Dementia Survey Report

Healthwatch Bury

February 2023

Contents

Introduction to Healthwatch Bury

This report has been produced by Healthwatch Bury. The Healthwatch network consists of 152 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London. We are all independent organisations who aim to help people get the best out of their local health and social care services, whether it's improving them today or helping to shape them for tomorrow.

Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience. We are the only body looking solely at people's experience across all health and social care in Bury. As a statutory watchdog, our role is to ensure that local decision makers put the experiences of people at the heart of their care so that those who buy (commissioners) and provide our services (NHS Trusts, GPs, the voluntary sector and independent providers) can benefit from what Bury people tell us. Our reports on various elements of health and social care in Bury can be found on our website at the following link: healthwatchbury.co.uk or by contacting us directly using the details on the back cover.

Executive Summary

Over Summer (July to September) 2022 Healthwatch Bury ran a research project into the experience of individuals living with dementia. This was done through a questionnaire, which was completed by 46 service users. The data gathered was both qualitative and quantitative data for a more comprehensive overview of their experience.

We wanted to learn about experiences of people living with dementia in Bury, their diagnosis and the role services play in supporting people with dementia and the experiences of their families and carers.

Our aims were to:

- understand the experiences of carers of people living with dementia and those they care for.
- understand and learn from their experiences of diagnosis and accessing care and support for themselves and the person they care for, in order to shape service improvement and provision locally

Key findings

- Diagnosis of Dementia in Bury is generally undertaken by GP Practices with a limited number of more complex cases referred to the Memory Clinic
- Experience of diagnosis was generally good although it could take years from initial raising of concerns to a confirmed diagnosis
- Referrals to support services provided by Alzheimer's Society were ad hoc and there were no consistent actions taken around advice and support at the point of diagnosis
- Results of memory tests and scans were often given by phone over the last two years causing greater upset and distress to patients and their families
- Little follow up contact by GP Practice after diagnosis with patients with families feeling they had been abandoned
- Little evidence of post diagnostic treatment such as cognitive stimulation therapy available in Bury

Our recommendations:

- ***Review diagnostic services and ensure a clear, effective, and consistent service is available to all residents in Bury***. Include review of best practice and other models of service delivery to ensure a robust, comprehensive, and equitable service is available to all residents of the Borough with updated guidelines and diagnostic tools.

- ***Ensure everyone involved in diagnosis of dementia has received appropriate and up to date training***. This will be dependent on the model of delivery but should include Memory clinic, GP Practice staff and frontline staff in Adult Care, Community services & Dementia support groups. Training should also be offered to patients, carers and family members to better understand the illness and its progression.

- **Ensure all services dealing with people getting a diagnosis and their families have access to the most current information and guidance to make sure there is consistency of information across the borough.** Inconsistencies and differences in what people are told causes additional stress, waiting and wasted resources, as well as harming trust in the system.

- ***Information on local support and advice to be available at point of diagnosis***. Clear and up to date information needs to be available at the time of diagnosis for carers and family members as this is key to addressing the feeling of abandonment and isolation felt by patients and carers. This should include details of Dementia support team, Alzheimer's advice and local community support groups for carers and patients.

- ***Improve communication with family members and carers and record any wishes they may have regarding communication with the patient/family.*** Ensure patients, carers and family have the information they need to help the patient live a quality life. It is important to ensure access to support and information as needs change as the illness progresses. Medical professionals should discuss and record the preferences/ wishes of primary carers regarding communication needs as evidence collected indicates that patients may be in denial about their symptoms and abilities, may minimise difficulties and may get aggressive or violent if the Carer tries to correct, redirect or provide their own observations or experiences about the patient's condition, causing distress to both patient and carer.

- ***Provide Patient and Carers with clear information about treatment, annual reviews and progression of the illness.*** This should include information about types of dementia, what happens next, referral to Alzheimer's support workers, who is responsible for ongoing care, crisis support, common infections such as delirium, ongoing tests, medication and planned reviews.

- ***Ensure appropriate diagnostic and support services are available for all forms of dementia and for patients with early onset dementia.*** Evidence gathered from the survey indicated that family members felt that some patients (especially from a professional or education background) were able to complete the diagnostic tests more easily and delay diagnosis. Evidence or observations from family members should be taken into account when concerns are raised & this could allow treatment to commence at an earlier stage. Concerns were also raised that diagnostic tests, advice, support and treatment appeared to be focused around Alzheimer's and that support and advice was not readily available for less common forms of dementia.

- **Ensure all communications are accessible to the people that need them.** In line with the Accessible information Standard and in a format that is most suited to them. This includes large print, simplified English, Easy read and translations where applicable.

Background

Dementia describes a group of symptoms that include problems with memory, thinking or language, and changes in mood, emotions, perception and behaviour.

Dementia is a progressive disease, which means symptoms may be relatively mild at first, but they get worse over time. Over 850,000 people live with dementia in the UK. Carers are often family members, a relative or friend. They play a critical role in caring for people living with dementia, including with day-to-day life, personal care, practical help, and making health care and financial decisions on their behalf. [1]

Dementia is a growing challenge. As the population ages and people live for longer, it has become one of the most important health and care issues facing the world. In England it is estimated that around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated at 850,000.

Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years. However, for some dementia can develop earlier, presenting different issues for the person affected, their carer and their family.

There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.

There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke.[2]

For older people with dementia Bury does well in terms of recorded prevalence and had the fifth highest recorded diagnostic rate in the country in 2020/21. 4.63% of all over 65s registered with a GP practice against an England average of 3.9%. Diagnosis rates for dementia in 2021 were good as was the quality rating for residential care and nursing home beds. However, annual reviews of people's dementia care plans are poor - only 26% of plans are reviewed annually (England average is 39.7%). Bury also had the 12th worst direct standardised mortality rate in England in 2020/21.[3]

There is also a requirement to review the whole of the dementia pathway in Bury to ensure that people diagnosed with Dementia have access to the post diagnostic support they require (e.g., Cognitive stimulation therapy, cognitive rehabilitation, occupational therapy) and that ongoing enhanced annual reviews (including reviewing, behaviour, risk and social circumstance, a physical health check, care

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[1] What is dementia? | Alzheimer's Society (alzheimers.org.uk)

[2] NHS England » Dementia

[3] Bury Mental Health Strategy Draft August 2022.pdf

plan and medication) takes place in line with NICE guidance. People with a diagnosis of dementia must also be provided with a named coordinator of care who will support partnership working with other agencies as required to support the development of a holistic personalised care plan.[4]

A Dementia Steering group has been established in Bury and work is underway to review services in line with NICE guidance and the GM Dementia Care Pathway. A National Audit of Dementia (NAD) assessment has been undertaken and the findings of this report will be forwarded to the Bury Dementia Lead for consideration.

