National Institute for Health and Care Excellence

Final

Ovarian cancer: identifying and managing familial and genetic risk

[A] Information and support

NICE guideline NG241

Evidence reviews underpinning recommendations 1.2.1 to 1.2.6 as well as bullet points 3, 6, 9 to 12 in table 1, bullet points 3 to 5 in table 2 and the section on reproductive choices in table 3 in the NICE guideline

March 2024

Final

These evidence reviews were developed by NICE

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Information and support

Review question

What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Introduction

Being diagnosed with an inherited increased risk of ovarian cancer is psychologically distressing. Those found to have a familial predisposition to ovarian cancer must deal with the knowledge that they are at a lifelong increased risk of developing ovarian cancer. Currently there is no effective surveillance, therefore women are offered risk reducing surgery which places them in a surgical menopause and impacts on their family planning. Despite this, the risk of ovarian cancer can never be reduced to nothing. As this risk is familial it is goes beyond the individual and impacts upon the wider family. Therefore, those found to have an inherited risk of ovarian cancer must explain this risk to their loved ones and encourage them to undergo testing that could have a profound impact on their lives.

Given these pressures those with familial ovarian cancer require information and support. Inherited risk is complicated as it is highly personalised and never absolute. As such, the information and the way it is delivered needs to be considered. Furthermore, given the risk is life long and dynamic, those found to have familial ovarian cancer may require lifelong support. Here we will discuss what information those with inherited ovarian cancer would find beneficial, the best way to deliver this information and what support these individuals need during their lives.

Summary of the protocol

See Table 1 for a summary of the Population, Phenomenon of interest and Context (PPCo) of this review.

Table 1: Summary of the protocol (PICo table)

Population	Women who: • carry a pathogenic variant that increases the risk of ovarian cancer, including in genes such as *BRCA1, BRCA2, RAD51C, RAD51D, BRIP1, PALB2, MLH1, MSH2* and *MSH6* • have a relative who carries a pathogenic variant that increases the risk of ovarian cancer, including in genes such as *BRCA1, BRCA2, RAD51C, RAD51D, BRIP1, PALB2, MLH1, MSH2* and *MSH6* • have a family history of ovarian cancer (with or without a family history of breast cancer) • have a family history or a diagnosis of a syndrome associated with an increased risk of ovarian cancer, for example Lynch syndrome • come from populations with an increased prevalence of pathogenic variants associated with ovarian cancer • have ovarian cancer (with or without breast cancer) Family and carers of people at increased risk
Phenomenon of interest	Potential themes include: • Uncertainty about prognosis & risk • Communication about risks with family members • Information about genetic testing process • Information about possible genes involved • Information about when to present (e.g., in high-risk patient group) • Healthcare professionals' knowledge of ovarian cancer • When to seek help • Who to contact [e.g. primary cancer team, community team] • Information about types of treatment (decision making) – what's involved and when to start, where treatment is carried out • What happens next after treatment • What's safe/not safe to do • New onset symptoms and who to contact • Psychological support and impact, plus anxiety • Type of support
Context	Included studies will be relevant for developing and improving information and support provided to women with familial ovarian cancer or who are at increased risk of ovarian cancer, and their families and carers, within a healthcare setting.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to NICE's conflicts of interest policy.

Qualitative evidence

Included studies

Twenty-five qualitative studies were included in this review: Battistuzzi 2019, Brain 2004, Brunstrom 2016, d'Agincourt-Canning 2006, Dancyger 2010, Dancyger 2011, Fadda 2020, Foster 2002, Gaba 2022, Gleeson 2012, Hughes 2010, Jeffers 2014, Lifford 2013, Lim 2004, Mireskandari 2006, Ormondroyd 2006, Pedrazzani 2022, Ratnayake 2011, Samson 2014, Seenandan-Sookdep 2016, Shilling 2020, Smits 2016, Wakefield 2011, Wright 2018, and Young 2019. The studies provided data on the information and support needs of women with familial ovarian cancer or who are at increased risk of ovarian cancer and their families and carers. Data collection methods included: semi-structured interviews (Dancyger 2010, Dancyger 2011, Foster 2002, Gleeson 2013, Lifford 2013, Mireskandari 2006, Ormondroyd 2012, Ratnayake 2011, Samson 2014, Seenandan-Sookdeo 2016, Smits 2016, Wakefield 2011, Wright 2018, Young 2019), interviews (not otherwise specified) (d'Agincourt-Canning 2006, Fadda 2020, Gaba 2022, Jeffers 2014, Shilling 2020), interviews and focus groups (Pedrazzani 2022), focus groups (Highes 2010) and open-ended questions (Lim 2004). There were two different publications by Dancyger (2010 and 2011) it is likely but not explicitly stated that participants are the same.

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

Summary of included studies

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies.

Study	Population	Methods	Themes applied after thematic analysis
Battistuzzi 2019 Italy	N=19 Age, mean (SD), years: not reported; range: 25 to 39 Women with a strong family history but no personal history of cancer who had CGC and *BRCA1/2* testing	**Setting:** Genetic-counselling hospital services **Data collection:** Semi-structured interviews **Data analysis:** Inductive theoretical framework	The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions and decision making Reasons for and against genetic testing
Brain 2004 United Kingdom	N=10 Age, mean (SD), years: not	**Setting:** Not reported **Data collection:** Semi-structured interviews	Deficiency in the information and support provided

Study	Population	Methods	Themes applied after thematic analysis
	reported; range: 27 to 62 Women newly identified as being at increased risk of developing familial ovarian cancer	**Data analysis:** Constant comparative analysis	Family as a source of information and support Impact of genetic risk information on emotions, decision making, and risk management Importance of ovarian cancer screening programs and surgical options
Brunstrom 2016 United Kingdom	N= 7 Age, mean (SD), years: not reported; range: 24 to 30 Female *BRCA 1/2* carriers who had predictive testing before the age of 30	**Setting**: Cancer Genetics Service for Wales **Data collection**: Semi-structured interviews **Data analysis**: Thematic analysis	Deficiency in the information and support provided The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions, decision making, and risk management
D'Agincourt-Canning 2006 Canada	N= 53 Age, mean (SD), years: not reported; range: early 20s to 60s Women and men who were eligible for and/or who had undergone genetic testing for hereditary cancer.	**Setting:** Hereditary cancer programme **Data collection**: Semi-structured interviews **Data analysis:** An interpretive process guided by constant comparative techniques.	Family as a source of information and support The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions, decision making, and risk management Reasons for and against genetic testing
Dancyger 2010* United Kingdom	N=30 Age, mean (SD), years: not reported; patients range: 34 to 71; relatives range: 20 to 65 10 patients and 20 relatives. Patients were	**Setting:** Clinical genetics services **Data collection:** Semi-structured interviews **Data analysis:** Interpretative phenomenological analysis	Deficiency in the information and support provided The role of the professional in providing information and support Family as a source of information and support The impact of the family on decisions about genetic testing

Study	Population	Methods	Themes applied after thematic analysis
	female patients affected by breast or ovarian cancer who had received a positive result from a *BRCA1/2* mutation search		Impact of genetic risk information on emotions, decision making, and risk management
Dancyger 2011* United Kingdom	N=10 families (including 10 female patients and their 22 relatives) Age, mean (SD), years: not reported; range: 20 to 71 Women affected by breast or ovarian cancer who had received a positive *BRCA1/2* result	**Setting**: National Health Service (NHS) clinical genetics services **Data Collection**: Semi-structured interviews **Data Analysis**: Interpretative phenomenological analysis	Deficiency in the information and support provided Family as a source of information and support The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions, decision making, and risk management
Fadda 2020 Switzerland	N=32 Age, mean (SD), years: not reported; ranges were: 26-35: n=8 36-49: n=21 50-60: n=3 Unaffected women carrying *BRCA1/2* pathogenic variants	**Setting**: Genetic-counselling hospital services **Data Collection**: Semi-structured interviews **Data Analysis:** Inductive approach guided by constant comparison	The role of the professional in providing information and support
Foster 2002 United Kingdom	N=15 Age, mean (SD), years: not reported; median: 46, range: 33 to 62	**Setting:** Genetics Clinic for predictive genetic testing **Data collection:** Semi-structured interviews	Need for support networks and support groups The impact of the family on decisions about genetic testing

Study	Population	Methods	Themes applied after thematic analysis
	Women at increased risk of developing breast and/or ovarian cancer due to their family history	**Data analysis:** Grounded theory	Impact of genetic risk information on emotions, decision making, and risk management Reasons for and against genetic testing
Gaba 2022 United Kingdom	N=24 Age, mean (SD), years: not reported; range: 34 to 46 Premenopausal women at increased risk of Ovarian cancer (*BRCA1/ BRCA2/RAD51 C/RAD51D/BRI P1* carriers or due to a strong family history)	**Setting:** Specialist high-risk familial cancer clinics, genetics, gynaecology/ gynaecological oncology clinics **Data collection:** Semi-structured interviews **Data analysis:** Grounded theory approach	Deficiency in the information and support provided Need for support networks and support groups The role of the professional in providing information and support Importance of ovarian cancer surveillance programs and knowledge of surgical options
Gleeson 2013 Australia	N=22 Age, mean (SD), years: 57.2 (9.1) Women diagnosed with ovarian cancer who were unselected for family history	**Setting:** Genetics services and a Gynaecologic oncology department at a hospital **Data collection:** Semi-structured interviews **Data analysis:** Transcendental realism	Tailor the delivery of information to suit the individual and their need and preferences
Hughes 2010 United Kingdom	N=17 Age, mean (SD), years: 49 (SD not reported); range: 24 to 77 *BRCA1* and *BRCA2* mutation carriers who had been through diagnostic or	**Setting:** Not reported **Data collection:** Focus groups **Data analysis:** Thematical analysis (no details given)	Deficiency in the information and support provided Need for support networks and support groups The role of the professional in providing information and support Tailor the delivery of information to suit the individual and their need and preferences Family as a source of information and support

Study	Population	Methods	Themes applied after thematic analysis
	pre-symptomatic genetic testing		
Jeffers 2014 United Kingdom	N=33 (In addition 4 health professionals and 3 relatives completed participant numbers) Age, mean (SD), years: not reported; range: 29 to 68 Women with a personal history of hereditary breast and/or ovarian cancer who had tested positive for a *BRCA* mutation	**Setting:** Regional genetics service **Data collection:** In-depth interviews (type not otherwise specified) **Data analysis:** Theoretical sampling	Deficiency in the information and support provided The role of the professional in providing information and support Family as a source of information and support Impact of genetic risk information on emotions and decision making
Lifford 2013 United Kingdom	N=21 Age, mean (SD), years: 48 (SD not reported); range: 37 to 66 Women, who discontinued OCS following surgery	**Setting:** Not reported **Data collection:** Semi-structured interviews **Data analysis:** Framework approach	Deficiency in the information and support provided The role of the professional in providing information and support Impact of genetic risk information on emotions and decision making Importance of ovarian cancer surveillance programs and knowledge of surgical options
Lim 2004 Australia	N=47 Age, mean (SD), years: not reported; range: 24 to 76 Unaffected women with mutation results available	**Setting:** Study sites across Australia **Data collection:** Structured interviews **Data analysis:** Interviews were analysed using thematic analysis	Family as a source of information and support Impact of genetic risk information on emotions and decision making Importance of ovarian cancer surveillance programs and knowledge of surgical options
Mireskandari 2006 Australia	N=15 partners of women Age, mean (SD), years:	**Setting:** Not reported **Data collection:** Semi-structured interviews	Need for support networks and support groups Family as a source of information and support

Study	Population	Methods	Themes applied after thematic analysis
	41.4 (SD not reported); range: 30 to 56 Women assessed as being at high risk of developing breast/ ovarian cancer	**Data analysis:** A multi-phase approach of Miles and Huberman	Impact of genetic risk information on emotions and decision making
Ormondroyd 2012 United Kingdom	N=25 Age, mean (SD), years: not reported; ranges were: 18-25: N=0 26-30: N=8 31-35: N=6 36-40: N=6 41-45: N=5 Women and men who tested positive for a pathogenic *BRCA1* or *BRCA2* mutation	**Setting:** A hospital **Data collection:** Semi-structured interviews **Data analysis:** Inductive theoretical framework	Deficiency in the information and support provided Impact of genetic risk information on emotions and decision making
Pedrazzani 2022 Switzerland	N=48 Age, mean (SD), years: 51.8 (10.9) Women who were confirmed carriers of pathogenic variants	**Setting:** Not reported **Data collection:** Semi-structured interviews and focus groups **Data analysis:** Inductive approach guided by constant comparison	Deficiency in the information and support provided The role of the professional in providing information and support Tailor the delivery of information to suit the individual and their need and preferences Impact of genetic risk information on emotions and decision making
Ratnayake 2011 Australia	N=39 Age, mean (SD), years: 58 (12.11) Individuals from families with	**Setting:** The Kathleen Cunningham Foundation Consortium for Research into Familial Aspects of Breast Cancer (kConFab) which is a research co-operative	Tailor the delivery of information to suit the individual and their need and preferences Family as a source of information and support

Study	Population	Methods	Themes applied after thematic analysis
	identified *BRCA1* or *BRCA2* mutations	**Data collection:** Semi-structured interviews **Data analysis:** Conceptual framework of Miles and Huberman	Impact of genetic risk information on emotions and decision making
Samson 2014 Canada Note: Women undergoing screening for ovarian cancer due to an HBOC genetic mutation were excluded	N=6 Age, mean (SD), years: 38.5 (SD not reported); range: 31 to 44 Women who had undergone genetic testing for hereditary breast/ovarian cancer and who had received a positive test result indicating that they carried a deleterious mutation in *BRCA1* or *BRCA2*	**Setting:** Specialised risk assessment clinic **Data collection:** Semi-structured interviews **Data analysis:** Grounded theory method	Need for support networks and support groups Impact of genetic risk information on emotions and decision making
Seenandan-Sookdeo 2016 Canada	N=15 Age, mean (SD), years: not reported; median: 44, range: 28 to 54 Women with a positive *BRCA1/2* result	**Setting:** A hereditary breast and ovarian cancer clinic **Data collection:** Semi-structured interviews **Data analysis:** Van Manen's (1990) selective approach	Deficiency in the information and support provided Family as a source of information and support Impact of genetic risk information on emotions and decision making
Shilling 2020 United Kingdom	N=11 Age, mean (SD), years: not reported; range: 38 to 77 Women with a known *BRCA 1/2* gene mutation	**Setting:** BRCA support groups and family history clinics **Data collection:** Semi-structured interviews **Data analysis:** The Framework Approach was applied to thematic analysis	Deficiency in the information and support provided Need for support networks and support groups The role of the professional in providing information and support

Study	Population	Methods	Themes applied after thematic analysis
			Tailor the delivery of information to suit the individual and their need and preferences The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions and decision making
Smits 2016 United Kingdom	N=9 Age, mean (SD), years: not reported; range: 44 to 77 Women at increased risk of ovarian cancer who had previously taken part in ovarian cancer screening	**Setting:** Participants' homes **Data collection:** Semi-structured interviews **Data analysis:** Interpretative phenomenological analysis	Deficiency in the information and support provided The role of the professional in providing information and support Tailor the delivery of information to suit the individual and their need and preferences
Wakefield 2011 Australia	N=39 Age, mean (SD), years: 58 (12.11) Relatives of high-risk mutation carriers	**Setting:** Research co-operative **Data collection:** Semi-structured interviews **Data analysis:** Conceptual framework of Miles and Huberman was used to guide analysis, and emergent themes analysis	Deficiency in the information and support provided The impact of the family on decisions about genetic testing Impact of genetic risk information on emotions and decision making Reasons for and against genetic testing
Wright 2018 United Kingdom	N=26 Ovarian cancer patients: Age, mean (SD), years: 64 (SD not reported); range: 48 to 82 Breast cancer patients: Age, mean (SD), years: 48	**Setting:** Hospital **Data collection:** Semi-structured interviews **Data analysis:** Thematic analysis	Deficiency in the information and support provided The impact of the family on decisions about genetic testing Reasons for and against genetic testing

Study	Population	Methods	Themes applied after thematic analysis
	(SD not reported); range: 33 to 62 Women with breast or ovarian cancer who had undergone genetic testing		
Young 2019 Australia	N= 21 families (n=67 young adults and their relatives) Age, mean (SD), years: 44.87 (17.47) Young adults and their relatives, with at least one member of the family having a *BRCA1/2* pathogenic variant	**Setting:** Metropolitan and regional genetic clinics that provide genetic testing services **Data collection:** Semi-structured interviews **Data analysis:** In-depth thematic analysis using a Family Systems Theory approach	Deficiency in the information and support provided The role of the professional in providing information and support Family as a source of information and support Impact of genetic risk information on emotions and decision making

CGC: cancer genetic counselling; OCS: ovarian cancer surveillance.
** It is likely that participants are the same in both studies*

See the full evidence tables in appendix D. No meta-analysis was conducted (and so there are no forest plots in appendix E).

Summary of the evidence

Nine main themes with a total of 58 subthemes relating to the information and support needs of women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families were identified through analysis of the included studies:

- Deficiency in the information and support provided (9 subthemes)
- Need for support networks and support groups (3 subthemes)
- The role of the professional in providing information and support (7 subthemes)
- Tailor the delivery of information to suit the individual and their need and preferences (4 subthemes)
- Family as a source of information and support (6 subthemes)
- The impact of the family on decisions about genetic testing (7 subthemes)
- Impact of genetic risk information on emotions and decision making (12 subthemes)
- Importance of ovarian cancer surveillance programs and knowledge of surgical options (4 subthemes)
- Reasons for and against genetic testing (6 subthemes)

The data from the included studies were synthesised and explored in a number of central themes and sub-themes (central themes shown in Figure 1; see appendix L for sub-theme maps).

Figure 1: Qualitative theme structure

1: Deficiency in the information and support provided

- More information needed on cancer surveillance including CA-125 testing, and surgery
- Need for more support following oophorectomy
- More information needed on male genetic risk
- More information needed on the benefits of genetic testing
- More information and support needed on how and when to inform family members about genetic risk
- More information and support needed on reproductive options
- Self-seeking information from alternative sources
- Feeling helpless due to a lack of available services
- It should be easier to access the system

2: Need for support networks and support groups

- Value in a support network where you can share similar experiences
- Stigma associated with support groups can be a barrier to joining
- Desire for support that can be adapted to the individual and their needs

3: The role of the professional in providing information and support

- Communication with professionals was supportive and informative
- Good to have professional support and advice when making decisions
- Desire for more time and opportunities for discussion with professionals
- Need for accurate information and advice from professionals
- Feeling pressured by professionals to adopt risk management behaviours
- Feeling unsupported by professionals.
- Desire for continuity and accessibility of care

4: Tailor the delivery of information to suit the individual and their need and preferences

- Desire for information to be offered in various formats, dependent on individual need and preference
- Feeling overwhelmed when there is too much information
- Preference for positive, hope giving information
- Need for information to be communicated at the appropriate time

5: Family as a source of information and support

- Importance of the family as a source of support
- Following information and advice provided by family members
- Lack of communication and support in the family.
- Partner's role in relaying information and providing support
- Coping with a partner who has a genetic risk
- Need for support at home after prophylactic oophorectomy

6: The impact of the family on decisions about genetic testing

- Decision-making influenced by family members' experiences
- Feeling obligated to have genetic testing to be able to inform family members about genetic risk
- Feeling obligated to have genetic testing due to family/external pressures.
- Receiving unwanted information from family members about genetic risk
- Family pressure to get tested due to the impact of genetic test results on children
- Which family members are affected impacts mutation carrier risk perception
- Decisions to get tested because of family member's positive result

7: Impact of genetic risk information on emotions and decision making

- Knowledge of genetic test results seen as important and valuable
- Genetic risk information relieves guilt associated with developing cancer.
- Positive genetic test results were unexpected and shocking
- Not thinking through the impact of receiving genetic testing results.
- Regret about knowing genetic test results
- Feeling at risk regardless of genetic test result
- A sense of duty to pass on genetic test results to family members
- A culture of openness in families facilitated communication about genetic risk
- Difficulty in communicating genetic risk to family members
- Coping with the emotions of genetic risk and the emotions of family members at the same time
- Deferring genetic testing due to not wanting to know genetic risk at that time
- Results of genetic testing did not influence decision making or behaviour.
- Results of genetic testing impacted on thoughts about childbearing

8: Importance of ovarian cancer surveillance programs and knowledge of surgical options

- Confidence in cancer surveillance for the detection of ovarian cancer
- Good to have the option to continue surveillance
- Clear knowledge of options available led to confident decisions to undertake surgery.
- Option of prophylactic oophorectomy came as a shock

9: Reasons for and against genetic testing

- Empowerment and taking control of the situation
- Getting tested for science
- Feeling like they had missed previous opportunities to get tested
- Being curious about family history
- Do not believe in genetic testing
- Believe cancer is caused by other factors

See also Appendix L for maps depicting only the main themes and each of the subthemes individually.

The quality of the review findings which ranged from low to high is summarised here according to the over-arching themes and sub-themes:

Main theme 1: Deficiency in the information and support provided (evidence from 16 studies)

- Subtheme 1.A: More information needed on cancer surveillance including CA-125 testing, and surgery (moderate quality).
- Subtheme 1.B: Need for more support following oophorectomy (low quality).
- Subtheme 1.C: More information needed on male genetic risk (high quality).
- Subtheme 1.D: More information needed on the benefits of genetic testing (high quality).
- Subtheme 1.E: More information and support needed on how and when to inform family members about genetic risk (high quality).
- Subtheme 1.F: More information and support needed on reproductive options (moderate quality).
- Subtheme 1.G: Self-seeking information from alternative sources (moderate quality).
- Subtheme 1.H: Feeling helpless due to a lack of available services (moderate quality).
- Subtheme 1.I: It should be easier to access the system (moderate quality).

Main theme 2: Need for support networks and support groups (evidence from 6 studies)

- Subtheme 2.A: Value in a support network where you can share similar experiences (high quality).
- Subtheme 2.B: Stigma associated with support groups can be a barrier to joining (moderate quality).
- Subtheme 2.C: Desire for support that can be adapted to the individual and their needs (low quality).

Main theme 3: The role of the professional in providing information and support (evidence from 10 studies)

- Subtheme 3.A: Communication with professionals was supportive and informative (high quality).
- Subtheme 3.B: Good to have professional support and advice when making decisions (moderate quality).
- Subtheme 3.C: Desire for more time and opportunities for discussion with professionals (high quality).
- Subtheme 3.D: Need for accurate information and advice from professionals (moderate quality).
- Subtheme 3.E: Feeling pressured by professionals to adopt risk management behaviours (low quality).
- Subtheme 3.F: Feeling unsupported by professionals (moderate quality).
- Subtheme 3.G: Desire for continuity and accessibility of care (moderate quality).

Main theme 4: Tailor the delivery of information to suit the individual and their need and preferences (evidence from 6 studies)

- Subtheme 4.A: Desire for information to be offered in various formats, dependent on individual need and preference (high quality).
- Subtheme 4.B: Feeling overwhelmed when there is too much information (low quality)
- Subtheme 4.C: Preference for positive, hope giving information (low quality).
- Subtheme 4.D: Need for information to be communicated at the appropriate time (high quality).

Main theme 5: Family as a source of information and support (evidence from 11 studies)

- Subtheme 5.A: Importance of the family as a source of support (high quality).
- Subtheme 5.B: Following information and advice provided by family members (low quality).
- Subtheme 5.C: Lack of communication and support in the family (high quality).
- Subtheme 5.D: Partner's role in relaying information and providing support (high quality).
- Subtheme 5.E: Coping with a partner who has a genetic risk (low quality).
- Subtheme 5.F: Need for support at home after prophylactic oophorectomy (low quality).

Main theme 6: The impact of the family on decisions about genetic testing (evidence from 9 studies)

- Subtheme 6.A: Decision-making influenced by family members' experiences (low quality).
- Subtheme 6.B: Feeling obligated to have genetic testing to be able to inform family members about genetic risk (high quality).
- Subtheme 6.C: Feeling obligated to have genetic testing due to family/external pressures (high quality).
- Subtheme 6.D: Receiving unwanted information from family members about genetic risk (low quality).
- Subtheme 6.E: Family pressure to get tested due to the impact of genetic test results on children (high quality).
- Subtheme 6.F: Which family members are affected impacts mutation carrier risk perception (low quality).
- Subtheme 6.G: Decisions to get tested because of family member's positive result (low quality).

Main theme 7: Impact of genetic risk information on emotions and decision making (evidence from 19 studies)

- Subtheme 7.A: Knowledge of genetic test results seen as important and valuable (high quality).
- Subtheme 7.B: Genetic risk information relieves guilt associated with developing cancer (moderate quality).
- Subtheme 7.C: Positive genetic test results were unexpected and shocking (high quality).
- Subtheme 7.D: Not thinking through the impact of receiving genetic testing results (moderate quality).
- Subtheme 7.E: Regret about knowing genetic test results (low quality).
- Subtheme 7.F: Feeling at risk regardless of genetic test result (moderate quality).
- Subtheme 7.G: A sense of duty to pass on genetic test results to family members (high quality).
- Subtheme 7.H A culture of openness in families facilitated communication about genetic risk (low quality).
- Subtheme 7I: Difficulty in communicating genetic risk to family members (high quality).
- Subtheme 7.J: Coping with the emotions of genetic risk and the emotions of family members at the same time (moderate quality).
- Subtheme 7.K: Deferring genetic testing due to not wanting to know genetic risk at that time (low quality).
- Subtheme 7.L: Results of genetic testing did not influence decision making or behaviour (high quality).

- Subtheme 7.M: Results of genetic testing impacted on thoughts about childbearing (moderate quality).

Main theme 8: Importance of ovarian cancer surveillance programs and knowledge of surgical options (evidence from 4 studies)

- Subtheme 8.A: Confidence in cancer surveillance for the detection of ovarian cancer (low quality).
- Subtheme 8.B: Good to have the option to continue surveillance (moderate quality).
- Subtheme 8.C: Clear knowledge of options available led to confident decisions to undertake surgery (moderate quality).
- Subtheme 8.D: Option of prophylactic oophorectomy came as a shock (low quality).

Main theme 9: Reasons for and against genetic testing (evidence from 6 studies)

- Subtheme 9.A. Empowerment and taking control of the situation (low quality).
- Subtheme 9.B: Getting tested for science (high quality).
- Subtheme 9.C: Feeling like they had missed previous opportunities to get tested (low quality).
- Subtheme 9.D: Being curious about family history (high quality).
- Subtheme 9.E: Do not believe in genetic testing (low quality).
- Subtheme 9.F: Believe cancer is caused by other factors (low quality).

See appendix F for full GRADE tables-CERQual tables.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question.

A single economic search was undertaken for all topics included in the scope of this guideline. See supplementary material 2 for details.

Excluded studies

Economic studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of included economic evidence

No economic evidence was identified which was applicable to this review question.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

Evidence statements

Economic

No economic evidence was identified which was applicable to this review question.

The committee's discussion and interpretation of the evidence

The phenomena of interest

This review focused on the information and support needs of women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers. The committee discussed that there would be several qualitative themes that they would expect to emerge from the evidence. They thought that people may value information about genetic testing, what the genes are that increase risk, information about when they should seek help. They also thought that people may talk about the support that they require to deal with uncertainty and how to communicate with family members. The committee also thought that it would be good to know what type of support people felt they would need (for instance to deal with psychological impact). Another theme they thought that would be helpful in this context is how the knowledge of healthcare professionals about ovarian cancer could be used to address people's needs. The committee decided not to make the list of potential themes exhaustive so that any other themes that identified information and support needs would be extracted. A number of themes that the committee expected did emerge from the evidence (for example communication with family members, information related to genetic testing and when and who to contact to access services); so these together with other themes emerging from the literature were discussed by the committee when developing recommendations.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from low to high. Concerns about the methodological limitations of the studies were assessed with the CASP checklist and ranged from "moderate" to "none or very minor concerns". The most common issues were the lack of explanation of recruitment approach, lack of justification for data collection and/or data saturation, a lack of consideration of the relationship between researcher and participants, no discussion of ethics approval and/or ethical issues in study methods, and limited information on data analysis including how presented data were selected and discussion of contradictory data. Concerns about relevance ranged from "minor" to "no or very minor". For most review findings concerns were "no or very minor" as the context of the studies was not substantially different to the context of the review question. Concerns about coherence ranged from "minor" to "no or very minor". For most review findings concerns were "no or very minor", as there was no data that contradicted the findings nor any ambiguous data. A small number of review findings demonstrated minor concerns due to vaguely described data in the underlying body of evidence. Concerns about adequacy ranged from "serious" to "no or very minor". There were serious and moderate concerns for review findings when some of the evidence offered thin data that was based on either one or two studies and a small number of participants. All other review findings were based on moderately rich data so there were minor concerns where review findings were based on evidence from a small number of studies and participants. The number of studies contributing to each subtheme ranged from 1 to 12.

Despite some of these quality concerns the committee felt that there was sufficient moderate to high quality evidence to base their recommendations on.

Benefits and harms

Information and support about familial ovarian cancer in all settings

The committee discussed the evidence from the main theme 1 and subthemes (deficiency in the information and support provided), which showed that people felt that the information and support provided to them is insufficient and would not allow them to make informed choices in shared decision making which is an essential component in clinical care (evidence was

mainly moderate to high quality with a number of subthemes reaching saturation). Therefore, more information and support has to be given to meet their needs. Sometimes women expressed fear that they may be misled by inaccurate information (subtheme 3.D – moderate quality) and to address this the committee emphasised that information needs to be balanced and accurate so that women know they have the correct details to base decisions on. Whilst this was moderate quality evidence the committee felt that the accuracy and balance of information is essential in a shared decision-making process. Women also reported that they felt that there should be more time and opportunities for discussion (subtheme 3.C – high quality) and that they felt overwhelmed by the amount of information that they received in one visit and that the relevant information was not always given in the right context (subthemes 4.B and 4.D – low and high quality). To address these concerns the committee recommended that information should be available on an ongoing basis, when needed and that it is relevant to the person's circumstances. It was noted that this may either be provided on an opportunistic basis in primary care or from the familial ovarian multidisciplinary team or other specialist services where applicable where people are already under the care of these services (see also below about evidence related to a recommendation on information related to how to access services). There was also evidence that information was not always sufficiently tailored to people's needs, for example that the format of the information was not meeting their needs (main theme 3 and subthemes – mainly moderate to high quality). The committee discussed that there are many decisions to make, and to make informed choices people's needs have to be taken into consideration and that this also relates to the Equality Act 2010 and accessible information standards. This not only related to moderate to high quality evidence but also to a legal duty therefore the committee made a strong recommendation specifically highlighting the tailoring of information to the person as an important factor in information provision.

Evidence from subthemes 1.H and 1.G (moderate quality) showed that women reported feeling helpless due to a lack of available services and did self-seek information from alternative sources to enable them to feel more confident in their knowledge when engaging in consultations with health professionals. Women also reported that it should be easier to access the system to get further advice if they needed it (subtheme 1.I). The committee agreed that this was consistent with their experience and that women should be given opportunities to review their decisions and that they should be made aware of the various options of how to access services for further discussions (including self-referral). Whilst an increase in accessing services would lead to more pressure on the system, the committee decided that people at risk of ovarian cancer have to make a number of decisions, for example related to genetic testing or risk-reducing surgery and that these decisions could be life-saving and despite pressures the committee felt that that a strong recommendation is needed so that information on how to access services is given.

There was also evidence about strong emotional or psychological components. The qualitative evidence demonstrated the emotional health needs of people and relatives affected by ovarian cancer or at risk of ovarian cancer. The evidence reached saturation regarding this topic as so many papers reported it (subtheme 7.J – moderate quality). There was also evidence about feeling unsupported by professionals and feeling under pressure (subthemes 3.E and 3.F – low and moderate quality). As a result, the committee encouraged healthcare professionals to ask people about their emotional health and psychological issues that may affect their ability to reach a decision, provide support if possible and if the level of emotional distress is high it may be necessary to refer the person to genetic counselling or psychological services. The committee acknowledged that a possible increase in referral to genetic counselling or psychological services would mean additional resources may be needed. However, they decided that it would be unethical to not refer people who are in a high level of emotional distress to the relevant service.

One subtheme specifically highlighted that people felt that there was insufficient information on male genetic risk (subtheme 1.C – high quality) and that people were not always aware that men could be carriers of pathogenic variants related to ovarian cancer even if they

cannot develop ovarian cancer. The committee agreed that this needed to be addressed and recommended that information should be provided to raise.

There were some positive subthemes showing that people found communication with professionals supportive and informative and that people valued their advice (subthemes 3.A and 3.B – high and moderate quality). However, in contrast to this other people also mentioned that they felt pressured by professionals and felt unsupported (3.E and 3.F – low and moderate quality). The committee discussed this and thought that access to professionals and how welcoming the services are would have a big effect on how supported a person feels and so they recommended that services should be easily accessible and welcoming to everyone particularly people who may have additional support needs (for example people with language or communication difficulties, physical disabilities and such like). Whilst the quality ranged only from low to moderate making reasonable adjustments related to accessibility is a legal duty and therefore the committee made a strong recommendation.

Key information about familial ovarian cancer (information in Tables 1 to 3)

There was some discussion around inclusivity related to the subtheme specifically highlighting people felt that there was insufficient information on male genetic risk (subtheme 1.C – high quality). Whilst men may not realise that the guideline applies to them, trans women and non-binary people with male reproductive organs may not only lack awareness but may also experience other barriers to accessing services. The committee therefore thought that specific information for men, trans women and non-binary people with male reproductive organs should be provided to improve access to services and uptake of testing in these groups.

The committee was expecting themes around information about symptoms of ovarian cancer but no such theme or subtheme was identified. However, they felt that it was important that healthcare professionals provide such information so that the person seeks help when they notice symptoms or signs. They were aware that these were in another guideline and cross referred to the section on awareness of symptoms and signs in the NICE guideline on ovarian cancer for what to look out for (BEAT as in Bloating, feeling full on Eating, Abdominal pain, Toilet changes).

The committee noted that people felt helpless about the availability of services (subtheme 1.H – moderate quality). They discussed that people are not always aware of what services are available to them and what the services do and why they may need to be referred to them. To address these feelings of helplessness the committee recommended that information is provided about pathways for risk assessment and referral to different services. Even though moderate quality the committee agreed that this was strongly recommended because people need to know the reason why they are being referred and what this means for them.

There were subthemes that highlighted emotional factors around feeling pressured (by healthcare professionals or family members – subthemes 1.E and 6.E which were both high quality) as well as feelings of guilt and stigma (subthemes 2.B and 7.B – moderate quality). The committee discussed that this places a psychological burden on the person which could lead to distress and anxiety. They therefore recommended that information and support about psychological factors such as anxiety, and psychological support services should be provided.

There was evidence that people had mixed feelings about support networks, which could be support groups or family members. They reported that they valued support networks where you can share experiences but other people felt that there was a stigma associated with joining support groups and that they felt that this could be a barrier (subthemes, 2.A and 2.B – high and moderate quality). There were also mixed feelings about the impact of the family on decisions. Theme 5 and subthemes related to the importance of family as a source of

information and support (low and high quality). However, there were also feelings of obligation and pressure related to families (subthemes 6.B, 6.C and 6.E – high quality), but it was also mentioned that a culture of openness in families facilitated communication about genetic risk (subtheme 7.H – low quality). The committee agreed that information should be given about relevant support networks and organisations and that they should also ensure that people know that they can bring a family member if they wanted to. Providing this information will give the healthcare professional the opportunity to find out whether the person has feelings of pressure from their families or feel stigma around accessing support networks which can then be addressed. The committee decided information such as this is strongly needed and support organisations are available that people could be sign-posted to and it is a given that people should be made aware that they can bring a family member along, so they made a strong recommendation about this.

Evidence from theme 6 (low and high quality) showed that people came up with their own reasons for and against genetic testing and the committee felt that this may not always be based on knowledge and accurate information. They therefore recommended that in genetic services information needs to be provided about genetic testing (both predictive testing and mutation finding), including details of what genetic testing involves, what the tests mean and how informative they are likely to be, and the likely timescale of getting the results. This will enable the person to make an informed decision. Whilst this is not all based on high quality evidence the committee thought that this is already current practice and an essential part of clinical practice.

One main theme emerging from the evidence was about the impact of genetic testing on the family (theme 6 – low and high quality) and people also wanted more information on how and when to inform family members about genetic risk. The committee agreed that genetic services would be best placed to provide information about the importance of, and how to discuss, the results of assessment and testing with relatives, including different methods of contacting relatives about cascade testing. The committee noted that this is consistent with their experience and that such information is already part of the service that is provided.

There was evidence that people sometimes do not think through the impact of receiving genetic test results (subtheme 7.D – moderate quality). The committee therefore recommended that genetic services provide information about potential next steps depending on the risk assessment so that people feel that they are better prepared for what may happen when they get their results. They made this a strong recommendation because providing this information crucial so that the person can mentally prepare for what is to come.

The committee discussed the evidence that showed that people wanted more information about reproductive choices (subtheme 1.F – moderate quality). The committee agreed that providing this information should be the responsibility of specialist services for people who have a pathogenic variant or likely pathogenic variant. People can then make their reproductive choices taking into account the increased risks associated with their pathogenic variant and the timing of risk-reducing surgery. Whilst this was moderate quality evidence the committee decided that this information is needed because of the choices people face and therefore made a strong recommendation that this should be provided.

The committee noted that there was an entire theme with 4 subthemes as well as another subtheme relating to information about surveillance (main theme 8 – low to high quality - and subtheme 1.A – moderate quality). Whilst the committee acknowledged that more information on this is valued by people, they wanted the content of this information to be based on the effectiveness evidence for surveillance because there are uncertainties about whether or not it is effective (see evidence report K). They therefore did not base the recommendations related to this on the reported qualitative evidence.

Cost effectiveness and resource use

There was no existing economic evidence in this area. Therefore, the committee based the recommendations on qualitative evidence, their knowledge and experience and on existing NICE guidance.

The committee recognised that there is high variation across the NHS in information and support provision to people with familial ovarian cancer. The committee explained that most of the recommendations in this area outline good practice principles and better use of existing information and support services. As a result, some services may have to review how information and support is provided to people at risk of familial ovarian cancer or those with confirmed pathogenic variants and their family members or carers. This may result in additional costs, such as the time required to update existing information and to develop new materials, for example, to target and engage men. However, the committee agreed that these costs are likely to be negligible.

It was also discussed that appropriate and timely information and support could lead to people making more informed healthcare decisions. For example, appropriate information and support at the right time may mean an individual taking up risk reducing surgery, which will substantially reduce their cancer risk and associated healthcare costs.

Some recommendations may require additional healthcare professional time. For example, more time may be required to discuss people's concerns and to enquire about their psychological and emotional issues.

Also, regular discussions of psychological and emotional problems could result in more referrals. However, it was discussed that addressing such problems early on could result in significant benefits to patients and cost savings to the NHS. For example, a lack of psychological support may prevent engagement with care, delay genetic testing or risk-reducing surgery uptake. All of these factors could result in higher overall long-term healthcare costs.

The committee highlighted the limited availability of specialist psychological services in certain regions. They noted that genetic counselling can help alleviate anxiety related to decision-making regarding genetic testing and risk-reducing surgery. However, the committee acknowledged that although genetic counselling may address certain psychological concerns, individuals may still experience ongoing emotional challenges related to their decisions and the impact on their family.

Considering the above, the committee emphasised the importance of a flexible approach that incorporates access to both psychological services and genetic counsellors. Ideally, people with psychological problems would be referred to specialist psychological services designed to deal with psychological issues arising due to genetic testing and risk management.

However, specialist psychological services are only available in certain regions. The committee explained, that where the development of specialist psychological services is still ongoing people could be referred to general psychological services. That is, services providing general mental health support not solely related to, for example, genetic testing and risk management.

The committee also discussed that ensuring access to genetic counselling may help alleviate the potential resource impact of referring people to specialist psychological services since appropriately trained genetic counsellors are equipped to address some of these issues effectively. The committee explained that genetic counselling is current practice in all services.

The committee discussed that only some men are currently accessing and engaging with genetic services. Raising awareness that men can be affected too will potentially mean that more men will access and use, for example, specialist genetics services and support groups.

As a result, there may be more pressure on existing services. However, the committee explained the importance of identifying carrier female relatives of men, as these individuals are at increased cancer risk. Identifying carrier female relatives of men will ensure timely and appropriate care, with potential cost savings to the NHS due to prevented cancers and associated costs.

The committee discussed that offering remote clinics or online appointments would benefit accessibility to services by reducing patients' need to travel to appointments in person. It was noted that most services are already operating a hybrid model of face-to-face and remote clinics and this would not require a reorganisation of services.

The committee also referred to existing NICE guidelines regarding people's experience in adult NHS and social care services, shared decision making and fertility problems. The recommendations related to these guidelines should already be implemented and would not require additional NHS resources.

Other factors the committee took into account

The committee noted that NICE guidance exists on providing information and support (including communication with the person and tailoring information to the person's needs) and so they cross referred to the relevant sections of the NICE's guideline on patient experience in adult NHS services, NICE's guideline on people's experience in adult social care services and NICE's guideline on shared decision making.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.2.1 to 1.2.6 as well as bullet points 3, 6, 9-12 in Table 1, bullet points 3 to 5 in Table 2 and the section on reproductive choices in Table 3 in the NICE guideline.

References – included studies

Qualitative

Battistuzzi 2019

Battistuzzi, Linda, Franiuk, Marzena, Kasparian, Nadine et al. (2019) A qualitative study on decision-making about BRCA1/2 testing in Italian women. European journal of cancer care 28(5): e13083

Brain 2004

Brain, K., Gravell, C., France, E. et al. (2004) An exploratory qualitative study of women's perceptions of risk management options for familial ovarian cancer: Implications for informed decision making. Gynecologic Oncology 92(3): 905-913

Brunstrom 2016

Brunstrom, Kate; Murray, Alexandra; McAllister, Marion (2016) Experiences of Women Who Underwent Predictive BRCA1/2 Mutation Testing Before the Age of 30. Journal of genetic counselling 25(1): 90-100

d'Agincourt-Canning 2006

d'Agincourt-Canning L (2006) Genetic testing for hereditary breast and ovarian cancer: responsibility and choice. Qualitative health research 16(1): 97-118

Dancyger 2010

Dancyger, C., Smith, J.A., Jacobs, C. et al. (2010) Comparing family members motivations and attitudes towards genetic testing for hereditary breast and ovarian cancer: A qualitative analysis. European Journal of Human Genetics 18(12): 1289-1295

Dancyger 2011

Dancyger, Caroline, Wiseman, Mel, Jacobs, Chris et al. (2011) Communicating BRCA1/2 genetic test results within the family: A qualitative analysis. Psychology & Health 26(8): 1018-1035

Fadda 2020

Fadda, Marta, Chappuis, Pierre O, Katapodi, Maria C et al. (2020) Physicians communicating with women at genetic risk of breast and ovarian cancer: Are we in the middle of the ford between contradictory messages and unshared decision making?. PloS one 15(10): e0240054

Foster 2002

Foster, C, Watson, M, Moynihan, C et al. (2002) Genetic testing for breast and ovarian cancer predisposition: cancer burden and responsibility. Journal of Health Psychology 7(4): 469-484

Gaba 2022

Gaba, Faiza, Goyal, Shivam, Marks, Dalya et al. (2022) Surgical decision making in premenopausal BRCA carriers considering risk-reducing early salpingectomy or salpingo-oophorectomy: a qualitative study. Journal of medical genetics 59(2): 122-132

Gleeson 2013

Gleeson, Margaret, Meiser, Bettina, Barlow-Stewart, Kristine et al. (2013) Communication and information needs of women diagnosed with ovarian cancer regarding treatment-focused genetic testing. Oncology nursing forum 40(3): 275-83

Hughes 2010

Hughes, Lisa and Phelps, Ceri (2010) “The bigger the network the bigger the bowl of cherries…”: exploring the acceptability of, and preferences for, an ongoing support network for known BRCA 1 and BRCA 2 mutation carriers. Journal of genet□ention□inging 19(5): 487-96

Jeffers 2014

Jeffers, Lisa, Morrison, Patrick J, McCaughan, Eilis et al. (2014) Maximising survival: the main concern of women with hereditary breast and ovarian cancer who undergo genetic testing for BRCA1/2. European journal of oncology nursing: the official journal of European Oncology Nursing Society 18(4): 411-8

Lifford 2013

Lifford, Kate J, Clements, Alison, Fraser, Lindsay et al. (2013) Catalysts to withdrawal from familial ovarian cancer screening for surgery and reactions to discontinued screening: a qualitative study. Familial cancer 12(1): 19-26

Lim 2004

Lim, Jacqueline, Macluran, Mariette, Price, Melanie et al. (2004) Short- and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. Journal of genetic counceling 13(2): 115-33

Mireskandari 2006

Mireskandari, S., Meiser, B., Sherman, K. et al. (2006) Evaluation of the needs and concerns of partners of women at high risk of developing breast/ovarian cancer. Psycho-Oncology 15(2): 96-108

Ormondroyd 2012

Ormondroyd, Elizabeth, Donnelly, Louise, Moynihan, Clare et al. (2012) Attitudes to reproductive genetic testing in women who had a positive BRCA test before having children: a qualitative analysis. European journal of human genetics: EJHG 20(1): 4-10

Pedrazzani 2022

Pedrazzani, C., Aceti, M., Schweighoffer, R. et al. (2022) The Communication Chain of Genetic Risk: Analyses of Narrative Data Exploring Proband-Provider and Proband-Family Communication in Hereditary Breast and Ovarian Cancer. Journal of Personalized Medicine 12(8): 1249

Ratnayake 2011

Ratnayake, Paboda, Wakefield, Claire E, Meiser, Bettina et al. (2011) An exploration of the communication preferences regarding genetic testing in individuals from families with identified breast/ovarian cancer mutations. Familial cancer 10(1): 97-105

Samson 2014

Samson, A, DiMillo, J, Theriault, A et al. (2014) Living with the BRCA1 and BRCA2 genetic mutation: learning how to adapt to a virtual chronic illness. Psychology, health & medicine 19(1): 103-14

Seenandan-Sookdeo 2016

Seenandan-Sookdeo, Kendra-Ann I, Hack, Thomas F, Lobchuk, Michelle et al. (2016) Parental Decision Making Regarding the Disclosure or Nondisclosure of a Mutation-Positive BRCA1/2 Test Result to Minors. Oncology nursing forum 43(3): 330-41

Shilling 2020

Shilling, V., Catt, S., Jenkins, V. et al. (2020) Using patient perspectives to inform communication training materials for health care professionals discussing BRCA mutation testing. Breast Cancer Research and Treatment 184(2): 491-498

Smits 2016

Smits, S, Boivin, J, Menon, U et al. (2016) The double-edged sword of ovarian cancer information for women at increased risk who have previously taken part in screening. Ecancermedicalscience 10: 650

Wakefield 2011

Wakefield, C.E., Ratnayake, P., Meiser, B. et al. (2011) “For all my family’s sake, I should go and find out”: An Australian report on genet□ention□inging and testing uptake in individuals at high risk of breast and/or ovarian cancer. Genetic Testing and Molecular Biomarkers 15(6): 379-385

Wright 2018

Wright, Sarah, Porteous, Mary, Stirling, Diane et al. (2018) Patie’t'' Views of Treatment-Focused Genetic Testing (TFGT): Some Lessons for the Mainstreaming of BRCA1 and BRCA2 Testing. Journal of genetic counselling

Young 2019

Young, Alison Luk, Butow, Phyllis N, Rhodes, Paul et al. (2019) Talking across generations: Family communication about BRCA1 and BRCA2 genetic cancer risk. Journal of Genetic Counselling 28(3): 516-532

Appendices

Appendix A Review protocol

Review protocol for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42022365282
1.	Review title	Information and support for women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers
2.	Review question	What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?
3.	Objective	To establish the information and support that is valued by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers
4.	Searches	The following databases will be searched: Cochrane Central Register of Controlled Trials (CENTRAL) Cochrane Database of Systematic Reviews (CDSR) Embase MEDLINE PsycINFO CINAHL Epistemonikos Searches will be restricted by: English language Human studies

ID	Field	Content
		The searches will be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion. The full search strategies for MEDLINE database will be published in the final review.
5.	Condition or domain being studied	Familial ovarian cancer
6.	Population	Inclusion: Women who: • carry a pathogenic variant that increases the risk of ovarian cancer, including in genes such as *BRCA1, BRCA2, RAD51C, RAD51D, BRIP1, PALB2, MLH1, MSH2 and MSH6* • have a relative who carries a pathogenic variant that increases the risk of ovarian cancer, including in genes such as *BRCA1, BRCA2, RAD51C, RAD51D, BRIP1, PALB2, MLH1, MSH2 and MSH6* • have a family history of ovarian cancer (with or without a family history of breast cancer) • have a family history or a diagnosis of a syndrome associated with an increased risk of ovarian cancer, for example Lynch syndrome • come from populations with an increased prevalence of pathogenic variants associated with ovarian cancer • have ovarian cancer (with or without breast cancer). Family and carers of people at increased risk Exclusion: • Children and young people under the age of 18
7.	Intervention/Exposure/Test	Not applicable (this is a qualitative review)
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	Systematic reviews of qualitative studies Studies using qualitative methods: semi-structured and structured interviews, focus groups, observations Surveys conducted using open ended questions with qualitative analysis of responses

ID	Field	Content
10.	Other exclusion criteria	Inclusion: Full text papers Exclusion: Conference abstracts Papers that do not include methodological details will not be included as they do not provide sufficient information to evaluate risk of bias/ study quality Surveys using mainly closed questions or which quantify open ended answers for analysis Non-English language articles Studies not published in the following countries: Australia, Canada, Europe, New Zealand and the United Kingdom. Studies with primarily breast or endometrial cancer populations or where it's not clear the cancer type
11.	Context	Included studies will be relevant for developing and improving information and support provided to women with familial ovarian cancer or who are at increased risk of ovarian cancer, and their families and carers, within a healthcare setting.
12.	Phenomenon of interest	Themes will be identified from the literature. Themes considered potentially relevant by the committee include: • Uncertainty about prognosis & risk • Communication about risks with family members • Information about genetic testing process • Information about possible genes involved • Information about when to present (e.g. in high risk patient group) • Healthcare professionals' knowledge of ovarian cancer • When to seek help • Who to contact [e.g. primary cancer team, community team] • Information about types of treatment (decision making) – what's involved and when to start, where treatment is carried out • What happens next after treatment • What's safe/not safe to do • New onset symptoms and who to contact

ID	Field	Content
		• Psychological support and impact, plus anxiety • Type of support
13.	Secondary outcomes (important outcomes)	Not applicable as this is a qualitative review
14.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI reviewer and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will be performed on all records; 90% agreement is required. Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions if relevant, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
15.	Risk of bias (quality) assessment	Quality assessment of individual studies will be performed using the following checklists: CASP checklist for qualitative studies Risk of bias of systematic reviews of Qualitative studies will be assessed using the ROBIS Systematic Review checklist. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
16.	Strategy for data synthesis	Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. A theme map will be developed from the extracted study themes. The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2018) approach will be used to summarise the confidence in qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data.

