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A qualitative study of recruiting for investigations in primary care: Plan, pay, minimise intermediaries and keep it simple

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Abstract

Objectives: We sought successful strategies to recruit patient and practitioner participants for studies from primary care.

Methods: We interviewed people who had participated and who had not participated in a randomised controlled trial that did not reach recruitment target and successful primary care researchers. The participants and non-participants were mostly Pacific peoples. Interviews were recorded, transcribed, and analysed and reported using qualitative description. The study took place in New Zealand in 2013–2014.

Results: A total of 31 people were interviewed. Researchers agreed that recruitment was usually the single most important phase of research but was usually under-planned and under-funded. All researchers recommended a pilot study that addressed recruitment. Successful researchers actively monitored recruitment and adapted the process as needed. Most projects were undertaken by our researchers recruited via an intermediary such as a general practice nurse. Strategies were adapted to the target population, such as specific acute or chronic conditions, age, ethnicity and gender. Intermediaries were actively recruited and retained in a manner that was often more intense than actual participant recruitment and retention. 'Layers' of intermediaries were kept to a minimum as each layer needed to be actively recruited and retained and each layer reduced participant recruitment rates. The task of intermediaries was kept simple and minimal and they were paid in some manner. Similarly, participant workload was kept to a minimum and they were paid in some manner that was intended to cover their participation costs and perhaps a little more. Even the most experienced researchers did not always achieve recruitment targets. Our interviews focused on patient participants but included recruiting general practitioners, nurses and others as research subjects.

Conclusion: Strategy details varied with the target population but had in common the need to intensively recruit and retain intermediaries, minimise layers of intermediaries, and the need to pay and minimise workload for both intermediaries and participants.

Keywords

Recruitment, patient selection, primary health care, general practice, family practice, research design

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Introduction

Researchers and funders often focus on the 'science' of new knowledge being sought in a study or trial, ignoring the fact that without recruiting sufficient numbers of appropriate participants, their best laid plans will come to naught. In the process, the 'science of recruitment' – knowledge of what works and what does not and why – remains under-developed.[1–5]

A review of trials funded by two large United Kingdom bodies found that fewer than one-third reached their recruitment targets, and a search for trial characteristics associated with successful recruitment was essentially unhelpful.[3] A systematic

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review of 14 studies that randomised recruitment to a 'real' randomised controlled trial showed better recruitment rates with telephone reminders, including the study questionnaire, monetary incentives, 'open' design (without placebo) and enlisting trained and culturally appropriate research assistants.[4] Another systematic review of 37 studies that randomised recruitment to real or mock randomised controlled trials, found better recruitment with strategies that increased people's knowledge and awareness of the problem being studied, monetary incentives, and 'open' design.[1] Some, but not all, of the studies reported in these reviews recruited from primary care. A survey of authors of primary care trials in the United Kingdom found that fewer than one-third of trials recruited to their original timescale.[6] Strategies requiring general practitioners (GPs) to gain patient consent were particularly slow.

This study was triggered by poor recruitment to a randomised controlled trial in which the intervention was starting a specific medication during an acute attack of gout. The recruitment strategy was based on primary care and focused particularly, but not exclusively, on Pacific people as the prevalence and morbidity from gout are high in that population. The trial was stopped after recruiting fewer than 10% of its target numbers. We sought to learn from recruitment failure in this trial, from participants, non-participants and researchers. We recognised that some of these researchers, and others in our academic networks, had been very successful in recruiting other trials. Our interest was primarily in recruiting patient participants to any study type. Many of the findings relate to engaging practices or practitioners and are therefore relevant to the separate issue of recruiting practices or practitioners themselves as research subjects. We sought and obtained stories and insights that might lead to consistent successful recruitment.

Methods

Participant selection

For patient participants, we used purposive sampling for maximum variance[7] according to two initial categories: people who had participated in the gout trial and others who were eligible but had not participated. Within each category, we sought people from the main demographic groups we considered may be associated with differences in response to recruitment strategies: males and females, the two main ethnic groups (Tongan and Samoan) sought in the trial, and people less than 40 years old and those 40 or older. These people were approached directly by our interviewers. Participant numbers were limited by the number of eligible participants and those fitting the selection criteria.

For researcher participants, we used purposive sampling,[7] based on convenience of the authors' knowledge and networks within New Zealand, to identify key informants with acknowledged expertise in recruiting for studies. We included senior researchers, senior advisors and project managers. All participants worked in primary care or community research, and their projects were generally low risk for patients. In our context, senior researchers who are principal investigators on one study will generally be co-investigators on others and have experience with hands-on project management. People who advise on studies have senior policy or service provider roles or community leadership roles and are often researchers themselves. In this case, we included advisors from the gout study and researchers with experience from a broad range of community and primary care studies including randomised controlled trials, observational studies and surveys. An independent academic approached potential interviewees on our behalf – none refused – and author T.W.K. approached them directly once they had confirmed initial interest. Participant numbers were limited by the needs of the study as saturation around successful strategies was reached within a small number of interviews.

