

# 'My GP journey'

Learning from the experience of seldom heard groups





General practice is under extreme pressure. The GP workload is increasing for a range of reasons. We have an ageing population. Surrey has more over-65s than the national average, and an increasing number of frail elderly people. More people are going to see their GP with an increasing number of chronic conditions. At the same time, the number of GPs and the percentage of overall NHS money spent on primary care is falling. Surrey has fewer GPs per 10,000 people than many other areas of the UK and many of these GPs are older and may be approaching retirement, so the problem is urgent. The drive for speedy access does not sit easily alongside seeing the same doctor for continuity of care, and GP surgeries are under pressure to do both.

Lack of capacity in primary care can lead to stress and frustration for patients and carers; problems going undiagnosed for longer than necessary; and people not getting the help they need. Good primary care is essential in prevention and early intervention, enabling people to stay at home with confidence rather than go into hospital and return home safely sooner if they do go into hospital.

The whole of the NHS is changing the way it plans services at the moment. Getting primary care right is described as a "key enabler" for the whole system – it has to be right for everything else to work. Engaging with and listening to patients and carers is essential in order to get things right – people who use services have very good ideas about how they can be improved.

Our research shows that people are by and large happy with the care they receive from their doctor. People told us it's the issues around communication and accessing services that could be improved. When a system is under such pressure it is hard to free up the capacity to think about how to do things differently. However, our research with seldom heard groups indicates that there are things that could be changed that may ease some demand both short and longer term. Some of these involve promoting awareness of existing options for access (such as online booking), some involve improved awareness of communication issues or the challenges presented by certain medical conditions and some involve bigger changes to the way primary care is delivered. We know these are all being considered by decision-makers and we will take every opportunity to ensure the voices of those who shared their experiences with us are heard as these decisions are being made.

GP access is a priority for Healthwatch Surrey. As the most frequently used service, it is regularly the most reported topic in our experiences gathered from the public, patients and carers.

Building on our previous work on GP appointments, we reached out to seldom heard groups across the county to get a better understanding of their patient journey when accessing their GP.

Through a series of 1-2-1 interviews and group discussions, we were able to gather in-depth feedback on all aspects of the patient journey, from joining the GP through to Pharmacy and follow-up appointments.

By listening to people and recording their experiences, we have formulated a number of recommendations designed to help those who plan and deliver primary care services to better meet the needs of patients.

We also discovered that many people are unaware of alternative ways to access information and advice on health issues, particularly the ability to access out-of-hours GP appointments through NHS 111 and the use of online GP appointment booking services.

While most of the people we spoke to were happy with the care that they received from their GP, they felt frustrated by access issues related to; the telephone booking system, communication, physical accessibility and continuity of care for complex conditions.

These findings are in keeping with our previous reports, 'Getting an appointment with your GP' (2014) and our survey of older people in the county, 'Just getting on with it' (2015), both of which can be found on the Healthwatch Surrey website.

#### We listened

The groups we spoke to included;

- members of the deaf community
- people with visual impairment
- carers for those with dementia
- people with physical disability/ mobility issues
- people who are homeless
- people living with mental illness
- people with low income
- people living with cancer
- people with aphasia (damage to parts of the brain responsible for understanding and using language)
- people for whom English is a second language
- people living with HIV
- people with long term health conditions
- people who are "working well"
- · parents of young children.

We spoke to 120 people, roughly half were male and half female with half under 50 years and half over 50 years old. People shared their experiences through a series of in-depth 1-2-1 interviews and group discussions, between November 2016 and January 2017.

#### We learned

In most cases our interviewees were happy with the care they received from their GP, with booking and communication issues aside, the end points of their journey were positive and constructive.

They respected their GPs and value the care they can access through the National Health Service.

This finding is in keeping with the latest Ipsos Mori GP Patient Survey (July 2016). This showed that nationally, 85% of respondents rated the 'overall experience of GP' as 'good' and 95% say they have 'confidence and trust' in their GP.

For the majority of the CCGs in Surrey, the 'overall experience of GP' rating as 'good' is higher than the national average.

They are kind staff and they always do their best to give you the appointment you need. The GP walked round when I was unable to get to the surgery.

Patient with visual impairment

#### Overall GP experience (rated good)



Here's an example of good practice - there's a Dr in \_\_ who books double appointments and uses Type Talk to contact her patients.

Patient who is deaf

My GP is excellent.
The surgery is excellent, a caring practice. The practice meets to discuss complex cases and combine their thoughts on them, which is good.

