Citizens Online

Digital exclusion in population screening programmes

An Equality Impact Assessment of Channel Shift from printed media to online information within NHS England's population screening programmes

Full Report

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THIS REPORT IN BRIEF

ABOUT

This research was commissioned by Public Health England's Screening Team. There has been a proposed change to the way important information for the public about population screening programmes will be produced. The proposal is to reduce printed leaflet numbers and increasingly refer people to online information. Some people may not have access to the internet or the ability to read information online. The purpose of this work was to provide Public Health England with an assessment of the potential impacts of these changes. The intention was to:

- Identify differences in the impacts of change, across the 11 screening programmes and on different types of people (like older people and disabled people).
- Make recommendations to Public Health England about how to manage change and reduce any risks.

METHODS

A mix of research and assessment methods were used:

- Reading existing reports covering this subject (a literature review).
- Looking at Public Health England's performance data, existing research and blog posts.
- Carrying out online surveys, telephone interviews and attending focus groups.
- Analysing data about the types of people being invited to screening and about people who aren't online.
- Risk scoring, weighting and rating.

CONCLUSION

The two screening programmes with the highest risks associated with the changes, are the Bowel Cancer and Diabetic Eye screening programmes, because of the large numbers of people involved and the percentage of them estimated to be offline.

This report recommends a phased approach to reducing printed leaflets, ensuring they remain included with the first invitation letter that people receive. Additionally, Public Health England and NHS screening services should ensure that people still have a choice about how they receive information and can continue to access it in a range of formats based on their needs.

INTRODUCTION AND RATIONALE FOR WORK

PHE SCREENING INFORMATION LEAFLETS

Public Health England (PHE) screening has been tasked with meeting a significant reduction in information leaflet printing spend by the Cabinet Office. The Secretary of State has indicated that this will come into effect on April 1st, 2020.[1] This is in line with the Government Digital by Default policy.[2]

As the national experts in population screening, PHE is responsible under the 'Section 7a' agreement for developing information to support local NHS screening to members of the public.

PHE applies each year for print spend approval, for the printing and distribution of leaflets to support the 11 national screening programmes. This is through the "professional assurance application" under the government's advertising and marketing spending controls.

PHE follows guidelines produced by the UK National Screening Committee in supporting informed choice in screening. This requires high quality information to be provided to members of the public invited for screening in appropriate formats for their needs.

PHE produce and advise on wording for screening invitation letters and printed public information leaflets. The leaflets provide the ethical foundation of the screening programmes in supporting personal informed choice amongst the public.

It is important that any changes to the screening invitation process do not negatively impact informed choice, or access to the programmes.

[1] The target indicated was a 75% cost reduction, however at the time of this research this had not been confirmed.

[2] Point 14 of the Government Digital Service Team's Digital Service Standard 2, requires services to phase out non-digital alternatives and encourage all of their users to use digital service, with assisted digital support if required.

PHE is supportive of developing its digital approach to screening information. As Professor Anne Mackie (2019) states in a blogpost for PHE, "Digital information opportunities ahead."[3]

> Reducing our reliance on printed leaflets and moving towards digital methods for providing screening information presents an opportunity for us to be innovative and add value to local screening services

However, we can't assume that everyone will have an easy time accessing information online. As the Department for Digital, Culture, Media and Sport (DCMS, 2018) point out in their 'Culture is Digital' report:[4]

> "Simply making digital content available does not mean that audiences will automatically engage."

Informed personal choice is central to the screening strategy and the information leaflets form a critical part of this process. Whatever changes are made to the information delivery system, they need to accommodate Informed Choice as a core principle.

PUBLIC HEALTH ENGLAND (PHE)

Public Health England is an executive agency of the Department of Health and Social Care. It is a distinct delivery organisation with operational autonomy that provides government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support. Its purpose is "to protect and improve the nation's health and wellbeing and reduce health inequalities."[5]

PHE SCREENING

National population screening programmes[6] are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC),[7] which makes independent, evidence-based recommendations to ministers in the 4 UK countries. PHE advises the government and

[3] PHE Blog: https://phescreening.blog.gov.uk/2019/05/29/digital-information-opportunities-ahead/
[4] Culture is Digital Report: https://www.gov.uk/government/publications/culture-is-digital

[5] About us – Public Health England, accessed 14/01/2020.

[6] https://www.gov.uk/topic/population-screening-programmes

[7] https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc

the NHS so England has safe, high quality screening programmes that reflect the best available evidence and the UK NSC recommendations.

PHE also develops standards and provides specific services that help the local NHS implement and run screening services consistently across the country. Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or informed decisions.

NHS SCREENING SERVICES AND LOCAL AUTHORITY PUBLIC HEALTH TEAMS

It is the responsibility of the NHS to deliver population screening services across England. Each of the population screening programmes has a Programme Manager who ensures that services are available, accessible and capable of delivering the work to the public. These services are made up of a high number of local providers and in some cases include midwifery and GP practices (Antenatal and Newborn screening).

Local authority Public Health teams also have responsibilities for local health outcomes, including prevention of ill health and promotion of healthy lifestyles and wellbeing. There are local and regional differences in how these services are designed and delivered.

THE EQUALITIES IMPACT ASSESSMENT

Public bodies have a general duty to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Equality Act 2010.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.

Health inequalities in England exist across a range of dimensions or characteristics and include some of the nine protected characteristics of the Equality Act 2010, socioeconomic position and geography.

These dimensions include those who are; not registered with a GP, gypsy and traveller groups, in prison, experiencing severe and enduring mental health problems, have drug or alcohol harm issues or have communication difficulties. These are not Protected Characteristics in themselves but can lead to health inequalities.

Screening inequalities can manifest at any point along the screening pathway. The pathway consists of:

- cohort identification (invitation)
- **provision of information about screening**[8]
- access to screening services
- access to treatment
- onward referral
- outcomes

The Public Service (Social Value) Act 2012[9] also provides PHE with a 'duty to consider…' social value within its activities and services. It's important to not only consider the risks of digitisation, but also the opportunities that it brings for people and services in potentially securing "… wider social, economic and environmental benefits."

If people do not have access to the internet (connectivity), no device to connect online, or any combination of low levels of digital skills, confidence, motivation or trust, this can lead to what is called "Digital Exclusion". This may also occur when services change the channels through which they communicate (e.g. from printed materials to online) – this is called "Channel Shift".

Providing people with the equipment, skills, confidence and motivation to engage with the online world generally has a positive effect on people's lives – this is called "Digital Inclusion". The skills people learn are often transferrable, resulting in other benefits like saving money and imporved social wellbeing.

If the public can be effectively supported to 'Channel Shift', then service providers may also achieve cost savings, as digital transactions are usually far cheaper than face to face or telephone. PHE is striving to reduce the printing spend yet not compromise accessibility or engagement with people. It does not want people to be disadvantaged by not having access to informed choice about screening.

[8] Provision of information about screening is the primary focus of this assessment

[9] https://www.gov.uk/government/publications/social-value-act-information-and-resources/social-value-act-information-and-resources

Citizens Online was commissioned by PHE to undertake an Equalities Impact Assessment on changing the way information is given to the public, reducing printed leaflet numbers and increasingly signposting people to online information.

This report details our research, exploring information within the eleven population screening programmes in England and identifying:

- Digital exclusion factors affecting different screening target groups
- Locations in England where digital exclusion may be experienced by screening target groups
- Digital inequalities issues for specific demographic groups, for example older people, disabled people and people who identify as lesbian, gay, bisexual, trans or queer (LGBTQ+)
- How screening information is currently produced and distributed
- How information is understood by screening target groups
- Impacts of reducing printed leaflet materials on the different screening population target groups
- Recommendations for how to effectively manage Channel Shift while mitigating the impacts and risks of the changes

This research explores the potential digital exclusion risks associated with the following screening programmes:

Abdominal aortic aneurysm screening programme (AAA)

Bowel cancer screening programme (BCSP)

Cervical screening programme (CSP)

Breast screening programme (BSP)

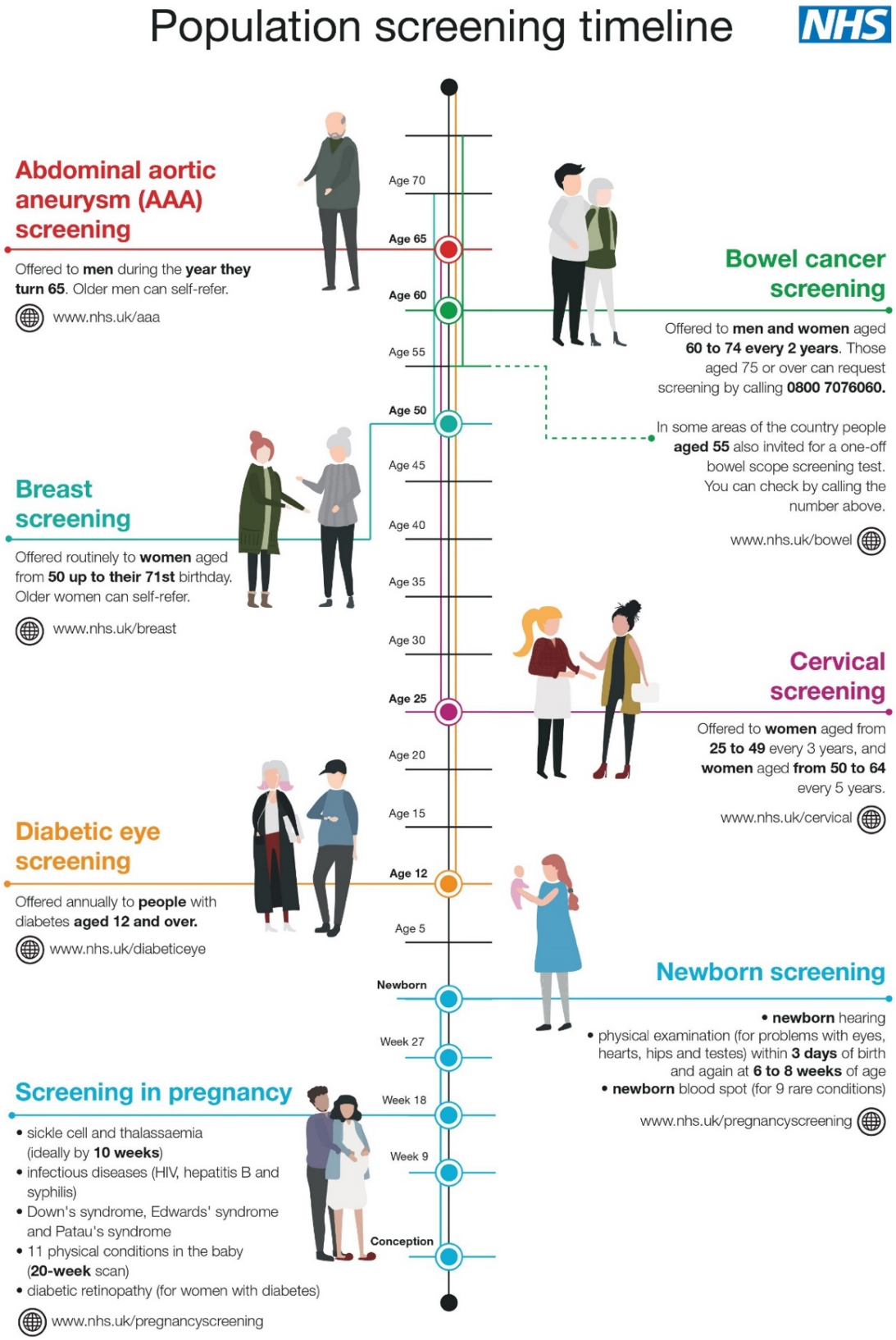
Cervical screening programme (CSP)

Diabetic eye screening programme (DES)

6 x antenatal and newborn screening programmes (ANNB).

The report also covers reviews of relevant literature, together with analysis of demographic and geographic data, and feedback from around 600 online survey responses, 17 telephone interviews, two site visits (focus groups) and a series of PHE meeting attendances.

Figure 1 NHS England Population Screening Programmes timeline



SUMMARY

At the heart of this work we sought to identify the potential impacts of a significant budget reduction to printed leaflets, on the target populations being invited for NHS England population screening.

This research does not recommend a choice of *whether* to continue with 'Channel Shift' and 'Digital by Default' or no - nor does it present an options appraisal with a single recommended course of action.

Rather, it assumes that change is inevitable (and desirable) and seeks to understand and present the best way to manage this and highlight actions that PHE and associated providers (e.g. local authority public health teams and NHS screening services) should consider.

What is clear from our review is that making such a change from printed materials to online is likely to have an effect on the public.

Change to the information will require a change in behaviour for some people and over time this will increase with more people needing to make the leap online. Managing communications with the public and staff teams delivering screening services will be paramount to ensuring a smooth transition which will minimise negative impacts.

We need to consider that stopping doing things is often much more difficult than starting them. More consideration needs to be taken when removing a service that people have become accustomed to and that they may depend on or feel attachment to.

The risk is that when something is removed, people may disengage entirely.

Printed information leaflets for population screening programmes have been provided for many years - care must be taken when making changes to or ending this system of delivering information. The public cannot be expected to automatically switch to a new way of doing things without help – and providing help with new ways of interacting and receiving information takes time. The growing body of evidence around human 'behaviour change' indicates that some people will adopt new communication practices early and other will take time and need ongoing support to maintain skills and confidence. This is particularly true of older people and using digital technology.[10]

[10] BT Get IT Together Longitudinal Study, Just Economics, 2014

The most effective way we can recommend approaching the change from printed materials to online information is to adopt these three top level principles and practices:

A. Avoid making all the changes at once. Plan a phased change programme. Starting with the programmes with target groups that contain the smallest number of people at risk of not being able to access online information. Learn from these groups and apply learning to the more challenging programmes.

B. Continue to send leaflets with prevalent invitations[11] and make changes to stop leaflets with incident invitations. Learn from this process as a staged approach to providing online information.

C. Ensure that NHS screening services provide high quality 'information channel' choices in the future for those that need them (including face to face, telephone, printed and digital). People with protected characteristics under the Equality Act should have their needs met and reasonable adjustments should be made to ensure information is accessible.

If these are followed, we consider programmes to have the greatest chance of minimising negative impacts and reducing the risk of undesired changes to the accessibility of screening.

FINDINGS

In this section we give an overview of the main considerations for PHE in managing the change from printed material to online information. We also prioritise the programmes in terms of a potential phased approach. The detailed analysis that sits behind these recommendations can be found in subsequent Appendices of the report.

PRIORITISATION OF SCREENING PROGRAMMES AND DIGITAL EXCLUSION RISK

We closely examined digital exclusion and equalities risk factors, for the target population being invited to each screening programme. We allocated a risk score and weighting to each factor. We have ranked each screening programme for likely risk for digital exclusion amongst its target group over the next five years.

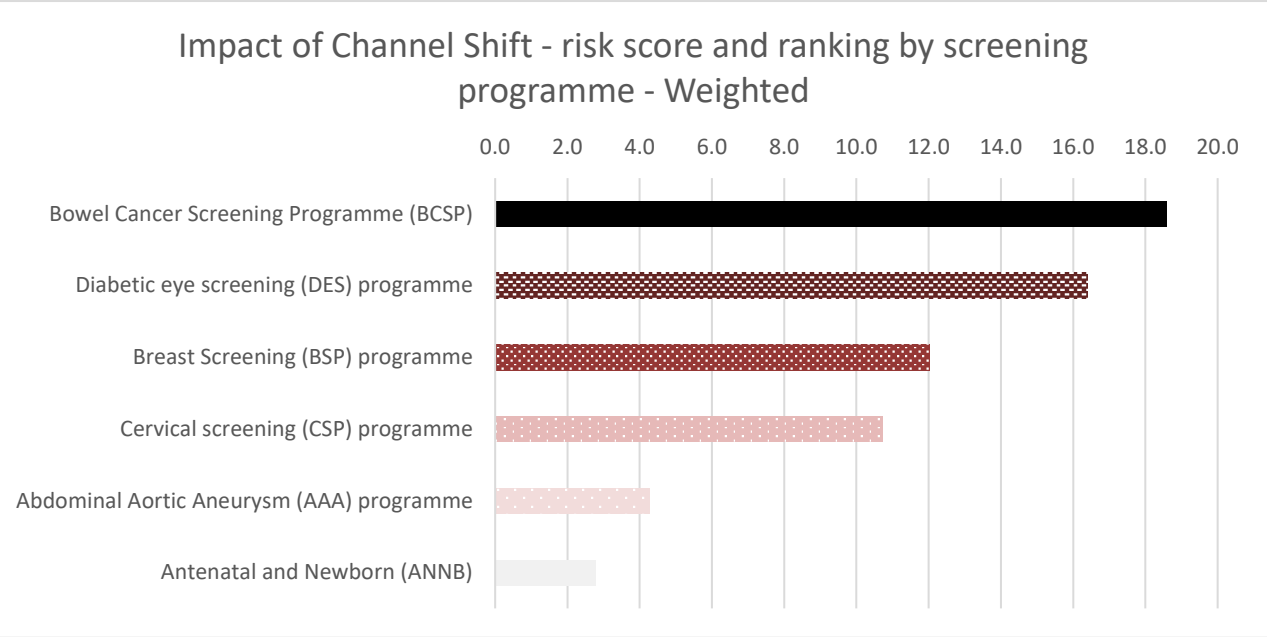
[11] All screening invitations are prevalent until an individual first accepts and attends for screening. Once that individual has accepted and attended screening, all subsequent invitations to them are incident invitations.

The programmes with more potential risk impact from Channel Shift have :

1. Larger target population numbers and frequency / number of leaflets produced (scale)
2. Larger target populations who are older and/or offline[12] (the key digital exclusion factors)
3. Qualitatively assessed levels of equality impact or sensitivity to change (interview / survey responses)

The data we used to estimate offline populations in England across all programmes was the Office for National Statistics (ONS) Internet Users survey.[13] The results of the risk profiling exercise are summarised in Figure 2.

Figure 2 risk rating of each screening programme – weighted



[12] The total number of digitally excluded people who might be affected is higher than those who are not regular internet users by the ONS definition we use in the table calculations. The ONS has a definition of 'offline' which is relatively narrow, whereas we know that more people struggle with specific types of online activity even if they are active internet users. For example, someone may be confident and happy to use social media but not happy to look at health information, pass over personal details, or make financial transactions online. These types of online users may still prefer to read printed information when engaging with a health service.

[13] ONS - Internet users, UK: 2019, accessed 25/09/2019

A full analysis of digital exclusion risks within each programme and across all of them can be found in **Appendix 1 – Screening Programmes and Digital Exclusion.**

Broadly speaking there are **two 'top risk' programmes – BCSP and DES**. This is owing to the large numbers invited over time and that the age groups of the target populations have a high proportion of 'offline' people.

There are **two 'middle risk' programmes – BSP and CSP**. The third and fourth places were difficult to agree as there were quite diverse factors influencing the weighting. However eventually the older population represented by the Breast Screening programme outweighed the large numbers invited to the Cervical Screening programme. Both services would still be considered as having significant potential impacts from going digital.

There are **two 'lower risk' programmes – AAA and ANNB**. These represent programmes where there are either a comparatively small number of invitations (AAA) or where people are having face to face contact as part of their service as well as being given written information (ANNB).

In Table 1 we provide a summary of each of the programmes and their most relevant associated risks, including any headline statistics or estimates. The population targets are based on our best estimate of the number of people eligible to access in each programme over the five years 2020-2025. Our estimates of Offline Populations (as a number or percent of the Target Population) are based on current age-related offline population data from the Office for National Statistics (ONS).

Table 1 Summary of each screening programme risks

Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
1	**Bowel Cancer Screening Programme** (BCSP)	**Target Population: 12.8m** **Estimate Percent Offline: 9.8%** **Estimate Number Offline: 1.25m**	We estimate **this target group has the most people likely to be offline over five years.** The percentage of offline people in this target group is second highest across all programmes. Over a third of the cases across all programmes, where we think people are less likely to access online information, are in the BCSP. This is because of the large target group size *and* older people being invited

Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
			to the screening programme (Eligibility is age 60+ not including one off Scope Screening offered in some areas at ages 55-59).
2	**Diabetic Eye Screening Programme** (DES)	**Target Population:** 3.7m **Estimate Percent Offline:** 28.4% **Estimate Number Offline:** 1m	We estimate **around 1 million** people in this programme **are offline**.[14] As age is a key factor in diabetes and digital exclusion, **the proportion (%) of people we suggest are offline is highest in this group.** The true figure may be higher, as we have made digital exclusion estimates based only on the age profile. There are other digital exclusion factors where Diabetes is more likely, such as deprivation and BAME[15] population. We estimate **28.4% of people** in this programme are more likely to **request non-digital information.** However, people with diabetes are already symptomatic and linked in with an NHS service which may offset some of the need over time.
3	**Breast Screening Programme** (BSP)	**Target Population:** 8m **Estimate Percent Offline:** 7.3%	The Breast Screening programme accounts for **17% of cases where an alternative to online information** is more likely to be needed. We estimate this to be at least **580,000 women,** which is around 7.3% of the 7.9 million to be

[14] The Target Population estimate for the DES is based on multiple factors including age and ethnic background, while our estimates for offline population are based on age alone (ONS data). Over 5 years, the target number does not multiply each year at the same high rate as other programmes, because screening is invited annually from the age of 12 and so the number of new people entering the programme happens at a lower rate.

[15] Black, Asian and Minority Ethnic (BAME)

Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
		Estimate Number Offline: 0.6m	invited to the screening programme between 2020 and 2025.
4	**Cervical Screening Programme** (CSP)	**Target Population:** 16.4m **Estimate Percent Offline:** 2% **Estimate Number Offline:** 0.3m	This screening programme has the **largest target** population and the largest leaflet screening budget across the programmes – however as the target group is younger, the proportion and number of people (328,000) estimated to be offline is significantly low, and low in comparison to other programmes. These two extreme factors balance out the risks meaning this programme takes one of the middle places in the overall risk rating.
5	**Abdominal Aortic Aneurysms Screening Programme** (AAA)	**Target Population:** 1.9m **Estimate Percent Offline:** 7% **Estimate Number Offline:** 0.1m	The estimated offline population for AAA population screening is relatively high compared to others at 7%. Yet, the lower number of people in the target group amongst the YPA programmes, results in **a low number of people estimated to be offline - 130,000.** The AAA programme is the lowest risk amongst the YPA programmes. All invitations will remain Prevalent and it is unlikely there will be any change to printing immediately.
6	**Antenatal & Newborn Screening Programme** (ANNB)* *across six programmes	**Target Population:** 3.3m **Estimate Percent Offline:** 0.5% **Estimate Number Offline:** 0.02m	**The ANNB programme remains the lowest risk overall across all programmes, when considering digital exclusion risk.** While the Target Population for invitations is estimated to be high, the lower age group and the fact that all women will receive face to face advice, information and support in the course of their pregnancy, makes this the lowest risk programme. The estimated

Risk Rating 1 = Highest 6 = Lowest	Programme	Programme Metrics (2020-25)	Risk Description
			offline population within this target group is 16,000

DIGITAL INEQUALITY AND PROTECTED CHARACTERISTICS

Any Channel Shift programme should give careful consideration to groups that are not / or find it difficult to get online. These groups are at risk of not receiving screening information and therefore may not able to make an informed choice about whether to attend an appointment. These groups include:

- Older people
- People on low incomes and/or socially excluded
- Disabled people (including learning difficulties / disabilities)
- Those who cannot get online (not connected / can't afford it)
- Those who choose not to be online (for a variety of reasons)
- Those for whom English is a second language
- People in residential care, in supported accommodation, or experiencing homelessness
- People in prison

PHE's 'Guidance on Equitable access to screening: Statutory duties under the Equality Act' (PHE, 2017a), asserts that "All eligible populations should have access to screening and understand the benefits and risks." Screening programmes are required to pay particular attention to reaching people with the 9 protected characteristics. It is against the law to discriminate against anyone because of:

- Age
- Gender reassignment
- Being married or in a civil partnership
- Being pregnant or on maternity leave
- Disability
- Race including colour, nationality, ethnic or national origin
- Religion or belief

- Sex
- Sexual orientation

The following is a summary of our key findings across the protected characteristic groups and in some of the special characteristics and intersections between them, for example disability and deprivation. We do not cover all characteristics here (excluding those where we found minimal levels of potential impact from going digital). The full detail is available in **Appendix 2 – Digital Inequality.**

AGE

We know from a variety of sources that older people are more likely to be digitally excluded – to be offline, to lack digital skills and to be less likely to have access to digital devices. According to the Office for National Statistics (ONS), **33% of people aged 65+ have not been online within the last 3 months**[14] – hence they are effectively not online.

Of these, the great majority (86%, or 29% of all people aged 65+) have *never* been online. More than half of the population aged 75+ (53.1%) are not online (have not used the internet within the last 3 months) and most (89%, 47% of all people aged 75 or over) of these have never been online.[16]

DISABILITY

Disabled people are among the demographic groups research has consistently identified as being more likely to be digitally excluded. ONS data on internet users shows ***the proportion of disabled adults who are not internet users remains considerably higher than for adults who are not disabled*** (21.6% compared to 5% in 2019, using the Equality Act definition).[14]

The 'Is England Fairer?' (Equality and Human Rights Commission – EHRC, 2018a) report found a clear intersection between disability and deprivation:

- "In 2015/16, 25.1% of disabled adults in England were living in poverty. The rate for disabled people increased by 2.4 percentage points between 2010/11 and 2015/16."

[16] ONS - Internet users, UK: 2019, accessed 25/09/2019

- "The poverty rate was high among people with social or behavioural, mental health, and learning or understanding or concentration impairments (37.6%, 34.5% and 31.0%)."
- "In England, disabled people were nearly three times as likely to experience severe material deprivation[17] as non-disabled people (37.1% compared with 13.8%)."
- "Disabled people were twice as likely as non-disabled people to be NEET (16.4% compared with 7.0%)"

Disabled people are more likely to experience deprivation (including financial hardship, low or no income). PHE data also suggests that coverage for some screening programmes is lower in areas of high deprivation.

Disability and deprivation are both factors that limit digital inclusion and these combined factors mean that a shift to online information may indirectly impact uptake, even if digital content has a high level of accessibility and is of good quality.

SEX

There is little difference between men and women with regard to levels of digital exclusion (92% of men are internet users, compared to 89.6% of women). However, there is some evidence that older women are more likely to be digitally excluded than older men.

Across the UK **63.2% of women aged 65 or over are internet users, compared to 71.1% of men.**[18] Screening programmes and information about them will impact on people according to the target demographic, which is limited by sex for some of the programmes, particularly where this overlaps with age.

RACE, NATIONALITY, ETHNIC OR NATIONAL ORIGIN

The proportion of Black, Asian and Minority Ethnic (BAME) adults who are not internet users is lower than the UK average (6.6% compared to 9.0%) and make up 8.6% of all the adults who are not using the internet in the UK.[16] However, the proportion of adults that are not internet

[17] "An individual is defined as deprived if they cannot afford 4 or more from a list of 9 items, such as replacing worn out furniture or keeping their accommodation sufficiently warm."

[18] ONS - Internet users, UK: 2019, accessed 25/09/2019

users varies by ethnicity: Chinese adults are considerably more likely to be internet users than average, while Indian adults are less likely to be internet users.

PHE already publish information in ten languages, however having English as a second language significantly impacts people's ability to understand both printed and online information. Online screening information should enable greater access to information in a range of languages – especially if digital technology than can read screens and translate text to speech in a wide range of chosen languages.

Cervical screening coverage is lower in Clinical Commissioning Group areas where a higher proportion of the population is BAME, a phenomenon that is more pronounced among the younger age group (25-49).

BEING PREGNANT OR ON MATERNITY LEAVE

Antenatal and Newborn screening programmes will affect people who are pregnant or on maternity leave, and any impact of moving information about these screening programmes online will affect this group. However, as detailed below, the risk in the case of these screening programmes is reduced, not only because of the lower age demographic associated with pregnancy, but also because of the frequency of face-to-face sessions.

GENDER REASSIGNMENT

The Government Equalities Office's National LGBT Survey (2019) found "higher inequalities in health satisfaction and outcomes" for LGBT people as a whole. Specifically, ***21% of trans respondents said their "specific needs were ignored or not taken into account when they accessed, or tried to access, healthcare services*** in the 12 months preceding the survey."

Stonewall (2018) recommend the government "Support healthcare services to routinely monitor patients' gender identity, where appropriate, and engage with the trans community to develop a Monitoring Information Standard for gender identity." We can make no specific recommendations regarding online information other than awareness of these issues and reference to the LGBT Foundation,[19] who offer training to show how screening services can be inclusive and accessible for trans people.

[19] https://lgbt.foundation, accessed 13/02/2020.

SEXUAL ORIENTATION

In 2016, the ONS estimated that 2% of the UK population, or just over 1 million people, identify as having a minority sexual orientation, according to the Government Equalities Office (GEO, 2019). Proportions were higher among younger age-bands (4.1% of 16-24 year olds compared to 2.9% of 25 to 34 year olds and 0.7% of those aged 65 and over).

While this may reflect differences in degrees of comfort with providing identity in government datasets, it could suggest that LGB people are less likely that the population as a whole to be digitally excluded – on the basis of the age profile alone.

MULTIPLE DEPRIVATION

The Index of Mulitple Deprivation (IMD) for England utilises a number of different domains – income (with subdomains on income deprivation affecting children, and older people, respectively), employment, education, health, crime, barriers to housing and services, living environment.

We know that digital exclusion is associated with deprivation in at least some of these domains (income, education). Level of education is also often identified as a factor in digital exclusion. Dutton and Blank (2019), for example, note that **just 36% of people with no qualifications are internet users.**

We know coverage for some screening programmes (AAA, breast, cervical, DES – see Appendix 2) is lower in more deprived areas.

In moving to a system where more information about screening programmes is delivered online, there is a risk this may further reduce coverage in areas of high multiple deprivation.

TESTING THE INFORMATION DELIVERY CHAIN

The following section sets out our findings and recommendations about the current syste of information transfer and how any change to develop digital information could best be managed to ensure digital inclusion and accessiblity. It is based on several pieces of work that are available as Appendices to this report:

- Appendix 3 – Thematic Review of YPA programmes (interviews and focus groups)
- Appendix 4 – Literature Review of Public Health Screening and Digital Exclusion

- Appendix 5 – YPA programme staff survey
- Appendix 6 – Digital Information opinion survey

The thematic review took analysed feedback from 17 telephone interviews with screening staff and 2 site visits (to the bowel cancer screening centre at St Mark's Hospital, London and the AAA screening clinic at Salisbury General Hospital). In addition, men attending for AAA screening at Royal Shrewsbury Hospital were asked about their online status and attitudes by screening staff.

We ensured that there was a good geographical spread of interviewees, and that all five Young People and Adult programmes were reflected. This work gave us rich insight into attitudes and behaviours of people working in and using the screening services. The assessment of digital exclusion risks across the programmes (Appendix 1) and digital inequalities across the protected characteristic groups (Appenix 2) also inform what follows here.

Screening programmes invite very large populations to be screened and so even a small drop in access could significantly affect the health benefit from the programmes. From our review there is little current evidence to suggest that moving screening information online will significantly improve coverage immediately (although the absence of evidence does not indicate that this is impossible, it simply means we found little evidence).

There are some indications that 'Channel Shift' may initially increase 'information barriers' to accessing some services for some people. There is certainly concern that this will be the case among workers who advise on or deliver the programmes. Survey responses from interested members of the public and a large number of health professionals, show a high degree of caution about Channel Shift to 'online only' information.

THE CURRENT INFORMATION SYSTEM

The system of invitations for all screening programmes starts with sending printed letters to eligible members of the public along with printed leaflets that provide further information that has been created by PHE, based on expert advice and best practice. The request to the member of public within the letter will be to explain that the person is eligible for a screening progarmme and explain the next steps.

There are a significant number of different providers across the screening programmes, delivered by NHS services (and private providers commissioned by the NHS). General information about the screening programmes is currently available in the following ways:

- GOV.UK website: https://www.gov.uk/topic/population-screening-programmes
- NHS.UK website: https://www.nhs.uk/conditions/nhs-screening/
- PHE Screening Blog: https://phescreening.blog.gov.uk/
- PHE Screening Helpdesk:[20]
    - Website: https://phescreening.blog.gov.uk/helpdesk/
    - Email: phe.screeninghelpdesk@nhs.net
    - Contact form: https://legacyscreening.phe.org.uk/email_us_form.php
    - Telephone: 020 3682 0890
- Bowel Cancer Screening Helpline: 0800 707 60 60
- Third party websites such as Jo's Cancer Trust and Bowel Cancer UK

Survey respondents frequently mentioned the benefits of printed information leaflets – a summary of the key advantages alongside disadvantages follows:

ADVANTAGES OF PRINTED LEAFLETS

- Familiar format
- Immediately accessible / available to those not online
- Can be read immediately / requires no further intervention
- Possible to write notes on them
- Tangible item to be held – makes it real
- Transferrable / can be passed on to friends and family or used as conversation prompt
- A physical reminder to make an appointment / stays visible e.g. stuck to fridge

DISADVANTAGES OF PRINTED LEAFLETS

- May not be read / can be lost or perceived as 'junk mail'.
- Out of date quickly / potential misinformation
- May not be accessible to those with sight loss / visual impairment
- Some people consider them aimed at a high level of education and literacy

[20] The PHE Screening Helpdesk is designed for professional queries and doesn't have access to appointment details or test results. In most cases if the public make enquiries to the Helpdesk, they are referred to their relevant local screening service.

- Costly (time, financial and environmental factors):
  - Administration time in ordering / receiving
  - Printing / production is not environmentally friendly
  - Need to be stored and storage paid for
  - Wastage of unused leaflets / disposal time and costs

ADVANTAGES OF ONLINE INFORMATION

- Can be kept up to date easily
- Less costly
- More environmentally friendly
- Can have more detailed supporting information such as travel information
- Can provide information in other formats and languages more easily

DISADVANTAGES OF ONLINE INFORMATION

- Risk of excluding people who aren't online and widening inequalities
- Volume of promotional email received
- Privacy and confidentiality concerns

Many of those with concerns about digital exclusion would be satisfied with a system where people retain or are offered a choice of how to receive the information and where multiple options remain available - including printed leaflets for those that need them.

RECOMMENDATIONS

Our recommendations are split across a range of thematic areas associated with the screening programmes and the proposed changes to printed and online information.

INVITATION LETTERS

Invitation letters are a critical part of the current communication process. Letters will continue to be sent out by screening services and GPs. There is no current proposal to change this. At this time the only change being proposed is what printed information is sent *along with* the letters - and the written content of the letters. How the screening services utilise the invitation letters, either as potentially the *only* piece of information, or as a method to *signpost* to online information, is paramount to managing risk.

1. Send leaflets with all prevalent invitations but remove leaflets from incident invitations. This will allow a phased approach to reducing leaflet printing numbers. Those receiving incident invitations should already have received a leaflet.
2. Ensure that incident invitations include clear accessible information about how to request a printed leaflet or equivalent information in a form that meets their needs. The wording should be changed on incident invitations to signpost to online information.
3. Commission research to find out the best text to use in 'Invitation Plus' and improved letters. Consider feedback and outcomes from Bowel Cancer Screening Programme which is trialling the 'Invitation Plus' approach.
4. Design an 'Invitation Plus' letter for all programmes, with the intention of improving on both prevalent and incident invitation letters. This would include essential screening information needed to support an informed choice.
5. When screening programme phone numbers are available for additional information or advice (e.g. Bowel Cancer Screening Programme), ensure they are clearly stated in all invitation letters.
6. Analyse feedback and results from the Antenatal and Newborn programme in use of QR codes used on posters, business cards and appointment booking letters.
7. Add QR codes to invitation letters across the programmes as an option to signpost to further online information. Learn from experience with QR codes in the ANNB programme. Give clear instructions in the letter how QR codes work. Test the approach, track and learn about public use of the links by analysing data.

8. Provide easily typeable hyperlinks[21] within invitation letters to signpost to online information (prevalent and incident). Test the approach, track and learn about public use of the links by analysing data. For example, direct links to online information about each programme could be as follows:
    - BCSP: gov.uk/screening/bowel
    - DES: gov.uk/screening/diabeticeye
    - BSP: gov.uk/screening/breast
    - CSP: gov.uk/screening/cervical
    - AAA: gov.uk/screening/aaa
    - ANNB: gov.uk/screening/antenatal-newborn

We've considered that QR codes and hyperlinks both potentially introduce a further barrier to accessing needed information, where people may 'put off' the job of looking online until later. This could have an impact on whether they book an appointment. However, they are options that on balance we think ought to be maintained or introduced, and more importantly tested and monitored.

ONLINE INFORMATION

There is a clear need for online information to be designed as mobile-first. From 40 million visits a month to the NHS.UK website, 65% are made by smartphone. 24% of visits are via a computer and 11% by tablet.

Online information needs to be easily accessible and high quality, meeting (or exceeding) national standards.[22] Online information also needs to be diverse in order to reflect the different needs of the public.

[21] Currently hyperlinks for PHE Screening may be allocated by the Government Digital Services (GDS). There are restrictions on what type of links can be published on GOV.UK where screening information is currently stored. Links are generated according to a standard naming convention and some are currently too long and / or complex for the average internet user to be able to copy into a website browser.

As examples of overly long hyperlinks, the current Bowel Cancer Screening page link on GOV.UK is: https://www.gov.uk/topic/population-screening-programmes/bowel and the PDF leaflet link is: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/815657/bowel_cancer_screening_invitation_leaflet.pdf

[22] Web Content Accessibility Guidelines 2.0 https://www.w3.org/TR/WCAG20/

We consider it essential to continue to produce or create new online information in multiple languages and a range of accessible document formats e.g. HTML web pages and PDFs. It is important to have different types of media such as audio and informational films / animations, to convey information.

Websites that host screening information must be easy to navigate on mobile devices (phones, tablets and laptops) as well as desktop computers.

9. Unify or consolidate information online between GOV.UK and NHS.UK so that the public have a single trusted source of information to go to.
10. Develop and expand the amount of screening information available in video format. Some excellent animation videos have been produced for the Antenatal & Newborn programmes. These could be extended and publicised widely.[23]
11. Continue to create online information in different languages and the ability to request information in a language that is different to those available as standard[24].
12. Consider adding accessibility tools to websites that include language translation options with screen readers.[25]
13. Ensure online materials meet the Accessible Information Standard.[26] This is a 'continued practice' recommendation as PHE are already doing this. This ensures that people with a disability, impairment or sensory loss are given information in a way they can access and understand.
14. When re-designing information delivery systems, create or develop 'digital reminders' as a way to supplement or eventually replace printed information that is currently valued highly by users, as a tangible physical reminder to make an appointment.

[23] Use of video as a learning tool globally has increased dramatically in recent years. Next to Google, YouTube is the most used website on the planet, with Facebook in number 4 (2020 figures). Both host video content and are used increasingly as places to find useful information. There are issues to consider around trusted information sources online, but the NHS and UK Government (both trusted brands) have a presence on both platforms.

[24] PHE Screening Information Team will continue to produce guidance in 10 languages. Requests for additional translations are managed and responded to at a local level by individual screening services.

[25] There are various commercial products available currently that include effective screen readers and use built in tools such as Google Translate to convert text to speech in most languages. These do not rely on the user having purchased their own screen reader software and equipment and tend to work well on mobile devices.

[26] https://www.england.nhs.uk/ourwork/accessibleinfo/

IT SYSTEMS

Feedback from our research broadly suggested that the IT systems required to engage digitally with the public were not currently fit for purpose or were slow to change. This has significantly hampered efforts to introduce more online support and information and make better informed decisions about what to communicate to whom, and when.

The main feedback was from services lacking demographic data about people in vulnerable groups when sending out initial invitations. For example, there not an option to send a different invitation to people with sight loss or a learning disability.

Many applications (or Apps) for personal digital health management have been created with a "design it and they will come" approach. This approach may not attract users whose health literacy, cultural values, or low levels of trust limits their willingness to use digital tools. While personal digital health management tools perform different functions than population health screening programmes, an analogy can be made - this is information that could protect someone's health, but only if they engage with it and take the decision to undergo screening. Hence, design that takes into account potential exclusion factors or distrust is important. One manager fed back to us:

> "The only way to cater for all the abilities [ ] of varying patient groups is to allow them to [ ] choose […] how they would like to receive their [ ] communications. [ ] Access to change their preferences could be through their GP or by way of a screening portal with key demographic cross referencing"

If it were technologically possible, linking online information about screening programmes to online booking of appointments could prove valuable.

15. PHE, NHS England, NHSX and NHS Digital should work together to create and develop systems that work around user needs. The digital technology needs to be capable of recording channel choice and communication preferences, as well as the specific needs of user groups e.g. disabilities, demographics and language needs.
16. NHS Digital should explore developing the NHS App to accommodate screening information and ultimately linking this to appointment booking where possible. Numerous App providers exist in the marketplace for digital health in which the NHS

App is one. There may be synergies or opportunities to develop good solutions with other providers.

TEXT MESSAGING

Text messaging (SMS) has proved an effective way of getting important information to users and signposting to online information through hyperlinks. PHE has, for example, updated service specifications for cancer screening to now include references to text messaging, timed appointments, reminder letters and GP endorsed appointment letters.

People with smartphones may be more likely to follow a web link in a text message than in a letter (though they may be reluctant to do this if they are not sure the link is safe).

Texting requires the services to obtain, store and process personal and sensitive data about members of the public. It is unlikely that this information will be known in most cases at the point of invitation. GP practices may hold mobile phone data, but its coverage and accuracy should be assessed before assuming it is viable for a blanket digital approach to sending out screening information.

Additionally, the IT systems needed for keeping and up-to-date screening population and patient data, to use for targeting initial invitation information are not yet in place.

Using texting for incident and surveillance[27] invitations is likely to prove very effective in future. Some local GP areas are already using the technology successfully to engage with patients.

NHS screening services should introduce text messaging as a cost-effective way to target messages to the public. However, texts can only be sent when phone numbers are available, and people have consented to be contacted in this way. PHE should provide expertise and advice to services from good practice examples.

17. Text messaging services for information, signposting and appointment booking should be explored and developed based on good practice and successful pilots in this area.
18. Consider special solutions for when the user may have their access to a phone wholly or partially controlled by someone else (consider supported housing or care provision).[28]
19. Consider ways to tailoring or change information content to engage clients who have low literacy, differing language skills, or limited digital literacy.[21]

[27] Follow up appointments in some screening programmes where periodic screening checks need to be made

[28] Recommendation transferred from the Cochrane Review 2019 (See Appendix 4 Literature Review)

20. Explore how clients perceive different sources of digital health interventions as more or less reliable, trusted, and credible and use only sources that are perceived as such, to send digital health messages. [21]

CALL CENTRES / HELPLINES

Call centres and helplines are an excellent resource for people who find written information of any kind (whether printed or digital) a challenge. They are also an expensive channel option (only 'face to face' interactions are more expensive). They require trained staff to respond to enquiries and increasingly, customer demand may mean having lines open longer.

It is unlikely to be financially viable to introduce new helplines into the system - the proposed reduction in printing budget will likely not cover the costs of new resources like this.

Currently, only the Bowel Cancer Screening Programme has a helpline. We expect that in other programmes where demand for printed leaflets may remain high (e.g. the Breast Screening Programme) but there is no national helpline to call, that other means of ensuring information is given over effectively will need to be prioritised and supported.

21. The screening helpdesk should continue to provide a phone line for enquiries as well as the existing channels of email and online web information and web contact form. It is likely that a switch to digital information will see an increase in enquiries to the Helpdesk and PHE Screening need to consider the potential to increase resources to accommodate this.
22. The Bowel Cancer Screening Helpline should continue to provide advice and support about the programme. Staff answering these calls should be given additional information and training to support people that may phone with enquiries about online information.
23. We recommend a local phone number be available wherever possible so people can call and request further information, alleviating pressure on the Screening Helpdesk. This need not be a central programme level call centre, but may be listed within the Invitation Letter e.g. a local screening service / GP etc. Staff responding to any phone enquiries may need extra support to advise the public effectively.

PRINTING BUDGET ALLOCATION

Our research assumes that there will be a reduction in leaflet printing budget based on the initial brief from PHE. While we do not know the exact amount that this may be, it is expected to take place and a figure of 75% reduction had been indicated. At the time of writing we were

not sure as to when this might take place, however April 2020 was indicated as being the start point for budget changes. Our Principle A for this work is to take a phased approach to a programme of change and this includes any approach to budget reductions.

24. We recommend taking a phased approach to budget cuts and reducing printing costs in programmes that present the lowest risk of digital exclusion first – namely starting with the ANNB programme which is already making changes through the Early Adopter pilot sites.
25. Consider reallocating any future reduced leaflet printing budget with different % shares across the programmes. PHE could consider our model for possible future demand for printed leaflets in estimating where future resources might be needed, based on future offline populations within each programme (see Appendix 1). This approach would avoid applying a blanket 75% reduction across all programmes and may better address needs of different equality groups (eg older people who are also offline).
26. Consider if future budget cuts in one geographic area or programme, present an opportunity to reallocate finance to an alternative location or programme where more need / demand for printed materials is likely. If there is demand, budget could be also redirected to support local projects tackling wider inequalities, not just digital exclusion.

GENERAL RECOMMENDATIONS

We've suggested some ideas for how PHE Screening and the NHS screening programme delivery services could work together and support each other to positively influence or effect change in adopting digital information. Key to this is the workforce - culture change across the health system is needed, to support improvements in confidence, skills and motivation. Using or promoting online services and information may be as much of a challenge across the workforce as it is with the public. The attitudes and behaviours of staff toward digital, significantly influence the public's ability to access and engage:

27. Support the NHS screening services and PHE workforce to better understand digital communication and engagement. Where encouragement, training and learning are needed, provide it.[29]

[29] There were notable levels of negativity towards digital information amongst the health workforce, evidenced in the surveys we undertook and also in some anecdotal feedback from staff working in some programmes, with specific reference to midwives.

28. Use public health, NHS and social care system levers and incentives (such as funding opportunities that might arise or programmes of work like Making Every Contact Count (MECC)[30] and the Widening Digital Participation programme[31]) to effect change and support digital engagement with the public.
29. Explore and support viable partnerships between NHS screening service providers and digital health technology providers (e.g. NHS App), who may be able to reach target audiences with key information in a timely way. A strategic framework is required to avoid a fragmented approach as there are many popular health apps.
30. Promote and celebrate digital innovation that is currently happening in some screening services. Share the learning from these projects and scale up good practice across the programmes.

CONCLUSION

There are three areas where this research offers insights to PHE and its partners and stakeholders on how to best manage change.

Firstly, it provides the information about which screening programmes have the highest levels of future digital exclusion risk, based on the demographics of the target population to be invited for screening over the next five years.

The Bowel Cancer Screening Programme and the Diabetic Eye Screening Programme are considered the most challenging areas of work. Specific risks are noted in all programmes, but the Antenatal and Newborn screening programme is considered both the furthest ahead and the lowest risk in terms of digital exclusion.

Secondly, it provides valuable background information on the experiences of people with protected characteristics of using health services and accessing health information online.

Where possible it relates these to individual programmes, for example how older people might understand and access information about Bowel Cancer Screening. We identify the key characteristics as age and disability and when combined with any level of deprivation (e.g. financial exclusion) this creates a compound effect on the likelihood of digital exclusion occurring.

[30] Making Every Contact Count - https://www.makingeverycontactcount.co.uk/
[31] Good Things Foundation and NHS England - https://www.goodthingsfoundation.org/projects/nhs-widening-digital-participation-phase2

Thirdly, we provide detailed information on the opinions, attitudes, behaviours and expectations of the public when engaging with screening information, both in the current system and in considering future changes to a 'digital first' system. We note that there is a significant level of concern about rapid change.

Our recommendations sit within a framework of overarching principles:

A) taking a phased approach to change;

B) maintaining the use of printed leaflets for prevalent invitations for the time being and looking to reduce, limit or end leaflets with incident invitations first, and;

C) promoting public choice and preference in future communications, and ensuring that online content is accessible and safe.

We hope that the comprehensive and detailed supporting information contained in the appendices is informative and supportive for several years from issue and that it can be used to inform the development of a digital service that is equitable and engaging for everyone.

Appendix 1 - Screening Programmes and Digital Exclusion

EXISTING COVERAGE AND POTENTIAL CHANNEL SHIFT IMPACT

Screening programmes are monitored via a number of Key Performance Indicators (KPIs). These focus around the following:

- **Coverage:**
    - Refers to the percentage of the target population who were screened adequately within a particular period.
    - May identify target population numbers for different **levels** of screening e.g. initial screening, annual and quarterly surveillance in the case of AAA, or;
    - May identify target population numbers for different **age groups**, as for cervical screening.
- **Uptake:**
    - Refers to the proportion of people adequately screened *out of those invited for screening*.
    - May identify target numbers to complete the screening process in % terms.
- **Process Targets:**
    - May include timeliness of appointment / consultation following invitation.
    - May include timeliness of follow up when a screen is positive.

Our research is concerned with any potential significant impact on coverage or uptake, when providing information online. But not with KPIs around timeliness of follow-up.

Coverage and uptake levels vary for each of the screening programmes. Figure 3 shows the Young Person & Adult Screening Programmes. Coverage levels are significantly higher for the Antenatal & Newborn Screening Programmes, as shown in Figure 4.

Coverage / uptake also varies across the country, in part because of differential take-up associated with demographic groups. While uptake of breast screening is falling slightly, these levels are broadly static. In the sections on each of the screening programmes below, we explore the extent to which coverage may be affected by moves towards providing information online. Our recommendations aim to prevent negative impacts on these trends.

Figure 3: % Screening coverage / uptake for Young Person & Adult Screening Programmes, 2013-18.

