



Public Health
England

Protecting and improving the nation's health

Antenatal and newborn screening digital information early adopter site evaluation report

Contents

Executive summary	3
Introduction	4
Objectives	5
Background.....	5
User research.....	5
Communication strategy.....	5
Process	6
Resources.....	7
Findings	10
Lessons learned.....	12
Communications.....	12
Resources	13
Local implementation.....	14
Text messages	15
Data returns.....	16
Issues and limitations.....	16
COVID-19.....	16
GOV.UK analytics.....	17
Different versions of the content.....	17
Conclusions and next steps	18
Appendix 1: timeline.....	20
Appendix 2: digital maturity assessment summary of responses.....	22
Appendix 3: data returns	25
Appendix 4: early adopter sites staff survey summary of responses	27
Appendix 5: local social media examples.....	33
Appendix 6: early adopter site dates.....	34
Appendix 7: early adopter data return survey	35

Executive summary

As part of the cross-government shift to 'digital by default', Public Health England (PHE) worked with 10 NHS antenatal and newborn (ANNB) screening providers to pilot giving screening information to pregnant women digitally, rather than in print, with a view to then rolling this out nationally.

From 6 January to 30 April 2020, these 'early adopter' sites used a range of resources developed by PHE to signpost pregnant women to a digital version of the 'Screening Tests for You and Your Baby' leaflet, only giving them a printed copy in special circumstances.

The project was a success and during the early adopter period, out of a total of 4,131 bookings, only 410 printed copies were handed out (or just under 10%). Take one outlying site out of the picture and the figures are even more impressive – just 12 printed copies from 3,203 bookings (less than 0.5%). Furthermore, sites reported that the change was easy to make and implement.

In response to a survey sent to sites at the end of the early adopter period, 18 out of 19 screening coordinators and midwives said the move to digital screening information had been a success, with one saying it had 'partly' been a success and none saying it had not.

In June 2020 Portsmouth provided details of a local survey of pregnant women which included feedback on the digital screening information. This was universally positive, with comments such as "all the info was there" and "easily accessible".

We are now helping more sites to implement the shift to digital information on request. As more sites do this, we will continue to print and make available a small quantity of printed leaflets for sites for those women who need them.

Introduction

PHE is supporting the NHS to deliver more screening information to the public digitally rather than using physical leaflets. This is because:

- it's part of the government's 'digital by default' commitment
- we want to meet public expectations for digital information
- digital information can be more engaging and better tailored to the individual
- it's easier and quicker to keep up to date
- we can save money that could be better used elsewhere

We started with ANNB screening as we thought this should be easier than the young person and adult (YPA) screening programmes. This is because:

- pregnant women are generally a more tech-savvy group than the target populations of some other screening programmes and are comfortable accessing pregnancy information digitally
- community midwives discuss antenatal screening and give a copy of the leaflet at the face-to-face booking appointment rather than sending an appointment by letter – so we don't need to worry about emails or text messages

The idea was to replace the printed version of 'Screening Tests for You and Your Baby' (STFYAYB) with a digital version in phone-friendly HTML format that pregnant women could be given a link to instead.

From January 2020 we worked with 10 NHS providers to pilot giving pregnant women the digital information instead of the printed leaflet. The pilot period ended on 30 April 2020, and we now expect these sites to continue giving out digital information as business as usual.

A full timeline of the project is available in [appendix 1](#).

Objectives

From the beginning the approach to the project was to make sure:

- the changes do not affect people's satisfaction with screening programmes
- we do not disadvantage those without internet access or those who have specific information needs
- we clearly communicate the changes to screening providers, commissioners, stakeholders and patient groups
- we maximise the opportunities of digital methods to expand and improve content, such as using interactive and multimedia content

Background

User research

To make sure we included as many stakeholders' views as possible when considering the move from printed leaflets to digital screening information we did a significant amount of user research. This included:

- [an initial survey of ANNB screening services](#)
- 2 focus groups with pregnant women, one group with English as a second language and the other from an area of social deprivation, which also included women with learning disabilities and mental health issues
- spending a day at St Mary's Hospital in Manchester talking to about 40 women attending antenatal clinics
- in-depth group discussions with ANNB screening co-ordinators
- [holding face-to-face events for screening co-ordinators](#)
- working with digital inclusion charity Citizens Online to [carry out an equality impact assessment](#) of the move to digital information

You can read more in our PHE Screening blog post, '[User research into antenatal and newborn digital screening information](#)'.

Communication strategy

Over the course of the project we have used the [PHE Screening blog](#) to:

- introduce the move to digital ANNB screening information and explain the reasons behind it

- ask for feedback from ANNB screening services and other stakeholders
- report findings from surveys, user research, meetings and events
- put a call out for sites interested in piloting the move to digital information ('early adopter sites')

At a meeting with interested screening co-ordinators on 2 October 2019, we made a request for those who would like to be early adopter sites to let us know. Thirteen sites expressed an interest, although 3 of these withdrew during the process. We kept in touch with the early adopter sites about their progress and any problems they encountered through:

- fortnightly Skype calls for any co-ordinators who wanted to dial in
- a [Knowledge Hub](#) group
- direct emails and phone calls, when required

Process

Once we had identified the early adopter sites, we worked with them to develop the resources needed for the move to digital information (see the 'Resources' section below for more details).

Starting in December 2019, the screening co-ordinators at the early adopter sites began delivering training to community midwives on how to reduce the number of printed copies of the STFYAYB leaflet they gave to pregnant women and use the resources to direct them to digital information instead.

We understood there would be certain situations when a woman would still require a physical copy of the leaflet and drew up a list of reasons to cover these. The reasons were:

- no phone or shared phone (socio economic reasons)
- no phone or internet (through choice)
- poor internet access
- English as a second language
- IT skills or confidence
- learning disability or literacy issues
- personal preference
- midwife decision (a catch-all category for anything not fitting elsewhere; in the end this was mostly used for those sites where, due to a misunderstanding, some community midwives used up existing leaflet stock before handing out digital information)

Once the community midwives had received the training, we encouraged the early adopter sites to select a date in early 2020 to start the pilot. [A full list of the sites and their training and 'go live' dates](#) is available on the PHE Screening blog and in [appendix 6](#) of this report. Our original aim was for the early adopter period to last from 1 January to 31 March 2020. In the end, the sites went live between 6 January and 31 March, so some were live for longer than others.

