

DRAFT

Tower Hamlets Community Intelligence Report 2015



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Introduction

What is the Community intelligence bursary

The aim of the Community Intelligence Bursary (CIB) programme was to ensure that the needs and views of the local community directly impact on how services are designed, commissioned and delivered in Tower Hamlets. The programme was developed by a partnership of Healthwatch Tower Hamlets, Tower Hamlets Clinical Commission Group, Tower Hamlets Citizens, Queen Mary University and Tower Hamlets CVS. In order to achieve this aim we developed local community and voluntary sector organisations to become community researchers in order to reach the unheard voices in the Borough.

Development of the programme

Community Intelligence Bursary Process

1. Bursary is open to voluntary and community organisations and individuals (supported by local organisation).
2. Successful groups take part in skills development programme and support.
3. All research gathered is combined into a single intelligence report
4. All groups/individuals who receive the bursary review the final intelligence report with key stakeholders and agree key issues and recommendations
5. The final community intelligence report together with key findings and recommendations goes to:
 - JSNA Board
 - Health and Wellbeing Board
 - VCS Health and Wellbeing Forum
 - CCG Governing Body
 - Health Scrutiny Panel
6. The impact of key findings /recommendations is reported back to the community.

We recruited 17 different organisations from across the Borough, who were then trained up in research skills by Queen Mary University and Tower Hamlets Citizens by a series of workshops and mentoring. This created a network of community researchers who not only had the skills but also had the contacts to carry this research out. There were a total of 33 researchers who were either staff members, volunteers or users from the different organisations. They were awarded certificates

for their skills, experience and work at the end of the training.

Application Process

1. The Bursary will be advertised widely through voluntary and community sector channels.
2. Groups and individuals (supported by a local organisation) will be invited to submit a project proposal
3. A panel of Healthwatch, CCG, VCS Health and Wellbeing Forum, LBTH will short list and make decisions on the final projects. Applicants may be asked to an interview or be asked to work more closely with relevant partner organisations to refine their applications.
4. An independent evaluation of the programme is undertaken to enable learning to be applied to any future Bursary programmes

What did we want to find out

Healthwatch consulted with the CCG, public health, social services and the voluntary community sector as to the type of intelligence that would have the greatest impact on commissioning and service design in the next two to three years. These priorities became the areas of research for the community organisations. The priorities were:

1. Carers
2. Older people
3. Children
4. Young people
5. Cancer services
6. GP Practice
7. Integrated Care
8. Eastern Europeans
9. Dual Diagnosis

What did the bursary achieve?

The bursary achieved a number of aims but also had number of positive outcomes that were unexpected. They were:

- A richness in information.
- Over 1200 people have been engaged.
- Created a network of community researchers
- Created a list of contacts of different third sector organisations and local community groups.

- Equality of information from all genders, ethnicities and age.
- Created a number of peer support groups as a result of the research being conducted.

What happens next?

Each organisation had created their own independent report based on their research. Their reports were then collated and went on to form this summary report which will be taken for to the commissioners and other health providers within the Borough.

A public event will take place on the 8th September 2015 to bring together the organisations who have delivered the project, members of the public, commissioners, Tower Hamlets Health and Well-being Board, Tower Hamlets Public Health, voluntary and community groups and other key stake holders. The purpose of the event is to discuss the recommendations through workshops and see how we can work together in bringing change to these Health issues.

Crosscutting Themes

There were a number of key themes that emerged as commonalities across the different reports, which we are looking to draw out further at the public event:

- Many of the reports draw attention to the huge richness of voluntary and community sector resources in the borough. The reports suggest areas where the marginal benefit/cost ratio of linking in to VCS provision, by social prescribing and in other ways, are high – such as peer support for cancer patients, those experiencing dual diagnosis, and for people experiencing loneliness. The report flags the potential for more services to be delivered out of community buildings and mosques.
- There is acknowledgement too that funding cuts are having an impact on local voluntary sector infrastructure and this is putting existing community services at risk. The impact is likely to be felt most by older people, and highlights a challenge for both voluntary and public sectors to ensure that provision remains available to meet demand.
- Issues around awareness of and accessibility of services are recurring themes in Tower Hamlets

given its cultural diversity. The research highlights some of the groups missed by current services, where outreach and culturally appropriate services might be targeted in order to combat specific gaps. These populations include Asian carers, Somali elders in need of residential care, and pregnant east European women.

- Several of the reports call for recognition of the role of carers and the burdens placed on carers by their caring responsibilities.
- There are a number of alarming stories that suggest the financial strains the NHS is under are having an unacceptable impact on certain need groups. The research pinpoints long waiting times for people needing sensory aids for example (a story of one man losing the sight in one eye before he could get an appointment for example), and long waiting times for statutory mental health services that, one report suggests, are putting people off. The financial hardships faced by many people experiencing cancer was another strong finding.
- The impact of the ‘wider social determinants’ of health – particularly unemployment and housing - on health outcomes, recur through the reports. Lack of unemployment opportunities for working age men is cited as a major contributory factor to their experience of mental health problems, and the impact of the wide availability of cheap fast food is flagged by another as a key determinant of poor diet choice.
- Several reports cite evidence of health services not being sufficiently responsive to the needs of citizens and incidences where insensitivities and cultural inappropriateness led to poor patient outcomes. The need to better understand and to capture patient experience comes across strongly through the research.

1. Carers

Account 3 – “Who Cares?”



Organisation

Account3 Ltd is a Black Minority Ethnic (BME) women led, training and development social enterprise that was founded in 1991. They focus on finding innovative solutions to social issues and problems which hinder the economic development of local people. The company operates a one-stop shop approach to providing advice, support, resources and education to local people.

Summary

The research aimed to understand the experience of informal carers, their expectations and perceived barriers with regards to services. Also the effects that caring responsibilities have on their health, social and economic circumstances. Ultimately, asking the question “who cares for them?”

Account3 collected the views of 40 informal carers through a series of interviews and focus groups using participatory methods. They worked with St Hilda’s, Black Women’s Health & Family Support, The Carers Centre, The Somali Integration Team, and the Welfare Rights Advisor in order to ensure diversity of participants. All research questions were designed by informal carers who also led focus groups.

Key findings

The findings identify carers’ journeys as emotional and psychosocial experiences that are at times completely shocking, baffling, overwhelming but also rewarding. The key issues that the research found were:

1. Recognition for informal carers

Many of the informal carers did not feel health and social care professionals acknowledged them as experts or “co-workers,” despite them seeing themselves as full time workers. This led to a negative impact on their mental well-being, as they felt “worthless.”

“I started to care for my mum since the age of 15, but I have been doing it properly since dad passed away, it is now 18 years.” Female carer

2. Support for carers.

From the discussion it was evident that there was psychological distress, and an overall deterioration in health endured by the informal carers. Isolation and lack of support might prove a high burden and can result in distress or mental health problems.

“My marriage broke down as a result of me trying to care, the best I can for my daughter. It was too much for him to take. Her condition and my time spent in caring for her, he could not handle it.” Female informal carer.

Carers frequently incur care-related costs. Many of them have experienced difficulties in obtaining either the Attendance Allowance or Disability Living Allowance. The reasons varied from the lengthy process, the number of hours required or difficulties obtaining a formal diagnosis. This resulted in the carer using their own money.

“I often had to make financial sacrifices...once I had to choose between my mum’s needs and my daughter’s needs for new shoes for school...” female informal carer.

From the research, it was clear that there are major issues around awareness of and access to health services. Many of the respondents found that they had problems either not knowing of the services available or issues with accessing the services.

Recommendations

The recommendations that have been put forward by the 40 informal carers:

1. To explicitly acknowledge the informal carer’s expertise and knowledge of the person they are looking after as part of building a carer’s confidence and resilience
2. To support the informal carers’ own health and well-being. Talk about and offer information and support around the carer’s need. Carers often think that their health needs are secondary to those of the person they assist. Their levels of stress are alarming, and some were crying out for counseling. Their psychological strain should be addressed with

support, counseling, and/or cognitive-behavior interventions.

3. Better identification and signposting. An over reliance on “self-identifying” means many continue to miss out on vital support services, which they have a right to as carers.
4. Need for simplification of forms.
5. Need for training. Informal carers requested access to training to enable them to perform their role better. Training suggested by participants in this study included training in raising confidence, First Aid, moving and handling.
6. To improve the taxi service that is currently being run out of a call centre based in Scotland. Those taking the calls have no local knowledge and drivers often do not understand the needs of the passengers with care needs, mobility issues etc.
7. Financial help for Carers. The financial burdens often put informal carers into a precarious situation, despite their role within the local and wider economy. Informal carers should be given extra financial help, failing to do so; can and does sometimes put the carer below the poverty line.

Black Women’s Health & Family Support – “How do Carers Find Out about Local services?”

Organisation

BWHAFS is a community-embedded organisation which was created by local women of Somali heritage three decades ago. Its range of services include health advocacy for BAME, African and Somali-speaking women (many of whom are lone heads of households), their families and refugees. It supports on average 2,900 vulnerable service-users yearly.

Summary

BWHAFS noted a growing number of isolated older women, widows and carers who had no first-hand contact with the Borough’s statutory or third sector services established to address their welfare, social and health care needs.

The research focused on how women from Somali heritage, accessed health services by undertaking one-to-one and group surveys with 30 hard-to-reach older female carers of Somali heritage. They also sought to understand their health and caring needs and priorities.

