



# Attention on prevention

Cervical, breast and bowel screening programmes in Newcastle

## About Healthwatch Newcastle

Healthwatch Newcastle is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012. We have a dual role to champion the rights of users of publicly funded health and social care services for both adults and children, and to hold the system to account for how well it engages with the public.

We collect feedback on services from people of all ages and from all communities. We do this through our network of voluntary and community sector organisations, during events, drop-in sessions and listening events at a range of venues across the city, online through the feedback centre on our website, via social media and from callers to our 'Just ask' helpline. As part of the remit to gather views, we also have the power to 'enter and view' services and conduct announced and unannounced visits.

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# 1. Introduction

In the United Kingdom there are 11 NHS population screening programmes<sup>1</sup>. This report focusses on the cervical, breast and bowel screening programmes.

## About cervical, breast and bowel screening

### NHS cervical screening programme

This is available to women aged 25 to 64 in England<sup>2</sup>. All eligible women who are registered with a GP automatically receive an invitation for screening by post after their 25th birthday. Women aged 25 to 49 receive invitations every three years. Women aged 50 to 64 receive invitations every five years.

Cervical screening is usually carried out by the practice nurse at GP practices. The nurse puts an instrument called a speculum into the vagina and uses a small soft brush to collect some cells from the surface of the cervix. These cells are checked in a laboratory for any abnormalities.

### NHS breast screening programme

This is available to women aged 50 to 70<sup>3</sup>. All eligible women who are registered with a GP automatically receive an invitation for screening by post within three years of their 50th birthday, and will be invited every three years until they are 70. Women can also request breast screening after 70 and be screened every three years.

Breast screening is carried out at special clinics or mobile breast screening units. The breast is placed on an X-ray machine and gently but firmly compressed with a clear plate so an X-ray can be taken to spot any tissue abnormalities.

### NHS bowel cancer screening programme

This report focuses on the Faecal Occult Blood (FOB) test bowel screening only, which is available to everyone aged 60 to 74 every two years. People eligible for FOB screening receive an invitation letter around their 60th birthday which describes the screening programme. A FOB sampling kit is sent around one week later. The sampling kit is completed at home by the individual being screened. The kit is used to collect small samples of faeces which are then posted to a laboratory so the samples can be checked for tiny amounts of blood.

## Cervical, breast and bowel screening uptake in Newcastle

In January 2017 a paper titled 'Health Protection Statistics for Newcastle'<sup>4</sup> was shared at Newcastle Health Scrutiny Committee with the aim of providing an overview of the performance of screening and immunisation activities in Newcastle. This paper presented data showing that breast and cervical screening uptake is low in certain areas of Newcastle, with GP practices serving seldom heard or deprived neighbourhoods consistently struggling to attain the national standard (70% for breast and 80% for cervical). The paper also showed that uptake for bowel screening was low.

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<sup>1</sup> Abdominal aortic aneurysm, bowel, breast, cervical, diabetic eye, sickle cell and thalassaemia, foetal anomaly, infectious diseases in pregnancy, newborn and infant physical examination, newborn blood spot and newborn hearing.

<sup>2</sup> Trans men aged 25 to 64 who are registered with a GP as female are routinely invited for cervical screening; further details at <https://tinyurl.com/trans-screening>

<sup>3</sup> Trans men aged 50 to 70 who are registered with a GP as female are routinely invited for breast screening, further details at <https://tinyurl.com/trans-screening>

<sup>4</sup> <https://tinyurl.com/ybfo4bqs>

The information in the paper led to us looking more closely at the uptake data for these screening programmes. We used Public Health England’s Fingertips Tool at <https://fingertips.phe.org.uk> to access the uptake data for the three screening programmes.

We could see there was a downward trend in England for uptake of both cervical and breast screening, with a fluctuating trend for bowel screening. These trends are reflected locally as shown in the table below, except for an anomaly in the breast screening data where there was an increase in uptake in 2014–15, followed by decreases in both 2015–16 and 2016–17.

We are performing well in Newcastle and Gateshead for breast screening in comparison to the England average. However, cervical screening in Newcastle and Gateshead has regularly been below the England average, especially recently.

Newcastle and Gateshead have also been performing below the England average for bowel screening, although recent data is showing an improvement, with figures above or matching the England average.

Both locally and across England, the uptake targets for breast screening (70%) are being met but targets for cervical screening (80%) and bowel screening (60%) are not being met.

Year	Cervical screening		Breast screening		Bowel screening	
	Newcastle Gateshead CCG	England	Newcastle Gateshead CCG	England	Newcastle Gateshead CCG	England
09/10	76%	75%	76%	74%	55%	55%
10/11	75%	76%	76%	75%	56%	58%
11/12	76%	75%	75%	74%	54%	55%
12/13	74%	74%	75%	73%	57%	59%
13/14	74%	74%	74%	73%	55%	56%
14/15	73%	74%	76%	73%	Data not available	59%
15/16	72%	73%	74%	73%	57%	56%
16/17	71%	72%	72%	72%	59%	59%

Table showing percentage uptake of the screening programmes in Newcastle and Gateshead in comparison to England

Table key: Blue shading = above England average, Red shading = below England average

On looking more closely at the uptake data specific to Newcastle GP practices, we could see that uptake was generally low in Benwell and Scotswood, Elswick, Westgate, Ouseburn, Byker and Walker. These areas are considered to have multiple indices of deprivation as defined by the Index of Multiple Deprivation study. Benwell and Scotswood, Elswick, Byker, and Walker, in particular, are considered to be in the top 10% of the most deprived communities in the England.

Having identified pockets of low uptake in Newcastle, we saw an opportunity to use our community engagement expertise to speak to people in these communities.

We considered this to be an important activity to undertake because:

- We do not really know why some people in the wards listed above are not taking part in screening programmes
- We wanted to ensure their views are heard (particularly those from seldom heard communities)
- We wanted to find out what activities would encourage people to take part in screening
- It would enable us to share some solutions with services that could increase uptake

It is also a topical issue nationally and locally because:

- Uptake of screening is decreasing in England for both cervical and breast screening (this also appears to be happening locally)
- Uptake of cervical and (until recently) bowel screening locally is below the England average
- Uptake targets for cervical and bowel are not being met locally or in England

The aims and objectives of our work were to:

- Engage with communities in Newcastle where uptake of screening is low to find out
  - Why people do not take part in screening programmes
  - What are the barriers to taking part
  - How these barriers could be overcome
- Identify solutions to the barriers, which could then be used to boost the uptake of screening in low uptake areas

## 2. Methodology

We used three techniques to gather views from people living in the areas listed above during autumn 2017. The techniques were focus groups, one to one interviews and surveys.

