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Design and Implementation of Novel Behavioural Science-Informed Interventions to Facilitate Screening Uptake

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Declaration

I hereby declare that the contents of this thesis are the products of my own work, and where this has been accomplished through collaboration with others, this has been described. Work including reproduced figures cited from other sources has been fully referenced, and permissions sought from the original author(s) in accordance with standard academic practice.

Amish Acharya

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Thesis Abstract

Breast screening saves 1300 lives annually, however, uptake in London remains below target. There are also disparities in attendance amongst several subgroups e.g. ethnic minorities, who could be considered underserved. Behavioural science is a field that can help understand the challenges to attendance and provide a means of developing behavioural change interventions.

This thesis aims to establish whether a behavioural science-informed intervention, designed with underserved communities, could significantly increase breast screening uptake.

The intervention, a novel animation delivered through a screening reminder SMS, encompassed several behavioural change techniques to address the determinants of non-attendance. The contents of both the SMS and animation were informed by an evidence-generating process. This included (1) a systematic review in which comparisons of the behavioural content of existing breast screening interventions was evaluated. (2) a modified Delphi process with screening experts to elicit the key aspects that need consideration when designing screening message interventions. (3) interviews and focus groups with representatives from underserved communities, to understand the specific barriers and facilitators they face.

Through a mapping and triangulation process, outputs from the evidence-generation were refined, and used to inform four co-design workshops. Participants representing underserved populations, community groups, and screening commissioners helped ideate, shape, and iterate the final intervention video and message.

The animation, sent via a behavioural science-informed SMS, was trialled against the current usual care message and video, and the existing video sent via the new behavioural SMS. Despite positive feedback, no significant difference in screening attendance was noted between the trial arms.

This research highlights the importance of an inclusive approach to intervention design and the need to use a multimodal approach to distribute screening information to achieve greater reach. However, more widespread infrastructural changes to the programme may be needed if the concerning decline in uptake is to be reversed.

Thesis Outputs

Publications

A. Acharya, V. Sounderajah, H. Ashrafian, A. Darzi, G. Judah. A systematic review of interventions to improve breast cancer screening health behaviours. *Preventative Medicine.* 2021;153:106828

C. Chan, V. Sounderajah, E. Daniels, A. Acharya, J. Clarke, S. Yalamanchili, P. Normahani, S. Markar, H. Ashrafian, A. Darzi. The Reliability and Quality of YouTube Videos as a Source of Public Health Information Regarding COVID-19 Vaccination: Cross-sectional Study. *JMIR Public Health Surveill.* 2021; 7(7):e29942

A. Acharya, H. Ashrafian, D. Cunningham, J. Ruwende, A. Darzi, G. Judah. Evaluating the impact of a novel behavioural science informed animation upon breast cancer screening uptake: protocol for a randomised controlled trial. *BMC Public Health.* 2022; 22(1):1388

A. Acharya, G. Judah, H. Ashrafian, V. Sounderajah, N. Johnstone-Waddell, A. Stevenson, A. Darzi. Investigating the Implementation of SMS and Mobile Messaging in Population Screening (the SIPS Study): A Delphi Study. *EBioMedicine.* 2023; 93;104685

Presentations

A. Acharya, V. Sounderajah, H. Ashrafian, A. Darzi, G. Judah. *Interventions to Improve Breast Cancer Screening Health Behaviours.* 2022. Australasian Society for Behavioural Health and Medicine Annual Scientific Conference. Perth, Australia.

A. Acharya , H. Ashrafian, A. Darzi, G. Judah. *Developing an animation using the Behaviour Change Wheel to facilitate breast screening amongst under-represented groups*. 2022. 36th Annual Conference of the European Health Psychology Society. Bratislava, Slovakia.

A. Acharya, G. Judah, H. Ashrafian, V. Sounderajah, N. Johnstone-Waddell, M. Harris, A. Stevenson, A. Darzi. *Investigating the implementation of mobile messaging in population screening programmes.* 2022. Public Health Science Conference. Glasgow, UK.

A. Acharya, A. Darzi. G. Judah. *RCT of an SMS and animated video intervention to increase breast cancer screening uptake.* 2023. 37th Annual Conference of the European Health Psychology Society. Bremen, Germany.

Public Health Contributions

Office for Health Improvement & Disparities. *Screening text message principles.* 2022. Online. Available from: https://www.gov.uk/government/publications/nhs-population-screening-effective-text-message-use/screening-text-message-principles

NHS England. *London Breast Screening Community of Practice*. 2023

List of Abbreviations

AI	Artificial Intelligence
BCT	Behavioural Change Technique
BCTT	Behavioural Change Technique Taxonomy
BCW	Behaviour Change Wheel
BSP	Breast Screening Programme
BSU	Breast Screening Unit
COM-B	Capability, Opportunity, Motivation- Behaviour Model
CONSORT	Consolidated Standards of Reporting Trials
COVID-19	Coronavirus Disease 2019
EU	European Union
GP	General Practitioner
HBM	Health Belief Model
HCP	Healthcare Professional
IMD	Index of Multiple Deprivation
I-SAM	Integrated Screening Action Model
ITT	Intention To Treat
ML	Machine Learning
MMAT	Mixed Methods Assessment Tool
MMS	Multimedia Messaging Service
NCSC	National Cyber Security Centre
NSC	National Screening Committee
NHS	National Health Service
PP	Per Protocol
PPIE	Public and Patient Involvement and Engagement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCS	Rich Communication Service
RCT	Randomised Control Trial
RoB 2	Risk of Bias tool 2
ROBINS-I	Risk-Of-Bias In Non-randomised Studies of Interventions
SMS	Short Message Service
TaTT	Theories and Techniques Tool
TDF	Theoretical Domains Framework
TPB	Theory of Planned Behaviour
TTM	TransTheoretical Model
UK	United Kingdom
USA	United States of America

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1. Introduction

1.1 Preamble

'Prevention is better than cure,' a phrase attributed to Desiderius Erasmus in the 16th Century[1], is a central tenet of modern healthcare. Paralleling this paradigm, screening aims to identify pathological change prior to the presentation or manifestation of symptoms. Through early detection, screening programmes facilitate early intervention, with the aim of subjecting patients to less invasive treatment regimens, and better health outcomes[2]. In 1968 Wilson and Jungner outlined the most commonly cited criteria to which screening programmes should adhere, these included the need for an acceptable screening test and knowledge of the natural course of the disease. Whilst there have been numerous expansions and refinements of these 10 principles, they remain at the core of screening programmes. As of 2022, the United Kingdom's (UK) National Screening Committee (NSC) considers 20 criteria for population-level programmes[3]. Notably, these recommendations include the requirement for the "complete screening programme" to be clinically, socially, and ethically acceptable. There are currently 11 active population-level programmes in the UK meeting these criteria[4]. They test for conditions ranging from diabetic eye disease to cancers, and infectious diseases in pregnancy. The NSC evaluation of these programmes is dynamic, with acceptability changing according to the wider healthcare context. As a result, screening programmes face challenges to meet changing expectations of patient care and service experience. Addressing the issues faced by screening services is crucial to maintaining current standards, and can also provide invaluable insights into how future population-level healthcare can effectively be conducted. This is particularly important given advances in the pre-emptive medicine, and the potential expansion of screening programmes[5,6].

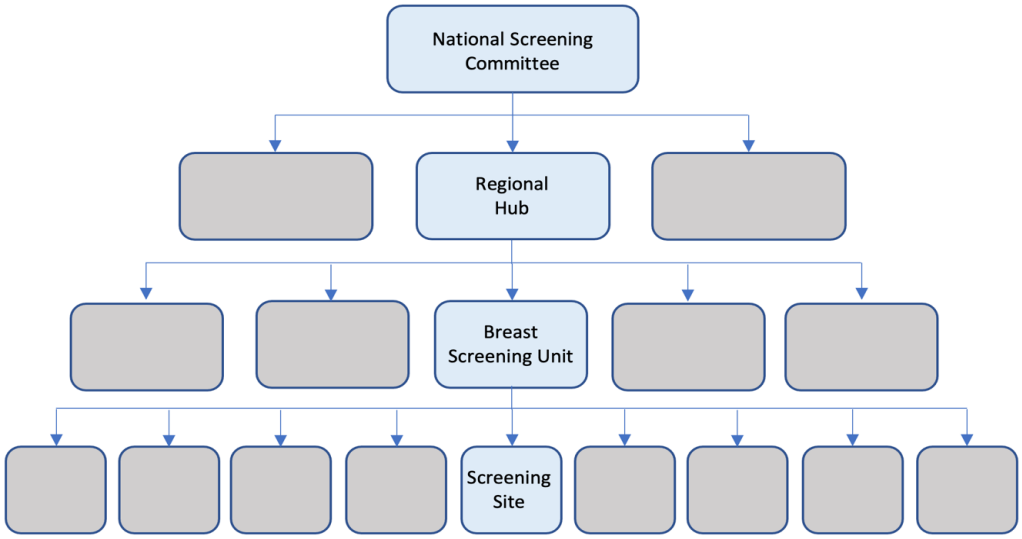
1.2 Overview of Breast Cancer Screening in England

The National Health Service (NHS) Breast Screening Programme (BSP) was established in 1988[7]. Initially it offered women aged 50 to 65, subsequently extended to those aged 70, a screening mammogram every 3 years[8]. The process involves asymptomatic women being invited to either a static or mobile screening site to have x-rays of their breasts to detect early cancer. The technique requires compression of each breast between plates and taking craniocaudal (top-down) and mediolateral oblique (angled) images. Compression is needed in order to reduce the overlay of dense fibro-glandular breast tissue, and minimise motion artifact, which facilitates the radiologist's examination of the films[9]. Following image capture, the films are reviewed by two independent readers before a result is released to the patient, which can be up to 2 weeks following the appointment[10]. Approximately 4.3% of women will be recalled for further testing, either due to technical issues or diagnostic suspicion. However, 8.6 out of every 1000 women who are screened will have cancer identified (0.86% detection rate)[11]. It is estimated that breast screening saving an estimated 1300 lives annually through earlier detection in the UK[12].

Similar to the other available population screening programmes in the UK, the NHSBSP is commissioned as part of NHS England's public health agenda. Unlike other healthcare services including the symptomatic breast cancer pathway, it is not administered directly through primary or secondary care networks. Instead, the UK is divided into screening regions, in which local services are delivered at individual units. These regional programmes can also incorporate a central administrative hub (**Figure 1-1**). For example, there are 9 screening sites (3 static and 6 mobile) within the North London Breast Screening Service, which is one of 6 services (or Breast Screening Units, BSUs) administered by the London regional hub[13]. Whilst ultimate oversight, key performance indicators and standards are set nationally, these services are agile

and versatile to the needs of loco-regional populations[14]. Addressing these needs may involve changing the provision of available screening units, altering invitation processes, and introducing adjunctive measures such as sending appointment reminders, to improve attendance. As discussed below, however, this de-centralised screening paradigm can contribute to geographical disparities in screening provision, and organisational inefficiencies, without necessarily leading to improvements for service users.

Figure 1- 1 Hierarchical structure of the NHS Breast Cancer Screening Programme.



1.3 Current Challenges

As one of the earliest population-level public screening programmes in the world, breast screening services in the UK have faced several concerns since their inception. These include isolated operational issues, such as the identification of 450,000 women who had been erroneously excluded from their final eligible screening invitation between 2009 and 2018[15]. There are also, however, longstanding questions, outlined in the Richards review, evaluating whether the ethos and conduct of breast cancer screening still adheres to the criteria placed upon national programmes[16]. These are particularly pertinent as the programme looks to extend its eligibility and is forced to tackle with growing non-attendance rates. Within the 2012

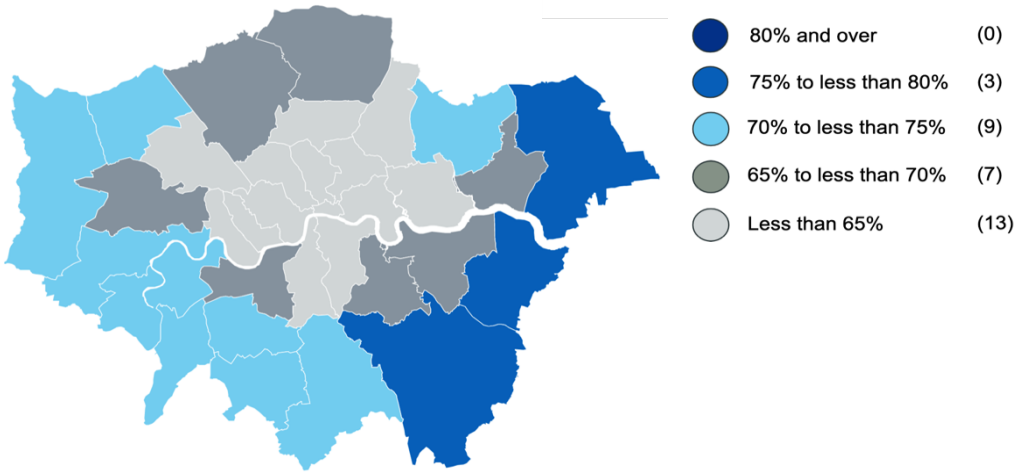
Independent review into breast screening, the benefits of screening including a 20% reduction in mortality, were balanced by issues regarding overdiagnosis. Moreover, the question was raised whether there was a need to screen as treatment continues to advance. Ultimately, the panel concluded that the benefits outweighed the risk, however this did lead to a substantial public debate on the need for breast screening[17]. There has therefore been a need for breast screening to demonstrate its utility, as well as adapt to the growing expectations and needs of the public.

1.3.1 Breast Screening attendance

Attendance at breast cancer screening has fallen. Screening programme can only be effective - in this case at reducing cancer-related deaths - if sufficient numbers of eligible people choose to attend[18]. Reducing attendance at screening could lead to fewer cases of breast cancer being detected in asymptomatic patients, and more at later stage, when treatment is more invasive. To understand the downturn in attendance, it is important to determine the two measures of attendance utilised by the breast cancer screening programme: coverage and uptake. Coverage represents the proportion of eligible women at a set point who have undergone a mammogram within that screening cycle (i.e. within the past 3 years). A high coverage rate provides an assurance that eligible women are being given the opportunity to screen. The *acceptable* threshold for coverage is 70%, whilst the *achievable* target level is set at 80%. Uptake, on the other hand, is the proportion of eligible women who have been screened within 6 months of the first offered appointment. It represents the proportion of women who have accepted their current invitation, and therefore the maximum number of people who could have cancer detected at a given time. In effect it represents how effective screening *can* be at early detection. For routine screening, as opposed to screening of women at high-risk, the acceptable and achievable uptake levels are the same as the levels for coverage[19,20].

In the beginning of 2020, prior to the pandemic, the coverage in England was 74.2%[21]. Whilst this was above the acceptable level it represented a marginal 0.4% point decrease from the previous year, and a 2.7% point reduction from a decade prior. Whilst, coverage fell amongst all eligible age groups, it was most marked amongst those aged between 65-69, with a 0.5% point fall over the past year. These trends were echoed in reductions in uptake, which had fallen below the acceptable threshold to 69.1% nationally, and 4.1% points lower than in 2009-2010[21]. Moreover, there are also longstanding geographical disparities in screening attendance. In 2019/20, all screening regions reached the acceptable coverage threshold, except for London which reported rates of 67.3%, 0.1% points lower than in 2018/19. On the other hand, East Midlands reported the highest coverage rate at 77.1%. Even between different local authorities (LA) within London, there is significant variance in coverage rates. Of the 32 London-based LAs reporting data, only 37.5% reached the acceptable threshold[21,22] (**Figure 1-2**). Areas such as Camden reported rates of 54.1%, Havering had the highest coverage of 78.7%, which is still below the *achievable* target. Similar disparities are seen with uptake. When examining uptake by BSU, as opposed to local authority, in early 2020 (prior to the COVID-19 pandemic) uptake in Outer North East London screening services was 67.9%, whilst in Central and East London it was substantially lower at 51.4%[21].

Figure 1- 2 Map demonstrating breast cancer screening coverage in London local authorities in 2020



Adapted from NHS Digital NHS Breast Screening Programme Statistics (2022). Online. Accessed 13/11/22.

There are several possible reasons for these geographical pattens including the demographic composition and the spatial accessibility of differing screening units. The former is discussed in depth in 1.3.2 and relates not only to socio-demographics but also medical factors associated with non-attendance, such as the number of illnesses a person has or co-morbidity. Spatial accessibility represents the environmental factors that lead to differing screening services being less reachable by the populations that need to use them[23]. For example, as shown in one study based in North Derbyshire, the odds of attendance were 13% lower for a 10 km increase in distance from the screening service, when adjusting for deprivation. However, there was no difference in attendance based on distance if the screening site was based in a more rural than urban setting, or if it was a mobile compared to a static site[24]. These findings have been supported by spatial models demonstrating that increased car ownership is positively correlated with increased breast cancer screening attendance, but high public transport usage within a geography demonstrates an inverse association, and lower uptake across that area[25]. Public transport is often considered to be a more time-consuming means of transportation compared to using a private vehicle. It is therefore posited by Wang, that when screening units are further away, attendance is lower in areas where reliance upon public transportation is higher[25].

However, despite these findings, overcoming non-attendance remains a significant challenge to breast screening units. Several measures and interventions have been undertaken to counteract these issues, but non-attendance continues to persist across geographies. Understanding and addressing accessibility and sociodemographic disparities will help to reduce heterogeneity in attendance between screening regions and provide more equitable access to services.

1.3.2 Healthcare Inequalities

In addition, to geographical disparities in uptake, there are documented associations with non-attendance amongst subgroups of differing ages, level of deprivation, ethnicity and level of medical co-morbidity. The term *underserved group* refers to subgroups that have lower rates of attendance than one would expect from population estimates, have differences in the way they interact with healthcare services, and potentially poorer health[26]. Most importantly, the traditional means of healthcare delivery often does not meet the diverse needs of these groups, leading (avoidably) to poorer health and wellbeing, or healthcare inequalities. There is no set definition of who can be considered underserved, but the differences in outcomes arise from the wider determinants of health which can include living conditions and community networks[27,28]. The term is context specific and can refer to a whole population or a particular subgroup who have a disproportionate difficulty accessing a particular healthcare service. This reduced access may be caused by geographic, economic or cultural factors[29]. Within breast cancer screening, therefore, several groups could be considered underserved, and the nature of these groups may change between the differing points of the screening pathway, from invitation to actually accessing an appointment, to onward referral and cancer outcomes.

Age

As mentioned previously, age could constitute one factor associated with being underserved, given the previously missed invitation of women aged between 68 and 71. Moreover, invitations to screening mammograms are limited to people of set ages, and there are discrepancies in the uptake across the eligible range. Statistics from 2020/21, which includes the pandemic, show the highest uptake nationally was amongst 65- to 70-year-olds (63.8%), which was 5.4% higher than those aged between 50 to 52. However, uptake of invitations amongst those who had previously been invited and not attended was 22.6% points lower amongst those aged 65 to 70 compared to aged 50 to 52 year olds[30]. This corroborates the existing literature suggesting that previous screening behaviour impacts upon future decisions to attend, and previous non-attendees are less likely to take up future invitations[31]. This is particularly important as the screening programme is examining extending eligibility in the AgeX^2 trial to women aged 47-49 and 71-73. The pilot starting in 2009 and stopping recruitment in 2020[21]. This lower uptake of invitations amongst those who have not screened previously and are older, is concerning given risk of breast cancer increases with advancing age. Similar findings regarding uptake amongst older cohorts have been noted in other countries, such as the US. This may suggest common barriers such as a lack of knowledge regarding eligibility amongst this cohort. However, in the US, it may also be due to lower insurance availability, which is not applicable in the UK healthcare system[32].

Deprivation

Increased deprivation, which is often measured through composite measures such as the Index Multiple Deprivation (IMD)[33], as well as surrogate markers including household value, has also been shown to be associated with worse cancer outcomes[34]. According to registry data the 5-year breast cancer survival rate was 3.4% lower amongst middle and most deprived groups than least deprived groups in some parts of the UK such as the West Midlands[35,36]. Similarly,

attendance at breast cancer screening has also been shown to be lower amongst people from areas with higher rates of deprivation. It is estimated that 38.8% of the geographical variability in coverage can be explained by inter-regional differences in deprivation[22]. The absolute difference in attendance may be decreasing over time – Douglas et al. found that between 2007 and 2012 the difference in coverage between the most and least deprived regions fell by 4% (from 12.3% to 8.3%)[37]. This lower attendance in people from areas of high deprivation is also noted at a regional level. Studies have demonstrated the odds of attendance at the first invitation to be 5% lower amongst the most deprived compared to the and least deprived quintiles in London, after adjusting for ethnicity, age and screening area[38]. In addition, there is a significant gradient across deprivation groups, with a gradual decline in uptake with increasing deprivation. This negative association between area-level deprivation and attendance has also been reported in other European countries, such as France, where funded population-level programmes are available[39].

Ethnicity

Minority ethnic groups are often considered underserved with respect to several types of screening, including breast cancer[40]. Whilst the age-adjusted incidence of breast cancer is lower amongst certain ethnic minorities compared to White women, groups such as Black African women are almost twice as likely to present with advanced disease[41]. There is therefore a clear need to optimise attendance at screening for these groups. Despite this, attendance at breast screening is often lower in minority ethnic groups. In a UK study of 50- to 52-year-old women, Jack et al. estimated that the odds of White women attending their first breast screening invitation was more than twice that of Black African women. Moreover, attendance amongst White women was almost three times that of Bangladeshi women[42]. Similarly, other studies have shown that within London, an area of high ethnic diversity, the odds of White women

attending is estimated to be almost six times that of Black women, and three times that of their Asian counterparts, when adjusting for age and socio-economic deprivation[43].

The relationship between ethnicity and breast cancer screening is, however, complex. Firstly, despite improvements in the coding of ethnicity data in health records, the completeness and accuracy of data remains poor. One study reported that up to 35% of patients belonging to a minority ethnic group had this data miscoded in the Hospital Episode Statistics[44]. Secondly, within broader ethnicity cohorts there are more nuanced trends. For example, in an analysis of attendance in Coventry and Warwickshire, attendance by Hindu-Gujarati women increased over multiple screening rounds, whilst uptake amongst Muslim women remained low. Despite this, across the initial screening rounds examined, both groups demonstrated uptake rates that were significantly lower than non-South Asian populations[45]. It is therefore essential to understand the similarities and differences in barriers to screening amongst more refined cultural groups, as well as broader ethnic classifications.

Co-Morbidity

In conjunction with the socio-demographic factors discussed, there is growing understanding of the role of multi-morbidity and clinical utilisation, as potential predictors of screening engagement. This is particularly pertinent given that there are common risk factors for breast cancer and other conditions, including cardiovascular disease[46]. In a meta-analysis Diaz et al. demonstrated that the odds of receiving a screening mammogram for those with a co-morbidity was two thirds that of those with no medical conditions, although heterogeneity was very high (I^2=99.5%)[47]. When examining studies from the UK, a retrospective analysis in Scotland demonstrated that the odds of attending a breast cancer screening appointment were 25% higher in patients with a Charlson Index of 0, compared to those with a score greater than or

equal to 3[48]. The Charlson Comorbidity Index is a weighted aggregation of 22 separate conditions, correlating with 10-year mortality. A score of 3 suggests one has multiple conditions including diabetes, heart failure, peripheral vascular disease or a previous stroke.[49]. Although the study demonstrated a reduced probability of attending amongst those who could be termed 'co-morbid,' it did not specify the influence of individual illnesses. However, they did note that the odds of attendance amongst individuals who had any previous malignancy was 38% lower than those with no previous history. Conversely, those with a previous non-malignant (or benign) growth were almost a third more likely to attend than those with no history of cancer[48].

Similar findings have been demonstrated with Danish registry studies [50,51]. These analyses also demonstrate that for some prevalent conditions such as chronic obstructive pulmonary disease or diabetes, the odds of attending was only marginally less than those with no disease (OR 0.93, CI: 0.93-0.94 and OR0.96, CI:0.95-0.97, respectively). Whereas with more severe chronic conditions including dementia the odds of attendance are substantially lower (OR0.60, CI:0.56-0.64). They also noted that this association with attendance was more profound within the first year of a chronic illness diagnosis. This suggests dealing with a new diagnosis leads to potentially less time, capacity and prioritisation of attending screening and receiving a potential diagnosis [50,51].

Mental health illness has also been associated with non-attendance at breast screening, independent of other conditions. Ross et al. found that even after adjusting for age, socio-economic status, marital status and geographical location, people with poor mental health status were 23% less likely to attend breast screening (OR0.77, CI:0.73-0.82)[52]. In a meta-analysis, Mitchell et al. found the pooled OR of attendance was 0.83 (CI:0.76-0.90) in those with mood

disorders (e.g. depression or anxiety) compared to controls. Moreover, those living with serious mental illness (e.g. schizophrenia, psychosis), were almost half as likely to attend (OR 0.54, CI:0.45-0.65). The authors estimate that this inequity amongst those living with mental health illness could lead to 90 preventable deaths in the UK annually[53].

Emerging Inequalities

Given the significant interest in addressing healthcare inequalities, there is also an increasing body of work examining the uptake of breast cancer screening amongst other, potentially less investigated, underserved population subgroups. For example, McCowan et al. found that the odds of attending breast screening in Scotland were 0.28 (CI: 0.24-0.33) amongst care home residents, and 0.55 (CI: 0.47-0.65) in those registered with learning disabilities[48]. Moreover, a Northern Irish study demonstrated that presence of any disability, defined by the authors as physical, learning or mental health illness, led to 29% lower age-adjusted odds of attendance at breast screening[54]. Other patient populations, such as trans people, may also have less access to screening services. Currently, trans women and non-binary people, assigned male at birth but who are registered with their GP as female, are invited to breast screening routinely. As are trans men and non-binary people assigned female at birth and registered with their GP as female. However, people registered with their GP as male irrespective of the gender they were assigned at birth, are not automatically invited[55]. Despite the paucity of breast screening specific information, the Stonewall report found that 14% people identifying as lesbian, gay or bisexual, and 37% of trans people avoided accessing healthcare services due to fear of discrimination[56,57]. Given the intersectionality of inequalities across health and social care services, there is potential that these groups also encounter difficulties accessing breast screening. With more than 2 million women screened annually in the UK, the population

invited to breast cancer screening is diverse[21]. In order to remain equitable, the breast screening programme will need to tackle the existing, and emerging, healthcare inequalities in the service.

1.3.3 Diagnostic Accuracy

In 2020/21 the false positive rate of breast screening was 3.1%[30]. The false negative rate, i.e. those who were given a negative result, but went on to develop cancer, is currently not calculable as insufficient time has passed to detect interval cancers. With advances in Artificial Intelligence (AI) and Tomosynthesis, an advanced form of 3D mammogram, on the horizon, the potential to detect breast cancers earlier is growing[58,59]. However, the breast screening programme also must contend with potential overdiagnosis. Defined as the "detection of cancers that would never have been found were it not for screening", overdiagnosis leads to the potential treatment of lesions that would not have caused an issue[60]. In the Marmot review, the panel estimated that approximately 19% of breast cancers diagnosed by screening, during the period a woman is eligible, are overdiagnosed. The figure reported was based upon the limited available evidence, which was subject to biases including a lack of internal validity and the use of historical cohorts, and therefore maybe an overestimation[17]. Recent case-controlled studies have estimated that 3.7 to 9.5% of screen-detected cancers are overdiagnosed[25]. In any case, the screening programme must be aware of the effect that increasing attendance will have in terms of increasing overdiagnosis, and thus potentially increasing harm, as well as the public perception of this risk compared to the benefit of screening.

1.3.4 Workforce

One of the biggest advantages of aforementioned AI mammographic systems is the diminished reliance upon the screening workforce. In 2016, there were 15% vacancies in the

mammographic workforce, with 25% of breast units lacking at least one breast radiologist[61,62]. This poses a significant challenge for all breast screening units nationally. Although, addressing workforce vacancies is beyond the scope of this thesis, one needs to consider the impact of increasing attendance upon services with existing workforce pressures. Moreover, the development of new innovations will need to require minimal time or involvement of screening staff, if they are to be feasibly incorporated into clinical workflows.

1.3.5 COVID-19 Recovery

The COVID-19 pandemic led to an unprecedented challenge to all healthcare services globally. The impact within breast cancer screening has been substantial, with cross-cutting consequences in several facets of the programme. As a result of the pandemic, breast screening services were required to cease to reduce the risk of transmission, for approximately 3 months. It is estimated that this suspension led to approximately 1 million missed mammograms nationally[63]. Following on from the previous decline in attendance, the pandemic, therefore, led to a precipitous fall in screening activity. In 2020/21, the total number of women screened fell by 44.1% compared to the previous year, with uptake nationally 7.3% points lower (61.8%), indicating that even when women were invited, they were less likely to attend. In London, coverage fell to 55.2% and uptake across the BSUs ranged from 48.3 to 61.3%[30]. Although services restarted in July 2020, there was a significant backlog of examinations. As a result, the breast screening programme entered a period of COVID-19 recovery. Furthermore, BSUs were mandated to reduce throughput because of infection prevention measures, as well as contend with worsening workforce availability due to staff sickness and isolation[64], which reduced capacity, making it harder to address the backlog.

COVID-19 is also likely to have exacerbated existing healthcare inequalities. Firstly, the pandemic was shown to disproportionately affect minority ethnic groups, those from higher deprivation, and those with multiple comorbidities, all groups who can be considered underserved with respect to screening[65]. Secondly, COVID-19 required certain adaptations within services, such that the needs of some individuals were possibly no longer being met. These changes included restricting face-to-face appointments (meaning many could no longer be accompanied), reduced communication with patients, and needing to contend with worsening healthcare mistrust[66,67]. Furthermore, underserved groups may have been less eager to attend the healthcare setting or use public transport to reach appointments given their increased risk from COVID-19. These factors could potentially have lessened the acceptability and access of breast cancer screening in underserved communities , widening existing disparities. In the wake of the pandemic, services will thus need to make considerable efforts to counteract these effects, even just to return to the pre-COVID-19 levels of uptake and coverage, which as described were already in decline.

1.4 Behavioural Science and Understanding Health Behaviour

To overcome these challenges, in particular those related to low breast screening uptake and health inequalities, it is important to understand why people do not attend, and how things can be changed. Behavioural science is a field of study that examines the cognitive, social and environmental determinants influencing behaviours[68]. It can be used to comprehend the drivers underpinning behaviours of individuals, communities and populations to design interventions and policies to improve outcomes[69]. Without this thorough understanding of the target behaviour, attempts to change behaviour are unlikely to be effective. Theories derived from behavioural science and health psychology have often been utilised to understand health-

related challenges, such as smoking cessation, encouraging physical activity and asymptomatic screening uptake[70–72].

1.4.1 Health Belief Model (HBM)

One of the most commonly employed frameworks, the HBM, developed in the 1950's by the US Public Health Service, was designed to understand "the widespread failure of people to accept … screening tests."[73,74] At the centre of the model were four (now five) constructs. *Perceived susceptibility* which refers to an individual's thoughts on their risk of getting a condition. *Perceived severity* of the condition and its consequences. *Perceived benefits* of the desired action to reduce the risk or severity of the condition. *Perceived barriers* to conducting the action including psychological and physical cost. Following the development of Social Cognitive Theory, an additional concept, *self-efficacy*, was added[75]. This refers to people's perception of their own ability to undertake the desired behaviour. These five constructs are influenced by 'modifying factors' such as an individual's socio-demographic factors, personality and knowledge, which will then result in an individual undertaking the behaviour or not. The HBM also described a stimulus that prompts the decision-making process regarding whether to perform a behaviour, also called a *cue to action.*

Given its origin within screening it is unsurprising that the HBM continues to be widely utilised to derive new interventions to improve breast cancer screening uptake. For example, Ghaffari et al. embedded constructs from the HBM within an educational intervention amongst Iranian women which improved breast screening intention immediately, and after 2 months[76]. There are, however, criticisms of the model. Firstly, although the concept of 'modifying factors' have now been incorporated, it does not specifically account for environmental factors e.g. accessibility, which may impact upon a behaviour, nor does it incorporate social norms [77]. As

discussed previously, given the association of deprivation with non-attendance, these considerations are important within breast cancer screening uptake. Secondly the model, like others, such as the Theory of Planned Behaviour (TPB), does not account for habit-formation or emotional processing[78]. Although habit formation is less relevant to a 3-yearly screening invitation, emotional processing, which involves modifying memory constructs underpinning emotions, may be an important consideration in those who have had a negative experience of screening[78,79]. Finally, whilst the HBM provides a framework to understand the factors associated with a health behaviour, it does not provide guidance on how these can be addressed to change behaviour. This limitation is also seen in other theories such as the Transtheoretical Model (TTM) or the Fogg's Behavioural Model (FBM)[80,81]. To develop an intervention, therefore, additional constructs and strategies are needed.

1.4.2 Theoretical Domains Framework (TDF)

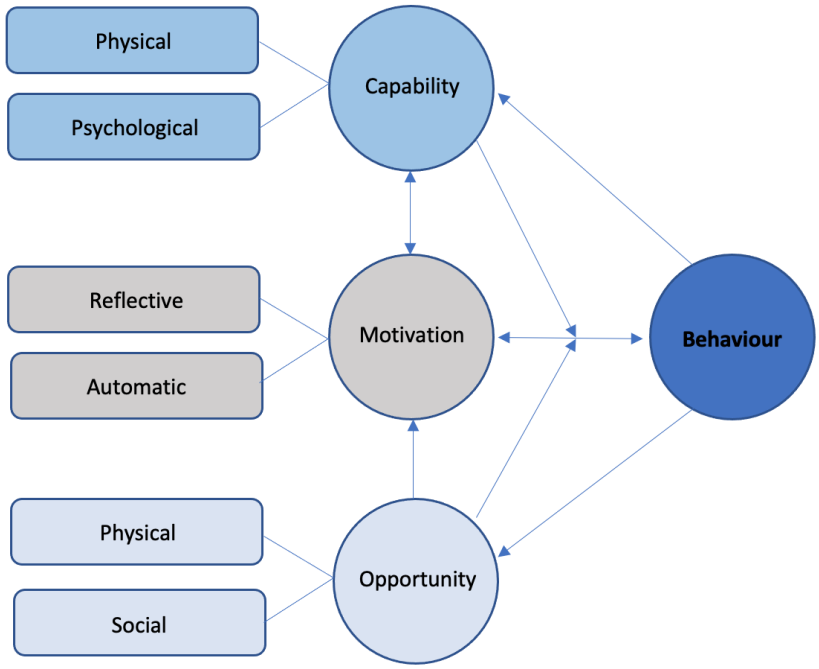
As described in 1.4.1 individual theories or models may lead to important determinants of behaviour being omitted. The Theoretical Domains Framework is a comprehensive and broad ranging tool that can help understand the barriers and facilitators of health behaviours. Although not a theory, it was developed from the synthesis of 128 constructs from 33 existing behavioural theories[82]. It therefore provides a comprehensive overview, with which to examine the influences on a health behaviour, and has been used extensively in implementation research[83]. As it is not a model of behaviour, it does not provide testable relationships between the 14 (originally 12) domains described and the behaviour. These domains are *knowledge*, *skills*, *social/professional role and identity*, *beliefs about capabilities*, *optimism*, *beliefs about consequences*, *reinforcement*, *intentions*, *goals*, *memory, attention and decision processes*, *environmental context and resources, social influences*, *emotion* and *behavioural regulation*. Each of these domains is defined, and has sub-domains provided. For example, optimism,

defined as "the confidence that things will happen for the best or that desired goals will be attained", has subdomains: optimism, pessimism, unrealistic optimism and identity[84]. The TDF will be used in Chapter 4 to frame the barriers and facilitators to breast screening from qualitative work.

1.4.3 Capability, Opportunity, Motivation- Behaviour (COM-B) Model

The TDF provides granularity when determining the motivational or psychological determinants of behaviour but in itself does not indicate how an intervention can address these barriers. The first step in understanding what techniques may potentially be effective, is to categorise, or map, the determinants elicited by the TDF to another framework, such as the Capability, Opportunity, Motivation- Behaviour (COM-B) Model (**Figure 1-3**)[85].

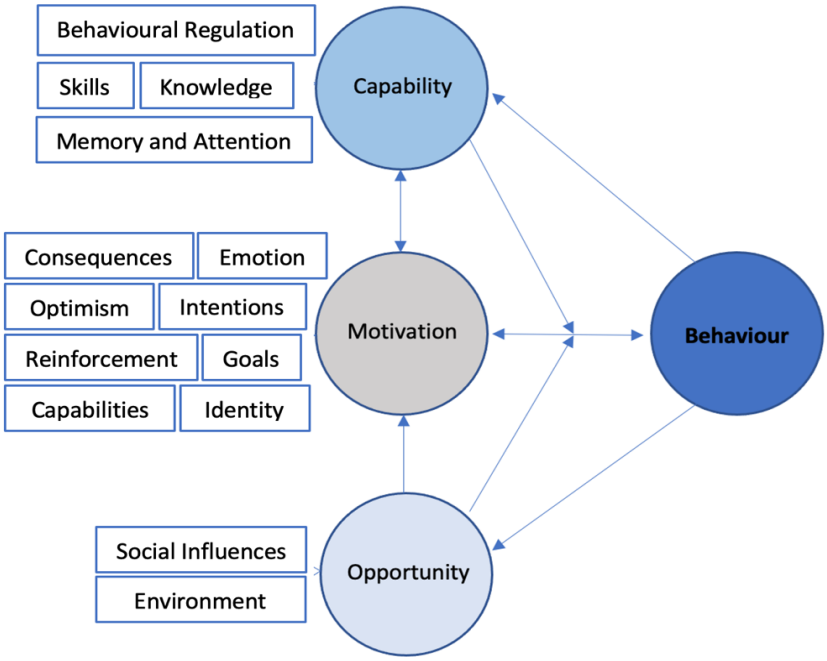
Figure 1- 3 Capability, Opportunity, Motivation- Behaviour (COM-B) model.



The COM-B, has previously been used in understanding the determinants of cervical screening non-participation, and developing interventions to increase bowel screening attendance[86–88].

The model incorporates three constructs: capability, opportunity, and motivation. Capability and opportunity modify the relationship between an individual's motivation and the desired behaviour, as well as influencing motivation directly. As a result, if an environment is conducive, and the more one feels capable, the more motivation they will have to conduct the target behaviour. Each of these three core elements are subdivided into two: reflective and automatic motivation, environmental and psychological capability, and social and physical opportunity. The model thus overcomes some of the limitations associated with other frameworks by acknowledging the influences of both internal and external stimuli. As discussed by West et al. both capability and opportunity influence an individual's motivation to enact a behaviour. For instance, an individual with more ability and who is within a more accommodating environment will tend towards undertaking a particular behaviour more. They therefore act to modify behaviour indirectly through the motivation-behaviour relationship, as oppose through direct impact upon behaviour[86]. In addition, the COM-B forms the hub of the Behaviour Change Wheel (BCW), and therefore provides the link between understanding the determinants of a behaviour (**Figure 1-4**) and developing an intervention to address them[85]. The COM-B will be used in Chapter 4 and 5 to map determinants and begin intervention development.

Figure 1- 4 Constructs from the Theoretical Domains Framework and Capability, Opportunity, Motivation- Behaviour (COM-B) model.



Capabilities- Beliefs About Capabilities, Consequences- Beliefs About Consequences, Environment- Environmental Context and Resources, Identity- Social/Professional Role and Identity, Memory and Attention- Memory, Attention and Decision Processes

Reproduced and modified from West R. and Michie S. A brief introduction to the COM-B Model of behaviour and the PRIME Theory of motivation, QEIOS, 2020[86]

1.4.4 Behavioural Change Wheel (BCW), Behaviour Change Techniques (BCTs) and the Theory and Techniques Tool (TaTT)

As described, the COM-B model forms the centre of the Behavioural Change Wheel (BCW). This synthesised 19 behaviour change cross-discipline frameworks through a systematic review. None of these frameworks was thought to be a comprehensive examination of behaviour or the behavioural intervention development process by itself. Outside of the COM-B core are 9 intervention functions, which describe the broad means that can be used to change behaviour[85,89]. These broad functions are coercion, education, enablement, environmental restructuring, incentivisation, modelling, persuasion, restriction and training. Each subdomain of the COM-B model is linked to multiple potential intervention functions. For example, a barrier to a behaviour may relate to psychological capability (such as a lack of knowledge). In this case, the intervention functions 'education,' 'training' or 'enablement' may be used within

an intervention to address this barrier[90] (**Table 1-1**). Although beyond the scope of this thesis, the BCW also links these intervention function to seven policy categories, which represent the ways governing bodies can support interventions.

The intervention functions are broad, and so an individual intervention may potentially use multiple strategies. Through a consensus of four behaviour change experts, these functions have been linked to smaller 'active ingredients' that bring about changes, or Behaviour Change Techniques (BCTs)[90,91]. These modular components of interventions provide detailed mechanisms to bring about behaviour change and have been compiled through an extensive evidence synthesis into a taxonomy (BCTT)[91]. Depending on the exact way in which a BCT is used it may relate to several intervention functions. For example, the BCT *information on health consequences*, could be leveraging *education*, but if being used to evoke an emotion regarding the target behaviour may be categorised as *persuasion.* It is however also possible to derive BCTs directly through mapping with behavioural constructs such as the Theoretical Domains Framework, without first examining intervention functions[90].

Table 1- 1 Matrix demonstrating the mapping of Capability, Opportunity, Motivation-Behaviour (COM-B) Model sub-domains to intervention functions.

		Intervention Functions									
COM-B Domain	**Sub-Domain**	**Coercion**	**Education**	**Enablement**	**Restructuring Environmental**	**Incentivisation**	**Modelling**	**Persuasion**	**Restrictions**	**Training**
Capability	Physical			■						■
	Psychological		■	■						■
Opportunity	Physical			■	■				■	■
	Social			■	■		■		■	
Motivation	Automatic	■		■	■	■	■	■		■
	Reflective	■	■			■		■		

Accompanying the BCTT is the Theory and Techniques Tool (TaTT), which is an online heatmap that links each BCT with a proposed mechanism of action (MoA). These mechanisms are constructs defined within behavioural science and signify how a BCT influences behaviour. The TaTT was developed in a 3-stage process. Firstly. a literature synthesis examined 277 behaviour change articles, finding 87 links between 51 reported BCTs and 24 MoAs. This was followed by an expert consensus involving 105 behaviour change experts voting upon the potential links between 61 BCTs and 26 MoAs. Finally, a triangulation exercise was used to determine the concordance between the literature review and consensus study. This process culminated in a matrix that provides a measure of the evidence underpinning the relationships between BCTs and their mechanisms (e.g. links, insufficient evidence, no links or no evidence)[93]. For example, there was sufficient evidence (in both the literature and consensus study) that the BCT *problem solving* affects behaviour by influencing an individual's *beliefs about their capabilities*. This can help those developing interventions select the most appropriate techniques, with sufficient evidence behind their use[93].

The BCW, BCTT and TaTT, therefore, provide a systematic and evidence driven means of mapping the determinants of a behaviour, in order to elicit the techniques an intervention could include to address them. Of note, the BCW, BCTT or TaTT do not contain information regarding acceptability, cost-effectiveness, or feasibility, which are left for researchers to determine. This process is used within this thesis to develop the intervention in Chapter 5.

1.5 Thesis Objectives

The aim of this thesis is to determine whether a behavioural science-informed intervention designed with underserved communities, can lead to significant increases in breast cancer screening uptake, when implemented into a population programme. Whilst uptake is not the

only important or relevant measure of intervention effectiveness, it provides a reproducible and tangible measure of the impact of a screening intervention. Furthermore, uptake constitutes a key performance indicator of the screening programme[19], therefore utilising this as the primary outcome measure will help to determine whether the effects of the intervention are clinically relevant. In order to develop this behavioural science-informed intervention and meet the overarching aims of this thesis, several intermediate objectives will need to be accomplished:

(1) Evaluate interventions that have been trialled to increase cancer screening attendance previously, their relative merits/shortcomings and the quality of the available literature. *(Chapter 2)*

(2) Understand how messaging interventions can be implemented within the infrastructure of screening programmes in a practical, effective, and acceptable way. *(Chapter 3)*

(3) Determine the barriers faced to breast screening in traditionally low-uptake groups. *(Chapter 4)*

(4) Compare and contrast the determinants of non-attendance amongst underserved communities with determinants in the wider population, and elicit key determinants to target within the intervention. *(Chapter 5)*

(5) Co-design an intervention to increase breast screening attendance, using behavioural science, informed by the findings from objectives (1)-(4). *(Chapter 5)*

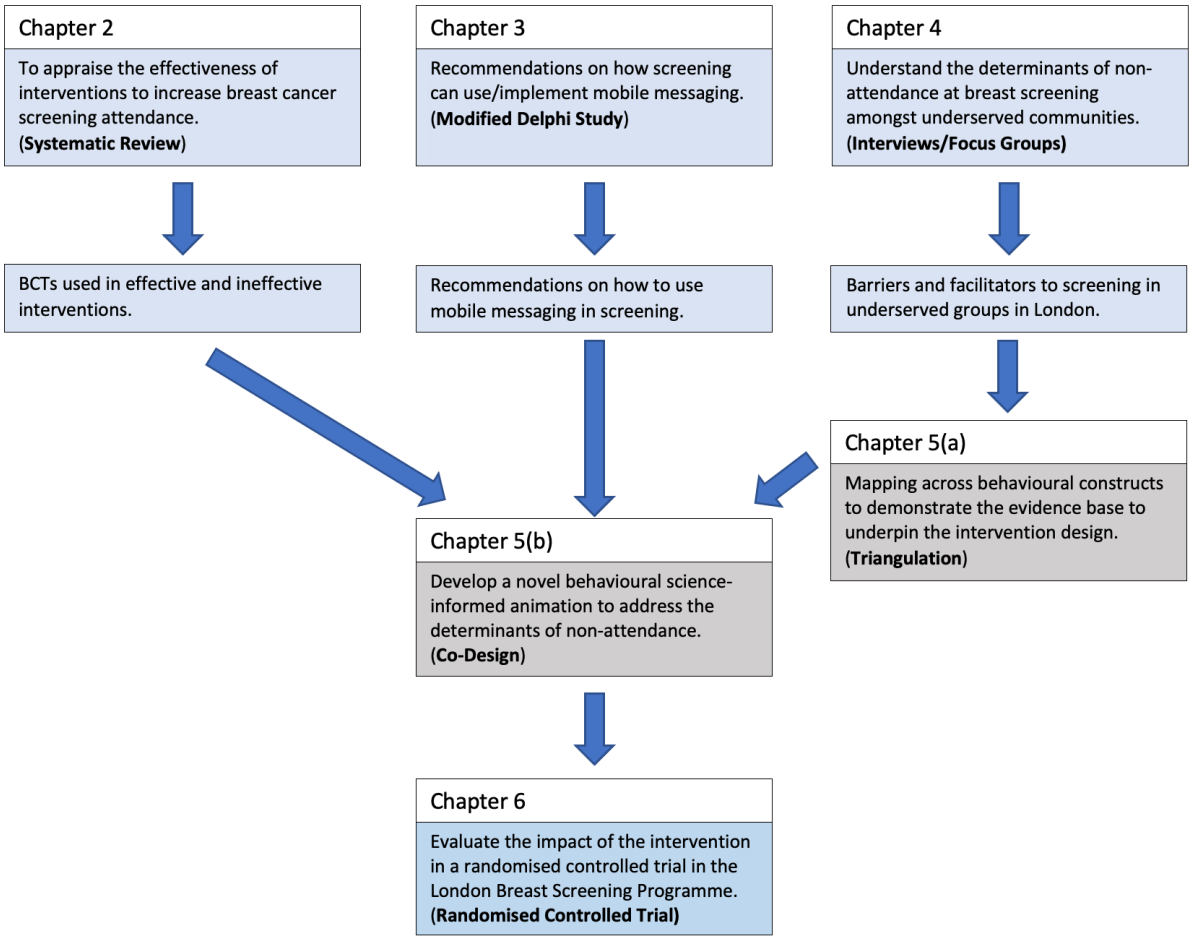
(6) Critically evaluate the effect of the intervention on increasing breast screening uptake in London (a region with longstanding suboptimal attendance rates). *(Chapter 6)*

1.6 Thesis Structure

To accomplish the objectives, this thesis explores several questions including what has been done previously, how interventions can be effectively implemented and why some communities attend less commonly than others. Each chapter details an individual study or

project examining these questions, with aim of resolving how breast cancer screening uptake can be increased on a population-level, whilst addressing healthcare inequalities (**Figure 1-5**).

Figure 1- 5 The thesis structure including chapters, aims, and outputs.



BCTs- Behavioural Change Techniques

Each formative study feeds into the intervention development and builds upon the findings of the previous studies, aiming to examine a complimentary facet or consideration for the effective development of an intervention to be deployed in a real-world setting.

1.7 Thesis Methodology and Research Paradigm

As described in 1.6, the thesis will use multiple methods to achieve objectives, incorporating both quantitative and qualitative analyses, where appropriate. The choice of methodology has been made to best examine the meaning of the research data with respect its practical consequences. This approach is in keeping with a pragmatist epistemology, in which the emphasis is placed upon the extrinsic utility of knowledge to address practical questions, as oppose its philosophical value[94]. Pragmatism developed in the 1800s, sits between positivist and constructionist viewpoints, with the acquisition of knowledge neither wholly an objective nor subjective phenomenon[95]. Moreover, the pragmatist epistemology highlights that observation is an active process. Contrary to the impartiality proposed by positivists, the pragmatist observer discriminates based upon expectation and interest, and therefore impacts upon the inquiry of knowledge[96,97]. Through this experience of the problem, it is possible to define objectives which can be acted upon.

Paralleling the pragmatist paradigm this thesis will look to elicit actionable knowledge for social gain, namely to improve breast screening uptake[97]. To achieve this aim not only does the choice of methods focus upon outputs over following strict theoretical processes, it engages stakeholders throughout. The perceptions of, amongst others, the service users, commissioners, and clinicians involved with screening helps to contextualise individual studies within the thesis, and examine whole systems as opposed to isolated facets. The hope is that this approach will help to develop understanding that is relevant to the current context, and which can be acted upon to improve breast screening uptake and experience.

2. Evaluating the Effectiveness of Existing Interventions to Increase Breast Cancer Screening Uptake

Outputs related to this chapter

A. Acharya, V. Sounderajah, H. Ashrafian, A. Darzi, G. Judah. A systematic review of interventions to improve breast cancer screening health behaviours. *Preventative Medicine.* 2021;153:106828

A. Acharya, V. Sounderajah, H. Ashrafian, A. Darzi, G. Judah. *Interventions to Improve Breast Cancer Screening Health Behaviours.* 2022. Australasian Society for Behavioural Health and Medicine Annual Scientific Conference. Perth, Australia.

2.1 Abstract

Background

Breast cancer screening attendance is low in several countries, forming a significant public health concern. Several interventions aimed at improving uptake have been developed. The aims of this systematic review are to evaluate the content of these interventions, how they attempt to bring about behavioural change, as well as critically examine the standard of the reporting literature.

Methods

A literature search was conducted of articles describing patient-facing interventions designed to increase breast screening attendance, compared to a control. Articles published between January 1st 2005 and January 1st 2021 were identified through Medline, EMBASE, Google Scholar, PsycInfo and PubMed databases. Data regarding study demographics, intervention delivery theoretical basis and content was extracted. Intervention content was coded using the

Behavioural Change Technique Taxonomy, to elicit the active ingredients of interventions. Self-reported or health record documented attendance at a screening mammogram was the primary outcome, at any timepoint following intervention delivery.

Results

54 full-text articles met the inclusion criteria. These detailed a total of 80 different interventions, with print the predominant means of delivery (39 interventions). Only half of the interventions were reported as effective. BCT coding demonstrated that 32 of the 93 BCTs were used. The most commonly used, *prompts/cues* was only moderately effective (62 interventions, 51.6% effective). Lesser used techniques such as *problem solving* (29 interventions, 69.0% effective) and *credible source* (20 interventions, 65% effective), were more effective. 'Covert learning' techniques had the greatest pooled effect (ES 0.12, 95% CI 0.05-0.19, $p<0.01$).

Conclusions

Despite high numbers of interventions being developed, these are often ineffective. A narrow repertoire of techniques has been used, with lesser investigated BCTs, such as problem solving, showing promise. These warrant further investigation, as do new technologies which may facilitate the integration of these more complex BCTs at the scale required by a population-level programme.

2.2 Introduction

By 2028, the UK government aims that 75% of cancers should be detected at an early stage. Cancer screening forms a central part of this public health policy[98]. However, as discussed in Chapter 1, breast cancer screening uptake in the UK has been gradually falling over the past decade. Similar patterns are seen in several countries worldwide, for example in 2017, within the European Union (EU) almost a third of member states reported screening rates below 50%[100]. Whilst in some contexts this low attendance may relate to the establishment of new population-level programmes; in countries such as Germany, which have had mammography programmes for over 15 years, attendance was still below 50%[100,101]. Moreover, several countries have reported prominent healthcare inequalities within their breast screening programmes. For example, in one American study, Black Medicaid insured women were significantly less likely than their White counterparts to undertake screening in 30% of the 44 states investigated[102]. Whilst the affordability of healthcare is an important barrier in the US which impacts accessibility, barriers regarding the acceptability and availability of screening are also experienced in the UK[103].

Breast cancer screening attendance is thus an important public health concern internationally, as demonstrated by its inclusion in the EU's Beating Cancer Plan and the Optimising Early Detection of Breast Cancer in Australia strategy[104,105]. As a result, there has been a concerted effort to design interventions to improve the uptake of screening mammograms. Prior to developing *de novo* means of tackling the challenge of cancer screening, it is integral that previous attempts are critically appraised. Understanding the relative successes and failings of these interventions, however, requires a robust means of comparison. Previous reviews on screening interventions have often relied upon limited, and somewhat arbitrary, categorisations to facilitate evaluation. For example, Duffy and colleagues undertook a rapid review of

evidence, dividing interventions based upon where in the screening pathway they act[106]. The authors acknowledge the limitations of their approach not only with respect to their search strategy, but also the inferences they can make due to their classification. For example, the use of SMS reminders was separated from direct contact e.g. telephone interventions promoting attendance. However, both types of interventions share characteristics, and could be seen primarily as a cue to action or use a range of techniques to increase screening. The over-simplification of the categorisation precludes the direct comparison of these two intervention types. In a resource limited healthcare system where only finite numbers of interventions can be deployed, there is a need to compare the relative merits of interventions. The method of classification suggested by Duffy et al. is therefore of lower utility to policy makers. Moreover, the limitations of the previous categorisations are particularly apparent with multi-modal or complex interventions, which could be placed into several categories. Related issues are seen in reviews by Agide et al., who compared individual v. community interventions[72], and Atere-Roberts et al. who used the Community Preventive Service Task-Force framework[107]. In both reviews interventions were categorised by scale, but did not compare specific interventions, determine how these interventions bring about changes in screening behaviour, or examine the feasibility of scaling interventions at a programme-level.

