

Improving access to cardiac rehabilitation in rural and remote areas: a protocol for a community-based qualitative case study

Patricia E Field¹

Richard C Franklin¹

Ruth Barker²

Ian Ring³

Peter Leggat^{1,4}

Karla Canuto^{1,5}

Author details can be found at the end of this article

Correspondence to:

Patricia E Field;
patricia.field1@my.jcu.edu.au

Abstract

Background/Aims Heart disease is the largest single cause of death and contributes to poor quality of life and high healthcare costs in Australia. There are higher rates of heart disease in rural and remote areas, with the highest rates in Aboriginal and Torres Strait Islander people. Cardiac rehabilitation is known to improve health outcomes for people with heart disease but referral rates remain low (30.2% overall and 46% following acute coronary syndrome) in Australia. Further, access to cardiac rehabilitation in rural and remote areas is affected by there being few centre-based services, and poor use of home-based services. The aim of this protocol is to investigate: (i) understanding of cardiac rehabilitation by health staff, community leaders and community participants discharged from hospital following treatment for heart disease; (ii) access and support for cardiac rehabilitation in rural and remote areas via health service availability in each community.

Methods A qualitative case study methodology, using an interpretive descriptive framework, will be used together with content analysis that will encompass identification of themes through a deductive/inductive process.

Conclusions To improve access to services and health outcomes in rural and remote areas, a strong evidence base is essential. To achieve this, as well as having appropriate methodology, it is necessary to build relationships and trust with local communities and healthcare providers. This research protocol describes a qualitative community-based case study, together with processes to build sound relationships required for effective data collection through semi-structured interviews or focus groups. Each step of the pre-research planning data collection and analysis is described in detail for the guidance of future researchers.

Key words: Cardiac rehabilitation; Community consultation; Qualitative research protocol; Rural and remote

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Introduction

Cardiac rehabilitation is recognised as post hospitalisation best practice for people with heart disease (Woodruffe et al, 2015), but referral rates in Australia remain low (30.2% overall and 46% following acute coronary syndrome; Gallagher et al, 2020). This is well below the recommended international referral rate of 65% (De Gruyter et al, 2014). Heart disease continues to be the largest single cause of death and contributes to significant illness, disability, poor quality of life and high healthcare costs in Australia (Australian Institute of Health and Welfare, 2014a, b). Rates of heart disease are higher in rural and remote areas, with the highest rates in Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare, 2014c). Poor social determinants of health, such as lower incomes and levels of education, high cost of food, and long distances to services, contribute to these higher rates (Heart Foundation of Australia, 2017a).

Barriers to access to cardiac rehabilitation in rural and remote areas include fewer health services including centre-based phase 2 cardiac rehabilitation (supervised ambulatory outpatient programme), per capita (Australian Cardiovascular Health and Rehabilitation Association, 2018; Australian Institute of Health and Welfare, 2019) and increased costs, largely as a result of distance and staff turnover (De Angelis et al, 2008; Birk et al, 2010;

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Brual et al, 2012; Beatty et al, 2013). A study of inpatient cardiac rehabilitation in four major regional hospitals in North Queensland found that discharge planning was fragmented, with cardiac rehabilitation referral rates of 31% (range: 6–53%) for patients admitted for ≥ 3 days, and 9% (range: 0–19) for patients admitted for ≤ 2 days (Field et al, 2021). Enablers for cardiac rehabilitation participation include numbers of referrals and service availability (Field et al, 2018), medical practitioner support and involvement of family and/or significant others (Sherwood and Povey, 2011; Jackson et al, 2012), as well as ensuring that programmes are appropriate for diverse populations including Aboriginal and Torres Strait Islander people (Hamilton et al, 2016; Field et al, 2018).

In the absence of centre-based phase 2 cardiac rehabilitation, or if people prefer home-based programmes, there are several phone support programmes available. These include two no cost programmes: Queensland Health's Coaching on Achieving Cardiovascular Health (Ski et al, 2015; Health Support Queensland, 2018) and Heart Foundation of Australia's My Heart My Life (Heart Foundation of Australia, 2017b) and several commercial programmes, including Cardihab (Cardihab.com) (Varnfield et al, 2014). Despite limited centre-based outpatient cardiac rehabilitation, referrals to Coaching on Achieving Cardiovascular Health are low (range 4.1–20.3%) for residents of North Queensland (Field et al, 2020).

