



Health Education
North Central and East London

***Supporting the Education and Empowerment of
Patients and Carers [SEEPAC]
A systematic approach within
Health Education North Central and East London [HE NCEL]***



Barts and The London
School of Medicine and Dentistry



May 2014

Research Team:

Barts and the London SMD, Queen Mary University of London

Angie Macknight – SEEPAC Researcher

Professor Annie Cushing - Principal Investigator

Dr Moira Kelly – Co-investigator

Professor Olwyn Westwood – Principal Investigator

Social Action for Health

Dr Rupesh Shah - Co-investigator

Elizabeth Bayliss - Co-investigator

University College London

Dr Caroline Fertleman - Co-investigator

Dr Paul McGovern - Co-investigator

Dr Alison Sturrock - Co-investigator

“There is a large and growing body of evidence that, done properly, a system that supports people with long-term conditions to manage their own health has benefits for the person, their health and for health services.

Creating such a health service requires shifting the habits of healthcare from focusing on managing disease to helping patients stay as healthy as possible. It requires a new understanding of the role of the patient; it demands a new understanding of the role of the clinician; and it needs health systems that have the infrastructure and processes to encourage and facilitate self-management by patients and self-management support by clinicians.”¹

The Health Foundation

***‘Sustaining and Spreading Self-Management and Support’
Lessons from Co-Creating Health Phase 2***

CONTENTS

	Page
Research Team	2
1. Executive Summary	5-6
2. Background	7-10
3. The Scoping Exercise	11- 12
4. Outcomes of the Scoping Exercise: Identifying Practice and Perceived Unmet Need	13-29
4.1 Breadth of initiatives within North Central and East London	13-17
4.2 Analysis of Good Practice Examples – A Discussion of Findings	18-27
4.2.1 Education and Training	18-20
4.2.2. Involvement, Engagement, Empowerment and Governance	20-22
4.2.3. Support for Self-Care	23-25
4.3 Case Studies	25-29
5. Recommendations on the best opportunities for the HE NCEL: Support the education and empowerment of patients and carers to be experts in their own care	30-31
6. Tangible steps that HE NCEL could take in 2014-15 to support current initiatives	32-33
6.1 The leadership role of HE NCEL in making this aspiration a reality	32
6.2 Suggested activities for HE NCEL as tangible next steps	33
7. References	34
8. Appendix:	35-58
Questionnaire items:	35-37
Table A1: Examples identified across the different London Boroughs served by HE NCEL	38-39
Table A2: Synopsis of the Activities Identified in the SEEPAC Project	40-58

1. EXECUTIVE SUMMARY

Health Education North Central East London commissioned a scoping exercise: Supporting the Education and Empowerment of Patients and Carers [SEEPAC]: A systematic approach within Health Education North Central and East London. Its remit included:

1. An analysis of the breadth of initiatives taking place within North Central and East London;
2. An analysis of good practice examples that LETB could learn from [either within North Central and East London or beyond];
3. Recommendations on the best opportunities for the LETB to more systematically support the education and empowerment of patients and carers to be experts in their own care;
4. Tangible steps that the LETB could take in 2014-15 to support [either through funding or other means] the training of patients [and carers] as experts in their own care.

The project was steered by a group from Barts and the London School of Medicine and Dentistry, Queen Mary, University London [QMUL], Social Action for Health [SAfH], [a community development charity working across 6 London boroughs including East London], and University College London Medical School [UCL]. The steering group was chaired by Professor Olwyn Westwood and Professor Annie Cushing [Barts and the London]. The project commenced in mid-January 2014, with fieldwork conducted between February and April. The fieldwork was undertaken by Angie Macknight, a researcher employed specifically for the project.

Initial contact was made with local networks across the NHS and community and voluntary sector by phone and email. Some contacts did not provide examples, but were an excellent source of referrals and helped identify unmet need. Information about examples of notable practice was gathered using an on-line semi-structured questionnaire hosted on Bristol Online Survey. In practice, one third of contributors entered their answers online. The remainder had telephone or face-to-face interviews with the SEEPAC researcher. The interviews were based upon the questionnaire, but provided a richer source of detail, understanding and potential learning. In mapping the range of activities and their location or point of access across HE NCEL 57 examples were collected. Five are pan-London and beyond with the remaining 52 were identified in ten of the thirteen London Boroughs served by HE NCEL.

The activities identified were tabled into one or more classifications: training and education; engagement and empowerment; and support for self-care. Each example is described by the nature of the activity. This is the start for the data tagging process necessary for searching the directory by key terms as a live on-line resource. The activities were also represented according to their location or point of access. Whilst this gave an indication of current activity, it is by no means exhaustive. Therefore, the level of activity in each borough only reflects what was uncovered and shared during the scoping exercise.

There is an analysis of the activity provided in a learning summary for each of the three classifications. Profiles of a number of examples follow which demonstrate notable practice in terms of reach, impact and/ or social value. Some of the case studies cited include:

- Advanced development programme in Islington

- Commissioning for Self-Care in Islington
- Focus on managing pain [Camden, City, Hackney, Newham and Tower Hamlets] Including a systematic review on the evidence for different types of pain management [Barts and the London]
- Maternity Services Liaison Committees [Tower Hamlets and Newham]
- TalkLab co-production with young people living with long-term conditions [Haringey, Islington and pan London]
- TB Awareness Project and Partnership [Redbridge]

Contributors were asked about what would improve their activity/ intervention and any unmet need or opportunities which might affect health and self-care. These were outlined using the same classifications of training and education, engagement and empowerment and support for self-care. This provided an overview of what these projects considered important to maintain and further embed good practice in health and self-care.

Our recommendations emphasise that no one sector or organisation can achieve this in isolation but needs to be a collaborative of multiple stakeholders. However, the NHS workforce and trusts have an integral role to play. The report concludes with a discussion about the potential role of HE NCEL as an agent and partner for change

The report seeks to draw out aspects of this role so that HE NCEL can begin to articulate what this means strategically and operationally under two major themes:

- Education and training of the NHS workforce and patients [face-to-face and on-line]
- Raising awareness of activities and schemes across the HE NCEL region to improve access to key services

As a network organisation drawing on employers, universities, medical schools and an Academic Health Sciences Network, HE NCEL is well positioned to play a pivotal role in facilitating and influencing progress. We would suggest tangible 'next steps' might be:

- A colloquium based around the SEEPAC project to share the existing learning and to engage with stakeholders to reveal useful data and resources;
- To commit to a *live* on-line directory, with relevant tagging and search function whereby information is available [for different sectors/cultures for shared learning];
- To generate innovation and development with seed funding to provide some continuity for promising projects to get to a stage of evaluation or beyond;
- To explore the possibility of developing a blended online and skills based experiential learning with potential partners such as the Health Foundation and the medical schools within the region, e.g. Self-Management and Expert Patient Programmes courses with colleagues/ services providers;
- To commission basic training in key areas, e.g. dementia awareness, sensory impairment, carer awareness, information routinely written using easy read for people with learning disabilities;
- To support the further development of the patient journey map through research or proto-typing with patients, carers and practitioners. [A recommendation by Social Change Agency report 2013 to Islington Clinical Commission Group].

2. BACKGROUND

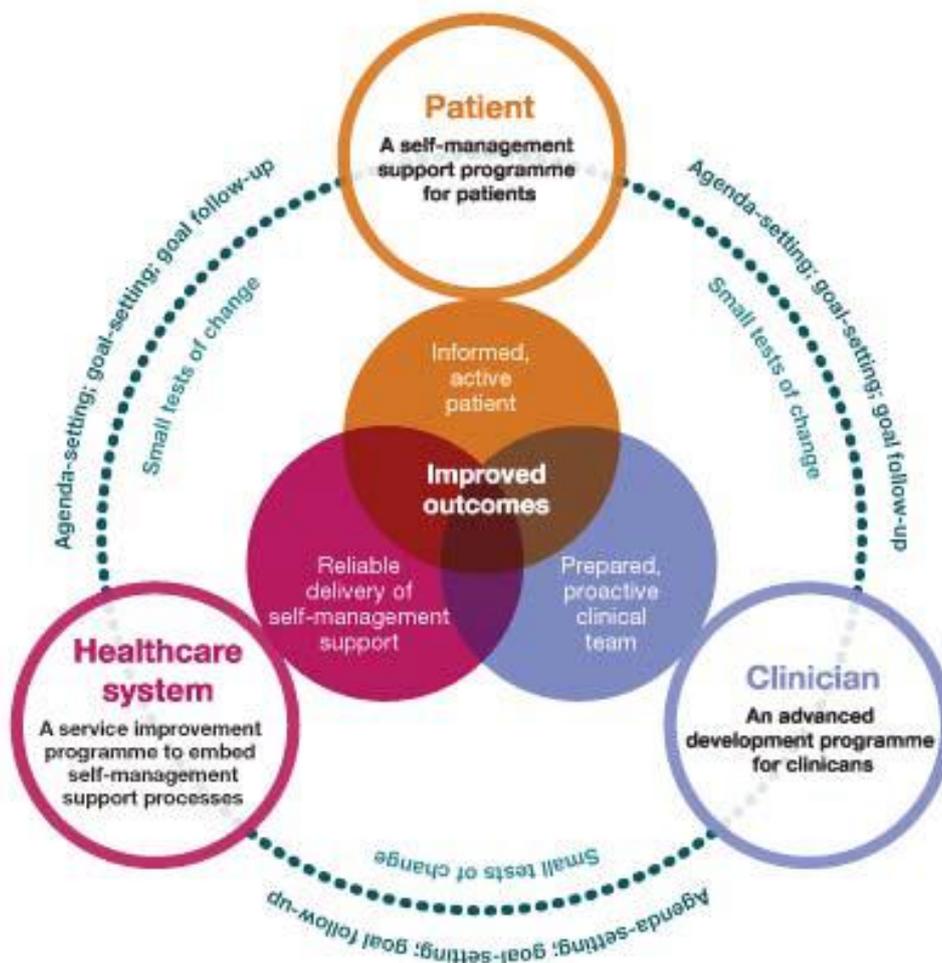
Within the HE NCEL localities there are areas of innovation where patients and carers are empowered to take control and manage their health, as well as sharing their knowledge, skills and experiences. There are 13 London Boroughs and 13 Health and Well-being Boards in HE NCEL to scope existing activity. Documentation of the extent and nature of these initiatives has commenced and will require a system for regular updating to capture the extensive activity that is evolving and changing. This project is aimed at not only identifying conventional good practice but also illuminating other less engaged and more marginalised members of the community. There is clearly potential for further support to promote collaboration between these groups and healthcare educational organisations and providers.

This project [known as SEEPAC] began as a scoping exercise identifying examples of good practice in patient and carer empowerment, health education and training in self-care in the NHS, other public sector organisations and voluntary groups to clarify the context and scope of this work. The conceptual understanding of the SEEPAC project has been informed by the work of three significant organisations: *The Health Foundation*, *Self Care Forum* and *Social Action for Health*. Key messages from these organisations are elaborated here since they served to influence the design of the scoping exercise questionnaire, and accordingly, the data derived for this report.

The Health Foundation This organisation has been at the forefront of collaborative approaches to care for people with long-term conditions for many years. It invested over £5 million in a large-scale demonstration programme called 'Co-creating Health' in 2008². This programme aimed to embed self-management support within mainstream health services across the UK and equip individuals and clinicians to work in partnership to achieve better outcomes. The Co-creating Health programme focused on developing the skills and attitudes of both people with long term conditions and their clinicians, while also ensuring systems and services are designed to support and facilitate self-management [see Figure 1]. Eight national demonstration sites were chosen to deliver the three training and information strands of the programme. Each site focused on one of four clinical areas: chronic obstructive pulmonary disease [COPD], depression, diabetes and musculoskeletal pain. All demonstration projects spanned primary and secondary care, and involved local teams of service users, clinicians and managers. One of the sites is located within Whittington Health, in Islington and within the HE NCEL region.

More recently the Health Foundation has commissioned original research to better understand why the practice of collaborative approaches has not followed the aspiration as widely or consistently as hoped. In their report for the Health Foundation, *'Enabling people to live well'*, Entwistle and Cribb³ consider ideas about how clinicians can work collaboratively with people with long-term conditions. Their critical analysis focuses on the Co-creating Health model as well as the Bodenheimer and colleagues' comparison on traditional and collaborative care in chronic illness. Some of the key points from this research are visited later in this report.

Figure 1: The Co-Creating Health Model²



Self-Care Forum: This is another key organisation, and at the start of the project the researcher interviewed Dr Jim Lawrie, Newham GP and a board member of the Self Care Forum. He welcomed the project as in his opinion, “Most people sign up to self-care, but find it difficult to put into action as they don’t know what it looks like. Examples will help with this.” The Self Care Forum uses a model which shows the spectrum of self-care through healthy living to in-hospital care [see Figure 2]. This helps make the link between self-care to stay health and prevent illness as well as self-management and support for people who are living with long term or life-limiting conditions. Consequently, the project also includes some examples which protect health such as breast feeding and promote healthy living such as relationships and sex education.

It is also noteworthy to consider the life-course approach to health as each stage of development has significant factors that affect health. From pre-natal life, to the early years through childhood and youth and adulthood to the ageing process, each stage will engage

different people, organisations and services. This approach can denote some natural partnerships and relevant settings through which to improve health and self-care.

Figure 2: Self-Care Forum Model



Social Action for Health [SAfH]: This was the third key conceptual model and a partner organisation for the SEEPAC project which has brought knowledge and experience of the complexity of community development. The SAfH 'Spiral of Participation' illustrates the organisation's approach to this complexity and recognises that there are different levels of social organisation and engagement [see Figure 3]. Through its own examples and input on the steering group, it has helped the project to fully appreciate the range of activities which contribute to empowerment. This has led us to be more explicit about levels of participation and power. For local people to contribute fully, they have a role to play in agenda-setting and decision-making. This means that the scope of the project goes beyond people in their roles as patients, service users, members or carers to also include that of co-producers and commissioners.

