

**Workshop of the WBMT  
in cooperation with the  
World Health Organization  
Hanoi, Vietnam**

**Dissemination of Information  
Nov 11, 2011 (15:30)**

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Nov 2011

# Objectives

**To discuss strategies on how best to:**

- **communicate effectively to the patients/donors, public and policy-makers about the value and the integration of hematopoietic stem cell (HSC) transplantation within a developing healthcare system**
- **disseminate information effectively to health care professionals for establishing the basic ethical, medical and infrastructure requirements for providing HSC transplantation or optimize existing transplant programs**

# **Dissemination of information:**

## **Target groups**

- 1. Patients and relatives**
- 2. Staff and colleagues**
- 3. Health authorities, government and international agencies**
- 4. Public including volunteer adult donors and cord blood donors**

**Aim: inform different target audiences the value and benefit of BMT**

# **Issues involved to achieve the goal**

- **How to be effective using media available**
- **Awareness of cultural & religious sensitivities**
- **Understanding of political and economical environments**
- **Knowledge of disease prevalence and burden (e.g. Haemoglobinopathy, HIV, Autoimmune Diseases)**

**No one size fits all: aim is to develop an adaptable framework**

# Patients and relatives

- **What to communicate ?**
  - Evidence based recommendations

# **What patient information should be provided? (evidence from cancer studies)**

- **Meaning of the disease, the extent of disease and suspected risk factors**
- **Proposed plan to investigation and treatment, including information on expected benefits, the process involved, common side effects, whether the intervention is standard or experimental and who will undertake the intervention**
- **Likely consequence of choosing a particular treatment, or no treatment**
- **Time and costs involved**

# **Information for patients should include:**

- **Effect of cancer and its therapy on physical, interpersonal and sexual relationships**
- **Typical emotional reactions**
- **Entitlements to benefits and services, such as subsidies for travel or prostheses; and**
- **Access to cancer information services**

**Multi-disciplinary team is essential to be effective**

# **Support needs for individuals and their families (+ donors):**

- **Education**
- **Counselling**
- **Exploring feelings with a member of the treatment team**
- **Access to a transplant support service and/or support group**
- **Assistance with practical needs (e.g. childcare transport)**



# **Culturally competence in managing patients**

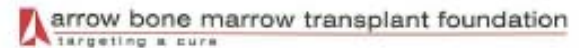
- **To provide training to improve their cultural competence (especially foreign workers)**
  - **‘Breaking bad news’, to whom; whether patient should know, how involved patient would like family members to be, Care beyond medical management: after death; how to express grief and to remember person**
- **Need to evaluate attitudes of medical, nursing and other staff to care for patients of different cultural backgrounds**

# **Culture competence**

- **To provide culturally competent communication and counselling, telephone help line; community support**
- **To assess cultural competence of printed education materials and other media used**
- **To mobilize religious groups, churches and other cultural specific groups**
- **To collaborate with other non-transplant related culturally competent health promotion**

# Not for profit organisations for patients in Australia: examples

- **Arrow BMT  
Foundation:-funds  
ABMTRR registry,  
research, BMT  
patient information  
book, patient  
supports**



# Not for profit organisations: examples

- “Cancer Council NSW” Peer supports:
- Telephone helpline

The screenshot shows the Cancer Council NSW website. At the top left is the Cancer Council NSW logo, a yellow flower. To the right is a navigation bar with icons for 'App', 'Preventing cancer', 'How you can help', 'Cancer action', and 'Shop'. Below this is a secondary navigation bar with links for 'Patients, families and friends', 'Schools, childcare, community', 'Preventing cancer', 'Cancer research', 'How you can help', 'Health professionals', 'Cancer action', 'Stat stats', 'Shop', and 'About us'. The main content area is titled 'Cancer Council Connect - Peer Support Program'. It features a search bar and a list of navigation links on the left. The main text describes the program as a one-to-one support program where a trained volunteer helps someone with a similar cancer and treatment. It includes a photo of a woman talking on a mobile phone. Below the text are sections for 'How the volunteer can help you' and 'We have volunteers available to support people with the following types of cancer'. The 'How the volunteer can help you' section lists: 'Supports before, during or after treatment and during recovery', 'Practical information gained through personal experience', 'Hope and encouragement, and a positive role model for recovery', and 'Ideas about where to find more information'. The 'We have volunteers available to support people with the following types of cancer' section lists: Anal, Bladder, Bowel, Brain, Breast, Head and Neck, Hodgkins Lymphoma, Gynaecological - ovaries, uterus, cervix and vulva cancer, Leukaemia (treated by stem cell transplant), Lung, Melanoma, Oesophagus, Pancreatic, Prostate, Sarcoma, Stomach, Testicular, Thyroid, and Transplant. At the bottom, there is a 'Cancer Answers' logo and a call to action: 'Want to talk to someone? Call Cancer Council Helpline on 13 11 20 or email using our [enquiry form](#)'.

