

## 'Jade Goody Effect': Increased Attendance at a Cervical Screening Program in the Portsmouth Hospitals

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### Abstract

We evaluated the impact of a celebrity's diagnosis and death of cervical cancer on the numbers of patients presenting for smear and colposcopy. We conducted a retrospective case-controlled cohort study comparing number of cytology samples, cases referred for colposcopy in 9/2008-6/2009 and their outcomes after a young celebrity's diagnosis and death of cervical cancer with numbers referred in the same period the year prior. There was a 10.6% increase in the number of cytology specimens (41843 vs. 37838) and colposcopy referrals increased by 64% (1270 vs. 775). High grade dyskaryosis or cancer cases increased by 109% (582 vs. 278), cervical cancer being diagnosed in 21 versus 14 patients (50% increase) but as a proportion of referrals remained similar (1.8% versus 1.64%). The publicity around death of cervical cancer had a significant effect on the uptake of cervical screening resulting in higher detection of high grade dyskaryosis and cervical cancer.

**Keywords:** Cervical Cancer; Screening; Health Behaviour

### Introduction

The impact of a celebrity suffering or dying from a specific diagnosis is an interesting phenomenon. Although health providers and screening programs utilise publicity in order to maintain coverage above certain threshold, it is often the personal stories in the media that cause surge in the screening program attendances. In the past we observed such behaviour following Angelina Jolie undergoing BRCA1 gene testing [1], called by some the "Angelina Jolie effect". Prior to this, the cervical cancer screening in the UK underwent a similar surge in attendance following the diagnosis and death of Jade Goody. This 27-year-old English celebrity known from the Big Brother was diagnosed with cervical cancer in August 2009 and died 7 months later in view of late diagnosis.

In the UK the cervical screening program in 2008/9 was based on cytology and HPV (human papillomavirus) testing collected at the GP practices every 3 years, starting from the age of 25. Although Jade Goody had health problems and reportedly had "rogue cells removed from her cervix" three times, she ignored the invite for the fourth treatment after the delivery of her second child out of fear [2]. So, although her late diagnosis wasn't a failure of screening services per se, the negative attention it created led to a surge in attendances for

smear tests and subsequently increased referrals to the colposcopy services, called by media and adopted by research papers as the "Jade Goody effect" [3].

### Aim of the Study

At the tenth anniversary of her death, this study aims to quantify the impact of celebrity's diagnosis and death of cervical cancer on the uptake of cervical screening invitation in the Portsmouth hospitals catchment area.

### Materials and Methods

This was a retrospective observational case-controlled study aiming to assess the workload in cytology and colposcopy services at Portsmouth Hospitals NHS Trust during the 9 months following the announcement of Jade Goody's diagnosis of cervical cancer. We compared the number of cytology samples, referrals to colposcopy services and the respective diagnoses with the caseload from the same 9 month-period the year prior. We also compared the number of patients who did not attend (DNA) their appointment (without prior cancellation or rescheduling).

### Time period

It is not very clear how long such effect on health behaviour lasts so we chose a year prior to the event to eliminate potential bias. Also, the screening system in the UK underwent changes in 2012, which makes later comparison with the year in question more difficult.

### Participants

We included patients of all age groups, subdivided in the analysis by age as < 25, 25 - 49, 50 - 64, > 65. All cytology samples and colposcopy referrals were included, irrespective of reason - either as a routine call/recall within the screening program or unscheduled appointment for suspicious symptoms.

### Colposcopy referrals

Colposcopy referrals were analysed by the group - women with abnormal smear from a routine recall or unscheduled smear, including patients younger than 25 years. The outcome of colposcopy referrals was recorded as colposcopy findings or the final histological diagnosis when available from diagnostic biopsy, large loop excision or hysterectomy. Where more than one specimen were received the most adverse histology was used. Cases were labelled as 'requiring ongoing surveillance' where colposcopy was unsatisfactory necessitating further appointments. Staging of the detected cancers followed the FIGO classification [4].

### Statistics

For the statistical analysis we have used the SPSS system, calculating the difference between the two cohorts using T test with p value < 0.05 considered statistically significant.

