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# The UK NHS cervical screening information leaflet: discourse, purpose and potential for change

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## ABSTRACT

**Background:** Cervical cancer screening prevents unnecessary deaths, yet rates of attendance have been dropping in the United Kingdom. Leaflets communicate screening information in invites to everyone eligible to attend. However, these information leaflets are known to be hard to understand and inaccessible. **Aim:** To understand how cervical screening is constructed in information leaflets and how this might impact engagement with screening programmes. **Method:** Discourse analysis of the current UK information leaflet, and a version redesigned with a public and patient involvement group. **Result:** The current leaflet uses discourses of neutrality and patient autonomy, with design akin to scientific texts. The redesigned leaflet presents a simplified, step-by-step guide to screening that aims to motivate and persuade readers. **Discussion:** The current information leaflet positions intended audiences as rational agents who have responsibility to make a choice to attend screening based on scientific information. The public's redesign positions the state as responsible for simplifying and convincing people to attend screening. The disjuncture may be due to different underlying ideologies – neoliberalism versus 'welfarism'. **Conclusion:** Shifting the current discourse to simplified and clearer language which emphasises choice in the process could help people make an informed decision to engage in screening.

## KEYWORDS

Discourse, gynae cancer, human papilloma virus, prevention

## BIOGRAPHY

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## Introduction

There were around 604,000 new cases of cervical cancer globally in 2020 (World Health Organisation, 2023) and there are around 3,200 new cases of cervical cancer in the UK every year (Cancer Research UK, n.d.). Cervical screening programmes can catch early abnormal changes in the cervix that lead to cancer. Removal of these abnormal cells prevents people developing, and potentially dying from, cancer (WHO, 2023). The UK, like many wealthier western countries, has a relatively high uptake of screening (WHO, 2023). Women<sup>1</sup> are invited every 3 years between the ages of 25-49, and every 5 years between 50-64. In recent years there has been a reduction in the amount of people attending their screening (NHS England, 2023a), and despite the overall high uptake of screening, inequities are apparent in screening, with ethnic minorities and those that are most deprived less likely to attend (Office for Health Improvements and Disparities, 2020).

This article unpicks how risk, human papillomavirus (HPV) and cervical screening are constructed in public health communication in the UK, by focusing on the information leaflet that is sent to all eligible to attend. The information leaflet may be the first explanation of cervical cancer screening a person encounters and could be a tool to overcome some myths and barriers to attendance. Here, a discursive analysis of the current information leaflet is presented, along with an analysis of a re-design of the leaflet. This re-design was developed through commentary of a patient and public involvement group.

## Literature review

Health screening programmes are offered to the whole, or a sub section, of a population. Despite their population focus, they are directed at individuals, which has led to debates on the ethics of screening healthy individuals as this can lead to overdiagnosis (de Koning, 2000). Overdiagnosis is when a cancer diagnosis is given after screening, which would not have otherwise been made in the patient's lifetime (Davies et al., 2018). There is some evidence that suggests there may instances of overdiagnosis in cervical cancer treatment (Hamashima et al., 2018), and some would argue that HPV cervical screening is not appropriate due to overdiagnosis risk (Malila et al., 2012).

Information provided in invitations to cervical screening tends to include an explanation of overdiagnosis (Public Health England, 2021), reflecting shifts in healthcare communication that emphasises patient autonomy over screening, in contrast to the typical paternalistic discourse in healthcare (Dahlborg et al., 2021). Although this information attempts to provide a balanced overview for people to make informed decisions on screening, public health campaigns attempt to persuade attendance at screening. Reviews of persuasion methods used in public health campaigns, such as nudging, recommend that public health bodies should seek to be transparent about wanting people to go for screening, or not offer it at all (Hofmann & Stanak, 2018). Equally, despite the emphasis on balanced information, providing people a leaflet about screening, and the offer of a screening programme, are a form of an educative nudge for people to attend (Busch et al., 2021).