2.2.1 Behavioural Change Technique Taxonomy (BCTT)

As described in Chapter 1 behavioural change techniques (BCTs) are the active modular units of interventions designed to modify behaviours[108]. They were derived through an expert-led Delphi consensus exercise and represent techniques from a wide range of behavioural disciplines. The BCT taxonomy is an iteratively refined hierarchical classification of 93 BCTs divided into sixteen higher order domains. Each BCT has a specific definition, with examples and qualifications provided. For example, *anticipated regret,* described as "raising awareness

of expectations of future regret," and the usage "asking the person to assess the degree of regret they would feel if they do not quit smoking" provided[91]. This standardised nomenclature has a number of benefits. Firstly, it provides a common framework to describe, understand and replicate interventions. When evaluating interventions, therefore, it enables a greater evaluation of *why* a particular intervention was effective[109]. Secondly, as the techniques are context-independent, they facilitate cross comparison of interventions, irrespective of whether they are multi-modal, used in different points in the pathway or at different scales. Finally, as machine-learning and natural language processing techniques advance, distilling interventions in this way, will facilitate the use of algorithms to predict success prior to development[110]. As of yet, however, no study has applied the BCT taxonomy to critically evaluate the relative merits of interventions designed to improve breast cancer screening uptake.

2.2.2 Aims

The primary aim of this systematic review is to appraise and contrast the components of effective and ineffective interventions to increase breast cancer screening attendance. To facilitate this assessment, the BCT taxonomy will be utilised to compare the behavioural content of each intervention, and if possible, analyses to determine the effect of individual BCTs will be conducted. Furthermore, theoretical basis of each intervention, how it was delivered, and the population it was tested upon will be elicited to ensure a comprehensive assessment can be made. In this way insights regarding the components of effective interventions will be identified which can inform the development of future interventions to increase breast screening uptake. These findings will be reported within the context of the quality of the reporting literature. This will help to identify potential biases that may skew the results and impact the generalisability of the findings in the development of tools for other healthcare contexts.

2.3 Methods

2.3.1 Study Design

This study was conducted as a systematic review of the literature. It was prospectively registered on the PROSPERO database (reference CRD42020212090) and undertaken in compliance with PRISMA guidelines[111]. As this constituted a retrospective review no ethical approval was required. A literature search of PubMed, PsycInfo, Google Scholar and Medline databases was conducted to include published articles from January 1st 2005 to January 1st 2021. This date range was chosen as the review represents an evaluation of contemporary breast screening interventions. Interventions designed prior to this point may no longer be relevant to the screening service, and furthermore, if effective are likely to have been already adopted by the programme. In addition, as mentioned previously, several countries had not developed programmes before this timepoint[101]. The interventions that had been trialled, therefore, would have been designed in a context that is less comparable to a population-level service.

The search strategy is detailed in the **Appendix 2-1.** Terms combined concepts pertaining to *mass screening, population surveillance, screening program*, cancer screening, asymptomatic screening, mobile screening, breast cancer, breast neoplasm, breast malignancy, attendance, uptake, coverage, adherence, compliance, interventions, health behavio?r,* and *behavioural science.* Standard Boolean operators AND/OR were used in conjunction with various combinations and permutations of these terms. All studies were reviewed and uploaded to the Cochrane database supported systematic review tool, Covidence (Melbourne, Australia). Two independent researchers blinded to each other's assessment screened abstracts, with discrepancies discussed until a consensus was reached. If no

immediate consensus could be reached a third author would hold the casting vote. All included abstracts were subsequently reviewed for full-text appraisal by the two authors.

Inclusion and Exclusion Criteria

All studies that examined the impact of an intervention upon breast cancer screening attendance in relation to a control standard were included. Observational studies and randomised controlled trials (RCTs) were eligible for inclusion, whilst protocols, feasibility studies and articles describing intervention design alone, were excluded. The primary outcome of interest was the difference in mammography attendance between control and intervention trial arm(s). Attendance could be self-reported, or health record derived at any time point. However, studies solely using surrogate measures of attendance such as intention to screen were excluded. This was due to the intention-behaviour gap[112], in which actions and intentions do not strongly correlate, and therefore, including scores of intention to screen could give a false impression of the effectiveness of an intervention. As there was no geographical restriction of the studies, a range of healthcare services could be represented including private, government-funded, or mixed systems. As a result, the nature of the control was not stipulated, but instead represented 'usual care' for that particular region. This included simple mobile reminders, letters, or general health advice from physicians. Furthermore, the nature of the intervention was not defined, providing that it was public, as opposed to physician, facing. Therefore, multi-faceted, phased or campaign based- interventions were all included, as well those targeting particular population subgroups.

2.3.2 Data Extraction and BCT coding

Study demographics and design including country of origin, date of publication, trial type, target population and outcome measures were all extracted from full-text articles. Details of

the intervention were also elicited including whether named behavioural theories were used within the development. When manuscripts provided insufficient details regarding the intervention, protocols, feasibility studies and cited presentations were searched. In addition, the authors were contacted in cases of ambiguity, to facilitate accurate BCT coding.

The intervention content from each included study was evaluated and mapped to the BCT taxonomy v1. This classification details 93 techniques, however a 94th, *increase positive emotions,* which appears as a footnote within the taxonomy was included, as a foil to the included *reduce negative emotions.* One author derived the BCTs within each intervention, whilst a second independent author validated this evaluation in 20% of interventions. Disagreements were discussed until a consensus was reached. This is in keeping with similar published systematic reviews[113]. Both authors had completed the online BCT training and had previous experience of coding intervention content[114]. The initial agreement between authors was high at 83.6%, and so further validation was not required. BCTs could have been intentionally included within the intervention or be present inadvertently. For example, an education session before a screening invitation may have the aim of increasing awareness, however the timing prior to the invitation could also act as a prompt and was therefore also coding as such. BCTs used in 3 or more interventions were compared in terms of the frequency of effective interventions employing them. In phased interventions, the content at each stage was coded separately.

2.3.3 Analysis

Data from included studies regarding study demographics, intervention descriptions and original author's conclusions were extracted by the researcher. This was combined with BCT coding, as described above. Although not a primary outcome of this systematic review, an

exploratory analysis was undertaken to determine statistically which BCTs were the most effective. The proportional effect of each intervention was calculated as an increase (positive) or decrease (negative) in uptake compared to the control. As several BCTs were used in too few studies, the analysis could not be undertaken at the individual BCT-level. However, as BCTs are grouped hierarchically into 16 taxonomical domains, the analysis was therefore undertaken to determine whether any BCT group had a significantly higher pooled effect size in comparison to the others. If only a single intervention used BCTs from a group, analysis of this group was precluded. The analysis was based upon the proportion differences using the inverse-variance, random effects model utilised by previous meta-analyses, and described by DerSimonian and Laird[115], and was conducted primarily by the supervisory team (HA). The I^2 statistic was used to estimate the degree of heterogeneity across studies with a value ranging from 0% (homogenous) to 100% (heterogenous)[116]. To assess the association between the intervention effectiveness and behavioural models named as being used in intervention development, or the number of BCTs included, Chi-squared tests were used. All analyses were undertaken using Stata version 15 (StataCorp, Texas, USA).

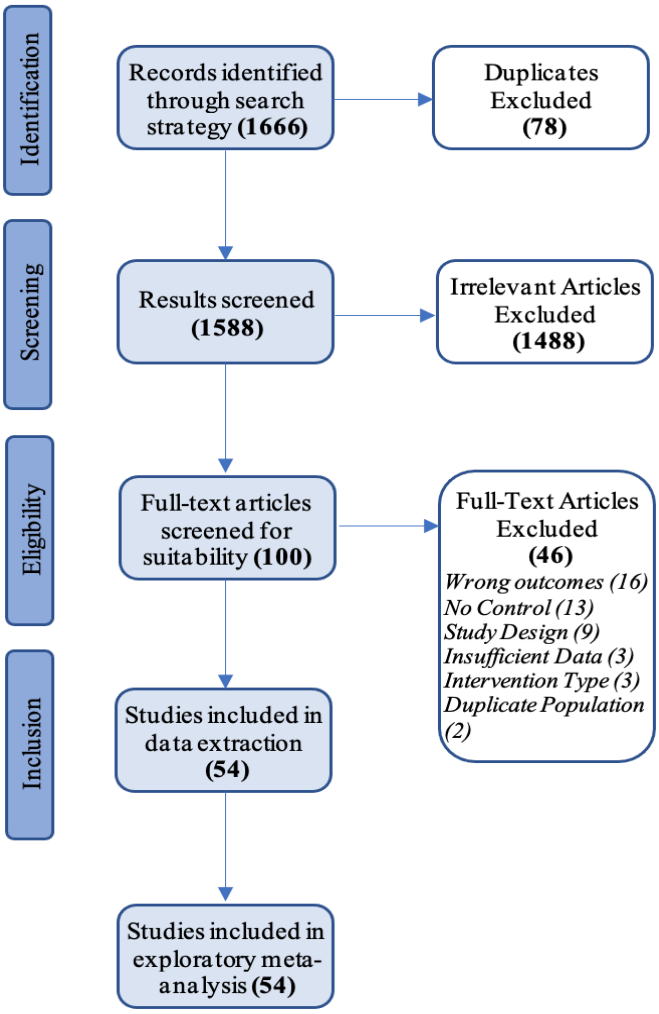
An assessment of the biases of the included literature was also undertaken by two independent authors blinded to each other's findings. Discrepancies were again discussed until a resolution was agreed upon. Authors used the Cochrane Risk-Of-Bias tool 2 (RoB 2) for randomised controlled trials[119], and the Risk-Of-Bias In Non-randomised Studies of Interventions (ROBINS-I) for observational studies[118]. Both are advocated by Cochrane to assess internal validity and provide an understanding of biases that may influence the conclusions that can be derived from the study. Both tools provide signalling questions to assess biases across several domains of interest including randomisation (if applicable), adherence, missing data and measurement of outcomes.

2.4 Results

2.4.1 Studies

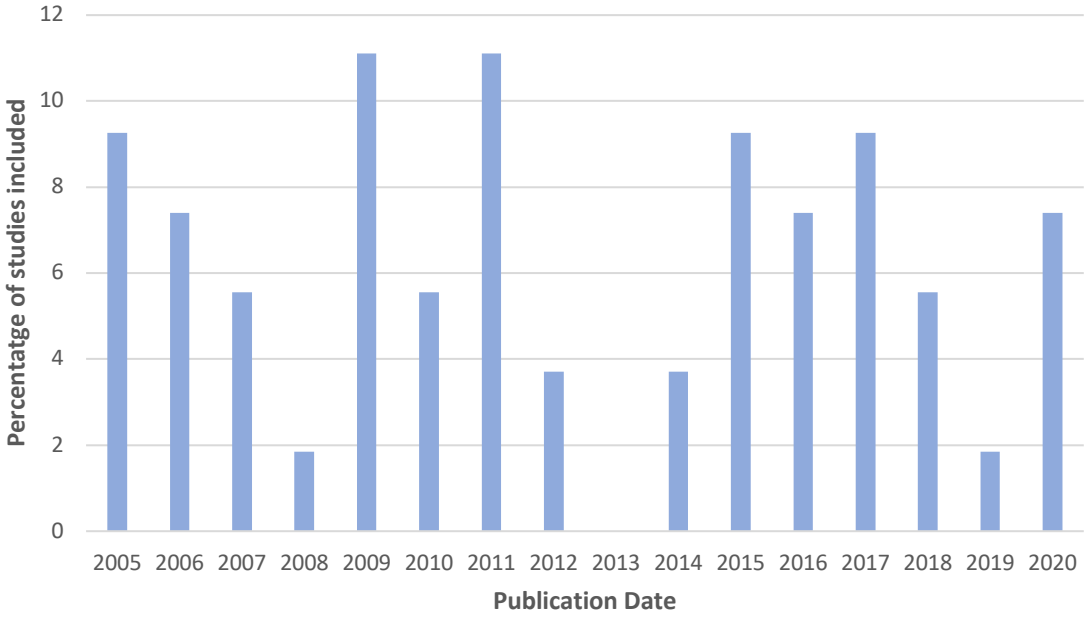
The search strategy elicited 1666 articles, which were screened for suitability for inclusion (**Figure 2-1**). Following blinded evaluation of abstracts by authors, 54 full text articles met the inclusion criteria (45 randomised controlled trials, and 9 quasi-experimental)[119–172].

Figure 2- 1 PRISMA diagram demonstrating selection of included studies.



The majority of included studies were from the US (70.4%), more so than Europe (14.8%), Australia (3.7%) and or other regions (11.1%). A relatively even distribution of publications were included across the permitted time period (**Figure 2-2**).

Figure 2- 2 Graph demonstrating the percentage of all included studies published per year.



Several outcome measures were reported by studies to evaluate attendance. These included health-record data (52.3%, 23/54), self-report measures (44.4%, 24/54) and a combination of the two (9.3%, 5/54). In two studies no information was provided on how attendance was derived.

Across the 54 studies a total of 468,381 female participants were recruited, of whom 220,309 received usual care (or control) and 248,072 intervention practices. Twenty-three studies examined interventions targeted at underserved groups, with the majority of these (69.6%) focussing upon minority ethnic or migrant populations, 8.7% on people from areas of high deprivation, 17.4% a combination of the two and 4.3% upon war veterans. The most frequently investigated minority ethnic group were African Americans, followed by Korean Americans Included studies are summarised in **Table 2-1**.

Table 2- 1 Data extracted from included studies.

Study	Country	Study Design	Inclusion Criteria	Control Description (n)	Intervention(s) Description (n)	Delivery Method	Theory used	Outcome Measure	Difference in uptake compared to control (%)	Conclusion
Abood et al. (2005)[119]	USA	Quasi-experimental	Aged 50-64, Under-/ Uninsured	Telephone call to schedule screening (992)	Scripted loss-framed messages (112)	Tel.	NS	HR at 6 months	+11.9*	Loss-framed communication strategy seems associated with increased mammography utilisation.
Ahmed et al. (2010)[120]	USA	RCT	Aged>40	Usual care including monthly newsletters on health topics including breast screening and access outreach workers (786)	Usual care and received a reminder letter signed by the medical director endorsing screening (785) Received the director's letter, if no mammogram at 3 months then a personalised letter from physician. If no appointment at 6 months then a worker conducted counselling tailored to barriers. (785)	Print In-person /Print	IDT, SLT IDT, SLT	NS	+3* +14*	The stepwise intervention significantly increased mammography, more so than the simple intervention which also led to significant higher rates than controls.
Allen et al. (2006)[121]	USA	RCT	Aged>40	Telephone calls to enquire about mammogram receipt only (169)	Barrier counselling tailored using a survey delivered by Latina/African American workers. Focus was upon importance of screening and scheduling a low-cost test. Mailed appointment reminders and brochures. (185)	Print /Tel.	AM, HBM PT, SLT TPB, TTM	SR at 6 months	+7.8*	Tailored counselling increased screening mammogram rate by 8% compared to controls.
Beauchamp et al. (2020)[122]	Australia	RCT	Aged 50-74, Identified Italian or Arabic as	English reminder letter with breast cancer stats, purpose of screening	Letter reminder in their preferred language, as well as English. The translation was simplified and included a photo and quote from an Italian or Arabic GP (572)	Print	NS	HR at 14 days	-1.5	Sending letters in preferred language showed no different to letters in English. Telephone call to women in their preferred

			preferred language	and booking information (460)(100)	A reminder call in their preferred language, lasting 4-8 mins. Participants could book the appointment during the call. (95)	Tel.	NS		+58.2*	language was 10 times more effective than usual care.
Bodurtha et al. (2009)[123]	USA	RCT	Aged>40	General print information on breast cancer prevention not tailored to risk level (450)	5-yr and lifetime breast cancer risk calculated using the Gail Model described in handouts. These addressed barriers, severity of breast cancer and benefits of screening. Instructions on scheduling a mammogram (449)	Print	HBM	SR/HR at 18 months	-2	A brief print intervention in the waiting room did not increase mammography rates, but was associated with improved rates in those most worried about breast cancer.
Bowen et al. (2017)[124]	USA	RCT	Aged 18-74 (>40 for mammo.), internet access at home	Received standard programme invitation and information (338)	Access to website with personal stories, messages about breast cancer tailored to an individual's risk and option to contact a health counsellor. Participants were also given the chance to make commitments and address their concern. A risk calculator, and genetic counselling was available. (334)	Web	SRM	SR at 12 months	+12*	The multi-faceted intervention significantly increased screening behaviour. The effects were stronger in those whose knowledge increased and worry decreased due to the intervention.
Carney et al. (2005)[125]	USA	RCT	Aged>50, 1 or more previous mammograms	General print information on breast cancer and state screening services sent twice. (132)	Educational and counselling calls to identify barriers, means to overcome them and stage of readiness to change. Two sessions were given 1 year apart, each lasting on average 6 mins. (126)	Tel.	TTM	SR at 15 months	+13*	Tailored counselling influenced women's behavioural stage relative to obtaining mammography leading to greater number of women being up to date with screening than controls.
Chambers et al. (2016)[126]	UK	RCT	Aged>50	Letter sent from the local breast screening centre to remind individuals to attend	Within 2 weeks of letter, received a telephone reminder (212)	Tel.	HBM, TPB	SR at 3 months	+9.6*	A simple telephone intervention doubled the uptake compared a letter alone, but was no additional effect of telephone support or anticipated regret.
					Within 2 weeks of letter, received telephone support addressing barriers and concerns identified (213)	Tel.	HBM, TPB		+4.4	

				(217)	Within 2 weeks of letter, received telephone support addressing barriers and concerns identified including two questions on anticipated regret (214)	Tel.	HBM, TPB		+6.2*	
Champion et al. (2006)[127]	USA	RCT	Aged 41-75, African American, Low income	Educational pamphlets targeting African American women, encouraging attendance and giving list of local screening facilities. (71)	Interactive tutorial narrated by local African American celebrity, asking about beliefs and knowledge of cancer screening. Tailored responses from storytellers persuaded participants to re-evaluate negative beliefs. Videos demonstrated mammography, a spiritual perspective and a doctor gave factual information. Lasted 20-40 mins. (138)	Computer	EPPM, HBM, TTM	SR at 6 months	+7.9	Interactive computer module was more effective at increasing mammography adherence than the targeted video but not the pamphlet (control). Interactive measures were more effective than non-interactive tools.
					Video of the computer program using the same local narrators and storytellers. The tone promoted self-efficacy, reduced fatalism and moderated threat. Lasted 20mins (135)	Video	EPPM, HBM, TTM		-7.5	Attendance in the video and computer groups was not significantly different from that in the pamphlet group
Champion et al. (2007)[128]	USA	RCT	HMO member	Usual care, which from some providers includes a written reminder (294)	Computer-tailored mailed newsletter with tailored information on participants' risk, benefits and barriers. If self-efficacy was low this was added. If previous non-attendance a page on how to arrange one was included. A physician-signed cover letter addressing age and family history (329)	Print	HBM, TTM	HR at 4 months	+9*	A combination tailored print and telephone intervention was the most effective intervention for 4-month uptake. Adding print materials appeared to have an additive effect on adherence. All 3 interventions outperformed controls
					Counsellors delivered tailored information covering the topics included in the newsletter and answered specific non-medical questions from clients. (314)	Tel.	HBM, TTM		+6*	

					Received combination of print letter and a counsellor's call within a week of the newsletter. (308)	Print /Tel.	HBM, TTM		+12*	
Champion et al. (2016)[129]	USA	RCT	Aged 51-75, Member of HMO	Usual care ranging from no additional materials to a post-card reminder when it was time to schedule the mammo. (537)	DVD lasting 10mins with women of different demographics delivering messages. These were tailored to perceived risk, benefits, self-efficacy, barriers and demographics previously identified. Demonstration of mammography was included (542)	Video	HBM, TTM	SR/HR at 6 months	-5.6	Neither DVD nor telephone intervention increased uptake. Women with low incomes receiving the DVD had higher uptake compared control
					Tailored telephone messages (over an average 11.3 mins) to perceived risk, benefits, self-efficacy, barriers and demographics previously identified. (559)	Tel.	HBM, TTM		-0.2	
Champion et al. (2020)[130]	USA	RCT	Aged 51-75, non-adherent to both colorectal and breast screening	Usual care depended upon health care providers including receiving reminder postcards when mammogram due (177)	Tailored messages based on individual's responses regarding knowledge, risk of cancer, benefits and self-efficacy for screening. Messages addressed the need for both colorectal and breast screening. Video clips demonstrated mammography. (180)	Web	HBM, TPB, TTM	SR/HR at 6 months	6.8	Tailored intervention did not significantly improved rates of mammogram alone between the groups.
					Tailored messages consistent with web-based algorithms to women's beliefs. Participants were asked if they wanted to book an appointment. Calls lasted an average of 19 mins. (168)	Tel.	HBM, TPB, TTM		6.4	
					Completion of the tailored web program with the phone intervention delivered 2-4 weeks later. (167)	Tel. /Web	HBM, TPB, TTM		4.4	

Chan EK et al. (2017)[131]	Canada	RCT	Aged 51-73, enrolled in screening mammogram program	Reminder postcard with "Mammograms save lives" and quotes from service workers. (2749)	A signed letter from their physician expressing concern regarding their overdue screening status in addition to the postcard (2749)	Print	NS	HR at 6 months	+10.4*	A signed letter from a physician significantly increased the percentage of women who returned for screening
Cuellar et al. (2017)[132]	USA	Quasi-experimental	Aged 40-64, member of employee wellness program	Promotional materials for the Wellness Programme (160789)	Employee Wellness Programme offering a $0-$75 reward for receipt of mammogram or other preventative measures recorded by score card (maximum annual incentive between $250-900) (160789)	NS	NS	NS	+2.7*	Financial incentives increased uptake of preventative care services, with a 5-7% increase in mammogram rates. Modest financial incentives, even below federally approved levels can drive behaviours
Cohen and Azaiza (2010)[133]	Israel	RCT	Aged 40-65	Usual Care materials including invitations (14)	Social worker explored stage of contemplation, individual risk-based recommendations, beliefs and barriers addressing them with a culturally tailored approach (26)	Tel.	HBM, TTM, CCA	SR at 6 months	+17.1	Cultural-based interventions increased mammography attendance but not significantly. Social and cultural barriers decreased.
DeFrank et al. (2009)[134]	USA	RCT	Aged 40-75, Stage Health Plan	Mailed reminder with last mammogram date, screening benefits, and contact information (799)	Telephone reminder with last mammogram date, benefits of screening, guidelines and contact information. Call lasted 69s and had a female voice. (1259) Letter reminder contained the same information as the telephone call, as well as a booklet incorporating figures regarding severity and susceptibility of breast cancer. (1269)	Tel. Print	NS HBM	SR/HR at 14 months	+5.5* +2.7	The automated telephone reminder was the most effective strategy to increase adherence, but enhanced print reminders performed similarly to usual care.
Dietrich et al. (2006)[135]	USA	RCT	Aged 50-69, overdue for cancer screening,	1 call where screening queries were answered and	A series of support calls over 18 months facilitating screen process, addressing barriers and detail explanations of screening.	Print /Tel.	NS	HR at 18 months	+10*	Telephone support can improve screening rates in those visiting migrant health centres.

			attended migrant health centre	advice given (694)	Aimed to prioritise screening and gave motivational support. Written recommendations, patient activation cards and reminders were also sent. (696)					
Fernandez et al. (2009)[136]	USA	Quasi-experimental	Aged>50, Hispanic farmer status	Initial invitation only (257)	Lay health workers held sessions lasting 1 to 2h using bilingual pamphlets, breast models and videos to educate and motivate to screen. A further contact at 2 weeks to assist booking.(207)	In-person /Tel.	LR	SR at 6 months	+5	A higher percentage of women in the intervention group than in the control group reported screening although this did not reach statistical significance.
Goldzahl et al. (2018)[137]	France	RCT	Aged 50-74	Printed invitation letter that explains process and rationale to screen (5277)	Addition of 3 official logos of the National Insurance Funds onto control letter (5296)	Print	LR	HR at 24 months	-1.1	No treatment led to a significant increase in mammography receipt including amongst first time and low-income subgroups. This may be due to many women not opening the letters or understanding them
					Simplified letter preferred by a sample of eligible women (5315)	Print	LR		-0.8	
					Logo and simple Letter (5300)	Print	LR		-0.7	
					Letter with social norms information (5307)	Print	LR		-0.5	
Han et al. (2009)[138]	USA	Quasi-Experimental	Aged>40, Korean American	Standard reminder untailored to cultural values (93)	2-hour education sessions in the community including case presentations and barriers to screening. Individually tailored follow up to counsel participants, identifying benefits and barriers to screening. (93)	In-person /Tel.	HBM, TTM	SR at 6 months	+31.9*	The multifaceted intervention led to significant increase in attendance, and was highly acceptable to participants. It did not improve screening knowledge.
Hegenschied et al. (2011)[139]	Germany	RCT	Aged 50-69	Written reminder to attend mammogram (2952)	Counsellor used baseline data to reduce an individual's barriers and increase facilitators to screening. They used facts about cancer risk, use of mammograms and recommendations. (2455)	Tel.	CM, HBM, TTM	HR at 3 months	+3.6*	The telephone counselling group had significant higher attendance than controls. The intervention was effective and acceptable.

Highfield et al. (2015)[140]	USA	Quasi-experimental	Aged 35-64, African American, Uninsured	Telephone reminder with scan details and location (151)	6–10 minute tailored telephone counselling reminder using salient barriers from local African American women and active listening. (88)	Tel.	TTM	HR at NS	+25*	The evidence-based intervention significantly increased attendance
Icheku et al (2015)[141]	UK	Quasi-experimental	Aged 50-70	An NHS trust headed invitation letter signed by GP lead (1452)	SMS reminder messages sent 1 week prior to appointments following invitation letter. (552)	SMS	LR	HR at 6 months	+8*	Letter intervention combined with SMS reminders were the most effective in improving breast screening uptake
Kearins et al. (2009)[142]	UK	Quasi-experimental	Aged 53-64	Invitation from screening service to a timed scan (5180)	A call to persistent non-attenders following the invitation letter to ascertain intention and answer queries. A reminder call was made 24h prior to the appointment. If no phone contact, a personal visit was undertaken (476)	In-person /Tel.	NS	HR at NS	+3.1*	Enhanced activity of phone calls led to moderate increases in screening uptake
Kerrison et al. (2015)[143]	UK	RCT	Aged 47-53, Invited to first routine screen	Printed invitation (435)	Reminder 48h prior to appointment (456)	SMS	NS	HR at 1st appointment	+5.3*	Sending a reminder before first routine breast screening appointment significantly increased attendance.
Kregting et al. (2020)[144]	Netherlands	RCT	Aged 49-75	Standard invitation and information leaflet (457)	Additional leaflet using simple text to increase knowledge regarding screening process, outcomes, benefits and harms. (531)	Print	NS	HR at appointment	+2	The leaflet did not lead to increased attendance but increased knowledge and positive explicit attitudes.
Kreuter et al. (2005)[145]	USA	RCT	Aged 40-65, African American	Received no printed materials during the study but did receive them at the end. (55)	Received 6 magazines over 18months. Magazines promoted mammography using tailored stories, was personalised to the recipient and used local African American artists' works. The magazine was tailored to cancer knowledge, risk, perceived barriers and use of screening and readiness to act. (48)	Print	LR	SR at 18 months	+10.1	Integrating culture into behavioural interventions may enhance their effectiveness for African Americans. Those who had behavioural and cultural stories were 2.6 times more likely than controls to attend mammograms. Using

					Received 6 magazines over 18months. Magazines promoted mammography using culturally tailored stories and was personalised to the recipient. The magazine was tailored to 2 of 4 cultural constructs (religiosity, collectivism, racial pride, time orientation), that they scored high on the pre-study survey. (44)	Print	LR		+9.1	magazines tailored on culture or knowledge alone did not significantly increase attendance compared to controls
					Magazine contained both types of tailored stories (45)	Print	LR		+21.1*	
Lakkis et al. (2011)[146]	Lebanon	RCT	Aged 40-75, Health insurance	SMS general invitation + 3 reminders (192)	In addition to the invite and 3 reminders at 4-week intervals, an SMS regarding the benefits of mammograms was sent (193)	SMS	NS	HR at 6 months	+0.9	The addition of an SMS about benefits did not improve uptake rates compared to usual care
Larkey et al. (2012)[147]	USA	RCT	Aged >18 (>40 for mammo.) Self-identified as Hispanic /Latina	Individual sessions with a *promotora* only and didactic teaching (402)	6 group-based sessions regarding screening with group exercises and interaction. Materials were designed to create interaction (604)	In-person	NS	SR at 3 months	-11.4	No significant difference in achievement of screening behaviour between groups but high attrition was noted.
Lee E et al. (2014)[148]	USA	RCT	Aged>40, Korean American Immigrants and married to a Korean American	Education session and DVD on improving diet (217)	A 30 mins DVD culturally tailored messages on screening to change health beliefs and increase spousal support. Group discussion with couple on the main messages and a home exercise for couples to do.(211)	In-person /Video	HBM, MoI	SR at 15 months	+14*	Women in the intervention group were more than twice as likely to have a mammogram within 15 months.
Lee E et al. (2017)[149]	USA	RCT	Aged>40, Korean American Immigrants and married to a Korean American	Received standard materials from healthcare provider (32)	Culturally tailored messages on screening to change health beliefs and increase spousal support, with a summary of the main messages and a home exercise for couples to do and report to study team by phone (23)	Web	HBM, MoI	SR at 2 months	+9.2	Greater uptake of mammography although the difference was not significant. This may be due to the short follow up and small sample size.

Lee H et al. (2017)[150]	USA	RCT	Aged 40-79, Korean-American Immigrant	Printed materials in Korean with details of a health navigator (60)	Application to send culturally tailored messages to increase education and motivation, as well as an in-app reward system, clinic information and an online health navigator to address logistical barriers (60)	Mobile App	FBM, HBM	SR at 6 months	+45*	Intervention received mammograms at a significantly higher rate. The app can positively influence health behaviours
Luckmann et al. (2019)[151]	USA	RCT	Aged 40-84, members of Fallon Health Clinic	Letter reminder only informing them of outstanding mammogram (10063)	Reminder calls 2 weeks after the control letter, with the offer to schedule one (10043)	Print /Tel.	NS	HR at 24 months	+2.2*	Reminder calls were more effective than counselling calls and letters, with the largest difference in those aged 40-49 years. No difference in adherence between counselling calls and letters.
					Further reminder letter 2 weeks after the initial letter and educational booklet, if no mammogram scheduled. This was followed by a counselling call to identify and overcome barriers and support screening 1 week later (10054)	Print /Tel.	PAPM		0	
Marshall et al. (2016)[152]	USA	RCT	Aged>65, Self-identified as African American and in fee-for-service Medicare	Printed educational materials on cancer and preventive services (720)	Patient navigation services discussing printed control materials, risks for cancer and barriers. Also helped arrange appointments and accompanied patients to appointments (638)	In-person /Tel.	NS	SR at 24 months	+5.8*	Patient navigation increased mammography utilisation, with the effect stronger on those not up to date
Merrick et al. (2015)[153]	USA	RCT	Aged 42-69 with network-model plan coverage	Standard reminder letter encouraging contact providers with medical questions and help finding a mammography facility. (1102)	Control letter offering a $15 gift card if receipt of mammography (1100)	Print	NS	HR at 4 months	-0.2	None of the incentives led to a significant increase in mammogram rates but the subset who had a mammogram most recently may be responsive to person-centred incentives
					Control letter offering a lottery for 1 of 5 $250 gift cards if receipt of mammography (1118)	Print	NS		+0.2	
					Control letter to indicate their preference of gift card or entering lottery (a person-centred incentive) (1107)	Print	NS		+1.5	

Michielutte et al. (2005)[154]	USA	RCT	Aged>65, Private healthcare	Educational materials regarding skin cancer, in same frequency as intervention. Physician facing skin cancer information. (914)	Simply written pamphlet on mammography for older patients, with key points such as coverage guidelines highlighted. Physician-facing materials were also sent. (997)	Print	NS		-0.8	No overall effect across all three stages of the intervention, although printed education materials (the second phase) appeared to lead to significant increase in attendance.
					Received initial pamphlet, and 4 months later were mailed educational materials and a fact sheet based upon HBM. The sheet emphasized age as a risk factor, the law for insurance companies and benefits of screening. (997)	Print	HBM	HR at 4 months	+3.5	
					4 months after receiving initial and secondary educational materials, contacted by a counsellor who identified her stage of change. Aim was to note why patient had not screen and the most important barriers addressed. (997)	Print /Tel.	HBM, TTM		+2.7	
Mishra et al. (2007)[155]	USA	RCT	Aged>42, Samoan ancestry	Print materials regarding screening from healthcare providers (385)	Multicomponent, involving educational booklets with Samoan artwork, idioms, and addressing culture-specific myths. Samoan health educators conducted sessions, approaching delicate discussions and religious sensitivities in skill exercises and role play. The sessions aimed at increasing knowledge, planning mammograms and addressing barriers. (391)	In-person /Print	AM, Freire's pedagogy,	SR at 8 months	+8	Despite implementation of a theoretically driven, culturally competent programme, no overall effect of the intervention was seen.
Moskowitz et al. (2007)[156]	USA	Quasi-experimental	Aged >50, Korean American	English language materials from providers (214)	Educational workshops in Koran American churches, incorporation of *Tell a Friend* materials, media campaigns and $15 incentive (205)	In-person	NS	SR at 48 months	+10.8	The multi-faceted intervention did not affect community-level screening practice

Nanda et al. (2020)[157]	USA	RCT	Aged 50-65, primary care patients	Usual care using printed letters and ad-hoc reminding (445)	Participants called to inform them they are due for a mammogram and opportunity to schedule in real-time (445)	Tel.	NS	HR at 6 months	+11*	The telephone call with access-enhancement significantly increased uptake compared usual care practice
Nguyen et al. (2009)[158]	USA	RCT	Aged>40, Vietnamese American	Community-wide breast cancer media campaign addressing stigma, knowledge and encouraging screening. (546)	In addition to media education, lay health workers two sessions of 90mins for 3-10 women. The first concerned breast cancer. mammography facts and motivation. Some used fear-based messages while others used positive messages. The second session 2 months later re-emphasized the benefits. Calls were conducted to help access screening (543)	In-person /Tel.	NS	SR at 24 months	+6.5*	Use of lay health workers with media education was significantly more effective than education-alone at receipt of mammography and breast cancer knowledge.
Page et al. (2006)[159]	Australia	RCT	Aged 50-54	A personalised invitation letter for a free mammo. at a local service (786)	Two personalised letters 6 weeks apart (785)	Print	NS	HR at 3 months	+3*	While 2 letters out-performed 1 letter, there was no difference between the letter and phone call and the 1 letter group
					A personalised letter with a follow-up telephone call at 6 weeks (785)	Print/ Tel.	NS		+2.3	
Paskett et al. (2006)[160]	USA	RCT	Aged>40, From a low-income, rural area with White, Native American, African American people	Printed brochure and invitation on cervical screening at 6 months, and one regarding breast screening at 9 months (418)	Local Native American and African American lay health workers delivered a 1-to-1 educational program in 3 visits over a 9-12month period. They provided materials about individual risk, addressed barriers and helped schedule mammograms. Two phone calls between the first 2 sessions were made to discuss barriers and determine stage of change. This was used to inform tailoring of mailing sent to each woman and postcards. (433)	In-person /Print /Tel.	CBM, MHCM, SLT, TTM	SR/HR at 12 months	+15.2*	Intervention group had higher mammography rates at follow-up than comparison group, this was for all three racial groups.

Phillips et al. (2010)[161]	USA	RCT	Aged 51-70, Assigned primary care provider	Provider based care materials (2078)	Trained patient navigators used a barrier-focussed culturally tailored approach with 3 calls over 2 weeks. They identified and addressed ways overcome barriers (1817)	Tel.	CMM	HR at 9 months	+11*	Mammogram adherence was higher in the intervention than control. Barrier counselling by patient navigators improved rates for low income, minority populations.
Puschel et al. (2010)[162]	Chile	RCT	Aged 50-70	Usual care including ad-hoc advice and information from primary physician (333)	Ad-hoc advice, a letter from the primary care physician, mammogram ordering information and a booklet with messages aimed to explore barriers/facilitators and containing reinforcing factors. (167) A telephone/home contact if no appointment 6 weeks after mail. Messages aimed to explore barriers/facilitators and reinforced factors such as clear information about the procedure (167)	Print Print /Tel.	PERM PERM	HR at 6 months	+45.8* +64.1*	Mailed intervention alone or with personal contact increased rate of mammography compared standard care. Personal contact plus mail had a greater effect than mail alone.
Russell et al. (2010)[163]	USA	RCT	Aged 41-75, African American, <250% federal poverty level	Culturally appropriate pamphlet on screening, and printed nutrition information 3 times. (90)	Combined intervention using a computer program with African American storytellers and demonstration of mammogram. A lay health advisor gauged understanding, addressed individual barriers and gave service information. They contacted participants 3 times to provide further counselling. A tailored mailed postcard was sent out. (89)	In-person /Print /Tel.	EPPM, HBM, SLT, TTM	SR at 6 months	+32.8*	Compared to the low-dose intensity comparison group, the intervention significantly increased adherence, mediated through progress in the stage of screening.
Sadler et al. (2011)[164]	USA	RCT	Aged >20 (>40 for mammo.) African American, attending specific salons	Received a training program on diabetes (120)	Trained cosmetologist led education to encourage clients to attend screening, with laminated mirror challenges posted in the salon, information from Black celebrities and breast models to demonstrate (112)	In-person	HBM	SR at 6 months	+21*	Participants in the intervention group had significantly higher frequency of mammogram than controls, associated with a shift in health behaviour.

Schapira et al. (2019)[165]	USA	RCT	Aged 39-48	Breast cancer risk assessment questionnaire following randomisation (102)	Decision aid that ascertained individual breast cancer risk, introduced decision problems, guidelines, comparisons of mortality reduction due to screening and pictographs comparing the outcomes of screening. (102)	Web	ET	HR at 12 months	-1	No significant difference in use of the decision aid and uptake of mammography despite increased knowledge
Secginli et al. (2011)[166]	Turkey	RCT	Aged >41, local to health centre	Received general health information from health centres but not about breast screening (93)	Nurse-led health promotion program including small group teaching on susceptibility, benefits and barriers to screening, instruction on self-examination, an educational booklet, a calendar to give salient points and allow planning, as well as a card designed as a cue to action (97)	In-person /Print /Video	LR, HBM	SR at 6 months	+5.8	No significant group difference in mammography rates, but the program increased perceived susceptibility, benefits of screening and confidence to screen, as well as decreasing perceived barriers to mammography.
Slater et al. (2017)[167]	USA	RCT	Aged 65-84, Medicare beneficiaries	Usual care practice from the health provider (4266)	Two mailers 1 month apart with a prompting card with a loss framed/high-efficacy message with contact details of screening navigation services (4225) Two mailers 1 month apart with a prompting card with a loss framed/high-efficacy message with contact details of screening navigation services with $25 on receipt of mammogram (4256)	Print /Tel. Print /Tel.	LR, TTM LR, TTM	HR at 12 months	+1.3* +3.4*	Significantly higher attendance was noted in those receiving mail and incentives than mail alone. Both groups had higher rates than controls
Tuzcu et al. (2016)[168]	Turkey	RCT	Aged>20, (>40 for mammo.) Migrant women	Received a standard program for women by the Family Health Centre(100)	A presentation including screening facts, barriers and messages regarding benefits of screening. A film displaying mammogram technique, and training for self-examination on a model. Two reminder cards on the importance of screening and inviting participants to a free mammogram (100)	In-person /Print /Video	HBM, HPM	SR at 6 months	+12.9*	Following the intervention, rates of mammography significantly increased. It was also associated with positive health beliefs (lower perceived barriers and high motivation)

Vernon et al. (2008)[169]	USA	RCT	Aged>52, US Veteran	Undertook an initial questionnaire including questions on screening history only. (1840)	Printed booklets developed from focus groups incorporating testimonials from veterans and how to access services. Messages were tailored to stages of change and aimed at leading to progress through the cycle. An exercise to encourage reflection and a letter to aid discussion with a doctor. (1857) Letter with messages addressing each individual's response to the theoretical constructs in the pre-study survey. The letter included feedback on decisional balance, gave motivational messages and suggested activities to help change. A reminder regarding the next mammogram was included. Two rounds of the intervention were undertaken. The group also received the targeted materials (1803)	Print Print	LR, TPB TTM, LR, TTM, TPB	SR at 15 months	+2.8 +2.8	The tailored and targeted intervention did not result in higher mammography rates than targeted-only intervention, and there was limited support of either over the usual care group.
Vidal et al. (2014)[170]	Spain	Quasi-experimental	Aged 50-69	Letter invitation only. Had to phone to change appointment time (9067)	After the letter received SMS reminder 72h before the appointment, with an ability to reply to the SMS to change the appointment time. (3719)	SMS	NS	HR at appointment	+9.9*	SMS reminders increased participation in a cost-effective manner, especially amongst those who had not previously participated in screening
Wang et al (2012)[171]	USA	RCT	Aged>40, Chinese American	Chinese breast cancer printed fact sheet with information on Asian women's risk, screening	A generic video with soap opera conversation involving common issues across differing ethnic groups such as knowledge, beliefs, barriers and risk. General incidence data presented by a non-Asian physician. (217)	Video	HBM	SR at 6 months	+7.4	The use of a culturally guided or generic video increased screening to a similar extent. Neither video was significantly superior to the print condition. The culturally-target approach seemed

				guidelines and information on local services (222)	Cultural video of Chinese breast cancer survivor telling their story to reframe ideas regarding risk and fatalism. A Chinese physician provides Asian breast cancer data and uses a model to demonstrate. (225)	Video	HBM		+9.2	to more efficacious in increasing amongst those of the lowest acculturation level.
Wu TY et al. (2015)[172]	USA	RCT	Aged>41, Self-identified Chinese/ Taiwanese American	Pamphlet on breast health, role of mammograms and the importance of screening (97)	Counselling tailored to baseline interviews including cultural issues, barriers and self-efficacy lasting up to 1h. Calls delivered in Cantonese/Mandarin/English (96)	Tel.	HBM	SR at 4 months	+7	No differences between print materials and counselling groups indicating that counselling was no more effective than the pamphlet. The intervention was well accepted, feasible and culturally appropriate.

*RCT- Randomised controlled trial, AM- Adherence Model, CBM- Communication-Behaviour Model, CCA- Cultural Competence Approach, CM- Conflict Model of Decision Making, CMM- Care Management Model, EPPM- Extended Parallel Process Model, ET- Exemplification Theory, FBM- Fogg Belief Model, HBM- Health Belief Model, IDT-. Innovation Diffusion Theory, LR- Literature Review, MHCM- Minority Health Communication Model, MoI- Kleinman's Model of Illness, PAPM- Precaution Adoption Process Model, PERM- Predisposing, Enabling Reinforcing Model, PT- Prospect Theory, SLT- Social Learning Theory, SRM- Levanthal's Self-Regulation Model, TPB- Theory of Planned Behavior, TTM- TransTheoretical Model, Tel- Telephone, Mammo- Mammogram, HR- Health record mammogram, SR- Self-reported mammogram, NS- Not stated, * Intervention led to significant change in outcome*

2.4.2 Interventions

A total of 80 different interventions (or stages of multi-step interventions) were included within the 54 studies. Only 50% of interventions were reported as being effective and leading to a significant increase in breast screening attendance compared to controls. In 57 out of the 80 (71.3%) the intervention was delivered by a single modality, whilst the remaining 23 (28.8%) utilised a combination. Print medium was the most commonly employed delivery mechanism (39 interventions, 48.8%), for example in pamphlets or augmented invitation letters. In 41.0% of those using print, an additional delivery method was used in conjunction. Newer methods including app-based mobile, web or computer based digital interventions were utilised less frequently (7 interventions, 8.8%). The remaining interventions used telephone (16 interventions), video-based (4 interventions), mobile messaging (4 interventions), in-person (3 interventions), or a mixture of delivery tools (7 interventions).

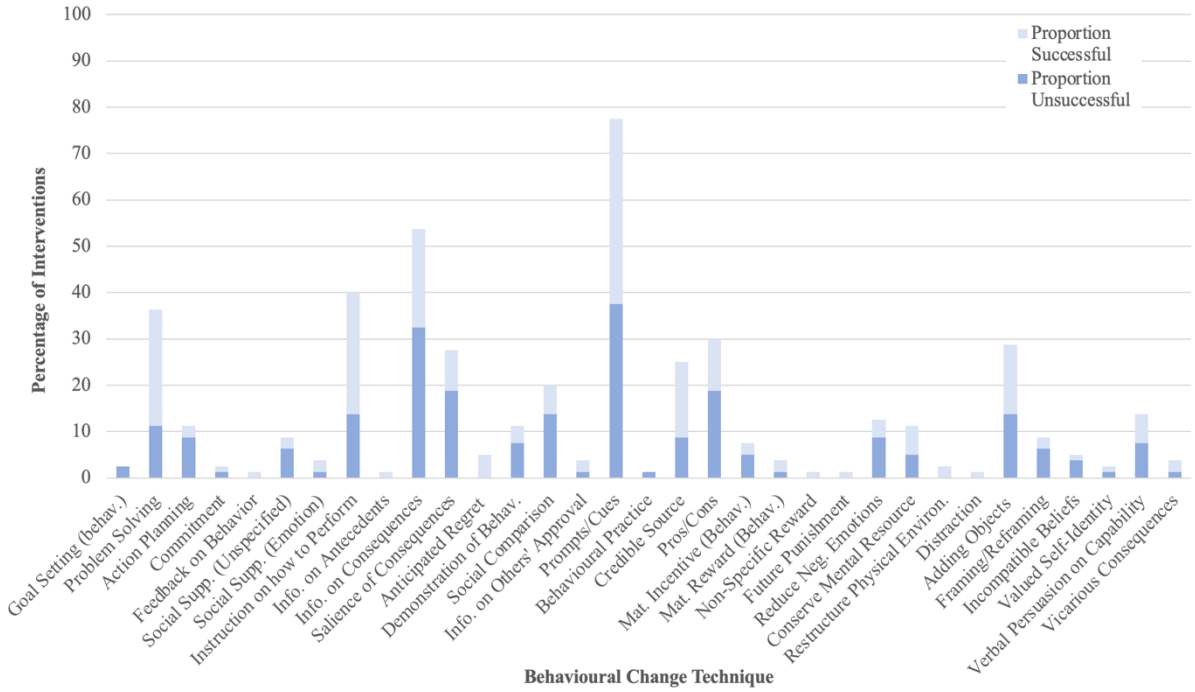
In 38 studies (70.4%) authors employed one or more named behavioural theories to frame the intervention design. The Health Belief Model (HBM) was the most frequently employed, underpinning the development of 31 interventions (81.6% of those using a behavioural theory), described in 21 studies. Of the 56 interventions created using a theory, only 26 (46.4%) were reported at as effective at increasing breast cancer screening uptake. There was no association between the proportion of effective interventions using a named theory compared to those which did not (46.4% v. 58.3% $\chi^2 = 0.95$, $P = 0.33$). No significant difference was also found on the use of any individual theory and the reported effectiveness of the intervention (**Table 2-2**).

Table 2- 2 Theories and theoretical basis underpinning interventions, and the proportion of these interventions which were effective and ineffective.

Theory/Theoretical Basis	Interventions Using Theory (n)	% Effective	% Ineffective	Chi Squared	P Value
None	24	58.33	41.67	Ref	Ref
Theory	56	46.43	53.57	0.95	0.33
Adherence Model	2	50.00	50.00	NA	NA
Communication-Behaviour Model	1	100.00	0.00	NA	NA
Cultural Competence Approach	1	0.00	100.00	NA	NA
Conflict Model of Decision Making	1	100.00	0.00	NA	NA
Care Management Model	1	100.00	0.00	NA	NA
Extended Parallel Process Model	3	33.33	66.67	NA	NA
Exemplification Theory	1	0.00	100.00	NA	NA
Fogg Belief Model	1	100.00	0.00	NA	NA
Health Belief Model	31	48.39	51.61	0.54	0.46
Innovation Diffusion Theory	2	100.00	0.00	NA	NA
Literature Review	14	28.57	71.43	3.14	0.08
Minority Health Communication Model	1	100.00	0.00	NA	NA
Kleinman's Model of Illness	2	50.00	50.00	NA	NA
Precaution Adoption Process Model	1	0.00	100.00	NA	NA
Predisposing, Enabling Reinforcing Model	2	50.00	50.00	NA	NA
Prospect Theory	1	100.00	0.00	NA	NA
Social Learning Theory	5	100.00	0.00	NA	NA
Self-Regulation Model	1	100.00	0.00	NA	NA
Theory of Planned Behavior	9	66.67	33.33	0.19	0.66
Trans Theoretical Model	23	52.17	47.83	0.18	0.67

Chi Squared statistic compares proportion of effective interventions using each theory to the 'none' group. Chi Squared is not possible if <9 interventions used the theory. Ref- Reference, NA- Not applicable due to zero error. Whilst 'literature review' is not a behavioural theory, it represents authors drawing upon a combination of behavioural theories where no singular theory predominated. It was included to examine the effectiveness of this approach.

Figure 2-3 Results from the behavioural change technique coding exercise showing the proportion of successful (effective) and unsuccessful (ineffective) interventions using each BCT.



Behav- Behaviour, Environ- Environment, Info- Information, Mat- Material, Neg- Negative, Supp- Support.

Coding (**Appendix 2-2**) demonstrated that of the 93 (94, including *increasing positive emotions*) techniques described by the taxonomy less than a third (32) of BCTs were used by studies (**Figure 2-3**). Interventions employed a median of 5 BCTs (interquartile range 3). There was no association between using higher (greater than 5) compared to lower (less than or equal to 5) numbers of BCTs, and the proportion of effective interventions (42.9% v. 53.8% effective, $\chi^2 = 0.88$ $P = 0.35$). Changing this threshold to 3 BCTs (51.7% v. 49.0% effective, $\chi^2 = 0.05$ $P = 0.82$) or 7 BCTs (42.9% v. 50.7% effective, $\chi^2 = 0.16$ $P = 0.69$) did not affect this finding. The technique used in the greatest proportion of effective interventions was *problem solving*, which was used in 29 interventions of which 69.0% increased screening uptake. *Credible source* (20 interventions, 65% effective) and *instructions on how to perform the behaviour* (32 interventions, 65.6% effective) were also commonly used in interventions that increased uptake. Four BCTs: *social support (emotional)*, *information on other's approval*, *material*

reward (behaviour) and *vicarious consequences* were also used in a high proportion of effective interventions (66.7%), however, they were not commonly used (3 interventions each). The most utilised BCT, *prompts/cues,* was used in 62 interventions (77.5%) of which 51.6% significantly increased screening uptake. Information based techniques used to increase motivation, by espousing the benefits of screening or consequences of non-attendance were also commonly used, but less effective. This included *information on health consequences* (43 interventions, 39.5% effective), *pros/cons* (24 interventions, 37.5% effective) and *salience of consequences* (22 interventions, 31.8% effective).

When employing a weighted random effects analysis (**Table 2-3**) upon the proportional changes in screening uptake elicited by BCTs categorised into taxonomical domains, *covert learning techniques* had the highest overall pooled effect size, or a pooled increase of 12% in attendance compared to control (ES 0.12, 95% CI 0.05-0.19). This group includes the BCTs *vicarious consequences, punishment* and *imaginary reward.* However only 3 interventions included BCTs from this group, all using the first of these techniques, therefore the finding may not be reliable and generalisable. The domains *self-belief* (ES 0.11, 95% CI 0.07-0.15), *social support* (ES 0.11, 95% CI 0.03-0.29), *regulation* (ES 0.11, 95% CI 0.08-0.13) and *identity* (ES 0.11, 95% CI 0.08-0.13) also demonstrated a high pooled effect size but were used in a greater number of interventions (8-18 interventions). *Associations,* which contains the BCT *prompts/cues*, had the lowest pooled effect (ES 0.05, 95% CI 0.05). All BCT groups in which there were sufficient studies to analyse, led to significant effect sizes, or increases in attendance. However, the I^2 statistic across all groups was very high (91.5-99.9%) demonstrating significant heterogeneity and precluded any further subgroup analyses. The very high heterogeneity greatly limits the interpretation of these findings and the inference that can

be made from the estimated effect sizes of BCTs. No interventions used any BCTs from the domain *scheduled consequences.*

Table 2- 3 Results from weighted random effects analysis showing pooled effect sizes of interventions grouped per the higher domain of the BCTs they use, compared to controls**.**

BCT Higher Group	Interventions Including BCT (n)	Pooled Effect Size	95% Confidence Interval	I Squared Statistic
Goals and Planning	35	0.07*	0.06-0.07	99.2
Feedback and Monitoring	1	NA	NA	NA
Social Support	8	0.11*	0.03-0.20	99.2
Shaping Knowledge	32	0.10*	0.08-0.11	99.6
Natural Consequences	46	0.06*	0.06-0.07	98.9
Comparison of Behaviour	21	0.08*	0.07-0.10	98.3
Associations	59	0.05*	0.05-0.05	99.5
Repetition and Substitution	1	NA	NA	NA
Comparison of Outcomes	37	0.06*	0.05-0.07	99.3
Reward and Threat	8	0.06*	0.03-0.08	99.9
Regulation	18	0.11*	0.08-0.13	99.0
Antecedents	25	0.10*	0.08-0.12	99.6
Identity	11	0.11*	0.08-0.13	99.2
Scheduled Consequences	0	NA	NA	NA
Self-Belief	11	0.11*	0.07-0.15	97.2
Covert Learning	3	0.12*	0.05-0.19	91.5

*NA- Not applicable due to insufficient numbers. *P < 0.05.*

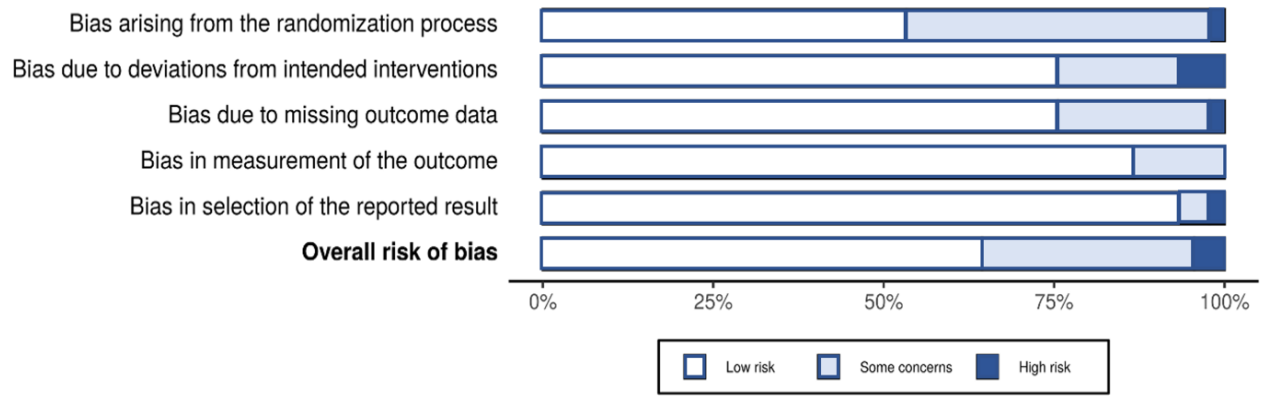
2.4.3 Risk of bias

The risk of bias assessment for RCTs and observational studies is shown in **Figure 2-4**. More than three quarters of observational studies (77.8%) demonstrated a moderate or severe risk of bias, more than twice that of RCTs (35.6%). One of the important sources of bias was the potential influence of external factors upon the likelihood of attendance. These included a

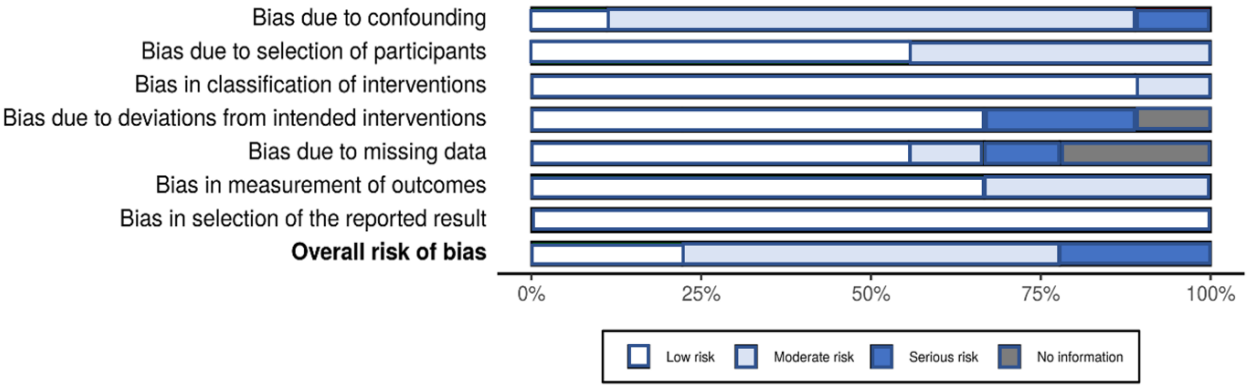
regional breast cancer campaign occurring during Moskowitz et al.'s observational study which may have differently affected screening behaviours within trial arms[156]. As a result, a severe risk of bias was recorded for this study. One of the values of these risk of bias tools is they can permit a sensitivity analysis to be undertaken by examining the outcomes within studies which have only a low risk of bias. Traditionally this is carried out as part of a meta-analysis, however given this formed a secondary outcome of this review, and the high level of heterogeneity this analysis would be inappropriate. Instead, the calculation of the proportion of effective and ineffective interventions using each BCT was repeated only including the 31 studies with a low risk of bias (**Appendix 2-3**). Similar results to the primary coding, were seen with this subgroup. *Problem solving* remained the BCT used in the highest proportion of effective interventions (19 interventions, 73.7% effective). *Credible source* (73.3%) and *instructions on how to perform the behaviour* (73.7%) were also frequently used in effective interventions. Again, *prompts/cues* was the most commonly used technique but less often effective (36 interventions, 61.1% effective).

