularly if they were frail since they would be likely to 'destabilise' at any time.

3.3.26 It was further argued by a minority that it provided a greater opportunity to interact with patients as well as with their relatives. It offered a chance to obtain that balance between what clinicians needed to do to reduce risk but at the same time understand more about patients' lives and what would make a difference to them. Spending a longer time with their patients might mean non-medical issues would be raised and a couple of GPs commented that already patients had noticed and appreciated the time that they had spent with them and had helped to resolve such issues. As a result, they thought care was beginning to become more patient-centred and far less doctor-centred.

3.3.27 But there was a stronger body of opinion that reported that they were not spending any longer with their patients since they knew the patients well and thus did not need to:

> *'These are patients we know incredibly well and are seeing all the time…certainly our heart failure and our palliative care patients we are looking after in a very Co-ordinated way and we would discuss them in a multi-disciplinary way anyway'*
> (GP Practice)

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[14] As noted earlier, respondents felt that it was too early to assess the impact upon patients of the Care Plan and it should be noted that the observations in this report were made by health professionals who were often at different stages in the implementation of the NIS.

> *'I don't think you spend that much time with patients…I know it says on there it should be half an hour, forty minutes but personally I would spend physically not any longer than I would have done for any other reason'*
> (GP Practice)

3.3.28 And some were simply not quite as positive about such extended encounters with patients as others might be:

> *'There are so many things that pop-up…I don't think the Co-ordinated Care is popping up but everything else is and it is only a matter of time before the CCG get their hands on it and we will get things jumping up all over the place'*
> (GP Practice)

3.3.29 Nevertheless, these GPs considered they would, though, spend more time reflecting on their patients' care as they would be going through the notes more closely.

> *'If you are a fairly good GP, you are seeing these people, and the whole point of a GP, is about you remember what you have done and continuity and bringing all those five minute, ten minute little chats all together and that is all going into this Care Plan so it is not the case that that then needs 45 minutes to go through, right you have got blood pressure, you have got diabetes, you have got some social care needs'*
> (GP Practice)

3.3.30 A second point raised in terms of the potential impact was there was an anticipation that patients would be seen more quickly and would be able to access service provision more easily. Referrals would be easier and most believed there would be less chance of service duplication.

> *'I think what they will hopefully notice is speed, they will notice things occurring much more rapidly - so if someone needs their kitchen sorted out, that will occur a lot quicker, the services will go in faster'*
> (GP Practice)
>
> *'They may get seen more quickly - if I go out to see somebody and I think they need a bit of therapy input or something, then I will have that conversation with somebody when I get back to the office - so, in theory if it is urgent, they could go out tomorrow morning instead of filling in a form, sending it off, waiting…we would look at it as a team and might even have joined up visits with the Physio'*
> (Community Health Team)

3.3.31 However, the Community Health Teams considered access to services had been made a good deal faster by the introduction of the integrated team rather than by the Co-ordinated Care NIS per se. And many GPs agreed.

> *'I might be, maybe we are patting ourselves on the back, but we have usually thought about quite a few of the issues - we already refer to the Physio if they need it, we have already thought of OT. What are*

> *Care Plans meant to be doing? There is simply not going to be a massive difference'*
> (GP Practice)

3.3.32 In reality, many believed little would change particularly in terms of patient experience. In the first place, at a general level it would either be difficult to pinpoint the change or it may go unnoticed.

> *'It is difficult to see really what kind of actual concrete difference the NIS makes - there is a quality aspect in terms of the recording of data and perhaps being a little prompter on moving things forward but for the actual patient experience, they are not going to see much difference…after all we are dealing with human beings, it is not a production line and there are so many variables'*
> (GP Practice)
>
> *'For some patients, it will be tokenistic…because they just want to come to the doctors, get their medicines, their bloods done or whatever it is and for us to sort them out and for them to go although I think for some patients it might be good'*
> (GP Practice)

3.3.33 Secondly, there was a large group of GPs across surgeries who did not believe that the care they provided would necessarily be any better or more Co-ordinated than before and, as such, the patients would again not notice any difference.

> *'If they didn't feel at the centre of good care, then this isn't going to make them feel like the centre of good care and if they are as cared for as they were before and now have felt a little bit extra, then they will like it but I don't know if it adds much other than, if you were to give them a copy of their B side of their prescriptions - thank you very much Doctor, I will stick it in my cupboard'*
> (GP Practice)

3.3.34 As a result, the danger was it would become or had the potential to become another 'tick box' exercise

> *'I don't feel that the care of the patient is that different really - we sit at a meeting here, we go through this tick box, have they been consented, do they have a Care Plan, tick, tick, tick, tick and then we say do they need any input from other teams and we say, yes, make a referral, the same as we would have done before'*
> (GP Practice)

3.3.35 It was also this group of GPs who argued that that it would make little difference because in effect they were doing it anyway, a point not lost on some:

> *'I don't know whether some GPs think we have all been doing this already so what is going to be different because we are truly holistic….and it is just trying to say to them, this is new, this is additional help and support for you to make life easier for you and most importantly for the patient…but it is trying to get this across'*

(Community Health Team)

3.4 Specific Features

The Multi-Disciplinary Team

3.4.1 **The Team:** Although some GPs reported that the integrated team was not fully operational, almost all welcomed the initiative and felt the introduction of a community geriatrician, community mental health nurse as well as of social workers were of huge and unquestionable benefit. However, in terms of the latter, for example, there were some GPs, as noted earlier, who, at the time of interview, had little knowledge of their existence or what benefit they might bring.

> *'I think it would be nice to know what can be offered by the community care team for the less medical problems'*
> (GP Practice)
>
> *'We have a heart failure service and a dementia clinic but if a patient comes now in this package and says I don't have anyone to care for me, we don't have anything to offer, we just take the information and then we just can't do anything about them any more than we were doing before'*
> (GP Practice)

3.4.2 It was additionally argued that for a full integrated service, teams such as the London Ambulance Service should be included but it was acknowledged that it might prove complex to marry networks and systems across providers. Other healthcare services mentioned were optometry or pharmacy as well as services provided by charitable organisations such as Age UK.

3.4.3 Nevertheless, it was also mooted by some interviewees that patients might find it hard to be confronted with more services surrounding them alongside the possibility of less contact with the GP.

3.4.4 There was some confusion, again already noted, as to whether Care Navigators were actually in place and whether the correct nomenclature was Care Navigator, Care Co-Ordinator or even Case Manager. However, that aside, what was seen as essential by the vast majority was a link-person who in essence would play the role of 'conductor'. In effect, they would form one of the essential pieces in the jigsaw.

> *'The thing is communication, making sure that there are people to talk to if there is a problem, so the patient knows who to ring to get help, so the Community Health Team knows who to ring to get help, so the GP knows….'*
> (Community Health Team)
>
> *'I have no idea if they are in post - I think there is one person in charge now and they are supposed to be looking at all this and being in overall charge like the conductor of an orchestra'*
> (GP Practice)

3.4.5 Finally, co-location of the multi-disciplinary team was also an issue raised during discussions with the Community Health Team and whether the proposed location of St Peter's was appropriate given its size.

> *'To be honest it is not really working for us - it is a good idea to have an integrated team, it is fantastic but the implementation has not really taken off in Tower Hamlets because there are lots of things that help integration which have not happened. Co-location is one. We should be but we are not, so we come together every morning and it so much easier if we were all in the same building - they are thinking about bringing everyone together at St Peter's but it is only a small office - whether they are going to execute that I doubt very much and it is not practical'*
> (Community Health Team)

3.4.6 **Multi-Disciplinary Team Meetings:** For most of the surgeries included in this evaluation, it was on the whole too early to make an assessment of how the actual MDT meetings were working and it was apparent that at the time of the interviews a number were still being established. Some GPs remained confused:

> *'I got confused because they said they were from the Co-ordinated Care team but they had the word Co-ordinated in their title which was very confusing for us because then they were the Co-ordinated, integrated care team or something they said....'*
> (GP Practice)

3.4.7 For those GPs who had not yet held a meeting with other professionals apart from those linked, for example, to diabetes or palliative care, it was thought that they would be a wholly beneficial idea. However, where they were functioning, it was considered that they were extremely variable both in terms of who attended and in terms of their outputs:

> *'I do try to go to the meetings and some of them are not productive and some are more productive than others - some of the surgeries are well organised and some clearly not...maybe the nurses don't turn up or someone else is missing or they haven't got the list to match up with the other list - so you are like guessing but I think it is much improved'*
> (Community Health Team)

3.4.8 That not all the team members were attending was partly explained for example, by the shortage of staff, particularly among the Allied Health Professionals, but it was seen to be particularly important if the Orion system was not functioning.