### Focus groups

We chose to use focus groups as it is a proven approach to obtain detailed information about personal and group feelings, perceptions and opinion.

We used our connections with community groups in the target areas to meet with groups of people to discuss the screening programmes relevant to them. In most cases we attended community meetings that were already running, which guaranteed an audience. In other cases community groups/organisations co-ordinated specific meetings at times most suitable for the communities they engage with. Most focus groups were held during the day, with some happening in the evening. Appendix one (page 18) details the format of all focus group sessions.

We knew this method may not have put us directly in contact with people who do not participate in screening programmes. As a result, the focus group questions about barriers and solutions were worded so everyone could participate.

We paid for venue hire, refreshments, travel costs, interpreting and other necessary support costs to help groups participate in the focus groups.

## One to one interviews

We chose this method of gathering information because academic work performed in the past<sup>5</sup> for bowel screening uptake had had success with this approach. We also thought this approach could put us directly in contact with people who had not participated in a screening programme in the past 12 months.

We contacted seven GP practices that were spread out within the six wards we were targeting. We asked the practice managers if the GP practice could send one to one interview invites out to their patients on our behalf. Two practices were able to do this for us (Thornfield Medical Group in Ouseburn and Denton Turret Medical Centre in Benwell and Scotswood).

Thornfield Medical Group and Denton Turret Medical Centre sent 2,160 invite letters (see appendix two - page 19) to people who had not participated in screening programmes in the past 12 months:

- Breast screening non-attenders (310 letters)
- Bowel screening non-completers (800 letters)
- Cervical screening non-attenders (1,050 letters)

This sample consisted of the majority of non-attenders at both practices. Appendix three (page 20) details the format of the one to one interviews.

## Surveys

We produced a survey for each screening programme (see appendix four - page 22) which could be completed on paper or online via SurveyMonkey. They were promoted through our online channels and e-newsletters.

People could complete a survey if they lived in the target areas and if they fell within the age of eligibility for the screening tests.

## 3. Findings

This section reports on the views obtained via one to one interviews, focus groups and survey participants.

We heard from 199 people in total. This is a relatively small sample size to draw conclusions from, but it is important to value the views that people shared with us.

The respondents included:

- Twelve focus groups, where we heard from 135 people; we held six women's groups (66 attendees), four men's groups (46 attendees) and two mixed groups (23 attendees)
- Twelve one to one interviews (seven women and five men)
- Fifty-two survey responses (37 cervical, seven breast, eight bowel)

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<sup>5</sup> Hall N, Birt L, Rees CJ, et al. Concerns, perceived need and competing priorities: a qualitative exploration of decision-making and nonparticipation in a population based flexible sigmoidoscopy screening programme to prevent colorectal cancer. *BMJ Open* 2016 <http://bmjopen.bmj.com/content/6/11/e012304>

The table below shows how many men and women we heard from with each research method. Not all respondents provided their gender so they are classed as ‘unknown’.

Gender	Focus groups	One to one interviews	Surveys	Total
Men	40	5	0	45
Women	47	7	30	84
Unknown	48	0	22	70
<b>Total</b>	<b>135</b>	<b>12</b>	<b>52</b>	<b>199</b>

The table below shows how many men and women we heard views from regarding each screening programme. Not all respondents provided their gender so they are classed as ‘unknown’. A total of 280 views were gathered because those who identified as female could give views about all three screening programmes.

Gender	Cervical	Breast	Bowel	Total
Men	0	0	45	45
Women	77	52	14	143
Unknown	39	26	27	92
<b>Total</b>	<b>116</b>	<b>78</b>	<b>86</b>	<b>280</b>

The demographics of the people we heard from is detailed in appendix five (page 30). Not all 199 respondents gave their demographic information as this was an optional part of the research. We worked hard and used our links within the community to ensure that our sample was as representative of Newcastle’s population as possible, however, we were not always able to visit each group due to staffing, diary clashes, or groups having full activity programmes, etc.

We would have liked to have heard from more men, people in employment and White British people. Due to the small sample size, other groups were also not fully represented in our study including Indian, Pakistani, Bangladeshi, Gypsy or Irish Traveller communities, and women’s groups (for bowel screening). Further work is needed within these communities to gather their views.

Due to the low rate of survey completion, the survey data has been combined with the rest of the data in most cases and it is clearly stated where it has not.

Additionally, due to the qualitative nature of the work – where the bulk of the information has been drawn from focus groups – it has proven not always possible to say how many people hold a particular view.

In this report we often refer to the number of times a view has been expressed. This reflects the number of times the view was raised within focus groups, one to one interviews and surveys, rather than the number of people who hold that view. For example, if the painful nature of a test was discussed in ten focus groups, mentioned in six interviews and highlighted in 30 surveys the view count would be 46.

### 3.1 Overarching themes

We have been able to identify some themes explaining why people choose to be screened, why people choose **not** to be screened (barriers to screening), and some solutions that may encourage people to be screened. These themes are different for each screening programme and are detailed later in this section. However, there were two common themes



arising across all three screening programmes: knowledge and information and screening age.

People felt that in order to encourage screening there should be more health promotion and information to raise people's awareness about the screening programmes. The people we heard from spoke about more health promotion work out in the community and health professionals mentioning the screening programmes at appointments when seeing patients who are eligible and/or due a screening test.

Some people also wanted to see the screening age lowered for all screening programmes. This view was raised 11 times, with some people sharing the following:

**'My Mum had cancer and I would like to be able to access breast cancer screening earlier, say when I am 38.'**

**'Think all screening should be done earlier: cervical – 16, breast – 16 and bowel – 20.'**

## 3.2 Cervical screening themes

### People's experiences

We heard from 116 people about the cervical screening programme: 28 of these people said they had a very good (11) or good (17) experience. Where this was qualified, reasons given for good experiences were good staff (7), good information given (1) and straightforward procedure (1).

