



**RBG Adult Customer Journey:
Experiences of Adult Social Care in
Royal Borough of Greenwich
2017/18**



We know that you want local services that work for you, your friends and family. That's why we want you to share your experiences of using health and care services with us - both good and bad. We use your voice to encourage those who run services to act on what matters to you.

We are uniquely placed as a national network, with a local Healthwatch in every local authority area in England.

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1. Introduction

1.1. Context

Since 2016, Greenwich Council has been undertaking a significant transformation programme across adult social care services. The intention is to streamline services internally, improving the customer journey experience, and the outcomes of people who are assessed for (and use) adult social care services funded by the local authority.

Greenwich Council approached Healthwatch Greenwich in February 2017, and later commissioned us to assist with gathering service user experiences of Greenwich adult social care services. These experiences will be used to help shape service development, and monitoring implementation of the new service.

Healthwatch Greenwich planned several engagement activities designed to gather information, including online and paper based surveys, focus groups, drop-ins to care homes, and one to one discovery interviews.

This report incorporates the initial findings from over 130 completed surveys, two focus group sessions, a visit to a local care home and four in-depth discovery interviews. It is intended to reflect people's experiences, update on the work being undertaken, and identify key lines of enquiry for the future.

1.2. Service user engagement

Greenwich Council is keen to talk to people who use services, as well as their friends, family members, and carers. The council is committed to the principles of co-production and have recently actively recruited people to form a service user reference group, intended to help assess, shape, and monitor the adult customer journey transformation programme.

1.3. Information gathered

Questions asked in the survey, the focus groups and one to one discussions have been deliberately broad in nature, intended to enable people to discuss the issues they feel are most pressing. They range from how people make initial contact with the local authority, through the assessment processes, to the quality of care and support they receive. The majority of respondents are adults who use services, their friends, family members and/or carers.

1.4. Constraints and disclaimers

- **Data collection:** The data identified in this report is limited in the sense that it is provided by a self-selecting group of people. The surveys and focus groups were promoted by Healthwatch Greenwich through existing channels (including ebulletins, social media and outreach sessions), as well as a direct mail out from the Royal Borough of Greenwich to around 200 current service users. This report relates to findings observed on the specific date(s) stated. Discovery interviews were carried out with service users identified through the surveys. Our report is not necessarily a representative portrayal of the experiences of all service users, carers, and staff, rather an account of what was observed and contributed at the time.
- **Sample size:** We have spoken to or received surveys from around 160 people since June 2017. This includes 122 fully completed surveys. There are approximately 3000 people who currently access Greenwich adult social care services. The number of carers, friends, and family is significantly larger.
- **Transparency:** Greenwich Council has commissioned Healthwatch Greenwich to undertake this work. It is designed to better understand the service user experience, and reflect that experience back to commissioners, decision makers and providers, with the sole intention of improving service quality. Healthwatch Greenwich is an independent organisation with no contractual obligation to deliver anything other than those objectives set out under the Health and Social Care Act 2012. Every report we produce is sent to the relevant provider for comment, factual accuracy checks and a formal response. No provider, commissioner or elected member can veto our reports or recommendations.

1.5. Acknowledgements

Healthwatch Greenwich would like to thank Royal Borough of Greenwich staff, Healthwatch volunteers, Greenwich service users, and carers, for their contribution to the work programme of Healthwatch Greenwich.

2. Findings

This is a summary of the key issues and themes expressed to us.

2.1. Communication and information

Many service users and carers expressed concern over both the lack of information available to those in need, and a subsequent unhappiness with the level of communication after initial contact has been made.

“I found it very difficult to find out practically everything, you cannot just go to one person/department and they give out information. i.e. services available, financial help, carers allowance, higher rate of DLA etc. At times I felt that I was getting nowhere.”

Several people felt that the knowledge and understanding of those undertaking assessments was not always as good as it should be.

“I find assessors [are] not all knowledgeable enough on Direct payments and what other options money can be used for, not just personal care.”

“More knowledge of disabled and elderly people’s needs when assessing them, rather than reading out of a book, as everyone is different...understanding that some disabilities get worse as one becomes older, do not stay the same, so one needs more care.”

Many people were happy with the available ways to contact the council, although several expressed concerns over both online and telephone processes - particularly during assessment processes.

“Have called in the past but telephone can cause distress which results in short term memory [loss].”

“Do not rely on online process!! It’s a flawed concept.”

A lack of clarity over the process, who to contact and what to expect caused deep concern amongst some respondents.

“Called initially and was pushed from pillar to post”

“Communication and named contact would be helpful. The whole system is so confusing, and I never know how to contact Greenwich Social Services for help - I often just struggle on as I don't know who to turn to.”

“Having a single contact point in the council that is responsible for your case, and not several departments and officers involved that don't know your condition or your needs.”

Case Study 1 - Asil and Dilek

We spoke to service user ‘Asil’ and his wife and carer ‘Dilek’.

A few years ago, my husband, Asil, suffered Encephalitis (an uncommon but serious condition in which the brain becomes inflamed/swollen). He was taken to a specialist hospital for Neuro-Disability and spent several months in hospital. Asil is in a wheelchair, with limited movement, and has no speech.

Hospital

The support Asil received in the hospital was amazing, and the nursing care was incredible. We found out about Headway (www.headwayselnwk.co.uk) in Abbey Wood, while at the Hospital. We spoke to them and they sent someone to meet with Asil, who agreed he would be well suited for the care they provide.

As Asil got closer to discharge, we tried to contact Greenwich Adult Social Care, leaving several messages and emailing. Eventually the social worker at the hospital got in contact with Greenwich Council on our behalf.

Social care assessment and reassessment

Once Asil was out of hospital, Greenwich Adult Social Care services carried out a full assessment and created a care plan. The care plan initially was very good, covering everything. It included pick-up and drop-off to Headway four days a week, and a one to one care worker to assist with lunchtimes. We didn't receive any additional information about other local support available.

After a reassessment we moved to direct payments, meaning I could hire and manage the care workers myself. The direct payments also covered additional beneficial support for Asil, like physiotherapy and hydrotherapy. All I had to do is keep receipts for any services he was receiving.

This lasted for two years before another reassessment, after which we were told that the direct payments would now only cover the care worker's support and transport.

“The reassessment felt so cold. No feelings were considered, and there was certainly no support for me as a carer.”

Asil did access a community physiotherapy session, but they were not specialised in brain injury and after a short period, said they couldn't do anymore. This is despite physiotherapy I had arranged separately having a very positive effect.

During this time, a joint financial assessment was completed and we received Disability Living Allowance (DLA) at the higher rate. Next year we are due a Personal Independence Payment (PIP) assessment.

Adult social care just seems so impersonal - especially the assessment process, which is not fit for purpose. The last assessment was conducted by an individual who read questions from the form, but was disconnected and inexperienced.

Support for carers

At the beginning, I felt really supported, but as time has gone on, the available support has shrunk and shrunk. Initially, we thought I would receive six weeks of respite a year, but this has not materialised. It is possible to fund respite yourself, but it is very expensive. For example, Leonard Cheshire (www.leonardcheshire.org), provide the specialist respite care needed for Asil, but it can be as much as £1700 a week. The only additional money I receive as a carer is £16 a week, which does not stretch very far.

Reliability of care providers

Asil has a care worker who assists him with eating lunch at Headway. We used to use a different care provider but had multiple issues with some of the workers. They would not engage with Asil and would frequently be late or not turn up at all. This often meant lunch being served, but Asil having to wait and watch. Headway staff are great and have stepped in before, but it's not their job to assist him in this way.

The unreliability of care staff is really problematic. Workers who arrive at unpredictable times are not suitable for providing care. If a care worker doesn't arrive, I must contact the provider to chase them up. Consistency and punctuality of care workers needs to improve. We also need a sense that our issues are being listened to. Asil needs regular specialist care but he had no consistency. On one occasion, a care worker was quite forceful with Asil and I had to make a formal complaint. Asil only receives 30-minute slots for his visits, and often the care workers will treat him as if he has a physical disability, but don't consider his head injury.

Frequently, care workers do not engage well or communicate with Asil directly. I have to show each new worker how to support him, which can take a long time; much longer than the 30 minutes slots the funding allows.

“New care workers often forget basic actions like introducing themselves, and asking permission to provide care, before they force themselves on to him.”

Transport consistency is another concern. It should arrive for Asil at 9:00am. I leave for work at 9:15am, so if Asil's transport is late, it means I am late for work. Luckily, my workplace is supportive, but this may not be the case for many carers.

Family carers also need to be supported. We need regular, meaningful, supportive assessments, with time taken to complete them. Family members are encouraged to look after their loved one, but very little support is provided for them.

“I worry about the future. I have to be confident that I can care for Asil and that he can receive the right care if I am unable to. I am working now but what happens when I have to stop?”

2.2. Timescales

A common complaint was the amount of time it took from initial contact, through assessment to receiving services. This caused distress and anxiety in the service recipient and their family, friends, and carers.

“It takes far too long, usually needs change during such long process - up to 9 months.”

“More prompt! Review should have been annual. Was postponed 4 times, over a one-year period. No explanation given. Meanwhile my situation had drastically changed! Too many errors, inaccuracies...[and] misinformation. Too many “assurances” not kept!”

“[It] has taken in excess of 24 months and long and drawn out process, [they] just accept services I use and are not interested in the rest.”

