



THE UNIVERSITY *of* EDINBURGH

## Edinburgh Research Explorer

# Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study

### Citation for published version:

Hallowell, N, Murton, F, Statham, H, Green, JM & Richards, MP 1997, 'Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study', *British Medical Journal (BMJ)*, vol. 314, no. 7076, pp. 281-3.  
<https://doi.org/10.1136/bmj.314.7076.281>

### Digital Object Identifier (DOI):

[10.1136/bmj.314.7076.281](https://doi.org/10.1136/bmj.314.7076.281)

### Link:

[Link to publication record in Edinburgh Research Explorer](#)

### Document Version:

Publisher's PDF, also known as Version of record

### Published In:

British Medical Journal (BMJ)

### Publisher Rights Statement:

© 1997 BMJ Publishing Group Ltd

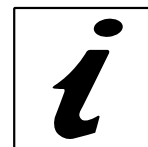
### General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

### Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact [openaccess@ed.ac.uk](mailto:openaccess@ed.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.





## Information needed to decide about cardiovascular treatment in primary care

John Robson

### Abstract

There is growing consensus that treatment of cardiovascular risks should be based on multiple rather than single factors and on absolute rather than relative risks. Thresholds for treatment should reflect the level of absolute risk at which the benefits and hazards of treating outweigh the benefits and hazards of not treating. Once a decision has been made to initiate a treatment programme, clinicians need to know the patient's absolute risk. At this level of risk, do the benefits of treatment outweigh the hazards? Given this information, which treatment option does the patient prefer? Using cardiovascular disease as an example, I review some measures that assist decision making in primary care. Practice guidelines should routinely include accessible presentation of treatment outcomes on benefit, hazard, and costs for a range of absolute risks. These measures enable patients and their doctors to weigh the pros and cons of treatment in their particular circumstances.

### Introduction

There are three main sources of information guiding decisions about cardiovascular treatment. Cohort studies provide information on multiple risk factors and subsequent cardiovascular events, so that a person's absolute risk may be estimated from a score.<sup>1</sup> Risk might be considered high if the chance of death or disease from a major coronary event exceeded 6% a year (60% in 10 years). However, risk alone reveals nothing about the advisability of drug treatment, and, although cardiovascular risk scores have been available for more than 20 years, uncertainty about their role has hindered integration into routine clinical practice.<sup>2-3</sup> The second source, based on clinical trials, yields at a particular level of risk a variety of treatment outcomes, including the "number needed to treat,"<sup>4</sup> years of life gained, adverse events, and costs.<sup>5</sup> The third source of information is the person to be treated, who, given an informed choice of treatment outcomes, can indicate his or her preference.<sup>6</sup>

### Assessing cardiovascular risk

Cardiovascular risk scores were originally designed to facilitate behavioural change by communicating the degree of risk to clinicians and patients. More recently, they have been used to target treatment more

effectively, because prediction of risk is improved when based on multiple rather than single risk factors. Relative risk scores such as the Dundee score, may have a continuing role in behavioural change, particularly among lower risk groups at younger ages.<sup>7</sup> However, relative risk has been criticised as a method of allocating treatment, and absolute risk (from which relative risk may be derived) is preferable.<sup>2-8</sup>

The main coronary risk scores are based on data from the American Framingham study,<sup>9</sup> the British regional heart study,<sup>10</sup> and Scottish survey and British trial data (Dundee score).<sup>7</sup> All were specifically devised to influence primary care doctors.<sup>11-12</sup> The Framingham study has the advantages of longer follow up over a wider age range for both sexes and is expressed as absolute risk.<sup>1</sup> In addition, it has shown that the ratio of serum total cholesterol concentration to high density lipoprotein cholesterol is a considerably better predictor than total cholesterol concentration alone. Five or 10 year risks may be estimated and scores tabulated by age so that the effects of multiple risk factors can be compared over time.<sup>13</sup> It has the disadvantage that it is based on an American population. Scores are also available for the risk of stroke.<sup>12-14-15</sup>

Recent cardiovascular guidelines in Europe<sup>13</sup> and New Zealand<sup>8</sup> adapted the Framingham data and incorporated other risk factors such as obesity and family history. This has made the risk equations more user friendly and has taken some account of specialists in hypertension, who variably recommend treatment at diastolic thresholds of 90, 95, and 100 mm Hg<sup>16</sup> even though data from both Framingham and the Medical Research Council indicate that systolic pressure is a considerably better predictor of stroke.<sup>14-17</sup>

Because prediction depends on the prevalence of the condition, none of the risk scores has a high predictive value. The scores overestimate risk, and only 60% of those subjects at highest risk (in the top 10% of the risk distribution) will actually have a coronary event within the next 10 years. Prediction is considerably worse at younger ages and lower levels of risk. Factors not included in the score, such as family history of cardiovascular disease (first degree relative aged under 55) or obesity, may mean that risks are higher than predicted. Social class and ethnic group may also be relevant. Nevertheless, for all their limitations, multiple risk scores are the best available tools for predicting risk and are superior to any one factor alone.

Academic  
Department of  
General Practice,  
St Bartholomew's  
and the London  
Hospital Medical  
School, Queen  
Mary and Westfield  
College, London  
E1 4NS

John Robson,  
senior lecturer

BMJ 1997;314:277-80

This article and entire  
section are available  
on the BMJ web site.



