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## **An Audit of Family History Referrals to a Nurse Led Family History Clinic**

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## **Introduction**

In the UK 42,000 new breast cancers are diagnosed annually, C.R.UK (2005), of these only 5-10% are thought to be attributed to specific identified genes or cancer family syndromes NICE (2004). However this is an important group because when a family history can be identified, it is sometimes possible to test for a specific gene fault, but most importantly having identified a high risk it is possible to modify the disease process by surveillance and early detection or risk reducing surgery.

As a consequence the National Institute for Health and Clinical Excellence have compiled guidelines for the identification and management of these families (NICE, 2004). Prior to these national guidelines practice was based on regional and unit specific guidelines and the guidelines attached to breast cancer treatment and risk. The NICE guidelines while outlining the general basis for managing these families have not determined the specific detail of service delivery or the adherence to these guidelines in referrals from primary and secondary care.

## **The Family History Clinic at RLUH**

The family history clinic at RLUH was started in 1993 and currently sees 200 new referrals per year for risk assessment, and has a further 1500 patients in an active surveillance

programme. When first set up all referral were seen with no attempt to filter these or acquire any extra information before the clinic visit.

In the year 2001 a triage method of vetting referrals was introduced. From this time:

- Those who were referred but who were not at increased risk of developing breast cancer by virtue of their family history were reassured by letter but not sent an appointment and not seen in the clinic.
- Referrals in which there was insufficient information to make a judgement regarding risk were returned with a request for further information (on a family history pro forma – see appendix 1).
- Where patients were judged to be at increased risk based on the information in the referral letter a detailed questionnaire was sent to the patient to confirm their family history and to expand on this to give details of cancers occurring in more distant relatives (appendix 2).

Once the detailed questionnaire is received from the patient the breast cancer risk is assessed using Claus tables, (Claus, 1994) and the patient sent an outpatient appointment. The patient is seen and assessed by the advanced nurse practitioner, their individual risk is discussed, the patient counselled and a surveillance programme instituted. Those at high

risk are offered the opportunity to meet the geneticist for genetic counselling and possible gene testing.

Practice was changed in 2004 such that patients who had not returned their questionnaire within 1 month were discharged, whereas before this time patients were given an unlimited time to complete their questionnaire. Since 2001 the family history service has been a nurse led service.

There is currently debate on the best way of providing this service. In particular:

- Is it appropriate for this to be a nurse led service?
- Is this a service that could be run in the community?
- Could this service be run by primary care physicians?
- Are current methods of surveillance effective?

The literature on this topic is reviewed below.

## Part 1

### **Literature Review**

This literature review will review the Current guidelines for referral of patients to a clinic for family history of breast cancer risk assessment and surveillance. It will also review the literature on risk assessment and its appropriateness and accuracy in primary care, current recommendations for surveillance in those with a family history, the psychological benefits of referral and the place of nursing practice in family history provision.

### **Introduction**

1 in 9 women develop breast cancer in the UK, which accounts for 30% of cancers in women. Seventy five percent of breast cancer patients are still alive five years after diagnosis and only 3-5% of breast cancers are inherited NICE (2004).

### **The Guidelines**

There is a plethora of guidelines for the management of patients with a family history of breast cancer.

Initially individual authors provided guidance in their papers. Articles by Claus et al (1994) and Gail et al (1989) were early papers recognising the inherited nature of some breast cancer. These papers were helpful in estimating risk but needed a basic level of understanding of breast cancer in order to be interpreted correctly. Evans et al (1993) and Eccles et al (2000) have published in a similar vein. These individual author papers have been superseded by guidelines written by professional bodies and Government organisations. Early guidelines written for the NHS breast screening programme, Austoker and Mansel (1995), included a page on family history. This was followed by: the Public Health Genetics Unit Guidelines (1998), Improving Outcomes Guidance for Breast Cancer (2002) and the much more detailed guidelines from the National Institute of Clinical Excellence (2004), the British Association of Surgical Oncology Guidelines, Sauven, (2003) and the Scottish Guidelines, SIGN (2005). The NICE Guidelines (2004) are much more comprehensive; they include the ideology of partnership with the patient, tailoring of services and give consistent advice. There is advice on all aspects of familial breast cancer risk from assessment, to surveillance, genetic testing and prophylaxis. These are clear guidelines. The evidence has been measured utilising both internal validity (the causal relationship between treatment and outcome) and external validity as it is recognised that much experiential practice is commonplace in this area. However the extended guidelines are long and run to 311 pages, 13 chapters and 26 appendices.

## **Risk Assessment Introduction**

The vast majority of breast cancer is sporadic and occurs in older age, there is therefore a need to establish the individual patient risk in order to offer advice, surveillance and counselling and although the NICE Guidelines talk of relevant family history the crucial role of risk assessment is underestimated. Accurate risk assessment is important as surveillance strategies are dependant on this NICE (2004).

The NICE Guidelines imply that risk assessment is straightforward, but the complexities of relative and absolute risk and the inaccuracies of patient histories make risk assessment an imprecise science particularly if the assessor is inexperienced and using only standard tables (Claus et al 1994, Gail et al 1989 and Evans et al 1994). Gail's model is based on external and internal factors (e.g. hormonal factors) governing the risk of developing breast cancer as well as family (1998). Colditz (1996) emphasises reproductive factors, while Claus analysed 4730 patients with histologically proven breast cancer and advised counselling for females due to the autosomal dominant nature of the disease (Claus et al 1994). Due to this complexity Evans et al (1994) highlight the value of family history clinics.

Collection of accurate information is vital (NICE 2004 4.3 point 9). Patients' knowledge of family history is often incomplete and inaccurate, and a questionnaire can be completed by the patient allowing more information to be gathered, but formal verification is only done prior to gene testing, (which is not offered to those in the moderate risk group) and very few people know their third degree history (personal experience of over 1000 family histories taken). Without accurate risk assessment patients may be given unnecessary surveillance on the one hand or false reassurance on the other.

### **Where and by whom should risk assessment be performed?**

The government's emphasis on a 'primary-care led NHS', NHS Executive (1994) has led to debate on whether provision of service for patients with a family history of breast cancer can also be provided in primary care, Emery et al, (1999), Watson et al, (2001), Rose et al (1999), Rose et al (2001), Gross et al, (2000) and Kumar and Gantley, (1999).

There is a clear expectation that GPs would be able to use the 2002 NICE Guidance, despite contradictory evidence in the same guidelines stating that GP's knowledge of genetics and family history is limited. A prospective study from the Netherlands concluded that the value of giving advice on genetic risk in primary care is questionable (De Bock et al, 1997), with the guidance over emphasising genetic testing at the expense of counselling, risk assessment and surveillance.

### **Do GPs accurately assess risk?**

'Assessment of risk is not an easy task for a GP' – so states SchARR's document on Public health genetics: implications of the 'new genetics' for primary care. SchARR (2001), Watson et al (2001) found GPs unsure of when they could reassure those at low risk, key to who should and should not be referred.

Others have similar doubts: Rose et al (1999) and Watson et al (2001) felt that training was insufficient, both demonstrated inaccuracy in the GP's ability to assess risk, (although training did improve accuracy). Rose et al (2001) questioned 282 GPs on referral of patients with a family history of breast/ovarian cancer, reviewing GPs' knowledge and expectations and found that the range of GPs making an accurate assessment of risk ranged from 21% to 63% and those referring appropriately from 40% to 80%. Five studies call in to doubt GPs understanding of cancer genetics, 3 used questionnaires, Rose et al (2001), Greenhow et al (1998), and Watson et al (2001), there was one randomised controlled trial, Watson et al (1998) and one semi structured interview Watson et al (1999). The qualitative aspect of the semi structured interview was powerful in its interpretation of comments made by the GPs even after training and showed that there was a level at which GPs felt unable to spend the time needed to develop the counselling skills in one specific area, understandable as they were likely to only be seeing one patient a month with this problem as found by Rose et al, 2001). Hicks et al (1996), Shere (2000) and Austoker (1994) were concerned about the necessary time needed for each consultation not necessarily available to GPs. Kumar and Gantley (1999) were also concerned about time but combined this with service provision as a limiting factor. Watson et al (1999) comments that the measure utilised to assess GP ability in this area made no effort to assess patient anxiety or their perceived risks, important as Evans et al (1993), have shown that only 17 of 155 patients accurately estimated their risk. Patient expectations of their GP are high and often unrealistic (Andermann et al 2001).

Yong et al (2003) bring up the area of paternal family history and the lack of attention sometimes given to a paternal family history in hereditary breast cancer and suggest that health care professionals under appreciate this. Their findings in this study showed that less

than a quarter of the health professionals used in the study knew the importance of a paternal family history. This would confirm the impression that the professionals do not always understand the family history risk assessment process since in an autosomal dominant gene family the paternal family history is just as important as the maternal family history.

### **What do patients want?**

Women however, do want the opportunity to discuss family history concerns in primary care (Audrain, 1998 and Andermann, et al, 2001). Andermann et al (2001) in a prospective descriptive study found that the length of consultation with the GP varied from less than 5 minutes in 44% of cases to over 10 minutes in only 18%. Given the information and psychological needs demonstrated in other studies it is difficult to see how these could be addressed in such short consultations.

In a telephone survey of 98 women with more than 2 first degree relatives with breast cancer Audrain et al (1998) evaluated preferences for type of provider and highlights the need for multi-disciplinary approaches. The telephone interview was highly structured with forced choice answers but little or no attention was paid to assessing how high the patients assessed their risk. The survey concluded that patients were more in favour of nurse specialists than primary care physicians.

