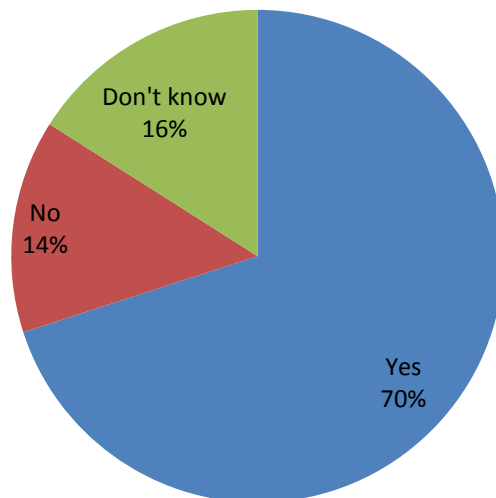


## Survey: Autism as a clinical priority for GP's in Herefordshire

The Survey was designed and implemented between The Autism Partnership Board and Healthwatch Herefordshire to find out more about the experiences of adults and children on the autistic spectrum and their parents and carers. 87 People completed the survey.

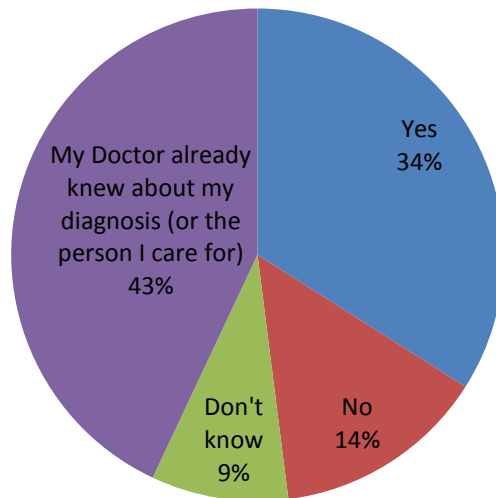
The Autism Partnership Board would like to see Herefordshire GP's formerly follow the example set out by the Royal College of GP's report 'Autism as a clinical priority for GP's 2014-17'

### 1. Does your Doctor know if you (or the person you care for) is on the Autistic Spectrum?



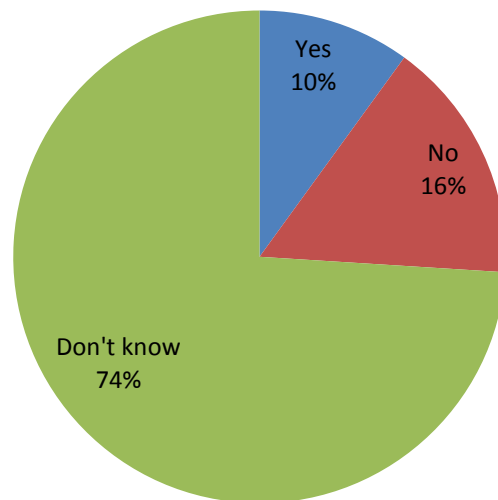
Value	Percent	Count
Yes	70.1%	61
No	13.8%	12
Don't know	16.1%	14
Total		87

2. If your Doctor does not know you (or the person you care for) is on the Autistic Spectrum, have you informed your Doctor about yourself (or the person you care for)?



Value	Percent	Count
Yes	34.5%	30
No	13.8%	12
Don't know	9.2%	8
My Doctor already knew about my diagnosis (or the person I care for)	42.5%	37
Total		87

3. Do you know if your GP Practice has coded your (or the person you care for) medical records accordingly on their computer system to reflect your diagnosis?



