Resume Kristine Barlow-Stewart

Name

Kristine Barlow-Stewart

Summary

Kristine Barlow-Stewart, AM, FHGSA, PhD, BSc received HGSA Genetic Counselling certification in 1991, the first in Australia, after leading the development of policy and training in this new field. She was the Foundation Director NSW Centre for Genetics Education (1989-2012); Foundation Director Master of Genetic Counselling Sydney University (2011-2018) and is currently a Senior Research Genetic Counsellor with the Children's Cancer Institute and Honorary Associate Professor, The University of Sydney. Kris has a career total of 133 publications including 56 peer reviewed articles in the last 5 years. In recognition of her contribution to genetics education and research and the development of genetic counselling profession, she was awarded a Member of the Order of Australia (2022) and the inaugural Australian Genetic Counsellor of the Year (2021

Current Appointments/Positions:

- Senior Research Genetic Counsellor, Children's Cancer Institute, UNSW, with the Zero Childhood Cancer program. Role is developing polices and healthcare provider and patient information for recruitment and conducting interviews as part of the psychosocial component of the PREDICT STUDY (Assessment of the utility of family-based (trio) whole-genome sequencing for cancer predisposition testing in sequential newly diagnosed paediatric and adolescent cancer patients) and the ZERO2 program as well as informing ethics and polices.
- Associate Professor, Northern Clinical School, Faculty of Medicine and Health, University of Sydney (Honorary)
- Consultant and Director of the Genetic Counselling Consultancy.

Previous Appointments/Positions:

- Senior Research Genetic Counsellor, School of Women's and Children's Health, UNSW, with the Mackenzie's Mission Research study investigating how best to offer free reproductive genetic carrier screening to the Australian population. Role is developing healthcare provider and patient online information for recruitment and returning results and providing genetic counselling to couples identified as having an increased chance of having a child with one or more of the ~750 conditions included in the screening www.mackenziesmission.org.au
- Foundation Director of the Centre for Genetics Education (CGE), a designated State-wide program of NSW Health 1989-2012, internationally recognized as a provider of genetics information for professionals and the community. Nationally and internationally recognised expert in the provision of information underpinning decision making and the societal and psychosocial impact of genetic counselling and testing.
- Foundation Director of the two-year full-time University of Sydney's Master of Genetic Counselling program, 2011-2018. Proposed the course in 2010 and implemented it in 2011. The program was internationally accredited and trained genetic counsellors to meet the needs of families faced with decisions regarding utilisation and impact of genomics technologies relevant to this proposal.
- Chair, Medical and Scientific Committee, Genetic Alliance (1989-2020)
- Chair, Clinical Genetics Network, NSW Health Centre for Clinical Innovation (2003-2020)

Awards and Honours

- 2022 Order of Australia (AM) for contribution to genetics in medicine and education
- 2021 Australian Genetic Counsellor of the Year (Australian Health Professionals Award)
- 2021 Finalist – Health Innovation and Impact Award (Australian Health Professional Award)
- 2018 Oration at the Human Genetics Society of Australasia conference (Sydney)

- 2013 Outstanding contribution to genetics education (NSW Health and Association of Genetic Support of Australasia.
- 2012 Outstanding contribution to the genetic counselling profession (Australasian Society of Genetic Counsellors)
- 2000 Commitment to the development of best practice guidelines: Familial Aspects of Cancer - A Guide to Clinical Practice (The Australian Cancer Society)

Academic Record and Qualifications

- University of Sydney, Australia BSc 1971 (Biochemistry, Genetics)
- University of NSW, Australia PhD 1979 Thesis entitled: *The study of chromosomal male sterility in wheat.*
- Fellow of the Human Genetics Society of Australasia (Genetic Counselling) 1991

Teaching and Mentoring

- Contributed to the development of short courses for UNSW for professionals both face to face and online in regard to familial implications of genomics and genetic counselling. Conducted workshops for the courses in Hong Kong (2019) and Sydney (2020). This work has served as a basis for the genomics short course currently being offered by UNSW Medicine and Health and a bespoke genetics and genomics course proposed to be offered with the Hospital Authority, Hong Kong
- Developed and implemented (as Course Director) the Master of Genetic Counselling program for the Faculty of Medicine and Health, University of Sydney
- 5 PhD - one primary completed
- 74 Master of Genetic Counselling students
- 4 UNSW ILP students undertaking a research project as part of their course requirements
- 7 Associate Genetic Counsellors undertaking their professional certification

Current research

- As the genetics education, ethics and counselling expert, leading the development of the education component for the establishment of a 'virtual consultation room' to supplement existing services with video conferencing and online genetic counselling and education for patients with mitochondrial disease (NHMRC partnership Grant – CIA Carolyn Sue, inaugural Kinghorn Chair, Neurodegeneration, Neura).
- Reporting on the results of Mackenzie's Mission in regard to the development and implementation of the education of recruiting healthcare providers, development of tools to address linguistic diversity of participants and the role of genetic counsellors in the implementation of national expanded reproductive genetic carrier programs.
- In the ZERO2 childhood cancer Precision Medicine program and its sub-studies within the Children's Cancer Institute: (1) Development of the Ethically Defensible Plan for return of results; (2) Psychosocial impact and evaluation of participation; (3) Development, implementation and evaluation of a model of e-consent; (4) Development of a policy for the return of genomic data
- A-GLIMMER - A-GLIMMER: Moratorium on Genetic Testing & Life Insurance: Monitoring the impact.
- EPIC-ID: The economic and social impacts of genetic sequencing for intellectual disability.

