

Reflections on the use of co-design to develop a genetic counselling curriculum fit for purpose for the genomic era: a case study

Alison McEwen, Jan McLean, Chris Jacobs
University of Technology Sydney

Abstract

The era of genomic medicine heralds a pivotal moment for the genetic counselling profession, forcing a re-evaluation of the traditional roles of genetic counsellors and the emergence of new roles. Education providers have an exciting opportunity to incorporate the complexity of a rapidly changing profession into curriculum design and the education of future generations of genetic counsellors. Co-design invites stakeholders to become participants, contributors and partners in the design process, to create a collective perspective on a complex issue. At University of Technology Sydney, the development of a new 'Master of Genetic Counselling' program began by asking how best to design curriculum in times of rapid change in the field. Using co-design principles, we engaged members of the profession and other key stakeholders in activities exploring this matter. Engagement in program design fostered a sense of ownership and commitment to educating the genetic counsellors of the future among the current workforce. Early work has prepared us to engage with students as partners and build the foundation for a flexible and emergent curriculum that is responsive to the changing needs of the profession.

Background: Genetic counselling education in Australia and New Zealand (Australasia)

The field of genetic counselling is radically changing. No longer confined to rare and inherited disease, genetic and genomic information is increasingly used in routine health care, to guide screening, treatment and prescribing decisions. There is a growing demand for expert health professionals who can effectively disseminate genetic and genomic information, help people to understand the information in the context of their own lives and families and facilitate informed decision-making about their health (Patch and Middleton, 2018). Genetic counsellors are ideally positioned to lead the way in embedding the use of genetic and genomic information into routine healthcare and facilitating the complex decision-making this requires.

Genetic counselling is a relatively new and small profession, having existed in its current form only since the late 1960s (Heimler, 1997; Stern, 2009). Current predictions indicate that there are approximately 7000 genetic counsellors working in at least twenty-eight countries (Abacan *et al.*, 2018). Recent literature documents workforce-demand trends for genetic counselling. In North America, it is predicted, on the basis of the current number of training positions (Hoskovec *et al.*, 2017), that the shortage of genetic counsellors engaged in clinical care may take six to eight years to address. In Australasia and the United Kingdom (UK), stakeholders agree that the current workforce is not able to meet the rising demand for genetic services (Barlow-Stewart *et al.*, 2015; Slade *et al.*, 2015).

There are twenty-four to twenty-eight genetic counselling graduates per year in Australasia from the two universities currently offering Master of Science in Genetic Counselling programs (Barlow-Stewart *et al.*, 2015). In several states in Australia and in New Zealand,

there are no training programs, making access to genetic counselling education difficult and expensive. A recent report prepared for the State Government (New South Wales Ministry of Health, 2017) identified the shortage of genetic counsellor education and the lack of regulation of the profession as major threats to the provision of genetic and genomic medicine in Australasia. In response, the Graduate School of Health at University of Technology Sydney (UTS) approached the profession in late 2016 to suggest the establishment of a new Master of Genetic Counselling. UTS is a young university, positioning itself at the forefront of dynamic, student-centred educational experience enhanced by advanced technologies and oriented to industry and professions (Foster and Mulhern, 2015).

At a time of disruptive change – owing to the emergence of genomic medicine – within the profession of genetic counselling, we were acutely aware of the need to design a program that would prepare students for future roles that might not yet exist. We sought an approach that allowed for close collaboration with those involved – including both industry and future students – in shaping this future direction and a curriculum design which would be responsive, agile and able to adapt to new and emerging directions in the field. This case study outlines the innovative approach, underpinned by co-design principles that we have taken to foster early industry engagement in program design, in preparation for working with the inaugural cohort of students as partners in a mutual and continuing learning journey.

Positioning of the Master of Genetic Counselling program at UTS

Uniquely in Australasia, this program is situated alongside other allied health disciplines in a Graduate School of Health, rather than within a medical school. This positioning assists in identifying genetic counsellors as autonomous allied health professionals and offers potential for inter-professional education and research opportunities with students in pharmacy, orthoptics, physiotherapy, clinical psychology and speech pathology. The initial program has been developed and it will be delivered by genetic counsellors with many years of clinical experience, supported by educational designers.

