



Guide to the creation of a Whole Systems Data Set

Project Sponsor: Tower Hamlets Together

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1. DOCUMENT CONTROLS

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2. EXECUTIVE SUMMARY

Background

- 2.1 Tower Hamlets has the lowest healthy life expectancy for both women (52.4 years) and men (54.0 years) in the country (1). This means that people in Tower Hamlets can expect to develop poor health ten years earlier than the average person in England. Based on life expectancies in the borough, this results in 30 years of poor health for women and 25 years for men. This burden of ill-health is, however, not equally shared across Tower Hamlets – in the 10 percent of most deprived areas, ill health strikes around 12 years earlier than it does in the most affluent areas among men and around 10 years earlier among women.
- 2.2 To help reduce these inequalities and the pressures they create on the health and care system, a partnership of local organisations was established. The partnership, called Tower Hamlets Together (THT), consists of the local authority, local NHS organisations and community and voluntary sector partners.

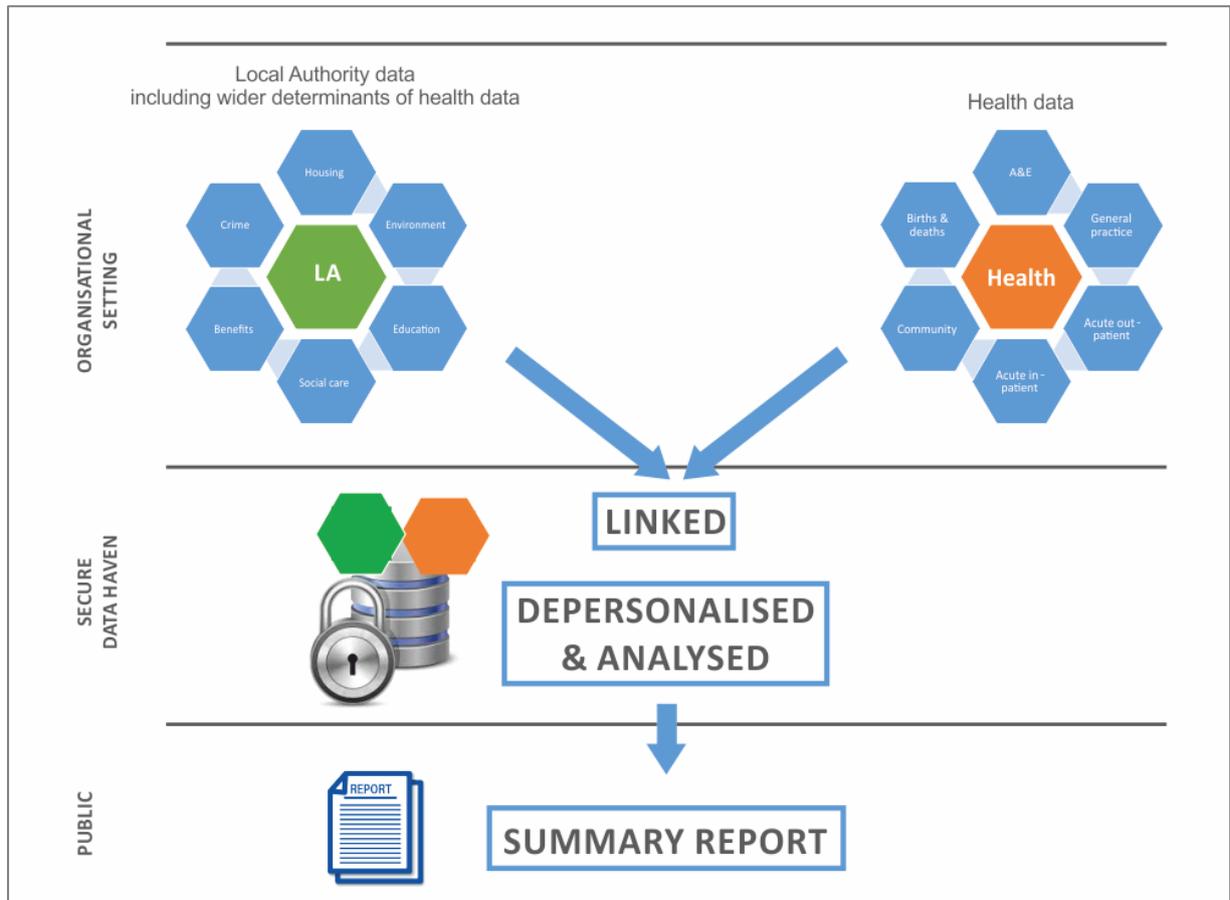
The Project

- 2.3 In this context, the Whole System Data Project (WSDP) has been established to describe and understand the relationship between inequalities in health and service use and the impact of the wider determinants of health across Tower Hamlets. It is intended to build the evidence, as identified in the Marmot Review, needed to support NHS England's New Models of Care (2), (3).
- 2.4 This ground-breaking project attempts to look at service provision and population need in an integrated manner not only across health, social care and community care, but across wider local authority services such as education, benefits, crime, environment and housing.
- 2.5 By including a more comprehensive and holistic list of public sector health and wellbeing activity for the whole Tower Hamlet's population, this project expects to establish a more complete picture of cost and need, so as to inform strategic direction, commissioning and resource allocation. A conceptual model of the project is provided in Diagram 1.

2.6 As it is the first time a local authority has tried to link health and local authority data to create a *de-personalised*¹ dataset of this nature, there was a need to undertake significant work in the project to address previously untested data protection and information governance requirements including the role of national bodies such as the [Confidentiality Advisory Group \(CAG\)](#) and the [Independent Group Advising on the Release of Data \(IGARD\)](#).

¹ <https://understandingpatientdata.org.uk/what-does-anonymised-mean>

Diagram 1: Conceptual Diagram of the Tower Hamlets Together Whole Systems Data Project



Crime refers to local authority crime data such as enviro-crime- anti-social behaviours.

3. INTRODUCTION

A. *The Project*

- 3.1 The Whole Systems Data Project (WSDP) is a ground-breaking project to link client level Local Authority data with health care data to produce a de-personalised dataset.
- 3.2 This dataset will be used to understand the relationship between the *wider determinants of health* and the uptake of health and social care services
- 3.3 The wider determinants of health are those social and residential factors that affect the health and wellbeing of residents such as social isolation, housing, income, education, crime and pollution. The London Borough of Tower Hamlet has legislated functions and powers to ensure that these societal factors are managed effectively as directed by the Local Government Act 1989.
- 3.4 By including a more comprehensive and holistic list of public sector health and wellbeing activity for the whole Tower Hamlet's population, this project expects to establish a more complete picture of activity, cost and need to inform strategic direction, commissioning and resource allocation.
- 3.5 The results of the work will provide a better picture of health and service variation, public sector costs of at-risk groups and the factors that affect this, to inform targeted and preventative allocation of resources to those groups with the greatest *need*.
- 3.6 The WSDP is intended to support a more comprehensive definition of a whole system that can support the move towards a local Accountable Care System (ACS).
- 3.7 As it is the first time a local authority has tried to link health and local authority data outside of social care to create a de-personalised dataset of this nature, there was a need to undertake significant work to address previously untested data protection and information governance requirements; including the development of public and patient involvement in the programme.
- 3.8 It should be noted that this is a one-year pilot, to demonstrate proof of concept in linking health and local authority data for operational needs.

B. Supporting New Models of Care across the Tower Hamlets partnership

- 3.9 This project is intended to act as a data and information framework to support the generation of evidence to drive strategy, planning, service transformation and New Models of Care.
- 3.10 New Models of Care are a cornerstone of NHS England's Five Year Forward View (4), (3).
- 3.11 The project is sponsored by NHS England via the Vanguard Programme. Each Vanguard is taking a lead on the development of new care models which will act as the blueprints for the strategic move directed by the Five Year Forward View (4).
- 3.12 The Tower Hamlets Vanguard acts as Multispecialty Community Provider partnership with a focus on moving specialist care out of hospitals into the community. The Vanguard also works to offer joined-up, person-focused support and care, helping people look after themselves better to reduce pressure on the health and care system.
- 3.13 The Tower Hamlets Vanguard is driven by a partnership of local organisations, known as Tower Hamlets Together (THT)², consisting of:
- Bart's Health NHS Trust
 - East London Mental Health Foundation Trust
 - London Borough of Tower Hamlets
 - Tower Hamlets Clinical Commissioning Group
 - Tower Hamlets Council for Voluntary Service
 - Tower Hamlets GP Care Group
- 3.14 In this context, the WSDP is a defined project to describe and understand the relationship between inequalities in health and service use across Tower Hamlets and the impact of the wider determinants of health. It is intended to build the evidence, as identified in the Marmot Review, needed to support New Models of Care across the THT partnership (2).
- 3.15 The project is jointly led by the Public Health Division at the London Borough of Tower Hamlets (LBTH) and the THT Public Health lead; in partnership with The Institute of Health Equity³ and in close collaboration with the THT partnership.

² <http://towerhamletstogether.com/>

- 3.16 The project is a pilot and the first step in testing a proof of concept to provide a strategic operational framework that meets and is responsive to residents' expectations for health, social care and the local authority to better understand local inequalities and meet resident's needs.
- 3.17 Whilst considered invaluable in informing future operations through local Joint Strategic Needs Assessments and the Health and Wellbeing Board, the project focuses on meeting the legal responsibilities by adhering to the strictest information governance rules and Data Protection requirements to engender trust and support of local residents.

C. *The audience*

- 3.18 In this guidance document, we outline the steps taken in the creation of the WSDP, specific challenges encountered and our approach to addressing these.
- 3.19 The document provides a guide to those local partnerships and public health departments aiming to maximise the use of routinely collected operational information across their partnership in an integrated manner to inform strategic direction, commissioning and resource allocation.

³ <http://www.instituteofhealthequity.org/>

4. BACKGROUND

A. *Where we are: Inequalities in Tower Hamlets*

- 4.1 Tower Hamlets has the lowest healthy life expectancy for both women (52.4 years) and men (54.0 years) in the country (1). This means that people in Tower Hamlets can expect to develop poor health ten years earlier than the average person in England. Based on life expectancies in the borough, this results in 30 years of poor health for women and 25 years for men.
- 4.2 In terms of deprivation and based on the Index of Multiple Deprivation (IMD) score, Tower Hamlets ranks 24th out of 326 local authorities in England on the proportion of most deprived neighbourhoods and third most deprived in relation to the 'extent' of deprivation (5).
- 4.3 The Borough is also the most deprived nationally with regard to income deprivation among both children and older people and has the highest level of income inequality in London (6). This inequality is reflected in the burden of ill-health. In the ten percent of most deprived areas, ill health strikes around 12 years earlier than it does in the most affluent areas among men and around 10 years earlier among women (1) (5).
- 4.4 Furthermore, Tower Hamlets is ethnically diverse with 69% of the population belonging to minority ethnic groups (i.e. not White British) and 32% of the population being Bangladeshi (7).
- 4.5 Within this particularly diverse and challenging environment, in order to raise residents' health status and reduce inequalities within the borough, local service providers need to work in an integrated manner to better understand inequalities and the relationship between the circumstances in which people live and their levels of ill-health and service usage. This in turn will help the local care system deliver services that best meets the needs of individual residents within resource limits.
- 4.6 As part of the Health and Social Care Act 2012, Tower Hamlets Council, Tower Hamlets Clinical Commissioning Group (CCG) and the Secretary of State have a legal duty to have regard to reduce inequalities in access to, and outcomes of, health services (8). In discharging this duty, it is essential that resources are targeted as effectively, efficiently and equitably as possible.

B. Cause and effect: wider determinants of health

4.7 There is a wide body of established evidence correlating the impact of the wider determinants of health on the wellbeing of residents and their reliance on services (2), (9), (10), (11). Many analyses of these broader determinants suggest that they are more important than health care in ensuring population health. Such determinants, along with life styles risks (e.g. smoking), are helpful in defining sub-groups of people at risk who potentially stand to benefit from preventive policies or actions. These at-risk groups include those living in cold or poor housing, living alone or with poor access to services, unable to afford to live healthily or have control of their lives, exposed to air pollution, frail and elderly or living with disabilities, long term sick, those with poor educational attainment.

C. Targeted resourcing: funding new models of care to reduce inequalities

4.8 Integrating services around the patient is a central component of the Five Year Forward View. One of the routes this document proposed for achieving this is through Multispecialty Community Providers (MCPs), such as the THT Vanguard. MCPs will become the focal point for a far wider range of care needed by their registered patients. Under this vision, one option is that MCPs could in time take on delegated responsibility for managing the health service budget for their registered patients. Where funding is pooled with local authorities, a combined health and social care budget could be delegated to MCPs.

4.9 A new variant of integrated care is also considered in the Five Year Forward View, in which single organisations provide NHS list-based GP and hospital services, together with mental health and community care services. The leadership organisations to bring about these 'vertically' integrated systems are known as Primary and Acute Care Systems (PACS). At their most radical, PACS would take accountability for the whole health needs of a registered list of patients, under a delegated capitated budget - similar to the Accountable Care Organisations (ACOs) that are emerging in Spain, the United States, Singapore, and a number of other countries.

