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

**Project Leader:** Wendy McPhee, Macmillan Uro-Oncology Project Nurse  
**Duration:** December 2012 – July 2014  
**Report Submitted:** June 2015  
**Contact Details:** wendymcphee54@hotmail.com  
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**Summary**

The Northern Ireland Cancer Centre at Belfast City Hospital hosts the specialist tertiary centre for testicular cancer. Approximately 70 men are diagnosed every year, attending for treatment and surveillance from all areas of Northern Ireland, some having to travel over 100 miles for their appointments at the cancer centre.

The diagnosis of cancer can be devastating for all patients but the very nature of testicular cancer in young men is particularly difficult. Despite a high cure rate, patients suffer significant complex physical, psychological and social morbidity due to the nature of the diagnosis and treatment. They find these difficult to address leading to tendencies of non-compliance with treatment and follow up which can be life threatening. Evidence shows that many cancer survivors have unmet needs, particularly at the end of treatment, whilst others struggle with the consequences of this treatment. One of the key interventions that could make a difference is patient education and support events.

One of the projects undertaken by the project leader as part of her post in 2012 was to pilot two nurse-led health and wellbeing events for men with testicular cancer. At the time there was a lack of specific information, support and holistic care for this group of patients within the Belfast Health and Social Care Trust; these events were designed to address these unmet needs. Following two well evaluated pilot events a need was identified to take these events ‘closer to home’; to more non-clinical locations such as sports/community centres in both town and rural communities; and to socially deprived areas around Northern Ireland.

The aim of the project was to develop and implement four health and wellbeing events for men with testicular cancer, in community locations in Northern Ireland. The methods and approaches used within the project were:

- Collection of baseline data
- Developing and delivery of the events
- Patient, carer and staff evaluations

The outcomes from the project included introducing patients and their wives/partners and carers to a range of local services and resources - both clinical and non-clinical such as counselling, complementary therapies and benefits advice to address their physical, emotional, social and
financial needs. Provision of information on cancer recurrence, long-term side effects of treatment, self-management, diet, exercise and lifestyle advice led to improved patient education and self-management leading to earlier interventions, which are linked to improved outcomes and more appropriate use of services. The health and wellbeing events also gave patients and carers the opportunity to speak about difficult subjects in a safe well-supported environment.

While the local, ‘closer to home’ events were evaluated well, it was eventually decided, for a number of reasons, that more centralised events would be more sustainable, giving all the information and support benefits of the local meetings, while minimising the demands on staff and patients alike.

Background to project

The Northern Ireland Cancer Centre (NICC) at Belfast City Hospital (BCH) hosts the specialist tertiary centre for testicular cancer (TC) where approximately 70 men are diagnosed every year. These men attend for treatment and surveillance from all areas of Northern Ireland, some having to travel over 100 miles for their appointments at NICC.

The profile of patients with TC tends to be young men who despite a high cure rate, with a 5 year relative survival rate of over 96% (Northern Ireland Cancer Registry, 2014), suffer significant complex physical, psychological and social morbidity due to the nature of the diagnosis and treatment (Carpentier et al., 2011). They find these difficult to address leading to tendencies of non-compliance with treatment and follow up which can be life threatening.

Information about current practice from the National Cancer Survivorship Initiative (NCSI) (National Cancer Survivorship Initiative, 2010) produced powerful evidence that follow up arrangements were not meeting the needs of survivors. NCSI addressed this by developing and pilot testing alternative models of follow up to ensure every cancer survivor is supported to lead as normal a life as possible. This included Health and Wellbeing (H&WB) clinics; one-off events that would enable survivors and their carers to manage the transition from active treatment to survivorship. Additional evidence showed that many cancer survivors had other unmet needs (Armes et al., 2009), particularly at the end of treatment, whilst some survivors struggled with the consequences of their treatment (Santin et al., 2012). One of the key interventions that could make a difference was patient education and support events (Department of Health, 2013).

One of the projects undertaken by the project leader as part of her post in 2012 was to pilot two nurse-led Health and Wellbeing (H&WB) events for men with testicular cancer. At the time there was a lack of specific information, support and holistic care for this group of patients within the Belfast Health and Social Care Trust (BHSCT); these events were designed to address their unmet needs. The H&WB pilot events were set up by the project leader in conjunction with the lead consultant for TC and the senior nurse cancer services. A working group for the pilot events was established which included allied health professionals (AHPs) and other colleagues including consultants, specialist registrars, clinical nurse specialist (CNS) for teenagers and young adults (TYA), a physiotherapist, the trust information manager, a social worker and the healthcare assistant (HCA) from the Teratoma Clinic.

Patients and carers attending follow up clinics in February and March 2012 completed questionnaires regarding services available to them at that time. The information collated from these questionnaires was used to help devise the H&WB programme. A second meeting of the group formulated the programme for the evenings and decided which groups of patients would be invited. Following these well-evaluated pilot events held in May and June 2012 (see Appendices 1 and 2), a need was identified to take these events ‘closer to home’, to more non-clinical locations such as
sports/community centres in towns, rural communities and socially deprived areas around Northern Ireland. A successful application by the project leader to the Foundation of Nursing Studies (FoNS) 'Patients First' programme provided learning workshops and the support of an external facilitator for the project leader. In addition a small bursary was provided to enable these events to be planned in four different venues and locations around Northern Ireland.

**Aim:**
To develop and implement health and wellbeing events for men with testicular cancer in community locations within Northern Ireland.

**Objectives:**
1. To engage with key stakeholders through workshops and meetings to develop a shared vision for the project. These stakeholders would include medical and nursing staff, allied health professionals (AHPs), social workers, personal and public involvement (PPI) representatives, carers, local cancer charities and volunteers.
2. To identify the key issues for patients with TC using a baseline evaluation of what services are currently in place to meet the needs of this group of patients. These include:
   - cancer recurrence
   - short and long term side effects of treatment
   - the importance of compliance with the active surveillance programme
   - sexual health, fertility and psychological concerns, self-management, diet, exercise and lifestyle advice.
3. To develop and implement a new service model of H&WB events which takes the form of a ‘one-stop-shop’ approach for services and support. The style is of an end-of-treatment supportive information and education event for patients and their wives/partners. It will be tailored to their particular needs bringing together a range of service providers from health, social, community and voluntary services.
4. To enable patients to access a range of services easily, which may lead to their unmet needs being identified and addressed. These H&WB events will amongst other things give patients the opportunity to speak about a difficult topic in a safe well supported environment.
5. To evaluate the effectiveness of the H&WB events from the perspective of patients, carers and staff through feedback using questionnaires, surveys, and patient and carer stories.

**Overview of the project:**
**Methods and Approaches:**
A number of methods were used to facilitate the changes to practice. These are outlined in the following table.
<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
<th>Participants</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial meeting to engage with key personnel to develop a shared vision for the project</td>
<td>Introduction to FoNS project. Identification of key issues around cancer survivorship and enabling transition post treatment. Values clarification exercise undertaken.</td>
<td>project team (PT), patient focus group (PFG), key stakeholders and relevant trust employees and volunteers</td>
<td>25.3.2013</td>
</tr>
<tr>
<td>Meeting to establish a patient focus group</td>
<td>Introduction to FoNS project, icebreaker. Purpose of group explained - to meet on regular basis to discuss and debate experiences and issues around TC.</td>
<td>project leader (facilitator), CNS TYA and 4 patient representatives</td>
<td>4.4.2013</td>
</tr>
<tr>
<td>Observation of current practice at Teratoma clinics. Patient stories</td>
<td>Baseline evaluation of what currently available to men in the form of information and support.</td>
<td>project leader</td>
<td>March - April 2013</td>
</tr>
<tr>
<td>Workshop to establish FoNS project team</td>
<td>Background of pilot H&amp;WB events; FoNS project presentation; icebreaker, and claims, concerns and issues exercise.</td>
<td>PT and PFG</td>
<td>2.5.2013</td>
</tr>
<tr>
<td>Patient and carer questionnaires undertaken at Teratoma clinics</td>
<td>Information collated to ascertain topics for inclusion in H&amp;WB events.</td>
<td>project leader and HCA from clinic</td>
<td>March - April 2013</td>
</tr>
<tr>
<td>Review of current literature and pathways currently in use</td>
<td>Development of patient treatment and information TC pathways to ascertain where and what information, support and education should be provided.</td>
<td>project leader, lead TC oncologist</td>
<td>May – August 2013</td>
</tr>
<tr>
<td>Londonderry H&amp;WB event</td>
<td>Held in Waterside Health and Social Care Centre.</td>
<td>PT and patient representatives</td>
<td>13.6.2013</td>
</tr>
<tr>
<td>Clogher H&amp;WB Event</td>
<td>Held in Corrick House Hotel.</td>
<td>PT and patient representatives</td>
<td>1.8.2013</td>
</tr>
<tr>
<td>Banbridge H&amp;WB Event</td>
<td>Held in the Camera Club Room, Banbridge Old Tech Building.</td>
<td>PT and patient representatives</td>
<td>5.9.2013</td>
</tr>
<tr>
<td>Ballymena H&amp;WB Event</td>
<td>Held in Cloughmills Community Centre.</td>
<td>PT and patient representatives</td>
<td>24.10.2013</td>
</tr>
<tr>
<td>Patient focus group meeting</td>
<td>Icebreaker, feedback from H&amp;WB events. Claims, concerns and issues exercise. Top three issues. Action plan.</td>
<td>project leader, CNS TYA &amp; 4 patient representatives</td>
<td>4.12..2013</td>
</tr>
<tr>
<td>Patient focus group and project team meeting</td>
<td>Icebreaker, feedback from H&amp;WB events and PFG meeting. Claims, concerns and issues exercise. How to take project forward. Action plan.</td>
<td>PT and PFG</td>
<td>20.2.2014</td>
</tr>
<tr>
<td>Patient focus group and project team meeting</td>
<td>Icebreaker, format of programme for 5th H&amp;WB event to be held in Belfast for all new patients diagnosed January 2013 – March 2014.</td>
<td>PT and PFG</td>
<td>2.4.2014</td>
</tr>
<tr>
<td>Belfast H&amp;WB Event</td>
<td>Held in the Seminar Rooms Suite, Cancer Centre, Belfast City Hospital for all new patients diagnosed January 2013 – March 2014.</td>
<td>PT and 3 patient representatives</td>
<td>8.5.2014</td>
</tr>
</tbody>
</table>
1. Engaging the team – how a shared vision was developed

