Original research

BRCA awareness and testing experience in the UK Jewish population: a qualitative study

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ABSTRACT

Background 1 in 40 UK Jewish individuals carry a pathogenic variant in *BRCA1/BRCA2*. Traditional testing criteria miss half of carriers, and so population genetic testing is being piloted for Jewish people in England. There has been no qualitative research into the factors influencing *BRCA* awareness and testing experience in this group. This study aimed to explore these and inform improvements for the implementation of population genetic testing.

Methods Qualitative study of UK Jewish adults who have undergone *BRCA* testing. We conducted one-to-one semistructured interviews via telephone or video call using a predefined topic guide, until sufficient information power was reached. Interviews were audio-recorded, transcribed verbatim and interpreted using applied thematic analysis.

Results 32 individuals were interviewed (28 carriers, 4 non-carriers). We interpreted five themes intersecting across six time points of the testing pathway: (1) individual differences regarding personal/family history of cancer, demographics and personal attitudes/approach; (2) healthcare professionals' support; (3) pathway access and integration; (4) nature of family/partner relationships; and (5) Jewish community factors. Testing was largely triggered by connecting information to a personal/family history of cancer. No participants reported decision regret, although there was huge variation in satisfaction. Suggestions were given around increasing UK Jewish community awareness, making information and support services personally relevant and proactive case management of carriers.

Conclusions There is a need to improve UK Jewish community *BRCA* awareness and to highlight personal relevance of testing for individuals without a personal/family history of cancer. Traditional testing criteria caused multiple issues regarding test access and experience. Carriers want information and support services tailored to their individual circumstances.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ One in 40 Jewish individuals carry a *BRCA1/BRCA2* pathogenic variant. Traditional family history-based genetic testing criteria miss over half of *BRCA* carriers. Unselected population testing is now being implemented in the UK and Israel.

WHAT THIS STUDY ADDS

⇒ This is the first qualitative research study into *BRCA* testing in the UK Jewish population. Differences in individual characteristics are critical to an individual's decision-making and experiences of genetic testing. Healthcare professionals, service integration, family relationships and Jewish community factors also play a role.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Carriers strongly desire a personalised information resource and more proactive management of downstream services. Consideration should be given to the development of these services, tailored to an individual's life stage, gender and cancer history, with signposting. Findings from this study will directly inform the pilot National Health Service Jewish population testing programme.

INTRODUCTION

BRCA1/BRCA2 pathogenic or likely pathogenic variant (PV) carriers have a 69–72% lifetime breast cancer (BC) risk, 17–44% ovarian cancer (OC) risk,[1] along with smaller increased risks of pancreatic, prostate and other malignancies.[2] These risks may be modified by a family history of cancer-affected first and second-degree relatives.[1 3] There are good data to demonstrate that even after adjusting for population ascertainment or family history, the cancer risks for *BRCA* PV carriers remain high and well above the thresholds of clinical intervention.[1 3 4] BC and OC are largely preventable if a *BRCA* PV is identified prior to cancer development, given effective risk management strategies including MRI/mammographic screening, medical prevention, risk-reducing mastectomy, risk-reducing salpingo-oophorectomy and pre-implantation genetic diagnosis, currently available through the National Health Service (NHS).[5–8]

Approximately 1 in 200 general population individuals carry a *BRCA* PV,[9 10] rising to 1 in 40 in the Ashkenazi Jewish (AJ)[3 11 12] and 1 in 100–140 in the Sephardi Jewish (SJ) (including Mizrahi Jewish) populations,[13] predominantly from three founder

mutations. *BRCA* PVs are associated with 10% BC and 41% OC cases in AJ individuals,[14 15] compared with 3% BC and ~15% OC in the general population.[16–18] Traditionally, genetic testing has been restricted to individuals fulfilling strict family history/clinical eligibility criteria including multiple BC/OC cases in relatives,[19 20] with ≥10% pretest *BRCA* probability.[21] This strategy misses 50–60% of *BRCA* carriers.[2 12 22] Additionally, in practice, there is severe underutilisation due to limited awareness and access, such that only 20–30% of eligible individuals undergo testing.[23] Resultantly, ~90% Jewish and ~97% general population *BRCA* carriers remain unidentified.[24]

A population-based genetic testing strategy in all adults regardless of cancer history would maximise carrier identification for cancer prevention.[25] Population-based *BRCA* testing has been shown to be acceptable with high satisfaction, decreases anxiety, and does not detrimentally impact psychological well-being or quality of life.[12] This approach is highly cost-effective in the AJ/SJ populations[12 26 27] and has led to calls for population *BRCA* testing.[25 28]

In 2021, Israel was the first country to offer population-based genetic testing, for all AJ women ≥25 years. NHS England Cancer Programme is piloting implementation of population-based *BRCA* testing for UK adult AJ/SJ populations in 2023.[29 30] However, qualitative research on how the Jewish population experience genetic testing in the UK is lacking. This qualitative study aimed to explore the awareness, experiences and satisfaction of traditional *BRCA* testing among the UK Jewish population, to help inform services as population-based genetic testing is beginning to be piloted in the Jewish population in England.

METHODS

Participant recruitment

Inclusion criteria: individuals aged ≥18 years with self-reported Jewish ancestry (defined as at least one AJ/SJ grandparent) who underwent *BRCA1*/*BRCA2* genetic testing in the UK. This study was publicised via a Jewish national newspaper (estimated circulation 20 000) and leaflets distributed through targeted Jewish charities and six general practitioner (GP) surgeries. Interested individuals registered online. Interviewees were purposefully sampled to ensure diversity with respect to age, gender, ethnicity, Jewish religious affiliation, testing provider, *BRCA* status, cancer history and location.

Consent

All participants provided written informed consent, which was reconfirmed verbally at interview.