> *'We don't get the Physios and the OTs coming, only the palliative care nurses and the district nurses, I mean if the Orion system is on and up and running and then everyone can access and decide about patients'*
> (GP Practice)

3.4.9 Although it was suggested that not all the professionals needed to come to every meeting, it was considered it would be useful that people came on occasions, not least so that professionals could offer different perspectives and establish a professional rapport. This was something that was particularly emphasised by members of the wider Community Health Team since they could then put 'faces to names'

3.4.10 Others felt that though the meetings might be merely an update from those under the Virtual Ward, this did not necessarily detract from their usefulness. What was more important was how they were conducted.

3.4.11 It was firstly argued that there was not enough time to go through all the patients so it was necessary to target those at high risk, otherwise it became yet again like a tick box exercise

'There is not enough time to go through them all because if you just target the ones that you think are at risk and not every single patient, then, because there are 40 patients on the list, you can't go through every single one, so you just target the ones that are high risk'
(GP Practice)

'All our meetings so far, we are literally tick boxing, we have coded them and we have done the Care Plans - we might say we think they would benefit from some input from the District Nursing team and do a referral but we have not seen anything result from that in any different way'
(GP Practice)

3.4.12 Secondly, how they had been run to-date in some practices had met with a good deal of criticism from some members of the Community Health Team. A number felt that, though it was not the case in all GP surgeries, often it simply was not worth turning up.

'All we keep getting back from these meetings is lists of numbers and for us to phone patients or go to see patients to get consent…we should have an opportunity to sit and talk through the cases and say this is what is happening, do we need to be involved, are we involved enough, do we need to be pulling back, what the GPs views are but that doesn't happen… because our MDTs are an absolute waste of time and they just sit…we go with a list of our current case load and the GP will go right, we don't need to talk about that one, we don't need to talk about this one, we will talk about this, this and this and then they will throw in again that we need to get consent and then the consent question comes up again '
(Community Health Team)

'A patient I had been asked to see and she was definitely on the Co-ordinated Care NIS as she is 87 and got various health issues and when I went to the MDT and wanted to raise this issue about this patient - it was not a big issue but something I wanted to make them aware of, they all sat around and said, they don't know who she is and then they said, she is so and so's patient and that doctor isn't in today - thanks - so I went, well I can tick that box then! And that is how it is working in some of the GP practices'
(Community Health Team)

> *'It is just about these GP meetings that we have- it is like, the GPs here are very into it and pushing it and we always have our meetings in the lunch room and at lunchtime and the GPs, you try and sit and have a meeting, the GPs come in, they quickly talk, having their lunch, go out again. It is just not a good setting to try and sit and properly discuss patients and their care and their concerns'*
> (Community Health Team)

3.4.13 One member of the Community Health Team reported how they felt it was almost impossible for somebody who was non-clinical to get a 'word in edgeways'. Another described turning up to a meeting and there was hardly anybody there. It seemed as this again fed into any difficulties within their relationships and indeed exemplified the lack of 'working together'.

> *'We went to a meeting last week ….there was just us there at the end - we managed to grab one GP and he was like, I don't know…and we sort of hobbled together a meeting - it was just all a little bit on the hoof, you know. And there was one there when it was all closed… they had all disappeared on PLT training with nobody having the decency to alert us and we are the ones that travel there to the GPs. It does feel a little bit like we are monitored whether we turn up at the meetings and I really wanted to highlight that it does happen both ways'*
> (Community Health Team)

3.4.14 Moreover, the Community Health Team explained how they, as a team, held their own meetings every day to screen referrals and discuss patients. Such sessions had also been running before the introduction of the Co-ordinated Care NIS.

> *'Every morning, we come together to do the screening of every new patient that is coming in and that has made a big impact and we can discuss patients and any concerns and how we are going to deal with it and do we need any extra input and it has been a real bonus'*
> (Community Health Team)
>
> *'The workload has increased but I also find we are now screening together as a team and it has made a lot of difference to communication and discussing cases together as therapists, nurses, case management or whatever'*
> (Community Health Team)

The Care Plan

3.4.15 The Care Plan was discussed in great length in almost all interviews. To the extent of having a patient's information all in one place was seen as particularly useful but it was heavily criticised in almost all discussions both in terms of its concept, its purpose and its form.

3.4.16 **The Concept and Purpose:** Many providers reported that they had immediately seen the advantage of having a comprehensive Care Plan. It was seen as a valiant attempt to have all the information about a patient in one place, thus avoiding fragmentation of care. It was also seen by some as a means by which professionals would be reminded of their patients so that they could reflect upon a patient and act as a focus for present and future care. In addition, it might also clarify and track a person's health and social care journey.

> *'By and large I think it is useful - and it is not just for doctors but also for health professionals involved. A document that spells out a lot of these things…out of which each health professional might need to know about a chunk of it is useful…Having all of that chunk in one place would be useful for the understanding and co-ordinating the care and people with problems would know whom to go to'*
> (GP Practice)
>
> *'It helps you summarise the main problems and you can look back at the notes, serving as reminder to reflect on the patient…'*
> (GP Practice)

3.4.17 Nonetheless, criticisms came from all quarters and focussed upon a number of aspects. In the first place, it was criticised as to its purpose and whether it was an actual 'care plan' or an 'assessment' and this, as one respondent pointed out, was not simply a matter of semantics since it affected how it would be interpreted and used. It certainly appeared to link in with the confusion already noted on the part of some of the Community Health Team as to whether patient lists given to them by GPs were referrals or not.

> *'What is a care plan? It is a plan of care. And it can't be a historical document. It is live. But as well as a referral there is also something called assessment so if you do a comprehensive assessment of a patient, that is about assessing their needs, that is a different document to the care plan - a care plan is a delivery model of care, different to a referral and is different to an assessment- so is it care plan, is it a referral, is it an assessment?'*
> (Community Health Team)

3.4.18 It was further emphasised by providers across professional groups that in order for it to be a document truly appropriate for an integrated care approach, it should be written by the range of professionals. Such an approach might also avoid the problem of the duplication of information from a patient perspective.

> *'Everybody needs to be involved in writing it, it should be a working document with all contributing'*
> (GP Practice)
>
> *'We need to promote team working …people coming together when the Care Plan is being drafted or the author engaging people with writing it…if people don't feel they are contributing to it other than being given a Care Plan in which they have no say, then they will protect their own professional registration to ask the questions themselves'*
> (Community Health Team)

3.4.19 Other members of the Community Health Team also reported that they would continue to do their own specialist care plan for their patients as well as an overall assessment since, as professionals, it was their duty and there remained a difference between a 'care plan' and an 'assessment'.

‘If I am professionally governed as an individual with my registrations and regulatory body do I just follow your care plan or do I make myself accountable by assessing the patients myself and old habits die hard - we work on the basis of diagnosis, treatment and evaluation and there needs to be a huge amount of faith to say, you have done my care plan and I just deliver it especially if you are not in my profession’
(Community Health Team)

‘The care plan does not include a lot of the assessment information and it shouldn’t as the care plan is only current for that day it is written and an actual assessment is designed to find out what the patient’s needs and wishes are….we will continue to do our own care plans’
(Community Health Team)

3.4.20 As a result, the chances were it would not necessarily avoid duplication of information nor would it avoid patients being asked to repeat their stories. Further, even though it would be extremely useful to have background information on a patient, it would still be necessary to ask detailed questions to ensure the information was both accurate and current.

‘I think the more information the better…it does save people an awful lot of work if you go armed with some information and sometimes it is about clarifying what information that we have got on them already…it may be inaccurate and it might have changed…it is just from a professional point of view that you have to clarify it…you are just double checking…it is a quicker assessment’
(Community Health Team)

‘I must admit, the one that I read I did learn a lot from and it did give some background to the patient before we saw them but we would still do our usual assessments’
(Community Health Team)

3.4.21 Even more pressing on providers’ minds was the fact that the needs of patients change and it had to be an on-going document and not one that was static.

