

RESEARCH ARTICLE

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# Improving the management of people with a family history of breast cancer in primary care: before and after study of audit-based education

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## Abstract

**Background:** In England, guidance from National Institute for Clinical Excellence (NICE) states women with a family history of breast cancer presenting to primary care should be reassured or referred.

We reviewed the evidence for interventions that might be applied in primary care and conducted an audit of whether low risk women are correctly advised and flagged.

**Methods:** We conducted a literature review to identify modifiable risk factors. We extracted routinely collected data from the computerised medical record systems of 6 general practices (population approximately 30,000); of the variables identified in the guidance. We implemented a quality improvement (QI) intervention called audit-based education (ABE) comparing participant practices with guidelines and each other before and after; we report odds ratios (OR) of any change in data recording.

**Results:** The review revealed evidence for advising on: diet, weight control, physical exercise, and alcohol. The proportion of patients with recordings of family history of: disease, neoplasms, and breast cancer were: 39.3%, 5.1% and 1.3% respectively. There was no significant change in the recording of family history of disease or cancer; OR 1.02 (95% CI 0.98-1.06); and 1.08 (95% CI 0.99-1.17) respectively. Recording of alcohol consumption and smoking both increased significantly; OR 1.36 (95% CI 1.30-1.43); and 1.42 (95% CI 1.27-1.60) respectively. Recording lifestyle advice fell; OR 0.84 (95% CI 0.81-0.88).

**Conclusions:** The study informs about current data recording and willingness to engage in ABE. Recording of risk factors improved after the intervention. Further QI is needed to achieve adherence to current guidance.

## Background

Breast cancer is the most common cancer in women and accounts for over 30% of new cancers in females, in the UK (Additional file 1: Box S1) [1-3]. National Institute for Health and Clinical Excellence (NICE) guidelines for familial breast cancer highlight the importance of recording family history as a predictor of risk for breast cancer. The key elements of the NICE guidelines are that people with a family history should be given lifestyle advice about their breast cancer risk including information about: hormone replacement therapy (HRT) and oral contraceptives, lifestyle (including diet, alcohol, etc.), breastfeeding, family size and timing. The guidance also

suggests that people with modifiable risk factors should have these managed in primary care. The level of risk depends on: the number of affected relatives, closeness of relationships and the age at which the relatives developed breast cancer; the guidelines recommend the use of information from family history which should be taken into account in assessing risk and in deciding whether and when to refer, and when to reassure [4].

Primary care has a role in prevention, promoting increased awareness, detecting presentation early as well as referral of suspected cancers. Reduction in risk through prevention is a core function of primary care. Additionally, early detection and management of cancers is important and clearly, recording of family history may help clinicians consider a diagnosis of cancer, stratify risk and make an appropriate decision about referral. The UK Cancer Reform Strategy [5] supports early diagnosis. The Royal

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College of General Practitioners (RCGP) National Audit of Cancer Diagnosis reported that 87% of cases presented with symptoms within primary care [6].

Many women consult their general practitioners (GP) each year with concern over breast cancer risk. 40–50 people with a positive family history of breast, ovarian or bowel cancer are found on a GPs list of 2000 patients [7]. Women with increased risk based on a positive family history as described within NICE guidelines may be advised to undergo a range of different forms of surveillance, genetic testing or even preventive management [8]. However, many can be reassured that their risk is not increased above that of the general population. These consultations also provide an opportunity to record non-modifiable risk of the woman and to give risk-reducing advice such as modification of lifestyle and environmental factors.

Audit, seeks to improve patient care and outcomes through a systematic review of care against explicit criteria and is an established method of promoting quality improvement in the care of patients. The Royal College of Physicians report “Teams without Walls” calls for greater use of audit as a means of continuous improvement [9]. English primary care lends itself to conducting clinical audit [10]. There is a registration based system where individuals can only register with one practice, and that practice acts as a gatekeeper to secondary care. Everyone has a national unique identifier, an NHS number, which helps identify their records. Primary care is universally computerised, nearly all clinicians complete computer records at the time of the consultation. Many practices have computerised since the 1990s; with data quality improving considerably after pay-for-performance based on computerised records was introduced in 2004 [11,12].

We carried out this study to determine whether an audit-based education improved risk factor management in women who have a low risk of breast cancer; using improved recording of family history and its risk factors in primary care computerised medical record systems as our audit criteria. The focus on the audit was to record family history and record risk factors where there was evidence that intervention in primary care affects outcome.

## Methods

### Overview

This is a before and after study of audit-based education (ABE), a non-judgemental quality improvement intervention to explore concordance with guidance in the management of people with a family history of breast cancer in primary care. The study consisted of two phases: (1) A literature review to identify the lifestyle factors that may reduce the risk of breast cancer, which might form part of a quality improvement (QI) initiative in this domain. The objective of the literature review was to inform

what elements of the NICE guidance might be amenable to interventions carried out in primary care; (2) Piloting the audit-based education process developed in the first phase in six volunteer practices.

