Macmillan Local Authority Partnership (MLAP)
Tower Hamlets Living with Cancer Programme

Annual Report
February 2018 – March 2019

1. Executive Summary

This report outlines the progress of the Macmillan Local Authority Partnership (MLAP) in the London Borough of Tower Hamlets, in the first 13 months - since the programme began in February 2018, to the end of March 2019. The report highlights key activities, achievements, and learning to date.

The overarching vision is that everyone living with and beyond cancer can easily access all the support they require to meet their holistic needs - which in turn will enable them to live as well and as independently as possible and to die well at the end of their lives.

In Tower Hamlets, this is in the context of 665 new cancer diagnoses a year, high levels of socio-economic deprivation, and a relatively young and ethnically diverse population. Evidence shows that Tower Hamlets residents experience relatively poor outcomes, with many areas for improvement in patient experience.

The MLAP programme sits within a complex landscape, with several key elements of the system undergoing transformation (for example, social prescribing, care coordination, and Information Advice and Guidance). Articulating precisely how work is aligned will become increasingly important over the coming months, as the programme moves towards developing and implementing a new model of care.

In Tower Hamlets, MLAP is well placed to deliver on the commitment to personalised care through an integrated approach and an emphasis on community-based support, as outlined in the NHS Long Term Plan and new 'Universal Personalised Care' model, as well as Macmillan's 'Right by You' strategy.

By the end of March 2019, the programme had made significant progress on the following key activities, which make up Phase 1:

- Programme set-up, including establishing governance and reporting structures, forging links with other transformation bodies and initiatives and developing a Logic Model.
- A comprehensive asset mapping exercise to understand the services which exist to support people's holistic needs and how they work together.
- Commissioning a Cancer Health Intelligence report.
- Insight gathering from 48 residents affected by cancer, to understand their experiences of support.
- Engaging with professionals from all sectors to gather their insight on gaps in provision and opportunities to improve how the system integrates.

Some key reflections from this programme to date:

- ❖ Many Tower Hamlets residents have unmet needs in relation to their emotional wellbeing, finance, housing, and ability to return to work.

- Many require support to make best possible use of available services – for example, people who are single, or have low levels of 'activation'.
- Sharing of information is an underlying problem, which makes it hard to ensure an integrated approach.
- There is a lack of coordination, which means that care is not seamless.
- A critical amount of knowledge is required about services and systems in order to effectively provide personalised and coordinated care.

As the MLAP programme moves to design and implementation phase, all partners will need to work together to develop a model and agree key 'tests of change' based on this robust understanding of the needs of the local cancer community and the health and care system.

2. Achievements to date:

- Established a programme and Board, and agreed governance and reporting structures.
- Established a comprehensive network of stakeholders.
- Established robust links to the Cancer Alliance, Transforming Cancer Services Team and East London Health and Care Partnership. Gained strong commitment from the London wide personalised cancer care sector to support the programme.
- Developed strong partnership with Barts Health who are the main acute provider for Tower Hamlets.
- Hosted a Theory of Change workshop and developed a Logic Model.
- Linked the programme to other transformation initiatives operating locally, regionally and nationally.
- Hosted five engagement workshops which were attended by 48 people affected by cancer living in Tower Hamlets. Produced thematically analysed insight reports for various audiences.
- Created a virtual network of people who want to be involved with co-production.
- Developed 5 case studies.
- Created a comprehensive asset map.
- Hosted an engagement event with 20 professionals who work with people living with cancer.
- Contributed to the Interim Evaluation Report.
- Established clear line of sight of all the transformation programmes with interdependencies to MLAPP; Information Advice and Guidance, Care Coordination, Adult Social Care, Social Prescribing.
- Commissioned the cancer health intelligence work and appointed a research analyst.
- Have agreement in principle from Adult Social care to include a mandatory field on Framework-i to capture whether a service user has cancer as their underlying health need.
- Begun to create an outline of a delivery model.
- Planning for the delivery of Cancer as a Long Term Condition (working title of CEPN training) progressing well.

3. Introduction: Macmillan Local Authority Partnership

Macmillan has developed a programme to build relationships with local authorities and other partners to develop new solutions. The Tower Hamlets Living with Cancer Programme, with a budget of a £1 million, is one of five Macmillan Local Authority Partnership pilots across England and Scotland. It will be developed and delivered over three years, having started in February 2018.