In a cross sectional questionnaire survey of 1000 women with a family history of breast cancer Brain et al (2000) asked the question 'Why do women attend familial breast cancer

clinics?' Brain et al (2000) reported higher levels of anxiety than the normal population and over estimation of breast cancer risk and discussed the psychological implications of this. There is no discussion on the accuracy of the information gathered and the implication of an inaccurate risk assessment. Mammography was surprisingly low on the list of patients' reasons for attending a clinic but this was not discussed as a primary issue but rather something that is important after risk is assessed and discussed. The authors recommend that cancer genetics services take into consideration the information and psychological needs of their client group and highlight that genetic testing is only helpful to some and is not available on demand. Other cancer related concerns that crop up in the consultation may also need further exploration and answers.

Michie et al (1997) found that patients came to the consultation expecting information, explanation, reassurance and advice if these issues were addressed there was a greater level of satisfaction.

### **GP Guidelines**

So if patients want to discuss family history in primary care, but GPs are not good at assessing risk, do guidelines help? De Bock et al (1999) developed a set of guidelines for use by GPs in Holland which were tested and found to be useful; in a study of 67 women there were less misclassified patients using the GP guidelines. De Bock demonstrates that with training GPs can accurately assess risk, but this study does not apply to the generality of GPs and Dobson and Eaton (2001, 2002) comment that GPs don't understand risk assessment and tend to refer too many women for genetic tests.

Young and Ward (1999) in Australia also produced guidelines for the estimation of risk; 67% supported the guidelines and found them to be useful. However Hibble et al (1998) make an editorial comment on the impact of such guidelines on the time restrictions faced by GPs, particularly as this is only one of many guidelines. Fentiman (1999) looked at reasons for GP referral and gives clear illustrations of who should be referred. Quality of referral of high- risk patients to geneticists can be improved by guidelines (Lucassen et al 2001), but this study did not look at the majority who fall in the moderate to low risk category. Emery et al (1999) has taken this one step further by developing a computer programme to assess the family history.

It appears that most GPs do not have the appropriate genetics training and while guidelines help the time to implement these is limited.

## **Education**

Watson et al (2001) evaluate the impact of two educational interventions on GP management of familial breast/ ovarian cancer cases in a cluster randomised controlled trial. This study resulted in a 40% improvement in GP decision- making. However it is doubtful if this study in a small interested group is applicable to the most GPs. Austoker (1994) in a two part series on cancer prevention also concludes that those in the front line of patient management and communication require more education and training.

The question has to be asked if it is worth acquiring the necessary complex skills if these are used infrequently. Most GPs will not see many patients with a family history of breast cancer; Kinmouth (2001) estimated that out of 24,269 consultations reviewed family history of breast cancer was mentioned to GPs infrequently. This is supported by a randomised trial looking at the prevalence of family history in general practice by Johnson et al (1995) which calculated that a GP with 2000 patients in his/her practice can have 40-50 patients with a history of colorectal, breast uterine or ovarian cancer under the age of 50 years.

Also although there is a move in guidelines such as those produced by NICE to engage GPs in the process of genetic diseases evidence from other sources, Greendale and Pyeritz (2001), Hayflick and Eiff (1998), Watson et al (1998) Elwyn et al (2000) suggests that, while interested GPs still feel the need for further education.

Kumar and Gantley (1999) highlight the tensions between policy makers and general practitioners in implementing 'new genetics'. A grounded theory interview study, done from the perspective of the GPs, examined the attitude and understanding of a small number of GPs and again showed concern over lack of genetic knowledge.

Emery et al (1999) in a systematic review of the literature found that GPs accept that they have an increasing role to play in genetics but lack confidence in their ability to do so because of educational limitations, however Shere (2000) adds in a letter to the BMJ adding that the appropriate time is also unavailable. With lack of education and time Kumar and Gantley (1999).not surprisingly showed that GPs are reluctant to take on these new roles.

Elwyn et al (2002) used a structured qualitative study in primary care using focus groups with 14 GPs. The GPs in this study had not considered managing the breast family history patients themselves.

Fry et al (1999) asked GPs for their views on their role in cancer genetics services in a cross sectional questionnaire survey of 397 GPs. Lack of GP confidence and experience is again identified, with GPs unsure what to refer.

The view of Leggatt et al (2000) promoting family history in primary care is challenged by Emery (2000) who suggests effective interventions must be available before family history is raised.

### **Nurses and risk assessment.**

With GPs unable and unwilling and specialist geneticists in short supply Gray et al (2000) recommend nurse led clinics as an option for review and risk assessment of family history patients. Although there is evidence that nurse led practice is being utilised in the area of family history of breast cancer clinics there is little in the literature that comments on this. Lessick et al (1997) in an article on breast and ovarian cancer highlight the need for an update on the genetics of these diseases and the implications for general nurses as they are the most omnipresent health care professionals. This is a rapidly evolving field in which technology is outpacing our ability to address the related psychosocial, ethical and legal issues, as well as to disseminate research and clinical findings in a timely manner. Such technologies are reported in the lay press, Perry (2001), Hope (2005) and Harding (2001), as quickly as in the scientific journals and these reports typically send persons to their

health care providers with questions about their risk and the need for testing. It is important to assess beliefs, past experiences coping mechanisms, general breast cancer knowledge, feelings regarding the medical community, lifestyle habits and lifestyle risk factors as a basis for tailoring the patient education to the needs of the individual but nurses with specialised knowledge would be needed to do this.

Bankhead et al (2001) looked at service provision using practice nurses in the taking of a family history. In this study the accuracy of patient information was not checked and other cancers in the family were not mentioned. Training is recognised as a need for nurses who provide risk assessment, information giving and service provision for genetic problems, Bankhead et al (2001) and Bernhardt et al (2000). Bernhardt et al (2000) evaluated nurses and genetic counsellors as providers of education about breast cancer susceptibility testing, this study showed differences in the levels of practice and the training, and was not sufficiently powered. However it is suggested that nurses will increasingly participate in cancer risk assessment and counselling and Prows and Latta, (1995) have designed a well set out educational programme for nurses.

Bankhead et al (2001) decided to review the information needs of practice nurses in the light of developments in genetics and found that nurses do collect family history information but this study does not examine closely whether they would specifically know what to do with specific breast cancer information, and therefore it is of little significance except to say that there is increasing evidence within the service that nurses are doing the referring rather than GPs, the impact this has on the quality of referrals is unclear.

In a questionnaire study Walter et al (2001) showed that practice nurses were more positive regarding this service than GPs and Johnson et al (1995), Hayflick and Eiff (1998), Gray et al (2000) recommend that nurses specifically trained in the area of genetic counselling and risk assessment could be used. Allinson (2004) evaluates a nurse led practice in America, however comparison was made with a symptomatic clinic which is entirely different and offers a very different type of service. There was 100% satisfaction with the service provided.

Calzone et al (2002) in another American study made a useful addition in respect of assessing core competencies for nurses in the role of advisors and practitioners in breast cancer family history. This article particularly challenged the educational competencies and found differences relating to the era in which training had initially been carried out and the ever-developing knowledge needs that come from a fast advancing specialty.

On the same theme an Australian editorial by Gaff et al (2001) recommends courses and further training in this area. There is a good section on counselling in this article, which recognises the need to be competent in the areas where there are underlying issues in order for the patient/family's information and psychological needs to be met. They point out that questions that are asked are often triggered by a recent critical event such as diagnosis death or an anniversary and this might affect the ability of the patient to accept appropriate services.

Peterson et al (2001) bring into the arena the educational aspects of nurses working in the area of cancer genetics in a questionnaire study which highlights a training need in the USA. They hypothesise that earlier trained nurses lack knowledge in basic cell biology and cancer genetics unless they have recently been on a course. Stoll (1996) suggests that specialist breast and ovarian cancer clinics should be staffed by oncology nurses and comments that risk relates to the surveillance offered as the author of this states that patients are more interested in the potential protective options than in the precise degree of risk. Stoll (1996) suggests that nurse led practice in this area needs backing from the self-help groups in order to be successful.

### **Genetics in Primary Care – Summary**

This whole area was discussed in 1995 at a workshop looking at the development of primary care in Europe, (Austoker, 1995). One of the issues under debate was the practicability of genetics in primary care. The workshop recognised the usefulness of GP input into this area but also saw the limitations. It recommended ‘appropriate referral to specialists’, ‘education of patients’ and ‘timely counselling’ and suggested that specialist genetic centres will remain but be enhanced by collaboration with other services to provide a comprehensive service.

Emery et al (2001) discuss some of these issues from the perspective of the geneticist and suggest that there is a need for knowledge that is relevant to the primary care situation.

Emery et al (1999) completed and published a systematic review of the literature exploring the role of primary care in genetic services. Included in the review were searches of 7

electronic databases, expert opinion and hand searches of the literature. 230 papers were identified of which 96 were examined in detail. 51 papers were included. Although large amounts of information were gathered which were pertinent to the subject there was a lack of information around GP's exact workload in this area. It was clear that GPs had a limited knowledge of genetics and that GPs only play a limited role in the provision of the service as a whole. Changing the way in which this service has been provided within primary care is seen to be complicated and this is in direct contrast to the need for more information and support to patients, as genetics as a field of medicine continues to increase in knowledge and detail.

### **The Importance of Psychosocial Support in the Family History Clinic**

Those in the family history clinic already have a powerful experience of cancer and therefore are often psychologically vulnerable (Stiefel et al 1997) and the psychological impact of risk assessment is closely linked to patients' perceived risk and the distress that may be present if risk is high (Cull et al 1999), although the benefits of good communication skills having a positive effect on patient perception is illustrated by Hopwood (2000).