Forty-four of these people described their experience of cervical screening as 'okay'. This was qualified by 18 people explaining that, although they found the process painful and unpleasant, they recognised the importance of the programme and continued to attend.

Seven people talked about having a bad experience and, where this was qualified, reasons given were staff being heavy handed (one) and appointment waiting times (one).

Fifteen people talked about experiences with the staff: 13 people shared positive experiences and two shared negative experiences.

### Positive quotes

**'Great experience. I've had lots of abnormal smears and even though that's bad the staff were always reassuring, never made me feel scared, very understanding. They explained things and that stopped me worrying.'**

**'Nurse has good approach – didn't feel embarrassed.'**

**'The nurse could see I was anxious and put me at ease.'**

### Negative quotes

**'Yes I've been and it was painful. The nurse was very rough and her manner was not nice.'**

**'Very painful (due to a health condition), so much so I screamed and the nurse asked if I had had children – it felt like she was judging me.'**

Finally, one person from the black and minority ethnic (BME) community described difficulty in accessing an interpreter for her appointment.

### Likelihood of future attendance

When people were asked if they would go to their next appointment 76 said that they would and 12 said they would not, with the rest (28) not answering the question.

The majority of people who said they would go in the future simply stated that they would continue to go as normal. Some people chose to qualify their reasons for future attendance:

- Five people explained that they go because it is an important test
- Four people explained that they had a history of cancer in their family so that encouraged them to go
- One person explained that they had had previous problems in the past and this encouraged them to go to their regular appointments

‘Yes – I would attend - all health appointments are important.’

‘Yes - important. History of cancer in family so I am cautious and want to keep an eye on it.’

### Barriers to attendance

Forty-one views were shared describing reasons why people may not attend. The main reason given was the embarrassing nature of the test (14 views), followed by fear of being diagnosed with cancer (five views) and the painful nature of the test (three views).

‘I keep getting letters asking me to make an appointment but I never do. I’m embarrassed. I asked if I could be seen by a woman, but I got a man. I’ve had two children but still get really embarrassed. Every time my Mum and sister have they come back abnormal and this puts me off even more.’

‘My sister had cervical cancer and I’d just rather not know, also I’m embarrassed.’

‘It hurts – they do not explain what’s going to happen.’

Four views were raised about the flexibility and accessibility of services, with some examples given below:

‘Public transport – one hour to get there (GP practice), hard with kids.’

‘Too far away.’

‘My son has been in hospital for a year and every time I had an appointment for my smear test (three times) he has been unwell, and I’ve been unable to attend. I’ve tried to rebook but because the appointments are always about eight weeks in advance I can’t predict how he will be when the appointment comes up and unfortunately each time he has been unwell.’

Three people from black and minority ethnic communities also raised the following:

‘Not speaking English makes it hard.’

‘Muslim ladies are very shy and many have only been seen by one man.’

‘Some countries don’t have screening programmes so it’s not part of our culture so when we get appointments we don’t go.’

Finally, 12 people felt comfortable enough to say that they will never go and four of them gave a reason as follows:

‘I’ve now had a hysterectomy.’

‘Don’t like feeling of the speculum.’

‘Bad experience from first one. Metal speculum wasn’t good.’

‘I have a disability which would make it very hard for me to get into and stay in the position required to have the test done. Reasonable adjustments were attempted, but I did not feel confident that I would be appropriately supported and no one was able to allay my fears.’

## Solutions to encourage attendance

Solutions identified by the people we heard from fell within the main themes of knowledge and information and flexible and accessible services.

### Knowledge and information

Thirty-six views were shared about improving people’s knowledge about cervical screening and raising people’s awareness through providing information. The people talked about starting health promotion as early as possible in as many communities as possible:

‘Education at schools, groups and communities.’

‘Maybe talk to people in school, you need to know about it from a very young age – when you get to my age you can get scared because you don’t know and then people don’t attend because they are scared.’

‘Make different communities aware – get health visitors or other health professionals to visit community groups in their settings and talk to people informally, or go to people homes to do the same.’

They also gave ideas on what needs to be communicated and, in some cases, how:

‘Provide information about the disease and about the screening process and in particular, how quick the process is.’

‘A publicity campaign with a slogan – say “Five minutes to save your life”.’

‘Promotional material should have quotes in about past experience.’

## Flexible and accessible services

Nine views were shared about making services more flexible and accessible. People talked about services needing to be more flexible with appointments:

‘Childcare may be an issue for some, which is one reason why flexibility is important. Needs to be family friendly in terms of times.’

‘Workers may struggle to get time off work and may have to use leave or unpaid leave. May disrupt half a day or an entire day depending on where the GP practice is in comparison to work. One reason why flexibility is important.’

‘If I could get an appointment on the same day or during the same week, I would usually know how my son was and would have a much higher chance of being able to attend.’

Some suggestions they thought may encourage people to attend included:

‘Setting up a clinic may be worthwhile and it should run when patients are most likely to attend.’