It aims is to develop a model of service delivery in partnership with local authorities, local health partners, third sector, communities and people affected by cancer. By using local health intelligence, identifying assets and gaps, using people affected by cancers' feedback

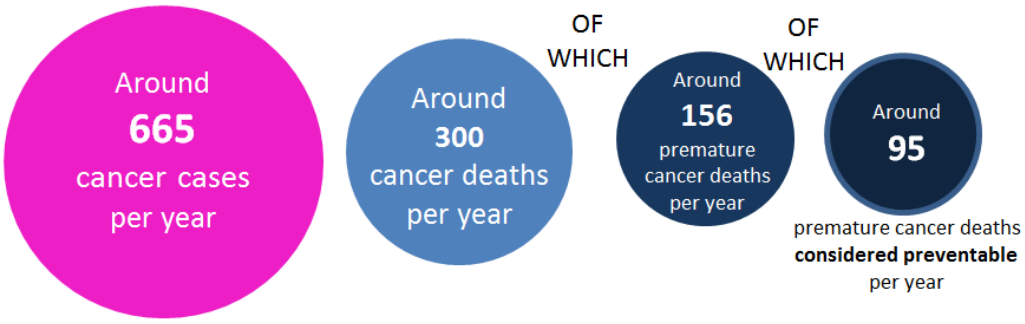
and harnessing sector wide expertise, the programme will ensure that everyone living with and beyond cancer can easily access all the support they require to meet their holistic needs - which in turn will enable them to live as well and as independently as possible and to die well at the end of their lives.

National context

Two million people are living with or beyond cancer in the UK. This figure will rise to 4 million by 2030. The number of older people (aged 65 and over) living with cancer has grown by 300,000 (23%) in the five years to 2015. By 2040 older people will account for 77% of all people living with a cancer diagnosis, an increase from the 2015 figure of 66%. The number of people who have survived five or more years since diagnosis has increased by over 260,000 (or 21%) in the five years to 2015. 50% of people with cancer in the UK now survive at least 10 years (April 2014).

Local context

Incidence and Mortality



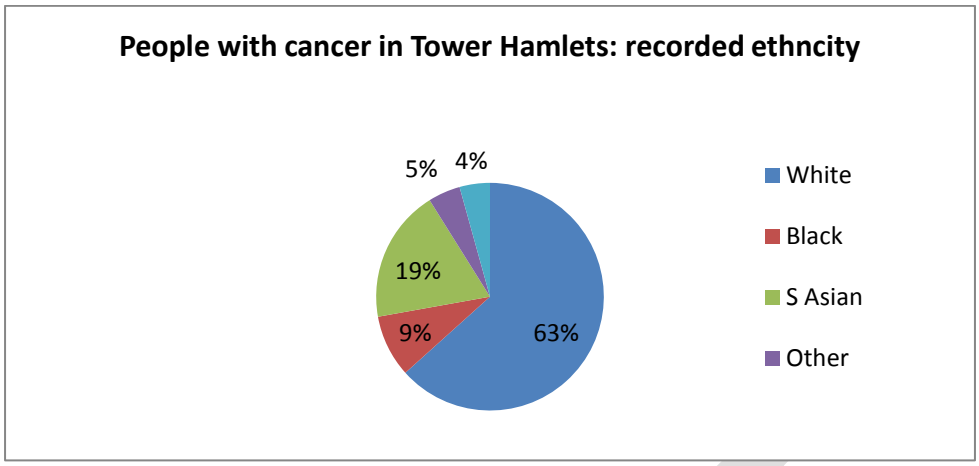
Cancer prevalence in Tower Hamlets (TH): alive and registered with GPs on 1 April 2018: 4338 people, of which: 2,413 female, 1,925 male.

Multi-morbidity - 60% of females and 68% of males have at least one other long term condition in addition to cancer.