The adoption of absolute, rather than relative, risk as the criterion for treatment inevitably prioritises older age groups. On this basis, healthy men aged under 50 years with a serum cholesterol concentration of  $\leq 9$  mmol/l do not require drug treatment. Although their relative risk is high compared with their peers with a serum cholesterol concentration of 5 mmol/l, even if they smoke and have raised blood pressure they are unlikely to reach a coronary event rate of 3% a year, the threshold at which the Sheffield group considers treatment appropriate.<sup>18-20</sup> Advice to stop smoking, exercise, and improve their diet remains the mainstay of intervention.

### Treatment thresholds and treatment outcomes

Once a person's absolute risk has been estimated how is the threshold at which treatment is indicated to be decided? More information is needed, and patients and their doctors require summaries of the hazards, benefits, and costs of treatment.

Risk scores describe the level, distribution, and relative importance of different factors but give no information on the outcomes resulting from treatment. The final choice of treatment is affected by the choice of outcome, cause of death or disease, deaths prevented or number needed to treat, years of life lost or gained, adverse events or indicators of quality of life, and cost. Should treatment of raised blood pressure depend on the risk of stroke or the risk of heart attack or both? Other outcomes may be decisive factors in treatment. The impact of diabetes on risk of stroke is modest, but the impact of raised blood pressure on diabetic renal disease is considerable.

#### Benefits of treatment

The manner in which benefits are expressed is particularly important. Expressing values as numbers needed to treat gives equal weight to the risk of dying from a heart attack at the age of 75 as at age 40. However, if years of life gained rather than numbers of deaths were used as the outcome, intervention would include more younger people and fewer older people.<sup>21</sup> Both measures are useful, as each expresses a different component of outcome.<sup>22</sup> An important gain in mean life expectancy would be about 60 days. This is not so small a gain as it seems, as it is averaged over all people receiving treatment.<sup>23</sup> For example, if all cancer were eradicated the mean gain in life expectancy would be only one year, although for the people who would otherwise have developed cancer the gain would be measured in decades.

The format in which these outcomes are presented may influence choice of treatment. Thus, presenting results in terms of years of life gained may lead to different treatments being preferred than when results are given as numbers needed to treat,<sup>24</sup> and relative risk may result in lower treatment thresholds than absolute risk.<sup>25</sup>

The number needed to treat to prevent one event or death is the reciprocal of the absolute difference in outcome between the treatment and control groups in a clinical trial<sup>26</sup> and is a measure of the absolute efficacy of treatment. Assuming a 30% reduction in coronary heart disease as a result of treatment with "statins"

**Table 1** Number of patients who would need to be treated with a "statin" for five years to prevent one coronary event by annual risk of coronary event (assuming treatment reduces number of coronary events by 30%)

Annual risk of event (%)	Number needed to treat
0.05	1332
0.1	666
0.5	133
1	66
2	34
3	20
5	14
7	10

(hydroxymethylglutaryl coenzyme A reductase inhibitors), 1332 people at low risk (with an annual coronary event rate of 0.05%) would require treatment for five years to prevent one coronary event. In contrast, 20 people would need treatment for five years to prevent one event if their annual risk was 3%. Table 1 shows the number needed to treat for different levels of risk.

#### Adverse effects and quality of life

There is most uncertainty about treating the many people at intermediate risk, rather than the smaller group at high risk who have most to gain from treatment. Small changes in the threshold of treatment in the intermediate range can turn large numbers of people into lifelong patients. Clinicians should require a high level of confidence in the extent of the benefits and hazards to convince them that treatment of such patients is worth while because small but serious risks applied to large numbers can transform gains in one area into a net loss.<sup>27</sup> If recommendations are uncertain or contradictory, patients and doctors require more information, accessibly presented, about the hazards and benefits of treatment so that they can make their own judgments.

Quality of life may be valued more than years of life, and the adverse effects of treatment may be decisive in the choice of treatment.<sup>28</sup> In the Medical Research Council trial of treatment of mild hypertension, for each cardiovascular event prevented, 33 men experienced adverse reactions (impotence and fatigue being prominent) and 20% stopped treatment as a result.<sup>17</sup> Although adverse effects of treatment can be incorporated in the concept of years of quality adjusted life gained,<sup>21</sup> the subjective perception of hazards can have profound effects on the choice of both patients and public.<sup>29</sup> This is shown by the unpopularity of prostatic surgery for urinary symptoms: after the risks and benefits of different treatments had been explained, the degree of inconvenience caused by the treatment and concern about impotence were the most important predictors of choice, and only 20% of men with severe symptoms opted for surgery.<sup>28</sup> Given an informed choice, patients often express preferences that are different from those of their doctors or peers.<sup>30 31</sup>

Decision analysis is able to concurrently assess the impact of multiple components, including quality of life, on treatment options,<sup>32-34</sup> but many questions remain. What is a reasonable number needed to treat or cost per year of life gained? How sensitive is the analysis to alterations in parameters? Do the results need further qualification for population subgroups?

### Cost and workload

The monetary cost of different treatments may be compared through cost-effectiveness analysis. Because gains are often fairly small, the conclusions of such analyses can be highly sensitive to minor changes in parameters, including drug costs.<sup>35</sup> While this may not be a problem when comparing two treatments under similar conditions or the incremental gains of extending a programme, it is a major issue when working out the basic costs of a programme for treating mild hypertension.<sup>36</sup> In addition, equity is omitted as a consideration in most analyses,<sup>37</sup> although there is no reason in principle why it should not be incorporated.<sup>38</sup>

Policy decisions may be influenced by both workload and the overall cost of a programme. These are determined by the size of the target population, and any new programme identifying treatment for more than 2% of the population has major implications for workload in primary care.<sup>2</sup> At a policy level, consideration should be given to whether greater benefit may be obtained at the same cost from some other intervention.

