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E. J. Maher

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REVIEW ARTICLE

## Managing the consequences of cancer treatment and the English National Cancer Survivorship Initiative

E. JANE MAHER

*Mount Vernon Cancer Centre, Northwood, Middlesex, UK, and Macmillan Cancer Support, London, UK*

### Abstract

**Background.** In 2007 the English National Cancer Survivorship initiative was launched as a partnership between a national charity, Macmillan Cancer Support, the English Department of Health (DH) and the quality improvement agency NHS Improvement. The initiative involved a number of work streams, one of which was to improve the detection and management of the Consequences of adult cancer Treatment (COT). **Material and methods.** The adult COT group took evidence from a range of stakeholders and published a vision and work programme focused on awareness raising, linking self-administered questionnaires to routine activity data collection and testing new models of care with a particular focus on pelvic cancers. **Results.** Key outputs include national media campaigns, publications demonstrating the value of linking cancer treatment episodes to routine recording of chronic illness, identification of sensitive Patient Reported Outcome Measures (PROMs) items for use in national surveys, evidence reviews and published national guidelines, together with the development of a three level risk stratified model of care. Pilot testing with survivors treated for pelvic cancers, and adult survivors with radiation-induced brachial plexopathy has been completed. **Conclusion.** Early results suggest that a systematic approach to the prevention, detection and management of some treatment-related consequences can significantly improve the ability of patients to manage their conditions. As a result of these findings, new services have now been commissioned by the NHS, initially for those with complex problems.

Prevention and treatment of cancer is improving. More survivors are now living long enough to develop treatment-related conditions [1,2]. In the UK there are currently two million people alive with a diagnosis of cancer which is set to grow to 4 million by 2030 [1]. The current estimate is that at least one in five of those who survive cancer in countries such as the UK, can expect ongoing physical and/or psychological problems related to their cancer and its treatment [3]. These can include, e.g. persistent fatigue, breathlessness, neuropathy, cognitive impairment, poor bowel and urine control, bone fracture and endocrine failure, as well as an increased risk of common chronic illnesses such as heart failure, osteoporosis and second primary cancer [4–8].

Most modern surgery, radiotherapy, chemotherapy and biological treatments can have consequences which develop immediately, or become apparent years, or even decades later. Adults treated as children pose a particular problem, with an emerging

pattern of increasingly complex and inter-related groups of problems arising years after successful treatment, including cardiovascular disease, endocrine abnormalities and neurological problems [5]. There is no suggestion that the rate of development of late consequences declines with increasing survival, indeed the reverse is true, particularly for the development of second malignancy [5].

With appropriate information and support, together with a well-organised programme of simple screening tests, many problems after cancer treatment can be prevented or managed by patients themselves, with the support of a primary care team. But, for a small but significant minority, the ongoing impact of cancer treatment will result in disabling complex problems requiring specialist multi-disciplinary help [9]. On the other hand, a cancer diagnosis can also offer a real opportunity for lifestyle changes and preventive interventions to reduce future disability from chronic illnesses.

*Making the case*

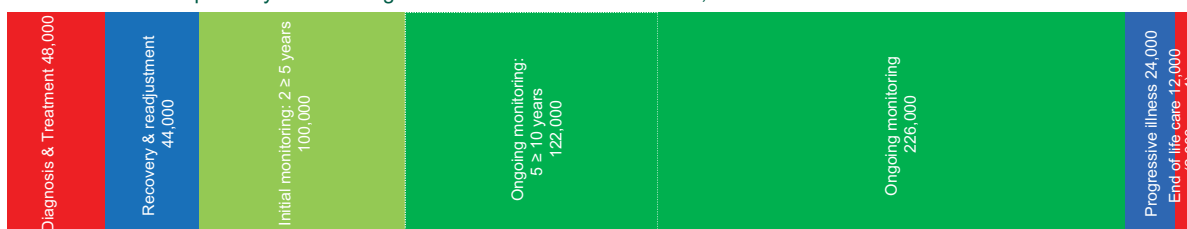
A first step was for Macmillan Cancer Support and NHS Improvement to commission base line studies to demonstrate the need for a survivorship initiative. The US National Health Interview Study had compared 5000 cancer survivors with over 90 000 people without a history of cancer, and found that cancer survivors were more likely to report poor health than those without a cancer diagnosis [10]. Similar findings were reported in the UK study [11]. A sample of 4892 individuals was drawn from an online panel of 400 000 together with telephone recruitment of 'hard to reach' groups. One thousand three hundred and seventy-two individuals had one or more of 10 chronic conditions but not cancer, 2740 without a previous diagnosis of cancer or another chronic condition were compared to 780 cancer survivors without active cancer in relation to 13 measures of health and well-being. The study showed that a significant minority (10–20%) of cancer survivors with no other chronic conditions had ongoing health problems and this rose to 25–30% with the addition of another condition. Overall the cancer only sample had poorer health than a population with no cancer or other diagnosed health condition in relation to general health, physical well-being and pain and made greater

use of health care resources compared with those without a chronic condition or cancer [11].