2.3. Understanding service user’s needs

There was a strong sense that the assessment process didn’t look at people in enough detail, and in some cases, simply didn’t understand the needs of the individual. This was exacerbated by the perception that assessment processes weren’t transparent enough.

“The assessment process can be humiliating and intrusive. The reviews can be stressful as can the monitoring process. All need improvement in terms of customer care and choice and control and support for the applicant. Especially for those with progressive impairments.”

A young woman with a brain injury, who attended one of the focus groups, had recently had her care reduced from 24-hour support to just four hours per day. Both her and her mother felt this was likely to have a significant negative impact on her independence. A multidisciplinary panel apparently made the decision, however, neither the service user nor her mother had been invited to participate, and the decision had been made without their input or involvement. The family felt that the local authority was relying on the family to take over the care, which significantly increased pressure on the family, and threatened to undo years of work supporting the young woman to live independently.

“Us families are not free labour!”

“Sadly, unless you scream and shout and make noise they’d be quite happy to brush you off.”

A service user with a disability expressed concern over the lack of control an individual has over the process, especially when the processes seem prolonged or disorganised, and the anxiety this can create.

“It is very stressful knowing someone else has control over whether you can get support for the most basic things. My assessment started over a year ago and I don’t have an outcome - they have refused to send me my assessment report - I was referred to the

wrong OTs and only found out after 6 months of waiting! A throwaway comment by the social worker caused me stress and anxiety!”

“I dread contact from them, prefer to use an organisation run by and for disabled people who understand independent living rather than having to educate social services staff.”

“Chap assessed my mother and I and that was that. Because I appeared to be coping well and competently, I’ve never heard from them since.”

One person felt that the whole process was too difficult, and was too much for their elderly mum to cope with.

HWG has recently been talking to the Nepalese community, many of whom came to the UK as older people (separating them out from many BME communities who first came to the UK at a younger age). As a result, translation services are essential for older Nepalese people who need support to navigate the care system. Whilst these do exist, they are not always well advertised, or accessed consistently by professionals.

Case study 2 - Jane

We spoke to service user ‘Jane’.

Support and information

I have received adult social care services since a spinal injury many years ago. I was put in contact with social services whilst I was in hospital. I was set up with a personal budget and direct payments. This was all very new to me, and I was provided invaluable support by Greenwich Association of Disabled people (GAD). This included information about legal duties as an employer and managing finances. They also did a six-week course that was hugely informative and empowering.

Very little support or training is given by the Royal Borough of Greenwich (RBG) and there is a severe lack of communication. I used to have a named Care Manager responsible for my case, whom I could contact for any issue, but this is no longer the case. I can call the duty line in an emergency, but I might get through to anyone and frequently have to spend time explaining my situation.

My personal budget can be spent differently but this must be agreed in my care plan and receipts for payments must be kept. This budget covers cost of my Personal Assistants (PAs),

special equipment (including a special mobile and tablet), and other activities that would be beneficial to me.

Assessments

Every year, three assessments take place: a care review, a financial monitoring review, and a 'charges for care' assessment. These can take hours, mostly because the assessors often haven't read notes, or my previous care plan. The annual reviews are supposed to be just that - a review, rather than a complete reassessment. It should look out for what is different, what has changed. I now write my own support plan to save time, even though it should not be down to me. Other people may not be able to do this.

As well as time consuming, these yearly reviews can be scary for individuals. There is always the fear that your support levels or budget will be cut. They are always carried out by a different person and can take multiple visits. The review should be from the end date of the last care plan but sometimes they go back to the very beginning of receiving support. When they don't read the previous care plan prior to the meeting, there can be a lot of repetition. Assessors should make sure they have all the information ready before the meetings, so they are prepared.

Two documents are produced at these assessments - a care plan and a support plan. These are very detailed, and every word needs to be agreed. This is tedious and time consuming. The support plan is the action plan including broken down by support and budget. The reviewer should complete the care plan.

Hard copies of bank statements must be submitted every year alongside a detailed form to fill out. This can be confusing if you have not done this before. All money must be accounted for. Sometimes it is necessary to save some money to cover holiday pay for a PA or an upcoming expense, but you are only allowed to hold a maximum of two months money at any one time. The council will claim the money back unless there is proof it is being spent, which can be frustrating.

“The council should be supporting us, acting as our allies. It shouldn't be a constant fight. We should not live under the threat of being penalised. People have had their money stopped or reclaimed because of simple mistakes.”

Money and anxiety

People are fallible but the fear of making a mistake can increase anxiety and stress during an already stressful situation. Sometimes there is not enough money for to cover the services you have. For example, pension provision for my PAs was not included in my budget, although there is a legal duty for me to provide one for them.

Peer support would be good to help others who are starting out with a personal budget. Currently, no support is offered by RBG other than a contact in the finance department. The financial monitoring should take place every year, but once I waited five years before they asked for the paperwork, and I had to supply details for that whole period. Luckily, I had kept all of my receipts for the whole time.

I can only roll over a couple of months of money, but I must work out holiday cover for my PAs and therefore I might need to ration support to ensure I am covered throughout the year. On one occasion, my money was stopped for three months due to a miscalculation. I eventually took the matter to safeguarding because I was left without a safety net and wasn't sure I would be able to pay for my support. This is why it is essential for reviews to be yearly, with confirmation they have been signed off. Policy changes happen yearly and charges for care must be personalised and kept up to date.

Having a PA in the house means there are all the additional expenditure you would expect from having an extra adult living with you (utilities, toilet paper etc.). It was originally agreed I could claim so much a month for these expenses, which I did for few years. However, this year receipts were requested for each item; an onerous, almost impossible task separating out portions of items like toilet paper, soap, tissues, washing gloves, milk, alcohol hand gel, from my shopping receipts. This seems punitive, stressful and unnecessarily bureaucratic.

“I am an active advisor and campaigner and I’m fortunate I can manage the paperwork. Others are not so fortunate.”

I want to keep busy, but I have been the victim of hate crimes. This means I do not go out alone, so my PAs enable me to live an independent life.

2.4. Volume of services available

Several service users and carers expressed concern over the amount of time available for care workers to complete basic tasks including cooking, cleaning, and shopping.

“They do not allow time for cleaning. I do a lot more hours than I am paid for which is ok as it's for my mum, but it means I can't get another job, also [for] someone who does not have family, their homes will get really dirty.”

“They only allow 20 minutes to make and eat lunch, which is not enough time make a hot meal.”

Similarly, whilst most carers wanted to be the ones to provide for their loved ones, many expressed that respite care is essential, but very difficult to get.

“We do most things ourselves and have the equipment we need. We would appreciate help with respite breaks.”

“I'd like to actually have some respite care, so that I can go away for a few days. I requested this for consideration when I had a carer's assessment six months ago. I've never heard a thing since.”

2.5. Personal health budgets

At both of the focus groups, service users and carers expressed concern over the implementation of personal health budgets and direct payments. There was confusion over what the money could be used for, and how it could be accessed. There was anxiety from some service users having to become employers of their care workers, with all the legal and financial implications. One person was very worried about how they would cope when their care worker was on maternity leave, as they needed to provide maternity pay, but there was no additional money available to provide cover. Some service users were able to have larger sums of money agreed up front to cover additional support costs (e.g. annual leave), but there appeared to be some inconsistency in how this policy was applied.

Case study 3 - Simon and George

We spoke to ‘Simon’, about his experiences caring for his friend ‘George’.

George was my friend of 17 years. He was hospitalised for heart valve replacement surgery in 2013, but recovered well and was able to return to work. However, six months later he had a stroke and suffered a significant loss of faculty. He spent three months in the neurosurgery department of Kings College Hospital, then was transferred to a unit at Lewisham Hospital which was brilliant.

Assessments

Here we contacted RBG adult social care services. They carried out an assessment and made adaption to his home prior to him being discharged. He was also given six weeks of reablement support after he was discharged from hospital, which included a care worker coming in morning and evening for about 15 to 30 minutes. During this time, I moved in with him for three months to offer my support. This led me to see the irregularity and inconsistency of the care workers. They would come to get him up in the morning any time between 8:00am to 11:00am.

During this time a social worker came to do a full assessment and care plan. It was extremely detailed, exhaustive and time consuming. Next, their colleague came to complete the finance plan based on the care plan which would lay out the cost of the care that was needed. A week later a financial assessment was done for George. The three different RBG staff did not seem to communicate with each other at all during this process. Therefore, each time, we had to go over and over the same details.

The financial assessment determined whether or not George would be entitled to financial support by RBG. As he owned his own home and had savings, he was not granted any financial support. RBG said they could still arrange support but George would have to pay himself. It felt so painful and unnecessary at such a stressful and painful time. We would have preferred the financial assessment before the needs assessment, as it could have reduced the long, stressful process.

Additional health needs

During this time, George suffered a psychotic break and was admitted to an Oxleas Mental Health unit for ten days. When he was released he had to go through the whole assessment process again, even though the outcome was the same.

We made the decision that rather than use the council care providers, we bought care from a private provider. They seemed to be better with their punctuality, but there was still a high turnover of staff. George was fitted with a pace maker which was a quite straight forward procedure, and he only had to stay in hospital overnight. He would have a thorough check-up every six weeks, arranged by Oxleas community services. He also had a personal alarm system that was provided by Greenwich at a cost to George of £25 per month.