We gave the early adopter sites a data collection form, as a crucial part of the project was to understand the proportion of women who still needed a physical leaflet and the reasons for this, so we can better meet their needs in the future. The form was designed for community midwives to complete and return to their screening co-ordinator, who would then submit the combined data from all community midwives using [an online survey](#). The form included:

- the number of bookings a midwife had made in a given period (suggested as every 2 weeks)
- the number of printed versions of STFAYB they had given out in the same period
- the reason for giving out each printed version (based on the list of situations above)

The combined data returns of all early adopter sites can be found in [appendix 3](#) to this report. A copy of the survey can be found in [appendix 7](#).

Resources

We were keen to run this project using an agile approach, so we aimed to produce a wide set of resources as quickly as possible and then work with sites to refine them based on user feedback and establish which would be most useful for the national rollout phase.

For instance, rather than commissioning an external video production company to record the short films demonstrating how community midwives could introduce the digital content in conversations with pregnant women, we recorded and edited these ourselves to save time and money.

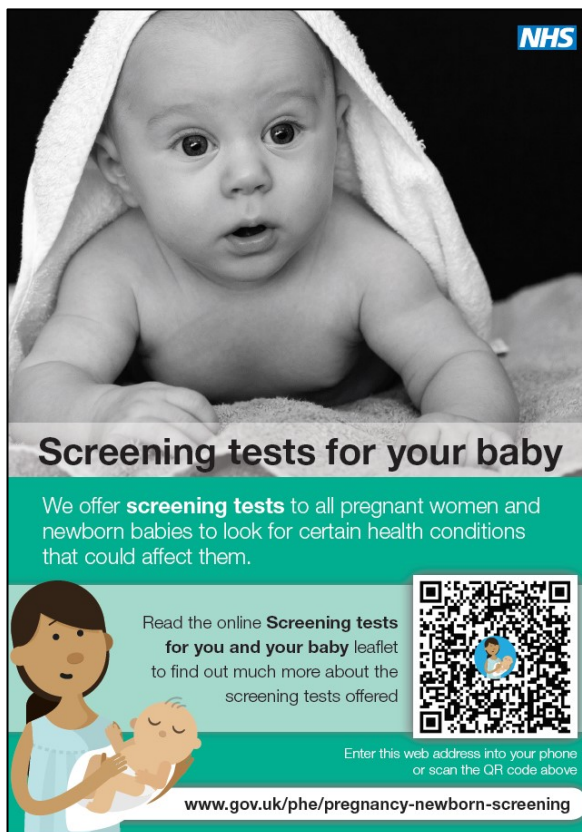
The resources we produced were:


- a checklist to help screening co-ordinators prepare for implementation of digital information
- a PowerPoint presentation for screening co-ordinators to cascade to all community midwives to prepare them for the change to digital information
- 2 videos, included in the training PowerPoint presentation, showing example conversations between a midwife and pregnant woman

- 2 posters (one for antenatal and one for newborn), available in A4 and A3, with a QR code and link to the digital ANNB screening information for clinics, waiting rooms and GP surgeries
- a 2-sided A5 flyer with important information for community midwives
- business cards to explain to women how to access the digital version of the leaflet
- a generic booking letter template highlighting the digital screening information to women
- a letter for PHE to send to all GP practices in the early adopter areas
- detailed instructions on how to create a home screen icon on iPhones or Android phones
- standard email, website and SMS text for providers to use to provide information about ANNB screening
- a form for community midwives to regularly complete and return to screening coordinators to record how many physical leaflets they've given out, and the reasons
- details of 2 online surveys, one for the early adopter sites to submit data returns to PHE and the other for community midwives to give feedback at the end of the early adopter period
- suggested content for social media posts, including a short (20-second) version of the screening animation, a screenshot from the animation and an example Instagram image

Download a **complete set of all resources** as a zip file.

The images below show the posters, flyer and business card.






Screening tests for you and your baby

NHS

Enter this web address into your phone or scan this QR code






www.gov.uk/phe/pregnancy-newborn-screening

Add an icon to the home screen of your phone


This enables you to click on the icon to go straight to the screening information, just like an app. Open the web browser and go to the link on the reverse. Then find the **add to home screen** option. Where this is depends on what phone you have and how old it is. If you need help, search online for what to do for your specific phone.

iPhones

1. Click on the share icon  at the bottom of the screen.
2. Scroll up or left and select **add to home screen**, then **add**.

Android phones  or 

1. Click on the menu icon (3 dots or lines).
2. Select **add to home screen**, then **add**.



Screening tests for you and your baby

Moving to digital information

Guidance for community midwives at early adopter sites

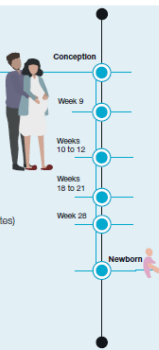
Public Health England (PHE) is helping NHS screening services to make more use of digital (online) information when offering antenatal and newborn screening.

This will have many benefits. Women will get more engaging information, for example using more videos and animations. Screening services will not need to manage so much leaflet stock. And PHE will be more environmentally friendly.

Screening in pregnancy

- sickle cell and thalassaemia (ideally by **10 weeks**)
- infectious diseases (HIV, hepatitis B and syphilis)
- Down's syndrome, Edwards' syndrome and Patau's syndrome
- 11 physical conditions in the baby (**20-week scan**)
- diabetic retinopathy (for women with diabetes)

www.nhs.uk/pregnancyscreening



The digital information covers the same content as the physical leaflet, summarised in this extract from the population screening timeline

Newborn screening

- **newborn hearing**
- physical examination (for problems with eyes, hearts, hips and testes) within **3 days** of birth and again at **6 to 8 weeks** of age
- **newborn blood spot** (for 9 rare conditions)

www.nhs.uk/pregnancyscreening

Most women should be able to access the digital version, possibly with some help from you. You should:


- signpost them to the digital information using the web address or QR code (Android phones and older iPhones will need a free QR code reader app installed)
- help them to save a link to the information as an icon on the home screen of their phone
- show them how to find their way round the information
- highlight the animation and ideally watch it with them



www.gov.uk/phe/pregnancy-newborn-screening

Adding an icon to the home screen of a phone

Open the web browser and go to the link above. Then find the **add to home screen** option. To do this on recent phones:

iPhones

1. Click on the share icon  at the bottom of the screen.
2. Scroll up or left and select **add to home screen**, then **add**.

