In the last newsletter I wrote about the issues encountered when a member of staff is diagnosed with cancer. It seems that this rang bells with some of you and I had a number of responses and comments. Here’s what they said:

“I stayed on the sick until I went for my radiotherapy as I didn’t really know how I would be treated at work. I couldn’t bear the thought of people talking behind my back about it and I couldn’t face talking about it all. This was probably the worse thing I could do…”

“I think a lot of the problem lies in fear of saying the wrong thing, whether they are just colleagues or in fact friends as well.”

“A lot of what you describe in your article rings true. I have chosen to go to the team I used to work with because I have absolute confidence in their clinical abilities. So far they have been marvellous. I do feel for my colleague, a breast care nurse who I would count as a friend, in having to provide the support that I need from her. I currently manage the chemotherapy unit so I am reluctantly intending to go to another unit for this part of my treatment.”

“I actually chose to have my surgery privately, partly because my chosen surgeon was fully booked and I would have ‘breached’ in the NHS, but also, as you point out, because I felt I wanted to preserve my privacy and dignity as much as I could, despite the fact that I also knew the anaesthetist and, of course, the radiologist well.”

“My poor colleague was barraged with questions from worried patients. After a while, because she was in such a difficult position, we decided that if she felt comfortable about telling patients, then she could. When the first two patients burst into tears we weren’t sure we’d made the right decision, particularly for her!”

“I don’t think I am a different BCN now. I can just report that cording is b***** painful! The only way to get rid of it is to stretch.”

Of course this group of patients is impossible to research as nobody knows where the next one is going to arise. Perhaps sharing the awareness of the issues will help us all learn from their experiences!

JAN MORRISON, Macmillan Lead Cancer Nurse and Breast Care Nurse at Kingston Hospital NHS Trust, has been reading your letters.

What happens when a colleague gets breast cancer? You told us!
TINA GLYNN, Haven Programme Manager in London, has this update on a charity that offers a free programme of care to support people with breast cancer and their families.

Breast Cancer Haven set to expand

Breast Cancer Havens in London and Hereford are welcoming day centres providing support, information and complementary therapies before, during and after medical treatment.

Our specialist clinical teams are led by experienced senior cancer nurses. Working alongside the NHS and other health care professionals, our “havens” promote integrated breast cancer care where conventional and complementary medicine work together to heal the body and mind. Our senior nurses are the link between conventional and complementary medicine, and liaise with the visitor’s GP and breast cancer team regarding her progress.

We are committed to making the Breast Cancer Haven programme accessible to anyone in the UK who is affected by breast cancer. That’s why we intend to create a national network of havens that are recognised as centres of excellence in integrated breast cancer care.

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LORRAINE BROWN, Breast Care Nurse Specialist, reports on good practice at Royal Hampshire County Hospital. She won the Innovation Award at the Liverpool BASO conference last July for this psychological service.

BCNs offer psychological screening for all patients one year on

It was almost five years ago that breast care nurses at our hospital identified an inequality in the standard service being offered to patients depending upon their treatment pathway. This resulted in the BCNs setting up a nurse-led psychological screening service in April 2003.

The nurse-led service involves all patients being invited back at 12 months following diagnosis and asked to complete a General Health Questionnaire (GHQ-12) prior to attending the appointment. The questionnaire is validated to detect psychological morbidity and a score of four or more indicates anxiety or depression.

The 45-minute appointment is an opportunity to ask questions and discuss feelings. This was not designed to replace the BCN’s intuition and experience, and more frequent follow-up with other members of the multidisciplinary team is employed regularly as required.

The uptake of the service is fairly high. Some 64 per cent of those invited both attend the appointment and return the completed questionnaire. Approximately 22 per cent either return the questionnaire or attend the appointment and just 14 per cent do neither. The service has resulted in an increase in of the BCN, statistics, genetics, breast screening, one-stop clinics, psychological issues, breast reconstruction, seromas, lymphoedema, physiotherapy and young women’s issues.

The final session was especially well received. A patient’s husband discussed the impact on him following the diagnosis of his wife’s breast cancer and how he managed to cope with small children and other responsibilities.

The main problem of the day was keeping to time, but feedback was very positive and a common theme was the request for a two-day event! The BCNs felt relieved that it went very well, but exhausted after the hard work, commitment and organisation that was required for this study day to take place. We hope that another one may be planned in the next year or two!