Key findings

Of 30 respondents, 27 older women interviewed were in contact with voluntary sector services including the Brady Arts Centre, Granby Hall, Wadajir, Ocean Somali Community Association (OSCA), Somali Integration Team, the Bromley-by-Bow Centre, Oxford House and the Legal Centre. Six had learnt of these services from family members, 2 through friends, 1 via a community centre, 2 via their GPs and 2 through emergency services while 5 undertook internet searches. When asked how health talks should be delivered, a majority of respondents suggested they should be delivered with support from bilingual interpreters, that illustrations should be featured and that they could also be publicised on screens in GP services. Some suggested regular talks.

Case study: Asha’s story

Asha is of Somali heritage and over 65 years of age.

“My son is ill. He suffers from mental illness. It came as a shock as all this was not communicated to me whilst I was in Somalia. I immediately started caring for him.

At that time, refugees from Somalia were mostly concerned with their immigration status. There were no Somali organisations where I could go and no one supported me to get the right advice.

My son was hospitalised in a mental institution several times. I became so worried and stressed that I became ill. I struggled for years to care for him without any outside support. I didn’t know where to go for help and my English skills were poor.

My son became suicidal. He attempted to kill himself several times. At that stage he did not have a permanent address in the UK and was not receiving any state benefits. On one occasion he became violent and pushed me. I fell and broke my arm.

In 2007, he was hospitalised once more. This time Social Services appointed a social worker for him. The social

worker supported him in getting welfare benefits and my son and I were referred to organisations for help.

I am an elderly person and I still care for my son but I also need to take care of myself. Because of language barriers, I could not go anywhere to access support.

A friend of mine told me about Black Women's Health & Family Support (BWHAFS) and the work they do for carers. Since then I have been attending the centre for general enquiries and support with my son's needs. I visit BWHAFS three times a week to socialise with other carers. I take part in their advice sessions, book my son's GP appointments and have joined the Lunch Club and sewing classes. Since attending my health has improved and I feel much happier within myself.

Overall, the research found that current services were not reaching these particularly vulnerable older women and carers due to technological and language constraints. These groups predominantly favoured the delivery of face-to-face information through community centre talks and GP services

Recommendations

1. Health service information should be targeted at women as they are the primary health and caring providers in families.
2. Important health messages should be promoted by the CCG and Healthwatch through a range of approaches. These should include partnerships with grassroots services that are able to engage with women from communities that are poorly served by current services including carers. Priority must be given to those from particularly disenfranchised communities such as those of Somali heritage who rely on oral traditions of communication and have limited reading, digital and English language skills. We think these groups could particularly benefit from health awareness activities and health talks and these could be provided through statutory/voluntary sector collaboration.
3. Health messages should be promoted through TV channels and touch screens at GP services in appropriate community languages so as to reach disenfranchised women and families through a range of approaches.

4. The CCG and Healthwatch should continue to work in partnership with small organisations to undertake further research into the changing needs of the borough's most vulnerable women and carers so as to support them in maintaining good health for themselves and their families and dependents.

Asian People's Disability Alliance – “Hidden Carers”



Organisation

Asian People's Disability Alliance is a grass roots disabled people's organisation. It is a user-led, needs-led, non-governmental and non-denominational organisation in its service delivery and campaigning. It provides culturally appropriate services to Asian disabled people, their carers and their families that mainstream services are often unable to provide.

Summary

The research was aimed at identifying Asian hidden carers who currently provide care and support to another person, yet are unrecognised for their commitment and do not have the formal support they require for their own physical and mental health needs.

The research looked at unsupported health needs for female Asian hidden carers. .

Many of the hidden carers were isolated and largely disenfranchised. Informal one to one interviews and small focus groups were held to gather their views. A total of 22 interviews were conducted.

Key findings

The key themes that researchers noted are as follow:

- i) Lack of control and choice, especially in regards to finances
- ii) No time for their own health and wellbeing

"I am not able to always communicate, expressing myself, I am disregarded and my wife has to be called, which makes me feel demoralised, belittled"

- iii) Often not caring through choice, more as an expectation. Caring as a duty.
- iv) No one asking them about how they feel, only this research.

"I felt lonely, there wasn't a shoulder to cry on, didn't want kids to see me"

"For services and support to offer a holistic approach that includes the needs of the carer and the person cared for and takes into account the carer's other responsibilities"

"As a carer when I seek support, it is only prescribed for my eldest son, who is under the adult disability team, however I have other children with medical conditions who need support physically and emotionally who are disregarded in receiving holistic care"

Case Study

A couple have 4 children, all with healthcare needs, the eldest has been diagnosed with having autism, potocki-lupski syndrome, is partially deaf in right ear, has arthritis, and his cartilages have not developed. He has a care package with social care.

Their second child has type 1 diabetes, rheumatism, anxiety and hypermobility. Their third child also has type 1 diabetes, suffers from urine infections and has a cyst on the left eye. Their fourth child has speech and language needs.

They only receive care support for their first child.

The mother suffers from the following conditions, enclosing spondylitis, osteoporosis, endometriosis, incontinence and their father suffers from the following conditions arthritis, chronic prostatitis, kidney stones, depression and anxiety, they are both carers for their children.

Recommendations

Short Term Recommendation:

- i) Drop in Sessions to identify hidden carers and raise awareness of disability conditions and the support available.
- ii) Training for hidden carers in health conditions, disabilities and caring roles.

Medium Term Recommendations:

- i) Review the current mental health support services, and whether they are fit for purpose for the Asian community in Tower Hamlets.
- ii) Develop a more holistic approach in health and social care support that takes into account the needs of carers, the person cared for and the family unit.
- iii) A language appropriate campaign to raise understanding and awareness of hidden carers and the value of caring. This should use translated documents.

Long Term Recommendations:

- i) A more culturally suitable informal and open service approach to support the Physical and Mental health needs of Asian Carers and hidden carers

2. Older People

Somali Senior Citizens Club – "Health and Social Care for Older Somali People"

Organisation

The Somali Senior Citizens' Group is an organisation that runs a number of services for the Somali community within Tower Hamlets.

Summary

Somali Senior's Citizen Club was commissioned to undertake an assessment of the present and future health and social care needs of older people (aged 55+) from the Somali community. The assessment also covered health, and housing and other welfare needs which impact on the need for social care.

The objectives of the project were to gather the views of older men and women in order to:

- Learn what the Somali community understand by care home services.

- Establish why the Somali community do not easily access care home services.

Key findings

The majority of participants were mistrustful of care home services and providers. The primary barriers to accessing services included lack of information, language barriers and access to a culturally appropriate service.

The following organisations provided outreach and venue support to the research:

- Al-Huda Mosque and Cultural Centre.
- Bustaan Radaa (Gate Housing Association).
- Queen Victoria’s Seaman’s Rest House.
- Somali Senior Citizen Club.
- Somali cafes.

75 older Somali people took part in the research via interviews and focus group discussions (24 women and 51 men). An overwhelming majority of these participants clearly stated that they don’t want to go to care homes unless there is improvement in a number of areas. 5 Participants are happy to go to care homes as they are now. 55 want to see care homes run by staff with similar backgrounds. 15 others don’t want to go to care homes at all.

Case Study 1

Mr Ali is an 82 year old Somali man who lives in a care home in the borough. When asked how he would like to see the care home in the future his answer was that he has been here for the last three years and wished all these three years that one day he would come across a Somali speaking person who can understand his needs.

“At many times I became angry and agitated because nobody speaks the same language as me that is why I like to be left alone in my room. Having someone who can speak my language will help me. I can tell my problems in my own language. This will help me and help reduce the isolation and loneliness I experience.”

Case Study2:

Ms Y, a 78 year old who lives in shelter home is very reluctant to go to home care as she thinks the home care is only for the people who have been abandoned by their families. She also believes that in a care home

environment personal services can be delivered by anyone, regardless of their gender, which is religiously and culturally inappropriate.

“I don’t want a man to wash me up, this is an embarrassing and very shameful”

Recommendations

- 1) In depth and detailed information to be available about current care homes and care providers.
- 2) More Somali speaking staff to be recruited to work in care homes and care services to address cultural and language barriers.
- 3) A consultation with a person’s family is standard before a final decision over their care is made
- 4) To engage with community organisations that are able to reach out to individuals who may be left out and in need.
- 5) Somali organisations to run care home awareness sessions regularly in order to deliver appropriate messages to the wider Community

Year Here – “How do you want to live when you’re 100 years old?”

Organisation

Year Here is a full-time postgraduate course in London designed to cultivate entrepreneurial approaches to entrenched social problems. It is immersive, action-oriented, and grounded in the daily experience of those at the frontline of inequality.

Summary

The research focused on how residents of Tower Hamlets experience ageing, use health care providers and engage with wider social support services. It looked into their needs and preferences of health and social care. They approached:

- People with limited social networks (and so at risk of becoming isolated).

- -People with moderate physical, mental health and mobility issues that restrict their ability to socialise and engage with the community.
- People who are currently facing social isolation and/or loneliness.

A total of 52 stakeholders were engaged through this research.

Key findings

The key areas of research were:

1. Wider social support

Every participant made a reference to the value that using wider social support services brings to their lives. Phrases such as “It has saved my life” and “It’s my favorite part of the week” came up multiple times in the transcripts.

A few participants (17%) spoke about their experience of having to fight for funding. With this theme frequently came feelings of being “undervalued”, “not cared about” or “forgotten about”.