4.10 Capitated payment (or capitation) means paying a provider or group of providers to cover the majority (or all) of the care provided to a target population, such as patients with multiple long term conditions, across different care settings (12). The amount per head are based on the estimated costs of individuals within a population and then uplifted for inflation..

- 4.11 Having whole population budgets and one control total will be pivotal for allocation of funds for the provision of services for local populations under new service models proposed under the Sustainability and Transformation Plan (STP), including the evolution to Accountable Care Systems (ACS). In line with the FYFV the WSDP enables the assessment of population *need* through the impact of the wider determinants of health from a public health perspective. This allows for preventative new models of care that tackle inequalities in health which cannot be effectively developed using purely activity data.
- 4.12 ACSs are systems in which NHS organisations (both commissioners and providers), often in partnership with local authorities, choose to take on clear collective responsibility for resources and population health. They provide joined up coordinated care. In return, they get more control and freedom over the total operations of the health system in their area; and work closely with local government and other partners to keep people healthier for longer, and out of hospital. Specifically, ACSs can agree an accountable performance contract with NHS England and NHS Improvement that can credibly commit to make faster improvements in key deliverables. Under an ACS a group of providers agree to take responsibility for all care for a given population for a defined period of time under a contractual arrangement with a commissioner. The ACS is able to develop and deliver preventive interventions for patients with a high-risk profile, as well as reactive interventions to avoid unnecessary hospital admissions.
- 4.13 Modelled on international successes, capitation payments to local health economies are considered capable of driving new integrated care models that can generate better outcomes for residents and financial gains for the economy which in turn can be reinvested into the local system (12). However, there are significant governance issues that need to be addressed in sharing budgets in this way. This includes how decisions are made and how organisations are represented in the decision -making process, how both reputational and financial risks are shared between organisations with very different accountability mechanisms and how each organisation meets its accountability responsibilities within a shared framework..

5. AIM AND SCOPE

A. Aim

5.1 The Tower Hamlets Together Whole Systems Data Project (WSDP) aims to establish an integrated health, social care and wider determinants of health dataset across Tower Hamlets which allows for effective epidemiological analysis, risk stratification and needs based resource allocation for the local population based on evidence. This is a defined one-year proof of concept project.

B. Objectives

5.2 To establish a truly integrated and de-personalised health, social care (H&SC) and wider determinants of health dataset for the local population which combines information from both the London Borough of Tower Hamlets (LBTH) and the NHS:

- a. To clearly describe the health and care provided to a risk stratified Tower Hamlets population with sufficient granularity
- b. To define and inform capitated budgeting for the Tower Hamlet population

5.3 To achieve 1(a) by quantitatively investigating the association between:

- a) the socio-demographic determinants,
- b) health status and
- c) service usage

to enable sufficiently granular identification of health inequalities in the Borough

5.4 To explain the variation in spend within budgets in Tower Hamlets based on an additive costs model of the wider determinants of health (the socio-demographic characteristics of the population). This will target efforts to align resource allocation to *need* under new models of care.

5.5 To inform local strategic development of new models of care and target resource allocation based on the principles of proportionate universalism so as to better meet the needs of the population of Tower Hamlets.

5.6 The project will include a robust Patient and Public Engagement Plan to work with resident and patient groups to inform, scope and test proposals and to be responsive to feedback.

5.7 The project will develop informatics capability within the local partnership of providers, Tower Hamlets Together (THT). It is intended that a successful project would be reproducible and as a result work is already underway with national partners (The Institute of Health Equity and NHS England New Models of Care Team) to further data integration from a Whole systems perspective.

c. Background

5.8 The underlying principles of the WSDP have been tested and applied in earlier work conducted by local authorities including London Borough of Tower Hamlets in the use of Local Authority data to both accurately estimate the local population and for public health accounting (13), (14) (6), (15). Here socio-economic features of neighbourhoods have been ranked and associated with admission rates and secondary care costs for adults.

5.9 The WSDP aims to look beyond simply using the standard indicators of the deprivation and health, such as the index of multiple deprivation (IMD) score, to determinants that are more specific and relevant to the context of Tower Hamlets residents such as poor housing, low income, educational attainment, housing tenure, crime, diversity and overcrowding. It also looks at access to local facilities that have the potential to promote resilience and social cohesion and reduce social isolation – such as community access to premises such as libraries and GP surgeries.

5.10 A key goal of the WSDP is to establish an evidence base system of payment to reduce health inequalities and improve health, social care and local authority services provided in our borough through better cost models at Lower Super Output Area level. The work is closely aligned with the development of neighbourhood statistics by the Office for National Statistics (ONS) and the Department of Communities and Local Government (DCLG) to measure variation in healthy life expectancy and levels of deprivation (16), (5).

5.11 The WSDP objective will be achieved by developing a data driven, evidence based, operationally focused approach which will describe the relationship between rates of diagnosed illness, levels of service use and social deprivation within each lower super output area (LSOA) of Tower Hamlets (17).

5.12 The WSDP will support an integrated approach to understanding local service provision within Tower Hamlets to inform how commissioners and providers target increasingly scarce resources.

6. METHODOLOGY

6.1 The project aims to establish the resident population of the local authority within a specific period of time and subsequently assess the level of health and social care activity retrospectively (Diagram 2).

A. *Stakeholder engagement*

6.2 Based on an initial value proposition (project brief), principle local stakeholders were engaged to ensure that there was collective support throughout the THT Partnership. This involved working closely with the local Clinical Commissioning Group and Commissioning Support Unit as well as local service providers, including the diverse service providers within the council, to win support and collaboration. This aimed to disseminate the project benefits at the highest levels across organisations to secure recognition and support.

6.3 The stakeholder engagement phase engendered a collective understanding of the project vision and the shared definition of the project aims and analytical needs.

6.4 The collaborative development of the project also highlighted significant overlap and duplication of efforts across other data centric projects in the region resulting in the move towards a more strategic approach to East London business intelligence needs.

B. *WSDP minimum dataset*

6.5 Underpinned by the project aims and the analytical needs, a core minimum dataset for the study of inequalities and population need in Tower Hamlets was defined based on the requirement to understand:

- 1) The wider determinants and health status;
- 2) Service usage;
- 3) Correlation of wider determinants and health status to service usage to inform a cost model.

6.6 It is acknowledged that this project only uses a limited amount of the data available across its service sectors. In the future the intention is to extend the data set subject to information governance and data protection standards. An extended data set will be fully discussed with local stakeholders, but, should include prescribing, additional

children and young people’s data and further mental health data including for children and young people, addiction and addiction service information.

6.7 The minimum dataset contains information needed for linkage and is therefore not retained for analysis. It also contains individual level information that is retained for analysis in a reduced/ aggregated form. The types of information and rationale for inclusion are summarised in Table 1 and a detailed list of data items is given in Appendix 1. The process is described in detail in Section C below.

Table 1: Details of Data Set and the Rational for Inclusion.

Sectors	Domains	Rationale and information included
Local Authority wider determinants of health routine datasets (London Borough of Tower Hamlets)	Housing	Housing plays a central role in the conditions of daily life of each individual, both at the household and neighbourhood levels. LBTH information provides a crude indicator of affluence – council tax band, social housing - as well as vulnerability – housing benefit, council tax exemptions, hostel residence, housing waiting lists and the house’s energy efficiency.
	Education	Education is a key determinant of future health, skills - including health literacy – and employment/income prospects. It also signifies the success of pre-school and school provision, as well as intergenerational skill transfer. LBTH data from the school pupil census covers school attended, key stage results, SEN, FSM, ethnicity and mother tongue.
	Library membership list	Libraries are a key community facility. Membership indicates a degree of social participation, as well as potential access to knowledge and mental stimulation through IT, books, etc. LBTH information covers membership, ethnicity and last contact.
	Public health birth and mortality files	Births and deaths are key health outcomes. They contribute to many outcome framework indicators. The information collected at birth gives a strong indication of future health and that at death provides an insight into the end of life. Information held from births covers date and place of birth, mother’s date of birth and birthweight. Similarly, for deaths the information covers gender, country of birth, dates of birth and death and place and, cause of death.
	Environmental health	Many factors that affect the stresses of daily living in local neighbourhoods are reported to environmental health. These cover anti-social behaviour, waste in front gardens and pests. Some housing information (see above) is recorded under this category – HMOs and right to buy – as well as parking permits and disability badges.
	Service site locations	Access to services and public facilities is a key measure of the responsiveness of the relevant services. One element of this is physical location – how close to these locations do people live? Systematic differences between areas can give rise to inequalities in access. As well as facilities run by NHS and other health providers, other sites are

		important to health – green spaces, fire stations, public transport, schools, premises selling alcohol, children’s centres.
Social Care Adult	Adult social care current users	Adults that qualify for some sort of social care support are the group that have some of the largest and often most complex health care needs. In particular, discharge from hospital requires a care plan and this initiates social care usage in existing users of acute services. Care packages cover: a. at home; b. nursing and residential care; c. Tele care; d. meals on wheels; e. day care centre; e. other: Care groups cover: a. physical and sensory disability/frailty b. sensory impairment; c. mental health d. learning disability e. other vulnerable people f. other and unclassified.
Social Care Children	Fostering	Children in care have some of the worst physical health among children – particularly dental health and those in care because of congenital health problems. They may also have mental health issues as a consequence of adverse childhood trauma (ACTs). Subsequent to childhood, ACTs and other adverse factors lead to many forms of adversity and behavioural issues in adulthood that impact on health.
	Adoption	Adopted children may experience ACTs prior to adoption, will similar consequences.
	Child protection, (neglect, abuse)	Child protection is usually a response to ACTs. The health and other consequences are as described above.
	Special educational needs	Special needs often arise from physical or mental health issues. In which case this will influence health care needs in childhood and beyond. If the needs are purely educational and result in poorer educational attainment, then that creates a lifetime risk of adverse consequences for employment, income and health.
	Youth services	Many users of youth services are likely to experienced ACTs, with consequences as described above.
Secondary Care (e.g. Bart’s Health NHS Trust)	A&E attendances	A substantial element of pressure on acute services is reflected in A&E. This includes many episodes that are potentially avoidable through integrated care and early preventative measures. Information on episodes covers method of admission, presenting condition, HRG code, episode dates and discharge destination.
	Elective inpatient admissions	Elective admissions reflect many of the referrals that originate from GPs. There is scope for reducing these through early prevention. Information on episodes covers GP code, admission method, specialty, main ICD code, HRG tariff, dates, dementia flag, discharge destination.
	Non-elective inpatient admissions	Non-elective admissions include emergency re-admissions which are strongly socially patterned. They are particularly amenable to action through integrated care. The information held is as for elective admissions.
	Outpatient	Outpatient visits occur for diverse reasons. In many cases

	attendances	a more integrated approach could prevent the need for these or divert them from the acute sector. Information
Mental Health Trust (e.g. East London Foundation Trust)	Inpatient admissions	Mental health is an essential feature of health and wellbeing and is strongly associated with poor health and life outcomes, also with increased use of health and care resources. Tower Hamlets has amongst the highest mental health need in the country. Including Mental Health Trust activity in the WSDP is essential. Admissions data will be extracted via the Mental Health Minimum Data Set (MHMDS).
	Community Services	This data will enable the project to understand Mental Health Trust activity provided through community sites and will be extracted via the MHMDS.
Primary Care	General Practice Register	This provides information on the registered population. This covers opt-out status, gender, ethnicity, date of birth, date of registration, Flag 4 code.
	GP consultations (Inclusion in QOF registers)	This represents a large part of NHS activity. The information covers basic information on numbers of attendances, telephone calls, prescriptions as well as vaccinations and immunisation, public health recording (such as blood pressure, smoking), QOF indicators and date of QOF assignment.
Community health	Community Nursing Service	These visits represent most of the NHS care provided at home. Information covers date of commencement, numbers of visits reason for visits.
NHS111	Emergency and ambulance calls	This reflects many initial contacts with NHS. Information covers GP code, location, date reason for call (ICD) and outcome.
Walk in centres		This captures many contacts that are not though GP or A&E. Information covers GP code, date, reason for attendance and outcome.

6.8 During the process of developing and refining the specification, discussions were held with the Confidentiality Advisory Group (CAG)⁴ (see Section D below), data controllers and suppliers of data. This resulted in some changes from the original outline specification. In particular:

- Opt-out status on the GP Register was added for selecting out records prior to linkage, after discussion with CAG (this may not be needed if patients who have opted-out are removed from the extract before receipt of data).
- Additional items were identified as requiring reduced identifiability, after discussion with CAG – in particular Eastings and Northings of all geographic

⁴ <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/>

locations were replaced with the published Eastings and Northings of the corresponding lower super output area (LSOA). The date of birth reduced to age in years and home addresses reduced to lower super output area.

- Some local authority datasets were dropped also due to access difficulties (out of borough activity data) and legal limitations (e.g. Electoral Register).