ROSEY WHITTLE, Macmillan Breast Care Nurse, reports a recent breast care study day.

NORTHERN IRELAND: Sharing our expertise with non-specialists

As breast care nurses, one of our major roles is the education of health professionals. In Northern Ireland there are 18 BCNs covering the five NHS breast units and the private sector. Therefore, we decided as a group to pool resources of time and expertise, and hold a regional study day for non-specialised nurses and allied health professionals (AHPs).

With some anxiety and trepidation, the day was planned for 2 October, using short sessions mostly by BCNs to cover general aspects of breast cancer. Sponsorship from pharmaceutical and medical companies provided an exhibition which allowed us to keep the delegate fee to a minimum.

Of 80 delegates who attended the event at the Comfort Inn, Antrim, 75 per cent were nursing staff from the acute and community sectors, and the rest were AHPs.

Each session was planned for 15 minutes, allowing 45 minutes for a surgeon and oncologist to discuss their topics in more depth. Other topics included the role of the BCN, statistics, genetics, breast screening, one-stop clinics, psychological issues, breast reconstruction, seromas, lymphoedema, physiotherapy and young women’s issues.

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institutions, we also undertake rigorous research to add to the evidence base for integrated breast cancer care.

Plans for our third haven in Leeds are well underway and we recently launched a £2,200,000 capital appeal to fund it. We are also expanding the support we provide to those unable to directly access our havens – through DVDs, booklets, telephone counselling and our website.

For more information visit www.breastcancerhaven.org.uk or contact Tina Glynn on 020 7384 0010.

referrals to counselling services and increased attendance to the local support group.

The consultations reflect the issues important to these patients one year following breast cancer – discussion frequently covers bone health, hot flushes, diet and weight gain, lymphoedema, fertility issues, breast reconstruction, body image, sexuality, risk of recurrence, survivorship and emotions.

The BCNs therefore feel this service should now be developed further, encompassing these issues. This means adopting a more holistic approach to patients’ needs without the focus on “depression”.

OPPORTUNITIES FOR PROFESSIONAL DEVELOPMENT

Younger women and breast cancer
Breast Cancer Care
12 February 2008 – Cardiff Marriott Hotel
Free! A two-three hour programme – find out more and reserve a place on 0845 092 0802 or email nursetraining@breastcancercare.org.uk

Advances in breast cancer treatments and care
Annual Healthcare Professional Conference – Breast Cancer Care
Friday-Saturday, 4-5 April 2008
Central London
“Where are we now?” Explore this question in key clinical areas ranging from risk reduction to metastatic disease. Fee: £40 (includes all lectures, accommodation and meals). Details on 0845 092 0802 or email nursetraining@breastcancercare.org.uk

Professional practice in breast care
(June 2008)
Breast care: support & practice
(November 2008)
These modules for health and social care professionals with an interest in breast care can be taken as standalone courses or part of a specialist degree pathway. Cost: £450 each. Contact Penny Howard on 0115 8231813 or email: penny.howard@nottingham.ac.uk

SPECIALIST COURSES IN LONDON

Breast surgery masterclass – 28 February 2008 – for breast care specialist nurses/experienced breast nurses

Breast surgery – 25 June 2008 – for all nurses who wish to increase their knowledge of breast surgery
Venue to be confirmed. Call 01394 461131 or email info@scm-ltd.com for registration form.

Advanced Breast Care Practitioner (Master’s level)
Cambridge
Summer 2008 (provisional)
Four consecutive days (can be a residential stay)
Course fee: £1,050 plus VAT
Key content
- advanced breast assessment and diagnostic skills including history taking and clinical examination
- enhanced communication and decision making skills
- role of the breast care practitioner – professional, ethical and legal dimensions.

Details from the postgraduate team on 01223 885911 or 01223 883213 or visit www.anglia.ac.uk/fhsc

Meet the organisers! (from left) Rosey Whittle (SEHSCT), Anne Carmichael (UIC), Elaine Heaney (NHSCC), Glenda Brown (BHSC), Cheryl Gregg (NHSCC), Anne Treanor (SHSCT), Brenda O’Kane (BHSC) and Jacqui McNicholl (SEHSCT)

VERIDEX: Gene search breast lymph node assay for molecular testing
Veridex is a study trialling the Veridex machine to accurately reflect the cancer status of lymph nodes. In the study run by Professor Mansel at the University of Wales Hospital, Cardiff, 83 patients were randomised to the trial between December 2006 and September 2007. As this newsletter was going to press, preliminary results were being presented in an abstract at the San Antonio Breast Cancer Symposium.