Data collection

In-depth semistructured one-to-one interviews were conducted via telephone/video call as per participant preferences, by one of two trained interviewers (KS/SO). A predefined topic guide was developed (online supplemental file 1) with wording and question order left open with probes to elicit further information when appropriate. A pilot interview was conducted to ensure the timing was feasible and to refine questions. Questions covered: background (personal/family *BRCA*/cancer history, family composition), sources and perspectives on *BRCA* awareness in the UK Jewish community, factors in testing decision, testing experiences, response to results and onward communication, post-testing needs/actions, satisfaction and suggestions for improvements. A sample of 30 interviewees was expected to provide sufficient information power.[31]

Analysis

Interviews were audio-recorded and transcribed verbatim; data were managed in NVivo v.12 (QSR International, USA). Applied thematic analysis was used to interpret themes specific to our analytical aims, and reflect the views and experiences of participants, rather than those predetermined by researchers. We coded transcripts both inductively and deductively using a three-step process: open coding (reviewing all text line-by-line and labelling), axial coding (categorising codes into groups and themes) and selective coding (refining relationships and developing themes through iterative discussions).

Patient and public involvement

We worked with Jewish charities and community representatives. This study was reviewed and endorsed by the Jewish Leadership Council. Participant recruitment was supported by charities Chai Cancer Care and Achienu.

RESULTS

It is not possible to know how many people saw publicity materials; however, 52 individuals registered initial interest. We contacted 33 individuals to review eligibility; one was excluded due to not having *BRCA* testing. We interviewed 32 eligible participants between March 2022 and January 2023. The median age was 46.5 years (IQR 34.0–52.3 years). Table 1 summarises participants' characteristics.

General satisfaction and decision regret

No participant expressed regret about their decision to have *BRCA* testing on explicit questioning and all were comfortable recommending testing to others. Several participants expressed frustration with not being offered testing earlier, particularly those who subsequently developed cancer. There was huge variation in testing experiences and satisfaction, as discussed below.

Themes

We identified six time points along the pathway: *BRCA* awareness, decision to have testing, access to testing, test experience, response to results and communication with family, and post-testing needs and service access. We used these time points to organise the five themes (1–5) we interpreted, which intersected along these at multiple points, as shown in figure 1. We present selected quotes as evidence, with a descriptor providing age/gender/cancer history, for example, (45/F/BC); all quotes are from carriers unless otherwise specified.

1. Individual characteristics
   - Personal/family history of cancer
   - Demographics and life stage
   - Attitudes and approach
2. Healthcare professionals' (HCP) support
3. Pathway access and integration
4. Nature of family/partner relationships
5. Jewish community factors

Individual characteristics

Individual characteristics appeared instrumental in explaining the differences in how participants experienced the entire testing pathway. These characteristics included a personal/family history of cancer, demographics (age/gender) and life stage, and attitudes relevant to testing.

Many participants first became aware of *BRCA* through a variety of sources, including newspapers or online:

Table 1 Participant characteristics

Total	32					
Gender	**Female**				**Male**	
	25 (78.1)				7 (21.9)	
Age	**20s**	**30s**	**40s**	**50s**	**60s**	**70s**
	2	8	12	5	3	2
Jewish ethnicity	**Ashkenazi**		**Sephardi/Mizrahi**		**Mixed**	
	27 (84.4)		1 (3.1)		4 (12.5)	
Jewish affiliation	**None**	**Reform/ Liberal/ Progressive**	**Modern Orthodox (including United Synagogue and Masorti)**		**Ultra-orthodox (including Haredi communities)**	
	3 (9.4)	10 (31.3)	17 (53.1)		2 (6.3)	
***BRCA* testing**	**NHS**		**Private**		**NHS & private**	
	24 (75.0)		6 (18.8)		2 (6.3)	
***BRCA* status**	**None**		***BRCA1***		***BRCA2***	
	4 (12.5)		14 (43.8)		14 (43.8)	
Personal cancer history	**None**	**Breast**	**Ovarian**	**Breast & ovarian**	**Pancreatic**	
	16 (50)	8 (25)	5 (15.6)	2 (6.3)	1 (3.1)	
Location	**London**	**Manchester**	**Leeds**	**Essex**	**Hertfordshire**	
	23 (71.9)	5 (15.6)	2 (6.3)	1 (3.1)	1 (3.1)	

Numbers with each characteristic are given, with percentages of total in brackets.
NHS, National Health Service.

> I had heard of it in passing, like basically when Angelina Jolie had her double mastectomy. (31/F/unaffected)

However, the personal significance of *BRCA* was only understood once this was linked to (new or pre-existing) information of a personal/family history of cancer.

> I remember thinking 'interesting, I know that my grandmother died of cancer, I should probably get this checked out.' (45/F/BC)

This was also apparent when one participant attempted to recommend testing to her friends:

> 'That's not a thing in my family'… they don't necessarily see the relevance or see it as a risk. (26/F/unaffected/non-carrier)

Having a personal cancer diagnosis positively impacted the decision to test. Cancer-affected participants were generally keen to know their *BRCA* status given its potential to impact treatment, help understand their diagnosis and to inform family. Unaffected participants tended to give greater consideration to the testing decision and were triggered more by an awareness of a strong family history or new cancer diagnosis/*BRCA* status in

