Jo's cervical cancer trust

Computer says no

The growing issue of access to cervical screening across the UK: The problems and how they can be overcome

June 2018

“We are so, so lucky to have screening. I delayed attending my test for a while and when I finally went, I needed treatment for abnormal cells on my cervix. I don’t want to think about what could have happened if I hadn’t been able to attend when I did, it’s so important to go as soon as you get that letter through. I won’t miss an appointment again.”

Foreword

Cervical cancer is one of the only cancers that can be prevented, through cervical screening and the addition of the HPV vaccination. This is highly unique and we are fortunate to have excellent cervical screening programmes in the UK, programmes that save thousands of lives every year. However, of the five million women invited every year for screening, over one in four don't attend. Attendance is falling year on year and as a result, lives are sadly at risk.

There are many barriers affecting awareness and intention to attend cervical screening, many are complex to overcome. Yet more and more women are telling us that they are struggling to get a cervical screening appointment. This needs to change.

It cannot be denied that our health service is under immense pressure, yet cervical screening offers a solution to the long-term cost of cancer by preventing it. It can protect health and save lives, yet the opportunities for women to access it across the UK are unequal. The programmes have been slow to adapt to modern lifestyles and there is wide variation in availability of GP appointments, whilst access through sexual health services is in decline and in some areas non-existent. Some groups of women, including those with a physical disability or who have experienced sexual violence, are further disadvantaged by the current setup and delivery. Greater responsibility, accountability and investment is urgently needed.

Solutions must be found and self-sampling presents an opportunity not only to increase attendance but also to reduce pressure on primary care. We hope to see this introduced soon along with more flexible, digital opportunities for inviting women, enabling booking of appointments and settings offering screening. The fewer barriers to attendance that exist, the more likely we are to see the numbers attending increase.

In England, there is a complex governance and commissioning structure which has led to fragmented provision and ownership over different aspects of the programme. There is also an IT system, deemed not fit for purpose many years ago, still in operation and this is not acceptable. There is excitement about the introduction of HPV primary screening, however the current environment in England has led to confusion, frustration and a lack of action and there are risks in moving to this new testing method without having a robust IT system in place to support it. We are calling for an urgent review of all of the screening programmes, however in England the need is critical.

We have a highly effective cervical screening programme with an extremely skilled and passionate workforce delivering a quality service to millions each year. It remains one of the best in the world, so it simply isn't good enough that women are unable to access it.

There is an urgent need for change and for that to happen now.

Robert Music
Chief Executive, Jo's Cervical Cancer Trust

"I had great difficulty booking my last smear as there were no appointments for over six weeks so I had to wait for new appointments to be released. By the time I got through on the phone, the appointments would be booked up for another week as the nurse only does tests one afternoon per week. I eventually had my test 5 months late and am now on yearly smears due to an abnormal result. This year when my reminder letter came I called my surgery but again they were booked up for weeks with appointments only available on Thursday afternoons which I could not make due to work as I'm a nurse and unable to swap shifts once the rota is out. My local hospital only does smear testing on Thursday afternoons too. I was offered a walk in service in their GUM Clinic with the condition I had a full STI check at the same time, I'm a married woman so this was a mortifying experience for me. All this to have a test we are told is vitally important not to avoid! Smear testing should be easily accessible for all women."

Contents

Executive summary 6

1. Current situation 8

a. How the cervical screening programmes work across the UK 8

b. Variations in uptake of cervical screening 9

2. Barriers to screening 10

a. Lack of convenient appointment times 10

b. Reduced availability at sexual health services 12

c. IT systems preventing innovation 15

d. Insufficient incentives 17

e. Fragmented governance and commissioning in England 18

f. Groups of women at a greater disadvantage 19

3. What do women want? 20

4. Recommendations 21

References 23

Executive summary

Cervical screening provides a high degree of protection against cervical cancer and thousands of lives are saved each year as a result of the high-quality programmes we have in the UK.

However, attendance is in decline with around 1.3 million women not attending every year. There are many psychological, cultural and literacy barriers to attendance, yet a growing issue is ability to access the test.

This report sets out to highlight factors impacting access across the UK, explore what women themselves want and need from the screening programmes and provide recommendations to ensure that every woman can access cervical screening.

Whether women can easily access screening is dependent on their location and personal circumstances. Some groups of women, including the transient population, those living with a physical disability and women who have experienced sexual violence, are further disadvantaged by the current delivery of the programme.