### Results

#### Cytology samples

The study period was from 9/2008 to 6/2009. There was a 10.6% increase in the number of cytology specimens processed by Portsmouth cytology services (41843 vs. 37838) in all age groups (Table 1). The number of unscheduled smears increased by 63% (from 775 to 1270 patients). The amount of women attending their first smear in this group marginally decreased (127 patients to 102 patients) but

when presented as a percentage of the unscheduled cohort, they represented 51% decrease which was statistically significant ( $p < 0.001$ ). The amount of DNA appointment also dropped in all groups, but most markedly in the 25 - 49 age group (from 5% to 1%).

Cytology Results	Control Period		Study Period	
	Number	% of total caseload, n = 37838	Number	% of total caseload, n = 41843
Inadequate	48	0.13%	45	0.11%
Borderline	385	1.02%	386	0.92%
Mild dyskaryosis	164	0.43%	257	0.61%
Moderate dyskaryosis	168	0.43%	302	0.72%
Severe dyskaryosis	102	0.27%	263	0.63%
Atypical glandular cells	7	0.018%	7	0.016%
Possibly invasive cancer	1	0.002%	10	0.02%
Referrals to colposcopy	775	2.05%	1270	3.04%
Normal cytology	37063	97.95%	40573	96.97%

**Table 1:** Cytology results.

N: Number.

### Colposcopy referrals

In the control group 37838 women were screened leading to 775 referrals to colposcopy (2.05%). In the study group, 41843 women were screened leading to 1270 abnormal results that needed referral (3.04%). That represents 1.5-fold increase in referrals, which was statistically significant ( $p < 0.001$ ). We provide a breakdown of the types of abnormal smears (Table 1) to see what the source of this increase was. The percentage of the inadequate and the borderline smears didn't change much (0.13% to 0.11% and 1.02% to 0.92% respectively) but the absolute numbers of the mild, moderate and severe dyskaryosis almost doubled in the study group.

Outcome	Only unscheduled cases				All cases			
	Control period		Study period		Control period		Study period	
	Number	% of total, n = 307	Number	% of total, n = 459	Number	% of total, n = 775	Number	% of total, n = 1270
Cancers	11	3.60%	15	3.27%	14	1.80%	21	1.65%
CGIN	8	2.60%	4	0.87%	10	1.30%	5	0.39%
CIN1	38	12.40%	57	12.40%	141	18.20%	251	19.80%
CIN2	40	13.03%	84	18.30%	112	14.50%	217	17.10%
CIN3	97	31.60%	141	30.70%	182	23.50%	251	19.80%
No dysplasia	85	27.70%	122	26.60%	226	29.20%	364	28.70%
Ongoing surveillance	11	3.60%	29	6.30%	51	6.60%	146	11.50%
DNA	17	5.50%	7	1.50%	39	5.03%	15	1.20%

**Table 2:** Colposcopy results in unscheduled cases and all cases.

CIN: Cervical Intraepithelial Neoplasia; CGIN: Cervical Glandular Intraepithelial Neoplasia; DNA: Did Not Attend; n: Number.

As shown in table 2, the cancer detection rate per abnormal smear has dropped insignificantly from 1.8% in the control group to 1.65% in the study ( $p = 0.86$ ). The percentage of women put on ongoing surveillance went up from 6.6% to 11.5% in the study group ( $p < 0.001$ ). There was a statistically significant increase in patient compliance to attend as the DNA appointment percentage fell from 5.03% to 1.2% in the main age group ( $p < 0.001$ ).

**Cancer detection**

The percentage of cervical cancers out of all smears (cytology specimens) increased from 0.03% to 0.04%, which was not statistically significant ( $p = 0.469$ , table 2). The 'Jade Goody effect' surprisingly didn't lead to an increased detection of cancers in the group aged > 50 years (drop 6 cases to 3 cases), while in the group aged < 50 years the detection rate went up by 125% (8 cases to 18 cases, table 3). This also changed the ratio of cancers diagnosed before 50 years/after 50 years from 4:3 (8 and 6 cases in control period) to 6:1 (cases 18 and 3 cases in the study period).

