HEALTHWATCH HACKNEY INTEGRATED CARE & RELATED THEMES

Person Centred Care | September 2014

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Preface: The Government's Better Care Fund

In June 2013 the government announced its "Better Care Fund" to promote the integration of health and social care services. The Better Care Fund was largely not new money, but rather a programme of incentives for the NHS and local authorities to work together by pooling their budgets.

The nationally pooled budget of £3.8 billion for 2015/16 will include a performance-related element of £1 billion that may be retained subject to performance against national and local targets. The guidance for the Better Care Fund was published in December 2013, and plans were to be submitted by the end of March 2014.

Once the plans were looked at the government issued new guidance in June 2014. The new resubmission date is September 19th 2014.

Hackney's Plans for the Better Care Fund

In Hackney the Better Care Fund totalled £18million, and is overseen by the Health and Wellbeing Board (www.hackney.gov.uk/health-and-wellbeing-board.htm)

For Hackney the total value of the pooled budgets making up the Better Care Fund is £20.078million, of which the performance related element is estimated at £5.39m.

From January 2014, statutory partners worked hard to put together plans for the Better Care Fund in Hackney. While adopting the principles of Patient Involvement, by using the National Voices 10 principles, no patients were involved in the steering group which oversaw the plans at this stage.

The initial plans were brought to the Health and Wellbeing Board in April 2014 and can be read here:

Main document:
http://mginternet.hackney.gov.uk/documents/s36252/Better%20Care%20Fund%20Plan%20-%20Report.pdf

Appendix 1 (includes details of public engagement):
http://mginternet.hackney.gov.uk/documents/s36253/Better%20Care%20Fund%20Plan%20-%20Appendix%201.pdf

Appendix 2:
http://mginternet.hackney.gov.uk/documents/s36254/Better%20Care%20Fund%20Plan%20-%20Appendix%202.pdf

In this the partners say:

"Our vision for integrated care is drawn from what people have told us is important for their health and wellbeing and we have adopted the National Voices Narrative for Person-Centred Co-ordinated Care as a guiding principle as it provides a shared understanding of integrated care in respect of the experiences, views and outcomes of patients, users and their carers"

National Voices principles

- be organised around the needs of individuals (person-centred)
- focus always on the goal of benefiting service users
- be evaluated by its outcomes, especially those which service users report
- include community and voluntary sector contributions
- be fully inclusive of all communities in the locality
- be designed together with the users of services and their carers
- deliver a new deal for people with long term conditions
- respond to carers as well as the people they are caring for
- be driven forwards by the commissioners
- be encouraged through incentives
- aim to achieve public and social value, not just to save money
- last over time and be allowed to experiment

Patient Engagement and Involvement in the Better Care Fund – Event 1st April
In February the members of the Health and Social Care Forum and Healthwatch Hackney met together and decided that the quickest way to have patient feedback to the Better Care fund process was to hold an event and invite as many people as possible to input.

Plans for the event were developed by a planning group made up of representatives from: Older People's Reference Group, Core Arts, Health and Social Care Forum, St Joseph's Hospital , Healthwatch Hackney, Age

The aim of the event was to look at different themes of the Better Care programme, and for patients to hear about the plans for that service area, and comment where they thought there were gaps or the focus needed to change.

Details of the event are in Appendix

One Hackney Programme

In April 2014 the CCG commissioned the programme called "One Hackney "– this aimed to use non-recurrent spend to fast-track Integrated Care for the 1700 most frail older people in Hackney. Four providers devised a joined up service (Hackney Council, Homerton Hospital, East London Foundation Trust (main provider of mental health services) and the Health and Social Care Forum (representing the voluntary and community sector).

Healthwatch Hackney were commissioned to provide patient input to this group. We worked with the Alzheimer's Society, St Joseph's Hospital, Age UK East London and the Carers' Centre to set up and support a Patient Group to brainstorm how services for this group of frail older people could be improved. This group was chaired by Lin Lahm (from the Older People's Reference Group) and Ida Scuollos (from the Patient Network).

Including other data

In the time to set up the event, and the pause to carry out the One Hackney patient input, we became aware of a number of other surveys and reports which involved patient feedback. We collected these surveys too, and included comments and recommendations from these too in the final report.

There is a full list of the data included on Page 13.

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Executive Summary

Keys Issues in Integrated Care

There were a number of issues that underlay discussions on Integrated Care. These included definitions, a need for a new and holistic approach to care more generally, including shifting the thinking from a medical model to a social model of care and effective and appropriate monitoring of provision. In particular, the following were considered key areas integral to the implementation of integrated provision:

- Greater partnership working involving service users, carers and the voluntary and community sector
- Accountability in care provision
- The need for 'supportive' care and appropriate levels of staff
- Clear information and signposting
- Greater service co-ordination and faster access
- Equal access to provision
- Greater patient choice

Key Areas of Care

a) Patient Centred Care for the Frail Elderly/ Long Term Conditions/Complex Needs

The elderly, particularly those over 75 years, were considered an especially vulnerable group and were likely to have a number of age-related co-morbidities. Key components of integrated care were seen to be greater co-ordination of service provision, continuity of care and effective hospital discharge.

Many thought that staff should receive training on the needs and conditions of elderly patients.

Evidence showed that many were perceived to be presently looked after by relatives, friends and neighbours rather than by statutory or voluntary sector provision. Of equal concern were those that were not part of the 'integrated care' vision but also may very well need the support it could potential offer.

Attention was also drawn to the difficulties for this group to access provision, the need for

advocates and the importance of 'seamless' care. The following areas were considered to be central in the development of integrated provision.

- Comprehensive Care Plans that cover care at home, hospital, discharge and post-discharge
- Care Plans that take into account the 'whole' person
- Involvement of relative and carers in drawing up the Care Plan
- Appropriate discharge procedures
- Avoidance of readmission
- Extended stays in hospital
- Appropriate care in Emergency
- Transport

b) Patient Centered Care for the End of Life

From the data, it was evident that patients wanted to be able to choose their end of life care, how it would be carried but at the same time make an informed choice. A further key issue was the effects of social isolation and to ensure patients have the appropriate support when needed.

c) Preventative Health Care

Believed by most to be at the forefront of integrated care, many patients emphasized the need for preventative services which included considering the social and economic determinants of health, such as housing, social isolation and so on. It was also unquestionable that concerns about these issues were frequently more important to patients than those about their health.

d) Financial Support within Integrated Care

Patients voiced a concern over the little amount of financial support they receive with integrated care services. When services were joined up, for example, financial pressure could be placed upon patients. Financial issues on discharge were also a key focus and it was evident that many needed support with issues such as Direct Payments and Personal Budgets.

e) Mental Health Care

Overwhelming, mental health issues, particularly among those with complex conditions or nearing the end of life, were seen as a major issue. Patients clearly wanted to be treated as individuals and to receive care catered for them as individuals but at the same time called for

mental health provision to be integrated with other health and social care services. Carers, too, should be included in any decision making.

There were reports of lack of co-ordination between services and a lack of understanding of both the needs of those with mental health issues as well as mental health issues themselves. Mental health difficulties could also be particularly traumatic for families and that there should be more support and advice provided in the early stages following diagnosis. Of particular note were complaints about how medication is handled, discharge and the lack of support in terms of community provision.

Dementia itself was clearly a focus but the work of the Alzheimer's Society appeared to meet with great approval.

Specific Themes

a) Communication

Poor communication was an issue across all the evidence. The referral process that often created long waits for appointments and poor communication between professionals/departments as well as between professionals were the main causes of complaint.

Many bemoaned the lack of information given to patients and called for patient information on health and social care to be more easily accessible and in one place and for health professionals to be able to guide patients to the information they need. Both GPs and the voluntary and community sector were seen as potential navigators. A range of venues and sites were suggested for disseminating information.

b) Continuity of Care

Patients wanted to see the same medical professional on a continuous basis so they could develop trust and a relationship, information would not need to be repeated and would be less likely to be diluted amongst many different medical professionals and it might mean there would be more time during an appointment. In addition, medical records were seen by some as a way of maintaining continuity of care but there were complaints that they were not always kept accurately and sometimes lost.

c) Sensitivity to Individual Needs

Patients with learning disabilities were seen as having unique needs which should be taken into account and respected by health professionals. An appropriate bedside manner, clearer communication, greater access to services and longer appointments were also seen to be essential.

e) Cultural Sensitivity

As Hackney is a hugely diverse borough, the needs of different populations have to be understood to provide effective health care. There remained issues of general discrimination, inadequate levels of interpretation and translation which in turn could result in medical complications as well as examples of insensitivities regarding dietary requirements.

There are also many communities about which there is inadequate information concerning health and social care, for example, such as LGBQT and Asylum Seekers. However, some groups within the Jewish community and Turkish community are better researched.

Carers

a) Informal Carers

Informal carers were seen as playing a vital role in patients' care not least because they frequently allowed the patient to maintain a level of independence while being looked after. Both elderly and younger were perceived to be frequently under pressure and there was a general view that they suffered from a lack of recognition, acknowledgement and support from service provision. Again the lack of information was seen to be an issue and many believed that having a named contact would be hugely beneficial.

b) Care Workers

Care workers came under a good deal of scrutiny with complaints focusing upon not simply the lack of care and support available but the way in which the carers carried out their work and the high turnover of staff which in turn could be deeply unsettling for the patient. Some, too, felt it was hard to make a complaint.

Recommendations[1]:

Overall Recommendations:

Overall, further research appears to be needed to:

- Understand both the barriers and enablers to the implementation of integrated care from the perspective of different provider teams. This may involve the need for greater staff training.
- Explore and examine patients' and carers' understanding of 'integrated' care and how holistic provision might look and apply to them
- Understand more fully how information to changes in service provision should be disseminated to both patients and carers including those with learning disabilities, mental health issues and those with different cultural needs.
- Understand how information can be best communicated at all stages of a patient journey including signposting to support mechanisms in the third sector
- How and in what way patients and carers from different groups and communities can be best supported through patient journeys

It is also suggested that further work and exploration is needed into the following issues:

- A greater exploration and examination of the factors involved in the discharge process is needed so that readmission is less likely and so that patients feel supported
- More research is needed on the cohort of patients who have extended stays in hospital with a detailed exploration of the factors underlying this phenomena
- More research is needed to understand how members of different groups and communities wish to end their lives and how best this could be incorporated into health and social care provision
- Greater work is needed to explore the links that could be developed between voluntary sector and statutory sector provision so that medical crises are avoided and social isolation reduced
- More research is needed in understanding and exploring the factors that would prompt service users based at home to attend more activities and have greater involvement in the community
- More research is needed to explore the factors, including support, that may be needed for the elderly to stay at home rather than go to hospital
- A greater understanding is needed regarding the impact of financial burden upon the elderly, how this will be effected by changes in integrated care provision and how this might be alleviated
- A greater understanding is needed of the role of carers (both informal and formal), how they can be more fully supported, how communication and information giving can be improved and the factors that might enable more productive relationships between patients and carers

[1] On a number these issues, there are already studies that have been carried out both at a national and regional level

- Given it is a recurrent theme, exploration of the need for greater signposting across health and social care provision may be useful. The development of a pilot project creating a specific 'signposting' role, seeking the views of both patients and professionals as well as mapping present signposting services may prove a practical way forward

In addition, more specific recommendations are broken down by themes in the Appendix I.

Introduction

Healthwatch Hackney is set up to bring the views of patients, carers and the community to health and social care commissioners and providers. With limited resources and the need to demonstrate measurable impact Healthwatch Hackney's Board identified four priority areas on which to focus Healthwatch activity until April 2015. They were developed in response to local community feedback through surveys carried out in the first months of 2013, comments collected from local residents and on commissioning plans and planning timeframes.

One of the priorities set was Integrated Care. We set out to gather patient views and experiences on integrated care, patient centred care and how to improve services to ensure a more holistic approach. Within this overarching framework of 'integrated care' we additionally focused on specific areas of care as well as specific themes and issues as listed below.

This report is thus the result of the compilation and collation of evidence collected from a broad range of sources, as listed below, over a three year period. Its purpose is firstly to inform the thinking behind the development of integrated care and the transformation of health and social care services in Hackney. Secondly and, as importantly, it aims to ensure that the voice of patients and users is clearly heard and, as a result, listened to at both a planning and decision-making level.

At the same time, it is not and nor does it purport to be a blueprint either for the views of the groups or for a full analysis of the services and provision on which it focuses particularly given the range and nature of the sources, the mixture of methodologies, the lack of rigour and consistency in the samples and so on.

Instead, it provides an overall framework and reflects the broad parameters of views and experiences that are common across a range of settings and, significantly, across a range of communities, patient groups, service users and carers.

Indeed, paradoxically, the limitations of the evidence and thus of this report are also its strengths. Precisely because the evidence was gathered over a relatively long time period, a range of health settings and services and involves a spectrum of opinions of service users and carers, this report is able to provide an unique overview that has enabled key themes to be drawn out, highlighting gaps in knowledge and focusing upon areas where more rigorous research is needed. Of particular interest too is, of course, that the broad evidence base has meant that the report raises questions which may not have been raised otherwise.

It will also be noted that many of the issues raised pertain not simply to the theme under which they are categorized here but often will be pertinent to a number of areas of care. Further, many of the discussion points and areas of concern for patients will be relevant not simply to the central focus of integrated care but to provision more generally. Hence, this report should be seen as an essential read for all social and health care providers and not

simply those who will be designing and commissioning integrated care provision.

Finally, it is of interest that there has been and there remains an unquestionable enthusiasm and energy for service user and patient involvement. It is not simply that attendance that events is high in Hackney but, as the comments reveal, there is a genuine interest among local residents to provide the information, arguments and evidence for the commissioners and strategic planners to 'get it right'. It is the role of Healthwatch to continue to develop their processes so that this can continue to be harnessed appropriately and usefully.

Methodology

Sources[2]

The data in the following report is sourced from the following events and documents. These are detailed more fully in Appendix II.

- ***Integrated Care is Better Care – Convince the Patient Event***, April 2014, organized by City and Hackney Health and Social Care Forum and Healthwatch Hackney
- Healthwatch Hackney, ***Workshop commissioned to input into One Hackney Programme***, *April 2014*
- Healthwatch Hackney, **General Comment Collecting, 2011 – 2014**, took place at a range of community venues including the foyer of Homerton Hospital
- Older People's Reference Group Focus Group @@@@
- Healthwatch Hackney, ***Speak Up for Your Health Event***, Alevi Centre, March 2014
- Age UK East London Telephone survey - ***Patients' Experience of Hospital Discharge Process***, March 2014
- Connect Hackney Survey, ***Connect Hackney – City and Hackney Together***, Hackney CVS, 2014
- Healthwatch Hackney ***Speak Up about Homerton Hospital Event***, December 2013
- ***Annual Survey of Service Users and Carers***, Alzheimer's Society, 2014
- **Healthwatch Hackney Enter and View Visits:-** RNRU (the Regional Neurological Rehabilitation Unit) December 2012, Acorn Lodge Care Home February 2013, BeisPinchos Care Home February 2013, the Lamb Ward at Homerton Hospital March 2014, and the Tomas Audley Ward at Homerton Hospital March 2014
- The People's Platform, ***End of Life Care In North East London – Perspectives of Patients and Carers, Personal Narratives and Attitudes on Death, Dying, Care and Beyond***, The People's Platform, September 2010

[2] All sources and further information can be obtained by contacting Healthwatch Hackney. Telephone: 020 7923 8351; Email: liz@healthwatchhackney.co.uk

Process

The methods used to collect the data included surveys, focus groups, individual interviews, observation and community outreach.

