

Diabetes research nursing

In this regular column, Shona Brearley discusses diabetes research nursing from a practical perspective, with the aim of sharing best practice ideas and giving readers the chance to ask for advice about their particular study. If you have any queries, or would like to contribute to this column, contact jdn@sbcommunicationsgroup.com.



Study recruitment is the biggest challenge for the diabetes research nurse

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This month, I thought I should discuss the biggest challenge to every diabetes researcher – recruitment to studies. During the feasibility phase of designing a study, there always seem to be many people with diabetes who could potentially fit the eligibility criteria but as soon as the study has been funded and received all its regulatory approvals, these people all seem to disappear. I recall one study which took so long to get through ethics and gain research and development approval that the desired type 2 diabetes population, who were angiotensin-converting-enzyme (ACE) inhibitor and statin naïve, had completely vanished by the time the study was ready to recruit. The moral of the story? – that researchers designing studies need to look very carefully at clinical practice and prescribing practices, as well as any planned changes to either of these before finalising protocols.

Approachability

The traditional method of recruitment involves a research nurse waiting around the diabetes outpatient clinic, identifying and speaking to eligible people. Whilst undoubtedly this is a successful approach, there are many factors which can influence a person's decision to participate or not. The most important factor, especially for research-naïve people, is the approachability of the research nurse and her in-depth knowledge of the study. The Scottish Diabetes Research Network (SDRN) surveyed people involved in research in Scotland and found that having a trusting relationship with the research nurse made them feel confident about participating (unpublished findings). So, first impressions count when asking people to become involved in research.

Although not a scientific trial, the diabetes research nurses in my research unit always wear their NHS uniforms when attending the outpatient clinic to recruit for studies, as they

believe that people will immediately recognise them as nurses and it helps develop a rapport with individuals. The Scottish public certainly seems to trust NHS branding.

Research nurses who approach people directly in the diabetes clinic must have in-depth knowledge of the studies that they are recruiting and they must be confident that they can answer any questions about the study accurately. Research nurses can use materials such as patient information sheets during discussions in order to reinforce certain points, but they must be able to answer questions, such as study duration and number of visits, without hesitation.

Anecdotally, our research nurses have commented on how it is more difficult to recruit people if the nurses feel they are not “on top form”, for example if they are having a bad hair day, if they slept in and had to rush to work, or if they had a row with their family members before leaving for work. Whilst this would be very difficult to measure and prove scientifically, I believe that it is very likely to be true as the research nurse has to appear motivated and committed to the study to develop the trusting relationship with the person with diabetes and recruit successfully. If your personal circumstances are distracting you, your body language, tone of voice or choice of words may not be optimal for recruiting.

Research registers

With the development of technology and clinical databases, several prototype “research registers” have been established. A number of pharmaceutical companies and contract research organisations have invited the public to register an interest in participating in studies. Whilst this approach appears to have been moderately successful in the US, uptake in the UK has been much lower. Within the last 7 years, the SDRN has set up its own research register, which has elicited a terrific response from the Scottish diabetes population. There are now

more than 11 000 people with diabetes who have registered their interest in participating in studies for which they are eligible. The SDRN research register sits on top of the national clinical database SCI-Diabetes (<http://bit.ly/143evE0>), so we can accurately identify eligible patients for studies by searching on any clinical parameter, which is routinely collected in everyday practice. This means, as well as increasing the recruitment rate, the screening failure rate has decreased.

So now, when a Scottish diabetes research nurse is at the recruitment stage, he or she simply completes the search request form and within 48 hours they will receive a list of people who fit the eligibility criteria. As these people have agreed to be approached about studies, they are normally very keen to be involved and it can be as simple as phoning them to explain about the study before sending out the patient information sheet and booking a screening appointment.

Professor Martin Gibson is leading on a similar research register in England, “Help Beat Diabetes” (www.researchforthefuture.nihr.ac.uk), which currently has 1250 volunteers recruited. The success of the Scottish diabetes research register has led the Scottish government to fund a project (SHARE) to create a register of up to 1 000 000 Scottish people who have agreed to being approached about research (www.registerforshare.org). This project will cover all clinical areas and both primary and secondary care.

Hard-to-reach groups

The problem of recruitment to studies of “hard-to-reach” groups, such as teenagers or minority ethnic people, will still exist as these groups may not be keen to join a research register. So blue-sky thinking may still be appropriate when the study



It is important for research nurses to be approachable and have an in-depth knowledge of the study when recruiting people with diabetes.

requires a hard-to-reach group. One great recruitment strategy proved very successful for one diabetes research nurse from Newcastle:

“I needed a focus group of teenage boys with type 1 diabetes so I decided to hold the focus group in St James’ Park (where Newcastle United play) and included a tour of the stadium after the focus group.”

A study in Edinburgh (PODOSA) required the recruitment of South Asian families to look at the effects of dietary advice on the progression to diabetes from impaired glucose tolerance (IGT). As the main cook in the family often did not speak English, as well as translating all study information into the appropriate language, mainly Urdu or Punjabi, the study employed dietitians who spoke Urdu and Punjabi to deliver the intervention (Douglas et al, 2011). Again, it may have been difficult for these families to express an interest in participating in research through either an approach by an English-speaking diabetes research nurse or by joining a research register.

Keeping people informed

From the patient advocacy point of view we owe it to people with diabetes to inform them about research projects and give them information to allow them to make an informed choice as to whether to participate or not. Advertisements in newspapers and on local radio always seem to generate favourable responses from patients (although, many years ago I was swamped when I advertised for type 2 diabetes patients to try a weight-loss drug – the phone rang non-stop for days). So, perhaps we just need to improve awareness of the studies that are being conducted in our local areas to help solve recruitment problems.

The SDRN recently audited around 300 research participants as they completed a trial and asked why they had taken part. A small percentage said that they thought that their diabetes care would improve and they would learn more about self-management, but the vast majority said that they were doing it so that others who have diabetes would benefit. This altruistic view was particularly prevalent amongst people with type 2 diabetes, who were well aware that their children and grandchildren were at significant risk of developing diabetes.

In conclusion, recruitment is often the greatest challenge in all studies, but if we can integrate the identification of eligible people with appropriate communication from the research team, then perhaps we can move studies forward more efficiently, with tangible benefits to people with diabetes once the results are published. Most studies will require a “mixed methods” model of recruitment with the percentage of recruits from traditional, research registers and blue-sky thinking varying dependent on the target population of the individual study. ■

Douglas A, Bhopal RS, Bhopal R et al (2011) Recruiting South Asians to a lifestyle intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes & Obesity in South Asians). *Trials* 12: 220