



Adults with care needs in
Tower Hamlets

A report on service experience 2018

healthwatch
Tower Hamlets

Healthwatch Tower Hamlets is an independent organisation led by local volunteers. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

Healthwatch Tower Hamlets gathers local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are made on how services will be delivered, and how they can be improved.

www.healthwatchtowerhamlets.co.uk





Executive Summary

We engaged with over 400 adults in Tower Hamlets to gather their experience of integrated social and health care services.

Our overarching recommendation is to consider developing Integrated Care Clinics for people with similar care needs or conditions based in their GP Practice or at Mile End Hospital. They could meet regularly for clinical care, information and peer support with the aim to both empower people to manage their care and also to provide them with local networks. Regular informal group clinics could talk about medical concerns, meet with medical staff and also build their knowledge of:

- Who's who in the GP Practice and when and how to access them. Phone, E-consultations, social prescribing, when should you request a home visit.
- Who's who in the Integrated Care system and when and how to access them.
- How to access, understand and utilise your medical records (including authorised family members or unpaid carers)
- How to prevent your health from deteriorating but how to prepare yourself if it does.
- How to access social care and community health services and support to work through the care assessment process.
- How to get the best from carers.
- Bespoke training focusing on technology use for health and care management. How to make use of information technology and services such as NHS Choices, Health apps etc. An introduction to assistive technology and how it can help you to maintain your independence.

- IT and assistive technology. Look at the possibility of providing group members subsidised computer tablets and WiFi and linking them to the practice and each other. Linking to IT volunteers/ambassadors who could attend and help with ITC knowledge development.

GP Practices are the best place for groups to meet people as people are already going there. People who are socially isolated often will not attend older people's services or day centres and will not actively seek support, as they are more likely to engage. If they feel that it is part of their clinical care it is less likely to be perceived as seeking help but as part of their GP service.

The rapid development of new housing and the redevelopment of community assets, such as Mile End Hospital, provide the opportunity to establish integrated Health and Wellbeing Centres that co-locate the Tower Hamlets Together services. This could include general, medical and nursing, therapy, specialist and social care services with supporting information and advice systems and voluntary and carer support services. With a key space for community organisations and activities these services could also potentially sit alongside community centres, day centres, supported housing and care homes, allowing people to develop and maintain strong community and social networks throughout their old age. Only people requiring highly specialist diagnostic equipment or acute hospital facilities would need to be transported out of their local area, addressing some of the key transport issues.



6 Key recommendations

1. Social Care Services and care agencies

1.1. Focus on recovery and preventative care, including reablement, occupational therapy and use of assistive technologies, to support people maintaining their independence within their own home for as long as possible.

1.2. Conduct care assessments from a person-centred perspective, taking into account the service user's needs and resources. Anticipate, as part of the care assessment process, how the user's needs may change in the future, and inform/ signpost them to relevant resources ahead of time.

1.3. Establish rapport with service users in such a way that a care assessment/ agreeing on a care plan is seen on both sides as a collaborative process rather than an adversarial one or a tick-box exercise.

1.4. Allow service users more flexibility in relation to their care schedule; allow them to re-allocate hours of care more easily.

1.5. Allow service users and third parties they specifically authorise (such as family members) to access their care plan and request adjustments or re-allocations online.

2. GP Surgeries

2.1. As much as possible, offer home visits to patients who are temporarily or permanently house-bound.

2.2. Identify patients at risk of loneliness and isolation and signpost them to resources such as volunteering, befriending services, community centres or day centres. Better information sharing between locum GPs can help in this respect, through ensuring all doctors seeing a particular patient have access to the same information and can recognise patterns indicative of loneliness.

2.3. Reduce the need for admin and paperwork (such as certifications for disability assessments) by offering patients (and other parties specifically authorised by patients, such as family members) online access to all their medical records; allowing them to print statements for care assessments as needed or to place requests for specific necessary paperwork online.

3. Hospital

3.1. Upon discharge, carry out a comprehensive needs assessment, to make sure patients are empowered to continue their care in the community.

3.2. Based on the results of the needs assessment:

- Offer self-care/ self-management information;
- Signpost to peer support groups around managing chronic conditions and resources offered by voluntary sector organisations (for example, Macmillan for a cancer patient).
- Refer to community services such as physiotherapy, ARCaRe, occupational therapy etc;
- Refer to social services for social care provision (including domiciliary care, home adaptations or assistive technologies);
- Offer a bespoke care package, which may include continuing care at home or in the community.

4. Other health services recommendations (e.g. district nurses, chiropody clinics, physiotherapists, psychotherapists etc.)

4.1. As much as possible, offer home visits to house-bound patients; or, where feasible, consider alternatives such as online consultations.



4.2. Proactively identify patients' needs and signpost / refer to community health services as needed.

5. Voluntary sector organisations and community centres

5.1. Improve older people's access to IT and new technologies, by offering bespoke training focusing on technology use for health and care management, as well as subsidised tablets and WiFi.

5.2. Provide alternatives to the current offer of "activities for older people", by offering a more diverse selection clubs and activities for the entire and activities for the entire community; bringing people together based on common interests rather than age group (ex: intergenerational befriending, community walking and exercising campaigns targeting people of all ages, hobby groups etc.)

5.3. Encourage older people to take part, along with other age groups, to activities outside of the usual community centre or day centre setting.

5.4. Encourage people in their 50's and 60's to take part in befriending schemes and other forms of volunteering to support older people with more complex needs.

5.5. Support people to apply for care assessments with the local council and disseminate information about resources available to them, particularly with groups who would have difficulties accessing information otherwise (eg: older people with no IT literacy or access; ethnic minorities speaking limited English etc.)

5.6. Organise events and activities (information sessions, hobby groups, intergenerational befriending and local history projects etc.) in sheltered accommodation schemes, for people who would have difficulty travelling elsewhere.

5.7. Follow the Aging Well Strategy proposal regarding providing transport to community centres and other activities for seniors; considering making use of school vans at times when they are not in use for their primary purpose.





Table of Contents

Executive Summary	1
Methodology	7
Background	10
Demographics of Tower Hamlets service users	10
Homecare	12
Economics of Tower Hamlets social care	12
Paid and unpaid care in the borough	13
Home adaptations, mobility aids and occupational therapy	16
Healthcare in Tower Hamlets: hospitals, GPs and community services	17
Community centres, day centres and social clubs	17
Local residents' experience with social care	18
Care assessments	19
Domiciliary care	23
Home adaptations, mobility aids and occupational therapy	27
Adults with care needs not receiving care	29
The language barrier	30
Unpaid and family carers	33
Local residents' experience with healthcare in the borough	34
Hospital services	35
GP services	37
District nurses/healthcare at home	40
The mental health of people with care needs	42
Active lifestyles and combatting loneliness	44
Community centres, organisations and day centres	47
Social isolation and loneliness	7
What we have learned	53
Integrated care and social prescribing	54
Recommendations	59
Social care services and care agencies	60
GP services	60
Hospital services	61
Other healthcare providers	61
Voluntary sector organisations and community centres	61
Insights from the Older People's Reference Group	61
Future of social care: worries and resilience	64

About this project

Healthwatch Tower Hamlets has, over the last 12 months, carried out a research project on the experiences of **adults with social and health care needs** in the borough. This includes domiciliary care, home adaptations for people living with as

disability or reduced mobility, sheltered housing, community services such as day centres or older people's clubs and medical services such as district nurses, chiropody, GPs and hospital services.

Our definition of adults with care needs includes all residents who need any form of support with day-to-day tasks or any other form of specialist assistance in order to live a full life to the maximum extent of their capabilities. The vast majority of people with care needs included in our sample were elderly, but other categories were included,

such as people with physical disabilities or mental health issues. Our research engaged with residents in receipt of such support, as well as residents not in receipt of support, who considered themselves as in need of it.

According to Age UK, **21%** of men and **30%** of women aged **65** and over in the United Kingdom needed help with at least one Activity of Daily Living (such as getting dressed, bathing or moving from one place to another), and **22%** and **33%** respectively needed help with at least one Instrumental Activity of Daily Living (such as cooking, cleaning or shopping). Of the **2.8 million** older people with care related needs, **900,000** currently do not receive any formal support.

Care needs in Tower Hamlets: the facts

Over 5% of the Tower Hamlets population have a severe physical disability. Approximately 22% of the population has a long-term illness, disability or infirmity.

The percentage of the Tower Hamlets population with a learning disability, known to health and social care services is around 0.26%-0.86%, which is consistent with the national estimates of people with moderate or severe learning disabilities.

1.1% of the Tower Hamlets population (2850 people) suffer from schizophrenia, bipolar disorder and other psychoses, compared to a national prevalence of 0.8% (1).

As per September 2015, there were 826 residents aged 65 and over with a diagnosis of dementia. The primary care recorded prevalence of dementia in Tower Hamlets was significantly higher (4.87%) than in London (4.27%) and England (4.27%) (2).



1 Source: Tower Hamlets "Time to Act: How we can look out for each other" evidence pack

2 Source: "AGEING WELL IN TOWER HAMLETS; A STRATEGY FOR IMPROVING THE EXPERIENCE OF GROWING OLDER IN OUR BOROUGH: 2017 TO 2020", April 2017 draft.

Methodology

In order to engage with Tower Hamlets residents on their care needs we carried out a variety of research activities including:

- Five focus groups with older residents, engaging with 29 respondents.
- Five in-depth interviews and 54 shorter semi-structured interviews with residents.
- A public event with 47 residents engaging through multiple innovative, interactive research methods.
- Visits to six hospital wards in the Royal London Hospital, the discharge lounge and transport pick-up desk; engaging with 74 patients.
- Consultation with the Tower Hamlets Older People's reference group on how to better integrate services.
- Secondary analysis of the 2015-16 service user survey for adult social care.
- Collection of additional data (a total of 215 extra comments) through our regular outreach in key community locations (hospitals, gp surgeries, community events etc.), Through NHS choices, patient opinion, social media and the Barts Trust PALS and complaints service .

All data collected has been included in our repository and coded using a nationally recognised coding matrix, which applies issue, care pathway location, and (positive, neutral or negative) sentiment.

Quality assurance of coding is ensured through the Healthwatch Tower Hamlets Patient Experience Panel, a team of service users and volunteers based in the local community, who meet regularly to code all comments received by Healthwatch together.



The Care Pathway

Care Pathway Locations Cover:

Transport (Ability To Get To-And-From Services)

Reception (Reception Services Including Back-Office)

Diagnosis/Testing (Diagnosis Of Condition, Including Testing And Scans)

Clinical Treatment (Treatment Received By Trained Clinicians)

Clinical Nursing (Care Received By Trained Nurses)

Discharge (Discharge From A Service)

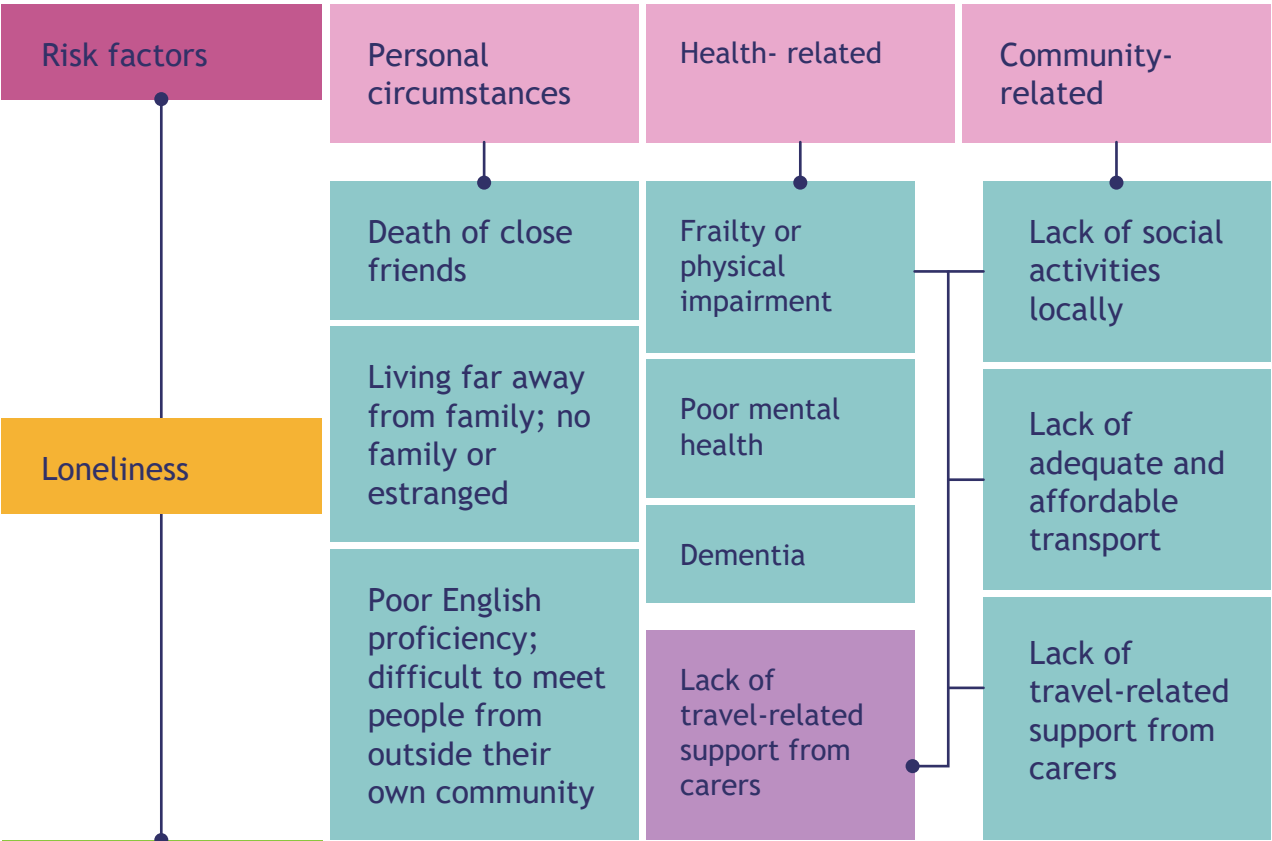
Follow On (Supplementary Services Following Discharge, Including Care Packages)

Community (Community-Based Services, Such As Social Care, District Nursing And Community Mental Health).

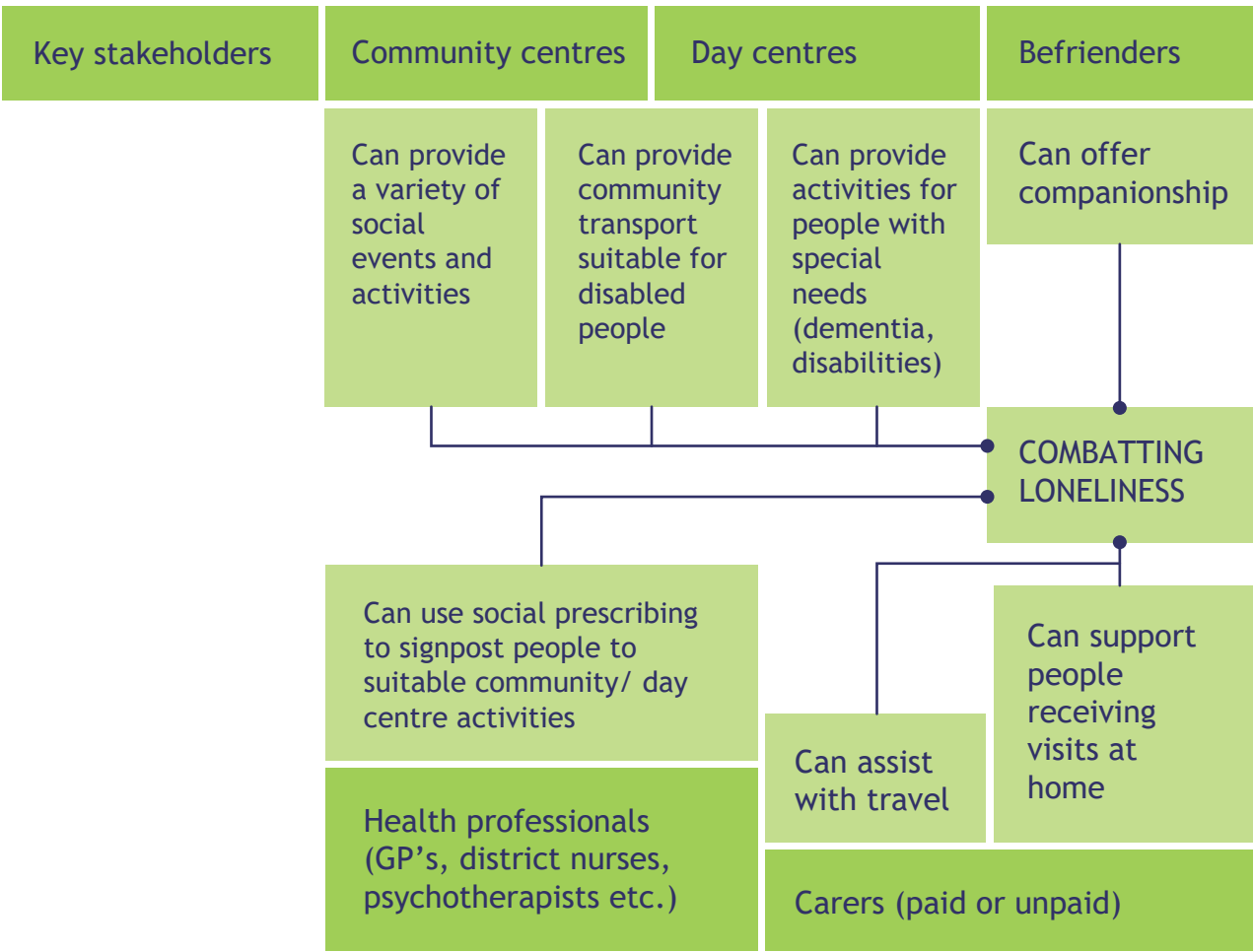
The opinion of Tower Hamlets service users has been analysed in relation to Tower Hamlets Together’s outcomes framework:

After using Tower Hamlets Together services we want residents to be able to say...

Around me	I feel safe from harm in my community
	I play an active part in my community
	I am able to breathe cleaner air in the place where I live
	I am able to support myself and my family financially
	I am supported to make healthy choices
	I am satisfied with my home and where I live
	My children get the best possible start in life
My doctors, nurses, social workers and other staff	I am confident that those providing my care are competent, happy and kind
	I am able to access the services I need, to a safe and high quality
	I want to see money is being spent in the best way to deliver local services
	I feel like services work together to provide me with good care
Me	It is likely I will live a long, healthy life
	I have a good level of happiness and wellbeing
	Regardless of who I am, I am able to access care services for my physical and mental health
	I have a positive experience of the services I use, overall
	I am supported to live the life I want



Mitigating risks



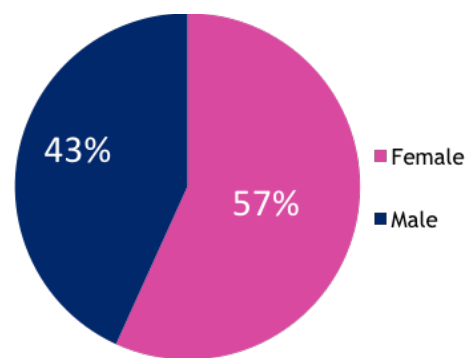
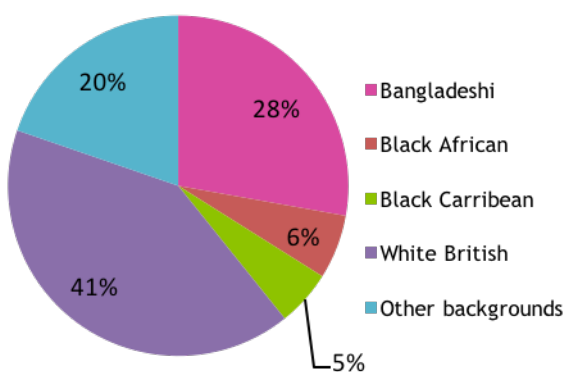
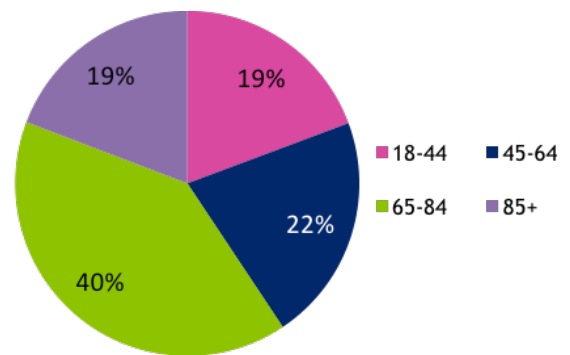
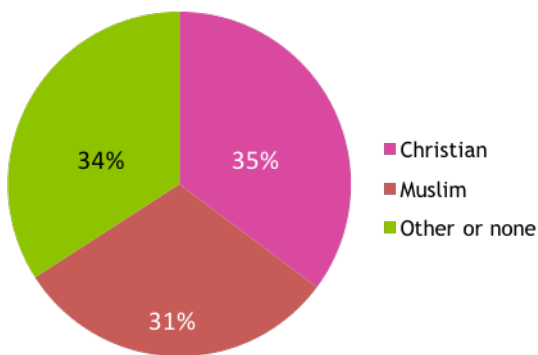
Background

Demographics of Tower Hamlets residents with care needs

Tower Hamlets is a borough characterised by sharp income and health inequalities. People typically start to develop poorer health around ten years earlier than London and England. On average, a man living in the borough starts to develop health problems from the age of 54 compared to 64 in the rest of the country.