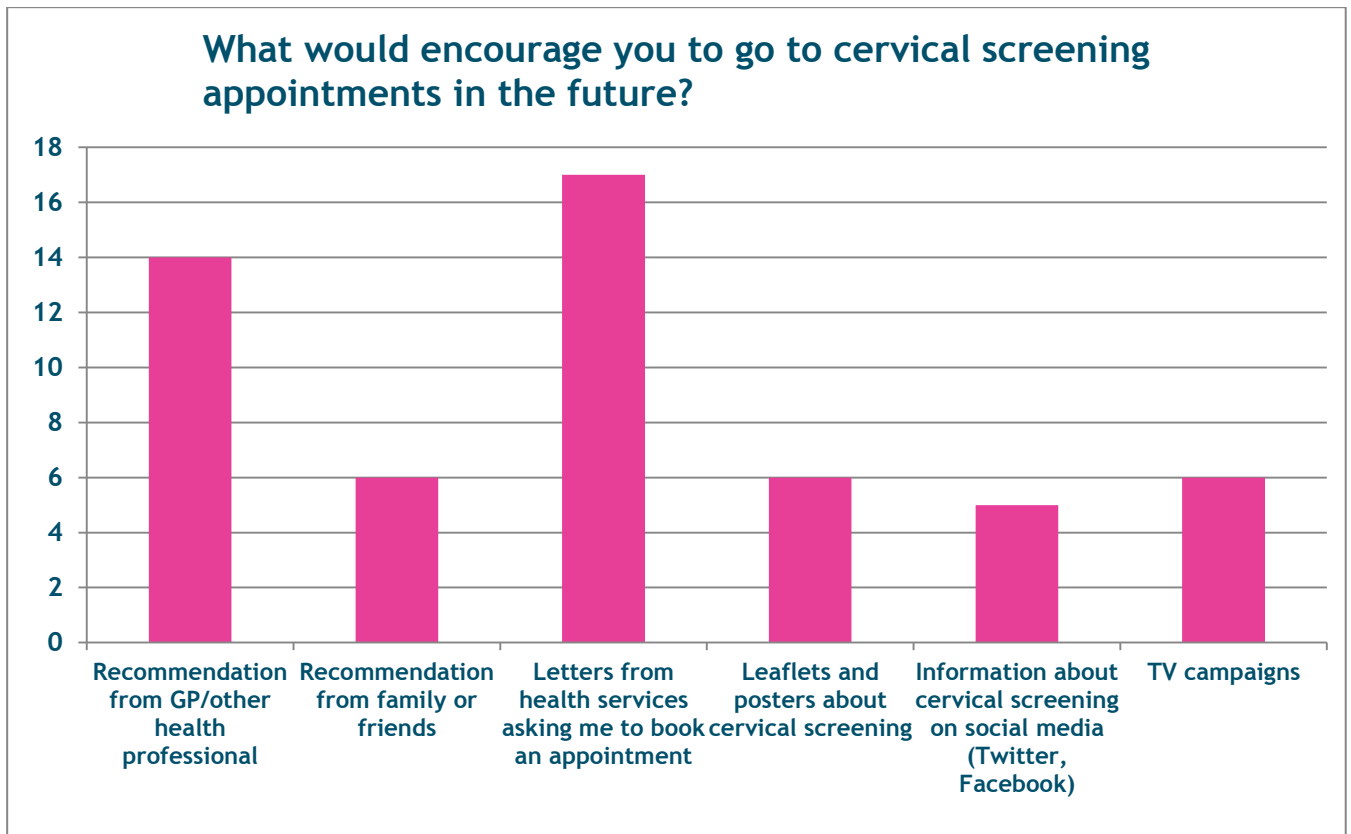
‘If the GP surgery could hold a couple of smear test appointments free each week, women like me with families with issues would be able to book in last minute.’

‘May not be able to afford to travel there. Perhaps take vans out to do it or have vans visiting work places.’

Discussions also brought forward other views including:

- Communicating that you don’t have to go in alone if that is an option (three views)
- For people with physical disabilities, a wheelchair-accessible room in hospital with a hoist, wider bed and enough space for several people would be useful; an option to also visit the room beforehand would be welcome (one view)
- Reminders to book appointments (two views)
- Receiving first invite letters in other languages (three views)

Finally, our survey highlighted some mechanisms that people feel encourage attendance and the results are shown in the graph below:



Seventeen out of 37 people suggested that letters from health services encourage them to book. This was not mentioned in the focus groups or one to one interviews, but two people did say that reminder letters would work.

Recommendations from a health professional or a friend or family member also scored quite highly in our survey, but neither were mentioned in the focus groups or one to one interviews.

### 3.3 Breast screening themes

#### People's experiences

We heard from 78 people about the breast screening programme. The most common views expressed when people talked about their experiences was that it was painful/uncomfortable (eight) and embarrassing (three):

**'Yes, I've had one, it was really uncomfortable, they're not gentle with you.'**

**'It is horrible as I am body conscious and embarrassed about my body.'**

Despite this, people still attend and this could be attributable to the staff at the unit and the efficiency of the service. The people we heard from often held the staff at the breast screening units in high regard, with eight views expressed. Below are some of the views held about staff at the unit:

**'Radiographer was 100%. Communication was spot on. Knew exactly what to do and was made to feel at ease.'**

**'The staff were really lovely and put you at your ease.'**

**'Good staff and well trained.'**

People also spoke highly of the service, with four views expressed including:

‘Service is very well organised and always on time.’

‘Friendly, reassuring, professional service.’

‘Mostly use RVI or mobile centre at Cramlington. Both very good.’

However, there were seven negative comments about the staff and the service including:

‘The staff in the mobile unit were not very friendly, I also felt very exposed, it was a really strange experience and the staff didn’t put me at my ease – they could have been more friendly.’

‘Wanted to change date but the service could not look a month ahead.’

‘Wait a while so once undressed can get cold.’

‘I was rushed to get dressed and undressed when I can’t leave my wheelchair.’

‘Attitude of staff was terrible. Staff member appeared to have no nursing experience. Didn’t put the effort in (to make reasonable adjustments) because I didn’t fit into their box as a patient.’  
(Comment from a disabled service user.)

### Likelihood of future attendance

When asked if they would go to their next appointment, 48 people said that they would and three said they would not.

The majority of people who said they would go in the future simply stated that they would continue to go as normal. Three people chose to qualify their decision to attend in the future and the reasons they gave focused on a history of cancer in the family and the importance of the test.

### Barriers to attendance

Eighteen views were shared describing reasons why people may not attend. The main reasons given were the cost implications of attending the test (six), followed by lack of information (two) and language barriers (two).

‘Not being able to get childcare or afford it.’

‘Not being able to park/get the bus/travel or afford it.’

‘Not being able to get the time off work or afford taking unpaid leave.’

‘Women don’t go because they don’t know enough about it. Need education at schools.’

‘Language barrier – not understanding letter then forget to call or can’t and then forget.’

Some other less common reasons for not attending were also raised, including:

- Poor experience of the service due to it being ineffective at making reasonable adjustments for a disabled person (one view)
- People not feeling the test is necessary (three views)
- Fear of receiving a cancer diagnosis (one view)
- Too embarrassed (one view)
- Not receiving a letter (one view)
- Forgetting to go (one view)

## Solutions to encourage attendance

Solutions identified by the people we heard from fell within the main themes of knowledge and information and flexible and accessible services.

### Knowledge and information

Twelve views were shared about improving people's knowledge about breast screening and raising awareness through providing information. As with cervical screening, people talked about education and awareness-raising but they were less specific about what was needed and only gave two specific ideas: awareness-raising in schools and talks at GP practices.