Recently available national data linkage facilities made it possible to demonstrate the prevalence of cancer survivors (defined as all those living with a diagnosis of cancer) for the first time in the UK [1] and to estimate numbers in different parts of the survivorship pathway, initially focusing on breast, lung, colorectal and prostate cancers [2]. For example in 2008, of women who were alive with a diagnosis of breast cancer, 48 000 were in the diagnosis and treatment phase; 44 000 in the second year following diagnosis (early recovery phase); 100 000 were two to five years from diagnosis, at the highest risk of recurrence (early monitoring phase); 122 000 were 5–10 years from diagnosis, and 226 000 were more than 10 years from diagnosis (in the later monitoring phase, when the risk of treatment-related chronic illnesses and second primaries emerge). In addition, an estimated 24 000 individuals had progressive incurable disease and 12 000 were in the last year of life, of whom 2000 would die within a year of diagnosis. Percentages in each treatment phase were different for different cancers (Figure 1). Considering prevalence in this way has provided initial

### Estimating numbers for the UK

Breast cancer care pathway – estimating the number of women in the UK, 2008\*



Colorectal cancer care pathway – estimating the number of people in the UK, 2008\*



Lung cancer care pathway – estimating the number of people in the UK, 2008\*



Figure 1. The Cancer Pathway.

guidance as to where healthcare resources might best be redeployed.

A second large patient survey demonstrated ongoing morbidity, in particular, in the year following treatment [12]. A sample of 1152 patients with breast, colorectal, haematological and gynaecological cancers from 66 UK cancer centres were surveyed at the end of treatment and six months later, with 30% reporting more than five moderate or severe unmet needs at the end of treatment and for 60% these had not improved six months later. This study highlighted the need for more effective rehabilitation in the year following treatment.

Finally, a survey by NHS Improvement generated a snapshot of opinion about follow-up care after cancer treatment [13]. Specialist doctors and nurses, primary care staff and patients were invited to complete a brief online survey publicised through a range of public and professional networks. A questionnaire explored current expectations (and willingness to change) and existing models of healthcare after cancer treatment. Over 3000 evaluable responses were received. Results suggested that while those professionals and patients who had only experienced current forms of hospital-based aftercare were concerned about change, newer more patient-centred and cost-effective forms of aftercare (such as open access patient triggered follow-up) were already being tested and were viewed positively by those professionals and patients who had experienced them. For example, 453 of 604 patients had only experienced hospital follow-up and only 33% of this group were positive about a possible move to supported self-management, however, of the 173 patients who had

experienced this model of care, 82% of them were positive about it.

Notably, around 80% of each of the four groups (77% of 804 specialist doctors, 84% of 558 nurses, 81% of 883 GPs and 84% of 604 patients) believed the detection of the late consequences of treatment to be an important part of aftercare [13]. While this was not a representative sample, the study generated considerable discussion about the way forward. These four studies provided part of the platform for a national survivorship initiative, including the issue of late consequences of treatment.

The English National Cancer Survivorship Initiative (NCSI) was launched in 2007 in the form of a partnership between the English Department of Health and the charity Macmillan Cancer Support. The vision of the NCSI ([www.ncsi.org.uk](http://www.ncsi.org.uk)) is that those living with and beyond cancer are supported to live as healthy and active a life as possible for as long as possible. The NCSI Vision [3] described five shifts necessary to improve care (Figure 2). The NCSI was originally comprised of seven workstreams (Figure 3).

NHS Improvement supported the delivery of the NCSI through piloting new risk stratified pathways focusing on breast, colorectal, lung and prostate cancer with the aims of improving patient experience of care over baseline and reducing the use of resources which add no value ([www.improvement.nhs.uk/cancer](http://www.improvement.nhs.uk/cancer)).

Based on discussions with patient and specialist groups, it was felt that an ambitious target of a 50% reduction in hospital outpatient attendances and a 10% reduction in unplanned admissions

**Five shifts in care and support for people living with and beyond cancer:**

1. a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.
2. a shift towards holistic assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow-up to personalised care planning based on assessment of individual risks, needs and preferences.
3. a shift towards support for self-management. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences. This approach empowers individuals to take on responsibility for their condition supported by the appropriate clinical assessment, support and treatment.
4. a shift from a single model of clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease as well as tailored support for those with advanced disease.
5. a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

Figure 2. Five Shifts to Improve Survivorship Care.