Co-morbidities (conditions are not mutually exclusive)

Male and female combined	
Comorbidity	Number affected
Hypertension	1670
CHD	424
Diabetes	884
Active Asthma	356
Stroke	211
COPD	415
CKD	768
Heart failure	117
Bipolar	31
Depression	203
Anxiety	318

Cancer and ethnicity:



People affected by cancer in Tower Hamlets have relatively poor outcomes, survival rates are lower and mortality rates are higher than in England and London. This is likely to be linked to more cancers being diagnosed late and as emergencies, and people having other comorbidities, such as diabetes and cardiovascular disease.

4. Macmillan Local Authority Partnership in Tower Hamlets

In Tower Hamlets the potential for a MLAP Programme was explored through the Public Health division who created the partnership and made a successful bid for the funding from Macmillan. Subsequently the programme was established within Adult Social Care which sits within the same directorate as Public Health - Health, Adults and Communities Services. The MLAPP Programme Lead reports to the Interim Divisional Director of Adult Social Care whilst working closely with a range of Public Health colleagues, but particularly with the Healthy Adults Team. From the Public Health team, analysts and the programme lead who holds cancer in their portfolio continue to support the programme, especially around access to cancer health intelligence; and the Assistant Director for the Healthy Adults Team attends the MLAP Programme Board. The programme reports to the Promoting Independence Board of the Tower Hamlets Together Partnership as well as convening its own local Programme Board each quarter.

The initial thinking behind the MLAPP programme from the partnerships' perspective is outlined below. It was seen as an opportunity to:

- Test an approach of working with local authorities to support people living with cancer.
- Explore how acute, primary and community settings could work together to find solutions for more personalised support outside of a hospital setting.
- Test how amenable clinicians are to people living with cancer having their holistic needs assessed in the community; and how elements of the Recovery Package might be delivered in the community. Understand what the expectation is after an HNA is completed… what happens next?
- Explore how social prescribing supports the delivery of the Recovery Package (solution, reach, limitations) and what opportunities such a service provides.
- Look at how we might establish a network of support and care (perhaps closer to home) alongside a people living with cancer' clinical pathway and understand what coordination / navigation support is required.
- Bring together professionals who support or could support people living with cancer by working together, look at the different roles of professionals in different parts of the system (generic and cancer specific) and how these might work together.

- Understand whether what we have in place is working well and where we need to make improvements.
- Explore the barriers to people accessing services (location, language, perception, accessibility, lack of knowledge, complexity of the system).
- Understand why services don't work for people.
- Influence people to understand their role beyond their own organisation.
- Establish a better triage process which would help identify whether people can benefit from information, advice and guidance from Adult Social Care.
- Understand how health and social care could help identify people living with cancer who could benefit from reablement support at the right point in their treatment pathway.

5. Aims and objectives of the programme

- Provide access to a full range of psychosocial services within or outside of the borough to meet holistic needs.
- Streamline processes of assessment, care planning and access to required provision, focusing on what is important to people with cancer.
- Enable people to have choice and control over their treatment and care.
- Improve access to information, advice and guidance from point of diagnosis, through treatment, living with and beyond diagnosis and to end of life.
- Enable earlier access to support closer to home and in local communities.
- Improve pathways back into clinical services in the event of recurrence.
- Improve knowledge and understanding on how to live and stay well through self-management.
- Create a network of support for people living with and beyond cancer in their own community.

6. Wider needs of people living with cancer:

Research published by Macmillan Cancer Support 'Hidden at Home- The social care needs of people with cancer' highlighted the range of social care needs of people living with cancer. The research indicated that people living with cancer have practical, personal and emotional needs. These include needs relating to mobility, practical tasks and personal care.

Further information about the needs of people affected by cancer can also be found here:

7. Some of the questions we posed at the start of the programme to prepare for engagement and asset mapping:

- How are we assessing people's holistic needs?
- Where do we send them?
- Who are the professionals involved?
- How do teams and services interface with each other?
- What are the different systems that people enter and flow through?

- Where, when, how, and from who do they get information, advice and support?
- Do people know where and how to get support?
- Do they use the services available?
- Do the services meet their needs?
- What links exist between the hospital and the community?
- How are people prepared to look after themselves?
- Do people need care navigation or coordination?
- What do people use in their local community?
- Are non-cancer specific services aware of the consequences of treatment and late effects of cancer?