‘It is monstrously thick but a care plan evolves as a patient gets better or worse so you have to keep changing it every time there is a change in the patient’s condition, you have to edit it, probably send another one in - it should not be fixed and I think we should just make a referral so that they are on the pathway and then what happens should be a fluid process. It is just too proscribed’
(GP Practice)

‘Don’t forget needs change year on year - it has to be constantly updated…and if what we are recording is set in stone and we haven’t seen them for another year, things have changed and so this

> *information really is of no use and you will be back to asking, asking, asking'*
> (GP Practice)

3.4.22 As a group of GPs pointed out, since up-dating it would once more mean that patients were continually asked the same questions, instead it needed to be an 'on-going conversation' for every clinician. One GP suggested that it should be linked to Reed codes so that so that any inputting could be automatically inserted into the Care Plan.

> *'But it is no use unless we make the Care Plan the live working document and what I mean is that we have built in progress reports and the ability to review it periodically for some patients every two weeks and we have already got MDT meetings and we have already got practice meetings and we already have staff talking to each other. And it needs to be altered, and have systems and processes for updating care plans as well as making them live documents, all needs to be built into the project if it isn't already'*
> (Community Health Team)

3.4.23 The chances were, it was thought by most, that they probably would remain 'passive' documents. Whereas some questioned whether anybody had read them yet, others felt that they would soon be submerged under the notes that are continuously written on a patient's records. In any case, unless they were read, data would be duplicated.

> *'And if I am a locum, I am unlikely to look at it…and it might be that it is only some time later that a District Nurse will see it unless it is updated. Also over time, it is going to go down, down, down as we don't access notes from a few years back unless we are really looking into a patients' notes and in two years someone may not even be aware it has been done'*
> (GP Practice)
>
> *'That is only going to work if whoever is coming has access and reads what the previous person has put - if you don't you are going to duplicate the data…'*
> (GP Practice)
>
> *'We are doing these Care Plans to get better money, great, tick box, great for patients but are they being Co-ordinated well, are people looking at them when they need to, I am not sure, you send them into the ether as far as I am concerned. I have no idea what the Single Point of Access does with them - are they in a file? They probably just get shelved and nobody really looks at them'*
> (GP Practice)

3.4.24 Similarly, the Community Health Team also felt that it was unlikely that their colleagues would read or update Care Plans on a regular basis and they believed that to do so they would have to return to the GP for the original document.

> *'I doubt very much they (the nurses) are going to look through and go, I wonder where the Care Plan is, I mean to look through what was put on*

there three months ago…'cos even if we did change it, we would have to go to the GP to say we have changed it as they have the original on a template'
(Community Health Team)

3.4.25 A number of respondents from the Community Health Team additionally believed that it was unlikely, too, that hospital consultants would look at them particularly if the patient is in a crisis although they possibly might at the point of discharge.

3.4.26 Finally, respondents from all professions, though they saw the potential use of the Care Plan, questioned whether it would be necessary at all, particularly once Orion was fully up and running.

'Why would you need it if you have access to the notes? I mean it should not be so proscribed...I don't think it will make any difference. Does that sound bad?'
(GP Practice)

'It is not a bad thing, it is not going to have a negative impact on the care we provide but I don't think it is adding much which is why we don't really look at it…'
(Community Health Team)

3.4.27 **The Form:** The first spontaneous comments about the actual form across the board tended to concentrate on the length of the document. Although it was acknowledged that the current form (at the time of this evaluation) was shorter than previous editions, it was still too long. Some reported that it took at least an hour and that time in the surgery was always at premium with pressure to deal with medical problems in the first instance.

'I'll be honest, when I first did it, it was just the most soul destroying thing I have ever done clinically…it is just too long'
(GP Practice)

'It is too long and I think we spend more time doing forms rather than doing the patient contact…and all those questions - I just don't think patients get it. It is tedious and should be shortened and simplified'
(GP Practice)

'Time is of the essence and you need to deal with the medical issues. The care plan is quite complex and takes time particularly with the language issue'
(GP Practice)

3.4.28 A number of GPs considered that it was unrealistic to sit typing it up in front of the patient at the same time as having a conversation and dealing with their medical needs. This had meant that they tended to complete the forms late at night or, in the case of one GP, coming in on a day-off to type them up. Completing it out of surgery time meant that they would then only need to spend the usual time in surgery. Others explained that for them it was taking up two sessions of surgery time.

3.4.29 Although perceived at one level by many providers to be an ‘enabling’ document, a number feared that given its length it ran the danger of becoming the opposite and might reduce care to merely ticking boxes:

> *‘I think at its best it should be an enabling document but at its worst it could be just kind of a tick box exercise’*
> (GP Practice)
>
> *‘I mean you have to ask what are the patients going to get out of it? Are they going to refer to it, no, are they going to sit down with a family member and ask them to go through it with them, probably not, so it turns into a tick box exercise and that is my biggest concern’*
> (GP Practice)

3.4.30 This might also be the case if practices did not run a ‘named doctor’ system since it might merely be a ‘stranger’ asking the questions. But, ironically, one of the benefits was seen to be that if a GP were to see a patient that was not ‘theirs’, such a detailed document may prove to be very useful as background information.

3.4.31 However for most GPs the likelihood was that they would be writing Care Plans for patients, in the main, that they knew well and who were regular visitors to the surgery. Given this was the case and since they often held conversations on topics other than their health, many argued it rendered a number of the questions unnecessary.

3.4.32 Even for those patients who were not ‘regular visitors’, it was felt to be inappropriate because there did not appear to be any valid reason to be asking such detailed questions.

> *‘I think it depends on the patient…so I had an 80 year old booked, who still works and is very independent and so me talking about advanced directives and lasting power of attorney and thinking about where he would like his care and so on wasn’t really appropriate and freaked him out actually - it was just counter intuitive for that particular patient’*
> (GP Practice)

3.4.33 GPs across the board stated that they were simply leaving questions blank and many argued, too, that as there were not always clear cut answers, it made it hard to ask them.

> *‘The kind of question where there is no clear answer and sometimes you just find yourself spending half an hour and you still don’t get an answer from the patient because there is no clear answer’*
> (GP Practice)
>
> *‘I suppose you should identify if they are depressed, that is a difficult question and it may be best done by someone else as it may be more appropriate for the person who deals with the day to day care’*
> (GP Practice)

3.4.34 GPs particularly queried whether it was necessary to ask questions about ailments when they did not affect the patient. One detailed their experience of a patient with incontinence but who was not concerned about it nor did they consider it to be affecting their lives negatively. A further example was cited by another GP about whether they should report whether a patient could or could not wash themselves if it simply were not an issue for them.

3.4.35 However, of greater concern to health professionals were the questions on future care and dying. Most felt that they were certainly appropriate questions to ask but there was a time and place for them and during the completion of the Care Plan was not always the best time to think about it.

'It is just not always the right time - for some patients you think I should have that conversation but I think sometimes pushing that question for the purpose of the Care Plan is not necessarily the right thing to do because it may not be right at that point - we are not sure where they are going, what their prognosis is'
(GP Practice)

'Asking about death is a good thing but a difficult question to ask…and it depends when you ask it because if you are asking just for the Co-ordinated Care NIS, it becomes a tick box thing - there is a time and a place'
(Community Health Team)

3.4.36 On the other hand, it did make at least one GP rethink their approach, acknowledging the benefits it might have for their patients:

'I wasn't really talking about resuscitation or lasting power of attorney unless they were heading towards the palliative care pathway so having that discussion with patients early on might actually get them to think about things like that which I don't think they do until they are already very ill…I think it also empowers patients and gets them to think about these things and gives them more control about what is happening'
(GP Practice)

3.4.37 But there remained a minority who felt that the question should not be asked:

'We have got a Bengali population, English, Somalian, and I don't think palliative care sits well with all of them and asking them about place of death is quite difficult and very tricky…we might say we would discuss it again later but that later doesn't seem to happen very often and it is not normally needed and normally when there is quite a lot of family around, they are going to expect to die at home'
(GP Practice)

3.4.38 Equally a subject of debate were the questions about 'wellbeing'. It was only a minority of respondents who welcomed such questions partly on the basis of the nature of this particular cohort of patients:

'I think they should be included because it changes your focus for these patients as for them it is about managing rather than curing and fixing.