George was offered 12 weeks of counselling from Time to Talk (oxleas.nhs.uk/services/service/greenwich-time-to-talk/), but it didn't really click with him. We tried the Carer's Centre at the Stables (www.thestablesse7.com), and whilst very good, the services they offered were not quite right for George. He also attended voice therapy at Lewisham Hospital with a very nice therapist, but the programme was quite restrictive. The loss of speech was very challenging for George, because his career and passion was singing prior to his stroke. He has received one-to-one support through the Terrance Higgins Trust (www.tht.org.uk) which was much more effective for him, and they really accommodated his needs.

Carer's support

George's GP was Dr Sabat at Plumstead Health Centre (www.plumsteadhealthcentre.org.uk). He was so supportive, and brilliant throughout. I had power of attorney and Dr Sabat was always available for George and myself. He is very knowledgeable and would bend over backwards for George.

"The communication between the NHS and social services was not clear, but Dr Sabat was always the first contact with any issue, and we knew we were in capable caring hands."

As I collect a pension I was unable to receive carer's allowance, however RBG has a scheme which did offer financial support. As I was caring for George for over 35 hours a week, I qualified for the scheme and I received an unrestricted £56 per month. The assessment form for this scheme was again very long and repetitive. We applied for a blue badge which took quite a while to come but was very useful when it did. George also had a Personal Independence Payment (PIP) assessment (www.gov.uk/pip/eligibility) which was punitive, and we heard nothing for six months. Eventually, I chased this and rang the ombudsman as well as speaking with my local MP. Once I did this it was sorted within day. George was also assessed for and received Employment and Support Allowance (ESA) for a year.

The assessment feels like it is done in the wrong order. If George had had the financial assessment first it would have avoided the other time-consuming assessment and care plan which was ultimately not needed. In July this year, George decided to sell his home and moved to a residential home in Wiltshire with 24-hour support.

2.6. Reassessment and financial monitoring

During the discovery interviews, the stress and anxiety caused by annual reviews and financial monitoring was a common issue. It was felt that annual reviews were overly long, that social workers hadn't always read the initial assessment, or even the previous review, and often seemed to be starting from scratch. Each year the local authority carried out a needs review, a cost review, and then a financial assessment, all of which carried the threat of services being cut or funding being reduced. Reviews are often late, and in at least one instance, a review was due before the previous one had been completed and signed off. This adds additional anxiety to an already complicated process.

The financial monitoring can be unwieldy, with patchy support given to service users. There have been multiple changes to what is allowable from a funding point of view, with additional restrictions placed more recently on spending that is not direct provision of a care.

All of this is in addition to the already difficult process of accessing funds through the DWP (for example, ESA, DLA, and PIP).

2.7. Consistency of support

A theme throughout all our discussions was the inconsistency of care. In particular, the punctuality and consistency of individuals coming in to provide care. Simple things like not arriving on time can create uncertainty, causing anxiety for carers, and significantly reducing the control a service user has over their own lives. Having to wait two to three hours to be able to get up in the morning, or to be put to bed, or having to go to bed at 6pm because that's when the care worker arrives, is a significant infringement on an individual's independence.

Constant changes of staff, and inconsistent handovers also mean that service users are not always getting the care they need, due to a lack of knowledge on the part of the care worker, time that should be spent providing care is then spent learning about the individual. Whilst staff changes are inevitable, care providers could make changes to the way staff are allocated and trained, to minimise problems.

Service users who have family that live in the same home providing care, are not able to use their care budget to pay them, even if that care would have to be provided if the family member did not live there. This creates an inequality in the system.

2.8. Respite care

Almost all the carers we spoke to, expressed the importance of respite care. Caring for an adult is time consuming, physically demanding and can be incredibly stressful. A short amount of time away each year, where a carer can be confident that their loved one is being treated well can make the difference between being coping and not coping. The care needs to be high quality, accessible both physically and financially, and flexible enough to meet the needs of service users and their carers. A relatively small amount of money invested in respite care, could see longer term savings from a reduction in the number of service users that end up in long term residential care, as well as improvements in the carer's own physical and mental wellbeing.

Case study 4 - Sarah and Helen

We spoke to 'Sarah', 'Helen's' mother and carer.

My daughter Helen is 35 years old and was born with disabilities. She attended a special education due to her Autism. We have had contact with Greenwich Adult Social Care Services through the Community Learning Disabilities Team (CLDT) since Helen was born. She was receiving a personal budget for the care she was receiving, and a reassessment was meant to take place every year. When she was older she was diagnosed with epilepsy. Helen has a brain pacemaker and is currently on four medications a day. She is observed often and there has been concern about her weight loss, so she has been referred to a metabolic specialist. She communicates non-verbally, and there is a concern about taking these medications on an empty stomach. She has liver problems which is also monitored regularly. Her epileptic fits can be very violent and when they happen she is at risk of hurting herself when she falls so she uses a mobility scooter whenever she moves around outside the house.

NHS continuing healthcare support

Five years ago, during a reassessment, I was told about the NHS Continuing Healthcare. I contacted Greenwich Clinical Commissioning Group (CCG) who carried out an assessment to see if we would qualify for this support.

“The assessment was very thorough, and we were told we met the criteria, which is done on a points system. I have found Greenwich CCG to be much easier to deal with than RBG.”

When we received funding through RBG's Community Learning Disability team (CLDT), we no longer had a named care manager (although we did at the start). This meant there was no continuity of support, and we would have to repeat information about Helen's situation repeatedly. CLDT were often not easy to get a hold of, and follow up by them was slow. We now have a named contact at Greenwich CCG, and even though it's not always easy to get through to them, at least we only have to deal with one person. Recently our case has been transferred to a new case manager and the handover has not been great. We are still waiting to hear from the new case manager who will contact us when he has reviewed our case. That said, our contact has been much more straight forward compared to CLDT.

Reassessment

Helen attended a day centre at Woolwich Dockyard five days a week which was really good for her. Transport to and from the day centre was included in the care package. However, a reassessment cut her days at the centre from five to four days a week (no longer attending on the Friday) for no apparent reason. There have also recently been two centre closures (Woolwich Dockyard and Sherard Road) and instead, 'Hubs' have opened across Greenwich. After transferring onto NHS Continuing Healthcare Helen was able to start attending for five days a week again. She goes to Trinity Day Centre and Abbey Wood Day Centre. The day services and transport to and from are paid directly by Greenwich CCG.

Transport can be very unreliable, and I have had to arrange for a cab to take Helen and her care worker, or take her myself more than once. Helen goes off site regularly during these days to go bowling and other activities. She also eats offsite three times a week. The day centres charge £38 a week to cover her refreshments, so I made the decision to provide her with all her snacks and refreshments for the day. I would rather her supply her with what she needs and pay for some additional drinks on an ad hoc basis.

All of Helen's one to one care is provided by personal assistants arranged by me, which means it is much more flexible. Respite is also paid out of our joint account which I can arrange. We have yearly audits with Greenwich CCG which I find much more straight forward. I have had a named contact who I can reach if I need support. Financial audits with CLDT would require copies of everything - luckily, I did have someone in the team who would photocopy these for me but there were always long delays.

Helen's main care worker is on maternity leave which has meant I needed to find cover and pay maternity leave. This was not factored into my funding, but my account is being looked at. You can apply for a one-off emergency payment if needed, for instance, if I had to go into hospital for any reason. The money we receive is restricted but can be spent on different things within reason. For instance, it can be used to buy equipment for Helen, or respite for me at Kemsing Road Respite Service.

When Helen goes to hospital either at Queen Elizabeth Hospital (QEH) or the neurology department at Kings College Hospital travel can be difficult.

“When Helen has stayed overnight at QEH, I cannot always stay with her as they do not make provisions for carers.”

QEH used to have a staff member who was a learning disability patient representative, and would provide support for patients with a learning disability and their carers, but I have recently found out that this post is no longer being funded.

Carer's support

We have received a lot of support from the Carer's Centre at The Stables. This support has included counselling and training as well as access to their spa. As a carer I was assessed by CLDT, but was not given a carer's budget. I do receive carer's allowance from the Government which is £61.50 per week. I retired two years ago at the age of 60 but when I reach the state pension age of 66 I will no longer receive carer's allowance, although I will be able to receive the state pension.

“I often think to the future and Helen's care. I have created a special will with a trust for Helen so financially she will be safe.”

My main concern is the need for continued support for carers, especially family members who provide 'cheap' support within the Borough. Without regular respite I could not provide the level of support needed for Helen, and my health would suffer. Information about the support available for carers should be communicated with them on a regular basis.

3. Recommendations

Based on our findings, we are proposing the following recommendations to feed into the service redesign:

1. Communication and information:

- 1.1. All staff (internal and external) who are involved in social care services should receive refresher training on the importance of effective communication with service users and carers.
- 1.2. Communication should happen via the methods preferred by the recipient (e.g. phone, email, face to face).
- 1.3. Clear policies need to be developed and shared with staff, service users and carers about when and how family, friends and/or carers will be involved and communicated with.
- 1.4. Information about what people can expect from social care services, including clear service user pathways (customer journeys) should be produced and made widely available.

2. Timescales:

- 2.1. A key driver for Greenwich council's adult customer journey transformation programme was the recognition that there were often significant delays in assessment, transfers and waiting times for services. It is essential that the length of time people wait from initial contact to assessment, and then from assessment to receipt of services, is kept to an absolute minimum.
- 2.2. The expected timescales should be clearly published, and explained to people at first contact. They should also form the basis of a high level KPI for all Greenwich services.
- 2.3. Reassessments and reviews should happen on a regular and clearly identified timetable (e.g. annually).

