

Researching in the community: the value and contribution of nurses to community based or primary health care research

Christine Barthow¹, Bernadette Jones¹, Lindsay Macdonald², Sue Vernall^{3,4}, Peter Gallagher⁵ and Eileen McKinlay⁶

¹Department of Medicine, Wellington Asthma Research Group, University of Otago, Wellington, New Zealand

²Department of Primary Health Care and General Practice, Applied Research on Communication in Health Group, University of Otago, Wellington, New Zealand

³Department of Primary Health Care and General Practice, University of Otago, Wellington, New Zealand

⁴Department of Public Health and General Practice, University of Otago, Christchurch, New Zealand

⁵Department of General Practice, Medical Education Advisor, University of Otago, Wellington, New Zealand

⁶Department of Primary Health Care and General Practice, University of Otago, Wellington Box 7343, Wellington South, New Zealand

Aim: To describe the role, contribution and value of research nurses in New Zealand community-based or primary health care research. **Background:** Research nurses are increasingly recognised as having a key role in undertaking successful research in hospitals and clinical trial units however only limited work has been undertaken to examine their role in community-based research. Undertaking health research in the community has unique challenges particularly in relation to research design and recruitment and retention of participants. **Methods:** We describe four community-based research projects involving research nurses, each with particular recruitment, retention and logistical problems. Vignettes are used to illustrate the role, contribution and value of research nurses in a diverse range of community research projects. **Findings:** The knowledge and skills used by research nurses in these projects included familiarity with communities, cultural competence, health care systems and practice philosophies and in particular with vulnerable populations. Their research actions and activities include competence with a broad range of research methodologies, organisational efficiency, family-centred approach, along with advocacy and flexibility. These are underpinned by nursing knowledge and clinical expertise contributing to an ability to work autonomously. These four projects demonstrate that research nurses in community-based research possess specific attributes which facilitate successful study development, implementation and outcome.

Key words: general practice research; primary health care research; research nurse; role; skills

Received 17 October 2013; accepted 30 December 2013; first published online 18 March 2014

Introduction

Community-based health research differs from research based in institutional settings such as

hospitals or clinical trials units. Fieldwork is undertaken in a variety of settings often using mixed methodologies including specific indigenous methodologies (Cram, 2001) with the research itself producing outcomes of more specific relevance to community and primary health care (Tapp and Dulin, 2010). The success of community-based research relies on pragmatic yet ethical study design

Correspondence to: Eileen McKinlay, RN MA (App): Senior Lecturer, Department of Primary Health Care and General Practice, University of Otago Wellington, Box 7343, Wellington South, New Zealand. Email: eileen.mckinlay@otago.ac.nz

© Cambridge University Press 2014

and skilled fieldwork including successfully recruiting from target populations (Velott *et al.*, 2008; Goodyear-Smith *et al.*, 2009). These factors make community-based research more challenging than research in hospitals or similar settings where access to participants is relatively straightforward and data collection occurs in controlled environments (Bell-Syer and Klaber Moffett, 2000; Sellors *et al.*, 2002; Foy, 2003).

Nurses who make clinical research their area of specialist practice are at the same time both health professionals and researchers (Mueller and Mamo, 2000; Becze, 2010; New Zealand Nurses Organisation, 2010). In hospital or similar settings they may specialise in one clinical area (eg, women's health) and work on sequential research projects, or in using one methodology [eg, randomised control trials (RCT)] and covering a number of clinical areas (Mais, 2006; Rickard *et al.*, 2006; Nagel *et al.*, 2010). Nurses with these backgrounds are usually members of interdisciplinary research teams. They develop and contribute advanced skills in research design and clinical techniques particular to research projects, frequently adopting the role as project manager (Bell, 2009).

There is strong evidence supporting the effectiveness of research nurses in hospital and similar settings (Rabins *et al.*, 2000; Kenkre and Chatfield, 2004; Stephens-Lloyd, 2004; Best, 2005; Mori *et al.*, 2007; Bell, 2009) but little is known about the role of research nurses in community-based research (Miller *et al.*, 2003; Rendell *et al.*, 2007; Velott *et al.*, 2008).

This paper aims to describe the role, contribution and value of research nurses in community-based research. It outlines four New Zealand (NZ) Health and Disability Ethics Committee approved community-based projects involving the contribution of research nurses.

A brief overview of the research area and the particular study is provided. This is followed by a description of the role of the research nurse and strategies used to meet a range of challenges, each illustrated with a vignette.

Community-based research involving indigenous peoples (Māori)

Since the 18th century, NZ-based research has historically been conducted 'on' rather than 'with'

Māori (the indigenous people of NZ). This involves a positivist or western approach, which imposes its own set of values and conceptualisations that differ from Indigenous ways of collecting and creating knowledge (Bishop and Glynn, 1999; Smith, 1999). This approach has often resulted in findings being framed using a 'deficit' model, and has left Māori with a deep distrust of, and unwillingness to participate in research (Bishop, 1998). Researching in Māori communities has often been associated with suspicion due to disrespect for cultural protocols; incorrect interpretation of results and lack of dissemination of results to the communities involved (Cunningham, 2000).