6.9 For practical reasons the minimum dataset was divided into:

- 1 *Local Authority Data*. This was collated by engaging with each individual service of interest within the London Borough of Tower Hamlets and its Data Controllers (diagram 2). A minimum dataset from each service was specified and a request made for the data. A local Data Controllers group workshop was held to present the work, get feedback, gain support and ensure due diligence to their legal responsibilities including those under the Data Protection Act. Data Controllers represented by the LBTH Partnership Joint information Governance Group (LBTH PJIG) were asked to oversee the work and provide governance in light of their role to meet Data Protection Act requirements, local interest in the work and the strategic needs of the local authority to have an integrated view of its services to better meet its statutory responsibilities under Local Government Act 1989 and The Health and Social Care Act 2012.
- 2 *Health care data* originates from a range of health care settings with the source and Data Controller being principally NHS Digital (diagram 2). Due to the nature of the local data hosting, primary care data and GP registers were available through local Data Controllers, who were consulted and agreed to the use of their data.

6.10 In this project both person level (e.g. date of birth) and residential property data (e.g. post code, UPRN) information are treated as personal information.

C. Data Controllers

6.11 Table 2 details the Data Controllers in this project. The specific data sets under their control that are to be used in this project are described in Appendix 1.

6.12 The recipient of the data cannot place conditions on the sender of the data. Where required, formal Data Sharing Agreements are required between partners in order to manage data access and processing including data linkage.

- 6.13 The secondary use of shared data across a whole system is explicitly highlighted in the Privacy Notice of the local authority. This Privacy Notice is aligned with the standards advocated by NHS Digital⁵ and those proposed by the General Data Protection Regulation⁶ (e.g. concise, clear and free of charge).
- 6.14 We will be using the opt-out process within primary care data to exclude individual's health data in-line with their expressed requests. The project will also aim to develop local capabilities further in this area (e.g. increasing public understanding via the public engagement and communications strategy and alternative technical opt-out solutions).
- 6.15 It is highlighted that each Data Controller should be fully compliant with the Data Protection Act and duty of confidentiality and complete a Privacy Impact Assessment as appropriate^{7, 8}.

⁵ <http://content.digital.nhs.uk/article/6973/Fair-Processing-for-CCGs>

⁶ <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/>

⁷ <https://ico.org.uk/media/for-organisations/documents/1546/data-controllers-and-data-processors-dp-guidance.pdf>

⁸ <https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notice-transparency-and-control/>

Table 2: Table Detailing Data Controllers and Data Processor Roles (including changing roles)

Data sources can be client level or property level, requiring the appropriate data protection consideration. For all Data Processing functions, Data Processing Agreements are held between Data Controllers and Data Processor.

Data processing status may differ due to stage of data flow. E.g. Health data from national data flows via the DARS process will have NHS Digital as initial data processor. The data processor for the Whole Systems Data project is the Clinical Effectiveness Group (CEG), Queen Mary University of London (QMUL).

Data (data sources and final)	Data Controller	Data Processor	Data Haven (project) Data Controller
Housing	LBTH	LBTH	LBTH
Education	LBTH	LBTH	LBTH
Social Care (children's and adults)	LBTH	LBTH	LBTH
Benefits	LBTH	LBTH	LBTH
Environment	LBTH	LBTH	LBTH
Library	LBTH	LBTH	LBTH
Enviro- Crime	LBTH	LBTH	LBTH
Linked LBTH data	LBTH	CEG, QMUL	
A&E	NHS Digital	CEG, QMUL	LBTH
Ambulance Data	NHS Digital	CEG, QMUL	LBTH
Acute Inpatient	NHS Digital	CEG, QMUL	LBTH
Acute Outpatient	NHS Digital	CEG, QMUL	LBTH
Accidents and Emergency	NHS Digital	CEG, QMUL	LBTH
General practice data	Tower Hamlets General practices	CEG, QMUL	LBTH

General practice register from NHS Discovery Project ⁹	Tower Hamlets General practitioners	CEG, QMUL	LBTH
National General practice register	National Health Applications and Infrastructure Services (NHAIS)	CEG, QMUL	LBTH
Births and Deaths data	Office of National Statistics (via DARS)	CEG, QMUL	LBTH
Final linked de-personalised WSDP Data Set	LBTH (Director of Public Health)	CEG, QMUL	LBTH

⁹ NHS Discovery is a project within the Clinical Effectiveness Group.

D. Data linkage

- 6.16 Local authority data does not hold one unique client identifier such as the NHS number. In many instances, each individual service or department uses its own unique client identifiers in addition to names, address data or birth date, post code and the Unique Property Reference Number (UPRN) to establish identity at person and property level. Therefore, local authority data will be linked to form a master index of local authority information. This is done using identifiers highlighted above.
- 6.17 Health data is sourced via a [Data Access Request Service \(DARS\)](#)¹⁰. Health data linkage is conducted by DARS using the NHS Number. The DARS data is used to develop a master index of health data which includes First Name, Surname, Gender, Date of Birth, Full Address and Post Code.
- 6.18 The linkage of health and local authority data requires personal identifiable information. Here deterministic data linkage is conducted using First Name, Surname, Gender, Date of Birth, Full Address, Post Code, NHS Number (where available).
- 6.19 In the future, our aim is to develop local capability to pseudonymise at source. However, this is not within scope of this pilot. To move away from the need to use identifiable data, it is possible to link health and local authority data using a pseudonym (an alternative to the personal data) by pseudonymising the data at source (refer to glossary). A conceptual representation of this project is provided in Appendix 2.
- 6.20 During the data linkage process, sensitive personal data such as sensitive clinical data will be isolated to protect confidentiality.
- 6.21 Initially the linkage of the health datasets and the linkage of local authority dataset will be conducted separately. Local authority data lacks a unique identifier across its various setting and therefore linked deterministically (largely) using personal identifiers. Health data is linked using the NHS Number as the unique identifier. Linkage across the local authority and health domains requires Section 251 approval (see Section D below). Linkage process between local and health data is dependent of data quality and relies on both deterministic and probabilistic linkages.

¹⁰ <https://dataaccessrequest.hscic.gov.uk/>

6.22 The data will be de-personalised within a 3-month window after health and local authority data is linked. The 3-month window is for checking links and for updating if new datasets are made available.

6.23 Depersonalisation involves the removal of unique personal identifiers such as NHS Number, names, addresses and Unique Property Reference Number etc., whilst other personal information which can be used in combination such as post code and date of birth, are reduced to age in years and Lower Super Output Area respectively.

6.24 No information will be held that will enable depersonalised data to be made identifiable again.

D. Legal approval

6.25 The use of client level personal identifiers to link datasets for purposes other than for direct care requires legal approval by the [Confidentiality Advisory Group \(CAG\)](#)¹¹ through a [Section 251 approval](#) (Appendix 3).

6.26 Diagram 2 below outlines the conceptual picture of the project approach based on Section 251 approval. The diagram draws particular attention to areas of information governance and data protections of particular significance to Section 251.

6.27 Central to the Section 251 application, the CAG requested the development of a Patient and Public Involvement Plan (PPI) with a clear feedback loop to the project Steering Group to inform project development. This is described in Section E below.

6.28 Working with CAG to obtain Section 251 approval has been important in shaping local thinking and developing the project. LBTH and THT were supported by the NHS England Data Privacy Support Unit and NHS Digital because of the novelty of the project - the first to attempt to link diverse local authority data sets with NHS datasets.

6.29 Legal approval to use identifiable data by the CAG does not sanction the release of identifiable health data by NHS Digital (health data controller). This is regulated by the [Independent Group Advising on the Release of Data \(IGARD\)](#)¹². IGARD is the replacement to the Data Access Advisory Group (DAAG). Approval from IGARD can be obtained through the DARS application process. Other governance bodies will also need to be considered based on the scope of the datasets and their Data Controllers requirements. A more detailed flow diagram showing the key elements (incl.

¹¹ <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/>

¹² <http://content.digital.nhs.uk/IGARD>

processes, sub processes and main project management [Prince 2] products) for the creation of a WSDP are outlined in Diagram 3.

E. Patient and Public Involvement Plan

- 6.30 A clear requirement by the CAG is evidence of local understanding and support for the WSDP with an effective feedback mechanism for residents.
- 6.31 Our approach to PPI builds on earlier work by groups such as [Healthwatch¹³](#), [National Voices¹⁴](#) and local [Waltham Forest and East London Collaborative \(WELC\)](#) engagement work.
- 6.32 The PPI activity aims to clearly articulate a narrative for the project that emphasises the benefit to the individual resident and the population as a whole.
- 6.33 A presentation for workshops was developed in collaboration with the wider public health team to contextualise the work, describe the planned methodology, detail specific areas of information governance and data protection and to describe the perceived value of this work to both individuals and to the wider resident population.
- 6.34 The PPI work has a clear approach to involve residents to ensure confidentiality and consent issues are discussed and feedback assimilated into the project development.
- 6.35 The PPI plan was developed in discussion with the CAG. When this plan has been implemented, the result and feedback from residents will be logged and reported back to the CAG as part of the CAG requirement for approval.
- 6.36 Following each workshop modifications were made to future presentations and where possible to the project methodology to ensure feedback was taken on board.
- 6.37 The WSDP PPI plan is appended (Appendix 4).

F. Data Haven

- 6.38 The extracted health and local authority data is to be stored and processed within a secure data haven. The WSDP Data Processor will operate within the secure data haven.

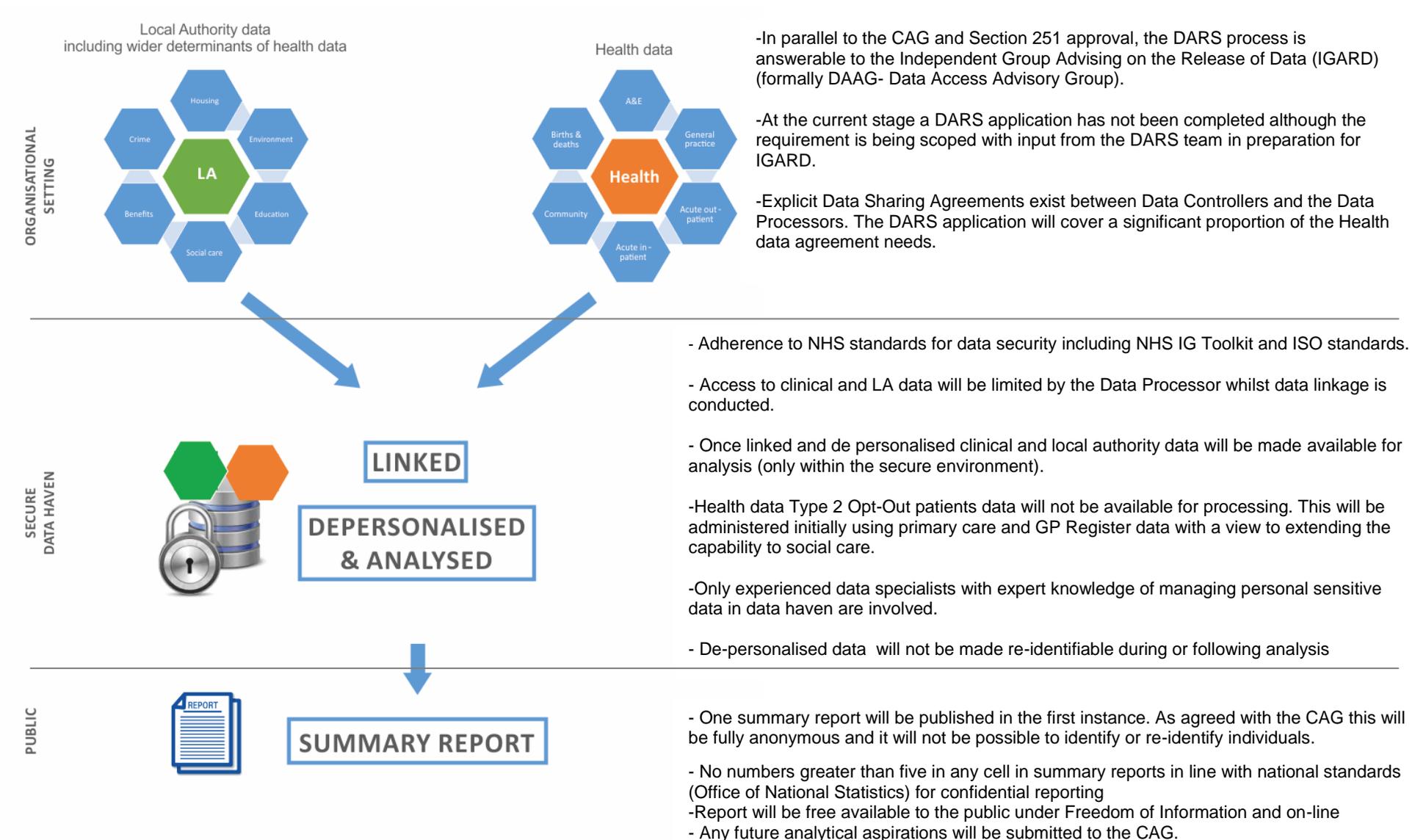
¹³ <http://www.healthwatch.co.uk/find-local-healthwatch>

¹⁴ <http://www.nationalvoices.org.uk/>

- 6.39 To identify a suitable host, an options appraisal of data warehousing solutions was conducted.
- 6.40 Potential options identified as meeting the NHS standards for hosting data securely included the local CSU, the Local Authority, commercial and charitable cloud solutions.
- 6.41 The options appraisal assessed information governance and data protection status, cost, time frame, responsiveness, experience, reliability, flexibility and demands in the future.
- 6.42 The data haven was required to meet [NHS Information Governance Tool Kit¹⁵](#) and ISO Information Security standards in order to act as Data Processor of identifiable patient level information. The data haven will also have to meet CAG and IGARD expectations.
- 6.43 The project team work in close collaboration with the selected data host to ensure the legal, technical and analytical requirements can be and are met.
- 6.44 The analytics for the project (Appendix 5) will be conducted only within the data haven environment on a predefined specification in line with the requirements of the Data Protection Act and Section 251 approval. Only security level controlled project leads will have access to the de-personalised data.