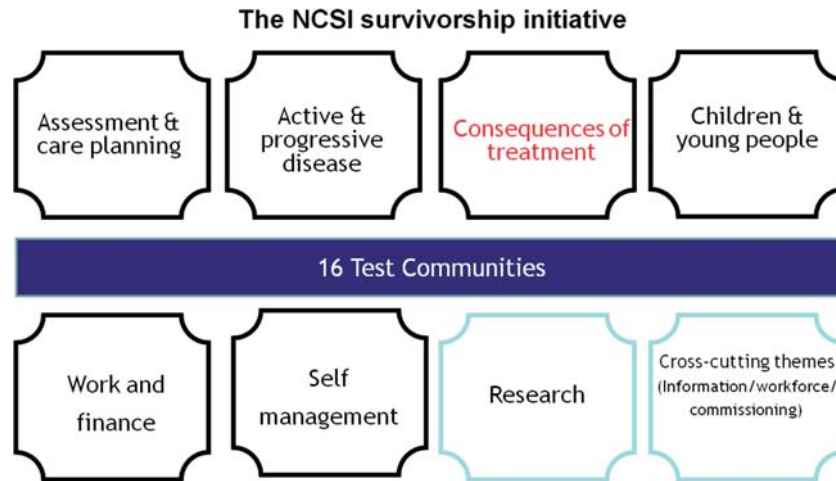


Figure 3. NCSI Workstreams.

should be promoted at the same time as introducing new care pathways including holistic needs assessment, treatment summary records and care planning at the end of initial treatment, together with piloting education and lifestyle change interventions.

*Early challenges in relation to detection and management of treatment-related consequences (COT)*

A particular challenge for the adult COT group was that, unlike management of survivors of childhood cancers where the issue of consequences of treatment was well-established and supported by good quality databases, academic clinical champions and an established research portfolio, the long-term effects of treatment of adults were largely ‘invisible issues’ and not prioritised by most specialists.

A programme of work was commissioned between 2008 and 2011 with funding from the National Cancer Action Team, the National Cancer Information Network, NHS Improvement, a Department of Health grant and Macmillan Cancer Support, together with a number of small local research funds. In addition, there was a generous

donation of time and expertise by lay and professional members of the group and international experts such as the Oncolink team from Penn Medicine, University of Pennsylvania ([www.oncolink.org](http://www.oncolink.org)). The group published its priorities in 2011 (Figure 4) [3].

*The need for routine recording of Patient Reported Outcome Measures (PROMS)*

While second malignancy and cardiac problems are detectable by clinical examination, biopsy, blood test and/or imaging, some troublesome treatment-related consequences involve clusters of symptoms. One patient described it as ‘it is the little things all together that wear us down’ [9] which can be more difficult to recognise. These include poor bowel and urine control and sexual problems after radiotherapy and surgery to the pelvic area.

The COT group proposed that the routine use of self-administered questionnaires should be used in addition to blood tests and imaging as the basis of stratified risk assessment for different care pathways and to trigger re-assessment after treatment. The aim was that initial specialist assessment could be done by

- The consequences of cancer treatment are **acknowledged** and therefore **described, measured, coded and enumerated** routinely by the NHS.
- Preventable consequences are avoided through universal access to the safest and most effective treatment.
- Where adverse consequences cannot be prevented, **effective and accessible services** are available for all patients in order to reduce functional impairment and alleviate distress whether physical or psychological.
- The nature and content of services provided is matched to need using **stratified assessment tools**.
- There is a **continuing research and development programme** to improve understanding of the consequences of cancer and its treatment and this research programme is seamlessly integrated into mainstream research into the treatment of cancer.’

Figure 4. NCSI COT Workstream Priorities.



telephone or online to enable those with rare conditions and/or living a long distance from specialist services to be able to assess themselves if they developed new symptoms so they knew when to ask for help.

The group took evidence from a number of experts in this field, and supported a pilot study, looking at obtaining permission for ongoing PROMs distribution from the time of cancer registration [14]. The group explored the potential of interrogating completed trial data sets and audits [15] to obtain the evidence for the natural history of treatment-related consequences detected by PROMs [16] and found multiple challenges in the form of inadequate follow-up, missing data and insufficient numbers of sensitive items. However, they were able to identify four items for inclusion in a national PROMs survey with a particular emphasis on bowel and urinary urgency. Initial analysis of the national survey has supported the early estimates of one in five with significant problems following pelvic cancer treatment.