### Literature review to explore the association of lifestyle factors with breast cancer

The literature review was conducted to identify the risk factors associated with breast cancer. A comprehensive search of numerous databases was carried out. The searches were limited to human subjects, English language and studies from the last ten years. The searches identified 1119 articles including 312 reviews. The initial search identified articles prior to 1/1/2010, and was used to inform the components of the audit based education programme. It has subsequently been reviewed to include major literature published since the start of the study.

Inclusion criteria;

- Data representative of the general population.
- Articles which discuss modifiable risk factors at population level risk.
- Articles only related to breast cancer and not breast cancer-associated problems (e.g. lymphedema in breast cancer patients).
- Studies of risk assessments with confidence intervals or at least P values.

Exclusion criteria:

- Small sample size (n) less than 50.
- Articles in relation to other issues such as familial risk factors and diagnostic tests (e.g. mammography).

The outputs of the searches were sorted based on title and abstract into those to be definitely excluded and those to retain. Findings from about 66 full texts which included systematic reviews and primary articles were used for the literature review. (A full copy of the literature review is available online at: [www.clininf.eu/fhbc](http://www.clininf.eu/fhbc)).

### Audit process

We developed an audit based education (ABE) intervention to support this process (Additional file 1: Box S2) [13]. ABE is a quality improvement (QI) intervention developed over the last 15 years by SdeL et al., which provides general practice based education, peer support and documents the gap between achievement and guidelines. In observational studies this intervention improved the quality of cardiovascular disease management [14,15], and has also been used in a quality improvement trial [16]; where it has produced a modest but statistically significant drop in systolic BP compared with usual practice [17]. The theoretical basis for this intervention is that

audit, feedback and professional meetings are known to have small but positive effects on the quality of data recording [18,19]. Any change in data coding that takes place might be explained by *control theory*, which suggests that improvements in the quality of data recording is most likely if feedback is accompanied by a target or action plan, ideally in writing [20].

In this study, the educational component included briefing about the importance of breast cancer and its family history (Additional file 1: Box S1 gives an overview). Additionally, we designed data extraction queries based on the output from the literature review. As family history and risk factors can be represented by a wide range of codes we used an established method to ensure we comprehensively extracted the relevant data. The variable list extracted is available on-line at: <http://www.clininf.eu/projects/fhbc>.

We extracted data from general practice EPR systems using Morbidity Information Query and Export SynTax (MIQUEST), a data extraction method sponsored by the Department of Health of England. We processed these data using SPSS (Version 18) for statistical analysis [21]. We report the completeness of recording of audit variables, demographics and key co-morbidities. We planned to eventually develop self-audit tools for general practice similar to those we had developed to identify errors in the coding of diabetes [22,23]. Any inconsistencies between in coding between baseline and subsequent collection; were corrected by creating a mapping between sets (Additional file 1: Table S2).

#### **Pilot audit based-education**

We collected initial data from six volunteer practices in South London and fed back these data to representatives of the pilot practices. The practices developed an action plan. This involved them deciding how they might raise general awareness of family history recording, and recording of lifestyle factors by feeding back the presentations from the baseline meeting, as well as discussing the workshop outputs at meetings held at general practices. The key points from the workshop were noted down and lead GPs who agreed to disseminate through their usual practice business processes. We then conducted a second data collection process with these practices, and then fed this data back to complete the audit cycle.

The data are reported as two cross-sections at two time periods, approximately 6 months apart. We used two cross sections at two different time points so that the data included recording of lifestyle factors about new patients who registered during the audit period. We hypothesised that a practice responding to the intervention might be most likely to ask new patients about any family history of breast disease.

We used Altman's method to assess any differences between before and after readings; this method is designed to be used to compare two cross sections measured at different time points [24]. We have reported crude and standardised rates of recording. The participant general practitioners agreed an action plan at the baseline presentation, which was shared with the rest of their practice. We report the characteristics, such as patient demographics, of the practices using descriptive statistics: mean and standard deviation (SD). We compared comparable data sets using Pearson Chi-square to report differences in proportion, and we used odds ratios (OR) and 95% confidence intervals to explore whether data recording by general practitioners had increased from pre-to post audit.

A baseline data collection (round 1) was made to investigate the extent to which NICE guidance was being followed in terms of the provision of lifestyle advice to women with a low risk of breast cancer who can be reassured and managed in general practice. We planned a data quality workshop (DQW) which is probably the most important component of the QI process; it is an interactive process involving representatives of each practice. The objective of the DQW was twofold: (1) To share baseline levels of recording between general practices and their general practitioners; (2) To recognise the value of recording family history and implementing an action plan for improved recording and management. The second data collection (round 2) served to measure any change in the quality of data recording after six months. An Example of a DQW presentation is available online at: [www.clininf.eu/fhbc](http://www.clininf.eu/fhbc).

#### **Ethical considerations**

This intervention meets the National Patient Safety Agency (NPSA) and National Research Ethics Service (NRES) descriptions of clinical audit [25]. Hence ethics approval was not sought. There was no attempt to influence the decisions of clinicians and patients.

#### **Results**

##### **Overview**

Although there are many risk factors associated with a family history of breast cancer; there is a much more limited number where intervention is known to affect outcome, which we included in the audit. Whilst recording of the numbers of cases of a family history of breast cancer did not increase, the odds ratio of recording risk factors where interventions might affect outcome did. However, practitioners felt they lacked knowledge of how best to record. Also they felt that their computer system did not readily support recording of family history.