Value	Percent	Count
Yes	10.3%	9
No	16.1%	14
Don't know	73.6%	64
Total		87

#### 4. Have you (or the person you care for) received an official diagnosis and where/how did you receive this?

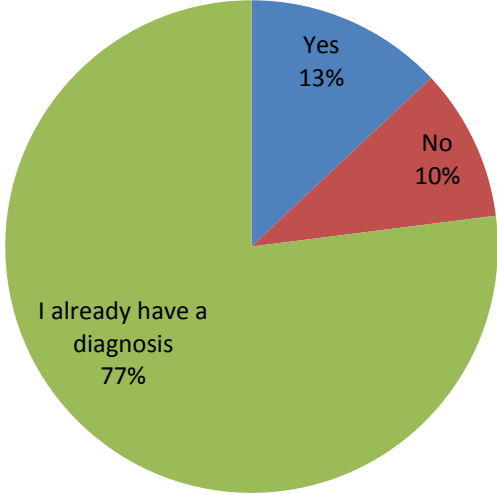
Count	Response
2	Maudsley Hospital
2	ADOS assessment
1	Asperger's Syndrome, January 1998
3	Birmingham Parkview Clinic
22	CAMHS
8	Child Development Centre, Ross Road
1	Consultant paediatrician
1	London hospital
2	Great Ormond Street
1	Haven't had one
2	I have not had a diagnosis
1	I received a diagnosis in London when living in another area
3	London
1	My son received his diagnosis from a psychologist at CAMHS
1	N/A

10	NO
1	Not sufficiently strongly affected for people to notice, except for some clumsiness of manner
1	Yes London.
1	Yes but was diagnosed in New Zealand
1	Yes from an Educational Psychologist when my son was 4 years old
1	Yes, 2008 from community paediatrician.
1	Yes, from psychiatrist, age 3 following multi agency assessment, in South Africa.
1	Guys & St Thomas's Hospital London
1	Yes. Hereford clinic
1	Yes. Jean Leas behaviour specialist
3	Before coming into our care under 15
1	When he was 4 in 2005
1	Bethlan hospital London
1	yes my daughter has a diagnosis from paediatrician and child assessment team 10 years ago
1	There is an official diagnosis somewhere on my sons file as we were accidently copied in on internal correspondence between our Doctor and the then County Psychologist
1	I arranged for assessment privately with a clinical psychologist. A 'more expert' psychologist did a more in depth assessment. Total assessment time 5-6 hours over 3 sessions.

1	via CAMHS in Hereford. BUT this took approximately 10 years from start to finish and my child was only tested because I specifically asked for this to be done.
1	No not yet. Been fighting for an official diagnosis for some years. Even though I have occupational therapist reports and school reports to support.
1	yes, started with GP, then tested a few things to rule out other possibilities, then gave diagnosis
1	I received a diagnosis of Asperger's from a Specialist from Shropshire, funded through my then GP service, as there were no specialist diagnostic service in Herefordshire. The Shropshire-based specialist was found through contact with the National Autistic Society. My own GP's at the time didn't even bother to diagnose or investigate until I requested it, even though they admitted they "knew something was wrong"...but they had no idea about Asperger's or any Autism Spectrum Conditions.
1	I received a diagnosis of Asperger's from a specialist in Shropshire, who was funded via my then GP as there were no diagnostic services in Herefordshire. His address was obtained through the National Autistic Society. None of the GP's in the Surgery at that time made any suggestions of 'help', and even the then social worker said it "was apparent there was something wrong" - but did or suggested nothing. It was only when I 'ran away' to Devon (for about the 3rd or 4th time) to a friend who has known me for nearly 30 years, because I was getting so distressed here, that I realised I could have an ASC, and, together, we phoned the NAS and spoke to them to see about getting a diagnosis. Speaking with the Specialist for the first time was revelatory as someone, for the first time in my entire life, understood me and what I was saying, and could explain why I was behaving as I was as it was very distressing and upsetting to me.
1	We first received an official diagnosis for Donald McMorran from Digby Tantam a few years ago but the Psychiatrist looking after Donald said that it was a "red herring". We have just received another official diagnosis of Autism for Donald from Dr Prasad, the Psychiatrist in charge of the Priory, The Rookery at Radstock, Somerset.
1	Yes when no speech developed by the age of 2 health visitor requested he attend an early year setting at my other sons primary school. We had a meeting with Paediatrician at school before his 3rd birthday where she said she wished to diagnose him as on the