John, aged 87, spoke about a men’s club he belongs to. He describes it as “fundamental to our lives – because we ain’t got much going’ for us these days”. The men meet weekly at Brownfields community centre for a ‘Men in Sheds’ type group. They do activities such as woodwork alongside socialising and trips. The men that visit the club need more support as some suffer from mental and physical health problems. He spoke about their struggle to keep the club going because funding was being cut and he described how this makes him feel.

“Basically how it goes is – I used to live in the future when I was young and that. Then I lived in the present. Now I live in the past and no one cares about people that live in the past. They figure we’re not worth it, that we don’t really know what we’re on about. So they close our stuff down.”

If wider social support services are unsuccessful in their endeavor to stay open, then service users are more likely to become lonely or isolated as their contact hours with services will decrease. In our research we found that lonely people are almost twice as likely to visit their

GP compared with patients who are not lonely and are more likely to visit A&E departments.

To maintain dignity and autonomy in older age is vital when providing good quality health and social care. They wanted face-to-face communication first, and then communication via the phone and then post as it would logistically work well occurred 6 times throughout the interviews. When asked if there was a place that they visited regularly to collect information GP surgeries was the only place that was mentioned more than once.

Having limited social networks has resulted in participants becoming lonely and suffering from mental health issues – depression and anxiety.

Case Study

Rose is 87 and lives in Poplar. She’s suffered from multiple bouts of cancer, which she has beaten. She goes to one lunch club a week but struggles to get out due to her mobility. She has lost the motivation to leave her house on a more regular basis because of her anxiety.

“I’m just lonely and depressed and have panic attacks. Sometimes I pick up the phone just because I want to hear voices... I don’t really know what else to do with my time. Apparently I might get an escort through the NHS (she laughs) not like one of those ones. Someone to take me out.”

Rose has a counselor; she has only seen her counselor twice. She said it hasn’t really helped her but she has really appreciated talking to an outreach worker who helps out at the ‘Neighbors in Poplar’ lunches. “It feels less formal”. She explains that the informality of a chat is much more likely to engage her and inspire her to open up.

2. Health Care Appointments

GP Concerns- A large majority (92%) of participants expressed their fondness of being treated by their own GP every time they visited their practice. A third of these people spoke about times they had been seen by a different GP recently. This caused problems such as misdiagnosis and patients becoming agitated due to a “shake-up” of routine. A third of people also said they have experienced long waiting times (anything from 2 days to 2 weeks).

Health Care Appointments being changed. 3 interviewees raised the issue of having appointment times and dates pushed back to later dates. In all 3 cases this led to their health issues worsening and impacting their day-to-day lives.

Arnold lives in Poplar with his son. For the past 5 years he has been suffering with Glaucoma, he has partially lost sight in his right eye. He began to lose sight in his left eye, and his GP referred him to Moorefield Eye Hospital. His appointment was scheduled for February 5th (2015) this appointment was cancelled a week before and rescheduled to July 14th (2015). Whilst waiting for his next appointment Arnold` lost sight completely in his left eye and has now been told that it is unlikely that he will regain his sight.

“What can I do, everything’s gone wrong. The only thing that makes me happy is reading – I love books I could read all day... I ended up in hospital cos of my mental state, I was ill. And now I don’t know what feels worse, now I can’t read because I can’t see. I can’t do the thing I love.”

General Practitioners. There are systematic, social and economic barriers to receiving GP care. From language barriers to financial situations and mobility combined.

Carers. of 24 one-to-one interviews with people being cared for at home two thirds (70%) of participants receive it from family members. We found evidence that this puts carers under a lot of pressure.

3. Support and Outreach Workers

Outreach and support workers were interviewed. The notes made included;

- Issues with pride from the elders.
- Better contact routes
- Navigators can be useful.
- Housing issues for elderly
- Social isolation
- Carers have limited responsibility.
- Family moving away.

Recommendations

1. Encourage collaborative funding. Organise networking events for services to discuss further growth and innovation together.

2. Citizens’ Forums - so that they can have autonomy on how things are run and on how money is spent.
3. Information booklet about the different services that could be available to them.
4. Train support staff in signposting
5. Older patients drop in days at GP surgeries. There should be opportunity at least one day a week for the over 60’s to get priority for an urgent appointment and reduce the waiting time between standard appointments.
6. Give younger patients a named GP. Having a named GP to go through the process of treatment with is very important for older patients, yet named GP’s are only allocated after the age of 75.
7. GP Checklist - is a small form that a patient can fill in whilst at home or in the waiting room before an appointment. It acts as a reminder for listing all the issues that need to be raised during an appointment.
8. Intermediate job role in GP Centres. Someone who can engage with patients on a more social level within waiting rooms would help many patients overcome issues of social isolation and loneliness.

The Collective of Bangladeshi School Governors in Tower Hamlets (CBSG)

Organisation

The Collective of Bangladeshi School Governors in Tower Hamlets.

Summary

The aim of the research was to gather the views of the younger older people of the Bangladeshi community on the types of health and social care services they would like to see available to them in the future.

They conducted interviews, surveyed through questionnaires, and held a workshop to gather the views of Bangladeshi people (aged between 45 and 60). A total of 50 people were interviewed - 21 of whom

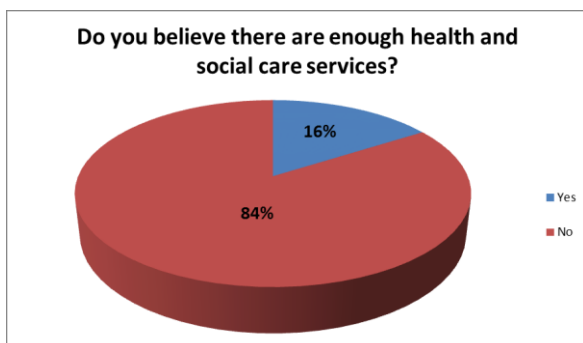
were female and 39 males. They also carried out a workshop which took place in the CBSG office in Brick Lane which 25 people aged between 45 and 60 attended.

Key findings

From the surveys, CBSG found:

A number of improvements were suggested for the GP service such as more GPs at the surgeries, shorter waiting times, more availability of appointments, organised and trained reception staff, telephone calls answered more quickly, thorough examinations where GPs do not rush, the need to explain prescribed medication, i.e. what it is for and how to take it, more interpreters, more female GPs and also GP surgeries to work on stressing the importance of cancellation of appointments so appointments can be given to someone else.

Many people mentioned past experiences of finding it very stressful to wait for long periods of time before being seen by the nurse or doctor.



14 people suggested technology/equipment provision for patient use at home

7 suggested supported housing/adaptations

12 suggested hospital letters to be sent in preferred language on request (Bengali).

A participant said that he had been dismissed from physiotherapy and given medication instead to help with his diabetic neuropathic pain, which has many side effects. He would prefer to go to physiotherapy instead and believes due to the shortage of physiotherapy services he is no longer able to attend thus he would like to see more physiotherapist places available in future.

Recommendations

1. Better technological support and equipment as a way of retaining autonomy for patients, but also a need to train them to use the equipment effectively.
2. Home adaptations
3. Care homes to be accessible to BME groups – by using bilingual carers.
4. Interpretation services available in health services
5. Better access to GP services
6. Improved GP service

St Hilda's East Community Centre – Older People's (55+) views on social care in Tower Hamlets



Organisation

St Hilda's is a lively Community Centre based on Club Row in the Weavers Ward of Tower Hamlets. It has various projects under one roof with excellent relationships to the age 55+ communities, as well as links to neighbouring community organisations across the borough.

Summary

The research looked at what older people (55+) thought about current older people's services and their expectations from Tower Hamlets as they get older. They collected views from the Caribbean, Bangladeshi and White British communities.

Interviews were conducted at various lunch clubs, centres and sheltered accommodation venues across the borough including:

St Hilda' East:

The Older People's Project Day Centre and Lunch Club. Boitok group -Bangladeshi Elders lunch club. Bondhon Project - supporting Bangladeshi women who are socially isolated and experiencing mental health issues. Food Co-op customers who met the criteria.

Sonali Gardens Day Care Centre - providing person centred care for Bangladeshi and other communities in Tower Hamlets. **Shebadan Project** - providing home care services to Bangladeshi and other communities.

LinkAge Plus, offering residents a range of social and health related activities

The Sundial Centre- day care and activities for older people.

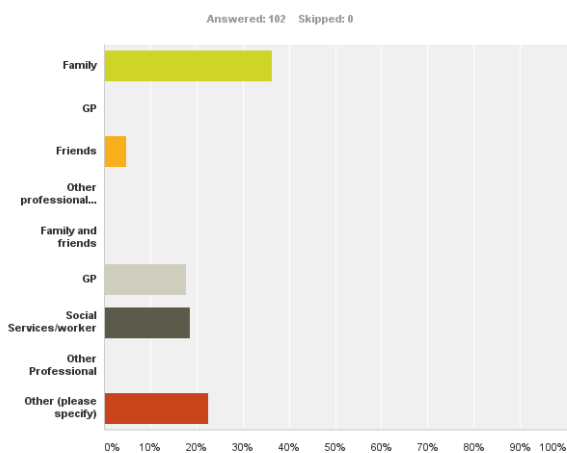
Several focus groups and one-to-one questionnaires were held at **Sheltered Accommodation** venues across the borough including:

Hogarth Court - General needs/independent living.
Donnybrook - Extra Care. **Sue Starkey House**, -Extra Care

Key findings

Key questions and findings included;

Q8 If you were to need extra support in your home where would you go?