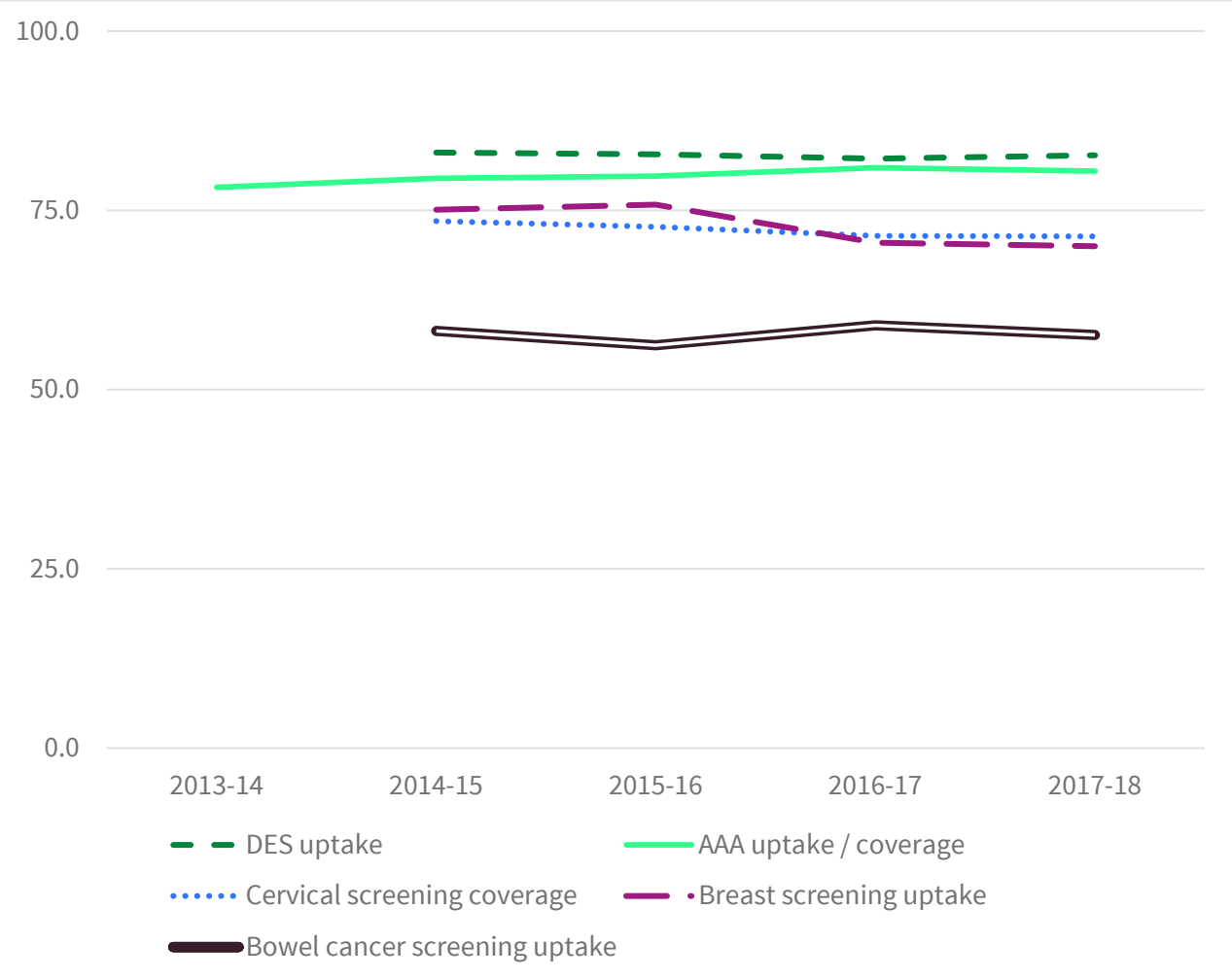
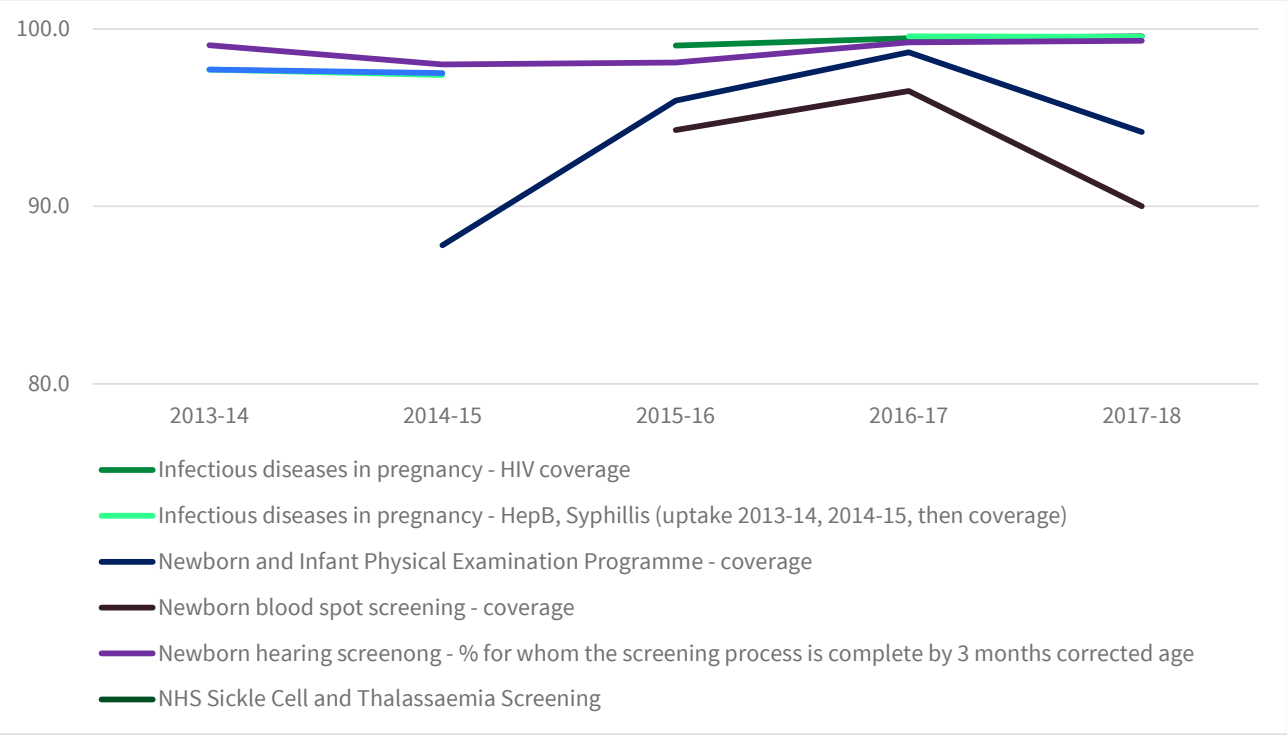


Table 2: % Screening coverage / uptake for Young Person & Adult Screening Programmes, 2013-18.

Adult and Young person screening programmes	2013-14	2014-15	2015-16	2016-17	2017-18
Diabetic Eye Screening Programme (DES) uptake		83.1	82.8	82.2	82.7
Abdominal Aortic Aneurysms Screening Programme (AAA) coverage / uptake*	78.2	79.5	79.8	80.9	80.5
Cervical Screening Programme (CSP) coverage**		73.5	72.7	71.5	71.4
Breast Screening Programme (BSP) uptake		75.1	75.8	70.5	70
Bowel Cancer Screening (BCS) uptake		58.2	56.2	58.9	57.6
*AAA figures are "uptake" for 2013-14, 2014-15, "coverage" thereafter					
**Cervical screening coverage is the percentage screened adequately within the previous 3.5/5.5 years, depending on age bracket					

Figure 4: % Screening coverage for Antenatal and Newborn Screening Programme (ANNB), 2013-18.



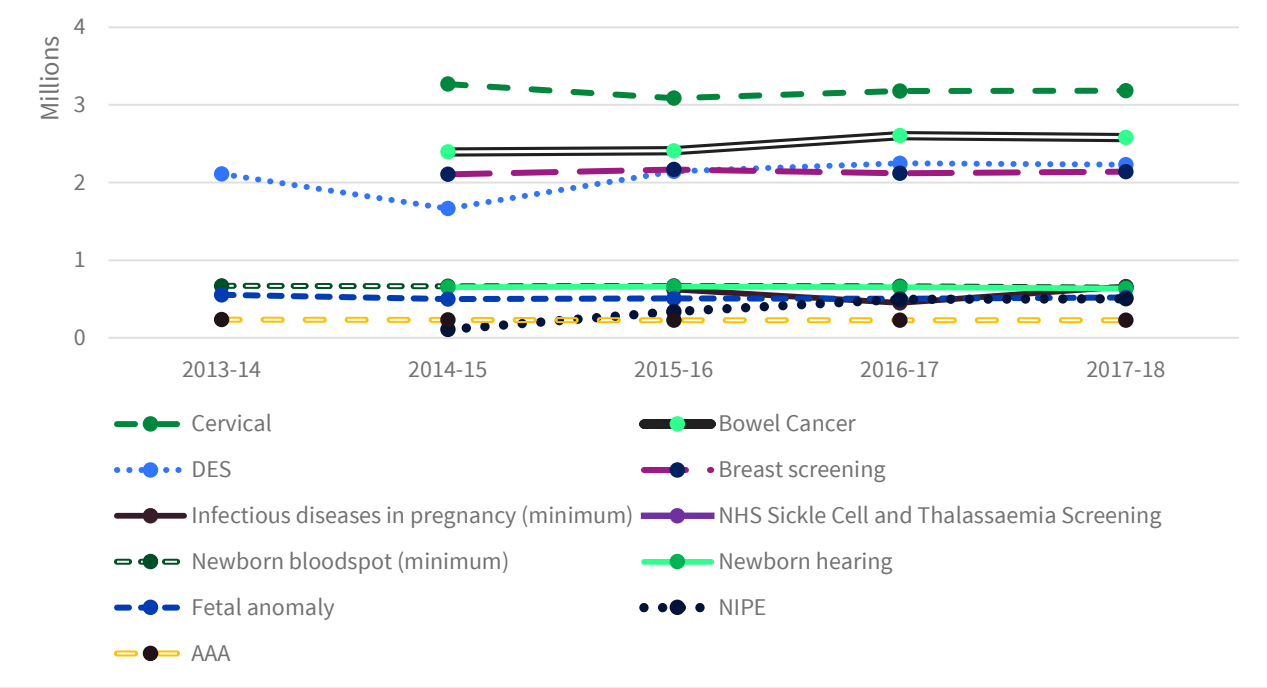
The target groups for each screening programme vary significantly. Data on the number of people tested annually (Table 3) provides insight into the relative order of magnitude of the programmes. Changes in coverage rates could affect total numbers tested, but we will set this

aside for now. Due to the different age profiles of people offered screening, these proportions do not necessarily transfer over to the numbers of people who may be offline, as we explore below.

Table 3: No. of people tested by screening programme, 2017-18, and approx. % of tests.

Screening programme	People tested	Approx. % of tests
Cervical	3,181,762	23
Bowel Cancer screening	2,579,831	18
DES	2,232,797	16
Breast screening	2,138,448	15
Infectious diseases in pregnancy (minimum)	659,995	5
NHS Sickle Cell and Thalassaemia Screening	651,652	5
Newborn bloodspot (minimum)	647,025	5
Newborn hearing	635,562	5
Fetal anomaly	519,864	4
NIPE	504,389	4
AAA	229,956	2
Approx. total (exc. two of three infectious diseases in pregnancy tests)	13,981,281	100

Figure 5: Millions of tests completed, by screening programme, 2013-14 to 2017-18



ESTIMATES OF DIGITAL EXCLUSION WITHIN SCREENING PROGRAMME POPULATIONS

We have produced estimates for how many people in each YPA screening programme target group might be offline. We calculated these by applying ONS estimates for the proportion of people offline, by age band to population, by single year of age. All calculations are based on the population who could be offered screening between 2020 and 2025. For example, we have taken the ONS estimate for the number of people aged 53-72 in 2018, who will be aged 60-74 between 2020-25.[32]

We have made all calculations on the basis of the most recent ONS Internet Users dataset, which is only one way to estimate levels of digital exclusion. These figures report that 3,883,000 adults aged 16 years and over in England, or 8.7% (and 9% across the UK), have never used the internet or last used it over three months ago. We have used this dataset as it has a large sample size and allows for both demographic and geographic analysis.

Other datasets are likely to produce higher figures for digitally excluded people.[33] Yates, Kirby and Lockley (2015:1) suggest "41% of the UK population have no access, limited access, or are limited users of digital media." As such, our estimates in this report represent the minimum number of people who are unlikely to engage with online screening information.

Finally, ***we have only made estimates of the number of people offline in each target group, based on age.*** Estimates do not take account of other factors associated with digital exclusion, or differentiate between geographic areas with similar age profiles, based on localised digital exclusion estimates. Age is the most significant factor when considering engagement with online information. Other factors, including disability and financial exclusion, are important and, if added, would increase the number of people expected to have some difficulty with online access.

[32] We have not attempted to account for the phenomenon of "digital disengagement", whereby people who have become internet users reduce or abandon digital technologies (Olphert and Damodaran, 2013 cited in McGillivray, Jenkins and Mamattah, 2017). Accounting for this process would elevate the proportions of people who are not internet users in the demographic groups.

[33] Based on people who have never or last the internet over three months ago

DIGITAL EXCLUSION FACTORS ACROSS THE PROGRAMMES

Table 4 summarises our estimates for the number and proportion of people who are offline, by screening programme. We estimate that across all programmes around 7.8% of individuals invited may be offline. This is lower than the national average estimate for England (8.7%) because of the different age profile. Specifically, because no screening programme covers people aged over 71.

Table 4: Estimated number and proportion of people who are offline, by screening programme

Screening Programme	Target Group	People in target group (2020-2025)	% Target populations	Approx. number of people in target group who are offline	% of target group who are offline	Share of digitally excluded population within programme
Bowel Cancer screening	Anyone aged 60-74 (aged 53-72 in 2018)	12,772,963	27.8	**1,250,000**	**9.8**	**37%**
Diabetic Eye	People with diabetes aged 12 of over	3,721,200	8.1	**1,000,000**	**28.4**	**31%**
Breast Screening	Women aged 50-71 (aged 43-69 in 2018)	7,961,334	17.3	**580,000**	**7.3**	**17%**
Cervical Screening	Women aged 25-64 (aged 18-62 in 2018)	16,356,023	35.6	**325,000**	**2.0**	**10%**
Antenatal & Newborn	Pregnant women, trans men, and non-binary people. Calculated from ONS Births by parent characteristics data, 2018	Approx. 3,300,000 (one parent only)	7.0	**16,000**	0.5	**4%**
Abdominal Aortic Aneurysms	Men turning 65 (aged 58-63 in 2018)	1,877,616	4.1	**130,000**	**7.0**	**1%**
Total	Combined total (ignoring overlaps)	**45,922,738**	100		**7.8**	**100%**

The following set of Figures include six maps, highlighting the CCGs ranked highest for digital exclusion risk, once adjustments for population are made. There is a map for each of the YPA programmes. There are differences in levels of risk for different areas, but there are also clear patterns, which are summarised in the combined map shown first.

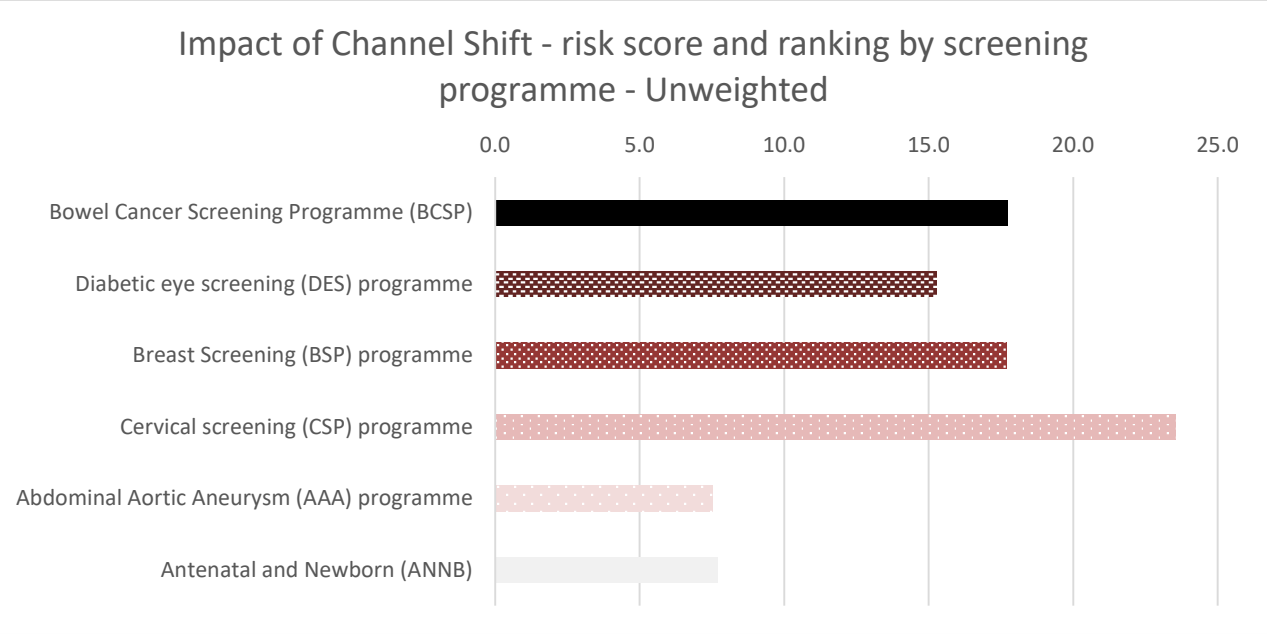
Areas highlighted include the South East coast (from Sussex to Kent), the East of England (around Norfolk and Lincolnshire) and in the West of England (in Herefordshire, Eastern Cheshire and Fylde and Wyre). These maps are intended as ***a guide to where paper, face-to-face, or phone-based communication about screening programmes may be most needed*** in numerical terms. They are adjusted to avoid over-representation of CCGs that have higher populations. Table 4 (above) represents a simplified version of a more complex and comprehensive analysis that returned a final risk score for each programme and enabled us to order them in priority. Our formula analysed data across 16 numerical or percentage metrics within each programme, comparing target populations over five years, offline populations within age groups and KPI data we were able to obtain from the PHE Performance Outcomes Framework, showing trends in uptake for example. Once we had obtained data for each metric, we applied risk weightings to different elements, to help us arrive at our risk score.

These were made up of the following:

- Scale of target population within the programme (0.5 weighting point) made up of three metrics:
    - Share of population
    - Share of print production
    - Share of print budget
- KPI performance (1 weighting point) made up of two metrics:
    - KPI trend (e.g. positive / negative / static)
    - KPI variance from the target
- Qualitative insights on the programme (1 weighting point) made up of 3 metrics:
    - Offline population
    - Equality Act protected characteristics impact
    - Programme sensitivities (anecdotal / literature review)
- Estimated share of offline contacts from the public (4 weighting points) made up of three metrics:
    - Offline demographic in relation to the programme
    - Age profile in relation to the programme
    - Estimates over 5 years, 2020-2025

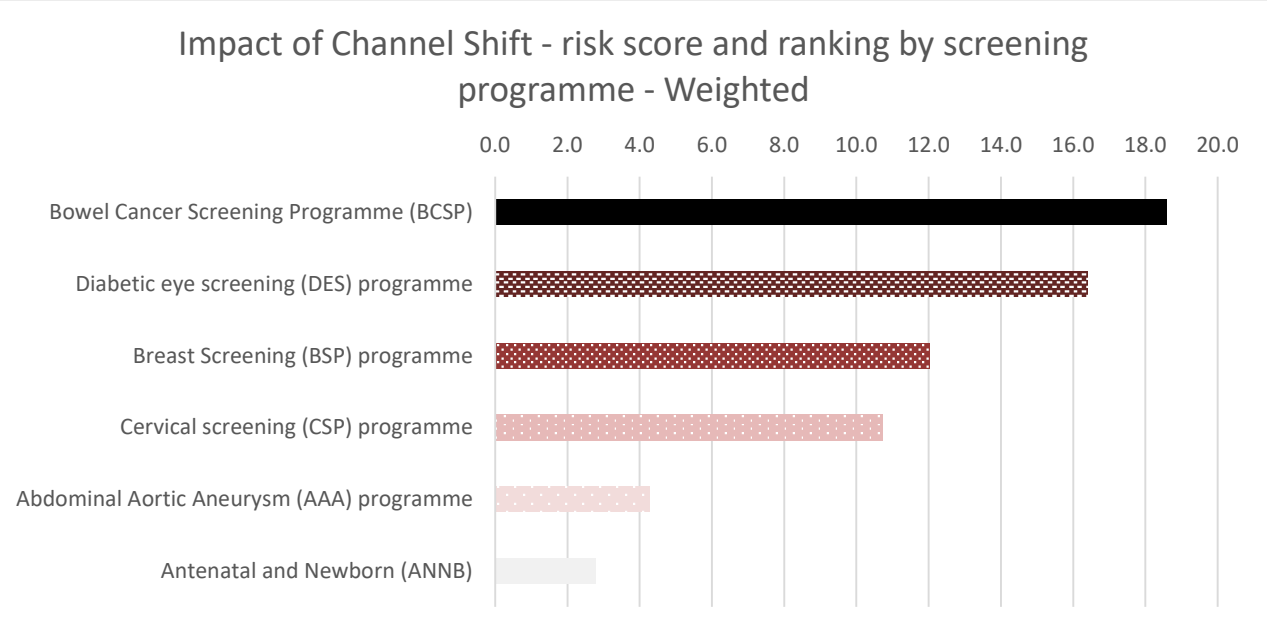
The final scoring of risk and impact, without the above weightings, is as follows:

Figure 6 Unweighted Risk Prioritisation of programmes



With the weightings applied, which are intended to include the specific digital exclusion impacts on each of the programmes, the prioritisation changes as follows:

Figure 7 Weighted Risk Prioritisation of programmes



In Table 5, we provide a summary of each of the programmes and their most relevant associated risks, including any headline statistics or estimates. The Population Targets are based on our best estimate of the number of people eligible to access each programme over the five years, 2020-2025. Our estimates of Offline Populations (as a number or percent of the Target Population) are based on current age-related offline population data from the Office for National Statistics (ONS).

Table 5 Summary of each screening programme risks

Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
1	**Bowel Cancer Screening Programme** (BCSP)	**Target Population: 12.8m** **Estimate Percent Offline: 9.8%** **Estimate Number Offline: 1.25m**	We estimate **this target group has the most people likely to be offline over five years.** The percentage of offline people in this target group is second highest across all programmes. Over a third of the cases across all programmes, where we think people are less likely to access online information, are in the BCSP. This is because of the large target group size *and* older people being invited to the screening programme (Eligibility is age 60+ not including one off Scope Screening offered in some areas at ages 55-59).
2	**Diabetic Eye Screening Programme** (DES)	**Target Population:** 3.7m **Estimate Percent Offline:** 28.4%	We estimate **around 1 million** people in this programme **are offline**.[34] As age is a key factor in diabetes and digital exclusion, **the proportion (%) of people we suggest are offline is highest in this group.** The true figure may be higher, as we have made digital exclusion

[34] The Target Population estimate for the DES is based on multiple factors including age and ethnic background, while our estimates for offline population are based on age alone (ONS data). Over 5 years, the target number does not multiply each year at the same high rate as other programmes, because screening is invited annually from the age of 12 and so the number of new people entering the programme happens at a lower rate.

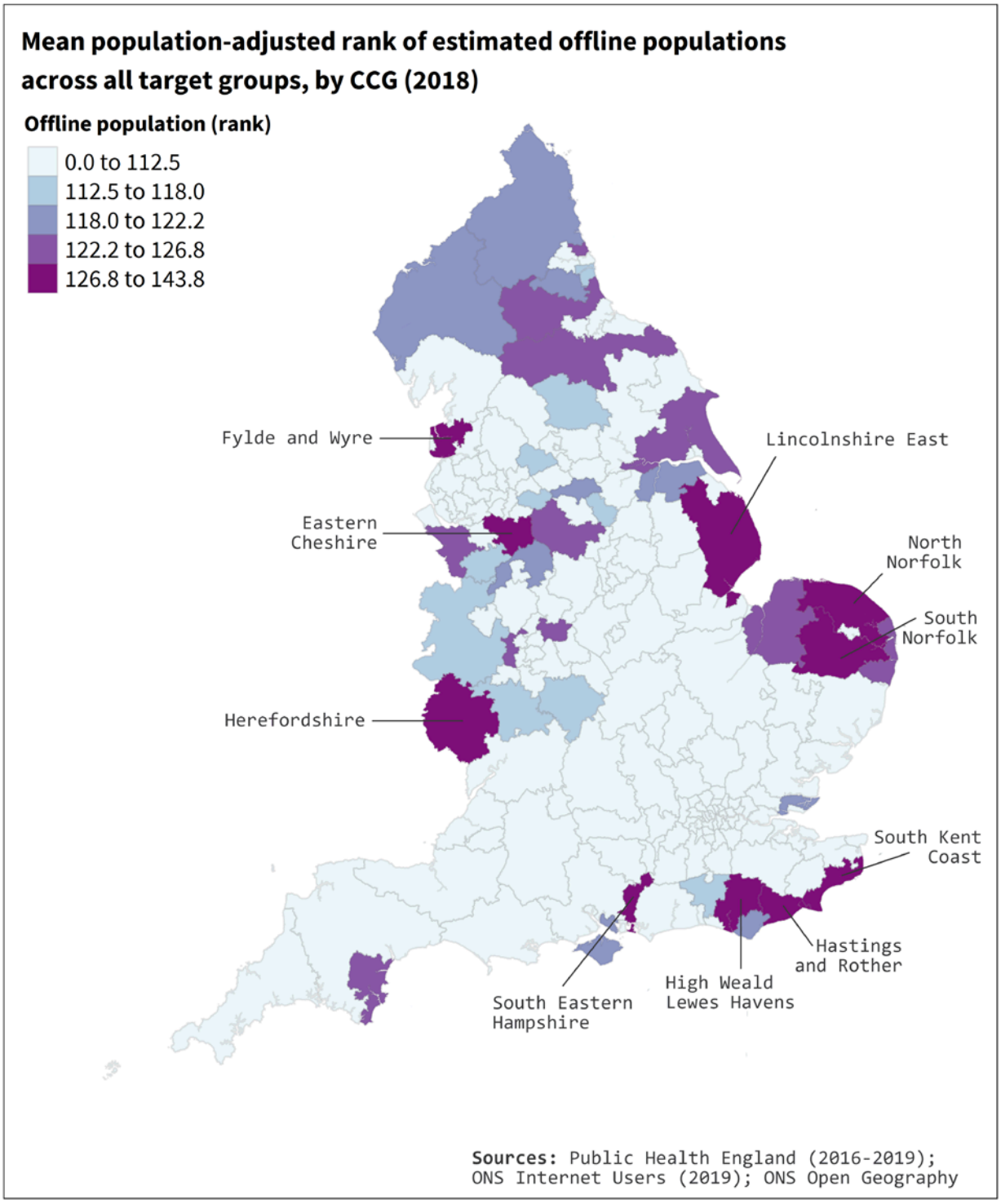
Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
		Estimate Number Offline: 1m	estimates based only on the age profile. There are other digital exclusion factors where Diabetes is more likely, such as deprivation and BAME[35] population. We estimate **28.4% of people** in this programme are more likely to **request non-digital information.** However, people with diabetes are already symptomatic and linked in with an NHS service which may offset some of the need over time.
3	**Breast Screening Programme** (BSP)	**Target Population:** 8m **Estimate Percent Offline:** 7.3% **Estimate Number Offline:** 0.6m	The Breast Screening programme accounts for **17% of cases where an alternative to online information** is more likely to be needed. We estimate this to be at least **580,000 women,** which is around 7.3% of the 7.9 million to be invited to the screening programme between 2020 and 2025.
4	**Cervical Screening Programme** (CSP)	**Target Population:** 16.4m **Estimate Percent Offline:** 2% **Estimate Number Offline:** 0.3m	This screening programme has the **largest target** population and the largest leaflet screening budget across the programmes – however as the target group is younger, the proportion and number of people (328,000) estimated to be offline is significantly low, and low in comparison to other programmes. These two extreme factors balance out the risks meaning this programme takes one of the middle places in the overall risk rating.

[35] Black, Asian and Minority Ethnic (BAME)

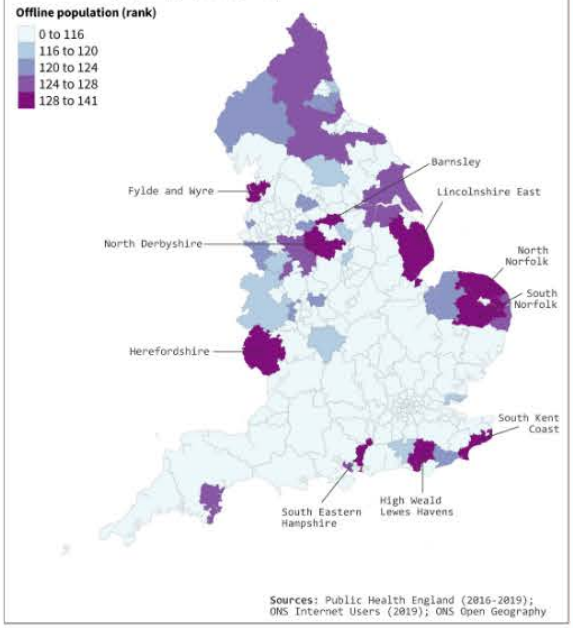
Risk Rating 1 = Highest 6 = Lowest	**Programme**	**Programme Metrics (2020-25)**	**Risk Description**
5	**Abdominal Aortic Aneurysms Screening Programme** (AAA)	**Target Population:** 1.9m **Estimate Percent Offline:** 7% **Estimate Number Offline:** 0.1m	The estimated offline population for AAA population screening is relatively high compared to others at 7%. Yet, the lower number of people in the target group amongst the YPA programmes, results in **a low number of people estimated to be offline - 130,000.** The AAA programme is the lowest risk amongst the YPA programmes. All invitations will remain Prevalent and it is unlikely there will be any change to printing immediately.
6	**Antenatal & Newborn Screening Programme** (ANNB)* *across six programmes	**Target Population:** 3.3m **Estimate Percent Offline:** 0.5% **Estimate Number Offline:** 0.02m	**The ANNB programme remains the lowest risk overall across all programmes, when considering digital exclusion risk.** While the Target Population for invitations is estimated to be high, the lower age group and the fact that all women will receive face to face advice, information and support in the course of their pregnancy, makes this the lowest risk programme. The estimated **offline population within this target group is 16,000**

The simplest way to understand the change is to consider the cervical screening programme, which in the unweighted version is the highest risk impact. This is due to the large scale of the programme and its budget – but when the weightings are applied, the age demographic begins to play a more important role in the risk rating and the CSP is rated lower risk impact for this reason. Whereas the Bowel Cancer Screening Programme begins to get a higher impact rating, largely because of the expected offline populations within the target age group for invitations.

Figure 8: Mean population-adjusted rank of estimated offline populations across all target groups, by CCG (2018)

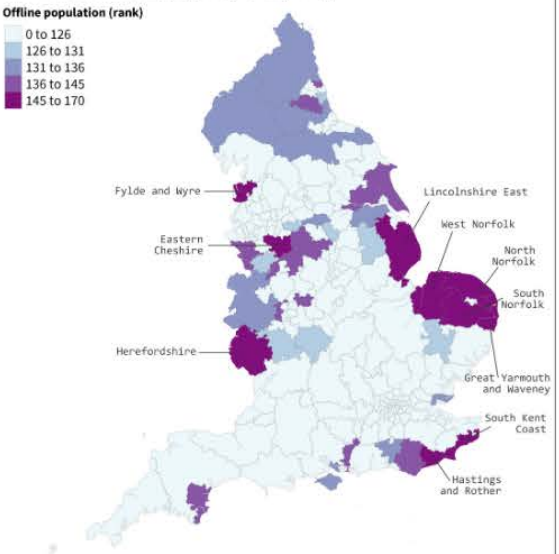


Population-adjusted rank of estimated offline population within AAA target group, by CCG (2018)



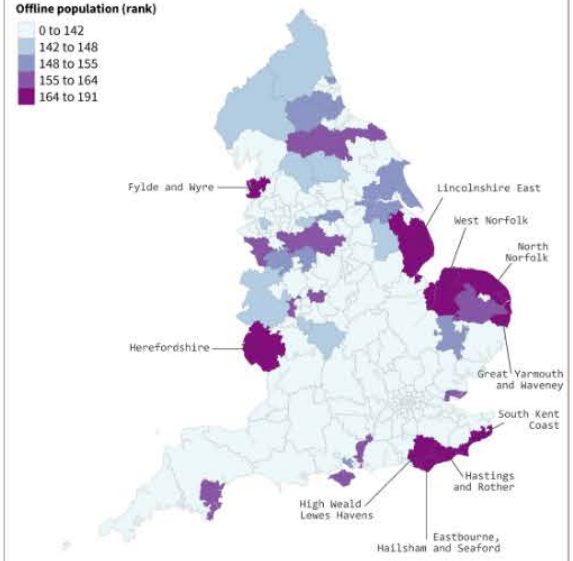
Sources: Public Health England (2016-2019); ONS Internet Users (2019); ONS Open Geography

Population-adjusted rank of estimated offline population within breast cancer target group, by CCG (2018)



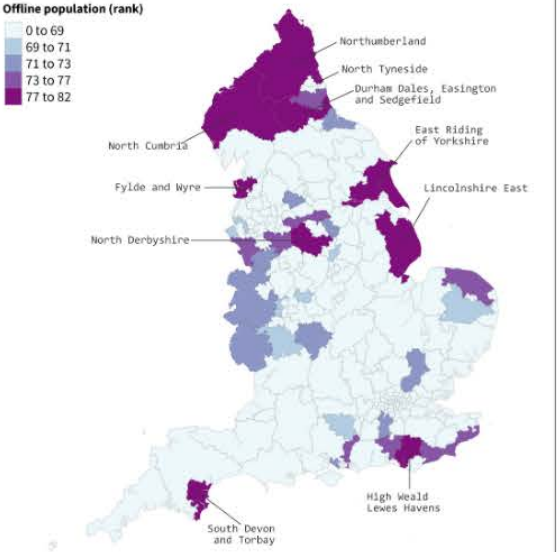
Sources: Public Health England (2016-2019); ONS Internet Users (2019); ONS Open Geography

Population-adjusted rank of estimated offline population within bowel cancer target group, by CCG (2018)



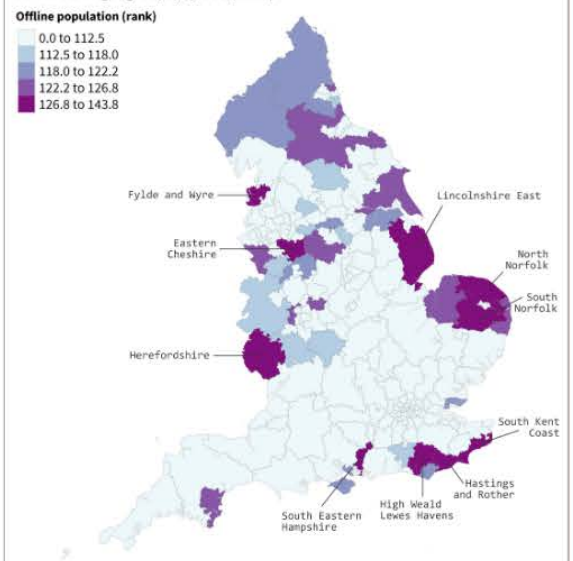
Sources: Public Health England (2016-2019); ONS Internet Users (2019); ONS Open Geography

Population-adjusted rank of estimated offline population within cervical cancer target group, by CCG (2018)



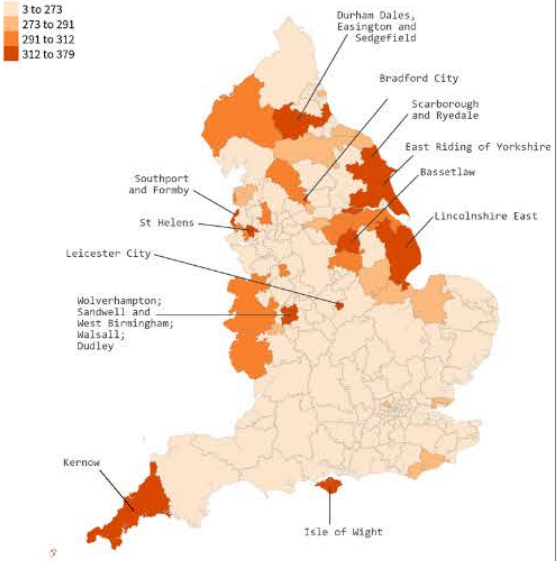
Sources: Public Health England (2016-2019); ONS Internet Users (2019); ONS Open Geography

Mean population-adjusted rank of estimated offline populations across all target groups, by CCG (2018)



Sources: Public Health England (2016-2019); ONS Internet Users (2019); ONS Open Geography

Combined prevalence ranking, by CCG (2019)



Sources: Public Health England National Cardiovascular Intelligence Network (2016) Prevalence estimates of diabetes by CCG (2019); ONS Census population estimates (2018) (Nomis); ONS Internet users estimates (2017-2019 mean) (derived from Labour Force Survey); Map boundaries: ONS Open Geography

LEAFLET PRINTING BUDGET

The purpose of this section is to offer PHE a future scenario of 'demand' on the leaflet printing budget and enable a prediction as to which programmes are more likely to experience pressures if public or NHS screening services continue to request printed information.

Table 5 presents the current % share of the printing budget (column A) alongside a % share of a future budget (column B)[36] based on our estimates of future offline populations in each programme between 2020 and 2025 placing a demand on the services.

In column B, we allocate the share according to the estimated levels of demand arising from digitally excluded people targeted in each programme. Our intention is to show where future demand is likely to be felt, not to advise on how to adjust future budgets. These decisions need to be made by PHE, based on a multitude of factors that go beyond our future digital exclusion scenario.

Table 6: Estimated share of digitally excluded contacts across programmes 2020-2025

Screening Programme	(A) Share of existing leaflet printing budget (%)	(B) Estimated future share based on demand from offline population (%)
Cervical	36.9	9.7
Bowel Cancer	26.9	37.2
Breast	19.0	17.3
Antenatal and newborn	8.8	0.5
Diabetic Eye	6.7	31.4
Abdominal Aortic Aneurysm	1.7	3.9
Total	100	100

ANALYSIS

Change from printed to digital information will be hardest at the beginning on all programmes. We have made estimates, over five years, on the numbers of 'offline populations' and our modelling saw the differentials on demand (represented in column B) widening as time went

[36] We have not estimated cost reductions that might be achieved through ceasing to send leaflets with incident invitations or looked at budgets in detail. For the calculation we also assume that future 'offline' populations will translate directly into a demand for printed leaflets. In reality this is likely to only be a proportion of the total offline population.

on. Therefore, we would advise caution across change in all programmes at the start of this process.

Bowel Cancer Screening: Due to the age group in this target population and the higher numbers of people offline, we estimate a higher share of demand on future printed materials.

Diabetic Eye Screening: Our calculations suggest this is the programme with the second largest share of future demand on the printing budget. This is due to the high numbers in the target population and the age band of the older cohorts invited each year for the test. However, this needs to be balanced with the fact that people invited to DE Screening are already symptomatic, receiving an NHS service and linked-in with support, so the demand for additional printed information may actually be less than indicated by future offline population estimation. The small share of the current budget would also support this. It may be possible to move the DES Programme to a Prevalent Invitation only system for leaflets in the near future.

Breast Screening: Largely unchanged – a small increase in share of demand on printed materials. Remains 'third place' in the list.

Cervical Screening: Currently the largest share of budget – however, owing to the age group of the target population, there are fewer people offline and therefore we predict a much lower demand for printed materials in future.

Abdominal Aortic Aneurysm Screening: While we predict a slightly higher share of future demand, the size of the current budget share is very small and target population is also small compared to other programmes. All invitations are prevalent and so we suggest little to no change with the future share of budget.

Antenatal & Newborn Screening: Our future demand scenario sees demand in this area drop even further than it currently is, but with an already smaller share of the current budget, some minimal level of printing capacity is expected to be necessary in future.

BOWEL CANCER SCREENING (BCSP)

Bowel Cancer Screening is offered to all men and women aged 60-74 every two years, and in some areas of the country people aged 55 are invited for a one-off bowel scope screening test. People aged 75 or over can also request screening over the phone. Looking at the first of these age bands, we can explore risk of digital exclusion. We do not make estimates for people aged 55 as this is not a country-wide offer, nor for people aged over 75. Assuming self-referral by phone is maintained, the people in this age group who are offline should not be affected by online screening information.

- There were over 12.8 million people in England aged 53-72 in 2018, who will be aged 60-74 in 2020-2025.
- This is equivalent to 22.8% of the population,[37] approaching one in every four people.
- The CCGs with the highest numbers and proportions of people in these age bands are presented in Tables 6 and 7, together with basic estimates for the number of people in these areas who are not internet users in Table 8.[38]

Table 7: 10 CCGs ranked highest for number of people in the Bowel Cancer Screening target group

CCG Name	People aged 53-72, who will be 60-74 in 2020-25	% of total pop'n	Est people offline in target group
Northern, Eastern and Western Devon	236,405	26.0	23,943
Birmingham and Solihull	223,863	19.0	21,387
Dorset	207,829	26.9	21,267
Cambridgeshire and Peterborough	200,975	22.6	19,690
Bristol, North Somerset and South Gloucestershire	198,100	20.6	19,347
Gloucestershire	163,139	25.7	16,159
Cornwall	162,110	28.5	16,639
Nene	156,794	23.8	15,419
Somerset	155,956	27.9	15,851
Leeds	155,723	19.7	15,122

[37] ONS 2018 Mid-Year Estimate

[38] These crude estimates are based on applying the national average for the age band, and do not take into account local factors, nor regional variation in the proportions of people who are offline or lacking digital skills.

Table 8: 10 CCGs ranked highest for proportion of people in Bowel Cancer Screening target group

CCG	2020-25 Bowel screening (anyone 53-72 will be 60-74)	% of total population to be screened 2020-25 Bowel screening	Est offline 2020-25 Bowel screening (anyone 53-72 will be 60-74)	% of Bowel screening 2020-25 bracket estimated to be offline
North Norfolk	54,273	31.2	5,723	10.5
Isle of Wight	42,940	30.3	4,459	10.4
Lincolnshire East	71,559	30.1	7,426	10.4
Northumberland	95,983	30.0	9,647	10.1
South Devon and Torbay	85,206	29.9	8,745	10.3
East Riding of Yorkshire	94,524	29.8	9,681	10.2
Fylde and Wyre	56,848	29.5	5,811	10.2
Hambleton, Richmondshire and Whitby	45,179	29.5	4,573	10.1
Scarborough and Ryedale	33,179	29.3	3,368	10.1
Hastings and Rother	53,903	28.6	5,542	10.3

Table 9: 10 CCGs ranked highest for number of people estimated to be offline in target group

CCG Name	2020-25 Bowel screening (anyone 53-72 will be 60-74)	% of total population to be screened 2020-25 Bowel screening	Est offline 2020-25 Bowel screening (anyone 53-72 will be 60-74)	% of Bowel screening 2020-25 bracket estimated to be offline
Northern, Eastern and Western Devon	236,405	26.0	23,943	10.1
Birmingham and Solihull	223,863	19.0	21,387	9.6
Dorset	207,829	26.9	21,267	10.2
Cambridgeshire and Peterborough	200,975	22.6	19,690	9.8
Bristol, North Somerset and South Gloucestershire	198,100	20.6	19,347	9.8
Cornwall	162,110	28.5	16,639	10.3
Gloucestershire	163,139	25.7	16,159	9.9
Somerset	155,956	27.9	15,851	10.2
Nene	156,794	23.8	15,419	9.8
Leeds	155723	19.7	15,122	9.7

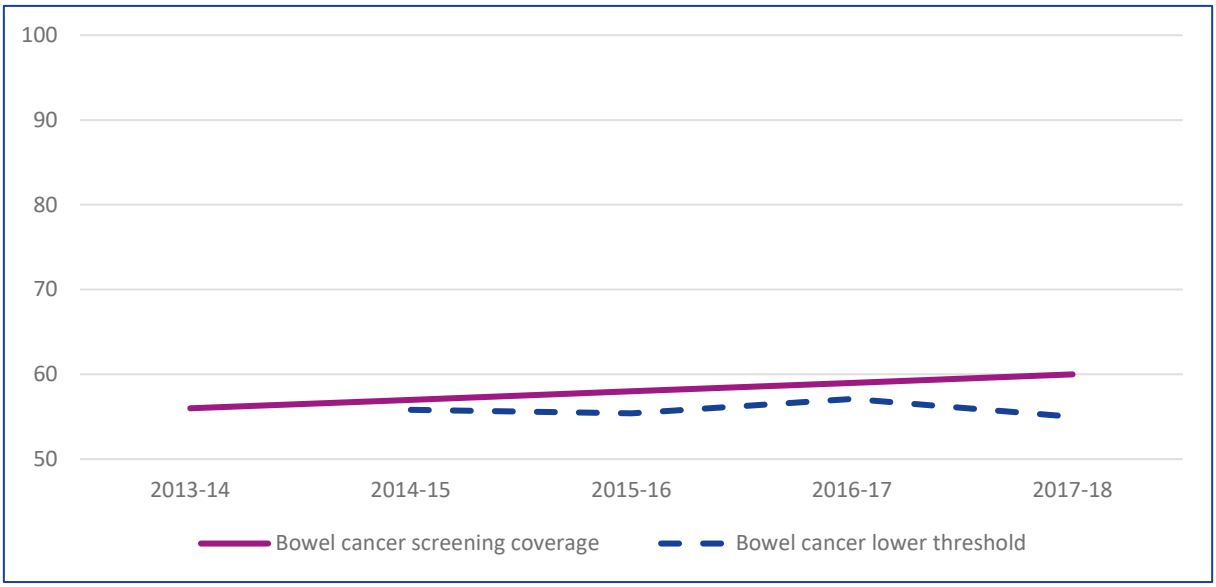
EXISTING COVERAGE AND POTENTIAL CHANNEL SHIFT IMPACT

The Independent Review (Richards, 2019) found performance against bowel screening targets is improving, and that further improvement is expected. As shown in Figure 9, bowel cancer screening met its lower threshold targets in 2017/18 – though it fell just short of the standard target (59.6% compared to 60%). There is considerable variation among local authorities; a 1.8-fold difference between the lowest coverage rate of 37.3% and the highest of 67% (PHE, 2017). Indeed, "One in five (32 out of 152) local authorities have less than half their eligible population with a screening test result recorded in the last 2.5 years" (ibid. 134).

However, while The Atlas reports that the "socioeconomic profile of the local population can also affect uptake of the screening test for bowel cancer", there is no information regarding affected groups. While we have not made a quantitative analysis regarding coverage and digital exclusion, there is a risk that a shift to online information could negatively impact take-up, as these groups are likely to be those more likely to be digitally excluded. Further, The Atlas reports that there have been trials and initiatives to increase uptake and, rather than online materials, these have emphasised enhanced leaflets and face-to-face consultation:

- a letter of endorsement from the person's GP
- an enhanced patient leaflet
- health promotion in a face-to-face consultation

Figure 9: Bowel Cancer Screening coverage against lower threshold target



DIABETIC EYE SCREENING (DES)

All members of the public with a diagnosis of diabetes, who are 12 years or over, are invited for diabetic eye screening annually. Identifying the prevalence of diabetes geographically within England, and cross referencing this with areas where we understand there to be higher prevalence of digital exclusion (offline populations), can provide some insight into the areas where the public might find it harder to engage with online information about the DES Programme.

The new Diabetes Prevalence Model (PHE, 2015) estimates the total number of adults (aged over 16) with both Type 1 and Type 2 diabetes in England as 3.8 million in England (2015)

- It is estimated that 3.8 million people aged 16 years and over in England have diabetes (diagnosed and undiagnosed). This is equal to 8.6% of the population of this age group.
- Diabetes prevalence is higher in men than in women; 9.6% versus 7.6%.
- Prevalence is higher in people from South Asian and black ethnic groups, compared with people from white, mixed or other ethnic groups; 15.2% versus 8.0%.
- There is a clear association between increasing age and higher diabetes prevalence; from 9.0% aged 45-54, to 23.8% aged and over.

At CCG level, diabetes prevalence ranges from 6.5% to 11.5%. CCGs with the highest estimated diabetes prevalence have high proportions of South Asian and black ethnic groups and high levels of deprivation. The CCGs with the highest numbers of people with diabetes, and the highest prevalence as a proportion of population are demonstrated in Table 9.

Table 10 breaks down our estimates for people with diabetes who may also be digitally excluded by age band.

Figure 10 shows a combined prevalence ranking for diabetes and digital exclusion, while the graphic on the following page shows the elements that are included in the combined ranking – and an alternative set of CCGs where risk of digital exclusion is highest in numerical, rather than proportional, population-adjusted terms.