Figure 2- 4 Aggregated results from the ROB 2 for randomised controlled trials (a) and ROBINS I for observational studies (b) assessments

(a)



(b)


Bias due to confounding
Bias due to selection of participants
Bias in classification of interventions
Bias due to deviations from intended interventions
Bias due to missing data
Bias in measurement of outcomes
Bias in selection of the reported result
Overall risk of bias
0%
25%
50%
75%
100%
Low risk
Moderate risk
Serious risk
No information

2.5 Discussion

Breast cancer screening attendance is a significant public health concern in many countries. To address these trends several interventions have been developed to increase uptake. This systematic review has highlighted the gamut of approaches that been designed and trialled. However, only 50% of the interventions included in this review significantly increased screening uptake compared to control measures and could be considered effective. Furthermore, these interventions only encompass a third of the described behavioural change techniques. BCTs such as *prompts/cues* and *information on health consequences* are commonly used, however are seen more frequently in interventions that are not effective. On the other hand, *problem solving* was utilised less often, but in a greater proportion of successful interventions. Analysis showed that BCTs from higher order domains including *covert learning, self-belief*, and *social support* may have a greater effect upon uptake than other strategies. However, few studies explored the use of these techniques, and high levels of heterogeneity limit these inferences. Furthermore, this study has found that using a behavioural theory (or theories), was not associated with intervention effectiveness. This was found when examining the influence of including any theory, and when examining the use of individual frameworks. This may suggest difficulty in translating theoretical constructs into practice and is of particular importance given the range of different contexts in which the screening interventions were employed.

This systematic review has also demonstrated that there are notable issues with the standard of the reporting literature. The majority of these issues were related to under-reporting of aspects of trial design. For example, while the overall the risk of bias amongst randomised trials was 64.4%, with respect to randomisation and allocation information, just over half of studies were rated as low risk. This was predominantly due to a lack of detail regarding these domains.

Reporting of intervention content was also often found to be poor. In order to facilitate the learning from studies it is imperative that an intervention's design, context in which it is tested and target population are fully reported. In addition, a lack of detail on how missing data was handled was noted in almost half of observational studies. Missing data was due to the dropout rate in studies. In addition, missing data was associated with self-reported screening attendance as an outcome, used in 24 of 54 studies. These measures are subject to response and attrition biases, as often participants are required to complete an exit questionnaire or interview. Levine et al. also note several other concerns with self-reported mammography, such as the difficulty for respondents to differentiate screening (asymptomatic) from diagnostic (or symptomatic) mammography, the lack of validation of reporting tools amongst minority ethnic groups, and telescoping[174] (meaning the effect of recalling more distant events as having happened more recently).

The high proportion of unsuccessful interventions may relate to the tendency to utilise a narrow repertoire of BCTs. This may be as there are well accepted common barriers to screening, such as poor health care access or lack of knowledge[149,157], which form the focus of the existing literature. On the other hand, some unused BCTs, such as *biofeedback,* may not be technically possible. Despite this, most studies utilised *prompts/cues* which includes appointment reminders. Using SMS reminders, not just in mammography, but with other screening programmes has led to an increase in uptake by 5%[174]. This is similar to the effect size of 0.05 elicited in pooled analysis of the higher domain *associations*, which includes *prompts/cues*, although as shown in this study only 51.6% of interventions using this BCT were effective. These findings also corroborate those by Duffy et al. demonstrating that reminders were the most commonly investigated technique across cancer screening programmes, and led to estimated increases in uptake between 3 and 10%[16,106]. Eliciting the true effect of *prompts/cues*

is however challenging, as any contact by researchers or patient navigation may be perceived as a call to action but this cannot always be clearly inferred from the intervention descriptions. This potentially inadvertent prompt may lead to an underestimation of the true effect size of intentional prompts within the research setting[153]. It again underlines the importance for transparency when reporting intervention content.

The use of reminders is also well studied in other fields, including the secondary care outpatient setting[175]. As a result, many programmes including the NHS Breast Screening Programme use reminders as standard practice[176]. Several studies investigated augmenting these reminders by incorporating different techniques. This, however, appeared to yield minimal success, and potentially to even be counterproductive, with three quarters of interventions using *prompts/cues* alone being effective, but only half of those using them in conjunction with other BCTs, being effective. There are several possible reasons for this. Firstly, the expected difference in uptake between an augmented reminder compared to a plain prompt (active control), is likely to be substantially less than that between a reminder and no prompt. As a result, investigating augmented reminders is likely to need larger sample sizes, meaning that studies may be underpowered. Secondly, the additional information placed within the reminder can increase the cognitive load upon the recipient[177]. This would be consistent with the finding that including higher numbers of BCTs was not associated with intervention success. Thirdly, as posited by the fuzzy-trace theory, these additional techniques may only be adding 'verbatim' details such as numerical information on screening rates, which is short lasting. The fuzzy-trace theory suggests that when an individual is provided meaningful information, such as screening data, the information is encoded in two separate ways. The first, is a 'verbatim' representation which is a more detail-orientated version including the exact words or statistics which can sometimes be recalled without understanding. The other representation encoded in

parallel is the 'gist' version, which is information's meaning to the person, which will ultimately impact upon decision making. 'Gist' representations are modified by factors including comprehension, numeracy, and baseline knowledge, but can be retrieved readily. On the other hand, the 'verbatim' representation is often inaccessible after the short-term. Therefore within screening interventions, if the additional behavioural techniques only impact the 'verbatim' representations, and the 'gist' of the message is largely unchanged, then the expected improvement in uptake would be low[178,179].

Examining techniques that work in tandem with prompts, may therefore hold more potential. This review has highlighted some techniques such as *vicarious consequences* and *imaginary reward* (part of the domain *covert learning*), *verbal persuasion about capability* (part of the domain *self-belief*), and *social support* which may show promise. Some of these techniques although less commonly employed, did show a high overall effect size, however, incorporating them into a breast screening context may be challenging. Attending screening is not often associated with a reward, and even the reassurance one may have from a negative result may be mitigated by other immediate factors such as pain. Furthermore, false reassurance for those who do ultimately test positive may weaken trust in the messaging. *Vicarious consequences*, which involves prompting observation of the consequences for others when they perform behaviour, therefore will likely involve drawing attention to a negative consequence or *punishment*. This may be seen as coercive and induce anxiety amongst recipients. *Anticipated regret* parallels this technique but increases awareness of one's own expectations of future regret, and therefore may be seen as less forceful. Furthermore, *anticipated regret* also performed well in this review (100% effective) but was utilised in fewer than the required numbers of studies for comparison (4 interventions). On the other hand, other techniques, such providing *verbal persuasion about capability* (45.5% effective used in 11 interventions), often

in conjunction with *prompts*, may be more feasibly incorporated. This could involve directly sending out messages or having patient navigation tools that argue against self-doubts, as was seen in several studies encompassing the domain *self-belief*. In addition, interventions that engage spousal or familial encouragement of attendance could be used to elicit feelings of encouragement from one's social network encouraging attendance (i.e. *social support*).

Credible source, or endorsement, on the other hand, performed well and has a growing body of evidence of its efficacy, being used in 20 interventions. This includes evidence within cervical and bowel screening. In the current study, almost two thirds of interventions using *credible source* led to significant increase in uptake, predominantly using written testimonials. This proportion is lower than those reported in other reviews, which demonstrate an estimated effect size of 2-3%, but unlike the existing literature the current study incorporates medical as well as cultural endorsement[106]. The role of the latter is an increasingly important consideration. This has been demonstrated in the increase of BRCA testing following Angelina Jolie's mastectomy[180], as well as the spike in cervical screening attendance following Jade Goody's death[181]. Furthermore, the rise of 'health-influencers' has also demonstrated the ability to provide this endorsement using less traditional media[182]. There is however contention as to what extent exposure to influencers would impact health behaviour. Whilst there is evidence regarding impact upon engagement metrics including *likes* or *shares,* there is a paucity of information on tangible outcomes. In one study by Fielden and Holch, using the Theory of Planned Behaviour, they demonstrated no impact of exposure to a social media video upon intention to attend cervical screening. Instead, they found the majority of participants preferred a discussion with a clinician[183], suggesting that endorsement from a healthcare professional may be more influential.

Despite some evidence for a preference for endorsement from a clinician, non-traditional media may facilitate the delivery of complex interventions to wider audiences. Social media platforms provide a direct access to large numbers of patients and have the capability to host interventions encompassing a wide range of BCTs. As shown in the current study however, most interventions utilised a print medium which is more limited in scope. As previously mentioned, considerations are also needed to avoid overloading print interventions, and distracting from the primary message. Whilst print materials will need to be maintained to avoid exacerbating inequalities in digital health literacy[184], emerging technologies may have an adjunctive role. For example, in unpublished findings from the Good Things Foundation, following the development of a Facebook page and an online community for the local population to ask questions, uptake of breast screening increased by 12.9%. They have also noted an improvement in user-experience, which is a key aspect of ongoing screening participation. Further investigation of the potential of digital tools is therefore needed[185].

In addition, emerging technologies may have a role in adapting theory-based interventions into differing contexts. To facilitate understanding of different determinants in various contexts, researchers often adapt more generalised theoretical frameworks to guide mapping, and co-design processes. Contrary to the existing literature which advocates the use of a theoretical foundation in intervention development to help understand how, why, when and for whom an intervention can work[186,187], this review found that using a named theory was not associated with intervention effectiveness. This may be attributed to a lack of detail within manuscripts but may also underline the difficulty in consistently applying theoretical concepts into practice. One challenge is from the methods used to understand behaviour – often surveys and interviews. Given that a high proportion of the interventions were targeted at populations who may be considered underserved (e.g. minority ethnic groups), it is important to ensure

representation of underserved communities to avoid response and sampling bias in the intervention development process. This may mean using appropriate sampling methods and participatory approaches to ensure the acceptability of interventions[188]. Whilst the use of a theoretical basis was not associated directly with effectiveness, there are benefits of incorporating a framework to guide development as espoused by the Medical Research Council (MRC). Using a theory ensures that intervention development is undertaken systematically and provides a strong rationale for the design[189]. This is particularly important when evaluating the impact of an intervention, and when looking to translate effective interventions into new settings. As discussed in Chapter 1, theoretical frameworks such as the TDF and the COM-B can also be used to link determinants underpinning a behaviour to the development of an intervention. None of the interventions within the current review utilised the TDF or COM-B. The most commonly used theory in this review, the Health Belief Model does not give a systematic way to develop interventions, which may explain why use of theory was not associated with effectiveness. On the other hand the BCW, used in other healthcare behaviour contexts, helps to map behavioural determinants to behavioural change techniques. It may therefore provide a novel means of addressing non-attendance in breast screening, and overcome some of the issues found with creating augmented reminders.. Moreover, they may help tackle the challenge of implementing interventions into real-world contexts.

Furthermore, when developing interventions at the population-level, it is important to ensure the findings from small subgroups are not assumed to be applicable to the wider population, or subgroup homogeneity. This is particularly important when value-based judgements are required, for example, with financial incentives. The value placed upon the reward will differ according to an individual's heuristics, and in some the presence of a reward may act as a disincentive by inducing anxiety. This would explain why only a third of interventions using

financial rewards were effective, which is consistent with findings from other screening programmes[190]. On the other hand, *problem solving*, which involves barrier identification and suggesting solutions, was the most effective BCT. This may be due to its individualised nature, however scaling such processes can be financially costly and labour intensive, although digital delivery methods, such as the mobile app used by Lee et al. may help to overcome these issues[150]. New web-applications, as well advances in machine learning techniques, may soon automate these processes and overcome these issues, enabling targeting BCTs feasibly at scale. Currently, *problem solving* may involve providing pragmatic solutions to common barriers and ask individuals to reflect on whether these affect them. To incorporate this at scale, a process of understanding and comparing (or triangulating) these common barriers is needed. This should involve a range of groups, which may require purposive sampling techniques to enable a representative population.

The findings of this review have identified important findings that can guide future intervention design. Firstly, less common-place BCTs, that have shown promise such as *anticipated regret* or *vicarious consequences* should be considered, with research into more than simple *prompts*. If *prompts/cues* are to be used with other techniques, consideration is needed on how these can be delivered at scale but avoiding over-complicating the reminder. Secondly, evaluating the scope for newer resources such as app-based messaging and social media to act as a complimentary delivery method to traditional methods. This may involve developing resources that can be delivered across different platforms and which encompass more complex BCTs. Thirdly, consider the role of automated or algorithmic barrier identification, to facilitate the targeting of behavioural change techniques feasibly at the population level . Until automated barrier processes have been validated, there is a need for robust participant sampling, participatory intervention development, and the triangulation of differing sources of

behavioural determinants to overcome the challenges associated with subgroup homogeneity. Finally, intervention content and design should be clearly defined by authors in publications, to facilitate critical evaluation of successes, and aid future endeavours to tackle the increasing demands faced by breast screening services.

2.5.1 Limitations

Despite using an appropriate methodology, the findings of this systematic review must be considered within the context of its limitations. Firstly, the review is reliant upon the information provided by authors, which was often sub-optimal. Although this was mitigated by searching protocols, presentations, and where applicable, directly contacting relevant authors, not all relevant data could be obtained. This would impact upon the accuracy of the findings, especially for the BCT coding and analysis. A lack of clarity regarding which techniques were being used could lead to the under-representation of some techniques. Furthermore, the data derived from studies was not conducive for meta-analysis. Whilst analysis was only a secondary exploratory aim, this evaluation of the effect of individual BCTs upon uptake was planned *a priori*, as it was felt it would provide valuable information for future intervention development. This analysis was precluded by the significant heterogeneity between studies. Whilst heterogeneity was expected given that the selection criteria was set to maximise the inclusion of a breadth of different interventions from a variety of healthcare systems, this will impact the generalisability of the conclusions.

The broad inclusion criteria also meant that there was a heterogeneity in the comparators, as no limit was placed upon the nature of the usual care standard. Whilst this enabled a range of studies to be included, and provided insights on how different tools could be integrated into healthcare systems, the variation in the control group procedures may limit understanding of

the true impact of interventions. As mentioned previously, some comparator groups included the use of reminders as standard practice in countries with longer standing programmes. Trialling augmented reminders in these contexts is likely to require greater sample sizes and may show comparatively lower effect size than if it were investigated in a country without reminders in place. Similarly, historical interventions trialled in countries with programmes established prior to 2005 which were not implemented due to a lack of effectiveness, would not have been included. Whilst this could be mitigated by expanding the temporal restriction, this is beyond the scope of this review which aimed at providing a contemporary review of interventions. Given the incidence, outcomes and conduct of screening has changed substantially, it would be unsuitable to examine older studies. Furthermore, current studies only estimated uptake at certain screening services. Many countries utilise mixed models of care in which government funded programmes are supplemented by privatised systems. These private providers will not necessarily contribute to public statistics, but will reduce attendance at the government funded programmes[191]. Whilst this may impact outcomes from interventions, in a randomised trial these factors would be expected to be evenly distributed across trial arms.

There may also be concern regarding the inclusion of observational studies which had higher risk of bias. Many of these studies involved pragmatic trials, and provide invaluable insights into the effectiveness, as opposed to the efficacy of interventions. However, the sensitivity analysis undertaken demonstrated that removing higher risk studies did not significantly impact upon conclusions.

2.5.2 Conclusions

Despite an increasing need to counteract recent trends in breast screening uptake in numerous countries, only half of existing interventions were reported as effective. There may be several

reasons for this, including the reliance upon commonly cited techniques, such as *prompts*, which have been well-investigated. Interventions utilising less commonly evaluated techniques including *vicarious consequences,* or *anticipated regret*, and *social support* may hold promise, and warrant further investigation. Techniques such as *problem solving* and *credible source*, which have a growing body of evidence underpinning their effectiveness, should also be considered. Emerging technologies, and the accessibility of non-traditional media resources, may facilitate the application of these BCTs in ways that are scalable, in order to reach a wide population. Technological advances, such as online communities, may also help improve user-experience which will help repeated attendance, which is ultimately the long-term aim of breast screening programmes. This review has therefore presented the state of interventions to increase breast screening attendance and utilised a validated framework to critically evaluate their behavioural content. In addition, is has provided a critical appraisal of the current literature and developed recommendations for future work.

3. Developing Principles for Mobile Messaging and SMS Use in Population Screening Programmes: a Delphi Study

Outputs related to this chapter

A. Acharya, G. Judah, H. Ashrafian, V. Sounderajah, N. Johnstone-Waddell, A. Stevenson, A. Darzi. Investigating the Implementation of SMS and Mobile Messaging in Population Screening (the SIPS Study): A Delphi Study. *EBioMedicine.* 2023; 93;104685

Office for Health Improvement & Disparities. *Screening text message principles.* 2022. Online. Available from: https://www.gov.uk/government/publications/nhs-population-screening-effective-text-message-use/screening-text-message-principles

A. Acharya, G. Judah, H. Ashrafian, V. Sounderajah, N. Johnstone-Waddell, A. Stevenson, A. Darzi. Investigating the Implementation of SMS and Mobile Messaging in Population Screening (the SIPS Study): Protocol for a Delphi Study. *JMIR Res Protoc.* 2021; 10(12):e32660

A. Acharya, G. Judah, H. Ashrafian, V. Sounderajah, N. Johnstone-Waddell, M. Harris, A. Stevenson, A. Darzi. *Investigating the implementation of mobile messaging in population screening programmes.* 2022. Public Health Science Conference. Glasgow, UK

3.1 Abstract

Background

Mobile messaging is an increasingly common means of communication in healthcare. Compared to other healthcare contexts, population screening programmes raise unique issues when implementing and using mobile messaging. Despite mobile messaging being advocated by national policy there is little guidance to facilitate its implementation. The aim of this study was to develop a list of expert-derived recommendations to assist the effective use of mobile messaging in adult screening programmes in the UK.

Methods

A modified Delphi study methodology was undertaken, beginning with an evidence synthesis - encompassing a literature review, public consultation, and expert scoping exercise - to derive an initial list of recommendations. The experts, from the intersecting fields of screening commissioning, public health, communications, academia and industry, voted upon the importance and feasibility of these items, using a 5-point Likert scale. Consensus was defined *a priori* at 70%, with recommendations reaching this threshold with respect to both importance and feasibility designated as 'core.' Those which were important but were not currently feasible were categorized as 'desirable.' The final items were then discussed with the experts at a consensus meeting.

Results

A total of 40 items reached consensus with respect to importance from the initial list of 101 recommendations. Of these, 23 were 'core' items, including the use of behavioural science messages to facilitate screening attendance, and the need to evaluate message impact upon healthcare inequalities. The remaining 17 items were 'desirable' and included message targeting and exploring the implementation of new messaging technologies.

Conclusions

The findings highlight the need for screening services to contemplate aspects of messaging other than content, such as timing, security and means of delivery. This will enable them to leverage these communication tools effectively. Moreover, it provides a template for the development of new interventions and novel messaging technologies within screening programmes.

3.2 Introduction

In population screening programmes, reminders are the main means of delivering behavioural content, namely as a *prompt* for an upcoming appointment. Kerrison et al. demonstrated that using plain SMS reminders as an adjunct to the traditional letter invitation increased breast cancer screening uptake by 5%[143]. As shown in Chapter 2, there has been variable success when these reminders are augmented further. For example, whilst including a means to reply to the SMS to change the appointment time was effective, incorporating information on the benefits of screening was not[146,170]. However, there are considerations beyond content that also need to be considered when employing *prompts*. Whilst an SMS reminder's content may act as a call to action to attend screening, the overall effectiveness of the message will also depend upon when, how and to whom it is delivered. For instance, a reminder sent too soon after an initial invitation to screen may be forgotten by the time the appointment is scheduled. Conversely, a reminder sent too close to the appointment time, may not provide sufficient opportunity to attend the appointment. Given the improvement in attendance associated with *prompts/cues*, the current screening infrastructure has an established means of delivering these reminder messages. Prior to developing a *de novo* intervention, it is important to establish whether these existing mobile messaging reminders can be optimised to improve attendance at population screening programmes. If a new intervention is needed it is also important to understand the different considerations regarding its delivery and evaluation that should be considered.

Mobile messaging is a term that encompasses a broad range of communication technologies and multimedia platforms delivered through mobile or hand-held devices[192]. These technologies include systems such as Short Message Service (SMS), Multimedia Message Service (MMS), Rich Communication Services (RCS) and app-based messages[193]. The use of

this mode of communication has grown significantly, in keeping with the increasing availability and use of mobile devices. In 2021, it was estimated the 88% of the UK adult population owned a smartphone, more than 5 times the ownership level in 2008[194]. Moreover, in one 2020 YouGov survey, 55% of UK consumers said they would prefer to receive an SMS over a phone call, however amongst those aged 55 phone calls were preferred[195].

Within healthcare, mobile messaging has also grown in popularity, with two-fifths of primary care practices using text messages to communicate with patients in 2017[196]. Whilst studies have shown that mobile messaging is an acceptable means of healthcare communication to patients including those from underserved groups, it is also extremely versatile[197]. Several mobile health (or mhealth) interventions have been trialled in a diverse array of clinical specialties including infectious diseases, dietetics, and surgery[198–200]. In each case the purpose of the intervention has been different, whether it be as a health promotion tool, an adjunct for disease monitoring or in treatment support.

Mobile communication from screening programmes, however, poses unique challenges. There are currently 11 adult screening programmes in the UK, which invite the public to test for conditions ranging from breast cancer to abdominal aortic aneurysms[201]. As the primary aim of screening is the asymptomatic detection of disease, those who are invited will not have been diagnosed with the condition being investigated. Invitees may therefore have no understanding of why they are being invited and lack awareness of the consequences of that condition. Moreover, in some programmes the invitation to screen will come from a central hub with whom an individual may not have previously communicated[202]. This can lead individuals to mistrust the information they receive or under appreciate the importance of attending. In addition, not all of these screening systems have access to primary care data, which can lead to

security concerns and issues regarding telephone number verification[203]. Screening services also serve very large populations, with the 11 programmes inviting an estimated 15 million people annually[16]. With such a diverse range of communication needs to be met, there are already concerns regarding the use of mobile technologies exacerbating inequalities in digital literacy[204]. At a population scale, such disparities can easily be widened, and therefore, any alteration of messaging must be evaluated closely. Implementing complex interventions into these pathways successfully, therefore, requires significant consideration.

There is, however, a lack of robust guidance on how to effectively utilise mobile messaging within screening programmes or how to integrate novel messaging interventions into screening processes and systems. Of the few existing frameworks, the predominant focus is upon a single service such as a GP practice[205]. In addition, the main recommendations address the content of the messages, but do not cover the other issues faced by screening services[206]. Any guidance for screening would thus need to take a multi-faceted approach in order to encompass the various important features of screening communication. This chapter describes the development of cross-programme guidance regarding the use and implementation of mobile messaging in population screening to address the paucity of current evidence.

3.2.1 Aims

The aim of this modified Delphi study is to develop a list of cross-programme recommendations on how screening services can effectively use or implement mobile messaging. This will a) standardise the approach taken by services and aid widespread implementation as advocated in the Richard's report[16], b) facilitate the successful introduction of novel messaging interventions, c) set the future direction of messaging in screening as

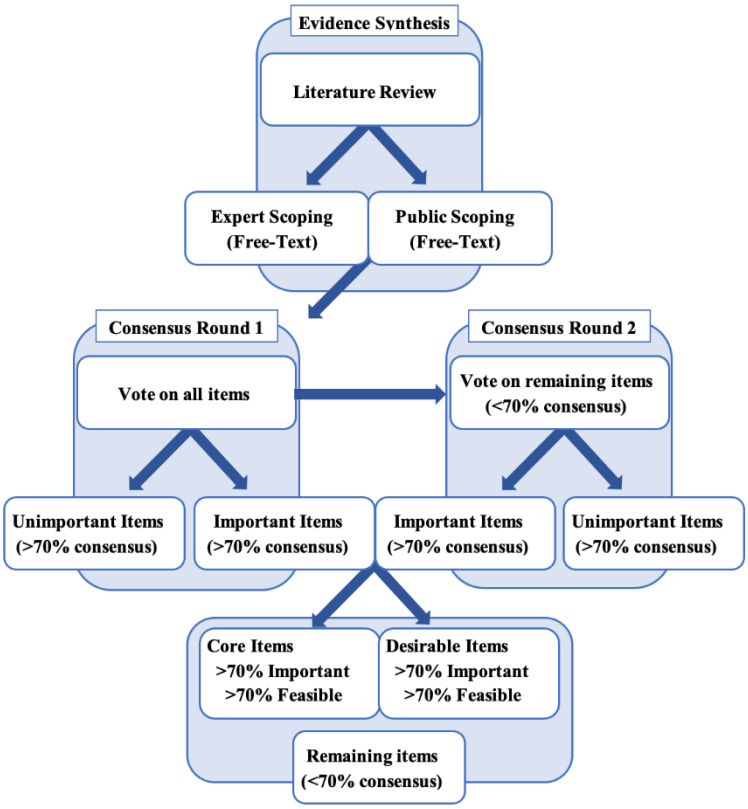
mobile technologies continue to evolve and d) help researchers understand the range of factors to consider when developing messaging-based screening interventions.

3.3 Methods

3.3.1 Study Design

The study was conducted in two distinct phases: evidence synthesis and consensus generation (**Figure 3-1)**. Ethics was prospectively granted by the Imperial College London Research Ethics Committee (reference 20IC6088). All participants, both experts and public, gave informed consent for each phase of the study they took part in, and had the freedom to withdraw without reason at any point.

Figure 3- 1 Study design and participant flow.



Evidence Synthesis

An evidence synthesis was conducted to determine the key considerations regarding mobile messaging implementation. This involved a literature review of available published academic and grey literature across Medline, EMBASE, Google Scholar databases. Search terms

included “text messag*,” “SMS,” “short message service”, “mobile messag*,” “mass screening,” “population screening,” terms related to individual active adult screening programmes, and standard Boolean operators OR/ANDs. The full search strategy can be found in the **Appendix 3-1.** Temporal restrictions were placed to include articles from the 1st January 2000. Given this study aimed at developing guidance relevant to screening services in England, this geographical restriction was placed upon academic studies involving patient populations. However, messaging frameworks or articles describing general healthcare messaging recommendations had no restrictions placed upon them, nor did they have to pertain directly to screening practice, as they gave provider-facing guidance and did not relate to specific patient populations. All titles and abstracts were independently screened by two researchers, with disagreements discussed until a resolution was achieved. Articles that described evaluations of multi-faceted interventions involving an mhealth message whose contribution could not be independently elicited from the other components were excluded.

Data regarding the role of the mobile message (e.g. reminder, health promotion), messaging interventions, and any potential areas of contention in the implementation of the message (e.g. privacy concerns) were extracted. This information was used to a) develop overarching themes or domains of interest regarding message implementation and b) to guide the development of an initial item list.

The second component first began by convening a steering committee encompassing members from Imperial College London, Office of Health Improvement and Disparities, and Public Health England. Members of the steering committee were selected based upon their experience of screening research, Delphi methodology, public health communication and screening governance. The committee oversaw an initial scoping exercise which was conducted

separately with members of the public and experts. Both groups completed an online questionnaire which was framed around the domains of interest elicited from the literature review. Each participant was provided with short prompts regarding topics related to the domains and were asked to give unrestricted free-text responses.

Service User Opinions

To ascertain the opinions of service users, a public scoping exercise was conducted. Adult members of the public based in England, who were eligible to attend one or more screening programmes, were invited to participate in the online questionnaire. Public participants were recruited through the online social research platform VOICE (Newcastle, UK). They were provided the initial list derived from the literature and encouraged to provide free-text feedback on each item. The aim of this exercise was to determine (1) whether any key aspects of mobile messaging had been omitted from the literature review, (2) to refine the initial item list and (3) to help contextualise the findings from experts' viewpoints. In order to achieve (3) the opinions of service users were available for experts to review during the consensus exercise regarding pertinent items e.g. preferred style of message. This would act to help guide experts' voting. Service user responses were optional, as it was anticipated that the public may not have awareness of some aspects, for example about messaging security measures.

Experts

For the expert exercise, participants were identified by the study steering committee and involved any individual deemed to have significant experience within the intersecting fields of screening provision, screening commissioning, public health, healthcare communications, preventative health research and industry. Experts held prominent regional or national roles within their field, and also had experience of one of the existing eleven adult screening

programmes or the currently piloted Lung Health Check. Two experts were members of the public with expertise in screening, again this was to ensure service user interests were represented. Experts provided free-text responses to prompts placed under each domain heading (**Appendix 3-2**). Responses from both the public and experts were analysed using an inductive thematic approach, described by Braun & Clarke[207]. This involved two authors familiarising themselves with responses, coding the text, and deriving recurring sub-themes. These sub-themes were discussed amongst the wider steering group and were used to develop the initial item list. Furthermore, qualitative data (summary or exemplar quotations) and quantitative data (frequencies of particular responses e.g. 50% mentioned this as a potential use) were elicited for use in the consensus process.

The initial item list, developed by the study steering group using outputs from the evidence synthesis, constituted single items for consideration within the final recommendations for services. When there was no available evidence to suggest whether two potentially contradictory statements were superior (e.g. improving personalised content using patient names versus maintaining security by avoiding identification) both were included. Feedback on this item list was also sought from relevant national stakeholder organisations including from representatives from NHS communications teams and the National Cyber Security Centre (NCSC).

Consensus

The consensus rounds were conducted as a modified Delphi study. Delphi studies have been previously used to derive agreement on the use or implementations of healthcare technologies, including surgical video-recording and artificial intelligence (AI) radiological systems[208,209]. They also can be conducted to synthesize the perspectives of a broad and diverse stakeholder

group such as described in this study, without one viewpoint being dominant[210]. This is particularly important given the representation of experts from differing screening programmes. Furthermore, the Delphi technique facilitates the development of expert-level consensus through an iterative process of voting and amending these ratings following feedback from the collective group. This is important, as the primary aim of this study is cross-programme consensus and thus a collective input is required. Finally, Delphi studies, unlike other methods such as the Nominal Group Technique lend themselves to being undertaken remotely, which given social distance requirements was mandated[211]. The modification of the traditional Delphi method, by incorporating a final meeting to review items, has also been shown to foster better collaboration and improve outcomes[212].

The expert group were invited to participate in two sequential consensus rounds. During each round experts were asked to rate the a) the importance and b) feasibility of incorporating the item pertaining to mobile messaging use in screening. Voting was undertaken for importance (1- extremely important, 2- important, 3- neither important nor not, 4- unimportant, 5- extremely unimportant) and feasibility (1- absolutely feasible, 2- feasible, 3- neither feasible nor not, 4- unfeasible, 5- absolutely unfeasible) using a 5-point Likert scale. Importance was defined as a consideration that was integral to the effective, safe or appropriate use of mobile messaging for screening services. Feasibility was defined as a characteristic that could be readily incorporated into the current infrastructure without significant outlay in financial, time, logistical or governance costs. In the first round participants were provided the feedback from both the expert and service user scoping exercise, as described. Experts were also provided another opportunity to give free-text suggestions for additional items they felt were relevant to screening services for voting in the second round. In the second round, participants were provided the data from the scoping, as well as aggregated data from other experts in round one.

3.3.2 Analysis

The threshold for consensus was defined *a priori* at 70%, in keeping with other published Delphi studies[213]. Items which reached consensus, with experts agreeing that it was unimportant or extremely unimportant (on Likert scale) were excluded from subsequent voting. Items which reached consensus as important or extremely important were included for discussion in the final meeting. Those important items that also reached consensus as feasible or absolutely feasible (on Likert scale) were designated as 'core' items. Those which did not reach the threshold regarding feasibility, but had agreement they were important, were labelled as 'desirable'. Items which did not reach consensus regarding importance (either positive or negative), and new suggestions from round 1, were voted upon in round 2. This second voting round took the same format as the first, with the same consensus threshold regarding importance determining the outcome of each item. All items which reached consensus, and those which did not after the two rounds, were discussed in detail at the consensus meeting. During this online meeting, experts were presented with aggregated voting over the two rounds, if applicable, for each item, and were provided an opportunity to discuss the item together. In addition to finalising the list of core, desirable and no consensus items, changes to the wording of recommendations were agreed upon to better reflect current practice.

3.4 Results

3.4.1 Participants

33 experts were recruited to the study with the majority working primarily in academia (25.8%), screening provision (19.4%), government health policy (19.4%), health communications (12.9%) and public health (12.9%). Within this group there was experience of all 11 active screening programmes, as well as the Lung Health Check (which is currently being piloted). Whilst some programmes such as cervical cancer screening (30.3% of experts) were well represented, others such as newborn blood spot screening (3.0% of experts) were less so. However, taking the newborn programmes as a collective greatly increased the representation (18.2% of experts).

In addition, 22 members of the public were recruited to participate and give feedback in the scoping exercise. All had previously been invited to, were familiar with, or had attended, at least one of the UK screening programmes. No participants were familiar with the newborn blood spot or the currently piloted Lung Health Check. The majority of public participants had received SMS reminders for health appointments (84.2%), whilst 79.0% used mobile messaging for personal communication, but only 5.3% used mobile messaging to send information to healthcare professionals.

3.4.2 Consensus Statements

Following the literature review, which was the initial phase of the evidence synthesis, several common areas for consideration were identified across research articles (**Table 3-1**) and grey literature (**Table 3-2**). These were aggregated by two independent researchers into 6 overarching domains: message content, timing, delivery, evaluation, security/governance and

research/future considerations. The scoping questionnaire and consensus item lists were mapped to these 6 domains. Through evaluation of the scoping responses, literature review and discussion amongst the study steering group an initial list of 101 items were developed and voted upon in the first consensus round (**Appendix 3-3**). This included items such as using factual national cost information (e.g. missed appointments cost the NHS £X per year) in reminder messages. Twenty-eight statements reached consensus regarding importance (>70% agreement) and were removed from further voting. A further 54 items did not reach consensus (in either direction) and were voted upon in the second voting round. During this second voting round, 12 items reached consensus and were included, with the remaining 42 items still not reaching consensus. There was no attrition of experts between voting rounds with 100% responding to both requests to vote. Cronbach's alpha across the two voting rounds was 0.966 and 0.778, respectively, indicating a high level of inter-rater reliability.

The final consensus meeting was attended by 29 out of 33 experts (87.9%). During this meeting there were no changes to which items were included into the final recommendation list. The wording of the items, however, was amended according to experts to better reflect current practice or to better guide screening services. Furthermore, as several items which had not reached consensus pertained to newer mhealth technologies (e.g. push notifications), it was decided that the experts present at the meeting would vote upon which technologies they felt held the greatest promise for services. App-based messaging (27.6% of experts) was considered the most promise, with push notifications (20.7%), calendar integration (20.7%) and multimedia messaging (17.2%) also considered as future priorities. Few experts felt bot-technology (6.9%) or enabling service users to select their message preferences e.g. timing or content (3.4%) were important considerations. Following the consensus meeting the finalised

list of core and desirable items was determined (**Table 3-3**). The items are discussed below, categorised according to domain.

Table 3- 1 Studies extracted in the evidence synthesis and identified areas of contention.

Author	Year	Type	Programme	Role of Message	Intervention	Author Conclusions	Areas for Consideration
Hirst et al.[214]	2017	RCT	Colorectal	Reminder to return kit	GP endorsed SMS at 7 weeks	Intervention did not lead to significant effect overall but increased uptake amongst first-time invitees.	Timing, Priming, Verification of numbers, Endorsement
Huf et al.[215]	2020	RCT	Cervical	Reminder to book	Behavioural science informed messaging	Endorsed SMS reminder 3 weeks after invitation increased uptake by 18 weeks	Behavioural science, Endorsement, Verification of numbers, Preferences of communication
Huf et al.[203]	2017	RCT	Breast	Reminder to attend	Two Behavioural science informed messages	Intervention did not lead to significant effect	Verification of numbers, Behavioural science, Endorsement
Icheku et al.[141]	2015	Observational	Breast	Reminder to attend	SMS 1 week prior to appointment and further if DNA	Screening coverage increased by 2.54% with SMS	Verification of numbers, Effect on Inequalities, Privacy concerns, Evaluating acceptability
Kerrison et al.[143]	2015	RCT	Breast	Reminder to attend, DNA SMS	SMS at 48h prior and further if DNA	Reminder increased attendance at first appointment offered. Effect size greatest amongst those from most deprived areas	Appointment details, Re-booking, Verification of numbers, Effect on inequalities
Ryan et al.[216]	2019	Observational	Cervical	Reminder to book	App-based message with an ability to book	Over 10% of non-attenders booked an appointment	Effect on Inequalities, Signposting to non-app means of booking, Evaluating impact

48h- 48 hours, DNA- did not attend, RCT- randomised controlled trial, SMS- short message service

Table 3- 2 Grey literature documents extracted in the evidence synthesis and identified areas of contention.

Author	Year	Country	Type	Field	Role of Message	Areas for Consideration
CRISP[217]	2013	USA	Guidance	Research	Mobile reminders, sharing information, health promotion	Evaluating impact, Maintaining security, Message tailoring, Timing, Consent and Opt-out, Effect on inequalities
Martinego et al.[192]	2020	UK	Guidance	Primary Care	Mobile reminders, sharing information, health promotion	Preferences of communication, Maintaining security, Verification of numbers, Bi-directional messaging, Training needs, Privacy concerns, Audit of messaging processes, Integration with EHR, Messaging confirmation
MDU[205]	2021	UK	Guidance	Primary Care	General communication	Preferences of communication, Consent and Opt-out, Maintaining security Privacy concerns, Evaluating acceptability, Communication needs
NHSX[206]	2022	UK	Guidance	General	General communication	Maintaining security
RCN[218]	2016	UK	Guidance	Nursing	Sharing information	Maintaining security, Evaluating impact, Accountability
Suggs et al.[219]	2015	Qatar	Guidance	General	Health promotion, sharing information	Effect on Inequalities, New technologies, Evaluating impact, Evaluating acceptability, Communication needs, Behavioural science, Endorsement, Timing
US HHS[220]	2010	USA	Guidance	General	Health promotion	Evaluating acceptability, Evaluating impact, Effect of inequalities,

Table 3- 3 The final recommendations that reached consensus

Domain	Item	Voting (%)			Designation
		R1 Imp.	R2 Imp.	R Feas	
Content	Using concise simple language (reading age of 9)	87.9	-	83.9	☑
	Using non-technical language with factual, non-coercive information	81.8	-	92.9	☑
	Specifying the date, time (am/pm), location	84.8	-	79.1	☑
	Include additional information such as what to bring, or what to do, where possible.	60.6	75.8	76.1	☑
	Specifying who has sent the message (e.g. screening service or GP practice) and purpose	90.9	-	92.9	☑
	Including weblinks to evidence or more information (e.g. screening website)	84.8	-	88.9	☑
	Providing a telephone number to book	81.8	-	81.8	☑
	Where appropriate using GP endorsement in reminder messages (e.g. [Practice name] encourages you to screen]	72.7	-	81.3	☑
	Sending messages to facilitate attendance at screening (without being coercive), which could use behavioural science	84.8	-	78.9	☑
	Using Did Not Attend Messaging (DNA) messages for missed appointments	60.6	84.8	75.0	☑
	Sending messages in English, but with language translations available (e.g. via weblink or by previous selection)	87.9	-	63.6	★
	Providing an ability to re-book in the message other than telephone no. (e.g. by text or weblink)	72.7	-	39.4	★
	Using messages tailored or targeted at certain groups (such as patients at higher risk of an illness)	54.5	84.8	48.5	★
Timing	2 messages maximum should be sent at 1 time in the programme ideally	57.6	78.8	78.8	☑
	Before an appointment 2 reminder messages should be sent at day 7 before then at day 2 before.	51.5	78.8	78.8	☑
	Following an open invitation (e.g. to book an appointment) or sending of testing kit 3 messages should be sent if there has been no booking or returned kit. These will be on average 12 days, 20 days then 28 days after the invitation.	54.5	72.7	72.7	☑
	Using confirmation texts immediately if a booking has been made or a kit has been received	78.8	-	57.6	★
Delivery	Flagging individuals who have who it might not be appropriate to message (e.g. following a miscarriage/patient passing away)	81.8	-	46.9	★
	Ensuring all services are integrated into the GP Spine to enable telephone number verification	93.9	-	63.6	★
	Verifying numbers through direct contact with patients where possible	81.8	-	50.0	★

	Enabling limited bi-directional messaging service (e.g. for booking, confirming locations, organizing translations)	48.5	72.7	36.4	★
Evaluation	Routinely evaluating the impact of new/different messages on regional healthcare inequalities	90.9	-	75.0	☑
	Measuring user satisfaction by recording opt-out rates	60.6	84.8	81.3	☑
	If no existing pathway is available, periodically assessing usefulness of messages/satisfaction through other means (online, telephone and in writing)	51.5	81.8	81.3	☑
	To ensure ongoing acceptability of messages to the public, introducing ongoing testing (e.g. online A/B testing, or User-experience trials)	63.6	78.8	72.7	☑
	Incorporating satisfaction measures into existing pathways (e.g. GP practices or NHSP Parent Survey) where possible	75.8	-	42.4	★
	Assessing measure mobile message delivery success reports and measure responses rates (e.g. in bi-directional messages, or appointment calls)	84.8	-	62.5	★
	When necessary using linked datasets (e.g. between screening services and GP data or hospital data) to facilitate the evaluation on healthcare inequalities	90.9	-	51.5	★
	Routinely collect measures of knowledge and attitudes (e.g. Decisional Conflict Scale) to screening to determine the effect on informed choice	72.7	-	27.2	★
Security	Maintaining consistency across media including publishing contact details/links on websites and in letters, so individuals can verify these as legitimate	84.8	-	84.4	☑
	Using MEF-registered (official) SenderIDs (e.g. "[Screeningservice] sent you a message", as opposed to "[+4478…] sent you a message")	87.9	-	50.0	★
	Defining a wrong recipient message receipt as a reportable breach	84.8	-	36.4	★
Research & Future	Using experimental methods such as Randomised Controlled Trials to determine the impact of novel messages	66.7	78.8	78.1	☑
	Using online experimental methods such as A/B testing to determine the impact of novel message	60.6	81.8	71.9	☑
	Routinely report the outcomes of trials/research on population inequalities (e.g. between different demographics, and individuals with different health conditions)	78.9	-	72.7	☑
	Prior to large trials, new messages should ensure Patient and Public Involvement and qualitative measures are undertaken	93.9	-	87.5	☑
	Screening services/NHSE Publishing their research priorities, to enable researchers to focus upon relevant areas (this includes non-content related areas)	84.8	-	79.1	☑
	Involving top-down infrastructure and governance support to facilitate research, including enabling trials across services/regions e.g. providing roadmaps for trial conduct, dissemination findings to stakeholders	75.8	-	60.6	★
	Implementing fast-track processes to enable widespread testing for messages with trial evidence	75.8	-	51.5	★
	Facilitate the examination of new technologies e.g. NHS approved app-based integration or push notifications	80.8	-	64.5	★

DNA- did not attend, GP- general practitioner, NHSE- National Health Service England, NHSP- newborn hearing screening programme, R1 Imp- percentage of experts voting item as 'important' or 'extremely important' in round 1, R2 Imp- percentage of experts voting item as 'important' or 'extremely important' in round 2, R Feas.- percentage of experts voting item as 'feasible' or 'absolutely feasible' in the round that reached consensus with respect importance, ☑ *core item,* ★ *desirable item*

Content

The content of mobile messages was the domain with the greatest number of agreed upon statements (13 out of 40 statements, 32.5%). These statements were divided into three sub-domains: language, appointment/screening details and facilitating attendance. Experts agreed that the language should be as "simplistic, and concise as appropriate" with 87.9% feeling this was important. The use of weblinks to additional information was voted as an important (84.8%), and feasible (88.9%) means of keeping messages succinct. Additionally, there was also consensus in the first round regarding the incorporation of appointment details (84.8% important, 79.1% feasible) the provenance and purpose of the message (90.9% important, 92.9% feasible). However as discussed in the consensus meeting, providing a lengthy or detailed explanation was felt to add little additional reassurance as to the messages' legitimacy, but convolute the content. The expert panel also agreed that it was important for mobile messages to facilitate attendance using behavioural science. Within the consensus meeting this item was reworded to include that this should be non-coercive, as some experts felt certain behavioural techniques such as loss aversion or anticipated regret could induce negative responses. This paralleled expert voting regarding cost information (e.g. missed screening appointments cost £X to the NHS) which did not reach consensus, but 57.8% of experts voted as 'unimportant' or 'extremely unimportant.' However, using tailored or targeted content was considered important (84.8%) but more than half of experts felt was not currently feasible (51.5%) as highlighted in the consensus meeting due to a "lack of data availability or analytical infrastructure."

Timing

Panellists were asked to vote on the most important and feasible timing of messages using a sliding visual scale. The optimal timing of the message was found to differ according to the

role of the message. Most experts (78.8%) agreed it was important and feasible to send two reminders, at 7 and 2 days before a timed or set appointment. However, when reminding an individual to book or return a testing kit, it was determined three reminders, at an average of 12, 20 and 28 days following the initial postal contact was optimal (72.7% important). Experts also agreed it was important (78.8%) and feasible (78.8%) to limit the length of messages to 320 characters (the equivalent of sending two SMS messages at one time). There were concerns raised during the consensus meeting that the services would contravene this recommendation at times, for example during the COVID-19 pandemic when more information regarding the use of non-pharmaceutical interventions, such as facemasks, was required. The original wording was therefore altered to highlight this recommended length as an optimal/ideal strategy to ensure services could be pragmatic.

Delivery

There were no 'core' recommendations within the delivery domain, with four 'desirable' items only. Telephone number availability limits mobile messaging use, and the best means to improve this remains unknown. Despite 93.9% of experts agreeing that verification by integrating or cross-referencing screening patient lists with GP systems (or 'the Spine') would be important, only 63.6% felt this was feasible. Furthermore, manual verification, involving a registrar at the service checking numbers, was also felt to be unfeasible (50.0%), whilst enabling individuals the ability to verify their numbers themselves either online or via the NHS app was not considered important (63.6% voted 'important' or 'extremely important'). Bi-directional (or two-way) messaging was also considered a desirable feature provided it was limited, as issues regarding response times, inappropriate data sharing and privacy concerns of unfettered use were concerns raised at the final meeting.

Evaluation

Evaluation items were subdivided into patient and service-level metrics, underpinning the complexities in understanding the effectiveness of mobile messages in the context of screening. Experts agreed that evaluating the impact of messages upon regional healthcare inequalities (e.g. how attendance in different population subgroups varies with messaging,) was important (90.9%) and feasible (75.0%). As discussed in the consensus meeting this could be facilitated using linked datasets to provide granularity on sociodemographic factors and by examining read receipts, both of which were considered desirable items, but not necessary for every programme such as those run through GP services. Regarding patient-level evaluation, experts highlighted the need for ongoing assessment of user satisfaction and acceptability. Experts agreed it was important (81.8%) and feasible (81.3%) to utilise a multi-modal approach to assess satisfaction and acceptability, if no existing methods had already been implemented, including using online surveys, telephone calls or in-person questions when individuals attend. However, only 42.4% of experts agreed that the using additional mobile messages to send assessments e.g. customer effort or net promoter scores was recommended. Net promoter scores are used in market research, and involves asking individuals to rate the likelihood they would recommend a service[221]. Those who score 9 or 10 are 'promoters', 6, 7 or 8 'passives' and those who rate it less than 6 'detractors'. The NPS is the percentage of promoters minus detractors, and thus ranges between -100 and +100. At the consensus meeting panellists felt this method might "annoy people" and make messages "seem less trustworthy."

Security

Recommendations regarding security were embedded throughout the other domains and this aspect has been of increasing concern in the wake of recent phishing attacks manipulating healthcare messaging. In keeping with recommendations of the National CyberSecurity Centre,

experts agreed (84.8%) that utilising a consistent approach (e.g. branding, style) across screening media was important, whether that be websites, letters, mobile messages or videos. This enables individuals to verify a message as legitimate. However, the use of the Mobile Ecosystem Forum (MEF) sender identifiers, where trusted organisations register on a regulated database to enable verification[222], and International Mobile Subscriber Identity (IMSI) to avoid sending messages when a mobile is roaming[223], which are also recommended by the NCSC, were considered only desirable, or unimportant, respectively.

Research & Future

Whilst methodological items regarding the use of RCTs and A/B testing to determine the impact of messaging were core recommendations, the use of feasibility trials (39.3%) were not considered important. Experts again highlighted the central role of service users in ensuring acceptability, agreeing that evidenced patient and public involvement was important (93.9%) prior to undertaking experimental trials. However, the role of screening services in supporting research was contentious. Experts within the panel suggested collaborative projects, although desirable, were not always feasible (60.6%) given the limited resources available to screening services. The suggestion made by the panel during the consensus meeting was that the most effective research studies will leverage the existing infrastructure of services, to minimise disruption and ease incorporation into the screening service.

3.5 Discussion

The use of mobile messaging has become ubiquitous in healthcare[224]. Whilst population screening uses messaging in reminders to promote attendance, and administrative tasks, there is little guidance on how services can and should implement mobile communication. This is the first study that provides an expert-derived list of recommendations to facilitate the integration of mobile messaging into population screening programmes. Moreover, the study has highlighted that to effectively implement mobile messaging, services need to consider more aspects than just message content. These aspects or domains of interest derived from the existing literature, include appreciating the optimal timing of messages, how to ensure successful delivery of messages, ways in which security can be maintained, how to measure message impact and how can research be undertaken effectively. In total, 23 core recommendations for services were derived across these domains, with a further 17 desirable items which will help guide the future direction of messaging in screening. As mobile messaging technology continues to evolve, these currently unfeasible items may become more achievable for screening programmes.

The development of this expert-derived list demonstrates that despite the differing needs and organisation of the 11 active adult screening programmes in the UK[201], there are core cross-programme principles that guide the use of communication tools. Ensuring that programmes adhere to the commonly accepted principles is important to ensure existing reminder messages are utilised effectively. For instance, following this Delphi the London Breast Screening service shortened their usual care reminder and removed extraneous details but kept those which were found to be important in this study. Furthermore, these recommendations from this study can provide the foundation for augmenting reminders further. It is unclear whether many of interventions identified in Chapter 2 using prompts plus other techniques were not

effective at increasing screening due to the selection of inappropriate techniques for the determinanrs faced, or other messaging characteristics, such as timing or length, not being optimal.

The recommendations also highlighted increasingly important issues to all screening programmes, such as healthcare inequalities, so it was unsurprising that several of the recommendations from this study refer to ways to prevent them[27]. Health inequalities are defined as "systematic, avoidable and unjust differences in health and wellbeing between different groups of people,"[225] and have become a central tenet of screening programme policy. Due to the diversity and size of the populations invited to screen, there is a significant potential for such disparities to exist. Communication from healthcare providers have the potential to either exacerbate or help to address these inequalities. As such, some of the core principles derived in this study are translatable to all forms of healthcare communication, for example the need for jargon-free, concise language. However, other items are more pertinent to screening programmes, such as routinely reviewing the impact of messages upon regional inequalities or specifying who has sent the message. The latter is particularly important as awareness of screening programmes is lower amongst minority ethnic groups by approximately 15%[226], and in some programmes such as breast screening, messages do not come from a GP, but a potentially unknown source. In addition, screening services must be able to cater for a broad range of communication needs. It was therefore considered desirable for mobile messages to have non-English translations available. Although translated written communication is available to providers, this is not always used by services. In one study of UK breast screening units, only 38% gave South Asian women non-English mammography leaflets, despite 85% of units having them available[227]. Making translated information obtainable through weblinks or enabling language preference selection would overcome this issue and facilitate access.

Disparities are also seen in the uptake of screening invitations, which is an increasing concern for programmes. As described in Chapter 1, breast cancer screening uptake has fallen over the past decade and is lower amongst certain sociodemographic groups including people from areas of higher deprivation and minority ethnic backgrounds[30,38, 228]. Similar trends are seen in other programmes, for example uptake of bowel screening has fallen 11.8% since 2010/11, and 11 London providers of abdominal aortic aneurysm screening reported a greater than 1% reduction in uptake over the past year[229,230]. Several core recommendations suggest ways services can use mobile messaging to address declining uptake. Experts agreed the use of behavioural science-informed messages can facilitate uptake and should be implemented. However, individual behavioural techniques such as referring to high social norms for screening behaviours did not reach consensus. This may represent, as highlighted in Chapter 2, the lack of robust, unequivocal evidence on the ability of each behavioural technique to improve uptake, or the lack of familiarity of included experts with these techniques.

The lack of consensus regarding specific behavioural techniques may also relate to the ethical issues surrounding behavioural interventions. During the consensus meeting, experts raised concerns regarding behavioural techniques impacting upon informed consent. Several experts noting that use of techniques such as *anticipated regret* or *loss aversion (*for example inducing feelings of missing out) could lead to screening invitees being made to feel 'guilty' about their choice not to attend. This may undermine informed choice, and impact negatively upon intention to attend future invitations. There is therefore a conflict in what an individual and a wider group consider as 'desirable behaviour.'[231] Although not attending screening is not recommended from a public health perspective, an individual may have reasons e.g. concerns over overdiagnosis, which may be well founded. Understanding these concerns is particularly

important when tailoring content to underserved groups, who may already have greater mistrust of healthcare systems due to previous negative experiences[232]. As a result, explicit efforts should be made (e.g. through public involvement including with underserved communities) to ensure content could not be considered coercive.