Despite the controversy around population screening programmes, public health discourse for cervical screening focuses on the need for it. This is particularly prevalent in the UK, where most recently it was described as problematic that 3 in 10 people invited do not attend a screening (NHS England, 2023b). Previous research has examined barriers to cervical screening. A lack of knowledge and negative perceptions of the test are key barriers for younger populations (Kirubarajan et al., 2021). Pain (or anticipated pain); fear of the unknown; body image concerns; along with concerns of who (e.g. male staff) perform the screen were barriers found by Wilding et al. (2020) in an online survey of women in the UK (34% of whom were overdue or had never been to screening). Whilst many studies have highlighted more systemic issues with cervical screening provision (Kirubarajan et al., 2021; Wilding et al., 2020; Wearn & Shepherd, 2022), some barriers to attendance relate to myths and expectations of what might happen during cervical screening, particularly in younger populations (Kirubarajan, 2021).

The main method used by the UK National Health Service (NHS) to communicate with those eligible for cervical cancer screening is through an information leaflet. Okan et al. (2019) and Charlton and Rodrigues (2024) have previously investigated how it is experienced. Both studies highlight that the information leaflet is confusing and easily misinterpreted, particularly concerning benefits, risks and what the results might be (Okan et al., 2019). Both studies also highlighted that difficulties with the leaflet are experienced more by those from ethnic minorities, with lower numeracy levels, and in Okan et al., (2019) lower education levels.

The lack of accessibility in information relating to cancer has been linked to widening inequalities for women. A recent Lancet commission argued that the inaccessibility of information perpetuates patriarchal power structures (Ginsburg et al., 2023). The dominant bio-medical model of healthcare proposes that if women only understood their risk, they would attend screening. In the UK, the NHS provides comprehensive and free of charge healthcare (Department of Health and Social Care, 2023). The NHS was born of a post-World War Two political ideology of 'welfarism' and a collective state and individual responsibility for health, with the state providing expertise and making decisions for patients (Dahlborg et al., 2021). More recently NHS health provision reflects neoliberal political ideology and what has been termed a 'new public management' discourse where the patient is able to make choices in a healthcare 'market' (Dahlborg et al., 2021).

Information leaflets are likely to reflect these political discourses, which may influence how people engage with cervical screening programmes. Previous examinations of information provided to patients for other healthcare problems have highlighted that although healthcare delivery aims to be person-centred, emphasising choice and autonomy (likely influenced by neoliberal marketized ideology), paternalism is still prevalent in the way that patients are constructed (Öresland et al., 2015; Ottesen & Strunck, 2023). The notions transmitted in official documentation will likely impact how healthcare professionals and patients engage with each other and act.

An additional element to cervical cancer and screening is the discussion of human papillomavirus (HPV). HPV is a precursor to developing cervical cancer (Franco et al., 2003). Since 2016 the NHS cervical screening programme first screens samples for HPV, before checking for abnormal cells (Department for Health and Social Care, 2016). This means that people are being told about HPV in the screening information leaflets. This was highlighted by

Okan et al. (2019) as an area of confusion, with participants often not previously knowing anything about HPV and the associated risks. The change to HPV becoming part of the screening, also means that people are being told in their results if they have HPV. People may not understand what HPV is due to the inaccessibility of the information leaflet. As HPV is transmitted via skin-to-skin contact (oral or genital), there is stigma associated to a diagnosis (Shepherd & Gerend, 2014) and this may cause distress.

A previous edition of the UK cervical screening information leaflet has been discursively analysed by Armstrong (2007). Their analysis highlighted that the discursive strategies in the leaflet present information as undisputed facts to readers and portrayed the screening as a simple and quick test. Armstrong (2007) contrasted this with how women talk about their emotional and physical experiences of screening, which can work to resist the official discourse. The information leaflet issued by the UK NHS has since changed, and despite Armstrong (2007) analysing the discourse of the original leaflet, there has been little research on the new leaflet.

The aim of the current study was to examine the current information leaflet given to people eligible for screening and analyse how information is constructed about risk, cervical screening and HPV. As Okan et al. (2019) highlighted that the benefits and risks of screening and HPV were poorly understood, we were keen to focus on these areas. A public and patient involvement and experience (PPIE) group recently redesigned the current information leaflet. This was also analysed to understand the differences in how risk, cervical screening and HPV were constructed, and what the implication of this might be.

## Methods

There were two stages to the study: first the redesign of the original leaflet (cf. Public Health England, 2021), which I have described below. The focus of the paper however is not on the process of the redesign, but an analysis of the redesign. In the second stage, the current information leaflet and the redesigned information leaflet were analysed using Willig's (2022) stages for discourse analysis.