Academic and Research leadership

- ***Publications***
    - 137 peer-reviewed journal articles (***57 2018-2023);*** 11 books, book chapters and reports; 12 invited papers in journals and newsletters and podcasts
- Foundation Director of the two-year full-time University of Sydney's Master of Genetic Counselling program, 2011-1018. Proposed the course in 2010 and implemented it in 2011. The program was internationally accredited and trained genetic counsellors to meet the needs of families faced with decisions regarding utilisation and impact of genomics technologies relevant to this proposal.

- Foundation Director of the NSW Health's Centre for Genetics Education (www.genetics.edu.au) ,1989-2012. Led the production for professionals and the community, training and print, on-line and multimedia resources on conditions with either a complete genetic basis or those involving inherited susceptibility, the impact of developing genetics technologies and risk-reducing strategies, based on both qualitative studies and randomize controlled trials. These are used internationally: four decision aids used by familial cancer clinics throughout Australia to provide decision support for women at increased risk of developing breast and/or ovarian cancer are now being translated into use for Malaysia and evaluated.
- Her research into experiences of genetic discrimination reported by those who had predictive genetic testing led to a Federal Inquiry into the Protection of Human Genetic Information conducted by the Australian Law Reform Commission (ALRC 2003). Provided the first international empirical evidence of such genetic discrimination that informed government policy and regulatory changes. Currently working with the Australian life insurance industry to analyse applications where a genetic test result is disclosed as per the Australian requirements (paper under review by European Journal of Human Genetics).
- 2020 – Conducted strategic review of uptake of genetic and genomic testing by non-genetics specialists and the model of care in NSW: *Current and Future Holistic Genomic/Precision Medicine Pathways for New South Wales Children/Families with Rare Genetic Disorders: Informing a Sydney Children's Hospital Network-Led Initiative* submitted to Luminesce Alliance - Innovation for Children's Health August 2020
- Worked with community members to establish the umbrella group Genetics Alliance Australia which represents >200 support groups; Chair of Professional Advisory Board (since 1989).
- Co-established the Jewish community genetic carrier screening program in 1995 based on close community governance and consultation and continue as member of the Community Genetics Advisory Board.
- Media interviews conducted 2016-2022: Print (18); Radio (22); Television (4); podcasts (3)

Professional Service and Activities

Peer review

- NHMRC Partnerships Grant Review panel 2012-2018
- NHMRC grant assessor
- Reviewer for 12 journals: Journal of Genetic Counseling, Patient Education and Counseling, European Journal of Human Genetics, BMC Medical Education, BMC Ethics, Clinical Genetics, Australian Journal of Public Health, Journal of Community Genetics, Australian Journal of General Practice, Medical Journal of Australia, American Journal of Medical Genetics, British Medical Journal.
- CARIF (Malaysia) grant reviewer.
- Ministry of Health Singapore grant reviewer

Conference organization and Scientific program committee

- 5th International Congress of Human Genetics – Japan 2016
- 13th International Meeting on the Psychosocial Aspects of Hereditary Cancer, Sydney 2013.
- International Human Genome Meeting, Sydney, 2012

State, National and International Committees

- Agency for Clinical Innovation Clinical Genetics Network (Chair 2006-2020; member since 1987) – formerly Genetics Services Advisory Committee NSW Health
    - For example, led the development of genetic testing policy directives regarding prenatal diagnosis and screening and DNA testing. Since 2014 she has been managing the development of an updated genetic testing policy for NSW (Genetic testing: Including DNA Diagnostic Testing, DNA Testing for Mutation Carriers and DNA Predictive and Pre-Symptomatic Testing) with consultation from all stakeholders to achieve consensus. Attached to the policy are seven different consent and request forms for genetic and genomic testing that have been submitted for use by all hospitals and services.

- NSW Health Genomics Strategy Steering Committee (2018-2020). Chair of the Community Engagement committee for the Genomic Strategy
    - For example, working on the national consent template.
- The NSW Register of Congenital Conditions Advisory Committee, Chair (current)
- Community Genetics Advisory Committee to the Jewish Community (Member since 1998)
- As a member of the National Pathology Accreditation Advisory Committee (2009-2011) she had direct influence in that role in laboratory requirements for genetic testing including consent and reporting of results.
- Global Genomic Medicine Education Committee (Australian representative nominated by the NHMRC since 2013)
- NHMRC Human Genetics Advisory Committee (2006-2012)

Contribution to the profession

- Human Genetics Society of Australasia
    - Master of Genetic Counselling course Accreditation Committee (current)
    - Board of Censors for Genetic Counselling (Chair 1999-2003; member 2004-2005)
    - Education and Social Ethics Committee – (1998-2012)
    - Secretary (1995-1997)

Research Grants

- Over her career, a successful investigator in 15 competitive grant applications, **$AUD 26.2 million in funding.**

Current and past Research Grants and collaborations (Grant body support is indicated)