### Findings from literature review about risk factors associated with breast cancer

The broad consensus from the literature review about risk factors associated with breast cancer is summarised below. These formed the “long-list” of potential variables that might be included in our audit-based education, quality improvement intervention.

- 1. Oral contraceptive pills (OCP).** There is evidence of an increase in the risk of breast cancer during use of OCP with higher dosage being related to higher risk [26-29]. After cessation of treatment the risk gradually decreases over time and disappears about 10 years after discontinuation of OCP [26,27].
- 2. Hormone replacement therapy (HRT).** Long term HRT apparently increases breast cancer risk especially when used from 50 years of age [30]. The risk is greatest for combined oestrogen-progestogen preparations (CHRT)[26,31,32] and lowest for oestrogen-only preparations of HRT (ERT) [33,34]. This effect is limited when Body Mass Index (BMI)<sup>5</sup> is less than 25 kg/m<sup>2</sup>. According to the recommendation by the British Menopause Society, HRT may be given for symptom relief in the short term (up to 5 years) but long term use needs to be assessed individually at regular intervals [35].
- 3. Breastfeeding.** Breastfeeding is reported to be protective for breast cancer [36,37]. Decreased risk is related to average length of time of breastfeeding [38,39]. Risk of breast cancer seems to decrease by approximately 4.3% for every 12 months of breastfeeding [27].
- 4. Alcohol.** It is reported that there is about a 10% increased risk of breast cancer for each additional unit (10–12 g) of alcohol per day [40]. Risk appears to be 28-50% greater for those who typically consume approximately two drinks per day compared to those who do not drink [41-44]. Consumption of one drink per day or less does not significantly affect risk of breast cancer [45-47]. There is no difference in risk based on type of alcohol consumed [48].
- 5. Obesity.** Increased weight from younger to older ages is reported to be associated with statistically significant increased risk of breast cancer for pre- and post-menopausal women [49-53]. A study reported that obese (BMI at least 30 kg/m<sup>2</sup>) post-menopausal women have 31% excess risk compared to those whose BMI is less than 25 kg/m<sup>2</sup> [54]. Moreover, post-menopausal obesity seems to be an important predictor of fatal breast cancer [55]. There are claims that there can be a protective effect on the development of cancer by maintaining normal BMI [56].
- 6. Diet.** Studies report that high consumption of fruit and vegetables may offer significant protection against breast cancer [57-60]. Meat, especially red meat intake, is reported by some studies to be associated with increased breast cancer risk [61-63], though a few studies found no association [64,65]. A review of 13 prospective studies claim that higher fat intake does not confer excess risk of breast cancer [66]. Polyunsaturated fatty acids, especially from fish or shellfish, may offer protection, and saturated fat is likely to increase the risk of breast cancer [67-69]. However, data about other dietary factors have been inconsistent.
- 7. Physical activity.** Increased total activity and recreational physical activity especially after menarche may decrease risk of breast cancer in postmenopausal women [70,71]. Between 75 and 150 minutes per week of brisk walking appears to decrease risk of breast cancer by 18% and strenuous physical activity at age 35 (rather than at 18 or 50 years) seems to result in a 14% risk reduction [71]. There seems to be a graded reduction in risk with increasing years of exercise [72]. A study reports that postmenopausal women with sedentary occupations have 49% higher risk of breast cancer than women in more physically demanding occupations [73].
- 8. Smoking.** There is evidence that smoking especially during the period between menarche and first childbirth may increase the risk of breast cancer [74]. The increase in risk may be from 32% to 83% in smokers [75,76].
- 9. Reproductive factors.** Overall risk of breast cancer in both pre- and post-menopausal women seems to increase with increasing age of first childbirth or first full term pregnancy, as well as with low parity and a nulliparous state [37,77]. Women with an age at first childbirth of 30 years or more are 5 to 7 times more likely to develop breast cancer compared with those aged less than 20 years [78,79]. Each additional birth may confer an average 10% reduction in breast cancer risk [80].
- 10. Severe lifetime events.** One study found that after adjustment for age, menopause and other potential confounders, severe life events increase the risk of breast cancer by 11 times [81].
- 11. Chemicals and radiation.** High exposure to polycyclic aromatic hydrocarbons may increase breast cancer risk by 50% [82]. Long term (more than 15 years) exposure to organic solvents, asbestos and vitreous fibres is likely to increase risk by 1.5 to 2 times [83]. Medium and high levels of occupational exposure to ionizing radiation, combined exposure to chest x-rays and occupational



radiation as well as therapeutic radiation (e.g. for skin problems) are reported to increase breast cancer risk [84-86]. Exposure to sunlight may, on the other hand, be protective for breast cancer [87].

12. **Healthy lifestyle index.** A recent case control study demonstrated that healthy lifestyle significantly reduces the odds of having breast cancer in both pre and post-menopausal women. Healthy lifestyle index was considered as the combined effect of moderate and/or vigorous-intensity physical activity, low consumption of fat, processed foods, refined cereals, complex sugars, and the avoidance of tobacco smoking and alcohol consumption [88].

