

Use of codesign in primary care research: real-life examples

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THE PARALLELS BETWEEN SHARED DECISION MAKING AND RESEARCH CODESIGN IN PRIMARY CARE

Shared decision making is central to patient-centred care¹ and an integral component of evidence-based practice. In shared decision making, the patient and the health professional collaborate and jointly decide about the patient's healthcare, be this further investigations to determine a diagnosis, interventions to try, both pharmaceutical and non-pharmaceutical, or overall an management plan.

The steps involved in shared decision making include communicating that a decision needs to be made; explaining the options and the benefits and harms (including the quantitative evidence) of each; eliciting, understanding and discussing the patient's experiences, expectations, preferences, values and circumstances; and incorporating these into the decision-making process.² Patients who are thus empowered to be actively involved in their own health management are more likely to make sustained behavioural changes leading to improved health outcomes.³

In line with the growing move towards shared decision making, there is a shift towards both the end-users of research and the researchers being actively involved in the codesign of a study.⁴ These key stakeholders may be patients, healthcare providers, community members or people involved in making policy. The research is carried out with and by local people, rather than on them. Just as shared decision making increases the likelihood that a chosen management plan will be acted on, research codesign improves that chances of study findings leading to the indicated changes in practice. When stakeholders have been involved in the cocreation of an intervention, its uptake will increase by those implementing it seeing its value, the emergence of grassroot champions, and a sense of stakeholder ownership and advocacy for the change.

End-users of research can be involved at any stage of its development, from assessing the need, designing an intervention, to implementing and evaluating it. This paper gives examples from my own work of codesign at these various stages and with different types of populations and end-users.

COLLECTIVE ENQUIRY BY THE PACIFIC COMMUNITY

In 2016, a New Zealand general practitioner and a patient attended a Patient and Clinician Engagement⁵ conference in America together, outlined in a short paper 'Traveling companions'.⁶ On their return, a Pacific People's Health Advisory Group and subsequently a Pacific Practice-Based Research Network were established, with the aim to reduce health inequalities experienced by Pacific people in South Auckland. A Collective was formed comprising these two groups plus university academics who provided them with training in research principles, including how to ask relevant answerable questions, and in Pacific research methodologies.⁷ Their collective inquiry generated prioritised research questions, of which the top two are 'How can we make it easier for our Pacific people to access and take medication to prevent gout?' and 'What sustained health promotion can we provide the South Auckland Pacific community about the relationship of rheumatic fever to sore throat, scabies, skin infections and home environment risk factors?', these being major health issues for this community. As well as literature reviews and prevalence studies, the proposals to answer both of these include using the Collective, Pacific patients and other key stakeholders to brainstorm and workshop a novel intervention tailored and targeted for the Pacific community, and then implement and evaluate this intervention. Graduate students have started on this work, and research proposals have been submitted or are in preparation.



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Underpinning this work is the Samoan research framework *fa'afaletui*, meaning 'ways of weaving together deliberations of different groups'.

Derived from the Pacific philosophy of connectiveness and a holistic worldview, *fa'afaletui* requires collective inquiry, whereby different perspectives: 'from the top of the mountain' (gives an overview of the landscape), 'from the top of the tree' (brings a middle-distance lens to the issue) and 'from the man in the canoe fishing' (closest to the school of fish and most affected by the problem) are woven together to create new knowledge.⁸ This lends itself to codesign and a participatory research approach using mixed methodologies.⁹

EXAMPLES OF CODESIGN WITH END-USERS

Codesign is not limited to local communities but can be used in national and global research. In an international study to determine research gaps addressing primary care organisation and financing in low-income and middle-income countries, a panel of clinicians and academics from 50 countries generated research questions. Responses were collated, coded and synthesised down to lists of questions that were then prioritised using a Delphi technique,¹⁰ and then checked against the literature to ensure they were truly gaps in knowledge.¹¹ Volunteer panellists then developed concept notes proposing how the top seven questions might be answered in their country.^{12 13} The voice of, and the coproduction of evidence by, healthcare providers and clinical academics is of great value if initiatives recommended by research are to have traction on the ground.

A further example of using the Delphi technique is a study to produce common rural-specific learning outcomes for medical students involved in community-based regional-rural placements through the University of Auckland.¹⁴ In this case, rather than these outcomes being prescribed by the academic general practice department which was directing the programme, the end-users (relevant clinical teachers and supervisors) developed and reached consensus on the learning outcomes to which they would then teach.

In New Zealand, a number of different Case-finding and Help Assessment Tool (CHAT) mental health and lifestyle electronic screeners have been modified and tailored using codesign, assessing their feasibility and acceptability with users and making appropriate changes to suit their context. Originally based on a paper tool,¹⁵ and then the electronic version eCHAT,^{16 17} there have been adaptations for various populations including VeCHAT for community-based veterans¹⁸ and a maternity screen MatCHAT.¹⁹

CODESIGN AND A BICULTURAL APPROACH

Another version, YouthCHAT, which is a self-administered digital tool screening young people for mental health concerns and risky health behaviours,²⁰ has undergone

many iterations to tailor it to specific contexts and populations, in response to cycles of feedback in acceptability and feasibility trials both with young people and with health providers.²¹

An iterative process of implementation, modification and evaluation was used to roll the tool out in Northland, New Zealand.²² This is a region with a high proportion of socially disadvantaged indigenous Māori. The YouthCHAT research team at the University of Auckland partnered with local Māori collaborators in Northland. Participatory research using codesign and Māori principles (*kaupapa Māori*) were seen to overlap, and the braided river (*he awa whiria*) metaphor was used to describe combining the strengths of these two distinct worldviews into a workable whole.²³

This study was informed by Normalisation Process Theory, which addresses the implementation and evaluation of complex interventions.²⁴ Barriers to implementing YouthCHAT were identified by users, and adaptations were made to the tool itself (such as full Māori translation into the local dialect, and more youth-friendly features suggested by adolescent users), the way it was used, and its integration into the health system. The tool was adapted for use by mobile nurses taking services out to young Māori in remote rural areas.²⁵ When New Zealand went into lockdown to eliminate COVID-19 spread in 2020, a remote functionality was programmed, so that a nurse could text or email a link for YouthCHAT to be completed on a mobile phone or other device. The nurse could access the electronic YouthCHAT report immediately, and then conduct a video or phone consultation with the young person. Tailoring the tool and its delivery for this vulnerable socioeconomically derived population is a move towards reducing their health inequities.²⁵

Once clinical staff realised that the primary goal of the project was to help them in their work and not just to collect their data and discovered that YouthCHAT saved them time and made their job easier, uptake escalated, as documented in our paper 'Implementing YouthCHAT – evaluation and development of an implementation framework', currently under peer review. Champions emerged and use spread to other clinics.

CONCLUSION

Ideally primary care is person-centred, relationship-based care, in which provider and patient share the decisions about the course of action and management plan for the patient's presenting conditions. The choice is made together with the patient, not solely by the provider. Congruently, a paradigm shift is occurring in primary care research, conducted with and for end-users, and not on them.²⁶ Codesign can be used to develop the research question, design the study, implement it and then disseminate the findings.

Randomised clinical trials control or adjust for different contexts and choose a population as homogeneous as possible, excluding atypical settings and outliers.²⁶ In

contrast, implementation studies embrace heterogeneity, with feedback processes leading to ongoing adaptation to changing contexts. An implementation framework then can be developed for context-sensitive scale-up that is equitable for different populations.²⁷ This type of research needs the input of end-users to ensure the uptake and effectiveness of an intervention. In the complex and messy real-life world of primary care, code-sign is paramount.

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