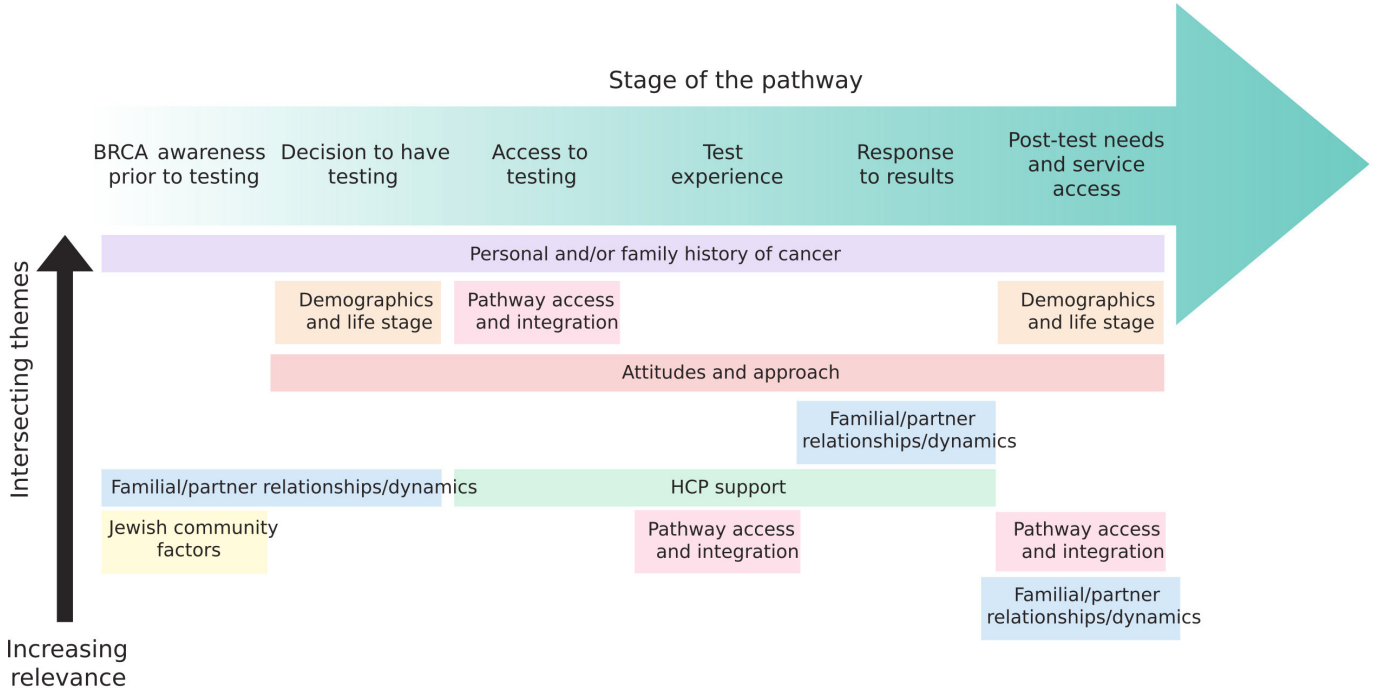

Figure 1 Chronology of testing pathway from awareness through to post-testing needs, with key intersecting themes at each stage. The most relevant themes at each stage are presented at the top. HCP, healthcare professional.

relatives. Affected participants, and those with a strong family history, generally found access to testing easier than others.

A personal cancer diagnosis framed the way participants responded to their results, with prioritisation generally given to modifying cancer treatments. Non-affected participants tended to have more diverse emotional responses and focused on the implications and risk management options for themselves and family. Support preferences also differed, with non-affected carriers strongly preferring separate support services to patients with cancer.

Life stage (age/marriage and family status) majorly influenced the decision to test and the type of support and information needed post-testing, including family planning/fertility-related services. Carriers preferred peer-support groups with others at a similar life stage, with information personalised to their needs (eg, impact of risk-reducing surgery for those with completed families vs those planning to have children). Male participants reported more barriers to awareness and testing, and different information needs (eg, prostate cancer risks) which were not always met. Individuals differed hugely in their approach to testing and response to results with some being pragmatic and others highly emotional. These approaches could determine whether they successfully obtained testing (with tenacity in the face of rejection by HCP), their response to results and their post-test needs, including desire for psychological counselling. For further details and supporting quotes, see table 2.

HCPs' support

Individual HCP majorly impacted participant experiences, both positively and negatively. For some, HCPs were the main influences in deciding whether to test.

> [My oncologist] was the one that persuaded me to go for genetic testing. (55/F/OC)
> [My GP] announced, "I've just been on a course about this… I don't think you'll carry a mutation, stop worrying about it"… I thought, 'Well he obviously knows what he's talking about.' (48/F/unaffected)

Some HCPs were knowledgeable, concerned and proactive in facilitating testing access. However, many participants described being rejected for years from accessing testing, sometimes with explanations that suggested a misunderstanding of genetics.

> [My GP said] it doesn't go through the father and that I don't qualify for genetic testing and there's nothing for me to worry about. (40/F/BC)

The manner in which individual HCP provided pretest and post-test counselling and met individuals' post-test needs varied between participants, whether in clinical-genetics or oncology, and in private or public settings.

> My oncologist was brilliant, he explained in very good detail about what it meant. (60/F/BC/OC)
> I did [testing] via a private [doctor]… It was a pretty horrible experience to be honest. I've since seen a genetic counsellor… via the [NHS]. They were amazing. (45/F/BC)

Pathway access and integration

The degree to which different NHS/private services were interconnected, with established referral routes, majorly impacted participants' access to services and support, and therefore wellbeing, separate to that of individual HCPs. Accessing private testing is often simpler, and proactive marketing can persuade individuals to test who previously had not considered it:

> There was an offer at Boots for this 23andMe Ancestry testing. I just thought that would be a bit of fun. (57/F/OC)

However, private *BRCA* results provision without post-test counselling caused great distress:

> I was utterly devastated… the realisation that I have perhaps given my children, had no-one to talk to… no-one who could explain anything to me. (32/F/unaffected)

An issue raised by several participants was the difficulty in accessing psychological support following results, particularly when a GP referral was required.

> [My genetic counsellor] sent a referral to my GP to ask for some psychological support. They haven't even responded. (23/F/unaffected)
> I was asking for psychological help… and it was very much like "No, we don't offer that, go back to your GP" but the GP doesn't want to know… it felt like every way I was turning, I was being rejected. (32/F/unaffected)

Regions with integrated referral networks for risk management services had a positive effect:

> I don't think I had to be referred again… they just continued booking appointments for me. (34/F/unaffected)

Nature of family/partner relationships

The nature of relationships between participants and their family significantly influenced an individual's testing journey. Awareness of *BRCA* risk was positively impacted by openness within families in sharing medical information. Where relatives chose not to disclose information about their *BRCA* carrier status, participant awareness was delayed, sometimes creating resentment:

> All my initial awareness was from within my family. [From] conversations with dad, I knew what the medical pathway looked like. (34/F/unaffected)
> My aunt is actually *BRCA* positive and decided not to share that with anyone when she found out in the mid-90s… initially I was really angry with her. (45/F/BC)