However, people were more specific about printed information and gave the following suggestions as to what it should include:

- Symptoms to look out for
- Statistics showing how often something is found – to allay fears
- The support available if someone does receive an abnormal result or a cancer diagnosis
- Quotes from people who have already been
- Information about patient transport

### Flexible and accessible services

Five views were shared about making the service more flexible and accessible. People talked about the service needing to be more flexible with appointments:

**‘Patients should be able to get an appointment when it is suitable for them.’**

**‘Appointments outside of work time.’**

One person stressed the importance of maintaining the mobile unit as it is easy to access and is one of the reasons she finds it so easy to attend. Another talked about the need for the service to get better at making reasonable adjustments for disabled people much more proactively, either on the day or rearranging the appointment if needed.

Discussions also brought forward other views, including:

- Help with costs of childcare, travel, parking (two views)
- Texts, phone calls or letters to remind me of my appointment (four views)
- Invite letters in other languages (one view)
- Easier access to interpreters for those with language barriers (one view)

## 3.4 Bowel screening themes

### People's experiences

We heard from 86 people about the bowel screening programme (45 men, 14 women and 27 unknown gender). The most common views expressed when people talked about their experiences was that it was easy to complete (ten), but unpleasant (four) due to the nature of the test.

**'Yes – it is easy but not pleasant.'**

**'The process is distasteful but a necessary evil.'**

Three people spoke about their ability to complete the test, two of whom found the test impossible to complete due to a bowel condition, and one whose physical disability meant he could not do the test:

**'I have tried but could not perform the test. Three samples needed to be given in a specific time frame. I have diverticulitis and irritable bowel syndrome so do not go often enough to provide enough samples. I would like to be able to complete the test due to family history and watching friends go through it (bowel cancer) but just couldn't do it.'**

Another person mentioned a concern with the self-seal on the sample bag. She was concerned that it would not stay sealed so put the sample bag in a plastic food bag for extra security.

The people we spoke to from the Chinese community (ten) said it would have been helpful to receive letters in their own language.

### Likelihood of future completion

When people were asked if they would complete the test again, 24 said that they would and two said that they would not.

The majority of people who said they would complete the test in the future simply stated that they would continue as normal. Two people qualified this further, with one giving the importance of the test as their reason. The other stated that, despite their reluctance to complete it due to its unpleasant nature, now they have completed it and realise how easy it is, they would be happy to do it again.

### Barriers to completion

The main reasons given for not completing the test were lack of knowledge (11), followed by the ability to do the test (eight), fear of receiving a cancer diagnosis/misdiagnosis (four) and the unpleasant nature of the test (four).

Four visually impaired people shared their difficulties of completing the test:

**'Didn't do it. Not useable for visually impaired people. May get covered in it and may cover bottle. Hygiene factor and spoon<sup>6</sup> too small.'**

**'Spoon size, seeing into the toilet.'**

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<sup>6</sup> People referring to a spoon have received the new faecal immunochemical test (FIT) because they are registered with a GP which is trialling this product. FIT is due to be rolled out across England in 2018.



**‘No – I do not have the knowledge to understand how to complete it. Put it off as do not know how to use spoon.’**

**‘How am I going to do this as a visually impaired person?’**

Two people referred to difficulties due to bowel conditions, such as diverticulitis and irritable bowel syndrome:

**‘I cannot go often enough in the time frame given.’**

**‘Due to my digestive system and bowel movements, I was not able to provide the samples in the sequence needed. I would have done it if I could have. I also found the letter confusing and difficult to understand.’**

One person with a physical disability explained that he simply could not complete the test himself and did not want to ask his carers to do it for him. He was invited to attend a centre to complete the test but could not afford the transport or get patient transport. He also could not claim back the cost of transport.

Four people explained that they did not want to complete the test because of its unpleasant nature:

**‘Preparing a sample at home is unpleasant.’**

**‘Just because it’s poo I won’t do it.’**

**‘No - (will not complete for) health reasons, hygiene, physically handling it, no gloves, physically sick.’**

**‘I did not like the idea of doing the test.’**

We also spoke to people from the refugee and asylum seeker community (ten people) and they identified some barriers specific to their community:

- Cultural and religious views that may make completing the test a challenge
- Bowel screening and bowel cancer not being a topical issue to asylum seekers or refugees; they often come from countries where there are no screening programmes and no health promotion regarding many conditions, so it is not something that is on their radar
- Many asylum seekers and refugees do not have a permanent address so may not even know about their eligibility for the test
- There was a suggestion that refused asylum seekers were not completing the test because they fear they may get charged for it
- Some asylum seekers or refugees worry that it would be used to track them down and send them back to their country
- Not wanting to add an extra burden if they are already dealing with lots of stressful circumstances

## **Solutions to encourage completion**

Solutions identified by the people we heard from fell within the main themes of knowledge and information, changes to equipment and communication needs.

## Knowledge and information

People shared views on improving people's knowledge about bowel screening and raising people's awareness through providing information. In particular, seven views were shared by people, suggesting that women's health was promoted more than men's and that this needs to be addressed:

**'There is lots of information out there for women and women's health, not so much for men.'**

**'Women's cancer is so much more high profile than men's – why?'**

**'More information on male cancers – including awareness, publicity and media.'**

There were seven views that education and awareness-raising should start at GP practices. GPs should share information about the test if they see someone at their surgery who is nearing their 60th birthday.

One person suggested that GPs should have a role in contacting those who have not completed it to find out why and to see if any support can be offered.

**'GPs should be more proactive and push cancer screening.'**

Two views stated that education and awareness-raising should happen in the community via community groups and community leaders. In particular, people at the refugee and asylum seeker group talked about the importance of health promotion by peers, which works particularly well for men. They suggested that it would be beneficial to train community leaders from seldom heard communities to do health promotion work within their communities. The community leaders would require training and funding to sustain the activity, but this would be the best way to get the message across.