ID	Field	Content			
		Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Applicability/relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. The more complex the finding, the more detailed the supporting data need to be.			
17.	Analysis of sub-groups	As this is a qualitative review, formal sub group analysis is not appropriate.			
18.	Type and method of review	☐	Intervention		
		☐	Diagnostic		
		☐	Prognostic		
		☒	Qualitative		
		☐	Epidemiologic		
		☐	Service Delivery		
		☐	Other (please specify)		
19.	Language	English			
20.	Country	UK			
21.	Anticipated or actual start date	November 2022			
22.	Anticipated completion date	March 2024			
23.	Stage of review at time of this submission	Review stage		Started	Completed
		Preliminary searches		☑	☑
		Piloting of the study selection process		☑	☑

ID	Field	Content		
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	5a. Named contact Guideline Development Team NGA 5b Named contact e-mail foc@nice.org.uk 5e Organisational affiliation of the review Guideline Development Team NGA, Centre for Guidelines, National Institute for Health and Care Excellence (NICE)		
25.	Review team members	Senior Systematic Reviewer. Guideline Development Team NGA, Centre for Guidelines, National Institute for Health and Care Excellence (NICE) Systematic Reviewer. Guideline Development Team NGA, Centre for Guidelines, National Institute for Health and Care Excellence (NICE)		
26.	Funding sources/sponsor	This systematic review is being completed by the Guideline Development Team NGA, Centre for Guidelines, which receives funding from the National Institute for Health and Care Excellence (NICE).		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with N'C''s code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a mem'e''s declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE		

ID	Field	Content	
		guidelines: the manual. Members of the guideline committee are available on the NICE website: [NICE guideline webpage].	
29.	Other registration details	None	
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=365282	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through N'C''s newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.]	
32.	Keywords	Breast Neoplasms; Caregivers; Female; Genes, BRCA1; Humans; Ovarian Neoplasms	
33.	Details of existing review of same topic by same authors	None	
34.	Current review status	☐	Ongoing
		☐	Completed but not published
		Yes	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	None	
36.	Details of final publication	www.nice.org.uk	

CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimally important difference; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; RoB: risk of bias

Appendix B Literature search strategies

Literature search strategies for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Database: Ovid Medline ALL

Date of last search: 23/01/2023

#	Searches
1	exp Ovarian Neoplasms/
2	(ovar* adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,kf.
3	or/1-2
4	exp Breast Neoplasms/
5	e“p "Neoplasms, Ductal, Lobular, and Medull”ry"/
6	((breast* or mammary) adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or dcis or ductal □ention□inrat* or intraductal* or lobular or medullary or metasta*)).tw,kf.
7	or/4-6
8	3 or 7
9	exp Genetic Predisposition to Disease/
10	Pedigree/
11	exp Neoplastic Syndromes, Hereditary/
12	((hereditary or inherit* or familial) adj3 (nonpolyposis or non polyposis) adj3 (colon or colorectal or bowel) adj3 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,kf.
13	((lynch or Muir Torre) adj2 (syndrome* or cancer*)).tw,kf.
14	HNPCC.tw,kf.
15	(peutz* □ention□itin* polyposis or STK11 or LKB1 or PJS or hLKB1 or (perior* adj1 lentigino*)).tw,kf.
16	((hamartoma* “r "polyps and sp”ts" or cowden*) adj2 (syndrome* or polyp*)).tw,kf.
17	((hereditary or inherit* or familial or adenomato* or attenuated) adj3 polyp* adj3 (coli or colon or colorectal or bowel or rectum □ention□itin* or gastrointestin* or syndrome* or multiple)).tw,kf.
18	gardner* syndrome*.tw,kf.
19	(MUTYH or MYH or FAP or AFAP or APC).tw,kf.
20	((familial or inherit* or heredit* □ention□inpos* or pre dispos* or susceptib* or ancestr* □ention□ilog* or descent) adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,kf.
2“	("hereditary breast and ovarian can”er" or HBOC or Li Fraumeni syndrome or SBLA or LFS).tw,kf.
22	(famil* adj2 histor* adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,kf.
23	risk factors/
24	((risk* or probabil*) adj3 (high* □ention□eas* or factor* or rais*) adj3 (mutat* or malignan* or gene* or variant*)).tw,kf.
25	((carrier* or gene*) adj3 mutat*).tw,kf.
26	exp Genes, Tumor Suppressor/
27	exp Tumor Suppressor Proteins/
28	((tumo?r* or cancer* or metastas?s or growth*) adj2 (suppress* adj1 (gene* or protein*))).tw,kf.
29	(anti oncogene* or antioncogene* or onco suppressor* or oncosuppressor*).tw,kf.
30	exp Fanconi Anemia Complementation Group Proteins/
31	(Fanconi An?emia adj3 protein*).tw,kf.
32	(BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2).tw,kf.
3“	("breast cancer gen” 1" “r "breast cancer gen” 2").tw,kf.

#	Searches
34	Rad51 Recombinase/
35	Ataxia Telangiectasia Mutated Proteins/
36	((Ataxia telangiectasia adj1 mutated adj1 (protein* or kinase*)) or ATM or AT1 or ATA or ATC or ATD or ATDC or ATE or TEL1 or TELO1).tw,kf.
37	Checkpoint Kinase 2/
38	(((checkpoint or check point or serine threonine) adj2 (protein* or kinase*)) or CHEK2 or CDS1 or CHK2 or HuCds1 or LFS2 or PP1425 or RAD53 or hCds1 or hchk2).tw,kf.
39	Carcinoma, Small Cell/ge [Genetics]
40	(small cell adj2 (cancer* or carcinoma*) adj2 gene*).tw,kf.
41	(SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A or SNF2-beta).tw,kf.
42	exp Sertoli-Leydig Cell Tumor/
43	(((Sertoli □entiodig) adj3 (tumo?r* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or andr?oblastoma* or SLCT or gynandroblastoma*).tw,kf.
44	(DICER?? or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 or K12H4?8-LIKE).tw,kf.
45	Epithelial Cell Adhesion Molecule/
46	Epithelial cell adhesion molecule*.tw,kf.
47	(EPCAM* or EP CAM or ESA or KSA or M4S1 or MK-1 or DIAR5 or EGP??? or Ly74 or gp40 or CD326 or GA733?? or GA 733 or KS1?4 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 or MOC-31 or Ber-Ep4 or TACSTD1).tw,kf.
48	or/9-47
49	8 and 48
50	Ovarian Neoplasms/ge [Genetics]
51	49 or 50
52	exp patients/px
53	exp family/px
54	caregivers/px
55	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*) adj6 (experience* or belief* or stress* or emotion* or anx* or fear* or concern* or uncertain* or unsure or thought* or feeling* or felt* or view* or opinion* or perception* or perspective* □ention□tud* or satisfact* or know* or understand* or aware* or sad* or priorit* or preferen* or expectation* or choice*)).ti.
56	stress, psychological/
57	adaptation, psychological/
58	emotions/
59	anxiety/
60	fear/
61	sadness/
62	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or consumer*) adj6 (advis* or advice* or counsel* or educat* or communicat* or informat* or learn* or lesson* or librar* or material* or need* or promot* or resource* or selfhelp* or self-help* or self help or selfcar* or self-car* or self car* or self-manag* or self manag* or support* or teach* or tool* or train* or tutorial*)).ti.
63	consumer behavior/
64	Diary as topic/
65	patient* report* outcome*.ti.
66	Genetic Counseling/
67	patient education handout/
68	patient education as topic/
69	consumer health information/
70	or/52-69
71	exp patients/
72	exp family/
73	caregivers/
74	(patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*).ti.
75	or/71-74

#	Searches
76	Information centers/ or information services/ or information dissemination/
77	libraries/ or library services/
78	health education/
79	Health Knowledge, Attitudes, Practice/
80	needs assessment/
81	learning/
82	decision making/
83	choice behavior/
□ention□inging/	
85	social support/
86	self-help groups/
87	self care/
88	(information* adj3 (available or availability or behavio* or need* or require* or seek* or access* or disseminat* or advis* or advice or counsel* or educat* or communicat* or learn* or material* or resource* or self help* or self car* or manage* or teach* or tool* or support* or train* or tutorial*)).ti.
89	((medical or health or electronic or virtual) adj4 (communicat* or educat* or informat* or learn*)).ti.
90	computer-assisted instruction/
91	exp internet/
92	exp computers, handheld/
93	mobile applications/
94	social networking/ or online social networking/
95	electronic mail/
96	text messaging/
97	hotlines/
98	exp teaching materials/
99	pamphlets/
100	(app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or myspace or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or smartwatch or smart watch or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube*).ti.
101	((mobile* or portable) adj4 application*).ti.
102	(computer* adj4 (handheld or palm top or palmtop or pda or tablet*)).ti.
103	bibliotherapy/
1□ention□ing□yrap*.ti.	
105	((book* or information*) adj2 prescription*).ti.
106	or/76-105
107	75 and 106
108	70 or 107
109	51 and 108
110	animals/ not humans/
111	exp Animals, Laboratory/
112	exp Animal Experimentation/
113	exp Models, Animal/
114	exp Rodentia/
115	(rat or rats or rodent* or mouse or mice).ti.
116	or/110-115
117	109 not 116
118	limit 117 to English language
119	qualitative research/
120	Nursing methodology research/
121	interviews as topic/
122	interview.pt.

#	Searches
123	e“p "Surveys and Questionnai”es"/
124	Narration/
125	health care surveys/
126	(qualitative* or interview* or focus or group* or questionnaire* or narrative* or narration* or survey*).tw.
127	(ethno* or emic or etic □ention□ing□ylog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
128	(hermeneutic* □ention□iger* or husser* or colaizzi* or van kaam* or van manen* □entiorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
129	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
1“0	"critical interpretive synth”s*".tw.
131	(realist adj (review* or synthes*)).tw.
132	(noblit and hare).tw.
133	(meta adj (method or triangulation)).tw.
134	(CERQUAL or CONQUAL).tw.
135	((thematic or framework) adj synthes*).tw.
136	or/119-135
137	118 and 136

Database: Ovid Embase

Date of last search: 23/01/2023

#	Searches
1	exp ovary tumor/
2	(ovar* adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).ti,ab,kf.
3	or/1-2
4	exp breast tumor/
5	((breast* or mammary) adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or dcis or ductal □ention□inrat* or intraductal* or lobular or medullary or metasta*)).ti,ab,kf.
6	or/4-5
7	3 or 6
8	exp genetic predisposition/
9	pedigree/
10	exp hereditary tumor syndrome/
11	((hereditary or inherit* or familial) adj3 (nonpolyposis or non polyposis) adj3 (colon or colorectal or bowel) adj3 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).ti,ab,kf.
12	((lynch or Muir Torre) adj2 (syndrome* or cancer*)).ti,ab,kf.
13	HNPCC.ti,ab,kf.
14	(peutz* □ention□itin* polyposis or STK11 or LKB1 or PJS or hLKB1 or (perior* adj1 lentigino*)).ti,ab,kf.
15	((hamartoma* “r "polyps and sp”ts" or cowden*) adj2 (syndrome* or polyp*)).ti,ab,kf.
16	((hereditary or inherit* or familial or adenomato* or attenuated) adj3 polyp* adj3 (coli or colon or colorectal or bowel or rectum □ention□itin* or gastrointestin* or syndrome* or multiple)).ti,ab,kf.
17	gardner* syndrome*.ti,ab,kf.
18	(MUTYH or MYH or FAP or AFAP or APC).ti,ab,kf.
19	((familial or inherit* or heredit* □ention□inpos* or pre dispos* or susceptib* or ancestr* □ention□ilog* or descent) adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,kf.
20	((hereditary breast and ovarian cancer) or HBOC or Li Fraumeni syndrome or SBLA or LFS).ti,ab,kf.
21	(famil* adj2 histor* adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).ti,ab,kf.
22	risk factor/
23	((risk* or probabil*) adj3 (high* □ention□eas* or factor* or rais*) adj3 (mutat* or malignan* or gene* or variant*)).ti,ab,kf.

#	Searches
24	((carrier* or gene*) adj3 mutat*).ti,ab,kf.
25	tumor suppressor gene/
26	exp tumor suppressor protein/
27	((tumo?r* or cancer* or metastas?s or growth*) adj2 (suppress* adj1 (gene* or protein*))).ti,ab,kf.
28	(anti oncogene* or antioncogene* or onco suppressor* or oncosuppressor*).ti,ab,kf.
29	Fanconi anemia protein/
30	(Fanconi An?emia adj3 protein*).ti,ab,kf.
31	(BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2).ti,ab,kf.
3“	("breast cancer gen” 1" “r "breast cancer gen” 2").ti,ab.
33	Rad51 protein/
34	ATM protein/
35	((Ataxia telangiectasia adj1 mutated adj1 (protein* or kinase*)) or ATM or AT1 or ATA or ATC or ATD or ATDC or ATE or TEL1 or TELO1).ti,ab,kf.
36	checkpoint kinase 2/
37	(((checkpoint or check point or serine threonine) adj2 (protein* or kinase*)) or CHEK2 or CDS1 or CHK2 or HuCds1 or LFS2 or PP1425 or RAD53 or hCds1 or hchk2).ti,ab,kf.
38	small cell carcinoma/
39	genetics/
40	38 and 39
41	(small cell adj2 (cancer* or carcinoma*) adj2 gene*).tw,kf.
42	(SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A or SNF2-beta).tw,kf.
43	androblastoma/ or Sertoli cell tumor/ or Leydig cell tumor/
44	(((Sertoli □entiodig) adj3 (tumo?r* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or andr?oblastoma* or SLCT or gynandroblastoma*).tw,kf.
45	(DICER?? or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 or K12H4?8-LIKE).tw,kf.
46	epithelial cell adhesion molecule/
47	Epithelial cell adhesion molecule*.tw,kf.
48	(EPCAM* or EP CAM or ESA or KSA or M4S1 or MK-1 or DIAR5 or EGP??? or Ly74 or gp40 or CD326 or GA733?? or GA 733 or KS1?4 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 or MOC-31 or Ber-Ep4 or TACSTD1).tw,kf.
49	or/8-37,40-48
50	7 and 49
51	ovary tumor/
52	genetics/
53	51 and 52
54	50 or 53
55	exp *patient/
56	exp *family/
57	*caregiver/
58	exp *parent/
59	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*) adj6 (experience* or belief* or stress* or emotion* or anx* or fear* or concern* or uncertain* or unsure or thought* or feeling* or felt* or view* or opinion* or perception* or perspective* □ention□tud* or satisfact* or know* or understand* or aware* or sad* or priorit* or preferen* or expectation* or choice*)).ti.
60	*physiological stress/
61	*psychological adjustment/
62	*emotion/
63	*anxiety/
64	*fear/
65	*sadness/
66	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or consumer*) adj6 (advis* or advice* or counsel* or educat* or

#	Searches
	communicat* or informat* or learn* or lesson* or librar* or material* or need* or promot* or resource* or selfhelp* or self-help* or self help or selfcar* or self-car* or self car* or self-manag* or self manag* or support* or teach* or tool* or train* or tutorial*)).ti.
67	*consumer attitude/
68	*literature/
69	patient* report* outcome*.ti.
70	*genet□ention□inging/
71	*patient education/
72	*consumer health information/
73	or/55-72
74	exp *patient/
75	exp *family/
76	*caregiver/
77	(patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*).ti.
78	or/74-77
79	*information center/ or *information service/ or *information dissemination/
80	*library/
81	*health education/
82	*attitude to health/
83	*needs assessment/
84	*learning/
85	*decision making/
8□ention□inging/	
87	*social support/
88	*self help/
89	*self care/
90	(information* adj3 (available or availability or behavio* or need* or require* or seek* or access* or disseminat* or advis* or advice or counsel* or educat* or communicat* or learn* or material* or resource* or self help* or self car* or manage* or teach* or tool* or support* or train* or tutorial*)).ti.
91	((medical or health or electronic or virtual) adj4 (communicat* or educat* or informat* or learn*)).ti.
92	*teaching/
93	exp *internet/
94	*personal digital assistant/
95	exp *mobile application/
96	*social network/ or *online social network/
97	*e-mail/
98	*text messaging/
99	*hotline/
100	*publication/
101	(app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or myspace or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or smartwatch or smart watch or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube*).ti.
102	((mobile* or portable) adj4 application*).ti.
103	(computer* adj4 (handheld or palm top or palmtop or pda or tablet*)).ti.
104	*bibliotherapy/
1□ention□ing□yrap*.ti.	
106	((book* or information*) adj2 prescription*).ti.
107	or/79-106
108	78 and 107
109	73 or 108
110	54 and 109

#	Searches
111	animal/ not human/
112	nonhuman/
113	exp Animal Experiment/
114	exp Experimental Animal/
115	animal model/
116	exp Rodent/
117	(rat or rats or rodent* or mouse or mice).ti.
118	or/111-117
119	110 not 118
120	(conference abstract* or conference review or conference paper or conference proceeding).db,pt,su.
121	119 not 120
122	limit 121 to English language
123	qualitative research/
124	nursing methodology research/
125	interview/
126	interview.pt.
127	exp questionnaire/
128	verbal communication/
129	health care survey/
130	(qualitative* or interview* or focus or group* or questionnaire* or narrative* or narration* or survey*).tw.
131	(ethno* or emic or etic □ention□ing□ylog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
132	(hermeneutic* □ention□iger* or husser* or colaizzi* or van kaam* or van manen* □entiorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
133	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
1“4	"critical interpretive synth”s*".tw.
135	(realist adj (review* or synthes*)).tw.
136	(noblit and hare).tw.
137	(meta adj (method or triangulation)).tw.
138	(CERQUAL or CONQUAL).tw.
139	((thematic or framework) adj synthes*).tw.
140	or/123-139
141	122 and 140

Database: Cochrane Database of Systematic Reviews, Issue 1 of 12, January 2023 & Cochrane Central Register of Controlled Trials, Issue 1 of 12, January 2023

Date of last search: 23/01/2023

#	Searches
#1	MeSH descriptor: [Ovarian Neoplasms] explode all trees
#2	(ovar* NEAR/5 (cancer* or neoplas* or carcino* or malignan* or tumor* or tumour* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)):ti,ab,kw
#3	#1 OR #2
#4	MeSH descriptor: [Breast Neoplasms] explode all trees
#5	MeSH descriptor: [Neoplasms, Ductal, Lobular, and Medullary] explode all trees
#6	((breast* or mammary) NEAR/5 (cancer* or neoplas* or carcino* or malignan* or tumor* or tumour* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or dcis or ductal □ention□inrat* or intraductal* or lobular or medullary or metasta*)):ti,ab,kw
#7	{OR #4-#6}
#8	#3 OR #7
#9	MeSH descriptor: [Genetic Predisposition to Disease] explode all trees
#10	MeSH descriptor: [Pedigree] this term only
#11	MeSH descriptor: [Neoplastic Syndromes, Hereditary] explode all trees

#	Searches
#12	((hereditary or inherit* or familial) NEAR/3 (nonpolyposis “r "non polypo”is") NEAR/3 (colon or colorectal or bowel) NEAR/3 (cancer* or neoplas* or carcino* or malignan* or tumor* or tumour* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)):ti,ab,kw
#13	((lynch “r "Muir To”re") NEAR/2 (syndrome* or cancer*)):ti,ab,kw
#14	HNPCC:ti,ab,kw
#15	(peutz* □ention□itin* NEXT polyposis or STK11 or LKB1 or PJS or hLKB1 or (perior* NEAR/1 lentigino*)):ti,ab,kw
#16	((hamartoma* “r "polyps and sp”ts" or cowden*) NEAR/2 (syndrome* or polyp*)):ti,ab,kw
#17	((hereditary or inherit* or familial or adenomato* or attenuated) NEAR/3 polyp* NEAR/3 (coli or colon or colorectal or bowel or rectum □ention□itin* or gastrointestin* or syndrome* or multiple)):ti,ab,kw
#18	gardner* NEXT syndrome*:ti,ab,kw
#19	(MUTYH or MYH or FAP or AFAP or APC):ti,ab,kw
#20	((familial or inherit* or heredit* □ention□inpos* or pre NEXT dispos* or susceptib* or ancestr* □ention□ilog* or descent) NEAR/2 (cancer* or neoplas* or carcino* or malignan* or tumor* or tumour* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)):ti,ab,kw
#2“	("hereditary breast and ovarian can”er" or HBOC “r "Li Fraumeni syndr”me" or SBLA or LFS):ti,ab,kw
#22	(famil* NEAR/2 histor* NEAR/2 (cancer* or neoplas* or carcino* or malignan* or tumor* or tumour* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)):ti,ab,kw
#23	MeSH descriptor: [Risk Factors] this term only
#24	((risk* or probabil*) NEAR/3 (high* □ention□eas* or factor* or rais*) NEAR/3 (mutat* or malignan* or gene* or variant*)):ti,ab,kw
#25	((carrier* or gene*) NEAR/3 mutat*):ti,ab,kw
#26	MeSH descriptor: [Genes, Tumor Suppressor] explode all trees
#27	MeSH descriptor: [Tumor Suppressor Proteins] explode all trees
#28	((tumor* or tumour* or cancer* or metastasis or metastases or growth*) NEAR/2 (suppress* NEAR/1 (gene* or protein*))):ti,ab,kw
#29	(anti NEXT oncogene* or antioncogene* or onco NEXT suppressor* or oncosuppressor*):ti,ab,kw
#30	MeSH descriptor: [Fanconi Anemia Complementation Group Proteins] explode all trees
#31“(("Fanconi Ane”ia" “□entiononi anae”ia") NEAR/3 protein*):ti,ab,kw	
#32	(BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2):ti,ab,kw
#3“	("breast cancer gen” 1" “r "breast cancer gen” 2"):ti,ab,kw
#34	MeSH descriptor: [Rad51 Recombinase] this term only
#35	MeSH descriptor: [Ataxia Telangiectasia Mutated Proteins] this term only
#36“(("Ataxia telangiecta”ia" NEAR/1 mutated NEAR/1 (protein* or kinase*)) or ATM or AT1 or ATA or ATC or ATD or ATDC or ATE or TEL1 or TELO1):ti,ab,kw	
#37	MeSH descriptor: [Checkpoint Kinase 2] this term only
#38	(((checkpoint “r "check po”nt" “r "serine threon”ne") NEAR/2 (protein* or kinase*)) or CHEK2 or CDS1 or CHK2 or HuCds1 or LFS2 or PP1425 or RAD53 or hCds1 or hchk2):ti,ab,kw
#39	MeSH descriptor: [Carcinoma, Small Cell] this term only and with qualifier(s): [geneti–s - GE]
#4“	("small c”ll" NEAR/2 (cancer* or carcinoma*) NEAR/2 gene*):ti,ab,kw
#41	(SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A “r "SNF2 b”ta"):ti,ab,kw
#42	MeSH descriptor: [Sertoli-Leydig Cell Tumor] explode all trees
#43	(((Sertoli □entiodig) NEAR/3 (tumor* or tumour* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or androblastoma* or andreoblastoma* or SLCT or gynandroblastoma*):ti,ab,kw
#44	(DICER* or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 “r "K12H48 L”KE"):ti,ab,kw
#45	MeSH descriptor: [Epithelial Cell Adhesion Molecule] this term only
#46	Epithelial cell adhesion NEXT molecule*:ti,ab,kw
#47	(EPCAM* “r "EP ”AM" or ESA or KSA or M4S1 “r "M” 1" or DIAR5 or EGP* or Ly74 or gp40 or CD326 or GA733* or GA 733 or KS14 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 “r "MOC”31" “r "Ber ”p4" or TACSTD1):ti,ab,kw
#48	{OR #9-#47}
#49	#8 AND #48
#50	MeSH descriptor: [Ovarian Neoplasms] this term only and with qualifier(s): [geneti–s - GE]
#51	#49 OR #50
#52	MeSH descriptor: [Patients] explode all trees and with qualifier(s): [psycholo–y - PX]

#	Searches
#53	MeSH descriptor: [Family] explode all trees and with qualifier(s): [psycholo–y - PX]
#54	MeSH descriptor: [Caregivers] explode all trees and with qualifier(s): [psycholo–y - PX]
#55	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*) NEAR/6 (experience* or belief* or stress* or emotion* or anx* or fear* or concern* or uncertain* or unsure or thought* or feeling* or felt* or view* or opinion* or perception* or perspective* □ention□tud* or satisfact* or know* or understand* or aware* or sad* or priorit* or preferen* or expectation* or choice*)):ti
#56	MeSH descriptor: [Stress, Psychological] this term only
#57	MeSH descriptor: [Adaptation, Psychological] this term only
#58	MeSH descriptor: [Emotions] this term only
#59	MeSH descriptor: [Anxiety] this term only
#60	MeSH descriptor: [Fear] this term only
#61	MeSH descriptor: [Sadness] this term only
#62	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or consumer*) NEAR/6 (advis* or advice* or counsel* or educat* or communicat* or informat* or learn* or lesson* or librar* or material* or need* or promot* or resource* or selfhelp* or self-help* or self NEXT help* or selfcar* or self-car* or self NEXT car* or self-manag* or self NEXT manag* or support* or teach* or tool* or train* or tutorial*)):ti
#63	MeSH descriptor: [Consumer Behavior] this term only
#64	MeSH descriptor: [Diaries as Topic] this term only
#65	patient* NEXT report* NEXT outcome*:ti
#66	MeSH descriptor: [Genetic Counseling] this term only
#67	MeSH descriptor: [Patient Education Handout] this term only
#68	MeSH descriptor: [Patient Education as Topic] this term only
#69	MeSH descriptor: [Consumer Health Information] this term only
#70	{OR #52-#69}
#71	MeSH descriptor: [Patients] explode all trees
#72	MeSH descriptor: [Family] explode all trees
#73	MeSH descriptor: [Caregivers] this term only
#74	(patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*):ti
#75	{OR #71-#74}
#76	MeSH descriptor: [Information Centers] this term only
#77	MeSH descriptor: [Information Services] this term only
#78	MeSH descriptor: [Information Dissemination] this term only
#79	MeSH descriptor: [Libraries] this term only
#80	MeSH descriptor: [Library Services] this term only
#81	MeSH descriptor: [Health Education] this term only
#82	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#83	MeSH descriptor: [Needs Assessment] this term only
#84	MeSH descriptor: [Learning] this term only
#85	MeSH descriptor: [Decision Making] this term only
#86	MeSH descriptor: [Choice Behavior] this term only
#87	MeSH descriptor: [Counseling] this term only
#88	MeSH descriptor: [Social Support] this term only
#89	MeSH descriptor: [Self-Help Groups] this term only
#90	MeSH descriptor: [Self Care] this term only
#91	(information* NEAR/3 (available or availability or behavio* or need* or require* or seek* or access* or disseminat* or advis* or advice or counsel* or educat* or communicat* or learn* or material* or resource* or self help* or self car* or manage* or teach* or tool* or support* or train* or tutorial*)):ti
#92	((medical or health or electronic or virtual) NEAR/4 (communicat* or educat* or informat* or learn*)):ti
#93	MeSH descriptor: [Computer-Assisted Instruction] this term only
#94	MeSH descriptor: [Internet] explode all trees
#95	MeSH descriptor: [Computers, Handheld] explode all trees
#96	MeSH descriptor: [Mobile Applications] this term only

#	Searches
#97	MeSH descriptor: [Social Networking] this term only
#98	MeSH descriptor: [Online Social Networking] this term only
#99	MeSH descriptor: [Electronic Mail] this term only
#100	MeSH descriptor: [Text Messaging] this term only
#101	MeSH descriptor: [Hotlines] this term only
#102	MeSH descriptor: [Teaching Materials] explode all trees
#103	MeSH descriptor: [Pamphlets] this term only
#104	(app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e NEXT mail* or facebook or facetime “r "face t”me" or forum* or handout* or hand-out* or hand NEXT out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or myspace or online or magazine* or mobile NEXT phone* or newsletter* or pamphlet* or palm NEXT pilot* or personal NEXT digital NEXT assistant* or pocket NEXT pc* or podcast* or poster or posters or skype* or smartphone* or smart NEXT phone* or smartwatch* or smart NEXT watch* “r "social me”ia" or social NEXT network* or sms or text NEXT messag* or twitter or tweet* or video* or web* or wiki* or youtube*):ti
#105	((mobile* or portable) NEAR/4 application*):ti
#106	(computer* NEAR/4 (handheld “r "palm ”op" or palmtop or pda or tablet*)):ti
#107	MeSH descriptor: [Bibliotherapy] this term only
#1□ention□ing□yrap*:ti	
#109	((book* or information*) NEAR/2 prescription*):ti
#110	{OR #76-#109}
#111	#75 AND #110
#112	#70 OR #111
#113	#51 AND #112
#114	conference:pt or (clinicaltrials or trialsearch):so
#115	#113 NOT #114

Database: CINAHL (The Cumulative Index to Nursing and Allied Health Literature)

Date of last search: 23/01/2023

#	Searches
S106	S44 AND S104 Limite–s - English Language; Human
S105	S44 AND S104
S104	S64 OR S103
S103	S69 AND S102
S102	S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99 OR S100 OR S101
S101	TI ((book* OR information*) N2 prescription*)
S100	□ention□ing□yrap*
S99	(“H "Bibliother”py")
S98	TI (computer* N4 (handheld OR palm top OR palmtop OR pda OR tablet*))
S97	TI ((mobile* OR portable) N4 application*)
S96	TI (app OR apps OR blog* OR booklet* OR brochure* OR dvd* OR elearn* OR e-learn* OR email* OR e-mail* OR e mail* OR facebook OR facetime OR face time OR forum* OR handout* OR hand-out* OR hand out* OR helpline* OR hotline* OR internet* OR ipad* OR iphone* OR leaflet* OR myspace OR online OR magazine* OR mobile phone* OR newsletter* OR pamphlet* OR palm pilot* OR personal digital assistant* OR pocket pc* OR podcast* OR poster? OR skype* OR smartphone* OR smart phone* OR smartwatch OR smart watch OR social media OR social network* OR sms OR text messag* OR twitter OR tweet* OR video* OR web* OR wiki* OR youtube*)
S95	(“H "Pamphl”ts")
S94	(“H "Teaching Materia”s+")
S93	(“H "Telephone Information Servi”es")
S92	(“H "Text Messag”ng")
S91	(“H "Em”il")
S90	(“H "Online Social Network”ng") OR (“H "Social Network”ng")
S89	(“H "Mobile Applicati”ns")
S88	(“H "Computers, Hand-He”d+")

#	Searches
S87	(“H "Intern”t+")
S86	(“H "Computer Assisted Instruct”on")
S85	TI ((medical OR health OR electronic OR virtual) N4 (communicat* OR educat* OR informat* OR learn*))
S84	TI (information* N3 (available OR availability OR behavio* OR need* OR require* OR seek* OR access* OR disseminat* OR advis* OR advice OR counsel* OR educat* OR communicat* OR learn* OR material* OR resource* OR self help* OR self car* OR manage* OR teach* OR tool* OR support* OR train* OR tutorial*))
S83	(“H "Self C”re")
S82	(“H "Support Gro”ps")
S81	(“H "Support, Soc”al")
S80	(“H "Counsel”ng")
S79	(“H "Decision Mak”ng")
S78	(“H "Learn”ng")
S77	(“H "Needs Assessm”nt")
S76	(“H "Health Knowle”ge")
S75	(“H "Health Educat”on")
S74	(“H "Library Servi”es")
S73	(“H "Librar”es")
S72	(“H "Selective Dissemination of Informat”on")
S71	(“H "Information Servi”es")
S70	(“H "Information Cent”rs")
S69	S65 OR S66 OR S67 OR S68
S68	TI (patient* OR parent* OR famil* OR relative* OR carer* OR caregiver* OR care-giver* OR inpatient* OR in-patient* OR spous* OR husband* OR wife* OR wive* OR partner* OR mother* OR father* OR sibling* OR sister* OR brother*)
S67	(“H "Caregiv”rs")
S66	(“H "Fami”y+")
S65	(“H "Patien”s+")
S64	S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63
S63	(“H "Consumer Health Informat”on")
S62	(“H "Patient Educat”on")
S61	(“H "Genetic Counsel”ng")
S60	TI patient* report* outcome*
S59	(“H "Diar”es")
S58	(“H "Consumer Attitu”es")
S57	TI ((patient* OR parent* OR famil* OR relative* OR carer* OR caregiver* OR care-giver* OR inpatient* OR in-patient* OR spous* OR husband* OR wife* OR wive* OR partner* OR mother* OR consumer*) N6 (advis* OR advice* OR counsel* OR educat* OR communicat* OR informat* OR learn* OR lesson* OR librar* OR material* OR need* OR promot* OR resource* OR selfhelp* OR self-help* OR self help OR selfcar* OR self-car* OR self car* OR self-manag* OR self manag* OR support* OR teach* OR tool* OR train* OR tutorial*))
S56	(“H "Sadn”ss")
S55	(“H "F”ar")
S54	(“H "Anxi”ty")
S53	(“H "Emoti”ns")
S52	(“H "Adaptation, Psychologi”al")
S51	(“H "Stress, Psychologi”al")
S50	TI ((patient* OR parent* OR famil* OR relative* OR carer* OR caregiver* OR care-giver* OR inpatient* OR in-patient* OR spous* OR husband* OR wife* OR wive* OR partner* OR mother* OR father* OR sibling* OR sister* OR brother*) N6 (experience* OR belief* OR stress* OR emotion* OR anx* OR fear* OR concern* OR uncertain* OR unsure OR thought* OR feeling* OR felt* OR view* OR opinion* OR perception* OR perspective* □ention□tud* OR satisfact* OR know* OR understand* OR aware* OR sad* OR priorit* OR preferen* OR expectation* OR choice*))
S49	(“H "Caregivers”PF")
S48	(“H "Family+”PF")
S47	(“H "Patients+”PF")
S46	S44 OR S45

#	Searches
S45	(“H "Ovarian Neoplasms”FG")
S44	S8 AND S43
S43	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42
S42	TI ((EPCAM* or EP CAM or ESA or KSA or M4S1 or MK-1 or DIAR5 or EGP??? or Ly74 or gp40 or CD326 or GA733?? or GA 733 or KS1?4 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 or MOC-31 or Ber-Ep4 or TACSTD1)) OR AB ((EPCAM* or EP CAM or ESA or KSA or M4S1 or MK-1 or DIAR5 or EGP??? or Ly74 or gp40 or CD326 or GA733?? or GA 733 or KS1?4 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 or MOC-31 or Ber-Ep4 or TACSTD1))
S41	TI Epithelial cell adhesion molecule* OR AB Epithelial cell adhesion molecule*
S40	TI ((DICER?? or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 or K12H4?8-LIKE)) OR AB ((DICER?? or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 or K12H4?8-LIKE))
S39	TI ((((Sertoli □entiodig) N3 (tumo?r* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or andr?oblastoma* or SLCT or gynandroblastoma*)) OR AB ((((Sertoli □entiodig) N3 (tumo?r* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or andr?oblastoma* or SLCT or gynandroblastoma*))
S38	TI ((SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A or SNF2-beta)) OR AB ((SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A or SNF2-beta))
S37	TI ((small cell N2 (cancer* or carcinoma*) N2 gene*)) OR AB ((small cell N2 (cancer* or carcinoma*) N2 gene*))
S36	(“H "Carcinoma, Small Cell”FG")
S35	TI ((((checkpoint OR check point OR serine threonine) N2 (protein* OR kinase*)) OR CHEK2 OR CDS1 OR CHK2 OR HuCds1 OR LFS2 OR PP1425 OR RAD53 OR hCds1 OR hchk2)) OR AB ((((checkpoint OR check point OR serine threonine) N2 (protein* OR kinase*)) OR CHEK2 OR CDS1 OR CHK2 OR HuCds1 OR LFS2 OR PP1425 OR RAD53 OR hCds1 OR hchk2))
S34	TI (((Ataxia telangiectasia N1 mutated N1 (protein* OR kinase*)) OR ATM OR AT1 OR ATA OR ATC OR ATD OR ATDC OR ATE OR TEL1 OR TELO1)) OR AB (((Ataxia telangiectasia N1 mutated N1 (protein* OR kinase*)) OR ATM OR AT1 OR ATA OR ATC OR ATD OR ATDC OR ATE OR TEL1 OR TELO1))
S33	(“H "Ataxia Telangiecta”ia")
S32	TI “ ("breast cancer gen” 1" “R "breast cancer gen” 2")) OR AB “ ("breast cancer gen” 1" “R "breast cancer gen” 2"))
S31	TI ((BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2)) OR AB ((BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2))
S30	TI (Fanconi An?emia N3 protein*) OR AB (Fanconi An?emia N3 protein*)
S29	(“H "Fanconi Syndr”me")
S28	TI ((anti oncogene* OR antioncogene* OR onco suppressor* OR oncosuppressor*)) OR AB ((anti oncogene* OR antioncogene* OR onco suppressor* OR oncosuppressor*))
S27	TI (((tumo?r* OR cancer* OR metastas?s OR growth*) N2 (suppress* N1 (gene* OR protein*)))) OR AB (((tumo?r* OR cancer* OR metastas?s OR growth*) N2 (suppress* N1 (gene* OR protein*))))
S26	(“H "Genes, Tumor Suppres”or")
S25	TI (((carrier* OR gene*) N3 mutat*)) OR AB (((carrier* OR gene*) N3 mutat*))
S24	TI (((risk* OR probabil*) N3 (high* □ention□eas* OR factor* OR rais*) N3 (mutat* OR malignan* OR gene* OR variant*))) OR AB (((risk* OR probabil*) N3 (high* □ention□eas* OR factor* OR rais*) N3 (mutat* OR malignan* OR gene* OR variant*)))
S23	(“H "Risk Fact”rs")
S22	TI ((famil* N2 histor* N2 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR metasta*))) OR AB ((famil* N2 histor* N2 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR metasta*)))
S21	TI “ ("hereditary breast AND ovarian can”er" OR HBOC OR Li Fraumeni syndrome OR SBLA OR LFS)) OR AB “ ("hereditary breast AND ovarian can”er" OR HBOC OR Li Fraumeni syndrome OR SBLA OR LFS))
S20	TI (((familial or inherit* or heredit* □ention□inpos* or pre dispos* or susceptib* or ancestr* □ention□ilog* or descent) N2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*))) OR AB (((familial or inherit* or heredit* □ention□inpos* or pre dispos* or susceptib* or ancestr* □ention□ilog* or descent) N2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)))
S19	TI ((MUTYH OR MYH OR FAP OR AFAP OR APC)) OR AB ((MUTYH OR MYH OR FAP OR AFAP OR APC))

#	Searches
S18	TI gardner* syndrome* OR AB gardner* syndrome*
S17	TI (((hereditary OR inherit* OR familial OR adenomato* OR attenuated) N3 polyp* N3 (coli OR colon OR colorectal OR bowel OR rectum □ention□itin* OR gastrointestin* OR syndrome* OR multiple))) OR AB (((hereditary OR inherit* OR familial OR adenomato* OR attenuated) N3 polyp* N3 (coli OR colon OR colorectal OR bowel OR rectum □ention□itin* OR gastrointestin* OR syndrome* OR multiple)))
S16	TI (((hamartoma* “R "polyps AND sp”ts" OR cowden*) N2 (syndrome* OR polyp*))) OR AB (((hamartoma* “R "polyps AND sp”ts" OR cowden*) N2 (syndrome* OR polyp*)))
S15	(“H "Pedig”ee")
S14	TI ((peutz* □ention□itin* polyposis OR STK11 OR LKB1 OR PJS OR hLKB1 OR (perior* N1 lentigino*))) OR AB ((peutz* □ention□itin* polyposis OR STK11 OR LKB1 OR PJS OR hLKB1 OR (perior* N1 lentigino*)))
S13	TI HNPCC OR AB HNPCC
S12	TI (((lynch “R "Muir To”re") N2 (syndrome* OR cancer*))) OR AB (((lynch “R "Muir To”re") N2 (syndrome* OR cancer*)))
S11	TI (((hereditary OR inherit* OR familial) N3 (nonpolyposis OR non polyposis) N3 (colon OR colorectal OR bowel) N3 (cancer* OR (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*))) OR AB (((hereditary OR inherit* OR familial) N3 (nonpolyposis OR non polyposis) N3 (colon OR colorectal OR bowel) N3 (cancer* OR (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)))
S10	(“H "Neoplastic Syndromes, Heredita”y+")
S9	(“H "Hereditary Disea”es")
S8	S3 OR S7
S7	S4 OR S5 OR S6
S6	TI (((breast* OR mammary) N5 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR dcis OR ductal □ention□inrat* OR intraductal* OR lobular OR medullary OR metasta*))) OR AB (((breast* OR mammary) N5 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR dcis OR ductal □ention□inrat* OR intraductal* OR lobular OR medullary OR metasta*)))
S5	(“H "Neoplasms, Ductal, Lobular, and Medulla”y+")
S4	(“H "Breast Neoplas”s+")
S3	S1 OR S2
S2	TI ((ovar* N5 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR metasta*))) OR AB ((ovar* N5 (cancer* OR neoplas* OR carcino* OR malignan* OR tumo?r* OR adenocarcinoma* OR sarcoma* OR angiosarcoma* OR lymphoma* OR leiomyosarcoma* OR metasta*)))
S1	(“H "Ovarian Neoplas”s+")

Database: Ovid PsycINFO

Date of last search: 23/01/2023

#	Searches
1	ovaries/
2	exp neoplasms/
3	1 and 2
4	(ovar* adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,id.
5	3 or 4
6	exp Breast Neoplasms/
7	((breast* or mammary) adj5 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or dcis or ductal □ention□inrat* or intraductal* or lobular or medullary or metasta*)).tw,id.
8	6 or 7
9	5 or 8
10	exp genetic disorders/
11	((hereditary or inherit* or familial) adj3 (nonpolyposis or non polyposis) adj3 (colon or colorectal or bowel) adj3 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,id.
12	((lynch or Muir Torre) adj2 (syndrome* or cancer*)).tw,id.