The institutional context plays a key role in shaping the program. The adoption of a co-design approach to curriculum design aligns with, and is enhanced by, the strategic direction UTS is taking to education to encourage partnership, co-design and 'future-thinking' curricula articulated in the 'UTS2027' plan. It is also encapsulated in the 'UTS Model of Learning', in which student-centred learning focuses on the effective application of knowledge and the development of professional, globally engaged citizens, well-grounded in the research and practices of their discipline (Foster and Mulhern, 2015).

The program is further strengthened by the UTS requirement for an Indigenous graduate attribute to be included in every course. An 'Indigenous Health Discipline' is embedded in the Graduate School of Health, providing a further unique opportunity to enhance the education of genetic counsellors to work with currently underserved populations. There is growing awareness of the importance of education and experience to prepare genetic counsellors to work with indigenous populations in Australia and New Zealand and to ensure that existing disparities are not exacerbated as genomic information becomes part of routine healthcare (Kowal *et al.*, 2015; Kowal, Easteal and Gooda, 2016; Nowak *et al.*, 2018). Coursework, clinical placements and research opportunities during the program all offer opportunities to enhance student experience of working with diverse populations.

Use of co-design in the UTS Master of Genetic Counselling development phase

Taking a co-design approach during the development of the program allowed us to engage with and draw upon the expertise of health professionals embedded in the profession, to imagine and design the initial curriculum. This work has positioned us to embed continuing co-design work into the program, working in partnership with students as the course unfolds. Here, we describe the work undertaken during the development phase, noting the ways in which this will be extended with the students as they begin their program.

Given our awareness of the shifting landscape into which graduates would emerge, we began by asking two key questions:

1. How do we design a new curriculum for a profession that is rapidly changing?
2. How does the changing nature of the way we work impact on curriculum development?

In order to develop a responsive, future-focused and emergent program that would address these questions, our co-design approach engaged the profession from the beginning in grappling with the challenges and possible solutions to program design. This approach will continue as the program commences, taking a whole-of-course approach and involving students as active partners in the continuing development of a new program to maintain a collaborative, respectful and future-focused learning environment.

Co-design is grounded in a democratic understanding of design in that it involves those affected by the design as collaborators in the process – who together envision and explore ideas in a hands-on way (Bjogvinsson, Ehn and Hillgren, 2012). Co-design and other participatory-design approaches have been used extensively in the social service sector and are increasingly being used in health (Bate and Robert, 2006). Co-design approaches are also being introduced in the education sector (Sewell et al., 2017). The process is collaborative and creative, involving those with and without training in design and with an emphasis on the importance of asking big, open-ended questions at the early stage. This early ‘fuzzy front end’ of design stage is characterised by ambiguity and chaotic exploration of ideas and possibilities (Sanders and Stappers, 2008). The collaborative, people-centred nature of co-design aligns well with the humanistic, Rogerian principles upon which genetic counselling is built (Marks, 2004).

Phase One: The first phase of developing the curriculum began late in 2017, by consulting with members of the Australasian Society of Genetic Counsellors (ASGC) through participation in teleconferences, phone conversations and face-to-face meetings. An invitation to participate was sent through the ASGC email list and went also to individual team leaders in Australia and New Zealand. Approximately seventy ASGC members participated in the consultation, which equated to almost twenty-five per cent of the 2017 membership.

The literature and the Human Genetics Society of Australasia Guidelines for Accreditation of Masters Programs (2017) informed the early conversations. Members were engaged with exploring the future of genetic counselling, including: what genetic counsellors would be doing and where they would be working; what should be included in an education program; what skills and attributes future graduates would require; the role of clinical placements and

Case Studies

research in genetic-counsellor education. The ideas emerging from these consultations were recorded and checked for accuracy by participants and then analysed thematically (Braun and Clarke, 2008). Using an iterative approach, emerging themes were explored during subsequent conversations.

Phase Two: Following the initial consultation, a Curriculum Advisory Committee (CAC) was established early in 2018. Membership of the establishment CAC included genetic counsellors, a clinical geneticist, an ethicist, scientists, researchers, a senior lecturer in Indigenous Health, a clinical psychologist and an educational designer. This group met monthly during the development phase to provide oversight and expert input into the curriculum.

