

“Fore-warned is Fore-armed –
Supportive Care for Prostate
Cancer Patients receiving
Curative Radiotherapy”

Wallace Crellin

&

Kath Schubach

Framework Background

- Consumers Health Forum of Australia (CHF) & National Health & Medical Research Council (NHMRC) led the development of this framework
- Model framework first developed in 2000-2001 as a partnership b/w consumers and researchers
- *Model framework for the consumer and community participation in health and medical research*

Benefits of using the Model Framework

- Improved understanding with the communities at a local level
- Contribution of significant consumer perspectives on its research, assisted by the use of the model framework
- Understanding the experience of working with consumers as partners in the research process
- Opportunity to implement and promote the role of the health consumer/community in the model framework both nationally and internationally

The importance of involving consumers in research

- Consumers can provide important input into decisions about research practise and policies
- To promote the partnership with consumers and researchers in the development of research goals, questions, and strategies
- Ethical requirements are met by shared responsibility of consumers, community members and researchers

Consumers in Research Projects

- Participants
 - people supplying the data
- Consumers
 - people in the research group
 - Associate Investigators?
 - People who have experienced the journey

Search for Suitable Consumers

- Difficulties
- Time consumption
- Disruptive consumers
- They are out there
- NHMRC – suggests sitting fees

Clinician and Consumer

- Primary driver - Scientist/Clinician
- Secondary driver – consumer
- Mutual understanding and respect
- Peter Mac Urology Research Group

Project Background

- Meeting the needs of Men with Prostate Cancer using a Consumer Driven multi-disciplinary approach'.
- Funding: Cancer Council – Pilot program \$150,000 for 2 Years developed RCT pilot
- NHMRC - \$500,000
- Completion of RCT February 2011
- Data Collation now completed

Pilot Program

- Commenced 2006
- Involved Clinical Nurse Specialist (Urology)
- Clinical Psychologist
- Development of intervention manual
Introducing Wal

Pilot Program

- **Principles of intervention**
- Patient centred
- Holistic care
- Consumer acceptability
- Cost effective
- Evidenced based