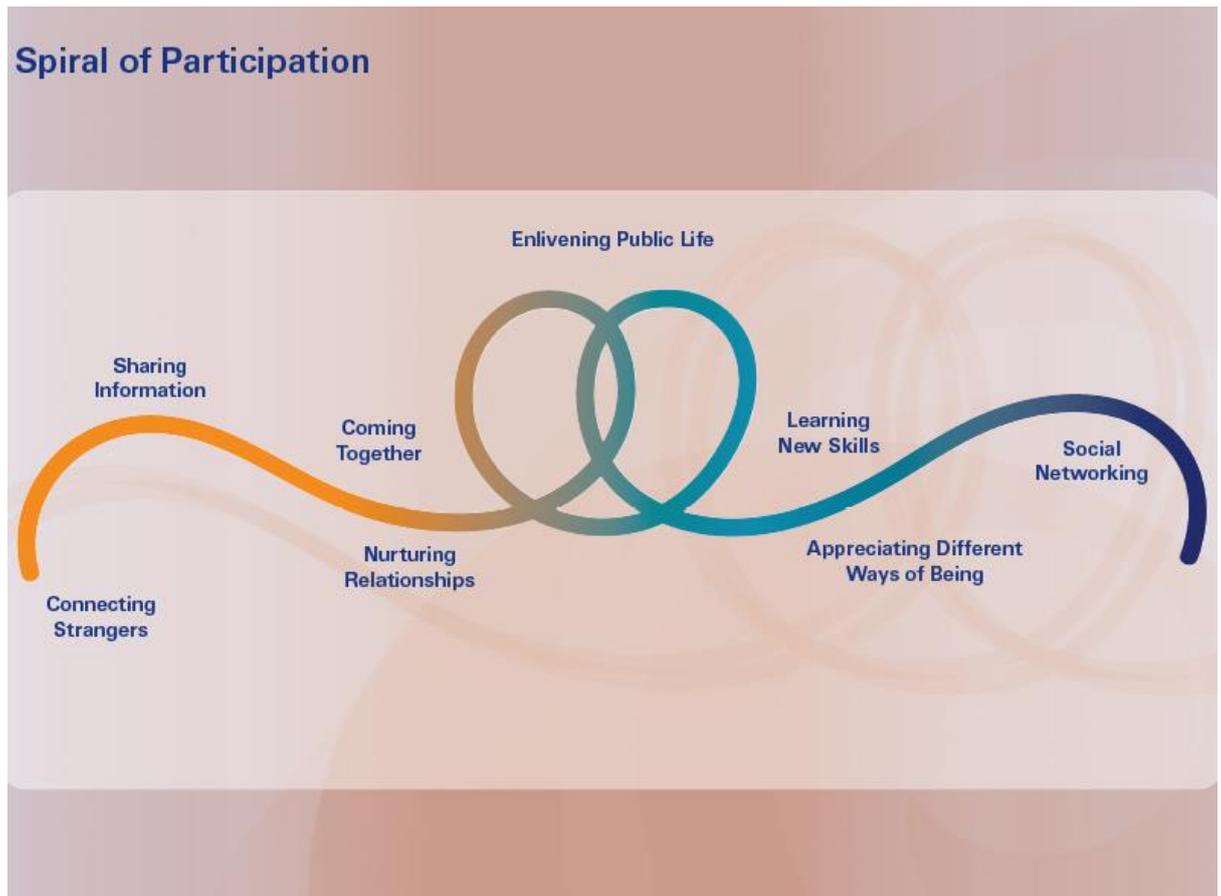
Inevitably this means that different sectors, professions, communities and individuals are interacting. Each has its own culture, history and language and behaviour and lived experience [i.e. life world]. They also have their own set of values. For SAfH, the four values that shape their work are:

- We start with the people
- People have the right to take control of their own lives
- People's health can be improved by tackling isolation, poverty, racism and unemployment
- Healthy communities are good for the whole society

These values recognise that there is a social dimension to health, that individuals can have an impact on their own and their community's health. However, meaningful participation and

empowerment involves identifying and sharing what different people value and contribute to these relationships and partnerships. Over the last two decades much has been researched and written about social capital and the impact it can have on health. It is an important element in understanding the range of different factors affecting people's health and self-care. As a consequence, the SEEPAC project has come to reflect supporting public, patient and carer education, engagement and empowerment in health and self-care.

Figure 3: Model for Social Action for Health [SAfH]



In scoping activity in the HE NCEL region and reporting good practice, it has been necessary to widen definitions of activity and judgements on good practice and value to include areas of patient education, engagement and empowerment beyond that which is more traditionally understood in healthcare circles.

3. THE SCOPING EXERCISE

The project commenced with a review of the role and remit of known examples of good practice in patient and carer empowerment, health education and training in self-care. Through the contributions of voluntary groups, community organisations, public sector organisations and a range of collaborative approaches, the information has grown to clarify the context and scope of this work as much as the content.

The fieldwork was conducted between February and April 2014, with the information gathered using an on-line semi-structured questionnaire hosted on Bristol Online Survey [see Appendix for the Questionnaire and Table 1 for the nature of questions used to derive information]. It was agreed by the Steering Group that a certain degree of flexibility was necessary with respect to the content and question structure in order to gain a clear understanding of the different and diverse practices across the region served by HE NCEL.

Table 1: Nature of questions used to derive information

Name and nature of the activity
Access arrangements: how do participants find out about the scheme
Client demographics and healthcare issues
History of how the activity was devised and who runs it
Timetable of activities: when, where and what happens
Challenges faced by <ul style="list-style-type: none">• Organisers• Participants
Impact of the activities on: <ul style="list-style-type: none">• Organisers• Participants
Methods of evaluating the success of the scheme
Issues faced with respect to unmet needs / opportunities for improvement
Funding for the scheme
Knowledge, skills and resources needed for success and longevity of the scheme
Contact details

Initial contact was made with local networks across the NHS, and community and voluntary sector by phone and email. These included:

- Carers' organisations
- Clinical commissioning groups
- Councils for Voluntary Services
- GPs and primary care
- Health and Well-being Boards
- Healthwatch groups
- Hospices
- Local and national self-help groups
- NHS trusts – communications teams, patient involvement or experience leads or groups, clinical directors, specific programmes and specialities, e.g. Expert patient programmes
- Religious organisations
- Social action groups in East London
- Social enterprises
- Universities – Queen Mary, University of London [QMUL], University College London [UCL] and University of east London [UEL]

Some contacts did not provide examples, but were an excellent source of referrals and helped identify unmet need. In practice, one third of contributors entered their answers on-line; the remainder had telephone or face-to-face interviews with the SEEPAC researcher. The interviews were based upon the questionnaire and provided a richer source of detail, understanding and potential learning. The researcher completed a draft version of the conversation using the questionnaire format, forwarded it to the contributor for comment, accuracy and revision as necessary, prior to uploading the approved version. The data were exported to and formatted within an Excel workbook [the Excel spread sheet of the raw data has been submitted with this report], together with transposed examples following the questionnaire structure and unmet need linked to specific examples. This format should enable the information to form the basis of the database to drive the on-line searchable directory. In this way the project aims to initiate the live resource and maximise its on-going usefulness to HE NCEL and contributing organisations.

4. OUTCOMES OF THE SCOPING EXERCISE

Identifying practice and perceived unmet need

The findings in this report according to the following headings:

- Breadth of initiatives taking place within North Central and East London.
- Examples of good practice [either within North Central and East London or beyond]
- Recommendations on the best opportunities for the LETB to more systematically support the education and empowerment of patients and carers to be experts in their own care
- Tangible steps that the LETB could take in 2014-15 to support [either through funding or other means] the training of patients [and carers] as experts in their own care.

4.1. Breadth of Initiatives within North Central and East London

This section maps examples across the range of activities and their location or point of access. Fifty seven examples were collected in total.

- Five are pan-London and beyond.
- The remaining 52 were identified in ten of the thirteen London Boroughs served by HE NCEL [see Table A1 in the Appendix] The limited time frame of this scoping exercise meant that some contributors were unable to participate. Nevertheless, their interest in the project and its potential for shared learning remains.

We believe that the data found are a worthwhile foundation on which to build a meaningful on-line database with a searchable directory hosted by HE NCEL.

The activities have been tabled into one or more classifications [see Table 2]

- *Training and education:* Usually courses, structured opportunities for learning, or resources which have a strong educational component.
- *Involvement, engagement, governance and empowerment:* Activities which offer different levels of participation and power to local people some of whom may be patients and/ or carers.
Support for self-care: Activities which recognise that self-care does not take place in isolation and are more focused on helping individuals and groups manage their care.

Clearly a number of initiatives and activities span two or all three of the classifications. Hence activities are listed by their primary focus and also appear under another classification if there is a strong secondary focus [see Table 2]. Each example is described by the nature of the activity. This starts the process of data tagging to allow for searching the directory as a live on-line resource.

Table 2 Classification of Activities identified in the HE NCEL region

Classification of Activities	Nature of Activity Numbers in brackets below relate to activities described in Table A2 [see Appendix]
Education and Training	<p>Advanced development programme for clinicians to support patient self-management and empowerment [1]</p> <p>Advanced Resuscitation of the New-born Infant – course for clinicians[2]</p> <p>Asthma – education and focus groups for children and young people living with asthma [5]</p> <p>Breast feeding workshops for pregnant women and their partners [9]</p> <p>Carer support [training for GPs / hospital staff] [11]</p> <p>Dementia – awareness for Black, Asian and Minority Ethnic faith leaders; Cognitive Stimulation Therapy [18,10,12]</p> <p>Expert Patient Programme – course for people with long-term conditions, New Beginnings for people with mental health conditions [23,36]</p> <p>Mental health - Psychological Health: A Foundation Training Course for Faith and Community Leaders; Talking therapy and crisis prevention course for faith and community leaders; Core Arts - Psychological Wellbeing through Creative Education and Practice [45,16]</p> <p>Pain management - visualisation of pain through photographic images; systematic review of different pain management courses; RCT of effectiveness of self-management courses for people with long term pain compared to usual care [56,39]</p> <p>Patient journey – focus group for parents about key areas in educating medical students about child health; undergraduate BSc in Paediatrics and Child Health learning from children and their families [25,43]</p> <p>Self-management – Self- management programme for adults with type 2 diabetes [28,50]</p> <p>Sensory Impairment – workshop on living with blindness and visual impairment for medical students [30]</p> <p>Sexual health – relationship and sex education for young people [7]</p> <p>Tuberculosis prevention - TB Awareness sessions for local communities, colleges and schools [53]</p>

Classification of Activities	Nature of Activity Numbers in brackets below relate to activities described in Table A2 [see Appendix]
Involvement, Engagement, Empowerment and Governance	<p>Advanced development programme co-led by lay tutors with long-term conditions [1]</p> <p>Advanced Resuscitation of the New-born Infant – one parent’s input into the course development [2]</p> <p>Asthma – education and focus groups involving children and young people living with asthma and their families [5]</p> <p>Breast feeding – network engaging local mothers as peer supporters, many who had previously used its services [9]</p> <p>Carers - GP liaison involving carers to identify their needs [26]</p> <p>Commissioning self-care – participatory budgeting engaging local people to commission local community based providers; Reviewing self-care in Islington involving stakeholders / people with long-term conditions; People’s Advisory Group [41,44,54]</p> <p>Community Health Action - local people setting the agenda, deciding what action to take and making changes to improve their own and the wider community’s health overcoming barriers and health inequalities.[27]</p> <p>Community group based physical activity / weight management / diabetes – local people and community organisations engaged in health improvement and decision-making about what is needed - Well London Stratford Village; My Weigh, Fit for Fun; Community prescribing [57,35,24,13]</p> <p>Co-production – Talk Lab with young people with long-term conditions setting the agenda and co-designing services with staff [15]</p> <p>Dementia - Cognitive Stimulation Therapy empowering people with dementia to have a voice and opinions; Dementia Action Alliance engaging people with dementia, their carers and local organisations and businesses to make the local community dementia-aware; [12,17]</p> <p>Disability – engagement and empowerment of disabled people to obtain the services they need to live independent lives and to promote a social model of disability and user run services [19]</p> <p>Expert Patient Programme – led by lay tutors who manage their own conditions; New Beginnings for people with mental health conditions led by lay tutors who manage their own conditions [23,36]</p> <p>Health and Well-being Board – input of different local people and service users at the start of meetings, e.g. people with learning disabilities, people with visual impairment, young people who had canvassed opinions from over 100 peers [51]</p> <p>Maternity services – local mothers engaging with local communities and maternity services to set the agenda, improve current provision and co-design future developments [34]</p>

Classification of Activities	Nature of Activity Numbers in brackets below relate to activities described in Table A2 [see Appendix]
Involvement, Engagement, Empowerment and Governance [continued]	<p>Mental health - Core Arts – member led community organisation [Psychological Wellbeing through Creative Education and Practice]; People’s Advisory Group on mental health involved in commissioning services; engagement of faith and community leaders [talking therapy and crisis prevention course; Psychological Health: A Foundation Training Course] [16,44,45]</p> <p>Patient journey - focus group involving parents about key areas in educating medical students about child health; undergraduate BSc in Paediatrics and Child Health with direct input from young people who have a long-term condition and a mother of twins [only one surviving]; Asthma focus. [43,5]</p> <p>Self-management – involvement of GP patients after visit to A and E in discussion about what happened and if they or the practice could do anything differently to improve health/ self-care; Self- management programme for adults with type 2 diabetes co-led by lay tutor with long-term condition and peer support network involving course graduates [42,50]</p> <p>Sensory Impairment – workshop developed and taught by visually impaired and blind tutors, trained to teach about the whole range of visual impairments [30]</p> <p>Sexual health - relationship and sex education for young people led by university students; user involvement in Men’s Safer Sex [MENSS] website development; engagement of local people and organisations in setting research priorities, membership of project steering groups and co-applicants on some research projects, Research and Innovation Forum, The Margaret Pyke Centre [7,55,46]</p> <p>Tuberculosis prevention – TB Awareness and partnership engaging local people and communities [53]</p>
Support for Self-Care	<p>Alcohol – Detox and rehabilitation; Down Your Drink [48,20]</p> <p>Asthma – education and focus groups for children and young people living with asthma [5]</p> <p>Bereavement – compassionate community support for people who are bereaved [14,37]</p> <p>Breast feeding – peer support network; workshops for pregnant women and their partners [8,9]</p> <p>Cancer – Citizens’ Advice Bureau support for patients and their families about finances and welfare benefits [6]</p> <p>Carer support – GP liaison to support carers and identify their needs; Carers’ passport [in-patients] and hospital support for carers; Carers’ information and support programme [for those caring for someone with dementia] [26,11,10,22]</p> <p>Chronic obstructive pulmonary disease [COPD] - Sing for your lungs [52]</p> <p>Commissioning self-care – participatory budgeting of local community based providers; Review of self-care in Islington [41,47]</p> <p>Community Health Action - To enable local people to take control of their own and the wider community’s health and to overcome barriers and health inequalities affecting people’s health [27]</p>