This report has been compiled by pulling together the data from the aforementioned sources. It has been thematically analysed into categories to identify issues that might improve the delivery of integrated care.

The following report is divided into four Sections:

- **Section One** – Key Issues in Integrated Care

- **Section Two** – Key Areas of Care

  a) Patient Centred Care for the Frail and Elderly/Long Term Conditions/Complex Needs
  b) Patient Centred Care for the End of Life
  c) Preventative Healthcare
  d) Financial Support within Integrated Care
  e) Mental Health Care

- **Section Three** – Specific Themes
  - Communication
  - Continuity of Care
  - Sensitivity to Individual needs
  - Cultural Sensitivity

- **Section Four** – Carers

- **Section Five** - Appendix

In the report, the themes from the report are summarized and supported with selected pieces of evidence from the collected data. The rest of the data is categorized by theme with the rest of the evidence presented in the Appendix.

Statements in italics are direct quotes and comments from patients. Only selected quotations have been inserted into this report. For further information please contact Healthwatch Hackney directly – liz@healthwatchhackney.co.uk

It will be noted that there is some variation in the annotation of quotations. Where the quotations emanated, for example, from an event or an Enter and View visit, it is noted as

such. The remainder of the quotations is taken from the wealth of comments that are passed to Healthwatch Hackney on a weekly basis and it has often only been possible to mark the date. Healthwatch Hackney is presently re-evaluating how evidence and information is collected so that it is of even greater use to both the statutory and voluntary sector.

Section One – Key Issues in Integrated Care

Comments about health and social care services in Hackney gave a glimpse of what integrated care currently looks like in the borough and what patient centred care should involve. The *Integrated Care is Better E*vent provided a focus for discussion and comment on the development of more co-ordinated provision. Three comments perhaps summed it up at the *Integrated Care is Better Care* Event:

- *Workout a way to make sure everyone is cared for, listened to, get the outcomes they expected and lay out discrimination* (2014)
- *It is essential that the patient feels in control- to ask "what matters to you?" instead of "what is the matter with you?"* (2014)
- *I do tend to be 'told' what my care needs are and would like to be 'consulted' more about what I would like* (BeisPinchos care Home, February, 2013)

a) General Issues

Evident in many of the sources appeared a number of core underlying issues

- It was seen to be as important to understand the barriers to 'integrated care' as it was to work with the 'enabling factors'
- There was evidence of some confusion over definitions – for example, what is meant by the 'whole person' – and that 'defining' or labeling 'people' was not helpful
- Underlying all integrated care provisions should be an assumption that the patient is asked what they needed rather than what was wrong with them
- There was a concern for appropriate monitoring to take place, for public/patient involvement in the commissionning cycle, for the development of 'best practice' and for monitoring of both providers and outcomes
- Health professionals were not always perceived to know what social care is and that there was a general perception that the system remains predicated on a medical and not social model

b) Specific Issues

There were additionally a number of specific areas of discussion which arose across the board. [3]

➢ There were calls for greater partnership working in Integrated Care across sectors but also that:

- Involved users not just in the planning of services but equally in provision – for example, Care co-Ordinators should have regular conversation with 'their' patients:
  - *Make sure they have a user group and are pro-active in this.* (2013)
- Involved carers:
  - *Providing more training on understanding the needs of carers* (2012)
  - *Much better integrated planning with full input from patients and carers* (2013)
- Involved the voluntary and community sector which was seen to be under-utlised. However, that the voluntary sector was seen to be always 'chasing funding' was a particular difficulty for continuous and consistent Care Planning. On the other hand, there was also a perception that it was hard for individuals living on their own to become engaged with the community and community provision
  - *Voluntary sector must be part of integrated care picture (2014)*
  - *Biggest issue is where is the place for the voluntary and community services in that circle in Mark Scott's presentation (CCG,) that is the hugest omission that actually it's not there on the table* (Integrated Care is Better Care – Convince the Patient Event, 2014)

➢ Accountability was seen as being critical:

- *The council could delegate the ongoing management of the package. The council is best doing the assessments - but there needs to be sensitivity, and you need a named person. And for the ongoing supervision you need a named person* (2013)

➢ There needed to be care that is considered 'supportive' at all levels

- *The consultant and main doctors, listen and considers concerns. The walk-in is*

[3] A number of these are dealt with in greater depth later in the report

convenient. There are long waiting times at clinic, whole day, even when scheduled still must wait . The attitude of the staff is not supportive. There should be electronic recording information about tests and risk. Otherwise it is same questions each time. They need more staff because they are understaffed, overstretched, and need to focus on efficiency. (2014)

- *We want care, and all the implications of that word – not mollycoddling, but doing what the person receiving the care perceives that they need* (2012)
- *GP need to provide more time to listen to the concerns of the patients rather then ignore the conversation. They are too quick to prescribe medication then offer an alternative treatment or after care (2011)*
- (Patient went in for operation)…t*urns out they put her on blood thinners to avoid clotting even though she'd said she was a bleeder, delayed healing and caused swelling, pain was due to broken hip bone (very old fashioned, not the way they do it now, still not sure if it was broken deliberately or accidentally), epidural done improperly due to crumbly spine but should've been able to pick that up in MRI or some scan, didn't say anything about the healing or swelling, the specialist confirmed what she'd worked out for herself, and said she should've had counseling support and special care for fibromyalgia because of low success rate… this second better specialist was also at the Homerton* (2014)

- Sharing information across providers was generally supported although consent was an issue for those who did not want to share the knowledge of all their specific illnesses. Signposting and clear information was also seen as being essential

  - *The last time I saw my GP it was fine, just about medication. If something could be improved, it would be to have a clearer explanation about what's going on and what's going to happen in terms of care.* (2013)

- The lack of coordination and slow access to service provision were common concerns. There was also a view that 'faster diagnosis' would be ensured by 'integrated' care

  - *Faster appointment systems should be put in place, improvement of patient-centered caring system* (Alevi Survey,2014)
  - *Better feedback from GPs after tests and referrals to the hospitals like blood tests* (Alevi Survey, 2014)
  - *The daily ring fencing of appointments for urgent cases should be available for the people who can not get appointment in that particular day* (Alevi Survey, 2014)

- Equal access to all Health and Social Care Services was considered to be a central foundation stone. In general, 'equality' and 'equal access' was sent to be lacking but at the same time, it was thought that they were both essential prerequisites for full engagement with the system.

  A perceived lack of respect and consideration for the elderly could also be detected among patients' experiences.

- *Doctors neglect older patients as we have had problem with my dad. We noticed that shaking of his left hand and his walking was not so good, which we were told was due to old age. We took him to an appointment at Moorfields eye hospital for minor surgery on Friday 7 October, only to be told by the surgeon that he could not operate on my dad as he is showing signs of Parkinson's disease. We told the surgeon what we had been told by the GP and was shocked and now written to my dad's GP which why we are here today to sort everything out* (2011)
- *When I go to the GPs and I say that I'm not feeling well, they shouldn't take that for granted because I'm actually not feeling well. I had to go back twice to tell them I wasn't feeling well, so the second time they finally understood that I wasn't well* (2013)

On the other hand, for example, evidence from the Alevi Survey pointed to a view that there was optimism that, with the implementation of 'integrated care', there would be greater 'respect' awarded to BAME patients.

The Healthwatch Hackney, *Integrated Care is Better Care – Convince the Patient* Event earlier this year also raised the following issues:

- It was seen as very difficult for statutory sector to reach all groups and it may require a third party/alternative groups to do so
- A better way is needed to measure how well we were accessing people and how communities knew the nature and type of services that were available
- How and to what extent equality, outcomes and impact were related and what was the nature of that relationship
- It was questioned whether taking services into community organisations, schools and workplaces would improve access
- It was important to take into account language and terminology and in particular to ensure that services are consistent in the terminology they used

- Patients needed to be fully informed of medical decisions and want a choice in their medication options. This was especially true of Complementary Medicine

  - *I am over 60 years old and suffer from prostate related problems longer than eight years. GP prescribed same medication causing my stomach to bleed a couple of times. I told my doctor that the medication I am on was causing the bleeding in my stomach but they said they couldn't help me in this case and kept prescribing the same medication – I don't know what to do.* (Alevi Survey, 2014)
  - *We need alternatives. Will complementary medicine be a 'choice?' On the NHS, it is not, then I will take the matter to the high court under Act 8 of the HRA and the money it cost you would have been better spend in granting the option in the first place. Including that it works and will save the NHS billions*

in the long run, people will get better, live longer, and save the billions finding the drug companies and organized crime (Integrated Care is Better Care – Convince the Patient Event, 2014)

- (I) *have been to series of conferences set up two years ago* (and) *went to the arthritis care one… we were told then that it was the government wish that integrated care should include things that make you feel better not necessarily medicine things like that* (but) *things like complementary medicine, people are going to be assessed and have care packages the way that people who just need social care that seems to have disappeared. Government said people would get the choice.* (2014)
- *Some of the patients have complained about lack of alternative treatments, for example: a long physiotherapy hasn't worked, although it has been reported to the GP there is no any other solution suggested* (Alevi Survey, 2014)
- *Holistic health centre system based around finance especially* (to stop) *misdiagnosis of young black men. If they go into hospital, care to stop suffering and to ensure appropriate care when they are in hospital. To make a choice for themselves.* (Integrated Care Event, 2014)

c) One Hackney

At the Healthwatch Hackney *Workshop commissioned to input into the One Hackney Programme,* held in April 2014, were a number of discussions about a new model for integrated care which would be centred around provision for a group of 'frail and elderly' patients with complex health needs. At present it is expected that this would involve approximately 1771 people. The model of care would be developed around four quadrants located in the four geographical quarters of the borough with a Quadrant Manager, Co-Ordinator and an administrator.

The Coordinator will take on the role of overseeing the care that patients receive, reviewing what is working and what isn't and will be the single point of contact for patients and their families.

During discussions, participants had the following concerns:

- Whether the criteria would be broad enough to include all those that need this type of provision
- Whether one Co-Ordinator would be able to manage the workload particularly if all cases were to be reviewed monthly. It was also suggested that there could be two Co-ordinators, one for co-ordinating medical issues and one for co-ordinating voluntary sector services
- Whether the role of the Co-Ordinator would prevent patients having to repeat their stories unnecessarily
- Whether the family/carers will have an opportunity to be involved in case meetings and have a say in plans/support options

- Whether the IT systems will be robust enough to provide good communication, co-ordination and sharing of information
- Whether there would be appropriate levels of support at discharge *(see below)* including an assessment of social and emotional needs. Some drew attention to evidence that showed that support can focus on 'personal care' at the expense of other outcomes. It was suggested that there could be a voluntary sector co-ordinator to support them as well as a leaflet informing patients of the support they might be able to expect with appropriate contact details
- Whether families/carers would be able to access the appropriate level of social and emotional support with financial consideration being taken into account at all times
- Whether there would be a free telephone number with a call back option for those using mobile phones that would give access to support 24/7. Whoever answers the phone should have immediate access to the care plan on 'Co-ordinate my Care.' Alternatively, if there is only a skeleton service at weekends and holidays and the coordinator is dealing with a case, calls should get passed through to the GP 'Out of Hours' service
- Whether staff would receive extra training and whether there would be enough flexibility as well co-ordination in the system to prevent, for example, patients from being 'passed around the system' and to ensure that there would also be enough flexibility in the criteria for certain services such as re-ablement
- Whether, as some suggested, it would be possible for patients to be involved in the training of Quadrant Co-Ordinators and Administrators
- Whether there would be regular evaluation of the model and how it is working

Section Two – Key Areas of Care

a) Patient Centered Care for the Frail and Elderly/ Long Term Conditions/ Complex Needs

The elderly were a particularly vulnerable patient group as they may be dealing with long term, chronic conditions along with various age-related co-morbidities. Frequently, this group had complex conditions requiring them to move from one care setting to another which may involve the use of many different services across health and social care. An integral component of successful healthcare for the elderly and to reduce hospital readmissions would be to enable the joining-up of all services, continuity of care and additionally effective hospital discharge.

Evident from the data available were a number of key issues. Firstly, many thought that staff should be educated on the needs and conditions of elderly patients, especially those with complex needs.

- *Understanding the complexity of older people's needs should be addressed* (2013)
- *Service users felt its very lonely* (Lamb Ward Enter and View, 2014)
- *Any elderly or vulnerable person who has no family or friend to help them should be assigned/offered an advocate when they go into hospital. This should be done as standard. It could be a volunteer role* (2014)

Secondly, a recent OPRG [Older People's Reference Group] focus group on Intregrated Care on the 3rd April 2014 asked participants who were over 75 and had complex needs to name those who they believed 'looked after' older people presently. It was notable that in their view the most common situation was where elderly people were looked after by those outside 'official' care. Participants' responses were, in order:

- Relatives, friends, neighbors (unpaid carers)
- Charities such as hospices, Macmillan, respite care, befrienders
- Social workers, home carers, paid support workers, mental health support workers
- Floating support workers such as housing, social landlords, wardens and staff of supported housing
- Community police and ambulance services
- Community/district nurses, GPs for medication and hospital referrals
- Day centres, computer cars and community transport

Interestingly, too, it was pointed out that there were other patients' who did not appear

to be part of the 'integrated care' vision but also very much needed the support it potentially could offer.

- *There are lots of people with long term health problems who don't need to go in and out for hospital all the time because integrated care isn't interested in this group of people and they are only interested very frail people - what actually happens to all those people who do have all those problems who are managing somehow but as time goes on they would need the support* (2014)

It was noted, too, in many sources that this cohort of patients had various barriers to accessing health and social care services and often may need the help of an advocate and other special accommodations.

- *People wait too long for the test and there are no seats available in the waiting people. People have to wait standing up. It is very difficult for someone who has heart problems and diabetes* (Alevi Survey, 2014)

An important part of integrated care would be the joining up services so such patients could remain 'healthy' and this might involve services that ranged from support groups, mental health provision, housing provision to simply making it easier for these patients to get simple treatments such as a blood test. Further, social isolation had to be overcome on a day-to-day basis which often hindered access to services.

Care Plans

It was evident that experience of Care Plans varied enormously and a good number clearly had no knowledge of any individual package of care.

