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

Summary 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)

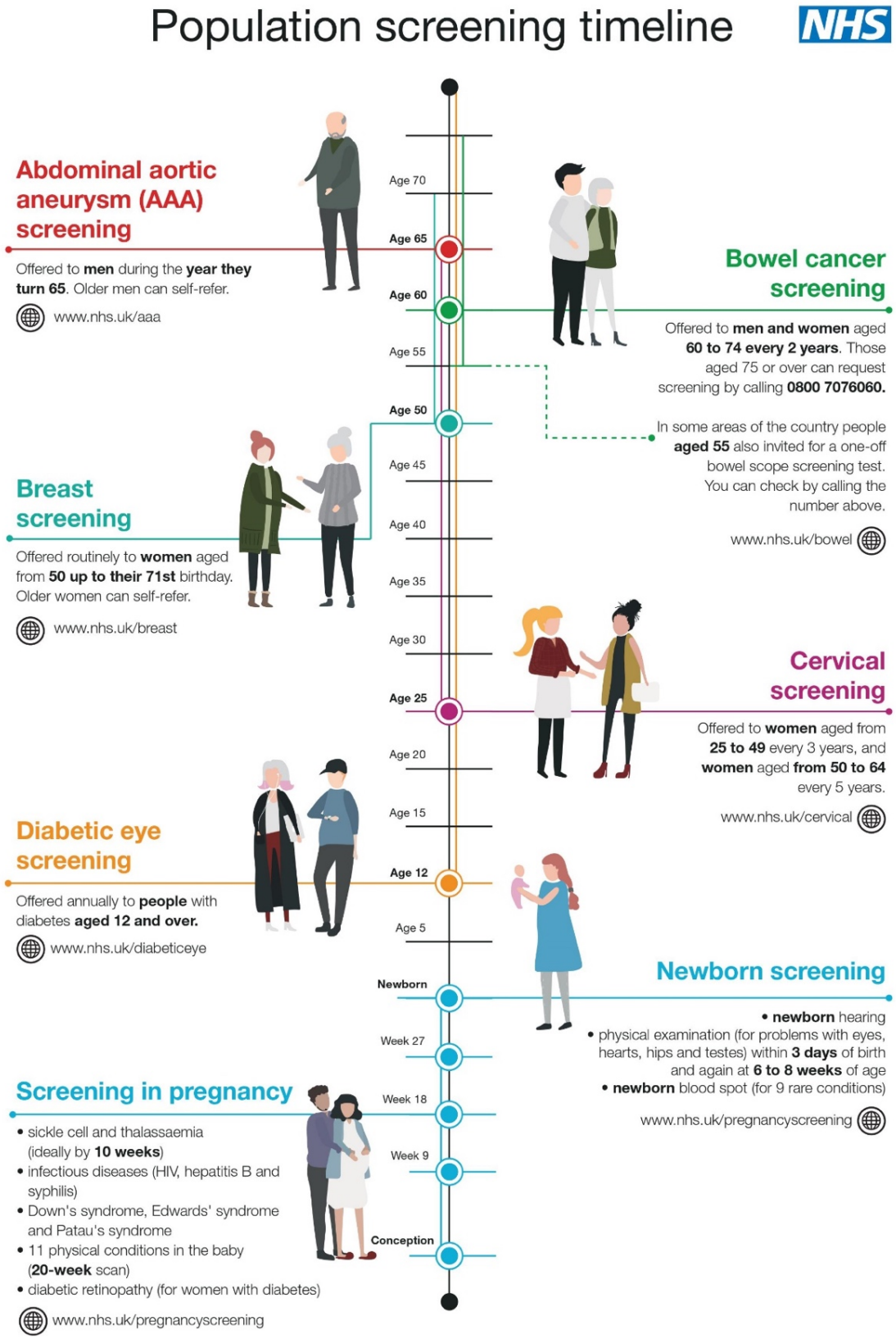
Cervical screening programme (CSP)

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.

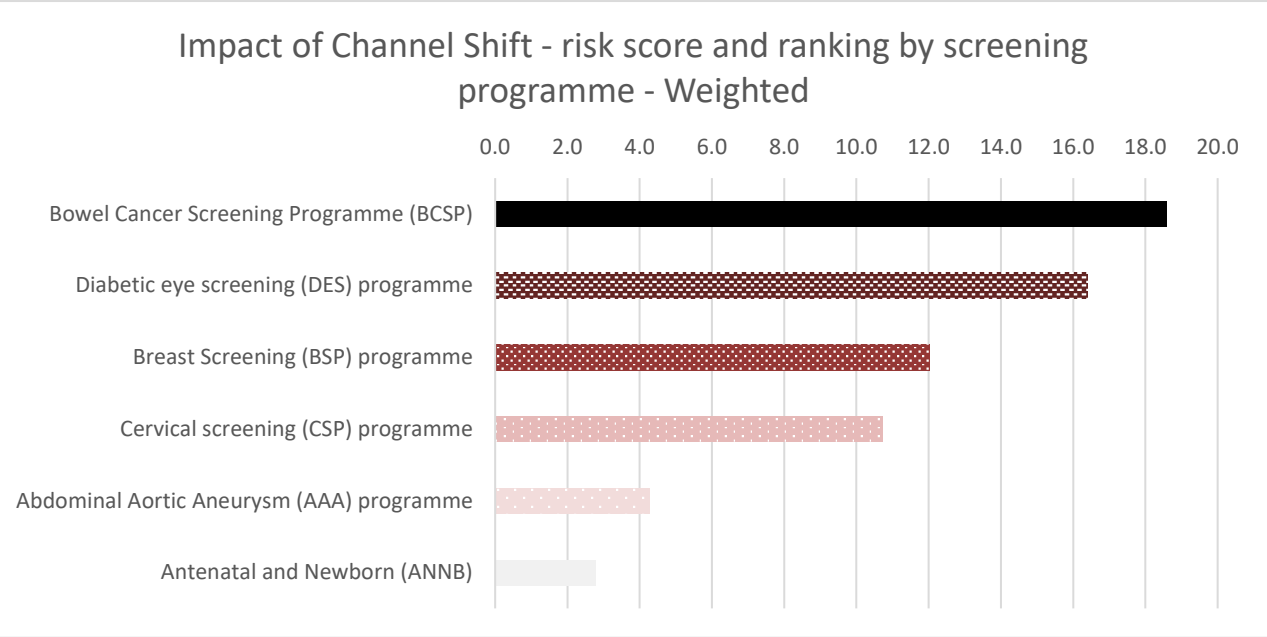
[11] All screening invitations are prevalent until an individual first accepts and attends for screening. Once that individual has accepted and attended screening, all subsequent invitations to them are incident invitations.

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.

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[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.

[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

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.

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.