Classification of Activities	Nature of Activity Numbers in brackets below relate to activities described in Table A2 [see Appendix]
Support for Self-Care [continued]	<p>Community based group physical activity / weight management / diabetes– Well London Stratford Village; My Weigh; Fit for fun; Community Prescribing, Armchair Aerobics for the Elderly [57,35,24,13,3]</p> <p>Dementia - awareness for Black, Asian and Minority Ethnic faith leaders; Cognitive Stimulation Therapy; Dementia Action Alliance [18,12,17]</p> <p>Diabetes - ‘HeLP-Diabetes’ on-line tool; Self- management programme for adults with type 2 diabetes with lay tutor input and peer support; Community Prescribing [28,50,13]</p> <p>Disability – engagement, empowerment and support for disabled people to obtain the services they need to live independent lives and to promote a social model of disability and user run services [19]</p> <p>Drugs - Detox and rehabilitation [48]</p> <p>End of life care - network of community support for people at the end of life, their families and friends [14]</p> <p>Expert Patient Programme – course for people with long-term conditions; New Beginnings for people with mental health conditions [23,36]</p> <p>Men’s health - ManMOT [on-line consultation with GP] [33]</p> <p>Mental health – support meeting for residents who have moved on from detoxification services; Jewish helpline to support individuals in emotional distress; drop-ins in Chalk Farm; Psychological Health: A Foundation Training Course for Faith and Community Leaders; talking therapy and crisis prevention course for faith and community leaders [21,31,45]</p> <p>Older adults – Homeshare to maintain independence at home; Armchair Aerobics for the Elderly [29,3]</p> <p>Pain management - visualisation of pain through photographic images; RCT of effectiveness of self-management courses for people with long term pain compared to usual care [56,39]</p> <p>Parents’ support - Tools for parents [Acutely Sick Kids Safety Netting Information For Families]; parents’ group for parents of children with life limiting conditions or disabilities; Noah’s Ark [4,40]</p> <p>Self-care - follow-up with GP patients after visit to A and E; locality health navigators [42,32]</p> <p>Smoking cessation – No smoking patrol of hospital volunteers offering information about local services for stopping smoking [38]</p> <p>Tuberculosis prevention - Redbridge TB Awareness and partnership [53]</p>

4.2. Analysis of Good Practice Examples – A Discussion of Findings

The scoping exercise and research aimed to highlight examples of the empowerment of people to improve health in North, Central and East London and stimulate the spread and innovation of such work. The definition of good practice depends on the outcomes that any initiative aims to achieve - We have explored this further via case studies [see below].

Preamble: Of particular relevance to the SEEPAC project was Sherry Arnstein's seminal paper on the "ladder of participation" which raised discussion about the types of 'citizen participation'⁴. The intervening years have seen the emergence of a wide range of initiatives aimed at engaging and involving people as 'co-producers' in the decisions that affect their lives⁵. In a range of sectors from environmental management to community development and academic research, members of the public have been offered greater influence over the judgements about purpose, knowledge and resources – judgements traditionally made professionals alone. Whilst the practices and processes of citizen participation have matured⁶, the involvement of public in health care is arguably at a less well developed phase than in other fields. Even within the sector there are great differences. As Dr Libby Sallnow at St Joseph's Hospice [an example contributor] commented, "What matters is that you know where you and your organisation are on the participation ladder and why. It is this understanding that allows you to develop and improve."⁷

A summary of learning for each of the three classifications is detailed here, followed by the profile of a number of case studies which demonstrate markers of progress highlighting notable practice in terms of reach, impact and/or social value. Much can be learned from how the different schemes operate and deliver their activities in patient education and their empowerment for self-care. [A synopsis of the activities identified in this Scoping Exercise may be found in Table A2 within the Appendix].

4.2.1. EDUCATION AND TRAINING

Clinicians, other health service, social care and integrated care colleagues: These examples highlight the potential to develop further knowledge and skills throughout the education and professional/ vocational training of colleagues within the sector. For example, '*Patient journeys*' give students and trained staff an opportunity to gain an insight into the impact of care pathways for patients and carers. They include lay tutors with long-term conditions which ensure that patients' experiences are at the heart of the course and model the collaborative relationship between the health professional and lay person.

There is a need for staff to understand how to make services accessible to people whatever their individual physical, sensory, intellectual, or psychological variations. These may cause individual functional limitation or impairments but they do not have to lead to disability or an inability to access services equitably. Volunteers will also need training related to their specific role if they are in contact with patients, carers or visitors. Significantly these programmes also further enhance and promote the patients' confidence and ability to manage their conditions and to influence others⁸.

Training for staff about collaborative approaches to care in self-management is an integral part of the *Health Foundation's 'Co-creating Health'* programme. Its emphasis on training for health professionals and patients in shared decision making, agenda and goal setting promoting equal responsibility and collaboration between patients and health professionals, is a model of care that provides a structure which has the potential to break down traditional barriers in health care, strengthening partnerships with our local populations with long-term conditions. It includes lay tutors with long-term conditions which ensure that patients' experiences are at the heart of the course and models the collaborative relationship between the health professional and lay person.

To note: Self-management processes need to be embedded in the health care system itself at every stage to ensure that this approach is mainstreamed. Patients who meet clinicians able to work with them in a collaborative approach will be better able to realise their potential in self-care.

Self-management courses for people living with long-term conditions: These courses are significant for developing self-management skills, self-confidence and self-efficacy amongst people living with long-term conditions. Some participants may benefit from the option to attend either a generic course or one which is specific to one type of condition. Although the self-management skills remain the same, a condition specific course can allow people with potentially stigmatising conditions [e.g. HIV, mental health] a safe place to learn and mix openly with the other participants.

The impact of the courses is well-established and they are designed with and delivered by lay tutors. However, their reach varies within and across boroughs. Some are delivered in a community language or provide a choice of generic or condition-specific courses.

To note: Some commissioners and providers have identified the need for greater flexibility and diversity to meet identified but unmet needs such as courses at weekends, courses for young people and courses in a wider range of languages.

Dr Dawn Carnes and colleagues [Centre for Primary Care and Public Health at Barts and The London School of Medicine and Dentistry, QMUL] have undertaken a systematic review [in press] on the evidence of benefit for different types of pain management courses and randomised controlled trial of the effectiveness of self-management courses for people with long term pain compared to usual care [August 2011 to July 2012]. This will further inform the commissioning and delivery of these courses. This is a good example of the growing research evidence base for training in self-management.

Training and education as self-management: Some examples indicate how access to learning can itself help people to manage their conditions and lives. *Core Arts* is a

members-led organisation that offers psychological wellbeing through creative education and practice [see case study below]. The *Cognitive Stimulation Therapy* approach uses a series of sessions exploring themed activities to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group.

Training and courses to raise awareness for healthy living and self-care: Some of the courses provide information, explore attitudes and beliefs and develop skills around key health issues [Relationship and Sex Education, tuberculosis TB prevention]. Others focus on the signs and symptoms of conditions [such as TB and dementia], where and how to get treatment and support for yourself and others [Talking therapy and crisis prevention course for faith and community leaders].

4.2.2. INVOLVEMENT, ENGAGEMENT, EMPOWERMENT AND GOVERNANCE

There are many variations of the Arnstein “Ladder of participation”. Earlier in the report we shared Social Action for Health’s “Spiral of Participation”. Figure 4 represents the “Waterfall of participation” used by Newham Clinical Commissioning Group

Reducing health inequalities by creating a community infrastructure: Organisations at the forefront of this work acknowledge that there is still much to learn to increase levels of participation and empowerment, e.g. Newham GPs and Wayne Farah, Vice-Chair and Non-Executive Director for Patient and Public Engagement, Clinical Commissioning Group. Other organisations aspire to reach the levels of participation achieved in Newham and as such are liaising to identify areas for development. For example, the Community Prescribing project in Newham offers in-active patients who are pre-diabetic or newly diagnosed, community-based physical activity classes. They are supported by a trained community prescription navigator to find the activity that is most appropriate for their needs. Such activities are run by local communities for health [e.g. The Well Centre, Bonny Downs Community Association, Age UK East London, Community Links: Asta community hub, Play, Grow, Sow Stratford, Newham African Caribbean Resource Centre, Subco Trust, London Tamil Sangam and West Ham United gym].

Newham’s vision within primary care is to reduce health inequalities by creating a community infrastructure that connects people with the resources they need to be healthy and supports them to manage the non-medical but health critical social determinants that influence their health status. Similar projects developing community infrastructure run in Redbridge [Fit for Fun, TB awareness, Psychological Health], Stratford Village, Newham [Well-London] and Tower Hamlets [My Weigh].

A number of health service contributors shared their examples of involving people with lived experience, patients, service users and carers in focus groups, course development or as educators. Some were one-off events and others part of a rolling programme. This will only increase if the health system supports the mainstreaming of this approach. Further to discussions above on their work, the Newham Clinical Commissioning Group [CCG] has a Patient Forum which is involved in the whole cycle of commissioning and a Community

Reference Group which consists of local residents and representatives from the voluntary sector and Healthwatch. The aim of the group is to provide an opportunity for local people to have their say about key priorities at the strategic level such as provision of district nursing, psychological support and language services. It is noteworthy that an area within Newham, Stratford Village local people took part in an event to select the local community activities which would be funded as part of their Well London project [participatory budgeting approach].

Figure 4: Newham Clinical Commissioning Group’s “Waterfall of participation”. Variation on Arnstein’s “Ladder of participation”. Social Action for Health’s “Spiral of Participation”.⁴



In Islington the Clinical Commissioning Group [CCG] has involved local people with long-term conditions in a review of self-care in the borough. They participated in a series of workshops and interviews. The first phase investigated contextual factors where obstacles inhibiting self-care may occur such as interpersonal relationships, social norms and environmental factors. Informed by the initial findings, the second phase of research tested the stages of a patient’s journey, to find out at what points these three contextual factors most affect empowerment to self-manage one’s health. The researchers used journey mapping, a service design tool to examine the stages of care experienced by patients with

long-term conditions. They built their own stages of the journey, drawing from established practice in journey mapping from other sectors.

In Hackney, the People's Network [a member-led voluntary group] provides direct input into commissioning of mental health services through its People's Advisory Group. Limited short term funding has supported Choice in Hackney to build its capacity as the only registered charity in the borough providing support for disabled people to obtain the services they need to live independent lives. It has worked to build stronger partnerships between User Voice organisations to promote a social model of disability and user run services. [The social model of disability includes people with physical disabilities, sensory impairment, mental health problems, learning disabilities and long term health conditions]. Healthwatch Hackney has worked with a range of local groups to bring key issues to the attention of the Health and Well-being Board. This has taken considerable contact time to prepare but if the commitments from Board members are carried through, it will have been time well-spent.

The Research and Innovation Forum at The Margaret Pyke Centre engages local people and organisations in setting research priorities, advising on project steering groups and acting as co-applicants on research projects. Also in Camden, Dementia Action Alliance has started engaging people with dementia, their carers and local organisations and businesses to make the local community dementia-aware.

In Tower Hamlets community health action takes the form of Health Wisdom groups. This is a Social Action for Health project which has developed over time since 2007. Now the groups are independent of Social Action for Health, local people set the agenda, deciding what action to take and making changes to improve their own and the wider community's health overcoming barriers and health inequalities. It is the approach of listening to local communities which first drew Social Action for Health's attention to the problems experienced by local mothers using maternity services. This coincided with the start of the statutory requirement for Maternity Services Liaison Committees [MSLC]. Since then Tower Hamlets has developed a thriving Mothers' Support Group whose members attend the MSLC and are part of the decision-making process and service improvement in the borough. Their governance role has helped to make the service more responsive to local mothers and families. It has also fed into training for midwives, Great Expectations which addresses staff attitudes and communication skills. [This example would be worth pursuing].

TalkLab has grown into a pan-London initiative which is available in Haringey and Islington. It brings diverse sets of expertise together with frontline workers, third sector, young people with long-term conditions and parents to design experiments for systems change learn from them and make offers back into the system to nurture sustainable change <http://talklab.nhs.uk/>.

Some of the other examples of collaborative and partnership working have started with individuals [local people, clinicians] or local organisations. It can start small. Each day Dr Jim Lawrie checks the records of patients who have attended the accident and emergency department at Newham hospital and phones them to check how they are feeling. They discuss alternative ways for them to cope should a similar problem arise including what the practice could have done. He is following the example of Dr C.M. Patel who has been doing this for over 5 years at his practice in another part of Newham.

4.2.3. SUPPORT FOR SELF-CARE

Is it contradictory to focus on support for self-care? There is growing disquiet about conceptions of people “as self-sufficient and narrowly rational actors” requiring a simple process of ‘activation’ to self-manage underlying some academic, policy and popular discourse⁸

In our evaluation of the different examples shared under the ‘aegis’ of support for self-care, some proposed re-conceptions of people’s lived experiences summarised as:

- “Vulnerable to bodily change, fragility and limitations
- Exposed to a variety of more and less readily identifiable social and cultural influences
- Socially interdependent, entwined in networks of relationships with others
- Having complex and sometimes competing sets of desires, demands and so on
- Not fully self-transparent [not having complete insight, for example, into what motivates them]⁸

This is not intended to undermine the legitimacy or value of collaborative approaches, rather it emphasises that no one approach is right for everyone and that it is important to build in some flexibility. The Health Foundation’s paper, “*Enabling people to live well*” cited above explores adopting a collaborative approach that goes beyond the joint goal-setting and division of tasks between the professional and the individual to more subtle aspects to their two-way interactions and relationship. “People experience their personal status and identify within relationships. The fine-grained aspects of the ways clinicians relate to [or *are with*] patients can reflect and communicate their attitudinal orientations to them”.⁸

The examples here demonstrate support as a part of self-care which will change over time. Indeed the role of supporter and beneficiary is also inter-changeable as people’s circumstances and experience vary [see Table 3]. The key to understanding those changes using a collaborative approach is about relationships.