# Not for profit organisations: examples

- Cultural based Patient support



**CanRevive Inc.**  
CANCER SUPPORT ORGANIZATION  
488 88 888 178 888 Charities Act No. 07800108

CanRevive Inc. is a voluntary non-profit making organization which provides emotional support and information for cancer patients and their families, was established in 1985.

**WELCOME MESSAGE**

**News Update**

**蘭蘭劇場慶更生Chinese Opera \$2 Raffle tickets winning numbers are below:**

1st Prize:	0334
2nd Prize:	1088
3rd Prize:	1388
4th Prize:	1311
5th Prize:	1278

Congratulation to all winners, please contact 02 8212 7769 to claim the prize.

**CanRevive Cancer Foundation**  
AGM No. 96 TF1 183 801

CanRevive Cancer Foundation was set up in June 2011 to raise funds for CanRevive Inc., a voluntary not for profit organization which since 1985 has provided support for those in the Chinese community touched by cancer.

Cancer is a formidable illness which will affect one person in three during one's life time. The cancer journey is a long and arduous and its treatment regime harsh and forbidding. Even in remission, the threat of recurrence casts a life-long shadow over the person affected.

CanRevive has, over the years, transformed the lives of many of its members through support groups and various programs. The volunteers, some personally touched by cancer have by their dedication, love and care inspired many clients to renewed hope, optimism and confidence to face every day challenges.

Our funding relies on donations. All donations are fully tax deductible.

[Please click here for the donation form](#)

**CanRevive Inc.**  
Cancer Support & Resource Centre  
**Sydney Head Office:**  
Address  
Level 4, 141 George Street,  
Sydney, NSW 2000  
Office Hour  
Mon - Fri 9am-4:30pm  
Centre Opening Hour  
Mon - Fri 10am-3:30pm  
Lunch Hour  
1pm-2pm  
Telephone  
(02) 8212 7769  
Fax  
(02) 8211 4832  
Email  
info@canrevive.com

**Hurstville Office:**  
Address  
G/F, 8 Park Road,  
Hurstville, NSW 2220  
Office Hour/Opening Hour  
Tuesday to Friday  
10:30am - 2:30pm  
Telephone & Fax  
(02) 8580 7788

# Dissemination of information:

## Target groups

1. Patients and relatives
- 2. Staff and colleagues**
3. Health authorities, government and international agencies
4. Public including volunteer adult donors and cord blood donors

# **Dissemination of information to staff & colleagues**

- **Foster team: empowering staff**
- **Improve knowledge and skill base: in-service training, participating scientific meetings, regular reviews**
- **Evidence of team work and experience of Tx team in patient outcome: centre effect papers**

# **Dissemination of information to staff & colleagues**

- **Enhance collaboration among colleagues**
- **Partnership/mentoring between countries with experience with those with little/no experience**
- **Quality Assurance Programs (internal & external)**
  - **RCPA CD34 QAP for stem cell quantification**
- **Registries – APBMT & ABMTRR**



# Examples: BMT network, New South Wales, Australia

The screenshot shows the website for the Blood & Marrow Transplant Network NSW. The browser window title is "Bone Marrow Transplant - Windows Internet Explorer" and the address bar shows "http://www.bmtnsw.com.au/index.php". The website features a navigation menu with links for Home, About BMT, About GMCT, Shop, Events, Resources, and Contact us. The main content area includes a large banner with the text "Blood and Marrow Transplant Network" and a video player. Below the banner is a section titled "About the BMT Network" which includes a photograph of a building and text describing the network's establishment in 2002 and its role in providing clinical guidelines and quality management services. To the right of the main content is a "Member Login" section with input fields for email and password, and a "Calendar of Events" for October 2011.