The panel did, however, advocate the use of GP-endorsed messaging, which has been shown to improve uptake by 4% compared to no reminder, and to be more effective than simple reminders alone[215]. Moreover, GP endorsement may be seen as a low-risk option by commissioners, given several programmes are delivered in primary care and the existing role of GPs in primary prevention. However, in addition to recommendations regarding ensuring content is non-coercive, core evaluation items included regularly measuring satisfaction and the acceptability of messages to service users.

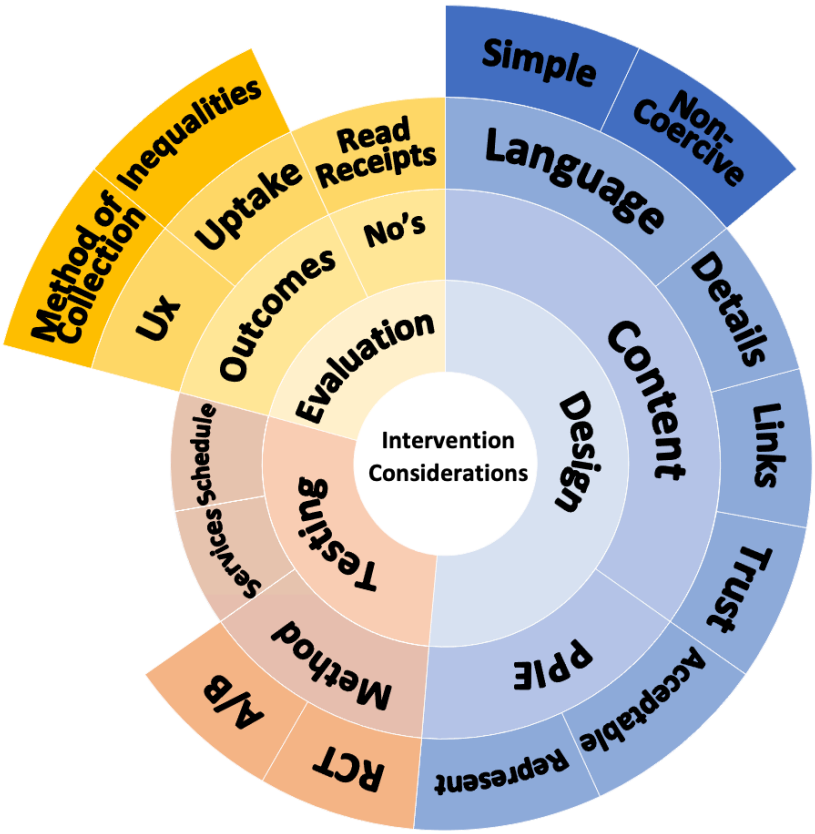
Another common theme evident in these recommendations, and of interest to all screening programmes is the need for security and maintaining user trust. In Q2 2021, almost 75% more health-related cyber security incidents were reported to the Information Commissioner's Office (ICO) compared the same time the previous year[233]. As messaging technology continues to develop and enable increasing functionality, there is also increasing potential for confidentiality and privacy breaches. In one evaluation of mhealth apps, 88% were found to contain code that could collect a user's personal data[234]. In the wake of the COVID-19 pandemic, where several high-profile security attacks in healthcare messaging occurred, services need to provide secure, and ultimately trustworthy communications[235]. Recommendations such as maintaining consistency across media (including in content and branding), have been shown to improve the responsiveness to public health messaging, and are an easy way screening services to achieve this trust[236,237]. On the other hand, desirable items

such as the use of MEF-registered sender identification, improving telephone number accuracy, and requiring wrong-recipient messages to be reportable breaches, were felt by experts to be difficult to undertake within the current data environment of screening services. These desirable items, however, provide a guide on what services should focus upon in the future.

In addition to guiding the implementation of mobile messaging of screening services by optimising message use, the current recommendations also provide a blueprint for the development, testing and evaluation of messaging interventions such as augmented reminders. Unlike previous recommendations, the developed guidance therefore provides information on how research can be appropriately conducted within population programmes. This may help overcome some of the challenges seen with the existing screening literature, as highlighted in Chapter 2, regarding the issues of subgroup homogeneity, and the feasibility of implementing interventions to the population-scale.

The guidance on conducting screening message research is not solely based upon methodological options discussed in the 'research & future' domain such as the recommendations to run RCTs or A/B testing but is multi-faceted with items from all 6 domains. When developing a new message-based intervention in screening one should synthesise relevant considerations for developing and testing screening interventions across the domains within the current study. A representation of the considerations relevant to the development and testing of novel message-based interventions is shown in **Figure 3-2**. This will assist the development and testing of a novel intervention within the subsequent chapters of this thesis, which will look to adhere to core recommendations shown in **Figure 3-2**.

Figure 3- 2 Considerations for developing and trialling new mobile messaging interventions in screening based upon recommendations.



A/B- A/B testing, Details- appointment details, Links- weblinks, No's- telephone numbers, PPIE- patient/public involvement and engagement, RCT- randomised controlled trial, Services- service involvement, Ux- user experience

3.5.1 Limitations

The findings of this study will need to be considered within the limitations of the methodology. The modified Delphi approach is an appropriate means for evidence generation in fields where little objective data exists. Moreover, it is one of the most widely used consensus development tools. However, several criticisms have been raised regarding the lack of reproducibility of the findings, and concerns regarding attrition biases[238,239]. The versatility of the methodology, which lends itself to complex areas of public health such as in the current study, can potentially diminish study quality, as there is currently no standardised method of undertaking or reporting Delphi studies. To overcome some of these limitations, a broad range of experts with significant cross-programme experience was recruited. This purposive sampling technique ensured that all programmes, including the piloted Lung Health Check, were represented. In

addition, the 100% retention of experts across voting rounds strengthens the validity of these findings. Despite this there was a greater preponderance of experts with experience of cancer screening programmes (75.8%, 25 out of 33 experts) compared non-cancer screening (48.5%, 16 out of 33 experts). This in part can be explained by the maturity of cancer, compared non-cancer, programmes. For example, in the UK, breast cancer screening was established in 1988, whilst abdominal aortic aneurysm screening only began in 2009[7,240]. Moreover, participants from fields such as the communications industry, are likely to have experience of multiple programmes, as their expertise lies with the technology as opposed to individual screening services.

Despite mitigations including recruiting participants from all services, a cross-programme consensus exercise does limit the utility of the findings to any one of the individual programmes. Nuances between individual screening services cannot be reliably determined due to low numbers of representatives from individual programmes. As such, understanding the priorities between screening programmes is difficult to ascertain. For example, whilst antenatal and newborn screening routinely meets its acceptable coverage thresholds, breast cancer screening does not. Increasing uptake is therefore more of a priority for the latter[241]. On the other hand, newborn screening is not in alignment with EURORDIS recommendations regarding public representation throughout the screening process[242]. The focus for this programme could therefore relate more to increasing engagement with the service rather than attendance.

The applicability of these finding would have also been improved by increasing the numbers of public participants from the target groups into the Delphi process. Although the aim of the study was to determine cross-programme recommendations, and a public scoping exercise was

undertaken, greater inclusion would have improved the robustness of the findings. However, in certain domains, e.g. evaluation, security, and future considerations, it would have been difficult to support the inclusion public members given these were predominantly provider-facing concerns. A future exercise validating the desirable and core outcomes could be undertaken amongst target public members to add to these findings.

Further work should also look to overcome these limitations by repeating the Delphi methodology at an interval with a different group of experts. This would add to the strength and generalisability of the findings and examine the effect of newer technologies. It would also allow assessment of the desirable category in this study, as one would expect items which are currently unfeasible to become core recommendations over time. In order to understand some of the findings from Chapter 2 further, it would also be useful to repeat the studies across differing healthcare systems, such as the US. Whilst some of the recommendations are likely to be the same, others would be expected to be more context dependent. Understanding these nuances may help the translation of effective message-based interventions to differing contexts, by providing an appreciation of what aspect of screening messaging are more relevant to various healthcare settings. Furthermore, it would also be useful to examine the needs of individual screening programmes. Although cross-programme consensus derived a generalisable list of recommendations, this process would ideally be supplemented with programme-specific expansions. For example, programme specific investigation could address issues regarding mobile communication in open invitations in breast screening, or in self-sampling kits in cervical screening. This would make the guidance more specific and relevant to these services.

3.5.2 Conclusions

Mobile messaging is a versatile, acceptable, and increasingly utilised means of healthcare communication. Population screening poses unique challenges to the effective implementation of mobile communication. Inappropriate or ill-considered usage can rapidly have a significant impact given the size of the populations these programmes serve, potentially leading to reduced uptake, a lack of service user trust, or widened healthcare disparities, all of which are existing concerns. This is the first study of its kind to describe a list of expert-derived recommendations for UK screening services, to enable services to effectively implement and utilise mobile messaging. The framework developed goes further than existing frameworks by addressing issues beyond message content and delivers cross-programme guidance. By incorporating an assessment of current feasibility, it also provides a list of desirable aspects of mobile communication, which will be of increasing importance as newer technologies become available to services. Furthermore, this framework can be adapted to differing contexts, for example, to the development of novel mobile interventions for screening. By applying the recommendations from this study, researchers can plan the design and evaluation of interventions in a way that is both appropriate and feasible within the current screening infrastructure.

This work has now formed part of UK national guidance for screening services in conjunction with the Department of Health and Social Care (DHSC). It is now available to screening services via GOV.UK[243]. As a result, future work will look to update these recommendations as the capabilities of screening services, needs of the population, and the availability of technology changes.

4. Understanding the Barriers and Facilitators to Breast Cancer Screening Faced by Underserved Populations

4.1 Abstract

Background

Several inequalities have been reported in the UK breast screening programme. People from minority ethnic groups, areas of deprivation and those with disabilities are often considered underserved. Intersectional approaches look to examine these characteristics in combination, to facilitate deeper understandings of systemic issues. The aim of this study was to explore the determinants of non-attendance amongst traditionally underserved communities, with a particular focus on those who represent multiple subgroups.

Methods

A systematic review of the literature undertaken using PubMed, PsycInfo, Google Scholar and Medline databases to examine the barriers and facilitators to breast screening faced by traditionally underserved groups in the UK (PROSEPERO CRD42022380979). Qualitative and quantitative descriptive studies published between January 1st 2005 to 1st June 2021 were included. Determinants were extracted using a convergent integrative approach. Identified determinants were used to develop topic guides for interviews and focus groups undertaken with purposively sampled participants representative of multiple underserved communities in London. An inductive thematic analytical approach was undertaken upon transcripts to elicit the key determinants to screening, as well as to identify potential means of addressing them.

Findings from the review and interviews were mapped to the Theoretical Domains Framework (TDF) to facilitate comparisons.

Results

A total of 18 full-text articles were included with the majority examining the influences upon minority ethnic groups. Common barriers were noted from the identified articles, within the TDF domains *emotions, beliefs about consequences, environment, social influences,* and *knowledge.* Similar findings were elicited through interviews in which fear of pain and exposure (*emotions)* were the most dominant barriers, whilst social support was both a notable facilitator and barrier to attendance. However, from the interviews, *knowledge* was found to be less influential beyond the understanding of risk factors mediating perceptions of susceptibility to breast cancer.

Conclusions

Existing work has predominantly focussed upon groups defined by isolated demographics. However, common determinants of non-attendance were noted within the existing literature, and the current work examining intersectional groups. Similarities included the influence of fear of pain and social networks. Future work should investigate whether such factors are also prevalent in the wider population, to facilitate the implementation of regional interventions to improve uptake.

4.2 Introduction

There is growing concern regarding the healthcare inequalities within breast cancer screening in the UK[27]. As outlined in Chapter 1, there are well-documented disparities in the attendance of specific subgroups. In 2011, Breast Cancer Now highlighted seven strands associated with healthcare inequalities: age, disability, ethnicity, gender, remote communities, sexual orientation, and socio-economic status[244]. One of the key conclusions from this report was that there is a paucity of evidence regarding the nature of the challenges faced by these groups in breast cancer care. As a result, several recent reviews have been undertaken to elicit the common determinants of breast cancer screening attendance amongst underserved populations. Baird et al. examined the barriers to attendance faced by non-White ethnicities in the UK to screening attendance, categorising these into knowledge, access and culturally related factors[245]. This provided an insight into the breadth of determinants faced by minority ethnic groups, for example how a lack of baseline screening knowledge is exacerbated by low health literacy, and inability to comprehend materials promoting attendance. However, the authors did not temporally restrict their search, and as such have included historical studies conducted prior to changes in screening practice, with determinants which may no longer be relevant. On the other hand, Matin et al. reported the barriers faced by women with disabilities, limiting their search between 2009 and 2017. These barriers were categorised into five dimensions of healthcare access: approachability, acceptability, availability, affordability, and appropriateness[246]. This review was not solely focussed upon breast screening, and encompassed studies involving disparate healthcare systems globally, impacting the applicability of the findings. Furthermore, neither review could conclude whether the determinants they elicited were common in other groups or the wider population.

By restricting reviews to cohorts defined by a single socio-demographic characteristic, the relevance of the conclusions from these reviews to screening programmes is limited, as several underserved groups must be considered[28]. In addition, the utility of the findings in the development of population-level interventions is also diminished, as they do not provide an indication whether certain barriers are seen across multiple subgroups and could be considered a higher priority. Moreover, the previous reviews may over-simplify the way in which healthcare inequalities develop, and the experiences of screening amongst underserved communities. *Intersectionality* is a concept, developed by Kimberlé Crenshaw, which examines factors such as age, class, gender, ethnicity and ability, as interacting phenomena[247]. Understanding how these entities inter-relate and impact upon individuals' lived experience provides a critical insight into how issues such as stigmatization and marginalization can occur. Framing healthcare inequalities through an intersectional lens has therefore been posited as a more in-depth examination of individual experience[248,249]. The importance of this approach can be seen in quantitative analyses, which have demonstrated that even amongst minority ethnic groups other factors can impact upon outcomes. For example, in one UK study, affluent South Asian women had a breast cancer survival 8 to 9% higher than those from the most deprived groups, suggesting that these groups have differing healthcare experiences, and subsequently outcomes[250]. In addition, when developing interventions to be delivered at a population-level it is important to gain insights of underserved and multiply underserved people, to avoid worsening existing disparities. An intersectional lens will help to prevent important, potentially surmountable, barriers in these groups being ignored. Moreover, when using multiple information sources to create an intervention, this approach provides further evidence on which barriers may be best to focus upon.

To effectively examine these multiple axes of inequality, it is important to overcome two main limitations of the existing literature. Firstly, this work will take an intersectional approach in order to determine the common barriers to screen between different underserved groups, and to facilitate more in depth investigation of the determinants across multiple groups. Secondly, to enable comparisons of determinants identified from differing sources, findings will be mapped onto the Theoretical Domains Frameworks (TDF), which has previously been used within systematic reviews to facilitate the comparisons of core themes[82].

Theoretical Domains Framework (TDF)

As discussed in Chapter 2, utilising singular behavioural theories to underpin intervention development can potentially lead to the omission of important factors that influence a behaviour. To overcome this limitation, the TDF was developed to provide a more holistic appraisal of behavioural determinants. Originally developed in 2005, it integrated the constructs from 33 theories of behaviour using an extensive consensus-driven approach into 12, now 14, overarching domains[251]. As a result, the TDF provides a comprehensive guide for the assessment of the determinants of health behaviours and provides a standardised means of describing these factors from differing information sources[84]. Evaluation of the TDF has shown it to be inclusive, eliciting beliefs that were not appreciated by researcher or expressed in previous research especially those involving emotional or motivational factors[89,252]. However, studies have shown that overly restrictive use of the TDF (e.g. as a framework for qualitative analysis) can lead to important contextual factors being neglected. McGowan et al. therefore suggest that domains are not solely adhered to, and researchers appreciate 'non-TDF' facets in data synthesis[253].

4.2.1 Aims

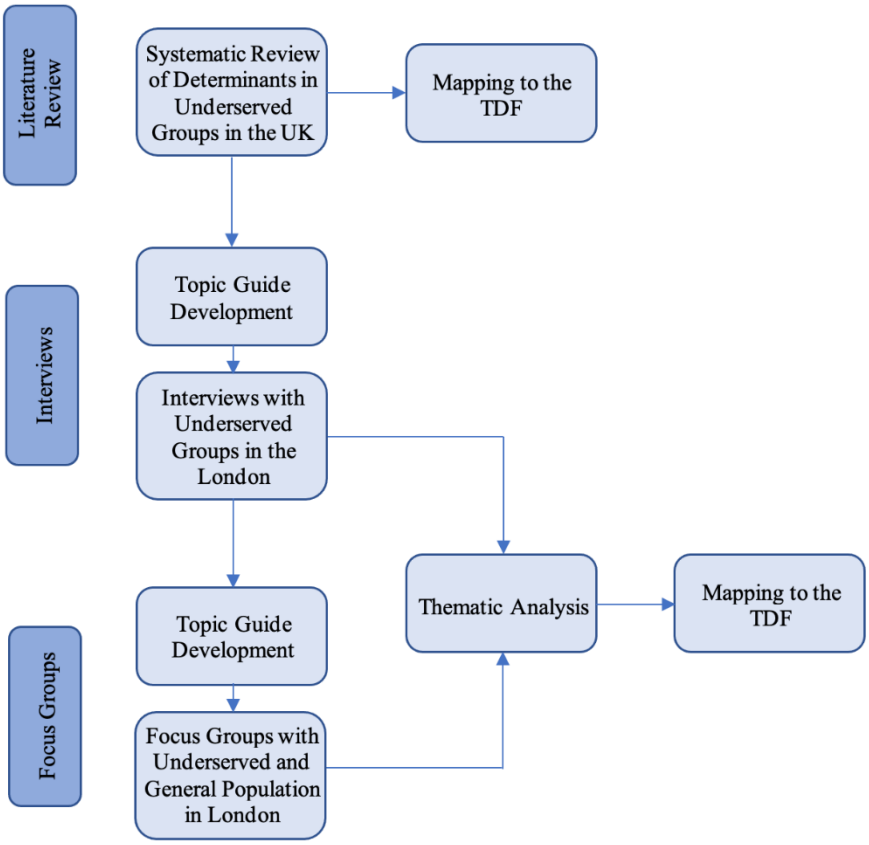
The aim of this chapter is to understand the determinants of non-attendance at breast cancer screening amongst traditionally underserved communities, including those who represent the intersectionality of multiple subgroups. To achieve this overarching aim, an evaluation of the literature will be undertaken to elicit the key determinants within population subgroups who have an established low uptake of screening and use this information to develop topic guides. These guides will be utilised in interviews and focus groups with individuals from underserved communities to understand the challenges they face, and whether these differ from the current literature. In addition to understanding the determinants, focus groups also examined the perceptions of participants toward existing screening materials. By mapping the outputs from the initial review, and the interviews/focus groups, to the TDF, subsequent comparisons of the common and important barriers to the uptake of breast cancer screening in the UK will be possible. Moreover, this process will facilitate future intervention development described in Chapter 5.

4.3 Methods

4.3.1 Study Design

This study was conducted in 2 phases: a literature review and interviews/focus groups (**Figure 4-1**).

Figure 4- 1 Flow chart demonstrating study stages and processes.



Systematic Review

A systematic review of the literature was conducted. It was registered on the PROSPERO database (reference CRD42022380979) and was undertaken in compliance with PRISMA guidelines[111]. No ethical approval was required. A search of PubMed, PsycInfo, Google Scholar and Medline databases was conducted, in addition to a grey literature search including PhD theses or local authority reports, plus a search of reference lists. The review included

publications from January 1st 2005 to 1st June 2021. This date range was chosen as this review looked to examine currently relevant determinants of breast screening non-attendance but remains comprehensive, encompassing the falling trend in national screening uptake over the past 15 years[254]. The barriers and facilitators highlighted in earlier studies may represent particular issues which have been addressed, for example by the widespread introduction of mobile screening services. In addition, socio-demographics and intersections of health inequalities are dynamic entities, with correlations also related to contextual factors. It would therefore be inappropriate to examine the barriers elicited in historical populations.

The search strategy is detailed in the **Appendix 4-1**. Terms were combined in various combinations with standard Boolean operators. These included *minority ethnic, migrant, Black, Asian, Arab, traveller, African, comorbidity, deprived, low socioeconomic status, disability, breast cancer screening, population screening, England, Wales, Scotland, Northern Ireland, National Health Service, uptake, attendance* and *coverage.* All studies were uploaded and assessed using the Cochrane database tool, Covidence (Melbourne, Australia). Two independent researchers undertook the initial title and abstract screening independently, with any disagreements discussed. Full-text manuscripts of included abstracts were evaluated for suitability in a similar manner.

Inclusion and Exclusion Criteria

All studies that examined barriers and facilitators to breast cancer screening amongst traditional underserved groups, including those from minority ethnic communities, those from deprived areas, those with multiple health problems and those living with disability were included. Given the breadth of inequalities that have been described, the focus of the review was upon groups with an established low uptake of screening. Any study involving populations based

outside of the UK were excluded as other healthcare systems have differing methods of delivering screening. Studies examining the barriers to symptomatic presentation, or attendance in primary or secondary care were also excluded as this represents a different care pathway. Studies that provided only quantitative associations e.g. the odds of uptake of differing subgroups with no indications of the determinants of the behaviour were also excluded. However, quantitative assessments of barriers e.g. surveys, were included, as were qualitative studies. Studies wholly examining the barriers to breast health awareness, without mentioning screening, and those investigating attendances at screening programmes generally, were also excluded.

Data Extraction, Synthesis and Topic Guide Development

Study demographics, design, location within the UK, date of publication and population characteristics were extracted from included full-text articles. As this review included mixed-methods studies, a convergent integrated approach to synthesis was undertaken. As described by the Joanna Briggs Institute regarding mixed methods review approaches and based upon the work of Hong et al.[255,256], this involves "qualitizing" quantitative data output from surveys following a familiarisation phase. Two researchers independently undertook this process by codifying the findings and discussions of quantitative articles using NVivo release 1.3 (QSR International, USA). To avoid omitting pertinent quantitative data, preliminary codes encompassed a statistical measure of the determinant. For example, if a study revealed that a lack of social support was significantly associated with non-attendance, then the initial code would involve terms such as *significantly* or *substantially* and other non-significant barriers were not included. The outcomes from this qualitizing process were then pooled with coded data extracted directly from qualitative studies. Analogous to the process of thematic synthesis

or meta-aggregative methodologies, codes were then examined in detail by researchers, in conjunction with the source material, to identify broader descriptive categories or subthemes.

The broader categories were then mapped by the researchers to TDF domains by one author and validated in approximately 25% of studies by a second. This enabled the differing areas of concern to be readily identified. The outcomes of the review were then used to construct semi-structured interview guides. To avoid overly restrictive application of the TDF, these guides were designed to encompass broader open-ended questions and a few narrower optional prompts. The focus group guides were based upon the findings from both the review, as well as interviews. All materials were developed in collaboration with a public representative on the research team to enhance acceptability and comprehension. To facilitate discussion between focus group participants these guides again began with open-ended questions, however these were optional, and the group was encouraged to lead the conversation.

Interviews and Focus Groups

Interviews and focus groups were conducted with individuals who lived in London and represented multiple underserved communities. These groups were chosen for interview as their views were not fully encompassed in the existing literature. Moreover, recruiting from within the NHS or screening service may have biased results, as it would not encompass those who have never taken up the invitation to screen whose contact/demographic details are not retained by the service. Focus groups were chosen in addition to interviews in order to better understand common shared experiences, as well as highlight areas of disagreement regarding breast screening. London was chosen as this was the region in which any intervention was likely to be trialled in. Recruitment was undertaken in collaboration with several specialist research departments such as the Patient Experience Research Centre at Imperial College

London and the VOICE network, as well as through advertising in public amenities including faith centres. The latter was facilitated by working with organisations such as the Oremi Centre, Asian women cancer group, and the Mosaic Community Trust, all provide support for traditionally hard-to-reach communities such as minority ethnic groups, those from deprived areas and those living with mental health illness and co-morbidity[257–259]. The aim of the interviews and focus groups was to gain a deeper understanding of the determinants of breast screening non-attendance, a recruitment target of 20 people was considered to be sufficient to reach thematic saturation based upon previous studies[243]. Electronic and paper posters detailing the study details were distributed (by AA) in person, and via email to the mailing list by the community organisations, to ensure participants were familiar with the source. Contact details to the study team (both electronic and telephone numbers) were available via these posters. Participants were also able to sign up of the study if they were present at the time of putting up posters in person at community organisations. A screening questionnaire (designed by AA) was sent to all potential participants once they had expressed interest in the study by contacting the study team and indicated verbal or written consent to receive the survey (in electronic or paper format, according to participant preference). The pre-screening questionnaire ascertained pertinent socio-demographics including age, ethnicity, co-morbidities, location (as an indicator of deprivation) and screening history. All questions were optional to avoid potential participants feeling mistrust or coerced into providing information they did not wish to share. Non-probabilistic sampling techniques were undertaken to ensure recruitment of individuals who represent multiple underserved groups, and those who had declined breast cancer screening on one or more occasions. This is in keeping with similar studies in underserved settings or with hard-to-reach groups[260]. Those who were ineligible for screening, could not provide explicit consent or were currently within NHS inpatient facilities were excluded.

Recruitment also involved snowballing of participants by forwarding study invitations to increase the potential sampling frame from included groups.

Interviews and focus groups were conducted online through the Zoom (California, USA) platform or via telephone, due to the restrictions of the COVID-19 pandemic. A female minority ethnic member of the research team conducted the sessions. This was undertaken to avoid participants suffering embarrassment of having a male interviewer and to ensure sensitivity to cultural attitudes. Moreover, as the primary investigator (AA) was a healthcare professional, it was felt that his presence at interviews would potentially preclude participants talking freely about negative experiences of healthcare or being critical of service. This was particularly important for those who were mistrusting of the healthcare system. Participants were given the option to invite carers or individuals who support them to interviews. The public representative from the research team assisted with focus groups. Participants were reimbursed for their time in accordance with National Institute of Health Research (NIHR) guidance and were provided basic training on the use of Zoom[26]. All participants provided informed consent including for the recording of sessions, and the Institutional Review Board at Imperial College London provided ethical approval for the study (reference 21IC6782).

4.3.2 Analysis

Review

An assessment of the quality of the reporting literature was undertaken by two independent researchers (AA and VS) using the Mixed Methods Appraisal Tool (MMAT)[261]. This tool allows the comparative appraisal of differing types of empirical studies including qualitative and quantitative descriptive research. The tool utilises two general screening criteria, regarding the presence of a research question, and whether the data would allow the question to be

answered. These are followed by 5 criteria specific to the type of research. For qualitative studies these include whether this approach was appropriate for the question, the adequacy of the data collection, whether findings were derived appropriately, if results were substantiated and the coherence between data sources, collection, analysis, and interpretation. For quantitative descriptive studies this included questions regarding sampling strategy, sample representation, measurements, non-response biases and statistical analysis. Each criterion is categorised as having been met, unmet, or that insufficient information was provided. In the current appraisal researchers agreed *a priori* that data collection adequacy would include details of sampling strategies, and whether criteria matched eligibility for breast screening. Studies that examined wider populations but did not delineate which barriers were specific to a breast screening cohort were considered unmet with respect to this criterion.

Interviews/Focus Groups

It was estimated that the recruitment target would be achieved in approximately 8-10 interviews and 2 focus groups of 5-6 people in keeping with similar studies[262,263]. Recordings from interviews and focus groups were transcribed verbatim by AA. An inductive thematic analysis was undertaken across interviews and focus groups in accordance with guidance provided by Braun & Clarke (2006) using NVivo release 1.3 (QSR International, USA)[207]. This involved six stages: familiarisation, coding, searching themes, reviewing themes, defining themes and reporting the analysis. Following familiarisation, a line-by-line coding approach was undertaken by two independent authors (AA and CG), one of whom conducted the interviews, on 20% of the dataset. Agreement was measured using Cohen's Kappa coefficient. Codes were then discussed, whilst reviewing the transcripts, and amended as necessary following discussion. This process was repeated for the originally coded transcripts, as well as a further 20% (total of 40% of transcripts). Agreement was again measured, and as this was

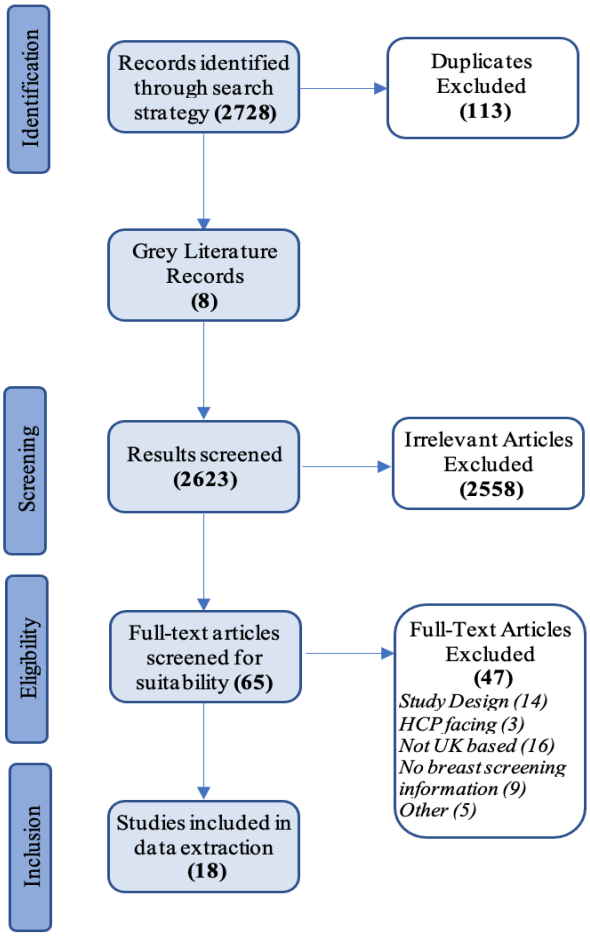
considered satisfactory, the remaining transcripts were coded by the primary researcher. Codes were collated inductively into broader sub-themes, with key influences underpinning sub-themes noted. These included reasons why particular sub-themes acted as barriers in certain contexts. Sub-themes were then grouped into themes. The collating of codes and sub-themes occurred following discussion between two researchers, with disagreements resolved by the involvement of a third independent author. Coding and discussion were conducted until thematic saturation was achieved. The themes were also ranked (called coding rank) according to how often codes relating to them were highlighted. For example, a theme ranked 1st had the greatest number of codes relating to it. To facilitate further triangulation, the subthemes were mapped to the TDF by one author and validated by a second independent researcher who had been involved in the coding process and was acquainted with the original dataset.

4.4 Results

4.4.1 Systematic Review

The search strategy elicited 18 full- text articles that were included in this study[264–281], of which 16 were qualitative (interviews, focus groups or a combination) and 2 were quantitative descriptive studies (questionnaires). The PRISMA flow chart of articles is shown in **Figure 4-2.** The majority of included articles were concerned with barriers faced by minority ethnic groups (11), whilst others examined deprived groups (2) and the remaining related to co-morbidity/disability (5). No study explicitly identified individuals as belonging to multiple underserved groups.

Figure 4- 2 PRISMA diagram demonstrating selection of included studies.



HCP- Healthcare professional, UK- United Kingdom

Several common themes were noted across studies, with the characteristics and observed determinants shown in **Appendix 4-2**. Amongst minority ethnic groups the most cited barrier was a lack of knowledge about screening, with 9 out of 11 studies reporting it[264–266,270–273,279,281]. This included not understanding information regarding eligibility, or the purpose of breast screening. Conversely, access to culturally appropriate health education, such as translated materials or those with minority ethnic group representation, was the second most common facilitator to attend screening[264–266,276,279,281]. Having materials that can be easily understood was particularly important as an inability to communicate or express oneself, for example due to not speaking English, was reported as a common barrier amongst minority ethnic groups (8 out of 11 studies)[267,270–273,276,279,281]. Some studies reported that language barriers led individuals to rely upon others, for example to translate information, which could induce a feeling of being a burden and embarrassment. This theme was related to cultural taboos, or seeing cancer as a stigma (4 studies)[264,272,276,279], as well as perceived low susceptibility (8 studies)[264–267,271,276,279,281]. The latter associated with an individual's perception of risk factors, breast cancer as a non-ethnic minority disease and beliefs about those who are diagnosed with cancer (or candidacy). Candidacy included beliefs that those diagnosed with breast cancer led more unhealthy lifestyles. Increasing awareness of breast cancer within one's social network, for example a family history of the disease, potentially reduced these barriers, was a strong facilitator.

In comparison, when examining studies involving those with co-morbidities or disabilities (**Appendix 4-3**), barriers regarding fear (5 out of 5 studies)[268,269,275,278,280] were more common than those regarding knowledge (2 out of 5 studies)[269,278]. Fear of the process, also seen in 7 out of 11 studies focussing on minority ethnic groups[265,267,270,271,273,279,281] included anxiety regarding the pain of mammography, as well as the need to be undressed. It was also related to

a feeling of vulnerability regarding breast cancer screening, which was noted in 3 of the studies focussing on those with co-morbidities/disabilities[269,278,280]. Given this subgroup were likely to have frequent healthcare interactions, it is notable that previous negative experience of screening and poor relationships with healthcare professionals was commonly reported to reduce intention to attended. However, healthcare professional endorsement of screening was the most common facilitator (3 out of 5 studies)[269,278,280]. This demonstrates the importance of these interactions and suggests the role of clinicians outside of the screening programme (e.g. GPs) in promoting attendance.

Only two studies met inclusion criteria and examined the barriers to screening faced by deprived populations (**Appendix 4-4**)[274,277]. The two studies highlighted a breadth of barriers including those seen with the other cohorts such as fear, a lack of knowledge, poor health reducing an individual's motivation/capability to attend and a low perceived susceptibility. The low number of studies included may be due to a paucity of empirical evidence in this area. It may also be due to the overlap of deprivation with other underserved groups. However, studies with other underserved populations did not report sufficient details to make this assessment. Evidence for this overlap can be seen when examining similarity in the barriers faced across underserved groups, and the broader TDF domains to which they relate (**Table 4-1**).

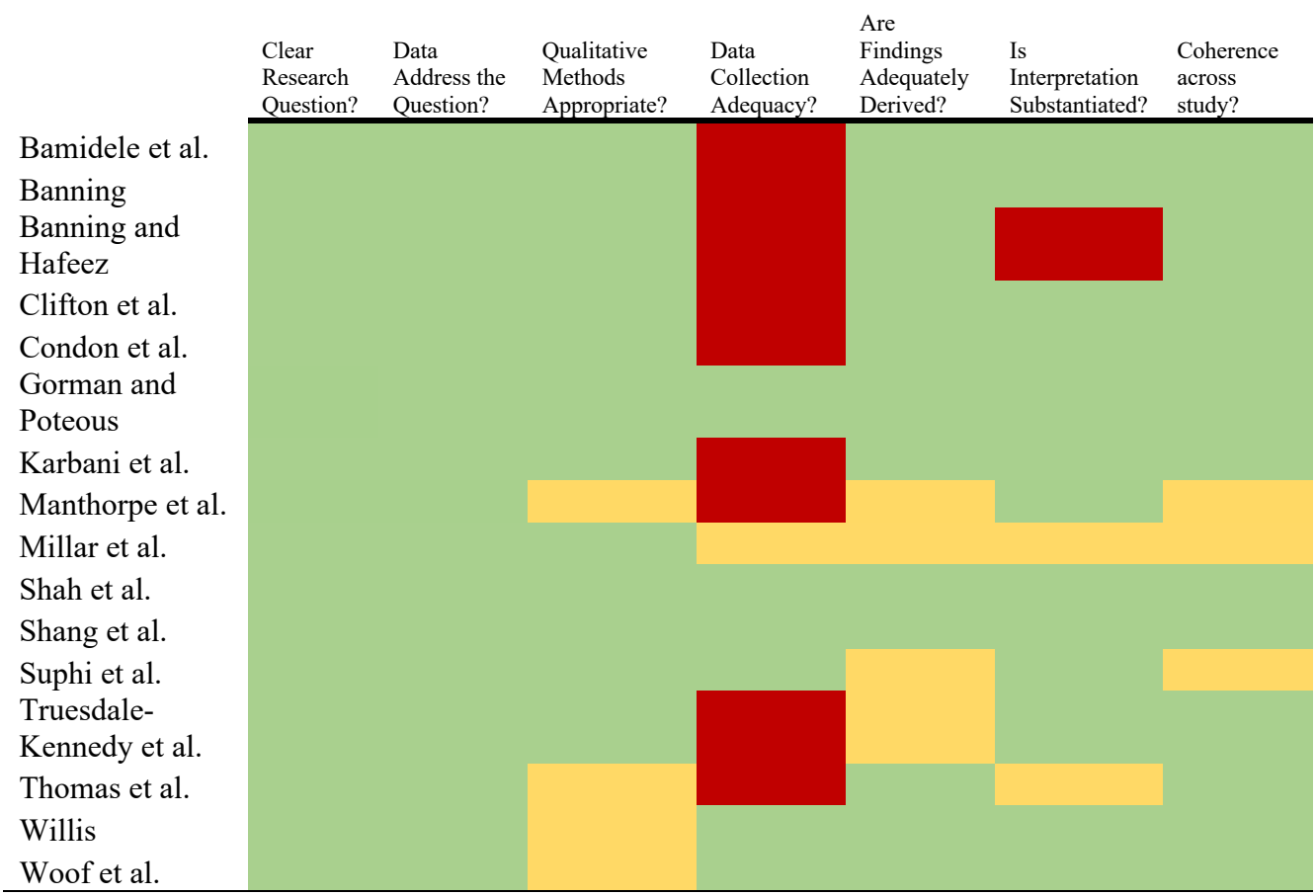
Table 4- 1 Barriers noted within the systematic review, the underserved groups that reported them, and the associated TDF domain.

TDF Domain	Barrier	Notes	Groups Reporting
Knowledge	Lack of knowledge about cancer/breast health	Feeds into ideas regarding candidacy	ME, MM
	Lack of knowledge about screening	Includes misinformation	ME, D, MM
	Low salience of breast cancer	Linked with susceptibility and candidacy	ME, D, MM
	Susceptibility	Includes risk factor knowledge	ME, D
Skills	-	-	-
Social Identity	Cancer as a stigma	Identity as one who does not get breast cancer	ME
	Candidacy	Ideas on who gets breast cancer, influenced by identity, norms, knowledge, and salience	ME
Beliefs about Capabilities	Health affecting attendance/volition		D, MM
	Feeling a burden	Burden on social contacts	MM
Optimism	Optimism	Includes fatalism and feeds into susceptibility and use of alternatives	ME
	Superstition		ME
	Susceptibility		ME, D
Beliefs about Consequences	Cancer as a stigma	Involves beliefs about the social consequences of cancer	ME
	Fear of consequences of the disease	Severity of the disease and treatment	ME, D, MM
	Low priority	Priority v. effectiveness	ME, D
	Perceived benefits of screening		ME
	Superstition	Beliefs about what happens to those attending screening	ME
Reinforcement	-	-	-
Intentions	-	-	-
Goals	Low priority	Not a goal priority	ME, D
Memory, Attention and Decision Process	Memory	Forgetting appointment	D, MM
	Decision Making	Decisions to attend made by others e.g. carers	MM

Environmental Context	Appointments	Includes convenience and receipt of invitation	ME, D, MM
	Communication/ Expression	Ability to make oneself understood, or understand materials	ME, MM
	Fear of process	Need to be exposed/inability to cover	ME, D, MM
	HCP characteristics	Includes gender, poor relationship with the individual, and diagnostic overshadowing	ME, MM
	Low priority	Competing appointments/priorities	ME, D
	Physical Access	Includes accessibility of service	ME, D, MM
	Previous negative experience		ME, D, MM
	Transnational health use	Screening in non-UK services	ME
	Use of alternatives to screening	Includes BSE or faith healing	ME, D
	Vulnerability	Linked to exposure and emotions	ME, D, MM
Social Influences	Cancer as a stigma	Group norms	ME
	Fear of process	Influences through sharing experience	ME, D, MM
	Feeling a burden	Burden on social contacts	MM
	Lack of social support	Includes social pressure/norms or social network experience	ME, D, MM
	Superstition	Linked with norms, fatalism, and consequences.	ME
Emotion	Expectation of anxiety	Unspecified anxiety or due to non-procedural screening issues	ME, D
	Fear of process	Pain, exposure or radiation	ME, D, MM
	Vulnerability	Linked to exposure and emotions	ME, D, MM
Behavioural Regulation	-	-	-

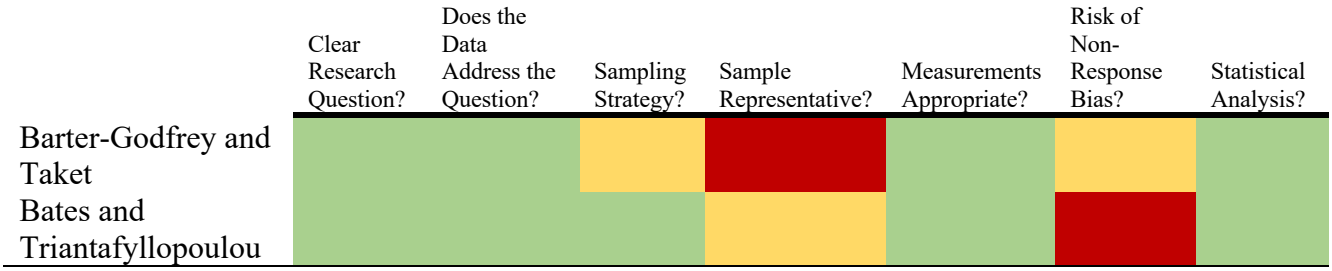
D- Those from deprived areas, BSE- Breast self-examination, HCP- Healthcare professional, ME- Those from Minority Ethnic groups, MM- Those living with multiple morbidities.

Table 4- 2 Quality assessment using the Mixed Methods Assessment Tool on included qualitative studies[261]



Green- criterion met, Red- criterion unmet, Yellow- insufficient information.

Table 4- 3 Quality assessment using the Mixed Methods Assessment Tool on included quantitative descriptive studies[25]



Green- criterion met, Red- criterion unmet, Yellow- insufficient information.

Quality Assessment

All studies demonstrated a clear research question and use of the data to address their hypothesis (**Table 4-2** and **Table 4-3**). However, 56.3% of the qualitative studies did not meet data collection adequacy. This was largely regarding sampling techniques, and recruitment of individuals not eligible for breast screening. For example, Bamidele et al. who examined factors associated with low uptake amongst Black African women included those aged between 35-70[264]. Whilst they justify this by describing the earlier risk of breast cancer amongst this cohort, including a pre-eligible cohort can skew the results, as they can report only anticipated barriers. In addition, someone who is fifteen years away from being invited to a mammogram may not have as much knowledge about the programme or salience about breast cancer than someone who has been routinely invited. In addition, grey literature such as a screening service report by Manthorpe et al. often failed to provide adequate detail regarding data handling or thematic construction[273].

4.4.2 Interviews and Focus Groups

In total 10 interviews, and 2 focus groups (9 participants) were conducted. Across the whole cohort, 84.2% reported being from non-White backgrounds, 47.4% were from areas of higher deprivation, and 84.2% reported an additional morbidity. The demographics for those who participated is shown in **Table 4-4**. All socio-demographic and medical factors were self-reported by the participants.

Across all sessions researchers found 9 key themes: *pain of the process, social influences, risk factors and susceptibility, healthcare professional endorsement, screening environment, knowledge, fear of consequences, preparation for an appointment* and *negative imagery* (**Table 4-5**). The frequency of the codes making up these broad themes is also given (or so-called code

rank). The initial Cohen's Kappa coefficient was 0.28 suggesting only fair agreement, however, after discussion and re-coding this increased to 0.72 indicating a substantial concordance between researchers.

Table 4- 4 Participant self-reported demographics and pertinent information.

Participant	Age	Ethnicity	Co-Morbidity	Area of Deprivation	Other Comments
1	50-55	White	Yes	Yes	Reported MH illness
2	61-65	Asian	Yes	NS	Reported English not first language
3	50-55	Asian	Yes	Yes	
4	61-65	Asian	Yes	NS	Reported high BMI
5	61-65	Black	No	No	
6	65-70	White	No	Yes	
7	50-55	Asian	Yes	Yes	Reported diabetes, blood pressure and disability
8	55-60	Black	Yes	Yes	Reported neurology
9	55-60	Black	Yes	No	Reported diabetes
10	60-65	Other	Yes	Yes	Reported mobility issues
11	55-60	Asian	Yes	No	Reported as a carer
12	50-55	White	No	Yes	
13	Over 70	Asian	Yes	Yes	Reported English not first language
14	60-65	Black	Yes	NS	
15	55-60	Other	Yes	NS	
16	61-65	Asian	Yes	NS	Reported high BMI
17	<50	Other	Yes	NS	Reported Latin American
18	50-55	Mixed	Yes	Yes	Reported hormone therapy
19	50-55	Black	Yes	NS	Reported high BMI, blood pressure and diabetes

All measures are self-reported. Participants in blue attended interviews, those in white attended focus groups. Area of Deprivation- relates to whether stated borough is in the top half of deprived regions according to Ministry of Housing, Communities & Local Government. BMI- Body Mass Index MH illness- mental health illness. NS- not stated.

Fear of, or anticipation of the pain of the mammogram was the most commonly cited barrier across the cohort. Codes relating to sub-themes regarding pain, such as the physical cause of the pain, or how the pain felt by friends/family during mammograms, were the most frequently

highlighted (coding rank 1). This was linked in some cases with previous negative experiences, with one interviewee noting, *"it was such a shock"* and that led her not to return. Poor experiences may have also been influenced by underestimating pain, with some participants reporting that the materials said it *"might be rather uncomfortable,"* when in fact their experience was worse. In addition to inaccuracy regarding the process, existing screening materials were also criticised within focus groups for a lack minority representation making them less relevant to participants, who were then unaware of what to expect. Of note, the barrier of anticipated pain was also expressed by individuals who had never attended, largely mediated by social influences, with one minority ethnic participant stating *"I've mixed thoughts on what other people's reactions have been. It's put me off…the pain and anxiety, more than anything."* This was common in the literature review, and overcoming this barrier would be an important consideration for a screening invitation.

Social influences were found to be an important determinant in deciding to attend screening, with second highest number of codes relating to this theme. Participants had differing perspectives on the injunctive social norms of their network, or what their social group expected them to do. This was influenced by the knowledge/awareness of their social group, with one minority ethnic participant reported, *"if the men, they know the importance, they will force their wives to go for breast screening."* Furthermore, one participant from a deprived area said her friends would say *"you should go for it"* although this did not convince her. On the other hand, others felt their social support network were against their attendance at screening, linked with cultural beliefs regarding tempting fate and fears about consequences reporting, *"the doctor will always find something."* However, more participants reported their social networks provided support, as opposed to discouragement, which facilitated the decision-making process. One Black participant from a deprived area of London noting, *"there*

has been a lot of encouragement in our society. There's been a lot of women going for screening, and they encourage each other as well". However, these differences of opinion would need to be considered when delivering an intervention at scale. Furthermore, given the individual(s) responsible for delivering social support was different amongst participants (e.g. a spouse, a friend, a son), it will be important to consider how this can appropriately and effectively be incorporated within an intervention delivered at a population level.

Both perceived low susceptibility and fear of consequences upon the individual (i.e. a cancer diagnosis) were also found to be substantial barriers. Within one of the focus groups, a discussion regarding Angelina Jolie came to the fore. Some participants reported this emphasized their fears about the impact of cancer, one woman living with multiple illness, in a deprived area saying, *"she doesn't have breasts…I was afraid, they would say that we have to remove your breast….I don't like my body like that."* However, such narratives did help women appreciate the risk factors for breast cancer (including genetics, with others noting alcohol, and obesity as contributory factors,) as well as improve the salience of breast cancer, including amongst social networks, *"even my son knows she* [Angelina Jolie] *had breast cancer…and he's obviously a man."* Several participants noted the association of feeling at low risk, with the potential for significant consequences of cancer led them to ignore screening. This was notable amongst those from minority backgrounds who reported co-morbidities. One participant saying, *"it sounds ridiculous but it's like an ostrich putting its head in the sand…you think you're better off [not knowing]."* Whilst another who had not attended previously, stated her lack of family history with *"none of my siblings have got any* [cancer diagnoses]", meant she had no reason to go. This perceived low risk (3rd most coded), was also used to justify avoiding the perceived negatives of screening. For example, one participant suggested as she felt she was low risk, she could not attend and avoid the unnecessary stress

associated with mammography. As she described, missing out on the *"anxiety because you don't know the results,"* or avoiding her fear of the consequences, which in itself was the 9th most coded theme. This participant, however, did also say that she would also like to receive support saying, *"I need reassurance for the test itself* [to have the mammogram]… *for me that would be from a medical professional."*

Healthcare professional endorsement was seen as a consistent facilitator. Most participants identifying, *"the GP is the point of contact for everybody"*. With some noting that on receiving healthcare messages from their practice they *"felt slightly encouraged"*. However, there was widespread acknowledgement that face-to-face GP engagement was variable, especially amongst those who frequently saw their doctor. One participant highlighted *"I like my GPs and trust them…but it depends on your GP",* whilst another who was diabetic and hypertensive saying, *"if I ring my GP and say I have got a breast screening and I'm just got anxiety* [sic]…*my GP would say what is this silly woman talking about."* This was echoed by other participants, who felt that GPs had a role in reassurance regarding screening but were often inaccessible. The feeling of inaccessibility may also be related to the more widespread use of GP endorsement to promote attendance at appointments undertaken remotely (i.e. via messaging interventions), as opposed to in person.

The desire for more emotional support, as opposed to factual information, from practitioners may be related to the broadly good knowledge demonstrated by interviewees, although some misinformation was noted. One Black woman noting *"the paperwork I felt was adequate…I think they send out a little leaflet."* As such most participants could recall the invitation process, rough ages of eligibility and the rationale. However, focus groups agreed the need to continue to provide basic information and *"mass education…you still need to make sure people*

understand who can get it [cancer] and how screening helps." This was important given several participants had heard incorrect information regarding the screening environment which could be addressed by providing basic information on the screening process. On the other hand, some participants had experienced genuine problems with screening centres. One woman, who was a carer, said her mother *"was in a wheelchair, and two people had to physically manhandle her like a piece of meat to get this test* [mammogram] *done."* This reiterated similar negative experiences of the healthcare system from participants, which appeared to heavily influence decision making. One Asian participant recounted how she had previously asked her GP for a mammogram being told, *"no, it will cost the NHS money…it made me feel like it was in my mind."* These feelings left participants examining alternatives including seeking screening mammograms in other countries, "*naturopathic medicines*" or disengaging with screening.

There were also misperceptions about mobile breast screening services, including that they were inferior to hospital-based screening, with one participant reporting that *"there's a question of how effective are the machines [sic] in these mobile setups,"* finding more reassurance when you can *"see the whole machinery and things in the hospital."* Such perceptions may have been different during the height of the COVID-19 pandemic, as a few participants did report that they would have considered changing the location of the appointment from a hospital, had they been invited during that time. However, their concerns regarding COVID-19 transmission had greatly reduced, likely because interviews were conducted at a time in which the mass vaccination programme in the UK had been rolled out.

Participants were also asked during focus groups to examine the materials including the website and videos sent by screening services, as well as to discuss interventions that would

help them attend. When examining existing materials participants felt these were not representative of minority or underserved groups. One Black interviewee said, *"so many black women have breast cancer, all the information didn't have a black person visualised on any of the information."* Furthermore, one participant living with a disability said, *"we need to make it [the materials] a bit diverse…that's why I think cancer doesn't concern me."* Others agreed, feeling passionately that this reinforced the feeling that screening was not there for them saying, *"that's why we don't go. You need to put us there…if I see that [screening video] I will just think it's for them not us."* In addition, to improving minority representation, participants felt *"story telling is a great way to get the message across, and to highlight…people's journey."* Other focus group participants agreed this narrative-based education would be more meaningful. One participant suggested *"use some form of animation to get the stories across….something which might be for people of different colours, cultures, types of people."*

Table 4- 5 Key themes and sub-themes from interviews and focus groups, exemplar quotes and influences underpinning these. TDF domains mapped to the sub-themes are also shown.