Interviews and analysis

Interview questions were constructed based on anecdotes heard by the researchers, mid-level theories[8] and the literature. The interview schedules are in Appendices 1–3.

Interviews with trial participants and non-participants were undertaken in the preferred language of the interviewee (Tongan, Samoan or English). Interviewers were bilingual in Tongan and English (author S.H.) or Samoan and English. They recorded the interviews and translated and transcribed them into English. Participant interviews were supplemented with questions about their experience with gout and response to the trial, asked by the research nurses during the trial process. One nurse was bilingual in Tongan and English and the other was bilingual in Samoan and English. They provided summary notes in English. Interviews with researchers and project managers were conducted in English by author T.W.K. and transcribed by a contracted third party. All interviews were conducted in person or by phone according to the preference of the interviewee and lasted between 15 and 45 min. The English summaries and transcripts were the main body of data analysed. Author T.W.K. read the transcripts repeatedly and used NVivo 10 (www.qsrinternational.com) to support coding and explore differences according to research context. Patterns were discussed with the other authors, returning to the data as needed. Findings were shared with three of the key informants, who confirmed the patterns identified. The overall mode of analysis and reporting was qualitative description, which seeks to identify themes that are 'naturalistic' with respect to the language used by the interviewees and therefore recognisable by relevant practitioners, rather than, for example, seeking high-level abstraction and theory construction.[8] Ethics approval was given by the University of Auckland Human Participants Ethics Committee, ref 9715. All interviewees signed a written consent form allowing their interviews to be recorded, analysed and reported anonymously. We followed the consolidated criteria for reporting qualitative research (COREQ) checklist for reporting qualitative studies.[9]

Table 1. Describing the interviewees.

	Tongan	Cook	Samoan	Māori	European	Role	Gender	Age
Participant role (17)	9	2	5	1	0	7 participants and 10 non-participants	15 males and 2 females	3 <41 years and 14 >40 years
Research role (14)	5	0	2	1	6	8 researchers and 6 advisors	9 males and 5 females	

The researchers and interviewers

Author T.W.K. is a senior academic general medical practitioner. He is male and New Zealand European. He is experienced in both quantitative and qualitative research methods and has experienced both successful and unsuccessful recruitment. Author S.H. is a journalist and runs a media and communications business. He is male and Tongan and bilingual in Tongan and English. Author B.A. is a senior academic general medical practitioner and public health specialist. He is male and New Zealand European. He is experienced in quantitative research methods and has experienced both successful and unsuccessful recruitment. Authors S.H. and B.A. both had roles in the gout study as advisor and researcher, respectively. Interviews with Samoan participants and non-participants were conducted by a female journalist who is Samoan and bilingual in Samoan and English.

Results

We interviewed 31 people: 7 participants and 10 non-participants from the gout trial; 8 senior researchers and project managers; and 6 research project advisors. Groups of interviewees are referred to as either researchers or patients (the latter including trial participants and non-participants). Further descriptive details are shown in Table 1. Direct quotes are attributed either to researchers (R1–R5) or to participants/non-participants (P1–P10).

The following roles are defined: participant – person whose data are collected as the central purpose of the study; intermediary – person who directly interacts with participants and recruiting manager – research team member responsible for recruiting, interacting with and managing the intermediary.

General

Researchers were unanimous and adamant that recruitment must be planned in more detail than was often done, and that recruitment commonly took more resources and more time than initially planned. Even the most experienced researchers had not always achieving recruitment targets. Researchers were also clear that project success depended in a very fundamental way on the recruiting manager. The ideal person had experience in recruiting, was highly organised, knowledgeable, dedicated, efficient, engaging, calm but energetic, persistent, imaginative, thick-skinned, realistic but optimistic, culturally sensitive, able to take initiative, a natural networker and preferably a health professional! Box 1 shows practical examples of keeping it simple.

Box 1. Keep it simple.

(Ringing a GP for initial contact) 'I would say "Hi, it's Dr [name] here, is Mark [target doctor] in?" Calling myself doctor and making it sound like I was on first name basis with the GP I was ringing – worked amazingly well!'

Ringing an intermediary or a participant – keep the study title short and clear: 'Hi, I'm phoning from the cough study'.

An invite letter must be simple and direct: 'You are invited to take part in a study about exercise and heart disease. Your doctor, Dr Smith, has approved and thought you may be suitable for this study. If you might be interested, please phone Miss Jones at the University of Auckland 3737599'.

A simple message and process at the reception desk:

As patients came up to the reception desk the receptionist would push to them a slip of paper about 10 cm by 20 cm with just two questions 'As a rule do you 30 minutes of physical activity five days a week, yes/no'. and 'If yes, would you like to talk to someone about taking part in a study, yes/no?' Those who ticked yes to the second question would be pointed to the research assistant sitting in the waiting room.