An important finding from Cull et al (1999) was that the risk counselling increased the accuracy of the patient's perception of their risk. Berkenstadt et al (1999) looked at Perceived Personal Control and comment that 'Genetic counselling is a communication process meant to help an individual or family comprehend medical facts.....to choose and follow the most appropriate course of action in view

of risks and family goals.’ Loss of control is important in the area of risk for a genetic disorder and can determine the type and length of counselling offered to patients.

Fallowfield (2001) concluded that patients want more rather than less information. Fry et al (2003) looked at the psychological impact of breast cancer genetics services in South East Scotland but the low risk group were not offered a service or face- to- face consultation which may lead to anxiety in these patients.

The question of how genetic risk is communicated and the pros and cons of ensuing counselling was reviewed by Penson et al (2000). This group, using a case study format concluded that most things can be reduced to a hypothesis or equation of risk; but genetics is an emotive area and advances in genetics are made rapidly. There is a need for clear and supportive communication in this area to facilitate adjustment.

Emery et al (1998) in a qualitative study using semi-structured interviews of 19 patients with a family history of colorectal cancer emphasises the patients’ beliefs, supports and family. Lloyd et al (1996) in a case control study of 62 patients from the Marsden with age matched controls from local GPs emphasise the importance of the family history clinic for these women who bear a heavy psychological burden for their family support from this type of clinic is important.

### **So is the management of patients with a family history of breast cancer appropriate in primary care?**

The literature suggests that the assessment of risk and the management of patients with a family history of breast cancer in primary care are fraught with difficulty and the GPs who would have to provide this service do not feel confident to do so.

Evans and Lalloo (2002) provide an alternative model stressing the importance of accurate risk assessment, counselling and management, and suggesting setting up of family history clinics in breast units and regional genetics clinics. Evans states that demand has increased for risk assessment and that risk should be accurately assessed and that processes put in place for 'appropriate counselling and management'.

### **Management of risk by mammographic surveillance.**

Key to the vision put forward by Evans and Lalloo (2002) above is the family history clinic where accurate risk assessment is made by appropriately skilled staff able to deal with the psychological sequelae, and can offer appropriate interventions for the prevention of breast cancer or the early detection and treatment of cancer.

The main intervention that has been used is that of mammographic surveillance, with much smaller numbers using pharmacological or surgical risk reduction.

### **Does Mammographic Surveillance Work?**

Liberman et al (1993), Myles et al (2001), Macmillan (2000), Isaacs (2002), Kerlikowske et al (1993), Kerlikowske et al (1996) and Kollias et al (1998) have all looked at mammographic surveillance in younger women with a family history of breast cancer.

Lieberman et al (1993) in a retrospective review found that 1.6 cancers per 1000 were found in the women aged between 35-39 years, compared to 1.4 per 1000 in women aged 40-49 years. It was concluded that early stage tumours can be detected on mammograms in those women aged between 35-39 years. Myles et al (2001) in a population at high risk found that screen detection rates at first and subsequent screens were 5.0 and 4.93 per 1000 respectively and concluded that mammography in this group is likely to be effective.

Macmillan (2000) combined results from 22 units in the UK and found a cancer incidence of 11.3 per 1000 per year with a median age of 43 years again concluding that screening is effective.

Lalloo et al (1998) completed a questionnaire survey of women attending a family history clinic in Manchester. 1259 women attended the clinic and completed the questionnaire. 16 cancers were detected giving a similar detection rate to women in the NHSBSP. The number of cancers detected in this study was larger than expected in this age group.

Despite these studies the efficacy of mammographic surveillance remains contentious.

Getzsche and Olsen (2000) argue that it is not justified in an overview of all randomised controlled trials, although comments on this conclusion by Koning (2000), Gray et al (2000) and Horton (2001) challenge this conclusion. As yet no study has demonstrated a reduction in mortality in those under mammographic surveillance although it is argued that this would be the case with a sufficiently powered study. However it is an established fact that screening in patients <50 years is more difficult than in the older and more fatty breast (Law and Faulkner, 2001, Kerlikowske et al, 1996, Getsche and Olsen, 2000). Despite this

Tilanus-Linthorst et al (2000) demonstrated that cancers could be detected and that these were detected earlier than symptomatic cancers.

### **Morbidity from Screening**

The issue of efficacy is important, as there is a morbidity associated with screening as illustrated by Seltzer and Glassman (2002). 2482 patients out of 8331 were recalled with an abnormal mammogram, and 281 were diagnosed with cancer (20% in the 40-49 age group). Mammography is not a precise modality and the uncertainty around benign imaging can increase anxiety. The paper also comments on the need to discuss openly the failings of mammography. Radiation also carries a risk of inducing cancer as discussed by Law (1997). This interesting paper looked at the risks of radiation in the overall screened population and those who might be at increased risk due to family history showed that caution should be employed in the younger (under 40) group of family history patients. Young breast tissue is difficult to interpret and false positive imaging may cause significant morbidity, (Seltzer 2002).

### **Current Recommendations for Mammographic Surveillance**

Presently the practical management of patients with an increased risk of breast cancer involves breast surveillance using mammography. Mammographic surveillance is recommended in this setting by all of the guidelines reviewed from the age of 40 years. Some outliers, Vogel (2003) and Isaacs et al (2002) recommend surveillance from 25, but without evidence to support this.

**What are women's views of this?**

'Despite the morbidity and lack of definite evidence of efficacy patients want mammography'; to quote Evans et al (1993) in a study assessing patients perceptions on their family history risk 'in the absence of proven benefit from screening women under 50 years for breast cancer and the increasing demand for information.....99% of our group felt it would benefit?

**Do women at increased risk take up screening?**

If mammographic surveillance is to be effective, patients must take up the offer of surveillance. Edwards et al (2003) performed a Cochrane systematic review looking at screening uptake. This review looked at 13 studies with reference to the change of uptake dependant on patients understanding of risk and shows that this may not correlate.

Although it has been suggested that patients with a family history be managed in primary care in practice GPs in this region cannot request mammography, and with IRMER guidelines all indications for mammography must be checked. There are no studies on the appropriateness of GPs requests for mammographic surveillance although Oakshott et al (1994) have shown that circulation of radiological guidelines does reduce requests for unnecessary investigations.

## **The importance of Clinical Examination**

Barton et al (1999) undertook the task of reviewing the effectiveness of breast examination as a screening tool and found that when used in conjunction with mammography there were reduced mortality rates. The use of independent clinical examination did not show this same benefit. Mitra et al (2000) pondered on the acceptability of breast clinical examination as an alternative to mammogram as a screening tool and concluded that breast examination was an acceptable alternative in some cases. This was a controversial paper and produced a response from de Woolf (2001) which argued strongly that this was a misguided approach to breast surveillance. This view was supported by Querci della Rovere (2001) and Warren (2001) in letters to the BMJ. Gui et al (2001) asked the question of whether or not clinical examination of the breast added to the mammogram and found that out of 31 cancers diagnosed, ten found in the high risk group would have been missed if mammography alone had been done. This area remains controversial.

## **MRI Surveillance**

Recent studies suggest that MRI is effective in detecting small tumours particularly in young dense breasts, Liberman (2004), and MARIBS study group (2005). These papers provide data from studies where surveillance by MRI has been reviewed. These studies involving women in whom there is a high risk of developing breast cancer due to an inherited fault show that there is a benefit of detection of otherwise occult lesions. The benefit to those patients at normal risk has not been shown and there is still uncertainty about the usefulness of this modality in patients at moderate risk as this group was not reviewed in the MARIBS (2005) study. The result of these studies implies that the

surveillance needs may require more specific attention to actual risk and benefit than is currently required if GP's assess risk, and adds to the argument for specialist breast units to be those responsible for surveillance in this group of patients.

### **Ultrasound Surveillance**

Although ultrasound of the breast may also be effective in diagnosing early breast cancer in the family history group O'Driscoll et al (2001), whole breast ultrasound is very time consuming and is not recommended in any of the guidelines.

### **Chemoprevention**

Cuzick et al (2003) present a summary of the findings of studies using Tamoxifen or raloxifene as prevention against breast cancer. An overview of five randomised prevention studies is given and the main findings suggest that there is some evidence to support the use of Tamoxifen as prevention for those at high risk of developing breast cancer, but the benefits are not without other medical complication and there are no guidelines that currently recommend the use of chemoprevention. It is worth commenting however that in order for the current chemoprevention studies to be ongoing and to be part of a range of options open to patients the problems specialist clinics are required as overseeing and financing this type of clinical trial in a primary care setting may prove difficult as there is not a large population that would be eligible for a study per GP practice.

## **Surgical**

Other forms of prevention include risk reducing surgery and Van Dijk et al (2003) present results of a questionnaire study looking at patient views of risk and risk reduction. The data collection and recording seems confusing and difficult to interpret however counselling had an effect on the view that the patient had of their risk.

## **Conclusion**

There is a plethora of family history guidelines, these have been developed initially by individual authors and been further developed and refined culminating in the NICE Guidelines, (2004) which are comprehensive. There is debate as to how this service should be provided; both where and by whom, this is eluded to in the NICE Guidance, but the literature is unclear with some authors suggesting that this service could and should be provided in primary care whereas others suggest this is not appropriate or possible.

In Liverpool GPs refer to a specialist family history clinic. In the light of the uncertainty in the literature there is a need for the referrals to the Family History Clinic at the Royal Liverpool University Hospital Breast Unit to be audited to fully understand the service

needs enabling service provision to be in the most appropriate setting with best practice in place. There is a need to review both the GP referrals and the internal referrals as there is pressure on the available capacity and the outcome of an analysis may allow streamlining of the service and improve its quality.