### Accessible summaries of treatment outcomes

These aids to decision making offer no tablets of stone. Instead, they provide estimates of the limits of uncertainty and a means to compare the relative value of different options. The presentation of a range of outcomes may not solve the problem, but it does establish a common currency in which options are explicit and decisions may be shared.<sup>23</sup> I discuss the use of such measures in the current debates on the treatment of raised blood pressure and cholesterol.

### Managing hypertension

While the New Zealand and European cardiovascular guidelines usefully summarise cardiovascular risk, neither provide an accessible summary of the numbers needed to treat, years of life gained, adverse event rates, costs, or workload at each level of absolute risk. Doubts remain about treating mild hypertension at younger ages. For example, 400 men aged 52 with systolic blood pressure < 150 mm Hg would require treatment for five years to prevent one stroke. This number falls to 250 for systolic pressure of 150-169 mm Hg and to 100 for systolic pressure of 170-199 mm Hg.<sup>39-40</sup> Lifetime treatment is estimated to add an average of 30 to 64 days to life expectancy; at 1995 prices, the cost ranged from £14 000 to £82 000 for men (greatest in the youngest patients) and from £28 000 to £252 000 for women for each quality adjusted life year gained.<sup>41</sup>

Patients and doctors need easy access to such data to inform their decisions. Table 2 shows a summary of outcome measures that might be included in future guidelines. It is not until annual cardiovascular risk is 1.5% or more that the benefits of treating raised blood pressure begin to become clear.<sup>8</sup> While a national strategy to reduce dietary salt and obesity would have considerably more impact than drug treatment, and at considerably less cost,<sup>1 42</sup> patients and their doctors must, for now, rely on evidence of this kind to inform their choice of treatment.

**Table 2** Summary of outcomes of treatment to reduce blood pressure in men aged 50 with raised blood pressure at different levels of cardiovascular risk. (Source of data: MRC Working Party,<sup>17</sup> Kawachi *et al*<sup>41</sup>)

	Annual risk of stroke or coronary event		
	0.5%	1.0%	1.5%
Systolic blood pressure (mm Hg)	150	160	180
Number needed to treat for five years to prevent one stroke	400	250	100
Mean benefit (gain in days of quality adjusted life)	30	45	65
No of patients experiencing adverse events per stroke prevented	80	50	20
Cost per quality adjusted life year gained (£)*	32 000	21 000	14 000

\*At prices in 1995.

### Managing serum cholesterol

The management of serum cholesterol presents greater uncertainty, although this is now changing for high risk patients. For people with heart disease and serum cholesterol above 6.5 mmol/l, and possibly at lower levels, treatment with "statins" to reduce cholesterol confers benefit.<sup>19 43</sup> For people without heart disease at lower absolute risk, recommendations for drug treatment based solely on their relative risk due to raised cholesterol have been controversial. The European Atherosclerosis Group<sup>13</sup> and a Sheffield group<sup>18 20</sup> have attempted to resolve the dilemma by recommending that treatment be based on absolute risk calculated with data from the Framingham study. Even with these more conservative guidelines, the number of people for whom treatment is recommended is substantially higher than reviews of previous trials seem to warrant. For people without pre-existing heart disease, adverse effects of treatment may be decisive, and further large scale trials are necessary to establish lower limits for treatment.<sup>27 44</sup>

The west of Scotland study indicates that, among healthy men with an average serum cholesterol concentration of 7 mmol/l and annual coronary event risk of 1.5%, 200 people would require treatment for five years to prevent one coronary death and 40 would require treatment for this period to prevent one coronary event.<sup>45</sup> Table 3 compares the results of this study with those of the Scandinavian simvastatin survival study.<sup>19</sup> Again, this simple summary of

**Table 3** Summary of outcomes of treatment with "statins" to reduce serum cholesterol concentration in people with and without pre-existing heart disease (Source of data: Scandinavian Simvastatin Survival Study Group,<sup>19</sup> Shepherd *et al*,<sup>45</sup> Yusuf *et al*<sup>46</sup>)

	Pre-existing heart disease	
	Yes*	No†
Annual risk of coronary event (%)	6	1.5
Mean serum cholesterol concentration (mmol/l)	6.7	7.0
Number needed to treat for five years:		
To prevent one coronary death	28	200
To prevent one coronary event	15	40
No of patients experiencing adverse effects per coronary death prevented	2‡	3
Cost per year of life gained (£)§	17 000	Not available
Proportion of population proposed for treatment (%)	0.3	20

\*Scandinavian study of men and women with mean age 58 years.

†West of Scotland study of men with mean age 55 years.

‡There was also a non-significant 12% excess of non-coronary deaths among women.

§At prices in 1995.

treatment outcomes would enhance future guidelines, although gains in life years were not available at the time, nor were costs in the Scandinavian study. Even at the low levels of adverse reaction reported, for every one person gaining from prevention of coronary death, two or three people would experience adverse effects from treatment. It is in these areas of uncertainty that there is the greatest need for accessible presentation of available data.