Theme	TDF	Sub-Theme	Example	Relevance of Domain	Influences
Pain of Mammogram Coding rank 1st	**Emotion**	*Expectation of pain leading to fear of attending*	*"I think that some of the leaflets did say it might be rather uncomfortable, nowhere was I told that it would be very painful indeed"* *"It makes me a bit nervous because of…the pain".*	Underestimation of pain in previous experience led to worse experience and anxiety at next appointment	1. Previous painful experience 2. Underestimated pain
	Environment	*Physical causes of pain*	*"I'm a tall woman as women go and I was, I had to sort of crouch down"* *"The third way in which it hurt was the little shelf"* *"It's only a few seconds"*	Physical causes of pain and sources during the examination	1. Not being able to adjust test 2. Technique used to screen
	Social influences	*Sharing experiences of pain*	*"What I've heard it's quite painful and it puts you off"* *"A couple of friends...they found it painful…they said not sure if they'll go back"*	Discussions regarding pain and sharing expectations led to anxiety or fear.	1. Social influences and sharing of negative experiences
Social influences from family and friends Coding rank 2nd	**Social influences**	*Social network opinions on mammogram/and attendance*	*"They [friends] say the doctor will always find something"* *"I think they think that if you don't feel anything…they [the family] probably think it's fine; there's nothing wrong…it should be fine, just leave it."* *"there has been a lot of encouragement in our society"*	Participants highlighted a mixed response of family and friends on mammogram from ambivalence to encouragement	1. Lack of knowledge or awareness, or misinformation shown by family/friends 2. Fear of consequences [see fear]
	Social influences	*Health as a priority*	*"My husband he said "it's nothing and you're fine. Your health is … and why you are thinking about it"* *"They are not interested. 'Oh, my wife should go for screening' They don't have any knowledge when they are not interested"* *"My daughter-in-law says, "Oh, it's important to do this"*	Participants highlighted familial influences impacted upon how health is prioritised. This could lead to less consideration of one's own health in favour of collective tasks.	1. External and environmental factors e.g. competing health interests
	Social influences	*Social encouragement*	*"With Asian people, they don't find 100% from husband."* *"Encouragement from my friends and family, made me decide in the end"*	Participants find social support encouraged them to overcome fears and anxiety. It was a strong determinant in making the decision.	1. Social group knowledge and previous experience of mammogram
Risk Factors and Susceptibility	**Knowledge**	*Knowledge of risk factors*	*"Touch wood there hasn't been any situations [breast cancer] in the immediate family. So maybe that's what put me off [screening]".*	Participants highlighted risk factors including genetics, alcohol and obesity as risk	1. Knowledge of risk factors

Coding rank 3rd			*"I think my risks are pretty low...I don't smoke, I don't drink, there's no family history…I'm healthy otherwise"*	factors. Unproven factors including stress and nutrition were also stated	
	Optimism	*Perceived low susceptibility*	*"Nobody's really to believe that cancer can happen to them...almost wishful thinking."* *"Especially South Asian, they think, 'Oh, cancer in me. It's not possible"* *"I haven't got any symptoms in the family that would indicate to me to go and have that scan. I would go when I'm ready"*	Participants believed that without family history, they could not be affected. No participant felt they were high or even average risk.	1. Awareness of that you do not need to have familial risk to have cancer
	Beliefs about Consequences	*Close contact impacting on risk*	*"Until a friend's got the symptom or a family member's gone through it, again they find a small lump, then possibly that would reassure me to go next year"*	Having a close contact affected by cancer increased screening behaviour.	1. Salience of the importance of screening
HCP endorsement /influence Coding rank 4th	**Social influences**	*HCP supporting screening*	*"She [GP] noticed that I hadn't had breast screening… she advised me that I should attend but there was no pressure there, there wasn't any in-depth discussion, she just said that she would recommend it."* *"GPs need to emphasise quite strongly the importance of these scans, and make the patients feel comfortable, and also make them aware that it is very critical."*	The predominant HCP influence came from GPs. This increased the salience of screening for some. This was predominantly advice as opposed to active encouragement.	1. Contact with GP or HCP 2. Influence of GPs
	Environment	*HCP availability to answer questions/provide endorsement*	*"So, the old one [GP] has left. The old ones, they kind of knew you at a personal level, and they would have a chat and tell you about these things"* *'The thing is I don't want to disturb my GP just to ask those sort of questions. I don't think it's fair on them"*	Many expressed the value of discussing this with their GP, however availability was often a barrier.	1. GP turnover 2. GP availability 3. Knowledge
Screening Environment Coding rank 5th	**Environment**	*Mobile v. Hospital*	*"I also feel very uncomfortable with the fact that all these mobile units are setup in public places"* *"If you've other health conditions it's not fair on the individual because they are going to get claustrophobia…it puts your mind at ease if you've got family who's able to stay.*	Mobile screening services were often criticised as areas of poor accessibility. There was also concern regarding their accuracy and safety impacting attendance.	1. Perceptions of the role of mobile units 2. Accessibility of mobile units
	Environment	*Accessibility*	*"Despite my mum being in a wheelchair…she couldn't get in the door…two people had to physically manhandle her like a piece of meat."* *"Travelling was no problem at all, and this was during a weekday. So, I had no issues with that."* *"Parking, and transport can be an issue. But that's a general hospital thing"*	The location of services was often far from individuals, however, was not often considered an issue. Accessibility for those less abled was a barrier.	1. Distance from screening services 2. Accessibility within departments

	Environment	*COVID-19*	*"I would have changed my appointment because of the fear of catching the infection [COVID] in the hospital environment, but not now."*	COVID-19 causing anxiety and potential as a barrier to attending screening	1. COVID-19 levels and restrictions
Knowledge Coding rank 6th	**Knowledge**	*Knowledge of purpose*	*"More opportunity for it to be caught earlier, as I said, they're looking for changes and not necessarily looking for cancer"* *"Catch it [cancer] earlier, and it can be treated"*	Participants were aware of the purpose and rationale including earlier detection.	1. Understanding and access to information on the purpose of screening
	Knowledge	*Knowledge of programme*	*"It's free. It's not that you are paying some money"* *"Once in three years, you have to go for screening and that is for you"*	Participants were aware of the programme and the processes.	1. Salience of screening
	Knowledge	*Misinformation*	*"I've heard this that the scans from a mobile unit rather than the hospital itself, many mistakes have been made in the diagnosis of cancer"*	Several participants displayed misinformation regarding screening	1. Access to correct information
	Knowledge	*Information sources and seeking behaviour*	*"Not enough information out there. That's what I feel anyway"* *"Educate them on how important these things are"* *"The basic information I was sent was adequate"*	Participants had different ideas about finding more information	1. Access to information sources
Preparation for mammogram after invitation Coding rank 7th	**Memory and Decision Processes**	*Memory*	*"I've got something in my kitchen, I write as well, and then I know, "Okay, on this day there's something happening"* *"I have a diary, and I make a note in my diary, and on my calendar, and my mobile phone."*	Participants described several methods of remembering appointments	1. Cognition 2. Availability of reminders
	Memory and Decision Processes	*Mental processes*	*"Nothing I've seen has made me think that programme's any different than it always was"* *"I was confident not to go"*	Participants described several mental processes on receiving the initial invitation.	1. Previous experiences 2. Confidence in decision making
	Decision Processes	*Practical processes*	*"If I didn't know how to get there I would look up"* *"If I'm going for an appointment, I will rest all day"* *"As soon as I get the letter. I just have to make arrangements, I've got to book this, I've got to book"*	Participants described physical preparation	1. Environmental factors
Negative images of screening Coding rank 8th	**Social Identity**	*Minority representation*	*"So many black women have breast cancer, all the information didn't have a black person visualised on any of the information."* *"Everything was felt very Eurocentric"* *"A lot of services are there for Caucasian people"*	Participants described the lack of minority representation in media or imagery associated with screening	1. Environmental factors 2. Attitudes of screening services
Fear of Consequences (not pain)	**Beliefs about Consequences**	*Impact of diagnosis on social network*	*"Some people if somebody comes to know that I have a cancer, they behave really differently"* *"all family they treat differently."*	Concern about the cultural impact of screening	1. Lack of knowledge on cancer treatment/pathways

Coding rank 9th				diagnosis on family, and so not want to attend.	
	Beliefs about Consequences	*Impact of diagnosis on individual*	*"it can be awkward because to think somebody may have cancer is a bit, at least in my country…You have to keep it quiet. Don't say it"* *"it's the fear of what's going to happen…maybe there's something there"* *"Oh god. What's going to happen? You might die".* *"It does worry us a lot to think, 'If a mammogram cannot pick it up"*	The anxiety and fear of a positive result and the impact of treatment on the individual was a barrier to attendance. Some preferring not to know.	1. Perceived severity of the condition and treatment
	Beliefs about Consequences	*Anxiety caused by perceived mammogram failings*	*"Does the breast screening programme have that balance right, are you getting people who are being treated that actually didn't need any treatment"* *"Some of my friends have been saying you can get false positive results, and that has created anxiety among a few of my friends…[so] I've not had it"*	Anxiety caused by perceived overestimation, overdiagnosis or failing of the mammogram, leading some participants not to attend	1. Perceived effectiveness of mammograms 2. Perceived susceptibility [see above]

Coding rank- frequency of codes referring to that theme across transcripts, *GP- general practitioner, HCP- healthcare professional, TDF Theoretical Domains Framework.*

4.5 Discussion

This study looked to determine the barriers and facilitators to breast cancer screening, by understanding the commonalities amongst underserved and multiply underserved groups. The existing literature on the determinants of attendance in certain underserved groups including those from areas of deprivation was limited and of variable quality. All identified studies investigated singular socio-demographic factors, with ethnicity the most commonly examined. Common TDF domains cited by the literature between the groups included beliefs about consequences, knowledge, emotions, social influences and environmental factors. Similarities were found with the results of the qualitative work conducted with participants who represented multiple differing underserved communities. Themes within the domain of emotions were mainly related to fear/expectation of pain from the mammogram, as well as a fear of exposure. Fear was also influenced by social networks sharing past experiences. Social influences also appeared to directly influence attendance behaviour, mainly through encouragement or support to attend. Beliefs about consequences or the impact of cancer on the individual was also found to be a strong determinant for non-attendance with many fearing a positive mammogram result would be life limiting. However, contrary to the findings from the literature review, knowledge and memory were not found to be significant barriers regarding screening from the interviews or focus groups. Environmental factors were also found to impact attendance. Whilst barriers including transport links were not commonly noted in interviews, the physical screening environment was a barrier. A lack of space within mobile units, especially amongst those with physical disabilities, and the machine contributing to pain were also noted.

There are well established inequalities in breast cancer screening in the UK. Lower than expected uptake of screening invitations has been noted in several population subgroups, including those from minority ethnic groups (e.g. Black women), areas of high deprivation and

those living with multiple illnesses or disability[37,52,282]. As discussed in the Marmot review, health inequalities are underpinned by the social determinants of health[283]. Dahlgren and Whitehead demonstrate the broad socio-economic circumstances that influence health outcomes, with personal characteristics including age and ethnicity at the core[29]. People who come from multiple underserved groups e.g. an ethnic minority and certain ages, represent an important cohort to investigate. Using an intersectional lens fosters a deeper understanding and will help develop relevant interventions that focus upon the barriers that potentially are most impactful.

Several common barriers to breast screening were noted amongst underserved groups. Fear of pain and fear of exposure were among the most frequently mentioned barriers in interviews and the review, amongst those from minority ethnic groups and those living with health problems. This is consistent with the wider literature; for example, one systematic review estimated that 25 to 46% of women did not reattend due to pain, which would be the equivalent of around 47 to 87,000 invited women in England not attending annually[284]. This is particularly important as regular participants of breast screening have a significantly lower risk of breast cancer death than intermittent or lapsed attenders[285]. Similar findings regarding fear of pain as a barrier have been found in other studies of underserved communities included in the present review, including ethnic minorities and those with intellectual disability[286,287]. Fear of pain has also been shown to lead to non-attendance even if individuals are aware of the importance of screening[288]. In the interviews, this effect was also noted amongst those who had never attended, primarily mediated through their social influences. In addition to affecting expectations of screening, social influences also appeared to directly impact upon screening decision-making. Participants were largely influenced by their friends' and families' perceptions of the utility of breast screening. This determinant was dependent on the

knowledge, past experiences and cultural values of their social network. However, in some instances participants rejected the opinions of their contacts. This variability may explain why interventions using normative messages e.g. X out Y people attend breast screening, can be effective, especially those using descriptive norms, however these findings are not consistent.[215,289]

The presence of social support for breast screening was found to be a strong facilitator to screening attendance, whilst its absence could be a barrier. This was noted in all three groups studied within the literature review and qualitative study. For example, participants highlighted the role of spouses, and how cultural values meant their endorsement would increase motivation. This was particularly important amongst those reliant upon support for communication or physical needs, as seen in the review. Studies have also reported the importance of this dynamic, with partners more often the 'discussion leader' in screening conversations[290]. Comparable findings have been shown in the wider literature on general populations, with Documet et al. demonstrating in a US population that the adjusted odds of self-reported attendance at breast and cervical screening was higher amongst those with social support. However, they found that social support did not impact the attendance at mammography of those from differing educational levels[291]. Post pandemic studies have also suggested that social or community support remains a strong determinant of attendance[292]. Increasing social support within the constraints of a scalable population-level intervention may however be challenging, as to be effective interventions would likely need to engage local and individual support networks.

Knowledge-based interventions are commonly utilised as described in Chapter 2. However, the current study has found contrasting findings with respect to the impact of knowledge upon

breast screening attendance. Whilst existing literature highlighted that a lack of knowledge about screening is a barrier amongst the differing underserved groups[276,281], qualitative work did not. This may be related to selection biases with interviews or may pertain to the effectiveness of more recent promotional campaigns to increase breast health awareness. Several charities including the Race Equality Foundation in 2020 and Breast Cancer Now in 2021, have launched media focussed at improving breast health awareness amongst underserved groups[293,294]. Though there is limited data to support the impact of public health campaigns such as these, a systematic review by Anastasi et al. on all breast screening awareness interventions did demonstrate that the use of media, for example posters, may increase the likelihood of attendance in the UK, although included studies were heterogenous and often limited in size[295]. Consequently, historical studies examining the awareness of these groups may not represent the current knowledge base. Furthermore, when examining common TDF domains in the qualitative study, despite knowledge-based factors such as 'what is breast cancer or screening' not appearing relevant, knowledge of risk factors did influence perceptions of susceptibility. All participants felt at low risk of cancer, which was largely underpinned by their perceptions of candidacy and whether they undertook lifestyles that they believed predisposed them to developing cancer. However, the studies have shown that differences in the incidence of breast cancer amongst minority ethnic groups are related to differences in risk factors such as obesity and parity. As lifestyles and risk change over time there will be a need for public health messaging to adapt[228].

Despite having awareness of the programme, participants did report the usefulness of educational materials. Access to information was also the most frequently mentioned facilitator within the systematic review. This suggests that even if the knowledge-gap is diminishing, there is value in embedding baseline knowledge into interventions. This includes giving

individuals an impression of the differing screening environments. This would help circumstances when reasonable adjustments are needed prior to appointments, avoiding negative experiences. There is a need however to make educational information culturally appropriate, whether that be translated, applicable for diverse communication needs, or content representing underserved groups. This will help engage those with lower health literacy or cognitive ability, with the former associated with a less positive attitude towards screening[296]. But as shown in the qualitative study, knowledge was only the 6th most coded theme, therefore interventions to increase attendance would likely need to also address more common barriers such as fear. Use of storytelling, or narratives, may allow multiple determinants to be addressed, and has previously been used effectively in screening[297]. Studies have demonstrated narrative-based approaches produce stronger engagement, and cognitive and affective reactions, than purely informational resources[298]. As with the Angelina Jolie- narrative[180], they may also be effective in engaging social networks, and therefore have significant potential within underserved groups.

The findings from this Chapter suggest that there are common barriers to breast cancer screening experienced by underserved and multiply underserved groups that could form the basis of a potential intervention. For example, a fear of pain and embarrassment (or feeling of vulnerability) were noted across all groups in the systematic review, and within interviews. Overcoming these perceptions would help reduce the anticipated fear and negative emotions toward screening. In addition, social support, which was also commonly cited as a facilitator, could also be utilised. Whilst consideration would be needed regarding which social connection was being targeted (e.g. spouse, friend), an intervention could leverage these connections for example by highlighting norms, or multiple narratives to facilitate attendance.

4.5.1 Limitations

The findings from this study need to be considered with the limitations of the methods used. Firstly, interviews and focus groups were conducted in a relatively small sample. Although thematic saturation was achieved, and the target population was purposively sampled to represent those with combinations of characteristics associated with underserved communities, not all perceptions may have been elicited. Furthermore, additional combinations of characteristics may not have been fully represented in the sample. The findings of this study therefore may not be generalisable. This was however mitigated by undertaking a systematic review of the existing literature which further contextualised findings from qualitative work. The general concordance between the findings from this and the interview study suggests that the elicited determinants of non-attendance are found in a larger population. Secondly, only two participants reported that English was not their first language. As there was no strict inclusion criterion that individuals had to speak English, with members of the research team able to conduct sessions in multiple languages, this information was not explicitly requested in the pre-interview questionnaire. Instead, these individuals volunteered this information to researchers directly prior to sessions. Individuals unable to speak or understand English represent a hard-to-reach group. Moreover, they have been shown to present with later stage breast cancers due to potential difficulty accessing services[299]. Having low numbers of these individuals involved in the current study may mean conclusions are less pertinent to these underserved groups and affects the generalisability of the findings.

Communication is a well cited barrier to the inclusion of certain communities to study involvement. This contributes to the under-representation of specific groups, or underserved communities within research contexts. However, other barriers such as a lack of trust and conflicting agendas between researchers and participants have also been noted[300]. The current

study may therefore have been subject to selection biases and may represent the views of those more willing to engage with research. This was mitigated by the involvement of community groups with established relationships with underserved populations, and a female researcher who has experience working within these contexts. This potentially helped reach those who would be less inclined to participate, by improving trust and overcoming cultural barriers associated with research amongst underserved groups[301]. In addition, the sampling techniques used, although non-probabilistic, facilitated the recruitment of individuals who self-identified as having characteristics associated with traditionally low-uptake groups. Snowballing techniques involving extending invitations to the contacts of those recruited, helped increase the spread within these communities using previous participants as more trusted messengers. Moreover, self-report measures, although limited, especially with respect to deprivation, helped to provide insights into the backgrounds of participants, without intrusive questioning leading to mistrust.

Further work should look to overcome these limitations by using more participatory research methods, working longitudinally in collaboration with communities to understand these determinants in context. This would help to give greater insights into issues with access, and potentially help understand the perceptions of those not wanting to engage with research. Moreover, future work should look to combine data analytics to statistically define the most common socio-demographic, geographic and medical factors associated with non-attendance. As described, the term *underserved* lacks a definition within the screening context, and therefore several different factors can be associated with non-attendance. The current study has examined the more commonly cited factors such ethnicity, deprivation, and medical morbidity/disability, however, to gain a better understanding of the barriers in underserved groups, a more objective definition is needed. This analytics-driven approach in combination

with a participatory method would also provide greater insights into the intersectionality of these characteristics, and which combinations of characteristics are associated with the lowest uptake. Furthermore, it would facilitate an understanding of the impact of other factors, such as the spatial accessibility of local screening services, within these populations. Finally, it is also important to understand whether the barriers highlighted in the present study of underserved groups are different to those seen in the wider population or are more influential versions of the same determinants. This would facilitate the implementation of interventions addressing these challenges into population-level programmes.

4.5.2 Conclusions

Several populations could be considered underserved with respect to breast screening. The existing literature has predominantly focussed upon those from minority ethnic groups, areas of deprivation and those with multiple illnesses/disability, with researchers considering these characteristics in isolation. Qualitative work has shown key themes associated with non-attendance behaviour between these groups, and which could be addressed within interventions, include fear of the process, lack of social influence, perceived low susceptibility and a need for healthcare professional endorsement. The impact of knowledge, however, was variable. Leveraging these findings in a narrative-based intervention has the potential to address the challenges faced by multiple underserved groups. However, for programme-level interventions it is also important to understand whether these challenges are also encountered in the wider population. Future work should look to examine this, as well as using a data driven approach, involving screening and public health datasets to precisely identify the combinations of demographic characteristics most commonly associated with non-attendance. These groups may therefore be considered to be the most underserved

communities with respect to breast screening. This could then feed into a large scale intersectional participatory study to examine associated determinants of non-attendance.

5. Development of a Novel Behavioural Science-Informed Animation and Reminder Message to Increase Screening Uptake

Outputs related to this chapter

A. Acharya , H. Ashrafian, A. Darzi, G. Judah. *Developing an animation using the Behaviour Change Wheel to facilitate breast screening amongst under-represented groups.* 2022. 36th Annual Conference of the European Health Psychology Society. Bratislava, Slovakia.

A. Acharya, G. Judah and A. Darzi. *Developing a novel animation in breast screening*. 2022. 1st London Breast Screening Community of Practice. London, UK.

5.1 Abstract

Background

Several barriers to breast screening attendance have been previously identified, especially amongst underserved communities. It is unknown whether these determinants are common in the wider population, and how they can be addressed to improve screening uptake. The aim of this study is to triangulate findings from earlier chapters and pre-existing research on the determinants of breast screening attendance, and to apply behavioural frameworks to inform the co-design of a novel behavioural science-informed reminder SMS and animation.

Methods

Data from 3 information sources: an interview study, a population-level survey and a systematic review of the literature, was extracted. This information was triangulated to elicit the common, and most pertinent, barriers to breast cancer screening attendance. Researchers determined the strength of the influence of each determinant, with the most important mapped

to the Theoretical Domains Framework and Capability, Opportunity, Motivation-Behaviour models. Using the Behavioural Change Wheel, and Theory and Techniques Tool, intervention functions and potential Behavioural Change Techniques (BCTs) that could address the barriers were elicited. Candidate BCTs were used to inform activities at four co-design workshops involving underserved groups. The output was an animation and plain text reminder which were further iterated through an extensive feedback cycle.

Results

Six high-priority, and eight medium-priority determinants were elicited through triangulation of information sources. Following the mapping exercise, 11 core BCTs, including the less commonly used *vicarious consequences* and highly effective *problem solving*, were taken forward. Co-design workshops using the Nominal Group Technique, developed an animation plot, text and imagery that utilised these BCTs within patient stories to improve breast screening uptake. A plain-text reminder incorporating behavioural science-informed wording was also developed. Both the text and animation were refined by key stakeholders.

Conclusions

This chapter explains the methodology utilised to develop a novel behavioural-science informed animation to improve uptake. By triangulating sources of information focussed on underserved communities, with population-level work, it was possible to create an intervention that could be acceptable at scale but potentially tackle inequalities. Moreover, by using a robust theory-based framework, in conjunction with complex intervention guidance from the Medical Research Council, this intervention has been developed to be feasibly implemented in a population-level screening programme.

5.2 Introduction

There is significant variability in the effectiveness, conduct and design of interventions in breast cancer screening[72]. Even just within London, there are substantial differences in the types of breast screening interventions being undertaken. For example, some interventions have been used to increase attendance, including personalised invitations or reminder telephone calls, whilst others were involved in supporting the delivery or provision of screening, such as education for GPs. There are also discrepancies as to where these interventions are conducted, with some areas having a substantially higher frequency of interventions tested[302]. This heterogeneity, also reported in Chapter 2, leads to difficulties when trying to evaluate the relative merits or failures of such interventions, and the methodology underpinning them[303]. As shown in the systematic review in Chapter 2, and contrary to the existing literature, use of a behavioural theory was not associated with effectiveness[304]. As discussed this is because there are additional considerations needed when implementing behavioural interventions, with theoretical foundation only one facet[303]. These considerations include fidelity, or the extent to which the behavioural intervention was implemented and received as intended[305]. Given the scale of population screening programmes, and the complexity with which they are administered, there is significant potential for intervention protocols to deviate. For example, the screening hub may not have a large proportion of correct telephone numbers to send an augmented reminder, or there may be a lack of training for screening services to deliver an educational intervention. As a result, the delivery and receipt of these interventions may not be in keeping with what was originally planned, leading to unreliable estimates of intervention effectiveness[305,306].

Several frameworks have been developed to help standardise the design and evaluation process of public health interventions. Some models such as the PRECEDE-PROCEED are widely

used but have faced criticism regarding the lack of detail surrounding intervention development and its complexity[307,308]. On the other hand, the Designing for Behavior Change guide provides little information regarding evaluation, and does not readily direct users to which precise techniques they could use to address a behaviour [309–311]. In 2021, the Medical Research Council (MRC) jointly with the National Institute for Health Research (NIHR) developed an updated guidance regarding the creation and evaluation of complex interventions[312,313]. At the core of this framework are 6 elements that are applicable across the implementation process from development and feasibility testing to evaluation (**Table 5-1**).

Table 5- 1 Core elements of the MRC framework on the development of complex interventions, with definitions and descriptions of how they pertain to the design process, and what design considerations have been highlighted Chapter 3 (consensus study).

MRC Element	Definition	Relation to Current Intervention Design	Specific Considerations from Chapter 3
Consider Context	Dynamic and multi-dimensional. Include physical, spatial, organisational, social, cultural, or economic features of system	Based in the NHSBSP in London during a time of COVID-19 recovery, which currently uses SMS reminders as standard	Details including need for COVID-19 information, Links to website booking
Programme Theory	The mechanism of action of the intervention, how components interact and the relationship to the contexts.	Behavioural intervention to increase screening uptake of a large diverse population. Using: (a) TDF to compare determinants (b) BCW to understand influences, and how interventions can function to address them (c) TaTT to assess how BCTs impact behaviour/alignment with intervention functions.	Mechanism cannot be coercive
Stakeholders	Stakeholders include service users and those whose professional interests impacted. This should impact the research perspective	Diverse service users, London screening hub, screening sites and services, NHS commissioners, clinicians, NHS Trusts, NHS England	Representative of stakeholders, Maintains trust
Key uncertainties	Emergent approach to explore the uncertainties faced through the process, and could be used to aid the framing of research question	Uncertainties in determining the impact of the intervention, how to optimise distribution, its accessibility to a diverse population and need to consider timed and open invitations.	Assurance of data accuracy/verification of delivery
Refine Intervention	Refining the intervention between stages involving potential users to ensure acceptability and feasibility	Need for an iterative process of refining and ongoing stakeholder and service-user input	Acceptability
Economic Considerations	Comparisons to alternative pathways/interventions with respect consequences and cost.	Costs will need to be minimised and ideally be a net zero to services e.g. an intervention based within the existing SMS reminders	Maintaining the schedule and length of current messages

BCW- Behaviour Change Wheel, COVID-19 – Coronavirus Disease 19, MRC- Medical Research Council, NHS – National Health Service, NHSBSP- NHS Breast Screening Programme

One of the key elements underpinning the design of the process according to the MRC framework is the 'programme theory'. Within the current circumstance this relates to the mechanism by which the intervention will increase screening uptake amongst the eligible population in London. From Chapter 3, efforts to increase screening will need to function in a non-coercive manner[241]. To achieve this, the design of the intervention will need to (A) address the determinants of non-attendance amongst traditionally underserved groups, as highlighted in Chapter 4, as well as in the wider population. (B) use behavioural techniques that will facilitate, not force, a change in attendance behaviours. (C) ensure the intervention can practicably be used within the screening context of London, e.g. by leveraging SMS, which is the predominant communication channel in the service[314]. To achieve (B), a process of mapping will need to be undertaken, which will incorporate several behavioural tools including the Theoretical Domains Framework (TDF), Behavioural Change Wheel (BCW) and Theories and Techniques Tool (TaTT)[82,85,92]. This process of mapping and triangulation would help to make better use of the evidence underpinning interventions in breast cancer screening. It is possible, therefore, to understand what the potentially appropriate intervention functions are, using the BCW, and to select BCTs with sufficient evidence that they address the relevant TDF determinants, using the TaTT. These frameworks are discussed in detail in Chapter 1, but a concise summary is provided below of each.

Theoretical Domains Framework (TDF)

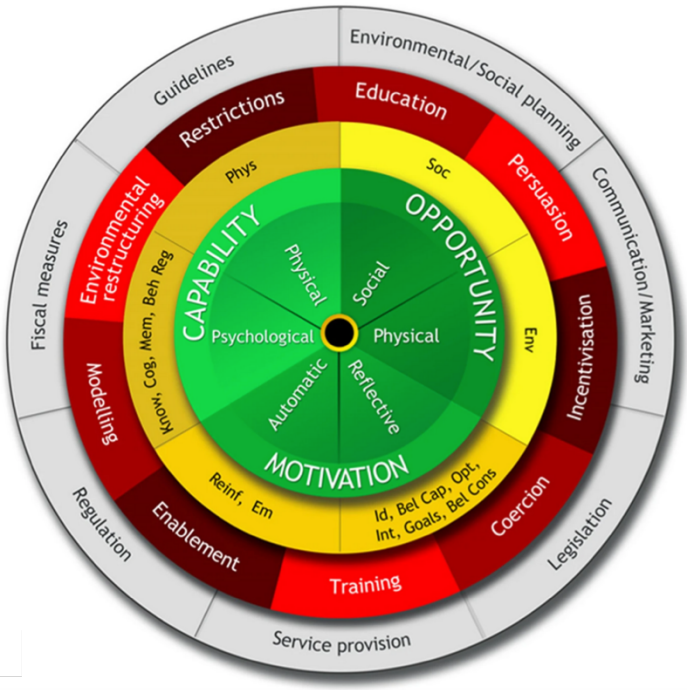
This framework encompasses 14 domains derived from the synthesis of 33 theories of behaviour change[82]. The TDF does not provide an indication of how the elements interact with one another, but does provide a comprehensive, evidence-based means of understanding the different influences upon a particular behaviour. Furthermore, the TDF can be used to guide qualitative study methodology, e.g. in development of topic guides[315]. In addition to deductive

methods, the TDF can facilitate the conduct of an inductive analysis, by helping to derive overarching domains which influence behaviour, and help derive commonalities within domains[253,316].

Behavioural Change Wheel (BCW)

The TDF has an established link to other behavioural science frameworks such as the Behaviour Change Wheel. This framework links a core behavioural system (the Capability, Opportunity, Motivation- Behaviour or COM-B model), to intervention functions and policy categories[85] (**Figure 5-1**).

Figure 5- 1 The Behaviour Change Wheel, demonstrating the COM-B model in the centre, TDF domains, associated intervention functions and policy categories.



Beh Reg- Behavioural Regulation, Bel Cap- Beliefs About Capabilities, Bel Cons- Beliefs About Consequences, Cog- Cognitive and Interpersonal Skills, Em- Emotion, Env- Environmental Context and Resources, Id- Social/Professional Role and Identity, Int- Intentions, Know- Knowledge, Mem- Memory, Attention and Decision Processes, Phys- Physical Skills, Reinf- Reinforcement, Soc- Social Influences

Reproduced with permission from Michie S, Atkins L, West R. (2014) The Behaviour Change Wheel: A Guide to Designing Interventions. London: Silverback Publishing. www.behaviourchangewheel.com[85].

As well as considering motivation, the COM-B model encompasses constructs such as habit formation and emotions (automatic motivation) and environmental context (physical opportunity), which are often not covered in other theories, such as the Theory of Planned Behaviour[89]. Having determined the influences upon behaviour using the TDF, it is possible to map these onto COM-B[252]. The BCW mapping framework can then identify all potentially appropriate intervention functions (which are broad categories of interventions). One of the key features of the BCW, is that the mapping from determinant to intervention function is achieved systematically, so all potentially suitable intervention options can be considered[317,318].

Theory and Techniques Tool (TaTT)

Once determinants are understood, and potentially broad intervention functions are identified, more precise Behaviour Change Techniques (BCTs) can be suggested. These modular or 'active ingredients' are the actual aspects of an intervention that bring about a change in behaviour[91]. When selecting the most appropriate BCTs to incorporate, several considerations are needed beyond logistics. This includes understanding how a BCT brings about its effect, or its mechanism-of-action (MoA)[93]. As researchers may differ in their understanding of how BCTs bring about changes in health behaviour, making a decision on which techniques to use becomes difficult. The Theory and Techniques Tool (TaTT) is an evidence-derived heat map that aims to link the defined BCTs to potential MoAs[92]. This map demonstrates which of 74 BCTs are linked and not linked to each of 26 MoAs from available evidence, and whether the evidence of the link meets a determined threshold, is inconsistent or inconclusive, or is largely absent. This provides a robust rationale for the utilisation of certain BCTs and helps to standardise the development of behavioural interventions[319].

5.2.1 Aims

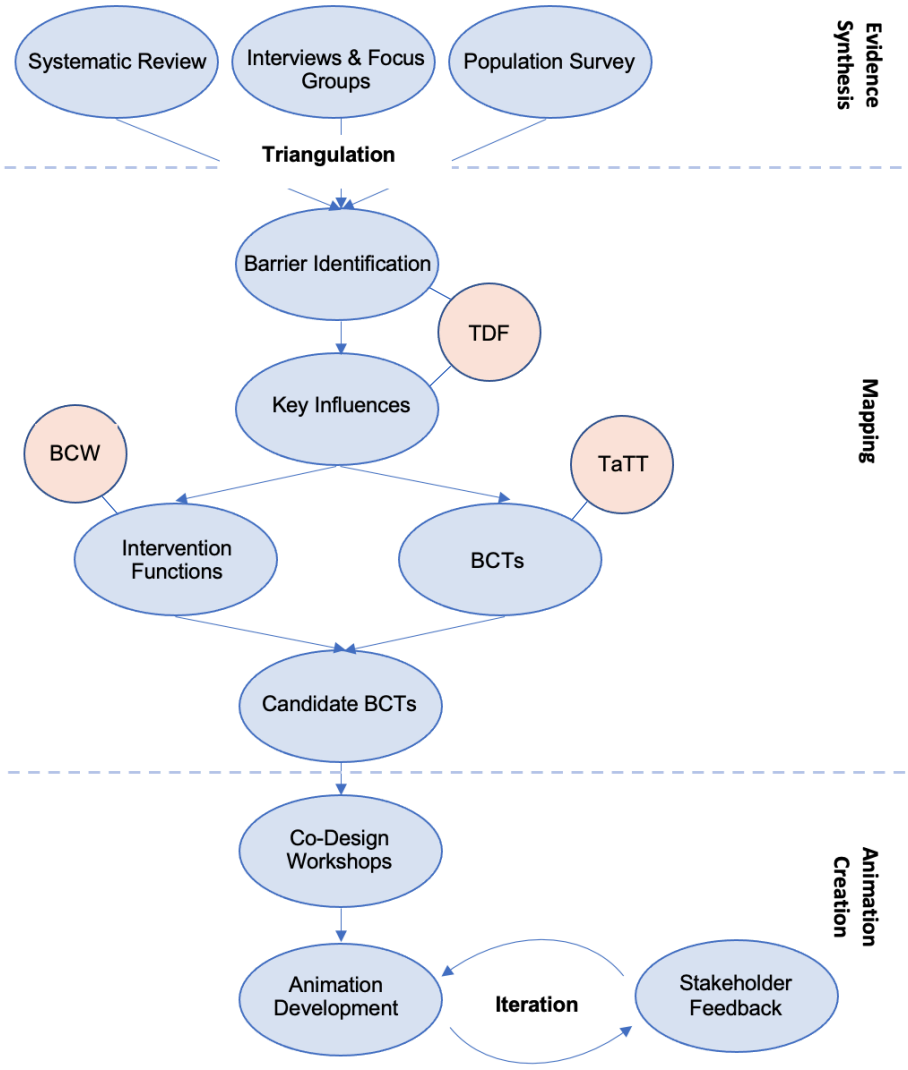
The aim of this chapter is to develop a novel behavioural science-informed animation, that uses Behavioural Change Techniques to address the determinants of non-attendance at breast cancer screening amongst underserved groups, as well as the wider population. To do this, this chapter will use a process of triangulation and mapping across behavioural frameworks (TDF, BCW, TaTT) in order to systematically design an intervention to address elicited determinants. Moreover, it will look to design behavioural SMS reminders that can be used within the current infrastructure of the screening service in London to facilitate delivery of this intervention in a population-wide programme.

5.3 Methods

5.3.1 Study Design

This intervention development was conducted in 3 phases: evidence synthesis, mapping, and animation creation (**Figure 5-2**).

Figure 5- 2 Intervention development stages



BCT- Behaviour Change Technique, BCW – Behaviour Change Wheel, TDF- Theoretical Domains Framework, TaTT- Theory and Techniques Tool

Evidence Synthesis

Three sources of information detailing the barriers and facilitators to attending breast cancer screening in London were obtained. These were (1) the systematic review on barriers, (2) interviews/focus groups with underserved population groups and (3) a population-level survey undertaken previously. The outputs from sources (1) and (2) were detailed in Chapter 4. The population survey was conducted by Huf et al. using questions developed in a pilot study and based upon the TDF[320]. It was distributed by an online company, Bilendi, to 1000 women based in the Southeast of England aged between 47 and 73 in 2018. Logistic regression analysis of this survey was reported to determine the effect of behavioural domains upon self-reported previous attendance and intention to attend in the future. Access to these data was made available to the current study team by the authors of the survey for its inclusion in the triangulation process. The aggregated outputs from the study have been presented online by Huf et al[320]. The outputs of all three sources were then triangulated to elicit the common and disparate determinants of non-attendance behaviour.

Triangulation is a strategy that involves the combination of several research methodologies in the study of an overarching concept. It can be incorporated into positivist (assuming a single measurable and objective reality), post-positivist (assuming a singular reality, in which hidden influences including interactions with the researchers act), pragmatist (allowing for singular and multiple realities) and constructivist approaches (assuming multiple realities and the relativism of knowledge)[321–325]. The current study utilised three of the four types of triangulation described by Denzin, namely, data triangulation (with differing populations studied), investigator triangulation (involving different researchers in interpretation), and methodological triangulation (use of surveys, interviews, and reviews)[326]. Theoretical triangulation (use of multiple theories in explaining the same phenomenon) was not used. This

process increased the rigor of the inferences derived from information sources by comparing the differing interpretations of researchers[327]. I undertook the triangulation process and validated findings with a panel of 3 independent researchers who were familiar with the data from information sources. Researchers considered the convergence, divergence, and complementarity of the information sources[328]. This helped formulate conclusions on whether a particular sub-theme should be shortlisted as a priority sub-theme and carried forward to the mapping phase, with researchers provided the following prompts during the evaluation:

1. The frequency with which a particular sub-theme was raised within and across information sources.
2. The strength of the sub-theme upon screening uptake, and whether such relationships are consistent within and across information sources.
3. The absence of conflicting evidence regarding the sub-theme's impact upon the target behaviour.
4. The significance of the specific influences underpinning breast cancer screening attendance, as opposed to more general health beliefs.

Mapping

I conducted the mapping process in conjunction with another researcher, re-examining shortlisted sub-themes from the evidence synthesis and coming to a consensus. As differing information sources were used, individual sub-themes could have multiple influences described. For example, a fear of pain could relate to social influences sharing experiences as determined in the interviews, or a previous negative experience as found in the systematic review. As a result, influences were allocated through discussion between researchers to a broader TDF domain, if this had not been done already, to facilitate further understanding of the determinants. Subsequently, each influence was categorised to a COM-B domain using the

BCW, which unlike the TDF highlighted what broad types of intervention (intervention functions) may be appropriate approaches to overcome each barrier and facilitate translation to BCTs. The list of potential intervention functions were refined through discussion, using the Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects and safety, Equity (APEASE) criteria[85]. These intervention functions, and behavioural determinants (using categorisations according to the TDF) were used to elicit candidate BCTs, with either strong, or inconclusive evidence behind their mechanism of action (MoA) as defined by the TaTT, and outlined in Chapter 1. Candidate BCTs were shortlisted again using the APEASE criteria[85,329], which can be used to direct the selection and implementation of appropriate interventions[329]. A panel of 4 researchers including clinicians and behavioural scientists, refined the list of candidate BCTs using APEASE, by assessing whether each technique could be practicably incorporated into an intervention that would be delivered at the population-level. To support judgments on the expected effectiveness of each BCT, the panel were provided findings from the systematic review in Chapter 2, including the percentage of effective existing interventions which had used each BCT previously.

Animation Creation

Four co-design workshops were held. These developed the idea to create an animation, which was further discussed with stakeholders from the screening service. Given the limitation of the screening communication system, this would have to be delivered via SMS, and therefore the decision was made that workshop would also develop wording for a behavioural science-informed plain text SMS. Each workshop had specified aims, but participants were able to deviate beyond these if necessary (**Figure 5-3**). Activities were developed using scenario cards that translated candidate BCTs into vignettes or messages. For example, one scenario involved asking a screening participant to consider bringing paracetamol (the BCT *problem solving)* to

avoid pain (the sub-theme *fear of pain*) (**Table 5-2**). These activities gauged participant feedback upon the effectiveness and acceptability of incorporating candidate BCTs into a variety of different aspects of the intervention (e.g. phrasing, imagery, and storyline and music). A Nominal Group Technique (NGT)[330] was utilised within workshops to elicit a consensus amongst participants. The NGT has previously been used in several studies, including online, and has been shown to be an effective and adaptable means of gaining consensus in small group settings[330,331]. The technique involves encouraging participants to generate ideas regarding topics, comparing ideas with those suggested by the expert panel, discussing, ranking/shortlisting, voting upon ideas and discussion of the voting[211]. This technique helped synthesise the outputs/voting from different workshop activities and refine the animation and SMS wording.

Figure 5- 3 Aims of the workshops which guided activities, with the intervention(s) they relate to in parenthesis.

Workshop 1 and 2	
• Review outputs from triangulation exercise. *(SMS/Animation)*	• Initial review/voting on imaging of screening process. (*Animation)*
• Review existing screening materials. *(SMS/Animation)*	• Develop a shortlist of preferred BCT phrasing for animation. *(Animation)*
• Suggestions for phrasing including candidate BCTs. *(SMS/Animation)*	• Develop an initial story/plot. *(Animation)*
• Initial voting on phrasing including those from the expert panel. *(SMS/Animation)*	• Suggestions to incorporate link into SMS. *(Animation)*
Workshop 3 and 4	
• Review outputs from workshop 1/2.	• Review of phrasing and initial vocal script. *(Animation)*
• Voting on refined imagery. *(Animation)*	• Review candidate music pieces to play over animation. *(Animation)*
• Voting on finalized SMS wording. *(SMS)*	• Voting on potential voice actors to play characters. *(Animation)*
• Review storyboards with imaging. *(Animation)*	• Set feedback schedule. *(SMS/Animation)*

Participants to these workshops were purposively sampled to ensure representation from underserved communities including people from minority ethnic groups, those with multiple co-morbidities, those from higher areas of deprivation and the trans/non-binary community[26]. Recruitment was undertaken in collaboration with community groups including the Oremi Centre and Asian women cancer group, as well as via the VOICE network, through posters in community and faith centres. The workshops were facilitated by Inclusively (London, UK), an organisation that specialises in co-creation of interventions with a diverse range of service users, including those from underserved communities. The timing of workshops was varied so that one of each pair were held during working hours, whilst the other was early evening. Participants were renumerated for their participation.

Table 5- 2 Example of activities used in workshops, how BCT content was incorporated, and outputs derived.
BCT- Behavioural Change Techniques

Example Activity	Description	How BCT content was incorporated	Outputs
Scenario Cards	Cards which have determinants/scenarios such as "*I think it will be painful*" and statements to address this. Participants commented on the wording of the statements and which were most relevant to them,	BCTs included within written statements to address determinants for example suggesting bringing painkillers *(problem solving)*	Preferences on BCTs Feedback on wording
Pictures of Screening	Pictures of various aspects of the screening process including compression of the breast. Participants highlighted aspects they felt useful and most appropriate style.	BCTs such as *demonstration of the behaviour* and *instruction of the behaviour* included in images	Preferences of style Storyboard information
Helpful Tips	Cards describing common areas of concern regarding determinants e.g. having to undress, who can accompany someone to screening, participants selected which were the priority areas to address.	BCTs related to *problem solving, social support* and the physical environment discussed	Storyboard information

Using the consensus derived from the first two workshops, the wording for the intervention SMS including a BCT was developed. A simple script was also developed collaboratively with the Inclusively team. The SMS wording was reviewed with participants in workshops 3 and 4. Discussion and voting was undertaken until a consensus was reached regarding the final

phrasing for the intervention SMS. The simple script was refined into a visual storyboard by the Inclusively team, using information synthesised by researchers including an understanding of the imagery agreed upon from the later workshops. Participants, NHS commissioners and breast screening services were then asked to feedback by researchers on the visual style and content of this storyboard. Their feedback included avoiding the companion entering the screening facility, as this was not permitted during COVID-19, and ensuring the imagery of the mammogram was accurate. The storyboard was refined and developed into an animation by the Inclusively team using Adobe Animate (Adobe Inc, USA).

The animation was then sent to all stakeholders as described under the MRC element in **Table 5-1**, including NHS commissioners, workshop participants, previously engaged community organisations and charities such as Gendered Intelligence, who work to improve the quality of life of trans people. Stakeholders were asked to feedback on various stages of the animation development over an 8-week period. The video was iteratively refined over this period, and a voice/music track added with feedback from stakeholders. Feedback included the styling of the character Faith's hair to be more representative of Black African culture and the volume level of the speech. If there was contradicting feedback regarding aspects of the video, a consensus was derived through discussion. Once all representatives had approved the animation it was considered complete.

5.4 Results

5.4.1 Barriers and Facilitators

The previously conducted survey elicited 8 sub-themes that were significantly associated with previous attendance at breast screening appointments[320]. These were lower controllability (the perception that one is in control of whether they attend), higher behavioural regulation (having a clear plan to attend), higher priority of screening over other activities, higher perceived value of screening, lower emotional consequences (including dreading going for screening), higher descriptive social norms (whether friends/family attend), fewer environmental barriers (such as transport or appointment times), and higher recall/memory (not forgetting the appointment). The review elicited a total of 26 sub-themes associated with attendance. These sources were incorporated into the triangulation process (**Table 5-3**).

Following the triangulation, 6 sub-themes were considered a high priority. Of these, 5 were barriers to screening: perceived low susceptibility, high perceived impact of diagnosis on the individual, high expectation of pain leading to fear, high vulnerability/fear of exposure, and low minority ethnic representation. Healthcare professional endorsement was considered a facilitator. A further 8 sub-themes were noted to be an intermediate priority and were also mapped to behavioural constructs and discussed amongst the panel. One sub-theme was 'minority ethnic representation', but this was not included in the mapping exercise following discussion, as it was felt this should occur throughout the imagery used in the animation and would not be resolved by discrete BCTs. The influences of these 13 included sub-themes were then mapped to the TDF and COM-B. The long list of potential intervention functions was derived using the BCW and refined using the APEASE criteria (**Table 5-4**). Whilst the function

‘incentivisation’ was thought to unaffordable, ‘coercion’ and ‘restrictions’ were considered unacceptable.

Table 5- 3 Triangulation of the determinants, and prioritisation for inclusion in the mapping process as determined by the panel.

Sub-Theme/Determinant	Information Source			Priority	Panel Comments
	Survey	Systematic Review	Interviews/ Focus Groups		
Anxiety regarding over/missed diagnosis			Variable	Low	Did not show consistency within source
Behavioural regulation				Low	Not consistent across sources
Cancer as a taboo			Variable	Medium	May be covered through addressing impact on the individual and imagery on survivorship
Candidacy				Medium	Maybe covered by addressing perceived susceptibility and that anyone can get cancer
Controllability				Low	May be addressed by social influence and fatalistic views. Not highlighted in other sources
Decision Making				Low	Not commonly cited
Difficulty reaching appointment/Access			NS	Low	Accessibility is a barrier to attendance but multifactorial issues including appointment availability
Expectation of anxiety				Low	Variable amongst groups. Not commonly cited
Fear of exposure*				High	Fear of exposure negatively influenced attendance and was seen amongst minority ethnic groups
Fear of pain*				High	Pain is a negative emotion and expectation was shown to influence decision to attend
Feeling a burden				Low	Not commonly cited
Forgetting appointment/Memory			NS	Low	SMS reminders now provide prompt and differing barriers with open and timed appointments
HCP endorsement		Variable		High	Negative experience of HCP making endorsement was variably identified as a barrier. Consistent as a facilitator of attendance
Health reducing attendance				Low	Inconsistent across groups. Acknowledge with priority

Impact of diagnosis on the individual				High	Consistent and relevant to attendance
Lack of knowledge	NS			Medium	Knowledge not significant in the survey. Simple information e.g. what is cancer? advocated in interviews. Access to culturally appropriate materials was a facilitator
Language barriers				Medium	Could be overcome through translations
Lower priority		Variable		Medium	Potential facilitator but not in many review studies
Low salience of breast cancer				Medium	Combine with susceptibility. Associated with candidacy and knowledge.
Minority representation				High	Can be addressed throughout without specific technique
Misinformation		Variable	Variable	Low	Differing perspectives across subgroups
Mobile v. hospital				Medium	Need to understand the cause of mistrust of mobile units and whether this could be addressed in imagery
Optimism/Fatalism		Variable		Low	Not consistent within or across source
Perceived low susceptibility	NS			High	Risk was associated with intention in the survey, and perceived low risk a barrier to attendance.
Perceived low value				Medium	Need to understand the influences behind this e.g. misinformation or risk. Affected intention in survey.
Previous negative experience				Low	Depends on individual experience with multiple influences
Social encouragement /support		Variable		Medium	Influence was variable, various groups responded to social encouragement differently.
Social network opinions	NS	Variable		Low	Variably mentioned across and within sources
Superstition		Variable		Low	Few studies, variable influence.
Transnational use				Low	Not often cited
Alternatives to screening		Variable		Low	Variable effect. Not often cited

*Blank box- Not mentioned, Green box- Facilitator, Red box- Barrier, Green/Red box- Barrier and Facilitator, HCP- Health care professional NS- Not significant or contradictory finding in information source, Variable-not consistently seen as a barrier/facilitator within information source. * Fear of process split into fear of pain and fear of exposure/vulnerability which were commonly cited in all 3 sources*

Table 5- 4 Priority sub-themes mapped to the Theoretical Domains Framework (TDF), Capability Opportunity Motivation - Behaviour Model (COM-B), and Intervention Functions from the Behavioural Change Wheel (BCW).

Priority	Sub-Theme/ Determinant	Influences from data	TDF Domain	COM-B Domain	Potential Intervention Function
High	Fear of exposure	Perceptions of vulnerability/alienation	Emotion	Automatic Motivation	Persuasion Environment Restructuring
		Lack of ability to cover up	ECR	Physical Opportunity	
	Fear of pain	Previous negative experience	Emotion	Automatic Motivation	Persuasion Enablement Modelling
		Social influence	Social Influences	Social Opportunity	
		Underestimated pain	Emotion	Automatic Motivation	
	HCP endorsement	Support from HCPs	Social Influences	Social Opportunity	Enablement (social)
		Access to HCPs	ECR	Physical Opportunity	
	Impact of diagnosis on the individual	Perceived severity of the condition	Beliefs about Consequences	Reflective Motivation	Persuade Education
		Severity of the treatment	Beliefs about Consequences	Reflective Motivation	
	Perceived low susceptibility	Optimism that no risk of cancer	Optimism	Reflective Motivation	Persuasion Education
		Cultural identity/Candidacy	(See below)	(See below)	
		Knowledge of risk factors	Knowledge	Psychological Capability	
Medium	Cancer as a taboo	Knowledge of consequence	Beliefs about Consequences	Reflective Motivation	Education (on consequences) Modelling
		Cultural values	SPRI	Reflective Motivation	
		Social influence	Social Influences	Social Opportunity	
	Candidacy	Cultural values	SPRI	Reflective Motivation	Persuasion

	Misinformation/Knowledge	Knowledge	Psychological Capability	
Lack of knowledge	Lack of knowledge about screening/eligibility	Knowledge	Psychological Capability	Education Environment restructuring
	Lack of access to translated information	ECR	Physical Opportunity	
Language barriers	Language barriers leading to people not being able to express themselves	ECR	Physical Opportunity	Environment restructuring
	Lack of access to translated information	ECR	Physical Opportunity	
Lower priority	Perception of effectiveness of mammogram	Beliefs about Consequences	Reflective Motivation	Education Training
	Fatalism	Beliefs about Consequences	Reflective Motivation	
	Competing appointments	Goals	Reflective Motivation	
Mobile v. hospital	Perceptions of mobile units and their role	ECR	Physical Opportunity	Environment restructuring Persuasion
Perceived low value	Screening not seen as effective	Beliefs about Consequences	Reflective Motivation	Persuasion Education
Social encouragement / support	Social support and normative behaviour	Social Influences	Social Opportunity	Education (for social influences) Enablement (social)

ECR- Environmental Context and Resources, SPRI- Social/Professional Role and Identity, HCP- Health care professional Intervention functions listed are those determined by researchers to be relevant to the specific influences/sub-themes described.

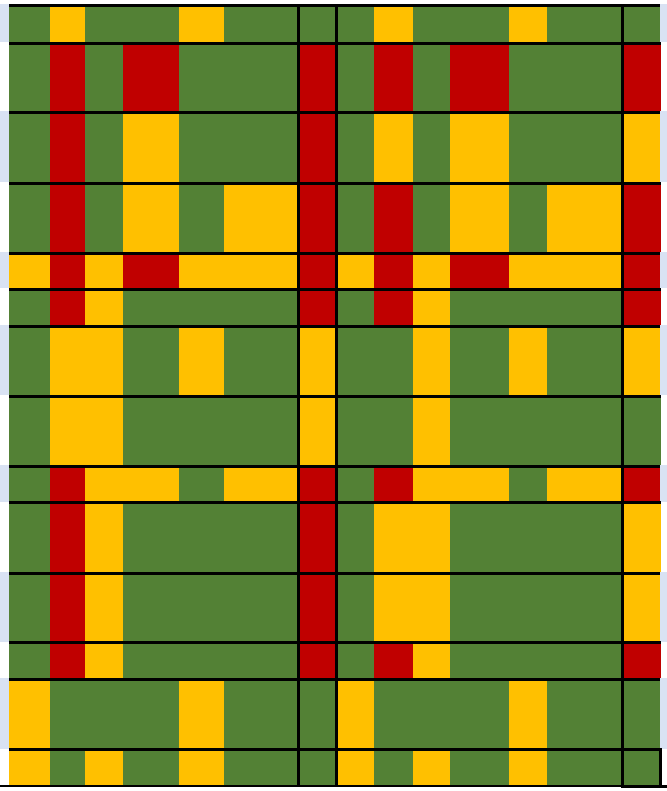
5.4.2 Candidate Behavioural Change Techniques

During focus groups, and as highlighted by stakeholders including the London screening hub and NHS screening commissioners, a low-cost tool, which can still be delivered to a broad population was required. The decision was made with stakeholders, therefore, that an animation would be created. This would enable more complicated BCTs to be delivered but allow for versatility in the imagery portrayed. Moreover, it could be delivered at no additional financial cost via weblink within the existing screening reminders, and thus would facilitate widespread implementation.

The BCW highlighted broad intervention functions which could be used to potentially address determinants. This helped to inform the list of candidate BCTs derived using the TaTT. The expert panel then applied the APEASE criteria to assess the suggested BCTs and create a shortlist of BCTs that would be appropriate to incorporate into either the SMS or the animation (**Table 5-5**). As described in the methods, these BCTs formed the basis for activities within co-design workshops, however, participants were also encouraged to create their own ideas.

Table 5- 5 Panel's APEASE assessment of the candidate Behavioural Change Techniques elicited using the Theory and Techniques Tool

BCT	Sub-Themes	SMS							Animation							Panel Comments
		A	P	E	A_f	S	E_q	?	A	P	E	A_f	S	E_q	?	
Adding objects to the environment	FoE, LB, MvH, LP															Objects added need to be feasible
Anticipated Regret	CT, FoE, IoD															If included avoid coercion and guilt
Commitment	Ca, CT, LP															Unclear effectiveness, unclear how to achieve
Comparison of future outcomes	IoD, PLV															Inconclusive effectiveness, need to avoid guilt
Credible Source	Ca, CT, HCP, PLS, PLV															Credible source likely to be HCP
Demonstration of the behaviour	FoP, SE															Difficult in SMS, varying effectiveness
Focus on past Success	FoP															Unfeasible for 1st time invitees/non-attendees
Framing	CT, FoE, FoP															Framing may minimise beliefs, variable effect
Goal Setting	LP															No effective interventions previously
Identity with changed behaviour	Ca, CT, PLS															Difficult in SMS, varying effectiveness
Incentive	IoD															Unfeasible, high financial cost
Information on Health Consequences	Ca, CT, IoD, LoK, PLS, PLV															Feasible and acceptable
Information on Emotional Consequences	CT, FoE, FoP															Acceptable if non-coercive/reassuring, avoid side-effects
Information on Social Consequences	CT, IoD, LoK, PLS															Maybe covered with other social techniques
Information on other's approval	HCP, SE															Need to make sure the correct 'voice'
Instruction performing the behaviour	LoK															Covered with demonstrating the behaviour
Problem solving	FoE, FoP, LB															Need to prompt self-identification and offer solutions
Prompts/Cues	LP															No benefit of additional prompt, covered by other means
Pros/Cons	HCP, IoD, PLV															Need to avoid fear, may be covered by other mean

Reduce negative emotions	FoE, FoP		Need to clarify how and avoid side effects
Remove Aversive Stimulus	FoE, FoP		Not practicable to change mammogram technique
Restructuring the physical environment	FoE, LB, MvH, LP		Restructuring must be feasible, unlikely in some areas
Restructuring the social environment	HCP, LB, LP		Impractical, inequity depending on social network
Reward	IoD		Unfeasible, high financial cost
Review outcome goals	LP, PLS		Impractical to review goals with individuals
Salience of Consequences	CT, IoD, PLS		Poor effectiveness previously, need to avoid fear
Social Comparison	Ca, HCP, PLS		Comparator needs consideration, impractical in short SMS
Social Reward	HCP, SE		Impractical and potential high financial cost
Social Support (emot)	FoE, SE		Nature of support would need to be agreed by services
Social Support (pract)	Ca, CT, HCP, LB, SE		Nature of support would need to be agreed by services
Social Support (unspec)	CT, HCP, SE		Practicability assumed low if unspecified action
Verbal Persuasion about capability	FoP		Wording needs to be checked to be acceptable
Vicarious Consequences	IoD		Avoid fear, can be linked to consequences

Social Support (emot)- Emotional Social Support, Social Support (pract)- Practical Social Support, Social Support (unspec)- Unspecified Social Support, FoE- Fear of Exposure, FoP- Fear of Pain, HCP- Health care professional endorsement, IoD- Impact of Diagnosis, PLS- Perceived Low Susceptibility, CT- Cancer as a Taboo, Ca- Candidacy, LoK- Lack of Knowledge, LB- Language Barriers, LP- Lower Priority, MvH- Mobile v. Hospital, PLV- Perceived Low Value, SE- Social Encouragement. A- Acceptability, P- Practicability, Effectiveness, A_f- Affordability, S- Side-Effects, E_q- Equity, ?- Whether BCT selected, Green box- Likely to be suggested in workshops, Yellow box- Consideration required if to be suggested, Red box- Unlikely to be suggested in workshop

5.4.3 Intervention Development

A total of 25 participants were recruited to four co-design workshops, which aimed at developing the BCT-informed content of the animation and plain-text SMS. All participants were aged between 47 and 73. Participants were 36% White, 24% Black, 28% Asian and 12% as 'Other' ethnicity. The majority (64%) identified as having multiple health conditions, including physical and psychiatric co-morbidities. Of all attendees, 44% had not attended a mammogram previously.

