

Developer& Year [#]	Country	Title	Target Population	DA designed exclusively for BRCA mutation carriers?	Risk management options addressed in decision aid	Format of decision aid	Decision aid Language	Presenta tion of risks and benefits in DA	Separate sections for BRCA1 & BRCA2 mutation carriers?	Decision aid facilitate s users to work through their values?	Patient & Public Involvement (PPI) in decision aid development?	Efficacy of decision aid on decision related & other relevant outcomes reported ?	DA provides recomme ndation for which option(s) the patient should choose?	Intended moment(s) of use of DA
Armstrong 2005	USA	Individualized Survival Curves Improve Satisfaction with Cancer Risk Management Decisions in Women With BRCA1/2 Mutations	BRCA1 & BRCA2 mutation carriers without OC or metastatic BC & significant residual BC or OC risk	Yes	Breast: Screening Prophylactic mastectomy; Chemopreven tion (tamoxifen, raloxifene) Ovarian: Prophylactic oophorectom y;	Paper Binder containin g survival & cancer incidence curves printed on transluce nt paper	English	Graphic presentat ion of cancer risks and risk reduction s with the various options by means of individual ized overall survival curves, and individual ized breast cancer incidence curves for alternativ e manage ment options and combinat	Risk estimates are individual ised therefore it is likely that BRCA 1/2 status is taken into account.	Not reported	Not reported	Yes See table 2	No	Mainly self-administer ed By patient.

								ions of options.						
Centre for Genetics Education NSW Health (2017)	Australia	Surgery to Reduce the Risk of Ovarian Cancer Information for Women at Increased Risk	women at increased risk of ovarian cancer	No	Ovarian: RR-BSO (main focus)	Paper booklet	English	Graph showing baseline OC risk at various ages according to family hx of OC, BRCA or Lynch syndrome status Text description of risks & benefits	No	No	Unclear	Unclear <i>? An earlier version of this DA appears to have been tested in Tiller 2006</i>	No	Self-administered by patient
Centre for Genetics Education, NSW Health (2012 update)	Australia	Information for Women considering Preventive Mastectomy because of a strong family history of breast cancer	Women with a strong family hx of breast cancer who may be considering preventive mastectomy.	No	Breast: Risk-reducing mastectomy (main focus) Following options addressed briefly: Lifestyle behaviours Screening/surveillance (mammography, MRI, ultrasound)	Paper booklet	English	Text description of risks and benefits	No	No	Yes	Not reported	No	Self-administered by patient

					Chemoprevention (anastrozole)									
Collins 2016	Australia	iPrevent®: a tailored, web-based, decision support tool for breast cancer risk assessment and management.	All women (including women at increased BC risk and known BRCA mutation carriers) Age 18-70yrs Without BC Without RRM Without mutation in cancer gene other than BRCA1/2 Without 'half' relatives with BC, OC, prostate or pancreatic cancer	No	Breast: Screening (mammography, MRI) Risk-reducing Medication (tamoxifen, raloxifene, anastrozole, exemestane) risk-reducing mastectomy premenopausal risk-reducing salpingo-oophorectomy Lifestyle Modification	Web-based	English	Breast cancer risks & risk reductions presented as words, percentages, a visual scale or pictogram and graphs risk management options appear are, tailored to the woman's risk category and her input data	Yes (indirectly) BRCA 1 or BRCA2 status inputted by user & risk estimates tailored accordingly	No	Yes	Reported in Lo 2018 (see table 2)	No	To be used collaboratively by healthcare providers and women
Harmsen 2018	The Netherlands	A patient decision aid for risk-reducing surgery in premenopausal BRCA1/2	BRCA1/2 mutation carriers who participate in a preference trial that compares	Yes	Ovarian: Risk-reducing salpingo-oophorectomy	Paper booklet	Dutch with English translation available	Shaded icon arrays to indicate % risk) and pie charts	Yes	Yes	Yes	No Testing of final DA not reported	Yes	To be used in addition to face-to-face consultation