## Conclusion

Absolute multiple risk scores usefully summarise risk and are better predictors than any single factor. However, risk is only half the story. Accessible presentation of numbers needed to treat, years of life gained, adverse events, cost, and workload is also needed for shared decision making, enabling patients and their clinicians to weigh the pros and cons of treatment in their particular circumstances. These measures should be routinely included in management guidelines. Decision tools may only approximate to the truth, but presenting a range of treatment outcomes establishes a common currency for informed choice. Placing finite limits on uncertainty is the best guarantee that treatment will be optimal and appropriate.<sup>47</sup>

I thank Carol Dezateux, Kambiz Boomla, Gene Feder, Rod Jackson, Anna Livingstone, Pat McBride, and the referees who commented on this article.

Funding: I wrote this article while on study leave funded by the Department of Health, the Royal College of General Practitioners, and the King's Fund.

Conflict of interest: None.

- Kannel WB. Framingham study insights into hypertensive risk of cardiovascular disease. *Hypertens Res* 1995;18:181-96.
- Randall T, Muir J, Mant D. Choosing the preventive workload in general practice: practical application of the Coronary Prevention Group guidelines and Dundee coronary risk-disk. *BMJ* 1992;305:227-31.
- Tunstall-Pedoe H. Value of the Dundee coronary risk-disk: a defence. *BMJ* 1992;305:231-2.
- Cook RJ, Sackett DL. The number needed to treat: a clinically useful measure of treatment effect. *BMJ* 1995;310:452-4.
- Drummond MF, Heyse J, Cook J, McGuire A. Selection of end points in economic evaluations of coronary-heart disease interventions. *Med Decis Making* 1993;13:184-90.
- Sutherland HJ. Assessing patients preferences. *Med Decis Making* 1995;15:286-7.
- Tunstall-Pedoe H. The Dundee coronary risk disk for management of change in risk factors. *BMJ* 1991;303:744-7.
- Jackson R, Barham P, Bills J, Birch T, McLennan L, MacMahon S, et al. Management of raised blood pressure in New Zealand: a discussion document. *BMJ* 1993;307:107-10.
- Anderson KM, Wilson PW, Odell PM, Kannel WB. An updated coronary risk profile. A statement for health professionals. *Circulation* 1991;83:356-62.
- Shaper AG, Pocock SJ, Phillips AN, Walker M. A scoring system to identify men at high risk of a heart attack. *Health Trends* 1987;19:37-9.
- Working Group of the Coronary Prevention Group and the British Heart Foundation. An action plan for preventing coronary heart disease in primary care. *BMJ* 1991;303:748-50.
- Kannel WB. Office assessment of coronary candidates and risk factor insights from the Framingham study. *J Hypertens Suppl* 1991;9:S13-9.
- Pyorala K, De Backer G, Graham I, Poole-Wilson P, Wood D. Prevention of coronary heart disease in clinical practice. Recommendations of the task force of the European Atherosclerosis Society and European Society of Hypertension. *Eur Heart J* 1994;15:1300-31.
- Wolf PA, D'Agostino RB, Belanger AJ, Kannel WB. Probability of stroke: a risk profile from the Framingham study. *Stroke* 1991;22:312-8.
- Coppola WTG, Whincup PH, Papacosta O, Walker M, Ebrahim S. Scoring system to identify men at high risk of stroke: a strategy for general practice. *Br J Gen Pract* 1995;45:185-9.
- Logan AG. Screening for hypertension in young and middle-aged adults. In: Canadian Task Force on the Periodic Health Examination, ed. *The Canadian guide to clinical preventive health care*. Canada: Minister of Supply and Services, 1994.
- Medical Research Council Working Party. MRC trial of treatment of mild hypertension: principal results. *BMJ* 1985;291:97-104.
- Haq IU, Jackson PR, Yeo WW, Ramsay LE. Sheffield risk and treatment table for cholesterol lowering for primary prevention of coronary heart disease. *Lancet* 1995;346:1467-71.
- Scandinavian Simvastatin Survival Study Group. Randomised trial of cholesterol lowering in 4444 patients with coronary heart disease: the Scandinavian simvastatin survival study (4S). *Lancet* 1994;344:1383-9.
- Ramsay LE, Haq IU, Jackson PR, Yeo WW. The Sheffield table for primary prevention of coronary heart disease: corrected. *Lancet* 1996;348:1251-2.
- Fletcher A. Pressure to treat and pressure to cost: a review of cost-effectiveness analysis. *J Hypertens* 1991;9:193-8.
- Pettiti DB. *Meta-analysis, decision analysis and cost-effectiveness. Methods for quantitative synthesis in medicine*. Oxford: Oxford University Press, 1994.
- Richardson WS, Detsky AS. Users' guides to the medical literature. VII. How to use a clinical decision analysis. B. What are the results and will they help me in caring for my patients? *JAMA* 1995;273:1610-3.
- Hux JE, Naylor CD. Communicating the benefits of chronic preventive therapy: does the format of efficacy data determine patients' acceptance of treatment? *Med Decis Making* 1995;15:152-7.
- Cranney M, Walley T. Same information, different decisions: the influence of evidence on the management of hypertension in the elderly. *Br J Gen Pract* 1996;46:661-3.
- Guyatt GH, Sackett DL, Cook DJ. Users' guide to the medical literature. II. How to use an article about therapy or prevention. B. What were the results and will they help me in caring for my patients? *JAMA* 1994;271:59-63.
- Davey Smith G, Song F, Sheldon TA. Cholesterol lowering and mortality: the importance of considering initial risk. *BMJ* 1993;306:1367-73.
- Wennberg JE, Barry JM, Fowler FJ, Mulley A. Outcomes research, PORTs and health care reform. In: Warren SK, Mosteller F, eds. *Doing more good than harm: the evaluation of health care interventions*. New York: New York Academy of Sciences, 1993;52-62.
- Robertson JAL. Policy goals for health and safety: another view. *Risk Analysis* 1995;15:289-91.
- McPherson K. The Cochrane lecture. The best and the enemy of the good: randomised controlled trials, uncertainty, and assessing the role of patient choice in medical decision making. *J Epidemiol Community Health* 1994;48:6-15.
- Chalmers I. What do I want from health research and researchers when I am a patient? *BMJ* 1995;310:1315-8.
- Tengs TO, Adams ME, Pliskin JS, Safran DG, Siegel JE, Weinstein MC, et al. Five-hundred life-saving interventions and their cost-effectiveness. *Risk Analysis* 1995;15:369-90.
- Russell LB. The role of prevention in health reform. *N Engl J Med* 1993;329:352-4.
- Field K, Thorogood M, Silagy C, Normand C, O'Neill C, Muir J. Strategies for reducing coronary risk factors in primary care: which is the most cost effective? *BMJ* 1995;310:1109-12.
- Russell LB. Cost-effectiveness of antihypertensive treatment. General considerations. *Hypertension* 1989;13:1141-4.
- Russell LB. *Is prevention really better than cure?* Washington DC: Brookings Institute, 1986.
- Ubel PA, DeKay ML, Baron J, Asch DA. Cost effectiveness analysis in a setting of budget constraints. Is it equitable? *N Engl J Med* 1996;334:1174-7.
- Lindholm L, Rosen M, Weinehall L, Asplund K. Cost effectiveness and equity of a community based cardiovascular disease prevention programme in Norsjo, Sweden. *J Epidemiol Community Health* 1996;50:190-5.
- Swales JD, Ramsay LE, Coope JR, Pocock SJ, Robertson JIS, Sever PS, et al. Treating mild hypertension. Agreement from large trials. Report of the British Hypertension Society working party. *BMJ* 1989;298:694-8.
- Beard K, Bulpitt C, Mascie-Taylor H, O'Malley K, Sever P, Webb S. Management of elderly patients with sustained hypertension. *BMJ* 1992;304:142-416.
- Kawachi I, Malcolm LA. The cost-effectiveness of treating mild-to-moderate hypertension: a reappraisal. *J Hypertens* 1991;9:199-208.
- Law MR, Frost CD, Wald NJ. By how much does dietary salt reduction lower blood pressure? III—Analysis of data from trials of salt reduction. *BMJ* 1991;302:819-24.
- Goldman L, Weinstein MC, Goldman PA, Williams LW. Cost-effectiveness of HMG-CoA reductase inhibition for primary and secondary prevention of coronary heart disease. *JAMA* 1991;265:1145-51.
- Jackson R, Beaglehole R. Evidence based management of dyslipidaemia. *Lancet* 1995;346:1441.
- Shepherd J, Cobbe MS, Ford I, Isles C, Lorimer AR, Macfarlane PW, et al. Prevention of coronary heart disease with pravastatin in men with hypercholesterolaemia. *N Engl J Med* 1995;333:1301-7.
- Yusuf S, Anand S. Cost of prevention. The case of lipid lowering. *Circulation* 1996;93:1774-6.
- Warren KS, Mosteller F, eds. *Doing more good than harm: the evaluation of health care interventions*. New York: New York Academy of Sciences, 1993.