The workshops utilised scenarios to encourage participants to create ideas on how BCTs could be incorporated into the content of the animation, which were later voted upon alongside those created by the expert panel. For example, in one activity participants were presented with quotes or priority sub-themes e.g. "I am not sure I am at risk" (perceived low susceptibility). Participants then were given the opportunity to write phrases that could address this. They were voted upon in conjunction with phrasing derived by experts encompassing the BCT *information on health consequences*. **Figure 5-4** shows the output of one scenario-based activity at one workshop with voting and comments from participants. Across the four workshops, consensus as to the content and style of the animation was derived in several different areas including plot, perspective and imagery, as well as the SMS text. The process for this is explained in the sections below.

Animation Plot

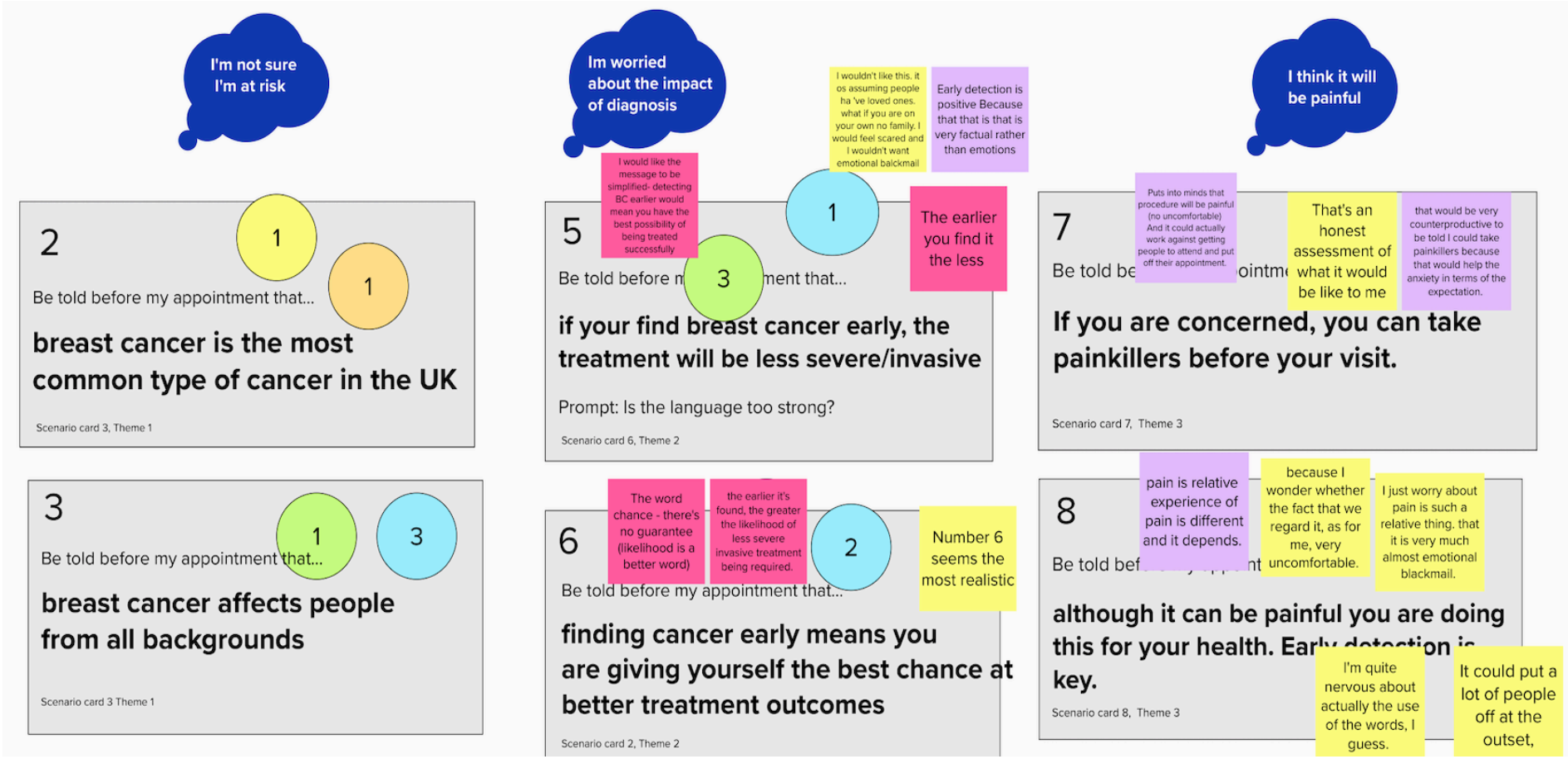
Workshop participants agreed that the main plot of the animation should show what happens during the mammogram, encompassing both *demonstration of the behaviour* and *instructions on how to perform the behaviour* (lack of knowledge). One participant stating the animation should be "open and honest" about what happens, to avoid misleading women. To overcome

differing levels of knowledge, which was a medium priority sub-theme, this demonstration was bookended with information regarding cancer, screening, and eligibility. Techniques to tackle perceived low susceptibility such as *information on health* and *social consequences*, were embedded within these parts. However, the use of statistics was contentious; some participants stated mentioning that 1 in 8 women are diagnosed with breast cancer, "made it seem the odds were in my [their] favour," so this messaging may not encourage attendance. More general statements, such as breast cancer being the most common cancer in the UK, and it can be asymptomatic were preferred.

Additionally, *problem solving* techniques were incorporated at various points throughout the plot to overcome barriers regarding exposure and pain. For example, as one character recalls their mammogram, they advise attendees what to wear to minimise exposure (fear of exposure). Participants however, felt that advice regarding bringing analgesia (fear of pain) elicited more fear, with one woman who had not previously attended asking, "is it that bad, I'm going to have to take painkillers?"

In addition, the plot encompassed BCTs such as *social support (practical),* with one character being accompanied by her daughter to help her navigate the service (social encouragement/support). Participants appreciated this would be helpful especially for those who had physical or communication needs, with one participant stating she "had never known someone could come and explain what's happening." The BCTs incorporated into this animation are detailed in **Table 5-6.**

Figure 5- 4 Example outputs from the 'Scenario Cards' activity in which participants were provided with determinants (described as anxieties) in speech bubbles and asked which statement (grey box) would best address them.



Statements were created by the panel to include BCTs, participants were also able to add their own statements. Following a discussion of all the statements, participants voted their top 3 statements (coloured circles), left comments (coloured textboxes) and discussed voting.

Animation Perspective

Several narratives were used throughout the animation, showing the experiences of breast screening of people from different backgrounds. This enabled the sub-theme of low minority representation to be addressed. Animated characters were chosen to represent different age groups, ethnicities (White, Black, Asian), have different medical backgrounds (multiple health illnesses), have differing needs (physical disability, communication needs) and could represent challenges faced by the trans community (trans women invited to screen). As a participant commented about one character, "I see a bit of me in her." Moreover, it helped overcome barriers regarding susceptibility by invoking *social comparison* techniques to highlight that people from differing backgrounds can still be affected by cancer.

In addition to having multiple characters represent differing perspectives, or stories, about screening, it was agreed that the animation should have a central narrator. 84% of workshop participants agreed this should be a specialist in breast cancer care such as an oncologist or surgeon. Participants felt that this "authoritative and knowledgeable professional" would add believability to the more technical information portrayed and help maintain trust. By utilising the image and voice of a practising breast cancer surgeon who works within London, not only would this narrator act as a *credible source* but provide healthcare professional endorsement or *another's approval* of screening.

Animation Imagery

Workshop activities also incorporated examination of differing imagery that could be incorporated within the animation. For example, as part of techniques to overcome challenges surrounding the perceived impact of a diagnosis on the individual, a high priority sub-theme, participants highlighted that they would like to see a "survivor" from cancer. This imagery was

therefore incorporated into one of the aforementioned vignettes, as was phrasing to elicit *anticipated regret* (or loss aversion) and *vicarious consequences* regarding a missed appointment. In addition, specific imagery was also used as part of *credible source* techniques. This included the use of NHS branding, realistic representations of hospital staff and screening services, all of which were felt by participants to increase the authenticity of the animation.

SMS Text

The workshop activities were also used to refine the wording for the behavioural SMS. Following voting, two different behavioural phrases were the most popular; 'detecting cancer early give the best chance to recover,' and 'breast screening saves 1300 lives per year.' Both address the impact on the individual, *reducing negative emotions* and *giving information on health consequences.* However, the latter statement required statistical literacy. Moreover, it may be impacted upon by an individual's cognitive bias, for example whether they feel 1300 lives is a large enough number to warrant attendance. As such, following discussion, the former was selected for the SMS.

5.4.4 Stakeholders and Refinement

The storyboard and initial animation were shared and refined extensively with stakeholders including: charitable organisations representing characters within the animation (e.g. Gendered Intelligence), clinicians (e.g. breast cancer surgeons), community groups (e.g. Oremi centre), NHS commissioners, NHS Identity team, NHS inequalities group, NHS screening services, two NHS Trusts and participants (workshops, interviews and focus groups). NHS stakeholders validated the accuracy and fidelity of the animation to current screening practice, as well as providing guidance regarding the practicality of the suggested *problem solving* techniques. Moreover, the NHS teams also provided approvals for NHS branding to be incorporated into

the animation to increase the trustworthiness of the information presented. Charitable and community organisations were asked to send the animation to their membership to try and identify potential unintended side effects.

During intervention development, the breast cancer screening services in London had begun a period of COVID-19 recovery. As a part of this process, services were utilising a hybrid model involving the use of the traditional timed invitation (when women are invited with an appointment at a particular time and date), as well as open invitations (when women are invited to book an appointment). Following feedback from stakeholders, the SMS message was made applicable to both invitation forms. Usual care messaging contained a large amount of COVID-19 information, some of which was no longer relevant. Within the intervention plain-text SMS, this extraneous wording was removed following discussion with stakeholders. This also helped reduce the number of segments required to send the SMS message, as fewer characters are required. As the screening services pay per message segment, the intervention SMS is more cost effective than the usual care message. Moreover, the storyboard, and in particular the call of action, was amended to ensure that it could be used in either approach. A refinement cycle was established, whereby the animation was periodically iterated based upon feedback, and then re-sent to stakeholders for further feedback. Once all stakeholders had approved the animation it was considered complete. The finalised storyboard is found in **Appendix 5-1**. The animation can be found at: https://www.imperial.ac.uk/patient-safety-translational-research-centre/patient--public-involvement/for-public-members-/nhs-screening/

Table 5- 6 Elements of the animation, Behavioural Change Techniques (BCTs) included and examples.

Sub- Theme/ Determinant	BCTs Incorporated	Example
Fear of exposure	Problem solving	*Aleema gets viewer to consider if they fear exposure and gives advice on what to wear to minimise exposure.*
	Demonstration of the behaviour	*Faith asks for a gown to cover herself reducing exposure in a respectful environment*
Fear of pain	Reduce negative emotions	*Faith says "it was a bit uncomfortable…only lasts a few minutes"*
	Instruction on how to perform the behaviour	*Explaining why it is important to compress the breasts (i.e. for image quality)*
HCP endorsement	Credible source	*Dr Rashid is an active breast surgeon in London and narrates.*
	Information on other's approval	*Devi calls her GP, who recommends she attends.*
Impact of diagnosis on the individual	Information on health consequences	*Martha talks about surviving cancer. Screen detection made the treatment less invasive*
	Vicarious consequences	*Martha is "worried for her family" but realises not screening could be worse*
	Anticipated Regret	*"If it weren't for screening it could have been a different story"*
Perceived low susceptibility	Information on health consequences	*"Anyone from any background can be affected."*
	Social comparison	*Imagery of people from all backgrounds attending, with suggestion others like you are attending*
	Information on other's approval	*Aleema does not know anyone who had cancer, but her friend recommends she goes*
Minority Representation	Social comparison	*4/5 of main characters are from minority ethnic groups. Faith has a physical disability. Martha has communication needs. Devi is from the LGBQT+ community.*

Cancer as a taboo	Information on health consequences	*Martha speaks about her cancer diagnosis openly. As screening found it early, she does not need invasive treatment, dispelling ideas about cancer consequences*
Candidacy	Social comparison	*"Breast cancer is the most common cancer in the UK, anyone can be affected"*
Lack of knowledge	Instruction on how to perform the behaviour	*Dr Rashid explains invitations, and how to book open appointments.*
	Demonstration of the behaviour	*Faith explains what happens during screening*
Language barriers	Adding objects to the environment	*Animation translations available in 16 languages. Voiceovers in common language*
Lower priority	Identity associated with changed behaviour	*"Time to put your health first." Faith suggests screening is "another thing to do" to be healthy.*
	Verbal persuasion about capability	*"It can be difficult to deal with them all [appointments]…but finding cancer early can make all the difference"*
	Action planning	*Book your appointment now on this telephone number*
	Problem solving	*"You can always change the appointment if it's not convenient on this number"*
Mobile v. hospital	Demonstration of the behaviour	*Martha is seen attending a mobile unit where she was diagnosed, so was accurate.*
Perceived low value	Pros/cons	*"Screening saves 1300 livers a year"*
	Salience of consequences	*"Cancers can spread…too small to notice…Breast screening can find cancer early"*
Social encouragement / support	Social support (emotional)	*Martha is accompanied by her daughter to the appointment to reduce her fear*
	Social support (practical)	*Aleema's friend offers translations to help her understand*

Aleema, Devi, Faith, Martha and Dr Rashid are all characters in the animation. GP- General Practitioner, HCP -Healthcare Professional.

5.5 Discussion

In addition to the variability in the effectiveness of existing screening interventions[332], across a traditional low-uptake region such as London, there are disparities in which and whether interventions are deployed. For example in Camden few interventions have been implemented despite its low coverage rate, whilst Richmond-upon-Thames has both a higher attendance rate and number of interventions[302]. To overcome these challenges, this chapter details the development of a novel behavioural-science informed animation, as well as SMS reminder, which can be deployed readily at a population-level and not limited to an individual area within London. These interventions may help address the priority determinants of non-attendance derived from three sources of information: a population survey, a systematic review, and a qualitative study with underserved groups. Using an extensive triangulation and mapping process with established behavioural frameworks such as the TDF, BCW and TaTT, it was possible to understand which Behavioural Change Techniques (BCTs) could effectively and feasibly be incorporated into interventions to address these determinants. These candidate techniques were used as the basis of co-design workshop activities, in which a novel narrative-based animation was created incorporating multiple BCTs, as well as the plain text for an augmented SMS reminder. The selected BCTs in the animation included *problem solving* and *credible source* which have shown promise from existing literature, as well as lesser used techniques such as *vicarious consequences* as described in Chapter 2. Intervention development has been guided by the MRC framework which advocates an ongoing cycle of feedback, and refinement. As a result, the interventions have been purposefully designed with a broad range of stakeholders to be readily implemented into the existing screening infrastructure, and across differing screening services in London.

The MRC guide on complex interventions suggests the use of a 'programme theory'. This describes how an intervention is expected to bring about its effect, and within the current interventions involves using BCTs. To determine which techniques could potentially address the priority determinants elicited from the triangulation exercise, the current chapter used frameworks such as TDF and BCW. Both tools allowed for an understanding of the influences underpinning barriers and helped to connect determinants to BCTs. One of the benefits of this approach was the holistic nature of these frameworks. Both have been used extensively in other health contexts such as smoking cessation and healthy eating[333,334]. However, Chapter 2 highlighted that in the existing literature, no behavioural theory was associated with effective interventions. One reason for this is that individual models are often designed with a specific sub-field or target behaviour in mind. When they are used in other contexts they can be improperly translated or involve aspects which are not relevant to the new target behaviour. Hagger and Weed use the example of smoking cessation and the Trans Theoretical Model (TTM) which was developed to explore the experiences of those who quit[335,80]. The TTM however assumes that the decision-making process is active, which may be the case with stopping smoking, but less relevant to screening where there are groups of people who may not attend because they are not aware of mammography or disengaged with healthcare services generally. In addition, the TTM does not given an indication how long it takes to transition through the model. This is important because whilst many antecedents to smoking may involve the context just before the individual lights a cigarette, the decisions regarding screening may occur months prior, when invitations are sent out. If models which are not designed to evaluate a specific target behaviour are used, it is important to appreciate how it differs and account for this accordingly. The current chapter circumvented this issue by using more generalised behavioural frameworks such as the TDF and BCW, which are more behaviour-agnostic.

Use of the TDF, BCW and TaTT in conjunction, enabled a move from understanding the determinants of screening behaviour to designing an intervention to address these issues. By linking barrier identification and BCT selection processes together in an evidence-based manner, these frameworks provided a systematic way of developing a behavioural intervention. The intervention chosen was an animation utilising a narrative-based sequence. Workshop participants favoured this approach as it enabled diverse representation of individuals and scenarios that may be encountered -a facet missing from existing screening materials. However, due to limitations of the screening communications, and concerns that sending out video directly to people could negatively affect the data costs of those from areas of high deprivation, it was felt this should be sent via an SMS link. This gave the opportunity to include BCTs within the message text, and as such a behavioural message was also developed.

An animation also afforded the introduction of multiple BCTs. These included *reducing negative emotions* especially with respect 'fear of pain' and embarrassment. These determinants were identified as common barriers across sources in the triangulation exercise. Including imagery of a person able to cover up, and using wording to allay the severity of pain, were two ways the final animation addressed these issues. *Credible source* techniques were also utilised to leverage the fact that 'HCP endorsement' was a strong facilitator in the triangulation process. The literature has been shown to increase screening uptake by 4% compared to no reminder[203], and therefore the final animation include within it a breast cancer surgeon. The decision was made to use the image and voice of a real surgeon, which added to the credibility and endorsement of the content. The animation also enabled other techniques to be used such as *vicarious consequences,* which have been shown to have a potential high effect size[332]. This technique involves highlighting the consequences to others e.g. friends and family, if someone does not or does screen, with impact of consequences on the individual a consistent

determinant across information sources. A culturally tailored intervention by Kreuter et al. using this technique led to a 21% increase in attendance at breast screening compared to controls, but few other studies have examined this BCT[145,332]. The use of an animation enabled incorporation of this diversity in techniques incorporated.

Using multiple BCTs also meant individuals can be receptive to the reasons to attend that are most pertinent to them, or 'motivationally salient'[336,337]. This is highlighted by the reason-based model of choice which posits that in areas of conflict (i.e. one choice does not clearly dominate another in terms of benefits) without a compelling reason to select the option, the tendency is to examine alternatives[337]. These reasons are context dependent and are not necessarily based upon maximising individual value. To facilitate screening attendance, the animation therefore needed to contain compelling reasons why attendance is better than non-attendance. As this was delivered on a population-level, and some of these reasons may not be relevant or persuasive to all individuals, multiple different techniques needed to be used.

As described above, the context in which the intervention is expected to work is an important consideration, as it can influence the decision-making process of potential invitees. Broadly, the intervention was developed for use by services across the London Breast Screening Programme (BSP). During development the London BSP was operating at a time of COVID-19 recovery, as well as facing the longstanding challenges outlined in Chapter 1. Although COVID-19 was a weak determinant of screening attendance behaviour in Chapter 4, the pandemic did pose logistical and design challenges[338,339]. The conduct of the breast screening programme had changed substantially since the pandemic with a temporary suspension of self-referrals for those aged over 71, more regional initiatives supported leading to less standardisation of approaches, and the use of open invitations in conjunction with the

traditional timed appointments. The last of these significantly impacted upon how the current intervention could effectively function within the screening pathway. Stakeholders highlighted that the animation would need to be applicable to both pathways (i.e. not refer to a timed appointment) and would need to ensure social distancing measures were followed. They also noted additional opportunity and motivational barriers faced when there is a requirement to call and book an appointment. As shown by existing studies, these difficulties are encountered even amongst those who intend to screen, leading to overall uptake rates 20% lower than with timed appointments[64,340]. Therefore, the current intervention incorporated suitable techniques, and was designed to work, within both invitation pathways, but ensured behavioural content remained prominent. Within the augmented SMS reminder, this involved altering the COVID-19-related information sent out (including removing unnecessary information), so that 'the gist' of why screening attendance is important was more clear, which has been shown to help with retention and readability of messages[178].

The MRC guide also underlines the need to understand how to best evaluate an intervention's effectiveness. This is linked to both the programme theory, and whether chosen techniques are acceptable and effective, as well as the context, including how feasible it is to evaluate differing aspects of the intervention. Often theory-informed interventions are evaluated in experimental conditions (e.g. with measurements of impact on intention, and not actual behaviour), which gives an indication of an intervention's comparative efficacy, not true effectiveness. For example, Dhakal et al. used breast screening intention as the primary outcome measure when evaluating an educational intervention developed with the Theory of Planned Behaviour (TPB), but this does not necessarily equate to actual screening attendance[341]. Whilst such studies are useful to understand whether an intervention has the expected effect on particular theoretical constructs such as self-efficacy or attitudes to screening, limited conclusions can be drawn

regarding whether these interventions work in real-world conditions[71,335]. To overcome these issues, when developing the current intervention there was a focus with stakeholders on how the animation could be integrated into the existing screening reminders so that a real-world assessment could take place. This is particularly relevant with behavioural interventions, given the importance to understand fidelity and the delivery of the intervention[108]. To achieve this, several public health frameworks such as RE-AIM, designed to improve the equitable and sustainable implementation of interventions, recommend the use of more comprehensive outcome measures, beyond just uptake[342]. This will need to include a means of understanding how the animation can influences attitudes to screening, and how individuals engage with the animation. The latter can be understood through user-based metrics such as website visits, clicks and time spent on the webpage.

5.5.1 Limitations

Despite the intervention addressing the facets of the MRC framework, there are several limitations of the methodology that need to be acknowledged. Although triangulation facilitated a broad understanding of the determinants of non-attendance, it is limited by the quality of the information sources involved. This was mitigated by using validated methods in developing these resources, including a semi-structured topic guide framed on the TDF, a systematic review and a cross-sectional questionnaire which had undergone pilot testing. Moreover, the use of multiple resources focussing on differing aspects of the same overarching phenomenon, gave a broader perspective on the target behaviour. However, when comparing these different sources, researchers were required to make judgements regarding the relative validity of each of the determinants. Similarly, such decisions were required in the mapping exercise. This can lead to inconsistencies, especially when information sources report contradictory findings, and there is scope for researchers to project their own interpretation

onto the data. This can lead to findings from the triangulation being potentially less generalisable or reproducible, as they involve a degree of judgement, or subjectivity. This effect was diminished by involving a panel of researchers provided with pre-defined criteria with which to assess the resources. Furthermore, this group incorporated the primary researchers of each information source and were therefore well placed to understand the context and meaning of the data. In addition, the reliance upon the input of a limited number of workshop participants, screening experts and other stakeholders could have also reduced the validity of the final interventions. Whilst the use of purposive sampling techniques ensured that workshops included representation from underserved, and multiply underserved groups, offering a diverse range of perspectives, it would be unfeasible to gather the viewpoints of all individuals across a population. The robust feedback and iteration phases were therefore crucial in ensuring that even if all possible determinants could not be addressed, those which were included were addressed in an acceptable and meaningful manner.

Further work should look to overcome these limitations by examining at a greater scale not only the presence of the determinants of breast screening attendance identified through the current triangulation, but the relative importance of these barriers/facilitators in sub-populations in different areas of London. To accomplish this, future work should also look to incorporate emerging techniques in online barrier identification which may increase the scope of the study, as well as developments in the BCT ontology which look to provide a greater understanding of the MoA of techniques and their precision[343,344]. These ontologies are being developed such that artificial intelligence and natural language processing tools can identify the most effective BCTs across a whole sub-field of literature. This would circumvent judgment-based errors and provide a more transparent approach to candidate BCT identification, which can be context-specific.

5.5.2 Conclusions

Through a process involving triangulation of data, mapping to theoretical constructs, selection of appropriate techniques and co-design, an animated video intervention to increase breast cancer screening uptake has been developed. Moreover, through purposive sampling and participatory research, this animation has been developed to address the healthcare inequalities in screening, which is a significant public health concern. Unlike the traditional means of addressing inequalities, this study has focused upon developing an intervention that can be implemented at scale, leveraging the existing resources and pathway of the population programme, making it potentially cost effective and more feasible to adopt. To achieve this, the study has followed core development processes outlined within the MRC guidance of complex interventions by appreciating the current context of breast screening, underpinning intervention development with established behavioural frameworks, engaging stakeholders, and iteratively refining the product. Furthermore, considerations regarding how to best evaluate the intervention have also been identified. This will ensure that a comprehensive trial can be undertaken to evaluate the real-world effectiveness of this intervention, including impact on healthcare inequalities.

6. Evaluating the Impact of a Behavioural Science Informed Animation and Message in an Area of Low Uptake: A Randomised Controlled Trial

Outputs related to this chapter

A. Acharya, H. Ashrafian, D. Cunningham, J. Ruwende, A. Darzi, G. Judah. Evaluating the impact of a novel behavioural science informed animation upon breast cancer screening uptake: protocol for a randomised controlled trial. *BMC Public Health.* 2022; 22(1):1388

A. Acharya, A. Darzi. G. Judah. *RCT of an SMS and animated video intervention to increase breast cancer screening uptake.* 2023. 37th Annual Conference of the European Health Psychology Society. Bremen, Germany.

6.1 Abstract

Background

Video-based interventions have shown promise in changing health behaviour across several disciplines. Few have been trialled within breast screening. The aim of this trial is to critically analyse the impact of two behavioural science-informed interventions: a reminder SMS, and the reminder SMS with a link to a novel animation, on attendance at breast screening, compared to a control message.

Methods

A 3-armed randomised controlled trial involving two separate breast screening services within the London region was conducted. One service utilised the traditional timed screening appointments, whilst the other employed a novel open invitation strategy because of COVID-19 recovery efforts. Eligible participants who were due for screening during the study period

were randomised at an individual level using a computer algorithm to either the control, behavioural SMS, or behavioural SMS + animation arm. The primary outcome was attendance at a breast screening appointment in the 3 months following the invitation. Secondary measures examined the influence of demographic factors, as well as the impact upon initial booking rates.

Results

34,047 women were enrolled (9027 timed, and 25,020 open). Univariate analysis revealed no significant difference between the control, SMS, and SMS + animation arms in the primary outcome of percentage attendance (71.9% v. 69.9% v. 71.7% respectively, χ =3.47, P=0.18) at timed appointments. Similar findings were noted with attendance at open invitations (47.4% v. 48.3% v. 48.1%, χ =1.40, P=0.50), however the intervention did lead to a significant increase in initial booking in the per protocol analysis (44.7% v. 46.3% v. 46.3%, χ =6.01, P=0.05). A questionnaire revealed positive feedback from viewers of the animation especially with respect to knowledge gained, however only 5.8% of those sent the link viewed the webpage.

Conclusions

Sending a reminder including a link to a behavioural science animation led to no significant difference in uptake of breast screening compared to being sent the behavioural SMS or control reminder with a link to a traditional screening video. The lack of impact of the animation is likely due to low viewership. Mistrust of SMS messaging, and the financial cost to view an online video may have been contributory factors. Future work should look to examine how video can be integrated into a more readily accessible pathways to enable improved viewership of the animation, and potentially improve its impact.

6.2 Introduction

The use of animated or video interventions has been shown to effectively alter intentions and health behaviour. For example, in one study by Wilding et al. patients who watched an animated film involving persuasion techniques demonstrated a 4% reduction in intention to ask for antibiotics compared to controls[345]. In addition, they demonstrated a sustained increase in the knowledge gained at 6 weeks. Moreover, amongst expectant fathers, Xia et al. demonstrated that the odds of abstinence of smoking at 6 months were 2.8 times higher amongst those receiving a video intervention on the risks of smoking to child health, compared to those receiving only leaflets. Furthermore, the odds of smoking cessation were also 1.64 times higher with the video compared to receiving text messages[346]. With the increasing utilisation and sharing of health information content on social media sites, videos provide a versatile public health tool[347].

However, there are concerns regarding the use of video-based interventions. Studies examining the quality of health content on video platforms such as YouTube, have shown that the overall reliability is poor[348]. Furthermore, there is little data to demonstrate that these interventions lead to long-term behaviour change. In the aforementioned study using an antimicrobial resistance video, other than knowledge, there were no differences in attitudes between the groups at 6 weeks, and no information on actual prescribing behaviour was provided[345]. Similarly, other studies have shown that video interventions have variable effectiveness with respect to addiction behaviours, or in sustaining behaviours[349]. For example, in one study investigating video interventions there was no difference in the numbers who had stopped smoking at both 3-months and 12-months compared those who did not receive the video[350]. Furthermore, as highlighted by the COVID-19 pandemic, there is also increasing concern

regarding the sharing of unregulated video content leading to misinformation, posing a risk to public health[351].

Chapter 2 demonstrated that within breast screening only 3 studies, all from the USA, have evaluated video-based interventions in isolation[129,171,127]. None of the 4 interventions within these studies was found to significantly impact upon screening attendance overall. However, subgroup analyses within these studies did reveal the interventions had a significant impact on underserved groups. For example, in Champion et al.'s 2016 study, women who were members of a North Carolina health maintenance organisation, with a household income of less than $75,000 had significantly more mammograms than controls following the DVD-based interactive video[129]. Wang et al. found that using a culturally targeted video based upon the Health Belief Model amongst Chinese American women in Washington DC or New York City, led to a 40.3% point increase in attendance but this was not significant compared to print media (31.1% point increase). However, the odds of attendance amongst low-acculturated Chinese-American immigrants i.e. those with lower English ability and who had been resident less than 10 years, was 1.7 times higher with the video than printed sheet[171]. In the third study by Champion et al in 2006, the video led to lower screening adherence amongst African-American women (24.6%) compared to an interactive programme (40.0%) and leaflet (32.1%)[127]. In all 3 studies, the interventions were targeted in the first, using an algorithm to the beliefs of participants enrolled, in the second culturally to include common barriers seen within Chinese American communities, and the third to barriers elicited in focus groups with African American women. This may explain why effects were not seen across the whole cohort. In addition, these videos were delivered in discrete sessions, and not available for repeat viewing or sharing, which is one of the advantages of the video medium when viewed through web links[352].

Existing studies have however, leveraged the versatility of videos over other media such as print. This includes the ability to incorporate multiple more, more complex behavioural change techniques such as *reducing negative emotions, verbal persuasion about capability* and *social comparison*[347,353]. They also utilised narratives from people of differing backgrounds to appeal to a broad audience and could be translated making them more accessible to underserved groups[354]. However despite the advantages of video as a delivery method, an intervention would only be expected to be effective if relevant BCTs that address pertinent influences upon the target behaviour.

The studies of video interventions in breast screening mentioned above also provide important lessons regarding how to test the impact of video interventions. Champion et al. 2016 not only examined mammography attendance, but examined how this was affected by baseline knowledge[129]. Wang et al. examined attendance, as well as the impact of the video on constructs such as knowledge[171], whilst Champion et al. 2006 investigated how interventions impacted upon participants' stage of readiness to screen (e.g. contemplation, pre-contemplation)[127]. Whilst increasing screening uptake is the primary objective of this study, as discussed in Chapter 5, an understanding of the influence upon other facets such as perceptions or knowledge of screening is also important. This approach is advocated by the MRC guidance on complex interventions, which states evaluations should "go beyond asking whether an intervention works."[313] This is particularly relevant in screening, in which an informed decision not to attend must be respected and not considered the same as someone who is precluded from attending because of systematic barriers. Moreover, given the recovery of breast screening outlined previously, and the introduction of new invitation processes, a comprehensive understanding of the intervention is needed within the current context.

6.2.1 Aims

The aim of this chapter is to evaluate the impact of the behavioural SMS, and the behavioural SMS with a link to the animation designed in Chapter 5, compared to the usual care SMS reminder. The primary outcome measure will be attendance at breast cancer screening following an invitation to either (a) a timed appointment or (b) an open invitation. Secondary aims will examine the impact of the interventions, controlling for available demographic variables, as well as examining the proportion of attendance compared to non-attendance for each trial arm, within differing demographic subgroups. The latter will give an indication of uptake in underserved groups. To provide a broader assessment of the intervention, secondary aims will also examine the impact of the interventions upon initial booking rates (open invitations only), as well as assess participants' perceptions of the animation, and related user metrics (e.g. click-through rates) as a measure of acceptability.

6.3 Methods

6.3.1 Study Design

This study was conducted as a 3-armed randomised controlled trial comparing the effect of the usual care SMS reminder (group 1), the behavioural SMS (group 2) and the behavioural SMS with link to animation (group 3). As outlined in Chapter 5, multiple differing SMS wording could not be feasibly used due to the constraints of the automated messaging system incorporated by the screening service, limiting what could be tested in the trial arms. To determine the effect of the animation the message wording between group 2 and 3 was kept the same for each reminder.

Ethical approval was granted by the London Surrey Research Ethics Committee (reference 22/LO/0325). The trial was prospectively registered on ClinicalTrials.gov (identifier NCT05395871).

6.3.2 Setting

The trial was conducted within the London services of the NHS Breast Screening Programme (NHSBSP) between July 2022 and January 2023. Participants were recruited from two of the six services: North London and Outer North East London. These services encompass areas of Barking, Barnet, Brent, Dagenham, Enfield, Haringey, Harrow, Havering, Redbridge, and West Hertfordshire[13]. A third service (Central and East London) was also recruited, and messages sent out however the invitation strategy within the units of this service changed during the trial. In addition, due to capacity issues some units within this service paused sending trial intervention messages, and later restarted. Data from this service has thus been excluded.

Inclusion criteria paralleled the eligibility of the screening programme, namely women aged 50 to 70, who had not been screened within the past 3 years and had not had a double mastectomy. Women who had opted out of receiving screening messages, or were in care at the time were excluded from the study pre-randomisation. During the trial period, women invited from the North London service were sent open invitations, whilst those invited from Outer North East London sent timed invitations. Given the differing demographics and invitation types of these services, they were considered separate cohorts for the trial.

6.3.3 Procedures

An *a priori* power calculation was undertaken assuming a 5% type 1 error probability, with 80% power and an assumed meaningful effect size of 3% in either intervention group compared to controls. This effect size was chosen firstly as previous studies have demonstrated that a reminder compared to no reminder within the same population increased attendance by 5%[143], and therefore a lower effect would be expected comparing two reminders. Secondly, on discussion with the screening services it was felt 3% was significant, as the London average coverage rate the two years prior to COVID-19 was 2.7% below the target threshold[21]. Following COVID-19 recovery in which screening uptake was expected to return to normal, a 3% increase would bring regions up to the target attendance rate. The power calculation yielded a minimum sample size of 2797 people per study arm (or 8391 in total). Sample size calculation was undertaken using data from timed appointments, as at the time of this trial no published effect sizes had been elicited with open invitations in the NHSBSP, which had only been introduced during COVID-19 recovery.

Two separate trials were conducted for those receiving timed (sent an appointment at a set time on a particular date) and open invitations (sent a letter to call and book an appointment).

Women were individually randomised using a computer-based algorithm. This system allocated women within trial locations based upon their last two digits of their NHS number in the ratio 34:33:33 (control: behavioural SMS: behavioural SMS + animation). NHS numbers do not include patient identifiers and are allocated to individuals at birth or at their first contact with the service[355]. As the number is unique to an individual, women who rescheduled appointments remained within the same trial arm. Researchers were blinded to these allocations, with only the screening staff having access to this system.

Figure 6- 1 Message templates for (a) timed and (b) open invitations, with behavioural SMS content highlighted.

(a)

Control	**Behavioural SMS**	**Behavioural SMS + Animation**
Don't forget your breast screening appointment is at [redacted] am on [redacted] at [redacted]. *To re-arrange or cancel your appointment call _____or visit www.london-breastscreening.org.uk* *For further info please click here: https://OLDLINK*	*Following the breast cancer screening letter you received, don't forget your appointment is at [redacted] on [redacted] at [redacted].* *Detecting breast cancer early gives you the best chance to fully recover.* *To find out why we're inviting you and what to expect watch this video: https://OLDLINK* *To re-arrange or cancel your appointment call _____*	*Following the breast cancer screening letter you received, don't forget your appointment is at [redacted] on [redacted] at [redacted].* *Detecting breast cancer early gives you the best chance to fully recover.* *To find out why we're inviting you and what to expect watch this video: https://NEWLINK* *To re-arrange or cancel your appointment call _____*

(b)

Control	**Behavioural SMS**	**Behavioural SMS + Animation**
Breast Screening appointments have changed. You will have received a letter on how to book an appointment. *Please call the London Breast Screening Hub_____ or visit _____ to arrange an appointment at your nearest location.* *For further info please click here: https://OLDLINK*	*Breast Screening appointments have changed. You will have received a letter on how to book an appointment.* *Please call the London Breast Screening Hub on _____or visit_____to arrange an appointment locally.* *Detecting breast cancer early gives you the best chance to fully recover. To find out why we're inviting you and what to expect watch this video: https://OLDLINK*	*Breast Screening appointments have changed. You will have received a letter on how to book an appointment.* *Please call the London Breast Screening Hub on _____or visit_____to arrange an appointment locally.* *Detecting breast cancer early gives you the best chance to fully recover. To find out why we're inviting you and what to expect watch this video: https://NEWLINK*

The wording of the messages was determined in workshops with participants from communities living in the trial regions and with representation from underserved groups (Chapter 5). This included using references to the screening invitation letter (e.g. "following the...letter you received") to ensure there was consistency across the materials. The wording used had to also align with NHS screening services guidelines regarding the minimum information that could be incorporated into a reminder. The formatting of the messages including the number sent (2 at one time) and ensuring suitability for the reading age of 9 were informed by the Delphi study with screening experts (Chapter 3). The message layout was also impacted by the technically capability of the automated message system. The message templates including the usual message sent is shown in **Figure 6-1**.

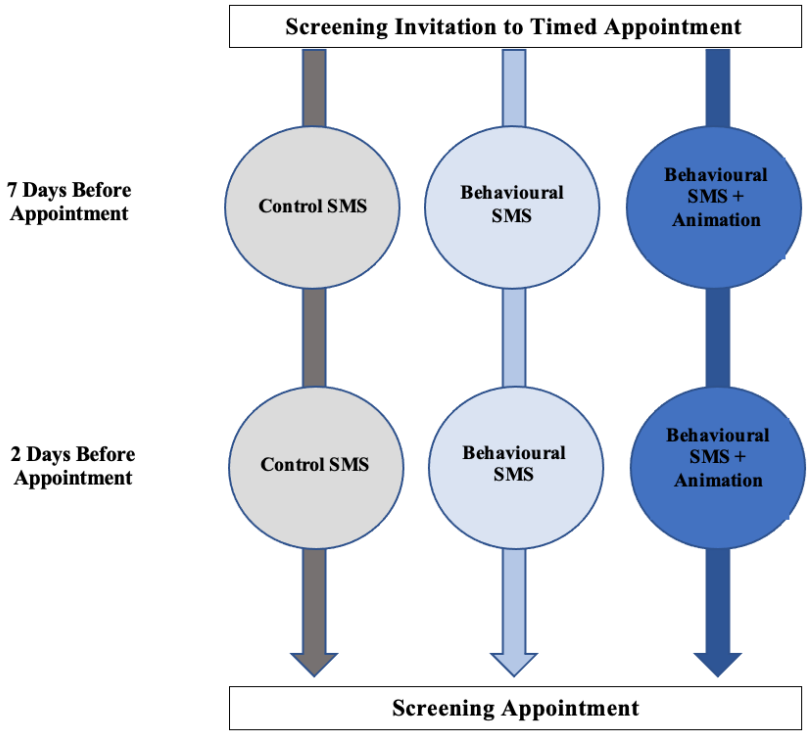
The control group received the SMS reminder which had a link to a 2 minute 51 second YouTube live-action video hosted on the London NHSBSP channel[202], which involves a client recounting their experience with screening. This was the standard procedure at the time of the trial. After discussion with the screening services it was felt to be unethical for control participants not to receive this information which would be considered standard of care. This contained the BCTs *information about health consequences* and *instruction on how to perform the behaviour* only. It was also used within workshops for participants to discuss when designing the animation. Due to constraints regarding management of the screening services' YouTube channel, it was not possible to elicit engagement metrics for this video for the duration of the trial.

Similarly to the control group video, the behavioural science informed animation was sent via a link within the behavioural SMS text. To avoid access to the video through public search, which would skew engagement results (e.g. clicks by the target population), the video was

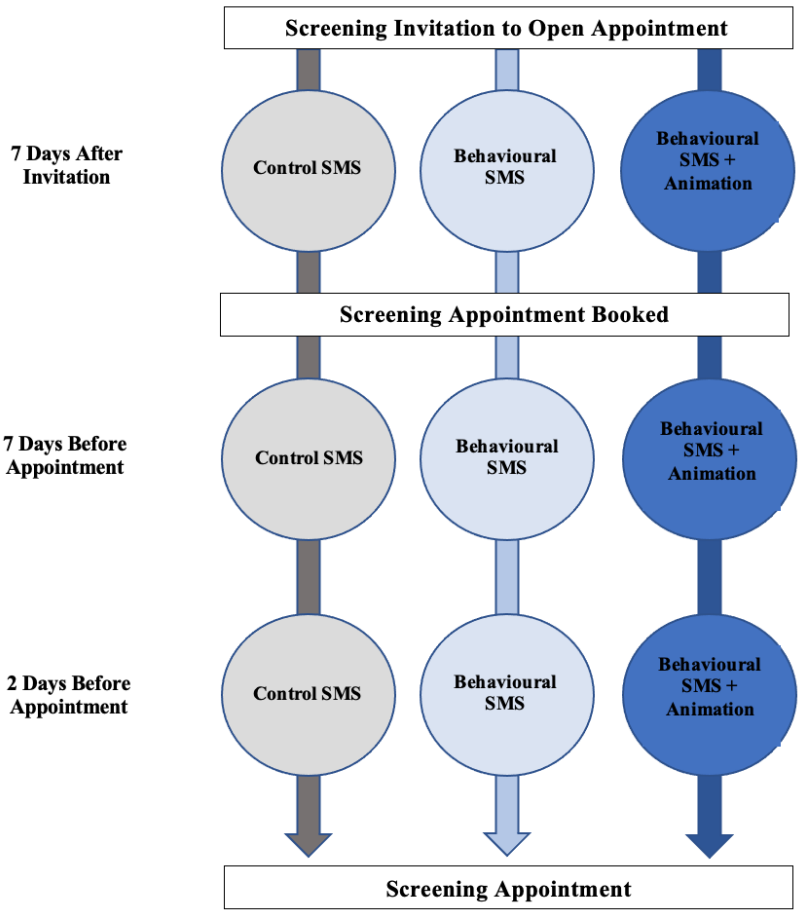
hosted on a private page on the Imperial College London. The link (imperial.ac.uk/nhs-screening) to the animation was only sent within the screening reminder SMS, and not shared with stakeholders or publicly to avoid contamination of user metrics/website data. Sixteen different language versions (Arabic, Bangla, Cantonese, Dutch, French, German, Hebrew, Italian, Polish, Portuguese, Romanian, Russian, Spanish, Swahili, Turkish and Urdu) of the video were created. Four of these versions had voiceovers and subtitles translated into the alternative language, whilst the remaining twelve had English voiceovers with translated subtitles alone. These alternative language versions were available on separate pages directly from the English version landing page. The hyperlinked text directing individuals to the translated versions was in the alternative language (e.g. *en Español*, for the Spanish version) to aid comprehension.

Figure 6- 2 Flow demonstrating messaging schedule for (a) timed and (b) open invitations.

(a)



(b)



Following a timed appointment invitation letter (sent approximately 6 weeks prior to an appointment), or booked open invite, women received reminder messages 7 days, and then again 2 days prior to the appointment, with the content the same at each timepoint. In addition, the open invitation cohort received a reminder to book their appointment 7 days after the open invitation letter (**Figure 6-2**). The messaging schedule was previously set by the London Breast Screening Programme as standard care and was consistent throughout the duration of the trial[13].

Online Survey

To assess perceptions of the animation as a measure of acceptability, an online survey was hosted on the animation page. This was accessible only to those who had clicked on the initial weblink in the behavioural SMS. The survey was available in English only and hosted on Qualtrics (USA). To avoid attrition biases, the survey was kept short and validated with

representatives from the intervention design workshop. NHS commissioners also had input in delineating which areas were the highest priority to understand. Likert questions (on a scale from 0- *not at all* to 10-*extremely*) were used to assess the extent to which the animation increased knowledge of screening, influenced the decision to attend and the realism of the narratives. A net promoter question was also included. As discussed in Chapter 3, this determines how likely an individual would recommend the animation by subtracting the percentage of detractors from promoters (with scores of 9/10 being promoters, 7/8 passives, and less than 7 detractors)[356]. A free-text space was also provided for participants to give other feedback.

6.3.4 Analysis

Data was reported in accordance with Consolidated Standards of Reporting Trials (CONSORT) guidelines[357]. Data was extracted by screening services directly from their database including demographic, outcome and trial arm allocation information. Telephone availability data is extracted by the breast screening service from the GP spine. The primary outcome was attendance, as recorded on the screening services' database, within 3 months of the initial invitation letter. This timeframe is similar to existing studies examining the effect of behavioural interventions on screening attendance[203]. Given the availability of mobile phone numbers on the screening system is not 100%, an intention-to-treat (ITT) and per protocol (PP) analysis for the primary outcome were reported, with the latter excluding those who did not have a valid mobile number. Secondary outcomes evaluated the impact of the intervention when controlling for demographic variable (age, ethnicity, index of multiple deprivation (IMD) decile and appointment type). For those invited to open invitations, a secondary outcome of whether the individual booked within 3 months following their *initial* invitation letter was also considered within analyses.

Chi-Squared tests were used to examine whether baseline categorical demographic variables (e.g. first v. recall appointment type) differed between trial arms. Normality testing using visual plot methods (density plots), and Kolmogorov-Smirnov tests were also undertaken for continuous demographic data to confirm the distribution. Non-parametric variables (e.g. age) were analysed using a Kruskal-Wallis test, whilst ANOVA testing was used for parametric variables to assess whether they differed significantly between arms.

Univariate analyses involved Chi-Squared tests of association to assess the primary outcome of whether attendance differed significantly between trial arms. A logistic regression model, with binary outcome of attendance or booking at 3 months was conducted to examine the influence of demographic covariates (age, ethnicity, IMD decile and first/recall appointment), as part of the secondary outcome, with trial arm included as a variable. Chi-Squared testing also examined the secondary aim of uptake in underserved groups. This involved comparing the proportion of attendance compared to non-attendance for each trial arm, within differing demographic subgroups, separately (e.g. non-White v. White ethnicity) and combinations of subgroups (e.g. non-White ethnicity, and high decile of deprivation), to give an indication of intervention effects amongst multiply underserved groups. Analyses were conducted separately for both the timed and open invitation cohorts. All analyses were conducted using R (version 4.2.2 for macOS).

User metrics were assessed in two ways for the intervention groups receiving the behavioural SMS + animation (group 3). The first involved the questionnaire available after watching the animation to provide feedback on the perceptions of participants. This involved numerical net-promoter scores, Likert scales and free-text responses (**Appendix 6-1**). Quantitative data were

aggregated into frequency distributions, whilst qualitative responses were coded by two independent researchers, and inductively thematically analysed to examine participants' perception of the video. The second means of assessing user metrics was through website data. This involved number of page visits, duration spent on the page and click-throughs. As the existing screening service video sent via the usual care SMS is publicly available on YouTube user metrics for groups 1 and 2 were not available for comparison. It was not possible to link user metrics with attendance or booking data due to the confidential way data was stored in the screening service.

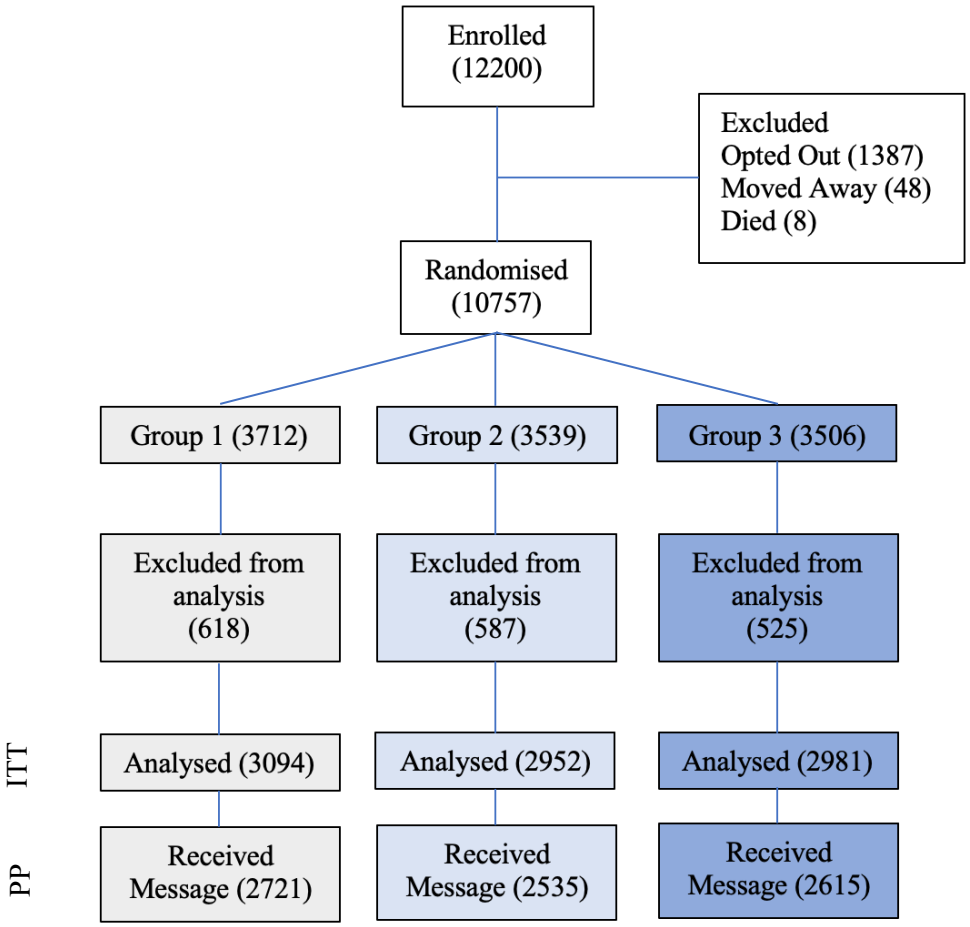
6.4 Results

6.4.1 Participants

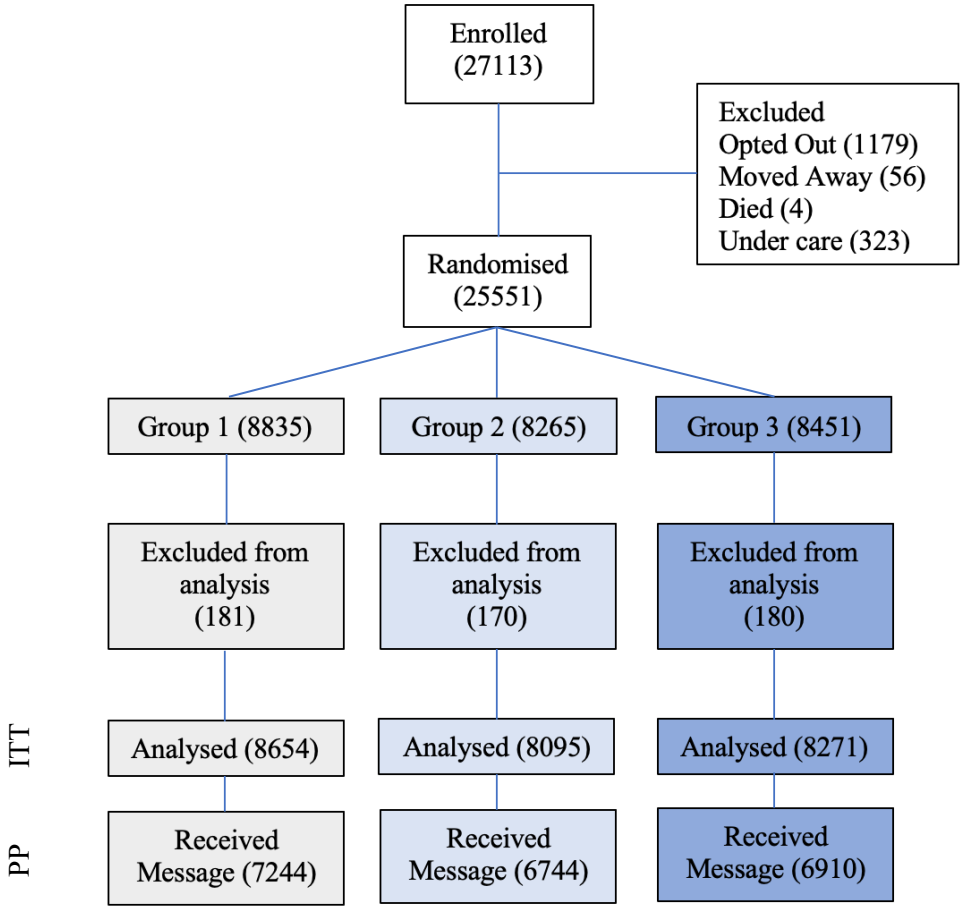
A total of 34,047 women were enrolled in the study (9027 to timed appointments, and 25,020 to open appointments). The CONSORT diagram for the study is shown in **Figure 6-3**.

Figure 6- 3 CONSORT diagram for (a) timed and (b) open invitations.

(a)



(b)



Those excluded from analysis include those invited for 'special' timed appointments which represents a different means of invitation and those who were identified as recently screened. Opted Out- opted out of screening. ITT- Intention to Treat, PP- Per Protocol.

6.4.2 Timed Appointments

The demographics for those receiving timed appointments are shown in **Table 6-1**. No significant differences were found between the participants in differing trial arms in age, ethnicity, IMD decile or the type of appointment (e.g. first) to which they were invited. A significant difference was found in the percentage of missing numbers in each group, with the group 2 having a higher proportion (12.1% v. 14.1% v. 12.3%, $\chi = 6.91$, P=0.03). The mobile numbers were available for 85.9-87.9% of participants in the timed invitation cohort, and this constituted the per protocol group.

Table 6- 1 Demographics of those receiving a timed invitation.