#### *Making the invisible visible*

Much of the first two years focused on raising awareness. For many of the more troublesome consequences of treatment, patients and their healthcare professionals fail to make the link to cancer treatment. The workstream received reports of patients troubled by multiple confusing symptoms but receiving neither a diagnosis nor help [9]. A key priority was to make such 'invisible' problems more visible through the use of routinely collected activity data linked to the systematic use of PROMs. In order to make the case for this, the group commissioned cross-sectional and longitudinal audits and revisited those clinical trial data sets which included PROMs. Several charities, including Macmillan Cancer Support, helped to bring these issues to the attention

of the media with significant press and television coverage. This approach was sometimes uncomfortable for professionals [17]. The NCSI also established an innovative community of clinical researchers ([www.cancerconsequences.org](http://www.cancerconsequences.org)) to provide leadership amongst nurses and therapists in this field.

#### *New models of care*

The workstream adopted the risk stratified chronic illness model [18] of care used by the rest of the NCSI (Figure 5) with level one focusing on prevention, information and supported self-management, level two on multidisciplinary assessment and brief intervention, and level three focused on complex multi-disciplinary case management. For those treated as adults, three broad groups were identified for early attention based on the numbers of people likely to be affected and the type of problem.

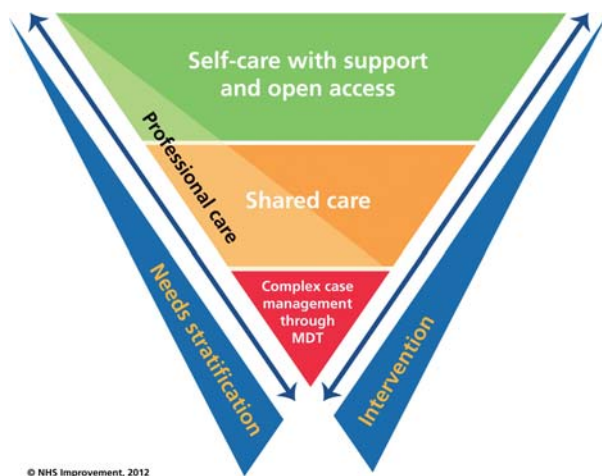
#### *Rare and complex issues*

The first group includes multifaceted issues affecting relatively small numbers, i.e. less than a thousand patients per million survivors. From time to time particular treatment regimes have resulted in clusters of complex problems affecting several hundred people. Typically (but by no means always) these develop over several years after cancer treatment and are often related to treatments which are no longer used.

For example, in the 1990s several hundred women in a number of European countries developed a series of complex injuries due to a radiotherapy technique used for breast cancer in the 1970s and 1980s. In 2008 there were 93 000 women alive with a diagnosis of breast cancer more than 20 years from diagnosis of whom around half would have had radiotherapy. Three hundred women were identified with severe complications including radiation-induced brachial plexopathy.

Problems included painful and disabling brachial plexopathy, fractures, lung fibrosis and necrosis. Guidelines for their management had been published in 1995 but not implemented [19]. Their story since the 1980s was captured in a narrative *Yesterday's Women* which describes the challenges faced by many with severe iatrogenic problems [20].

The NCSI approach was to work with them through their national support group RAGE (Radiation Action Group Exposure). Patients were contacted by phone or e-mail using a structured assessment to clarify their problems and were then matched to the expertise of individual specialist groups. Small teams of specialists volunteered to take part in one-off bespoke multi-disciplinary



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Figure 5. NCSI Risk Stratification Model.

assessment and care planning clinics, which were held across the UK with the aim of assessing and legitimising problems, to facilitate access to appropriate local services, and to identify individuals who might benefit from more intensive evidence-based treatments.

From the testing process involving 13 test sites, at least 40 occupational therapists, oncologists, pain doctors, palliative medicine specialists and specialist nurses, three centres emerged with the interest and expertise to act as ongoing regional assessment centres, with one centre for national coordination and case management of particularly complex problems. All members of RAGE were invited to attend an Assessment and Care Planning clinic, followed by allocation to a palliative care doctor, GP or oncologist to coordinate ongoing care. A few patients remained generally well but had severe and progressive problems related to brachial plexopathy and were identified as potentially benefitting from a more intense rehabilitation programme available at the Royal Hospital for Rheumatic Diseases at Bath. The model of care was accepted by the English specialist commissioning board and services for this group will be commissioned for the first time from 2012 [21,22].

This approach of at a distance triage and be-spoke multi-disciplinary assessment and care planning is seen as a potential model for complex problems following head and neck cancers, sarcomas, brain tumours, bone marrow transplants and the more severe problems following pelvic radiation therapy [20].