**Meeting with Key Stakeholders (25.3.2013):**

Following discussion with the senior nurse cancer services in the Trust, the initial project team meeting with the key stakeholders was held on 25th March 2013. The project leader invited 14 Trust personnel including four patient representatives, consultants, clinical nurse specialists (CNS), a healthcare assistant (HCA), service improvements leads, senior management, allied health professionals, the trust information manager, the trust project manager for transforming cancer follow-up (TCFU) and the volunteer coordinator. These attendees were invited as a broad representation of BHSCT management, employees and service users, some of whom would be involved in the project.

The evening meeting was held in the NICC to plan the ‘closer to home’ H&WB events. This was a convenient location for everyone; the time chosen as interfering the least with both the clinical teams’ and patients’ study and work commitments. It commenced with a presentation by the project leader on the background to the FoNS ‘Patients First’ Programme. The senior nurse cancer services agreed to facilitate the workshop on behalf of the project leader and she undertook a modified values clarification exercise (Warfield and Manley, 1990) that resulted in everyone identifying their key values in relation to the H&WB events (see Appendix 3). By listening to everyone’s perspective and following a debate on what we hoped to achieve with the project, a shared vision was developed. Clarifying the values and beliefs and agreeing the common or shared values and beliefs is the first step towards collaborative practice development work (McCormack et al., 2013).

**Patient Focus Group**

**Meeting to establish a Patient Focus Group (4.4.2013):**

Due to the difference of opinion of the two patient representatives at the first project team workshop with key stakeholders, it was proposed to form a patient focus group (PFG) for this project. The project leader believed that this might also assist with future thoughts and ideas for health promotion and awareness.

Eight patients were identified and personal invitations and phone calls to join the group were made by the project leader; four of whom were able to attend. To help facilitate the evening meeting the project leader was joined by the CNS for teenagers and young adults (TYA).

The evening began with an explanation of the purpose of the patient focus group and the completion of consent forms (see Appendix 4). The patient focus group was described as an informal
collection of people sharing the same characteristics – i.e. men with testicular cancer, who would meet on a regular basis to discuss and debate experiences and to offer suggestions on various topics including: the H&WB events (where and in what venues events will be held), sexual health, prostheses and health promotion and awareness sessions and advice.

The project leader put the following questions to the patient focus group verbally; an animated discussion ensued.

1 What do you want to know?
2 How do you want the H&WB event to be presented?
   • Short talks from medical/nursing/AHP staff?
   • Patients’ perspectives?
   • Question and answer sessions?
   • What do you want included?
   • Do you want quizzes and prizes? – Famous Faces with TC and Know your Balls?
3 Do you want your wives, partners or carers to attend?
4 Timing of event in post treatment phase?

The project leader stressed to the group that honesty in answering the questions was very important as the views and opinions of everyone present would be very useful to them to help determine the programme and contents for the events.

The four members of the PFG were all very enthusiastic and joined in a lively discussion. One participant had attended a pilot H&WB event the previous year, his feedback and thoughts on the topics and issues added to this informal debate. These are their suggestions:

• Mentor or support person for those newly diagnosed/treated
• Share experiences either 1:1 or in a group
• Patient’s perspective
• Support group in each area that H&WB events to be held
• Health promotion
• Youth forum – not necessarily just TC
• Importance of active surveillance programme – why do patients not attend appointments?

Workshop to establish FoNS Project Team (2.5.2013):

The FoNS project team was made up of the project leader, the lead consultant TC, the specialist oncology registrar (SpR), the trust information manager, a physiotherapist, a social worker, the CNS TYA and a HCA in addition to the four patient representatives and one carer who had attended the workshop. The project leader facilitated the workshop providing the background from the H&WB pilots and subsequent FoNS application and programme.
Icebreakers were used at all the workshops and meetings, the purpose being to introduce and acquaint those persons present with each other, thus creating a comfortable environment in order to explore the thoughts, ideas and feelings of those present.

After the icebreaker and introductions, the workshop was based around a discussion of some key questions that the project leader had identified:

- Who? Which patients to invite to the events?
- What? The programme content proposal included the results from 62 patient and carers surveys conducted at the Teratoma Clinics in February and March 2013.
- What is self-management?

The questions produced a lot of discussion and an action plan, with practical tasks, was developed. See Appendix 5 for the notes from this workshop.

<table>
<thead>
<tr>
<th>Action Plan</th>
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<tbody>
<tr>
<td>Dates and locations to be proposed and agreed.</td>
</tr>
<tr>
<td>Request postcode trawl of TC patients diagnosed 2008 – 2013 residing within 30 mile radius of each proposed location.</td>
</tr>
<tr>
<td>Venues to be identified, researched and booked by members of the project team who have local knowledge of chosen area.</td>
</tr>
<tr>
<td>Invitations to be sent out 4 – 6 weeks in advance of each event. This to be followed up by a phone call 1- 2 weeks prior to the event.</td>
</tr>
</tbody>
</table>

2. Collecting baseline data

**Observation at Teratoma Clinics**

Baseline evaluation of what was currently available to men in the form of information and support was collected by informal observation of practice at the twice monthly Teratoma clinics during March and April 2013. It was noted that no information was currently provided to patients on testicular cancer or survivorship and health promotion.
**Questionnaires**

To determine what patients and carers wished to be offered at these health and wellbeing events, the project leader, lead consultant TC and trust information manager devised two questionnaires – one for patients and one for carers. All relevant patients attending the clinics were identified and a questionnaire given to the patient and his wife/partner on arrival at the clinic.

Verbal consent was obtained from those interested in participating by the project leader. The questionnaires were not anonymised at this time as relevant information e.g. telephone numbers and e-mail addresses would be useful for invitations to future events. However, the collected data for use in evaluations and reports was anonymised. A leaflet containing a brief explanation of what a H&WB event is was included with the questionnaire and participants were asked to tick which topics were most relevant to them. In total 62 questionnaires were completed at 3 Teratoma Clinics and 1 Outpatient Clinic – 47 patients and 15 carers. The information was collated and topics identified (see Appendix 6 for the full findings).

**Treatment and Information Pathways**

The development of testicular cancer patient treatment and information pathways was undertaken by the project leader as part of her post. A working group including the Belfast H&SC Trust (BHSCT) information manager, Northern Ireland Cancer Network (NICaN) information manager and transforming cancer follow-up (TCFU) project manager was established to develop these pathways for diagnosis, post treatment and discharge. The aim of this working group was to ascertain where, when and what information, support and education should be provided at different stages of the patient journey. This work was undertaken from May through to August 2013.

Once this work was completed and agreed the project leader held regular education sessions for the outpatient clinic nurses on how to inform and advise patients on aspects of testicular cancer, survivorship, self-management and healthy life style advice. Additionally outpatient nurse guidelines, action plan and protocols for testicular cancer treatments were created by the project leader in collaboration with the testicular cancer consultants. This work is now fully embedded into clinical practice.

**3. Development and delivery of events**

Proposed venues for the H&WB events

Patients were identified with the help of the Northern Ireland Cancer Centre IT managers using the postcodes of those diagnosed and treated for testicular cancer from 2008 to 2013. A review of the
medical notes of each patient was undertaken by the project leader to ascertain suitability to attend an event. The following tables show the number of postal and telephone invitations made by the project leader, and the responses across each of the locations.

**County Londonderry area:**
A member of the patient focus group identified the Waterside Health Centre as a suitable venue to hold the first H&WB event on 13.6.2013. The Health Centre, overlooking the River Foyle, had two rooms at the top of the building that had sufficient space for approximately 30 patients, wives/partners. One room was used for the presentations and information stands. The second room with easy chairs was ideal for refreshments and for everyone to chat together. He also sourced a local caterer to supply the refreshments.