Further context:

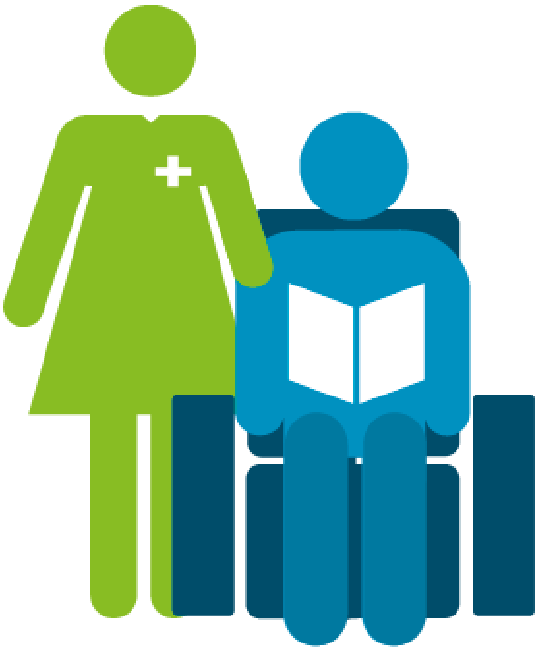
NHS England profile of dementia: NHS England » Dementia

World Health Organisation profile of dementia: https://www.who.int/news-room/fact-sheets/detail/dementia

National Institute for Health and Care Excellence (NICE) Guidline:

Dementia: Assessment, management and support for people living with dementia and their carers: https://www.nice.org.uk/guidance/ng97

Alzheimer's society factsheet on Dementia



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[4] Bury Mental Health Strategy Draft August 2022.pdf

Methodology

Survey questions were produced based on patient and carer feedback about local dementia services and the aim was to gather more in-depth feedback about local services in Bury.

Following its official launch in June 2022, the survey was distributed and promoted in a range of ways, including:

- Promotion via Healthwatch Bury's website and social media channels (Twitter and Facebook)
- Promotion via face-to-face engagement, including, park bench surgeries and stalls at local community events.
- Promotion via Dementia Steering Group
- Promotion via visiting local groups. We visited Dignifying Dementia group; Bury Carers Hub coffee mornings; Brandlesholme Coffee Mornings, Church groups, Rekindle support group.
- Asking statutory organisations, health and social care providers, local businesses, voluntary sector partners and community groups to promote the survey.
- Direct emails to existing contacts and organisations.
- Hard copies were available on request.
- People were invited to arrange a one-to-one telephone call, face to face interview or participate in a focus group if preferred.
- We have included comments from respondents in detail as part of this report as we feel their words are more powerful than a generic summary.

Findings

Please see the survey findings below:

Question 1 - Have you or someone you care for had a diagnosis of dementia?

The vast majority of people we heard from (89%) had already had a formal diagnosis. This is likely due to the networks and partners we work with and shared this project with will be predominantly working with people that have had that first diagnosis.

Question 2 - Please tell us about your experience getting a diagnosis

Positive comments	Negative comments	Standout comments
Diagnosis was simple ///	Wrong scan arranged	
Memory clinic helped	Long wait for diagnosis //////////	6 months – 3 years (one 10 years)
Medication made a difference	No direction or advice after diagnosis /////	“felt very much on my own”
Face to face GP appointment	Diagnosis included unnecessary travel /	
Offered a range of tests	No physical observation for diagnosis	
GP was good //	Not enough help post diagnosis	
Mental health service was good	Results of scan never given to us /	
	Difficult to contact GP or get appointments ///	
	Difficult to contact social worker	
	All done over the phone in a few minutes, not thorough or didn’t feel listened to /	
	Left suffering whilst waiting for diagnosis //	
	Had to chase up results of scan after months	
	No consistency from GPs //	“Passed from pillar to post”
	No contact to check on you	
	Difficult to get diagnosis from GP /	“Lots of chasing and no support”

	Need a new referral if medication needs changing	
	Took a long time to get into memory clinic /	
	Referrals not made /	
	Better communication between GP and patients	

Question 3: How easy was it to access the help and support you needed?

Around 60% of respondents had found accessing the help and support they needed ‘Difficult’ or ‘Very Difficult’. 15% had found it ‘Easy’ or ‘Very easy’ to access the required support. This indicates that more awareness raising is required to ensure all patients have the right information about accessing services should they need to use the help and support.

Question 4: Have you been referred to support services (Alzheimer’s Society/Carers Hub etc.)

Nearly half the respondents (48%) stated that they had been referred to support services, another 16% said they had made a self-referral. 36% had not been referred to any further support.

Question 5: How did you feel about the treatment, care or support that you were offered?

32% of the respondents said they were ‘Satisfied’ or ‘Very Satisfied’ with the care or support they had been offered; 34% said they were ‘Dissatisfied’ or ‘Very dissatisfied’ with the offered care and support.

Question 6: Are you aware of ‘This is Me’ booklet?

64% of the respondents stated that they were not aware of the booklet. 13% said they were aware of it but had not yet used it and 22% stated they were aware of it and were using it.

Question 7: Are you aware of ‘Dementia Friends’ training?

67% of the respondents were not aware of ‘Dementia Friends’ training, 11% said they were aware of it had not completed the training and 22% had completed the Dementia Friends training.

Question 8: If you have completed the training, how did you access it?

Out of those (8) who had completed the training 5 had accessed it through their work. One respondent had completed the training online after they’d been a carer for 9 years and one person had been signposted through the Bury Carers Centre. This indicates that employers are great at raising awareness about the condition but more work may be required for making the training accessible for those who are no longer in employment to make sure they have an opportunity to become more informed.

Question 9: What is working well and what improvements could be made to dementia services in Bury?

What works well	What improvements suggested	General comments
Bury Carers Hub is exceptional in its support for carers //	Getting more information at first signs from medical practitioners. More information about local services. ////	'A one stop shop doesn't suit everyone with dementia.'
Unpaid volunteers who strive to help people.	More advice and guidance for carers. More understanding of needs of carers. More support and training for carers ////////	/If I have a medical problem, looking after someone's personal care and other needs can be or become extremely difficult.'
The Memory Clinic staff helpful and friendly	Respite	
Decaff Greenmount	More support for people who have no family nearby.	'I get no support for my father, who lives alone. I do not live near him. He needs to socialise with people but unless I take him (which I am severely limited to be able to do) then he sees no one.
Merrie Melodies/Musical Memories/Singing for the Brain ///	More social groups and activities for people who are profoundly deaf and have dementia on all days of the week. ///	
Family support	More contact from relevant services. Dementia registers that's used to contact families to check in on them on a regular basis. ////	'There have been times when I have been desperate for help due to changes in behaviours which I did not understand. I did not get the support I needed, and no one has bothered to follow up my calls.'
Dementia café	More connection between GPs and services after diagnosis/ Referrals. Easier access to a consultant.///	
Social worked arranged care leave and respite care.	Designated contact for a primary carer – what to expect and what can be accessed. //	'Lots of services, got lots of numbers but confusing as to who does what. Could do with one adviser/one point of contact.'
Bury lending library for equipment, rails etc. very good.	Designated GPs for dementia care //	

	More of a person-centred approach to enable the individual to received the personalised care. //	‘My mum even before dementia didn’t like going to new places, which she didn’t like or thought they were spying on her and trying to possess her. My anxiety wasn’t good trying to get her to places and this was never acknowledged or taken into consideration in any help suggested.’
	Speed of access to mental health team and diagnosis	
	More support from social workers – Adult Care	
	More face to face and less over the phone.	
	Dementia plan in place as soon as told about dementia.	
	More understanding about different types of dementia.	