	<p>Autism Spectrum. When we hesitated she explained that she could only request for additional help with his needs if he had an official diagnosis. Part of me wanted to say no because I knew that all of our hopes for both ours and our children's future had just been stolen never to return. But the reality was he had no speech did not interact with anyone other than me or my husband and spent most of his time screaming. Hope was already a distant memory.</p>
1	<p>The NHS failed to diagnose my daughter's autism. She was referred to CAMHS as she was refusing to go to school, but the locum, Dr Krishnam, did not choose to give her a proper assessment. I had to pay for private assessments.</p>

5. If you have not received a diagnosis, do you want one, either for yourself or for the person you care for?



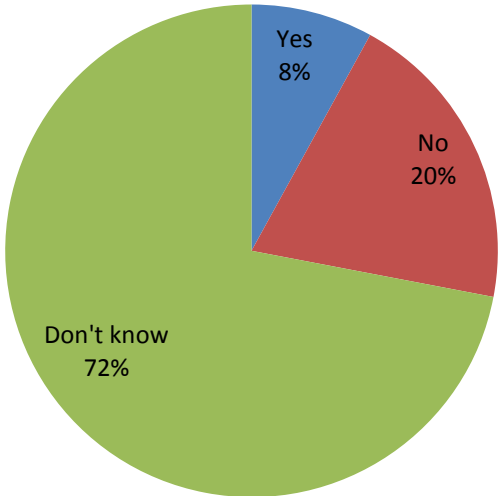
Value	Percent	Count
Yes	12.6%	11
No	10.3%	9
I already have a diagnosis	77.0%	67
Total		87



## 6. Has your GP Practice offered you any of the following reasonable adjustments?

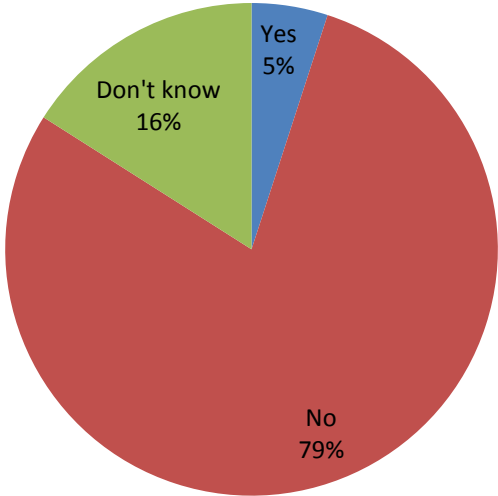
	Yes	No	Don't know	Responses
Offered you early/late appointments	17.2 % 15	71.3 % 62	11.5 % 10	87
Offered you longer appointments	10.3 % 9	73.6 % 64	16.1 % 14	87
Provided somewhere quiet to wait or allowed you to wait outside and call you in	12.6 % 11	77.0 % 67	10.3 % 9	87
Allowed you to see the same clinician	20.9 % 18	64.0 % 55	15.1 % 13	86
Provided you with alternative ways of booking appointments, such as online, that do not involve the telephone	32.2 % 28	51.7 % 45	16.1 % 14	87
Your clinician explains at the beginning of the consultation what will happen and how long it should take	10.3 % 9	74.7 % 65	14.9 % 13	87
Your clinician writes down the key points at the end of the consultation for you to take away with you	2.3 % 2	86.2 % 75	11.5 % 10	87
You are given the option to have someone else with you during the consultation if you want it	40.2 % 35	36.8 % 32	23.0 % 20	87
Provided you with accessible information in a format that you understand about how and when appointments are available, how to get prescriptions, or access services like cancer screening tests	21.8 % 19	55.2 % 48	23.0 % 20	87

**7. Do the receptionists or nurses at your GP Practice know that you (or the person you care for) are on the autistic spectrum from the codes entered on to the computer system?**