A routine that was simplified for the receptionist:

When a person comes to reception, the receptionist would enter their ID number into an i-Pad, hand it to the patient and say 'please fill this is for the doctor'. If the patient asked a question, they would say 'there is a nice welcome screen that tells you all about it. If you've got any questions come back and let me know'.

Another study had a little notice folded to sit upright on the reception desk facing the patients saying 'Can't shake that cough?' Patients reading this self-referred to the study.

Regular contact with practices:

The project manager would visit practices on a fairly regular basis without harassing them. She would make an 'excuse' to visit them. She'd often take them morning tea. She'd find out first what they liked. The Pacific practices wanted different food then the non-Pacific practices. She would say: 'I was just passing by and I've popped in to see how you're doing. Is there anything I can help you with?' What she wanted to do was to 'razz them up' but she did it a way that they didn't feel threatened.

Recruitment as most important phase of research

No researcher wants to find themselves in this irretrievable situation:

> I was appalled when I realised we were coming to an end and we had so few patients. I kept thinking something is going to change. (R1)

Participants were clear that recruitment was the single most important and most time-consuming phase of quantitative research and often of qualitative research. Success or failure of an entire project depends on successful recruitment:

> I say that [recruitment] is the most important part of this trial. If you don't get that you are not going to be able to answer your question. (R2)

New researchers were strongly advised to seek advice from others who had successfully recruited for similar studies.

Pilot study

All researchers recommended a pilot or feasibility study (they used both terms without distinguishing) that included testing recruitment:

> the bottom line is do a feasibility study first and if you can't recruit at the rate and deliver the intervention with people being happy about it and the rate of recruitment being fast enough then don't do it that way. (R2)

In practice, many successful projects treated the initial phases of the 'full' study as a pilot, closely monitoring recruitment and adapting the process, especially in the early stages. Several researchers commented that funding for a pilot study was more difficult to obtain than funding for a full trial, and two noted that even funded and successful pilot studies did not guarantee that a full study proposal would receive funding.

Active monitoring and management

Successful projects actively monitored recruitment and adapted the process if needed:

> So we put a lot of effort and time into making sure that that's right. If it's not working then change something. (R2)

Imagination and modest cost could turn stagnant recruiting into overnight success:

> That's when we come in with strategies like this with the $50 [supermarket] voucher and a bottle of wine [for intermediaries]. All of a sudden … (Interviewer: So that wasn't there from the start?) Nope no it was initiatives we put in after we were kind of going this isn't really working. (R3)

Monitoring and feedback to practices included not just numbers, but also categories of patients:

> But the thing is we changed our emails to practices to say, 'Hey look don't forget about the kids, send us through your kids'. So then all of a sudden we got a little flurry of kids coming through. (R3)

Feedback to the practice was essential and needed to be planned and monitored and adjusted:

> We could actually measure how many [patients were recruited]. They did lots the first two or three weeks then it dropped right off. So we … sent them an email to the right person. So you've got to figure out who the best person is. Once a week they get an activity report … As soon as they could see the little graph they'd say; 'Oh I can see we've only done two this week maybe I need to do more' and it would go up again. … That was an email reminder but targeted to the right person; sometimes practice manager, sometimes receptionist, sometimes nurse. Absolutely and it was automated. It was really simple and they still get them. It could be phone calls. (R4)

Pay for recruitment

Researchers were all clear that if they could not afford to pay for recruitment they could not afford to do the study. They planned to pay both participants and intermediaries:

> Incentives, payments, rewards absolutely. It's a must. (R3)

Putting peoples' names in the draw for a prize was acknowledged as a common form of incentive but was not favoured by at least one researcher:

> I think if you're going to give somebody something you give them something. I disagree with, I'm not very keen on gambling anyway … I'd prefer to say yep this is what we'll give you for your time. (R2)

Paying participants was seen as an issue of respect, of meeting genuine costs, and also of managing patient perceptions and expectations:

> There has to be some recognition for their time and even more so if you're asking them to go somewhere. (R4)

> It's about recognising you are asking them do something additional even though if they went on that medication with their doctor they'd have to do exactly the same thing its irrelevant. So there needs to be some awareness for petrol costs or whatever it may be. (R3)

None of the researchers made any attempt to estimate real patient costs or put a monetary value on time spent, apart from reimbursing direct costs such as travel. Payment was seen as a token of appreciation rather than a calculated payment for service. Typical payments might be one or two $20 vouchers for a baseline assessment and one for a follow-up interview. One researcher noted that teenagers would give up

two or three weekend mornings for an exercise study that offered a single $20 mobile phone 'top-up'.

Payments for intermediaries were more inventive, often an incentive rather than a recompense for costs. The best advice seemed to be to always leave something. Small items marked with the study logo were welcomed; *'Never underestimate the power of a free pen'*. (R3)

Intermediaries such as receptionists and nurses responded willingly to $10 vouchers per participant recruited and/or $50 vouchers on reaching targets. Payments to intermediaries worked well when incentive targets are set at an achievable level and regular feedback informed them of how they are progressing towards their target. Two researchers specified that payments were based on the number of participants entering a study rather than the number referred.