3. Understanding service user's needs:

- 3.1. Initial assessments should be carried out face to face and ideally in the service users home, unless otherwise requested.
- 3.2. Assessment processes should be simple, well explained, consistent and focused around the service user's needs.

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- 3.3. The council should adopt a ‘trusted professional’ model to ensure that once an assessment is undertaken, the service users do not need to repeat information until they are due for review or re-assessment.
 - 3.4. Service users should always receive a copy of their assessment and support plan.
 - 3.5. RBG should ensure that translation services are fully available and advertised to service users from initial contact through to annual review. Particular consideration for this should be given to members of the Nepalese community.
 - 3.6. Service users need to be involved all decisions made about their care, during assessments and reviews. No decision should be made about an individual’s care and support package, without fully involving the service users (and carers).

4. Volume of services available:

- 4.1. Whilst Greenwich Council hasn’t had the severity of cutbacks of other many other local authorities, budgets are still tight, and there is a general perception that assessment decisions are being made based on available funds, rather than individual’s needs. The Council should ensure that care workers are allocated enough time to carry out the support needed (e.g. 15 minuite slots for personal care or 30 minutes slots for cooking and supporting with lunch/dinner). The council should try to be more transparent in its decision-making processes, clearly identifying the rationale for any reduction in services or funding.

5. Personal health budgets:

- 5.1. Greenwich Council should work more closely with Greenwich CCG’s continuing health care team. Processes and good practice should be shared, and changes implemented to improve services across the board.

6. Re-assessment and financial monitoring:

- 6.1. More support should be given to carers and service users to assist with the financial monitoring. Annual reviews should not be punitive.
- 6.2. Funds provided for care and support should only be clawed back in exceptional cases.
- 6.3. Reviews should be consistent, carried out within a reasonable time scale and staff carrying them out must read the previous year’s review and current care plan, before undertaking them. They should focus on changes since the previous one.

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- 6.4. Service users and carers should not have to go through their entire history and care needs each year.

7. Consistency of support:

- 7.1. The lack of punctuality, handovers, and consistency of staff from care providers is a significant concern for people. We recognise that recruitment and turnover of care staff is a significant problem nationally, so RBG should work with providers to identify and share best practice, as well as ensuring that they are paying care providers a realistic hourly rate.
- 7.2. RBG should also ensure that consistency of staff, effective handovers, and punctuality of directly funded providers are key performance indicators, monitored very closely.
- 7.3. The council should revisit the policy of not paying family members for essential care.
- 7.4. Lewisham and Greenwich NHS Trust should review its policies with regards to overnight stays at QE Hospital, with a view to enabling carers of vulnerable service users to stay overnight.
- 7.5. From assessment onwards, service users and carers should be allocated a named key worker (care manager/coordinator), who will be the main point of contact. This person will support the user to navigate processes and will lead on ensuring that services are being provided when and how agreed.

8. Respite care:

- 8.1. Family and friends are most likely to be a person's carer (which can save the local authority money). This can be an exhausting and stressful job. To prevent burn out and additional stress and anxiety, consistent respite packages should be made readily available to carers - particularly for those caring for their loved one full time. These should be flexible, affordable, and well advertised.

4. Next Steps

Much of the information gathered in this report is known to Greenwich Council either in part or in full. Greenwich Council have taken the significant positive step of implementing the transformation programme, partly because of previous feedback gathered from service users. Healthwatch Greenwich will be continuing to gather feedback from people who use the services to support this process. In addition, we will be supporting Greenwich Council with their new customer reference group, aimed at working towards a co-production model for adult social services. It is important that the customer reference group acts as a hub for a feedback from the wider community about how the service changes are implemented and monitored going forward.

Over the next 12 to 18 months, as the transformation is implemented, we will be seeking to identify what impact the changes have had on the service user experience.

5. Royal Borough of Greenwich Response to the report

As is standard for Healthwatch reports, a draft copy of this report was provided to the Council to check for factual accuracy and provide a response. This is reproduced in full below:

We are grateful for Healthwatch Greenwich's work in compiling this report and value the recommendations which have been made. We have in place a transformation programme and two of the projects that sit within that programme, namely the Adults Customer Journey and Co-Production projects, will look to incorporate the findings into their outputs. The Adults Customer Journey project includes a comprehensive review of our systems and processes and we will endeavour to ensure that the report and its recommendations are carefully considered within this work. It has been encouraging that the recommendations made in this report reflect many of the issues that the project seeks to address.

Since 2016, Royal Borough of Greenwich has been engaged in delivering a transformation programme in Health and Adult Services to review and improve services. The Adults Customer Journey project, conducted in partnership with Oxleas Health, Healthwatch Greenwich, residents and service users, is a key part of this programme and seeks to improve services and broaden our understanding of the needs and views of our residents.

The Adults Customer Journey project is a core component of adult social care transformation in Greenwich and the mechanism with which we will take forward our research findings and the recommendations put forward in this report. The project, which began in 2016, is reviewing and redesigning services to embed the service user voice and make services more person-centred. The project seeks to reduce handovers and provide greater continuity in both the assessment process and delivery of support, whilst also building upon our integrated services. This project seeks to review the complex array of services, thresholds, and pathways in use across the health and social care systems to ensure that our new customer journey focuses on improving the user experience.

In the Royal Borough of Greenwich, there is a positive history of joint working between the Council and health care providers. A number of our teams are integrated teams comprising

both Oxleas and Council personnel. However, services continue to face significant pressures on capacity driven by an increasingly ageing population, with people living longer often with complex, chronic ill health conditions. Within this challenging environment it is often too easy for the experience of the service user to get lost. Our approach has therefore been centred on the need to involve service users, voluntary organisations, clinicians and professionals and other interested parties in redesigning the pathways through which our service users are navigated. This is a form of co-production.

Health and Adult Services' collective vision and commitment is to co-produce services with residents through a range of measures and activities. Co-production has been a valuable tool in helping us to ensure our service redesigns will be more reflective of both service users' hopes and aspirations and the need to make pathways between organisations appear seamless. There is widespread recognition across Adult Social Care that co-production is an effective catalyst to more successful and sustainable systems of care and support on national and local levels. It promotes a platform of shared decision-making and equal partnership between residents and Council officers. Our aim is to make all health and adult social care services more person-centred, enabling people to have more influence in shaping service designs. We recognise that there is a gap between our current position and our aspirational level of service-wide co-production.

Co-production in this project began through our partnership with Healthwatch Greenwich who worked with us to map the experiences and views of adult social care service users and carers. A survey and two focus groups contributed to this scoping, and engagement was developed through the formation of a User Reference Group. Each focus group proved valuable in bringing together different residents who shared their own experiences and participated in exercises to evaluate service provision in case study scenarios. Discovery interviews have been informative in illustrating in clearer detail the experiences service users, carers and families have had in recent years. The User Reference Group has also convened residents with a range of health and social care needs to help shape this project and provide steer and input into the redesign of services. The group has met several times on a monthly basis and have received project materials to review and feedback on, creating a culture of co-production and transparency between officers and residents. To embed the service user voice further, members of this User Reference Group have been included in the membership of our internal project Steering Group. The formation of the User Reference Group has been the most

effective measure in enabling the Council to work in partnership with residents, service users and carers, reflect on current services and map improvements.

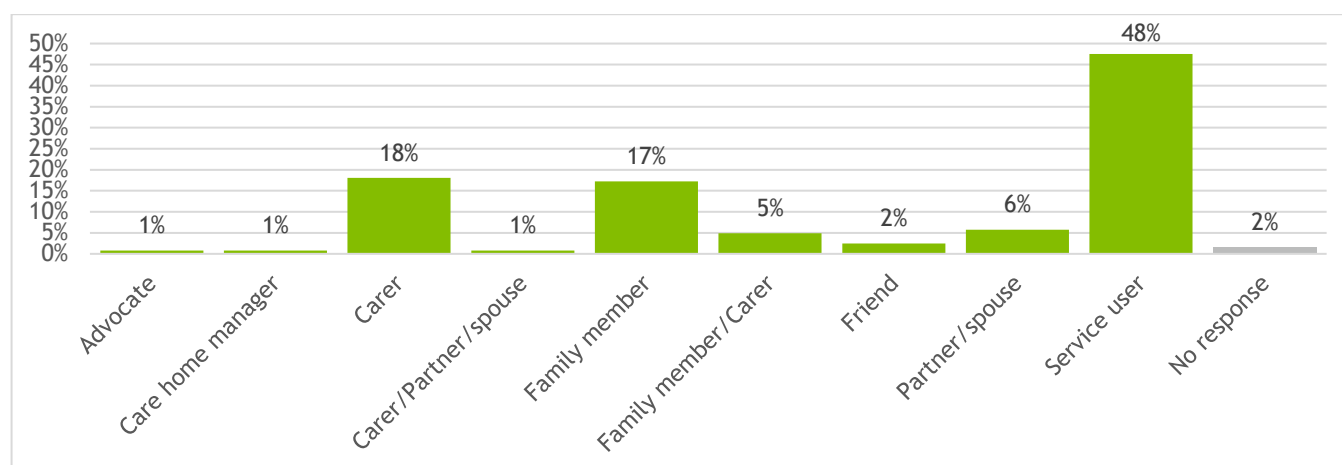
We are appreciative of the views and experiences people have provided to inform this report and the on-going insight from service users and partners. We fully intend to deliver on the recommendations made in this report and we welcome a fuller exploration of service users' experiences through continued research and consultation. If anyone is interested in finding out more about the work we are doing or getting involved in co-producing the new model please get in contact with the transformation team at :