A priority for us was to support the group to work collaboratively, while also provoking them to think in different ways about future possible directions, given that one of the challenges we face in graduating students into an evolving profession is preparing them to work in jobs that do not yet exist. The first CAC meeting was key to setting up this way of working and, to achieve this, we used a unique approach. To challenge the group to imagine the future roles graduates might take on, committee members participated in a facilitated workshop, at which teams were given the task of 'making' the present and future states of genetic counselling. 'Making', through use of a range of craft materials, is a design technique developed by Sanders and Stappers (2013) and used to facilitate collective sense-making; participants in it are supported to make imagined futures more tangible and able to be 'seen'. Underpinned by co-design principles, 'making' involves teams in working to create imagined future states together by 'doing', rather than beginning with talking – the more traditional approach.

Sanders and Stappers (2013) propose that, through 'making', groups can tap into implicit knowledge about how they feel and imagine in ways that can't be easily expressed in words. Working in small groups, CAC members first used a range of craft materials, images and words to 'make' the present state of genetic counselling and then went on to 'make' the future state. The collages and structures emerged from a process of selection of words and images, the creation of structures and the use of linking materials – all this in a manner that initially felt unstructured and uncomfortable. As we worked, we came to understand that it was not about the 'look' of what we made; rather, it was the links, bridges, silo-like structures, root-base pictures and much more that came together as a story. Following the 'making', the members of each group in turn talked about what they had produced and identified those ideas which were of crucial importance in their imagining of present and future states – a process captured in notes, photographs and audio recordings. That other groups were invited to comment and ask questions about what they had produced allowed everyone to explore together common themes as well as differences.

This collaborative, engaging exercise helped the members of the CAC get to know each other; it built empathy, as members of CAC began to understand each other's philosophies of genetic counselling and create future ways of working together in partnership. The members of the CAC were also invited to talk about their experience of the session. They described feeling surprised by the way that 'making' helped to extend their thinking and, in later CAC meetings, referred back to this workshop. The outcomes went well beyond our expectations, allowing us to imagine possible futures of the profession and to peer into these futures from different angles, bringing to light both commonalities and differences.

Learning from this exercise was then reapplied in a subsequent meeting, at which CAC members participated in a client journey-mapping exercise, aiding the identification of key touchpoints between client and genetic counsellor prior to, during and subsequent to a referral to a clinical genetic service. Visualising the key moments when genetic counsellors and clients interact – and the events that occur around those interactions – assisted with confirmation of core skills identified in the earlier consultation. The client journey-mapping exercise allowed us to revisit several key themes identified during the ‘making’ workshop and to extend our thinking regarding inclusion of curriculum activities to explore the themes with students.

What have we learnt from these activities?

Five key themes related to curriculum development emerged from the preparatory design activities. The themes encompassed both broad concerns regarding the future of the profession of genetic counsellors and guidance to inform the development of a future-focused curriculum for an evolving profession. The five themes and ways we have addressed these in early curriculum development are discussed as follows:

Autonomy and maintenance of fundamental skills: A key theme that emerged from this work was the identification of growing autonomy and professional identity by a motivated and empowered genetic-counselling workforce, highlighting the importance of education that fosters a strong professional identity as students enter the profession. Participants strongly endorsed a continued focus on core skills in communication and counselling and facilitation of client understanding.

Anxiety and uncertainty: There was some anxiety about the unknown future of the profession and an awareness of the need for resilience, flexibility and adaptability amongst genetic counsellors as the profession evolves. The importance of developing a curriculum that is responsive to the changing environment was highlighted.

Genomics and technology: Participants identified the importance of having a skilled, evidence-based workforce, able to embrace and use new and emerging technologies and work positively with uncertainty. Participants commented on the increasingly diverse range of roles genetic counsellors are undertaking and identified the need to prepare students for new, as yet unknown, roles in the near future.