Having a supportive partner/family member was key for some in deciding to test, while for others, family was a negative influence because of the anticipated guilt associated with heritability:

> My mum was worried and said 'can you go and get tested?' (41/F/unaffected)
> [Mother] wasn't keen for me to be tested while she was still alive… she didn't want to have that feeling of having passed on a bad gene. (48/F/unaffected)

After receiving positive results, close family members provided crucial support for many participants. However, not everybody found this:

> I'm getting told, "Well you decided to have the genetic test, you've opened up a whole can of worms." (57/F/OC)

Family dynamics appeared to strongly influence response to, and sharing of, results. Some felt able to share positive results widely including with more distant relatives and communicate with their children in an age-appropriate way, while others lacked confidence or knowledge in doing this:

> I think it's very important to be honest and open… my kids all know about it… they're not frightened. (48/F/unaffected)
> When I'm 100% clear on all the ins and outs and I have that clarity myself then I'm able to work out how to say it correctly. (41/M/unaffected)

Table 2 Selected quotes to evidence the relevance of individual characteristics along various stages of the testing pathway

Theme	Explanation
Personal/family history of cancer	
Testing decision: "It wasn't really even a big decision… it didn't cross my mind to even question why." (60/F/BC/OC)	When suggested by oncologists, affected patients found the testing decision straightforward, often motivated by how *BRCA* status can impact treatment options, help explain the cause of cancer and/or provide information for relatives.
Test access: "It was all really easy to do. We were very lucky though, because we had a very clear family [history], we had enough cases to prove that it was needed." (33/F/OC) "[My GP] requested genetic testing, which was rejected… I didn't meet the criteria under the NHS for genetic testing." (40/F/BC)	Unaffected participants with a strong family history found testing more accessible than those without (under existing NHS eligibility criteria).
Response to test result: "I wanted an answer as to why I'd got breast cancer at 39… It made me feel a bit better about things." (49/F/BC) "I'm really unhappy about it because I could've avoided what's happened to me in this last 2 years." (64/F/BC/OC)	Once individuals received their positive result, a personal cancer diagnosis framed their response. Some affected patients found some comfort in an explanation, whereas some others affected were angry as they felt that their cancer may have been prevented had they known their *BRCA* status earlier, especially those who previously were not eligible for testing under the NHS criteria.
Support needs: "Those of us who haven't had cancer feel very uncomfortable being part of the cancer community because we… feel guilty that we've had a chance that they haven't had." (48/F/unaffected) "I don't feel like [the cancer charity] is my resource to use… I'm really healthy, this seems ridiculous… it felt kind of rotten." (33/F/unaffected)	The need for support services to be tailored to individuals' needs was often discussed by non-affected carriers who noted their discomfort using the support services together with affected carriers and that they wanted these services to be offered separately.
Demographics and life stage	
Testing decision: "I was 18 at the time… I wasn't ready to be tested." (23/F/unaffected) "[My daughter] wants to get tested at 18… I'll be there to support her." (49/F/unaffected) "I wasn't going to deal with it during university… after university I was getting married and we thought, 'Now's a good time to find out'." (34/F/unaffected) "Then I had two children and after that, I really wanted to find out so that I could have all the options available in terms of increased scanning or surgery." (48/F/unaffected) "My dad ignored her because he didn't understand how [her] ovarian cancer could affect him as a male." (48/F/unaffected) "[My brother] just showed no interest in getting tested and maybe felt the risks were lower… there's no urgency for him right now." (26/F/unaffected/non-carrier)	Participants varied in when they felt ready to have testing. Some participants (or their children) want to be tested in early adulthood, whereas for others, a trigger was becoming engaged/starting a family. Some preferred to wait until they had completed their family. The influence of gender on testing decision was seen in many discussions. Male gender appeared to be a barrier to awareness and testing for some, with individuals sometimes struggling to persuade (or not even thinking to ask) male relatives to test.
Response to test results: "Because they'd said, 'You can't be screened until 35' my mind told me that I couldn't get cancer [yet]… I hit 35… and that's the minute I think I started panicking." (48/F/unaffected)	Age can also moderate response to results, as the same carrier can experience different emotions over time.
Support needs: "It would be good to have a bit more information on pregnancy and fertility, contraception, children, there wasn't much." (33/F/unaffected) "I found it relatively helpful but they were all double my age and all got kids already… I don't see any relation… I found that quite hard." (23/F/unaffected) "The problem is that all the other women were all pre-menopausal… as an older woman who's post-menopausal and hasn't got children, I feel like they just don't care." (57/F/OC) "Everything's all about breast cancer, it's all about women." (48/M/unaffected)	Life stage can greatly influence an individual's information and health service needs. Some younger adults wanted to learn about family planning implications, differing from adults who had completed their family. Age also impacts screening service access with a younger participant wanting to know how they would be informed when they became eligible, whereas those already eligible would be referred directly after receiving their results. In a similar way to how cancer-unaffected individuals want separate support groups to those affected by cancer, people wanted support groups with others at a similar life stage and found limited value when this was not met. Male carriers had some different information needs from female carriers which were not always met, for example, wanting clarity on male carrier risks and risk management options.
Personal attitudes/approach	
Test access: "It's only because my sister went away, did a family tree… took it back to [the doctor]… And he went "go on then, it can't hurt"… I'm horrified by that." (45/F/BC)	Several participants explained how knowledge and tenacity were key to navigating an obstructive health system to access testing, whereas others were not successful.
Test response: "I was completely devastated." (57/F/OC) "My heart just dropped and I wasn't expecting it." (23/F/unaffected) "My first panic was for my children: 'Oh my gosh, I've now given this to my kids'." (40/F/BC) "I'd say, 'What's the next step?' I'm a practical person in my nature. I'm not emotional'." (41/M/unaffected) "I was relieved, obviously, but actually the relief was mainly for mum not having to worry about it." (30/M/unaffected/non-carrier)	There was enormous individual variation in the response to positive results, from shock, concern about children to a more pragmatic response. Even individuals who struggled to access testing for years could be surprised by a positive result. Non-carriers expressed relief at finding their negative results, for themselves and for their families.
Support needs: "I needed psychological support and also a bit more information about the fertility process." (23/F/unaffected) "I'm me and I'm dealing with it my way." (75/F/pancreatic cancer)	Substantial individual differences were seen regarding the need for different post-test services, whether or not they wanted additional support, including psychological counselling.