Table 3: Essential support initiatives in the region which are putative areas for HE NCEL collaborations

Navigators: advisors on services
Peer-support
Community support
On-line support
Professional care and pastoral support:

Navigators: Several projects employ community or locality navigators to help people to identify appropriate self-care activities or support. There is usually follow up by the navigators to find out how the person is getting on. Equally, the beneficiary can contact the navigator for further assistance. The role of navigator may be a useful model for helping frontline organisations, such as the *Salvation Army*, to refer a person to the appropriate service needed.

Peer supporters: These are trained volunteers or sessional workers who provide support for others around a particular health issue or activity. *The Islington Peer Support breastfeeding network* delivers a comprehensive service to women in the borough by women who have successfully breast fed their own baby for over 3 months. *Health buddies* in Redbridge are trained sessional workers who raise awareness about tuberculosis within their own and other local communities. Many charities and voluntary groups provide opportunities for peer support. For example, parents whose children use or have benefited from Noah's Ark hospice provide support on a voluntary basis to other parents in a similar position.

Community support from befriending and outreach: There are a number of examples which involve befriending and outreach within local communities. Newham bereavement service assesses the bereavement needs in Newham in order to provide support that is sensitive to the cultural, religious and language requirements of the borough's population. The service attempts to engage the community in providing this support using a 'compassionate communities' model. In Hackney *St Joseph's Hospice* and *Social Action for Health* are developing a network of community support for people at the end of life, their families and friends. The project aims to develop skills and confidence in local people to become 'Compassionate Neighbours' and to change the way people are supported and to start a social movement modelled on Kerala's [India] Neighbourhood Network for Palliative Care. Outreach is an important part of all community support as it initiates contact and builds relationships and trust.

On-line support: Not everyone has reliable access to a personal computer so services cannot rely solely on on-line support. However, it can be a bridge or introduction to local services as in ManMOT in Haringey. Equally, it can be a stand-alone tool to help people self-manage their condition or make changes to improve their health ['HeLP-Diabetes' and Down Your Drink]. Big White Wall is an on-line peer support network for emotional health that encourages users to be open about what is on their mind, to learn more about themselves and to work through what is troubling them. The services provided by Big White Wall are delivered in a partnership with the Tavistock and Portman NHS Foundation Trust. The researcher was unable to include this as an example in the time, but it would be worth pursuing.

Professional care and pastoral support: With time and support, this is an area of professional practice which could offer many notable examples. It would also create greater awareness of the skills and creativity required of professionals to support their patients and service users. Where professional care can link in with pastoral support the benefit can be even greater. Redbridge is one borough which has shown on-going partnership working with the voluntary, community, faith and public sectors to support psychological health. The funding of a community based post to support psychological health has provided a means to initially raise awareness about issues and services. Over time this has evolved to meet the training needs of community and faith leaders to be able to support and signpost local

people living with long-term conditions. It has also fostered greater understanding of the complementary contributions made by health service staff and leaders providing pastoral and faith-based support.

The respective success of the following examples can be measured in terms of their reach, impact and social value.

4.3. CASE STUDIES

Advanced development programme:

This is a programme of workshops designed for clinicians to develop the skills required to support and motivate patients to take an active role in their own health, e.g. motivating and managing patients with long term condition. It includes the training in skills to facilitate change in patients' self-management behaviours. The Co-Creating Health model [upon which the ADP is based] with its emphasis on training for health professionals and patients in shared decision making, agenda and goal setting promoting equal responsibility and collaboration between patients and health professionals. The benefit is a model of care that provides a structure which has the potential to break down traditional barriers in health care, strengthening partnerships with our local populations with long-term conditions.

London: a better place for young people to grow up in: *TalkLab Consortium*

This is a group of designers, filmmakers, health professionals, system change experts and young people with a shared purpose – to do just that. It is an interdisciplinary group working closely with an acute Paediatric department. It is an innovative approach to co-production which has been attracting attention across the city, most recently in Haringey and Islington. TalkLab is not the only example of engaging young people in planning improvements to their care and lives but it has the potential to be a more sustainable approach as it is not tied to any one location. It also supports an approach to help children and young people with long-term and life-limiting conditions to plan and prepare for transitions, particularly to adult services. The project certainly demonstrates reach and social value. Its impact will be better understood if they are able to secure funding for evaluation.

Pain Management:

Several examples were chosen as pain often accompanies many people living with long-term conditions.

Dr Dawn Carnes and colleagues [Centre for Primary Care and Public Health at Barts and The London School of Medicine and Dentistry, QMUL] have undertaken a systematic review of the evidence of benefit for different types of pain management courses and a Randomised controlled trial of the effectiveness of self-management courses for people with long term pain compared to usual care [August 2011 to July 2012]. Their findings are to be published this year and provide an insight into learning to be shared about self-management for people living with pain. There are also two free one day conferences about non-drug pain self-management, one in London and one in Warwick featuring the work.

The systematic review found evidence of benefit [compared to usual care or waiting list control] in courses that:

- included a psychological component;
- were led by a health care professionals [better outcome for pain severity] and/or lay tutors [better outcomes for self-efficacy];
- were group based [as opposed to one to one or internet driven];
- were short [<8 weeks] or long [> 8 weeks] the length, or duration of the courses did not affect outcomes.

Qualitative research highlighted how important social interaction was for course participants. The randomised controlled trial followed 703 people with long-term conditions in London and Warwickshire over one year. Participants were recruited from 33 GP practices. They were randomly allocated to receive the self-management course [and continue with usual care] or continue with usual care and a relaxation CD. The self-management courses were for between 8-16 participants delivered over 3 days in one week [10.00 am -2.45 pm] with a 2 hour follow-up session 2 weeks later to discuss achievements and setbacks. The course was led jointly by a lay tutor [who was living with a long-term condition] and a health care professional. All the tutors were trained together as a group. The course was based on cognitive behavioural principles and it covered pain education, reflection, acceptance, problem-solving, goal setting and action planning, communication, socialisation, relaxation posture and movement. Sixteen courses were done in London, these are now completed [August 2011 to July 2012].

Professor Joanna Zakrzewska [Facial Pain Unit Lead, Eastman Dental Hospital] points out, “as all pain specialists know, patients attending pain clinics need extra consideration as they often come to us once all other specialists have failed to provide support.”

http://www.britishpainsociety.org/members_newsletter.htm Pain News Summer 2012, p 92. Time to listen and explain.

In this example, the patients living with pain have worked with a photographic artist to create images that either describe the type of pain they have or the effect it has on them. These are then used by other patients to help the clinician understand their pain especially if they are a non-English speaker. The cards are also used in psychology sessions to understand effects of pain. Currently there are 54 different cards and patients are asked to select a few cards that describe their pain. Some images have fire and burning which depicts neuropathic pain, others knives depicting sharp pain and electrical images or stones depicting heavy and dull pain. The team has also produced a series of images as patients go through their service to show that there is hope at the end even if not a cure. As part of the development, conversation between patients with pain and their clinicians using the cards have been filmed. A multi-disciplinary team of clinicians, psychologists, linguists, and artists are analysing these conversations from different perspectives to better understand how these images have been used by different clinicians seeing pain patients to see how they may work. This initiative has the potential to reach many people living with pain as it does not rely on words. Its impact is currently being evaluated. If it does demonstrate its benefit, there is also scope to develop it as an app for charting progress.

Commissioning for self-care in Islington:

The systematic approach to self-care commissioning in Islington is evident by the number of examples cited. Likewise, the links with the Health Foundation demonstration project 'Co-creating Health' have provided an invaluable resource and opportunity for reflection and shared learning. There is access to Self-Management Courses for adults with type 2 diabetes for people with long-term conditions in English and Turkish, with a peer support network and Expert Patients' Programmes [generic courses for people with long-term conditions and one for people with mental health conditions]. Crucially there is also a course for clinicians [primary and secondary care] to further develop their knowledge and skills to make collaboration with patients in the self-management of their condition achievable and empowering. There is interest in developing this as an on-line resource for parts of the course to make it more accessible with greater reach. There would still need to be a practice-based element to refine skills.

Suggestion: To ensure that health professionals are trained to work cooperatively with expert patients across HE NCEL to derive benefit from their experience, knowledge and sharing issue empathetically with new patients

Health navigators are a relatively new role in Islington. Two full-time members of staff with good local knowledge support people with long-term conditions to access activities which can help with their self-management. Alongside this, the engagement lead from the CCG is currently exploring options to commission community-based groups and organisations to get involved with self-care support in Islington. So the two aspects of development should evolve to complement one another.

Islington could also draw upon the experiences from Social Action for Health [East London] and RedbridgeCVS as they highlight the importance of longer term funding and support to build the relationship and trust necessary for a community development approach. As well as looking to what can be developed in Islington, there is interest in working cross-border with other commissioners and providers so that the money follows the patient or service user. There is a willingness and openness to trial new approaches and several of the ideas included in the recommendations section originated from Islington.

Core Arts - Psychological Wellbeing through Creative Education and Practice

"Core Arts was set up in 1992 by an artist, Paul Monks, using vacant space in the old Hackney Hospital. His studio became a haven for artistic expression, as curious patients seeking refuge from the monotony of life on the psychiatric ward immersed themselves in a world of paint and colour.

Core Arts is now well-known as an innovative leader in mental health creativity, cultural diversity and social enterprise. With no analytical or clinical agenda, its expansive programme and member led ethos focuses on what people can achieve, supporting them to increase their capacity for innovation and learning, problem solving, confidence and leadership skills. Run by professional artists, writers and musicians in their own right, some of whom have been through the psychiatric system themselves, creates a genuine, exciting atmosphere of mutual learning and shared experience." [see Figure 5]

Figure 5 Core Arts – location and examples of their work



In describing their approach, Core Arts [based in Hackney]: members, tutors and volunteers come from across London. People with personal budgets often choose to spend their allocation for community care services on a personalised programme from Core Arts. Therefore, the reach of the organisation goes beyond Hackney to other boroughs. There is a commitment to reaching the people who face the toughest barriers. The impact on people's lives and self-management of enduring and severe mental health conditions has influenced many others, including statutory services, to improve the potential for equality and lasting change for people who are generally regarded as having little to offer society. The ethos of valuing everyone and their contribution runs through all aspects of Core Arts as a members-led organisation.

Maternity Services Liaison Committees [Tower Hamlets and Newham]

This project demonstrates positive impact and social value for local mothers, their families and staff working in maternity services reaching across two boroughs. Social Action for Health first started to host the Tower Hamlets Maternity Services Liaison Committee [MSLC] Project in 2009. In Tower Hamlets, over 100 women participate in the Mothers' Support Group from Bengali, Somali, White British, Nigerian, Angolan, Chinese, Indian and African/Caribbean communities with a regular group of around 15-20 women. In Newham [started in 2012] over 50 women participate in the Mothers' Support Group. When gathering feedback Health Guides and other members of the Mothers' Support group get women to talk about the positive aspects of their experience and to propose solutions for any negative facets to their care. At the groups, mothers talk about the agenda for the next Liaison Committee, Health Guides and other members share any issues local women have raised and the group decides who will attend the next committee meeting. Usually about 9 local mothers attend to feedback issues at the meeting. The Mothers' support group also provides training and support for women to take on new roles in the community, e.g. as health guides.

There has been a growing appreciation amongst local women about the pressures on staff and they have suggested ways to support them. However, attitude and communication remain key issues which need further improvement so this is the priority for the committee and staff training.

Redbridge TB Awareness Project and Redbridge TB Partnership

This award-winning project has attracted a great deal of attention from neighbouring boroughs and European colleagues. There are a number of reasons for highlighting this example. First, it demonstrates a thorough understanding of the health issues affecting

people within the borough and makes rigorous use of local public health intelligence. Secondly, the delivery of the project has been successful as it has been supported by an effective partnership with a broad membership. Thirdly, the model of using community health buddies has created a community infrastructure of knowledge and support which is more sustainable. It is an approach which RedbridgeCVS would use for other health issues.

It aims to:

Raise awareness of TB symptoms and TB services by delivering training amongst local communities as well as health professionals and providing education materials to support the awareness-raising events.

- Support TB prevention, early diagnosis and treatment through joint working between the group members
- Wherever possible, provide Redbridge community representation in other TB policy forums within and outside Redbridge.
- Encourage local and regional policy makers and commissioners to reflect these objectives in their policy and commissioning decisions, both in the area of TB and in other areas which impact on the prevention and control of TB.
- Inform the work of TB Alert [national charity] within the Redbridge area.

5. Recommendations on the best opportunities for HE NCEL: Systematically support the education and empowerment of patients and carers to be experts in their own care

The scoping exercise has provided an outline of a broad range of examples found in a relatively short time frame. Whilst not exhaustive, there were interesting projects which would have enhanced this learning but time and work pressures prevented their participation. Contributors were asked about what would improve their activity/ intervention and any unmet need or opportunities which might affect health and self-care. The responses are categorized into the following broad themes:

- Education and training
- Patient empowerment
- Support for Self-Care
- Raising awareness of activities and schemes
- Accessibility of services

Education and Training

Training for health staff:

- Advanced Development Programme to be more accessible across London, possibly via e-learning packages or workshops
- Initial training and continuing professional and vocational training for staff in primary, secondary and integrated care about sensory impairment, carer awareness, dementia awareness, the benefits of self-management courses, asthma management, TB diagnosis and treatment
- Wider use of the patient journey and their experience of care pathways as an approach in education and practice
- Use of the clinician-focused evaluation tool to measure learning and retention
- Breast feeding training in midwifery and health visiting curriculum

Courses for people living with long-term conditions

- Self-management courses and expert patient programmes in different community languages, specifically for younger people, for pain management
- Access to, or development of, visual and hands-on teaching resources, e.g. pain management, health implications of obesity

Broader education

- Asthma education in schools

Networking and shared learning

- Development of broader networks collaborating across sectors: e.g. those involved in *Self-management and Expert Patient Programmes* proposed by Whittington Hospital.