Given the known barriers to cardiac rehabilitation, healthcare system changes are required to improve access to cardiac rehabilitation, especially in rural and remote areas of Australia. Flexibility and inclusiveness (Fernandez et al, 2008) are known to be necessary components to achieve sound results based on strong relationships and trust with local communities. These relationships and trust need to be established in pre-research planning. For this study, the pre-research planning will include engaging with four communities in isolated locations of rural and remote Australia with a population range of 500–3500. These communities comprise a range of individuals and families, with various occupations, generally disadvantaged by socioeconomic status and social determinants of health, including limited general services and healthcare provision (Heart Foundation of Australia, 2017a), as well as a higher proportion of Aboriginal and Torres Strait Islander people than Queensland overall.

Further, to address population diversity and provide a culturally sensitive approach for data collection especially for Aboriginal and/or Torres Strait Islander people (Dimer et al, 2013), it will be necessary to adapt data collection processes. Simple English is necessary for written and verbal communication and collaborative yarning (dialogue circle) will be offered as an alternative to audio recording for data collection. Yarning is a process by which data is collected using a 'storyboards' technique, where text is written by the researchers during and after the yarning discussion, and regularly checked with the participants to ensure accuracy (Shay, 2021).

This research protocol builds on previous research and investigates factors that need to be addressed to improve access to cardiac rehabilitation in rural and remote areas of Australia, including previously completed studies that aim to improve access to cardiac rehabilitation in rural and remote areas of Australia (Field et al, 2018, 2020). These studies informed the direction, development and framework (Table 1) of this research protocol.

Aims

The aim of this study will be to investigate:

- Understanding of cardiac rehabilitation by health staff, community leaders and community participants discharged from hospital following treatment for heart disease
- Access and support for cardiac rehabilitation in rural and remote areas via health service availability in each community.

Methods

Qualitative case study methodology with an interpretive descriptive framework will be used to provide direction and focus on the practical aspects of knowledge, in a logical systematic manner, so that the researchers' engagement with the data makes it possible to interpret the

Table 1. Framework for data collection to improve access to phase 2 cardiac rehabilitation in rural and remote areas

Primary questions and area of interest

Post discharge and referral plan:

- Community participants' understanding and suggestions
- Staff role and suggestions

Cardiac rehabilitation: service availability and access

- Community participants' understanding and suggestions
- Staff role and suggestions

Improving cardiac rehabilitation:

- Community participants' understanding and suggestions
- Staff role and suggestions

The way forward:

- Community participants and staff: assimilating information into revised cardiac rehabilitation models for improving access to cardiac rehabilitation in rural and remote areas of Australia

content beyond the obvious (Denzin and Lincoln, 2011; Teodoro et al, 2018). Based on an integrative literature review on barriers, enablers and pathways to cardiac rehabilitation in rural and remote areas (Field et al, 2018), initial primary themes and areas of interest were identified (deductive analysis) (Clarke et al, 2015) (Table 1). This preliminary analysis also provided the framework for the study and guided the development of semi-structured conversational interviews that will be used for data collation via purposefully sampled interviewees or focus groups members.

The analysis, including identification of secondary themes (induction), will be guided by the six steps identified by Clarke and Braun (Clarke et al, 2015), and conducted according to consolidative criteria for reporting qualitative research (COREQ) (Tong et al, 2007).

Inclusion criteria

Participants will be included if they meet the following criteria:

- Community participants:
 - Adults ≥18 years
 - Men and women including Aboriginal and/or Torres Strait Islander peoples, discharged from hospital following treatment for heart disease in the past 2 years, who live independently and are eligible for cardiac rehabilitation according to National Heart Foundation of Australia and Australian Cardiac Rehabilitation Association (2004) recommendations (Woodruffe et al, 2015)
- Local and visiting health centre staff including nurses, doctors, allied health professionals, health service managers
- Community leaders employed in leadership positions or recognised as leaders by the local community.