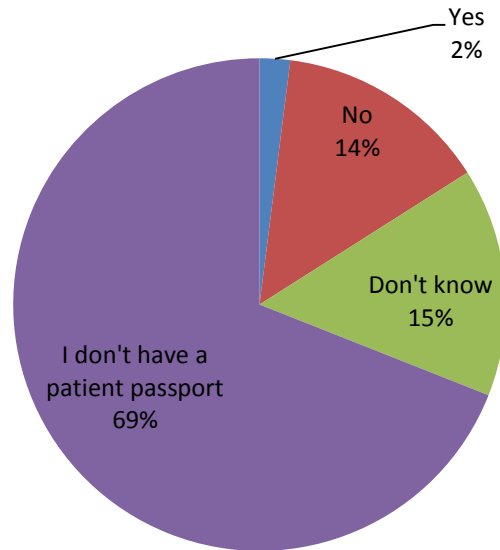
Value	Percent	Count
Yes	8.1%	7
No	19.5%	17
Don't know	72.4%	63
Total		87

8. Do you (or the person you care for) have a patient passport?



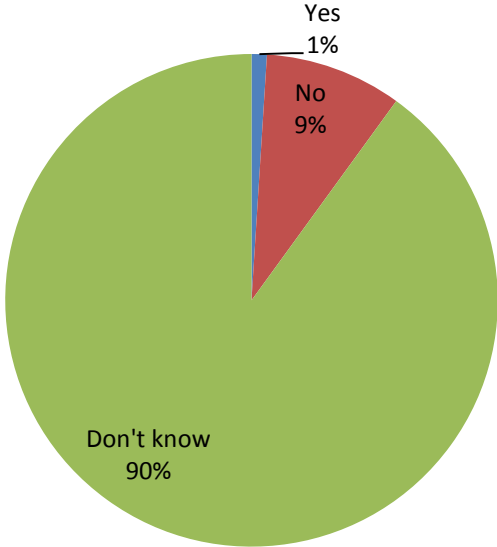
Value	Percent	Count
Yes	4.6%	4
No	79.3%	69
Don't know	16.1%	14
Total		87

9. If you (or the person you care for) has a patient passport, has anyone asked to see it?



Value	Percent	Count
Yes	2.3%	2
No	13.8%	12
Don't know	14.9%	13
I don't have a patient passport	69.0%	60
Total		87

10. Has your GP Practice had Autism awareness training?



Value	Percent	Count
Yes	1.2%	1
No	9.2%	8
Don't know	89.7%	78
Total		87

## 11. Are there any good or bad things you would like to mention about your GP Practice?

Count	Response
1	All ok
1	Always attend at home if requested.
1	Always over runs so the person I care for suffers more anxiety
1	As a carer my GP has offered the flu jab each year
1	Continuity of service. Always supportive
1	Doctors seem stressed and grumpy these days. Always feel I'm wasting their time.
1	Dr Conway at St Katherine's in Ledbury has been very understanding and supportive
1	Dr Jones was the most patient and did try
1	GP has some knowledge but mostly knows about autism at the higher level of the spectrum.
1	GP practice hasn't got any autism awareness.
1	GPs have been good and supportive and always agree to care sitting in with the autistic person.
1	Hard to get appointments with the same doctor
1	I am afraid to ask my GP for a diagnosis as an adult, I don't know where else I could get one.
1	I think my GP practice could benefit from autism awareness training.
1	It would be great for my son to have a designated GP, so he only gets to see one named Doctor.