adultstransformation@royalgreenwich.gov.uk

Appendix 1: Survey findings

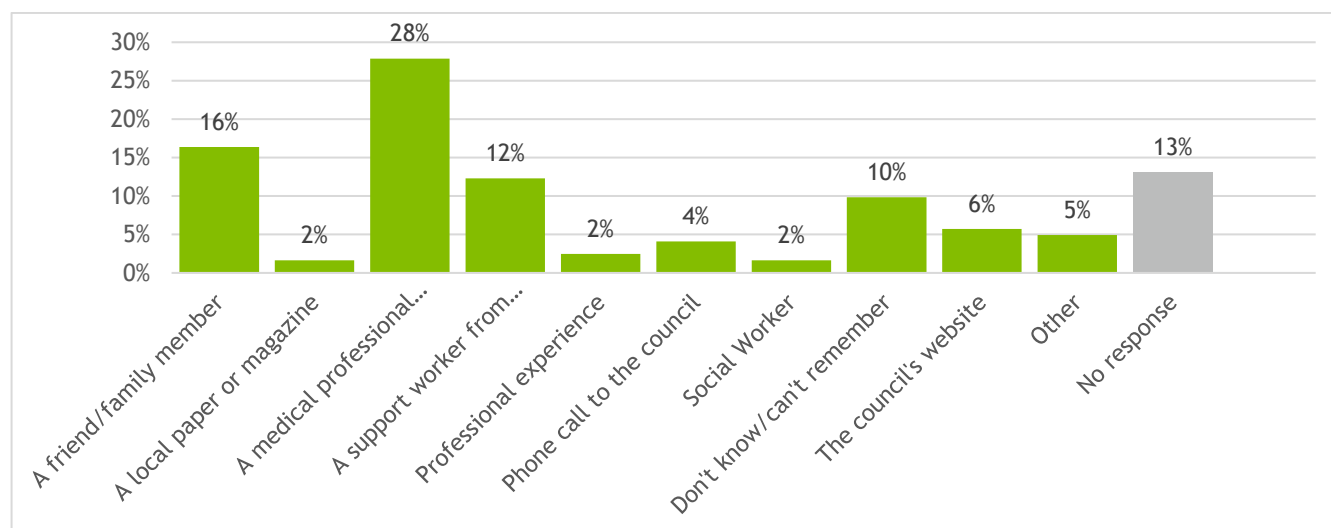
Between June and November 2017, 122 surveys were completed. There were three variations of the survey, all asking very similar questions, with the majority of the data being directly comparable. Around 60 surveys were completed online, 40 were posted back to us following a direct mailout by Royal Greenwich to around 200 current service users, with the remainder being completed through various direct contact and outreach sessions.

Who is completing the survey?



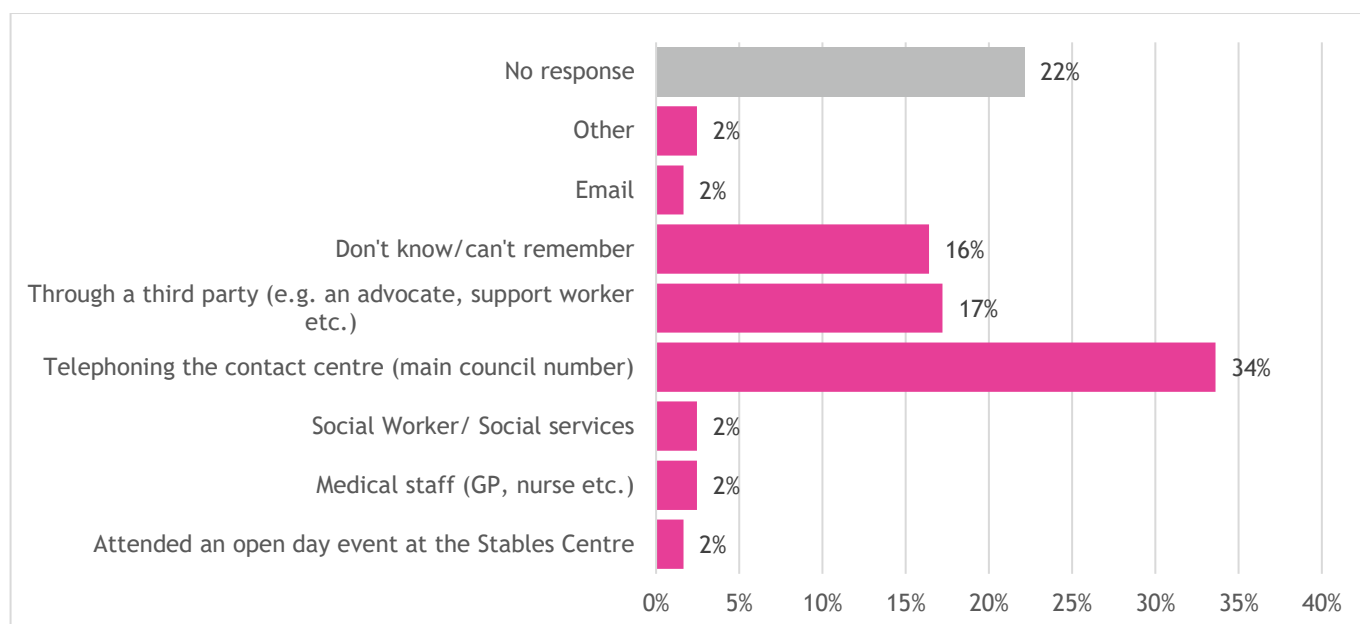
The vast majority of respondents were service users, or friends, family and/or carers of service users.

Where did you find out about Greenwich services?



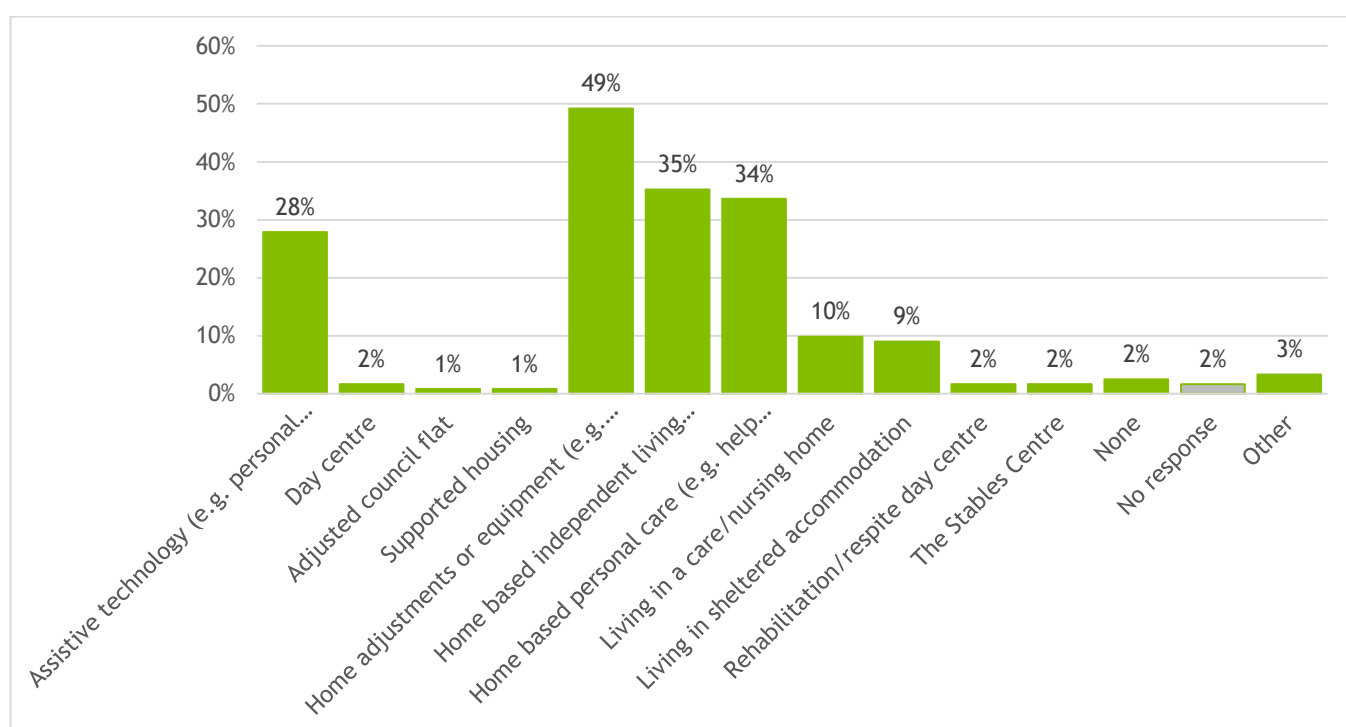
Medical professionals were the most likely method for people to find out about social care services, following family and friends. Many of the people who spoke to us had been receiving services for several years (see below) so the initial contact and assessment processes had slipped from their memory.

How did you first make contact with Greenwich council?



‘Other’ includes voluntary sector organisations and family members. Calling the council’s contact centre number was the most likely route into services, followed by being supported by an advocate such as a friend, family member or support worker from a voluntary organisation.