Table 10: Top ten CCGs ranked by prevalence of Diabetes – number of people

CCG	Number	Prevalence
North, East, West Devon	64,861	8.8%
Dorset	57,473	9.0%
Birmingham Cross city	56,452	9.9%
Cambridgeshire and Peterborough	55,218	7.8%
Cornwall	44,779	9.8%
Sandwell and West Birmingham	43,324	11.5%
Gloucestershire	42,305	8.4%
Nene	42,108	8.2%
Somerset	41,240	9.2%
Oxfordshire	39,560	7.3%

Table 11: Top ten CCGs ranked by prevalence of Diabetes, proportion

CCG	Number	Prevalence
Sandwell and West Birmingham	43,324	11.5%
Brent	29,552	11.4%
Bradford City	6,665	11.1%
Wolverhampton	22,294	11.0%
Leicester City	29,194	10.9%
Redbridge	24,903	10.8%
Harrow	21,408	10.8%
Ealing	29,145	10.7%
Croydon	30,994	10.4%
Newham	26,801	10.4%

Table 12: Diabetes prevalence and digital exclusion risk by age group

Age band	Never used internet, or last used over 3 months ago (%) (UK) (2015)2	Expected diabetes prevalence (%) (England) (2015)3	Estimated population with diabetes (England) (derived)	Estimated offline population with diabetes
16-24	0.7	0.8	49,543	347
25-34	1.2	1.2	89,832	1,078
35-44	2.6	3.5	248,758	6,468
45-54	6.1	9.0	693,032	41,582
55-64	13.2	12.7	785,246	103,653
65-74	29.3	16.9	893,293	261,735
75+	66.7	23.8	961,595	641,384
Total			**3,721,300**	**1,056,246**

Figure 10: Combined prevalence ranking - diabetes and non-internet users, by CCG (2019)

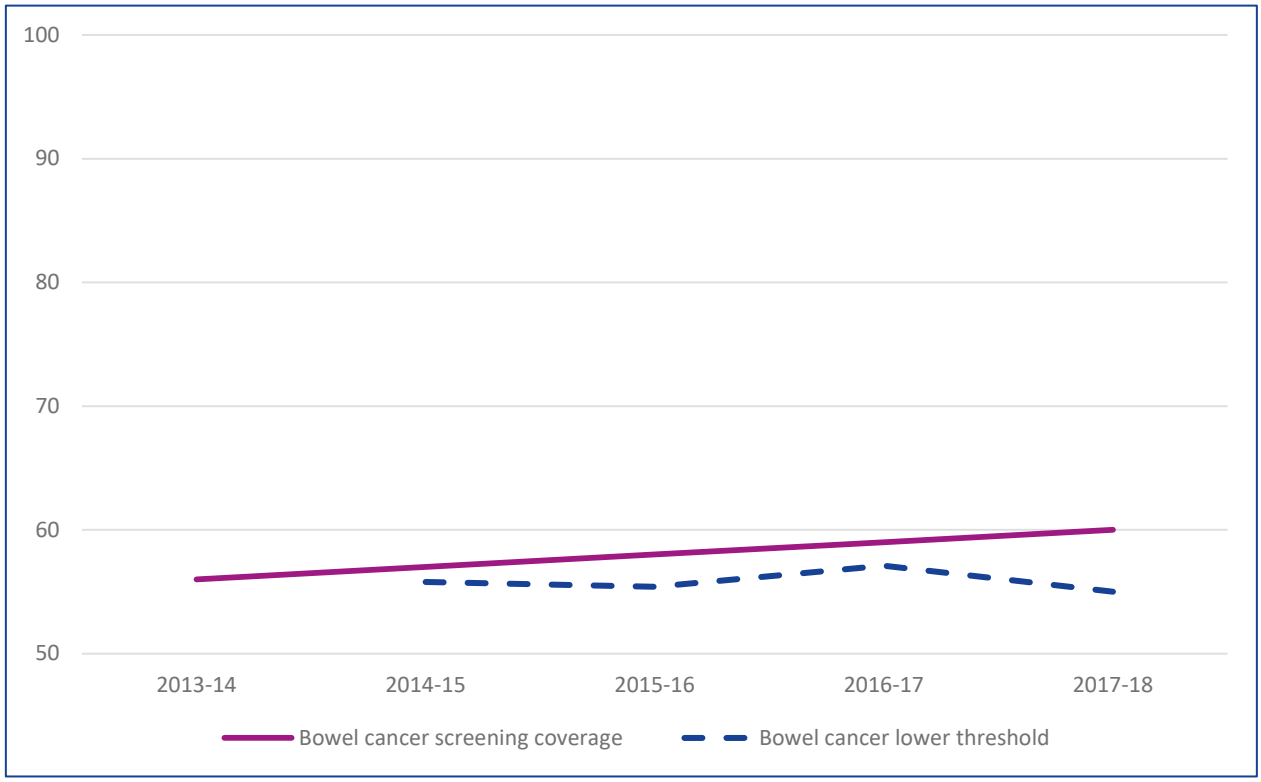
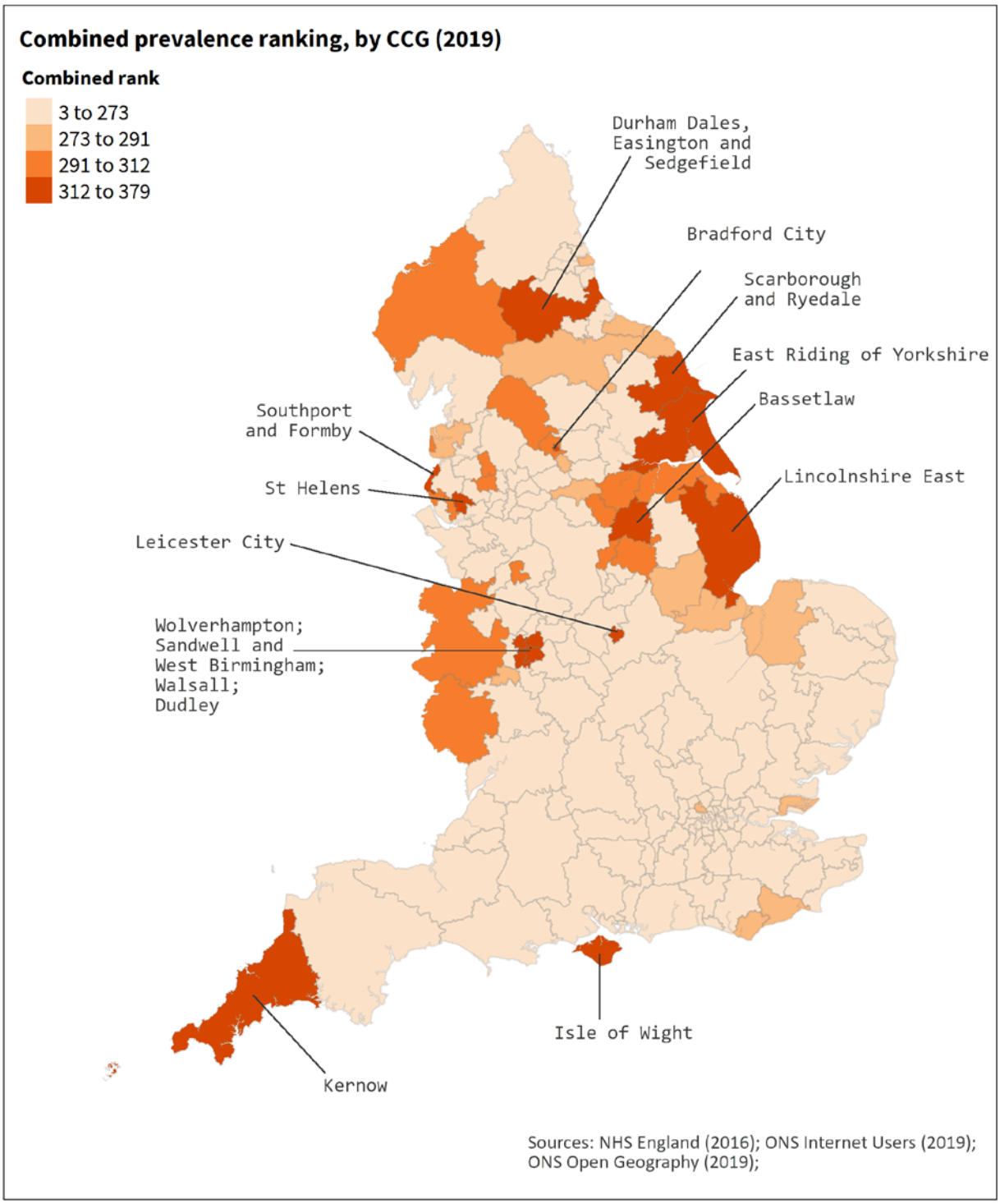
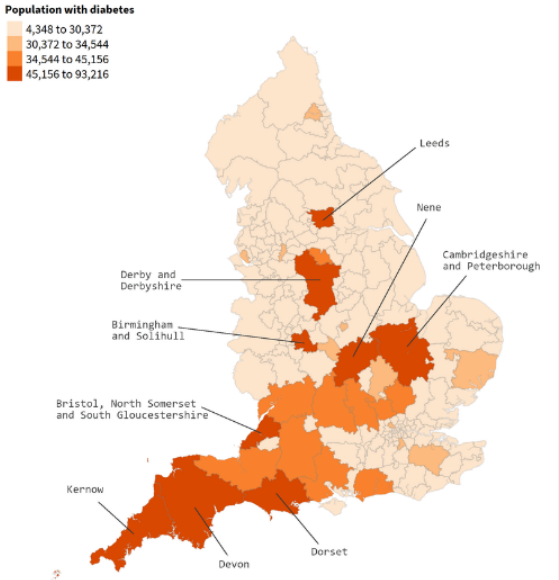


Figure 11: Diabetic Eye Screening Coverage, vs lower threshold (75%)

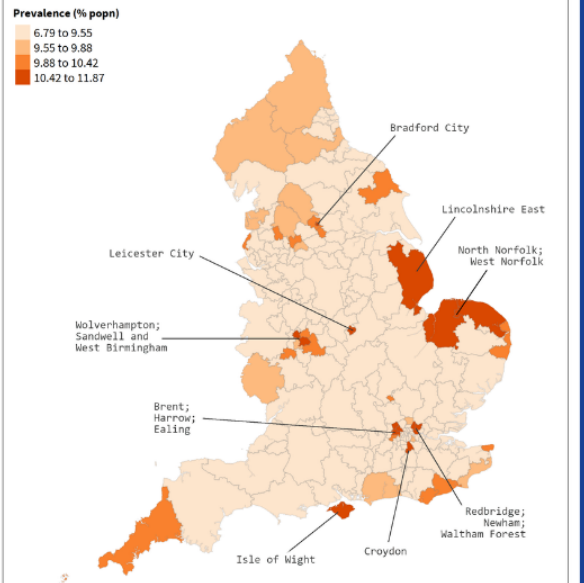


Adult population with diabetes, by CCG (2019)



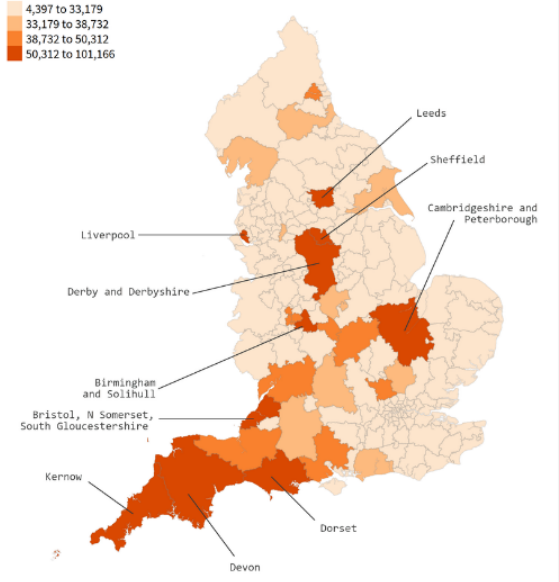
Sources: Public Health England National Cardiovascular Intelligence Network (2016) Prevalence estimates of diabetes by CCG (2019); ONS Census population estimates (2018) (Nomis); Map boundaries: ONS Open Geography

Prevalence of diabetes, by CCG (2019)



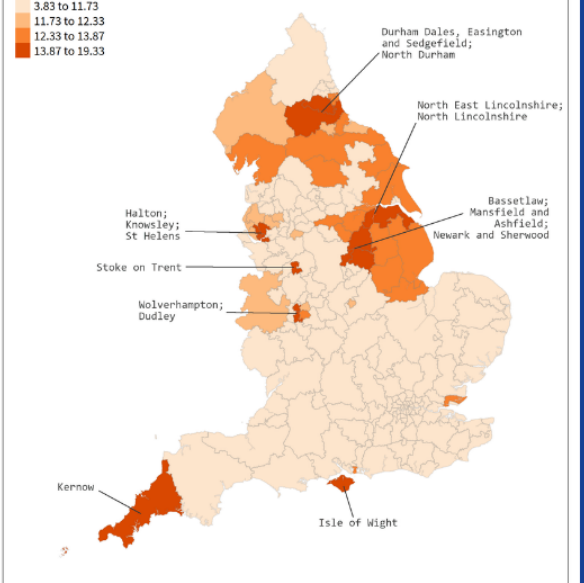
Sources: Public Health England National Cardiovascular Intelligence Network (2016) Prevalence estimates of diabetes by CCG (2019); ONS Census population estimates (2018) (Nomis); Map boundaries: ONS Open Geography

Non-internet users population, by CCG (2019)



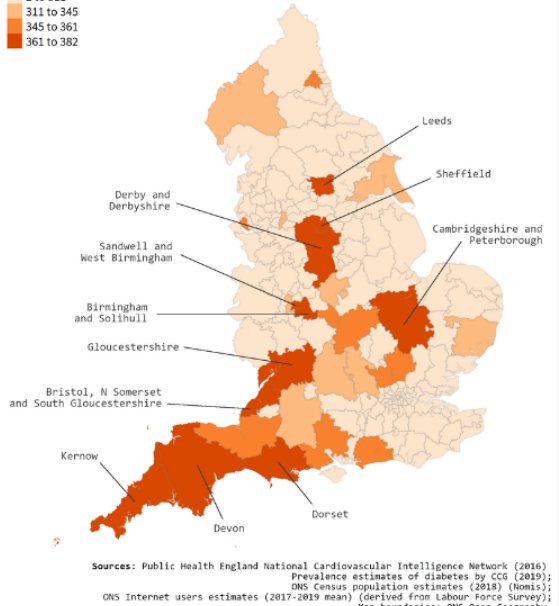
Sources: ONS Census population estimates (2018) (Nomis); ONS Internet users estimates (2017-2019 mean) (derived from Labour Force Survey); Map boundaries: ONS Open Geography

% non-internet users, by CCG (2019)



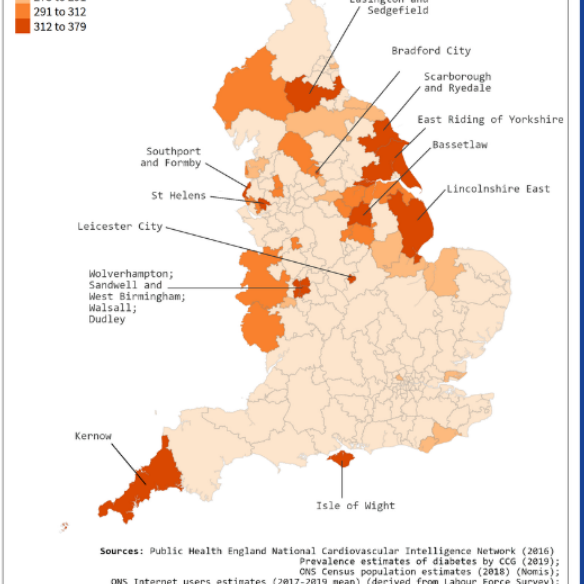
Sources: ONS Census population estimates (2018) (Nomis); ONS Internet users estimates (2017-2019 mean) (derived from Labour Force Survey); Map boundaries: ONS Open Geography

Combined ranking of populations, by CCG (2019)



Sources: Public Health England National Cardiovascular Intelligence Network (2016) Prevalence estimates of diabetes by CCG (2019); ONS Census population estimates (2018) (Nomis); ONS Internet users estimates (2017-2019 mean) (derived from Labour Force Survey); Map boundaries: ONS Open Geography

Combined prevalence ranking, by CCG (2019)



Sources: Public Health England National Cardiovascular Intelligence Network (2016) Prevalence estimates of diabetes by CCG (2019); ONS Census population estimates (2018) (Nomis); ONS Internet users estimates (2017-2019 mean) (derived from Labour Force Survey); Map boundaries: ONS Open Geography

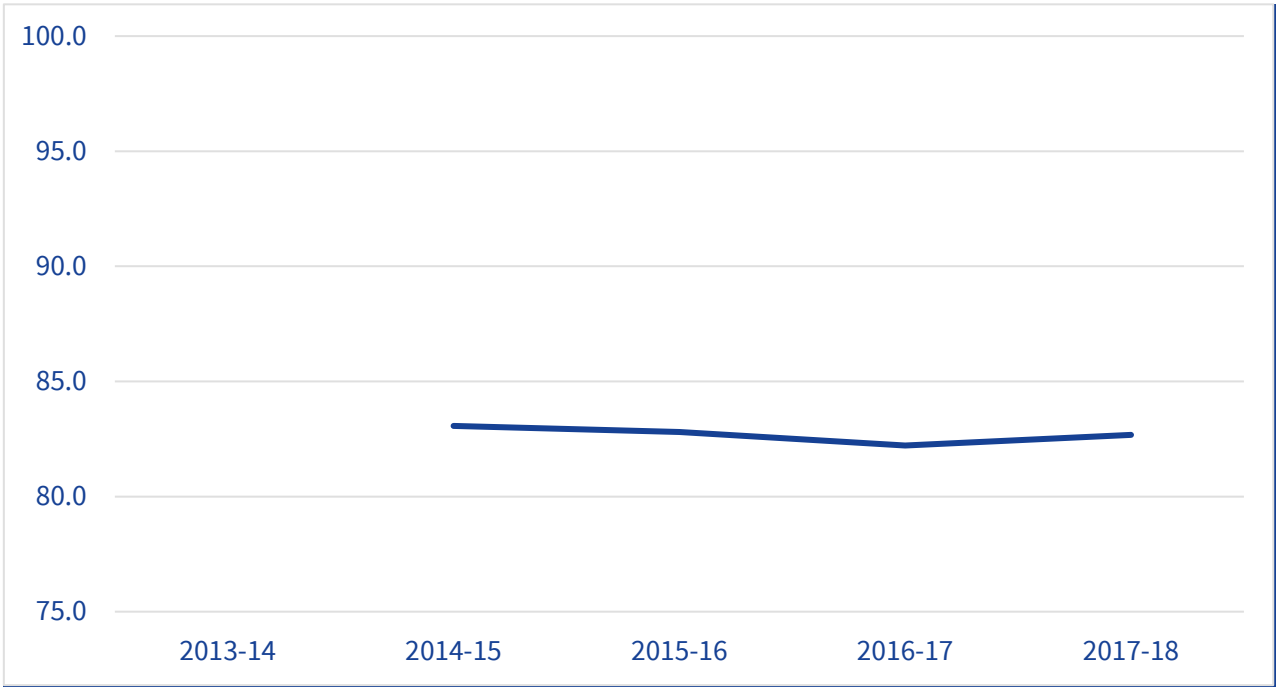
EXISTING COVERAGE AND CHANNEL SHIFT IMPACT

There is no analysis of Diabetic Eye Screening in The Atlas (PHE, 2017). The Independent Review (Richards, 2019) reports that "The service is seen as successful as diabetes is no longer the leading cause of blindness in working age people. Uptake of screening is generally high" Coverage – at 82.7% in 2017/18 – exceeds the lower threshold of 75% (see Figure 12), while still falling below the agreed standard (85%).

As with other screening programmes there are demographic groups less likely to attend, in this case younger people (age 20-45) and socioeconomically deprived groups. Like Richards (ibid.), Ahmad and Neilson (2019) identify "low screening uptake in the working age population, especially those living in the most socioeconomically deprived areas."

Factors associated with lower uptake were cited as: living in areas of high socioeconomic deprivation, young age, having a long duration of diabetes, poor glycaemic and blood pressure control or belonging to BAME groups. While not all of these factors are associated with digital exclusion, socioeconomic deprivation is – as discussed above. Having a long duration of diabetes is likely to be associated with people who are older, which would also be associated with digital exclusion.

Figure 12: Diabetic Eye Screening Coverage, vs lower threshold (75%)



BREAST SCREENING (BSP)

Breast screening is offered routinely to women aged 50-71.

- There were over 9.4 million women in England aged 43-69 in 2018, who will be 50-71 in 2020-2025.
- This is equivalent to 33.3% of women;[39] approximately one in every three (or 16.8% of the population; approximately one in every six people).

The CCGs with the highest numbers and proportions of people in these age bands are presented in Tables 12 and 13, together with basic estimates for the number of people in these areas who are not internet users (Table 14).[40]

There are ten CCGs with over 7,000 women in the target group, and two where over 10,000 women are expected to be offline. While it may be appropriate to see risk in proportional terms, these numbers are significantly higher than the 2-4,000 women who are offline in the areas where the highest proportion of women are in the target group for breast screening.

Figure 13 maps CCGs ranked highest for estimated offline population within the breast screening target group, once adjusted for population.

This again highlights CCGs around the periphery of England, with a particular emphasis on the east of England – in alphabetical order: Eastern Cheshire, Fylde and Wyre, Great Yarmouth and Waveney, Hastings and Rother, Herefordshire, Lincolnshire East, Norfolk (North, South and West), and South Kent Coast.

[39] ONS 2018 Mid-Year Estimate

[40] These crude estimates are based on applying the national average for the age band, and do not take into account local factors, nor regional variation in the proportions of people who are offline or lacking digital skills.

Table 13: 10 CCGs ranked highest for number of people in Breast Screening target group

CCG	Women 43-69, who will be 50-71 in 2020-2025	% of women	Est women offline in target group	% of Breast screening 2020-25 bracket estimated to be offline
Birmingham and Solihull	173,632	28.9	10,275	5.9
Northern, Eastern and Western Devon	162,532	35.2	10,679	6.6
Cambridgeshire and Peterborough	148,543	33.4	9,081	6.1
Bristol, North Somerset and South Gloucestershire	147,265	30.5	8,980	6.1
Dorset	140,553	35.9	9,376	6.7
Leeds	117,544	29.2	7,128	6.1
Nene	116,435	34.9	7,150	6.1
Gloucestershire	116,405	36.1	7,402	6.4
Oxfordshire	112,147	33.3	6,799	6.1
Cornwall	110,356	37.8	7,372	6.7

Table 14: 10 CCGs ranked highest for proportion of people in the Breast Screening target group

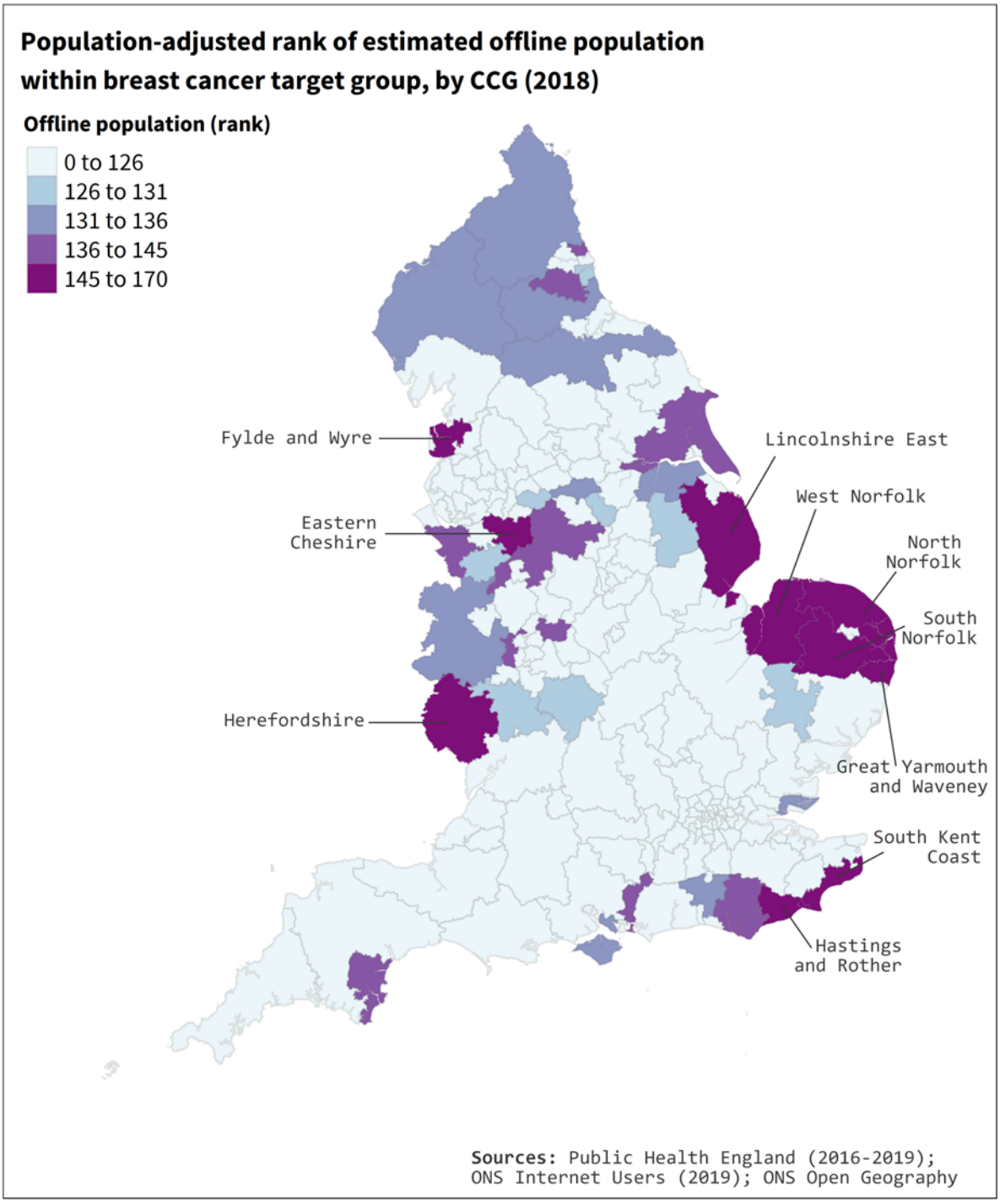
CCG	Women 43-69, who will be 50-71 in 2020-2025	% of women	Est women offline in target group	% of Breast screening 2020-25 bracket estimated to be offline
Hambleton, Richmondshire and Whitby	29,929	39.6	2,005	6.7
Northumberland	64,572	39.4	4,336	6.7
East Riding of Yorkshire	63,313	39.1	4,218	6.7
Isle of Wight	28,253	39.1	1,930	6.8
North Norfolk	34,691	38.9	2,434	7.0
High Weald Lewes Havens	34,589	38.7	2,194	6.3
Lincolnshire East	46,776	38.7	3,212	6.9
South Devon and Torbay	56,635	38.5	3,852	6.8

Eastern Cheshire	38,803	38.3	2,450	6.3
North Cumbria	61,788	38.3	4,021	6.5

Table 15: 10 CCGs ranked highest for number of people estimated to be offline in target group

CCG	Women 43-69, who will be 50-71 in 2020-2025	% of women	Est women offline in target group	% of Breast screening 2020-25 bracket estimated to be offline
Northern, Eastern and Western Devon	162,532	35.2	10,679	6.6
Birmingham and Solihull	173,632	28.9	10,275	5.9
Dorset	140,553	35.9	9,376	6.7
Cambridgeshire and Peterborough	148,543	33.4	9,081	6.1
Bristol, North Somerset and South Gloucestershire	147,265	30.5	8,980	6.1
Gloucestershire	116,405	36.1	7,402	6.4
Cornwall	110,356	37.8	7,372	6.7
Nene	116,435	34.9	7,150	6.1
Leeds	117,544	29.2	7,128	6.1
Somerset	106,547	37.2	7,035	6.6

Figure 13: Population-adjusted rank of estimated offline population within the breast screening target group, by CCG (2018)



EXISTING COVERAGE AND CHANNEL SHIFT IMPACT

The Independent Review of Adult Screening Programmes in England found that "Coverage of breast screening has decreased over the years, but is still reasonably good in comparison with that in other developed countries" (Richards, 2019: 120). Coverage was 74.9% on 31st March 2018, compared to 75.4% in 2016/17 (Figure 14), and 75.9% in 2007/08 – peaking at 77.2% in 2011/12. Further, coverage varies across the country, ranging from 69.3% (London), to 78.4% (East Midlands):

- Seven local authorities reported coverage of 80% or more, while 35 of the 150 reported coverage below 70%.
- Only 60% of women who received their first invitation were screened, compared with 86.3% of those who had been screened within the last five years. Uptake was lowest amongst those who received a routine invitation, having failed to respond to a previous invitation.
- Uptake has fallen markedly amongst those receiving a first invitation for screening (from 68.1% in 2007/08 to 60.0% in 2017/18).

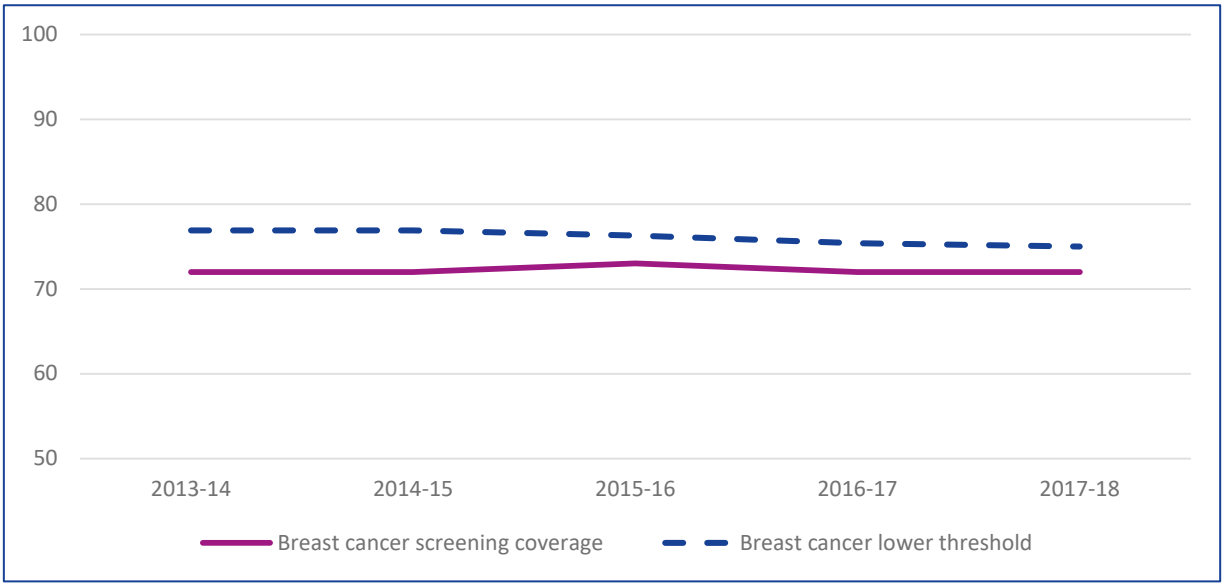
The Atlas (PHE, 2017) reports that local authority values ranged from 56.3% to 86.4%, which is a 1.5-fold difference between local authorities – and that almost one-quarter of local authorities (n=35) failed to meet the national minimum standard of 70% of women to be adequately screened.

Again, the "socioeconomic profile of local populations, which affects rates of screening acceptance" is mentioned, but with no detail about the demographic groups less likely to take up screening.

There is a hint of a suggestion that information currently provided – based on fully informed consent – may have an influence "according to the profile of the local population served." Interviews with the Breast Screening National Programme Manager and team suggest people in socially deprived areas, people who are BAME, and people who have learning disabilities or are transient (in particular London, but also North West) are hardest to reach (in common with other programmes).

This would suggest some overlap with people who are more likely to be digitally excluded, and a risk that a shift to online information could reduce coverage. Interviews also identified that take-up is lowest for first mammograms, when women haven't established habit, and it is possible that online information could help to reduce anxiety about this, in a way printed material cannot. Interviewees felt that the benefits of videos that are already available are known already. There was concern about anything that might reduce take up, including move to online-only information and leaflets which emphasise risks, particularly when information found through online search could be from alternative sources, such as news emphasising risks (e.g. BBC, 2018).

Figure 14: Breast screening coverage against lower threshold target



We have not conducted quantitative analysis on the relationship between coverage and digital exclusion. However, the lower age profile of the breast screening target group suggests this may not be as much of an issue as with other screening programmes. Further, there is some evidence that social media campaigns have been able to increase coverage rates – indicating that digital screening information may not be a barrier to increased coverage:

> "First-time appointments at the North Midlands Breast Screening Service increased by an average of 12.9% between three-year screening cycles from 2014 to 2018. The service has also shot up the league table for uptake levels, going from 58th to 11th in the country between 2016-17 and 2017-18." (Digital Health Age, 2019).

CERVICAL SCREENING PROGRAMME (CSP)

Cervical screening is offered to women aged 25-49 every three years, and women aged 50-64 every five years. Recently, it was identified that coverage has fallen: "During the past 5 years, 5-year coverage has fallen from just over 80% to just under 80%, and more so in 25- to 30-year-olds" (Albrow et al., 2012):

- In England, there are 16.4 million women who will be in these age brackets in 2020-25, 9 million who will be aged 25-49 and 5.7 million who will be aged 50-64.
- We estimate approximately 335,000 women will not be internet users (2.0%)
- There are far more women in the older age bracket who are not internet users: 277,427 women aged 43-62 (who will be 50-64 between 2020-25) are estimated to be offline, compared to just 50,899 aged 18-42 (who will be 25-49 between 2020-25).

Tables 15 and 16 show the number and proportion of women who are not internet users, according to the ONS Internet Users data (from the 2019 Labour Force Survey). This data suggests there are 557,000 women who are not internet users in the Cervical Screening Programme target demographic (2.5% of the 21.9 million people in the demographic, according to this dataset). However, this figure is reduced by applying the proportional figures to 2018 estimates of people who will be within the target demographic in 2020-2025.

Table 16: Women who are (not) internet users, by age band – UK, 2019.

	No. of women who have used internet in last 3 months	No. of women who are not internet users	No. of women who have never used internet	No. of women who have used internet over 3 months ago
All	24,255	2,771	2,354	417
16-24	3,373	10	7	3
25-34	4,436	18	9	9
35-44	4,164	43	25	18
45-54	4,477	115	84	31
55-64	3,830	266	196	70
65-74	2,747	583	478	105
75+	1,229	1,735	1,554	181
25-54	**13,077**	**176**	**118**	**58**
45-64	**8,307**	**381**	**280**	**101**
Cervical screening population	**21,384**	**557**	**398**	**159**

Table 17: Proportion of women who are/not internet users, by age band – UK, 2019

	Proportion of women who have used internet in last 3 months	Proportion of women who are not internet users	Proportion of women who have never used internet	Proportion of women who have used internet over 3 months ago
All	89.6	10.2	8.7	1.5
16-24	99.5	0.3	0.2	0.1
25-34	99.5	0.4	0.2	0.2
35-44	98.9	1	0.6	0.4
45-54	97.5	2.5	1.8	0.7
55-64	93.4	6.5	4.8	1.7
65-74	82.4	17.5	14.3	3.2
75+	41.4	58.4	52.3	6.1
25-54	**98.6**	**1.3**	**0.9**	**0.4**
45-64	**95.6**	**4.4**	**3.2**	**1.2**
Cervical screening population	**97.5**	**2.5**	**1.8**	**0.7**

Tables 18 to 19 show that the highest numbers of women in the target group for the Cervical Screening Programme are urban; in the top ten ranked CCGs by this measure, only Manchester and Brighton and Hove are outside London.

The proportion of women in the target group is above two-thirds of women in eight of these CCG areas, and virtually two-thirds in the remaining two CCGs.

The number of women estimated to be offline is over 1,000 in each of these CCGs. However, the number of women who are offline is – as with the other screening programmes – higher (above 3,700) in the larger CCGs, with rural south-west CCGs featuring alongside Leeds, and Birmingham and Solihull.

Finally, the proportion of women estimated to be offline is higher (above 2.5%) in rural eastern and northern CCGs, North Norfolk, Hambleton, Richmondshire and Whitby, Fylde and Wyre (Table 19). These CCGs have a larger population of older women, who are more likely to be offline.

Figure 15: CCGs ranked by population estimated to be offline within Cervical Screening target group

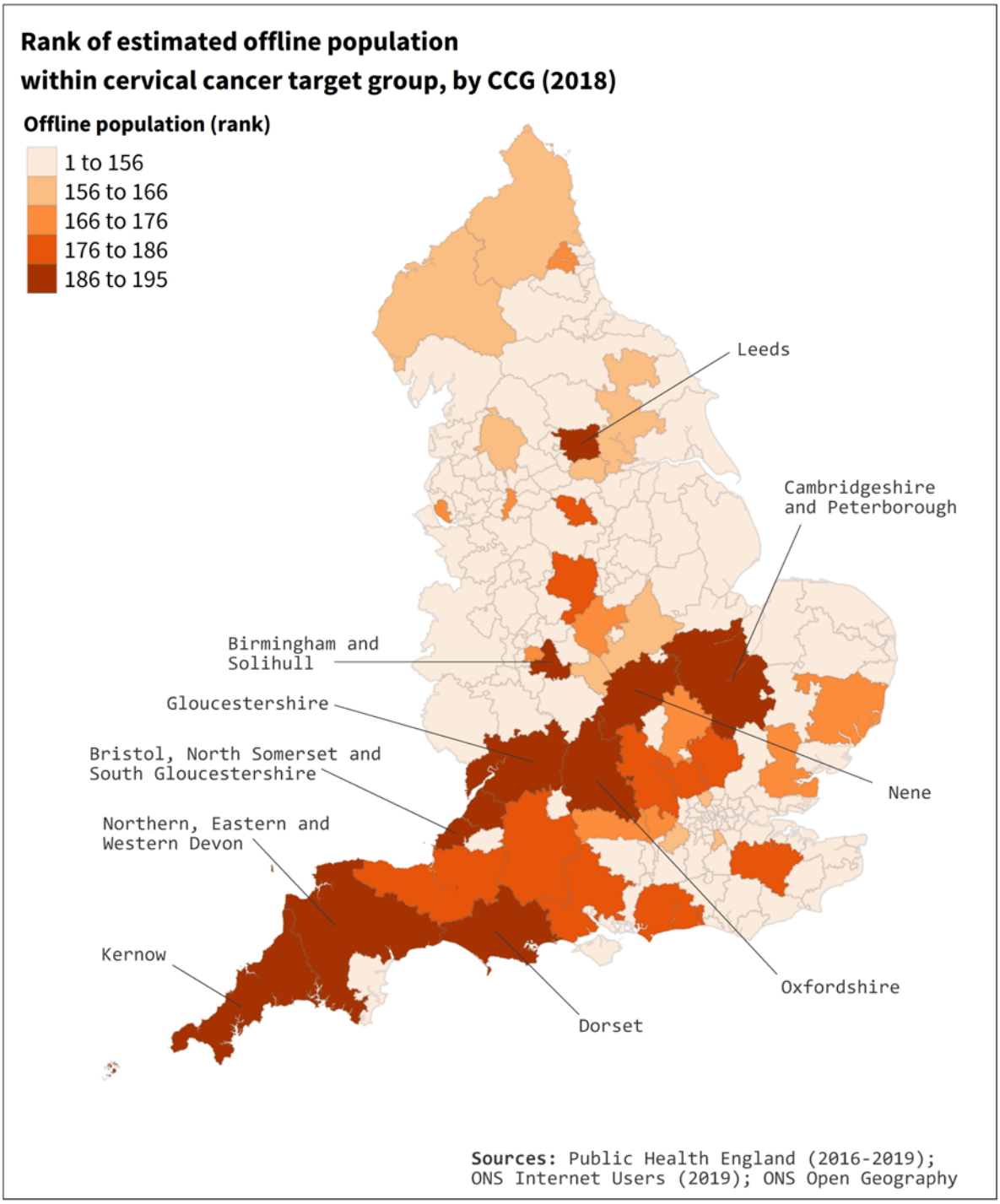


Table 18: Top ranked CCGs where the age profile of population indicates higher estimated proportion of women who are in the Cervical Screening Programme target demographic

CCG	No. of women aged 18-62, 2020-2025 target group	Proportion of women in target group (%)	Estimated number of women offline	Estimated proportion of women offline (%)
Islington	85,159	71.6	1,200	1.4
Lambeth	114,247	70.5	1,742	1.5
Wandsworth	118,917	70.0	1,708	1.4
Southwark	110,202	69.4	1,764	1.6
Tower Hamlets	104,656	68.9	1,317	1.3
City and Hackney	98,020	67.9	1,454	1.5
Hammersmith and Fulham	62,651	66.8	1,043	1.7
Brighton and Hove	96,475	66.8	1,625	1.7
Lewisham	102,134	66.5	1,761	1.7
Manchester	178,887	66.2	2,578	1.4

Table 19: Top ranked CCGs where the age profile of population indicates higher estimated numbers of women who are not internet users in the Cervical Screening Programme target demographic

CCG	No. of women aged 18-62, 2020-2025 target group	Proportion of women in target group (%)	Estimated no. of women offline (%)	Estimated proportion of women offline (%)
Birmingham and Solihull	352,327	58.7	6,415	1.8
Northern, Eastern and Western Devon	254,453	55.1	5,602	2.2
Bristol, North Somerset and South Gloucestershire	289,264	59.8	5,352	1.9
Cambridgeshire and Peterborough	254,279	57.2	5,229	2.1
Dorset	206,981	52.9	4,767	2.3
Leeds	245,365	61.0	4,359	1.8
Nene	189,296	56.7	4,045	2.1
Gloucestershire	178,989	55.5	4,018	2.2
Oxfordshire	195,241	57.9	3,989	2.0
Cornwall	156,270	53.5	3,721	2.4

Table 20: Top ranked CCGs where the age profile of population indicates higher estimated proportion of women who are not internet users in the Cervical Screening Programme target demographic

CCG	No. of women aged 18-62, 2020-2025 target group	Proportion of women in target group (%)	Estimated no. of women offline (%)	Estimated proportion of women offline (%)
North Norfolk	44,406	49.8	1,139	2.6
Hambleton, Richmondshire and Whitby	39,798	52.6	1,010	2.5
Fylde and Wyre	50,595	51.4	1,279	2.5
Isle of Wight	37,043	51.3	935	2.5
South Devon and Torbay	75,912	51.6	1,902	2.5
Lincolnshire East	62,713	51.8	1,567	2.5
East Riding of Yorkshire	84,557	52.3	2,113	2.5
Northumberland	89,088	54.3	2,220	2.5
Southport and Formby	30,693	50.8	757	2.5
Scarborough and Ryedale	30,505	52.5	751	2.5

EXISTING COVERAGE AND CHANNEL SHIFT IMPACT

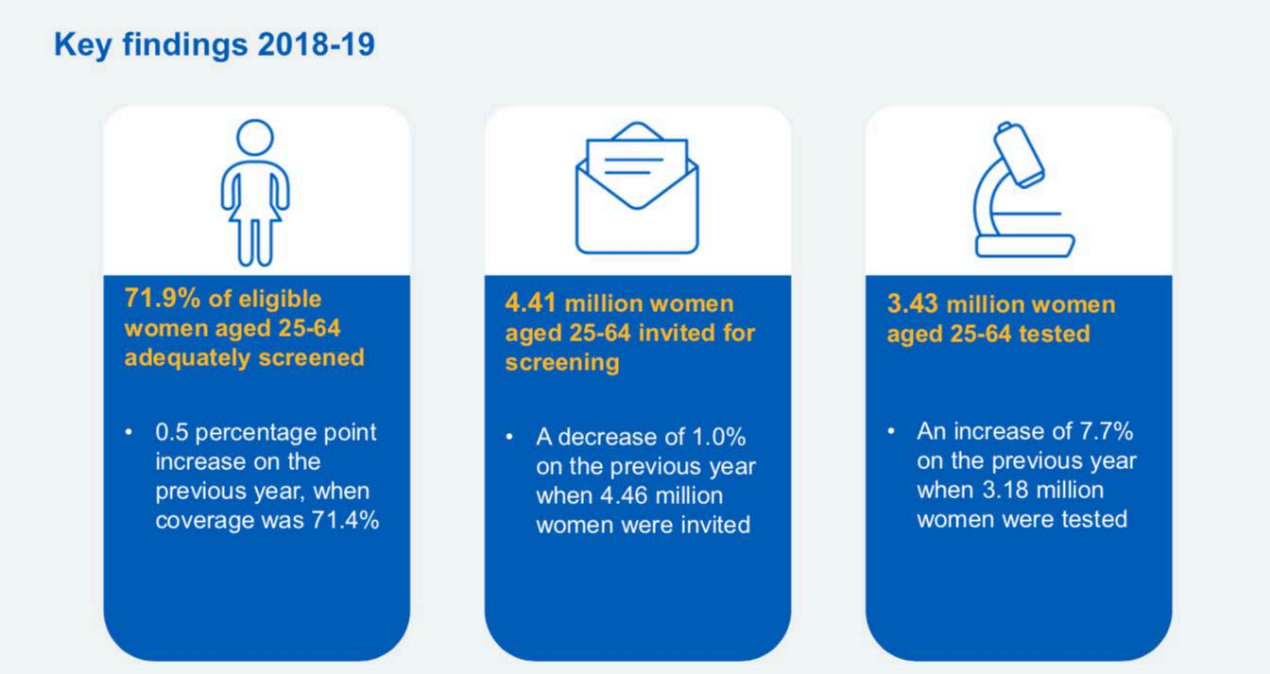
Coverage varies across the country and was historically at a 20-year low around 8 years ago (Albrow et al., 2012), with coverage reducing further since that time.

The Independent Review (Richards, 2019) noted that coverage is "is particularly low in deprived populations and populations with high proportions of ethnic minority populations", and among women in the youngest age band (25-29 years).

In the case of deprived populations and some ethnic minority populations, this is likely to be associated with higher risk of digital exclusion.

However, the situation is changing, and the programme has moved to a new pathway nationally from December 2019, using HPV primary screening; this may well see a different response to screening coverage over the coming years.

Figure 16 Cervical Screening Programme England 2018-19 Key Findings[41]



Coverage remains lowest in the younger screening cohort, where there are also the highest number of abnormalities picked up.

Given the youngest age groups are more likely to be digitally capable and engaged, they may be less affected by the digitisation of information – however, other factors affect digital exclusion, such as poverty, language, literacy, numeracy and lower levels of educational attainment.

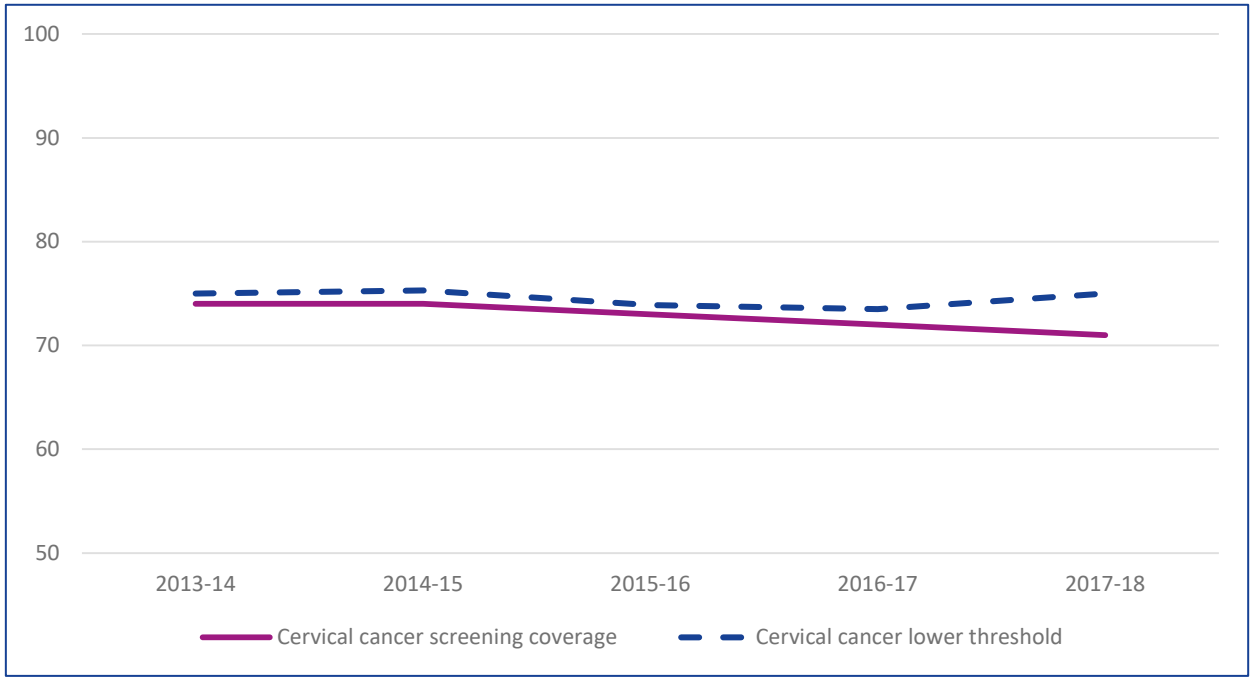
The Atlas (PHE, 2017) finds that – compared to an England value in 2015 of 73.5%, rates at different local authorities ranged from 56.5% to 84%, a 1.5-fold difference between local authorities.

There was only one local authority district where the minimum threshold rate of 80% coverage was reached. The existence and effectiveness of "strategies used to reach underserved groups in the local population" are identified as possible causes of unwarranted variation, and pre-screening reminders, personalised reminders for non-participants, and GP endorsement of

[41] Image copyright 2019 NHS Digital

cervical screening are recommended as effective interventions to increase coverage. Again, there is no mention of online information as likely to improve coverage and, given the potential overlap with digitally excluded groups, there is some risk that a shift to online information will reduce take-up.

Figure 17: Cervical screening coverage against lower threshold target



However, the younger demographic suggests coverage issues are less likely to be exacerbated by online information than other screening programmes.

As Albrow et al. (2012) state, “The problem is that women who have not taken up invitations for screening constitute a difficult-to-reach group, and it would seem that there is no 'one-size-fits-all' solution to this problem. Different women require different strategies to encourage increased uptake.”

They argue, “Initiatives to increase uptake will need to be research-led, because there have not been convincingly effective strategies identified to date. Candidate initiatives include self-sampling for HR-HPV, text messaging, and other forms of help for women.”

There has since been some evidence (Richards, 2019) that technology can be utilised to increase uptake:

- A large-scale pilot in London has shown that it is possible to send text reminders to the large majority of women who are due for screening. This includes women who have never previously attended screening. Furthermore, this pilot resulted in an increase in uptake of over 4%.
- Social media programmes, in some areas, have led to increases in uptake. A peak in the number of women tested in 2009 can almost certainly be attributed to the widespread publicity, following the death of Jade Goody from cervical cancer.

Overall, we summarise that, while this evidence has not explored the impact of moving to online screening information, it suggests that coverage is unlikely to be dramatically exacerbated by greater use of technology.

ABDOMINAL AORTIC ANEURYSM SCREENING (AAA)

Screening for abdominal aortic aneurysms is offered to men in the year they turn 65. Once someone has attended screening, they may have follow-up 'surveillance' appointments annually or quarterly:

- The ONS Mid-Year Estimate for 2018 suggests that, in England, the number of men aged 58-63 (those who will turn 65 in the next five years) is 1.9 million.
- The ONS Labour Force Survey 2019 identified that, across the UK, 7% of people in this age bracket (55-64) are not internet users.[42]
- This means **there are approximately 131,000 men who are not internet users** (assuming the proportion holds for England[43] – and over the time period[44]) in the target group.

Assuming PHE continue to send printed leaflets with all prevalent invitations, the plan to shift to online information will not affect the AAA screening programme, because all invitations in this programme are prevalent and sent as a 'one-off'. Follow-up appointments for those who have attended screenings (surveillance) may happen quarterly or annually.

[42] The ONS Labour Force Survey for 2019 suggests 4.9% of men aged 55-64 in the UK have never used the internet, and 2.1% of people in this category last used the internet over 3 months ago.

[43] Data by age is not available for England, but as England makes up 84% of the UK population, and 80% of people who are not internet users, we consider it reasonable to apply the same proportion. If anything, the proportion of people who are not internet users may be slightly lower, but it would be advisable to exercise caution and retain the higher estimate.

[44] The proportion of people who are not internet users is expected to decline, but it is not possible to predict the rate at which this will happen. Over the past decade, the rate at which people become internet users has begun to stall. It is also possible that people who are currently internet users lose their interest as they age. For the purposes of this exercise it is perhaps best to assume that the number of people who are not internet users in this demographic group is not likely to change *significantly* one way or the other– at least during the next few years. Even if many people in this group do become internet users, as new users they may lack the skills and/or confidence to feel comfortable with online information about screening programmes.

Tables 20 and 21 show the top ten Clinical Commissioning Groups (CCGs) where the *proportion* of men in the target group is highest, and those where the *number* of people estimated to be offline in the target group is highest.

As the total population in CCG areas varies significantly, there is no overlap between these two lists. In Northumberland for example, 9% of men are in the target group for the AAA Screening Programme. However, as the total population of men in the area is just 156,000, the total number of people estimated to be offline is under 1,000. By contrast, in Bristol, North Somerset and South Gloucestershire CCG areas just 6% of men are in the target group, yet because the population of men is higher – 476,500 – the estimated number of men who are not online is more than twice as high, and among the highest in England: 2,000.

Table 21 Clinical Commissioning Group by proportion of men in target group for AAA screening

CCG Name	Target group men 58-63 turning 65 in 2020-2025)	Proportion of total men (%)	Estimated no. of men offline in target group
Northumberland	14,041	9.0	983
North Norfolk	7,359	8.7	515
Isle of Wight	5,991	8.6	419
North Cumbria	13,521	8.6	946
East Riding of Yorkshire	13,362	8.6	935
Fylde and Wyre	8,067	8.6	565
South Devon and Torbay	11,833	8.6	828
South Tyneside	6,214	8.5	435
Scarborough and Ryedale	4,691	8.5	328
Lincolnshire East	9,874	8.5	691

Table 22: Clinical Commissioning Groups by number of men aged 55-64 estimated not to be internet users

CCG Name	No. of men in target group (men aged 58-63, turning 65 in 2020-2025)	Proportion of total men (%)	Estimated no. of men offline in target group
Northern, Eastern and Western Devon	33,941	7.6	2,376
Birmingham and Solihull	33,371	5.8	2,336
Cambridgeshire and Peterborough	29,442	6.6	2,061
Dorset	28,871	7.6	2,021

Bristol, North Somerset and South Gloucestershire	28,565	6.0	2,000
Gloucestershire	23,657	7.6	1,656
Cornwall	22,785	8.3	1,595
Nene	22,595	6.9	1,582
Leeds	22,461	5.8	1,572
Somerset	22,102	8.1	1,547

Men aged over 65 can self-refer. The proportion of this population that are not internet users is considerably higher. Among men aged 65-74, 15.9% are estimated not to be internet users (12.7% have never used the internet). Among men aged 75 and over, this figure rises to 46.2% (40.1% have never used the internet). Arrangements for self-referral should not be based on an expectation that people will engage with online information.