The concept of cultural safety, originating in NZ within nursing in the 1980s, was developed by Irihapiti Ramsden as a direct response to addressing health inequalities for Māori (Ramsden, 1989). Cultural safety recognises the bi-cultural nature of clinical practice for NZ health professionals and acknowledges the validity of Māori beliefs and values in the healthcare context alongside the bio-medical model (DeSouza, 2008; Woods, 2010; Doutrich *et al.*, 2012).

In the 1990s Kaupapa Māori Research (KMR) emerged in the health research arena as a contemporary discourse, directly arising from Māori lived realities and experiences (Smith, 1999). The principles of KMR relate to issues such as ownership of knowledge, culture and the desire for self-determination in all phases of the research process, including recruitment of participants, ensuring that:

"...everyone who is connected with the research project is enriched, empowered, enlightened and glad to have been part of it".

(Mead, 2003: 318).

Project: The Pukapuka Hauora Asthma Study

The Pukapuka Hauora project employed a longitudinal, qualitative design to explore Māori parents' perspectives of managing their children with asthma in Aotearoa NZ. The project aimed to provide an in-depth understanding of issues currently facing Māori parents including the challenges, successes, and beliefs about asthma management held by the families and the wider Māori community.

A KMR study was developed, conducted and led by a Māori research nurse (B.J.) over a three-

Primary Health Care Research & Development 2015; **16**: 224–234

Box 1 'Whānau Tuatahi' Framework illustrating key Māori concepts for community-based research (Jones et al., 2010)

Concept	Research nurses role
Whakawhirinaki (<i>trust</i>)	A nurse-led approach to a Māori health provider established a connection with the community and demonstrated that the research team was both trustworthy and genuinely interested in meaningful consultation. This face-to-face approach involved learning about the community before explaining the purpose of the study (Walker et al., 2006). Permission to conduct the research was then sought and specific protocols and issues such as preferred methods for recruiting were incorporated into the design of the project
Whakawhanaungatanga (<i>building relationships</i>)	Developing and maintaining on-going involvement with the community was a key focus for the nurse. This was dependent on a mutually respected relationship with the Māori community nurses who were the 'culturally-based' interface between the research team and the community. This relationship provided an effective way of introducing the research nurse and at the same time providing support for potential participants (Boulton et al., 2009). Before the project began the research nurse accompanied nurses from a Māori Health Provider on home visits in order to learn local customs, protocols and culturally acceptable approaches to recruitment
Whakamana (<i>empowerment</i>)	The research nurse, with expertise in patient-centred care, was well placed to support families in health-related decision-making including validating successful asthma management and providing advice when needed
Ngāwari (<i>flexibility</i>)	Flexibility in this context allowed participants to define their own terms about where, when and with whom they would conduct the interviews. The research nurse, familiar with community nursing practices, respected various cultural practices and provided times and venues that would suit the busy lives of participants
Utu (<i>reciprocity</i>)	Many participants wanted to discuss issues that were impacting on them and their families before addressing the research agenda. A nursing background proved invaluable to contextualise parents' concerns; provide informed responses to their health-related questions; and arrange referrals to other health professionals as required
Hurihuringa (<i>reflexivity</i>)	It was vital to ensure that the involvement of researchers in the community was viewed as positive and that the resulting analysis and interpretations were an accurate reflection of a Māori world view. Nurses have a professional responsibility to maintain reflective practice which aligns well with this need. The research nurse was uniquely suited to feedback interpretations of the preceding interview to the participants at follow-up visits to ensure correct understanding and emphasis.

year period during which, and in collaboration with a Māori Health Provider, 32 families were recruited (Jones et al., 2013). To capture seasonal variations, four semi-structured interviews were conducted over a 12-month period. Additional data collection used a range of tools such as 'Photovoice' (Catalani and Minkler, 2010), lung drawings and a structured health questionnaire which augmented these interviews and provided a holistic picture of the asthma management. Interpretive phenomenological analysis (Larkin et al., 2006), underpinned by KMR, was used as the method of analysing the data (Jones et al., 2010).

Challenges and strategies

While a number of Māori researchers have described principles underpinning KMR methodologies

Primary Health Care Research & Development 2015; **16**: 224–234

(Smith, 1999; Cram et al., 2003), the implementation of these principles has not been well documented. The Pukapuka Hauora project focused on the practical application of these principles and in particular the role of a Māori research nurse and in doing so resulted in the development of a Whānau Tuatahi (Family Centred) framework to guide other researchers undertaking research with Māori. The core concepts (Box 1) of: Whakawhirinaki (trust); Whakawhanaungatanga (building relationships); Whakamana (empowerment); Ngāwari (flexibility); Utu (reciprocity); and Hurihuringa (reflexivity), highlighted the particular value of a Māori research nurse to the success of the project (Jones et al., 2010)

In addition, Māori communities consist of a wide diversity of Māori peoples, each with distinct

protocols and procedures that may vary from one Iwi (tribe) to another. The research nurse needed to have an understanding of this multiplicity and be able to respond to the diversity of each participant (see Vignette one). This enabled on-going trust between participants, whānau and research nurses. Another critical element of maintaining *whaka-whirinaki* (trust) and credibility in the eyes of the participant was to be able to demonstrate a clinical understanding of the disease process, medication uses and side effects, along with health system processes in response to matters raised by participants. Furthermore, knowledge exchange (including clinical advice) was a way of embodying the principle of *Utu* (reciprocity) and was an expectation of the Māori community. The complex nature of researching chronic illness such as asthma also requires the expertise of the research nurse to use clinical judgement while in the field to assess and negotiate appropriate referrals within a somewhat difficult to navigate health system. (McEldowney and Connor, 2011). This Māori-centred approach was welcomed and endorsed by families in the Māori community as evidenced by participant feedback and the hundred per cent retention rate for the duration of the study. (Jones *et al.*, 2010).

