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# Rational care or rationing care? The case of cervical screening across the United Kingdom

#### Hannah Flynn<sup>a,\*</sup>, Philippa Lewis<sup>b</sup>

<sup>a</sup> PenCLAHRC, National Institute for Health Research, Plymouth University Peninsula Schools of Medicine and Dentistry, Devon, United Kingdom

<sup>b</sup> Honorary University Fellow, Plymouth University Peninsula Schools of Medicine and Dentistry, Devon, United Kingdom

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#### ABSTRACT

In 2003, The National Health Service Cervical Screening Programme (NHSCSP) in England modified its recommendation by increasing the age at which to begin screening from 20 to 25. This was on the grounds that normal changes in the cervix before the age of 25 are often identified during screening as being abnormal, resulting in many young women receiving unnecessary treatment at both a significant psychological cost to the patient and a financial cost to the service. In 2011, the cervical screening programme in Northern Ireland was also amended followed closely by Scotland in late 2012. Some 10 years later, Wales finally altered cervical screening policy in January 2013 and now invite women for an initial screen at the age of 25, in line with the rest of the United Kingdom (UK).

The withdrawal of cervical screening from 20 to 24 years in England was the first occasion globally, where a population cancer screening programme was withdrawn. Although the changes in England were perceived by some as "rational care" – as they encourage utilisation of beneficial services while discouraging use of those that may lead to more harms than benefits, many people also believe them to be "rationing care". In fact, even now, a decade on from the policy alterations in England, people are still vociferously exhibiting their discontent at the decision; exacerbated by national media headlines such as: "Denying young women smear tests is a disgrace". Yet with recent, rather alarming analysis of trends in England suggesting a rise in the incidence of cervical cancer in young women, it seems of great public health interest to consider whether such a rise is attributable to reduced cervical screening activity and reflect on whether the decision to alter cervical screening policy for those under the age of 25 was, in fact, a rational and correct decision

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#### 1. Introduction

In 2003, The National Health Service Cervical Screening Programme (NHSCSP) in England modified its recommendation by increasing the age at which to begin screening

*E-mail addresses*: Hannah.flynn@pcmd.ac.uk (H. Flynn), pippa.lewis@doctors.org.uk (P. Lewis). from 20 to 25. This was on the grounds that normal changes in the cervix before the age of 25 are often identified during screening as being abnormal, resulting in many young women receiving unnecessary treatment at both a significant psychological cost to the patient and a financial cost to the service [1]. In 2011, the cervical screening programme in Northern Ireland was also amended followed closely by Scotland in late 2012. Some 10 years later, Wales finally altered cervical screening policy in January 2013 and now invite women for an initial screen at the age of 25, in line with the rest of the United Kingdom (UK).

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<sup>\*</sup> Corresponding author at: Health Services Researcher, PenCLAHRC, Room N6, ITTC Building, Tamar Science Park, Derriford PL6 8BX, United Kingdom. Tel.: +44 1752 762135.

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The withdrawal of cervical screening from 20 to 24 years in England was the first occasion globally, where a population cancer screening programme was withdrawn. Although the changes in England were perceived by some as "rational care" - as they encourage utilisation of beneficial services while discouraging use of those that may lead to more harms than benefits, many people also believe them to be "rationing care" [2]. In fact, even now, a decade on from the policy alterations in England, people are still vociferously exhibiting their discontent at the decision; exacerbated by national media headlines such as: "Denying young women smear tests is a disgrace" [3]. Yet with recent, rather alarming analysis of trends in England suggesting a rise in the incidence of cervical cancer in young women, [4] it seems of great public health interest to consider whether such a rise is attributable to reduced cervical screening activity and reflect on whether the decision to alter cervical screening policy for those under the age of 25 was, in fact, a rational and correct decision.