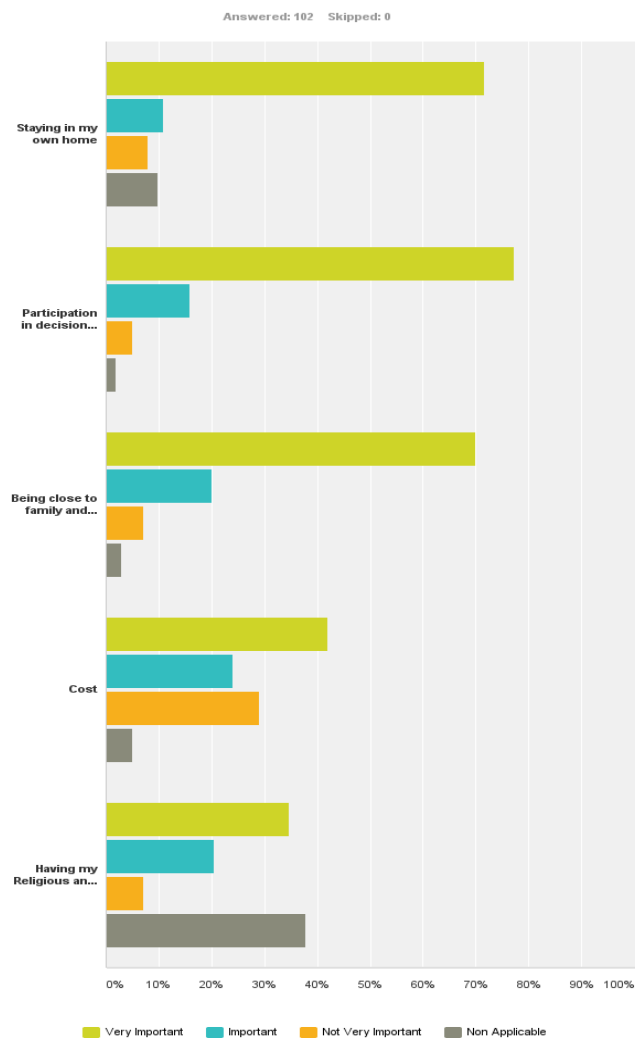


There is an overwhelming importance of Community Organisations and Services, because of the connection and trust service users have to them and their staff.

Just 32 participants out of 102 knew about all the services that were mentioned. 64 participants did not know about services or just knew about some services. Therefore, better promotion of services is needed and more outreach work.

When asked about the services that the participants thought would help the elderly, these included lively, sociable activities including those that keep people active. Things that would involve members of society.

Q21 What are the most important factors when considering your care in the future?



When asked about their expectations of care, as they get older, 57 said they would like to be cared for/looked after/supported/have extra support, adding comments such as: “With respect and care”, “Like an individual.”

Case Studies

Rabban Khan, Age 62 - In 2001 Rabban became sick after an accident at work and has not worked since. He separated from his family and lives alone. He became quite depressed due to his family situation, deteriorating health and being at home alone. Mr Khan was referred by his GP to *Community Options*. He has a good relationship with his support worker, who he believes treats him with respect and communicates with him well. He feels in general though, that not all services are as understanding of his needs or mental health issues and sometimes feels professionals are not

as caring. Without the social services he attends Mr Khan knows he would be isolated and feel more depressed. Attendance and socialisation at these events offsets his depression and is good for his wellbeing. Without them *"I would feel so alone and sad. I don't like lonely"* Mr Khan says.

Alvin Davidson, Age 89 - Alvin has a daily carer in the morning that he has had for some time now. Initially he had different people, which he did not like: *'some of them did not know how to care; some did not even know how to make a cup of tea. Things would go missing from my house and people get away with it and I cannot prove anything with all different people chopping and changing.'*

Alvin was not treated as individual. There was no scope for a relationship with his carer to flourish. He is more satisfied with his regular carer now, though he is often pushed for time and any added trips to the shops or to top up his electricity key rely on his carer's goodwill and time

Recommendations

1. Carers – this should include staff training which seeks to build a relationship-based practise and a continuity of staff.
2. Time allowance with carers - time with carers to be better matched to the needs of the individual
3. Services - more services and activities to take people outside of their homes.
4. Outreach Work
5. Better advertising of services
6. Sheltered accommodation- Clinics/advice sessions held weekly/monthly at sheltered accommodation venues. This will allow residents to be listened to and signposted where needed.
7. Support that prepares older people for staying in their homes

3. Children and Young People

Bangladesh Football Association – “Healthy Eating Research Project”

Organisation

The Bangladesh Football Association UK.

Summary

Research with children 6-11 year olds to find out their existing knowledge around healthy eating; their eating habits after school and before bedtime; their reasons for eating chicken and chips; and their parents attitudes to food.

The project worked with 30 children that regularly attend the football academy. They used a series of football exercises/activities to gather the information and also conducted surveys with 15 parents.

The following methods were used to get feedback from children and their parents:

- a) **Warm Up** – Children were asked to do a stretch while warming up and answer “What is healthy?” Children took turns to do a stretch and say something related to healthy eating.
- b) **Drink Run** – After a running drill, children chose drinks from 3 different boxes, one contained water, one contained fizzy drinks and one contained juices. Once they chose a particular drink they were asked to give a reason why they choose that drink.
- c) **Dribble to Healthy Eating** – Children were asked to dribble with a ball and go to the appropriate station when called. Stations were labelled healthy / unhealthy. Each station had different types of food.
- d) **Penalty Shoot Out** – Children took turns taking penalties. Afterwards they were asked if they ate chicken and chips after school. Every time they scored they had to give a reason why they ate chicken and **chips. The aim was** to get at least 2-3 answers from each child as to why they eat chicken and chips.

- e) **Food Chart** – children were given a food chart to record what they eat between 3.15pm and 9pm for a week. This was to help find out what they were eating after school, how much and the frequency.
- f) **Focus Group**. After collecting the weekly food chart and doing the above exercises a group of 8-10 children were chosen and asked why they “really” eat chicken and chips, why they eat high amounts of food after school, what they drink a lot of at home, what their parents offer them, and whether their parents are encouraging them to eat all the time. This was to get in-depth information about the reasons for their eating habits.
- g) **Survey with Parents** - A short survey was conducted with parents whose children participated in the project to find out their attitudes to food and healthy eating (and any barriers to healthy eating). They were asked questions in relation to their child’s food chart for example, why they buy chicken and chips and what their child consumes during the evening.

Key findings

A) Baseline knowledge about healthy eating. Children are very knowledgeable, educated and have a good understanding of what food and drink is healthy for them and what is bad for them. The question is how many of them follow their understanding when buying food. Do they opt for a sandwich or McDonalds or do they order water/juice with their meal instead of coke. This is an area where more research needs to be done and some kind of education needs to follow where children are encouraged to implement what they learn. If children are encouraged to follow what they learn then they can influence their parents.

b) Eating habits after school. The food chart and the parent’s survey were very similar. The food chart revealed around 20% of children had small snacks after school and a main meal around 7-8pm. The rest 80% had snacks, a mini meal and later a main meal. Those who had a main meal around 4:30pm had snacks up to bedtime.

From speaking to the parents the research found that around 40% of parents gave food straight after school and another 25% on the way home. However the vast majority 75% gave food at home as snacks but included a meal sometimes to keep the hunger away until the main meal at 7-8pm. The other 25% gave food as main meal and later snacks before bedtime. We feel the snacks and mini meals before the main meal is a contributing factor to increase in obesity in primary school children. Parents are also creating the lifetime habit which children will later find difficult to break.

c) Type of food and the amount children eat. The food children eat at meal times is generally healthy and wholesome and not much junk or fried food. Occasionally there is chicken and chips on the menu but on the whole children are eating cooked food such as spaghetti, pasta, chicken and mash potato, rice and curry, tuna salad, etc. However, the concern is the snacks they are consuming – crisps, biscuits, chocolate, chicken and chips, pizza, etc. They are also eating fruits and sandwiches in addition to this as a healthy option. We could not measure the amount children were eating and generally because it was a healthy eating research project parents and children did not want to be seen as unhealthy or overeating.

d) Reasons for Eating Chicken and Chips. From children's point of view it tasted good, and parents gave it as lunch or dinner and as a treat. From the parent's point of view the children wanted it/liked it, it was convenient, cheap, filling, and as a family they ate it as well when they did not cook. It was difficult to find alternatives and there were very few other food outlets and alternative food was expensive especially for families who wanted a quick meal.

e) Parents attitudes to food. Generally parents were well educated and placed importance on it. They wanted to give a balanced diet to their children. Around 10% felt they may be encouraging overeating in their children and they made sure their children finish their meal. The other 90% said they were more relaxed. They made sure their children did eat but did not encourage overeating. They said children were hungry after school and it was a task to find them healthy food to keep their hunger at bay until meal time. This was a challenge for them.

