Objectives:
- To identify research priorities in cancer care informed by patient and carer experiences;
- To develop effective methods of patient and carer involvement, particularly with marginalised groups.

Methods: People affected by cancer are invited via local media to participate in Research Advisory Groups. Respondents are invited to local meetings, co-facilitated by a researcher and a local person, such as a patient involvement worker. To date, Advisory Groups have been established in eight different areas of Scotland, including urban, rural and island communities. In order to involve marginalised groups, work is underway with Chinese people, profoundly deaf people, young people and people in areas of social deprivation.

Participants are asked to discuss their experiences of cancer, cancer treatment and care. Meetings are audiorecorded and transcribed. A summary of each group's discussion is circulated to all the other groups. Data analysis allows us to identify the most important issues for research, in collaboration with the Advisory Groups. Research priorities are identified, so that the Cancer Care Research Centre's work is driven by patient and carer priorities. Centre staff work closely with health professionals, policy makers and the voluntary sector to influence change based on patient and carer experiences.

Results: The work is on-going. By September, we will be able to present a detailed account of the process of patient and carer involvement and initial findings relating to the research priorities identified. We will discuss the methods we are using to engage marginalised groups in the research process. We will be able to discuss the advantages of the methods and the difficulties and reflect on our experiences as researchers and those of the patients and carers who are involved. Ideally, we would like to involve a patient or carer as co-presenter.

1618 POSTER

Systematic literature review about the involvement of people affected by cancer in research, policy, planning and practice

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Background: The Cancer Care Research Centre aims to find out what is known about the involvement of people affected by cancer in research, policy, planning and practice.

Objectives: The purpose of the literature review is to address the following questions:
1. Why people affected by cancer are involved in research, policy, planning and healthcare practice;
2. How are they involved, and
3. What influence does their involvement have?

Methods: The systematic review carried out included a range of literature comprising different types of empirical studies and also non-research publications. Documents were searched for systematically from key electronic health and social care databases, hand-searching and by an internet search. Criteria for including and excluding documents were applied which resulted in the inclusion of 300 documents for the review. A meta-ethnography was adapted to analyse the evidence and an appraisal of the strength of evidence was carried out using quality criteria.

Results: The work is on-going. By September, we will be able to present a detailed account of what is known about the involvement of people affected by cancer in research, policy, planning and practice. We will report on reasons given for involving people affected by cancer, the methods used to involve them and the influence that their involvement has had on research, policy, planning and the practice of care. We will report relationships between espoused reasons for involving people affected by cancer (theory), how they are involved (process) and the influence that their involvement has had (outcome).

1619 POSTER

Nursing for dreams

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Background: this article will not talk about research, nursing studies, literature review, nursing planning, care models. I will not even mention data, statistics, average values. This abstract will not show you anything extraordinary or innovative. It will talk about the nursing for dreams. It does not exist in any nursing theory but comes from an experience in which, thanks to my profession, I was able to realize a big dream which belonged only to a great young woman.

Experience: her name is Emily (it should be more correct to say "her name was" but I like to remember her as if she was present here and listening to me). At the beginning of August 2004 she has been defined terminally ill patient, because of a PNET. The time for her was rolling by upside down: other 3–4 months of life more when the life was exploding in her. Emily's dream was to make a journey in Jamaica as soon as she was feeling better. Her parents and friends realized that this dream was unfeasible but maybe there was still the possibility to do something for her. So on the occasion of her eighteenth birthday, parents, relatives and friends organized an unforgettable holiday at Capo Verde. The necessary of a medical figure was the only one condition imposed by the medical staff. That was necessary both for the management of the analgesic therapy (Emily's pain was harsh and almost continuous, VAS = 8), and for the management of all the possible medical complications which could happened. I have been picked out as medical figure both for my young age and for my good relationship with Emily and my good knowledge of her case and clinical history.

Outcome: this experience has been a concentrate of surprise and difficulty both from a human point of view and from a professional one. The responsibilities and difficulties were not little and I realize in particular now, thinking of them with hindsight, but it was well worth it. In those moments I realized what means to be the first person responsible for a particular choice both from a deontological point of view and an ethical one. I have also touched with my hands the meaning of holistic assistance. The nursing for dreams is a new prospect to which our profession has to yearn for because all our patients, oncological and not, are entitled to see their dreams, small or big, achieved.

1620 POSTER

Understanding the care and support needs of children and young people with cancer – a participatory research study

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Background: How children and young people experience care and treatment and what they perceive as important has received little attention. Previously, the focus has been upon identifying aspects of care from the perspective of parents. In order to provide services that genuinely meet their needs, children and young peoples' views must be sought.

Methods: A descriptive study to explore perceptions of care and support needs was undertaken. Thirty-eight children and young people with cancer aged between 4 and 19 years at different stages of the cancer journey participated. Participatory-based, age appropriate research methods were used to collect data, including play and puppets, 'draw and write' technique, peer interviews, semi-structured interviews and focus groups. Data were analysed using thematic coding.

Results: Through talking about their experiences, participants identified positive and less positive aspects of care. The perception of care and support needs of participants varied according to age. Whereas for younger children their focus was on their immediate needs, such as availability of toys and how treatments limited their activities, older children focused more on issues related to treatment and being involved in decisions. Communication and information were important issues that featured in the stories of all participants.

Conclusion: This study identifies the care and support needs of children and young people from their viewpoint. The findings have implications for services caring for children and young people with cancer. This paper will present the study, reflect on the findings and explore in detail the theme 'talk to me not through me'.

1621 POSTER

"Learning to live with cancer" – the ARC Irish experience!

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Patients react to a cancer diagnosis with a variety of emotions and psychosocial oncology focuses on how the physical manifestations of cancer impact upon the cognitive, behavioural, social and spiritual components of the lives of patients with cancer. Psychosocial interventions aim to alleviate the emotional and social impact of cancer on patients and their families. Information is a basic form of support. Correct and adequate information is essential to helping patient and family adapt to a diagnosis of cancer and develop coping skills. Studies suggest that patients who receive good information are more satisfied with their care and demonstrate lowered levels of anxiety and depression. The role of support groups has