> *If we have got that Care Plan, even if it is not static as a person changes, it is useful'*
> (Community Health Team)

3.4.39 Most argued, in contrast, that it was again a very difficult question to answer. Firstly, it was hard to know what it actually meant and it was also likely to change on a daily basis

> *'What does it actually mean? I am dealing with patients for whom wellbeing will change on a daily basis…they have good days and bad days - they are patients with chronic conditions. Running down the street?! So for me it means I need to look at my patient and perhaps maximise whatever I can for them and their care'*
> (GP Practice)
>
> *'I mean it is difficult from both ends - how much do you ask…most are not well but what does that mean? I mean what is the understanding of the patient when you mean 'general wellbeing' – different people understand it differently'*
> (GP Practice)
>
> *'I think it is also why you are asking it. I mean it can have some value but could be based on unrealistic expectations but does that mean you don't ask it? It just depends on the patient, some will get upset'*
> (Community Health Team)

3.4.40 Respondents equally queried whether they were necessary questions to insert on the Care Plan since as a GP it was likely that you would know anyway.

> *'I think these are pointless questions because you can gauge how they are feeling because you know your patients - if the consultations are nuanced, you have got to see beyond what they are telling you, that is what we are taught - I mean if they have got a terminal illness, you are not going to assume they are feeling fantastic are you?'*
> (GP Practice)

3.4.41 However, there was a vociferous minority who pointed out that the Care Plan seems to have been based on very much a medical model of care, in spite of the questions on wellbeing, and one which might be used within an institutional environment such as a nursing home:

> *'It asks very, very superficial questions and it is a medical practitioner asking social questions for things we already have a care plan or support plan for…it looked to me like 20 years old and I was not sure who produced it….it really reminded me of institutional forms…designed to use in a nursing setting'*
> (Community Health Team)

3.4.42 Finally, it was debated whether or not GPs should give the completed Care Plans to the patient. Some were clearly doing so but other GPs felt that it would breach confidentiality.

Consent

3.4.43 The issue of ‘consent’ was discussed with some enthusiasm with respondents and raised a gamut of ethical issues. Most agreed, consent was an important issue to raise with patients but the question was how, why and in what way.

3.4.44 In the first place there was again variation of how it was been asked. Some patients were being sent the Consent Form, including those who were within the Network that was ‘selecting’ patients on behalf of GPs. Other GPs, for example, reported that they were only asking for verbal consent and not written.

3.4.45 Most interviewees reported that some of their patients were surprised at being asked since many felt it was assumed and it could seem out of place within a consultation.

> *‘I wasn’t too sure what purpose consent served to be honest - it is the sharing of data but since patients always assume that data is shared anyway it seems a bit pointless’*
> (GP Practice)
>
> *‘I suppose it is good to clarify it but you have to ask patients to give consent to something that they take for granted, it is not the most brilliant moment in the consultation’*
> (GP Practice)

3.4.46 It was also noted that it had coincided with a good deal of national press about the sharing of care records. However, very few health professionals reported that patients had refused and in the few cases that there were, it was mainly due to a concern about sharing data across organisations and with the local authority.

3.4.47 In most cases, GPs suggested that patients would probably sign most things if they were asked and believed that patients would not read it either. But this did concern some interviewees:

> *‘Patients trust the GP so most likely they will say yes to anything we are saying but is that really fair?’*
> (GP Practice)

3.4.48 More questioning was a further group of GPs scattered across practices who described a sense of unease about obtaining the consent. They firstly raised the question as to whether the consent and its implications were fully explained to patients particularly those with dementia or mental health issues.

> *‘We have to use our communication skills accordingly so people understand and it does feel that consent with some people, where there is poor understanding, that it is a bit of sham - they say yes without understanding and unless you got into it and it takes a long time and we don’t have that time’*
> (GP Practice)

'We are in an uncomfortable position with consent and people trust us and will agree to what we want them to do but we are not sure how the information is being handled although we say it is in their best interests'
(GP Practice)

3.4.49 Secondly, it was asked why consent was needed when the Network had access in any case and, further, it was felt that it was not fully informed consent because there was a lack of clarity as to the purpose and future use of the information.

'There is a wider thing, the Network has access anyway and the NHS spine mechanism assumes everybody has consented, it does not actually ask them, you have to physically opt-out….and it is not informed consent because I do not hold all the information about what it is going to be used for'
(GP Practice)

3.4.50 It was, too, a question of trust. One surgery who reported that the majority of their patients who were included in the NIS had been consented verbally on the basis that patients had, to date, trusted what they had done for them – for example, prescribing medication, referring to the District Nurses and so on and that it somehow belied that sense of confidence by obtaining actual written consent.

3.4.51 Given that many of the patients were elderly and 'vulnerable' one GP raised a additional concern about the role of the Network since many of their patients were wary of agreeing to something through someone else they did not know. In this particular case, the GP was seeing their patients personally to discuss it.

3.4.52 Within the Community Health Team there was also a query raised as to the point of it since they would naturally obtain consent for any referral anyway. One member of the team recalled how they had asked a GP why it was necessary but found it hard to obtain a satisfactory reply:

'We have been asked to do it over the phone, asked to go round and see the patient but we don't know what we are asking…blanket consent seems like a waste of time given we ask consent every referral on. I said to a GP, consent for what and he said it is to become part of the Co-ordinated Care NIS and then it was sort of, right on to the next patient and this happens week after week, after week'

3.4.53 They argued that it was absolutely essential that if they were obtaining consent, they needed to be able to give a clear rationale as to why and made a call for clear guidelines distributed to everybody.

3.4.54 And there was always the issue that the GPs were being paid for the 'consent'.

'What I would not like to see if it becomes a burden as it is a GPs' target – they get our staff to do it, because if we have x number of activities to do, we don't want x plus 10% because 10% is the consent'
(Community Health Team)

'So we are acting in their best interests but then to say you don't have to have consent and then to say we will pay you sounds a little bit back-handish to me'
(GP Practice)

3.4.55 Nevertheless, there was an equally strong viewpoint cutting across the above discussions that suggested consent could enable more of rapport with both the patient and possibly the carer and/or wider family even though it could be time consuming.

'I mean a lot of the time we work on implied consent but it is nice to have it a little bit more crystallised in this scheme so if a patient is not particularly happy, you can question why and address any concerns that they have and then it is a way of really making sure that you are trying to get them involved in this as well rather than just sort of turning up and just saying do whatever you have to do doctor'
(GP Practice)

3.4.56 Finally, apart from those who were from the local authority in the Community Health Team who suggested that the locally authority consent form should be used, no-one brought up the format and wording of the form itself.

Single Point of Access

3.4.57 The general consensus was that the Single Point of Access was working well. GPs commented that it made their lives easier and the service was efficient and fast.

3.4.58 Any concerns that there were appeared to be unique to particular surgeries rather than across practices. Thus, it was only one surgery that complained that they only seemed to be available during 'working hours' and that whether the service was fast depended very much on the time of day of the referral. Another, too, had had some difficulty finding the right forms to complete. However, there were a couple of practices who commented that it was sometimes unclear as to whether the service had received the details of a referral but this was certainly not the reported experience of most.

3.4.59 Nonetheless there did appear to be an issue mentioned in some interviews about a lack of understanding of how and what should be referred. More vociferous were the Community Health Team who complained that the team working in the Single Point of Access were not clinically trained which in turn caused difficulties for them:

'Because they are not clinicians they will put onto EMIS whatever is written on the referral - so if the referrer indicates they want a two hour response, they will treat it as a two hour response rather than actually looking. Given we have always had a really long waiting list for community, referrers were always happy to put in a higher urgency to hopefully get a patient seen quicker and we are trying to get some GPs out of the habit of doing that, because we are trying to pick everybody up very quickly at this point. So it will come in as a two

hour response needed when actually the person is still safe at home and they could be seen within the one to five days'
(Community Health Team)

3.4.60 It was, though, acknowledged that the Single Point of Access was probably overworked with a high turnover of staff and there was a perception on the part of some that as soon as staff were trained, they would leave. There was one suggestion that there should only be one pathway but again the clear disadvantage would be the extra workload.