Cultural engagement and diversity: The ‘making’ activity concerning the positioning of Indigenous Australians in the present state of genetic counselling demonstrated the need for profound change in approaches to indigenous genetic health. Enhancing access for Indigenous Australians and working effectively with many ethnic groups in an increasingly globalised world were identified as important, supporting inclusion of cultural safety and engagement across all aspects of the curriculum.

Barriers to increasing diversity within the profession were also noted. Participants spoke both about the need to increase diversity amongst people entering the profession and about the translation of positive benefits to the communities which genetic counsellors serve.

Research education: Participants expressed varying views on the role of research in genetic-counsellor education, with a small minority indicating that completion of a research project should not necessarily be a core component of the course. Most participants endorsed the

Case Studies

importance of research education in preparing graduates for participation in clinical research after entering the workforce. The importance of preparing graduates competent in critical appraisal of literature to inform evidence-based practice was strongly endorsed.

These themes have been used to inform the preparation of graduate attributes and course intended learning outcomes for the UTS Master of Genetic Counselling, providing us with clear guidance from key stakeholders embedded within the profession as to what they believe graduates should 'look like' and what they should be able to do. The themes were used to guide early curriculum development activities across the coursework, research and clinical-placement domains.

As educators, we have a responsibility to assist students to work with and embrace uncertainty, ambiguity and complexity. Reflective-practice supervision fosters resilience and contributes to the development of coping skills and a sense of professional belonging and identity (Beddoe and Davys, 2016). Weekly small-group reflective-practice supervision has been embedded across the entire program, providing students with a strong foundation from which to enhance the development of resilient and autonomous practitioners with a well-developed professional identity.

We acknowledge that we have not yet included students in the development of this new Master of Genetic Counselling program. However, adoption of a co-design approach to the development of the program provides us with a unique opportunity to engage, from the beginning, with the incoming students as partners in the learning and teaching journey.

Our work to date is underpinned by core values of respect, openness and a desire to work collaboratively – in partnership with our colleagues in the profession and with others – to develop a program that is responsive to the rapid and disruptive changes occurring in genetic and genomic healthcare. These core values provide a strong foundation for the whole-of-course approach to involving students as active partners in the continuing development and delivery of the UTS Master of Genetic Counselling.

The extent to which students can actively shape who they are becoming has been examined by Kelly Matthews, who is a leader in 'students as partners' work in Australia (Matthews *et al.*, 2018). She challenged us to explore this with the students over time, both while they are studying and as they enter the workforce. We believe the students entering our program are likely to be better able to imagine and understand the multiple futures into which they will emerge as graduates, for they are not conditioned to the traditional models of genetic-counselling delivery. Our inaugural students began their program in February 2019 with a co-design 'making' workshop and a client journey-mapping exercise (similar to the activities undertaken by the CAC), facilitating a culture of mutual inquiry and learning 'with' each other and academics from day one. As with the artefacts created by the CAC, the recordings, notes and photographs will be used by staff and students to underpin and inform our work together.

Closing thoughts and future work

Routine use of genetic and genomic technology is rapidly being integrated into healthcare, resulting in changes in the ways in which we conceptualise health and wellbeing. Uncertainty and anxiety about the future are common themes emerging in the preparatory work,

Case Studies

reflecting broader current concerns within the profession about the role of genetic counsellors in the era of precision medicine. Feelings of uncertainty and anxiety are normal responses to rapid change, such as the profession is now experiencing, as are feelings of excitement and hope at the possibilities that lie ahead. Genetic counsellors are well placed to lead change, facilitating new ways of working with complex information and taking up new roles, while maintaining the core counselling and communication skills that have always been central to the profession (Austin, 2016; Bamshad, Magoulas and Dent, 2018). In this environment, positioning the education of a new generation of genetic counsellors within an institutional and course-level framework that encourages co-design, partnership and future thinking provides an ideal opportunity to contribute to change leadership.

The high level of engagement in the co-design process, from within the genetic counselling profession and from other colleagues in the field, suggests broad support for and interest in the education of future genetic counsellors in Australasia. Engaging the profession as partners early in the design process is helping to foster a sense of ownership and commitment to educating the next generation of genetic counsellors. We look forward to extending this work to include the students, engaging them as partners in learning and teaching and facilitating collaborative, respectful, open relationships in the continuing co-design of this program.