Community-based research involving young children

The involvement of young children in community-based longitudinal studies poses unique challenges which endure throughout the research project. Research with this vulnerable group must comply with very specific ethical and legal requirements relating to the capacity of children to make decisions and the associated roles and responsibilities of their parents or guardians (Diekema, 2006; Powell and Smith, 2006; Knox and Burkhart, 2007; Christian *et al.*, 2010). The process of recruitment and retention in a longitudinal study is made more complex by the evolving capacity of the child to make decisions [Children's Hospitals Australasia and the Paediatric Society of Aotearoa New Zealand (CHAPSANZ), 2010]. As a child matures, there are increasingly complex and competing demands: the child to express their individual rights, the parents' desire to contribute to research, the researchers' need to keep the child's best interest as a primary concern (Ministry of Health, 1998; CHAPSANZ, 2010). Parents and researchers must also be aware of possible power imbalances and coercion (Edwards and McNamee, 2005; Powell and Smith, 2006;

Vignette One

During my second interview, Mrs Maraea raised concerns about her six-year-old son Tama often missing school days due to his asthma. He was falling behind with his school work and requiring more frequent visits to the after hours or emergency doctor. We had discussed the preventative and acute management of his asthma, and it was clear that Tama's asthma was generally well-controlled at home, however from the history it became evident to me that there was a pattern of his symptoms worsening during school semesters. Our interviews had included discussion regarding medications and asthma triggers such as the environment, pollens, dust and mould, etc., and Mrs Maraea had an excellent understanding of these. Discussion about specific conditions in the school revealed Tama did not have easy access to his inhalers (school policy kept all medications in the main office) and he was too shy to ask to use them due to teasing by some of his peers.

With agreement from Mrs Maraea I arranged a referral to a local Māori Asthma Service to deliver a school-based, asthma education package including school staff, Mrs Maraea, Tama and his classmates. Six months later I was met by an excited mother saying that Tama had not missed any school days and his asthma had been well controlled over that period. She explained how the nurse had provided asthma training to Tama's teacher as well as his whole class, so they all supported Tama in recognising any early signs of asthma, and the school also allowed Tama to keep his medication in the class room. A three-month follow-up interview confirmed that Tama had remained well with no further school days missed due to asthma.

Singh, 2010). All these tensions must be taken into account whilst at the same time seeking to fulfil the requirements of the research project.

Project: The Probiotic Study

A RCT of effects of probiotics on development of atopy and allergic disease in early childhood (The Probiotic Study) was a community-based longitudinal double-blind placebo RCT involving children less than seven years old, which tested an intervention to prevent the development of allergic disease. The intervention was either oral probiotic or placebo given to the mother during pregnancy and lactation and also given to the child for the first two years of life (Wickens *et al.*, 2008; 2012; 2013).

Research nurses (B.J., C.B.) have been involved over a seven year study period. They initially recruited the mothers of index children (before birth) and made frequent research visits over the first two years of the child's life and then single follow-up study visits at four and six years of age.

While the initial study intervention (taking probiotics/placebo) had the potential to benefit the child, the low risk, follow-up procedures included in the two, four and six year visits to assess the study outcomes had no direct benefit for the majority of the children. Furthermore, some procedures (eg, skin prick testing and blood tests) while low risk, occasionally cause discomfort and children are often apprehensive before these begin.

Challenges and strategies

Central to the success of this research was the design and enactment of legal, ethical and child-friendly protocols and the processes for the provision of information, gaining consent and collecting data.

In this study the research nurses utilised a broad range of knowledge and skills to provide information for parents in addition to, gaining and later regaining informed consent from parents (see Vignette two). Throughout the study it was also important to acknowledge the evolving capacity of the young child. By the four- and six-year follow-up visits this increasingly involved gaining assent from the child at each stage of the research visit.

Participant retention over the seven years has been high, with questionnaire data collected at age 6 for 89.03% of the infants who were eligible at birth. (Wickens *et al.*, 2013) One factor contributing to this commitment was the ongoing relationship with the key research nurses in the study

Primary Health Care Research & Development 2015; **16**: 224–234

enabling parents to deepen their trust and commitment to the research process.

Community-based research involving highly sensitive issues (mental health)

Society's negative perceptions and stigma about mental illness create significant challenges when establishing a protocol for community-based mental health research. People with mental illness may not recognise or admit they are unwell, and may continue to deny this once diagnosed, let alone agree to enter a research study of which their mental state is the focus (Corrigan, 2004; Woodall *et al.*, 2011). They may also be concerned that involvement in a study will cause them distress, to relapse or that participation may impede their recovery (Woodall *et al.*, 2010).

Access to potential participants through general practice settings in any community-based research is a two-step process. The first step is to recruit the general practice through interested GPs and the second step is to work with GPs to identify and approach potential participants (Bower, 2009). As well as general concerns about lack of time and workload pressures, some GPs specifically decline to recruit participants to mental health research due to lack of perceived relevance of the research to their clinical practice, or concerns for their patients as participants (Hummers-Pradier *et al.*, 2008).

