

Do health and social care services in Tower Hamlets work well together?

A Community Engagement Report

September 2018



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Do services in Tower Hamlets work well together?

It is typical for complex patients, over the course of their journey, to see more than one medical professional and also for social care and community services to be involved.

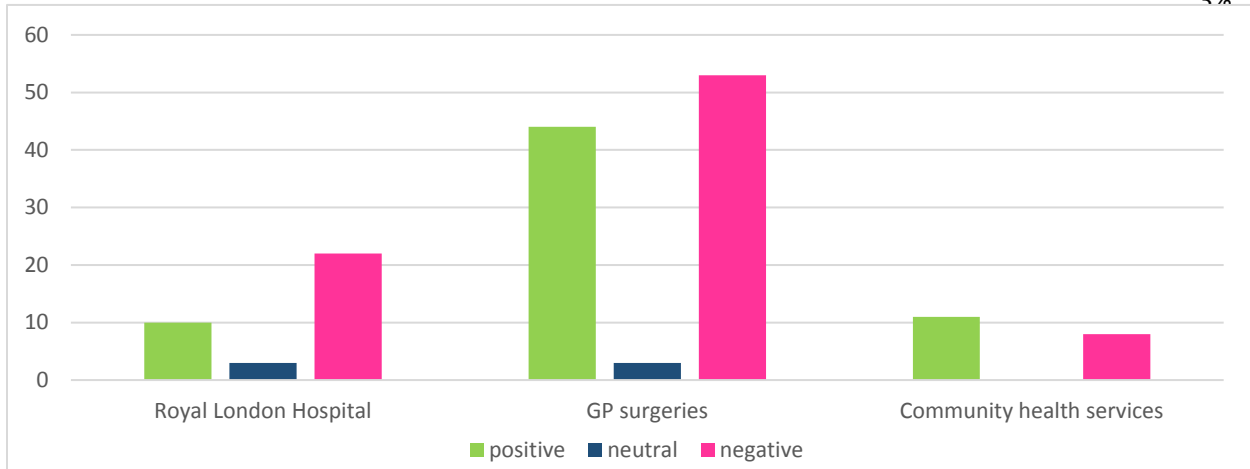
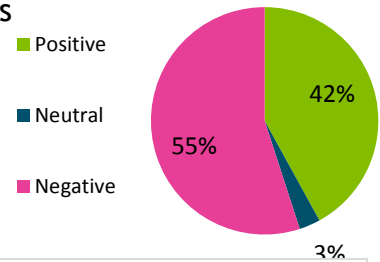
For example, a pregnant woman will be referred by her GP to antenatal midwifery services. If she suffers from a mental health issue and takes medication for it, she may also be referred to the Community Mental Health Team or a consultant psychiatrist in the hospital. If she has a sensory disability (for example, she is blind or deaf) she may need further assistance from a community service for disabled people. A person suffering from fibromyalgia may be treated by a neurologist, a pain team specialist and a surgeon, in the same hospital or in different settings. An older and frail person with mobility issues may be discharged from hospital after a fall with a care package involving domiciliary care, home adaptations and physiotherapy appointments.

We have set out to examine the question: **Do health, social care and community services in Tower Hamlets work efficiently with each other?** To answer this question, we conducted a snap survey online (16 respondents), carried out in-depth interviews and analysed data obtained through our usual channels.

The bigger picture

Overall, residents' opinion of *cooperation between services* is leaning negative (based on 50 individual comments collected in 2017 and 2018, 172 issues).

Most comments referred to GP surgeries. The Royal London Hospital, on the other hand, had the highest percentage of negative feedback (62%).



When services work well with each other

“Lucy” (name changed) is an active senior who lives independently and takes part in multiple community volunteering projects. She suffers from various long-term conditions, including arthritis, heart disease and a sensitivity to chest infections. She does not currently need any kind of assisted living or domiciliary care services, but she expects that she might in the future, particularly after her having undergone major heart surgery.

Community health services available in the borough have empowered Lucy to have a healthier lifestyle and continue to live independently.

Her GP referred her to a falls prevention class, which she found useful: *“I did 10-12 sessions through my GP- it was very good. I do appreciate these classes and going to them- FULL MARKS! And very nice people delivering them too!”*.

She also attended various activities provided by the Barts Health Respiratory Care and Rehabilitation Service (ARCaRe). Apart from offering a useful service in itself, the physiotherapists at ARCaRe gave Lucy the opportunity to find out about even more useful services in the community that allowed her to live independently in her home: *“I went to see them and they assessed me, they have their team of trained physios. My arthritis was quite bad, so I wasn’t suitable for the usual exercising classes they do- but I was told I could do tai chi and it was FANTASTIC! After 1-2 classes, you really find your flow and energy. Their exercises are designed to help you breathe better, deeper- or help you move your body. They teach you how to use your lungs. I was so impressed. Then 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. They also asked if I needed adjustments in my kitchen. That was very good, many people in my 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.”*

ARCaRE also offered signposting to mental health services:

“[At the ARCaRE class] 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. So 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.”

“Miriam” (name changed) had been suffering from depression for many years when she became pregnant. She was taking antidepressants prescribed by her GP, and she was concerned about how her diagnosis and her treatment could impact upon her pregnancy and her new baby.

A referral made by her GP to Gateway Midwives and the Community Mental Health team ensured that Miriam’s mental health was taken into account and addressed throughout her pregnancy, leading to better outcomes for herself and her new baby.

Miriam’s named GP was already familiar with her medical history and was able, from the beginning, to support her:

“My GP has always been very supportive and has been my main medical support for depression for many years. When I fell pregnant she referred me to the Gateway midwives and my midwife was very good, kind, supportive, professional and informative. (I also had a fantastic student midwife).”

Because of her antidepressant treatment, Miriam’s GP also referred her to the perinatal mental health team, where she has been seen by a Clinical Nurse Specialist, who provided valuable support:

“I noticed in a letter she felt I had some PTSD (which no one has diagnosed before) and after having many bad experiences with psychologists / therapists she is probably one of the few who has bothered to listen to my story and understand my experience. I saw her only a few times during the pregnancy and after as my mood was good and stable but I feel this can at least partly be attributed to the good support network provided. I did feel very emotional postnatal and with difficulty establishing breastfeeding but this is to be expected and stabilised again. Overall I felt all the professionals I saw for my mental health were all very caring, dedicated and had good communication between them. I think this is important to note as with all the privatisation and breaking up of services the communication between teams will be disjointed or lost and this is extremely dangerous for patients with mental health problems.”

Generally, people who have experienced services working well with each other spoke about efficiency, good admin and good communications. GPs, midwives and mental health professionals play a particularly important role in signposting patients towards community resources.

Services that work well with each other do so *as a network*. Support networks for patients (whether support is provided by professionals or peers) emerge from successful collaborations.