More from Chris Morris, Research Nurse at Cardiff University, on 02920 746609.
Over 100 nurses attended *The ripple effect of breast cancer*, our two-day conference in Newcastle. Sessions included aromatase inhibitors, family history and screening, sexuality, targets of targeted therapies and menopausal symptoms.

Dr Carmel Sheppard, Consultant BCN at Portsmouth Hospital NHS/University of Southampton, urged delegates from across England and Wales to be gearing up for the NHS National Mastectomy and Breast Reconstruction Audit (NMBRA) which was to commence in January (see page five). As BCNs are closely involved with patients who are offered reconstruction, it is vital for them to be aware of the audit and its potential benefits to patients.

Breast reconstruction is an evolving area of care. New reconstructive techniques have been introduced in recent years, and there is currently disagreement about the peri-operative, oncological, and cosmetic outcomes following immediate reconstruction in certain patient groups. As a result there is currently considerable variation in practice across England and Wales.

The nine month, prospective audit will provide information on the accessibility of immediate and delayed reconstruction, the choice of reconstruction methods and information given to patients. Both NHS and private patients are eligible for inclusion and will be followed up at three and 18 months through patient-reported outcome questionnaires.

A workshop by Dr Sheppard (see story “... on the family”) explored the “ripple effect” of breast cancer on the family – that is, the impact of the diagnosis on family functioning, structure and interaction. She spoke about how the family is affected by a breast cancer diagnosis and its major role in

Dr CARMEL SHEPPARD, forum committee member, reports on a workshop from the recent BCN conference in Newcastle.

### ... on the family

**Patients**

*Patients’ behaviour may include:*
- feeling protective towards the family
- putting on a brave face
- being selective in the information they pass on to loved ones
- feeling guilty at not fulfilling normal roles
- avoiding being too close to loved ones for fear of losing them or, alternatively, feeling closer
- not wanting to be a burden to the family
- feeling guilt about potential genetic links.

**Strategies for nursing care in working with patients:**
- Explore with the patient the potential impact for the family as they see it.
- Role play breaking bad news to family and friends.
- Give advice about telling children.
- Offer written information to family members.
- Encourage them to involve partners.
- Delegate some responsibilities to others to help them feel they are contributing.

**Partners**

*Feelings and behaviours may include:*
- isolation
- loss of role in protecting loved one
- helplessness – not knowing how to help
- avoiding contact for fear of hurting their loved one
- developing closer intimacy for fear of losing their partner
- responding with anger (regain control and protect)
- anxiety and depression
- avoiding deeper conversation for fear of saying something wrong
- denial.

**Strategies:**
- Include partner in discussions (with patient’s permission).
- Ensure good understanding and allow time for partner.
- Acknowledge the partner’s support as useful.
- Give permission for feelings and encourage partner to articulate these.
- Offer written information and advice on support groups.
- Give advice on how to talk to loved ones.
- Explore the effects on them and the family.
patient support. “Communication and honesty are the key to supporting one another,” she said.

Jane Pickard (Matron, Breast Care Services, University Hospitals of Leicester NHS Trust) spoke about how clinics for older patients are developing. After discussions with these patients and their care providers, a specific older person’s clinic has incorporated many changes. For example, it was moved to the afternoon so patients would have time to get there. Also, raised seats and wheelchair spaces were provided.

One of the more unusual developments was that a specific physician and anesthetist were present in the clinic to assess patients with complex medical histories. This would then save the patient having to make several other hospital appointments to assess their suitability for surgery.

In her keynote address to the conference, Helen Barlow, Nurse/Allied Health Professional Director for Greater Manchester and Cheshire Cancer Network, gave an overview of developments in the NHS and Department of Health which will impact on breast cancer services in the future, identifying anxiety and depression—a valuable finding in the current climate of reconfigurations and redundancies.

As ever the networking opportunities were fantastic and this allowed delegates to exchange ideas and suggestions with each other. I came way from the conference motivated and invigorated by what I had heard and seen, and I hope everyone left with the same impetus.

Children
Feelings and behaviours may include:
- behaviour being affected
- a potential role change with increased responsibility to take on mother’s role
- guilt about previous behaviour
- anger towards the parent
- fear of being without parent
- distancing themselves or become overly clingy
- rejection
- physical symptoms such as bed wetting.