### Findings from literature review about effective interventions in reducing the risk of breast cancer

Our final list of variables for inclusion into the audit-based education programme is those where change may reduce the risk of breast cancer; they include: weight control, dietary change, physical activity and reduction of alcohol intake. These are all variables readily extracted from primary care computer systems.

1. **Weight control.** Reduction in body weight is reported to reduce breast cancer risk, especially in postmenopausal women [49,89].
2. **Diet.** The evidence for effectiveness of dietary change in reducing breast cancer risk is relatively limited. A randomised trial in women with early stage breast cancer reported that a reduction in the amount of dietary fat of 18-19 g per day was associated with a decreased risk of breast cancer recurrence [90].
3. **Physical activity.** A minimum of 150 minutes and up to 420 minutes per week of moderate to vigorous intensity physical activity may decrease the risk of breast cancer [91].

4. **Alcohol intake reduction.** There is evidence that decreasing (by one drink or less per day) or stopping alcohol consumption altogether may reduce breast cancer risk in post-menopausal women [49,89].

### Practice profile and inter-practice variation

The practices were drawn from across London, they were largely in mixed areas with a social class distribution approximating to or just below the national average; two practices could be described as inner city, and one practice was located in a more affluent area. The practice population had a population younger than the national average, with an excess of younger women (Figure 1); The mean age recorded in the first round of data collection was 33.74 years while that recorded in the second round was 32.90 years (Additional file 1: Table S1). The practice populations had grown from a combined list size of 27,148 to 31,794 between the first and second data collections, though there was no statistical difference in the age-sex profile (Figures 2 and 3). Most of this growth occurred in practice 6 (out of the 6 practices taking part), which accounted for two-thirds of this growth (3,049/4,646 = 65.6%) (Additional file 1: Table S1). There was variation in the recording of data between practices before and after the intervention across the whole population (Chi-square  $p < 0.001$ , Table 1). No single practice had the highest level of recording in all domains.

### Pilot audit-based education intervention

The baseline data collection of lifestyle factors took place as planned with the exception of the technical problems reported above. The focus of the practices action plan was on improving quality of data recording at new patient medicals.

We extracted a dataset that would provide insight into whether the elements of a family history of breast cancer identified in the literature review were recorded.

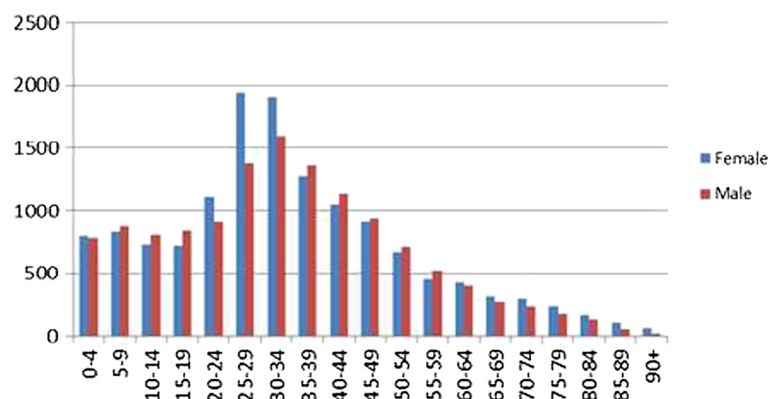


Figure 1 Age-sex profile of the combined practice populations.

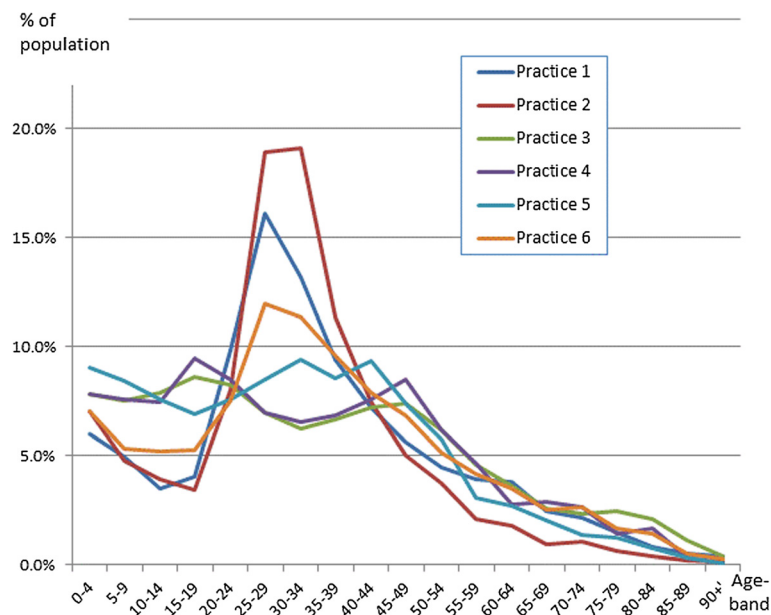


Figure 2 Age-band distribution by practice.