Android phones  or 

1. Click on the menu icon (3 dots or lines).
2. Select **add to home screen**, then **add**.

Digital information is ideal for most people with a visual impairment. Information about producing large print and audio versions of the information is at phescreening.blog.gov.uk/large-print-audio

A few women will not be able to use the digital version. In these cases you can provide a physical copy of the leaflet. PHE is auditing the number of leaflets used by the early adopter sites so you'll need to regularly provide details to your screening co-ordinator so they can collate and return them.

Please do not use more leaflets than are essential!

We asked the early adopter sites how many copies of the printed resources (the antenatal poster, midwife flyers and business cards) they were likely to need and arranged for these to be printed and delivered through APS, our print provider.

We also asked the sites with a standing order for the STFAYB leaflet with APS to reduce the quantities once they started signposting to the digital information instead.

The full suite of resources was also available to download from KHub.

Findings

Overall, the early adopter sites told us they found the switch from printed to digital information very straightforward. They emphasised how asking midwives to signpost pregnant women to online resources rather than giving them a printed leaflet was a minor change that was easy to implement.

The data sites have sent us shows that during the early adopter period they:

- made 4,131 bookings
- gave out 410 printed leaflets

This suggests just under 10% of women would require a printed version of STFAYB.

However, some sites also reported teething problems, particularly with a misunderstanding which meant some leaflets were given to women who did not necessarily need them.

One site was particularly affected by this, and if its data is removed the other 9 sites:

- made 3,203 bookings
- gave out 12 (twelve) printed leaflets

Based on this data, fewer than 0.5% of women required a printed leaflet.

The reasons for leaflets being given out were:

- no phone/shared phone (socioeconomic) – 19
- poor internet access – 64
- English as second language – 49
- IT skills/confidence – 51
- learning disability/literacy issue – 4
- personal preference – 7
- midwife decision – 215

It was not always clear on the data return forms why a leaflet had been handed out, which is why these figures add up to one fewer than the total number of leaflets handed out (410).

At the end of the early adopter period we sent the screening coordinators a link to a survey asking for the views on the move to digital information. We also asked them to share the survey with midwives. We sent several reminders asking coordinators to

complete the survey and by the time it closed 7 out of 10 had responded, along with 12 community midwives.

Feedback was overwhelmingly positive, with several sites saying they found the move to digital information easier than expected. In general, both screening coordinators and midwives said women were very happy to receive information digitally, and in some cases expected it. Sites were also mostly positive about the resources and support provided by PHE.

Overall, 18 out of 19 respondents said the move to digital screening information had been a success, with one saying it had 'partly' been a success and none saying it had not.

A full round-up of the survey responses can be found in [appendix 4](#).

In June 2020 Portsmouth provided details of a week's worth of data from a local survey of pregnant women which included feedback on the digital screening information. This was universally positive, with 43 out of 46 women saying they remembered receiving the digital leaflet. All 43 of these women said it provided them with all the information they needed. Comments included:

- "very informative"
- "fair amount of information"
- "all information provided"
- "information satisfied my curiosity"
- "very helpful"
- "gave all the information I needed"
- "all the info was there and easily accessible"
- "easy to navigate and find the information needed"

Lessons learned

Communications

The first 2 face-to-face meetings were very successful and well attended. But in general, it proved quite challenging to stay in regular contact with all the early adopter sites. This is understandable, as this project was just one very small part of their day jobs. We were very keen not to burden them with unnecessary requirements but on the other hand needed to stay in touch to understand how the project was progressing and what more we could do to support them.

Some sites did not tell us how many printed resources they required before the deadline, which meant we had to arrange another order from APS. We also tried to arrange for other sites to send over leftover stock, but this was not successful. In the end, we set up a process for APS to hold a small supply of materials in stock which sites could then order from the web shop in the usual way.

We had limited engagement from sites with our fortnightly calls. Initially, some sites had difficulty accessing Skype due to their provider IT systems. We clarified they could also join the calls by phone, but this did not make much difference and on any given call we would usually only have one or 2 sites joining. It is hard to know if this meant that everything was going well at most sites, or if they either did not have time to join the calls or had technical difficulties preventing them from doing so.

We had similar problems with the KHub group, which we initially thought would be an ideal solution for staying in touch and creating a community where sites could discuss experiences and support each other. Some sites engaged with it initially, but this petered out quite quickly. We offered additional support using KHub, but there was not any take up for this.

The communications team at one of the sites got in touch to ask what other sites were doing to promote the digital information through local social media channels. We put out a message on KHub and via email asking the other sites to provide us with a contact from their communications team so we could arrange a group Skype call, but this met with no response. We've since found out that some sites did use local social media effectively, and you can see some examples in [appendix 5](#) of this report.

Our instructions to sites about how to use the business cards were not as clear as they could have been. The community midwives were meant to use the cards during the appointment to show the woman how to access the digital information, but not to give them out unless there was a clear reason, for example if the woman had left her phone at home and needed to refer to the instructions later. However, several sites reported at

the start of the project their community midwives had been handing out considerable quantities of the business cards to women during appointments.

At the initial meetings, screening co-ordinators expressed the importance of primary care in this project. Even though not many sites had direct referrals from GPs for booking appointments, primary care plays a vital role in supporting pregnant women and acting as an information gatekeeper. Sites wanted PHE to write to GP surgeries in early adopter areas, as they felt this would have greater impact than if they did this. Getting this letter out provide to be challenging, however, as it needed joint signing and branding with NHSEI and approval to be sent out via screening and immunisation teams. This delay somewhat lessened the usefulness of the letter. In future, such communications should be considered earlier in the process. After the letter went out some GPs contacted the helpdesk requesting posters.

Resources

In general, feedback on our resources was extremely positive. Most sites said they found nearly all of them useful. Many sites told us that they had initially been wary of the amount of work involved in being an early adopter site as they thought they would need to develop resources locally.

But once they realised that PHE had done this for them, they said that the amount of work involved was much less than expected.

Sites had constructive feedback about some of the resources, including:

- that the information on the midwife flyers could be provided electronically, rather than in print
- that the link on the posters could be shortened and given the same prominence as the QR code
- that the cascade training could be best delivered as a short, informal chat with lead midwives, who could then share it with the community midwives
- that it was important to stress to other sites that the change from printed to digital information was simple to make
- that it would be useful to provide a QR code to the digital information as a separate image file, to make it easier to include in local resources

Overall, the most popular resources were the posters and business cards.