### Redesign with patient and public involvement and engagement group

A newly established patient and public involvement and engagement (PPIE) group were recruited by the author via People in Research website, sent the current information leaflet, and asked to attend a meeting to discuss how the document could be changed. The current information leaflet is sent with an invitation leaflet to everyone eligible for cervical screening, every time they are invited (every 3 years (ages 25-49), or 5 years (ages 50-64); Public Health England, 2021). The group (who all identified as women) were purposively selected to be diverse, in terms of age, UK geographic location, and ethnic background (4 White British, 1 Black British, 1 Vietnamese British, 2 South Asian British). Some members also had lived experience of neurodiversity and mental health problems. They were asked to consent to take part in, what we called, a 'co-design' meeting<sup>2</sup>. After the meeting, the main points of the PPIE group were used to form a re-design of the information leaflet. Ethics approval was sought

from the UWE FREC (HAS.23.03.094). The main points that informed the leaflet redesign are shown in Table 1.

**Table 1.** Key ideas from the PPIE group for changes to the information leaflet.

Point	Idea - Points highlighted for change during the PPIE meeting
1	The visualised ratio of risks to benefits- remarkably risk heavy
2	Length of the document – too long won't be read, with personally irrelevant information.
3	Information people care about (what happens at the screening) should be the first thing in the leaflet.
4	Key persuasive messages to be made bold and obvious.
5	Confusing, inaccessible language throughout the leaflet
6	Animations and VLOGS, particularly for ethnic minorities can help model behaviour and normalise attending screening.
7	The explanations relating to risk and HPV were unclear, and HPV needs normalising due to stigma.
8	Importance of explaining choice in terms of the screening process (e.g. to stop at any time) and that companions, different sizes of speculum and so on are possible.
9	Lack of clarity on regularity of testing, wording suggesting that once this test is done there will be no repeat testing in the future.
10	A lot of repetition of information throughout the leaflet.
11	Starting simple and signposting people to further information is needed.
12	Needs more visual aides to help the leaflets readability – e.g. flow charts.
13	Needs frequently asked questions or myths section to address common concerns.

## Willig's (2022) Discourse Analysis

Willig's (2022) discourse analysis steps were applied to both the current information leaflet and the redesigned version of the leaflet. This approach is heavily informed by Foucauldian Discourse Analysis, with an understanding that dominant discourses available privilege certain versions of reality that reinforce structures of power associated to them. In health communication research, this can be used to understand for example the roles of different actors in healthcare, and who is responsible for 'good' healthcare behaviour. Willig's (2022) steps were followed. First discursive constructions of risk, cervical screening and HPV were identified; these were then examined for how they were situated within wider discourses (stage 2); the context of when these discourses were deployed (e.g. within this type of leaflet, what action does it have, stage 3); what type of agency the subject positions have (stage 4), how does this limit what can be said or done (e.g. in terms of who and when screening is appropriate, stage 5); and how, once discursively positioned as such, women may think and feel about cervical screening, HPV and risk (stage 6). For the purposes of answering the research question, analysis focused on how cervical screening, risk and HPV were constructed, what subject positions were afforded by these discourses and their implications for agency (stage 4).

## Reflexive statement

Following quality guidelines in qualitative research (Elliot et al., 1999) it is important to recognise my perspective, and its role in the research – here it is relevant to highlight that I was likely sensitised to elements during analysis that may impact on people's uptake of cervical screening. I am passionate about the role of cervical screening, particularly as a close

friend survived a gynae-cancer. Equally, as the facilitator of the PPIE group meetings, and the person who implemented the redesign, I may lack sensitivity to other understandings of the redesign that could be relevant to this analysis, for example how it may position readers' agency.

## Results

Here, the results of analysing both information sheets will be discussed, with a focus on how screening, risk and HPV are constructed, and the implications of the ways that the author of the leaflet and reader are positioned as a result of these constructions. The analysis of the NHS leaflet is presented first, followed by the analysis of the redesign.

The detailed analysis is presented here, to give space for examples from the leaflets. The discourses identified are then described in the discussion section and integrated with wider literature.

### The NHS information leaflet

Screening in the leaflet is constructed as a short ("1 to 2 minutes", page 4) unthreatening scientific procedure for women of a certain age to consider as a preventative offer. For example, speculums are used to "gently open" the vagina, with a "small soft brush" used to take samples (page 4), emphasising the non-threatening nature of the procedure. Readers' choice to have screening is highlighted throughout, starting with the first two sentences of the information sheet present screening as a "choice" that is down to the individual to "decide" on:

It is your choice whether to have a cervical screening test or not. This guidance aims to help you decide. (lines 1 and 2, page 1).