For a woman, it is 56 compared to 64. This indicates that, while Tower Hamlets is a relatively young borough, with only 8.6% of residents aged 60 and over⁶, people may develop complex care needs earlier in life.

Based on the list of people who were invited to take part in the 2015-16 Service User Survey for Adult Social Care, which is sent to all adult service users in the borough, Tower Hamlets recipients of care have the following demographic characteristics.



⁵ Source: "AGEING WELL IN TOWER HAMLETS; A STRATEGY FOR IMPROVING THE EXPERIENCE OF GROWING OLDER IN OUR BOROUGH: 2017 TO 2020", April 2017 draft.

⁶ For comparison: London average is 15.5%; England and Wales average is 23.2%. Source: Population Estimates 2015 Analysis of the 2015 mid-year population estimates for Tower Hamlets (July 2016); published by the London Borough of Tower Hamlets.

Compared with the general borough demographics:

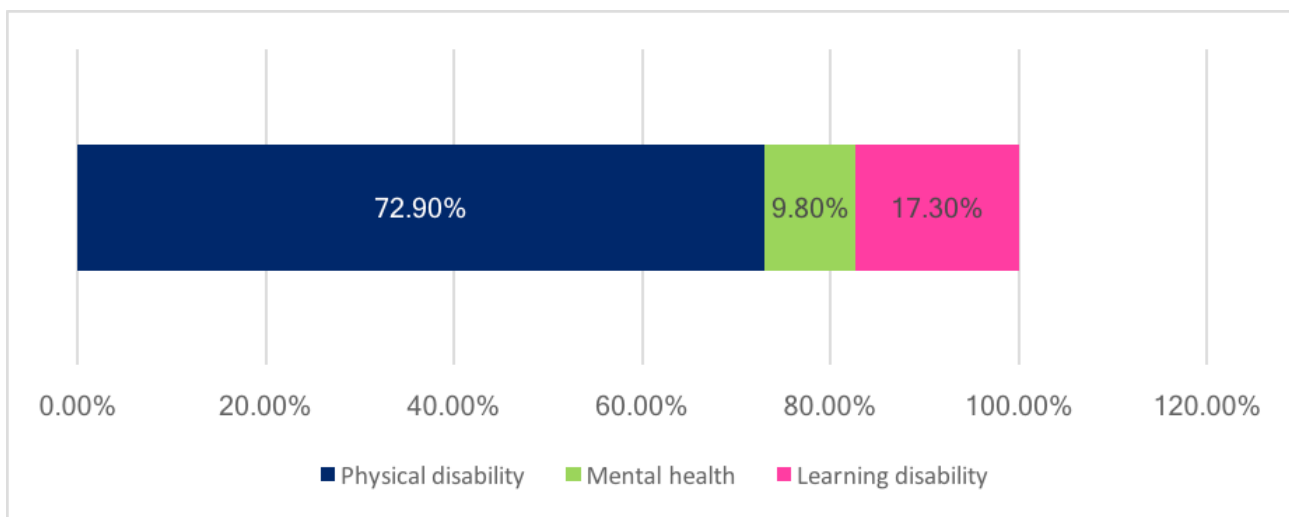
Women are slightly over-represented among care users, possibly because they tend to be over-represented among the older age groups.

People aged 65 and over make up 59% of all social care users; this is a lower percentage than the England average, where 76% of all adults to receive publicly funded domiciliary care are 65 and over. White British people are over-represented among care users (41% of care users, compared with 31% of borough residents).

Black or Black British people are slightly over-represented (11% of care users, compared with 7% of borough residents). Bangladeshi people are slightly under-represented among care users (28% of cared users, compared with 32% of borough residents).

People of Christian faith are slightly over-represented among care users; and people of Muslim faith slightly under-represented. This is in line with the ethnicity demographics of the group.

Most people receiving social care in Tower Hamlets suffer from various physical disabilities and infirmities, with only a minority affected by mental health issues (including dementia), or by learning disabilities.



7 Source for comparison: Ethnicity in Tower Hamlets Analysis of 2011 Census data, published by the Borough of Tower Hamlets February 2013

8 Source for comparison: Religion in Tower Hamlets, 2011 Census Update (Factsheet 2015-02), published by the Borough of Tower Hamlets

Homecare

Residents’ experiences with homecare represent an important part of our report. Homecare (or “domiciliary care”) is care provided in an individual’s own home, often of a personal nature such as help with dressing, washing or toileting. Care packages including homecare are designed to help people remain living independently in their own homes and give them choice and control over how they live. Homecare can be arranged by Adult Social Care Services following an assessment of need, or can be arranged privately by the individual themselves, or by someone acting on their behalf. Some homecare is arranged following a stay in hospital or a crisis which is referred to as a reablement package and is generally for a short period of time, around 6 weeks.

According to the United Kingdom Homecare Association (UKHA), nationally homecare helps almost a million older and disabled people each year to remain independent at home. According to UKHA estimates, the majority of adults who use domiciliary care services are 65 years of age or over. In 2015, 76% of all adults to receive publicly funded domiciliary care in England were 65 years of age or over.

Between 2009 and 2015 the number of people receiving local authority funded domiciliary care in the UK decreased by 20% and gross expenditure by local authorities on domiciliary care continues to decrease. However, the number of registered healthcare providers and the professional carer workforce are increasing.

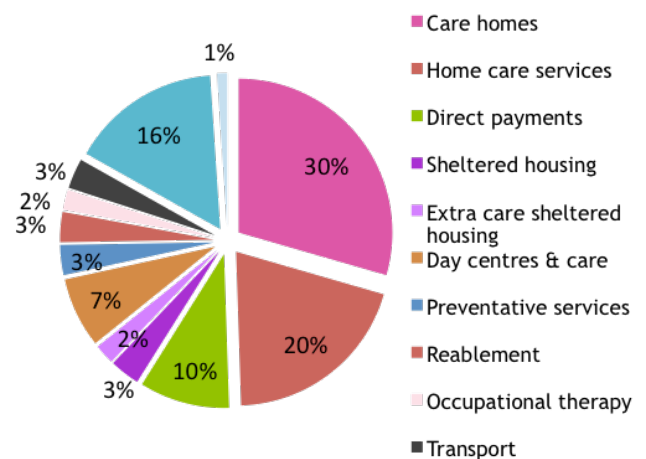
Around 3,500 adults in Tower Hamlets get support from social care at any one time; round 51% of these get help at home from a care worker. Only 16% live in a care home or a nursing home. 93% of adults with a mental health issue who reduce social care live independently, as do 69% of people with a learning disability. The England averages are 57% and 75% respectively.

As of November 2016, the Care Quality Commission had rated 12 social care services in Tower Hamlets as “good”, 12 as “requiring improvement” and 2 as “inadequate”.

Economics of Tower Hamlets social care

The budget for adult social care was £93 million in 2015-16. Care homes are the biggest area of spend at £28 million, despite the fact that they are being used by a relatively small percentage of the borough’s population with care needs. The Tower Hamlets Council has expressed the view that this is too high and they are aiming to reduce it by providing more community alternatives to help people live independently where possible.¹²

Around 95% of care and support from the Council is provided by other organisations on their behalf.



9 Source: UKHCA Manifesto 2017; <https://www.ukhca.co.uk/downloads.aspx?ID=460#bk1>

10 Source: “An Overview of the Domiciliary Care Market in the United Kingdom” (UKHCA publication, May 2016)

11 Source: “An Overview of the Domiciliary Care Market in the United Kingdom” (UKHCA publication, May 2016)

12 Source: Adult Social Care: How are we doing? The “Local Account” of Adult Social Care in Tower Hamlets Spring 2017

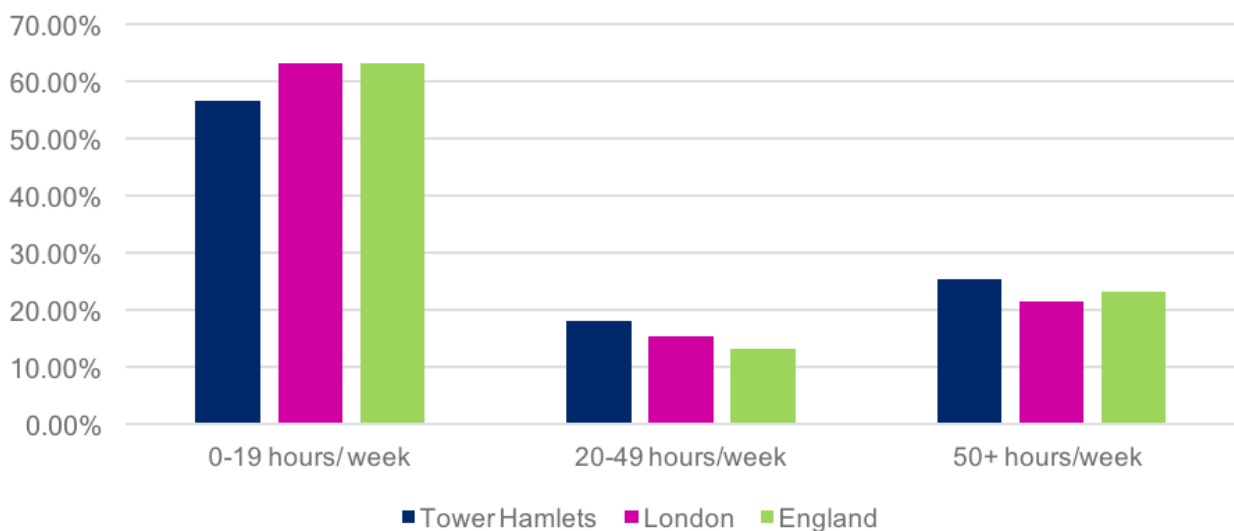
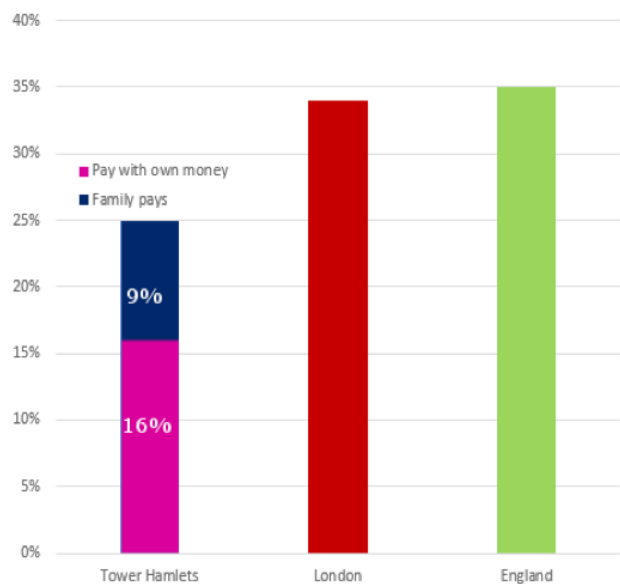
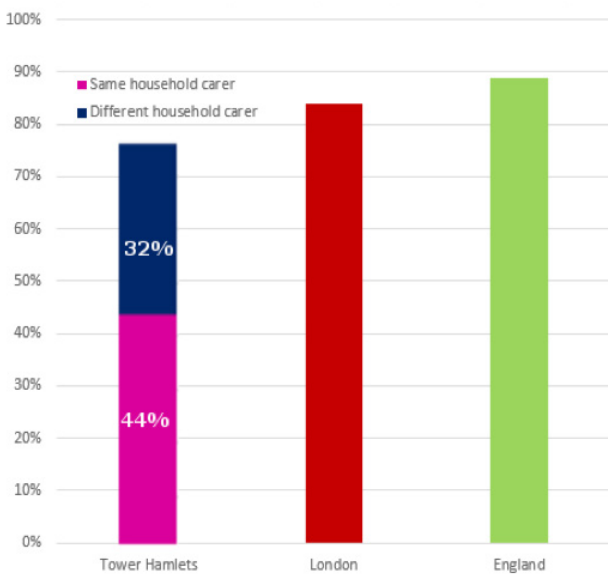
Paid and unpaid care in Tower Hamlets

In the 2015-16 Service User Survey, 44% of respondents reportedly received care from someone living in the same household (such as a spouse, parent or child) and a further 32% received care from a family member, friend or neighbour living in another household.

Paying for extra care is less common: 16% of respondents reported paying for extra care and support with their own money; a further 9% stated that their family pays for it.

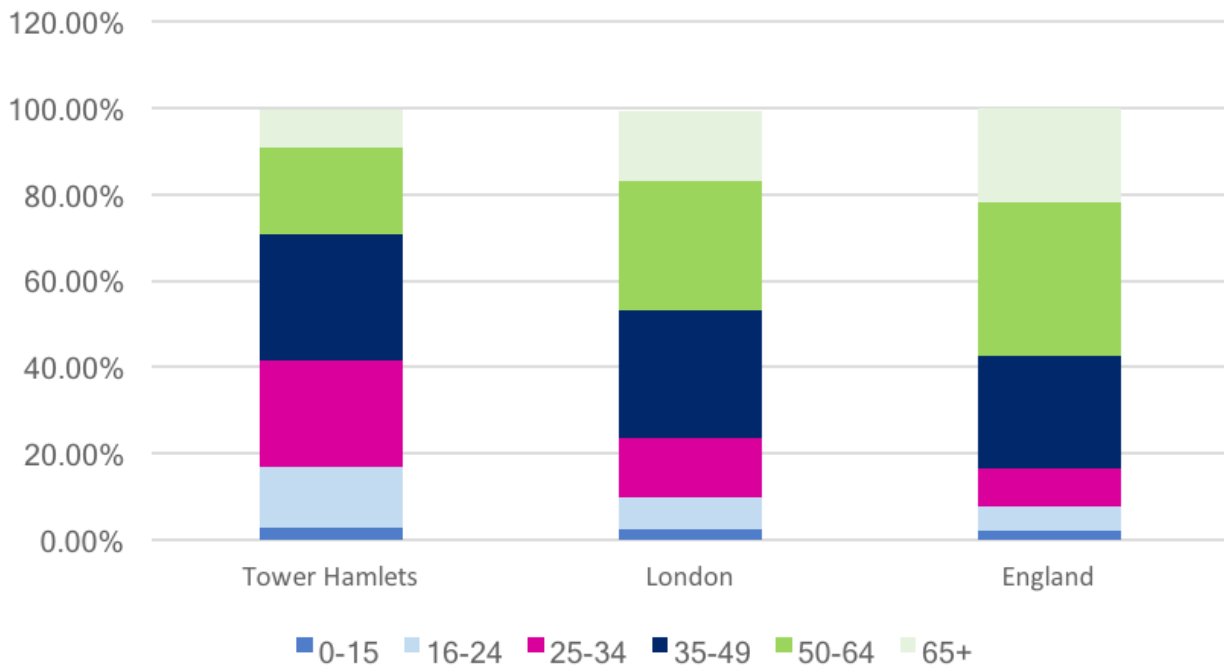
Tower Hamlets has one of the lowest proportions of residents providing unpaid care nationally, with only 7.6% of Tower Hamlets residents providing unpaid care.¹³ However, in terms of provision, carers in Tower Hamlets provide more hours of care than their peers in other parts of the country.

Tower Hamlets residents are less likely than London and England averages to either receive unpaid care or to “top up”



¹³ Source: Characteristics of Carers in Tower Hamlets; research briefing by Tower Hamlets Council, February 2015

Tower Hamlets also has a higher percentage of young carers: 17% of all Tower Hamlets carers are aged under 24, more than twice the national average.



The Bangladeshi population is the largest ethnic group in Tower Hamlets providing unpaid care (42%) and provides the highest level of care with 29% of carers delivering over 50 hours per week in the borough.¹⁵

The Health Survey for England 2012 found that care was most commonly provided to a parent (46% male and 47% female carers), while 22% men and 15% women reported caring for a spouse or partner. A greater proportion of Tower Hamlets residents live in ‘age mixed households’ than for England (40.2% vs 22.2%).¹⁶

Tower Hamlets is one of the country’s most deprived boroughs, with 44% of households in income poverty. 56% of Tower Hamlets pensioners live on a low income, compared with 18% nationwide.

For many Tower Hamlets residents with care needs, care provided by the council or the NHS represent the only form of care service they can afford. If these services are insufficient for their needs, supplementing them with private professional care services may not be an option.

14 Source: JSNA Factsheets, Carers’ Health, October 2016
 15 Source:- Carer’s Health, October 2016
 16 Source: JSNA Factsheet - Loneliness and Isolation in Older People, January 2016

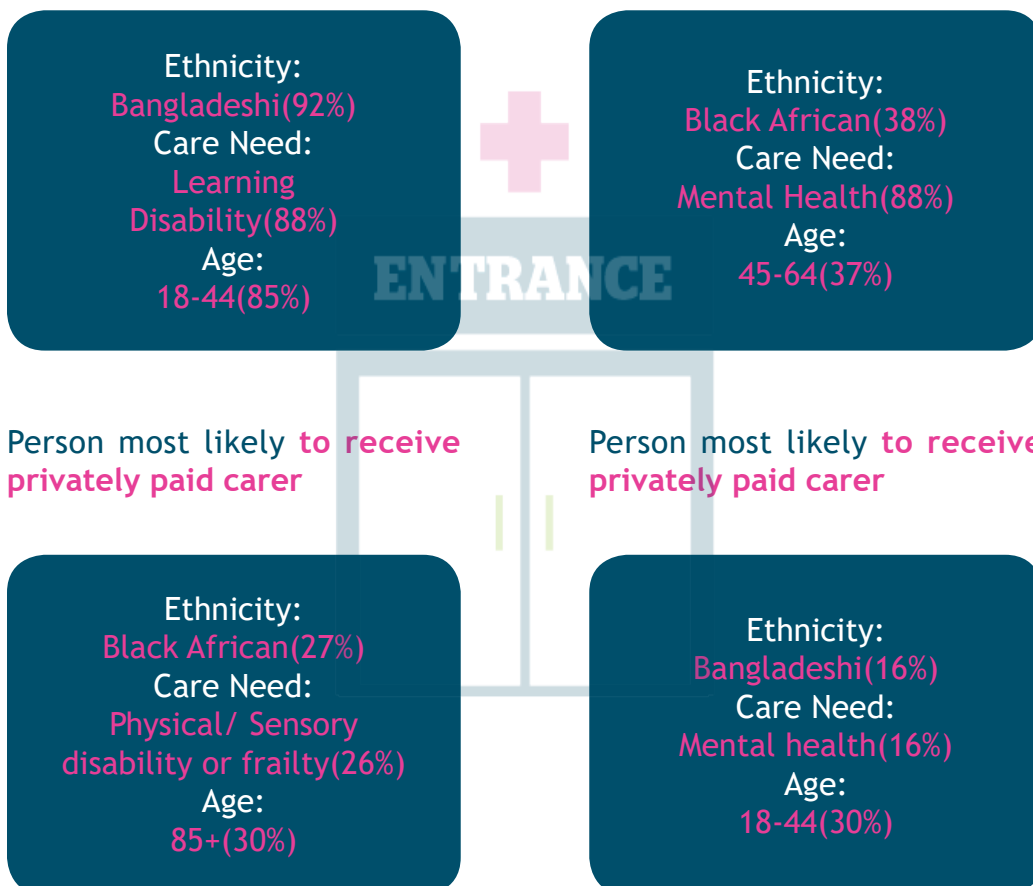
Compared with their peers in other parts of the country, Tower Hamlets residents with care needs are somewhat less likely to have the support of an unpaid family carer (although it could be the case that, for cultural reasons, de facto carers may not always identify as such). Those who have access to neither unpaid care by family members nor to privately financed professional care are strongly dependent on services provided by the authorities; with little to no other options available. This may especially be the case for adults with mental health issues aged younger than 65. Lack of diversity and choice in care options might be a contributing factor towards poorer mental health outcomes.

Tower Hamlets has the fifth highest hospital admission rates for mental health reasons in London (457 per 100,000 compared to 326 per 100,000 nationally); as well as the second highest suicide rate in London.

When care is provided by an unpaid carer, such as a family member (either exclusively or as a supplement to publicly funded professional care services), unpaid carers are likely to be younger and to do more hours of care work than their peers in other parts of the country. This could pose a risk for their health and well-being, as well as for their educational outcomes and employability.

Person most likely to receive care from an unpaid carer

Person most likely to receive care from an unpaid carer



Home adaptations, occupational therapy and reablement

Occupational therapy is a healthcare profession that focuses on developing, recovering, or maintaining the daily living and working skills of people with physical, mental, or cognitive impairments. Across the UK, occupational therapy services are available free of charge from the NHS and social services, for people who have a disability which affects their normal daily living activities such as dressing, washing, bathing, getting on and off the toilet, getting in and out of the bath, and preparing and cooking a meal. It also includes issues such as access to employment, education, housing and leisure opportunities. Tower Hamlets residents can access occupational therapy services after having their needs assessed by the Council, either in person or over the telephone.

The council can offer advice to residents who need specialist equipment in their home to help them live independently with a disability and may in some cases provide such equipment which will assist in overcoming difficulties subject to an assessment of personal needs to determine eligibility. This may include improving safety by installing stair and grab rails, improving access through ramps, widening doors, or installing a stair-lift, or other options such as adapting a kitchen or bathroom.

Occupational therapy is also used as part of the reablement process, which consists of a short-term care package (up to 6 weeks) intended to support people to regain the skills necessary for daily living, which have been lost through deterioration in health and/or increased support needs. According to the Social Care Institute for Excellence: Prevention

Library, a 2014 Tower Hamlets based study found that 63% of residents using an occupational therapy-led reablement service had their reablement cases closed without further support needs identified.

