

What do Reading people know about TB?



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Contact Healthwatch Reading at:
3rd floor, Reading Central Library
Abbey Square, Reading
RG1 3BQ
Telephone 0118 937 2295
Email info@healthwatchreading.co.uk

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What do Reading people know about TB?

A community survey led by Healthwatch Reading

Survey aim: Reading Borough Council Public Health Team asked Healthwatch Reading to undertake a survey to provide a baseline of public awareness against which to evaluate the success of current and future TB campaigns.

About the survey respondents:

Total: 326 people, 48% of whom were aged 16-34, the main target group

Ethnicity: Most (55%) described as White British, then 8% Pakistani, 6% Indian, 6% other White, 5% Black African, 3% Mixed, and 10% other (mostly Nepalese)

Birth country: Most (62%) were born in the UK, then 8% from Nepal, 5% Pakistan, 4% India and the rest from a variety of countries.

Time in the UK: 31 people had been living here for five years or less, 74 had been here for between 6 and 60-plus years; the majority had always lived here

Residence: Most respondents (56%) said they lived in the Reading RG1 and RG2 postcodes. A small number lived outside of Reading borough, including Slough, Bracknell and Maidenhead.

Survey duration: The project ran from 1 August 2017 and 31 October 2017.

Survey method: Healthwatch Reading visited 12 community groups or events to ask and/or assist people in completing the anonymous survey. The survey questions and format were decided by Public Health.

Community impact: Reading Borough Council's Public Health team and South Reading Clinical Commissioning Group have welcomed the report, saying it will help influence a forthcoming TB action plan. They have also acknowledged the need to work with communities on reducing the stigma of TB.

Main survey findings:

- 91% had heard of TB before this survey
- 80% or more people knew that persistent coughing, or coughing up blood are symptoms of TB; the least known symptom was swollen feet
- 60% correctly identified some TB risk factors e.g. living in overcrowded homes
- 51% believed (wrongly) that a person with 'sleeping TB' can pass it on
- 32% believed (wrongly) that the BCG vaccine protects you from TB for life
- 25% do not know that you can carry TB germs even if an X-ray shows you have a clear chest
- 30% believed (wrongly) that having a TB test/treatment can affect your UK immigration status if you come from another country
- 36% would be embarrassed to tell family or friends if they had TB
- 41% do not feel that TB is relevant to them or their family
- Most people learned about TB from friends/family (36%), TV or school
- 83% believe NHS staff would treat TB-infected people with respect
- 65% of people do not feel that Reading residents know enough about TB

Introduction

About Healthwatch Reading

Healthwatch Reading was launched in April 2013 as part of a new national network of organisations in every local authority area, to give the public a greater say and influence over NHS and social care services.

Healthwatch Reading has a strong track record of reaching out and listening to diverse communities including people with mental health needs, the Nepalese and Polish communities, and the wide variety of people who visit local GP surgeries and A&E. Healthwatch Reading also speaks up for people via its place on the Reading Health and Wellbeing Board (HWBB), which oversees progress on local priorities to improve health and wellbeing of the Reading population.

Background: TB in Reading¹

Latest data shows there were 25 notified cases of TB in Reading people, in 2015, a higher than average rate compared with England and the South East of England. These cases mostly affected people who were aged on average, 41 years, and living in the Reading Borough Council wards of Park, Abbey and Whitley, according to a paper presented to the Reading HWBB in July 2017.

These high rates spurred the HWBB to set a priority to reduce TB incidence, in the Reading Health and Wellbeing Strategy 2017-2020. Other actions have included:

- The launch of a local plan in 2015, to increase primary care referrals to the hospital-based new entrant screening service to offer free testing for latent TB countries into the UK in the previous

five years. Since early 2016 it has tested 85% out of 271 invited for screening and found 20% carried TB (and could be offered treatment);

- An awareness event was held in January 2016 for Reading healthcare workers, to encourage them to refer eligible people to the new service;
- A public awareness event was held on 24 March 2017 (World TB Day), Broad St Mall, Reading, covering symptoms, risk factors, testing and treatment.

Aims of the survey

Reading Borough Council Public Health Team, with funding from South Reading CCG, commissioned Healthwatch Reading to undertake a knowledge, attitude and belief survey about TB. Healthwatch Reading was selected for its expertise in public engagement.

The project aims were to:

- provide a baseline against which to evaluate the success of current and future TB campaigns;
- provide insight into the knowledge, attitudes and behaviours of local populations around TB, with a focus on surveying population groups living in the areas of South Reading where TB is more common; and
- signpost people to further information, resources or local screening services.

¹ Report to 14 July 2017 meeting of Reading Health and Wellbeing Board <http://www.reading.gov.uk/media/7436/Item12/pdf/Item12.pdf>

Introduction

How the survey was carried out

Healthwatch Reading staff aimed to survey at least 150 people, particularly 18-34 year-olds who might have been born in, or had lived during the previous five years, in one of 58 countries outside of the UK where TB rates are high. (See Appendix 1 for full demographics)

We approached 12 different community events, community groups or service providers which we believed offered an opportunity to reach a diverse group of people. All 12 agreed to let us visit to promote and carry out our survey.

The survey locations included:

- a ‘fresher’s fair’ at Reading College
- a ‘fresher’s fair’ at the University of Reading

- the Indian Community Centre
- the Pakistani Community Centre
- a South Reading GP surgery waiting room
- a local homeless hostel
- a mental health event at a South Reading community centre
- a Baptist church community group
- the Reading Older People’s Working Group.

(See Appendix 2 for a full list of survey events and dates)

During the project duration we also promoted the survey on the Healthwatch Reading website, through an electronic and postal monthly newsletter, at local Patient Voice meetings and through Facebook and Twitter channels.



Local Freshers Fairs were a great venue to capture responses from a high number of young people.

Introduction

Our promotional material included artwork - particularly flags of countries where TB rates are high, and text translated into other languages - which are provided freely to local areas by the national charity TB Alert.

We exceeded our target for respondents, by surveying 326 people in total, due to high responses from students at the fresher fairs.

The ethnicity of respondents was in line with Reading's official population figures set out in the Joint Strategic Needs Assessment (JSNA), including:

- White British (55% of survey respondents) - compared with 66.9% JSNA figure;
- Pakistani (8%) - compared with 4.5% JSNA;
- Indian (6%) - compared with 4.2% JSNA. (See Appendix 1 for full ethnicity breakdown).

Apart from seven surveys completed online, the majority of people filled in a paper copy. Healthwatch Reading knew from previous projects that survey responses can be higher if people are personally approached by a person who can:

- explain the reason why their views are important and the potential impact for local people



Colourful promotional material - and a freebie! - were used to engage potential survey respondents.



Our project work also involves liaising with other experts in community engagement - such as Cecily Mwaniki, from Berkshire Healthcare NHS Foundation Trust.

Introduction



Visiting community groups in person was an important way of promoting inclusion, explaining survey questions, and showing people their views were valued.

- assure people that their views are anonymous
- assist in explaining or simplifying questions that people might not understand because they do not understand English or have lower than average literacy levels
- provide information about accessing local services related to the survey topic.

The survey was designed by Public Health, based on a validated World Health Organisation survey. This type of survey is 'quantitative', which aims to generate data from answers to set questions, from enough people to be representative of the group you are interested in. This is different from 'qualitative' research, where people are given an opportunity to share their experiences and views in more depth, such as through a semi-structured interview or conversation.



We brought our portable info & advice stand to a variety of community events to promote the survey.



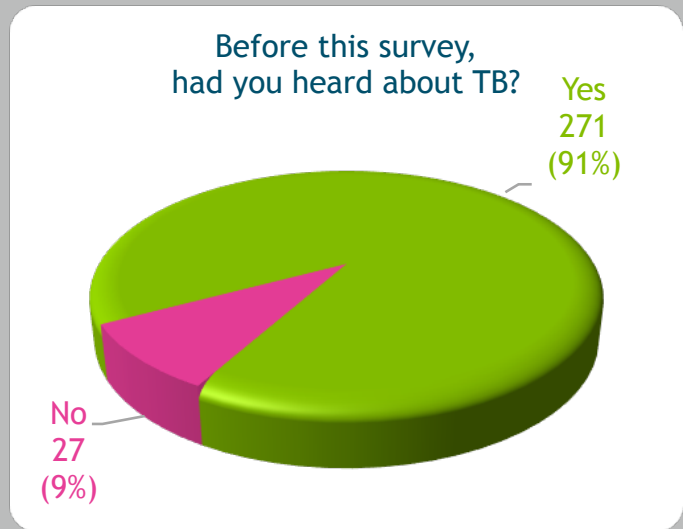
We also worked in partnership with NHS staff during the project to gather intelligence on TB, treatment, and target groups, including TB nurses Kay Perry, TB Nurse from the Royal Berkshire Hospital and Chrissy Long, Latent TB Manager from the NHS South Reading CCG.