Project: The Antidepressant Cessation Trial (ACT)

The ACT is a study based in three geographical regions. The study is a triple blinded RCT in which participants recruited by GPs entered one of two arms; either continuing their medication or tapering to placebo.

After an initial approach to the general practice by the principal investigator, research nurses (including S.V.) have been involved in the recruitment of GPs and study participants as well as the refinement and implementation of study procedures. The research nurses used general practice electronic practice management systems to identify potential participants whose suitability was assessed by each GP before being sent study invitation letters from their GP. Following a favourable response the respondents were then screened for eligibility by the

Vignette Two

During a phone call explaining the six year follow-up study, I quickly became aware that the family faced significant challenges with their daughter, Debbie. She was finding primary school difficult and the parents were stressed. I focused on their concerns, acknowledging their challenges. Then I explained that the visit was long and complex. It involved pre-collection of a faecal sample, questionnaires, spirometry, exhaled nitric oxide (eNO) measures, allergy skin prick testing, swabs, eczema skin checks and blood tests. For some families offering partial study involvement was an important option.

I thought they may decline further involvement. However, the parents were keen to continue and a collaborative plan was developed to meet Debbie's needs. The visit was planned for Debbie's best time of day, in the family home where they felt most secure, and with a specific support person. We prioritised specific study measures and not others. The skin prick testing procedure required the parents to be well prepared and together using appropriate language we sought Debbie's assent. We first demonstrated the measures on an adult. We aimed just to try the eNO and spirometry, and the parents were made aware that these measures are difficult for most six year olds and not always successful. This approach prepared the parents, encouraged them to affirm effort, and not to pressurise Debbie.

The visit was very successful with Debbie saying she enjoyed the visits. She attempted each procedure except for the skin prick testing and this decision was respected.

Feedback from the parents revealed Debbie was extremely proud of herself, and enjoyed giving 'news' to her school class the following day. She showed her certificate/sticker chart from the visit and demonstrated the breathing techniques she learned when doing spirometry.

research nurses. Once in the study, research nurses interviewed participants over an 18-month period. Participants were seen four times during the first month, and thereafter at three monthly intervals with a mental health assessment being completed on each occasion.

Challenges and strategies

Mental health studies are difficult to undertake in any setting (Corrigan, 2000). It is challenging to recruit when both GPs and potential participants for documented reasons are disinclined to take part (Zullino *et al.*, 2003; Furimsky *et al.*, 2008). In this study research nurses were aware of reluctance by both parties and worked to form effective, strong and trusting relationships with both parties (see vignette three).

Research nurses had a key role in communicating clearly about the study. This included giving information about participation, risks and benefits and ensuring questions and concerns about the study were addressed. Similarly they made sure the ethical requirements for informed consent were met and revisited as the study progressed.

Research nurses had clinical and research responsibilities to the referring GP, the participant

and the research team. Research nurses were endorsed to use their own clinical judgement over and above standard psychiatric rating scales if they had clinical concerns. This included an assessment of each participant's mental health status and consultation with clinical members of the research team if indicated. In response they made autonomous clinical decisions and when necessary actioned further referrals back to GP.

Data collection of naturally occurring interactions between individuals and health professionals

Consultations between a patient and a health professional are generally considered private or privileged conversations with content potentially delicate, sensitive or distressing. Therefore asking patients to have their consultations recorded for viewing and study by researchers at a later date is a significant request. As well, health professionals have concerns that their professional attitudes, actions and clinical judgement may be opened up to unwelcome scrutiny. It is an undertaking which requires careful planning, rigorous study procedures,

Primary Health Care Research & Development 2015; **16**: 224–234

Vignette Three

I saw Jane Brown at a routine study assessment where standard psychiatric scales were administered. While she did not meet criteria for depression she had some symptoms of depression including low mood, however I realised this may be influenced by a persisting flu-like illness for the past two weeks and encouraged her to keep in close touch. Three days later she phoned me after-hours on the 24-hour study number with additional concerns.

In talking to her about how she was feeling I assessed that her mood had deteriorated rapidly to the extent that she wanted to stay in bed all day, was tearful, had no appetite or energy, but had no suicidal thoughts. I advised Jane to see her GP that day and checked she knew how to do this. Jane went on to visit the GP. The GP rang me and requested a 'code break' to reveal which study arm Jane was in. The code was broken by a GP independent to the research who then communicated directly with Jane's GP.

The GP re-prescribed the anti-depressant medication and also diagnosed a chest infection. An assessment using standard psychiatric scales confirmed my clinical assessment of moderately severe depression. As per study protocol Jane formally exited the study although continued to complete study requirements. When I saw Jane two weeks later, I was pleased to find her mood had improved and a further phone call a month later confirmed she was feeling well and undertaking all her social commitments.

and an ability to respond simply, clearly and honestly to participant questions (Rushmer *et al.*, 2011).

Project: Communication in General Practice

The aim of the Diabetes Tracking Study was to help researchers and primary health care teams better understand communication processes in chronic care conditions such as diabetes. It involved recruiting a number of newly diagnosed patients with diabetes and video-recording all their interactions with health professionals for a period of six months.