The occupational therapy-lead and multiagency service delivering reablement in Tower Hamlets currently receives 100 referrals a month, from a variety of sources, including a First Response team based at the local authority who people and their families can contact themselves. 40% of referrals come from hospitals (including community hospitals) with other community-based health teams also making referrals, including community learning disability teams and community mental health teams (17).



Healthcare: GPs, hospitals and community health services

Whether people's social care needs stem from old age, frailty, disability, physical or mental illness, they are likely to also have extensive experience with healthcare services in the borough, including GPs, hospitals, and community-based services such as physiotherapy and chiropody. According to the 2016 JSNA on Older People, 63% of older Tower Hamlets residents had a limiting long-term condition which limited their day-to-day activities "a little" (26%) or "a lot" (37.6%). A higher proportion (37.6%) of older residents had a long-term illness which limited day-to-day activities "a lot" compared to London and England (18).

Tower Hamlets is home to 37 GP surgeries, as well as to the Royal London Hospital, a large teaching hospital providing district general hospital services for the City and Tower Hamlets and specialist tertiary care services for patients from across London and elsewhere. It is also home to the Mile End Hospital, which offers a variety of services relevant to older people and people with care needs, including cataract surgery, diabetic medicine, memory services, rheumatology and community services such as continence and chiropody.

Services including district nurses, community geriatricians and the Tower Hamlets Rapid Response Team are provided by the East London Foundation Trust (ELFT), as part of Community Health Services (CHS), which have been developed to provide co-ordinated health care for adults living in Tower Hamlets. The teams are multi-disciplinary, aligned to local GP practices and provide a seven-day service.

The Admission Avoidance and Discharge Service and Rapid Response Team provides urgent assessment, treatment and care within the person's home in order to

prevent avoidable hospital and

emergency department attendance. They work closely with the Physician Response Unit (PRU) and accepts referrals from this service, as well as from GPs, social workers and care home staff.

Since June 2017, the Tower Hamlets Neighbourhood Care Team scheme has been trialled in Shadwell and Limehouse by the East London Foundation Trust, as a new approach to community nursing, in which the nurses have the freedom to plan their hours around the needs of the patient, in a self-managing team.

The Dementia Care Team, based at the Mile End Hospital, is the Community Mental Health Team for older people with dementia. It is an integrated health and social care team, that provides psychiatric and social needs assessment, intervention and treatment to the individual and their carer(s).

Community centres, day centres and social clubs

A community centre is a place where people from a particular neighbourhood can meet for social events, education classes, or recreational activities. Many community centres offer bespoke activities for older people (usually active seniors) such as exercise classes, IT or language classes, lunch clubs, social games such as bingo or talks on various health and well-being topics. Tower Hamlets has over 60 community centres and associations; some of those are faith-based or ethnicity-based, serving primarily speakers of certain languages or people of a certain cultural background.

A day centre is a place providing care and recreation facilities for those who cannot be fully independent for reasons of physical or mental health. Unlike in a community centre, residents typically need to go through a care assessment

There are currently nine day centres in Tower Hamlets. The Pritchard's Road Day Centre specialises in adults experiencing mental health issues; the Russia Lane Day Centre specialises in users who have moderate to severe dementia and the Create Day Centre specialises in adults with learning disabilities; all other day centres bring together users with a varied number of long term conditions.

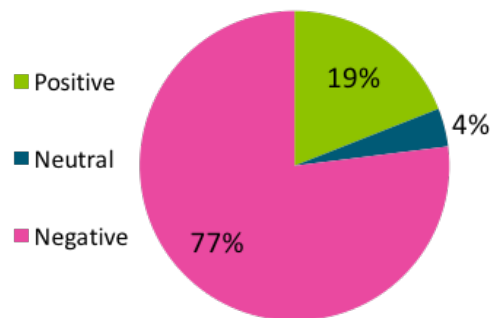
The Alzheimer's Society provides the Thursday Coffee Club in Bow, a social

club for people with dementia, as well as their families and carers, where they can receive information/support and take part in various activities. The East London Mosque also hosts the Alzheimer's Society's Bangladeshi Dementia Café, facilitated in Sylheti.

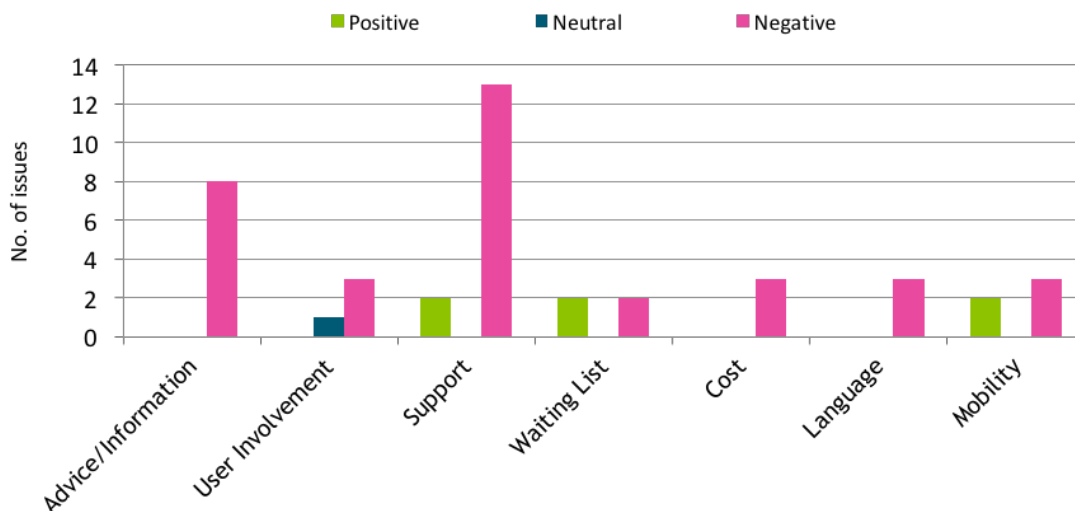
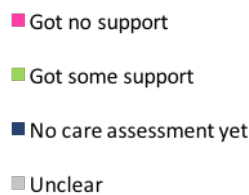
Local residents' experience with social care in the borough

Care assessments

22 people gave feedback on care assessments, and opinion about it is 77% negative. Most service users feel unsupported by a complicated and overly bureaucratic assessment system.



Out of all service users interviewed, only 55% had obtained some support, and 27% had not had their care assessment yet.



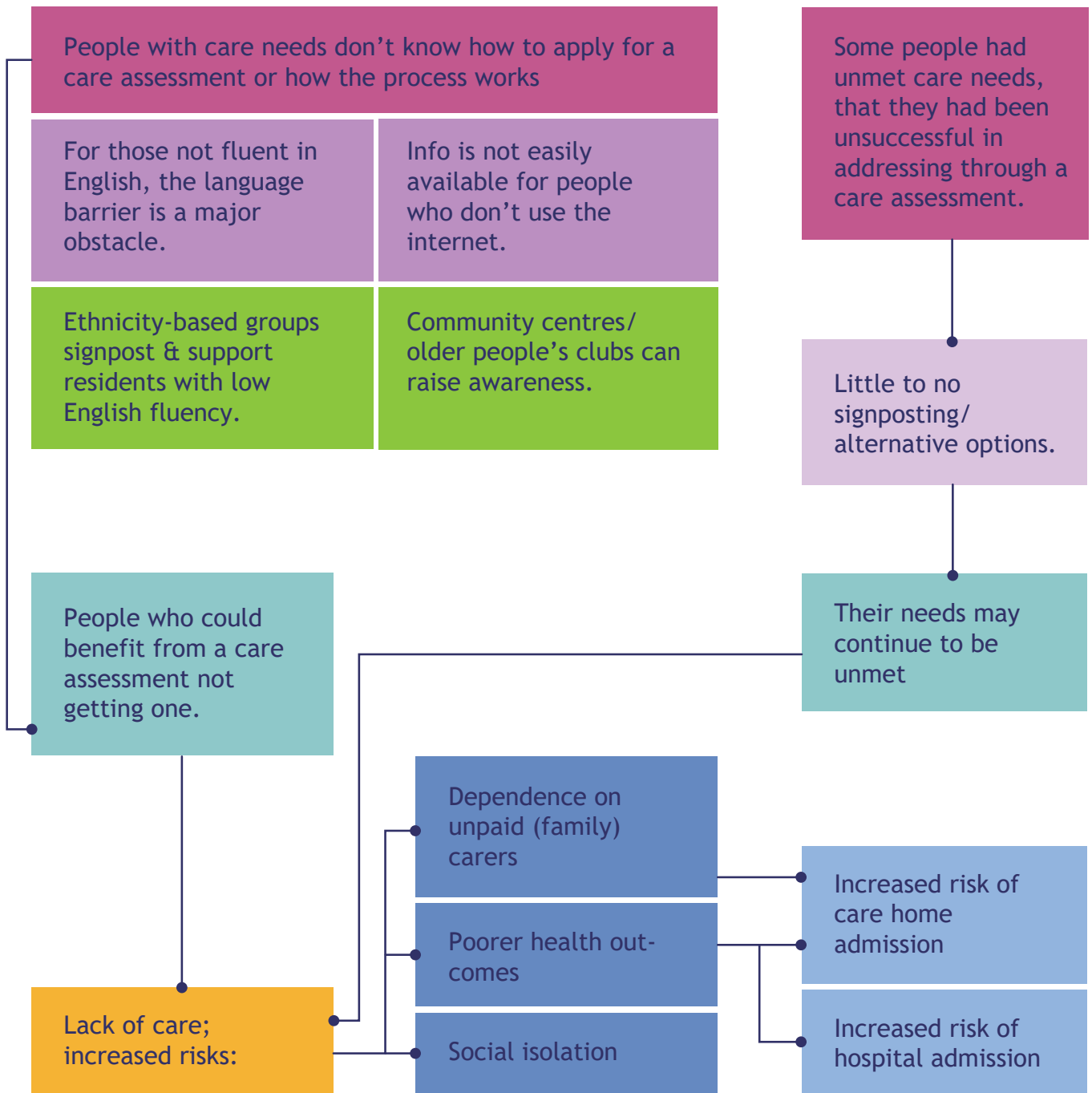
Care assessments key findings

Many of the people we spoke to did not know how to obtain a care assessment, which led to them not applying for help that they could have been eligible for. Older people who were not internet-literate and people with a low level of English fluency found it the most difficult to find information.

- ee *[I had a care assessment] because an accident happened [but received no support]. I cannot go shopping or to the mosque on my own. (Disabled Bangladeshi man in his 60's, interview).*
- ee *I'm not confident... I need help with housework and don't receive anything. In the future I'll try to have a care assessment, but I don't think I'll get [the care I need]. I don't know how to go about it, wouldn't know who to ask. (White British woman in her 70's, focus group).*

Others have had unsuccessful care assessments; and received little to no signposting about alternative support available to them through other public resources, charities or community organisations.

I have pain that comes and goes, so I would like to apply for personal independence payments to get some occasional help with cleaning and care at home; I'm in the process of applying [with help from the Community of Refugees from Vietnam - East London]. I currently manage by myself, but it's difficult to get a care assessment [because of the language barrier]. (Vietnamese cardiology patient in his 50's, interview).



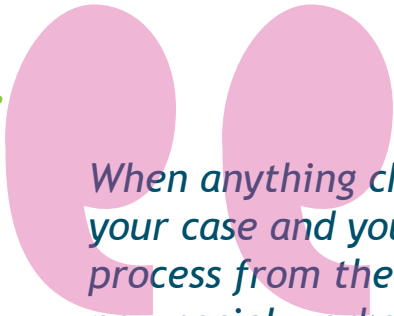
Service users/carers perceive the care assessment process as adversarial and uncaring; partly because they find it overly bureaucratic/ not person-centred, and partly because, knowing that local councils have limited resources, they feel that users only receive as little care as services can get away with; leaving them distrustful of social workers.

☺☺ *To be honest, I thought [the assessment process for renewing a Blue Badge] was entirely silly. The man came down, took one look, they make you walk up and down... I walked up and down with a bottle of oxygen on my back and a walking stick and he said, "You're disabled". That was ridiculous. (Disabled White British man in his 80's, focus group).*

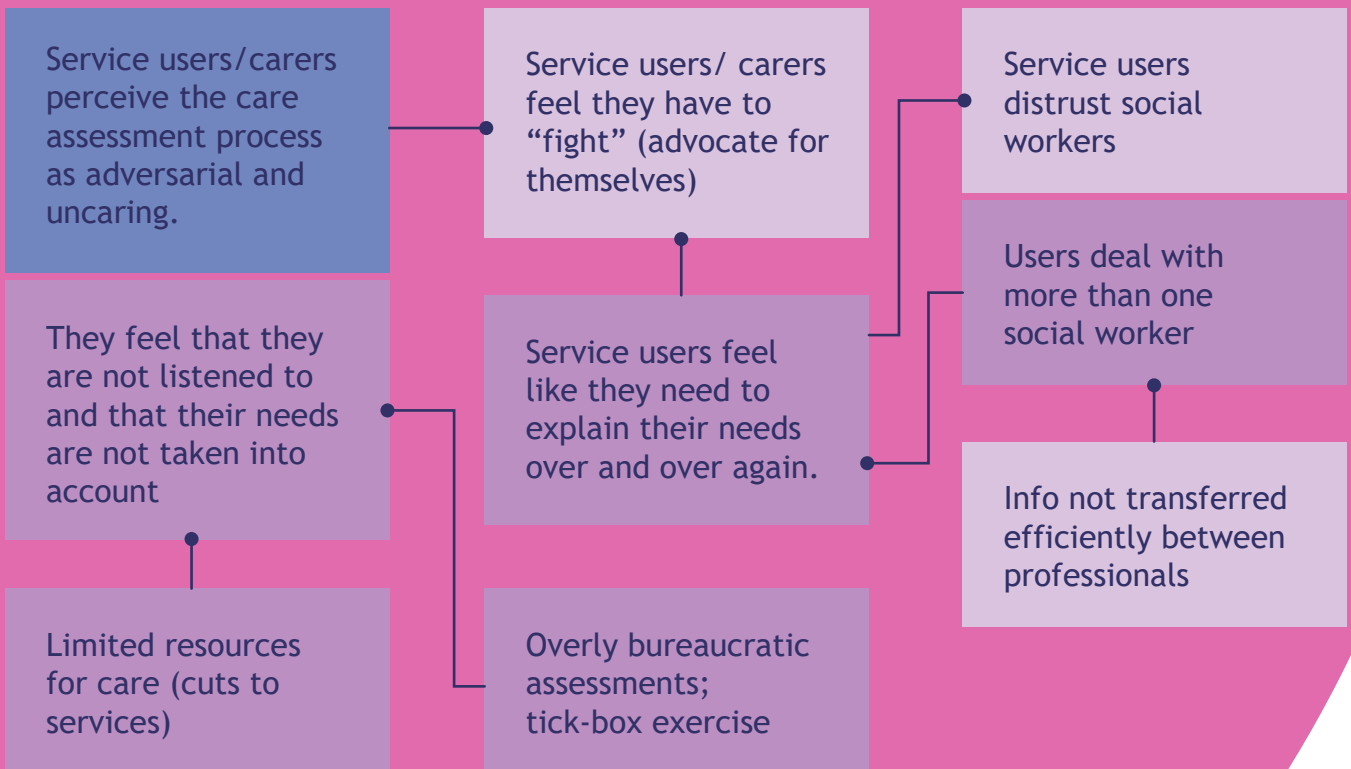
☺☺ *I feel offended [when social workers ask about my income or circumstances] and I am getting frightened of giving them my personal data (White British woman in her 60's, focus group)*

☺☺ *I don't remember much of my care assessment, it was a long time ago, but they come around every year, to renew it. They can never understand my needs... Even if they try to do. There is not enough budget, so I can't blame them. (White British woman in her 70's, focus group).*

It is common for a care user to deal with multiple social workers; when this happens, information is not circulated efficiently between them; which makes the process more difficult.



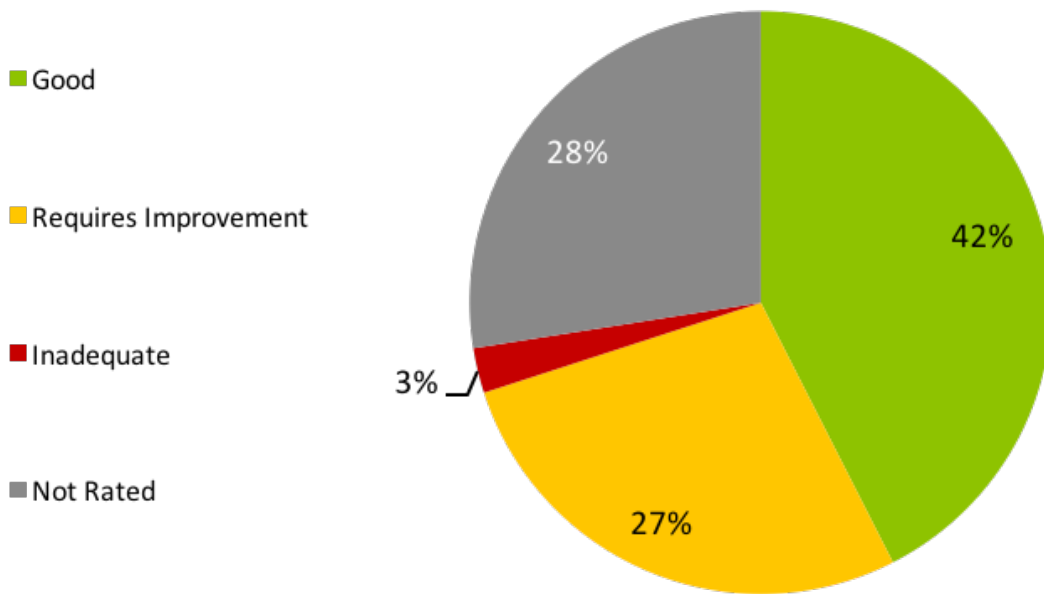
When anything changes, they close your case and you have to take the process from the beginning, with a new social worker- and then the new social workers don't know what they are talking about. Only once when I had a very simple request- I needed to re-allocate 2 hours of care to a different day- it got sorted in 8 days. Usually it's a very frustrating process to amend. It would be better if you could go back to the social worker you had before, but cases get re-allocated. (Wife and carer of elderly dementia patient, White British, interview).



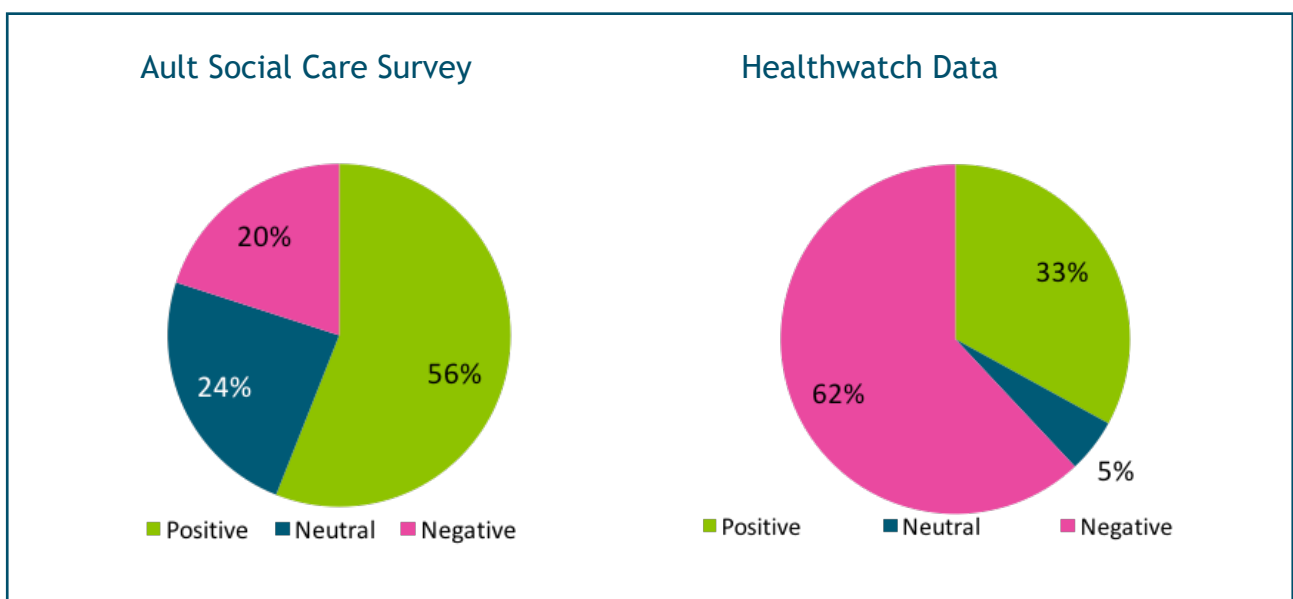
Domiciliary care

In order to assess residents' experience with domiciliary care, we have carried out a secondary analysis of the 2015-16 Service User Survey for Adult Social Care and we have engaged face-to-face (through focus groups and interviews) with 33 recipients of domiciliary care services.

Out of 40 domiciliary care providers available to Tower Hamlets residents, 17 were rated Good by the CQC, 11 were rated Requires Improvement and one Inadequate.



The adult social care survey data shows people mostly satisfied with the care that they receive at home; on the other hand, the data collected by Healthwatch independently paints a more negative picture of residents' experience with adult social care.