¹⁵ <https://www.igt.hscic.gov.uk/>

Diagram 2: Conceptual Diagram of WSDP with Section 251 Approval



4) *Training and Organisational Development*

6.45 A principal objective of the WSDP is to drive a cultural shift towards evidence-based integrated care and commissioning that embeds the wider determinants of health and inequity within strategic, planning and commissioning processes.

6.46 An important output from the work will be to document the methodological processes in sufficient detail so that that future iterations of the work can be conducted by staff This will also include hands on training of staff to replicate those elements of the work that are completed by specialists or tendered partners. The lessons learn will also feed into strategic planning and operations for the local authority and also the wider THT informatics strategy and business intelligence approach.

6.47 Lessons learnt will be fed into local and national business intelligence developments and the Sustainability and Transformation Plan.

7. GOVERNANCE GROUPS

The project functions under a clear governance structure (see diagram 4) with the Whole Systems Data and Health Inequality Steering Group (WSD&HI) acting as the project board (terms of reference are available on request). There is lay representation on the WSD&HI Steering Group.

There are two elements to the governance of this project:

1) Project governance: to ensure that the project aligns with local strategic objectives and is embedded into local decision-making, the WSD&HI Steering Group reports to the Tower Hamlets Together (THT) Board via the THT Strategic Systems Development Group. The THT Board has agreed to convene a Stakeholder Council, made up of lay representatives, to critique and input into the working of the Board, to act as a critical friend, this is in development.

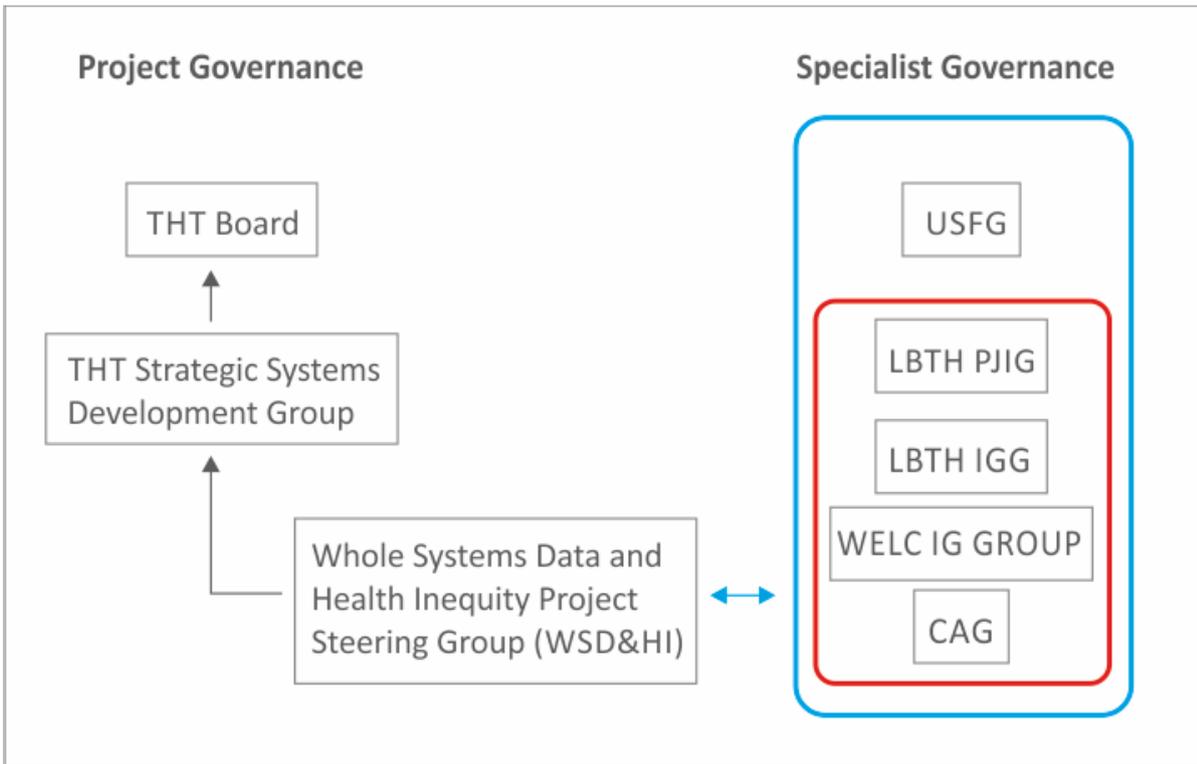
2) Specialist Governance

a) Information Governance for local authority and NHS: to ensure that the project adheres with local, regional and national information governance standards the project reports to the London Borough of Tower Hamlets Partnership Joint Information Governance Group (LBTH PJIG), corporate information governance issues go to the LBTH Information Governance Group (LBTH IGG). For wider conformance to regional information governance, matters go to the Waltham Forest and East London Information Governance (WEL IG) Group.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent and to provide advice to the Secretary of State for Health on whether an application should be approved. The CAG also considers the 'other' legislative requirements including the Data Protection Act.

b) Patient and Public Involvement Governance: to ensure that the project has sufficient and appropriate involvement of patients and the public, a PPI subgroup is implementing the PPI plan for this project (Appendix 4). The project has been discussed and reviewed at the THT User and Stakeholder Focus Group (USFG) which provides lay, patient and carer representation across all the organisations in THT.

Diagram 4: Whole System Data Project Governance Structure



Key:

- *CAG: Confidentiality Advisory Group*
- *USFG: User and Stakeholder Focus Group*
- *LBTH IGG: Information Governance Group*
- *LBTH PJIG: Partnership Joint Information Governance Group*
- *WELC: Waltham Forest and East London Collaborative*
- *THT: Tower Hamlets Together*

Bold titles indicate where lay representation occurs.
 Specialist Governance Groups in *blue boundary*
 Information governance groups are within the *red boundary*

8. CONCLUSION

A. *Lessons learnt*

8.1 This document outlines the steps taken by the WSDP to implement a shared vision for the use of routine operational information in an integrated manner across the THT partnership.

8.2 The project attempts to address some of the principle concerns in the care and wellbeing of residents by aiming to better understand entrenched inequalities and target the needs of residents.

8.3 Principle elements for consideration in the creation phase of a Whole Systems Data Project include:

- A definitive project and analytical approach
- A clearly defined data set
- Patient and Public Involvement Plan
- Secure Data Haven
- Confidentiality Advisory Group Section 251 Approval
- Good management of patient opt-outs.

8.4 It is clear that the significant issues identified in linking many different local authority data sets to health data, including confidentiality and consent issues, need careful scrutiny and management of solutions. Substantial strengthening of specialist governance arrangements are needed to retain public confidence in managing the linking of these sensitive data.

8.5 The project has made significant progress in addressing the challenges encountered. Achievement of the aims and objectives of the project will justify this effort, particularly in the context of current strategic needs as indicated by the Five Year Forward View and the need to deliver New Models of Care through Sustainability and Transformation Plans.

8.6 It is recognised that Local Authority operations and services models vary hugely in how services are delivered and commissioned. As such the methodology described in this document is not prescriptive but is designed to act as a guide to those considering the development of their own Whole Systems Dataset.

B. Next steps

Public patient Involvement

Implementation of the plan (at Appendix 4) is being taken forward through both greater engagement of the public in project governance structures and holding workshops to discuss the use of linked data. In both cases the design and conduct of engagement is being integrated with similar work being undertaken in setting up the STP and developing the new finance models for care based on capitation. The intention is to have an integrated and coherent outward-facing model of engagement across all new developments. A proposed feature of future workshops will be to have a rolling panel design – in which a core group of individuals attend three workshops, complemented by new recruits at each workshop. A report on the progress of and findings from the engagement plan will be presented to the Confidentiality Advisory Group at the end of 2017.

Record linkage

Following conditional approval for linkage of patient data with local authority data, the patient data will be extracted from various sources (principally NHS Digital, local authority and GP systems). Local authority data will be linked using deterministic linking. Health data will be principally linked using the NHS Number. Local authority and health data will then be linked using both probabilistic and deterministic options dependent on data quality. Once this is done, records will be de-personalised to reduce the chance of subsequent identification of individuals. The de-personalised, linked records will be stored in a secure area, separate from any potentially identifiable NHS or local authority records.

Analysis

De-personalised records will be used in the analysis, aggregated to Lower Super Output Area (LSOA). The purpose of the analysis will be:

- a) To identify inequalities in need for services between small areas, so as to inform new models of person-based financing of services. For this purpose, data on utilisation of services for key conditions or living circumstances (such as diabetes or obesity -related morbidity, or people living alone) will be related to levels and accessibility of the supply of services to model demand for services. Similarly need will be assessed from the relationships between socio-economic area characteristics, recorded prevalence of morbidity (from GP practice data) and outcomes (such as mortality). Bringing these together will simultaneously identify where high levels of need lead to high levels of service utilisation, but also where there is a mismatch between utilisation and need (the so called “inverse care law”. This will form the basis both of service planning – to better match service provision with need- and of identification of the factors that should influence needs-based capitation funding.

- b) To identify areas where high levels of need lead to patient pathways that result in high levels of utilisation and adverse outcomes. In these instances, the use of patient funding to undertake early preventative action either through more intensive early interventions e.g. home insulation, facilitating greater levels of activity or improved diet. The aim of this would be to both improve outcomes for those with the greatest need and to reduce the overall cost of the pathway on NHS and Local Authority services.

Strategy

This project represents a proof of concept for the use of linkage of NHS and Local Authority information to improve health and wellbeing in Tower Hamlets. The specific concepts which are being assessed (as described above) are:

- Public and patient acceptability
- Feasibility of linkage and modelling
- Capability to support understanding and management of health inequalities
- Usefulness in informing finance and service models based on need
- Facilitating effective early prevention based on partnership working
- Improving outcomes at reduced cost to the NHS and Local Authority

C. Summary

The WSDP is proof of concept project which aims to integrate Tower Hamlets health, social care and local authority data to better understand the impact of the wider determinants of health on the health and service use of our resident. Directed by Patient and Public Involvement and in securing CAG Section 251 conditional approval the project is now in its implementation phase of aggregating, linking and de-personalising the data requirements for the analytical stage. The work sets a course for the future of integrated data in the public sector for secondary purposes in order to reduce inequalities in health and drive the Five Year Forward View (3).

9. GLOSSARY

Accountable Care System (ACS)	An ACS brings together a number of providers to take responsibility for the cost and quality of care for a defined population within an agreed budget. ACSs can take many different forms, from fully integrated systems to looser alliances and networks of hospitals, medical groups and other providers.
Data Controller	A person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed.
Data Processor	In relation to personal data, means any person (other than an employee of the data controller) who processes the data on behalf of the data controller.
Data / Safe Haven	A service that provides a technical solution for storing, handling and analysing identifiable data. It has been certified to the ISO information security standard and conforms to the NHS Information Governance Toolkit. Data is stored, processed and managed within the security of the system. A file transfer mechanism enables information to be transferred into the secure area simply and securely.
De-identified	Information which identifies an individual has been removed, but there is still some risk of re-identification (Caldicott2 guide references p47)
De- personalised	This is information that does not identify an individual, because identifiers have been removed or encrypted. However, the information is still about an individual person and so needs to be handled with care. It might, in theory, be possible to re-identify the individual if the data was not adequately protected, for example if it was combined with different sources of information. Other words synonymous terms include: De-identified, pseudonymised, key-coded, masked, anonymised in context, effectively anonymised, non-disclosive, non-identifiable, de-identified data for limited access.
Deterministic data linkage	This is the simplest kind of record linkage, called deterministic or rules-based record linkage, generates links based on the number of individual identifiers that match among the available data sets.
Easting and northing	The terms easting and northing are geographic Cartesian coordinates for a point. Easting refers to the eastward-measured distance (or the x-coordinate), while northing refers to the northward-measured distance (or the y-coordinate)
Identifier	An item of data, which by itself or in combination with other identifiers enables an individual to be identified. Examples include:
Lower Super Output Area	Super Output Areas are a geography for the collection and publication of small area statistics. They are used on the

Neighbourhood Statistics site and across National Statistics. There are currently two layers of SOA, Lower Layer Super Output Area (LSOA) and Middle Layer Super Output Area (MSOA). They can be compiled from post codes

Opt-Out

Patients have an option in how data collected routinely for service provision is subsequently used. Their option is recorded as an 'opt-out' This is recorded on systems like the general practice clinical system.

There are two types of opt-out:

- A type 1 opt-out prevents information being shared outside a GP practice for purposes other than direct care.
- A type 2 opt-out prevents information being shared outside of NHS Digital for purposes beyond the individual's direct care.

