

A research organisation developed a nursing research model to focus on volunteers' needs, promoting participant recruitment and engagement in future studies

# Research model places volunteers at centre

## In this article...

- › Factors preventing volunteer participation in research studies
- › Principles of the Volunteer-Centric Model for nursing research
- › How to put the volunteer first when conducting research

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Recruiting participants to research studies can be challenging. The Cambridge BioResource nursing team at the National Institute for Health Research has developed the Volunteer-Centric Model for research, which provides strategies for optimising volunteer recruitment, engagement and retention. Key to the model is ensuring the volunteer's experience remains paramount throughout the research process. This article describes the Volunteer-Centric Model, its key principles and how these facilitate the effective and efficient delivery of research.

The number of people in the UK participating in clinical research is increasing; in 2014/2015 at least 620,000 volunteers participated in studies supported by the National Institute for Health Research (NIHR, 2015). This number will likely increase as the Department of Health seeks to expand research participation to improve the nation's health and wealth.

The NIHR Cambridge BioResource (CBR), established in 2005, includes over 16,000 volunteers who can be contacted to take part in a variety of research studies investigating links between genetics, health, disease and the environment. Volunteers join by donating a blood or saliva sample, from which their DNA is

extracted. They are then invited to take part in studies based on their genetic make-up and other information such as sex and ethnicity.

Attracting and retaining study participants is essential to the success of CBR and the studies it supports. Volunteers receive no feedback on genetic information and there is no financial incentive offered for joining. Although they are reimbursed for their travel expenses, there are no extrinsic incentives or rewards. Engaging these volunteers therefore presents unique challenges as there are no perceived, or actual, direct benefits such as receiving a trial drug or having access to new treatments.

## Background

It is widely acknowledged that recruitment and retention to research is a challenge. Volunteer participation can be negatively affected by a variety of factors, such as:

- › Work/inability to take time off;
- › Additional travel;
- › Lack of interest/inclination;
- › Time;
- › Transport;
- › Physical limitations (Newington and Metcalfe, 2014; Gul and Ali, 2010).

Although many difficulties are practical, researchers need to recognise barriers and implement strategies to overcome them (Gul and Ali, 2010).

While engaging volunteers continues to be a challenge for many research groups, the CBR reliably meets recruitment targets of the projects it supports. The team reflected on this success and identified that nursing practice is a key factor. To define our practice, we developed the

## 5 key points

- 1** Recruiting and retaining volunteers for research is challenging
- 2** Research studies should focus as much on the needs of volunteers as those of researchers
- 3** Having a flexible approach to research can help engagement with hard-to-reach groups
- 4** Good practice should be shared among researchers
- 5** The Volunteer-Centric Model can be adapted to fit different fields of research



Nurses can alter their working patterns to engage volunteers at convenient times

FIG 1. THE VOLUNTEER-CENTRIC MODEL FOR NURSING RESEARCH



Volunteer-Centric Model (VCM) of research nursing to promote excellence in research delivery; this seeks to consider the needs of volunteers and keeps them at the centre of practice.

We are always looking for ways to improve how we engage with volunteers and can make research more accessible in the wider community. The CBR's organisational culture supports this by encouraging flexible working, autonomous practice and fostering change. For our volunteers, the VCM means we prioritise their needs – we want them to feel we will go the extra mile to make their participation in research an easy, positive experience. For researchers using CBR, our model facilitates a collaborative approach, with a focus on delivering the study on time and with appropriate consideration of resources.

Our approach enables us to engage with hard-to-reach volunteers and ensures we deliver scientifically sound research – we believe it could help other researchers

to improve recruitment and engage with wider populations.

### The Volunteer-Centric Model

Nursing models were developed to guide practice and education; they help to describe the beliefs, values and goals of nursing practice, and what skills and knowledge are needed to achieve these (Murphy et al, 2010). While many have been criticised for their complex concepts and use of jargon (Kenny, 1993; Hodgson, 1992), the VCM is intended to be simple, adaptable and universally understood.

Using strategies to standardise and improve care is advocated by the Research Governance Framework (DH, 2005), as well as being consistent with the Good Clinical Practice principles set out by the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH, 2005).