- **CURRENT**

TITLE	*INVESTIGATORS/ GRANT TYPE*	*FUNDING SOURCE*	*YEAR FUNDED*	*FUNDS AWARDED*
Delivering precision diagnosis to patients with mitochondrial disease: Using digital technologies to enhance the delivery pathway to provide an accurate genetic diagnosis for patients with mitochondrial disease	C Sue, E Coiera, K Barlow-Stewart, S Kummerfeld, D Schofield, S Berkovsky, R Davis	NHMRC Partnerships Grant APP1179029	2020-2025	$1,273,553
A-GLIMMER: Moratorium on Genetic Testing & Life Insurance: Monitoring the impact.	P Lacaze, J Tiller, L Keogh, A McInerney-Leo, A Belcher, K Barlow-Stewart, T Boughtwood, M Delatycki, I Winship, M Otlowski	Genomics Health Futures Mission – Ethical, legal and social issues	2020-2023	$500,000
Mackenzie's Mission for research into offering reproductive genetic carrier screening across Australia	E Kirk, N Liang, M Delayticki, K Barlow-Stewart & many others	Medical Research Futures Fund	2019-2022	$20,000.000

EPIC-ID: The economic and social impacts of genetic sequencing for intellectual disability.	Schofield D, Roscioli T, Mattick J, Kasparian N, Dinger M, Barlow-Stewart K, Cowley M, Field M, Buckely M, Shrestha R	NHMRC Partnership Grant. APP1113895	2016 -2022	$1,263,576

- **PAST**

TITLE	***INVESTIGATORS/ GRANT TYPE***	***FUNDING SOURCE***	***YEAR FUNDED***	***FUNDS AWARDED***
Implementing mainstreaming of genetic testing of women with ovarian cancer: Evaluation of a training program for oncology health professionals	Meiser B, Gleeson M, Kentwell M, Friedlander M, Tucker K, Taylor N, Kirk J, Barlow-Stewart K	Astrazeneca, Contract Research	2017	$236,363
Sydney Vision Initiative- a new way to combat untreatable blindness	Jamieson R, McCluskey P, Lisowski L, Alexander I, Grigg J, Tam P, Schofield D, Simunovic M, Barlow-Stewart K	Sydney Research Excellence Initiative 2020 (SREI).	2017	$150,000
When the stakes are high: Psychological and behavioural impact of genomic testing for breast cancer risk	Meiser B, James P, Mitchell G, Halliday J, Young MA, Barlow-Stewart K, Roscioli T, Kelly P	Cancer Council of New South Wales APP1079897	2016 -2018	$353,608
Exome sequencing for pre-conception counselling in consanguineous couples	Kirk E, Barlow-Stewart K, Roscioli T, Meiser B, Buckley M, Mahmoud I, Burnett L	Apex Foundation for Research into Intellectual Disability Ltd	2014	$40,000
Cluster randomised controlled trial of an online psycho-educational intervention for people with a family history of depression for use in general practice	Meiser B, Mitchell P, Schofield P, Trevena L, Barlow-Stewart K, Dobbins T, Christensen H	ARC Linkage Grant LP120200075	2013 -2016	$513,514
Cluster-randomised trial of a colorectal cancer family history assessment website for use in general practice.	Trevena L, Meiser B, Kirk J, Barlow-Stewart K, Dobbins T, Goodwin A.	Cancer Australia, Priority-driven Collaborative Cancer Research Scheme	2010-2012	$550,665
The development and trial of tailored	Kasparian N, Meiser B, Menzies S, Mann G,	Cancer Council NSW	2010-2011	$142,500

psycho-educational resources for melanoma patients	Butow P, Barlow-Stewart K.			
Psychosocial impact of hereditary cancer and the development and evaluation of effective patient education and decision support strategies	Meiser B, Lobb E, Tucker K, Barlow-Stewart K, Andrews L, Kirk J, Friedlander M, Mireskandari S, Kasparian N, Wakefield C	Strategic Research Partnership Grant. The Cancer Council of New South Wales ID SRP 06-X5	2006	$1,017,582
Preimplantation Genetic Diagnosis: Psychological Impact	Barlow-Stewart K, Jansen R, McMahon C, Meiser B, Roberts C, Strong K	Fertility Society of Australasia	2006	$15,000
Cultural Constructions of Inheritance, Genetics and Cancer. A study of Chinese Australians.	Eisenbruch M, Meiser B, Barlow-Stewart K, Tucker K, Goldstein D.	Multicultural Health Program, SESAHS	2001	$10,000
Gendering in women's health and cancer.	Eisenbruch M, Meiser B, Barlow-Stewart K, Tucker K, Goldstein D.	Women's Health Program, SESAHS	2001	$25,000

Publications

(a) Peer reviewed journals

2023

1. Wedd L, Gleeson M, Meiser B, O'Shea R, Barlow-Stewart K, Spurdle AB, James P, Fleming J, Nichols C, Austin R, Cops E, Monnik M, Do J, Kaur R.J Exploring the impact of the reclassification of a hereditary cancer syndrome gene variant: emerging themes from a qualitative study. Community Genet. 2023 Apr 3. doi: 10.1007/s12687-023-00644-0. Online ahead of print.PMID: 37012465
2. Tiller J, Bakshi A, Dowling G, Keogh L, McInerney-Leo A, **Barlow-Stewart K**, Boughtwood T, Gleeson P, Delatycki M, Winship I, Otlowski M, Lacaze P. Community concerns about genetic discrimination in life insurance persist in Australia: a survey of consumers offered genetic testing. Accepted by Eur J Hum Gen April 2023.
3. White S, Mossfield T, Fleming J, **Barlow-Stewart K,** Ghedia S, Dickson R, Richards F, Bombard Y, Wiley V. Expanding the Australian Newborn Blood Spot Screening Program using genomic sequencing: do we want it and are we ready? Eur J Hum Genet. 2023 Mar 20. doi: 10.1038/s41431-023-01311-1. Epub ahead of print. PMID: 36935418.

