

Australian Cancer Survivorship Centre

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Cancer Nurses Society of Australia Winter Congress 2016



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On the road to recovery: developing evidence based,
consumer informed resources for Arabic, Italian and
Vietnamese cancer survivors living in Australia

Georgina Wiley

Program Manager

Presenting on behalf of the project team: A/Prof Michael Jefford, Ms Amanda Piper, Ms Linda Nolte, Prof Phyllis Butow, Prof Penelope Schofield, Dr Melanie Price, Fiona Douglas, Jane Roy and Rosemary Kelada

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Overview

- Background
- Project aim
- Methods
- Results
- Resource development
- Key learnings
- Next steps
- CALD network

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Background

- Australia has one of the most culturally diverse populations in the world with approximately 28% born overseas
- Recent Australian research shows that:
 - CALD migrants have a poorer cancer experience
 - CALD migrants with cancer report inferior quality of life, higher levels of unmet needs and depression
 - Survivors from Arabic, Chinese, Greek-speaking backgrounds report unmet need for culturally appropriate information

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Background

For Anglo-English speaking Australian groups:

- The period after finishing treatment (the survivorship phase) can be distressing
- Consumers are often fearful of the cancer coming back
- Consumers can have financial, family, physical and/or emotional concerns
- Consumers are at risk of recurrence, long-term and late effects from cancer and its treatment

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Background

- Work undertaken by Phyllis Butow et al which highlighted the need for resources written for and translated to language groups
- Consideration of cultural differences (attitudes and beliefs) and language (the meaning of 'cancer survivor') are important
- It is not adequate to simply translate existing information materials
- Grant funding sought by Cancer Australia

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Project Aim

To develop culturally-appropriate information about cancer survivorship for people with Arabic, Italian and Vietnamese-speaking backgrounds

1. Understand conceptualisation of survivorship post treatment & the unique information needs
2. Develop/adapt written information material tailored to specific CALD groups
3. Disseminate written information materials widely

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Method

Focus groups

Recruitment from community groups and hospitals

- Two focus groups for each three languages
- Semi-structured interviews, with language speaking researchers
- Participants were asked how they define survivorship, about life after cancer treatment, and what their information needs were
- Recorded, transcribed and translated by NAATI accredited translators

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Results

- 39 survivors and carers participated
- Thematic analysis revealed unique challenges and needs in each of the language groups

Key themes:

- Emotional health (all groups)
- Religion and faith (Arabic and Italian)
- Culturally appropriate language (Arabic and Vietnamese)
- Stigma (Arabic and Vietnamese)
- Healthy living after cancer (all groups)
- The concept of survivorship (Arabic and Vietnamese)
- Need for greater cancer awareness (Arabic and Vietnamese)

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Resource Development

- Resources developed using Cancer Council 'living well after cancer' resource as well as Peter Mac 'Just take it day by day' DVD and various ACSC resources
- Professional editing undertaken
- Draft content reviewed by bi-lingual health care professionals
- Content translated
- Re-reviewed by HCP's and consumers
- Design process and typesetting
- Print and dissemination

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Key learnings

Number of learnings throughout the development process:

- Awareness of how words/phrases are conceptualised by difference groups
- Difficulty recruiting FG participants
- Importance of engaging with community groups
- High cost of translation of FG recordings
- Translation process
- Booklet presentation (decision made to make resources bilingual)

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Resources

On the Road to Recovery
العربية | Arabic



على الطريق الى الشفاء

معلومات للأشخاص الذين في طريق الشفاء
من السرطان ولمقدمي الرعاية لهم

معلومات
عملية ودعم

للحصول على المعلومات والدعم، اتصل
13 11 20

On the Road to Recovery
Vietnamese | Tiếng Việt



Hành trình Hồi phục

Tập sách thông tin này dành cho những
người đang hồi phục sau khi được điều trị
bệnh ung thư và người chăm sóc cho họ

Thông tin
thực dụng và
thông tin về
việc giúp đỡ

Muốn biết thông tin và việc giúp đỡ, xin gọi
13 11 20

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Next Steps

- Arabic and Vietnamese resources published with Italian to shortly follow
- Article being drafted - to concentrate on lessons learnt from resource development process
- Received funding from Cancer Australia *Supporting people with cancer* Grant initiative to continue work
- CALD Network

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Acknowledgements

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- The project was a collaboration between the Australian Cancer Survivorship Centre – A Richard Pratt Legacy, Peter MacCallum Cancer Centre and Cancer Council Australia



Australian Government
Cancer Australia

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Project Team

- Georgina Wiley – Project Manager, ACSC
- Michael Jefford – Director, ACSC
- Amanda Piper - Acting Manager, ACSC
- Phyllis Butow - Psycho-oncology Co-operative Research Group
- Penny Schofield – Swinburne University
- Linda Nolte – Manager, ACSC
- Melanie Price - Psycho-oncology Co-operative Research Group
- Fiona Douglas - Cancer Council Victoria
- Jane Roy – Cancer Council Australia
- Rosemary Kelada – Consumer Representative

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CALD Network

- Outcome of the project
- The network brings together professionals and organisations who are currently working or interested in working in the field.
- There is enthusiasm among individuals and organisations who are working with CALD populations to work collaboratively;
- There is a need to consider how we work for and with community groups
- Recognition that there is potential to reach wider audiences when organisations engage in more collaborative work.

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VCCC Survivorship Conference – Save the Date!



The VCCC Survivorship Conference: Improving Outcomes for Cancer Survivors and The Fourth Psycho-Oncology Research Conference: Living with and Beyond Cancer

VCCC Survivorship Conference
Thursday 13th October

Victorian Psycho-Oncology
Research Conference
Friday 14th October

9:00am – 5:00pm

The VCCC Survivorship Conference will provide a platform in Victoria for disseminating new research in the field of cancer survivorship. The inaugural conference will include discussion about issues facing survivors, models of post-treatment survivorship care, challenges conducting cancer survivorship research and future directions for survivorship care and research.

The Fourth Psycho-Oncology Research Conference will deliberate the lived practical challenges of cancer survivorship. The conference will address the issues of identity, development and the use of 21st century technology.

International Speakers

of the OCS in 1999, Dr. Rowland has

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Contact Details

For further information, to order resources or to enquire about the “CALD Network” please contact Georgina Wiley – Georgina.Wiley@petermac.org or 03 9656 9040

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References

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