Recommendations

a) Continue healthy eating education. However, there needs to be more focus on whether children are implementing their learning when making decisions about food when they are out and about i.e. when they go shopping do they end up in McDonalds or a healthy cafe/food outlet. Do they order water or order Coke? We feel education needs to focus on implementation and encouraging children to eat healthily. They will then influence their parents. If children refuse to eat chicken and chips their parents will provide alternatives.

b) Educate Parents on overeating/snacks

c) Research on exercise and active living. There needs to be a separate piece of research on how much exercise children are doing after school.

d) More healthy food outlets in the borough. It should be easier to attain planning permission to open new healthy food outlets around primary and secondary schools. We would also recommend that tax relief and other incentives are given to cafes and shops selling healthy food at lower prices for children and families. Businesses participate in the scheme and get incentives to do so. Also, start a scheme where existing chicken shops participate and introduce healthy food like sandwiches, wraps, deli food, more juices, etc. and they are given incentives to buy equipment and to enable them to sell healthy alternatives at a lower price. They should be given incentives to participate in the scheme.

e) Provide after school food packs – including fruits, snacks and light healthy food so children are not given unhealthy snacks on the way home or when they go home. This should keep their hunger away until their meal time.

Leaders in Community – “Young Peoples Mental Health”



Organisation

Leaders in Community (LiC) Consultancy CIC is a pan-London youth led social enterprise that was established 6 years ago. They are passionate about creating avenues

for young people to drive social change in their environment. Their aim is “To inspire and empower a generation of young leaders to influence positive change within local communities and organisations”.

Summary

The research surveyed young people to better understand their awareness levels and attitudes towards mental health, and gather suggestions on how best to tackle issues related to young people and mental health. Healthwatch Youth Panelists received training through the CIB process to become peer researchers and undertake the fieldwork research.

Young people have greater access to their peers so they were in the best position to conduct the research. They surveyed a total of 237 young people across LBTH aged between 15 and 24 years old.

Key findings

More teenage young men stated that mental health was an important issue to them than men aged over 20 years. The opposite trend can be seen for female respondents.

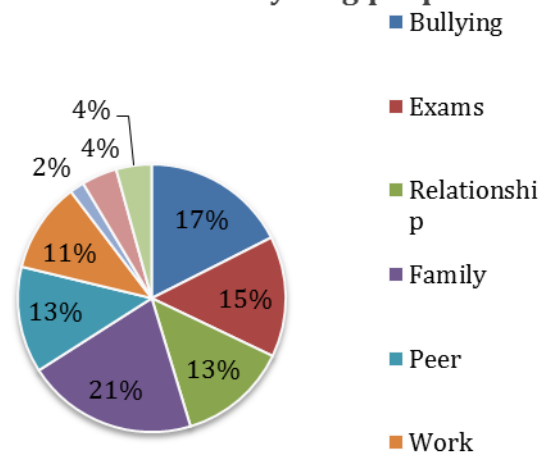
The vast majority of young people were unaware of both the national and local mental health services available to them. Aside from GP’s, hospitals, Childline and Talk to Frank, awareness of other services that were presented to respondents was extremely low.

“My grandmother suffers from one form of mental health issue which is depression and one of my friends had previously been in depression, so it’s quite close and meaningful to me. It is also significant to me because I want to be able to help my friends and family if a situation arises in the future and the fact that Mental Health is something which is under-addressed worldwide even though it plays a major part in everyone’s wellbeing.”

stigma (41%) attached to mental health illnesses, and fearing the possible adverse reaction of their loved ones (16%) if they were to discuss mental health issues with them.

21% of those surveyed stated that simply not knowing where to receive support would be a barrier for them in trying to access help.

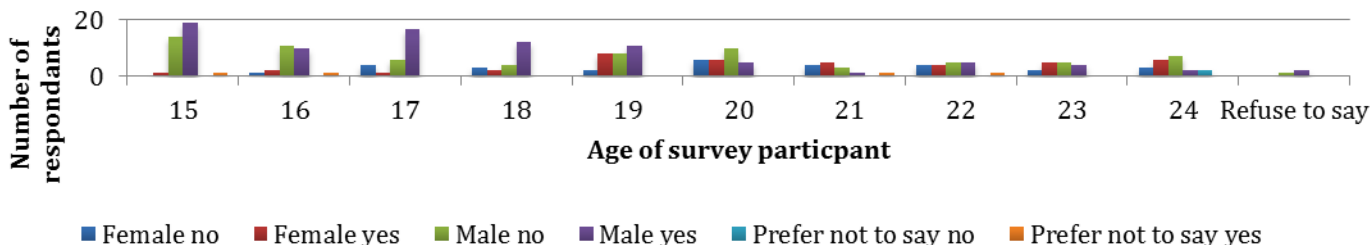
fig 2.4 What do you think could trigger or lead to Mental Health issues in young people?



Recommendations

1. Healthwatch and LiC to train more Peer Researchers from the Healthwatch youth Panel –so that they can build a social action campaign together on this issue.
2. The Youth Panel to meet with service heads from bodies such as the CCG, CAMHS and Public Health LBTH to discuss possible collaborative work as well as offer the services of the peer researchers to assist with on-going/external projects.
3. LiC to liaise with Youth Services LBTH/Young Mayor’s Team LBTH to work collaboratively on the next steps of the Mental Health awareness

fig 1.7 Is Mental Health important to you?



4. Long-term conditions

Toynbee Hall – “What makes the biggest difference: Supporting Cancer Patients.”



Organisation

Toynbee Hall is a 130-year-old community settlement that gives some of the country’s most deprived communities a voice, providing access to free advice and support services and working with them to tackle social injustice. For the last four years, Toynbee has provided Macmillan benefits advice services for cancer patients and their families living in Tower Hamlets.

Summary

The research aimed to explore the kinds of support that would make the biggest difference for people with cancer and their families.

The following questions were asked:

- What support do cancer patients require?
- What services are available?
- How can services be improved to provide greater support?

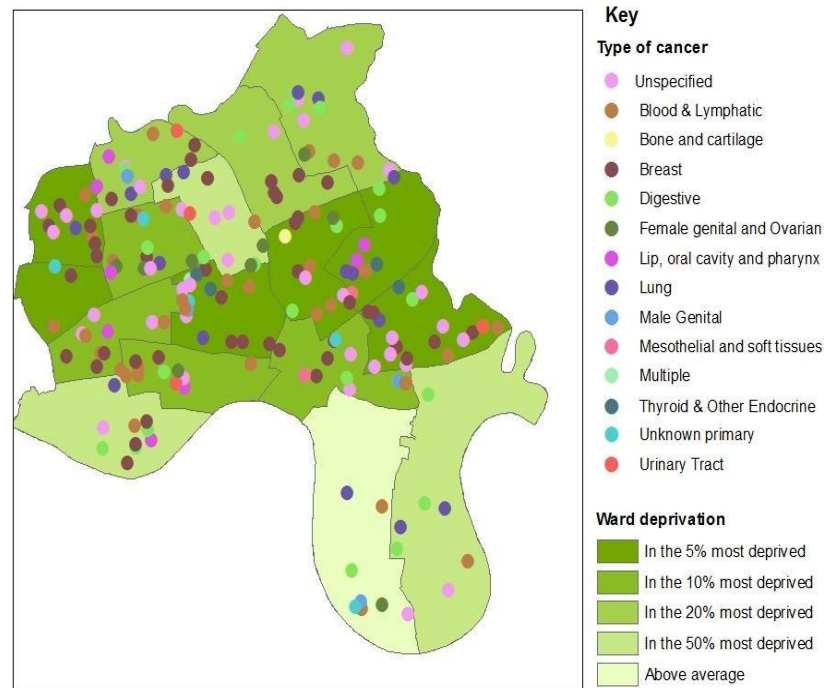
They also conducted interviews and a focus group with cancer patients and their families. Sixteen people took part. They came from diverse backgrounds and varied in terms of age, gender, ethnicity, marital status, stage of cancer and cancer type. Thirteen of these respondents were cancer patients and three were patients’ family members.

Key findings

The Geographical Information Systems (GIS) maps provide a visual overview of where cancer support services are based. They mapped the locations of 1182 anonymised Toynbee Hall clients, approximately 200 of whom live in Tower Hamlets and then added another

layer to show the poverty in Tower Hamlets based on the Index of Multiple Deprivation (Department for Communities and Local Government, 2011). Different types of services were then identified in the map to show their availability in socially-excluded areas in Tower Hamlets.

Toynbee Hall's Clients in Tower Hamlets



Case Study

Linda’s story - Linda is a Cypriot woman in her 60s who lives alone. She was diagnosed with cervical cancer in 2009 and Non-Hodgkin lymphoma in 2013. Following the researcher’s introduction, Linda’s recollection of her cancer journey focussed on a lack of support:

“Nobody came to see me; nobody asked me if I needed anything, nobody helped me in any way at all. ... No services at all. ... It chokes me up just to think about it. (Linda)”

Sharing how she was told about her first cancer, Linda said:

“When I opened the door, she [my GP] didn’t ask if I was with anybody, she didn’t ask me to sit down. ... You can imagine my shock: I’m standing at the door and this doctor is telling me that I’ve got cancer. What do you do? (Linda)”

Cancer has changed Linda, from 'a very outgoing person' to someone who does 'not leave the house':

If I don't go out anywhere, I don't spend any money. And when I go shopping... I can't spend more than £20. So I make sure what I buy is enough to see me for the whole week. (Linda)

For Linda, fear for her health and financial difficulties mean she has to 'stay at home 24/7'. Her account strongly calls for financial assistance as well as psychological and social support for her, especially considering she does not have close contact with family and friends.

Understanding and positivity

The participants noted that 'sincerity' (Zariya) and positivity help them cope better with the draining physical impact. Health professionals play a big part of their journeys, so doctors and nurses' accounts placed great importance on this need and this research suggests that they are largely helpful.