		mutation carriers: Development process and pilot testing	RRSO with salpingectomy and delayed oophorectomy Pre-menopausal, age 25-45 yrs, completed childbearing, not currently being treated for malignancy		Risk-reducing salpingectomy			were used for risk communication. Text description of benefits & risks						
Healthwise staff a (2020 update) DA reviewed and content assessed as current 2023	USA	Breast Cancer: What Should I Do if I'm at High Risk?	Women at high risk for breast cancer	No	Breast: Screening/surveillance RRM BSO Chemoprevention	Web-based (with option to print as pdf)	English	BC risks depicted using shaded icon arrays Text description of benefits & risks DA allows users to compare benefits and risks of 2 options side by side by selecting the options they want to	No	Yes	Not reported	Not reported	No	Self-administered by patient

								compare from a dropdown list						
Healthwise staff b (2020 update) DA reviewed and content assessed as current 2023	USA	Ovarian Cancer: Should I Have My Ovaries Removed to Prevent Ovarian Cancer?	Women who at high risk of ovarian cancer	No	Ovarian: BSO Screening	Web-based (with option to print as pdf)	English	Test Description of baseline OC risks for women with 1 or 2 first degree relatives with OC and for BRCA mutation carriers Text description of benefits and risks of BSO DA allows users to compare the benefits and risks of the 2 options (BSO, no surgery) side by side	No	Yes	Not reported	Not reported	No	Self-administered by patient

Jabaley 2020	USA	Development and Testing of a Decision Aid for Unaffected Women with a BRCA1 or BRCA2 Mutation	BRCA 1/2 mutation carriers without a personal history of breast or ovarian cancer 'previvors'	Yes	Breast: Surveillance /Screening ((Breast self-exam, Clinical breast exam, , MRI, Mammography) Prophylactic Mastectomy Chemoprevention (tamoxifen, raloxifene) Ovarian: Screening (TVU, CA125) Prophylactic Oophorectomy OCP	Paper/ electronic pdf	English	Bar charts depicting cancer risks Text description & tables showing risks & benefits	No but cancer risks and recommended ages for ovarian risk management options reported separately for BRCA1 & BRCA2 mutation carriers.	Yes	Yes	Yes (information related outcomes only)- see table 2.	No	Intended to be Initially initiated by clinicians (designed with the possibility of being initiated by patients).
Kaufman 2003	USA	Development of an Interactive Decision Aid for Female BRCA1/BRCA2 Carriers	BRCA1 & BRCA2 mutation carriers	Yes	Breast: Screening (Breast self-exam, Clinical breast exam, Mammography) Chemoprevention (tamoxifen, raloxifene)	CD-Rom	English	Text description of risks & benefits Risks portrayed using bar charts (eg. depicting cumulative BC risk	Yes	Yes	Yes	Yes Reported in Schwartz 2009 & Hooker 2011 (see table 2)	Partly During the 'decision task' activity, the highest preference score indicates the risk management	Self-administered by patient to be used in addition to comprehensive genetic counselling sessions

					Prophylactic mastectomy Ovarian: <i>not main focus</i> Screening (CA-125, transvaginal ultrasound) Oral contraceptives Prophylactic oophrectomy			to age 50 and age 70)					ment option that is most consistent with the values and preferences the woman entered in the decision task	
Kautz-Freimuth 2021 DA (A) 'Previvors'	Germany	Development of decision aids for female BRCA1 and BRCA2 mutation carriers in Germany to support preference-sensitive decision-making	BRCA1/2 mutation carriers (in Germany) without a history of cancer (previvors)	Yes	Intensive breast cancer screening Risk-reducing bilateral mastectomy: Risk-reducing salpingo-oophrectomy	Paper brochure & electronic pdf version	Germany	Reported only briefly Average risks of breast cancer and ovarian cancer each subdivided into BRCA1 and BRCA2 mutations Lifetime, age and time-related	Yes	Yes	Yes	No	No	To be used in post-test genetic counselling and given to women to take home