<table>
<thead>
<tr>
<th>Invitations posted 2nd Class</th>
<th>Posted replies</th>
<th>Telephone calls using Trust landline. Daytime over 3 days.</th>
<th>Telephone calls using colleague’s Trust mobile. Evening calls over 2 days.</th>
<th>Personal invites at clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Calls                      No reply                  Yes</td>
<td>No Calls                  No reply                  Yes</td>
<td>No</td>
</tr>
<tr>
<td>57</td>
<td>3</td>
<td>108                       49                        9</td>
<td>16                        24                     16</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 messages left</td>
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</table>

**County Tyrone area:**
The second event was held in the Corrick House Hotel on 1.8.2013.

<table>
<thead>
<tr>
<th>Invitations posted 2nd Class</th>
<th>Posted replies</th>
<th>Telephone calls using Trust landline. Daytime over 3 days.</th>
<th>Telephone calls using colleague’s Trust mobile.</th>
<th>Personal invites at clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Calls                      No reply                  Yes</td>
<td>No Calls                  Yes                     No</td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>3</td>
<td>35                        6                         6</td>
<td>19                        16                     9</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 messages left</td>
<td></td>
<td></td>
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</tbody>
</table>

**Banbridge, County Down:**
Contact was made with Banbridge Council to hire the Camera Club Room at the Old Tec Building with catering included. Event date 5.9.2013.

<table>
<thead>
<tr>
<th>Invitations posted 2nd Class</th>
<th>Posted replies</th>
<th>Telephone calls using colleague’s Trust mobile. Evening calls</th>
<th>Text messages using colleague’s Trust mobile.</th>
<th>Personal invites at clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Calls                      No reply                  Yes</td>
<td>No Texts                  No reply                  Yes</td>
<td>No</td>
</tr>
<tr>
<td>71</td>
<td>2</td>
<td>14                        3                         11</td>
<td>5                         42                     15</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 messages left</td>
<td></td>
<td></td>
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</tbody>
</table>

**Cloughmills Community Centre, County Antrim:**
A second member of the patient focus group arranged for the hire of the Community Centre in the village of Cloughmills, he also organised the catering for the evening held on 24.10.2013.
The programme for these events was developed out of the 62 questionnaires from patients and carers attending the Teratoma clinics. Patients and carers were asked what sort of information they would like to receive at the H&WB events. The following table show what percentage of patients and carers wanted the different types of information to be included (see Appendix 6 for the full findings).

<table>
<thead>
<tr>
<th>Invitations posted 2nd Class</th>
<th>Posted replies</th>
<th>Telephone calls using colleague’s Trust mobile. Evening calls</th>
<th>Text messages using colleague’s Trust mobile.</th>
<th>Personal invites at clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Calls</td>
<td>No reply</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>81</td>
<td>16</td>
<td>21</td>
</tr>
</tbody>
</table>

In addition emails were used by 3 of the patients.

Table: Percentage of patients and carers who wanted certain types of information

Following comments from patients and carers from the pilot events, the programme was revised for the ‘closer to home’ events to include a patient story and talks from the physiotherapist and social worker.
4. Evaluating the effectiveness of the ‘closer to home’ H&WB events:

<table>
<thead>
<tr>
<th>Venue</th>
<th>Invitations posted</th>
<th>Patients</th>
<th>Wives</th>
<th>Carers</th>
<th>HCP’s + Patient Rep</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waterside HC Londonderry</td>
<td>60</td>
<td>10</td>
<td>6</td>
<td>8</td>
<td>8</td>
<td>25</td>
</tr>
<tr>
<td>Corick House Hotel Clogher</td>
<td>40</td>
<td>6</td>
<td>3</td>
<td>7</td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>Camera Room, Old Tech Building, Banbridge</td>
<td>71</td>
<td>13</td>
<td>9</td>
<td>8</td>
<td></td>
<td>32</td>
</tr>
<tr>
<td>Community Centre Cloughmills</td>
<td>81</td>
<td>17</td>
<td>10</td>
<td>10</td>
<td></td>
<td>38</td>
</tr>
</tbody>
</table>

Numbers attending the event in Londonderry were disappointing. During follow-up phone calls reasons given for non-attendance were that the date was not suitable, people were on holiday or had a previous engagement, they work away from home, had no babysitter available, had carer responsibilities, were not interested, or it was too long from diagnosis (have moved on with their lives). Several of the men were very interested in the concept and asked to be invited to another event that would be within a reasonable distance.

Key differences between this first local H&WB event compared to the original H&WB pilots held in 2012 included:
- One of our patient representatives was included – he informed the audience of his experience of testicular cancer and what he had learnt from it.
- The quizzes and prize giving were removed to make time for presentations from the social worker and physiotherapist.
- Funding was available for sandwiches and refreshments.
- Improved attendee surveys - service users, carers and HCPs were asked to complete these to ensure a comprehensive evaluation of events.

The number of attendees in Clogher was once again low. This could have been due to the geographical area being covered for this event – Counties Tyrone and Fermanagh are both very rural and sparsely populated areas. Distances to the event were also much further and the access to the hotel on country roads was difficult. A number of patients were on holiday or working. Six men asked for invitations to the next scheduled event in Banbridge – two of them did not wish to be seen at the hotel as their wider family network were unaware of their testicular cancer diagnosis and their attendance could have been noticed. This can be a problem for those living in remote areas where everyone knows or thinks they know each other’s business; one of the reasons we concluded it would be better for these events to be held in Belfast.

Changes were made to the methods of contacting patients for the third event at Banbridge. Firstly, the written invitation was signed by the lead testicular cancer consultant rather than the project leader and secondly, there was trust agreement from the cancer services manager for the use of text messaging as a way of contacting patients.

Numbers for the fourth event at Cloughmills were boosted by invitations being sent to those men who had requested notification of a further event due to work or personal commitments on the evening of their local event.
The events were evaluated by a survey given out to all patients, carers and health professionals. In total 112 surveys were handed out and 99 were returned. The evaluation was very positive. The location, access and convenience were seen as good to excellent, the event was judged to be the right length of time, the presentations were good and participants’ expectations were met. Participants were generally very satisfied but did make some suggestions for additions and improvements (see Appendix 7 for the survey and full results).

Suggestions for improvements

5. Planning for the future:

The following questions were developed by the project leader following the evaluation of the four ‘closer to home’ events. These questions would need to be addressed by both the project team and patient focus group at future meetings:

- How to set up future events?
- What? - content and delivery of events
- Where future events to be held? – financial constraints
- Where in patient journey should H&WB events fit?
- Who will provide and host events?
- Organise a meeting of the project team and patient representatives to discuss the evaluation from the events and how to take H&WB events forward.
- Presentation of the project and findings to wider key stakeholders to be debated.

Meeting of Patient Focus Group (4.12.2013):

A meeting of the patient focus group was held in December 2013. It was attended by five patient representatives. The meeting was facilitated by the project leader and co-facilitated by the CNS TYA and aimed to discuss the effectiveness of the four regional ‘closer to home’ H&WB events. The project leader started the meeting with a brief introduction on the background and overview of the project and the earlier pilots. After that, one of the patient representatives spoke about his experiences at the three events he had presented at. He fed back to the group his thoughts and comments. These included telling his story of late diagnosis, his reaction to treatments, coping with ‘A’ level exams, having good family support and being grateful for his treatment and care from the
lead testicular cancer consultant and oncology team. He now wished to give back by continuing to be part of these events both for the course of the project and in the future.

A claims, concerns and issues exercise was undertaken by the group. Claims are: what are the positives? Concerns: what are the challenges or worries? Issues: what questions are raised as a result of the concerns?

<table>
<thead>
<tr>
<th>Claims</th>
<th>Concerns</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Both Londonderry and Cloughmills venues good</td>
<td>• Fine line when discussing long term side effects</td>
<td>• Branding of event - what would you call it? Suggestion - ‘Let’s talk balls’. Don’t send out invitations – ensure patients aware of post treatment plan. Communicate what is going on by personal invitation</td>
</tr>
<tr>
<td>• Question and answer sessions after the lead consultant’s presentation were very useful. Being able to talk to medics and AHPs</td>
<td>• Small numbers attending events</td>
<td>• Language – too in-house; event is something interesting to go to but there is a need to use simpler language in order for people to understand. Need to get message and language right, a suggestion to use an agency to shape communications; organise gala event for example have a ‘Ball – Ball’</td>
</tr>
<tr>
<td>• Relationship with lead TC consultant improved</td>
<td></td>
<td>• Credibility – lay out as part of treatment plan – for those on active surveillance programme and post treatment follow-up. Lead TC consultant attending events gave kudos. Everyone comes to Belfast for follow-up so Thursday evening after Teratoma clinics would be ideal time to hold events</td>
</tr>
<tr>
<td>• Know all the information possible to find out</td>
<td></td>
<td>• Size of event – if too large then can lose intimacy</td>
</tr>
<tr>
<td>• Learnt a lot from events</td>
<td></td>
<td>• When is the right time to hear the information?</td>
</tr>
<tr>
<td>• Good that doctor points out risks</td>
<td></td>
<td>• Venues – how far from home? How far will people travel?</td>
</tr>
<tr>
<td>• Meeting others with TC post treatment</td>
<td></td>
<td>• Awareness of testicular cancer - huge body of work needed to bring TC to forefront – Movember campaign for example</td>
</tr>
<tr>
<td>• Attend in first year of treatment</td>
<td></td>
<td>• Embarrassment – telling others your cancer story</td>
</tr>
<tr>
<td>• Patients stories</td>
<td></td>
<td>• Stigma re cancer in Northern Ireland especially in older age group</td>
</tr>
<tr>
<td>• Writing questions down more measured way of answering</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This exercise stimulated a much wider discussion which resulted in points for future consideration. These are noted below:

- How would we get patients to come to these events, what benefits will be gained, there is a need to know what the evening is about first.
- Some would like wives to attend; others thought this was not essential.
- Those wives who did attend found the evening to be very beneficial and were able to understand the greater picture of testicular cancer. Possible scope for breakout sessions for wives, these would need to be structured.
- Some men may wish to attend more than one event - different topics would need to be presented.
Too much information squeezed into the time-frame - need core information especially fitness.