Additional investigations findings.

From discussion with 2 Carers who wanted to talk to Healthwatch Bury in more detail about their experiences, we conducted a more detailed face to face discussion and found their experiences at the diagnostic stage and ongoing care management were extremely distressing for themselves and the Patients.

- The experience of diagnosis with GP was unsatisfactory and distressing, hurried and unsympathetic. Little support offered.

- Diagnosis given over the telephone in a short phone call. Difficult to have a conversation or for the Carer to contribute. Very little information given about assistance: “An appalling process. I felt left to get on with it myself. Had to self-navigate the system”.

- Carers are not able to talk to the GP or medical professionals about the issues they are experiencing. “No one would listen to me”.

- Not enough information and consideration given to less common forms of dementia, at diagnosis and for ongoing advice and support. Early onset dementia support networks not available and many groups mainly cater for older dementia patients (80+) not for people in their 60’s. Carers own experience of Frontotemporal dementia (FTD) with behavioral variant (a rare form of dementia) is exhausting and extremely challenging. Carer has managed to find a FTD Partner support group himself based in Stockport which has been crucial to understanding this progressive degenerative variation. No information was made available to the Carer locally. Fortunately was able to research this himself but not all Carers would be able to do this.

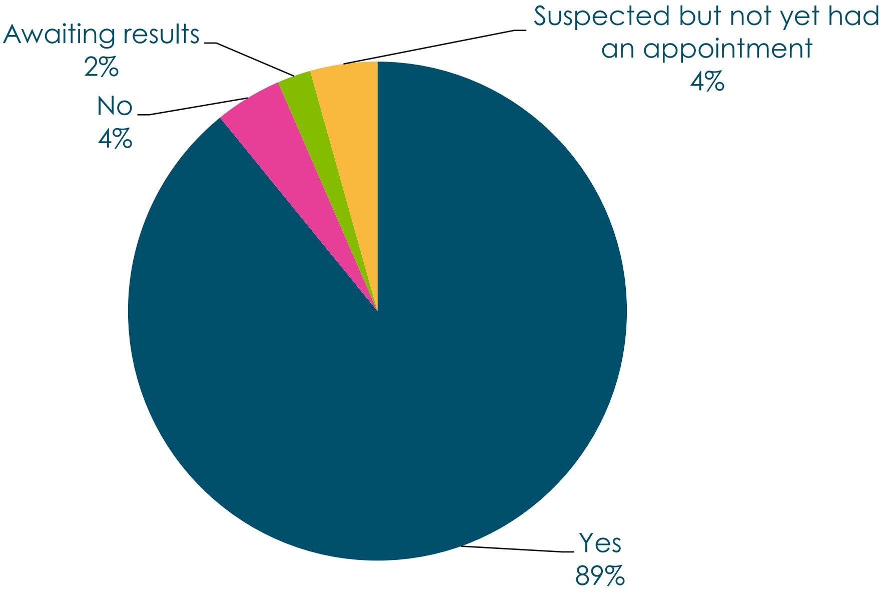
- Dementia review meetings do not seem to have much of a purpose and specific requests eg to the Memory team & Salford Royal Cerebral Function Unit for a separate Carers review meeting, were ignored. Meeting with both Patient and Carer may result in distress, aggression and abuse to the Carer or the Carer may not feel able to give an accurate description of the condition in front of the Patient.

- We found that there was often a lack of information on the results of the MRI scans, prognosis and progression given to the Carer.

- A general ‘induction to practicalities’ for Carers of dementia patients would be helpful at an early stage of illness.

Results

1. Have you or someone you care for had a diagnosis of dementia?



2. Please tell us about your experience getting a diagnosis (For example: What worked well? What could have been better?)

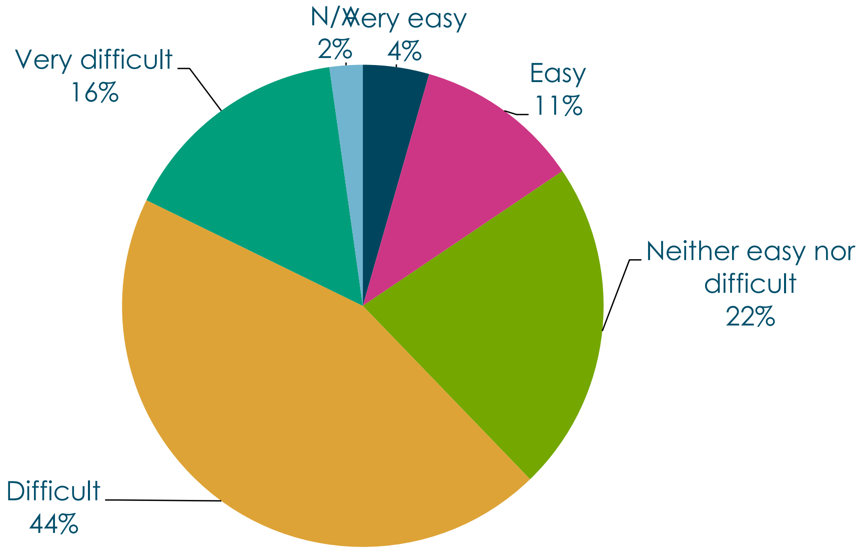
Default table grid
Diagnosis was quite simple despite being early in the pandemic.
Failed memory test, face to face with doctor, referral for scan but wrong one arranged, still waiting for alternative test.
Quite straightforward once the request for a memory test was made to the GP
Just appointments at the memory clinic
I spoke to Annemari (Healthwatch Bury) at the recent Bury Carers' Coffee Morning and mentioned the following letter and note etc that I have copied here. (Something I didn't mention is that my wife, with her type of dementia, easily passed the standard test(s) for dementia which seem to be more geared up for Alzheimer's). The letter resulted in a meeting and invitation to be a member of the Dementia United Bury Delivery Group. The last meeting, I went to was shortly before the pandemic (February 2020) and neither myself or the Bury Carers' representative have heard anything more since then.
We had to wait a long time to get a diagnosis and start my husband medication
Dr diagnosed after scan and test, sent to memory clinic for retest and tablets, review after 6 months then discharged. No direction advice or help given other than a blue written folder.
Only negative was that it took a year to complete and involved travel, which took a lot of time and effort. Also, I think it would be better if people were assessed by observation not paper tests.
It being done over the phone felt incomplete. No physical observation could be made.