Some participants talked about the importance of clear communication, with positive accounts of the step-by-step explanations provided and more negative descriptions stressing the lack of clarity. Different experiences suggest the importance of patient-centered care that provides information that patients require and communication that suits their needs. Robert, a bladder cancer patient, for instance, described a negative experience. He felt treated 'as a body' rather than as a person. His examination was intrusive and onerous to the extent that he delayed re-examination when he noticed symptoms returning.

It makes my eyes water thinking about it [the examination]. They've got to put a camera up your penis ... and you're lying down, and there's like, four or five people round you. ... You feel bad in yourself for letting all these people round you messing with you. (Robert)

For a few other respondents, understanding their needs meant understanding their difficulty of waiting for three hours for a chemotherapy session. They said that it takes six hours to complete a session of treatment and they are often exhausted by the time they complete the treatment and make their way home. Reducing the waiting time would have been a clear improvement for

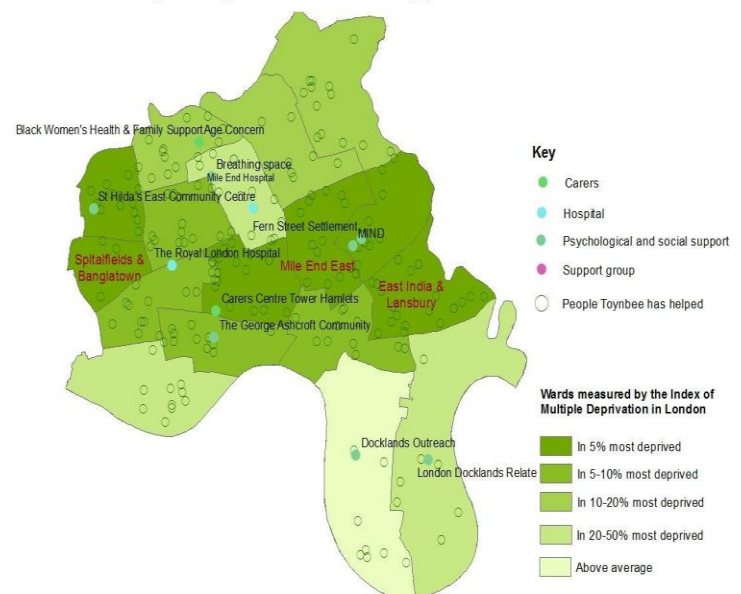
them. St Bartholomew's Hospital, for instance, has been making efforts to do so.

Having someone to talk to

Some respondents, such as David and Mark, highlighted the importance of psychological therapy and workshops. But sometimes, other patients can also be a good source of psychological and social support. This was emphasized in our interview with Joseph, a fiercely independent older man who had previously worked as a nurse:

By speaking with the patients who had the same cancer treatment ... you feel much better, you talk it out (Joseph).

Psychological and Social Support in Tower Hamlets



From this map, we would also like to draw attention to the lack of psychological and social support services for people with cancer in three wards: Spitalfields and Banglatown; Mile End East; and East India and Lansbury. These three are among the 5% most deprived wards in London, suggesting a greater need for local service provision.

Resolving money worries

In this study, apart from those who had already retired or been unable to work because of other illnesses, all the cancer patients and family members had to either stop working or reduce working hours. They therefore believed that it was 'foundational' (Debbie) to receive help in resolving their money worries.

Integration of services

Most respondents had multiple needs and issues. Many of them had benefits issues; Perm, Mark and Linda had housing problems; Zariya had a child care issue because her five-year-old daughter was not allowed in the hospital. This range of issues demonstrates the variety of needs among people affected by cancer. Integrated services are required to provide 'one-stop' access to support.

Recommendations

Short term:

- Hospitals should develop strategies to reduce patients' waiting time for treatment sessions, such as that for chemotherapy.
- Hospitals can investigate starting a support group in the borough or building on existing social groups.
- There needs to be an information pack which is updated regularly. The pack should include main services such as psychological and social support services, generalist, benefits and debt advice, exercise groups and older people's services. This information pack can be given to the patients at the point of diagnosis.

Medium term:

- Further training should be provided to help both doctors and nurses understand patients' experiences and develop better and more positive communication skills.
- Hospitals, Macmillan or other support services could set up a befriending scheme where volunteers who have recovered from cancer support patients in the hospital.
- Macmillan can act as an initial point of contact and be more proactive in referring people onwards to other services.

Long term:

- Health providers should work with the media, encouraging positive thinking on living with cancer.



Eden Care

Eden Care – “The Voiceless”

Organisation

Eden Care's objectives are not to replace existing provision, but work in partnership with other providers. They plan to engage service users in a culturally inclusive manner to increase and enhance their quality of life through friendship and advocacy. Their befriending and advocacy service works with adults and young people who are terminally ill or reaching the end of their lives.

Summary

Eden Care's research method was based on obtaining qualitative data through interviewing 10 service users from a BME background who had differing health needs. By using a 'one on one' interview method of gathering data researchers acquired first-hand information on how service users felt about NHS services.

Key findings

Case Study 1 - Almas Miah - Father of Mahima Begum

Condition: Cerebral Palsy



“I and my wife have to take turns staying awake at night time, in-case she chokes, and she has an epileptic fit, her medication has to be done on the spot.”

“I could do with a lot more help, the only care my daughter needs is 24 hours care, throughout the rest of her life.”

Almas strongly believes that the lack of communication between hospital staff and his family were contributing factors to the ill health of Mahima on the day she was

born. He is now faced with caring for his daughter for the rest of her life and struggles to meet all of her needs including providing all night supervision due to the risks of Mahima choking during the night. He also struggled to understand the complexity of words, medical acronyms and terminology used by some of the NHS staff. For Almas' wife, English was not her first language and to compound matters further, she also found their use of medical terminologies difficult to understand. Almas' wife would have benefitted from pre-natal classes delivered in the Bengali language in order to understand the process in having a baby and to become familiarised with the services on offer at the hospital.

Case 2: Rushna Khanam - Sister of Shopna Khanom

Condition: Terminal Cancer



"The G.P's kept on saying that it's probably nothing... gastric pains... they said it was kidney stones".

"They found out (after 6 months) that she doesn't have kidney stones, she's actually got stage 3 cancer".

In a desperate attempt to treat Shopna's illness her family took her abroad to Bangladesh and India to receive traditional folk medicine which was ineffective. This exacerbated the problem as the treatments given had almost killed her. Rushna believed that if the NHS had played a more active role in persuading the family not to seek treatment abroad this could have saved the family from the unnecessary journey.

Rushna also believes that there is a lack of awareness of the symptoms and conditions related to cancer especially around prevention, it's detection at the earliest stage and in how to cope with these life changing conditions.

Case study 3: Abu Mumin – Son of Late Saleha Begum

Condition: Died of Heart Failure

(Whilst in hospital) "She wasn't well and was on lots of medication, she needed a wash and all of our family members were there, and to our shock and surprise, two male nurses came to give my mother a full wash, we were horrified and shocked"...Why was her dignity and care not a priority"?

Abu Mumin's account in the shortfalls of the care provided to his mother where cultural and religious sensitivities have been overlooked goes to show that there is still a long way to go in order to truly make our health services more inclusive for our boroughs diverse needs.

In an interview, the Imam of East London Mosques, Shaykh Abdul Qayyum reinstated the importance of meeting the needs of the Muslim and wider community during their time of need.

Recommendations

1. Promote Bilingual Services

Translation services for Bengali speakers should be promoted extensively throughout Bengali and Muslim media channels including TV, Radio stations and print media. This would help raise awareness for patients to use the bilingual services on offer and to feel more confident in using NHS services independently.

2. Culturally Inclusive Training

NHS staff should also be given culturally inclusive, local training in order to understand Muslim sensitivities, especially when personal hygiene care is given by nurses of the same gender and not the opposite as this can easily offend.

3. Greater emphasis to be given to disabled patients

More awareness training for NHS staff to understand the unique needs for disabled patients. This awareness could be relayed through a scheme in where staff can have immediate access to patients' specific needs.

4. Community empowerment through locally delivered services

More services delivered through local organisations such as mosques and community centres being trained

in delivering awareness on campaigns on preventing common health illnesses.

5. Senior Management Team at the Royal London Hospital

To advance greater care, The Royal London Hospital staff should be more reflective of the local community including the senior management team.

6. GP Services

Al-Ishaara



Organisation

Al Ishaara is a local charitable company that has worked with and for deaf and hard of hearing people since 2008. They provide a broad selection of deaf friendly services in Tower Hamlets ranging from children's and adults Islamic classes, a Friday community sermon translated into BSL, a deaf youth service, marriage service, a dedicated deaf employment service and multiple events across the year to improve community cohesion across the UK.

Summary

The research sought to investigate access to GP Practices for the deaf community living in Tower Hamlets and also how GP practices could play a greater role as places to receive wider health and wellbeing support, i.e. linking patients into health programmes, community services, welfare support, social activities etc.

This research also sought to identify communication barriers and highlight the needs of the deaf and hard of hearing (HOH) community when accessing GP services.

Al-Ishaara gathered the views of parents and children with Special Education Needs on how services could work better together to improve the quality of their

care. A combination of methods was used to gather information, from surveys, to focus groups.