Social workers have a bad reputation and need new branding; they are there to open doors for financial aid issues and social support.

**Meeting of the Patient Focus Group and Project Team (20.2.2014)**

A meeting of the patient focus group was held in February 2014. At the meeting were the project leader and CNS YTA, who was co-facilitating, other members of the project team, including the lead testicular cancer consultant, the social worker and physiotherapist, and three new patient focus group members. Before business began the new members were introduced and consent forms were signed. The new testicular cancer consultant was introduced and welcomed. After this, the project leader gave a presentation of the project to date.

The main purpose of the meeting was to conduct a claims, concerns and issues exercise and to develop an action plan for the next stage of the project. As before, the project leader explained that claims are favourable assertions about the project, concerns are worries and issues are questions arising from the concerns. Participants’ claims and concerns were written on sticky notes and then attached to the relevant A3 poster and were then discussed in order to create questions and an action plan to move the project forward. The following table summarises the claims, concerns and issues raised at the event.
<table>
<thead>
<tr>
<th>Claims What are the positives?</th>
<th>Concerns What are the challenges? What’s not right?</th>
<th>Issues Questions arising from the concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Being able to talk to medics and HCPs</td>
<td>• Small numbers attending the events</td>
<td>• How can we improve attendance at the events?</td>
</tr>
<tr>
<td>• Learnt a lot from the events</td>
<td>• Size of venue – numbers invited to attend</td>
<td>• How do we encourage men to attend? Credibility of the service – everyone comes to Belfast for follow-up so Thursday evening after Teratoma clinics would be ideal time to hold events. Consultant attending events gave kudos to event.</td>
</tr>
<tr>
<td>Question and Answer sessions after consultant presentation very useful</td>
<td>• Location of venues</td>
<td>• Did the regional approach work?</td>
</tr>
<tr>
<td>Writing down questions is a more measured way of answering</td>
<td>• Fine line when discussing long term effects</td>
<td>• Poor uptake of attendance; it was felt to be a moderate success. It did however succeed in providing education on TC to some, especially wives, partners, or parents.</td>
</tr>
<tr>
<td>Londonderry, Banbridge and Cloughmills venues good</td>
<td>• Stigma re: cancer in NI (older generation).</td>
<td>• Where is the best place to hold events? Size and location?</td>
</tr>
<tr>
<td>Good that doctors point out the risks</td>
<td>• Embarrassment – telling others your cancer story</td>
<td>• 1 – 2 H&amp;W events to be held per year in central location. On average 70 new patients are diagnosed with TC per year. Estimated approximately 50 people would attend (this includes wives etc). This number would be too many for the Macmillan Support and Information Centre (maximum 35). Agreed the Cancer Centre Level 1 foyer to be used for information stands and catering, whilst Seminar Room 3, which can hold 50–60 persons, would be used for the main event.</td>
</tr>
<tr>
<td>Know all the information possible to find out</td>
<td>• Awareness of TC. How to bring it to the forefront?</td>
<td>• How much do men want to hear re: long term side effects?</td>
</tr>
<tr>
<td>Improved relationship with consultant</td>
<td>• When is the right time to hear the information?</td>
<td>• Most people want to know all the information possible. These should be included as part of the health awareness and survivorship education.</td>
</tr>
<tr>
<td>Meeting others with TC post treatment</td>
<td></td>
<td>• How do we change people’s attitude to cancer?</td>
</tr>
<tr>
<td>Patients stories</td>
<td></td>
<td>• Stigma is now less of an issue than it was in the past; more a generational problem. Positive messages coming from the media, charities etc.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• How do we make people more aware of TC?</td>
</tr>
<tr>
<td></td>
<td>• By participating in Men’s’ Health Awareness campaigns (e.g. Movember); ‘Know your balls’ posters and credit card size leaflets in local taxis. Football/rugby clubs; part of school curriculum; involve journalists. Co-ordinate resources for health awareness and promotion. Excellent survival and cure rates of TC need to be highlighted.</td>
<td>• These events should be part of the TC treatment plan and should happen post chemotherapy or within first few months for those on active surveillance programme.</td>
</tr>
<tr>
<td></td>
<td>• These events should be part of the TC treatment plan and should happen post chemotherapy or within first few months for those on active surveillance programme.</td>
<td>• How will these be funded in the future? These twice yearly H&amp;W events could become part of HCP’s job plans (this would need management discussion). Funding for catering – ‘Friends of the Cancer Centre’ to be approached.</td>
</tr>
</tbody>
</table>
Finally an action plan was developed:

- Who will take ownership of the patient focus group and events at the end of project leader’s post? Future ownership will need to be a trust employee (current member of project team?) with input from patient focus group?

- Where and when should the Belfast H&WB event be held? Thursday 8th May 7-9pm in Cancer Centre. The project leader to book Seminar Rooms 2 and 3.

- When, where and to who the project should be presented to? Which Key Stakeholders to invite?

It was agreed that there would be a further meeting of the project team and patient focus group on 2nd April 2014 to discuss everything further.

**Meeting of Patient Focus Group and Project Team (2.4.2014)**

A next meeting of the patient focus group and project team was held in April 2014. The aim of the meeting was to consolidate what had been learnt from the ‘closer to home’ project and the first four meetings and to decide who and how to invite patients, speakers, the content and timing of the programme for the fifth and final H&WB event which was scheduled to be held in Belfast in May 2014. The meeting was facilitated by the project leader and co-facilitated by the CNS TYA.

The meeting decided on a number of issues relating to the invitations and content of the programme. It was decided that all new patients diagnosed between January 2013 and March 2014, a total of approximately 90 patients from the testicular cancer database, would be invited. A number of suggestions were made regarding details of the invitations based on previous feedback and these were agreed. In terms of the content of the programme, the following were agreed:

- All agreed that the ‘Know your balls’ quiz was educational and the ‘Famous Faces’ could be used as an icebreaker. Quiz sheets would be entered in a draw for prizes and the answers would be available at end of the event.
- After discussion, it was decided that pizzas would be popular but that the project leader would need to check whether this was permitted by the Trust and undertake a risk assessment. Healthy snacks, tea, coffee and soft drinks would be available to everyone on arrival.
- The Trust Information Manager agreed to make sure all relevant materials were available, including both travel and life insurance information, which had been identified by the patient focus group.
- In terms of the format of the programme, it was agreed to include more patient stories. All members of the PFG present agreed to tell their stories; these would be interspersed between medical staff and AHPs’ presentations.
- It was agreed that one or two of the specialist registrars should be invited to present on sexual health and fertility issues.
- Should there be a separate session for wives/partners/carers? After much discussion and debate it was agreed to split the men from their significant other after the sexual health presentation for a 15 minute discussion by each group. A further room was booked for this to take place.
- Question and Answer session – should these be written on paper and given to medical staff or use mobile phones to text? All agreed that paper would be best.
Final event and evaluation

The Belfast H&WB event was held on Thursday 8th May 2014. Attendance was 60, which included 24 patients, 20 carers (wives/partners/parents), 12 HCPs and 4 patient representatives (see Appendix 8 for the final programme). A questionnaire was used to evaluate the event. All participants were asked about the venue and the vast majority found it good or excellent (>90%) in terms of location, ease of access, comfort, availability of parking, and food. The length of the event was neither too long nor too short (96% of patients, 100% of carers and professionals).

More extensive questions were asked regarding the content of the evening. Firstly, the three patient perspective presentations were evaluated. One hundred percent of patients, carers and professionals thought the talks were relevant and were the right length of time (good or excellent). Secondly, the presentation on testicular cancer was positively rated (either good or excellent) by all participants. Thirdly, the session on sexual health was either rated good or excellent by all participants, in terms of the content and the length of the session, participants also highly rated the breakout sessions at this point. Fourthly, both the presentation on support available from social services and the presentation on physical activity were universally rated good or excellent (see Appendix 9 for the full evaluation). There were information stands at the event and these were evaluated as providing good or excellent information and were approachable. Overall, everyone said the event had met their expectations and rated their satisfaction as 8, 9 or 10 out of 10.