People who gave positive feedback about their GPs mentioned that they are able to cooperate efficiently with both hospital consultants and community services, and that they provide patients with referrals, signposting and social prescribing, while remaining at the centre of the team providing treatment:

- It's an amazing surgery, I was under their care when I gave birth with my first child. They're very efficient with signposting, social prescribing and referrals- they pick up on your needs and send you to exactly where you need to be.
- I had an urgent referral which the hospital was not responding to. My symptoms worsened and so I went to see the doctor. Who immediately sorted out all the tests for me and got in touch with the Registrar at the hospital. The swiftness and concern with which the doctor handled my case was highly commendable. It was the best experience I had seeing a GP.
- I became unwell recently after returning from holiday. The doctor was very friendly and professional and even saw me again without formally booking due to the state I was in which was much appreciated. Resulted in a referral to the hospital and a swift diagnosis. I also have a child with SEN and the receptionist recommended I see this particular doctor, who has also been amazing. This health centre and its GPs have supported me with chronic and acute medical problems excellently for the past 20 years. My previous GP helped me get a prompt hospital appointment when I had a suspicious looking mole on my left arm a few years ago. This prompt GP followed by a prompt hospital appointment saved my life; the mole turned out to be a malignant melanoma.

Flexibility is also praised by patients:

- I've had a couple of operations and they've always been on top of it. Coordinated my hospital appointments when I needed it.
- I needed a very important appointment which they chased up for me and got me in with a choice of dates. Thank you!

GPs receiving positive feedback on working with other health providers also organise efficiently *within the surgery*; admin and medical staff work well with each other:

- Everything is processed quickly and efficiently- blood results, follow up appointments, emails and texts, usually within a couple of days. The GP goes above and beyond to help, referrals are quick and he follows everything up. The nurse is also very thorough, nothing is missed. The reception staff are so helpful when you need to change or cancel appointments. I have asthma and diabetes and they help me to manage them effectively. The staff are wonderful and I see the same two practice nurses all the time. I have set dates for everything so I don't need to make appointments. For the children you just ring up, they ring back within 10 minutes and you get an appointment the same day.
- I have found the booking appointment easy and receptionists courteous. The time taken to book an appointment seems very efficient and have so far been able to book an appointment between one to three days of my call. The Drs I have had appointments with are respectful, courteous and informative, have had ongoing treatment or explorations if needed booked within a short time period.

Medical staff at the Royal London Hospital are, in return, praised for communicating efficiently with GPs:

- Child with breathing difficulties. The experience in A&E was positive as they got the help they needed and were diagnosed on the spot. They were then referred back to their GP for a follow up visit.

The ability to respond promptly to referrals from GPs and other hospitals is also praised:

- Was seen within one hour after being referred by Whips Cross. The facial surgeon was top class and told my grandson everything they were doing at every stage and answered all of his concerns.
- Once referred by the GP we were faced with a long wait for the initial appointment, however there was a very understanding and kind member of staff at the central appointments who explained us to keep ringing and ask for cancellations which we did. We managed to get an appointment within two weeks.

Some consultants are commended for being able to organise necessary testing or referral to other departments swiftly and efficiently:

- I contacted the on-call gastroenterology registrar for urgent advice. The doctor listened to my concerns, reassured me and arranged tests for my complaint. She then took time to keep me informed by regular phone calls in the following weeks of the findings of my tests. She made a worrying couple of weeks a lot more bearable with her kindness and compassion.
- In one hour on Monday I had an appointment with a doctor and with his referral I was in the walk-in X-ray department at Barts. Had the chest X-ray within minutes and was back home in bed in just under an hour. Superb service. Thank you for these very fine facilities.

When needed, good consultants can also signpost outside of the strictly clinical realm, to health-promoting activities or community services:

- I had been diagnosed with lumbar canal stenosis early in 2009 and advised by the wonderful consultant I saw then that I would probably need surgery in 18 months to three years, but that in the meantime I should focus on maintaining my weight (I am a healthy weight), strengthening my core, and 'Darcey Bussell'. After a few seconds thinking he was suggesting I take up ballet, I realised that he was referring to pilates. The following day I took up pilates. I also walked a very great deal, almost every day (I was then 62 and had taken early retirement). I did not need the operation until 2015. The operation was a phenomenal success, the staff were wonderful, and I shall be forever grateful. I believe my rapid recovery was due to the excellent treatment at the hospital and to the fact that I followed the original consultant's advice. The operating consultant was outstanding.

For patients with mental health needs, psychotherapists, support groups and community mental health teams also need to work closely with GPs and other health providers. For people who may be in mental health crisis, efficiently processed referrals and short waiting lists are valuable:

- Kind care and short waiting time. As above, was treated with kindness and respect and very short time from referral to being seen. Was left feeling there was hope for support and care (Community Mental Health team).
- Very easy [to access the service, got an appointment in] one week after I was referred, I'm taking part in activities- drop-in on Fridays, creative writing, Time To Talk peer support groups (Voluntary organisation for mental health support).

Therapists themselves can also signpost clients to further resources, leading to improved health outcomes:

- Psychological therapies Mile End hospital. [The therapist] is very good. Gave me lots of information. Quite inclusive. Referred me to YouTube videos to watch to help support my therapy. I had 20 weeks of therapy and it was quite intensive. Reflecting on the service I would recommend developing local resources. They should do supporting videos with local therapists. They could be providing reminders of what users could be doing after the end of their therapy to self-manage, so when patients leave things don't just come to an abrupt end. This could fit into the recovery college model. It seems more therapeutic if it is local - you identify with it more.

When services don't work well with each other

Lucy, who is in her early 70's, is the youngest patient to date to have undergone a TAVI (Transcatheter Aortic Valve Implantation) surgery in the UK. The preferred treatment for Lucy's condition is currently open-heart surgery. TAVI is a relatively new procedure, and it is typically only offered to high-risk candidates for conventional surgery (typically old and frail patients who are not well enough to have open-heart surgery). Because of her multiple co-morbidities, including arthritis, osteoporosis and high sensitivity to chest infections, Lucy had to advocate for herself and persuade the multidisciplinary team to allow her to have a less invasive TAVI procedure instead.

Lucy was discharged from hospital without any leaflets or information about how she could manage her condition further. What's more, her GP was not properly informed of her needs post-surgery.

"I asked my consultant about aftercare for my recovery period and the consultant said "We're not good at things like that." I had just had a heart valve replaced! But there was nothing available for people who had undergone the TAVI procedure.

After discharge, follow-up appointments should have been at 6 weeks- I pushed it to 4 weeks instead, because I was nervous; no one had spoken to me about what to expect after the procedure. I asked about patient groups, but they couldn't tell me anything about any."

It is only by chance, while visiting St Thomas' Hospital for unrelated dental treatment that Lucy found out about support groups and resources available to cardiac patients who have undergone surgery in London:

"I had surgical dental treatment with the top surgeon at Guy's Hospital, it was brilliant. I didn't know they also had a cardiology department, but I saw the sign on the hallway and so I stepped in. I wanted to find out if they could direct me towards any heart groups locally. It was very clean, and nurses were very helpful in trying to find out when and where such groups meet. They have a heart patients' group, and also a post-surgery group, specifically for cardiac surgery."

