Research Update

CLINICAL INVESTIGATION

South East Scotland Cancer Research Network: an opportunity to expand

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After the introduction of the cancer research networks in Scotland in 2002, the opportunity arose to address the inequality of access to clinical trials for patients who live in rural areas and attend a district general hospital in the south east of Scotland. Working closely with local staff, a network nurse identified a suitable portfolio of studies appropriate to run in a hospital that previously had very limited trial activity. Funding was secured for a dedicated local research nurse to work with clinicians on a variety of cancer trials. As a result of this initiative, studies were opened and patients recruited to studies in breast cancer, leukemia, myeloma, lymphoma and colorectal cancer. Local governance and ethical requirements were addressed and patients are now being recruited to studies previously unavailable to them unless they were prepared to travel long distances for their treatment and follow up.

Keywords: cancer • district hospitals • equity of access • governance • infrastructure • portfolio • research

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With more than 200 types of cancer, each with different causes, symptoms and treatments and affecting more than one in three people at some point in their lives, it can be said that cancer is a common disease [101].

Both survival rates and treatments are improving and advances in prevention, early detection and treatment continue to be made. However, the number of cancers diagnosed in Scotland continues to rise, from 26,169 in 2000 to 29,449 in 2010 [102]. Cancer survival rates are better than ever before [101]; however, more clinical trials are needed to combat this common disease.

Background

The South East Scotland Cancer Research Network (SESCRN) is one of four Scottish cancer research networks. It was set up in 2002 with funding from the Chief Scientist Office (CSO) of the Scottish Government.

The aim of the cancer research networks are ultimately to increase, support and sustain clinical trial activity in cancer care in partnership with the UK Clinical Research Collaboration.

One of the significant benefits to having a dedicated network is that it provides an appropriate infrastructure to enable high-quality oncology trials to be conducted across a number of clinical settings within and outside of the NHS.

Working in close collaboration with the NHS, Cancer Research UK, Edinburgh University and the Experimental Cancer Medicine Centre, the SESCRN supports cancer research activity across a number of health boards covering Lothian, the Borders, Dumfries and Galloway, and Fife.

The initial focus for increasing trials activity for the network was within the Edinburgh Cancer Centre in Lothian (UK). It led the way in developing a robust infrastructure

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to support and increase trial activity THAT could then be used to support the limited resources available to the periphery hospitals situated in more rural areas.

Aims

The main aim of the networks, in line with targets set by the CSO, was to double patient recruitment over a 3-year period between 2002 and 2005.

Prior to the inception of these networks recruitment to cancer clinical trials ran at approximately 3.7%; however, by 2005/2006 patient recruitment to cancer clinical trials had more than doubled and ran at approximately 13.9% [1], emphasizing the success of the cancer networks. However, most of the activity within the south east of Scotland was still within NHS Lothian, home to the Edinburgh Cancer Centre.

Another aim of the networks set by the CSO was to improve equity of access for patients to cancer clinical trials regardless of where they live. This is in line with 'Better Cancer Care', a key policy document produced by the Scottish Government [2], which recognized that the opportunity to participate in clinical trials was restricted unless patients were prepared to travel long distances to main cancer centers for treatment and follow up.

The aim of this paper is to look at how the SESCRN addressed this disparity in one of the local cancer hospitals within the south east of Scotland.

Method

■ Local initiative

To address the need for equity of access, the focus of one of the network senior nurses was changed and their role was developed to facilitate and support clinicians and local hospital staff to run oncology clinical trials in their local hospital. Some key elements in developing this framework for support are detailed below.

■ Identifying opportunities to increase research activity amongst clinicians

The nurse focused initially on identifying colleagues in the hospital with an interest or desire to see clinical research taking place. A nurse consultant, consultant hematologist, clinical oncologist, pharmacist and governance manager were all approached and were keen to support this initiative, provided someone was able to support and drive the necessary requirements to conduct research.

■ Identifying studies that could be conducted locally

With these key players on board a suitable portfolio of studies were identified by exploring the National Institute for Health Research Clinical Research Network portfolio database [103]. Many studies were considered unsuitable for a local cancer hospital at the initial stage as some required specialist services to be in place or to be run by a dedicated team of staff, for example, in the management of Phase I studies. Instead, trials were initially identified that were relatively straight forward and could be run without overly changing current practice or impacting heavily on an already overstretched NHS hospital. However, all staff were keen to ensure appropriate studies were selected and had the potential to offer direct benefit to patients on study. Therefore, trials that were selected included some translational and questionnaire-type studies, but also a number of clinical drug trials.