Barriers affecting accessibility of cervical screening include:

Lack of appointments

- Almost one in 10 women were only offered times they couldn't make the last time they tried to book an appointment
- 7% were told no appointments were available when they last tried to book
- There is no national sample taker database so assessing workforce capacity is not possible

Reduced availability at sexual health services

- A higher proportion of abnormal results are taken in sexual health however access across the UK is patchy and declining
- Since 2013 there has been a 52% reduction in samples taken in England and 42% reduction in Wales
- In Scotland, sexual health services in Forth Valley took five samples in 2017 compared to over 4,000 in Greater Glasgow and Clyde

IT systems preventing innovation

- In 2011 the IT system in England was deemed "no longer fit for purpose" and seven years on little progress has been made
- The move to HPV primary screening presents significant risk if it is implemented into a programme without a robust IT system underpinning it
- There is a need for changes across all the IT systems to become more customer focused, including enabling changes in how the programme communicates with women
- Self-sampling could increase participation and reduce pressure on primary care but the current IT systems do not allow for pilots to count towards coverage

Insufficient incentives

- Inclusion of cervical screening indicators in the quality and outcomes framework (QOF) rewards GP activity however there is little financial incentive for provision outside of the GP settings
- Over inflated GP lists mean in some areas unnecessary payments are being made and coverage statistics are inaccurate

Fragmented governance and commissioning in England

– NHS England is responsible for the programme however delivery of different parts of the programme are split between NHS England, Public Health England, GP practices and local authorities, resulting in a complex and fragmented environment with a lack of accountability and leadership
– There have already been widely documented concerns over workforce capacity and IT capability, especially around the move to HPV primary screening. The fragmented governance and commissioning environment is exacerbating these issues and preventing progress

Our recommendations

1 An audit should be undertaken in each country with Government, NHS, commissioners, providers and public health specialists working together to assess what more can be done to ensure all women can access cervical screening at a location, time and service appropriate to them.

In England, the audit must include a review of the commissioning and delivery structure which has created confusion, inequality and a lack of accountability. This includes adherence to the Section 7A agreement statement that services should optimise attendance rates and maximise accessibility of the service for all groups in the community

2 The Department of Health and Social Care, along with NHS England and Public Health England, must urgently conduct a review of the IT landscape in England and commit to investing in a system which is fit for purpose, fit for the future and safe.

3 Women should have to wait a maximum of four weeks for a cervical screening appointment in primary care. Early morning, evening and weekend appointments should be offered at GP practices and where practices do not provide screening or do not have adequate resource to cope with demand, women must be provided with fully accessible alternatives.

4 Changes to QOF, including those in Scotland, must be closely monitored and not result in screening being deprioritised as this could affect activity to improve access. Action must be taken if a negative impact is detected. Local incentive schemes, targets and KPIs should be considered, especially when coverage is below average.

5 An integrated approach to commissioning and delivering screening must be taken across primary care and sexual health to ensure cervical screening is available in the settings in which populations require. Adequate resourcing and funding must be allocated with procedures in places to prevent over screening.

In England a national budget line for cervical screening in sexual health services will facilitate this offer.

6 Funding is urgently needed for large-scale pilots on self-sampling and it is essential that pilots can count towards national coverage statistics to fully assess the impact. The robust IT system in Scotland presents an opportunity for such a pilot, findings of which will benefit the whole of the UK.

1. Current situation

a. How the cervical screening programmes work across the UK

Cervical screening aims to reduce the number of women who develop cervical cancer and the number of women who die from cervical cancer.

Women aged 25 to 49 receive a cervical screening invitation via post every three years and women aged 50 to 64 receive one every five years.

Up to five million women are invited every year across the UK, however around 1.3 million don't attend[1] meaning over one in four are missing out on a potentially life-saving test, with attendance in decline.

The cervical screening programmes are about to undergo their biggest change since their inception by moving to the more accurate HPV primary screening. While the experience for women will remain the same, analysis of the sample will change from cytology to detection of high-risk HPV, the cause of 99.7% of cervical cancers. Every country has a different timescale for roll-out starting with Wales in October 2018.

The UK National Screening Committee advises on screening policy across the UK but the commissioning and delivery structures for cervical screening are different in each country:

England:
The programme is commissioned by NHS England as part of the Public Health Section 7a agreement. Screening is primarily carried out at GP practices as part of the GP Contract, with additional funding through the quality and outcomes framework (QOF) which is part of the General Medical Services contract for general practices. The Section 7a Service Specification states that the cervical screening programme as a whole should, "optimise attendance rates and maximise accessibility of the service for all groups in the community". It specifies that providers should have procedures in place to support hard-to-reach groups and that there should be easy access to screening appointments.

NHS public health functions agreement 2017-18: Service Specification no.25 Cervical Screening:

The provider will have procedures in place to identify and support those persons who are considered vulnerable/ hard-to-reach, including but not exclusive to, those who are not registered with a GP; homeless people and rough sleepers, asylum seekers, gypsy traveller groups and sex workers; those in prison; those with mental health conditions; those with drug or alcohol harm issues; those with learning disabilities, physical disabilities or communications difficulties. (p.15)

The days and hours of operation of both screening appointments and colposcopy clinics will be locally determined and appropriate for the local populations. Easy access to initial screening appointments and timely further examination is essential, and this is a key criterion of quality for the entire screening pathway. (p.29)

In some areas local authorities provide cervical screening through sexual health services or genitourinary (GUM) services to all women, or to some groups of women on an opportunistic basis. This used to be a wider offer but since the 2012 Health and Social Care Act, sexual health services have been commissioned through local authorities who have no mandate to include cervical screening in their service.