(Accepted 9 January 1997)

# Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study

N Hallowell, F Murton, H Statham, J M Green, M P M Richards

## Abstract

**Objectives:** To describe women's information needs prior to genetic counselling for familial breast or ovarian cancer.

**Design:** Prospective study including semistructured telephone interviews before genetic counselling, observations of consultations, completion of postal questionnaires, and face-to-face interviews within two months of counselling.

**Subjects:** 46 women attending genetic counselling for familial breast or ovarian cancer.

**Main outcome measures:** Subjects' understanding of process and content of genetic counselling before attending and attitudes about their preparation for the counselling session.

**Results:** Although all women interviewed before the clinic expected to discuss their risk of developing cancer and risk management options, there was evidence of a lack of knowledge about the process and content of genetic counselling; 17 (37%) women said they did not know what else would happen. Most women interviewed after counselling viewed it positively, but 26 (65%) felt they had been inadequately prepared and 11 (28%) felt that their lack of preparation meant that they could not be given an accurate estimation of their risk of cancer.

**Conclusions:** Some women felt that they did not obtain optimum benefit from genetic counselling because they were inadequately prepared for it. We suggest that cancer family history clinics should provide women with written information about the process and content of genetic counselling before their clinic attendance.

## Introduction

As the genetic basis for common multifactorial disorders becomes increasingly recognised there will be increasing demand for genetic counselling. It is therefore important to determine efficient ways of providing this service. Recent studies have looked at the provision of information during genetic consultations<sup>1</sup> and counsellees' expectations before attending cancer family history clinics.<sup>2</sup> Using data obtained during a prospective study of genetic counselling for breast or

ovarian cancer,<sup>3</sup> we present suggestions for the use of written information by family history clinics.

## Subjects and methods

### Subjects

We recruited subjects from Cambridge Cancer Family History Clinic. After excluding those who had had breast or ovarian cancer or who had previously attended genetic counselling, we invited all women referred between February 1994 and February 1995 to take part. We approached 59 eligible women and recruited 46. The participants were aged 22-59 years (mean 40 years), and table 1 shows details of their family history of cancer.