'It would make it a lot easier if there was one pathway but then that means that every social work or carer type call would go through the Single Point of Access and that would increase their workload massively…'
(Community Health Team)

3.4.61 Others put forward a solution that the staff in the Single Point of Access should have a flow chart so that there would be a greater understanding of which cases should be directed and where they should be channelled. Either way, it was spontaneously suggested that it was a massive change and it would take time for its effectiveness to be realised and subsequently evaluated.

3.4.62 Finally, there was some inconsistency in opinion as to who was able to telephone the Single Point of Access. Some respondents believed the patients had access but there were equal numbers who thought that it was only the GP or the Community Health Team.

Orion

3.4.63 The south west locality had originally been selected as the subject of this evaluation on the basis that it was where the new Orion computer system was being piloted. At the time of the interviews, however, it was not clear to many respondents as to whether it was functioning or not. This may have been the result of the time-span of the study but there were conflicting accounts throughout. Some believed it had been turned on but not everybody could see everybody else's notes and others said it was not working at all.

3.4.64 The vast majority of respondents believed that when it was fully and running it would be hugely beneficial and even potentially act as the barometer for the NIS itself.

'It is a great idea because it is Co-ordinated and everyone will know what is happening - you won't have to make numerous phone calls about what is that person doing, who is the person responsible'
(GP Practice)

'We need it to be functional, not just another piece of software and people need to be able to use it in conjunction with other clinical systems we us…It has to be user friendly. Orion should be able to do that. We want to see it work and once the IT information mechanisms are all there, we will be in a better place to see if (the Co-ordinated Care NIS) is working or not'
(Network Team)

3.4.65 Ironically, at the same time as being seen as a useful adjunct to the Care Plan, it was also clear it raised the question of whether both systems were necessary.

3.4.66 There was a certain amount of concern that the hospital would not be able to access all the notes and also some questioned the level and extent of local authority information that would be accessible to the health services. Others were sceptical that there were not enough computers held by the Community Health Team and a number of those that were there were not working.

> *'We have got apparently got about 300 new PCs that have been bought but it is like giving us a Roll Royce without an engine because the infrastructure isn't in place in the buildings to be able to accommodate them. So the first piece of work that is being done is to improve the networks, the systems in the buildings - the money has been secured to do that -it is a total frustration for us and we are kind of moving faster than we have got our systems and processes in place to be able to support us in what we need to do'*
> (Community Health Team)

3.4.67 Others questioned who was going to input the data and how accurate it would be but there remained across the board an element of both scepticism and frustration:

> *'Optimism does not come very easily when you look at what has gone before. How long has the computer system been talked about?'*
> (GP Practice)
>
> *'I can't believe they did not sort out the computer glitch before… I would have thought it would have been thought out properly'*
> (GP Practice)

Mental Capacity Assessment

3.4.68 The issue of assessing mental capacity was discussed in the majority of interviews with GP practices. Most acknowledged that it was a complex area but felt it was appropriate to 'tighten up' practice. Some GPs alluded to the extra time it might take to do it more formally but suggested that for their purposes it would not be too much of a burden. During the time of the study, a number of GPs had attended training and this had been very much welcomed particularly since it was thought that it made them reflect upon their practice.

3.5 Issues in Evaluation

3.5.1 As noted earlier, the majority believed it was too early for this evaluation to be carried out not least since it was an on-going programme and, for example, the multi-disciplinary teams were not yet fully functioning. Further, data took a long time to process.

> *'It is too soon to expect any results - it's going to take a good year before it even starts filtering through and the data is also several months out of date anyway so yes, maybe in 12 months' time'*
> (Network Team)

3.5.2 Again there was a range of opinion as to how it should be measured and a number commented that it would prove very difficult to have measureable outcomes particularly since it would be so different for each patient unlike measuring diabetes care or blood pressure. It would be very hard, for example, to link the writing of a Care Plan to any difference in a patient outcome.

3.5.3 However, most believed that a reduction in hospital admissions would be used as an outcome measure but it was explained during interviews that for the group of patients included in the Programme, hospital admission was often unavoidable.

> *'I mean are they going to beat us with a stick if we have doubled the admissions – we have identified patients at high risk and we have had a lot of those patients admitted but there was nothing we could do'*
> (GP Practice)

3.5.4 Indeed, it was argued by some, the key principle should be 'better health' believing the only way to evaluate such a Programme would be by looking at patients' experience of their pathway and the quality of their care, either clinical or non-clinical, including the quality of specific events, such as the discharge process.

> *'I think some of the outcomes must be around have we made any significant clinical difference to the patient so it is getting the right coding to follow the patients correctly'*
> (Community Health Team)
>
> *'Take a palliative care person….what would be a positive outcome would be if they had had what they wanted and what they asked for and what was discussed with them and planned'*
> (GP Practice)

3.5.5 Further not only were some were less sure that the NIS would actually prevent admissions but that was the aim across all care in any case.

> *'On paper it should prevent admissions I don't know where the evidence is that it actually does….but we have been doing that for years anyway – the job is to do everything you can to find unique way of keeping them from going into hospital'*
> (Community Health Team)

3.5.6 Nonetheless there was a vociferous minority who were surprised that there did not seem to be any established goals and standards and, although recognising the complexity and difficulties in measuring outcomes, felt there should be something to show that it was worthwhile.

‘There has to be something they are measuring it against. I think you would not institute such change without some method of evaluating the effectiveness….they must have some measures in mind and they need to make it clear what those measures and goals are’
(Community Health Team)

‘We need to see what is happening at the other end - so by doing Care Plans we have shown less hospital admissions, more patient satisfaction, better overall care… you are not going to get those figures but that is what would make it worthwhile – the hospital, ambulance saying, no more do they go and visit Mrs X and find they have not got a clue what is going on’
(GP Practice)

4. MAIN FINDINGS - PATIENTS

4.1 General Themes:

4.1.1 Many of the patients interviewed in this evaluation were elderly and frail and found it hard to remember clearly what had happened, when and why. Some were also unable to detail any of their medical conditions and might quite easily have reported the only ailment they had, for example, was ‘asthma’. Their stories were frequently disjointed, often repeated and rarely consistent. It was clear, though, that the interviews provided the patients with an opportunity to talk about their situation.

4.1.2 In spite of the complexity of interviewing this cohort of patients it was possible to draw out a number of key themes and make recommendations for further in-depth work in Phase II.

4.1.3 Although many were confused as to who the professionals were who might visit them, far more of an issue seemed to be the feeling of loss of ‘control’ with different people coming in and out.

4.1.4 This evident sense of ‘loss of control’ was also apparent in terms of feeling in control of their ‘information’ and the history of their own medical problems. Almost all spontaneously described what happened when their current medical issues started and this not only appeared to form a central part in their ‘stories’ but appeared to need ‘recognition’.

4.1.5 It appeared that just as services are thought to be renowned for working in ‘silos’ it seemed that patients thought in a similar way. Thus, many patients were not surprised that different providers did not talk to each other and, though it would be appreciated if they did, they did not expect them to.

4.1.6 However, most patients, too, also found it difficult when professionals knew nothing about them and hoped that any new system would alter this.

4.1.7 The evidence showed, too, that many, but not all, of those interviewed did feel 'listened to' and could cite examples of when this had happened. However, it was equally clear that the tendency was for patients to feel 'listened to' on specific issues and within specific services rather than an overall feeling of being 'in control' of their care. Care happened to them.

4.1.8 Indeed, it was striking how many patients clearly felt overwhelmed by their overall circumstances and a sense that old age could bring with it not just a loss of dignity and a feeling of helplessness but also an acceptance of 'what is'. During interviews, patients often described serious failings in their health care with equanimity and acceptance. To some extent, too, this was also the case with younger relatives and 'informal' carers

4.1.9 It was also evident that frequently it appeared that it was not a question of whether patients felt the services had failed them or not. Instead there appeared to be a need to improve communication to enable patients to understand what is happening to them and what has happened in the past at the same time as providing the appropriate level of support to patients so that they are able to articulate what they needed. Many were unaware of their entitlements (health or social care) and how they could be obtained. Thus, they were also oblivious of services they were not receiving.

4.1.10 It was also apparent that, from their perspective, help was based on a 'one size fits all' basis rather than on a personalised basis.