Patient with an acute condition

We're lucky to have all the options for help in this country - pharmacy, GP, out of hours, 111, A&E etc.

Patient with multiple sclerosis

## Common themes

Despite the fact the majority of participants were happy with the care they received when they got to see their GP, there were common themes relating to; the telephone booking system, communication, physical accessibility and continuity of care for complex conditions.

These included:

- difficulty booking GP appointments
- the need for increased awareness of conditions
- difficulties relating to physical accessibility
- problems with translation and language support
- lack of signposting to specialist care
- desire for continuity of care for long-term conditions
- lack of awareness of patient participation groups.

Recommendations are included at the end of this report.



# Difficulty booking GP appointments

The majority of people we spoke to reported frustrations with booking appointments at their GP surgery.

- Those not able to use the phone found the phone-focussed booking system was a barrier to them making their own appointments.
- Those that could use the phone found that the phone lines were often busy, which caused them to wait for long periods on the phone, or in some cases, to go to the surgery to book appointments in person, which was particularly difficult for some (see p. 12).

Within our groups, there was limited awareness of current online GP appointment booking systems. Despite frustrations with the telephone booking, these systems were not being used, even by those who regularly managed their time online.

People who did use the online booking were very happy with it as a means of getting appointments, test results and access to their medical records.

This finding is also in keeping with the Ipsos Mori GP Patient Survey (July 2016) which showed that nationally there is only 31% awareness and 8% use of online booking for appointments.

Ensuring an accessible online booking system will be particularly beneficial to those who due to communication barriers cannot use the phone.

We also found little or limited awareness of the NHS 111 service as a means of accessing medical advice and referrals to out-of-hours GP services.

# Need for increased awareness of conditions

Three groups specifically mentioned the benefits of increasing awareness of their conditions amongst GPs and practice staff:

- people caring for patients with dementia
- people with aphasia
- people with sensory impairment

There was a common perception amongst these groups that surgery staff did not have enough awareness or understanding of the conditions, particularly the ways in which they affected communication.

The aphasia support group worker told us that they had offered to make a presentation to practice staff, explaining the challenges faced by those with the condition, but that the practice hadn't taken up the opportunity.

"We want to share our expertise to help people with aphasia and enhance the service that patients receive, as well as making GPs aware that there are long term services available to support these people and their families. We've offered to make a short presentation but there's never been any take up".

Dyscover - a charity providing long term support for people with aphasia and their families

Carers for those with dementia wanted practices to have better signposting (leaflets and posters) to carers' support groups. They understood how isolating life as a carer was without this help and felt that the GP at diagnosis would be the ideal place to signpost people to support groups.

# Difficulties relating to physical accessibility

A number of the people we spoke to had issues with physical access to their GP surgeries. Perceived lack of disabled parking, poor access for wheelchairs, no disabled toilet provision and automatic door phasing all caused problems for those with mobility issues.

#### **Accessibility rights**

By law, under the Equality Act 2010 all health services are required to make 'reasonable adjustments' to make sure they are accessible to all. This duty requires GPs and dentist practices to anticipate the needs of disabled people and where possible, make adjustments to provide the same level services as for non-disabled patients.

For more information, see the back cover of this report for NHS England contact details.

There should be more specialised training of GPs and practice staff - they think they know dementia but they don't.

Carer for patient with dementia

## Common themes

If we had some way of letting the receptionist know that I had limited speech, it would help as they could speak slower and relieve the pressure of the queue.

Patient with aphasia

They need a deaf awareness leaflet to let them know little things that can be done for lip readers e.g. don't sit with light behind, obstruct mouth, talk slow not loud, look at me not the screen.

Patient who is deaf

#### The Accessible Information Standard

The Accessible Information Standard came into force on 31st July 2016. Its purpose is to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand so they can communicate effectively with health and social care services.

Put simply, the standard requires that service providers:

**1. Identify** Ask if people have any information or communication

needs and find out how to meet those needs

**2. Record** Record those needs in a set way

3. Flag Highlight on a person's file using alerts to flag

these needs and how to meet them

**4. Share** Share information about a person's needs with

other NHS and adult social care providers, when

they have consent to do so

**5. Act** Make sure people get information in an accessible

way and communication support if they need it.