Domiciliary care key findings

In most cases, most people that we spoke to have found carers (as individuals) useful and supportive. They felt much less supported, however, by care agencies and social care services. Receiving insufficient care time is a concern raised by several patients.

- *I have two carers. They're ok, good, no complaints. I get one hour of personal care in the morning- a 45-minute bath and then personal care. In the evening it's just 30 minutes, but I'm happy with that. They prepare food; when needed I get 1 hour of cleaning or 30 minutes of shopping. (Vietnamese man in his 80's, interview).*
- *I was assessed for one hour a week and that's not enough, I can't do anything for myself. There's so many problems there. 1 hour a week is insufficient for my needs - services have been cut. (White British man in his 70's, focus group).*
- *Age UK Sitting and Companionship Services- I was happy with it overall, but unhappy with the lack of communication with Headquarters. I made complaints, and it was taken as "We have to write a report about it, and it's complicated...". It escalated, and we decided that we can't work together anymore. (Wife of dementia sufferer, interview)*

In some cases, service users were able to obtain flexible care, adapted to their needs. This may empower them to continue leading an active lifestyle and socialise, to the extent of their abilities. In other cases, however, lack of flexibility on the part of carers and care agencies can constitute an obstacle to socialising or attending community events; rendering people who would otherwise be able to take part practically house-bound.

- *My carers made a care plan with the Council first, but I had to make adjustments, directly with the carers. I didn't want to get the lunch hour because I don't like typical British food- I prefer coming to the Lunch Club at the Vietnamese Cultural Centre for food that I am more used to; and I can take public transport on my own for it. (Vietnamese man in his 80's, interview).*
- *I would like my care to be more flexible though the morning carer is very good, but I could do with 10 extra minutes, the evening carer can't be flexible with our appointments for when I need to participate in events in the evening. Overall- I think that's one of the things that makes people house-bound even if they otherwise could keep active- they may miss their carer. I sometimes go without housework or shopping if I need to be somewhere else in the community; that's how people who otherwise could leave their home become house-bound and stop attending things. (White British wheelchair user in her 70's).*

Some patients mention services they wish they could have had, but that carers cannot regularly provide. This include assistance with various household tasks, as well as with travel and attending community events. Not all service users felt confident communicating their needs to their carers.

☺☺ *Got support after been discharged from Mile End hospital, but I cancelled the service because the person that was coming used to just make the bed and wanted to have a chat. They never offered to Hoover, and for me it's hard to do, but they never offered so I never asked them. They asked me if I needed help to wash myself, I didn't need that, I'm independent. (White British woman in her 70's, focus group).*

Several people have dealt with unsupportive and unprofessional carers, who failed to perform their duties, potentially putting service users' well-being at severe risk.

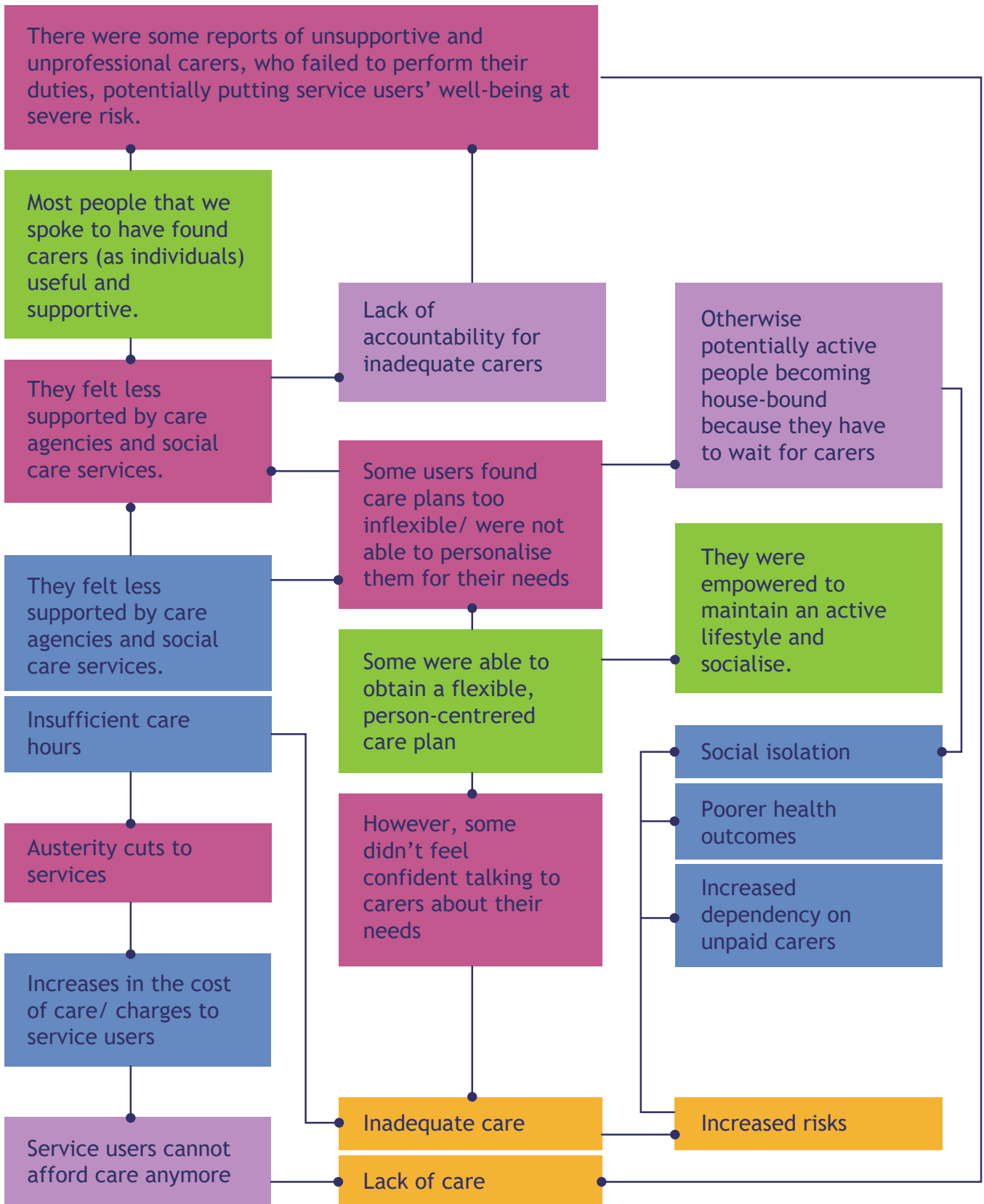
☺☺ *I had a carer sent over by the local authority. They were sitting down and smoking 10-20 cigarettes and doing nothing. (Black British disabled man in his 60's, focus group).*

☺☺ *[My father in law is a wheelchair-bound dementia sufferer] His care workers do not provide personal care, despite being on their duties. They only make tea and assist with medication, if the client says personal care, they say it's not in their duty and the social worker does not enforce this with the agency as she is supposed to be the care-coordinator. They are supposed to spend 30 minutes on each*

visit but often they spend 15 minutes and write on the log book 30 minutes. Often care workers do not visit every day, but they would write on the log book that they visited him every day as the client is illiterate and does not speak or read English, so the care workers abuse the system. (Son-in-law of Bangladeshi dementia sufferer, interview).

With recent changes to service provision and austerity cuts, many people reported having to give up care at home they have benefitted from, as it became unaffordable. Some also became ineligible for certain types of care. According to the care recipients we have spoken to, cuts have been implemented without proper consultation or explanations for patients. Increases in the price of care are seen as prohibitive and unfair, especially with carers being perceived as underpaid.

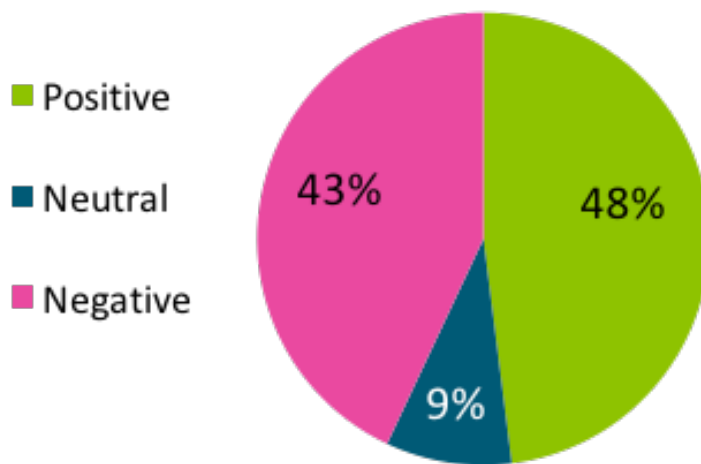
☺☺ *I have a problem with the council- they gave me this care grant and now, just because I have a small pension, they tell me they have to deduct £46 a week from it). I appealed that, and I asked, how do you assess us, how do you look it out? They got back to me and said they took my disability allowance into account. You shouldn't do that, because it is independent. And now they sent a letter saying I need to pay £76. Who has that kind of money? Who decides this? (Black British disabled man in his 60's, focus group)*



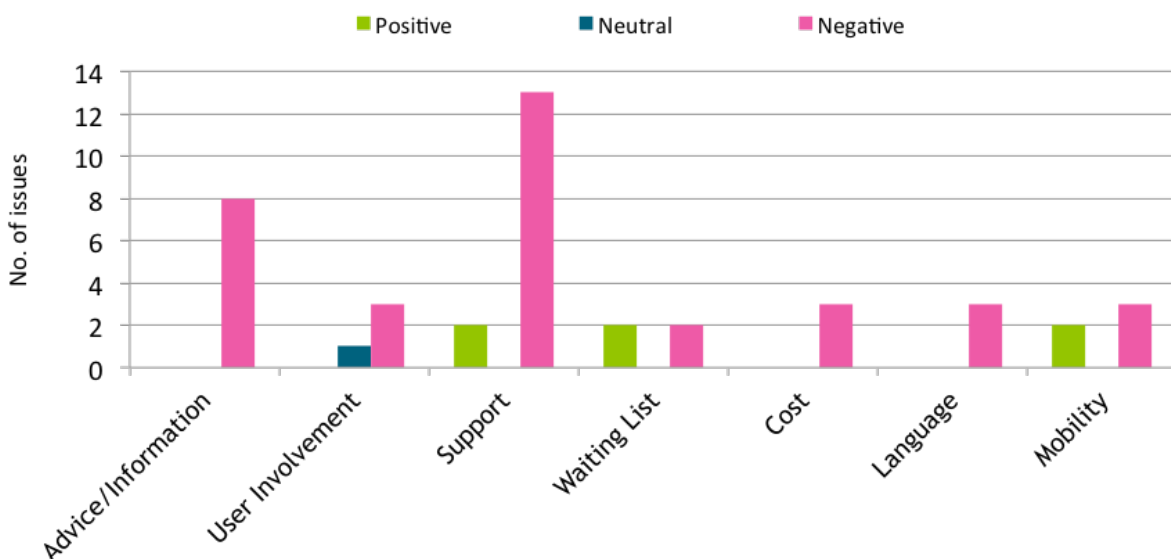
Home adaptations, mobility aids and occupational therapy

We have spoken to 25 people who received, in various forms, mobility aids or home adaptations, Opinion of these services is mixed. Service users consider home adaptations to be a valuable

resource, that empower them to continue maintaining an independent lifestyle; but they complain about long waiting lists and some found communication with occupational therapists or Social Services difficult.



Most adaptations offered were designed to help service users their bathrooms with better ease.



Home adaptations are a useful resource for people with care needs, empowering them to remain independent for longer.

ee *I had trouble getting in and out of the bath, so they gave me hand rails so now I can get in and out easily. This young man arrived [for assessment] he stood me in the bath, made me turn around then he asked me where I wanted the handrails; he didn't make the decision without my input. That was very good. I had bought handrails before, from the Lloyds pharmacy, I saw the brand being advertised- and they fell off. [They were secured to the wall with suction pads]. They gave me very good handles, from the same manufacturer, and drilled them through. They also asked if I needed adjustments in my kitchen. That was very good, many people in my [falls] class had their kitchen redone. I didn't need it at the time but I'm in their system, I can request an assessment if my circumstances change in the future. (White British woman in her 60's, interview)*

ee *I had to wait 6 months for a wheelchair, but it was too long of a wait, so I decided to get one on my own. (White British man in his 80's, interview)*

ee *I have a wet room, walk in shower, handles in the shower, handles on the door, rails to go upstairs and the service is good, it was quick once I had it approved, but it took 5 years to get the shower. (Indian woman in her 60's, interview).*



However, some service users had to wait a long time in order to get the adaptations they needed; to the extent that some paid privately for adaptations instead.

Some users felt frustrated and unsupported during the care assessment process.

“I had a bath. Now, I couldn’t get into that bath. And I tried explaining them- they wouldn’t do it. They kept asking: “Can you sit here? Can you swing your legs over?” I said: “I told you from the beginning: I cannot lift my legs. It’s very very hard to understand what they’re saying when they’re not saying what you want them to. It’s difficult to communicate to them about my needs. (White British woman in her 70’s, focus group)

“I wouldn’t know how to get care at home. I’m worried and unhappy about my finances Vietnamese woman in her 70’s, interview).

“I’ve been given a certain amount from the council while I’m waiting for my operation, because I can’t travel, I need to get my shopping done... But I don’t know if I can use it to choose and hire a carer, or how it works. (White British woman in her 70’s, focus group).

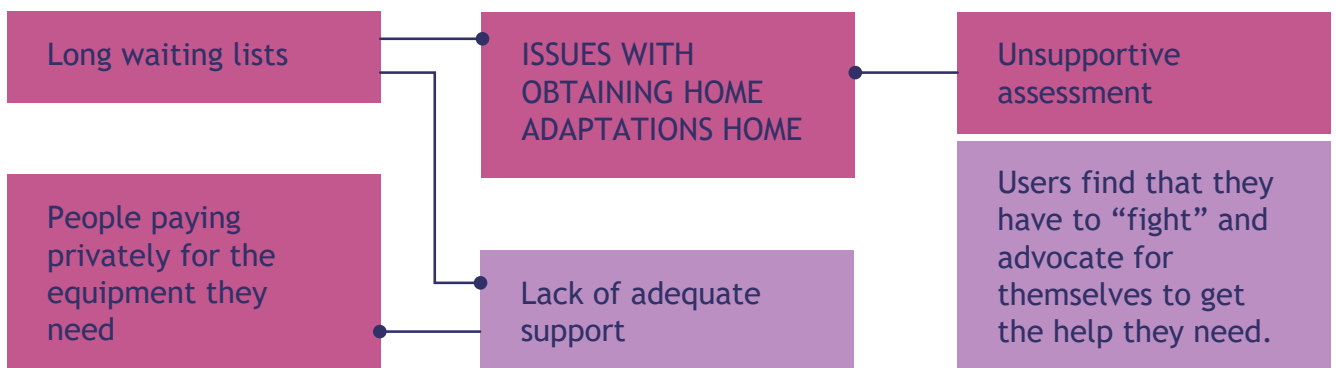
“I need a service [information/ guidance] on how to apply for a carer. I don’t have good balance, so I depend on transport services for getting around. Please reduce the price of transport services! (Disabled White European woman in her 30’s, interview).

“I need help with housework right now and don’t receive anything. In the future I’ll try to have a care assessment, but I don’t think I’ll get [the care I need]. I don’t know how to go about it; I wouldn’t know who to ask. (White British woman in her 70’s, focus group).

Adults with care needs not accessing care services

Apart from service users who had used domiciliary care services in the past but were forced to give them up for financial reasons, when charges increased, we have also encountered several residents who mentioned that they need or could benefit from social care but did not currently have access to it. The reasons for this were:

Lack of knowledge about how to access care and the costs it may entail:



Difficulties with the care assessment process, or failed care assessments.

- ee** *I came home after kidney surgery, with no care package arranged for me at all. I was in pain, suffering from angina, arthritis and other health problems- I can't do things like open jars and I have difficulty getting in and out of the bath. So, I called Adult Social Services for an assessment, and she [the professional conducting the assessment] asked me all sorts of questions... I told them before they came in I am not on benefits, I'm a retired doctor, so to qualify for assistance you need to be on benefits... I have a cleaner and gardener coming to my house every week, that I pay for privately. My cleaner does my laundry, she takes clothes up and down the stairs [which I couldn't manage on my own]. I casually pay a neighbour on occasion to buy groceries and cook for me. (Indian woman in her 60's, interview).*
- ee** *[I had a care assessment] because an accident happened [but received no support as a result]. I cannot go shopping or to the mosque on my own. (Bangladeshi man in his 60's, interview).*
- ee** *My son got in touch with the council to find out how to get help after I was discharged from hospital. That was on August bank holiday. It is now October and I still haven't heard anything back. (White British woman in her 80's, interview)*

The language barrier

Language and cultural barriers can be an important obstacle to accessing good quality care.

In a discussion about care assessments, multiple Chinese and Vietnamese residents have made statements such as:

"I wouldn't know where or how to receive a care assessment because of the language barrier."

"At the moment I'm still able to manage, but I will be looking [for home care services] in the future. I have no idea [what is available], I depend on the Community of Refugees from Vietnam for advice [because I don't speak English]."

Ethnicity-based organisations such as the Community of Refugees from Vietnam or the Bangladesh Welfare Association can, in some circumstances, be the only ones able to offer support in dealing with the local authorities to obtain care. Depending on such organisations to navigate the system of care assessment and social worker appointments can significantly slow down the process.

ee *I had heart surgery at the (now closed) London Chest Hospital; good service but no care package. I have pain that comes and goes, so I would like to apply for personal independence payments to get some occasional help with cleaning and care at home; I'm in the process of applying [with help from the Community of Refugees from Vietnam - East London]. I currently manage by myself, but it's difficult to get a care assessment [because of the language barrier].” (Vietnamese cardiology patient in his 50's, interview).*

This sentiment is echoed by multiple residents who don't speak English fluently. In dealing with social services, carers, as well as medical professionals such as GPs and hospital consultants, service users who don't speak English rely on family members or community charitable organisations for assistance.

ee *Language is my main concern. I speak only very basic English; my children help me with translation sometimes, but for more complicated things I can get an interpreter.” (Vietnamese woman in her 70's, interview).*

With over one third of adult residents primarily using a language other than English, Tower Hamlets is the fourth most linguistically diverse area in England and Wales. While the majority of non-native speakers are fluent in English, around one quarter said in the 2011 Census that they could not speak English 'well' or 'at all'; including 27% of Bangladeshi residents and 22% of Somali residents.

According to 2011 Census data, older residents were more likely than younger residents to have low proficiency in English: one in five (21 per cent) residents aged 65 and over said they could not speak English well or at all, compared with just 3 per cent of young adults aged 16-24. The vast majority (93 per cent) of older Bangladeshi women had poor proficiency levels.

Some are highly appreciative of the support that they receive within their families and communities; some of them are happy being looked after by family members and prefer not to have a paid carer. They may, however, need other forms of support, such as community transport or home adaptations.

- *When my husband was still alive [and severely disabled] we didn't have a carer, I did it all myself. My husband wouldn't have wanted a carer (White British woman in her 80's, focus group).*
- *My daughter looks after me, she does a lot of things. She receives carers' allowance, I'm happy with this arrangement. My daughter doesn't drive though, and it's difficult for me to travel on public transport. (White British woman in her 70's, focus group)*

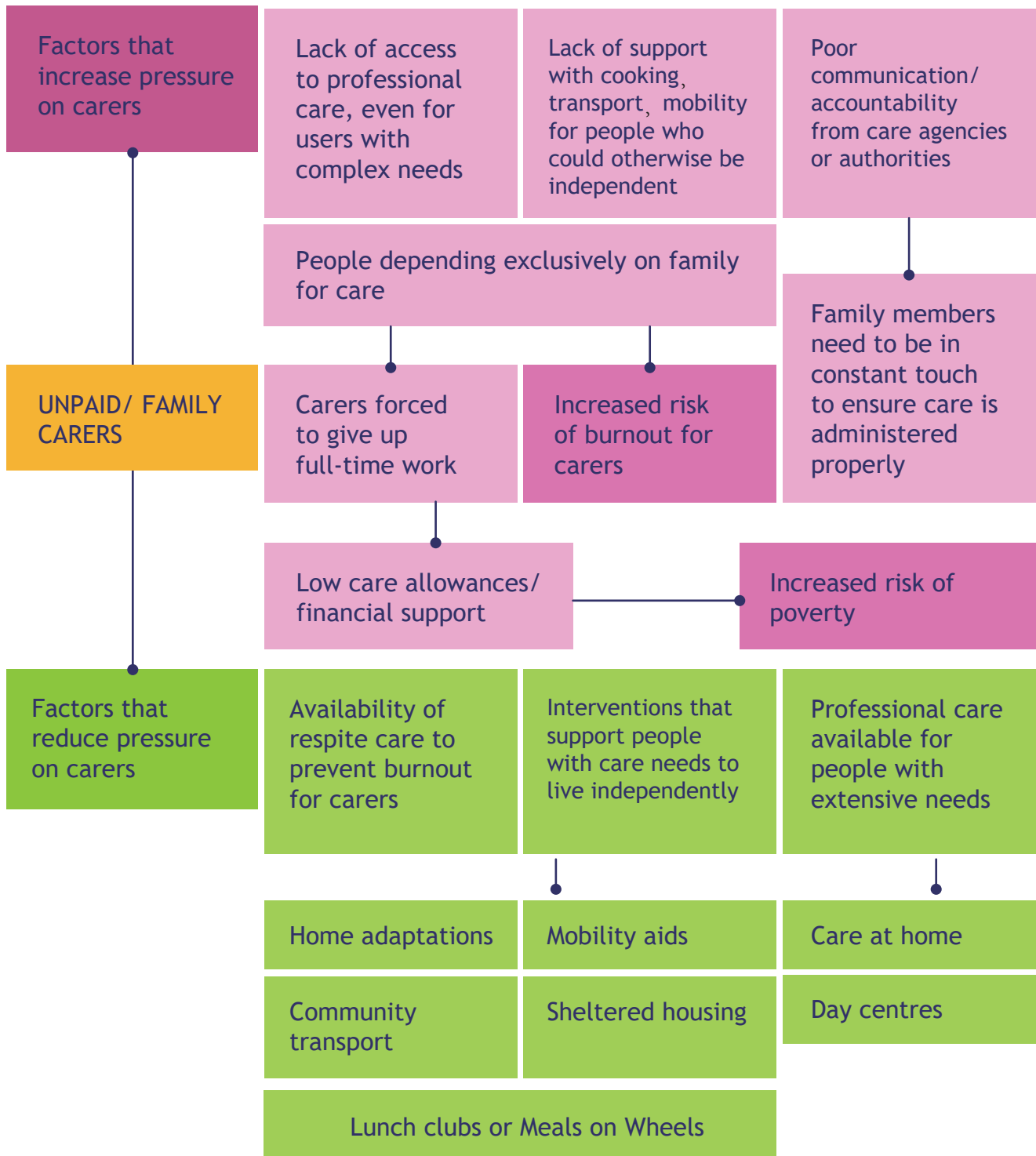
On the other hand, depending exclusively on unpaid care can be stressful for some, who were not able to get publicly funded care and who could not afford to pay privately for it, or who don't know how to get any kind of support through their local authority. Some of those who only receive help from family members wish they had a professional carer instead.