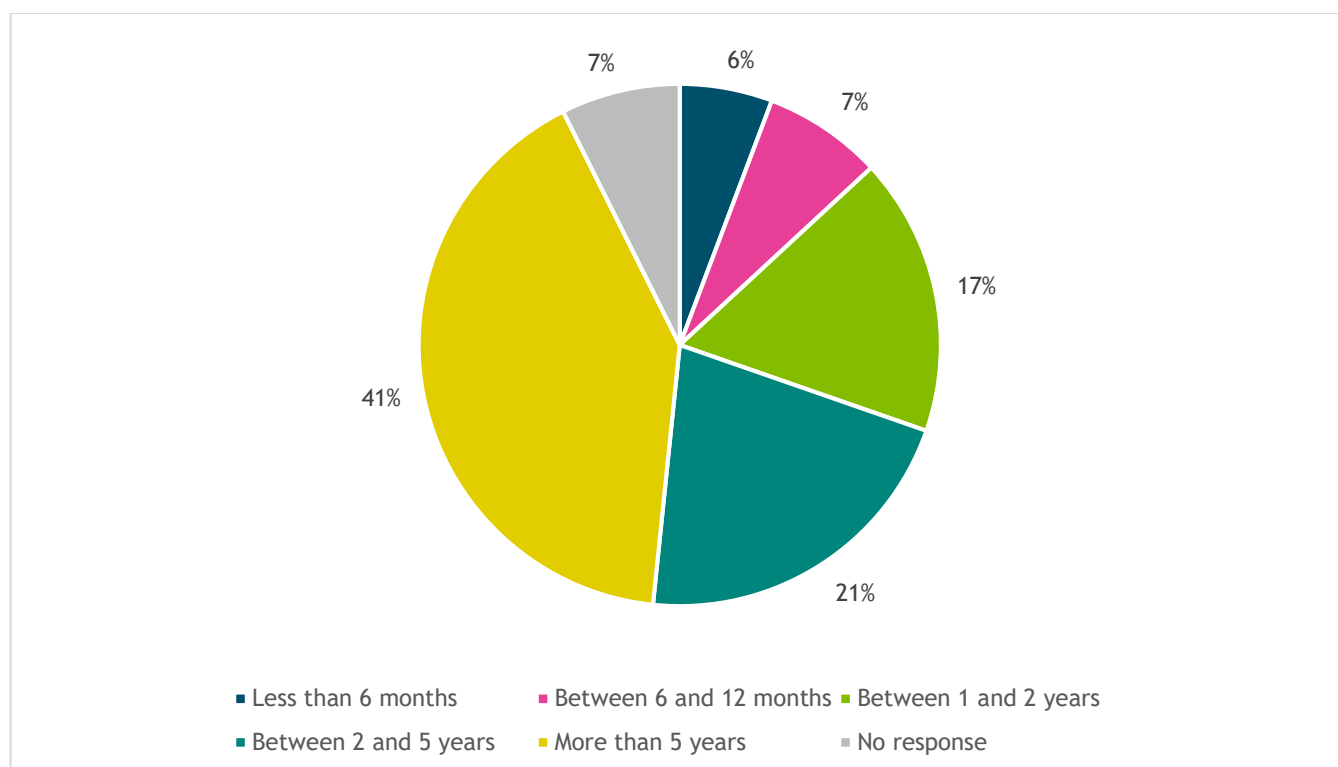
What services have you received/do you receive?



The number represents percentage of respondents who receive each service.

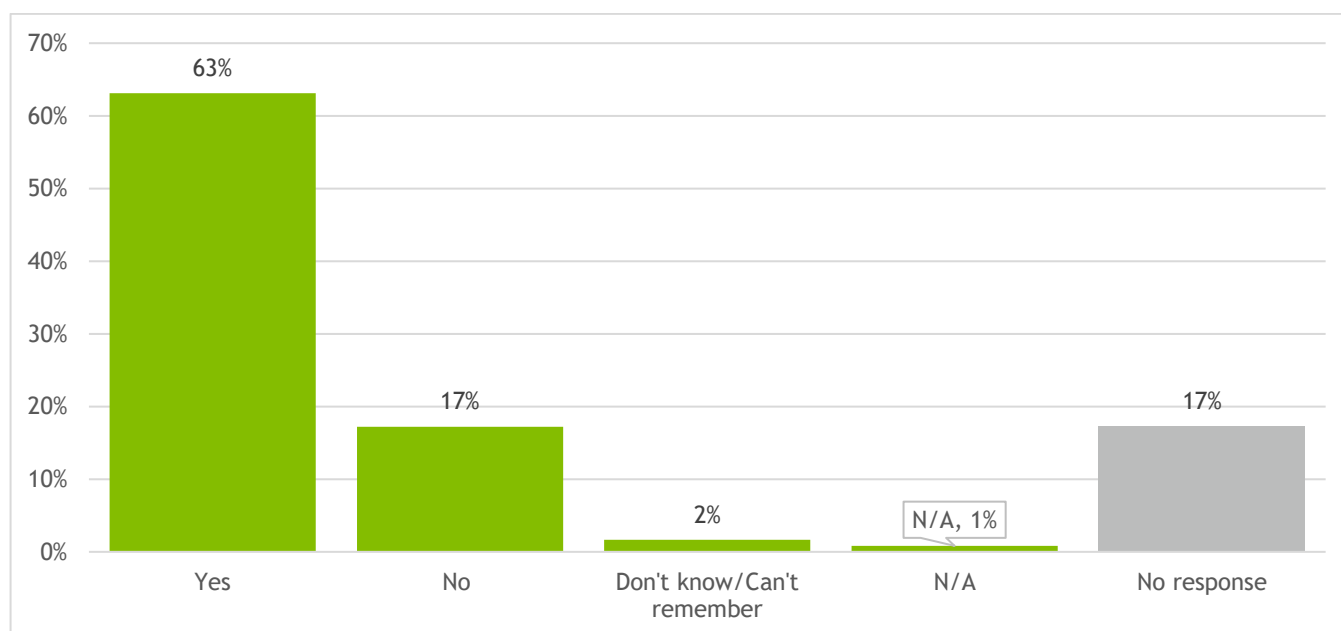
‘Other’ includes occupational therapist (OT) and physio assessments, fall prevention support, supported housing and nursing services. Most respondents have received multiple services, for example, support at home, assistive technology, and home adjustments.

How long have you been receiving services?



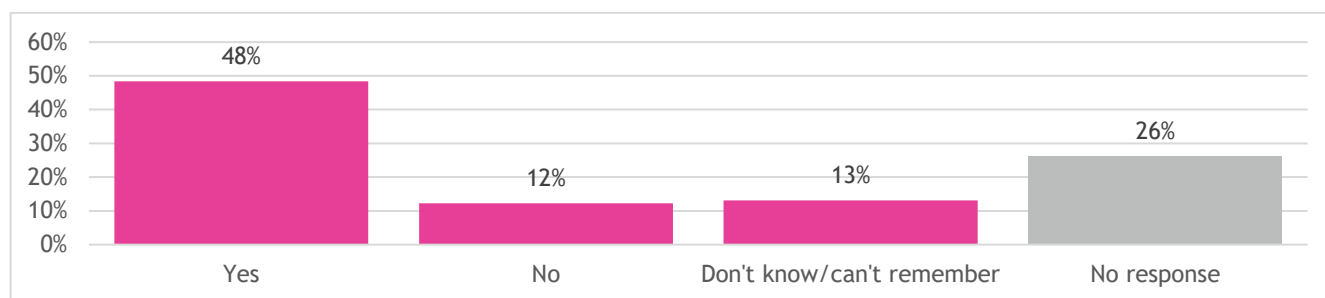
Almost two thirds of respondents have been receiving services of one form or another for more than 2 years.

Were you assessed/do you remember the assessment process?



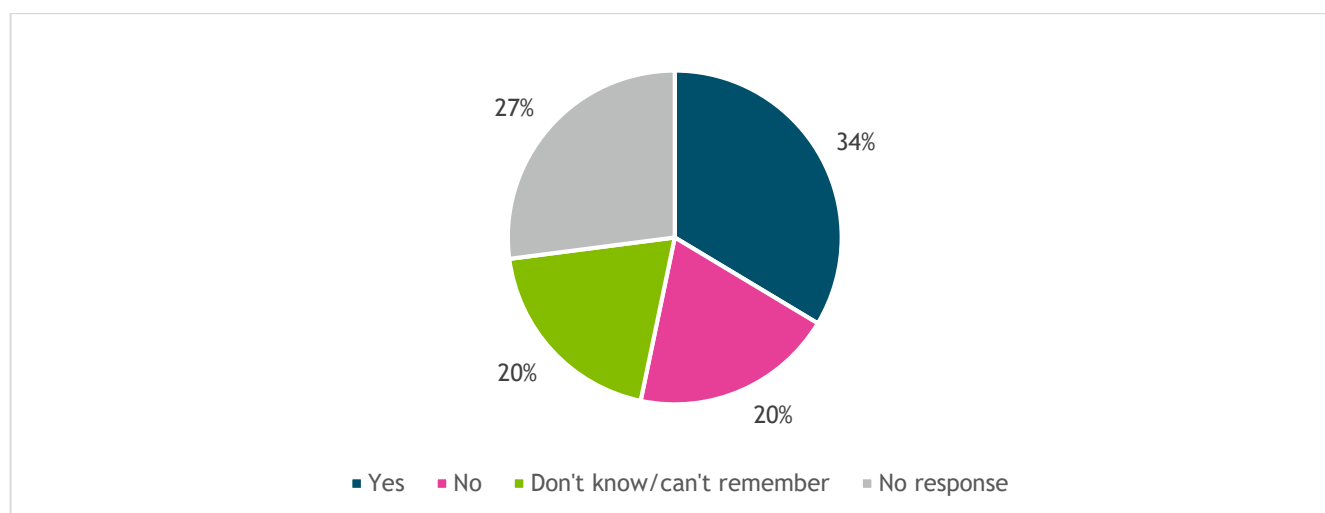
19% of respondents either weren't assessed or don't remember being assessed for services. 41% have been receiving services for more than 5 years, so it would be reasonable to assume that this may contribute to people not remembering.