The diagnosis was given by the doctor after completing a list of standard questions. That was it. No signposting to agencies etc was given. Have had to learn what is and what isn't available.
My husband had a memory test by the GP in June 2019 and was told to repeat it a year later but due to Covid this couldn't take place. He had another memory test with the GP in 2021 following an MRI scan (scan was ok). I think the GP would have left it at that, but we were both concerned about his deteriorating condition, and I asked for suggestions of a way forward. The GP then referred him to the Memory Clinic, and he had a lengthy memory telephone assessment, involving both of us. In October of 2021 we had a telephone consultation with a lovely junior (I think) doctor who spoke to the consultant - he then gave who a diagnosis of Mild Cognitive Impairment. Then in 2022 we had a telephone appointment with a nurse from the Memory Clinic who initially was going to discharge my husband. However, after discussion she spoke to the consultant. He agreed to see him/ us(?) after a further memory test (which was face to face) and MRI scan. These took place in May and June 2022. He has an appointment with the consultant in August 2022. I feel that the process seems to be taking a long time, though I understand that the pandemic has caused a delay. We were hoping that early intervention would hopefully help to reduce his deterioration, but we are more than 3 years since first approaching the GP. The gentleman who did both memory tests offered some useful advice. However, we are really anxious for more help and support.
It was straightforward although dad went for a brain scan, and we were never given the results of this. It was his GP that said he had dementia, but we don't know if this was based on symptoms or evidence from scan.
Find it difficult at times to contact social worker and doctors
Nothing worked well, took a very long time to get response. Then a diagnosis was given and confirmed over the phone in a 5-minute call, then felt left and abandoned. No appropriate history taken from either of us.
I had to go to the doctor several times about loss of memory before I was sent for MRI. Probably took over 6 months before I was diagnosed with Alzheimer's Disease.
We knew something wasn’t right with my mum after lockdown. The GP’s have been supportive and helpful. The doctor gave a diagnosis of dementia In December and referred my mum to the memory clinic she was not seen until May. She suffered for many months with sleepless nights and worrisome confused days for all these months. The memory clinic prescribed her with anti-anxiety medication which helped straightaway, and mum is now doing quite well. Very frustrating to have to wait so long to see the specialist team.
My mother-in-law was given a face-to-face GP appointment and offered a range of tests however I had to chase up the results of her brain scan which had been received by the surgery almost two months earlier.
Family have known Mum probably had dementia for 10 years. Had first memory test 9 years ago & was just above the threshold. Second 3 years later & was just below threshold, MRI scan was inconclusive. She was a former primary school teacher so we felt she could cover it quite well. Third test October 2021 and score had dropped quite a bit, MRI scan was again inconclusive as she became very agitated and moved about but GP concluded she probably had Alzheimers. Took a long time & she lived alone so couldn't get any help without the diagnosis.
Early diagnosis would have helped, got passed from pillar to post and different GPS all the time, no consistent care from GP
Through pandemic so all over the phone, never saw anyone. Sent for a brain scan mum had vascular dementia. Never saw a person but they did their best. Once diagnosis received, we heard nothing so one service finished and we didn't know where to go. There was no contact to check in on you.
Very difficult to get diagnosis from GPS, lots of chasing and not much support

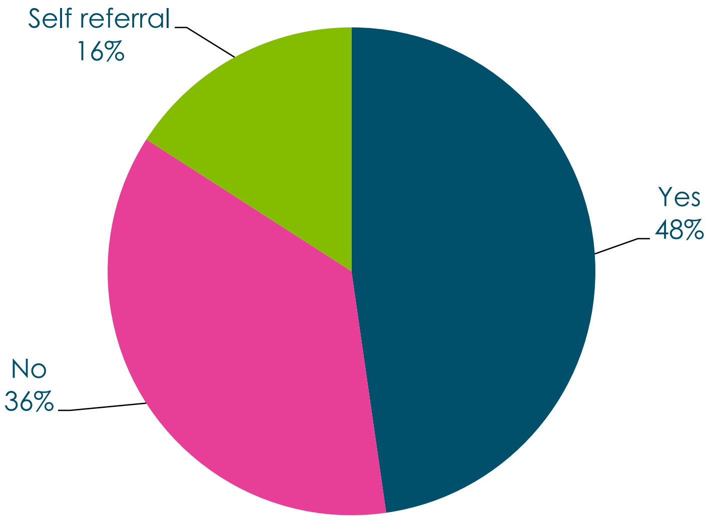
Terrible. Took very long to get dad diagnosed as he was under threshold on test. Inconsistent GP visits and hard to get appointments
When I brought up my concerns in a consultation with the GP, we were required to book an appointment with a nurse to do a preliminary assessment. That showed that there was something but needed further assessment from a doctor in the practice that has more experience in this area. We were told we would get a phone call with an appointment within 2 weeks. While waiting we found out that my mother had cancer which is incurable. After the 2 weeks I contacted the doctors to find that nothing had even been put on the system about needing that appointment. But they couldn't do it anyway as the doctor is off at the moment with covid and is retiring at the end of this month and they don't know who is taking over that role. When I asked what we do now then I was told phone next month then we might know who is taking over. Its very hard to get a normal doctor's appointment at any time let alone an extended one so what help is there for us to get a diagnosis?
I raised concerns with my mother's GP and a memory test was arranged. An MRI at Fairfield and a diagnosis given. About three months from start to finish
Difficult getting diagnosed. Sisters in a care home and we have been trying for a while to get her a diagnosis and get a regular gp
It took far too long and too many visits to the GP
It was bad because my husband was diagnosed during lockdown, we received diagnosis over the phone which was hard At the time o couldn't think of questions to ask.
Its very difficult to get a diagnosis of Dementia quickly. Because of the complexity of the disease.
Took a long time to get to memory clinic. Sorted medication out now discharged if medication needs changing must go to doctors and be referred again!!!
My wife was diagnosed before I came to Bury. Tadcaster York is where she was diagnosed. Noticed going in all cupboards looking for things. GP did the diagnosis test with her/memory test/copy shapes etc. She passed for months but failed one after a while they sent her for scan. Diagnosed mixed dementia.
GP - good
Relative spent 5 weeks in hospital following deterioration in mental health at home. No diagnosis forthcoming in hospital but relative not deemed well enough to go home. Family told a 6-week assessment from community mental health team would be in place on discharge to a care home (temporarily). Hospital failed to make a referral. When family eventually contracted mental health team directly told it could be 'months' before she was seen due to backlog. Family left in limbo unsure what in her best interests and what would be affordable. Really needed her to be somewhere where her capability or otherwise to manage to live alone could be assessed.
The NHS Mental Health Service was good. Assessments were timely and referral to her doctor worked well.
Several years ago. Referred by GP to specialist and got diagnosis though specialist. NHS referral - hospital visit Easy to get diagnosis.
I was told Mum had dementia but not sent for tests for another 3 years. At that stage asking the questions wasn't good and made her worse. Wouldn't go to Memory Clinic after that first experience. Eventually had a nurse, came to visit from the clinic and tablets given to help, but then referred to own doctors. However, tablets needed to be changed as not good. Dr referred to the clinic but 6 monthly waiting list. However, i rang them and I was lucky as they dealt with me and came out to Mum. This was back in 2013. Eventually back to my GP who used to ring me every 2 weeks to measure her medication and alter.
Diagnosis was fine, GP diagnosed her. Realised she wasn't reading as much not remembering what read. GP went through an agility type test questions for dementia testing. Diagnosed 12 years ago. (Mum)

Went to doctors, first diagnosed with mild cognitive impairment. It got worse. Had a scan and diagnosed later.
More information re: groups, felt very much on my own.
We went to Salford Royal - which was a trek. They monitored my husband for some time - with memory tests etc. He was diagnosed seven years ago - we stopped going to Salford Royal because of the journey involved and he was getting frustrated with the tests. Now we are under our doctor now and my husband attends a day centre twice a week. It would have helped to go to our local hospital instead of all the travelling.
My husband was diagnosed a while ago because he was forgetting things. We went to see doctor for memory test. He diagnosed mild cognitive behaviour, which he said could develop into dementia. He had a brain scan and was diagnosed with Alzheimer's.
Better communication between GP and patients
After going to the doctor for a memory check and then getting appointments with memory clinic in Bury September 2014 discharged 2015 - I then felt we were here on our own - I just carried on looking after my husband - we both just carried on until sadly he started to deteriorate. - getting in touch with the Bury Carers Hub was really a godsend. Wish I had known about Admiral nurses too. This is just a very brief outline of what went on.
If I could have seen someone face to face, it would have been better. I'm fed up with the Covid excuses! If it hadn't been for the mental health Liaison Team. I would not have had any support at all. I was disappointed with both my GP Practice and my husband's consultant no help at all.

