

# Improving Experiences for Patients with Autism in General Practice

Healthwatch West Sussex, Autism Support Crawley and Poundhill Medical Group working together to improve GP services for children with additional needs, October 2016.  
[Survey summer 2016]



*Some of the doctors have been really good with Ben and others not so much. One of the receptionists was very rude and made me feel like I was bothering her, I was already stressed out and she made it worse and then Ben picks up on my stress.*

## Foreword

*We approached Healthwatch West Sussex because a large number of our parent/carer members were really struggling to access local GP surgeries and we thought that simple measures could be really effective. The survey has backed this up, and now we feel really confident that new measures are going to be implemented to improve provision. Pound Hill Medical Group have been a breath of fresh air to work with in order to create a better experience for our families when accessing their GP practice.*

Maria Cook, Chairperson, Autism Support Crawley

*When Healthwatch West Sussex approached us, we were more than happy to look into the problem as we want patients to get the most out of our practice. The changes we have developed are easy to implement and have benefits for us as well as the patients.*

Perry Anderson, Practice Manager, Poundhill Medical Group

## Acknowledgements

Healthwatch West Sussex would like to thank everyone who has contributed to this work and in particular, all of the people who have taken the time to complete the survey and share their views and to those who have entrusted us with their personal stories.

## Background to the research

In the spring of 2016 Healthwatch West Sussex was invited to speak to parents and carers who attend the Autism Support Crawley (ASC) voluntary group. The group supports over 500 families in and around the Crawley and Mid Sussex area.

At this meeting people expressed their frustrations with the service they received at local GP Practices. Poundhill Medical Group was specifically mentioned because on the night of the Healthwatch visit, several members in attendance were registered there. It is one of the largest practices in the Crawley area.

Healthwatch facilitated a meeting in April between Autism Support Crawley and the practice manager at Poundhill Medical Group. The practice was enthusiastic in their response, and their desire to improve patient experience. An informal project group comprising key ASC members, Poundhill's Practice manager, and Healthwatch West Sussex was formed. The project group noted that there was already a PACEsetter<sup>1</sup> within West Sussex that had looked at engaging and improving GP relationships with parents and their children with additional needs was discussed. The surgery that carried out this work, St Lawrence's Surgery in Worthing, worked with local parents from a Parent Carers Forum. Together they introduced some new measures to St Lawrence's including a 'passport' for use by patients with additional needs. Although this work was noted, the project group felt that work could be done locally to meet need.

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<sup>1</sup> [PACE Setter](#) "The PACE Setter Award is a new improvement programme for practices providing primary care services to children, young people, their families and carers. It is the Primary and Community Care Quality Mark for Children and Young People's NHS Services.



It was agreed at this meeting that the first course of action would be to survey members about their experiences of using local GP Practices, and what measures they thought might be helpful in Crawley.

## Survey Methodology

As this work reflects and focuses on the experiences of local people, we have used alternative names in this document, to keep the stories personal, but also to keep sources anonymous. Great care has been taken to make sure any identifiable information has been removed. As part of the Healthwatch West Sussex assurance work, a draft of this document was shared with Autism Support Crawley and Poundhill Medical Group, as well as our quality assurance team and Board.

Survey questions were agreed by Autism Support Crawley representatives, the Poundhill Medical Group and Healthwatch. Healthwatch agreed to set up and run the survey, which was hosted on Survey Monkey. The link was emailed to members of the group by Autism Support Crawley and people were given the month of June 2016 to complete the online survey.

## Who responded?

104 People completed the survey, with almost 9 out of 10 of respondents caring for someone with Autism Spectrum Disorder



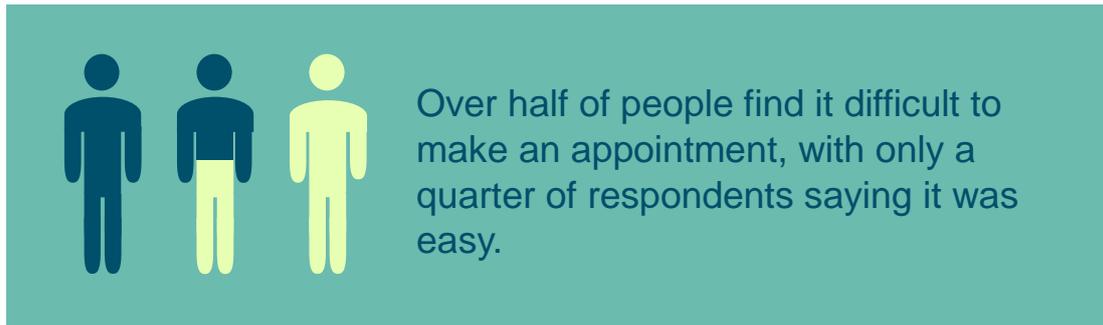
- 64% of respondents are registered at Crawley GP Practice, with between 1-5 people at each practice. Higher number of responses were registered at Saxonbrook (7%), Poundhill (8%) Woodlands and Clerklands (9%) because they represent over 40% of all GP patient registrations within Crawley.
- A third of respondents were outside of Crawley CCG area, which reflects the demographic of the ASC group attendance
  - 9% of respondents were registered at a Horsham practice
  - 11% from just outside of Crawley/surrounding towns