The only resources sites told us they had not used were the 2 training videos. We decided to remove these from the resource list when we rollout the change from printed to digital information nationally.

The way we responded to feedback from sites on the resources during the early adopter period was a good example of agile working. Examples of this include:

- making the STFAYB animation more prominent in the online leaflet and commissioning a set of short, programme-specific animations to further supplement the online information
- developing a newborn version of the poster to complement the original version, which was focused on antenatal screening
- producing a written script for community midwives to explain how to access and save the digital information on a smartphone, in response to more appointments being conducted by phone due to the coronavirus outbreak

We've also updated the printed resources following feedback and organised another print run with APS. As well as the original 3 resources (A4 antenatal poster, midwife flyer and business cards) we've also now printed:

- A3 antenatal posters
- A4 newborn posters
- a small number of roller banners (for those sites unable to stick posters to walls)

Local implementation

In their initial responses to our digital maturity assessment, most sites had been very confident that any necessary IT changes required locally would be easy and quick to make. Changes included:

- adding a link to the digital leaflet to online self-referral forms, local apps or digital handheld notes
- changing booking appointment templates (for example to include the QR code)

In the end, though, many sites said it took longer than expected for their IT departments to make these adjustments. We will amend the implementation checklist for the national rollout to advise sites to allow more time for this.

One site said delivering the training to large groups of midwives at a time proved difficult. For example, it made it hard to show them all how to save the digital information on smartphones and it was not possible to give them one-on-one support.

Another site was not able to run the training due to the tight timeframe and the practicalities of releasing midwives for the training. Instead, the screening coordinator met with the community lead midwives to cascade the training to them. As the lead midwives see their teams every day it was easier for them to discuss the plan in small groups or with individuals to get the message out.

For the national rollout, we will suggest the training is best done in small groups, or via cascade from lead midwives.

One site set up a stall in a hospital foyer and encouraged all passers-by (not just pregnant women) to test out the digital information. This was a success and something we will suggest other sites consider. For example, grandparents might be interested in accessing the information for their children or grandchildren.

Text messages

One of our original aims for the project was to test the use of text messages to signpost pregnant women to the digital information. We were always concerned the main barrier to success was getting the link onto women's phones, particularly as even the short URL created by the Government Digital Service (GDS) for this project (www.gov.uk/phe/pregnancy-newborn-screening) is still on the long side. If midwives could easily send a text message to a woman during the booking appointment, she could then just click on the link to get to the information.

Early in the project we found a company which could arrange this and set up a demonstration for the early adopter sites. Several of them expressed an interest but none ended up implementing this, or any equivalent system, during the early adopter period. It would be useful to explore the reasons for this in more detail, but we suspect it's due to the long timescales for new technology to be reviewed and approved at local provider level, as well as concerns about the information governance issues around using text messaging in screening.

We still feel this would be a good solution, however, and hope that as more providers start making use of text messaging in adult screening it will become easier to implement this for ANNB screening.

The coronavirus pandemic has affected how maternity services carry out 'first contacts' and bookings with women, as these are mostly now taking place by telephone or video link, rather than face-to-face.

Women should continue to receive the information in STFAYB, and we have developed a simple text message template for providers which contains a link to the HTML version of the leaflet and guide on how to save the information to a phone. This can be sent manually from a work mobile phone to women as part of their virtual discussions. Local screening midwives have begun to trial this at the time of writing this report, and early indications of ease of implementation and effectiveness are positive.

Data returns

We did not receive many data returns from sites, and very few through the online survey. To date, we have only received 5 this way.

Some sites said community midwives had expressed concerns about the extra workload of filling in the forms to feed into the survey, despite us trying to explain how important this information was and how it would only be needed for a short period of time. We also encouraged sites to send us less frequent returns if this would be easier for them. Another site reported difficulty in accessing the survey, so emailed their data returns instead. We have received several more data returns in this way.

The combined data returns of all early adopter sites can be found in [appendix 3](#) to this report.

For future projects, we need to consider whether we could realistically expect staff to take on extra work, even we made it clear it would not be much of a burden. We would either need to find a way to obtain data without needing the midwives to do anything, or we would need NHSEI to mandate a new data requirement, as PHE cannot do this.

Issues and limitations

COVID-19

The coronavirus outbreak has had an impact on the project, particularly in terms of our ability to gather feedback.

For example, completing data returns is likely to have become a much lower priority for community midwives, which may be a reason for the limited number we received.

Due to social distancing measures, we were also unable to run face-to-face focus groups with pregnant women or midwives to find out their views on the move to digital information. In response to this, we've adapted the short survey for midwives and/or screening coordinators at the early adopter sites to fill out to try to get more information about the views of women locally.

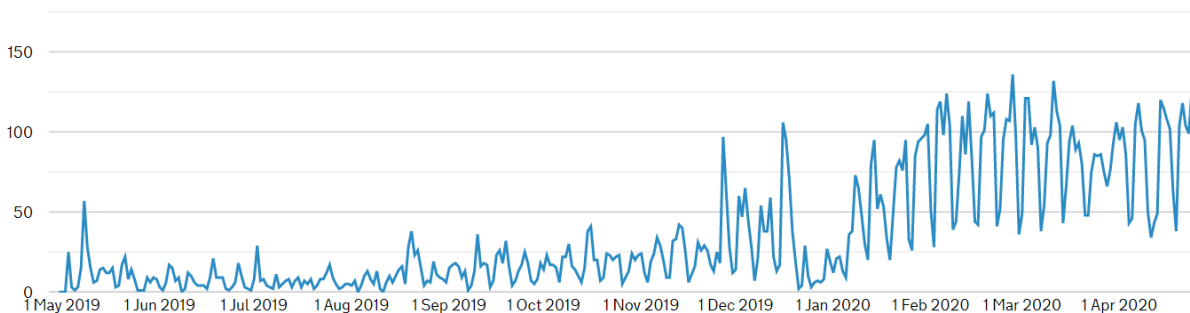
Our final meeting with the early adopter sites had to change from face-to-face to online and was shorter than originally planned. This was our final opportunity to gather information about what had worked well and what had not during the pilot, so it was a great shame not to have been able to see them in person.

GOV.UK analytics

We originally hoped to use website analytics to look at how many people from the early adopter sites were accessing the digital content on GOV.UK. But it proved to be impossible to distinguish between website visits from the early adopter sites and website visits from people in the rest of the country.