Strategies:
- Encourage patient to involve teachers.
- Provide child centred information.
- Offer opportunity to talk and ask questions.
- Role play with patient about how to talk with children.
- Encourage patient to be open and honest.
- Find out about children’s services in locality and national support agencies – for example, Winston’s Wish.

Examples included the planned extension of the national breast screening programme from ages 50-70 to include ages 47-73 years, and the increase in survivorship due to improved treatments—an outcome that the new Cancer Reform Strategy in England aims to further.

Sue Cruickshank, lecturer in cancer nursing at Napier University, described a Cochrane Review assessing the effectiveness of interventions by BCNs on quality of life outcomes for women with breast cancer. The review supports claims that BCN interventions are beneficial, especially in identifying anxiety and depression—a valuable finding in the current climate of reconfigurations and redundancies.

A version of this article first appeared in Cancer Nursing Practice, www.nursing-standard.co.uk/cancernursing

UPDATE: The National Mastectomy and Breast Reconstruction Audit

We hope you are now aware of this important audit being conducted on behalf of the Healthcare Commission.

The project is being led by British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS), the Association of Breast Surgery at BASO and the RCN with support from the Clinical Effectiveness Unit of the Royal College of Surgeons of England and the Information Centre for Health and Social Care.

The RCN is represented within the audit team by Carmel Sheppard (Project Team Lead Specialist Nurse).

This will be the first national prospective audit in this area. Beginning in January 2008, it will collect in-patient clinical data for all women undergoing immediate or delayed reconstruction after mastectomy for breast cancer in both the NHS and private sector. The dataset is now available on the website: www.ic.nhs.uk/canceraudits

These women, along with a mastectomy-only cohort, will then be followed up through centrally developed and distributed patient-reported outcome questionnaires at three months (to investigate satisfaction with care, information provision and choice) and 18 months (to investigate outcomes after mastectomy and/or reconstruction).

This project will provide us with information regarding accessibility to both immediate and delayed reconstruction. Furthermore, data will be collected on types of reconstruction available as well as choice and information available to patients regarding these options.

A pre-audit organisational study to register units (NHS and private) and provide site-specific data is ongoing.

As breast care nurses we play a pivotal role in guiding patients through the options available and counselling them regarding choice. It is therefore essential that we are all engaged in supporting this national project.

A series of regional half-day workshops is being held to demonstrate the audit system and inform anyone involved in the care of these patients about the project and how to participate. To book into these events, call 0845 300 6016 (option one)

Carmel Sheppard

For more information, visit: www.ic.nhs.uk/canceraudits or email: mbr@ic.nhs.uk
Breast Care Nursing News

SUE SCARROTT, Senior CNS Breast Care at Cheltenham General Hospital, has some answers!

How do you prove your worth?

The 2006 British Association of Surgical Oncology Breast Conference in Liverpool highlighted the fact that some clinical nurse specialists were being asked to justify their roles. Some had been asked to work regular shifts on the wards and some units had seen redundancies.

While it is reasonable and appropriate to review practice regularly, it seems absurd that CNSs need to justify their role in a specialty as researched and evidenced based as breast care.

At this year’s BASO conference, I was toldingly, when asked about the loss of these specialist posts at a conference on how nursing leaders might influence the future of cancer care, Professor Weir-Hughes (at that time Chief Nurse at the Royal Marsden Hospital) stated: “We have manifestly failed in making the outcomes of practice visible. That is why we are in the position of losing posts, because we have not been able to demonstrate the outcomes of those roles.” It is therefore vital that CNSs have flexible and effective systems to measure, audit and appraise activity.

To try and address this important issue myself, the CNS team and the team administrator set about developing a system for recording activity that would be easy, flexible and lend itself to adaptation and audit. It also had to have the ability to capture non-clinical information and be simple enough to store electronically. In response to these

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In a similar vein, here’s a report from MARK FOULKES, Nurse Consultant in Cancer Care/ Trust Lead Cancer Nurse at Royal Berkshire Foundation Trust.

Another approach to recording and measuring CNS activity

Measuring and recording nursing activity and tying this to clinical effectiveness has been problematic throughout nursing history. The major difficulty is that nurses do not always rigorously record or attempt to measure what they do. A key factor is that nurses are continuously involved in activities where recording of information in “live time” is impossible unless an exceptionally portable system is used. As a result the first step in evaluating nursing roles is often not clearly present.