The specialist clinic is nurse led and provides family history of breast cancer risk assessment, surveillance by mammography or MRI imaging, clinical breast examination, counselling and follow-up. Currently all referrals for this service are vetted by the breast nurse practitioner and what this project intends to address is to analyse/audit all referrals over 4years to a specialist breast unit for a family history of breast cancer over two periods of time (October 2001- December 2002 and January 2004-October 2005).

Referrals will be reviewed for

- Appropriateness according to current guidelines.
- Accuracy of information given by the patient to the GP will be matched to a questionnaire completed by the patient when this is possible and
- An analysis of any other information contained in the referral letter which might indicate the reason for referral.

## **Project Plan**

I aim to analyse the information contained in family history referrals from:

1) GPs to the family history clinic at The Royal Liverpool University Hospital Trust and specifically to look at the information supplied by the GP in order to obtain a Family history clinic appointment. There will be a further analysis done comparing the patient questionnaire information with the information supplied on the GP referral to check for appropriateness of referral and completeness of information. Therefore the questions to be asked are:

- Is the information sufficient in the initial referral letter to make a judgement on the need for referral?
- Was there a need for referral based on the information provided?
- What was the reason for referral?
- Does the history provided by the GP match that provided by the patient on further questioning?

2) To analyse the information contained in family history referrals from Internal Referrals to the family history clinic at RLUH. Internal referrals of new patients to the family history clinic come via a symptomatic breast clinic attendance and a copy of the GP letter of that appointment is sent to the advanced nurse practitioner and acts as a referral letter. The guidelines are readily available to the doctors in the clinic and therefore all patients should be assessed as at least moderate risk. Therefore the information supplied by the patient on return of a questionnaire will be specifically reviewed, assessing whether the patient is at least at a moderate risk of developing breast cancer. An assessment will also be made of the need for referral based on the information provided. The reason for referral in this case is because a senior doctor/nurse has already assessed the patient to be at increased risk of breast cancer with a possible genetic problem being present in the family.

The project will also compare and contrast the two groups above.

## **Part 2**

### **Presentation of intended project to a group of my peers given to breast unit audit meeting**

#### **Rationale for project.**

There has been a family history breast cancer risk assessment and surveillance clinic at the Royal Liverpool University Hospital Trust since 1993. This has been a nurse led clinic since 2001 and also the referral letters have been vetted due to pressure on places for new patients and the knowledge that not all patients are at increased risk and therefore would not benefit from extra surveillance.

Since the service became a nurse led practice all referral letters have been kept with a view to analysing the quality and content of the referrals in the light of family history guidelines and patient comments at the time of hospital visit which showed that there was some confusion around the reason for their visit. (E.g. some were expecting a mammogram, others genetic testing and some didn't understand the reason for the visit). This would suggest that GPs are not explaining much about the patients risk before referral. A good place to start seemed to be the referral letters and what was included in them.

### **Background information**

Guidelines have been in existence from the unit and the regional genetics service.

NICE guidelines were in place, 2002 guidelines for breast (general guidelines) and the more recent 2004 guidelines specifically written for this group of patients.

BASO guidelines are available to surgeons for use in their clinics; these were the Guidelines for management of breast disease and more recent breast family history guidelines by Sauven (2003).

Specific training in risk assessment and surveillance recommendations undertaken by both of the breast nurse practitioners in Manchester (St Mary's Hospital)

Ethics approval sought for a study/audit to review all the referrals to the family history clinic.

An extensive literature review was undertaken under headings of:

- Risk Assessment and

- Who should perform it? The main question being whether this should be a nurse led practice versus guideline recommendations for GPs to be able to undertake this area of practice.
- Mammographic Surveillance.
- Genetic implications.
- Psychosocial effects of a gene positive family history.
- A review of the most recent guidelines from NICE has been undertaken which showed that there has been a clear shift in thinking to the suggestion that risk assessment could be performed by the GP using the current guidelines.

**Progress so far:-**

Design of database pro forma and data collection and the subsequent development of a database and excel spreadsheets to enter data for further analysis.

**Why audit the referrals?**

What the Literature says: in particular papers which imply that GPs do not know what to do with the new genetics as seen in the literature review.

Training issues around understanding what constitutes a family history and also time to provide this service as noted in the literature review.

No mention is given in the literature on the accuracy of the information provided by the patients at the time of initial consultation and I feel that there is some time needed for patients to find out more about their family history before risk assessment should be attempted.

There is anecdotal evidence that the patients come to the family history risk assessment clinic expecting to have a mammogram sometimes irrespective of their age or level of risk.

Will the referral letters bear this out?

No explanation is given to the patient by the GP of what to expect in a family history clinic.

Is this also reflected in the referral letters?

Some patients come to the clinic expecting genetic testing.

The pro forma design incorporates information that is usually contained in referral letters for this service. And will include patient name, age, date of birth, number of relatives mentioned with breast cancer and the ages of diagnosis of those relatives. Other types of cancers in the family will be recorded, if given, as well as closeness of relationship to the patient and age of diagnosis. Other reasons for referral will also be captured in the database such as mammogram requests and anxiety in patients.

The data base will capture referral details on all referrals and then a sub group analysis will be performed on the group who have returned questionnaires and been seen in the family history clinic. This will be by direct comparison to the data as it is given. Separate evaluation will be made of the wording in the referrals such as 'very high risk' and 'anxious'.

This project is planned in the hope that I gain insight into the reasons why GPs refer patients for risk assessment. I would like to prove that accuracy improves risk assessment and thereby helps with anxiety and psychological morbidity.

### **Questions from the Floor**

Q. Do what the GPs write in a referral letter influence what you do?

A. Only in that if the GPs have referred a patient appropriately they will receive the appropriate action. When responding to patients that are not going to receive an appointment a letter is sent to the patient outlining their history as the GP has given it and they are given the chance to respond by ringing us on our dedicated line if they have any questions about the letter or the fact that they will not receive an appointment. I am not particularly influenced by wording which overstates the risk however I appreciate that many patients that want to have an extra mammogram might be upset when they don't have one.

Q. Do GPs currently have guidelines?

A. Yes GPs have the regional guidelines and they also have access to the NICE and BASO guidelines on the websites if they choose to use them.

Q. At what stage is the cancer registry checked (patients are aware of the family history allowing them to have mammography and can make up their family history)

A. The cancer registry is checked by the geneticists when ascertaining the high risk families. Currently we do not check the history of the moderate risk patients.

Q. If you are suspicious would you check with the cancer registry?

A. If I think that there is some doubt about a high risk family history because the history doesn't quite add up then I will mention this in the referral letter to the geneticists.

Unfortunately there is not the time or people resource to check all of the patients in this way.

Q. I have some concerns over inappropriate referrals and the fact that people may not really have enough history to provide surveillance. What are we doing about those patients who are inappropriate?

A. We are writing to patients who are at obvious low or population risk at the point of referral. No patients receive any surveillance without there being enough evidence from the history that they have given and if they are uncertain about their family history surveillance is not started until the information is complete.

Q. How many new referrals do we receive?

A. I see 6 new patients a week some of which are GP referrals some internal referrals and some genetic referrals for surveillance. A proportion of all of the referrals do not receive appointments and this averages I think about 40 patients a year and some patients do not complete the questionnaire that I send out to them so that they are then discharged back to the GP. I can't give you a specific figure of exactly how many are referred. That is partly what I will be able to do when I complete the project.

Q. If a person had a father with prostate cancer would they be screened?

A. Not if that was the only family history present. It is one of the related cancers in a breast gene fault and may be significant when seen in the light of a strong (more than one paternal aunt with breast cancer) total family history. Often the paternal family history is underplayed.

Q. Would you perform gene testing before embarking on any form of screening?

A. No as this would exclude the moderate risk group in whom there is an increase of risk up to as much as 1:4. Currently geneticists are only offering gene testing to high risk families (1:2 -1:3).

Q. Are you not worried that as prostate cancer is common some people are assessed as high when it is just a sporadic history.

A. As I explained previously the whole family history is taken and you could argue that breast cancer is common as well – more common than prostate cancer. The key is that you are looking for patterns in the family that would suggest that there may be a gene fault in the family and therefore you would expect the cancers to be occurring at a younger age and with greater frequency than they do in sporadic cancers.

Q. Any ways of reducing patients risk?

A. Risk reducing surgery is an option for high risk and gene carrying patients but we do not usually offer this to patients in the first stage of a consultation and usually there would need to be a high risk or proven gene fault for this to be considered. That is why the risk assessment is so important. There are some studies that have looked chemoprevention but not much to offer patients currently.

Q. What evidence is there that attending family history clinic is beneficial?

A. It depends what you are measuring. If you want to know if patients are happy with their risk assessment then I don't know perhaps the PIMMS study (a psychological survey of

patients being screened by mammography due to a family history of breast cancer) will answer that question. In terms of the efficacy of the surveillance offered there is a study which is looking at this in larger numbers which should publish in a couple of years called FH01.

## **Summary**

The presentation to a group of peers was helpful, and allowed me to further refine my project plan. It was very interesting to note that although this was a very well educated group from the point of view of breast cancer knowledge they still had a poor understanding of family history with a number of fundamental misconceptions. There was a tendency for individuals to address their own knowledge needs and ask questions that interested them about family history rather than to comment more generally about the efficacy of the project and project plan, although useful comments were made.