2022

4. Archibald AD, McClaren BJ, Caruana J, Tutty E, King EA, Halliday JL, Best S, Kanga-Parabia A, Bennetts BH, Cliffe CC, Madelli EO, Ho G, Liebelt J, Long JC, Braithwaite J, Kennedy J, Massie J, Emery JD, McGaughran J, Marum JE, Boggs K, **Barlow-Stewart K**, Burnett L, Dive L, Freeman L, Davis MR, Downes MJ, Wallis M, Ferrie MM, Pachter N, Scuffham PA, Casella R, Allcock RJN, Ong R, Edwards S, Righetti S, Lunke S, Lewis S, Walker SP, Boughtwood TF, Hardy T, Newson AJ, Kirk EP, Laing NG, Delatycki MB, The Mackenzie's Mission Study Team. (2022) The Australian Reproductive Genetic Carrier Screening Project (Mackenzie's Mission): Design and Implementation. *Journal of Personalized Medicine*. 2022; 12(11):1781. https://doi.org/10.3390/jpm12111781
5. Cheng l, Meiser B, Kirk E, Kennedy B, **Barlow-Stewart K,** Kaur R (2022) Factors influencing patients' decision-making about preimplantation genetic testing for monogenic disorders, *Human Reproduction*, 37 (11): 2599–2610 https://doi.org/10.1093/humrep/deac185
6. Hunter, J.D.; Robertson, E.G.; Hetherington, K.; Ziegler, D.S.; Marshall, G.M.; Kirk, J.; Marron, J.M.; Denburg, A.E.; **Barlow-Stewart, K**.; Warby, M.; Tucker, K.M.; Lee, B.M.; O'Brien, T.A.; Wakefield, C.E. What's in a Name? Parents' and Healthcare Professionals' Preferred Terminology for Pathogenic Variants in Childhood Cancer Predisposition Genes. J. Pers. Med. 2022, 12, 1327. https://protect-au.mimecast.com/s/7bTFCk81N9tnNw9NOuQnis6?domain=doi.org
7. Trevena L, J, Meiser B, Mills L, Dobbins T, Mazza D, Emery J, D, Kirk J, Goodwin A, Barlow-Stewart K, Naicker S: Which Test Is Best? A Cluster-Randomized Controlled Trial of a Risk Calculator and Recommendations on Colorectal Cancer Screening Behaviour in General Practice. Public Health Genomics 2022;25:193-208. doi: 10.1159/000526628
8. Cheng L, Meiser B, Kirk E, Kennedy D, Kaur R, **Barlow-Stewart K**. (2022) Exploration of decision-making regarding the transfer of mosaic embryos following preimplantation genetic testing for aneuploidy (PGT-A): a qualitative study. Human Reproduction Open 2022(4): hoac035
9. Gereis, J. M., Hetherington, K., Ha, L., Robertson, E. G., Ziegler, D. S., **Barlow-Stewart. K.,** Tucker. K. M., Marron, J. M., Wakefield, C. E. (2022) Parents' understanding of genome and exome sequencing for pediatric health conditions: A systematic review. Eur J Hum Genet 30(11), 1216-1225. https://doi.org/10.1038/s41431-022-01170-2
10. Dowling G., Tiller J, McInerney-Leo, A., Belcher, A., Haining C, **Barlow-Stewart K,** Boughtwood T, Gleeson P, Gleeson P, Delayticki M, Winship I, Otlowski M, Jacobs C, Keogh L, Lacaze P (2022). Health professionals' views and experiences of the Australian moratorium on genetic testing and life insurance: A qualitative study. *European Journal of Human Genetics* 30:1262-1268 DOI: 10.1038/S41431-022-01150-6
11. Cullen, M.B., Meiser, B., **Barlow-Stewart, K**., Green, M., Appelbaum, P.S., Carr, V.J., Cairns, M.J., Lebowitz, M.S. and Kaur, R., 2022. Perceptions of causal attribution and attitudes to genetic testing

among people with schizophrenia and their first-degree relatives. *European Journal of Human Genetics*, 30(10):1147-1154