#	Searches
13	HNPCC.tw,id.
14	(peutz* □ention□itin* polyposis or STK11 or LKB1 or PJS or hLKB1 or (perior* adj1 lentigino*)).tw,id.
15	((hamartoma* “r "polyps and sp”ts" or cowden*) adj2 (syndrome* or polyp*)).tw,id.
16	((hereditary or inherit* or familial or adenomato* or attenuated) adj3 polyp* adj3 (coli or colon or colorectal or bowel or rectum □ention□itin* or gastrointestin* or syndrome* or multiple)).tw,id.
17	gardner* syndrome*.tw,id.
18	(MUTYH or MYH or FAP or AFAP or APC).tw,id.
19	((familial or inherit* or heredit* □ention□inpos* or pre dispos* or susceptib* or ancestr* □ention□ilog* or descent) adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,id.
2“	("hereditary breast and ovarian can”er" or HBOC or Li Fraumeni syndrome or SBLA or LFS).tw,id.
21	(famil* adj2 histor* adj2 (cancer* or neoplas* or carcino* or malignan* or tumo?r* or adenocarcinoma* or sarcoma* or angiosarcoma* or lymphoma* or leiomyosarcoma* or metasta*)).tw,id.
22	Risk Factors/
23	((risk* or probabil*) adj3 (high* □ention□eas* or factor* or rais*) adj3 (mutat* or malignan* or gene* or variant*)).tw,id.
24	((carrier* or gene*) adj3 mutat*).tw,id.
25	((tumo?r* or cancer* or metastas?s or growth*) adj2 (suppress* adj1 (gene* or protein*))).tw,id.
26	(anti oncogene* or antioncogene* or onco suppressor* or oncosuppressor*).tw,id.
27	(Fanconi An?emia adj3 protein*).tw,id.
28	(BRCA* or IRIS or PSCP or BRCC1 or BRIP1 or BACH1 or FANC* or PNCA* or RNF53 or PPP1R53 or FAD* or FACD or GLM3 or BRCC2 or XRCC11 or TP53 or P53 or PALB2 or RAD51* or R51H3 or BROVCA* or TRAD or BARD1 or MLH1 or MSH2 or MSH6 or PMS2).tw,id.
2“	("breast cancer gen” 1" “r "breast cancer gen” 2").tw,id.
30	((Ataxia telangiectasia adj1 mutated adj1 (protein* or kinase*)) or ATM or AT1 or ATA or ATC or ATD or ATDC or ATE or TEL1 or TELO1).tw,id.
31	(((checkpoint or check point or serine threonine) adj2 (protein* or kinase*)) or CHEK2 or CDS1 or CHK2 or HuCds1 or LFS2 or PP1425 or RAD53 or hCds1 or hchk2).tw,id.
32	(small cell adj2 (cancer* or carcinoma*) adj2 gene*).tw,id.
33	(SMARCA4 or BRG1 or CSS4 or SNF2 or SWI2 or MRD16 or RTPS2 or BAF190 or SNF2L4 or SNF2LB or hSNF2b or BAF190A or SNF2-beta).tw,id.
34	(((Sertoli □entiodig) adj3 (tumo?r* or adenoma* or cancer* or carcinoma* or neoplas* or metasta*)) or arrhenoblastoma* or andr?oblastoma* or SLCT or gynandroblastoma*).tw,id.
35	(DICER?? or DCR1 or GLOW or MNG1 or aviD or HERNA or RMSE2 or K12H4?8-LIKE).tw,id.
36	Epithelial cell adhesion molecule*.tw,id.
37	(EPCAM* or EP CAM or ESA or KSA or M4S1 or MK-1 or DIAR5 or EGP??? or Ly74 or gp40 or CD326 or GA733?? or GA 733 or KS1?4 or MIC18 or TROP1 or BerEp4 or HNPCC8 or LYNCH8 or MOC-31 or Ber-Ep4 or TACSTD1).tw,id.
38	or/10-37
39	9 and 38
40	exp patients/
41	exp Family/
42	caregivers/
43	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*) adj6 (experience* or belief* or stress* or emotion* or anx* or fear* or concern* or uncertain* or unsure or thought* or feeling* or felt* or view* or opinion* or perception* or perspective* □ention□tud* or satisfact* or know* or understand* or aware* or sad* or priorit* or preferen* or expectation* or choice*)).ti.
44	Psychological Stress/
45	adjustment/
46	Emotions/
47	Anxiety/
48	Fear/
49	Sadness/
50	((patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or consumer*) adj6 (advis* or advice* or counsel* or educat* or communicat* or informat* or learn* or lesson* or librar* or material* or need* or promot* or resource* or selfhelp* or

#	Searches
	self-help* or self help or selfcar* or self-car* or self car* or self-manag* or self manag* or support* or teach* or tool* or train* or tutorial*)).ti.
51	Consumer Behavior/
52	journal writing/
53	patient* report* outcome*.ti.
54	Genetic Counseling/
55	client education/
56	health information/
57	or/40-56
58	exp Patients/
59	exp Family/
60	Caregivers/
61	(patient* or parent* or famil* or relative* or carer* or caregiver* or care-giver* or inpatient* or in-patient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*).ti.
62	or/58-61
63	Information Services/
64	Information Dissemination/
65	Libraries/
66	Health Education/
67	Health Knowledge/
68	Needs Assessment/
69	Learning/
70	Decision Making/
71	Choice Behavior/
72	Counseling/
73	Social Support/
74	Support Groups/
75	Self-Care/
76	(information* adj3 (available or availability or behavio* or need* or require* or seek* or access* or disseminat* or advis* or advice or counsel* or educat* or communicat* or learn* or material* or resource* or self help* or self car* or manage* or teach* or tool* or support* or train* or tutorial*)).ti.
77	((medical or health or electronic or virtual) adj4 (communicat* or educat* or informat* or learn*)).ti.
78	Computer Assisted Instruction/
79	exp Internet/
80	exp mobile devices/
81	mobile applications/
82	Social Networks/ or Online Social Networks/
83	Electronic Communication/
84	Text Messaging/
85	Hot Line Services/
86	exp instructional media/
87	(app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or myspace or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or smartwatch or smart watch or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube*).ti.
88	((mobile* or portable) adj4 application*).ti.
89	(computer* adj4 (handheld or palm top or palmtop or pda or tablet*)).ti.
90	Bibliotherapy/
□ention□ing□yrap*.ti.	
92	((book* or information*) adj2 prescription*).ti.
93	or/63-92
94	62 and 93
95	57 or 94

#	Searches
96	39 and 95
97	animal.po.
98	(rat or rats or rodent* or mouse or mice).ti.
99	or/97-98
100	96 not 99
101	limit 100 to English language
1“2	"EXPERIENCES (EVEN”S)"/ or INTERVIEWERS/ or INTERVIEWING/ or INTERVIEWS/ or NARRATIVES/ or PHENOMENOLOGY/ or QUALITATIVE METHODS/ or QUESTIONNAIRES/ or QUESTIONING/ or exp SURVEYS/
103	(qualitative* or interview* or focus or group* or questionnaire* or narrative* or narration* or survey*).tw.
104	(ethno* or emic or etic □ention□ing□ylog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
105	(hermeneutic* □ention□iger* or husser* or colaizzi* or van kaam* or van manen* □entiorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
106	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
1“7	"critical interpretive synth”s*".tw.
108	(realist adj (review* or synthes*)).tw.
109	(noblit and hare).tw.
110	(meta adj (method or triangulation)).tw.
111	(CERQUAL or CONQUAL).tw.
112	((thematic or framework) adj synthes*).tw.
113	or/102-112
114	101 and 113

Database: Epistemonikos

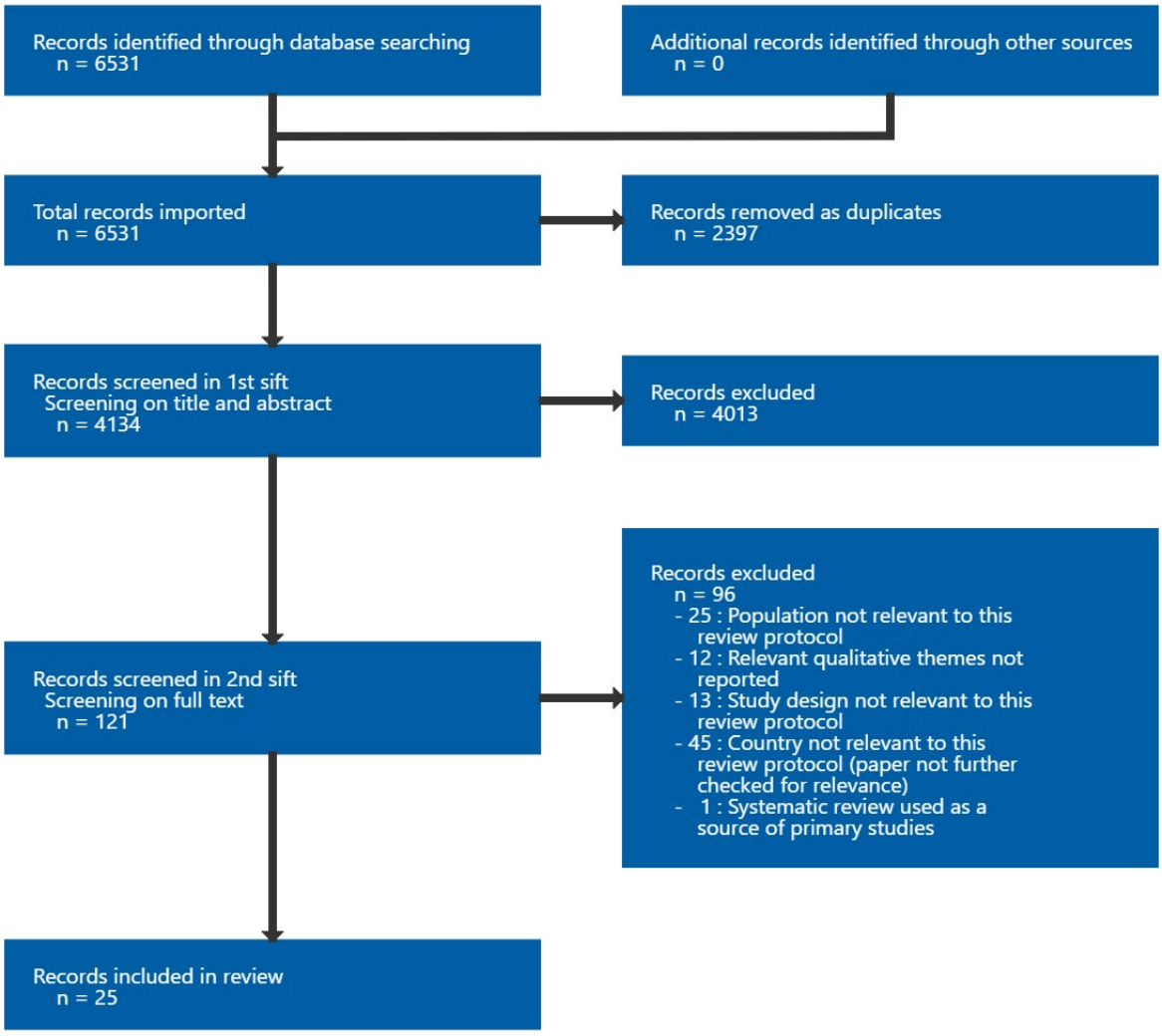
Date of last search: 23/01/2023

#	Searches
1	(advanced_title_en:(((ovarian OR breast) AND (familial OR hered*) AND cancer)) OR advanced_abstract_en:(((ovarian OR breast) AND (familial OR hered*) AND cancer)))
2	(advanced_title_en:((advis* OR advice* OR counsel* OR educat* OR communicat* OR informat* OR learn* OR lesson* OR need* OR promot* OR resource* OR selfhelp* OR self-help* OR self help OR selfcar* OR self-car* OR self car* OR self-manag* OR self manag* OR support* OR teach* OR experience* OR belief* OR stress* OR emotion* OR anx* OR fear* OR concern* OR uncertain* OR unsure OR thought* OR feeling* OR felt* OR view* OR opinion* OR perception* OR perspective* □ention□tud* OR satisfact* OR know* OR understand* OR aware* OR sad* OR priorit* OR preferen* OR expectation* OR choice*)) OR advanced_abstract_en:((advis* OR advice* OR counsel* OR educat* OR communicat* OR informat* OR learn* OR lesson* OR need* OR promot* OR resource* OR selfhelp* OR self-help* OR self help OR selfcar* OR self-car* OR self car* OR self-manag* OR self manag* OR support* OR teach* OR experience* OR belief* OR stress* OR emotion* OR anx* OR fear* OR concern* OR uncertain* OR unsure OR thought* OR feeling* OR felt* OR view* OR opinion* OR perception* OR perspective* □ention□tud* OR satisfact* OR know* OR understand* OR aware* OR sad* OR priorit* OR preferen* OR expectation* OR choice*))
3	1 AND 2
4	(advanced_title_en:((qualitative* OR interview* OR focus OR group* OR questionnaire* OR narrative* OR narration* OR survey*)) OR advanced_abstract_en:((qualitative* OR interview* OR focus OR group* OR questionnaire* OR narrative* OR narration* OR survey*))
5	3 AND 4
	[Filters: protocol=no]

Appendix C Qualitative evidence study selection

Study selection for: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Battistuzzi, 2019

Bibliographic Reference	Battistuzzi, Linda; Franiuk, Marzena; Kasparian, Nadine; Rania, Nadia; Migliorini, Laura; Varesco, Liliana; A qualitative study on decision-making about BRCA1/2 testing in Italian women.; European journal of cancer care; 2019; vol. 28 (no. 5); e13083

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Italy
Setting	Women with a strong family history but no personal history of cancer who had had clinical BRCA1/2 testing
Data collection and analysis	Semi-structured interviews face-to-face with women. The interview guide developed from the literature and expert consultation, with phrasing and order of questions left open. Probes used when appropriate. Interviews were audio-recorded and transcribed verbatim. Questions covered: reasons for having genetic testing; personal reactions to test results; decision to share or not to share information learned during genetic counselling with relatives and friends; feeling of being treated differently after test results; changes or difficulties in relationships with significant others; concerns about having passed on a pathogenic variant to offspring; preventive and risk management strategies adopted following receiving the result; and perceived personal control and planning for the future. Informational saturation was reached. Interviews were analysed using an inductive theoretical framework, with the thematic analysis aiming to reflect participants' views and experiences. All the transcripts were coded using a multi-step process involving open coding, axial coding and selective coding, through multiple, iterative discussions between the researchers.
Recruitment strategy	Italian women with a strong family history but no personal history of cancer who had had CGC and BRCA1/2 testing at the San Martino Polyclinic Hospital in Genoa, Italy, between January 2005 and March 2012 were eligible to participate in the study if aged between 18 and 40 years, as women of reproductive age were the focus of the overall research project.

Study dates	December 2012 to April 2013
Sources of funding	This study was funded by Italian taxpayer donations in support of the San Martino Polyclinic Hospital to Liliana Varesco. Nadine Kasparian is the recipient of a National Heart Foundation of Australia Future Leader Fellowship (101229) and a 2018-2019 Harkness Fellowship in Health Care Policy and Practice from the Commonwealth Fund
Inclusion criteria	Inclusion: Italian women with a strong family history but no personal history of cancer who had had CGC and BRCA1/2 testing at the San Martino Polyclinic Hospital in Genoa, Italy, between January 2005 and March 2012 were eligible to participate in the study if aged between 18 and 40 years, as women of reproductive age were the focus of the overall research project.
Exclusion criteria	None
Sample size	n=19
Participant characteristics	**Age (years) at time of BRCA testing** Range: 22 to 39 **Age (years) at interview** Range**:** 25 to 39 **Children range** 0 to 2 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity**

	Not reported **Education** Not reported
Results	Themes reported in the study: • I had already made up my mi–d - example quote “When they told my mother that she was BRCA1-positive, that’s when I decided “Ok, let’s do it”. What was holding me back was that I’m afraid of blood tests and I was really scared of that, but then I just decided I wanted to do it.” (Battistuzzi 2019, p3) • Thinking it through – example quate: “I chose to know about it, it was an informed choice and now that I know I think I’ll live differently. I mean, I can’t live with uncertainty, so I’d rather know than not know.” (Battistuzzi 2019, p3)’It's the right thing to do – example quate: In retrospect, I don’t know whether I would do it again. I think maybe I’d want to spend more time thinking about it….” (Battistuzzi 2019, p3)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Brain, 2004

Bibliographic Reference	Brain, K.; Gravell, C.; France, E.; Fiander, A.; Gray, J.; An exploratory qualitative study of wo’e''s perceptions of risk management options for familial ovarian cancer: Implications for informed decision making; Gynecologic Oncology; 2004; vol. 92 (no. 3); 905-913

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Not reported
Data collection and analysis	Semi-structured interviews 2 weeks after participa’ts' appointments at the ovarian clinic, which followed a topic guide developed in consultation with key clinical staff, including topics such as experiences of the CGSW, perceptions of the information received regarding risk management options, and views on ovarian cancer screening and prophylactic oophorectomy. Interviews analysed via constant comparative analysis.
Recruitment strategy	Participants were identified by the CGSW and sent an introductory letter and information sheet with their clinic appointment letter, together with a form indicating consent to be contacted by the researcher to arrange a convenient time for an interview. Participants were assured confidentiality and that their decision to participate would not affect the medical care they received.
Study dates	January to June 2001
Sources of funding	The research was facilitated by grants from the Wellcome Trust, Cancer Research UK and Tenovus.
Inclusion criteria	Women newly identified by the Cancer Genetics Service for Wales (CGSW) as being at increased risk of developing familial ovarian cancer
Exclusion criteria	Women identified by the clinical team as experiencing significant mental health problems, those with a previous or current diagnosis of ovarian, breast or colorectal cancer, and those who had already had prophylactic oophorectomy (PO)
Sample size	n=10
Participant characteristics	**Age** (years): Range: 27-62 **Mutation status** Not reported

	Cancer diagnosis Not reported **Ethnicity** Not reported **Education** Not reported **Children** Not reported **Undergone predictive genetic testing**: n=2 [n=1 identified gene carrier, n=1 awaiting the results of mutation detection in an affected family member]
Results	Overarching themes reported in the study were: • Reactions to ovarian cancer screening – example quote: "...my husband...has to realise what the consequences are of me having this operation, and that it's all going to fall on him'' (Brain 2004, p909) • Reactions to the option of prophylactic oophorectomy – example quote: ''I knew he (Consultant) was going to say that (regarding the option of surgery), but it was still a shock... It's like meeting a new partner and the first thing they say is 'Let's have a baby.''' (Brain 2004, p908)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Minor concerns due to a lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Highly relevant

Brunstrom, 2016

Bibliographic Reference	Brunstrom, Kate; Murray, Alexandra; McAllister, Marion; Experiences of Women Who Underwent Predictive BRCA1/2 Mutation Testing Before the Age of 30.; Journal of genetic counselling; 2016; vol. 25 (no. 1); 90-100

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting	Cancer Genetics Service for Wales
Data collection and analysis	Semi-structured interviews following a basic yet flexible interview plan to allow the participant go into detail on aspects important to them. Thematic analysis undertaken following Braun and Clarke's (2006) six steps of thematic analysis and taking an inductive approach with no pre-determined coding framework to let the analysis reflect the issues and themes important to the participants. This was an iterative process.
Recruitment strategy	The CGSW (Cancer Genetics Service for Wales) maintains a database of all women identified to be BR½1/2 carriers. All women on this database between the ages of 18– 30 who understood English and had capacity to consent were eligible for the study. Eligible participants were identified by members of the CSGW clinical team and sent information packs with an invitation letter signed by their Consultant Geneticist. Interested participants returned a reply slip to the first author, who then contacted them directly.
Study dates	April- August 2011
Sources of funding	Unfunded

Inclusion criteria	Women under 30 in South Wales who have not had cancer but have been identified to be BR½1/2 carriers.
Exclusion criteria	Not understanding English and not being able to consent
Sample size	n=7 female BR½1/2 carriers who had predictive testing before the age of 30
Participant characteristics	**Age** Range: 24-30 **Age at testing** Range: 22-28 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Not reported **Children range** 0-2 **Time since testing range**

	<1 ye–r - 4 years
Results	Themes reported in the study were (regarding genetic testing): • Motivations for genetic testing: Removal of Uncertainty – example quote: “I mean the minute you get a letter sayi“g "Look, this gene is in your fami”y," I figured I am either going to sit there wondering forever, do I? Don’t I? Jumping every time I feel any slight lump or I could just find out one way or the other.” (Brunstrom 2016, p93) • Motivations for genetic testing: Empowerment – example quote: “I think I have that extra little bit of knowledge which might make the difference in terms of protecting myself, if you are unaware of your status then perhaps you ignore things or not be in the habit of looking for them.” (Brunstrom 2016, p93) • Motivations for genetic testing: Nothing to Gain by Waiting – example quote: “Waiting with that uncertainty would be equal to having a positive result.” (Brunstrom 2016, p93) • Motivations for genetic testing: Family Obligations – example quote: “I wanted to know and especially with a girl and just thought well it’s there and if she wants to find out at least she knows there is this 50/50 and she can make her own decisions from there then.” (Brunstrom 2016, p94) • Perceived Advantages of Having the Test at This Age: No Regrets – example quote: “I know there are a lot of people that would probably wish they didn’t know I wouldn’t go back and change it. There is not one thing I can think of for me to say I wish I didn’t know. Because it is something you have got to deal with.” (Brunstrom 2016, p94) • Perceived Advantages of Having the Test at This Age: Counselling Process Increased Knowledge and Awareness – example quote: “I think I have that extra little bit of knowledge which might make the difference in terms of protecting myself. If you are unaware of your status, then perhaps you ignore things or not be in the habit of looking for them.” (Brunstrom 2016, p95) • Perceived Disadvantages Having the Test at this Age: Forced Into Making Unexpected Difficult Decisions – example quote: “It’s probably the thing that I have struggled with the most since finding out about it, I’m not ready to have children yet, and I think it’s a decision that kind of got forced on me like, it’s something to think about earlier that I would of normally because I think if my mum had known she had the gene, would she have just had me and known that she could pass it on.” (Brunstrom 2016, p95) • Perceived Disadvantages Having the Test at this Age: Remaining Uncertainty – example quote: “I did think it would settle me, I sort of thought well if I know either way that it will be it, but obviously it is not because there is a residual worry day in, day out.” (Brunstrom 2016, p95) • Perceived Disadvantages Having the Test at this Ag“: "No Man’s L”nd" – example quote: “If I knew I was still, I don’t know, still written down somewhere, or I knew that someone was going to check on me or they were aware I have this risk and I don’t know, it’s just that they would know and someone professional would be checking up on me. (Brunstrom 2016, p97)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

D'Agincourt-Canning, 2006

Bibliographic Referenc'	''Agincourt-Canning L; Genetic testing for hereditary breast and ovarian cancer: responsibility and choice.; Qualitative health research; 2006; vol. 16 (no. 1)

Study Characteristics

Study type	Ethnographic
Country/ies where study was carried out	Canada
Setting	Hereditary cancer programme
Data collection and analysis	Semi-structured interviews were conducted and analysed using an interpretive process guided by constant comparative and iterative techniques.
Recruitment strategy	Cascade sampling. Participants were initially recruited through a hereditary cancer program to which they had been referred for genetic counselling for breast-ovarian cancer because of their personal and/or family histories of the disease. These participants then aided further recruitment by contacting other family members who were eligible for, or considering, genetic testing
Study dates	19–8 - 2001
Sources of funding	This research was supported by the Canadian Breast Cancer Foundation, the Huntington Society of Canada, and the Earl and Jennie Lohn Foundation

Inclusion criteria	Women and men who were eligible for and/or who had undergone genetic testing for hereditary cancer
Exclusion criteria	None
Sample size	n=53 of women and men who were eligible for and/or who had undergone genetic testing for hereditary cancer.
Participant characteristics	**Age** Range: early 20s to 60s **Mutation status** Not reported **Cancer diagnosis** 14 affected by breast-ovarian cancer 25 cancer free but at high risk **Ethnicity** Not reported **Children** Not reported **Education:** 38% high school 49% further vocational training or university. **Relationship to index patient**

	4 spouses **Testing status** 39 chose to undergo testing. 4 waiting for the index test results before proceeding further 6 refused testing
Results	Themes reported in the study were: • Accepted testing: The embodied self – example quote: “I just knew that I had to do this. I don’t know why I knew, but I knew I had to do it and I had to get going on it and not keep waiting and waiting.” (D’Agincourt-Canning 2006, p104) • Accepted testing: The familial-relational self – example quote: “I wanted to get tested more for my kids. And for Alice, she’s the youngest [sister in the family]. She’s like my best friend, Alice and I. So yes, I kind of wanted to find out not more so for myself, but just to see if they would possibly have the gene or that I have passed it onto my children.” (D’Agincourt-Canning 2006, p106); “I didn’t pay much attention to it [genetic testing] until my mom and everybody pursued it further. Then I didn’t have much choice whether I wanted to pay attention to it or not… With my mom, there’s not one visit that goes by, that she doesn’t say something about it. Like we cannot go and have a visit without that being some type of focal line. She’s really pushing me to be genetically tested.” (D’Agincourt-Canning 2006, p107) • Accepted testing: The civic self – example quote: “The advantage is just information to the people doing cancer research. That is the only reason I said yes [to the testing]. The larger your sample size, the better your results… If our family is showing a lot of this, there is a good chance that we would have these genes that could help somebody’s research project and provide answers down the line for some other people, maybe even for us.” (D’Agincourt-Canning 2006, p109) • Declined testing: the embodied self – example quote: “The genetic testing, I would sort of be willing to do it if they have something that could alter the genes or kill it or, I don’t know, do something. But they don’t know. They cannot at this point as far as I know/ there is no way that they could do anything. It’s just finding out that’s it there.” (D’Agincourt-Canning 2006, p110) • Declined testing: The familial-relational self – example quote: “You have this information that I don’t know if you, if you / if people should have. If they know how to monitor it, you know? I think that, you know, a couple of members in my family if they found out that they had the gene. I think it would just, like I am really worried about my sister, you know, because I think that if she found out that she had the gene she’d panic.” (D’Agincourt-Canning 2006, p111)

	• Receiving unwanted information from family members about genetic risk – example quote: “I think it was no big deal to them [mother and aunts], but they didn’t think about what it was going to do to their kids and their grandkids. Because this is a never-ending thing now. Like we opened a box that’s never going to close, like it’s an open door to forever. Like I said, once you open that door you can’t ignore what’s behind it.” (D’Agincourt-Canning 2006, p108) • Family pressure to get tested due to the impact of genetic test results on children – example quote: “I think it’s very irresponsible. I mean if he doesn’t have it, he doesn’t have to worry about worrying his kids about it. If he does, she’d [his adult daughter] better get tested pretty soon. It’s ridiculous. I think it’s very irresponsible, if you have something like that and you can, you know, make sure. ’Cause I mean you’re giving your kid no option to have themselves checked, have themselves have any preventative stuff if they have to, or testing that they should have. It’s horrible. I think it’s very cruel.” (D’Agincourt-Canning 2006, 109)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Dancyger, 2010

Bibliographic Reference	Dancyger, C.; Smith, J.A.; Jacobs, C.; Wallace, M.; Michie, S.; Comparing family members motivations and attitudes towards genetic testing for hereditary breast and ovarian cancer: A qualitative analysis; European Journal of Human Genetics; 2010; vol. 18 (no. 12); 1289-1295

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK

Setting	National Health Service clinical genetics services in London, UK
Data collection and analysis	Semi-structured interviews 1 month after test result consultations, starting with a schedule but probing topics as they arose. During the interviews, the patients were asked about their consultation and to describe their decision-making process regarding communicating information to relatives. The relatives were asked what they were told by the patient, how they reacted to the information, how they perceived their own risk and whether they intended to do anything as a result of receiving this information. The interview were analysed using interpretative phenomenological analysis. Only families where the patient and at least two relatives were interviewed were included in the analysis. This paper presents the results of one category: motivation for testing.
Recruitment strategy	Eligible index participants were female patients affected by breast or ovarian cancer who met clinic eligibility criteria and had received a positive result from a BRCA1/2 mutation search. All index patients were recruited from one of two participating National Health Service clinical genetics services in London, UK. Patients were recruited after blood had been taken for testing but before receiving their test result. Relatives recruited by the index patient were genetically related to the index patient but the degree of genetic relatedness was not specified. The index patient had to have informed them of their genetic test result but it was not necessary for the relative to have undergone predictive testing. All participants were >18 years of age and spoke English
Study dates	20–6 - 2008
Sources of funding	UK Department of Health Grant
Inclusion criteria	Female patients affected by breast or ovarian cancer who met clinic eligibility criteria and had received a positive result from a BRCA1/2 mutation search. Relatives recruited by the index patient were genetically related to the index patient but the degree of genetic relatedness was not specified. The index patient had to have informed them of their genetic test result but it was not necessary for the relative to have undergone predictive testing. All participants were >18 years of age and spoke English.
Exclusion criteria	None
Sample size	n=30 (10 index patients and 20 relatives)
Participant characteristics	**Index patient age** Range –4 - 71 **Relatives age**

	Range –0 - 65 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Not reported **Children** Not reported
Results	Themes reported in the study were (regarding genetic testing): • Families committed to testing: Not fully thought through – example quote: “The genetic counsellor was right, you do need time to think about it, but by the time I did go and see her, I had made up my mind that I wanted the tests and even though she was persuading me, or trying to persuade me to wait a little while, I almost did wait ... then when I thought about the 40 thing again and that was unclear in my mind, I said no I want the tests now” (Dancyger 2010, p1292) • Families committed to testing: Testing for oneself – example quote: “Do I really want to know the outcome of it? …well, if the outcome is good, then it puts your mind at rest. And if it’s not good, well you can do something about it.” (Dancyger 2010, p1292) • Families uncertain about testing: Testing in the future – example quote: It’s not really something I need to know right now. But maybe it will change ... I’m just really busy... it’s not top of my list of things to worry about or to go and do .. I don’t have health issues on the mind at the moment but I guess when I’m forty or fifty those, my mind will probably be a bit more concerned about these things. (Dancyger 2010, p1293)

	• Families uncertain about testing: Ambivalence – example quote: “If you’ve been tested and you’ve got your result and it’s negative … what happens in 10 years’ time if they find more genes, you know? Are you back down that route again, that you thought you were fairly safe, and then you’re not?” (Dancyger 2010, p1293)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity or mention of ethics)*
Overall risk of bias and relevance	Relevance	Highly relevant

Dancyger, 2011

Bibliographic Reference	Dancyger, Caroline; Wiseman, Mel; Jacobs, Chris; Smith, Jonathan A; Wallace, Melissa; Michie, Susan; Communicating BRCA1/2 genetic test results within the family: A qualitative analysis.; Psychology & Health; 2011; vol. 26 (no. 8); 1018-1035

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	National Health Service (NHS) clinical genetics services
Data collection and analysis	Semi-structured interviews 1 month after test result consultations which started with a schedule but probed topics as they arose. The patients were asked about the consultation and to describe their decision-making process regarding communicating information to relatives. Relatives were asked to relay what they were told by the patient, how they reacted

	to the information, how they perceived their own risk and whether they intended to do anything as a result of receiving this information. Interview transcripts were analysed using interpretative phenomenological analysis. Only families where the index patient and at least two relatives were interviewed were included in the analysis.
Recruitment strategy	Index patients were recruited by genetics clinicians after blood had been taken but prior to receiving their test result. If patients stated they had shared their test result with at least two family members, they were requested to invite relatives with whom they had shared their test result to take part. Index patients had control over which, if any, relatives were invited to take part. Biological relatives may or may not have undergone predictive testing. Relatives wishing to take part contacted the researcher and were interviewed between 1 and 9 months after the index patient interview.
Study dates	Between 2006 and 2008
Sources of funding	The study was funded by a UK Department of Health Grant
Inclusion criteria	Females aged 18 years and over, who spoke English, were affected by breast or ovarian cancer and who had received a positive result from a BRCA1/2 mutation search at one of two UK NHS clinical genetics services.
Exclusion criteria	Not reported
Sample size	n=10 families (including n=10 female patients and n=22 relatives)
Participant characteristics	**Age (years)** Range: 20-71 **Mutation status** BRCA 1 positive: n=7 BRCA 2 positive: n=6 Untested: n=11 Negative: n=5

	Awaiting result: n=3 **Cancer diagnosis** Breast: n=7 Ovarian: n=3 Breast and Ovarian: n=3 **Relationship to index patient** Daughter: n=6 Son: n=4 Sister: n=5 Brother: n=2 Cousin: n=2 Niece: n=2 Aunt: n=1 **Ethnicity** Not reported **Education** Not reported

	Children Not reported
Results	Themes reported in the study were: • Responsibility to tell – example quote: “I phoned both the girls on their mobiles, on the way home ... Straight away. I wasn’t in a great hurry to tell the boys... ... ... [Son1] ... he’s got two sons, so he hasn’t got any daughters... and [Son2] hasn’t got any children.” (Dancyer 2011. p1023) • Emotional and developmental readiness – example quote: “We agreed not to speak to [sister]. I will tell [sister], she needs to know. She was undergoing some tests for something ... and she was very depressed, she was quite frightened by it.” (Dancyger 2011, p1025) • Communicating in the context of the existing family culture – example quote: “In close relationships you’ve got to have a good reason not to tell people things...to find out at a later stage that some information was withheld from you, can open the door to all sorts of mistrust ... if you want to have a relationship in which there’s suspicion and mistrust, then you keep under things. If you don’t want to have that sort of relationship, then you maintain openness and honesty (Dancyger 2011, p1028)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Moderate concerns due to a lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. Ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.)*
Overall risk of bias and relevance	Relevance	Relevant *(Data not separated for at-risk ovarian and breast cancer patients)*

Fadda, 2020

Bibliographic Reference	Fadda, Marta; Chappuis, Pierre O; Katapodi, Maria C; Pagani, Olivia; Monnerat, Christian; Membrez, Veronique; Unger, Sheila; Caiata Zufferey, Maria; Physicians communicating with women at genetic risk of breast and ovarian cancer: Are we in the middle of the ford between contradictory messages and unshared decision making?.; PloS one; 2020; vol. 15 (no. 10); e0240054

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Switzerland
Setting	Genetic-counselling hospital services based in the French and Italian parts of Switzerland
Data collection and analysis	Data were collected through retrospective, biographical interviews following the Grounded Theory design. Participants shared documents accumulated over their lifespan with the research team (such as copies of medical letters and notes). Questions covered multiple aspects related to the management of participants' genetic risk over time and to the relationships with healthcare providers and in general with the healthcare system.
Recruitment strategy	An inductive approach guided by constant comparison was used.
Study dates	Between 2011 and 2014
Sources of funding	The author was supported by the Swiss National Science Foundation
Inclusion criteria	Unaffected female carrying BRCA1/2 pathogenic variants discovered at least three years before the interview
Exclusion criteria	Not reported
Sample size	n=32
Participant characteristics	**Age (years)** 26-35: n=8 36-49: n=21

	50-60: n=3 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Secondary education: n=19 University education: n=13 **Children** No children: n=7 Had children before the testing: n=14 Had children after the testing: n=11 **Years elapsed since genetic testing** 3-6: n=9 7-12: n=23

	Undertaken measures Breast surveillance: n=1 Breast and ovarian surveillance: n=9 Prophylactic bilateral annexectomy + breast surveillance: n=12 Prophylactic bilateral mastectomy + ovarian surveillance: n=4 Prophylactic bilateral annexectomy + mastectomy: n=6
Results	Themes reported in the study were: • The normative message – example quote: “Every time, he [the gynecologist] tells me that he’s not going to let me cross 40 years with my ovaries. He says: <Take your time, but you will have to remove them>”. (Fadda 2020, p6) • The over-empowering message – example quote: “He kept telling me it was up to me, that he could not put himself in my shoes. I told him: <But what about if I were your sister?> His answer was always: <Look deep inside, talk about it, talk to your husband,’it's up to you to decide, an’ I'll be there to do what you decide>.” (Fadda 2020, p6) • The minimizing message – example quote: “It’s like with your dentist: if you don’t have cavities, if you just want to go to the dental hygienist, then they’ll give you an appointment in three months. But if you say: <I ’an't stand it anymore, I have an abscess>, they’ll find you an appointment, they’ll cancel the appointment for the person who isn’t sick in order to treat the person who is.” (Fadda 2020, p7)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Moderate concerns due to no explanation of recruitment approach, a lack of researcher reflexivity, no discussion of ethical issues and concerns regarding data analysis.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Foster, 2002

Bibliographic Reference	Foster, C; Watson, M; Moynihan, C; Ardern-Jones, A; Eeles, R; Genetic testing for breast and ovarian cancer predisposition: cancer burden and responsibility.; Journal of Health Psychology; 2002; vol. 7 (no. 4); 469-484

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	UK
Setting	Royal Marsden NHS Trust Genetics Clinic for predictive genetic testing
Data collection and analysis	Women were interviewed five weeks before receiving their genetic test result using semi-structured interviews focusing on experiences of cancer in the family and reasons for having the predictive genetic test, employing broad, open-ended questions along with further probing questions to clarify or obtain more detail. Interviews analysed using a grounded theory approach.
Recruitment strategy	A consecutive series of 18 healthy women with a family history of breast/ovarian cancer attending the Royal Marsden NHS Trust Genetics Clinic for predictive genetic testing were invited to participate. Women were invited to participate by their consultant cancer geneticist (RE) or clinical nurse specialist (AA-J) during their genetic consultation and women expressing an interest in the study were then contacted by the researcher (CF).
Study dates	1998-1999
Sources of funding	Cancer Research UK
Inclusion criteria	(i) known BRCA1/2 mutation in the family, i.e. an affected family member had already been tested and identified as a carrier of the BRCA1 or 2 gene mutation; (ii) blood taken from the study participants for BRCA1/2 analysis; (iii) over 18 years of age; (iv) female; (v) unaffected with breast/ovarian cancer at the time of the test; and (vi) no known psychiatric history.
Exclusion criteria	None
Sample size	n=15 women at increased risk of developing breast and/or ovarian cancer due to their family history.
Participant characteristics	**Age** Median: 46 years

	Range: 33–62 years **Mutation status** Not reported **Ethnicity** Not reported **Marital status** Married/living with partner: N = 12 Divorced/separated: N = 2 Single: N = 1 **Number of daughters (sons)** One: N = 7(5) Two: N = 6(3) **Age of children** Median: 21 years Range: 3–40 years **Education** Left school at or before 16: N = 7

	Left school at 18 or College/specialized training: N = 4 University or equivalent: N = 4 **Employment** Employed: N = 12 Not currently employed: N = 3 **Confirmed line of transmission of BRCA gene mutation** Maternal line: N = 13 Paternal line: N = 2 **Type of cancer** Breast cancer only: N = 10 Breast and ovarian cancer: N = 5 **Number of affected first degree relatives (number deceased)** Median: N = 1 (N = 1) Range: 0–3 (0–3) **Risk management** Mammography: N = 13 Ovarian ultrasound: N = 6

Results	Themes reported in the study: • Cancer burden – example quote: “I suppose it’s in the back of the mind, if people talk about it then it comes up and if people talk about it I do get upset over my sister and my mum quite easy um, but I don’t get into major conversations unless it’s for some particular reason, um and I don’t greatly think about cancer.” (Foster 2022, p474) • It’s in the family – example quote: example quote: “None of my mum’s sisters have had cancer. I have asked if there is cancer in the family and no one’s had breast cancer [. . .] I say, ‘well you know like where does it come from?’ [present in mother and sister].” (Foster 2022, p474) • Developing awareness – example quote: “I only found out about it when my mother was diagnosed and my father gave me a copy of the letter that [consultant] had written to my mother saying would I please go and have um, you know, check-ups and I said ‘why on earth should I have check-ups, mum’s ill, why should I go?’ and he said ‘well it’s in the family’. And I said ‘hang on a second you had better tell me all about this’ …And that was the very first time that I knew about it.” (Foster 2002, p475) • Untimely deaths – example quote: “All the others were um, you know, not elderly but they have lived the ripe of their lives and I have put that down to, like me granddad who died of cancer that was natural because he was in his 70s or 80s you know when the body breaks down sort of thing.” (Foster 2002, p475) • Beyond the family – example quote: “That was a time when it does make you think yourself. [. . .] You think ‘I wonder if I can cope that well?’. I am sure if it was me in that situation I would fall apart a bit really. Um she just seemed to cope so well and she had got two children under 5 you know she was just so young.” (Foster 2002, p476) • Vulnerability – example quote: “Well, the fact that, I mean most of the female family members have died from breast cancer, I mean that’s a fairly strong indication.” (Foster 2002, p477) • Out of sight, out of mind – example quote: “[Sister 1] died in 1986, mum was diagnosed in something li’e ‘88 um, so both [sister 2] and I looked at each other… We said that there really is something that is not right about this, two people in our family, it’s not right it’s got to be hereditary. Sue (46 years) [Sue is referring to her immediate family here. In her extended family there have been numerous cases of breast/ovarian cancers.] My mum and my dad, neither of them had cancer, um nor has my brother, um so you could say that the four of us, um have been okay. So it sort of makes me feel um, that I won’t get it… I feel that I am okay, I don’t think that I will have this gene.” (Foster 2002, p477) • Balancing risk – example quote: “My sister can’t deal with it, internalises it, you know, whereas I need, I need to deal with it.” (Foster 2002) (Foster 2002, p478) • Responsibility – example quote: “I don’t feel that I have got a decision to make. I mean I see this as, as being the next, the next step forward. I don’t want to be seen to be making the decision anyway I think it’s a case of got to know, not will I want to know. Um, because I am not looking at me now I am looking at my family. I think when it comes to family you can’t really be selfish and worry about how you feel about the gene. I mean I brought the

	children into the world and I owe it to them to be able to relieve, rather than leave them any worry and make provision." (Foster 2002, p479) • Dual motives: Selfishness and altruism – example quote: "Here's me perfectly healthy, [. . .] and my mother desperately ill and for me to be worrying about the genetic test and the effect on me, I mean I feel guilty every time I go in and have the screening I feel like I am using up valuable resources which is why when they said would you do this, would you do this [research] I say yes, yes, yes, if there is anything that I can do because I really feel very self indulgent taking up everybody's time." (Foster 2002, p480)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Gaba, 2022

Bibliographic Reference	Gaba, Faiza; Goyal, Shivam; Marks, Dalya; Chandrasekaran, Dhivya; Evans, Olivia; Robbani, Sadiyah; Tyson, Charlotte; Legood, Rosa; Saridogan, Ertan; McCluggage, W Glenn; Hanson, Helen; Singh, Naveena; Evans, D Gareth; Menon, Usha; Manchanda, Ranjit; PROTECTOR, team; Surgical decision making in premenopausal BRCA carriers considering risk-reducing early salpingectomy or salpingo-oophorectomy: a qualitative study.; Journal of medical genetics; 2022; vol. 59 (no. 2); 122-132

Study Characteristics

Study type	General qualitative inquiry Qualitative substudy nested within a multicentre, observational cohort trial (PROTECTOR: Preventing Ovarian Cancer through early Excision of Tubes and late Ovarian Removal)

Country/ies where study was carried out	United Kingdom
Setting	Not reported
Data collection and analysis	In-depth semi structured telephone interviews using a predeveloped topic-guide including: background (family structure, support network, occupation, hobbies); risk-reducing surgery for OC/BC prevention; health values; satisfaction-and-regret. Interviews were analysed using a grounded-theory approach and analysis was performed in parallel with data collection and finalised once theoretical saturation was reached.
Recruitment strategy	Participants were recruited to the PROTECTOR trial through specialist high-risk familial cancer clinics (FCC), genetics, gynaecology/gynaecological oncology clinics.
Study dates	Between November 2018 and October 2019
Sources of funding	The study is supported by researchers at the Wolfson Institute of Preventive Medicine, Queen Mary University of London, and the work was supported and funded by Barts and The London Charity and Rosetrees Trust.
Inclusion criteria	Premenopausal women (follicle stimulating hormone levels<40), aged >30years, at increased risk of OC (BRCA1/ BRCA2/RAD51C/RAD51D/BRIP1 carriers or due to a strong family history)
Exclusion criteria	Postmenopausal, previous bilateral salpingectomy or bilateral oophorectomy, pregnancy, future plan of childbearing (surgical arms only), prior OC/peritoneal malignancy, <12months from cancer treatment, OC suspicion at baseline.
Sample size	n=24
Participant characteristics	**Age** Range (years): 34-46 **Mutation status** Not reported **Cancer diagnosis** Not reported

	Education Not reported **Children** Not reported **Carrier status** BRCA 1 carrier: n=14 BRCA 2 carrier: n=10 **Ethnicity** Caucasian: n=22 Asian: n=2 **Personal history of BC** Yes: n=4 No: n=20 **Number of relatives with Ovarian Cancer (not mutually exclusive)** 1 FDR: n=5 1 SDR: n=6 2 SDR: n=3

Results	Overarching themes reported in the study were: • Menopause – example quote: “I wasn’t happy with the impact of going in to menopause straight away and although you obviously have HRT options which might be offered if you go to a good gynaecologist, I just, I wasn’t convinced that HRT brings you back up to an even keel or level, the way that I’m feeling right now which is basically very balanced.” (Gab 2021, p6) • Cancer risk reduction: surgical choices – example quote: “There is no screening on the NHS for ovarian cancer and that means my only other option is to have my ovaries out.” (Gaba 2022, p4) • Surgical complications – example quote: “…the trade-off between having two surgeries as opposed to one, that does feel absolutely fine to me, and that’s maybe becaus’ I've had positive experiences with surgery before.” (Gaba 2022, p7) • Sequence of ovarian and breast prophylactic surgeries – example quote: “Because I’ve never had an operation, I thought it would be better to have a minor operation first, just to kind of prepare me rather than going straight into major surgery, that was one reason but the other was the ovarian cancer prevention felt more pressing becaus’ I'm on the breast screening programme and it didn’t feel quite so urgent.” (Gaba 2022, p7) • Support with decision making – example quote: “…my experience of [gynaecology] appointments is that people just present things to you, and very quickly you have to make a decision, and there isn’t a way to just, some of the decisions take a lot of discussion, and coming back to it, and rethinking, and I just feel that there isn’t that space for it…” (Gaba 2022, p7) • Satisfaction with treatment choices – example quote: “I’d done quite a bit of research myself. I found all of the people that I’ve met within the team have been fantastic and haven’t just treated me like Patient X who doesn’t know anything at all.” (Gaba 2022, p8)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Unclear as to whether all, or what proportion of participants were recruited from the PROTECTOR study to participate in the qualitative substudy. There was a lack of researcher reflexivity, no description of how presented data were selected, nor discussion of contradictory data.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Gleeson, 2013

Bibliographic Reference	Gleeson, Margaret; Meiser, Bettina; Barlow-Stewart, Kristine; Trainer, Alison H; Tucker, Kathy; Watts, Kaaren J; Friedlander, Michael; Kasparian, Nadine; Communication and information needs of women diagnosed with ovarian cancer regarding treatment-focused genetic testing.; Oncology nursing forum; 2013; vol. 40 (no. 3); 275-83

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	Two major genetics services in Sydney and Melbourn and a Gynaecologic oncology department at a major teaching hospital in Sydney
Data collection and analysis	Semi structured interviews using a guide with extensive experience as both a cancer genetic counsellor and an oncology nurse and including questions on the preferred timing of information about TFGT, what type of information and what level of detail women require about TFGT, how women want the information about TFGT presented, and which health professionals should deliver information about TFGT Interviews were analysed for emergent themes using transcendental realism.
Recruitment strategy	Two groups of women were recruited, including 1) women with advanced ovarian cancer who had already undergone TFGT at a genetics service under a research protocol to determine eligibility for participation in a PARP inhibitor trial, and 2) women diagnosed in the previous 6–20 weeks with invasive ovarian cancer, whose family history had not been collected and who had never undergone genetic counselling or testing. Women were recruited either 1) through two major genetics services in Sydney and Melbourne with a letter of invitation sent by each woman’s treating clinician, or 2) through a Gynaecologic oncology department at a major teaching hospital in Sydney.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Women diagnosed with ovarian cancer who were unselected for family history

Exclusion criteria	Women <18 years with insufficient English language knowledge to complete the interview unaided
Sample size	n=22
Participant characteristics	**Age at interview (years)** Mean (SD): 57.2 (9.1) **Age at diagnosis (years)** Mean (SD): 55 (8.65) **Ethnicity** Not reported **Education** Not reported **Children** Not reported **Previous cancer** Breast cancer: n=2 Endometrial cancer: n=1 **Family history of breast or ovarian cancer** Yes: n=11 No: n=8

	Unknown (adopted): n=3 **Mutation status** BRCA carrier: n=4 Inconclusive result: n=8
Results	Overarching themes reported in the study: • Timing of Delivery of Treatment-Focused Genetic Testing Information – example quote: “Once you wake up from the surgery, and for the two weeks after the surgery, your head is in such a spin that I’m not sure you could even digest that information.” (Gleeson 2013, p279) • Preferences for Information – example quote: “But I guess at the time that was all I wanted to know, there was hope that something would give me better treatment than the other. And that’s what we’re looking for.” (Gleeson 2013, p279) • Format of Information Delivery – example quote: “I just think that basically it’s got to be face-to-face first, because it’s all about communication and trust.” (Gleeson 2013, p280) • Preferences for Format of Educational Materials – example quote: “I think, in booklet form, it can be a little bit off putting because you think, “Oh God, I’ve got to read through all this.”” (Gleeson, p280)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Minor concerns due to a lack of researcher reflexivity, no discussion of ethical issues raised by the study, and no description of how presented data were selected nor discussion of contradictory data)*
Overall risk of bias and relevance	Relevance	Highly relevant

Hughes, 2010

Bibliographic Reference	Hughes, Lisa; Phelps, Ceri; “The bigger the network the bigger the bowl of cherri”s…": exploring the acceptability of, and preferences for, an ongoing support network for known BRCA 1 and BRCA 2 mutation carriers.; Journal of genet□ention□inging; 2010; vol. 19 (no. 5); 487-96

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Wales, United Kingdom
Setting	Not reported
Data collection and analysis	Participants attended one of three focus groups, facilitated by a lead researcher and a co-moderator. A semi-structured topic guide was used exploring the acceptability and preference for a support network. Discussions were thematically analysed
Recruitment strategy	Male and female BRCA1 and BRCA2 mutation carriers registered within the Southeast Wales region of the Cancer Genetics Service in Wales (CGSW) who had been through diagnostic or pre-symptomatic genetic testing were sent invitation letters. Men were offered the alternative option of participating in a telephone interview, using the same topic guide as for the focus groups. The suitability of participants was assessed by the clinical members of the research team to avoid recruitment of individuals who may be suffering from ill health or be too psychologically vulnerable to participate. [Note that despite efforts to include men, only women participated in the study]
Study dates	Mar–h - April 2007
Sources of funding	Tenovus the Cancer Charity supported the study
Inclusion criteria	BRCA1 and BRCA2 mutation carriers registered within the Southeast Wales region of CGSW who had been through diagnostic or pre-symptomatic genetic testing
Exclusion criteria	Participants aged <18 years, and anyone living outside of the Cardiff and Vale NHS Trust region.
Sample size	n=17
Participant characteristics	**Age** Range (mean) in years: 24-77 (49)

	Cancer diagnosis Not reported **Ethnicity** Not reported **Education** Not reported **Children** Not reported **Carrier status** BCRA 1 mutation: n=9 BRCA 2 mutation: n=8 **Length of time since they had known their carrier status** Range (mean) in years: 0.5-11 (5) **Previous testing** Diagnostic testing: n=7 [n=6 had a previous diagnosis of breast cancer, n=1 had a previous diagnosis of ovarian cancer] Pre-symptomatic testing: n=10
Results	Overarching themes reported in the study:

	• The Family Gene (Family as a Support System, Concern for Partners and Male Relatives, Providing Support for Children, Communication Within the Family) – example quote: "I think a lot depends on your family as well and the support you've got at home and both of us [referring to sister Alex] have got good husbands and children…I'm lucky that I've got a good supportive family…" (Hughes 2010, p490) • A Common Identity (Altruism) – example quote: "I suppose for me I thought "Is there anyone else the same age as me who's affected by this" and I remember I was in Paddington [train station] and I was looking at people going "well wonder if you've got the gene, I wonder if you've got that then, I wonder if you're just walking around and you've got it", and that was my first instinct. So I think for me perhaps it would have been good to have someone of my own age group to talk to...." (Hughes 2010, p491-492) • Labelling and Stigma (The Stigma of Seeking Support) – example quote: If you'd have asked me if I'd go to a support group I think I would say probably 95% sure I wouldn't. If however you said to me we're going to have a support group and these are the topics we're going to talk about throughout the year, one is going to be insurance, another is going to be telling your daughter. Those sorts of things I would think well actually I think I might go to that, rather than this apparent unstructured [support group] thing." (Hughes 2010, p492) • The Importance of Professional Input (The Fear of Being Misled, Seeking Information) – example quote: "You see that's why we need proper people because I have been giving [you] the completely wrong information and you'd have all alone home...thinking oh my god…I think you've got to have the true facts. I think there's a lot of bogus stuff out there really." (Hughes 2010, p493); "I think to talk to a professional is quite daunting when you're young. You know I really do because nothing is in layman's terms then, whereas all you want to know is "what's my chances, can I live with this, you know what's the screening process like, and all the rest of it", do you know what I mean?" (Hughes 2010, p493) • Getting the Right Balance (Responding to Triggers) – example quote: "I think it depends what stage of the process you're at as well and how you're feeling emotionally. Sometimes you just think "no I can't quite cope with that sort of side yet" but maybe in 6 months time you maybe thinking "yeah maybe now I'd be ready to go to it". All depends what stage you're at, you know. And it's such a personal thing isn't it to go down that route or not. Yeah it would be great for some but not for all so. Again if it's one item within the package it's an extra thing you could latch on to." (Hughes 2010, p493)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Minor concerns due to a lack of researcher reflexivity, no description of how presented data were selected, nor discussion of contradictory data.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jeffers, 2014

Bibliographic Reference	Jeffers, Lisa; Morrison, Patrick J; McCaughan, Eilis; Fitzsimons, Donna; Maximising survival: the main concern of women with hereditary breast and ovarian cancer who undergo genetic testing for BRCA1/2.; European journal of oncology nursing : the official journal of European Oncology Nursing Society; 2014; vol. 18 (no. 4); 411-8

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Regional Genetics Service
Data collection and analysis	In-depth individual interviews of two groups of women. Most women in one of the groups had recently received a positive result and had therefore not undergone risk reducing surgery at the time of their first interview and were facing decisions on how they would manage the results of their gene status. These women were interviewed over a two-year period between once and four times, with the number of times being driven by theory development. Field notes were made immediately after the interview. Theoretical sampling was introduced once leads became apparent in the data. Data collection and analysis were carried out simultaneously as the study developed, and stable patterns became apparent as more ‘empirically grounded’ questions were asked.
Recruitment strategy	Women were recruited through a Regional Genetics Service and invited to participate by a consultant geneticist.

