

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

Dissemination of Information

Nov 11, 2011 (15:30)

David Ma

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. Haemoglobinopathies, HIV, Autoimmune Diseases)

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

Patients and relatives



- **What to communicate ?**
 - **Evidence based recommendations: Australian Cancer Network - Clinical Practice Guidelines for the Diagnosis and Management of Lymphoma**

What patient information should be provided? (Evidence from cancer & surgical studies)

- **Meaning and extent of disease; suspected risk factors**
- **Proposed investigations and treatment, including expected benefits, the process, side effects, whether Rx is standard or experimental and the Rx team**
- **Likely consequence of choosing a particular treatment, or no treatment**
- **Time and costs**

Culture competence in managing patients

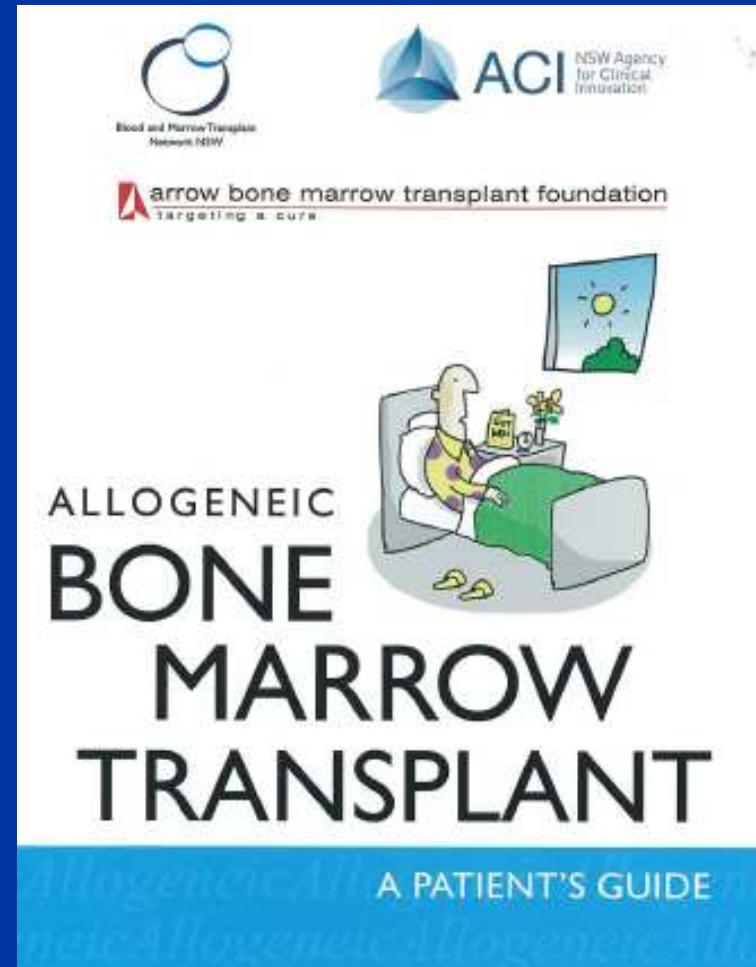
- **To provide culturally competent communication and counselling, telephone help line, community support**
- **To assess cultural competence of printed education materials and other media**
- **To mobilize religious and other cultural specific groups**
- **To collaborate with other non-transplant related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

Culturally competence in managing patients

- To provide training & evaluation of workers' competence in dealing with cultural issues
 - '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 the person

Examples: Not for profit organisations for patients in Australia

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





Allogeneic BMT Peer Support Induction Training (Telephone helpline)

Looking after both the caller and the
volunteer helper

Sponsored by:



St Vincent's
Hospital Sydney



Arrow Bone Marrow
Transplant Foundation



Dissemination of information:

Target groups

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2. Staff and colleagues

3. Health authorities
international

4. Public including
and cord bloc



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 team in better patient outcome**
 - **publications demonstrating centre effect**

Dissemination of information to staff & colleagues

- Enhance collaboration among colleagues
- Partnership between countries with experience with those with little/no experience : learn from their mistakes
- Registries – e.g. APBMT & Austr BMTRR
- Quality Assurance Programs for lab
 - e.g. Australasian CD34 QAP for HSC quantification

Participants in Royal College of Pathologists of Australasia (RCPA) CD34 QAP



37 in Australia

18 in Asia

- Hong Kong
- India
- Malaysia
- Phillipines
- Singapore
- Taiwan
- Thailand

2 in South Africa

1 in NZ

1 in Oman

Examples of global collaboration: 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/. The website features a navigation menu with links to Home, About INCTR, Organization, Programs, INCTR Awards, Meetings, Network Magazine, Media Center, and Resources. The main content area includes a "Welcome to INCTR" section with contact information, a description of the organization, and sections for "Helping INCTR", "Become a Member", "Organization", "Network Magazine", and "New Tweets from INCTR".

INCTR
Rue Engeland 642
B 1180 Brussels, Belgium
P: +32 . 2 . 373-9323
F: +32 . 2 . 373-9313
[Branches and Offices](#)

Find us
f t YouTube


INCTR is an NGO in official relations with WHO

Welcome to INCTR

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.

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](#)

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](#)

New Tweets from INCTR

6:27 AM
3/11/2011

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

- To build cancer Rx and research in countries with limited resources via long term collaborative projects coupled to training and educational programs with technologically advanced countries**
- To take advantage of unique opportunities for cancer research in emerging countries**

Dissemination of information: Target groups

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2. Staff and colleagues
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government and
international agencies**
4. Public including
volunteer adult donors
and cord blood donors

Prime Minister
Australia
1996-2007



Health authorities, Government policy makers, International Agencies

- **Appreciate their responsibilities in healthcare & other matters**
- **Understand cost-benefit**
 - **assessing disease burden such as Disability Adjusted Life Years (DALYs)**
 - **Demonstrate value of BMT in economic term and in their terms (popularity)**

Health authorities, Government policy makers, International Agencies

- How to get them on side : communicate effectively, public supports (advocacy groups)
- Value of data collection and registries (to provide evidence)

Dissemination of information: Target groups

4. Public including volunteer adult donors and cord blood donors



Public including volunteer adult donors and cord blood donors

- **Donors (WHO principles)**
 - informed consents (family and non-family)
 - education and recruitment
 - appreciation of their contributions and care for their well-beings
- **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
 - Dealing with government and other authorities
 - Funding raising and awareness campaigns
 - Use of celebrities e.g. South Korean actresses (volunteer donors), sport heroes

Elements of effective communication

- Clarity
- Objectives
- Understanding the receiver
 - Consistency
 - Completeness
 - Feedback
 - Timing & Time



Thank you



References

- <http://www.arrow.org.au/>
- <http://www.usaid.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>

DISSEMINATION OF INFORMATION ON HSCT

Wish list
Priorities

SNAPSHOT OF CURRENT STATUS ON DISSEMINATION OF INFORMATION ON HSCT:

- **What is the commonest medium of communication in your centre/country?**
- **Is internet access widely available? Any limitations or restrictions?**
- **Describe the access of supportive services for patients and families, and donors?**
- **Describe your country's volunteer/ charitable support organizations? Does your centre or country have advocacy groups for transplantation?**