1	My GP tries during appointments but I don't think he understands my Autism.
1	My GP is very thoughtful which makes a huge difference for us.
20	NO
1	None of the GPs has seemed phased by dealing with and talking to someone with autism.
1	She does also have a flu jab - because she gets upset if she feels ill
1	The GP receptionists do not understand my condition at all.
1	They are very accommodating for my son.
1	They are very helpful and understanding!
1	They give me biscuits
1	They let me know as a carer I am entitled to a flu jab each year
1	Very happy with the service my autistic son and I receive.
1	Waiting times makes him stressed
1	We have very rarely had to use the services of our GP Practice for a few years
1	Welcoming and helpful
1	had to wait 1 hour 30 minutes to see a nurse with no explanation or reason for delay
1	had to wait an hour to see a nurse with no information
1	surgery not supportive lack of patience and explanation

1	My GP Practice is good, Quay House and Credenhill Surgery). We have only been registered with them for 10 months therefore I don't know the answers to some questions but they have not been made obvious from the visits we have had so far.
1	I didn't know that the GP could diagnose autism. I do not know whether it is on Donald's notes because the Psychiatrist in Herefordshire would not accept the diagnosis of Autism even though he was diagnosed by Digby Tantam originally.
1	Real desperation has to set in before we will even consider go to see GP. So really can't say they know us at all.
1	When I need to talk to someone about something regarding my son it can takes weeks to get an appointment and sometimes things can't wait weeks.
1	On the occasions I've taken my son to the GP or nurse (for vaccinations) I've always found them to be very sensitive to my son once I've informed them of his diagnosis. They have treated us both with respect and consideration. Before my son was placed into the CDC system it was the GP who I took my initial concerns about him to and I found her to be truly excellent. She listened intently and took my concerns very seriously and passed it all on to the CDC. The Health Visitors were USELESS; so much so that I haven't bothered to use them for my daughter (second child) at all for any aspect of her development.
1	They don't have much to do with my son and seem aloof I always have to say he has Asperger's at each consultation
1	I don't think it is worth having a diagnosis as an adult. there is not services available for me anyway
1	We use Alton street surgery. The doctor that I see are always very understanding and extremely patient with my son. They follow my lead and also get the appointment done efficiently and as least traumatic as possible for my son.
1	The system that is in place is not autism or parent carer friendly. to get an appointment you have to phone and speak to reception, then wait for a Dr to call back to speak to you to see if they think they should see you or your child. I would be happy to discuss this further on why it doesn't work for families like us and causes undue extra stress. We have been given a room to



	<p>sit in but it isn't appropriate. Again I would be happy to explain further. It feels that my surgery which was once a patient first practice, is not a business first one.</p>
1	<p>Don't honour repeat prescriptions because consultant hasn't done annual confirmation that medicine still required &amp; do not inform patient that prescription request rejected. Receptionist said only Carers employed as Carers could get flu jab not parent-carer. Carer lead is admin rather than clinician. Reception said must see GP, GP said could have told reception (needed referral to private doctor having obtained private scan).</p>
1	<p>Our GP practice is usually very helpful and if any specific requests are made regarding appointments, they are usually dealt with sensibly and reasonably. We do not have a great deal of experience of consultations directly regarding autism related issues, more general health.</p>
1	<p>The GPs my daughter has seen are sympathetic and believe her when she says she has anxiety, unlike the schools she has attended and the LEA, who just threaten me with fines for her non-attendance.</p>
1	<p>I am sure my GP just thinks I am odd and wants me to get on with the appointment and hasn't got time for talking about a late autism diagnosis.</p>
1	<p>Waiting in the waiting room is extremely difficult with my child. The other patients waiting make this even more stressful for us both.</p>
1	<p>My GP Practice did not even have TIMED telephone appointments until I explained the importance of them. I had no idea what time the Doctor was going to phone - anytime from 8am - 10pm! They also used 'withheld' numbers - so I didn't even know it was them, and it created a lot of anxiety. They also had no idea about my not being able to wait in a crowded waiting room. However, having reached a 'crisis' point in the Summer, when all 'healthcare' was virtually inaccessible, they have tried very hard to put things in place, and I now have the MOST understanding GP AND Practice, EVER in my life. The 'out-of-hours' service at the Hospital, though, is NOT Autism friendly, AT ALL - and they have NO IDEA about anything - including often unsympathetic receptionists who have NO understanding at all. I would have had to leave, on many occasions, unless I had a friend acting as an excellent 'advocate' for my needs in those situations, as I cannot access them alone because it is too traumatic and they make me feel guilty for not being able to do what they require, even though it is impossible for me. I feel</p>