	Two sampling approaches were used; the first group had received a positive BRCA result within 6-24 months prior to study entry, and the second group had received their test result within one month prior to study entry and were selected sequentially. The study was approved by the local Ethics Committees and met the governance requirements of the relevant hospital Trust. Women were provided with an information leaflet prior to the study and consented to each interview. They were made aware of their right to withdraw from the study at any time. To prevent distress in participants they were provided an opportunity for debriefing after the interview and if necessary, follow-up support from a member of the clinical team.
Study dates	Between December 2006 and March 2010
Sources of funding	The research was funded by Health and Social Care, Research and Development study
Inclusion criteria	Adult women with a personal history of hereditary breast and/or ovarian cancer (HBOC) who had tested positive for a BRCA mutation, and were fluent in English
Exclusion criteria	Not reported
Sample size	n=33 (in addition four health professionals and three relatives completed participant numbers)
Participant characteristics	**Age at diagnosis (years)** Range: 29-68 **Mutation status** Not reported **Ethnicity** Not reported **Education** Not reported **Cancer type**

	Breast: n=25 Ovarian: n=4 **Children** Yes: n=22 No: n=4
Results	Themes reported in the study were: • Behaving altruistically – example quote: “I thought well at least it was nothing I had done to myself that give me the cancer, you know because all through I kept thinking was it something I had done you know? Was it my lifestyle that caused me to get it and then when I found out it was the gene I thought well, I don’t know, a bit of relief sort of thing you know that I didn’t cause it myself and it was out of my hands sort of thing.” (Jeffers 2014, p415) • Stag—2 - Confirming genetic vulnerability – example quote: “I was OK the day they told me I had the faulty gene but it was the next day it hit me. I just was really upset and then my family will not really talk about it, my bigger sister says she’s definitely not going to get tested and then the other one, she’ll just not talk about it.” (Jeffers 2014, p415) • Striving to contain cancer – example quote: “I really want to write things down about how Annoyed I am. you give me this information, and nobody has done anything about it. I found out in April about this gene and I’m none the wiser you know, I’m not. It’s like somebody has given you, not a death sentence, but this thing could kick off at any time, especially auntie Susie dying from it last year. I just don’t think it’s right to give people, tell people that and then there is nothing to back it up” (Jeffers 2014, p415) • Reconstituting identity – example quote: “Especially with the genetic thing, I mean it’s just like sharing things and talking to other people, that’s where you come in, you can talk to them and you know get what they want and they know what you are talking about whereas somebody that hasn’t been there, don’t really, they sympathise with you and like they listen to you but it just goes over their head.” (Jeffers 2014, p416)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Relevant *Data not separated for at-risk ovarian and breast cancer patients*

Lifford, 2013

Bibliographic Reference	Lifford, Kate J; Clements, Alison; Fraser, Lindsay; Lancastle, Deborah; Brain, Kate; Catalysts to withdrawal from familial ovarian cancer screening for surgery and reactions to discontinued screening: a qualitative study.; Familial cancer; 2013; vol. 12 (no. 1); 19-26

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Not reported
Data collection and analysis	Semi-structured interviews were conducted on topics including: family history of cancer, Ovarian Cancer Screening (OCS) history, provision of information and decisions about OCS, feelings about OC risk, reasons for bilateral salpingo-oophorectomy, feelings about withdrawal from OCS and screening experiences. The interviews were analysed using a framework approach.
Recruitment strategy	Women, who discontinued Ovarian Cancer Screening (OCS) following surgery and indicated their interest in being interviewed, were approached with the agreement of, or by, their clinical team. Women were purposively selected according to family history (only those with Ovarian Cancer in their family), age, cancer-specific distress, geographical area, screening phase at the time of surgery and gene mutation status.

	Women received an invitation letter, information sheet and consent form. Ethical approval was granted from the Eastern Multi Centre Research Ethics Committee
Study dates	Not reported
Sources of funding	Participants were part of the Psychological Evaluation of Familial OCS (PsyFOCS) study, which is funded by the BUPA Foundation.
Inclusion criteria	Women, who discontinued OCS following surgery and indicated their interest in being interviewed.
Exclusion criteria	Not reported
Sample size	n=21
Participant characteristics	**Age at surgery (years)** Mean: 48 Range: 37-66 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Not reported

	Children Not reported **Time from surgery to interview** Range: 6 mont–s - 2 years 11 months **Years on UKFOCSS (Phase 1 or 2)** Range: 6 mont–s - 4 years 11 months **Phase 2 screening (no. of participants)** Yes: n=12 No: n=9 **History of screening results (no. of participants)** Normal: n=4 Abnormal: n=17
Results	Overarching themes reported in the study were: • Abnormal screen test results – example quote: "…I'm getting older and I believe the risks are higher as you get older…and I just felt I was being advised…and it was an intuitive…and the blood results were going up, so it was a combination…one year she said to me, ''why you don't have your ovaries removed'' and I said ''well because I'm fine and I don't worry about it, as far as I know''…because you never know sub-consciously, and I said ''and I'm not high risk'', so she looked at me and said ''why do you think we screen you?''…and I remember saying ''oh ok'' (Lifford 2013, p22); "…I had got cysts on my ovary…they kept an eye on me and my bloods shot up or something so they called me…it [surgery] just felt right at the time, you know to take away the worry because when they found that the bloods had gone up I just thought of my mother…" (Lifford 2013, p24)

	• Age – example quote: "…so I hit 50 and thought, you know it had been recommended, and I you know, spent the whole year thinking I must do it, I must do it." (Lifford 2013, p23) • Change in OC risk information/realisation – example quote: "…they isolated the BRCA1 gene then and I thought oh I may as well just have them out as they were no good to me anyway…well I had already sort of made the decision anyway, but then that just confirmed everything…" (Lifford 2013, p23) • Sense of loss at the removal of screening – example quote: "…I would have been happy to carry on [with screening] to be honest but it's a bit pointless I suppose for the study but er I quite like receiving all the checks and that…it could just as equally be breast cancer as against ovarian…" (Lifford 2013, p23) • Acceptance that screening is no longer necessary – example quote: "I hadn't realised that you can still get ovarian cancer after you have had your ovaries removed…I thought when I was opting for surgery that was that, but apparently not…at 2 % I don't think I'd trot off for a blood test mmm don't know…the screening wouldn't show it up anyway, would it?" (Lifford 2013, p24)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Minor concerns as researchers do not explain how the participants were selected, nor why some people chose not to take part. The researchers did not critically examine their own role, including their potential influence and bias during the study)*
Overall risk of bias and relevance	Relevance	Highly relevant

Lim, 2004

Bibliographic Reference	Lim, Jacqueline; Macluran, Mariette; Price, Melanie; Bennett, Barbara; Butow, Phyllis; kConFab Psychosocial, Group; Short- and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer.; Journal of genet□ention□inging; 2004; vol. 13 (no. 2); 115-33

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	Study sites across Australia
Data collection and analysis	The following five open-ended questions were asked to participants: • How did you feel about the result of your genetic testing? • Has it affected your relationships with immediate family members? • How have other members of the family responded? • What are some advantages and disadvantages of receiving a result? • Has it changed your life/activities in any way? Interviews were analysed using thematic analysis
Recruitment strategy	Women were recruited either on entry to the main kConFab study or at approximately 3 years follow-up when their clinical information is being updated. Invitations to participate in the study were mailed from the coordinating research centre along with a detailed information and consent form, a questionnaire booklet, and reply-paid envelope. Women were provided with a free-call number if they wished to obtain further information about the study. Women were given the option to complete either the questionnaire or the interview component only, or both. Participants were recruited through 11 study sites across Australia. The study was approved by each of the institutional ethics committees.
Study dates	Between August 2001 and July 2002
Sources of funding	The research was supported by grants of the National Health and Medical Research Council of Australia, and a grant from the Breast Cancer Association of Queensland. KConFab has been funded by the Kathleen Cunningham Foundation, National Breast Cancer Foundation, National Health and Medical Research Council, Anti Cancer Council of Victoria, Anti Cancer Foundation of South Australia, Cancer Foundation of Western Australia, Queensland Cancer Fund, and NSW Cancer Council.
Inclusion criteria	Unaffected women participating in the Kathleen Cunningham Consortium for Research into Familial Breast Cancer Psychosocial Study. This included women who have a family history consistent with a dominantly inherited susceptibility to breast cancer and come from a family that meets the following eligibility criteria: families in which a predisposing mutation

	has been identified, (two or more carriers or likely carriers amongst first and second degree relatives from the informative side of the family) and families in which no predisposing mutation has been identified (four or more cases of breast or ovarian cancer on one side of the family, or two or more cases of breast or ovarian cancer, in the same of adjacent generations, if at least one of these cases “s "high-”r”sk", for example breast plus ovarian cancer, or onset less than 40 years or bilateral breast cancer, and two or more living, affected family members, and four of more living first, or second degree unaffected female relatives of affected cases. The study focussed on a subsample of the kConFab Psychosocial Study which included unaffected women with mutation results available, recruited between August 2001 and July 2002. All these women had received a predictive rest where a family specific mutation had already been delineated in another family member.
Exclusion criteria	Non-English speaking, aged less than 18 years, and serious mental illness
Sample size	n=47
Participant characteristics	**Age, years: Number (%)** Less than 30 years: n=4 (8.5) 30-39 years: 13 (27.7) 40-49 years: 11 (23.4) 50+ years: 19 (40.4) Range: 24-76 Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported

	Education, Number (%) Postschool qualifications: n=19 (43.2) No postschool qualifications: n=25 (56.8) **Number of children, Number (%)** No children: n=10 (21.3) 1-2 children: 22 (46.8) Three or more children: 15 (31.9) **Mutation status, Number (%)** Positive: n=23 (49) Negative: n=24 (51) **Time since result, Number (%)** 1-6 months: n=11 (23.4) 7-12 months: n=11 (23.4) 13-36 months: n=12 (25.5) 37-70 months: n=13 (27.7)
Results	Themes reported in the study were: • Advantages – example quote: “The ovaries can be removed when you are finished with them. I know I will have a better quality of life mentally because I ’on't have to worry about ovarian cancer which is hard to detect.” (Lim 2004, p125)

	• Disadvantages – example quote: “It would have been better to find out later in life” (Lim 2004, p127) • Lifestyle Changes or Life Changing Experience – example quote: “My perspective has changed. I used to think that success was to do with money and material things. Now I focus more on family and friends.” (Lim 2004, p127) • Changes over time – example quote: “Before I was tested my father said he didn’t think I should have… children. When I was pregnant, he said I should terminate it. When he found out I was negative, he was relieved.” (Lim 2004, p128)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Moderate concerns due to lack of justification for data collection, and no discussion of data saturation. There was a lack of researcher reflexivity and limited description of data analysis.)*
Overall risk of bias and relevance	Relevance	Relevant *Data not separated for at-risk ovarian and breast cancer patients*

Mireskandari, 2006

Bibliographic Reference	Mireskandari, S.; Meiser, B.; Sherman, K.; Warner, B.J.; Andrews, L.; Tucker, K.M.; Evaluation of the needs and concerns of partners of women at high risk of developing breast/ovarian cancer; Psycho-Oncology; 2006; vol. 15 (no. 2); 96-108

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	Not reported
Data collection and analysis	Semi-structured telephone interviews using an aide-memoire, outlining the major questions and topics to be covered whilst leaving phrasing and order of questions open. Questions targeted partners’ experiences and perspectives in a number of

	areas including: relationship, future planning, children, communication, screening and prophylactic surgery decision-making, and support and information needs. The interviews were analysed using a multi-phase approach with initial phases of purely descriptive coding using the interview questions followed by a more interpretive phase of coding where inter-relationships between codes were identified.
Recruitment strategy	The medical records of the Clinic were reviewed by treating clinicians to identify participants for the study. The clinicians involved in patient care contacted the women by letter. They explained the purpose of the study and asked permission for their partners to be approached by the research team.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Women who had attended the Hereditary Cancer Clinic at the Prince of Wales Hospital and were assessed as being at high risk of developing breast/ovarian cancer (women with a family history consistent with a dominantly inherited susceptibility to breast/ovarian cancer), were partnered at the time of consultation, aged 18 years and over, and fluent in English. Note: Women who had undergone genetic testing and were found not to be breast/ovarian cancer mutation carriers were also included.
Exclusion criteria	Women who had a prior diagnosis of breast and/or ovarian cancer.
Sample size	n=15 partners of women
Participant characteristics	**Age (years)** Mean (range): 41.4 (30-56) **Mutation status** Not reported **Cancer diagnosis** Not reported

	Ethnicity Not reported **Wife/part’er's risk status, Number (%)** Unknown mutation status: 5 (33) Carriers: 7 (47) Non carriers: 3 (20) **Wife/part’er's prophylactic surgery status, Number (%)** No surgery: 11 (73) Bilateral prophylactic mastectomy: 1 (7) Bilater prophylactic oophorectomy: 3 (20) **Relationship status** Married: 14 (93) De facto: 1 (7) **Education** No post-school qualifications: 2 (13) Post-school qualifications: 13 (87) **Relationship length, years**

	Mean (range): 15.6 (6-31) **Children** Mean (range): 1.8 (0-3)
Results	Themes reported in the study were: • Communication patterns among couples – example quote: “If it did come up and we had a short conversation, she approached it as if it wasn’t a possibility like she was talking about someone else.” (Mireskandari 2006, p100) • Partners’ involvement in decision-making – example quote: “I think because I am taking a lot of it in, she feels like I’m confident in what I am doing...I don’t feel like she is doing it and then having to take it all on herself} I am actually taking a lot of the burden off her by making the decision with her. She is not making the decision all by herself I’ve actually helped her to make the decision.” (Mireskandari 2006, p101) • Genetic testing results and mutation status – example quote: “I was shocked, scared about finding out the results. I was taken back. I was upset. I think I wasn’t expecting it, I wasn’t expecting any of it. I was quite upset.” (Mireskandari 2006, p102) • Partners’ information-processing style – example quote: “Basically, my feeling is a very selfish feeli–g - how would I cope in life without h–r - I wouldn’t cope without her. She’s my everything, she is my best friend, my soul mate, my sounding board, the person I like to argue with and we fight, we play, we have fun and she is the mother of my children. And I don–t - I can–t - see life without her, I honestly can’t visual life without her...and to have her taken away from me wasn’t on the cards, wasn’t something I could think about, it’s still not something I could think about...” (Mireskandari 2006, p103) • Partners’ supportive role – example quote: “I feel deficient a lot of the time in the support or the lack of support that I’m actually showing her. I’m not quite sure from time to time whether I should be holding back...or whether to challenge her at the right time, right place. It’s something that constantly causes me difficulty” (Mireskandari 2006, p103) • Support for partners themselves – example quote: “I doubt that I’ve actually talked to anybody much about it, no. I guess probably like most men [laugh] I guess I feel it’s a decision or position that I’ll have to resolve myself.” (Mireskandari 2006, p104) • Partners’ information needs – example quote: “Let me put it this way, I am more informed than her basically because I remember all the statistics and stuff that goes past her, it all sort of bamboozles her a bit, but I listen and make sure I relay it all...so she understands what’s going on as well, so we all know exactly where we’re up to and what’s happening in our lives.” (Mireskandari 2006, p104)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Minor concerns due to a lack of researcher reflexivity, ethical approval was not described nor consideration of ethical issues in study method, and there was no description of how presented data were selected.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Ormondroyd, 2012

Bibliographic Reference	Ormondroyd, Elizabeth; Donnelly, Louise; Moynihan, Clare; Savona, Cornelie; Bancroft, Elizabeth; Evans, D Gareth; Eeles, Rosalind; Lavery, Stuart; Watson, Maggie; Attitudes to reproductive genetic testing in women who had a positive BRCA test before having children: a qualitative analysis.; European journal of human genetics: EJHG; 2012; vol. 20 (no. 1); 4-10

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Royal Marsden, and St Mary's Hospitals
Data collection and analysis	Semi-structured interviews guided by the following open-ended topics: Motivation for having a genetic (BRCA) test, reactions and accommodation to receiving a positive result, effects on reproductive decision making, knowledge of and attitude towards prenatal testing, knowledge of and attitude towards PGD, relative acceptability of PND/PGD, Interviews were analysed using thematic analysis according to an inductive theoretical framework.
Recruitment strategy	Participants were recruited at two UK hospitals (Royal Marsden, and St Mary's Hospitals) and were invited more than 6 months after their BRCA test result. Participant information sheets carried a brief description of prenatal diagnosis (PND) and preimplantation genetic diagnosis (PGD). The study was approved by the Royal Marsden NHS Foundation Trust Ethics Committee.

Study dates	November 2007 until March 2010
Sources of funding	The research was supported by Cancer Research UK (Number C1226 A7920) and NIHR support to the Biomedical Research Centre at The Institute of Cancer Research and RMH.
Inclusion criteria	Women and men aged 18–45 years who tested positive in the preceding 5 years for a pathogenic BRCA1 or BRCA2 mutation, at the time of testing did not have children, were with or without a personal history of cancer (those with a personal history of cancer were not within 2 years of diagnosis), and no serious mental health contraindications.
Exclusion criteria	Not reported
Sample size	n=25 women
Participant characteristics	**Age (years)** 18-25: n=0 26-30: n=8 31-35: n=6 36-40: n=6 41-45: n=5 **Mutation status** Not reported **Cancer diagnosis** Not reported **Education** Not reported

	Sex Female: n=25 Male: n=0 **Surgery** Mastectomy (including treatment/prophylactic): n=15 Oophorectomy (prophylactic): n=2 None: n=8 Cancer diagnosis: n=6 **No of children** 0: n=17 1: n=6 2: n=2 **Ethnicity** White, British: n=20 White, Other: n=5
Results	Overarching themes reported in the study were: • Impact of BRCA result on thoughts about having children – example quote: ”My cancer, in my head, was gone, so I was fine I would make sure it didn’t come back, but now the cancer gene sits here every single day and I can’t do

	anything with it .. (having a child would) increase my risk but it's not even comparable to the gene risk" (Ormondroyd 2012, p6) • Value of life at risk of HBOC – example quote: "Everyone at the table asked the same question to each other …we agreed that if (earlier generations) had decided not to have children then none of us would be there. That was a kind of powerful idea and I think we all wanted to be there" (Ormondroyd 2012, p7) • Awareness of reproductive options and counselling/support needs – example quote: "She [doctor]was definitely under the impression that we'd made a decision but it was actually just so we could learn about the options y she had a power point that she ran through on her laptop and explained the process but I don't think she was geared up to be talking to someone for the first time" (Ormondroyd 2012, p8)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Pedrazzani, 2022

Bibliographic Reference	Pedrazzani, C.; Aceti, M.; Schweighoffer, R.; Kaiser-Grolimund, A.; Burki, N.; Chappuis, P.O.; Graffeo, R.; Monnerat, C.; Pagani, O.; Rabaglio, M.; Katapodi, M.C.; Caiata-Zufferey, M.; The Communication Chain of Genetic Risk: Analyses of Narrative Data Exploring Proband-Provider and Proband-Family Communication in Hereditary Breast and Ovarian Cancer; Journal of Personalized Medicine; 2022; vol. 12 (no. 8); 1249

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	Switzerland

Setting	Women participating in the CASCADE study
Data collection and analysis	Individual semi-structured interviews and focus groups using a guide were undertaken aiming to collect narrative data from a sample of women identified as carriers of hereditary breast and ovarian cancer (HBOC) associated pathogenic variants. The data were analysed using the method of constant comparisons and inductive analysis with focus group data analysed first to identify the topics emerging, followed by analysis of individual interviews to gain a deeper understanding of the experiences.
Recruitment strategy	Individuals were recruited from the CASCADE study, an open-ended cohort designed to elicit factors that enhance cascade genetic screening for HBOC and Lynch syndrome in Switzerland. Confirmed carriers of pathogenic variants were recruited from university centres, cantonal hospitals, and private praxis in three linguistic regions of Switzerland.
Study dates	Between April 2019 and November 2021
Sources of funding	Funded by University of Basel, Forschungsfonds 2017; the Swiss Cancer League—KLS-4294-08-2017 and the Swiss Cancer Research Foundation—KFS-5293-02-2021.
Inclusion criteria	Women who were confirmed carriers of pathogenic variants who were 18 years or older
Exclusion criteria	Not reported
Sample size	n=48 (n=28 individual interviews, n=11 focus groups)
Participant characteristics	**Age at interview (years)** Mean (SD): 51.8 (10.9) **Mutation status** Not reported **Cancer diagnosis** Not reported **Children** Not reported

	Ethnicity White European: n= 38 Ashkenazi Jewish: n=4 Asian: n=1 Unknown: n=5 **One or more previous cancer diagnosis according to linguistic region** French: n=27 German: n=14 Italian: n=7 **Education** ≤High school/Technical school: n=14 Some college/Complete college: n=14 University/Post-graduate degree: n=19 Unknown: n=1
Results	Overarching themes reported in the study: • Communication between healthcare providers and probands: situational challenges: 1. Variability in the approach to family communication – example quote: “I received a letter from the hospital explaining what it was and that I could possibly have the gene mutation and that I should contact Dr . . . And that’s what we did,

	together with the sister. Afterwards we had all the genetic meetings with her. She (the physician) explained it very well. So, for me it was never the case that I was somehow all alone and badly informed." (Pedrazzani 2022, p5) 2. Difficulty in receiving information about family communication – example quote: "So, for me the shock of finding out that I had this mutation was even greater than finding out to have a cancer. I did the test, and I got the results. It was terrible for me because it meant that I could have passed on this mutation to my daughter, and I felt guilt." (Pedrazzani 2022, p5) 3. Inconsistency in the follow-up of the issue of family communication – example quote: "No, let's say they gave me a lot of information all at once at the beginning, so understanding and remembering everything was a bit of a struggle. (. . .) So, I remembered this thing, I told them (family members), but I didn't remember it specifically. Today I came, I spoke again about this thing here (with the physician) because I had not well understood it (. . .) I could resume some aspects that I had not understood, because it is not obvious on so many things to understand them all obviously." (Pedrazzani 2022, p5) • Probands' decision-making regarding family communication: multiple logics of action: 1. Responsibility – example quote: "I did my part. I explained to them (my relatives) what had happened to me. What could possibly happen to them... Or not. I hope it never happens to them. But I thought it was important to communicate on the subject… It has been a burden on me that. I mean it's not easy, to take the step, to do that, it's hyper personal anyway…" (Pedrazzani 2022, p7) 2. Self-preservation – example quote: "It was difficult to communicate that I was ill…So only my sister knew and I only decided to tell my parents when I got home. Also, because I spent 3–4 days crying all day long . . .It was clear that I was ill but I didn't... I didn't say it because I was mad as hell, honestly, I was mad at the world. I didn't want to say it out loud so it became reality even if it was reality. . .The looks of pity as if I were going to die at any moment. I won't say... maybe because of those looks I never said it." (Pedrazzani 2022, p8) 3. Protection of others – example quote: "I never talked to my sister, I don't even know how she reacted (to my situation). She is scared (about cancer). She's really scared. She's always been afraid." (Pedrazzani 2022, p8) • Proband-mediated communication: the complexity of arbitration and the urgency of support: 1. The complexity of arbitration – example quote: "I did not tell to my father because this will take on enormous proportions for him and me, it will add something to me." (Pedrazzani 2022, p36)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Ratnayake, 2011

Bibliographic Reference	Ratnayake, Paboda; Wakefield, Claire E; Meiser, Bettina; Suthers, Graeme; Price, Melanie A; Duffy, Jessica; Kathleen Cuningham National Consortium for Research into Familial Breast, Cancer; Tucker, Kathy; An exploration of the communication preferences regarding genetic testing in individuals from families with identified breast/ovarian cancer mutations.; Familial cancer; 2011; vol. 10 (no. 1); 97-105

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	The Kathleen Cunningham Foundation Consortium for Research into Familial Aspects of Breast Cancer (kConFab) which is a research co-operative which has recruited more than 10,000 individuals with a strong family history of breast and/or ovarian cancer, many of whom have never attended a family cancer clinic for advice
Data collection and analysis	Semi-structured telephone interviews probing first participants' understanding of the role of services provided by familial cancer clinics in Australia, and then asking the participants to describe their personal experiences of genetic testing and disclosure of their test results and cancer risk with their family members and then to describe their information support needs and preferences when communicating with their relatives about hereditary cancer and genetic testing availability. 4 interview schedules were prepared, with variations in the wording of interview questions to ensure the applicability of questions to the four anticipated naturally occurring groups of participants.

	The conceptual framework of Miles and Huberman was used to guide data collection and analysis, which took place concurrently, with newly emerging themes used to create new lines of questioning for subsequent interviews
Recruitment strategy	Recruitment of participants through kConFab
Study dates	Not reported
Sources of funding	kConFab is supported by grants from the National Breast Cancer Foundation, the National Health and Medical Research Council (NHMRC) and by the Queensland Cancer Fund, the Cancer Councils of New South Wales, Victoria, Tasmania and South Australia, and the Cancer Foundation of Western Australia. One author is supported by a Postdoctoral Training Fellowship from the National Health and Medical Research Council of Australia (ID 510421) and another by a Career Development Award from The National Health and Medical Research Council of Australia (ID 350989).
Inclusion criteria	Being from a family with identified BRCA1 or BRCA2 mutations; being 18 years of age or older; and having sufficient English skills to enable participation in a telephone interview
Exclusion criteria	Not reported
Sample size	n=53 but interviewed n=50; n=39 purposively selected for transcription and qualitative analysis
Participant characteristics	**Sex** Male: n=11 Female: n=28 **Age (years)** Range: 20-71, mean 58 (SD 12.11) **Mutation status** Not reported **Ethnicity** Not reported

	Children Not reported **Educational level:** No post-school qualifications: n=17 Post-school qualifications: n=22 **Genetic testing result as disclosed through familial cancer clinic** BRCA1/2 positive: n=15 BRCA1/2 negative: n=13 Awaiting result: n=2 Not disclosed: n=9 **Previous cancer diagnosis** Breast: n=8 Ovarian: n=1 Prostate: n=0 Other type of cancer (except non-melanoma skin cancer): n=4
Results	Themes reported in the study were: • Communication about genetic testing results with other family members – example quote: 'Most assuredly I think it's my duty. Whether they did it [predictive genetic testing], or not, that's their choice, but I felt very, very strongly that it was my responsibility to pass it on to any members of the family" (Ratnayake 2010, 101)

	• Preferred support to assist with the communication of increased genetic risk and the availability of genetic testing to other family members – example quote: “I would love a brochure that I could actually pass [on].” (Ratnayake 2010, p102)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Samson, 2014

Bibliographic Reference	Samson, A; DiMillo, J; Theriault, A; Lowry, S; Corsini, L; Verma, S; Tomiak, E; Living with the BRCA1 and BRCA2 genetic mutation: learning how to adapt to a virtual chronic illness.; Psychology, health & medicine; 2014; vol. 19 (no. 1); 103-14

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Canada
Setting	Specialised risk assessment clinic
Data collection and analysis	Semi-structured interviews taking a grounded theory approach and undertaking data collection and analysis concurrently allowing initial interviews and analysis to shape future interview questions and guide further data collection in order to better understand the participants’ experiences.

Recruitment strategy	Women were recruited at a specialized risk assessment clinic through invitation letters disseminated by a designated nurse.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Participants were French or English-speaking women who had undergone genetic testing for hereditary breast/ovarian cancer (HBOC) and who had received a positive test result indicating that they carried a deleterious mutation in BRCA1 or BRCA2.
Exclusion criteria	Women undergoing screening for ovarian cancer due to an HBOC genetic mutation
Sample size	N=6
Participant characteristics	**Age (years)** Mean: 38.5 Range: 31-44 **Age at receipt of positive test result (years)** Mean: 35.5 Range: 30-39 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity**

	Not reported **Age of children (years)** Mean: 8.75 Range: 20 mont–s - 19 years **Urban: Rural home (ratio)** 4:2 **College: University (ratio)** 2:4 **Sought additional care** n=1
Results	Themes reported in the study: • Physical task: attempting to limit the impact of the test result – example quot“: "I basically went home, and we cleaned out the cleaners. My husband and I we researched, uh the chemicals that are in, um, our products, to see, you know the; th’re's so many products, chemicals that imitate hormones, especially estrogen… I thought well, with the girls, t’ey're [young], I should start no‘. 'Cause for me, in my case’ I'm [older], whatever happened in the past, I ’an't change. But, I knew I could do something for t”em" (Samson 2014, p112) • Psychological task: living with uncertainty – example quot“: "… as far as just knowing? Then no. I think if anything, it empowered me more to do something with myself instead of just, you know, floating along and thinkin’ I'll be alive til’ I'm 80 someth”ng" (Samson 2014, p112) • Social task: finding effective support – example quot“: "So I, as soon as she, as soon as she was diagnosed with breast cancer I actually felt a bond with her. And then to find out after; because when she would talk to me I already knew all of this stuff, and of course she, she d’dn't know I was BRCA2 positive. Um, until pretty much when she was through all her chemo and radiation and then, and then she started talking about getting tested and stuff and t’at's

	when I told he‘; 'cause like I said I ’on't tell people tha’ I'm (laughs); I ’on't tell people... Well I thought that she cou–d - yeah exactly. I thought she would understa”d." (Samson 2014, p113)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Moderate concerns due to a lack of detail reported on data collection and data analysis, and no discussion of data saturation. There were some concerns about the potential influence of researchers on study findings, ethical approval was not described and there was a lack of discussion about the credibility of the findings)*
Overall risk of bias and relevance	Relevance	Relevant *(Data not separated for at-risk ovarian and breast cancer patients)*

Seenandan-Sookdeo, 2016

Bibliographic Reference	Seenandan-Sookdeo, Kendra-Ann I; Hack, Thomas F; Lobchuk, Michelle; Murphy, Leigh; Marles, Sandra; Parental Decision Making Regarding the Disclosure or Nondisclosure of a Mutation-Positive BRCA1/2 Test Result to Minors.; Oncology nursing forum; 2016; vol. 43 (no. 3); 330-41

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Canada
Setting	A western Canadian hereditary breast and ovarian cancer clinic

Data collection and analysis	Semi structured interviews based on Hermeneutic phenomenology, an interpretive approach rooted in the study of the lived human experience were conducted using a conversation script consisting of open-ended questions designed to elicit parents' decision-making processes, experiences, and perceptions regarding the disclosure or nondisclosure of mutation positive BRCA1/2 test results to minors. Van Manen's selective approach was used for data analysis because it reflects the underpinnings of hermeneutic phenomenology.
Recruitment strategy	The genetic counsellor offered eligible participants recruitment packages. Interested participants contacted the principal investigator (PI) directly by telephone to review the study's eligibility criteria and their role in the study. During the initial telephone contact (initiated by potential participants), the PI reviewed the study criteria, answered questions, and instructed interested participants to forward signed consent forms and completed demographic information.
Study dates	Between 2008 and 2012
Sources of funding	Funded by Hack's Canadian Breast Cancer Foundation (Prairies/ NWT) Chair in Psychosocial and Supportive Care Oncology Research, the Foundation for Registered Nurses of Manitoba, Inc., Graduate Award, the Marion Saydak Memorial Scholarship, and Lesley F. Degner's Chair in Evidence-Based Nursing Practice Graduate Studies Tuition Award from the Canadian Institute of Health Research, all awarded to one author.
Inclusion criteria	• Able to speak and read English • Aged 18 years or older • Received a positive BRCA1/2 test result from a hereditary breast and ovarian cancer clinic • Had at least one child who, at the time of disclosure, was aged 6–18 years • Had child who, at the time of the initial research conversation, was aged younger than 19 years • Either disclosed or did not disclose to a minor a positive BRCA1/2 test result within one year of receipt • Received a positive BRCA1/2 test result between January 1, 2008, and December 31, 2012
Exclusion criteria	Not reported
Sample size	n=15 women with a positive BRCA1/2 result
Participant characteristics	**Age at interview (years)** Median (range): 44 (28-54) **Children**

	Not reported **Gender** Female: n=15 **BRCA1/2 status** BRCA1: n=6 BRCA2: n=9 **Cancer status** Affected: n=8 (n=6 had breast cancer and n=2 had ovarian cancer) Unaffected: n=7 **Ethnic background** Caucasian: n=9 Ashkenazi Jewish: n=3 Icelandic: n=2 Ukrainian: n=1 **Education level** High school: n=2 Community or technical college: n=5

	University (undergraduate studies): n=6 University (graduate studies): n=2
Results	Overarching themes reported in the study: • Influential factors: 1. age, condition, maturity of children 2. emotional readiness 3. gender 4. timing 5. honesty • Parental decision making – example quote: “I don’t know if I looked for any. My only support system would have been my husband. We had a discussion ourselves [about] how much information we were going to give them.” (Seenandan-Sookdeo 2016, p335) • Supportive resources – example quote: “Support was always there through [name of member of genetics team], my family doctor, and my sisters. I mean, I had that. I just had made up my mind and didn’t think it was a big deal at the time. . . . I’ve never heard anybody ask about [disclosure]. . . . I think they could bring it up, like, “Have you [thought] about whether or not you’ll talk to your children at some point about this?” (Seenandan-Sookdeo 2016, p336) • The inner circle – example quote: “We just sat down and explained to them what the results or findings were and . . . risk-wise, what that meant for me personally and then, risk-wise, what that meant for them being male, [and] how I was going to proceed with this information and and what a positive, really positive bit of news it is in that we have the ability then to take that information and be proactive about it. So, we very much viewed this information as a positive in our lives.” (Seenandan-Sookdeo 2016, p337) • Knowledge deficit – example quote: “It does become sort of less clear to me with a male. I mean, obviously, a son, if they marry and have children . . . they have the potential to have daughters. I’m not sure at what point it sort of becomes more important for him to have this information because how would it change what medical follow-up he has at this point?” (Seenandan-Sookdeo 2016, p337) • Parental recommendations – example quote: “Is there some type of place you could go to help you choose your words for them to understand at their level? Or some type of visual [on the] Internet where you can go for a visual presentation for them to understand at their level?” (Seenandan-Sookdeo 2016, p338) • Deficiency in the information and support provided – example quote: “I mean, any healthcare provider or doctor in explaining to somebody that they have this genetic result should take it a step further. If you want to share the

	information with [your children], but you're not sure how to do it, you know, maybe there could be some assistance in that regard." (Seenandan-Sookdeo 2016, p334)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Shilling, 2020

Bibliographic Reference	Shilling, V.; Catt, S.; Jenkins, V.; Fallowfield, L.; Using patient perspectives to inform communication training materials for health care professionals discussing BRCA mutation testing; Breast Cancer Research and Treatment; 2020; vol. 184 (no. 2); 491-498

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting	BRCA support groups and family history clinics.
Data collection and analysis	Semi-structured interviews focused around five broad topics: discussion of risk and presentation of risk information; information needs and information provided; communication style and approach; understanding; decision-making. The interviews were analysed using a thematic analysis with the framework approach applied.

Recruitment strategy	Participants were recruited via BRCA support groups and family history clinics. The invitation was circulated by group coordinators; those interested contacted SHORE-C researchers directly. Potential interviewees were sent the Participant Information Sheet in advance of a telephone call from a researcher. Though largely a sample of convenience, the researchers purposely sampled women who already had a breast cancer diagnosis, together with others without breast cancer who had tested positive for a gene mutation and who may have had risk reducing surgery.
Study dates	Not reported. Before 2020
Sources of funding	This study was funded by a grant awarded to Professor Dame Lesley Fallowfield by the Breast Cancer Research Foundation
Inclusion criteria	Women with a known B1/2 gene mutation who were over 18 years of age and able to speak and read English were eligible for the study.
Exclusion criteria	Women in the process of genetic testing without a known result were excluded.
Sample size	n=11 women with a known BBRAC1/2 gene mutation
Participant characteristics	**Mutation status:** BRCA1: 4 BRCA2: 7 **Age** Range: 38 -77 **Time since BRCA diagnosis** Range (years): –1 - 20 **Cancer diagnosis** Not reported **Ethnicity**

	Not reported **Education** Not reported **Children** Not reported **Marital status:** Married/partner: 10 Widow: 1 **Employment status:** Full-time/part-time 10 Retired: 1
Results	Themes reported in the study were: • Risk: Communication style and delivery of information – example quote: “My mum […] just wants to be told what’s the best thing to do and get on with it and she puts her head in the sand. Whereas I need to know my percentage of risk.” (Shilling 2020, p493) • Risk: not understanding the full details – example quote: “I’ve come away with, at the moment, I’m 65% lifetime risk. They have talked to me about the yearly risk figures, but I get too confused. And I know it’s cumulative, but it doesn’t really mean anything to me.” (Shilling 2020, p493) • Decision-making being influenced by family experiences – example quote: “I think because I knew that those two people had actually got a gene fault. As soon as I knew I had it, it was like crikey, I just want, I want shot of anything that might put me at the same sort of risk as they had really.” (Shilling 2020, p494) • Empowerment – example quote: “As my godmother said to me, who also had this gene mutation […] information is power, and if you know you’ve got it you can do something about it.” (Shilling 2020, p495)

	• Information and understanding – example quote: “Perhaps you’re better off just having the blood test. And then, saying to you, right, if you test positive for this gene fault, then we invite you to come up here to discuss it all.” (Shilling 2020, p495) • Communication and improvement – example quote: “How do you understand information? How do you make decisions? […] that could be the first thing and then that sets the basis of the relationship.” (Shilling 2020, p495) • Accessing the system: process and frustration – example quote: “I felt like I’ve been frustrated because by the time that I went to the genetic counsellor, I’d been trying for three years to get it” (Shilling 2020, p495); “And now I’ve had my oophorectomy, there’s been no sort of follow-up. Which I suppose there’s no need for it, but I think it would be nice if you could have […] OK, you’ve had this now, you’ve reduced your risk to this, and just a bit more discussion about the next step.” (Shilling 2020, p495) • Emotional and social drivers – example quote: “All BRCA people I think are making decisions in the context of previous experience. We have trauma through multiple diagnoses or deaths or whatever in our families, of other people, which has affected us and we are making our decisions based on that. It’s not just the scientific risk of what our particular gene means to us scientifically and from a biological perspective. It’s what you’ve experienced psychologically also is influencing your decision-making.” (Shilling 2020, p496)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Smits, 2016

Bibliographic Reference	Smits, S; Boivin, J; Menon, U; Brain, K; The double-edged sword of ovarian cancer information for women at increased risk who have previously taken part in screening.; Ecancermedicalscience; 2016; vol. 10; 650

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Wales and England, United Kingdom
Setting	Interviews were conducted in the participants homes
Data collection and analysis	Semi-structured interviews informed by the topic guide covering Ovarian Cancer (OC) symptom perceptions, experience of symptoms, and anticipated presentation in the presence of OC symptoms. Other topics that arose during interviews were explored through the use of probes and prompts. Transcripts were analysed using interpretative phenomenological analysis using an iterative process.
Recruitment strategy	Participants were a subset of women who had taken part in an earlier quantitative study of the determinants of anticipated presentation with Ovarian Cancer symptoms and prior to that a psychological evaluation of familial OC screening (PsyFOCS) among women at increased risk of OC. The subset interviewed were purposively selected for recruitment to reflect a variety of ratings of what women would do if they experienced symptoms of OC, levels of OC worry, and geographical proximity (women within two hours travelling distance of the Cardiff research base). Participants were sent study invitation materials and once consent had been obtained, the researcher telephoned to answer any questions about the research study and arranged an interview time. At the time of the interview, participants completed a further consent form and were given the opportunity to ask questions. Cardiff University School of Medicine Research Ethics Committee provided approval for this study.
Study dates	Not reported
Sources of funding	Stephanie Smits was funded through a PhD studentship which received 50% funding support from the Medical Research Council and 50% from Cardiff University. Usha Menon was supported by the National Institute for Health Research, University College London Hospitals Biomedical Research Centre.
Inclusion criteria	Women who had taken part in an earlier quantitative study and a psychological evaluation of familial OC screening (PsyFOCS), who reflected a variety of ratings of what women would do if they experienced symptoms of OC and levels of OC worry (the sample that the subsets were selected from had an average worry score of 6.2, standard deviation 1.9, range 3–12), and who lived within two hours travelling distance of the Cardiff research base
Exclusion criteria	Not reported

Sample size	n=9
Participant characteristics	**Age (years)** Range: 44-77 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Not reported **Children** Not reported **Years in Ovarian Screening** Range: 1-10 **Anticipated presentation time** Immediately: n=4

	Up to 1 week: n=3 Over 3 weeks: n=2
Results	Overarching themes reported in the study were: • Ovarian cancer symptom information sources – example quote: “It can be overwhelming sometimes, you get too much information” (Smits 2016, p6) • Personal barriers and facilitators – example quote: “If you’re armed with that information then the doctors can’t say ‘oh you’ll be all right, love, you know, it’s just a bit of ageing and diverticulitis or whatever’. If you actually know that information, it’s easier to push” (Smits 2016, p6) • System barriers and facilitators – example quote: “You would have to go through it all [family history] and whatever… you’ve got to keep going through the same thing all the time.” (Smits 2016, p6)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Wakefield, 2011

Bibliographic Reference	Wakefield, C.E.; Ratnayake, P.; Meiser, B.; Suthers, G.; Price, M.A.; Duffy, J.; Tucker” “"For all my family’s sake, I should go and fin” ”ut": An Australian report on genetic counceling and testing uptake in individuals at high risk of breast and/or ovarian cancer; Genetic Testing and Molecular Biomarkers; 2011; vol. 15 (no. 6); 379-385

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	Research co-operative that recruits families
Data collection and analysis	Semi-structured interviews firstly probing participants' reported reasons for and against genetic counselling attendance and genetic testing uptake and secondly exploring their communication preferences regarding genetic testing. Interviews were analysed using the conceptual framework of Miles and Huberman, with data collection and analysis taking place concurrently and newly emerging themes used to create new lines of questioning for the following interviews.
Recruitment strategy	39 participants who were recruited through the Kathleen Cunningham Foundation Consortium for Research into Familial Aspects of Breast Cancer (kCon-Fab). kConFab is a research co-operative that recruits families with four or more cases of breast or ovarian cancer on one side of the family and two or more living affected relatives with breast or ovarian cancer and four or more living first- or second-degree unaffected female relatives of affected cases
Study dates	Not reported. Before 2011
Sources of funding	NHMRC grants
Inclusion criteria	Being from a family with an identified BRCA1 and/or BRCA2 mutation; being 18 years of age or older; and having sufficient English skills to enable participation in a telephone interview.
Exclusion criteria	None
Sample size	n=39 relatives of high-risk mutation carriers
Participant characteristics	**Age, mean (SD), years** 58 (12.11) **Mutation status** Not reported

	Cancer diagnosis Not reported **Ethnicity** Not reported **Children** Not reported **Sex** Male: 11 **Educational level** No post-school qualifications 17 Post-school qualifications 22 **Marital status** Married or living as married 24 Separated 8 Widowed or never married 7 **Genetic testing result** Positive 15