- The remaining 13% were a variety of respondents from outside of the area, with a smattering from Coastal West Sussex CCG, and several from other home counties, but within commuting distance of Crawley. This is likely to be as a result of the survey being forwarded to a wider network.

## What did respondents think about their GP Practice?

When asked about the service provided by their GP, on the whole respondents were complimentary. With almost two thirds saying they understood their doctor's advice and getting treatment from a nurse was easy. Problems with appointments echo other stories Healthwatch have heard from other populations in the area.



Nearly a third of respondents reported that they had difficulty using the waiting room. Just over a quarter found talking about their medical needs, and speaking to receptionist difficult, although the majority reported no problem with this.

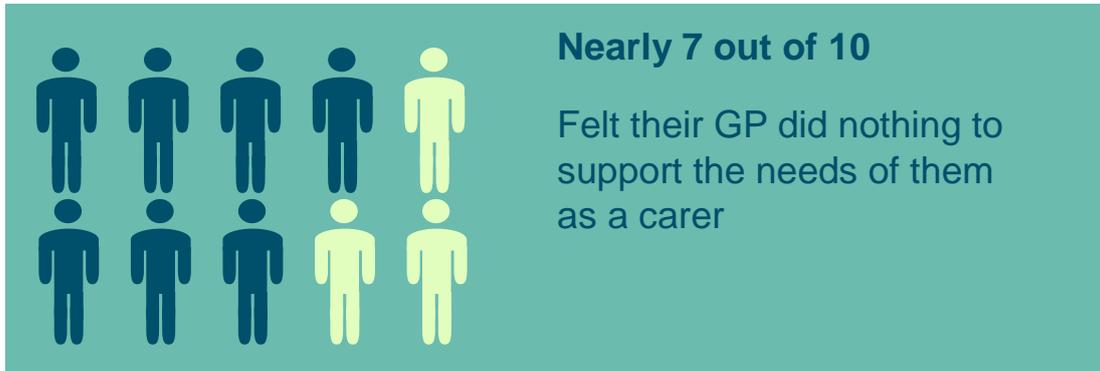
*The waiting room is stressful. Doctor won't do a home visit when my son has been too ill and distressed to leave the house.*

*Both my children are on [spectrum]. Never was any thought given, i.e. where we are waiting, how long we are waiting, etc.*

*Need a quieter place to wait. Access to early appointments so less time waiting around and understanding that these children can't describe their symptoms and may need visual representation.*

## What isn't working?

The positive comments were contrasted with over half of all respondents saying that they didn't feel, or couldn't say that their doctor has understood the needs of someone with Autism Spectrum Disorder. Only 3% were confident their Doctor understood ASD and the patient's needs.



*Have had GPs ask me for details about it, so have never had full confidence that they do understand.*

*The only doctor who understands is Dr Moley, no others do, just look at you like an idiot and rush you out the door. So makes me not want to go there anymore.*

*I spoke to one doctor who told me “have you tried talking to him”. Had to make a second appointment just to be heard. Felt like first doctor had no time or understanding. Always seems to be a battle. Thankfully a second doctor helped us and gave us options.*

*No one ever checks that what they say and/or do has been understood. Vulnerabilities only seem to be acknowledged for people with physical difficulties.*

*No understanding that my son with autism will not go out if appointment is not for him.*

*It has taken a long time to get them to accept that they need to talk to me as my son’s appointee as they do not recognise this term. They event tried to charge £38 for a GP letter to support his free bus pass!*

## How can GP Practices improve patient experience?

The survey asked people to explain how, if changes were implemented, these would improve the experience of both the person and the practice. Overwhelming people told us these would reduce the **stress** and **anxiety** suffered by their child and themselves when visiting the surgery.

## Families told us;



Other people can't see my son's disability so don't understand why he behaves in this manner, which often leads to disapproving looks or negative comments about 'behaviour'.