Survey Findings

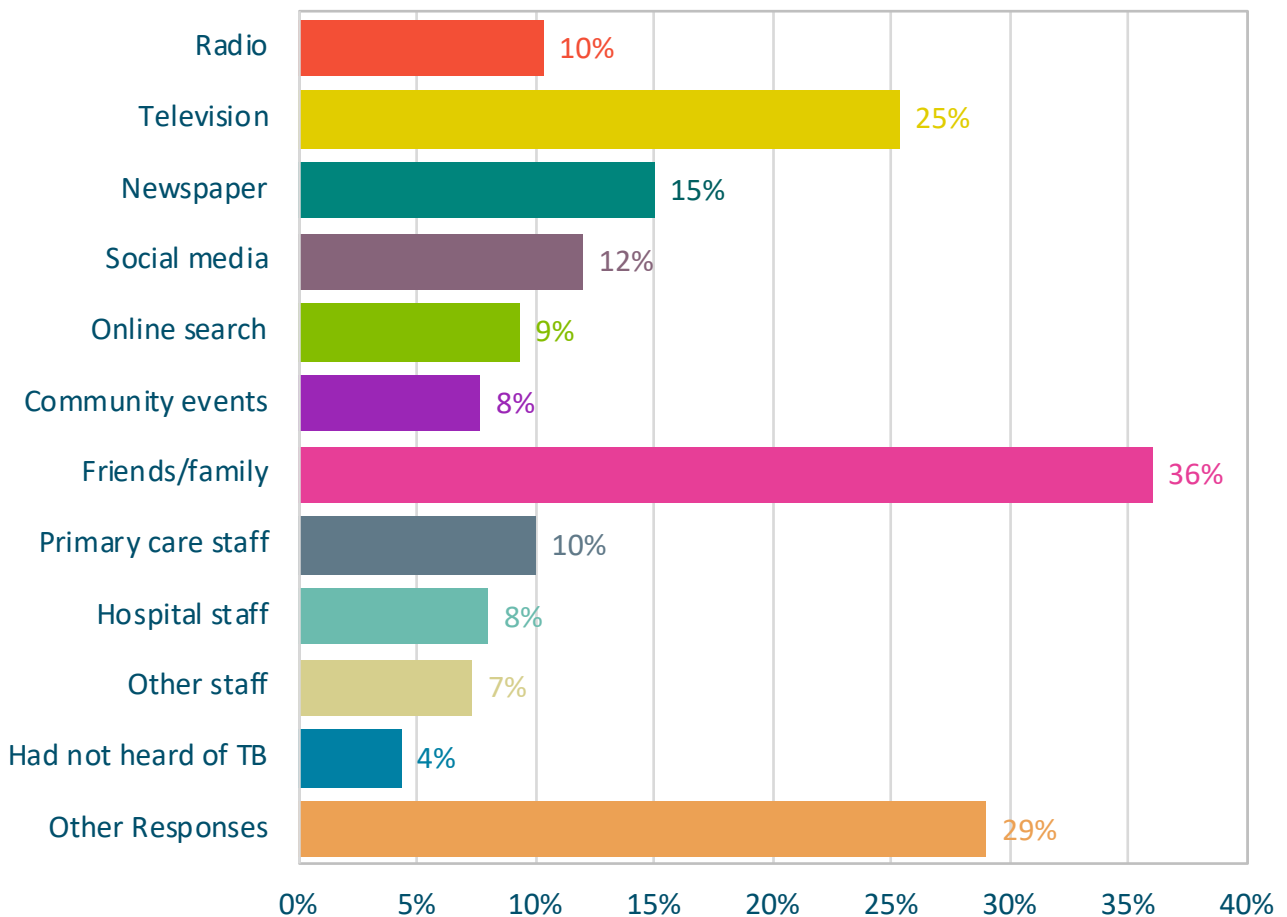
General knowledge and awareness about TB

91% of people had heard about TB.

Most people learned about TB from family and friends. 'School' was the most common source of knowledge in the 'other' category.



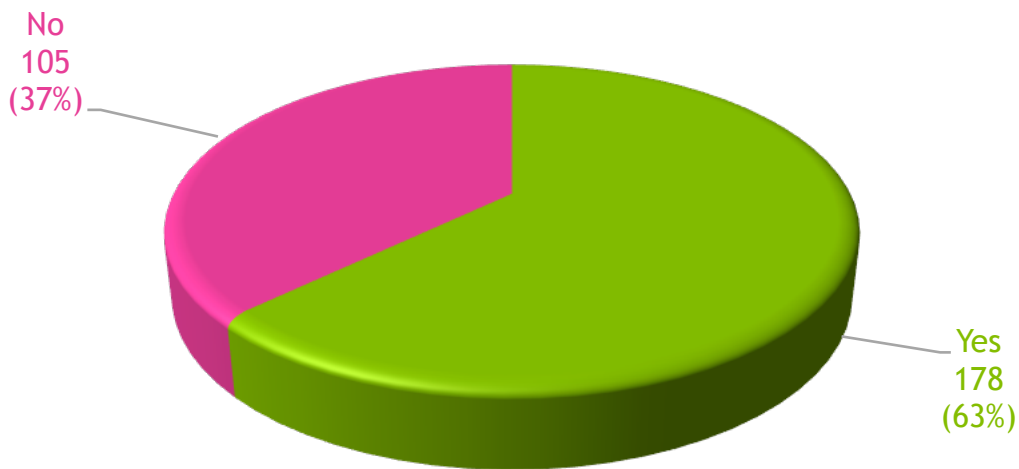
Where did you learn about TB?



Survey Findings

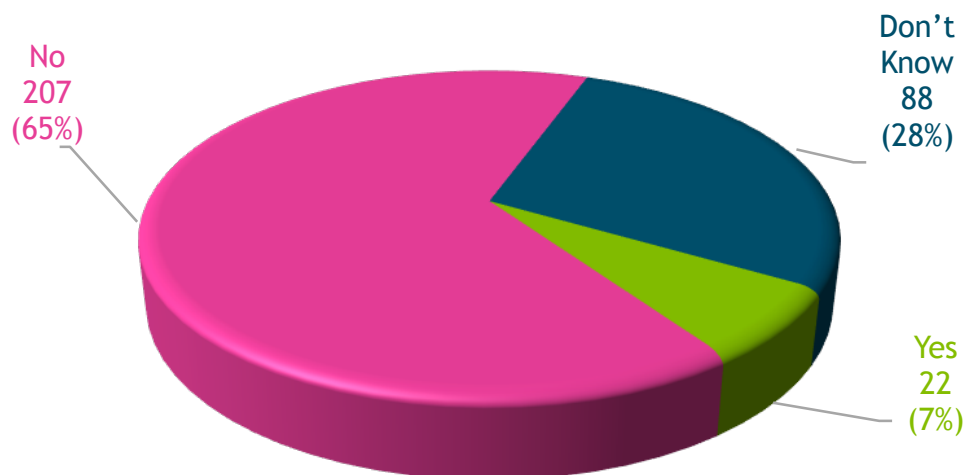
Nearly two-thirds of people (63%) had received a BCG vaccination to help protect against TB

Have you ever received a BCG vaccination to protect yourself against TB?



Almost two-thirds of people (63%) felt people in Reading did not know enough about TB

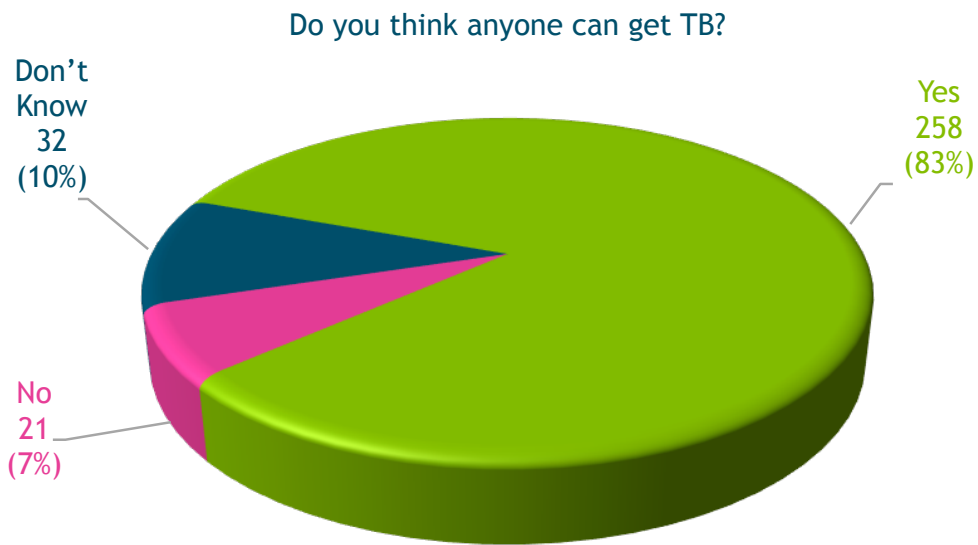
Do you feel people in Reading know enough about TB?