- *I live alone but my daughter checks every day to see if I'm OK. She has her own household, you know- a job, and a child, and a dog- but she comes whenever she can. (White British woman in her 80's, interview)*
- *I would like to have a personal hygiene helper and a helper in general. At the moment only my son helps me. (Indian woman in her 80's, interview)*

Respondents acknowledged the pressure that unpaid carers can be under (including financial pressures) and expressed a desire for more support for carers than is currently available.

- *Someone I know had a stroke, her daughter gave up her job to look after her, and now she lives on £60 a week from direct/personal independence payments [paid by the council for her mother's care]. How can you live like that? She gave up a job with £200/£300 a week and she lost her home. (White British man in his 70's, focus group).*
- *My wife needs to keep in constant contact with the care worker and the agency- she needs to be her father's unofficial social worker and hold the care worker to account- it's like a second part time job for her" (Son-in-law of Bangladeshi dementia patient, interview).*





According to the 2015-16 Care Service User Survey, 44% of Tower Hamlets social care users reportedly received care from someone living in the same household (such as a spouse, parent or child) and a further 32% from a family member, friend or neighbour living in another household.

Tower Hamlets has one of the lowest proportions of residents providing unpaid care nationally, with only 7.6% of residents providing it. However, according to the

JSNA Factsheet on Carers' Health, October 2016, carers in Tower Hamlets provide more hours of care than their peers in other parts of the country. Tower Hamlets also has a higher percentage of young carers: 17% of all Tower Hamlets carers are aged under 24, more than twice the national average.

The Bangladeshi population is the largest ethnic group in Tower Hamlets providing unpaid care (42%) and provides the highest level of care with 29% of carers delivering over 50 hours per week in the borough.

Local residents' experience with healthcare in the borough Hospital services

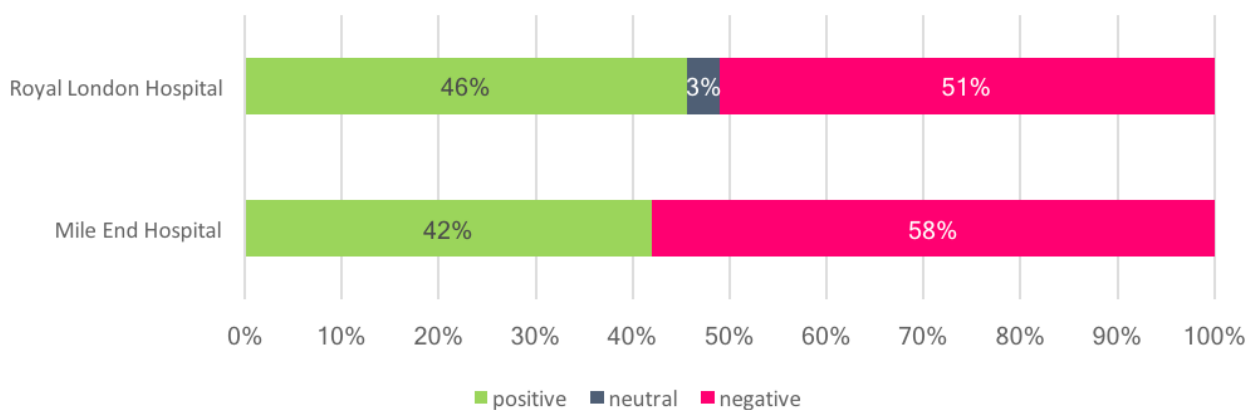
Whether people's social care needs stem from old age, frailty, disability, physical or mental illness, they are likely to also have extensive experience with healthcare services in the borough, including GPs, hospitals, and community-based services such as physiotherapy and chiropody.

According to the 2016 JSNA on Older People, 63% of older Tower Hamlets residents had a limiting long-term condition which limited their day-to-day activities "a little" (26%) or "a lot" (37.6%). A higher proportion (37.6%) of older residents had a long-term illness which limited day-to-day activities "a lot" compared to London and England.

Tower Hamlets is home to the Royal London Hospital, a large teaching hospital providing district general hospital services for the City and Tower Hamlets and specialist tertiary care services for patients from across London and elsewhere; as well as to the Mile End Hospital, which offers a variety of services relevant to older people and people with care needs, including cataract surgery, diabetic medicine, memory services, rheumatology and community services such as continence and chiropody.

As well as interviewing people about their experience with hospital services in the borough, in January 2018 we have conducted Enter and View visits in eight departments and wards of the Royal London Hospital, including 14E and 14F, the two wards dedicated to care of the elderly.

According to comments from 15 users of the Mile End Hospital and 65 users of the Royal London Hospital (collected in 2018, 2017 and 2016), opinion of both services is mixed.



Hospital services key findings

Many users with care needs are unsatisfied with the hospital transport service provided by the Royal London Hospital. At our January 19 visit, we have learned that out-patients using hospital transport to return home after medical appointments or treatments such as kidney dialysis may wait for over one hour to be picked up. Inpatients leaving the hospital may wait in excess of two hours. However, patients were broadly happy with the quality of the transport service.

Delays in transport can cause delays in receiving necessary treatments (such as dialysis) and have a knock-on effect on other appointments patients may have, such as with district nurses or carers, and generally make medical appointments more time-consuming than they need be.

- *We need to be ready for collection two hours before appointment and are normally collected on time. Typically waited up to one hour for return trip. (Group discussion, 3 patients, transport desk Enter and View)*
- *Dialysis is provided on “first come, first served” basis as equipment becomes available. Thus, delay in transport can result in additional delay waiting for the equipment. (Renal patient, transport desk Enter and View)*

Using hospital services as an out-patient can be a frustrating and time-consuming experience; service users often experience delays and cancellations, sometimes caused by administrative errors. Communication with the hospital about these issues is difficult.

- *[I’m on a waiting list for some operations] and I found out today that nothing was being reported.*

Yesterday I phoned them and couldn’t get through, there was nobody on the number I was given. There was nobody there, so I phoned again today, and they said that... well, I told them, they were going to put me on a list, as soon as they get the information, but they’re not getting the information. I’m waiting for the doctor to phone [about this]. (White British woman in her 70’s, focus group).

- *They called to give me a Saturday appointment for an ultrasound I had already done- I called them back to let them know, and they take you from pillar to post until I finally got to speak to them. They send out double appointments for the same thing in error- this happens a lot. The new SMS reminders are helpful though. (Indian woman in her 60’s, interview)*

Older people’s wards and acute care wards at the Royal London Hospital offer good care; people are mostly satisfied with the attitude of staff members and the quality of treatment.

Some people are discharged from hospital without a proper care plan in place. Additionally, some people felt that they were discharged too early, while they still needed hospital-based care; in some cases, this can lead to hospital re-admission.

- *I had deep vein thrombosis in my right leg, I was swollen like an elephant. I went into the Royal London - got no aftercare, no nothing. Now, I live alone, I’m elderly, you see, there are a lot of stairs in my house, it’s all stairs. Not a damn thing [was done to support me]. (White British woman in her 60’s, focus group)*

☺☺ *I was unwell over Christmas and my daughter brought me into A&E. They said my salt levels were very low. They thought it was viral. Gave me something for it and sent me away. Following Wednesday, I came back again. They kept me in for two days and then sent me home again. I still felt dizzy, but they said it was normal as your salt levels came back up. I came back in yesterday morning, they found an infection in my lungs and now they've confirmed I have pneumonia. (White British woman in her 70's, Enter and View)*

Some patients report not receiving follow-on appointments (possibly because of admin errors). People also face delays and difficulties in getting the care they need, because discharge summaries and other relevant paperwork are lost, incorrect, or received too late.

- ☺☺ *When you get out of hospital, and you need therapy... Right now, it's really hard to get an appointment for any kind of follow-up care after a hospital discharge where we are. You try to make an appointment and spend hours on the phone, so you just give up. There's a lot of breakdown with aftercare for this reason. (White British woman in her 60's, focus group)*
- ☺☺ *I had a bypass on the 8th of May 2017 at Barts Hospital. I was discharged on the 14th May. It will be nearly*

three weeks since the discharge that my GP and myself are waiting for the discharge summary. I have called several times to Barts Hospital each time I'm being transferred from one department to another. I would really appreciate if I can be helped in that respect so that I can receive the right treatment which is to follow after the surgery. (Cardiology patient, Patient Opinion review)

Hospital-based community services based at the Mile End Hospital, such as ARCaRe, physiotherapy or occupational therapy, play an important role in signposting and referring patients to further support, such as psychotherapy or home adaptations.

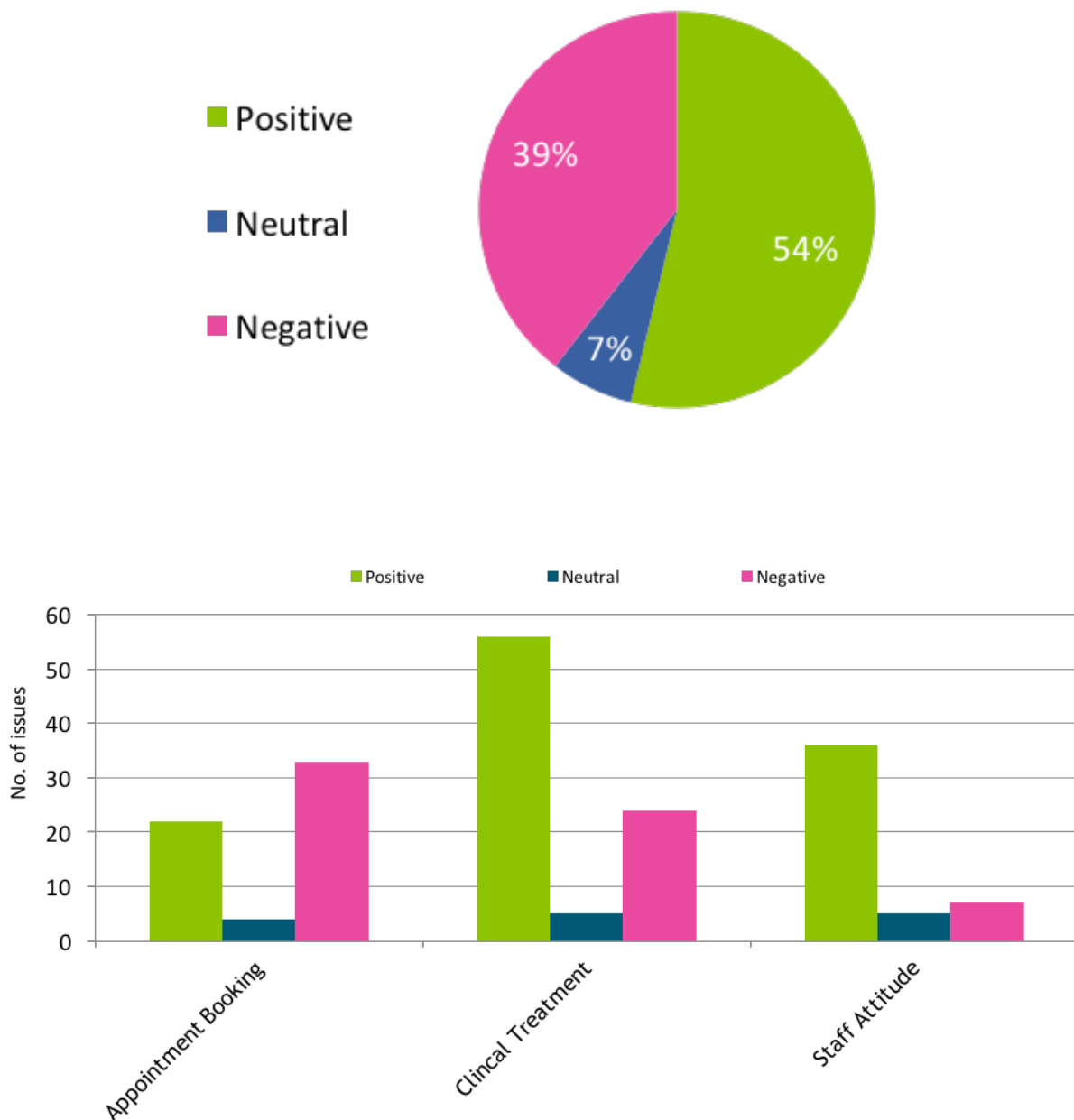
- ☺☺ *I went to see [the ARCaRe service] and they assessed me, they have their team of trained physios. I was so impressed. [After a breathing/ tai chi class] you have tea and biscuits, and someone gives a talk about healthy living. [At ARCaRe, if you take part in their activities] they ask if you need help at home. I had trouble getting in and out of the bath, so they gave me hand rails- so now I can get in and out easily. We were asked if we would like to speak to someone [about our mental well-being], so I got a wonderful psychologist straight through, without a waiting list. (White British woman in her 60's, interview).*



GP services

Based on comments from 86 elderly residents and residents with care needs, collected in 2018 and 2017, opinion of GP surgeries in the borough is leaning positive.

The opinion of users with care needs about GP surgeries is broadly similar to that of the general borough's population (as described in our GP reports). Service users with care needs were broadly happy with the quality of the treatment they received and the attitude of staff member, but attitude about appointment bookings is leaning negative.



GP services key findings

Continuity of care and developing a personal relation with GP surgery staff is particularly important for the elderly. According to some respondents, a GP who sees the same patients regularly and knows their medical history well is better empowered to identify their care needs and connect them with relevant community resources.

- *I have been at this surgery for over 70 years and seen many staff come and go. I am very happy with the doctors here. I have been seeing the same GP for some time now and they are really nice, I feel that I can talk to them openly and comfortably. The GP has helped me with my issues. I would definitely recommend this surgery. Overall I am just very happy and content with service and care that I receive from my Dr here. (NHS choices review)*
- *I was with the doctors at Brick Lane for 46 years, there was a lovely Asian doctor- I mean, he's not the original one but they got to know you. There were always lovely doctors, it was all terrific. (White British man in his 70's, focus group)*

GP surgeries don't always communicate efficiently with patients and local authorities around issues such as care assessments and disability benefits; for some people, this can make obtaining the care they need even more difficult.

- *They make a lot of admin errors; referrals often go missing. My dad has received some disparaging remarks from them. He had suffered a stroke and needed to get his medical history for his disability assessment- the receptionist said something like "Oh, it's just your benefits, it's not important"; so my dad lost his temper a bit and then they*

sent him a warning letter. They make it very difficult for people to access their medical records- they have a complicated, confusing policy- it's particularly difficult for people who are unwell. They make him stand a lot when he queues for his paperwork- they don't think to ask if he needs a seat or whether he isn't feeling too unwell to stand. (Son of disabled White British man, interview)

Some surgeries enforce an "only one issue per appointment" policy; in some cases, complicated by not being able to make more than one appointment in advance. This is particularly unpopular with service users with care needs, who typically suffer from various ailments and related co-morbidities. It has been suggested by multiple respondents that more flexibility around this issue could actually result in less pressure on GP services, as people would need to make less appointments.

- *Let patients talk about more than one issue, this will stop patients from making another appointment, doing this will probably free up a lot of appointments. (Bangladeshi woman in her 60's, interview)*
- *There's also a "rationing" of appointments going on. My dad has to have multiple routine appointments scheduled for his chronic conditions- but every time he has to make a new appointment, for an unrelated issue, they make him cancel the ones that he had scheduled before. (Son of disabled White British man, interview)*

When users with care needs experience delays, difficulties in booking or admin issues from GP surgeries, this can have a disruptive knock-on effect on their routine and make it more difficult for them to meet their needs. The same thing can happen when family carers make appointments to look after their own health.

- *My mother came [to the GP surgery] three times trying to make an appointment and each time she was turned back, it is a real struggle for her as my father (her husband) needs 24hr care and it is hard for her to leave her house to be turned back each time. (Daughter of Bangladeshi patient, interview).*
- *Appointment letters without contact number on them- admins mistakes can waste our time. (White British man in his 70's, focus group)*

Long waiting lists for appointment were also cause of concern:

- *I think GPs should be better organized by taking earlier appointments; especially for us elderly. It's hard to get an appointment-they should do something about it, because you don't know when you're going to be ill - and to wait for 2 weeks for an appointment when you're 82 years of age- you know what I mean? It's a bit much! (White British woman in her 80's, focus group)*

Efficient booking and triage systems make it easier for people to see their GPs, contributing to greater flexibility in care and preventing hospital admissions.

- *My GP is excellent. I like their booking and triage system- if you need to be seen on the same day it can happen- not with your own doctor, because your doctor may not be working that day... but any doctor. They also have a good call back system, so you can ask for a telephone appointment. Having been a doctor that's a good thing, I don't like wasting my colleagues' time. (Indian woman in her 60's, interview).*



District nurses/ healthcare at home

Only a small number of patients we spoke to directly received visits from district nurses or other health professionals.

When they did, the support they received was generally praised:

- [District nurses] were brilliant. [My husband] had a moisture lesion... A bedsore. They came with dressings and took care of it- at first several times a week, then less and less as it healed. They also took over from the Continence Service at Mile End Hospital when he became entirely housebound and unable to attend any longer. (Wife of dementia sufferer, interview).
- After my double hip replacement surgery, physiotherapists from Mile End Hospital came to my home to help me recover. They were excellent. They did a course in a modern hospital and found out how to do it properly. Everything they did was perfect. (White British woman in her 70's, focus group)

A few other patients mentioned receiving home visits from their GP. They were mostly happy with their experience.

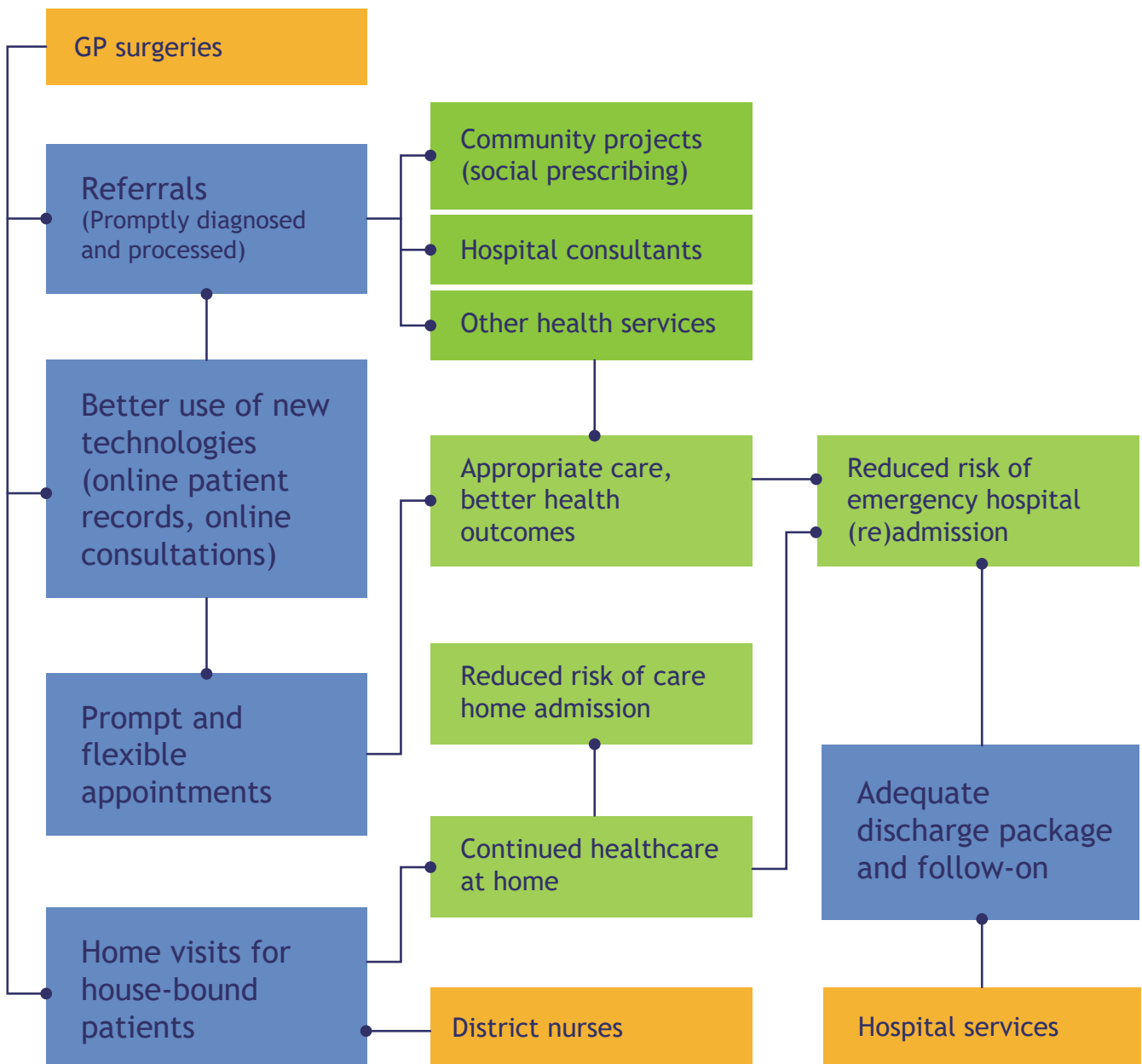
- Called yesterday for home visit for housebound grandmother, Dr swiftly called back, arranged visit 2 hrs later. Assessed my Gran, made good plan for any deterioration. Helpful, professional Dr. Very much appreciated (NHS Choices review)

On the other hand, several others, not currently receiving visits, pointed out that, while receiving personal care and domestic help is useful to them, they wish they could receive *certain forms of medical care* in their own home, which could prevent their state from worsening to the extent that they need a hospital admission. Lack of options for receiving medical care in one's own home means that older people with complex care needs are more likely to need to be admitted to a care home or nursing home.