HPV is constructed as something common, pernicious, and causal of cervical cancer. For example, HPV is positioned as potentially being "at very low and undetectable levels" in the body, which can be had and dispelled by the body "without you ever knowing you have it" (page 2). As such, the reader should anticipate that they may have HPV. At the same time, HPV is positioned as something that can cause cells to become "abnormal", which can "develop into cancer" (page 2). So, despite being common, it is also deadly.

Risk is constructed as linked to both screening and HPV, and is something that is both fixed and predetermined, but under the readers' control. For example, on page 3, engaging with screening is proposed as a way of understanding if you have HPV. Understanding if you have HPV allows the reader to determine their risk of getting cancer.

If you have a negative result for the most common types of HPV that cause cervical cancer, your risk of cancer is very low (page 6).

Risks are constructed as contrastive to benefits, sometimes to quite stark visual effects. For example, on page 7, the leaflet presents the risks and benefits of cervical screening, 'to help [people] decide' on their 'choice' (line 1). First, described in two short sentences under the header of "possible benefits" is the prevention of cancer. Next over 11 lines of text, taking up just under half a page, "possible risks" are discussed. As the leaflet states, these risks do not

actually relate to screening, but to the colposcopy that would be offered if abnormal cells are identified. Risk is implied throughout the leaflet, positioning it as something that is relevant to most aspects of cervical screening.

The construction of screening as “soft” and “gentle” along with its clinical nature, draw on ideas of healthcare and safety, and positions screening as something simple to engage with. When described as a way of managing the hidden disease HPV, there could be little reason for the reader to not engage with screening.

However, these constructions are embedded within a lengthy leaflet (9 pages), dense with text, which posits screening as something that requires some in depth consideration. The leaflet is designed like a scientific textbook, which both boasts the authority of the writer (as science is associated with factuality) and positions the author as neutral – a key tenant of scientific/academic writing (Katz, 2009).

The reader is positioned as someone who is subjected to the unavoidable threat of HPV, but holds overall responsibility for their health, and must rationally make considered choices to attend cervical screening.

### The re-designed leaflet

Screening is constructed in this leaflet as a step-by-step process to engage with. This is achieved by the numbering of the elements of screening, and the flow chart design. Colour is used to emphasise the different stages that the individual will go through, aiming to make it visually clear the different points being made, and to make it easier to follow. There are limited visuals or colours used in the original NHS leaflet. The PPIE group requested the inclusion of colour and images, which is partially reflective of what has been previously found in medication information leaflets (however for medication there was a reported concern of colours/images being too akin to advertising; Fuchs et al., 2007).

Screening is positioned as something that is relevant to everyone, with frequently asked question boxes on the second page clarifying its relevance to those who have had the HPV vaccine and who have not had sex.

Screening is also positioned as simple, and person centred by the emphasis on control and flexibility in the leaflet. For example, in most of the steps, there is a suggestion of how to impose the control, by calling the receptionist with “any concerns”, by “taking a friend or support worker” and by emphasizing that “you can ask the nurse to stop at any point”.

HPV is constructed as normal (“is really common”) and related to cancer (“it can cause cancer”), and something you either do or do not have (e.g. positive vs. negative test results in section 7). HPV is also suggested to be a hidden and hard to detect virus “it can lay dormant for years”.

Risk is mostly implicit in the leaflet, constructing the notion that it is not something central to screening, with only the numerical benefit of screening emphasised in bold on the top right-hand corner of the first page (“70% of people survive cervical cancer thanks to screening”). When risk is explicitly discussed, it is minimised with text stating “There are minimal risks of the screening, but huge benefits to prevent developing cervical cancer”.



These constructions are embedded in a short, colourful two pager with multiple images (see Figure 1). In this way, the leaflet reflects common media/advertising conventions, attempting to engage potential readers and persuade them to do or buy something. As such, the author is positioned as an advocate of screening who wants to enable people to attend.

Figure 1. The redesigned leaflet.