- To feel heard and have consistency of care will mean it's one less battle, one less fight and like someone is prepared to take charge of the medical care of the family. Instead of fighting for everything I'd feel empowered
- Parents wouldn't have to put up with unwelcome stares and others judging them and their children
- Children could make noise without disturbing others
- Anxiety levels wouldn't rise
- Won't have to explain every time
- It would make the communications with doctors surgery so much more pleasant if we didn't have to navigate around the rudeness/incompetence of the receptionists
- To be taken seriously when I speak and not just try to rush me out the door. It takes a long time for me to express what the problem is
- Helps to manage expectations of autistic child
- Makes carer and [autistic patients] feel respected
- Would feel a bit more like the doctors understood

## What's working, and what isn't?

When asked what measures could be undertaken to improve the experience, most measures suggested were responded to enthusiastically.

Which ideas do you think would be helpful to you?

Answer Options	Very helpful	Slightly helpful	Not helpful	Not sure/prefer not to say
A symbol on patient files to remind staff that the patient has ASD	68	4	0	1
A photo guide about how to use the GP surgery	44	18	7	4
Longer appointments for patients with ASD	50	23	0	0
A card which patients could show to remind staff they have ASD	42	22	5	4



Training for staff on how to help patients with ASD	69	4	0	0
Text message when doctor/nurse is ready, so patients can wait outside the surgery	61	10	1	1
Autism Support Crawley to attend meetings of the surgery's Patient Participation Group	51	12	1	9
You to attend meetings of the surgery's Patient Participation Group	31	22	5	15

100%

wanted longer appointments for people with autism  
 wanted training on autism for surgery staff

- 97% wanted a text message alert so they could wait outside their surgery
- 99% were interested in a flag on a patients file
- 88% wanted a card to show the receptionist
- 86% wanted Autism Support Crawley to work with Patient Participation Groups

## Photo Guide to Surgery

85% of people responding wanted a photo guide to surgery. The Royal College of General Practitioners have produced a good example of a [leaflet](http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~//media/Files/CIRC/Autism/RCGP-Going-to-the-doctor-easy-read-version-March-2015.ashx)<sup>2</sup>, along with a toolkit for GPs earlier this year.

<sup>2</sup> <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~//media/Files/CIRC/Autism/RCGP-Going-to-the-doctor-easy-read-version-March-2015.ashx>

## Over 60 people gave us ideas for improvement

People have put forward some insightful and useful suggestions, which we have edited down to remove duplicates. Overwhelmingly the top feedback was on **Waiting rooms** and **waiting times**, with these two areas cited as the biggest problem for families.

### To reduce the distress of waiting before arriving:

I shouldn't have to almost beg to get an appointment then still get turned away.

Doctor isn't my first choice. When I take my child there he needs to be there!

- Doctor and nurse that could do home visits for children who find it too stressful to go to the surgery
- A series of visual that carers can have to prepare their child/adult, which must not contain photos of staff as they may not be present on the day itself
- A video of the facilities, doctors, nurses, rooms, procedures (e.g. blood pressure) available on the surgery website
- Make it easier to make an appointment. If my daughter is ill she will worry and overthink it
- Named GP for carers and patients - not to have to be triaged by calling up then waiting for a call back - just call up and the receptionist book an appointment
- Understand if you have to rebook appointments several times as you may not always be successful in getting your child out of the house/to the appointment
- Have pictures of the doctors and photos / social story / a video walk through of what might happen
- Markers on notes to flag up difficulties
- If the doctor is running late they could phone and let you know. Say if they are running ten or twenty minutes late phone and let you know to come later so you are not waiting any longer than you have to

### To reduce the distress of waiting after arriving:



I think the text message idea would be amazing to inform when ready. On a recent visit, we arrived just before appointment time and booked in using the screen ... we were informed the wait time was approximately 23 minutes. My son went into meltdown, kicked the door and walked out.

I managed to calm him and we went up to wait, he wouldn't go in waiting room though, the wait ended up being longer than 23 minutes and we very nearly had to leave before the appointment as he was struggling!

If we could have waited outside and got a message when GP was ready or nearly ready, this would have made such a difference to our experience.

- The current location means we have to park our car far away and make him walk all the way. Parents with autistic children might understand how difficult and traumatic it is for them and the parents
- Quick check in with correct waiting time information on the auto check in screen
- Turn the music off in the waiting area or a separate waiting area would be helpful, or have a quiet area in the waiting room
- More things for children to do and sensory equipment/toys kept in the office and available upon request

- Free Wi-Fi

(Healthwatch is aware some practices have limited access to Wi-Fi and this can be an issue for staff, let alone patients)

- Understand waiting is a big issue for those with autism and offer first thing or last thing appointments and to be on time
- Understanding frontline staff - who are polite, don't lose vital paperwork, who don't treat patients with contempt, speak to someone [on Autism Spectrum Disorder] clearly and if they have a problem not to get cheated off if they don't understand

### To make the consultation with the GP more appropriate:



My son who is very hyperactive can be very poorly but still run around when others would be flat out. This has happened before and was told he is fine as he is running around, that night an ambulance had to take him to hospital.