8. Local or national landscape /contextual issues to be aware of:

a. There is a strong need to articulate how this programme will develop and sit alongside an already complex system of service transformation / review work going on:
   i. through the Tower Hamlets Together Partnership
   ii. within local health and social care integration and restructure
   iii. through the development of the Locality Health and Wellbeing Committees
   iv. via a review of the care coordination service
   v. via a review of the social prescribing service
   vi. via a review of the Information Advice and Guidance services
   vii. through the *Tackling Poverty* agenda funded by the Mayor's office
   viii. through the developments funded by the Cancer Transformation Fund via the Cancer Alliance and the STP
b. Clarify how it will add value to existing services / arrangements and future plans e.g. plans in motion through the Cancer Transformation Funding (CTF) available via UCLH Cancer Collaborative, the STP's Living With and Beyond Cancer and End of Life Care plans, the local Macmillan and primary care social prescribing projects, the implementation of the Recovery Package by Barts Health hospital sites, cancer case management support for people with breast cancer on stratified follow-up pathway in north east London etc.
c. Establish how this programme will link to work underway to meet the needs of people living with cancer with other long term conditions and complex health profiles in Tower Hamlets.

9. Programme set up and stakeholder engagement

- Developed relationships with key individuals in the Public Health and Adult Social Care teams (e.g. communications lead, data analysts, programme leads, senior managers) to start putting in some structure around the development and delivery of the programme and identify key allies.

- Engaged with Adult Social Care colleagues through the help of the principal social worker and the workforce development lead, met key staff members from a variety of teams, presented to their senior leadership meetings, met with individuals to map how their service works and explore where the gaps and opportunities lie for people living with cancer.

- Initiated discussions with Adult Social Care (ASC) Transformation Manager on whether cancer codes can be included within the ASC IT platform so that services users affected by cancer can be identified easily to track usage.

- Reviewed all current documentation relating to the programme and strategic plans in Tower Hamlets - (bid, partnership agreement, logic model, role description, Tower Hamlets Together Outcomes Framework, JSNA, Health & Well Being Strategy, interim review of Community Insights Programme etc.). Drafted key documents to support the programme:
    - Agenda for programme board
    - Draft terms of reference for programme board
    - Theory of Change session notes
    - High level project plan
    - Options for gathering health intelligence data
    - Outline of programme scope
    - Co-production and engagement options
    - Work-streams – options, membership and Terms of Reference
    - Draft governance and reporting structure
    - Risk log

- Recruitment - agreed changes to funding to create a programme coordinator role to support MLAPP. Recruitment began in July 2018 and candidate took up their post at the end of October 2018.

- Developed a comprehensive stakeholder list and met with key partners who were involved in the development of the Macmillan Local Authority Partnership bid to understand their expectations from the programme, their aspirations for Tower Hamlets, and where and how they might like to be involved.

- Reviewed all relevant Living With and Beyond Cancer documents from pan London programmes (Transforming Cancer Services Team) and the UCLH Cancer Collaborative. Met with Sharon Cavanagh, Macmillan Integrated Cancer Programme Lead for the UCLH Cancer Collaborative and Liz Price, Associate Director (Personalised Care for Cancer), and Transforming Cancer Service Team (TCST) London, to brief them on MLAPP and understand the context in which this programme sits. We agreed to share plans and attend the Alliance's Expert Reference Group for Living With and Beyond Cancer and the Pan-London Living with and Beyond Cancer Partnership Group. They raised a number of queries which has been at the heart of our discussions to date:

    - Adaptability and potential for replication elsewhere?
    - Degree of buy in from local authority (LA) and capacity within services to support people living with cancer?
    - Access to community assets (voluntary and community groups) to help with consequence and build resilience in people affected by cancer? Access to vocational rehab?
    - LA and wider workforce's understanding of cancer and its consequences? How they can support the Living With and Beyond Cancer agenda long term?
    - Potential MLAPP links to wider primary care, psychological support and rehabilitation projects across London?