- [My mother, in her 90's, dementia sufferer, receives care at home 3 times/ day, but] needs more medical care - daily monitoring of her blood pressure etc. I'd feel more confident if we maybe had the district nurse coming in once a week or every other day. I could cope if I had more medical support at home I think. She doesn't like taking pills and I think she would be better with injections. I try and phone the GP, but they are reticent to do home visits. The district nurse every other day would be good. Mum's confined to bed at home. Maybe if they could do a drip at home. Just hook her up and keep an eye on her there she wouldn't need to come into hospital so frequently. You get the personal care but not the clinical care at home. It would be good to have both. She was out for six days, discharged and then back in for six days. If it was planned better, I don't think she would've needed to come back in. (Son of White British woman in her 90's, Enter and View)

Availability, quality and flexibility of care received from hospital, GP and community health services have a knock-on effect (positive or negative) on users' overall access to care and quality of life.

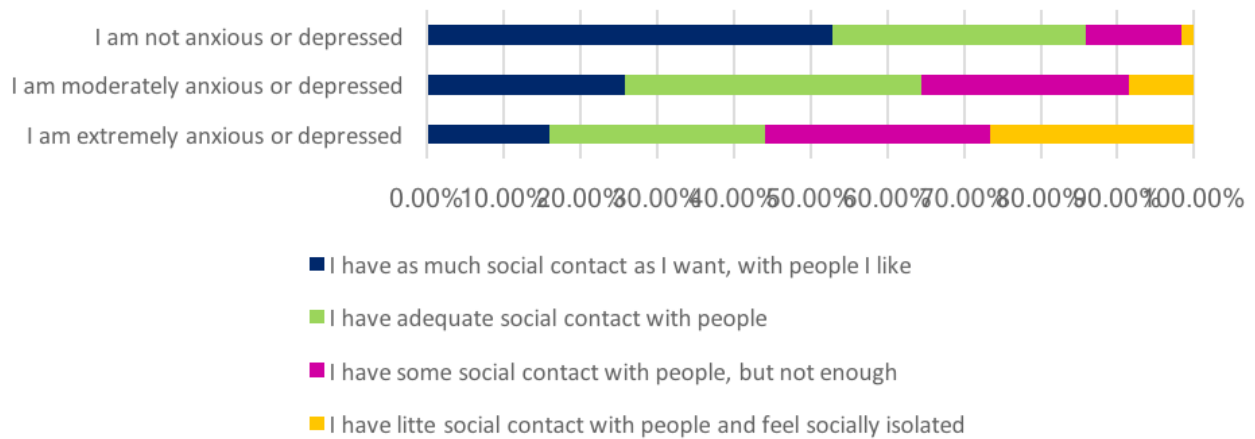
An integrated care system, in which services work well together, has the potential of reducing pressure on both primary care and hospital services; as well as supporting residents to achieve better health outcomes and remain independent for longer.



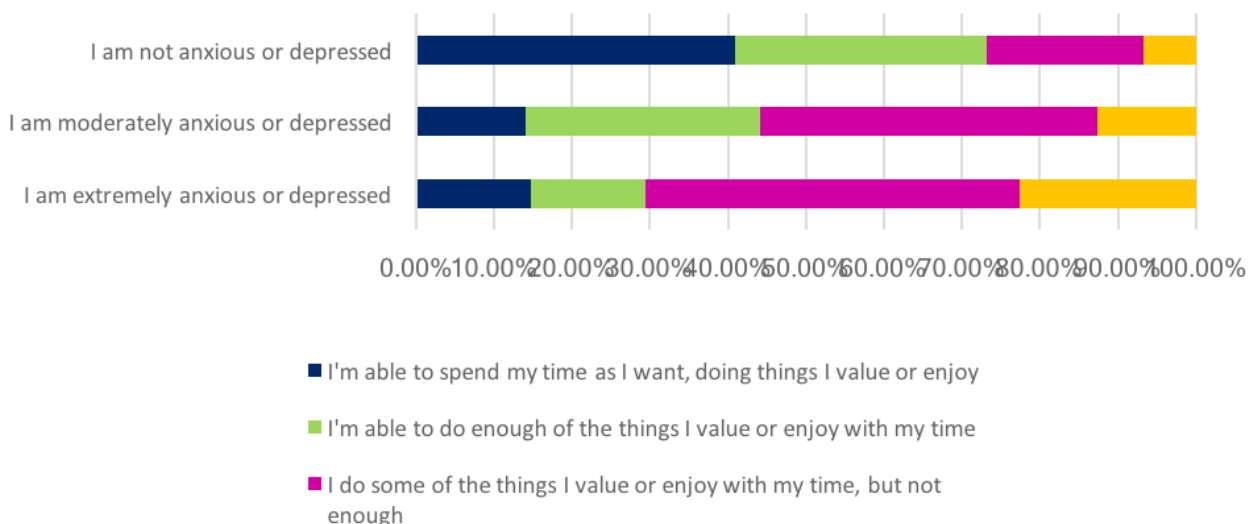
The mental health of people with care needs

According to the Tower Hamlets Adult Social Care Survey 2016, 58% of community social care users in Tower Hamlets report feeling either “moderately” or “extremely” anxious or depressed. According to the Tower Hamlets JSNA on Older People 2016, depression is estimated at 10-15% of the population (1,580-2,370) and severe depression is estimated at 3% (474). Approximately 11.4% of the Serious Mental Illness register is made up of people aged 65 and over.

Experiencing depression and anxiety is strongly associated with social isolation. 56% of Tower Hamlets Adult Social Care Survey respondents who describe themselves as “extremely anxious or depressed” state that they do not get enough social contact, compared with only 14% of those who do not consider themselves anxious or depressed.



Experiencing depression and anxiety is also strongly associated with reportedly not being able to spend time on things they value and enjoy. Over 70% of respondents who feel extremely anxious or depressed state that they don't get to spend enough of their time on things they value and enjoy, compared with only 26% of those who do not.



Only a few of the people that we have interviewed had used mental health services in the borough, whether community-based, hospital-based or through their GP surgeries.

In some cases, for people with low to moderate mental health needs, referral happened from one community service to another:

- “[I’m taking classes on breathing, balance and falls prevention with ARCaRe at the Mile End Hospital]. At the end of class, we were asked if we would like to speak to someone [about our mental well-being], so I got a wonderful psychologist straight through, without a waiting list. I went to see my psychologist and found myself in a room full of cheery people- they were all happy to work there and do things for other people- made me realise I haven’t experienced that kind of joy in a while. She helped me get over my rather weird reaction to doctors; and helped me understand what my triggers were for getting upset- it helped a lot”. (White British woman in her 60’s, interview).
- “My diabetes support group referred me to therapy. I didn’t find it all that helpful. I find psychologists very intruding- what would help me more when I’m feeling down is talking to a few good friends. From my point of view, a befriending service would do more for my mental health than actual therapy, but they don’t offer much support for that. (Indian woman in her 60’s, interview).

Other respondents mentioned GPs as having the responsibility for identifying and supporting people who may have mental health needs. They also expressed concern with medication for mental health being over-prescribed, when therapy, social prescribing or other types of intervention may be more suitable.

- GPs should do health checks more often, not just once in a couple of years, that way they can notice mental health issues too. Every six months maybe. -I heard something on the radio about how important it is to catch and diagnose mental health issues sooner- make a plan to do that. Some people who are only slightly unwell can get better before they get worse. (Group discussion, focus group).
- I think doctors overprescribe [medication for mental health] because it’s easy for them to do it than to put them in touch with services that can talk to them, talk their problems through, whatever. It’s far easier to just write a prescription and go “Pffftttt...” [Makes dismissive gesture] (White British woman in her 70’s, focus group).



Active lifestyles and combatting loneliness

Most people we spoke to were relatively active seniors, who take part in various hobbies and activities in the community. Participants to our five focus groups and our Locality Event generally agreed that Tower Hamlets is a borough where a lot of entertainment and socialising options are available for those interested.

Socialising:



Hobbies:



Entertainment:



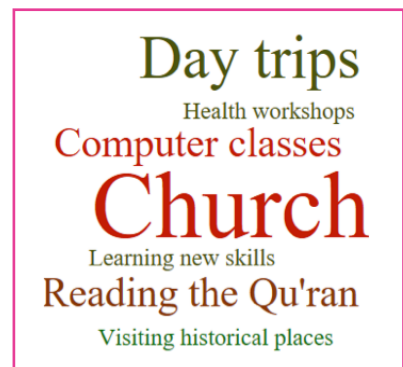
Physical activity:



Volunteering:



Other:



Active lifestyles key findings

The top activities named as things they enjoyed doing in their free time were reading, watching TV, walking (alone or in groups) and taking part in activities in local community centres. They also took part in befriending activities.

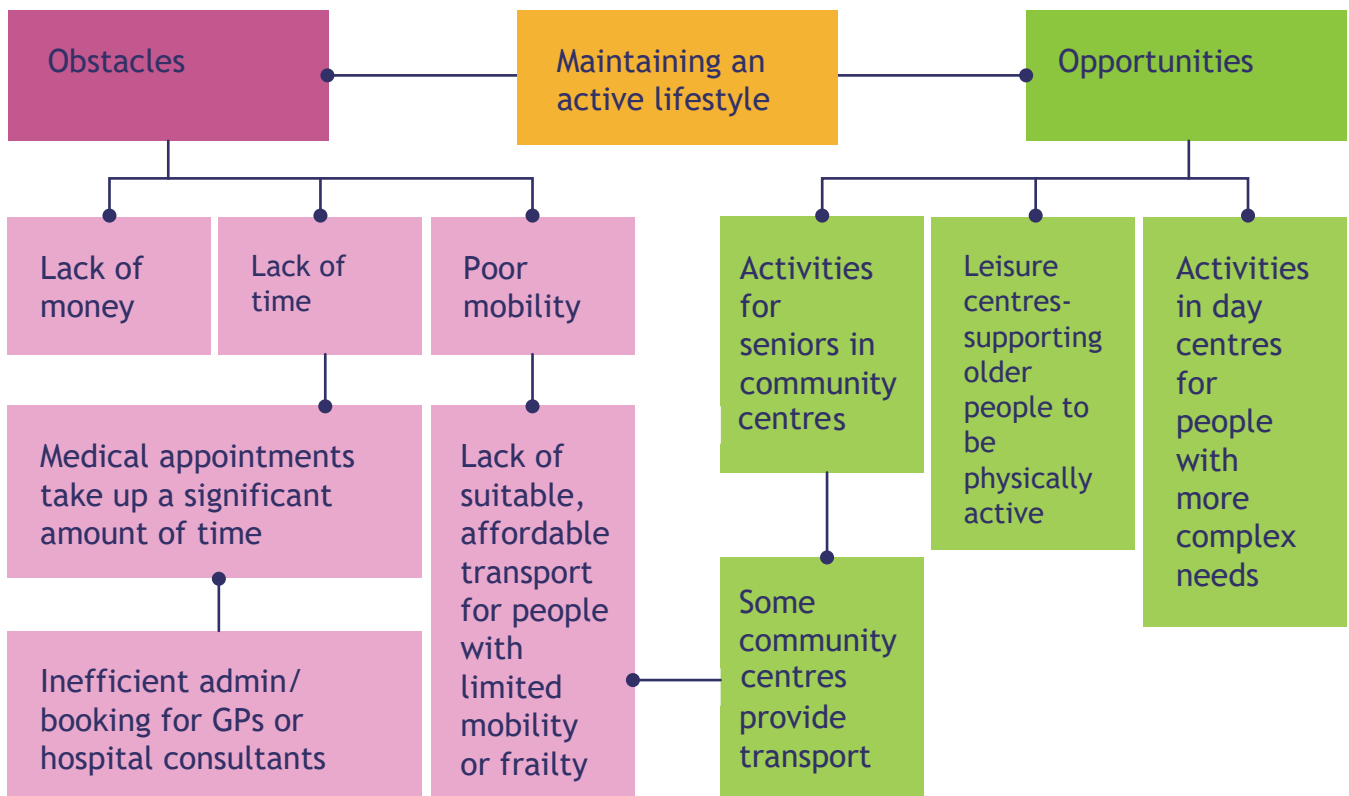
In terms of obstacles to doing more of the things they enjoy, service users mention health and mobility issues, as well as time and financial constraints. Lack of affordable, appropriate transport is a problem for people with mobility issues.

- *I used to enjoy fishing, I can't do this right now because I am wheelchair-bound (White British man in his 80's, interview)*
- *I wish I could read more, but I have bad eyesight. What would help me? New eyes! (White British woman in her 70's, focus group)*

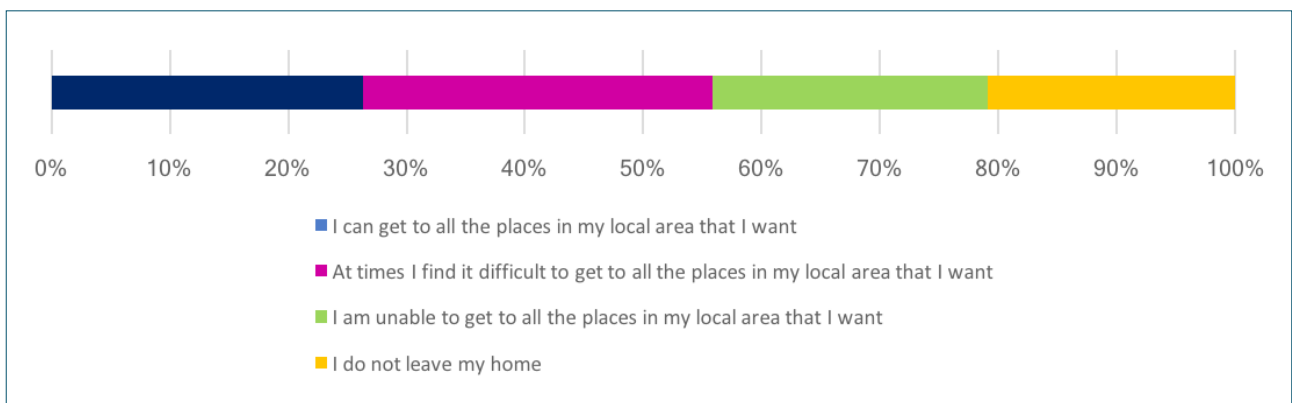
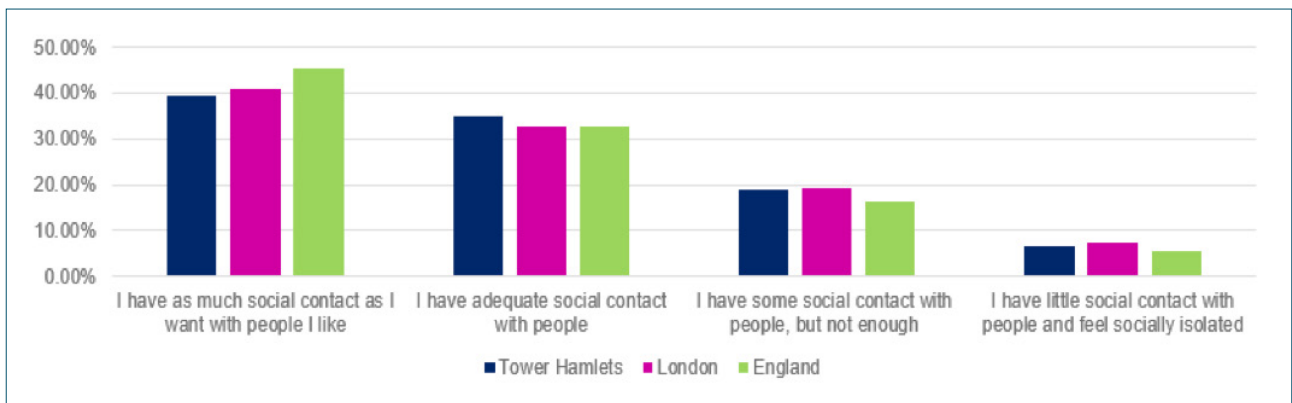
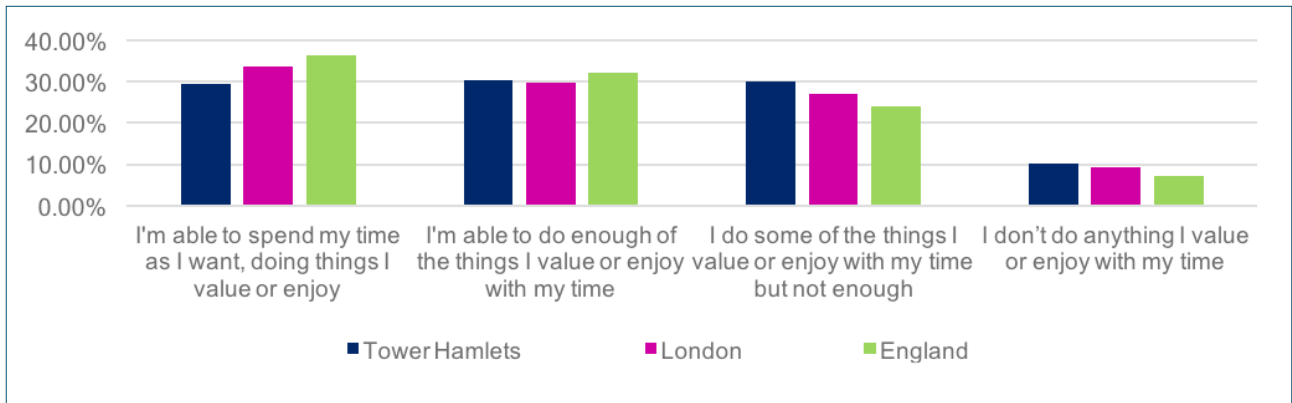
- *It is expensive to travel when we need to take taxis everywhere, they got more expensive nowadays, we can't afford to go out to events. (Group discussion, focus group).*

Several service users pointed out that looking after their health is a particularly time-consuming task, partly because booking healthcare appointments (with GPs, hospital consultants or community health services) can be inefficient.

- *Most people have regular medical appointments (GP, hospital etc.) and they want to keep it because there is a long wait time between referral and appointment and long wait in the waiting area. Some of the time you have to wait for unreasonable amounts of time. (White British woman in her 60's, focus group)*



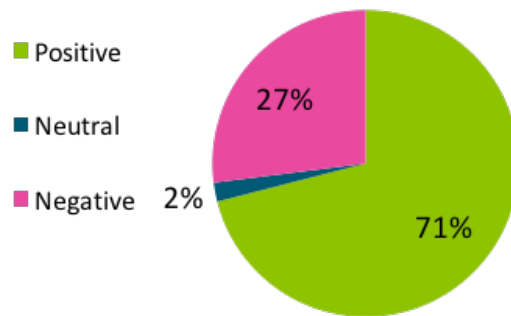
According to the Tower Hamlets Adult Social Care Survey 2016, 60% of Tower Hamlets care users find that they are able to do at least enough of the things that they enjoy or value with their time. This is below England averages and slightly below London averages. Levels of social isolation are broadly in line with London averages, and indicative of an urban borough. 20% of survey respondents were entirely home-bound and less than 30% say that they are able to get to all the places in their local area that they want.



Community centres, organisations and day centres

Overall, opinion of community centres/ organisations and day centres is broadly positive. They are seen by residents as an important community resource.

13 residents gave feedback on community centres/ organisations and day centres



For active seniors, community centres offer a wide range of activities to keep them active and offer socialising opportunities.