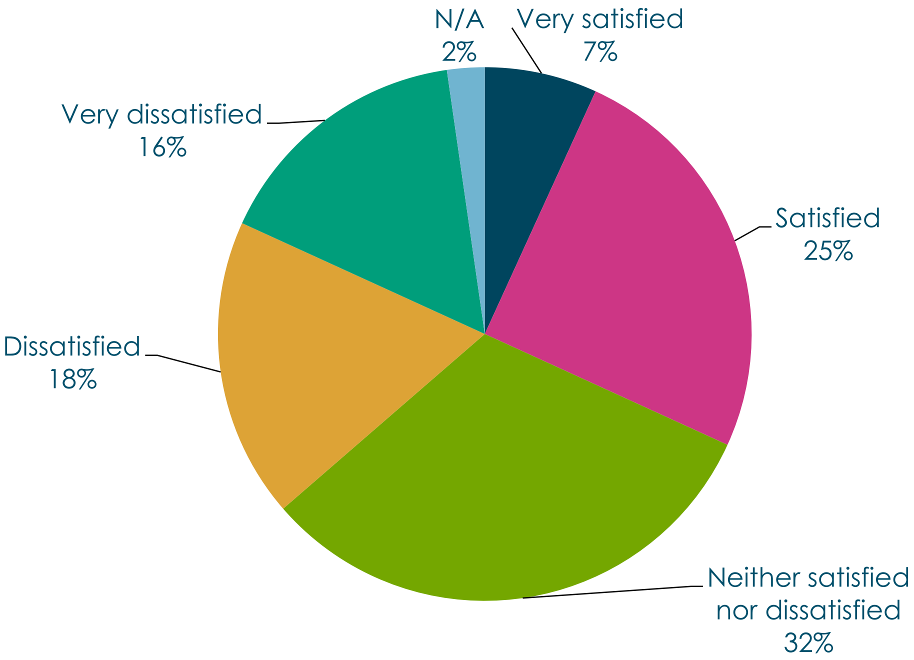
3. How easy was it to access the help and support you needed?



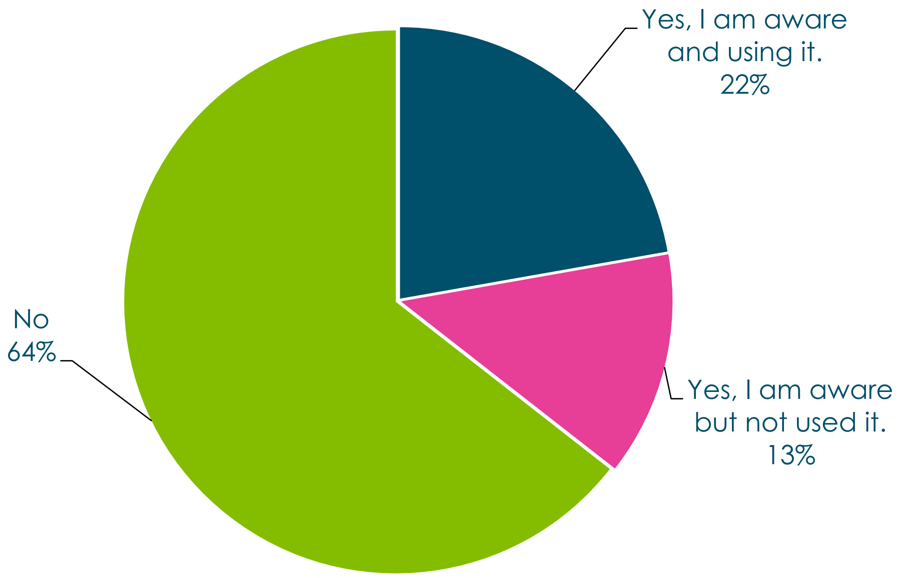
4. Have you been referred to support services (Alzheimer's Society / Carers Hub etc?)



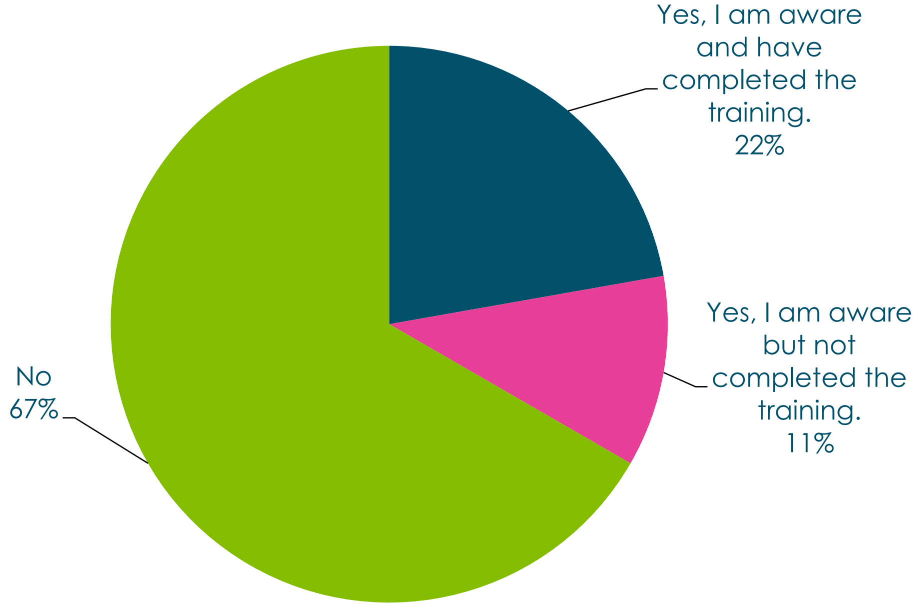
5. How did you feel about the treatment, care or support that you were offered?



