

## **PRIORITY BRIEFING**

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. They were compiled in 2-3 days.

### **What are the psychological impacts of receiving cancer surgery at a distant location?**

**Question ID: 1**

**Question type:** Intervention

**Question:** What are the psychological impacts of receiving cancer surgery at a distant location?

**Population:** Adults with cancer requiring surgery.

**Intervention:** Surgery at a distant location (more than 50 miles or two hours travelling time from the patient's home).

**Control:** Surgery at a non-distant location (less than 50 miles or two hours travelling time from the patient's home).

**Outcome:** Qualitative interviews of patient experience to explore the psychological impact on patients and carers/families of travelling long distances from home for cancer surgery. Interviews would also include discussion about measures that might have improved their patient experience and how the psychological impact may be mitigated. Patient and carer satisfaction questionnaire. Measures of social support and social isolation. Health related quality of life.

### **Centralisation of cancer services:**

The Department of Health Cancer Reform Strategy published in 2007 set out a programme of action to improve cancer outcomes. The strategy recognised that 'New models of care can bring considerable advantages to patients. The strategy sets out a range of ways in which service models for cancer could be improved, based on two key principles: first that care should be delivered locally wherever possible to maximize patient convenience; and second that services should be centralized where necessary to improve outcomes. The strategy also states that 'Care must be delivered by providers who conform to national standards such as the NICE Improving Outcomes Guidance which are fully integrated with other services within the cancer network.'

As a result of these initiatives surgery for many rarer cancers is performed at fewer, central locations which may be remote from a patient's place of residence.

### **Rarer cancers:**

The most common cancers diagnosed in the UK are bowel cancer, breast cancer, lung cancer, skin cancer and prostate cancer. However, it has been estimated that 52% of cancer deaths in the UK are from less common cancers.

## **The Health Problem**

Patients travelling to a distant location for cancer surgery have reported feeling both physically and emotionally isolated from their normal support mechanisms (e.g. visitors who are able to take laundry home, chat about things that have happened within the local community, provide new supplies of reading material, food or drink, talk to health professionals and express thoughts and questions that the patient may have had before surgery but is not so able to express post-surgery, retain information provided by health professionals on behalf of the patient, people who are aware of the patients' history and background and can make appropriate small-talk etc etc). Whilst the nursing team can provide some emotional support, anecdotally this is felt to be very different from that which might be provided by a patient's family, friends, colleagues, church or chapel community etc. Undergoing surgery at a distant location may limit the number of people able to visit (e.g. colleagues dropping in after work) and may preclude visits from elderly partners/family members. Feelings of isolation and loneliness may be compounded by patients in neighbouring beds (who have not travelled long distances for their treatment) being surrounded by a steady stream of visitors. In addition to the impact on the patient there may be a greater psychological impact on carers, children and other dependents if a patient receives cancer surgery at a distant location.

It is possible that the psychological impact of receiving cancer surgery at a distant location may be greater for some individuals/groups of individuals than others leading to health inequalities.

Surgery is seen as the point in a patient's cancer journey at which they feel most emotionally and physically vulnerable and the experience at this time has been described as being a pivotal point in influencing the subsequent road to recovery. Feelings of positivity, maintaining low stress levels and building a fighting spirit are all strategies encouraged in cancer care but which may be difficult to engender during a two-week hospital stay isolated from your community.

## **NHS Priority:**

### **Regional**

#### **SW SHA Priorities framework 2008-11**

- Reduce mortality rates from cancer in people aged under 75.

### **Local**

#### **Local perspective**

- Reduce deaths from cancer by improving prevention, early diagnosis, treatment and long-term care (CPCT)
- Promoting health and wellbeing and reducing health inequalities (CPCT Transforming Community Services agenda)
- Acute services closer to home (CPCT Transforming Community Services agenda)

- Health inequalities (Plymouth PCT and NHS Devon)
- Torbay Care Trust's Strategic Plan promises to commission services and target funding to reduce health inequalities

## **Existing Research**

### **Published research**

We identified little research that focused on the patient experience of distant cancer surgery in terms of the psychological impact of being away from the home community.

We found one systematic review published in 2000<sup>1</sup> on the impact of travel on cancer patients' experiences of treatment. The review included 11 relevant studies (approx. 3755, in some papers it was not clear how many patients had been surveyed) from six countries. Most of the papers are concerned with aspects of travelling to repeated radiotherapy appointments and in most the distances covered and travelling times are less than those specified in this question. Three papers<sup>2,3,4</sup> addressed concerns of temporary separation from the home environment but were considered to have limited generalisability since they included individuals from minority groups (e.g. Inuits in Canada, immigrants in Israel) traveling very great distances (e.g. by air) for treatment.

### **Ongoing research**

We were unable to identify any ongoing research in this area.