Where access is provided, in some areas it is through funding from local authority public health budgets and in other areas local funding arrangements have been made with NHS England to fund the service. Coupled with increased pressure on sexual health and declining numbers of services, access is fragmented and in many areas significantly diminished.

Wales:

The Screening Division of Public Health Wales is responsible for managing, delivering and quality assuring the cervical screening programme in Wales. GPs are funded to carry out screening through the GP contract and cervical screening is mainly carried out in primary care. It is the responsibility of Health Boards to decide where screening can take place for their population and in some areas it is offered through community or sexual health services. However, there are Health Boards where no screening is offered at the local sexual health service and others where there is no sexual health service at all.

Scotland:

The National Services Division commissions and co-ordinates the cervical screening programme in Scotland. Health Boards decide where screening can take place, which is primarily through GP services and some sexual health services. In April 2018 the new Scottish GP Contract came into force which removed QOF.

Northern Ireland:

The Public Health Agency has responsibility for commissioning, coordinating and quality assuring the cervical screening programme. The majority of screenings are carried out at GP practices, however some sexual health services provide screening too. Health and Social Care Trusts are responsible for sexual and reproductive health services and whether cervical screening is provided as part of this service.

b. Variations in uptake of cervical screening

Screening coverage is currently at:*

72.0%	73.4%	77.0%	76.8%
England	Scotland	Wales	Northern Ireland

National statistics hide great differences across areas, ranging from 80.0% in Shetland to 53.8% in Kensington & Chelsea, and among age groups, with attendance among 25 to 29 year olds (one of the groups most at risk of cervical cancer) as low as 43.9% in Westminster.

The ten areas with the lowest attendance in the UK are all in London (Kensington & Chelsea, Westminster, Camden, Hammersmith and Fulham, Tower Hamlets, Islington, Harrow, Hounslow, Ealing and Newham). Greater Glasgow and Clyde has the lowest uptake in Scotland at 70.0%; Hywel Dda UH in Wales at 75.5%, and Belfast HSC Trust has the lowest uptake in Northern Ireland at 72.3%.

While some women may actively decide that cervical screening is not for them, our research suggests that many of those who do not attend would do so if there were fewer barriers to screening.

* Coverage in England and Scotland is based on age appropriate coverage whereas Welsh and Northern Irish data uses five year coverage only

2. Barriers to screening

The barriers to women attending cervical screening are wide ranging and many women will experience more than one. They span physical, psychological, cultural, literacy and access. Awareness campaigns, community outreach and printed information can address and overcome many of these barriers, but not all.

a. Lack of convenient appointment times

"[I would attend if I was] able to book an appointment when I phone up and not having to keep calling back."

GP practices are the primary provider of cervical screening across the UK, therefore women should not struggle to make an appointment with their GP practice. However, availability of cervical screening appointments varies greatly across the country. In some practices screening is restricted to certain days or times, which can particularly disadvantage those who work or travel and we are seeing more and more women expressing frustrations about their ability to get an appointment.

"Terrible service from my GP surgery made it impossible - took time off work three times to attend smear test appointments and three times they were cancelled at last minute, on one occasion I was already [at] the surgery when I was informed it had been cancelled. I simply gave up."

It is not mandatory for practices to provide screening. If they opt out then they should have alternative provision for women, however this may be at a cost to other practices or local services and presents an additional barrier to attendance especially for women who are already faced with significant personal barriers.

"Finally given into my justified chronic fear of a smear test, only to be told there are no appointments for 10 weeks."

Provision of appointments is in part dependent on the availability of trained sample takers, generally nurses. Yet there is no national database for the sample taker workforce; instead each area is responsible for its own database or system, with some more developed than others. There is currently no consistent or systematic approach to monitor the number of active sample takers and the training requirements of this workforce across the country, therefore it is not possible to identify if a declining workforce is a contributing factor to the availability of appointments.

"The three times I did call the doctors to arrange an appointment they had no available to book at all."

Worrying numbers of women were told no appointments were available when they last tried to book an appointment (7%) and almost one in 10 (9%) were only offered times they couldn't make. A quarter (24%) were only offered appointments during 9-5. One in eight (13%) report finding it difficult or even impossible to book a test with almost one in ten (9%) having to wait over four weeks for an appointment.[2]

"When you receive 'the' letter & try to book an appointment but you're told there are no appointments left and to call back later in the week to see if new dates have been released."