It was also very unfortunate that due to a change in the law, from 20 December 2019 GOV.UK could only collect usage data from people who explicitly consented to cookies being used. This means only a small proportion of site visits have been recorded and it makes it very difficult to see the impact of the early adopter sites.

Having said that, this graph showing unique page views for the HTML version of STFAYB shows an initial increase in daily visitors from December, which likely relates to the cascade training at the early adopter sites, and then more consistently from mid-January.



Different versions of the content

The issue of having a number of different versions of ANNB screening information on the internet is something we're very aware of. This was raised in some of our user research and also as part of the Citizens Online equality impact assessment. Information is currently available on:

- GOV.UK in PDF format
- GOV.UK in HTML content (this is the accessible, phone-friendly content we developed for the early adopter sites to promote to pregnant women)
- NHS.UK
- other third-party websites

The danger is women could easily think they've found the official screening programme digital information but in fact have reached a different website. This could be because they entered the weblink incorrectly and the search results brought up another link higher up in the list.

We have no way of quantifying how much of an issue this was but we are keen to address this by asking GDS if they can make the link to the digital information even shorter, for instance in the form www.gov.uk/annbscreening.

In the longer term, we want to remove the PDF version of the leaflet from GOV.UK, as this would make searching for the HTML version (either on Google or on GOV.UK) easier. We also want to work with NHS Digital to eventually rationalise screening content on GOV.UK and NHS.UK into one location.

Conclusions and next steps

The early adopter period ended on 30 April. The early adopter sites should now be using the digital information as 'business as usual' and no longer need to send us regular feedback or data returns.

We had originally hoped to rollout the digital information across all providers in England by July, but this will not be possible due to the impact of coronavirus. However, this also presents us with an opportunity. As providers across the country have had to significantly cut down face-to-face contact with people, the need to be able to provide and access health information electronically is growing.

We are currently exploring ways to support interested providers using digital ANNB screening information, while also being conscious of the pressures they are likely to be under. For instance, we have included information about the move to digital information in the coronavirus-related technical guidance which has been issued to all screening services to help them adapt to the current situation. We are also giving presentations to local screening co-ordinators as part of the regular regional meetings organised by QA colleagues.

Thirty-six providers have contacted us already through the PHE Screening Helpdesk and we have drafted a standard response providing guidance and directing them to the resources.

We hope the early adopter sites will act as champions to promote the move to digital information. For example, some of the sites have agreed to contribute to a blog post for the PHE Screening blog.

In general, we feel that this project has been extremely successful. In large part this has been due to us taking a flexible and agile approach to supporting sites and learning as we went along in terms of what worked and what did not.

To return to our original objectives, we feel:

- the changes have not affected people's satisfaction with screening programmes
- we have not disadvantaged those without internet access, or those who have specific information needs
- we have clearly communicated the changes to screening providers, commissioners, stakeholders and patient groups
- we maximised the opportunities of digital methods to expand and improve content, such as using interactive and multimedia content

We will continue to print and make available a small quantity of printed leaflets for sites for those women who need them, an approach supported up by the Citizens Online project ([the summary report of the equality impact assessment](#) is now available). We would aim to print no more than 5% of previous levels and review this on a bi-annual basis.

In terms of next steps, we will:

- work with GDS to try to produce a shorter weblink for the digital leaflet
- finalise and publish the new programme-specific animations within the digital leaflet
- try to move all ANNB screening services to using the digital leaflet by the end of March 2021
- aim to continue providing the hardcopy resources such as posters and business cards to trusts for free for the next couple of years
- explore other ways of publicising the weblink to pregnant women, for example by text message, printed link on handheld notes or digital link in trust apps and websites
- provide information about the successful completion of the project to NHSEI and local screening commissioners so they can encourage other trusts to move to digital information
- ensure the requirements to provide digital screening information are captured in the ANNB screening service specification for 2021/22
- work with the early adopter sites to produce a blog post about the ease and benefits of switching to digital ANNB screening information

Appendix 1: timeline

18 March 2019 – blog post announcing the project and asking providers to fill in a survey.

29 May 2019 – blog post from Anne Mackie further outlining the approach.

27 June 2019 – blog post sharing findings from the survey and asking for sites interested in piloting digital information to get in touch.

30 July 2019 – blog post inviting ANNB screening co-ordinators to attend a meeting in Birmingham on 2 October.

August 2019 – commissioned Citizens Online to do an equalities impact assessment for digital change.

25 September 2019 – blog post discussing the findings of the user research, including focus groups and discussions with an antenatal clinic and newborn screening coordinators.

30 September 2019 – blog post from Rich Denyer-Bewick at Citizens Online outlining the equalities impact assessment for digital change.

2 October – ANNB screening coordinator meeting in Birmingham.

15 October 2019 – blog post summarising the meeting on 2 October.

18 October 2019 – blog post from Rich at Citizens Online asking people to complete a survey for the equality impact assessment.

27 November – ANNB screening coordinator meeting in Birmingham.

December 2019 – first early adopter sites start their digital information training.

17 December 2019 – blog post from Kacie Gibson, an ANNB screening coordinator at North Bristol NHS Trust, talking about her experience of the 2 October meeting.

6 January 2020 – first early adopter sites go live with digital ANNB screening information.

21 January 2020 – blog post explaining how to save digital information on smartphones and providing links to QR codes.

3 March 2020 – **blog post from Rich Denyer-Bewick at Citizens Online sharing some initial feedback from the equality impact assessment.**

8 April 2020 – final meeting with early adopter sites to discuss progress and lessons learned.

30 April 2020 – end of early adopter period.

Appendix 2: digital maturity assessment summary of responses

Do your trust's senior leaders understand the need to adapt to a digital world?

7 responses were 'yes, gradually', 4 were 'absolutely, it's a priority' and 2 were 'absolutely, it's a top priority'. 12 out of 13 sites said it was a similar situation in terms of maternity leadership. One response mentioned that the trust is moving to electronic leaflets as part of a strategy to go paperless. Another said that their IT system is not currently fit for purpose.

Does your trust have the following?

A digital transformation strategy – 8 responses

A digital inclusion, participation or engagement strategy – 3 responses

An IT usage policy – 11 responses

One response said that a digital strategy is currently being written.

How effectively does your trust use technology internally, to enable staff to do their jobs?