Personal Data

Data which relate to a living individual who can be identified from those data, or from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller, and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual (Section 1 of the DPA)

Prince 2

PRINCE2 (an acronym for PRojects IN Controlled Environments) is a project management method. Used extensively by the UK Government, PRINCE2 is also widely recognised and used in the private sector, both in the UK and internationally.

Proportionate universalism

To reduce the steepness of the social gradient in health (reduce inequalities in health), it is believed that actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. This is called proportionate universalism

Pseudonym

A fictitious name used to conceal identity. Individuals are distinguished in a data set by using a unique identifier, which does not reveal their 'real world' identity.

Pseudonymisation

- 1) The process of distinguishing individuals in a dataset by using a unique identifier which does not reveal their 'real world' identity
- 2) Technique that replaces identifiers with a pseudonym that uniquely identifies a person which is typically combined with other anonymisation techniques. It can be reversible or irreversible

Pseudonymisation at source

Pseudonymisation at source is a process that replaces identifiers in a data set with a coded reference or pseudonym so

information about an individual can be distinguished without their 'real-life' identity being revealed. If the process of pseudonymisation is 'enterprise wide', meaning it is standard across the whole health and social care system, it is then possible for it to be safely linked with another data set and the identity of the individual protected ([Caldicott2 main report](#))

Secure Data Haven or safe data haven

This is a location where data can be the data is stored, processed and managed within the security of the system that has been certified to the ISO27001 information security standard and conforms to NHS Digital's Information Governance Toolkit. A file transfer mechanism enables information to be transferred in and out of that environment simply and securely.

Sensitive Personal Data

Data that identifies a living individual consisting of information as to his or her: racial or ethnic origin, political opinions, religious beliefs or other beliefs of a similar nature, membership of a trade union, physical or mental health or condition, sexual life, convictions, legal proceedings against the individual or allegations of offences committed by the individual ([Section 2 of the DPA /Caldicott2 guide references page 49](#)).

Unique Property Reference Number

A Unique Property Reference Number (UPRN) is a unique alphanumeric identifier for every spatial address in Great Britain and can be found in Ordnance Survey's Address products. It provides a comprehensive, complete, consistent identifier throughout a property's life cycle – from planning permission through to demolition.

10.ABBREVIATION

Abbreviation	Term
CAG	Confidentiality Advisory Group
DAP	Data Protection Act
DARS	Data Access Request Service
DCLG	Department of Communities and Local Government
FTP	File Transfer protocol
IGARD	Independent Group Advising on the Release of Data
IMD	Index of Multiple Deprivation
LBTH	London Borough of Tower Hamlets
LSOA	Lower super output area
NEL CCG	North East London Clinical Commissioning Group
ONS	Office for National Statistics
PJIG	Partnership Joint Information Governance Group
PPI	Patient and Public Involvement
THT	Tower Hamlets Together
UPRN	Unique Property Reference Number
USFW	User and Stakeholder Focus Work Stream
VPN	Virtual Private Network
WELC	Waltham Forest and East London Clinical Commissioning Group
WSDP	Whole Systems Data Project

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12. APPENDICES

Appendix 1: Whole Systems Data Project Data Sets

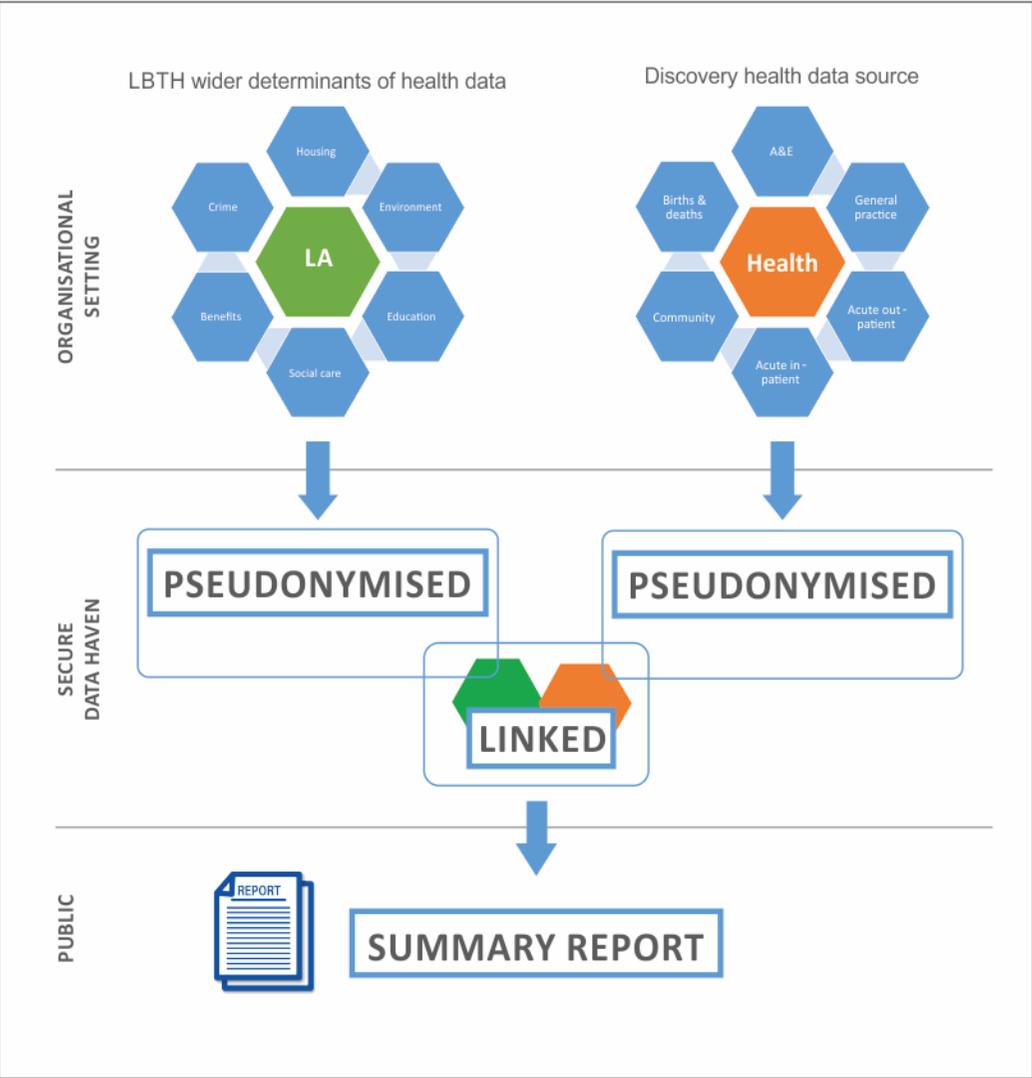
WHOLE SYSTEMS DATA PROJECT DATA SET				
Health care setting	Individual or Property LEVEL	DATA SOURCE	INITIAL SNAPSHOT DATES	USES
			Single snapshot of data at one point during the year (dependent on system capability and service)	
GP REGISTER (Patient Master Index (PMI)/Exeter system)	I	NHAIS	All people with LBTH address wherever GP is located	
GENERAL PRACTICE DATA	I	All patient clinical records with an LBTH postcode	01/01/2015 to current	To access healthcare activity and health status
ACUTE CARE DATA including mental health activity	I		01/01/2013 to current	To access healthcare activity and health status
All hospital attendance for patients with an LBTH post code				
Inpatient	I			
A&E	I		01/01/2013 to current	
Outpatient (including mental health community based data)	I		01/01/2013 to current	To access healthcare activity and health status

Community nursing data	I		01/01/2013 to current	To access healthcare activity and health status
NHS 111/ Ambulance	I		01/01/2013 to current	To access healthcare activity and health status
Walk In Centres	I		01/01/2013 to current	To access healthcare activity and health status
Public health birth and mortality files	I			To access healthcare activity and health status
Birth Data	I	Originally from ONS via NHS Digital	Births (All births in TOWER HAMLETS from 01/ 2013 to current	
Deaths Data	I	Originally from ONS via NHS Digital	Deaths (All deaths in TOWER HAMLETS from 01/ 2013 to current	
LBTH DATASETS				
Housing				
Local Land and Property Gazetteer	P		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Council Tax	P		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Social Housing	I		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Housing benefit	P		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Council Tax Reduction Scheme			LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Housing Waiting List	I		LBTH Snapshot data between	Proxy or indicators of wider

		30/06/2016 to current.	determinant of health
Hostels and Halls of Residence		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Right to buy properties	I	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Energy efficiency rating	P	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Education			
School Pupil Census (Children living in LBTH attending school in LBTH)	I	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Standard Assessment Test	I	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Social Care			
Adult Social Care current users		LBTH Snapshot data between 30/06/2016 to current.	Care Activity
Children's social services	I	LBTH Snapshot data between 30/06/2016 to current.	Care activity
Library membership			
		LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health (proxy for social isolation)
Environmental health & Enviro-crime data sets			
Anti-social behaviour ASB	P	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Waste in front gardens	P	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health
Pest control	P	LBTH Snapshot data between	Proxy or indicators of wider

		30/06/2016 to current.	determinant of health
Current HMO listing	P	LBTH Snapshot data between 30/06/2016 to current.	Proxy or indicators of wider determinant of health

Appendix 2: Conceptual Diagram of WSDP Without Section 251 using Pseudonymisation at Source



Pseudonymisation at source: whereby the Data Processor removes identifiable personal information and replaces this with a pseudonym.

When the pseudonymisation occurs with the same tool the pseudonym (key) can be used as a unique identifier to link the separate (Health and LBTH) datasets.

Appendix 3: Confidentiality Advisory Group and Section 251 application

It is recognised that there are essential activities of the NHS and wider community of partners, that require the use of identifiable patient information in the absence patient consent.

Approval by the CAG under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 enables the processing of patient identifiable information without consent. Approved applications enable the data controller to provide specified information to the applicant for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Secretary of State (SofS) for Health on whether an application should be approved.

As such, Section 251 provides the legal basis for this to occur enabling the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information for medical purposes, where it was not possible to use pseudonymised or partially anonymised¹⁶ information and where seeking consent was not practical, having regard to the cost and technology available.

This WSDP Section 251 is a non-research application. It outlines the context and approach that details the aims to satisfy the CAG of the value of the work and lengths to which the THT partnership have gone to protect and manage the clients information in line with structures legislations and requirements on the Data Protection Act. A particular focus of the Section 251 application is on the 8 principles of the Data Protection Act which both meet the need to satisfy the CAG requirements but also the needs of the data Controllers to show due diligence to safe guard and ensure that the data they are to protect is managed and processed appropriately. The due diligence of the Data Controllers is ideally documented through a Privacy Impact Assessment (PIA)¹⁷.

The General Data Protection Regulation (GDPR) is the new legal framework of the European Union. This will apply to the UK from May 2018 and UK's decision to leave the EU will not affect the commencement of the GDPR. The GDPR applies to 'controllers' and 'processors'. The definitions are broadly the same as under the DPA – i.e. the controller says how and why

¹⁶ <https://understandingpatientdata.org.uk/what-does-anonymised-mean>

¹⁷ <https://ico.org.uk/media/for-organisations/documents/1595/pia-code-of-practice.pdf>

personal data is processed and the processor acts on the controller's behalf. If you are currently subject to the DPA, it is likely that you will also be subject to the GDPR. If you are a processor, the GDPR places specific legal obligations on you; for example, you are required to maintain records of personal data and processing activities as well as informing residents of organisational information / data use activities (i.e. through a Privacy Notice /Statement¹⁸). You will have significantly more legal liability if you are responsible for a breach. These obligations for processors are a new requirement under the GDPR.

However, if you are a controller, you are not relieved of your obligations where a processor is involved – here the GDPR places further obligations to ensure your contracts with processors comply with the GDPR. In this context a rigorous approach to PIA will strengthen processes to meet IG standards.

For this project, the local General Practice Care Group acts as Data Controllers for the local general practice data in partnership with local partners through the data sharing agreements. These Data Controllers have a Data Processing Agreement with Clinical Effectiveness Group at Queen Mary University of London.

London Borough of Tower Hamlets is the Data Controller of the Local Authority data.

The [Data Services for Commissioners Regional Office](#) (DSCRO) acts as Data Controller for the nationally sourced health data.

The data haven is required to meet the standards specified by NHS Digital (NHS IG Tool Kit) and the needs of the CAG to gain Section 251 approval.

Data flows will occur securely via N3 and/or Public Sector Network (PSN), encrypted.

Linking data with Section 251 (please refer to diagram 2): The Data Processor is able to use personal client level data from health and LBTH Data Controllers to directly link the health and LBTH data. The linkage will be conducted within a secure data haven. The data will not be held separately in the data haven by the Data Processor. The linked dataset will then be de-personalise within a 3 month window of time with meet the Data Protection Acts regulation to not hold personal data more longer than is necessary whilst allowing enough time to ensure that the linkages can be validated and/ or newly available data included.

¹⁸ <http://www.cqc.org.uk/about-us/our-policies/privacy-statement>

In the long term it is proposed that techniques for pseudonymisation at source are developed. Here no personal identifiable data will be used to link data sets. This will enable *Linkage without Section 251 (appendix 3)*. Here Data Processor will pseudonymise the data either 1) within the secure environment of the Data Controller or 2) within their distinct data havens that meet the national and Data Controller standards.