Only 1.3% of the female adult population had a history of breast or bowel cancer recorded. This increased to 1.8% in the after group, with this history being recorded for 2.8% of new patients (Table 2). Across the risk factors there was a large rise in the recording of information about family history of cancer in new

patients; though overall FH recording was a little lower in new patients (40.6% compared with 43.0%). Alcohol consumption and smoking were consistently almost universally recorded; approximately three-quarters got lifestyle advice. New patients had both less contraceptive needs and pregnancies recorded; though had much

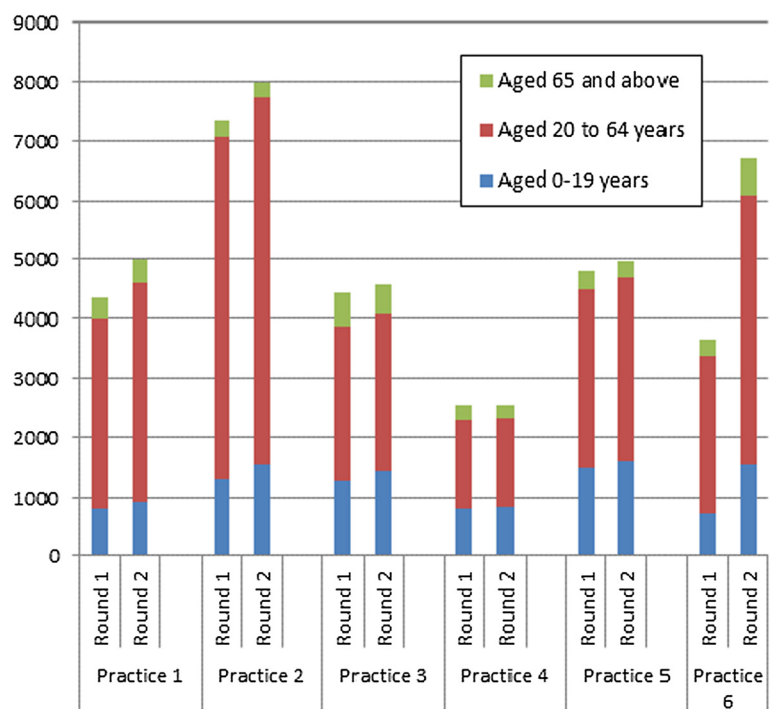


Figure 3 Age-bands at first and last data collections.

**Table 1 Variation in recording of key audit variables between practices for the first and second data collections in Adult Population (over 18 years)**

%	All family history	Family history of cancer	Alcohol consumption	Smoking status	Lifestyle advice	Practice population (n)
<b>First data collection</b>						
Practice 1	33.6	2.8	89.2	97	75.8	3627
Practice 2	36.7	4.9	84.8	97	74.7	6158
Practice 3	34.4	7.4	65.3	96.5	74.7	3315
Practice 4	11.6	1.3	80.1	98.6	58.8	1841
Practice 5	57.5	10.2	73.8	95.6	81.4	3462
Practice 6	53	2.1	95.8	98.7	75	3000
<b>All</b>	<b>39.3</b>	<b>5.1</b>	<b>81.9</b>	<b>97.1</b>	<b>74.6</b>	<b>21403</b>
<i>Chi square</i>	p < 0.001	p < 0.001	p < 0.001	p < 0.001	p < 0.001	p < 0.001
<b>Second data collection</b>						
Practice 1	37.8	6.2	96.2	98.8	75.2	4161
Practice 2	40.5	8.1	89	98.1	77.7	6596
Practice 3	33.5	6.8	73	97.5	79.8	3285
Practice 4	13.6	2.5	80.6	99.2	50.7	1824
Practice 5	51.2	5.1	76.3	97.5	73.7	3512
Practice 6	45.7	1.9	90.8	97.2	60.5	5314
<b>All</b>	<b>39.8</b>	<b>5.4</b>	<b>86</b>	<b>97.9</b>	<b>71.3</b>	<b>24692</b>
<i>Chi square</i>	p < 0.001	p < 0.001	p < 0.001	p < 0.001	p < 0.001	p < 0.001

The proportions were different for all key variables.

higher requirements for oestrogens and hormone replacement therapy recorded.

After the educational intervention, there was an increase in the rate of recording in all categories of data other than 'Life-style advice/education' (Table 3). However, the 95% confidence intervals for family history and family history of cancer data recording were not statistically significant; the Odds Ratio (OR) was 1.02 (95% CI 0.98 to 1.06); and 1.08 (95% CI 0.99 to 1.17) respectively. There was a statistically significant, 36% increase in the recording of alcohol consumption; (95% CI 1.30 to 1.43); and 42% increase for smoking; (1.42, 95% CI 1.27 to 1.60). There was a fall of 16% in the recording of lifestyle advice given which was also significant; the OR was 0.84 (95% CI 0.81-0.88). The changes by practices are shown in Figure 4.