- *I am not aware of any healthcare package. I find the staff kind and obliging. I still attend the GP where I was registered prior to admittance here and I am awaiting confirmation about an appointment with a dentist* (BeisPinchos Care Home, February, 2013)
- *I don't know about a care plan. I think some staff are very helpful and handle residents well. The doctor has visited recently* (BeisPinchos Care Home, February, 2013)
- *My son visits regularly, he is a pharmacist, and my daughter does my laundry. They bring me 'treats'. I don't know about any discussion regarding my care* (BeisPinchos Care Home, February, 2013)

Others felt that they were involved and the following quotation was very much echoed by residents in the Acorn Lodge Care Home visited in 2013:

- *Yes, I am – although I would like to be a bit more involved. I do have a meeting with staff to talk about my care about once every three to six months. I would like to be a bit more involved though. At the moment I am a resident of the care home – but there are sheltered houses here and one day I would like to progress on to a more independent living situation, but with my carer coming with me to give me the care I need* (BeisPinchos Care Home, February, 2013)
- *They are very caring in getting relatives involved and keeping us informed. Whenever they need to do anything with my* (XXX)*, they will ask me. Then they will say what is going to happen, and make sure I am au fait with it. Yes it's all planned out, she is in palliative care now* (Acorn Lodge Care Home, February 2013)

Both elderly patients and carers additionally wanted to be involved in the drawing up of Care Plans and many wanted the family to be involved as well but opinion varied as to the level and balance of involvement between service users and their families. Some argued, too, that community advocates additionally should be involved where relevant.

- *I am not really consulted on care planning as such, but it is my wife who is ill and I do a lot of the caring for her as best I can. I find at meal times I spend a lot of my time feeding her, so my own food goes cold and I don't get chance to eat properly. It would be good if a staff member could help me feed her so that I can eat* (BeisPinchos Care Home, February, 2013)
- *I don't know if my family are involved in my care planning. I wish they were. I feel bad about being in a care home because of cost. My family visit only very occasionally. No I don't attend the therapists' sessions* (BeisPinchos Care Home, February, 2013)

It was apparent that patients wanted their care package to take into account emotions, mental health, dignity, self-respect, values, interests, hobbies, "likes and dislikes," physical abilities and disabilities including those unseen such as hearing, eyesight and incontinence.

Overwhelmingly and across many settings, carers and patients voiced the need for Care Plans to be in place that would track the patient journey and cover periods of hospitalizations, hospital discharge and care at home thus creating greater continuity of care. In particular, patients needed to know who to contact when their Care Plan is not working or if a problem or crisis arises.

The OPRG focus group suggested four essential items that should be included in the development of any new format for Care Plans, as follows:

- A single point of contact,
- Up to date list of medication,
- List of key workers, treatments and people that will be coming into their home
- Regular reviews of their Care Plan.

Discharge needed to be 'smooth' for this group of patients. It was suggested by one source that it might be possible to have somebody working in the discharge process in the hospital in that could actually pull it all together and be the voice that says, "Hang on, before you discharge this person there is a few things we need to put in place." Some suggested that the role of the Care Co-Ordinator (see above) could encompass this to ensure that any discharge plan was realistic.

Discharge from hospital also needed to be supported by an assessment of social and emotional needs with a holistic approach rather than just medical. It might also, it was thought, be useful if patients and families could receive a leaflet telling them what they could expect both in hospital and when being discharged and who they could contact for help.

- *Pharmacy dispensers, transport and social work teams need to be fully integrated for safe hospital discharge*
- *There is a lack of communication between the nursing staff who is discharging patients and the transport services who arrange the vehicle appointments. Patients often have to sit through hours of waiting time between their releases and when the vehicle arrives. This becomes especially problematic when these hours overlap during meal times, leaving patients to go hungry*
- *One area where integrated care could work is when somebody is discharged from hospital. You could have a situation based on personal family where somebody has been in hospital and they have had for example a kidney or urine infection and there is a cause for that, that needs to be unpicked… they're discharged from hospital but not necessarily the way where all the mechanisms that need to support them at home are set up, for example they could be discharged where GP wasn't informed or contacted so it wasn't very clear what was going to happen about their issues. There was no planned bathing service and this is somebody that needs a bathing service, which is kind of linked to the current urinary kidney issues as well so they were discharged without that input in place, without any assessments. Therefore, they were discharged so could be weeks when they're back in hospital very quickly* (2014)
- *There needs to be a 24 hour phone line when discharged- you need a family or community advocate too* (2014)
- *There is also a lack of communication for necessary accommodation in outpatient homes. Patients are discharged without hospital staff thoroughly going over the necessary lifestyle changes*
- *Discharge service is not a good service; they should be ready for when the patient comes out of hospital, they wait until they come out* (2013)

And patients reported a number of worrying experiences

- *He had a recent operation only a day ago as a follow up from a surgery he had four months ago. He was wheeling himself around very slowly; he obviously had not recovered yet. He had just returned from outside in his wheelchair shivering with a light blanket around him and hospital clothing. He commented that "discharge takes forever", his previous discharge was delayed by a full day because they didn't have an ambulance for him despite having told him there would be one for him. Additionally he commented that "They let me go without talking to me, I wasn't prepared at all. I couldn't live in my home comfortably because they hadn't made the changes they said they would. I had even paid for the services too but no one ever came. They never talked to me about how to take care of myself or how to adjust my living." The pharmacist was also not notified of his prescription in time to pick up his medication prior to leaving the hospital so he was without medication for a day. He said that "the day before is not enough time to discharge me" and suggested that all discharge arrangements should be made days before hand to leave time for adjustments. His recent operation was not due to poor post-op care, he did have medical check-ups after the original surgery but he had to take the initiative to set up his discharge care. He also added that "Ward wise things are good, I mean some specialist don't show up on time or at all but I understand that they're busy.*" (2013)
- *There was no care plan when discharged* (2014)
- *Care plan in place but carers don't actually follow it e.g. food he likes because he can't speak* (2014)
- *He doesn't get much information from staff, he doesn't know which care home he's going to or when he's going; Doesn't know if they're preparing him for discharge. I understand what's happening, though I don't know the names of the tablets but I don't need to know* (Lamb Ward, Homerton Hospital, March 2014)
- *I don't mean to make a fuss, but I have to answer as honestly as I can. Following a stroke no assessment was done by The Royal London social worker, as I was informed that, as I lived in Hackney, they would refer my discharge assessment to the social worker at the Homerton Hospital, who is employed by the London Borough of Hackney. I was given no assessment by the Homerton as they felt, that the Medical staff at the Royal London knew what was good for me. I contacted the Homerton and spoke directly to a woman social worker, who should have completed a home assessment prior to my being discharged. Here again she felt that the Royal London knew best and that my problems couldn't have been so acute, that they would allow me to be discharged. This social worker informed me that due to the amount of work and the few people available, they would do an assessment two weeks after I had been discharged. Neither Social Services departments were aware of the difficulties I faced going home to an empty flat alone, having had a stroke, which left me paralysed down my left side with limited mobility. This was all compounded by being a partially sighted person….I do appreciate there is a finite amount of services, both within the NHS and Local Authorities, but to leave vulnerable isolated patients with no support or care is inhumane to say the least* (RNRU, December 2012)
- *I've been hospitalised five times with the shakes or fainted, four times in the Homerton. Last time I went in an ambulance after I passed out at Bingo. I fainted and nobody noticed, but my carer noticed. I went on my own in the ambulance. I*

> *went into casualty and then the doctor said I could go home. But then the discharging doctor said I could not go home until I had seen a psychotherapist. I had to wait overnight for this until 10 o'clock the next day. (2013)*

Many suggested that discharge should be late rather than early and that staffing in hospitals needed to be increased at weekends so that the process is not impeded in any way.

Having left hospital, the elderly needed to feel safe in their homes and needed to be able to access appropriate support. For example, elderly patients, who might already be confused, should not be discharged back home in the middle of the night without support. It was suggested that a home monitor could be provided for those people but that the underlying purpose should be about care rather than merely a job and should be monitored to ensure that the care is being provided effectively. The need to address emotional needs, particularly at high risk times (nights, weekends, holidays) was also stressed.

Factors in hospital readmission

From the comments collected, it seems as though many patients were readmitted to the hospital or other clinical centres because they go in for one condition and the other conditions or illnesses were not addressed. The patient then has to go back to hospital later for a complication for a different condition that was not addressed at the previous hospital visit.

There was an unquestionable call for service providers of health and social care services not simply to look at patients holistically and identify those patients that were in need but to acknowledge the possible communication barriers that can prevent patients from voicing their concerns and needs or other issues with their co-morbidities particularly if they had multiple conditions. Helping patients holistically before their conditions worsen might thus reduce the rate of hospital readmission.

Age UK conducted a telephone survey in 2014 targeting elderly patients at local Hackney GP practices. It appeared from the evidence that elderly patients were more likely to be readmitted to the hospital because of their vulnerability both in terms of health and in terms of their confidence in using the hospital services. Other factors might be access to the GP, GP opening hours, issues in communicating with their GP, a health emergency and lack of knowledge of out-of-hours provision. Further, it may also be important for patients to understand their own health so that they know the warning signs of when they should seek help from the GP and when they should attend A&E.

In the survey, over half of the 57 respondents said they did not consult a medical professional before admission and almost all felt that nothing more could have been doing to avoid them going to the hospital. Indeed, all 57 reported they believed that hospital

was the best place for them and only 13 reported that they would have preferred to have been treated at home. The remainder of the sample argued that they preferred to be in hospital as they were not able to care for themselves at home, they needed special equipment (such as X-rays, blood transfusions CT scans, wheelchairs etc) and nurses. One respondent said that she lived in a second floor flat and, being immobile, was happy to have a change of environment at the hospital. Generally, though, many patients did not feel as if they had another choice.

- *Hospital was the only option and there was no opportunity to phone the doctor. It was a Friday evening. She was aware of the side effects of the chemotherapy, but her husband was disabled at the time and so put caring for her husband over caring for herself. She did phone her GP, and spoke to the receptionist telling them she couldn't cope. The receptionist was very sympathetic but didn't offer her any help. She herself blanked their situation out. So yes perhaps hospital could have been avoided.* (Age UK Telephone survey - *Patients' Experience of Hospital Discharge Process*, March 2014)

Patients that stay in the hospital for extended period of time

There is small set of patients that go to the hospital and end up staying for a long time. However, there is little evidence on this and more research is needed.

It is suggested, however, that patients feel safer in the hospital than they do at home while they are unwell and some patients may feel they have no other option. Certainly the Age UK Survey noted above found that hospital was a preferred choice. In addition, patients may not have adequate care plans to release them from the hospital. A care plan could help them be independent even if they are unwell.

Emergency Care

Emergency care was seen overall to be an important part of the integrated care process. When a patient came into A&E, especially older patients and those with multiple and/or complex needs, they were often readmitted to the hospital. Continuity of care was perceived to begin at the emergency care stage. Again, patients needed effective communication throughout the process, thorough information on their condition and again there and proper hospital discharge with a care plan to stay healthy.

It was additionally felt that there was still room for improvement in terms of the communication and information given to this cohort of patients in terms of what services are available and how to access them. GPs were seen to have a critical role in this but paramedics could also play a role in provision of information. Some suggested they should carry telephones.

Nonetheless there was an acknowledgement that there were pressures from national targets.

Transport

Difficulties with patient transport were a recurrent theme in the evidence. The Age UK survey noted above reported that 63% of respondents called an ambulance to get to the hospital while the remainder used minicabs, taxis, hospital transport or relatives.

The majority of complaints centred upon reliability:

- *Dial-a-ride and taxi ride provide an inadequate service they either deliver people too late or too early – this happens so often especially when we have our exercise classes. People arrival very early or very late to go to class and then we have the same problem when class ends* (2011)
- *I have spoken to on the drivers as to why they have this practice of bringing a mini bus to collect one person. I was told that all are administered from a call center in Aberdeen. So they don't know local places and send out the wrong type of vehicle* (2011)
- *I had an appointment on the 1st July for 10am at the Homerton. The transport came at 10 to 10 and we didn't get there till 10.30-11. I didn't know if I would be seen. I was seen, but not until 12.30* (2013)
- *Wheelchair users have no back up to pick you up, nobody seems to care, we couldn't get on black cab, we need a back up service* (2013)
- *I'm disabled and need to travel to another borough for treatment but don't feel confident of transport outside the borough. Hospital transport not provided so have to take a cab*

Other service users reported inefficiencies and examples of miscommunication:

- *I was not successful in getting a car booked, I came in for injections and rang sometime ago to book transport but the computers were down so I rang back later in the day. They still couldn't book the car so I called a few days later but couldn't get through. Then Friday I booked a taxi, then could not go home because I had been given an anaesthetic and needed someone to accompany me. At UCL you can book transport 6 to 7 months ahead. Now I can't get a taxi because they won't let me go home without someone with me. Last visit, they told me I could not have a person in the ambulance with me*
- *There needs to be more co-ordination between people looking after us. More specific coordination. Waiting for transport takes too long*
- *There were all these miscommunications with the hospital and the transport service, they said that since I wasn't 70 I didn't qualify for transport which is ridiculous because I'm in a wheelchair – I've been using the transport service for years now. They know me here, the boys at the transport desk they spoke up for me and said that I've been using the ambulances for years of course I'd needed it now. I ended up waiting for a good five hours before my daughter called into the hospital and squared it all*

away

Entwined with these reports, also appeared to be incidents of simply unpleasant experiences.

- *My neighbour went to the opticians in Kingsland Shopping Centre. They put drops in her eyes. She is 81 and was alone. Nobody called to ask if someone could pick her up, or offered to get her a taxi. Because of the sunlight, she was unable to see and had great difficulty and discomfort in getting home* (2011)
- *Today I had transport from St Leonard's. The driver acted badly and then said "You can report me if you like"* (2013)
- *With hospital transport for medical services the drivers turn up late, it makes us late for appointments. Once the driver went off without collecting me. Another time, they came to the Homerton and went to outpatients, and the driver was nasty and took the appointment letter out of my hand so quickly that it tore in my hand* (2013)

b) Patient Centered Care for the End of Life

Evident in the 2010 People's Platform, End of Life Care Report, were two key themes. Firstly, patients wanted to be able to choose their end of life care and how it would be carried out but, secondly, at the same time they wanted to be able to make an informed choice. Patients called for full information about their options so that they had all the information needed to make choices for themselves. Further, they needed to be able to access that information possibly through links with social services. It was pointed out that access included overcoming language or cultural barriers. Those attending the *Integrated Care is Better Care – Convince the Patient* Event, also drew attention to the following issues that should be considered in developing more patient-centred end of life care.

- Patient wishes at all times should be respected
- It was important to hold conversations with patients at an early stage to record what people wanted and then make sure that it happens. GPs might even approach the issue at retirement age, suggesting a 'life plan' to include making a will and Lasting Power of Attorney
- GP care plans tended to be very much based on a 'medical model' but should take into account the social, emotional, faith and cultural needs of the patient
- Social isolation and the need for adequate information

Nonetheless, Healthwatch evidence is relatively scanty in this area. There is information from an Enter and View, carried out at BiesPinchos on Orthodox Jewish end of life care for example but for the other minority groups in Hackney there is little information on their preferences and what support they might need for end of life care. The views of these communities need to be explored in more details so that effective systems can be put in place.