BC, breast cancer; GP, general practitioner; NHS, National Health Service; OC, ovarian cancer.

Some non-carriers experienced strong feelings of guilt, particularly when close family members such as a sister tested positive.

> I just felt so bad… I was quite unprepared in how to support her. (26/F/unaffected/non-carrier)

This guilt was reignited years later when their sister began risk-reducing surgery. Furthermore, they felt unable to express these emotions to close family as they saw it as inappropriate given the sister's greater support needs. This participant highlighted the need for all family members (including non-carriers) to access psychological counselling, as and when required, which may not be immediately after results provision.

> Maybe at that point, if I had been able to reach out… I maybe could have talked through some of those feelings of guilt and then also just known, 'This would be the best way to support her right now'. (26/F/unaffected/non-carrier)

Jewish community factors

Several Jewish community factors impacted awareness, test decisions and access to post-testing services. It was generally perceived that there was insufficient community awareness.

> It almost feels as though there's a vacuum in the Jewish community. (64/F/BC)
>
> Super low, in my age group anyway, none of my friends had heard about it. (26/F/unaffected/non-carrier)

However, some participants mentioned outreach in synagogues and schools, and there was a sense that awareness was improving.

> In my Sixth-Form we had a Jewish organisation come in and talk to the girls. (23/F/unaffected)

Several participants described potential barriers to awareness including stigma, marriageability and (Haredi communities) not being online. These negatively impacted results-sharing.

> It's stigmatised… No one wants to say, 'Oh, we have this in our community'. (23/F/unaffected)
>
> My mother… originally she swore everybody to silence because she was worried that these relatives won't get married. (41/M/unaffected)

The genetic testing for recessive conditions, already established in the Jewish community for those considering marriage/having children, was seen as a good foundation for building awareness and testing for *BRCA*.

> Genetic testing for us as a specific community is available… [as with] Tay-Sachs you need to be aware of it. (26/F/unaffected/non-carrier)

Several Jewish charities provide support for carriers. Many participants found this helpful, but there was insufficient awareness of and a lack of clarity over who was eligible.

> I felt like a little bit of an imposter, given that I'm not really an active Jewish person but it was really great. (48/F/unaffected)
>
> MARS… were amazing. But people are not aware of these charities. (40/F/BC)

> They said, "We won't be able to support you with the fertility issues because you're not married and you don't have cancer." (23/F/unaffected)

Participant suggestions

Suggestions for improving *BRCA* awareness and testing experience were explored with participants, particularly with regard to the planned population-based genetic testing for the Jewish population in England. Some examples are presented in table 3.

DISCUSSION

Main findings

This qualitative study of Jewish individuals who have undergone *BRCA* testing finds no regret about being tested, but this may be limited by a short follow-up. There was large variation in satisfaction at different points of the testing pathway according to individual characteristics, life stage and service integration. Participants often became aware of *BRCA* through national media sources; however, many were unaware of any personal relevance until connected to a personal/family history of cancer. Several participants suffered from NHS testing access restrictions, with some even experiencing a second cancer diagnosis before being offered testing. We found that individual characteristics played a greater role than Jewish affiliation in testing experiences, with gender, cancer history and life stage interpreted as major factors in testing decisions and in determining post-testing needs. Personal attributes such as tenacity were key for some in accessing testing, resulting in inequities in healthcare provision. HCPs and systems varied greatly in their ability to meet carriers' needs, demonstrating the importance of trained and 'aware' HCPs and integrated referral networks in optimising experiences and well-being. There was a strong preference for information and support services to be personalised to individual circumstances, particularly regarding cancer history, life stage and gender. Non-affected carriers were uncomfortable being part of the cancer community. Carriers frequently highlighted the lack of a personalised information resource or signposting towards such services. Jewish-specific factors were raised around the need for greater community awareness and clarity over eligibility of charitable support, which was often excellent although potentially underused.

Strengths and limitations

This is the first qualitative research study into *BRCA* testing in the UK Jewish population. We used purposive sampling to ensure diversity among participants with respect to carrier and non-carrier status, age, gender, cancer histories and Jewish affiliation (or no affiliation). Participants were based across the main locations of UK Jewish communities, although most were from London. Therefore, it is possible that views and experiences of those from other locations may differ. We did not sample for or record marital status and the presence of children, although our sample included participants with and without children. Other limitations included the long 10–15 years' timeline of testing experiences described, which may not reflect current practice in all cases and may be subject to recall bias. The perception of regret may be impacted by the length of time which has elapsed since testing, and in some cases, a shorter follow-up may not be sufficient to capture this. We did not include any participants who declined testing, and this may limit the ability to draw balanced conclusions about testing drivers. However, previous quantitative data have highlighted being single and concerns about confidentiality, insurance and marriage ability as barriers to testing.[32] We only included two participants under 30 years of age, which may restrict the applicability of findings for this age group.

Interpretation

Our finding that personal engagement is required to decide to test is in keeping with the Precaution Adoption Process Model,[33]

Table 3 Suggestions for improvements regarding awareness and testing experience in the UK Jewish community