Some comments were sparked because of famous people developing breast cancer and the articles then contained in the popular press regarding this. On reflection I was surprised by the misconceptions present in this group of people since they all work in the area of breast cancer treatment and diagnosis from screening through to palliative care. This would therefore seem to support my view that family history of breast cancer risk assessment is a specialist area. Furthermore it will be interesting to see if the results of the audit show a similar level of understanding to this group of peers.

### **The Modified Project Plan**

An audit of referrals to a family history of breast cancer risk assessment and surveillance clinic.

In particular:

The appropriateness of referral both by GPs and Internal referrers.

The accuracy of GP reported family history as found in the referral letter compared with that found in the returned questionnaire.

Reasons for referral as described in the referral letters.

### **Part 3**

## **An Audit of Referrals to a family history of breast cancer risk assessment and surveillance clinic**

### **Project development and Ethical Approval**

The planned project would require access to sensitive data concerning individuals with a family history of breast cancer and therefore consideration was given to the ethical implications of a research/audit project on this group of patients. I already had access to all of the data in my role as breast nurse practitioner and as the sole lead for family history risk assessment. Consideration had therefore to be given to the way in which data was collected and kept, whether in a secure environment or not and whether the project outcomes would help in the development of the service that is already provided. Prior to commencement of this project ethical approval was sought from the local research ethics committee and approval was given for this project as an audit.

One of the main questions asked by the research committee was whether or not this needed to be a research project or an audit project and the outcome was approval for an audit project.

There were not thought to be any issues of data protection as all patient information was anonymous and all of the data was to be collected on site and entered onto a secure database. The Trust Research and development department required that the project be registered and the trust audit department were informed of the project but did not need to oversee the project as it was part of a personal Masters Project.

The database was a specifically designed Access database and all other data was collected on an excel spread sheet. The referrals to the family history clinic at RLUH have been analysed.

### **Referrals to the family history clinic at the Royal Liverpool University Hospital Trust.**

There are two ways in which patients can be referred to the family history clinic at RLUHT. They can be referred to us via their GP or they can be referred after a visit to one of our symptomatic breast clinics by a doctor or nurse practitioner.

GP refer patients in a variety of ways:

- a) On a specifically designed family history pro forma (Appendix 1)
- b) Via a GP letter
- c) On a general breast referral pro forma (Appendix 5)
- d) Very occasionally via a mammography request form.

In 2001 due to a wait of almost two years for an appointment and just prior to the nurse led practice commencing it was decided that vetting of the family history letters was appropriate as it was noticed that patients were being seen with little or no significant family history. Therefore the letters were to be vetted for appropriateness of referral. In some instances there was insufficient information to make any judgement and at that time a family history pro forma was sent to the GP for details that were necessary but not included in the text of the referral. Occasionally there was enough information in the referral letter to see that (if the information was correct) the patient was not at increased risk and the patient was sent a detailed letter discharging them and explaining why it is not necessary for them to be seen. In most cases the information is sufficient to be able to see that the patient (if the information in the referral letter is correct) is at increased risk and therefore needs to be sent a questionnaire to more precisely estimate risk. See vetting outcomes.

GP referrals for family history clinic arrive in the breast unit and are vetted and placed into four categories:

Vetting Outcome 1

Enough information in referral letter for questionnaire to be sent to the patient – Questionnaire sent to the patient. Sample letter appendix 6  
Patient seen in clinic on return of questionnaire, if questionnaire not returned patient discharged

Vetting outcome 2

Enough information in referral letter to estimate patient to be at low risk – Personal letter sent to patient discharging back to GP  
Sample letter appendix 7

Vetting outcome 3

Insufficient information in the referral letter to assess appropriateness of referral – family history pro forma sent to GP. Sample letter appendix 8

Vetting outcome 4

Patients who did not return a questionnaire were discharged back to the GP. Sample discharge letter appendix 9

Internal referrals

Internal Outcome 1

Most internal referrals come from doctors/nurse practitioners working in the symptomatic breast clinic and are produced as a result of family history taken at a previous clinic visit.

Sample letter see appendix 10

Some internal referrals come from patients seen by the oncology team who may have already had breast cancer but who are interested in whether there is an increased risk to their family. The patients in the oncology referral group were not included in the study. All of these patients were sent a questionnaire

Internal outcome 2  
Internal referrals who did not return the questionnaire  
were discharged  
Sample discharge letter see appendix 11

## **Methods**

Two time periods have been chosen 2001-2002 – this was the first two years of use of the questionnaire and coincided with the time at which the service became entirely nurse led, this was compared with the most recent two years (2004-2005) to determine differences with time and specifically to assess the impact of a change in practice in 2004. In 2004, due to outpatient waiting targets changing from, 17 weeks to first appointment from referral to, 12 weeks to first appointment from referral if a patient did not return their questionnaire within 4 weeks we breached those targets in some cases. This led to discussion around how to manage the return of questionnaires and it was thought

reasonable to give patients a time limit to return their questionnaires. Therefore the patients who did not return their questionnaires on time were discharged back to their GP. A standard letter was designed to send out in these cases, appendix 9.

For most of the analyses these two periods are combined to give an overall result for all referrals over the whole period.

Data was entered on to an Access database and Excel spreadsheet. All patients were assigned a patient code, each had their date of birth, age, date of referral and GP code recorded. Four separate data sets were then compiled depending on the vetting outcome:

- i) Data collected from the initial GP referral letter on those who were discharged because they were not at significantly increased risk (Vetting outcome 2) included:

The following data items were collected: patient ID, GP ID, patient date of birth, type of referral, breast cancer history (including age of diagnosis and distance of relationship to the patient), any other cancers and the age of diagnosis, action taken and whether or not the information was confirmed or not, comments by GP.

- ii) Those patients who returned a family history questionnaire (Vetting outcome 1):

Part A (Data taken from the GP referral as above), the following data items were collected: patient ID, GP ID, patient date of birth, type of referral, breast cancer history (including age of diagnosis and distance of relationship to the patient), any other cancers and the age of

diagnosis, action taken e.g. whether or not a questionnaire, pro-forma or discharge letter was sent, comments by GP.

Part B (Data taken from the patient questionnaire), the following data items were collected: breast cancer diagnosis in relative, maternal or paternal, degree of closeness to the patient and age of diagnosis, any other cancers maternal or paternal type of cancer and age of diagnosis given.

Part C (Data recorded after the clinic visit and risk assessment): the following data items were collected: Outcomes recorded as: risk assessed, genetic referral and surveillance given, whether patient followed up or discharged.

- iii) Those GPs who were sent a pro forma asking for further details around the family history (Vetting Outcome 3) as there was not enough information in the referral letter. This is the case when no ages are given of relatives or no details of relatives and their closeness to the patient. This data set included only those GPs who did not return a pro forma, those who returned information became part of the previous groups.

Information was recorded on a spreadsheet and the following data items were collected: patient ID, GP ID, patient date of birth, date of referral, details of family history as appearing on the letter and comments by the GP.

- iv) Those patients who were thought to be at least moderate risk from the details as supplied in the referral letter and were therefore sent a questionnaire (vetting outcome 4) but failed to return the questionnaire.

Details of this group of patients were recorded on a spreadsheet and the following data items were collected: patient ID, GP ID, patient date of birth, date of referral, date questionnaire sent, outcome, patient's breast cancer history, degree of relationship and age of diagnosis, any other cancers and any other details given, comments by the GP.

All patients who returned questionnaires were seen in the family history clinic.

An inappropriate referral is defined in this study as a patient who is not at significantly increased risk as defined by the guidelines (regional genetics guidelines and NICE, (2004) guidelines) and as determined by the best information available on that patient, which will be the returned questionnaire where that has been possible and on the referral letters alone where there is sufficient information to make that assessment.

**The appropriateness of referral was assessed in two stages:**

Firstly: Analysis of the information contained in the initial referral letters, those discharged at the point of referral, as part of the vetting process.

Secondly: by comparing the information provided in the patient questionnaire with that provided in the initial referral.

**The accuracy of GP reported family history compared with actual:**

This was determined by comparing the information contained in the referral letter and with the information contained in the questionnaires as returned by the patients

### **Analysis of GP Referral Letters comments**

It is easy to assume that the referral process is relatively straightforward and 'pure', and that those patients referred to the family history clinic are referred because of their family history of breast cancer and nothing else. However when requesting family history appointments GPs use a variety of expressions in addition to specifically mentioning the family history of the individual involved and it may be that these subsidiary factors are what have triggered the referral, and may be of equal or more importance to the referral and subsequent consultation as the family history. Generally these extra terms have been used in those referred by letter rather than on a pro forma. The sections of both of the databases and the spreadsheets were reviewed in order to analyse this data and common expressions used in the GP referral letter. These were classified into the following groups and counted.

Expressions used:

- i) Anxious/ worried/concerned patient needs family history appointment.
- ii) Counselling requested.
- iii) Strong/Difficult family history, please see and advise.
- iv) A Family History Risk Assessment/Opinion/management wanted.
- v) Hormone replacement therapy (patient wanting to go onto HRT or has been on HRT for a long time and has a family history of breast cancer) opinion wanted.
- vi) Oral Contraceptive pill (patient on long term OCP but has a family history of breast cancer) opinion wanted.
- vii) Cosmetic (patient considering cosmetic surgery but has a family history of breast cancer)
- viii) Diagnosis/death of a relative due to breast cancer, please see.

ix) Surveillance/screening required.