Practices varied in whether they expected payments to go to the practice, the group of staff acting as intermediaries or the individual intermediary. Researchers preferred some or all of the payments to go to the individual intermediary or at least their group. Recruitment feedback to practices would identify individual intermediaries.

Recruitment of relatives and friends of happily enrolled participants was the most successful source of new enrolments for several studies. No researchers mentioned incentives to current enrolees to recruit more people.

All researchers considered that historical reservations about payments were outdated:

> One of the things that is a little bit irritating with the ethics committees is they won't let you tell people [ahead of time] there is a payment. But when you pay people they say well why didn't you tell me beforehand I might have been more interested … I think in a place like [poor area] a $5 to $10 food voucher is quite a valuable thing. I think ethics committees are somewhat out of touch. I guess they don't want coercion but … it's a very low risk [activity for participants]. (R1)

> [Researchers] thought they had difficulty persuading the ethics committee that [payment] was necessary or appropriate. I think that there are so many precedents now that shouldn't be an issue. … I think that's become usual practice. It's been that way for over 10 years now I'd say. (R2)

Minimise intermediaries

All researchers agreed that there should be only one layer of intermediaries between the recruiting manager and participants. Each layer needed a specific incentivised strategy to actively recruit and retain participants, and success depended on the weakest link in the chain. Researchers in New Zealand tried to avoid involving Primary Health Organizations (PHOs) as an obligatory intermediary between themselves and general practices, that is, avoided the situation where their only contact was with the PHO, which then interacted with practices, which were then expected to identify and invite participants:

> The reason it's not working is because we have to through a PHO. (R3)

The only exception mentioned was a project to provide cardiovascular risk assessment software and support to practices, in which a PHO actively advocated and supported software uptake and created an incentive scheme for practices to participate.[10] Researchers were clear that, in general, 'PHO problems' are not 'practice problems' and PHOs have relatively little scope to construct financial or other incentives that are meaningful to practices.

Two researchers told of help from non-governmental organisations with connections to specific patient or public communities, such as the Arthritis Foundation, Grey Power, New Zealand Aged Care Association and Alzheimer's New Zealand and Asian community agencies. There was still only one layer of intermediaries – the organisations allowed individual employees or volunteers who had front-lines contact with potential participants to act as intermediaries.

This was a separate issue from engaging PHOs and other organisations to promote a message of support for a study. Most researchers thought that attaining support from relevant organisations was important to create legitimacy for their project in the eyes of their intermediaries and participants.

Minimise intermediary burden

Intermediaries identified potential participants and might initiate the invitation process. The next step was taken back to the research team:

> The recruitment doesn't depend on them [intermediaries], it depends on me. So either I'm in the practice myself in the waiting room or whatever or one of my research nurses are or we send out a letter of screening that goes to all of their potentially eligible participants. We've done that lots. (R2)

Inclusion and exclusion criteria, applied by the intermediary, must be kept to a minimum:

> Now that's one of my key things; if you have too many exclusion criteria it becomes too much hard work and people don't want to do it. (R3)

The same researcher noted that exclusions also reduce the value to the intermediary of any incentive based on the number of participants entering a study.

The whole approach could be called 'light touch' *(R2)* by which she meant:

> I design the trials so that it takes minimal effort by all the practice staff. They don't have to do much, they don't have to assess much … they hardly know I'm there. (R2)

Once participants were identified, researchers generally preferred to undertake any further assessment away from the

practice – such as at the patient's home or at a university facility.

More often than not, researchers were asking intermediaries and participants to undertake activities with no immediate or likely benefit to them personally. Occasionally, a fortunate researcher could offer clinicians the opportunity to participate in research that allowed them access to a service they thought would be valuable to their patients and make their own work easier or more interesting. One example was a trial of direct GP access to an exhaled breath analysis that promised to diagnose *Helicobacter pylori* infection quickly – recruitment 'sold out' very quickly. Another example was a trial of point-of-care testing devices in a rural setting.

Minimise participant burden

Participant load included the initial information and consent process:

> You want a one page participant information sheet if you can get away with it. Lately I have been able to, one page, so it's quick. And a quick consent really really simple and just do the absolute necessary things that you need. (R2)

As the same researcher explained, if a series of assessments on a series of participants were required, then enough research staff should be made available to manage participants without any waste of their individual time:

> I try to keep it minimal and just to the things you really have to measure. … Don't go collecting extra data. It's just you know you think oh yeah it's only an hour and a half of their time but that makes a difference you know. So keep the participant load to a minimum and don't see them too often. Usually people say let's see them at baseline, six weeks, three months, six months, 12 months. I'd say for one that's a huge participant load and two your measures are going to be more intensive than your intervention if you are giving a brief intervention of physical activity of something. … So there are some really really important reasons that you might need to do an in between measure like at the end of the program or for safety. But usually I say try and do it beginning, end, minimal. Try and make your measures less intensive than your intervention. (R2)

