



Development of an EORTC Quality of Life Module specific to Melanoma

Julie Winstanley



The University of Sydney

MELANOMA Institute Australia

Melanoma Institute Australia, The Poche Centre



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Progress report since QLG meeting in April 2010

- Groundwork completed in Australia for Phase 1 module development, using EORTC methodology
- QoL issues list generated in an Australian melanoma population, ready for review
- Preparation of grant application to EORTC QLG for a full Phase 1-4 study involving seven countries (5 languages in all)



Investigators and collaborators – EORTC Grant

Principal Investigator

A/Professor Julie Winstanley

Melanoma Institute Australia (MIA), The University of Sydney, Australia

Associate Investigators (within Australia)

Professor Madeleine King

PoCoG, The University of Sydney

Professor John Thompson

Director, MIA and The University of Sydney

Professor Rick Kefford

Westmead Institute Cancer Research and Melanoma Institute Australia

Professor Edward White

Osman Consulting Pty Ltd and University New South Wales

Ms Bridget Myles

Quality of Life (QOL) Study Co-ordinator, Melanoma Institute Australia

Ms Elizabeth Paton

Executive Officer, Australian/New Zealand Melanoma Trials Group (ANZMTG)

Project Core Collaborators (within the EORTC Quality of Life Group (QLG))

Dr Lonneke van de Poll-Franse

Eindhoven & Tilburg University, **The Netherlands**

Dr Mia Bergenmar

Karolinska Institute Stockholm, **Sweden**

Professor Michael Koller

University of Regensburg, Regensburg, **Germany**

Dr Anna Constantini

Sant'Andrea Hospital, Sapienza University of Rome, **Italy**

Project Collaborators (not members of the EORTC QLG)

Dr Jennifer Garioch

Norwich and Norfolk University Hospital, Norwich, **England**

Dr Julia Steinbauer

Department of Dermatology, University of Regensburg, Regensburg, **Germany**



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Timelines – EORTC Module development

- **Phase 1** – Generation of Quality of Life (QoL) issues across different cultures (6 months, commencing September 2010)
- **Phase 2** – Operationalisation of melanoma issues into items (6 months, commencing March 2011)
- **Phase 3** - Pre-testing (6 months, commencing September 2011)
- **Phase 4** – International field-testing (1 year, commencing March 2012)
- **Final Report/Analysis phase** (6 months, commencing March 2013)



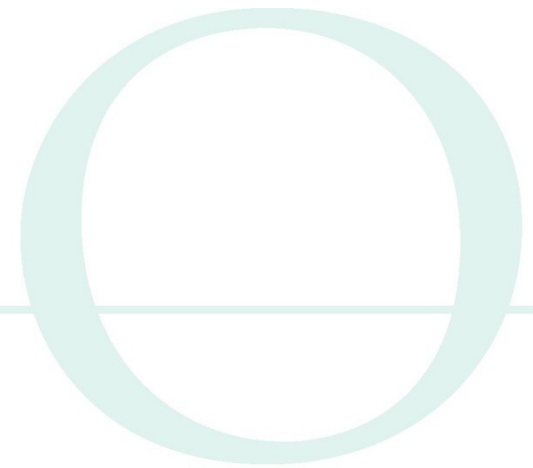
Phase 1 – September 2010 to March 2011 – 6 months

Generation of final QoL issues across different cultures

- Overall aim: Health Care Professionals and Patients will be interviewed in seven different countries; Anglo-Saxon countries: Australia, New Zealand and England, Northern Europe: The Netherlands, Germany, and Sweden, Southern Europe: Italy.
- The QoL issues list will be translated into 4 languages (Dutch, German, Swedish and Italian) by the EORTC Translation Unit.
- **Aim for each collaborating centre to interview 5-7 Health Care Professionals and 8-10 Patients and provide data to lead centre in Sydney**
- Ethics approval will be needed in each jurisdiction for patient interviews, participants will be purposively selected to include patients in all stages of Melanoma, balanced numbers of males/females and treatment phases
- Structured interviews will be held according to the EORTC module development guidelines and will assess whether included issues are relevant or missing, and will consider their relative importance.



Australian QoL issues list: Step 1



144 issues across 12 themes

1. Support (n=29)
2. Information/Education staff (n=21)
3. Dark thoughts (n=27)
4. Overall meaning of QOL (n=19)
5. Effects surgery drugs (n=11)
6. Clinical staff (n=11)
7. Resignation (n=9)
8. Life adjustments (n=4)
9. Information/Education (self taught) (n=7)
10. Change social activities(n=2)
11. Employment /financial (n=2)
12. Most helpful/unhelpful individual (n=2)



Australian QoL issues list – Step 2

108 issues across 10 themes

- Some issues were duplicated across several themes e.g. depression/anxiety appeared in overall meaning of QOL, support and dark thoughts
- Reduced to 108 ‘unique’ issues by assigning duplicate issues once only to the theme which was most appropriate



Australian QoL issues list – Step 3

73 unique issues across 7 themes

- Reviewed by core research team at MIA and collapsed issues with similar meaning
- Questionnaire developed for Phase 1 clinician and patient interviews in Australia
- Ready for piloting with this group this morning before translating for use in the collaborating centres



Today's Session – QoL issues list

- Complete the questionnaire provided with the list of 73 issues, across 7 domains, and rate for relevance to Melanoma patients ('relevance' is the frequency with which a specific complaint occurs and the trouble it may cause)
- Then, go back through each section and if you marked an issue as 'no' or 'little' relevance, put a note on why
- 10 - 15 minutes – return to group discussion



Today's Session – Group discussion

- As a group, we want to achieve a consensus on the QoL issues which should definitely be included in a new module (i.e. that you think affect melanoma patients most profoundly)
- Are there any issues which you think are **not relevant** and should **not** be included?



Today's Session – Group discussion

- How many of our 73 QoL issues are already covered by the QLQ C30
- Review the items on the QLQ-C30
- Indicate on your questionnaire where you think overlap occurs
- What QoL issues are missing from both questionnaires?
- Do we need to add any missing QoL issues to our questionnaire for Phase 1