	attending Hereford Hospital is NOT an option for anyone who is on their own and who has an ASC because it is not safe to do so.
1	Our GP's and team are extremely caring and professional however our experience before diagnosis showed limited experience of ASD
1	It is not always easy to get an appointment when you want one. Especially if you wish to see a certain Dr.
1	if I explain the situation when I have had to book an appointment that it is not possible to wait in the waiting room that we must go straight through otherwise the appointment is not going to happen then I am met with a little disbelief but efforts to be helpful. When my daughter arrives they begin to understand the difficulty of waiting but it would be nice not to have to go through this each time. Generally they try to be helpful but I think because the autistic scale is so wide maybe people go on their past experience of who they have met on the scale and don't realize that autism sometimes comes with extremely complex needs.
1	Bad points are total lack of communication when referring to other agencies and not being informed of outcome. Losing copies of confidential reports sent in for GP's. Lack of support and understanding for the carer. I discovered carers support myself and think it's a shame the surgery hadn't referred me.
1	They are always polite and take their time with my son unless it is a new GP who doesn't seem to be aware of his needs
1	In the PAST they followed reports given by other authorities such as CAMS. This led to me not being listened to.
1	My autistic child is a very healthy boy so he hasn't visited the doctors in years. So feel I wouldn't be able to give my opinion on the above question.
1	Having only been with the surgery for less than a year I don't know some of the answers and can only go on my experience to date.
1	I don't think the doctors who see my son understand that Autism has such a wide variation in 'symptoms' and each person's needs can differ a lot.

1	It is very difficult to get an immediate appointment with a doctor you want to get the appointment with. If you book on-line it is normally at least two weeks in advance - which is only really good for non-emergencies. You cannot book on-line to see a nurse.
1	The practice have always been polite when I take my son to the GP but he doesn't need to go very often. I am very car with the go that he needs to explain clearly what he expects from my son and we always go into appt together.
1	Patient's can't get an appointment without a telephone consultation first. So you phone the receptionist, and then you have to wait for a doctor to phone back. If you're lucky, the receptionist can give you a period of time within which to expect this, but even so the resulting call, when it comes, is "number withheld", which means that you don't really know who's calling until you answer. Although I am what is often described as "high functioning", I hate the phone at the best of times (as many on the Spectrum do), and I find this procedure very disturbing for two reasons. 1. I don't find a telephone consultation helpful, and 2. I'm uncomfortable answering the phone if I can't be certain who it is.
1	After having the diagnosis and the paperwork not following up the recommendation even though I asked for it.
1	There is only one doctor at the surgery that i am confident enough to take my son to as they listen and are very understanding about his autism and explain things well to him.
1	I have had difficulty with getting repeat prescriptions for my son - sometimes not put through system or incorrect. My son doesn't automatically get offered the flu jab I have to remember to book it
1	Putting most things down to ASD instead of looking separate. For example when my son had severe anxiety I had to push for mental health service. Just wanted us to go away with answer that's autism! Which was very upsetting. My son had 12weeks of therapy in the end, which really pulled him through. Thanks to my persistence. Doctors do not know much about the condition. One size fits all, I feel the response in my experience.
1	It's really hard to get an appointment so you can't see the same person, and although you can book online, the online appointments available are weeks in advance

