

CANCER SERVICES FORUM

Cancer Services Forum is a publication aimed at PCO commissioners and their teams, cancer network management teams, service managers in cancer centres and cancer units, clinicians, pharmacists, nurses and other cancer care professionals. The pace of change in the planning, commissioning and delivery of UK cancer services can be overwhelming—the aim of *Cancer Services Forum* is to communicate expert opinion on the implications of cancer policy and service initiatives on a regular basis, frequently and in a timely fashion.

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Dear Colleagues,

In the past 2 months we have seen the publication of three major reports that will have an impact on the way chemotherapy is delivered in future years.

The report on chemotherapy from NCEPOD (National Confidential Enquiry into Patient Outcome and Death), *For better, for worse?*, makes disturbing reading. Although we are using increasing amounts of cancer chemotherapy, there are many aspects of governance and collaborative working across organisational boundaries that need to be improved to make sure patients have access to safe services. Many of these issues have also been addressed in a report from the National Chemotherapy Advisory Group—*Chemotherapy Services in England: ensuring quality and safety*, which sets out a clear vision for what is required from cancer networks, working in partnership with their constituent organisations and stakeholders, to deliver a safe, high-quality service. In addition, Professor Mike Richards' report for the Government, *Improving Access to Medicines for NHS Patients*, gives a firm steer on the difficult question of a patient's right to purchase additional treatments whilst retaining eligibility for NHS care.

As a network medical director, it seems abundantly clear to me, that the only way these national reports will be acted on at a local level is through close cooperation between all those involved in cancer care—patients and carers, commissioners, health professionals, the voluntary sector and the pharmaceutical industry. There is a lot of work to be done.

Nigel Marchbank,
Clinical Director, Sussex Cancer Network

Chemotherapy: putting patient safety first

Plus a comment from Alison Jones, Chair of the Association of Cancer Physicians

Comment on recommendation 11 of Mike Richards' report

David Thompson, Lead Pharmacist, Yorkshire Cancer Network

Chemotherapy: putting patient safety first

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Introduction

The 12 months since the publication of the *Cancer Reform Strategy* have been marked by landmark announcements and publications on treatments and services for people with malignant disease. The National Patient Safety Agency (NPSA) has issued key alerts on oral chemotherapy (January 2008) and use of vinca alkaloids (August 2008).

In November, the National Cancer Director for England, Mike Richards, issued his much-heralded recommendation to allow patients to partially fund their care while remaining within the auspices of the NHS. Just days later, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD, Panel 1) issued a 140-page report on deaths following chemotherapy or other systemic anti-cancer therapy (SACT), accompanied by responses from specialist organisations and the National Chemotherapy Advisory Group (NCAG).

- NCEPOD is an independent organisation, largely funded by the Department of Health, that reviews clinical practice and identifies areas where changes can be made to improve the safety and efficacy of patient care
- Its recommendations are based on critical examination, by senior specialists, of what has actually happened to patients during the designated study period
- Each year, organisations and individuals are invited to suggest topics for forthcoming enquiries, using a Study Proposal Form, which is made available on the NCEPOD website (<http://www.ncepod.org.uk/>) when the call for proposals is announced
- Participation in NCEPOD enquiries, when requested, is mandatory for trusts under Department of Health guidance on Clinical Governance. Additionally, the General Medical Council requires clinicians to take part (Good Medical Practice, 2001)

Panel 1: *What is NCEPOD?*

NCEPOD report: *For better, for worse?*

Some difficult questions were posed when NCEPOD looked at the final 30 days of life among patients who died following administration of SACT (in England, Wales and Northern Ireland; summer 2006). However, as NCEPOD chair, Professor Tom Treasure comments in his foreword to the report, *For better, for worse?*, questions, no matter how difficult, must be asked, or else remain unanswered—hence NCEPOD’s decision to pursue its enquiry into deaths post-SACT.

Unfortunately, NCEPOD has not been able to formulate a complete picture of the circumstances surrounding deaths in the 30 days following SACT during the study period. The return rate of questionnaires (63%) and case notes (52%) fell far short of the usual NCEPOD participation level of over 80%. A few clinicians were resistant to the enquiry, saying that no-one, except the doctor in charge of each case, is in a position to judge the appropriateness of care.