The main aims of the VCM (Fig 1) are to define and promote our organisational culture, and facilitate the recruitment and

positive engagement of volunteers. It encapsulates our six interconnecting principles of practice:

- » Successful delivery of research;
- » Standardise practice;
- » Collaborative working;
- » Promote autonomy;
- » Maximise engagement and accessibility;
- » Positive experience and re-engagement.

Each principle comprises key components that help to guide the practical application of the model.

### Successful delivery of research

This principle aims to ensure research:

- » Is delivered on time;
- » Adheres to protocol;
- » Is scientifically sound;
- » Considers the volunteer's perspective throughout.

To achieve these objectives, all research staff practise in line with the study protocol, local policies and the principles of good clinical practice. We encourage

## Nursing Practice Innovation

### BOX 1. THE VCM MODEL IN PRACTICE

Cambridge BioResource's organisational culture has helped us implement several strategies to support the recruitment and engagement of hard-to-reach volunteers. These include working flexibly, to allow staff to contact volunteers outside office hours, and providing staff with mobile phones so they can reach volunteers by text message. This has been especially successful with younger volunteers, who often wish to communicate in this way.

These volunteer-centred solutions have allowed us to effectively engage with a population that is often under-represented in research. We have also found that, once we have engaged volunteers in research, they are much more likely to take part in other research studies in future.

The interventions outlined here are underpinned by three of the model's principles: successful delivery of research, maximising engagement and accessibility, and positive experience and re-engagement.

research nurses to be involved in setting up the study and reviewing its paperwork, enabling us to ensure the volunteer's safety and successfully translate the research into lay language.

Research nurses liaise with clinical researchers to discuss the study's day-to-day running including timeframes, sample collections and research parameters to ensure a flexible, adaptable approach. Good working relationships with researchers are vital so we can advocate for our volunteers and identify any issues promptly.

#### Standardise practice

Standardising best practice is important to ensure consistently high standards of service delivery. The principle aims to ensure positive engagement of volunteers and consideration of funding.

The CBR nursing team encourages an environment of critical thinking and reflective practice to provide high-quality care and successfully implement change. A supportive workplace culture and problem-solving approach is imperative. We advocate the sharing of our processes, experiences and ideas with our team and wider research colleagues via informal meetings or organised forums (for example, sharing CBR policies with teams



Volunteers can be informed about the research study and about its outcomes

that may be setting up research visits or doing them for the first time).

Being considerate of funding means adopting practices to ensure nurses are working in an efficient, effective manner – an objective reflected in the NIHR's (2016) *Adding Value in Research* directive. Applying our model is cost effective, as time and resources are valued appropriately – for example, off-site visits are undertaken only after the cost/benefit has been considered, and when researchers know the value of the samples collected and treat them accordingly.

#### Collaborative working

Working collaboratively means we fully engage with all stakeholders (for example principal investigators, researchers, clinical teams, volunteers) to ensure delivery is successful and volunteers have a positive experience. We strive to maintain good communication with stakeholders to encourage open discussions on all aspects of study management.

Research nurses ensure the study sees volunteers' needs as equal to those of the researcher. We critically review study parameters – including sample requirements, appointment times and locations, fasting requirements – to maximise the flexibility we can offer, which should result in a positive volunteer experience and improve re-engagement rates.

While individual nurses each have autonomous responsibility for individual studies, we work collaboratively within the team to share outreach visits geographically, thereby ensuring timely and cost-effective working. The CBR also works alongside other BioResource centres, clinical research facilities and NHS clinics for volunteer recruitment and recall appointments, which helps us to:

- » Support cross-sector working;
- » Share good practice;
- » Ensure efficient use of resources.

#### Promote autonomy

Promoting autonomy is a key theme of the VCM and pivotal to our nursing practice and the working culture of our nursing team. We work closely with medical and research staff but are not led by them. Research nurses have the authority to make decisions and the freedom to act within their own scope of practice and knowledge base. Autonomous practice is empowered and supported by the positive culture of our nursing team and encouraged in our day-to-day activities; we believe that, along with leadership, it is key to successful study delivery.

To make informed decisions, nurses require a good knowledge of research methodology and nursing practice. Additionally, developing policies and standard operating procedures to standardise and promote safe, excellent practice further helps the team work autonomously. This commitment and expertise are instrumental in ensuring consistent delivery of recruitment targets and high levels of volunteer satisfaction.