	Negative 13 Awaiting result 2 Not disclosed 9
Results	Themes reported in the study: • Attend–d - having a strong family history – example quote: ‘‘My grandmother had had ovarian cancer many years ago and with that knowledge we decided it would be a good idea to get it do”e." (Wakefield 2011, p381) • Attend–d - requests from relatives – example quote: ‘‘Because my aunt cracked the whip . . . She cracked the whip and we all did as we were told.’’ (Wakefield 2011, p381) • Attend–d - prevention and risk management – example quote: ‘‘So I could make an informed decision as to what to do from then on.’’ (Wakefield 2011, p381) • Attend–d - to help scientific research – example quote: ‘‘Maybe it mightn’t help us but it might help somebody one day.’’ (Wakefield 2011, p382) • Attend–d - asked to have genetic testing by a family member – example quote: ‘‘My cousin who died who was the one who turned out that she was BRCA1 [carrier] and wanted us to get tested, she kind of made us promise we’d do it ourselves before she died.’’ (Wakefield 2011, p382) • Attend–d - benefit for children/family – example quote: “I was probably upset that I may have it and then I thought that for all my family’s sake I should go and find out.’’ (Wakefield 2011, p382) • Did not atte–d - not had the time to attend – example quote: ‘‘I had a letter from . . . kConFab, yes, advising me that a gene had been located . . . I was given an option of going further in finding out more about it, which I have accepted, but so far I haven’t done the next step . . . there wasn’t any urgency . . . it’s a little bit awkward for me to get a day off.’’ (Wakefield 2011, p381) • Did not atte–d - don’t believe it but curious – example quote: ‘‘just for curiosity . . . I don’t know if I’d believe it all, but I’d be open to it’. (Wakefield 2011, p381) • Did not atte–d - believe external factors causing cancer – example quote: ‘‘I just feel, you know, we create a lot of our own issues and we can even change our DNA . . . I know why I got cancer . . . I was very careless with chemicals. I used to be spraying the garden, trying to have the best roses and it would drift over me.’’ (Wakefield 2011, p381) • Did not atte–d - do not value genetic counselling – example quote: ‘‘I tell my daughter; just because that was my experience in life she doesn’t need to get it . . . I believe that the body has the power to heal itself.’’ (Wakefield 2011, p382) • Did not atte–d - did not know about the services – example quote: ‘‘No, I’ve actually never heard of it [an familial cancer clinic].’’ (Wakefield 2011, p382)

	• Did not atte–d - testing not accessible – example quote: 'KConFab sent out a recommendation to go and get tested, which I haven't done . . . I'm keen to have the gene test but just haven't managed to coordinate it yet.'' (Wakefield 2011, p382) • Did not atte–d - it would not alter behaviour – example quote: ''It wasn't necessarily going to change anything if the gene was there or not in terms of my lifestyle, you know, I exercise, am healthy, you know, I don't smoke. I do all those things anyway so if I knew it wasn't going to change my life.'' (Wakefield 2011, p382)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Wright, 2018

Bibliographic Reference	Wright, Sarah; Porteous, Mary; Stirling, Diane; Lawton, Julia; Young, Oliver; Gourley, Charlie; Hallowell, Nina; Patients' Views of Treatment-Focused Genetic Testing (TFGT): Some Lessons for the Mainstreaming of BRCA1 and BRCA2 Testing.; Journal of genetic counselling; 2018

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting	Hospital

Data collection and analysis	Semi-structured, interviews using a topic guide on: diagnosis of cancer; family history of cancer; expectations and experiences of genetic testing; relevance of TFGT for self and family; views on mainstreaming and/or the timing of testing in relation to cancer diagnosis and opinions about care. Field-notes were also kept of observations at the weekly breast multi-disciplinary team meeting and in the "new patient" gynaecology clinic. The data were analysed using a thematic analysis and taking an inductive and deductive approach.
Recruitment strategy	Patients were recruited from a teaching hospital in the UK. Breast cancer patients were identified by the clinical genetics department. Ovarian cancer patients received information packs from their oncologist when they presented for check-ups and were given the opportunity to speak to SW in a separate clinic area if they expressed an interest in participation. in addition, consultants were asked to use professional discretion in introducing the study to individual patients, so as to prevent women who were particularly upset during consultation from being approached.
Study dates	January to November 2017
Sources of funding	Breast Cancer Now
Inclusion criteria	Having been offered TFGT; being over 18 years of age; and, being a native English speaker.
Exclusion criteria	None
Sample size	n=26 patients with breast or ovarian cancer who had undergone genetic testing
Participant characteristics	**Patients with breast cancer** **Age** Mean 48 Range 33–62 **Mutation status** Not reported **Cancer diagnosis** Not reported

	Ethnicity Not reported **Education** Not reported **Marital status** Married/Partner 15 Single 2 Divorced 1 **Children** Yes 14 Yes (adopted/non-biological) 1 No 3 **Employment** Employed 10 Unemployed/not working 4 Retired 4 **Time since cancer diagnosis** > 2 years 1 < 2 years 17 **Timing of BRCA test** Prior to any treatment 5 During neo-adjuvant chemotherapy 7 After wide local excision 6 After surgery (ovarian) – **BRCA result** Pathogenic variant 4 No known pathogenic mutation found 12 VUS 2

	Self-reported family history of cancer None/none known, + past cancer diagnosis – None/none known 3 ≥ 1 first- and second-degree relative (BRCA and/or OVCA) 2 ≥ 1 first-degree relatives (BRCA and/or OVCA) 7 ≥ 1 second-degree relatives (BRCA and/or OVCA) 2 ≥ 1 first-degree relatives (other cancer) 4 **Anticipated and/or previously asked for genetic test?** Yes 8 No 10 **<u>Patients with ovarian cancer</u>** **Age** Mean 64 Range 48–82 **Mutation status** Not reported **Cancer diagnosis** Not reported **Ethnicity** Not reported **Education** Not reported **Marital status** Married/Partner 8 Single – Divorced – **Children** Yes 8

	Yes (adopted/non-biological) – No – **Employment** Employed – Unemployed/not working 4 Retired 4 **Time since cancer diagnosis** > 2 years 1 < 2 years 7 **Timing of BRCA test** Prior to any treatment – During neo-adjuvant chemotherapy – After wide local excision – After surgery (ovarian) 8 **BRCA result** Pathogenic variant 4 No known pathogenic mutation found 4 VUS – **Self-reported family history of cancer** None/none known, + past cancer diagnosis 1 None/none known 2 ≥ 1 first- and second-degree relative (BRCA and/or OVCA) 1 ≥ 1 first-degree relatives (BRCA and/or OVCA) 1 ≥ 1 second-degree relatives (BRCA and/or OVCA) 1 ≥ 1 first-degree relatives (other cancer) 2 **Anticipated and/or previously asked for genetic test?** Yes 2 No 6
Results	Themes reported in the study:

	• The Offer of genetic testing: Initial Reactions – example quote: “I went to see oncologist and she said”, "I think it’s a good idea if we check for the BRCA gene at this point." Which made me quite angry because I felt that had I had it done when I’d asked for it two years before I could have avoided all of this.” (Wright 2018, p1464) • Views of Care Pathways: Timing of genetic testing in Relation to Cancer Treatment – example quote: “No I didnae sort of think, oh my God no, something else, you know. I was quite willing, you know. I don’t know, I think I just, to me it’s just all, it was just partly what I needed to do, kind of thing, you know.” (Wright 2018, p1466) • Participants’ Motivations for Undergoing genetic testing: Constructing Hope for Prevention – example quote: “I was more concerned that they were carrying it than whether I had it or not, because, well, I wasn’t as young [laughing] as I used to be, and you know, I’d had, I’d got the cancer so, you know … That was, that was my main reason was to see if they were all right, and if they needed to be tested.” (Wright 2018, p1467)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No reflexivity)*
Overall risk of bias and relevance	Relevance	Highly relevant

Young, 2019

Bibliographic Reference	Young, Alison Luk; Butow, Phyllis N; Rhodes, Paul; Tucker, Katherine M; Williams, Rachel; Healey, Emma; Wakefield, Claire E; Talking across generations: Family communication about BRCA1 and BRCA2 genetic cancer risk.; Journal of genetic counceling; 2019; vol. 28 (no. 3); 516-532

Study Characteristics

Study type	General qualitative inquiry

Country/ies where study was carried out	Australia
Setting	Metropolitan and regional genetic clinics in Australia that provide genetic testing services
Data collection and analysis	Semi-structured interviews conducted either for patients and relatives together or individually (participants who had not shared their genetic test results with their relatives or who were not comfortable being interviewed with relatives and young adults to provide privacy and autonomy in their response to questions relating to their personal experiences of family communication and preferences for resources and support) on questions related to family dynamics and attitudes toward hereditary cancer, and the content and process of communication among family members. The interviews were analysed using in-depth thematic analysis taking a family systems theory approach.
Recruitment strategy	Participants were recruited from four metropolitan and regional genetic clinics in Australia that had provided genetic testing services to at least one member of the family and were invited to participate through a mailed study package. Some families expressed their interest in participation at a genetic information day, where the study was introduced to attendees. A researcher made phone contact to answer questions, confirm consent and inquire whether relatives were interested in participation. Suitable times were arranged for family and young adult interviews. Questionnaires were completed online or in written form prior to the interview. All participants signed a written consent form. Ethics approval was obtained from the relevant hospitals.
Study dates	Between 2016 and 2017
Sources of funding	Authors were supported by the School of Psychology Margaret Stewart Fund Scholarship and a Career Development Fellowship from the National Health and Medical Research Council of Australia. The Behavioural Sciences Unit at the Kids Cancer Centre is supported by the Kids with Cancer Foundation and the research was conducted to fulfil a Doctor of Philosophy degree requirement.
Inclusion criteria	Young adults aged 18–40 years old and their relatives, with at least one member of the family having a BRCA1/2 pathogenic variant, identified during index or predictive search genetic testing between 6 months and 20 years prior to recruitment. Respective husbands or partners of both carriers and young adult offspring were also eligible to participate.
Exclusion criteria	Individuals who were unable to converse in English, and/or considered by a health professional to have a condition that would significantly interfere with their ability to understand the requirements of the study
Sample size	n=21 families (n=67 young adults and their relatives)

Participant characteristics	**Age (years)** Mean (SD): 44.87 (17.47) Range: 18-87 **Mutation status** Not reported **Cancer diagnosis** Not reported **Family members, no (%)** Young adults: n=32 (47.76) Parents: n=23 (34.33) Grandparents: n=2 (2.99) Aunts/uncles: n=6 (8.96) Partners (male): n=3 (4.48) Non-biological sister: n=1 (1.49) **Race, no (%)** Caucasian: n=44 (65.67) Caucasian with Jewish ancestry n=11 (16.42)

	Other: n=12 (17.91) **Education, no (%)** High school graduate or below: n=11 (16.67) Diploma or college: n=24 (36.36) University degree: n=21 (31.82) Post-graduate degree: n=10 (15.15) **Among women, n=49** Had risk reducing mastectomy: n=16 (32.65) Had risk reducing hysterectomy/oophorectomy: n=12 (24.49) Cancer diagnosis: n=9 (13.43) **Results of BR½1/2 testing, no (%)** Positive test result: n=38 (56.72) Negative test result: n=6 (8.95) Not tested (at-risk): n=8 (11.94) Not tested (spouse, partners): n=15 (22.39) **Time since BR½1/2 testing, n=44** Less than 1 year ago: n=2 (4.54)

	Between 1 and 5 years ago: n=24 (54.55) Between 5 and 10 years ago: n=11 (25) Greater than 10 years ago: n=7 (15.91) **Children** Not reported
Results	Themes reported in the study were: • A responsibility to protect – example quote: “Well, mum was the first one, the pioneer, and un- fortunately she lost her life to it. We were fortunate enough to be informed that we could prevent it, so she [sister] was second in line and just sort of done it better. Then I was third in line, so I did it better than her” (Young 2019, p521) • ’It's a ’women's problem” – example quote: “His sister had already been tested previously but nobody had ever mentioned once, that because she had the gene he could have the gene, we ’didn't know that it would pass through the male line…if they had said it earlier on he may have got tested” (Young 2019, p525) • Family culture influences communication – example quote: ’It's that I think her natural reaction is just stress and’it's’ going to be quite overbearing stress when ’ou're just trying to manage your own feelings.” (Young 2019, p525) • Adversarial growth and connection – example quote: “As much as our family are very loving and very supportive, they don't get it… having a [carrier] sister…I can get on the phone sometimes and we can just say - blurt out anything - and we get it. We really do get it.” (Young 2019, p526) • Key events can be relational turning points – example quote: “It definitely brought the partners into the family closer and, you know, everyone has a look at each other’s boobs…I guess we were open as much as we could with each other so that that made the journey easier for each other.” (Young 2019, p526) • Health professionals can help facilitate communication and emotional support – example quote: “I didn't know that mum felt guilty…and [aunt said]…‘awh it sucks that my sister is going through this’, so…maybe it is good for…a health professional to probe and ask questions, and go, oh you felt this but you didn't know that she felt this…and I can go, ‘that's a stupid thing to feel, mum ’don't feel guilty about that’…” (Young 2019, p527)

Critical apprais–l - NGA Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Appendix E Forest plots

Forest plots for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE tables for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Table 4: Evidence profile for Theme 1: Deficiency in the information and support provided

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme 1.A: More information needed on cancer surveillance including CA-125 testing, and surgery					
3[a]	3 studies using semi-structured interviews	Women did not know what to expect at their ovarian clinic appointment, such as transvaginal ultrasound and blood samples being taken for CA-125 testing. They reported being unclear about the significance of raised CA-125 levels and felt they had not received enough information. Concerns were also raised regarding the surveillance process and delivery of results. Women did not feel reassured about their negative results, and worried that ovarian cancer may have been missed. Women reported concerns about the detrimental consequences of early menopause following oophorectomy and suggested that HRT options might only be offered if you had access to a good gynaecologist. Women were unsure about surgery but reported they would probably go ahead once they had received further information. "I hadn't realised that you can still get ovarian cancer after you have had your ovaries removed…I thought when I was opting for surgery that was that, but apparently not…at 2 % I don't think I'd trot off for a blood test mmm don't know…the screening wouldn't show it up anyway, would it?" (Lifford 2013, p24)	Methodological limitations	Minor concerns as per CASP qualitative checklist *No explanation of recruitment approach, researcher reflexivity and how presented data was selected.*	Moderate
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 1.B: Need for more support following oophorectomy					
1 (Shilling 2020)	1 study using semi-structured interviews	Women expressed disappointment with the follow-up provided after oophorectomy and reported feelings of abandonment. "And now I've had my oophorectomy, there's been no sort of follow-up. Which I suppose there's no need for it, but I think it would be nice if you could have […] OK, you've had this now, you've reduced your risk to this, and just a bit more discussion about the next step." (Shilling 2020, 495)	Methodological limitations	None or very minor concerns	Low
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 1.C: More information needed on male genetic risk					
5[b]	4 studies using semi-structured interviews; 1 study using semi-structured interviews and focus groups	Women and their family members reported a lack of information around the genetic link with ovarian cancer and males. Women reported uncertainty in how to proceed with information on their own genetic status with their male children. Communication with males was minimal and there tended to be a belief that genetic risk was a wo'an's problem, perpetuating a lack of clarity around how it affects men. Males themselves appeared unclear about the purpose or implications of genetic testing and risk reducing measures available to them. "His sister had already been tested previously but nobody had ever mentioned once, that because she had the gene he could have the gene, we'd'dn't know that it would pass through the male line…if they had said it earlier on he may have got tested" (Young 2019, p525)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of discussion of data saturation, researcher reflexivity, ethical approval, ethical issues, how presented data was selected and discussion of*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				contradictory data	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.D: More information needed on the benefits of genetic testing					
4[c]	4 studies using semi-structured interviews	Women and their families reported a lack of understanding about what genetic testing means, and uncertainty about what could be done if a variant was detected. This led to ambivalence around testing as women struggled to see the added value of knowing their mutation status. "It doesn't really mean that much because you still don't really know you're going to get it it's not really going to help you... Information that is a little bit scary but not amazingly useful." (Dancyger 2010, p1293)	Methodological limitations	Minor concerns as per CASP qualitative checklist *No mention of ethics. No reflexivity from researcher on their role and impact on their research*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.E: More information and support needed on how and when to inform family members about genetic risk					
4[d]	1 study using semi-structured interviews; 2 studies using semi-	Women expressed a desire for help and advice on how best to communicate genetic risk within the family, particularly around how and when to communicate genetic risk to children. Women wrestled around choices of disclosure and non-disclosure and expressed a need for some advice or support around this. Some women reported that	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
	structured interviews and focus groups; 1 study using focus groups	neither the genetic specialist nor other providers addressed the topic of family communication. "I mean, any healthcare provider or doctor in explaining to somebody that they have this genetic result should take it a step further. If you want to share the information with [your children], but you're not sure how to do it, you know, maybe there could be some assistance in that regard." (Seenandan-Sookdeo 2016, p334)		*reflexivity, no description of how presented data were selected, nor discussion of contradictory data.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 1.F: More information and support needed on reproductive options					
1 (Ormondroyd 2012)	1 study using semi-structured interviews	Women's awareness of reproductive options was limited, with some women learning via the media rather than from health professionals. Women reported feeling paralysed by an inability to move forward and make reproductive decisions due to the complexity in using reproductive technologies. As a result of conversations in a support group for carriers of the BRCA mutation, women made revelations about their own lives in relation and how their existence would not be possible if different reproductive choices had been made. "Everyone at the table asked the same question to each other …we agreed that if (earlier generations) had decided not to have children then none of us would be there. That was a kind of powerful idea and I think we all wanted to be there" (Ormondroyd 2012, p7)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 1.G: Self-seeking information from alternative sources					

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
2[e]	1 study using semi-structured interviews; 1 study using semi-structured interviews and focus groups	Women reported seeking information themselves for general knowledge. They found it difficult in approaching the necessary professionals for advice and felt that any information is a good thing. By sourcing their own information, women felt more confident in consultations and that they have sufficient knowledge to engage with health professionals. "If you're armed with that information then the doctors can't say 'oh you'll be all right, love, you know, it's just a bit of ageing and diverticulitis or whatever'. If you actually know that information, it's easier to push" (Smits 2016, p6)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 1.H: Feeling helpless due to a lack of available services					
1 (Brunstrom 2016)	1 study using semi-structured interviews	Women described being stuck waiting or unable to act on the results of their genetic test because of the lack of surveillance available to them. Women wanted more contact with genetic services, particularly for reassurance that somebody was responsible for their care and available to support. "If I knew I was still, I don't know, still written down somewhere, or I knew that someone was going to check on me or they were aware I have this risk and I don't know, it's just that they would know and someone professional would be checking up on me. (Brunstrom 2016, p97)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 1.I: It should be easier to access the system					
2[f]	2 studies using semi-	Women and their families found it a struggle to gain access to testing and appointments and felt they had to push for their own follow-up	Methodological limitations	None or very minor concerns	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	structured interviews	appointments. They reported undertaking testing if it was more easily accessible to them. "I felt like I've been frustrated because by the time that I went to the genetic counsellor, I'd been trying for three years to get it" (Shilling 2020, p495)	Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	

BRCA: breast cancer gene; CA-125; cancer antigen 125; CASP: critical appraisal skills programme; HRT: hormonal replacement therapy.
a Brain 2004, Gaba 2022, Lifford 2013
b Brain 2004, Dancyger 2011, Pedrazzani 2022, Seenandan-Sookdeo 2016, Young 2019
c Dancyger 2010, Wakefield 2011, Wright 2018, Young 2019
d Hughes 2010, Jeffers 2014, Seenandan-Sookdeo 2016, Pedrazzani 2022
e Pedrazzani 2022, Smits 2016
f Shilling 2020, Wakefield 2011

Table 5: Evidence profile for Theme 2: Need for support networks and support groups

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 2.A: Value in having a support network where you can share similar experiences					
4[a]	3 studies using semi-structured interviews; 1	Women expressed value in being able to talk openly about concerns and share similar experiences. Parents expressed concern for their children when they refused to talk to them and felt it would be beneficial to know that their children had access to others to talk with. Younger women reported desperation in terms of identifying others in	Methodological limitations	Minor concerns as per CASP qualitative checklist	High

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
	study using focus groups	the same position who they could talk to. Women who were able to communicate with an individual who shared a similar experience, whether that be a family member or a stranger, said it helped and brought comfort. Women felt it would be beneficial to be the one to provide support for others going through the same thing. "I suppose for me I thought "Is there anyone else the same age as me who's affected by this" and I remember I was in Paddington [train station] and I was looking at people going "well wonder if you've got the gene, I wonder if you've got that then, I wonder if you're just walking around and you've got it", and that was my first instinct. So I think for me perhaps it would have been good to have someone of my own age group to talk to...." (Hughes 2010, p491-492)		*No reflexivity from researcher on their role and impact on their research.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 2.B: Stigma associated with support groups can be a barrier to joining					
3[b]	2 studies using semi-structured interviews; 1 study using focus groups	Women expressed negative perceptions of what a support group involved along with fears of lack of anonymity and worry about being exposed to fearful ideas. Partners reported feeling like they should deal with the issues themselves, and that since their wife's needs had been central had not actively sought support for themselves. "If you'd have asked me if I'd go to a support group I think I would say probably 95% sure I wouldn't. If however you said to me we're going to have a support group and these are the topics we're going to talk about throughout the year, one is going to be insurance, another is going to be telling your daughter. Those sorts of things I would think well actually I think I might go to that, rather than this apparent unstructured [support group] thing." (Hughes 2010, p492)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, ethical approval was not described nor consideration of ethical*	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				issues in study method, and there was no description of how presented data were selected.	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 2.C: Desire for support that can be adapted to the individual and their needs					
1 (Hughes 2010)	1 study using focus groups	Women wanted support that could be adapted to suit the individual at any specific time, to reflect their change in emotional needs over time. Parents expressed a desire for support that could be tailored to younger children, specifically in the form of a workshops to provide them with information relating to genetic risk is a less frightening way. “I think it depends what stage of the process you’re at as well and how you’re feeling emotionally. Sometimes you just think “no I can’t quite	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, no description of*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		cope with that sort of side yet" but maybe in 6 months time you maybe thinking "yeah maybe now I'd be ready to go to it". All depends what stage you're at, you know. And it's such a personal thing isn't it to go down that route or not. Yeah it would be great for some but not for all so. Again if it's one item within the package it's an extra thing you could latch on to." (Hughes 2010, p493)		*how presented data were selected, nor discussion of contradictory data.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme.
a Foster 2002, Hughes 2010, Samson 2014, Shilling 2020
b Gaba 2022, Hughes 2010, Mireskandari 2006

Table 6: Evidence profile for Theme 3: The role of the professional in providing information and support

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 3.A: Communication with professionals was supportive and informative					
4[a]	2 studies using interviews (one semi-structured	Women valued access to support outside of the family and reported a helpful attitude by professionals. Satisfaction appeared to be linked with a more personalised approach, such as when information was tailored to the individual's pre-existing knowledge base.	Methodological limitations	Minor concerns as per CASP qualitative checklist	High

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
	and one type not otherwise specified); 1 study using semi-structured interviews and focus groups; 1 study using focus groups	"I received a letter from the hospital explaining what it was and that I could possibly have the gene mutation and that I should contact Dr . . . And that's what we did, together with the sister. Afterwards we had all the genetic meetings with her. She (the physician) explained it very well. So, for me it was never the case that I was somehow all alone and badly informed." (Pedrazzani 2022, p5)		*Lack of researcher reflexivity*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 3.B: Good to have professional support and advice when making decisions					
4[b]	4 studies using semi-structured interviews	Women welcomed the advice of professionals and found them to be knowledgeable, supportive, and sympathetic. Their advice helped women come to a decision, particularly around surgery. "…I'm getting older and I believe the risks are higher as you get older…and I just felt I was being advised…and it was an intuitive…and the blood results were going up, so it was a combination…one year she said to me, ''why you don't have your ovaries removed'' and I said ''well because I'm fine and I don't worry about it, as far as I know''…because you never know sub-consciously, and I said ''and I'm not high risk'', so she looked at me and said ''why do you think we screen you?''…and I remember saying ''oh ok'' (Lifford 2013, p22)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity*	Moderate
			Relevance	Minor concerns No explanation of how participants were selected	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 3.C: Desire for more time and opportunities for discussion with professionals					
3[c]	2 studies using interviews (one semi-structured and one type not otherwise specified); 1 study using semi-structured interviews and focus groups	Women expressed a desire for more time and opportunities for discussion with professionals. They found that information could be complex, particularly around surgery and genetic risk and one appointment was not sufficient to make an informed decision. Women had questions after their appointment and/or later in life but were unsure where to go or how to make further contact. "…my experience of [gynaecology] appointments is that people just present things to you, and very quickly you have to make a decision, and there isn't a way to just, some of the decisions take a lot of discussion, and coming back to it, and rethinking, and I just feel that there isn't that space for it…" (Gaba 2022, p7)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, no description of how presented data were selected, nor discussion of contradictory data.*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 3.D: Need for accurate information and advice from professionals					
2[d]	1 study using semi-structured		Methodological limitations	Minor concerns as per CASP	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
	interviews; 1 study using focus groups	Women expressed a fear of being misled and misleading others with inaccurate information and advice. They highlighted the need for professional, accurate input. "You see that's why we need proper people because I have been giving [you] the completely wrong information and you'd have all gone home...thinking oh my god…I think you've got to have the true facts. I think there's a lot of bogus stuff out there really." (Hughes 2010, p493)		qualitative checklist *Lack of researcher reflexivity*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 3.E: Feeling pressured by professionals to adopt risk management behaviours					
1 (Fadda 2020)	1 study using semi-structured interviews	Women reported being pressured to adhere to medical recommendations such as prophylactic risk-reducing surgery and medical exams. This made women feel frustrated and obligated to undergo procedures that did not align with their own wishes. In some cases, this led to arguments with professionals. "Every time, he [the gynecologist] tells me that he's not going to let me cross 40 years with my ovaries. He says: <Take your time, but you will have to remove them>". (Fadda 2020, p6)	Methodological limitations	Moderate concerns as per CASP qualitative checklist *No explanation of recruitment approach, a lack of researcher reflexivity, no discussion of ethical issues and concerns*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				regarding data analysis.	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 3.F: Feeling unsupported by professionals					
3[e]	1 study using interviews one type not otherwise specified); 2 studies using semi-structured interviews	Women reported feeling like their genetic condition was not taken seriously and expressed concerns with the lack of time given for consultations and the negative attitudes of professionals. They expressed anxiety and nervousness whilst waiting for surgery, to the extent of not being able to enjoy normal life. Women found it difficult when professionals took a neutral stance and did not give advice or their opinion, leading to overall feelings of a lack of support. "I really want to write things down about how Annoyed I am. you give me this information, and nobody has done anything about it. I found out in April about this gene and I'm none the wiser you know, I'm not. It's like somebody has given you, not a death sentence, but this thing could kick off at any time, especially auntie Susie dying from it last year. I just don't think it's right to give people, tell people that and then there is nothing to back it up" (Jeffers 2014, p415)	Methodological limitations	Moderate concerns as per CASP qualitative checklist *No explanation of recruitment approach, a lack of researcher reflexivity, no discussion of ethical issues and concerns regarding data analysis.*	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 3.G: Desire for continuity and accessibility of care					
2[f]	2 studies using semi-structured interviews	Women expressed difficulties in accessing primary care and long onward referrals. They had difficulties communicating with their GP and felt frustrated with the lack of continuity of care which meant having to repeat the same information on various occasions. Women who had a GP who was aware of their risk status helped them feel confident in presenting and expressing their concerns. Continuity of care and continuity of information was described as disjointed. "You would have to go through it all [family history] and whatever… you've got to keep going through the same thing all the time." (Smits 2016, p6)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				of studies or participants	

CASP: critical appraisal skills programme; GP: general practitioner.
a Gaba 2022, Hughes 2010, Jeffers 2014, Pedrazzani 2022
b Dancyger 2010, Gaba 2022, Lifford 2013, Young 2019
c Gaba 2022, Jeffers 2014, Pedrazzani 2022
d Hughes 2010, Smits 2016
e Fadda 2020, Jeffers 2014, Smits 2016
f Shilling 2020, Smits 2016

Table 7: Evidence profile for Theme 4: Tailor the delivery of information to suit the individual and their needs and preferences

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 4.A: Desire for information to be offered in various formats, dependent on individual need and preference					
4[a]	3 studies using semi-structured interviews; 1 study using focus groups	Women expressed various ideas about how they would like to see information presented. Some felt that information should be delivered verbally as it provides the opportunity to answer questions whilst fostering trust. However, others felt nervous about receiving information face-to face and preferred information to be on a website. They particularly thought this helpful for men who otherwise might not be interested or available to receive the information face-to face. It was acknowledged that online information may not suit those with a lack of access or confidence in computer use. Others expressed a desire for a short leaflet, as opposed to a lengthy booklet as they felt this would be less overwhelming. Other suggestions included a letter and phone line or call back service. Women acknowledged that the preferred format varied depending on the individual as well as the timing of information delivery, however agreed that it was key for information to be accurate, up-to-date and from professional and trusted sources. "I think to talk to a professional is quite daunting when you're young. You know I really do because nothing is in layman's terms then,	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, no discussion of ethical issues raised by the study, and no description of how presented data were selected nor discussion of contradictory data*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
		whereas all you want to know is "what's my chances, can I live with this, you know what's the screening process like, and all the rest of it", do you know what I mean?" (Hughes 2010, p493)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 4.B: Feeling overwhelmed when there is too much information					
1 (Smits 2016)	1 study using semi-structured interviews	Women felt that information on ovarian cancer was daunting, particularly facts and figures for success and survival rates. They avoided seeking information so as not to be overwhelmed, however described information as important for general knowledge. "It can be overwhelming sometimes, you get too much information" (Smits 2016, p6)	Methodological limitations	None or very minor concerns	Low
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 4.C: Preference for positive, hope giving information					
1 (Gleeson 2013)	1 study using semi-	Women felt it was important to receive positive, hope-giving information including emphasising the potential benefits of new drugs	Methodological limitations	Minor concerns as	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
	structured interviews	in treating ovarian cancer, and that other treatment drugs that may be available. “But I guess at the time that was all I wanted to know, there was hope that something would give me better treatment than the other. And that’s what we’re looking for.” (Gleeson 2013, p279)		per CASP qualitative checklist *Lack of researcher reflexivity, no discussion of ethical issues raised by the study, and no description of how presented data were selected nor discussion of contradictory data*	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 4.D: Need for information to be communicated at the appropriate time					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
2[b]	1 study using semi-structured interviews; 1 study using semi-structured interviews and focus groups	Women expressed preferences for information to be delivered at certain times. Women going through cancer diagnosis or recovering from surgery felt they had enough to worry about without the added stress of further information that they believed was not relevant at the time. Women recognised that their own physical and psychological state influenced their levels of attention and understanding. "Once you wake up from the surgery, and for the two weeks after the surgery, your head is in such a spin that I'm not sure you could even digest that information." (Gleeson 2013, p279)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, no discussion of ethical issues raised by the study, and no description of how presented data were selected nor discussion of contradictory data*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme.
a Gleeson 2013, Hughes 2010, Ratnayake 2010, Shilling 2020
b Gleeson 2013, Pedrazzani 2022

Table 8: Evidence profile for Theme 5: Family as a source of information and support

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 5.A: Importance of the family as a source of support					
4[a]	2 studies using semi-structured interviews; 1 study using focus groups; 1 study using structured interviews	Women highlighted the importance of families in providing psychological and emotional support, and in aiding decision making, particularly in discussions on disclosing genetic risk to children where couples collectively made decisions together. Women reported feeling more supported around certain family members, particularly those with similar experiences. "I think a lot depends on your family as well and the support you've got at home and both of us [referring to sister Alex] have got good husbands and children…I'm lucky that I've got a good supportive family…" (Hughes 2010, p490)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.*	High
			Relevance	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 5.B: Following information and advice provided by family members					
1 (Dancyger 2010)	1 study using semi-structured interviews	Women reported following the information and advice provided by family members, rather than information and advice from professionals. "The genetic counsellor was right, you do need time to think about it, but by the time I did go and see her, I had made up my mind that I wanted the tests and even though she was persuading me, or trying to persuade me to wait a little while, I almost did wait ... then when I thought about the 40 thing again and that was unclear in my mind, I said no I want the tests now" (Dancyger 2010, p1292)	Methodological limitations	Minor concerns as per CASP qualitative checklist□enti on*tion of ethics. No reflexivity from researcher on their role and impact on their research*	Low
			Relevance	Minor concerns *Data not separated for at-risk ovarian and breast cancer patients*	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 5.C: Lack of communication and support in the family					
4[b]	4 studies using semi-structured interviews;	Women reported disclosing genetic status to certain family members only with an expectation that the information would then be passed on throughout the family. In some cases, this led to a general lack of communication. Increased anxiety about cancer led to a reluctance to acknowledge and discuss the genetic testing and some family members were unsupportive and unwilling to be involved in the testing process. Women reported families having a stoic approach which did not facilitate communication. One man wished his father had provided more information about his genetic risk but his father's perception that his mutation status was a sign of weakness had prevented communication. "I was OK the day they told me I had the faulty gene but it was the next day it hit me. I just was really upset and then my family will not really talk about it, my bigger sister says she's definitely not going to get tested and then the other one, she'll just not talk about it." (Jeffers 2014, p415)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, no description of how presented data were selected, nor discussion of contradictory data.*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 5.D: Partner's role in relaying information and providing support					

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
3[c]	2 studies using semi-structured interviews; 1 study using focus groups	Partners reported how it was important that they provide adequate and effective support to their spouse. However, many felt deficient and unsure how to navigate that role. Others felt they were good at relaying information when their affected other was not able to understand. One woman reported their spouse as their only support system. "I feel deficient a lot of the time in the support or the lack of support that I'm actually showing her. I'm not quite sure from time to time whether I should be holding back...or whether to challenge her at the right time, right place. It's something that constantly causes me difficulty" (Mireskandari 2006, p103)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 5.E: Coping with a partner who has a genetic risk					
1 (Mireskandari 2006)	1 study using semi-structured interviews	Partners reported feeling on a constant state of alert without much opportunity to relax that guard and feeling selfish that they don't want to lose their partner. Living with the knowledge that their partner was at high risk of developing cancer was distressing but open communication appeared to help with the adjustment. "Basically, my feeling is a very selfish feeli–g - how would I cope in –y life without h–r - I wouldn't cope without her. She's my everything, she is my best friend, my soul mate, my sounding board, the person I like to argue with and we fight, we play, we have fun and she is the mother of my children. And– I don–t - I can–t - see life without her, I honestly can't visual life without her...and to have her taken away from me wasn't on the cards, wasn't something I could think about, it's still not something I could think about..." (Mireskandari 2006, p103)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of researcher reflexivity, ethical approval was not described nor consideration of ethical issues in study method, and no description of how presented data were selected.*	Low
			Relevance	Minor concerns Some of the population had unknown mutation	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				status or were non-carriers and data was not separated.	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 5.F: Need for support at home after prophylactic oophorectomy					
1 (Brain 2004)	1 study using semi-structured interviews	Women were concerned about the impact and inconvenience of prophylactic oophorectomy, particularly about being unable to look after family members and difficulties in relinquishing the role of caretaker within the family. They highlighted the need for extra support at home. '...my husband...has to realise what the consequences are of me having this operation, and that it's all going to fall on him'' (Brain 2004, p909)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme
a Hughes 2010, Lim 2004, Seenandan-Sookdeo 2016, Young 2019
b Dancyger 2011, Jeffers 2014, Ratnayake 2010, Young 2019
c Hughes 2010, Mireskandari 2006, SeenandanSookdeo 2016

Table 9: Evidence profile for Theme 6: The impact of the family on decisions about genetic testing

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 6.A: Decision-making influenced by family members' experiences					
1 (Shilling 2020)	1 study using semi-structured interviews	Women reported how the experiences of family members influenced their decision making. "All BRCA people I think are making decisions in the context of previous experience. We have trauma through multiple diagnoses or deaths or whatever in our families, of other people, which has affected	Methodological limitations	None or very minor concerns	Low
			Relevance	None or very minor concerns	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		us and we are making our decisions based on that. It's not just the scientific risk of what our particular gene means to us scientifically and from a biological perspective. It's what you've experienced psychologically also is influencing your decision-making." (Shilling 2020, p496)	Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 6.B: Feeling obligated to have genetic testing to be able to inform family members about genetic risk					
8[a]	7 studies using semi-structured interviews; 1 study using interviews (type not otherwise specified)	Women felt a sense of obligation to undergo genetic testing so that the information could be passed on to family members, giving them the opportunity to make decisions about their health and future, such as managing their risk. Sometimes family members would instigate this obligation, where they would impart pressure due to an inability to access testing themselves until the index patient had been tested. The obligation to get tested was described as more pressing where children were involved, as it was felt particularly important that they had the opportunity to make decisions about their own health. "I wanted to get tested more for my kids. And for Alice, she's the youngest [sister in the family]. She's like my best friend, Alice and I. So yes, I kind of wanted to find out not more so for myself, but just to see if they would possibly have the gene or that I have passed it onto my children." (D'Agincourt-Canning 2006, p106)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 6.C: Feeling obligated to have genetic testing due to family/external pressures					
3[b]	3 studies using semi-structured interviews	Women reported feeling obligated to have genetic testing due to well-meaning relatives who applied pressure, due to thoughts that receiving the information would be in the individuals' best interests. Likewise, women reported feeling responsible for carrying a genetic mutation and subsequently pressured other family members to get tested.	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
		"I didn't pay much attention to it [genetic testing] until my mom and everybody pursued it further. Then I didn't have much choice whether I wanted to pay attention to it or not… With my mom, there's not one visit that goes by, that she doesn't say something about it. Like we cannot go and have a visit without that being some type of focal line. She's really pushing me to be genetically tested." (D'Agincourt-Canning 2006, p107)	Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 6.D: Receiving unwanted information from family members about genetic risk					
2[c]	2 studies using semi-structured interviews	Women reported feeling forced to live with information about their genetic risk that they would rather not have. Family members had received and shared information about their mutation status that affected their own lives, and they were not emotionally ready to receive the information. "I think it was no big deal to them [mother and aunts], but they didn't think about what it was going to do to their kids and their grandkids. Because this is a never-ending thing now. Like we opened a box that's never going to close, like it's an open door to forever. Like I said, once you open that door you can't ignore what's behind it." (D'Agincourt-Canning 2006, p108)	Methodological limitations	Moderate concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				selected nor discussion of contradictory data.	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 6.E: Family pressure to get tested due to the impact of genetic test results on children					
4[d]	3 studies using semi-structured interviews; 1 studies using interviews (type not otherwise specified)	Women felt it was important to get tested to establish their children's risk. This caused frustration when some family members with children refused to get tested due to their own views about genetic risk. Many women saw the benefit in sharing information, for some this extended to the point that they thought it irresponsible for those family members with children to not get tested. "I think it's very irresponsible. I mean if he doesn't have it, he doesn't have to worry about worrying his kids about it. If he does, she'd [his	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		adult daughter] better get tested pretty soon. It's ridiculous. I think it's very irresponsible, if you have something like that and you can, you know, make sure. 'Cause I mean you're giving your kid no option to have themselves checked, have themselves have any preventative stuff if they have to, or testing that they should have. It's horrible. I think it's very cruel." (D'Agincourt-Canning 2006, p109)	Adequacy	None or very minor concerns	
Sub-theme 6.F: Which family members are affected impacts mutation carrier risk perception					
1 (Foster 2002)	1 study using semi-structured interviews	Women reported feeling more vulnerable when the affected individual was a first degree relative, compared to a second degree relative. This feeling was also reported according to proximity of age where women were either more or less concerned about mutation carrier risk depending on whether siblings and cousins of a similar age were affected. "[Sister 1] died in 1986, mum was diagnosed in something like '88 um, so both [sister 2] and I looked at each other… We said that there really is something that is not right about this, two people in our family, it's not right it's got to be hereditary. Sue (46 years) [Sue is referring to her immediate family here. In her extended family there have been numerous cases of breast/ovarian cancers.] My mum and my dad, neither of them had cancer, um nor has my brother, um so you could say that the four of us, um have been okay. So it sort of makes me feel um, that I won't get it… I feel that I am okay, I don't think that I will have this gene." (Foster 2002, p477)	Methodological limitations	None or very minor concerns	Low
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 6.G: Decisions to get'tested because of family member's positive result					
1 (Battistuzzi 2019)	1 study using semi-	Women reported that a family member's positive test result provided the motivation to have genetic testing. For one woman the motivation was so strong it trumped her phobia of needles.	Methodological limitations	None or very minor concerns	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	structured interviews	"When they told my mother that she was BRCA1-positive, that's when I decided "Ok, let's do it". What was holding me back was that I'm afraid of blood tests and I was really scared of that, but then I just decided I wanted to do it." (Battistuzzi 2019, p3)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	

BRCA: breast cancer gene; CASP: critical appraisal skills programme.
a Battistuzzi 2019, Brunstrom 2016, D'Agincourt-Canning 2006, Dancyger 2010, Foster 2002, Shilling 2020, Wakefield 2011, Wright 2018
b D'Agincourt-Canning 2006, Foster 2002, Wakefield 2011
c D'Agincourt-Canning 2006, Dancyger 2011
d Battistuzzi 2019, D'Agincourt-Canning 2006, Foster 2002, Shilling 2020

Table 10: Evidence profile for Theme 7: Impact of genetic risk information on emotions and decision making

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 7.A: Knowledge of genetic test results seen as important and valuable					
13[a]	9 studies using semi-structured interviews; 3 studies using interviews (type not otherwise specified); 1 study using	Women felt that knowing about their genetic risk was better than not knowing, as it provided them with the opportunity to learn about their options and subsequently manage their health and risk, such as undergoing surgery or lifestyle changes. They reported that knowledge was powerful. Women who received negative results reported that knowing gave them, relief and freedom from stress.	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of explanation of recruitment approach, and researcher*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
	structured interviews	"Do I really want to know the outcome of it? …well, if the outcome is good, then it puts your mind at rest. And if it's not good, well you can do something about it." (Dancyger 2010, p1292)		*reflexivity. No description of how presented data were selected.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.B: Genetic risk information relieves guilt associated with developing cancer					
2[b]	2 studies using semi-structured interviews	Women reported that learning about their genetic status relieved them from feelings of guilt and responsibility for having caused their cancer. "I thought well at least it was nothing I had done to myself that give me the cancer, you know because all through I kept thinking was it something I had done you know? Was it my lifestyle that caused me to get it and then when I found out it was the gene I thought well, I don't know, a bit of relief sort of thing you know that I didn't cause it myself and it was out of my hands sort of thing." (Jeffers 2014, p415)	Methodological limitations	Minor concerns as per CASP qualitative checklist *No mention of ethics. No reflexivity from researcher on their role and impact on their research*	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.C: Positive genetic test results were unexpected and shocking					
5[c]	3 studies using semi-structured interviews; 1 study using semi-structured interviews and focus groups; 1 study using structured interviews	Women and their family reported feelings of shock and disbelief when found to be mutation carriers. Women with children felt guilt at the thought of passing the mutation onto their child. "So, for me the shock of finding out that I had this mutation was even greater than finding out to have a cancer. I did the test, and I got the results. It was terrible for me because it meant that I could have passed on this mutation to my daughter, and I felt guilt." (Pedrazzani 2022, p5)	Methodological limitations	Minor concerns as per CASP qualitative checklist *mention of ethics. No reflexivity from researcher on their role and impact on their research*	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.D: Not thinking through the impact of receiving genetic testing results					
2[d]	2 studies using semi-	Some women and their family members made the decision to undergo genetic testing on the expectation that they would not be a mutation carrier. Others reported not making an informed choice about testing.	Methodological limitations	Minor concerns as per CASP	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
	structured interviews	Women reported feeling unprepared and did not consider the implications of positive test results. "The genetic counsellor was right, you do need time to think about it, but by the time I did go and see her, I had made up my mind that I wanted the tests and even though she was persuading me, or trying to persuade me to wait a little while, I almost did wait ... then when I thought about the 40 thing again and that was unclear in my mind, I said no I want the tests now" (Dancyger 2010, p1292)		qualitative checklist *No mention of ethics. No reflexivity from researcher on their role and impact on their research.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.E: Regret about knowing genetic test results					
2[e]	1 study using semi-structured interviews; 1 study using structured interviews	Women and their family reported how knowledge of their mutation status made the risk a reality and invoked fear and anxiety. As a result, knowledge was perceived by some as undesirable. "It would have been better to find out later in life" (Lim 2004, p127)	Methodological limitations	Minor concerns as per CASP qualitative checklist *No mention of ethics. No reflexivity from researcher on their role and*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				impact on their research.	
			Relevance	Minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.F: Feeling at risk regardless of genetic test result					
2[f]	2 studies using semi-structured interviews	Women felt burdened with a sense of risk regardless of whether they had the predictive test and the result. "If you've been tested and you've got your result and it's negative … what happens in 10 years' time if they find more genes, you know? Are you back down that route again, that you thought you were fairly safe, and then you're not?" (Dancyger 2010, p1293)	Methodological limitations	Minor concerns as per CASP qualitative checklist *No mention of ethics. No reflexivity from researcher on their role and impact on their research.*	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.G: A sense of duty to pass on genetic test results to family members					
4[g]	3 studies using semi-structured interviews; 1 study using semi-structured interviews and focus groups	Women and their families felt a sense of duty and responsibility to disseminate information about their mutation status to family members, particularly close family. They felt that by sharing this information, they would enable family members to manage and act upon their own risk status. The responsibility to share genetic information with family members was perceived by some women as burdensome and to rid themselves of the responsibility, were proactive in telling family members about their result. Some women who were prevented from passing the information to family members due to their right not to know, wrestled with the sense of duty they felt and the need to respect family members wishes. The sense of duty stopped when it came to children as most women and their families agreed it was the parents who had the ultimate responsibility to tell their child. "I did my part. I explained to them (my relatives) what had happened to me. What I could possibly happen to them... Or not. I hope it never happens to them. But I thought it was important to communicate on the subject… It has been a burden on me that. I mean it's not easy, to take the step, to do that, it's hyper personal anyway…" (Pedrazzani 2022, p7)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				contradictory data.	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.H: A culture of openness in families facilitated communication about genetic risk					
1 (Dancyger 2011)	1 study using semi-structured interviews	Women who were part of families where open communication was apparent had an expectation that genetic information should be shared. They reported that withholding mutation information would have been unusual and potentially problematic for relationships. They felt motivated to share information due to general patterns of communication within the family. "In close relationships you've got to have a good reason not to tell people things...to find out at a later stage that some information was withheld from you, can open the door to all sorts of mistrust ... if you want to have a relationship in which there's suspicion and mistrust, then you keep under things. If you don't want to have that sort of relationship, then you maintain openness and honesty (Dancyger 2011, p1028)	Methodological limitations	Moderate concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented*	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				data were selected nor discussion of contradictory data.	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.I: Difficulty in communicating genetic risk to family members					
4[h]	3 studies using semi-structured interviews1 study using semi-structured interviews and focus groups	Women found it difficult to communicate information on their mutation status to family members. Some felt conflicted with a sense of duty to inform relatives, with the burden of talking about themselves including communicating their fears, wishes and emotional experiences. As a result, some women were selective with the information that they passed on, in some cases leading to information being withheld. Other reasons such as geographical distance between families and a breakdown in the relationship led to difficulty in communicating genetic risk. Parents reported not wanting to burden children with the information, particularly when they were at a young age. “It was difficult to communicate that I was ill…So only my sister knew and I only decided to tell my parents when I got home. Also, because I spent 3–4 days crying all day long. I was clear that I was ill but I didn’t... I didn’t say it because I was mad as hell, honestly, I was mad	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was*	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		at the world. I didn't want to say it out loud so it became reality even if it was reality. . .The looks of pity as if I were going to die at any moment. I won't say... maybe because of those looks I never said it." (Pedrazzani 2022, p8)		*not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.*	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.J: Coping with the emotions of genetic risk and the emotions of family members at the same time					
4[i]	2 studies using semi-structured interviews; 1 study using interviews; 1 study using structured interviews	Women worried about the implications that their mutation status might have on family members and how their family might emotionally cope with information. This was particularly evident when it came to parent-child relationships due to parental guilt about passing on the pathogenic variant to their children which made it difficult for children to express their concerns freely. Some women distanced themselves from family members during genetic testing and surgery. "It's that I think her natural reaction is just stress and it's going to be quite overbearing stress when you're just trying to manage your own feelings" (Young 2019, p525)	Methodological limitations	Moderate concerns as per CASP qualitative checklist *Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher*	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.	
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	None or very minor concerns	
Sub-theme 7.K: Deferring genetic testing due to not wanting to know genetic risk at that time					
4[j]	4 studies using semi-structured interviews	Women reported postponing genetic testing due to the timing not being appropriate. They felt that information on their genetic status was burdensome, either because of their own stage of life, or due to a sense of duty to pass on the information once known to family members and didn't want to burden others. Some women struggled to	Methodological limitations	Moderate concerns as per CASP qualitative checklist	Low