4.1.11 To some extent, the majority of patients did not appear to worry about their health per se. Of greater concern was their future and what would happen if their health deteriorated in terms of who would look after them and how they would manage.

4.1.12 When asked to detail their concerns, the majority highlighted non-medical issues such as the need to find a carer or a solicitor, their inability to leave the home, their housing conditions, the lack of available transport (or appropriate transport that catered for their needs), the lack of suitable aids (e.g. stair lift) and above all, the fear that something might happen to their 'informal' carers.

4.1.13 A good number requested telephone numbers of key services so that they had them to hand when needed. This would include both health and social care.

4.1.14 A number too particularly asked for 'someone to talk to' and emotional support when they needed it. Although befrienders were appreciated, this was not the same as having a phone line or simply someone with whom to talk. It was clear, too, that for those who had built a strong relationship with a professional which clearly could be from across the social and health care spectrum (e.g. GP, Community Nurse, social worker) it was greatly appreciated. Such relationships tended to be individually based and not professionally based. For some, however, gender mattered but for most it was a question of 'individuals' and the relationships that had been hitherto built. Those who did not have such relationships tended to be those who asked for someone to talk to or at least for someone to ask them how they felt.

4.1.15 Remarkably few patients attended Day Centres. Whereas for some this was clearly a conscious decision, others were unable to access them. It was evident, too, that there was a section of the sample that were simply unaware that they existed. Some, too, were aware that they no longer qualified for voluntary sector provision.

4.2 Service Provision

4.2.1 Experiences of service provision varied enormously. Previous experiences, either their own or those of members of their immediate family, were hugely influential. One man, for example, was causing concern in his family because he was reluctant to mention that he was not well in case he suffered the same fate as his now deceased wife.

GPs:

4.2.1 Perceptions of GPs varied enormously. Some were relied upon totally and were the main contact for the patient.

4.2.2 Complaints tended to centre upon waiting times for appointments, the fact that patients were only allowed to mention one problem at a time and rushed appointments.

4.2.3 A surprising number of patients had been registered at the same surgery for quite some time and, in some cases, over 60-70 years. More recently a number appeared to have encountered difficulties such as the GP not being able to visit at home because they were ‘outside the area’. One man discovered, too, that, because he had not been to the surgery for some time, the practice had simply taken him off their list with no notice.

Community Care:

4.2.4 Many described in detail how long they had waited for appointments and services cutting across all sectors.

4.2.5 Although there were complaints about waiting for District Nursing, Physiotherapy or Occupational Therapy, in the main, concerns focused upon individual professionals who might say they would phone back or call back but did not.

4.2.6 There were difficulties for patients when professionals did not say when they were visiting, often not even giving a time slot.

4.2.7 Obtaining the appropriate level of social care also seemed especially hard. Some carers were reluctant to be honest about the care they gave ‘informally’ in case it affected the patient’s ‘formal’ care.

4.2.8 Further, it was issues such as waiting for pressure stockings or for the right sized pads that tended to cause distress for both the patient and the family/carers.

4.2.9 In addition, there seemed to be a general acceptance that service provision, especially in terms of equipment and aids, was a ‘one size fits all’. One patient was extremely distressed, too, that her carer would not dust her glass collection and another had no-one to help her take her curtains down so they could be washed.

4.2.10 Some believed, too, that they had only finally received what they had asked for because they were forceful characters.

Hospital Provision:

4.2.11 A number of patients reported being asked to report to hospital only to find that when they arrived, there was neither a record of them nor of their notes.

4.2.12 Some told stories of doctors who never explained anything but, more critically, hospital doctors were accused of making their minds up about a case without any consultation with the patient.

4.2.13 There were a number of complaints about the poor food in hospital and general hospital services such as cleaning.

4.2.14 The perceived lack of support following discharge often led to concerns about potential future episodes as well as coming out of hospital with no 'after care'.

4.2.15 Having to attend three different hospitals was a particular issue for a number of patients and even though this might change with the closure of the London Chest, this in itself brought more anxieties.

4.2.16 Transport was a particular issue and patients tended to believe it would be compounded by the closure of the London Chest Hospital.

Mental Health:

4.2.17 Although some patients had been referred to Mile End for mental health issues, none were aware of any GPs carrying out a Mental Capacity Assessment

4.2.18 A number of patients noted that they had seen the consultants and doctors at Mile End but never ‘recently’. Almost all stated it had been quite some time, usually over six months to a year, since they had last been assessed.

Care Homes:

4.2.19 There was a general consensus that patients thought that care homes were the ‘beginning of the end’

4.2.20 In all three cases where patients were known to have had experience of care homes, all had had extremely bad experiences ranging from ‘weeping bed sores’ resulting in hospitalisation, bruises covering the body to only been ‘changed’ three times a day and showered once a week.

4.3 The Co-ordinated Care NIS

4.3.1 Similar to health and social care professionals, the vast majority welcomed the idea and the concept of the Co-ordinated Care NIS. Even for those who had not experienced it and had no recollection of it, there was a request for more holistic care, a named person and particularly an option for emotional support. However, for those that had come across it, their experience did not always appear to relate to the concept.

4.3.2 Only a few had any memory of the Co-ordinated Care NIS being discussed with them. Some were not sure and confused it with other care plans they might have had, for example, those drawn up by Social Services or by the Community Health Team.

4.3.3 A number thought they had had the Consent Form but then it transpired on prompting that this might have been the form regarding the national Summary Care Records. A couple of patients did have the Consent Form at home but simply had not returned it.

4.3.4 For those that did have a recollection of the Form, it did not appear that they expected their care to change in any way. This may well be a reflection of their own ‘silo’ thinking.

4.3.5 One patient thought that his Care Plan was purely for hospital treatment but the last time he had been to hospital, he had not given it to the doctors as they were very busy and he thought they might lose it if he had or certainly might forget to return it to him.

4.3.6 A further patient recalled how they had felt particularly rushed when the Care Plan was being done and there had been no time to talk or discuss anything.

4.3.7 One patient, who remembered the process in some detail, argued that the questions on his ‘future’ were rather ‘jumping the gun’. However, he was able to talk about his feelings of ‘depression’ during the session for the first time.

4.3.8 Some patients interestingly considered that having details of their past history would be tremendously helpful independent of whether they recollected the Programme. However, it was suggested that it may not make any difference if the NHS had no money as was expected in the future.

4.3.9 It appears how the Co-ordinated Care NIS was explained to them was critical in whether they remembered it or not.

5: NEXT STEPS

It is suggested that Phase II should consist of interviews with the same patients[15] in order to:

- Assess the impact of the Co-ordinated Care NIS through the tracking of the experiences and journeys of the same cohort of patients
- Explore the mechanism/s through which the concept of integrated care could be best communicated to patients
- Explore the mechanism/s through which patients will be able to articulate what they need and how services might be best accessed
- Explore in more detail the essential qualities and role of a designated link person such as the Care Navigator
- Explore in more detail the connection between continuity of care and continuity of care professional
- Explore in more detail why, how and in what way patients would like greater involvement in their own care and what that might mean to the individual
- Explore and examine in greater detail the issues of loneliness and isolation[16]
- Explore potential mechanisms for longer term evaluation

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[15] It is anticipated that some of the patients may have died in the interim period. If this is the case, it is recommended that other patients are selected. It also may prove useful to recruit a further group of patients as a separate group to discuss the relevant themes.

[16] It would be expected that this would be linked with the recent work carried out by Tower Hamlets Friends and Neighbours

APPENDIX I

EMAIL FOR PRIMARY AND COMMUNITY HEALTH TEAMS

Dear

Tower Hamlets Co-ordinated Care – Network Improved Service

The CCG has appointed Kate Melvin, in partnership with Urban Inclusion (Healthwatch) to do some patient focused evaluation of the experience of patients in the coordinated/ integrated care programme over the next six months.

The core focus of these programmes is the cultural shift towards partnership patient-centred working in a holistic way. The CCG is thus keen to uncover and explore not only the barriers and enablers in their implementation of the new approach to-date but equally to make recommendations and how and in what way service provision could be improved for the benefit of patients. A significant part of the evaluative process will be interviews with those patients within the locality who have consented to be part of the new system of care. In order to make sense of their responses we also need to understand their context, so as part of the evaluation, primary and community healthcare teams involved in the provision of services within this programme will be invited to take part in discussions.