#### Qualitative findings – feedback from the workshop

The practices we approached readily agreed to participate, and saw value in improving their data, and participating in the audit. Qualitative feedback at the workshop highlighted how both practitioners recorded and computerised medical record systems were inconsistent in how family history was recorded; and stated that when new patients register is the best time to improve recording. Discussions with practitioners, at the time of the baseline data workshop and presentation revealed inconsistent use of codes, others using high level non-specific codes (e.g. family

history of cancer) rather than disease specific codes. In addition, there was very little use of negative codes (e.g. no family history of breast cancer.) The computerised records factors included reporting differences in where in the system family history was recorded, inconsistency in the information requested (for example some systems asked which family member), and inconsistencies in the coding system (for example there are codes for a negative family history of breast cancer, whereas there are for no family history of bowel and ovarian cancer; 122 f. and 122G. respectively)). There are also family history codes in different parts of the coding hierarchy; practitioners did not like the codes that displayed an asterisk (i.e. The family history of neoplasm, 124. codes, display as FH \*. The specific code for "FH\*-breast" is 1243. They reported these as potentially paternalistic; it felt to practitioners wrong that explicit records of a family history of cancer were data that could not be displayed as such on the computer screen and hence be readily shared with the patient.

#### Discussion

##### Principal findings

Whilst overall the participants in the audit and feedback intervention improved the quality of their data after the audit, there was considerable variation reported between practices and practitioners; and though some improved their coding during the audit period, others did not. We

**Table 2 Rates of recording of data relevant to the assessment of a family history of breast cancer, in adult females (over 18 years)**

%	Practice population (N)	All family history	FH of neoplasm	FH of breast/bowel cancer	Alcohol intake	Smoking status	Lifestyle advice	Oral contraception	Oestrogens/HRT	Pregnancy ever
<b>Baseline</b>										
Practice 1	2105	36.4	3.8	0.9	92.4	98.8	78.9	14.9	5.9	19.5
Practice 2	3193	40.1	6.8	1.8	89.1	98.8	77.6	8.6	3.7	20
Practice 3	1646	37.7	8.6	2.3	72.2	98.1	73.9	9.2	13.7	22.4
Practice 4	908	14.5	1.5	0.7	87.3	99.8	64.3	5.9	14.1	21.5
Practice 5	1687	60.8	13.3	0.7	75.9	96.7	84.8	10.3	9.4	33.1
Practice 6	1658	56.9	2.4	1.1	98.3	99.5	77.6	6.1	2.2	15.8
All	11197	42.6	6.4	1.3	86.5	98.6	77.3	9.5	7.1	21.7
<b>Post Audit</b>										
Practice 1	2481	41.8	7.7	2.5	97.9	99.6	76.1	20.8	10	15.9
Practice 2	3403	45.3	11	2.7	92	99.4	79.1	13.4	5.3	20
Practice 3	1644	36.6	7.8	1.9	80.1	99	79	14.7	18.3	22.6
Practice 4	911	15.9	2.7	0.9	87.4	99.9	53.9	8	21.3	22.5
Practice 5	1684	54.9	6.9	0.7	78.1	98.8	75.9	13.8	13.8	31.4
Practice 6	2839	46.6	2.3	1	93.3	98.6	59.5	8.3	0	19.6
All	<b>12962</b>	<b>43.0</b>	<b>6.9</b>	<b>1.8</b>	<b>89.8</b>	<b>99.2</b>	<b>72</b>	<b>13.5</b>	<b>8.9</b>	<b>21.1</b>
<b>New patients</b>										
Practice 1	744	47.7	15.6	4.7	98.9	98.9	80	16.5	1.7	7.9
Practice 2	877	50.7	21.2	3.6	92.8	99.2	91.1	9.5	2.3	11.5
Practice 3	173	28.3	6.9	0.6	93.6	97.7	20.8	4.6	2.3	19.7
Practice 4	86	29.1	12.8	1.2	72.1	100	36	3.5	8.1	19.8
Practice 5	209	11.5	0.5	0	86.6	94.7	42.6	3.3	3.8	16.7
Practice 6	583	32.1	3.6	1	91.9	97.4	46.3	6.5	0	11.1
All	<b>2672</b>	<b>40.6</b>	<b>13.0</b>	<b>2.8</b>	<b>93.2</b>	<b>98.3</b>	<b>68.1</b>	<b>9.8</b>	<b>19</b>	<b>11.6</b>

found that a wide range of different codes were being used to represent the same clinical problem, some practitioners coded in a highly specific way while others were much less specific using high level codes. The practitioners who participated in our audit placed their emphasis on improving the quality of recording after doing new patient medical examinations; this may lead to the

anticipated rate of improvement in data quality to the rate of turnover or growth of the practices when new patients are registered.