- Publicised the programme through a range of channels:
    - Council website
    - All staff newsletter
    - Managers' briefing
    - Councillors' briefing
    - Newsletters and e-bulletins (CCG, community and voluntary sector forums and organisations etc.)
    - Community and Voluntary sector's channels
    - All social media channels within partner organisations

- Developed a good understanding of how the MLAPP programme has been established and developed across the different pilot sites. Reviewed their staffing arrangements, governance and reporting structures, operating systems and key programme documents (e.g. PID, communication and engagement plans, stakeholder maps, risk strategy, role descriptions for staff, etc.), to unpick what worked well, establish realistic timescales for completion of different phases of work and understand challenges and mitigations. Attended regular "Learn and Share" events with site leads, evaluation leads and Macmillan partners.

- Attended a number of organisational development sessions with the Tower Hamlets Together Partnership for the Promoting Independence work-stream which the MLAPP programme reports into. This helped socialise the programme with key stakeholders who will be a key in helping us develop and integrate future service models.

- Hosted a Theory of Change workshop to develop a logic model - 37 stakeholders from across Macmillan, TCST, East London Health & Social Care Partnership (ELHCP – the STP for north east London), Tower Hamlets CCG, Adult Social Care, Public Health, primary care, LA Commissioning, voluntary and community sector and UCLH Cancer Collaborative came together for the workshop on Friday 27th April 2018

- Met with Chris Banks, CEO of the GP Care Group. He outlined how GP practices are clustered in networks and localities, the recent changes in the teams who support practices (network managers, coordinators, and administrators), the role of the Primary Care Development Collaborative and the possible opportunities for MLAPP to link to the developments around the Locality Health and Wellbeing Committees.

- Received strong endorsement for the programme from Interim Chair of Tower Hamlets Together (THT) Partnership, Isabel Hodkinson who is also on the CCG Executive Board and chair of the Primary Care Development Collaborative.

- Established a strong link to the East London Health & Social Care Partnership (ELHCP – STP for North East London), through Sue Maughn, Commissioning Director Cancer NEL who provides direction and oversight to the cancer programme in NEL. She is a member of the MLAP Programme Board. The Programme Lead joined the Living With and Beyond Cancer Strategy Group for North East London and contributed to their priority setting and planning around personalisation. Learning from MLAPP will feed into the ELHCP's future plans around personalisation, social prescribing, and support for stratified follow up people living with cancer (breast, prostate and colorectal).

- Met with the Directors of Public Health and Adult Social Care and the Head of Integrated Commissioning to brief on progress and outline timescales for developing recommendations / commissioning intentions. We also agreed the timing of taking a paper to the Health and Wellbeing Board (later in 2019, with recommendations needing discussion and approval) and the THT Partnership. Have agreed to present at Public Health senior leadership meeting in spring 2019.

- Met with CCG project / programme leads for personalisation and long term conditions to understand what plans are currently in progress and how our aims and objectives might be aligned.

- Attended (and or hosted) the following regular meetings and one off events:

- Last Year of Life (LYOL) Steering Group – members of this group will help design aspect of the provision needed for those needing palliative / end of life support.
- End of Life (EoL) Champions' Group – as above.
- Tower Hamlets Cancer Strategy Group – this group has enabled the programme to be a part of the planning and development of local initiatives, support scoping and asset mapping and will be critical to development of the service delivery model.
- UCLH Cancer Collaborative – Living With & Beyond Cancer – Expert Reference Group (LWBC ERG) – as above.
- Pan London Living with and Beyond Cancer Partnership Meeting with Transforming Cancer Services Team (TCST) – to share local learning and connect with initiatives being developed elsewhere.
- Attended the Tower Hamlets Social Care Pan Providers' Forum – this provided an opportunity to become familiar with CVS organisations who are commissioned by Adult Social Care to deliver a range of services.
- Social Prescribing Partnership Group – to shape and influence future commissioning of this service.
- Tower Hamlets Allied Health Professional's Professionals' (AHP) Conference - led by an Occupational Therapist in Adult Social Care. It was an opportunity to understand how they support people living with cancer in hospital, community and home settings, and also highlight the MLAP Programme's aims and identify potential stakeholders. We made contacts with staff who can advise on home adaptations; work with the reablement service and housing teams.
- Hosted the Macmillan Networking Breakfast Meeting - a well-attended session which enabled asset mapping, helped us understand current and emerging issues around funding, agree next steps on how to engage people living with cancer and carers and develop case studies.
- Attended the Barts Recovery Package Implementation Group to explore the challenges and opportunities of undertaking holistic needs assessments and hosting Health and Wellbeing events.
- Joined the Macmillan London Recovery Package Community of Practice.
- Attended the LBTH Manager's Conference.