Identified needs to address	Participant suggestion
***BRCA* awareness**	
Insufficient *BRCA* awareness and understanding across the Jewish community	***Broad community education***: "There needs to be a lot more education … I think for the Jewish community it is a priority." (57/F/OC) "Events, presentations, it doesn't just have to be in the synagogues, it could be anywhere." (49/F/BC) "Going to different communities and talking about [it]." (60/F/BC/OC) ***Proactive charity outreach:*** "The charities need to put it out there what they're doing … people [going] out there raising awareness." (36/F/unaffected) "Social media marketing is definitely the way, using their targeting to reach appropriate audiences." (40/F/BC) ***Education in schools***: "Teachers who are teaching about genetics in Biology, having appropriate training… who could then refer to [a charity for more support]." (23/F/unaffected) "It should start in schools… certainly in the Jewish schools … not to scare them but just to know the risks." (55/F/OC)
Limited awareness of the personal relevance of *BRCA* testing for Jewish individuals, particularly in those without a personal/family history of cancer	***Align with recessive testing***: "AJ have an awareness [of] recessive genetic disorders that affect the Jewish community disproportionately… I think it compares well … it could sit with them [as something also] worth getting tested." (34/M/unaffected) ***Use key risk statistics:*** "I think the statistics need to be a bit more prominent in the blurb that's going out there." (55/F/OC) ***Include positives***: "It's got to be addressed in a way that [includes] the positive sides, if you can catch something earlier, or at least be aware that you need surveillance … we're luckier than the [last] generation." (57/F/OC) ***Personal stories***: "Medical professionals … can talk from a clinical point of view but I think people want to see a person who's been there, done that and … come out the other end." (48/F/unaffected)
Poor awareness among some GPs, oncologists and HCPs on *BRCA*-related issues and referral pathways	***HCP education:*** "Educating the doctors … they've got to be more aware of the risks in families." (64/F/BC) "There's a lot of education still to go into doctors, GPs." (60/F/BC/OC)
Decision to have *BRCA* testing	
Lack of clear, accessible information about *BRCA* testing, how to get testing and what it involves	***Clarify it is free and accessible:*** "The fact that it is a free and accessible service I think is good to make people aware of as well." (26/F/unaffected/non-carrier)
Access to *BRCA* testing	
Easier testing access for those who do not meet NHS eligibility criteria	***Expand BRCA testing for all Jewish people***: "I don't understand why it's not standard." (45/F/BC)
Experience of testing (including pretest counselling)	
Insufficient information resources with different levels of detail and using alternative channels for people who vary in the way they process information and make decisions	***Resources to take away:*** "I think I would have benefited from … a printed document that I could have processed in my own time." (45/F/BC) ***Use succinct, key information***: "Just how much information do you really need? You could put most of the relevant information on one side of A4." (64/F/BC)
Lack of tailored information relating to differences in life stage, gender and cancer status to support testing decision	***Male-relevant information:*** "It's all about women but… men need to be tested as much as women." (48/M/unaffected) "If you are considering trying to have children then this… is another really important piece of information." (26/F/unaffected/non-carrier)
Response to test results and communicating to family	
Better access to psychological support when receiving *BRCA* results, and over time, for those who need it	***More time and support when receiving results***: "It would be good … to just have someone … to talk a little bit more, have a bit more time dealing with the impact of that knowledge in that moment." (48/F/unaffected) "I like lots of scientific information about risks etc., but I could have done with a lot more pastoral care … from a general psychotherapeutic point of view." (57/F/OC) ***Psychological support***: "It's not just telling them the information before … it's picking up the pieces after… if you offer testing, you have to offer the [psychological] counselling." (60/F/BC/OC) "It's a very lonely process… there should be a much higher level of support there." (23/F/unaffected)
Increased support for carriers who find it difficult to communicate results with their children and family	***Geneticist letter***: "A letter written by a geneticist would have been better, just to explain it better." (60/F/BC/OC) ***Community contact:*** "I'd prefer to get a mentor, somebody who I can thrash it out with and have a bit of a discussion." (41/M/unaffected)
Post-test needs and service access	
Peer-support groups with members who have similar characteristics in terms of cancer history (or lack of), life stage etc—ensuring that unaffected carriers can access groups that are outside of cancer services	***Peer support:*** "Support group meetings … they're so useful … [meeting others] takes that fear factor out … [you] can ask the embarrassing questions, it's so important." (48/F/unaffected) "If I'd have had a community to go "this is real and this is with all of us, and here are some likeminded people", that would have probably given me more comfort." (49/F/unaffected) "Peer support is the key… a peer from your same community would be really good… those of us who haven't had cancer feel very uncomfortable being part of the cancer community." (48/F/unaffected)
A central information resource with a range of information covering various circumstances and levels of detail, signposting to support	***Centralised resource:*** "You need a central place to go and get all your information and maybe your referrals … it would link all the different [support] … people want different things." (60/F/BC/OC)
Insufficient information on fertility issues	***Family planning information:*** "It would be good to have more information on pregnancy, fertility, contraception, children. There wasn't much." (33/F/unaffected)
Improved case management—including access to ongoing support, a more proactive system of referrals/reminders for the various risk management services available at different stages	***Case management***: "The one thing I wanted… was someone to hold my hand through the process. I haven't had that at all… there isn't anyone who holds the process together." (23/F/unaffected) "It would have been good for the original team, the family history clinic to then ask me to come back and keep some kind of support overall of those decision-making processes." (48/F/unaffected) "It would be nice if you could speak to a specialist nurse or somebody who if you did have a question you could phone up and just ask." (48/F/unaffected)

BC, breast cancer; GPs, general practitioners; HCPs, healthcare professionals; NHS, National Health Service; OC, ovarian cancer.

which conceptualises behaviour change progressing between unaware to unengaged, undecided, deciding and acting (or not). Thus, knowledge about *BRCA* alone is insufficient to lead to a decision to have testing; this knowledge must be perceived as personally relevant, often due to a personal/family history of cancer. This study compliments quantitative findings showing high satisfaction with *BRCA* testing in population-based genetic testing trials among carriers and non-carriers in the UK,[34] Israel[35] and Canada.[36] A large UK randomised trial demonstrated high testing uptake which did not vary by Jewish affiliation, age or gender, but was significantly associated with being married/cohabiting.[32 37] Although we also did not see a major impact of Jewish affiliation, we found that gender, cancer history, anticipated guilt and life stage are major factors in testing decision and in framing post-testing needs. We find differences in the understanding of *BRCA* as an issue affecting men, including misunderstandings around paternal inheritance even among HCPs. Another qualitative study found that men are underinformed about *BRCA*-related risks and may differ in their appraisal of uncertainty, yet still have strong concerns for their family and would benefit from dedicated resources.[38] These are are not always clearly available/signposted.