12. Nevin, S.M., Wakefield, C.E., **Barlow-Stewart, K**., McGill, B.C., Le Marne, F., Beavis, E., Boggs, K., Dale, R.C., Gill, D., Kothur, K., Macintosh, R., Sachdev, R., Bye, A., & Palmer, E.E. 2022. The psychosocial impacts of genetic testing on parents of a child with a developmental and epileptic encephalopathy. *Developmental Medicine & Child Neurology*, *64*(1), pp.95-104. https://doi.org/10.1111/dmcn.14971
13. King E, Halliday J, Archibald A, **Barlow-Stewart K**, Delatycki M, Newson A, McClaren M (2022). Development and use of the Australian reproductive genetic carrier screening decision aid. Eur J Hum Genet 30, 194–202 (2022). https://doi.org/10.1038/s41431-021-00991-x
14. Sa'at, H., Lee, Y. K., Yoon, S. Y., Wong, S. W., Woo, Y. L., **Barlow-Stewart, K**., & Mohd Taib, N. A. (2022). The needs of Southeast Asian BRCA mutation carriers considering risk-reducing salpingo-oophorectomy: a qualitative study. *Familial cancer*, *21*(1), 21-33. https://doi.org/10.1007/s10689-021-00232-6
15. **Barlow-Stewart, K.,** Bardsley, K., Elan, E., Fleming, J., Berman, Y., Fleischer, R., Recsei, K., Goldberg, D., Tucker, J. and Burnett, L., 2022. Evaluating the model of offering expanded genetic carrier screening to high school students within the Sydney Jewish community. *Journal of community genetics*, *13*(1), pp.121-131. https://doi.org/10.1007/s12687-021-00567-8
16. Gregory, G., Das Gupta, K., Meiser, B., **Barlow-Stewart, K**., Geelan-Small, P., Kaur, R., Scheepers-Joynt, M., McInerny, S., Taylor, S., Antill, Y. and Salmon, L., 2022. Polygenic risk in familial breast cancer: Changing the dynamics of communicating genetic risk. *Journal of genetic counseling*, *31*(1), pp.120-129. https://doi.org/10.1002/jgc4.1458
17. Tiller JM, Cousens NE, Kaur R, Rowley S, Ko YA, Mahale S, Bankier A, Meiser B, **Barlow-Stewart K,** Burnett L, Jacobs C. (2022) Population-based BRCA1/2 testing programmes are highly acceptable in the Jewish community: results of the JeneScreen Study. Journal of Medical Genetics 60(3):256-273
18. Righetti, S., Dive, L., Archibald, A.D., Freeman, L., McClaren, B., Kanga-Parabia, A., Delatycki, M.B., Laing, N.G., Kirk, E.P., Newson, A.J. and **Barlow-Stewart, K.,** 2022. Correspondence on "Screening for autosomal recessive and X-linked conditions during pregnancy and preconception: a practice resource of the American College of Medical Genetics and Genomics (ACMG)" by Gregg et al. *Genetics in Medicine*, *24*(5), pp.1158-1161.
19. Sa'at, H., Lee, Y. K., Yoon, S. Y., Wong, S. W., Woo, Y. L., **Barlow-Stewart, K**., & Mohd Taib, N. A. (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. https://doi.org/10.1007/s12529-021-09984-y
20. Cheng L, Meiser B, Kirk E, Kennedy D, Kaur R, **Barlow-Stewart K**. (2022) Decisional needs of patients considering preimplantation genetic testing: a systematic review. Reproductive BioMedicine Online, 44(5), 839-852

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21. Tiller, J., Keogh L, McInerney-Leo, A., Belcher, A., **Barlow-Stewart K,** Boughtwood T, Gleeson P, Dowling G, Prince A, Bombard Y, Joly Y, Delayticki M, Winship I, Otlowski M, , Lacaze P 2021. A step forward, but still inadequate: Australian health professionals' views on the genetics and life insurance moratorium. (2021). J Med Genetics https://doi.org/10.1101/2021.05.25.21257683
22. Tiller, J., McInerney-Leo, A., Belcher, A., Boughtwood T, Gleeson P, Delayticki M, **Barlow-Stewart K,** Winship I, Otlowski M, Keogh L, Lacaze P 2021. Study protocol: the Australian genetics and life insurance moratorium—monitoring the effectiveness and response (A-GLIMMER) project. BMC Med Ethics 22, 63 (2021). https://doi.org/10.1186/s12910-021-00634-2
23. Yanes, T., Kaur, R., Meiser, B., Scheepers-Joynt, M, Mcinerny S, Taylor S, **Barlow-Stewart K,** Antill Y, Salmon L, Smyth C, James P, Young, M. 2021. Breast cancer polygenic risk scores: A 12-month prospective study of patient reported outcomes and risk management behaviour. Genetics in Medicine https://doi.org/10.1038/s41436-021-01288-6