You can read more about the obligations of primary care providers at <a href="https://www.england.nhs.uk/ourwork/accessibleinfo/">www.england.nhs.uk/ourwork/accessibleinfo/</a>

# Problems with translation and language support

Three groups specifically described the access difficulties they faced due to needing a translator or language support:

- people who are deaf or have hearing loss
- people for whom English is a second language
- people with aphasia

Members of the deaf community consistently reported problems accessing GP appointments due to the lack of provision of BSL interpreters, hearing loops or SMS numbers. When email was offered as an alternative, messages could be left unanswered for up to 2 weeks due to the "telephone focussed booking systems".

Patients with aphasia and those with English as a second language also struggled to make telephone appointments and have often had to rely on friends or relatives to communicate with reception staff on their behalf. This often left them feeling disempowered: "we don't want to have to rely on other people".

The groups felt there was a lack of understanding from the surgery staff and suggested various ideas such as visual aids, prompt cards and an increased use of non-telephone alternatives to make booking and attending appointments easier for those with specific communication needs.

### Lack of signposting to specialist care

The people we spoke to understood that GPs are not specialists but generalists: 'not everyone can be an expert in everything', however, they were aware that in some surgeries there were medical staff with greater specialist knowledge or interests e.g. elderly care, neurology, that they were not automatically signposted to.

They often had to rely on internet research to find the GP with specialist interests within their own GP surgery and ask specifically to be seen by that GP.

Receptionists could have an important role to play in signposting patients to the appropriate professionals for their condition.

# 'There is an MS Nurse in the area but she is difficult to get hold of.'

Patient with multiple sclerosis

'Dr --- is superb, when I registered with him 2 years ago, he said I was the first HIV patient he had seen and didn't know much about it so could I tell him some information.'

Patient with HIV

# Desire for continuity of care for long-term conditions

Many of our interviewees made a point of mentioning their preference for seeing the same GP for condition-related issues. For minor ailments, they were happy with any GP.

Often this was because patients felt that they got along well with their GP and didn't want to have to go over their history again and again, wasting the GP's time as well as their own.

Two patients told us that they had moved GP practices in the recent past and that there wasn't an effective hand-over of information between doctors. Both would have welcomed an introductory meeting to discuss their specific needs and give continuity to their care.

#### 'I would rather wait to see the doctor that knows me, although I know I could see another doctor more quickly.'

Patient with diabetes

# 'Having a 'pass' to see a preferred doctor is important to me.'

Patient with cancer

### 'When you can see the same doctor it is a happy experience.'

Patient over 65 yrs

# Lack of awareness of patient participation groups (PPGs)

PPGs can be invaluable sources of patient feedback and participation. They can develop mutually supportive networks for patients and the practice, outside of individual appointments.

However, despite this a number of our interviewees were unaware of their practice PPG and others told us that they'd asked to be a member but this had not been followed up.