Other qualitative studies comprising AJ carriers and non-carriers within an Israeli population testing trial found similar themes of overcoming barriers to access/referral, and lack of support from HCPs.[39] Although only 0.5% of the UK population are Jewish,[40] this is much higher in certain areas such as North London/Manchester, and local GPs need better information of *BRCA* testing as population-based *BRCA* testing is piloted in their communities.

The finding of lack of sufficient knowledge/information provision regarding family planning options/reproductive choices for young adults is consistent with previous work,[41] highlighting limited progress in this area. Young carrier women may feel additional pressure in making important life decisions, while also not yet being eligible for screening services, and may feel abandoned.[42] They appreciate greater clarity in available risk management options under screening age and the opportunity to discuss family planning options with specialists.[43]

We described the importance of familial dynamics for awareness and support, building upon previous work highlighting the changing nature of discussions over time and contrasting impacts on different relationships.[44 45] Families may act as barriers as well as facilitators of awareness and testing. This has important implications for the need for confidential pretesting and post-testing support services, particularly in communities where sharing of results is not always encouraged/forthcoming. Some carriers faced difficulties discussing *BRCA* with family, especially children. There is variation in levels of parent–child disclosure of results, and we echo previous calls for the need for interventional tools and involvement by genetic counsellors to support family dialogue.[46]

We did not explore the complex decision-making around risk-reducing surgery. While risk-reducing surgery is associated with high satisfaction and reduced anxiety/cancer worry,[47 48] many carriers may decline or choose to delay risk-reducing surgery,[49] and there are difficult issues in balancing risk reduction with fertility and menopause, highlighting the need for integrated specialist support services.[50 51]

This work seeks to identify lessons from the clinical/family history criteria setting and highlight these for planned Jewish population testing services. Qualitative research of pilot trials has shown high acceptability and satisfaction of population-based *BRCA* testing, with reduced anxiety in low-risk individuals.[52] Further work will be helpful to monitor and improve services after implementation of Jewish population *BRCA* testing. These findings apply only to the UK Jewish population, and further studies are required into the attitudes and experiences of testing in the UK general population.

CONCLUSION

This qualitative study finds no decision regret with *BRCA* testing, although variation in satisfaction with routine testing experiences. Individual characteristics in cancer history, demographics and attitudes appeared instrumental in explaining this variation. A major impact was seen from HCPs and the level of integration of referral networks, along with Jewish community factors. Many study participants wanted earlier access to testing, including those with and without a personal cancer history. The planned NHS Jewish *BRCA* population testing programme addresses this issue for others. Key recommendations are provided to improve and personalise awareness and testing experience for the UK Jewish community as population-based genetic testing is implemented:

- For all Jewish individuals who are offered/considering genetic testing, *BRCA* awareness and knowledge need to be associated with issues of personal relevance such as the increased cancer risks, opportunities for screening/prevention along with support available, for decision-making.
- Men are relatively underinformed and may differ in their appraisal of their *BRCA*-related risks due to low awareness of paternal inheritance, yet still have strong concerns for their family and would benefit from dedicated resources.
- Education materials are required for HCPs, particularly GPs and oncology teams, on population-based genetic testing including eligibility criteria and referral pathways.
- The established Jewish community testing provision for recessive disorders can be used to build awareness and signpost towards *BRCA* testing, while ensuring that differences in implications are clearly highlighted.
- Pretest information should be clear and accessible, with signposting towards further information and decision support resources.
- Post-test information and support services should be clearly signposted, including information on psychological support, peer-support groups, risk management services/decision-making, cascade testing, family planning and support for familial sharing of results.
- Engagement, information and support services (including peer support) should be tailored to individual circumstances relating to life stage, gender, cancer history and religious community affiliation. In particular, non-affected carriers want separate services from patients with cancer. An online platform can provide a useful mechanism for signposting services, while multiple outreach channels and formats may be needed.
- Consideration should be given to proactive case management for support of *BRCA* carriers.

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JEWISH HEREDITARY CANCER REVIEW

Qualitative sub-study – BRCA Carriers: Review of Hereditary Cancer Awareness and BRCA Testing in the UK Jewish Population (v7_19. 9. 21)

Research Aims to explore:
Routes to BRCA awareness.
Factors influencing decision to have BRCA testing.
The BRCA testing process – how it was accessed and what it involved.
Information provision and support prior to, during and after testing.
Satisfaction with the testing process experience and suggestions for improvement.
Perspective on BRCA awareness and testing in the UK Jewish community.

1. **Introduction**
   - Introduce self and research study.
   - Purpose of the research.
   - Confirm use of audio/video recorder.
     Stress all identifiable information will be kept confidential and only anonymised quotes may be published/presented.

2. **Participant background**

Topic	**Question**	**Prompts**
Age and gender	*Can you please state your age and gender?*	*/*
Occupation	*How would you describe your occupation?*	*Full time, part time, paid, unpaid*
Community affiliation	*Which sector of the Jewish community do you most affiliate with?*	*Haredi/Ultra-orthodox, US/Federation/Orthodox, Masorti, Reform/Liberal/Progressive, not-affiliated*
Relationship status	*What is your current relationship status? Do you have children?*	*Married, single, with / without children …*
Family composition	*Who lives at home? Tell me about your relationships?*	*Partner, children, parents, siblings, ages*
Time of testing	Can you tell me when the genetic testing took place?	*Month, year*
BRCA awareness	*What awareness did you have about BRCA risks prior to exploring testing yourself?*	*Increased risk, Jewish community risk?, Celebrity- Angelina Jolie*
Personal history	*What is your personal history as regards BRCA? Has anything changes since you sent back your participant form?*	*Type of BRCA carrier (1/2), if personal history of cancer (which, age of diagnosis, what status)*
Family history	*What is your family history as regards BRCA (which family members are BRCA carriers and/or have been affected by cancer)?*	*Type of BRCA carrier (1/2), family history of cancer (which, age of diagnosis, what status/outcome)*

3. **Sources of BRCA awareness -** before receiving any pre-test information/counselling.