Other suggestions included:

- Ensure coverage of the programme on local and national news (two views)
- Run advertising campaigns (two views)
- Advertise screening in motorway services (one view)
- Ensure that information was included in the welcome pack for refugees and asylum seekers (one view)

## Changes to equipment

Six views were shared regarding the equipment provided and the following suggestions for improvements were made:

- Provide gloves and wipes
- Providing a teaspoon size spoon would make it easier for visually impaired people
- Equipment allowing double bagging or a double bottling would be beneficial

## Communication needs

Six views were shared regarding communication needs and the following suggestions were made:

- Send invite letters and instructions in other languages, large print or audio to those who need it
- Provide contact information for the Newcastle Chinese Healthy Living Centre so that the Chinese community can use that centre to help them access NHS services and interpreting support

## 4. Recommendations

Below are some recommendations based on the views we have gathered. The first set of recommendations are to be considered by all three screening programmes, followed by recommendations tailored to the cervical, breast and bowel screening programmes.

1. NHS England should work with Newcastle City Council's Public Health Team and screening units to ensure that the appropriate bodies are resourced (funding, time, resources and expertise) to provide comprehensive and regular community outreach, particularly to seldom heard groups, men's groups (for bowel screening) and schools.
2. NHS England should work with Newcastle City Council's Public Health Team and screening units to explore how the appropriate bodies can be resourced (funding, time, resources and expertise) to train and support community leaders to deliver and sustain health promotion activities in their communities.
3. NHS England should consider incentivising general practices (perhaps via the Quality and Outcomes Framework) to follow up patients by phone who do not take part in screening, to provide information and encouragement.
4. NHS England should work with Clinical Commissioning Groups to explore how all patients receive invite letters in their preferred format (another language, large print, braille, etc.)
5. GP practices and screening units should ensure that robust processes are in place to make reasonable adjustments for people with disabilities when completing their screening test, as described in the duty to make reasonable adjustments in the Equality Act 2010.
6. If a GP or other health professional sees a patient who is due a screening test in the near future, this should be raised with the patient.
7. GP practices should work with their patient participation groups (PPGs) to consider how they could help practices improve their screening uptake.
8. Newcastle City Council's Public Health Team to include targeted information about screening programmes in the refugee welcome pack.

## Recommendations for cervical screening

1. Newcastle Gateshead CCG, with NHS England, should explore if and how cervical screening appointments could be offered out of hours, as done by the South Tees Out of Hours GP service <https://tinyurl.com/y9xodzpa>.
2. The No Fear cervical screening campaign should use the information gathered to inform the cervical screening toolkit for GP practices.
3. General practices should review how to make their cervical screening services more accessible to patients, in particular, offering appointments outside of work hours. Practice PPGs could help gather patient views on this.
4. Invite letters should provide clear information on accessing an interpreter for appointments.

## Recommendations for breast screening

1. The Newcastle Breast Screening Service should consider offering appointments outside of work hours and allow people to book further than two weeks in advance.
2. The Newcastle Breast Screening Service should review its process for making reasonable adjustments for disabled patients, and consider consulting with disabled patients about the process and how improvements could be made.
3. Invite letters should provide clear information on accessing an interpreter for appointments.

## Recommendations for bowel screening

1. NHS England should consider the suitability of equipment when it changes the bowel screening to the new faecal immunochemical test (FIT); this should include spoon size, double bottling, double bagging, wipes, etc.

## 5. Acknowledgements

We would like to thank all the people and the community groups who gave their views to inform this work.

Our Research Champions, who are all volunteers, helped us design the project and accompanied Healthwatch Newcastle staff to some of the one to one interviews and focus groups: our thanks go to Cath Smart, Violet Rook, Steve Whitley and Linda Woodcock.

We are grateful to Thornfield Medical Group and Denton Turrett Medical Centre for helping us access screening non-attenders. Thanks also go to The Northern Cancer Alliance for advice and financial support.

# Appendices

## Appendix one

### Screening focus groups facilitators brief

Explain what Healthwatch Newcastle is.

Explain that

- We are looking into the uptake of breast, cervical and bowel screening in Newcastle
- Generally, at a city wide level, uptake of the screening programmes in Newcastle is good
- However, we know that there are small areas in Newcastle where uptake is low. The areas are Benwell and Scotswood, Elswick, Westgate, Ouseburn, Byker and Walker
- We are trying to find out why uptake is low in these areas. We have been going out to community groups in these areas to find out from them why they think people don't attend, what the barriers are and how those barriers could be overcome
- We have also worked with two GP practices in these areas and asked them to send letters out to people on our behalf to help us source the opportunity to talk to people on a one to one basis.
- We would like to talk to you about these screening programmes today. We will only talk about the ones you are eligible for
- Before we start, a bit of information:
  - Cervical screening is offered to women aged 25-49 every three years and then every five years until they are 64.
  - Breast screening is offered to every woman aged 50 to 70 every three years.
  - Bowel screening is offered to men and women aged 60 to 74 every two years. A kit is sent out which people have to complete and return by post. You are required to collect three stool samples.
  - You may have been invited for a bowel scope at 55. This is a different test that is not included in the scope of our work.

Any information you share with us today will be kept confidential and will not be shared with third parties in a way in which they could identify you. A report will be written summarising our findings. No one will be named within that report.

### Cervical screening questions:

#### To be completed with women over 25

1. If you have been to an appointment before, how did you find the experience?
2. Are you likely to attend future screening appointments?
3. If you have never been to an appointment before, why not?  
What we are really trying to get from you here is what stops you going to screening sessions
4. What would encourage you to attend screening sessions in the future?

## Breast screening questions

### To be completed with women over 50

1. If you have been to an appointment before, how did you find the experience?
2. Are you likely to attend future screening appointments?
3. If you have never been to an appointment before, why not?  
What we are really trying to get from you here is what stops you going to screening sessions
4. What would encourage you to attend screening sessions in the future?

## Bowel screening questions:

### To be completed with men and women over 60

1. If you have completed the bowel screening kit before, how did you find the experience?
2. Are you likely to complete it again?
3. If you have never completed the kit before, why not?
4. What would encourage you to complete the kit in the future?

## Close

1. Ensure a monitoring form is completed
2. Ask if they would like to complete a flu vaccination questionnaire

## Appendix two

### One to one invite letter

Dear patient

Your GP practice has kindly agreed to send this letter to you on our behalf, because we do not have your personal details to contact you directly.

Healthwatch Newcastle works to make sure that those who plan and run social care and health services listen to the people using their services and use this information to make services better.

We are currently looking in to why people might not take up the opportunity to have screening (breast, bowel and cervical). We will also explore how more people might take advantage of these important services.