- Train more doctors to understand and look at notes before you see them so they can see that there may be a communication issue or to be briefed on needs so is prepared
- Make sure the doctor understands the needs of the person on the spectrum and that what they are saying may not always be completely correct, plus their experiences are often different to a neuro-typical person, e.g. pain, hearing, smell etc., so not to necessarily base their experiences on neuro-typical experiences
- To give you more time to explain your problems
- To take me serious and not look at me like an idiot or dismiss parent's concerns as being overprotective
- More check-ups for carers, as carers never have time to look after themselves
- Better staff understanding on autism and sensory issues
- Double appointments - they often need the doctor/nurse/receptionist to speak slower and clearer, and more time allowed to process what they have been told before answering, so there is often a gap in conversation so not to just carry on talking
- More patience when talking to them, understanding that they might not be able to take medication like others can
- Awareness training and retraining for ALL staff, including GPs, with automatic training for new employees
- Allow processing time
- Listen to the parent/carer. We know our children best
- Understanding of sensory issues re: touch when listening to chest, doing injections and any kind of examination



- Try to offer constructive help to carers. "You are dealing with a lot aren't you!" Is not solving anything and neither is just giving you antidepressants
- Create privacy to talk about child without other children hearing

### Other things that would help patients on Autism Disorder Spectrum:

We've had massive problems with is the Child Development Centre and Child and Adolescent Mental Health Service and passed backwards and forwards delaying the referral.

- Better communication with Child and Adolescent Mental Health Services (CAMHS)
- Not to have to remind every time
- Not to change brand of medication so the texture and flavour remain consistent
- Not just with autism but allow parents to order repeat prescriptions online for the children so it saves a visit to the surgery. Currently you can only do your own (adult) repeat prescriptions online

Information displayed for other surgery users - so they can become more informed regarding difficulties faced by autistic people/carers

### Child Development Centre (CDC) and Child and Adolescent Mental Health Service (CAMHS)

During the course of this work we were given a large number of stories about CAMHS and CDC (Crawley Hospital, operated by Sussex Partnership NHS Foundation), and as a result Healthwatch West Sussex will be looking at these stories separately and producing a report.

#### Recommendations for an 'ASD Friendly GP Practice'

Following the Survey, the project team met to discuss the ideas that were feasible, and this was agreed by all to fall into 5 achievable ideas for improving the experience of patients and their carers.

1. A rolling staff training programme for all staff including GPs to understand working with families and carers
2. Improvements to waiting areas and the waiting experience, and a photo/image guide for surgeries
3. Notes on files, flags and markers.
4. A programme to support Carers including regular checks/flu jobs
5. Improved knowledge of referral routes for both patients and staff (including CAMHS, CDC and London Hospitals)



The details of what was agreed to be implemented at Poundhill can be found in Appendix 1

## Next steps

- An action plan for Poundhill has been produced by the Practice Manager
- Healthwatch West Sussex and ASC will promote this survey and the work of Poundhill to other practices in Crawley, Horsham and Mid Sussex via the CCG and Practice manager networks.
- Healthwatch West Sussex will ensure the public and key stakeholders are aware of the research

## Appendix 1

### Pound Hill Medical Autism Support Action Plan

	Description	Additional information
<b>Training</b>	Autism Awareness Training for all Clinical Staff	Completed during survey
	Autism Awareness Training for all Administration / Reception Staff	Completed during survey
	AIS Training for all Clinical Staff - Elearning module	Completed during survey
	AIS Training for all Reception / Administration staff - Elearning module	Completed during survey
	AIS / Autism Awareness Training to form part of new staff induction training including medical students and training doctors.	Induction Form to be updated
<b>Communication</b>		
	Create / Source 'About Me' document for children / young adults	Working with partner organisation
	Create / Source 'About Me' document for Adults	Working with partner organisation
	Letter to all pts with Autism or carers providing copies of the above 'About me' documents	Practice to create and circulate
<b>Patient Records</b>	Ensure all records are correctly coded with diagnosis of Autism	Practice to search and recode with GP Partners
	Major Alert in Autistic Patients records with details of communications needs.	Part of letter to all patients carers



	Check Pts with Autism are eligible for annual flu Vaccination	No, they are not automatically eligible unless in another at risk group. Perry to discuss with GP Partners and decide if should be added.
	Code Parents / Carers of pts with Autism as Carers - this will ensure they are eligible for Flu Vaccination and invited	As part of the letter to ask who are the carers.
	Discuss with Autism Support what would be involved in a carer health check	Meeting arranged
<b>Waiting Room</b>	Awareness Posters for Waiting Rooms	Source Posters / funding sorted
	Patient call to mobile when waiting for appointment.	As part of letter above inform patients of process.