

HCAI RESEARCH NETWORK

SURF: Involving patients and public in healthcare-associated infection research

7 February 2008 - Regent's College Conference Centre, London

Workshop Report

Over recent years, the field of infection and antimicrobial resistance has become a focus of concern not only for healthcare providers, professionals and policy makers, but also for patients and the public. While researchers and practitioners may have considerable insight into the needs for research within a particular field they may have less of an insight into the concerns and issues important to patients and the wider public and may thus make assumptions based on narrow perspectives and a 'media' focused agenda. This said, there is an increasing recognition among researchers working in the field of infection and microbiology that current initiatives to improve the scope and quality of research necessitate the inclusion of patient and public perspectives. However, unlike other specialties, where service user involvement in healthcare research is well established, for example cancer and mental health, researchers in infections and microbiology (with the exception of Human Immunodeficiency Virus) have little experience of working with patients and the public to prioritise, design and conduct research and little or no access to service users able to contribute in an authoritative way to the research enterprise.

WORKSHOP OBJECTIVES

In order to establish strong public involvement in healthcare associated infection research, the Healthcare Associated Infection Research Network (HCAI-RN) aims to establish a Service User Research Forum (SURF). In doing so a SURF Workshop has been designed to attract people from all walks of life who may have an interest in:

- deciding how best to involve patients and public in future infection-related research;
- identifying the most important areas for research in this field;
- becoming involved in developing, designing and conducting new research;
- keeping the general public informed by publicising research findings.

THE PROCESS

The first SURF Workshop for Healthcare Associated Infection and Antimicrobial Resistance (HCAI/AR) Research was held on Thursday 7th February 2008 at Regent's College Conference Centre, London and was attended by 10 members of the public interested in becoming involved in HCAI/AR research. The morning session commenced with a welcome and general introduction from Alison Tingle, the HCAI-RN's Principal Research Officer. Professor Robert Pratt, Director HCAI-RN, was introduced and gave

a presentation which set the context for the day. Robert described the National Health Service and Department of Health (England) strategy for patient and public involvement and explained why in particular HCAI and AR are priority fields of research. He then outlined why service user involvement in this area is so crucial and how the aims of SURF might address this current deficit.

The morning was then dedicated to two external speakers, Sarah Buckland, Director of INVOLVE, and Geoffrey Aitchison, Co-ordinating Secretary of the Diabetes Research User Group at Warwick University Medical School.

Sarah delivered a presentation which explained to participants the work of INVOLVE and what public involvement in research is all about, providing some examples of areas of research such as arthritis and breast cancer where members of the public were actively involved in several aspects of the research process.

Following this Geoffrey gave a presentation on what it is like to be involved in a user research group. As the group's lay secretary, Geoff outlined his individual and the groups' contributions to research, which included advising research staff on all aspects of diabetes research, from first idea to final result.

After coffee, Simon Jones, SURF Coordinator, gave a short presentation on the research process, outlining how a research idea becomes a research proposal and the process that the proposal goes through from peer review to commissioning. Participants then gathered together to undertake a short exercise on assessing/reviewing a research proposal. Participants were given a sample proposal to read and asked to consider and discuss as a group how easy/difficult such an exercise was. Having completed the exercise participants were then asked to identify the training needs they themselves might require and training needs that could be useful to researchers. The list of needs identified were as follows:

Training needs for users

- Familiarisation with the layout of a research proposal document and guidance as to how to peer-review and assess the proposal, e.g. what sections to concentrate on?, how should feedback be formatted?, what types of comments are expected?, how much detail is needed? etc.;
- Guidance as to what other resources are available to research a subject further;
- Information Communications Technology training, e.g. using internet research resources, using PowerPoint, networking with other service users etc.

Training needs for researchers

- Guidance to make the patient the focus of the research;
- More concise research proposals;
- How to summarise proposals in plain English;
- Focus on key aims and benefits of research;
- How to stratify patients and service users for research (e.g. MRSA, CDiff patients);
- Defining the scope of a proposal effectively.

RESEARCH PRIORITIES

After lunch, Heather Loveday, Deputy Director HCAI-RN, gave a presentation entitled 'Setting the Scene'. Participants were informed about the way in which HCAI and AR is organised and funded in England. This also included information on how research is nationally co-ordinated, what the functions of research networks are, where research funding comes from and how the research agenda is informed. Following this, the participants gathered together again for the second exercise of the day; identifying research priorities in the following four areas:

1. What do we know about infections?;
2. What is the impact of infection on patients and carers?;
3. How do we improve practice?; and
4. What do we need to do to prevent acquisition and spread?

Heather facilitated this session with a brief presentation of the four broad areas of research need within this field. With a nominated spokesperson and scribe, participants brainstormed where they thought research was needed. The groups' initial brainstorming has been returned to the participants for further elaboration.

The final session of the day, entitled 'How Do I Get Involved?' was led by Alison Tingle. Alison outlined some of the questions that participants may want to ask before committing themselves to involvement in SURF, for example, 'How often are meetings?' and 'Do I get paid travel expenses?' She explained what SURF could offer participants and asked participants to complete the registration form in their delegate pack should they be interested in further involvement.

WORKSHOP EVALUATION

At the end of the workshop participants were asked to complete a short evaluation form. Of those that returned a questionnaire, most had either a good or excellent overall impression of the event. One participant commented that the presentations had been interesting and that there were good opportunities throughout the day for participant input.

All participants who completed the question agreed that the workshop had given them a clearer idea of what public involvement in research was all about and that the information they received had 'reinforced previous knowledge'. The majority of participants agreed that the workshop had given them an insight into how a research proposal is assessed, how research is organised and funded, and how SURF will develop in the future.

The venue and catering were fairly well evaluated. However, although the venue provided for people with disabilities, our disabled participants pointed out that future SURF venues could be more 'friendly' to those with disabilities, e.g. easier access to the disabled facilities.

Over half of the participants thought that the information and assistance they received prior to the workshop was either good or excellent, with the vast majority rating the assistance they received once at the workshop and the content of their delegate packs as either good or excellent.

SURF MEMBERSHIP

As a result of the workshop, eight delegates signed up to form the first members of SURF, seven as Core Members and one as an Associate member. As a Core Member, participants will be asked to attend SURF meetings (usually in London) at least two/three times per year. Some activities will be home based and there may be opportunities for other activities which involve travel, such as visits to research centres for meetings with research staff, or attending conferences. All reasonable travel costs will be reimbursed. As an Associate Member, participants will be asked to undertake activities which can be completed from home. For example, commenting occasionally by post or by email on: important questions and issues which come up about HCAs; the designs of specific studies and research methods; and the quality of patient leaflets. No travel is required in this role.

NEXT STEPS

SURF members delegates have until 14 March 2008 to further expand upon the Research Priorities list that they created at the event. This list focused on identifying research priorities in the following areas: What do we know about infections?; What is the impact of infection on patients and carers?; How do we improve practice?; and What do we need to do to prevent acquisition and spread? Once this process is complete and we have heard back from all members, we will post a date for the first official SURF Members Meeting along with details of our plans for a SURF Training Day and Open Information Day.