"Considering how important it is for women to make sure they go to the doctors to have a smear test, I couldn't get an appointment until March [two months away]! I hope it's because everyone is having it done and not because there's no staff to do it #SmearTest"

The NHS and GP practices are facing huge pressures dealing with an ageing population, increases in lifestyle related illness, declining workforce and diminishing budgets. Yet, if women are unable to attend screening, the pressure and costs of a cancer diagnosis will bring added strain and life-long costs.

With closures of sexual health services and fewer offering screening, primary care is also faced with an increase in demand. However, it should not be women who lose out. It is essential providers can cope with the demand.

> *"I'm a GP and a colposcopist and I'm also representing the RCGP. In defence of primary care at the moment, as you know, we are under huge amounts of pressure. Cervical screening was covered in core funding, but one of the issues with reduced access to sexual health clinics is it is now assumed that we in primary care have the capacity to take on the extra screening. So, in my area, we know that as the contraception and sexual health (CASH) clinics, the sexual and reproductive health (SRH) clinics, have reduced in number, access has gone down. And so those women who were due to go to the contraception clinic now, if they are going to go, they are going to go to GPs, but that is extra work for GPs, because they weren't doing that work before, and I think we have to acknowledge that primary care doesn't have the capacity at the moment to take on much extra work, because we are already taking on extra contraception work because of this issue. I do think there will be opportunities under federated practices and primary care homes, but it will be a while before they kick in. So it is really about working together rather than this, 'primary care can take this on'."*
>
> — Health Matters – Your questions on cervical screening, Public Health England, September 2017

Work as a barrier

"My shift pattern and commute can make it difficult to be available during opening hours."

For women who work, accessing convenient appointments can be challenging. One fifth (18%) struggle to get an appointment around work and 11% would be encouraged to attend if they didn't have to take holiday from work.[3] This presents an additional barrier to the test. While GPs should provide accessible appointments for women, there is also a role for employers. Time to Test is a Jo's Cervical Cancer Trust campaign for employers that encourages them to raise awareness of cervical cancer and cervical screening in the workplace, as well as pledging to allow their employees the time to go for screening if they can't get an appointment outside of working hours.

"I used to work night shifts so it was difficult to find time to go for a smear, then I had my first child and put it off, then I had a day job and found it difficult to get childcare. Eventually I had one done but a good two years late."

"Work aren't happy with me making appt in work time but I have no other choice because I work full time."

b. Reduced availability at sexual health services

Provision of cervical screening through sexual health services* across the UK is patchy and often subject to local relationships and procurement of funds. In some areas sexual health services no longer offer cervical screening and in others it is offered on an 'opportunistic basis', the definition of which varies from area to area and may mean all women who are overdue and present at the service, or may be restricted to certain groups, for example, women who have HIV or street sex workers.

Accessing screening at sexual health services benefits many women including those unable to get an appointment at their GP practice, women who don't engage with the health service for a wide range of social or cultural reasons but may present at sexual health services and women not registered with a GP.

In England 5.2% of samples taken at a GP come back as abnormal rising to 8.1 % in NHS Community Clinics[4] (mainly sexual health services) and increasing considerably to 12.3% in GUM clinics. The percentage of samples that come with high grade abnormalities from Integrated Sexual Health Clinics in Wales is double that of those from GPs (2% v 1.1), clearly showing these service are supporting those at greater risk of cervical cancer.[5]

* in this report, 'sexual health services' includes 'integrated sexual health services', CASH clinics and GUM clinics

Access at sexual health services in England:

The complexity of commissioning arrangements and funding streams, coupled with well documented workforce and budgetary pressures, mean many local authorities have reduced access to cervical screening at sexual health clinics since 2012. 140,813 tests were taken in community clinics (largely sexual health services) and GUM services in 2009/10 and this has dropped to just 56,347 in 2016/17, a reduction of 84,466 tests.[6]

Number of samples examined by pathology laboratories from GUM & NHS Community Clinics

	2013-14	**2014-15**	**2015-16**	**2016-17**
North East	8,487	8,329	7,916	6,283
Yorkshire and Humber	6,817	5,951	4,794	2,338
North West	22,765	24,203	22,585	14,106
East Midlands	4,991	3,971	2,293	1,199
West Midlands	9,339	8,958	6,177	5,023
East of England	9,588	7,522	4,455	2,612
London	39,621	27,301	21,627	14,375
South West	7,114	7,040	8,136	7,584
South East	N/A	N/A	3,501	2,827
South East Coast	4,567	3,446	N/A	N/A
South Central	3,739	2,166	N/A	N/A
England TOTAL	**117,028**	**98,887**	**81,484**	**56,347**

Freedom of Information requests[7] show that over the course of one year (between September 2016 and 2017), the number of local authorities offering cervical screening to all women decreased from 41 to 26 and the numbers not offering increased from 12 to 14.