Patient Focus Group and Project Team meeting (3.7.2014)

Facilitated by the project leader, the aim of the meeting was to discuss the evaluations from all 5 H&WB events, to conduct a claims, concerns and issues exercise for the whole project and to decide on the key messages for the presentation to key stakeholders and lead trust and national and local charity personnel planned for later that month (27.7.2014).

As before, the project leader facilitated the claims, concerns and issues exercise. The exercise identified a number of positive aspects of the project and the H&WB events. Events had met information needs, and had been positive in their focus. Changes made as a result of feedback along the way had been beneficial, for example, the breakout sessions for women and scheduling review appointments on the same day for those who had to travel long distances. The challenges were both practical (staff time, travelling distances, numbers of participants etc) and related to testicular cancer itself (engaging with some patients is difficult and the diagnosis may be unknown to a patient’s wider circle of family/friends). The questions which arose from this discussion were mainly practical and concerned the location of events and fine tuning of invitations, content of events, timing and funding (see Appendix 10 for full details). The discussion of these issues led to the formulation of four key actions to take forward for future events:

1. Signposting
   How will patients know events are happening? Treatment pathway – nursing input required; should this be part of the social worker’s brief? Set dates for the events well in advance and incorporate on same day as testicular review clinic.

2. Invitations
   Invite all eligible patients? Best method via an appointment letter including a flyer of the event. Patients more likely to recognise this as part of their care plan.

3. Follow-up of invitations
   Use of text messaging using Trust mobile phone has proven to be the most useful method in both time and numbers. Agreed wording of text message set by management.
4. **Surveys**

Take out questions related to venue. Continue to monitor expectations, satisfaction and content.

The meeting also decided on the main points to be included in the presentation for key stakeholders arranged for the end of the month.

**Key Stakeholders, Patient Focus Group and Project Team meeting (28.7.2014)**

The meeting, held at the end of July 2014, was facilitated by the project leader and attended by the project team and patient focus group and key stakeholders including cancer services managers, Macmillan managers, the Friends of Cancer Centre, the social workers manager and transforming cancer follow up project manager. In brief, the meeting covered:

<table>
<thead>
<tr>
<th>What</th>
<th>Who</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview of the FoNS project</td>
<td>Project leader</td>
<td>Background and findings from the project and evaluation from all 5 H&amp;WB events. A booklet with this information was available for all attendees.</td>
</tr>
<tr>
<td>Overview of the testicular service</td>
<td>Lead oncology consultant</td>
<td>The demographics of testicular cancer, the history of chemotherapy in NI and the development of H&amp;WB events for this difficult to reach group of patients.</td>
</tr>
<tr>
<td>Patients and carers’ voices</td>
<td>Three members of the patient focus group</td>
<td>Personal involvement in the project and how this has benefitted them and their wife/partner. The carer was unable to attend but wished her voice to be heard about the breakout session where she felt that all the women present appreciated the opportunity to discuss and ask the female specialist registrars questions.</td>
</tr>
<tr>
<td>Information and Support</td>
<td>BHSCT Information Manager</td>
<td>BHSCT role in providing information and support at the H&amp;WB events and the difference this has made to a number of men accessing the information and support services provided by the Trust.</td>
</tr>
</tbody>
</table>

**Discussion**

The benefits of the project included:

- Introducing 70 patients and 48 wives/partners and carers to a range of services that helped with their physical, emotional, social and financial needs.
- Improved patient education and self-management leading to earlier interventions, which are linked to improved outcomes and more appropriate use of services.
- Provision of information on cancer recurrence, long-term side effects of treatment, self-management, diet, exercise and lifestyle advice.
- Opportunity for patients and carers to speak about difficult subjects in a safe well-supported environment.
- Signposting to local services and resources – both clinical and non-clinical - such as counselling, complementary therapies and benefits advice.

Through engagement with the key stakeholders, project team and patient focus group regular meetings and workshops were organised to identify the key issues and concerns for men with testicular cancer. Each member of the project team brought their individual expertise and experiences to the table for discussion and dissemination. The inclusion of patient representatives on the project team ensured there was patient involvement in the development, design and delivery of these H&WB events.
In total 70 patients and 48 carers attended the five events with 14 HCPs and 3 patient representatives involved in hosting and participating in them during the summer of 2013 through to the spring of 2014. The events focused on introducing patients and their wives, partners and parents to a range of services to help with their physical, psychological, emotional, social and financial needs. Information was provided on cancer recurrence, side effects of treatment, self-management and diet, exercise and lifestyle advice. It was also an opportunity to speak with the HCPs about issues that concerned them; also signposting to local and national services and resources both clinical and non-clinical.

Implications for Practice:

- Feedback from patients and carers was very beneficial. Firstly, the project team felt reassured that the events had been positively received and were beneficial. Secondly, improvements to the programme were made as a direct result, for example the partner/female break out session at the final Belfast event hosted by female specialist registrars, was a great success. The men were able to ask questions that they would otherwise not have done with women present and the wives/partners found their discussions very helpful and offered them additional support.

- The unique insights of the patient focus group greatly benefitted the project and the patient volunteers themselves. They identified the need to use consultants’ signatures on invitations as a better way of inviting patients. The three patient representatives spoke very eloquently of what they had learnt about the disease and the benefits they and their partners had gained through participating in these events. All three remain keen to support future work.

- There is a need to explore new and practical ways of doing things. Using the trust’s text messaging service was a very efficient way to invite and remind patients about events. And more patients were able to attend when the event was held on the same day as scheduled review appointments.

- Survivors of testicular cancer responded well to being part of a tumour specific event in comparison to generic events.

- It is important to respond to practical and financial changes. The initial aim of this project was to introduce ‘closer to home’ health and wellbeing events. However, low attendance and funding made the ‘closer to home’ events unsustainable and the aim was revised to two events in Belfast as part of the end of treatment pathway for the approximately 70 new patients diagnosed each year.

- The work of this project team has enabled the development of a ‘Food for Thought and Checklist’ which may be of use to teams interested in running health and wellbeing event (see Appendix 11).

Further development

The format of the events organised by this project team was used for a further H&WB event that was held in the Cancer Centre in Belfast in March 2015. Forty patients, wives/partners and carers attended.

Comments from an email sent to the project leader from the testicular cancer consultant (Dr Bode Oladipo) sums up the success of the project:

“The HWB was very successful on 23rd March, and there is no doubt that the groundwork you had laid over the preceding years played a major role in that. For example:

- Your piloting of the events in different parts for the country helped to identify that a central Belfast location would be best received by patients, and has helped attendances.
• The topics for discussion (medical overview, sexual health and fertility, social worker and physio) were selected as the main areas to be covered. This was down to the positive feedback from your events during your project work.
• The structure of the evening/break out session is also a direct result from the events you planned, especially the success of your last one in May 2014

The rapport with patient speakers, for example Eamon, was already established through you and your project, and we were able to build on this to get other patients involved.

Your dedication to ensuring that these events don’t stop with the end of your project was clear. The presentation to the stakeholders and universal support of all was a direct result of this. This also contributed to the additional support we got from MacMillan.

Overall your project has helped establish a baseline framework for us to make these a regular feature, with the overall aim of incorporating it into patients’ follow-up ‘survivorship’ plan.”

References


Robinson, D.S. (December 2006) Men’s’ Experiences of Testicular Cancer and its Treatment: A Grounded Theory Study. Faculty of Life and Health Sciences, University of Ulster.


Scullion, F., Rudge, J. and Davies, N. (July 2010) National Cancer Survivorship Initiative (NCSI), Assessment and Care Planning Workstream.


Acknowledgements
My grateful thanks to Professor Tanya McCance who provided the guidance and support to apply to the FoNS ‘Patients First’ programme, also to Dr McAleer (Lead TC Consultant) and Sally Campalani.
(Senior Nurse Cancer Services) for their encouragement and belief in me to undertake and complete the project.

Thank you very much to the Project Team: Margaret, Renee, Robby, Joanna, Gayle, Bode, Rosie, Catherine, Julia and Aya and the Patient Focus Group: Eamon, Martin, Rob, Anthony, Richard, Rob and David. Without their continued help and support this project would not have been possible.

Many thanks to Jo Odell for her continual advice and support throughout the project and beyond.

Presentation of the H&WB project

- Professional Nurses Forum, BCH September 2013
- Abstract and poster submitted for the Chief Nursing Officers Conference on July 2013. The poster was highly commended by the team of judges after the first prize had been announced.
- The Project Leader was invited as a novice speaker to present the FoNS project at the UKONS conference in Belfast in November 2014, in addition to the poster being on display (Appendix 12).
- A case study of the project was included in Macmillan’s Recovery Package December 2014.
- A report on the 2014 UKONS Annual Conference held in Belfast 14–15 November 2014: focus on living with and beyond cancer, patient information and innovations in treatment and care appeared in the ecancer journal 9 509/DOI: 10.3332/ecancer.2015.509. This article included a synopsis of my presentation.
APPENDICES

1. Health & Wellbeing Pilot Events May and June 2012

2. Evaluation of H&WB Pilot Events from 2012

3. Values Clarification Exercise March 2013

4. Consent form for Patient Focus Group

5. May 2013 workshop discussion points

6. Information collated from Patients and Carers Questionnaires collected from Teratoma Clinics

7. Evaluation of four local H&WB Events – Survey and Evaluation

8. Programme for Final H&WB Event Belfast May 2014

9. Evaluation of Belfast H&WB Event

10. Results of claims, concerns and issues July 2014

11. Health and Wellbeing events food for thought and checklist

12. Poster for UKONS Conference November 2014
Appendix 1

Health & Wellbeing Events Pilot May and June 2012

The programme for the events consisted of two presentations: the first, given by the Lead Consultant was on the aetiology of testicular cancer (TC), treatments, side effects, signs of recurrence and the relevance of the Surveillance Programme that all men with TC go on to following treatment. The second presentation was given by the Clinical Coordinator for Outpatient Services who had written a Master’s Thesis on young men with TC. This presentation focused on sexual health and fertility problems.