# I requested when I joined the surgery, but I've not heard anything'

Patient with multiple sclerosis

# Tm aware of the group but I don't think they'd have anyone like me.'

Patient with visual impairment

#### Tm interested in being part of the group and may join when I'm feeling better.'

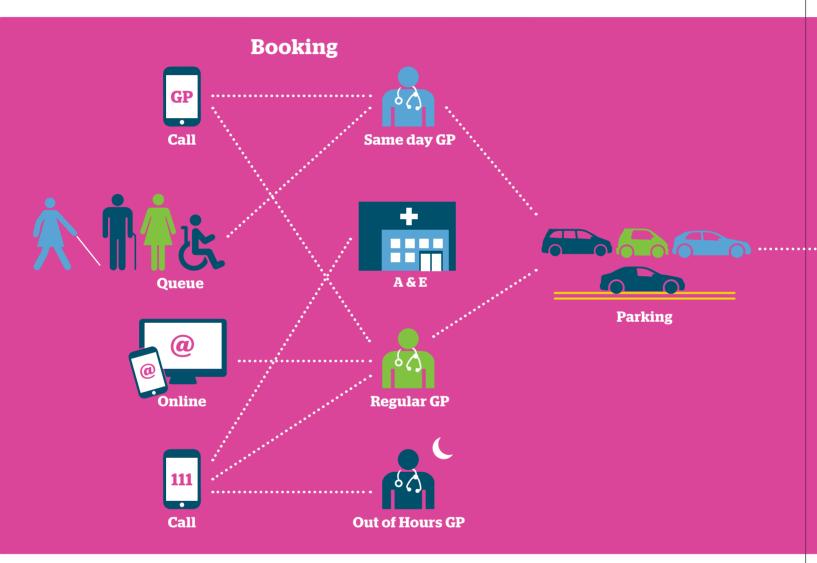
Patient with an acute condition

# The patient journey

**Booking** methods

Appointment types

**Parking** 



### 'You can easily wait on the phone for half an hour.'

Patient with cancer

### 'I need an appointment in 2-3 days, not 2-3 weeks!'

Parent of young child

#### I can book online but if my preferred doctor isn't available, I can't book far enough ahead.'

Patient with diabetes

#### I have to go in person because I don't speak good enough English to speak on the phone.'

Patient for whom English is a second language

### I can't get an appointment to fit in with working hours.'

Patient who is "working well"

#### 'The only way really is to walk to the surgery at 8 and queue outside.'

Carer for patient with dementia

#### 'Parking is useless, elderly people end up parking on the double yellow lines and it's already a narrow street.'

Patient with visual impairment

#### 'Parking is difficult.'

Patient with multiple sclerosis

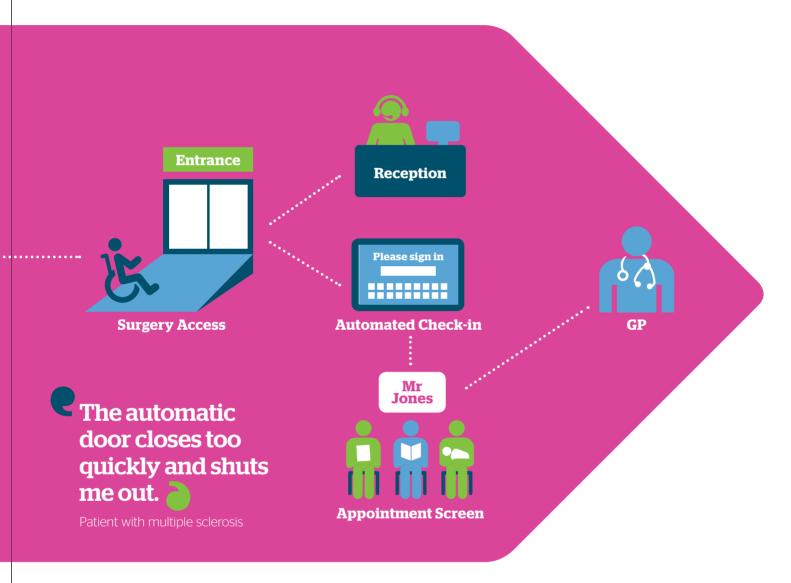
### "There aren't enough disabled spaces."

Patient with multiple sclerosis

#### Access

#### Reception

#### **GP**



### 'I can't get an electric wheelchair up the ramp.'

Patient with multiple sclerosis

### I can't get up the ramp with nothing to hold on to.'

Patient with multiple sclerosis

#### 'If we have to wait outside, the dementia patient can wander off.'

Carer for patient with dementia

# I don't want to tell the receptionist what's wrong, it's none of their business.'

Patient with cancer

#### 'She turned the screen round to say 'is this you' and there was my condition in big letters for everyone to see.'

Patient with HIV

There are kind staff and they always do their best to give you the appontment you need. The GP walked round when I was unable to get to the surgery.'

Patient with visual impairment

# The patient journey



#### **Phone**

Of those that we interviewed, around 60% used the phone to book GP appointments.

Many said that they would like the option of booking a scheduled phone appointment with their GP for straightforward issues such as medication dosages and side effects.

Telephone consultations would, they felt, save the GP's time as well as their own. Unscheduled telephone appointments were not thought to be useful because they involved unknown periods of waiting and a high risk of missing the call.

Around a quarter had at some point requested a same day 'emergency' appointment, despite feeling that their situation wasn't strictly an emergency.

I have to say it's urgent, even when it's not urgent, just to get an appointment.'

Carer for patient with dementia

I never have a problem getting an appointment, call at 8.30, wait 5 mins and get appointment the same day.'

Patient with multiple sclerosis



#### In person

A significant proportion of people in the groups we spoke to felt that the best option was to go to the surgery and wait to book an appointment, despite the fact that many of these people had mobility issues.

There was concern amongst the carers for patients with dementia and older, less able patients about the hazards of queuing outside.