	Group 1	Group 2	Group 3	P-Value
Total (N)	3094	2952	2981	
Median Age (IQR)	59 (53-64)	59 (54-64)	59 (54-64)	0.94
Ethnicity (n)				
White	1596	1473	1501	0.99
Black	279	250	268	0.81
Asian	338	342	328	0.43
Mixed	37	27	27	0.51
Other	44	27	29	0.16
Not Stated	800	833	828	0.89
IMD (Decile)(n)				
1	19	20	28	
2	395	388	373	
3	338	300	362	
4	340	330	318	
5	358	363	324	
6	371	334	350	
7	326	284	298	
8	289	286	289	0.87
9	424	436	432	
10	231	202	201	
Not Stated	3	9	6	
First Invitation (n)	858	881	861	0.19
% Missing Mobile Number	12.1	14.1	12.3	0.03
Median No. of Days to Attend (IQR) from Letter	28 (28-39)	28 (28-39)	28 (28-38)	0.51

IQR-Interquartile Range, n- Number, N-Total Number, No,- Number

Univariate analysis revealed no significant difference between the control, SMS, and SMS + animation arms and the primary outcome of percentage attendance (71.9% v. 69.9% 71.7%, χ^2 =3.47, df=2, P=0.18). Similarly, no difference was noted between the trial arms in the per protocol analysis (76.2% v. 74.9% v. 75.6%, χ^2 =1.16, df=2, P=0.56). Logistic regression model (**Table 6-2**) demonstrated that the impact of intervention group did not affect attendance at timed appointments when controlling for demographics. However, it showed being older age, Black/Asian/Mixed/not stated ethnicity, higher deprivation level and first invitation were significantly associated with non-attendance at timed screening appointments (negative

coefficients). Not stating ethnicity, which was coded as a dummy variable in the model, was the strongest predictor of non-attendance at timed appointments (β=-2.13, z=-29.48, P<0.001).

Table 6- 2 Generalised Linear Model (logistic regression) of variables and the binary outcome of attendance.

Variable	B	SE	Z	P-Value
Group 2	-0.033	0.067	-0.490	0.624
Group 3	-0.059	0.067	0.883	0.377
Age	-0.052	0.005	-10.404	**<0.001**
Ethnicity				
Black	-0.304	0.107	-2.838	**0.004**
Asian	-0.372	0.094	-3.962	**<0.001**
Mixed	-0.585	0.260	-2.253	**0.024**
Other	-0.059	0.287	-0.205	0.837
Not Stated	-2.130	0.072	-29.482	<**0.001**
IMD Decile	0.024	0.011	2.132	**0.033**
First Invitation	-0.962	0.074	-13.077	**<0.001**
Constant	4.945	0.316	15.642	**<0.001**

β- Coefficient, SE- Standard Error, Z- Wald's Z Score.

Subgroup Examinations

To examine the impact of the interventions upon attendance amongst underserved groups, Chi-squared analysis was undertaken across the intention-to-treat cohort. This compared the proportion of attendance compared to non-attendance for each trial arm, within differing demographic subgroups (**Table 6-3**). Amongst a multiply underserved group (i.e. those from high IMD decile 1-5 *and* non-White ethnicity) the behavioural SMS + animation group had a 5.2% higher attendance compared to controls; however this was not significant, possibly due to the low numbers in this cohort (Group 1 attendance 77.8% v. Group 2 attendance 78.4% v. Group 3 attendance 83.0%, χ^2= 3.41, df=2, P=0.17). A measure of co-morbidity, or disability is not available through screening service data.

Table 6- 3 Percentage attendance across collated subgroups for each of the 3 trial arms (excluding missing or not stated data).

	Total n/N (%)	Group 1 n/N (%)	Group 2 n/N (%)	Group 3 n/N (%)	χ^2	P-Value
Ethnicity						
White	3957/4570 (86.6)	1378/1596 (86.4)	1276/1473 (86.6)	1303/1501 (86.8)	0.15	0.95
Not White	1631/1996 (81.7)	562/698 (80.5)	521/646 (80.7)	548/652 (84.0)	3.54	0.17
IMD (Decile)						
1-5	2805/4256 (65.9)	976/1450 (67.3)	897/1401 (64.0)	932/1405 (66.3)	3.59	0.17
6-10	3610/4753 (75.9)	1246/1641 (75.9)	1163/1542 (75.4)	1201/1570 (76.5)	0.49	0.76
First Invitation	1179/2600 (45.3)	406/858 (47.3)	379/881 (43.0)	394/861 (45.8)	3.33	0.22
Incident Screen	5249/6427 (81.7)	1820/2236 (81.4)	1686/2071 (81.4)	1743/2120 (82.2)	0.63	0.73

First Invitation- Prevalent screening invitation, Incident Screen- Any subsequent screen following the first, n/N- number of attendees/total sample, P-value represents the comparison of the proportions of attendees v. non-attendees, across the 3 trial arms as determined by the Chi-Squared test.

As not stating ethnicity was found to be the strongest predictor of non-attendance at timed appointments, an examination of the demographics of this subgroup was undertaken (**Table 6-4**). Chi-Squared analysis of 2x2 contingency tables of IMD (high v. low), appointment type (1st v. recall), mobile phone availability (missing v. available), and attendance (attended v. did not attend) demonstrated significant differences between those who had no ethnicity stated and those that did. Attendance in this group was 2.5 times lower than the pooled rate across all other ethnicities (34.1% attendance v. 85.1% attendance). In addition, compared to the remainder of the cohort, the not stated ethnicity group had a significantly lower age, and higher deprivation, first invitation and missing number proportion. This group could therefore be considered the 'hardest-to-reach group.'

Table 6- 4 Demographics of the 'Ethnicity Not Stated' group compared to all other ethnicity groups.

	Ethnicity Not Stated	All Other Ethnicities	Coefficient	P- Value
Total (N)	2461	6566	-	-
Median Age (IQR)	56 (51-62)	59 (55-64)	417.74	**<0.001**
IMD 1-5 (n)	1517	2739		**<0.001**
IMD 6-10 (n)	938	3815	286.66	
First Appointment %	70.3	13.3	2838.00	**<0.001**
% Missing No.	24.5	8.42	413.08	**<0.001**
Attendance %	34.1	85.1	2271.64	<**0.001**

IQR-Interquartile Range, n- Number, N-Total Number, No,- Number, Age is compared using a Kruskal-Wallis test following normality testing, all other categorical variables were analysed using a Chi-Squared test

6.4.2 Open Invitations

The demographics for those receiving open invitations to book are shown in **Table 6-5**. No significant difference was found between the participants in differing trial arms with respect any demographic. The mobile numbers were available for 83.7-83.3% of participants in the open invitation cohort, and this constituted the per protocol group.

Univariate analysis revealed no significant difference between the control, SMS, and SMS + animation arms and the primary outcome of percentage attendance at 3 months (47.4% v. 48.3% v. 48.1%, χ^2 =1.40, df=2, P=0.50)**.** Similarly, no difference was noted between the trial arms in the per protocol analysis (52.2% v. 53.4% v. 53.0%, χ^2 =2.15, df=2, P=0.34). In terms of booking following initial invitation, no significant difference was found between the control, SMS or SMS + animation groups (40.5% v. 41.8% v. 41.7%, χ^2, df=2, =3.39, P=0.18) at 3 months. However, when examining booking rates amongst the per protocol cohort, a significant difference was found favouring the intervention groups (44.7% v. 46.3% v. 46.3%, χ^2 =6.01, df=2, P=0.05).

Table 6- 5 Demographics of those receiving an open invitation.

	Group 1	Group 2	Group 3	P-Value
Total (N)	8654	8095	8271	
Median Age (IQR)	58 (52-63)	58 (53-63)	57 (52-63)	0.70
Ethnicity (n)				
White	2404	2331	2317	0.31
Black	531	508	518	0.92
Asian	1063	986	1031	0.85
Mixed	96	99	105	0.61
Other	316	285	306	0.82
Not Stated	4244	3886	3994	0.38
IMD (Decile)(n)				
1	141	155	186	
2	713	604	635	
3	997	864	982	
4	1172	1125	1120	
5	1107	1073	1059	0.08
6	1184	1185	1161	
7	1120	1028	1004	
8	1094	1005	1029	
9	712	682	719	
10	394	355	349	
Not Stated	20	19	27	
First Invitation (n)	3120	2836	2969	0.35
% Missing Mobile Number	16.3	16.7	16.5	0.78
Median No. of Days to Attend (IQR) from Letter	46 (34-66)	46 (34-64)	45 (33-64)	0.41

IQR-Interquartile Range, n- Number, N-Total Number, No,- Number

The logistic regression model (**Table 6-6**) demonstrated that the impact of intervention group did not affect attendance at open appointments when controlling for demographics. However, it showed being of a older age, Black/Asian/Mixed/'Other'/not stated ethnicity, higher deprivation level and first invitation were significantly associated with not attending open appointments. First invitation was the strongest predictor of not booking open screening appointments (β=-1.49, z= --34.17, P<0.01).

Table 6- 6 Generalised Linear Model (logistic regression) of variables and the binary outcome of attending open appointments.

Variable	β	SE	Z	P-Value
Group 2	0.022	0.033	0.655	0.513
Group 3	0.033	0.033	0.983	0.326
Age	-0.032	0.003	-12.636	**<0.001**
Ethnicity				
Black	-0.157	0.059	-2.659	**0.007**
Asian	-0.161	0.045	-3.578	**<0.001**
Mixed	-0.304	0.120	-2.524	**0.012**
Other	-0.580	0.072	-8.022	**<0.001**
Not Stated	-0.372	0.042	-8.863	**<0.001**
IMD Decile	0.103	0.006	16.927	**<0.001**
First Invitation	-1.488	0.044	-34.172	**<0.001**
Constant	1.892	0.160	11.791	**<0.001**

β- Coefficient, SE- Standard Error, Z- Wald's Z Score

When examining booking, the model (**Table 6-7**) demonstrated that a younger age, 'Other' or not stated ethnicity, higher deprivation level and first invitation were significantly associated with non-attendance. First invitation was the strongest predictor of not booking open screening appointments (β=-1.29, z= -29.35, P<0.01).

Table 6- 7 Generalised Linear Model (logistic regression) of variables and the binary outcome of booking open appointments following initial invitation.

Variable	β	SE	Z	P-Value
Group 2	0.045	0.033	1.353	0.176
Group 3	0.056	0.033	1.686	0.092
Age	-0.023	0.002	-9.236	**<0.001**
Ethnicity				
Black	-0.107	0.058	-1.850	0.064
Asian	-0.063	0.044	-1.446	0.148
Mixed	-0.123	0.119	-1.032	0.302
Other	-0.456	0.072	-6.294	**<0.001**
Not Stated	-0.338	0.041	-8.157	**<0.001**
IMD Decile	0.093	0.006	15.346	**<0.001**
First Invitation	-1.288	0.044	-29.352	**<0.001**
Constant	1.024	0.159	6.446	**<0.001**

β- Coefficient, SE- Standard Error, Z- Wald's Z Score.

Subgroup Analysis

Chi-squared analysis examined the proportion of attendance at open invitations compared to non-attendance within differing demographic subgroups for each trial arm (**Table 6-8**). Amongst a multiply underserved group (i.e. those from a high IMD decile 1-5 *and* non-White ethnicity) the behavioural SMS group had a 2.2% higher attendance compared to controls, however this was not significant (Group 1 attendance 51.1% v. Group 2 attendance 53.3% v. Group 3 attendance 52.1%, χ^2=0.92, df=2, P=0.63). Regarding booking amongst those invited to their first appointment, there was a significantly higher proportion booking within each intervention group compared to controls (**Table 6-9**) (Group 1 booking 20.2% v. Group 2 booking 22.7%, Group 3 booking 22.6%, χ^2 =7.22, df=2, P=0.03). No significant difference was seen in booking rates within the approximated underserved groups (44.4% v. 45.2% v. 45.7%, χ^2 =0.36, df=2 P=0.83).

Table 6- 8 Percentage attendance across collated subgroups for each of the 3 trial arms in the open invitation cohort (excluding missing or not stated data).

	Total n/N (%)	Group 1 n/N (%)	Group 2 n/N (%)	Group 3 n/N (%)	χ^2	P-Value
Ethnicity (n)						
White	5232/7052 (74.2)	1772/2404 (73.7)	1703/2331 (73.1)	1756/2317 (75.8)	4.90	0.08
Not White	3339/5844 (57.1)	1120/2006 (55.8)	1095/1878 (58.3)	1124/1960 (57.3)	2.48	0.29
IMD (Decile)						
1-5	5002/11933 (41.9)	1702/4130 (41.2)	1604/3821 (42.0)	1696/3982 (42.6)	1.60	0.45
6-10	6971/13021 (53.5)	2392/4504 (53.1)	2301/4255 (54.1)	2278/4262 (53.4)	0.85	0.66
First Invitation	2281/8925 (25.6)	773/3120 (24.8)	735/2836 (25.9)	773/2969 (26.0)	1.55	0.46
Incident Screen	9710/16095 (60.3)	3331/5534 (60.2)	3174/5259 (60.4)	3205/5302 (60.4)	0.08	0.96

First Invitation- Prevalent screening invitation, Incident Screen- Any subsequent screen following the first, n/N- number of attendees/total sample, P-value represents the comparison of the proportions of attendees v. non-attendees, across the 3 trial arms as determined by the Chi-Squared test.

Table 6- 9 Percentage booking across collated subgroups for each of the 3 trial arms in the open invitation cohort (excluding missing or not stated data)

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	Total n/N (%)	Group 1 n/N (%)	Group 2 n/N (%)	Group 3 n/N (%)	χ^2	P-Value
Ethnicity (n)						
White	3943/7052 (55.9)	1357/2404 (56.4)	1294/2331 (55.5)	1292/2317 (55.7)	0.45	0.80
Not White	2936/5844 (50.2)	987/2006 (49.2)	955/1878 (50.9)	994/1960 (50.7)	1.32	0.52
IMD (Decile)						
1-5	4323/11933 (36.5)	1448/4130 (35.1)	1403/3821 (36.7)	1472/3982 (37.0)	3.77	0.15
6-10	6042/13021 (46.4)	2066/4504 (45.9)	2003/4255 (47.1)	1973/4262 (46.3)	1.31	0.52
First Invitation	1945/8925 (21.8)	630/3120 (20.2)	644/2836 (22.7)	671/2969 (22.6)	**7.22**	**0.03**
Incident Screen	8390/16095 (52.1)	2870/5534 (51.9)	2742/5259 (52.1)	2778/5302 (52.4)	0.31	0.86

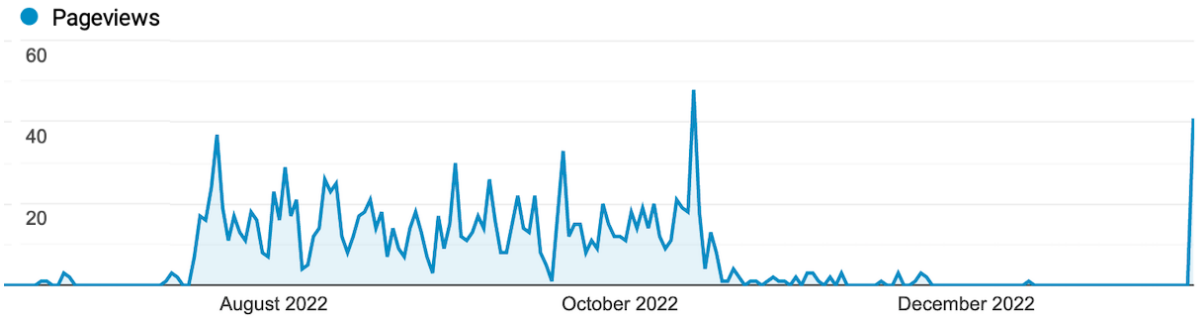
First Invitation- Prevalent screening invitation, Incident Screen- Any subsequent screen following the first, n/N- number booked/total sample, P-value represents the comparison of the proportions of those who booked v. those who did not book, across the 3 trial arms as determined by the Chi-Squared test.

6.4.3 User Metrics

The webpage hosting the animation was viewed 1552 times during the study period (**Figure 6-4**), representing 5.8% of the total population that had been sent the link within the SMS. It was not possible to determine whether individuals who had clicked the link included those who were later precluded from analysis but sent a screening reminder e.g. those sent 'special appointments' but did not include those excluded pre-randomisation. The most popular language was the English version (91.2% of views), whilst Spanish (1.2%), Arabic (1.2%) and Romanian (1.0%) were the most viewed translations. The average time spent on the webpage was 10 minutes and 1 second. The bounce rate is a measure of engagement and reports the

number of people who land on the webpage and do nothing (e.g. do not click on an item or internal page links)[358]. A high bounce rate indicates that a substantial proportion of visitors to a site do not browse the content and leave. For the current video pages this was 37.2%. Whilst there is no set definition of a 'good bounce rate' some sources suggest a value less than 40% is considered optimal[359], and suggests high engagement with the webpage, and the content.

Figure 6- 4 Reported page views for the duration of the study period. Message reminders were sent between July and October 2022, with follow-up period ending January 2023.



Survey responses were provided by 25 participants with 38.1% respondents aged between 50 and 55. The majority (60%) identified as White, whilst 25% were Black and 10% Asian. Almost a third (31.6%) of survey participants had never attended screening, whilst 10.5% were intermittent attendees. Most respondents (83.3%) highlighted that all the narratives were equally influential upon them. When assessing knowledge gained from the video, 80% reported learning some to lots of new information, whilst the remainder gained no to some new knowledge. Whilst 15% of respondents felt the stories were of average realism, 30% felt they were realistic and 55% extremely realistic. The video was found to somewhat strongly influence the decision-making process to attend breast screening in 75% of participants, whilst 20% reported a neutral effect, and 5% negative effect. Regarding changing individuals' opinions on attending screening, 40% said the video made them somewhat to a lot more likely to attend, 45% reported no change, and 15% reported it made them somewhat to a lot less likely

to attend. The video was also shown to be strongly recommended to friends/family with a net promoter score of +25 (30% detractors scoring 5/6, 15% passives scoring 8, and 55% promoters scoring 9/10). Two themes were elicited from the free-text feedback: promotion and realism. The latter referred to belief of some respondents that “really [sic] persons would be much better,” and others reporting that the process shown was more idealised than in real life. One participant commented, “while the video is good it's not accurate” with the real-life experience not meeting their expectation. On the other hand, there was also a common promotion theme noted. One respondent stating it “helped me see why I need to go.” In addition, a further respondent had “shared the video with learners, and their friends and other teachers,” which highlights the benefit of this medium for engaging wider audiences.

6.5 Discussion

This study has shown that augmenting reminder message content using behavioural change techniques, either through changing the SMS wording, or adding a link to an animated video, may not impact upon attendance at either timed or open breast screening invitations. Furthermore, no significant differences were also found between the ITT trial arms for booking rates following open invitations. However, in the per protocol analysis (including only those who had valid mobile numbers and received the reminders), intervention arms significantly increased booking rates at 3 months following the initial open invitation, however this did not translate to increased attendance. In addition, the trial demonstrated that the novel open invitation strategy (adopted in response to COVID-19 pressures) had substantially worse uptake, with an overall attendance rate 19.8% points lower than timed invitations.

The addition of a weblink to a behavioural science-informed animation did not significantly impact attendance by 3 months. This may have been due to the low numbers of those received the link visiting the page (5.8%). However, a positive response was seen in the metrics of those who did visit the video, with the average time of 10 minutes spent on the page, more than the 3 minutes and 34 second run time of the video. Moreover, questionnaire feedback revealed that 40% of respondents said the video made them more likely to attend. In addition, those who viewed the video reported they were more inclined to share the video with social networks, however, there were low numbers of participants who completed the survey, and therefore likely selection bias. Moreover, in absolute levels the attendance amongst non-White participants to timed appointments in the behavioural SMS +animation group was 3.5% above that of controls, but this difference was not significant. However, it is important to note that the analysis was not powered for subgroup analysis, so it is possible that a significant difference was not detected as this analysis was underpowered. With open invitations, behavioural SMS

+animation group significantly outperformed controls with regard to booking in first time invitees (20.2% v. 22.6%). With respect to other underserved groups, again absolute differences were higher amongst those receiving the behavioural SMS + animation compared to controls with respect to booking and attendance, but these were not significant.

Breast cancer screening uptake in London has been lower than other regions and was significantly impacted upon by the COVID-19 pandemic, with uptake falling by 5.2% points in 2020/21 compared the year prior. However, in 2021/22 the uptake of screening fell by a further 3.7% points[360]. Despite the introduction of a new behavioural science based SMS, and SMS + animation, developed using a co-design process with service users, uptake did not significantly improve with either timed or open invitations. Screening represents a specific type of health behaviour. Unlike lifestyle-based behaviours e.g. healthy eating, which require regular engagement, it should be carried out in discrete episodes years apart[361]. Moreover, akin to health checks, individuals are asymptomatic at the time of the invitation[362]. According to Prospect Theory, they may therefore perceive screening as a risky health behaviour (i.e. engaging with screening carriers a risk of receiving a cancer diagnosis)[363]. Behavioural interventions, therefore, have a narrow timeframe in which they are to act, or effectively turn a well individual with low intention to be screened to someone who attends but may have a cancer found. This can be examined using the Transtheoretical model which posits that individuals transition through six stages of behavioural change from pre-contemplation through to action, maintenance and potentially relapse. Using this model an individual within the pre-contemplative stage who is potentially unaware about the risk of non-attendance, would need to transition through contemplation, preparation, before they act[364]. However, timed screening invitations are sent approximately 6 weeks prior to the appointment, and the reminder message is sent only 7 days before. Augmenting the reminder text with BCTs may therefore

be too late to influence this multi-stage behavioural progression. Furthermore, it is possible that by the time an individual received a reminder, the decision-making process has been completed, with 7 days too short notice to rearrange other priorities[365]. Moreover, the content of SMS is limited, even more so than non-digital methods, which are not restricted to 306 characters, which may have limited the effectiveness of the BCTs incorporated[366].

To circumvent these issues the behavioural animation was designed to incorporate more BCTs, could be viewed multiple times and had multiple language translations. Whilst it was still sent only a week before timed appointments, it could have also been re-watched by those invited by open invitations to help the decision-making process. Despite this, it led to a non-significant less than 1% increase in attendance (open invitation). However, behavioural SMS + animation group did tend toward significance (P=0.09) within regression modelling for booking, suggesting that the animation may lead to higher booking than the control message, when controlling for covariates. Furthermore, amongst those with available mobile numbers, the behavioural SMS, and SMS + animation group had a significantly higher booking rates following the initial invitation compared to controls. This suggests that the intervention message acts as a stronger prompt or call to action to book the appointment, which may be through the provision of additional *information on the health consequence*s leading to reframing mammograms as less of a risk[367,368]. This was particularly noticeable in first-time invitees, in which the initial booking rate in the intervention groups was significantly higher (2.4%) than controls. These women may have less experience of what occurs at screening, its purpose, or benefits[369]. The additional knowledge provided by interventions, as demonstrated by 80% of questionnaire respondents reporting they had gained new information, may have helped address this gap leading to higher booking rates. However, the increased booking rates did not translate into differences in actual attendance. This may be related to the lag between

booking and the time of appointments, which may enable additional barriers, especially opportunity barriers (e.g. clashing priorities) to reduce attendance. Moreover, booking rates refer to those who booked after an initial invitation, and those who did not book may have received further invitations. Overall attendance, therefore, may not differ if these additional prompts (i.e. repeated invitations) were as effective as the interventions were, in getting individuals to book at *any time point*. Similar findings have been seen in other fields, with an intervention involving sending multiple SMS to improve sex behaviours leading to 14% higher odds of condom use at 1 year, which was greater than one-off remote video interventions[370].

The viewership of the actual video, however, was low. Given the null findings regarding attendance were found in both the intention-to-treat and per protocol analyses, the reasons for low views are not solely attributable to the 16-17% of missing numbers. One reason for this may be the availability of internet access, especially amongst vulnerable populations[371]. Whilst this has increased, the Office of National Statistics estimating that in 2019, 73% of people aged 55 to 64 had access to the internet on their mobile phones[372], this does not necessarily correlate with video-watching capability, which requires larger amounts of mobile data. Barriers including the types of device and mobile internet packages may also impact upon access to video health content in general[373]. However, the decision was made to send this approved video-based health information using the reminder SMS, as it was assumed this would enable individuals to view material at their own leisure. In addition, by sending video information accessible by a single click, it was thought that individuals would require less digital literacy to interact with content, overcoming issues regarding the second-order digital divide[374].

A further reason for the low viewership of the video may be related to security concerns and mistrust[375]. The current screening video used by the screening service (sent as a link in group

1 and 2) has an estimated 21,300 views, which equates approximately to 968 views per month it has been available[202]. The intervention animation had 1552 views, or 282 views per month it was sent. The current video is publicly available on YouTube, is searchable, and is hosted on the official London Breast Screening website, as well as being sent through reminders across all regional breast screening services. As such the accessibility of the current video is greater than the intervention animation, with only a proportion of viewers directed through SMS links. Whilst SMS is a low-cost, widely accepted health communication strategy, following high-profile issues during the COVID-19 pandemic, security concerns have become more apparent[231]. This may lead to recipients being less inclined to follow a weblink in the SMS, especially as it was not an NHS webpage or channel. The National Cyber Security Centre advocate that businesses avoid using weblinks due to this mistrust[237], but within the limited screening infrastructure, SMS remains a predominant communication channel. Advances with app-based messaging, the integration of digital healthcare services and regulation of content by hosting sites may provide more widespread, trustworthy means of video delivery in the future[376,377].

In addition, as shown in Chapter 2, few video-based interventions have been successfully used in breast screening interventions. Those which were only used video as part of multifaceted interventions, with video content delivered directly to participants such as Tuzcu et al. who provided a 15- minute video in conjunction with reminder cards and in-person presentations[168]. However, several behavioural remote video-based interventions have, however, successfully been developed in other health contexts. For example, McDonagh et al. used a video-based intervention hosted on YouTube based on the Self-Determination Theory, to significantly increase physical activity compared to controls[378]. One of the potential reasons for the success of this intervention is that it encouraged relatedness by facilitating participants to share and

comment on videos. This aspect of social media was not used by the screening animation, but there is already a substantial forum for discourse on breast screening, and a potential valuable means of providing additional support[379]. This is particularly important given social influences are a strong barrier and facilitator to screening behaviour as seen in Chapter 5. Moreover, Marshall et al. demonstrated a significant increase in knowledge of and intention to accept the HPV vaccine following a video intervention using BCTs such as information on health consequences, credible source, pros and cons and anticipated regret[380]. Whilst the current animation used similar BCTs, Marshall et al. sent out the video by email, which may have made content more accessible, as recipients were already using the internet. In addition, participants in this trial were much younger than breast screening age[380], and therefore, this may also be indicative of the differences in the digital capabilities of these populations.

This study has also highlighted the striking healthcare disparities across population subgroups, corroborating existing evidence[38,42,381]. Logistic regression models for timed appointments demonstrated that people who are of lower age, non-White ethnic group (excluding 'Other'), higher deprivation decile and invited to their first appointment are significantly less likely to attend. Existing studies have demonstrated these disparities within the NHSBSP[37,282]. Less information is available with the use of open invitations. The current study has shown people from high deprivation and first-time invitees were also less likely to attend open invitations. Contrary to timed appointments, only people from 'Other' ethnicities (e.g. those of Arab origin), and those who did not have a recorded ethnicity were less likely to attend open appointments compared to White invitees. This may suggest that there are common barriers to open invitations across ethnicities which may relate to a lack of knowledge regarding this new screening process, or environmental factors such as an inability to book via telephone, which are noted with cervical screening, and could form targets for future interventions[382].

In addition to these known disparities, the current study also examined the demographics of people where no ethnicity was stated on the record which is derived by the screening service through summary care records. This group was kept within analysis as it constituted a significant population within the timed cohort (27.3%). Compared to those from all other ethnicities, this not stated group were of significantly younger age, from areas of higher deprivation, included more first-time invitees, and had fewer available mobile numbers. The attendance rate was 51% points lower than that pooled from people of the other ethnicities. As such, this cohort could be considered the hardest-to-reach population, or those who are at the intersection of several underserved populations. It is improbable that attempts to address barriers using population-level measures would be optimal within this group. The significantly lower mobile phone number availability on the GP Spine, would suggest that those in this subgroup have limited healthcare engagement, require more bottom-up, or personalised methods and should be focused on by targeted interventions and policies.

6.5.1 Limitations

The findings from this chapter need to be considered with the limitations of the methodology. Although higher than in previous studies due to the extraction from GP datasets, missing mobile numbers were noted in 12-17% of participants. Moreover, according to GOV.notify receipts, between July and October 2022, 5.1-7% of SMS sent by the London breast screening hub were undelivered. As a result, not all allocated participants may have received the intended intervention impacting upon the findings (including those in the PP group). In addition, missing records were noted within demographic data. Whilst this was dealt with through the creation of the ‘not stated’ ethnicity dummy variable, missing data was also found in other areas including IMD and the reason the episode was closed. The accuracy of this data is also variable,

with studies highlighting issues regarding an over-representation of 'other' codes in health datasets, and poor correlation with self-reported ethnicity[383].

The trial was also undertaken during COVID-19 recovery which may have impacted the findings in several ways. Firstly, the booking data recorded represents the response to the initial open invitation received by a participant. The attendance rates were, however, higher than booking rates. This would suggest that a proportion of attendees responded to subsequent invitations that were sent out by the screening service once an individual had been recorded as did not attend. Whilst each episode may be considered as a separate, discrete encounter, and the use of NHS numbers ensures individuals remain within the same trial arms, certain individuals may have had a greater exposure to the interventions. For example, by not booking straightaway, they would receive further letters/reminders, which ultimately impacted upon their attendance behaviour, and skewed results. COVID-19 also led to local-level changes to facilitate screening. The randomisation processes would have ensured these were equally distributed across trial arms. However, if individual clinics were disrupted, as was seen with the Central and East London service, in which booking into specific clinics was temporarily ceased and restarted due to a lack of appointments or staff, this would not necessarily have been accounted for through randomisation as only particular geographies were affected. Whilst the screening hub alerted researchers to these changes, which led to the exclusion of this data, temporary fluctuations in clinic availability were still possible.

Further work should look to overcome these limitations by supplementing service-derived attendance data, with unit level measures of attendance (i.e. at the level of the individual clinic rather than wider regional service). This may be achieved through questionnaires undertaken at the time of screening or booking and may also help collect missing demographic data within

screening records. Questionnaire data may also enable an understanding of the influence of the animation specifically on attendance and gain greater feedback regarding its acceptability and the reasons whether it was not watched. Moreover, future work should look to examine unrecorded environmental factors upon attendance rates, such as dropped call rates. These occur when an individual attempts to book an open invitation but is unable to connect with the screening hub. This is potentially an additional, unforeseen barrier, and may have led to participants not being able to book despite the stronger prompt to do so from the interventions. One of the limitations of the study has also been not being able to directly link watching the animation, and attendance behaviour. In some trials these outcomes are derived using self-reported questionnaires, however other measures such as booking rates would not then be available, and they would also subject to response biases[384]. To gain a deeper understanding of the impact of the video, a participant could be asked to provide an identifier that can be linked to their health record, but this may lead to mistrust and data privacy concerns. Future work should examine how individual level click through or viewing data could potentially be measured and explore the potential to host the video on existing healthcare platforms such as the NHS app, where an individual's care record is already available.

6.5.2 Conclusions

Neither the use of a behavioural science-informed reminder, nor this SMS with a link to a novel animation led to significantly different attendance at either timed or open invitations to breast screening. Despite positive feedback from a video questionnaire, suggesting increased knowledge acquisition and a willingness to share the video, low click-through rates are likely to have negatively impacted upon its utility. Both intervention groups did, however, appear to significantly increase booking following the initial open invitation, suggesting the behavioural SMS was a strong prompt. This was particularly notable amongst first-time invitees. However,

concerning trends in uptake rates were noted. These included the dramatically lower attendance following open compared to timed invitations, and the disparities amongst underserved groups including those with lower potential healthcare engagement, who could be considered the hardest-to-reach. Future work should look to address the limitations within the current study and examine novel ways to disseminate video screening content to make it more readily accessible and trusted.

7. Discussion

The uptake of breast cancer screening is an increasing public health concern. For a second consecutive year following the COVID-19 pandemic, national uptake remained approximately 62%, despite substantial efforts to increase attendance[385]. These trends act in opposition to NHS England's target to diagnose 75% of cancers by stage I or II by 2028[2]. As a result, the UK government has pledged £10 million to increase the speed of diagnosis by adding 29 new breast screening units[386]. These policy measures will look to overcome some opportunity barriers, such as the availability of appointments and travelling distance to screening services. However, they do not impact an individuals' motivation or capability to attend.

Behavioural science has an established role in understanding the breadth of determinants of health behaviours, as well as the development of interventions to address them[70,387]. A broad spectrum of barriers to attendance at breast screening exist, and the influence of these upon an individual's decision to attend may change between cycles[388,389]. This thesis sought to understand the determinants of breast screening behaviours, especially amongst underserved groups, and develop and test a novel intervention informed by behavioural science to address these determinants, in the context of the London Breast Screening Programme. An animated intervention was developed based on the determinants identified in underserved groups, the general population and existing literature. This video used techniques such as *anticipated regret, credible source, information on health consequences* and *social comparison*, and was delivered using an augmented reminder SMS that also included *reducing negative emotions.* However, neither this video, nor this behavioural science-informed SMS reminder were effective at increasing screening attendance. Despite this, there are several findings from this thesis which require further consideration.

7.1 Main Findings and Significance

7.1.2 Use of Mobile Messaging Reminders in Screening

In London, message reminders sent after a letter invitation to attend an appointment are currently standard practice. Simple neutral reminders are estimated to increase uptake by 5%[143], by utilising the behavioural change technique *prompts and cues* to facilitate attendance. However, the systematic review in Chapter 2 found that while this technique is frequently employed within interventions to increase breast screening uptake, these interventions are often not effective (62 interventions, 51.6% effective). Other techniques such as *problem solving* (69% effective), *credible source* (65% effective) and *instructions on how to perform the behaviour (65.6% effective),* were used in a greater proportion of successful interventions. In addition, some techniques such as *vicarious consequences* were rarely tested, but showed promise.

The low rate of effective interventions in the existing literature (50%) may be related to the difficulty of implementation into real-world screening programmes. In the UK, there are 11 adult screening programmes, all of which are administered differently[4]. Chapter 3 looked to develop best practice regarding the implementation of mobile messaging into screening programmes, providing 23 core aspects to be considered across 6 domains: content, timing, delivery, evaluation, security and research. These included keeping content to a reading age of 9, limiting message length to 2 messages and maintaining consistency across media. These principles built upon existing guidelines, for example from the National Cyber Security Centre[237], consolidating recommendations relevant to screening. It also looked to provide forward looking guidance, recommending 17 desirable items, as messaging technology advances.

Despite establishing this messaging framework, and grounding the intervention in behavioural science, as discussed below, neither augmented message reminder impacted upon breast screening uptake in Chapter 6. Across timed appointments, uptake in the intervention reminder with animation link group was 71.7% compared to 69.9% in the intervention reminder, and 71.9% amongst controls (P=0.18). Similarly, uptake of open invitations was also not significantly different between the intervention reminder and animation link, intervention reminder only, or control arms (48.1% v. 48.3% v. 47.4% respectively, P=0.50). The only significant difference noted between trials arms was within the per protocol analysis (including only those who received the messages) for open invitation booking rates. The intervention arms had 1.6% points higher booking rate than the control arm (44.7% control v. 46.3% intervention SMS v. 46.3% intervention SMS + animation, P=0.05), however this did not translate to higher levels of subsequent attendance. The reason for the largely null findings may relate to the similarities of all 3 trials arms. For example, control message wording was amended following the guidance from Chapter 3. This involved being shortened, simplified, with wording clarified to improve understanding, making it similar to intervention content. In addition, both the intervention and control messages also contained weblinks, albeit the latter to an older YouTube-hosted video on screening[202]. These similarities are likely due to the narrow way in which the current SMS reminder infrastructure can be altered, with new technologies such as direct video messaging not available, and the limited possible content of messages.

As shown in Chapter 5, only certain Behavioural Change Techniques (BCTs) can be feasibly translated into plain text, and those which are amenable to inclusion, may not necessarily be delivered in a manner that brings about behaviour change within the limited numbers of words available. Moreover, as discussed in Chapter 2, adding behavioural techniques to reminder text

may only lead to increasing complication of the underlying prompt, requiring cognitive processing without necessarily significantly impacting upon behaviour. The animation which was designed to address a broader range of screening barriers, also had to be delivered through plain text weblink due to constraints in the messaging system (with a click through rate of 5.8%). As highlighted by the pictorial superiority effect, images are more likely to be recalled than text, and may improve engagement with content[390,391]. Delivering the animation directly (as a video message) may potentially have improved the impact of this intervention, but due to restrictions in available messaging technology this was not possible.

In addition, despite the versatility of SMS, there were some areas in which the current screening infrastructure limits the utility of reminders to deliver interventions effectively including requiring set timing or the inability to change who is the sender of message (e.g. GP). Research on digital triggers, or behavioural cues delivered through a digital medium, has shown them to be multi-faceted tools[16]. Whilst broad cross-programme considerations regarding content and timing in relation to messaging about screening appointments were determined in Chapter 3, mobile messages can be complex delivery mechanisms. Individual programmes determine the nature of the reminder (e.g. to use SMS as opposed to voice or images), the effective schedule (the time of day) and sender (screening service, GP). In breast screening these are determined pragmatically and have been designed to deliver prompts to attend but have not been optimised to deliver more complex interventions. For example, studies have shown that cognitive functioning alters over the day and varies with age, with those over 50 exhibiting elevated performance in the morning (so-called *morningnesss*)[392,393]. Receiving an intervention, that requires the individual to process more, potentially new, information at a sub-optimal time of day may lead to distraction or avoidance, reducing effectiveness. During the trial the exact timing of messages sent from the breast screening hub varied daily but they were always sent

within working hours. Moreover, mobile triggers are perceived to be more disruptive to users if they occur when individuals are engaged in complex tasks. Studies has shown that disruptive prompts are twice as likely to be dismissed, or ignored, than those not perceived by users to be as disruptive[394]. Although incorporation of interventions into the existing appointment reminder system makes them more feasible and low-cost, alternative mechanisms of delivery (e.g. an app or push notification alerting an individual to view content at their leisure) may need to be explored to improve efficacy of intervention messages sent at variable times throughout the day.

7.1.3 Behavioural Frameworks in Screening Interventions

One of the core components of the animation design process, or programme theory[313], was the use of behavioural science constructs, as outlined in Chapter 4 and 5. Findings from Chapter 2 suggested there was no association between the proportion of effective interventions using a named theory compared to those which did not in the published literature (46.4% v. 58.3% respectively P = 0.33). One potential reason for this may be that over-reliance upon individual theories could lead to important determinants being missed. The design of the intervention in Chapter 4 therefore utilised behavioural constructs, such as the Theoretical Domains Framework (TDF) and Capability Opportunity Motivation-Behaviour (COM-B) model that took a more holistic approach. As discussed previously, these frameworks include a broad range of potential determinants including motivational influences such as emotions, that may impact screening behaviour. Moreover, these frameworks have been previously used to understand the determinants underpinning a behaviour and used these to systematically inform intervention development (by means of the Behaviour Change Wheel, (BCW) and Theories and Techniques Tool (TaTT)[315,395].

Framing interviews and focus groups using the TDF elicited the common barriers amongst those from underserved populations to attendance at breast screening. These included fear of the pain of mammography, a perceived low susceptibility of breast cancer and the impact of social influences. Similar findings have been shown in other studies, such as those from other countries[23]. The qualitative study reported in Chapter 4, however, also demonstrated that similar barriers are noted amongst multiply underserved (those who share characteristics with several underserved groups). These individuals represent an intersectional group, who may face several, harder challenges to attend, however, the current literature has not explored challenges faced by these groups to breast screening attendance in the UK[245]. Chapter 4 focussed upon three groups predominantly, namely ethnic minorities, those from areas of high deprivation and those with multiple morbidity/disabilities, as well as those representing combinations of these groups. Several complex influences were found to underpin broader determinants of screening behaviour within interviews. Tackling these barriers therefore required a more multimodal approach with several potential challenges needing to be addressed at once. For example, susceptibility was associated with a lack of understanding about risk factors and their significance, cultural optimism that things are 'ok' if one is asymptomatic, and salience of the disease within social networks. To help address issues regarding perceived susceptibility, one would need to provide knowledge, increase awareness of the disease, and reframe perceptions of illness in the asymptomatic. This therefore led to the design of an intervention that could incorporate multiple techniques.

To facilitate the design of the intervention at a population-level, a triangulation process was undertaken. This provided methodological validity and robustness to the findings, by facilitating the convergence on the most significant barriers across information sources. These high priority barriers were noted within the existing literature (from a systematic review),

underserved groups (from interviews/focus groups) and the wider screening populations (from a previously published survey). The key identified determinants included fear, healthcare professional endorsement, susceptibility, and perceived impact of a cancer diagnosis. This triangulation of determinants was followed by a mapping process which helped to categorise the underlying nature of these determinants (TDF/COM-B), the potential intervention functions (BCW), and potential behavioural techniques with evidence to support their ability to address the identified determinants (TaTT). The process has been utilised by several other interventions, including those used to increase presentation with symptomatic cancer[396], and provided a robust framework to underpin intervention design. However, as discussed below, none of these frameworks were screening specific, and therefore important considerations may have been missed. In addition, the TaTT helps to identify which BCTs have established links to mechanisms of actions aiding selection. This, however, promotes researchers to use BCTs which have previously been investigated rather than those which do not yet have an evidence base, but may be effective. To mitigate this, BCTs with 'inconclusive links' according to the TaTT were also considered for inclusion. Whilst this widened the scope for the intervention, it may still mean potentially effective techniques were excluded.

The theoretical basis used within this study was not utilised by any of the interventions described in Chapter 2[332]. However, in keeping with those studies, the intervention development involved using a more generalised theoretical approach, used in other disciplines, and applied it to screening. As described above, screening poses challenges not seen with some other common health behaviours such as smoking cessation or physical activity. There is therefore a need for a more comprehensive, and specific, model of screening behaviour, which encompasses the multiple considerations needed when understanding the determinants of non-attendance. The Integrated Screening Action Model (or I-SAM) is a theory-based approach to

understanding screening behaviour, as well as providing targets for interventions. The I-SAM consists of three broad components: the screening behaviour process, the environmental influences affecting invitees, and participant influences[397]. Environmental influences (opportunity), involving the effect of social support as well as physical access, and the participant influences, which include emotions, risk (motivation), conflicting priorities and self-efficacy (capabilities) are based upon components of the COM-B. However, unlike COM-B, the I-SAM includes a screening behaviour process incorporating the stages of engagement with screening akin to the Stages of Change seen in the TransTheoretical Model[80]. This tracks an individual's screening behaviour from being unaware and unengaged, to undecided to act, then finally those who act and those who repeatedly attend. This stage-based approach enables a population to be segmented according to how far along the sequence individuals are, and subsequently, facilitate the targeting of interventions by stage. In addition, the model acknowledges that screening involves infrequent repeated behaviours which can be maintained or lapsed. Although this model has not been studied in practice, this approach holds promise[398].

In order to be feasible to apply within a resource-limited population-level programme, such models would need a reproducible means for screening services (or those implementing interventions) to elicit which stage people are at, as well as evidence-based behavioural techniques linked to these stages. Automating stage classification through online methods (e.g. online surveys sent at the time of the invitation) may assist identification at scale[343], whilst machine learning may improve selection of evidence-based behavioural techniques. The latter is being examined more generally by the Human Behaviour Change Project, who are using algorithms to gather information about behaviour change interventions from the existing literature and using these to predict the most effective BCTs to increase a target behaviour within novel scenarios. Whilst the project focused only on outcome prediction in smoking

cessation this could be undertaken in other areas such as screening[110,399]. Moreover, if algorithms could also incorporate the stage of the screening behaviour process, this could facilitate the development of more targeted, and effective screening interventions.

7.1.4 Access to Screening Information

One of the limitations of the delivery mechanism of the animation (weblink to animation within an SMS), was the reliance upon individuals to click on a weblink to a potentially unknown page. The click-through rates in Chapter 6 were low (5.8%) but low rates are also seen other studies, for example, Middleton et al. used SMS weblinks to increase HIV awareness, but the click through rate was 14.4%[400]. The need to click through to watch a video is associated with additional barriers including privacy concerns, access to mobile internet, and having the time to view content. Screening interventions may therefore be delivered more effectively using alternative methods to video, or a combination of methods including video.

Print-based media was commonly used in existing interventions, as described in Chapter 2. Although letters can be expensive, and limited in the information they can portray, they may overcome challenges associated with mobile number availability and trust. Furthermore, letter invitations are sent out earlier than SMS messages, approximately 6 weeks prior to timed appointments, which may help target those who are undecided or unengaged with screening. Incorporating Quick Response (QR) codes, which have been used in diabetic eye screening materials, into invitation letters may signpost invitees to more in-depth information, such as the animation, with fewer privacy concerns[401]. This is particularly important for first-time invitee, who are likely to need greater screening information provision, and had lower attendance for both timed (β -0.96, Z -13.1, $P<0.01$) and open invites (β -1.49, Z -34.2, $P<0.01$). Using QR codes however requires individuals to have sufficient digital literacy, and the

necessary hardware to read the code as not all smartphones equipped with in-built readers. As 39% of people aged over 52 reported utilising the internet more since the start of the pandemic, as well as the more widespread use of QR codes in COVID-19 information, this issue may be waning[402,403].

Plans for wider distribution of screening information must also account for the fact that individuals may not be invited to screen until years after seeing materials. For this reason, formal health campaigns involving TV advertisements may not have the impact seen in other health behaviours despite their scope[236,404]. Alternatively, the widespread use of app-based communications may provide a useful means of disseminating health information. WhatsApp is the most commonly downloaded app globally, and accounts for 20% of total smartphone use[405]. In a Brazilian study by Pereira et al., 35 women aged 45 to 69, received an educational intervention involving daily videos, messaging and pictures posted on a dedicated WhatsApp group about breast cancer. This led to an increase in the understanding about breast cancer in all domains tested including a 10% point increase in knowledge about mammography[406]. Moreover app-based communications readily facilitate the sharing of information to one's own social networks, with no additional cost. For example, in a study using the WhatsApp groups of three community organisations to increase mental health awareness, one in five users shared the content, and for every person who shared the material, approximately fifty additional people viewed the content[407]. Sending screening interventions via app-based communications may therefore increase their reach. Furthermore, as highlighted in Chapter 4, the perceptions of social influences were a strong determinant of screening behaviour, impacting upon how health was prioritised and perceptions of mammography. Leveraging *credible source* by using trusted senders of the information, may increase the impact of interventions. If the source was

a healthcare professional (or GP practice) messaging could be timed to coincide with an upcoming screening appointment, thereby also increasing salience.

7.1.5 Underserved and Multiply Underserved Communities

One of the core approaches of this thesis has been the examination of the disparities that exist within the breast screening programme. These include lower uptake amongst those from minority ethnic groups and those from areas of high deprivation, who are at risk of later diagnosis as a result. Given stage at diagnosis is a strong predictor of survival, these inequalities are a significant concern[408]. In Chapter 4, through collaboration with several community organisations it was possible to recruit participants with characteristics of multiple underserved groups. One recent criticism of trial methodologies is the failure to include people from diverse backgrounds such as those who are from 'multiply underserved', or intersectional groups[409]. Involving intersectional groups in research provides a more accurate depiction of the nature of disparities, and how they manifest in different population segments. Comparing the perceptions of those from an intersectional group to the wider population (from a population survey), and the existing literature on underserved populations, helped to provide insights into the nature of the barriers faced to screening. This included determinants such as *a fear of pain* or *exposure*, *perceived value of screening* and *low priority* which were common amongst underserved groups and the wider populations. On the other hand, barriers such as *low salience of breast cancer,* seeing *cancer as a taboo* and *candidacy* were only seen in underserved communities.

The inclusion of underserved groups (in both barrier identification and co-design) did not however translate into impact of the intervention. Other than a 2.4% higher rate of booking amongst first time invitees from the SMS + animation group compared to controls (P=0.03), no significant difference was found between trial arms and the uptake of screening amongst

demographic subgroups. This included an examination of an approximated multiply underserved group (high deprivation and non-White ethnicity) where there was an absolute difference of 5.2% in the attendance rate between those who received the SMS + animation and controls, however this was not significant. A similar, but lesser, non-significant difference between attendance in the animation and control group (+2.2%) was also noted in this multiply underserved group with open invitations. Neither difference was significant, which may be due to an insufficient sample size (1201 timed, and 3053 open), or may be related to the small numbers involved in the barrier identification limiting generalisability of findings, as discussed below. In either case the trend of the intervention appearing to have potential greater impact in multiply underserved groups warrants further examination and may inform the development of targeted video interventions.

The subgroup analysis in Chapter 6 did, however, further emphasize the current nature of the disparities in breast cancer screening in London. Similar to the existing literature, this analysis showed that being from a non-white ethnicity (Black, Asian, Mixed), area of higher deprivation, and a first-time invitee was associated with non-attendance in both timed and open breast screening invitations[338,410]. Furthermore, the evaluation of those who had no ethnicity stated, demonstrated that attendance in this group was 2.5 times lower than the pooled rate across ethnicities. Not having an ethnicity coded on the screening system, was also associated with higher levels of deprivation, being a first-time invitee and having an absent telephone number on the system. As ethnicity data and telephone number can be drawn from the GP electronic health record, this suggests that this group may not have a primary care physician or have lower clinical utilisation. Non-2 week wait GP referrals contribute approximately 8% of the diagnoses of breast cancer, with 2 week wait responsible for a further 51.2% and screening 32% of diagnoses[411]. Cancers diagnosed within this underserved group with lower healthcare

utilisation are therefore likely to be later, including as emergency presentations, with worse outcomes. This subgroup could thus be considered a very hard-to-reach group, who have lower engagement with traditional clinical pathways. Novel interventions, which may circumvent these conventional healthcare interactions, such as remote diagnostics e.g. using telemedicine, or opportunistic testing at other allied health interactions e.g. in pharmacies, may be more effective. Implementing changes to how breast screening is delivered, which is not easy given technology limitations[106], would require significant participatory work with this very hard-to-reach group regarding whether new testing approaches are needed, and what resources including screening information provision, would be needed to make them effective.

7.2 Strengths and Limitations

The current context of the screening service, with reducing uptake and increasing disparity, has galvanized a move to find novel means of addressing the challenges to attending faced by service users. This thesis has presented a theory-based exploration of existing interventions, determined the barriers faced by underserved groups, and co-designed (with members of relevant groups) and tested a novel behavioural science-informed intervention. The process used a robust, theory driven approach to intervention design, with inputs on behavioural determinants triangulated from multiple sources, thus increasing validity of findings. The intervention was designed and evaluated in a robust way, through a large RCT embedded in the screening service.

One of the key strengths of the approach has been the incorporation and testing of the intervention into the existing infrastructure of the screening service. This has enabled the real-world testing of a video, and its impact upon actual health outcomes as opposed to surrogate measures such as intention, or engagement metrics. The methods from this study are therefore

now being used by health video content developers including YouTube[412], and the NHS England Health Inequalities Action Group[413], to inform how upcoming social marketing and health campaigns can be developed and evaluated in a systematic manner. This includes understanding how video health information can impact upon tangible health outcomes. A core component of this thesis that facilitated a real-world evaluation, was the development of robust recommendations on the use of messaging in screening programmes. The findings from this Delphi have been published as national guidance on GOV.UK in collaboration with the Office of Health Disparities[243]. The guidance has meant the intervention development was completely informed by what is currently achievable by screening services, as well as encompassing service perceptions on how messaging can work in practice.

Another strength was in the inclusive approach that was undertaken with intervention development. This involved working with organisations that have established relationships within communities, which enabled substantial participation from individuals who may not traditionally be included in research. This gave understanding beyond what is gained from the existing literature on the determinants of screening behaviour and involved multiply underserved individuals in both interviews and co-design, but in whom there is very little research into screening behaviour in the UK. The participatory approach also benefitted the refinement of the intervention, which involved receiving feedback from more established, and increasingly recognised underserved groups, such as the LGBTQ+ community[57]. One of the benefits of the inclusivity of the thesis, beyond intervention design, has been the information garnered about aspects of the screening experience which impact upon these groups. For example: the inaccessibility of some screening services, the current level of misinformation regarding breast screening, and the difficulties these groups have found interacting with

screening staff. These insights are being fed back to screening commissioners, which may help improve the screening experience.

However, the work in this thesis also has important limitations. Firstly, the methodology used is reliant upon the individuals who participated in studies. Assuming subgroup homogeneity, as outlined in Chapter 2, may lead to an intervention not being effective when deployed at a population-level. The current methodology, although purposively sampling those from underserved groups, could only elicit the perspectives of a few people. Whilst the process of triangulation helped to provide broader insight, these findings cannot be considered representative of entire populations. Those recruited to interviews or workshops may represent a more engaged, and not representative subsection of these communities. Attempts were made to minimise these biases through collaboration with community organisations and a triangulation process involving comparing findings to the wider literature and large population survey. In addition, participants included those who had leadership roles within certain communities and could speak to the experience of others who were not physically present. However, as the subsequent intervention development is reliant upon understanding these determinants, this limited sampling would impact the findings from this thesis.

Secondly, the development and evaluation of the intervention was subject to what is currently achievable within the London Breast Screening Programme. Although the ability to integrate feasibly into the current infrastructure was an advantage of the methodology, it also restricted what was achievable. As a result, the trial design was controlled and may not have been optimal. This included the screening service request to change existing control message format (e.g. adding paragraph spaces) to match the intervention content, which may have improved the readability of the usual care message but consequently may have diminished effect sizes.

Furthermore, there were limitations in the trial data that was received, including missing ethnicity data, and an inability to determine whether individual messages were read or not. In addition, comparable analytics regarding click-through and viewership in either the control or the augmented SMS only arms were not available. Moreover, to control who could see the animation, and elicit webpage analytics, it was necessary to host the animation on the university website. As a result, the link to the animation carried the name of the university and not the screening programme, nor the existing video hosting site. This difference may have increased security concerns and led to mistrust of the message affecting the results.

Finally, this thesis has been conducted during, and in the immediate wake of, the COVID-19 pandemic. This period represented a significant disruption to healthcare, research, and public life. Widespread and sustained changes were made to healthcare practice, information dissemination and social norms[66,340]. The impact of these changes upon the current findings cannot be underestimated, not least due to the changes in the way screening and research had to be conducted. For example, changing of invitation methodologies because of recovery capacity at one recruited screening site midway through the trial, led to this data needing to be excluded from the trial. The need to use remote methods for interviews and workshops, may have facilitated the recruitment of more co-morbid patients (by reducing physical access requirements), but may have precluded those without reliable internet access or lower digital literacy from participating. How individuals perceive health as a priority, and their trust in health services, may also have been affected by the pandemic, impacting their behaviours in the trial, as well as the intervention development. There was also a need to make the interventions applicable to both timed and open interventions. There is less evidence available regarding how the latter impacts breast screening behaviour, and whether differing barriers are seen with open invitations, which may have affected the utility of the intervention in this

pathway. Whilst interviews and focus groups were undertaken during the period in which open invitations were available, as this was a new invitation method no participant had experience of this pathway. Whether the findings reported within this thesis would have differed had studies been undertaken prior to the pandemic is not discernible, but consideration should be given to the relevance of the results as a 'new normal' is found.