Finally it should be noted that patient experiences of end of life care were sometimes extremely positive

- *If you are in hospital you think that if you are seen as the awkward patient you will get targeted by nurses. Especially if you are at the end of your life, you need your dignity* (2013)
- *Care was brilliant* (St Joseph's Hospice ' (Integrated Care is Better Care – Convince the Patient Event, 2014)
- *St. Joseph's team were so good when she was being cared for in bed. The Macmillan nurse arranged for a Marie Curie nurse to be with her friend every night to give the family/friends a rest –if necessary. Also as soon as her friend was referred to St. Joseph's team,-district nurses and a Macmillan nurse had regular contact with her –ringing regularly to see if she needed any support. The GP was also 'extremely supportive' – professionally ,emotionally and practically* (Integrated Care is Better Care – Convince the Patient Event, 2014)

c) Preventative Healthcare

Prevention should, it was thought by many, be at the forefront of integrated care. An emphasis on preventative care will save the NHS money and allow service users to have empowerment over their choice to be healthy. Critically, it is also important for reducing admissions to hospital for elderly patients. Many patients emphasized the need for preventative services that included the social and economic determinants of health, such as housing, jobs, role of the family, exercise and access to those services and facilities. In particular, GPs were seen to be the starting point.

- *There is too much neglect amongst families, not enough emotional aspiration support within the family* (2013)
- *GPs want to see us not more than 10 minutes which is inadequate. Most of them won't be dealing more than one health problem during each appointment and consequently it poses difficulty in terms of getting another appointment as it is time consuming and also makes out health problem to become chronic and prevents from an early intervention* (Alevi Survey, 2014)

The following are examples of patients' concerns of implementing preventative health care into health and social care services.

- *If money is invested in prevention you save money and that is absolute key for it to be a holistic approach to definitely include those services that allow people to feel they can carry on within independent lives with dignity…and actually financial support*

needs to go in to making sure organisations continue what they are doing in order to support them. (2014)

- *Where we are able to, we should also take responsibilities for our own health and wellbeing and that means we need to exercise - we need to just be aware of our bodies, keep weight steady, where possible need to take responsibility… we can't always rely on other people for our health and wellbeing as adults..if we are able to do it we need to be able to look after ourselves much better* (2014)

One of the key social determinants in prevention was seen to be housing and many participants stated they wanted better health care links with Housing Associations. In particular, it was felt that older patients and those with multiple and complex needs should have adequate housing that was both accessible and safe.

- *The thing about OTs is that they don't link up with the Housing Associations* (2012)
- *There is an urgent need for a larger number of supported housing projects.* (2013)
- *Lack of liaison between Mental Health Service and Housing Benefits Service* (2013)

However, for some, their experience with their Housing Association had been positive:

- *If I needed one, my social support at my housing association would give me advice. The social support is very good, they help with things like making appointments and phone calls because of my stutter. I have not used the hospital* (2012)
- *I need more space – I want to move out away from my mother, but whatever happens I need help to move out. The OTs will support my application, but I want it to go smoothly. I am scared* (2013)

Perhaps as if not more important was social isolation which could either cause or make health problems more difficult. It was evident that many elderly residents in Hackney do participate in volunteer activities, both faith based activities and organized group activities. 56.2% of respondents (600) from a Connect Hackney Survey said they attended group activities at least once a week and 36.6% of respondents attended a faith based activity once a week. However, well over a half said they either never, hardly ever or only sometimes felt happy with their social lives. The majority also stated they would like to attend more group activities and would like to get out more.

- *In terms of the role of the voluntary sector there is actually a lot of evidence of preventative services provided by the voluntary sector e.g. exercise, balance classes actually cost-wise saves money. The voluntary and community sector needs to be integral to any plans* (2014)

Relevantly, too, a fifth reported they lived alone and nearly 60% said they either often or sometimes lacked companionships. Of particular note was the level of social isolation and disconnection from their communities with under a third (28%) who felt they were part of

their neighbourhoods.

When the survey asked what prevented older people from participating in the local community, the largest responses were transportation, limited mobility, costs, not knowing what services are available and not feeling safe after dark. When the same respondents were asked to identify services that would help older people to be more socially connected most listed befrienders visiting people in their homes, classes and learning activities, lunch clubs, day trips, social outings and exercise classes.

Finally, while 48.1% of respondents were concerned about a health need, it was changes such as feeling safer at home and outside, having more fun, more day trips and outings, and feeling less lonely that were perceived to be the most positive for them.

d) Financial Support

Patients voiced a concern over the little amount of financial support they get with integrated care service provision. There was evidence that when services are joined up, financial pressure can be put on patients of which hospitals or health and social care services may be unaware. For integrated care to be successful, the services had to be used and if they were too costly, the patients will not utilize them.

- *With integrated care there is a big chunk that has been missed out that is financial support – anybody with long term conditions are entitled to some sort of benefits and that is something the GPs don't recognize… most of the services don't know anything especially social services to sign post people to benefits they are entitled to…I think that needs to be bought in because that is really important. I have got a long-term condition that doesn't mean I have to go to a hospital or anything like that but I need a lot of support to be able to manage my conditions.* I *went to the arthritis care seminar two years ago when they were talking about this and that is one of the most important things to put in place. What about your home circumstances? How are you managing with your money? What sort of support do you need? That is really important. That needs to be recognised in this whole bundle* (2014)
- *Our GP referred my wife to a private specialist practice (the reason is it is very costly for NHS) for her neck pain due to discs touching each other because of the wear off soft pads between them. We were told to pay £50 for each visit and we can't afford it. We expect to be referred to the NHS specialist to be looked after not a private practice* (2014)

Following discharge, it was seen important for patients to be able to link up with a range of services, both statutory and non-statutory to provide on-going support and to help people manage their own care.

- *Care support groups no longer funded because it isn't ring-fenced* (2014)
- *Care Breaks have been stopped* (2014)
- *Financial support to manage condition e.g. home situation, finances* (2014)
- *Getting written form to apply for support is difficult* (2014)
- *There are other systems now coming into place where it would be a credit system and not a debit system (2014)*

Whereas, some argued that local benefits' offices should be involved and GPs should refer to them, others thought the local authority might or should fund or provide some support, possibly a few hours a week or pay for people themselves.

And when it came to Personal Budgets, some patients were simply confused:

- *I have Direct Payments through a third party. My brain can't cope with a Personal Budget. I am on Direct Payments. I don't have a Personal Budget. I have been on Direct Payments for so long that I have got used to it. The monitoring is now not onerous, but I wouldn't want more hands on responsibility. I have just read the latest training pack on Personal Budgets, and it says "if you are worried about any of this, contact your Direct Payments advisor" – well who is that? I was looking to get a Personal Budget. But the way she* [social worker] *spoke about it – and the small amount they would give me – I wouldn't be able to manage it. She was so off-putting. I thought that I would have a lot of work to do for a small amount of money, and that I wouldn't have enough money to cope with doing it. I don't think I can go on to a Personal Budget, because I don't qualify for enough care. When I tried to have this, when I needed help with shopping, because I couldn't carry things – that is what they told me* (2012)
- *What happens if you are on a Personal Budget? How do you get on to Personal Budgets? I read everything they send me – if there is a Personal Budget Department, why I don't know the name of it, or anyone who works there? I last had an assessment a year ago or more. They didn't talk about Personal Budgets. I think they sent me a leaflet but I put it in the bin. For Personal Budgets I think you need to publicise a contact name and department, the method of transfer and I think they need to sell the benefits. I'm confused about this – does it still exist?* (2012)
- *I have got to have my other hip replaced and I am dreading it. Last time I spent a lot of money going into the care home. This time I will spend that money buying in my own private homecare – I will probably get quite a lot more for it than using the homecare system. I have just got a new wheel chair – it cost me £5000, which I borrowed. It will only last 4 years, and I may not have finished off paying for this one, before I need another one. The Council give you what they give the agency – a flat rate of £11 per hour. When the council buys the care from the agency they are not charged VAT. If an individual or co-op buys the same care from the agency they have to pay VAT at 20%. So if I pay my care worker the London Living Wage £8.70 an hour, I am left with only £2.30 for employer's liability, payroll services,*

sick leave, holiday. It can't be done. Accepted the lowest price for overnight sleep in care is £37.50. I only get funded at £35. I am worrying why I have not got enough. It's because of the increase in prices have eaten into the funding for on-costs. If I have to use an agency for holiday cover it costs me more than the hourly rate I am given. Holiday cover is funded at £11 per hour, and the agency charges £14 per hour. So the on costs have gone before I've even thought about it. I am interviewing someone at the moment who wants to bring her baby with her. I am considering taking her, because I will be able to pay her the minimum wage, because she will need to take a lot of breaks. Because I get higher rate DLA – for 1 hour a day homecare 7 days a week they want to take the whole of my allocated budget for the week of £50. With us at home it is extremely difficult to get good care-workers, because the hourly rate is not that high. And we have to keep money aside for holidays, payroll. If you don't have the money to pay, you can't get good people. I think the care-workers get £6 when they are new, and some get £7. One person charged me £70 a night emergency respite. They did nothing – just came over to sleep. When I spoke to other social workers they thought it was too much.

e) Mental Health Care

The importance of how mental health provision is integrated with other services was, for many, of key importance. Ideally, integrated provision would enable greater continuity of care and thus create more holistic health provision especially for older patients with complex conditions, chronic illness, or nearing the end of life. It was seen to be of particular importance since according to the 2012/2013 JSNA, 17% of the 2,825 older people receiving Hackney Council social care packages also had mental health difficulties with a high incidence of both dementia and depression.

Participants at the *Integrated Care is Better Care – Convince the Patient* Event highlighted a number of issues that in their view should be considered in the development of any package:

- More training for consultants and healthcare staff
- Collaboration between users and professionals in developing the service
- Inclusion of the voluntary and community sector
- Rapid intervention in A&E to provide effective interventions once admitted
- Consideration of the impact that a 'fall' can have on the progression of Alzheimer's and the of subsequent repeated visits to hospital
- The use of Advanced Directives

Those with mental health issues wanted the mental health services to empower them as individuals and to be tailored to their specific needs. On the one hand service users wanted their mental health care to be integrated with other health and social care services but at the same time, each person was seen to have unique needs which should be reflected in their mental health care. GPs should also, it was thought, listen to the people who care for mental

health service users on a day to day basis.

Presently, it was argued by some, that there is little co-ordination between services:

- *There needs to be better liaison between all services in relation to mental health* (2013)
- *There is a lack of liaison between Mental Health Service and Housing Benefits Service* (2013)

In particular, mental health needs were often seen not only to be neglected but also misunderstood

- *Health and well being should be culturally sensitive and be tailored to an individual's holistic needs. Physical health is sometimes completely neglected at the expense of mental health (*2013)
- *Do GPs really think of their patients' well being and is there any compassion? GPs need to understand the social aspects of mental health as this is crucial to one's general well being* (2013)
- *Homerton nursing staff in the ward I was in, didn't seem to understand how to care for someone with Alzheimer's* (2013)

There were reports, too, that there was also a lack of understanding of mental health issues.

- *Sometimes there aren't enough people to support people with mental health needs such as adequate advocacy provisions* (2013)
- *Last week I was an impatient in UCLH – it was diabolical. They don't think it's necessary for medics to inform people, they just give them medicines. I had to complain, because they don't give feedback. Because I live alone, I don't get any help with all of this. As a result I had to call them a lot. Then they called me and I have had to sign a contract to say not to ring them. I have also been banned from calling my GP. I have also been barred from MIND, and so I cannot access the Advocacy for All project. I have tried to have all these organisations help me, but the stress of it overwhelms me. Last week I ended up in the psychiatric ward following an event like this. It wasn't at the Homerton, it was another Trust because I am over 65. There are so many things that have gone wrong over the years. The only people who have helped me are CHOICE in Hackney and the Director of Medicine at the Homerton* (2013)
- *I have a history of mental health illness. I was having trouble with my medication, my GP tried to help. He changed my medication, but this triggered a psychotic episode, and I was hospitalized.. It happened very quickly, within a few days. I am only just recovering from it now nine months later. My GP was very apologetic. I know he was doing his best, and I have discussed it with him. If I could make a recommendation it would be that GPs should not be able to change medication for mental health issues without referring to a psychiatrist* (2013)
- *Mental health wards are not therapeutic environments or conducive to recovery, the wards only 'contain' people* (2013)

- *Mental health wards should promote recovery and rest, and not just contain.* (2013)
- *It's reducing people to consultants' expectations – they don't care about you, they just care that they look like they are doing their job* (2013)
- *Staff on wards they misunderstand the culture. If you do not complain, then you get deeper into the situation .The best idea is to negotiate the base in which you are in the situation. During crises you might need a lot of drugs but it should not be for life*

It could be particularly traumatic for the family and this was noted by those at Acorn Lodge and by those who had contact with the Alzheimer's Society.

- *It's difficult because there is so little out there about dementia, and what there is, is so frightening. The family has just heard the word, then their family member comes on the ward. There is no support for early stages, it's all moderate to advanced. So they are completely overwhelmed and scared. They feel like they are abandoning their family member* (Acorn Lodge Care Home, 2013)
- *Sometimes we have a situation where a family is on its knees caring for a family member with dementia. We had a case where they came here and said "take her now", they didn't even want to come and view here first. Then later the son felt bad he had "dumped" his mother here. But in fact his mother fitted in well, she was feeding other residents, pushing the trolley around. We said "take what you are feeling out of this, and just sit and watch her for 15 minutes". He did this, and then agreed that she fitted in well here* (Acorn Lodge Care Home, 2013)
- *Sometimes we say to family members – come and sit in on the training. Afterwards they will say that there are things their family member does that they did not realise was a symptom of their dementia. There are some things that families find very difficult, like the decreasing functionality – not being able to do the sequence of dressing. We don't stop residents from their way of dressing, we try to help the families understand that they see things differently now. So when families say "but she looks like a clown", we say "that's your perception, to her she looks beautiful"* (Acorn Lodge Care Home, 2013)
- *As the carer of someone with dementia it is good to have someone who can advise that certain 'stages' of dementia are normal, and how to deal with it. Our contact has a wonderful sense of humour and helps me see that all is not lost* (Annual Survey of Service Users and Carers, Alzheimer's Society, 2014)
- *You could understand that some carers have full time jobs, don't live with the dementia sufferer and having chosen not to have children are in no way prepared for what everyone now feels is their duty of care*(Annual Survey of Service Users and Carers, Alzheimer's Society, 2014)
- *What about support groups for people who work? Where is the help with the dealing with the resentment & guilt? Why do you assume that someone can simply put their life 'on hold' with no support?* (Annual Survey of Service Users and Carers, Alzheimer's Society, 2014)

Unquestionably there were those who felt that more support and advice in the early stages would have been useful:

- *Poor early support, long waiting time to be seen and very poor support over the phone at this time when I really needed help. I blame most of my stress on the time I had to wait from 13 the of January to 13th of May* (Annual Survey of Service Users and Carers, Alzheimer's Society, 2014)
- *It's good to talk about other things that can help too – like speaking to people, exercise, eating well – which can lead to recovery*

Healthwatch Hackney have also discovered serious worries about how medication is handled