"I could go around work and school runs as well as helping with nervousness and embarrassment...my last test was due in November but I was told by the centre that they can no longer do smears due to funding being stopped. It has taken almost six months to get a GP appointment."

Where local authorities are offering cervical screening through sexual health services, the funding streams vary. For example, Greenwich Council uses its public health budget, in Derby there is an agreement with NHS England and the cost of cervical screening is included in the sexual health block contract and Wigan has integrated commissioning and service provision which brings together primary care and sexual health utilising a section 75 agreement.

Access at sexual health services in Scotland:

Health Boards can choose to commission cervical screening at sexual health clinics and the majority offer it to restricted groups on an opportunistic basis. In the last couple of years overall access to screening at sexual health clinics has remained roughly the same, however there are big differences between Health Boards with Forth Valley taking five in 2017 and Greater Glasgow and Clyde taking over 4,000.[8]

Number of cervical screening samples taken at Sexual Health Clinics

	2013	2014	2015	2016	2017
Ayrshire	1,214	1,375	1,500	1,534	1,506
Dumfries & Galloway	N/A	N/A	156	129	175
Tayside	341	267	223*	31*	267
Borders	N/A	211	202	197	167
Fife	1,238	1,564	1,631	1,874	1,854
Grampian	N/A	235	271	232	288
Forth Valley	7	17	13	5	5
Greater Glasgow & Clyde	6,574	6,187	5,345	4,945	4,531
Lanarkshire	1,333	1,248	1,249	1,199	1,174
Western Isles	1,523	1,508	1,513	1,636	1,578
Orkney	N/A	N/A	N/A	N/A	N/A
Shetland	N/A	N/A	N/A	N/A	N/A
Highlands	N/A	N/A	N/A	N/A	N/A
Lothian	N/A	N/A	N/A	N/A	N/A
Scotland TOTAL	**10,707**	**12,612**	**12,103**	**11,782**	**9,967**

*data incomplete due to change in recording samples

Access at sexual health services in Wales:

Health Boards choose whether to commission cervical screening in sexual health clinics and there is patchy availability with samples from Integrated Sexual Health Clinics dropping from 9,363 in 2015/16 to 6,313 in 2016/17, and Cwm Taf University Health Board has seen a 70% decrease in tests over the past two years.[9]

Number of samples examined by pathology laboratories from Integrated Sexual Health Clinics

	2013-14	2014-15	2015-16	2016-17
Abertawe Bro Morgannwg UHB	N/A	730	651	369
Aneurin Bevan UHB	N/A	3,181	3,074	2,243
Betsi Cadwaladr UHB	N/A	878	813	978
Cardiff and Vales UHB	N/A	656	708	612
Cwm Taf UHB	N/A	2,345	2,261	715
Hywel Dda UHB	N/A	1,746	1,435	1,067
Powys Teaching HB	N/A	16	12	18
Wales TOTAL	**10,254***	**9,552***	**9,363***	**6,002**

*A small proportion of women could not be allocated to a Health Board

Access at sexual health services in Northern Ireland:

The Northern Ireland cervical screening programme engages with sexual health clinics through the five Health and Social Care Trusts. The number of samples does not vary per year however, there is a large variation between Trusts. Opportunistic samples are taken at sexual health clinics and there are no restrictions to who can access the service. Sample takers are however responsible for informing women of their result.

Number of samples processed by NI CytoPathology laboratories from Sexual Health Clinics[10]

	2014-15	**2015-16**	**2016-17**
Belfast and South East Trusts	1309	1311	1274
Northern Trust	429	431	433
Western Trust	585	615	644
Southern Trust	41	42	14
Northern Ireland TOTAL	**2364**	**2399**	**2365**

c. IT systems preventing innovation

The four cervical screening programmes in the UK are underpinned by different IT systems. There are challenges and constraints with each system but in England the system is in urgent need of nationally coordinated investment to provide a comprehensive system across the screening pathway.

There is no definitive list of all of the IT systems underpinning England's cervical screening programme, although there are thought to be around 350 systems in existence across GP surgeries, laboratories and in colposcopy. This vast number of systems, and the complexity involved in providing seamless transfer of data between them, is in contrast to much more straightforward counterparts in the devolved nations, and also the breast and bowel screening IT systems in England.

In 2011, the IT system in England was deemed "no longer fit for purpose" and seven years on, little progress has been made.

> *"The IT systems which support cervical screening are now around 30 years old and are no longer fit for purpose. Information is held on over 80 separate systems covering different parts of the country. There is no national database. As cervical careening starts at age 25 and ends at age 65 many women will move across boundaries, making it very hard to track their screening histories. Linkage of cervical screening information with hospital information (e.g. on colposcopy and histology) is difficult to achieve, hampering quality assurance of the service."*
>
> — An Intelligence Framework for Cancer, 2011

NHS England has outsourced one transformation project to Capita, this concerns replacing the 83 databases that support the invitation and recall aspect of the programme to facilitate the move to HPV primary screening.