There are two main approaches to data linkage are: 1) deterministic (all or nothing linking on selected demographic variables) 2) probabilistic.

Deterministic data linkage relies on the actual content of the demographic data fields matching exactly or to a predetermined level of accuracy (e.g. allowing for common misspellings or transcription error) while probabilistic linkage relies on a statistical model to estimate the predictive probability that a link is correct. The latter is considered to be more reliable and complete when data quality issues reduce matching rates. Probabilistic data linkage is also considered to be more appropriate because as the number of data sets increases the cumulative negative impact of data quality on the linkage increases.

On review of the time scales, capabilities and resources including funding, the WSDP was deemed to require Section 251 to achieve its goals.

Appendix 4: Patient and Public Involvement Plan



Barts Health NHS Trust
East London NHS Foundation Trust
Tower Hamlets Clinical Commissioning Group

Whole Systems Dataset Project

Patient and public communication and involvement plan

Version 4, 25 January 2018



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**TOWER HAMLETS
TOGETHER**

Delivering better health
through partnership

Contents

Section

- 1.0 Introduction and context
- 2.0 Objectives of this plan
- 3.0 Considerations and implications
- 4.0 Approach and timeline
- 5.0 Governance
- 6.0 Resources
- 7.0 Narrative and workshop presentation
- 8.0 Findings from patient and public involvement activities
- 9.0 Conclusions and future activities

1.0 Introduction and context

Tower Hamlets Together (THT) is a partnership of local health and social care organisations with a vision to improve the health and wellbeing of local communities. One of the key projects being delivered by THT, that will act as key enabler to achieving this vision, is the Whole System Data Project (WSDP). The WSDP has been established to describe and understand the relationship between inequalities in health and service use and the impact of the wider determinants of health across Tower Hamlets. This ground-breaking project attempts to look at service provision and population need in an integrated manner; not only across health, social care and community care, but across wider local authority services such as education, benefits, crime, environment and housing.

By including a more comprehensive and holistic list of public sector health and wellbeing activity for the whole population of Tower Hamlets, this project aims to establish a more complete picture of cost and need, and will inform capitation and local budgeting.

As this is the first time a local authority has tried to link health and local authority data to create a depersonalised dataset of this nature, and in line with THT's commitment to patient and public involvement, there was a need to develop this patient and public communication and involvement plan.

2.0 Objectives of this plan

By delivering this plan we aim to:

- Develop a clear, understandable narrative that explains the purpose and aims of establishing the WSDP;
- Obtain views from our local population towards the concept of developing the WSDP;
- Compile these views into a report to share with the Confidentiality Advisory Group (CAG) as part of our application to proceed with the project;
- Use the views obtained to further develop the project and identify further communication and involvement requirements to support ongoing development of the WSDP;
- Ensure that we deliver on the recommendations from the CAG response from the meeting on 8th June 2017.

3.0 Considerations and implications

- The creation of a WSDP in Tower Hamlets is a first of type, so there isn't scope to adopt a tried and tested approach to communication and involvement.
- However, we can learn from similar data sharing/integration initiatives, some of which have encountered significant opposition. Typically, this is either due to information being misinterpreted or a lack of information provided leading people to draw their own conclusions. Once people formulate a view on an issue it's very hard to change, so it is important to have a clear plan in place before any proactive communication and/or involvement activity takes place.
- Experience tells us that issues can escalate quickly so it's important to consider the timing of communication and engagement activities. We need to have a clarity on the proposals along with a robust narrative to support any challenge toward the project. We need to be in a position to answer any questions in an accurate and timely manner should they arise.
- Engagement activity to obtain initial views toward the model needs to be well managed and contained, otherwise we run the risk of the project being communicated too widely before we are in a position to handle any challenge/objection to the proposals.
- It was therefore recommended that initial engagement activity takes place with a small number of patient and public representatives to 'test the water' (see **section 4.0**). Lessons learnt from this then informed the remainder of the communication and involvement activities.
- The terminology we use in doing so was also a key consideration. The term 'data' should be avoided where possible with 'information' being used in its place. We will not refer to the Whole

System Dataset, rather a ‘project’ that ‘aims to make better use of health and social care information to improve health’.

4.0 Approach and timeline

Given the qualitative nature of the feedback we wish to obtain from patients and members of the public, our approach will comprise a number of focus groups with people who are representative of the data we wish to integrate as part of the WSDP.

As we are exploring a concept that is both new and complex, we held a pilot focus group with members from the Tower Hamlets Together User and Stakeholder Focus Workstream to both test our engagement approach and also obtain their views toward the concept of creating a WSDP, the feedback from this focus group are on pg. 15 below. The User and Stakeholder Focus Workstream comprises the following members:

- 4 x patient and carer representatives
- Healthwatch lead
- Barts Health Patient Experience lead
- ELFT Patient Experience lead
- CCG engagement lead
- THT communication and engagement leads

Comments and views obtained during this pilot focus group were used to refine our narrative and the format of subsequent focus groups. Two further focus groups were held to support the initial application to the CAG’s June meeting, with reports being compiled to summarise the outcomes of each (see below). Following the CAG meeting, the number of groups to be engaged were discussed and expanded to widen the scope and the audience to ensure the views of our diverse population are captured. See table below for details and numbers of residents we have already and plan to engage.

The table below outlines the timelines for the delivery of this plan:

Deadline	Action	Description	Number of lay reps
24 February	Draft slide deck developed	This slide deck will provide an overview of the WSDP and will be used as basis for the focus groups.	
3 March	Approval of slide deck	The slide deck will be shared with members of the WSDP working group for comment, with a view to a final version being approved.	
3 March	Establish who will run pilot focus groups	This needs to be someone who has experience of facilitating open dialogue with focus group members whilst also ensuring someone is present with an in-depth knowledge of the WSDP to ensure questions can be answered accurately.	
8 March	<ul style="list-style-type: none"> • User and Stakeholder Focus workstream meeting 	We will use this meeting to pilot the narrative slide deck ahead of visiting any further patient/resident representative groups. (see section 8.1)	3
12 April	Refresh narrative slides	Based on feedback from the pilot focus group, refresh narrative slides for use at subsequent focus groups.	
12 May	<ul style="list-style-type: none"> • Healthwatch 	Hold focus group with patient/public	1

		representatives organised by Healthwatch Tower Hamlets (see section 8.2)	
15 May	<ul style="list-style-type: none"> Carers Forum 	Focus group with local carers organised by Tower Hamlets Carers Centre (see section 8.3)	5
18 May	Submit plan to CAG	Submit communication and involvement plan, along with outcomes of focus groups, as part of submission to CAG.	
June	Consider feedback from CAG 8 th June Meeting	Meet to consider the feedback from CAG and initial focus groups and next steps – specifically whether planned focus groups need to be adapted in line with CAG feedback, and, if any further focus groups (apart from those already planned) are required.	
6 November	<ul style="list-style-type: none"> Older People’s Reference Group 	Focus group with local older people (joint-facilitated with internal and external facilitators) (see section 8.4)	30
17 November	<ul style="list-style-type: none"> East London Foundation Trust user group 	Focus group with local mental health service clients (facilitated by external facilitator) (see section 8.5)	17
21 November	<ul style="list-style-type: none"> Poplar Harca Housing Association 	Focus group with local social housing tenants (facilitated by external facilitator) (see section 8.6)	10
23 November	<ul style="list-style-type: none"> Local patient leaders group 	Focus group with local patient leaders (facilitated by external facilitator) (see section 8.7)	10
December	Compile final PPI activity report for CAG including plan for future activity (see section 9)	For the 6month report as requested by CAG	TOTAL NUMBER OF LAY PEOPLE ENGAGED: 76
January 2018	Ensure findings are embedded and shape both the project and wider system (see section 9)		

5.0 Governance

The delivery of this plan was managed by the WSDP Communication and Involvement Sub-Group (with oversight from the WSDP Steering Group), the membership of which comprises:

- Sue Hogarth, Public Health Consultant, Tower Hamlets Together
- Krish Thiru, Public Health Intelligence, London Borough of Tower Hamlets
- Jessica Neece, Communications Lead, Tower Hamlets CCG
- Anna Wilson, Communications Lead, London Borough of Tower Hamlets
- Abigail Gilbert, Public Health Locality Manager – South East London Borough of Tower Hamlets

6.0 Resources

Adequate resources were made available for PPI and engagement activities described above with an expert external facilitator employed for a number of the focus groups.

7.0 Narrative slide deck



USING INFORMATION TO IMPROVE HEALTH AND WELLBEING

Abigail Gilbert (Public Health Locality Manager, LBTH)
Krish Thiru (Public Health Informatics Manager, LBTH)
Alex Trewitt (Communications lead, THT)



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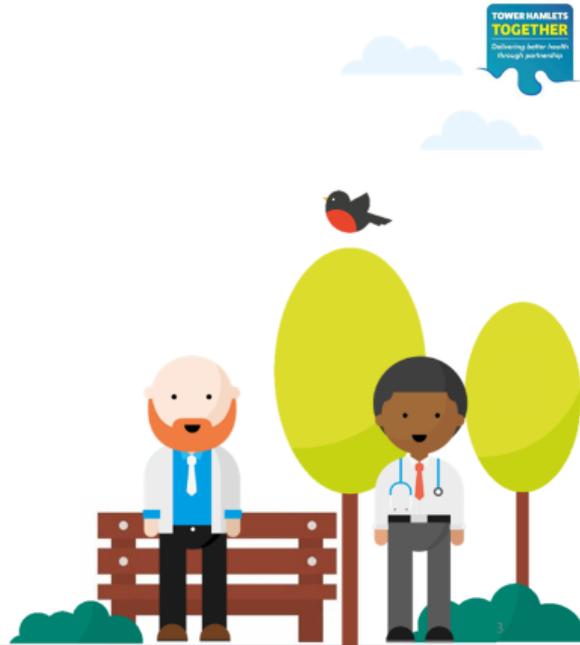
THE PROJECT AIMS

- To make better use of information to understand variation and need in health and service use
- To understand the impact of the wider determinants of health such as environment, employment, social support, crime on health and service use.
- Use our understanding of residents needs to provide better and preventative services



PURPOSE OF TODAY

- We want to get the support and views of local people to help develop this project
- We are running a number of workshops like this and will write a summary of the important issues raised.
- Please feel free to ask questions during the presentation if anything is unclear.



SERVICES ACROSS THT PARTNERSHIP

Barts Health NHS Trust

TOWER HAMLETS

GP CARE GROUP CIC
LOCAL PEOPLE. LOCAL HEALTH.

NHS Tower Hamlets Clinical Commissioning Group

East London NHS Foundation Trust

thcvs Council for Voluntary Service

As a Whole System



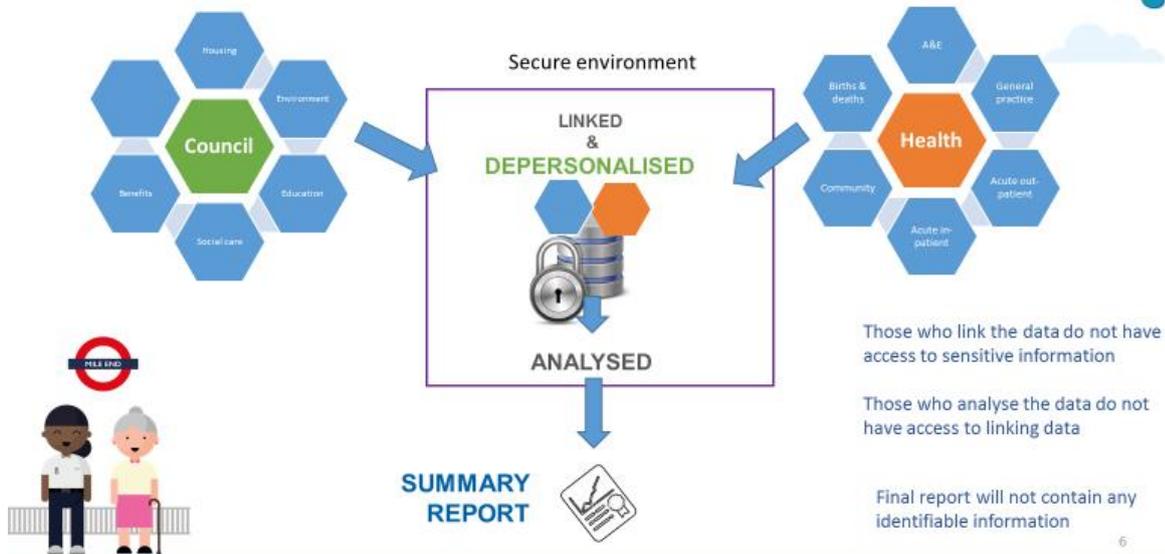
WHAT INFORMATION DOES IT INCLUDE?



These services largely function separately



HOW ARE WE PLANNING TO DO THIS?