Because of an increased risk of chest infections post-surgery, Lucy now needs to take antibiotics in situations where they wouldn't be ordinarily prescribed. Her hospital consultants wrote to her GP surgery in this respect, but her GP seemed not to take note:

"My GP did not read the letter from my respiratory consultant and refused to prescribe me antibiotics. He proceeded to explain to me about antibiotic resistance- and I kept thinking: "You haven't read the letter, have you?"

“Jolene” (name changed) is an older woman living in Hackney and suffering from multiple physical and mental health conditions, who has spent a long time in the Mile End Hospital. She is severely depressed and has had a schizophrenia diagnosis which may or may not have been accurate in the 70’s. Negative experiences with some psychiatrists in her youth left her with a lifelong distrust of the medical profession. She also suffers from diabetes and back pain and she is generally frail. After a mini-stroke, she became unable to walk unassisted. She is receiving care in her own home through the council, as well as visits from district nurses.

When Jolene suffered an accident that caused her leg to become injured, her wound became infected, but she refused treatment. The care she received was unsatisfactory to begin with, but her injury made things even worse. Her daughter and main carer “Martha” saw no other choice but to apply to a court order to have her sectioned, so that she can receive treatment.

Jolene was not able to make full use of her care package, because of admin and communication issues between stakeholders (local authorities, NHS, the care agency). This increased the pressure on Martha as her carer and next of kin, and made her recovery more difficult.

“My mum came out of hospital with a care package in place- but this has been done with no consultation with either myself or her (at the time she had been deemed legally able to make decisions). Care workers were put in place, but it took six months after discharge to get her physio and speech therapy; because they just forgot her in the system.

From last year, I kept noticing personality changes in my mum. She stopped letting her carers in and she wasn’t managing well- ever since she came back from hospital. I thought we needed to review her care package, but she would say she can do it all herself, and they said she had the mental capacity to make decisions for her own care, so I stepped back. I did try to request a support worker to help once a week with shopping and cleaning, and we never got one.

My mum started having a lot of pain, it became difficult for her to walk, she wasn’t letting the carers in- carers were constantly calling me to open the door. We tried setting up a tele-care service that would give carers access to keys (through an outdoor key box)- but it turned out no one knew the password and then the keys went missing, so it doesn’t work- they still have to call me. We’ve been chasing this for two years at no avail.”

Jolene has spent time as an inpatient in the Leadenhall Ward at the Mile End Hospital, as well as the Homerton Hospital. In both hospitals, psychiatry wards did not work well with other hospital departments, which meant a poorer standard of care for her physical ailments.

She was initially sectioned and admitted to the psychiatric ward in Homerton Hospital; where staff did not have the proper training to look after her leg injury. They told Martha: *“your mum seems to have capacity/to know what’s going on- but she should have been brought into A&E instead, we don’t have the capacity to look after her physical health but now that she’s been sectioned it’s fallen under our responsibility”*.

Consequently, on a daily basis she had to be transported on a wheelchair to the hospital’s Accidents and Emergencies unit, to have her bandages changed. She had to wait alongside all other A&E patients in the waiting room, sometimes for more than four hours. There was also poor communication between weekdays and weekend staff within Homerton hospital.

“The weekend staff didn’t even know my mum was there; she was still in her nightdress, her bandages were smelling because they didn’t know or notice they needed change, they forgot to give her lunch.”

After she was transferred to Mile End Hospital, the poor standard of care continued. The transfer was poorly managed with pertinent information poorly communicated between medical teams.

“My mum kept requesting that her bandages be changed, staff said “only if and when required”- but they hadn’t been changed since Monday! She kept requesting paracetamol or other painkillers, but they were not given to her. They refused to give her her insulin until the next day!”

Jolene’s discharge back into the community was poorly handled, causing both her and Martha additional stress.

The medical team have disregarded Martha’s concerns, communicated little in regard to the progress of her mother’s care and omitted her and her advocate’s requested invitation to discharge planning meetings. Jolene has been discharged with an insufficient care package in place, and with insufficient notice for Martha to prepare adequately (including ensuring that Jolene’s home is suitable for her to live in, in relation to her impairments and needs. Jolene arrived home to no food in the fridge or meal provision, a prescription to the wrong medication and no suitable bed to sleep in (she had to sleep in an armchair).

“Grace” (name changed) suffers from severe endometriosis, which is causing her an unbearable amount of pain. She is managing her condition primarily with large doses of prescription opiates, prescribed by her usual consultant gynaecologist.

Because of severe aches, she has been admitted to the Royal London Hospital by her consultant. Grace has very deep veins, meaning she can only be cannulated by an anaesthetist, with ultrasound guidance. She is also intolerant to oral paracetamol but can tolerate it intravenously.

Miscommunications between Grace’s consultant, other doctors in the Gynaecology department and the Pain Team left Grace’s pain poorly managed.

From the beginning, she received lower pain medication dosages than those prescribed, which were insufficient, to the extent that her continued pain and nausea prevented her from eating. She states that the Pain Team were unwilling to deal with her case, as they found it too complex.

“Instead of resting, as you do when you’re unwell, I found myself having to advocate for myself and to keep trying to get through to the nurses, just to see if they had done what I or my consultant had asked for - simple things that make all the difference, like making sure they chase things up- that just wasn’t happening, they weren’t doing what they were supposed to do.”

Grace’s regular consultant only saw her once, and prescribed intravenous paracetamol, as well as buscopane, to be administered through a cannula, and referred her to the anaesthetist. Said anaesthetist only showed up after 10 pm in the evening and unsuccessfully attempted to cannulate Grace (the cannula broke because of rough handling by a nurse). A referral for a new cannula was not put in place promptly, causing Grace to remain in severe pain, without her prescribed treatment, over an entire weekend.

A different consultant saw Grace on Sunday evening, and wrongly noted that she was allergic to paracetamol; which Grace promptly corrected. However, when she was cannulated on Monday, Grace found that the intravenous paracetamol has been removed from her prescription list, possibly because of the misunderstanding with the consultant. A nurse later explained to Grace that the Pain Team (whom were not, to her knowledge, involved in her care at the time) had ordered she can have only oral paracetamol (which she was intolerant to) but not intravenous). Until her discharge several days later, Grace has been unable to see her usual consultant or to have her prescription list corrected.

“I feel like the doctors, nurses, people in charge don’t listen to patients- they act like they’re above patients and only they know what’s best. They close their ears- my mum could hear me screaming in pain, crying, calling her constantly, day and night- but they were taking no notice of me.”

“George” (name changed) is a senior citizen who suffers from arthritis and a slight mobility impairment (he walks with a cane and has difficulty bending down). He regularly used the foot clinic at the Mile End Hospital for toenail cutting until cuts to the service made him ineligible. Because of his arthritis, he experiences persistent pain that he manages with a complex prescription, including paracetamol, tramadol and fentanyl patches.

He is also undergoing physiotherapy and using other community health services.