**Blood & Marrow Transplant Network NSW**

**ACI** NSW Agency for Clinical Innovation

Home About BMT About GMCT Shop Events Resources Contact us

## Blood and Marrow Transplant Network

Member Login [Become a member >](#)

  
  
 [Forgot your password?](#)

### Calendar of Events

October 2011

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

### About the BMT Network

The NSW BMT Network was established in 2002 as part of the Government Action Plan for Health (GAP), and now includes all public hospitals in NSW conducting BMT.



The BMT Network is one of twenty clinical networks operating under the auspices of the Greater Metropolitan Clinical Taskforce (GMCT). It is a clinician-based group (medical, nursing, allied health and scientific personnel), and includes consumer representatives. In conjunction with Area Health Services and NSW Health, the BMT Network facilitates the development of clinical guidelines, protocols, clinical education, patient information, research and provides a network quality management service.

The Network convenes several working groups, including an Allogeneic group, an Autologous group, a Laboratory Science group and a Nurses group. The Network has a yearly scientific forum which provides clinicians with an opportunity to communicate current practice, achievements, and to share ideas.

Done

Start Bone Marrow Transpl... Novell GroupWise - Mailbox

Internet 100% 08:23 AM

# Examples: International Network for Cancer Treatment and Research (INCTR)

The screenshot shows the Firefox browser window displaying the INCTR website. The address bar shows [www.inctr.org/home/](http://www.inctr.org/home/). The page features a navigation menu with links: Home, About INCTR, Organization, Programs, INCTR Awards, Meetings, Network Magazine, Media Center, and Resources. The main content area is titled "Welcome to INCTR" and includes the following sections:

- INCTR Contact Information:**

Rue Engeland 642  
B 1180 Brussels, Belgium  
P: +32 . 2 . 373-9323  
F: +32 . 2 . 373-9313  
[Branches and Offices](#)
- Find us:** Social media icons for Facebook, Twitter, and YouTube.
- WHO Logo:** INCTR is an NGO in official relations with WHO.
- Description:** The International Network for Cancer Treatment and Research is a not-for-profit organization dedicated to helping build capacity for cancer research and treatment in developing countries.
- Organization:** INCTR's headquarters are located in Brussels and it has Branches and Offices located throughout the world. It has staff and consultants dedicated to the accomplishment of its goals.
- Network Magazine:** Network Magazine is published every 3 months. Current and previous editions are available on-line and can be downloaded as PDF documents. [Read more](#)
- Helping INCTR:** Help INCTR bring comfort and hope to those who need it most by making a donation, volunteering, or supporting our activities. [Help INCTR](#)
- Become a Member:** INCTR's success depends greatly upon the support of individuals, institutions and corporations worldwide. Members participate in ongoing projects, serve on committees, or simply provide financial and moral support. [Become an INCTR Member](#)
- New Tweets from INCTR:** (Partially visible)

The Windows taskbar at the bottom shows the system clock as 6:27 AM on 3/11/2011, along with various application icons.

# **Examples: International Network for Cancer Treatment and Research (INCTR)**

- To build capacity for cancer treatment and research in countries with limited resources through long term collaborative projects coupled to training and educational programs.**
- To promote international collaboration directed towards cancer control between technologically advanced countries and countries with limited resources.**
- accomplished through the development of networks and partnerships with corporate, professional, academic, governmental and non-governmental organizations, bringing together special expertise to bear upon all aspects of cancer research and cancer control.**
- To take advantage of unique opportunities for cancer research in developing countries**