								(10 year) risks						
								Personal risk of breast cancer and ovarian cancer						
								Effect of RRM on risk of developing breast cancer						
								Effect of BSO on risk of developing ovarian cancer & survival <i>-unclear if test descriptions, graphic depictions or both were used</i>						
								pros/cons, overview table of each intervention						

Krassuski 2021	Germany	Decision Aids for Preventive Treatment Alternatives for BRCA1/2 Mutation Carriers: a Systematic Review	Decision aids applicable to BRCA mutation carriers	NA	Various- see individual included studies	Various- see individual included studies	Various- see individual included studies	Various- see individual included studies	see individual included studies	see individual included studies	see individual included studies	Not Reported	see individual included studies	see individual included studies
Kurian 2012	USA	Online Tool to Guide Decisions for BRCA1/2 Mutation Carriers	female <i>BRCA1/2</i> mutation carriers unaffected by cancer Age 25-69 yrs Who have NOT undergone breast screening, risk-reducing breast or ovarian surgery and have NOT taken risk-reducing medication.	Yes	Breast: Screening (mammogram, MRI, both) Prophylactic mastectomy (at various ages). Breast & Ovarian: Prophylactic oophrectomy (at various ages).	Web-based	English	Outcomes shown in decision aid are shown as bar charts & % probability of each outcome.	Yes	No	Not reported	Reported in Schackman 2013 (see table 2)	No	Designed for joint use by <u>cancer unaffected</u> women with BRCA mutations and their health care providers.
Mayo Clinic Staff (2020 update)	USA	Prophylactic oophorectomy: Preventing cancer by surgically removing your ovaries.	women at high risk of ovarian cancer (including BRCA mutation carriers & those with Lynch syndrome)	No	Breast & Ovarian: BSO (main focus) Screening for OC, RRM and OCP mentioned briefly as alternatives	Web-based	English	Text description of risks and benefits	No	No	Not reported	Not reported	No	Appears self-administered

Mayo Clinic Staff (2021 update)	USA	Preventive (prophylactic) mastectomy: Surgery to reduce breast cancer risk	Women at high risk of breast cancer (both cancer unaffected & cancer affected)	No	RRM (bilateral & contralateral) - <i>main focus</i> Following options also mentioned briefly: Chemoprevention Breast cancer screening BSO Healthy lifestyle	Web-based	English	Text description of risks & benefits	No	No	Not reported	Not reported	No	Appears self-administered
Metcalfe 2007	Canada	Development and testing of a decision aid for breast cancer prevention for women with a BRCA1 or BRCA2 mutation.	BRCA 1/2 mutation carriers unaffected by BC or OC	Yes	Preventive Mastectomy Preventive salpingo-oophrectomy before age 50 Tamoxifen for 5 years Breast screening	Paper booklet	English	Probabilistic information on likelihood of benefits and risks of each option depicted using text & shaded icon arrays	Not Reported	Yes	Yes	Yes Use of the decision aid decreased decisional conflict, increased knowledge levels & decreased uncertainty about each option Efficacy tested further in RCT reported in Metcalfe 2017 (see table 2)	No	Self-administered designed to be used in addition to standard genetic counselling

NICE 2017 (Pre-menopausal)	UK	Taking tamoxifen to reduce the chance of developing breast cancer Decision aid for premenopausal women at high risk	Pre-menopausal women at high risk of breast cancer BC unaffected	No	Risk-reducing medication (Tamoxifen for 5 years)	Paper (pdf)	English	Yes Risks and benefits of each option displayed in tabular form & using shaded icon arrays.	No	Yes	Yes	Not reported	No	Intended to be used in conjunction with healthcare professionals within secondary care or specialist genetic clinics, who have expertise in familial breast cancer.
NICE 2017 (Post-menopausal)	UK	Taking a medicine to reduce the chance of developing breast cancer Decision aid for postmenopausal women at high risk	Post-menopausal women at high risk of breast cancer BC unaffected	No	Risk-reducing medication: Anastrozole for 5 years Raloxifene for 5 years Tamoxifen for 5 years	Paper (pdf)	English	Yes Risks and benefits of each option displayed in tabular form & using shaded icon arrays.	No	Yes	Yes	Not reported	No	Intended to be used in conjunction with healthcare professionals within secondary care or specialist genetic clinics, who have expertise in familial breast cancer.
TILLER 2003 (updated 2008)	Australia	A decision aid for women at increased risk for ovarian cancer.	Women at increased risk of ovarian cancer	No	Watchful waiting Screening Use of OCP	Paper booklet with separate values clarification	English	Text description of benefits & risks	Not reported	Yes	Yes	Yes Pilot testing of the DA with at-risk women	Not reported	Self-administered