During each evening three market stalls were manned by the Physiotherapist + Fitness Trainer, Social Worker, Citizens Advice Personnel and the Trust Information Manager. These staff in addition to the Consultants and Nurses ensured someone was available to offer information, support and advice to the patients and their wives/partners and answer any queries they had, referring onto other services when needed.

Volunteers were on hand to assist with registration, refreshments, anyone needing extra attention (one patient was visibly impaired, requiring individual assistance) and the marking of the two quizzes.

As the patients and their partners arrived they were greeted and given two quiz sheets which were used as ‘ice breakers’ – ‘Know your Balls’ and ‘Famous Faces with TC’.

During the tea/coffee break everyone was encouraged to visit the market stalls. A ‘Question and Answer’ session hosted by the Consultants followed. The Project Leader had requested patients and their partners to write down any questions they had during the break. These were collected by the volunteers and given to the Consultants. Following this session the results of the quizzes were announced and prizes, donated by the Lead Oncologist and Macmillan, were presented. Completed evaluation forms were collected by the volunteers at the end of the event.

In total 44 people attended these two events; this included 26 Patients and 18 Wives/Partners/Carers. There were 8 HCP’s and 3 volunteers at each event.
Appendix 2

Evaluation of the H&WB Pilot Events

Overall usefulness of the evening

- 85% Very useful
- 12% Quite useful

Liked best about the evening overall:
- Presentations from medical staff clear and concise and very informative
- Opportunity to ask questions and speak to Doctors
- Loved all the Macmillan books and stuff
- First opportunity to meet other people with testicular cancer
- Open relaxed atmosphere
- Informal and informative

Liked least?
- Nothing

What would have made the evening better?
- Food

Most useful Market Stall

- Physio + Fitness: 39%
- Patient Information: 31%
- Social Work + Financial Advice: 19%
- No comment: 11%

Suggestions for future events:
- More information on long term side effects
- Partners perspective
- Easier picture quizzes
- Contact email address to forward questions or suggestions.
- More time for questions

Time of day best suited to hold event

- Evening: 92%
- Afternoon: 4%

Actions to take forward for future events:
Following these well evaluated pilots of nurse led Health and Wellbeing (H&WB) events a need was identified to take these events ‘closer to home’ to more appropriate locations such as sports/community centres in both town and rural communities, also to socially deprived areas around Northern Ireland.
Appendix 3

Values Clarification Exercise
(used at meeting with Key Stakeholders March 2013)

- Share knowledge from professionals to those affected by testicular cancer.
- Inform the professions regarding the personal experiences during diagnosis, treatment and follow up of those with testicular cancer.
- Identify the issues affecting those with testicular cancer.
- Provide sign posting to accessible and tailored support for services which promote healthy living and lifestyle changes when needed such as exercise programmes, diet and smoking cessation clinics.
- Inform those patient who wish it about the possible late effects of testicular cancer and it’s treatment, to the degree that they wish it and in the form that they wish it.
- Informing patients about what to do to avoid late effects in life of treatment*
- Inform those patients that do not want specific information about late effects with general healthy lifestyle advice.
- Provide feedback to services regarding the experience of patients with testicular cancer.
- Bring about change in the experience of those with testicular cancer.
- Shape the future of service for those with prostate cancer.
- Identify local champions to take forward work with this patient group.
- Identify possible scope for mentoring.
- Identify areas in the pathway that need to be addressed such as:
  - Early detection and awareness-raising amongst young male boys in school and work places.
Appendix 4

Patient Focus Group consent form

April 4th 2013

PATIENT CONSENT FORM

Please initial each box if you agree:

I understand that I am volunteering to take part in this focus group and that I may pull out at any time without giving a reason

I understand that I may contact the Facilitator Wendy McPhee if I have any questions or concerns at any time during the Focus Group.

I understand that quotations from me may be used in study reports and in the Testicular Health & Wellbeing programme, but these will be anonymised.

I agree to take part in this Focus Group

Name___________________________________      Date_____________

Signature_________________

Facilitator

Name___________________________    Date_____________

Signature_________________

One copy of this form will be left with you, and one copy taken by the Facilitator
Appendix 5

May 2013 Workshop discussion points

Who to invite to H&WB events?
• Patients diagnosed with testicular cancer since 2009 + wife/partner/friend?
How they will be invited?
• Written invitation plus details of event
• Telephone to confirm attendance
• Recruitment from clinic

What?
The programme content proposal included the results from 62 patient and carers surveys conducted at the Teratoma clinics.
• SMA Key messages on TC – incidence, side effects of treatment, long term effects and outcome for patients. Importance of surveillance follow-up programme to be explained.
• Physical activity and fatigue – Physiotherapist
• Social work and psychological issues – Social Worker
• Healthy eating (leaflets provided by the Trust Information Manager)
• Clinical Coordinator for Outpatient Services to be invited to give presentation on sexual health and fertility. If unavailable one of Specialist Registrars to be asked.
• Patients’ Perspective – two patients agreed to speak from their perspective at events
• Inclusion/exclusion of speakers/market stalls
• Timings of speakers – programme of evening to be decided at the core project group meeting to be held on
• Quizzes to be included? – After much discussion it was agreed that the time would be better utilised by speakers. The ‘Know your balls’ quiz sheet to be given out for educational purposes.

What is self-management? – this question was asked of the team. Comments included:
➢ Healthy lifestyles
➢ Education and awareness of symptoms
➢ Self checks
➢ Attendance of appointments – feedback from why patients fail to attend clinics.
➢ Surveillance patients – identify relapse early → good prognosis
➢ Knowing your body – when to see GP
Appendix 6
Information collated from Patients and Carers questionnaires

Any other topic? – Please write a brief description.

<table>
<thead>
<tr>
<th>Evaluation of topics for inclusion in Health &amp; Wellbeing Events</th>
<th>Yes</th>
<th>No</th>
<th>No comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about cancer recurrence?</td>
<td>Patients 96%</td>
<td>Carers 93%</td>
<td>4%</td>
</tr>
<tr>
<td>Long term side effects of treatment?</td>
<td>Patients 83%</td>
<td>Carers 93%</td>
<td>17%</td>
</tr>
<tr>
<td>Self-management?</td>
<td>Patients 68%</td>
<td>Carers 86%</td>
<td>21%</td>
</tr>
<tr>
<td>Diet, exercise and life style advice</td>
<td>Patients 77%</td>
<td>Carers 86%</td>
<td>21%</td>
</tr>
<tr>
<td>An opportunity to talk to doctors, nurses, and other health care professional about issues that concern you?</td>
<td>Patients 83%</td>
<td>Carers 93%</td>
<td>11%</td>
</tr>
<tr>
<td>Signposting to other local services and resources, both clinical and non-clinical, such as counselling, complimentary therapies and benefits advice?</td>
<td>Patients 72%</td>
<td>Carers 93%</td>
<td>22%</td>
</tr>
<tr>
<td>A chance to meet other people affected by cancer?</td>
<td>Patients 65%</td>
<td>Carers 86%</td>
<td>28%</td>
</tr>
</tbody>
</table>

‘More information about prostheses – offered one but had very little information regarding them’

<table>
<thead>
<tr>
<th>Would you attend such an event if asked?</th>
<th>Yes</th>
<th>No</th>
<th>No comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients 74%</td>
<td>Carers 73%</td>
<td>26%</td>
<td>27%</td>
</tr>
</tbody>
</table>

If no can you give a reason why?

<table>
<thead>
<tr>
<th>Patients:</th>
<th>Carers:</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Full time worker - very little spare time’</td>
<td>‘Just like to keep it to myself’</td>
</tr>
<tr>
<td>‘Moved on’</td>
<td>‘Husband does not want to’</td>
</tr>
<tr>
<td>‘Do not want to’</td>
<td></td>
</tr>
<tr>
<td>‘I like to move on and not dwell on the past’</td>
<td></td>
</tr>
<tr>
<td>“Feel past stage of requiring such support. Would have been great during or shortly after treatment”</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Would you bring your wife or partner/carer?</th>
<th>Yes</th>
<th>No</th>
<th>No comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients 75%</td>
<td>Carers 19%</td>
<td>6%</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 7

### Evaluation of first four local H&WB Events

#### The Survey

**Question 1. Venue**

<table>
<thead>
<tr>
<th>Location</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of access</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car parking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 2. Testicular cancer—Dr McAleer**

<table>
<thead>
<tr>
<th>Topic relevance</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 3. Sexual Health**

<table>
<thead>
<tr>
<th>Topic relevance</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 4. Social work support**

<table>
<thead>
<tr>
<th>Topic relevance</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 5. Physical activity**

<table>
<thead>
<tr>
<th>Topic relevance</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 4. Please rate the market stalls for...**

<table>
<thead>
<tr>
<th>Approachability</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 5. Did the event meet your expectations?**

- Yes [ ]
- No [ ]
- If no, please state why

**Question 6. Overall satisfaction**

On a scale of 1 to 10 with 10 being the most satisfied, how would you rate the event overall?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

**Question 7. How could we improve?**

Please take this opportunity to make any suggestions you can think of which would improve this event.
The Evaluation
The following evaluations from the patients, carers and healthcare professionals attendee survey forms completed at each of the four events in Londonderry, Clogher, Banbridge and Cloughmills.