However, the heavy workload of the thinly spread oncology workforce was also considered to play a part in the shortfall of returns. It is also possible that some of the questionnaires may not have reached the intended consultants (this is the first time that NCEPOD has looked at medical/clinical oncology).

That said, this is the first NCEPOD enquiry to find that instances of good practice (35% of the cases reported) were outnumbered by cases where management was deemed by the assessors to leave room for improvement (49%). In 8% of cases, the care provided was judged to be ‘well below an acceptable standard’. Moreover, looking at the last course of chemotherapy given before the patient died, the final decision to treat was inappropriate in 19% of cases, according to the assessors.

Many more instances of less than good practice are itemised in the full report, which can be downloaded at <http://www.ncepod.org.uk/2008sact.htm>. A few key examples, along with the corresponding NCEPOD recommendations, are listed in Table 1.

FINDING	RECOMMENDATION
43% of patients who died suffered grade 3/4 toxicity	If there is grade 3/4 toxicity in the previous cycle of chemotherapy, dose reduction or G-CSF prophylaxis should be considered, depending on treatment intent
During the patient’s last cycle of SACT, dose reduction was used in 23% of cases and dose delay in 13%. The assessors judged that dose reduction was warranted in 33% and dose delay in 26%	Clinicians should follow good practice and consider dose reduction/delay where indicated
No duly signed consent form for SACT was recorded in 43% of cases, and where consent forms were used: 14% did not document the grade of doctor taking consent, 25% did not list common toxicities and 48% did not list serious toxicities	Greater standardisation of consent forms is required, to include the name and grade of doctor, who should be sufficiently experienced to judge whether the patient has considered the risks and benefits
Three hospitals allowed junior doctors in the first 2 years of specialist training (SHOs and ST1/2s) to initiate SACT	Junior doctors at SHO or ST1/2 level should not be authorised to initiate SACT
Essential pre-treatment investigations were omitted in 14% of cases	Results of pre-treatment tests should be assessed before every cycle
There was no record of toxicity assessment results from the previous cycle of SACT in 36% of cases	Toxicity checklists should be developed to aid the process of care and record keeping
No assessment of tumour response was made in 46% of cases	Tumour response should be assessed and recorded at appropriate intervals, depending on the treatment intent and the regimen used
Only 53% of notes included evidence that a pharmacist had checked the SACT prescription	All SACT prescriptions should be checked by a pharmacist who has undergone appropriate specialist training, demonstrated competence and is locally accredited for the task

Table 1: Examples of NCEPOD findings and recommendations



However, Professor Treasure emphasises that the findings must be seen in context. Death within 30 days is a rare event in chemotherapy, and that the advances in such treatments have transformed the outlook for people with cancer, giving many, longer and better lives than in the relatively recent past. Furthermore, many of the deaths recorded are likely to have occurred despite the best medical practice. Professor Treasure also cautions against over-interpretation of the findings, as it is impossible to know the extent to which the responding hospitals and clinicians are representative of cancer services as a whole, across the countries studied.

For better, for worse? was launched on 12 November 2008, at a packed event featuring presentations from senior NCEPOD personnel, Mike Richards and representatives of clinical oncology, medical oncology, acute medicine and palliative medicine.

Some of the delegates were disappointed by the absence of data on deaths following SACT as a

proportion of total SACT recipients, which they felt would provide a benchmark for individual cancer services. In fact this information gap reflected one of the major findings of the NCEPOD study—lack of audit at local level—and is addressed in one of the NCEPOD recommendations:

“Cancer service managers and clinical directors must ensure time is made available in consultants’ job plans for clinical audit. They must also ensure that the time allocated is used for the defined purpose.”