6. Are you aware of 'This is Me' booklet?



7. Are you aware of 'Dementia Friends' training?



8. If you have completed the training, how did you access it?

No. I don't think it was available at the time of the diagnosis when it might have been most useful.
Online and later face to face. Online/postal not much help. The online was after I'd been carer 9 years
Through my employer.
Through work, before mums' diagnosis
Former work role many years ago. Also, through an Alzheimer Society & Sport England Initiative around Dementia Friendly Swimming I set up in my former role
I work for council
Through work
Went on training course.
Bury Carers

9. What is working well and what improvements could be made to dementia services in Bury?

Getting more information at first signs from medical practitioners
More advice and guidance for carers Respite
What's working well Bury Carers' Hub is exceptional in its support for carers. The activities they provide, advice and advocacy are helpful, and I don't know what I'd do without them. Improvements – in addition to those indicated in Section 2 Services available and signposting. Something that states what the dementia services in Bury are or what needs can be provided for doesn't exist. In my experience, it's often several services that might need to be accessed according to circumstances, e.g., GP, Memory Team, Hospital, Incontinence & Stoma, Occupational Therapy, Community Dental Service, Bury Council Adult Care. The key issue then is trying to ensure that they understand the needs of someone who can't articulate their symptoms and rely on their carer to do this and understand their patterns of behaviour. I've had contact with The Alzheimer's Society and Dementia UK Admiral Nurses, mainly on helplines when I've needed more immediate advice on specific issues. Experienced carers are sometimes better 'qualified' and more accessible than GPs and others to advise on a range of matters and that's where on-line communities and social media groups come in. Therefore, 'signposting' to relevant services is essential (although there is the obvious difficulty of raising expectations beyond what can be delivered and when). But who does this and how detailed because as symptoms develop different or varied solutions are needed? Referrals. Confirmation of a referral being in the system is needed with an estimate of timescales involved for an appointment, with contact details for checking if overdue. When long waits are involved, this is essential. For example, I've had experience of a

referral for an Occupational Therapist lost in system and where numerous phone calls were needed to sort out. With the Community Dental Service, I was concerned that the referral was overdue, and potentially lost but was assured it was in hand, the process involved and an idea of timescales. For the Incontinence & Stoma Service a referral was made by Bury Adult Services that I backed up with a letter 4 months later and shortly afterwards got a home visit. In all these instances it's the 'not knowing' of timescales that is frustrating notwithstanding that the pressures on the NHS now and into the future. However, I must say that I have found the staff to be very helpful at appointments.

Type of dementia. Most services seem to be geared up to Alzheimer's, which is quite understandable given its prevalence, but consideration should be given to rarer and early onset dementias because they are less understood and provided for by services.

Carers and the NHS system. We are told to register as being a carer with our GP. I have done this but have not been able to find out what this means in practice by a GP or the CCG. There should be a CCG and/or national guidelines. In simple terms I'd like to see a policy whereby some priority is given to carers who need a GP consultation, including for possible referral. The point being is that if I have a medical problem, looking after someone's personal care and other needs can be or become extremely difficult. (I can give examples if you'd like to hear about them).

Again, I am quite happy to discuss to issues raised.

There are none !!! with the exception of unpaid volunteers who strive to help people but have little support or funds and have set up own groups

I get no support for my father, who lives alone. I do not live near him. He needs to socialise with people but unless I take him (which I am severely limited to be able to do) then he sees no-one. He cannot do telephone chats as he is profoundly deaf.

Accessible groups available on all days through the week. Activities for those with a diagnosis.

There are lots of different 'types and varieties' of Dementia. A one stop shop doesn't suit everyone with Dementia. There needs to be a lot more understanding of needs of carers.

The Memory Clinic staff have been helpful and friendly, but I feel easier access to a consultant would have been useful. It will have been over 3 years since we first raised concerns before we see a consultant. We are not complaining, however. I just want to help my husband in every way I can.

No support or training given to family trying to care for the person with dementia. We were given booklets to read but they didn't help with the day-to-day tasks such as best techniques to help dad stand or what to do when he refused medication etc.

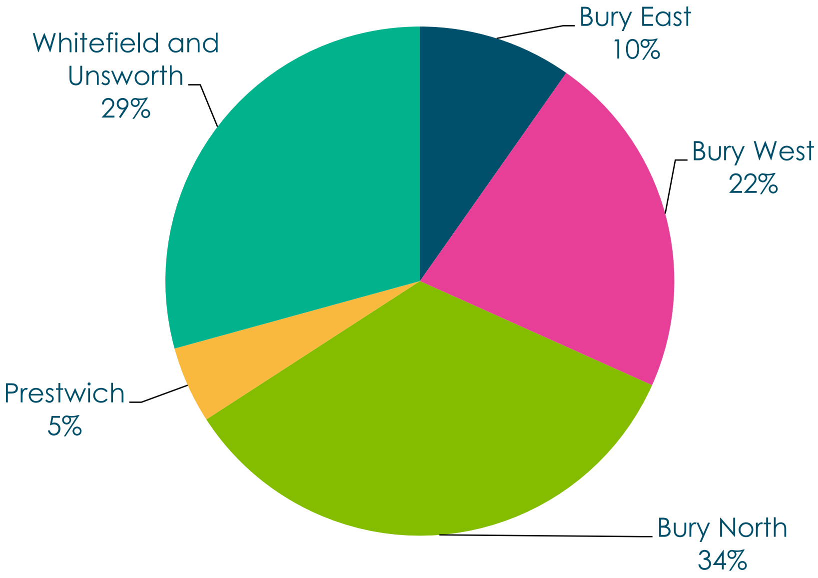
Initially we were told he would be under the 'memory clinic' but we have no idea what this is. He did not have regular assessments with GP and the consultant only ever did telephone appointments, so we had no idea if/when medication needed tweaking, what symptoms were dementia or likely to be caused by infections. We were not told what to look out for and dad ended up with Suspected Deep Tissue Trauma to the heels of his feet. We had no idea what this was and what signs to look out for. Trying to get short term emergency care support was impossible. When dad got urine or chest infections his dementia needs dramatically increased meaning, we needed care support. We couldn't afford financially to cover the hours we needed and were unable to get any help over a bank holiday weekend. Dad had to be admitted to hospital as we were unable to meet his care needs at home without assistance. The timescales for social services to carry out the financial assessments to enable an increase in carers hours meant he had to go to hospital instead. Being allocated a new social worker every time there was a change in circumstances was frustrating. It felt like no one really understood our family situation and my dad's needs. There was no consideration for my mum's needs or wellbeing (officially his carer), other