### **Internal Referrals**

Internal referrals are usually made after a patient has been seen in a symptomatic breast clinic. At that time a family history is taken and there are guidelines present that enable the breast nurse practitioners and doctors to assess risk. Patients are referred by a copy of the letter sent to the GPs which is sent to the family history risk assessment clinic and are then sent a questionnaire to complete. An assumption is made that these patients will fulfil the correct criteria for risk assessment.

All the internal referral patients are sent a questionnaire and therefore the data on these patients is contained in dataset ii) as detailed above i.e. Patients who have returned a family history questionnaire.

Part A (Data taken from the copy letter – appendix 10), the following data items were collected: patient ID, GP ID, patient date of birth, type of referral, action taken e.g. whether or not a questionnaire, pro-forma or discharge letter was sent.

Part B (Data taken from the patient questionnaire), the following data items were collected: breast cancer diagnosis in relative, maternal or paternal, degree of closeness to the patient and age of diagnosis, any other cancers maternal or paternal type of cancer and age of diagnosis given.

Part C (Data recorded after the clinic visit and risk assessment), the following data items were collected: Outcomes recorded as risk assessed, genetic referral and surveillance given, whether patient followed up or discharged.

The unreturned questionnaire group information was collected and is included in the spreadsheet mentioned above in group iv) of the GP referrals.

Internal referrals have been assessed for appropriateness of referral.

## **Results**

### **Referrals to the Family History Clinic**

1077 referrals to the family history clinic have been analysed. 920 of these were GP referrals, and 157 internal referrals of patients who had been referred to the breast unit with a symptomatic problem but were discovered to also have a family history of breast cancer.

The mean age was 40 years. The patients were overwhelmingly, but not exclusively, female 1075 (male 2).

**Table 1: Summary of Number and Type of Referrals**

<b>Referral Type</b>	<b>Number of each type</b>	<b>No Appointment</b>	<b>Unreturned Pro forma</b>	<b>Questionnaires Sent</b>	<b>Questionnaires Not Returned</b>	<b>Questionnaires Returned</b>
GP ref	920	209	81	630	186 (29%)	444

Int ref	157			157	87(55.4%)	70
Total	1077			787	276	514

### **GP Referrals**

After initial referral 209 (22.7%) patients were not given appointments and discharged at this point on the basis of the information provided by the GP i.e. there was enough information in the initial referral to determine that the patient was at low or population risk and therefore would not require extra surveillance and did not need to be given an appointment i.e. the referral was inappropriate.

A further eighty one (8.8% of GP referrals) GPs were sent family history pro formas to provide further information but did not return these. It is not possible to assess the risk for these patients as no further information was provided by the GP.

Also it was not possible to assess risk on those patients who did not return a questionnaire.

630 patient questionnaires were sent out. 444 (70%) patients returned their questionnaires (186 not returned, 29%). These questionnaires are sent out to the patients to obtain greater detail particularly regarding second and third degree relatives and to give the patient the opportunity to check family histories with other family members. This process is vital to accurate risk assessment as often patients will not know accurate details of their family history at the point of first contact.

Of those who returned questionnaires 90/444 (20%) were assessed as low risk.

Therefore of all GP referrals 299, (45.7% of GP referrals), were not at increased risk and did not need to be referred.

There are a further 15 patients who were inappropriate referrals in that they were not eligible for increased surveillance as defined by the NICE Guidelines. 11 patients were at moderate risk but over the age of 50 (NICE Guidelines stipulate that these patients should be discharged to the National Breast Screening Programme at 50 years of age). 2 patients were at high risk but were over 60 years of age and (again as per the Unit Guidelines extra surveillance is not indicated) were therefore not eligible for extra surveillance and therefore discharged. Finally 2 more patients were at high risk but very young and therefore not eligible for surveillance at the current time.

Therefore including these patients in the inappropriate referral group 314 out of 840 referrals were inappropriately i.e. 37.4%.

444 GP referrals were sent questionnaires, returned them and were seen in the clinic. The GP Referral letter specifically asked for mammographic surveillance in 154/444 even though this was inappropriate in 13%. (20/154) of these were too young for surveillance and the average age of this group was only 29 years.

**Table2: Numbers of Referrals sent by individual GPs**

No of referrals Sent	1	2	3	4	5	6	7	8	9	10
No of GPs Sending	146	87	45	24	10	12	7	4	2	1

The median number of referrals is only 2 and the mean number of referrals is 2.3. However as can be see from the data above the commonest number of referrals is only 1 with 146 GPs referring only 1 patient, with only 87 GPs referring 2 patients, and 45 GPs 3 patients. The data is however is skewed by a small number of GPs referring a much larger number of patients.

**Table 3: Outcomes after risk assessment**

	High	Moderate	Low
GP	155/444 (35%)	199/444 (45%)	90/444 (20%)
Internal	23/70 (32%)	29/70 (41%)	18/70 (25%)

**Table 4: Type of referral**

Type of ref	2001	2002	2004	2005
Letter	101 (72%)	167 (62.5%)	121 (32%)	80 (37.5%)
FH pro forma	10 (7%)	36 (13.4%)	129 (34%)	107 (50%)
BG pro forma	14 (10%)	26 (9.7%)	35 (9.3%)	10 (4.6%)
Internal	15 10.7%	37 (13.8%)	91 (24 %)	16(7.5%)
Total per year	140	267	376	213

**Internal Referrals**

There were 157 internal referrals, this represents 16.9% of referrals to the family history clinic. Of the 157 referrals who were sent questionnaires only 70 (44.5%) of these were returned, of these 18 were at low risk. So that 18/70 (25%) were inappropriate referrals. Interestingly this group of patients were less likely to return their family history questionnaire with 87/157 (55%) not returning their questionnaires as opposed to 186/630 (29%) of GP referrals.

**Table 5: Questionnaire return Rate with Time**

Year	% returned	% not returned
2001	62%	38%
2002	72%	28%
2004	61.5%	38.5%
2005	65%	45%

**Family History as stated in the Initial Referral Letter compared to the Information from the Patient Questionnaire.**

The accuracy of the initial information contained in the GP referral has been compared with the more detailed information subsequently available from the family history questionnaire completed by the patient.

Third Degree Relatives: 303/444 patients had no third degree relatives with a family history of breast cancer. 141/444 patients had third degree relatives with a family history of breast cancer, but this history as recorded in the patient questionnaire matched the information in the referral letter in only 5 (3.6%) patients.

Second Degree Relatives: 187/444 patients had no second degree relatives with a family history of breast cancer. 257/444 patients had second degree relatives with a family history of breast cancer, but this history as recorded in the patient questionnaire matched the information in the referral letter in only 23 (9%) patients.

First Degree Relatives: 72/444 did not have any first degree relatives with a family history of breast cancer. 372/444 patients had first degree relatives with family history of breast cancer, but this history as recorded in the patient questionnaire matched the information in the referral letter in only 98 (26%) patients.

### **Other Cancers.**

There were other cancer types mentioned in the GP referral letters and the patient questionnaires.

**Table 6: Numbers with ‘any other cancers’ (types of cancers mentioned in list of ‘any other cancers’), by referral letter and questionnaire:**

	GP letters	Family History pro forma	General Breast pro forma	Internal referral
‘Any other Cancer’ in initial referral	37 (14%)	27 (20%)	2 (4.4%)	5 (7%)

Additional 'Any other Cancer' in questionnaire	207 (78.6%)	111 (81%)	39 (86%)	61 (87%)
Total number in whom 'Any other cancer'	262	137	45	70
Number having no other cancers	55 (20%)	26 (19%)	6 (13.3%)	9 (12.8%)

357 patients mentioned any other cancers when returning their questionnaires and this was matched by the GP referral letter in only 66 (18%) overall; 37/262(14%) of letter referrals; 27/137 (20%) of family history pro-forma and 2/45 (4.4%) of general breast unit referrals.

Overall a further history of other cancers was given in 207/262 (79%) of referral letters, 39/45 (87%) of general breast pro formas, 61/70 (87%) of internal referrals but in only 11/137 (8%) of family history pro forma. Conversely one GP letter recorded a third degree history which was not then present on the questionnaire.

There were 96 patients in whom there was no other cancer apart from the breast cancer in their family history 55 (20%) who were referred by letter, 26 (19%) referred by family history pro forma and 6 (13.3%) referred on general breast pro formas.

A data query looking at ovarian stomach and leukaemia has revealed that 125 patients recorded that there was a maternal history of either, of which 22/125 (17.6%) were also mentioned in the GP referral. The same query run on the paternal histories obtained in 76 patients showed that 3/76 (3.9%) of GPs mentioned the same history. This means that

82.4% of maternal and 96.1% of patients had a possible significant family history that was not mentioned by the GP.

There were 53 patients in whom the maternal other cancers in the family occurred at under 50 years of age and of these 26 had family that were under 40 years of age at the time of diagnosis. Also there were 29 patients in whom there was a family history of cancer diagnosed under 50 years of age, of these 15 were under 40 years of age.

Where the 'other cancers are paternal prostate there were 23 in total, there were a further 16 maternal prostate cancers recorded, of these only 2 were on the GP referral.

Where the 'other cancers' were maternal ovarian there were a total of 43 patients who described an ovarian history, 22 of these were also in the GP referral letter. There were a further 7 patients who had been referred with ovarian histories who turned out to have uterine or cervical family histories and not ovarian as stated. This is a common source of misunderstanding in patients and the difference between ovarian uterine and cervical cancer is often explored during a consultation.

**Table 7: Other types of cancers recorded from the questionnaires**

Lung,	uterine,
cervical,	ovarian,
stomach,	leukaemia,
bowel,	liver,
prostate,	bladder,
brain,	oesophageal,
throat,	renal,

sarcoma, bone,  
melanoma, neuroblastoma,  
myeloma, pancreatic,  
testicular.