Overlaps with Centre for Genetics Education NSW Health (2017) DA					Prophylactic oophorectomy	on exercise		Numerical information on risk reduction of different options provided as % reduction of risk				attending a familial cancer clinic demonstrated women reported that the decision aid had increased their knowledge, led to more accurate expectations of benefits and risks, assisted them in arriving at a decision, and reduced their decisional conflict and uncertainty		
Unic 1998	The Netherlands	Assessment of the Time-trade off Values for Prophylactic	Healthy women suspected or known to have a	No	Prophylactic mastectomy Breast cancer screening	Paper brochure & videotape	Unclear	Text description & some risks &	Not reported	Yes	Yes	Yes (see table 2) Reported in Stalmeier	No* *Advice based on women's	DA informational material viewed and

		Mastectomy of Women with a Suspected Genetic Predisposition to Breast Cancer	genetic predisposition to breast cancer			(provided as part of a Shared Decision Making Program (SDMP))		benefits explained through interviews in the video [§] <i>§full details not reported in article.</i>				1999 (see table 2)	<i>preferences subsequently given by clinicians as part of the wider SDMP</i>	read at home-provided as part of a Shared Decision Making Program (SDMP)
VANROOSMALEN BJC 2004a	The Netherlands	Randomised trial of a decision aid and its timing for women being tested for a BRCA1/2 mutation.	Women undergoing testing for a BRCA1/2 mutation	No (Designed for women undergoing genetic testing therefore participants are not necessarily aware of their BRCA status at the time of use)	Breast cancer screening Prophylactic mastectomy Ovarian cancer screening Prophylactic oophorectomy	Paper brochure and video	Dutch	Yes Text description of benefits & risks of each option in qualitative terms & where possible in quantitative terms Video portrayed consequences of the options through interviews with BRCA mutation carriers	No	Not reported	Yes	Yes (see table 2) Additional efficacy testing reported in VANROOSMALEN JCO 2004b (see table 2)	No	brochure and video to be viewed at home. DA is considered suitable for use either before or after a genetic test result.

								Photographs showed results of prophylactic mastectomy						
VANROOSMALEN JCO 2004b	The Netherlands	Randomized Trial of a Shared Decision-Making Intervention Consisting of Trade-Offs and Individualized Treatment Information for BRCA1/2 Mutation Carriers.	BRCA 1/2 mutation carriers (both BC or OC affected or unaffected) without distant metastasis, had not undergone both RRM & RR-BSO	Yes	Breast: Breast Cancer screening Prpphylactic mastectomy Ovarian: Ovarian cancer screening Prophylactic oophrectomy	Face to face and telephone TTO interviews.	Dutch	individualized treatment information was shared with the women using two bar charts, one for life expectancy (LE) and one for quality-adjusted life expectancy (QALE). The bar charts presented the treatment options relative to each other	Unclear	Yes	Not reported	Yes (see table 2)	Unclear	Interview administered by a research assistant Subsequent to use (at home) of an informational DA

Witt 2014 (Cardiff University)	UK	Ovdex The Oophorectomy Decision Explorer v5	Women at increased risk of ovarian cancer	No	BSO (main focus) OCP & lifestyle behaviours briefly mentioned	Web-based booklet	English	OC risks & complications/side effects of BSO displayed using shaded icon arrays and text description Benefits and risks of the 2 options (BSO, no surgery) compared side by side in a table	Unclear mentions that information can be personalised by answering 3 questions on linked website (no longer in use)	Yes	Yes	Not reported	No	Self-administered by patient? Unclear
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