\*\*\* visit [cervicisr.co.uk](http://cervicisr.co.uk) for this information in other formats/languages\*\*\*

### YOUR CERVICAL SCREENING STEP BY STEP

- 1. INVITATION**  
Everyone with a cervix should be invited to a screening, for ages 25-49 every 3 years, 50-64 years every 5 years.
- 2. BOOKING APPOINTMENT**  
You will need to book an appointment with a nurse for the screening. Tell the receptionist of any concerns you have or if you might need a double appointment.
- 3. ATTENDING**  
When you go to your appointment try to wear comfortable clothes and don't forget you can take a friend or support worker with you to the appointment.
- 4. ENTERING THE ROOM**  
The nurse will have a chat with you about what will happen and any questions you have or anything you might want to request for the screening.
- 5. THE SCREENING**  
You will sit on the couch, well before this is confirmed. The nurse will use a speculum to do the screening. You can ask them to stop at any point.
- 6. AFTER**  
The nurse will take up a sample and send it off for a test. It will first be tested for HPV and then for cells that indicate cancer if HPV is present. You can carry on with your day. Very occasionally people experience some spotting, so wearing a panty liner can be helpful.
- 7. RESULTS**  
This will be:  
  - HPV negative**  
Reassured in 3-5 years as normal.
  - HPV positive, no cancer indication**  
Reassured in 1 year.
  - HPV positive, with concerning cells**  
Come back for further testing.
  - Indefinite**  
They don't run the tests properly, so re-attend in 3-6 months.

### 70%

of people with cervical cancer survive thanks to screening. This would be more if everyone attended.

**Know this!**  
You can request nurses of specific genders.  
Double appointments can be helpful if you think it might take some time to feel comfortable.

**Know this!**  
You can ask the nurse to stop at any point.  
If you want you can sometimes keep your underwear on during the screen.  
Nurses use a speculum to perform the screen - they come in a variety of sizes so you can request what size you want. They can use lubricant to assist.

**Know this!**  
HPV is really common - 8 out of 10 people will get it at some point.  
Most of the time the body clears it itself - like a cold. It can also lay dormant for years, when active and the body doesn't clear it, it can cause cancer.

**Know this!**  
A friend or support worker can be helpful.

## Frequently Asked Questions Cervical screening

**What if I've not had sex?**

Although it's less likely you will get cervical cancer if you have not had sex, it is still possible so it's still important to get screened. Getting screened does not affect your virginity.

**What are the risks of screening?**

There are minimal risks of the screening, but huge benefits to prevent developing cervical cancer. If you get invited back to investigate any potentially cancerous cells, the risk of removing those cells will be explained.

**But I've had the vaccine...**

Great! However the HPV (human papillomavirus) vaccine does not vaccinate against all types of HPV (there's over 100) so it's still important to attend and reduce your risk of developing cervical cancer.

**What happens in between screening?**

If you develop any symptoms of cervical cancer you need to book to see your GP, not wait for your screening. Symptoms are:

- Unexpected bleeding (between periods, post menopause, during or after sex)
- Changes to vaginal discharge

**I want more information**

There's a wealth of reliable information from the NHS and Jo's cancer charity, websites below:

[www.nhs.uk/cervical](http://www.nhs.uk/cervical)  
[www.joscancer.org.uk](http://www.joscancer.org.uk)

Follow this QR code for some videos designed by NHS Scotland about screening and what happens:

The reader is positioned as someone who needs convincing to go to, and needs digestible information to understand screening. Messages are personalised to the reader, by the text designed to be read as if the writer was talking directly to the individual reading it (e.g. "you" will have to do X, "you" can request X). Key messages are provided on the redesigned version of the leaflet at points where they become relevant. There is an assumption throughout the redesigned version of the leaflet that that the reader is unlikely to have attended a screening before, and do not know these key messages.

## Analysis summary

In the current NHS information leaflet, readers are constructed as rational agents that can have freedom of choice over what medical screening they undertake. To help make this choice, the state is providing information in a scientific format which projects the image of neutrality over what choice the reader makes, but positions screening as simple to engage with. In contrast, the redesigned information leaflet positions the reader as in need of simple information provided in an advertisement style to engage readers, and to emphasise the person-centredness of screening, with the role of the state being an advocate of screening.

For both leaflets, the epistemic authority is held by the state, with readers in need of education, but the current leaflet constructs readers as having high levels of ability to process scientific information, and the re-design constructs readers as requiring easy access information. Readers are positioned as having higher agency over their healthcare in the

current leaflet, whilst at the same time requiring skills to process a lot of high-level information. Agency in the re-designed leaflet relates to the process of screening, rather than opting to engage with screening. However, notions of agency are tempered in both leaflets by the ever-present likelihood that the reader will have HPV – a hidden and unseen threat for all, diminishing the notion that there is real agency in the process as they are likely already effected by something that may cause them to have cancer.