#### Maximise engagement and accessibility

Attracting and recruiting as many suitable volunteers as possible is done via a proactive, flexible and positive approach. Recruitment is supported through various communication methods (post, email and text message) to engage a range of volunteers. Dependent on study protocol, we offer appointments at varied times and locations to suit volunteers' commitments. This facilitates the participation of hard-to-reach volunteers, such as working parents or those without transport.

Within the VCM, the research nurse is pivotal in adapting the research protocol to suit volunteers as much as possible, and will liaise closely with the researcher to accomplish this.

### Positive experience and re-engagement

It is important to give volunteers a positive research experience to encourage future participation and promote research within the wider community. We recognise that research participation is usually driven by altruism, with no extrinsic rewards or incentives for our volunteers – our aim, therefore, is to make participating as easy and enjoyable as possible.

Our approach is supportive and flexible so volunteers can influence appointment locations and timing, and we aim to let them guide the duration and style of research visits. We work hard to ensure their contributions are acknowledged and take time to explain the importance of their participation.



**16,000**  
NIHR Cambridge  
BioResource volunteers  
who can be contacted  
to participate in research

Research nurses are engaged in various patient and public involvement activities, including producing regular newsletters that update volunteers on research outcomes. Within the CBR, we engage a lay panel to help guide our interaction with volunteers and continually improve our service.

Box 1 outlines how the VCM works in practice.

### Findings and discussion

The VCM provides our team with an important resource, defines our working practice and guides staff in their interactions with volunteers and researchers. Using a volunteer-centric approach helps with problem solving and to ensure positive outcomes.

Use of the term “volunteer” is particularly important for us as it ensures participants are seen holistically and as research partners, rather than just the source of a sample or a recruitment number. The success of our approach is demonstrated by the scale and type of our volunteers’ participation: of 977 appointments between January 2015 and January 2016, 41% took place before 9am at volunteers’ requests. Although we offer off-site visits for most studies, a flexible approach to appointment timings resulted in over 60% taking

**TABLE 1. EXAMPLES OF VOLUNTEER-CENTRIC PRACTICE**

Volunteer-Centric Model principle	Practical example
Promote autonomy	Volunteer attends appointment but reports feeling ill. Research nurse makes clinical decision to postpone participation (needs of volunteer placed above research requirements)
Maximise engagement and accessibility	Research nurse alters working pattern to facilitate evening phone calls or pre-work appointments (ensures engagement of hard-to-reach volunteers)
Standardise practice	Research nurse shares standard operating procedures with other research teams and uses Volunteer-Centric Model to guide practice (provides leadership and support)
Positive experience and re-engagement	Research nurse visits volunteer at work, in a suitable location. Volunteer’s daily routine is unaffected and volunteer happy to participate in future (reduced “cost” of participation for volunteer)

place within our research facility in the same period.

Other groups have expressed an interest in the VCM, suggesting its impact and applicability could be widespread. The important element when considering its transferability is to keep the volunteer at the centre of care. This may mean re-thinking working practices and facilitating change – for example, although off-site visits may not be undertaken as standard within other areas, they may be beneficial to engage hard-to-reach volunteers. This change may need to be supported through nurse-led development of relevant policies and risk assessments, and will also require management support.

The model could also have benefits and be applied to other clinical services. It can be adapted – for example, client-centric model, patient-centric model – thereby providing a greater sense of ownership over its implementation. Its emphasis is on focusing the service around the client group. Table 1 provides some simple examples to further illustrate how the VCM can be used in practice.

### Conclusion

The VCM shows that in research nursing, as in clinical nursing, the patient/volunteer belongs at the centre of our work and that this can be achieved. The model could be used widely to address challenges commonly associated with recruiting and retaining research volunteers. It provides a useful framework for practice and promotes an organisational culture that facilitates a positive research experience for volunteers. The principles behind it are key to optimising accessibility to research, improving how we engage with volunteers and providing volunteers

with a positive experience to encourage re-engagement in the future.

● For more information on the Volunteer-Centric Model, visit: [Bit.ly/CBRVolunteerModel](http://Bit.ly/CBRVolunteerModel)  
We gratefully acknowledge the participation of all NIHR Cambridge BioResource volunteers, and thank the NIHR BioResource centre and staff for their contribution. We thank the National Institute for Health Research and NHS Blood and Transplant. Further information can be found at [www.cambridgebioresource.org.uk](http://www.cambridgebioresource.org.uk)

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