Reassurance through surveillance in the face of clinical uncertainty: the experience of women at risk of familial breast cancer

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Abstract

Objective To identify the main issues raised by clinicians when they are counselling women at risk of breast cancer and explore the response of a group of women 1 year after counselling.

Design A qualitative study which involved the thematic analysis of a series of transcripts from clinical consultations, semi-structured interviews and focus groups.

Participants First, a series of clinical consultations ($n = 153$), involving seven clinicians, were randomly selected during a Medical Research Council funded study of genetic assessment (TRACE). Second, a group of women ($n = 43$), involved in the TRACE study, were interviewed, or joined a focus group, 1 year after their genetic assessment.

Conclusions There was evidence that, although the clinical consultations were embedded with multiple messages of uncertainty, the women's accounts did not reflect this. The women talked about the reassurance they had found because they had met with an expert and become members of the surveillance society. The authors highlight the tension that exists because of the difference between lay expectations about on-going surveillance and the realities of collective service provision.

Introduction

Background

Breast cancer is the most common female cancer in developed countries¹ and recent advances in molecular genetics indicate that between 5% and 10% of all female breast cancers are due to genetic pre-dispositions.^{2,3} The identification of gene mutations has enabled pre-symptomatic genetic testing for

susceptibility to the disease in some cases⁴ but it has been recognized that a number of questions need to be answered about the shape of future services for at-risk women.^{5,6} The past 20 years has seen a focus, in the psychosocial genetics literature, on the genetic counselling encounter with specific reference to how counsellors interpret and act on clinical risk figures.⁷⁻¹² This paper is concerned with informing service delivery by using research to increase our understanding about the genetic

assessment process. It will focus on the main issues raised by clinicians when they are counselling women at risk of familial breast cancer and the response of a group of women 1 year after counselling.

In 1996, the Medical Research Council funded a 3 year study in Wales (the TRACE study) to investigate the psychosocial and health economic consequences of providing a specialist genetic assessment service for women at risk of familial breast cancer.^{13–15} A total of 833 women, who had been referred by their G.P. or consultant, were recruited and randomized to one of two groups. Women in both arms of the trial were clinically examined and, where appropriate, offered a mammogram and entry to a chemoprevention trial. All women were offered annual surveillance for the duration of the study. Women in the control arm were given a generalized risk level (low, moderate, or high) whilst women in the trial arm were given a specific percentage risk (computer calculated) and the offer of pre-symptomatic testing if their risk was 25% or greater and they had a living affected relative who was willing to have gene testing.

Research study

Two qualitative data sets were collected during the TRACE study. First, 153 clinic consultations were randomly selected for tape recording, and involved four surgeons and three geneticists. Second, a sample of women ($n = 43$) were randomly selected from women who were called for their first annual review between September and November 1997. Twenty-four women were interviewed by either V.B. or J.J. and the remaining women joined one of six focus groups led by H.B. All the encounters took place within 4 weeks of the annual clinic visit. Each encounter was tape recorded. All the tapes were transcribed, made anonymous and analysed to identify key themes. The transcripts are identified by a code for clinician, or researcher, and a TRACE study number.

Clinicians' messages: the realities of medical uncertainty

It has long been recognized that modern developments in medicine uncover and create uncertainties and risk not known or experienced before. Fox¹⁶ argues that there is a need to recognize the uncertainties that occur as a result of the limitations of current medical knowledge, and the incomplete mastery of available knowledge by any one clinician. This complex relationship between risks and realities is nowhere more evident than in the field of medical genetics. Transmission of risk information is the everyday reality of medical genetics, with geneticists demonstrating greater tolerance for ambiguity and uncertainty than general practitioners.¹⁷

The thematic analysis of the clinical consultations highlighted that they were embedded with multiple messages of uncertainty. Although each clinician's consultation was unique and idiosyncratic (a finding highlighted by Freidson¹⁸ and Bloor¹⁹) they were all constructed using the language of uncertainty. For example 'probably', 'possibly', 'might be', 'difficult to say', 'looks like', 'just a guesstimate' and 'certain hints that might give us a clue' were some of the words and phrases commonly used. Although it has been suggested that this retention of uncertainty by clinicians is one way of retaining control over patients and treatments,²⁰ it could also be argued that, in a world where clinicians are facing increasing legal challenges, it is extremely functional.