Empowerment

- Education workshops and resources for encouraging change in professional culture for co-production in the management of health
- Partnerships with communities on access to resources to take charge of their own health e.g. promoting healthier communities. [It is often services which are hard-to-

reach, rather than the people who would access them – comment from local Healthwatch].

- Greater involvement of users in research with less bureaucracy
- Offer training opportunities and services across borough borders to maximise uptake of places and access but also to put the patients at the heart of the service
- Faith and community leaders recognised by health professionals and policymakers as professional peers
- Funding of shared learning sets around community based approaches
- Greater engagement and empowerment of: people with mental health problems, and people with dementia and their carers

Support for Self-care

- Development of an e-learning version of the self-management programme [though it has evaluated less favourably in comparison with a group setting for pain management]
- Video suite of stories people with long-term conditions [Whittington is developing this]
- Out-of-hours support for patients

Raising Awareness of Activities and Schemes

- Promote the known examples which demonstrate reach and sustainability, impact and social value
- Make the most of the award winners' learning
- Film making the case for Self-Management Programme, Advanced Development Programme and peer support
- Signposting information, e.g. Homeshare
- Services are hard to reach not groups
- Greater awareness of community based and non-medical approaches to self-care such as arts, horticulture
- Advertising relevant learning opportunities so that there is greater awareness. HE NCEL a credible source if linked with local communities could broaden awareness

Services

- Longer cycle of funding [beyond 1 year] and a longer lead in time for applications so that services are less affected
- Improved accessibility to services:, e.g. services for men; Home dementia services, exercise groups for disabled, culturally appropriate youth activities, drop-in breastfeeding service, , talking therapies in community languages and detox services
- Faith and community leaders wanted to play a part in supporting NELFT's chaplaincy services and local hospitals – and should be approached and trained accordingly.
- Drug and alcohol issues within local communities to be taken seriously – to be supported by professionals who are aware of cultural norms and adhere to professional ethical guidelines [especially confidentiality]

6. TANGIBLE STEPS THAT HE NCEL COULD TAKE IN 2014-15 TO SUPPORT CURRENT INITIATIVES

The activities found by the SEEPAC project span education, empowerment and support for self-care. These markers of progress are not confined to any one type of organisation, sector, specialism or condition, but represent innovation in the form of demonstration sites as well as smaller changes in daily practice. All have something to teach and recommend. However, where there is evidence of effective partnership-working and coordination there are tangible benefits for local people and services. Nevertheless, those at the forefront of collaborative practice stress the importance of mainstreaming these approaches and further embedding them within care pathways if the full benefits are to be realised.

6.1. *The leadership role of HE NCEL in making this aspiration a reality:*

HE NCEL has made a significant commitment to changing the culture in the health economy by the commissioning of this scoping exercise. It has demonstrated the legitimacy of the work and modelled the very collaborative approaches being advocated. However, the unmet need and recommendations listed in the previous section dictate that no one sector or organisation can achieve this alone. It is clear from the list of examples that much of the activity is on the fringes of the core mandate of HE NCEL. However, as a network organisation drawing on employers, universities, medical schools and an Academic Health Sciences Network, it is well-placed to play a central role in facilitating and influencing progress.

There is a real case to be made for the benefits of the shift to collaborative and proactive health care and to keep it on the agenda as part of patient-centred service change and patient-led pathway redesign. However, there needs to be clarity about what engagement and empowerment in health and self-care actually look like. The examples gathered so far could form the core of a growing directory which could inspire and inform local people, providers and commissioners about what is practically possible. Whittington Health has already identified the need to communicate more broadly about the benefits of self-management to clinicians and is intending to commission a film for this purpose. It may be appropriate for HE NCEL to support this venture so that it can reach an even wider audience of educators and practitioners.

Culture change is a theme which resonates through many of the examples. Education, training and workforce development are instrumental in establishing professional and multi-disciplinary culture and practice. As the largest Local Education and Training Board in London, HE NCEL has the mandate to support the NHS workforce and health community to provide the best possible outcomes and experiences for patients and people. Therefore, this is an obvious area of activity for HE NCEL to support. Specific suggestions for undergraduate, postgraduate and continuing professional development are included focusing on patient journeys and experience.

Sustainability remains an issue for many of the projects. The risk is that they may not survive to demonstrate their impact sufficiently to attract longer term funding. HE NCEL could explore the feasibility of supporting evaluation of projects through education placements or direct funding. If this was appropriate, the SEEPAC steering group would be delighted to assist HE NCEL in identifying suitable projects to approach.

6.2. Suggested activities for HE NCEL as tangible next steps

- Learning event/ colloquium-based around these findings to share the existing learning and to engage with stakeholders to find out what might be most useful
- To commit to a live on-line directory populated and curated on an on-going basis with examples which would involve development of a simple website, database, relevant tagging and search function. It would need to traverse different sectors and cultures to provide effective shared learning
- To explore the possibility of developing a blended online and skills based experiential learning Advanced Development Programme [2/3 of the course more widely available] with potential partners such as the Health Foundation and/or the local demonstration site at Whittington Health, e-health unit [University College London], and Islington CCG. To incorporate this training and/ or a patient journey approach more widely into undergraduate and postgraduate healthcare education programmes
- To commission basic training that covers key information about making services accessible such as dementia awareness, sensory impairment, carer awareness, information routinely written using easy read for people with learning disabilities
- To promote the provision of Self-Management and Expert Patient Programmes courses with colleagues/ services providers
- To encourage stronger links between students and community based organisations using collaborative approaches to increase greater understanding and respect such as community placements and volunteering
- To generate innovation and development with seed funding to provide some continuity for promising projects to get to a stage of evaluation or beyond
- To support the further development of the patient journey map through research or prototyping with patients, carers and practitioners. [Research recommendation from OSCA [social change agency] report 2013 to Islington Clinical Commission Group]

REFERENCES

1. Newbronner, E, Chamberlain, R. Borthwick, R., Baxter, M., Sanderson D Sustaining And Spreading Self-Management Support – Lessons From Co-Creating Health Phase 2, Health Foundation September 2013
2. Co-creating Health Health Foundation 2008
<http://www.health.org.uk/public/cms/75/76/313/551/Co-creating%20health%20briefing%20paper.pdf?realName=vK5jXO.pdf>
3. Entwistle, V.A., Cribb A. Enabling people to live well: Fresh thinking about collaborative approaches to care for people with long-term conditions. The Health Foundation May 2013
4. Arnstein, S R [1969]. "A Ladder of Citizen Participation," JAIP,35 [4] 216-224
<http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>
5. "Participate Now" a platform for sharing initiatives in Public Participation from the Open University and Open Democracy, the Knowledge Portal called 'Practice in Participation' [www.practiceinparticipation.org] and Participaedia from Harvard and the University of British Columbia
6. Bell, S, Morse, S. and Shah, R. [2012]. Understanding stakeholder participation as part of sustainable development. Journal of Environmental Management, 101[1] 13–22.
7. Sallnow, L., Paul, S [2014] Understanding community engagement in end-of-life care: developing conceptual clarity. Critical Public Health DOI 10.1080/09581596.2014.909582
8. Da Silva D. Helping People Help Themselves. The Health Foundation, May 2011

APPENDIX:

Supporting Education and Empowerment of Public, Patients and Carers

QUESTIONNAIRE ITEMS:

THE ACTIVITY AND HOW IT WORKS

1. What is the name of the activity?

2. What are the main aims for this activity? [For example, relating to patient self-management, decision-making role of local people in service planning, patient education and support, leadership roles within the community, expert patients as teachers, etc.]

3. Please describe the activity: What learning is included? [Optional]

[Select all that apply]

Relaxation, e.g. physical movements, mindfulness, stress management, yoga,
Problem-solving, psychological approaches [e.g. cognitive behavioural therapy, behavioural change techniques]

Learning to be part of a group/community

Learning to use equipment for health and health monitoring

Patients/carers as educators, e.g. NHS staff and health professional students

Learning about health and medical information

Building confidence and skills to find your way around health services and talk to NHS staff about your health

Building confidence and skills in taking on new roles and responsibilities

Building confidence and skills to take on a governance role in health and health services

Other [please specify]:

4. How do potential participants find out about the activity? [For example, word of mouth, invitation from a health professional or outreach worker, link via a website or social media]

5. Where do the people who participate in the activity come from? [Select all that apply]

Barking & Dagenham Barnet Camden City Enfield Hackney Haringey

Havering Islington Newham Redbridge Tower Hamlets Waltham Forest

Do not know Other [please specify]:

6. Who is this activity for? [For example, young carers, people with long term health conditions, specific cultural groups [e.g. Bengali-, Gujarati-speaking etc.], open to any individual or group.]

7. Which group started up this activity and how long has it been running? [For example, a partnership between 2 or more organisations [names], an informal partnership of young people, parents, sports groups and youth workers wanting to improve facilities for teenagers in their neighbourhood [2 years], staff and patients from GP practice [name; 4 years]

8. Who decides what activities should happen? [For example, health professionals, community health champion, service users, or planned and decided jointly]

9. Who runs the activities? [For example, a network of local community groups, expert patients, a team of different health professionals, a partnership of local people, or volunteers.]

10. How often does the activity take place and how long are the sessions? [For example, a weekly group that lasts for 2 hours, a one-off training course, and every appointment at the clinic] Please specify

11. Where does the activity take place? [For example, place of worship, community centre, GP practice, school]

12. What challenges [if any] have people faced participating in this activity? [For example, needing extra support to get started, respite cover or child care, transport, communication difficulties, lack of self-confidence, worrying about what happens after the activity ends.]

13. What are the challenges [if any] for people running this activity? [For example, getting enough people involved, keeping people motivated and attending regularly, enough time to build links and trust with local groups, access to suitable, affordable locations, gaining new skills, getting support from others, and showing the activity works.]

WHAT DIFFERENCE THE ACTIVITY MAKES

14. What effects has this activity had on the participants and those running it? [For example, feeling more positive, better informed, able to walk to the shops, mixing with other people, being more confident, more in control of own health condition, more job satisfaction, better understanding of what matters to local people, better use of patients' and staff time.]

15. Has this activity affected the way participants engage with others? [For example, started volunteering for a homeless charity, trained as a patient educator, joined the tenants' association, accessing health service appropriately]

16. How do you know whether the activity is successful? [For example, user forum, feedback surveys, audit, research evaluation, anecdotes.]

17. What would improve this activity? [For example, extend opening hours; start up in another area, include patients as co-trainers on a self-management course, more funding, independent evaluation of the activity]

18. We would be interested to hear about any unmet needs or other opportunities for improving public, patient and carer engagement and self-care. Please give details below so that we can feedback to HE NCEL

WHAT SUPPORTS THE ACTIVITY

19 [a] How is the activity funded? [For example, core funding, a charitable grant, a contract or service level agreement, sponsorship, only volunteers' time and skills] Please explain below.

19 [b] How many people are involved in running the activity? Please give details of approximate hours of staff and volunteer time per week.

20. What knowledge, experience and skills are needed for the activity? [For example, medical or health knowledge, technical knowledge of how equipment works, lived experience of a long term condition, advocacy skills, volunteer management skills.]

RESOURCES, REPORTS AND CONTACT DETAILS

21. What resources are available to support or promote your activity? [For example, self-care DVDs, short interview clips with service users and staff, reports, articles]

22. Would you be willing to make these resources available for other people to share?

23. If you are willing to be listed in a directory for HE NCEL, please supply contact details.

- Name of Organisation
- Name of Contact
- Contact details
- Web site

Table A1: Examples identified across the different London Boroughs served by HE NCEL

On-line	Pan London	Barnet	Camden	City	Enfield	Hackney
Down Your Drink	Jewish helpline	CAB Macmillan Care	Advanced Resusc of the Newborn Infant – course	Homeshare project	Carers' passport	Barts Sexpression
HeLP diabetes	Salvation Army Residential Detox Centre	Focus group for parents	Cognitive stimulation therapy	Interactive workshop on living with blindness and visual impairment	Enfield Carers Hospital Support Worker	Compassionate neighbours
User involvement in the Men's Safer Sex [MENSS] website development	User engagement in health and social care one borough	Parents' Group Noah's Ark Hospice	Dementia Action Alliance	Pain management - Systematic review and RCT of the effectiveness of self-management courses	GP liaison project	Core Arts Psychological Wellbeing via Creative Education and Practice
			Drop-ins at Chalk Farm Corps [church and facilities]			Disabled person's user-led organisations and capacity building
			Patient journey			Pain management - Systematic review RCT of effectiveness of self-management courses
			Research and Innovation Forum, The Margaret Pyke Centre			People's advisory group
			Sing for your lungs			User involvement Health and Well-being Board

Haringey	Islington 1	Islington 2	Newham	Redbridge	Tower Hamlets
Carers' information and support	Advanced development programme [clinicians]	Locality Health Navigators	Barts Sexpression	Armchair exercise for older people	Barts Sexpression
Co-production - Talklab with young people link	ASK SNIFF - Acutely Sick Kids Safety Netting Information For Families	New Beginnings Expert Patient Programme	Community Prescribing	Dementia awareness for BAME groups	Health Action - Wisdom Groups
Focus group for parents	Asthma focus groups with teenagers and children	No Smoking Patrol	Maternity Liaison Services Committee	Fit for Fun	Interactive workshop on living with blindness and visual impairment
ManMOT	Breastfeeding peer support programme	Patient journey	Newham Bereavement Service	Psychological health foundation training for faith leaders	Maternity Services Liaison Committee
Patient journey	Breastfeeding workshops for parents	Review of self-care	Pain management - Systematic review and RCT of the effectiveness of self-management courses	Psychological health: talking therapies and crisis prevention	My Weigh
Sing for your lungs	Co-production - Talklab with young people	Self-management course diabetes	Participative budgeting	TB awareness	Pain management - Systematic review and RCT of the effectiveness of self-management courses
	Expert Patient Programme	Sing for your lungs	Patient follow-up after A and E visits		
	Focus groups for parents		Stratford Village Well London Project		