Those of us tasked with the responsibility of facilitating the education of new generations of genetic counsellors have an exciting and daunting opportunity to educate future change leaders. Working with students as partners in the co-design of a curriculum that is reflexive and able to adapt to and lead change is one way the program at University of Technology Sydney can contribute.

Acknowledgements

We wish to thank the many people who participated in the consultation and the members of the CAC for their insight and support. We wish to thank A/Prof Clara Gaff for her encouragement and comments on an early draft of this paper.

Reference list

Abacan, M., Alsubaie, L., Barlow-Stewart, K., Caanen, B., Cordier, C., Courtney, E., Davoine, E., Edwards, J., Elackatt, N., Gardiner, K., Guan, Y., Huang, L., Ingvaldstad Malmgren, C., Kejriwal, S., Kim, S., Lambert, D., Lantigua-Cruz, P., Lee, J., Lodahl, M., Lunde, A., Macaulay, S., Macciocca, I., Margarit, S., Middleton, A., Moldovan, R., Ngeow, J., Obregon-Tito, J., Ormond, K., Paneque, M., Powell, K., Sanghavi, K., Scotcher, D., Scott, J., Serra Juhé, C., Shkedi-Rafid, S., Wessels, T., Yoon, S. and Wicklund, C. (2018) 'The global state of the genetic counseling profession.' *European Journal of Human Genetics*, 27, 183-197. Available at: <https://doi.org/10.1038/s41431-018-0252-x> (Accessed: 6 February 2019).

Austin, J. (2016) '2020 Vision: Genetic Counselors as Acknowledged Leaders in Integrating Genetics and Genomics into Healthcare.' *Journal of Genetic Counseling*, 25(1), 1-5. Available at: <https://link.springer.com/content/pdf/10.1007%2Fs10897-015-9913-x.pdf> (Accessed: 13 March 2018).

Case Studies

- Bamshad, M.J., Magoulas, P.L. and Dent, K.M. (2018) 'Genetic counselors on the frontline of precision health.' *American Journal of Medical Genetics*, 178C, 5-9. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1002/ajmg.c.31610> (Accessed: 21 April 2018).
- Barlow-Stewart K., Dunlop K., Fleischer R., Shalhoub, C. and Williams, R. (2015) *The NSW Genetic Counseling 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*. Retrieved from https://www.saxinstitute.org.au/wp-content/uploads/The-NSW-Genetic-Counselling-Workforce_June2016.pdf (Accessed: 6 February 2019).
- Bate, P. and Robert, G. (2006) 'Experience-based design: from redesigning the system around the patient to co-designing services with the patient.' *Quality & Safety in Health Care*, 15, 307-310. Available at: <https://qualitysafety.bmj.com/content/15/5/307> (Accessed: 16 April 2018).
- Beddoe, L. and Davys, A. (2016) *Challenges in Professional Supervision: Current Themes and Models for Practice*. London: Jessica Kingsley Publishers. ISBN-10: 1849054657
- Bjögvinsson, E., Ehn, P. and Hillgren, P. (2012) 'Design Things and Design Thinking: Contemporary Participatory Design Challenges.' *Design Issues*, 28(3), 101-116. Available at: https://www.mitpressjournals.org/doi/abs/10.1162/DESI_a_00165 (Accessed: 16 April 2018).
- Braun, V. and Clarke, V. (2008) 'Using thematic analysis in psychology.' *Qualitative Research in Psychology*, 3(20), 77-101. Available at: <https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa> (Accessed: 16 April 2018).
- Foster, N.F. and Mulhern, C. (2015) *Making a Place for Curricular Transformation at the University of Technology Sydney*. Available at: <https://doi.org/10.18665/sr.241927> (Accessed: 18 May 2018).
- Heimler, A. (1997) 'An oral history of the National Society of Genetic Counselors.' *Journal of Genetic Counseling*, 6(3), 315-336. Available at: <https://onlinelibrary.wiley.com/doi/10.1023/A%3A1025680306348> (Accessed: 16 April 2018).
- Hoskovec, J.M., Bennett, R., Carey, M.E., DaVanzo, J.E., Dougherty, M., Hahn, S.E., Wicklund, C.A. (2017) 'Projecting the supply and demand for certified genetic counselors: A workforce study.' *Journal of Genetic Counseling*, 27(1), 16-20. Available at: <https://doi.org/10.1007/s10897-017-0158-8> (Accessed: 16 April 2018).
- Human Genetics Society of Australasia, (2017) *Accreditation of Masters in Genetic Counseling Programs*. Available at: www.hgsa.org.au/documents/item/5 (Accessed: 16 April 2018).
- Kowal, E., Gallacher, L., Macciocca, I. and Sahhar, M. (2015) 'Genetic Counseling for Indigenous Australians: an Exploratory Study from the Perspective of Genetic Health Professionals.' *Journal of Genetic Counseling*, 24(4), 597-607. Available at: <https://onlinelibrary.wiley.com/doi/10.1007/s10897-014-9782-8> (Accessed: 16 April 2018).