Acute versus chronic conditions

One researcher reflected that different strategies were needed to recruit participants with acute rather than chronic conditions. People with chronic conditions could potentially be identified from a list and were potentially 'available' for recruiting all the time. People with acute conditions were potentially 'available' for only a short period of time, which might even be at night or on a weekend. Even 'common' acute conditions such as gout or sore throat appeared to be very 'uncommon' if a salaried recruitment manager was sitting in one place waiting for them:

> So I think paying per item is a good way to go. In the sore throat study I had the [recruitment] manager on a salary and I changed that to [payment for] patients recruited because again we were starting to chew through the salary. We were going to be out of money if we kept paying her a weekly wage because we just weren't getting the patient numbers. (R1)

Researchers speculated that patients with acute pain were more concerned about quick relief than making decisions about entering a trial. This was supported by one potential participant who did not enrol:

> If they're already unwell, it might be too much to commit to something … so they need to have time to think about it. (P1)

Appropriate study design

One researcher reflected that perhaps he had been too strongly wedded to randomised controlled trials. In the context of patients not wanting to be randomised, he now recognised that individual patient stories could be compelling, as in the following quotes from the gout trial, and could be collected in non-randomised study designs:

> Before I joined the study, gout … affected my work to a point where I had to miss work for a few days and even up to week … I couldn't walk, stand and couldn't go to church and work. … I heard on the radio about the gout study … There was a big change to my gout since the day I joined the study … After the first day I started taking the medication the pain started to slowly decrease up to today. Today I feel no pain, I can walk properly and even can now run. I followed exactly the instruction for the blister pack. It was great. It was easy to know which medication to take and when. (P2)

> With the gout, I was unable to walk. At times I will be crawling on the floor because I can't get from one area to another or I have to call someone to help me … Since I joined the gout study I hardly have a gout attack. I was able to eat what everybody eat. I had a pain of 7/10 and it has been 0 since after 4 days starting on the blister pack. (P3)

> Thanks a lot, it helps out heaps. (P4)

Engaging GPs to support patient recruitment

For recruiting patients from primary care, contact with GPs was generally necessary to inform and get their agreement for other staff to act as intermediaries in recruiting patients from their practice. Researchers were clear that GPs themselves are not good intermediaries. Engaging GPs generally required a direct approach from a colleague:

> [I was successful in recruiting] because I was a GP in [region] and I just rang every GP in [region] and asked them if they would take part. Probably about two thirds of them said yes. … So just word of mouth and personal contact and persistence. You know I kept ringing, kept ringing and kept ringing until I got them at lunchtime and asked them. (R2)

GPs needed to see the research question as relevant and important. This was partly to engage their own interest and support for staff as intermediaries, and partly because the GPs saw themselves as responsible for protecting their patients from low-value research.

Engaging GPs as research participants

GPs also needed to see the research question as relevant and important if they were to themselves agree to be participants. Researchers agreed that GPs saw themselves as overwhelmingly busy so that a request to take part in research was in competition with the rest of their work and life:

> It's not only that you've got to have a really good question and it seems relevant … but for me there's somehow got to be a win you know. (R5)

Paying GPs as participants needed to recognise that they often ran a small business.

> [Without paying] you're docking their pay by getting them to take part in research. So I am a real advocate of paying the GPs for their time. Not an incentive to recruit absolutely not it's just a reimbursement for their time and costs and it probably doesn't cover them all. (R2)

Payment varied from one-third to the full amount they would earn if they spent the same time seeing patients, but the strongest recommendation was the full amount. On the other hand, incentives did not always have to be large. One researcher doubled response to a GP survey when a single chocolate mint was stapled to the questionnaire:

> I just remember thinking the difference was that chocolate I'm sure. It's just the little acknowledgment. If you give them something even no matter how little there is a slight feeling of oh I want to do something back, you know. (R2)

What do patients think?

Researchers agreed that they needed a communications strategy built upon knowing the reasons people might or might not want to participate in their trial, where potential participants might seek information, and also what potential misinformation could be actively averted. Answers to these questions could be generic within a particular target community as well as specific to a study or condition. In the case of the gout study, many patients responded because they hoped for a treatment better than what they already had. Some hoped for a single treatment to cure them long term, despite previous disappointment.