Table A2: Synopsis of the Activities Identified in the SEEPAC Project
Direct collaborations between community and ‘front line’ NHS or medical school colleagues highlighted

Name of the activity	Main aims of the activity	Description of the activity.
<p>1. Advanced Development Programme [ADP]</p>	<p>This programme is designed for clinicians to: Develop the skills required to support and motivate patients to take an active role in their own health. Improve skills at motivating and managing patients with long term conditions; Learn skills to facilitate change in patients’ self-management behaviours;</p> <p>Learn skills in setting an agenda with patients for each consultation; Learn to set and follow-up on self-management goals with patients. In addition to the three workshops this training provides: improved clinical outcomes; Greater job satisfaction for professionals from working in partnership with patients.</p> <p>The Co-Creating Health model [upon which the ADP is based] with its emphasis on training for health professionals and patients in shared decision making, agenda and goal setting promoting equal responsibility and collaboration between patients and health professionals.</p> <p>It is a model of care that provides a structure which has the potential to break down traditional barriers in health care, strengthening partnerships with our local populations with long-term conditions.</p>	<p>Delivered in 3 sessions approximately one month apart. Training: presentations, experiential exercises and skills practice with professional actors. Innovative features include: The role of people living with a long term condition as co-trainers alongside local clinicians, The use of patient feedback data to help clinicians assess their strengths and identify their own development goals</p> <p>The course is delivered to multidisciplinary and multi- agency groups of people. The ADP focuses on the skills necessary to create the following processes, called “enablers” that are central to success.</p> <p>These enablers consist of: Agenda setting: helps the health care professional to co-create an agenda with their patient to consider and explain what both parties would like to achieve during the consultation. Collaborative goal setting: uses a patient-centred approach facilitated by the clinician to elicit and agree on specific, achievable and realistic behavioural goals that the patient wants to achieve. Goal follow-up: using systems to ensure that there is continual regular contact between patient and their health care providers, ensuring support, motivation and advice in relation to their goal[s]. Theoretical knowledge, an understanding of the evidence base, and practical skills practice are covered and tested.</p>
<p>2. Advanced Resuscitation of the Newborn Infant – course</p>	<p>To improve competence and confidence of health care providers in responding effectively to new-born emergencies / awareness of importance of human factors and communication within team and with family in managing the sick new-born infant</p>	<p>A two day simulation based course</p>

Name of the activity	Main aims of the activity	Description of the activity.
3. Armchair Aerobics for the Elderly	Mobility for older adults / social interaction	Light exercise for older people Armchair aerobics
4.ASK SNIFF - Acutely Sick Kids Safety Netting Information For Families	To devise an online educational tool for parents to be able to identify when their child is unwell and to seek medical attention promptly	Taking short video clips of unwell children in A&E or on the ward [with written consent from parents] to eventually use in an online/DVD format educational tool for parents to be able to spot the signs that their child is unwell, when to seek medical attention, to act as safety netting advice for parents
5.Asthma focus groups with teenagers and young children	<p>To provide an opportunity to learn more about asthma and check out differences in understanding</p> <p>To involve young children and teenagers with asthma and their families in the development of services To provide an opportunity for the young people and their families to link in with charities and the local authority as well as the wider NHS team.</p>	<p>Two focus groups have been planned with children with asthma and their families.</p> <p>The first has already taken place [teenagers and younger children] Held at Arsenal FC.</p> <p>Attended by representatives from Asthma UK, Islington Clinical Commissioning Group, the Children and Young People's Officer from Islington Council, staff from UCH and the Whittington.</p> <p>Separate sessions were run for younger children, teenagers and parents.</p> <p>Younger children: focused on what asthma is and producing some fun resources with key messages about it.</p> <p>Teenagers discussed what it was like living with the condition with a psychiatrist who is very experienced in liaison work with young people. Parents shared their experiences of NHS services and particularly accessing health care in emergencies.</p> <p>The second focus group will be just with teenagers and their families. This will concentrate on the transition to adult services. There will be a chance to learn about the differences to paediatric service, but the young people will be able to talk about what they would want from their patient journey. The learning from both focus groups will be combined and used to make service improvements.</p>
6.Barnet Citizens Advice Bureau Macmillan Project	Assisting patients and their families who suffer from cancer to sort out their finances and help them claim welfare benefits	Meeting patients at the hospital where they are being treated or we offer appointments in bureau or home visits when they are not well enough to visit outside their home.

Name of the activity	Main aims of the activity	Description of the activity.
7.Barts Sexpression	<p>To provide comprehensive and age-appropriate Relationships and Sex Education [RSE] to young people within our local communities [Tower Hamlets and Newham].</p> <p>To empower young people to make autonomous and informed decisions about sex and relationships through delivering effective, interactive RSE via trained medical student volunteers.</p>	<p>Go into local schools, and teach groups of young people about the following topics: sex, relationships, STIs, contraception, self-esteem and decision-making.</p> <p>A variety of methods and media are used, including quizzes, games and video media.</p>
8.Breastfeeding Peer Support Programme – Islington	<p>To improve the rate of initiation and continuation of breastfeeding in Islington. As well as initiating the post of Infant Feeding Coordinator to lead Islington towards Baby Friendly accreditation</p>	<p>In 2006, the Islington Strategic Partnership initiated a Breastfeeding Peer Support Project as part of their healthy eating interventions to tackle the obesity in children of Islington and following the government aims of increasing breastfeeding rates to improve child health and reduce health inequalities.</p> <p>By 2009 funding enabled start of the “enhanced” project, employing some of the volunteers [1, then 1.5 WTE] to extend the reach of peer support to: • postnatal wards at Whittington Hospital, providing early support • home visits within 2-3 days of leaving hospital to women in 3 targeted wards where breastfeeding rates were lower – enabling resolution of any difficulties early at the time of the highest drop-off rate In 2010, extra funding enabled employment of further 1.5 WTE peer supporters to 3 WTE, increasing reach to: UCLH hospital postnatal wards; and now 3 wards in the south of the borough [Caledonian, Bunhill, Canonbury]</p>
9.Breastfeeding workshop for parents	<p>To provide basic information to women and their partners to help them get breastfeeding off to a good start.</p> <p>To provide some of the input that women would have previously gained culturally from other family members.</p>	<p>A 2 hour workshop for pregnant women and their partners which provides basic information about breast feeding and getting started in the first days and weeks. It is based on a curriculum which is approved by the UNICEF Baby Friendly Initiative. Alongside some myth busting, there is time for questions and discussion. An appointment to have an individual consultation with the infant feeding specialists can be made in certain circumstances, e.g. a woman expecting twins. Part of the Whittington Hospital's bid for UNICEF Baby Friendly Initiative [BFI] accreditation. Now involves asking women for feedback about their experiences with infant feeding + greater emphasis on informed choice and the importance of the relationship between the mother, her baby and the wider family.</p>

Name of the activity	Main aims of the activity	Description of the activity.
10.Carers Information & Support Programme	Education, information advice and support for carers of people with dementia who are patients of Haringey Memory Service	An eight week course organised and facilitated by Memory Service staff. Each week has a different topic and speakers are invited in to present to the carers
11.Carer's passport - supporting carers of inpatients in hospital	To allow carers to attend a ward at a time convenient to them and the patient. To allow carers to benefit from cheaper car parking in the hospital car park. To remind staff that carers are important to many patients especially those that are vulnerable, e.g. dementia, chronic conditions	Carers are given a card to carry on the ward. They present the card to our cashiers and get a card for their car and discounted parking rates for a week's parking.
12.Cognitive Stimulation Therapy group	To give people with mild to moderate dementia space where their opinions are heard and validated through exploration of a range of exercises linked to different aspects of life. The UK Government NICE guidance on the management of dementia recommend the use of group Cognitive Stimulation for people with mild to moderate dementia, irrespective of drug treatments received.	This weekly session is part of a wider programme* To make opportunities available for people with dementia to engage in activities and have their contributions heard and validated. Cognitive Stimulation Therapy CST is an evidence-based programme with a structured approach which looks at different topics each week. These include food and drink, childhood and school days; current affairs, sounds; people and places. This weekly group session [90 minutes] runs alongside a parallel session for group members' carers. In the final half hour, both groups join together for refreshments and a discussion about what both groups have been doing and discussing. There are 14 sessions of themed activities which can continue as a maintenance activity afterwards on a monthly basis. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. The effects of CST appear to be of a comparable size to those reported with the currently available anti-dementia drugs. The wider programme includes a creative memory project, guided museum and gallery visits and a gardening project is about to begin.

Name of the activity	Main aims of the activity	Description of the activity.
<p>13. Community prescribing – diabetes</p>	<p>To offer in-active patients who are pre-diabetic or newly diagnosed community-based physical activity classes.</p> <p>To offer a range of options which allow people to participate as part of a group or hub so that there is a social aspect to the activity.</p> <p>To promote the services of local community providers so that local infrastructure is developed and maintained.</p> <p>To deliver an evidence based approach which enables local people and communities for health to take action to improve individual health and strengthen local infrastructure</p>	<p>Newham has the third highest rate of type 2 diabetes in the UK with 18,577 people [5.2% of residents] diagnosed. In this pilot programme, patients from four GP practices can be referred by their GP or practice nurse to participate in a wide range of free activities run by local groups. These encourage people to be more active in a group setting. After a discussion with the GP or nurse, people speak to a community prescription navigator who shows them video clips of the activities and helps them to identify which option would work best for them.</p> <p>[The navigators are trained and paid staff that can support and advise people about starting to exercise safely].</p> <p>Activities range from gardening, Zumba, chair-based exercise, tai chi, gym hubs, Nordic walking.</p> <p>The GPs have developed the inclusion and referral criteria. The funding for the activity follows the patient. If someone finds the activity does not suit them, community providers can support and signpost them to other appropriate classes within the scheme. [There is a bonus scheme to encourage retention].</p> <p>Such projects often have a dropout rate of 80-90%. This pilot has had a 50% success rate.</p> <p>There is an evaluation running alongside the pilot to assess whether the evidence-based process has been successfully implemented. They take place in local community venues. Sessions can be flexible to meet the needs of different groups, e.g. women and men only, week days and at weekends.</p>
<p>14. Compassionate Communities Hackney</p>	<p>Developing a network of community support for people at the end of life and their families and friends.</p> <p>Aims to develop skills and confidence in local people to become 'Compassionate Neighbours' and to change the way people are supported and to start a social movement</p>	<p>Local people interested / volunteers are identified through outreach work. Volunteers have a 6 day training course over 6 weeks, run by Social Action for Health and St Joseph's Hospice. Once trained, they become a 'Compassionate Neighbour' are linked with a carer or an individual with a life threatening illness to support them socially and emotionally, to negotiate health and social care services and to empower them to remain a connected part of their community.</p> <p>Compassionate Neighbours also raise awareness of issues relating to death and dying among their wider community and look at ways of initiating social change in relation to them.</p>

Name of the activity	Main aims of the activity	Description of the activity.
15.Co-production - TalkLab with Young People	<p>To enable young people with long-term conditions to become 'co-producers of health and autonomous partners in treating, managing and preventing disease.</p> <p>To equip them with the skills needed for the above and to help them to lead fuller lives</p>	<p>Bring diverse sets of expertise together with frontline workers, third sector, young people and parents to design experiments for systems change, learn from them and make offers back into the system to nurture sustainable change</p>
16.Core Arts - Psychological Wellbeing through Creative Education & Practice	<p>To use the arts to break down many of the prejudices associated with people with mental health problems and promote access and participation</p> <p>To provide an environment in which our members are able to express themselves and their ideas and know they will be heard and respected To respond to our members' creative assets, drive and imagination and celebrate their talent and abilities through exhibitions and events</p> <p>To use Social Enterprises and Social Firms to offer new opportunities for individuals to become economically independent To strengthen local networks to help members integrate into the community</p> <p>To focus on quality and equality in all aspects of our work To ensure the organisation's direction is dictated by those who use it</p>	<p>Core Arts combines being able to understand the experiences of psychiatric patients with a natural ability to nurture individual artistic talent.</p> <p>To see beyond the individuals diagnosis and look at the person as an artist who also happens to experience mental distress.</p> <p>At Core the sense of equality is evident in the ways in which diversity is valued, addressed and celebrated. Where often individuals are seen as being 'unemployable' and economically void, here their skills are highlighted, their strengths developed and their confidence raised.</p> <p>Core Arts is open Monday to Friday on a term-time basis with additional events and activities running outside of main hours.</p> <p>Runs 50-60 workshops per week for members. Each member chooses his/her own package of learning. They set clear learning goals and review their achievements regularly. The areas covered are art, horticulture, media and music. Members progress both within the centre and onto external courses</p>
17.Dementia Action Alliance	<p>The aim is to improve the living experience of people affected by dementia in our communities.</p>	<p>A Dementia Action Alliance encourages and includes people in the community who provide services to the public, e.g. surgeries, shops, banks, post offices social clubs, to know the needs of people living with dementia and to support them appropriately – this might mean making some alterations to the way they provide services to meet the needs of people affected by dementia.</p>