KEEPING YOUR INFORMATION SAFE

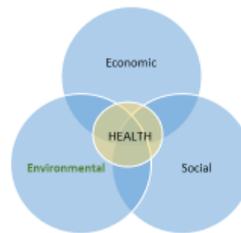


1. All data is protected under NHS and national standards for security and governance
2. Personal information is held separately from service information
3. After linking the information is depersonalised:
 - Removing names and addresses
 - Remove date of birth
 - Remove post codes
4. Those who have opted out will be excluded
5. Experienced specialists using established processes
6. Only summary report produced (no numbers less than 5 included)
7. Overseen by governance bodies



1) Benefits: Health and environment

- **Child**
- Living in social housing
- Single parent household
- On benefits
- More than three children in household



Evidence driven change

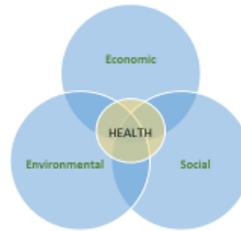
Understanding of local children's asthma admissions to A&E and length of stay correlation with poor quality housing or environment.

Intervention: Support resource allocation for prevention – e.g. double glazing schemes or influence planning.



2) Benefits: Health and social/ economic circumstances

- Elderly male
- Living alone
- Poor energy rating of home



Evidence driven change

Better evidence on the distribution and characteristic of housing stock and residents needs

Intervention: Council targeting boiler replacement through general practices



Can you think of other individuals / groups who can benefit from such preventative services?



3) Benefits: Health and social circumstance

- Frail elderly female
- Living alone
- Low mobility



Evidence driven change

Understanding of distribution and characteristics of population

Intervention: Support the development of a home reading mobile library service



Why we need to do this in Tower Hamlets

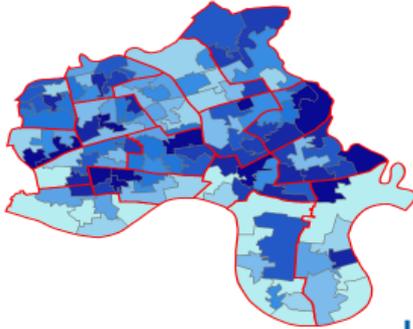
- We have the highest rate of poverty in the UK
- 1 in 5 families household income less than £15,000
- 25% of 10 to 11 year olds are obese.
- the second highest premature death rate for circulatory, cancer and respiratory disease in London
- Lowest healthy life expectancy in the country (52 years for women 54 for men).
 - Meaning in Tower hamlets we develop poorer health 10 years earlier than the rest of England and have ~30 years poor health.
 - 10 years difference between least and most affluent



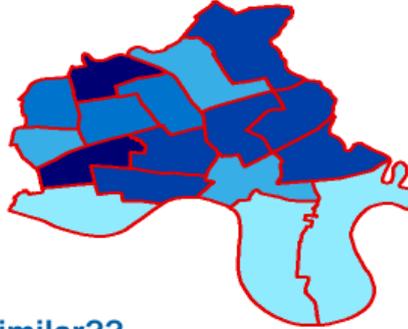
CLEAR LINKS BETWEEN DEPRIVATION AND HEALTH



Deprivation in Tower Hamlets



Circulatory Disease Mortality Rates in Tower Hamlets



Look similar??

WHERE AND WHEN IS THIS HAPPENING?

- The local authority uses its information to better services (e.g. housing and environment).
- The NHS has a history of using its information across sites and settings to collectively better services (e.g. A&E waiting time, Cancer referral to testing times).
- No where else is looking at bettering services using information from across the Whole System
- We are the first to try this approach
- Our experience will be shared with other parts of the country



RECAP ON MAIN POINTS

1. This project aims to link health and local authority information to better understand variation and health needs and service use of residents.
2. To link the data we will need to use personal information.
3. Linking data will be separated from service data.
4. Once linked the information will be depersonalised – *this means it will not contain any personal information (no names, addresses, date of birth etc.)*
5. Individuals who have opted out of their health data being used will not be included in the project.
6. We will use this information to provide better services around prevention



DISCUSSION

What's good about this project?

What can be better and how?



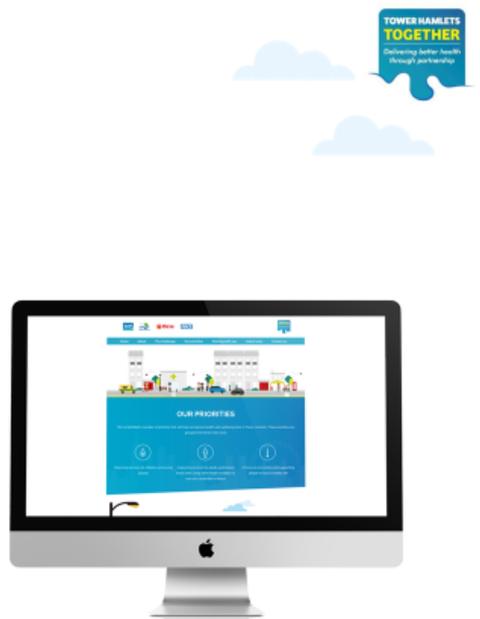
The project is funded by Tower Hamlets Together

- **Tower Hamlets Together** is all about health and social care organisations working more closely in a coordinated way to improve the health and wellbeing of people living in Tower Hamlets
- We aim to reduce duplication of services and improve the overall experience and outcomes of services
- We also aim to allocate resources better so that we focus on preventative care and services



WHERE TO FIND OUT MORE

- Visit our website: www.towerhamletstogether.com
- Register to receive our newsletter: <http://www.towerhamletstogether.com/contact-us>
- Follow us on Twitter: [#TH2GETHER](https://twitter.com/TH2GETHER)
- Send us an email: thccg.towerhamletstogether@nhs.net



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8.0 Findings from patient and public involvement activities

In line with our communications and involvement plan and the expectations raised by CAG in their initial response, early engagement has been undertaken in the form of three focus groups held with patient/carer representatives.

The first focus group, held with members of the Tower Hamlets Together User and Stakeholder Focus workstream, acted as a pilot to test-out both our engagement approach and our narrative for the project to ensure subsequent engagement activities were as effective as possible and met the objectives outlined in our plan. All focus groups were led by WSDP leads from London Borough of Tower Hamlets.

Below is a summary of the main outcomes from each of these focus groups. It should be noted that further engagement activity is planned (as detailed in section 4.0 of our communications and involvement plan).

8.1 Findings from pilot focus group held on 8 March 2017

Participants:

- 3 x patient and carer representatives
- Healthwatch lead
- Lead from The Zacchaeus Project (supporting older people)
- Tower Hamlets CCG engagement lead
- THT communications lead
- East London STP engagement lead

Key themes emerging

Level of support towards the project

- There was a high level of support for the project from all members – there was no resistance/concerns raised toward data being used in this way.
- There was a feeling that anything that's being done to reduce health inequalities in the area can only be a good thing.
- Many participants assumed this type of data analysis took place already – it didn't feel like something new or contentious with risks being mitigated for potential benefits to the individual and population.

More focus on carers

- When a carer asks for an appointment and the organisation offers a slot, it is often out of kilter with carers ability to attend and so DNA. As such, this shows up in the data as DNA. The reason for DNA is that the appointment was not suitable - not that the carer didn't want to attend.
- Is there scope eventually to actually look at carers as part of this project?

Purpose of the engagement

- Questions were raised about the rationale for engaging with people – what is it trying to achieve and what aspects are people able to influence?
- The narrative needs to be clearer – why should we be excited about this project? What difference will it make for local people?

Ability to opt-out of data analysis

- A question was raised about whether people can choose to opt-out of the data being analysed. It was explained that if the patient has already opted-out of any aspect of the data being collected, their data will not be analysed as part of the WSDP.
- One participant raised the issue that many people aren't aware of their right to opt-out of data being collected, especially those of registered with their GP a long time ago.

Scope to include data from smaller organisations

- One participant asked whether it would be possible to extend the scope of the project to include data from other, smaller organisations. It was explained that this is a pilot with defined aims and limited resources. However, the intension is that a framework will be developed whereby wider service providers can also be included in the datasets. However, small organisations and charities were not as well developed at collecting information in a standardised was and in will be more difficult to collate this information. It is proposed that this should be a long term goal.

8.2 Findings from focus group held on 12 May 2017 (hosted by Healthwatch Tower Hamlets)

Participants:

- 2 x Healthwatch representatives
- Patient representative
- Lay public health representative

Key themes emerging

Level of support towards the project

- Overall, participants felt this was a necessary and valuable project

General considerations/views toward the project

- Healthwatch has implemented a national coding systems for collating community feedback that may support future data collation and engagement in this area. The aim is for 10,000 comments in the first year.
- Tower Hamlets has particular needs, such as English as second language, and faith-centred communities that can be approached through their religious centres, churches, mosques and voluntary sectors.
- Many poorly heated and overcrowded homes. The group felt that understanding these will help wider health needs and targeting of services.
- It was felt that currently, services are not good at sharing information and this should already be done as best practice. Only then can their individual needs be met. The sharing should only be between public sector bodies that target prevention, although the group felt that charities and voluntary sector also had a legitimate right.
- The local authority should be able to distinguish between social housing and private rented sectors to target poor services.
- Overcrowding is recognised as a significant factor for health issues in Tower Hamlets.
- Services working together can be more effective at using limited resource. For example, meals on wheels being able to give wider support to individuals to alleviate loneliness
- The local Ideas Store are an effective way for targeting social isolation and digital exclusion. Many individuals do not have internet at home.

Depersonalisation of data

- Participants stated that the chief concern was that the data would get into the hands of the private sector. It was explained that safeguards were in place and the group were happy with the steps taken and the reassurances provided.
- A further comment was that this work needs to result in sectors and services sharing budgets. It was asked whether there was potential for the project to support people to be more accountable for spending – like participatory budgeting like with the LAP Local Area Partnerships of old
- One participant felt that depersonalisation of the data was in fact losing something despite strong views about confidentiality This highlights a paradox in the minds of those present. They felt in some way that the project did not go far enough, but understood the issues around data protection. This increased their support for the project.
- The group wondered if there could be some dummy data that could be shared with people so they knew what it looked like and what would happen to their data. We described the maps that the project is likely to produce and the level of granularity – “you will be on the map but you won’t be able to identify yourself”. Future presentations will aim to show dummy data.

8.3 Findings from focus group held on 15 May 2017 (hosted by Tower Hamlets Carers Centre)

Participants:

- Carers centre representative
- 5 x carers/patients

Key themes emerging

Level of support towards the project

- Overall, participants felt the benefits far outweighed the costs. They are keen to be kept informed of how the project develops.
- They were reassured by the level of effort taken to protect the data and protect the identity of individuals.
- The group felt the problems arising from not sharing and not collectively using this information were greater than those posed by using the information.
- They see that this project supports prevention in the long term, and that is cost effective. They would hope that this will support joint planning eventually.
- They group also viewed this as an important resource that could provide evidence for resourcing community based services and support for carers, that was pre-emptive, that could potentially prevent more acute scenarios developing and the need for hospital based services.

Health of the carer

- This was one of the most important points made by the group. If the carer gets ill/disabled then this has an impact on the person cared for. Efforts need to be made to protect the health and wellbeing of carers. It does not feel that this happens at the moment.
- Could the project help this in any way?

- One member of the group stated that she was a diabetic and is a carer for her husband. She often cannot take up the referrals that are made for her. Would the data set identify this?
- What happens if a carer needs a routine operation? The stress of being a carer takes its toll on health. There are no preventative health strategies for carers. Carers are getting older. The extraordinary low healthy life expectancy for both women and men in tower hamlets will impact on carers disproportionately.

Not enough information on what is available from the council

- This was a repeated theme throughout the meeting.
- One example given – which brought into focus how systems could trust carers more – was the Silver Book in Singapore. This book has everything that you are entitled to. Singapore provides a suite of provision per capita in case of need and citizens use this as and when needed. So the entitlement is a given. The assumption is that people will need services and people can invoke the need.
- Here we are subjected to tests to find out if we are entitled to something. There is a very different assumption underlying the two systems. Yet we notice that what we experience here (Tower Hamlets and UK) is very wasteful and service led. The client needs to organise around the service rather than the opposite. This leads to repeated duplications, cancellations and delays in service.

Cuts in services and income

- Those present did not know the amount of money that they are entitled to. This links to the above point about not enough information being available.
- Carers do not know what they are entitled to. “We don’t know how much is going to change when a new policy is introduced. We cannot gauge the impact”.
- Carers have experienced recent cuts to their income. One participant had lost £40 per week due to changes in their entitlements. Bedroom tax applied to an extension that the council built for their disabled son that took 20 years to materialise. This family were asked if they wanted to downsize
- Participants felt that having one person who knows the family and co-ordinates care is a good idea. There was a moment of reminiscence about the key worker scheme that operated under community care.

Status of carers with LBTH services and health services

- Carers are called many times by services.
- Services don’t leave a message to say who called and the number they called from is a general number that people cannot ring back on.
- Many services ask to speak to the cared for person and are reluctant to talk to the carer due to confidentiality.
- The suggestion is that why can’t there be one front sheet that all services use so that they know the situation and know in advance the person who they need to speak with and best times to call as a minimum.
- When families ask for specific small things like the spelling of a name, a time to ring, this is not implemented.
- In addition, social workers may change and the family may not be notified.