than being offered a card to have treats like hair apts etc. No one seemed to consider that mum might need regular time off to maintain her own health and wellbeing.
More information
Would need a full discussion to explain.
My dad also has dementia that was diagnosed 8 years ago, and we started to send him to Pinfold Lane. Sadly, this centre has closed, and he is unable to get to the Grundy centre as easily. Pinfold lane was a small group, and it suited my dad. Now we must send him to the Grundy which seems much bigger, and we can't really use ring and ride as getting him on time for ring and ride taxi is unpredictable. There is the Nicky alliance centre which has been amazing fir my dad we have managed to get him there with the help of carers but now that my dad's disease is progressing, they cannot cater for him at the Nicky.
More contact from relevant services would be appreciated.
Clear pathways so family & friends can understand the diagnosis, who does it & what happens next Access to information at diagnosis & likely timescales (it took 4 months from diagnosis to first contact with support with no information from GP other than she had been referred - but no information on where she had been referred to) GP involvement was fine but she was told over the telephone & not face to face & family was left unclear as to what to expect next. Alzheimer's worker information was clear and helpful when we did get a visit but left to family to follow up to access services. GP did put her on medication & this was reviewed twice after one & 2 months. Greater involvement from Alzheimer's Society with regular drop in sessions for support would be useful & also a course for Carers to learn more about what to expect. Rochdale services were good & I expected similar services in Bury but this was not the case.
Dcaf works well, merry melodies is very good, could do with more throughout Bury
Should be a dementia register where it's used to contact families on a regular basis to check in and offer services
There seems to be very little connection between GPS and services after diagnosed
No support for carers once diagnosed. Didn't get told about any services that could help us
A contact that calls and talks to the primary carer about what to expect and what can be accessed.
Have designated GPS for dementia care
There have been times when I have been desperate for help due to changes in behaviours which I did not understand I did not get the support I needed, and no one has bothered to follow up my desperate calls
When first diagnosed you don't really need a lot of help or even know what you will need. Could do with being contacted later as often carers are elderly themselves and maybe forget help first offered
More of a person-centred approach is needed, to enable the individual to receive the care needed for their own personal needs.
The doctor could be more helpful. I have accessed groups for carers but nothing really from Bury dementia services
We had a stairlift/downstairs toilet we put in ourselves. We had carers come in when I was recovering from stroke through council from Killelea (3 years ago). She is now in a home 'Alexandra' Used to use De-Caff services with wife when I could, daughter found it. The social worker arranged care leave and respite for us, that was great. 10 years caring for

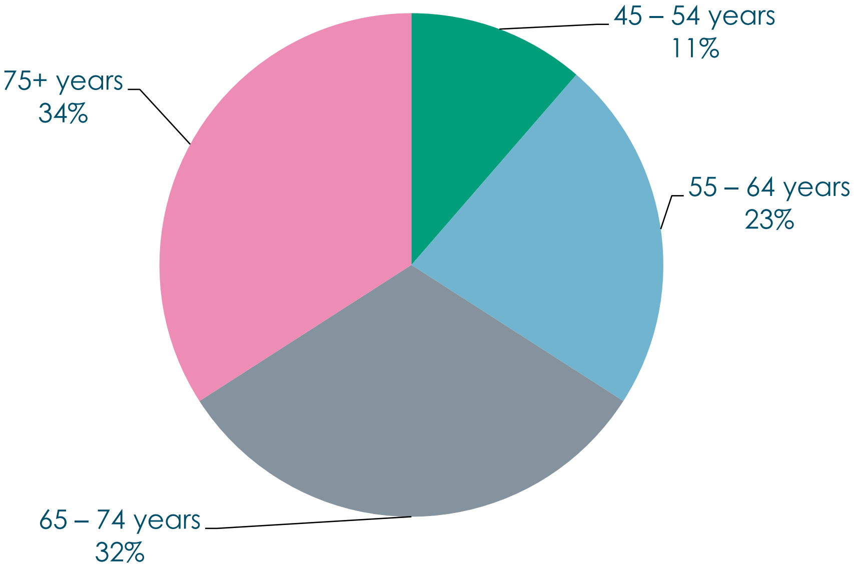
wife alone before social worker. Daughters were very active to make sure the care chased for us. Had a social worker and in touch with Bury Council. Daughters helped a lot as worked for the NHS. Had a dedicated social worker and helped us get a home for my wife.
I had a lot of support Singing for the Brain Musical Mem Dementia Cafe
At present no evidence anything working well! Need improvement in speed of access to mental health team and diagnosis. Also, more support for family members advice.
Once a diagnosis is made, there is little support from the social workers on Adult Care. You feel you are on your own. I am appalled at Persona's reduction in services for people living with dementia.
Managed by herself until several falls and then GP advised she needed a care home - Minden Health Centre. More concerns now about services not being face to face - GP Access.
My mum even before dementia didn't like going to new places and this gave her anxiety. This was never acknowledged, and everything is around going to places, which she didn't like or thought they were spying on her and trying to possess her. My anxiety wasn't good trying to get her to places and this was never acknowledged or taken into consideration in any help suggested. Didn't always feel people understood my Mum's dementia. Also, everything always seemed to be in Bury and Whitefield but not in Ramsbottom.
Very difficult to access the help needed for myself as a carer. Card from Bury Council to access money for carer activities, didn't go or left alone as no support. Got into contact with Alzheimer's Society through the Fire Station at Whitefield. Moved to Tottington became too far to travel. Nobody gave us support services. Mum's support was very good, district nurses, doctors, mediation supply social workers. Bury lending library for equipment, rails etc. very good. Me as a carer received no respite, not suitable as I would not leave house. I needed at home support - not available, asked for the day centre - told need to pay. I was given a card to access carers activities to give me a break. Got no support with looking after mum so could not use these services. No carer support for adult support. Even asked Jigsaw but as I lived with the person could not come in. 'This is Me booklet was completed but not followed by staff. No support for carer (daughter) even after mum passed away. Support needed mentally, with benefits and housing. Still on carers allowance for 8 weeks. Caused rent arrears.
Lots of services, got lots of numbers but confusing as to who does what could do with one adviser one point of contact
More information re: services. I had to find out myself or friends.
We like to go to the Carers Hub. Trying to fit everything in with no-one to look after my husband Is a challenge, not enough hours in a day. I have been thinking of contacting the wellbeing team to see if that helps me - someone face to face would be good.
I think it would be helpful if someone could maybe once a week come to our home and ask how things are going between carer and the one who is being cared for.
I think the services are good.
As soon as told about Alzheimers/Dementia a plan should be put in as soon as possible.
More face to face and less over the phone.

Demographics

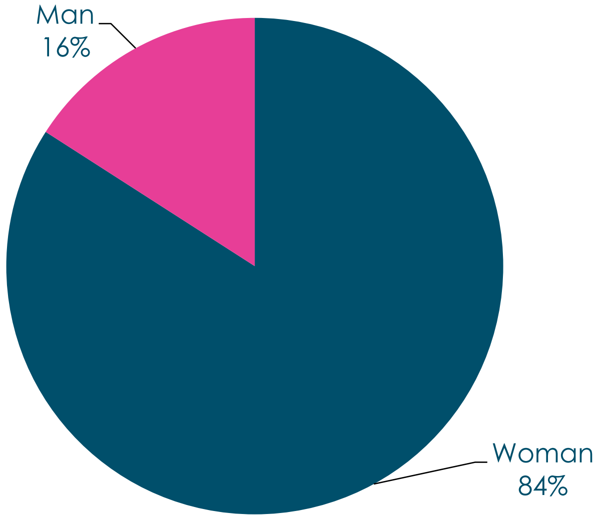
10. Please tell us which township you currently reside in?