### Results of the Analysis of GP letter comments

**Table 8: Subsidiary Expressions used in Referral Letters to the Family History Clinic in those who did not return their questionnaire (107 patients were referred by letter out of a total of 187)**

<b>Expression</b>	<b>Number</b>	<b>Percentage</b>
Anxious/worried	10	9.3%%
Genetic Testing	6	5.6%%
Counselling		
Strong/Difficult Family History	3	2.8%
Risk Assessment/Opinion/Management	12	11.2%
Hormone Replacement Therapy	3	2.8%
Oral Contraceptive Pill	0	
Cosmetic Opinion	2	1.9%
Diagnosis of Death in Family	0	
Surveillance/Screening	12	11.2%

**Table 9: Subsidiary Expressions used in Referral Letters to the Family History Clinic in those who did return their questionnaire (262 letters of 444 referrals)**

<b>Expression</b>	<b>Number</b>	<b>Percentage</b>
Anxious/worried	38	14.5%
Genetic Testing	20	7.6
Counselling	11	
Strong/Difficult Family History	8	
Risk Assessment/Opinion/Management	153	58.4%
Hormone Replacement Therapy	13	5%
Oral Contraceptive Pill	3	
Cosmetic Opinion	2	
Diagnosis of Death in Family	29	11.1%
Surveillance/Screening	160	61%

**Table 10: Subsidiary Expressions used in Referral Letters to the Family History Clinic in those who were not given an appointment on the basis of their initial referral. (85 referral letters out of 209 referrals).**

<b>Expression</b>	<b>Number</b>	<b>Percentage</b>
Anxious/worried	9	11%
Genetic Testing	2	2.4%
Counselling	1	1.2%
Strong/Difficult Family History	1	1.2%
Risk Assessment/Opinion/Management	38	44.7%
Hormone Replacement Therapy	3	3.5%
Oral Contraceptive Pill	1	1.2%
Cosmetic Opinion	0	
Diagnosis of Death in Family	13	15.3%
Surveillance/Screening	37	43.5%

## **Discussion**

### **GP Referrals**

37.4% of all GP referrals to the family history clinic were inappropriate. 35.6% because they were not at sufficiently increased risk of developing breast cancer by virtue of their family history and a further 1.9% by virtue of their age.

This study and the literature call in to doubt the suggestion in the NICE Guidelines (2004) that GPs should be able to assess those patients who are at medium and high risk by virtue of their family history, but agrees with the ScHARR consensus statement (2001) that 'the assessment of risk is not an easy task for a GP', and this is confirmed in Liverpool where over 1 in 3 referrals to the family history clinic is inappropriate.

Both Rose et al (1999) and Watson et al (2001) found that GPs had insufficient training for carrying out accurate risk assessment, in the paper by Rose et al (1999) those referring accurately varied from 40-80%, not dissimilar to this study where 62% of referrals were appropriate. Due to this complexity noted by Evans et al (1994) and found again in this study Evans suggests specific family history clinics and one wonders if the NICE Guidance is not a step backwards in this respect.

Watson et al (2001) demonstrated that education can improve GPs management of breast cancer family history, and this is undoubtedly true, but it is difficult to give every GP this level of knowledge and expertise particularly as pointed out by Kinmouth (2001) and Johnson et al (1995) that family history consultations are not common in primary care.

This confirms the findings in this study where the median number of referrals in 4 years is only 2 per GP, although most GPs referred only 1 patient. It does not seem sensible (even

if possible) to try and educate hundreds of GPs to such a high level when a comprehensive service for the region can be provided by two highly trained advanced breast nurse practitioners.

An important consideration as regards surveillance is that GPs in this region cannot request mammography. If therefore a GP is to do the risk assessment the patient would then need to be referred to a regional centre for surveillance and the risk assessment would be reviewed again for the purposes of IRMA guidelines.

There is also the requesting of MRI imaging that is sometimes necessary in gene positive families that will also not be able to be provided directly by the GP.

This type of surveillance will become utilised more in the near future as a result of the MARIBS study and NICE are currently reviewing guidance for this. The fact still remains however that there needs to be some interface between the patient needing the investigation or surveillance and the GP in order for this facility to be provided.

The fact that 1.9% of referrals were 'inappropriate' because of the patient's age raises an important question as to the reason for referral to a family history clinic, this is dealt with in more detail below. NICE Guidance links referral very tightly to the need for surveillance and suggests that if surveillance is not appropriate then nor is referral as there is no point in referring patients if no action ensues.

However I would disagree with what is a limited view of the benefits of the family history clinic, particularly when run on a counselling model of practice as is the case in Liverpool.

Even though patients do not warrant increased surveillance by virtue of their age (which may be too young or too old) if they are still at increased risk they do have many pertinent and relevant questions about what that means to them and their families. These patients are often very worried and where possible these worries should be addressed, which is part of the reason for a family history consultation.

This is, however only a small number in this study (15) and even if this group are excluded from those considered to be inappropriate referrals, 35.6% are still inappropriately referred as they have no increased risk.

Eighty one GPs (almost 10%) who were asked for more information concerning their patient's family history, when asked to complete a pro forma failed to respond. There is no data on this should be, but when a pro forma is sent out asking for more information the local family history guidelines are enclosed with this, and a possible explanation for the pro forma not being returned is that on reading the guidelines the GP realised that the patient was not in fact at increased risk and therefore could be reassured and did not need referral.

30% of those referred for a family history appointment did not return their questionnaire and the exact reason for this is unclear. At a superficial level at least one would expect that someone who asks to be referred because of their family history would then fill out a questionnaire to make sure that they were indeed seen.

However as detailed below the actual reason for referral can vary even though family history is the stated reason for referral. Many, patients and doctors, have a faith in

mammography so that the patient wants a mammogram and once this has happened e.g. through a symptomatic clinic they will no longer pursue the family history referral.

### **Referral Method**

Referral method changed markedly during the period studied. Initially most referrals were by letter 72% reducing to 37%, while family history pro forma referrals increased from 7% to 50%. The breast unit has seen increased use of pro forma for both symptomatic and other referrals since their introduction in 1999, this may be a general trend as this trust uses pro forma for referral in many other areas as well as breast. All of the online referrals use pro forma. The reason for the increased use of pro forma has not been assessed in this study. While the pro forma is undoubtedly an improvement on a letter which often leaves out vital information, it still is not sufficient and ideally the GP would ask the patient to complete the family history questionnaire before referral as this is the only method of getting accurate information.

### **Comments on the information in the referral letter as compared to the information in the patient questionnaire**

The NICE Guidance clearly states that in the assessment of family history risk in breast cancer a family history should be taken which includes first, second and third degree relatives where possible. Where the patient has third degree relatives cancers in these relatives can make a difference between the patient being at a low or a high risk.

In this study when a third degree history of breast cancer was present this was recorded by the GP in the referral letter in only 3.5%. Once again the suggestion by NICE that GPs can take an adequate family history and manage these patients in primary care is challenged. Even for second degree relatives an accurate history was only recorded in 9%. For first degree relatives the easiest and most obvious group there was only a match in 26%.

In the case of other cancers mentioned as part of this audit there are currently no guidelines that include other cancers. This is because, simplistically at least, the indicators for family history and its significance are usually seen within immediate family members and a positive breast cancer history is the first necessary factor. However with greater experience of risk assessment, particular in those who subsequently are proven to be at increased risk by virtue of carrying a recognised breast cancer gene, so the importance of this other, ‘non-typical’ cancers becomes apparent. These other cancers are probably more significant than has previously been commented upon. Since this information is not part of most of the guidelines issued it seems that the specialist knowledge that is required is only available in a specific family history risk assessment clinic.

Patients do not know their detailed family history without further investigation and questioning of other family members. A key finding of this study is that referral without completion of a patient questionnaire (which although more detailed is aimed to allow for collection of all relevant family history up to third degree relatives) is inadequate, and this will lead to a change in practice, see below.

## **Outcomes of Risk Assessment**

Just over 35% of those seen in the clinic are at high risk, just over 45% at moderate risk and 20% at low risk. Interestingly this is similar for both the 'refined GP referral group' i.e. those in whom those obviously at low risk have been discharged, and the internal referral group. In both groups a small number of those at low risk are seen in clinic. As can be seen a third of those seen are at high risk and are therefore referred on to the regional genetics service for further counselling and possible gene testing.

### **Internal Referrals**

30% of the questionnaires sent to patients who were internal referrals were not returned despite having a family history suggesting that they were at increased risk by virtue of this, and would benefit from increased surveillance. Referral is therefore a more complex process than merely identifying a risk and asking the patient to attend. The patient too must be concerned. In those patients who did not return their questionnaire their concern was for their symptomatic problem (this is how and why they had been referred) and once they had been reassured regarding this their family history was not of concern to them.

Secondly for many patients with a family history the issue is one of surveillance, their level of worry has been heightened for some reason at that point and they want a mammogram to be sure they do not have a breast cancer. Most patients going through the symptomatic

clinic do have a mammogram or ultrasound, and so for many their main desire for a screening test has been satisfied.

However with such a high rate of non return of questionnaire it does call in to some doubt this method of referral with a family history identified in a patient who does not specifically present with this. Most do not want to take this further and the referring doctor should probably have a more open and overt discussion with the patient at the outset to ask if this is something for which they would like to be referred.

The reverse is also seen in patients who do not actually have a family history that conveys increased risk, and yet they are still worried and on occasions are referred with a supposed symptomatic problem when their real concern is over their family history.