Case Studies

Kowal, E., Easteal, S. and Gooda, M. (2016) 'Indigenous Genomics.' *Australian Science*, 18, 18-20. Available at: <http://www.australasianscience.com.au/article/issue-september-2016/indigenous-genomics.html> (Accessed: 16 April 2018).

Marks, J.H. (2004) 'The importance of genetic counselling.' *American Journal of Human Genetics*, 74(3), 395-396. Available at: [https://www.cell.com/ajhg/fulltext/S0002-9297\(07\)61856-4](https://www.cell.com/ajhg/fulltext/S0002-9297(07)61856-4) (Accessed: 16 April 2018).

Matthews, K., Dwyer, A., Hine, L. and Turner, J. (2018) 'Conceptions of students as partners.' *Higher Education*, 76(6), 956-971. Available at: <https://link.springer.com/article/10.1007%2Fs10734-018-0257-y> (Accessed: 8 January 2019).

Nowak, K.J., Bauskis, A., Dawkins, H. and Baynam, G. (2018) 'Incidental inequity.' *European Journal of Human Genetics*. 26, 616-617. Available at: <https://doi.org/10.1038/s41431-018-0101-y> (Accessed: 8 January 2019).

NSW Ministry of Health, (2017) *The Changing Landscape of the Genetic Counseling Workforce, Final Report*. Available at: <http://www.health.nsw.gov.au/workforce/alliedhealth/Documents/gsw-final-report.pdf> (Accessed: 6 February 2019).

Patch, C. and Middleton, A. (2018) 'Genetic counseling in the era of genomic medicine.' *British Medical Bulletin*, 126(1), 27-36. Available at: <https://academic.oup.com/bmb/article/126/1/27/4958384> (Accessed: 8 January 2019).

Sanders, E. and Stappers, P. (2008) 'Co-creation and the new landscapes of design.' *Co-Design*, 4(1) 5-18. Available at: <https://www.tandfonline.com/doi/abs/10.1080/15710880701875068> (Accessed: 16 April 2018).

Sanders, E. and Stappers, P. (2013) *The Convivial Toolbox: Generative Research for the Front End of Design*. Amsterdam: BIS Publishers. ISBN-10: 9063692846

Sewell, A., Cody, T., Weir, K. and Hansen, S. (2017) 'Innovations at the boundary: an exploratory case study of a New Zealand school-university partnership in initial teacher education.' *Asia-Pacific Journal of Teacher Education*, 46(4), 321-339. Available at: <https://www.tandfonline.com/doi/abs/10.1080/1359866X.2017.1402294> (Accessed: 16 April 2018).

Slade, I., Riddell, D., Turnbull, C., Hanson, H. and Rahman, N. (2015) 'Development of cancer genetic services in the UK: A national consultation.' *Genome Medicine*, 7(18). Available at: <https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-015-0128-4> (Accessed: 13 April 2018).

Stern, A.M. (2009) 'A quiet revolution: The birth of the genetic counselor at Sarah Lawrence College, 1969.' *Journal of Genetic Counseling*, 18(1), 1-11. Available at: <https://onlinelibrary.wiley.com/doi/10.1007/s10897-008-9186-8> (Accessed: 13 April 2018).