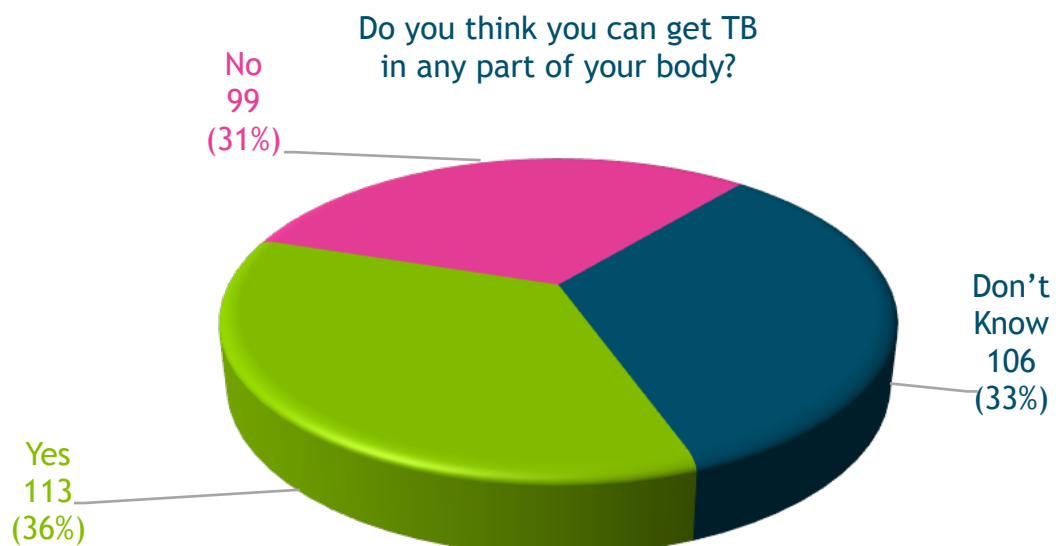
Survey Findings

Knowledge about risk-factors, symptoms, prevention and treatment

Most people (83%) knew that anyone can get TB

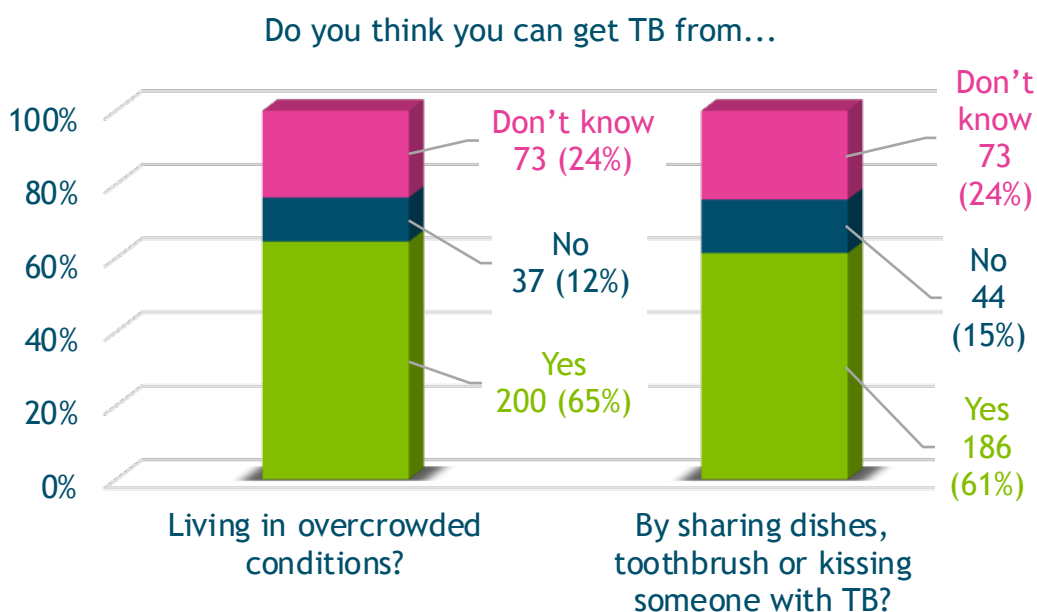


Only 35% knew that TB can affect any part of your body

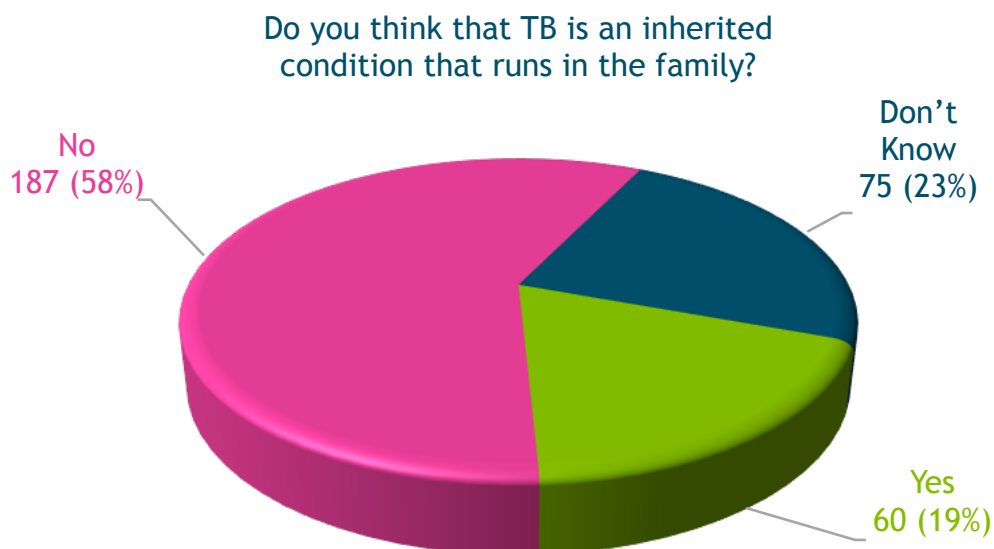


Survey Findings

More than 60% knew rightly that living in crowded conditions is a risk factor for contracting TB. However 60% wrongly thought you could get TB by sharing toothbrushes with infected people, and nearly one-quarter were unsure.



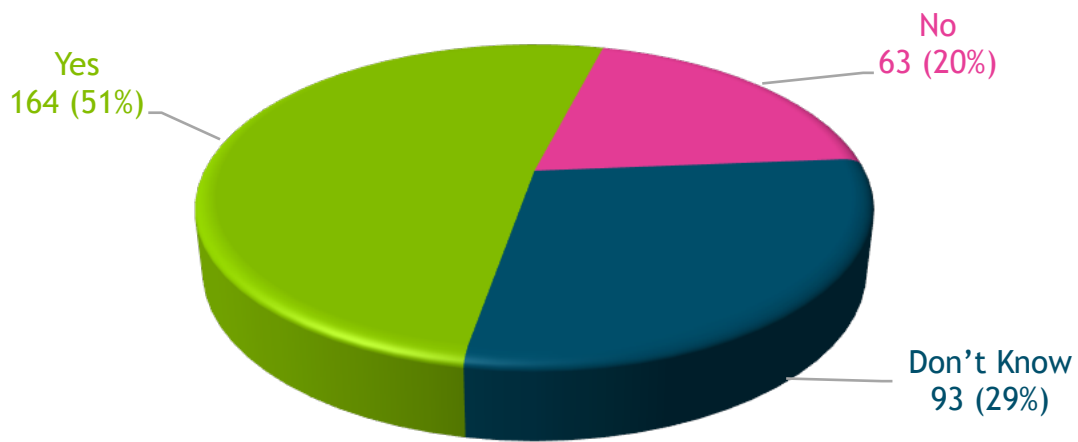
Nearly 60% knew that TB is not genetic, while 23% were unsure.



Survey Findings

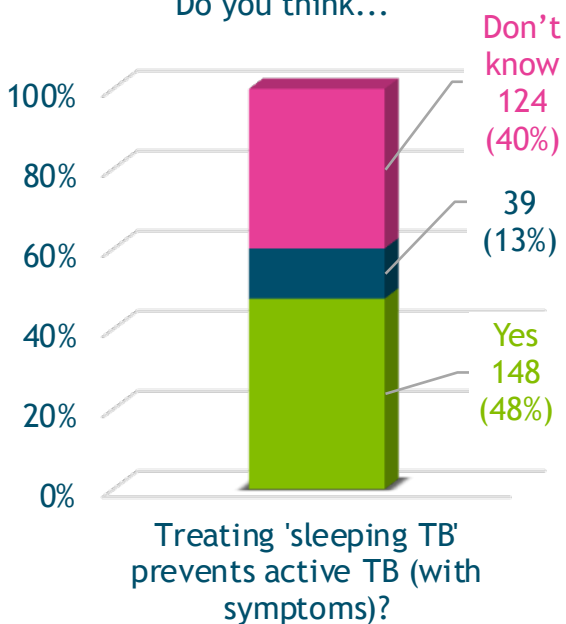
More than half (51%) mistakenly believed that people with latent (sleeping) TB could spread TB to others; 29% were unsure.

Do you think that if a person has dormant (sleeping/no symptoms) of TB they can spread it to others?



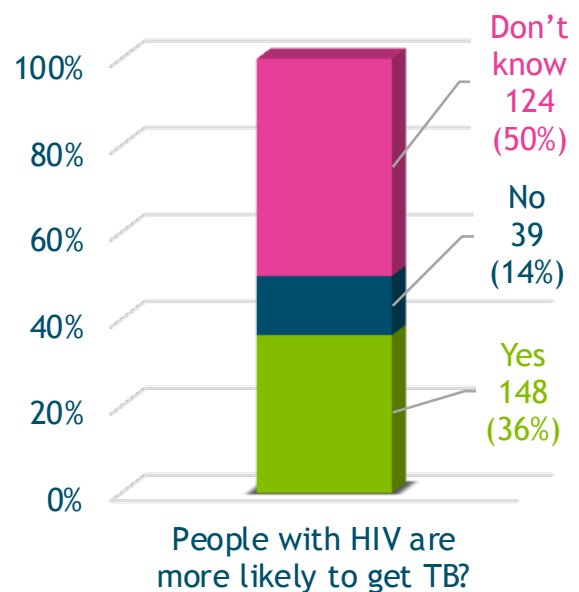
Less than half (48%) knew that treating latent TB can prevent active TB.

Do you think...



Only 36% knew that having HIV put you more at risk of TB.

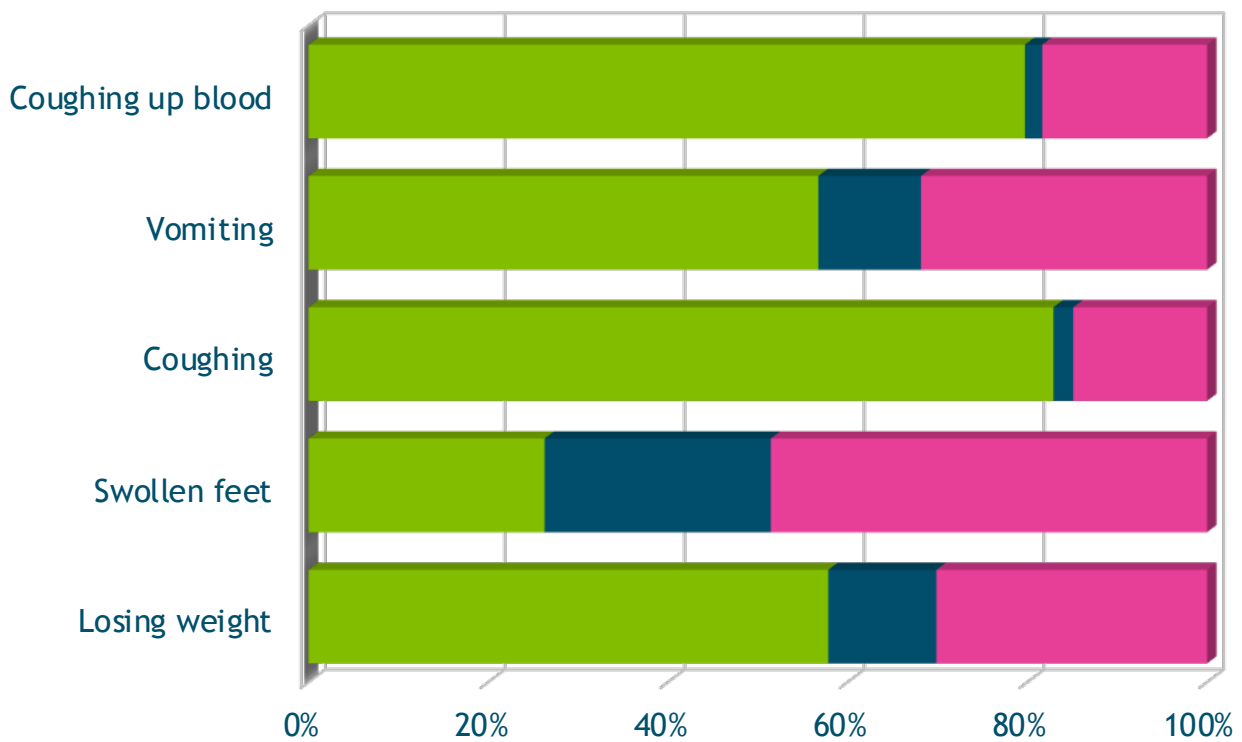
Do you think...