Access to services – especially financial services

- CPN has filled in an application for one participant three times to try and get a holiday paid for from their personalised budget
- Could the data be flagged if the person has an advocate?
- Repeated reassessments - the slightest change in service provision will require a reassessment of the person cared for. For example, there may be a new charge implemented which means they need to revisit the power of attorney all over again. Many people do not have formal power of attorney and when you do it’s hard for services to hear about/work with this.

Life stages and caring

- The need for care and the identified carer is often identified in childhood. Yet there are different services that support or try to support carers – children’s social care, working age teams and teams who work with older people. The Carer and the cared for need to move from one team to the next and face reassessment and different criteria / eligibility for support from these teams- leading to reassessment that is completely predictable.
- One person informed person to deal with diverse needs only would help (this is expected to need a whole systems view of the client).

'Did not attend'

- The group felt this was a key area of research that the project could contribute toward. The data exercise could tell who the DNAs were but could not give the reason. The group felt that the reason was important to know. They also felt that the data quality should be treated with suspicion.
- There are many people in the Bangladeshi community who have the same name, address, date of birth and postcode as dates of birth are often assigned e.g. 1/1/59. Has the project thought about this? NHS number or the NI number would be more unique. The Carers Centre representative gave us an example of a white British woman whom she was liaising with the council over an appointment/referral and there were two people of same date of birth and postcode who were muddled up.
- It was clarified that not all the data would be matched 100% and therefore some people would be lost. This would include groups where there were five or less, for risk of being able to identify individuals. This reassured the group and it was emphasised that this data matching was not going to be used for the provision of services, but to understand the patterns of need in the Borough. There will not be any letters issued, referrals made etc as a result of the data matching. This would be impossible as the key information about the identity of the person people is removed.

Different criteria for NHS and Social Care

- One participant explained that the person they care for had their home mobile foot clinic service cut and they were asked to go to Mile End Hospital. This cared-for person also attends a day centre most days of the week. This service is provided by the Council who pays for transport. However, the NHS will not provide transport costs for the foot clinic. This person cannot get to Mile End Hospital without transport and misses day care. It has taken a long time but the carer's husband now has the out of hours home visit for this chiropody. There was no consultation or warning of this and painful delays in getting foot care.
- Is this an example of where NHS number and NI number could help automatically support those whose services change?

Housing

- One of the carers lived in privately rented accommodation. This tenure is an increasing percentage of the housing stock in Tower Hamlets. It would be good to see how many carers live in this sector and living conditions and health need.
- They explained they undertake a lot of housing repairs themselves rather than waiting. There was a great deal of cynicism expressed by this carer who had waited 20 years for an extension to be built for her disabled son. Her son's needs were known in childhood. And so much strife and ill health could have been prevented by having this facility throughout her son's life not just in adulthood. She is now charged bedroom tax.

Opt-out

- It was explained to the group how opting-out of sharing personal data for non-clinical purposes works with the GP and for local authority services via privacy agreements. The group felt that these opting out processes were "buried" and general practice patients were not informed adequately. Also people do not often know what it means to opt in or out - this includes staff and recipients of services. The clause also needs to be made in plain English.

8.4 Findings from focus group held on 6 November 2017 (hosted by Older People's Reference Group)

Participants:

30 older people, residents and users of health and social care services

Format:

The format for this event was designed to make best use of a relatively short slot in a wider agenda.

Participants received a short briefing, accompanied by a printed handout (the PowerPoint slide deck).

The audience then worked in smaller groups to discuss their ideas and questions and a representative reported back to the whole group.

Conclusions:

- most participants would like more information on the objectives, progress and ultimate use of the information.
- some were concerned that access to information was restricted to IT users and, for this group in particular, this was not necessarily a viable option.
- there was general agreement and understanding that health and wellbeing indicators in Tower Hamlets were among the worst/lowest in the country and that any project which sought to address the situation was to be welcomed.
- most groups spent some time discussing the potential health outcomes from the project, although it was explained that this was not the purpose of the discussion.
- groups identified the fluid nature of the population in Tower Hamlets, with an ever-changing population, a changing economic demographic (sic), and a large number of residents who may not be known to either Council or Health services
- some of the sub-groups were cautiously supportive of the idea
- possibly the biggest concern was that of the security (illegal access) of the information, coupled with
- confidentiality (who would have authorised access). The issue of 'opting out' was discussed. Many knew that it was possible but observed that it is not made easy and many people are unaware that they can opt not to share their information.
- some people thought that this coupling of information had already taken place, or that the decision to do so had been taken and the focus groups were 'window dressing'

Summary:*Main concerns:*

- Data security
- Data confidentiality
- Validity of data (shifting population)
- Cost
- Access to information
- Understanding Health outcomes

Positive Responses

- Tower Hamlets needs to do something
- Information already exists
- Could result in streamlined services
- Project looks at wider health determinants
- Could result in more equitable distribution of services

8.5 Findings from focus group held on 17 November 2017 (hosted by East London Foundation Trust People Participation Group)**Participants:**

17 users of East London Foundation Trust mental health services and a variety of Tower Hamlet's health and council services and carers.

Format:

Discussion circle.

Participants received a briefing, accompanied by a printed handout (the PowerPoint slide deck).

Comments made:

- early contributions were guardedly positive
- 'don't understand the problem with releasing information'
- 'postcodes are already used in a variety of ways'
- 'it's a good idea – there can't be any buck passing'
- later comments became more critical
- are there any issues relating to the compatibility of department's computer systems?
- how much will it cost?
- if it doesn't work, will there be significant exit fees?

- what are the safeguards for vulnerable groups (who don't understand the process)?
- is everyone 'in' unless they opt out and what are the implications of the imminent changes in Data Protection?
- access to information was also discussed and the problem of access to IT was raised. The language of the hand-out was 'not helpful'
- there was a lengthy discussion about confidentiality/anonymity and the point at which the postcode was removed from the linked data
- there was considerable debate about the potential health outcomes and benefits of the project
- participants would like more information, in a clearer format, not focussed on IT, and with a vivid picture of what the future would look like if it is successful. Timing and progress were also mentioned.
- one participant was concerned that the information could be used for 'nefarious' purposes, i.e. social engineering and moving people around.

Summary:

Main concerns:

- Data security including Data Protection implications
- Data confidentiality
- Validity of data (quality outputs require quality inputs)
- Cost, including how NHS money might otherwise be spent
- Exit fees
- Compatibility and security of IT systems
- Understanding Health outcomes
- Potential for unacceptable use of the data
- information needs to be more accessible, with clearer examples
- there are many needs in Tower Hamlets, loneliness, stress, anxiety, drug & alcohol issues. Will this project help

Positive Responses

- Information already exists
- could avoid 'buck passing'
- 'good idea'

8.6 Findings from focus group held on 21 November 2017 (hosted by Poplar Harca Housing Association)

Participants:

10 residents and members of Poplar HARCA Housing Association.

Format:

The format was a discussion circle.

Participants received a briefing, accompanied by a printed handout (the PowerPoint slide deck).

Comments made:

From the outset, the discussion focussed on costs, funding and the impact of the project on NHS resources.

- attention was drawn to the continual reduction in NHS funding in Tower Hamlets
- participants wanted more information on how the project is funded, managed, the administration costs and what analysis there had been on the effect on other services
- participants thought it would be helpful to see a cost benefit analysis
- examples were given of reduction in services and possible GP surgery closures
- further examples included dentist services, manual handling specialists, and occupational therapists
- it was felt that information was unclear on longer term benefits
- there was concern about data security including 'cyber attacks'
- there was a discussion about opting out. 'There is a vague understanding of opt out, but it's not easy'
- 'don't see the point of it'
- 'don't think it will help'

Summary:**Main concerns:**

- Cost, including how NHS money might otherwise be spent
- Understanding Health outcomes
- information needs to be more accessible, with clearer benefits and reassurance that funds are being used appropriately.

Note:

This was a challenging meeting with one very vocal and disruptive participant.

We (facilitator and group) struggled to manage the interruptions and it made it difficult to maintain a constructive

8.7 Findings from focus group held on 23 November 2017 (hosted by Tower Hamlets Clinical Commissioning Group)**Participants:**

10 Patient Leaders.

Format:

A discussion circle. The review was structured to capture positives and concerns in separate discussions.

Participants received a briefing, accompanied by a printed handout (the PowerPoint slide deck).

Suggestions made:

The discussion began with some suggestions about providing information more widely in the borough, including: Council leaflet (A5?) in

- ideas store
- GP practices
- one stop shops
- carer centres
- on the Council website
- CCG
- hospitals
- local press
- schools

Early positive comments:

- 'it's a good step'
- 'it will benefit in the next 5 – 10 years'
- 'good for policy'
- 'good for the long run'
- 'information sharing is a great idea'
- 'provides structure for preventative services'
- 'our voice has been heard'
- 'it recognises the need and can see that it could make things better'

Concerns

- 'what if it collapses half way through (e.g. funding)?'
- what are the implications of 'opt out' on validity of data?
- is there potential to manipulate the data?
- its idealistic
- there's a cost, what's the ROI?
- how will it be monitored to ensure that it's achieving what it set out to do?
- will feedback on progress be published?
- is there an impact on Council tax?
- is the project being communicated effectively?
- are Faith leaders engaged?
- 'Tower Hamlets is a great place to work, but not to live'

Summary

This group had the most balanced response to the presentation and focussed largely on the project's strategic objectives, rather than the detail of eventual health outcomes.

8.8 Overview and summary of findings of groups in sections 8.4-8.7 (compiled by external facilitator)

The four groups had different levels of understanding of the current situation regarding individual's data and their responses reflected their appreciation and how this project might help Tower Hamlets manage its scarce resources in the future.

Some key themes emerged:

Opportunities:

- Nearly all participants understood Tower Hamlet's poor ranking in most Health & Wellbeing indicators
- There was an acknowledgement that something needs to be done.
- Although not universal, there was some agreement that this project has the potential for the Council and Tower Hamlets NHS to work together more effectively to address the issues
- concerns about data security were based largely on general information and the media, rather than on specific or personal experience
- some participants recognised that is not a short-term exercise and that it would take some time for benefits to be seen

Concerns:

- Cost
- Opportunity cost to the NHS
- Impact on Health outcomes
- Data security
- Data confidentiality
- People not known to Council or NHS
- Risk of inappropriate use of data

Needs:

- More information on project, objectives and progress
- More channels of communication, not just IT based
- Clearer demonstration of the benefits to the community

9.0 Conclusions and future activities

In the interests of time and the requirement of CAG to submit a report at 6 months following their decision to give conditional approval for WSDP, this report has been compiled to ensure that CAG have oversight of all the findings from recent resident engagement activities.

In terms of ongoing engagement, we are currently exploring options to continue discussing data with our residents more widely, and in terms of this project, how we analyse the data and use the products that this project generates.

In line with the objectives of this plan and its findings, the next steps are to ensure that they shape the project and inform the wider system around the use of data. To that end, this report will be taken to the following local forums, the relevant findings presented to them to ensure that the findings are acted upon.

- Where findings relate to particular client groups e.g. carers, local leads will be approached to ensure they are aware of, and act on, the findings.
- Tower Hamlets CCG Business Intelligence and East London Health and Care Partnership (our local Sustainability and Transformation Plan) - who are developing the use of data for patient management
- LBTH ICT Transformation Procurement Programme – who are currently the implementing a common business intelligence and data integration solution in LBTH

- Tower Hamlets Together Community Insights Network – who are collating and distributing insights from residents around all issues around health and social care to ensure that these findings are included
- Tower Hamlets User and Stakeholder Focus Workstream – who have resident reps and engagement leads from across the Tower Hamlets Together partnership to ensure that we are taking the findings to all the correct forums

Appendix 5: Analytical Approach

1. Based on earlier work by Harper and Mayhew, the analytics firstly builds a detailed picture of the population by matching the GP Register and selected administrative data from within the local authority together with data on births, deaths and the Unique Property Reference Number (UPRN) from the Local Land and Property Gazetteer (LLPG). The output from this stage is an estimate of population, by age, sex and ethnicity and the number and type of households ((18), (14), (13)).
2. The second stage involves the identification of at risk sub-groups that are a priority for the council, NHS and other providers (e.g. older people living alone, low income populations or living in poorly heated homes). These are informed by both earlier research and local specialist knowledge.
3. Descriptive analysis and mapping is undertaken of:
 - 3.1. wider determinants of health such as low income, social housing, educational attainment etc.;
 - 3.2. current health status drawn from medical records (e.g. Quality and Outcomes Framework (QoF) data, smoking status, body mass index (BMI));
 - 3.3. Health service usage data such as admissions to hospital and use of social services (10), (19), (20).
 - 3.4. The correlation between health service usage levels, the wider determinants and health status to inform a model of cost.
4. Techniques including multiple logistic regression are used to identify factors of significance in relation to service usage through the linking of three types of data (wider determinants, current health status and service use)
5. The final stage involves modelling capitated budgets which reflect the totality of expenditure across the health and care economy for population sub-groups including their size and resource needs (having regard to both preventative and conventional interventions). Sub-groups will be broken down using techniques such as programme budgeting, detailing both service needs and outcomes, which take into account needs (met and unmet) informed by, and based on, exposure to relevant wider determinants of health.
6. Through the classification and prioritisation of the wider determinants of the health in Tower Hamlets the analytics of this work will feed directly into the JSNA and the local commissioning priorities of the THT partnership.