- *The medication in which I was given was forced. I did not know how I felt about it. They said I had to take medication. It is clear it was a form of punishment for my wrong doing.*
- *Took me into hospital feed me trial drugs. They should send professionals who are full of sympathy, rather than medication. It's a one way conversation*
- *People with Mental Health needs should have the opportunity to go somewhere independent where they can express their concerns/views on e.g. the nature of medication they are receiving* (2013)
- *I have side effects – weight, shaking, sexual drive, dribbling* (2013)
- *Staff never watched patients taking their medication. People would sometime save their medication to sell or take it all at once. I did write to PALS but I did not receive any response to my complaint* (2013)
- *I don't feel empowered enough with the consultant to say "I don't want this" or "Can I try a different medication" or "Can we work together on this"* (2013)
- *I felt forced to take the medication – have to take it or be taken to hospital as punishment* (2013)
- *It's impossible to change the medication, impossible to say this is the wrong one* (2013)
- *People should have an opportunity to an independent counsellor [when medication is prescribed*
- *Consultants' emphasis is on the medical side,, it should be about healing people*
- *Why can't doctors try the drugs that we have to take, just to see what it feels like? When I was diagnosed with schizophrenia – I thought they thought I was a sicko – just a name tag. You are not born taking medication. If you say you are sick then you are sick*
- *Why can't they once a year try what they are giving us? For one week – just to see what the patients are going through?*
- *If you feel like a doctor is listening to you, and they give you a choice in medication, it feels empowering. I have a good GP now, but I had ones before who haven't listened – especially the ones who have seen me as coming from another culture*
- *It's impossible to say to the Doctor that you are not very happy with your medication.*

- *I have seen the same thing on the wards, people say they are unhappy on meds and consultants suggest that they actually up their dosage*
- *Medication is forced on people. I know white poor people who have ended up in the mental health service.. They took drugs and ended up hurting themselves. I am taking medication for 32 years. Either you don't want to take it or you end up in a dumbfounded situation.*
- *The medication is not the final solution to everything. The consultant forced me to go on medication. I was only having issues and concerns with my neighbours at the time*
- (They) *took me into hospital to feed me trial drugs. They should send professionals who are full of sympathy, rather than medication. It's a one way conversation*
- *I had Respinol for six weeks, I had a lot of anxiety. After six weeks it was enough. I said I didn't want it anymore, I couldn't take it, it was making me worse. But they gave me another 6 weeks*
- *Staff are not recording where they give you the Depo injection, whether it is left or right side, so the injections continue on the same side and become very sore*
- *I think they give you tablets unless you haven't taken them, then they give you injections*
- *I was pressurized into having injections, I wasn't given the choice of tablets*
- *With tablets you have more to prove, or you will end up back on the wards*
- *I think there are issues with pharmaceutical companies, means GPs are pushing certain medication. It's about the pharmaceutical companies making money.*
- *Mental health shouldn't be about burying people alive*
- *The systems that uses medication to experiment with people. It does not have any ability to use to be of the benefits to the people.*

And patients who were not 'white' tended to be perceived as having the hardest time:

- *For white men the medication is seen as "this will get you back to work", for black and ethnic minority we get stuff shoved on us but I know white guys too who have medication forced on them*
- *Ethnic minorities get the worst treatment. Big Bad Black Men 'example' many of the Black Men are treated very badly in the system*
- *Unless there is a white person above a black person, they will always make things bad. It was very different in Holland, you were always asked your opinion, always given a choice*

The discharge process was highlighted as a particular problem

- *We should forget about 'discharging' someone with mental health needs. Instead we should substitute this with referrals to some pathways. Some valuable pathways have however been closed e.g E9 where people could just drop-in and wind off* (2013)

Of equal concern appeared to be the lack of more general support in the community for this group of service users.

- *Music therapy, Core Arts aid recovery through its music programmes, we are redefining out interpretation of integrated care from the definition* (2014)
- *It's good to talk about other things that can help too – like speaking to people, exercise, eating well – which can lead to recovery* (2013)

Nonetheless, when provision was perceived as being good, it was very much appreciated.

- *The thing about* (soup kitchen) *here is that you are recognsied as an individual. Once you are on benefits you can lose your identity. We are not herded together here like sheep. This is not to criticise too severely other places, they are charitable, but most places you go, people give you a plate of food and don't speak to you. Here they know your name, they speak to you – it gives you a lift. And there are people here who are depressed and have problems, and you need a lift.*

The Alzheimers' Society – Dementia

According to the 2012/2013 JSNA, 145 of the 472 service users over the age of 65 to whom Hackney Council delivered social care services were dealing with dementia. It is also notable that the JSNA recorded that the black Caribbean population of older people showed a higher prevalence of dementia compared to other ethnic groups.

The Alzheimer's Society's 2014 Annual Survey of Service Users and Carers showed the particularly positive results in terms of the support they received from their Dementia Advisors with 95.5% of respondents stated that they felt their Dementia Advisor listened to them and 88.5% of respondents stated that they felt their Dementia Advisor was caring towards them. A further 61% of respondents stated that the support given by their Dementia Advisor has improved their quality of life.

- *There is always room for improvement but at the moment you are doing a very good job.*
- *The Dementia Advisor is very easy going and easy to confide in and explains things fairly easily*
- *Having the opportunity to talk about my Alzheimer's to understand it better. I also talked about the future, as I want to be prepared. The Dementia Advisor didn't shy away from her questions about the end*
- *The Dementia Advisor is very easy going and easy to confide in and explain things fairly easily*
- *You* (Dementia Advisers) *are the only people who really understand what is like for people to live with dementia. Streets ahead of the medical "experts". You have*

helped us with small practical suggestions help contacting with medical staff plus real kindness and friendly understanding

- *I have found the friendly supporting valuable – she is like a friend to me*

But it was the wider family and/or carer who were equally grateful

- *I found your service very good in every way. Thanks very much for all the support you have given to my Dad and myself*
- *Please do not stop this service! Families like mine would have been at a total loss if we only had our GP to rely on. Dementia needs dedicated practitioners as every patient is different and their needs are so intense*
- *I am unable to find fault. I have always been able to speak to someone as soon as I have an enquiry / difficulty*
- *From my partners Alzheimer's diagnosis 5 years ago, my dementia adviser has always been on call for me/us. I have had excellent support from gaining a P.O. Attorney, dealing with medical professionals and social services. Recently I have had help finding a private helper and without the support of my Dementia Advisor I would not have been able to do my job as a full-time carer*
- *It is the fact that there is a dedicated contact person available for any query, however trivial it may seem*
- *I would like to say that* (Dementia Advisor) *has made a difference to mine and my mothers' life. She is a very calming influence and has given me lots of practical tips*
- *I only hope that the carers and people with dementia could get the support we have had. I don't know how I could have continued on caring without it.*
- *As the carer of someone with dementia it is good to have someone who can advise that certain stages of dementia are normal. And how to deal with it. Our contact has a wonderful sense of humour and helps me see that all is not lost*
- *By ensuring that communication with the patient is made initially via the carer as initially I had problems with memory clinic contacting my mother direct which caused untold confusion and upset and this has now been solved*
- *Simply that* (the Dementia Adviser) *found us in shock following my wife's diagnosis, resisting all approaches from outside. She organised a programme for dealing with the future from your excellent literature. But more than this, she made contact with the various agencies in the City of London – including the Community Charge – which reduced our monthly payments* (Annual Survey of Service Users and Carers, Alzheimer's Society, 2014)
- *When my husbands Alzheimer's was less advanced,* (X) *helped me to problem solve different challenges that came up. She also told me about activities and helped me to find support from social services as my husbands disease advanced, she supported through difficult decisions*
- *I attend carers' support groups and enjoyed speaking to other carers, but the one on one support was very important for me and far outweighed the group support. I think there are so many private issues and issues particular to one's situation that cannot be addressed in a group setting.*

It was of particular note appeared to be that service users wanted to know there was someone there if need be

- *That I can get in touch and talk to someone, when the going is really tough*
- *I feel more reassured to know that someone is interested and knowing they are there as a solid point of contact*
- *Someone to talk to about a range of things and has the time to do so. Someone on the end of a phone.*
- *I feel very happy to be around good people like the Dementia Advisor*
- *On the whole I keep very healthy and don't need any particular support at the moment – but pleased to know support is available if required.*
- *Simply knowing someone is there and being linked in other services*
- *Know that if I need any help I can contact* (them)
- *The reassurance that my Mum is on someone's radar & that if something happened to me they might just step in and do something*
- *I think they are doing a wonderful job and they are always there when you needed them. If you call to speak to your own adviser and he is not there they make sure he got the message*
- *They are a listening ear, someone I could communicate with in*
- *The adviser is always got ear to listen*

The advisors were also seen as a purveyor of information especially in terms of social services, information on stimulation therapy, support services such as Dial-A-Ride activities available, for example, clubs, group therapy, social events and so on. Many also valued the Dementia Booklet and a DVD that was specific to Afro-Caribbean patients. The vast majority of respondents felt that the information given by the Dementia Advisors was easy to understand and support in understanding was always offered.

- *The fact that she is a font of knowledge on a subject which is foreign to many including GPs the Alzheimer society has been an invaluable part of the last five years since my mother was diagnosed*
- *They explained the nature of the disease very well and talked about strategies for managing behavior – sign posting to relevant services and the gave me a good range of relevant literature.*
- *I look forward to do the DA visiting because she takes time to explain things in a gentle way that I can understand. She has given me information that has helped me like the mobile library services. This has been good for me as I can now go out*
- *Practical advice and his empathy – very caring approach and very calm and pleasant manner. Felt that there was someone who was not only competent but also understood the issues and could be turned to in need.*
- *It has been helpful to have information about the groups and to be in the company of other who have similar difficulties as myself as well as the information about DA gave me.*

- *The information you gave us, if I wanted to ask a question you could give us an answer*
- *It always helps - the activists are particularly useful. Keeps your mind alive and helps prevent isolation*
- *The most help so far has been filling in the terms for applying for right for attorney*
- *It is good because it tells you about things you never knew*
- *The two good things were the physical help with improving the flat with the safety rails and her big help in organizing helper to fill in form for careers allowance both would not time happened without DA input*

Indeed, it was only a very small minority who had any criticisms of the work the Society does and these tended to focus on the promptness of service rather than the service itself.

Section Three – Specific Themes

a) Communication

Poor communication was an area of concern that tended to come up repeatedly between patients and professionals as well as between professionals.

- *There needs to be a better system of communication between staff members. Homerton needs to make more efforts to keep patients in the loop of diagnoses, appointments, treatments and so on*

Referral process

The referral process, also termed service to service communication, appeared to present a significant barrier for patients seeking specialist services within the NHS. Patients had to see a GP prior to obtaining a referral to a specialist, without which the patients ccould not see the specialist. Patients voiced concerns that they were not being seen quickly enough which could adversely impact their health particularly if they had to wait too long to obtain specialist help.

- *My GP sent me to the hospital to have a blood test done and the hospital told me that when the results were in my GP would contact me. They haven't yet and that was 3 months ago so I will have to call them* (2013)
- *GPs are useful and helpful if the health problems aren't serious but if the health problem is serious and needs specialist care they are acting like gate keepers and do not refer us to the specialists in time. They don't make the referrals unless we insist.* (Alevi Survey, 2014)
- *Specialist diagnosis takes too long to be made and causes serious health problems and people die waiting the diagnosis.* (Alevi Survey, 2014)
- *My dad is having lots of trouble because he cannot feel his feet. He was referred in January 2013 to the foot specialist at the Neurological and Neurosurgical hospital in Queen's Square. He didn't hear from them for ages. When he phoned up he found out that something had gone wrong with the referral from the GP, and they did not have the referral. My dad went back to the GP, and the GP referred him again. But the same thing happened. My dad then phoned the hospital to check that he was on the system; they said that he was, but he did not believe them. He sent the receptionist a card-saying thank you for being so helpful and checking that I am on your list for an appointment. Finally in July he had a letter from them saying he was on their system, and in October he had an appointment for an initial assessment.* (2013)
- *When my referral from the GP for mental health support was passed to the Homerton there was no communication. I had to call to find out when my appointment with a*

therapist would be, but they just kept promising a call back. I didn't get one until after I went private through BUPA, which was too late. (2013)

- *Generally the staff at the hospital are very helpful- not always but generally. But once I had to get a tooth taken out and the dentist sent a letter to the Homerton. I waited for the Homerton to send me a letter giving me the date of my appointment. I waited for months and never got a letter. I went back to my dentist and asked if they had referred me and they showed me a paper copy of a letter they had sent to the hospital referring me. So I went down to the Homerton myself- to the outpatient reception and I asked them what had happened and I found out they had sent me a letter but they had sent it to my old address. They said I had missed all these appointments, three appointments. So I gave them my new address and told them to update the file. Still I didn't get a letter, and I had to go back three times before they updated their system with my new address. They should have staff who are better trained so that they know how to update the files then and there, I asked them to update it but the person probably didn't know how to use the system. They should be more efficient* (2013)

Long waiting times, not only for the referral process but also for the appropriate communication between medical professionals and departments, could additionally impact upon care adversely.

- *The A&E is getting worse too, the time you have to wait to be seen and the time they actually take to diagnose you are ridiculous. It's completely inadequate how long they take when looking you over, you'd expect after waiting for hours to actually be given a real amount of time with a doctor, but no. Nothing*
- *They also informed us that delays in blood test results by GPs is taking too long which can make patients end up taking the wrong dosage of medicine* (Alevi Survey, 2014)
- *My son fractured his fibula and they put a cast on it. We had an appointment for them to take it off but their computer system was down and they called us and asked if we could come at 4.30 instead of 1pm. We got there and they told us we were late and should've come at 1pm and they'd put us down a Did Not Attend. We didn't have the name or department of the person who called us, so we waited and waited until 7pm and no one saw us. We asked the people in the plaster room if they could take the cast off but they said no, because you have to X ray the leg first. We went back the next day and they took the plaster off without X-raying it. They told my son to walk on his leg and now he's got a lump so I'm going to go back this week and have them check it. I've never heard from the physio and my son's leg has been broken for two months. They can't do anything about the fact that their computers go down, but when they call to tell you to come later they should give you the name and department of who's calling and then tell the receptionist that your appointment time has changed* (2013)
- *The databases do not appear to be connected up. I was referred from urology to the physiotherapy department and the Computer data in one department was not accessible in physiotherapy department* (2013)
- *A good thing for us would have been a way of exchanging X-ray results. If you have an X-ray done in one hospital, another hospital wouldn't have a copy. Some gave us*

copies on a CD or they would pass on results – but the next hospital wouldn't be able to read the data. If there could be a national method of reading data –It damages child to keep doing X-rays over and over again

The lack of continuity in the care system also tended to exacerbate difficulties.