### **Feasibility**

This question was originated by and developed with a member of the Cornwall and Isles of Scilly Cancer Patient and Carer Group and has the support of this group. The question is also supported by Cornwall Local Involvement Network (LINK), NHS Cornwall and Isles of Scilly, clinical nurse specialists and clinicians and other local cancer patient support groups.

There may be the potential to update the existing systematic review.

## References

1. Payne S, Jarrett N, Jeffs D. (2000). The impact of travel on cancer patients' experiences of treatment: a literature review. *Eur J Cancer Care (Engl)* 9(4):197-203.

This literature review aims to identify the impact of travel on cancer patients' experiences of treatment. With centralization of cancer services, patients may have to travel considerable distances from their homes and families, to receive specialist cancer treatment. Centralization of cancer services may have advantages in terms of concentrating clinical expertise, enhancing the range of ancillary facilities and rationalising the provision of expensive specialist equipment, but it is not known to what extent patients are affected by additional travel and the prospect of separation from their social networks. A systematic literature search using MEDLINE, SSCI, SOCA and PSYCHLIT, identified 11 relevant studies from six countries. The review showed a paucity of research on the implications of receiving cancer treatment far from home. Most studies can be criticised on methodological grounds. The evidence that travel distance and difficulty increases psychological distress, and reduces compliance with treatment and take up of treatment is largely inconclusive. However, travel to cancer treatment is described as inconvenient and a practical hardship for many patients. It may be perceived, or experienced as, a barrier to treatment. Future studies should evaluate the impact of travel to treatment on quality of life and perceived social support.

2. Martin B, Smith W, Orr P, Guijon F. (1995) Investigation and management of cervical intraepithelial neoplasia in Canadian Inuit: enhancing access to care. *Arctic Med Res* 54 Suppl 1:117-21.

Cervical intraepithelial neoplasia (CIN) is a major cause of morbidity among Circumpolar women. Cervical cancer comprised 15% of all cancers in Canadian Inuit women from 1969-1988. The age standardized incidence for invasive cervical cancer in Canadian Inuit women is 3.1 times the rate in the general Canadian population. Management of CIN in women of remote Arctic regions has traditionally required multiple visits to specialized medical centres for diagnosis, therapy and follow-up. Such centralized care requires separation of women from their families, resulting in significant medical, emotional and economic costs for the patient, her family and community. In the Canadian Central Arctic, a program for the diagnosis and therapy of CIN has been established using colposcopy with loop electrosurgery, performed by a trained local family practitioner and visiting gynecologist. Early program evaluation has indicated reduction in medical expenditures due to travel costs, minimal procedure-related morbidity and discomfort, and improved patient satisfaction associated with reduced separation from family and community. It is hoped that the program design, which harnesses technology in order to provide improved care closer to home, will be applicable to other Circumpolar regions.

3. Baider L, Kaufman B, Ever-Hadani P, Kaplan De-Nour A. (1996) Coping with additional stresses: comparative study of healthy and cancer patient new immigrants. *Soc Sci Med.* 42(7):1077-84.

The adjustment and psychological distress of 166 cancer patients, who are new immigrants from the former Soviet Union, was assessed and compared to that of 288 healthy new immigrants from the the former Soviet Union. The healthy new immigrants had many adjustment problems and their psychological distress was fairly high. The cancer patients reported extremely severe psychological distress. In the healthy immigrants, age contributed to distress while family support had significant protective effects especially in the male immigrants. In the patients, these differences were even more extreme with family support being protective in the male group but not in the female group. Intrusiveness (IES) seems to be maladaptive adding to distress. The results clearly indicate that additional stresses, such as immigration, make cancer patients more vulnerable. The results also suggest possible interventions, especially those that will help to decrease intrusiveness.

4. Davis C, Girgis A, Williams P, Beeney L. (1998) Needs assessment of rural and remote women travelling to the city for breast cancer treatment. *Aust N Z J Public Health* 22(5):525-7.

The purpose of this study was to assess the needs of rural women travelling to the city for breast cancer treatment. Participants included 80 women aged between 34 and 80 years living in rural NSW and South Australia who travelled for breast cancer treatment. After completing treatment, participants completed a brief telephone survey on the needs of rural women travelling for treatment. Findings revealed that more than 90% of women travelled for treatment due to the lack of available treatment centres closer to home and on average they spent 6.79 weeks (SD = 4.73) away from their home and family. Findings also showed that 89% identified specific problems for rural women, with social and practical support being primary concerns. Although the majority of women were provided with some type of social support, only 39% of women received financial assistance and 19% of these women had trouble claiming money for which they were eligible. Recommendations of appropriate interventions to ensure equity in the availability and access to breast cancer treatment for all women are discussed.