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
		see the added value of knowing their mutation status and saw little they could do to manage their risk. This was particularly true in younger woman who acknowledged that their desire to be tested may change in time. "It's not really something I need to know right now. But maybe it will change... I'm just really busy... it's not top of my list of things to worry about or to go and do... I don't have health issues on the mind at the moment, but I guess when I'm forty or fifty those, my mind will probably be a bit more concerned about these things" (Dancyger 2010, p1293)		*Lack of discussion of data saturation and the form of data is unclear. There is a lack of researcher reflexivity. ethical approval was not described, nor discussion of ethical issues. There was no description of how presented data were selected nor discussion of contradictory data.*	
			Relevance	Minor concerns *Data not separated for at-risk ovarian and breast cancer patients)*	
			Coherence	Minor concerns *Findings included mildly contradicting*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				views on theme	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 7.L: Results of genetic testing did not influence decision making or behaviour					
4[k]	2 studies using semi-structured interviews; 1 study using interviews (type not otherwise specified); 1 study using structured interviews	Women reported indifference to results of genetic testing and did not consider them important factor in their decision making. They felt that the information did not make any impact on their current measures of health surveillance. "It wasn't necessarily going to change anything if the gene was there or not in terms of my lifestyle, you know, I exercise, am healthy, you know, I don't smoke. I do all those things anyway so if I knew it wasn't going to change my life." (Wakefield 2011, p382)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.*	High
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	None or very minor concerns	
Sub-theme 7.M: Results of genetic testing impacted on thoughts about childbearing					
2[l]	2 studies using semi-structured interviews	The results of genetic testing caused some women to focus their attention on the implications this had on family planning. In some cases, this led to women feeling forced into making unexpected and difficult decisions at a young age. One woman reported revaluating plans to try for a pregnancy, whilst another reported a heightened awareness of how illness in general can be hereditary not just in relation to mutation status. "It's probably the thing that I have struggled with the most since finding out about it, I'm not ready to have children yet, and I think it's a decision that kind of got forced on me like, it's something to think about earlier that I would of normally because I think if my mum had known she had the gene, would she have just had me and known that she could pass it on." (Brunstrom 2016, p95)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme.
a Battistuzzi 2019, Brain 2004, Brunstrom 2016, d'Agincourt-Canning 2006, Dancyger 2010, Jeffers 2014, Lifford 2013, Lim 2004, Samson 2014, Seenandan-Sookdeo 2016, Shilling 2020, Wakefield 2011, Young 2019
b Dancyger 2010, Jeffers 2014
c Battistuzzi 2019, Jeffers 2014, Lim 2004, Mireskandari 2006, Pedrazzani 2022
d Battistuzzi 2019, Dancyger 2010
e Dancyger 2010, Lim 2004
f Brunstrom 2016, Dancyger 2010
g Dancyger 2011, Pedrazzani 2022, Ratnayake 2010, Young 2019
h d'Agincourt Canning 2006, Dancyger 2011, Pedrazzani 2022, Ratnayake 2010
i Dancyger 2011, Jeffers 2014, Lim 2004, Young 2019
j Dancyger 2010, Dancyger 2011, Samson 2014, Wakefield 2011
k Brain 2004, d'Agincourt-Canning 2006, Lim 2004, Wakefield 2011
l Brunstrom 2016, Ormondroyd 2012

Table 11: Evidence profile for Theme 8: Importance of ovarian cancer surveillance programs and knowledge of surgical options

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 8.A: Confidence in cancer surveillance for the detection of ovarian cancer					
2[a]	2 studies using semi-structured interviews	Women reported feeling confident in cancer surveillance that included transvaginal ultrasound together with serum testing for increased levels of the tumour marker. A screen detected abnormality was considered a sufficient reason to consider surgery. "…I had got cysts on my ovary…they kept an eye on me and my bloods shot up or something so they called me…it [surgery] just felt right at the time, you know to take away the worry because when they found that the bloods had gone up I just thought of my mother…" (Lifford 2013, p24)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Minor concerns due to a lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.*	Low
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns *Evidence comes from a small number of studies or participants*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 8.B: Good to have the option to continue surveillance					
3[b]	3 studies using semi-structured interviews	Women who had the option to continue with surveillance felt pleased that this was available to them. Women felt more concerned about ovarian cancer, compared to breast cancer as they were unable to self-examine their ovaries. They felt that without surveillance they would be forced to consider surgery. "There is no screening on the NHS for ovarian cancer and that means my only other option is to have my ovaries out." (Gaba 2022, p4)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Minor concerns due to a lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.*	Moderate
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				Evidence comes from a small number of studies or participants	
Sub-theme 8.C: Clear knowledge of options available led to confident decisions to undertake surgery					
3[c]	2 studies using interviews; 1 study using structured interviews	Women had a clear knowledge of the options available to them, which led some women to confidently decide to undertake surgery. "The ovaries can be removed when you are finished with them. I know I will have a better quality of life mentally because I don't have to worry about ovarian cancer which is hard to detect." (Lim 2004, p125)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Lack of explanation of recruitment approach, and researcher reflexivity. No description of how presented data were selected.*	Moderate
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 8.D: Option of prophylactic oophorectomy came as a shock					
1 (Brain 2004)	1 study using semi-structured interviews	Women reported that the option of prophylactic oophorectomy came as a shock. Some women had not previously been aware of their increased risk of ovarian cancer, whilst other women although aware of their increased risk, were still surprised when it was discussed. ‘‘I knew he (Consultant) was going to say that (regarding the option of surgery), but it was still a shock... It’s like meeting a new partner and the first thing they say is ‘Let’s have a baby.’’’ (Brain 2004, p908)	Methodological limitations	Minor concerns as per CASP qualitative checklist *Minor concerns due to a lack of explanation of recruitment approach, and no description of how presented data were selected.*	Low
			Relevance	Minor concerns *Lack of explanation of recruitment approach*	
			Coherence	Minor concerns *Findings included mildly contradicting*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				views on theme	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme.
a Brain 2004, Lifford 2013
b Brain 2004, Gaba 2022, Lifford 2013
c Brain 2004, Gaba 2022, Lim 2004

Table 12: Evidence profile for Theme 9: Reasons for and against genetic testing

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 9.A: Empowerment and taking control of the situation					
1 (Foster 2002)	1 study using semi-structured interviews	Women reported feeling the need to cope with whatever was thrown at them by taking action, which contributed to their decision to undergo genetic testing. This was sometimes at odds with the coping styles of their family members. "My sister can't deal with it, internalises it, you know, whereas I need, I need to deal with it." (Foster 2002, p478)	Methodological limitations	None or very minor concerns	Low
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 9.B: Getting tested for science					
3[a]	3 studies using semi-structured interviews	Women who had the option of undergoing genetic testing as part of a research project perceived it as their duty to get tested. They felt it was a way to do their part to advance medical science and help others, in addition to finding out genetic information for themselves. "The advantage is just information to the people doing cancer research. That is the only reason I said yes [to the testing]. The larger your sample size, the better your results… If our family is showing a lot of this, there is a good chance that we would have these genes that could help somebody's research project and provide answers down the line for some other people, maybe even for us." (D'Agincourt-Canning 2006, p109)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 9.C: Feeling like they had missed previous opportunities to get tested					
1 (Wright 2018)	1 study using semi-structured interviews	Women who had previously decided against genetic testing chose to get tested after receipt of a new offer as they felt it allowed them to revisit missed opportunities. Some women were angry as they been keen to proceed previously but had been advised to take some time to think about it and had subsequently developed cancer. "I went to see oncologist and she said, "I think it's a good idea if we check for the BRCA gene at this point." Which made me quite angry	Methodological limitations	None or very minor concerns	Low
			Relevance	Minor concerns *Also included breast cancer patients and*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
		because I felt that had I had it done when I'd asked for it two years before I could have avoided all of this." (Wright 2018, p1464)		*data was not separated between ovarian and breast cancer patients*	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 9.D: Being curious about family history					
3[b]	3 studies using semi-structured interviews	Women reported being struck by the realisation that cancer runs in the family and subsequently explored the possibility of genetic testing to confirm the existence of a mutation risk. "I only found out about it when my mother was diagnosed and my father gave me a copy of the letter that [consultant] had written to my mother saying would I please go and have um, you know, check-ups and I said 'why on earth should I have check-ups, mum's ill, why should I go?' and he said 'well it's in the family'. And I said 'hang on a second you had better tell me all about this' …And that was the very first time that I knew about it." (Foster 2002, p475)	Methodological limitations	None or very minor concerns	High
			Relevance	None or very minor concerns	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Minor concerns *Evidence comes from a*	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				small number of studies or participants	
Sub-theme 9.E: Do not believe in genetic testing					
1 (Wakefield 2011)	1 study using semi-structured interviews	Women reported placing little value on genetic testing and subsequently did not communicate with their family the possibility of attending a familial cancer centre to get tested. "I tell my daughter; just because that was my experience in life she doesn't need to get it . . . I believe that the body has the power to heal itself." (Wakefield 2011, p382)	Methodological limitations	None or very minor concerns	Low
			Relevance	Minor concerns *Recruitment was through an existing breast cancer research project*	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	
Sub-theme 9.F: Believe cancer is caused by other factors					
1 (Wakefield 2011)	1 study using semi-	Women reported a belief that cancer was caused by external, not genetic factors and subsequently did not see any value or importance in genetic testing.	Methodological limitations	None or very minor concerns	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	structured interviews	"I just feel, you know, we create a lot of our own issues and we can even change our DNA . . . I know why I got cancer . . . I was very careless with chemicals. I used to be spraying the garden, trying to have the best roses and it would drift over me." (Wakefield 2011, p381)	Relevance	Minor concerns *Recruitment was through an existing breast cancer research project*	
			Coherence	Minor concerns *Findings included mildly contradicting views on theme*	
			Adequacy	Serious concerns *Evidence comes from a small number of studies or participants*	

CASP: critical appraisal skills programme; DNA: deoxyribonucleic acid
a D'Agincourt-Canning 2006, Foster 2002, Wakefield 2011
b Battistuzzi 2019, Foster 2002, Wakefield 2011

Appendix G Economic evidence study selection

Study selection for: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

One global search was undertaken – please see Supplement 2 for details on study selection.

Economic evidence tables for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

No evidence was identified which was applicable to this review question.

Appendix H Economic model

Economic model for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

No economic analysis was conducted for this review question.

Appendix I Excluded studies

Excluded studies for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Excluded effectiveness studies

Table 13: Excluded studies and reasons for their exclusion

Study	Exclusion reason
Andersen, M Robyn, Bowen, Deborah, Yasui, Yutaka et al. (2003) Awareness and concern about ovarian cancer among women at risk because of a family history of breast or ovarian cancer. American journal of obstetrics and gynecology 189(4suppl): 42-7	- Country not relevant to this review protocol (paper not further checked for relevance)
Augestad, Mirjam Tonheim, Hoberg-Vetti, Hildegunn, Bjorvatn, Cathrine et al. (2017) Identifying Needs: a Qualitative Study of women's Experiences Regarding Rapid Genetic Testing for Hereditary Breast and Ovarian Cancer in the DNA BONus Study. Journal of genetic counseling 26(1): 182-189	- Population not relevant to this review protocol *Themes relevant but population focussed on breast cancer. [4 diagnosed with ovarian cancer and 1 BRCA mutation carrier 29%, 13 diagnosed with breast cancer]*
Babb, Sheri A, Swisher, Elizabeth M, Heller, Hope N et al. (2002) Qualitative evaluation of medical information processing needs of 60 women choosing ovarian cancer surveillance or prophylactic oophorectomy. Journal of Genetic Counseling 11(2): 81-96	- Country not relevant to this review protocol (paper not further checked for relevance)
Bakos, Alexis D, Hutson, Sadie P, Loud, Jennifer T et al. (2008) BRCA mutation-negative women from hereditary breast and ovarian cancer families: a qualitative study of the BRCA-negative experience. Health expectations : an international journal of public participation in health care and health policy 11(3): 220-31	- Country not relevant to this review protocol (paper not further checked for relevance)
Baty, Bonnie Jeanne; Kinney, Anita Yeomans; Ellis, Sara Marie (2003) Developing culturally sensitive cancer genetics communication aids for African Americans. American journal of medical genetics. Part A 118a(2): 146-55	- Country not relevant to this review protocol (paper not further checked for relevance)
Bernhardt, Barbara A, Geller, Gail, Strauss, Misha et al. (1997) Toward a model informed consent process for BRCA1 testing: A qualitative assessment of women's attitudes. Journal of Genetic Counseling 6(2): 207-222	- Population not relevant to this review protocol *Participants do not have familial ovarian cancer nor at increased risk of ovarian cancer*
Bradbury, Angela R, Patrick-Miller, Linda, Pawlowski, Kimberly et al. (2009) Learning of your parent's BRCA mutation during adolescence or early adulthood: A study of offspring experiences. Psycho-Oncology 18(2): 200-208	- Country not relevant to this review protocol (paper not further checked for relevance)
Brandner, S., Muller-Nordhorn, J., Stritter, W. et al. (2014) Symptomization and triggering processes: Ovarian cancer patients' narratives on pre-diagnostic sensation experiences and the initiation of healthcare seeking. Social Science and Medicine 119: 123-130	- Relevant qualitative themes not reported *Themes focus on major concerns regarding their pre-diagnostic experiences and how their*

Study	Exclusion reason
	symptoms and circumstances eventually led them to seek medical care.
Buchanan, Adam H, Skinner, Celette Sugg, Rawl, Susan M et al. (2005) Patients' interest in discussing cancer risk and risk management with primary care physicians. Patient Education and Counseling 57(1): 77-87	- Country not relevant to this review protocol (paper not further checked for relevance)
Campacci, Natalia, de Campos Reis Galvao, Henrique, Garcia, Lucas F et al. (2020) Genetic cancer risk assessment: A screenshot of the psychosocial profile of women at risk for hereditary breast and ovarian cancer syndrome. Psycho-oncology 29(4): 681-687	- Study design not relevant to this review protocol *Study does not report qualitative data (no quotes, only overview of themes). Overview of families' profiles and the challenges of the oncogenetics setting.*
Chopra, Ishveen and Kelly, Kimberly M (2017) Cancer Risk Information Sharing: The Experience of Individuals Receiving Genetic Counseling for BRCA1/2 Mutations. Journal of health communication 22(2): 143-152	- Country not relevant to this review protocol (paper not further checked for relevance)
Claes, E., Evers-Kiebooms, G., Boogaerts, A. et al. (2003) Communication with close and distant relatives in the context of genetic testing for hereditary breast and ovarian cancer in cancer patients. American Journal of Medical Genetics 116(1): 11-19	- Population not relevant to this review protocol *Themes relevant but population focussed on breast cancer [11% had a personal history of ovarian cancer and 6% had a personal history of ovarian or breast cancer, whilst 83% had a family history of breast cancer]*
Clarke, S.; Butler, K.; Esplen, M.J. (2008) The phases of disclosing BRCA1/2 genetic information to offspring. Psycho-Oncology 17(8): 797-803	- Relevant qualitative themes not reported *Themes centre around the research trial not general practice. Population were participants of a group therapy trial.*
Crook, Ashley, Plunkett, Loren, Forrest, Laura E et al. (2015) Connecting patients, researchers and clinical genetics services: the experiences of participants in the Australian Ovarian Cancer Study (AOCS). European journal of human genetics : EJHG 23(2): 152-8	- Relevant qualitative themes not reported *Themes centre around the research trial not general practice*
Crotser, Cheryl B and Boehmke, Marcia (2009) Survivorship considerations in adults with hereditary breast and ovarian cancer syndrome: State of the science. Journal of Cancer Survivorship 3(1): 21-42	- Study design not relevant to this review protocol *Mixed methods review without any relevant qualitative data*
Crotser, Cheryl B and Dickerson, Suzanne S (2010) Women receiving news of a family BRCA1/2 mutation: Messages of fear and empowerment. Journal of Nursing Scholarship 42(4): 367-378	- Country not relevant to this review protocol (paper not further checked for relevance)
Cypowyj, C., Eisinger, F., Huiart, L. et al. (2009) Subjective interpretation of inconclusive BRCA1/2 cancer genetic test results and transmission of information to the relatives. Psycho-Oncology 18(2): 209-215	- Population not relevant to this review protocol

Study	Exclusion reason
	Themes relevant but population focussed on breast cancer. [3 with a history of ovarian cancer 10%, 26 breast cancer, 1 other cancer]
Dagan, Efrat and Goldblatt, Hadass (2009) The twilight zone between health and sickness: a qualitative exploration with asymptomatic BRCA1 and 2 mutation carriers. Women & health 49(4): 263-79	- Country not relevant to this review protocol (paper not further checked for relevance)
Dean, M. (2016) "It's not if I get cancer, it's when I get cancer": BRCA-positive patients' (un)certain health experiences regarding hereditary breast and ovarian cancer risk. Social Science and Medicine 163: 21-27	- Country not relevant to this review protocol (paper not further checked for relevance)
Dean, Marleah and Davidson, Lindy G. (2018) Previvors' Uncertainty Management Strategies for Hereditary Breast and Ovarian Cancer. Health Communication 33(2): 122-130	- Country not relevant to this review protocol (paper not further checked for relevance)
Dean, Marleah and Rauscher, Emily A (2017) "It was an Emotional Baby": Previvors' Family Planning Decision-Making Styles about Hereditary Breast and Ovarian Cancer Risk. Journal of genetic counseling 26(6): 1301-1313	- Country not relevant to this review protocol (paper not further checked for relevance)
Dean, Marleah, Scherr, Courtney L, Clements, Meredith et al. (2017) "When information is not enough": A model for understanding BRCA-positive previvors' information needs regarding hereditary breast and ovarian cancer risk. Patient education and counseling 100(9): 1738-1743	- Country not relevant to this review protocol (paper not further checked for relevance)
Dekeuwer, Catherine and Bateman, Simone (2013) Much more than a gene: hereditary breast and ovarian cancer, reproductive choices and family life. Medicine, health care, and philosophy 16(2): 231-44	- Relevant qualitative themes not reported *Themes are not entirely relevant. study explored the way in which BRCA1/2 carriers reflected on the acceptability of taking the risk of transmitting this mutation to the next generation, arguments they used in favour or against taking that risk, and in the light of these arguments, their opinion on the acceptability of PGD as a reproductive option.*
Dibble, K.E., Donorfio, L.K.M., Britner, P.A. et al. (2022) Perceptions and care Recommendations from Previvors: Qualitative analysis of female BRCA1/2 mutation Carriers' experience with genetic testing and counseling. Gynecologic Oncology Reports 41: 100989	- Country not relevant to this review protocol (paper not further checked for relevance)
Douglas, H.A.; Hamilton, R.J.; Grubs, R.E. (2009) The effect of BRCA gene testing on family relationships: A Thematic Analysis of Qualitative Interviews. Journal of Genetic Counseling 18(5): 418-435	- Study design not relevant to this review protocol *A thesis of a secondary analysis of Hamilton 2005*
Dwyer, A.A., Hesse-Biber, S., Flynn, B. et al. (2020) Parent of origin effects on family communication of risk in brca+ women: A qualitative investigation of human factors in cascade screening. Cancers 12(8): 1-16	- Country not relevant to this review protocol (paper not further checked for relevance)

Study	Exclusion reason
Forbes Shepherd, Rowan, Forrest, Laura E, Tutty, Erin et al. (2021) Unselected Women's Experiences of Receiving Genetic Research Results for Hereditary Breast and Ovarian Cancer: A Qualitative Study. Genetic testing and molecular biomarkers 25(12): 741-748	- Relevant qualitative themes not reported *Themes centre around experiences of the research study*
Forrest, K., Simpson, S.A., Wilson, B.J. et al. (2003) To tell or not to tell: Barriers and facilitators in family communication about genetic risk. Clinical Genetics 64(4): 317-326	- Population not relevant to this review protocol *Population includes Huntington's disease as well as breast cancer/Ovarian. Patients at risk for Huntington's disease (n=16, 43%) as well as at risk for HBOC (n=21, 57%).*
Gaba, F., Oxley, S., Liu, X. et al. (2022) Unselected Population Genetic Testing for Personalised Ovarian Cancer Risk Prediction: A Qualitative Study Using Semi-Structured Interviews. Diagnostics (Basel) 12(5)	- Population not relevant to this review protocol *Women were recruited with no personal history of ovarian cancer or prior ovarian cancer susceptibility gene testing. It is unclear whether the women had a family history of ovarian cancer but no participant fulfilled the standard NHS clinical criteria for genetic testing. Only 2/9 included participants had first degree relatives with ovarian cancer Cand all participants received low-risk results. In addition, the study is nestled within a prospective cohort, pilot/feasibility study and some of the themes focus on experiences of the research trial*
Gill, G., Beard, C., Storey, K. et al. (2020) "It wasn't just for me": Motivations and implications of genetic testing for women at a low risk of hereditary breast and ovarian cancer syndrome. Psycho-Oncology 29(8): 1303-1311	- Population not relevant to this review protocol *Themes relevant but population focussed on breast cancer. 14 first-degree relatives (FDRs) had breast cancer and three FDRs had ovarian cancer 16%]*
Green, J; Murton, F; Statham, H (1993) Psychosocial issues raised by a familial ovarian cancer register. Journal of medical genetics 30(7): 575-9	- Study design not relevant to this review protocol *Narrative synthesis of qualitative methods. Does not contain relevant quotes.*
Green, J, Richards, M, Murton, F et al. (1997) Family Communication and Genetic Counseling: The Case of Hereditary Breast and Ovarian Cancer. Journal of genetic counseling 6(1): 45-60	- Population not relevant to this review protocol *The population had a family history of either breast cancer or ovarian cancer and does not separate the two so unclear how many included*

Study	Exclusion reason
	in the study had a family history of ovarian cancer Also publication date is 1997.
Hallowell, N., Alsop, K., Gleeson, M. et al. (2013) The responses of research participants and their next of kin to receiving feedback of genetic test results following participation in the Australian Ovarian Cancer Study. Genetics in Medicine 15(6): 458-465	- Relevant qualitative themes not reported *Themes centre around experiences of the research study*
Hallowell, N., Foster, C., Eeles, R. et al. (2004) Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. Social Science and Medicine 59(3): 553-565	- Population not relevant to this review protocol *Unclear how much of the population is at risk of ovarian cancer. [2 had been treated for ovarian cancer, 26 had at least one first-degree relative affected with either breast/ovarian/ endometrial/prostate cancer, in addition to other relatives with these or other cancers]*
Hallowell, N., Murton, F., Statham, H. et al. (1997) Women's need for information before attending genetic counselling for familial breast or ovarian cancer: A questionnaire, interview, and observational study. British Medical Journal 314(7076): 281-283	- Study design not relevant to this review protocol *Quantitative study*
Hallowell, N, Foster, C, Eeles, R et al. (2003) Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information. Journal of medical ethics 29(2): 74-3	- Population not relevant to this review protocol *Themes relevant but population focussed on breast cancer. [27 had been previously treated for breast cancer, 2 for ovarian cancer 7%]*
Hamilton, Rebekah J; Bowers, Barbara J; Williams, Janet K (2005) Disclosing genetic test results to family members. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing 37(1): 18-24	- Population not relevant to this review protocol *Population includes people tested for Huntington's disease, or hereditary breast and ovarian cancer. 14 of the 29 (48%) participants had positive HBOC results. Most participants were from the USA but also includes those from Canada and Denmark. Study looks at the experiences of people disclosing genetic results to biological family members. Think we could exclude it based on the population and country.*
Hamilton, Rebekah and Hurley, Karen E (2010) Conditions and consequences of a BRCA mutation in young, single women of childbearing age. Oncology nursing forum 37(5): 627-34	- Relevant qualitative themes not reported *Themes as not relevant. The study examined young women's understanding of HBOC risk and how being single affected the*

Study	Exclusion reason
	meaning of that risk. USA and Canadian study.
Hamilton, Rebekah, Williams, Janet K, Skirton, Heather et al. (2009) Living with genetic test results for hereditary breast and ovarian cancer. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing 41(3): 276-83	- Population not relevant to this review protocol *Study is follow-up of the previous Hamilton 2003 study of participants (n=7) who agreed to be interviewed at time point 2 and 3.*
Hamilton, RJ (2003) Experiencing predictive genetic testing in families with Huntington's disease and hereditary breast and ovarian cancer. Experiencing Predictive Genetic Testing in Families With Huntington's Disease & Hereditary Breast & Ovarian Cancer: 213p-213p	- Study design not relevant to this review protocol *Study is a dissertation. Most of participants (n=13) reside in the USA. n=4 from Canada and n=1 from Denmark*
Hendricks-Sturrup, R.M.; Joseph, L.; Lu, C.Y. (2021) Patient-reported outcomes following genetic testing for familial hypercholesterolemia, breast and ovarian cancer syndrome, and lynch syndrome: A systematic review. Journal of Personalized Medicine 11(9): 850	- Study design not relevant to this review protocol *Systematic review of qualitative and mixed methods studies. No relevant qualitative data for inclusion but included studies list was checked for relevant papers.*
Hofferbert, S., Worringen, U., Backe, J. et al. (2000) Simultaneous interdisciplinary counseling in German breast/ovarian cancer families: First experiences with patient perceptions, surveillance behavior and acceptance of genetic testing. Genetic Counseling 11(2): 127-146	- Study design not relevant to this review protocol *Quantitative analysis*
Hoskins, Lindsey M, Roy, Kevin, Peters, June A et al. (2008) Disclosure of Positive BRCA1/2-Mutation Status in Young Couples: The Journey From Uncertainty to Bonding Through Partner Support. Families, systems & health : the journal of collaborative family healthcare 26(3): 296-316	- Country not relevant to this review protocol (paper not further checked for relevance)
Hurley, K., Rubin, L.R., Werner-Lin, A. et al. (2012) Incorporating information regarding preimplantation genetic diagnosis into discussions concerning testing and risk management for BRCA1/2 mutations: A qualitative study of patient preferences. Cancer 118(24): 6270-6277	- Country not relevant to this review protocol (paper not further checked for relevance)
Hurtado-de-Mendoza, Alejandra, Gomez-Trillos, Sara, Graves, Kristi D et al. (2021) Process evaluation of a culturally targeted video for Latinas at risk of hereditary breast and ovarian cancer. Journal of genetic counseling 30(3): 730-741	- Country not relevant to this review protocol (paper not further checked for relevance)
Jennings, C., Wynn, J., Miguel, C. et al. (2022) Mother and daughter perspectives on genetic counseling and testing of adolescents for hereditary breast cancer risk. Journal of Pediatrics	- Population not relevant to this review protocol *Population includes mother/daughter combination, with the daughters at adolescent age <18years. Study also partly conducted in USA and has a focus on breast cancer risk.*

Study	Exclusion reason
Jones, T., Howard, H., Freeman-Costin, K. et al. (2021) Knowledge and perceptions of BRCA1/2 genetic testing and needs of diverse women with a personal or family history of breast cancer in South Florida. Journal of Community Genetics 12(3): 415-429	- Country not relevant to this review protocol (paper not further checked for relevance)
Kajula, Outi; Kuismin, Outi; Kyngas, Helvi (2018) Identification as a Mutation Carrier and Effects on Life According to Experiences of Finnish Male BRCA1/2 Mutation Carriers. Journal of genetic counseling 27(4): 874-884	- Relevant qualitative themes not reported *Themes are not focussed on information and support needs though there is evidence around the effects of knowledge of BRCA mutations. Studies looks at the experiences of men identified as BRCA mutation carriers. Could also exclude as population is men who are the BRCA carriers when the population is family/carers of people at increased risk.*
Kamara, Daniella, Weil, Jon, Youngblom, Janey et al. (2018) Cancer Counseling of Low-Income Limited English Proficient Latina Women Using Medical Interpreters: Implications for Shared Decision-Making. Journal of genetic counseling 27(1): 155-168	- Country not relevant to this review protocol (paper not further checked for relevance)
Kenen, R.; Ardern-Jones, A.; Eeles, R. (2004) We are talking, but are they listening? Communication patterns in families with a history of breast/ovarian cancer (HBOC). Psycho-Oncology 13(5): 335-345	- Population not relevant to this review protocol *Unclear how at risk the population is for ovarian cancer. [21 adults who have not had breast/ovarian cancer but have two or more cases of breast/ovarian cancer in the family]*
Kenen, R; Arden-Jones, A; Eeles, R (2004) Healthy women from suspected hereditary breast and ovarian cancer families: the significant others in their lives. European journal of cancer care 13(2): 169-79	- Population not relevant to this review protocol *Unclear how at risk the population is for ovarian cancer. [21 adults who have not had breast/ovarian cancer but have two or more cases of breast/ovarian cancer in the family] Publication date 2004.*
Kenen, R; Ardern-Jones, A; Eeles, R (2003) Living with chronic risk: healthy women with a family history of breast/ovarian cancer. Health, Risk & Society 5(3): 315-331	- Population not relevant to this review protocol *Unclear how at risk the population is for ovarian cancer. [21 adults who have not had breast/ovarian cancer but have two or more cases of breast/ovarian cancer in the family] Publication date 2003.*
Kenen, Regina; Ardern-Jones, Audrey; Eeles, Rosalind (2003) Family stories and the use of heuristics: women from suspected hereditary breast and ovarian cancer (HBOC) families. Sociology of health & illness 25(7): 838-65	- Population not relevant to this review protocol

Study	Exclusion reason
	Unclear how at risk the population is for ovarian cancer. [21 adults who have not had breast/ovarian cancer but have two or more cases of breast/ovarian cancer in the family] Publication date 2003.
Kinney, Anita Yeomans, Gammon, Amanda, Coxworth, James et al. (2010) Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies. Genetics in medicine : official journal of the American College of Medical Genetics 12(2): 105-15	- Population not relevant to this review protocol *Only 20% of the population had a family history of breast or ovarian cancer. Study explores attitudes about BRC1/2 testing but it's appears as though only a small number of participants have an ovarian cancer risk. Study is also from the USA so could be excluded based on country*
Klitzman, R. and Chung, W. (2010) The process of deciding about prophylactic surgery for breast and ovarian cancer: Patient questions, uncertainties, and communication. American Journal of Medical Genetics, Part A 152a(1): 52-66	- Country not relevant to this review protocol (paper not further checked for relevance)
Kne, Alyssa, Zierhut, Heather, Baldinger, Shari et al. (2017) Why Is Cancer Genetic Counseling Underutilized by Women Identified as at Risk for Hereditary Breast Cancer? Patient Perceptions of Barriers Following a Referral Letter. Journal of genetic counseling 26(4): 697-715	- Country not relevant to this review protocol (paper not further checked for relevance)
Li, S.-T., Sun, S., Lie, D. et al. (2018) Factors influencing the decision to share cancer genetic results among family members: An in-depth interview study of women in an Asian setting. Psycho-Oncology 27(3): 998-1004	- Country not relevant to this review protocol (paper not further checked for relevance)
Lifford, K.J., Clements, A., Fraser, L. et al. (2013) A qualitative study of women's experiences of familial ovarian cancer screening. Psycho-Oncology 22(11): 2576-2584	- Relevant qualitative themes not reported
MacDonald, D.J., Sarna, L., Weitzel, J.N. et al. (2009) Women's Perceptions of the Personal and Family Impact of Genetic Cancer Risk Assessment: Focus Group Findings. Journal of Genetic Counseling: 1-13	- Country not relevant to this review protocol (paper not further checked for relevance)
Machirori, Mavis; Patch, Christine; Metcalfe, Alison (2019) Black and Minority Ethnic women's decision-making for risk reduction strategies after BRCA testing: Use of context and knowledge. European journal of medical genetics 62(5): 376-384	- Population not relevant to this review protocol *Unclear what proportion of participants are at risk for ovarian cancer. participants had a family and personal history of various cancers including breast, ovarian, lung and prostate cancers. (n=6, 60% had positive BRCA mutations, only 1 participant had a family history of ovarian cancer)*
Mallen, A.R., Conley, C.C., Fuzzell, L. et al. (2021) "I think that a brief conversation from their provider can go a very long way": Patient and provider perspectives on barriers and	- Country not relevant to this review protocol (paper not further checked for relevance)

Study	Exclusion reason
facilitators of genetic testing after ovarian cancer. Supportive Care in Cancer 29(5): 2663-2677	
Matsukawa, Manami, Torishima, Masako, Satoh, Chika et al. (2022) Japanese women's reasons for accompaniment status to hereditary breast and ovarian cancer-focused genetic counseling. Journal of genetic counseling 31(2): 497-509	- Country not relevant to this review protocol (paper not further checked for relevance)
Mellon, S., Berry-Bobovski, L., Gold, R. et al. (2006) Communication and decision-making about seeking inherited cancer risk information: Findings from female survivor-relative focus groups. Psycho-Oncology 15(3): 193-208	- Country not relevant to this review protocol (paper not further checked for relevance)
Mellon, S., Berry-Bobovski, L., Gold, R. et al. (2007) Concerns and recommendations regarding inherited cancer risk: The perspectives of survivors and female relatives. Journal of Cancer Education 22(3): 168-173	- Country not relevant to this review protocol (paper not further checked for relevance)
Mellon, S, Gauthier, J, Cichon, M et al. (2013) Knowledge, attitudes, and beliefs of Arab-American women regarding inherited cancer risk. Journal of genetic counseling 22(2): 268-76	- Country not relevant to this review protocol (paper not further checked for relevance)
Mendes, A., Chiquelho, R., Santos, T.A. et al. (2010) Family matters: Examining a multi-family group intervention for women with BRCA mutations in the scope of genetic counselling. Journal of Community Genetics 1(4): 161-168	- Relevant qualitative themes not reported *The study qualitatively assesses a multi-family group intervention for women who tested positive for BRCA mutations and their families*
Metcalfe, A., Werett, J., Burgess, L. et al. (2007) Psychosocial impact of the lack of information given at referral about familial risk of cancer. Psycho-Oncology 16(5): 458-465	- Population not relevant to this review protocol *The relevant quotes were not from people at risk for ovarian cancer.*
Metcalfe, A., Werrett, J., Burgess, L. et al. (2009) Cancer genetic predisposition: Information needs of patients irrespective of risk level. Familial Cancer 8(4): 403-412	- Study design not relevant to this review protocol *A mixed methods study with a narrative synthesis for results. No qualitative themes or quotes.*
Miller, F.A., Carroll, J.C., Wilson, B.J. et al. (2010) The primary care physician role in cancer genetics: A qualitative study of patient experience. Family Practice 27(5): 563-569	- Population not relevant to this review protocol *Unclear how much of the population is at risk of ovarian cancer. Patients referred for genetic testing. Most (21/25) were referred for BRCA1/2 testing, 4 referred for hereditary nonpolyposis colorectal cancer testing*
Myklebust, Marion; Gjengedal, Eva; Stromsvik, Nina (2016) Experience of Norwegian Female BRCA1 and BRCA2 Mutation-Carrying Participants in Educational Support Groups: a Qualitative Study. Journal of genetic counseling 25(6): 1198-1206	- Relevant qualitative themes not reported *Themes very relevant but centre around experiences of the research study*

Study	Exclusion reason
Norris, Joan, Spelic, Stephanie Stockard, Snyder, Carrie et al. (2009) Five families living with hereditary breast and ovarian cancer risk. Clinical journal of oncology nursing 13(1): 73-80	- Country not relevant to this review protocol (paper not further checked for relevance)
Ormondroyd, E, Moynihan, C, Ardern-Jones, A et al. (2008) Communicating genetics research results to families: problems arising when the patient participant is deceased. Psycho-oncology 17(8): 804-11	- Population not relevant to this review protocol *Does not include participants specifically with familial ovarian cancer or who are at increased risk of ovarian cancer. Study explored the process of post-mortem dissemination within families of the research finding of BRCA2 mutations in men with prostate cancer.*
Patenaude, Andrea, DeMarco, Tiffani, Peshkin, Beth et al. (2013) Talking to Children About Maternal BRCA1/2 Genetic Test Results: A Qualitative Study of Parental Perceptions and Advice. Journal of Genetic Counseling 22(3): 303-314	- Country not relevant to this review protocol (paper not further checked for relevance)
Perry, CE (2005) Managing susceptibility to hereditary breast and ovarian cancer. Managing Susceptibility to Hereditary Breast & Ovarian Cancer: 256p-256p	- Study design not relevant to this review protocol *publication type is a dissertation. Also from the USA.*
Phelps, C, Wood, F, Bennett, P et al. (2007) Knowledge and expectations of women undergoing cancer genetic risk assessment: a qualitative analysis of free-text questionnaire comments. Journal of genetic counseling 16(4): 505-14	- Relevant qualitative themes not reported *Themes centre around experiences of the research study*
Pozzar, Rachel A, Hong, Fangxin, Xiong, Niya et al. (2022) Knowledge and psychosocial impact of genetic counseling and multigene panel testing among individuals with ovarian cancer. Familial cancer 21(1): 35-47	- Country not relevant to this review protocol (paper not further checked for relevance)
Puski, Athena, Hovick, Shelly, Senter, Leigha et al. (2018) Involvement and Influence of Healthcare Providers, Family Members, and Other Mutation Carriers in the Cancer Risk Management Decision-Making Process of BRCA1 and BRCA2 Mutation Carriers. Journal of genetic counseling 27(5): 1291-1301	- Country not relevant to this review protocol (paper not further checked for relevance)
Quinn, Gwendolyn P; McIntyre, Jessica; Vadaparampil, Susan T (2011) Preferences for hereditary breast and ovarian cancer information among Mexican, Cuban and Puerto Rican women at risk. Public health genomics 14(45): 248-58	- Country not relevant to this review protocol (paper not further checked for relevance)
Quinn, Gwendolyn P, Pal, Tuya, Murphy, Devin et al. (2012) High-risk consumers' perceptions of preimplantation genetic diagnosis for hereditary cancers: a systematic review and meta-analysis. Genetics in medicine : official journal of the American College of Medical Genetics 14(2): 191-200	- Study design not relevant to this review protocol *Systematic review to assess high-risk consumers' knowledge and perceptions of Preimplantation Genetic Testingfor hereditary cancers. Includes both quantitative and qualitative studies. No relevant qualitative data*

Study	Exclusion reason
Rauscher, Emily A; Dean, Marleah; Campbell-Salome, Gemme M (2018) "I Am Uncertain About What My Uncertainty Even Is": Men's Uncertainty and Information Management of Their BRCA-Related Cancer Risks. Journal of genetic counseling 27(6): 1417-1427	- Country not relevant to this review protocol (paper not further checked for relevance)
Sa'at, Hamizah, Lee, Yew-Kong, Yoon, Sook-Yee et al. (2022) Decision-making for Risk-reducing Salpingo-oophorectomy (RRSO) in Southeast Asian BRCA Mutation Carriers With Breast Cancer: A Qualitative Study. International Journal of Behavioral Medicine 29(1): 1-13	- Country not relevant to this review protocol (paper not further checked for relevance)
Sermijn, E, Goelen, G, Teugels, E et al. (2004) The impact of proband mediated information dissemination in families with a BRCA1/2 gene mutation. Journal of medical genetics 41(3): e23	- Study design not relevant to this review protocol *No qualitative data. Quantitative study.*
Shaw, J., Bulsara, C., Cohen, P.A. et al. (2018) Investigating barriers to genetic counseling and germline mutation testing in women with suspected hereditary breast and ovarian cancer syndrome and Lynch syndrome. Patient Education and Counseling 101(5): 938-944	- Population not relevant to this review protocol *Themes relevant but population focussed on endometrial cancer. [3 with ovarian cancer 37%, 5 with endometrial cancer]. Unclear whether the participants had lynch syndrome.*
Shkedi-Rafid, S., Gabai-Kapara, E., Grinshpun-Cohen, J. et al. (2012) BRCA genetic testing of individuals from families with low prevalence of cancer: Experiences of carriers and implications for population screening. Genetics in Medicine 14(7): 688-694	- Country not relevant to this review protocol (paper not further checked for relevance)
Sussner, Katarina M, Edwards, Tiffany, Villagra, Cristina et al. (2015) BRCA genetic counseling among at-risk Latinas in New York City: new beliefs shape new generation. Journal of genetic counseling 24(1): 134-48	- Country not relevant to this review protocol (paper not further checked for relevance)
Suttman, Alexandra, Pilarski, Robert, Agnese, Doreen M et al. (2018) "Second-Class Status?" Insight into Communication Patterns and Common Concerns Among Men with Hereditary Breast and Ovarian Cancer Syndrome. Journal of genetic counseling 27(4): 885-893	- Country not relevant to this review protocol (paper not further checked for relevance)
Swisher, E M, Babb, S, Whelan, A et al. (2001) Prophylactic oophorectomy and ovarian cancer surveillance. Patient perceptions and satisfaction. The Journal of reproductive medicine 46(2): 87-94	- Country not relevant to this review protocol (paper not further checked for relevance)
Tezak, Ann Louise, Weidner, Anne, Clouse, Kate et al. (2021) Using an anthropological lens to explore motivators and challenges for follow-up care decision making among female BRCA1/2 carriers at risk for inherited cancer. Human Organization 80(3): 203-213	- Country not relevant to this review protocol (paper not further checked for relevance)
Underhill, Meghan L and Crotser, Cheryl B (2014) Seeking balance: Decision support needs of women without cancer and a deleterious BRCA1 or BRCA2 mutation. Journal of Genetic Counseling 23(3): 350-362	- Country not relevant to this review protocol (paper not further checked for relevance)
Vogel, R.I., Niendorf, K., Lee, H. et al. (2018) A qualitative study of barriers to genetic counseling and potential for mobile technology education among women with ovarian cancer. Hereditary Cancer in Clinical Practice 16(1): 13	- Country not relevant to this review protocol (paper not further checked for relevance)

Study	Exclusion reason
Wakefield, Claire E, Kasparian, Nadine A, Meiser, Bettina et al. (2007) Attitudes toward genetic testing for cancer risk after genetic counseling and decision support: a qualitative comparison between hereditary cancer types. Genetic testing 11(4): 401-11	- Population not relevant to this review protocol *Mixed population (22% at risk of hereditary nonpolyposis colorectal cancer and 78% at risk of breast/ovarian cancer), results not reported separately for target population*
Werner-Lin, Allison (2008) Formal and informal support needs of young women with BRCA mutations. Journal of psychosocial oncology 26(4): 111-33	- Country not relevant to this review protocol (paper not further checked for relevance)
Werner-Lin, Allison V (2007) Danger zones: risk perceptions of young women from families with hereditary breast and ovarian cancer. Family process 46(3): 335-49	- Country not relevant to this review protocol (paper not further checked for relevance)
Wiseman, M.; Dancyger, C.; Michie, S. (2010) Communicating genetic risk information within families: A review. Familial Cancer 9(4): 691-703	- Study design not relevant to this review protocol *Narrative review of mixed methods studies.*
Young, Alison L, Butow, Phyllis N, Vetsch, Janine et al. (2017) Family communication, risk perception and cancer knowledge of young adults from BRCA1/2 families: A systematic review. Journal of Genetic Counseling 26(6): 1179-1196	- Systematic review used as a source of primary studies Included papers' country of origin not relevant to this review protocol (paper not further checked for relevance)
Zilliacus, Elvira M, Meiser, Bettina, Lobb, Elizabeth A et al. (2010) Women's experience of telehealth cancer genetic counseling. Journal of genetic counseling 19(5): 463-72	- Population not relevant to this review protocol *Themes relevant. Population includes mostly those with breast cancer [only 1 participant with breast and ovarian cancer]*
Andersen, M Robyn, Bowen, Deborah, Yasui, Yutaka et al. (2003) Awareness and concern about ovarian cancer among women at risk because of a family history of breast or ovarian cancer. American journal of obstetrics and gynecology 189(4suppl): 42-7	- Country not relevant to this review protocol (paper not further checked for relevance)

Excluded economic studies

No economic evidence was identified for this review. See supplementary material 2 for further information.

Appendix J Research recommendations – full details

Research recommendations for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

No research recommendations were made for this review question.