Research nurses have been instrumental in developing the methodology used, which evolved through a series of health communication studies conducted between 2003 and 2011 by the Applied Research on Communication in Health (ARCH) group (Dowell *et al.*, 2007; Dew *et al.*, 2010). The nurses (L.M., S.V.) were involved in study design, ethics application, recruitment and retention of participants (both health professionals and patients), video recording consultations, data management, analysis and dissemination of results (Dowell *et al.*, 2007).

Challenges and strategies

Successful recruitment to studies of this kind depends on the research nurse (L.M.) proactively attending to very real concerns that participants (both health professional and patient) might have (Rushmer *et al.*, 2011). These concerns include

worries about confidentiality, informed consent, anonymity, how the data will be used, disruption to normal work, and whether or not people will act normally when they are being video-recorded (see vignette four).

Preparation and teamwork was very important. Being involved in the project from the beginning allowed the research nurses to discuss what was practical, ethical and realistic in clinical settings. This sometimes led to refining the research procedures with some of the original ideas for data collection being adapted to the specific context.

Before starting the fieldwork the research nurse took time to establish effective relationships with health practitioners taking part, and became thoroughly confident with the recording equipment. This ensured the fieldwork went smoothly, unobtrusively and with minimal disruption to the everyday running of the medical practice. More importantly, the participants did not detect any nervousness or anxiety from the research nurse so were able to relax and the consultations proceeded in a typical manner.

The research nurse was the key person who assured participants about data confidentiality, respectful use of data and how the data was interpreted and reported. As such she was the link between participants, data and the research team.

A key feature of the methodology lay in giving participants maximum control over data collection. This meant that health professional participants

Primary Health Care Research & Development 2015; **16**: 224–234

Vignette Four

During one round of data collection I arrived at a general practice and greeted the receptionist. The receptionist recognised me and knew that I had arrived to do some recording. She waved me through to the GP; who had previously agreed to participate on that day. The GP glanced up from her desk, her shoulders sagged and she gave an imploring painful, half apologetic smile. 'Not a good day for it?' I asked, while lowering my bundles of recording equipment. She hesitated and I quickly suggested: 'Shall we try next week?' She readily agreed and the subsequent re-arranged recording went smoothly.

Sensing cues from participants, then responding swiftly and flexibly while maintaining a focus on achieving the goals of the research project, was important for this project and strategically for future projects.

chose a time for data collection that suited them best, and all participants (both health professionals and patients) were reminded that they could stop the recording at any stage without needing to give a reason. After each recording, participants were thanked and asked briefly if they felt comfortable about the process. 'Thanks very much. Was that ok? Are you happy for us to keep that recording?' Very often patients seemed almost surprised to be asked and replied 'Oh I forgot it [the camera] was there'.

Discussion

Research nurses played a central role in each of these four community-based research projects. They drew on a unique combination of professional knowledge, skills and attitudes to facilitate the success of the research. This combination included an understanding of the broad context, and complexity of health care and health care delivery in the community. In particular they used knowledge of health conditions, family well-being, psychological responses to health concerns and cultural context. This was combined with an understanding of the research process, methodological challenges, ethical frameworks and relevant professional legislation.

Like their hospital based research nurse colleagues, research nurses are well prepared to independently perform a broad range of research activities in community settings (Pick *et al.*, 2011). Key activities in these four projects involved the explanation of methodologically complicated studies; gaining participant consent; employing a range of clinical assessment tools and standardised research instruments, utilising advanced information and technology skills as well as undertaking data

management and analysis. In the conduct of these projects, the research nurses employed communication strategies to negotiate complex relationships. These skills enabled them to accommodate particular participant health needs especially those of indigenous peoples or those with sensitive health issues.

Research nurses should be involved in all aspects of a study including inception, design, testing, fieldwork, analysis and interpretation and dissemination of results. In addition, they are well placed to advocate and negotiate for participants to ensure that the research demands are reasonable (De Maeseneer *et al.*, 2003; Mold and Peterson, 2005). This commitment enables development of a robust study design aimed to offer reciprocity to the participant, increase knowledge and ultimately benefit individual health care or health care delivery.

The studies described in this paper demonstrate that research nurses are able to discern what is likely to facilitate successful recruitment as well as acceptable study procedures using a strong awareness of legislative and ethical principles, cultural safety and professional skills of communication (Loh *et al.*, 2002). This is a significant advantage when working with participants who are indigenous, vulnerable or who experience health disadvantages (Harris *et al.*, 2006; 2012). Representation of such participant groups is critical to robust research datasets but are often absent or underrepresented (Robson and Harris, 2007).

Some projects demonstrated community-based research nurses using the two-stage recruitment strategy. They initially worked with individual GPs to recruit general practices into a research study and then built up personal, trusted and on-going relationships in each practice (Goodyear-Smith *et al.*, 2009). A variety of complex computer programme/

Primary Health Care Research & Development 2015; 16: 224–234

software and audio/video recording technologies were used in these projects. For example, to identify potential participants from electronic data bases, to record interactions within consultations and to utilise appropriate technology for testing and measuring procedures.

In community-based research, field-work is usually isolated from the institutional or academic environment and/or the general practice team. To implement research procedures in participants' homes requires skill in making safety and risk assessments and the confidence to work remotely from the research team and associated clinicians (University of Otago, 2012). Research nurses draw on professional skills to ensure a safe working environment and to make flexible decisions about their own and the participant's safety (Williams *et al.*, 1992).