3 responses were 'not very effectively', 5 were 'average', 4 were 'quite effectively' and 1 was 'very effectively'.

While one response mentioned that community midwives are provided with tablets and laptops, others said that a lack of computers limits staff ability to do their jobs.

What is the level of digital skills of your staff?

One response said that they didn't know what digital skills or gaps exist in their workforce, 9 said 'it varies', 1 said it was 'basic' and 2 said it was 'good'.

Does your trust have an active digital skills and development programme for staff?

7 responses said 'yes', 4 said 'no' and 2 didn't know.

What digital skills support is provided?

Support from IT service desk – 6 responses

Online training from external provider – 1 response

In house one to one support – 3 responses
In house drop in support sessions – 5 responses
In house online courses and materials – 7 responses

How confident are your staff in helping pregnant women with basic digital skills?

10 responses said it varied and 3 said they were 'confident'.

What methods does your trust currently use to communicate externally with pregnant women?

A large mix of approaches were used, including mobile apps, social media, websites, SMS messages, phone calls, face to face appointments, online newsletters and printed posters and leaflets.

If your trust has a website, is there a dedicated maternity page/section?

All 13 trusts have a dedicated maternity page on their website.

Information provided varied a lot, with a couple of responses mentioning it included screening information.

Are there plans to update the page in the next 12 months?

5 responses said 'yes' and 1 said 'no'.

1 person said that making changes was 'nearly impossible', 1 said 'quite challenging', 5 said 'quite easy (within a few weeks)' and 1 said 'really easy (within a few days)'.

Which of the following approaches do you use to understand the needs of pregnant women in developing or improving your services?

A wide variety of approaches were used, including user stories, co-production, focus groups, social media, online surveys and website analytics.

How effectively does your trust ensure that your services are accessible to everyone?

5 responses said this was 'average', 3 were 'effective' and 3 were 'very effective'. One mentioned that they specifically target women from disadvantaged groups.

Do your staff use digital devices as part of their work?

11 responses said 'yes', with no-one saying 'no'. All devices were provided by the trust, with no-one having to use their personal devices. Most responses said that devices provided were laptops and phones, with some trusts also providing tablets.

How good is the internet in your trust?

1 response was 'terrible', 1 was 'patchy', 3 were 'usually ok', 5 were 'good most of the time' and 1 was 'excellent'.

How good is your IT provision in your trust?

1 was 'not good at all', 1 was 'not very good', 5 were 'average', 2 were 'good' and 1 was 'very good'. One commented that while the technical support was excellent, hardware was less so. Many people said that community staff could do with better access to digital devices.

Does your trust collect patient mobile phone numbers?

7 responses said 'most of the time' and 4 were 'all of the time'.

Does your trust collect patient email addresses?

1 response was 'never', 5 were 'not usually', 3 were 'some of the time', 2 were 'most of the time' and no-one said 'all the time'.

How do pregnant women in your trust access their personal maternity records?

3 trusts had digital notes, 6 had locally developed handheld notes and 2 used the Perinatal Institute handheld notes.

Appendix 3: data returns

Reasons for handing out printed leaflets

#	Reason
1	No phone/shared phone (socioeconomic)
2	No phone internet (choice)
3	Poor internet access
4	English as second language
5	IT skills/confidence
6	Learning disability/literacy issues
7	Personal preference
8	Midwife decision

Combined early adopter sites

Date	Number of bookings	Leaflets given out	% leaflets given out	Reason
06/02/2020	449	111	24.73	4 (1), 8 (110)
20/02/2020	517	120	23.21	3 (15), 5 (4), 8 (101)
06/03/2020	265	0	0	
19/03/2020	699	10	1.43	1 (2), 4 (1), 6 (1), 7 (2), 8 (3)
20/03/2020	483	168	34.78	1 (17), 3 (49), 4 (47), 5 (47), 6 (3), 7 (5)
30/03/2020	283	0	0	
15/04/2020	374	1	0.27	8 (1)
22/04/20	290	0	0	
06/05/2020	771	0	0	
Total	4,131	410	9.93	

Luton and Dunstable

Start date of submission	End date of submission	Number of bookings	Leaflets given out	% leaflet given out	Reason
13/01/2020	26/01/2020	220	110	50	8 (110)
27/01/2020	09/02/2020	225	120	53.33	3 (15), 5 (4), 8 (101)
10/02/2020	23/02/2020	216	71	32.87	1 (10), 3 (14), 4 (47)
24/02/2020	08/03/2020	267	97	36.33	1 (7), 3 (35), 5 (47), 6 (3), 7 (5)

North Tees and Hartlepool

Start date of submission	End date of submission	Number of bookings	Leaflets given out	% leaflet given out	Reason
06/01/2020	19/01/2020	153	0	0%	
20/01/2020	02/02/2020	154	4	2.6%	1 (1), 7 (1), 8 (1)
03/02/2020	16/02/2020	152	3	1.97%	6 (1), 8 (1)
17/02/2020	01/03/2020	156	1	0.64%	7 (1)
02/03/2020	15/03/2020	158	1	0.63%	1 (1)
16/03/2020	30/04/2020	484	0	0%	

South Warwickshire

Start date of submission	End date of submission	Number of bookings	Leaflets given out	% leaflet given out	Reason
06/01/2020	20/01/2020	76	1	1.32%	4 (1)
21/01/2020	?	28	1	3.5%	4 and 8 (1)
17/02/2020	02/03/2020	51	0	0%	

Portsmouth

Start date of submission	End date of submission	Number of bookings	Leaflets given out	% leaflet given out	Reason
03/02/2020	17/02/2020	292	0	0%	
18/02/2020	03/03/2020	265	0	0%	
04/03/2020	17/03/2020	283	0	0%	
18/03/2020	31/03/2020	374	1	0.27%	8 (1)
01/04/2020	14/04/2020	290	0	0%	
15/04/2020	30/04/2020	287	0	0%	

Appendix 4: early adopter sites staff survey summary of responses

Seven screening co-ordinators and 12 community midwives completed the survey.

How would you rate the early adopter site resources developed by PHE?

Cascade training – out of the screening coordinators who took the survey, 3 said 'excellent' and 4 said 'good'. Out of the midwives who took the survey, 6 said 'excellent', 3 said 'good', 1 said 'neutral', 1 said 'poor' and 1 said 'N/A'.