In many instances, people went in person because they weren't able to use the phone:

- Patients who are deaf:
   Some said that using Text
   Type caused the surgery to hang up, presuming it was a sales call
- Patients with mental illness: some had no access to a phone or were not equipped to call
- Patients for whom English is a second language: couldn't understand English well enough to book by phone
- Patients with aphasia: often have limited or no speech which makes it difficult to use the phone.

Booking is difficult for those with aphasia, reception staff do not understand the condition so shout instead of slowing down.'

Patient with aphasia



#### **Online**

The British Medical Association and NHS England have a joint commitment to encourage GP practices to register patients for online services by 31st March 2017. (Source: NHS England)

Most individuals were not aware of an online booking system, even if there was one available at their practice.

Many stated that they would prefer to use an online system, or email, particularly the younger patients who were used to functioning in a digital environment, for example, using online ordering for groceries and booking holidays.

I would definitely prefer to book appointments online, is that available at any GP? It would save me ringing up and speaking to the receptionist.'

Parent of young child

I tried the online service when it was new but it wasn't working properly and put me off. I prefer online or phone.'

Patient with an acute condition

Text alerts for appointment reminders are good.'

Patient with diabetes



#### **NHS 111**

There was little awareness that NHS 111 could be used to access out-of-hours GP appointments. Those that were aware of NHS 111 assumed that it was simply an advice line

As of May 2017, Surrey commissioners have begun the re-procurement process for the current NHS 111 and GP out-of -hours services. A Patient and Carer Advisory Group (PAG) has been established to assist CCGs with plans for public and stakeholder engagement. They are planning a series of events to gather views and feedback from patients and carers regarding the NHS 111 and the GP out-of -hours service.

The CCGs would very much like to hear from patients, carers and stakeholders on what is working well and what is working not so well in order that they can make improvements where possible. People are invited to share their views and feedback. More information can be found on the Healthwatch Surrey website.



#### **A&E** visits

Contrary to recent media coverage of people using A&E as an out-of-hours service, those that we interviewed rarely, if ever, went there.

The only people who had used A&E as an out-of-hours service were parents of young children. These people weren't aware of the out-of-hours booking facilities available through NHS 111.

"The NHS 111 service is staffed by a team of fully trained advisers, supported by experienced nurses and paramedics. They will ask questions to assess your symptoms, then give you the healthcare advice you need or direct you to the local service that can help you best. That could be A&E, an out-of-hours doctor, an urgent care centre or a walk-in centre, a community nurse, an emergency dentist or a late-opening chemist. Where possible, the NHS 111 team will book you an appointment or transfer you directly to the people you need to speak to. If NHS 111 advisers think you need an ambulance, they will immediately arrange for one to be sent to you."

(Source: NHS Choices)



#### Access & Parking

Many of the less physically able participants found the surgeries difficult to navigate, with slopes that were too steep for wheelchairs and automatic doors that closed too quickly, shutting the patient out.

Those with limited mobility found the lack of handrails on the approach to some surgeries tricky because there was 'nothing to hold on to'.

#### I worry that the door is going to slam on me. If I were on my own, it could knock me over.'

Patient with visual impairment

Parking was something that was felt to be a problem for nearly all interviewees.

Some chose to park in a nearby supermarket and walk, and others to park on roads nearby. Many found the experience of trying to find a space extremely stressful.

Four out of five patients with multiple sclerosis had trouble finding parking places. One patient said he has to arrive an hour early in order to park.

Holders of blue disabled badges were frustrated because of the limited number of disabled parking spaces.

# The patient journey



#### **Reception and waiting**

The vast majority of comments concerning receptionists were not positive.

Most patients did not like being questioned about their reasons for wanting an appointment. Many felt that reception staff could be unhelpful.

Patients who are deaf and Patients with aphasia felt that reception staff would benefit from communications training so that they could support them when they were asking for an appointment: 'Talking louder doesn't help.'

The comments were the same, whether they concerned talking to receptionists over the phone or in person.

Carers for patients with dementia felt that it would be helpful if the reception staff could see by looking at their record that they were a carer and ask if the appointment was for them or the person that they cared for.

There was also concern over the extent of the personal information to which reception staff had access.

Some of the patients with HIV were concerned that receptionists had access to confidential medical information, one had even requested a confidentiality agreement to ensure that this wasn't the case.

Another found that their patient confidentiality was breached when a receptionist turned the screen round thereby displaying the name of their condition to others waiting in the queue.





#### **Pharmacy**

The people we spoke to were satisfied with pharmacy services, many of them using the online ordering facility, even if a carer made the order and collected the prescription.