During assessment, did you have to answer questions or provide information more than once?



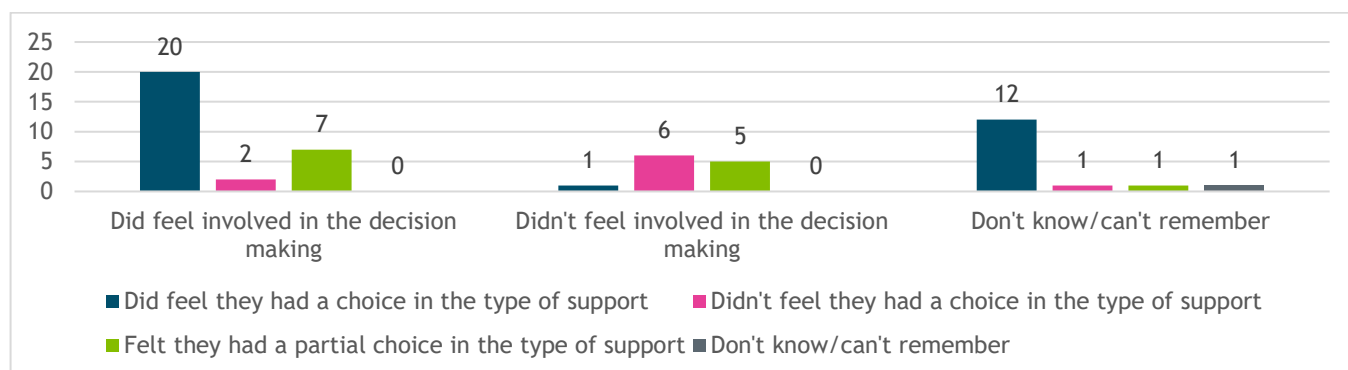
80% of those who remember their assessment, had to answer questions, or share their information more than once. This can cause significant frustration for people during the process.

Did you receive a copy of your assessment for your feedback?



34% of respondents remember receiving a copy of their assessment for feedback. One in five didn't get a copy.

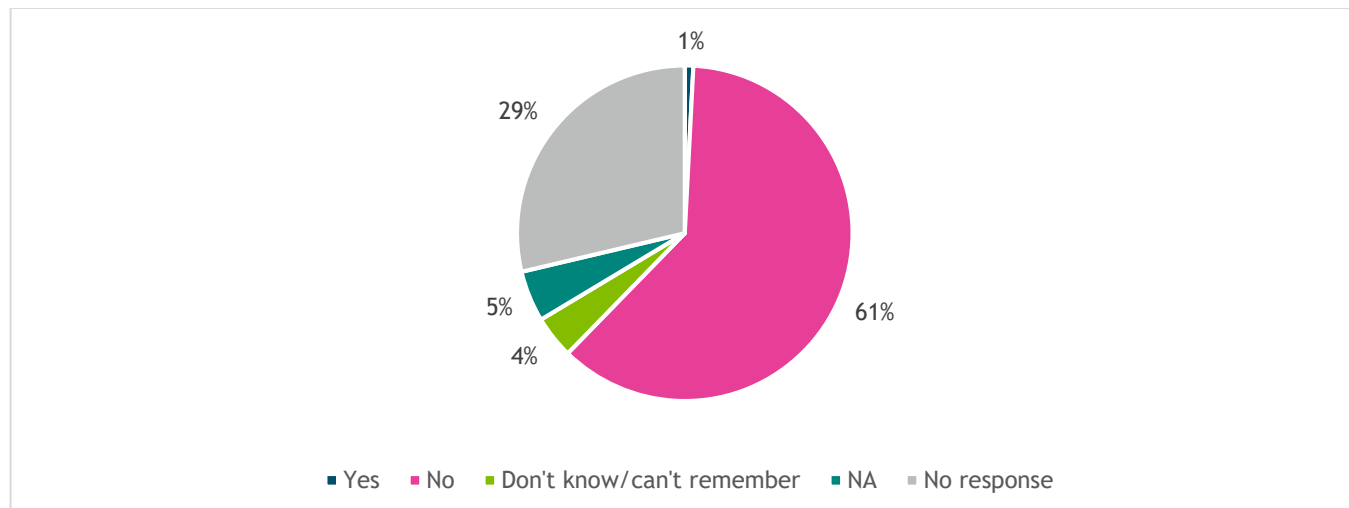
Did you feel involved in the decision making during the assessment process, and do you feel you had a choice in the type of care and support you received?



People who felt involved in the decision-making process, are far more likely to feel they have received the right type of support, than those who didn't feel involved in the process.

There was a relatively low response rate to this question, which could imply that even if people were involved in decision making, they may not be explicitly aware that this was happening.

Have you ever used the Royal Greenwich online assessment tool?



Only one respondent had used the online assessment tool. This may reflect the general age range of respondents (66% were over the age of 56, and one in five were over 76 years old). Alternatively, it may simply be a result of the online tool not having been available for long.

What could be changed to improve the application process?

As discussed in section two, whilst service users were broadly positive about the assessment processes and the services they received, there were clear areas for improvement. This included the time taken from initial contact to receipt of services, the general lack of information about the assessment process, and for some, a sense of one size fits all during the assessment process.

Some service users felt that the process was too impersonal and that an interview at home would have helped the assessor to get a fuller understanding of their condition.

“The process of getting any help at all is far too complicated and time exhausting...”

“The NHS local doctor’s surgery and especially local hospitals do not give out this information unless one asks, but if one doesn’t know about it, how can one ask?”

“It has been good!”

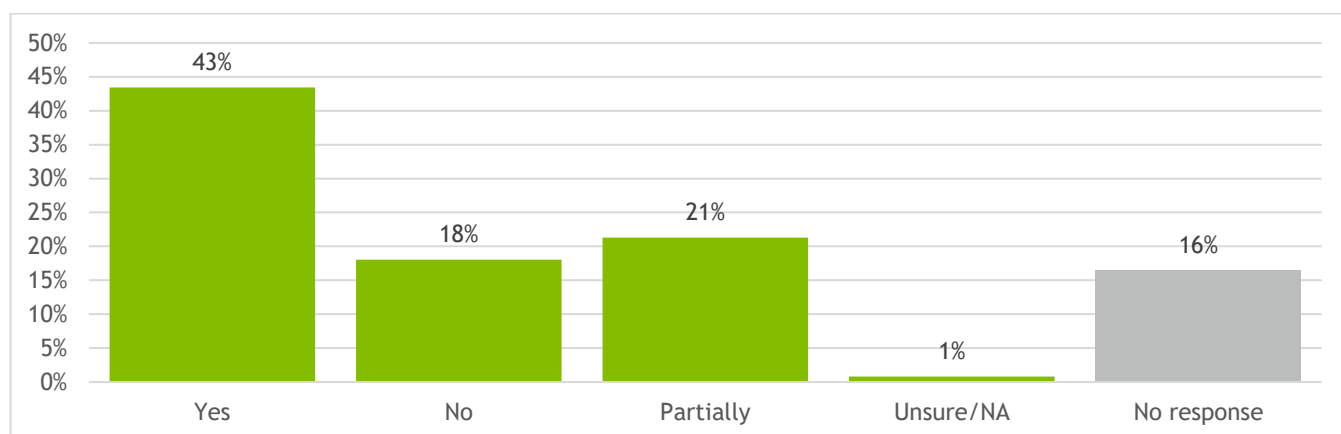
“I twice had surgery, was immobile, had no-one to help (live alone) was told I should get help but didn’t. Last time it took 3 months before NHS and Greenwich “care” came to help!”

“...carer assessments are useless as nothing ever comes from them, being sent information on my son’s condition didn't help.”

“This went smoothly. There is an element of repeat questions but at a time of some tension there is a purpose in ensuring the person has made the right choice for them.”