## Discussion

Discourse analysis has drawn out the different ways risk, HPV, cervical screening, women, and the state are constructed in cervical cancer screening information leaflets. Differences highlighted in the discourse of the current information leaflet compared to a version redesigned by a PPIE group, reflect the ongoing dichotomy found in healthcare information between paternalistic healthcare delivery versus autonomous patients (Dahlborg et al., 2021). Whilst many healthcare policies suggest there is a need for a move towards more patient-centred care (Ottesen & Strunck, 2023), emphasising patients as autonomous, when given the opportunity to change the leaflet to what they feel would be more helpful patients shift the discourse to more paternalistic discourse over attendance to screening, with autonomy in the process of screening. Overall, there is a divide in these two perspectives over the ways information leaflets about cervical cancer screening should be used (mostly to inform or to motivate?).

These findings align with and develop previous work on cervical cancer screening information leaflets. Okan et al. (2019) highlighted that cervical screening information leaflets are poorly understood and inaccessible to their target population, which was reflected by the suggested changes from the PPIE group to simplify and increase accessibility of the leaflet. Armstrong (2007) analysed a previous version of the information leaflet and argued information was presented as undisputed facts, that women resist by disputing points made in the leaflet. Although the information was often presented as facts in the current information leaflet too the analysis presented in this paper also showed how the information leaflet (as proxy for the state) constructs women as rational agentic decision makers, with freedom of choice. The state is positioned as a provider of the information to enable the woman to make a choice. Instead of resisting facts in the document, the PPIE group resisted this construction by reversing it – suggesting instead that the state has a role to advise people what to do to protect their health, as women are not the experts. This position is aligned with a ‘welfarism’ ideology of healthcare, a historical foundation of the NHS, where there is a collective responsibility for health between the state, individual and community (Dahlborg et al. 2021).

How the role of the state and women are constructed in the current information leaflet reflects neo-liberal ideas of choice and responsibility (Gabe et al., 2015). The current UK government policy for health screening states that screening should be done based on ‘personal informed choice’ (UK National Screening Committee, 2023). In specific reference to ‘personal informed choice’, the policy states that people must be given ‘accessible, accurate, evidence-based information’, covering several areas, including the condition, the testing process, risks, limitations, benefits, uncertainties, and possible outcomes. As such, this policy drives the length and coverage of the current information leaflet. From a critical standpoint, this policy could be argued as removing the state’s role in the health of its citizens, and pushing

the responsibility onto individuals (Brown & Baker, 2012). As such, it is the individual who has the responsibility to choose if they get screened, but it is also the individual who will have to deal with the consequences (Gabe et al., 2015). For example, if someone chose not to get screened, but then developed cervical cancer, this would be down to their own choices, not a lack of state provision.

The concept that the current cervical screening information leaflet is providing people with the ability to make a 'personal informed choice' is questionable. As highlighted in this study, and by Oken et al. (2019), the information leaflet is experienced as inaccessible, unclear, and long. The PPIE group that informed the redesign analysed for this paper argued for the reduction of the document's length, suggesting the length itself would be off-putting to many readers. As such, the document's accessibility and usefulness may be hindered by the dogmatic inclusion of all the points that the 'personal informed choice' policy has decided must be included in the information leaflet. Furthermore, 1 in 6 adults in the UK have low levels of literacy (National Literacy Trust, n.d.). Thus, the construction of the public as being unable and unlikely to understand all the information provided in the current information is not an underestimation. Instead, the re-design reflects the reality that if espousing 'personal informed choice', simplified and concise messages are likely to be better received.

The Lancet Commission on inequity in cancer care for women highlighted the model of 'personal informed choice' is something that replicates patriarchal power structures. The model suggests that if only people knew enough, they would attend screening, when in fact there are multiple systemic barriers to people accessing screening (Wilding et al., 2020). Cervical cancer screening is a multistep process, where people must first decide it is something they want to do, and then book and attend an appointment (often whilst juggling work and caring responsibilities). This process is not easy for people eligible for cervical cancer in the UK (e.g. people that identify as a women). Breast screening often follows a similar process (e.g. get an information leaflet, make a decision, book an appointment, and then attend). Bowel screening, which is available to all who are ages 60-74 (both males and female), follows a different process (NHS, n.d.). A test is sent through the post. Whilst there is still a 'choice' to be made on whether you use the test, the delivery of the test provides a clearer message that this is something the state has invested in for you and probably thinks you should do.