Question 1:
*Venue: Location, Ease of access, Comfortability, Car Parking and Food.*

**Venues overall**

- Excellent: 24%
- Good: 75%
- Average: 1%

Question 2
*Was the length of time of the event?*

<table>
<thead>
<tr>
<th></th>
<th>Too short?</th>
<th>Just right?</th>
<th>Too long?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Question 3
*Presentations:*
1. Patients perspective – Eamon/Martin
2. Testicular cancer – Dr McAleer
3. Sexual Health – Dr Rosie Douglas/Dr Catherine Davidson
5. Physical Activity – Joanna

Overall participants rated the presentations: Pass percentage 97%, Excellence percentage 78%

Question 4
*Information stands:*

**Approachability**

- Poor: 2%
- Average: 3%
- Good: 19%
- Excellent: 76%

Question 5
*100% of all who attended the 4 events (patients, carers and HCP’s) indicated that the event met their expectations.*

Question 6
Overall Satisfaction from all who attended the 4 events:
Using numerical scale of 0 - 10 with 0 = dissatisfied and 10 = completely satisfied

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2%</td>
<td>9%</td>
<td>25%</td>
<td>64%</td>
</tr>
</tbody>
</table>

Dissatisfied  Satisfied

Question 7
How could we improve? Patients and Carers Comments:

- More information on emotional support
- Great to have the opportunity to hear Dr McAleer
- Very informative and worthwhile for all involved in the journey
- Provide earlier in cancer journey
- A great opportunity to meet others and hear from specialists and professionals
- Good concise talks
- Would welcome regular sessions
- Very useful seminar
- No improvements needed
- Just continue doing the same at regular intervals for future patients. Much appreciated
# Programme for the Final H&WB Event held in Belfast May 2014

## Programme for the Evening

**TESTICULAR CANCER HEALTH & WELLBEING EVENT**  
Thursday 8\textsuperscript{th} May 2014 at 6.30 - 9pm

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>18.30:</td>
<td><strong>Arrival:</strong> Registration, Survey Forms, ‘Know Your Balls Quiz’, Tea, coffee and biscuits available</td>
</tr>
<tr>
<td>18.40:</td>
<td><strong>Welcome &amp; Introduction of team:</strong> Wendy McPhee</td>
</tr>
<tr>
<td>18.50:</td>
<td><strong>Patients’ Story:</strong> Eamon</td>
</tr>
</tbody>
</table>
| 19.00: | **Dr McAleer**  
Testicular cancer: recurrence and signs to look out for  
Long term side effects of treatment, active surveillance programme, self-management and health promotion. |
| 19.15: | **Patient’s Story:** Martin                                         |
| 19.20: | **Split session:**  
Dr Aya El-Helali and Dr Julia Stewart – (Wives/Partners/Parents)  
Dr Bode Oladipo and Dr McAleer - (Patients)  
Sexual health, fertility and testosterone replacement |
| 19.35: | **Refreshments:** Pizza, Fresh Fruit and Cold drinks available.  
Time to visit and collect information from tables and chat to staff |
| 20.15: | **Robby Nelson** – Social Work Support                               |
| 20.25: | **Joanna Freeburn** – Physical Activity                              |
| 20.35: | **Patient’s Story:** Richard                                         |
| 20.40: | **Question and Answer Session**  
Dr McAleer, Dr Oladipo, Dr El-Helali and Dr Stewart                   |
| 21.00: | **Finish**                                                           |
## Appendix 9

### Evaluation of Belfast H&WB Event

**Question 1 – Venue**

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Carers</th>
<th>HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Poor</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>5%</td>
<td>30%</td>
<td>65%</td>
</tr>
<tr>
<td><strong>Ease of access</strong></td>
<td>30%</td>
<td>70%</td>
<td>41%</td>
</tr>
<tr>
<td><strong>Comfort</strong></td>
<td>35%</td>
<td>65%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Car parking</strong></td>
<td>5%</td>
<td>34%</td>
<td>61%</td>
</tr>
<tr>
<td><strong>Food</strong></td>
<td>5%</td>
<td>8%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>30%</td>
<td>70%</td>
<td>18%</td>
</tr>
</tbody>
</table>

**Question 2. Was the length of the event...**

<table>
<thead>
<tr>
<th></th>
<th>Too short?</th>
<th>Just right?</th>
<th>Too long?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>96% patients</td>
<td>100% carers and HCPs</td>
<td></td>
</tr>
</tbody>
</table>

**Question 3. Presentations:**

1. *Three patient perspective presentations*

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Carers</th>
<th>HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
</tr>
<tr>
<td><strong>Topic relevance</strong></td>
<td>27%</td>
<td>73%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Information provided</strong></td>
<td>20%</td>
<td>80%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Length of talk</strong></td>
<td>33%</td>
<td>67%</td>
<td>12%</td>
</tr>
</tbody>
</table>

2. *Testicular cancer*

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Carers</th>
<th>HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
</tr>
<tr>
<td><strong>Topic relevance</strong></td>
<td>26%</td>
<td>74%</td>
<td>12%</td>
</tr>
<tr>
<td><strong>Information provided</strong></td>
<td>18%</td>
<td>82%</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Length of talk</strong></td>
<td>22%</td>
<td>78%</td>
<td>6%</td>
</tr>
</tbody>
</table>

3. *Sexual Health*

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Carers</th>
<th>HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
</tr>
<tr>
<td><strong>Topic relevance</strong></td>
<td>26%</td>
<td>74%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Information provided</strong></td>
<td>30%</td>
<td>70%</td>
<td>19%</td>
</tr>
<tr>
<td><strong>Length of talk</strong></td>
<td>35%</td>
<td>65%</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Usefulness of breakout session</strong></td>
<td>22%</td>
<td>78%</td>
<td>12%</td>
</tr>
</tbody>
</table>
4. Social work support

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th></th>
<th>Carers</th>
<th></th>
<th>HCPs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
</tr>
<tr>
<td>Topic relevance</td>
<td>36%</td>
<td>64%</td>
<td>19%</td>
<td>81%</td>
<td>11%</td>
<td>89%</td>
<td></td>
</tr>
<tr>
<td>Information provided</td>
<td>23%</td>
<td>77%</td>
<td>25%</td>
<td>75%</td>
<td>11%</td>
<td>89%</td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td>27%</td>
<td>73%</td>
<td>30%</td>
<td>70%</td>
<td>11%</td>
<td>9%</td>
<td></td>
</tr>
</tbody>
</table>

5. Physical activity

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th></th>
<th>Carers</th>
<th></th>
<th>HCPs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
</tr>
<tr>
<td>Topic relevance</td>
<td>32%</td>
<td>68%</td>
<td>35%</td>
<td>65%</td>
<td>11%</td>
<td>89%</td>
<td></td>
</tr>
<tr>
<td>Information provided</td>
<td>23%</td>
<td>77%</td>
<td>37%</td>
<td>63%</td>
<td>11%</td>
<td>89%</td>
<td></td>
</tr>
<tr>
<td>Length of talk</td>
<td>23%</td>
<td>77%</td>
<td>35%</td>
<td>65%</td>
<td>11%</td>
<td>9%</td>
<td></td>
</tr>
</tbody>
</table>

Comments:

Patients: “Knowledgeable, informal and enjoyable!”

Carers: “Very informative – great knowledge”

“Knowledgeable, engaging and good links for information provided”

“Good suggestions and links to”

Question 4. How do you rate the question and answer sessions?

- Patient’s Q & A session
  - 55% Good
  - 45% Excellent

Question 5. Please rate the information stands for ....

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th></th>
<th>Carers</th>
<th></th>
<th>HCPs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
</tr>
<tr>
<td>Approachability</td>
<td>27%</td>
<td>73%</td>
<td>31%</td>
<td>69%</td>
<td>12%</td>
<td>88%</td>
<td></td>
</tr>
<tr>
<td>Information provided</td>
<td>30%</td>
<td>70%</td>
<td>25%</td>
<td>75%</td>
<td>11%</td>
<td>89%</td>
<td></td>
</tr>
</tbody>
</table>

34
Comments from patients:

I got some information that I found hard to get online!

Macmillan supported event. All experiences of Macmillan support have been absolutely amazing!

Question 6. Did the event meet your expectations? Yes? No?