1	Planned appointments are ok for my child, but when I have to go in an emergency/at short notice, it can be very difficult to prepare my child for this and the appointment is then hard.
1	My sons had measles, mumps, rubella vaccine separately but were sent the invite that said they must have the booster. One of my boys was terrified by the injection, the nurse asked me to hold him whilst she tried to do it, but we couldn't go ahead, he now has a fear of needles, is there an easier way to go about this with a child with autism when they are older?
1	<p>When I first registered with my current Practice, there were not even TIMED telephone appointments available - so it caused great anxiety waiting from 8am - 10pm, and then they used 'withheld' numbers - so I wasn't sure who it was that was calling. They also expected me to be able to wait in a crowded waiting room, and only took into consideration 'physical' difficulties / wheelchair access. However, following a 'crisis' point in the Summer, the Practise have been outstanding and have really tried their best to be accessible - with input from the Practise Manager, as well as much more knowledge and understanding from my GP. As a result, I feel much safer and more understood by them, and less 'condemned'. The 'out-of-hours' service based at the County Hospital, however, is still totally inaccessible for me if I am alone - as they have NO understanding or sympathy for the difficulties I have, and don't make ANY 'reasonable adjustments' - because the Receptionist just didn't care. I don't feel safe to be admitted to the County Hospital, or even attend any appointments there unless I have a really GOOD, competent and suitably trained support worker with me, or friend who is able to advocate for my needs and, as this is not an option for most of the time, I do miss out on 'medical care' - particularly in emergencies, as I don't feel safe going with the ambulance crew alone, because it would all end up in 'meltdown' at the hospital, and then I would be 'stuck' trying to get out quickly and back home. I also had real difficulties trying to find understanding GP's in the Primecare / out-of-hours service - and still feel scared when I have to speak to them because I don't know who is on duty and if it's going to be an abrupt, non-caring one with no ASC awareness who I speak to, and these can't help with whatever the problem is and often leave me feeling more distressed with just trying to explain...so it is with real fear and trepidation that I attempt the 111 Service, and hate being put through to Primecare until I can ascertain which GP is on duty and whether they are Autism Aware or not. Some of them have even made me ILL because they have caused huge emotional upset on top of a physical issue which has caused me to phone in the first place!</p>

## 12. What GP Practice are you (or the person you care for) registered with?

Count	Surgery
9	Alton Street Surgery, Ross on Wye
5	Belmont Medical Centre
5	Cantilupe
1	Fownhope Medical Centre
1	G4E Surgery
2	Golden Valley (Peterchurch)
1	Golden Valley (Ewyas Harold)
3	Greyfriars
1	Hereford Health Authority
1	Kings Street
1	Kingsland
3	Kington
3	Marches Surgery, Leominster

Count	Surgery
12	Moorfields House Surgery
3	Nunwell Surgery
2	Pendeen, Ross on Wye
6	Quay House Medical Centre
8	Sarum House
4	St Katherines, Ledbury
2	Wargrave House Surgery
3	Weobley
3	Westfield Surgery
2	Bobblestock
3	Prospect view Malvern

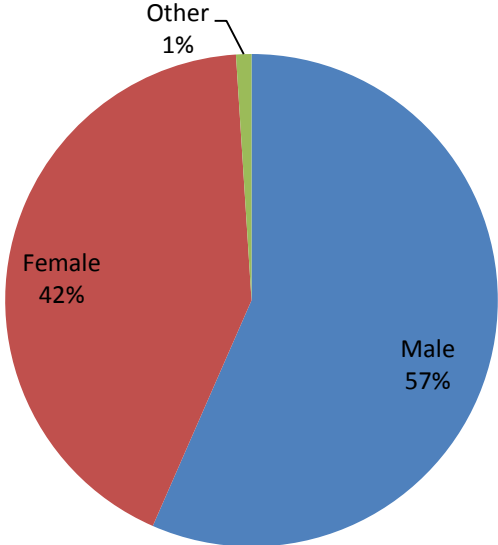
**13. How old are you (or the person you care for) ?**

Count	Age
2	5
2	7
2	8
3	9
2	10
3	11
5	12
6	13
2	14
4	15
10	16
3	17
2	18
2	19
1	20
3	21

Count	Age
2	23
1	24
1	26
2	27
1	28
1	29
1	32
2	34
2	35
1	36
2	38
3	39
1	43
1	47
3	50
1	54

Count	Age
1	63
1	65
1	66
1	68
1	76

14. What gender are you?



Value	Percent	Count
Male	56.5%	48
Female	42.4%	36
Other	1.2%	1
Total		85