Lack of communication is another feature of the NCEPOD findings. Several examples are highlighted in the report, for example:

- Poor communication between clinicians and patients
- Poor communication between specialist clinicians and colleagues in other services, e.g. acute medicine
- Poor communication between different hospitals and trusts

- Lack of clear referral pathways
- Poor documentation of key issues such as SACT toxicity in patients’ records
- Lack of access to patients’ oncology records on admission to another service, e.g. A&E

As with other patients admitted as emergency cases, many SACT recipients who become inpatients during the last 30 days of life are not admitted to the hospital in which they had received their elective care—15% in the NCEPOD report. A survey respondent from a district general hospital (DGH) told NCEPOD: “Oncology notes are not held at the DGH, and are not available to us. Communication with oncologists is effectively non-existent.”

Specialist perspectives *General medicine*

Professor Derek Bell, academic representative from the Society of Acute Medicine, reiterated the pressing need to improve communication between oncology services and acute/emergency



care, including formal arrangements for patients' notes, access to advice and patient pathways. He emphasised that the deaths studied by NCEPOD represented a particularly vulnerable population; most were elderly, 86% were receiving palliative treatment and 21% were severely debilitated (performance score 3 or 4).

Oncology

Dr Jane Barrett, chair of the Joint Collegiate Council for Oncology (JCCO), pointed out that changes had already been set in motion since the NCEPOD collected the data in 2006. For example, JCCO guidelines for cancer networks were issued in February 2007, and the Cancer Doctors of the Future initiative was launched in November of the same year, with the aim of foreseeing changes in cancer care needs and provision (due for review in April 2009).

Dr Alison Jones, chair of the Association of Cancer Physicians agreed with NCEPOD that morbidity

and mortality audits should be a standard of care for oncologists, and proposed that audit should be assessed routinely during consultant appraisals. She presented a flowchart showing the various pathways by which patients who feel unwell after SACT seek help. Some call their GP or NHS Direct, and some attend A&E, often at a local hospital rather than where they received their cancer treatment. Even those who use the emergency telephone number provided by their cancer team run the risk of speaking to a non-specialist, particularly if they call out of hours. For patients who may have neutropenic sepsis, this initial contact for help is vital, and should trigger rapid assessment and delivery of intravenous antibiotics. Unfortunately, the network of pathways provides many opportunities for treatment to be delayed or missed entirely. Some patients are even given potentially fatal advice: to go to bed and rest. Dr Jones called for several fundamental service improvements in

cancer care, for example:

- All units delivering SACT to have agreed policies for out-of hours care, to include 24-hour telephone access to a consultant oncologist/haematologist
- Units to be staffed by 10 whole-time equivalent consultant oncologists
- Improved education of junior doctors in both oncology and A&E
- Patient education on making contact in an emergency
- Rolling audits of neutropenic sepsis
- Use of prophylactic growth factors and antibiotics to prevent neutropenic sepsis, and improved door-to-needle times to manage the condition

Palliative care

Dr Teresa Tate, Medical Advisor to Marie Curie Cancer Care, said the NCEPOD report highlighted one of the most challenging aspects of cancer care—when and how to say no to proposed



chemotherapy: “The findings show that there is little clarity about the aim of chemotherapy. Yet this is something that should be documented and understood by patients so they can take part in these important decisions.”

She also urged cancer services to adopt a proactive end-of-life care pathway to ensure timely and appropriate initiation and delivery of palliative care. This would enable patients to make decisions in advance, in case they become too debilitated at a later stage.

NCAG response

NCAG issued a consultation document, *Chemotherapy Services in England: Ensuring Quality and Safety*, to coincide with the NCEPOD report. It takes account of the findings of both NCEPOD and the national overview of peer-review appraisals, 2004–2007. The latter has shown that only about a half of all chemotherapy services have cancer network-wide agreements on regimens and protocols/guidelines for chemotherapy delivery.