Most had responded to a personal invitation letter from their doctor, whom they expected to know they had gout and to contact them only about a study their doctor considered might benefit them, mirroring the responsibility researchers had noted in their conversations with GPs. Many had heard about the study earlier and discussed it with family, friends, at church or other social gatherings before or after the invitation letter, or had heard about it from a community radio station in the Tongan or Samoan language:

> I first heard it on radio but I signed up when my doctor wrote. I think it was a letter from my doctor or from your study. (P5)

> Yes I have friends and family members who know I have gout and they have gout too and we did discuss it at our church and kava club. We all wondered about it in the same way I guess. Will this be a different or better cure? Will it be long-lasting? And because there is not a single cure for everyone with gout, people will always look out for something that will suit them – and I'm the same too. I thought it would be different and new otherwise why would my doctor want me to come to you? And I think it was different in some ways but generally speaking it was about the same. Except having to take the pills everyday. I didn't know about that. I've always lived and hoped that there will be a life-time cure but I think if there was we would have heard or known about it by now. (P5)

> I think all of those you'll need to use because not everyone will hear it on the radio and the word will take a while to get around. But definitely through the churches and other community groups. They will get the word out much quicker. (P6)

They understood that it can be difficult and slow to recruit participants and recommended and expected multiple strategies and enough time for these to work. Consistent and clear messages were needed, along with an indication of the participant commitment required. Several advocated using a front-person or 'champion' who was credible to the target community:

> It isn't easy to get people to commit to something like this unless they see its worth or value. So you need a lot of time to do work in advance and during the recruitment. There is a need to make sure that the information is consistent and clear. What do you want from us and what do we get for the co-operation you require. If it is not explained clearly, people will interpret it to suit themselves or they will take away the wrong message and once that takes hold, it isn't easy to do away with it. (P5)

> You also need key individuals to lead or champion your cause. It means it will be an expensive exercise but as we found out doing the [named] campaign, these things take time because people are not easily persuaded anymore. They often become cynical if the claims of help or assistance is far-fetched or difficult to believe. (P5)

> I will support it because I know that they will need it. But I can't guarantee that they will act on it on my recommendation alone. You can't just rely on one way or one person to make things happen for you. The more ways you use, the better your chances are and you will need a lot of time – and patience. (P5)

The strongest appeal of the gout study seemed to be the promise of free expert help:

> Free medicine and advice and the chance to talk to someone new or different. (P5)

> A specialist or someone new that I can talk to about my own gout experience. The other issues were important but not as important as someone with specialist knowledge. (P6)

> Yes the thought of getting help and advice from another doctor, someone like a specialist did appeal to me. And so was the free medicine but more important was a different doctor and a more informed expert from the university. I was expecting a lot of help. (P6)

Gout had some stigma attached to it, which may have put off some potential participants. It was also clear that this may apply to many other conditions:

> I know some people who do have gout in my church but won't admit they have it – and they're ashamed and will go on to use medicine other people are using or they treat themselves with what they hear other people find effective. I know that some people do that a lot. (P8)

Several participants indicated that they were happy to encourage others to join the study but noted that they would want to be quite confident of the study benefits before recommending it to others:

> I think that if you offer help through the study and then persuade those people to help you bring others into the study. Some people will feel obliged to help you because you have helped them. But they will need time to do that because they need to be convinced first that your advice is effective. (P8)

> I would recommend it highly because I know what it did for me. If it wasn't for the study I wouldn't be this comfortable or knowledgeable. I told my brother about this because he has gout too. He was surprised by how much I know and how little he knew. (P7)

> I think we can encourage them especially if the results are positive and that it works. I don't see any point in recommending something which won't work because you don't want to disappoint and let people down. (P6)

Potential participants who did not enrol in the study gave several reasons. The most common was that they did not have gout at the time. Some would have been happy to be contacted again, when they might have had gout, and may even have been disappointed or frustrated that researchers had not attempted to contact them again. This underlines recruitment difficulties specific to studies of acute rather than chronic problems:

> You should have rung me last weekend because I was really suffering from gout in my leg and I couldn't walk. (P9)

Others reasons included being busy at work at the time, having no transport at the time, using alternative treatments with traditional medicines, acupuncture or dietary supplements and other means of self-help:

> I had a neighbour who I talked to at the time about my symptoms and he said that it sounded like I had gout and he gave me some of his medication to try. I was pretty lucky. (P9)

> My minister suggested this to me. I confided in him that I was having these symptoms and he suggested that I take [nutritional supplement]. He said other people with similar symptoms have also tried [nutritional supplement] and have had the same results. (P10)

For others, the researchers had failed to communicate key messages:

> I thought it must be a new company trying to promote their new medicine. It needs to be advertised better, maybe even in a television commercial. (P9)

Discussion

Successful researchers stated repeatedly that recruitment was the single most important component of running a study, and that recruitment is, more often than not, under-planned and under-resourced. Even the most successful researchers had stories of failure, but they had learned to actively monitor recruitment and adjust strategies, if needed, during the course of recruitment. There is no single 'recipe' for recruitment, but many examples of effective strategies adapted to their context.