Name of the activity	Main aims of the activity	Description of the activity.
18.Dementia Awareness within Black, Asian and Minority Ethnic Communities	<p>Create an understanding of dementia across the diverse population of the London Borough of Redbridge</p> <p>To empower and educate local residents to consult with their general practitioner when they felt it was appropriate</p> <ul style="list-style-type: none"> • Being aware of lifestyle choices [such as diet, exercise and social interactions] that may prevent or delay the onset of dementia • Knowledge that dementia can impact on any family, even though they may be well organised, educated and financially secure <p>To build empathy towards families affected by dementia and the importance of offering respite to neighbours, friends and family members</p>	<p>As part of a project commissioned by NHS North East London and the City, RedbridgeCVS's Psychological Health Community Development Officer and colleagues from the Living Well Resource Centre spoke to over 1000 local people from Black, Asian and Minority Ethnic communities about dementia. Intervention</p> <p>A specialist programme was developed by RedbridgeCVS's Psychological Health Community Development Officer to engage Black, Asian and Minority Ethnic [BAME] residents in order to increase awareness of dementia and the pathways to services in Redbridge.</p> <p>The programme was delivered twenty times in eighteen different community settings, tailored to meet the needs of each group [including, in some cases, communicating in a range of different languages]. The community and faith organisations were visited at times and place of their choosing.</p>
19.Disabled Person's user led organisation, partnership and capacity building	<p>To build the capacity of Choice in Hackney as the only registered charity providing support for disabled people in Hackney to obtain the services they need to live independent lives</p> <p>To build stronger partnerships between User Voice organisations within Hackney to promote a social model of disability and user run services. [The social model of disability includes people with physical disabilities, sensory impairment, mental health problems, learning disabilities and long term health conditions.]</p>	<p>This work pulls together several complementary areas of work. The capacity building work with Choice in Hackney has involved approaches to fundraising, business planning, quality mark accreditation, developing their IT [contact management database], Communication strategy and website. Choice provides advocacy services, practical support, training and leisure activities for disabled people.</p> <p>As part of the User voice project, Choice is also offering social enterprise support workshops [using appreciative enquiry and mentoring]. The partnership building has brought together a number of user led groups: Hackney People First, POHWER, Disability Back-up, and the People's Network on an advisory group. Links with deafPLUS and Foresight Hackney are also being developed.</p>
20. Down Your Drink	<p>DownYourDrink [DYD] was developed over 10 years ago as a tool to help hazardous and harmful drinkers cut down on their drinking. It is now freely accessible to the public as a website if they choose to set up their own personal account.</p> <p>Within the programme there are warnings for users who are physically dependent on alcohol about the hazards of stopping drinking suddenly and the need to see their GP for help with detox.</p>	<p>DownYourDrink is an on-line intervention for hazardous and harmful drinkers. The core components are: 'Should I cut down?': Motivational Interviewing to enable the user to reach a considered decision. 'Planning to cut down': helps plan a specific change. 'Cutting down': uses Behavioural Control and Cognitive-behavioural techniques to help users reduce consumption 'Staying on track': focuses on relapse prevention. Interactive e-tools, e.g. drinking episode diary give opportunities for users to reflect on the role alcohol plays in their life and consider alternatives.</p> <p>It has a strong theoretical and empirical foundation.</p>

Name of the activity	Main aims of the activity	Description of the activity.
21.Drop-ins at Chalk Farm Salvation Army Corps [church and facilities]	To provide a safe and accepting place for anyone to have a hot meal, use facilities such as showers, and access practical, emotional and spiritual support [if requested]	Chalk Farm SA hosts two drop-ins per week. Monday is for men only and Wednesday is mixed. Faith House started the drop-ins and runs them but needed a bigger venue to meet the demand for the service. The drop-in accepts anyone. People are welcomed, asked to sign in and offered a hot drink and food. If they are willing staff and volunteers have a chat and find out if there is anything that they can do to help. This might involve signposting to relevant services or acting as an independent go-between.
22.Enfield Carers Hospital Support Worker	Support carers via the hospital support process	To support carers through the hospital support process, to engage with staff and professionals at the hospital and improve communications and carers.
23.Expert Patients' Programme [EPP]	<p>An NHS licensed programme designed to build participants' confidence and help them learn to manage their long-term health condition better.</p> <p>To help patients to take responsibility for their own care, while also encouraging them to work in partnership with health and social care professionals.</p>	<p>The Expert Patients Programme is delivered under licence from Stanford University, built on an evidence base of what works [No room to change the ability to adapt or change the programme].</p> <p>The Expert Patients' Programme is a free NHS course for people with one or more long-term health conditions, e.g. Parkinson's disease, chronic fatigue, depression, arthritis, diabetes, fibromyalgia, diabetes, Chronic Obstructive Pulmonary Disease [COPD], heart disease, sickle cell, HIV, a physical disability or any other condition or multiple conditions.</p> <p>The course lasts for six weeks - participants acquire a 'Tool kit' of techniques and skills which helps them to break out of the vicious cycle of pain, stress/anxiety, physical limitations, fatigue, sleep problems, difficult emotions [anger, fear, frustration], and depression.</p> <p>The course is run by two trained tutors who themselves live with long-term conditions. They can give practical advice based on their own life experiences. Courses are currently delivered in English and Turkish</p>

Name of the activity	Main aims of the activity	Description of the activity.
24.Fit for Fun	<p>To help people who would not normally undertake regular physical activity to get involved in 20 weeks of free training in an activity suited to the members of their organisation</p> <p>To help them to work out ways to measure the impact of the exercise on the people taking part.</p> <p>To work with them in order for them to be able to continue with the activity once the 20 weeks have ended.</p>	<p>RedbridgeCVS has been running the Fit for Fun programme since April 2008. In that time over 2,500 people have taken part in activities as a group. These include Boxing Fitness, resistance sliding, Zumba, Yoga, Keep Fit, Chair-based exercises, Line dancing etc.</p> <p>Each group is offered 20 one hour sessions in an activity of their choice. The trainers are all fully qualified and vetted.</p> <p>Participants are asked to fill in forms about how fit and active they feel. This is done at the start, middle and end of the 20 weeks.</p> <p>The Fit for Fun coordinator also works with the groups to try and identify ways that they can continue with the exercise once the funding has finished.</p>
25.Focus group for parents	<p>To get parents to identify key areas for focus in educating medical students about child health.</p>	<p>Focus group with volunteer parents of children who had previous been involved with the hospital. They attended a 90 minute focus group facilitated by myself [Academic Clinical Fellow in paediatrics] to identify key themes for the focus in undergraduate paediatric training.</p>
26.GP Liaison Project	<p>Supporting GP Practices in the London Borough of Enfield to identify and support family carers.</p> <p>To empower and consult with carers about primary care services in the borough and to feedback comment around gaps in services.</p> <p>To raise awareness of carers needs and services available with all practices in the borough.</p>	<p>Host carers information stands in practices; display literature about carer support ; attend staff meetings and undertaker carer awareness training ; attend GP quarterly meetings and present to the GP about the project and carers needs; place carers self-referral post boxes in practices; attend flu clinics to talk to carers;</p> <p>Have designated carers notice boards in some surgeries; attend PPG's and practice meetings; report feedback to the CCG; host a quarterly GP Carers Forum; liaise on behalf of carers when they have problems with the GP practice.</p>
27.Health Action – Health Wisdom Groups	<p>To enable local people to take control To overcome barriers affecting people's health To tackle health inequalities and to improve lifestyle</p>	<p>Listening to local communities and finding out the issues which affected them, issues and experiences shared with service providers and signposted local people and groups to the right services.</p>

Name of the activity	Main aims of the activity	Description of the activity.
<p>28.HeLP-Diabetes - Development, Evaluation and Implementation of a web-based self-management programme for people with type 2 Diabetes</p>	<p>We have developed an internet-based self-management programme for people with type 2 diabetes ["HeLP-Diabetes", or Healthy Living for People with type 2 diabetes]. HeLP-Diabetes was developed as part of a National Institute for Health Research [NIHR] Programme Grant for Applied Research.</p>	<p>We adopted the Corbin and Strauss model of the work required for self-management of a long-term condition, which includes medical management [e.g. adopting healthy behaviours, working with health professionals, managing medicines], emotional management [e.g. managing the strong negative emotions resulting from being diagnosed with a long term condition including anger, guilt, shame and despair], and role management [e.g. managing the disruption of one's biographical narrative]. This model gave us an overarching framework of patients' requirements.</p> <p>We developed the intervention through a process of participatory design and input from people with type 2 diabetes was a crucial component. Focus groups and interviews with people living with the condition informed the content and features of HeLP-Diabetes. We also had regular input from health professionals to maximise the potential for integration with routine clinical practice. 3. We reviewed the behaviour change literature to identify behaviour change techniques that were most likely to be effective in helping patients achieve sustainable behaviour change.</p>
<p>29.Homeshare</p>	<p>To help older people or householders with a disability to keep their independence and remain in their own home;</p> <p>To provide a simple affordable service for people who feel vulnerable or isolated, or who need help and companionship around the home.</p>	<p>Homeshare offers a fee-based service to match householders with suitable Homesharers across London. Householders may be older or disabled residents who would benefit from having someone living in their home. The Homesharers are not carers and if personal care is needed this should be arranged separately. What they offer is the companionship and security of someone in the householder's home and help with some domestic tasks.</p> <p>Carefully selected Homesharers can help with things like cleaning, laundry and shopping, as well as providing friendship and security. To provide people with affordable accommodation and an opportunity to share with someone who benefits from that communal living; To give family piece of mind about their relative knowing that they are not living alone.</p> <p>The scheme divides opinion. People either support the idea as it promotes independence and addresses loneliness and affordable housing. Alternatively, they disprove of it as allowing strangers into vulnerable people's homes.</p>

Name of the activity	Main aims of the activity	Description of the activity.
30. Interactive workshop on living with blindness and visual impairment	To show students what it is like living with sight loss, To make them more comfortable communicating with people who have a visual impairment, TO cover the legal aspects of not doing it correctly [this is now covered in other parts of the curriculum so less time is spent on this in the workshop]	An interactive workshop for medical students about living with blindness and communicating with people with sight loss, led by two trained lecturers, one who is partially sighted and the second who has a severe visual impairment. The workshop involves direct student participation for about 50% of the session whilst the rest is lecture, training, demonstration and discussion. There is space for questions throughout the session. Students have an opportunity to use different pieces of equipment such as a liquid level indicator for pouring water, using a mobile phone by touch, telling the colour of something, threading a needle, measuring something, signing your name, identifying things by touch and reading medical packets. Electronic versions of leaflets and other relevant information are made available to the students.
31. Jewish Helpline	To provide support to individuals in emotional distress who are struggling to cope with life's difficulties.	A telephone support and crisis line, run and entirely staffed by volunteers. We are open from 12-12 Sunday - Thursday, 12-3pm on Fridays [closed for the Jewish Sabbath and High Holy days]. Our service is anonymous, confidential and of course non-judgemental. Our 60 or so volunteers receive 11 weeks of training before they take calls and additionally there is mandatory on-going training three or four times a year. In addition all volunteers receive telephone supervision during or after their shift.
32. Locality Health Navigator	To support people with long term health conditions to self-manage	Contact patients via phone or at home or a place in the community to explore with them what support they need to self-manage and undertake goal planning Use motivational techniques to find out what "blocks people" from seeking support to self-manage Referral to appropriate services within a 2 weeks period and check those referrals have been responded to and are working Immediate support, e.g. form filling, phone calls and letters. Advocates in medical practices to Patients and Staff about services available. Identify gaps in services and look to create opportunities to meet these gaps Offer some case management

Name of the activity	Main aims of the activity	Description of the activity.
33.ManMOT Men's Health Improvement Programme	An online personalised health information, advice and support resource to empower men to take control of their health.	Man MOT is a pilot project being trialled in one London Borough. Designed by and for the men of Haringey, especially those who are seldom heard to provide a One stop shop based around online GP surgery; information on local services; signposting; lifestyle information and advice emphasising prevention and early intervention It will provide information to overcome health illiteracy amongst men, signpost to overcome ignorance of existing services and give 'permission' to use existing services removing fear of 'wasting doctor's time'
34.Maternity Services Liaison Committee and Mothers' Support Group Tower Hamlets and Newham	To improve the quality of maternity services being offered in Tower Hamlets and Newham by supporting local mothers to influence policy and practice by consulting mothers about their experience of using the maternity services and communicating such experience to those involved in providing services and by enabling a group of mothers to participate in the Tower Hamlets Maternity Services Liaison Committee [MSLC].	Following Department of Health new guidelines on effective multi-disciplinary maternity services forum, Tower Hamlets PCT commissioned Social Action for Health to establish the local MSLC. SAfH used our Health Guide model to facilitate community sessions with local women focussing on maternity services. The health guide sessions encouraged feedback on services and created opportunities for participants to think about recommendations. In Tower Hamlets, over 100 women participate in the Mothers' Support Group from Bengali, Somali, White British, Nigerian, Angolan, Chinese, Indian and African/Caribbean communities with a regular group of around 15-20 women. In Newham [started in 2012] over 50 women participate in the Mothers' Support Group.
35.My Weigh	To deliver a multi-component [including dietary advice, exercise and motivational support] cultural, gender sensitive and lifestyle appropriate weight management programme across Tower Hamlets and to embed it within local service networks. [Other weight management programmes such as Weight Watchers, are often not culturally or gender specific]. To reach and engage local men and women who are overweight or obese from all communities through a range of marketing tools	My Weigh is a 12 month multi-component programme to enable overweight and obese adults in Tower Hamlets to reach and sustain a healthier weight and lifestyle. Participants enrol on to a 12-week Core Programme providing healthy eating, physical activity advice and motivational support on a weekly basis. Progress is monitored weekly as part of the 12-week Core Programme and the target at the end of the Core Programme is to achieve a 5% weight reduction. The underlying principles of the programme are based on NICE guidance including concepts affecting behaviour change.