Survey Findings

The most well-known symptoms of TB were coughing (83%), or coughing up blood (80%); the least known was swollen feet (26%)

How many of the following do you think are symptoms of TB?
Please tick as many as you think.

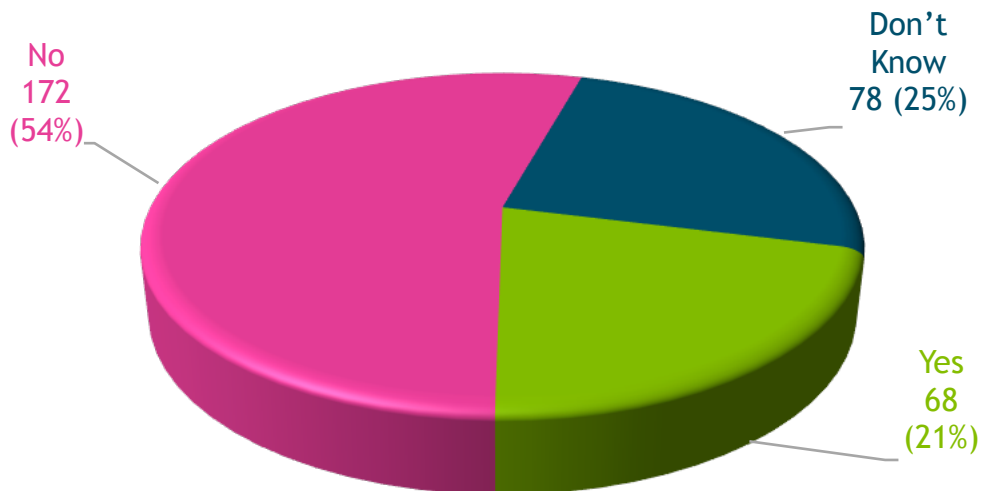


	Losing weight	Swollen feet	Coughing	Vomiting	Coughing up blood
■ Yes	173	72	262	164	248
■ No	36	69	7	33	6
■ Don't know	90	133	47	92	57

Survey Findings

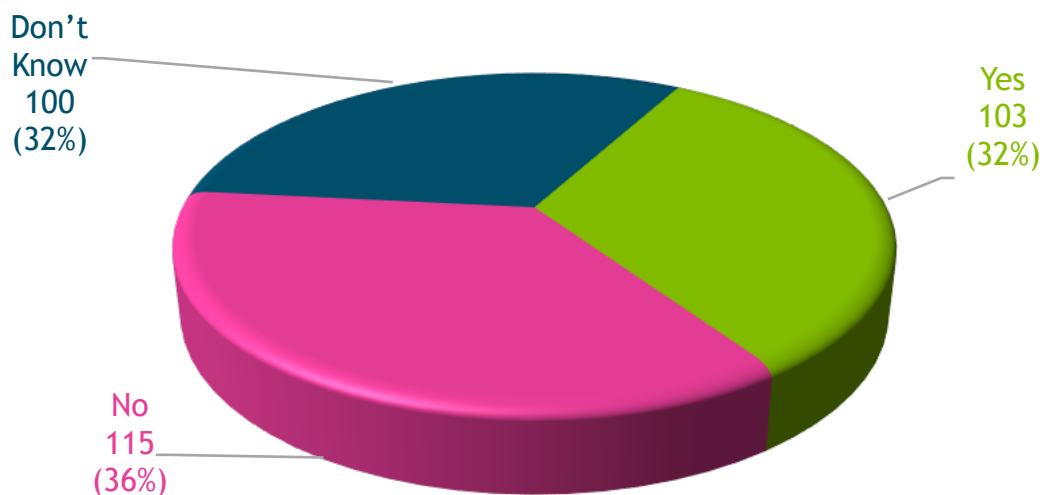
Only 54% knew that a clear chest X-ray does not mean you don't have TB germs in your body; 25% were unsure

Do you think a clear chest x-ray means that you do not have TB germs in your body?



Only 36% knew that a BCG vaccine's protection may not last for life

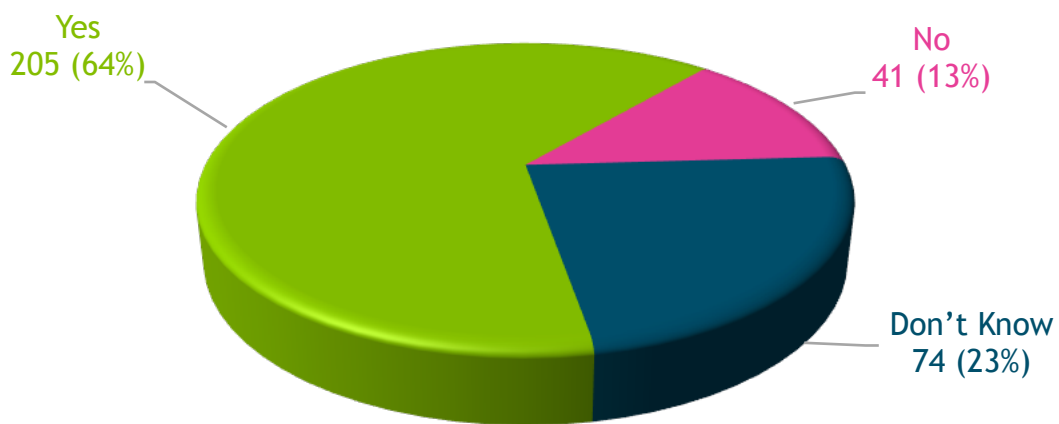
Do you think the BCG vaccine will protect you from getting TB for your whole life?



Survey Findings

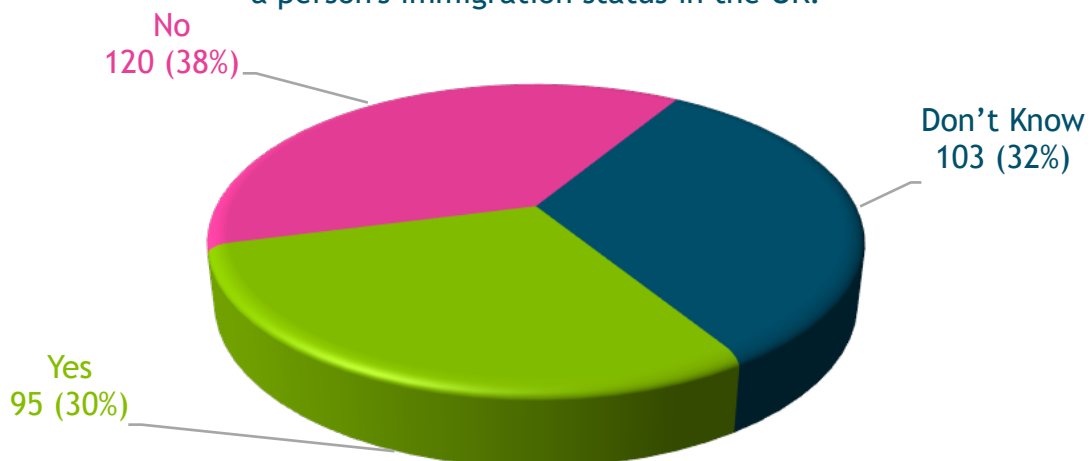
Nearly two-thirds of people knew that people should seek treatment for TB if they have had a cough for more than three weeks

Do you think that people should seek treatment for TB if they have a cough for more than three weeks?



Only 37% knew that being tested or treated for TB does not affect a person's immigration status in the UK, 32% were unsure

Do you think that having a TB test or being treated for TB affects a person's immigration status in the UK?



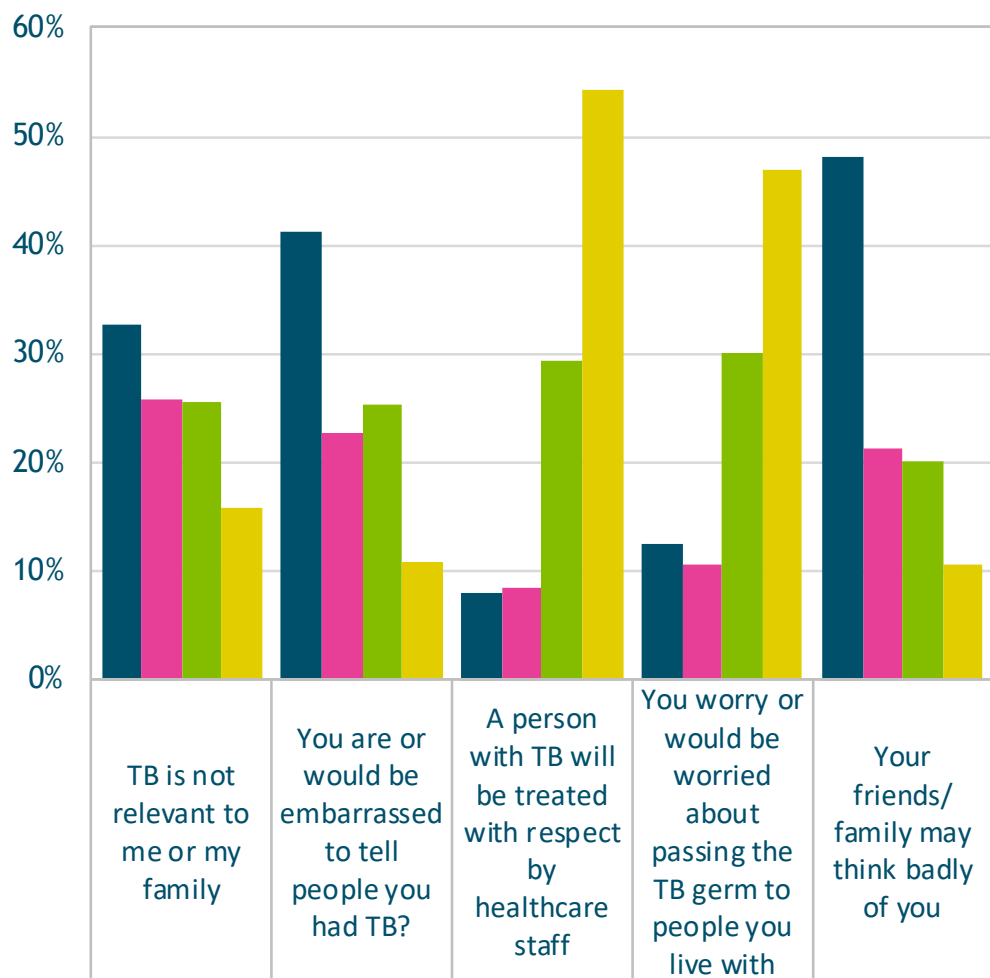
Survey Findings

Personal attitudes about TB

- 77% would be worried about passing on TB germs if they had TB;
- 36% would be embarrassed to tell people if they had TB; and
- 30% felt friends or family would think badly of them if they had TB
- 41% believed TB was not relevant to them or their family