#### Implications of the findings

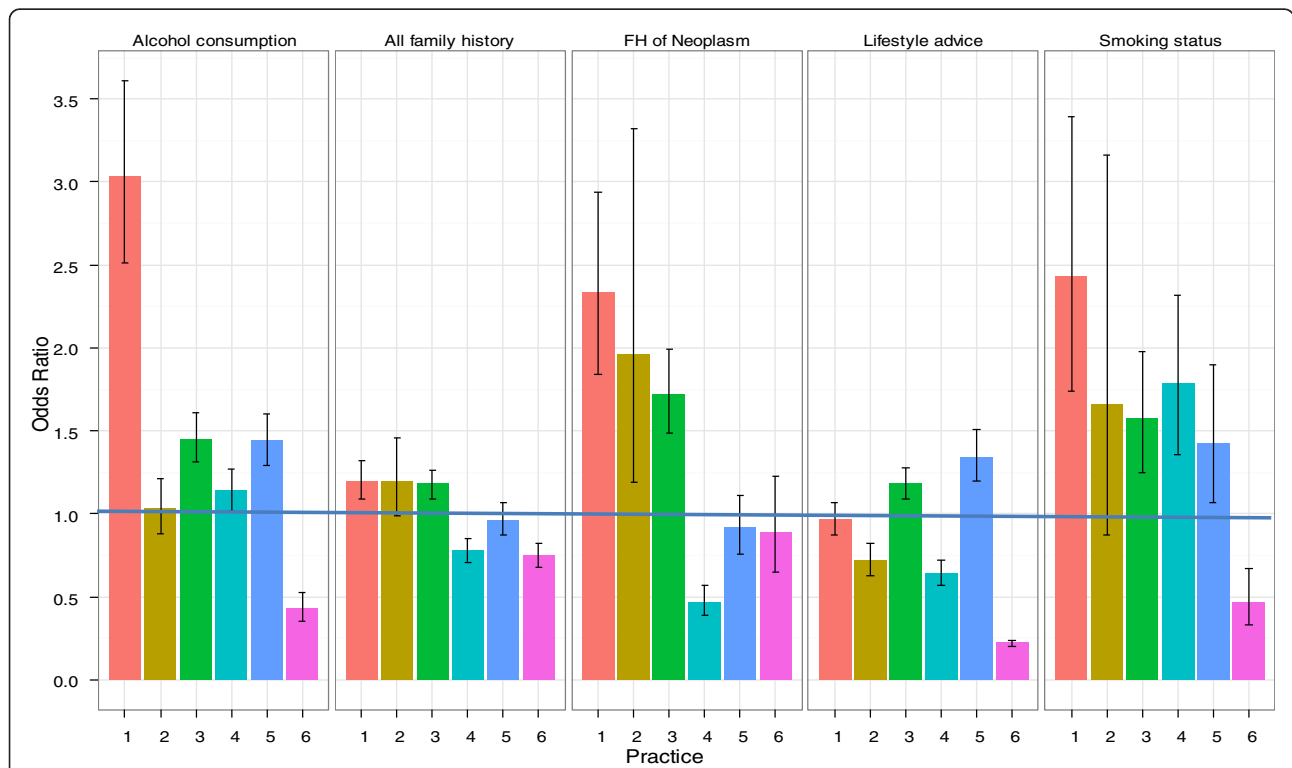
Although general practice is encouraged to record family history there are no national standards that need to be



**Table 3 Odds ratios (OR) and 95% Confidence Intervals (CI) for a change in data recording between the first (baseline) and second data collections**

	All family history	FH of neoplasm	Alcohol consumption	Smoking status	Lifestyle advice
<b>Practice 1</b>	1.20	2.33	3.03	2.43	0.97
OR (95% CI)	(1.09 to 1.32)*	(1.84 to 2.94)*	(2.51 to 3.61)*	(1.74 to 3.39)*	(0.87 to 1.07)
<b>Practice 3</b>	1.18	1.72	1.45	1.57	1.18
OR (95% CI)	(1.09 to 1.26)*	(1.49 to 1.99)*	(1.31 to 1.61)*	(1.25 to 1.98)*	(1.09 to 1.28)*
<b>Practice 5</b>	0.96	0.92	1.44	1.42	1.34
OR (95% CI)	(0.87 to 1.07)	(0.76 to 1.11)	(1.29 to 1.60)*	(1.07 to 1.90)*	(1.20 to 1.51)*
<b>Practice 2</b>	1.20	1.96	1.03	1.66	0.72
OR (95% CI)	(0.99 to 1.46)	(1.19 to 3.32)*	(0.88 to 1.21)	(0.87 to 3.16)	(0.63 to 0.82)
<b>Practice 4</b>	0.78	0.47	1.14	1.78	0.64
OR (95% CI)	(0.71 to 0.85)	(0.39 to 0.57)	(1.02 to 1.27)*	(1.36 to 2.32)*	(0.57 to 0.72)
<b>Practice 6</b>	0.75	0.89	0.43	0.47	0.22
OR (95% CI)	(0.68 to 0.82)	(0.65 to 1.2294)	(0.35 to 0.53)	(0.33 to 0.67)	(0.20 to 0.24)
<b>All</b>	1.02	1.08	1.36	1.42	0.84
<b>OR (95%CI)</b>	(0.98 to 1.06)	(0.99 to 1.17)	(1.30 to 1.43)*	(1.27 to 1.60)*	(0.81 to 0.88)

An OR >1 suggests that data recording is more likely after the second data collection.  
 \*statistically significant change.