7.3 Future Considerations

As described throughout this chapter, the findings from this thesis could shape future directions for research into screening uptake. These can be categorised into two broad areas:

1. Personalisation of screening information sources and invitation methodology
2. Translation into other screening programmes

Personalisation

The approach described in this thesis employed the idea of proportionate universalism[283]. This describes the concept of providing resources to whole populations but focussing upon those in most need. Within the current intervention, the behavioural techniques incorporated were based upon barriers predominantly faced by underserved communities, but also relevant to the wider population. The integration of multiple techniques addressing several barriers enabled individuals from differing backgrounds to relate to the narratives that were most relevant to them but ensured that the intervention could be appropriate to deliver at-scale. However, the animation does not specifically target barriers, or provide the most salient information for an individual nor was it delivered in an optimal way for everyone. Future work should examine how the reach of the animation could be improved by understanding how people prefer their health information to be received (e.g. SMS link, email, push-notification), integrating the animation into these streams and targeting information sources to the individual. Moreover, it

could examine the impact of opportunistic exposure to the animation (e.g. playing in a GP waiting room) or at other screening appointments. One criticism of targeted or tailored approaches is the lack of feasibility of using these interventions in population-level programmes[414], but advances in Machine Learning (ML) and Artificial Intelligence (AI) may make this possible.

People require differing amounts and sorts of information to make a decision to act. The utility of the information provided therefore varies between individuals. Using data sources which assess the utility of differing information streams, such as online search habits, it is possible to understand what knowledge is useful for different people in various contexts and make predictions about what information would best suit their needs. Within behavioural economics this could be considered a "choice engine", and examples of similar processes are seen with current online search algorithm recommendations[415,416]. Within breast screening, this scenario, simply, could involve utilising demographic data, combined with other sources, to tailor the information received by first-time invitees or previous non-attendees (videos, SMS, letters) to focus more information on the process and rationale behind screening, compared to repeated attendees. More dynamically, this could be used to tailor the information to the individual's position within their stage of engagement with screening, for example in models such as the I-SAM and alter communications according to their progression with the use of AI/ML. For example, an individual who is 'unaware', according to I-SAM, could be provided resources to increase salience, whilst those who had 'decided to act' sent information to enhance prioritisation. Understanding how the stages could be determined through existing big data resources would therefore be an invaluable next step in this process.

AI and ML techniques could also be used to personalise the *choice architecture,* or the nature in which the choice to attend is presented. Breast screening has traditionally invited individuals using timed appointments, in which the *default* is attendance at a pre-specified time (i.e. women are opted-in)[417]. Through necessity this was changed during COVID-19, with the introduction of open invitations, which had a much lower uptake. However, in some circumstances, people may find an open invitation preferable to a timed appointment. Personalising the appointment-type delivered according to socio-demographic, and clinical utilisation data may help overcome difficulties with appointments. Moreover, the invitation strategies and the way that screening information (including the animation) is provided prior to these appointments could be optimised using algorithms to maximise uptake but retain autonomy. For example, if data shows that some individuals do not attend after a letter and SMS, but are more responsive to an email, then the communication strategy could be tailored to this need[418]. Within the current limitations of the screening service this is not yet possible, but determining the impact of differing invitation methodologies, and how this alters between people would be an important piece of future work.

Translation to other screening programmes

In Chapter 3, cross-discipline recommendations were made for all eleven screening programmes in the UK. Despite their differences, several of these programmes have found a decline in uptake, especially following the pandemic[419]. The development of a behavioural science-informed animation could readily be translated into other programmes including bowel or cervical screening, adapting the content to the specific barriers faced with each screening type, with some challenges common across programmes[420]. One advantage of exploring these areas is that both are currently or will be utilising at home testing. In these circumstances, there is no time-pressure to return a sampling kit, and therefore there is a greater opportunity to send

video-based education, overcoming timing challenges associated with integration into reminders. Moreover, cervical screening is administered by GP services, which have the availability of more versatile communication systems, the video links can be sent through a mixture of letters, SMS and email which may help address issues with click-throughs. Further as patients are more used to receiving communication from their GPs, this may help address mistrust of weblinks.

7.4 Conclusions

Breast screening uptake has precipitously declined since the COVID-19 pandemic to concerning levels. There has been variable success of interventions described within the literature to improve uptake. These interventions often use a narrow repertoire of behavioural change techniques, whilst lesser used techniques have shown promise. Despite an expert led consensus on how to use mobile messaging in screening, and an extensive assessment of the determinants of screening including amongst underserved groups, the co-designed, behavioural science-informed animation and reminder sent within screening reminders failed to increase uptake. Although booking rates to open invitations were found to be significantly higher amongst those who received either intervention, this did not translate to increased attendance. Qualitative feedback regarding the video, as well as engagement metrics of those who viewed the animation, were positive, yet the number of people clicking on the link was very low.

Understanding the information needed to facilitate attendance, making it relevant to individual circumstances and making it accessible on a population-level are areas that continue to need further research. Whilst the majority of research has focussed on the first of these areas, less is understood about the other two. Without participatory research incorporating multiple groups, important barriers to attend screening can be missed, and even

if these are addressed, if interventions are inaccessible they will likely be ineffective. Whilst personalised and targeted interventions often refer to improving content, they should also take into account how individuals prefer to receive healthcare information. This will include understanding the influences of social networks and newer communication technologies. Evaluating the impact of existing resources including the current animation, distributed through differing methods, may provide a low-cost way of providing this information, without developing interventions *de novo*. But as breast screening enters its fourth decade, widespread infrastructural changes to the programme are likely needed if the concerning decline in uptake is to be reversed.

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Appendices

Appendix 1-1

No appendices in chapter 1.

Appendix 2-1 Search strategy for Medline database

Search Number	Terms	Articles
1.	mass screening[MeSH Terms] OR (population surveillance[MeSH Terms] OR (screening program*) OR (cancer screening) OR (asymptomatic screening) OR (mobile screening)) OR (mammography[MeSH Terms] OR (screening mammography)	658,571
2.	breast cancer[MeSH Terms] OR (breast neoplasms[MeSH Terms] OR (breast malignancy)	301,150
3.	(patient compliance[MeSH Terms] OR (coverage) OR (attendance) OR (uptake) OR (compliance) OR (adherence)	792,541
4.	1+2+3	3,348
5.	(intervention) OR (health behavio?r) OR (behav* science) OR (nudge) OR (nudge theory) OR (theory of planned behavio?r) OR (health belief model) OR (fogg's behavio?r model) OR (social learning theory) OR (transtheoretical model) OR (capability, opportunity, motivation, behavio?r) OR (TTM) OR (HBM) OR (SLT) OR COMB)	6,589,663
6.	DATE 01/01/2005- present	18,375,499
7.	4+5+6	1666

Appendix 2-2 BCT coding outcomes.

Study	Behavioural Change Technique (BCT)
Abood et al. 2005	Information about health consequences Anticipated Regret
Ahmed et al. 2010 (1)	Prompts or Cues Credible Source
Ahmed et al. 2010 (2)	Prompts or Cues Credible Source Problem Solving Information about health consequences
Allen et al. 2006	Prompts or Cues Adding objects to the environment Problem Solving Conserving mental resources Instruction on how to perform a behaviour
Beauchamp et al. 2020 (1)	Prompts or Cues Instruction on how to perform a behaviour Credible Source
Beauchamp et al. 2020 (2)	Prompts or Cues Instruction on how to perform a behaviour Conserving mental resources

Bodurtha et al. 2009	Prompts or Cues Instruction on how to perform a behaviour Salience of consequences Information about health consequences Pros/cons Action planning Adding objects to the environment
Bowen et al. 2017	Prompts or Cues Information about health consequences Salience of consequences Commitment Problem Solving Reduce negative emotions Social Comparison
Carney et al. 2005	Prompts or Cues Instruction on how to perform a behaviour Problem Solving Information about health consequences
Chambers et al. 2016 (1)	Prompts or Cues
Chambers et al. 2016 (2)	Problem Solving Prompts or Cues Framing/Reframing
Chambers et al. 2016 (3)	Prompts or Cues Problem Solving Anticipated Regret Framing/Reframing
Champion et al. 2006 (1)	Verbal persuasion about capability Credible Source Demonstration of the behaviour Information about health consequences Problem Solving Social Comparison Pros/cons Reduce negative emotions Framing/Reframing
Champion et al. 2006 (2)	Verbal persuasion about capability Credible Source Demonstration of the behaviour Information about health consequences Social Comparison Pros/cons Reduce negative emotions Framing/Reframing
Champion et al. 2007 (1)	Credible Source Information about health consequences Salience of consequences Pros/cons Instruction on how to perform a behaviour
Champion et al. 2007 (2)	Credible Source Information about health consequences Salience of consequences Pros/cons Instruction on how to perform a behaviour verbal persuasion about capability Problem Solving
Champion et al. 2007 (3)	Credible Source Information about health consequences Salience of consequences

	Pros/cons Instruction on how to perform a behaviour verbal persuasion about capability Problem Solving
Champion et al. 2016 (1)	Instruction on how to perform a behaviour Information about health consequences Demonstration of the behaviour Salience of consequences Reduce negative emotions
Champion et al. 2016 (2)	Instruction on how to perform a behaviour Information about health consequences Reduce negative emotions Salience of consequences Verbal persuasion about capability
Champion et al. 2020 (1)	Demonstration of the behaviour Prompts or Cues Pros/Cons Information about health consequences Salience of consequences
Champion et al. 2020 (2)	Prompts or Cues Pros/Cons Information about health consequences Salience of consequences
Champion et al. 2020 (3)	Demonstration of the behaviour Prompts or Cues Pros/Cons Information about health consequences Salience of consequences
Chan EK et al. 2017	Prompts or Cues Credible Source
Cuellar et al. 2017	Material Incentive Material Reward
Cohen et al. 2010	Social Comparison Verbal persuasion about capability Distraction Reduce negative emotions Problem Solving Incompatible beliefs Commitment
DeFrank et al. 2009 (1)	Prompts or Cues Information about health consequences Pros/cons Information about other's approval Instruction on how to perform a behaviour
DeFrank et al. 2009 (2)	Prompts or Cues Information about health consequences Pros/cons Information about other's approval Conserving mental resources Salience of consequences Social Comparison
Dietrich et al. 2006	Prompts or Cues Problem Solving Action planning Adding objects to the environment Conserving mental resources Instruction on how to perform a behaviour
Fernandez et al. 2009	Prompts or Cues

	Pros/cons
	Social Comparison
	Instruction on how to perform a behaviour
	Information about health consequences
	Verbal persuasion about capability
Goldzahl et al. 2018 (1)	Credible Source
	Prompts or Cues
Goldzahl et al. 2018 (2)	Information about health consequences
	Action planning
	Prompts or Cues
Goldzahl et al. 2018 (3)	Credible Source
	Information about health consequences
	Action planning
	Prompts or Cues
Goldzahl et al. 2018 (4)	Social Comparison
	Prompts or Cues
Han et al. 2009	Information about health consequences
	Salience of consequences
	Problem Solving
	Instruction on how to perform a behaviour
	Pros/cons
	Prompts or Cues
Hegenschied et al. 2011	Problem Solving
	Pros/cons
	Instruction on how to perform a behaviour
Highfield et al. 2015	Problem Solving
	Prompts or Cues
	Information about health consequences
	Adding objects to the environment
	Verbal persuasion about capability
Icheku et al. 2015	Credible Source
	Prompts or Cues
Kearins et al. 2009	Prompts or Cues
	Instruction on how to perform a behaviour
	Adding objects to the environment
Kerrison et al. 2015	Prompts or Cues
Kregting et al. 2020	Prompts or Cues
	Pros/cons
	Information about health consequences
	Instruction on how to perform a behaviour
Kreuter et al. 2005 (1)	Credible Source
	Salience of consequences
	Information about health consequences
	Prompts or Cues
	Problem Solving
	Adding objects to the environment
Kreuter et al. 2005 (2)	Information about health consequences
	Prompts or Cues
	Adding objects to the environment
	Vicarious Consequences
	Social Comparison
	Incompatible beliefs
	Valued self-identity
Kreuter et al. 2005 (3)	Credible Source
	Salience of consequences
	Information about health consequences
	Prompts or Cues
	Problem Solving

	Adding objects to the environment Vicarious Consequences Social Comparison Valued self-identity Incompatible beliefs
Lakkis et al. 2011	Pros/cons Prompts or Cues
Larkey et al. 2012	Goal setting (behaviour) Instruction on how to perform a behaviour Prompts or Cues Social Support (unspecified)
Lee E et al. 2014	Social support (unspecified) Adding objects to the environment Credible Source Reduce negative emotions Information about other's approval Social Support (emotional) Prompts or Cues Social Comparison
Lee E et al. 2017	Social support (unspecified) Adding objects to the environment Credible Source Reduce negative emotions Social Support (emotional) Prompts or Cues
Lee H et al. 2017	Problem Solving Social Comparison Adding objects to the environment Non-specific Reward Prompts or Cues
Luckmann et al. 2019 (1)	Prompts or Cues Instruction on how to perform a behaviour Pros/cons
Luckmann et al. 2019 (2)	Incompatible beliefs Problem Solving Prompts or Cues Pros/cons Social Support (unspecified) Adding objects to the environment Instruction on how to perform a behaviour
Marshall et al. 2016	Instruction on how to perform a behaviour Problem Solving Adding objects to the environment Social Support (emotional) Information on antecedents Information about health consequences
Merrick et al. 2015 (1)	Material Incentive Prompts or Cues
Merrick et al. 2015 (2)	Material Incentive Prompts or Cues
Merrick et al. 2015 (3)	Material Incentive Prompts or Cues
Michielutte et al. 2005 (1)	Prompts or Cues Information about health consequences
Michielutte et al. 2005 (2)	Prompts or Cues Information about health consequences Salience of consequences Action planning

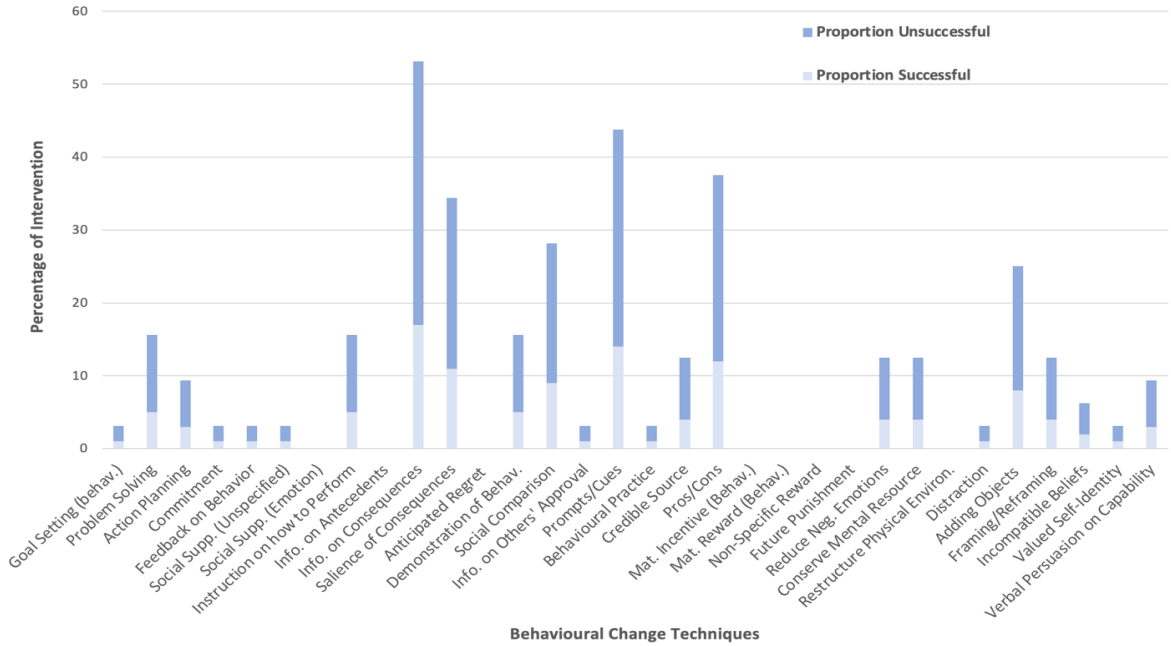
Michielutte et al. 2005 (3)	Prompts or Cues Information about health consequences Salience of consequences Action planning Problem Solving
Mishra et al. 2007	Information about health consequences Social Support (unspecified) goal setting (behaviour) Demonstration of the behaviour Instruction on how to perform a behaviour Action planning Salience of consequences Behavioural practice/rehearsal
Moskowitz et al. 2007	Instruction on how to perform a behaviour Material Reward Material Incentive Information about health consequences Adding objects to the environment Social Support (unspecified)
Nanda et al. 2020	Prompts or Cues Instruction on how to perform a behaviour Conserving mental resources
Nguyen et al. 2009	Future Punishment Vicarious Consequences Instruction on how to perform a behaviour Pros/Cons Conserving mental resources Information about health consequences Adding objects to the environment
Page et al. 2006 (1)	Prompts or Cues
Page et al. 2006 (2)	Prompts or Cues
Paskett et al. 2006	Information about health consequences Salience of consequences Problem Solving Instruction on how to perform a behaviour Prompts or Cues
Phillips et al. 2010	Prompts or Cues Problem Solving Instruction on how to perform a behaviour Adding objects to the environment
Puschel et al. 2010 (1)	Credible Source Instruction on how to perform a behaviour Prompts or Cues
Puschel et al. 2010 (2)	Credible Source Instruction on how to perform a behaviour Prompts or Cues Framing/Reframing Reduce negative emotions
Russell et al. 2010	Adding objects to the environment Restructuring the Physical Environment Instruction on how to perform a behaviour Verbal persuasion about capability Problem Solving Prompts or Cues Credible Source Information about health consequences Demonstration of the behaviour Social Support (unspecified)

Sadler et al. 2011	Credible source Verbal persuasion about capability Social Comparison Prompts or Cues Adding objects to the environment Demonstration of the behaviour Information about health consequences
Schapira et al. 2019	Salience of consequences Conserving mental resources Information about health consequences
Secginli et al. 2011	Instruction on how to perform a behaviour Action planning Adding objects to the environment Information about health consequences Problem Solving Pros/cons Prompts or Cues
Slater et al. 2017 (1)	Prompts or Cues Problem Solving Anticipated Regret Action planning
Slater et al. 2017 (2)	Prompts or Cues Problem Solving Anticipated Regret Material Incentive Material Reward
Tuzcu et al. 2016	Prompts or Cues Demonstration of the behaviour Instruction on how to perform a behaviour Information about health consequences Pros/cons Problem Solving
Vernon et al. 2008 (1)	Prompts or Cues Pros/cons Conserving mental resources Information about health consequences Salience of consequences Social Comparison Adding objects to the environment
Vernon et al. 2008 (2)	Prompts or Cues Pros/cons Conserving mental resources Information about health consequences Salience of consequences Social Comparison Adding objects to the environment framing/Reframing Problem Solving Reduce negative emotions Feedback on Behaviour
Vidal et al. 2014	Prompts or Cues Restructuring the Physical Environment
Wang et al 2012 (1)	Information about health consequences Adding objects to the environment Social Comparison
Wang et al 2012 (2)	Information about health consequences Social Comparison Salience of consequences

	Framing/Reframing
	Adding objects to the environment
Wu TY et al. 2015	Verbal persuasion about capability
	Problem Solving
	Prompts or Cues
	Pros/cons

(1) refers to the first intervention described in a study with multiple interventions or multi-staged interventions

Appendix 2-3 Proportions of successful and unsuccessful interventions using BCT in studies with a low-risk of bias only.



Behav.- Behaviour, Info.- Information, Mat.- Material, Neg. – Negative, Supp.- Support

Appendix 3-1 Search strategy for Medline database

Search Number	Terms	Articles
1.	(antenatal screening[MeSH Terms]) OR (cancer screening[MeSH Terms])) OR (cancer screening test[MeSH Terms])) OR (mass screening[MeSH Terms]) OR (screen[MeSH Terms]) OR (population screen*)	245,668
2.	(papanicolaou test[MeSH Terms]) OR (papanicolaou smear[MeSH Terms]) OR (cervical smear[MeSH Terms]) OR (vaginal smear[MeSH Terms]) OR (pap* smear) OR (smear test*)) OR (cervical cancer screen*) OR (cervical screen*) (pap* test)) OR (smear test*)	26,924
3.	(mammographies[MeSH Terms]) OR (mammography[MeSH Terms]) OR (breast cancer screening) OR (x ray screening)) OR (mamm*) OR (breast screen*)	37,531
4.	(procedures, sigmoidoscopic surgical[MeSH Terms]) OR (bowel cancer screen*)) OR (bowel screen*) OR (colorectal cancer screen*) OR (colorectal screen*) OR (f?ecal occult blood test) OR (f?ecal immunochemical test) OR (f?ecal immuno-chemical test) OR (sigmoidoscop*) OR (colonoscop*) OR (flexisigmoidoscopy)) OR (bowel scope)) OR (colo-rectal cancer screen*)) OR (colo-rectal screen*)	71,430
5.	(neonatal screening[MeSH Terms]) OR (prenatal screening[MeSH Terms])) OR ((neonat* or newborn or pregnan* or prenatal or antenatal or pr nata on ante natal or fetal or fetal or fetus or foetus) OR (newborn and infant physical exam* OR NIE OR (newborn blood spot) OR neonatal blood spot) OR (f?etal abnormality test*)) OR (f?etal abnormality screening) OR (ultrasound screen*)) OR (ultrasound assess*)) OR (structural survey)) OR (chorionic vill* sampl*)) OR (amnio*) OR (nuchal translucency) OR (ultra-son*)	22,774
6.	("diabetic retinopathy/diagnosis"[MeSH Terms]) OR (diabet* eye screen*) (diabet* eye test*) OR (diabet* maculo*) OR (diabet* vision screening)	28,260
7.	((pregnan* or antenatal on ante natal) and (div of human immunodeficiency virus or hepatitis or hepb or hep b or syphilis or sexually transmitted infection* of sexual transmitted disease*) and screening).	205,796
8.	(abdominal aortic aneurysm[MeSH Terms]) OR (AAA)) OR (aneurysm screen*)) OR (aortic screen*) OR (aortic aneurysm screening)	31,441
9.	1-8	1,296,928
10.	(messaging, text[MeSH Terms]) OR (mobile messag*) OR (SMS) OR (healthcare messag*) OR (patient messag*)) OR (mobile communication) OR (cell messag*)OR (cell communication) OR (WhatsApp) OR (MMS) OR (multimedia messaging) OR (bidirectional messaging) OR (bi-directional messaging) OR (App* messag*)	25,503
11.	9+10	832
12.	Limit Date Limit Language	749

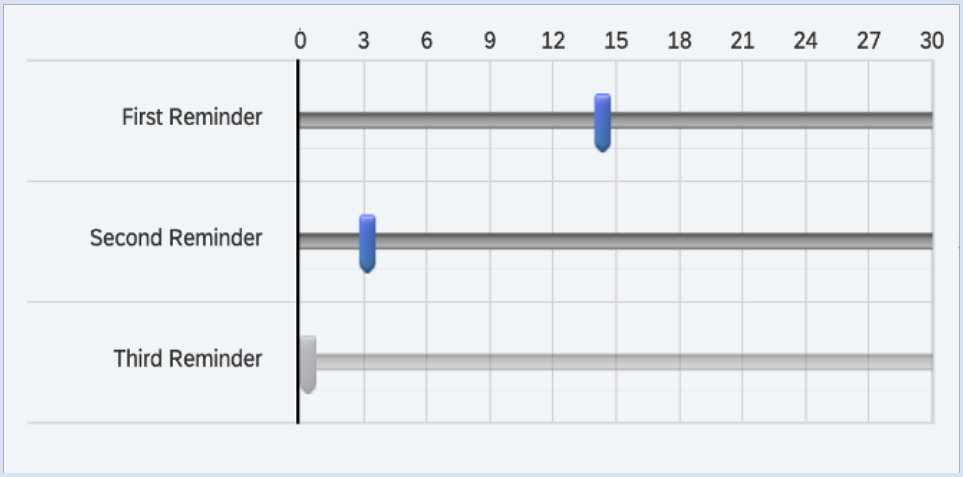
Appendix 3-2 Prompts used to elicit free-text responses in the scoping exercise.

Domain	Prompt
Content	The language used in messages (e.g. style, or availability of non-English translations) Details of the appointment (e.g. time or location) Links or reference to more information (e.g. website URLs) Ways to accept or reschedule the appointment How to consent to messages (e.g. Opt-out) and Coercion Using GP endorsement Using cost information (e.g. cost of missed appointments) Targeted (to particular groups) and Tailored Messaging (to meet an individual's needs) Including messages with Did not attend (DNA) information (e.g. number, frequency, content) Other comments
Timing	Number of messages (1 standard SMS is 160 characters) Timing of messages compared to appointments Time of day of messages Time of week of messages Other comments
Delivery	How to verify participants' mobile numbers Using Bi-directional messaging (where patients can respond back to you) Using multimedia messaging Other comments
Security	Ensuring secure messaging Ensuring confidentiality Response in the event of data breaches Maintaining trust Other comments
Evaluating Messages	How to evaluate service user satisfaction How to evaluate individual service outcomes (e.g. number of messages correctly delivered) How to evaluate regional or national message outcomes How to link message outcomes and uptake Other comments
Research and Future Considerations	How to effectively conduct research in messaging The capacity for screening messaging to support research Implementing new research findings into messages Using emerging/new technologies (e.g. app-based messaging, virtual messaging How to develop and highlight research priorities Other comments
	Other Comments/Areas for consideration

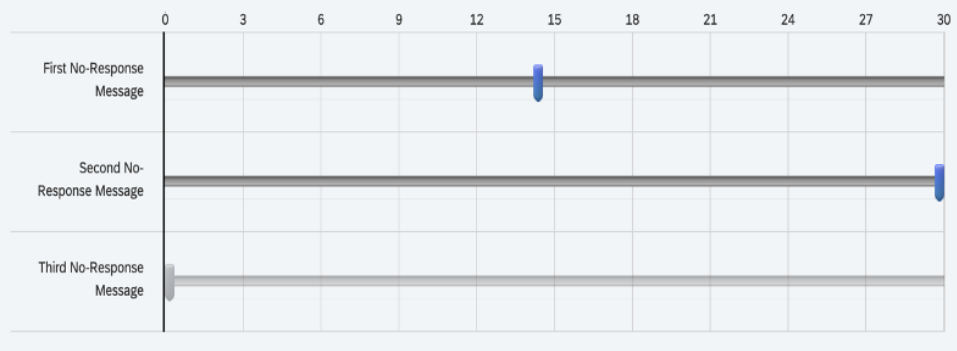
Experts were given free-range to comment on each prompt but suggested that they include their perceptions of the relevance, importance and topicality of the prompt on screening messaging or any evidence that they were aware of relating to the topic.

Appendix 3-3 Initial item list presented in the first consensus round with experts asked to report the importance and feasibility of each based upon a 5-point Likert scale.

Domain	Item
Content	1. Using concise simple language (reading age of nine) 2. Using non-technical language with factual, non-coercive information 3. Using messages two segments long (approx. 320 characters) 4. Enable messages to spread over multiple texts. 4. Sending messages in English, but with language translations available (e.g. via weblink or by previous selection) 5. Specifying the date, time (24h), location and what to bring 6. Specifying who has sent the message (e.g. screening service or GP practice), and purpose 7. Give a detailed purpose of the message 8. Using patient name in reminders 9. Including weblinks to evidence or more information (e.g. screening website) 10. Providing a telephone no. to re-book 11. Providing service addresses in reminder 12. Providing an ability to re-book in the message other than telephone no. (e.g by text or weblink) 13. Integrating message appointments into the MyGP app 14. Including one step opt-out (e.g via a link or text STOP to the number) 15. Where appropriate using GP endorsement in reminder messages (e.g [Practice name] encourages you to screen] 16. Using GP endorsement involving the GP/nurse name in preference to Practice name 17. Using generic endorsement to screen. 18. Using factual national cost information (e.g. missed appointments cost the NHS £X per year) in reminder messages 19. Using service specific/regional cost information (e.g. missed appointments cost your hospital £X per year). 20. Using opportunity cost information (e.g. missing appointments may mean delays in diagnosis) in reminder messages 21. Using limited Did Not Attend Messaging (DNA) messages 22. DNA messages stating the purpose and importance of the scan 23. DNA messaging to encourage to contact service/GP 24. Sending health promotion/improvement messages periodically regarding importance of screening, which could use behavioural science 25. Using messages tailored or targeted at certain groups 26. Enable individuals to determine the style of messaging they receive 27. Use of explicit statement invoking normative behaviour or social norms. 28. To ensure ongoing acceptability of messages to the public, introducing ongoing testing (e.g. online A/B testing, or User-experience trials) 29. Keep a record of the content of messages sent out previously
Timing	30. Sending messages during the working week (Mon-Fri 0900 to 1700) 31. Sending messages during weekends or out-of-hours 32. Send messages at a consistent time of day 33. Allowing preferences of time to be selected (either via website or text reply) 34-36. For reminder messages, it is important and feasible to send messages at the following times (slide the scale along), if is not important keep the slider at 0 days.



37-39. For open invitations (e.g. to book an appointment) or return of kits (e.g. FOBT), it is important and feasible to send messages at the following times when there has been no response. If it is not important keep the slider at 0 days.



40. Using confirmation texts immediately if a booking has been made or a kit has been received
41. Using confirmation texts immediately if an appointment has been attended.
42. Sending messages with status updates regarding results (e.g. results are expected in 2 weeks)
43. Record the timing of messages to facilitate future investigation into optimal schedules.
44. Coordinate timing of messages with those sent for other appointments to avoid happening at the same time

Delivery	45. Avoiding verifying the recipient identity through messages to avoid safeguarding or security issues 46. Enable recipient identity verification through messages 47. Flagging individuals who have opted out or who it might not be appropriate to message (e.g. following a miscarriage). 48. Flag individuals who have not attended previously 49. Ensuring all services are integrated into the GP Spine to enable telephone number verification 50. Enable linking to hospital services to enable telephone number verification 51. Verifying numbers through direct contact with patients where possible 52. Enabling voluntary online verification through screening websites/apps 53. Enable verification through response SMS 54. Enabling limited bi-directional messaging service (e.g. for functions such as booking, confirming locations, organizing translated messages) 55. Enable message-and-response services to be used for screening services 56. Using MEF-registered (official) SenderIDs (e.g [Screeningservice] sent you a message, as oppose [+4478…] sent you a message) 57. If an undeliverable message is received, flag this for verification 58. If a message requiring response (e.g. confirmation) is not answered, re-send messages requesting response.
Security	59. Reducing weblink/URL use- and where possible all should be human readable and easy to remember 60. Avoid including specific appointment details 61. Avoiding including contact details of services, which are better listed from official sources 62. Using bland messaging to avoid risk of breach (no results, patient addresses or personalised information)

	63. Maintaining consistency across media including publishing contact details/links on websites and in letters, so individuals can verify these as legitimate 64. Not allowing messages to be received if IMSI (a phone's ID) is roaming 65. Flag to the service if IMSI (a phone's ID) is roaming 66. Defining a wrong recipient message receipt as a reportable breach 67. Log unsent/undeliverable messages 68. Avoiding shortened URL use in reminders 69. Use of links to non-screening service resources e.g. charities 70. Use of links to screening service resources hosted on 3rd party sites 71. Adding security disclaimers/privacy wording into reminders
Evaluating Messages	72. Measuring user satisfaction by Customer Effort (e.g. on a scale of 'very easy' to 'very difficult', how easy was it to interact with the screening message) 73. Use Net Promoter Scores (e.g. On a scale of 0 to 10, how likely is it that you would recommend this system to a friend or colleague) 74. Measure satisfaction by response to text 75. Measure satisfaction with system-reliability scales. 76. Measuring user satisfaction by opt-out number 77. Measure time to book, where applicable, as a determinant of message effectiveness 78. Use uptake rates as a measure of message effectiveness 79. Incorporating satisfaction measures into existing pathways (e.g. GP practices or NHSP Parent Survey) where possible 80. If no existing pathway is available, periodically assessing usefulness of messages/satisfaction through multiple means (online, telephone and in writing) 81. Use digital one click surveys or links to questionnaires 82. Assessing service outcomes measure SMS delivery success reports and measure responses rates (e.g. in bi-directional messages, or appointment calls) 83. Linking screening datasets to aid evaluation of national impact of messages and effect on healthcare inequalities 84. Examining healthcare inequalities directly through surveys and qualitative tools
Research and Future	85. Using experimental methods such as Randomised Trials to determine national message or novel messages 86. Use online experiments (including A/B testing) to determine national message or novel messages 87. Routinely report the outcomes of trials/research on population inequalities 88. As part of the design of new messages, evidencing Patient and Public Involvement and qualitative measures prior to trialling 89. Mandate that feasibility trials are undertaken prior to trials within screening services 90. Mandate that message-based trials are registered with an appropriate registry 91. Screening services are to be involved directly with research governance procedures 92. Publishing research priorities by screening services/PHE to enable researchers to focus upon relevant areas (this includes non-content related areas) 93. Involving top-down infra-structural and governance support to facilitate research, including enabling trials across services/regions 94. Screening services to facilitate the sharing of outputs from research with service users 95. Screening services to facilitate the sharing of outputs from research with other services 96. Implementing fast-track processes to enable real-world testing for messages with trial evidence 97. Facilitate collaborative funding applications with services for message-based research 98. Examining the use of new technologies such as message app-based integration 99. Examine the use of push notifications 100. Examine the use of bot technology or chat-bot responses 101. Examine use of calendar integration

Appendix 4-1 Search strategy for Medline database

Search Number	Terms	Articles
1.	((ethnicity[MeSH Terms]) OR (disability, intellectual[MeSH Terms])) OR (communication disability[MeSH Terms])) OR (bipolar depression[MeSH Terms])) OR (borderline schizophrenia[MeSH Terms])) OR (catatonic schizophrenia[MeSH Terms])) OR (bipolar affective psychosis[MeSH Terms])) OR (bipolar depression[MeSH Terms])) OR (comorbidity[MeSH Terms])) OR (comorbidities[MeSH Terms])) OR (asian[MeSH Terms])) OR (black[MeSH Terms])) OR (indian[MeSH Terms])) OR (chinese[MeSH Terms])) OR (japanese[MeSH Terms])) OR (african[MeSH Terms])) OR (somalia[MeSH Terms])) OR (pakistani[MeSH Terms])) OR (migrant[MeSH Terms])) OR (immigrants[MeSH Terms]))) OR (black[Title/Abstract])) OR (traveller[Title/Abstract])) OR (gypsy[Title/Abstract])) OR (indian[Title/Abstract])) OR (pakistani[Title/Abstract])) OR (asian[Title/Abstract])) OR (arab[Title/Abstract])) OR (carribean[Title/Abstract])) OR (chinese[Title/Abstract])) OR (japanese[Title/Abstract])) OR (non-white[Title/Abstract])) OR (non-european[Title/Abstract])) OR (minority ethnic[Title/Abstract])) OR (homeless[Title/Abstract])) OR (no fixed abode[Title/Abstract])) OR (physical disability[Title/Abstract])) OR (depression[Title/Abstract])) OR (anxiety[Title/Abstract])) OR (bipolar affective disorder[Title/Abstract])) OR (multi-morbidity[Title/Abstract])) OR (deprivation[Title/Abstract])) OR (deprived[Title/Abstract])) OR (low socioeconomic status[Title/Abstract])) OR (poor[Title/Abstract])) OR (low education[Title/Abstract]) OR (IMD [Title/Abstract]) OR (Index of Multiple Deprivation [Title/Abstract])	2,451,083
2.	((((((breast cancer screening) OR (breast screening)) OR (population screening)) OR (asymptomatic screening)) OR (mammogram)) OR (mammography)) OR (breast screening programme)	782,728
3.	((((((((((((((((((((England) OR (Wales)) OR (Scotland)) OR (Northern Ireland)) OR (United Kingdom)) OR (UK)) OR (National Health Service)) OR (NHS)) OR (Birmingham)) OR (London)) OR (Manchester)) OR (Newcastle)) OR (Leeds)) OR (Nottingham)) OR (Oxford)) OR (Cambridge)) OR (Cardiff)) OR (Edinburgh)) OR (Belfast)) OR (Glasgow)) OR (Aberdeen)) OR (Liverpool)	2,831,614
4.	(((((attendance) OR (uptake)) OR (adherence)) OR (compliance)) OR (invitation)) OR (coverage)	1,293,661
5.	1+2+3+4	3,627
6.	Restrict date	2,755
7.	Restrict English	2,728

Appendix 4-2 Barriers and facilitators to screening amongst minority ethnic groups extracted from included studies.

Study	Study Type	N	Location	Population	Exclusion Criteria	Barrier	Facilitator	Authors' Conclusions
Bamidele et al. 2017	Focus Group	25	Luton	Black African Origin Aged 35 to 70 Conversational English	NS	Fear of consequences of the disease Lack of knowledge about screening Lack of knowledge about cancer/breast health Cancer as a stigma Candidacy Susceptibility Optimism HCP characteristics Appointments Perceived benefits of screening Use of alternatives to screening	Social support Access to culturally appropriate health education Knowledge of screening	There is a need for culturally relevant interventions to improve knowledge of screening and cancer. Black African women's awareness reduces their perceptions of stigma and severe outcomes.
Banning, M. 2011	Semi-Structured Interviews	10	UK	Black Women Aged 27 to 58 Fluent in English	History of breast cancer	Susceptibility Lack of knowledge about cancer/breast health Lack of knowledge about screening Fear of process	Previous experience of screening awareness Access to culturally appropriate health education Knowledge of screening	Black British women require health education focussing upon the risk factors of cancer, technique and screening recommendations.
Banning, M. and Hafeez H. 2010	Focus Group	20	London	Pakistani Origin Muslim Belief Aged 20 to 59 Fluent in English	History of breast cancer	Lack of knowledge about screening Lack of knowledge about cancer/breast health HCP characteristics Lack of social support	Access to culturally appropriate health education Social support	Shyness was not found to be apparent in this group but was less awareness of breast health. Need for

						Susceptibility		culturally relevant health education.
Barter-Godfrey, S. and Taket, A. 2007	Cross-sectional survey	85	South-East London	Minority Ethnic Groups Aged 50 to 64	NS	Communication/Expression Susceptibility Expectation of anxiety Perceived benefits of screening Vulnerability Low priority+ Low salience of breast cancer+ Fear of process+ Appointments+	Personal health+ Perceived benefits of screening+ Anticipated regret+ HCP endorsement+ Personal risk factor+ Family history+	The most important factor was whether there was a positive attitude towards screening (impacted on by factors such as anticipated regret). There is a strong emotional component to decision making.
Condon et al. 2021	Focus group /Interviews	41	Wales and South-West England	Roma, Gypsies and Travellers	NS	Fear of consequences of the disease Transnational health use Communication/Expression Fear of process Lack of knowledge about screening Vulnerability	Family history	Screening behaviours differed between Roma and Traveller groups. Screening contravened modesty ideals among Travellers
Gorman, D.R. and Porteous L.A. 2018	Interviews	11	Lothian, Scotland	Polish Migrants Aged 50 to 70	NS	Lack of knowledge about screening Communication/Expression Physical Access Transnational healthcare use Appointments Optimism Superstition Fear of process Susceptibility		Polish women had difficulty accessing screening in Scotland, and often use multiple health systems. Language issues and misunderstanding about screening are also key barriers.
Karbani et al. 2011	Interviews	24	West Yorkshire	South Asian Previous Breast Cancer Aged 39 to 70	NS	Lack of knowledge about screening Communication/Expression Lack of knowledge about cancer/breast health Cancer as a stigma	Social Support Spirituality	Poor knowledge remains an important feature of South Asian communities, but this is variable in

						Superstition Fear of consequences of the disease Lack of social support		the literature. Explanations are culturally influenced.
Manthorpe et al. 2008	Interviews	18	London	Minority Ethnic Groups Aged >53	NS	Communication/Expression Lack of knowledge about screening+ Fear of process+ Previous negative experience+ HCP characteristics + Fear of consequences of the disease +	Social support Personal risk factor+ Family history+	The main factors noted across the population included previous experience, knowledge and general attitudes to breast health.
Shang et al. 2015	Interviews	22	Manchester /Liverpool	Chinese Aged 50 to 70	History of breast cancer	Fear of consequences of the disease Cancer as a stigma Communication/Expression Physical Access Fatalism Lack of knowledge about cancer/breast health Susceptibility Perceived benefits of screening	Convenience/Appointments Access to culturally appropriate health education	Distinctive social and cultural context influences attendance. Most agreed cancer was curable but traditional views persist including fears on the consequences.
Thomas et al. 2005	Focus group /interviews	135	Harrow /Brent	Minority ethnic Aged 20 to 75		Low salience of breast cancer Lack of knowledge about screening Superstition Cancer as a stigma Communication/Expression Susceptibility Fear of process Vulnerability HCP characteristics Perceived benefits of screening Previous negative experience	Access to culturally appropriate health education HCP endorsement Social Support Mobile units/Access HCP characteristics	Screening attendance is compounded by cultural factors. Important barriers included health Beliefs, communication issues and HCP attitudes

					Lack of knowledge about cancer/breast health Candidacy		
Woof et al. 2020	Interviews	19	East Lancashire	Pakistan-born Aged over 47 Area of high deprivation	Communication/Expression Fear of consequences Fear of process Lack of knowledge about screening Vulnerability Perceived benefits of screening Susceptibility	Access to culturally appropriate health education Social Support HCP characteristics	Language barriers were problematic including compromising confidentiality. Lack of knowledge on the purpose of screening and modesty issues were noted.

[+] *Determinant reported in a wider study population which was not discernible from the underserved subgroup. HCP- Healthcare professional*

Appendix 4-3 Barriers and facilitators to screening amongst those living with multiple illnesses or disability extracted from included studies.

Study	Study Type	N	Location	Population	Exclusion Criteria	Barrier	Facilitator	Authors' Conclusions
Bates, C. and Triantafyllopoulou, P. 2018	Survey	131	England and Wales	Intellectual disability Aged 50 to 70	Ineligible for screening	Decision making and processing Fear of process Physical access Communication/Expression Previous negative experience		Lack of capacity is a barrier to breast screening, with decision-making involving social care staff.
Clifton et al. 2016	Semi-structured Interviews	14	London and Dorset	Self-reported mental health illness Eligible for cancer screening	NS	Lack of knowledge about screening Decision making and processing Health reducing attendance/volition Previous negative experience Vulnerability Fear of process Fear of consequences of the disease HCP characteristics Appointments Physical Access Memory Feeling a burden	Motivation Perceived benefits of screening HCP endorsement Prompts Good relationship with HCP Personal health	Mental health service users face barriers including knowledge of screening, attitudes regarding mental illness, health service delivery, service users concerns and practicalities.
Shah et al. 2021	Interviews	6	UK	Physical impairments from cerebral palsy Aged over 50 years	NS	Physical Access HCP characteristics Previous negative experience Fear of process	Previous positive experience Mobile units/Access Convenience/Appointments	Physical and environmental barriers contributed to the low uptake of screening as did a lack of HCP knowledge.
	Focus groups	19	Northern Ireland	Intellectual disability	NS	Lack of knowledge about cancer/breast health	Previous positive experience	Knowledge of breast awareness

Truesdale-Kennedy et al. 2011				Aged over 31 Invited to breast screening in the last year		Lack of knowledge about screening Low salience of breast cancer Fear of process Vulnerability Fear of consequences of the disease	HCP endorsement Access to culturally appropriate health education	and cancer within people with intellectual disability is limited. Findings highlight the lack of accessible information for this group.
Willis, D. 2016	Semi-Structured Interviews/ Focus Observation	12	Lothian	Intellectual disability Aged over 45	NS	Memory Health reducing attendance/volition Previous negative experience Fear of process Vulnerability Lack of social support	Social support Obligation (including feeling one has to go) HCP endorsement	There appeared to be barriers in access and how the conduct of the screening service impacted the experience.

[+] *Determinant reported in a wider study population which was not discernible from the underserved subgroup. HCP- Healthcare professional*

Appendix 4-4 Barriers and facilitators to screening amongst those from areas of high deprivation extracted from included studies.

Study	Study Type	N	Location	Population	Exclusion Criteria	Barrier	Facilitator	Authors' Conclusions
Millar et al. 2012	Focus Group	11	Scotland	Low-Income	NS	Fear of consequences of the disease Fear of process Appointments Physical Access Low priority Memory Health reducing attendance/volition Expectation of anxiety	Social Support Prompts Mobile units/Access Family history Access to culturally appropriate health education	Barriers mirrored those from other research including anxiety about the process, life issues and access.
Suphi et al. 2020	Semi-Structured Interviews	36	Glasgow, Lanarkshire, Lothian, Fife	Living in deprived areas (Aged 50-54) Living rural deprived areas (Aged 50 to 70) Living in deprived areas with a disability (Aged 50 to 70)	Not received first invitation, Said will never attend, history of breast cancer	Lack of knowledge about screening Susceptibility Use of alternatives to screening Fear of process Vulnerability Fear of consequences of the disease Low salience of breast cancer Lack of social support Appointments Physical Access Low priority Previous negative experience	Family history Mobile units/Access Social Support	Screening relevance was low due to perceived susceptibility. Attitudinal differences distinguish the needs of the sample, with psychological barriers present amongst the most fearful. Practical barriers affected those who were more open to screening.

[+] *Determinant reported in a wider study population which was not discernible from the underserved subgroup. HCP- Healthcare professional*

Appendix 5-1 Finalised storyboard for the animation

Storyboard

Breast cancer screening intervention

Inclusively Imperial College London

Character Overview

Dr. Rashid
NHS Breast Cancer Consultant

Faith
Story 1

Inclusively Imperial College London

Aleema
Story 2

Character Overview

Inclusively Imperial College London

Martha
Story 3

Devi
Story 4

Introduction, scene setting and facts

Inclusively Imperial College London

NHS What to expect from your breast screening

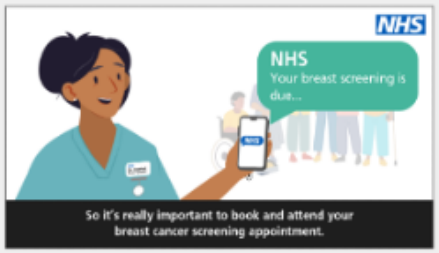
Voice over:

Description of animation:
Open with NHS Logo, and text on screen

Voice over:
Hello! I'm Dr Rashid, I'm an NHS breast cancer consultant

Description of animation:
The logo fades to introduce Dr Sabina Rashid. She is a Consultant Breast Surgeon. She is in her late 30s and dressed in scrubs. Her name badge reads 'breast technician'

Voice over:
Breast cancer is the most common type of cancer in the UK. Anyone from any background can be affected. Cancer is when abnormal cells in our body grow uncontrollably, and sometimes spread. Because cancers can be small or deep inside, you may not feel a lump or notice anything, but you may still have cancer. Breast screening helps us find it early, making it more likely that you recover fully. Breast screening saves 1,300 lives a year.



Voice over:
So it's really important to book and attend your breast cancer screening appointment.

Description of animation:
Dr. Rashid lifts up a mobile phone with NHS logo SMS as a visual cue

Faith's story

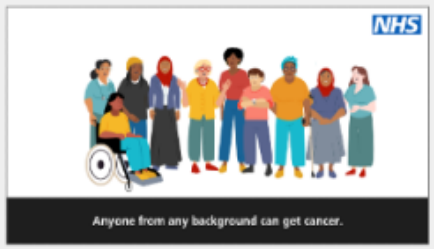
Inclusively Imperial College London

Voice over:
I have lots of medical problems and appointments and sometimes it's hard to find the energy to deal with them all. And, of course, it's a little scary to think about finding something but I know early detection can make all the difference.

Description of animation:
Frame sits on Faith as she explains her story

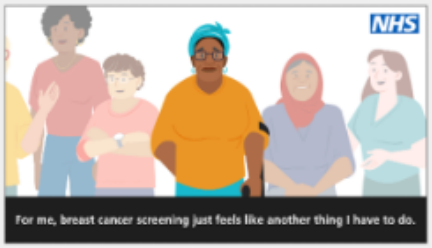
Voice over:
I've been to lots of breast screening appointments now, and know what to expect. Each time has been a little different. Although it's a bit uncomfortable, I go because it's better to know.

Description of animation:
Show Faith arriving at a hospital unit and introduced to a room by a nurse



Voice over:
Anyone from any background can get cancer.

Description of animation:
Dr. Rashid fades to become one of a group of people of various diversities. The five characters we're going to tell the story of come together or are made more prominent. Then they all fade away to show Faith.
This text is said by the group all together (not Dr Rashid).



Voice over:
For me, breast cancer screening just feels like another thing I have to do.

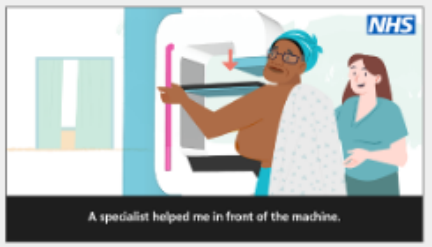
Description of animation:
Still of Faith.

What happens at your breast screening (1)

Inclusively Imperial College London

Voice over:
At the screening centre, they checked my details then I was led to the scanning room. I went behind a curtain to undress my top half. The technician needs this to get proper scans. I asked for a gown so I could cover myself.

Description of animation:
Show technician directing [Faith] to changing area. Show [Faith's] hand picking up hospital gown. Cut to [Faith] emerging from changing area.



Voice over:
A technician helped position me in front of the machine.

Description of animation:
visualise a technician leading the person to the machine and positioning the person to carry the screening out properly. We want to make these frame make it feel that it's not just a technical experience
(See image 1 in Mural)

What happens at your breast screening (2)

Inclusively Imperial College London

Voice over:
It was a bit uncomfortable...

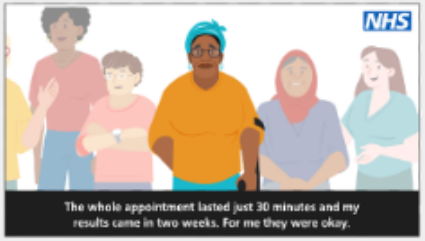
Description of animation:
Demonstrate the procedure without squeezing the breast (See image 2 in Mural). Breasts are placed onto the X-ray machine and squeezed between 2 pieces of plastic. Patients need to stay still while the X-rays are taken. It only takes a few seconds.

Voice over:
...but it went quickly.

Description of animation:
The machine tilts to one side so they can take an X-ray of the side of the breast.

Faith's story to Martha

Inclusively Imperial College London



Voice over:
The whole appointment lasted just 30 minutes and my results came in two weeks. For me they were okay.

Description of animation:
Faith explains this then fades back into the group of 5 people.

The group fades back and Martha transitions forward.

Voice over:
I avoided having my mammogram for ages as I was so worried about cancer.

Description of animation:
Fades out and Martha fades in. Martha is a white woman in her 50s who has hearing aids.

Martha's story

Inclusively Imperial College London

Voice over:
You see, my husband passed away from cancer, and I was afraid the scan might show something. I worried how it would affect my family.

Description of animation:
The frame keeps focused on Martha and her daughter appears and they link arms in comfort and solidarity as Martha explains their circumstance

Voice over:
When I got the text, I told my daughter about it. She said she would come with me.

Description of animation:
The frame pulls out to show a mobile phone and the SMS.

Martha's story

Inclusively Imperial College London

Voice over:
Having her bring me to my appointment made me feel less nervous, and made talking to the team easier.

Description of animation:
The frame shows Martha and her daughter waiting outside a mobile unit for her screening appointment. The technician comes to the door and says something. The daughter responds and signs to Martha: "It's your turn. I'm here to support you". Fade out (don't show them entering the unit).

Voice over:
My results showed that I had cancer, but thanks to screening they found and treated it early, and I've now got the all clear. Finding it early also meant the treatment was more manageable. If I hadn't gone to screening, it may have been a different story.

Description of animation:
Pan back to Martha in the forefront with her daughter

Aleema's story

Inclusively Imperial College London

Voice over:
I didn't think I needed breast screening. I don't know anyone who has had breast cancer. I was also worried about being undressed in front of people.

Description of animation:
Still shot of Aleema +/- with her friend

Voice over:
I spoke to my friend, who showed me a leaflet of what happens. I learned that the screening staff are women and that it's best to wear a separate top and skirt to make it easier to stay covered up.

Description of animation:
Show Aleema talking to a friend (pamphlets in the background - friend not giving her a translated pamphlet)

End of Aleema's story and start of Devi's story

Inclusively Imperial College London

Voice over:
I got a letter inviting me to breast cancer screening.

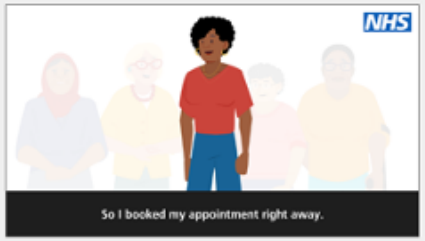
Description of animation:
Aleema fades out to Devi.Show Devi at home receiving a letter

Voice over:
My GP explained that all transgender and non-binary people registered with a GP as female are invited to breast screening. I didn't know, but because I'm on hormones my risk of breast cancer might be higher.

Description of animation:
Show Devi on the phone to her GP.

Devi's story

Inclusively Imperial College London



Voice over:
So I booked my appointment right away.

Description of animation:
Show Devi on the phone. Start moving back to the group.

Voice over:
Although we have different stories, it's important for us all to attend breast cancer screening.

Description of animation:
The animation pans back to Dr. Rashid who runs through the final messaging.

Close and call to action

Inclusively Imperial College London

Voice over:
Finding breast cancer early makes it more treatable.

If you've been invited to book, do it now. If you have an appointment booked already, it's important to attend. You can always change it if it's not convenient. The number is in your letter or SMS. It's time to put your health first.

Voice over:
NA

Description of animation:

NHS logo and where to find out more information. Call the London Breast Cancer Screening Hub at 020 3758 2024 or visit /www.london-breastscreening.org.uk/

Appendix 6-1 Video feedback questionnaire

Demographics

Q1 Consent

Q2 How old are you?
- 50 to 55
- 56 to 60
- 61 to 65
- 66 to 70
- Prefer not to say

Q3 Which best describes your ethnic background?
- Arab
- Asian or Asian British
- Black, African, Caribbean, or Black British
- Mixed or Multiple Ethnicity
- White
- Any other ethnic group
- Prefer not to say

Q4 If any other ethnic group, please specify.

Q5 Have you been invited to attended breast screening in the past?
- Yes
- No
- Prefer not to say

Q6 How often have you attended breast cancer screening in the past?
- Never attended
- Sometimes attended
- Always attended

Rating Section

	Scale										
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
How much did you learn about breast cancer/breast cancer screening from watching the video?	No information was new					Some of the information was new					All the information was new
How relatable did you feel the breast cancer screening stories were?	Extremely Unrelatable					Neither relatable nor not					Extremely relatable
What were your thoughts regarding attending breast cancer screening BEFORE watching the video?	Not planning to go					Undecided					Definitely planning to go
Has the video changed your opinion on attending breast cancer screening?	Made me a lot less likely to go					No change					Made me a lot more likely to go
How likely are you to recommend the video to a friend, family member or colleague?	Not at all likely					Neutral					Extremely likely

Q12 Which story did you feel was the most influential on you?

Q13 If you have any further comments about the video, including suggested improvements, please write them below.