We would like to meet with you on a one-to-one basis to talk about these screening programmes and gather your views and ideas. To make this as easy as possible for you we can:

- Come to your home or a venue that suits you
- Talk to you on the telephone
- Arrange and pay for an interpreter if needed
- Pay reasonable childcare expenses
- Pay reasonable travel expenses

If you would like to have a one-to-one discussion with one of our staff (or you have any questions) please call us on **0808 178 9282** (free from landlines) or **0191 338 5720** or email [rachel@healthwatchnewcastle.org.uk](mailto:rachel@healthwatchnewcastle.org.uk) before **13 December** to arrange a convenient time.

Alternatively, we have a short online survey. If you prefer to complete an online survey please visit the Healthwatch Newcastle website at [www.healthwatchnewcastle.org.uk/about-us/our-work/](http://www.healthwatchnewcastle.org.uk/about-us/our-work/) before **8 December**.

If you choose to take part in this piece of work, all information will be treated confidentially and will remain anonymous. What you say will not be passed on to your GP practice in a way that can be linked to you and it will not affect the care you receive today or in the future. The information you share will be used to write a report. You will not be identifiable in the report.

Yours sincerely

Rachel Wilkins  
Project Manager

## Appendix three

### Screening interviews

Thank person for getting in touch to take part in our research

Explain what Healthwatch Newcastle is

Explain that

- We are looking into the uptake of breast, cervical and bowel screening in Newcastle
- Generally, at a city wide level, uptake of the screening programmes in Newcastle is good
- However, we know that there are small areas in Newcastle where uptake is low. The areas are Benwell and Scotswood, Elswick, Westgate, Ouseburn, Byker and Walker
- We are trying to find out why uptake is low in these areas. We have been going out to community groups in these areas to find out from them why they think people don't attend, what the barriers are and how those barriers could be overcome
- We have also worked with two GP practices in these areas and asked them to send letters out to people on our behalf to help us source the opportunity to talk to people on a one to one basis.
- We would like to talk to you about these screening programmes today. We will only talk about the ones you are eligible for
- Before we start, a bit of information:

- Cervical screening is offered to women aged 25-49 every three years and then every five years until they are 64.
- Breast screening is offered to every woman aged 50 to 70 every three years.
- Bowel screening is offered to men and women aged 60 to 74 every two years. A kit is sent out which people have to complete and return by post. You are required to collect three stool samples.
- You may have been invited for a bowel scope at 55. This is a different test that is not included in the scope of our work.

Any information you share with us today will be kept confidential and will not be shared with third parties in a way in which they could identify you. A report will be written summarising our findings. No one will be named within that report.

### **Cervical screening questions:**

#### **To be completed with women over 25**

1. If you have been to an appointment before, how did you find the experience?
2. Are you likely to attend future screening appointments?
3. If you have never been to an appointment before, why not?  
What we are really trying to get from you here is what stops you going to screening sessions
4. What would encourage you to attend screening sessions in the future?

### **Breast screening questions**

#### **To be completed with women over 50**

1. If you have been to an appointment before, how did you find the experience?
2. Are you likely to attend future screening appointments?
3. If you have never been to an appointment before, why not?  
What we are really trying to get from you here is what stops you going to screening sessions
4. What would encourage you to attend screening sessions in the future?

### **Bowel screening questions:**

#### **To be completed with anyone over 60**

1. If you have completed the bowel screening kit before, how did you find the experience?
2. Are you likely to complete it again?
3. If you have never completed the kit before, why not?
4. What would encourage you to complete the kit in the future?



## Close

3. Ask person which GP Practice they are registered with
4. Ask person monitoring questions
5. Thank person for their time
6. Tell them that a report summarising the findings should be published in April 2018

## Appendix four

### A Healthwatch Newcastle survey on cervical screening

Healthwatch Newcastle is an independent organisation, here to listen to people's experiences of health and social care services. The feedback we gather is used to help improve services for everyone.

We are currently seeking people's views about cervical screening.

**If you are a woman aged between 25 and 64 and live in Benwell and Scotswood, Byker, Elswick, Ouseburn, Walker, or Westgate please complete this survey by 30 November 2017. At the end of the survey there is an option to enter a prize draw to win a £25 Intu shopping voucher.**

The information you provide will feed into our research project looking at how to increase the uptake of cancer screening in Newcastle.

If you take part in our survey all information will be treated confidentially and will remain anonymous. What you say will not be passed on to your care provider in a way that can be linked to you and it will not affect the care you receive today or in the future.

If you have any queries or would like to find out more please phone Healthwatch Newcastle on 0191 338 5720 or email [info@healthwatchnewcastle.org.uk](mailto:info@healthwatchnewcastle.org.uk)

Thank you for taking the time to complete this survey.

Please return the survey to FREEPOST HEALTHWATCH NEWCASTLE.

### Cervical screening survey

#### 1. Have you been for cervical screening before?

Yes

No  **please go to question 4**

#### 2. When did you last attend your cervical screening appointment? (please give the year)

**3. How did you find this experience?**

- Very good
- Good
- Bad
- Very bad

Please give a reason for your answer

**4. What stops you going to cervical screening appointments?**

- Concerns about pain
- Fear of being told I have cancer
- Having the test is embarrassing
- Concerns about cleanliness
- Worried that the test will be performed by a man
- Difficulty getting to appointments
- Appointment times do not suit me
- Negative experiences I have heard from other women
- I was not aware I should have the test
- Do not see the point
- Other... please say \_\_\_\_\_

**5. Are you likely to attend future cervical screening appointments?**

- Yes
- No

**6. What would encourage you to go to cervical screening appointments in the future?**

- Recommendation from GP/other health professional
- Recommendation from friends and family
- Letters from health services asking me to book an appointment
- Leaflets and posters about cervical screening
- Information about cervical screening on social media (Twitter, Facebook)
- TV campaigns

Other... please say \_\_\_\_\_

**7. Which GP practice are you registered with?**

**8. Would you like to share more?**

Healthwatch Newcastle can call you to hear more about the issues you face. If this is of interest to you please leave your details below

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

**9. Everyone who completes this survey can be entered into a prize draw to win a £25 Intu shopping voucher. If you would like to take part please provide your full name and email address or phone number**

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

**Thank you for completing the survey!**

## **A Healthwatch Newcastle survey on breast screening**

Healthwatch Newcastle is an independent organisation, here to listen to people's experiences of health and social care services. The feedback we gather is used to help improve services for everyone.