Exclusion criteria

People with a medical diagnosis of mental impairment, or who are unable to comprehend the process despite assistance of a support person or interpreter and thereby do not fulfil the requirements of informed consent as per NHMRC research guidelines (National Health and Medical Research Council et al, 2018) will be excluded from the study.

Ethical approval

Ethical approval has been granted from the Townsville Hospital and Health Services (HREC/2019/QTHS/59212; JCU Ethics Committee acknowledgement: H8467). All participants will be required to sign an informed consent form.

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Settings

The focus of this research will be four communities in rural and remote Australia. Each community has contrasting demographic profiles that include farming, tourism, small industry, mining, commercial and government services. All communities have a higher proportion of Aboriginal and/or Torres Strait Islander people than Queensland (4%) (Australian Bureau of Statistics, 2016). Two communities include a proportion of Aboriginal and/or Torres Strait Islander people (8% and 16%), who are part of the larger community, and two communities are designated communities with majority of Aboriginal and/or Torres Strait Islander people (91% and 99%) (Australian Bureau of Statistics, 2018).

Pre-research planning

Community focused pre-research planning is required in preparation for the research. It is important that networks include local government, community organisations, education, health, transport and social services (Woods, 2006). The coordinating primary investigator made three visits to each community to develop networks and build trust with community members and health staff.

The proposed research was discussed at meetings with local organisations. Ideas were sought and education on heart disease and risk factors was provided. Follow-up notes were sent by email and between community visits further email and phone updates were provided. This process resulted in sound networks in each community that will provide a nexus for ongoing consultation, and recruitment of community participants and health staff.

Recruitment and consent

Recruitment and interviewing of community members and health staff will be undertaken over a 2–6-week period as per best practice for community consultations (Department of Prime Minister and Cabinet, 2016). Community participants will include both people who participated in cardiac rehabilitation, or did not participate or complete the programme, thus providing important insights into barriers to attending cardiac rehabilitation as well as an opportunity to explore the reasons why they did or did not attend. Community leaders and staff will be recruited according to the inclusion and exclusion criteria.

Information about the research, process of data collection, including confidentiality and withdrawal if required, will be explained as part of the recruitment process (National Health and Medical Research Council et al, 2018). Recruitment of community participants will be through health staff, or community organisation members, who will be briefed about the project, and asked to contact potential participants.

A simple English brochure describing the project and contact details (**Appendix 1**) will be provided so that potential participants may contact the coordinating primary investigator, or leave their contact details. Health staff, including nurses, medical officers, Aboriginal and/or Torres Strait Islander Health workers and local and visiting allied health professionals will be recruited through routine staff meetings. Community leaders will be recruited through regular meetings and ongoing liaison with community organisations.

During the first meeting between the participant and coordinating primary investigator, further verbal and written information about the project will be reiterated. Before obtaining written consent, the choice of audio recording or yarning with note taking (Shay, 2021), and use of information for the development of revised models of cardiac rehabilitation, will be discussed. Every effort will be made to ensure proportionate representation of men and women, with a specific effort made to over-recruit Aboriginal and/or Torres Strait Islander people, given their rates of heart disease in rural and remote areas are twice that of the general population (Australian Institute of Health and Welfare, 2016). To help ensure good communication with Aboriginal and Torres Strait Islander people, an Aboriginal and/or Torres Strait Islander health worker, Aboriginal and/or Torres Strait Islander liaison officer or a participant's family member will assist with communication and language interpretation as required (National Health and Medical Research Council et al, 2018; National Health and Medical Research Council, 2018).

In recognition of their expertise and contribution, community participants will be given a AUD\$50.00 voucher for the local store. Transport to attend interviews or focus groups and refreshments will also be provided as required. The location of interviews or focus

groups will be discussed with the potential participant to ensure that they are comfortable with the environment. However, should it become difficult to carry out interviews or focus groups in the communities, for example because of COVID-19 restrictions, it will be possible to conduct the discussion using an online application such as Zoom. It is reported that relationship-based face-to-face discussion is preferred by populations in rural and remote areas, particularly Aboriginal and Torres Strait Islander people (Dimer et al, 2013). Poor quality internet can also result in difficulty with using online communication. This reinforces the need to develop sound community relationships before recruitment and data collection. If transport is required, distances are not great within rural and remote communities because of small populations. If networks and trust have been developed, transport can be negotiated through the local council or health services with payment of expenses, or hire, as necessary.