None of the CCGs identified as those with the highest levels of multiple deprivation are among those with the highest numbers of men in the target group for AAA Screening, nor those with the highest numbers estimated to be offline by age profile. However, this does not mean there is no relationship between the two sets of CCGs.

In addition to the factor of age, we already know that coverage for AAA Screening is lower in the most deprived deciles. Moving to a system where more information about screening programmes is delivered online could risk worsening coverage in areas of high, multiple deprivation.

EXISTING COVERAGE AND CHANNEL SHIFT IMPACT

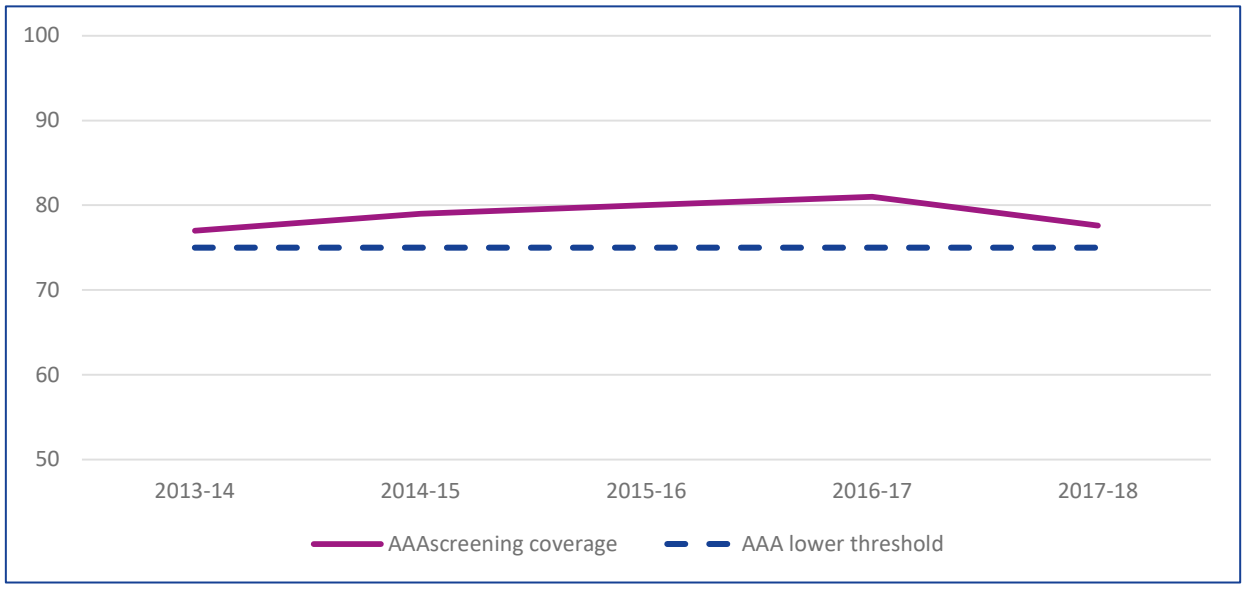
The Independent Review of Adult Screening Programmes in England (Richards, 2019) found uptake of AAA Screening is high; with 80.5% of eligible men tested within a year and three months of being invited for screening.

Coverage is generally improving (2013/14 to 2017/18, Figure 18 – a dip in the final year is attributed to a commissioning process in London). However, there is variation among CCGs, with rates ranging from 59.0% to 87.2% in 2014/5, a 1.5-fold difference (PHE, 2017).

The 2nd Atlas of Variation in NHS Diagnostic Services in England (henceforth 'The Atlas', PHE, 2017: 131), states that the "socio-economic profile of local populations… is known to affect rates of screening acceptance."

This is confirmed by the Independent Review, which notes that coverage was "lowest in the most deprived decile (70.5%) and highest in the most affluent decile (87.6%)." This has an impact on the aim of the screening programme, as "detection of aneurysms is highest in the most deprived populations." Were the AAA Programme to be affected by a shift from paper-based to online screening information, it is likely this effect would be exacerbated, as digital exclusion is associated with greater deprivation.

Figure 18: AAA Screening coverage against lower threshold target



ANTENATAL & NEWBORN SCREENING PROGRAMME (ANNB)

The Antenatal and Newborn (ANNB) Screening Programmes have a lower combined risk rating and potential impact from changes than the YPA programmes, for three main reasons:

1) Every woman who receives the screening invitation has some form of face-to-face contact with a health professional (e.g. midwife), whose role it is to explain screening options and help women make an informed choice. This increases the chances of effective messaging and information transfer.

2) The demographic for pregnant women is younger than 55, therefore this group have a lower risk of being digitally excluded (they are more likely to be digitally literate and own a connected device).

3) In terms of printed leaflet spend, the ANNB Programme is a very small percentage of the overall budget and so, in trying to ascertain where the risks will arise from any budget cut, other programmes are affected to a much greater degree.

When we commenced our research, we were made aware of these lower risk factors by PHE, however we continued to investigate equality impacts in this programme. Our tests of the system continued to support PHE's theories that this programme was lower risk – however ANNB is not entirely without risk from change.

PHE RESEARCH INTO ANNB AND DIGITAL INFORMATION

In summer 2019, prior to the Early Adopter pilots, PHE carried out focus group and observation / interview work to gather qualitative evidence about attitudes toward digital information in the ANNB Programme. PHE sought to find out the views of pregnant women on the existing screening information and the proposed changes.

The focus groups took place in London, at St Mary's Hospital in East London, and also in Kirkby, Liverpool. The groups included women for whom English isn't a first language and also women from more disadvantaged backgrounds.

The main headline findings were:

- Overall the vast majority of women were positive about the changes and welcomed online information.
- The ANNB video was very popular.
- The majority of women were confident using the internet and used to finding out information online.
- However, although not directly affected themselves, women did comment that not everyone has the internet or a smartphone, connection can be limited and there is a risk of confusion in information from other websites.

EARLY ADOPTER SITES

ANNB was chosen by PHE to pilot new changes and approaches to offering online / digital information instead of printed leaflets – these were tested at 10 'Early Adopter' NHS Trust sites across England, who expressed an interest in trying out new information delivery methods.

For the Early Adopter sites, PHE Screening mapped the process for how a pregnant woman would receive information leaflets and had suggested an alternative process for signposting pregnant women to the information online, including 'business cards' with links and QR codes that women could scan or type in with a mobile device.

There were still leaflets available for women, but the team asked midwives to record a reason why the leaflet had been given, such as:

a) I don't have access to the internet

b) I'm not confident using the internet, etc.

Flyers and posters were produced to raise awareness of the online information. Although this was still printed on paper, it was necessary in the transition period to embed the new website with information. The current ANNB leaflet is also 57 pages long, so the flyers and posters were still a significant reduction in the print costs.

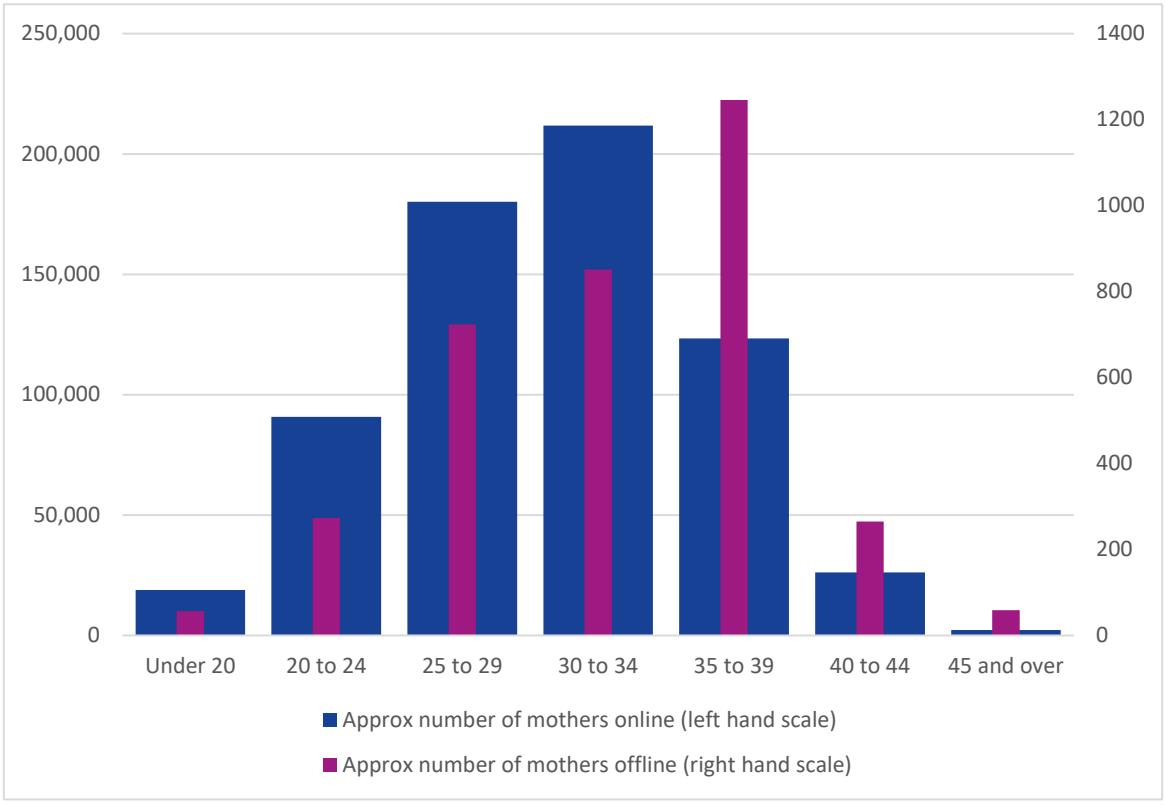
The PHE screening team continued to monitor the phased roll-out with the Early Adopter sites throughout our research period.

BEING OFFLINE IN MOTHERHOOD

The chart below shows data from ONS "Births by parents' characteristics" dataset on annual live births in England and Wales, by age of mother.[45] We have split the data on total number of mothers into those estimated to be online and offline, for each age group. The blue wide bars show the proportion of mothers in each age band (left-hand scale), the purple narrow bars show the *different* proportions of mothers estimated to be offline.

The age band where a higher *number* of mothers are expected to be offline is the 35-39 age group (a higher *proportion* of older mothers are offline, but the *numbers* of mothers in these age bands are lower).

Figure 19: Distribution of mothers estimated to be on/offline, by age band



[45] ONS Births by parents' characteristics data is available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsbyparentscharacteristics, accessed 18/03/2020.

Appendix 2 – Digital Inequality

EQUITABLE ACCESS – STATUTORY DUTIES AND PROTECTED CHARACTERISTICS

PHE's guidance on "Equitable access to screening: Statutory duties under the Equality Act" (PHE, 2017a) asserts that "All eligible populations should have access to screening and understand the benefits and risks".

The "NHS population screening: inequalities strategy" (PHE, 2019a) sets out how Public Health England and partners "aim to tackle screening inequalities". The strategy notes that the Health and Social Care Act (2012) introduced specific legal duties on health inequalities which PHE must meet on behalf of the Secretary of State for Health and Social Care. The duty requires public authorities to have due regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service.

Screening programmes are required by the act to pay particular attention to reaching people with the nine protected characteristics. It is against the law to discriminate against anyone because of:

- Age
- Gender reassignment
- Being married or in a civil partnership
- Being pregnant or on maternity leave
- Disability
- Race including colour, nationality, ethnic or national origin
- Religion or belief
- Sex
- Sexual orientation

As in other settings, people are protected from discrimination on the basis of these protected characteristics when using public services. Public services can also take voluntary action to help people with a protected characteristic if they are at a disadvantage or have particular needs.

The 2019 strategy notes that "Variation in participation exists both within and between national screening programmes and, generally, people at higher risk of the condition being screened are less likely to participate". The strategy "seeks to address the unwarranted and unfair barriers that may mean people do not engage with an offer of, or participate in, screening or who are disadvantaged in maximising the benefits of screening."

Communication barriers are listed as examples alongside physical, cultural and social barriers. Below, we explore how people with protected characteristics may be affected by reducing printed information.

We also examine some other sections of the population who do not have a protected characteristic, who the 2017 guidance notes "should still have access to screening in a way that meets their needs".

In other words, we explore the risk that encouraging people to learn more about screening online may exacerbate communication barriers. We identify demographic groups more likely to experience digital exclusion, and screening programmes where these groups are more likely to be represented and therefore the risks are greater.

To conduct this research, we have reviewed the literature on digital exclusion,[46] searched for and summarised literature we have identified (relevant to digital transformation and Channel Shift of screening programmes), and explored the Office for National Statistics (ONS) audit of data sources and publications that are available to understand equalities (2017).[47]

AGE

The Office for National Statistics audit data sources and publications that can help us to understand equalities (ONS, 2018). Their aim was (and is) to "ensure that the right data are

[46] Previous reviews of the literature on digital inclusion and/or digital skills include the *Rapid Review of Evidence for Basic Digital Skills* conducted by the University of the West of Scotland (McGillivray, Jenkins and Mamattah, 2017) on behalf of the SCVO. Age UK have produced two reports with a focus on older people: *Digital Inclusion Evidence Review* (Davidson, 2018), preceded by the *Digital Inclusion Evidence Report* (Green and Rossal, 2013).

[47] ONS Equalities data 2017: https://www.ons.gov.uk/methodology/methodologicalpublications/generalmethodology/onsworkingpaperseries/inequalitiesdataauditfocusonethnicity

available to address the main social and policy questions about fairness and equity in society, including outcomes for all nine of the protected characteristic groups covered by the Equality Act (2010)."

The initial audit identified "400 sources of data in a variety of formats, including articles, statistical bulletins, CSV files, datasets or tables, headline commentary and figures, infographics, statistical releases and web tools". Their aim was (and is) to "ensure that the right data are available to address the main social and policy questions about fairness and equity in society, including outcomes for all nine of the protected characteristic groups covered by the Equality Act (2010)". The report emphasises an intersectional perspective that takes account of cross-cutting axes of disadvantage:

> It is recognised that disadvantage may be experienced differently by those with multiple protected characteristics, for example, a woman from an ethnic minority group. This is referred to as intersectionality. For this reason, it is important that data are available to effectively monitor the intersection of different protected characteristics.

This is an approach we adopt where possible below, noting the ways in which age, disability, and ethnicity can interact with regard to the likelihood of individuals being internet users.

We know from a variety of sources that older people are more likely to be digitally excluded – to be offline, to lack digital skills, and to be less likely to have access to digital devices.

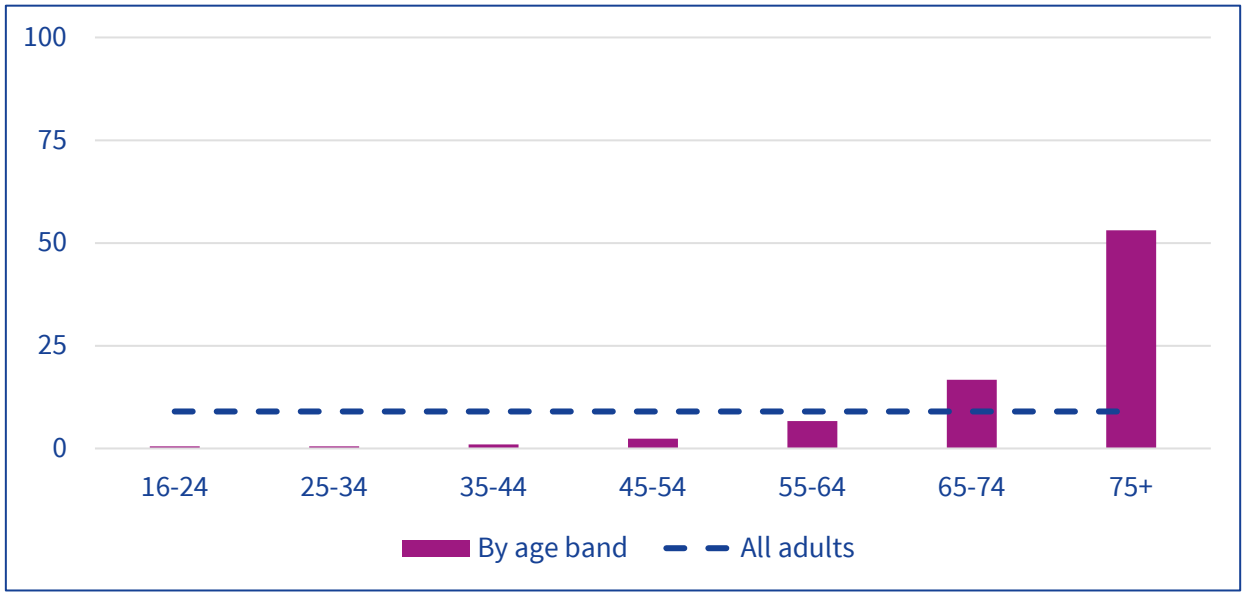
According to the Office for National Statistics (ONS), **33% of people aged 65+ have not been online within the last 3 months** – hence they are effectively not online. Of these, the great majority (86%, or 29% of all people aged 65+) have *never* been online. More than half of the population aged 75+ (53.1%) are not online (have not used the internet within the last 3 months); and most (89%, or 47% of all people aged 75 or over) have never been online (Figure 20).[48]

[48] ONS - Internet users, UK: 2019, accessed 25/09/2019

We also see a correlation between age and lack of access to devices. The 2019 *Lloyds UK Consumer Digital Index*[49] provides data on the proportion of households without smartphones, laptop/PCs, and tablets.

In each case, the proportion is highest for people aged 65 or over.[50] Finally, older people are also more likely to lack digital skills. The 2019 Lloyds *UK Consumer Digital Index* [51] found **55% of people aged 65 and over were missing either Essential Digital Skills**[52] or Foundation skills, compared to just 6% of those aged 15-34.[53]

Figure 20: Proportion of adults who are not internet users, by age (ONS, 2019)



[49] Lloyds UK Consumer Digital Index, 2019 – data derived from Appendix 24, based on an Ipsos MORI face-to-face Omnibus survey of 4,190 participants aged 15+ years in Great Britain and Northern Ireland.

[50] The picture for tablets is marginally more complicated as younger people seem less likely to have these, likely due to preference for other devices.

[51] This research was conducted by Ipsos MORI, through their face-to-face Omnibus survey (also known as CAPIBUS). CAPIBUS is a nationally and regionally representative sample of adults aged 15+ in Great Britain: 4,190 participants aged 15+ years in Great Britain and Northern Ireland.

[52] The Essential Digital Skills Framework defines the Essential Digital Skills "adults need to safely benefit from, participate in and contribute to the digital world". They are structured around four areas: Communicating, Handling information and content, Transacting, and Problem solving.

[53] Foundation skills are: turning on a device, using controls on a device, using accessibility tools on a device, interacting with the home screen on a device, connecting devices to safe and secure WiFi, knowing that passwords and personal information need to be kept safely, and being able to update and change passwords when prompted to do so.

Figure 21: Proportion of households without devices, by age band

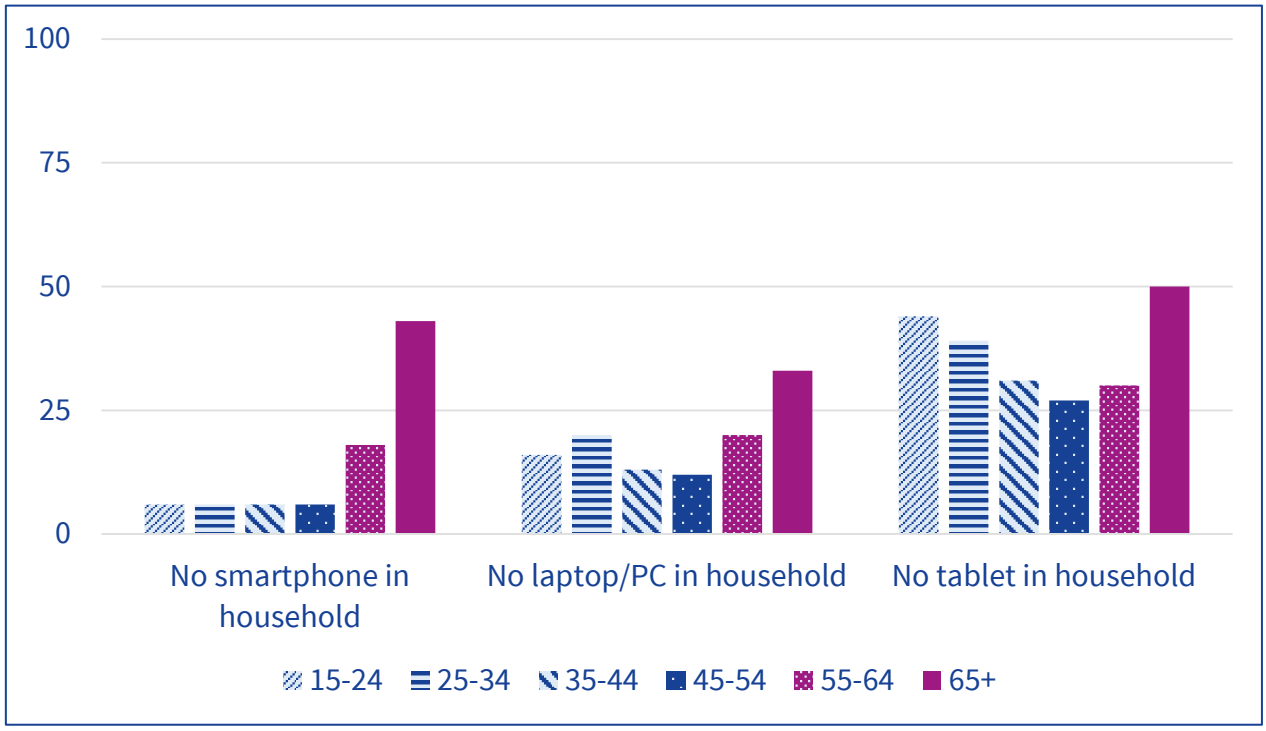


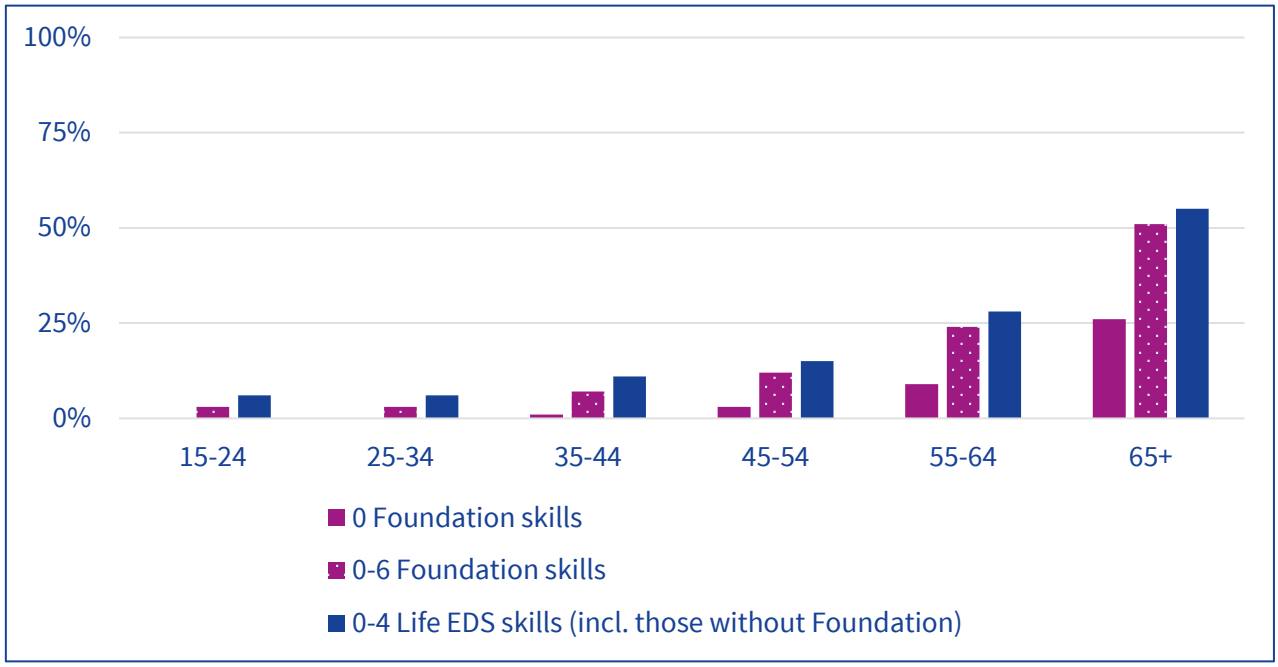
Table 23: Proportion of households that do not own particular devices by age band

	No smartphone in household	No laptop/PC in household	No tablet in household
15-24	6%	16%	44%
25-34	6%	20%	39%
35-44	6%	13%	31%
45-54	6%	12%	27%
55-64	18%	20%	30%
65+	43%	33%	50%

Table 24: Missing Foundation and/or Essential Digital Skills, by age band (Lloyds, 2019)

	0 Foundation skills	0-6 Foundation skills	0-4 Life EDS skills (incl. those without Foundation)
15-24	0%	3%	6%
25-34	0%	3%	6%
35-44	1%	7%	11%
45-54	3%	12%	15%
55-64	9%	24%	28%
65+	26%	51%	55%

Figure 22: Missing Foundation and/or Essential Digital Skills, by age band (Lloyds, 2019)



Overall, these data indicate that age is strongly correlated with digital exclusion. Data regarding age and digital exclusion can be used to explore the risks of digital exclusion associated with six of the PHE screening programmes, which are offered to defined groups of people based on their age. This can also help identify areas in England where there are higher numbers and/or proportions of people who are more likely to be digitally excluded.

This is relevant to decisions around moving information about screening programmes online. This is unlikely to concern the overwhelming majority of younger adults, who have strong preferences for digital communications. Three-quarters (75%) of 16 to 24-year-olds agree with the statement "*I would prefer to send emails rather than letters wherever possible",* compared to just 36% of over-74s (Ofcom, 2018b). While Ofcom do not report data on how people would prefer to receive information, only 23% of people aged 75 and over agree they "*only use post if there is no alternative*" (compared to around half, 48%, of 16 to 24-year-olds).

Where coverage rates differ for medical screening programmes at present, the impact of age appears to be in the opposite direction; younger people are less likely to participate in cervical and diabetic eye screening (the other screening programmes largely only cover older demographics). However, there is still a risk that a shift to online information could impact take-up.

DISABILITY

The Equality Act 2010 defines disability as follows:

> "(1) A person (P) has a disability if—
> (a) P has a physical or mental impairment, and
> (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.
> (2) A reference to a disabled person is a reference to a person who has a disability.
> (3) In relation to the protected characteristic of disability—
> (a) a reference to a person who has a particular protected characteristic is a reference to a person who has a particular disability;
> (b) a reference to persons who share a protected characteristic is a reference to persons who have the same disability."

Disabled people are among the demographic groups research has consistently identified as being more likely to be digitally excluded.

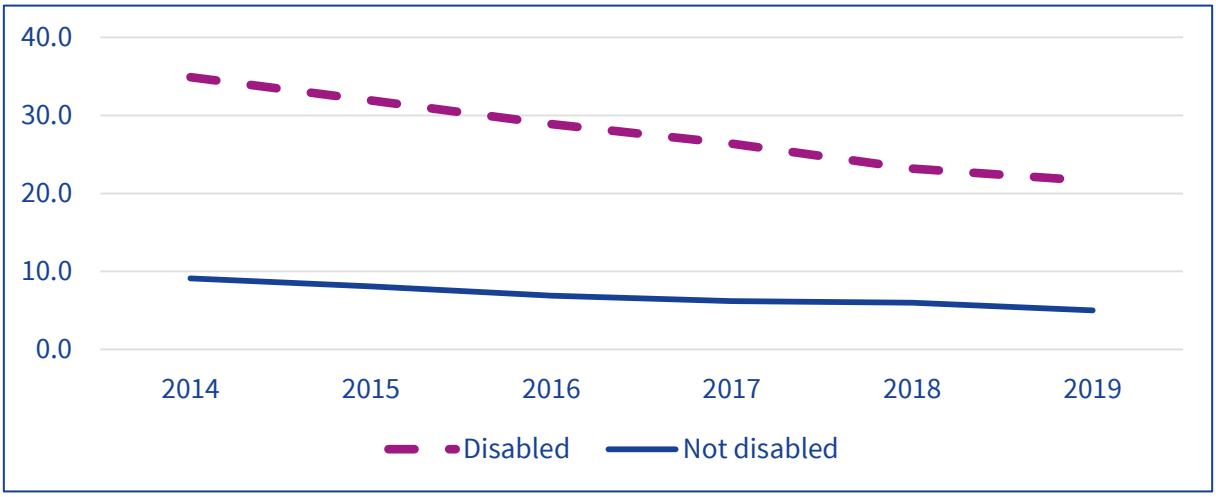
In their study on disability and the digital divide, conducted among disabled and non-disabled respondents in a deprived area of Sunderland, Macdonald and Clayton (2013) found that those with a disability were far less likely to use technology than their counterparts in the control group (42% of those with impairments had never used a mobile phone or a computer or accessed the web, compared to 28% of the control group).

Ofcom (2018b) reported that 53% of disabled people have a smartphone in their household (though this is higher – 70% – among people with a learning disability), compared to 81% non-disabled people. Technological developments such as “improvements to the text relay service for deaf, hearing- and speech-impaired users, enabling it to be accessed by a mobile phone or tablet, and the ability to increase the image on a tablet screen” can help those with impairments to access services online.

As a result, the rate at which disabled adults have become regular internet users has been much faster over the past year (rising from 64.9% to 78.3%, compared to a rise from 90.8% to 94.8% among adults who are not disabled, Figure 23).

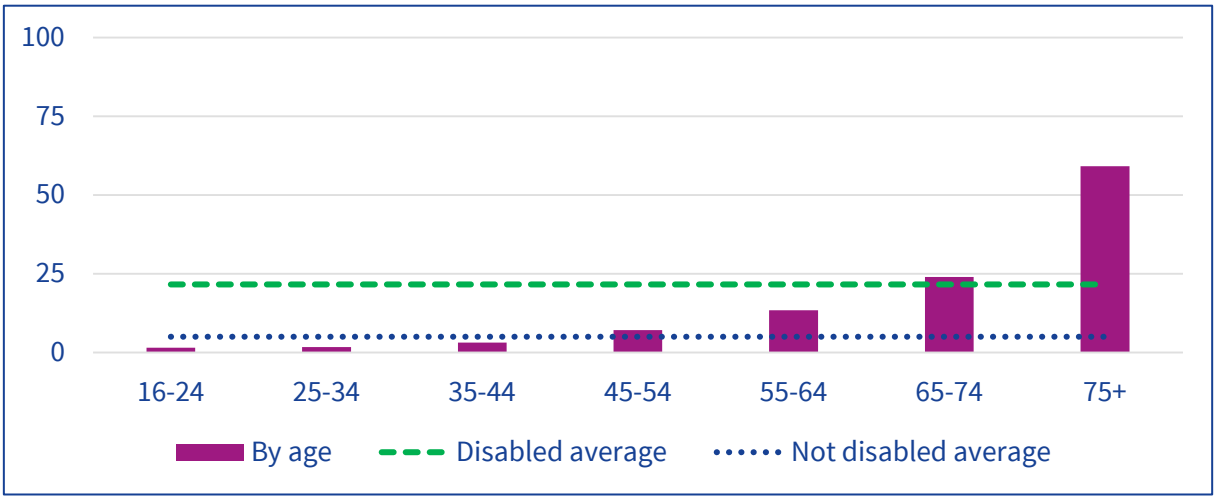
Despite this, ONS data on internet users shows ***the proportion of disabled adults who are not internet users remains considerably higher than for adults who are not disabled*** (21.6% compared to 5% in 2019, using the Equality Act definition).

Figure 23: Proportions of disabled and non-disabled adults who have never used the internet or last used it over three months ago (ONS, 2014-2019)



There is a clear intersection between age and disability: disabled people are less likely to be internet users, the older they are. Among disabled people aged 75 and over, 59% are not internet users (more than ten times the rate for adults who are not disabled, on average). Indeed, "there is no difference [in levels of internet use] when looking at 16-34s (99% of non-disabled people vs. 98% of disabled people)" (Ofcom, 2018b).

Figure 24: Proportion of people who are not internet users: disabled people by age (ONS, 2019)



As shown in Table 25 (taken from Ofcom 2018b), ownership of devices varies significantly for disabled people. For example, just 54% of disabled people own any computer for personal use (and 64% within their household), compared to 77% among non-disabled people (85%). Just 45% own a smartphone for personal use (53% within the household), compared to 75% among non-disabled people (81%).

Table 25: Ownership of devices, disabled and non-disabled people

	Household ownership		Personal use	
	Non-Disabled	Disabled	Non-Disabled	Disabled
Landline	66%	74%**	56%	66%**
ANY mobile	91%	80%*	86%	71%*
Simple mobile	22%	36%**	18%	31%**
Smartphone	81%	53%*	75%	45%*
Any computer (PC/laptop/tablet)	85%	64%*	77%	54%*
Tablet	63%	44%*	52%	34%*
Games Console	38%	23%*	24%	13%*
Smart TV	48%	30%*	43%	26%*
InternetΔ	NA	NA	92%	67%*

*Source: Ofcom Disability Consumer Research. Question: Q1. Does your [household] have... QL. Which of the following do you currently ever use, if at all? Base: non-disabled: 17,510, all disabled: 3524. Note: ** indicates that a disability group is significantly higher than non-disabled consumers while * indicates that a disability group is significantly lower than non-disabled consumers (significance tested to 95%).*

ΔInternet relates to personal use anywhere (i.e. both in and outside the home). The survey does not capture whether respondents have internet access at home.

While experiences are differentiated based on the nature of disabilities or impairments (people using wheelchairs may have problems gaining access to public IT equipment, whereas people with visual impairments may need specialist software and training), there is a particular risk associated with Channel Shift for disabled people.

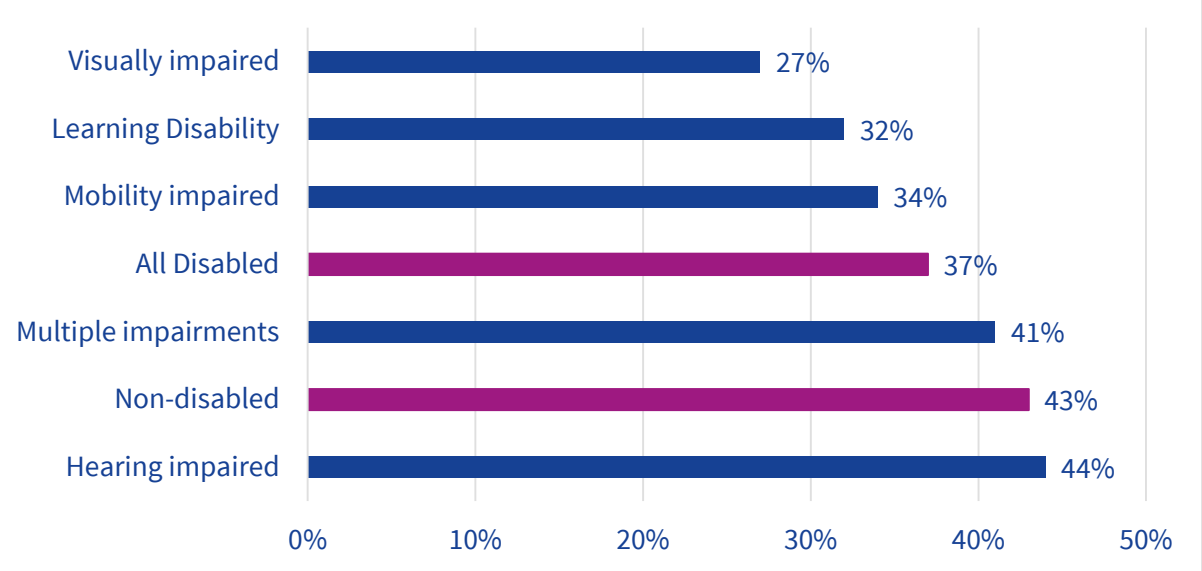
For Macdonald and Clayton (2013: 705) shifts toward online provision of services carry the risk that:

> *"disabled people who are not engaging in digital technologies... have the potential of becoming further excluded and experienc[ing] more disabling barriers significantly reducing their life chances".*

There is already a gap between disabled and non-disabled internet users with regard to accessing public services: 37% vs. 43% (Ofcom, 2018b). Similar divides exist for shopping – 47% vs. 60%, and banking – 45% vs. 61%.

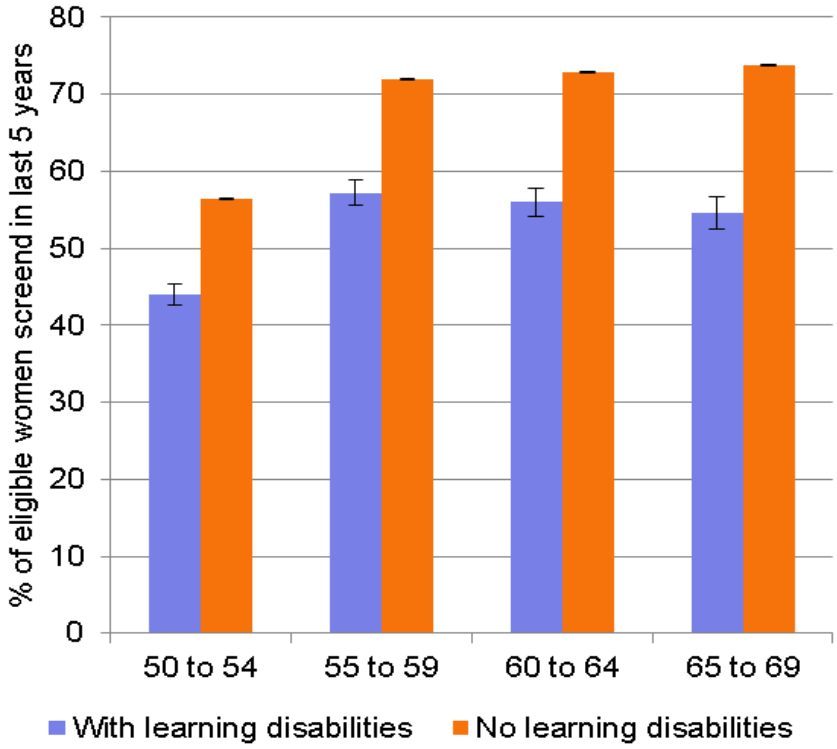
This gap varies among people with different impairments: it is largest for visually impaired people (27% vs. 43%), while hearing impaired people are as likely as non-disabled people to use the internet to access public services (44% vs. 43%, see Figure 25).

Figure 25: Proportion of people using the internet to access public services (benefits, government, council), by disability type



There is some evidence that coverage for screening programmes is already lower for some disabled people. Figure 26 shows the lower proportion of eligible women who have had breast screening in the past five years among people with learning disabilities (Mackie, 2019b).

Figure 26: Breast screening coverage, by age and learning disability



ACCESSIBILITY

The "NHS population screening: inequalities strategy" includes reference to the Accessible Information Standard (NHS England, 2017), which "ensures that people with a disability, impairment or sensory loss are given information in a way they can access and understand and any communication support that they need".

The 2017 guidance recommends that local screening services should meet this standard. Such a requirement would need to be carried over to any online screening information, in accordance with the Web Content Accessibility Guidelines (WCAG) 2.1 (W3C Web Accessibility Initiative, 2018). New regulations implementing the EU Directive on the accessibility of public sector websites and mobile applications (European Parliament, 2016) are now in UK law.

The "Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018" (UK Statutory Instruments, 2018) apply to new public sector websites from 23 September 2019, to existing public sector websites from 23 Sept 2020, and to public sector mobile applications from 23 June 2021. The Government Digital Service (GDS) provides Guidance for

"Understanding new accessibility requirements for public sector bodies" (GDS, 2018). PHE note that existing "national screening invitation leaflets can be easily resized and used with screen readers if required", and ***information in HTML format offers further possibilities to give users control and ensure accessibility***.

PHE also provide guidance on "Reasonable adjustments for people with a learning disability" (PHE, 2018), explaining how local screening providers should adapt services to help people with learning disabilities access them. People who have a learning disability, or who struggle with written English, can access easy-read leaflets (PHE, 2019). Clearly, these easy-read leaflets can be provided online, though at present this is only in the form of a downloadable pdf, rather than in HTML format.

INTERSECTION BETWEEN DISABILITY AND DEPRIVATION

The "Is England Fairer?" (Equality and Human Rights Commission – EHRC, 2018a) report found a clear intersection between disability and deprivation:

- "In 2015/16, 25.1% of disabled adults in England were living in poverty. The rate for disabled people increased by 2.4 percentage points between 2010/11 and 2015/16."
- "The poverty rate was high among people with social or behavioural, mental health, and learning or understanding or concentration impairments (37.6%, 34.5% and 31.0%)."
- "In England, disabled people were nearly three times as likely to experience severe material deprivation[54] as non-disabled people (37.1% compared with 13.8%)."
- "Disabled people were twice as likely as non-disabled people to be NEET (16.4% compared with 7.0%)."

Disabled people are more likely to experience deprivation (including financial hardship, low or no income). PHE data also suggests that coverage for some screening programmes is lower in areas of high deprivation. Disability and deprivation are both factors that limit digital inclusion and these combined factors mean that a shift to online information may indirectly impact uptake, even if digital content has a high level of accessibility and is of good quality.

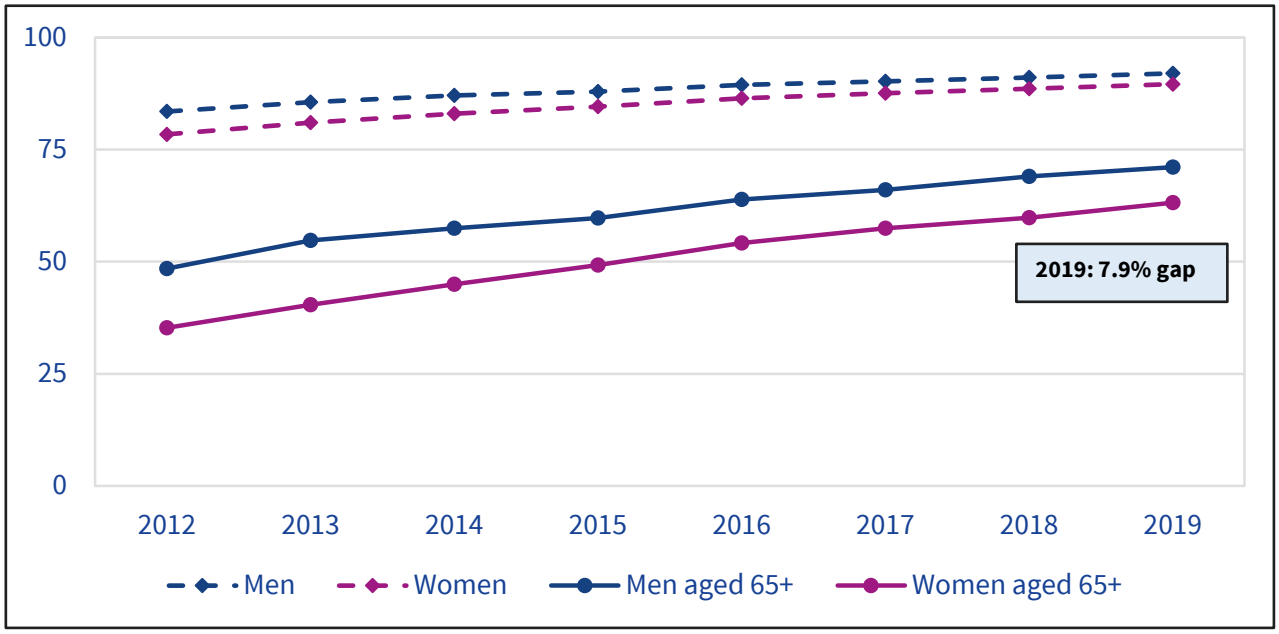
[54] "An individual is defined as deprived if they cannot afford 4 or more from a list of 9 items, such as replacing worn out furniture or keeping their accommodation sufficiently warm."

SEX

At the overall population level, there is little difference between men and women with regard to levels of digital exclusion (92% of men are internet users, compared to 89.6% of women). However, there is some evidence that older women are more likely to be digitally excluded than older men.

Across the UK, **63.2% of women aged 65 or over are internet users, compared to 71.1% of men** (Figure 27). Screening programmes and information about them will impact on people according to the target demographic, which is limited by sex for some of the programmes, particularly where this overlaps with age.

Figure 27: Proportion of adults who are internet users, by sex (ONS, 2012-2019)



RACE, INCLUDING COLOUR, NATIONALITY, ETHNIC OR NATIONAL ORIGIN

In the 2011 Census, 80.5% of people in England and Wales said they were White British, and 19.5% were from ethnic minorities. Table 26 shows data from the ONS Internet Users dataset (itself taken from the Labour Force Survey), which details the number and proportion of adults

who are not internet users, broken down by ethnicity provided by respondents.[55] This shows that the proportion of BAME adults who are not internet users is lower than the UK average (6.6%, compared to 9.0%), and makes up just 8.6% of all the adults who are not using the internet in the UK.

However, the proportion of adults who are not internet users varies by ethnicity: Chinese adults are considerably more likely to be internet users, while Indian adults are less likely to be internet users.

It is likely that the level of internet use is probably influenced by all three factors (age, income and ethnicity), rather than ethnicity alone. Unfortunately, the ethnicity breakdown in the 2011 Census – which enables analysis by median age – is not the same as that used by the ONS Labour Force Survey. Nonetheless, Table 27 shows that the median age of the UK's White population is considerably higher (41) than for BAME populations (18-30).

Table 26: Adults not using the internet, by ethnicity (ONS, 2019)

	Approximate pop'n ('000)	% not internet users	Number not internet users ('000)	% of UK adults not using the internet
UK	52,930	9.0	4,800	100
White	46,736	9.4	4,382	91.3
BAME Total	**6,231**	**6.6**	**413**	**8.6**
Indian	1,191	9.3	111	2.3
Pakistani	842	8.5	72	1.5
Black/African/Caribbean /Black British	1,483	6.8	102	2.1
Other ethnic group	842	5.3	44	0.9
Bangladeshi	385	8.1	31	0.6
Other Asian background	649	4	26	0.5
Mixed/multiple ethnic background	570	3.9	23	0.5
Chinese	269	1.4	4	0.1

[55] A small number of respondents who chose not to declare their ethnic group are excluded from this analysis.