NCAG’s key recommendations include:

- Establishment of an acute oncology service in every hospital that has an A&E department
- Discussion of common and serious toxicities with the patient, supported by written information and recorded on the consent form
- Rigorous capacity planning, aimed at minimising inpatient chemotherapy delivery and maximising the use of local services
- Clear, accessible policies for managing chemotherapy complications in and out of hours
- Development of a three-level chemotherapy service
 - o Comprehensive 24/7 care, covering all cancers and all cancer treatments
 - o 24/7 care, for a limited range of cancers and treatments
 - o Satellite care, offering non-complex treatment close to patients’ homes, with formal links to the above
- Systematic collection of data on chemotherapy activity and outcomes

- Uptake of electronic prescribing by all chemotherapy services

A ‘wake-up call’

Summing up the NCEPOD report and the presentations and discussions that accompanied its launch, Mike Richards urged oncology healthcare professionals to see the findings, “as a wake-up call, not a threat”. He said: “Systemic therapy for cancer is good, and its use has increased by 60% in just 4 years. Our priority now must be to deliver it as safely and effectively as possible.”

Please click [HERE](#) to send us your comments. We will print a selection of comments in future issues of *Cancer Services Forum*.



Comment from Alison Jones, Chair of the Associate of Cancer Physicians

The NCEPOD report should be welcomed by the oncology community as presenting an opportunity to develop audit tools and adopt an open approach to monitoring the appropriateness and safety of SACT at local, network and national level. It should lead to the development of practice guidelines and recommendations to improve the patient experience.

The incidence of neutropenic sepsis leading to death is of particular concern, and raises important questions about: dosing of chemotherapy and decision-making processes in very sick patients, the use of primary and secondary prophylaxis of neutropenia in-line with recognised international guidelines, and the need for agreed pathways of care, both

within units delivering SACT and across unit boundaries.

Elsewhere, the report highlights the need for ongoing and iterative discussion of the risks and benefits of chemotherapy for individual patients in terms that the patient can understand. It also stresses the importance of introducing supportive or palliative care services early in the course of metastatic disease as part of a holistic package of care, rather than as “opt out” when SACT is deemed no longer appropriate. Within oncology, a culture of audit should be encouraged, with attention to audits of mortality, neutropenia and patterns of care. The profession itself is aware of the need for communication, and there are opportunities to build this into both appraisal and revalidation.



Comment on recommendation 11 of Mike Richards' report, *Improving access to medicines for NHS patients: a report for the Secretary of State for Health*

David Thomson, Lead Pharmacist, Yorkshire Cancer Network

Recommendation 11:

The Department of Health should take a lead on commissioning a national audit of demand for unfunded drugs and on the outcome of treatments, working closely with professional organisations and NHS managers.

It is clear that PCTs (Primary Care Trusts) are best placed to audit the demand for unfunded drugs, as they are likely to be reviewing exceptional and individual case requests for drugs that they don't routinely fund on an ongoing basis. This type of audit should be reasonably straightforward and should provide some useful national data on variability of decision by PCT.

In my view, the bigger challenge is that of auditing the outcome of treatments. The guidance is not clear as to whether it is the outcomes of all cancer therapies or specifically those for "unfunded" cancer therapies that should be audited. Particularly for "non-NICE"

drugs, commissioning colleagues increasingly want to see data on outcomes for their patients—to see that the benefits seen in trials are seen in practice in their patients. There is a risk that the small number of local patients may skew the results, and therefore the proposal for a national approach is welcome.

However, there is a danger that current exceptional case and individual case request mechanisms for unfunded drugs can lead to perverse incentives to use the drug in situations where it may be less effective, i.e. the drug being used in a later stage of disease, or the use in a different population from the trial. This may lead to poorer outcomes than expected. If we assume that "unfunded" means "not approved/reviewed by NICE", then the other risk is the potential for individual PCT's to fund the same drug in different subsets of patients deemed more "cost-effective". Any outcome data would have to be interpreted with this in mind.

These recommendations coupled with the National Chemotherapy Advisory Group (NCAG) report and many other developments in chemotherapy services mean we have to solve the issue of data collection. E-prescribing systems will assist in the collection of some of the required data. However, I believe that the data and audit collection required by these developments will need e-prescribing solutions to link with other clinical systems in trusts and networks, to provide some overall context to the data. We must solve this one step at a time and start by playing our part in ensuring that all chemotherapy is prescribed electronically.

Please send us your comments on Mike Richards' report. We will print a selection of comments in future issues of *Cancer Services Forum*

[Click here to view, *Improving access to medicines for NHS patients: a report for the Secretary of State for Health* by Professor Mike Richards](#)



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