- *My son has* (XXX). *I've been waiting for nappies to be collected for two years, I have thirteen boxes of nappies for 3-5yr olds in my attic. My son is 7 and they don't fit him, I tried taping two of them together but they cut into him. He also has epilepsy so loses continence a lot. We don't receive the nappies and we can't buy them in the right size because we don't know where to get them. We had an incontinence nurse who was meant to send us bed sheets and the right nappies but we haven't had any for two years. We make bed suits for him instead but the safe space he sleeps in is made of plastic and the urine aggravates his eczema. In June or July he was measured at school and they took the measurements and called the company in front of me and gave them the measurements, they didn't take our address as they said they had it on the computer. We never got them. Then people leave and new people take over and you have to explain the whole situation again. We were buying nappies ourselves, we didn't know we were entitled to them until we met other parents at a disabled children's parents group. They should make parents know their rights* (2013)
- *At Homerton they wanted to cut the toe to save the leg. The GP said don't go back to Homerton go to Whitechapel. The GP at Whitechapel A&E told me to go back to my GP as he was paid a lot of money to take responsibility. I said I didn't come here to discuss salary. In the end he gave me the pain killers and a letter to take to my GP with 10 points telling him what to do. Eventually when the GP did send me it was vascular and I needed an operation. It was cancelled 3 or 4 times. They said it should be ok in a few days, but then I lost my eyesight*

Communication to service users

Patients unquestionably wanted full disclosure of information on their health conditions. Without full information, patients could not make informed decisions on their healthcare needs. They also wanted service providers to be openly communicative, for example, notifying them of appointment changes, medication issues, etc.

- *You need to look at how to sort out letters, not getting information to the patients and then you are told you have a health problem* (2013)
- *At first I was in for infection removal and antibiotics, but it turned out to be a major problem, so it is good they found the main problem. I am extremely impressed with the staff and the services. But half of the explanation about the problem should be in detail, and the information about the operation is not clear….there should be a better communication. The staff needs to talk more with*

the patients (2014)

- *Better communication from staff, not only when events like this occur, but also just in general. There's a general lack of communication about what's going on. I know there are posters etc, but really there needs to be an improvement in the level of face to face communication about what is going on during the day,* (BeisPinchos Care Home February 2013)
- *I think that communication could be improved – especially from the top. For example, there is a complaints book but of course not everyone can get to it. I think there should be a complaints and comments form in every room so that people can jot things down as they think of them* (BeisPinchos Care Home, February 2013)
- *There hasn't been anything lacking in terms of info, but it also depends on what questions you ask* (Acorn Lodge Care Home, February 2013)
- *I would say communication is the biggest issue at the Homerton Hospital. I am asthmatic, and when I go there I am waiting ages, I keep having to go to reception to ask what is happening* (2013)
- *You have to push the GP to send you to the Homerton – or any hospital. When you have been, you wait months for the results. 3 or 4 months – why is that? You keep going to the GP and asking ,"When are the results coming? The problem I have is back". The GP shows you the computer, there is nothing? But the problem is still here. Then you can either ask the GP to send you again to the Homerton. But I give up, I just take paracetomol" (2013)*

Signposting

There was a need for patient information on health and social care to be easily accessible in one place and for health professionals to guide patients to the information they need. In order for patients to make informed choices on their care, patients need full information on their condition and what services they can access. Some commented how easy it would be to produce a leaflet for distribution on the wards which would ideally inform patients what to expect and who the people are who were involved in their care.

Some argued for GPs to be the navigator for services but they should at least have the right information to hand

- *Kind of need to be on the ball in knowing about different services……a lot of GPs are proactive but you need to take that first step to make the appointment to ask. You could display more leaflets in GPs, but also don't bombard patients with too much information. Extremely lucky here in Hackney that we have 21 children centres, high demand, extremely helpful* (2014)
- *Health information displays in most GP practices are rubbish*

Others felt that a real problem appeared to be in hospitals

- *The x-ray was taken more quickly and accurately than last week, as I had about*

seven last week for one hand, today's was four. I arrived at 9:15, wasn't seen until around 10 am. Would have been more happier if I had been given some leaflets or written descriptions on how to exercise my hand after injury rather than quick demo as I was bound to forget. There should be notice boards about waiting periods. Or at least apologize for being late. The last time I emphasized about getting out as easily as possible despite being there for a long time as I had therapy which I can't miss, I ended up missing half of it because they didn't bother to tell me they would be long again

- *I went to the Royal London Hospital on Thursday 22nd September 2011, and I found it terrible, shocking – the communications and the staff were all over the place. I went in, and the signposting was terrible, it took me half an hour to find out where I was going. When I got there, the consultant called me through, and went straight into asking about what had happened as she took off her coat and switched on her computer. I was left to close the door. She made a hurried diagnosis, didn't explain it to me and then invited in three other people without asking me. She didn't introduce them, but they introduced themselves. One was a student from the US, and the other two were consultants. She then said they needed a blood sample and x-ray, but didn't explain that she meant straight away. She gave me the slip to get this done. I was left again trying to find my way round the hospital to reception. Reception said they couldn't make me an appointment, it had to be made by a nurse. The nurse said it wasn't her, and passed me back to reception. By this time my distress was obvious, and the consultant came out and realised that I didn't understand, and went through it with me quickly. She said don't worry I will explain more at your next appointment. She then left me to find the other departments around the hospital, which took another 45 minutes* (2011)
- *It's difficult to find information because the staff is not helpful and so many people need access. There is too much of a queue, I couldn't even get information, the staff is too tense, bad attitude and too quick. They need more people, more handouts and pamphlets, the staff need to take time and be more concerned and helpful. There should be improvement with access to the services* (2014)
- *I was seen promptly, I have given useful information. But there is a long wait to get information, not well signposted. They will need to employ more people and give them a better training* (2014)

It was argued that the voluntary and community sector should also play a role in signposting and information-giving and the problem appeared to be a general one and not service specific

- *Need flexible holistic support, need somebody who is there for you as a core advocate to do that to help navigate. There are number of organisations48 including the voluntary sector who help with holistic support* (2014)
- *Better care and thought for families of patients. More information for families* (2013)
- *It very difficult to find out support what type of health and social care service is available for our clients. It's only at networking events where we meet*

commissioners that we find out what their entitlement or services available. (2011)

At the event at the Alevi Centre, participants were asked where they wanted to see the signposting of health and social care services. Their responses were as follows:

- Community centres and their websites
- GP surgeries
- Reception areas of hospitals, dentists and opticians
- Local newspapers, radio and television
- School billboards
- Libraries
- Local busses and bus stops
- Sent to families by post by health centres

b) Continuity of Care

Patients wanted to develop a relationship with the health professionals that they see on a continuous basis so that are able to confide in the same medical professional over time. Patients also wanted their GP to know their medical history at the start. In part patients want to see the same health professional so that they do not have to repeat information that they have told a different medical professional previously. Repeating information also ran the risk of important information getting lost amongst the different medical providers. Further, an appointment had only a small amount of time for patients and medical professionals to exchange information. If patients saw the same medical professional, time would be saved for other information and concerns to be discussed.

- *I keep seeing a different doctor rather than the same one. I have asked the receptionist but they don't tell why or does not respond to my request. I have a stress related problem and it would help to see the same person*
- *Very friendly, trying to help identifying the problem properly, I don't know if they have the GP history because I came to the hospital directly. But I felt they don't know at all. So I don't feel confident about them. I need to be informed about the end of issue* (2014)
- *There should be the same doctors for the same family members* (Alevi Survey, 2014)
- *You can't phone in get an appointment when you need an appointment, can't phone week in advance to get a appointment with a specific GP. Continuity of care is very important as my GP knows my history but they need to find the right system* (2011)
- *I think the GP service is a bit better A&E. Because with the GP you get to make appointments with the same person again and again. So if you have a problem consistently coming up again, you don't have to explain yourself all over. It's just more consistent I guess*

- *More permanent doctor most here are locums therefore no continuity of care so you have to repeat the same thing about yourself constantly at every appointment* (2011)
- *The GP keeps on changing consistently I have seen four different doctors in a month. You need to get appointment quicker when you need one- two week wait - you should be able to get an appointment when needed* (2011)
- *I keep seeing a different doctor rather than the same one. I have asked the receptionist but they don't tell me why or does not respond to my request. I have a stress related problem and it would help to see the same person* (2011)
- *Sometimes when my physio is off I have someone else and then I don't get the care I need. Like I need help with learning to stand again, but that physio has got her own patients so she's not going to spend the hour helping me, so she will just put me on the exercise bike. It's frustrating* (2012)
- *I'm not too fond of my GP. I don't know my doctor because they keep changing. I never see the same doctor, sometimes they leave, sometimes I can't see the same person because they are with someone else. Every time I see a new one I have to tell them what I am allergic to again. The service could be improved if more attention was paid to the patient. Form a relationship with them so we can trust them more* (2013)
- *If I could change one thing about the GP it would be being able to see your own doctor* (2013)

Continuity of care was seen as being integral to building relationships and trust

- *It's difficult until they have established a relationship – it takes time. You can't just take someone out of the air* (2012)
- *Another problem at the GPs is seeing different doctors each time. We need to be seen by the same doctor, which could be more effective as we develop a relationship and they are aware of our medical history. We think it will be better if the local NHS sorts out the locum doctors' problems in Hackney Health Centres.* (Alevi Survey, 2014)
- *I have been a patient of the Allereton Road Surgery for several years. For approx. the last two years, since Dr. Wetzler left, there has been no continuity. It seems that every time I visit the Surgery I see a different GP. They are all very professional, but it is not possible to build the relationship, which should exist between GP and patient*

Medical Records

Medical records were perceived to help maintain continuity of care. However there was evidence that service users have complained that proper medical records are not being kept or that they have been lost which impedes on both continuity of care and trust. Thorough and organized medical records might equally save medical professionals and patents valuable time.

- *The problem is the Homerton not running in parallel with them* (the maternity services) *For example, the midwives come from the Homerton – the doctors at the*

GP will have made the appointment, booked it and sent the info in advance. So when you get to see the midwives, the records have not been updated. The GP is then updating them verbally, saying this was sent to you – maybe a week ago. And sometimes appointments get cancelled and you have to rebook because Homerton haven't picked up the booking

- *If there was another hospital that I could go to I think I would prefer that. Records are important, doctors can only do so much if the records are not updated. So they start asking a sick person what they should have on their record from the GP practice*

c) Sensitivity to individual needs

A recurring sentiment throughout the report is that patients clearly wished to be treated as individuals, noting that each individual patient has a different set of circumstances that need to be considered by health professionals. Integrated care ideally should seek to give patients more dignity, respect, and independence, which can be achieved through understanding patients' needs holistically. It was noted on more than one occasion, for example, that those with severe learning disabilities 'miss out', particularly children.

- *GPs can sometimes not understand the needs of kids with disabilities. (2013)*

In particular, patients with learning disabilities voiced a greater need for health professionals to understand their needs and communicate accordingly and to take into account any limitations they may have when they are managing their health not least so that patients do not feel disadvantaged.

- *It annoys [*my family member with a learning disability] – *they need their* (care workers) *total attention. I said it is not furniture – this is a person with feelings – I said it a lot of times (2012)*
- *I have a learning disability, and I know that with the government cutbacks it isn't the doctor's fault, but I have had epilepsy from birth and when I went to the doctor he wrote me a note to go back to work. But if I go back to work and have a seizure, then what happens? He isn't my orginal GP, he doesn't know about my health or me. I want to work, just not the job he wants me to work. I am dyslexic as well, I want a doctor who will understand me and help me go forward with life. Listen to us more, people with learning disabilities have opinions as well, listen to us* (2013)
- *The GP said I needed to get a cholesterol test done – but I felt under undue stress – too stressed to go and sit in the hospital waiting for six hours as happened last time. I feel they should be more compassionate and understand people's situation and treat us as an individual. I think they should have this test at the GPs, and I don't think I need it at present, but this is causing me unnecessary stress* (2011)

Above all, patients wanted sympathy when appropriate from health professionals and a bedside manner was an important part of a patient's perception of their healthcare. Health professionals, for example, needed to ask patients with learning disabilities what they could do to help them understand health concerns. How patients felt medical professionals related to them about their health condition was seen to impact upon their overall health care experience.

- *Some doctor's attitude without respect causes offence to people and their rights to access medical services and discourages people to see the doctor, for example by asking a questions like 'what's the problem this time?' , 'Why are you here again this time?* (2014)
- *Another time I was seen by a nurse who took my height and weight on a machine. She said hold your breath, hold your nose – and it wasn't very pleasant. I don't know* (why)*, it might be to do with my epilepsy* (2013)
- *Staff are dismissive of me because of my communication difficulties. I would like them to try harder – even if they are unsuccessful – they could be seen to try.* (2013)
- *Took me into hospital feed me trial drugs. They should send professionals who are full of sympathy, rather than medication. It's a one way conversation (2013)*

Health providers needed to tailor their communication style and time management during appointments to suit each person's needs. However, patients may also need to communicate their needs with their health provider.

- *My neighbour is blind, and has COPD and when she was in hospital they would come and put her tablets down – she couldn't see them. They hadn't read her notes* (2013)
- *What I found interesting and concerning was that there was no provision or allowance for communication support for people with dementia, stroke or learning disabilities. It is so important that care workers working with this segment of the community have some level of training to use total communication (i.e. gestures, MAKATON signing, pictures, drawing, simplifying language, drawing etc) to get the message across and to understand the needs of one of the most vulnerable in our society* (2013)

Patients with disabilities needed specialized care, information should be made more accessible and communicated and disseminated in different forms. Further, easy read and lay terms needed to be used when communicating.

- *At A&E at the Homerton, they could improve it for people hard of hearing. It is a large area, and noisy and you can't hear when your name is called* (2013)

- *The talking signs at the Homerton – I miss them – they went when they redeveloped the coffee shop at the Homerton, at least a year ago. They were a very useful tool – especially at first. Especially for anyone visually impaired* (2013)
- *Hospital records do not indicate that an individual has a learning disability therefore they are not given priority or the right support during health visits/appointments. There are not enough preparation for the service-user before attending health appointments or appointment times were not long enough – causing distress, agitation, unsuccessful outcomes* (2012)
- *For a Personal Budget,* [my family member with a Learning Disability] *has had three assessments by three different Care Managers in the last two years – and we do not know what is happening. Nothing came back. I don't know if anyone has a Personal Budget – but social services needs to come out and tell us about it – not only about homecare providers, but about adult social care altogether. They make so many confusions between Direct Payments and Personal Budgets. It's simple –one is where you tell council what you want and they do it. The other is where they put the money in your account and you do it* (2012)

They also tended to want medical professionals to spend more time with them during their appointments. Certainly, seeing the same medical professional might help make a short appointment more helpful rather than spending greater amounts of time having the patient reiterate their health conditions. Some patients felt as though they needed more time for the appointment to be effective and this should be considered by health care providers. Some, too, expressed dissatisfaction with their GP services because they had been requested to make appointments by telephone when there was not enough time to talk properly about their health issues.

- *I am a carer for an adult with a profound learning disability. The GP is not too bad, he always feels listened to. My main concern is that there is not enough time to go through all the health concerns. He is a young man with a learning disability and it takes time* (2013)
- *Some patients are being given information which is quite sensitive, and there is not much time for the surgeon to come in and talk to you, it is quite rushed even though it's a very sensitive topic* (fertility), *I felt so kind of cold because there was no real kind of contact with nurses because there was such a volume of patients to get through in a day and they just treat you as a number not a person.* (2014)
- *I am a carer for my adult son who has a profound learning disability. When you get an appointment at the GPs you are given a time, but then you sit there waiting way beyond the time. What is the point of the appointment? It puts the rest of the appointments out of sync. Everyone turns up on time. When they do see you, you are rushing out of the chair* (2013)

However, hospital provision did not appear to be any more satisfactory for this group of patients.