Appendix K Qualitative themes

Qualitative themes for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Figure 3: Thematic map for the information and support needs for women with familial ovarian cancer or who are at increased risk of ovarian cancer and their families and carers

Figure 4: Sub-theme map for deficiency in the information and support provided

Figure 5: Sub-theme map for need for support networks and support groups

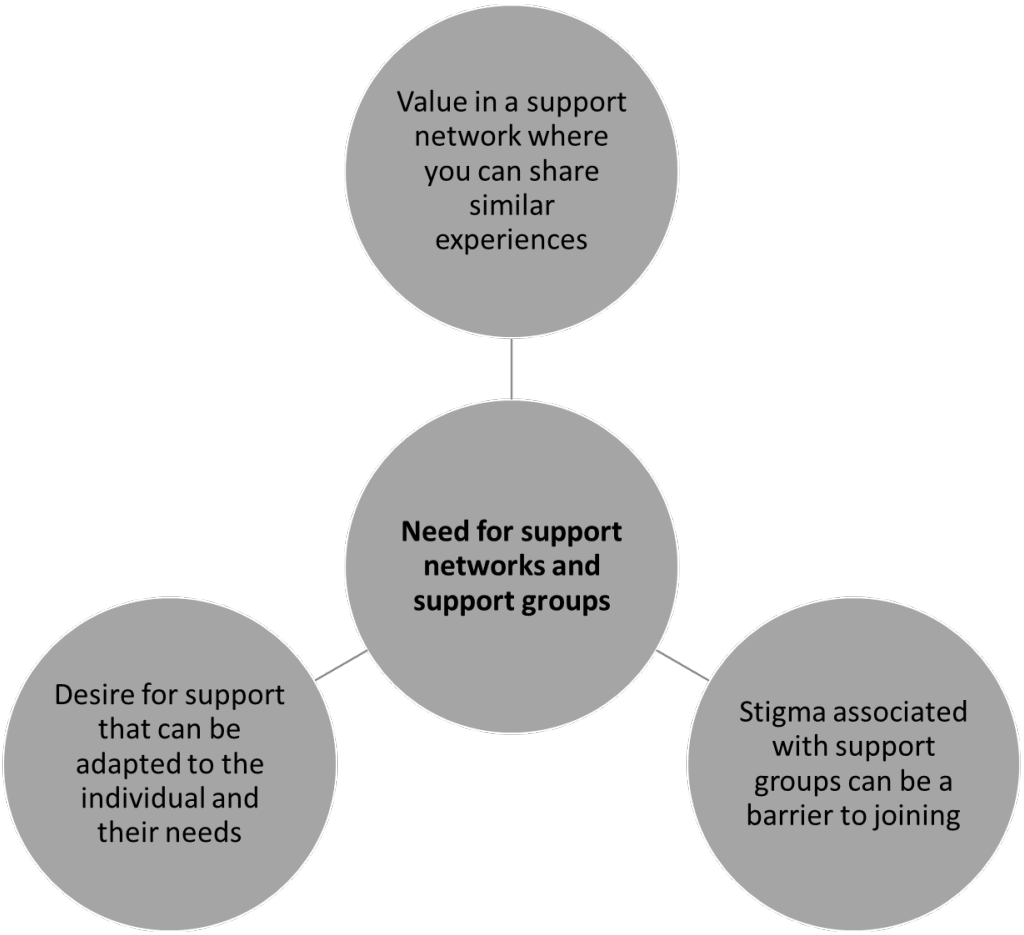


Figure 6: Sub-theme map for the role of the professional in providing information and support

Figure 7: Sub-theme map for tailor the delivery of information to suit the individual and their need and preferences

Figure 8: Sub-theme map for family as a source of information and support

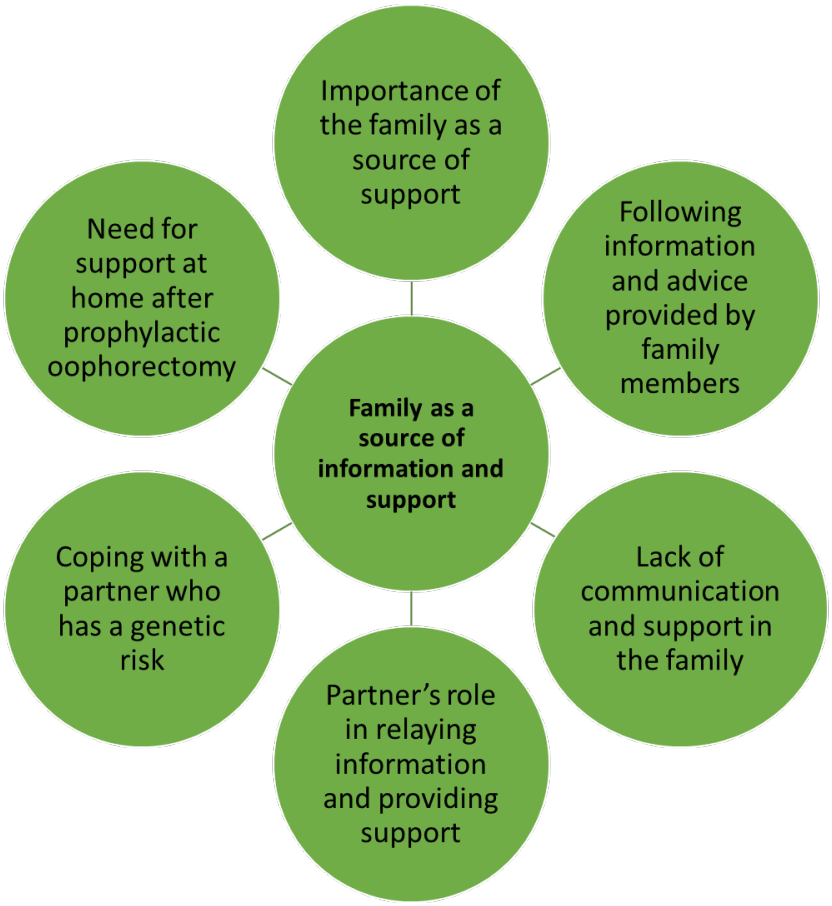


Figure 9: Sub-theme map for the impact of the family on decisions about genetic testing

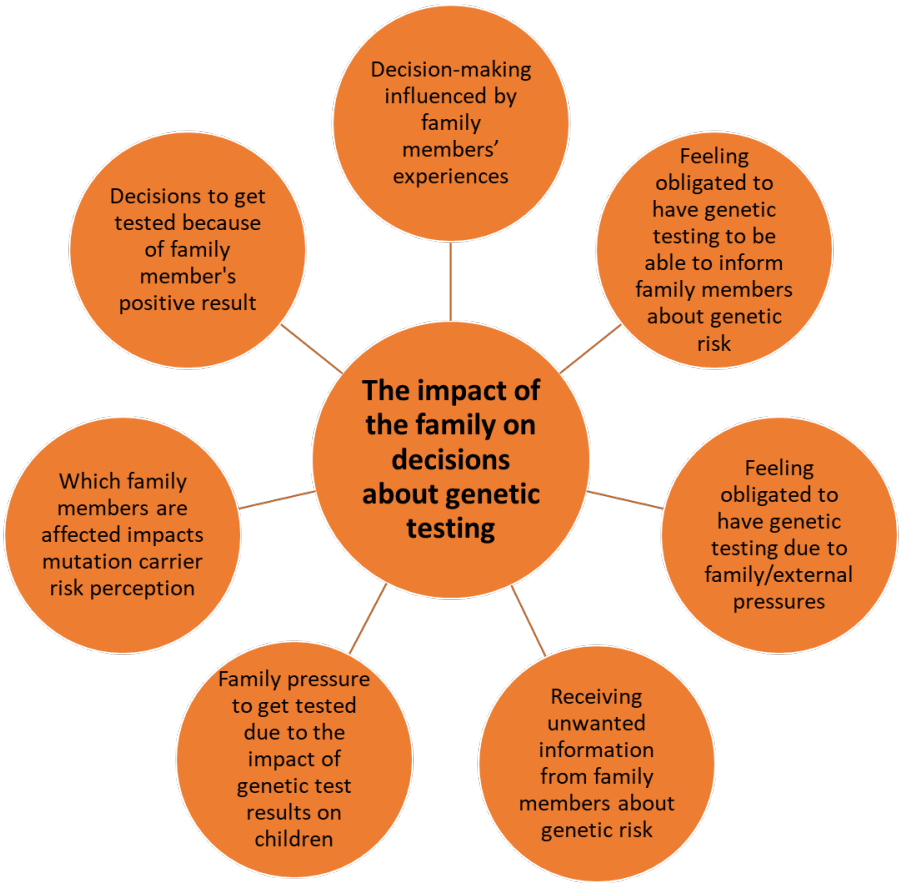


Figure 10: Sub-theme map for impact of genetic risk information on emotions and decision making

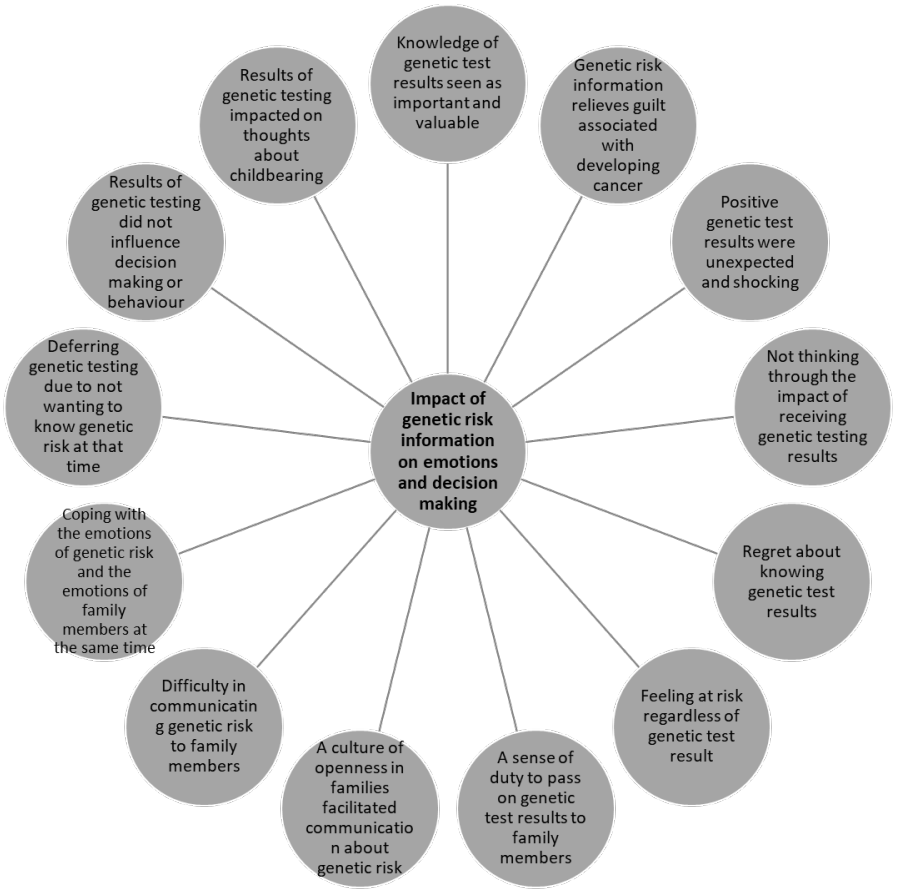


Figure 11: Sub-theme map for importance of ovarian cancer surveillance programs and knowledge of surgical options

Figure 12: Sub-theme map for reasons for and against genetic testing

Appendix L Qualitative quotes

Qualitative quotes for review question: What information and support is needed by women with familial ovarian cancer or who are at increased risk of ovarian cancer (with or without breast cancer), and their families and carers?

Table 14: Theme 1: Deficiency in the information and support provided

Study	Evidence
Sub-theme 1.A: More information needed on cancer surveillance including CA-125 testing, and surgery	
Brain 2004	‘‘Just go there once a year, have that done.’’ p908
Brain 2004	‘‘He said that the ovaries looked alright, you know. But they are not saying there can’t have been a small little tumour starting’.’ p908
Brain 2004	‘‘I won’t really be happy until I have been back and they have told me that it (ovarian mass) was due to ovulation, because it should have gone by then.’’ p908
Brain 2004	‘‘When you get told all your levels are raised, you think, ‘Oh my god, what does this mean?’’’ p908
Brain 2004	‘‘The letter asked me to come back for another test, because they may be falsely raised, but it doesn’t even explain why they may be falsely raised.’’ p908
Brain 2004	‘‘...it’s not as straightforward as we will take those two things out, whoosh, gone.’’ p909
Brain 2004l	“Once you start shrivelling up, you do go old quicker if you lose the two ovaries, don’t you?’’ p909
Gaba 2022	“I wasn’t happy with the impact of going in to menopause straight away and although you obviously have HRT options which might be offered if you go to a good gynaecologist, I just, I wasn’t convinced that HRT brings you back up to an even keel or level, the way that I’m feeling right now which is basically very balanced.” p6
Lifford 2013	“I hadn’t realised that you can still get ovarian cancer after you have had your ovaries removed…I thought when I was opting for surgery that was that, but apparently not…at 2 % I don’t think I’d trot off for a blood test mmm don’t know…the screening wouldn’t show it up anyway, would it?” p24
Sub-theme 1.B: Need for more support following oophorectomy	
Shilling 2020	“And now I’ve had my oophorectomy, there’s been no sort of follow-up. Which I suppose there’s no need for it, but I think it would be nice if you could have […] OK, you’ve had this now, you’ve reduced your risk to this, and just a bit more discussion about the next step.” p495
Sub-theme 1.C: More information needed on male genetic risk	
Brain 2004	“So then that put a different perspective on it, because whereas I thought it was all the men... I discovered then that I was possibly involved in it more so than I thought. So that was a bit of a shock as well.’’ p909
Dancyger 2011	“Is it a male thing as well? I thought it was a female thing. I haven’t spoken about it to my brothers at all.” p1023
Pedrazzani 2022	“Actually, the communication to the family was delegated to me. (. . .) Perhaps it was implied, they spoke more in the feminine, then for the offspring, they spoke in the masculine. (. . .) This thought made me think that there was no need to tell to my uncles. I understood so . . . but then it is the perception.” p5

Study	Evidence
Pedrazzani 2022	“I also realize with my brother that he really doesn’t want to talk about it, because with men it’s like this that the disease only comes to them when they’re in their 50s and 60s. (. . .) But for him it’s right at the moment that he doesn’t know and he doesn’t think about it.” p8
Seenandan - Sookdeo 2016	“It does become sort of less clear to me with a male. I mean, obviously, a son, if they marry and have children . . . they have the potential to have daughters. I’m not sure at what point it sort of becomes more important for him to have this information because how would it change what medical follow-up he has at this point?” p337
Young 2019	“His sister had already been tested previously but nobody had ever mentioned once, that because she had the gene he could have the gene, we didn't know that it would pass through the male line…if they had said it earlier on he may have got tested.” p525
Young 2019	“There's never any publicity or any thinking that males have breast cancer…you wouldn't…ever hear men check.” p525
Young 2019	“If and when it becomes the thing where you can use the information and are able to do something with it, then absolutely I wanna do everything I can to stay kicking. If it is just some gathering information to have it handy, I don't know how to process that…all its going to do is [say] I'm going to die… Hopefully there is scientific progress, but until that happens, I don't want to know.” p525
Sub-theme 1.D: More information needed on the benefits of genetic testing	
Dancyger 2010	“It doesn’t really mean that much because you still don’t really know you’re going to get it it’s not really going to help you... Information that is a little bit scary but not amazingly useful.” (p1293)
Dancyger 2010	“I will do it soon, it’s better to know at the end of the day .. I don’t know how to prevent it, there isn’t a way ... I don’t know what to think about me doing it ... it’s not something I would go out of my way to try and find out or to try and do.” p1294
Dancyger 2010	“I thought it was a good idea … Um, early detection and, you know, take steps to ... you can’t avoid it, or you can .. well if you do find out early enough you can do something, I don’t know.” p1294
Dancyger 2010	“I thought it was a good idea ... Um, early detection and, you know, take steps to...you can’t avoid it, or you can...well if you do find out early enough you can do something, I don’t know.” p1294
Dancyger 2010	“We hoped it was going to just pass by and stuff; but as she has it now, maybe we might also have it.” p1294
Wakefield 2011	‘‘No, I’ve actually never heard of it [an familial cancer clinic.” p382
Wright 2018	“She said, "you don’t have to have it," you know, she was very, very nice about it and said, you know, "It’s there, the test’s there if you would like to have it." And I thought it seemed silly not to have it. As I say, it wasn’t anything that was going to be painful or intrusive as far as I was concerned.” p1465
Wright 2018	“No I didnae sort of think, oh my God no, something else, you know. I was quite willing, you know. I don’t know, I think I just, to me it’s just all, it was just partly what I needed to do, kind of thing, you know.” p1466
Young 2019	“I don't know if it [genetic testing] actually means anything…it doesn't mean you're not going to get it anyway, does it?” p525
Sub-theme 1.E: More information and support needed on how and when to inform family members about genetic risk	

Study	Evidence
Hughes 2010	“It was really difficult when I was diagnosed [referring to being informed of carrier status] because my sister was over the moon that she didn’t have it and I did. She felt guilty that I had it and that she didn’t.” p491
Hughes 2010	“They know everything there is to know… So they’re not frightened. But I mean they also know that there is a possibility that they will inherit this gene as well.” p491
Hughes 2010	“I’ve got sons and that was the only thing I said to [genetic counselor that I worried about was that I had to go home and tell them. It didn’t matter about anything else only that I had to tell them.” p491
Jeffers 2014	“I haven’t approached the girls on it yet. My husband doesn’t want to approach them for some reason at the minute. I don’t know what to do with them to tell you the truth. It is good, I think it’s good when they know. My husband’s not as keen on the idea. He says that if they are tested and one has and one hasn’t (the gene) you know, but I don’t feel like that, I feel they are better to know. I don’t know what point of view there would be on that?” p415
Pedrazzani 2022	“No, that communication on her side (the genetic counsellor) was just too soft. And that applies to the family clarification as well, exactly the same. It shouldn’t be “it would be best to inform your relatives”, but: “We request you to clarify your family status.” Clearly and unambiguously described. Not “you could”. But: “Go there! Do it!” p5
Pedrazzani 2022	“Because of the speed with which everything happened, it (the topic of family communication) was touched on but not explored. It was said that there was a possibility to communicate to the boys and close family members, as there was heredity. This was communicated. (. . .) It was probably enough at that moment. Because you’re in a situation of turmoil (. . .) Maybe it would have been different, if illness happened afterwards.” p5
Pedrazzani 2022	“It was mainly the geneticist who encouraged me to talk to the family. Then when I went back to my gynecologist, he asked me if I had other family members, how they had taken it. Just out of interest. But...more than out of medical concern.” p5
Seenandan-Sookdeo 2016	“I mean, any healthcare provider or doctor in explaining to somebody that they have this genetic result should take it a step further. If you want to share the information with [your children], but you’re not sure how to do it, you know, maybe there could be some assistance in that regard.” p334
Seenandan-Sookdeo 2016	“I think that, even though it may be a difficult topic for some individuals . . . it’s an important one for healthcare professionals to raise—not to push information on people, but I think [it’s] just a topic that has to sort of be out there. And then, hopefully, there’ll be some resources that you can refer them to or make an offer to meet again to discuss this at whatever point in time.” p334
Seenandan-Sookdeo 2016	“The most support we got when we went through for the testing was . . . [name of member of genetics team]. So, I could have asked any questions that I wanted. They were very informative. . . . The support was good. They have a lot of information for me, and they were good to me. . . . When I went home, I went to see my family doctor, and we’re very close. . . . I really trust him, and we had a long talk, and he was a big support to me. . . . I don’t think anybody really asked me . . . if I was going to share that with my children or not. . . . Maybe I would have gotten some different ideas. I don’t know. I probably would have done the same things. . . . I think it would have been helpful.” p336
Seenandan-Sookdeo 2016	“Support was always there through [name of member of genetics team], my family doctor, and my sisters. I mean, I had that. I just had made up my mind and didn’t think it was a big deal at the time. . . . I’ve never heard anybody ask

Study	Evidence
	about [disclosure]. . . . I think they could bring it up, like, “Have you [thought] about whether or not you’ll talk to your children at some point about this?” p336
Seenandan-Sookdeo 2016	“I think it would be really good for the parents who choose to share it with their minor children, if they did have some kind of education forum, a workshop in kid-friendly language, graphics, and charts. Even if they had an information package for kids, saying, “This is what it means, and it doesn’t mean that your parent is going to have this.” . . . I think brochures, pamphlets, and even a kids help phone that they can call if they have questions. . . . If you need tips or guidelines, or this is how you could discuss it with your kid; maybe there could be some assistance in that regard.” p337-338
Seenandan-Sookdeo 2016	“Is there some type of place you could go to help you choose your words for them to understand at their level? Or some type of visual [on the] Internet where you can go for a visual presentation for them to understand at their level?” p338
Seenandan-Sookdeo 2016	“Aside from the insurance pieces, are there other kinds of cons to knowing this information? What are other people concerned about? What are people’s experiences . . . when they sort of give this information to their family? What about males— what sort of impact does it have? Are there certain tests and things that they should be having? I’m not sure about that because, again, the information I’ve gotten has been a little bit inconsistent.” p338
Pedrazzani 2022	“In the department they told me: “You have to communicate with your family . . . ”. But it was a bit abstract. I mean, I would have left from there and I might have done nothing too . . . ” p5
Pedrazzani 2022	“No, that communication on her side (the genetic counsellor) was just too soft. And that applies to the family clarification as well, exactly the same. It shouldn’t be “it would be best to inform your relatives”, but: “We request you to clarify your family status.” Clearly and unambiguously described. Not “you could”. But: “Go there! Do it!” p5
Pedrazzani 2022	“Because of the speed with which everything happened, it (the topic of family communication) was touched on but not explored. It was said that there was a possibility to communicate to the boys and close family members, as there was heredity. This was communicated. (. . .) It was probably enough at that moment. Because you’re in a situation of turmoil (. . .) Maybe it would have been different, if illness happened afterwards.” p5
Pedrazzani 2022	“It was mainly the geneticist who encouraged me to talk to the family. Then when I went back to my gynecologist, he asked me if I had other family members, how they had taken it. Just out of interest. But...more than out of medical concern.” p5
Sub-theme 1.F: More information and support needed on reproductive options	
Ormondroyd 2012	“Everyone at the table asked the same question to each other …we agreed that if (earlier generations) had decided not to have children then none of us would be there. That was a kind of powerful idea and I think we all wanted to be there.” p7
Ormondroyd 2012	“She [doctor] was definitely under the impression that we’d made a decision but it was actually just so we could learn about the options y she had a power point that she ran through on her laptop and explained the process but I don’t think she was geared up to be talking to someone for the first time.” p8
Ormondroyd 2012	“I found myself thinking, I’m testing her for this how do you know the baby they pick out is not gonna have something else? Am I being too obsessive about this? The difference between having the CVS and PGD is, I got pregnant naturally so this is the baby that was intended to be ... that’s what made me say, look, I don’t think PGD is for me.” p8

Study	Evidence
Ormondroyd 2012	"... do you get to go and point and say 'I'll have that one and that one?' .. I just see this can of worms that ultimately has got to be opened. I never imagined that having a family would involve this". p8
Sub-theme 1.G: Self-seeking information from alternative sources	
Pedrazzani 2022	"I might have been able to go to him again, but somehow I looked for (information) then in other places." p5
Smiths 2016	"I think any information is a good thing isn't it, prevention is better than cure…whatever information is quickly absorbed, because if it doesn't apply to you, it could apply to another member of your family or a friend or something which could be useful. So I think any information is good whether it's something you already knew or something new that you've learned." p5
Smits 2016	"If you're armed with that information then the doctors can't say 'oh you'll be all right, love, you know, it's just a bit of ageing and diverticulitis or whatever'. If you actually know that information, it's easier to push." p6
Smits 2016	"If you want to check [the internet] that before you go to your GP, just 'cause you think you're worrying about nothing, you know, it's private." p5
Sub-theme 1.H: Feeling helpless due to a lack of available services	
Brunstrom 2016	"If I knew I was still, I don't know, still written down somewhere, or I knew that someone was going to check on me or they were aware I have this risk and I don't know, it's just that they would know and someone professional would be checking up on me." p97
Brunstrom 2016	"So they are saying there is nothing we do, and it's like oh great, so I've got a ticking bomb.....I've got my results, I know it and that's it. I just can't do anything with them." p95
Sub-theme 1.I: It should be easier to access the system	
Shilling 2020	"I felt like I've been frustrated because by the time that I went to the genetic counsellor, I'd been trying for three years to get it." p495
Wakefield 2011	''KConFab sent out a recommendation to go and get tested, which I haven't done . . . I'm keen to have the gene test but just haven't managed to coordinate it yet.'' p382

Table 15: Theme 2: Need to support and support groups

Study	Evidence
Sub-theme 2.A: Value in having a support network where you can share similar experiences	
Foster 2002	"I have found that it is always better discussing problems. You know, if I have got a problem I share it around, because I always feel better. I don't keep things in." p475
Foster 2002	I felt that [. . .] you weren't supposed to cry, you know you weren't supposed to be upset and you know once they were buried then that was it sort of attitude so I did feel very alone a lot of the time." p475
Foster 2002	"think that it's healthier to talk about it rather than to bottle it all up." p475
Hughes 2010	"I suppose for me I thought "Is there anyone else the same age as me who's affected by this" and I remember I was in Paddington [train station] and I was looking at people going "well wonder if you've got the gene, I wonder if you've got that then, I wonder if you're just walking around and you've got it", and that was my first instinct. So I think for me perhaps it would have been good to have someone of my own age group to talk to...." p491-492

Study	Evidence
Hughes 2010	“My one daughter has had the test and she knows she carries the gene but I feel there’s no support for her. I don’t need the support but I think that she does…I do worry is she still thinking about it because she wouldn’t talk to me. So is she worried, is she, is it up in her mind? And she’s got nobody to talk to really. So I do worry that she’s worried about it.” p491
Hughes 2010	“You do feel different from the rest of the population and I just think it’s that isolation. So if you had people who were alike who had the same kinds of problems you could think oh yes that happened to me and shouldn’t you try this or you know…Yes you can talk to a friend but you can’t talk to anyone about a gene who hasn’t got it themselves… I do remember the emptiness, I do remember, not being dramatic who can I talk to about genes?” p491
Hughes 2010	“I just wish there was somebody else there that I could’ve gone and spoke to about the same things. That’s why I had to come.” p492
Hughes 2010	“I think that’s a good idea but I think you come down to again the person’s needs to the person who they are going to phone. Because I could phone somebody like Helen and she was like really positive, where I think that this lady by here had more in common with me...” p492
Hughes 2010	“I would definitely be on the other side of the phone to help somebody else.” p492
Hughes 2010	“You get great strength from it I think if you can help each other in any way or even if somebody wants to contact you and say look could you just have a word with somebody who’s thinking about surgery and maybe come along and see your scars you know… Because my cousin has just had surgery last week… we’re very close, and I feel I can give her some support now. And I can see that she is thinking oh yes and she’s seen me going the process before and that was beneficial to her.” p492
Samson 2014	"Umm, there's a, Facebook has a, bunch of different groups where people blog, and they just talk about their different experience, and so on… Um I've read some of them, uh, I could see where we have simialrities about, how we wamt to change out lifestyle, and, some of them I just don't seem to, to get. You know they... To relate to them. Um, I would like to meet other women who have, um, this gene mutation, just to find out what they;re doing, you know - people that are local, um, maybe there's a support group somehow that we can discuss the different, um.. options together, and decide, you know, just to have a support group, but um, that's yeah." p112-114
Samson 2014	"There could have been someone like right there that day? Like I would volunteer, you know, to do something like that. I would volunteer to… to just be on wait, you know, waiting there when someone's getting their results or you know… knowing that someone might be getting that that day. You could just say like, you can leave here and call that person right now. And talk to them, and set up a meeting with them." p112
Samson 2014	"So I, as soon as she, as soon as she was diagnosed with breast cancer I actually felt a bond with her. And then to find out after; because when she would talk to me I already knew all of this stuff, and of course she, she didn't know I was BRCA2 positive. Um, until pretty much when she was through all her chemo and radiation and then, and then she started talking about getting tested and stuff and that's when I told her; 'cause like I said I don't tell people that I'm (laughs); I don't tell people... Well I thought that she could - yeah exactly. I thought she would understand.. " p113
Shilling 2020	“As far as the geneticist, the genetic counsellor, the Family History Clinic, they’re talking to you on a professional level, which is fine. That gives you the

Study	Evidence
	knowledge and the data and the facts, but then you need, sometimes you need a friend in the same boat." p496
Sub-theme 2.B: Stigma associated with support groups can be a barrier to joining	
Gaba 2022	"I know there are [online] forums, but a lot of it, there's a lot of fearful ideas there, and my cousin was saying that she just had to stop going on those forums." p7
Hughes 2010	"If you'd have asked me if I'd go to a support group I think I would say probably 95% sure I wouldn't. If however you said to me we're going to have a support group and these are the topics we're going to talk about throughout the year, one is going to be insurance, another is going to be telling your daughter. Those sorts of things I would think well actually I think I might go to that, rather than this apparent unstructured [support group] thing." p492
Hughes 2010	"You think a support group, it's just going to be a load of women sitting round a table chatting." p492
Hughes 2010	"Basically a support group to me is someone gaining the knowledge or seeing what other people who've gone through it can give you information on." p492
Hughes 2010	"I think something that would put me off which I don't know what the solution is, is actually anonymity. Because if I went to a group and I met one of my friends there then we might say to each other 'gosh I didn't know you had blah, blah, blah…And that's something that would bother me because I haven't told anybody…I haven't told my family members some of them." p492
Mireskandari 2006	"I doubt that I've actually talked to anybody much about it, no. I guess probably like most men [laugh] I guess I feel it's a decision or position that I'll have to resolve myself." p104
Sub-theme 2.C: Desire for support that can be adapted to the individual and their needs	
Hughes 2010	"I think it depends what stage of the process you're at as well and how you're feeling emotionally. Sometimes you just think "no I can't quite cope with that sort of side yet" but maybe in 6 months time you maybe thinking "yeah maybe now I'd be ready to go to it". All depends what stage you're at, you know. And it's such a personal thing isn't it to go down that route or not. Yeah it would be great for some but not for all so. Again if it's one item within the package it's an extra thing you could latch on to." p493
Hughes 2010	"I want to know about the genes, the genetics. So if there was a newsletter about, you know if you've advanced any further in certain things...." p493
Hughes 2010	"To have like a workshop that they can all go to, it wouldn't be frightening to them they could learn everything about it and then it wouldn't be so frightening and daunting." p491
Hughes 2010	"Because what suits one might not suit another, and at different stages and at different times of your life it will all change, I think. A newsletter definitely, a web forum definitely, you know some sort of chat room definitely, again professional and mixed." p493

Table 16: **Theme 3: The role of the professional in providing information and support**

Study	Evidence
Sub-theme 3.A: Communication with professionals was supportive and informative	

Study	Evidence
Gaba 2022	“I’d done quite a bit of research myself. I found all of the people that I’ve met within the team have been fantastic and haven’t just treated me like Patient X who doesn’t know anything at all.” p8
Hughes 2010	“Family is fine. We can talk about anything but there is a limit on what you can talk about sometimes. You know I think in some cases they would be reluctant to talk and I think… I know myself I’ve spoken of things I know I can’t talk to her [daughter] about, to a Macmillan [UK cancer charity-funded] nurse. I felt a lot better for it. So I think you know it is a good thing, a good idea to be able to talk to somebody who doesn’t know you intimately.” p490
Jeffers 2014	“Especially with the genetic thing, I mean it’s just like sharing things and talking to other people, that’s where you come in, you can talk to them and you know get what they want and they know what you are talking about whereas somebody that hasn’t been there, don’t really, they sympathise with you and like they listen to you but it just goes over their head.” p416
Pedrazzani 2022	“I received a letter from the hospital explaining what it was and that I could possibly have the gene mutation and that I should contact Dr . . . And that’s what we did, together with the sister. Afterwards we had all the genetic meetings with her. She (the physician) explained it very well. So, for me it was never the case that I was somehow all alone and badly informed.” p5
Pedrazzani 2022	“(The physician) was absolutely available afterwards. I didn’t feel the need to see him again. Anyway, he’s a great person, I really found him to be totally adequate.” p5
Pedrazzani 2022	“I saw the psychologist to help me deal with the situation. And then she told me about it (communication), saying: “Now you have to communicate, you have to talk about it”. . . . And so, it was she who . . . convinced me to do it.” p7
Pedrazzani 2022	“I’m satisfied with what they told me... (The doctor) talked to me well . . . , she explained me well (. . .) I immediately sent the test results to my two sisters because of what Dr. G. told me to tell to my family and I also informed all the other family members.” p11
Pedrazzani 2022	“When I was told the result, he told me that he had prepared a letter for the families, that I had to distribute. It explained what to do and that you had to approach. (. . .) I thought it was good, it was important, it gave importance, credit, I thought, to what was happening.” p11
Sub-theme 3.B: Good to have professional support and advice when making decisions	
Dancyger 2010	“The doctors have said that it was good to know so they can go for all the check-ups.” p1293
Gaba 2022	“Counselling from my doctor really helped. She was knowledgeable, supportive and sympathetic of my situation. She recommended surgery as I have had all my kids, am 46 and because my aunt died of ovarian cancer at 45.” p4
Lifford 2013	“…I’m getting older and I believe the risks are higher as you get older…and I just felt I was being advised…and it was an intuitive…and the blood results were going up, so it was a combination…one year she said to me, ‘‘why you don’t have your ovaries removed’’ and I said ‘‘well because I’m fine and I don’t worry about it, as far as I know’’…because you never know sub-consciously, and I said ‘‘and I’m not high risk’’, so she looked at me and said ‘‘why do you think we screen you?’’…and I remember saying ‘‘oh ok’’ p22
Lifford 2013	“…[the surgeon] read my family history…he said ‘‘if you were my wife I would strongly be advising you to have your ovaries out’’. And I thought well that’ll do for me…” p23

Study	Evidence
Lifford 2013	"…so I hit 50 and thought, you know it had been recommended, and I you know, spent the whole year thinking I must do it, I must do it." p23
Young 2019	"I didn't know that mum felt guilty…and [aunt said]…'awh it sucks that my sister is going through this', so…maybe it is good for…a health professional to probe and ask questions, and go, oh you felt this but you didn't know that she felt this…and I can go, 'that's a stupid thing to feel, mum don't feel guilty about that'…" p527
Sub-theme 3.C: Desire for more time and opportunities for discussion with professionals	
Gaba 2022	"…my experience of [gynaecology] appointments is that people just present things to you, and very quickly you have to make a decision, and there isn't a way to just, some of the decisions take a lot of discussion, and coming back to it, and rethinking, and I just feel that there isn't that space for it…" p7
Jeffers 2014	"It actually does affect the risk level I am on. I really hadn't got a clue about that. . I just thought oh he's going to tell me there's a wee gene. it was like then there were all the questions.of course I didn't think about it until I was home and then I didn't really know what or who to ring.because he's a Professor, I thought I'm not ringing a Professor, so I really didn't know who I should have rang to ask the stupid question because I don't know if my own Doctor would know a lot of the answers." p415
Pedrazzani 2022	"I'm really starting to get into it (communication to children) now. Before I was more about saving my own skin, that's done, for now anyway, and now I want to save my kids." p5
Sub-theme 3.D: Need for accurate information and advice from professionals	
Hughes 2010	"You see that's why we need proper people because I have been giving [you] the completely wrong information and you'd have all gone home...thinking oh my god…I think you've got to have the true facts. I think there's a lot of bogus stuff out there really." p493
Hughes 2010	"I think it should be a mixed bag of professional and informal peer help." p 492-493
Hughes 2010	"I didn't even realise it was called BRCA until I was in here…So I can't tell them anything about it because I don't know anything about it myself, basically." p493
Smits 2016	"…you can get rogue information and you can think, 'Oh that's alright then, they told me on the internet there's no need to do so and so', which if you had gone to the GP… he could have done something or helped something." p5
Sub-theme 3.E: Feeling pressured by professionals to adopt risk management behaviours	
Fadda 2020	"Every time, he [the gynecologist] tells me that he's not going to let me cross 40 years with my ovaries. He says: <Take your time, but you will have to remove them>". p6
Fadda 2020	"My gynecologist would like me to decide immediately for both the interventions. <<It's foolish to wait for the disease>>. She said that to my face. She said: <<I don't know what's better, whether to have the operation or to have the disease. Think about it. Because with the disease, you know when you're going in, but you don't know when you're going out>>." p6
Fadda 2020	"I don't want to think about cancer all my lifetime. I want to feel good in my skin for 11 months and 25 days in a year. Before the exam, I suddenly dream that I have a breast growing up on my back, or that I break the imaging machine, this kind of things. Or I think <that's it, this time they are going to find something>. Thus, I agree to have 5 days in a year that I continuously think of cancer. That's it. And he [the radiologist] cannot understand. [. . .] I have to fight not to do an

Study	Evidence
	exam despite I'm in good mental health. Well, I can demand not to do it, don't I?!?" p6
Sub-theme 3.F: Feeling unsupported by professionals	
Fadda 2020	"He kept telling me it was up to me, that he could not put himself in my shoes. I told him: <But what about if I were your sister?> His answer was always: <Look deep inside, talk about it, talk to your husband, it's up to you to decide, and I'll be there to do what you decide>." p6
Fadda 2020	"He said: <Look, this is my position: it is your choice, it is your body>. <Okay>, I told him, <then I'm using you as a manpower: I would like you to do the intervention because you know me, I want you to do the surgery> And we planned the date". p7
Jeffers 2014	"I really want to write things down about how Annoyed I am. you give me this information, and nobody has done anything about it. I found out in April about this gene and I'm none the wiser you know, I'm not. It's like somebody has given you, not a death sentence, but this thing could kick off at any time, especially auntie Susie dying from it last year. I just don't think it's right to give people, tell people that and then there is nothing to back it up" p415
Jeffers 2014	"I really want to write things down about how annoyed I am. you give me this information and nobody has done anything about it. I found out in April about this gene and I'm none the wiser you know, I'm not. It's like somebody has given you, not a death sentence, but this thing could kick off at any time, especially auntie Susie dying from it last year. I just don't think it's right to give people, tell people that and then there is nothing to back it up." p415
Jeffers 2014	"I wonder will he hurry it (surgery) up. You are sitting there thinking is it starting to work, is the cancer maybe there. it's like a time bomb you know. You are just feeling all the time and the least wee thing you are like, not paranoid, but I would certainly be quite aware of things." p415
Smits 2016	"Some GPs don't give a damn and others don't know the information." p6
Sub-theme 3.G: Desire for continuity and accessibility of care	
Shilling 2020	"The genetics team believe that the gynaecology team and the breast team speak with each other. And that it's actually like a multi-disciplinary team approach and it's not. And that's a real shame actually because the two in these genetic areas go hand in hand and yet they don't. p496
Smits 2016	"You would have to go through it all [family history] and whatever… you've got to keep going through the same thing all the time." p6
Smits 2016	"It's better to see the same one as you don't have to keep going through the same thing all the time." p6
Smits 2016	"It seems to give me peace of mind, because you don't have to continually repeat all the time." p6
Smits 2016	"They didn't know anything about my family history at all. Okay, my file obviously would be that thick coming from when I was born, 'cause they don't have time to look at it do they?" p6

Table 17: Theme 4: Tailor the delivery of information to suit the individual and their needs and preferences

Study	Evidence
Sub-theme 4.A: Desire for information to be offered in various formats, dependent on individual need and preference	
Gleeson 2013	"I just think that basically it's got to be face-to-face first, because it's all about communication and trust." pg280
Gleeson 2013	"I think, in booklet form, it can be a little bit off-putting because you think, "Oh God, I've got to read through all this." p280
Hughes 2010	"I think to talk to a professional is quite daunting when you're young. You know I really do because nothing is in layman's terms then, whereas all you want to know is "what's my chances, can I live with this, you know what's the screening process like, and all the rest of it", do you know what I mean?" p493
Hughes 2010	"I think the website is a good idea because men will go onto a website whereas they wouldn't come to anything like this." p490
Hughes 2010	"They try to keep things secret. They don't like to share anything do they you know, or tell people about their health problems." p491
Hughes 2010	"Like a call back service, where you could leave a message, you know I have got some questions, I have got some queries, please could you get back to me. People can't be available 24/7 can they...?" p493
Hughes 2010	"I would embrace all of the forms of different branches we've mentioned this morning. Not particularly that I might use all of them but they would be there to access at any given point in your life should things change or as your children grow up. So I think all forms—the bigger the network the bigger the bowl of cherries. Maybe there's a cherry for every little problem you might come across." p493
Ratnayake 2010	"I actually would expect whoever is the first to put me on the list to approach me first and let me know of that."p102
Ratnayake 2010	"Somehow if that letter went to my relatives, I'd like my name and phone number on it, so they could ring me." p102
Ratnayake 2010	"I would love a brochure that I could actually pass [on]."p102
Ratnayake 2010	"It's easily accessible and they can do it at their own time … and they can find out if the website is, with full coverage they can actually look up whatever information they want to know."p102
Ratnayake 2010	"'A lot of people don't have the availability to computers. A lot of the younger ones and as I say, I have but I know my mother wouldn't even know how to turn a computer on." p102
Shilling 2020	"My mum […] just wants to be told what's the best thing to do and get on with it and she puts her head in the sand. Whereas I need to know my percentage of risk." p493
Shilling 2020	"They may well have done but, to be perfectly honest, numbers and I don't mix. It won't have meant anything other than you're not at major risk." p493
Shilling 2020	"I've come away with, at the moment, I'm 65% lifetime risk. They have talked to me about the yearly risk figures, but I get too confused. And I know it's cumulative, but it doesn't really mean anything to me." p493
Shilling 2020	"Perhaps you're better off just having the blood test. And then, saying to you, right, if you test positive for this gene fault, then we invite you to come up here to discuss it all." p495

Study	Evidence
Shilling 2020	"I did feel that the communication with the surgeons and the oncologist as well, and always having a nurse in the room is so, so, important. And then, having the letter to follow-up afterwards to the GP, that I get copied on, to explain what it was we talked about." p495
Shilling 2020	"How do you understand information? How do you make decisions? […] that could be the first thing and then that sets the basis of the relationship." p495
Shilling 2020	"They don't just tell you they are going to do x, y and z; they involve you. And they listen to what you say." p495
Shilling 2020	"Know not everybody has somebody they can go with but that to me, sitting there hearing those risks when you're just by yourself […] Then having to sit on the train and absorb it all by yourself on the way home." p495
Sub-theme 4.B: Feeling overwhelmed when there is too much information	
Smits 2016	"It can be overwhelming sometimes, you get too much information." p6
Smits 2016	"It could put some people off if they knew the statistics for success rates, survival rates." p5
Smits 2016	"Cause too much information could really put that wheel in your head turning... because I just wouldn't want to go down the road of just Googling the word and no, no, that would just put my head into override I expect." p6
Sub-theme 4.C: Preference for positive, hope giving information	
Gleeson 2013	"But I guess at the time that was all I wanted to know, there was hope that something would give me better treatment than the other. And that's what we're looking for." p279
Gleeson 2013	"Don't make the documents too much doom and gloom. Give it a very confident hope kind of thing. Otherwise if it's too much of gloom and doom there's, "Oh forget it!" p 280
Sub-theme 4.D: Need for information to be communicated at the appropriate time	
Gleeson 2013	"Once you wake up from the surgery, and for the two weeks after the surgery, your head is in such a spin that I'm not sure you could even digest that information." p279
Gleeson 2013	"I would be thinking after the surgery . . . because it's a real minefield just to get through the surgery and the diagnosis . . . after the surgery you're actually thinking, "Okay, I'm on the other side now. Where am I going?" p279
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Gleeson 2013	"You're going through the shock of everything then anyway, so you might as well. One more little shock and one more little test isn't going to be as traumatic or stressful to you." p279
Gleeson 2013	""I think at that time when I'm diagnosed I just want to know what it means for me." p279
Gleeson 2013	"I think it's too much too soon because . . . it's enough to cope with your own diagnosis, let alone also worry about the implications for other family members." p279
Gleeson 2013	"I don't think that you need to be more worried about, "Oh crap, now I've got ovarian. I'm going to have breast." Yeah, I think that would be too much information at that stage." p279

Study	Evidence
Pedrazzani 2022	“The oncologist, I can’t tell you right now if she’s been talking to me about the mutation running in the family, I don’t know. (. . .) When I was with her for the first time, I wasn’t doing so well psychologically.” p5
Pedrazzani 2022	“He (the physician) did talk to me about all of this, but it was rather at the beginning. So sometimes I think it would have been necessary to take up the subject again later on. Because I was just informed by him once I had gotten the result, and I didn’t really have any questions until later.” p5
Pedrazzani 2022	“No, let’s say they gave me a lot of information all at once at the beginning, so understanding and remembering everything was a bit of a struggle. (. . .) So, I remembered this thing, I told them (family members), but I didn’t remember it specifically. Today I came, I spoke again about this thing here (with the physician) because I had not well understood it (. . .) I could resume some aspects that I had not understood, because it is not obvious on so many things to understand them all obviously.” p5

Table 18: Theme 5: Family as a source of information and support

Study	Evidence
Sub-theme 5.A: Importance of the family as a source of support	
Hughes 2010	“I think a lot depends on your family as well and the support you’ve got at home and both of us [referring to sister Alex] have got good husbands and children…I’m lucky that I’ve got a good supportive family…” p490
Lim 2004	“I found it difficult to tell my sister who was positive, but she asked and was fine about it.” p123
Lim 2004	“I was able to talk about it with my sister. We came to the same decision… my cousins made different decisions… it was good to get another view.” p123
Seenandan-Sookdeo 2016	“No. Maybe a little bit— again with the life insurance. I did inquire [to an insurance agent] a little bit about that, asking the questions about how insurance companies might respond to that knowledge. I was really quite firm in my mind that it’s just way too young right now.” p335-336
Seenandan-Sookdeo 2016	“I think that, when we [the parents] talked about going for testing, it was kind of agreed between the two of us that it was something that the children would know the results of. . . . I mean, if, for some reason, they heard something on the news or read something and had a question, we would not have any problem discussing anything with them. We try to be open.” p335
Young 2019	“It definitely brought the partners into the family closer and, you know, everyone has a look at each other's boobs…I guess we were open as much as we could with each other so that that made the journey easier for each other.” p526
Young 2019	“My aunty had to deal with it at a younger age, as opposed to my mum who dealt with it at an older age. So, her [aunt's] mind is probably even more vulnerable and that gives me the chance to relate to that.” p526
Young 2019	“as much as our family are very loving and very supportive, they don't get it… having a [carrier] sister…I can get on the phone sometimes and we can just say - blurt out anything - and we get it. We really do get it” p526
Sub-theme 5.B: Following information and advice provided by family members	
Dancyger 2010	“The genetic counsellor was right, you do need time to think about it, but by the time I did go and see her, I had made up my mind that I wanted the tests and even though she was persuading me, or trying to persuade me to wait a little

Study	Evidence
	while, I almost did wait ... then when I thought about the 40 thing again and that was unclear in my mind, I said no I want the tests now" p1292
Sub-theme 5.C: Lack of communication and support in the family	
Dancyger 2011	"I'm not sure what she said about my brother...I haven't spoken to my brother in a few months actually." p1028
Dancyger 2011	"It's been an issue, that, everybody's not willing to talk about because we know we lost two of my mum's sisters to the breast cancer thing and it is a really hard thing, we know it's in the family, but, like don't go there." p1030
Dancyger 2011	"It's kind of a scary thing to think about, you can still have it, because my mum's had it and she's had it as well ... it's just something I don't want to look into because I don't want to get myself scared ... when you're so aware that this thing could happen, you just keep thinking ... you just get scared and life isn't normal anymore ... it's just a topic in my house, we don't want to dwell on it." p1030
Dancyger 2011	"Mum told me not to tell [sister] that I'd gone up with her...she always thinks I'm the favourite anyway, she would have got a little bit jealous." p1030
Jeffers 2014	"I was OK the day they told me I had the faulty gene but it was the next day it hit me. I just was really upset and then my family will not really talk about it, my bigger sister says she's definitely not going to get tested and then the other one, she'll just not talk about it." p415
Ratnayake 2010	"I could tell my mother and most of them would know within a day—I'm being sarcastic. No, I think I'd just do it through the normal family grapevine that exists." p101
Young 2019	"We all talk about how stoic the women [are] in the family…but when it comes to health and illnesses they kind of, they toss them underneath the rug…and kind of go, ah yeah it'll be alright." p525
Young 2019	"because he doesn't want to see it as a sign of weakness." p525
Young 2019	"my family isn't great in saying what they need from one another." p525
Young 2019	"She I think struggled with the fact that she was left out… She was sad for the fact that we [Giselle and second sister, Wendy] were having to face something and we were kind of relieved that she didn't have it." p526
Sub-theme 5.D: Partner's role in relaying information and providing support	
Hughes 2010	"They are dramatically affected by this as well… it is going to be life changing for both people isn't it and I think they need to be prepared for it as well. So I think definitely bringing your partners is good, like you say they are your rock aren't they." p490
Mireskandari 2006	"Let me put it this way, I am more informed than her basically because I remember all the statistics and stuff that goes past her, it all sort of bamboozles her a bit, but I listen and make sure I relay it all...so she understands what's going on as well, so we all know exactly where we're up to and what's happening in our lives." p104
Mireskandari 2006	"There were times that I've felt I could have been more supportive but I guess it was a question of whether I was going to spend time with her and whether she needed me at the hospital with her or to run off and make sure that the kids were fine}so it was just a juggle}that was difficult." p103
Mireskandari 2006	"I feel deficient a lot of the time in the support or the lack of support that I'm actually showing her. I'm not quite sure from time to time whether I should be