The main increase in detection was in early stages - 300% increase in detection 1A1 stage cervical squamous carcinoma (3 patients versus 9), and 66.6% increase in detection 1A1 stages of cervical adenocarcinoma (3 patients versus 5), while there was a drop in cervical squamous carcinoma 1B1 66.6% (from 3 to 1 patient). In each group there was one patient with cervical adenocarcinoma stage 1B1 and cervical squamous carcinoma stage 2B, which still represents drop in incidence.

Age	Group	No Dyskaryosis		More surveillance		CIN1		CIN2/3		Cancers/ CGIN		DNA		Total
< 25	Control	7	20%	4	11%	7	20%	12	34%	1	3%	4	11%	35
	Study	7	17%	11	27%	6	15%	14	34%	0	0%	3	7%	41
25 - 49	Control	160	27%	32	5%	105	18%	244	42%	16	3%	30	5%	587
	Study	229	24%	110	12%	189	20%	390	41%	21	2%	11	1%	950
50 - 65	Control	58	40%	12	8%	29	20%	37	25%	5	3%	5	3%	146
	Study	119	48%	24	9%	56	21%	63	24%	4	1%	1	0%	267
> 65	Control	1	14%	3	43%	0	0%	1	14%	2	27%	0	0%	7
	Study	9	75%	1	8%	0	0%	1	8%	1	8%	0	0%	12

**Table 3: Colposcopy and histology results across age groups.**

*CIN: Cervical Intraepithelial Neoplasia; CGIN: Cervical Glandular Intraepithelial Neoplasia; DNA: Did Not Attend.*

There was 1 case of pelvic metastasis from breast cancer recurrence, which was indirectly picked up with smear showing severe dyskaryosis. The screening program incidentally detected 3 cases of endometrial cancer in both the study group and the control group. The percentage of all cancers (targeted and incidental) detected through screening per total number of smears increased from 0.02% to 0.05%, although this was not statistically significant ( $p = 0.473$ ).

The variation across the study and control months in referrals to colposcopy is shown in figure 1. The surges were the highest in September 2008 (within 1 month post Jade's diagnosis) and March (Jade's death). These increases in referrals were statistically significant ( $p < 0.001$ ).

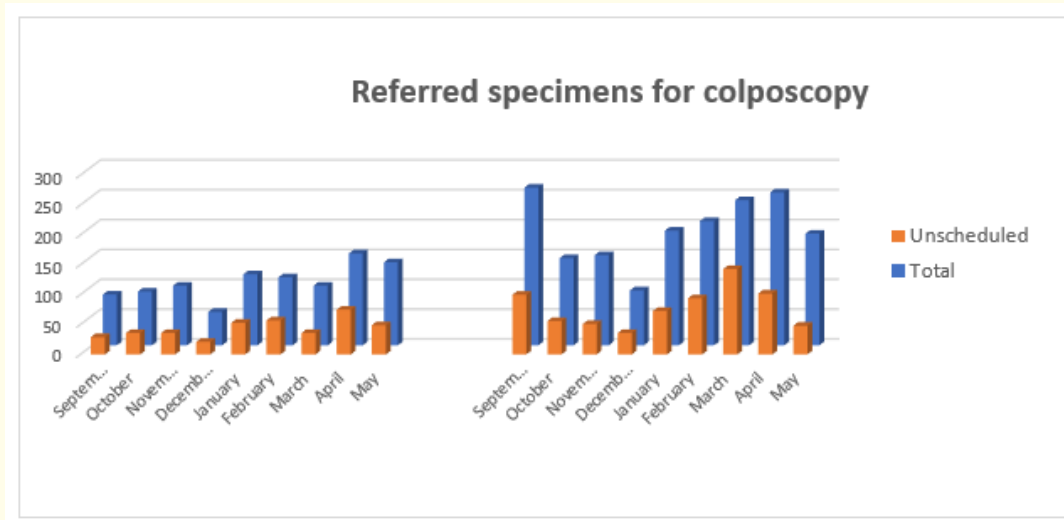


Figure 1: Referred specimens to colposcopy per month.