Topic	**Question**	**Prompts**
BRCA awareness prior to starting the testing	*When and how did you first hear about BRCA genes?*	*Age, how long before getting tested – from who, through what channel*

process		
BRCA understanding prior to starting the testing process	*Before embarking on the testing process, how much did you understand about BRCA genes and the implications of being a carrier?*	*Basic (cancer-related), a little (increased risk for some cancers), quite a lot (Jewish risk), a lot (personal/family implications), very high level (workings of cancer pre-disposition genes)*
BRCA and the Jewish Community	*What is your understanding of the BRCA mutation within the Jewish Community?*	*Before embarking on the testing process, did you know about the increased presence of the BRCA mutation in the Jewish Community?*
Source of BRCA information prior to testing	*Before embarking on the testing process, where or to who did you turn to find out more about BRCA?*	*Family, friends, doctor, Jewish community information (specify), cancer charity campaign, Internet, social media (specify), other media, reading, other*
Trustworthiness of sources	Considering the sources of BRCA information, what did you find most trustworthy and why?	

4. Factors in BRCA testing decision

Topic	**Question**	**Prompts**
Key trigger and other factors influencing decision to test	*What was the key trigger, had the most impact in your decision to get tested? What other factors were an influence?*	*FH of cancer/BRCA carrier, curiosity/want to know own status, to be empowered to manage risk, to inform other family members, impact on children, reassurance. pressure from family, altruism*
Factors influencing when to get tested	*What influenced when you decided to get tested?*	*Cancer scare/diagnosis, relative/s being affected by cancer, as soon as you became aware of risk, starting family planning, finished having children, not initially wanting to know, concerns re: RRS; wish to stay healthy; other*
Which testing service provider you chose and why	*Which service provider did your testing, what influenced this choice and how did you find them?*	*Offered NHS, not offered NHS, private provider name - recommendation, timing/speed of results, accessibility, price, insurance, clinician referral, internet search, advert, other*

5. The BRCA testing process

Topic	**Question**	**Prompts**
Access to BRCA testing	*What was involved in getting a referral and registering for genetic testing? How long did you have to wait? What, if any, were the barriers to accessing the testing service?*	*GP referral to RGC, clinician referral to private service, no referral but clinician involvement required to register, no referral or*

		registration requirements e.g., age – waiting days, weeks, months
Testing service components	*What did your testing service include?*	*Pre-test information (leaflets, website), pre-test counselling (phone, F2F), sample taking (blood/saliva), results report (soft/hard copy), results to referring clinician, post-result info/counselling*
Appointment type and length	*What type of professional did you meet at your BRCA testing appointment/s?*	*Genetic counsellor, clinical geneticist, oncologist, customer support professional, another clinician or health professional*
	Were the appointments face-to-face or delivered remotely?	*Face-to-face, remotely, mix (specify which were face-to-face and which were remote)*
Length of the testing process	*From initial contact with your service provider, how long was it before your sample was taken?*	*Immediate, week, fortnight, month, several months*
Turnaround time for results	*How long after providing a sample did it take to receive your results?*	*Number of days, weeks, months*
Cost of being tested privately – not relevant if tested on the NHS.	*What was the cost of your testing service? Were some components optional/priced separately and were there any hidden costs?*	

6. Information provision and support

Topic	**Question**	**Prompts**
Pre-test information and support	*What information did you receive from your testing provider prior to being tested?*	*BRCA mutation risk, carrier implications, inheritance, service process, option to not go ahead with testing, other*
Information on giving a sample	*How did you find the process of giving a sample?*	*Very easy and clear, easy, not very easy, not at all easy or clear*
Results reporting and support	*How were your results reported to you and by whom?*	*Lab report, written report with lab results, phone call, F2F meeting - with genetic counsellor, customer service professional, administrator, other*
Clarity and fullness of results	*Were the results clear? Were you satisfied with the amount of information you received?*	*Yes, no, too much information, would have liked more information*
Post-test counselling	*What, if any, post-test counselling was provided? What information did you receive regarding options to manage your cancer risk?*	*None, web-based support, phone support, face to face session, mix of options*

7. *Actions taken after positive test result*

Topic	Question	Prompts
Information disclosure	Who did you decide to share the results of your BRCA testing with? What impacted your decision making?	Family disclosure, physician disclosure?
Support for BRCA carriers	Did you seek out any support about BRCA? Where did you look for support?	*BRCA carrier support groups, other*
Post-BRCA testing intervention	*What, if anything, have you done to manage your risk since finding out that you are a BRCA carrier?*	*breast screening, medical prevention for breast cancer, surgical prevention of breast cancer, surgical prevention of ovarian cancer, lifestyle, PGD*

8. **Satisfaction with the testing process**

Topic	Question	Prompts
Testing service satisfaction	*How satisfied were you overall with your testing service? Would you recommend it and if so to who and why?*	*Extremely, very, satisfied, neither satisfied nor dissatisfied, dissatisfied, very dissatisfied*
Regrets	*Do you have any regrets about the choice you made? If you had the chance to make your decision again, would you do anything differently?*	*No regrets, regret choice of provider, regret decision to be tested, regret not discussing testing with other family members in advance, regret not understanding the impact on other close relatives*
Suggested improvements.	*Is there anything that would have improved your testing experience?*	*More pre-test info, more counselling, clearer results, seamless connection to further services, other*

9. Perspective on BRCA awareness and testing in the UK Jewish community.

Topic	Question	Prompts
BRCA awareness in the Jewish community	*To what extent do you think the UK Jewish community are aware of their increased BRCA risk?*	
	Do you think there is enough awareness about BRCA risks among the UK Jewish community	
Access to BRCA testing	*Do you think there is sufficient access to BRCA testing services for Jewish people in the UK*	*Fine, insufficient, should be available to all on NHS, private services should be moderated*
Improving awareness and testing access	*Do you have any suggestions for awareness and testing access can be improved in the Jewish community? Would you be open to supporting these changes in some way?*	*Develop a resource for accurate BRCA information provision, work to improve access to NHS testing, run a GP awareness-raising campaign to improve referral, provide subsidies for testing*

Final steps:
Thank the participant.
Check whether they have remaining questions or comments about the topic.
Reassurance about confidentiality and anonymity
JHC Review contact details should they want further information.