

Digital exclusion in population screening programmes

Appendix 4

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

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 households⁸⁹ 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 \(pdf\)](https://www.ofcom.org.uk/data/assets/pdf_file/0018/105507/internet-use-attitudes-bulletin-2017.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.

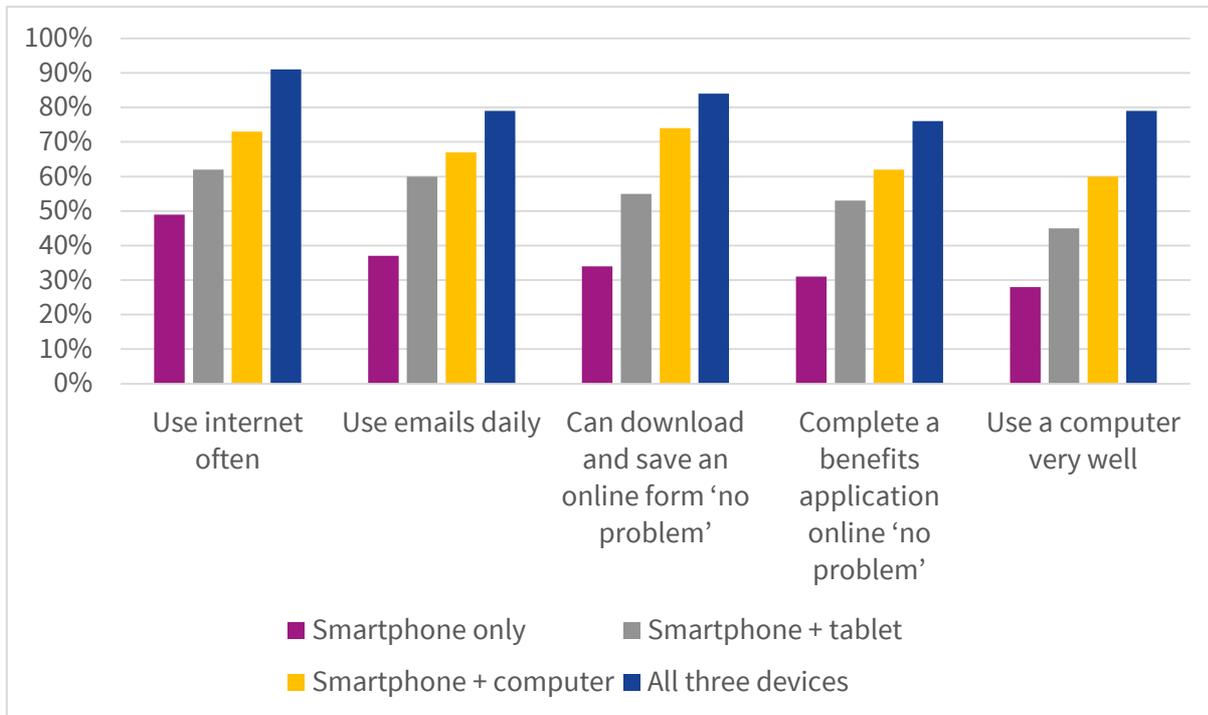
While smartphone-only or smartphone-by-circumstance users may struggle to access information about screening programmes, ownership of smartphones does nonetheless provide a channel for communication. Indeed, Ofcom (2019b) also reports that “**Nearly every adult in the UK uses a mobile phone** (96%). 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.

	<p>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.</p>
<p>Netherlands</p>	<p>Leaflet redesigned in 2018 and is now more comprehensive (length increased from 4 to 8 pages).</p> <p>Leaflet refers patients to website for more details, including e.g. short videos</p>
<p>Catalonia</p>	<p>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.</p> <p>Leaflet includes reference to web page for additional information.</p> <p>New flyer that includes information on risks (over-diagnosis, false positives and false negatives) also being sent to all women.</p>
<p>Dalarna county, Sweden</p>	<p>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.</p> <p>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.</p>

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 nulliparous⁹⁴ 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.

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