Providing equitable accessible information must be informed by research on ethical healthcare communication. There has been a significant shift away from paternalistic forms of communication in healthcare, along with discussion on the ethics of using any persuasion in communication (e.g. nudging; Swindell et al., 2010). Arguments often maintain that persuasion should be left out of healthcare communication, to give patients more freedom of choice in their healthcare decisions. Given how previous abuses of more paternalistic communication have fed into anti-science movements (Batelaan, 2020), it is sensible to be cautious. In this paper, this is particularly pertinent, given some broader evidence on the harm of overdiagnosis in cancer screening (de Koning, 2000), although the evidence of overdiagnosis in cervical cancer screening is limited (Hamashima et al., 2018).

The public involved in this study suggested changes that create a more paternalistic discourse, for a leaflet that is already sent to all eligible for cervical screening with invite letters (which are considered a type of nudge; Busch et al. 2021). Yet, for people to have the choice in the decision to get screened or not, information required to decide must be accessible to all. Health and science literacy is broadly acknowledged as poor, particularly in marginalised

communities (Sørensen et al., 2015; Paakkari, 2020). The implications of making the information leaflet more accessible/engaging (led by PPIE) has been a shift to more paternalistic discourse, which may not sufficiently engage with issues such as overdiagnosis. Although outside the scope of the current study, future PPIE work could focus attention on how to discuss issues like ethical communication, overdiagnosis and the importance of this to the public, in an engaging way.

There are some limitations inherent in the study design; the author actioned the redesigned version of the leaflet that they subsequently analysed. Being engaged with this process may have influenced their analysis, for example by focusing on differences between the two information leaflets, which hold similar information in different formats. Future research could enrol other researchers to do the analysis or focus solely on information leaflets and the different ways different countries might deliver this information. However, the current study's unusual design has moved away from traditional study design that use interviews to gain an understanding of patients' experience of health communication. With the increased focus on the use of PPIE in healthcare research, this paper shows a more unusual and novel way to integrate this work into understanding how health communication could be changed and potentially improved in practice.

Re-imagining the information leaflet so that it is more in-line with the way that the public from this study would like it to be could have number of potential positive impacts. Wilding et al. (2020) suggest that barriers to attend cervical screening include being at a low perceived risk, being unsure of the process, and being concerned that male healthcare professionals will conduct the test. Making information leaflets accessible will clarify these points to people eligible for cervical screening. More research needs to investigate the accessibility of the current information leaflet, and the ethics of the proposed amendments from the re-design. In future research, more attention should be paid to people with different cultural backgrounds, those with English as a second language, and the needs of people with neurodivergence and disabilities. Information leaflets are one part of the puzzle to enhancing cervical cancer care. They are often the first official communication about cancer and HPV risk an individual will get and may have an ongoing impact on their engagement with preventative screening programmes. Continuing to develop understanding of how best to communicate risk of developing cancer (including the role of HPV) is important to prevent further reductions in engagement with preventative screening.

## Conclusions

This study focused on how risk, HPV, and cervical screening were constructed in information leaflets that the UK government uses to communicate information about cervical screening to potential attendees. In the current leaflet there is a focus on choice to attend screening. In contrast, potential attendees of cervical screening emphasis choice in the process of attending cervical screening when re-designing the leaflet. The current leaflet reflects marketized neo-liberal discourses of healthcare, whereas the redesign reflected more paternalistic discourses. However, both situated patient choice and agency in discourses of HPV of being unavoidable, likely and causal of cancer and as such something there is little choice over. The discourses of choice in the current leaflet may relate to why there is a

reduction in uptake of screening. If the overall aim of the screening programme is to engage the whole relevant population, a simplified and clearer approach could be more effective.

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## Notes

- 1) 'Women' is used throughout this article for consistency with prior literature, but mean this to represent anyone with a cervix who is eligible for cervical screening regardless of their gender identity.
- 2) Co-design is a contested term that can mean different things (Moll et al., 2020; Williams et al., 2020) – the term is used here as the aim was the think about a re-design with (co) people.

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