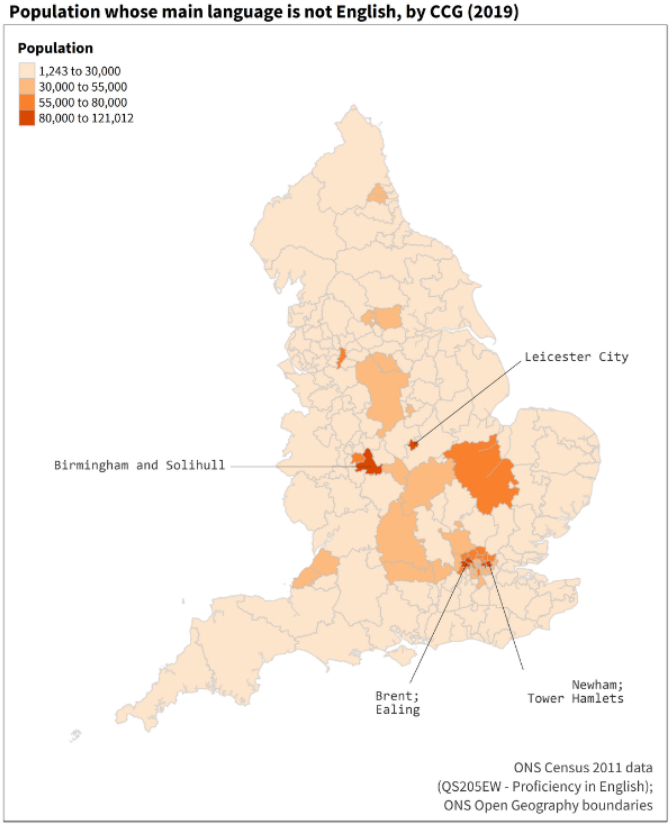
Table 27: Median age by ethnicity (Census, 2011)

Ethnicity	Median age
White	41
Black	30
Other	30
Asian	29
Mixed	18
All	**39**

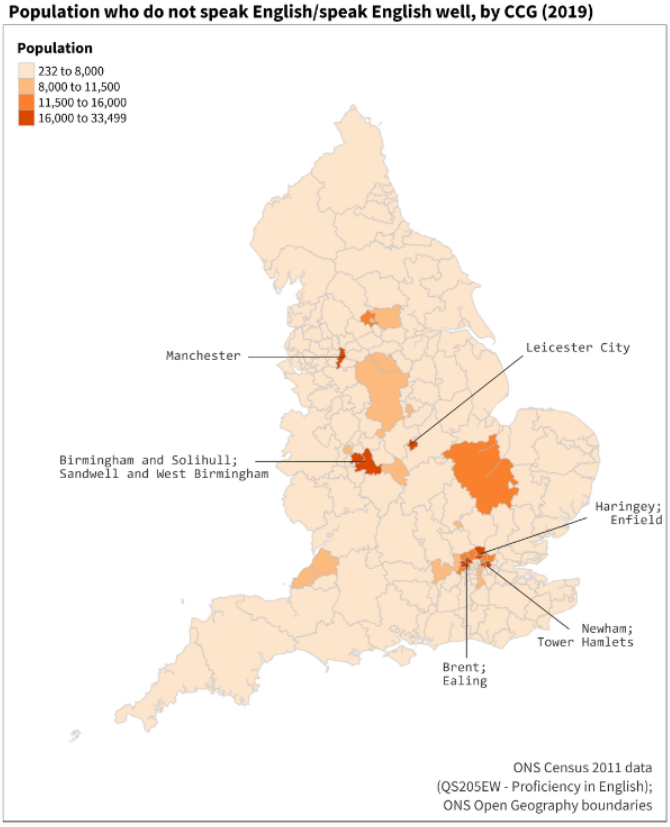
One factor likely to be associated with race, with regard to nation origin, is proficiency speaking/reading English. The 2011 Census does not provide data on reading proficiency but does enable us to explore CCGs where a lower proportion of the population are able to speak English or speak English well (Tables 28 and 29), which we can assume is correlated with reading ability. If anything, ***online screening information should enable greater access to information in a range of languages. However, this relies upon initial communication about any web-based content being possible to understand.***

The 2011 Census recorded just over 4 million people for whom English was not their main language (8%)

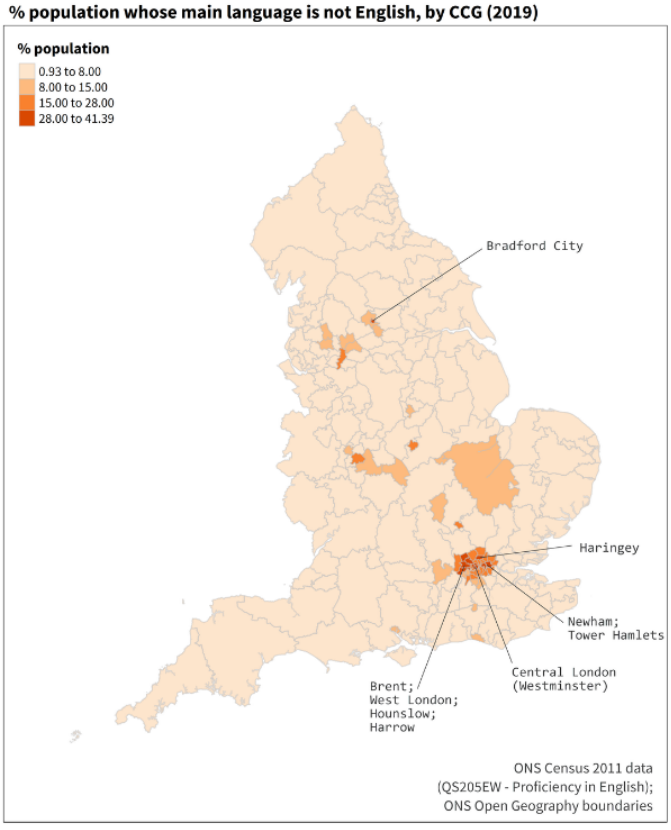
Population whose main language is not English, by CCG (2019)



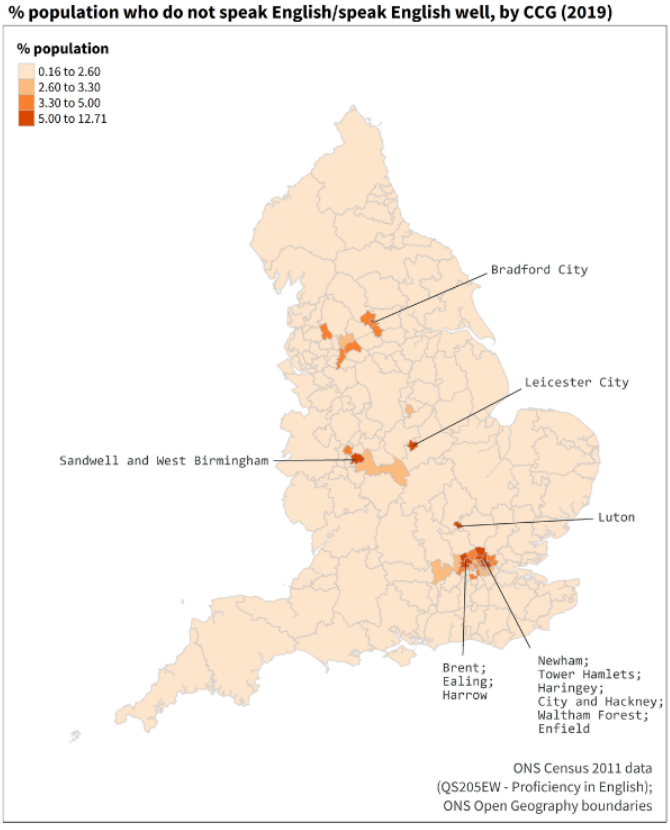
Population who do not speak English/speak English well, by CCG (2019)



% population whose main language is not English, by CCG (2019)



% population who do not speak English/speak English well, by CCG (2019)



844,000 people reported they could either not speak English at all or could not speak it well (1.7%)

Table 28: Top CCGs ranked by number of people whose main language is not English (Census, 2011)

CCG Name	Main language not English	% Main language not English	Cannot speak English / speak English well	% Cannot speak English / speak English well	Cannot speak English	Cannot speak English %
NHS Newham	121,012	41.4	25,488	8.7	3,815	1.3
NHS Brent	110,480	37.2	23,694	8.0	3,830	1.3
NHS Ealing	109,375	33.9	23,253	7.2	3,549	1.1
NHS Leicester City	86,716	27.5	23,523	7.5	4,705	1.5
NHS Birmingham CrossCity	84,352	12.4	23,384	3.4	4,680	0.7
NHS Tower Hamlets	82,880	34.2	19,307	8.0	3,778	1.6
NHS Barnet	79,678	23.4	13,552	4.0	1,897	0.6
NHS Sandwell and West Birmingham	78,085	17.5	26,953	6.0	5,218	1.2
NHS Haringey	72,436	29.7	17,582	7.2	2,684	1.1
NHS Cambridgeshire and Peterborough	71,450	8.9	15,083	1.9	2,328	0.3

Table 29: Top CCGs ranked by proportion of people whose main language is not English, and who cannot speak English, or cannot speak English well (Census, 2011)

CCG Name	Main language not English	% Main language not English	Cannot speak English / speak English well	% Cannot speak English / speak English well	Cannot speak English	% Cannot speak English
NHS Bradford City	28,978	38.0	9,698	12.7	1,825	2.4
NHS Newham	121,012	41.4	25,488	8.7	3,815	1.3
NHS Brent	110,480	37.2	23,694	8.0	3,830	1.3
NHS Tower Hamlets	82,880	34.2	19,307	8.0	3,778	1.6

NHS Leicester City	86,716	27.5	23,523	7.5	4,705	1.5
NHS Haringey	72,436	29.7	17,582	7.2	2,684	1.1
NHS Ealing	109,375	33.9	23,253	7.2	3,549	1.1
NHS Slough	35,876	27.1	8,263	6.2	1,392	1.1
NHS Sandwell and West Birmingham	78,085	17.5	26,953	6.0	5,218	1.2
NHS City and Hackney	57,681	23.9	14,176	5.9	2,421	1.0

There has been some research into rates of digital exclusion and race. Bartikowski, Laroche, Jamal and Yang (2018), studying multiple countries, found "the positive effect of mobile internet use is weaker for ethnic minority than for majority consumers and stronger in poorer than in richer countries".

Of more direct relevance to England, a systematic overview of research into the "uptake and use of ICT by immigrants and ethnic minorities" in the EU was published in 2009. The report (Borket, Cingolani and Premazzi, 2009) emphasises that results should be considered preliminary and partial, and notes there is little comparative data on the use of the internet by immigrants and ethnic minorities – whether quantitative or qualitative. Despite this, it highlights that "**immigrants and ethnic minorities show ICT adoption rates similar to the EU population, despite their worse socio-economic status**".

This can be explained by different factors (Borket, Cingolani and Premazzi, 2009: 10):

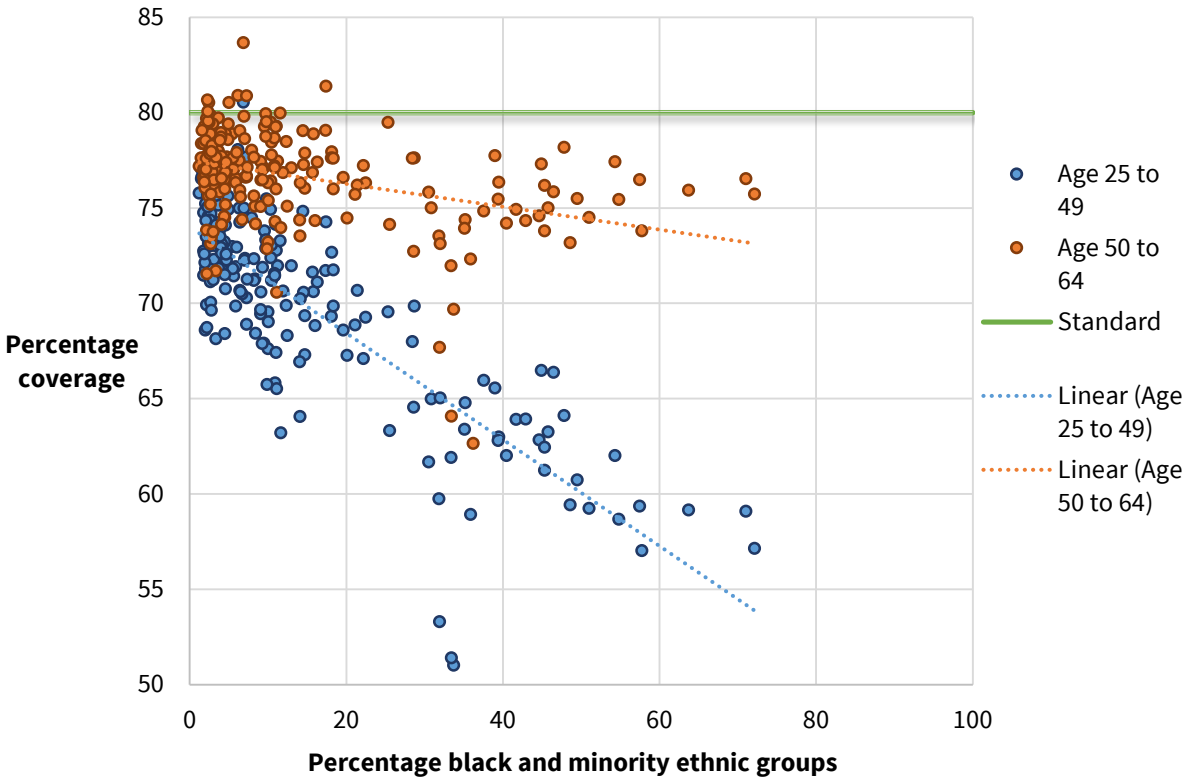
- the on average younger age of this population group which entails a greater familiarity with ICT;
- the need to keep in touch with often distant social networks of family and friends, both within Europe and across the world;
- the need to 'connect' and 'go digital' for education and work purposes in the host society".

We know that cervical screening coverage is lower in CCG areas where a higher proportion of the population is BAME (Figure 28), a phenomenon that is more pronounced among the younger age group (25-49).

Further:

- "50% more women of screening age from black and minority ethnic groups (12%) than white women (8%) say they have never attended a cervical screening appointment.
- Social and ethnic minorities, single mothers, those with lower levels of education are associated with a more negative experience of maternity services in relation to some aspects of care, including screening.
- Within the ANNB screening programmes failure to address the needs of mothers with protected characteristics can result in a lifetime of disability and disadvantage. This is illustrated by the personal experiences of the antenatal sickle cell and thalassaemia screening programme in women and couples at risk of having a baby affected by one of the conditions" (Mackie, 2019b).

Figure 28: Cervical screening coverage vs. age and proportion BAME population



INTERSECTION WITH DEPRIVATION

According to the Government's "Ethnicity Facts and Figures" service (Gov.uk, 2018), people from ethnic minority groups (except the Indian group) were more likely than White British people to live in the most deprived 10% of neighbourhoods in England (in 2012/13).

- White people were least likely to live in the most deprived neighbourhoods – 8.7% lived in the most deprived 10% of neighbourhoods.
- Among the broad ethnic groups, Black people were most likely to live in the most deprived neighbourhoods, followed by Asian people – 19.6% and 17.1% of these groups respectively lived in the most deprived 10% of neighbourhoods.
- Among the specific ethnic groups, Pakistani and Bangladeshi people were most likely to live in the most deprived neighbourhoods – 30.9% of Pakistani people and 27.9% of Bangladeshi people lived in the most deprived 10% of neighbourhoods.
- Pakistani and Bangladeshi people were over three times more likely than White British people to live in the most deprived 10% of neighbourhoods in England.

There is also an intersection with age – a higher proportion of older people identify as White:

- Among people aged 60 or over, 95.3% identify as White (12 million people).
- There are around 600,000 Black, Asian and Minority Ethnic (BAME) people aged 60 or over (595,585 at the time of the 2011 Census).

With regard to health outcomes, the "Is England Fairer?" report (EHRC, 2018a) highlights limited data on the experience and health outcomes of Gypsies, Roma and Travellers (GRT), and with regard to differing migrant groups.

GRT are described as facing "numerous barriers in accessing health services in England, particularly across primary care. Barriers include not being able to register with a GP, which requires proof of identity and address; poor literacy skills; fear of discrimination; and over-reliance on Accident and Emergency services".

These barriers may affect access to information about screening – particularly if it is online. Posted letters will not be an appropriate means to pass on weblinks, and lower literacy skills are likely to be accompanied by lower-level digital skills (though we are not aware of any research backing this up).

With regard to migrants, the EHRC (2018a) highlight that "perceptions of health services can be negatively influenced by poor experiences with GPs, which is often migrants' first experience with healthcare". This is exacerbated by "confusion over entitlement to healthcare… as a result of poor understanding and misapplication of guidelines in England" including fear of detention or removal as a consequence of sharing personal data when accessing health services. This may affect willingness to engage with online information sources about screening programmes.

RELIGION OR BELIEF

We found limited evidence linking religion or belief to digital exclusion risk in population screening programmes. ***While there may be some risk of lower use of internet in some religious communities, it is unlikely this would significantly impact willingness to access online information about screening***.

ORTHODOX JEWISH

Non-Orthodox Jewish communities are generally open to technological developments, but Orthodox (especially Haredi) Jewish communities often formally forbid internet use; though this may be accompanied by pragmatic acceptance (Čeyka, 2009). In addition to the possible impact of excluding people with no or limited access to the internet, or limited skills, motivation or trust in online information associated with limited or recent use; there could be claims of religious discrimination if official information is only made available online.

PLYMOUTH BRETHREN CHRISTIAN CHURCH

Traditionally, members of the Plymouth Brethren/Exclusive Brethren/Raven-Taylor-Hales Brethren Christian Church have had no or limited access to computers. However, the Church's position has been relaxed, and most Brethren businesses now have access to computers and email.

OTHER RELIGIONS

Čeyka (2009) also notes that some Amish and Hutterite communities restrict access to computers and/or the internet, and that Salafi and Wahhabi Muslims may take a conservative approach to the internet, in order to live in accordance with their religious traditions, though

he also notes that this is regularly combined with internet use with the aim of increasing support for the religion.

BEING PREGNANT OR ON MATERNITY LEAVE

Antenatal and Newborn screening programmes are directed at people who are pregnant or on maternity leave, and moving information about these screening programmes online will clearly affect this group. However, as detailed below, the risk in the case of these screening programmes is reduced, not only because of the lower age demographic associated with pregnancy, but also because of the frequency of face-to-face antenatal and post-natal sessions.

The *Equalities data audit* (ONS, 2018) "did not find any regularly updated sources that would provide evidence of women's perceived experiences of pregnancy or maternity discrimination".

The more recent publication of the Equality and Human Rights Commission's research findings and recommendations from interviews with 3,034 employers and 3,254 mothers (EHRC, 2018b) found that "10% of mothers said their employer discouraged them from attending antenatal appointments; if scaled up to the general population this could mean up to 53,000 mothers a year". This potentially provides a benefit of online information in that it could be accessed by those unable to attend antenatal appointments.

The above literature review includes examples suggesting use of the internet to access information is high during pregnancy, though risks remain regarding lower internet use among particular demographic groups (Lagan, Sinclair and Kernohan, 2010; Sayakot and Carolan-Olan, 2016; Guendelman, Broderick, et al., 2017; Acquavita, Krummel, et al., 2019).

GENDER REASSIGNMENT

The Equality Act 2010 defines gender reassignment as follows:

> "(1) A person has the protected characteristic of gender reassignment if the person is proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other

attributes of sex.
(2) A reference to a transsexual person is a reference to a person who has the protected characteristic of gender reassignment.
(3) In relation to the protected characteristic of gender reassignment—
(a) a reference to a person who has a particular protected characteristic is a reference to a transsexual person;
(b) a reference to persons who share a protected characteristic is a reference to transsexual persons."

The ONS (2018) says there is "currently no source that provides an estimate of the magnitude of the population", and states that the "lack of data and geographical coverage has serious implications for our ability to be able to draw robust conclusions about the population as a whole".

The Government Equalities Office's National LGBT Survey (2019) found "higher inequalities in health satisfaction and outcomes" for LGBT people as a group. Specifically, ***21% of trans respondents said their "specific needs were ignored or not taken into account when they accessed, or tried to access, healthcare services*** in the 12 months preceding the survey". Meanwhile, 18% said they were "subject to inappropriate curiosity" and 18% also said they "avoided treatment for fear of discrimination or intolerant reactions".[56]

In addition, research by Stonewall (2018) provides more detail on the healthcare experiences of trans people:

- Three in five trans people (62%) said they have experienced a lack of understanding of specific trans health needs by healthcare staff; 41% had experienced this in the last year.
- Two in five trans people (40%) said they have experienced difficulty accessing healthcare because they are LGBT.
- 20% of trans people have witnessed discriminatory or negative remarks against LGBT people by healthcare staff in the last year alone.

[56] Stonewall's (2018) research finds higher proportions: 36% of non-binary and 48% of trans people have experienced inappropriate curiosity from healthcare staff because they're trans; 37% of trans and 33% of non-binary people avoided treatment for fear of discrimination.

- One in five trans people (20%) have been pressured to access services to suppress their gender identity when accessing healthcare services.
- Almost one in five trans people (18%) aren't out to anyone about their gender identity when seeking medical care.

The report includes testimony from people complaining of being "outed as trans without my consent by NHS professionals to other NHS professionals" and "being asked intrusive and completely irrelevant questions by NHS professionals about my transition". While these experiences are not of direct relevance to screening programmes or online information, they are the context in which information will be passed on, and the need for specific information identified.

Stonewall (2018) recommends the government "Support healthcare services to routinely monitor patients' gender identity, where appropriate, and engage with the trans community to develop a Monitoring Information Standard for gender identity". We can make no specific recommendations regarding online information other than awareness of these issues and reference to the LGBT Foundation,[57] who offer training to show how screening services can be inclusive and accessible for trans people.

The LGBT Foundation notes that PHE (2019b)'s current leaflet on information about screening programmes for trans (transgender), non-binary and intersex people in England encourages people to speak to their GP to ensure they are opted in to the relevant programmes, but that this relies on the service user being comfortable talking about being trans or about their gender non-specific identity (Mather, 2020).

Mather (2020) describes how one AAA service identified trans women in their community who were eligible to be AAA screened. The service amended the screening invitation letter so that it was gender neutral and explained to the person that they were now eligible for the test due to their age, rather than focusing on gender. The use of gender-neutral language where appropriate in online information can be recommended.

[57] https://lgbt.foundation, accessed 13/02/2020.

BEING MARRIED OR IN A CIVIL PARTNERSHIP

It is hard to see how screening information delivered in a different format will have a differential impact based on marital/partnership status. We are not aware of any research suggesting higher levels of digital exclusion, nor lower take-up of screening programmes, associated with people who are married or in a civil partnership.

SEXUAL ORIENTATION

The Equality Act 2010 defines sexual orientation as follows:

> "(1) Sexual orientation means a person's sexual orientation towards—
> (a) persons of the same sex,
> (b) persons of the opposite sex, or
> (c) persons of either sex.
> (2) In relation to the protected characteristic of sexual orientation—
> (a) a reference to a person who has a particular protected characteristic is a reference to a person who is of a particular sexual orientation;
> (b) a reference to persons who share a protected characteristic is a reference to persons who are of the same sexual orientation."

In 2016, the ONS estimated that 2% of the UK population, or just over 1 million people, identified as having a minority sexual orientation, according to the Government Equalities Office (GEO, 2019). Proportions were higher among younger age bands (4.1% of 16 to 24-year-olds compared to 2.9% of 25 to 34-year-olds and 0.7% of those aged 65 and over).

While this may reflect differences in degrees of comfort with providing identity in government datasets, it could suggest that LGB people are less likely than the population as a whole to be digitally excluded – on the basis of the age profile alone. We are not aware of any research regarding rates of digital exclusion among people who are lesbian, gay or bisexual, however.

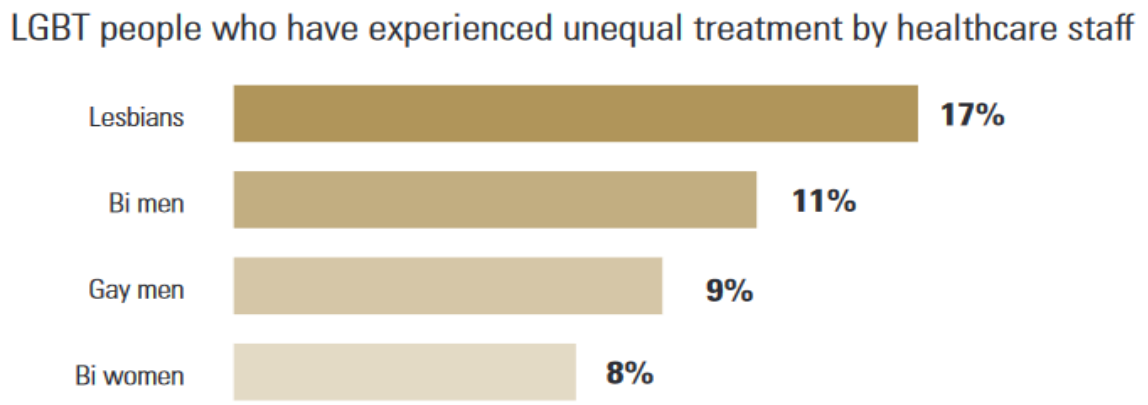
The Government Equalities Office's National LGBT Survey (GEO, 2019) found "higher inequalities in health satisfaction and outcomes" for LGBT people as a group, while research by Stonewall (2018) highlights negative experiences of healthcare for LGB people specifically. Unfortunately, much of this data is not broken down to cover sexual orientation.

- One in seven LGBT people (14%) have avoided treatment for fear of discrimination because they're LGBT.
- 30% of lesbians have experienced inappropriate curiosity from healthcare professionals, as well as 23% of bi women and 17% of gay and bi men.
- One in eight LGB people (13%) have experienced some form of unequal treatment from healthcare staff because they're LGB (Figure 29).
- Almost one in four LGBT people (23%) have witnessed discriminatory or negative remarks against LGBT people by healthcare staff.
- One in twenty LGBT people (5%) have been pressured to question or change their sexual orientation when accessing healthcare services – rising to 9% of LGBT people aged 18-24, 9% of BAME LGBT people, and 8% of LGBT disabled people.
- One in five LGBT people (19%) aren't out to any healthcare professional about their sexual orientation; 40% of bi men, 29% of bi women, 11% of lesbians and 10% gay men.
- 7% of LGB people who aren't trans have been outed without their consent.

While these experiences are not of direct relevance to screening programmes or online information, they are the context in which information will be passed on. We can make no specific recommendations regarding online information other than awareness of these issues and reference to the LGBT Foundation.[58] PHE screening teams have already had training about how screening services can be inclusive and accessible for trans people.

[58] https://lgbt.foundation, accessed 13/02/2020.

Figure 29: LGBT people who have experienced unequal treatment by healthcare staff (taken from Stonewall, 2018)



PEOPLE EXPERIENCING (MULTIPLE) DEPRIVATION

The Index of Mulitple Deprivation (IMD) for England utilises a number of different domains – income (with subdomains on income deprivation affecting children, and older people, respectively), employment, education, health, crime, barriers to housing and services, living environment. We know that digital exclusion is associated with deprivation in at least some of these domains (income, education).

We know coverage for some screening programmes (AAA, breast, cervical, diabetic eye screening – see below) is lower in more deprived areas. Hence, there is a risk that moving to a system where more screening information is being delivered online, may worsen coverage in areas of high deprivation. In this section we explore the data on multiple deprivation, digital exclusion, and screening coverage.

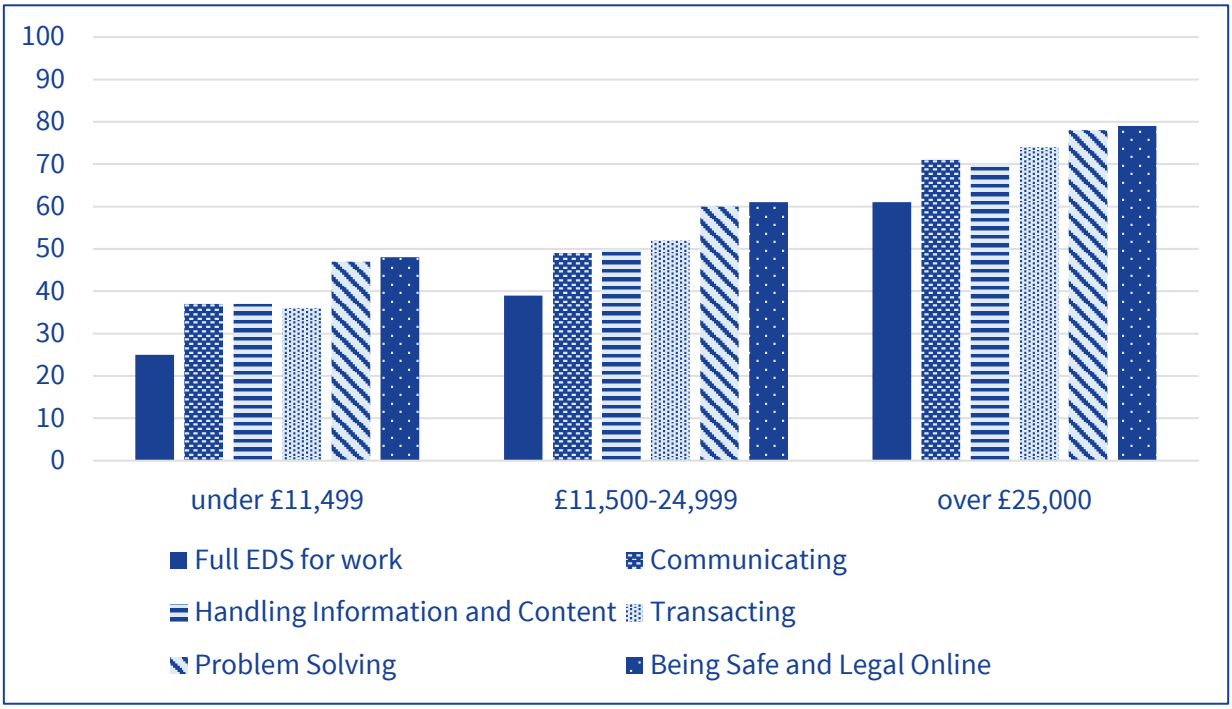
People on lower incomes, for example, are less likely to be internet users, and are much more likely to have fewer digital skills. The 2019 *OxIS Report* suggests 40% of people earning less than £12,500/year (the lowest income category used in their research) were not internet users (Dutton and Blank, 2019). The 2019 Lloyds *Consumer Digital Index* (CDI) found that **just 25% of**

people earning under £11,499/year have skills in each of the five Essential Digital Skills groups, compared to 61% of people earning over £25,000.[59]

Figure 30 shows that this holds true across each group of digital skills, with the gap largest (38 percentage points) with regard to skills related to "Transacting" – viewing payslips, submitting holiday and sickness e-forms, making online expense claims and/or booking transport and accommodation online.

In addition, the 2018 CDI estimated that almost one in five of all working-age benefit claimants had low or no digital capability (18%), which is an estimated 1.2 million people.

Figure 30: Essential Digital Skills for Work by income bracket, 2019



Level of education is also often identified as a factor in digital exclusion. Dutton and Blank (2019), for example, note that **just 36% of people with no qualifications are internet users** (a

[59] Lloyds Consumer Digital Index, 2019. Likewise, The 2018 Lloyds CDI found that just 64% of those earning under £17,499 a year had all five Basic Digital Skills, compared to 84% of those earning between £17,500 and £39,999, and 94% of those earning over £40,000

percentage which seems relatively static – the equivalent estimates from OxIS for 2011 and 2013 were 31% and 40% respectively).

With the increasing reach of internet connectivity/use, "social exclusion and economic disadvantage have become stronger determinants of digital disengagement than they were when research into digital divides started, indicating the emergence of a digital underclass" (Helsper and Reisdorf, 2016: 13).

Research by the Carnegie UK Trust (Martin, Hope and Zubairi, 2016) found strong relationships between digital exclusion and social exclusion, using analysis of the Scottish Household Survey.

The research found internet access was most strongly correlated with access to a car, flying for leisure and having a driving licence – but also associated with attending cultural events or places in the past 12 months, undertaking activities such as reading, dancing, singing, playing a musical instrument in the past 12 months, using council services in the past 12 months, volunteering, and visiting outdoors for leisure and recreation at least once a week.

Of particular relevance to this project, **people who were not using the internet were found to be more likely to have visited the doctor once a month or more** (as well as to have used a post office once a week or more and used public transport once a week or more; Martin, Hope and Zubairi, 2016: 11).

This might suggest good face-to-face alternatives for people who are unable to access screening information online. It appears possible that this is particularly linked to mental health, which was positively correlated with internet access in the research: 49% of those with above average mental health had access to the internet, compared with 38% of those without internet access (ibid.)

We already know that coverage for AAA, breast, bowel and cervical screening is lower in the most deprived deciles (Figures 31 to 34).

Given the asssociation between deprivation and internet use, there is a risk that moving to online information will compound and potentially exacerbate lower coverage among deprived demographic groups.

Figure 31: Coverage of AAA screening, and aneurysms detected, by Index of Multiple Deprivation decile

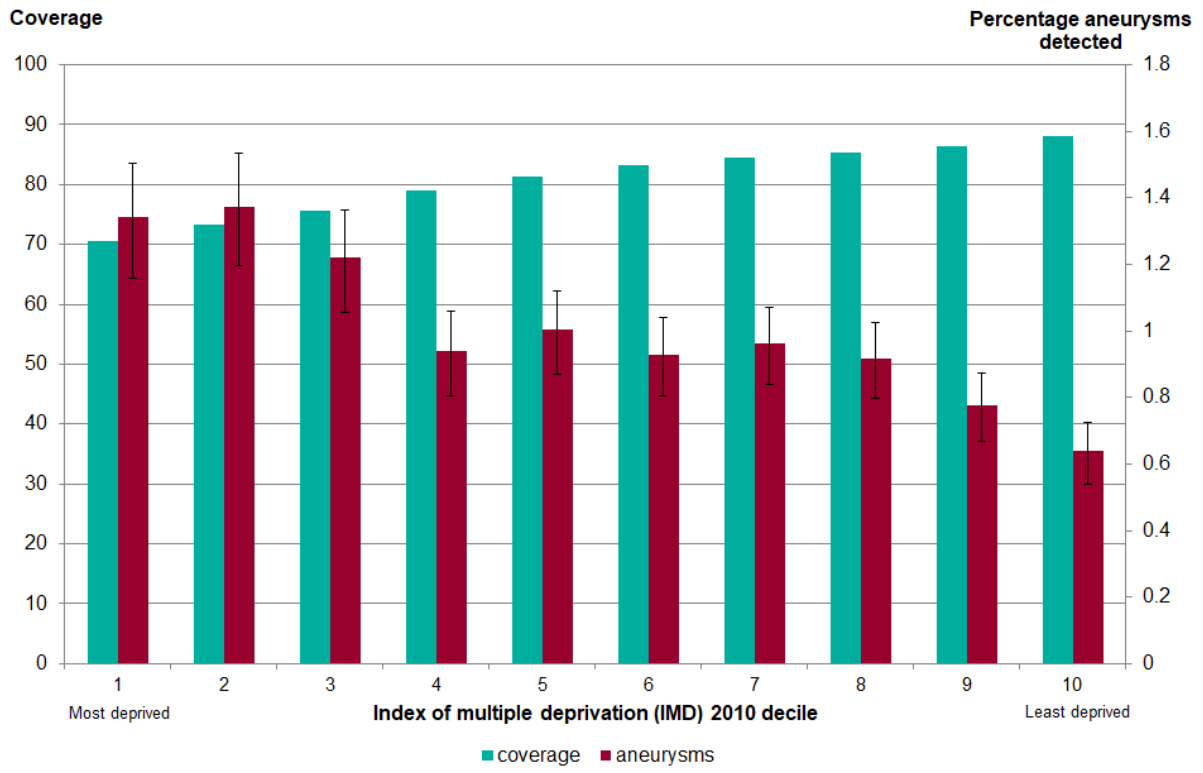


Figure 32: Coverage of breast screening by Index of Multiple Deprivation score

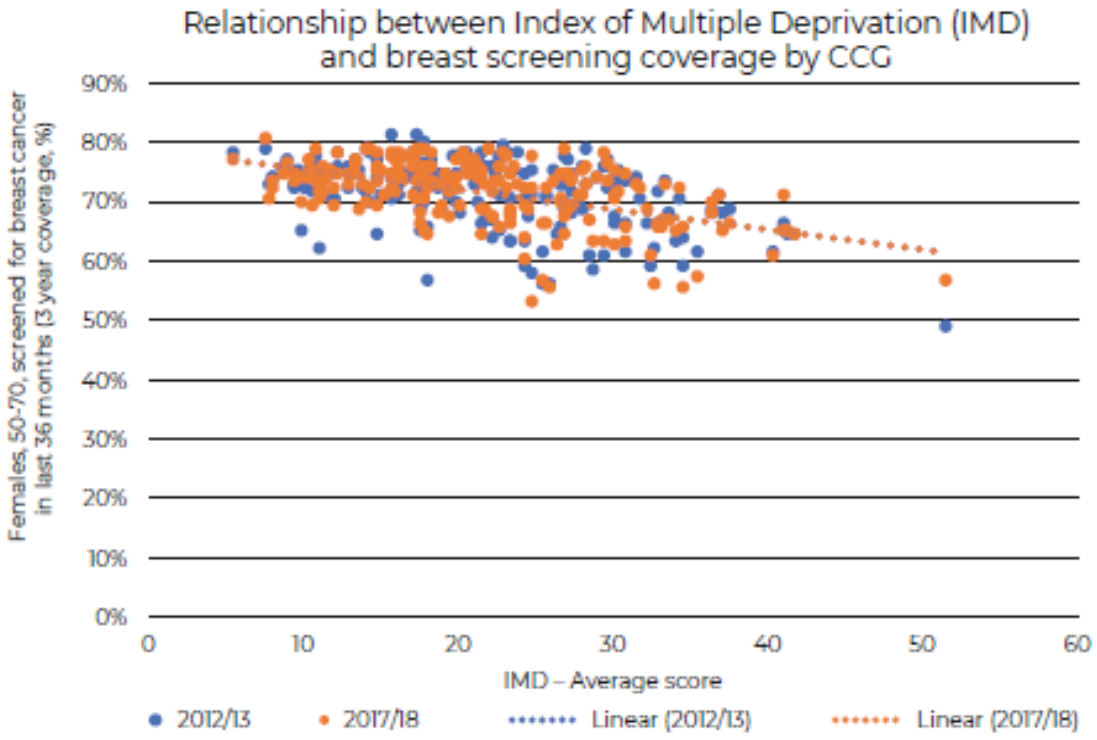


Figure 33: Coverage of cervical screening by Index of Multiple Deprivation score

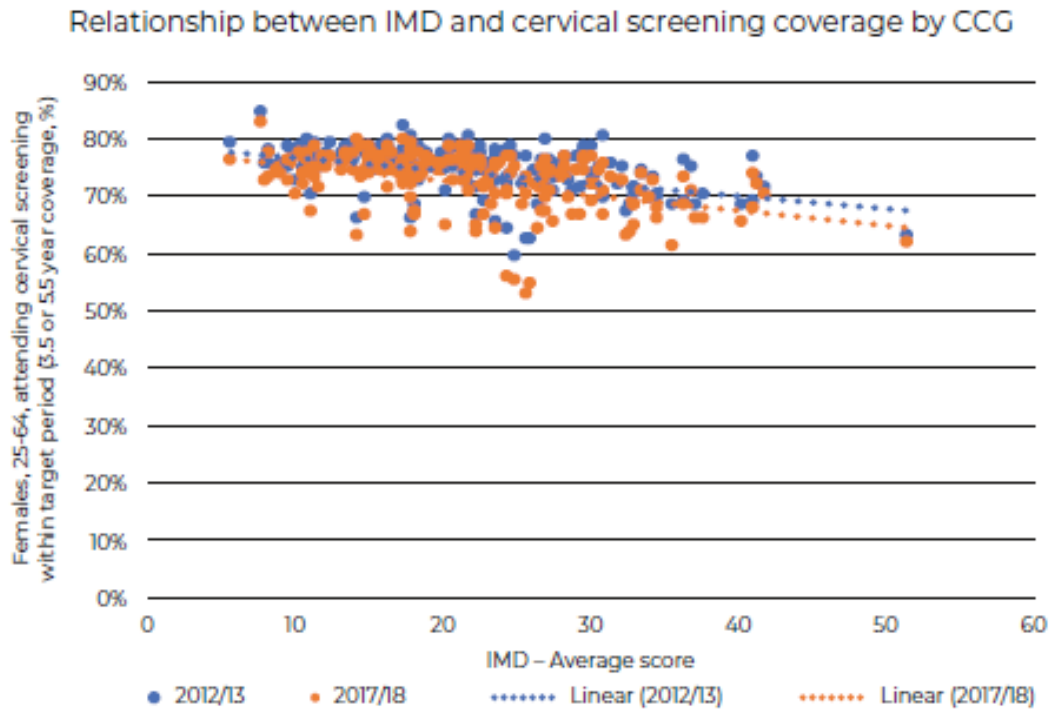
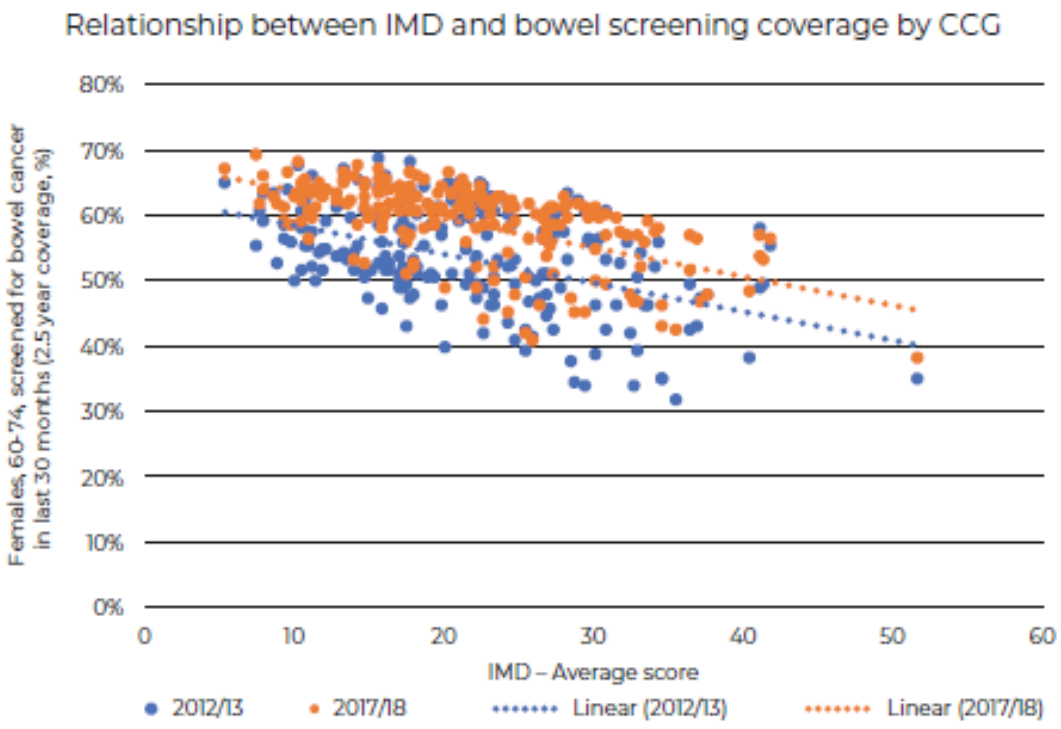


Figure 34: Coverage of bowel screening by Index of Multiple Deprivation score



Tables 30 and 31 show the 10 CCGs with, respectively, the most deprived Lower Super Output Areas (LSOAs)[60] on average, and the highest proportion of LSOAs in the most deprived 10% nationally, according to the 2019 *Index of Multiple Deprivation* (Ministry of Housing, Communities, and Local Government, 2019).

This clearly identifies NHS Bradford City CCG as an area with a high level of multiple deprivation – with the highest average level per LSOA, and nearly four in every five LSOAs (79%) among the most deprived nationally.

NHS Liverpool CCG and neighbouring NHS Knowsley CCG also contain high levels of multiple deprivation, while the Manchester, Blackpool and Hull CCGs also cover areas where the average LSOA is among the 10 CCGs with highest multiple deprivation, and the proportion of LSOAs among the 10% most deprived is highest.

[60] LSOAs are geographic units the size of neighbourhoods, each made up of around 400 households and approximately 1,500 people. The IMD ranks these LSOAs by their level of Index of Multiple Deprivation.

In moving to a system where more information about screening programmes is delivered online, there is a risk this may further reduce coverage in areas of high multiple deprivation.

Table 30: 10 CCGs where the average LSOA is most deprived

CCG	Average rank of LSOA	Rank of average LSOA	% of LSOAs in most deprived 10% nationally	Rank of % of LSOAs in most deprived 10% nationally
Bradford City	30,498	1	79.1%	1
Blackpool	26,765	2	41.5%	6
Manchester	26,418	3	43.3%	5
Knowsley	26,200	4	46.9%	3
Sandwell and West Birmingham	26,107	5	30.9%	12
Liverpool	25,834	6	48.7%	2
Barking and Dagenham	25,552	7	3.6%	109
Hull	25,223	8	45.2%	4
City and Hackney	24,999	9	10.7%	61
Nottingham City	24,459	10	30.8%	13

Table 31: 10 CCGs with the highest proportion of LSOAs among the 10% most deprived nationally

CCG	IMD – Average rank of LSOA	IMD – Rank of average	IMD – Proportion of LSOAs in most deprived 10% nationally	IMD – Rank of proportion of LSOAs in most deprived 10% nationally
Bradford City	30,498	1	79.1%	1
Liverpool	25,834	6	48.7%	2
Knowsley	26,200	4	46.9%	3
Hull	25,223	8	45.2%	4
Manchester	26,418	3	43.3%	5
Blackpool	26,765	2	41.5%	6
Blackburn with Darwen	23,820	12	36.3%	7
South Tees	22,063	26	36.2%	8
Birmingham and Solihull	22,638	20	33.9%	9
Halton	21,746	32	31.7%	10

Appendix 3 - YPA Programmes thematic review of site visits and interviews

BACKGROUND

During December 2019 and January 2020, we carried out a series of telephone interviews and site visits. These were intended to add a qualitative dimension to the other sources of evidence in this report. In particular we wanted to gain a picture of the realities of information provision in frontline local screening services.

We carried out 17 telephone interviews (12 with local services and five with National Programme Managers for YPA Screening) and two site visits (to the bowel cancer screening centre at St Mark's Hospital, London, and the Abdominal Aortic Aneurism (AAA) screening clinic at Salisbury General Hospital). In addition, men attending for AAA screening at Royal Shrewsbury Hospital were asked about their online status and attitudes by screening staff.

Interviewees were either suggested by National Programme Managers at the YPA Screening Programmes Team Meeting in December 2019 or were identified as local services with particular interest in or experience of inequalities from analysis of PHE Screening Blogs. We ensured that there was a good geographical spread of interviewees, and that all five Young People and Adult programmes were reflected.

Fuller notes on the interviews and visits were made, but the following is a summary of the key themes.

OPINION ON LEAFLETS CURRENTLY PROVIDED

There were mixed opinions on the leaflets currently provided with invitation letters. Some interviewees felt they were good and clear and provided the information people needed to make an informed choice. But others felt the leaflets had gone too far in considering risks. They

felt that in responding to the Marmot review[61] of benefits and harms of screening, there is now undue emphasis on downsides and that this might discourage some people from attending.

The leaflets were felt to be aimed at quite a high educational level, with references to Cochrane Reviews etc. This might appeal to some people, but not to others.

Several interviewees made the point that the information leaflets are part of a wider information environment, and people consume facts and misinformation from a range of sources including the media. Two examples quoted were a widely viewed BBC piece "Breast screening does more harm than good"[62] and a *Daily Mail* article "I'm due an oldie's health check – but what if it costs me my licence?"[63] Both were felt to have discouraged screening.

The possibility of not being able to drive if a large aneurysm is detected is clearly an important issue for some people. At the AAA screening clinic we attended, a man was shocked to be told that he had a large aneurysm and so could not drive. He was a van driver, so this had a serious impact on his livelihood and quality of life. The leaflet explains "during the time when a large AAA is untreated you may need to stop driving" – but he hadn't read this.

Some services were using the PHE leaflets not just with the invitation letter, but for wider public awareness campaigns of their own (e.g. alongside leaflets from other organisations including Cancer Research UK and Jo's Cervical Cancer Trust). There was concern that if print production was reduced, screening services would lack the materials they need to increase public awareness.

> *"The leaflets are good for what they do, when people are invited for screening. But we need more information at both ends of the spectrum. Better awareness for the wider public at one end and more personalised information at the other".*
>
> **Diabetic eye screening manager**

[61] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3693450/

[62] https://www.bbc.co.uk/news/health-44016206

[63] https://www.dailymail.co.uk/debate/article-6580001/TOM-UTLEY-driving-potty-Im-oldies-health-check.html

It was felt that there was good public awareness of mammograms and smear tests but much less of home bowel screening tests or AAA screening. Several interviewees suggested that people often do not welcome the arrival of the invitation to bowel and AAA screening.

> *"I was happy not knowing about this. Now you've planted a seed of doubt. It's one more thing to worry about."*
>
> **AAA screening patient**

One local AAA screening manager made the point that we also need better professional awareness. Even some local GPs are not aware that the AAA test is available.

Interviewees were very positive[64] about the Easy Read leaflets and recognised the valuable work which has gone on to develop these, with the involvement of user groups. In fact, some argued for wider adoption of the Easy Read versions as the standard leaflets:

> *"If the average national reading age really is 9, why don't we just use the Easy Read leaflet for everybody?"*
>
> **AAA screening manager**

Having leaflets available in other languages was welcomed. However, these leaflets are only currently available in 10 languages, whereas a much greater number of languages are actually spoken. In Newham we were told that there are over 100 languages spoken; and with dialects there is even more diversity.

There was some concern that the leaflets in other languages may not be as up to date as the English-language versions.

[64] The PHE Screening Team reported that instances have occurred in the past where some people provided negative feedback about Easy Read leaflets – thinking they were the standard leaflets and being offended at the 'simplified information'.

PROS AND CONS OF PRINTED VS ONLINE INFORMATION

- Avoid making all the changes at once. Take a phased approach, starting with leaflets with the least amount of difficulties expected

Screening Equalities Impact Assessment recommendation

Interviewees expressed consistent views on the on the pros and cons of providing printed leaflets, compared with online information, and a good understanding of the issues. All of the following were expressed spontaneously by one or more interviewees:

ADVANTAGES OF PRINTED LEAFLETS

- Familiar format
- Can be read immediately without having to go somewhere else for information
- Available to those who aren't online
- Can be shared with family

"You really need a leaflet if you're going to share information with your family. You can't just give them a website address."

Bowel screening focus group participant

DISADVANTAGES OF PRINTED LEAFLETS

- May not be up to date
- Costly
- Service needs to order and store
- Bad for environment – lots of waste
- Might get lost in junk letters

"It's much easier to update information online than it is to wait for a print run to be used up."

AAA screening manager

ADVANTAGES OF ONLINE INFORMATION

- Can be kept up to date

- Less costly
- More environmentally friendly
- Can have more detailed supporting information such as travel information
- Can provide information in other formats and languages more easily

"You might mislay the leaflet, but you can easily go back and look again at online information."

Public Health doctor

"You're more likely to read the initial information on a leaflet that comes through the door, but to go online if you want more detailed follow-up information."

AAA manager

"Having online information is particularly helpful for people with visual impairments. You can enlarge the type or use a screen reader."

Bowel screening manager

"As well as information about the test, people need practical information, like how to find the hospital and travel information. In Devon and Cornwall that could be down to the detail of ferry timetables. This could be done much better online,"

AAA screening manager

"People need to know you can get the 241 bus to outside the hospital. Online, you could link to bus routes and times."

Community health worker

DISADVANTAGES OF ONLINE INFORMATION

- Risk of excluding people who aren't online and widening inequalities
- Volume of promotional emails received
- Confidentiality concerns

"We all get bombarded with marketing emails. Important screening information could get lost, or even end up in the spam folder."

Breast screening manager

"I wouldn't be sure about the security of information online. Could it be intercepted? Who is it shared with?"

AAA screening patient

On our visit to an AAA screening clinic, we heard that the screening leaflet (2018) used to refer to "normal result" but the text has been updated to read "no aneurysm found". Staff said they were now unable to use the old leaflets and had a boxful, which would be scrapped. They observed that this illustrated the cost and environmental impact of using print leaflets.

USING HYPERLINKS TO ONLINE INFORMATION IN PRINTED INVITATION LETTERS

- Provide easily typeable hyperlinks within letters.
- Add QR codes within letters with clear instructions on how to make them work.
- Continue to send leaflets with Prevalent Invitations and make changes to stop Incident Invitations.
- Ensure incident invitations include clear accessible information about how to find information online as well as how to order a printed leaflet.

Screening EIA Report recommendations

Several interviewees said that more could be made of the invitation letter, and this could mean that it wouldn't be necessary to include a separate information leaflet. This has been described as an "Invitation Plus" leaflet.

An Invitation Plus leaflet should include sufficient information to make an informed choice, with information on how to find further information online as well as how to order printed information (if necessary, in different languages or an Easy Read version).

We were told that some invitation letters already include a link to online information – but this still requires people to type in the URL to go to the website (some interviewees said that getting an email or a text with a clickable link makes more sense than a letter with a website address).

URLs should be as short and simple as possible. It was pointed out that the bowel cancer screening leaflet currently recommends going to a "difficult to type" URL.[65]

> *"I've got sausage fingers. I can't type in a long website address. And it's even harder with little keys on a phone."*
>
> **Bowel cancer focus group member**

Several interviewees said they didn't really understand why people were directed to GOV.UK for online versions of the leaflets and to NHS.UK for further information. This was seen as a confusing message for the public.

Once a short URL is clicked, online information should be quick to access – and should download quickly in case broadband or mobile connectivity is poor. The need for online information to work well on a mobile phone, as the most used device, was emphasised.

One option is to include QR codes in letters and leaflets (and on the kit for bowel cancer screening). This would avoid the need to type in a URL. There wasn't much enthusiasm for this, as it was felt that the concept wasn't well known or adopted.

When asked about QR codes, none of the participants in the bowel cancer screening group had heard of them. When they were shown one, they had a vague recollection but still didn't know what to do with it.

Awareness of QR codes is also low amongst staff. The AAA screening leaflet includes a QR code providing link to information at www.nhs.uk/aaa, but AAA screening staff we talked to hadn't noticed this or had assumed it was a bar code for ordering more leaflets.

[65] www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy

ATTENDANCE AND BARRIERS

We asked about barriers to attendance at screening to see how far these might be information linked.

A common response from interviewees was that we shouldn't assume invitation by letter is a particularly effective mechanism at the moment. Letters don't always get through – there are a lot of returned "not known at this address" letters, particularly in London. Post that comes through the letterbox could be thought to be utility bills or junk mail. It was felt that younger people, in particular, would often ignore postal mail.

We were told that, even if people attend the screening, they are often poorly prepared and clearly haven't read the letter and/or leaflet.

- Some people arrive for diabetic eye screening not appreciating that they will be having eye drops and won't be able to drive home.
- Some men sit up after the AAA scan and say, "What was that for then?"

With the quick turnaround of screening appointments, there isn't much time to provide information and correct misconceptions at the appointment itself.

'Did Not Attend' (DNA) is clearly seen as a significant problem in all screening programmes. We were told about one recent breast screening clinic in Stoke, where, out of 157 women invited to attend, only 41 attended, and there were 116 DNAs (74%).