10. Engagement with Barts Health

- Established strong relationships with the Recovery Package Manager, the Cancer Patient Experience Lead and the Macmillan Director of Nursing for Cancer & Palliative Care/Senior Lecturer, who is the vice-chair of the Tower Hamlets MLAPP Programme Board.
- Attended a two day workshop with Clinical Nurse Specialists (CNSs) from different tumour types to explore how personalised care and support is provided, and where there are opportunities to look at other roles and ways of working. (Awaiting notes from the session and outcome from the national programme work using the Calderdale Framework.)
- Agreed to host a session with CNS colleagues to process map holistic support pathways for people living with cancer – extending from the hospital out into the community.
- Started to look at logistics of holding Health and Wellbeing Events in the community in Tower Hamlets.
- Started to explore how we might engage with clinical teams in the Trust and link with the Recovery Package and Patient Experience Implementation Groups when looking at options for a future service.

11. Engagement with primary care

- Attending the Tower Hamlets Cancer Strategy Group chaired by the Macmillan Lead GP.
- Co- created training needs assessment and session plan for primary care and wider workforce on 'cancer as a long term condition'.
- Contributed to the Network Incentive Scheme (NIS) enabler for primary care to assess the quality of Cancer Care Reviews (CCR).
- Discussed options for engaging GPs. The aim is to gather qualitative feedback from GPs on supporting people living with cancer and undertaking CCR.
- Attended two of the eight local health and well-being committees to raise the profile of the programme.

12. Engagement with professionals supporting people affected by cancer

Hosted an engagement event with 20 professionals from a range of agencies (Barts Health, Macmillan Information and Support Managers, St Joseph's Hospice, Macmillan Social Prescribing, Maggie's Barts, Trekstock, CLIC Sargent etc.) supporting the holistic needs of people living with and beyond cancer to.

The aims of the session were to:

- Gather insight on services available and gaps in provision
- Assess how different parts of the system work together
- Understand where we could improve connections and communication across agencies
- In future, where would we intervene and invest?

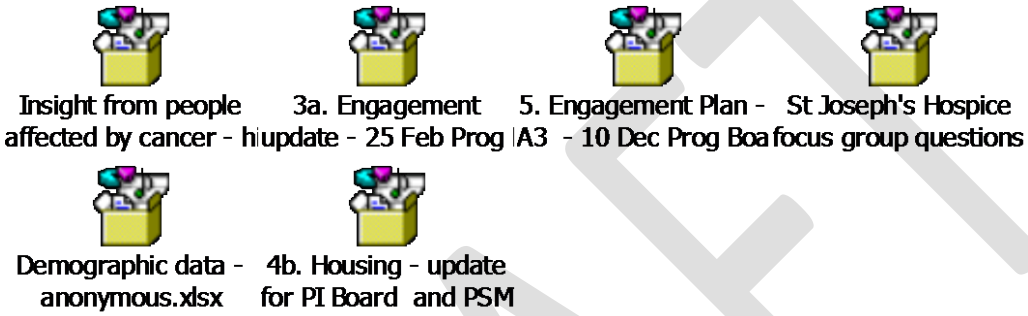
Please see attached session plan and associated slides:

Slides - 20 March - professionals engagen

13. Engaging people affected by cancer:

- Mapped out our options for engaging people affected by cancer, begun compiling a list of organisations, groups / forums, services and individual engagement specialists available to support this work-stream.
- Reviewed all council communications, engagement and co-production strategies, plans and frameworks.
- Developed a topic guide and questions for focus groups and engagement workshops.
- Agreed the number of engagement sessions to be supported by Macmillan Engagement Lead for North East London.
- Attended the Health and Wellbeing Forum hosted by Tower Hamlets CVS to highlight our plans to engage local residents and garner support. THCVS set up a page on their website about the programme and helped push out regular communications to their wider network.
- Created publicity flyer advertising the opportunity for people affected by cancer to get involved. Sent to a range of organisations (e.g. CVS, newsletters, partner organisations, engagement leads in the CCG, ELFT etc.). Promoted through social media platforms.