24. **Barlow-Stewart K,** Conaghan J, Clinch T, Howat, A Crawford H, Richards F, Kapp R, Fleming. J. 2021. Consultands' and Support Persons' Experiences of Presymptomatic Testing for Huntington Disease in Australia. Archives of Health Archives of Healthcare 2(1):1-10] DOI: https://doi.org/10.1057/ahc000007
25. Nisselle A, Janinski M, Martyn M, Kaunein N, **Barlow-Stewart K,** Belcher A, Bernat J, Best S, Bishop M, Carroll J, Cornel M, Dissanayake V, Dodds A, Dunlop K, Garg D, Gear R, Graves D, Knight K, Korf B, Kumar D, Laurino M, Ma A, Maguire J, Mallett A, McCarthy M, McEwen A, Mulder N, Patel C, Quinlan C, Reed K, Rooney Riggs E, Sinnerbrink I, Slavotinek A, Suppiah V, Terrill B, Tobias E, Tonkin E, Trumble S, Wessels T-M, Metcalfe S, Jordan H, Gaff C. 2021. Ensuring Best Practice in Genomics Education and Evaluation: Reporting Item Standards for Education and its Evaluation in Genomics ('RISE2 Genomics'). Gen Med *Genet Med* (2021). https://doi.org/10.1038/s41436-021-01140-x
26. Cousens NE, Tiller J, Meiser B, **Barlow-Stewart K**, Rowley S, Ko Y-A, Mahale S, Campbell I, Kaur R, Bankier A, Burnett L, Jacobs C, James P, Trainer A, Neil S, Delatycki, Andrews L. 2021.Evaluation of two population screening programmes for BRCA1/2 founder mutations in the Australian Jewish community: a protocol paper. BMJ Open 2021;11:e041186. doi: 10.1136/bmjopen-2020-041186
27. Das Gupta K, Gregory G, Meiser B, B**arlow-Stewart, K**, Geelan-Small P, Kaur R, Scheepers-Joynt M, McInerny S, Taylor S, Antill Y, Salmon L, Smyth C, Young M, James P, Yanes T. Communicating polygenic risk scores in the familial breast cancer clinic. Patient Education and Counseling 2021 https://doi.org/10.1016/j.pec.2021.02.046.
28. Speechly C, Stenhouse, R, Berman Y, **Barlow-Stewart K,** Fleming J, Petrie D, Culling. B (2021) Genetic Counselor, Patient and Carers' Views on the NSW/ACT Clinical Genetics Service Information System. Journal Genetic Counseling 30(5):.1440-1451.
29. Schlub G, Crook A, **Barlow-Stewart K**, Fleming J, Kirk J, Tucker K, Greening. S Helping very young children understand inherited cancer predisposition syndromes using bibliotherapy. J Gen Couns, online 31 March 2021 https://doi.org/10.1002/jgc4.1396

2020

30. Thomas LA, Lewis S, Massie J, Kirk E, Archibald A, **Barlow-Stewart K**, Boardman F, Halliday J, McClaren D, Newson A, Delatycki M. 2020. Which types of conditions should be included in reproductive genetic carrier screening? Views of parents of children with a genetic condition. *European Journal of Medical Genetics*, *63*(12), p.104075.
31. Gleeson M, Kentwell M, Meiser B, Do J, Nevin S, Taylor N**, Barlow-Stewart K**, Kirk J, James P, Scott C, Williams R, Gamet K, Burke J, Murphy M, Antill Y, Pearn A, Pachter N, Ebzery C, Poplawski N, Friedlander M, Tucker K and the Australian Genetic Testing Mainstreaming Collaborative Group, 2020. The development and evaluation of a nationwide training program for oncology health professionals in the provision of genetic testing for ovarian cancer patients. Gynecologic Oncology 158 (2):431-439
32. Yanes, T., Kaur, R., Meiser, B., Scheepers-Joynt, M, Mcinerny S, Taylor S, **Barlow-Stewart K,** Antill Y, Salmon L, Smyth C, James P, Young, M. 2020. Women's Responses and Understanding of Polygenic Breast Cancer Risk Information. Familial Cancer https://doi.org/10.1007/s10689-020-00185-2
33. Gonzalez T, Harris R, Williams R, Wadwell R, **Barlow-Stewart K,** Fleming J, Buckman M. Exploring the barriers preventing Indigenous Australians from accessing cancer genetic counseling. *Journal Genet Counseling* (2020) 29 (4) Special Issue: Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine Special Issue – Part 3: 542-552
34. Kotwal H, Fleming J, **Barlow-Stewart K**, Boyle J, Silberbauer L, Leffler M, Murray L, Palmer E. Pre-genetic clinic resource evaluation for adults with intellectual disability: the pre-genetic clinic aid. *Journal Genet Counseling* (2020) 29 (4) Special Issue: Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine Special Issue – Part 3: 668-677
35. Putt, S., Yanes, T., Meiser, B., Kaur, R., Fullerton, J.M., **Barlow-Stewart**, K., Schofield, P.R., Toma, C., Peay, H. and Mitchell, P.B., (2020). Exploration of experiences with and understanding of polygenic risk scores for bipolar disorder. Journal of Affective Disorders 265: 342-350
36. Meggiolaro, Natalia, **Kristine Barlow-Stewart,** Kate Dunlop, Ainsley J. Newson, and Jane Fleming. Disclosure to genetic relatives without consent–Australian genetic professionals' awareness of the health privacy law. BMC Medical Ethics 21, no. 1 (2020): 13.

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(b) Reports, Books and Book Chapters

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2. **Barlow-Stewart K,** Dunlop K, Fleischer R, Shalhoub C, Williams R (2015). The NSW Genetic Counselling Workforce: Background Information Paper: an Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Centre for the NSW Ministry of Health, May 2015
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(c) Invited papers in journals and newsletters and podcasts