- *My husband has autism, failed to complete two endoscopies & long waits – they knew he had autism but did not sedate him or offer a sedative* (2013)
- *In the hospital, when you are waiting – if you ask they say "Go back and sit down" and that can be difficult if you have learning disabilities. (2013)*

And access appeared to be an issue across the board

- *There is a fear of access, people who choose not to access services through fear.* (2014)
- *There is a lack of disability access to GPs' other services* (2013)
- *In some GP surgeries we are not able to see doctors but nurses as we were told not to take doctor's time if our health problem was not urgent.* (2014)
- *People with learning disabilities have difficulties accessing services, like to going to the GP surgery, making appointments, and the time scale- people with learning disabilities need longer time scales. Another issue is getting appointments themselves, and accessing hospital appointments. They need health checks, and to know what they are, regular checks, specialists, and support. Its a nightmare for parents and carers, it is exhausting* (2013)
- *I am carer for my adult son who has a profound learning disability. I have an issue getting an appointment for him at the GP. You can't make an appointment ahead now – I have to call on the day, but you can't get through. It's really difficult when you have someone with challenging behaviour who is sick, and you are hanging on the phone and can't get an appointment. Can't there be some kind of special arrangement for people with a learning disability? We just end up at A&E* (2013)
- *The emergency clinic at London Hospital is not very good access for wheelchairs _ I have photos of this. The phone out of hours service will direct you to the dentist on duty and when I tried this the dentist was inaccessible for a wheelchair* (2011)

d) Cultural Sensitivity

As Hackney is one of the most diverse boroughs in London, the needs of all populations must be accommodated by the health services. Patients voiced the need for medical staff to be more attuned to cultural sensitivities including both religious and gender. There was a view that certain conditions are discriminated against and there is regular stereotyping in terms of race, gender and age.

A number of groups clearly felt that they were discriminated against as the following indicated:

- *Ethnic minorities get the worst treatment. Big bad black Men 'example' many of the black. Men are treated very badly in the system* (2013)
- *Receptionists at GP surgeries are mostly very rude and are not patient enough. Some of the Turkish speaking patients think their approach is racist and they don't care*

about their problems (Alevi Survey, 2014)

- *For white men the medication is seen as, "this will get you back to work", for black and ethnic minority we get stuff shoved on us* (2013)
- *I am 60 year old man and facing discrimination from the Bengali receptionist at my GP Surgery due to a conversation that went between us. In this conversation I was asked if I was Muslim. When I replied 'yes' to that question I was faced another question why we didn't cover out heads as all Muslims supposed to and she found out that I belong to 'Alevi' sect instead of 'Sunni'. Since then she started discriminate against us by not allocating appointments when ever I requested and was told there weren't any available. However we were able to make appointment on the phone same time and when we question her approach she was denying and saying she was unaware of the availability. When we made a complaint I found out that she made a note against my family members that 'they are aggressive patients'* (Alevi Survey, 2014)
- *I find the receptionist attitude racist- they talk to people who don't speak English rudely. When you come to the reception the receptionists are looking at you and talk amongst themselves and sometimes ignore you. I think that the manager's attitude encourages the receptionists' behaviour. I have complained but I've received no response from the practice manager. I once helped another patient when the Turkish interpreter was away on holiday for 1:30hrs and the receptionist was very rude. I was just trying to help them* (Alevi Survey, 2014)
- *They are listening to their patients, but it's difficult to arrange appointments, everyone needs to call at 8:00am and to get appointment two weeks later. I don't ever contact the GP directly. They need to improve the appointment system and interpreting services. Front desk people need to be more polite and patient with people with little English language skills* (2014)

Language barriers to health and social services and the lack of interpreters have been documented frequently but they remain an area of concern.

- *There are no services in the patients' own languages about their health issues. When the patient requires additional information this is not taken seriously. The linguistic skills of the nurses are not sufficient, especially those from EU countries* (Speak Up about Homerton Hospital Event, 2013)
- *We would like to have female interpreters for female patients* (Alevi Survey, 2014)
- *More bilingual health professionals would be helpful* (2013)
- *Bilingual advocacy provision needs to be increased* (2013)
- *Front desk staff can be trained for better understanding of religious and cultural sensitivity. They also can be a little more patient with people with language barriers* (Alevi Survey, 2014)
- *I want to see the optician but I don't know where to get an interpreter* (Alevi Survey, 2014)
- *I couldn't have interpreter, even I had an appointment before I go, they don't supply interpreter. I had an head injury and urgent appointment for GP, but I could have an*

appointment for hospital three month later, which can be dangerous. They should have interpreter, they should provide an earlier appointment for the hospital, they can pick assistant for using the services while they are in because they don't understand any of signs or directions or notes. (2014)

- *Although the interpreters are helpful there is not enough interpreters and it is difficult to find them. This causes further problems which are hard and expensive to solve* (2013)
- *I am unconfident to go to GP because of language barriers*
- *Patient's need time with the interpreter to enable them to ask specific questions about their medication and dietary needs*

It could also result in medical complications:

- *Interpreting mistakes led to wrong diagnosis and there were surgical complexities* (2013)
- *When I went to hospital they couldn't find interpreter for me, then they suggested I should bring an interpreter myself. I am unemployed, I wouldn't be able to afford a private interpreter, I suggested that they take my blood and send it the results to my personal GP but they never understood me. They couldn't understand I have epilepsy. They should've diagnosed my epilepsy and have treated me properly. They found out about it when I fainted at the GP's health centre and had a seizure. They took me to University College London Hospital* (urgent services) *now they treat me there* (2013)
- *My doctor in the hospital prescribes me medicine even though we don't understand each other. He prescribes it anyway* (Alevi Survey, 2014)
- *Because of the language barrier we wait much longer than other people who can speak English. Also the language barrier is causing wrong diagnosis and consequently wrong prescription for people e.g. antibiotics are prescribed for asthma patients. There were interpreters available more often than before but now only once a week or no interpreter available* (Alevi Survey, 2014)

Food was also an issue that could be both culturally and faith sensitive. The Homerton Hospital was cited as an example where there was no Kosher or Halal food on sale.

- *There was no kosher food for her or her son to eat while they were waiting for their appointment. Upon asking staff the only kosher food available was in a staff only room* (2013)
- *The food and drink offered at Homerton does not seem to match the community needs of Hackney. Much of what is offered is a bit pricey, and may consequently be out of reach for Hackney residents. Furthermore, given the diverse communities that go to Homerton, I wonder if dietary needs are being met. One person asked us where they could get Kosher food* (2013)
- *Their needs to be a greater understanding by health professionals about the cultural dietary needs of the community. This would help when they are giving advice to their patients to take this into consideration* (2011)

LGBQT

According to the April 2014 Hackney Facts and Figures Update, nearly 2% of the population are homosexual or bisexual but reports suggest that this is an underestimation particularly given the fact that individuals may not feel comfortable discussing their sexuality. There is also evidence that this community needed support with social care.

- *Had problems with a local practice when a doctor left,* (there was a) *male locum who replaced her, walking in on his phone, just typed without listening, answered his mobile several times during appointment, got up and walked out in disgust…, she walked to another nearby* (surgery) *and had problems there, those practices were run by Muslim men and felt no sympathy with her…there were repeated cultural problems with sexuality. GPs in Manchester had training and signs up about LGBT friendliness, but here there's no sensitivity….mentioned it to a gay practice manager but wouldn't talk to the GP because don't know how they'd take it,* (she) *wouldn't feel she could complain about discrimination for herself but knows the avenues to follow, many don't (2014)*

There was also a sense that there might still be an element of prejudice.

- *I had one* [carer] *who was competent, but she never spoke to me. She was quite a devout Muslim, and I wondered if it was that I am a lesbian. Also as I am a lesbian, when you keep getting different people you don't know what their attitude is going to be. It wasn't that people were directly homophobic, it was the not-knowing.* [I had] *… care workers who aggressively preached the Bible at me including cures for homosexuality!* (2012)

- *On discharge from hospital I also made it clear to all parties that as a Gay man living alone at home, with no family, I did not have a support network in place, which would pick up their lack and duty of care too me. I was made to feel by the people I was talking with, that* [they] *did not approve and were certainly not prepared to assist me. In the end I was offered no support or Care at all. One complaint* [about homophobia] *even went to Hackney council, but it still didn't get dealt with* (2012)

Jewish Community

Hackney houses one the largest Charedi Orthodox Jewish Communities outside of Israel. According to the 2011 Census, 7.4% of the borough's population is Charedi Jewish. The Charedi population is growing steadily, with about 50% being under the age of 19[4].This means that the health and social care needs that are specific to the Charedi Jewish Community need to be taken into consideration at different points in health service delivery. There has been evidence that the Charedi community are setting up their own health care system similar to other communities for example in Haringey:

[4] Hackney.gov.uk/hackney-the-place-diversity

- *In the Charedi community we are setting up a private GP practice – there are some already – and the GP has capped his fees. The difficulty is that they cannot write NHS prescriptions* (2011)

However, there was evidence of a more general difficulty with anti-Semitism.

- *She said that maybe they don't like treating Jewish people nicely* (Enter and View – Lamb Ward, Homerton Hospital March 2014)
- *My care worker made a remark I thought was anti-Semitic. I spoke to the person in the office she said that she is not anti-Semitic – she passed it off as joke. But you don't make jokes like that….Maybe they are trained in keeping meat and milk separate, holidays etc – but they also need to know about talking in a sensitive manner and what may be offensive. There was also the issue of care-workers who don't understand English ways. It bothers me when there is someone who doesn't know what a teapot is, or common English parlance. A lot of elderly English people like to have things done in certain ways – like they like the tea things set out, and they like to have tea in a tea-pot. I prefer African care workers because of my language, but the agency mostly sends West Indian care workers* (2012)

Nonetheless there were many positive comments during the BeisPinchos Enter and View visit carried out in February 2013. The Home appears to be a good example of culturally and religiously appropriate linking of health and social care. The improvements suggested by the residents concerned communication and environment, rather than any insensitivities regarding their religion or culture.

- *I don't think about it because I am satisfied. My husband lives here too and they do everything to make us as comfortable as possible* (BeisPinchos Care Home, February 2013)
- *I used to use the gym. The carers take you out to walk now – if there are enough carers. We go out – we go to Canary Wharf there are a lot of companies there who help raise money for Jewish charities* (BeisPinchos Care Home, February 2013)
- *Yes, they're very good. We had a meeting here on Sunday and we were able to talk about anything. It's very good* (BeisPinchos Care Home, February 2013)
- *Residents are well cared for, there is a pleasant atmosphere. There is a social program including outings to places like Canary Wharf, Shopping Centers etc for which there is a small charge made. It's very hard to be bored. Nobody is allowed to sit in front of the TV all day. A rabbi comes every Saturday* (2013)

Turkish Community

Turkish is the second most common language in Hackney after English. An estimated 6% of

the borough's population is Turkish or Kurdish[5] and there is evidence that Turkish and Kurdish individuals face barriers to health and social care because of both language and nationality. The Alevi survey revealed that accessing GP appointments was a particular issue. Calling the surgery at 8am is not always a solution and more often than not, Turkish speaking patients are not aware of the services provided – for example, home visits or telephone advice. Again referrals are slow and late diagnosis can cause severe problems.

- *Homerton should provide language specific* (Turkish) *domestic violence services, such as drop-in* (2013)
- *After I was discharged they didn't offer me any support or resources on how to take care of myself. They finally tried to call to check in but no one could actually talk to me because no one spoke Turkish.* (2013)
- *There are always some delays. Turkish or Kurdish interpretation is needed* (2013)

Turkish support workers have reported that the most common issue raised is waiting times for referrals and they felt that it would be a great help if letters could be sent out in Turkish.

Asylum Seekers

Asylum seekers were perceived to be a particularly vulnerable population. Their access was seen to be generally reduced given the nature of their plight, especially when trying to register for a GP and they equally suffered from a lack of information on service provision.

- *The reception worker said that I am not allowed to see a GP because no evidence of my passport and my husband passport* (2014)
- *When I come to London I didn't have any ID and any document from home-office and they asked for my ID or any document that had my name on it. I have been registered to Broadway Market GP. They wanted to see my ID and proof of address. I don't live in one address but I showed an address at Hackney which belong to my relative in order to register to a GP* (2014)
- *I have been refused for the first attendance because I didn't have my documents so I had to wait for two months to be registered. I cannot give any proof because I don't have any relevant document regarding to my status and I am not confident to give any documents* (2014)
- *The receptionist was not kind, and she ignored us because no English, and not interpreter the only thing we understood is 'doctor, passport'* (2014)
- *She was not patient enough to me, she just tried to finish her duty and didn't*

[5] 2011 Census

give enough information about the procedure of what steps do I need to follow in order to register with a GP (2014)

- *Bureaucracy seems to take precedence over 'potential' patients or people's needs. Requirement to produce requested documentation is a major deterrent if one is not able to produce one or none of them at all. I am also afraid of both being reported and deported as 'my papers' are not in order yet* (2014)
- *I am a failed asylum seeker who has lodged in an appeal application. I am in a very precarious position and am 'scared to death' of being reported and let alone deported. I am not very sure of where all the information being requested from me will end up* (2014)
- *My concern now is that people are afraid to register to any GP or have a medical attention because they do not have the passport in their hands or there are over stayers, scroungers, or no legal status in the UK* (2014)

However, for some experience had been more positive.

- *Yes, she was helpful and this was really nice of her to explain the procedures and what I should do to register* (2014)

Section Six – Carers

a) Informal Carers

The role of provided care workers was clearly pivotal in a patient's wellbeing. They were generally seen to play an important role as they allowed the patient to maintain a level of independence while being looked after.

Patients with carers tended to be vulnerable and frail but the carers themselves talked about the pressure they are so often under trying to hold a job as well as co-ordinate the care of their relative or partner. They may also themselves become vulnerable through caring and would benefit from emotional support but not necessarily psychological therapies. But there could be equal pressure on young carers who may have had to give up education and employment opportunities.

Significantly, there appeared to be the lack of recognition, acknowledgement and support carers received from service provision.

- *GPs should listen to carers' concerns not just patients* (2014)
- *Family carers should be included in care plans* (2014)
- *Family care is not mentioned and that's important if they are going to withdraw any care plans. (2014)*
- *When I am making an appointment to see the GP, sometimes I can wait up to 3 or 4 weeks to see any doctor. I was trying to make an appointment for my mother who has diabetes, and the delay doesn't help if you are waiting for medication* (2013)
- *Care or support services are not notified when vulnerable patients are discharged, especially from A&E* (2013)

A main consideration as well for carers appeared to be information about the care of the patient and about care planning. At the *Integrated Care is Better Care* Event, for example, it was thought that there was not enough information available to patients and carers about what to expect from health and community services and that patients and carers should be aware or have access to all the information about their own care, choices they have, and whom they can contact in case an issue arises.

In addition, having a named contact who could be 'held to account' would be a relief although others believed they would still prefer it if they handled and co-ordinated all the care.

However, information also seemed to play a further role of allaying concerns about future uncertainties.