- Met with Zack Ahmed, Coordinator for the Community Insights Programme in Public Health and Xia Lin, Research & Evaluation Manager at Toynbee Hall to discuss existing insight sources and options for further engagement work i.e. approaches, timelines, questions, topic guides, location, briefing of community insight researchers etc.
- Created a database for people affected by cancer who would like to join our network/mailing list – to receive invites to engagement sessions, and updates on the programme etc.
- Planned and delivered 1 day training to Community Insight Researchers who helped facilitate specific sessions.
- Case studies – 5 written up and 3 under development. Have requested further case from adult social care to illustrate when and how people living with cancer have accessed Adult Social Care and Barts Health.
- Please see attached – brief insight report, engagement plan update for board, engagement delivery plan, topic guide, demographic profile:



14. Engagement with organisations, wider systems, transformation leads: analysis

Held a series of meetings with a variety of teams and service managers within a range of organisations across the sector to understand how they currently support people affected by cancer. Information gathered is being captured in a data base, which when complete will be shared with organisations and agencies for accuracy checking and further input.

Asset type: organisations, services, individuals, systems and processes
Sources: directories, face to face meetings, reports
Location: in and out of borough, those based around hospitals

Map to: concerns check list / HNA
Classify across different phases of treatment:

- Receiving a cancer diagnosis
- Starting and going through treatment
- Finishing treatment and recovering
- Cancer in incurable but treatable
- End of life - dying

Please see attached a list of organisations and transformation programmes mapped to date:

15. Cancer Health Intelligence work

- Drafted service specification for Cancer Health Intelligence work.
- Attended a meeting with the Clinical Excellence Group (CEG) to review and agree the data requests made for MLAPP, clarify the data sets available currently through the East London data base and those which will have to be extracted from EMIS, agreed the logistics of how and when this data will be made available
- Appointed a health intelligence analyst to draft a report outlining the narrative to go with the data.

16. Programme Evaluation

- Reviewed programme level and proposed local level evaluation framework developed by SCIE / SQW for the Scottish sites.
- Hosted the first Measuring Impact work-stream meeting – discussed existing evaluation framework and aspects which need amending to reflect local context and arrangement (detailed notes of session available).
- Took part in an interview with the evaluation lead and contributed to the Interim Evaluation Report.

17. Developing training for cross sector workforce: 'Cancer as a long term condition'

- Co-wrote an application to CEPN to secure funding from Health Education England (HEE) to run training sessions for the wider cross sector workforce (e.g. social workers, mental health and community health services teams, social prescribers, navigators, pharmacists, hospital based support staff, district nursing etc.) on cancer as a long-term condition and how to have good conversations. Initial plans involved hosting 4 half day sessions to be held over spring / summer 2019, delivered by a multi-disciplinary team, using patient case studies to drive the learning and discussions.
- Met with Sarita Yaganti, Cancer Strategy Implementation Lead at Transforming Cancer Services Team (TCST) for London, to find out more about the training package being developed by them to enhance primary care's understanding of cancer as a long-term condition, how to undertake Cancer Care Reviews and improve patient outcomes and experience.
- Met with Anne Page, Lead for Workforce Strategy in Adult Social Care to explore options for undertaking a training needs assessment (TNA) with social care staff and encourage them to attend the training.
- Have completed and circulated the TNA and have begun planning session content with Macmillan GP and TCST. Have developed 5 patient case studies.

TNA - final draft.docx

18. Training sessions & external events:

- JSNA training - delivered by Public Health
- Tower Hamlets Together (THT) Quality Improvement methodology (QI) Session for Promoting Independence work stream
- Data sources and introduction to statistical metrics – delivered by Public Health
- Induction on the Care Act – delivered by Adult Social Care

- "Presenting data and data visualisation" – delivered by Public Health
- "Influencing & Negotiation Skills"- delivered by Macmillan
- "AHP into Action – Supporting People Living with and Beyond Cancer" – National Conference
- "Coaching for Health and Well Being Training" – 2 day training funded by Adult Social Care.
- 'Meeting the changing needs of people living with cancer' - The King's Fund & Macmillan conference
- 'Pragmatic public health research, monitoring and evaluation' – 6 session evening course delivered by Queen Mary University London (QMUL).