There was a lot of consistency in understanding of barriers to attendance, with the following mentioned spontaneously by interviewees:

- Didn't receive invitation letter
- Received letter but mislaid it
- Lack of time
- Difficulty taking time off work
- Difficulty in getting or changing the appointment
- Lack of engagement in own health and care
- Misconceptions about what screening involves
- Thinking screening is unnecessary if no symptoms

- Cultural and religious barriers
- Fatalism

There was an appreciation that appointments for screening are not always at convenient times to fit in with work or care commitments. The Jo's Cervical Cancer Trust Time to Test[66] campaign was commended as a way of encouraging employers to ensure that employees have time to attend screening.

Appointments for screening in general practice (GPs) can be difficult to get at a convenient time or to rearrange. Some interviewees said that having information online would be more useful if it was linked to the ability to book appointments, rather than just providing information.

A number of interviewees mentioned cultural barriers to screening – the breast, bowel and cervix are all parts of the body which aren't talked about, particularly in some South Asian and Gypsy/Traveller communities.

There can be a problem with invitation letters arriving "on the family doormat". We were told how some husbands might tear up the invitation letter, saying "the wife isn't going to that". It was suggested that, if contact information were available, information could be directed more confidentially by email or text to the woman herself.

It was suggested that people might not attend because, if they had no symptoms, they saw no need. Also, some felt if they were going to get cancer, there was nothing they could do about it. This fatalistic attitude had been encountered in Muslim communities ("I can't avoid getting cancer and if I do Allah will provide") but also amongst older white people ("You've got to go with [die of] something").

HARD TO ENGAGE GROUPS

- Ensure online materials meet the Accessible Information Standard so they can be used by people with disabilities, impairments or sensory loss.

[66] https://www.jostrust.org.uk/get-involved/campaign/time-test

- Continue to create online information in different languages with the ability to request further information.
- Provide more information in video format.

Screening EIA Report recommendations

Some groups experience greater barriers than others and experience more inequalities in accessing screening services. Again, interviewees were clear about who these might be, with a lot of consistency in identifying the following:

- Transient populations (including people experiencing homelessness)
- BAME groups
- People whose first language isn't English
- People in care homes/supported accommodation
- People in long-stay hospitals
- Prisoners
- People with learning disabilities
- Older people with mobility problems

There is a strong correlation between those who are experiencing inequalities in screening, and wider health inequalities and social deprivation. However, it was pointed out that not attending screening is by no means always linked to deprivation. Some of the worst take-up is amongst busy, young, urban professionals who don't find time to attend screening (cervical and diabetic eye screening). These are the group who are most likely to be online and with the most potential to be engaged through digital channels.

London and other cities have particularly transient populations who are hard to engage through letters in the post. We were told that in London 25% of people move home each year, and in Hammersmith and Fulham it's as high as 33%.

Again, these are likely to be younger people, including students and those in short-term, unstable employment. Furthermore, people who move home frequently are often not registered with a GP. As well as mobile workers, those not registered with a GP might include offenders, Traveller families and people experiencing homelessness etc.

LEARNING DISABILITY, FAMILY CARERS, AND PAID CARE WORKERS

We heard examples of good practice in engaging with people with learning disabilities and people in care homes who may have low take-up of screening.[67]

We were told that although people with learning disabilities are eligible for all screening programmes, only 60% access screening.

Accessible information in Easy Read or video formats was seen as particularly important here. There was particular concern about the difficulties of engaging people in care homes, long-stay hospitals and prisons. These settings are unlikely to provide free access to the internet for residents. Care homes often have poor IT infrastructure, including lack of wi-fi for residents. Care home staff are usually poorly paid and don't have digital skills themselves, let alone having the time and ability to act as digital champions for residents.

> *"Our care homes aren't digitally savvy. Care home staff come from deprived groups themselves."*
>
> **AAA screening manager**

[67] https://phescreening.blog.gov.uk/2019/02/04/focusing-on-carers-is-helping-to-improve-access-to-aaa-screening-for-men-with-learning-disabilities/

https://phescreening.blog.gov.uk/2019/06/07/new-bowel-cancer-screening-easy-guide-published-thanks-to-input-from-our-experts-by-experience/

https://phescreening.blog.gov.uk/2019/03/20/north-east-experts-by-experience-help-develop-new-screening-easy-guides/

https://phescreening.blog.gov.uk/2019/04/15/weve-updated-our-easy-read-guide-to-cervical-screening/

https://onlinelibrary.wiley.com/doi/abs/10.1002/pon.5311

UNDERSTANDING OF THE ONLINE POPULATION – AND WHO IS DIGITALLY EXCLUDED

Interviewees had a good general understanding of the characteristics of who's online and who's digitally excluded. They appreciated that hard-to-engage groups (such as those listed above) closely match those who are less likely to be online.

Several interviewees said they would like to have a much more granular and evidence-based picture of digital take-up in their local population. We were shown mapping by Index of Multiple Deprivation for screening areas, and interviewees felt they could infer that the most deprived areas are also the most digitally excluded. They were very interested in the data sources being used for this Equality Impact Assessment and wanted these to be shared more widely in the screening programmes.

A commonly expressed view is that it's hard to generalise about the digital capability of screening populations, particularly those which have a long age span (diabetic eye and cervical). Even those with an older population will include very varied levels of digital ability and confidence. Interviewees pointed out the differences, in particular, between women aged 50 at the beginning of breast screening age range and 70 at the end. Those who are using computers at work or recently retired are more likely to be online than older people.

There was some evidence from local satisfaction surveys of acceptance of online communication, particularly amongst younger populations.

- In North Nottinghamshire, the diabetic eye screening patient satisfaction survey had more responses from people under 40 online and from people over 60 on paper.
- In Shropshire, Telford and Wrekin, a recent surveillance survey of 150 patients who attended for AAA screening (115 responses) asked how they were currently communicated with, and how they would prefer to receive communications. In total, 107 (93%) said they had received a letter with a printed leaflet; 24 (20%) said they would prefer to receive an email.

Particular insights into online take-up and behaviour were provided by the bowel cancer patient focus group at St Mark's Hospital, London.

- All members of the small group (5 people aged 66-73) were online but their uses of the internet were very narrow. They were niche users – one only ever went online to shop on eBay, another mainly used the internet for painting-by-numbers apps.

The same impression of narrow use was gained from men aged 65 attending AAA screening in Shropshire.

- All were online for purposes including news, sports results, weather, buying tickets, food shopping, keeping in touch with friends and Facebook. But none mentioned accessing health information online.

At St Mark's there was little enthusiasm for accessing screening information online, and all said if they did, they would still print it off. None had printers at home and they would need to go to the public library to do this:

> *"I always want to print off information, even if I get it online* [all participants agreed]. *But I haven't got a printer at home* [none of the participants had]. *There's a printer in the library but it's often broken or there's a queue. Libraries are really useful for getting online, but many are closing. But you'd need to be able to use the internet already before you'd go there to use a computer."*

Another participant pointed out that some libraries have classes in how to use the internet but nobody else had heard of that:

> *"I wouldn't be concerned about privacy looking at bowel cancer screening information in the public library. I don't mind if someone sees I'm looking at bowel cancer information on the screen. But I wouldn't want to provide personal data on a public access computer* [all agreed]*."*
>
> *"If I'm looking at information online, I'm always worried it's going to crash, and I'll lose the information. That happens in the library sometimes. Or my phone might run out of battery before I'd finished reading the information."*
>
> **Bowel screening focus group participants**

The focus group was a valuable reminder that digital inclusion is much more nuanced than simply being online. Just because somebody does online shopping does not mean they will have the motivation and confidence to access health information online.

MULTI-CHANNEL INFORMATION AND CHANNEL CHOICE

- Ensure that information on channel choice (face to face, telephone, printed, digital) remains available into the future for those who need different options.
- We cannot expect the public to switch to new ways of doing things without help.
- Make a phone number (e.g. Bowel Cancer Screening Helpline) available wherever possible.
- People with smartphones may follow a link in a text message, but may not unless they know it is safe.

Screening EIA Report recommendations

Focus group participants had a perception that increasingly in society people are given no alternative but to do things online. They were keen that channel choice (including face to face, telephone and print) continues to be available:

> *"I don't like being forced to do things online nowadays. I have to get my parking permit online now. Some benefits are only online too. We should have a choice."*

Bowel screening focus group participant

Screening programmes have utilised a variety of information channels and formats to provide digital information. Text messaging and video seem to be the most common.

Screening programmes in some parts of the country have piloted the use of text messages for appointment reminders, and to provide a link to online information. We were told of a randomised controlled trial in Hillingdon which demonstrated success in using text message

reminders to improve take-up of cervical screening.[68] This has now been rolled out to all London boroughs[69] and is also being adopted in Cheshire and Merseyside.

In London it had proved possible to get mobile phone numbers for 88% of the target population for cervical screening. It is likely that mobile phone ownership is even higher than this. Interviewees (above) commented that people are more likely to still have the same mobile number, and less likely to have the same land address, between screening appointments (particularly amongst younger, transient populations).

However, a London-based community health project which has been leading work on outbound telephone calling for appointment reminders in breast and cervical screening, [70] said that it was common for phones to be swapped around between friends and family members.

It was fairly common for a different person to answer the phone when a reminder call was made. The cervical screening text messages include a reminder that the cervical screening appointment is due and encouragement to contact GP [number given] to make appointment.

The text message also includes a link to information on NHS.UK.[71] However, although the text messages have proved successful in increasing attendance for cervical screening, they have been less effective in improving access to online information. We were told that click-through from text to online information in the London project was as low as 2%.

We heard from others that there was some reluctance to open links in text messages (and emails) unless there was confidence in the source. Patients said that they'd be confident in following a link if it looked to be from the NHS, and even more so if it was recommended by a health professional.

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[68] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32981-1/fulltext

[69] https://phescreening.blog.gov.uk/2019/07/15/gp-endorsed-text-reminders-help-increase-cervical-screening-attendance-in-london/

[70] https://phescreening.blog.gov.uk/2019/05/03/tackling-screening-inequalities-in-bame-communities/

[71] https://www.nhs.uk/conditions/cervical-screening/

> *"There's a lot of health information online which you can't trust. I saw Brillo pads can give you cancer, or maybe can be used to detect bowel cancer.*[72] *Something like that. But if NHS staff gave me the address of a website, I'd trust it and go and visit it. My physio does that already."*
>
> **Bowel screening focus group participant**

However, lack of confidence and trust in information is not confined to online sources. A patient at the AAA screening clinic we attended was initially suspicious of the letter he received inviting him for screening, because he had never heard of AAA screening. At first, he assumed that the letter was marketing from a private provider for a 'well man' check-up and was concerned that they had his contact details. It was only when he looked at the letter and leaflet more closely that he was reassured by the NHS logo.

There is good recognition of the value of videos in providing more information about screening. Interviewees suggested that this is particularly valuable for certain populations (e.g. people with learning disabilities) who might find it difficult to use text information, and also to prepare people who might be nervous about healthcare environments, equipment etc.

We heard of a number of examples of good practice in the use of video, and a widespread view that this is one of the most positive aspects of moving to more information being provided in digital forms.[73]

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[72] This is presumably the article which the focus group participant remembered seeing https://www.dailymail.co.uk/health/article-3168433/Swallowing-sponge-string-diagnose-throat-cancer-Tiny-Brillo-pad-detects-telltale-signs-disease-passes-gullet.html

[73] https://www.youtube.com/watch?v=c26m8QStw5M&feature=youtu.be

[73] https://www.youtube.com/watch?v=kvFapvm5lC4&feature=youtu.be

[73] https://www.dbth.nhs.uk/cervical-screening/

[73] https://www.youtube.com/watch?v=vdHyWD539GQ

PATIENT RECORDS AND PERSONALISED INFORMATION

- IT systems lack flags for special needs. We need better information on who to communicate with, when and how.
- It is unlikely that screening programmes will have details of mobile phones and special needs (although GP practices may have) or these may not be accurate.

Screening EIA Report recommendations

The most commonly expressed frustration in interviews with screening staff was the limited amount of information available on IT systems about the special needs of patients, including whether they speak languages other than English, have a learning disability etc.

There was a generally held view that if the patient data was available then the potential of online information could be realised by targeting patients with personalised information that was relevant to their needs. This could include linking to much richer information online – in video form, languages other than English, British Sign Language or Easy Read.

In some programmes, patient data is sent to GP practices as prior notification to allow for checking on currency of information and addition of any special needs. However, GPs might not have the information either.

- We were told that 2.5% of the population have a learning disability but only 0.6% are recorded as having a learning disability on GP records.
- One AAA screening service said that out of 5,000 men scheduled for screening this year only 4 are identified as having a learning disability, although the total must be much higher.
- Another screening service said they had a stock of Easy Read leaflets but had only been able to send them out 25 times this year, as they had no patient data with which to target them.

"We don't have information about the individual men attending for screening so we can't provide information relevant to their individual characteristics."

AAA screening manager

"Our legacy IT systems are poor. We only know name, address, age, gender, NHS number. My wish list would be to have ethnicity, language and any disability as well."

Cervical screening manager

LEVERS, INCENTIVES AND ENABLERS

Interviewees told us of several examples of creative use of funding opportunities, and contractual and system levers, as mechanisms for developing better information delivery mechanisms – including digital.

Interviewees mentioned that NHS Trusts can get CQUIN incentive payments[74] in their contract for initiatives which reduce inequalities. This could include information and communications campaigns, including digital.

In Cheshire and Merseyside, screening services have put in successful bids to the Cancer Transformation Fund[75] for a total of £1.35 million to fund projects to improve communication and engagement, and drive take-up. The new funding has been allocated by the Cheshire and Merseyside Cancer Alliance[76], with planning and implementation facilitated by the Alliance in collaboration with Champs Public Health Collaborative, NHS England/Improvement and Public Health England.

Projects are using the principles of Making Every Contact Count (MECC)[77] and include patient navigators, text reminders and an online toolkit of information resources (see below).

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[74] Commissioning for Quality and Innovation: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/09/public-hlth-comms-intent-2017-18.pdf

[75] https://www.england.nhs.uk/cancer/cancer-alliances-improving-care-locally/nhs-england-support-and-funding-for-cancer-alliances/

[76] https://www.cheshireandmerseysidepartnership.co.uk/news-and-publications/188-1-3-million-funding-secured-to-reduce-lives-lost-to-cancer-in-cheshire-and-merseyside

[77] https://www.makingeverycontactcount.co.uk/

A diabetic eye screening service showed how the Failsafe[78] system used in screening services could be used to check whether the right information is being provided at the right time. Failsafe is a quality assurance process to ensure nothing goes wrong, preventing loopholes and risks in the system. Audits are carried out to ensure that the right processes are in place, including provision of information.

Under the Equality Act 2010, organisations have a legal duty to make changes in their provision to ensure that services are as accessible to people with disabilities as they are for everyone else. These changes are called "reasonable adjustments".

For screening services this could, for example, mean ensuring that people with learning disabilities can access information in Easy Read or can get a longer screening appointment because of a disability.

Specifically, the NHS Long Term Plan makes the commitment that "by 2023/24, a digital flag in the patient record will ensure that staff know a patient has a learning disability or autism".[79] The reasonable adjustment flag indicating that the patient has particular needs will be added to the patient's Summary Care Record on the NHS Spine.[80]

We were told that the reasonable adjustment flag is being piloted in Gloucester and Devon, and will be rolled out to other locations and care settings.

INNOVATION IN DIGITAL INFORMATION

- "Digital health management tools are available but may not be trusted. The NHS app needs more exploring."
- "Linking online information with appointment booking could be valuable."

[78] https://www.gov.uk/government/publications/diabetic-eye-screening-programme-failsafe-procedures

[79] https://digital.nhs.uk/services/reasonable-adjustment-flag

[80] https://www.youtube.com/watch?time_continue=20&v=JH7FGKnmnw8&feature=emb_logo

Screening EIA Report recommendations

Finally, in our interviews we heard encouraging examples of where local screening services have been developing innovative approaches, including developing digital information delivery.

In the North Midlands, the breast screening service set up a Facebook page[81] to provide information on eligibility for breast screening, screening dates by GP practice, accessing services, and alleviating concerns and misconceptions.

Women are also able to leave comments and reviews of the service. Information, including videos, is shared on other local Facebook pages, including GP practices, disability and community groups, LGBTQ+ groups – and women's own Facebook pages.

Funding through the NHS Widening Digital Participation[82] programme enabled the service to engage a digital agency, Redmoor Health,[83] as social media specialists to make their efforts more effective. Initially there were 140 followers; this was up to 1,722 by February 2020.

The health improvement practitioner in North Midlands (Stoke) told us that the real value of the Facebook page is that it doesn't only provide top-down information. For instance, on a day when the service had 116 DNAs, they posted this on the Facebook page and got 15,000 engagements, 945 shares and 148 women engaged.

> *"Peer-to-peer motivation is much stronger than us telling them. We would never have been able to distribute 945 leaflets to a targeted audience. This uses the power of sisterhood for women to share experiences and motivate each other through a digital channel that many women in their fifties use."*

Health improvement practitioner

[81] https://www.facebook.com/NorthMidlandsBreastScreeningService/

[82] https://digital.nhs.uk/news-and-events/latest-news/new-social-media-techniques-used-to-boost-cancer-screening-rates

[83] https://redmoorhealth.co.uk/

The Facebook initiative has led to a 12.9% increase in breast cancer screening take-up (against the backdrop of a 4% annual decrease) and is a case study in the Independent Review of Adult Screening Services.[84]

Women in the North Midlands (and some elsewhere) were posting enquiries about breast screening, sometimes out-of-hours. So the service is now working with Redmoor to develop a chatbot which can answer the most frequent questions while building up a knowledge bank of responses to further questions as they come in.

We were told that most queries are fairly repetitive, so it is easy to build up a bank of FAQs, derived from questions on Facebook and questions in clinics. There is now interest in doing something similar for cervical screening.

An increasing number of digital health management tools are being developed, including the NHS's own app. Several interviewees looked forward to a time when the patient's own digital health management tool could include information about screening, the ability to book screening appointments online and to access results. There was very little awareness of the NHS app, and whether any functionality relating to screening was being planned.

In South Devon and Exeter, we were told of interest in utilising the Patients Know Best (PKB) portal.[85] There could be real advantages in patients having a personal online portal like this, where they can access information in a form to suit their own preferences – language, Easy Read etc.

Test results, where appropriate, could also be made available. Users would get an email to say new information was available in their PKB account. We heard that various logistics around information governance are slowing this adoption but there was certainly enthusiasm for this personalised digital approach.

[84] https://www.england.nhs.uk/wp-content/uploads/2019/02/report-of-the-independent-review-of-adult-screening-programme-in-england.pdf

[85] https://patientsknowbest.com/

There are signs of more partnerships developing between screening services and digital health providers. In addition to Facebook and PKB (above), the digital health company iPlato[86] are now working across London (and from April in Cheshire and Merseyside) to provide the technical platform for outbound text reminders for cervical screening. This initiative was highly commended in this year's Jo's Cancer Trust Cervical Screening Awards.[87]

The text reminder service is one of three new programmes we were told about in Cheshire and Merseyside, funded by the Cancer Transformation Fund. The second is an online toolkit to support community engagement. The new platform will provide links to online resources, from e.g. Jo's Cervical Cancer Trust and Cancer Research UK, which can be used by screening and community engagement staff. A digital platform developer is being identified, with appropriate procurement, so that work can be initiated soon.

We heard of examples of not only providing information online but also providing support and skills to use it. Community Links in London is providing multilingual health facilitators who encourage take-up of breast cancer screening through outbound telephone calling. At the same time, Community Links are also running two digital skills programmes: Tech Know for young adults, and Click Start for over-50s, to gain digital competence and confidence.[88]

In Cheshire and Merseyside, a new team of patient navigators for breast and bowel cancer screening is being set up, with eight full-time staff, based in each of eight screening providers. The navigators will support engagement and improve take-up of the screening programme. Linking people to appropriate online resources (including those in the online toolkit above) would be an appropriate part of the navigator's role.

[86] https://www.iplato.com/

[87] https://www.jostrust.org.uk/about-us/news-and-blog/press-releases/hammersmith-fulham-gp-federation-wins-cervical-screening-award

[88] https://www.community-links.org/youth-employment/digital-skills-classes/

INTERVIEWEES

Amanda Brooks, Failsafe Officer, North Nottinghamshire Diabetic Eye Screening

Zoraida Colorado, Health Programme Lead, Community Links, London

Marie Coughlin, Screening and Immunisation Manager, Cheshire and Merseyside

Karen Emery-Downing, National Programme Manager, Bowel Screening Programme

Becky Harris (and team), AAA Screening Programme Manager, Dorset and Wiltshire

Jacquie Jenkins (and team), National Programme Manager, Breast Screening Programme

Iveta Olejkova, Team Leader, North Central London Diabetic Eye Screening Programme, North Middlesex Hospital

Gill Newman, Health Improvement Practitioner, North Midlands University Hospital NHS Trust and Cameron Booth, Digital Advisor, Redmoor Health

Patient representative group, St Mark's Hospital, Harrow (with thanks to Andrew Prentice, Health Improvement Principal, St Mark's Bowel Cancer Screening Programme)

Gill Pickersgill, Communications and Engagement Team, Doncaster & Bassetlaw NHS Trust, Doncaster Royal Infirmary

Lynda Pike, Programme Manager, South Devon & Exeter AAA Programme, Torbay Hospital

Patrick Rankin, National Programme Manager, Diabetic Eye Screening

Steve Robinson, Senior Project Manager – Integration Projects, NHS Digital (Reasonable Adjustments)

Dr Jo Ruwende, Consultant in Public Health, NHS London

Steve Seaton, Programme Coordinator, Bristol, Bath & Weston AAA Screening Programme

Jessica Smith, Screening Coordinator and Technician, Shropshire, Telford & Wrekin AAA Screening Programme, Royal Shrewsbury Hospital (with thanks for also obtaining views of men attending for AAA screening)

Katie Storer, Programme Facilitator, Cervical Cancer Screening Programme

Ruth Stubbs, National Programme Manager, Cervical Screening Programme

Lisa Summers, National Programme Manager, AAA Screening Programme

Julie Tucker, Team Leader, North East & Cumbria Learning Disabilities Network, Newcastle

Appendix 4 - Literature Review

DIGITAL EXCLUSION RESEARCH

Digital exclusion has different causal factors:

- a function of a lack of connectivity;
- a lack of access to devices;
- lack of digital skills, or;
- lack of confidence, motivation, interest or trust in digital technology.

It may affect a combination of the following groups:

- People who don't have a connection to the internet (this could be due to a technological or a financial barrier)
- People who don't have access to the necessary equipment needed to connect (this could be a financial or motivational barrier)
- People who don't have the skills, confidence or motivation to be online
- People who may be unable to physically use technology without adaptations (e.g. a significant disability)

Digital exclusion is not something we can measure directly. Citizens Online use a combination of other measures to identify demographic groups who are more likely to be digitally excluded. Some of these measures include age, low income, disability, geographic isolation, and poor connectivity (fixed line or mobile). Some of these metrics overlap with protected characteristics under the Equality Act (2010) and are discussed in a section on these below.

Key national surveys and datasets exploring current levels of digital exclusion include ONS data on internet users (2019a) and internet access (2019b); Ofcom's *Connected Nations* (quarterly, 2018a, 2019a), *Adults: Media use and attitudes* (2019b), and *Access and inclusion* (2018b) reports; the Lloyds Bank *UK Consumer Digital Index* (CDI, 2019) and Business Digital Index (BDI, 2019), and a range of other reports from academic or third sector organisations focused on digital inclusion such as doteveryone's *Digital Attitudes* report (2018) and the Oxford Internet Institute's report on *Perceived Threats to Privacy Online* (Dutton and Blank, 2019).

A number of these sources identify age, disability and income as factors likely to influence digital exclusion. In the words of Ofcom (2018b),

> *"Participation in communications markets and society will not always be affected by factors such as age, disability or income, but we consider that a person's ability to participate is more likely to be affected if two or more of these factors apply to them."*

Ofcom (ibid.) add that:

> *"People's circumstances can change over time, and life events such as bereavement or illness can temporarily reduce people's ability to participate in society or increase their dependence on certain communications services."*

The Scottish Council for Voluntary Organisations (SCVO) literature review (McGillivray, Jenkins and Mamattah, 2017) summarises recent evidence and learning (2012-2017) around basic digital skills development in the UK. Highlighting the "potential detriments that may be encountered by those who are not able to access the internet". The report notes that:

> *"Policy positions advancing digital-by-default approaches to service provision or the provision of favourable prices/rates for online customers or service applicants – might potentially serve to amplify such exclusion".*

With regard to the demographic groups affected by digital exclusion and hence by moves toward digitalising service provision, the report notes that "literature on the topic strongly evidences the link between social and economic disadvantage and digital disadvantage / exclusion" (2017: 5), cites studies identifying a link between disability and the digital divide, and notes a "lack of skills/confidence resulting in lower rates of computer use in disadvantaged groups" that cannot be addressed through the provision of infrastructure (connectivity and devices) alone. The literature review also notes that:

> *"Those in receipt of benefits – and who are therefore either (or in combination) unemployed, unwell or in receipt of a low wage – are among the least likely to be able to access information and opportunities online."* (McGillivray, Jenkins and Mamattah, 2017).

Ofcom (2019b: 2) highlights higher digital exclusion among households allocated to the DE socio-economic group according to the NRS demographic classification: "One in seven adults

of working age in DE households[89] do not go online, and when they do, one in five only go online via a smartphone" (see above for a discussion of the impact of smartphone-only internet use).

CONNECTIVITY

Underpinning access to and use of the internet, and the development of digital skills, is infrastructure providing connectivity. Ofcom's latest data for England highlights that, as of May 2019, 99% of premises have access to a download speed of 10Mbit/s or higher, and 95% have access to Superfast broadband – up from 92% in 2017, though only 8% have access to full fibre.

In total, 78% of premises and 82% of the geographic area of England are estimated to be covered by all 4G operators (Ofcom, 2019a). Just 2% of premises are unable to access the Universal Service Obligation minimum of 10Mbit/s download and 1Mbit/s upload, though this still amounts to 484,000 homes (down from 790,000 in 2017).

Connectivity is significantly lower in rural areas – 11% of rural premises in England cannot access Universal Service Obligation (USO) speeds, around 322,000 homes. Similarly, while just 3% of the geographic area in rural areas can be described as a "complete not spot" (no coverage from any operator), only 42% of properties in rural areas have good 4G coverage from all four mobile operators (Ofcom, 2018a).

Availability does not imply uptake – Ofcom (2018a) data shows **only 44% of homes and businesses in England have taken up services that deliver superfast speeds**. In rural areas the amount of data used each month (download and upload) remains much lower than in

[89] Internet use and attitudes, 2017 Metrics Bulletin, Ofcom (pdf) The NRS social grade system allocates households to different classifications based on the occupation of the head of the household. DE households are those defined as working class (D: semi-skilled and unskilled manual workers) or non-working (E: state pensioners, casual and lowest grade workers, unemployed with state benefits only). ABC1 households include upper middle class (A: higher managerial, administrative or professional), middle class (B: immediate managerial, administrative or professional) and lower middle class (C1: supervisory or clerical and junior managerial, administrative or professional) households.
https://www.ofcom.org.uk/__data/assets/pdf_file/0018/105507/internet-use-attitudes-bulletin-2017.pdf

urban areas (176GB compared to 250GB). Further, **around a third of the most financially vulnerable group live in households without internet access** (29%). [90]

People classified as "most financially vulnerable" are less likely to have a landline, mobile, fixed broadband and/or pay TV and are more likely than average to live in a mobile-only household (28% vs. 21%); 8% have access [to the internet] only via a mobile. Those who do have broadband are significantly less likely than average to have a superfast connection; 58% of the most financially vulnerable with broadband have a standard broadband connection (Ofcom, 2018b).

DEVICE OWNERSHIP AND USE

There have been dramatic changes in the availability and diversity of devices used to access online information in the past decade. As a result, "PCs are declining in popularity – only 40% of adults are using desktop computers to access the web. Rather, 71% of internet users access the internet using smartphones and, notably, smart TVs are also increasing in popularity with 21% of adults accessing the web through their TV" (McGillivray, Jenkins and Mamattah, 2017). OxIS (Dutton and Blank, 2019) find 92% of households have a mobile phone and note that use of free Wi-Fi (68%) exceeds use of the internet in schools and at work (60%).

While we would expect ownership to be affected by financial situation, Ofcom (2018b) reports that just **5% of people say they do not have a communications service they feel they need due to cost** (down from 10% in 2015). However, 17% of 16 to 24-year-olds say they have experienced difficulties paying for communications services, and over a third of people reporting long-term mental illnesses say they have experienced these difficulties in the last year (35%). This may help to explain why use of the internet in libraries is increasing – 19% in 2019, compared to 10% in 2005 (Dutton and Blank, 2019: 7).

[90] Ofcom (2018b) explains that "the financial vulnerability analysis is based on creating three distinct household types by combining household income, working status and the size of the household (including the number of children)." The most financially vulnerable group is made up of a mix of older and retired people (around 30%), and larger families (around a quarter of these households comprise more than five people). In other words, "a limited income, multiple dependents, or a combination of both, categorise consumers into the most financially vulnerable segment."

Ofcom (2018b) states that "Disabled people are generally less likely than non-disabled people to personally use most communications services and devices". The largest disparities are found in smartphone ownership – **53% of disabled people have a smartphone in their household, compared to 81% non-disabled people**.

The ability to access the internet "on the go" has proved popular: 75% of adults had done so in 2016 via mobile or smartphone, laptop, tablet or alternative hand-held device, including almost all ages 16-24 (McGillivray, Jenkins and Mamattah, 2017). However, only 33% of over-65s had accessed the web using a mobile device (ibid.). Ofcom (2019b) finds that "One in three adults never use a computer to go online and one in ten only use a smartphone". We discuss differential ownership of devices in greater detail under the section on age as a protected characteristic below.

Ofcom (2019b) estimates that around a quarter of UK adults "only use devices other than a desktop or laptop to go online". This is higher among DE households (33%) than in ABC1 households (18%). Around 13% of DE households only use a smartphone to go online – compared to around 6% of ABC1 households (and 8% of UK adults on average). Many tasks are more difficult to achieve using only a smartphone or tablet – including creating a CV, and completing benefits applications (Ofcom, 2016) – and, potentially, accessing information about screening programmes.

Research by Citizens Advice Scotland (2018) found people reliant on smartphones to access the internet were less likely to say that they can use a computer "very well" (28%, compared to 41%), and less likely to access their email "daily" (37%, compared to 48%).

Citizens Advice Scotland's research into "the Smartphone Deficit" goes on to detail examples of the lower levels of digital capability associated with people who are "Smartphone by Circumstance". In other words, "Smartphone by Circumstance" refers to people constrained in their choice of device by costs and other barriers, rather than opting to use a smartphone primarily out of choice.

Table 32 and Figure 35 detail the lower internet use and confidence (together with greater experience of problems) reported by those with only a smartphone, compared to people who also own tablets, computers, or (at the highest levels of confidence and internet use) people with all devices. The proportion of smartphone-only users who report they can complete a benefits application online "no problem" is, at under a third (31%), less than half that for users

of all devices, 76%. This leaves a large proportion of smartphone-only users who experience some problems – at least when filling in such applications. This proportion of users are potentially unlikely to be able to gain a full appreciation of online screening information.

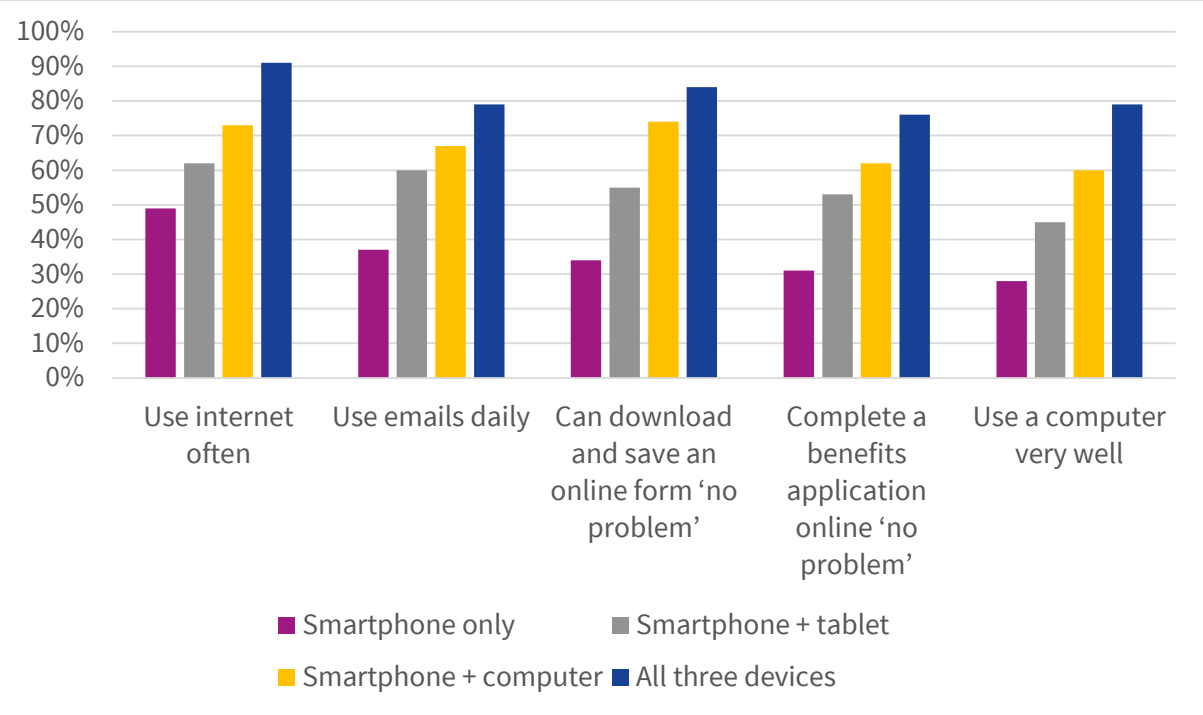
While smartphone-only or smartphone-by-circumstance users may struggle to access information about screening programmes, ownership of smartphones does nonetheless provide a channel for communication. Indeed, Ofcom (2019b) also reports that "**Nearly every adult in the UK uses a mobile phone** (96%). This is the case across all age groups; mobile phone use ranges from 100% among 35 to 44-year-olds to 81% of those aged 75 and over."

This suggests short message service (SMS) could be utilised to mitigate the effect of moving information about screening online, by using text messaging to remind those who have not taken up screening about the opportunity to receive further information in leaflet form. People with smartphones may even be more likely to follow a weblink in a text message than in a letter (though they may be reluctant to do this if they are not sure the link is safe).

Table 32 Ability to carry out digital tasks for smartphone-only users vs those with access to any device for using the internet. Source: Citizens Advice Scotland *Locked out* report

	Smartphone only			Access to any device for internet		
	No problem	**Yes, but with some difficulty**	**Not at all**	**No problem**	**Yes, but with some difficulty**	**Not at all**
Download and save an online form	34%	41%	25%	47%	32%	21%
Complete form	34%	49%	17%	48%	38%	14%
Scan a document	22%	36%	42%	37%	31%	32%
Upload form	24%	43%	33%	29%	37%	34%
Complete a benefits application online	31%	48%	21%	42%	41%	17%

Figure 35: Digital indicators by internet devices used, Source: Citizens Advice Scotland *Locked out* report



INTERNET ACCESS AND USE

For estimates of internet access, households and individuals statistical bulletins are derived from the Opinions and Lifestyle Survey, which has a smaller sample size (net sample size of 2,754 for 2018) than the Labour Force Survey (approximately 41,000 households) from which estimates for the internet users statistical bulletin are derived.

Across the two datasets, the ONS suggests **93% of all households in Great Britain had access to the internet in 2019** – an increase of 23 percentage points in the last decade. A similar proportion, **91%, of adults in the UK are estimated to be recent internet users** (last three months), with 87% expected to use the internet daily in 2019, and an additional 4% using it at least weekly but not daily. There has also been significant change with regard to internet use: the percentage of adults aged 65 years and over who had never used the internet has declined by 29 percentage points since 2011 (to 29%, alongside a decline of 6 percentage points in adults aged 16 to 64 years to 2%).

Further, **84% of all adults used "mobile internet" in 2019**, using a smartphone, laptop, tablet or handheld device to access the internet – and 64% of households connected via mobile broadband in 2019. The proportion of internet users is relatively high by comparison with other countries: of all adults aged 16 to 74 years, the UK ranks third out of all EU countries (after Denmark at 98% and Luxembourg at 97%), 95% in the UK are recent internet users compared to the EU28 average of 85%.

While the above ONS data highlight that the vast majority of adults in England are internet users, a significant minority are not. Across Great Britain, 7% do not have access to the internet. Of these, 61% felt that they did not need it, 34% felt a lack of skills prevented them, and 33% were put off by privacy or security concerns. Furthermore, as hinted above, a large proportion of current internet users, particularly among older adults, have only begun to use the internet in the past decade.

Those who remain non-users remain convinced that it is often "easier to do things without technology" (72%), though even among internet users a significant minority agree with this statement (35%, Dutton and Blank, 2019: 16). These findings are relevant to engagement with online screening information: people who are not internet users will want printed information, and they may be joined by a significant minority of internet users who can access online information but would prefer not to.

MEDIA LITERACY AND ONLINE BEHAVIOUR

The fact that people use the internet does not imply ability or motivation to access online information about screening programmes. Ofcom and others (e.g. Yates, Kirby and Lockley, 2015) talk about the concept of "limited use" or "narrow" internet users – those who only carry out four of 15 types of online activity (as opposed to medium at 5-9 types, and broad at 10-15).

NARROW USERS

According to Ofcom (2018b), a quarter of all UK adult internet users can be classified as "narrow" users. Those aged 55+ are particularly likely to be classified in this category: 32% for 55 to 64-year-olds, 49% for 65 to 74-year-olds and 55% for those aged 75+. The top five activities are listed as general surfing/browsing, sending/receiving emails, instant messaging, social networking and online TV/TV viewing.

These top five activities are broadly the same across age and socio-economic groups, although the proportions of the groups doing the various activities differ and there are exceptions to this list by age group. As Yates, Kirby and Lockley (2015: 17) emphasise, "those with the least access, who are making the least use and the least varied use of the internet, are older adults or those in social class group DE".

Most people are unlikely to access information related to their personal health choices on a regular basis. The most financially vulnerable are also likely to use the internet for fewer purposes – just 41% use the internet for finding information on health (Ofcom, 2018b).

ATTITUDES TO DIGITAL

Further considerations related to media literacy and online behaviour are worth considering as they may affect the likelihood of people participating in screening programmes and/or to develop informed consent beforehand.

Doteveryone's *Digital Attitudes report* (2018), for instance, shows that people want to know what happens to their data ("94% say it's important to know how their data is used") and how they can control the information they share – but feel resigned to agreeing to terms and conditions they don't have the time to read (58% sign up without reading) or understand (51%). They report that 89% of people say, "companies should do more to make terms and conditions understandable and clear", though 43% say there's "no point reading T&Cs because companies do what they want anyway".[91]

DIGITAL HEALTH

While concerns may be lower for public sector organisations generally, concerns around health may well be higher than in other areas: **around a third (31%) of people say they keep medical details private online** (Dutton and Blank, 2019). While this may not affect their willingness to explore online information about screening programmes, some wariness might exist among a section of this significant minority, even if submission of medical details is not required.

[91] Surveys of 2,038 people were conducted by BritainThinks between 4th and 6th December 2017, and were weighted to be representative of the British adult population by gender, age, and region according to ONS figures.

Services need to give due consideration to the Data Protection Act and General Data Protection Regulation when collecting, storing and processing data, making clear privacy statements about how data will be used. New digital information should be tested specifically with user groups who are concerned about online privacy. There will be a desire to collect data about how sites are used, but this should be balanced against the additional concern this may create. Even if there is little justification for concern about anonymised data, a perception of risk could affect people's willingness to access information and ultimately participate in screening.

TEXT MESSAGING

A (qualitative) 2019 Cochrane Systematic Review of "Clients' perceptions and experiences of targeted digital communication accessible via mobile devices" for antenatal and newborn and related health services, found that "clients' experiences of these types of programmes were mixed" (Ames, Glenton, Lewin, et al., 2019). In short, from the 35 studies from around the world that were included (all published before 2017), the Cochrane reviews found that:

> *"Many clients like receiving messages from the health services by mobile phone. However, some clients have problems receiving messages due to lack of network access, internet, or phone, or language, reading, or privacy issues. Clients' experiences are also influenced by message timing, frequency, content, and sender."*

More specifically, the following findings were reported by the review:

- Programmes provided them with feelings of support and connectedness.
- Messages were shared with friends and family.
- Some clients had poor access to cell [mobile] networks and to the internet.
- Others had no phone, had lost or broken their phone, could not afford airtime, or had changed their phone number.
- Women had their access to phones controlled by others in some cases.
- The cost of messages could also be a problem, and many thought that messages should be free of charge.
- Language issues, as well as skills in reading, writing, and using mobile phones, could also be a problem.
- Clients dealing with stigmatised or personal health conditions were concerned about privacy and confidentiality.

- Some clients suggested using neutral language and tailoring the content, timing and frequency of messages.
- Clients wanted messages at a time and frequency that was convenient for them.
- Short message service (SMS) was preferred to interactive voice response.
- New knowledge, reminders, solutions and suggestions about health issues were preferred as content types.
- Clients' views about who sent the digital health communication could influence their views of the programme.

Key questions that the review raised concerning this research are:

1. Have solutions been considered for when clients may have their access to a phone wholly or partially controlled by someone else? (supported housing or care provision)
2. Have solutions been considered for tailoring or changing intervention content to engage clients who have low literacy, differing language skills, or limited digital literacy?
3. Has an attempt been made to explore how clients perceive different sources of digital health interventions as more or less reliable, trusted, and credible? Has an attempt been made to use those sources that are perceived as trusted, reliable, and credible to send digital health messages?

ESSENTIAL DIGITAL SKILLS FRAMEWORK

One way to understand digital literacy is through the Essential Digital Skills Framework (ESDF).[92] The *Lloyds UK Consumer Digital Index* reports annual estimates based on this framework. The ESDF divides a total of 24 skills into five categories (within two contexts: "Life" and "Work"): Communicating, Handling Information and Content, Transacting, Problem Solving, and Being safe and legal online. Underpinning these five categories are seven "Foundation Skills".[93] The 2019 edition of the report suggests (see Table 33 for age breakdown):

[92] The Essential Digital Skills Framework defines the digital skills adults need to safely benefit from, participate in and contribute to the digital world: Essential digital skills framework (gov.uk), accessed 16/12/2019.

[93] The seven Foundation Tasks refer to the abilities to: turn on a device, use the controls on a device, use accessibility tools to make a device easier to use, interact with the homes screen on a device, connect a device to

- 11.9 million people (22%) do not have the Essential Digital Skills needed for day-to-day life in the UK
- 4.3 million people (8%) do not have any Foundation Skills, and
- 10.3 million (19%) lack at least one Foundation Skill

Table 33: Foundation and Essential Digital Skills for Life, UK adults and by age band

Skills level	All Adults	15-24	25-34	35-44	45-54	55-64	65+
0 Foundation skills	8%	0%	0%	1%	3%	9%	26%
0-6 Foundation skills	19%	3%	3%	7%	12%	24%	51%
0-4 Life EDS skills (Have Foundation)	3%	2%	3%	3%	3%	5%	4%
0-4 Life EDS skills (incl. those without Foundation)	22%	6%	6%	11%	15%	28%	55%

While data around the specific skills that make up the framework are not available, it is worth noting that "I can check if online information is true or false", "I can save information to find it again from a different computer, tablet or phone", "I can use online chat to ask for help with a website or app", and "I can recognise suspicious weblinks" are among the Essential Digital Skills. Hence, it is not only people who do not have connectivity or devices, nor only people who are not internet users who are "digitally excluded". People who are online but lack these (among other digital skills) may be poorly equipped to access and gain the benefits of online information about screening programmes.

The NHS Digital (2019) report on digital inclusion reports that only **around half (54%) of adults in the UK looked up health information online over the past three months**, though clearly this can cover a wide variety of activities and says little about ability or willingness to access information about screening on the basis of a weblink in a letter.

a safe and secure Wi-Fi network, understand that passwords and personal information need to be kept safely, and to update and change a password when prompted to do so. See SCVO's toolkit "Understanding & Measuring Essential Digital Skills" for more information.

There is a clear need for online information to be designed mobile-first, as of the 40 million visits a month to the NHS.UK website, most (65%) are made by smartphone; 24% are made by computer and only 11% by tablet).

There has been an increase in the number of people booking appointments online (18% in 2018, up from 12% in 2017) and ordering repeat prescriptions online (17% in 2018, up from 12% in 2017). However, the proportions of people doing this are still low. This is related to low awareness of GP online services (40% of adults).

There could be synergies between online screening information and take-up of other digital health services, but low take-up at present could also suggest a risk of reduced coverage for screening if information is online-only.

CHANNEL SHIFT IN SCREENING PROGRAMMES, HEALTH, AND BEYOND

As part of this research, Citizens Online sought to identify existing research on experiences with moving from printed to online screening information in other countries (see Table 34). While we were unable to identify any published research in the UK, we did source interesting summaries of approaches elsewhere – though some of these are restricted to breast screening.

Table 34: Screening arrangements in different countries

Country	Arrangements
Switzerland	Several cantons (member states of the confederation with populations between 16,000 and 1.5 million people) who only send a short, 1-page leaflet with the basic information and a **link to a website where the full brochure can be downloaded** in 11 languages. This is the only case where data on impact was provided, suggesting there is no significant difference in participation rates between cantons who send the full brochure and those that send only the leaflet ("participation is relatively low with an average of 50% which does not change much"). Others use a full brochure of 26 pages.
Norway	Invitation letter with time and place for screening, information about possibilities to withdraw from receiving further invitations, not having their data stored, etc. Additional two-sides of A4 sheet also available.

	Patients referred to webpages for more extensive information (including references to scientific papers) and could also call or write to the Cancer Registry, or their GP.
Netherlands	Leaflet redesigned in 2018 and is now more comprehensive (length increased from 4 to 8 pages). **Leaflet refers patients to website for more details**, including e.g. short videos
Catalonia	One invitation letter for women aged 50 to 69 years (provides very brief information about benefits, appointment date, the requirements for doing the mammogram, a phone number for those who want to reschedule the appointment) and a flyer with additional information regarding risks and benefits for women 50 to 52. **Leaflet includes reference to web page for additional information**. New flyer that includes information on risks (over-diagnosis, false positives and false negatives) also being sent to all women.
Dalarna county, Sweden	Screening is devolved to the counties in Sweden. In Dalarna county, the invitation, information and appointment time are all on a single sheet of paper. **Letter includes a web address** for those who wish to know more, and a telephone number for those who wish to change or cancel the appointment.

We also conducted a limited search of existing literature to find references to experiences of digital transformation and Channel Shift of screening programme information and/or the value of online information. While there is some literature on digital transformation of health services, such as GP online consultations (e.g. Banks, Farr, et al., 2018; Carter, Fletcher, et al., 2018), and literature around screening programmes and social exclusion/deprivation, there is little that combines both.

With regard to digital transformation of health services broadly, NHS Digital (2019) has a report on digital inclusion for health and social care, which includes advice on providing accessible online services. The report mentions that "***People who have characteristics that are protected under the Equality Act 2010 (age, disability, race) are less likely to have access to the internet, and the skills to use it***", as we discuss in more detail below.

ANTENATAL AND NEWBORN SCREENING INFORMATION

Literature on screening programmes and the internet that we were able to identify is focused on antenatal and newborn screening (ANNS).

This is perhaps unsurprising: as Sayakhot and Carolan-Olah (2016) observe, "pregnancy care generally involves medical monitoring and prenatal testing, which can be anxiety provoking. Consequently, many pregnant women utilise the Internet as a source of information, and as a means to help them deal with doubts, and to navigate pregnancy-related decisions".

Sayakhot and Carolan-Olah (2016) provide a systematic review of "internet use by pregnant women seeking pregnancy-related information", identifying seven publications studying between 182 and 1,347 pregnant women. They find that "Most women searched for information at least once a month" and "The majority of women found health information on the internet to be reliable and useful".

However, one study found that "**women with higher education were three times more likely to seek advice than women with less than a high school education**".

The same paper also identified that "single and multiparous women were less likely to seek advice than married and nulliparous[94] women".

Further, they write that "**it can be difficult for women to distinguish accurate from inaccurate sources on the internet… Internet users are hesitant about the reliability of health information they accessed. Without proper guidance, information on the internet can be harmful, confusing and overwhelming**".

These findings may well apply more broadly to other screening programmes and are mitigated in the case of antenatal and newborn screening, as midwife and other appointments offer opportunities to provide clarity about sources, discuss questions, and offer reassurance. One study reported that 51% of pregnant women stated that they shared information obtained on the internet with health professionals.

It should be noted, however, that only one of the papers included data on women searching for information on screening tests – and in this case the searches only covered calendars rather than information about the tests themselves.

[94] 'Nulliparous' is the medical term for a woman who has never given birth, whether by choice or for any other reason.

In addition, only one of the papers covered the UK. This study (Lagan, Sinclair and Kernohan, 2010) found a high level of internet use for information about pregnancy: "Almost 94 percent of women used the Internet to supplement information already provided by health professionals and 83 percent used it to influence their pregnancy decision making. Nearly half of the respondents reported dissatisfaction with information given by health professionals (48.6%) and lack of time to ask health professionals questions (46.5%) as key factors influencing them to access the Internet." However, the study methodology involved an online questionnaire, so it would have excluded digitally excluded people.

Guendelman, Broderick, et al. (2017) do cover low users and non-users of health information on the internet, in the USA. They write that while "97% of the participants reported that they had searched for health information on the Internet in the past year, 42% did not engage in digital health-management practices. Among the low users and non-users, 49% expressed interest in future adoption of digital health tools". They cite other studies which they note "have shown that individuals with a lower socio-economic status and of non-white race or Hispanic ethnicity are less likely than their more affluent, white counterparts to engage in Internet health-seeking behaviours, although results documenting these disparities have been inconsistent".

Guendelman, Broderick, et al. (ibid.) emphasise that use of the internet for health management purposes was low compared to other searches, and note that much health management information and technology design has not been oriented towards excluded groups:

> *"When compared with other web-based searches, we found a much lower use of the Internet or other digital tools for health-management practices such as for accessing personal health information or scheduling appointments through patient portals, communicating with providers through secure email messaging or video chats, use of health tracking apps or wearables, or engaging with social networks or patient groups on the Internet…*
>
> *…many applications for personal digital health management have been created with a "design it and they will come" approach that may not be appropriate or meaningful for use by individuals whose health literacy, cultural values, or trust limits their ability or willingness to use digital tools…"*

While personal digital health management tools perform different functions from population health screening programmes, an analogy can be made – this is information that could protect someone's health, but only if they engage with it, and make an informed decision to undergo screening. Hence, it is important for design to take potential factors of exclusion or distrust into account.

