



FoNS Improvement Insights

Promoting the Health and Wellbeing of Men with Testicular Cancer through Information and Support

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Duration of project: December 2012 – July 2014

Keywords: Health and wellbeing, testicular cancer

Project background

The Northern Ireland Cancer Centre at Belfast City Hospital hosts the specialist tertiary centre for testicular cancer. Patients with testicular cancer tend to be young but despite a high cure rate, the nature of the condition may lead to complex physical, psychological and social morbidity leading to non-compliance with treatment and follow up which can be life threatening. Evidence suggests that a key intervention that could make a difference is patient education and support. The project leader had already piloted two health and wellbeing events and following these, it was decided to develop events that were 'closer to home' in order to meet the needs of patients including those in rural and socially deprived areas.

Aim and objectives of the project

The aim of the project was to develop and implement health and wellbeing events for men with testicular cancer in community locations in Northern Ireland. To achieve this aim, the following objectives were identified. To:

- Engage with key stakeholders to develop a shared vision for the project
- Identify the key issues for patients with testicular cancer using a baseline evaluation of what services were currently in place
- Develop, implement and evaluate a new service model of health and wellbeing events in the form of a 'one-stop-shop' approach for services and support to enable patients to access a range of services

Key activities and outcomes of the project

- Developing and engaging the team

A number of meetings and events were held to develop and engage the stakeholders. Firstly, key stakeholders, including clinical staff, patient representatives, management and allied health professionals, were invited to an evening workshop. To encourage discussion about what people expected from the project and to enable the development of a shared vision, a modified values clarification exercise was conducted. Another outcome of this workshop was an identified need to engage broader patient input. Eight patients were identified and invited to come to a meeting about the project, of which four were able to attend. After an introduction by the project leader, the patients were asked about the format and content of the events, timing, and whether partners/wives should be invited. The following month, a project team was established at a meeting, including clinical staff, allied professionals, the trust information manager

and a social worker, in addition to the four patient representatives and one carer.

- Collecting baseline data

A questionnaire was given to patients and carers at the outpatient clinic. The aim of the questionnaire was to discover what information was most important to people. The most popular topics for inclusion in the new health and wellbeing events were cancer recurrence, the side effects of treatment, and diet and exercise.

- Delivery and evaluation of events

Four local health and wellbeing events were held over the period from June to September 2013. Patients with testicular cancer from each local area were invited by letter and/or phone. Numbers at some of the events were disappointing, but this was thought to be due to a number of factors, such as other commitments and length of time since diagnosis. Each event was evaluated by survey and some changes were made to the programme along the way but overall the evaluation was very positive.

- Final event and future plans

Following each of the four local events a project group meeting was held as the project leader believed it was important that all team members and stakeholders were included in the decision making. At the last meeting, the group agreed the details of a final health and wellbeing event to be held in Belfast. Attendance at the final event was good and the event was evaluated very positively; the presentations were useful, the length of the event appropriate, and overall, the event met the expectations of those that attended. While the local, 'closer to home' events were evaluated well, for a number of reasons it was decided that more centralised events would be more sustainable. They would provide the information, support and the benefits of the local meetings and enable staff involvement to be optimised.

Implications for practice:

- Engagement with the key stakeholders, project team and patients through regular meetings and workshops can help to identify key issues and concerns
- Involvement of patients in focus groups can greatly benefit any project
- There is a need to explore new and practical ways of inviting and reminding patients about events e.g. using trust's text messaging services
- Feedback from patients and carers is beneficial and provides unique insights that can influence the development of a project

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstd=55845>

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