Within specialist practice this difficulty is often amplified. CNSs work across a range of clinical environments and encompasses much that is not directly clinical (and therefore difficult to outline in the medical or nursing record). Roles may be wide-ranging and nebulous.

The current situation within the NHS means that there is a process of realigning and reappraising cancer services after a period of continued investment. This process has led to re-evaluation of CNS roles in cancer and palliative care with particular regard to cost effectiveness and delivery of local and national objectives, and many of these CNS roles have been put at risk.

Tellingly, when asked about the loss of these specialist posts at a conference on how nursing leaders might influence the future of cancer care, Professor Weir-Hughes (at that time Chief Nurse at the Royal Marsden Hospital) stated: “We have manifestly failed in making the outcomes of practice visible. That is why we are in the position of losing posts, because we have not been able to demonstrate the outcomes of those roles.” It is therefore vital that CNSs have flexible and effective systems to measure, audit and appraise activity.

To try and address this important issue myself, the CNS team and the team administrator set about developing a system for recording activity that would be easy, flexible and lend itself to adaptation and audit. It also had to have the ability to capture non-clinical information and be simple enough to store electronically. In response to these
PDA is docked to the CNS’s computer. Once the record tab is clicked on, this allows for accurate analysis of activity and also, since a patient identifier is used, patient outcomes (such as length of hospital stay or number of re-admissions) can be audited.

The system is currently being fitted to the computers of all CNS team members, and they now have PDAs and are looking forward to using them. The system also has potential uses in recording other regular interventions – for example, the holistic assessment of patients at key stages of the journey and information provided to the patient along information pathways.


Method:
Each CNS completes a daily timesheet recording the number, type and duration of contacts (see chart). A one month prospective audit was undertaken in October 2005 to quantify the time we spent in direct patient contact outside of the consultant clinics. Time spent performing other duties – for example, ward visits, meetings and clerical tasks – was not studied.

Results:
- 776 patient contacts (84 each per week)
- 9.8 hours each per week on telephone calls (average 22 hours per week)
- 8.5 hours each per week on face-to-face contacts (average 19.5 hours per week)

Conclusions:
- 49 per cent of CNS time is spent supporting patients outside of consultant clinics
- 26 hours are spent each week by each CNS in direct contact with patients or 70.2 per cent of each WTE’s working week
- This is equivalent to more than seven clinics per CNS per week @ 3.5 hours per clinic
- 98 per cent of queries to the department were dealt with by the CNS. Only two per cent were referred onward.

Payment by results:
All CNS clinics are recorded on the trust’s patient administration system (PAS) to ensure that activity is recorded and therefore charged for by the trust. Currently the CNSs run nurse-led clinics for:
- seroma aspirations
- prosthetics
- lymphoedema
- surgical/treatment choices
- reconstruction choices
- results.

As long as CNSs are being asked to justify their role, the daily timesheet is an ideal tool to ensure our practice can be regularly reviewed and justified.

Contact Sue Scarrott on 0845 422 3216 or email: sue.scarrott@glos.nhs.uk

requirements a solution was proposed based on the use of a palm top computer or PDA.

In this system the CNS enters a set of data corresponding to each interaction or task carried out. The CNS logs the activity under their own personal number and records
- whether the episode is patient related or not
- if not patient related, whether it is education, administration, multidisciplinary team working or service development
- if patient related, then a patient identifier is entered
- time taken
- whether the intervention is at level one, two or three. This relates to complexity and there are definitions of these categories for each tumour group.

Once the record tab is clicked on, this record is saved on the PDA and another episode can be entered. When the PDA is docked to the CNS’s computer, the individual records automatically download to a database and the episodes on the PDA are cleared.

This allows for the maximum portability of the system and data can be entered in “live-time” with a minimum amount of time spent on data entry. The database allows for accurate analysis of activity and also, since a patient identifier is used, patient outcomes (such as length of hospital stay or number of re-admissions) can be audited.

The system is currently being fitted to the computers of all CNS team members, and they now have PDAs and are looking forward to using them. The system also has potential uses in recording other regular interventions – for example, the holistic assessment of patients at key stages of the journey and information provided to the patient along information pathways.

Against Breast Cancer (ABC) is a charitable organisation based in Oxford that funds breast cancer research into long term survival. The charity aims to develop a vaccine.