At present, research implies potential but there is little specific evidence regarding screening itself. Acquavita, Krummel, et al. (2019) find "low-income pregnant and postpartum women showed some interest in utilizing technology for health-related information and interventions" but note that:

> *"There is no large evidence base regarding the feasibility of using technology to help with promoting healthy behaviours in low-income pregnant and postpartum women, although many related findings suggest that education dissemination through the Internet is possible and could be effective, as is suggested in this survey".*

However, Guendelman, Broderick, et al. (2017) go as far as to suggest that:

> *"as a somewhat larger percentage of mothers of young children than first-time pregnant women engaged in Internet search activities, pregnant women's Internet use should be considered an important target for intervention".*

In other words, if online information about antenatal and newborn screening is effective, it could play an important role in ultimately improving the reputation and thereby increasing engagement with other online screening information.

Discussing preconception consultation around carrier screening, outside the PHE screening programme remit, Metcalfe (2012) writes that, "challenges exist in terms of approaches to ensure couples receive adequate information to make personally relevant decisions and for ongoing health professional engagement".

In this context, "Use of printed and reputable online information, ideally produced with the input of consumers" is presented as "a valuable adjunct to the [face-to-face] discussion, which should explore the patient's understanding of the conditions in question and the potential benefits and concerns they might have about finding out that they are a carrier including implications for insurance and potential for discrimination."

Metcalfe raises the valuable point that "though the patient/couple might decide not to be tested at that time, raising their awareness is useful in itself, as the effectiveness of screening should not be measured by test uptake alone". It may be that any impact of shifting to online information about screening is not felt immediately, but the availability of more information ultimately increases understanding/uptake.

One benefit of online information could be greater feedback regarding questions about screening programmes. Tamminga, van Dussen, et al. (2017) explored questions emailed to the website for non-invasive prenatal testing (NIPT) in The Netherlands. NIPT refers to testing for Down syndrome, offered in The Netherlands since 2014 to some women (at increased risk). In the first year of the study, around 3,000 tests were conducted, and the two websites covered by the study received a total of 233 visitors over two years, with one of the websites receiving around 1,000 visitors each month.

For the authors, these numbers highlight that "the Internet holds great potential to support health information gathering and decision making". Most questions related to eligibility for the screening, suggesting that the information about the screening itself was of appropriate quality and of use to visitors.

A study into false-positive newborn screening results, conducted in the USA (Schmidt Castellanos-Brown, et al., 2012), found "Many parents turned to the Internet for information. Some reported feeling reassured by information they found… [while other] parents chose not to seek online information, as a kind of self-protection".

Though the study was about the results of screening programmes, rather than the process itself, the finding that "some sought information from the Internet to relieve their anxiety, but this sometimes increased anxiety" may have more general application.

Hosting information about screening programmes online enables more information to be provided, via hyperlinks to further information, and means consumption of information takes place in a context where people will be more able and/or likely to seek additional information from the internet, which could either increase anxiety or otherwise reduce willingness to participate.

CERVICAL SCREENING INFORMATION

An exception to the emphasis on antenatal and newborn screening is Ryan, Waller and Marlow's (2019) survey of invitation and booking processes for cervical screening – the first study to assess preferences for booking screening appointments in Great Britain. They found ***over half of women would book a screening appointment via a website using a smartphone (62%),*** a computer (58%) or via an app (52%).

Consistent with the digital exclusion research we have presented above, they found women who were older, or from lower social grades, were less likely to say they would use online booking methods. As part of the research, Ryan, Waller and Marlow (2019) explored barriers to attending screening, with ***31% of participants agreeing they "might forget to book an appointment after reading this letter"***. A weblink to online information about screening in a letter could potentially introduce a further barrier where people might put off the job of looking online later and this could ultimately have an impact on whether or not they book an appointment. People who intended to be screened but were currently overdue ("intenders") were found to be significantly more likely to endorse the statement "I might forget to book an appointment after reading this letter" than those who were up-to-date with screening and intending to go in the future ("maintainers").

Ryan, Waller and Marlow's (2019) research also explored preferences regarding channels for invitations. While this is not a direct analogue for information about screening, the clear – and in some cases statistically significant – preference for posted letters raises some concern. Among all participants, 92.5% found posted letters acceptable, compared to 80.7% for text messages, 75.8% for a mobile phone call, 72.5% for email, and just 62.3% for landline. While in each case a majority find the channel acceptable, **the 20 percentage point gap between posted letters and emails suggests a reluctance to endorse online channels.** Though acceptance of email was higher among the youngest age group (80.9%), 25 to 34-year-olds also had a higher rate of acceptance of posted letters (94.7% – perhaps surprising, though it could be explained by a preference for official communications to come in this format in order to distinguish themselves).

Meanwhile, **among the oldest age group – 55 to 64-year-olds – acceptance of email was just 60%**, while posted letter acceptance was even higher than the average (95.9%), leading to a percentage point gap of 35.9% (a statistically significant gap which was similar for other alternatives to post – text, mobile and landline calls receiving approval rates between 60.4% and 65.6%).

This suggests a significant minority of this age group – approximately a third – may not engage with online information about screening. At the same time, there was a significant difference between acceptance of email and posted letters among people allocated to social classification E (60%, compared to 85.2%). However, there was no difference between intenders and maintainers with regard to this question – both groups preferred post (91% and 93.4% respectively) to email (75.1% and 75.2%). Meanwhile, ***people who gave their ethnicity as other than White preferred text (90.5%) and email (88.9%) as a channel as a whole*** (compared to 85.9% for post) by statistically significant margins. The authors conclude:

> *"Signposting online booking services, if available for nurse appointments, to groups of the screening-eligible population (i.e. younger women who are more likely to be 'intenders') may be an effective means of increasing uptake. This survey suggests that there are likely to be age and socioeconomic inequalities in the use of online bookings. For example, women aged 45–54 years and women aged 55–64 showed less interest in using online booking methods. Thus, ensuring that traditional telephone booking options remain available is important".*

If it were technologically possible, linking online information about screening programmes to online booking of appointments could prove valuable. The argument around telephony may have a wider application beyond booking appointments – a telephone option for information about screening programmes could be of value, if not options for people to access printed information or discuss screening with their GP.

SOCIAL MEDIA

Finally, there is some evidence that social media campaigns have been able to increase coverage rates. While not of direct relevance, this suggests that digital screening information may not be a barrier to increased coverage, and that coverage can be increased by using digital methods alongside a shift to online information:

> *"First time appointments at the North Midlands Breast Screening Service increased by an average of 12.9% between three-year screening cycles from 2014 to 2018. The service has also shot up the league table for uptake levels, going from 58th to 11th in the country between 2016-17 and 2017-18."* (Digital Health Age, 2019)

SUMMARY

While comments are made regarding the potential benefits of online information (including in Lagan, Sinclair and Kernohan, 2010; Metcalfe, 2012; Guendelman, Broderick, et al., 2017, for example), this needs to be set against the risk that internet use varies significantly among different demographic groups and that encouraging people to access information online may lead them to compare the information with sources which may not be credible and could increase anxiety (Sayakhot and Carolan-Olah, 2016).

In short, ***there is little current evidence to suggest moving information about screening online will improve coverage, and some indications that it may increase barriers***. At the time of writing we are aware of only one trial of shifting from print to digital for screening leaflets, which is being undertaken by Jo's Cervical Cancer Trust.

Appendix 5 - YPA Programme Staff Survey

This survey ran in February and March 2020 for four weeks and was promoted across the YPA programme service staff. There were 12 respondents who completed the survey and although the response was low it provided consistent views to those captured in the interviews and site visits (detailed in Appendix 3).

COST SAVINGS AND ENVIRONMENTAL IMPACT

Respondents saw clearly the cost saving and environmental advantages of replacing printed leaflets with online information:

> "It would be a significantly positive step in terms of the sustainability agenda and the essential changes we absolutely must make in this area"

> "Good for the environment to use less paper in the system- supports sustainability across the health and social care system"

> "The biggest benefit would be that online information does not have the cost of producing and posting leaflets"

> "It's cheaper"

> "Online information is more sustainable, saves on printing and delivery costs etc."

> "Saving on printing and delivery costs - those funds can be diverted elsewhere"

> "Reduction in outgoings"

> "Reduces costs of producing leaflets"

> "Reduced cost of printing and postage"

> "Environmentally sound"

> "Less wastage"

> "Access and less paper waste"

> "Less waste, financial savings and environmental savings"

"Some people will support the reduction of printed materials as an environmental benefit"

EASIER TO UPDATE

Another commonly perceived advantage is being able to update information more easily and flexibly if online rather than in print form:

"Updates can easily be made"

"Changes or updates to information leaflets can be made quickly and easily so they are always up-to-date"

"Ability to change content or wording of standard information materials more easily/rapidly/responsively"

"Ability to change content or wording of standard information materials more easily/rapidly/responsively"

ABILITY TO ACCESS MORE INFORMATION

The advantages of being able to provide access to more detailed information online were also seen:

"People can access more information easily by using links (one click to other information)"

"Ability to provide more detailed information for those who want it via hyperlinks"

"Public can have access to more information online"

"Using technology means information is always available, with access and timing suitable for them"

"Helps people on the go to access information promptly"

"Providing multiple forms of information is likely to increase access and be more inclusive"

"Greater ability to access information in other languages / formats"

"The service can provide more information to the public online which will help them make an even more informed choice than with printed leaflet, of whether or not to attend for screening. Providing only a printed leaflet could, in some ways, be limiting because

individuals may read only that and not bother to access more information that's available to them online"

APPROPRIATE IN MODERN SOCIETY

Some respondents noted that accessing information online is the norm in modern society:

"Most communication with the services we use are delivered electronically these days, from council tax accounts, energy companies to dentists and GPs and acute hospital services. Not only is this expected, but it is my view that only using traditional comms, through printed letters etc., is now a risk as people don't expect it and as such may ignore letters that they are not expecting (who doesn't have a stack of unopened mail by the front door!)"

"Most people nowadays prefer to look online for information"

"For a large majority of the eligible populations, electronic communications and online resources will be a welcome change and what they are now accustomed to in a rapidly progressing digital world"

"Most people now seem to prefer to access information online, rather than in printed format. Online information can be saved to individual devices and printed if required. There will always be times when an individual wants printed information and cannot do this at home so I would hope this can be made possible via local services e.g. GP practice, hospital service etc. However, I do think that posters are a must as they are used to advertise the service and also inform where to go for online information."

RISK OF EXCLUSION

While seeing benefits in terms of cost saving, environmental sustainability, more up to date content and providing access to more detailed information, concerns were also expressed about the risks of excluding key sections of the population who may not be online.

"The age groups the cancer screening programmes cover are such that not all people are comfortable with accessing online resources"

"Not everyone is tech savvy or have access to this medium. There are still many individuals who would prefer paper"

"I know a few (mainly older) people who remain eligible for specific screening services but who would not have access to information that was provided purely online"

"Excludes many groups who cannot afford or are not technically savvy enough"

"I think that many individuals will not be able to access online information due to lack of smart phones and computers. The poor, elderly and LD communities will be particularly impacted"

"Risk excluding some with protected characteristics - older people, those living with disability and those in living in deprivation"

"Will support access by some groups only"

"People who are unable to access the internet easily would not see the information"

"Exclusion of groups without access to online information thereby increasing inequalities and marginalisation of groups"

"Some groups may be left behind as they do not have access to the technology that supports its delivery, or they do but are not comfortable/capable with using the internet as a means of managing their healthcare needs"

"A large proportion of patients and the public are being expected to access information and guidance on their care digitally. We cannot assume and neither do we have evidence that most of the population have access and/or know how to use digital media sources. We carried out a survey of ~ 1100 men over 65 in London regarding their care in AAA surveillance with the option to complete online or complete and post with pre-paid envelope. Response rate was 52%, less than 1% completed online. Assumptions that everyone uses digital media will impact on those with protected characteristics and those experience deprivation"

INFORMED CHOICE

Respondents were aware of the importance of informed choice about screening procedures and were keen to ensure any changes to information provision is not a risk to this.

"Some people might not get the information to make informed choice so not take up invitation"

"Some patients may not have access to, or be comfortable with, using digital solutions for communication and resource finding and as part of our responsibilities to ensure people are making informed decisions about the healthcare they receive, considerations must be made to support these groups having access to the information they need to achieve this"

"Some people will not have access to the information resources either because they don't have the required technology, or they don't know how to use it. There is a risk that people will be less likely to make an informed choice about participating in a screening programme if detailed information to support an invitation is easy to skip or is not provided in an obvious way"

IMPACT ON TAKE-UP

Others were concerned about that a move to online information might have an adverse impact on take up of screening.

"Could have an unknown impact on uptake. Inability to access online resources could make people think screening isn't for them"

'Uptake might go down if people need help with accessing information"

"Reducing uptake of the programme, people not fully informed about the screening they are being offered - benefits and harms."

"Those who struggle to access the information may choose not to attend"

"People might not be 'bothered' to go online to read the information. Maybe providing too much information could be confusing for the public, knowing what to read first"

"Some people may not click into the links for information. However, those people may not read a printed leaflet either. And anyone who decides not to attend for screening will do so, whether they receive their information in printed format or online"

CONSISTENCY OF INFORMATION

Some respondents pointed out the importance of ensuring consistency between information available in different formats and channels.

> *"It would be important to make sure that all messages are consistent across all information and across all services. Conflicting information would confuse the public and leave the service open to criticism"*

> *"Too much information can confuse people"*

> *"Confusion due to many sources of information available online - information overload"*

DATA SECURITY AND STABILITY

Others were concerned about the vulnerability of online information to technical faults and data breaches.

> *"There is a risk of 'losing' digital resources should either PHE/NHS IT have problems or if the individual has IT problems or no access to the internet"*

> *"How do you monitor if information received? Need to hold more data so more risk of breaches"*

> *"There may be complaints from service users who don't want information online (if there is no choice)"*

MAKING CHANGE GRADUALLY

There was support for implementing any shift from print to digital in a phased way.

> *"It's important to adapt to the changes in how we access information. However, not everyone is moving at the same pace, changes must not exclude patients and citizens who are not quite there yet or who do not have means to access digital information sources. It is about striking the balance for me"*

> *"I think smart comms strategies using e-communication will improve participation in many population groups as we are becoming more and more reliant on small nudges to support us turning intention into action"*

"One step change would not be something I felt comfortable with. I think the change needs to be implemented gradually and tested for risk as we go. I do think implementation should happen in all areas at the same time, as running pilots in specific geographies may result in a biased recommendation and either end up informing wider change that either benefits or disbenefits populations. A planned, staggered approach across all services with agreed metrics by which we monitor effectiveness feels like the safest way to transition"

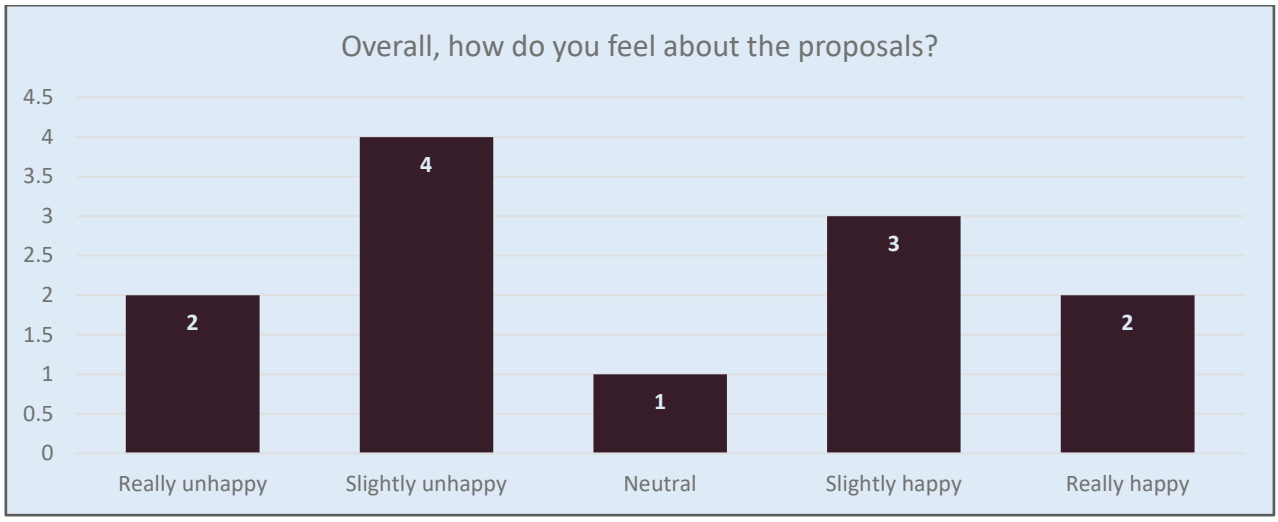
Q1. In which screening programme do you work?

All five YPA programmes were represented. Four respondents worked only on a single programme, while the others worked on multiple, including four respondents who work on all five YPA programmes.

Abdominal Aortic Aneurysm (AAA)	Bowel Cancer Screening (BCSP)	Breast Screening (BSP)	Cervical Screening (CSP)	Diabetic Eye Screening (DES)
7	5	7	6	7

Q4. Overall, how do you feel about the proposals?

Feeling	Count
Really unhappy	2
Slightly unhappy	4
Neutral	1
Slightly happy	3
Really happy	2



5. How do you think information for people invited for screening in your programme should be provided (if contact details were available)?

Please rank the following methods in order (1 being most preferable, 5 being least preferable method).

	Number of respondents who selected this as most preferable	Overall score (higher = *less* preferable)
Letter and printed leaflet	**4**	**29**
Letter with link to online information	3	31
Text message with link to online information	1	44
Telephone number to call for information	0	52
Email with links to information or attachments	2	36
Talking face to face	2	60

Free text comments on Q5:

People should be able to choose how they want the information presented to them

> *"I am concerned about using email or text messages. What if people were to change email address or change mobile phone number. They might not receive any information at all."*

"An invite letter is more preferable to any other method of invite as it's a more reliable method of making sure the correct individual has been reached. Maybe some information from the leaflet could be included on the reverse of the letter with links to more information. Alternatively sending a leaflet in the first letter and for follow-on letters, then just include links to online information. Text messages are fine as a reminder only. Emails are good as they can contain a lot of information and links, but not everyone uses email. A phone number is a good option but not everyone will take time to make that call. Talking face to face could be a back-up option as some people might not remember every detail they were given."

"I would prefer a system that catered for individual preferences so that people could choose whether to receive paper or electronic communications, in the same way that many banks and utility companies offer a paper-free service on request."

"People still like a printed leaflet, especially older people. If people are expected to look for information online it has got to be easy. My concern it might put people off going to screening"

"Any telephone numbers for patients must be free of charge. Face to face would be ideal but realistically not possible due to demands on the time screening staff have to spend with patients."

"I don't think the majority of people will call for information and I'm not sure how frontline staff will assure themselves people are undertaking a test having understood the relevant information."

6. If information leaflets for the public were provided only online rather than in print, how would this affect the risk of being excluded from your programme for each of these groups? (Table is split into 2)

Each level of response (from reduced risk to highly increased risk) was awarded a numerical score, and for each demographic category, the number of responses in each level was multiplied by that score.

	Score	Older people (age 65+)	People with low income	Disabled people (physical / mental health)	People with moderate / severe learning difficulties / disabilities	People with lower literacy
Reduced risk of exclusion	-1	0	0	0	-1	-1
No/negligible effect	1	1	4	3	1	3
Moderately increased risk of exclusion	3	9	9	18	18	12
Highly increased risk of exclusion	5	25	20	5	15	10
Total score		**35**	**33**	**26**	**33**	**24**

	Score	People in residential care / supported living (e.g. care homes)	People whose first language isn't English	LGBTQ+ people	Younger people (under 35)	People in prison
Reduced risk of exclusion	-1	0	-2	-2	-6	0
No/negligible effect	1	2	4	8	5	2
Moderately increased risk of exclusion	3	12	15	0	0	6
Highly increased risk of exclusion	5	20	0	0	0	25
		34	**17**	**6**	**-1**	**33**

Five categories were all scored very similarly as being most at risk of exclusion:

- Older people (age 65+)
- People in residential care / supported living (e.g. care homes)
- People in prison
- People with low income
- People with moderate/severe learning difficulties / disabilities

Appendix 6 - Digital Information Opinion Survey

As part of this assessment, Citizens Online created a simple online survey (5 to 10 minutes completion time), and sought to collect the views of:

- Health professionals
- People who have been invited to, or undergone screening
- Interested members of the public

SUMMARY FINDINGS

The survey was undertaken in order to investigate the feelings of interested and informed people, and to establish some points of importance relating to the Channel Shift proposals and their potential impact on the public and on the service. With a sizeable number of respondents (579) and a detailed dataset of responses that presents some consistent themes and messages, the survey is a helpful and solid piece of research that can inform this assessment and resulting actions and decisions. The survey analysis suggests that:

- There is a balance of responses, from those expressing unhappiness and concern to those expressing unqualified approval, with many people striking a balance between the advantages and the potential problems of the proposals.
- Far more women (466) than men (54) participated, and many more health professionals (479) than members of the public (100).
- 59 respondents (10%) said they are disabled.
- 39 respondents (7%) gave their race or ethnicity as other than White.
- 18 (3%) respondents said their sexual orientation was other than straight/heterosexual (17), or that their gender identity was not the same as that assigned at birth (1).
- There is little difference between demographic groups in the range of issues raised.
- When examined at sentence level, the detailed written responses were skewed towards those tagged as 'con',[95] reflecting the fact that those with concerns had generally more to write about than those who felt the proposal was a positive step.

[95] Roughly, expressing concern or opposition to the proposals; tags are further explained in the analysis below.

- Many people raised the issue of digital exclusion due to skills, confidence, connectivity and affordability. These were the most common themes of people's responses, though many other themes were cited.
- There were intersecting demographics that people expressed concern about, chiefly older people and some disabled people; but also, those who have poorer digital skills or poorer English language skills; those who live with poverty; and those who are in 'harder to reach' communities or locations. Few, if any, people suggested that the switch to digital information would be beneficial in addressing exclusion.
- A recurring theme was respondents reporting that *they themselves* are confident and regular internet users who would be comfortable with digital information but expressing concern for others (either in the general or referring to specific groups they are in contact with) who do not enjoy the same access or skill levels. So while this online survey by definition will not have been accessible to everyone, we can have confidence that most respondents were not simply thinking of their personal needs and abilities when they completed the survey.
- A theme within several responses was 'readiness' - the suggestion that the switch is a good idea in principle, but people are not quite ready for it yet.
- Accessibility and 'findability' were also frequently mentioned, with many respondents being concerned that digital information would be hard to access, find or re-find. The convenience of a paper leaflet was also frequently mentioned, though many people also mentioned digital formats as being more convenient and accessible.
- For those more in favour of a shift to digital, sustainability issues and cost-saving were most frequently referred to. Many people said that online information would be their preference and that is in some ways more convenient. The possibility of automatic translation via online language tools was also mentioned, which is balanced against many other respondents mentioning language capability as a digital exclusion risk.

"Within AAA we deal with patients who may struggle with online only info - some patients in this age group (65+) don't have access to online services and/or don't have any computer/ technical skills."

tags: accessibility, concern, exclusion

- Health screening practitioner, female, age 45-54; overall feeling: "Neutral"

RECOMMENDATIONS

Based on survey responses, which come from interested members of the public and from a large number of health professionals, ***a high degree of caution about Channel Shift to 'online only' information exists***.

Any Channel Shift should be accompanied by careful consideration of groups that are not online or find it difficult to get online and would be at risk of not receiving necessary information and potentially not able to make an informed choice about whether to attend an appointment.

These groups include:

- Older people
- People who are already poor and/or socially excluded
- Disabled people whose disabilities affect them in a way that makes It hard for them to complete tasks online
- Those who cannot get online, or choose not to be online for a variety of reasons

Survey respondents frequently mentioned the beneficial features of printed information leaflets:

- They are a helpful physical reminder to make an appointment
- People can write other notes and reminders on them
- They are easy to stick on the fridge
- They are easy to pass on to a friend or family member

In considering Channel Shift, services should consider ways in which online information could be supplemented with some form of digital reminder or notes system.

It seems that ***many of those with concerns about digital exclusion would be satisfied with a system where people have a choice and where multiple options remain available - including printed leaflets for those that need them***.

METHOD

The survey was hosted on Mentimeter[96] and was accessible via a public link. We are not aware of any digital accessibility or usability problems with the Mentimeter interface that might have prevented or dissuaded people from participating.

As well as being publicised on the PHE screening blog,[97] the survey was promoted on Citizens Online's Facebook and Twitter accounts, through the Digital Inclusion Slack space which we run, and at events including PHE's Screening Inequalities conference,[98] and the Royal College of Midwives annual conference.

The survey was open from 11th October 2019 to January 2020 (latest data downloaded 16th January). Respondents who had responded 'N/A' to the early question "What's your interest?" had not completed any other questions either, so we removed these blank responses (n = 9), leaving **579** responses to the survey.

We then split the data into two sets, one for the personal and demographic data about the respondents and one for the opinion (sentiment) data. This separation allowed for examination and coding of the sentiment data without contamination with any personal information about the respondent. After the coding process was complete, we merged the data sets together again, and analysed the sentiment data according to the various demographic groups of interest.

Our survey analysis takes place in two main stages:

1. **The overview of the survey data:** the numbers and types of respondents, general demographic information and a summary of the *overall feeling* (in response to the question *"Overall how do you feel about changing from printed leaflets to online information?"*) that people reported about the Public Health England (PHE) proposals.
2. **The thematic sentiment analysis of the written responses** to the survey question *"What are your opinions on changing from printed leaflets to online information?"* where the themes and issues raised by respondents are explored.

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[96] https://mentimeter.com/, accessed 21/01/2020.

[97] https://phescreening.blog.gov.uk/2019/10/18/online-screening-information-leaflets-tell-us-your-views/, accessed 21/01/2020.

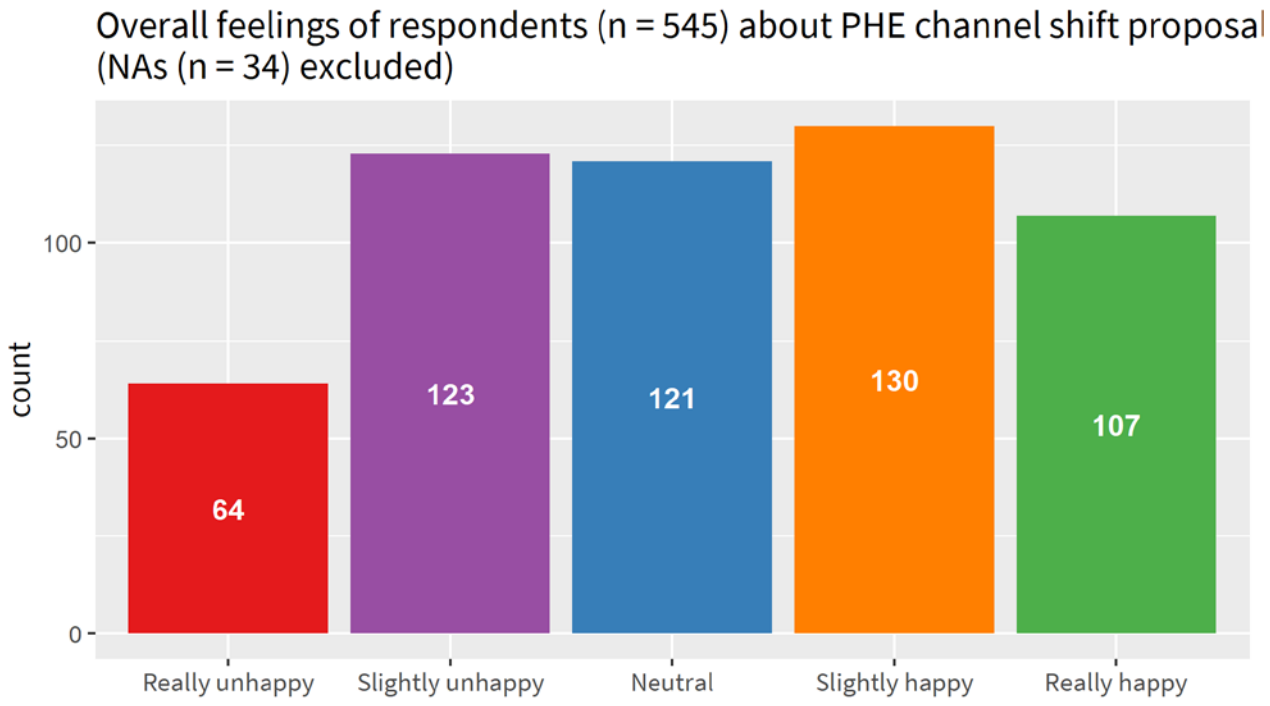
[98] https://www.phe-events.org.uk/hpa/frontend/reg/thome.csp

SURVEY ANALYSIS PART 1: OVERVIEW

"OVERALL HOW DO YOU FEEL ABOUT CHANGING FROM PRINTED LEAFLETS TO ONLINE INFORMATION?"

Figure 36 shows the overall feelings of survey respondents about the proposed changes. 34 of the 575 respondents did not give a response to this question; these have been excluded from the analysis.

Figure 36: Survey respondents' overall feelings about the Channel Shift proposal



The chart shows a good spread of feelings, with the more moderate central responses being predominant but also significant numbers of people answering "Really unhappy" or "Really happy."

"I think overall this is to be welcomed but it's important that information remains available in a range of formats - including printed - so that everyone

can be informed about screening in a format that suits them."

tags: choice

- Member of the public, male, 35-44; overall feeling: "Slightly happy"

Figure 37: Overall feelings of respondents about PHE proposals: no further written response

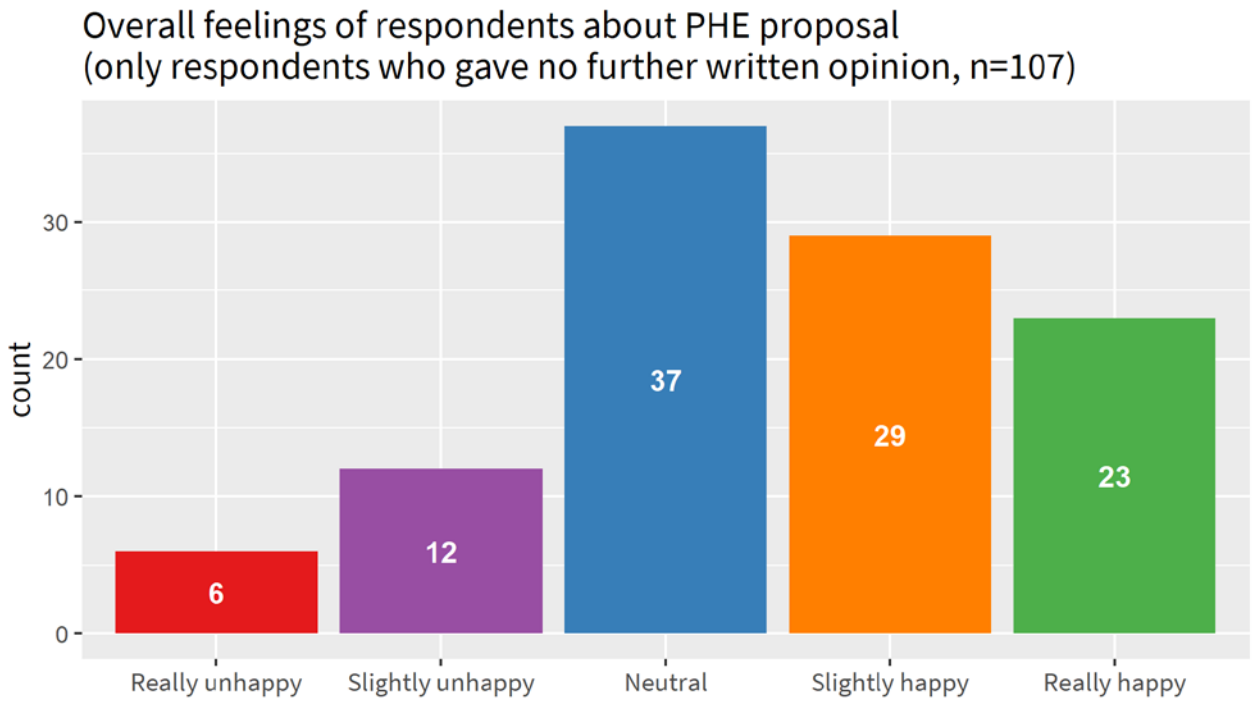
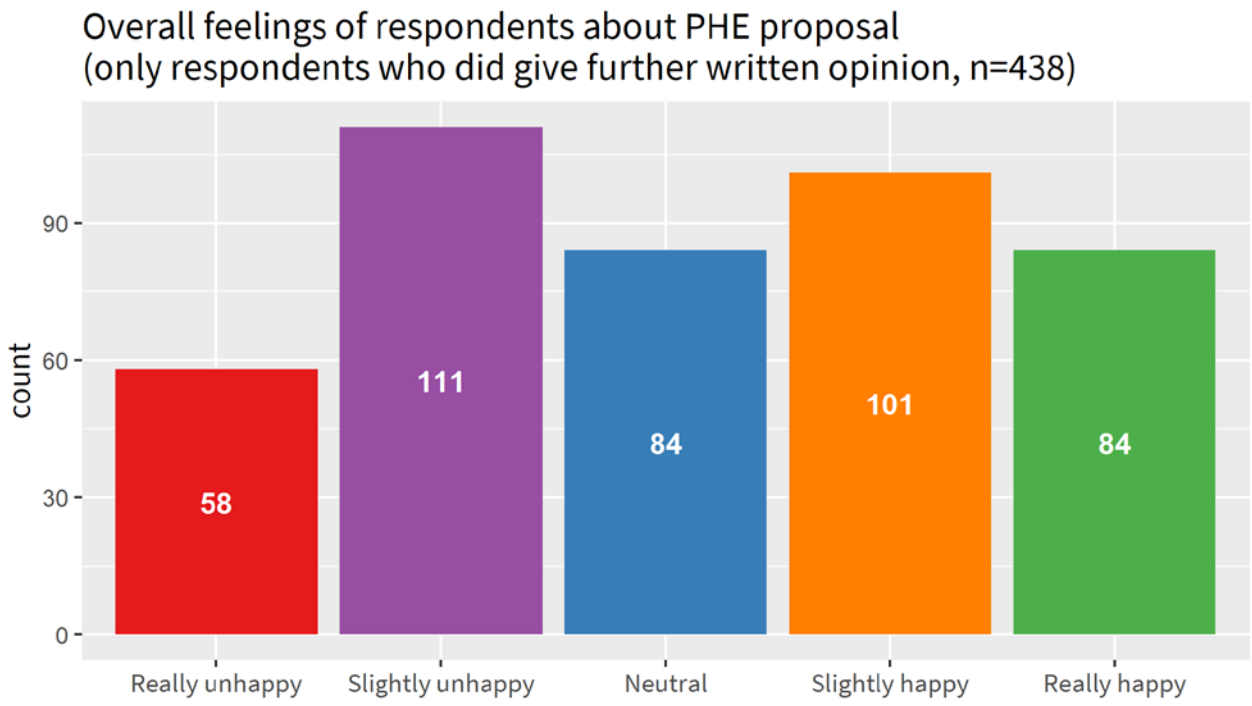


Figure 38: Overall feelings of respondents about PHE proposals: further written response provided



Figures 37 and 38 are included in order to show that "neutral" and "happy" respondents were more *likely* not to provide further written opinions, whereas "really unhappy" respondents were *very unlikely* (n=6) not to give additional written explanation of their feelings.

169 of 187 (90%) of 'unhappy' respondents added further comments, compared to 185 of 237 (78%) of 'happy' respondents.

DEMOGRAPHIC SUMMARY OF RESPONDENTS

Table 35: Survey respondents by race/ethnicity

Respondents (n=579) by race	n
White (British / Irish / Traveller / Other)	476
Black (African / Caribbean / Other)	10
Mixed (any mixed background)	11
Asian (Indian / Bangladeshi / Pakistani / Chinese / Other)	17
Other	1
NA	64

Table 36: Survey respondents by religion or belief

Respondents (n=579) by religion or belief	n
Christian	222
No particular religion / belief	220
Atheist	31
Pagan	3
Other	6
Jewish	2
Muslim	6
Agnostic	4
Hindu	6
Buddhist	1
NA	78

Table 37: Survey respondents by other protected characteristics

Other protected characteristics	n
I'm married / in a civil partnership	303
English is not my first language	18
I'm a carer for someone else	27
I'm serving / have served in the armed forces	4
I am pregnant or a new mother	15
NA	257

(NB the above "other protected characteristics" figures add up to more than 579 because 42 respondents had 2 or more characteristics, and all have been counted in the table).

OVERALL FEELINGS OF MEMBERS OF THE GENERAL PUBLIC VS. THOSE OF HEALTH PROFESSIONALS

Of the 579 respondents, the majority (**479, or 83%**) were health professionals, with just **100** (**17%**) being members of the general public.

The health professionals group includes programme colleagues and managers, screening practitioners, and PHE colleagues and managers, but the analysis below does not split results up according to these categories: health professionals are treated as a single group.

Members of the public include some who have been invited to screening and some who have not, but again this distinction is not used in the analysis below.

The shapes of these charts (Figures 39 and 40) is very similar, which suggests that there is little difference in the distribution of overall feelings held by these two groups. We will look later at some of the detail of the comments made by members of each group.

“I think this is an opportunity to make savings, but may create a barrier for those less IT literate - although it may also present a more effective translation service”

tags: cost, exclusion, language

- Health screening practitioner, female, age 55-64, **with a mental health condition, physical impairment and a longstanding illness**; overall feeling: “Slightly happy”

“I am bombarded with online information links all the time and it's difficult to know if they are from a trusted source.”

tags: reliability, trust

- Member of the public, female, 45-54, **mixed race**; overall feeling: “Really unhappy”

Figure 39: Overall feelings of health professionals (24 gave no response to this question)

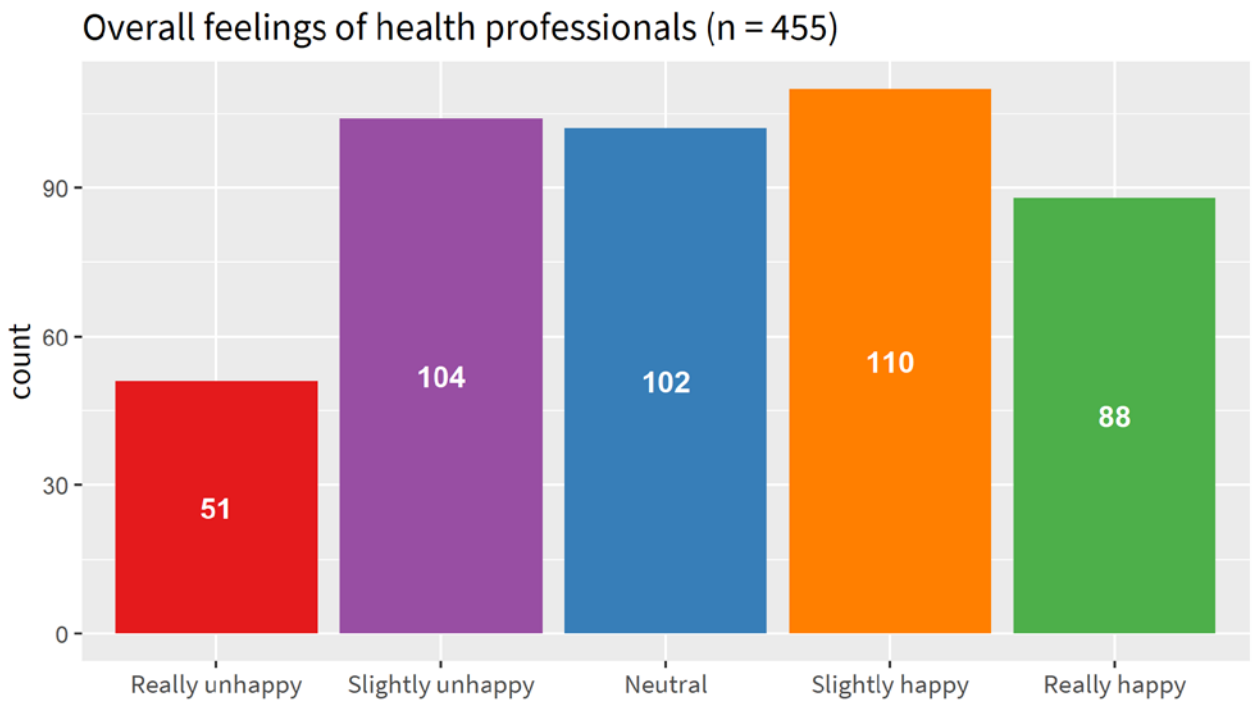
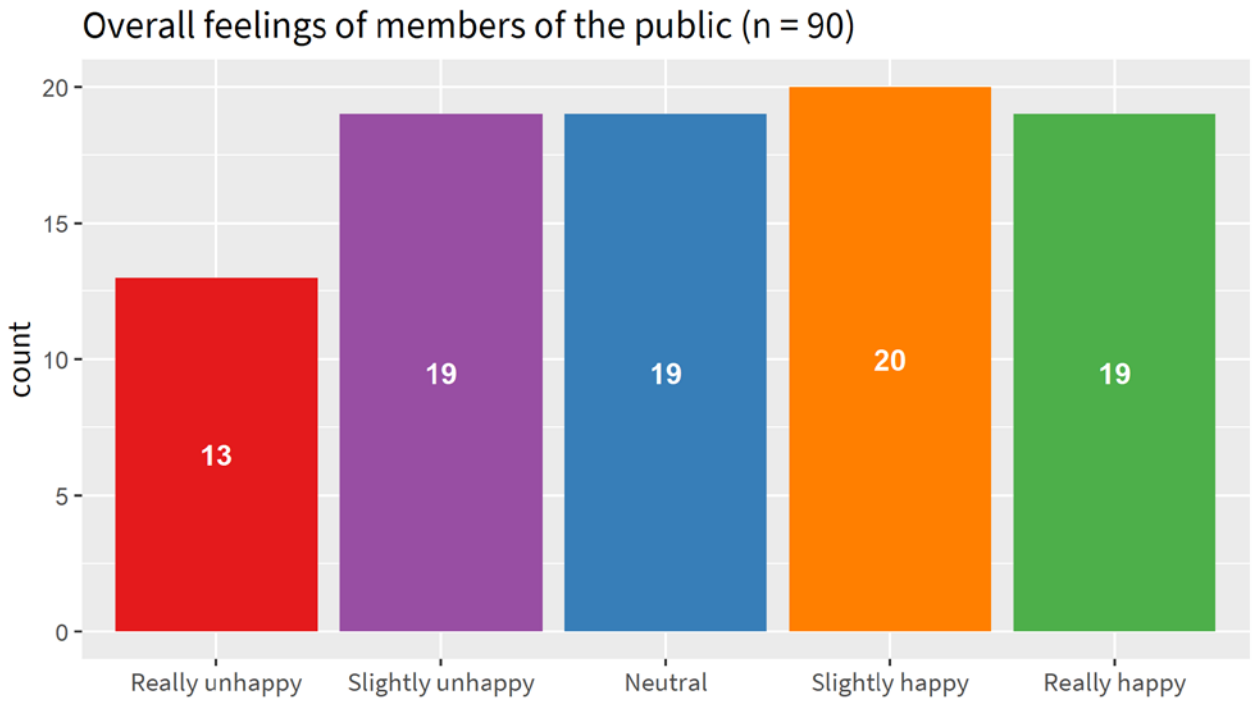


Figure 40: Overall feelings of members of the public (10 gave no response to this question)



OLDER RESPONDENTS (AGED 65+) - OVERALL FEELING

The age band breakdown of the 579 respondents was as follows:

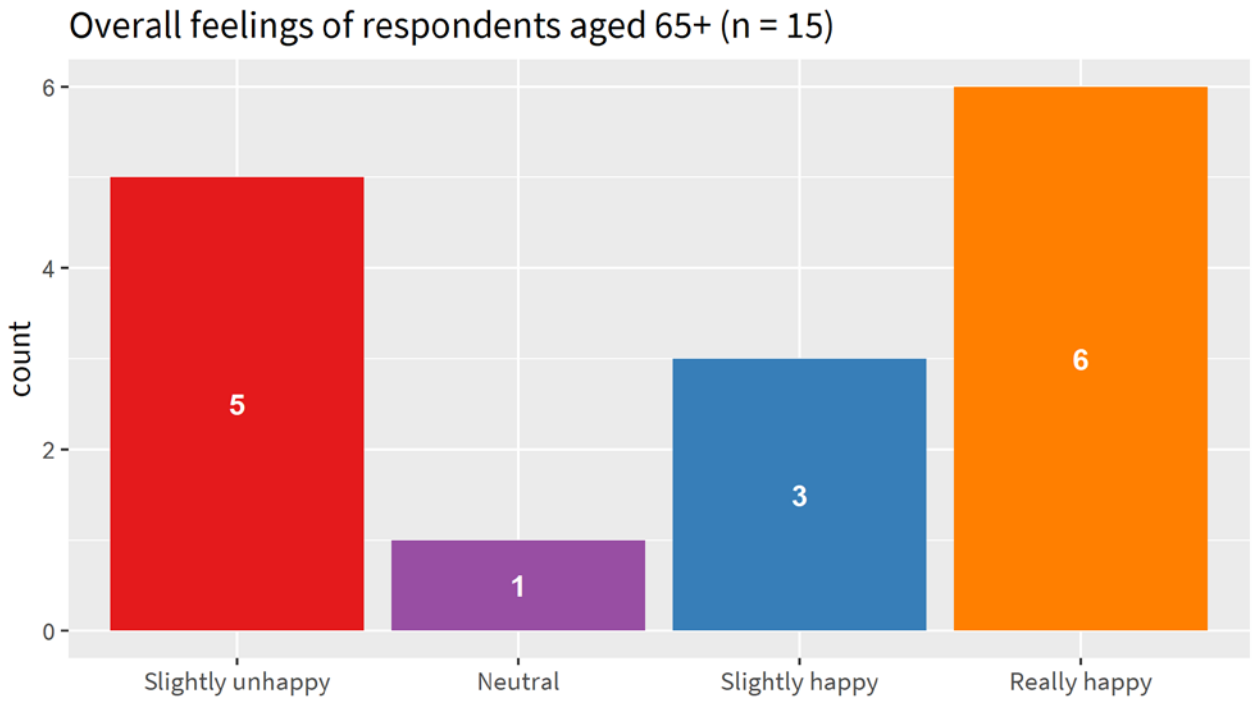
Table 38: Respondents, by age band

Age band	18-24	25-34	35-44	45-54	55-64	65-74	*No age given*
n	13	75	123	181	117	15	55

The age band with the highest number of respondents - by far - was 45-54. Just 15 respondents gave their age as 65+, of whom 7 were members of the public.

Nobody aged 65+ said they were 'really unhappy' with the proposal; in fact, more people who told us they were in this age group were happy than unhappy.

Figure 41: Overall feelings of respondents aged 65+



"I might lose a leaflet, but I can find online information again when I need it"
tags: findability

- Member of the public, male, **65-74,** longstanding illness; overall feeling: "Really happy"

DISABLED RESPONDENTS

59 respondents (10%) said they are disabled in some way, of whom 9 reported being disabled in 2 or more categories of disability given in the survey. 449 respondents (77.5%) did not see themselves as disabled, with 71 (12.3%) not giving any answer.

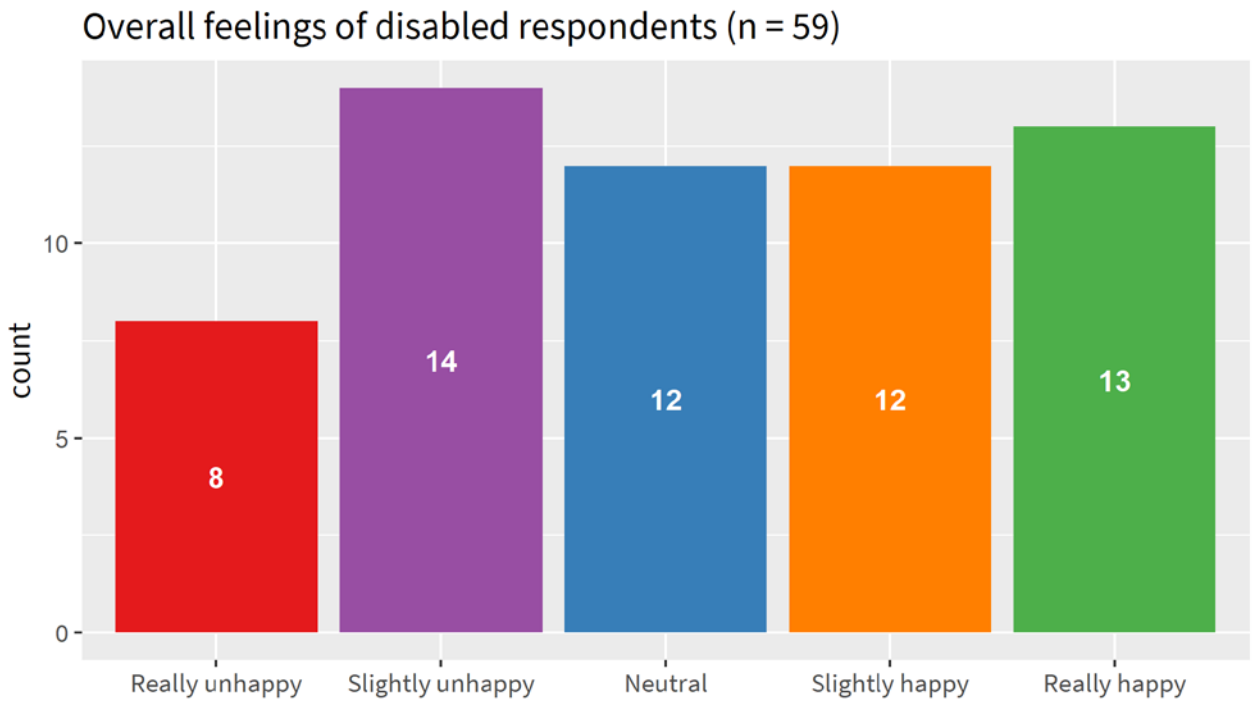
Table 39: Respondents by disability status

Disability status	n
No disability	449
Mental health condition	13
Physical impairment	14
Long standing illness	18
Other developmental condition	1
Sensory impairment	6
Autistic spectrum	2
Learning disability / difficulty	5
Did not answer	*71*

"Because I have learning differences including autism, I find it very helpful to have printed information as well as digital, and to have things explained face to face."
tags: disability, channel preference, accessibility

- Member of the public, female, age 45-54, with **physical impairment, longstanding illness, autistic spectrum, learning disability/difficulty**; overall feeling: "Slightly unhappy"

Figure 42: Overall feelings of disabled respondents about the Channel Shift proposal



There is little to deduce from the figures above, except to note that disabled respondents are far from being unhappy overall with the proposals: there is a fairly even spread of feeling.

LGBT+ RESPONDENTS; SEXUALITY AND GENDER

We then examined the respondent group according to their gender, gender identity and sexuality. There was quite a high proportion of respondents who opted to skip some or all of these questions. Still we can draw some conclusions.

There were far more female respondents (466) than male (54).

1 respondent said that their gender identity is not the same as assigned at birth. **17** of those who responded to the question about sexual orientation gave an answer that was other than heterosexual/straight.

These 18 people have been combined into a single sub-group for the purposes of the further analysis. There is no clear pattern in their overall feelings about the proposals compared to the full sample.