Poor coordination between the Pain Team at the Royal London Hospital and his own GP surgery often leave George in pain, without his regular medication.

“The fentanyl can only be prescribed by the specialist at the pain clinic- but getting an appointment there is like chicken eating eggs- you can’t get an appointment for more than 26 weeks!”

George’s prescription can only be ordered for one month at a time, and it needs to be reviewed every six months with his GP.

“Every time I see a new GP (in my practice- very often) I have to have an argument about how I really do need my prescription. Same thing happens whenever I see a new physiotherapist. Because of the complicated and repeated process of ordering and reviewing, I’m often in pain because I don’t get my medication in time. I feel like I am fighting a losing battle.”

The introduction of an e-referral system and online booking in his GP surgery should have made the referral process easier; instead it made it more complicated.

After having a surgical procedure at UCLH, George needed a referral from his GP for a follow-up appointment. He made an appointment (which he could only have in two weeks’ time) and his GP sent the referral. In order to make the appointment with his GP, George needed to go through a user-unfriendly online consultation form:

“Despite the fact that I only needed a referral, I had to fill in a long and complicated form about my health and symptoms. Not sure why that was necessary.”

George then received a letter informing him that the hospital only accepts e-referrals, along with login instructions. However, the only way to obtain his user id was to make another appointment in person with his GP, through the same time-consuming process.

“I had to go online, I registered, it’s a complicated procedure. For registration, I needed to get a password- and the only way to get the password was to go see my GP in person! This has taken two visits already; I can’t see how it’s quicker.”

“Aidan” (name changed) is a four week old baby diagnosed with DiGeorge syndrome. Because of it, he has heart problems and had to have surgery within the first twelve hours of his life.

He spent his first three weeks in St Thomas’ hospital, before being discharged and sent home. A week later, he started experiencing seizures, possibly because of some of the medications he needed to take. He was admitted to the Royal London Hospital for observations.

The hospital was poorly equipped to meet Aidan’s needs and communication with St Thomas’ Hospital in regard to his case was poor.

“No effort was made to get his medical records and what was known about him from St Thomas’ Hospital”- he is a complex patient and has spent the first three weeks of his life in that hospital!”

Aidan also suffered from a calcium deficiency, as a co-morbidity of his illness. However, the pharmacy in the Royal London Hospital could only supply orally administrable calcium, which he was unable to swallow. Aidan’s parents found the attitude of pharmacists to be poor and unsupportive; they did not seem interested in or able to find a solution.

This has led Aidan’s parents to feel much less trustful of treatment their son was receiving at the Royal London, and to insist that he should be transferred back to St Thomas’ Hospital.

Generally, people who have experienced services working poorly with each other complained about referrals being processed too slowly or lost, GPs hesitating to provide necessary referrals, long waiting lists, user-unfriendly booking systems made worse by admin and planning errors, as well as poor communications and insufficient availability of information.

There are reports of GPs being reluctant to provide the referrals that patients need.

- My dad is 87 and we're not happy with his GP- as a matter of fact we're getting a second opinion today. He started to have memory problems; and so far no one assessed him properly. He also suffers from incontinence, he has hernia, balance and mobility problems- but when I asked the GP to refer him to physio he just asked "What for?"- and to this day we still don't have a referral. I asked him to refer him to an assessment for domiciliary care too, and he didn't.
- I am a mental health service user. I was told to wait until the doctor had read my files and they would get back to me about a referral to a local CMHT. I have been a lifetime user of the services. After the doctor had read my files their tone changed and I felt dismissed and judged. I was told that I didn't 'look' like I had psychosis and that I am stable. I was not asked any questions about these symptoms and I do in fact suffer severely with psychotic symptoms at the moment and am in fact very unstable and at a very difficult time in my life. I was told a letter was sent to me but I never received it and have still not heard from the support worker that I was offered help from as a replacement for the CMHT that I am unable to be referred to. I have always been a service user of a CMHT and am distressed at the prospect of not having access to this service.

Processing specialist appointments in the Royal London Hospital can take a long time; some patients found themselves not just receiving appointments scheduled far in advance, with a long wait, but also waiting a long time to even find out when and if they can receive an appointment.

- I had an appointment for a consultation for back pain in December. Since the appointment, I was advised they will write to me for a spinal injection appointment. I had waited till end of January; I didn't receive any letters for an appointment so I phoned them the reception advised I have to wait a minimum of two months for an appointment. Despite the fact that I was in pain I had waited over two months and phoned them they kept me waiting over 40 minutes when I phoned them and passing me from one reception to the other in the end only to be told that the doctor who had done the consultation has not even booked my appointment.
- My doctor sent all my info [about my pregnancy] to the RLH but warned me to consider looking for another hospital as they are notorious for not getting back to doctors' referrals and they've had several ladies go without booking in appointments till 16+ weeks!

Communication between GPs and hospitals can be affected by admin issues on either end, including loss of patient records or error in medical files.

- My mum was diagnosed with Parkinson's in June 2017, since then she has been completely house bound as her disease has progressed very quickly. Twice she has been told by the consultant who sees her that a Parkinson's nurse would be in contact but there was no such contact. Her GP had to chase the Parkinson's nurse. An appointment was given and attended with the nurse. Changes to her drugs were made which were not discussed with her. No notes of it were sent to her GP. It was only a few months after when she saw the consultant again that she was asked why she's still on her old medication. If she hasn't been told and if her GP hasn't been alerted, then of course she won't know. But no this was the patients fault for not being able to read minds.
- I went with my son to ENT clinic 2. After appointment, we were told he needs to be seen in one month. Receptionist was unable to do this. She wouldn't go see the doctor to ask what to do, she couldn't overbook. She said only the secretary of Dr. B. can over book. I will be given appointment by post. When my appointment came via post, it was at the wrong clinic and with the wrong doctor. I was trying for 3 days to get through. At first I kept getting cut off. Finally got through to Dr B.'s secretary. She was kind enough to get me an appointment. I don't understand when the paper said appointment in 1 months' time, I was given an appointment in five months' time!
- Because I have a high risk pregnancy, I was referred to be seen by a consultant at 12 weeks. Guess what am at week 30 and haven't heard anything! I went to the antenatal department to ask if they can check why there has been a delay. Rude guy at reception says that it's for my midwife to chase at GP. I said she has and no one got back to her and I have called your department and no one picks up the phone! At my 28 weeks I again got my midwife to do another referral and she dropped it off by hand and I still haven't heard anything or been contacted to go see the high risk consultant.
- I had to call the GP practice because none of the hospitals had received the referral letter two weeks after the initial GP appointment. The specialist referral appointment can't proceed until the referral letter is received. The receptionist was unable to advise regarding this administrative query on which hospital or whether the referral letter has been sent at all. The receptionist did recommend/arrange a call back with the on-duty doctor for clarification. However, the on-duty doctor was displeased. She referred to the query as a non-urgent issue and it should not be a call-back matter.
- I went to the doctor (GP) to inform them of my pregnancy and they said they would refer me to the hospital for scans etc. However, I was never offered an appointment. When I phoned the surgery to find out what happened, they said they would look into it and phone the hospital and get back to me, but never did.