ABC’s research has a unique three-pronged approach that looks at how the cancer cell, patients’ natural resistance and their environment (especially diet and lifestyle) interact. The research is also different in that it works with human tissue rather than animal models.

To commemorate the birthday of the charity’s founder, Patricia Leatham, a pink patio rose called “Imagine” was launched in August at a champagne reception on board the historic RS Hispaniola on the River Thames. Simon Cowell, X Factor presenter and ABC patron, hosted the event for 90 corporate and individual donors.

For every rose that is sold a donation is made to Against Breast Cancer by World of Roses (www.worldofroses.com) and this will help ABC achieve its dream of imagining a future free of breast cancer.

More information at www.aabc.org.uk

Julie Cowell (centre) attended the launch with Dr Margaret Spittle OBE, who treated her for breast cancer, and her son Simon.
WHO’S WHO: RCN Breast Care Nursing Society

Forum committee members represent breast care nurses on various national, regional and local breast service organisations/committees. For example, British Association of Surgical Oncology (BASO) and the NHS Breast Screening Programme. Currently the committee has representatives from all four countries in the UK.

Maria Noblet, Chair
Clinical Nurse Specialist at the Nightingale Centre, University Hospital of South Manchester, NHS Trust

- developing breast care nursing practice
- new ways of working
- breast screening.

Telephone: 0161 611 3113
Email: maria.noblet@smuht.nwest.nhs.uk

Dr Emma Pennary
Nurse Consultant and Head of Health Professional Training at Breast Cancer Care

- breast cancer in younger women (including pregnancy associated breast cancer and impaired fertility)
- metastatic breast cancer (incidence, treatments and impact)
- written information (language, effectiveness)
- men with breast cancer (incidence, treatment and impact)
- targeted therapies (molecular pathology and novel agents).

Telephone: 020 7886 1425
Email: emmap@breastcancercare.org.uk

Nikki West
Consultant Nurse, Cardiff Breast Unit

- diagnostics
- referral of patients
- cognitive behaviour.

Telephone: 02920 743351
Email: nicola.west@cardiffandvale.wales.nhs.uk

Jan Morrison OBE
Macmillan Lead Cancer Nurse and BCN at Kingston Hospital NHS Trust, Kingston upon Thames, Surrey

- general support of women with breast cancer
- professional development of oncology and breast cancer CNSs
- development of new roles to ensure good care and support for people with cancer.

Telephone: 020 8934 3122 (direct line)
Email: jan.morrison@kingstonhospital.nhs.uk

Victoria Harmer
CNS Breast Care at St Mary’s Campus, Imperial College Health Care NHS Trust, London.

- surgery
- sexuality
- how patients are left after treatment
- treatment trade-offs.

Telephone: 020 7886 1425
Email: victoria.harmer@imperial.nhs.uk

Rosey Whittle
(Co-opted member)
Macmillan BCN at Ulster Health, Dundonald, Belfast, South Eastern Health and Social Care Trust.

- breast reconstruction
- psychological aspects of diagnosis and follow-up

Telephone: 028 9055 0499
Email: rosey.whittle@setrust.hscni.net

Pauline McIlroy
(Co-opted member)
Breast CNS, the Beatson West of Scotland Cancer Centre, Glasgow.

- dealing with complex patients such as those requiring neo-adjuvant, multimodality treatments or treatment during pregnancy
- providing a quality service for our metastatic patients who are living much longer and face years of dealing with this chronic situation.

Telephone: 0141 301 7639
Email: pauline.mcilroy@northglasgow.scot.nhs.uk

Dr Carmel Sheppard
(Invited member)
Consultant Nurse at Portsmouth Hospitals NHS Trust/University of Southampton.

- follow-up
- experience of partners
- role of BCN
- lead nurse clinician on national breast reconstruction audit.

Telephone: 02392 762382
Email: carmel.sheppard@porthosp.nhs.uk

Veronica Rogers
(Invited member)
BCN at Derby City General Hospital

- support and information for patients and professionals

Telephone: 01332 789476
Email: veronica.rogers@derbyhospitals.nhs.uk

Karen Wingfield
(Newsletter editor)
BCN at Cardiff Breast Unit

- psychosocial issues and breast cancer.

Telephone: 02920 715058
Email: karen.wingfield@cardiffandvale.wales.nhs.uk