Key findings

Key questions were asked to parents or adults who were deaf. They included the following;

Parents were asked what difficulties they face when visiting the GP as a deaf person or parent of a deaf child. The issues were:

1. Need to book BSL interpreter communications problem
2. Communication barriers need to communicate in BSL
3. Want to book interpreter but they didn't provide one
4. CSW level 3 is wrong should be interpreter level C
5. Communication problem with GP without interpreter (British Sign Language) "I needed British Sign Language interpreter at GP appointment but they sometimes don't provide a BSL Interpreter for me"

Q- Which health programmes are you aware of that benefit your child or yourself?

1. Most health programmes are not deaf friendly. They need to provide visible hand or BSL interpreter.

Q – Have you received any information from your GP regarding health programmes suitable for the Deaf?

"Very difficult [to make appointment], as I have to drive there because I can't use Type Talk and doctor doesn't have a text phone."

From the focus groups, it was found that both the hard of hearing and deaf groups received no information from their GP regarding health activities that are suitable for those that are deaf.

The Deaf Community is facing constant difficulty with telephone appointment booking systems, verbal prompts when their doctor is ready to see them, and rarely have a clear understanding of their diagnosis and treatment.

Waiting times for interpreters in GP appointments seem to be a massive problem. At the moment many people have to wait weeks to book a sign language interpreter who can make sure the patient and clinician are able to clearly communicate. There is an obvious link between these delays and poorer general health

Recommendations

1. The views of the local deaf and hard of hearing community about how GP Practices could play a greater role as places to receive wider health and wellbeing support need to be listened to.
2. The views of parents of children with Special Education Needs and children themselves need to be listened to on how services could work better together to improve the quality of their care.
3. Better forms of communication from all services through leaflets, videos and information boards in practices. Provide trained professionals in BSL to communicate effectively about the needs of the service user.

Asian Women Lone Parent Assoc



Summary

Through a focus group/workshop and one to one's, thirteen women were consulted on how to improve Asian lone mothers' access their GPs for their health and wellbeing needs; what would they like from their GP and what are the barriers to them accessing health services in Tower Hamlets.

The women ranged from ages 18 to 45 years old and consisted of a mixture of Indian, Bengali, Sri Lankan and Pakistani women who arrived in the UK through marriage and those born and brought up in the UK.

Most of the women attended GPs in the Limehouse, Poplar and Gill Street areas.

Key findings

In general it was found that the women had a positive experience in Tower Hamlets with health services for them and their children. The main use of health service was of their GP. Frequency of accessing their GPs varied for the women and much of this depended on their children's health needs. Examples included twice a week, once a month, once every two weeks, and twice a month.

It was found that the biggest challenges faced in trying to help women and their children to be healthy and well were in relation to access and support services including getting their children into a good school, support to find a job/volunteering, knowledge and support to access local exercise services for themselves and their children, wanting to swim but not knowing how to, finding healthy food expensive, managing their child's fussy eating habits particularly around not eating fruit and veg. Stress was a common challenge with two women saying they would like help to go on holiday so they and their children can feel better, managing own illnesses such as tuberculosis and eating habits.

With regards to mental health most of the women knew what this meant in that it related to 'your' mind. Four women did not know what this was. Interestingly over half did not know where to go to access mental health services. Three mentioned their GP as a source of help and one mentioned counselling.

Getting housing and a job were seen as the most common needs in regards to improving general health and wellbeing, examples given included getting a good permanent home, support with childcare, a positive change programme for women, help with jobs and support with housing to alleviate stress and help with mental health.

Specifically with sexual health most women would go to their GP. One mentioned not having a female doctor has prevented her seeking help and that she is now waiting for a female doctor.

Recommendations

1. To look at a holistic programme that addresses all the needs of the women impacting on their mental and physical health. Stress is significant factor in their lives so looking at activities that will help alleviate this would be key.
2. Health programmes would need to be highly sensitive in addressing the cultural needs to really have a significant impact on health and wellbeing and in further increasing their capacity to access health and wellbeing services in Tower Hamlets.

Stalwart Communities Limited

Summary

This study was designed to assess the need for, and possible benefits of, provision of a personalised educational health information service for families that have individuals with serious illness and chronic conditions. It aimed to provide an initial step towards evaluation of the resources that might be needed to deliver it. The family of interest is the group of related individuals whose lives are, or are likely to be, most affected by a health disorder – for practical purposes, the group living at the sufferer’s home.

Researchers conducted a series of interviews with each family, with family members together and individually. Each family was asked to assess how well or otherwise it had been advised about the patient’s problem and the future, and to give an idea where the best advice came from.

Twenty-six families were admitted into the study, ranging in size from more than 10 down to 4 members. Seven families gave their region of origin as in the United Kingdom, 11 in Asia, 5 in Africa, 2 in the Caribbean, and 1 claimed origin in more than one of these regions.

Key findings

Most of the information that families knew about the illness was from their doctors.

Families were asked a series of questions to understand the family’s feelings. These included:

How much do the problems affect you? It was found that 92.3% said that it affected them a lot.

Over half of the families have said that they wanted to know more about their family member’s disorder/illness.

While a majority of families drew information from both hospital-based doctors and general practitioners, individuals did so to a rather smaller extent – perhaps suggesting that access to doctors for all but the ‘principal’ caring family member may be more difficult.

A majority of the individuals studied are themselves made vulnerable by the contrast between satisfaction from factual information they gather and constant anxieties prompted by the suffering they see close at hand. Inevitably, some of them will fail to respond to some other of contemporary life’s challenges. They may themselves become the patients of tomorrow.

Recommendations

1. Further interviews should be carried out as soon as possible, and that results – with a more thorough analysis, engagement with professionals and the third sector, and a wider discussion – be put together in the near future.

7. Eastern European Communities

DASL's – “Research into the Health Care needs of people from the Eastern European Community in Tower Hamlets”

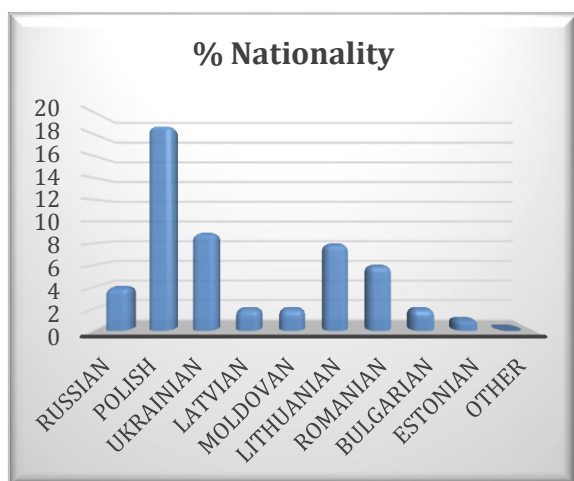


Summary

DASL aimed to acquire a mixture of feedback both from prospective health care service users and professionals who have worked with people from the Eastern European Community (EEC).

DASL worked with EEC service users and staff from Providence Row, NHS health visitors, The Fellow Centre, Doctors of the World, Vision Care for the Homeless, Tower Hamlets Community Mental Health Teams, Substance Misuse Services and GP Practices and Health Care Centres.

They used two questionnaires, one for individual service users and one for professionals. The service users were interviewed on a 1:1 basis and also in groups.

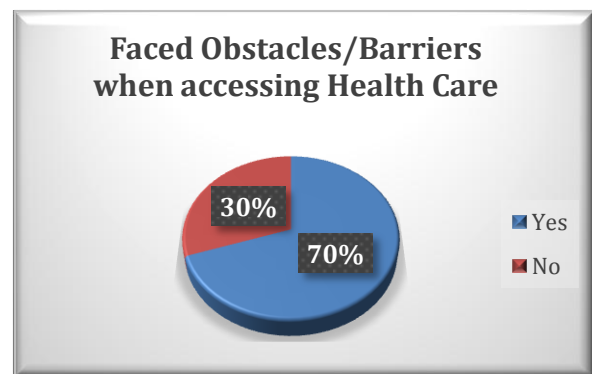


Key findings

All had accessed some form of health care, with the majority accessing a GP surgery, NHS Hospital and Dental care.

40% stated that the registration process for GP's was complex and lengthy, some waiting months before they were informed that they had been successfully registered.

Women who had been pregnant said they were unaware of any ante natal care or what they could access in the way of pregnancy support. One woman stated that she felt alone and frightened and didn't know where to turn for help.



Most stated that language was the biggest barrier with 77% saying this caused problems when trying to access health care along with the second being homelessness with 45% saying they experienced problems.

Antenatal care was raised by the women we interviewed and also by some of the professional agencies. It was stated that women at any stage of pregnancy were not aware of health care, ante natal classes, activities or follow up care required during pregnancy. Those that had accessed support found the language barrier confusing and felt they were unsure of health care requirements.

Some people we interviewed felt that a lack of adequate identification (e.g. passports, birth certificates, NIN cards, etc.) was a barrier to accessing health care and registering with a GP practice. Concerns were raised by one professional agency that when a person is trafficked or endured forced labour, very often they flee without any documents or identity.

Recommendations

1. Information about health care services for people from the EEC be available in accessible formats (language, electronically via websites, literature in accessible venues), specifically Polish and Russian. Extend the hospital telephone translation into English, Bengali and Polish & Russian
2. Translation be available for pregnant women at every stage of pregnancy – including written information about stages of care.
3. Registration at health care practices is explained or accessible in written information in EEC languages, or alternative information about where people can go if they are not eligible to register with a particular practice.
4. Better advocacy and support from specific agencies who are clearer of EEC issues
5. Some organisations are already putting into practice ways to improve access to health care for their service users, lessons and good practice should be shared across the sectors.
6. Training for health care professionals on the intricacies of the EU regulations and health care in the UK for EEC.