In order to make the numbers manageable, the evaluation is being conducted in one locality only and the SW has been chosen because of the Orion pilot.

Kate will be aiming to contact healthcare teams within the locality over the next month in order to discuss the possibilities for arranging meetings and times for discussions. We do understand how busy healthcare professionals presently are and every attempt will be made to arrange times that are convenient for you.

All discussions and meetings will last no longer than one hour and the information collected will be held in the **strictest confidence.** In reporting the findings of the study, no names will be given and every effort will be made to ensure people, practices or healthcare teams cannot be identified by any other references. In accordance with standard practice, the meetings will be digitally recorded so that all views and opinions are accurately captured. The tapes will be kept secure and accessed **only** by the researcher and the research team. After the project is complete, all records will be destroyed.

If you have any questions in the meantime, please do not hesitate to contact Kate directly on 07748 762 986 and her email address is .

We are very grateful for your time and support in this project.

Yours sincerely

APPENDIX II

Unit/Department Name
2nd Floor, Alderney Building
Mile End Hospital
Bancroft Road
London E1 4DG

Tel:
Fax:
Email:
www.towerhamletsccg.nhs.uk

March 2014

Dear Patient/Carer

As part of an initiative to improve health and social care for patients, a specific programme of care has been developed that aims to change the way patients receive care and the way their care is organised and administered. It is a new and additional service to the usual GP care.

It is important that the views, opinions and experiences of those patients who have been invited to be part of this new programme are both heard and understood so that these new services that are offered to patients can be further improved. In particular, it is important that services are very much based on the needs of the local community and focus on the priorities of patients. An independent organisation, Urban Inclusion Community (Health Watch) has therefore been asked to carry out an evaluation. The evaluation will also include discussions with GP practices and community health teams.

We are aware that you are part of this new programme of care and we would now very much like to invite you to take part in this evaluation. Becoming 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 so that the people who provide the services can be sure that they are right for you and for other people like you who are using them.

The evaluation will involve an initial discussion with an independent researcher which will subsequently be followed up by a second and final discussion in a few months. Although these discussions could last between 45 minutes and one hour, the length will very much depend on how you feel at the time. The evaluation may also potentially involve one or two brief follow-up conversations on the telephone. All those taking part in the evaluation will receive £40 cash as a token of thanks for their time.

The researcher is totally independent and all discussions will be entirely confidential. There will be a report but, no names will be given and every effort will be made to make sure people cannot be identified by any other references – such as where they live, what they do for a living or details of their household. As is normal practice in such a study, the meetings will be recorded so that all views and opinions are accurately captured. The recordings will be kept secure and used only by the study team. After the evaluation is complete, they will be destroyed.

The name of the lead evaluator is Kate Melvin and she can be contacted for any further information and to answer any questions you might have about the evaluation. Her contact details are 07748 762 986 or, alternatively, katemelvin2@gmail.com.

Finally, we understand that you have already consented to the sharing of your data where appropriate as part of the new programme of care. However, if you do not wish to take part in this evaluation, please fill in the attached slip and return it in the stamped addressed envelope.

We are very grateful for your time and support in this project and we would like to emphasise that your decision about whether or not to take part will in no way affect any future care you might need. All patients receiving care within this programme are being sent this letter but only the study team will be aware of the names of those who finally take part. Neither the commissioners of the study nor the primary and healthcare teams will be aware of the names of those patients selected for interview during this evaluation.

Many thanks indeed for your support

Yours sincerely

Dianne Barham
Chief Operating Officer
Healthwatch
Commissioning Group
Tower Hamlets

Dr Sam Everington
Chair
NHS Tower Hamlets Clinical

EVALUATION – TOWER HAMLETS COORDINATED CARE

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

Signed…………………………………….

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

Surname ………………………………………………

First name: ……………………………………………..

Address: ………………………………………………

………………………………………………

……………………………………………….

APPENDIX III

DISCUSSION GUIDE FOR HEALTHCARE PROFESSIONALS
TOWER HAMLETS CO-ORDINATED CARE – NETWORK INCENTIVE SCHEME - EVALUATION

Notes:
This is the guide for use in the group discussions to be held with GPs and Practices. It will be adapted for the Community Health Teams. It is relatively focussed on the basis that their time will be very limited.
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.

Introduction to Discussions
The Tower Hamlets CCG have commissioned an independent evaluation of the Co-ordinated Care NIS. This evaluation is essentially 'patient focused' and interviews will be held with those patients who have consented to be part of the new system of care. However in order to understand the whole process, it was felt that it would be particularly useful to speak to healthcare professionals as well in order to understand any issues that have arisen in the implementation of the programme to-date but equally to make recommendations about how the programme could be improved for the benefit of patients.

This will be a fairly informal session that is anticipated to last no more than an hour. In order to obtain an accurate record, I would like your permission to record the discussion. 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. General background information **Introductory questions:** • Brief details of surgery – size, make-up, demographics of area etc
2. Integrated Care - General • What has been their involvement in the setting up of 'Integrated Care' in the network? ○ As a GP? As a Practice? • And in the setting up of this particular programme – Co-Cordinated Care NIS? • How and in what way do the two programmes differ? • Would they have liked more involvement in the decision making process about the programmes of care?

    - If yes? Why? What involvement would they have liked?
    - If not, why not?

- In general, what are the challenges for primary care in moving towards greater integrated care?
    - Eg IT
    - Merging of organisational cultures
    - Different approaches to working
    - Building new relationships
    - Single Assessments etc
    - Access to appropriate information
    - Resources
    - Training
    - Co-location of teams
    - Etc

- And what are the enablers?
    - Eg Commitment to the process
    - Appropriate training/skills re integrated care
    - Locality/network approach

- In their view, to what extent is there now a 'shared vision' within the locality about integrated care?
    - And within the network?
    - And between primary and secondary care?
    - And between practices and community health teams (etc)?
    - To what extent and how have barriers been broken down between different teams working together?
    - What does this mean in practice?
    - Can examples be given in terms of how it plays itself out?
    - What have been the challenges in creating this?
    - And the enablers?

- In their view, to what extent is there now a 'shared vision' across health and social care provision?
    - What have been the barriers?
    - And the enablers?
    - In terms of barriers, how and in what way might they be resolved?

3. Co-ordinated Care Network Incentive Scheme – The GP/Staff Perspective

- In their view, how is the programme working to-date?
    - What to-date have been the enablers?
    - And the difficulties? What? In which part of the system?

- In their view, what are the main challenges in this programme from a practical point of view?
    - Identification of appropriate patients
        - Mandatory
        - Discretionary
    - Single assessments (joint assessments?)
    - Correct referral mechanisms
    - IT systems
    - Care plans
    - Discharge systems
    - Rapid Response
    - Resources – including staffing (staff turnover) and time

- In particular, have there been any issues with the single point of access to-date?
    - If so, what?
    - How will they be resolved?
- And who normally organises and deals with the Care Plan?
    - Why?
    - If by Practice Nurse, how is it then discussed with the GP?
- And in terms of the single assessments, have there been any particular issues?
    - If so, what?
    - And Mental Capacity assessments?
- What have been the specific benefits of working with the Orion system?
    - And the difficulties, if any? Why? In what way?
- In their view to what extent is thinking shifting among care professionals from 'responding to needs' to the 'identification of problems early'
    - What are the difficulties for this to happen?
    - Why?
- Have there been many organisational changes within your practice as a result of this new programme of care?
    - If so, what?
- To what extent has it worked towards the further development of the 'network' system?
    - How? In what way?
- In their view, does the programme have full support from all levels of professionals?
    - If not, why not?
- Is it regarded within your practice as a separate programme of care?
    - How? In what way?
    - Or one that is becoming very much part of your normal provision?
- Do they feel, from their perspective that individual members of the practice have had enough support in the implementation of this programme?

    - If not what support would they have liked? And information?
- In their view, are the Community Healthcare Teams made up of the ‘right’ personnel?
    - If not, who should be in the teams?
    - And the geriatrician?
- To what extent do they think primary care staff are able to maintain having patients at the centre of their care at the same time as merging cultures and organisations?
- In their view, how should their performance on this programme be measured?
    - Why?
    - To what extent, does it make a difference that there are no longer targets for each aspect of care?
        - How? In what way?
    - To what extent, if at all, is alignment of performance targets an issue?