**Table 1** Family history of cancer of 46 women attending genetic counselling

Type of familial cancer	No (%) of women
Breast and ovarian cancer	10 (22)
Breast cancer only	18 (39)
Ovarian cancer only	16 (35)
Breast cancer and uterine or stomach cancer	2 (4)

### Data collection

We collected data from interviews, observations, and questionnaires (see table 2). We recorded and transcribed the interviews and consultations with the women's consent. The study was approved by Cambridge Local Research Ethics Committee.

### Data analysis

We coded the interview transcripts using the computer package Atlas-ti (Thomas Muhr, Berlin). Categories were based on the interview questions and recurring themes identified.<sup>4</sup> The consultations were coded as agenda setting, family history, epidemiological, genetic, risk and screening information, surgery, hormone therapy, DNA testing, and other. We analysed the questionnaire data with the statistical package spss.

### Clinic procedures

Before their appointment, counsellees were sent a form asking them to list affected relatives and their

Centre for Family Research, Faculty of Social and Political Sciences, University of Cambridge, Cambridge CB2 3RF

N Hallowell, research associate  
F Murton, research associate  
H Statham, senior research associate

M P M Richards, reader in human development

Department of Midwifery Studies, University of Leeds, Leeds LS2 9LN

J M Green, senior lecturer

Correspondence to: Dr Hallowell.

BMJ 1997;314:281-3

**Table 2** Timing and method of data collection from 46 women attending genetic counselling for familial cancer

Timing	Method	Data collected	No of women
1 Week before consultation	Semistructured telephone interview	Expectations of counselling, perception of risk, details of referral	46
Consultation	Observation	Audio tapes of consultation	46
2-4 Weeks after consultation	Postal questionnaire	Attitudes to counselling, presentation of risk information, and DNA testing	43
4-8 Weeks after consultation	Semistructured face to face interview	Attitudes to counselling, recall and understanding of information	40

This article and entire section are available on the BMJ web site.



**Table 3** Response of 42 women who attended genetic counselling for familial breast or ovarian cancer to the question "Overall, how satisfied are you with your experience of genetic counselling?"

Degree of satisfaction	No (%) of women
5 (very satisfied)	23 (55)
4	12 (26)
3	5 (11)
2	4 (9)
1	0
0 (not at all satisfied)	0

type of cancer, relationship to counsellee, date of birth, diagnosis and death, and details of hospitals where they had been treated. A few women contacted the clinic for further information and were told the approximate duration of the consultation, that they would not have a physical examination, and to write down questions for discussion. No physical examinations were performed during the consultations, although some counsellees were asked to donate blood for research purposes. Women were referred elsewhere for breast and ovarian screening.

## Results

### Preclinic expectations

Before attending the clinic, participants were asked "What do you hope to get out of the appointment?" All expected to discuss their family history, their own and other family members' risks, and options for risk management. However, there was widespread uncertainty about what else would occur, and 17 (37%) women said that they had no idea about what else to expect.

Unfamiliarity with the process and content of counselling inhibited counsellees from formulating questions in advance. In answer to the question "Have you any particular questions you want to ask the counsellor?" 13 (28%) women said they had not prepared questions as they envisaged their role in the consultation as passive—they assumed that the counsellor would question them and make recommendations.

### Consultations

The counsellors tried to establish the counsellees' expectations at the beginning of the consultations by asking them why they had been referred and what they expected. However, only one counsellee revealed her uncertainty at this point. The counsellees' lack of preparation became more apparent when the family history was taken as many became embarrassed when they were unable to provide information.

### Responses to postclinic questionnaire

Despite the women's high level of satisfaction with the consultation (see table 3), 12/43 (28%) said that they had been disappointed by some aspect of genetic counselling (for example, not having DNA testing or not being given enough information).

### Responses to postclinic interview

Although 16 (40%) women said that they had not known what to expect, most participants regarded counselling as a positive experience. However, only 14 (35%) women reported feeling adequately prepared—

"If there was anything I could change, it would be to let somebody know earlier what it really entails. Because I didn't know what to expect. I didn't know...they're going to talk to you about your family history. They are going to relate your family history to histories that they already have."

Eleven (28%) women said that they would have liked to have known beforehand exactly what details of family history were needed. Some had not realised the importance of male or distant relatives or that they would be asked for health details of family members not affected with cancer. They worried that the gaps in their information meant that they were unable to obtain an accurate estimate of risk, despite the fact that the counsellors always stressed the provisional nature of estimating risk.

Two (5%) women wished that they had been advised to prepare questions, as they had not realised that counselling was a two way process. Four (10%) women who received a qualitative risk estimate said it would have been helpful if they had been given a numerical risk, and two were not aware that this was possible.

Six (15%) women said the consultation did not match up to their expectations: four had thought that they would have a blood test (it was unclear whether they envisaged this as diagnostic or DNA testing), and two had expected to have a clinical examination or screening—"I had no idea what was going to happen. I thought maybe I was going to have a full examination.... I've never had a mammogram, and I thought maybe that would happen."