**Figure 4 Odds ratios (OR) and 95% Confidence Intervals (CI) for a change in data recording between the first (baseline) and second data collections.** An OR >1 suggests that data recording is more likely after the second data collection. Only practice 3 had the OR of recording all data domains increased after the intervention than before.

adhered to; this should be corrected. Pilot practices appeared willing to engage in this initiative and we hope that a broader group of practices would want to engage in this type of quality improvement. Although we did achieve some progress, the rate of progress was slow. Moreover, despite our assumption that improved data recording might be found in new patients, we would hope that existing patients might also benefit from this intervention. Raising awareness about good quality recording would steadily improve recording and data quality over time. We should consider building on this, maybe creating a preferred list of codes that could appear in a data entry form, or template, to facilitate the consistent collection of data which has been collected in this audit. A recommended code list could facilitate data entry and the audit of quality; and ultimately the quality of care.

#### **Limitations of the method**

Integrated risk assessment tools for cancer are not embedded within primary care computer records. We did not explore whether integrated tools would be a greater stimulus to data recording and risk assessment. Such systems would raise awareness around familial breast cancer and then allow direct integration of family history into electronic GP records.

The data we looked at were those related to reducing cancer risk. Recording of these data *per se* does not mean that a risk assessment has been carried out. We made the same assumptions as when we have critically appraised diabetes [22,23]; namely that data recording approximates to the clinician's engagement with the care process whilst recognising that computer data can under or over represent the actual care provided to an individual patient.

There were gaps in the data collection, particularly BMI data; however this aspect of the project is probably the easiest to put right.

We did not take into account women's views of how they perceive risk, the current services, or where they see gaps in provision [92-94].

It is recognised that good quality recording of family history is a neglected theme in providing care, and more could be done in primary care [95,96]. Other studies have also found recording of family history of breast cancer to be limited in terms of recording [97].

The theory of diffusion of innovation may provide insights into how change in data recording may be adopted [98]. This theory describes the very slow process whereby innovators take on a new process, followed by early adopters, and followed in sequence by other groups. However diffusion can be a slow process, taking many years – an intervention like audit based education might accelerate uptake of guidance. Other initiatives

have required the setting of a recommended coding list to encourage consistency of coding [99]. Involvement of the appropriate primary care society and support from cancer charities, professional associations and academies may also facilitate the uptake of good and accurate data recording. Since initial risk assessment of a new patient is a crucial component which takes place at new patient medicals, then practice nurses will also need appropriate education [100].

Inconsistencies in family history recording were likely to be related to data recording rather than data extraction. Other than our queries having a code error for BMI, the data collectors did not report any problems with data extraction, we have a set format for reporting these [92]. In the qualitative results section we explained how personal practitioner preference for using either generic or specific codes, and the nature of the coding system was responsible for variation in the prevalence and granularity of the coding used. In addition, variation in picking-lists (the lists practitioners select codes from) and different ways that computerised medical record system vendors create these lists tends to foster and perpetuate differences in coding between practices [101]. The creation of limited lists of codes for pay-for-performance that has driven standardisation of coding [102]. We have demonstrated some success with a similar approach, a recommended limited list of codes, for the recording child safeguarding issues in primary care; where flagging issues can help with stratifying risks in later consultations [103].

#### **Call for further research**

A consensus building exercise is needed to offer preferred coding strategies. Risk stratifying software should be piloted and compared with ABE and usual practice, as a tool for conducting risk assessments. Looking at rates of appropriate referral for breast assessment would be one measure. Measuring the need for genetic counselling or onward referral to genetics centres could serve as another outcome measure. The opportunity now exists for building on what has been learned from previous trials, which took place prior to the widespread use of computers to support chronic disease management [104,105]. Strategies such as providing online risk assessment tools, directly to patients, could be considered, however a recent trial has indicated that such online tools may have limited impact [106].

#### **Conclusions**

We implemented audit-based education (ABE) in six practices; and it has provided insight into the level of data recording, and that improved assessment of family history and other risk factors is most easily improved at the time of new patient appointments. However, more

needs to be done to improve assessment across practice populations.

There was no significant change in the recording of family history of disease or cancer after the audit, though the recording of risk factors improved.

The study provided insight into variation and issues with current data recording, the willingness of practitioners to collaborate and rate of change achieved by audit and feedback. Whilst recording of risk factors improved with audit-based education further interventions are needed to raise data quality and care to standards where people with a small increased risk are adequately flagged in primary care records.

## Additional file

**Additional file 1: Box S1.** Epidemiology of breast cancer in the UK. Box S2. Audit-based education (ABE) – a quality improvement method. The quality improvement strategy developed by the Primary Care Data Quality Programme (PCDQ). Table S1. Age-sex profiles of participating practices. Table S2. Growth in practice populations between first and second data collections. Table S3. Availability of key data fields in first and second data collections.

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

IR conceived the audit design with SdeL, secured the funding, presented the intervention, wrote the first draft document and responded to further drafts. SC carried out the breast cancer risk literature review and contributed to all drafts of the paper. TC carried out the data analysis and was involved in the writing of the early draft documents and contributed to all drafts of the paper. IJ developed the final paper and assisted with the revision of the final paper. AT recruited practices to take part in the audit and contributed to all drafts of the paper. SdeL conceived the audit design with IR, worked with colleagues to develop the audit package, led the informatics aspects of the study, wrote the first version of the complete paper from draft documents supplied by IR, SC, and TC, and contributed to all drafts of the paper. SdeL also wrote the first revision post peer review. All authors read and approved the final manuscript.

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