<u>3. Co-ordinated Care Network Incentive Scheme – The Patient Perspective</u>

- In their view, how aware do they think the patients are that they are under this package of care?
    - How? In what way?
- To what extent is ‘consent’ understood by the patients?
    - To what extent, if at all, does the ‘consent’ affect the nature of your relationship with the patient?
    - How and in what way does it change the nature of the partnership?
- How many in their experience have ‘refused’?
    - Why?
- To what extent, do they think patients understand what this package entails?
- In your initial conversations with patients about this package of care, how and in what way do you emphasise ‘well being’?
    - To what extend do you think this is important? Why?
    - Does it enable to patient to function better?

- To what extent, if at all, do you talk about the future and the duration of the package?
- In their view, what will patients notice that is different?
    - How? In what way?
- In their view, what are the key benefits to patients of this new programme?
    - Why? In what way?
- Which of these do you think they notice the most?
    - Change in nature of GP approach
    - Spending more time with the GP – how much?
        - How and in what way does that create a different experience of the patient?
    - Change in nature of relationships with GP
    - Emphasis on well being
    - Focus on social care as well

- In their view, does it empower patients?
    - How? In what way?
    - What does this mean in practice?
    - And carers?
- In your view, are you able to provide ‘more responsive’, ‘pro-active’ care as hoped?
    - In what way
    - If not, why not?
- What, in their view, will ‘better’ care mean for their patients?
    - In terms of your approach
        - eg the way well being is all part of it
    - Or in terms of effect on them?
    - More independent?
    - Better able to function
    - Less fragmentation of care
    - More Involved in decisions about their care
- And ‘quality’?
- In their view, what outcomes should the programme be achieving for patients?
    - How should these be measured?
- Are the ‘right’ patients being targeted?
    - If not, who should be on the programme? Why?
- To what extent, if at all, do you feel you need/ed extra training for this new approach to care?

4. Conclusions

- What are the key ingredients for this package of care to be sustainable?
    - Eg Low staff turnover
    - Alignment of outcomes
- And to become ‘ingrained’ in thinking?
    - And in practice?
- In their view, what would be the most effective way to evaluate the pilot from the perspective of the patients?
    - Why?
- How might the programme benefit from this evaluation?
    - In what way?
- If they were managing the programme, what changes would they make?
    - Why?

THANK AND CLOSE

Respondents will also be asked how they recommended that patients should be selected. It will be explained that the Network Managers will be administering the recruitment of patients in the first instance

APPENDIX IV

DISCUSSION GUIDE - PATIENTS
TOWER HAMLETS CO-ORDINATED CARE - NETWORK INCENTIVE SCHEME - EVALUATION

Notes:
This is the guide for use in the group discussions to be held 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 participants will have been asked if they have seen or are due to be seen by other 'researchers' or 'interviewers' before being recruited
Please note that this is the guide for the FIRST interview with patients. A second guide will be drawn up for the second stage of this evaluation in May following the mid-term report and the findings from the first stage.

Introduction to Discussions
The Tower Hamlets CCG have commissioned an independent evaluation of the Co-ordinated Care NIS. Although discussions are also being held with GPs, practice staff and Community Health Teams, this evaluation is very much patient focused. 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.

As previously mentioned, being involved will mean two relatively short discussions and possibly one or two telephone conversations. 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. General background information

Introductory questions:

- Brief life details
  - Age, marital status,
  - Details of home life
    - Who lives with them
    - Family details etc
  - General lifestyle questions:
    - Whether manage to get out? If not, how they manage etc
    - Socialising etc

2. General Health Issues

- Can you talk a little bit about your health?
- Are there any health issues that are concerning you?
  - Do you have any particular conditions?
  - For how long have you had them?
- Which health professionals do your see regularly?
  - GPs/CHTs /hospital doctors etc
  - How often?
- Do you see other services as well?
  - Eg social workers/befrienders etc
- What do you normally do if you are particularly worried about your health?
  - Talk to a friend or family?
    - If so who?
    - Why?
  - Speak to a health professional?
    - If so, who?
    - Why?

- Whom do you normally contact if you have an immediate health concern?
  - Has this always been the case?
    - If no, why not?
    - What has changed?
- Over the last few years what have been the main concerns about the health care you have received?
  - Eg, delayed appointments/waiting times/discharge from hospital/duplication of provision/repeating their stories etc
  - Is there anything in particular that has made you concerned?
    - If so, what?
  - At the time of (each instance) what would have made it better for you?
    - How? In what way?

2 Introduction to the Co-ordinated Care Programme

- Are you 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 is 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?
- **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 for:
        - 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***
- Have your relationships with health care professionals changed in any way?
    - 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 that they are more involved with their care than previously?
  - In what way? How?

- 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?
- Have you had to contact the services in an emergency at all in recent months?
  - Who did you contact? Why?
  - Are you aware whether it was a central number or not?
  - What happened?

- Or for anything else?
  - Who did you contact? Why?
  - Are you aware whether it was a central number or not?
  - What happened?
- Have they been to hospital in recent months?
  - If yes, was there anything different in your experience this time compared to experiences previously? If so, what?
- Have you seen any 'new' health or social care professionals over the last few months (eg 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 given a 'new' assessment?
    - How did you feel about this?
    - Was it different from previous assessments? How? In what way?
- 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’
  - Social care
  - The future
  - Issues within the care plan?
- How do you feel about discussing such things with your GP?
  - Who would you like to discuss them with?
  - Why?
- To what extent do you think that this 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?
- Overall, how do they feel about the care so far?
  - What other changes would you like to make?
- Is there anything that is of particular concern to you at the moment?
  - If so what?
  - Have you discussed it with anyone?
    - What did they say?
    - How do you feel about it?
  - If not, why not?

3. Conclusions

- 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 – DISCUSS FUTURE MEETINGS

APPENDIX V

Participant Information Sheet

March 2014

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

What is the purpose of the study?
The purpose of this study is to understand the views, opinions and experiences of those patients who have consented to receive coordinated and enhanced care as part of an initiative to improve health and social care services. Discussions are also taking place with the primary and community care health teams in the South West locality to hear and understand their views about the new provision

Who is organising and funding the study?
The study is being funded by the Tower Hamlets Clinical Commissioning Group (THCCG)

Why have I been invited?
You have been asked to participate on the basis that you are a provider of primary and/or community care services in Tower Hamlets

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

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

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

What are the possible risks and disadvantages of taking part?
There is a possible disadvantage in spending time to take part in the interviews.

What are the possible benefits of taking part?
Those taking part would be contributing to a study which we hope will prove of benefit to health and social care services. It is important that the THCCG understands the views and experiences of providers as well as patients so that services can be improved for the benefit of patients

Will my taking part in the study be kept confidential?
The lead evaluator will follow ethical practice. All data from interviews will be treated as entirely confidential by the researcher. The participation of all those taking part will also

be entirely confidential. THCCG are aware that all practices within the South West locality have been invited to take part but will not be aware of the names of any individual taking part.

All data from interviews will only be available to the lead evaluator. It will be securely stored and will be treated as confidential at all times. All interview transcripts will have any personal identifying information removed before analysis and will be destroyed as soon as the project is complete. Quotations from the interviews will be used in the final report but every effort will be made to ensure that any references to any participant omitted so that they will remain, at all times, unidentifiable.

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

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

What will happen if I don't want to carry on with the study?
You can withdraw from the study at any time and your data will be destroyed immediately.

If you wish to provide any feedback, please contact:

Dr Isabel Hodkinson
isabel.hodkinson@nhs.net
You will be given a copy of the information sheet and signed consent form to keep. Thank you again for considering taking part in this study and taking the time to read this information.

CONSENT FORM

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

Title of Project: Evaluation – Coordinated and Enhanced Care Programme

Name of Researcher: Kate Melvin (Lead Evaluator)

Please initial box

For Participating Healthcare Professionals

1. I confirm that I have read and understand the information sheet, dated March 2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

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

____________________ ____________________ ____________________

Name Date Signature

Please complete and sign this form and return it to Kate Melvin **at the time of the interview.**