In some cases, GPs and consultants may not agree on the best course of treatment for the patient. This can create undue stress for patients. Some medical professionals may intervene when they agree with the patients that other members of the medical team are not providing adequate care.

- I have had extensive and numerous consultations and guess what - I am still walking around with the same painful ingrown toenail. I am begging for surgery, but the specialist sees no "need". Luckily, the amazing GP I have understands how urgently I need surgery and put me on the NHS waiting list straight away.
- My mum registered with the GP few months ago. After waiting for 2 weeks for appointment with the GP twice, twice we requested both the GP's we saw to refer her to the relevant specialist that she is under already but got discharged as she moved addresses. So she needed a new referral closer to her current address. Third time saw another GP who tells us that no referral has been made and they don't even have the full medical records from the previous GP. The last GP we saw has promised to make the referral so let's see. They were also very nice and treated my mum as a person and her patient compared to the first two GP's who didn't even bother making any sort of communication with my mother who is the patient and as she speaks no English and treated her like an object!
- I need to be on medication for lupus for the rest of my life- and my GP stopped prescribing it to me anymore! My consultant at the Mile End Hospital gave me emergency prescriptions of my medicine- I don't think I'd be alive without her!

Having insufficient or contradictory information about available community or public health services makes it more difficult for people to access and benefit from them:

- Never having been informed of any free Antenatal Classes during any stage of the pregnancy and being reluctant to pay the required amount for the NCT classes, I was at a very late stage informed that the Royal London Hospital provided classes which I could attend. Having requested these at 27 weeks, I was informed I was too late to book them. Having then enquired at the Barkantine Centre if they could provide me with any antenatal classes I was informed, to my surprise that I was too early to book them.
- I was told that I should get an appointment at the Foot Clinic to get my toe nails cut. I didn't receive the appointment. I went back to the nurse at the GP and she said to contact them. I tried to phone again and again but they would never pick up. In the end I went in. The lady there said that I was not on the system. When I went to the GP they said the service was changing and that I might have to pay some money. I'm ok to pay some money but I don't know where to go. But the women at Mile End (the foot clinic) said I should get a letter confirming an appointment on 9 May at 10:30. I went in there and they said they couldn't do it. They said I didn't have an appointment. But I had a text with the time and clinic. They just waste my time. They could just tell me I'm not entitled to the service and I would go.

How could services work better with each other?

After having undergone heart surgery (a TAVI procedure) at the St Bartholomew's Hospital and receiving little to no post-discharge follow-on support, Lucy continued to attend regular physiotherapy sessions and classes at ARCaRe, which supported her recovery. As she developed complications from a chest infection, she was re-admitted to the hospital.

Lucy's story prompted a physiotherapist from ARCaRe to take initiative and start a dialogue with the hospital, with a view to offer better post-discharge support to patients who have undergone heart surgery, and specifically for those who have had TAVI procedures.

"I told my physio at ARCaRe that I was going to the hospital for a chest infection so she reassessed me- and I just found out that they are doing heart care as well, so I enquired about going into her heart class. I mentioned to her that after I had heart surgery I received practically no aftercare following my discharge- there was nothing available for people who had undergone the TAVI procedure. So the ARCaRe physio said she would talk to Barts Health not just about me attending her class, but also about rehabilitation for patients who have undergone TAVI. This is a very exciting development."

For her chest infection, she has been treated by a joint group of medical professionals, who took into account holistically her complex health situation.

Lucy had been a patient of similar "joint teams" in the past; she had not been properly informed of their purpose and approach, so she had found it to be a pointless exercise. In this instance, however, the team worked better among themselves and with other professionals in the hospital, which empowered them to provide Lucy with the treatment she needed.

"I changed my mind recently on the concept of joint clinics. For example- (rheumatology + respiratory). The first time I was referred to one I found it irrelevant and upsetting even; why did I need to be seen by this joint group I knew nothing about? But I have since found that a joint group like this were able to get me the treatment I urgently needed; they have the power to do what they are told [by patients].

When I got the chest infection, they referred me to Barts and I got the attention I had needed for two years or more. The doctors that I had seen on my latest consultation with the team were brilliant, they explained everything very intelligently ; not like in the beginning, when no one explained anything to me- now they were very good, very particular."

Our Adult Social Care report (2018) contained two key recommendations for integrating services.

1. 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 and 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.

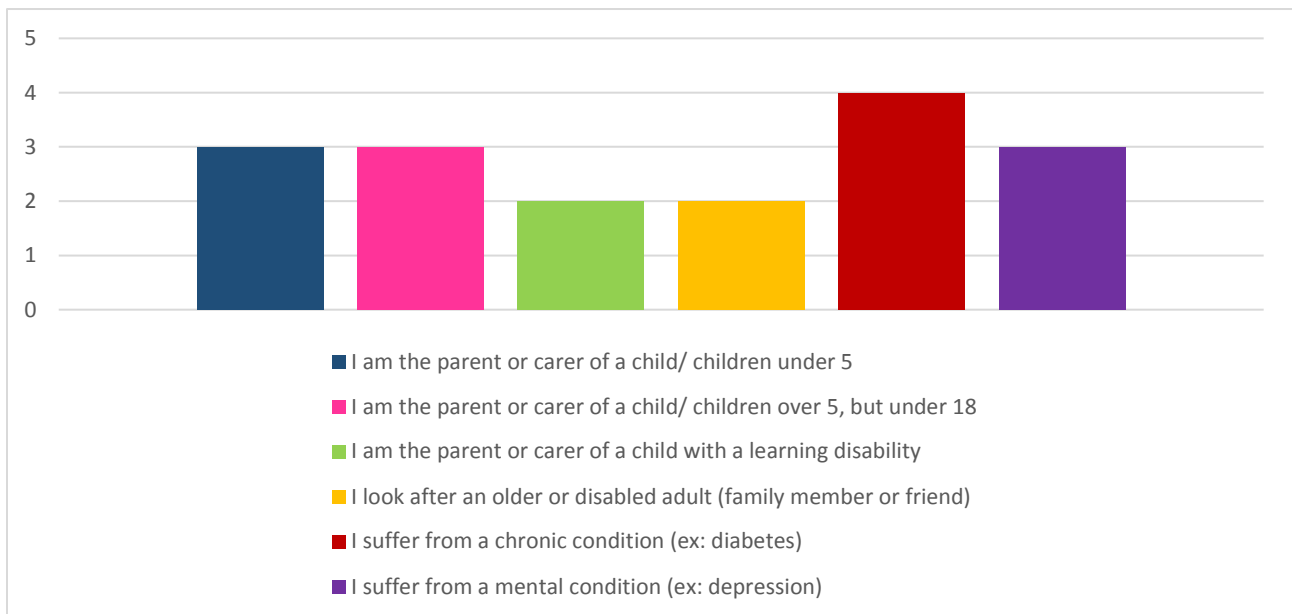
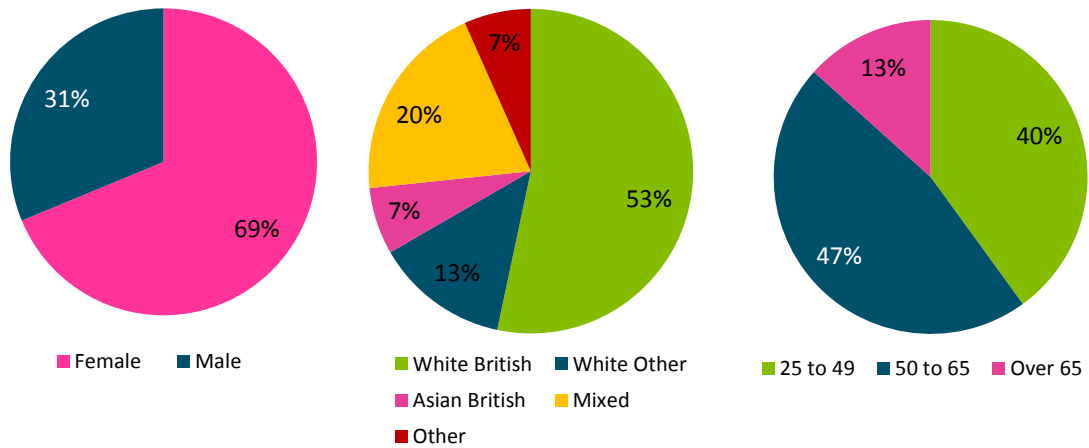
2. To introduce integrated Health and Wellbeing Centres that co-locate the Tower Hamlets Together services. This could include general, medical and nursing, therapy, specialist and social care services with supporting information and advice systems and voluntary and carer support services.