Data submission process (number of leaflets handed out) – of the coordinators, 1 said 'excellent', 5 said 'good' and 1 said 'poor'. Of the midwives, 5 said 'excellent', 5 said 'good', 1 said 'neutral' and 1 said 'poor'.

Community midwife flyer – of the coordinators, 6 said 'excellent' and 1 said 'good'. Of the midwives, 5 said 'excellent', 5 said 'good', 1 said 'neutral' and 1 said 'N/A'.

Poster – of the coordinators, all 7 said 'excellent'. Of the midwives, 6 said 'excellent', 4 said 'good' and 2 said 'neutral'.

Business cards – of the coordinators, all 7 said 'excellent'. Of the midwives, 5 said 'excellent', 5 said 'good', 1 said 'neutral' and 1 said 'N/A'.

Please comment on your answers to the above question if you wish

Comments included 'all resources were very useful' and 'resources provided were fantastic'.

A couple of comments said they were not aware of any training at their trust.

A couple of the screening coordinators mentioned difficulties in getting the midwives to fill in the data return form.

One comment said the posters and business cards were particularly well received.

What do you think of the HTML version of the Screening tests for you and your baby leaflet that women have been signposted to? How could it be improved?

The general impression was positive, with comments including 'appropriate and aimed at the right level' and 'the women have been impressed by it'.

A few comments mentioned making it available in more languages. Another said it should be clear on the translated versions what the language is (by adding a label in English).

Other comments mentioned including information about timings of tests and making the animation stand out more to stop people skimming past it.

Two comments mentioned the length, with one saying: 'I think having separate sections makes it look like there is a lot of information to read and I'm not sure women will read all the sections unless they are particularly keen for information or have a specific concern. A leaflet that looks like a leaflet on the screen might be less daunting.'

One comment said midwives were finding it time consuming and complicated to explain to women how to save a link to the digital leaflet on their phones.

Are midwives in your area encouraging women to watch the animation at the start of the online screening leaflet?

Of the screening coordinators, 4 said 'yes', 2 said 'no' and 1 said 'not sure'. Of the midwives, 5 said 'yes', 1 said 'no' and 6 said 'not sure'.

Comments suggest midwives had generally been advised to do this, although one coordinator said: 'I think this is too much information crammed into a small space of time and even I find it difficult to follow in places.'

How would you rate these aspects of being an early adopter site?

How well prepared you felt – of the screening coordinators, 5 said 'excellent' and 2 said 'good'. Of the midwives, 4 said 'excellent', 4 said 'good', 1 said 'fair' and 3 said 'neutral'.

The support provided by PHE – of the coordinators, 5 said 'excellent' and 2 said 'good'. Of the midwives, 5 said 'excellent', 3 said 'good' and 4 said 'neutral'.

The support from senior managers at the trust – of the coordinators, 4 said 'excellent' and 3 said 'good'. Of the midwives, 4 said 'excellent', 3 said 'good' and 5 said 'neutral'.

Whether the project was seen positively by colleagues – of the coordinators, 2 said 'excellent', 4 said 'good' and 1 said 'neutral'. Of the midwives, 2 said 'excellent', 9 said 'good' and 1 said 'neutral'.

Your own confidence with IT and digital content – of the coordinators, 4 said 'excellent', 2 said 'good' and 1 said 'neutral'. Of the midwives, 7 said 'excellent', 4 said 'good' and 1 said 'neutral'.

Please explain briefly your experience of being an early adopter site

Feedback was overwhelmingly positive, with several sites saying the change to digital information was easier than expected. Comments included 'didn't really impact on workload or current way of working', 'easier than I thought it would be' and 'surprisingly positively received'.

Less positive aspects mentioned included the difficulty in getting data returns from community midwives and varied support from senior management, with difficulties around the digital aspects of change (such as websites).

One midwife said they weren't aware their site was an early adopter.

In general, were the conversations and informal feedback about digital information from women:

- very negative
- slightly negative
- neutral or mixed
- slightly positive
- very positive

Of the screening coordinators, 4 said 'very positive', 2 said 'slightly positive' and 1 said 'neutral or mixed'. Of the midwives, 6 said 'very positive', 5 said 'slightly positive' and 1 said 'neutral or mixed'.

Please summarise any feedback from women you could share

Generally, coordinators and midwives said women had been very happy to receive information digitally. Comments included:

- 'Most women I have spoken too liked being able to view it on their phone as and when. It was also a tool that their partners could also access on their own phones.'
- 'Prefer information digitally to a leaflet they may lose.'
- 'Women were really positive about having digital access to the booklet. One woman commented that it was "about time".'
- 'The women found it easy to navigate the site. They found the subtitles in the animation very helpful. Women were moving onto digital access and being more environmentally friendly.'

Other feedback covered:

- a few women also wanting a hard copy of the leaflet
- the importance of sharing the information before the booking appointment

- problems with lack of signal or data, meaning women cannot access the digital leaflet during the appointment
- a suggestion for 'a system whereby they could register on the site and enter their estimated date delivery (EDD) so they could reminders of screening tests'
- voiceover in other languages for animation
- the importance of showing women how to access the leaflet on their phones, although this has met with some resistance from midwives as 'the process can take away valuable minutes of an already time restrained booking appointment'
- difficulties using the QR code on some phones

What additional training or resources could we develop?

Suggestions included:

- 'I think their needs to be a longer time frame for the roll out to allow suitable cascade training for all.'
- 'Ensure all women have access to their notes and leaflets online – encourage trusts to do it as it works well.'
- 'An extended audio/video version of the leaflet would be useful for women who struggle to read as the short video alone is not really enough to make an informed choice.'
- 'Animations for each screening programme.'
- 'Something that would make it easier for the women to understand that the electronic version link can and should be saved for use throughout antenatal and newborn events. I don't know how it can be made easier though as I don't find it difficult.'
- 'Possibly a video for community midwives to explain the move to a digital version highlighting the benefits as some community midwives are resistant to change.'
- More face to face training with midwives for those who are not tech-savvy
- Wallet cards for parents

What advice do you have to other sites moving to digital ANNB screening information?