Some women said their anxiety about what would occur or the information they might receive had affected the way they approached the consultation—"I was in such a state when I got there. [My friend] and I sat in the car counting down.... And I'm saying to [my

### Key messages

- Genetic services are coming under increasing pressure as more women are referred for genetic counselling because of a family history of breast or ovarian cancer
- We interviewed women before and after they attended genetic counselling to find their views of the process
- All women interviewed before the clinic expected to discuss their risk of developing cancer and options for risk management, but many said they did not know what else would happen
- Women interviewed after counselling generally viewed it positively, but most felt they had been inadequately prepared and some felt that their lack of preparation meant that they could not get an accurate estimation of their risk of cancer
- Women need information about genetic counselling before they attend the clinic so that they are adequately prepared, and a written leaflet describing the process and explaining some basic genetic facts could be a cost effective means of providing this

## Suggested content of information leaflet about genetic counselling

*Description of process of genetic counselling as practised in clinic*— This should inform counsellees about what will occur during their consultation: that their family health history will be discussed, whether blood may be taken, and whether screening or physical examination may be performed. It should also emphasise that counselling is a two way exchange and encourage counsellees to prepare questions for the counsellor. An indication of whether it would be appropriate for a partner or close relative to attend the consultation would be helpful

*Description of content of genetic discussions*— This should outline the topics that may be discussed during the consultation: family history, risk assessment, and options for risk management for both counsellee and relatives. A list of all the details of the family history that the counsellee needs to bring to the consultation should be included. It should be emphasised that information about all known blood relatives, male and female and not just those affected by cancer, may be helpful

*Background information*— This should include brief epidemiological facts about the cancers (for example, the population risk of breast cancer is 1 in 12 and about 5% of cases of breast cancer are caused by an inherited predisposition), a simplified illustration of autosomal dominant inheritance, and a brief description of current research into cancer genes and the implications for DNA testing

obtain a definitive risk estimate. These findings suggest that counsellees would benefit from receiving information about the process and content of genetic consultations before they attend. A cost effective way to implement this suggestion would be to send counsellees a leaflet describing the practice of genetic counselling in a particular clinic and including some background information about familial breast and ovarian cancer (see box).

Many studies report that patients often prefer written to oral information<sup>5</sup> and that receiving written information before treatment reduces anxiety,<sup>6</sup> is reassuring,<sup>7</sup> and increases patient satisfaction.<sup>6, 8</sup> We believe that the service delivery in cancer family history clinics could be improved by the use of written information, as it would not only allay anxiety about the forthcoming consultation but also focus counsellees' concerns and ensure they bring the relevant information. This may reduce the need for clinics to contact counsellees for further information and the number of requests for follow up consultations.

We thank Professor B A J Ponder, Dr C Eng, Maggie Ponder, and all the women who took part in this study.

Funding: This study was funded by the Medical Research Council. The familial cancer clinic was supported by grants from the Cancer Research Campaign to B A J Ponder.

Conflict of interest: None.

friend], 'You listen for me because I can't take it in....' And both of us were just like messes in the car.... Just before I went in for the appointment, my mind just went blank."

## Discussion

Our subjects reported a high degree of satisfaction with counselling, but uncertainty about what the consultation entailed meant that a substantial proportion did not formulate questions in advance. Indeed, only 35% of the women considered themselves adequately prepared. Most knew that they wanted information about their risk of cancer and 38 (83%) received a quantitative risk estimate, but 11 (28%) felt that their lack of preparation meant that they could not

- 1 Michie S, Axworthy D, Weinman J, Marteau T. Genetic counselling: predicting patient outcomes. *Psychol Health* 1996;11:797-809.
- 2 Julian-Reynier C, Eisinger F, Chabal F, Aurran Y, Nogues C, Vennin P, et al. Cancer genetics clinics: target populations and counsellees' expectations. *Eur J Cancer* 1996;32A:398-403.
- 3 Richards MPM, Hallowell N, Green JM, Murton F, Statham H. Counseling families with hereditary breast and ovarian cancer: a psychosocial perspective. *J Genet Counseling* 1995;4:219-33.
- 4 Pope C, Mays N. Reaching the parts that other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995;311:42-5.
- 5 Weinman J. Providing written information for patients: psychological considerations. *J R Soc Med* 1990;83:303-5.
- 6 Austoker J, Ong G. Written information needs of women who are recalled for further investigation of breast screening: results of a multicentre study. *J Med Screening* 1994;1:238-44.
- 7 Hjelm-Karlsson K. Comparison of oral, written and audio-visually prepared information as preparation for intravenous pyelography. *Int J Nurs Stud* 1989;26:53-68.
- 8 Gibbs S, Waters WE, George CE. Communicating information to patients about medicine. *J R Soc Med* 1990;83:292-7.

(Accepted 8 January 1997)

## A PATIENT WHO CHANGED MY PRACTICE

### The question that made all the difference

A 43 year old woman presented at my outpatient clinic with a moderate depressive disorder associated with the break up of a relationship. She had become progressively more withdrawn and isolated. Further questioning revealed that she had for many years avoided going out on her own and this included shopping and going on public transport.

As part of her treatment I planned to use a behavioural model and started to explain to her about keeping a diary about her mood and activities. She fully agreed to this and had nodded in agreement as I wrote down examples. But as she came to leave and I was writing down the time and date of her next appointment,

something in the way she looked at the card made me hesitate and then ask, "Can you read and write?"

She blushed, hesitated, and then hesitatingly admitted that she could not.

Following this revelation we were able to get her help, and when she could read and write she could venture to the shops and on public transport as she could now read the labels, directions, and bus numbers.

I now check that all my patients can read and write.