Respondents revealed the stigma surrounding TB but also showed confidence in NHS staff to treat them well.

Your feelings about TB. Please tick one box in the scale



■ You strongly disagree	33%	41%	8%	13%	48%
■ You disagree somewhat	26%	23%	8%	11%	21%
■ You agree somewhat	26%	25%	29%	30%	20%
■ You strongly agree	16%	11%	54%	47%	11%

Discussion

The survey findings suggest that most people in Reading have, at the very least, heard about TB. This could be because nearly two-thirds of respondents had previously received a BCG vaccine, which is given to offer protection from TB.

People were most knowledgeable about the facts that anyone can get TB, that symptoms can include coughing or coughing up blood.

However, people were less knowledgeable about other facts, such as symptoms also including weight loss, vomiting, or swollen feet; that having HIV can put you at greater risk of TB; or that the BCG vaccine is not a lifelong guarantee against TB.

The most worrying lack of knowledge surrounded latent, or 'sleeping' TB, with less than half of people not realising that treating latent TB can prevent people developing active TB with symptoms. More than half of people wrongly thought that people with latent TB can pass on TB germs to others, which may affect whether people agree to be tested for latent TB, due to fear or stigma. Three in 10 people felt family or friends would think badly of them if they had TB, and a greater number - 36% - would be embarrassed to tell people if they had TB. If people who have TB are afraid to be open with those closest to them, then this may affect their ability to take preventative measures to spread the infection.

The survey also revealed confusion about whether TB affects a person's immigration status, and this could be another barrier to people recently arrived in the UK from seeking testing or treatment. However, people expressed strong confidence in the NHS, with 83% believing healthcare staff would treat them with respect if they did have TB.

The survey suggests that people gain

knowledge and awareness of TB mostly through family and friends, television, or education at school or university. Only 8% said they learned about TB from community events, and 18% from health professionals. In answering this question, people might have been recalling the first time ever they were made aware of TB, as the question did not specifically ask people if they recalled any locally run public awareness events in Reading.

Overall, there appears to be an appetite for further public awareness initiatives about TB, with nearly two-thirds believing that people in Reading do not know enough about TB.

The findings show that families and schools are the most common sources of current knowledge about TB, which may suggest that future awareness campaigns should involve individuals who are willing to spread correct information to their own families, and educational institutions that can build TB information into lessons, or host targeted sessions from experts.

To reach the most at-risk groups, materials or information should include translated, simple to understand text and/or photos or images. Verbal information sessions should also be supported by professional translators, as we found that some people could not take part in the survey due to language barriers.

The survey findings should inform the work of a dedicated Latent TB Programme Manager for South Reading, who has been in place since September 2017. Their role will be to work closely with TB nurses, Reading Public Health Team and community groups to reach out to less well-served communities to improve uptake of testing and encourage early presentation and timely onward referral with TB symptoms.

Discussion

Healthwatch Reading highlights a selection of other initiatives from across England that Reading services might consider trialling:

Find & Treat outreach service, University College London Hospitals NHS Foundation Trust

Find & Treat is a specialist outreach team working with more than 200 NHS and third sector, frontline services to tackle TB among homeless people, drug or alcohol users, vulnerable migrants, and people who have been in prison. The team includes former TB patients who work as peer advocates, TB nurse specialists, social and outreach workers, radiographers and expert technicians.

The service brings a mobile X-ray unit into all London boroughs to screen people for active TB. The outreach team also finds people who have stopped treatment before completing the full course, supports them to resume treatment, and provides practical assistance such as residential TB treatment for homeless people.

<https://www.uclh.nhs.uk/OurServices/ServiceA-Z/HTD/Pages/MXU.aspx>

Newham, east London, Latent TB screening and treatment closer to home

New patients joining GP surgeries at risk of latent TB, are offered free screening. If they test positive, they can choose to have treatment designed to prevent them from getting active TB, from one of 26 Newham pharmacies, closest to where they live. This convenience may increase the likelihood that people complete the full course of treatment. NHS officials are also working with the local housing department to ensure

they take action against private landlords who allow overcrowded homes (where TB could be more likely to spread).

<https://www.gov.uk/government/case-studies/pioneering-a-latent-tuberculosis-tb-programme-in-newham>

Doncaster health bus reaching out to asylum seekers and refugees

Rotherham, Doncaster and South Humber NHS community trust launched a scheme in 2015 to send its brightly coloured health bus to visit the Doncaster Conversation Club every two months. The club is a regular group for asylum seekers and refugees who practise English and the visits allowed people to get on-the-spot testing for latent TB, and then treatment if they tested positive. Those who had been treated could then provide peer support and the regular bus visits allowed follow up care during treatment.

<https://www.gov.uk/government/case-studies/identifying-and-treating-tuberculosis-tb-in-under-served-groups>

Response

Response from South Reading Clinical Commissioning Group (CCG) and Reading Borough Council

South Reading CCG and Reading Borough Council thanks Healthwatch Reading for this comprehensive analysis of the knowledge, attitudes and behaviours of the local population relating to TB. As a locality we have higher rates of TB than neighbouring CCGs and the England average, so this is an important issue for the people of Reading and 'Reducing the Number of People with Tuberculosis' has been adopted as a priority of the Reading Health and Wellbeing Board. This survey enables us as a system to gain a better understanding of how local people think about TB during the first phase of a communication and engagement campaign focussing on sleeping (latent) TB. Together we have worked hard to widely promote the signs and symptoms to TB and latent TB at events and public engagement opportunities. We have created a set of locally tailored public information to raise the profile of TB and latent TB with the eligible community. We have worked with local GP practices to flow referrals through to secondary care for latent TB testing and this process is embedded and is starting to work well.

We acknowledge, however, that while referrals are starting to be made effectively, a substantial proportion of people invited choose not to attend their screening appointment. The results of the survey show that there is still work to tailor this campaign so that people are better informed about the reason they are being asked to attend the appointment. The survey also tells us that stigma around TB is still an issue for some communities and as a system we recognise that further work with affected communities is needed.

The results of this survey were discussed at a Berkshire wide TB workshop on 5 December 2017 with the aim of reflecting on our progress so far and setting our priorities and activities for 2018/19. The outputs from the workshop will form an action plan which will be managed and implemented by the Latent TB project manager who is part of the Berkshire TB Operational Group who will monitor the overall action plan. The latent TB programme is part of the wider Berkshire TB strategy and is overseen by the Berkshire TB Strategy Group.

Conclusion

This project exceeded its aim of surveying at least 150 people, with a total response of 326 people.

The findings show which facts about TB the public are most aware of, and where there are gaps or mistakes in knowledge. The survey also highlights personal fears or beliefs about TB that might affect uptake of screening or treatment.

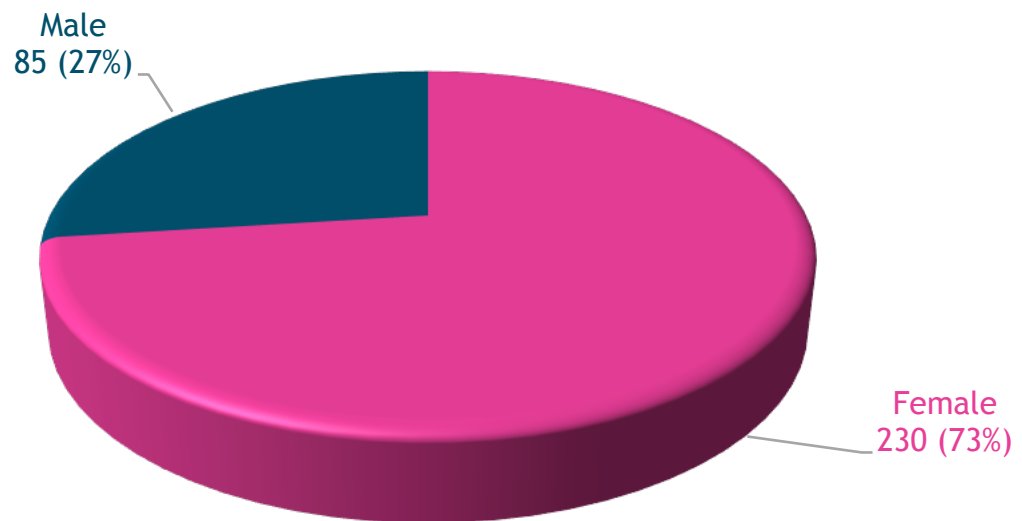
We are pleased that the findings will influence a forthcoming TB action plan and that the CCG and RBC have acknowledged the need to further work with affected communities on addressing the stigma surrounding TB.

We thank all the people in Reading who shared their views in survey responses, and the community groups and organisations that facilitated our efforts in reaching a wide range of people.