Most of the trials we learned about had used indirect recruitment, such that there was at least one 'layer' of intermediary between the researchers and their target participants. Such layers must be kept to a minimum, preferably to one. In the New Zealand, primary care context recruiting patient participants generally meant dealing directly with receptionists, practice nurses and doctors in general practices. Doctors in primary care were generally included by way of seeking approval and permission (in the case of small business owners) rather than being involved in recruitment in an on-going way. Successful strategies required a personable, energetic and well-organised project manager. During recruitment, more attention was typically directed to intermediaries than to the target participants. Detailed planning and imagination were applied to minimising the research burden of all intermediaries and all participants. Wherever possible, workload was diverted to research staff. Participants were not paid as such but costs were recognised and recompensed. There was a sense from several researchers that they felt payment was pragmatically essential but they needed to choose their words carefully to justify payment within ethical guidelines of non-coercion.

Strengths of this study include interviewing participants and eligible non-participants in a trial, together with senior researchers, project managers and advisors. The researchers included some of the most published academics in the country and together they had extensive experience with recruiting a wide range of intermediaries and participants for quantitative and qualitative, interventional and observational studies. Limitations include interviewing participants from only one trial. The need for translation of patient interviews was both a strength (it allowed access to people who would otherwise be unheard) and a weakness (in that it required a further element of interpretation). Author T.W.K. reviewed each of the translated interviews with the interviewer/translator to help ensure interpretation was appropriate to our investigation.

The gout study that started this investigation appeared to fail due to poor recruitment. Coincidentally, the central question being addressed – was a particular drug regimen safe and effective – was answered by a publication of a similar trial while the New Zealand study was underway.[11] Meanwhile, it became apparent that, even with the small numbers involved, the New Zealand trial collected powerful stories from patients who told of their lives being greatly improved by the trial regimen, while also effectively piloted using of medication 'blister packs' to make the complex regimen simple for patients to use. These stories and the technique of blister packing have since been widely used in New Zealand to promote a change of practice, and, we think, have changed practice in a way that the numerical results from an overseas trial would never have done. One of the lessons for us is therefore to recognise that the decision to use a randomised controlled trial had direct implications for recruitment and to question whether this was the best research method for bringing about a specific change in practice. This is an issue we have raised in the context of another recent trial.[12]

Recruitment of relatives and friends of happily enrolled participants was the most successful source of new enrolments for several studies. No researchers mentioned incentives to current enrolees to recruit more people. However, several participants noted that they would want to be quite confident of the study benefits before recommending it to others, which has implications for recruiting to blinded trials.

PHOs are the main organisational groups for general practices in New Zealand. Each country has its own models and its own terminology such as primary care trusts and independent practitioner associations. We expect that everything we say about PHOs in New Zealand will apply to their equivalents elsewhere. PHO involvement can offer a researcher access to routine meetings of groups of doctors, and can sometime allow access to data that is held by PHOs from or on behalf of practices. In our experience, PHO and practice policies around privacy and data governance are often so inconsistent and poorly worked out that the access to data is not forthcoming. At worst, involvement of PHOs becomes an additional and unhelpful intermediary layer between researchers and target patients.

Findings from this study are consistent with findings and recommendations from other studies. GPs were more likely to respond to a survey endorsed by a trusted network of professionals combined with explicit compensation payment.[13] GP recruitment was more successful when undertaken in person by doctors with whom they had a previous relationship.[14] General practice recruitment was improved by getting buy-in from all practice staff, minimising disruption to a practice and being flexible to accommodate the work routines of different practices.[15] Projects need to reduce the layers of intermediaries.[16] One group of authors has suggested that trials run in primary care should include nested studies of recruitment strategies.[2] We think this study emphasises more than much previous work the need for a systematic approach to recruitment that is well-resourced and planned before the study, monitored and adapted throughout the recruitment phase of the study, uses multiple channels of communication customised to the target audience, and that manages, rewards and minimises the research burden for intermediaries and participants.

If the purpose of your research is to recruit, measure then finish the study, the methods above are relevant and useful. There are very different processes for recruiting if you seek a long-term learning partnership with a community, such as for advocacy and action research. These were strongly articulated by Māori and Pacific interviewees. They spoke of multiple processes within one overall message of relationship, reciprocity, and respecting and building mana (Māori) or va (Pacific). These are not further detailed here as there is strong Māori and Pacific literature on the subject,[17–19] and researchers who are not themselves Māori or Pacific and familiar with these ideas should seek to work with someone who is.

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The authors declare that there are no conflicts of interest.

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Supplementary materials

We have provided the interview guides. We do not have permission from our interviewees to make the transcripts of their interviews available beyond the researcher team.

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Appendix 1

Interview guide for patients who participated in the gout study

Name Stayed in study/entered and withdrew
Age Gender

Check if gout still ok and discuss and advise to see doctor as needed.

We had trouble getting as many patients as we wanted in the gout study. We want to ask you why you came and how we might get more people like you into a study like this in the future/get more people like you into a study and stay in the study.