1. **Barlow-Stewart K** (March 2020) Getting the balance right – life insurance and genetics in Australia. Commissioned by Swiss Re Insurance
2. Insight genomica podcast (2018) Demystifying Genetics with Kristine Barlow –Stewart https://itunes.apple.com/au/podcast/demystifying-genetics/id1387090904
3. **Barlow-Stewart K** (2017) Personalised medicine: More than just personal AQ - Australian Quarterly Volume 88 Issue 2 (Apr/Jun 2017)
4. Royal Australian College of Physicians (2017). Interview with **Prof K Barlow-Stewart** - Genomics for the Generalist https://www.imsanz.org.au/latest-news/racp-podcast-genomics-for-the-generalist
5. **Barlow-Stewart K** (2012) The Centre for Genetics Education. International Innovation, Research Media Ltd, UK
6. **Barlow-Stewart K** (2011) Genetic disorders. CHECK program for the Royal Australian College of General practitioners
7. **Barlow-Stewart K** (2009) Genetic Discrimination – Australian experiences and policies. Genewatch. The journal of the Council for Genetic responsibility**.**
8. **Barlow-Stewart K** and Burnett L (2006). Ethical considerations in the use of DNA for the diagnosis of diseases. Clin Biochem Rev Vol 27; 53-61
9. **Barlow-Stewart K** (2004). Commercial interest in a person's genetic information. Living ethics. Newsletter of the St James Ethics Centre. Issue 57, pp 14.
10. **Barlow-Stewart K** (2001). Decision-making in the era of the genetic revolution. Living Ethics: Newsletter of the St James Ethics Centre, Issue 45.
11. **Barlow-Stewart K** (2001). Benefits and burdens for families in the age of the New Genetics. Reform, Australian Law Reform Commission, Issue 7.
12. **Barlow-Stewart K,** Petrie, D, O'Reilly A and Smith R (1999). Needs and experiences following the diagnosis of a genetic disorder. Newsletter of the Association of Genetic Support of Australasia, No. 40.

Conference presentations

- **Last 6 years (including published proceedings where available)**

Invited presentations

1. Genetics education strategies for professionals and the community underpinning the provision of genetic counselling. 13th International Congress of Human Genetics April 3-7 2016 Kyoto Japan
2. Integrating variant calling teaching into the Master of Genetic Counselling program. Transnational Alliance for Genetic Counseling (TAGC) 4th International meeting. May19-20 2016 Barcelona Spain.
3. Genetic Information Nondiscrimination Act and Insurance. The chemopreventative effect of aspirin in Lynch syndrome carriers: Development and evaluation of an educational leaflet. The 15th International Meeting on the Psychosocial Aspects of Hereditary Cancer 23-26 September 2017 Kuala Lumpur Malaysia
4. Genetics information and life insurance – policy update. Garvan Institute of Medical Research. December 6 2017
5. Addressing the needs of Indigenous communities to enable informed consent and engagement. RCPA Pathology Update A bridge to the future 2-3 March 2018 Sydney
6. Ethics in genetic research. Centre for Ethics in Medicine and Society & Sydney Health Ethics Intensive Research Ethics Course 6-10 May 2018, Bowral, NSW
7. HGSA Oration: I want to be a genetic counsellor … and this is my story. The 42nd Human Genetics Society of Australasia Annual Scientific Meeting Sydney, New South Wales August 4–7, 2018
8. Ethics in genetic research. Centre for Ethics in Medicine and Society & Sydney Health Ethics Intensive Research Ethics Course 5-9 May 2019 and 2022, Bowral, NSW
9. Getting the balance right. Zurich Re Insurance conference 2020. Postponed from March 2020 to March 2021 due to COVID, Zurich Switzerland.

Platform presentation selected from submitted abstract

1. Informing preparation for Personal Genomic Screening. Fleming J, Terrill B, Dziadek M, Kirk E, Roscioli A, Barlow-Stewart K. European Meeting on Psychosocial Aspects of Genetics May 21-24 2016 Barcelona Spain
2. Australian Life Insurers use of genetic test results in underwriting decisions. K. K. Barlow-Stewart, M Liepins, M. Otlowski, A. Doble. The 41st Human Genetics Society of Australasia Annual Scientific Meeting Brisbane, Queensland August 5–8, 2017 Twin Research and Human Genetics
3. The evolving landscape of genetic counselling in the genomic era. K Barlow-Stewart, T Dwarte, R O'Shea, M Dinger, and B Terrill. First World Congress of Genetic Counseling. 4-6 October 2017 Wellcome Trust Cambridge UK
4. Screening strategies for recruitment and result reporting to maximise utility of whole-of-life genomics. L Burnett, K Barlow-Stewart, E Richardson, M-A Young, S Kummerfeld, W Kaplan, B Terrill. The 43rd Human Genetics Society of Australasia Annual Scientific Meeting, Wellington New Zealand, August 3-6 2019 Twin Research and Human Genetics (2019), 22, 330–370
5. Informing practice post-implementation of a moratorium on genetic test result disclosure by Life Insurers in Australia. K. Barlow-Stewart, B. Vargas Murillo, M. Otlowski, A. Doble. Familial Cancer conference (KConFab) 26-29 August 2019 Salt Beach, Kingslciff NSW
6. Helping very young children understand inherited cancer predisposition syndromes using bibliotherapy. K. Barlow-Stewart, G. Schlub, A. Crook, J. Fleming, J. Kirk, K. Tucker and S. Greening. The 53rd European Society of Human Genetics (ESHG) Conference: Berlin, Germany June 6-9 2020 Held virtually due to COVID