Capita is also responsible for a larger transformation project in primary care, however many concerns have been expressed regarding the viability and progress of this project:

"At this stage we have serious reservations about the transformation project and would not be able to support it without significant further exploration and examination. We raised some of the issues, particularly regarding some of the technical proposals, at the committee and the responses we received further exacerbated our concerns."

— Letter from the joint chairs of the BMA and RCGP Joint GP IT Committee to NHS England, February 2018

A report in May 2018 by the National Audit Office,[11] highlights numerous service failings and concerns about patient safety caused by the 2015 contract with Capita as well as areas affecting cervical screening in particular. This includes cases of women incorrectly notified they were no longer part of the programme and delays in letters being sent out.

"Although NHS England has saved significant sums of money, value for money is not just about cost reduction."

— NHS England's management of the primary care support services contract with Capita, May 2018

The recent breast cancer screening system failure, where 450,000 women did not receive their invitations,[12] highlights the critical nature of the screening IT systems and the scale of damage when things go wrong. Yet we are faced with a situation where serious concerns over the IT systems underpinning the cervical screening programme have been raised for many years but are not being addressed.

The move to HPV primary screening is extremely positive as it has the potential to prevent an additional 500 women from developing cervical cancer each year. However, it is a major change and presents significant risk if it is implemented into a programme without a robust IT system underpinning it. Concerns have already been raised over the current Capita project and these must urgently be addressed, but this project is effectively a sticking plaster over just one part of the programme, the call and recall process. The screening pathway is far greater than this and also includes transfer of data between laboratories and colposcopy, it is here where there are additional systems in dire need of improvements. Investment in a coordinated, cohesive IT system spanning the full cervical screening pathway in England is long overdue and crucial. Without this there is a potential risk of serious systems failures or oversight which could cost lives.

Improvements needed across the UK

There are further constraints affecting the IT systems in England, Wales, Scotland and Northern Ireland, where the largely inflexible systems are unable to adapt to the changing needs of women and the programme.

There is a pressing need to future-proof these systems to enable the programmes to become more customer focused and responsive; this includes changing how we communicate with women, with nation-wide opportunities for email or text. Demographical data, other than age and location, is not available meaning it is impossible to establish which women are not attending and where to focus campaigns and outreach. Better data would allow more targeted activity, saving money and resources in the long-term. HPV vaccination status is not always recorded, which could influence future communications with woman and if, as research suggests, screening intervals can be extended for vaccinated women, this is vital data to have at hand. Furthermore, the systems cannot effectively measure the impact of much needed large scale pilots on self-sampling, as self-sampling cannot be registered against a woman's record or count towards coverage statistics.

d. Insufficient incentives

Cervical screening is included as part of the Quality and Outcomes Framework (QOF) for GPs in England, Wales and Northern Ireland. This means that GP practices receive payments for having a protocol in place for cervical screening and for achieving coverage targets. Cervical screening is an optional, not essential, part of the GP contract so changes to cervical screening indicators in QOF could have a damaging impact on activity to increase awareness and attendance among those in primary care. Removal or changes to an existing incentive may suggest that the service is no longer a priority for the health service and may impact activity or investment to improve access.

Some areas have implemented local incentive schemes or targets to further incentivise uptake, this includes stretch targets for priority practices in Trafford and additional incentives to practices in Islington.

Inclusion of cervical screening indicators in QOF reward GP activity in delivery of screening, however there is little financial incentive for provision outside of the GP setting. GPs receive payment for all samples taken in their population, regardless of where the sample was taken with no national payment or incentive for provision in sexual health. The commissioning environment in England is effectively a barrier to provision. Across the UK, collaboration and remuneration across primary care and sexual health are needed to overcome these barriers otherwise options for women are reduced. Local areas have a responsibility to protect the health of their populations so should actively work to tackle declining screening attendance.

The Scottish health system recently ended QOF. Whilst it is too early to tell if this will have an impact on coverage, the removal of incentives could lead to decreasing activity to improve awareness and access to the programme. This must be closely monitored.

As part of the GP contract, any woman who has been invited three times and not attended is marked as an ‘exception report’. Exception reports count towards coverage statistics and, on the understanding that the GP has reached out three times, payments are still made. While in many cases there are legitimate reasons for exception reporting, and a wide range of methods employed to ensure women can make an informed decision about attending, in some places huge numbers of women are exception reported when they may not actually be living in the GP catchment area. Comparing population projections for local authorities or Clinical Commissioning Group (CCG) mid-year population estimates with eligible population for screening shows large disparities in some areas.