1. (All) We think that people who joined the study probably heard about it several times. What about you? When did you first hear about the study? Did you hear it anywhere else or from anyone else after that?
2. (All) We think that people who joined the study probably talked it over with family or friends. What about you? Who did you talk it over with and what did they say?
3. (All) We think that people who joined the study were probably fed up and frustrated with their gout and ready to give anything a go. What about you? How long have you had gout? How many doctors and nurses had you been to with your gout before joining the study?
4. (All) Has any doctor suggested you take a tablet every day to stop gout? Had you heard of allopurinol before?
5. (All) We think that people who joined the study probably thought they would get better medicine in the study than from the doctors they had already seen. What about you? Did you think you would get just a little help? Or a lot of help? Or did you think you would get cured for life? And what actually happened for you?
6. (All) As a gout patient, your doctors and nurses have probably given you a lot of information about gout, but was there anything new that you learned about gout through this study that you think we should share more with our community?
7. (All) If we started the study again, what advice would you have for us about the best way to invite you or recruit someone like you into the study? (Your church – who, radio – which station, caravan in a market – which market, a letter or personal advice from your doctor, from your nurse?) Please expand or explain.

8. (All) If we were running a new study the same as this one and a friend asked you about it, and asked if he or she should join the study, what would you say to them? Please explain more/why do you say that?
9. (All) When we publicised the study we advertised several things. Which ones attracted you the most? Blister packs? Free medicine? Not paying to see a doctor? Time to talk?
10. (Withdrew) You started in the study then pulled out. That's your choice, that's ok, but I wonder if you can tell me about why, and what we could do next time to make it work for you/easier for you? Would payment, transport or something else help?

Before we finish can I please confirm some details? Ethnicity/s? Where were you born? When did you come to New Zealand?

Appendix 2

Interview guide for patients who did not participate in gout study

Name Eligible, declined/not eligible – no pain/not eligible – other

Age Gender

Check how gout is, discuss and advise to see doctor as needed.

We had trouble getting as many patients as we wanted in the study. You found out about the study but were not eligible/decided not to go in the study.

We want to ask you why you asked about the study and how we might get more people like you into a study like this in the future.

1. (All) We think that people who asked about the study probably heard about it several times. What about you? When did you first hear about the study? Did you hear it anywhere else or from anyone else after that?
2. (All) We think that people who asked about the study probably talked it over with family or friends. What about you? Who did you talk it over with and what did they say?
3. (All) We think that people who asked about the study were probably fed up and frustrated with their gout and ready to give anything a go. What about you? How long have you had gout? How many doctors and nurses had you been to with your gout before joining the study?
4. (All) Has any doctor suggested you take a tablet every day to stop gout? Had you heard of allopurinol before?
5. (Declined) You could have come into the study but chose not to. What finally put you off?
6. (Declined) We wonder if some people did not come into the study because they were scared of what doctors and nurses might tell them – how about you? We also wonder if some people just don't want to be lectured about what they eat and drink, just don't want to know – how about you?
7. (All) We think that people who joined the study probably thought they would get better medicine in the study than from the doctors they had already seen. What about you? How much help did you expect to get from the study? Did you think you would get just a little help? Or a lot of help? Or did you think you would get cured for life?
8. (All) If we started the study again, what advice would you have for us about the best way to invite you or recruit people like you into the study? (Prompts: your church – who, radio – which station, caravan in a market – which market, a letter or personal advice from your doctor, from your nurse?) Please expand or explain.
9. (All) If we were running a new study the same as this one and a friend asked you about it, and asked if he or she should join the study, what would you say to them? Please explain more/why do you say that?
10. (All) When we publicised the study we advertised several things. Which ones attracted you the most? Blister packs? Free medicine? Not paying to see a doctor? Time to talk?

Before we finish can I please confirm some details? Ethnicity/s? Where were you born? When did you come to New Zealand?

Appendix 3

Interview guide for researchers

Check: Participant Information Form (previously provided) – any questions?

Thank you.

1. We approached you because you had been involved in one or more studies based on primary care or the community. Can you please briefly describe this study/these studies?
2. How many people did you plan to recruit and how many did you end up recruiting?
3. How long did you plan for recruitment to take and how long did it really take?
4. How long did you plan your study to last? How long did it really last?
5. Did participants withdraw from the study before it was finished?
6. Please describe and explain how you went about recruiting your participants. How much time and cost was involved? Which research staff did this involve?

Did strategies vary between ethnic or other groups of participants (such as by gender or age)? (Prompts)

a. Relationships with communities
b. Ethnic concordant researchers
c. Language concordant researchers
d. Radio
e. Print media
f. Electronic media
g. Social network media
h. Personal invitation
i. From general practice or other health care provider
j. Church or other social/community organisation
k. Patient support group, society or network
l. Incentives, payments, rewards

7. Please describe how you went about retaining you participants. How much time and cost was involved? Which research staff did this involve? Did strategies vary between ethnic or other groups of participants (such as by gender or age)? (Prompts)

    a. Relationships with communities
    b. Ethnic concordant researchers
    c. Language concordant researchers
    d. Frequent contact – how?
    e. Incentives, payment, rewards

8. What advice about recruitment and retention would you have for others trying to undertake this sort of study?