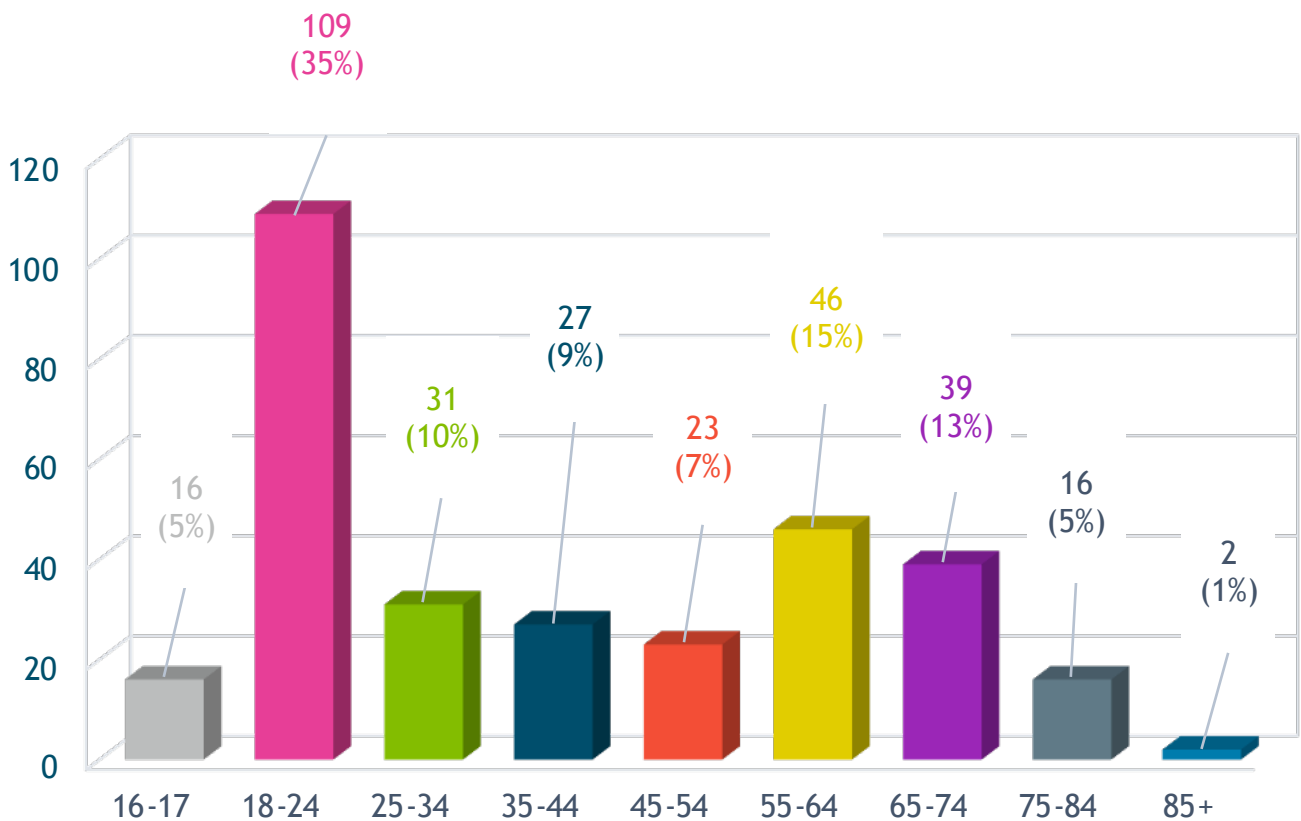
Appendix 1:

About the people who answered the survey

What is your gender?

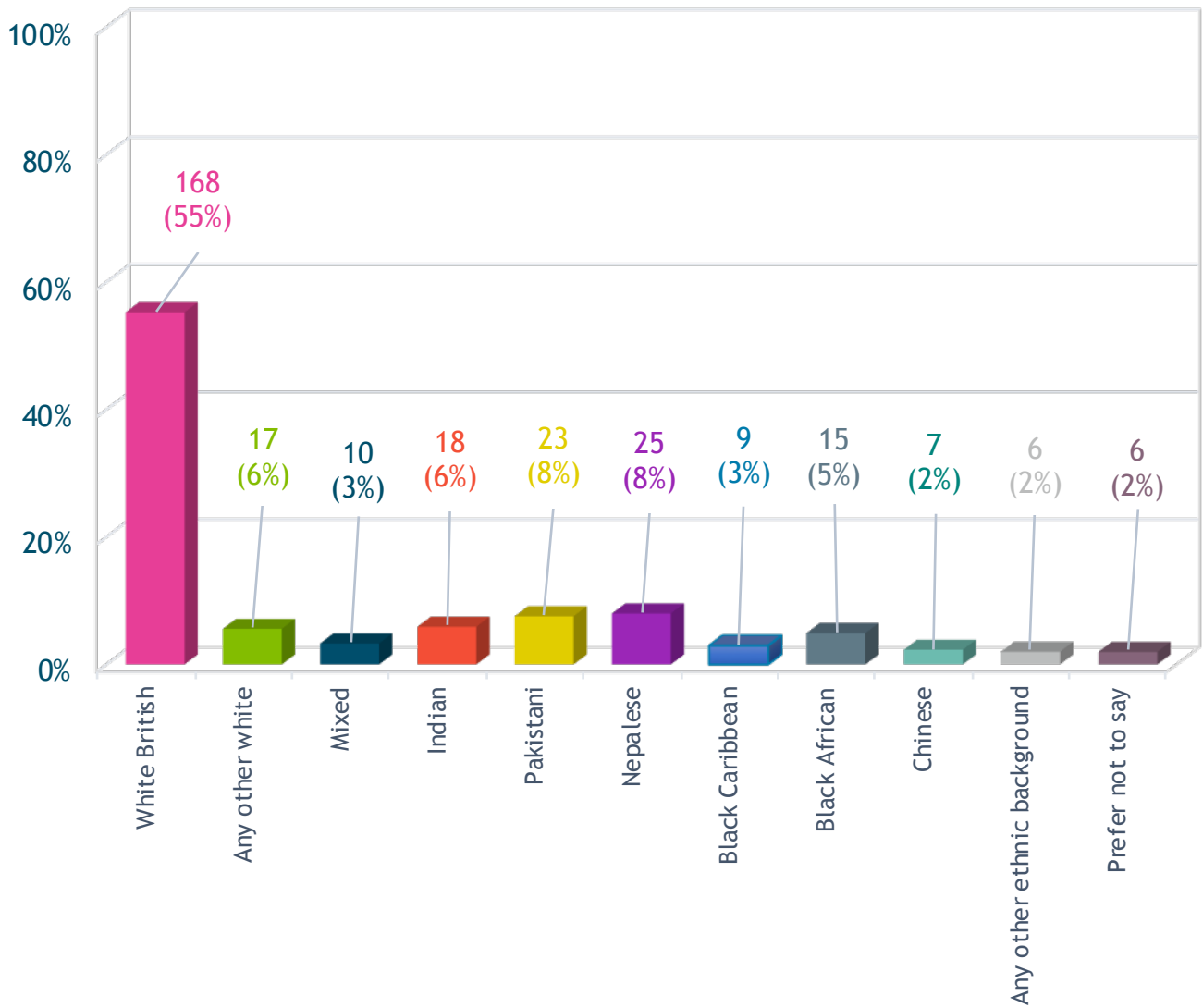


How old are you?



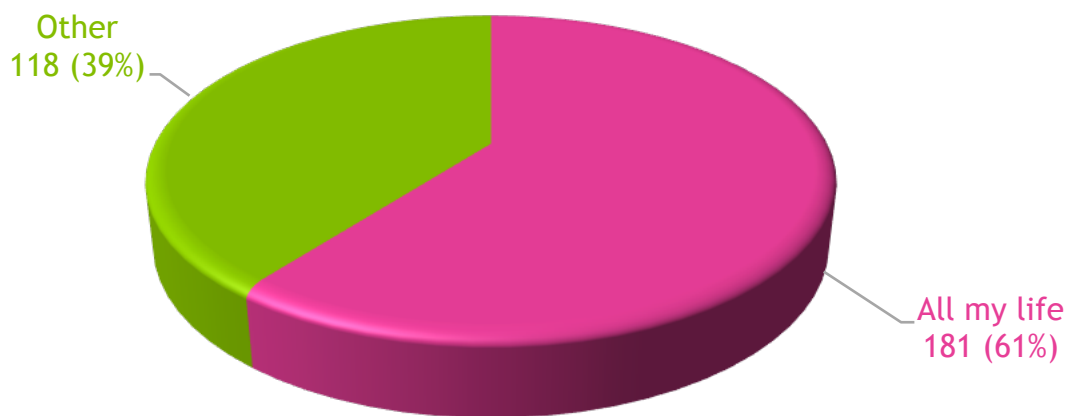
Appendix 1

What is your ethnicity?



Appendix 1

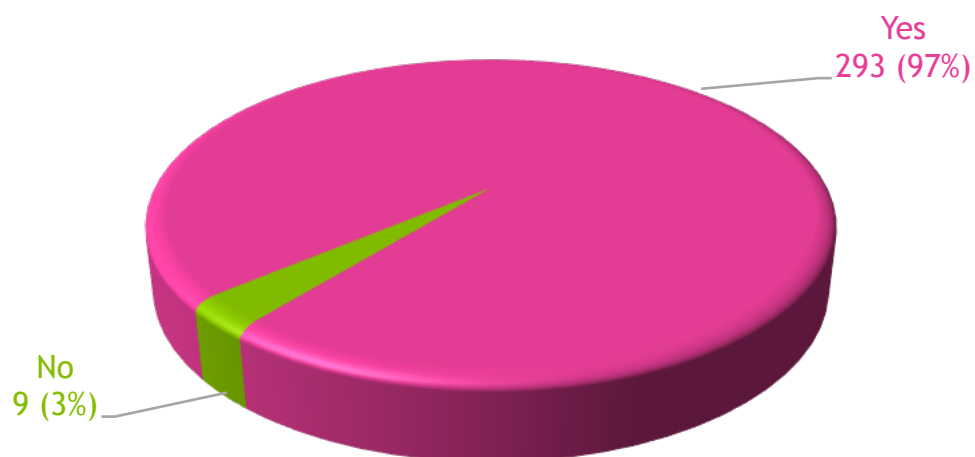
How many years have you been in the UK?