For example in Hammersmith and Fulham CCG, over 20% overinflated GP registered population for 25-49 year old women compared to the CCG population (over 10,000 more people on the GP list than in the CCG area) and in Lambeth local authority 10% overinflated list for 50-64 year olds (over 4,000 additional people).[13 14 15]

This means that payments are being made for women who no longer live in the area. Regular list cleansing will not only save funds, which could be invested in increasing awareness and access, but it will also result in more accurate coverage statistics. It is stated in the service specification in England that lists should be maintained and cleaned but this is evidently not always happening. There is a potential role for the Care Quality Commission or primary care contracting teams to encourage list cleaning and BMA guidance is available on the process.

e. Fragmented governance and commissioning in England

NHS England is responsible for the cervical screening programme in England however delivery of different parts of the programme is split between NHS England, Public Health England, GP practices and local authorities. This creates a complex and fragmented environment causing confusion, frustration and means some pressing issues are not being tackled.

The majority of the programme is commissioned through NHS England, Public Health England sets standards and provides quality assurance and training, GP practices (sitting under NHS England) deliver screening and some sexual health services (sitting under local authority public health) offer screening. This complex structure and lack of oversight is having serious repercussions across the programme where conflicting priorities, lack of investment and a lack of collaboration is hampering progress and creating strain. The programme is facing multiple problems, including the critical IT situation and patchy sexual health service provision, and there is a clear need for these problems to be recognised and decisive action to be taken to tackle them. Increased collaboration across all responsible for the programme from the top down is essential with engagement from the experts who are delivering and managing the programme. We have heard from so many people who are delivering or commissioning services who are frustrated and fed up.

The move to HPV primary screening is happening amidst this.

This major programme change requires considerable changes across all aspects of the programme including laboratory set up and configuration. However, there have already been widely documented concerns raised, including over workforce capacity and IT capability. Furthermore we are aware of significant concerns among those involved in delivery of the programme. Ultimately this more effective test will save lives, yet as the roll-out date moves closer there is a pressing need for clearer guidance, oversight and more robust systems to facilitate a safe and effective roll-out.

Confusion regarding roles and responsibility can be seen in a recent report[16] which found 37 local authorities and 76 CCGs do not think that they have a role to play in increasing cervical screening coverage. Some stated it was the role of Public Health England, others said NHS England, several local authorities said it was the responsibility of their CCG, while several CCGs said it was their local council or public health team.

The transfer of public health into local authorities has meant that sexual health services, a key setting for cervical screening, is now sitting with local authorities. There is no national mandate or budget for the service to provide screening. Unless local agreements have been put in place to fund or reimburse sexual health services, provision of this service is at the cost of shrinking public health budgets. Funding streams are further complex as GP practices are paid for samples taken within their registered population, even for those taken in sexual health. Local authorities have a responsibility to protect the health of their population and deliver services which fit local demand. The environment they are operating in is resource stretched but if access through sexual health services continues to decrease it is women who will lose out.

Opportunities for assessing local need and providing an integrated, collaborative approach to service delivery present through the Cancer Vanguard and Cancer Alliances. However, it should not be the case that only some areas see the benefit. There is a dire need for increased collaboration, communication and resourcing across the programme.

f. Groups of women at a greater disadvantage

There are many barriers impacting intention and ability to attend, with location being a key factor in how easily women can access an appointment. However, there are some groups of women who face additional barriers and may be at greater disadvantage.

"I have had serious health issues which have prevented me from attending"

In the UK, there are around 12 million disabled people with 50% to 60% reporting mobility as their impairment.[17] For women **living with a physical disability**, especially those who are bed or housebound, getting to a GP or having a house visit from a trained sample taker is not always possible.

"You have to book very much in advance & being someone who is disabled & housebound it is difficult to pull it together"

One in five women aged 16 to 59 has experienced some form of sexual violence since the age of 16.[18] For **survivors of sexual violence**, the prospect of screening can be extremely difficult or traumatic. The test itself and having to explain or relive the experience present additional barriers and can make presenting at a GP impossible. There are some excellent specialist clinics catering to victims of sexual violence, such as My Body Back Project in London and Glasgow. Unfortunately, these vital services are few and far between, extremely underfunded, oversubscribed and struggling to keep up with demand so women are faced with long waiting lists and most will have to travel a long distance to get to a clinic. There is a pressing need for investment in specialist support services to provide cervical screening to survivors.

For **transient populations**, including women who are without a fixed address or who have just moved to the country, women who are homeless, in prison or who travel, accessing screening can be impossible. Sexual health services have previously provided screening for women not registered with a GP so reduced provision will be felt among this group.

Anxiety, fear and extreme pain are just some of the factors which can contribute to having a bad experience and can prevent attendance, especially if women feel they have to revisit the same setting or sample taker. Self-sampling and flexibility on where to attend can help reduce some of these barriers.

Just over half (53%) of **Black, Asian and minority ethnic women** think screening is a necessary health test compared to 67% of white women.[19] Language and literacy barriers coupled with additional barriers such as fear and misconceptions around the disease mean awareness and attendance of screening is lower. Well woman and community clinics focus on the health of the woman as a whole, including screening, and reduction in availability of these services can impact the women most in need.