The role of researcher and health professional although a difficult nexus (Richards and Schwartz, 2002) is also a strength. This strength is particularly evident when the research includes sensitive topics such as mental health or working with vulnerable populations such as with children or when professional judgement is required; for example when participants enquire about health concerns or appear unwell unwell (Areán and Gallagher-Thompson, 1996). Mutual trust and endorsement from the research team is essential as research nurses need to act flexibly and autonomously on the team's behalf to make decisions as required. Regular debriefing as the fieldwork progresses is vital.

Summary

The research nurse brings a rare combination of clinical, communication, cultural and technological abilities along with well-honed research skills. The projects reported in this paper although small in number and size demonstrate the breadth of skills nurses contribute to community-based research. Involving research nurses facilitates high-quality research. Further study is required to describe the range and scope of community-based research nurse practice and the ideal model of education and skill preparation required to support it.

Acknowledgements

The acknowledge study participants and study teams involved, in particular the following *Primary Health Care Research & Development* 2015; **16**: 224–234

principal investigators and collaborators: Dr Tristram Ingham & Ms Cheryl Davies (The Pukapuka Hauora Asthma Study); Professor Julian Crane and Dr Kristin Wickens (The Probiotic Study); Associate Professor Dee Mangin and Professor Anthony Dowell (Antidepressant Cessation Trial); Professor Anthony Dowell and Dr Maria Stubbe (Applied Research on Communication in Health).

Financial Support

This project received no specific grant from any funding agency, commercial or not-for-profit sector.

Conflicts of Interest

None.

Ethical Standards

The four studies referred to in this paper received ethical approval from NZ Health and Disability Ethics Committees. Two vignettes are based on composite participant issues and two are based on actual participants. For the latter, permission to use was sought from participants.

References

- Areán, P.A. and Gallagher-Thompson, D. 1996: Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *Journal of Consulting and Clinical Psychology* 64, 875–80.
- Becze, E. 2010: Defining the role of the clinical research nurse. *ONS Connect* 25, 12–13.
- Bell, J. 2009: Towards clarification of the role of research nurses in New Zealand. *Nursing Praxis* 25, 4–16.
- Bell-Syer, S. and Klaber Moffett, J. 2000: Recruiting patients to randomised trials in primary care: principles and case study. *Family Practice* 17, 187–91.
- Best, I. 2005: Central role of the research nurse in improving accrual of older persons into cancer treatment trials. *Journal Clinical Oncology* 23, 7752–57.
- Bishop, R. 1998: Freeing ourselves from neo-colonial domination in research: a Maori approach to creating knowledge. *International Journal of Qualitative Studies in Education* 11, 199–219.
- Bishop, R. and Glynn, T. 1999: Researching in Maori contexts: an interpretation of participatory consciousness. *Journal of Intercultural Studies* 20, 167–82.
- Boulton, A., Gifford, H. and Potaka-Osborne, M. 2009: Realising Whanau Ora Through Community Action: the Role of Maori Community Health Workers. *Education for Health Journal* 22, 188–99.