Sarah Beesley is a lecturer in psychological medicine in Glasgow



## Netlines

### Medline on the web

- One of the best biomedical sites on the web has just got better. The United States National Center for Biotechnology Information at the National Library of Medicine has for some time offered free access to a subset of Medline dealing with genetics as part of its Entrez series of interlinked databases (<http://www4.ncbi.nlm.nih.gov/Entrez/>). Now the whole of Medline is available on the site through an experimental service, PubMed (<http://www4.ncbi.nlm.nih.gov/PubMed/>). In PubMed retrieved citations are not only linked to related articles or sequences, as in the Entrez databases, but there is also a PreMedLine section, containing references to articles that have not yet made it into the official Medline database
- You can even include hypertext links in your own web documents to articles in PubMed (such as <http://www4.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8520280&form=6&db=m &Dopt=r>) or, more powerfully still, call up a whole swathe of related articles in a single web address (try <http://www4.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m&form=6&uid=8520280 &Dopt=m>)

### Kawasaki disease

- Following complaints on television that too many British doctors are ignorant of Kawasaki disease, the Royal College of General Practitioners has prepared a fact sheet (<http://www.rcgp.org.uk/news/rcn0009.htm>), which is available on the RCGP's excellent web site (<http://www.rcgp.org.uk/index.html>)
- Those keen to know more about the aetiology of the condition should consult an article by Nigel Curtis of St Mary's Medical School available on line on [http://www.sm.ic.ac.uk/paediatrics/kawa\\_cml.htm](http://www.sm.ic.ac.uk/paediatrics/kawa_cml.htm)
- Support for families affected by the disease is available from the Kawasaki Families' Network (<http://ourworld.compuserve.com/homepages/kawasaki/>). The network can also be contacted by email on [kawasaki@compuserve.com](mailto:kawasaki@compuserve.com)

### Government information on the web

- If you tend to misfile or throw away the paper versions of official government communications, don't despair—you can access government press releases on the Central Office of Information's web site (<http://www.coi.gov.uk/coi/>). Of particular relevance here are the Department of Health's press releases (<http://www.coi.gov.uk/coi/depts/GDH/GDH.html>)
- The Department of Health itself has its own home page (<http://www.open.gov.uk/doh/dhhome.htm>), nested within the government information service (<http://www.open.gov.uk/>). On the DoH home page you will find a search facility plus links to DoH publications. Several mouse clicks down the line you will find the full text of (so far) only one government white paper on health (<http://www.the-stationery-office.co.uk/publicat/bydoh.htm>), published by the newly privatised successor to HMSO, the Stationery Office (<http://www.the-stationery-office.co.uk>)

### Talking digital

- In his book *Being Digital* (see <http://tulpi.interconnect.com.au/~pg/Negrop.htm> for a review) Nicholas Negroponte envisages a

world where everyday devices are networked and have enough intelligence to talk to one another, so that the refrigerator can talk, say, to your car or to your toaster. Perhaps one day your electrocardiograph will be able to talk directly to the Cardiac Arrhythmia Advisory System (CAAS) at the University of Oklahoma Health Sciences Center (<http://wailer.uokhsc.edu/eintheoven.html>). This expert system is able to interpret and advise on electrocardiograms over the web. According to its creators, its intended uses include decision support for rural and non-specialist practitioners and continuing medical education. Although still in demonstration mode, CAAS will accept interesting electrocardiograms for analysis in digital or in deadtree format

- In a similar vein to CAAS is Hepaxpert (<http://www.ping.at/hepax/>), a program that will interpret serology results for hepatitis A and B over the web
- On a more technical level, communication between medical imaging devices will be made easier by the launch of a new standard for digital imaging and communications in medicine, termed DICOM 3 ([http://www.xray.hmc.psu.edu/dicom/dicom\\_home.html](http://www.xray.hmc.psu.edu/dicom/dicom_home.html)). The new standard provides a detailed specification for formatting and exchanging images between imaging devices. For a tutorial on DICOM, particularly as DICOM 3 relates to cardiology, see [http://www.xray.hmc.psu.edu/dicom/acc\\_tut/tutorial.html](http://www.xray.hmc.psu.edu/dicom/acc_tut/tutorial.html)

### *E coli* O157:H7 and meningococcal meningitis

- The closing months of 1996 were marked in Britain by outbreaks of *E coli* O157:H7 infection and meningococcal meningitis. The Public Health Laboratory Service has published online fact sheets about *E coli* O157:H7 on <http://www.open.gov.uk/cdsc/ecolifac.htm> and about meningococcal disease on <http://www.open.gov.uk/cdsc/mengfact.htm>
- Further information on *E coli* as a pathogen is available from the *E coli* index at the University of Birmingham (<http://sun1.bham.ac.uk/bcm4ght6/res.html>) and from the American Food and Drug Administration's Bad Bug Book (<http://vm.cfsan.fda.gov/~mow/intro.html>)
- Those keen to keep up to date with emerging infections worldwide should visit the home page of the Program for Monitoring Emerging Diseases (ProMED) on <http://www.healthnet.org/programs/promed.html> and or join the ProMED mailing list by sending an email with the message "subscribe promed [your email address]" to [majordomo@usa.healthnet.org](mailto:majordomo@usa.healthnet.org), leaving the subject line blank

Compiled by Mark Pallen  
email [m.pallen@ic.ac.uk](mailto:m.pallen@ic.ac.uk)  
web page <http://www.qmw.ac.uk/~rhm001/mpallen.html>

If you are not yet on line you can find help in getting connected in the *ABC of Medical Computing* (eds Nicholas Lee and Andrew Millman, BMJ Publishing), which has Mark Pallen's *Guide to the Internet* as a supplement.