Study	Evidence
	holding back...or whether to challenge her at the right time, right place. It's something that constantly causes me difficulty" p103
Mireskandari 2006	"I think because I am taking a lot of it in, she feels like I'm confident in what I am doing...I don't feel like she is doing it and then having to take it all on herself} I am actually taking a lot of the burden off her by making the decision with her. She is not making the decision all by herself} I've actually helped her to make the decision." p101
Mireskandari 2006	"I feel as though I don't always offer enough support and I feel it's a shortcoming...I do feel at times I'm not enough of a support, I feel that maybe I'm letting her down in some way." P103
Seenandan-Sookdeo 2016	"I don't know if I looked for any. My only support system would have been my husband. We had a discussion ourselves [about] how much information we were going to give them." p335
Sub-theme 5.E: Coping with a partner who has a genetic risk	
Mireskandari 2006	"Basically, my feeling is a very selfish feeling - how would I cope in –y life without her - I wouldn't cope without her. She's my everything, she is my best friend, my soul mate, my sounding board, the person I like to argue with and we fight, we play, we have fun and she is the mother of my children. And– I don't - I can't - see life without her, I honestly can't visual life without her...and to have her taken away from me wasn't on the cards, wasn't something I could think about, it's still not something I could think about..." p103
Mireskandari 2006	"I suppose it would be good to have periods of normality when one doesn't have this anxiety but it's never really far away, so it just means that I'm on almost constant state of alert without much opportunity to relax that guard, so I'm always aware of the issue and that creates stresses of its own." p103
Mireskandari 2006	"If it did come up and we had a short conversation, she approached it as if it wasn't a possibility} like she was talking about someone else." p100
Sub-theme 5.F: Need for support at home after prophylactic oophorectomy	
Brain 2004	"...my husband...has to realise what the consequences are of me having this operation, and that it's all going to fall on him.' p909
Brain 2004	''I thought it was inconvenient, but it would be far more inconvenient to be ill and die of cancer.'' p909

Table 19: Theme 6: The impact of the family on decisions about genetic testing

Study	Evidence
Sub-theme 6.A: Decision-making influenced by family members' experiences	
Shilling 2020	"All BRCA people I think are making decisions in the context of previous experience. We have trauma through multiple diagnoses or deaths or whatever in our families, of other people, which has affected us and we are making our decisions based on that. It's not just the scientific risk of what our particular gene means to us scientifically and from a biological perspective. It's what you've experienced psychologically also is influencing your decision-making." p496
Shilling 2020	"I think because I knew that those two people had actually got a gene fault. As soon as I knew I had it, it was like crikey, I just want, I want shot of anything that might put me at the same sort of risk as they had really." p494
Sub-theme 6.B: Feeling obligated to have genetic testing to be able to inform family members about genetic risk	

Study	Evidence
Battistuzzi 2019	“It’s a matter of responsibility. If I had no children… I think I might have been more fatalistic. After all, lots of people are treated successfully nowadays, you could think, ‘if I get the disease, I’ll deal with it’. But having a family, that gives you a responsibility towards other people. You can’t say no.” p5
Brunstrom 2016	“I wanted to know and especially with a girl and just thought well it’s there and if she wants to find out at least she knows there is this 50/50 and she can make her own decisions from there then.” pg94
Brunstrom 2016	“I couldn’t 1 day turn round to them and say, "By the way, your grandmother had this gene. "She’s actually, she’s got the ovarian cancer as well now, so she’s actually terminally ill, so they are going to lose their grandmother in the next year or two, and I couldn’t turn round and say when they are older and say, "You know what happened to grandma? Oh well, you know she died of this; its genetic, and I’ve never found out." p94
Brunstrom 2016	“I wasn’t planning on having children until I was in my 30s because I wanted to actually go back to university and do some more studying, and it was a case of which one do I do first? The studying or the family? And obviously the studying can wait, the history in our family is pretty early onset; it can’t always wait.” pg94
Brunstrom 2016	“It came thick and fast really all the testing, everyone was taking their turn to go up.....I just took my turn basically, it was never any question I wouldn’t have it done.” p94
D’Agincourt-Canning 2006	“I wanted to get tested more for my kids. And for Alice, she’s the youngest [sister in the family]. She’s like my best friend, Alice and I. So yes, I kind of wanted to find out not more so for myself, but just to see if they would possibly have the gene or that I have passed it onto my children.” p106
D’Agincourt-Canning 2006	“I felt that it [genetic testing] would also be important for me, but this was a secondary thing . . . the primary thing I was thinking about is risk for my family.” p106
D’Agincourt-Canning 2006	“I have children, so, you know, to me it would just naturally follow that you would do that [have testing], so you would be armed with the knowledge for your children. And for me, knowing that I don’t have the gene is wonderful, ’cause now I don’t have to worry about my children. . . . If I had tested positive, then I would have had my ovaries removed as well. I mean that would be the, you know, the carry on with that. But for me I needed to know simply because of my children. I mean, now they don’t need to be tested.” p107
Dancyger 2010	“I’ve got daughters ... they’ve got daughters, as well … if I had got it, then they could be screened.” p1291
Dancyger 2010	“My mum’s saying, you’ve got to get tested, and so I said, yeah, I¢ll get tested, but I didn’t really y I didn’t really know what to do y she was telling me to have this test done, and I was like, yeah, yeah, I¢ll have it done y She wants us to have that test.” p1291
Dancyger 2010	“We were just concerned about our kids... if I didn’t have my daughter… I might not ...I would like to know if my daughter’s got a chance of y and then perhaps when she has kids, there might be a way of preventing it from passing on.” p1291
Dancyger 2010	“I’ve got two young children, so I thought I need to know, because if I do carry it and I can prevent things, then I will do whatever I have to do to do so.” p1291
Dancyger 2010	“The only way they could start the testing was to test somebody in the family who had actually had it, and so [Lucy] spoke to me y she had, sort of, set the ball rolling y I’m really only doing this, you know, to help the next generation down.” p1291

Study	Evidence
Dancyger 2010	“She’s just very happy to help out. I think she feels that because she survived. She survived it and therefore she’s got the responsibility to try and help the rest of us if she can.” p1291
Dancyger 2010	“She’s gone to so much trouble y all her sort of resources being put into it y there is a slight responsibility on me to follow through y I ought to carry on now and take care of myself y when I started it all off I was partly thinking I don’t really mind not knowing now but maybe in five, ten years time I will want to know and maybe in five, ten years time [Rose] won’t be around to be tested y I should get right on with it really I think, having got the result.” p1291
Dancyger 2010	“Obviously I’m concerned about my daughter y I hope she hasn’t inherited it from me and that’s my big concern.” p1292
Dancyger 2010	“It was offered to me on account of the fact that I have had breast cancer and ovarian cancer y and I said okay, yes please y for my children, really. So that they could be monitored y But I leave it up to them, they’re all adults.” p1293
Foster 2002	“I don’t feel that I have got a decision to make. I mean I see this as, as being the next, the next step forward. I don’t want to be seen to be making the decision anyway I think it’s a case of got to know, not will I want to know. Um, because I am not looking at me now I am looking at my family. I think when it comes to family you can’t really be selfish and worry about how you feel about the gene. I mean I brought the children into the world and I owe it to them to be able to relieve, rather than leave them any worry and make provision.” p479
Foster 2002	“I’ve got children so that makes a big difference to me. Um it’s not just about me and my health and whether I get cancer and whether I die. It’s my children and my family and how it’s going to affect them. [. . .] this is for their future as well.” p479
Shilling 2020	“So, there was this pressure, I felt, that what if she’s got this and she doesn’t know and I do, and anything happens to her and I haven’t told her then I’m going to be responsible.” p496
Wakefield 2011	“‘I was probably upset that I may have it and then I thought that for all my family’s sake I should go and find out.’’ p382
Wakefield 2011	‘‘I’m always a bit petrified that it could get handed down to my daughter and like my granddaughter.” p382
Wright 2018	“I was more concerned that they were carrying it than whether I had it or not, because, well, I wasn’t as young [laughing] as I used to be, and you know, I’d had, I’d got the cancer so, you know … That was, that was my main reason was to see if they were all right, and if they needed to be tested.” p1467
Wright 2018	“I would have said, given that I was 67 it wasn’t particularly because of me it was because of my children, and that … yeah, I decided to have it.” p1467
Sub-theme 6.C: Feeling obligated to have genetic testing due to family/external pressures	
D’Agincourt-Canning 2006	“I didn’t pay much attention to it [genetic testing] until my mom and everybody pursued it further. Then I didn’t have much choice whether I wanted to pay attention to it or not… With my mom, there’s not one visit that goes by, that she doesn’t say something about it. Like we cannot go and have a visit without that being some type of focal line. She’s really pushing me to be genetically tested.” p107
Foster 2002	“I didn’t want it [the test] but every now and again I have to be, you know, sensible [. . .] if you want my honest opinion on that you will probably hate me for it, but it’s to keep everybody else happy. [Researcher: Do you mean family?] No, not so much the family but the doctors.” p479

Study	Evidence
Wakefield 2011	‘‘My cousin who died who was the one who turned out that she was BRCA1 [carrier] and wanted us to get tested, she kind of made us promise we’d do it ourselves before she died.’’ p382
Wakefield 2011	‘‘Because my aunt cracked the whip . . . She cracked the whip and we all did as we were told.’’ p381
Sub-theme 6.D: Receiving unwanted information from family members about genetic risk	
D’Agincourt-Canning 2006	“I think it was no big deal to them [mother and aunts], but they didn’t think about what it was going to do to their kids and their grandkids. Because this is a never-ending thing now. Like we opened a box that’s never going to close, like it’s an open door to forever. Like I said, once you open that door you can’t ignore what’s behind it.” p108
D’Agincourt-Canning 2006	“She’s dead now so, and she was only . . . 67 when she died [from breast cancer]. So she’s, she wasn’t that old but she had chosen not to have the genetic testing done. I had encouraged her to do that but she wouldn’t. And um, even when she found out that I’d had it done and I did have the BRCA1 gene, she still would/she was still in denial and felt that it didn’t matter, didn’t mean that she had it.” p108
Dancyger 2011	“We didn’t talk about it much as a family ... everyone was just anxious...really scared, that, ‘oh my God, maybe we’re going to be next.” p1027.
Sub-theme 6.E: Family pressure to get tested due to the impact of genetic test results on children	
Battistuzzi 2019	“There’s this aunt of mine, she’s eligible for testing like I was, but she always refused to have it. We just can’t get her to do it even though she has a daughter, so it would really be the right thing for her to do, but there is no way she will do it, and we have no idea why.” p5
D’Agincourt-Canning 2006	“I think it’s very irresponsible. I mean if he doesn’t have it, he doesn’t have to worry about worrying his kids about it. If he does, she’d [his adult daughter] better get tested pretty soon. It’s ridiculous. I think it’s very irresponsible, if you have something like that and you can, you know, make sure. ’Cause I mean you’re giving your kid no option to have themselves checked, have themselves have any preventative stuff if they have to, or testing that they should have. It’s horrible. I think it’s very cruel.” p109
Foster 2002	“I have talked to my brother and have tried to persuade him to have it done because he has got two daughters and so I have suggested that it’s a good idea and he said that it was too much trouble and he couldn’t be bothered.” p480
Shilling 2020	“You might be interested to talk to my brother […] he’s been avoiding getting tested for about a year now, and I don’t really understand what he’s playing at because he’s got two daughters.” p496
Sub-theme 6.F: Which family members are affected impacts mutation carrier risk perception	
Foster 2002	“[Sister 1] died in 1986, mum was diagnosed in something like ‘88 um, so both [sister 2] and I looked at each other… We said that there really is something that is not right about this, two people in our family, it’s not right it’s got to be hereditary. Sue (46 years) [Sue is referring to her immediate family here. In her extended family there have been numerous cases of breast/ovarian cancers.] My mum and my dad, neither of them had cancer, um nor has my brother, um so you could say that the four of us, um have been okay. So it sort of makes me feel um, that I won’t get it… I feel that I am okay, I don’t think that I will have this gene.” p477
Foster 2002	“[In] my generation, there is myself and my older sister. I am 44 and my older sister is 47, um I have one female cousin, my mother’s sister’s daughter who’s

Study	Evidence
	um, 49 and I also have one female cousin on my father's side who also has breast cancer coming from both her grandmothers [. . .] So we range from 40–49 among my first cousins and it's the youngest of us who has now had breast cancer." p477
Sub-theme 6.G: Decisions to get tested because of family member's positive result	
Battistuzzi 2019	"When they told my mother that she was BRCA1-positive, that's when I decided "Ok, let's do it". What was holding me back was that I'm afraid of blood tests and I was really scared of that, but then I just decided I wanted to do it." p3

Table 20: Theme 7: Impact of genetic risk information on emotions and decision making

Study	Evidence
Sub-theme 7.A: Knowledge of genetic test results seen as important and valuable	
Battistuzzi 2019	"I chose to know about it, it was an informed choice and now that I know I think I'll live differently. I mean, I can't live with uncertainty, so I'd rather know than not know." p3
Battistuzzi 2019	"Sometimes people say that they don't want to know, that it's better not to have the information. But that's not right—we have to know what the problem is and what we can expect. Once we know we can choose, we can even decide to do nothing about it." v
Brain 2004	"... if it was 'No, you're not' (carrying the gene), I would think 'Oh great—I didn't have my ovaries out''. c
Brunstrom 2016	"I mean the minute you get a letter saying "Look, this gene is in your family," I figured I am either going to sit there wondering forever, do I? Don't I? Jumping every time I feel any slight lump or I could just find out one way or the other." p93
Brunstrom 2016	"I think I have that extra little bit of knowledge which might make the difference in terms of protecting myself, if you are unaware of your status then perhaps you ignore things or not be in the habit of looking for them." p 93
Brunstrom 2016	"Waiting with that uncertainty would be equal to having a positive result." p93
Brunstrom 2016	"I thought I can't wait until after I'm 30. It is always going to be on my ind.....there is no point in burying my head in the sand, you've either got it or you haven't. You may as well find out now." p93
Brunstrom 2016	"I know there are a lot of people that would probably wish they didn't know I wouldn't go back and change it. There is not one thing I can think of for me to say I wish I didn't know. Because it is something you have got to deal with." p94
d'Agincourt Canning 2006	"I just knew that I had to do this. I don't know why I knew, but I knew I had to do it and I had to get going on it and not keep waiting and waiting." p104
d'Agincourt Canning 2006	"Knowing gives you more control." p104-105
d'Agincourt Canning 2006	"At least we know. This wasn't something that we could find out and do at all before. And I think the more people that find out that they can do this, um, the more informed decisions that they can make, you know? We need to know as much as we can about our bodies." p105

Study	Evidence
d'Agincourt Canning 2006	"I needed whatever information I was going to receive, and I was . . . grateful is the wrong word, but it's, I think that the value of having this testing for women cannot be underestimated." p105
d'Agincourt Canning 2006	"As soon as I found out about the gene, all I wanted to do was get tested. Because I just had to know. I don't know [whether it's] because I am stubborn and nosy, but I had to know." p105
Dancyger 2010	"It is really scary y but it's good to know as well." p1293
Dancyger 2010	"Do I really want to know the outcome of it? …well, if the outcome is good, then it puts your mind at rest. And if it's not good, well you can do something about it." p1292
Dancyger 2010	"Forewarned is forearmed y It's knowing your enemy." p1292
Dancyger 2010	"Better to know y than to bury your head in the sand." p1292
Dancyger 2010	"I will do it soon, it's better to know at the end of the day ...I don't know how to prevent it, there isn't a way y I don't know what to think about me doing it ... it's not something I would go out of my way to try and find out or to try and do." p1294
Jeffers 2014	"I know BRCA 2 is you know, it's a blessing really because an awful lot of people that can't find out. I found out so now I know you know, to keep a good eye on myself and if I am afraid, go to the Doctor or whatever." p414
Jeffers 2014	"I was actually relieved and happy in a way, knowing that they did find the gene that was causing it because I have raised a family and that it will help them. There were times, yes; I would have felt angry because I was the only one to get the cancer." p414
Jeffers 2014	"It is a double edged sword I think. If I hadn't had the gene I probably would have said I am a lucky woman but there is something getting my relatives so I suppose that might have been an unknown gene and my daughter would be left, a 12 year old. Part of me is relieved but I still wish it wasn't me if you know what I mean?" p414
Lifford 2013	"…they isolated the BRCA1 gene then and I thought oh I may as well just have them out as they were no good to me anyway…well I had already sort of made the decision anyway, but then that just confirmed everything…" p23
Lim 2004	"I can do something about it and have more control. I also think about it more often when dealing with other issues like the contraceptive pill." p125
Lim 2004	"It reinforced my need to research the are and sort out what I need to do for the future. Increased education rather than having a big shock when I do get cancer. I can be more prepared by knowing about treatment options." p125
Lim 2004	"The grandchildren can do something about it." p125
Lim 2004	"It removed the uncertainty and I feel I don't need to be as vigilant." p127
Lim 2004	"Peace of mind that I haven't passed it on the my children." p127
Lim 2004	"My perspective has changed. I used to think that success was to do with money and material things. Now I focus more on family and friends." p127
Lim 2004	"I've changed my attitude. I don't take myself as seriously anymore, I find it unnecessary to stress over things that used to be important to me." p128
Lim 2004	"It probably influenced my decision to move to the country. It made me think about life… working long hours… life doesn't need to be like this. It makes you step back and look at what you're doing." p128
Lim 2004	"Before I was tested my father said he didn't think I should have… children. When I was pregnant, he said I should terminate it. When he found out I was negative, he was relieved." p128

Study	Evidence
Lim 2004	“I feel better physically, less tense.” p120
Samson 2014	"I basically went home, and we cleaned out the cleaners. My husband and I we researched, uh the chemicals that are in, um, our products, to see, you know the; there's so many products, chemicals that imitate hormones, especially estrogen… I thought well, with the girls, they're [young], I should start now. 'Cause for me, in my case, I'm [older], whatever happened in the past, I can't change. But, I knew I could do something for them." p112
Samson 2014	"… as far as just knowing? Then no. I think if anything, it empowered me more to do something with myself instead of just, you know, floating along and thinking I'll be alive till I'm 80 something." p112
Seenandan-Sookdeo 2016	“We just sat down and explained to them what the results or findings were and . . . risk-wise, what that meant for me personally and then, risk-wise, what that meant for them being male, [and] how I was going to proceed with this information and and what a positive, really positive bit of news it is in that we have the ability then to take that information and be proactive about it. So, we very much viewed this information as a positive in our lives.” p337
Seenandan-Sookdeo 2016	“I told her we have cancer in our family, and I was glad to have the information. I said that people who are BRCA2 positive don’t necessarily get cancer, that most people who get cancer have no genetic reason for it. I was lucky in some ways because I can be proactive by having surgeries to lower my cancer incidence. I talked about eating healthy, not smoking or drinking. They were things she could do now to limit her chances of having cancer, heart disease, diabetes. They were all good things to do anyways. That there was no reason to worry, and she didn’t have to make any decisions now about testing. The conversation was in the car, where all deep conversations take place.” p337
Shilling 2020	“As my godmother said to me, who also had this gene mutation […] information is power, and if you know you’ve got it you can do something about it.” p495
Wakefield 2011	‘‘So I could make an informed decision as to what to do from then on.’’ p381
Young 2019	“I think the earlier the better…I haven't hidden anything from them. I sort of talk to them in a way that they can understand, like you don't need to tell them too much and they know. We sort of [tell them we are] teenage mutant [ninja turtles].” p524
Sub-theme 7.B: Genetic risk information relieves guilt associated with developing cancer	
Dancyger 2010	“I really want to know whether I have a genetic basis for this cancer for years I’d thought why did I get it at 37? What did I do wrong in my life ... did I eat the wrong foods? Did I not do enough exercise?” p1292
Dancyger 2010	“Obviously I’m concerned about my daughter … I hope she hasn’t inherited it from me and that’s my big concern.” p1292
Jeffers 2014	“I thought well at least it was nothing I had done to myself that give me the cancer, you know because all through I kept thinking was it something I had done you know? Was it my lifestyle that caused me to get it and then when I found out it was the gene I thought well, I don’t know, a bit of relief sort of thing you know that I didn’t cause it myself and it was out of my hands sort of thing.” p415
Sub-theme 7.C: Positive genetic test results were unexpected and shocking	
Battistuzzi 2019	“When they gave me the result I was speechless, totally shocked, and scared. What was my life going to be like now?” p5

Study	Evidence
Jeffers 2014	“and he says (partner) “but, sure, it’s what you thought” and I says “yes, what I thought but I really didn’t want it to be true. he says “you know, you knew” and I says “I know but it wasn’t really reality then. “but Colin, you know, it’s OK for you, you know, if our child, any child we have ends up with a cancer, it is because I have knowingly given it to them.” p414
Jeffers 2014	“people do talk about that process of preparing themselves before they get a test result and lots of people that I see end up saying things like that they were, at one level, kind of prepared that this is what was going to happen and they were going to get a positive test result, but then, there’s something different about being prepared for that and actually getting the information and it’s as if then something has changed, something very qualitative has moved or shifted, that they couldn’t have anticipated before. I don’t think that people react badly to it, it is just that it is a big change.” p414
Lim 2004	“I was more upset than I expected… I thought the odds would come out in my favour.” p121
Lim 2004	“I thought I'd had time to prepare and that I had not much of a chance of being positive. I cheated myself. I felt like I was smashed in the chest.” p121
Lim 2004	“I would have preferred to get the gene because I have no children and my sister does.” p123
Mireskandari 2006	“I was shocked, scared about finding out the results. I was taken back. I was upset. I think I wasn’t expecting it, I wasn’t expecting any of it. I was quite upset.“ p102
Pedrazzani 2022	“So, for me the shock of finding out that I had this mutation was even greater than finding out to have a cancer. I did the test, and I got the results. It was terrible for me because it meant that I could have passed on this mutation to my daughter, and I felt guilt.” p5
Sub-theme 7.D: Not thinking through the impact of receiving genetic testing results	
Battistuzzi 2019	“I took it lightly. I didn’t really think about the before and the after, or about the consequences if I turned out to be positive. I mean I knew what it meant in terms of all the appointments every six months and all the rest, but I didn’t think that would matter too much… When I saw what they [relatives who tested positive] had to deal with, that’s when I understood what it could involve.” p5
Battistuzzi 2019	“I was so sure, I don’t know, I did it carelessly, I wasn’t worried at all. If the result had been positive, I think it would have been a real blow.” p5
Battistuzzi 2019	“In retrospect, I don’t know whether I would do it again. I think maybe I’d want to spend more time thinking about it…” p5
Dancyger 2010	“The genetic counsellor was right, you do need time to think about it, but by the time I did go and see her, I had made up my mind that I wanted the tests and even though she was persuading me, or trying to persuade me to wait a little while, I almost did wait ... then when I thought about the 40 thing again and that was unclear in my mind, I said no I want the tests now.” p1292
Dancyger 2010	“Thinking about it in hindsight, I don’t think if I thought I had any chance of having it, I would’ve had the tests done. I really don’t. I was really, really shocked. Yeah, I was quite flippant about having the tests because, ah yeah, do it ... I know I’m going to be all right (laughs).” p1292
Dancyger 2010	“I didn’t even think about it ...didn’t even question it. It was just, okay fine, I’ll do it and I’ll deal with whatever I’ve got to deal with when I know I’ve got to deal with it...After I’d had it and come home, I think that’s when the panic hit me and

Study	Evidence
	I thought, oh God, you know ... this really could happen, I could really have this ... the implications really hit me, and I think for a couple of days I probably was a bit low thinking ... worrying." p1292
Sub-theme 7.E: Regret about knowing genetic test results	
Dancyger 2010	"We hoped it was going to just pass by and stuff; but as she has it now, maybe we might also have it." p1294
Lim 2004	"It would have been better to find out later in life." p127
Lim 2004	"If I think about it too much I can get depressed." p127
Sub-theme 7.F: Feeling at risk regardless of genetic test result	
Brunstrom 2016	"I did think it would settle me, I sort of thought well if I know either way that it will be it, but obviously it is not because there is a residual worry day in, day out." p95
Dancyger 2010	"If you've been tested and you've got your result and it's negative … what happens in 10 years' time if they find more genes, you know? Are you back down that route again, that you thought you were fairly safe, and then you're not?" p1293
Sub-theme 7.G: A sense of duty to pass on genetic test results to family members	
Dancyger 2011	"I phoned both the girls on their mobiles, on the way home ... Straight away. I wasn't in a great hurry to tell the boys... ... ... [Son1] ... he's got two sons, so he hasn't got any daughters... and [Son2] hasn't got any children." p1023
Dancyger 2011	"I think everybody's got a right to know if they've got a mutant gene in the family and there's a possibility that they could develop breast cancer or ovarian cancer... You've got a right to know and then they can perhaps do something about it." p1023
Dancyger 2011	"It was in their interests both to have the test and to tell them the outcome." p1023
Dancyger 2011	"If you've got something like that, that you could have passed on ... you have a duty to at least give them the option if they want to know, which is exactly what mother did don't think there's any other way to handle something like that." p1023
Dancyger 2011	"My sister-in-law told my brother. He doesn't really want to know, but I think he should know, for his own sake and his two boys." p1024
Dancyger 2011	"I have this information ... they've got to be aware ... it was niggling at me the whole time, this burden I have ..." p1024
Dancyger 2011	"I've discharged my responsibility by telling her...that's her decision. I've got to respect that now ...I can say to them, 'do this, do that', but it's their decision ...I can't force them into doing it, can I?...I think it's downright irresponsible not to." p1024
Dancyger 2011	"My brother needs to know and his wife ...then the decision has to be theirs, it's their children, not mine. Once I've passed on the information, I can't do anything else. It is up to them." p1024
Dancyger 2011	"I could then make the decision as to whether I felt my family would benefit from the knowledge ...I obviously wouldn't talk to the children of my siblings...I would certainly tread very carefully in terms of who is responsible for particularly a younger person." p1024

Study	Evidence
Dancyger 2011	“My brother, I really agonized about how I was going to do it, [he] had told me, ‘don’t ever tell me anything about it, I don’t want to know’ which is difficult because he has two daughters and two sons...I don’t want to go to my grave knowing I’ve got this information and not passing it on ... You could circumvent him, and the girls and the boys could have the blood test.” p1025
Dancyger 2011	“I thought I’ve got to reassure her...I gave a percentage; I said it reduces with age, so probably the chances are absolutely slim ...I was quite selective because I think that’s what I was worried about, that Aunt might get worried ...” p1025
Pedrazzani 2022	“I did my part. I explained to them (my relatives) what had happened to me. What I could possibly happen to them... Or not. I hope it never happens to them. But I thought it was important to communicate on the subject… It has been a burden on me that. I mean it’s not easy, to take the step, to do that, it’s hyper personal anyway…” p7
Pedrazzani 2022	“Genetic risk is part of my life and our life. For me what was very important was that my family knew about it. I have a sister who tested positive (. . .) she’s much younger than me, she’s 13 years younger, so she was tested a few years ago. So, for me it’s very important that she knew that there was this risk.” p7
Pedrazzani 2022	“To the people you care about, you want to say it despite this difficulty... with a person that you know and that you care about, it is more difficult to do because emotionally you are more taken... (I felt bad) for my sisters because they have children, they have nieces and nephews, so the more people you care about, in my opinion, the more difficult it is to say it.” p7
Pedrazzani 2022	“The responsibility in the family is so needed. That’s not modern, nowadays people are no longer responsible for the cousins, grandparents, the widowed aunts, it’s not like it used to be. This is something (genetic risk) that I have to actively tell people, and I think it’s also something that should be emphasized by the authorities. This is a problem in our society.” p7
Pedrazzani 2022	“I almost felt a little responsible for bringing this to the public. (. . .) Simply when I got into a conversation with someone, I actually communicated it openly because I think the more we know about it, the better. And yes, the way we were actually badly informed, that doesn’t help anyone or anything.” p7
Pedrazzani 2022	“This is what I said to myself, I have this thing that is not good, how can I make it useful? Communicating it as my mother did with me, it came to my mind afterwards, as an information to have. Then everyone has their own time, and maybe like me you do it in stages. But it’s important to give the information so that everyone can decide what to do next. In a certain sense it’s not pleasant, it’s not easy, it’s not nice, but it’s useful information to know in order to make informed choices and not to say “if we had known about it before . . . ” (Sonia, 34 y.o., no cancer diagnosis)—I p7
Pedrazzani 2022	“Communication is a due act, in the sense that (. . .) it is right and proper to talk about it. (. . .) I feel like I did the right thing. That I communicated. (. . .) in my opinion this (communication to relatives) is a right thing.” p7
Pedrazzani 2022	“It was only two years ago that I had more to do with my cousins and that I realized that the two of them didn’t know much and didn’t have much information. And yes, I felt a bit guilty afterwards, because I thought I should have informed them a lot more.” p11
Ratnayake 2010	“Most assuredly I think it’s my duty. Whether they did it [predictive genetic testing], or not, that’s their choice, but I felt very, very strongly that it was my responsibility to pass it on to any members of the family.” p101

Study	Evidence
Young 2019	“well, mum was the first one, the pioneer, and un- fortunately she lost her life to it. We were fortunate enough to be informed that we could prevent it, so she [sister] was second in line and just sort of done it better. Then I was third in line, so I did it better than her.” p521
Young 2019	“I think it's because they're my little cousins and I feel responsible…whereas I don't really [feel] responsible for [my aunt]. She's an adult, she can do what she wants.” p521
Sub-theme 7.H: A culture of openness in families facilitated communication about genetic risk	
Dancyger 2011	“In close relationships you’ve got to have a good reason not to tell people things...to find out at a later stage that some information was withheld from you, can open the door to all sorts of mistrust ... if you want to have a relationship in which there’s suspicion and mistrust, then you keep under things. If you don’t want to have that sort of relationship, then you maintain openness and honesty.” p1028
Dancyger 2011	“I don’t believe in secrets really ... by not telling and sharing these things like a family, I think you’re lying to them really.” p1027
Dancyger 2011	“It’s important to talk about important things in your life to the people that are close to you.” p1028
Dancyger 2011	“I think there’s a natural affinity between Claire and John, and equally, a natural affinity between me and Helen ... if I had something urgent to tell anybody, I’d want to tell them all, but I’d probably think of ringing Helen first. And I suspect Claire would think of ringing John first. The members of the family that probably talk least are me and my brother...that’s not a problem, it’s just ... we don’t get around to it.” p1028
Dancyger 2011	“I can talk to John much more easily than David even though it’s only phone calls; we’ve always been very close.” p1028
Dancyger 2011	“Mum told everyone ...I don’t really think it’s my place to. I would let them discuss it within their family ...Each family unit will deal with it their own way.” p1028
Sub-theme 7.I: Difficulty in communicating genetic risk to family members	
d’Agincourt Canning 2006	“You have this information that I don’t know if you, if you / if people should have. If they know how to monitor it, you know? I think that, you know, a couple of members in my family if they found out that they had the gene. I think it would just, like I am really worried about my sister, you know, because I think that if she found out that she had the gene she’d panic.” p111
Dancyger 2011	“It’s still something that we talk about, who’s going to do it, and what we’re going to say and it’s not been resolved. It’s still something that is discussed but we haven’t come to a conclusion.” p1029
Dancyger 2011	“We agreed not to speak to [sister]. I will tell [sister], she needs to know. She was undergoing some tests for something ... and she was very depressed, she was quite frightened by it.” p1025
Dancyger 2011	“I must admit I felt a little bit guilty telling Margaret, I almost felt as though I ought to have been positive as well. But she was very pleased for me of course (Jill, F3 Cousin, Negative) p1025
Dancyger 2011	“I mean at the back of my mind I’m thinking, is my mum trying to soften the blow slightly here? (Anna, F3 Daughter, BRCA2þ) p1026
Dancyger 2011	“My brother knows that I have been tested, but I haven’t talked to him at length about the risks down the family ...In a way, I don’t want [David] and his family to

Study	Evidence
	know about it, but on the other hand, I want them to know about it, to be safe, but not yet, they're too young. Too young to get involved in all this genetics and fear... especially the 14 year old, she's got to enjoy her life, before she gets into any of this." p1026
Dancyger 2011	"The issue that we faced was at what point we tell my daughter? Bearing in mind that through this whole process she has been pregnant ... do we worry with that, at this present time, no let's wait until we get the results, and so on ... So there was this whole issue of, when do we tell, who do we tell, what do we tell?" p1026
Dancyger 2011	"I was still feeling a bit down, I suppose, with the news, I just really wanted to, not to talk about it as well too much ...I didn't tell her about me passing it to my children and things like that because I didn't want to believe I would do that ...It is really hard to tell somebody; it's not something you want to say with your mouth ..." p1026
Pedrazzani 2022	"It's not that I go to take all the relatives and "You know I had this". "I hang out with a lot of people but nobody knows about my illness." p8
Pedrazzani 2022	"After my chemo (I wrote to my relatives). It was not possible before, I was so weak that it was not possible. But I did it maybe a year and a half after the cancer was discovered . . . When I started to get better . . . " p8
Pedrazzani 2022	"So, it's difficult to talk to someone who you do not have any kind of contact with—because I know I had some distant relatives in Italy somewhere. And we didn't want to call them, since they are too far away. We tried to tell someone in the extended family who was closer to them, so that they could then transmit it. But really, with people who I barely know, I just do not feel comfortable to call them and confront them with something like that." p8
Pedrazzani 2022	"It was difficult to communicate that I was ill…So only my sister knew and I only decided to tell my parents when I got home. Also, because I spent 3–4 days crying all day long. I was clear that I was ill but I didn't... I didn't say it because I was mad as hell, honestly, I was mad at the world. I didn't want to say it out loud so it became reality even if it was reality. . .The looks of pity as if I were going to die at any moment. I won't say... maybe because of those looks I never said it." p8
Pedrazzani 2022	"I never talked to my sister, I don't even know how she reacted (to my situation). She is scared (about cancer). She's really scared. She's always been afraid." p8
Pedrazzani 2022	"I decided to inform only my cousins and not my uncles or aunts because of their age. I felt it would be "too much for them". For the same reason, I did not ask my parents to take the test. I didn't want to put them in a difficult position, also in relation to possible feelings of guilt for having transmitted me the mutation." p8
Pedrazzani 2022	"Yes, I just think my dad has closed the chapter on that (cancer), that's a story from the past that he's certainly carrying it with himself, but he didn't want it to be present anymore. It's probably wrong (of him), it's hard to describe, it's just a very extreme story from the past. And for me it is just, that for me the genetic defect is more acute/present than for my father. But I think, as long as I'm healthy, it's okay for my dad the way it is. And with my brother I find it very difficult (to talk to him) because he has a lot of trouble to find grip under his feet." p8
Pedrazzani 2022	"I think it makes a difference, because strangely enough I haven't talked about it so much with my sister, because I've always been afraid of scaring her, about me or whatever. With my partner or with my circle of friends I could talk about it again very well. They took it in a completely different way." p8
Pedrazzani 2022	"I did not tell to my father because this will take on enormous proportions for him and me, it will add something to me." p36

Study	Evidence
Pedrazzani 2022	“So, I know that my cousin who...who started the whole thing (communication to relatives), she had a hard time with it. She had the impression that she...that she was dropping a bomb. She was not well for a while. Moreover, when she knew I was positive, she was afraid to see me. (. . .) She was afraid that I would be mad at her.” p11
Ratnayake 2010	“No, it was just the opportunity, you know. They live in the country and, you know, we only get together at funerals really. We don’t even get together at weddings, there’s just too many of us, you know, and it’s not a thing you want to bring up at a funeral”. p101
Sub-theme 7.J: Coping with the emotions of genetic risk and the emotions of family members at the same time	
Dancyger 2011	“Because she’s not our true sister, she’s always felt a little bit that me and my sister are close and she’s not so close and when I had the test ...I think she felt quite close to me ... and then when me and my sister’s got it, it just makes her feel more outside ...I think she was a bit disappointed in that way, probably felt more left out.” p1029
Dancyger 2011	“I remember thinking, well does that mean that me and Laura and Sarah are not going to be as close because I haven’t got it and they have?” p1029
Jeffers 2014	“the initial cancer diagnosis; you are dealing with it sort of from a very personal point of view. When you go to Genetics, it’s e all of a sudden it’s not just you anymore. It’s the wider family and the implications for it and sort of not as much worried for myself then as for my own family and my brother and cousins and just the far reaching impact of what was happening to me. It was a different sensation completely from the diagnosis of cancer.” p414
Lim 2004	“My youngest brother felt better as he wasn't the only one, but he felt angry about getting it.” p123
Young 2019	“It's that I think her natural reaction is just stress and it's going to be quite overbearing stress when you're just trying to manage your own feelings.” p525
Young 2019	“I think for a long time I've always thought they just can't deal with it but actually it might not be that they can't deal with it, it's that I've made a decision somewhere that I think it's my job to protect them.” p526
Sub-theme 7.K: Deferring genetic testing due to not wanting to know genetic risk at that time	
Dancyger 2010	“Every time my mum phoned, I was thinking, she’s going to hassle me about having those tests and I think I even lied to her and told here that I’d phoned [the genetic counselor and she wasn’t there and I’m waiting for her to call me back.” p1292
Dancyger 2010	“It’s not really something I need to know right now. But maybe it will change... I’m just really busy... it’s not top of my list of things to worry about or to go and do... I don’t have health issues on the mind at the moment, but I guess when I’m forty or fifty those, my mind will probably be a bit more concerned about these things.” p1293
Dancyger 2011	“It doesn’t really mean that much because you still don’t really know you’re going to get it .. it’s not really going to help you .. Information that is a little bit scary but not amazingly useful.” p1293
Dancyger 2011	“That’s the side puts me off from having the test, it’s the knockon effect for your children ... When you look at the their ages and you think, you know, they’re going to be armed with that information now ... it’s a lot for them to take on at that age.” p1293

Study	Evidence
Dancyger 2011	“If it was me on my own I would have the test done without question y but because my daughter’s 12, once I know that result, if it’s not a good result, then she’s going to know that.” p1293
Dancyger 2011	“I’m sure, at some point, I will have it done y. But when, I don’t know y I think if it was me on my own I’d definitely have it done, but it’s just the implications with my daughter. p1293
Dancyger 2011	“No-one really wanted to do the tests because it’s kind of scary.” p1027
Dancyger 2011	“I don’t want to look into because I don’t want to get myself scared ...I don’t want to have it and when you’re so aware that this thing could happen, you just keep thinking in the back of your head, you just get scared and life isn’t normal anymore when you’re scared of something like that.” p1027
Samson 2014	"No. I hadn't intended to find out… ummmm, not… for awhile. Maybe not until I was done having kids, because I didn't want… I didn't want the pressure of like - should I have them sooner? Closer together? Should I… I didn't want to be considering, you know, they;ve already started to talk to me - you know, when you're done having your kids, you should have your ovaries remobed, and that sort of thing. And I didn't want to deal with that>" p 113
Samson 2014	"So, yeah. I guess, I guess, I think I've known about it but it's been very much like back burner stuff. And also I was having children, I was breastfeeding, and, I didn't want to do any testing until that [process]; that part of my life was over. Because I-there was nothing I was going to be able to do in terms of like, prophylactic surgery or, or even I can't even get, be properly, couldn't be properly screened when I was breast feeding, so, I waited until I was pretty much at the end of that and then I've started into the screening process." p114
Wakefield 2011	“‘I had a letter from . . . kConFab, yes, advising me that a gene had been located . . . I was given an option of going further in finding out more about it, which I have accepted, but so far I haven’t done the next step . . . there wasn’t any urgency . . . it’s a little bit awkward for me to get a day off.’’ p381
Sub-theme 7.L: Results of genetic testing did not influence decision making or behaviour	
Brain 2004	‘‘I think if I had the genetic test back positive, I don’t think I would consider surgery then. I’d only consider it if there was something wrong with my ovaries.’’ p910
d’Agincourt-Canning 2006	“We are very aware of it. It’s not like it’s taken us by surprise. I mean my mom has lived with it for over thirteen years and we knew about my aunt [died from ovarian cancer]. So for the last twenty years we’ve been very aware of it. And we, I think we’ve taken the appropriate steps to not/ I mean yes, to protect ourselves and also to know early on if there’s anything. . . . So this wouldn’t change anything for me if I was confirmed that I had this breast cancer gene or this defected gene. It wouldn’t change anything for me. It wouldn’t change my lifestyle. It wouldn’t change what I am doing. It doesn’t change my predisposition to having the disease.” p110
d’Agincourt-Canning 2006	“The genetic testing, I would sort of be willing to do it if they have something that could alter the genes or kill it or, I don’t know, do something. But they don’t know. They cannot at this point as far as I know/ there is no way that they could do anything. It’s just finding out that’s it there.” p110
Lim 2004	“I have always been careful and will continue with monitoring”. p127

Study	Evidence
Wakefield 2011	‘‘It wasn’t necessarily going to change anything if the gene was there or not in terms of my lifestyle, you know, I exercise, am healthy, you know, I don’t smoke. I do all those things anyway so if I knew it wasn’t going to change my life.’’ p382
Sub-theme 7.M: Results of genetic testing impacted on thoughts about childbearing	
Brunstrom 2016	“It’s probably the thing that I have struggled with the most since finding out about it, I’m not ready to have children yet, and I think it’s a decision that kind of got forced on me like, it’s something to think about earlier that I would of normally because I think if my mum had known she had the gene, would she have just had me and known that she could pass it on.” p95
Ormondroyd 2012	“My cancer, in my head, was gone, so I was fine I would make sure it didn’t come back, but now the cancer gene sits here every single day and I can’t do anything with it .. (having a child would) increase my risk but it’s not even comparable to the gene risk.” p6
Ormondroyd 2012	“You want to get pregnant and that’s your end result y so it’s probably worked out well knowing at that time that I’ve got the gene, cause it does make you stop and think really, what are we doing? OK we want this but .. you do get a bit lost for a little while.” p6
Ormondroyd 2012	“If you’ve got that gene, god what other gene might you have that they don’t know about at the moment.” p6

Table 21: Theme 8: Importance of ovarian cancer surveillance programs and knowledge of surgical options

Study	Evidence
Sub-theme 8.A: Confidence in cancer surveillance for the detection of ovarian cancer	
Brain 2004	“‘I see myself now as ‘Oh, I’m ok at the moment, yes, I’ve had this screening done now.” p908
Brain 2004	‘‘It’s like prevention—that’s the way I look at it. I’m not worried about this ovarian cancer now, because I have been checked’’. p908
Brain 2004	“And that’s what I’m aiming for with doing all these things—early detection, so it can be done, sorted, or I haven’t got a hope.’’ p908
	“I’d only consider it (surgery) if there was something wrong with my ovaries or there was something showing there’’. p909
Lifford 2013	“…I had got cysts on my ovary…they kept an eye on me and my bloods shot up or something so they called me…it [surgery] just felt right at the time, you know to take away the worry because when they found that the bloods had gone up I just thought of my mother…” p24
Sub-theme 8.B: Good to have the option to continue surveillance	
Brain 2004	“The thing that seemed to stick in my mind, was that you don’t have to have the ovaries removed, you can stay on screening...that was nice really’’.pP908
Gaba 2022	“There is no screening on the NHS for ovarian cancer and that means my only other option is to have my ovaries out.” p4
Gaba 2022	“From the very beginning I felt I was more concerned more about the ovarian cancer risk than the breast cancer risk, because I felt like I could effectively examine my own breasts and keep a check on that, but I can’t check my ovaries.” p4

Study	Evidence
Lifford 2013	"…I would have been happy to carry on [with screening] to be honest but it's a bit pointless I suppose for the study but er I quite like receiving all the checks and that…it could just as equally be breast cancer as against ovarian…" p23
Sub-theme 8.C: Clear knowledge of options available led to confident decisions to undertake surgery	
Brain 2004	''...if they turned round and said, 'Well, the protein level's so high that it's almost certain that you will get it,' well fine—you'd get shot of them (ovaries) straight away''. p909
Gaba 2022	'It's [RRESDO] acceptable because it's my decision making as well, it's not at the fault of any health professional, no-one is making me do it this way, it's my decision and I'm aware of that." p6
Gaba 2022	"…the trade-off between having two surgeries as opposed to one, that does feel absolutely fine to me, and that's maybe because I've had positive experiences with surgery before." p7
Gaba 2022	"When I realised that I'd have to go through with a number of operations to help reduce the risk, I made sure that I was in the best possible health beforehand to deal with those and I was really glad that I did." p7
Lim 2004	"The ovaries can be removed when you are finished with them. I know I will have a better quality of life mentally because I don't have to worry about ovarian cancer which is hard to detect." p125
Lim 2004	"I have had a mastectomy. I know I have a decreased chance of dying of breast cancer. I have also had a hysterectomy as my sister had ovarian cancer." p125
Sub-theme 8.D: Option of prophylactic oophorectomy came as a shock	
Brain 2004	''I knew he (Consultant) was going to say that (regarding the option of surgery), but it was still a shock... It's like meeting a new partner and the first thing they say is 'Let's have a baby.''' p908
Brain 2004	''I was shocked because that (risk of ovarian cancer) didn't enter my head.'' p908

Table 22: Theme 9: Reasons for and against genetic testing

Study	Evidence
Sub-theme 9.A: Empowerment and taking control of the situation	
Foster 2002	"My sister can't deal with it, internalises it, you know, whereas I need, I need to deal with it." p478
Sub-theme 9.B: Getting tested for science	
D'Agincourt-Canning 2006	"The advantage is just information to the people doing cancer research. That is the only reason I said yes [to the testing]. The larger your sample size, the better your results… If our family is showing a lot of this, there is a good chance that we would have these genes that could help somebody's research project and provide answers down the line for some other people, maybe even for us." p109
Foster 2002	"Here's me perfectly healthy, [. . .] and my mother desperately ill and for me to be worrying about the genetic test and the effect on me, I mean I feel guilty every time I go in and have the screening I feel like I am using up valuable resources which is why when they said would you do this, would you do this [research] I say yes, yes, yes, if there is anything that I can do because I really feel very self-indulgent taking up everybody's time." p480
Wakefield 2011	''Maybe it mightn't help us but it might help somebody one day.'' p382

Study	Evidence
Sub-theme 9.C: Feeling like they had missed previous opportunities to get tested	
Wright 2018	“I went to see oncologist and she said, "I think it’s a good idea if we check for the BRCA gene at this point." Which made me quite angry because I felt that had I had it done when I’d asked for it two years before I could have avoided all of this.” p1464
Wright 2018	“I think to myself if they gave me the test when my sister was diagnosed five years before I got my cancer, if they gave me the test … I would never have had cancer.” p1464
Sub-theme 9.D: Being curious about family history	
Battistuzzi 2019	“I had talked about it [wanting to be tested] with my family doctor… I told him about my family history, as I’d been doing with other doctors ever since I was a teenager, but they always told me it was too early, and I should wait before thinking about it seriously.” p3
Battistuzzi 2019	“Well, considering that both my grandmother and my aunt on my mother’s side died of breast cancer (…) my mother raised us with the idea that prevention is important. (…) As for the test, once we were waiting for my mother’s result, it was obvious to me that I would do it too.” p3
Battistuzzi 2019	“Well, considering that both my grandmother and my aunt on my mother’s side died of breast cancer (…) my mother raised us with the idea that prevention is important. (…) As for the test, once we were waiting for my mother’s result, it was obvious to me that I would do it too.” p3
Foster 2002	“I only found out about it when my mother was diagnosed and my father gave me a copy of the letter that [consultant] had written to my mother saying would I please go and have um, you know, check-ups and I said ‘why on earth should I have check-ups, mum’s ill, why should I go?’ and he said ‘well it’s in the family’. And I said ‘hang on a second you had better tell me all about this’ …And that was the very first time that I knew about it.” p475
Foster 2002	“None of my mum’s sisters have had cancer. I have asked if there is cancer in the family and no one’s had breast cancer [. . .] I say, ‘well you know like where does it come from?’ p474
Wakefield 2011	‘‘A whole heap of my family went because we had lost other cousins to breast cancer." p381
Wakefield 2011	‘‘My grandmother had had ovarian cancer many years ago and with that knowledge we decided it would be a good idea to get it done." p381
Sub-theme 9.E: Do not believe in genetic testing	
Wakefield 2011	‘‘I tell my daughter; just because that was my experience in life she doesn’t need to get it . . . I believe that the body has the power to heal itself.’’ p382
Wakefield 2011	‘‘just for curiosity . . . I don’t know if I’d believe it all, but I’d be open to it”. p381
Sub-theme 9.F: Believe cancer is caused by other factors	
Wakefield 2011	‘‘I just feel, you know, we create a lot of our own issues and we can even change our DNA . . . I know why I got cancer . . . I was very careless with chemicals. I used to be spraying the garden, trying to have the best roses and it would drift over me.’’ p381