■ Identifying barriers to running trials locally

One hospital within the south east of Scotland had very little oncology research activity. There were several clinicians who were keen to participate in trials but were unable to maintain the demands of managing frequent amendments and keeping up-to-date with the necessary data capture without network support.

To overcome some of these demands, the nurse identified the following:

■ Research governance requirements

Meeting the necessary research and ethical governance requirements were essential and the nurse guided staff on the training needs of those who would be involved in any aspect of conducting trials. Appropriate training was carried out by an approved trainer to ensure research was conducted in accordance with Good Clinical Practice guidelines [3].

Standard Operating Procedures were used from the SESCRN's Lothian resource and adapted to meet the local needs of the hospital.

■ Identifying ongoing requirements to support increased activity

Within a few months a small portfolio of suitable studies had been identified in the hematology and breast cancer practice and these were submitted for research management approval. At the same time, management staff at the hospital and the nurse explored options to fund a part-time research nurse, to manage the portfolio and support the clinicians to carry out oncology research. Local funding was found to support the initiative and a part-time research nurse was appointed.

Results

As a direct result of this one, very focused, part-time research nurse and the commitment and enthusiasm of local staff, this small district hospital has been able to run numerous studies in breast cancer, leukemia, myeloma and lymphoma and is about to open a second study in colorectal cancer.

The studies are all run in accordance with Good Clinical Practice guidelines [3], amendments for studies are managed efficiently, implemented as soon as they are approved and the data are fully captured and submitted on time.

The opportunity to grow the portfolio further has arisen and other clinicians within the local hospital are asking for the research nurse's support to begin studies in their specialized disease site.

The foundations to carry out cancer clinical research in this local hospital are now in place and ready to be expanded if further funding can be sourced to increase the research nurse's post to full time.

Limitations

With only one, part-time research nurse employed on a fixed-term contract, there is a limit to how much further the portfolio can be expanded and additional sources of funding need to be considered to maintain and develop local clinical trial activity.

With recent advances in the diagnosis of cancer and its management and treatment, patients now live much longer, and so to recognize the effect a study drug or intervention treatment has on survival or recurrence, trial patients are often followed up for many years. Therefore when a study closes to recruitment, the workload may reduce but the data management continues for many years, having a long-term impact on the research nurse's workload.

The complexity of cancer clinical trials is also increasing. Many of our cancer treatments are now specifically designed to target a specific genotype of the individual patient rather than a treatment to suit many. This can make recruitment difficult as a smaller sample of the population will be eligible and, if suitable, the demands of the study can be greater with limited flexibility in timeframes to screen and treat the patient. Closer monitoring, detailed preparation and sample analysis are routine for such studies, and one part-time nurse could not manage these studies single handed.

It is anticipated that funding will continue for this post, although, like many other areas of industry, research is experiencing difficulties maintaining funding in such a challenging economic climate. We are, however, hopeful that following the success of this post and the significant impact it has had on patient recruitment to cancer clinical trials, the CSO will recognize its value and give continued and increased funding to develop and expand its remit further.

Summary

The success of this initiative has ultimately been due to the enthusiasm and commitment of local staff, who are keen to offer their patients the option to participate in cancer clinical trials and the patients taking the opportunity to become involved in the varied portfolio of clinical studies offered to them.

The foundation to run trials in this local hospital is now established with the opportunity to expand this to other disease sites and generally increase the number of trials within the portfolio.

Further funding is now required to make the existing research nurse post more permanent but also increase the manpower to do more valuable research and deliver trials in more complex settings.

Future perspective

The SESCRN has had a significant impact on increasing cancer research activity across the south east of Scotland since its inception in 2002, and recognizes the benefit a dedicated senior nurse has had on integrating clinical trials into a local cancer hospital. Despite this success, challenges remain in sourcing permanent funding for the existing part-time post and also for increased funding to allow the recruitment numbers to increase further and allow local staff to expand and cover clinical trials in other disease sites. Addressing these challenges will form part of the senior nurses continued role.

Financial & competing interests disclosure

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Executive summary

- Since its inception in 2002 the South East Scotland Cancer Research Network has been instrumental in increasing research activity across the region to more than 13.9%.
- Having a dedicated research nurse to focus on activity outside the main cancer center was essential to implement a robust infrastructure to deliver clinical trials in a district hospital.
- Identifying key players within the district hospital was essential to the success of this initiative and allowed a suitable portfolio of studies to be selected and delivered locally.
- A key objective of the senior nurse is to now source funding to maintain the existing post and expand the portfolio to new disease sites.

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