- *Sonali Gardens Day Centre- Very good, mostly yoga, watch movie and enjoy together. Everything is fine there. (Pakistani woman in her 60's, interview).*
- *[I come here] nearly every day. I feel there's plenty going on, you have to go out and do it... [In the St Mathias Community centre] we have bingo, sing song, dancing, arts... There are nice meals, social things... Most of it is accessible to everyone; if you don't like exercising, you can have a chat, play bingo, there's painting here... (White British woman in her 70's, focus group)*

For service users with limited literacy, or those who are unable to speak English, community centres provide important assistance with accessing health and social care services; as well as offering older people the opportunity to socialise with others who speak their own language and are from a similar culture.

- *I can't read and write, I never learned to. I never went to school. I can read a little bit now but I can't write, I can't spell. Sister C. from the community centre (Neighbours in Poplar) supports me with talking to authorities and finding out what's available for me. (Indian woman in her 60's, focus group).*

- *At the moment I'm still able to manage, but I will be looking [for home care services] in the future. I have no idea [what is available], I depend on the Community of Refugees from Vietnam for advice [because I don't speak English].” (Vietnamese woman in her 70's, interview).*

For service users with high needs (such as severe dementia) day centres play a crucial role in combatting isolation and loneliness, as well as offering carers a certain degree of respite.

- *Russia Lane Day Centre- They're brilliant- they offer a home away from home! They are a willing to take everyone, with any kind of dementia- they are willing to accommodate everyone. Activities- they have painting, cooking, baking, gardening, arts and crafts, bingo, a snooker table... Anything you can think of. People with dementia are definitely at risk of isolation- it would have been awfully boring for both my husband and myself if it us just us at home. I don't have activity planner skills; I wouldn't know how to keep him occupied for the whole day. Having a team of people who know how to design activities specifically for people with dementia is a great idea. (Wife and carer of dementia patient, interview).*

Only a small number of people have been dissatisfied with the services provided by community centres. A minority of service users report that people of different backgrounds and ages do not necessarily socialise together, and that activities are not always inclusive.

- I did try to go to lunch clubs in community centres, but parking is awful, plus I found them very clique-y, each in their own little group- the Somali hang out with their own, the Bangladeshi hang out with their own- they don't promote multicultural. I tried offering my assistance as a volunteer, but they never got back to me. (Indian woman in her 60's, interview)
- Over 50's group- they're mostly over 60's really. Many play bingo, there used to be a painting group, they tried starting a dancing and exercise group... It was stupid, because three quarters of the people coming are too old to do any of that. (White British woman in her 70's, focus group).

In certain cases (particularly day centres for users with more complex needs, as opposed to community centres activities for active seniors with low care needs), eligibility criteria or high costs can make activities less accessible:

- For some community centres/ day centres, you can only go if you are assessed and receive a grant, otherwise they won't take you. (Group discussion, focus group).
- Some people [with advanced dementia or special needs] have trouble finding a day centre that would take them (Wife and carer of dementia patient, interview).

Community centres and day centres have also been affected by budget cuts. Services such as transport for users and certain activities have been cut once funding ran out, leaving them less accessible to the public.

- I used to attend a community centre, they provided transport to and from activities, but they stopped that too. (Black African man in his 60's, focus group)



Social isolation and loneliness

According to the Tower Hamlets ‘Loneliness and Isolation in Older People’ JSNA Factsheet 2016:

“A national study of ageing among persons aged 52+ reported a prevalence rate of feeling lonely ‘often’ (chronic loneliness) as 9%, with reported loneliness being highest among those aged 80+ at 17%. [...] Yet, research has estimated rates of chronic loneliness to be far higher in inner city boroughs (16%). Given the characteristics of the Tower Hamlets population and levels of deprivation rates of loneliness are likely to reflect this higher rate of 16%, which would equate to approximately 2,560 persons. It is important to consider that this figure excludes those who are lonely some of the time. A model that estimates subjective loneliness at borough, middle and lower super output areas, ranks Tower Hamlets as 1 out of 33 for London and 1 out of 326 for England, meaning that persons aged over 65 living in Tower Hamlets are predicted to be among the loneliest in both London and England.”

Adequate services (including care at home and community centres/ day centres) can give people access to social activities and do more of the things that they enjoy. Lack of care at home, or poor-quality care, on the other hand, is related to isolation and loneliness.”

Only a small number of our service users shared with us personal experiences of loneliness and isolation; mentioning friends who passed away or general societal changes.

● I feel lonely nowadays, because I’ve always been an activist, I’m used to being with people. Now I sit down, and I think about the work that I used to do in my youth back in South Africa- and I feel lonely. Before, people used to have open doors, remember? The old days... That is gone, so I do get a little bit lonely. But I always like

to come down and chat with my neighbours here- that fills in the gaps. (Black African man in his 60’s, focus group)

I’m quite old, so many of my friends are no longer alive. I only have some friends at the community centre; so, I do feel lonely sometimes. I just watch TV at home, I have nothing to do; with my health I’m worried about travelling long distance. I really don’t know [what communities could do to tackle loneliness], at my age... I’m over 90! Family members should stay together; my children are now retired, so they should make time”. (Vietnamese man in his 90’s, interview).

A lot more people mentioned that, while not having experienced loneliness themselves, they were aware of other lonely people, or of loneliness and isolation as a general problem in the community.

● People who socialize with their neighbours in the building [sheltered accommodation for seniors] tend to always be the same, others don’t want to get involved. There are people who don’t want to come down and interact. It’s their attitude, some people just don’t bother. It’s a sad situation, we try to draw them in, but they don’t respond. We had a guy who died... His body wasn’t found for two weeks. (Group discussion, focus group)

Social isolation and loneliness key findings

Lack of adequate social care can be an important contributing factor in isolating people with care needs; several of the people we spoke to felt that, with better support, they could feel less lonely.

- *My father in law used to go to a gardening project in Mile End Hospital- a minicab took him and dropped him off. Now he can't, he's been too ill. If a carer took him in a wheelchair, with some assistance he could still do it- but a service like this is just not available. He can only rarely see friends and family His care worker provides no personal care, no shopping- nothing like that. I think he feels lonely and isolated. (Son in law and carer of Bengali dementia sufferer in his 80's, interview)*
- *My family members look after me, no carer. I cannot pursue any hobbies. I may need a walking frame and there are hazards such as stairs in my home, I may also require stair lifts. We should have better access to basic healthcare.” (White British man in his 80's, interview)*

In terms of key actors for tackling social loneliness, service users have identified community centres, informal groups, faith groups, befrienders, as well as professional carers, local authorities and health providers.

Community centres and day centres offer structured or semi-structured social time, educational, health-promoting or leisure activities. Many of the service users we spoke to considered them crucial in combatting loneliness, especially since for older people with no close family members

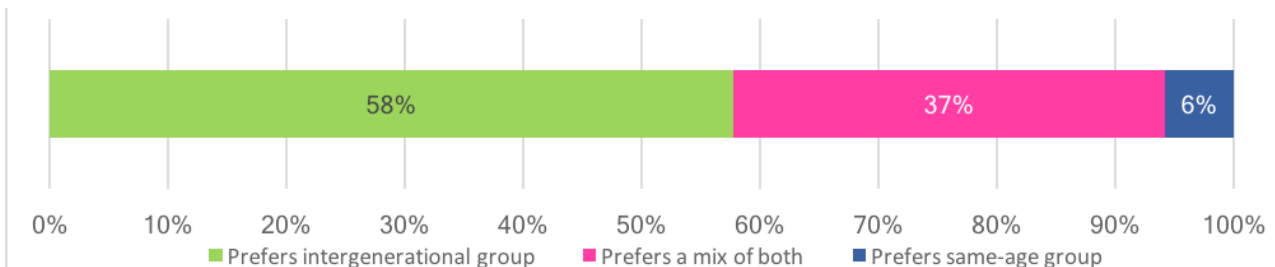
or friends living nearby, they may offer the primary form of socialisation available to them.

- *Some of us only see people when they come to these clubs- they have no one else. Our neighbourhood is changing, our old neighbours are dead or have moved; so, the Community Centre offers us something to do. Otherwise you don't see your neighbours like you used to. (Group discussion, focus group).*
 - *At home, I'm always alone. I feel lonely. I like coming to the day centre to talk to others. (Disabled Bengali woman in her 40's, interview)*
- Some, but not all community centres provide transport. Multiple residents have expressed the view that professional carers should support service users with attending community centres and activities, by helping with transport, informing their clients of socialising opportunities, as well as through more informal support and encouragement.
- *Carers should engage more and provide more services based on physical and social activities such as trips, visits to farms, beach etc (Bengali woman in her 60's, interview)*

Befriending schemes have also been suggested as a solution for combatting loneliness; some of our responders were actively involved in befriending schemes.

- A befriender with similar interest could help [people who are house-bound, or who don't particularly like what local community centres offer.] Culture/ language-based befriending would also be useful for isolated people who are not fluent in English. (Group discussion, locality event).

- *A lot of older people wouldn't want to have children running around. I prefer being with people my own age. People of my own age can understand it more- we've been through all, from being young, having kids... We've had similar experiences. But kids can help too... The Scouts used to come around. They were young boys and girls, but they were brilliant. Lovely people, they made you laugh, they were great. You don't see enough of that. (White British woman in her 70's, focus group)*

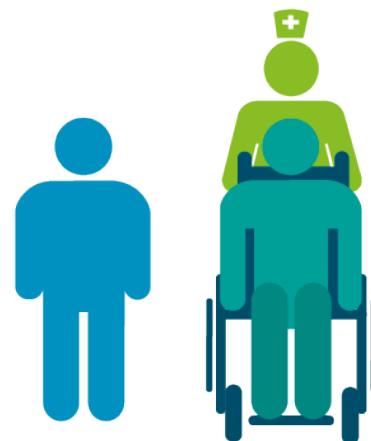


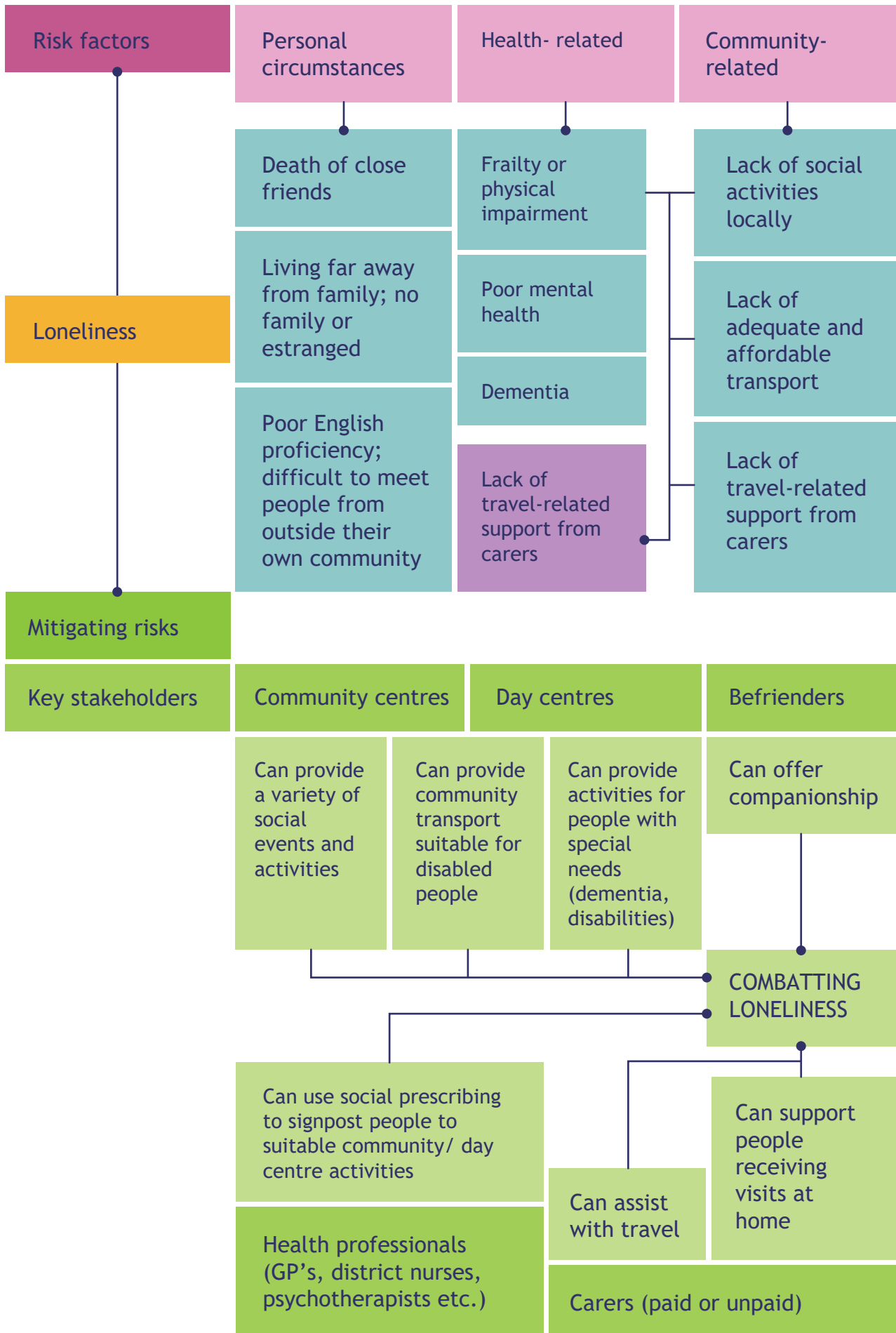
Intergenerational befriending and activities were viewed particularly favourably by respondents. Most of the participants to our locality event and focus groups expressed a preference for intergenerational activities over activities targeted exclusively at one age group.

- *[Intergenerational is better because] families are mixed-age groups (White British woman in her 70's, focus group)*
- *Intergenerational befriending would also give older people the opportunity to make a difference in their community by passing on their knowledge and experience to the younger generation. (Group discussion, locality event)*
- *Intergenerational befriending is nice, but not all the time. Definitely want to interact with the younger generation, so we can learn more; but sometimes you want to be among your own age. (Group discussion, focus group).*

Healthcare providers and social services were also thought of as potentially able to identify and support people at risk of isolation:

- *GP surgeries can help in that direction- some offer a space where you can just have a cup of tea and talk to someone. (Group discussion, focus group)*





What we have learned

We have encountered both positive and negative experiences of people's experience with healthcare and social care services.

- Our respondents tended to be broadly satisfied with the quality of medical care they received from GPs, hospitals and community health services, but found booking appointments with GPs, hospital consultants or community clinics a frustrating, time-consuming experience. Services were perceived as busy and over-stretched and under pressure.
 - Those who spent time in hospital as inpatients, whether in older people's wards or otherwise, were happy with the care they received and the attitude of staff members, whom they described as kind and dedicated, but many reported dealing with very poor follow-on after discharge or being discharged without an appropriate care plan to help them manage.
 - Those who received adaptations to their home or mobility aids through the NHS or local social services found them useful, and most of those receiving care at home had overall positive feedback about their carers as individuals; but many felt unsupported by social services and care agencies. Those who had had negative experiences with their care workers felt that social services and care agencies fail to keep carers accountable for providing adequate care.
 - Many people had limited knowledge of any social care options and resources available in the borough (including domiciliary care, home adaptations, occupational therapy or day centres).
 - The care assessment process was, for many users, a difficult bureaucratic process that some perceived as unfriendly and adversarial. Their perception was that social services, under pressure from austerity cuts, only want to give them as little care as they can get away with.
 - Community centres, day centres and befriending schemes were seen as a crucial resource for combatting loneliness and isolation in people with care needs; but some service users found them difficult to access, because services such as community transport or certain activities had become unavailable because of funding cuts.
 - Many of the people that we interviewed were active seniors, with a relatively good quality of life and involved in their community; however, they were overwhelmingly pessimistic regarding the ability of Social Services to provide the care that they may need in the future. Some of them had already been affected by cuts to public services, and the majority expected things to get worse in the future.
- More importantly, none of these aspects happen in a social vacuum. The extent to which services collaborate with each other and have a knock-on effect on each other (positive or negative) can have a great impact on the outcomes that service users achieve and the kind of life they are empowered to live.**



Integrated care and social prescribing

What do we mean ?

Integrated care happens when NHS organisations work together to meet the needs of their local population. Some forms of integrated care involve local authorities and the third sector in working towards these objectives alongside NHS organisations. The most ambitious forms of integrated care aim to improve population health by tackling the causes of illness and the wider determinants of health.

Tower Hamlets Together is a Tower Hamlets-based example of an integrated care partnership, between Tower Hamlets Council, Tower Hamlets GP Care Group, Tower Hamlets Clinical Commissioning Group (CCG), East London Foundation Trust, Barts NHS Trust and the Council for Voluntary Service. One of their goals is improving health and wellbeing amongst adults, particularly those with a long-term condition or who are vulnerable to illness, by promoting measures such as having a single point of contact for all care needs, reducing duplication across services, improving the way information is shared between those providing care, and improving awareness of/ access to health, social care and wellbeing support.

Social prescribing, sometimes referred to as community referral, is a means of enabling GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services. Social prescribing schemes can involve a variety of activities which are typically provided by voluntary and community sector organisations. Examples include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of sports.

***The Bromley by Bow Centre, based in Tower Hamlets,** is one of the oldest and best-known social prescribing projects. Staff at the Centre work with patients, often over several sessions, to help them get involved in more than 30 local services ranging from swimming lessons to legal advice.*

Engaging with a variety of respondents as part of our research project, we have found that service users were very interested in and supportive of a more integrated care system, making more use of social prescribing.

66

“We aren’t worried specifically about getting a carer, but it shouldn’t be the way it is now, [social care] should blend in naturally. Rather than us having to worry about getting a carer, this should happen automatically, through GPs and other health professionals who see us, if God forbid we deteriorate, as we go older- in the future, I would say we should be able to go from here to there without worrying.”

White British man in his 70’s, focus group

3 Source: <https://www.kingsfund.org.uk/publications/making-sense-integrated-care-systems>

4 Source: <https://www.kingsfund.org.uk/publications/social-prescribing>

Better integration and prescribing could have a strong positive impact on the health and well-being outcomes of residents with care needs, as well as reduce pressure on the core services such as GPs, hospitals and domiciliary care services. On the other hand, lack of integration and communication between services leads to poorer outcomes for patients, which in turn lead to less efficient use of services.

The extent to which adults with care needs achieved a good level of happiness and well-being, and the extent to which they felt supported to live the life they wanted was strongly related to their individual experiences with care providers, including professional carers and care agencies, social care services and the NHS.

Those who had a broadly positive experience, receiving flexible, person-centred care, were better empowered to take part in activities they enjoyed than those whose carers were less able to offer them a degree of flexibility. (For instance: a Vietnamese service user suffering from urinary incontinence received personal care and help with washing every morning, then travelled to a community centre lunch club, where he socialised with his peers and ate food that he enjoyed more than what carers could have prepared. Everyday support from carers made it possible for him to do things that he enjoyed, despite his conditions. In contrast, a wheelchair-bound but otherwise active woman mentioned having to choose at times between attending community events and receiving help with basic necessities such as cleaning and shopping, because her carer cannot offer her a more flexible schedule).

For example, in an efficient, well-integrated care system, a GP identifies an elderly patient living alone and making appointments often as being at risk of isolation and loneliness, and signposts her to a local community centre, for activities including befriending, gentle exercise and healthy eating workshops.

The GP also refers the patient to a community physiotherapy service and a falls prevention class. The physiotherapist asks the patient about the difficulties she experiences at home and learns that she has trouble getting in and out of the bath; so, they refer her to a service that can provide her with the handrails she needs.

As years go by, her mobility deteriorates further, but she continues to regularly attend activities at the community centre, which provides transport. Through a programme funded by the local authority, she gets a free tablet and internet access. She takes an IT class tailored for older people's needs and learns the basic of using the tablet; which allows her to keep in closer touch with her children, who live abroad, as well as to find out about other activities and support available locally.

As she now needs regular help in her daily life, the community centre and her GP provide her with information about getting a care assessment; with help from workers at the community centre, she is able to make an application for a care assessment and receives a flexible care plan (for example, through personal independence payments). Her GP surgery allows her and her children to access her medical records online; which, in turn makes it easier for her to request adjustments to her care plan from social workers. She also takes advantage of online consultations and GP home visits when needed.

In a less functional, less integrated system, the same patient spends a lot of time looking after her health; and not much time doing anything else.

She finds that booking appointments for her GP surgery takes a long time, and she finds the doctors rather dismissive, but she does not know what to do about it. Sometimes, the GP is the only person she gets to speak to the entire day. She feels increasingly lonely and isolated, and her mental health also deteriorates. Eventually, she finds out that a community centre exists in her area, but without encouragement she feels too apathetic to bother going; besides, with her worsening mobility issues, she finds it hard to travel there by public transport.

