Impact of Alopecia on Quality of Life.
Disclosures: Prof Fran Boyle

- The Patricia Ritchie Centre, Mater Hospital, North Sydney has trialed scalp cooling devices made by Penguin, Dignitana and Paxman.
Alopecia: a sine qua non for cancer

Prince of Wales Hospital Appeal
Madarosis: its underrated cousin

The Scar Project
And men: often overlooked
And opportunities to experiment
If you cannot fix it, why measure it?

- Standard QOL measures used in cancer do not even include hair loss as an item
  - EORTC QLQ C 30
  - FACT-G
- Some Breast Cancer measures do include aspects of body image and its impact on others
  - Br 23 includes
    - Less feminine
    - Less attractive
    - Dissatisfied with body
  - FACT B
    - I am bothered by hair loss
And PRO-CTCAE may be not much better

NCI PRO-CTCAE™ ITEMS
Item Library Version 1.0
English
Form created on 22 June 2019

As individuals go through treatment for their cancer they sometimes experience different symptoms and side effects. For each question, please check or mark an X in the one box that best describes your experiences over the past 7 days...

1. In the last 7 days, did you have any HAIR LOSS?
   ○ Not at all  ○ A little bit  ○ Somewhat  ○ Quite a bit  ○ Very much
Overview of QOL impact of scalp cooling

- Systematic Review of Scalp cooling studies
  - Most used EORTC QLQ C 30 +/- Br 23
  - Despite improvements in hair preservation, overall QOL impact inconsistent
  - Failure to separate successful cooling vs unsuccessful cooling
- Called for better measurement tools

Marks et al, Br Ca Res Rx 2019
Can we do better? Hair QOL

95 issues identified in interviews with patients and health professionals in 4 countries.

43 summarised for next phase of testing in 5 themes:

- Information / preparedness
- Impact on self
- Impact on others
- Management of hair loss
- Regrowth

CHILL consortium.
Hair QOL Phase 3
Testing in progress
In 10 countries.
Mater Patient Experiences: Focus Groups

› “I was able to hide my breast cancer diagnosis from my work colleagues and son.”
› “It helped me take a little control at a chaotic time.”
› “I have lost a lot of hair, but can get by with using a cap to cover the crown.”
› “I worried when my hair started to fall out…its important to know what to expect”
› “The regrowth is very fast – I now look like I have a “Mullet” with thick curly hair on top.”
› “No-one is cutting me any slack because I don’t look sick!”
› “I needed more information for my hair dresser: no-one had heard of it”

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Shaw J et al , Supp Care Cancer 2016
Madarosis and QOL

- Focus groups in Australia identified multiple issues
  - Timing of loss vs scalp hair
  - Information
  - Impact on eye comfort
  - Impact on self / communication
  - Impact on others
  - Management / Regrowth

- QOL tool in development and timeline study

Smith K et al, Support Care Ca, 2018
Korean CADs

Chemotherapy-induced Alopecia Distress scale

- 4 subscales
  - Physical
  - Emotional
  - Activity
  - Relationships

- Awaiting validation in other languages

Cho et al, Annals of Oncology 2013
Patient decision support.
www.scalpcooling.org

Hundreds of thousands of people yearly lose their hair through chemotherapy regardless of age, gender or race: everyone can be affected by hair loss. Take a look in the mirror: what does your hair mean to you?

Alopecia and scalp cooling

This website is intended for patients with cancer who are receiving chemotherapy and for whom there is a chance of hair loss. Hair loss is a side effect of many types of chemotherapy. Everyone experiences hair loss differently. Some patients are not bothered by it, while others think it is terrible.