Two interviewees used the Pharmacy2U service and felt that this was of benefit.

**Pharmacy2u** is an NHS electronic prescription service which allows you to manage repeat prescriptions online and have them delivered free to the home. (Source: Pharmacy2u.co.uk)

Nepalese community group members reported problems understanding medication and dosage, unless the pharmacist explains it to them. Along with other patients (people with visual impairment and those with aphasia, for example) they found this problem to be particularly challenging if the packaging changed between prescriptions.

# "The prescriptions go direct from the surgery to the chemist and the chemist texts when it's ready."

Patient with an acute condition

### Toften get more help from the pharmacy than the GP.'

Carer for patient with dementia

# 'Once in a while the pharmacist will take me into a little room and explain the medication, it really helps.'

Patient for whom English is a second language

### Recommendations and next steps

In keeping with our previous research people were happy with the GP care they received. The main frustrations raised were access issues relating to the telephone booking system, communication, physical accessibility and continuity of care for complex conditions.

### What should decision makers and planners do?

 Those planning the future of health services in Surrey (e.g. through Sustainability and Transformation Plans) should ensure that access to primary care is at the heart of those plans and that the process of accessing primary care services is improved by listening to patient and carer feedback.

Clinical Commissioning Groups (CCGs) should:

- review why awareness of NHS 111 is low, engage with patients and carers to initiate new plans to promote the full range of services it offers including access to out-of-hours GP appointments.
- conduct further research into why people who already manage their time online do not know about or use online GP booking.
- review their primary care strategy to ensure GPs are encouraged to promote online booking, make registration to the online system easy and to try to understand barriers to patient use.

#### What should individual practices do?

- Comply with the Accessible Information Standard.
- Ensure that for those who are deaf there is provision of a regularly monitored email, SMS services and access to a BSL interpreter when needed.
- Raise awareness of long term conditions (in partnership with community groups) within the reception and staff teams, e.g. dementia, aphasia and sensory impairments.
- Provide posters/leaflets signposting to local support groups for long term conditions.
- Consider testing automated door phasing systems with patients that have sensory impairments and mobility issues.
- Consider inviting patients with long term conditions to attend staff training sessions to talk about living with their condition.
- Consider how appointments for long term condition related queries vs. minor ailments are handled to allow priority for continuity of care

- for long term condition related appointments.
- Consider the role receptionists can play in matching patients with GPs who may have a special interest in certain conditions.

### What can Healthwatch Surrey do to help?

- Encourage people to attend their local Sustainability and Transformation Plan (STP) consultations to help shape any system wide changes.
- Encourage system leaders to take every opportunity to engage effectively with the public and listen to their views about what works well and less well.
   The public, patients and carers have good ideas based on their own experiences and these should be fully incorporated into future plans.
- Help raise awareness and understanding of NHS 111 services, GP online booking and alternatives to GPs for minor ailments.
- Healthwatch Surrey can link PPGs and GPs with local community groups for awareness raising events or literature, based on local patient population needs.

#### What can patients do to help?

- Share your views as part of the NHS 111
   procurement process (Summer 2017) to identify
   what works well and what less well, to help shape
   the future service.
- Attend STP engagement events and get involved in plans to help shape primary care services.
- Contact your GP surgery to get involved or give feedback to your local PPG to help improve the service.
- Register for online services including; appointment booking, repeat prescriptions and access to a summary of your medical records.
- Share your experiences of local health and social care services, good or bad, with Healthwatch Surrey. Contact details are on the back page of this report.

## What next?

Healthwatch Surrey will share the findings of this report with those that took part, Commissioners, GPs, Practice Managers, Patient Participation Groups and the public to raise awareness of the findings and recommendations contained in the report. An impact report based on this initial report will be published in Summer 2017.

If you have concerns about the accessibility of services at your GP practice, either in terms of physical access or the accessible information standard you can contact NHS England in the following ways;

Telephone: 0300 311 22 33

Email: england.contactus@nhs.net

Post: NHS England, PO Box 16738, Redditch, B97 9PT

For those living in the North West Surrey CCG, the CCG can be contacted directly on;

Telephone: 01372 232450

Email: Contactus2@nwsurreyccg.nhs.uk

Post: The Customer Service Team, North West Surrey Clinical Commissioning Group,

58 Church Street, Weybridge, Surrey, KT13 8DP.

### **About Healthwatch Surrey**

Healthwatch Surrey is an independent local watchdog that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

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