- Bower, P.E.A.** 2009: Improving recruitment to health research in primary care. *Family Practice* 26, 391–97.
- Catalani, C.** and **Minkler, M.** 2010: Photovoice: a review of the literature in health and public health. *Health Education & Behavior* 37, 424–51.
- Children's Hospitals Australasia and the Paediatric Society of Aotearoa New Zealand (CHAPSANZ).** 2010: *Charter on the Rights of Tamariki/Children and Rangatahi/Young People in healthcare services in Aotearoa New Zealand: a consensus statement*. New Zealand: Children's Hospitals Australasia and the Paediatric Society of Aotearoa New Zealand.
- Christian, B.J., Pearce, P.F., Roberson, A.J.** and **Rothwell, E.** 2010: It's a small, small world: data collection strategies for research with children and adolescents. *Journal of Pediatric Nursing* 25, 202–14.
- Corrigan, P.** 2000: Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology: Science and Practice* 7, 48–67.
- Corrigan, P.** 2004: How stigma interferes with mental health care. *American Psychologist* 59, 614–25.
- Cram, F.** 2001: The validity and integrity of Māori research. In Editor, M. Tolich, *Research ethics in Aotearoa New Zealand*, Volume 4. Auckland: Pearson Education, 35–52.
- Cram, F., Smith, L.** and **Johnstone, W.** 2003: Mapping the themes of Maori talk about health. *New Zealand Medical Journal* 116, 1–7. Retrieved 2 June 2013 from www.nzma.org.nz/journal/116-1170/357/
- Cunningham, C.** 2000: A framework for addressing Maori knowledge in research, science and technology. *Pacific Health Dialogue* 7, 62–69.
- De Maeseneer, J.M., Van Driel, M.L., Green, L.A.** and **Van Weel, C.** 2003: The need for research in primary care. *The Lancet* 362, 1314–19.
- DeSouza, R.** 2008: Wellness for all: the possibilities of cultural safety and cultural competence in New Zealand. *Journal of Research in Nursing* 13, 125–35.
- Dew, K., Stubbe, M., Macdonald, L., Dowell, A.** and **Plumridge, E.** 2010: The (non) use of prioritisation protocols by surgeons. *Sociology of Health & Illness* 32, 545–62.
- Diekema, D.S.** 2006: Conducting ethical research in pediatrics: a brief historical overview and review of pediatric regulations. *The Journal of Pediatrics* 149, S3–11.
- Doutrich, D., Arcus, K., Dekker, L., Spuck, J.** and **Pollock-Robinson, C.** 2012: Cultural Safety in New Zealand and the United States looking at a way forward together. *Journal of Transcultural Nursing* 23, 143–50.
- Dowell, A., Macdonald, L., Stubbe, M., Plumridge, E.** and **Dew, K.** 2007: Clinicians at work: what can we learn from interactions in the consultation? *New Zealand Family Physician* 34, 345–50.
- Edwards, S.** and **McNamee, M.** 2005: Ethical concerns regarding guidelines for the conduct of clinical research on children. *Journal of Medical Ethics* 31, 351–54.
- Foy, R.E.A.** 2003: How evidence based are recruitment strategies to randomised controlled trials in primary care? experience from seven studies. *Family Practice* 20, 83–92.
- Furimsky, I., Cheung, A., Dewa, C.** and **Zipursky, R.** 2008: Strategies to enhance patient recruitment and retention in research involving patients with a first episode of mental illness. *Contemporary Clinical Trials* 29, 862–66.
- Goodyear-Smith, F., York, D., Petousis-Harris, H., Turner, N., Copp, J., Kerse, N.** and **Grant, C.** 2009: Recruiting of practices in primary care research: the long and short of it. *Family Practice* 26, 128–36.
- Harris, R., Cormack, D., Tobias, M., Yeh, L., Talamaivao, N., Minster, J.** and **Timutimu, R.** 2012: The pervasive effects of racism: experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine* 74, 408–15.
- Harris, R., Tobias, M., Jeffreys, M., Waldegrave, K., Karlsen, S.** and **Nazroo, J.** 2006: Effects of self-reported racial discrimination and deprivation on Māori health and inequalities in New Zealand: cross-sectional study. *The Lancet* 367, 2005–09.
- Hummers-Pradier, E., Scheidt-Nave, C., Martin, H., Heinemann, S., Kochen, M.M.** and **Himmel, W.** 2008: Simply no time? Barriers to GPs' participation in primary health care research. *Family Practice* 25, 105–12.
- Jones, B., Ingham, T., Cram, F., Dean, S.** and **Davies, C.** 2013: An indigenous approach to explore health-related experiences among Maori parents: The Pukapuka Hauora Asthma Study. *BMC Public Health* 13, 228. Retrieved 2 June 2013 from <http://www.biomedcentral.com/1471-2458/13/228>
- Jones, B., Ingham, T., Davies, C.** and **Cram, F.** 2010: Whānau Tuatahi: Māori community partnership research using a Kaupapa Māori methodology. *Mai Review* 1–14. Retrieved 2 June 2013 from <http://review.mai.ac.nz>
- Kenkre, J.** and **Chatfield, D.** 2004: Study site coordinator/clinical research nurse. *Clinical Research Focus* 15, 5–9.
- Knox, C.A.** and **Burkhart, P.V.** 2007: Issues related to children participating in clinical research. *Journal of Pediatric Nursing* 22, 310–18.
- Larkin, M., Watts, S.** and **Clifton, E.** 2006: Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology* 3, 102–20.
- Loh, W.Y., Butow, P.N., Brown, R.F.** and **Boyle, F.** 2002: Ethical communication in clinical trials. *Cancer* 95, 2414–21.
- Mais, K.** 2006: The role of the research nurse in hospital-based oncology clinical trials. *Nursing* 1, 22–23.
- McEldowney, R.** and **Connor, M.J.** 2011: Cultural safety as an ethic of care a praxiological process. *Journal of Transcultural Nursing* 22, 342–49.
- Mead, H.** 2003: *Tikanga Maori. living by Maori values*. Wellington: Huia Publishers.
- Miller, K.L., McKeever, P.** and **Coyte, P.C.** 2003: Recruitment issues in healthcare research: the situation in home care. *Health & Social Care in the Community* 11, 111–23.
- Ministry of Health.** 1998: *Consent of child and youth health: information for practitioners*. Wellington: Ministry of Health.
- Mold, J.W.** and **Peterson, K.A.** 2005: Primary care practice-based research networks: working at the interface between *Primary Health Care Research & Development* 2015; 16: 224–234