#### 2. The aetiology of cervical cancer

Cervical cancer is the third most common cancer found in women worldwide and is responsible for more than a quarter of a million deaths each year [5,6]. Specifically, in the UK, approximately 2800 women each year are diagnosed with the disease, resulting in an average of 950 deaths [7]. As of 2009, it has been estimated that the lifetime risk of a female living in the UK developing cervical cancer is 1 in 136 [8]. The aetiology of cervical cancer is well understood, with the disease manifesting as an oncogenic infection usually triggered by the presence of human papillomavirus (HPV). In fact, HPV is reportedly present in 99.7% of all cases; detected through the identification of HPV DNA in cervical cancer cells [9]. Although there are around 140 types of HPV, around 40 specific subtypes affect the genital area. These can be sub-divided into those that are low risk for cervical cancer (such as HPV- 6 and HPV- 11, which are responsible for causing genital warts) and those which are high risk for cervical cancer. The high risk types which occur frequently in cervical cancer include HPV-16 and HPV-18; together these account for over 70% of all invasive cases.

Typical tumour development involves infection by HPV through sexual exposure. In a proportion of cases the HPV genome integrates into cervical cells and the expression of the oncogenes E6 and E7 results in dysregulation of the cell cycle and malignant transformation [10]. Yet for most women, high-risk HPV infections are transient as the HPV is unable to incorporate itself into the cell DNA and disrupt cell reproduction. Within one year, around 70% of new infections do clear and approximately 90% of new infections clear within two years [10]. However, persistent infection by a high-risk HPV type is the most important causal factor for the development of cervical pre-cancerous and cancerous lesions.

#### 3. Vaccinating against HPV

A vaccine specifically designed at preventing infection from HPV has been developed and is currently offered as part of national programmes in many countries. However, concerns over the efficacy of the vaccine have recently emerged. Reports suggest that the HPV vaccine only protects against 4 out of the 200 HPV types, therefore not conferring 100% protection [11]. In fact, trial results suggest that the vaccine only offers 70% protection against all forms of HPV [12]. This leaves a 30% chance, once vaccinated, of being infected with another form of HPV which could later develop into cancer. As it will take many years for the vaccine's long term effects, side-effects and outcomes with respect to cervical cancer morbidity to become evident, cervical cancer screening remains the primary preventive strategy and diagnostic tool for identifying this form of cancer in women [13,14].

#### 4. Cervical cancer screening

Cervical screening is primarily utilised to reduce the incidence of the disease through the detection of presymptomatic cancer and precancerous lesions of the uterine cervix [15,16]. The screening itself is based upon the premise that normal cervical epithelium progresses through from cervical intraepithelial neoplasia (CIN) to invasive cancer [17]. The CIN grading system distinguishes three particular stages: CIN 1 (mild dysplasia); CIN 2 (moderate dysplasia); and CIN 3 (severe dysplasia). It is important to note however, that not all cases of CIN 1 and 2 develop into cancer and even with more severe changes in CIN3, research suggests that only 50% of these cases will progress to become cancerous [18]. However, if cancer does progress to become invasive, it is thought that in more than 90% of these cases the invasive disease occurs within a small area of the cervix known as the transformation zone [5]. The progression here is slow, which allows changes to be detected early through cytological screening [19].

In addition to being an early detection and diagnostic tool, cervical screening can also be utilised to reduce the morbidity and mortality caused by cancer which has already progressed [20]. In such instances, cervical screening can detect asymptomatic micro-invasive and invasive cancers which would normally go unnoticed. This improves the chance of a positive prognosis following appropriate treatment [17].

#### 5. Why did screening policy change?

The appropriate age at which to start screening is heavily dependent upon three key determinants: the underlying age-specific incidence of cancer, the (possible age-specific) effectiveness of the screening test to detect pre-cancerous lesions, and the effectiveness of treatment for screen-detected lesions [21]. In understanding why UK policy altered, it is therefore necessary to consider the following.

#### 5.1. Low incidence rates

The basis for the initial research into the effectiveness of cervical screening with age, centred upon the apparent low incidence rates of cervical cancer amongst those under 25. In 2008, the estimated incidence of cervical cancer in those aged 20–24 was just 3.2/100,000, with only 63 cases

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