Other answers:

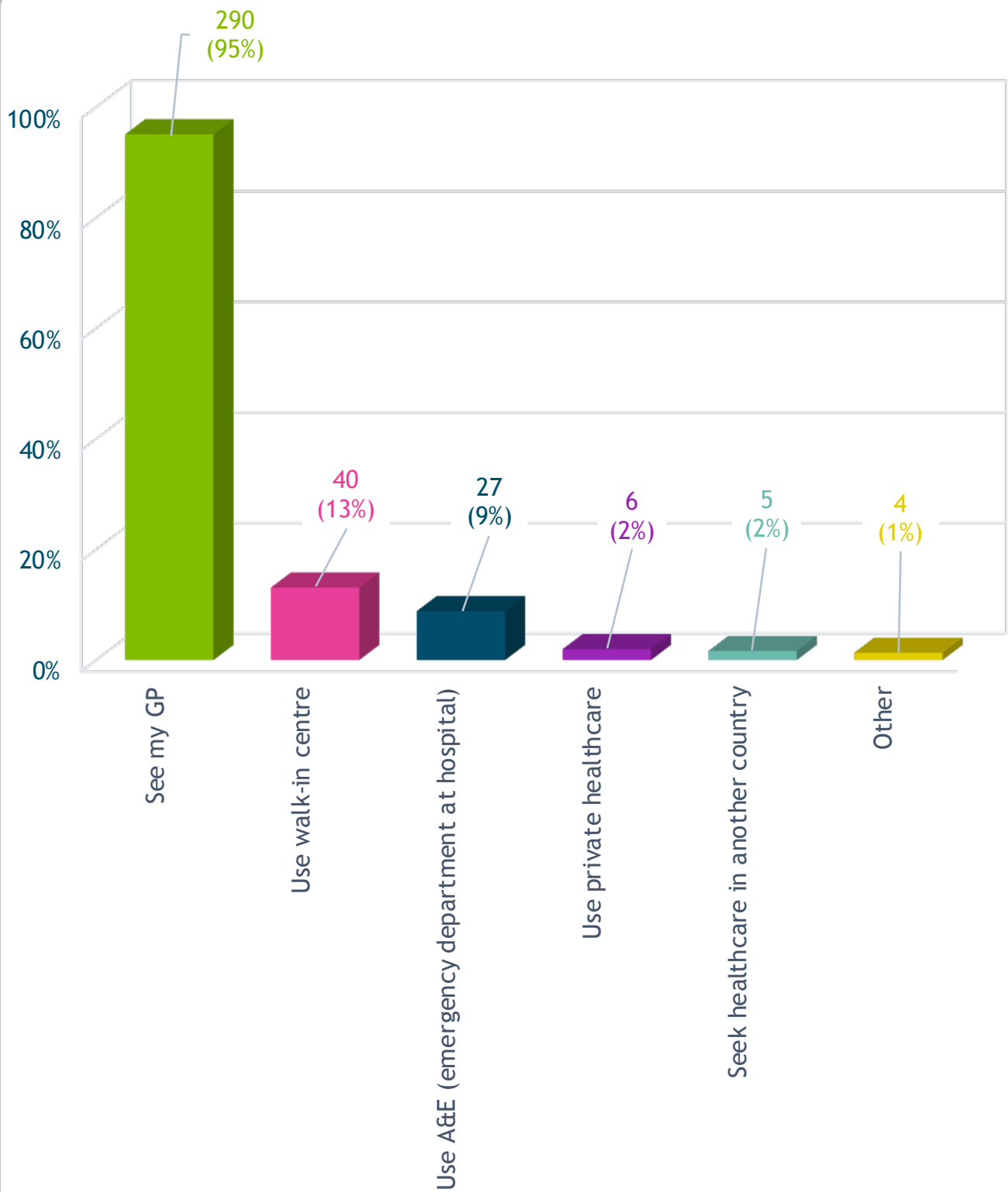
Up to 5 years	31 people	21-29 years.....	3 people
6-10 years	17 people	30-39 years.....	9 people
11-19 years	18 people	40-49 years.....	11 people
20-29 years	5 people	50-59 years.....	10 people
		60 and over	1 person

Are you registered with a GP surgery?



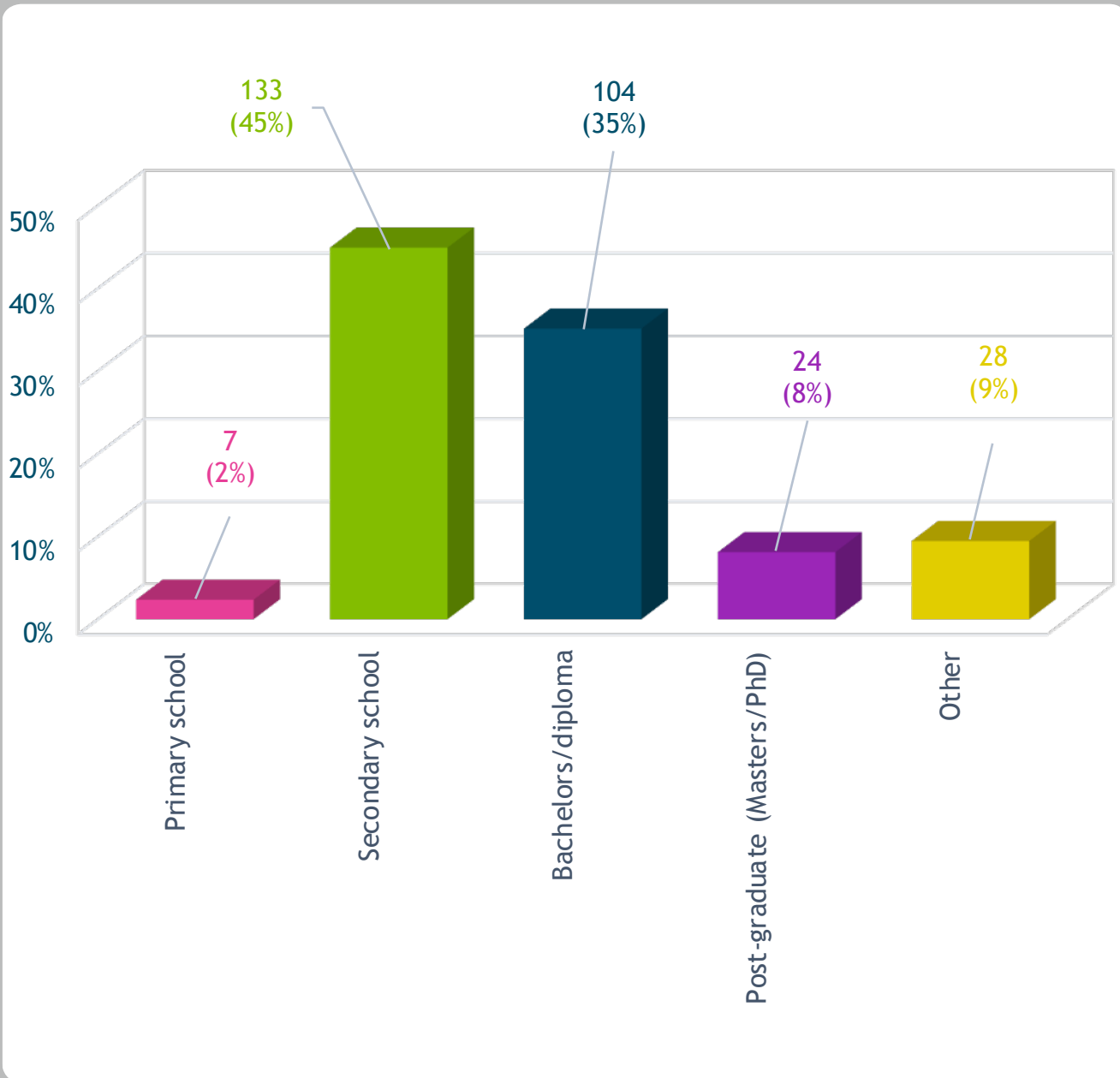
Appendix 1

How do you normally access health care services?



Appendix 1

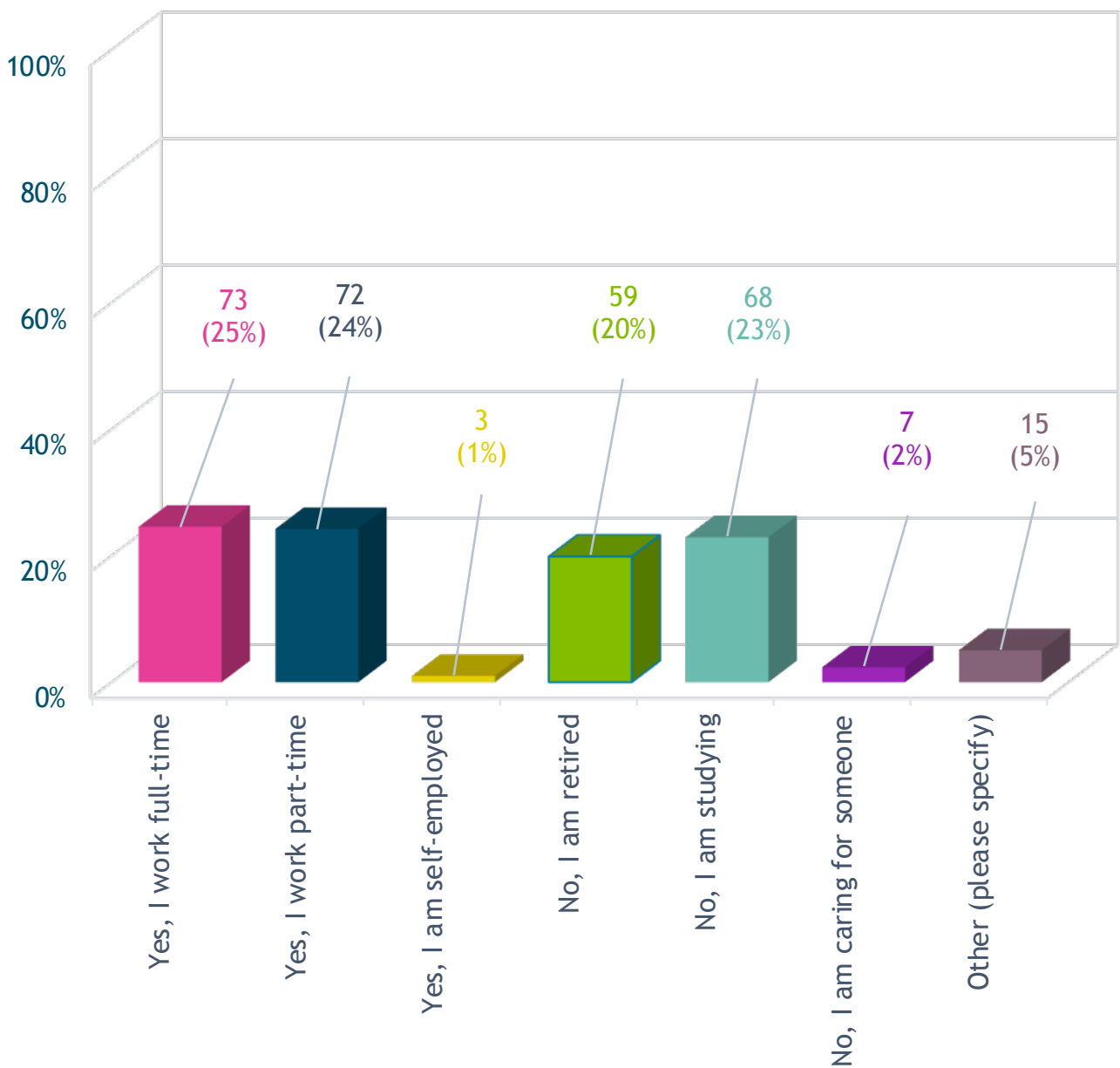
What is your highest level of education?