- research and quality improvement. *The Annals of Family Medicine* 3, S12–20.
- Mori, C., Mullen, N. and Hill, E.** 2007: Describing the role of the clinical research nurse. *Research Practitioner* 8, 220–28.
- Mueller, M.R. and Mamo, L.** 2000: Changes in medicine, changes in nursing: career contingencies and the movement of nurses into clinical trial coordination. *Sociological Perspectives* 43, 43–58.
- Nagel, K., Gender, J. and Bonner, A.** 2010: Delineating the role of a cohort of clinical research nurses in a pediatric cooperative clinical trials group. *Oncology Nursing Forum* 37, E180–85.
- New Zealand Nurses Organisation.** 2010: *New Zealand competency framework for clinical research nurses*. Wellington: New Zealand Nurses Organisation.
- Pick, A., Liu, A., Drew, V. and McCaull, J.** 2011: The role of the research nurse. *Nursing Times* 107. Retrieved 4 September 2013 from <http://www.nursingtimes.net/Journals/1/Files/2011/4/21/Research%20nurse%20role.pdf>
- Powell, M.A. and Smith, A.B.** 2006: Ethical guidelines for research with children: A review of current research ethics documentation in New Zealand. *Kōuitui: New Zealand Journal of Social Sciences Online* 1, 125–38.
- Rabins, P., Black, B., Roca, R., German, P., McGuire, M., Robbins, B., Rye, R. and Brant, L.** 2000: Effectiveness of a nurse-based outreach program for identifying and treating psychiatric illness in the elderly. *Journal of the American Medical Association* 283, 2802–09.
- Ramsden, I.M.** 1989: Equalising the partnership. *Kai Tiaki Nursing New Zealand* 82, 2.
- Rendell, J., Merritt, R. and Geddes, J.** 2007: Incentives and disincentives to participation by clinicians in randomised controlled trials. *Cochrane Database of Systematic Reviews* 2, 1–22.
- Richards, H.M. and Schwartz, L.J.** 2002: Ethics of qualitative research: are there special issues for health services research? *Family Practice* 19, 135–39.
- Rickard, C.M., Roberts, B.L., Foote, J. and McGrail, M.R.** 2006: Intensive care research coordinators: who are they and what do they do?: Results of a Binational Survey. *Dimensions of Critical Care Nursing* 25, 234–42.
- Robson, B. and Harris, C.** 2007: *Hauora: Maori standards of health IV: a study of the years 2000–2005*. Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare Wellington.
- Rushmer, R., Themessel-Huber, M., Coyle, J., Humphris, G., Dowell, J. and Williams, B.** 2011: Is the routine recording of primary care consultations possible...and desirable? Lessons for researchers from a consultation with multiple stakeholders. *Patient Education and Counseling* 82, 247–53.
- Sellers, J., Cosby, R., Trim, K., Kaczorowski, J., Howard, M., Hardcastle, L., Sellers, C. and Woodward, C.** 2002: Recruiting family physicians and patients for a clinical trial: lessons learned. *Family Practice* 19, 99–104.
- Singh, I.** 2010: Cryptic coercion. *Hastings Center Report* 40, 22–23.
- Primary Health Care Research & Development* 2015; **16**: 224–234
- Smith, L.** 1999: *Decolonising methodologies: research and indigenous peoples*. Dunedin, New York: Zed Books, Otago University Press.
- Stephens-Lloyd, A.** 2004: The extended role of the clinical research nurse: building an evidence base for practice. *Nursing Times Research* 9, 18–27.
- Tapp, H. and Dulin, M.** 2010: The science of primary health-care improvement: potential and use of community-based participatory research by practice-based research networks for translation of research into practice. *Experimental Biology and Medicine* 235, 290–99.
- University of Otago.** 2012: *Home and community based research visits: field work health and safety guidelines*. Dunedin: University of Otago.
- Velott, D.L., Baker, S.A., Hillemeier, M.M. and Weisman, C.S.** 2008: Participant recruitment to a randomized trial of a community-based behavioral intervention for pre-and inter-conceptual women findings from the Central Pennsylvania Women's Health Study. *Women's Health Issues* 18, 217–24.
- Walker, S., Eketone, A. and Gibbs, A.** 2006: An exploration of kaupapa Maori research, its principles, processes and applications. *International Journal of Social Research Methodology* 9, 331–344.
- Wickens, K., Black, P.N., Stanley, T.V., Mitchell, E., Fitzharris, P., Tannock, G.W., Purdie, G. and Crane, J.** 2008: A differential effect of 2 probiotics in the prevention of eczema and atopy: a double-blind, randomized, placebo-controlled trial. *Journal of Allergy and Clinical Immunology* 122, 788–94.
- Wickens, K., Black, P., Stanley, T.V., Mitchell, E., Barthow, C., Fitzharris, P., Purdie, G. and Crane, J.** 2012: A protective effect of *Lactobacillus rhamnosus* HN001 against eczema in the first 2 years of life persists to age 4 years. *Clinical & Experimental Allergy* 42, 1071–79.
- Wickens, K., Stanley, T.V., Mitchell, E.A., Barthow, C., Fitzharris, P., Purdie, G., Siebers, R., Black, P.N. and Crane, J.** 2013: Early supplementation with *Lactobacillus rhamnosus* HN001 reduces eczema prevalence to 6 years: does it also reduce atopic sensitization? *Clinical & Experimental Allergy* 43, 1048–57.
- Williams, T., Dunlap, B., Johnson, B. and Hamid, A.** 1992: Personal safety in dangerous places. *Journal of Contemporary Ethnography* 21, 343–74.
- Woodall, A., Howard, L. and Morgan, C.** 2011: Barriers to participation in mental health research: findings from the Genetics and Psychosis (GAP) Study. *International Review of Psychiatry* 23, 31–40.
- Woodall, A., Morgan, C., Sloan, C. and Howard, L.** 2010: Barriers to participation in mental health research: are there specific gender, ethnicity, and age related barriers? *BMC Psychiatry* 10, 103. Retrieved 4 September 2013 from <http://www.biomedcentral.com/1471-244X/10/103>
- Woods, M.** 2010: Cultural safety and the socioethical nurse. *Nursing Ethics* 17, 715–25.
- Zullino, D., Conus, P., Borgeat, F. and Bonscak, C.** 2003: Readiness to participate in psychiatric research. *The Canadian Journal of Psychiatry* 48, 480–84.