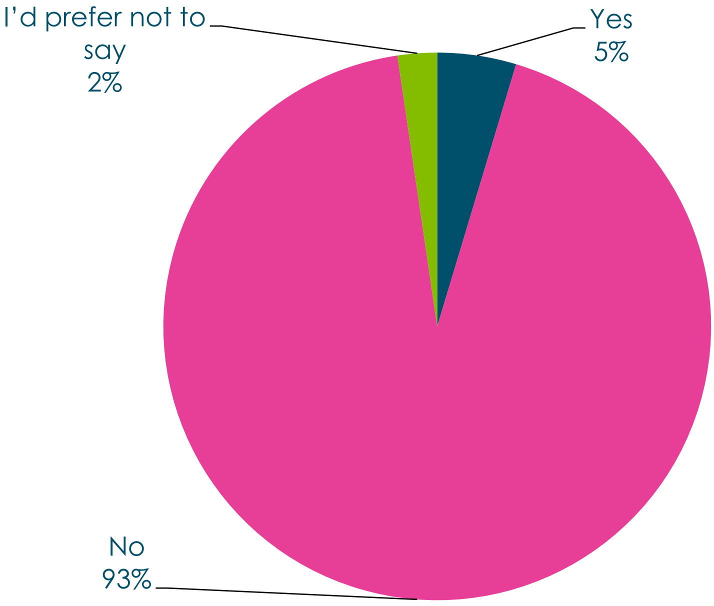
11. Please tell us which age category you fall into:



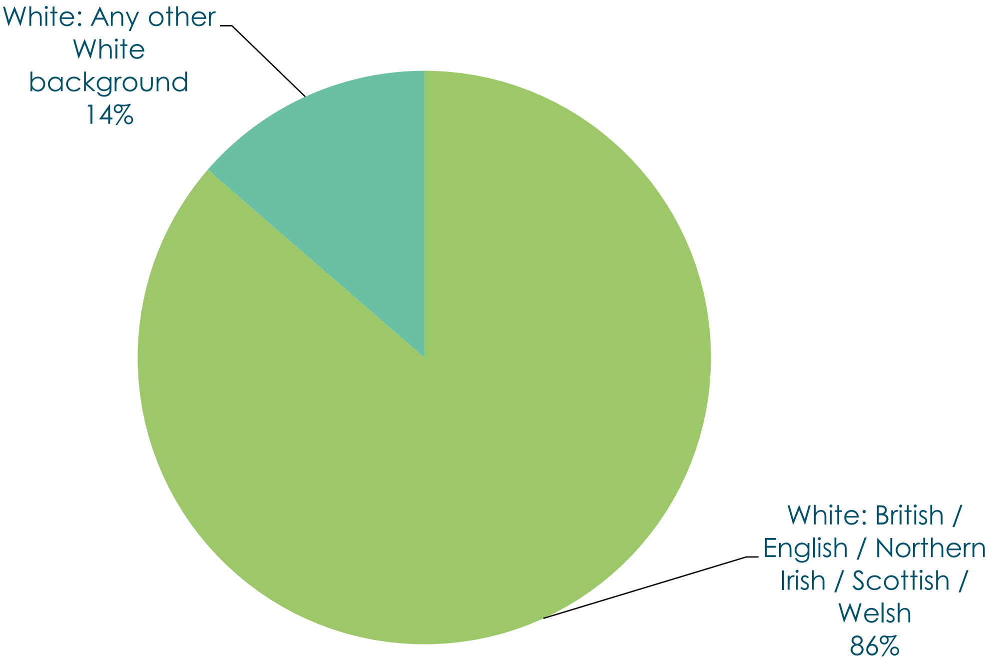
12. Please tell us which gender you identify as:



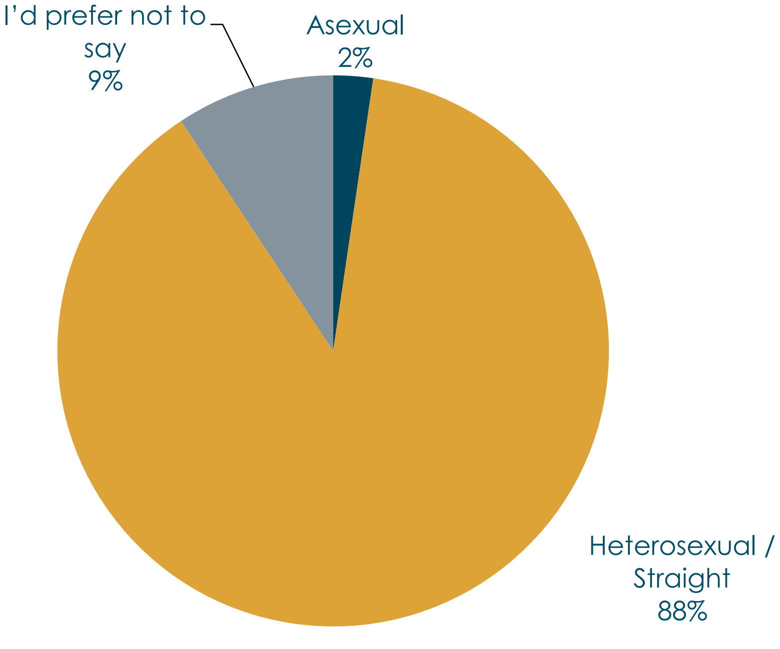
13. Is your gender different to the sex that was assigned to you at birth?



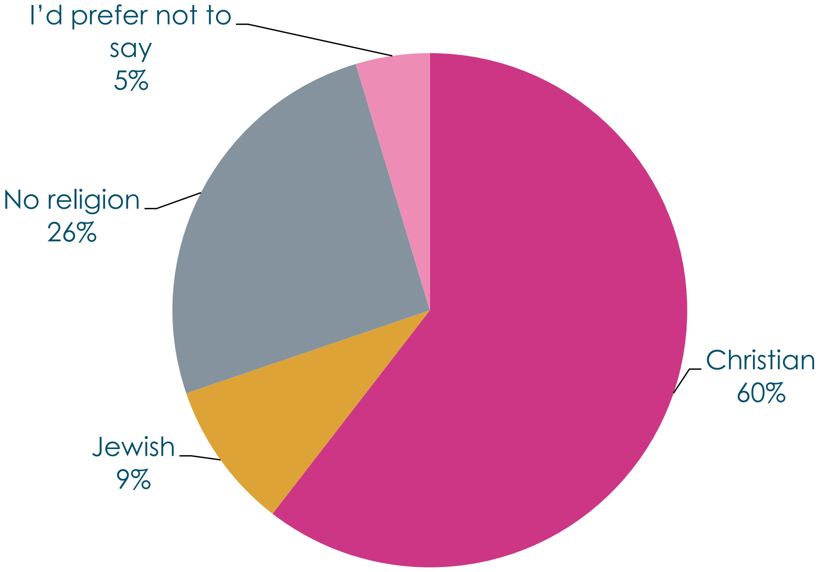
14. Please select your ethnic background:



15. Please tell us which sexual orientation you identify with:



16. Please tell us about your religion or beliefs:



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Contact us

If you require this information in an alternative format, please contact our office via the details below.

healthwatch
Bury

Healthwatch Bury CIC
Bridge House
Yeargate Industrial Estate
Heap Bridge
Bury BL9 7HT

Healthwatchbury.co.uk
Tel: 0161 253 6300
Email: info@healthwatchbury.co.uk
Tweet: @healthwatchbury
Find us on Facebook

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