Sample size

People will be individually interviewed and/or focus groups undertaken until data saturation has been reached (Patton, 1990). This will be confirmed when repeated themes emerge, thereby ensuring research questions can be answered and further data collection is redundant (Patton, 1990). Based on previous qualitative community studies, it is anticipated that this will be achieved through 10–15 interviews or focus groups lasting 15–25 minutes for individual interviews, and 1–2 hours for focus groups (White et al, 2009; Van Gelderen et al, 2017; Nyumba et al, 2018). Longer times have been allowed for focus groups, as it is anticipated that several people will generate more discussion, and refreshments will be provided. The number of participants for focus groups are anticipated to be between three and six participants (Nyumba et al, 2018), but will be expanded as required.

Data collection and validation

Data collection will be through semi-structured conversational interviews or focus groups involving information-rich participants (health staff and community participants). Participants will be purposefully selected, according to the inclusion criteria.

As the populations are small, there may be fewer potential participants for the study. If there are insufficient community participants who have been discharged from hospital in the previous 2 years, the recruitment timeframe will be extended. If this happens, recall bias will need to be considered as there is a reported 20% loss of recall over 12 months and 50% for more extended periods (Hassan, 2006). However, recall will be assisted because heart disease represents a significant event in people's lives, and this is known to improve people's recollection of major events (Smith et al, 2003; Heart Research Australia, 2016). Clear open-ended interview questions (Mason, 2010) (Table 2) that explore issues by asking the same question in different ways and checking for correlation will assist with validation and triangulation (Denzin and Lincoln, 2011).

Triangulation will also be assisted by collecting data from different sources (staff and community participants) as well as follow-up clarification meetings to address questions that may arise from the initial interviews. This process will provide a depth of information, as well as increasing credibility and validity of findings (Denzin and Lincoln, 2011). Prompts are included in the interview schedules because of the conversational semi-structured interview format, thereby ensuring required data is collected.

Both community participants and staff questions will be tested through pilot interviews and adjusted as required. Should adjustment be necessary, an amendment will be submitted to the approving human research ethics committee. All interviews and group discussions will be conversational and exploratory to gain a rich description of community participants and health staff's experience of cardiac rehabilitation and support services.

During the interview process, requests for further information on attending cardiac rehabilitation or the need to emotional support may arise. To address this support can be arranged a through the local health centre, GP, mental health services, and/or the telephone support home-based programmes Coaching on Achieving Cardiovascular Health (Health Support Queensland, 2018) or My Heart My Life (Heart Foundation of Australia, 2017b).

Demographic data

Before the interviews and focus groups, participants will be asked to complete a voluntary questionnaire (Appendix 2). Data collection is not mandatory, and non-completion will not preclude participation. Staff data collection will be as per Appendix 3; health staff data collection will follow the same process.