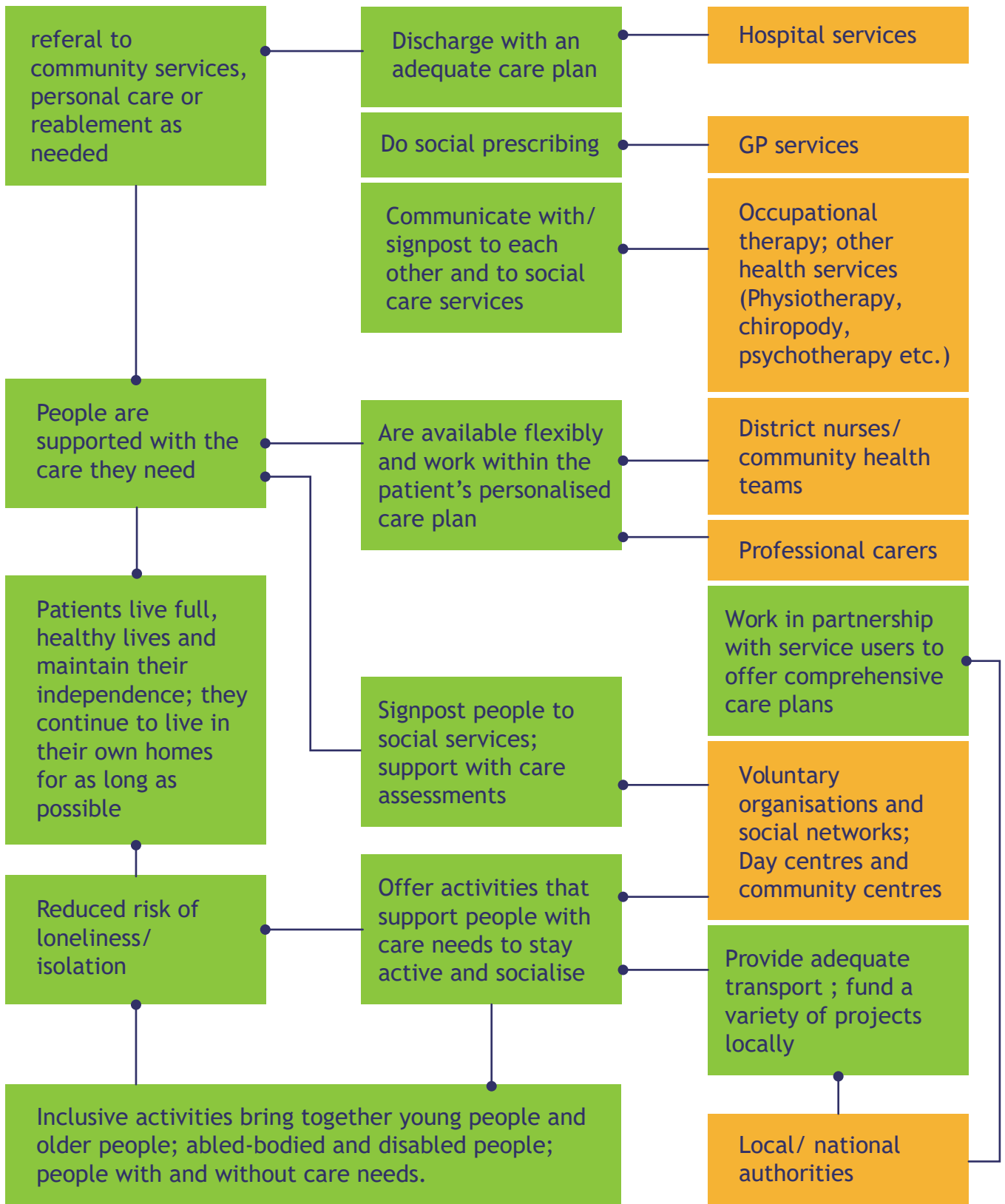
Her worsening health (made even worse by difficulties in getting an appointment with her GP and difficulties travelling to the GP surgery) leads to a hospital admission. Discharged without a care package in place, she is re-admitted two days later. As she is not computer-literate and cannot afford internet access, she does not know how to find out more about managing her chronic conditions or available social support; and her hospital consultants provide her with no such resources upon discharge. When she eventually gets a care plan, after a long care assessment process, she finds that her carer cannot do many of the things that she needs and fails to even perform the full extent of duties specified in her care plan. She would like to complain, but does not know how, or finds communication with social services difficult. While she is referred to a day centre, she finds it impractical to go, because she needs to wait at home for her carer instead; and the care agency cannot accommodate changes of

schedule. Her loneliness worsens, and she becomes entirely house-bound.

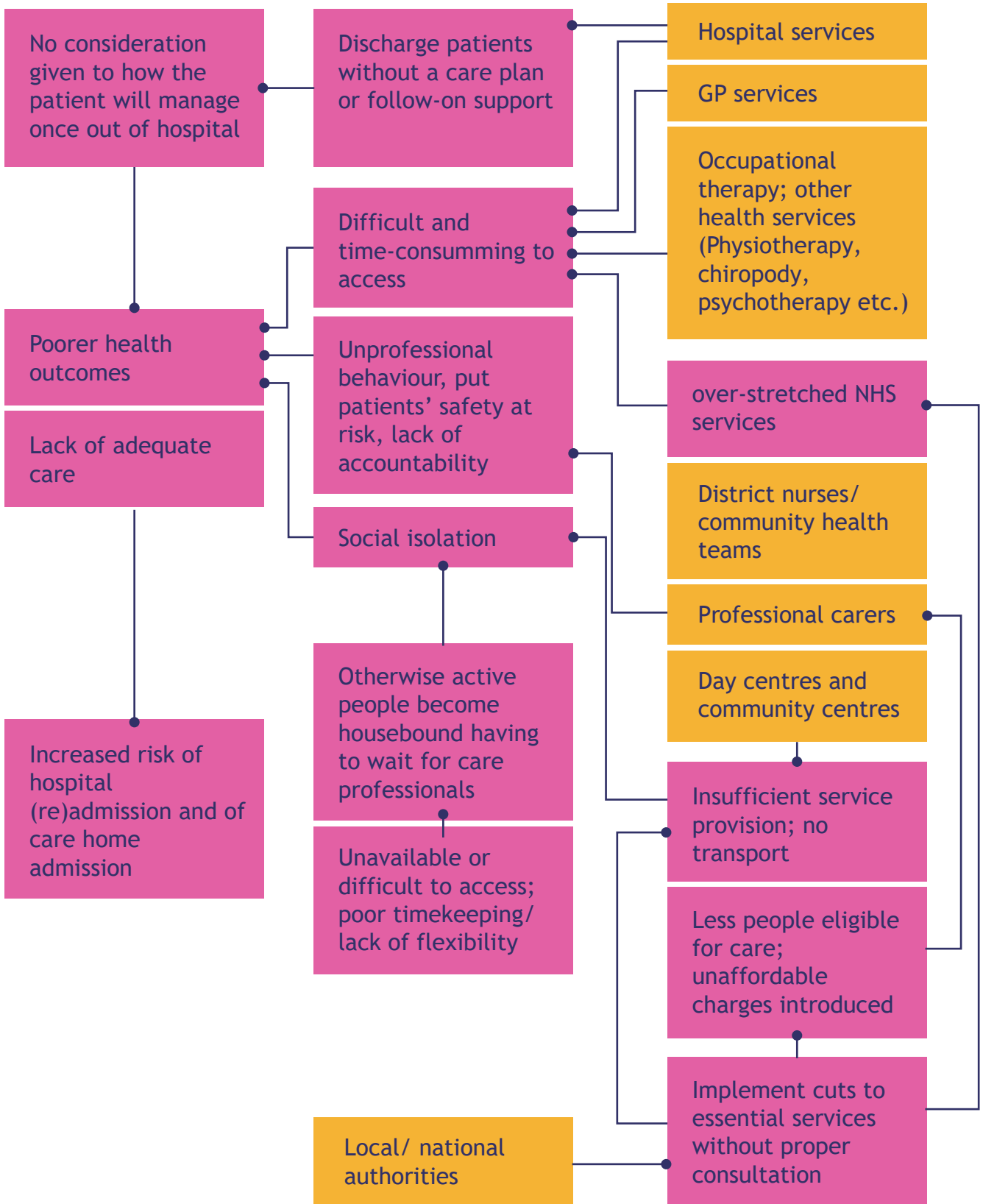
As time goes by and her health deteriorates even further, she now needs medical care regularly. Her GP does not do home visits, and it is difficult to get support from district nurses. After spending months in an older people's hospital ward, she finds that the only way to get the constant care she needs is to spend the last years of her life in a care home.



When services work well with each other



when services don't work well enough with each other



Recommendations

The findings of our report highlight the need for a person-centred, integrated care system, in which the service user is empowered to work in partnership with all care providers (including healthcare providers such as hospitals and GPs, social services, care agencies, but also community organisations, community centres and informal social groups) in order to obtain the best outcomes for themselves and live the best life they are able to within the limitations of their condition, disability or age.



Social Care Services and care agencies recommendations

- Focus on recovery and preventative care, including reablement, occupational therapy and use of assistive technologies, to support people maintaining their independence within their own home for as long as possible.
- Conduct care assessments from a person-centred perspective, taking into account comprehensively the service user's needs and resources. Anticipate, as part of the care assessment process, how the user's needs may change in the future, and inform/ signpost them to relevant resources ahead of time.
- Establish rapport with service users in such a way that a care assessment/ agreeing on a care plan is seen on both sides as a collaborative process rather than an adversarial one or a tick-box exercise.
- Develop stronger links with the Tower Hamlets Carers' Strategy in order to improve services for family/ unpaid carers; offer more respite care for people with complex needs depending primarily on a family carer.
- Allow service users more flexibility in relation to their care schedule; allow them to re-allocate hours of care more easily.
- Allow service users and third parties they specifically authorise (such as family members) to access their care plan and request adjustments or re-allocations online.

GP surgeries recommendations

- Consider introducing shared appointments, Care Condition Groups and Clinics for older people and other

groups of people with similar care needs, operating on a similar model with Baby Clinics. These groups could be led by nurse practitioners with support from healthcare assistants and could function as "information hubs" on topics around self-care, accessing social care services and community health services, as well as offering people with care needs a mutual support network.

- Invite guests such as social care advisors, health trainers and occupational therapists to attend these Care Condition Groups to provide support and disseminate information.
- Through Care Condition Groups and patient groups, train older people, as well as family members and other carers, to make use of information technology and services such as online consultations, appointment booking and NHS information sources and introduce them to assistive technology options in the future.
- As much as possible, offer home visits to patients who are temporarily or permanently house-bound.
- Identify patients at risk of loneliness and isolation and signpost them to resources such as volunteering, befriending services, community centres or day centres. Better information sharing between locum GPs can help in this respect, through ensuring all doctors seeing a particular patient have access to the same information and can recognise patterns indicative of loneliness.
- Reduce the need for admin and paperwork (such as certifications for disability assessments) by offering patients (and other parties specifically authorised by patients, such as family members) online access to all their medical records; allowing them to print statements for care assessments as needed or to place requests for specific necessary paperwork online.

Hospital recommendations

- Upon discharge, carry out a comprehensive needs assessment, to make sure patients are empowered to continue their care in the community. Based on the results of the needs assessment:
- Offer self-care/ self-management information;
- Signpost to peer support groups around managing chronic conditions and resources offered by voluntary sector organisations (for example, Macmillan for a cancer patient).
- Refer to community services such as physiotherapy, ARCaRe, occupational therapy etc;
- Refer to social services for social care provision (including domiciliary care, home adaptations or assistive technologies);
- Offer a bespoke care package, which may include continuing care at home or in the community.

Other health services recommendations

(ex: district nurses, chiropody clinics, physiotherapists, psychotherapists etc.)

- As much as possible, offer home visits to house-bound patients; or, where feasible, consider alternatives such as online consultations.
- Proactively identify patients' needs and signpost/ refer between community health services as needed.

Voluntary sector organisations and community centres

- Improve older people's access to IT and new technologies, by offering bespoke training focusing on technology use for

health and care management, as well as subsidised tablets and WiFi.

- Provide alternatives to the current offer of "activities for older people", by offering a more diverse selection of clubs and activities for the entire community; bringing people together based on common interests rather than age group (ex: intergenerational befriending, community walking and exercising campaigns targeting people of all ages, hobby groups etc.)
- Encourage older people to take part, along with other age groups, to activities outside of the usual community centre or day centre setting.
- Encourage people in their 50's and 60's to take part in befriending schemes and other forms of volunteering to support older people with more complex needs.
- Support people to apply for care assessments with the local council and disseminate information about resources available to them, particularly with groups who would have difficulties accessing information otherwise (ex: older people with no IT literacy or access; ethnic minorities speaking limited English etc.)
- Organise events and activities (information sessions, hobby groups, intergenerational befriending and local history projects etc.) in sheltered accommodation schemes, for people who would have difficulty travelling elsewhere.
- Follow the Aging Well Strategy proposal regarding providing transport to community centres and other activities for seniors; considering making use of school vans at times when they are not in use for their primary purpose.

Tower Hamlets Together recommendations

With the development of new housing and the redevelopment of community assets in the Borough we should be looking at the establishment of integrated Health and Wellbeing Centres that co-locate the Tower Hamlets Together services particularly for older people or those with complex care needs. This could include general, medical and nursing, therapy, specialist and social care services with supporting information and advice systems and voluntary and carer support services. With a key space for community organisations and activities they could also potentially sit alongside community centres, day centres, supported housing and care homes allowing people to develop and maintain strong community and social networks throughout their old age. Only people requiring highly specialist diagnostic equipment or acute hospital facilities would need to be transported out of their local area addressing some of the key transport issues.

We have engaged and discussed the preliminary findings of this report with members of the Tower Hamlets Older People's Reference Group

The Tower Hamlets Older People's Reference Group is a forum organised by Age UK East London, which aims to promote the engagement of older people in the design and delivery of NHS and the local authority services intended for them. Managers and policy makers frequently speak to the Group, answer questions and listen to comments from members on how well their services are working. A delegation from the Group sits on the Tower Hamlets Older People's Pathways Board, attended by managers from London Borough of Tower Hamlets, senior NHS managers and representatives of other voluntary sector organisations.

What we have learned

Members of the group saw **GP surgeries** as crucial for ensuring further integration of care services in Tower Hamlets; as they are ideally placed to provide signposting and social prescribing. However, some residents pointed out that GP services are already highly over-stretched, so responsibility is best shared with other stakeholders, such as Age UK, social services and local organisations. (It is also noteworthy that better integration and social prescribing with GP surgeries functioning as a referral hub could ultimately result in reducing the pressure on GP services themselves).

IT systems used by various providers (GPs, hospitals, social services etc.) need to be better integrated and communicate better with each other. GP-hospital computer links have been poor in the past but are now improving; which in turn results in an overall improvement in communication between GPs and hospitals. More movement in this direction is needed.

There is a need for improvement on **post-treatment follow-on**, from both primary care and hospital services; after people are being treated, the conversation needs to remain open on how they manage their condition and how their needs may have changed.

Austerity cuts to community and social services (such as domiciliary care or exercises classes in community centres) have resulted in increased pressure on primary care services and have made it harder to integrate services.

A lot of people with care needs are not aware of the services available to them. An **“A to Z” care brochure or directory**, featuring information about

everything from care assessments to community centres to disability services etc. would be useful.

Tower Hamlets Together is currently developing the Public Facing Portal, an online tool to help residents and staff find the services they need; however, since a significant proportion of older people are not IT literate, it would need to have a print version, which could be displayed in community centres, GP surgeries waiting rooms etc. or mailed to residents in sheltered housing. East End Life used to offer a somewhat similar service, but it has been discontinued. The New ‘Our East End’ publication, which is distributed to hospitals, GP surgeries, could provide a regular pull out on using health and social care services.

The future of social care: worries and resilience

Over the course of the six focus groups we have conducted in the community in November and December 2017, we have engaged with participants on their expectations regarding the availability of social care for the elderly and about how they expect adult social care to change in the future

The majority of our respondents were active seniors in their 60's and 70's, with relatively low care needs; but who expected to need adult social care services at some point in the future.

Overall, focus group participants felt worried and pessimistic about the perspective of needing care at home.

Not confident [that we will be able to get the care we need in the future], not really. (majority of the group agreed). I'm happy with my current level of support, but I'm concerned about my independence in the future. (Group discussion, focus group)

I'm worried about it. The future will be worse. (Group discussion, focus group)

Most people that we have engaged with expected adult social care (in the borough and nationally) to become less available and more expensive. They had noticed (and some even experienced personally) the effect of austerity cuts and they expected the same trend to continue.

I think it's going to get worse, they're gonna cut the budget; and the first thing to go is social care. I don't know what we can do about it... People's wages should go up, in general... Why is the stuff in shops so expensive? [Are you saying that if the economy was better, we would receive better care as well?] Yes. I need help now (White British woman in her 70's, focus group).

My housing benefit was taken away because I had £50 a week extra from my pension. And I have to pay all of that towards my rent, because they say I have too much money! I gave 24 years of my life to the British Army, served all over the world, and this is what they're doing now, I'm being penalised! I think that is disgusting. They take all your money away from you, and they say a lot but don't really do anything to support you. (White British man in his 70's, focus group)

My husband is 82 and needs home assistance and respiratory assistance, he's diabetic. I'm worried because his state pension is under threat from cuts. (White British woman in her 70's, focus group). In 10 years' time maybe, there won't be any social care available, we'll all have to pay for it. We'll end up like America, we'll all have to have insurance (Group discussion, focus group)

Some people are abusing [the system] now, so there will be lack of resources. NHS will not be the same, there may not be an NHS. Rich people will afford the private service, but we can't. (Group discussion, focus group)

Focus group respondents believed that governments should invest more funding in social care (although they thought it unlikely that they actually would). Many felt powerless about influencing government policy, and that they are not being adequately consulted. On a deeper level, some felt that they are not being valued as members of society, and that they are not supported fairly based on the contributions they have made throughout their lives.

I get a care grant from the council, and they sent a letter, saying that they want people to pay more money. They didn't discuss anything [didn't consult care users] then they sent a letter saying that you must pay £46 a week- so I appealed that. Now they say I must pay £76! I'm a pensioner, that's the only money I get, so how can I pay this money? I can't pay! There's another letter they sent- a consultation, but when they say "consultation" they've already decided what they want to do! [Rest of the group agreed that council do not take their views into account]. (Black British man in his 60's, focus group).

I just wish they treated us like human beings, not like this... When [politicians? Authorities?] talk about the National Health Service, the first thing they say is that the elderly are living longer than they should do! The government only expect us to live until 70-80. When you hear politicians talk about the elderly, you get the sensation they are waiting for us to kick off! Most of the people here went through the war, and I've done National Service after the war, so I've done my bit- as far as I'm concerned, now I reached the age there should be a certain amount of human kindness, but there's not. (White British man in his 80's, focus group)

We should ask the government to ringfence funding for social care for older people, people shouldn't have to pay for this, we worked all our lives and paid taxes, we shouldn't pay for our care now. We should petition the government and put pressure on them. [Some group participants agreed that this is a good course of action, others were sceptical that it would make a difference] (Group discussion, focus group)

Local government should use the revenue they get from new building projects for social care. The profits from these projects go to a select few people, not to the community, like it should. (Group discussion, focus group)

People expected to rely on their own savings or their families to obtain care. While some saw some opportunities for getting better support in voluntary/ third sector and community organisations, the vast majority were highly sceptical of the state's/ local authorities' ability to provide the care they may need in the future.

I hope my kids will look after me, otherwise what can we do? (White British woman in her 60s, focus group)

I don't think [I could trust the local authorities with my care]. I get a pension from the borough, but the pension was not mine, it's what my husband paid in for, he was an officer in Tower Hamlets. I've never had care from anyone apart from my daughter and my son. (White British woman in her 70s, focus group)

I have my wife; she'll look after me. (Chinese man in his 80's, focus group)

You've got to have people you can trust. Friends, family (Group discussion, focus group)

When asked what local authorities and the NHS could be doing differently, many expressed a desire for a more integrated care system, including support for voluntary sector providers.

● *We aren't worried specifically about getting a carer, but it shouldn't be the way it is now, [social care] should blend in naturally. Rather than us having to worry about getting a carer, this should happen automatically, through GPs and other health professionals who see us, if God forbid we deteriorate, as we go older- in the future, I would say we should be able to go from here to there without worrying. (White British man in his 70's, focus group)*

● *The council used to care for you to get back to the community (after hospital discharge) but now, as they don't share how to access the services, someone may suffer for many years before they find the solution for their needs. They should promote properly what you are entitled to get. When you phone to the council asking for advice, you don't get help. There is lack of communication. There is lack of awareness. We need to understand what we can get and what we should pay. This way to run the services make rich just the agency. There is lack of info about how to make a complaint. Some support services (advocacy) are insufficiently promoted, but they may be useful. Make the access to use them easier (without referral introduced couple of years ago) (Group discussion, focus group)*

● *The council should provide better access to community centres. They should give more funding to support activities, building's maintenance etc. We spend around 60K/year, we are running our activities with the Big Lottery Fund and next summer our funding will run out. (Group discussion, focus group)*

What Happens Next

Under the Health and Social Care Act 2012 Healthwatch Tower Hamlets has a statutory duty to:

1. Promote and support the involvement of local people in the commissioning, the provision and scrutiny of local care services.
2. Enable local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.
3. Obtain the views of local people regarding their needs for, and experiences of, local care services and importantly to make these views known.

4. Make reports and recommendations about how local care services could or ought to be improved. These should be directed to commissioners and providers of care services, and people responsible for managing or scrutinising local care services and shared with Healthwatch England.

In line with these duties a copy of this report will now be circulated to the following organisation:

- Tower Hamlets Together Promoting Independence Workstream
- Tower Hamlets GP Care Group
- Tower Hamlets Clinical Commissioning Group;
- Tower Hamlets Health Scrutiny Sub Committee
- Tower Hamlets Health and Wellbeing Board
- The Care Quality Commission
- Healthwatch England

Disclaimer

Please note this report relates to findings from 400 local people gathered in 2017-2018 . This report is not representative portrayal of the experience of all service users, only an account of what was observed by Healthwatch Tower Hamlets.