'It's only a guesstimate': uncertainties in assessing genetic risk

The most important element in determining a level of risk liability is family history. The consultations usually opened with information gathering: who had developed cancer, the age it had manifested, where the primary tumour had been located and what the outcome had been. This was followed by several questions about the regularity of periods, age of menarche, age of menopause, number of children, the use of any

medication, the contraceptive pill, hormone replacement therapy and any known allergies.

During this stage of the encounter, there was a sense the clinician was carrying out a process of categorization. It was, however, a process that the women were not privy to. They were unaware of the value that was being given to each of the elements and how they were adding up in the clinician's mind – they were just waiting for their risk level to be given. Before clinicians provided risk information they usually talked about the relevance of family history in determining levels of risk, the risk of breast cancer in the general population and finally, for women in the trial arm, how the computer was going to be used to calculate the risk figure. To retain the anonymity of the geneticists coding has been omitted from the following quotation:

I plug that data into a computer, there's nothing magic about it but it just compares with huge numbers of American families...and using various mathematical, sort of algorithms, it sort of models your family on their family. It tries to estimate what someone in your position's risk might be.

The main reason for the encounter was then made explicit:

With your family history the spectre always raises its ugly head 'Is there a gene running in your family?' (Clinician 1.1033)

The clinicians seemed to be posing a question to which there would be a definitive reply of either 'yes there is a gene' or 'no there isn't a gene'. But that was not the case. The majority of women, regardless of how the assessment had been made, were presented with risk and uncertainty. The examples taken from the transcripts have been divided to distinguish between the two arms of the trial and the language of uncertainty italicised. To retain anonymity coding has been omitted from this section. First, the cases where assessment was made by surgeons without the computer:

You've got two first degree relatives and an aunt so that does certainly put you in a higher risk category. The question is *how high is not easy to determine...probably somewhere between 1 in 5 and 1 in 10*

On another occasion:

It's difficult to say how much risk there is ...so it *maybe...*

The women in the trial arm were getting a computer assessment but still the liability was given as 'about':

It's obviously an estimate because no-one can predict these things too accurately.

Just by looking at it *I think* it. (hesitation) one can say that *it's more likely* it's chance ...

'It *doesn't tell us exactly* but the risk it was *suggesting* was *about...*and that's based on what we know at the moment.'

The uncertainty was then underlined:

We're not sure whether you have got a genetic problem...*it is possible* that all three cases could have happened by chance...*it's not easy to say... but I could be wrong...*

Regardless of the method of calculation the genetic assessment left the women with a high degree of uncertainty.

'We don't know': uncertainties in medical knowledge

Having provided the women with a genetic assessment the consultations then moved on to a discussion about the state of current medical knowledge. Although each clinician used their own unique repertoire to talk about the uncertainties, an analysis of the transcripts confirmed that phrases such as 'I don't know', 'we don't know' or 'we're not sure' appeared over 250 times in the 153 consultations. Gaps in current medical knowledge meant clinicians were unable to give definitive answers about the causes of breast cancer, the most effective methods of cancer prevention and surveillance, or the feasibility of gene testing in particular cases.

The causes of breast cancer

The clinicians were very clear that there was no simple answer to questions about the causes of breast cancer:

It's *something* to do with a 20th century lifestyle...we don't know what it is so *we can't tell you*. (Clinician 1.0313)

The environment or diet were proffered as potential causal agents:

They're [breast cancers] due to things such as environmental factors...um...lifestyle factors... hormonal factors...um there's *no one sort of simple cause* and effect. (Clinician 4.1650)

One woman asked the clinician whether it could be caused by shock:

You mean sort of stressful events... (slight hesitation) ... *there's no proof* to say that stress does it, but the more you get to know the women you realise how many traumatic events they've had ... (Clinician 2.0341).

Another woman was concerned about whether breast feeding was related:

The evidence about breast feeding is pretty weak but one determining factor, which is a bit stronger, is age of first pregnancy. (Clinician 1.1033)

But then uncertainty was added:

...but you know like all things there are trade-offs, it's only a very weak determinant. (Clinician 1.1033)

The importance of age at pregnancy in terms of hormonal changes was discussed in another consultation:

...if you're not having children that does put you at higher risk...and having children very late...having children has a protective effect...but it's *probably* a multitude of different things. (Clinician 2.0341)

Another clinician described being childless as having:

...a definite effect, it's not high, but it's there, ...a small effect... (Clinician 6.0279)

Trying to arrive at an explanation for why breast cancers happened was important to the women but the clinicians responded by underlining the uncertainties.

Prevention and surveillance

After the genetic assessment there was a discussion about prevention and surveillance. The frequently used strategy by the clinician

was the rhetorical question with the negative reply:

You may ask what can you do about risk and the answer is not a lot... (Clinician 6.1123)

Because:

There's no way, that we know, that people can prevent breast cancer. (Clinician 6.0387)

The use of Tamoxifen was discussed but again caution was sounded:

We don't know whether it makes any difference...*we don't know* whether it works or not... (Clinician 2.1610)

A similar approach was taken if the issue of prophylactic mastectomy was raised:

One of the problems with mastectomy is...although it gets rid of most of the risk there could be breast tissue in other places. (Clinician 1.1100)

There may be a lack of certainty in terms of current knowledge about cancer prevention but was there anything more certain about cancer surveillance?

... at the moment we don't have a...certain prevention...but we have ways of checking to find if it does happen... (Clinician 6.0529)

Two areas of medical surveillance were discussed, clinical examination and mammography:

...we adopt what's called a surveillance approach – we keep an eye on you. You're examined by people who are used to examining people with breast lumps on a regular basis... (Clinician 6.0160)

But again the air of uncertainty was raised:

Mammograms are the best early detection but *we don't know* how good they are. (Clinician 6.1122)

In addition, personal surveillance and a healthy lifestyle were encouraged:

There's nothing really you can do except to learn and practice self-examination properly. (Clinician 6.0160)

...you know... a healthy balanced diet...not the excessive fat...a bit more health conscious. (Clinician 2.0341)

...if women get overweight they have higher rates of breast cancer and so avoiding a lot of animal fat is sensible...(Clinician 6.0529)

But there was uncertainty even about that:

...we're *not entirely sure* whether that's true or not. (Clinician 6.1123)

The message from the clinicians was quite clear: there are still areas of uncertainty in terms of both prevention and on-going surveillance.

Uncertainties in gene testing: 'it's like a needle in a haystack job'

The third area where incomplete medical knowledge was acknowledged was the field of gene testing. The majority of women, in their baseline questionnaire, gave finding out whether they carried the breast cancer gene as their main reason for joining the TRACE study. In practice, fewer than 50 women actually proceeded with molecular testing. It was during their first clinic visit that most women discovered having the gene test was not a realistic goal: they were either in the control arm of the trial or they did not fit the criteria: gene testing was only offered to women with a 25% risk or greater who had a living affected relative willing to proceed with testing. The clinicians acknowledged gene testing was still a very new technique and 'still in its infancy'.

It's not like walking into Marks and Spencers – 'I'll have one of those'...it's not a trivial thing. (Clinician 1.0449)

So genetic testing is not a realistic proposition except in a very limited number of families...it's like looking for a needle in a haystack. (Clinician 3.0121)

The problem was:

Often we can't find the fault either because it's on a different breast cancer gene or it's on this gene but the testing isn't sensitive enough at the moment to pick it up. (Clinician 3.0107)

But there was hope:

Here's a haystack, we know there's a needle in it...with you we're not even sure if there is a needle to find, we've got a whole haystack to look

at...we're in better shape than we were two or three years ago... (Clinician 1.0449)

Clinicians' response to uncertainties: the use of the 'but'

The clinicians, when counselling women, were explicit about the uncertainties that exist because of gaps in current medical knowledge. However, they recognized the tension that exists between providing the women with false reassurance, that might reduce a commitment to personal surveillance, and creating unnecessary anxiety by failing to give some reassurance. One strategy adopted by the clinicians to cope with this dilemma was the ambiguous one-liner: a positive and negative statement joined by the word 'but'. For example, when discussing whether the woman was a gene carrier one clinician said:

It's a possibility, it's not a certainty, **but** it's certainly a possibility. (Clinician 1.0294)

On another occasion:

...you know you *can't say* it is [genetic], you *can't say* it isn't...There're *certain hints*...**but** it's not the sort of thing we say oh 'yes definite', it's *sort of in between*...things are looking promising **but** you are not entirely out of the woods yet... I'm less worried about you now...**but** you're not off the hook yet... (Clinician 1.0252)

It doesn't look as though there is a problem **but** there are a couple of possibilities... (Clinician 3.0375)

We're not trying to alarm you **but** just to say you have to be careful. (Clinician 2.1610)

Sometimes the negative came first:

'So you *can't rule it out*, **but** it's not shouting at you either. (Clinician 1.1033)

You're in the moderate to high risk group **but** the *odds* are still in your favour (Clinician 6.1122)

For the clinicians there was an acceptance that new technology, whilst providing opportunities for prediction, brought ambiguity and uncertainty. The question that has been left unanswered is how women will respond to this

move from traditionally accepted medical certainties. Could it be, as Buckman²¹ suggests, that the doctor's message is not necessarily what patients want to hear? This issue will be explored in the next section which looks at the women's accounts 1 year after their genetic assessment.

Women's voices: the realities and the reassurance

The women who were interviewed had all experienced the 'uncertainty' in counselling, described in the first part of the paper, and been given a personal level of risk liability. The data analysis shows, however, that their stories were not embedded with the language of uncertainty but described how they, as asymptomatic women, had come to be reassured by joining the surveillance society.

Life before trace: anxieties and perceptions of risk

The women gave three main reasons for becoming involved in the TRACE study. First, there were those for whom the trigger had been personal anxiety. They talked about 'getting really frightened', of being 'quite worried', of 'having this fear':

I used to worry all the time and get myself really ill over worrying... (HB.0135)

This anxiety was often rooted in the fact that cancer had been a life and death reality in their family, or they had experienced a breast problem:

It's quite worrying really when there is such a large proportion of your family who have it... (HB.0235)

I found this breast lump...**UGH**...(strong expression of disgust), so I went along to the hospital and told him my family history and that was that... (HB.0191)

It was this anxiety that had convinced one woman there was no alternative but prophylactic mastectomy:

Like before I went to clinic, then if somebody had offered me a mastectomy I would have said '**Yes Please**' (strong emphasis) – just to get rid of it, I was so frightened. (JJ.1349)

Second, there was a need for more information and this search was closely linked to getting advice on what should be done to reduce their chances of getting breast cancer.

The final reason women gave was a change in their family situation that had heightened their awareness of personal vulnerability. The relationship between individual perceptions of risk and proximity of affected cases has been recognized^{22,23} and links with the work of Schutz²⁴ on zones of relevance. Schutz argues that individuals structure their knowledge into zones of relevance, which decrease in degrees of clarity and precision as they move outwards from areas of personal concern. Breast cancer had returned to a central zone of relevance for these women:

My mother developed breast cancer a number of years ago, then three years ago my eldest sister had it, at the same time I had a neighbour who had it. I was surrounded by it ... (HB.0129)

It's worse because it was my sister who died. ...it was just that it brings it home, her being so close. (JJ.1260)

Often the women made connections between themselves and the person who had cancer with things 'just seeming to fall into place' because they were at a similar age or looked like them.

For this group of women, risk had become a reality and, as Hilton²⁵ has argued, getting information and taking action to increase chances of early detection are important strategies used to cope with uncertainty.

Genetic assessment: a new identity

Davis,²⁶ in his work on the medical management of identity, argues that clinicians give patients a clinical identity which is then translated into an appropriate social identity. The issue of social categorization, or the social construction of personal identity by the medical profession, as discussed by Freidson,¹⁸ is important in terms of women at risk of breast cancer. Parsons,²⁷ in his

concept of the sick role, defines sickness in terms of deviance and vulnerability. Doctors are the recognized healers in society and the official gatekeepers with the authority to legitimate sickness and offer appropriate treatment. Patients, on the other hand, are vulnerable and obliged to consult and co-operate with medical expertise. For Parsons²⁷ the doctor–patient relationship is one of ‘trust in the expert’, with a visit to the doctor being the signal that the individual is willing to accept medical management.

Although the women did not have any physical illness, in the accepted sense, their stories contained several important references to emotions and patterns of behaviour traditionally associated with the sick role. First, an emphasis was placed on the importance of going to see an ‘expert’:

It’s very important for peace of mind...the peace of mind knowing that I’ve been checked professionally... (VB.0022)

Second, the clinician’s emotional neutrality was not questioned:

...it’s nice to know that somebody is keeping an eye on you and that the best is being done for you. (HB.0069)

The expectation that ‘the best’ service was an annual examination by ‘someone who knows what they are looking for’ (JJ.0135) was a recurring theme. This was reflected in a very clear distinction made by the women between local surveillance and a specialist clinic:

...you go to your GP and you feel you’re a bit of a bother...you’re a bit obsessive...here it’s their job...I feel so much more reassured ...they’re only concerned with just your breasts, so they know their stuff... (VB.0073)

Second, in acknowledging medical expertise, several women talked about handing over responsibility to the clinician:

I didn’t have to worry at all, I had given it all to them...that’s been a wonderful release for me.’ (HB.0115)

Some women referred to this new found relationship in terms of ‘safety’, ‘support’ and

‘being looked after’. They had seen an expert, they were going to be screened regularly and this would increase their chances of early detection. The women seemed happy to hand over control to the medical profession and be relieved of responsibility, but what was the clinicians’ response? The analysis of the clinical data indicates that they fulfilled a traditional medical role in four areas. First, the clinicians provided the women with the support expected, with the offer of ‘keeping an eye on you’ regularly made. The reassurance was given that they were there to help and support the women at any time:

If you have any worries if you ring up you would be seen immediately... (Clinician 3.0352)

Second, the clinicians fulfilled their obligation to reassure the patient they were not responsible for their condition:

You can’t change your genetics or your history, you’ve got that and that’s it, you can’t do much yourself. (Clinician 4.0279)

Third, the clinicians acted as important gatekeepers of surveillance. It was on the basis of their classification into low, moderate or high risk groups that they made decisions about the women’s access to gene testing, a chemoprevention trial and where and when any future follow-up would take place at the end of the trial. Howson²⁸ notes a similar phenomena in her work on cervical screening: ‘risk categories have been important in establishing boundaries around those who should and should not be screened’. Finally, all the women were seen by a breast surgeon who carried out a clinical examination. The surgeons gave the results using phrases such as: ‘well that’s fine’, ‘everything looks OK’, ‘everything is fine at the moment’, ‘no, nothing to panic about, no your breasts are quite normal’ or ‘no you’ve nothing to worry about’.

It has been seen that although the women did adopt some elements associated with the sick role there were two differences. First, they were seeking a consultation with an expert when they had no symptoms. Second, the clinician was unable to offer any treatment and openly acknowledged that there was no agreed recovery

process. These well women were being reassured that they could do nothing about their problem but put faith in the medical profession who would 'keep an eye on them'. Once having handed over the responsibility the only way forward was to accept medical surveillance. It has been argued that this 'health promoting self'²⁸ is not suffering the effects of 'medicalisation' but rather is a consenting partner, actively seeking to remove the unpredictability and uncertainty from their everyday life by joining the surveillance society.²⁹⁻³¹

Post-clinic reappraisal: reassurance secured

The majority of women, in their pre-clinic questionnaire, had given gene testing as one of their main reasons for joining the trial. In practice this was only available to a small group, none of whom were included in this study. The reality therefore was that, post-clinic, although their genetic risk had been assessed the possibility of them being a gene carrier had not been eliminated. This, however, was not reflected in their stories. One explanation for this could lie in what has been described by Davis³² and Blaxter³³ as 'retrospective reconstruction'. These authors argue that individuals are capable of retaining a degree of stability in the face of uncertainty by a process of ongoing redefinition:

For the individual, past, present and future cannot be separated, for he continually recreates the past in the light of the present and interprets the present in the light of the imagined future. (Blaxter 1976 p.12).

The analysis identified several strategies that the women had adopted which enabled them to live without their previously reported high levels of anxiety. The first strategy was to relegate the importance of risk, with several women saying that their actual risk made very little difference to them. The fact that, without gene testing, the maximum risk that could be given was 50% had not escaped the notice of some women:

When you're used to working in a world of 0-100%, 40% doesn't actually sound that high. (JJ.0135)

This relegation of risk was closely related to the second strategy adopted to remove unpredictability. Concerns about establishing carrier status were overtaken by concerns about their present physical condition. There was a realization that it was not the risk that would kill but the cancer. The reality was that their risk assessment had not eliminated the uncertainty, but the mammogram and clinical examination had given them a degree of reassurance for the year ahead. This 'all clear' from the expert was the key:

It's, it is reassuring and, you know, it's just peace of mind. (JJ.0364)

As long as the clinician says there are no lumps then I will be happy. (HB.0149)

I can feel quite detached now...quite unemotional, you can think well it's not going to happen today. (JJ.0402)

The women's previous concerns about the risks had been relegated as they focused on the apparent certainty provided by the medical expert that they were 'part of a system'.