### Discussion and Conclusion

On the tenth anniversary of Jade Goody’s death this article adds to the body of evidence describing the effect, which is demonstrated by an improved uptake of cervical cancer screening. This led to a higher detection rate of moderate (168/0.43% versus 302/0.72%) and severe dyskaryosis (102/0.27% versus 263/0.63%) and suspected invasive cancer on cytology samples (1/0.002% versus 10/0.02%). Although the number of cancers detected was higher in the study group, the proportion was similar (1.80% and 1.65%), which demonstrates consistent diagnostic performance of the program. Similarly, the outcome of unscheduled smears and subsequent colposcopy were mostly similar across the two groups. The increased patient compliance with the screening program was reflected in less DNA appointments in the study group (5% versus 1% in the 25 - 49 age group).

The main strength of this study is the in-depth breakdown of cytology and colposcopy outcomes by type of changes and age of patients. As such we were able to demonstrate that increasing awareness improves compliance with the screening program (higher detection of precancerous and cancerous stages, less DNA appointments) without burdening the system with unnecessary referrals stemming from increased public anxiety. Another strength is the large cohort of patients analysed, which is particularly important in accurate interpretation of results with very small numbers (21 detected cervical cancers out of 41,843 samples).

The main weakness of this publication is the retrospective design and regional setting, which can represent bias since demographical characteristics and socioeconomic status influence health behaviour. As shown by Marlow, *et al.* [5] younger women and patients of lower socioeconomic status were more likely to be influenced by Goody’s story. Therefore, our results may not be transferable to other regions or countries. Another limitation (although it is not a study weakness per se) is reflected in the increased number of patients under surveillance, which obscures the true number of patients’ final diagnosis. With the media attention, not only women got more anxious about missing life-threatening cancer, but also colposcopists were more cautious in discharging patients from follow-up.

Our results are similar in many aspects to the previously published data on the Jade Goody effect, such as general increase in number of patients attending screening program, lower rate of DNA appointments and proportionately increased detection of high grade lesions

and cancers [3,6]. Casey, *et al.* focused also on the screening-naïve patients and showed a 2.23-fold increase in high-grade-disease symptomatic women attending their first smear post Goody's diagnosis. This suggests that the publicity might encourage screening in a population at high risk too anxious to go to doctors. The same authors also analysed surges by year quarters showing increase around diagnosis and reported death, while our study provided data on individual months, demonstrating very short response time (surge in screening uptake within 1 month from breakthrough announcements - diagnosis, death).

Further studies should focus on using information from studies like this in order to develop a robust system of attention reinforcement, possibly in cooperation with social media. In more than 1200 articles in the newspapers and other media regarding Jade Goody's journey, only less than 10% offered some medical information, such as mentioning screening, vaccination or risk factors for cervical cancer [7]. This study can also serve as a background information for researches in health behaviour, aiming to improve compliance with the screening programs.

In summary, Jade Goody's case should not be forgotten as its effect on health behaviour of women in 2009 resulted in an increased uptake of cervical cancer screening and considering the increase in high grade and cancer detection possibly saved up to twice as many lives.

### Impact Statement

#### What is already known on this subject?

Jade Goody effect has been described in the literature as a surge in the cervical cancer screening uptake following her death in 2009 and it has been documented in scientific papers on national and regional level.

#### What do the results of this study add?

We offer detailed analysis of various subtypes of cytological and histological outcomes, demonstrating that the main increase in detected abnormalities (as a proportion) were moderate and high dyskaryosis, which represent the main target group for colposcopy (i.e. suspected advanced precancerous or micro-invasive stages). We also demonstrate that the main change in uptake is among women in Jade Goody's age group (25 - 49), rather than older population (> 50). Lastly, we show the increase in cervical cancer detection in very early stages (1A1) and proportionate drop in other stages (1B1, 2B).

#### What are the implications of these findings for clinical practice and/or further research?

By publicity the uptake increased by almost 11%, which translated in extra 7 cases of cervical cancer detected in our cohort. Screening program directors may use the published data as a benchmark for efficiency of new publicity-oriented activities, encouraging people to engage with the screening.

### Acknowledgement

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### Disclosure

Authors have no conflicts of interest.

### **Data Availability**

Data are available upon request from the corresponding author.

### **Ethics**

This study follows the principles of the Declaration of Helsinki and as an observational descriptive research does not require ethical approval.

### **Conflicts of Interest**

None declared.

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