With a key space for community organisations and activities 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.

Since our report has been published, we have engaged with local residents on this topic in a variety of ways:

- We have conducted a snap survey, that received 16 responses.
- We have designed an interactive activity for a community stall, receiving 20 responses.
- We held four in-depth interviews with local residents with complex health needs, who extensively use health services in Tower Hamlets.

Survey respondents were a diverse group:



Our in-depth interview respondents:

Lucy

White British woman in her 70's

Lucy is a senior who suffers from various long-term conditions, including arthritis, heart disease and a sensitivity to chest infections. She has recently undergone heart surgery (TAVI procedure) at St Bartholomew's hospital.

She attends physiotherapy sessions and health awareness/wellbeing classes provided by ARCaRe at the Mile End Hospital.

George

White British man in his 60's

George is a retired health and social care professional who suffers from arthritis and a slight mobility impairment (he walks with a cane). He regularly used the foot clinic at the Mile End Hospital for toenail cutting until cuts to the service made him ineligible.

Because of his arthritis, he experiences persistent pain; for his treatment, he needs to see the Pain Team at the Royal London Hospital and his GP regularly.

Martha

Caribbean woman in her 30's

Martha is the main carer for her mother, Jolene, who suffers from multiple physical and mental health issues: Jolene cannot walk unassisted, is severely depressed and has been diagnosed with schizophrenia in the 70's.

Martha looks after her mother after her discharge from the Leadenhall Ward in the Mile End hospital. She is also the mother of a school-aged child.

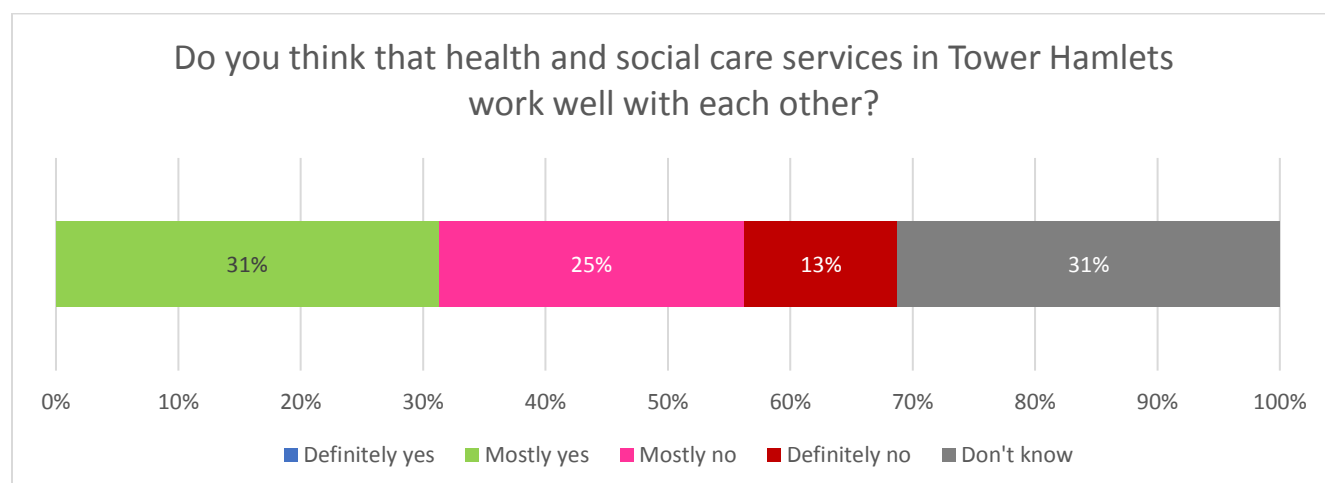
Indira

Asian British woman in her 70's

Indira is a retired doctor who spent her career in multiple medical roles in Tower Hamlets.

She suffers from diabetes, arthritis, as well as from a mild to moderate hearing impairment.

The opinion of survey respondents on whether services work well with each other was divided, and largely in line with the data shown in our repository.

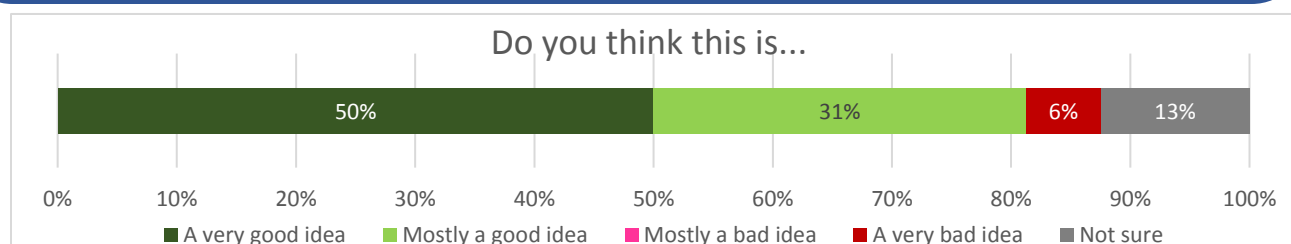


- ☛ *Lack of awareness by doctors of what help could be accessed [is a problem].*
- ☛ *I work in the NHS and recognise that although the joint working is far from perfect, it is better than most.*
- ☛ *They both have their own agendas involving money rather than people.*
- ☛ *Experience limited, but my mother's discharge from hospital this year worked.*
- ☛ *There was however a complete lack of info on how the system worked.*
- ☛ *I have some experience of care given to my late wife. It was overall good, but not perfect.*

The idea of co-locating services in a Health and Well-being hub has been welcomed by most survey respondents and by the four interview respondents, even though some had certain reservations about the practicality of it.