# Examples: Funding supports



The image is a screenshot of the Australia Awards website. At the top, there is a blue header with the Australian Government logo and the text 'Australian Government AusAID'. Below this is a brown horizontal bar. The main content area has a dark blue background with the 'Australia Awards' logo, which features a white star. Below the logo, there is a paragraph of text describing the awards as an Australian Government initiative. This is followed by another paragraph explaining that the awards include Development Awards and Endeavour Awards. A link for 'More information on Australia Awards (external website)' is provided. The next paragraph states that development awards have been a part of the Australian Government's overseas aid program since the 1950s. A section titled 'The overarching goals of Australia's development awards are:' lists two bullet points: 'to develop capacity and leadership skills so that individuals can contribute to development in their home country' and 'to build people-to-people linkages at the individual, institutional and country levels.' The following paragraph details the types of awards, including long-term and short-term awards, and lists specific programs like Australian Development Scholarships (ADS), Australian Leadership Award Scholarships (ALA Scholarships), Australian Regional Development Scholarships (ARDS), Australian Leadership Awards Fellowships (ALA Fellowships), and Prime Minister's Pacific-Australia Awards. Finally, a link is provided for more information on applicant eligibility criteria.

[More information on Australia Awards \(external website\)](#)

Development awards have been an important component of the Australian Government's overseas aid program since the 1950s, supporting its aim to help developing countries to reduce poverty and achieve sustainable development.

The overarching goals of Australia's development awards are:

- to develop capacity and leadership skills so that individuals can contribute to development in their home country
- to build people-to-people linkages at the individual, institutional and country levels.

Development awards provide opportunities for long and short term study and professional development. Long term awards include Australian Development Scholarships (ADS), Australian Leadership Award Scholarships (ALA Scholarships) for high achieving applicants and Australian Regional Development Scholarships (ARDS). Short term awards include Australian Leadership Awards Fellowships (ALA Fellowships), the Prime Minister's Pacific-Australia Awards and short courses.

More information, including applicant eligibility criteria can be found at

- [Australian Development Scholarships](#)
- [Australian Leadership Award Scholarships](#)
- [Australian Regional Development Scholarships](#)
- [Australian Leadership Awards Fellowship](#)
- [Prime Minister's Pacific-Australia Awards](#)

**AusAid:-  
fellowship  
exchange  
programmes  
for mid career  
health  
professionals**

# Dissemination of information:

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4. Public including volunteer adult donors and cord blood donors

# **Health authorities, Government policy makers, International Agencies**

- **Understand cost-benefit**
  - **assessing disease burden such as Disability Adjusted Life Years (DALYs)**
  - **Demonstrate value of BMT in economic terms**
- **Appreciate their responsibilities**
- **How to get them on side : communicate effectively, public supports (advocacy groups)**

# **Health authorities, Government policy makers, International Agencies**

- **Partnerships between countries with experience with those with little/no experience**
- **Value of data collection and registries (to provide evidence)**

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4. **Public including volunteer adult donors and cord blood donors**



# **Public including volunteer adult donors and cord blood donors**

- **Donors**
  - informed consent (family and non-family)
  - Education and recruitment
  - Appreciation of their contributions and caring for their well-beings (donor risks- e.g. no CVC for volunteer donor in Australia)
- **Public awareness**
  - Methods – written, visual and audio media; power of new cyberspace social networks & personal touches – non medical language
  - Benefits of HSCT – life saving

# **Public including volunteer adult donors and cord blood donors**

- **Advocacy groups**

- **Counselling, education programme, peer & family supports and fundraising**
- **Dealing with government and other authorities**
- **Funding raising and awareness campaigns**
- **e.g. BMT support organisations, Arrow BMT Foundation (patient information book & ABMTRR), Cancer Voice, consumer/patient representatives in health services (ALLG)**
- **Use of celebrities e.g. South Korean actresses as donors**

# Elements of effective communication

- Clarity
- Objectives
- understanding the receiver
  - consistency
  - completeness
    - feedback
  - Timing & time

# References

- <http://www.arrow.org.au/>
- <http://www.ausaid.gov.au/>
- <http://www.canrevive.com/>
- <http://www.cancercouncil.com.au/editorial.asp?pageid=229>
- <http://www.canceraustralia.gov.au>
- <http://www.inctr.org/programs/>
- <http://sydney.edu.au/medicine/hocmai/about/index.php>

**Thank you**