#### *More common, clusters of troublesome symptoms*

The second grouping was of problems which may affect thousands of people per million survivors e.g. the issue of poor bowel control after treatment for pelvic cancers such as colorectal, prostate and gynaecological malignancy. About 17 000 people are treated with radiation therapy in the UK every year and an estimated 80 000 are alive [6]. For 20 000 of these, bowel and/or urine control will be a significant problem and for at least 8000, urge incontinence is a significant issue [6]. This is often not recorded as, without a prompt, patients often fail to tell health professionals.

There is widespread professional nihilism that nothing can be done about these symptoms [6].

Recent data demonstrates that a systematic approach to enquiry and diagnostic testing reveals multiple causes of poor bowel control, each of which needs diagnosing and treating with simple interventions which can result in significant symptomatic improvement [23,24].

Guidelines commissioned from the British Society of Gastroenterology were published in GUT in 2012 [6] together with a diagnostic algorithm and testing of their use is ongoing in four centres with promising results [22,23]. The key learning from both groups was the need to frame the clusters of problems arising from treatment in the context of a similar 'recognised' illness for which services are already available, e.g. inflammatory bowel disease, which involved interesting a group of non-oncologists who were not necessarily interested in cancer. The British Society of Gastroenterology have now identified the management of cancer treatment-related problems as one of their top three priorities for 2013. Other important elements in moving the work forward included: the early introduction of PROMS to promote the feasibility of at a distance self-assessment [15]; encouraging the reinforcement of information about the risk of future problems (and what can be done about them) at the end of treatment (as well as at the time of consent); ensuring primary care teams record risk related to treatment as part of their electronic record; ensuring clear routes of access through a trusted source, e.g. a specialist nurse; evidence-based diagnostic pathways and management guidelines including brief interventions with at least one specialist team. Again, it identified a need for regional centres based either in cancer centres or gastroenterology centres to coordinate, manage and carry out research into the more complex cases.

#### *Increased risk of chronic illness in large populations*

The third problem identified by the COT work-stream is the increased risk of common chronic illness in large numbers of survivors in the decades following treatments, including the risk of cardiovascular disease, stroke, osteoporosis and second malignancy. A first step was demonstrating that cancer diagnoses and treatments could be linked to the incidence of chronic illnesses using routinely collected activity data in primary care, e.g. an increased cardiovascular disease in breast cancer and osteoporosis in prostate cancer [4]. A priority is to ensure that cancer is more reliably coded in primary care electronic records and that GPs conduct a proactive cancer care review at the end of cancer treatment [25].

If a cancer diagnosis presents an opportunity to promote a healthier lifestyle, segmentation of prevalence data can enable more effective presentation of the 'size of the prize'. In England, successful lifestyle interventions such as weight management or exercise programmes sustained for 200,000 people approaching end of treatment, more than 5 years from diagnosis and at higher risk of disabling chronic illness than those without a cancer diagnosis (both

due to treatment and predisposing issues) could benefit a population of over 1.2 million now. Two members of the COT workstream went on to chair the Macmillan Physical Activity Group with initiatives including an evidence review [26], pilot testing within community leisure centres with a training programme for leisure centre trainers. In April 2012, Macmillan Cancer Support and the Ramblers Association assumed responsibility for Walking for Health – an England-wide scheme which has been in operation for a decade. It provides short, easy and free led-walks for the public. There are 56,000 participants taking part in Walking for Health and 650 local schemes, usually coordinated by local authorities and led by 12 000 trained volunteer walks leaders ([www.walkingforhealth.org.uk](http://www.walkingforhealth.org.uk)). This is the first time cancer survivors have been specifically targeted.

## Conclusion

### *Learning from the consequences of treatment work stream*

We have had to constantly remind ourselves that the consequences of treatment are not on most busy specialists' agendas and learned that it is necessary to engage both senior managers (for their vision, sponsorship, authority and flexible funding) and middle managers (for the provision of resources, release of staff, sustainability). We have learned the importance of engaging clinicians outside the cancer specialist arena as they are often the ones who see people with late effects from cancer treatment and have solutions for their problems, e.g. primary care physicians who see cancer as an acute illness and gastroenterologists in relation to pelvic radiation-related side effects. It is essential to engage the academic community, researchers are very important to give credibility and present early reports at meetings attended by influential people. They challenge sloppy thinking and create the sort of data which is important for sustaining services but can slow things down in the early stages when building a case for change. Lastly, it is important to play a long game – change takes time.

The COT workstream of the NCSI has made a start but there is much work to do. Cross European collaboration offers a great opportunity for the future.

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