Consider the following idea:

In a "Health and well-being hub", a GP surgery shares a building with other medical services (for example, a dentist and a chiropody clinic), social care services (for example, the local disability assessment service) and/or community services (for example, a lunch club for the elderly).



The main perceived advantages of a Health and Wellbeing Hub named by survey and interview respondents were:

It will be more convenient to access

- [This model offers] ease of accessibility and availability without too much traveling for the very young, disabled and elderly.
- Because it's easier for people to access all these services.
- Services are scattered all over the place. Would be good to have a single building housing some of these together.
- It might simplify transfer across services for patients/ clients.

It will save the NHS money

- There must be economies of scale.
- While it may be a costly investment at first, in the long run this will mean less rent to pay, so cost savings. Staff could be reduced, if they are multi-skilled and properly trained; and job-shares could create more opportunities for local people.

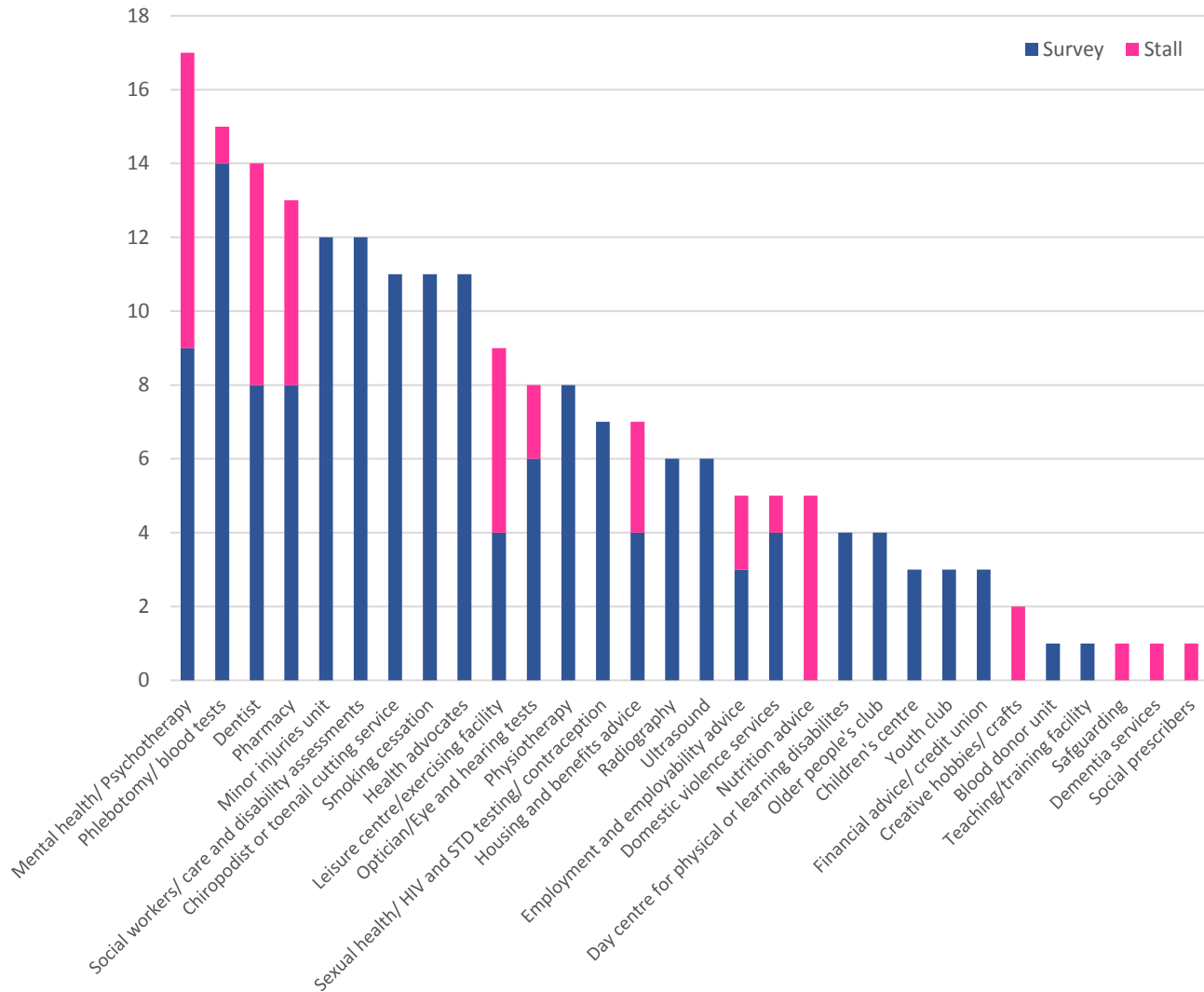
It was successful in other communities

- The one stop shop module has proved to work well in other sectors of the NHS, so I am sure it can work well here.
- Polyclinics properly designed have had excellent results in other countries. Their rejection here previously was irrational.
- That's what they do in France I think- when you're admitted to hospital you're not just shoved between departments, you're treated as a whole, there's a smooth process from tests to physio and so on- and you have surgery only when you're urgently serious.

It will help services work better together

- Co-location provides the first step to cross-fertilisation of ideas - which would require deliberate facilitation.
- Helps services work more creatively together. Enables people to discover different services when they access one in the building.
- An integrated, collaborative model like this would encourage people to offer mutual support themselves, instead of trotting around between hospitals.

Both the 16 survey respondents and 20 people who took part in an interactive research activity at our stall in a community event (Tower Hamlets Health and Well-being fair) gave their opinion on what services could be co-located **together with a GP surgery**:



The top medical services considered for co-location were:

- Mental health support/ psychotherapist (17)
- Phlebotomy/ blood tests (15)
- Dentist (14)
- Pharmacy (13)
- Minor injuries unit (12)
- Chiropodist/ toenail cutting (11)
- Smoking cessation (11)

The top non-medical services considered for co-location were:

- Social workers/ care & disability assessments (12)
- Health advocates (11)
- Leisure centre/ exercising facility (9)
- Housing and benefits advice (7)

The four respondents interviewed in-depth gave a more detailed description of how such a health and wellbeing hub would look like if they were to design it:

George

“There should be a central diagnosis hub clinic (incl. phlebotomy, radiography, ultrasound etc. Where feasible, they should do all tests on the same day, and send results to the appropriate consultant.

They should use an e-consult service for referrals, giving patients and relevant consultants online access to medical records.

Public health policy should also allocate public funding to giving back night classes and incentivise people to take part in social and health promoting activities- this doesn't necessarily have to share space with the diagnosis hub though.”

