

IAF/23/01 - Adaptation of the Advanced Symptom Management System for the Delivery of Supportive Care to People with Head and Neck Cancer

Head and Neck cancer (HNC) is the 6th most common cancer type in Scotland and rates are increasing. HNC treatment usually involves surgery, which may include removal of the voice box (laryngectomy) and radiotherapy. These treatments can have significant side-effects which can last a long time or even for life. A recent survey by The Swallows HNC charity showed that even after successful treatment, most patients continue to struggle with significant physical problems such as swallowing difficulties, loss of voice, stiffness of the jaw and dry mouth. They also found that many patients were very anxious about the cancer returning. After laryngectomy, patients have a big change to their body image and communication which can be upsetting and isolating.

To address these complex problems, HNC patients are usually under the care of multiple health professionals including Surgeons, Oncologists, Speech and Language Therapists and Dieticians. Clinical Nurse Specialists (CNSs) provide a contact point for patients and give them support in other ways such as with personal finances. The British Association of Head and Neck Oncologists (BAHNO) produce guidelines about the care HNC patients should receive. After completing treatment, patients are seen as an out-patient every 2-6 months. This is often in a busy clinic with the focus being primarily on detecting recurrent cancer and physical symptoms. Between appointments we rely on patients flagging up issues to the team (usually the CNSs).

There is good evidence that health-related computer programmes and mobile phone applications can be used to provide effective healthcare in some situations. These kinds of digital health tools can be used to support routine care, expand services and/or provide a service where none currently exists. They can do this without significantly increasing the number of staff or resources required. Digital health tools can be available to patients at home, whenever needed. There are no such digital health tools for HNC used in the UK.

The Advanced Symptom Management System (ASyMS) is a smart phone-based application which has been tried and tested in patients with other types of cancer. In this project we aim to adapt it for HNC patients. This is important because HNC patients experience specific and unique problems. We hope the tool will provide an easy way for HNC patients to report new symptoms so their clinical teams can act on them quickly. The ASyMS-HNC app will provide advice for managing symptoms at home based on patients' particular needs. We know that the presence of some symptoms after treatment for HNC may indicate the cancer has returned – such as new pain or a new neck lump. The app could give us an early warning that something is wrong before patients are seen in clinic.

The project will have two main parts. Firstly we will create new content for the tool. The content will be composed of 1) symptom questionnaire and 2) self-management

resources. Once we have a prototype, or draft, tool we will get feedback from patients about the design and content. We will collect this information via surveys and focus groups with HNC patients and the clinicians involved the multi-disciplinary team. Once ASyMS-HNC is complete we will recruit a small group of patients to try it alongside normal clinical care in a pilot study. The results of this study will help us iron out any technical problems, check the App is easy to use and that patients find it worthwhile. If the pilot study is a success, we would hope to run a bigger study in the future to look at whether using it improves the health of HNC patients.