- *I think when I am not around there needs to be someone to speak up for my* [family

member*]. Every parent is concerned about the future. It keeps changing and I don't know where I am. With cutbacks you don't know what will happen with a money making organisation running services. Care Homes want to cut costs and do the bare minimum. I worry because I will not be around. Things could get to be very serious. A lot of people say the same things. All these things are a worry for the future. More so because other family members don't know how it works. As you get older, the more you fear for your relatives and their wellbeing. Who will take care of them, who will look after all these people?* (2012)

Financial issues, too, were clearly a concern. A number of carers drew attention to the fact that spouses are not eligible for Carers' Allowance but carry out significant amounts of unpaid care.

- *Mum never had care packages in hospital or out of hospital,* (they) *never asked it was just assumed that she would look after her mum and also all the care support groups are now not being funded anymore. She goes to the Carers UK AGM every single year, have done for the last ten years her mum passed away four years ago (*but) *still kept on going because it has become thing for her I didn't know, they give councils loads of money because it is ring fenced, nobody gets care breaks because it is ring fenced* (2014)

Nonetheless, the Event also recorded that carers reported a very positive experience of the 'First Response Team', a team that would work with some for six weeks intensively and then withdraw and questioned whether lessons could be learned from it. The general feeling at the Event was that the integrated care plan needed to look at longer term care, past the six weeks.

b) Care Workers

Patients within the more formal care system a number of complaints about the care provided and the 2014 Connect Hackney Survey revealed that only 33.9% were pleased with their homecare.

Some felt they were simply not getting enough care and there was inadequate support in the system.

- *I don't believe I have enough care. 30 minutes is so short – when they ring the bell, it takes me so long to get to the door, that we have lost 5 minutes already. Sometimes when the bell rings people have gone before I get there. They used to give me an extra hour. I can't do things like cut onions. I've got arthritis in all my joints, as well as cellulitis which the nurse comes to dress. The carer who comes in the evening for 30 minutes doesn't have time to help me with things like cutting food. I have lost two or*

three carers because it is not possible to do all the tasks I need in the time. My carers are OK, they come on time. The problem is that the time is not enough. With a slow person like me you need more time. 30 mins for Personal Care, dressing up and feeding is too short – not enough for her wellbeing. Carer always in a hurry and leaves to get somewhere else (2012)

- *Care managers being disenchanted leads to lower quality care assessments. People going through assessments feel criminalized. It was following the yearly review. I really feel this should be done by someone senior, but it was done by another care worker and there were several Health and Safety issues. For example there was a faulty bath board, and the intercom not working. I reported these to the care-worker, and they should have been reported to Social Services, but they weren't. I complained, and the manager came and did the review herself. In the first review there was a whole list of things about equipment and the care-worker wrote it all down in front of me, but it was not picked up. Yes I had a re-assessment last year, but I didn't get more care. I know I need the help. But those who tell the truth don't get the help. Those who lie get it. Next month I will be 76, why should I tell lies? When my old man was still around, he got a good amount of care time, because I would fight with them. But I am home now on my own, and who is going to fight for me? Hackney open the case to do the review, then someone comes and does the review with you, then they close the case the minute they have completed the paperwork. So there is no named person doing the review. So if you are on Direct Payments the case is opened and closed within three weeks and there is no-one you can go back to. The last Care Manager said they would take away two of the five days support. Also reduce the total amount – I said you have got to be joking. Whoever makes this decision should have to look after my* [family member] *for a week and see if they can cope* (2012)

Others felt that the care, when provided, did not fulfill their expectations or their needs.

- *The carers normally just about stay the full allotted time – this started once they had to clock in and out, which they do do. My normal care worker stays for the right time, but for example she is on holiday now, and the cover care worker stayed for half an hour instead of an hour. I think in general timing and punctuality has got better as a result of the Homecare Report – and I have a care worker who I have had for some time, so we have a good working relationship. I feel that the care-workers, even though they are coming to your house and logging in – there is not much checking of the time they spend in the service users house going on by the agency. For example if they spend only half an hour, instead of an hour, as just happened to me – it should flag something up. But nothing happens – it is up to me to pick up the phone to the agency and follow it up. I would like to know what are the agency doing with the logging in information? Can we have a report on the data? Did care workers come on time? I didn't know what time the care worker would come. And there were a couple of times when I didn't get anyone. I rang the care agency, and then someone would come late morning, when it was too late* (2012)
- *The agency doesn't care – as long as they cover the hours – if some service users are unhappy. Carer workers come in and make an agreement with the agency. Then they don't come back after a while, just when they are beginning to get used to my* [family

member]. *The agency starts giving the same workers night work – more hours and more pay. So now they are not coming here – and now I am looking for another worker. It's not easy as* [my family member] *can be scared of the worker.*

There could also be the additional problem of patients becoming dependent upon carers who then leave.

- *I am worried that* [my family member] *is getting too attached. The one care worker does a lot of hours – almost seven days a week. I am concerned that they are getting too close. My worry is that she will leave – there is no loyalty or commitment. Sometimes people just leave. I don't like it when they develop a very strong relationship. I keep talking to the agency about it. I too am used to her. I have confidence in her, I don't have to worry. I can't face it when we have to start all over again. I am a bit suspicious about the agency. It's a gut feeling – I think they have some favourites who they give the work to. Then I am stuck to find someone else to come in to cover.* [My family member] *plays up when she has the cover worker. If she doesn't trust and doesn't feel that they are confident, then she gets agitated and difficult. If the agency don't give them enough hours, the care worker will have no commitment. But if they do give them enough, then they can build up some kind of commitment and loyalty. I am not sure if it is right. For me it would be better if it was two workers – give the second one 4 or 5 hours and the first 20 or 25 hours* (2012)

Equally difficult, it was suggested, was making a complaint:

- *I don't put up with unfair behaviour with carers or agencies. I raise concerns and people don't like it. They say they want to hear, but if it is not good, it makes you unpopular. I've said it to senior care managers. People go quiet. People have such hierarchy in Social Services – I don't know who to talk to – big list of hierarchy. Worse – I don't know who is managing what. I leave messages and they don't get back. People leave and you don't know. I think they had me down as a difficult client, because a couple of times people came to the door and said "I am a good carer". I'm not a difficult client, I just know what the expectation should be, and want people to live up to it. Nothing has changed. Other than changing the carer, which is not dealing with the issue at all. The carer's report writing is very bad. They would often not write down what had happened. For example, it would not be recorded when I was feeling particularly bad, like after my operation. So I wrote it down myself. I would say that I physically needed more help, and it would not be written down. There were times when I couldn't get out of bed, and it would not be written down. You can ring 6262, but you can be on the line for 45 minutes without being able to get through. I am frightened to rock the boat. And Hackney seems to have a one size fits all policy* (2012)

APPENDIX I

Recommendations

AREA	SUGGESTED ACTION TO BE TAKEN
Care Plans for the elderly/Frail/Long Term Conditions/Complex Needs	Care Plans should include the complete patient journey including what should happen after hospital discharge including a full and holistic support package Care Plans should include details of medication/reviews, concerns of patients etc Care Plans should provide a contact number and details of a named contact person Care Plans should involve patients and carers as well as those from all sectors of provision
End of Life Care	End of life care should be discussed with patients providing them with full information so that they are able to make informed choices Patients should be linked into to information about social opportunities including contacts, clubs, activities etc
Preventative Health Care	Greater links should be forged between the voluntary and community sector and health and social care services to provide preventative services. Where already in place, patients need full information about opportunities and access Healthcare systems should develop greater links with housing associations and work closely with social services in this area
Carers	Carers need to be more fully supported, have access to all the appropriate information Carers should also be involved at all stages of the journeys of the patients for whom they care including the development of the care Plan Patients need access to greater information about 'carers' including their role, responsibilities etc Greater training for carers may also be needed
Emergency Care/Discharge	Greater attention needs to be paid to the hospital discharge process to prevent readmission An emergency telephone link could be installed with a 24 hour nurse on the line to make recommendations to patients Introduction of a discharge advocate/coach that helps

	patients through transitional care post hospital or A&E to prevent readmission Transport and discharge need to be linked more effectively (it is understood that this is being considered by the CCG and the Homerton Hospital presently)
Financial support	More effective dissemination of information is needed to help patients navigate financial issues and to understand what resource are available for which purpose Pamphlets, a website or call centre may alleviate this
Communication	All communication lines should be made more effective Waiting times for referrals should be improved There should be greater use of lay terminology given the levels of health literacy
Mental Health Care	There should be greater consideration of alternative therapies More consideration should be given to understanding those with mental health issues Greater support should be given to mental health patients in terms of daily living tasks and social determinants of health
Cultural Sensitivity	Greater attention needs to be given to cultural sensitivities including availability and use of interpretation services More specialized training may be need for particular cultural groups in Hackney

APPENDIX II

"Integrated Care is Better Care – Convince the Patient" event 1st April 2014 at Hackney Empire 2

City and Hackney Health and Social Care Forum (HSCF) and Healthwatch Hackney

Aims of event

- To ensure that the public and VCS understand the plans for integrated care / better care locally
- To ensure commissioners and service deliverers hear and take account of the experiences of VCS groups and the public
- To influence future commissioning decisions

Planning Group

Jackie Brett (HSCF), Malcolm Alexander (Healthwatch Hackney Board member), Shirley Murgraff (Older People's Reference Group), Elaine Peers (Health and Wellbeing Board support), Michael Kerrin (St Joseph's Hospice/HSCF), Paul Monks (Core Arts/HSCF), Liz Hughes (Healthwatch Hackney)

Outputs

- A verbal report to the Health & wellbeing board that evening with the emerging themes from patient / user and Voluntary & Community sector
- A written report that will go to participants via email, be on the HSCF & HWH website and go to the Health & wellbeing Board members.

Outcomes

- That recommendations from the event are taken into the Better Care plans
- That VCS and patient representatives are better able to input to ongoing plans for Integrated Care
- That developments for Integrated Care are better able to include patients and community reps at the heart of the planning, and through feedback

Chairs:

- **Malcolm Alexander:** Chair of the National Association of LINks Members (NALM) and vice chair of the Patients' Forum for the London Ambulance Service. He is a Healthwatch Hackney Board Member.
- **Michael Kerin:** is the Chief Executive of St Josephs Hospice and City & Hackney Health and Social Care Forum Health & Wellbeing Board Representative.

Key note speakers:

- Roy Lilley: Over view of Better Care national policy
  Independent health policy analyst
- Maureen Ford: Experiences of using local services
  Disability BackUp
- Stephen Laudat: Experiences of using local services
  The Peoples Network
- Mark Scott: Over view of local plans
  City and Hackney Clinical Commissioning Group

Workshops
Fully Integrated Mental Health Services

- Service Describer: Dean Henderson (Borough director, East London Foundation Trust).
- Facilitator: Shabira Papain (Social Action for Health)

Long term conditions

- Service Describer: Leanne Jenkins (Homerton Hospital_
- Facilitators: Rosemary Jawara (Beersheba Livingwell & CCG Patient Rep)/ Dianne Barham (Healthwatch Hackney

Hospital Discharge

- Service Describer:Jarlath O'Brien (Homerton Hosptial A&E)
- Facilitator: Alistair Wallace (Mobile Repair Service)

Emergency and Urgent Care

- Service Describer: Jean Lyons (Homerton Hospital)
- Facilitator: Malcolm Alexander (Healthwatch Hackney Board member), Victoria Holt (CHUHSE)

Outpatients and planned operations

- Service Describer: Leanne Jenkins (Homerton Hospital)
- Facilitator: Jon Pushkin (London Older People's Advsory Group)

End of Life Care

- Service Describer: Mark Scott (City and Hackney CCG)
- Facilitator: Michael Kerin (St Joseph's Hospice) and Lin Lahm (Older People's Reference Group)

Equality Of Access

- Service Describer: Siobhan Harper (Director of Patient and Public Involvement, City and Hackney CCG)
- Mervyn Eastman (Change Agents)
-

Panel – response to workshops and Question and Answer

Chaired by Councillor Jonathan McShane (Chair of Hackney Health & Wellbeing Board)

- Clare Highton Chair, City & Hackney Clinical Commissioning Group
- Dean Henderson Borough Director, East London Foundation Trust
- Devora Wolfson Assistant Director, London Borough of Hackney
- Jeremy Taylor Chief Executive , National Voices
- Mark Cockerton Chief Executive, City & Hackney Urgent Healthcare Social Enterprise
- Maureen Ford Disability Back Up
- Tracey Fletcher Chief Executive, Homerton Hospital

Co-ordinated by Health and Social Care forum and Healthwatch Hackney, with support from Age UK London/London Older People's Advisory Group

APPENDIX III

Detailed list of Sources

The majority of the data in this report comes from:

1. The Integrated Care Event "Integrated Care is Better Care – Convince the Patient" described in this paper, event organised by City and Hackney Health and Social Care Forum, and Healthwatch Hackney

2. Healthwatch Hackney, *Workshop commissioned to input to One Hackney programme April 2014* We worked with the Alzheimer's Society, St Joseph's Hospital, Age UK East London, and the Carers' Centre to set up and support a Patient Group to brainstorm how services for this group of frail older people could be improved. This group was chaired by Lin Lahm (from the Older People's Reference Group) and Ida Scuollos (from the Patient Network).

3. Healthwatch Hackney, General Comment Collecting, 2012 – 2014, which took place at a range of community venues including the foyer of Homerton Hospital. Where people had more to say, Healthwatch Hackney called people back for a longer comment or one-to-one interviews about their experience

We have also included:

- The feedback from the OPRG [Older People's Reference Group] focus group on Intregrated Care on the 3rd April 2014

- Healthwatch Hackney, *Speak Up Event*, Alevi Centre, March 2014. This event was attended by over 100 Turkish speaking older people. Comments relating to integrated care are included here.

- Age UK East London Telephone survey - *Patients' Experience of Hospital Discharge Process*, March 2014. Age UK spoke to 57 older people from 10 different GP practices, who had recently been discharged from hospital, about their experience

- Connect Hackney Survey 2014. As part of the evidence gathering for a bid to the National Lottery, the partners (including Age UK East London, the Older People's Reference Group, Hackney Council and Hackney CVS) collated over 600 responses to a survey amongst older people in Hackney focusing on loneliness and isolation

- Healtwatch Hackney *Speak Up about Homerton Hospital Event*, December 2013

- ,*Annual Survey of Service Users and Carers*, Hackney and the City Alzheimer's Society, 2014. The Alzheimer's Society in Hackney carried out 2 separate surveys in 2014. Dementia Advisors surveyed 24 dementia patients about their service, then 44 carers for dementia patients were surveyed about the support their family member receives.

- Healthwatch Hackney Enter and View visits RNRU (the Regional Neurological Rehabilitation Unit) December 2012, Acorn Lodge Care Home February 2013, BeisPinchos Care Home February 2013, the Lamb Ward at Homerton Hospital March 2014, and the Tomas Audley Ward at Homerton Hospital March 2014

- The People's Platform, *End of Life Care In North East London – Perspectives of Patients and Carers, Personal Narratives and Attitudes on Death, Dying, Care and Beyond,* The People's Platform, September 2010

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