There were several comments about how straightforward sites had found the move to digital information, including:

- it's very easy
- easy to adopt
- it's a positive move, keeping with the times to give women information in the easiest way possible
- don't worry about it
- women are happy with online content
- it's easier than it looks, don't be scared

- much easier to implement than it initially appears, very positive project

Other advice from coordinators included:

- making sure the business cards are not given to everyone instead of the leaflet, just to those who have difficulty accessing the digital version
- cascading to as many staff as possible prior to launch
- training the midwives to teach women to access the site and bookmark it for easy access
- encouraging midwives to show women the animation during the appointment
- advertising the web address and QR code on your trust social media pages and website
- creating a link between your self-referral online and the screening website so the women are prompted to access the site
- keeping all hard copies in the office so midwives cannot easily access them, making it easier to monitor who needs hard copies
- meeting with your managers and getting the HOM (head of midwifery?) involved
- doing a step-by-step plan of what resources you may need nationally and locally
- meeting with the IT department to discuss what online services can be altered
- arranging teaching rollout session in advance for anyone involved in the booking procedure

Other advice from midwives included:

- making sure everyone knows how to use their work phone or tablet before you show them how to get the link onto the phone
- asking colleagues or PHE for support
- telling families prior to booking

Overall, do you think that moving to digital screening information has been a success?

Six out of 7 coordinators said 'yes', 1 said 'partly'. All 12 midwives said 'yes'.

Please explain your answer.

Reasons given included positive feedback from women, cost benefits for trusts and environmental benefits (less paper).

Other comments included:

- 'Majority of women have received the screening information and are more likely to read it as a digital copy as many would just place the leaflet in their notes and never read it.'

- 'I think current circumstances have highlighted the benefit of digital information as it can be given out without face to face contact so can be given at any time.'
- 'Well received, and great advantages for women where English is not first language as the page can be saved in their own language' (although another comment said some languages common in their area had not been included).
- 'Information is easily accessible, and the animation is of great benefit in explaining to women about the tests.'
- 'It has made access to the information easier for women and professionals.'

One comment mentioned some resistance to change from midwives.

Do you have any other comments or suggestions for PHE about the move to digital information?

One comment said: "My only concern is that women who do not have access to digital resources may not disclose this to their midwife due to concerns around stigmatization of poverty and therefore I think it would be helpful to find ways of reaching these women – maybe hard copies either laminated in waiting rooms or a few available to take away and read."

Appendix 5: local social media examples

Below are examples of social media posts created by trusts to promote digital antenatal and newborn screening information.



NHS Royal Free London @Roy... · Mar 11

Are you **#pregnant**? Before your midwife booking appointment, read about the **#NHSscreening** tests you'll be offered online. **#Screening** tests are always a choice. Watch this short video for more info or read the full resources on the **@PHE_uk** website: bit.ly/32EWocO



0:13 · 269 views health of you and your baby.

1 Like



royalfreelondonnhs Royal Free Hospital

For more information or support, speak to your midwife or doctor

or go to www.nhs.uk/pregnancyscreening

449 views · Liked by gregwooton

royalfreelondonnhs Are you **#pregnant**? Before your midwife booking appointment, read about the **#NHSscreening** tests you'll be offered online. **#Screening** tests are always a choice. Watch this short video for more info or read the full resources on the **@PHE_uk** website: <https://bit.ly/32EWocO>

2 March



NHS North Tees and Hartlepool NHS Foundation Trust

24 January · 🌐

All pregnant women and newborn babies are offered screening tests to look for certain health conditions that could affect them.

Members of the maternity service were talking to visitors at the University Hospital of North Tees this week offering information, advice and support.

Pictured are Jackie Cotton, Sally Jackson, Margaret Appleton and Stephanie El-Malak.

For more information visit www.gov.uk/phe/pregnancy-newborn-screening



70 Likes · 1 comment 5 shares

Like Comment Share

Appendix 6: early adopter site dates

Trust	Training commenced	Go live
East and North Hertfordshire NHS Trust		3 February 2020
East Kent Hospitals University NHS Foundation Trust	13 January 2020	13 January 2020
East Lancashire Hospitals NHS Trust		n/a (withdrawn)
Heart of Engand NHS Foundation Trust	22 January 2019	27 January 2020
Homerton University Hospital Foundation Trust		n/a (withdrawn)
Luton and Dunstable University Hospital NHS Foundation Trust	4 December 2019	13 January 2020
Mid Cheshire Hospitals NHS Foundation Trust	End of January	31 March 2020
North Tees and Hartlepool NHS Foundation Trust	9 December 2019	6 January 2020
Portsmouth Hospitals NHS Trust	January 2020	3 February 2020
Royal Free London NHS Foundation Trust	9 December 2019	24 February 2020
Sandwell and West Birmingham Hospitals NHS Trust		n/a (withdrawn)
South Warwickshire NHS Foundation Trust	9 December 2019	6 January 2020
The Dudley Group NHS Foundation Trust	Mid-January	3 February 2020

Appendix 7: early adopter data return survey

Below is a screenshot of the online survey which the early adopter trusts used to submit information about how many printed leaflets they gave out and the reason or reasons why women needed them. The results were used to estimate the proportion of women who required printed leaflets.

Page 1 of 1

This form is for early adopter sites using the digital version of the Screening tests for you and your baby leaflet to provide data on how many people still required physical leaflets and the reasons for this.

Data submissions should only be made by antenatal and newborn screening co-ordinators or their designated proxy.

- Which early adopter site are you from?*
- Name of person making this submission*
- Start date of data submission*
- End date of data collection*
- Number of bookings during this period for the whole Trust (dates are inclusive so please include bookings on the start date and end date)*
- Number of physical copies of STFAYB given out during this period for the whole Trust (dates are inclusive so please include leaflets given out on the start date and end date)*
- Reasons for physical copies (multiple options can apply to each person so the total of these reasons could be greater than the number of physical leaflets given out)*

	Number
No phone or shared phone (socio economic reasons)	<input type="text"/>
No phone/internet (through choice)	<input type="text"/>
Poor internet access	<input type="text"/>
English as a second language	<input type="text"/>
IT skills/confidence	<input type="text"/>
Learning disability/literacy issues	<input type="text"/>
Personal preference	<input type="text"/>
Midwife decision	<input type="text"/>

Please now press the **Submit** button to submit your data.

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, research, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000

www.gov.uk/phe

Twitter: [@PHE_uk](https://twitter.com/PHE_uk)

www.facebook.com/PublicHealthEngland

© Crown copyright 2020

OGL

You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit [OGL](https://www.ogil.io). Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published: December 2020

PHE gateway number: GW-1810



PHE supports the UN Sustainable Development Goals