Table 2. Open-ended questions for patients and staff

Patients	Staff
<p>When you were discharged from hospital, what information were you provided with about your health care when you got home?</p> <p>Prompts: Were you referred to a centre or home-based cardiac rehabilitation* programme or a community nurse or allied health professional? What follow-up medical appointments did you have? Did you receive medication on discharge from hospital? Did you and your doctor receive information about your ongoing care from the hospital (medical discharge summaries)? When did these arrive, and do you know what they advised for your ongoing care?</p>	<p>Can you tell me your role in providing support for people in the community and/or health care?</p> <p>Prompts: Do you understand what is meant by cardiac rehabilitation? Are you aware of the COACH home-based cardiac rehabilitation programme?</p>
<p>Can you tell me about any difficulties or what made it easy for you to get health care or cardiac rehabilitation when you went home from hospital having been treated for heart disease?</p> <p>Prompts: Did anybody phone or visit you to see if you needed any support?</p>	<p>What do you think are the most important aspects of post-discharge care for people with heart disease and how will this be able to be achieved in your area?</p>
<p>When you got home, who did you contact, or who contacted you about your follow-up care?</p>	<p>What do you think are the main factors that prevent people from attending cardiac rehabilitation or seeking post discharge health care?</p>
<p>Out of all the health care that you received after coming home from hospital what do you think helped you most?</p>	<p>Do you have any guidelines for providing care for people recently discharge from hospital after treatment for heart disease (eg insertion of stents, coronary artery bypass graft surgery or myocardial infarction)? (health staff only)</p>
<p>Can you tell me if anybody discussed things that you could do to improve you overall health?</p> <p>Prompts: Were you given any brochures?</p>	<p>What do you think that people need to understand about their ongoing care and health plan once they have returned home after in-hospital treatment for heart disease?</p>
<p>What information was most helpful?</p>	<p>How do you make sure these people get the information that they need, and how will this be done? (health staff only)</p>
<p>What things do you think could have been done that you think would have made a difference to your recovery?</p>	<p>Can you describe any cardiac rehabilitation services that are available locally?</p> <p>Prompts: What about visiting and local health professionals and related services, such as gymnasiums and support groups? Any further comments or suggestions?</p>
<p>Since your first hospital admission for heart disease have you had to go back for further treatment? If so can you tell me about it?</p>	<p>Can you tell me about the COACH or any other home-based cardiac rehabilitation programme available for people in this area?</p> <p>Prompts: Any comments or suggestions?</p>
<p>What is worrying you most about your heart problem? Do you need somebody to talk with somebody about this?</p>	<p>Who is responsible for organising essential post hospitalisation follow-up and care?</p> <p>Prompts: How do you think that this can be improved?</p>
<p>Any other comments that you would like to make?</p>	<p>What do your think could be done to improve provision of cardiac rehabilitation and follow-up?</p>
	<p>Any other comments that you would like to make?</p>

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Analysis

Audio interviews will be professionally transcribed verbatim and NVivo-12 software will be used to facilitate thematic analysis of participants' responses, as distinct units of meaning with headings (nodes), and subheadings developed through reflective induction (Grbich, 2013). This process will enable confirmation and clarification of the primary questions/ areas of interest (Table 1), and the development of secondary themes that capture 'levels of patterned responses of meaning' (Braun and Clarke, 2006). Further, consistency will be considered with quotations from transcripts used to illustrate primary themes or areas of interest and secondary themes. The same process will be used for documented records of yarning discussions. Overall a flexible approach that includes researcher interpretation and judgement will be used (Braun and Clarke, 2006).

Community participant demographic data will be stratified by age, sex, Aboriginal and/or Torres Strait Islander peoples, general population and heart disease. Staff data will be stratified by professional classification and role, whether community based or visiting service providers and working with Aboriginal and/or Torres Strait Islander Peoples or the general population.

Reflexivity and rigour

The analysis will be undertaken by the coordinating primary investigator, reviewed by the primary investigator and discussed with the research team to ensure reflexivity, rigour, clarification and verification (Daws et al, 2014). Reflexivity includes considering the researcher's situation in the research, based on self-critique of personal experience (Patnaik, 2013).

Possible bias and preconceived ideas will be minimised by using:

- Australian Cardiovascular Health and Rehabilitation Association (ACRA) core components of cardiovascular disease secondary prevention and cardiac rehabilitation (Woodruffe et al, 2015)
- Findings of the previous integrative literature review (Field et al, 2018)
- Demographic study of heart disease, hospitalisation and referral to Coaching on Achieving Cardiovascular Health in Queensland (Field et al, 2020).

These guidelines and studies provided an objective basis for data collection and analysis. Following data collection, emergent themes will be discussed with a community reference group (face to face or via teleconference), thereby providing opportunities for member checking to ensure accuracy and clarification (Denzin and Lincoln, 2011), as well as ensuring an iterative process that will review and build ideas towards the ultimate goal of improving access to cardiac rehabilitation for rural and remote areas of North Queensland. Individual community participant interviews will not be confirmed or clarified, as a previous research study demonstrated that interviewees may have concerns or feel uncomfortable about how they sounded or what they said in their interviews, rather than inaccuracy (Mero-Jaffe, 2011). Every effort will be made to minimise bias in data collection through adherence to rigorous qualitative methods including ensuring data saturation (no new information forthcoming) is achieved, and ensure findings are reviewed by a community reference group.