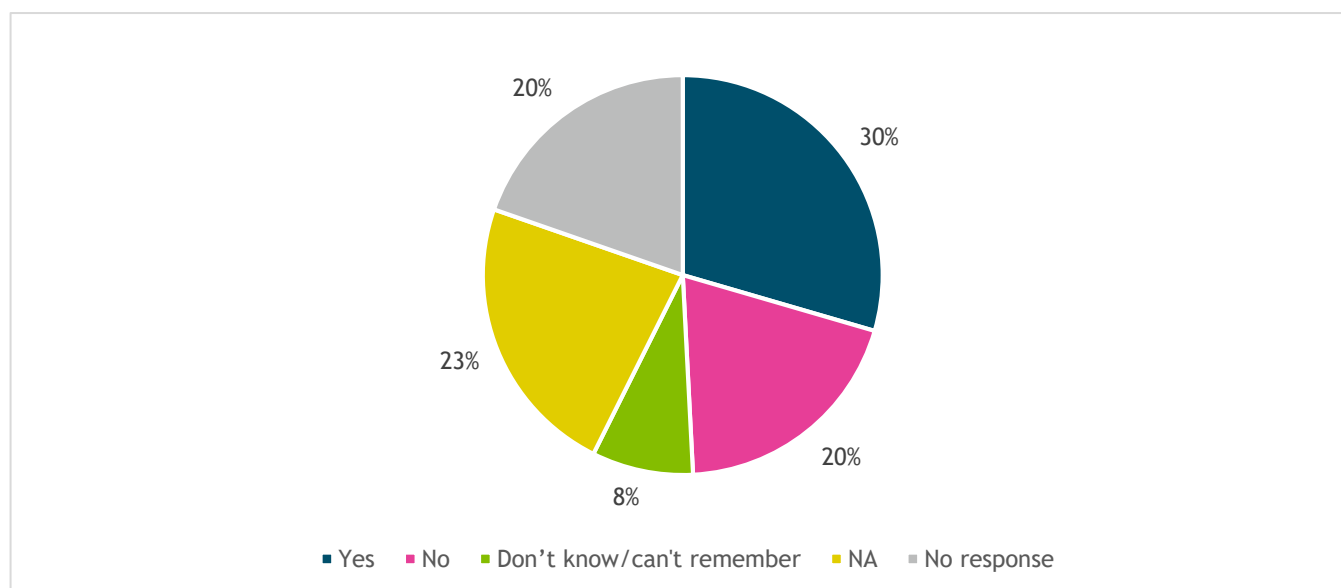
“Do not use the internet so would not use the online self-assessment tool”

Do you feel you received the right kind of care and support (after assessment)?



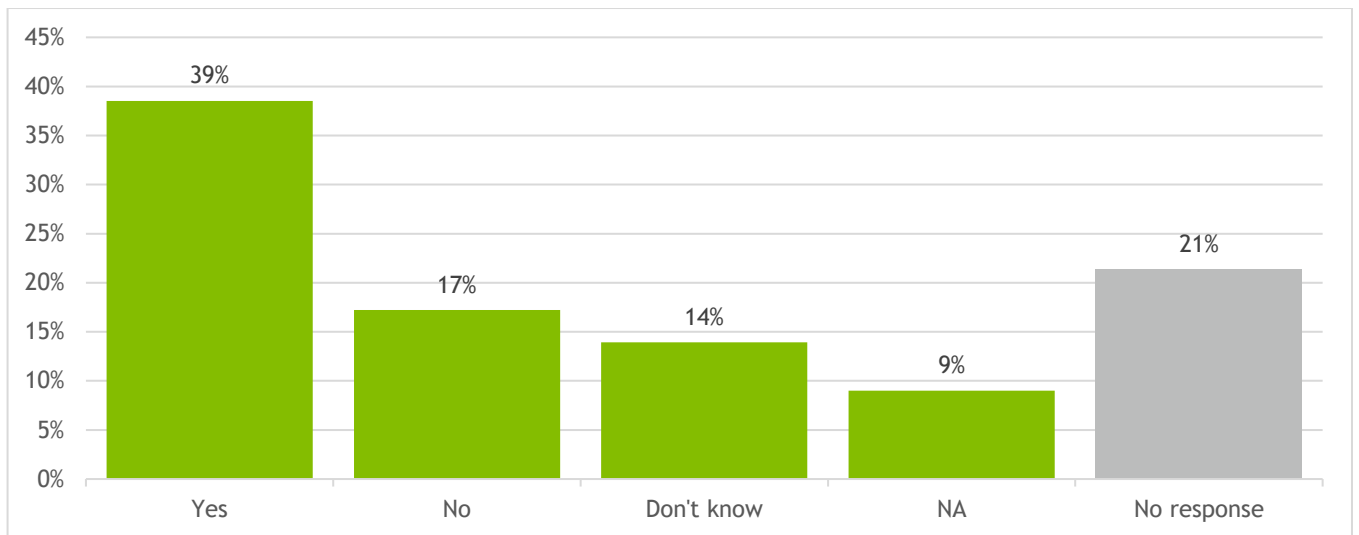
43% of respondents felt that they receive the right kind of care and support with a further 21% feeling they partially receive the right kind. Nearly one in four do not feel they receive the right kind of care and support, which needs further investigation.

Have you ever experienced delays when transferring from service to another?



Nearly a third (30%) of those who had, and could remember, transferring from one service to another had experienced delays during the transfer.

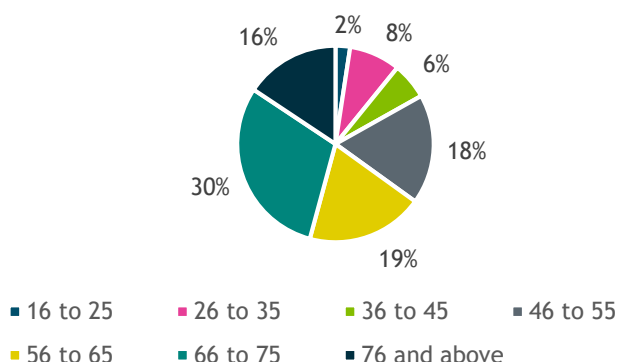
Would you recommend the services you received to a friend/family member?



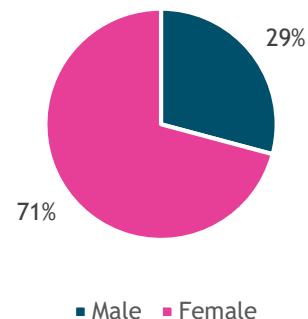
55% of those who expressed an opinion said they would recommend the services to family and friends. 25% wouldn't recommend and 20% weren't sure.

Appendix 2: Demographics

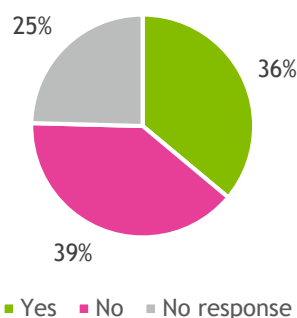
Age breakdown



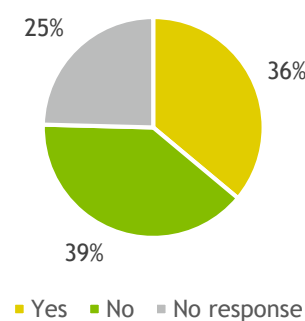
Gender



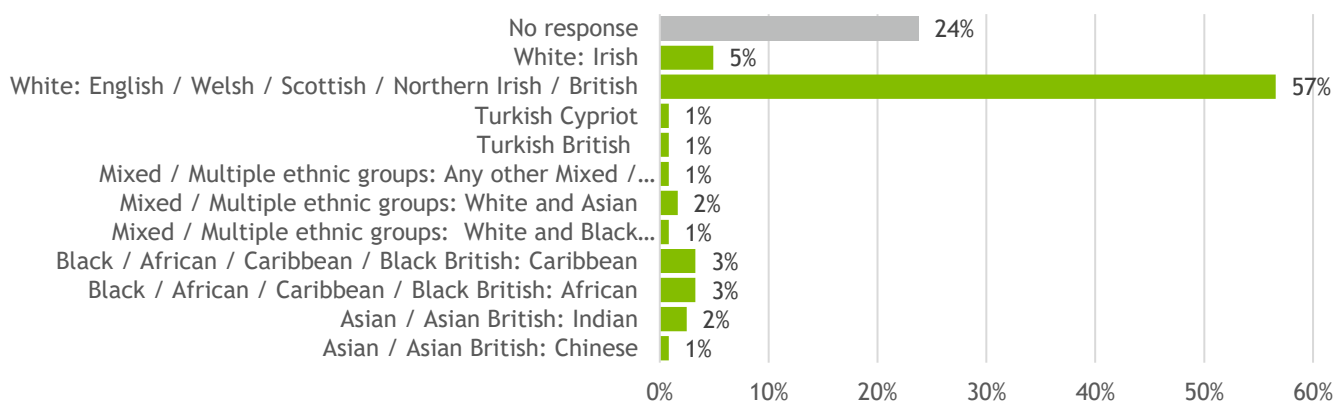
Carer



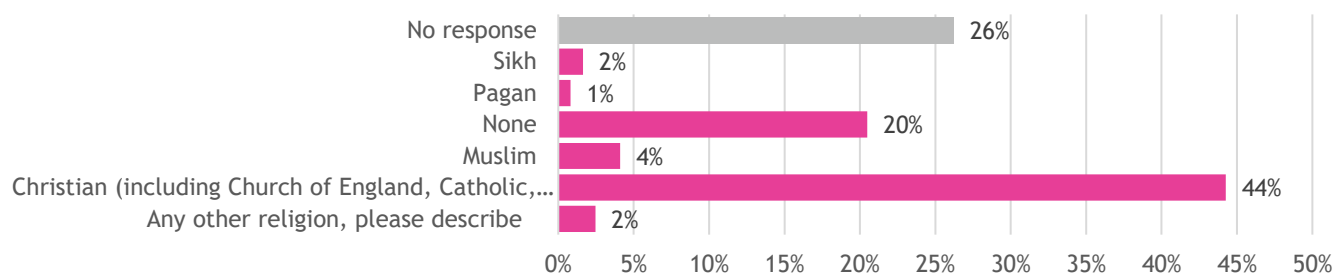
Disability



Ethnicity



Religion



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