"In Manchester they used to have well woman's clinics and you could have everything done including a smear test. But they stopped years ago. On the day, you didn't have a choice because you were there and then they said, 'right, why not have your smear test, too?' and you're there thinking well I'm here I might as well have the smear test done"

3. What do women want?

Cervical screening is an extremely intimate test and can be unpleasant or difficult for many reasons, yet not attending is the biggest risk factor for cervical cancer. Greater numbers than ever are not attending and if we are to change this, we must listen to what women want and what they need.

"Trying to fit it in as a teacher is tricky."

Greater flexibility over how women receive and book appointments has the potential to positively impact attendance, this includes sending appointment times and dates with the invitation letter (33% say it would encourage attendance), providing opportunities to book online (32%) and sending text reminders (21%).[20]

"The venues and times are very often not convenient, so I have to delay making an appointment until I can make arrangements."

Over a quarter (28%) want more flexible appointments at GP surgeries (rising to 33% of those who have delayed), one in seven (15%) would be more encouraged to go if they could access a drop-in service at their GP surgery, attend a walk-in appointment at a sexual health service (13%), attend at a community clinic (12%), or visit a mobile screening clinic (12%).[21]

"It's very difficult to get through to my doctor's surgery on the phone, you can be on hold for at least 20 minutes on a good day. Also I work full time and it's hard to get an appointment that fits in with my working day."

Among young women who have delayed attending, 25-29 year olds one of the most at risk groups of cervical cancer, over half (57%) would like to be able to attend a different GP surgery other than the one they are registered with, e.g. close to work, and over a third (35%) would like a walk-in appointment at a sexual health service.[22]

Alternative sampling

There is a growing appetite for self-sampling and a building evidence base in favour of the test as part of the cervical screening programme. 80% of women would prefer to do an alternative, non-speculum, test at home rising to 88% among those who have delayed.[23]

Research shows among older women, particularly those who have been put off by the speculum examination, self-sampling may be an effective way of increasing uptake.[24] It can help overcome many of the barriers which result in unequal access to screening including for women who have experienced sexual violence who can take the test into their own hands and those who are housebound. The introduction of HPV primary screening facilitates opportunities for self-sampling and further research is needed to better understand the most effective way to incorporate it as part of the national programme.

4. Recommendations

Every woman should be able to access cervical screening

Cervical cancer is one of the only preventable cancers. This is highly unique and, thanks to our excellent cervical screening programme, many thousands of lives have been saved in the last 30 years. However, far more must be done to reduce the inequalities in access that exist and ensure as many women as possible are able to take up their invitation.

It is only through collaborative national and local action, with clear lines of accountability, oversight and leadership, that this can happen.

1 An audit should be undertaken in each country with Government, NHS, commissioners, providers and public health specialists working together to assess what more can be done to ensure all women can access cervical screening at a location, time and service appropriate to them.

In England, the audit must include a review of the commissioning and delivery structure which has created confusion, inequality and a lack of accountability. This includes adherence to the Section 7A agreement statement that services should optimise attendance rates and maximise accessibility of the service for all groups in the community

2 The Department of Health and Social Care, along with NHS England and Public Health England, must urgently conduct a review of the IT landscape in England and commit to investing in a system which is fit for purpose, fit for the future and safe.

3 Women should have to wait a maximum of four weeks for a cervical screening appointment in primary care. Early morning, evening and weekend appointments should be offered at GP practices and where practices do not provide screening or do not have adequate resource to cope with demand, women must be provided with fully accessible alternatives.

4 Changes to QOF, including those in Scotland, must be closely monitored and not result in screening being deprioritised as this could affect activity to improve access. Action must be taken if a negative impact is detected. Local incentive schemes, targets and KPIs should be considered, especially when coverage is below average.

5 An integrated approach to commissioning and delivering screening must be taken across primary care and sexual health to ensure cervical screening is available in the settings in which populations require. Adequate resourcing and funding must be allocated with procedures in places to prevent over screening.

In England a national budget line for cervical screening in sexual health services will facilitate this offer.

6 Funding is urgently needed for large-scale pilots on self-sampling and it is essential that pilots can count towards national coverage statistics to fully assess the impact. The robust IT system in Scotland presents an opportunity for such a pilot, findings of which will benefit the whole of the UK.

"And so here I am today, stronger, more determined and more responsible. The journey I thought I would take when that first phone call was made after the smear and then getting the all clear has been much longer, emotional, exhausting and scary than I imagined, but I am eternally thankful. By having that smear I am now in control, educated, well informed and know my body and current health. [....] What would I say to other people? Please go for your smear. It may be scary, but there is endless help and support out there. Every woman should be able to get tested."

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