Name of the activity	Main aims of the activity	Description of the activity.
36.New Beginnings Mental Health Course	<p>Part of the Expert Patients' Programme [EPP]. It is an NHS licensed programme designed to build participants' confidence and self-management skills to help them live with &/ or recover from their mental health condition. Like the Expert Patients Programme,</p> <p>New Beginnings is delivered under licence from Stanford University, built on an evidence base of what works. There isn't therefore the ability to adapt or change the programme. It aims to help patients to take responsibility for their own care, while also encouraging them to work in partnership with health and social care professionals.</p>	<p>The New Beginnings Mental Health Course is a FREE self-management course made up of 7 weekly sessions each lasting 2 hours 30mins and is aimed at people living with, or in recovery from, a mental health problem [max 12 people / course]</p> <p>Topics and activities to enable management /adapt to problems encountered in daily living</p> <p>Run by trained facilitators who have experience and an understanding of mental health conditions.</p>
37.Newham Bereavement Service	<p>To assess the bereavement needs in Newham and to provide support that is sensitive to the cultural, religious and language requirements of the borough's population.</p> <p>To engage the community in providing this support using a compassionate communities model.</p>	<p>In Newham: A team of trained volunteers to provide support to the bereaved [of a relative / significant person in their life / and for people who have a serious illness and their families and friends].</p> <p>Services include regular visits and company paid to service users by volunteer befrienders and bereavement support groups that offer activities such as gardening.</p>
38.No Smoking Patrol	<p>To make people [usually patients and/ or visitors] aware that it is a no-smoking site and to offer information [and originally promotional items] about smoking cessation services locally.</p>	<p>Volunteers walk around the hospital grounds in twos during office hours. They approach anyone who is smoking to start a conversation about support for stopping smoking as well as highlighting that it is a no-smoking site.</p>
39.Pain management - Systematic review and RCT of the effectiveness of self-management courses for people with long term pain compared to usual care [August 2011 to July 2012].	<p>To conduct a systematic review of the literature about self-management courses for chronic pain To develop and test the effectiveness and cost effectiveness of a self-management intervention using randomised controlled trial methodology</p>	<p>Systematic review on: The existing evidence of benefit of self-management interventions for chronic musculoskeletal pain The systematic review found evidence of benefit [compared to usual care or waiting list control] in courses that:</p> <ul style="list-style-type: none"> • included a psychological component; • were led by a health care professionals [better outcome for pain severity] and/or lay tutors [better outcomes for self-efficacy]; • were group based [as opposed to one to one or internet driven]; • were short or long [$<$ 8 weeks] the length or duration of the courses did not affect outcomes.

Name of the activity	Main aims of the activity	Description of the activity.
40. Parents' Group - Noah's Ark Hospice	For parents with a child who has been diagnosed with a serious illness to support / learn from each other about similar situations they are going through. Parents also share experiences and can provide emotional support to each other	Six parents' groups a year for parents to meet and share experiences. Most meetings are held on weekdays and a crèche is provided for children not in school. Transport can also be arranged if needed. Includes a facilitator to talk and get to know each other. Once or twice a year the group may have a particular theme with a speaker and in April we are planning a 'Pamper Day'. Rays of Sunshine, a wish granting organisation, will be offering treats for parents in the form of spa type treatments. Representatives from PALS hospital teams have also attended for question and answer sessions.
41. Participatory Budgeting at Launch of Stratford Village surgery Well London project	The event was held to celebrate the start of Well London in Stratford Village and also for the community to decide which projects would be delivered in their community from April 2014 to March 2015.	At the launch of the Well London Stratford Village project, 25 local residents and groups promoted their ideas by using pictures, role play, humour, testimonials to an audience of almost 100 people. Local residents and patients from the Stratford Village surgery selected thirteen projects and there will be something for everyone. The projects cover a range of topics: self-care accredited training, growing herbal medicines, mentoring for young people, social club for older people, flash dance performance on the banks of the River Thames, exercise sessions family healthy eating enterprises mental health support,
42. Patient follow up after An A and E visit	Supporting patients to recognise alternative pathways to a/e and to have more confidence with self-care	Records of patients who have attended the A/E department are checked at the local hospital and phone them to check how are they feeling and to discuss alternative ways for them to cope should a similar problem arise and suggest ideas to maintain and improve their general health
43 Patient journey	To give undergraduate medical students on the BSc in Paediatrics and Child Health an understanding of how medical conditions impact on children and their families, and the challenges families face in negotiating health services. To offer medical students an opportunity to learn directly from children and their families	The patient journey is an important part of the 1 year course at UCL. Each student works with a child and their family to learn about their journey. The patient journeys are anonymised and written up in a 1200 word document. These are shared across groups of students as part of discussion and reflection. They also have sessions as a group with a family member or child to listen to their story and ask questions.
44 People's Advisory Group	To influence commissioning of mental health services by feeding ideas/comments/work plans into the CCG mental health programme board	A service user group commissioned to provide advice to the CCG about mental health services, moving to active participation in commissioning by training, empowerment and active influence on how services are commissioned

Name of the activity	Main aims of the activity	Description of the activity.
<p>45. Psychological Health: A Foundation Training Course for Faith and Community Leaders and A course on talking therapies and crisis prevention</p>	<p>To enable community and faith leaders, who are often the first points of contact for BAME community members facing psychological distress</p> <ul style="list-style-type: none"> (i) Course on recognition of psychological disorders (ii) Course on Talking therapies and crisis prevention 	<p>A result of much previous engagement work and continued through a BAME Psychological Health Network. Course [i] commitment was one day per week for 6 weeks</p> <p>The course content is around being able to:</p> <ul style="list-style-type: none"> • Recognise common psychological disorders and how they may manifest themselves • Become aware of local systems and pathways to services – and how to appropriately refer people to these • Further develop their listening skills Understand NHS models of psychological health / Mental Health Act and the role of advocacy within the NHS • Help alleviate stigma and discrimination in relation to psychological distress and illness • the cultural and religious models of psychological ill health and distress in local BAME communities <p>Leaders from the six largest faith communities of Redbridge participated in an eight day training course [ii] delivered by Daybreak Counselling Service and North East London NHS Foundation Trust. The training was offered to 14 participants from the six most prevalent faiths of Redbridge: Buddhist, Christian, Hindu, Jewish, Muslim and Sikh. As well as giving basic information about NHS models of mental illness and local care pathways to services, the programme focused on the importance of communication techniques and the potential role of talking therapies in the prevention a crises situation due to psychological ill-health. Participants were taught what the NHS means by a “severe mental health disorder”, how to recognise key symptoms and how to find appropriate help. This included focusing on the role of NELFT in supporting people in a mental health crisis and how to access their “Mental Health Direct” telephone service. This part of the programme was delivered by NELFT.</p>
<p>46. Research and Innovation Forum, The Margaret Pyke Centre</p>	<p>A Research and Innovation Forum, with 40 lay members including patients, local residents and representatives of local community groups.</p>	<p>The Research and Innovation Forum, which was set up with funding from a UCL Public Engagement Beacon Bursary, meets regularly to help develop research proposals and funding applications. Researchers tell forum members about their work and ideas for the future. In turn the members will comment and offer suggestions and constructive criticism on research studies. Aimed at making sure research is relevant to the needs of patients and the community. Members [wide range: age, ethnicity and income] help disseminate research study findings and improve communication with different audiences. Importantly, the forum helps researchers link with groups of people who are normally hard to reach</p>

Name of the activity	Main aims of the activity	Description of the activity.
47. Review of self-care in Islington	For the long-term sustainability of the NHS, we need to shift from a traditional paternalistic approach within care towards a more collaborative model empowering people with long-term conditions [LTCs] to self-manage their conditions and pursue optimal health. This review draws upon discussion and work between commissioners, providers and people with long-term conditions to better understand current services and what should be available in the future to meet the range of needs. It also informs Islington's integrated care status.	Islington has twice the London average of people with severe enduring mental health problems, many of whom are at risk of dying at a far younger age than the national average, often due to their pre-existing long-term condition. This is currently the Year of Care which is a focus for Islington Clinical Commissioning Group to further embed a care planning approach. The Self-Care work complements this initiative. Islington chairs a self-care working group which meets regularly. Currently it is reviewing services, identifying gaps in provision and developing service improvements. This involves strengthening KPIs for existing services, commissioning research about factors affecting self-care for people with long-term conditions and supporting non-traditional providers to develop simple evaluation tools to measure the impact of their work. Involves interactions between : <ul style="list-style-type: none"> • KPIs, Islington is part of a learning set with NHS England to trial the Patient Activation Measure [PAM]. • OSCA [Social Change Agency] were commissioned by the CCG to: Engage with individuals with Long Term Conditions • The CCG has commissioned Age UK Islington to deliver a Health Navigators service which helps people with long-term conditions to find relevant support local community services to meet their needs.
48. Salvation Army Residential Detoxification Centre	Greig House is a residential detoxification and rehabilitation centre offering expert help to men and women with drug and alcohol problems.	The centre provides a high quality, holistic service, while respecting your rights and personal freedom. Clients who come to us for help are at their most vulnerable. We provide a quality, holistic service, respecting the rights of individuals and supporting them to achieve their individual goals. Counselling medication therapies group therapy Holistic therapies, e.g. Art Complementary therapies
49. Salvation Army Support meetings	Patient education and support, patient self-management	Monthly meetings with support work

Name of the activity	Main aims of the activity	Description of the activity.
50. Self-Management Programme [SMP] for adults with type 2 diabetes and on-going peer-led support to course graduates	<p>To support adults living with type 2 diabetes to develop the knowledge, skills and confidence to self-manage their condition and improve self-efficacy</p> <p>To model effective partnership working between a person living with the condition and a health care professional</p>	<p>The course provides the opportunity for adults living with Type 2 diabetes to understand more about their condition and to develop the knowledge, confidence and skills to help them manage their diabetes more effectively. This course is free to participants and runs over 7 weekly sessions.</p> <p>Each session lasts three hours. The sessions are delivered by two specially trained self-management tutors [one clinician with experience of working with diabetic patients and the other a lay person living with diabetes or who has close experience of diabetes such as a carer].</p> <p>Benefits to participants include: increased confidence in self-managing their diabetes, improved emotional well-being and quality of life, feeling better able to make decisions in partnership with clinicians, improved communication skills, greater confidence about planning ahead, increased knowledge about their own health, improved diabetes control learned alongside other people with similar experiences. This programme also involves periodic 'train the trainer' courses where lay and health professional tutors learn together. After the course, graduates can attend the support group known as the "SMP Reunions", and continue with goal setting, action planning, and problem solving. There is also chair based exercise provided by an external teacher and everyone brings food to share</p>
51. Service user input on the Health and Well-being Board meeting	<p>A focus on local people and what matters to them. To provide feedback and concrete examples of what action would benefit local people and specific service users To hold members of the Health & Well-being Board to account for the actions they agree to implement</p>	<p>Healthwatch Hackney invites local people from specific networks or user groups to attend the first 15 minutes of each Health and Well-Being Board meeting. The small group of local people shares practical examples of what would make a difference to their lives. At its most successful, this is a list of 3-4 actions which is within the power of members of the Board to change. Individual members of the Board agree at the same meeting or at a later date what action their organisations are going to make. The groups who have participated so far are local young people [who had asked other young people what they wanted to change in Hackney], people from the Learning Disabilities forum, blind or partially sighted people living in Hackney.</p>
52. Sing for your Lungs	<p>A singing group for patients who have chronic respiratory disease and breathlessness</p>	<p>Weekly group at the Whittington Hospital. Self-referral with advertising through pulmonary rehabilitation, Long term exercise groups for COPD patients, GP surgeries, and hospital outpatient notices.</p>

Name of the activity	Main aims of the activity	Description of the activity.
53.TB Awareness Project and Redbridge TB Partnership	<p>To raise awareness of TB symptoms and TB services by delivering training amongst local communities / health professionals and providing education materials to support the awareness-raising events.</p> <p>To support TB prevention, early diagnosis and treatment through joint working between the group members</p>	<p>Redbridge Council for Voluntary Services [Redbridge CVS] organised a workshop in autumn 2012 together with TB Alert [a national charity], inviting a broad range of relevant organisations including Public Health, Barking Havering and Redbridge University Hospitals NHS Trust [BHRUT]'s TB Chest Clinic, TB patients, and voluntary organisations representing high risk groups. Based on the discussions and suggestions at the workshop, a Local TB Partnership was set up from February 2013 with commitment and funding from Public Health Redbridge.</p> <p>The Redbridge Local TB Partnership: a collaboration between London Borough of Redbridge [Public Health and Housing], Barking Havering and Redbridge University Hospitals NHS Trust [BHRUT], Redbridge Clinical Commissioning Group, TB Alert, TB patients, Public Health England Redbridge CVS and other voluntary sector organisations representing HIV, homeless people, drug and alcohol services and migrant communities. The partnership oversees the delivery of the TB awareness project and ensures that relevant agencies are fully engaged in tackling TB in their respective forums, by discussing local experiences or issues about TB and feeding these into local and national TB policy forums and vice versa</p>
54.User engagement in health and social care in one borough	<p>Encouraging feedback from residents in the borough, feeding back the information to commissioners and providers</p>	<p>Outreach at health and social care venues Enter and views Case studies Focus groups surveys telephone and e-mail inquiry and feedback communication/platform Information events User Engagement and Health/Care Professional workshops</p>
55.User involvement in the Men's Safer Sex [MENSS] website development	<p>To involve service users in the development of the content and design of the website. The aim of the website is to increase condom use by heterosexual men attending sexual health clinics.</p>	<p>The user involvement started with interviews with 20 men who were attending the sexual health clinic. This was followed by a series of focus groups and three men from the groups became actively involved as user representatives to comment on an on-going basis.</p>
56.Visualisation of pain through photographic images	<p>Use of psychology sessions to understand effect of pain</p>	<p>Patients with pain worked with a photographic artist to create images that either describe the type of pain they have or the effect it has on them. Which are then used by other patients to help the clinician understand the pain especially if non English speaker</p>

Name of the activity	Main aims of the activity	Description of the activity.
57.Well London Project: Stratford Village	Well London is a model used to deliver engaging health and wellbeing programmes that improve the health outcomes of communities.	<p>Identification of community needs and ambitions with regards to health and wellbeing. Collective agreement about priorities and what works well that can be up-scaled- appreciative enquiry and story-telling Encouraging communities [residents and Stratford Village Surgery patients] to work with local community groups to develop proposals and bid for projects delivery-funding Determining what receives community support through presentations, questions and voting- participatory budgeting process Recruitment of volunteers to support chosen projects to ensure sign posting, support and successful delivery- Well London Delivery Team Variety of workshops and training to underpin volunteering and health promotion- SLaM, RSPH, Youth.com, etc. Monitoring, evaluation and legacy</p> <p>Projects and activities taking place in Well London areas will contribute to one or more of the following outcomes of increasing levels of physical activity; improving healthy eating; improving mental well-being; bringing communities together and making use of open spaces.</p>