Indira

“A GP could co-locate with a chiroprapist, dentist, mental health services, a health visitor for older people, children's services, speech and language therapy for special needs- and if enough space maybe a coffee shop and a community social space, as well as social services and benefits advice. The social space could be used for learning activities, exercise classes, things like a youth club or an older people's club, but all scheduled at different times.

A hub like this could have patients fill in one form at the beginning, which then everybody shares. Having this as an online portal would work for younger people, but not for older people with low web literacy. Providing laptops and volunteers to teach them would be useful for some older people, but not for others. Some just need to be shown while others just plain fear tech.”

Martha

“Mental health services and social services should be co-located and working together. Not just the Community Mental Health Team but also services from psychosis, schizophrenia, Alzheimers etc. Rather than having a clear separation between clinical and social care, these services should be integrated and then divided by condition and need.

Community and preventative services who do outreach, like the Welllbeing Network ran by Mind in Hackney, would also belong. The hub could also include a GP surgery- when someone has complex needs and are using multiple services- the GP seems to always be the last who knows.

Lucy

The hub could include a GP surgery plus multiple specialist services catering specifically for people who have been discharged from hospital into the community- such as those who have undergone major surgery or recovering cancer patients. A physio superhub would be very relevant. Chiroprody and care assessments would belong as well.

There should also be “education for wellness” classes, with local consultants, experts, representatives of charities.

There should also be support for young mothers and children. Something like the Sure Start centres that have been closed.”

A small number of respondents (surveys and interviews) raised concerns about possible obstacles and disadvantages:

Housing multiple services together would be difficult and possibly less accessible for areas further away

- *Not sure about lunch clubs etc. Would complicate building spec.*
- *Most GP surgeries don't have buildings designed that way*
- *Most elderly people would need transport.*

This model could cause over-stretching of services instead of savings

- *There are no economies of scale for the patient. Parking is harder. Queues for reception are longer. Diseases spread more easily. This is quite possibly the single worst thing you could do. I caught chicken pox at the age of 36 and from a doctor's waiting room! It was really serious.*
- *It's good in theory but could it work in practice? Do you have any case studies from which to determine positives and areas for development?*

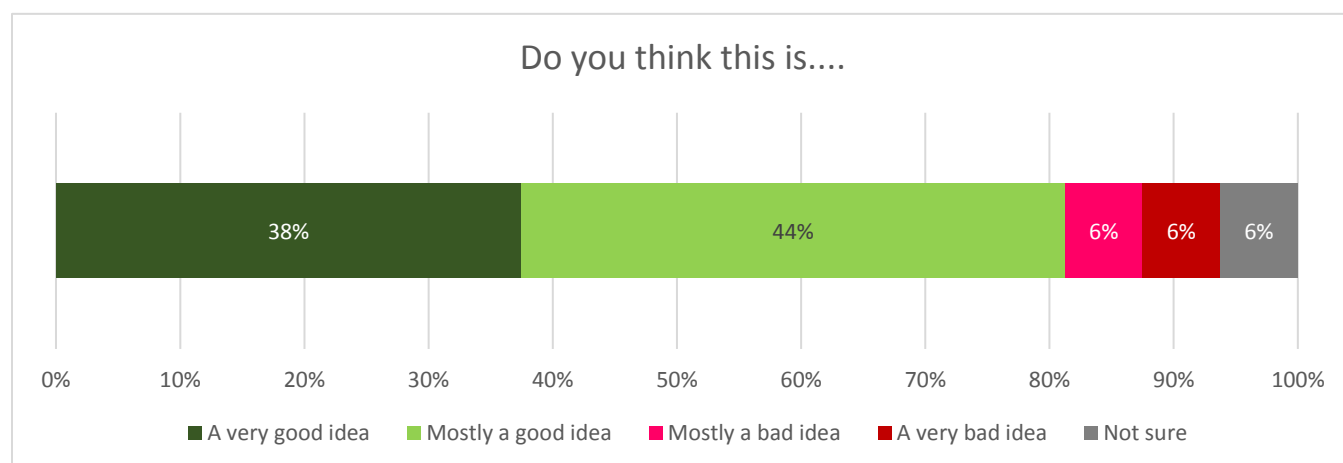
Not all available services would be well used

- *I'm not sure lunch clubs etc. are the new way- the elderly in some years are not going to be the same as the elderly now, they will be the people now in their forties and fifties, who are more comfortable with technology and finding services online.*

Most respondents were also open to the idea of dedicated support groups having regular group consultations led by a nurse or health visitor, attended by GPs or other professionals as needed.

Consider the following idea:

In your local GP surgery, a group of people who all suffer from the same condition or otherwise have similar issues meet weekly. The meetings are led by a nurse or a health visitor, who checks upon their health, responds to their queries and gives them advice pertaining to their condition. The nurse/health visitor also signposts them to various community resources available to them. If necessary, the nurse/health visitor arranges doctors' appointments for those who need them or assists them to fill online forms for telephone/online GP consultations.



The main advantage that respondents identified was the opportunity to share learning in a group:

- Patients could support each other, lessening the load on professionals.
- It is a good idea, to make it sociable. There is a senior ladies' group in Wapping—they are always doing social things but not as much about health. They would love to learn, for example, how to use a defibrillator or what to do if someone has a heart attack. I'd like my husband to learn this kind of thing in case it's happening to me!
- I did some work to try and get the CCG to commission exactly this idea in 2017! Glad it's being considered. Yes this would join up well-being support with physical health services and help people access care more quickly.
- Because people often learn more from their peers.
- Allows people to share knowledge and help each other.
- Helpful to discuss and talk in an informal way.
- People can learn from each other discuss if they choose to their symptoms, and diagnosis and make them feel less alone.

One of the interview respondents (Indira) was already familiar with such groups and believed the model should be expanded:

- There are already diabetes support groups at Mile End Hospital, and there's a group for people who do cardiac rehab and then have a talk with the dietitian- this model could be extended to parents with young children- do parenting classes, involve Maternity Mates. Groups like that could possibly reduce the need for GP appointments.

The main disadvantage identified was the lack of accessibility for some users; several respondents suggested informal online support groups as an alternative:

- 1. I have artificial hips, and when I need a revision, it is hugely helpful to have friends with similar conditions/online forums so I know what to expect. 2. Why would this need to be nurse led? This would be expensive and not necessarily cost-effective. 3. For some conditions getting to the venue would be hard/impossible, and for others online forums might be better anyway.
- More opportunity to spread disease. This exists online via social media and people would not leave their house to use it. Transport is so difficult, and you can't park any more.
- May need help to do so and if house bound no use.

One of the interview respondents also pointed out that a model depending on social prescribing and signposting may also lead to further pressure on community services:

- This model (nurse-led disease-oriented groups + social prescribing) risks to rely on a voluntary sector that is already way over-stretched for grants; is it ethical for a doctor to prescribe a course of treatment the ability of which depends on a smaller and smaller funding pot, and which therefore may not be available? Social prescribing is a great idea- but where is the money coming from?

People with chronic conditions and expecting parents were expected to benefit the most from such groups:

