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ORIGINAL ARTICLE

"Out of the blue": A qualitative study exploring the experiences of women and next of kin receiving unexpected results from BRA-STRAP research gene panel testing

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Abstract

In the genomic era, the availability of gene panel and whole genome/exome sequencing is rapidly increasing. Opportunities for providing former patients with new genetic information are also increasing over time and recontacting former patients with new information is likely to become more common. Breast cancer Refined Analysis of Sequence Tests—Risk And Penetrance (BRA-STRAP) is an Australian study of individuals who had previously undertaken *BRCA1* and *BRCA2* genetic testing, with no pathogenic variants detected. Using a waiver of consent, stored DNA samples were retested using a breast/ovarian cancer gene panel and clinically significant results returned to the patient (or next of kin, if deceased). This qualitative study aimed to explore patient experiences, opinions, and expectations of recontacting in the Australian hereditary cancer setting. Participants were familial cancer clinic patients (or next of kin) who were notified of a new pathogenic variant identified via BRA-STRAP. In-depth, semi-structured interviews were conducted approximately 6 weeks post-result. Interviews were transcribed verbatim and analyzed using an inductive thematic

approach. Thirty participants (all female; average age = 57; range 36–84) were interviewed. Twenty-five were probands, and five were next of kin. Most women reported initial shock upon being recontacted with unexpected news, after having obtained a sense of closure related to their initial genetic testing experiences and cancer diagnosis. For most, this initial distress was short-lived, followed by a process of readjustment, meaning-making and adaptation that was facilitated by perceived clinical and personal utility of the information. Women were overall satisfied with the waiver of consent approach and recontacting process. Results are in line with previous studies suggesting that patients have positive attitudes about recontacting. Women in this study valued new genetic information gained from retesting and were satisfied with the BRA-STRAP recontact model. Practice implications to facilitate readjustment and promote psychosocial adaptation were identified.

KEYWORDS
adaptation, genetic counseling, genetic testing, psychosocial, qualitative research, recontacting, retesting

1 | INTRODUCTION

With rapid advances in genomic testing technologies, recontacting individuals with new genetic information has become a current topic of debate in clinical genetics. Recontacting has been defined as a process of "identifying and re-establishing contact with former patients who could benefit from new information related to their health condition" (Carrieri et al., 2019). Recontact may occur on the basis of new genetic test results, reclassification of a variant, new research opportunities, or a change to risk management recommendations (Otten et al., 2015). Despite the speed at which new opportunities for recontacting are emerging, patient expectations and experiences of recontacting are poorly understood. As such, there is little consensus among genetic health professionals about how best to approach recontacting in routine clinical practice (Dahle Ommundsen et al., 2022).

In the cancer setting, identifying individuals with pathogenic variants in cancer predisposition genes can provide opportunities for cancer prevention and early detection, through access to evidence-based screening and risk management protocols. Traditionally, genetic testing was offered to a limited cohort of patients based on stringent personal and/or family history criteria, and involved analysis of single genes and syndromes at a time. In recent years, however, the development of massively parallel sequencing platforms has made it possible to simultaneously analyze many genes in a single test—also known as "panel testing." This approach increases the diagnostic yield across a much larger number of cancer predisposition genes (Kurian et al., 2014; Southey et al., 2021; Susswein et al., 2016), but simultaneously increases the likelihood of ambiguous or unexpected findings which can be complex for both patients and healthcare providers to navigate (Dwarte et al., 2019; Hooker et al., 2017).

With panel testing now routinely offered in clinical settings, questions have been raised about the diagnostic potential of this technology for families in whom previous genetic testing has been uninformative (i.e., no pathogenic variants detected). For many of these families, historical DNA samples remain stored in laboratories for potential future retesting. In the context of hereditary breast and ovarian cancer, previous genetic testing that analyzed only *BRCA1* and *BRCA2* would today be considered out of date (Hooker et al., 2017). However, retesting of samples is usually performed on an ad hoc basis, with a number of practical,

What is known about this topic

The need to recontact patients with new information is likely to increase with improvements in genomic technologies. Literature suggests patients have positive attitudes about being recontacted with new genetic information. However, few studies have explored actual patient experiences. Concerns have been raised among healthcare providers, including potential to cause distress and considerations regarding the requirement versus burden of reconsent.

What this paper adds to the topic

This study adds a valuable patient perspective to recontact literature. Interviews with women who were recontacted with a new genetic result indicate positive experiences of recontact and that women valued the new genetic information. Women's accounts suggest positive adaptation to the new results. Also, that retesting and recontact, alongside timely genetic counseling, is acceptable to patients and does not cause harm in the absence of potentially onerous reconsenting processes.

ethical, legal, financial and social issues often preventing larger scale, systematic efforts for retesting and recontacting (Mueller et al., 2019; Vora et al., 2022).

While studies of healthcare professionals indicate that recontacting patients with new clinically actionable information is seen as ethically desirable (Carrieri et al., 2017a; Otten et al., 2015), the implementation of routine recontacting procedures is often considered unfeasible due to a lack of time, resources and appropriate infrastructure (Carrieri et al., 2016; Otten et al., 2015; Vora et al., 2022). There is also some concern among genetic healthcare professionals regarding the potential to establish a duty or responsibility to recontact, which could leave them legally vulnerable in cases where their former patients have not been recontacted (Mueller et al., 2019; Otten et al., 2015). Concerns have also been raised among healthcare professionals about the potential of causing distress for patients who no longer wish to be contacted, or were unaware of the durability of their consent to future retesting and/or recontacting at the time of their initial test (Doheny, 2022; El Mecky et al., 2019).

However, there are a limited number of empirical studies available that provide a patient perspective on recontacting. Available studies suggest that most individuals have positive attitudes toward being recontacted (Carrieri et al., 2017b; Dahle Ommundsen et al., 2022; Rasmussen et al., 2019), and may even have an expectation that they will be recontacted if there is new clinically actionable information available (Carrieri et al., 2017b). In a qualitative study of UK patients seen by genetics services for a range of health conditions, participants overall had positive attitudes toward being recontacted, though some expressed concern about the potential psychological impact of being recontacted with uncertain information (Carrieri et al., 2017b). A survey of Norwegian women previously tested for *BRCA1* and *BRCA2* also demonstrated high interest in being recontacted with new genetic information among the majority of respondents, though a small number reported the potential for recontact to be stressful or bring back "bad memories" (Dahle Ommundsen et al., 2022). In a qualitative study of men with Lynch syndrome who were recontacted with new information regarding prostate cancer risk, the practice of recontact was associated with minimal emotional distress, with the new information integrated into existing health beliefs (2019).

While the available data provides a useful starting point for understanding recontact in the hereditary cancer setting, most of these studies have been hypothetical in nature. To date, there are no published studies providing a patient perspective on actual experiences of being recontacted with information about new pathogenic variants following retesting. This study aimed to explore patient experiences, opinions and expectations of retesting and recontacting in the Australian hereditary cancer setting.

2 | METHODS

A qualitative approach was used to explore patient experiences, opinions, and expectations of recontacting in the Australian hereditary cancer setting. Ethical approval was granted by the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Reference 16/240).

2.1 | Setting and participants

Participants were recruited from six Australian Familial Cancer Clinics (FCCs) across three states (New South Wales [NSW], Australian Capital Territory [ACT], South Australia [SA]) involved in the Breast cancer Refined Analysis of Sequence Tests—Risk And Penetrance (BRA-STRAP) study. BRA-STRAP is an Australian study of individuals previously tested for *BRCA1* and *BRCA2* through participating familial cancer clinics (FCCs), with no pathogenic variants detected. Using a waiver of consent, stored DNA samples were sent to an external research laboratory and retested using a panel of twenty-four genes commonly included on panel tests for breast and/or ovarian cancer predisposition (as described in Southey et al., 2021). At the time of their initial testing, individuals signed a consent form that explicitly stated the potential for future testing of stored DNA samples as knowledge about genetics improves. However, the detail in which this was discussed during the consent process may have varied, depending on a wide range of factors (e.g., patient information preferences, healthcare professional communication styles, time constraints).

Clinically significant results (i.e., variants with clinical risk management implications) were returned to the FCC, who were then responsible for recontacting the patient (or their nominated next of kin, if deceased) and providing appropriate genetic counseling and confirmatory testing of the research result in an accredited laboratory. Approximately 5500 FCC samples have been retested to date, and 250 clinically significant variants returned to FCCs.

Strategies for return of BRA-STRAP results were established at the individual FCC-level and, therefore, varied. Two clinics initially notified patients (or next of kin) of the availability of new results via letter. One clinic specified the variant identified and the other only provided generic information about the availability of new information. Both letters invited individuals to contact the clinic for further information, and were followed up with a phone call by a genetic counselor if no response was received. The other four clinics notified individuals by phone call by a genetic counselor. During these calls, the genetic counselor explained that new genetic information was available and offered to provide information about the variant over the phone at the time. All individuals were offered an appointment to discuss their results and management implications in more detail.

2.2 | Recruitment

Potential participants were identified by participating FCCs. Individuals were eligible to participate in an interview if they met the following criteria: (a) were recontacted regarding a clinically significant variant identified by the BRA-STRAP study and had attended an appointment to discuss the results; (b) over the age of

18; (c) able to participate in an in-depth interview in English; and (d) able to provide verbal informed consent. Probands and next of kin were eligible to participate regardless of sex or gender. The study title "BRA-STRAP" was omitted from recruitment materials to avoid a perception that the study was not relevant to men and impacting recruitment.

At the time of their BRA-STRAP results appointment, potential participants were asked by the geneticist or genetic counselor whether they were willing to be contacted by the researchers regarding participation in the qualitative study. Those who consented were contacted by phone four weeks later to confirm eligibility, obtain verbal informed consent, and schedule an interview. Interviews were conducted as close to six weeks as possible following the appointment to discuss BRA-STRAP results.

2.3 | Data collection

In-depth, semi-structured interviews were conducted via telephone by a member of the research team (AM, AW, CS; all of whom are trained genetic counselors with previous experience conducting qualitative research interviews). Open-ended questions were designed to explore the following topics: emotional experiences of recontacting, decision-making about receiving results, family communication, opinions about retesting, and ethical issues (see Appendix S1 for interview schedule). Interviews were audio-recorded and transcribed verbatim for analysis. Transcripts were de-identified and pseudonyms assigned.

2.4 | Data analysis

An inductive approach was used to analyze interview transcripts, guided by reflexive thematic analysis methods described by Braun and Clarke (2006, 2019). Reflexive thematic analysis facilitates the identification and analysis of patterns or themes in the data, acknowledging the researchers active role in knowledge production (Braun & Clarke, 2019). The data was organized and analyzed using Microsoft Excel. The first three transcripts were independently read and line-by-line coded by two researchers (AM & CS), with codes assigned to pieces of text to describe patterns of meaning interpreted by the researchers. Based on these interpretations, AM & CS met to develop an initial coding framework for subsequent transcripts, which was reviewed and refined after AM, CS and AY independently coded a further six transcripts. Codes were reviewed by the broader research team (AM, CS, AW, AY) and collated into preliminary themes. Overall, 20 interviews were independently co-coded by both AM and CS, three by CS, three by AM, and four by AY only. The team met regularly to review and further refine themes.

These team meetings also served as an opportunity for self-reflexivity and discussion of the potential influence of the researchers' subjective values on the analysis approach. The analysis team were all cisgender females with either clinical experience (AM, CS, AW) and/or research experience (AY, AM, AW, CS) in cancer genetics. The team actively maintained an open and critical stance during the data analysis process and engaged in discussions regarding the impact of the researchers' experience as genetic counselors (AM, CS, AW) on the analysis, in particular positive attitudes toward genetic testing and information. Furthermore, the inclusion of a researcher from a non-genetics professional background (AY) was intended to provide a different perspective and actively challenge any clinical assumptions.

In line with recommendations by Vasileiou et al. (2018), a number of factors were used to determine sample size adequacy. In addressing the study objectives, the authors sought to capture and explore the diversity of experiences within the cohort (e.g., type of variant returned, method of recontact, proband versus next of kin). Based on previous qualitative studies in this area, the research team set an initial target sample of 25 participants. Research team meetings were used to frequently evaluate the extent to which new information or themes were being generated from the data, and whether further participants were needed to achieve a comprehensive understanding of the topic. Recruitment was discontinued when there was consensus among the research team that sufficient data had been obtained to address the research objectives.

Quotes are presented using pseudonyms, participant age, whether they were a proband or next of kin, and the gene in which a pathogenic variant was detected through BRA-STRAP.

3 | RESULTS

Thirty participants were recruited and interviewed from six FCCs between February 2019 and February 2021. Seventeen interviews were conducted by AM, 12 by CS and one by AW. On average, interviews took place 84 days (range 32–401 days) after participants' received their BRA-STRAP result. Interviews were an average length of 48 min (range 24–73 min).

Participant characteristics are summarized in Table 1. The average age of participants was 57 years (range 36–84 years), all of whom were female. Four main themes were identified by the thematic analysis: the sudden impact of unexpected genetic information, recontact as a trigger for revisiting experiences of cancer; the clinical utility and value of recontact; and making meaning after recontact and moving on.

3.1 | The emotional impact of unexpected genetic information

The majority of participants reported that they were not expecting to be recontacted in the future with new genetic information, even if they were aware retesting may occur.

TABLE 1 Participant characteristics ($n = 30$).

	N
Age (years)	
35–44	6
45–54	8
55–64	8
>65	8
Gender	
Female	30
Recontacted individual	
Proband	25
Next of kin	5
Pathogenic variant carriers	
PALB2	14
CHEK2	10
ATM	3
MLH1	1
MSH6	1
RAD51C	1
Education level	
High school	8
Certificate/Diploma	10
University	12
Employment	
Employed	19
Unemployed	1
Retired	10
Marital status	
Single	6
Married/De facto	20
Separated/Divorced	2
Widowed	2
State	
NSW	22
SA	6
ACT	2
Children	
0	5
1	9
2	11
>3	5

> That really came out of the blue. I just thought it was done and dusted, really. And I guess the phone call threw me a little bit.
>
> Barbara, 43, Proband, ATM variant

Most expressed feelings of surprise or shock upon receiving new genetic information from BRA-STRAP. For many, the recontacting process initially triggered a range of emotional responses, including anxiety, disappointment, confusion and curiosity.

> It was full-on, because I guess I hadn't prepared myself for that reality. And also the emotions that come from finding out that.
>
> Patricia, 39, Next of kin, PALB2 variant

> At first, I found it very overwhelming and of course, human nature is only gonna possibly think of the worst.
>
> Tessa, 50, Next of kin, PALB2 variant

For many women, the negative emotions experienced because of the recontact were closely tied with feelings of uncertainty, as the new information raised questions regarding their risk of developing cancer and the implications for their family.

> So what does this mean? And also, gradually as I thought more and more about it, it's like the stone in a pond with the ripples going out and out and out to my children, and then my half-sister, and then my cousins, and so, you start thinking how this might affect other people, as well as myself.
>
> Edna, 67, Proband, PALB2 variant

For some women, the timing of recontact coincided with significant life events or cancer-free milestones. Receiving unexpected news while already navigating a significant event or milestone appeared to add an extra layer of complexity to the emotional impact of the new genetic information.

> I was just a bit disappointed, maybe because I just reached that [five years cancer-free] milestone, that really important milestone, and I just found out I was pregnant.
>
> Carla, 37, Proband, PALB2 variant

3.2 | Revisiting experiences of cancer

For many participants, prior genetic testing experiences were closely tied to their cancer diagnosis and treatment journeys. Participants reported seeking closure upon completing their cancer treatment and moving on with their lives. As part of this process, most had also accepted and moved on from their uninformative genetic testing results.

> I'm sure at the time I understood and took it in but so much happened around that time that everything becomes a bit of a blur, really. And also, once it's all done and dusted, I zipped it up and put it away, out of your mind.
>
> Emma, 54, Proband, PALB2 variant

For those with a personal history of cancer, being recontacted with new genetic information often initiated a resurfacing of experiences and negative emotions related to their initial cancer diagnosis and treatment.

> You sort of get taken back again a bit to diagnosis and all the treatment I've had, and you sort of think, "Oh god, what's gonna happen now?"
>
> Jessica, 54, Proband, CHEK2 variant

Similarly, the next of kin who received new genetic information from retesting of a deceased relative reported a resurfacing of grief.

> She died in such a horrific way and it really brings that to the surface again. Losing a parent, you push that down, you forget about it, you move on with life.
>
> Dana, 36, Next of kin, PALB2 variant

3.3 | The clinical utility and value of recontact

Despite the initial shock at receiving the new information, most women stated a preference to know so that they could use the information to manage their future health.

> Having cancer was, that was awful, but I think knowing that there is something that we can do is better than not knowing.
>
> Anna, 72, Proband, PALB2 variant

In most cases, provision of genetic counseling to help women understand what the result meant for their cancer risk, and the actions recommended based on that risk, resolved the uncertainty raised by the new information.

> But I think, overall, it's been a positive experience because we can understand a bit more what happened in our family and why it's happened and have a bit more of an understanding going forward for how to deal with risk and how to minimise risk for other family members.
>
> Barbara, 43, Proband, ATM variant

In cases where the information was perceived to significantly increase women's risk, the information was seen as providing clinical value and the management plan provided a sense of control and empowerment.

> So it meant to me that I can be on the front foot for monitoring for hopefully not getting another cancer back, to get myself informed about what options are available for treatment for me or for monitoring.
>
> Debra, 43, Proband, PALB2 variant

A couple of women previously diagnosed with breast cancer did express some regret at not having the information at the time of their diagnosis, as they felt they may have made different treatment decisions.

> If I had known about it initially when I first got tested, then I would've just had a mastectomy then… if I'd known then what I know now, it would've been completely – it would have been an easy decision to make.
>
> Carla, 37, Proband, PALB2 variant

For some next of kin who subsequently tested negative, the reduced level of cancer risk and reduction in screening behaviors, as well as removal of risk for their children, was highly valued and described as profound.

> Its effect on my life is quite profound because now I don't have to have the regular testing. I don't have to worry about my children. I don't think about the potential I might have to have a mastectomy or anything like that.
>
> Patricia, 39, Next of kin, PALB2 variant

Some women experienced prolonged periods of uncertainty due to a perceived delay in access to genetic counseling and reported that this caused significant distress.

> When I got the letter, I had all these questions. There was nobody to be able to contact. That caused that grief for a few weeks thinking the worst… Three weeks, it just felt like three years.
>
> Veronika, 49, Proband, CHEK2 variant

A small number of participants (3/30) expressed mixed feelings about receiving the new genetic information. These mixed feelings largely related to uncertainty about the clinical utility of the result itself, rather than the retesting and recontacting process. Some women who were notified of a pathogenic variant in a moderate risk gene expressed an ongoing sense of uncertainty about the extent to which the new genetic information altered their cancer risks.

For these women, the clinical utility of the new information appeared to be less than for those with a clear change to management recommendations.

> [If it were BRCA1 or BRCA2] I would have probably been worse, as in upset more, but at least I'd know, "Right, that's it, I'd have to have my breasts off" and do all that and it would have to be done, no questions asked. But with this one, it's still – do I or don't I?
>
> Claudia, 59, Proband, CHEK2 variant

Regardless of whether the result influenced their own personal risk management, most participants valued the information for the potential clinical utility for their relatives.

> I don't know how helpful it is for me, but you know it's so helpful for my children, which is amazing. And as I said, knowledge is power and the more knowledge we have, the better we can conquer.
>
> Susan, 49, Proband, CHEK2 variant

3.4 | Finding meaning and moving on

The value of the new genetic information for many women extended beyond the clinical utility. Many women described ways in which they found meaning in their experiences of recontact. Almost half of the participants reported that the new genetic information provided an explanation that helped them make sense of their own cancer diagnosis and/or family history of cancer.

> There was a sense of relief that there was a name for it. That there was a link. That there was a reason. That it wasn't just chance.
>
> Judith, 50, Proband, CHEK2 variant

Following previous uninformative genetic testing, some participants had attributed their cancer diagnoses to potential lifestyle risk factors, such as diet, exercise and alcohol consumption. The presence of an underlying genetic cause provided a sense of emotional relief that their cancer diagnosis was beyond their personal control.

> I haven't caused my cancer. I feel quite relieved. Which is probably a strange thing, but I felt quite relieved, quite happy to have that result. I just felt much better emotionally, that those doubts that I had maybe somehow contributed and all the rest, they disappeared.
>
> Yolanda, 68, Proband, CHEK2 variant

Despite their relived experiences of grief, next of kin reflected on what the result would have meant to their deceased relative and found spiritual meaning in the results.

> She [daughter] would have been happy. She loved her nieces, she was a very good aunty to them and she would've been happy, if she's watching up there. It could save them. That'll make her very, very happy.
>
> Theresa, 78, Next of kin, PALB2 variant

Many participants also reported gratitude and that being recontacted with this new information gave them a sense of being cared for.

> I'm grateful that someone has taken the time to let me know about it. I have only had positive feelings about it, even though it's not a very nice thing, but I feel grateful that someone's gone to the trouble of retesting and letting me know about it and explaining it to me.
>
> Alexa, 73, Proband, CHEK2 variant

Some women also acknowledged finding meaning in the prospect that their retesting could benefit others though research.

> For other people going through it in the future as well, the more that we know about it – because that accumulative information is not available for my generation of people going through it, the more people that they cater for, I think it's a positive thing.
>
> Debra, 43, Proband, PALB2 variant

Having understood the health implications of the result and finding meaning in the experience, most women described coping well with being recontacted overall. Women accepted the information and changes in their cancer risk and described moving on from the experience, just as they had from their previous cancer diagnosis and experience of genetic testing.

> I just thought, "Okay. Well, I've got a name for it now, and things don't change. Just get back to living, and keep doing what I've always done and just live my life to the fullest and be appreciative that I'm still here.
>
> Veronika, 49, Proband, CHEK2 variant

Most women saw it as a positive experience and described factors that helped them move on, including a pragmatic personality, personal resilience and a clear understanding of what action to take to manage their risk.

> You've got to overcome and adapt, you know? I can't change the situation, so I have to be able to deal with

> the situation. So I'm always positive. I'm like, 'Yep. Okay. What do we do? What do I need to do?'
>
> Kate, 63, Proband, PALB2 variant

4 | DISCUSSION

This qualitative study explored the experiences of women, or their nominated next of kin, who were recontacted with a new genetic result, in some cases years after their original genetic testing. The findings suggest women cope well after being recontacted with new genetic results and greatly value the information, despite initial shock and surprise and potential revisiting of difficult emotions associated with their personal or family history of cancer.

Causing distress is a concern reported by clinicians when recontacting former patients, particularly given the lack of ongoing contact and knowledge of current patient circumstances (Vora et al., 2022). Receiving a diagnosis that threatens one's health is a stressful event, whether through recontact or otherwise. In this setting, recontact caused some women to revisit experiences of a cancer diagnosis or the death of a relative, which had the potential to cause distress (Dahle Ommundsen et al., 2022). Experiencing uncertainty regarding what the information meant for their health and their family was also reported as a source of distress for participants. However, reported distress was short-lived for most women, who valued the results and came to terms with their revised risk after genetic counseling without requiring special or prolonged intervention. This is consistent with literature demonstrating stronger preferences to be informed of clinically actionable information (Bijlsma et al., 2020; Godino et al., 2021), and that most people cope well with genetic results, including those that are unexpected or uncertain (Bradbury et al., 2018; Forrest et al., 2022; James et al., 2022; Velthuizen et al., 2021).

This process of coming to terms with the implications of a health threat, and the outcomes of that process has been termed *adaptation* and is a key outcome of genetic counseling (Biesecker & Erby, 2008; Skirton, 2001). Several theories and scales have been developed to understand and measure adaptation, with constructs that align well with the accounts of women in this study (Read et al., 2005; Skirton, 2001; Taylor, 1983). Using such theories in the interpretation of our findings can provide a framework for understanding women's experiences and ways that health professionals can recognize where and how their input may be required to facilitate adaptation for patients.

The Theory of Cognitive Adaptation proposed by Taylor (1983) describes adaptation as a process that involves finding a sense of control, finding meaning in the experience, and restoring positive self-views, which were all present in the accounts of women in this study. A sense of control was important to women in this study, both from their accounts of their cancer experiences and of recontact. Prior to recontact, women described having made a conscious decision to move on from their previous experiences and were no longer seeking information about genetics or cancer risk. In this setting, recontact disrupted the sense of control they had established and forced them to revisit uncertainty regarding their risk and potential risks for family members. Women's sense of control and certainty was restored when they knew what action to take to manage their cancer risk. The recommended actions also provided valuable context to help them understand their risk, as reported in other settings (Rasmussen et al., 2019; Willis et al., 2021).

Women discussed many ways in which they made meaning of the new genetic information, which incorporated both clinical and other ways in which the genetic information was important or useful to them. Personal utility is increasingly recognized as an important motivator and outcome of genomic testing and encompasses a broad range of concepts, such as improved understanding of a condition, enhanced coping, ability to plan and communication about results (Kohler et al., 2017; Mackley et al., 2017; Turbitt et al., 2023). Among women for whom no change in clinical management was recommended, having an explanation for their personal and family experience of cancer was still of significant value, as reported in other contexts (Young et al., 2018). Being able to share their results with family members and empower their family to take a proactive approach to their health was also of great value (Young et al., 2018). Some next of kin even found spiritual meaning in the results, describing a sense that their relative is still looking after them and the family from beyond the grave. The emphasis on aspects of personal utility in these accounts supports previous literature regarding the importance of personal utility in making sense of and adapting to genomic information (Kohler et al., 2017; Turbitt et al., 2023).

Restoration of positive self-views was also observed in women's accounts of being recontacted (Taylor, 1983). A particularly poignant example is provided in the accounts of women previously diagnosed with cancer, for whom the genetic result provided relief from self-blame for their diagnosis. This was also observed in the sense of hope and belief among women that their result can change outcomes, for self and family, as well as the altruistic hope that their participation may help others beyond their family, which have also been reported elsewhere as motivators for undergoing genetic testing (Finn et al., 2022; Sanderson et al., 2022). The sense of still being looked after, and the gratitude women expressed for being recontacted also reflect their positive attitudes to being recontacted and the sense of self-worth that it provided.

Adaptation has also been described as a measurable outcome of genetic testing. For example, Read et al. (2005) developed and validated a scale that has been used to measure adaptation specifically in the genetic setting (Gray et al., 2014; Talati et al., 2021). Their model proposes five domains that can be measured to demonstrate adaptation, evidence of which can be identified in the accounts of women in this study: *non-intrusiveness*, or an absence of intrusive thoughts about the genetic information; *support*, feeling able to discuss their results and a sense of being cared for; *certainty*, understanding the origins and risks of the genetic information; *self-efficacy*, feeling able to take action to control the risks; and *self-worth*,

a sense of self-esteem after learning of the genetic condition (Read et al., 2005). The alignment between these various models of adaptation and our findings supports their utility for measuring adaptation and for genetic health professionals in the clinic setting in identifying patients having difficulty adapting. These models may also be useful for identifying ways to provide support and facilitate the adaptation process.

An example of difficulty adapting is provided by women in our study who reported that long wait times for genetic appointments left them in a distressing state of prolonged uncertainty. Women who reported residual uncertainty after genetic counseling, such as those receiving a moderate risk result, also reported more ambivalent views toward being recontacted and the utility of the information, as observed elsewhere (James et al., 2022; Reyes et al., 2022). Uncertainty has been identified as a barrier to positive adaptation, as it presents challenges in the identification of effective coping resources (Biesecker & Erby, 2008). When there is no clear action to take in response to a health threat, genetic counselors may need to provide additional support and emphasize emotion-focused coping strategies over action-focused to meet clients' need for control and certainty (Biesecker & Erby, 2008; Skirton, 2001; Walker et al., 2004). This may also have implications for deciding which results to return in certain settings. Many studies have reported hypothetical participant preferences to receive both actionable and non-actionable results from genomic testing (Bijlsma et al., 2020; Godino et al., 2021; Mackley et al., 2017). However, the literature and our findings suggest that uncertain information is more difficult to adapt to and less well received.

The issue of whether there is a duty to recontact with new genetic information and how it should be done has been ongoing for some years. The debate has largely centered around balancing the benefits against the costs or available resources and respect for autonomy and individuals' right not to know (Giesbertz et al., 2019; Otten et al., 2015). Studies on retesting and recontact have demonstrated some individuals prefer not to be recontacted, or alternatively choose to opt out of receiving new results when reconsented (Henrikson et al., 2021; Velthuizen et al., 2021). However, concerns that retesting may not align with patient preferences or cause undue distress were not observed in this cohort of women, despite the unexpected nature of the new genetic results. Rather, being recontacted was seen as a natural extension of clinical care and many reported gratitude for being recontacted and feeling cared for. Positive attitudes to being recontacted have been reported elsewhere (Mighton et al., 2021), with Velthuizen et al. (2021) even reporting higher satisfaction for carriers than non-carriers. Our findings suggest that a model of providing clinically actionable information only when a result is found, could reduce the time burden on clinics and is acceptable to patients when provided with timely and appropriate genetic counseling.

Managing the return of clinically actionable genetic information to the next of kin of a deceased patient or research participant presents additional challenges. While probands are commonly encouraged to nominate a next of kin to receive results on their behalf (documented on the genetic testing consent form), clinicians often have no way of knowing whether the next of kin has been informed of this (Daniels et al., 2017). This raises issues of consent and autonomy when returning information to next of kin, which must be balanced against the potential value of the genetic information for the family (Giesbertz et al., 2019). While a limited number of next of kin were interviewed, the findings of this study suggest that recontacting the next of kin of a deceased proband with new results is acceptable, which has been observed in other studies (Crook et al., 2015; Daniels et al., 2017; Gordon et al., 2019). Next of kin in our study did not appear to experience difficulties adapting to the information that were unique to next of kin, although the meaning next of kin ascribed to the information at times differed. It should be noted, however, that literature regarding return of clinically actionable results to next of kin, while supportive, is limited and further research is indicated to determine how best to prepare for and undertake this task.

5 | LIMITATIONS

This study provides a valuable perspective on recontacting women with new genetic results in the Australian setting and included a diverse group of participants with regard to age and education. However, our findings do only represent the views of women as very few males received results from the BRA-STRAP study and none participated in this study. We also do not have data on the ethnicity of participants and thus cannot comment on the relevance of these findings to different ethnic groups in Australia. As we do not have access to the dates of participants' original testing, we are unable to comment on whether the duration of time since initial testing influenced experiences of recontacting.

A limitation of this study is that the recruitment strategy targeted only individuals who opted to receive the new genetic information. It is possible that some individuals did not respond to recontact attempts, or declined to receive their results, and our findings may not reflect the perspectives of these individuals. The transferability of these findings is further limited by the possibility that women were more likely to participate if they had a positive experience of recontact, and the small number of next of kin who participated.

6 | PRACTICE IMPLICATIONS

The findings of this study support the recontact of patients or their nominated next of kin to disclose new clinically actionable results. The results also suggest that retesting and recontact is acceptable to patients and does not cause harm in the absence of potentially onerous reconsenting processes, if results are provided with timely genetic counseling. This provides guidance to clinical services with limited resources who are considering large-scale recontacting of patients. However, literature regarding the experiences and preferences of next of kin, clinicians with experience recontacting and

those who decline the offer of new information is limited and further research in these areas is recommended.

7 | CONCLUSION

This study explored the experiences of women previously tested for *BRCA1* and *BRCA2*, or their nominated next of kin, who were recontacted with new genetic results. The women in this study adapted well to the new results, valued the information, and reported positive experiences of recontact. However, women who perceived their results as uncertain also perceived less value in the results and less positive attitudes to recontacting. The findings support previous literature suggesting that recontact for new clinically actionable information is desirable and add that recontact can lead to positive outcomes for patients and their relatives.

AUTHOR CONTRIBUTIONS

Authors AW, AM, KT, and MS were involved in study conceptualization and interview guide development. Authors KT, RH, NP, LA, JK facilitated participant recruitment. AM and CS conducted all interviews, and coded the interview transcripts. Thematic analysis was done by AM, CS, AY, and AW. AM and AW prepared the original manuscript draft, and all authors reviewed and edited the submitted manuscript version.

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CONFLICT OF INTEREST STATEMENT

Authors A Morrow, C Speechly, AL Young, K Tucker, R Harris, N Poplawski, L Andrews, T Nguyen Dumont, J Kirk, M Southey and A Willis declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions. Further information is available in the Appendix S1 or by contacting the corresponding author.

ETHICS STATEMENT

Human Studies and Informed Consent: Ethical approval was granted by the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Reference 16/240). The research was undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research. Informed consent was obtained from all study participants. Participant identifiers have been removed, so the person(s) described are not identifiable.

Animal Studies: No non-human animal studies were carried out by the authors for this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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