Strengths and limitations

Of primary importance in this project protocol is the pre-research planning, consultation, and development of trusting relationships in rural and remote communities. Qualitative research needs to be attuned for various environments and the authors propose that this project protocol for research in rural and remote communities including Aboriginal and/or Torres Strait Islander people will provide a template that can be adapted to a range of environments.

Significance

Ultimately, this proposed research aims to identify factors (barriers and enablers), that need to be addressed in order to develop model(s) that improve access to cardiac rehabilitation and/or locally based support for people discharged from hospital with heart disease in rural and remote areas of Australia. It is proposed that information gathered in this research, in combination with the final stages of the full research project, will lead to realising the

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Key points

- Referral and access to cardiac rehabilitation remain sub-optimal overall, with lower levels in rural and remote areas.
- Further research is required to develop new approaches (models) to improve access to cardiac rehabilitation in rural and remote areas.
- Developing sound community relationships requires extensive pre-research planning to ensure trust, which is necessary for effective research.
- This protocol for a qualitative community-based case study will inform and guide future research to improve health outcomes and could be applied in a range of locations.
- Improving access to cardiac rehabilitation in rural and remote areas has implications for other environments and chronic disease risk factor management.

benefits identified through access and subsequent cardiac rehabilitation attendance (De Gruyter et al, 2016; Heart Foundation of Australia, 2017c). The initial awareness raising, and improved understanding of cardiac rehabilitation, including management of risk factors for chronic disease, will be initiated through community consultation. Should participants wish to make lifestyle changes they will be linked into appropriate health care and/or support organisations.

Conclusions

To improve access to services and health outcomes in rural and remote areas, a strong evidence base is essential. To achieve this, as well as having appropriate methodology, it is necessary to build relationships and trust with local communities and health care providers. This research protocol describes a qualitative community-based case study, together with processes to build sound relationships required for effective data collection through semi-structured interviews or focus groups. Each step of the pre-research planning, data collection and analysis is described in detail for the guidance of future researchers.

Author details

¹College of Public Health, Medicine and Veterinary Sciences, James Cook University, Townsville, Australia

²College of Healthcare Sciences, James Cook University, Cairns, Australia

³Division of Tropical Health and Medicine, James Cook University, Townsville, Australia

⁴Faculty of Health Sciences, Flinders University, Adelaide, Australia

⁵Wardliparingga Aboriginal Health Equity, South Australian Health and Medical Research Institute, Adelaide, Australia

Conflicts of interest

There are no conflicts of interest to declare.

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Appendix 1

How can you talk to the research team?

If you would like more information you can contact:

Pat Field: 0409 778 489

email: patricia.field1@my.jcu.edu.au

or ask any staff member who will make sure that Pat gets the message.

I look forward to meeting you and having a chat!

Who are we?

We are from James Cook University trying to find out how much health care and support is available for people who have returned home after treatment in hospital for a heart problem.

We are working closely with the hospital and health centre staff who are happy to assist



Happy heart – happy life



What do we need to know?



Many people everywhere, get heart problems and sometimes need hospital care, and health services support when they go home.

We would like to hear the story of people when they come home from hospital after treatment for heart sickness.



How will we find out?

Pat Field is a JCU researcher, and would like you to tell your story about what happened to you after you got home from hospital. Pat would like to know if you knew what to do, when you got home. Things like how much walking is best, what sort of food is good, when you next see your doctor. Who told you this? How did you get on as time went by? Did you feel sad and did anybody help you with this?



Do you want to chat?

If you want to have a chat with Pat, please let one of the hospital staff members know and they will introduce Pat, who will tell you how you can help and will arrange a time to meet with you in private. Before you tell your story you will be asked to sign a form to let us know that you understand your part in the project and you are happy to tell your story.

Only the researchers will know what you have told us, unless you take part in a group discussion. If this happens all people are asked not to talk about what is said at the meeting to other people.

If you decide that you no longer want to take part you can leave at any time.

Appendix 2. Community participants data collection

Date	Surname	Given name	Sex	Age	Ethnicity	General population: country of birth	Email/ postal address	Heart disease based on person's description	Requested report

Appendix 3. Health staff data collection

Date	Surname	Given name	Sex	Ethnicity	Email/ postal address	Professional classification	Community based or intermittent visits	Report requested

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