This move away from uncertainty was reflected in the women's 'recipes for everyday living'.²⁴ These formulae for making sense of life enable individuals to deal with routine matters of everyday living without constantly returning to previous uncertainties. They guide day-to-day decision making and form an important part of the process of 'retrospective reconstruction'.^{32,33} The recipes contained clear messages about being positive and taking control:

I think at some stage or another you have to take control of your life... (HB.0040)

I actually looked at things bleakly for a little while, but life goes on and you have to look at taking on the problem... you've got to be positive. (HB.0069)

For some women there was a recognition that the responsibility did not lie with them:

It's no good getting your hair off, you can't do anything about it can you? (HB.0079)

What's the point, you're just worrying yourself about something you've no control over. (JJ.0097)

This strategy also involved a strong faith in future medical advances:

As far as I'm concerned I've got my future to look forward to. The way I look at it is if I do carry the gene we're probably talking may be 10, 20 years time and you got to think how advanced medicine will be then. (JJ.1346)

There was also a conviction that things would be different for them:

If they had started this screening earlier my aunt may have still been alive. (HB.0082)

I want to make sure that what happened to mum doesn't happen to me. (JJ.1445)

The focus of the women's accounts was not the uncertainties that had been talked about in clinic but the reassurance they had gained. Parsons argues³⁴ that the medical profession need to manage illness in such a way as to enable sufferers to establish a relatively 'normal social role', something the clinicians in this study had achieved. Although they had talked about 'uncertainty', at the same time they had provided the women with an assurance that, at the present moment, there was no sign of breast cancer. This is how the women talked about it:

I haven't thought about it throughout the year...at least now I know that I'm OK. (VB.0200)

It's the reassurance of knowing that I'm having yearly check-ups. (JJ.1346)

The message from the women was very clear: by becoming members of the surveillance society they were able to relegate their concerns about carrier risks and breast cancer to a lower zone of relevance, at least for one more year.

Conclusion

This paper has been concerned with professional and lay responses to probabilistic and conditional thinking which has been associated with post-modernism.³⁵⁻³⁷ This thinking is seen to contrast sharply with the traditional world view associated with medicine. Mishel²³ argues that this 'new world view', which accepts uncertainty as a natural phenomenon and defines it as an

opportunity rather than a threat, is the only way forward. Individuals who constantly face the threat of uncertainty need the support of health care providers who believe in the probabilistic paradigm to develop 'a new sense of order'.²³ This research has shown that clinicians and women at risk held very different perspectives on uncertainty. The clinicians, for whom counselling was part of their everyday working routine, were comfortable with concepts of uncertainty whilst the women, for whom the problem was personal and specific, resolved the unpredictability by focusing on the reassurance they had been given. This difference can be best understood by moving away from the concept of uncertainty embedded in traditional medical sociology and accepting the argument made by Atkinson³⁸ that the concepts of uncertainty and certainty in medical discourse are not mutually exclusive, but should be seen as dialectically interdependent. For Atkinson, any sense of uncertainty simultaneously implies the existence of a province of meaning in which certainty and trust are relatively stable. As Light³⁹ points out, medical training for uncertainty also implies training in strategies for retaining personal autonomy and clinical control. In counselling women at risk of familial breast cancer, there might be uncertainty about the medical facts under discussion, but there was no uncertainty about the personal expertise and practice of each clinician. This finding is in line with that of Calnan⁴⁰ who argues clinical effectiveness and clinical uncertainty rarely become an issue in the clinician-patient relationship. Although multiple messages of uncertainty were given throughout the clinical consultation, the women were able to focus on those areas where certainty and trust remained relatively stable. The clinicians might use the language of uncertainty but the encounter still provided the women with the certainty they were seeking. It can be argued that this certainty came from their perception of the clinician's professional expertise and their role as the gatekeeper to surveillance.

It is this access to surveillance, defined as important by the women, that raises important questions about future service delivery. A recent

report in Wales,⁴¹ based on discussions with experts and clinicians, made the following recommendations about future services for women at risk:

- (a) Low Risk Women to be returned to their GP
- (b) Moderate Risk Women over 40 to be offered mammography and clinical breast examination every 18 months until they are 50 and then returned to the standard breast screening programme.
- (c) High Risk Women to be offered more detailed genetic assessment with annual mammography and clinical breast examination between 35 and 50 and every 18 months over 50.

Although these recommendations are still under discussion they do reflect current clinical thinking and represent a change from the level of surveillance experienced by women during the TRACE study. It highlights a constant tension between service provider and service user and raises the inevitable question: is it possible to match lay expectations, rooted in a personal and specific perspective, with the realities of collective service provision?

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