The doctors and advanced nurse practitioners working in a breast clinic achieved 75% accuracy on their initial assessment of family history risk. 25% of these referrals turned out to be inappropriate referrals because of low risk as opposed to 45.7% of GP referrals (which includes the group of patient discharged due to being at low or population risk at the time of referral). The most likely explanation for this is that the history is now more complete and patients' initial knowledge around the cancer in their family is not the same as when they were first asked.

It is easy to assume that the large number of inappropriate referrals is due to poor knowledge, but this is not the case for those who refer internally who have a wide breast cancer knowledge base and detailed family history knowledge. The common factor for

both groups is that the only family history available to them at the point of referral is the family history as reported by the patient. This is sometimes incomplete and may on further investigation be inaccurate. Accurate risk assessment can only be carried out on a detailed family history when the patient has had chance to delve in to the family history by asking other family members.

### **Questionnaire Return Rate over time**

During the time period over which data was collected for this study there was a change in administrative practice. For an individual patient the completion of the family history questionnaire can be a difficult and traumatic event taking a prolonged period and potentially opening up very emotional family wounds. Therefore when the clinic was set up patients were purposely given as much time as they needed to complete the questionnaire. As time has gone on this system has fallen foul of the government outpatient targets. Firstly the requirement to see all patients within 17 weeks and more recently to see all patients within 13 weeks of referral. As a result of this patients are now given just one month to complete the questionnaire and if this has not been received back in this time frame the patient is discharged. There was concern that this might have resulted in less patients returning their questionnaires because of the reduced time available, and therefore to patients not attending the clinic who did have a strong family history but felt unable to complete the questionnaire in the stipulated time frame. From this point of view the data in this study is reassuring. The questionnaire return rate in 2005 at 65% is slightly higher than that in 2002 under the 'old regime' and there has not been any significant change in return rate over the period.

### **Comments on the subsidiary statements on the GP Referral letters**

There are marked differences in the expressions used in the GP referral letters when these are analysed in to the three groups above i.e. Those without a significant family history, those who were sent questionnaires but did not return them and those that did return their questionnaires.

Interestingly in the group with no increased family history risk a death in the family was mentioned most frequently at 15% (0 in the non return group). This would appear to be a strong motivator for the patient, and induces a large amount of worry and anxiety so that the GP feels obliged to refer the patient despite the absence of a strong family history. This is supported by the work of Gaff et al (2001) who point out that questions are often triggered by a recent critical event such as diagnosis of a new cancer or death. In the group that did not return their questionnaires no deaths were mentioned, as opposed to being mentioned in 11% of those who did return their questionnaires, suggesting again that a personal experience of death and breast cancer is a powerful motivator.

It is also interesting that the topics covered in the list of reasons for referral are almost identical to the chapter headings for the NICE (2004) guidelines. In the case of referrals to this unit it would suggest that GPs do not feel able to discuss these issues with the patients at the time of their consultation.

In those that did not return their questionnaires risk assessment is mentioned in only 11% in contrast to 58% in those who did return their questionnaires. Surveillance and screening is mentioned in only 11% compared to 61% in those who did return their questionnaires.

This may give us a further clue as to why the questionnaires were not returned in this group. The function of the family history clinic is to provide risk assessment and surveillance, and it seems that these were not the specific needs of this group which may be why they did not complete the questionnaires. It may be, in a similar way to the internal referrals, that the main felt need was a symptomatic problem and that once this had been met the patient did not wish to pursue the family history further, and that the family history was an issue identified by the GP but not a felt need of the patient.

### **Who Should Provide the Family History Service?**

There is discussion in the literature as to the role of nurses in service provision in this area. Lessick et al (1997) point out the knowledge gap amongst nurses. Bankhead et al (2001) looked at practice nurses taking a family history but no assessment of accuracy was performed. On the basis that nurses are ubiquitous Prows and Latta (1995) developed an educational programme for nurses, but although Walter et al (2001) showed practice nurses to be more positive than GPs these studies of general nurses have the same problems as General Practitioners ie how can general nurses acquire the level of knowledge and skill required for such a specialist area. Gray et al (2000) recommend that nurses specifically trained in the area of genetic counselling and risk assessment could be used. This audit supports this statement, demonstrating a breast family history clinic providing efficient risk

assessment which frequently picked up other cancers and nuances missed by the referring doctor.

### **Summary - Family History Risk Assessment is a Specialist Service**

Much of the literature on family history risk assessment has suggested that this could be done in primary care by primary care physicians. This position is also taken by the NICE guidance, and the government's recent white paper has added to this pressure to move services into the community, in an attempt to only provide in hospital what must be done in hospital, consideration has been given within this Trust to moving the family history service to the community to be provided by primary care.

This study clearly demonstrates that this is not a viable option. It may be possible for one or two GPs to take a special interest in breast family history and to run this service, but this would not be possible for the 'generality' of GPs who do not have the appropriate knowledge or skills as this study clearly demonstrates, and would only be recreating the current service in a different physical setting, but breaking the all important link to the surveillance, diagnostic and treatment arms of the service.

### **Change of Practice learning points**

**Referral without a completed Questionnaire is unsatisfactory.**

This study has highlighted and confirmed what was known intuitively from seeing patients in the clinic i.e. that it is not possible to take a meaningful family history from a patient at first meeting. To meaningfully assess risk patients need to investigate and confirm their family history with other family members.

This will lead to a change in our practice. Previously we have accepted GP referral letters' or referral letters on a pro forma and then sent out a questionnaire to the patients to complete. This is time consuming for the breast unit, and does not fit well with the government outpatient targets. We will now change our practice so that an electronic version of the family history patient questionnaire is put on to the hospital website which has to be completed by the patient for all referrals. It is also important for those in the community asking patients to fill in a questionnaire before their referral will be accepted to understand the reason for this and an explanation will be present on the website to explain this fully.

### **Internal Referrals**

For those patients who have been referred for a different breast problem, but in whom a family history is identified i.e. the internal referrals the doctor or nurse practitioner make, should have a more comprehensive discussion with the patient at the outset regarding what is needed for a formal risk assessment to take place and then to ask patients if this indeed something for which they would like to be referred. Education of the breast unit staff is needed on this point to reduce the questionnaire non-return rate.

**OK to discharge after a month.**

The third important finding confirms that a change of practice that already has taken place is safe. It was thought that fewer patients were returning their questionnaires and therefore being inappropriately discharged because of time constraints imposed by the government targets. This is not the case and therefore the current practice of discharge after one month is safe and can continue.

### **Conclusion**

Kumar and Gantley (1999) highlight the tensions between policy makers and general practitioners in implementing the new genetics, and this is apparent in the breast family history service at RLUH.

The literature suggests that the assessment of risk and the management of patients with a family history of breast cancer in primary care are fraught with difficulty and the GPs who would have to provide this service do not feel confident to do so.

Evans and Lalloo (2002) provide an alternative model stressing the importance of accurate risk assessment, counselling and management, and suggest setting up family history clinics in breast units and regional genetics clinics. Evans states that demand has increased for risk assessment and that risk should be accurately assessed and that processes put in place for 'appropriate counselling and management'.

This remains a very good conclusion, and accurate assessment of the situation, yet it is possible for middle managers who may not have read the literature, and who do not understand the complexities of risk assessment to view family history clinics as an area of service that can move into the community to fulfil the governments agenda of moving service from hospital to primary care.

What counts, as this study has so eloquently shown is not the physical location of a service but rather the skills and knowledge base that those providing the service have so that risk assessment can be made accurately, surveillance can be appropriately implemented and all with care, compassion and counselling to address the information, psychological and surveillance needs of these worried patients.

### **What Have I learnt from the Project?**

1. That the service as it stands may be unnecessarily complicated. Simplification of referral will be useful and allow for smoother service provision.
2. The realisation of what I *do* know has been one of my learning points. It seemed like a simple audit of information gathered over four years but is in fact a knowledge base that will help to allow the service and my practice to develop.
3. For my colleagues there is a lesson to be learnt regarding referral from the symptomatic clinics. The unexpected lack of completion of questionnaires by patients who will have been estimated to be at increased risk of breast cancer points to a need to understand what the patient wants. In our desire to inform

and provide a good quality service perhaps we miss the fact that patients are not asking questions about their breast cancer risk and are even scared about the implications of 'risk', a complex subject for anyone.

4. As to the service given by primary care, the majority get it right. However the fact that they refer for advice on a large range of issues all covered by NICE guidelines implies that they need the service as it is provided. Hopefully with the intention to change the referral to include more detailed information and with patients able to choose whether they respond or not to the questionnaire prior to referral a more streamlined service will be achieved.
5. It is undoubtedly right that this specialist service should continue in the specialist setting as the in-depth knowledge and training needed is not currently available in the community.

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## **Appendices**

### **Appendix 1**

Family History Pro forma sent to GPs if information insufficient

### **Appendix 2**

Questionnaire sent to patients at risk

### **Appendix 3**

Sample of letter to the patient on discharge as no risk on history given.

### **Appendix 4**

Project Presentation Slides

### **Appendix 5**

General Breast Pro forma

### **Appendix 6**

Sample of referral letter. Vetting outcome 1

### **Appendix 7**

Sample of referral letter where no significantly increased risk. Vetting outcome 2

**Appendix 8**

Example of referral letter with insufficient information. Vetting outcome 3

**Appendix 9**

Sample of discharge letter from an unreturned questionnaire.

**Appendix 10**

Sample of a Rapid Diagnosis internal referral

**Appendix 11**

Sample of an Internal referral unreturned questionnaire discharge letter.

**Word Count 19,986**