19. Reflections on asset map

Emerging themes from our asset mapping exercise:

- Sharing of information is an underlying problem, which makes it hard to ensure an integrated approach.
- The funding of some key assets due to end this year (e.g. Macmillan Social Prescribing service, Toynbee Hall Macmillan Welfare Benefits and Advice service, Macmillan Live Well and Information Support Service at St Joseph's Hospice).
- There is no cancer-specific peer support group hosted in the borough (there is a bereavement group in Poplar). St Joseph's Hospice is the only organisation to run cancer support groups outside of a hospital setting in east London. It is currently searching for alternative hosts, for when funding ends.
- There is a lack of coordination, which means that care is not seamless for the person living with cancer. This lack of coordination exists:
    - Between cancer-specific services and generic health and wellbeing services
    - In the transitions between teams, and at the end of treatment
    - Between different teams and different sectors
- Care navigation support is only available to a defined group of patients included in the Integrated Care Pathway cohort (with a dementia diagnosis, on the palliative care register, living in a care home, or a discretionary 12%).
- There is inconsistency and variation in:
    - Whether people's needs are identified at the right time
    - Ability to access existing support
    - The quality of this support
    - How Holistic Needs Assessments (HNAs) are done, and the extent to which care planning is personalised
    - How well information is shared between the key professionals and family who form a 'team around the person'
- A huge amount of knowledge is required in order to effectively provide personalised and coordinated care:
    - Knowledge of the holistic needs of people with cancer, and of cancer as a long term condition
    - Knowledge of what's available for people in their local community
    - Knowledge of how professional roles can work together, and of how different parts of the system work
    - Knowledge of the broader health and wellbeing services that could offer useful support.
    - Adult social care is an area that other professionals commonly report a lack of knowledge on how and when to refer.
- Communication between the hospital and GPs - it's unclear what proportion of patients' treatment summaries are being shared with GPs to enable personalised care in the community.
- Cancer Care Reviews by GPs are no longer incentivised through payments. There is no data on quality, impact, or frequency of these reviews. Insight suggests that patients are not getting the support they would like to receive.

20. Challenges and Learning - Reflections

- There were significant challenges around identifying operational leads to set up and progress activities within each identified work-stream. At the start it would have been helpful to have greater clarity on the exact contributions the different partners would make to help develop and progress the programme; this has been a work in progress.
- Agreeing the support and staffing required to manage and develop a programme of this nature was time consuming and convoluted; learning should be used to shape future initiatives.
- The programme board consists mostly of senior members of the partner organisations with less operational staff being involved , so they have not always been able to provide the level of input required to progress activities at different phases
- At the start there was lack of clarity on how this programme would develop and dovetail with other transformation programmes within Tower Hamlets, across North East London Health and Care Partnership (STP), across NEL and NCL Cancer Alliance Footprint. This has required significant oversight and management by the programme lead.
- There is a lack of clarity on a) how learning from phase one of the programmes will be used to develop commissioning intentions and b) how we ensure we fit in with the Integrated Commissioning Team's timescales for commissioning and procuring new services to improve outcomes for people affected by cancer. Further discussions need to take place with commissioning leads to manage this risk.
- "Cancer Health Intelligence Report" was delayed due to lack of capacity and clarity as to who will undertake the different segments of work; there were unrealistic expectations on what was feasible from within the Public Health resources.
- Attracting people affected by cancer to join the co-production group to be involved fully at each phase of the programme, has been difficult, so we have agreed to have a flexible approach by maintaining a virtual network of people who can be called upon to join activities as and when required.
- We set unrealistic time frames for the delivery of each phase of the programme, whilst not being resourced and supported in the same way as the sites in Fie, Dundee and Durham, to enable us to deliver. Plans have been reviewed and adjusted and more resources are being sought through dialogue with Macmillan.
- We don't have enough information through asset mapping and system mapping to understand: how much each service is being used, the quality of the services, accessibility and impact on patient / care experience.
- We have limited understanding of how patients flow between different parts of the system and across sectors so we need to undertake some process mapping.