Posters selected from submitted abstract

- The 41st Human Genetics Society of Australasia Annual Scientific Meeting Brisbane, Queensland August 5–8, 2017 Twin Research and Human Genetics (2017), 20, 446–480
    1. Uptake of polygenic risk information among women at potentially high breast cancer risk. Tatiane Yanes, Bettina Meiser, Rajneesh Kaur , Maatje Scheepers-Joynt, Mary-Anne Young, Kristine Barlow-Stewart , Geoff Lindemann, Tom John, Marion Harris, Yoland Antill, Jo Burke, Tony Roscioli, Jane Halliday, Phillip Mitchell, and Paul James.
    2. Experiences and attitudes of adults with neurofibromatosis type 1 attending a specialist skin clinic. Mei Yi Wong, Hilda A Crawford, Rosie O'Shea, Gayle Fischer, Kristine Barlow-Stewart, and Yemima Berman.
    3. Exploring the experiences and support needs of non-carrier fathers of children with fragile x syndrome. Jacintha Luermans, Jane Fleming, Rosie O'Shea, Mike Field, Kristine Barlow-Stewart, Emma (Elizabeth) Palmer, and Melanie Leffler.
    4. A survey of the Australasian genetic counselor workplace: 15 years on. Bruce Massey, Ron Fleischer, Jane Fleming, Kristine Barlow-Stewart, and Alison Colley.
    5. The chemopreventative effect of aspirin in Lynch syndrome: development and evaluation of an educational leaflet. Cassandra McDonald, Rajneesh Kaur, Bettina Meiser, Rosie O'Shea, Maira Kentwell, Kristine Barlow-Stewart, Gillian Mitchell and Finlay Macrae.
    6. Exploring women's experiences of current and emerging antenatal screening technologies in New Zealand. Christina Buchanan, Jane Fleming, Bronwyn Culling, Annabelle Kerr, and Kristine Barlow-Stewart.
- The 42nd Human Genetics Society of Australasia Annual Scientific Meeting Sydney, New South Wales August 4–7, 2018 Twin Research and Human Genetics (2018), 21, 429–476
    1. Exploring the barriers preventing indigenous Australians from accessing cancer genetic counseling. Gonzalez C, Williams R, Fleming J, Barlow-Stewart K,Wadwell R, Harris R, Buckman M.
    2. Breast cancer and polygenic risk: changing the dynamic of communicating genetic information. Gregory G, Yanes T, Meiser B, Barlow-Stewart K, Fleming J, Young M, James P. Yanes T, Meiser B, Kaur R, Scheepers-Joynt M, Young M, Barlow-Stewart K, John T, Harris M, Antill Y, Burke J, Roscioli

T,Halliday J, Mitchell P, James P. Polygenic breast cancer risk: a prospective study of uptake and outcomes among high-risk women

3. Pre-genetic clinic resource evaluation for adults with intellectual disability: the pre-genetic clinic aid. Kotwal H, Fleming J, Barlow-Stewart K, Leffler M, Palmer E
4. Development and evaluation of an information brochure in parents of children with congenital heart disease . Hunt A, Hilton D, Barlow-Stewart K, Fleming J, Winlaw D, Blue G.
5. How different forms of information delivery affect the genetic counseling process. Moore K, Kamien B, Shalhoub C, Freeman L, Berman Y, O'Donnell S, Buckman M, Lynch S, Joyce M, Fleming J, Barlow-Stewart K, Hopper B.
6. Jewish community genetic carrier screening: attitudes and experiences. Reid S, Barlow-Stewart K, Fleming J, Kirk E, Berman Y, Andrews L, Cousens N, Fleischer R.
7. B Views of Genetic Service clients about the Genetic Information System. Speechly C, Berman Y, Barlow-Stewart K, Stenhouse R, Fleming J, Petrie D, Culling
8. Consumer perceptions and experiences regarding the use of genetic information in insurance.. Vargas Murillo B, Otlowski M, Doble A, Barlow-Stewart K.

- The 43rd Human Genetics Society of Australasia Annual Scientific Meeting, Wellington New Zealand, August 3-6 2019 Twin Research and Human Genetics (2019), 22, 330–370 https://doi:10.1017/thg.2019.80
  1. Carey-Anne Evans, Alyssa Wilson, Ying Zhu, Michael Buckley, Kristine Barlow-Stewart, Tony Roscioli Evaluation of a Clinical Genomics Course: Considerations for Australia and Internationally
  2. Kristine Barlow-Stewart, Brenely Vargas Murillo, Margaret Otlowski and Alan Doble. Genetic Discrimination Concerns in Travel Insurance – The Pre-existing Medical Condition Rule
  3. Catherine Speechly, Rachael Stenhouse, Yemima Berman, Kristine Barlow-Stewart, Jane Fleming, Dianne Petrie and Bronwyn Culling. Genetic Counselor, Patient and Carers' Views on the NSW/ACT Clinical Genetics Service Information System
- The 52nd European Society of Human Genetics (ESHG) Conference: Gothenburg, Sweden June 15-18, 2019 European Journal of Human Genetics (2019) 27:1174–1813 https://doi.org/10.1038/s41431-019-0494-2
  1. K. K. Barlow-Stewart, B. V. Murillo, M. Otlowski, A. Doble. Genetic discrimination concerns in travel insurance - the pre-existing medical condition rule
  2. K. Barlow-Stewart, J. Luermans, J. Fleming, R. O'Shea, M. Field, E. E. Palmer[3], M. Leffler· Exploring the experiences and support needs of non-carrier fathers of children with fragile X syndrome