



# FoNS Improvement Insights

## 'Tell it like it is' – Delivering Information to Young People Undergoing Bone Marrow Transplantation

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### Project background

The Teenage Cancer Trust Unit at University College London (UCL) has traditionally been an oncology unit but has expanded to accommodate the sub specialities of haematology and bone marrow transplantation (BMT). There is widespread agreement in both practice and the cancer literature that information giving to patients is a fundamentally important part of oncology care and service delivery and is supported by government policies.

In relation to teenagers with cancer, it is evident that adolescents require age appropriate information but this need is often not met. The project built on previous work in which it was noted that young people appeared to engage more with their peers when undergoing BMT. This resulted in the production of an award winning short film prior to the project, presented at the 2010 European Bone Marrow Transplant conference. It is also acknowledged that adolescent patients require shorter and more digestible information and employ a variety of media when communicating with peers and others. The project explored ways of improving information giving to the younger person to increase their understanding of the BMT experience.

### Aim and objectives of the project

The initial aim of the project was to develop age appropriate information for young people about BMT using a variety of modern media. A secondary aim was to use the project as a vehicle for developing a more effective and positive workplace culture. The objectives were to:

- Explore and understand patient views about current information delivery in relation to the experience of having a BMT
- Engage with stakeholders to create age appropriate information for adolescent BMT patients
- Evaluate information provided from the perspective of patients and families
- Facilitate a group of ward based nursing staff to enable them to become empowered to improve practice in the clinical environment

### Key activities and outcomes from the project

An externally facilitated Appreciative Inquiry (AI) workshop for all key stakeholders focused on co-creating a vision for the service, based on what already worked well, whilst acknowledging the challenging work. From this, a working group developed a questionnaire to explore the views and experiences of young people and parents (n=20) about the information they received concerning BMT. The findings (n=7) led to the following initiatives:

- Creating an age appropriate BMT information booklet  
A supplementary 18 page information booklet was developed from an existing 38 page version and is currently under review prior to ratification by JACIE, a European governing body regulating the standards and practices across BMT centres. This will then be evaluated by service users prior to full production as a BMT information booklet.
- Development and production of a DVD as preparation for BMT  
The production of the DVD involved staff and patients and a production company to undertake the editing. Staff and young people evaluated the DVD in March 2011 and feedback was unanimously positive. It generated positive discussions and further ideas about the use of DVDs in other clinical information sharing situations.

The exploration of further possibilities for information giving about BMT using modern media e.g. MSN messaging continues to be explored beyond the project. The use of practice development and AI approaches enabled meeting the project aims and is fostering changes to the ward culture.

### Implications for practice:

- The project demonstrated the need for flexible styles of facilitation from coaching and collaboration, to a more formal, directive approach
- Establishing clear lines of communication between project leads and key stakeholders was critical to the success of the initiative
- An externally facilitated After Action Review (AAR), re-energised project working at a time when the clinical environment was very demanding and when finding time for the project was challenging
- The use of practice development approaches does not necessarily result in rapid cultural change, but has enabled systems and processes to be put in place that make cultural change possible

A full project report including references can be accessed from: <http://fons.org/library/report-details.aspx?nstdid=11370>

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