100% patients, carers and HCPs said yes.

Comments: Patients

“All aspects covered”

“Very informative meeting. Exceeds expectations”

“Very good; very informative & reassuring. Can help men get the help they may well need”

“Very informative and well presented. All in a very friendly manner”

“Excellent idea; Glad I came”

“Excellent to have the opportunity to meet the other women with no men present”

Carers:

HCPs:
Question 7. Overall satisfaction:

![Satisfaction scale 0 - 10](image)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90%

- **Patients**
  - “I can’t think how it could be improved. Very good”
  - “None needed! Found the evening very helpful. Excellent event”
  - “Best event yet. Breakout session very useful”

- **Carers**
  - “More events”
  - “I hope more people who are affected by this cancer can have an opportunity to be part of this”

- **HCPs**
  - “Hard to see how. Your commitment is really appreciated”
  - “Information on support groups”

Question 8. How could we improve?

<table>
<thead>
<tr>
<th>Patients</th>
<th>Carers</th>
<th>HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I can’t think how it could be improved. Very good”</td>
<td>“None needed! Found the evening very helpful. Excellent event”</td>
<td>“Best event yet. Breakout session very useful”</td>
</tr>
<tr>
<td>“More events”</td>
<td>“I hope more people who are affected by this cancer can have an opportunity to be part of this”</td>
<td></td>
</tr>
<tr>
<td>“Hard to see how. Your commitment is really appreciated”</td>
<td>“Information on support groups”</td>
<td></td>
</tr>
<tr>
<td>“Addressing issues for those attending at their stage of recovery or other”</td>
<td>“None – just maybe closer to home”</td>
<td></td>
</tr>
<tr>
<td>“Seemed main focus on sexual health. Maybe info on all aspects eg mental/wellbeing. Also maybe someone to explain more of support assistance eg financial”</td>
<td>“Lot of info about chemo effects (understandably). However my husband did not need chemo. Info for men not needing chemo- what side effects would they maybe experience? Also what partners might need to take into account. “ I felt the fertility talk and being taken into ‘breakout group’ was helpful in answering any questions us ‘carers’ may have had”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It was ‘comforting’ to know other carers were in same boat”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Keep going with the support groups as it is really helping my partner deal with the emotional side of things. Thank you”</td>
</tr>
</tbody>
</table>
Appendix 10
Results from Claims, Concerns & Issues Exercise July 2014

The results are listed in the table below:

<table>
<thead>
<tr>
<th>Claims What are the positives?</th>
<th>Concerns What are the challenges? What not right?</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Information needs met</td>
<td>➢ Low turnout</td>
<td>➢ Are venues outside Belfast viable?</td>
</tr>
<tr>
<td>➢ Focused on recovery</td>
<td>➢ Engaging with some patients is difficult</td>
<td>Low turnout at some of the venues outside Belfast was discussed. It was felt that people are willing to travel to an event if they feel it is providing something they value</td>
</tr>
<tr>
<td>➢ Relaxed atmosphere</td>
<td>➢ Confidentiality amongst local population; diagnosis unknown to wider circle of family/friends</td>
<td>How to optimise attendance?</td>
</tr>
<tr>
<td>➢ Events flowed well</td>
<td>➢ Timing of event variable in patient journey 0 – 4 years</td>
<td>Consultant signature (SMA (Dr McAleer or BO (Dr Bode Oladipo)) on invitation. Review appointment on same day for those travelling from a distance</td>
</tr>
<tr>
<td>➢ Content of programme valued</td>
<td>➢ Staff availability/time</td>
<td>Opt out not opt in for patients – events to be part of post treatment pathway for all TC patients</td>
</tr>
<tr>
<td>➢ Venues accessible</td>
<td>➢ Travel time</td>
<td>Is there anything about design of event that needs changing? Content good. No change needed. Breakout session an improvement – takes away from more clinical aspect of event.</td>
</tr>
<tr>
<td>➢ Breakout sessions good – additional support for patients and carers</td>
<td>➢ Events time limited by travel</td>
<td>Is there a time of year more suitable? How many events a year? Two events a year – Spring and Autumn (April and September)</td>
</tr>
<tr>
<td>➢ Patients travelling a long distance – review appointment same day. Establish a better way of inviting patients – consultant signature plus personal invites at clinic</td>
<td>➢ Maximum – minimum number constraint.</td>
<td>How will they be funded? Evaluation from the five events held around NI has shown Belfast to be the best value. Arrangement and agreement with a local cancer charity to fund catering for events – approximately £150 - £200 per event (maximum numbers 50). Managerial agreement to allow non-medical staff time owing for 3 hour events. This will be a professional development undertaking for medical staff.</td>
</tr>
<tr>
<td></td>
<td>➢ IT compatibility in remote setting</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11

Health and Wellbeing events – food for thought and checklist

Wendy and the team at Belfast undertook a highly collaborative project to develop ‘closer to home’ health and wellbeing events for men with testicular cancer in Northern Ireland. Their extensive work raised a lot of questions and has led to the development of this checklist.

**Invitations:**
What type of approach is best? Landline telephone, mobile, in person at clinic, letter?
Does the trust have a text system and will they allow you to use it?
Who should send the invitations? A consultant might give the event more gravitas/seriousness
Credibility of the organiser with the client group important?

**Timing of events:**
Is travel involved? Daytime or evening? Working or non-working client group? Can it be timed to go with regular follow-up clinics?
When is the best time post treatment?

**Location of events:**
A non-healthcare environment may be more relaxed. Is this something that a member of the client group could arrange?
Local or central?

**What should be included/the agenda:**
- Who are the stakeholders?
- Food and drink? Who will pay? Does the trust need to be consulted? Risk assessment?
- What information do people want? How do you find out? How will patients be involved in this? Would a patient focus group help?
- Would break-out groups be of benefit? Do you want to divide the group by sex? Would it be beneficial to have patient/non-patient perspectives?
- What about icebreakers/quizzes, prizes – put people at ease
- Input from social work/physio/OT/information management/CNS’s etc
- What are the needs of the client group? Physical, psychological, emotional, social, financial
- Language – avoid in-house jargon
- How much information is manageable in one evening/event?
- What about: diet/lifestyle, treatment, fertility issues, self management, exercise?

**Organisation and sustainability:**
- Funding – how much do the events cost to hold and who will pay?
- How long does it take to organise? Is any administrative support needed?
- IT support for database searches
- Can it become part of the treatment plan/follow-up plan?
• Attend once or more than once? If the latter need varied content?
• What range of staff need to be involved? How can they be compensated for out of hours?
  Part of job plan?
• Number of events required per year? Dependent on number of patients diagnosed?

Evaluation:
How will you evaluate?
What are you looking for?
Who needs this information?
Appendix 12

Poster from UKONS Conference November 2014

Promoting the health and wellbeing of men with testicular cancer through information and support
W. McPhee and Dr J.J. McAleer
Cancer Centre, Belfast City Hospital

Background

- The diagnosis of cancer can be devastating for all patients but the nature of testicular cancer in young men is particularly difficult.
- Despite a high cure rate, patients suffer significant complex physical, psychological and social morbidity due to the nature of the diagnosis and treatment.
- These can be difficult to address leading to a tendency to non-compliance with treatment.
- Belfast City Hospital (BCH) hosts the specialist tertiary centre for men with testicular cancer (TC).
- Approximately 350 men have been diagnosed over the past five years.
- These men attend for treatment and surveillance from all areas of Northern Ireland (NI).
- Recent pilot study of nurse-led health and wellbeing (H&WB) events for TC patients, men prefer these events ‘closer to home’, particularly in rural areas.
- Successful application to the Foundation of Nursing Studies (FoNS) ‘Patients First’ programme, £5,000 bursary granted.

Roles of multiprofessional project team
Consultant Oncologist, Specialist Registrar, BHCS IT Information Manager, Social Worker, Physiotherapist, CNS Teenagers and Young Adults, Health Care Worker from Teratoma Clinic

‘Closer to home’ events

<table>
<thead>
<tr>
<th>Venue</th>
<th>Invitations posted</th>
<th>Patients</th>
<th>HCP’s + Patient Rep</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waterside H.C. Londonderry</td>
<td>60</td>
<td>10</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Cregagh House Hotel Clougher</td>
<td>40</td>
<td>6</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Camera Room, Old Tech Building, Cregagh</td>
<td>71</td>
<td>13</td>
<td>9</td>
<td>31</td>
</tr>
<tr>
<td>Community Centre Cloughmills</td>
<td>81</td>
<td>17</td>
<td>10</td>
<td>38</td>
</tr>
</tbody>
</table>

Using numerical scale of 0-10 with 0 being dissatisfied and 10 being completely satisfied:

`Very informative and worthwhile for all involved in journey.`

Feedback indicates patients would like these events early in their cancer journey.

Events consistently well evaluated with 75% of patients being completely satisfied with the venue and content of the events. This also included the information and support given.

Plan to add these events to patient treatment pathway during first year.

H&WB events twice yearly to become part of job plan. Recruitment of a CNS for Testicular Cancer would help to ensure the sustainability of project.

On-going evaluation through patient stories and patient focus group feedback to inform the team for future programmes.