Other responses: mostly 'College'

Appendix 1

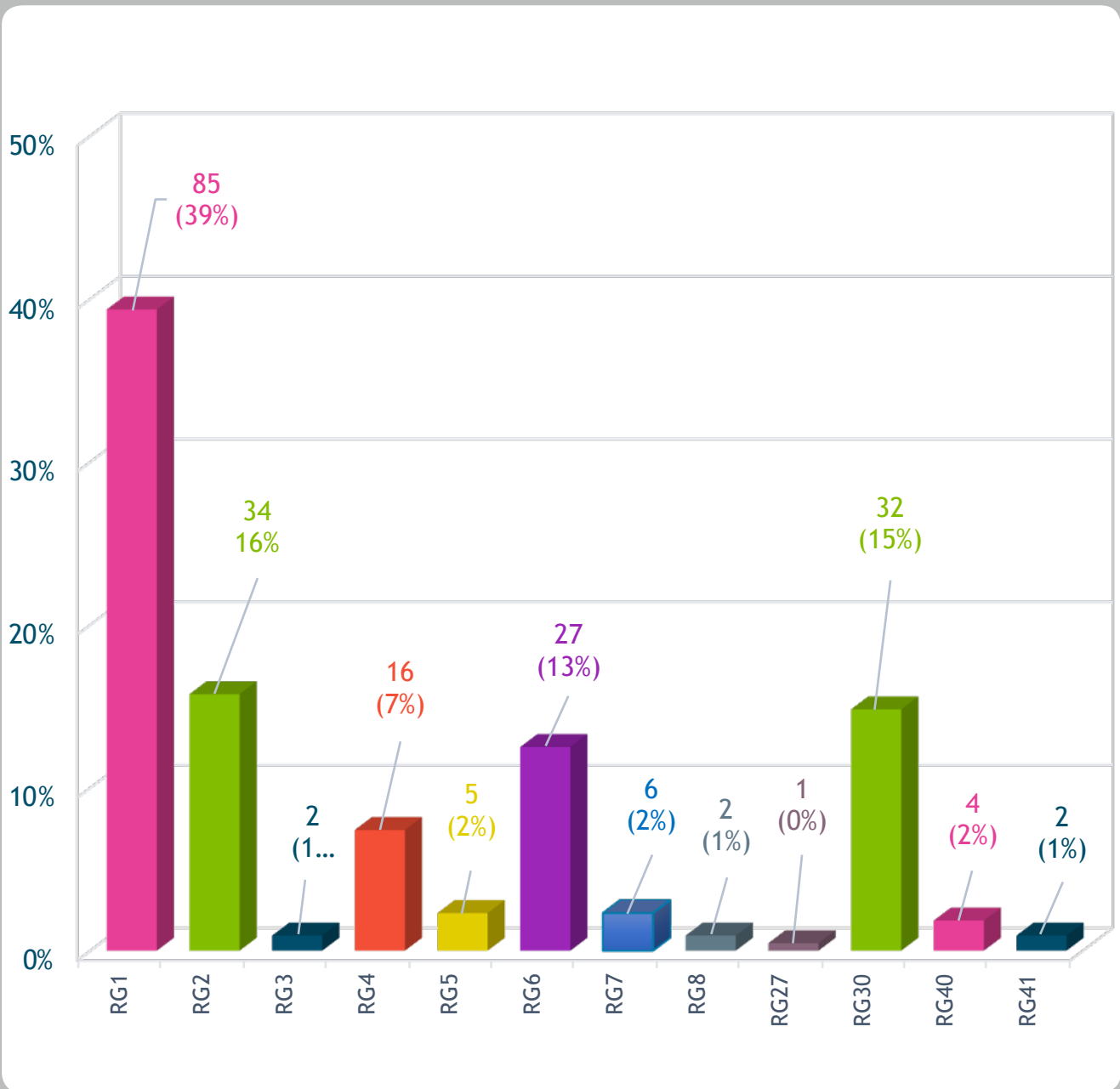
Are you employed?



Other responses: mostly full-time mum/housewife

Appendix 1

What is the first half of your postcode?



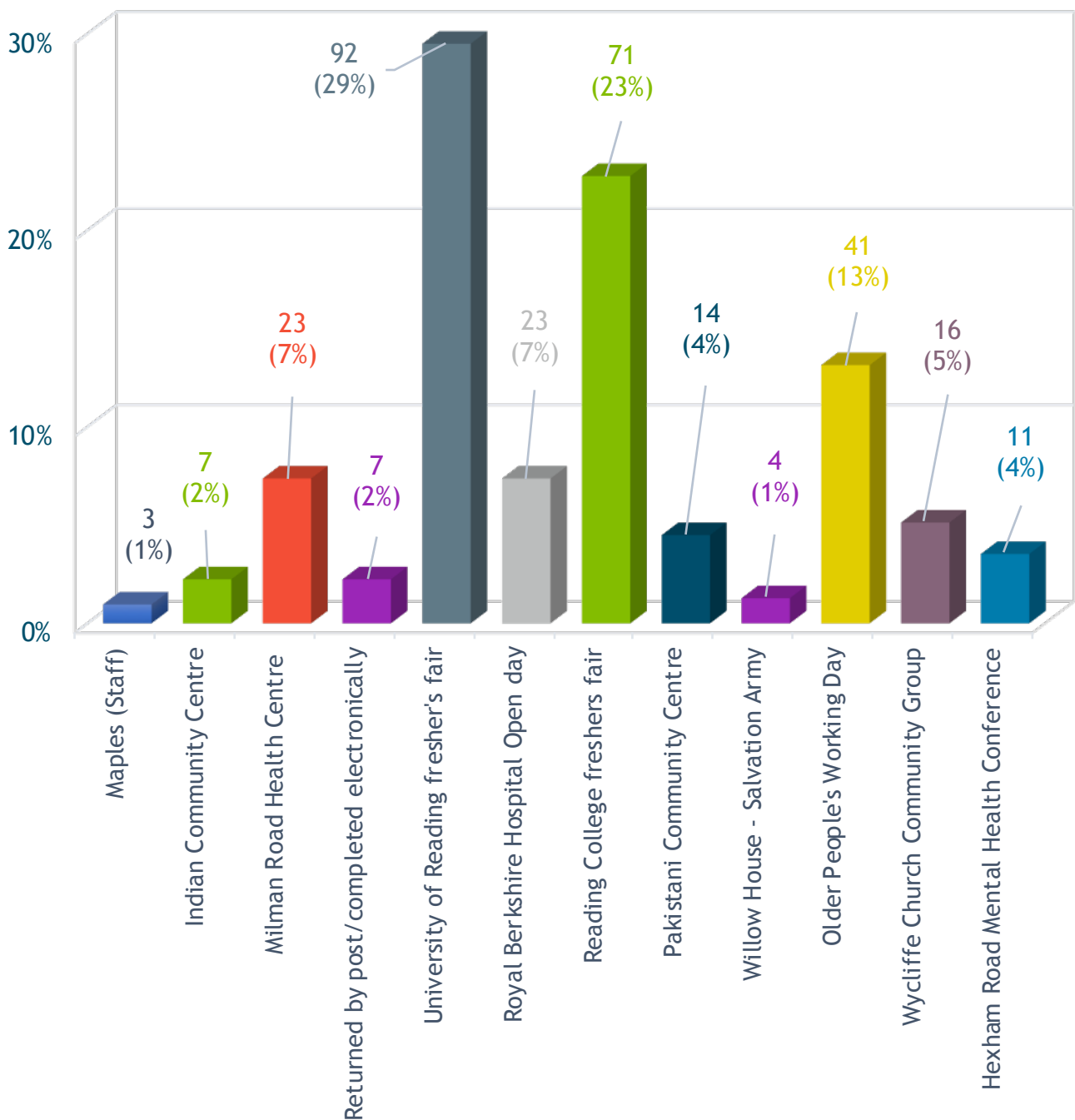
Other responses:

- Tilehurst or Calcot Postcode 9 people
- Slough postcode..... 6 people
- Bracknell postcode 5 people
- Maidenhead postcode 4 people

Appendix 2:

Where and when the survey was conducted

Which Healthwatch Reading interview session?



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Contact Healthwatch Reading at:
3rd floor, Reading Central Library
Abbey Square, Reading
RG1 3BQ
Telephone 0118 937 2295
Email info@healthwatchreading.co.uk