Table 40: Respondents by gender

Gender	n
Female	466
Male	54
No answer given	59

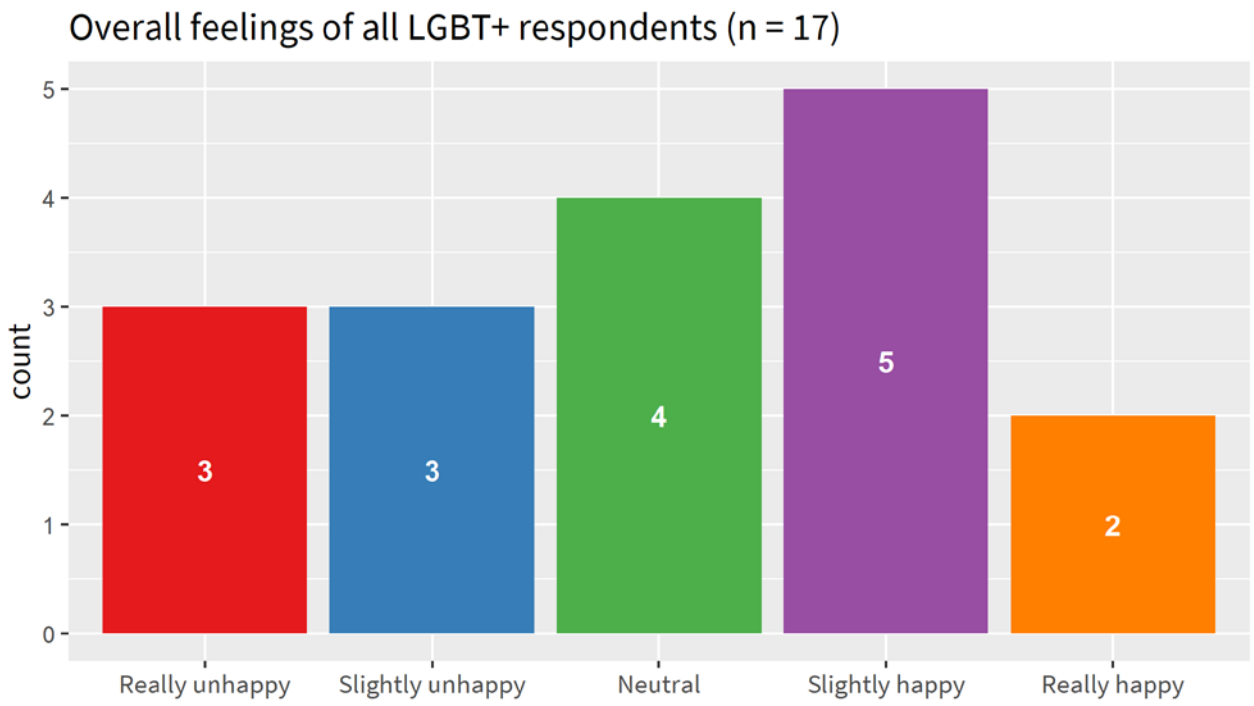
Table 41: Gender identity

Gender identity as assigned at birth	n
Yes	515
No	1
No answer given	63

Table 42: Sexual orientation

Sexual orientation	n
Heterosexual / Straight	477
Gay	4
Bi/polysexual	8
Lesbian	5
No answer given	85

Figure 43: Sentiments of LGBTQ+ survey respondents (1 of the 18 did not answer this question)



Again, there is an even spread across the range here, with no strong pattern, and given the small sample size we cannot draw any conclusions here.

SURVEY ANALYSIS PART 2: THEMATIC SENTIMENT ANALYSIS

WHAT ARE YOUR OPINIONS ON CHANGING FROM PRINTED LEAFLETS TO ONLINE INFORMATION?

We then analysed the textual responses provided in response to the survey question, "What are your opinions on changing from printed leaflets to online information?"

In total there were **565** responses, provided by **438** respondents. However, these responses ranged from the very short to rather longer paragraphs. Within paragraphs there might be different points relating to different aspects of the proposals or providing further detail.

We split the responses down into separate sentences[99] for more fine-grained analysis, which created a total of **930** sentence-level *tokens*. We exported the sentences to a spreadsheet and then coded each token in Excel. Although respondents had already provided their overall feeling about the proposals (see previous section), for a more detailed and sensitive assessment of what they thought, we examined and coded their responses at sentence level through a separate coding process.

This is important because, for example, a respondent who is really unhappy about the idea might still have one positive thing to say about it; conversely someone who says they are really happy with it might, as an aside, also mention a concern that they have. The sentence-level thematic analysis allows us to pick up such nuances.

CODING PROCESS

FILTERING

Firstly, any empty tokens, meaningless fragments, and duplicate and near-duplicate comments from the same person were coded with the code ign for ignore and were removed

[99] Based on an approach documented by Silge & Robinson, *Text Mining with R* (https://www.tidytextmining.com/). They recommend a semi-automated sentiment analysis of a text corpus at single word level, but here we were happy to do the coding manually at sentence level.

from this part of the analysis. Some other comments that were out of scope (e.g. relating more to general issues around healthcare or personal experiences not related to screening) were also removed.

Any comments that were mainly about the survey process itself, rather than the Channel Shift proposal, were tagged as meta. These comments are reproduced below (Table 42) as they may be a useful resource, but were not further included in the thematic coding analysis.

TAGGING

Remaining sentences were tagged for their overall sentiment, this being one of pro (generally positive about the proposal), con (generally against, concerned or negative), and neu (neutral or balanced overall),[100] and then allocated where appropriate up to four further tags to pick out the main theme(s) of the sentence. The tags were not pre-specified, but emerged through the coding process. Occasionally a sentence would not be given any further tag apart from the overall sentiment tag, but the majority had one or more thematic tags assigned.

SOME NOTES ON THE CODING TAGS USED

A total of **66** tags were used, and these are explained briefly below.

- exclusion - this was used for general digital exclusion comments; nearly always in conjunction with another tag such as age or poverty
- concern - this was used when a comment expressed a sense of concern for a group of people
- readability, accessibility, affordability, connectivity, skills, confidence - these are fairly self-explanatory, and were used when these aspects of digital exclusion were mentioned or implied.
- poverty - as above, but includes references to “deprivation” etc. Not quite the same thing as affordability
- sustainability - used as a catch-all for references to the environment or being “green”

[100] Note: We maintain the use the names of the tags (con, neu, pro) throughout, rather than expanding these to full words such as “against” or “positive”, because of the potentially loaded meanings and presumptions of such words. For example, it would seem unhelpful to label a response raising concerns about the impact of proposals on a particular group as “negative”; similarly, ‘neu’ might be used to tag a comment that contains strong ideas both in favour and against the ideas, but which is balanced overall. “Neutral” would not seem to be a fair ‘translation’ of the tag in such cases. We hope that by retaining the tags themselves in the discussion here, we maintain a degree of agnosticism about attaching value judgements to the tags.

- paper - only used when paper was literally used as a reason for being pro or con. Similarly, waste
- clarity, quality - these are only used in reference to these aspects of paper leaflets. See also…
- printing - where a respondent refers to a local body printing out leaflets themselves as a workaround or supplement to online-only information
- channel preference - generally used about the respondent themselves or a group they know well, with reference to stated preference for communication via a particular channel or medium. A lot of responses contained these statements, many about a personal preference, which might not be ultimately that useful for this exercise
- fine - tags comments that are basically "I'm online and it works for me"
- both - used to tag responses that basically say, "both paper and online should/must be provided." Sometimes in the sense of having one channel as a backup for the other, not necessarily having same priority for both
- accessibility - usually refers to strict technical accessibility issues but can be just to do with a general sense of how easy a user may find it to access information. See also…
- findability - used to tag comments about how easy it is to *retrieve* or *search for* information
- email - plenty of comments referred to issues and concerns around email, particularly about retrieval and about information being lost in "too much email"
- convenience - a very common tag, this refers to what people will find it easy to obtain, access, retrieve or annotate. See also usefulness
- uptake - specifically refers to the uptake of screening itself (e.g. the impact of information on this). By contrast…
- engagement - refers to how likely it is that users will *choose* to access information in a particular format e.g. via an app. also "effectiveness" - how easy it is for the information to get to the users?
- reach - refers to the effectiveness (or not) of a channel at reaching particular groups that are "harder to reach"
- information - tag used to pick out comments that refer to how well the information will be communicated or how clear it will be in different formats. See also…
- promotion - where health promotion impacts of Channel Shift are referred to. Sometimes friends or family are used alongside, where leaflets (for example) are referred to as being easy to share. Also, shareability
- consent - where information on screening is linked to the issue of (informed) consent
- demography - used where a respondent refers in non-specific terms to 'certain groups'
- age - very common tag, used for comments that claim age as a significant factor, usually older people having less opportunity to access information but sometimes in reference to younger people preferring online information. Used only where age is specifically referred to as a factor
- disability - tags comments where the needs of, or impact on, disabled people are specifically referenced

- readiness - used where comments say it's too soon for the proposed changes, or "not yet", or "more work is needed first" - in terms of the spread and adoption of technologies and internet access across the country (in general, or sometimes with reference to a specific group e.g. a patient group)
- language - self-explanatory; often refers to access issues for people with ESOL
- inequality, discrimination - where comments refer to particular groups being unfairly treated or discriminated against by the proposal
- supplementing - where professionals will be required to provide extra support for users in lieu of, or to assist with access to, online information. For example, assisted digital, or training.
- cost - a very common tag. Self-explanatory, and generally used where cost or money is specifically referred to
- resources - used only where "resources" are actually referred to and it is *not* obvious that these are the same as, or a euphemism for, "money"
- women - used to tag comments where a user group is specifically referred to as being women
- choice - a bit like both but where flexibility or user choice is emphasised
- currency - where comments refer to how up to date (or not) information can be
- reliability, trust - comments about (perceptions of) how reliable online information is. Also: security, confidentiality

'META' COMMENTS ABOUT THE SURVEY PROCESS

Several respondents pointed out some potential issues with the survey being online, in terms of its reach and accessibility. Although these comments were not included in the further sentiment analysis, they are recorded here.

While people who are not skilled online were by definition unlikely to access the survey, and may have found themselves excluded, the survey nonetheless appears to have captured a range of views including many people expressing concern about access to information for others who are not online.

Table 43: Survey comments about the survey process (tagged 'meta') (n=16)

id	token	tag1
6	I assume you have undertaken this survey offline as well as online?	meta
6	Otherwise I imagine you will get a skewed response from those who are skilled already online.	meta

6	Can I ask that you share the survey through the local health watch and through the patient organisations for these screening programmes, if you have not already?	meta
7	This survey will obviously not capture the views of those unable/unwilling to use digital.	meta
23	Many of the people who would be most affected by this change are unlikely to see this digital survey or to be able to complete it.	meta
23	I have needed support to do this.	meta
23	I hope that these people are consulted and supported to do so where needed.	meta
113	What about the people who can't access an online survey to tell you that online doesn't work for them?!	meta
114	Slightly skewed that the survey about whether or not to move information online, is only appearing online.	meta
136	As this survey was not written in Easy Read, a format which many people with a learning disability require, how to you expect to hear from this group?	meta
143	I feel the collated results from this survey may give a biased view of the ease of switching to online information as only those confident with IT and the internet will complete the survey and it will miss the views of those most vulnerable.	meta
313	Is this survey being produced on paper as well?	meta
365	I am concerned about your methods of an online survey.	meta
365	Surely you are only targeting the people who already use the internet and therefore receiving a very biased response.	meta
400	This is an online survey, therefore, it can be assumed people completing this survey have access and are comfortable with using the internet.	meta
471	This survey is a bit odd as it asks if you are a screening professional then treats you as a screening recipient.	meta

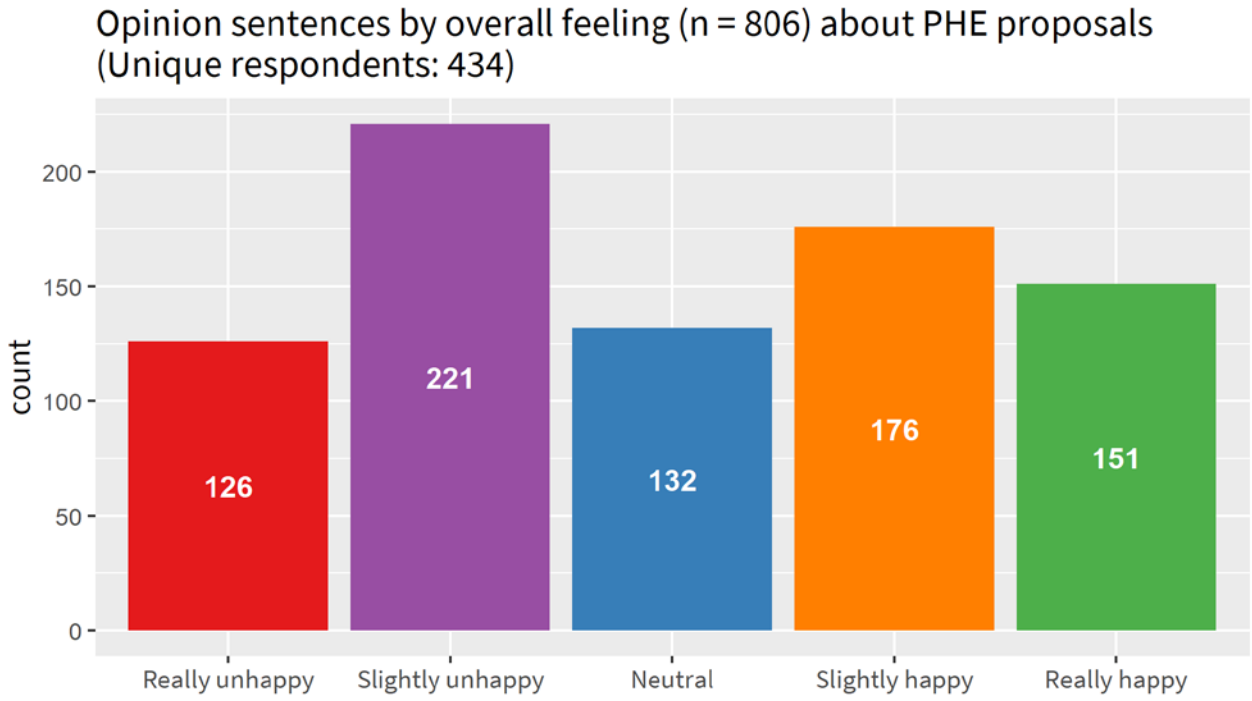
SENTENCE-LEVEL SENTIMENT ANALYSIS - OVERVIEW

After we removed fragmentary, out of scope, duplicate and meta comments, there were **806** sentence-level comments remaining, from **434** (**75%**) of the original 579 respondents. This is a very respectable percentage of respondents to have received written comments from.

In this section we check the correlation between the coding of each sentence token and the overall feeling reported by the relevant respondent.

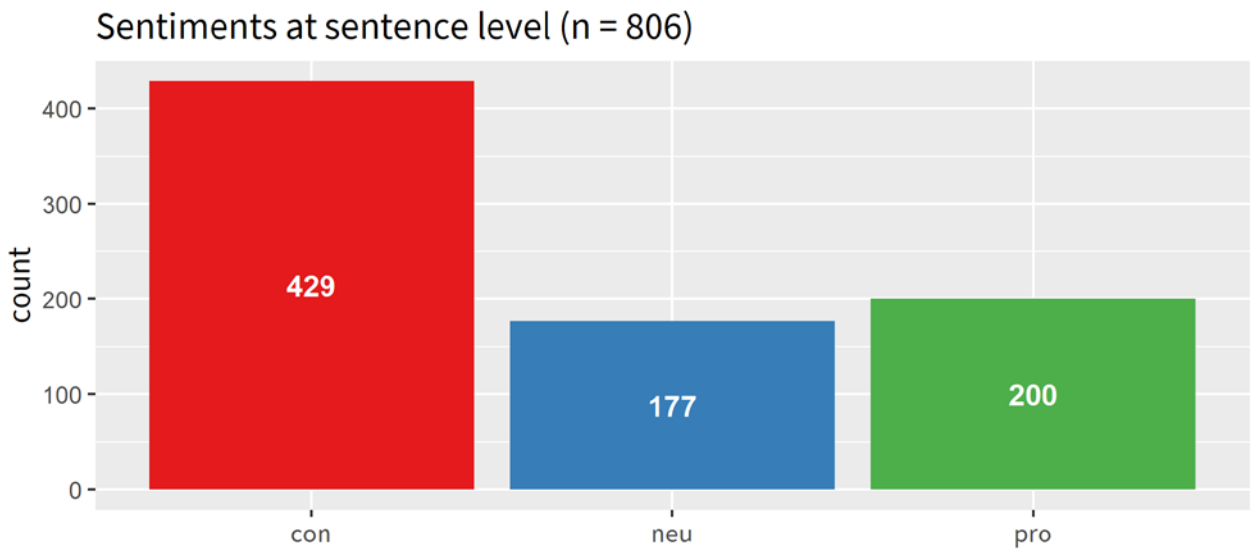
While **221** sentences come from people who feel "slightly unhappy" with the proposal - more than any other category - overall there is a good balance in this corpus between "unhappy," "neutral," and "happy" respondents.

Figure 44: Sentence-level analysis: summary of overall reported sentiment



As a baseline, if every sentence from a respondent who felt 'unhappy' overall was expressing a concern or criticism of the proposals (i.e. should be tagged con) then we would expect to have 347 (126+221) con sentences (43%); and if every sentence written by 'happy' respondents was in favour of the proposals (taggable as pro) then we should have 327 (176+151) pro sentences (41%), and 132 neu sentences (16%).

Figure 45: Sentence-level analysis: summary of tagged sentiment



However, when the sentences themselves were tagged for sentiment, the majority (**429, or 53%**) were labelled con as against **377** others (see Figure 45). This is not surprising, for the reasons outlined above. For example, those with concerns about the proposals may write more sentences explaining their position than those who are less concerned or enthusiastic. This applies also to those who described themselves neutral overall, and even those who were happy overall may have had concerns to express.

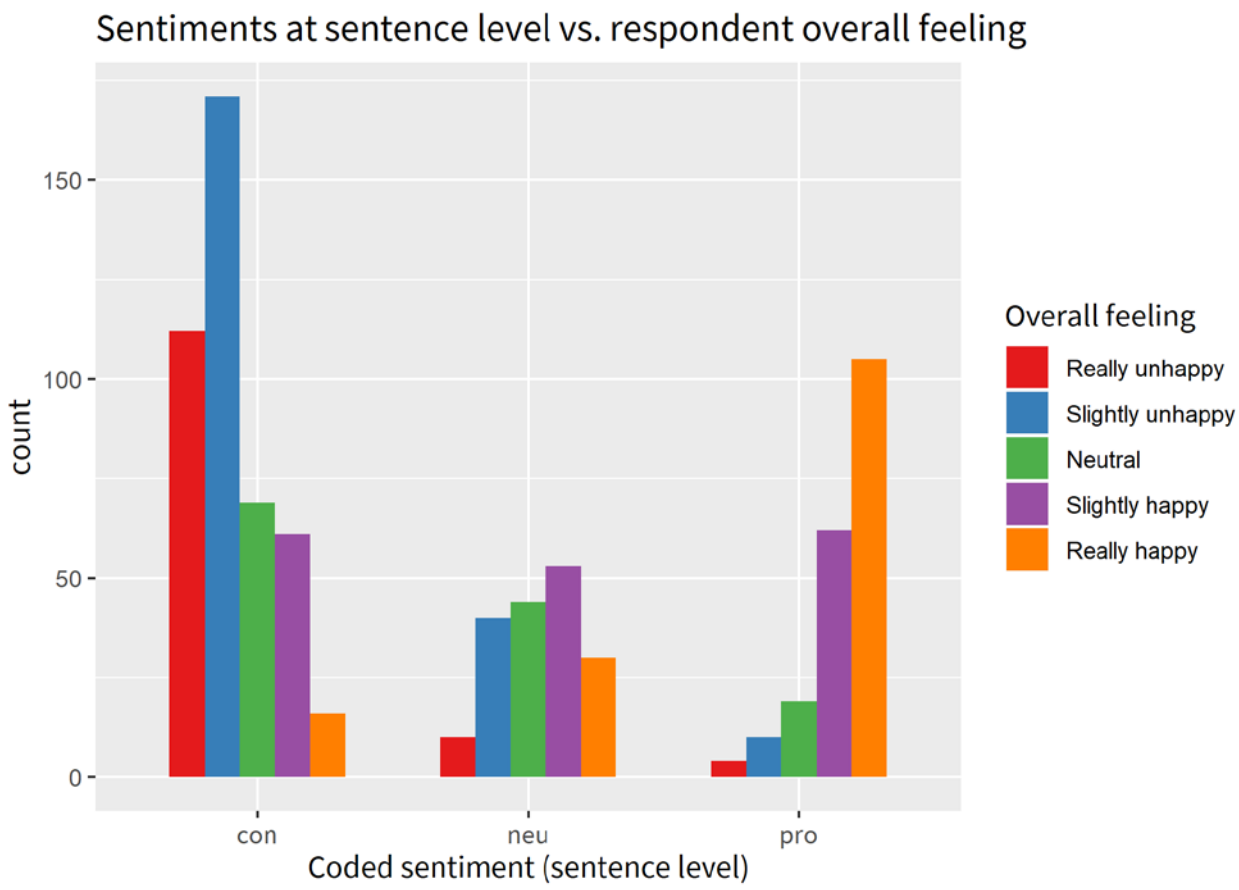
- 41% of sentences were written by people who were *slightly* or *really happy* overall, yet only 25% of sentences themselves were tagged as pro in the coding process
- 43% of sentences were submitted by people who were *slightly* or *really unhappy* overall, yet 53% of sentences themselves were tagged as con
- 16% of sentences were written by people whose feelings were *neutral* overall; 22% of sentences were tagged as neu in the manual coding process

CORRELATION BETWEEN REPORTED SENTIMENT AND TAGGED SENTIMENT

The correlation between reported sentiment and tagged sentiment is examined in the chart below. Most of the sentences tagged pro came as expected from respondents who had reported themselves happy with the shift proposals, while those tagged neu show a spread across all reported sentiment categories. Sentences tagged con are again predominantly from

those who reported themselves as unhappy overall with the idea, but there are also around 150 sentences here from those who are neutral or happy overall.

Figure 46: This chart shows the proportions of opinion sentences, tagged according to three sentiment categories (con, neu, pro), against the overall feeling category of the respondent



We can conclude that there seems to be generally a good correlation between the feelings respondents reported themselves, and the tagging of their comments.

Those who felt *slightly unhappy* overall were very likely to submit sentences that were tagged con, and very unlikely to express opinions coded as pro. By contrast, those who described themselves as *slightly happy* overall wrote as many con sentences as pro.

- Respondents who were generally positive about the Channel Shift proposals were still relatively likely to submit opinions that expressed concern or caution about the proposals in some way;

- Whereas respondents who felt unhappy overall were relatively unlikely to include comments with a more positive angle

"Whilst it is a good way forward environmentally, it may discourage less confident people or people with no access to a pc, phone or internet taking part in screening programmes."

tags: sustainability, accessibility, uptake

- NHS colleague/manager, female, 45-54; overall feeling: "Slightly unhappy"

CODING RESULTS: TAG POPULARITY

Table 44: The 20 most used coding tags in the sentiment analysis

tag	number of sentences
exclusion	195
concern	157
age	112
accessibility	97
convenience	74
channel preference	69
sustainability	53
both	51
choice	49
information	47
cost	45
connectivity	41
language	36
paper	32
skills	30
findability	30
readability	26
women	22
demography	22
readiness	21

In terms of digital exclusion, then, the issues most likely to be raised by survey respondents were: age, accessibility, connectivity, language, skills, readability, women and demography.[101]

Accessibility can to some extent be regarded as a proxy for a concern for disabled people, though this is not necessarily what respondents had in mind. Accessibility issues can be related to ageing-related changes as well. In terms of the Equality Act protected characteristics, age, disability, language and gender are the characteristics most likely to be referred to in the survey. But other issues not directly related to protected characteristics are also prominent here: in particular those relating to connectivity (related to income/poverty) and educational attainment level (the readability tag relates to this).

Sustainability concerns and convenience also feature in the top 20 tags.

Table 45: Most used coding tags, by sentiment (con, neu, pro) subset

con		neu		pro	
tag	**usage**	**tag**	**usage**	**tag**	**usage**
exclusion	168	choice	35	sustainability	44
concern	128	both	35	cost	35
age	85	concern	26	accessibility	28
accessibility	47	exclusion	25	paper	28
channel preference	46	accessibility	22	convenience	25
convenience	41	age	19	channel preference	11
information	36	language	13	fine	11
connectivity	29	channel preference	12	language	11
skills	26	connectivity	10	currency	10
readability	19	convenience	8	waste	10

[101] See notes on coding tags above for explanation

The data here suggests that the main opinions broadly against the proposals referred to the risk of **exclusion** for particular groups, with **older people** and those lacking **skills** and **connectivity** (those digitally excluded) being the most predominantly mentioned. Few if any people suggested that the switch to digital information would be beneficial in addressing exclusion.

Accessibility and **findability** were also frequently mentioned, with many respondents being concerned that digital information would be hard to access, find or re-find. The **convenience** of a **paper** leaflet was also frequently mentioned, though many people mentioned digital formats as being more convenient and accessible than the current formats.

"Out patients often make notes on their leaflets for when they see a health professional as reminders."

tags: convenience, usefulness

- NHS colleague/manager, female, 45-54; overall feeling: "Really unhappy"

For those more in favour of the proposal, **sustainability** issues and **cost**-saving were most frequently referred to. Many people said that online information would be their preference and that is in some ways more convenient. The possibility of automatic translation via online **language** tools was also mentioned (many other respondents mentioned language factors as a concern).

For those with more neutral/balanced views in their written responses, the concept of **choice** and multiple options being available was a dominant theme. Many similar issues around **accessibility** and **connectivity** concerns were also raised.

"Online is the way to go - with option to print for certain patient groups"

tags: choice

- PHE colleague/manager, female, 45-54; overall feeling: "Slightly happy"

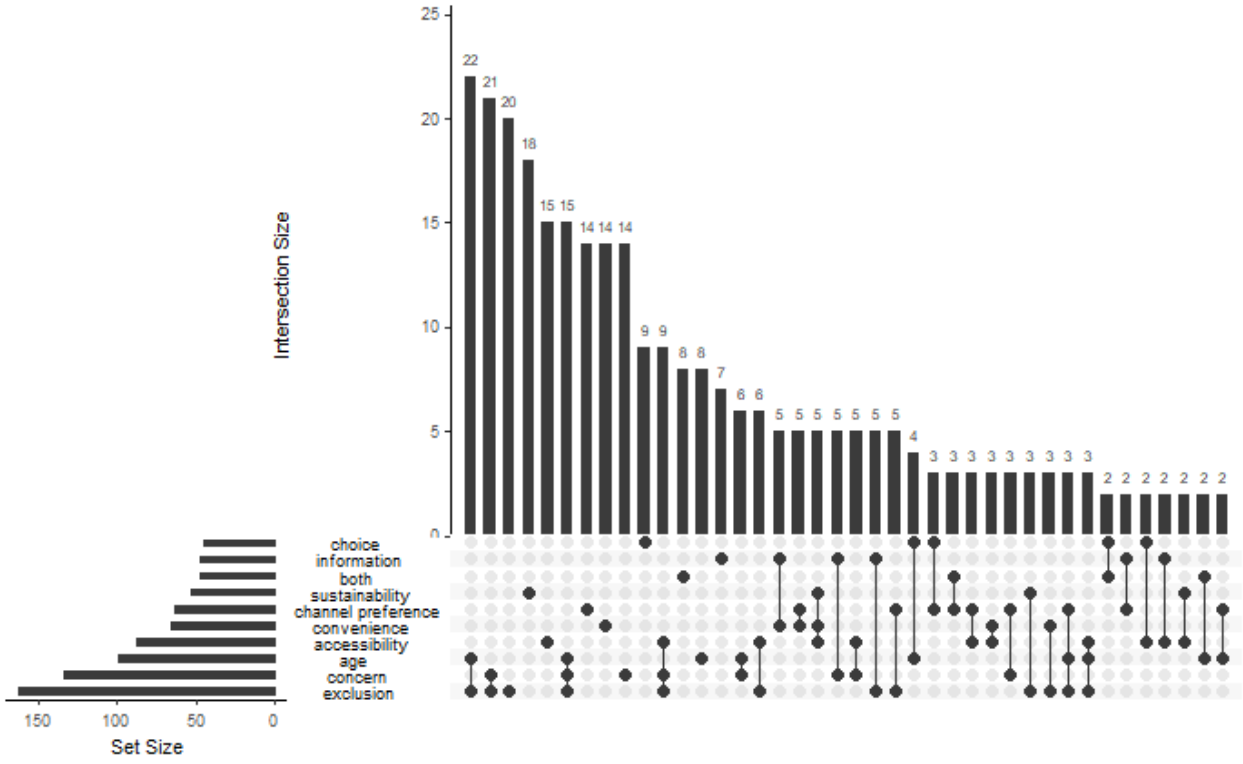
The next section looks at the associations between tags: which tags tend to be found together. This helps us to see how different themes in the dataset are connected.

3.10 SET ANALYSIS

These charts tell us which tags are associated with each other, i.e. assigned to the same sentence tokens. They are presented overall and then by subset according to the three sentiment tags (for clarity, only the most prevalent tags are included here).

SET ANALYSIS OF TAGS ACROSS FULL DATASET

Figure 47: Set analysis of full dataset (not all possible intersections are shown for reasons of space)



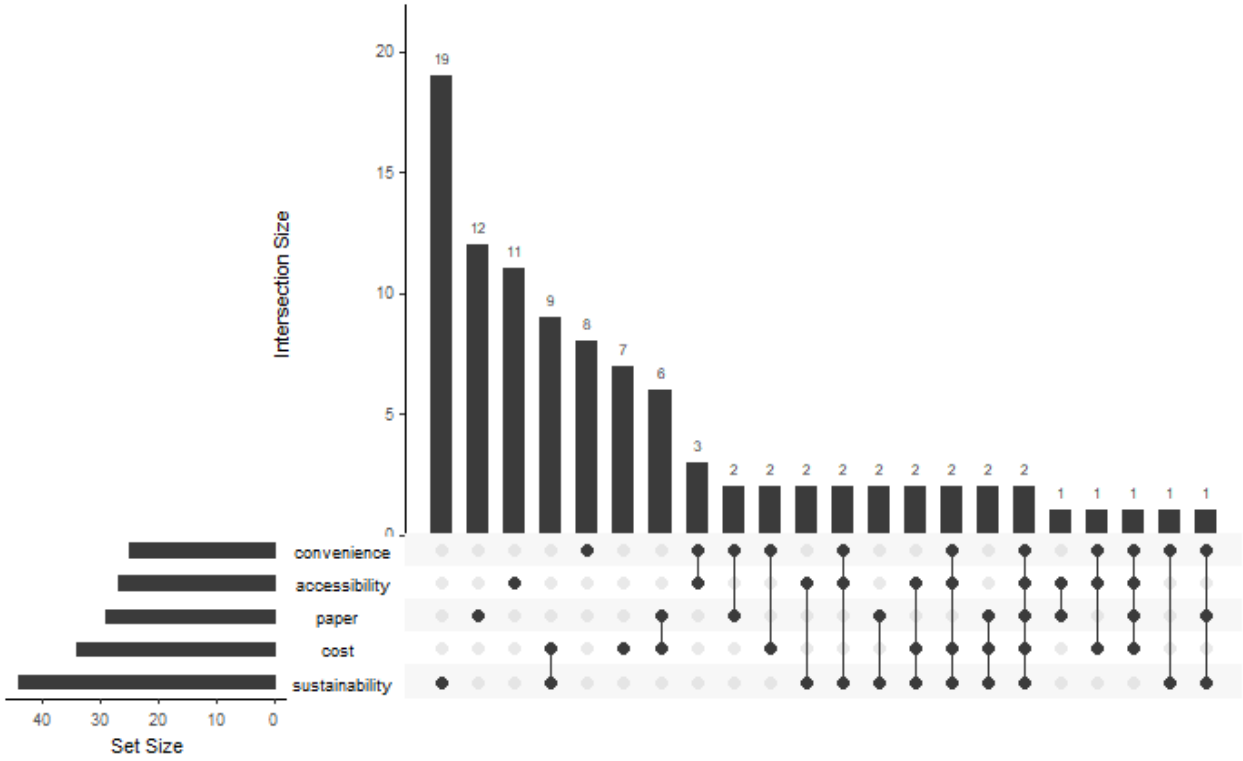
Explanation

The display of results for the set analysis may look confusing at first. For each of these ten most used tags (exclusion being the most used tag and choice being the tenth most used), the dots at the bottom show the various intersections (combinations) of tags that exist in the data, and how many times that particular intersection occurs. Lone dots not connected to a line show occasions where a tag is the sole tag assigned to a token.

The chart above shows that, for example, the tag exclusion is strongly associated with age (22+15+3+3 = 43 times) and concern (21+15+9 = 45). Sustainability is commonly used alone (n=18) but is also associated with accessibility and exclusion.

SET ANALYSIS OF TAGS WITHIN ‘PRO’ SUBSET

Figure 48: Set analysis of the top 5 tags within the 'pro' subset

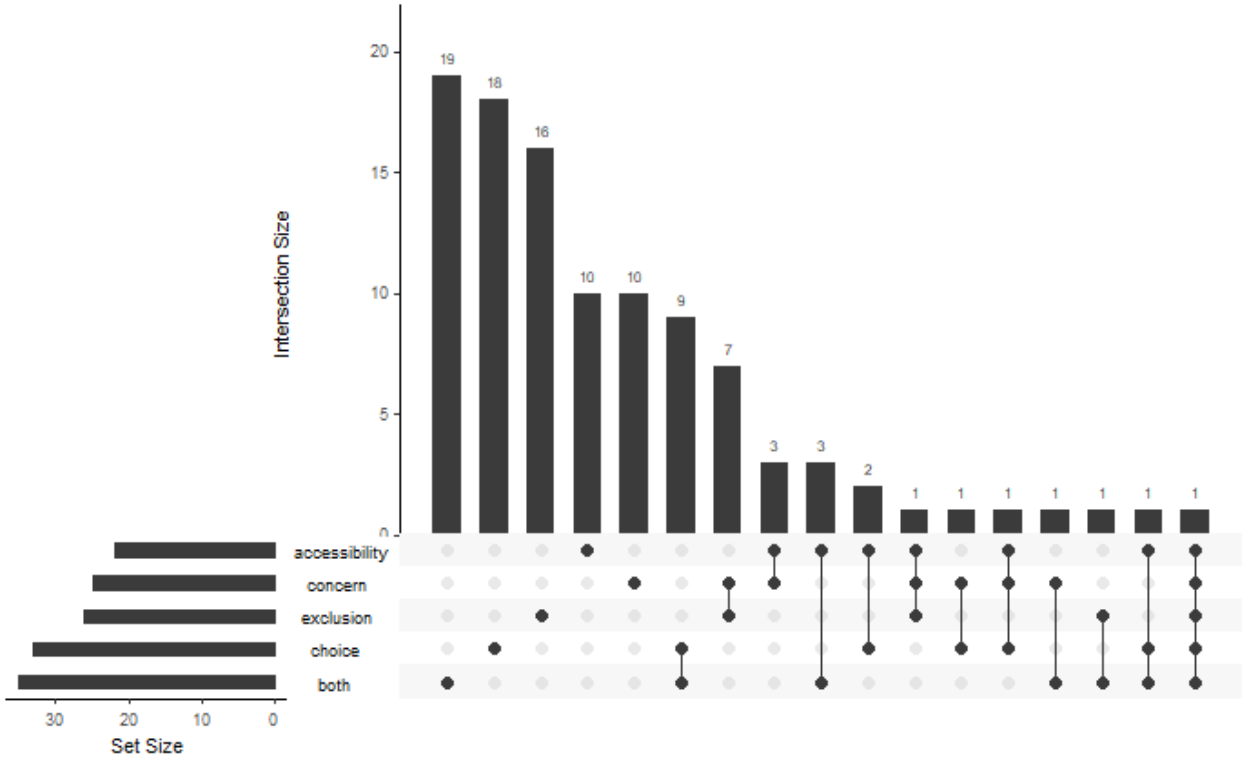


In this example, the tag sustainability, the most common tag within the pro subset (assigned to 44 of 200 sentences), occurs as the sole tag (of these five) for 19 sentences within this subset. It occurs with the second-most common tag, cost, 17 times in total. Paper and cost were relatively likely to be mentioned together (11 times); similarly, convenience and accessibility were also likely to be mentioned together (11 times).

This chart shows that the predominant themes cited by people commenting in favour of the shift to digital were sustainability and cost, with accessibility and convenience benefits also being noted often.

SET ANALYSIS OF TAGS WITHIN ‘NEU’ SUBSET

Figure 49: Set analysis of the top 5 tags within the 'neu' subset



The comments in this subset largely relate to the idea of choice or multiplicity of format for service users, as well as concerns about exclusion. Accessibility as an issue is related to the promotion of choice as well as to exclusion. There are relatively few associated tags in this subset: the 5 most common intersections are the tags on their own.

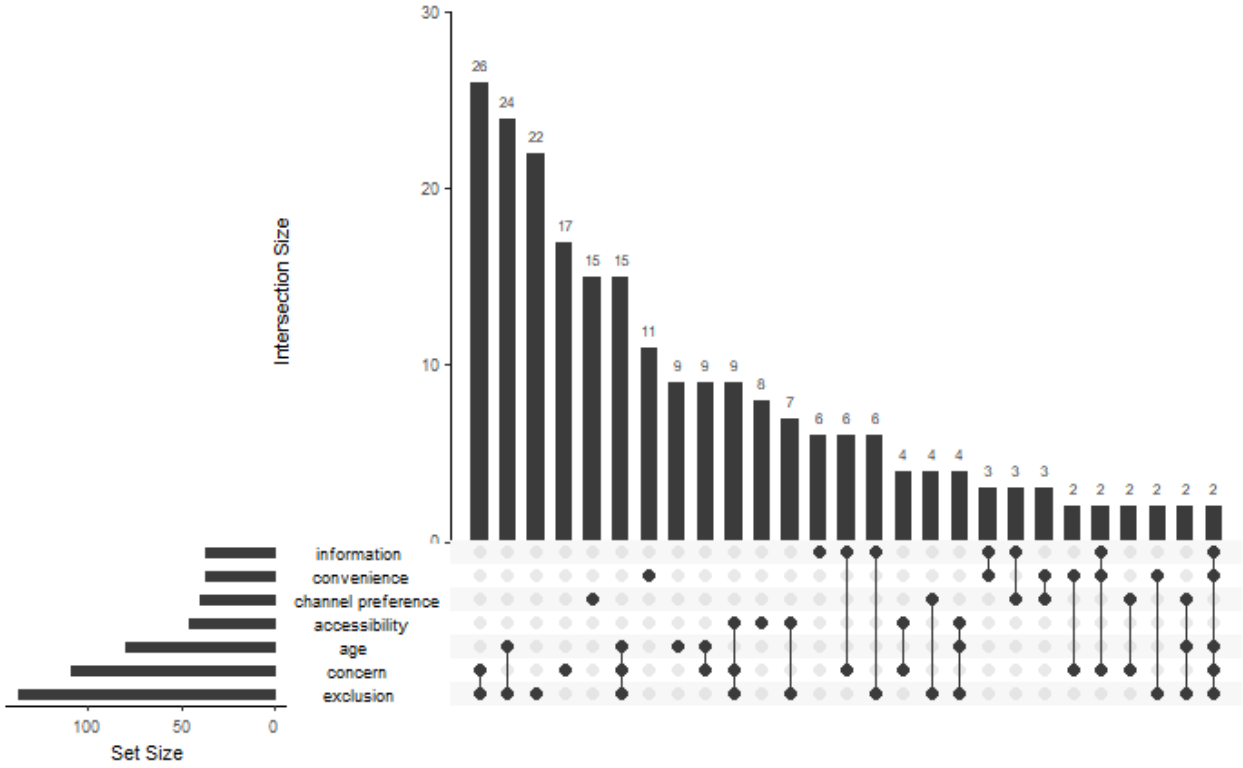
“The negative points are it makes it difficult to highlight information to patients and service users or write explanatory notes on them”

tags: information, annotation

- PHE colleague/manager, female, 35-44; overall feeling: “Slightly unhappy”

SET ANALYSIS OF TAGS WITHIN ‘CON’ SUBSET

Figure 50: Set analysis of the top 7 tags within the 'con' subset



Exclusion is the most-commonly used tag on sentences tagged con, and it is strongly associated with the other top tags in this subset. Of 128 sentences tagged concern, 62 (nearly half) are also tagged exclusion (71 of 153 sentences if you include those from the neu subset as well).

This chart shows the themes that were most prominent in the subset that was largely concerned or critical of the proposals: as already noted, age and exclusion are predominant but concerns around information getting to people and concerns over losing the convenience of paper leaflets were also regularly cited.

MOST POPULAR TAGS BY DEMOGRAPHIC SUBSET, AND SENTENCE SAMPLES

In this section, we examine the different subsets of the respondent sample, when divided by professional/public, age (65+), disability, and gender/sexuality.

HEALTH PROFESSIONALS VS GENERAL PUBLIC

The tags used most for responses by **members of the public** are shown in Table 45 below.

Table 46: The 10 tags used most for responses by members of the public

tag	no. of sentences	% of all sentences
concern	31	13.6
exclusion	28	12.3
accessibility	14	6.1
age	14	6.1
convenience	12	5.3
channel preference	11	4.8
findability	11	4.8
fine	9	3.9
choice	8	3.5
readability	7	3.1

This reflects the themes that were most commonly mentioned by members of the public. For example, accessibility was used to tag 14 response sentences, which is 6.1% of all the sentences contributed by members of the public.

The tags used most for responses by **health professionals** are shown in Table 46 below.

Table 47: The 10 tags used most for responses by health professionals

tag	no. of sentences	% of sentences
exclusion	167	13.2
concern	125	9.9
age	97	7.7
accessibility	80	6.3
convenience	61	4.8
channel preference	55	4.3
sustainability	46	3.6
both	45	3.6
information	43	3.4
connectivity	41	3.2

Comparing these, there is little difference. The top six tags are the same - though in a slightly different order – indicating that **the most prominent issues for members of the public are not different overall to those for health professionals**. There are some differences lower down the table though, with members of the public being more likely to comment about the findability and readability of information, but health professionals being more likely to mention sustainability and the quality of the information.

OLDER PEOPLE

This group is a subset of the whole respondent sample – i.e. these may also be member of any other subset: they maybe health professionals or members of the general public, for example. As mentioned above, the sample of respondents who reported being aged 65+ is not large: only 14 people. The tags used most for responses by **respondents aged 65+** are shown in Table 47 below.

Table 48: The tags used most for responses by respondents aged 65+

tag	no. of sentences	% of sentences
exclusion	4	11.4
cost	4	11.4
accessibility	4	11.4
concern	3	8.6
sustainability	3	8.6
channel preference	2	5.7
fine	2	5.7
skills	1	2.9
choice	1	2.9
convenience	1	2.9

DISABLED PEOPLE

59 respondents said that they are disabled. The tags used most for responses by **disabled respondents** are shown in Table 48.

"It is exclusionary and does not consider disabled people"

tags: exclusion

- Member of the public, female, 25-34, **with a mental health condition and physical impairment**; overall feeling: "Really unhappy"

Table 49: The tags used most for responses by disabled respondents

tag	no. of sentences	% of sentences
exclusion	33	15.9
age	24	11.5
concern	18	8.7
accessibility	15	7.2
cost	8	3.8
convenience	8	3.8
sustainability	8	3.8
channel preference	7	3.4
language	7	3.4
readiness	7	3.4

LGBTQ+ PEOPLE

18 respondents are in these categories. The tags used most for responses by **LGBTQ+ respondents** were:

Table 50: The tags used most for responses by LGBTQ+ respondents

tag	no. of sentences	% of sentences
exclusion	9	16.4
concern	6	10.9
convenience	4	7.3
age	4	7.3
accessibility	3	5.5
disability	2	3.6
sustainability	2	3.6
language	2	3.6
readiness	2	3.6
inequality	2	3.6

ILLUSTRATIVE SELECTION OF COMMENTS

We manually picked a selection of 50 comments from the corpus of responses, with the intention of showing a range of examples of the comments that were submitted. The selection mirrors the proportions of the whole dataset in terms of the balance of "overall feeling" of the respondents. Some of the quotes have been inserted in places into the survey analysis text above; the remainder are presented below.

"A discussion about the side effects is more beneficial to patients."

- Health screening practitioner, female, age 25-34, **with a mental health condition**; overall feeling: "Neutral"

"both options should be available, on line there should be more languages available that what is currently in either written or on line" tagged: choice

- NHS colleague/manager, female, 45-54; overall feeling: "Neutral"

"I think there should be an option for those who may have any kind of special needs to be given a printed leaflet." tagged: choice, accessibility

- PHE colleague/manager, female, 25-34; overall feeling: "Neutral"

"Need to make sure there is still face to face discussion opportunity" both, supplementing

- NHS colleague/manager, female, 55-64; overall feeling: "Slightly happy"

"There are some groups who may still benefit from printed information e.g. older age groups, those who don't have internet access" exclusion, age, connectivity

- PHE colleague/manager, female, 45-54; overall feeling: "Slightly happy"

"I am all for trying to save paper and resources but I believe both options should continue as not everyone can manage online, being able to print online information should continue." paper, both

- NHS colleague/manager, female, 35-44; overall feeling: "Slightly unhappy"

"Completely appreciate the need to reduce spending & keep up with the times, but reducing inequalities is a significant part of PHEs work." cost, concern

- PHE colleague/manager, female, 35-44; overall feeling: "Slightly unhappy"

"I'm happier to read paper information than online and sometimes I think it is easier to highlight areas to ask questions this way" readability, information

- NHS colleague/manager, female, 55-64; overall feeling: "Neutral"

"Printed leaflets are often clearer and more inviting to read." readability, clarity

- PHE colleague/manager, female, 25-34; overall feeling: “Neutral”

“Helpful to have physical or at least reliable unchanging record of what has been sent and when that enables easy follow-up.” reliability, tangibility

- PHE colleague/manager, male, 35-44; overall feeling: “Neutral”

“In my opinion, there still needs to be an option to speak to someone face to face or on the phone as that is the preferred communication modality for many.” choice, channel preference

- Member of the public, female, 25-34; overall feeling: “Really happy”

“There are certain groups that will be affected e.g. those from areas of deprivation or higher diversity and allowances to continue with paper needs to be made there” demography, exclusion

- NHS colleague/manager, female, 25-34; overall feeling: “Really happy”

“Incredibly concerned about inequalities and leaving people behind.” concern, exclusion, discrimination

- Health screening practitioner, female, age 25-34; overall feeling: “Really unhappy”

“Also likely that individual organisations will print themselves, meaning poor quality printed leaflets will be given out.” quality, printing

- Health screening practitioner, male, age 35-44; overall feeling: “Really unhappy”

“Whilst I'm online a huge amount I still like to come away from appointments with literature I can share with my partner, refer back to easily” channel preference

- Member of the public, female, 25-34; overall feeling: “Really unhappy”

“PHE has no idea how to implement this step and it's up to screening coordinators to find a way, without additional resources for maternity.” resources

- NHS colleague/manager, female, 25-34; overall feeling: “Really unhappy”

“This is something for the future.” readiness

- NHS colleague/manager, female, 35-44; overall feeling: “Really unhappy”

“I think that it is possible that patients will not go online to look at information and will therefore attend appointments without the correct information.” concern, information

- Health screening practitioner, female, age 35-44; overall feeling: “Slightly happy”

“Main concern is about exclusion for those women with minimal access to technology” concern, exclusion, women

- Health screening practitioner, female, age 45-54; overall feeling: “Slightly happy”

“I'm also concerned that messages may not reach people who don't speak English”

concern, language

- NHS colleague/manager, female, 45-54; overall feeling: "Slightly happy"

"If the process was fully online, I would be concerned about not having a physical reminder in the form of a letter." concern

- PHE colleague/manager, female, 45-54; overall feeling: "Slightly happy"

"We deliver care to many women who do not have access to internet, have special needs, do not speak English etc" concern, exclusion, language, disability

- Health screening practitioner, female, age 35-44; overall feeling: "Slightly unhappy"

"The other issue we have as health promotion teams is that we do not have access to printers or budgets to print off leaflets so having access to hard copies for health promotion purposes would be good. Thank you" cost, printing, promotion

- Health screening practitioner, female, age 45-54, **Asian, Muslim**; overall feeling: "Slightly unhappy"

"We run the risk of a decrease in uptake of screening if we switch to online information."

Uptake

- Health screening practitioner, female, age 45-54; overall feeling: "Slightly unhappy"

"It is easier to discuss things with clients if you have a paper copy in your hand and to give them to take away to reread later maybe with extra links"

information

- Health screening practitioner, female, age 55-64; overall feeling: "Slightly unhappy"

"It takes longer accessing the information online than just reading through a leaflet that is at your fingertips." Efficiency, readability

- NHS colleague/manager, female, 35-44; overall feeling: "Slightly unhappy"

"If people have to do to do this it may discourage them from taking part in screening programmes?"

Uptake

- NHS colleague/manager, female, 45-54; overall feeling: "Slightly unhappy"

"Disadvantages the elderly, can't take the leaflet with you to places and not everyone has an ability to access. " Accessibility, convenience, age, inequality

- PHE colleague/manager, female, 45-54; overall feeling: "Slightly unhappy"

"Also disadvantaged groups which we are trying to target may not have easy online access"

concern, exclusion, connectivity

- PHE colleague/manager, male, 45-54; overall feeling: "Slightly unhappy"

"I feel the young people are more likely to access online and that they are overloaded with leaflets."

Age, convenience, findability

- Health screening practitioner, female, age 45-54, **longstanding illness**; overall feeling: "Neutral"

"Excellent idea it will be much more environmentally friendly, Online information, if designed correctly is more readable and easy to understand, more information can be available via additional links so people can read as much or as little as needed"

accessibility, sustainability, information

- Health screening practitioner, female, age 45-54; overall feeling: "Really happy"

"Patients can ask questions at screening if they want f 2 f." Supplementing

- Health screening practitioner, female, age 55-64; overall feeling: "Really happy"

"It's environmentally friendly and may save money" sustainability, cost

- Health screening practitioner, female, age **65-74**; overall feeling: "Really happy"

"I think leaflets get lost or left unread too easily." Convenience, reach

- NHS colleague/manager, female, 35-44, **bi/polysexual**; overall feeling: "Really happy"

"Absolutely agree that digital is more cost effective and easier to access." cost, convenience

- NHS colleague/manager, female, 35-44; overall feeling: "Really happy"

"It will make it easier to update information and easier to link to FAQs and things to think about before and short films to help allay any fears or concerns." Information, currency, video

- PHE colleague/manager, female, 45-54, **with a physical impairment**; overall feeling: "Really happy"

"I think it is a good idea although printed information should be available."

both

- Health screening practitioner, female, age 45-54; overall feeling: "Slightly happy"

"Less waste and ensures receipt" reliability, waste

- Member of the public, female, age 45-54; overall feeling: "Slightly happy"

"Will help to save money and the environment by reducing paper waste"

Cost, paper, waste

- NHS colleague/manager, female, 55-64; overall feeling: "Slightly happy"

Appendix 7 - Table of Figures

Appendix 8 - Bibliography

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