8. Dual Diagnosis

East London Radio– “Somalia Men – small problem or a big issue?”



Healthcare

Organisation

East London Radio (media) and Meducate Healthcare (public health) collaborated on this hugely important

topic regarding dual diagnosis: mental health and substance abuse in regards to Somali men’s health.

Summary

This project set out to investigate the potential link between mental health and substance abuse and the current service provision in a hard to reach group – the male Somali community in Tower Hamlets.

The aim was to answer three questions:

1. What are the experiences of people who have mental illness and a pattern of substance misuse?
2. What are the issues in relation to accessing services?
3. What would help people to move forward in their lives?

The research used face-to-face open questionnaires with the community. Additional case histories were transcribed, as the interviewees (45 interviews were conducted) wanted their stories told. Two podcasts were selected, as the narratives required a public platform. The age range of the participants was from 25 years to 79 years with a mean of 42 years.

Key findings

On questioning the male Somali community face-to-face the project became aware that the fundamental issue was not about a mental health diagnosis, but lay in an absence and misunderstanding of its manifestation.

Loneliness was expressed as a common state of ‘mental health.’ Isolation, worthlessness and hopelessness were given as descriptors of current ‘feelings’. Prescription and over the counter medicines (analgesia) in particular were taken to dull sensory pain, like ‘feelings’. The men expressed themselves in terms of feeling marginalised by lack of work opportunities, changing roles within their families and parenting gaps. Even in their own communities, they recognise that it is a spiral of decline that needs to be challenged.

The Somali community continue to feel relegated in Tower Hamlets, due in part to the written language difficulties. Somali language is an oral language, hugely descriptive and pictorial.

We cannot accept that mental health is just a medical problem. However, we can give testimony to the dearth of untapped skills and experience that already exists in the community. This should be explored, harnessed and utilised. There is an absence of career or coaching for this cohort; and the Job Centre and benefits trail has failed to harness their previous expertise, skills and knowledge.

In general, services seemed adequate, flexible and easy to access. Mental health seemed to be the more prevalent of the two topics (alongside substance abuse) and evidence suggested collaboration between other services to meet medical, social and psychological conditions.

93% were currently unemployed and the length of time was between 1 year and 12 years. However, 'feelings' were frequently mentioned. Descriptors around unemployment included 'hopeless'; 'waste'; 'sad'; 'angry'; 'unhappy' as the commonest themes.

2% of the participants declared they had mental health problems. Diagnosis was given medically and they were on antidepressant medication.

"I'm on tablets. My friends know. It helps me. When I had a job, I wasn't on tablets." - S.M 39 years, E.1.

Few knew how to start a conversation with their GP about how they were feeling.

"The doctor ask me what wrong, I say I have pain, he say where.....? I get tablets for pain in head" - O.H, E14

Mental Health remains a taboo topic within the community (Use of language, 'mad, bad') and is still misunderstood.

"I go to Germany. I have family there. Nobody knows me. I have bad demons." A.M, E.2 55 years

Loneliness and feelings of 'sadness' and 'despair' is often treated with painkillers, often prescribed, but more frequently self-medicated

Recommendations

1. The community wants to become empowered to be more responsive to their care needs:

We suggest development of an App (Software application) that is both written and pictorial telling

people how to recognise symptoms of mental health/Substance Abuse. This could be developed in the schools within the Science and Technology curricula or indeed within QMU (Computing) and the community could have a say. An example of such an App is one that has been put together by "One in Four" aimed at teenagers. It addresses the difficult issue "What to say to the Doctor" when you are feeling depressed, lonely etc.

2. The need for formal education, such as ESOL in a place of study, not a community facility:

They identified the local University (Queen Mary), which they felt was most appropriate. This may create a revenue stream for the Institution and potential employment of Tutors. This visibility would enable them to engage in a mixed community and share a life-long learning platform.

3. Parenting skills were identified as a key issue. Grandfathers, uncles, brothers and fathers all stated they felt a cultural gap due, in part to language:

Formal parenting classes – particularly for men – many of whom have adopted many childcare responsibilities.

4. Football is a national sport in Somaliland. It is played in small groups within the community in public spaces within the borough:

We suggested that a football league is set up. The local authority could sponsor the kit. This would give out a clear message of 'Health for All' It would create a platform for stronger family bonds, time to talk and the added health benefits of engagement.

5. Men expressed an interest in their history and culture being on the schools curriculum and were willing to give their time voluntarily.

Suggestions included participation in Black History month in the schools and perhaps access to the Whitechapel Gallery, to tell their stories.

In addition they expressed a need to engage with the wider community in the Borough and participate in the voluntary sector. This would enable them to create a working profile whilst they gain experience and build skills.

6. Meeting care needs alongside an ageing population- it was felt that keeping fit and active was very important as its benefits include mental health.

A designated care agency set up in the borough would benefit the community, in keeping people independent in their own homes whilst providing additional employment opportunities. This initiative may attract government funding and business loans and potential private investors.

Providence Row Housing

Summary

This explored the experiences of people with dual diagnosis in Tower Hamlets: A participatory research project conducted by Providence Row Housing Association's Peer Consultancy Team

Dual diagnosis refers to people who are experiencing mental health difficulties and use drugs and/or alcohol at the same time. This has long been a challenging area for support providers who struggle to define which should be viewed as the predominant underlying need and which should therefore be treated first. As a result, people with dual diagnosis have often found themselves being bounced back and forth between mental health and substance misuse treatment services.

Eleven separate target groups were identified for the community intelligence program. We chose to target people with dual diagnosis from homeless or insecurely housed populations.

Providence Row investigated the following questions:

1. What are the experiences of people who have mental illness and a substance misuse and/or alcohol issues (often referred to as dual diagnosis)?
2. What are the issues of accessing services?
3. What would help people to move forward in their lives?

The research team (three women and three men) all had lived experience of requiring support for a range of presenting needs. Creating a 'peer consultancy'

The methods used in the research included:

Group Work: Participatory Appraisal - PA is a series of interactive, visual tools and techniques that can be used to help overcome barriers such as formal literacy and numeracy. PA sessions were delivered at 10 different sites across the borough. 56 people attended the sessions- 34: Male, 22: Female.

Interviews were also used in this research, 2 men were interviewed. One is White British and the other of mixed heritage. 1 woman was also interviewed. She was White British.

Key findings

1. Relationships – people placed a great deal of emphasis on feeling able to 'relate' to or feel some affinity with their human points of contact through the various services they interacted with. A sense of commonality and understanding was deemed a strong determinant of the level of success achieved in both drug & alcohol and mental health services. It appears that there is a direct correlation between caring and empathy, the building of a relationship, and the perceived quality of support received.

2. Housing – "Warehousing" people with similar problems together has a negative impact on recovery. It is more difficult to stop using drugs and alcohol and remain abstinent when surrounded by others who are using heavily. This in turn has a negative impact on mental health.

Another important factor that arose was the 'moving on' process. Many of our participants felt that they had been 'forgotten about' once placed in a hostel. With some reporting little or no structured support or advice around re-housing.

3, Access to Support - Many people felt that they didn't know about all the services they could access. They also spoke about the challenge of having to navigate help for different presenting needs and the difficulty of having to repeat their story every time they meet someone new.

Waiting times - There appeared to be a vast difference in the waiting times for initial contact with certain services. For instance the waiting time for an assessment for statutory Mental Health services was often felt to be overly long, whereas the waiting time for an assessment for drug or alcohol services was found to be short in comparison.

Formality of services - Participants felt that drug and alcohol services tended to be less formal which made access and engagement easier for them. Statutory mental health services on the other hand were thought to be too structured and formal. This meant people often felt more comfortable seeking help from drug & alcohol services.

Communication - Communication of information between services was felt to be poor. Service users found themselves repeating their stories over and over again across a range of services. Many found this frustrating and disheartening. The fact that there doesn't seem to be any central information hub or collection point for services users' information was a recurring theme in our research.

Peer Support - Almost every participant through the research spoke of the value of lived experience in the delivery of services.

4. Use of time -Participants who had stopped using drugs & alcohol and felt their mental health was stable spoke overwhelmingly about the importance of having something positive to do with their time.

5. Understanding dual diagnosis - Many participants had been passed from service to service until they found one that 'fits' their support needs. Instead people feel they require help for a set of problems that all impact on each other.

Recommendations

1. Statutory mental health services should consider how to become more effective at engaging those with dual diagnosis who are unable to access overly structured support. An example of this would be to provide in-reach to hostels and other homelessness services
2. Drug & alcohol and other mental health services should also be providing in-reach to hostels. This will help initiate contact for those requiring support
3. Staff in voluntary sector services should be enabled to understand how to engage people with dual diagnosis more effectively. This could be done through the provision of training and networking by statutory mental health services, which would

also facilitate more effective joint working and information sharing

4. A better relational approach should be adopted by services offering support to people with dual diagnosis. A good working example of this is the Enabling Environment (EE) and Psychologically Informed Environment (PIE)
5. A single point of assessment and access to support for people with dual diagnosis
6. Lived experience should be incorporated into service delivery wherever possible. This could be done in several ways:
7. Employing more people with lived experience within services
8. Expanding the Recovery Club model to be used within more services
9. More peer delivered support services
10. More service user involvement in commissioning and designing of services