We are currently seeking people's views about breast screening.

**If you are a woman aged between 50 and 70 and live in Benwell and Scotswood, Byker, Elswick, Ouseburn, Walker, or Westgate please complete this survey by 30 November 2017. At the end of the survey there is an option to enter a prize draw to win a £25 Intu shopping voucher.**

The information you provide will feed into our research project looking at how to increase the uptake of cancer screening in Newcastle.

If you take part in our survey all information will be treated confidentially and will remain anonymous. What you say will not be passed on to your care provider in a way that can be linked to you and it will not affect the care you receive today or in the future.

If you have any queries or would like to find out more please phone Healthwatch Newcastle on 0191 338 5720 or email [info@healthwatchnewcastle.org.uk](mailto:info@healthwatchnewcastle.org.uk)

Thank you for taking the time to complete this survey.

Please return the survey to FREEPOST HEALTHWATCH NEWCASTLE

## Breast screening survey

### 1. Have you been for breast screening before?

Yes

No  **please go to question 4**

### 2. When did you last attend your breast screening appointment? (please give the year)

### 3. How did you find this experience?

Very good

Good

Bad

Very bad

Please give a reason for your answer

### 4. What stops you going to breast screening appointments?

Concerns about pain

Fear of being told I have cancer

Embarrassment of having to remove my top for the test

Worried that the test will be performed by a man

Difficulty getting to appointments

Appointment times do not suit me

Negative experiences I have heard from other women

I was not aware I should have the test

Do not see the point

Other... please say \_\_\_\_\_

**5. Are you likely to attend future breast screening appointments?**

Yes

No

**6. What would encourage you to go to breast screening appointments in the future?**

Recommendation from GP/other health professional

Recommendation from friends and family

Letters from health services informing me of my next breast screening appointment

Leaflets and posters about breast screening

Information about breast screening on social media (Twitter, Facebook)

TV campaigns

Other... please say \_\_\_\_\_

**7. Which GP practice are you registered with?**

**8. Would you like to share more?**

Healthwatch Newcastle can call you to hear more about the issues you face. If this is of interest to you please leave your details below

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

**9. Everyone who completes this survey can be entered into a prize draw to win a £25 Intu shopping voucher. If you would like to take part please provide your full name and email address or phone number**

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

**Thank you for completing the survey!**

## A Healthwatch Newcastle survey on bowel screening

Healthwatch Newcastle is an independent organisation, here to listen to people's experiences of health and social care services. The feedback we gather is used to help improve services for everyone.

We are currently seeking people's views about bowel screening.

If you are aged between 60 and 74 and live in Benwell and Scotswood, Byker, Elswick, Ouseburn, Walker, or Westgate please complete this survey by 30 November 2017. At the end of the survey there is an option to enter a prize draw to win a £25 Intu shopping voucher.

The information you provide will feed into our research project looking at how to increase the uptake of cancer screening in Newcastle.

If you take part in our survey all information will be treated confidentially and will remain anonymous. What you say will not be passed on to your care provider in a way that can be linked to you and it will not affect the care you receive today or in the future.

If you have any queries or would like to find out more please phone Healthwatch Newcastle on 0191 338 5720 or email [info@healthwatchnewcastle.org.uk](mailto:info@healthwatchnewcastle.org.uk)

Thank you for taking the time to complete this survey.

Please return the survey to FREEPOST HEALTHWATCH NEWCASTLE.

### Bowel screening survey

Men and women aged between 60 and 74 are invited to participate in bowel screening every two years.

#### 1. Have you received a bowel screening kit?

Yes

No  please go to question 5

#### 2. Did you return the bowel screening kit?

Yes

No  please go to question 6

#### 3. How easy was it to use the bowel screening kit?

Very easy

Easy

Hard

Very hard

Please give a reason for your answer

**Are you likely to return the bowel screening kit again?**

Yes  please go to question 7

No  please go to question 6

Don't know  please go to question 6

**4. If you had received a kit, would you have returned it?**

Yes  please go to question 7

No

Don't know  please go to question 7

**5. What stopped/stops you from returning the bowel screening kit?**

Preparing a sample at home is unpleasant

Fear of being told I have cancer

Negative experiences I have heard from other people who completed the bowel screening kit

I was not aware I should have the test

Do not see the point

Other... please say \_\_\_\_\_

**6. What would encourage you to return the bowel screening kit in the future?**

A bowel screening kit that is easier to use and understand

Opinion of GP/other health professional

Opinion of friends and family

Leaflets and posters about bowel screening

Information about bowel screening on social media (Twitter, Facebook)

TV campaigns

Other... please say \_\_\_\_\_

8. Which GP practice are you registered with?

9. Would you like to share more?

Healthwatch Newcastle can call you to hear more about the issues you face. If this is of interest to you please leave your details below

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

10. Everyone who completes this survey can be entered into a prize draw to win a £25 Intu shopping voucher. If you would like to take part please provide your full name and email address or phone number

Name \_\_\_\_\_

Phone number \_\_\_\_\_

Email \_\_\_\_\_

**Thank you for completing the survey!**



## Appendix five

### Demographic data

Gender		Sexuality	
Male	45	Heterosexual	76
Female	84	Bisexual	6
Transgender		Gay man	8
Unknown	70	Gay woman	2
Age		Other	3
17 and under		Prefer not to say	104
18-24	2		
25-49	39	Ethnic groups	
50-64	43	British	72
65-79	26	Irish	
80+	6	Gypsy or Irish Traveller	
Unknown	83	Other white background	5
Disability		Indian	
Yes	29	Pakistani	1
No	84	Bangladeshi	
Unknown	86	Chinese	29
Carer		Other Asian background	1
Yes	15	White & Black Caribbean	
No	100	White & Black African	
Unknown	84	White & Asian	
Employment		Other mixed background	1
Student	7	Caribbean	
Employed/self-employed	29	African	5
Not in paid employment	30	Other Black background	
Retired	49	Arab	1
Unknown	84	Other ethnic background	
Marital status		Unknown	84
Single	32		
Divorced	13		
Married	43		
Civil partnership	2		
Living with partner	3		
Widow	7		
Unknown	99		

## Contact details



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please call Freephone 0808 178 9282**