Feed back from Pilot group

- Positive feed back
- Peer Support
- Information provided
- Group size

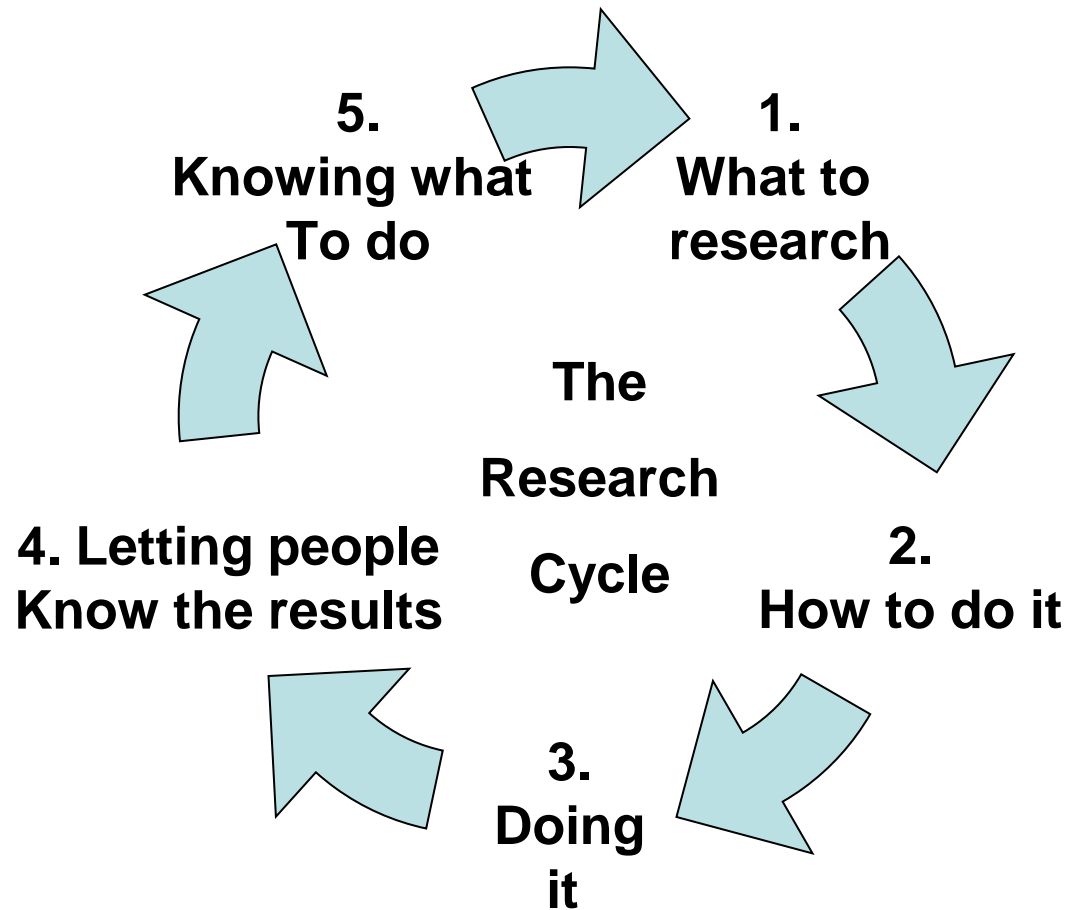
Amendment to Intervention

- Psychologist removed from intervention
- Up skilling of Urology Nurse
- Advanced communication skills
- Role play

RCT

- Randomised Control Trial commenced 2006
- Completed 2010
Final numbers
- 165 Intervention & 167 Control
- Four psycho-educational discussion groups
Delivered Wk 1, 4 & 7 and 6 weeks post
treatment completion
- One-on-one meetings with Clinical Nurse
Specialist

Stages of the Research Cycle



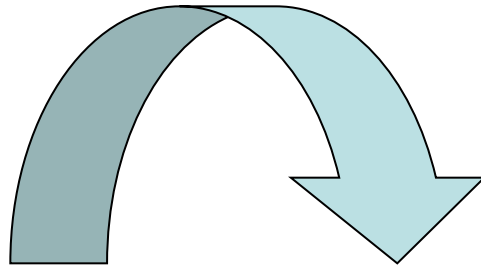
My Personal Research

- Cancer Information and Support Services, Cancer Council, Victoria
- Active Surveillance
- Tutored in increasing degree of difficulty
- First experience in medical science research
- Associate Investigator

Quality of Life Considerations

- Is “Forewarned is Forearmed” a realistic hypothesis?
- “How can I thank you enough? You saved my life!”
- It ain’t necessarily so!
- Subsequent quality of life?
- We would like to hear “You helped me maintain a good quality of life”

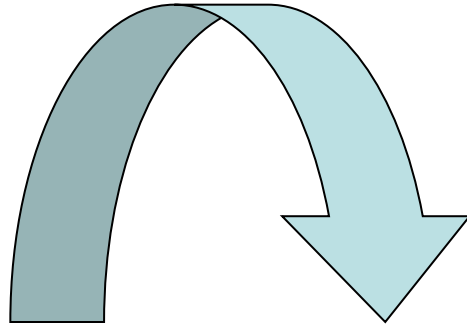
Stage 1: Research Cycle



Deciding what to research

- General Interest in men's health
- Promotions for men to be tested for Prostate Cancer via PSA
- Investigator's support for their menfolk?
- Well structured discussions about problems during treatment
- No other similar research

Stage 2 of Research Cycle



Deciding How to Do It

- Choose the Best Multi-Disciplinary Research Team
 - Radiation Oncologists
 - Psychologists
 - Behavioural Scientists
 - Nurses
 - Radiation Therapists
 - Statistician, and
 - a Civil Engineer

The Project Plan

- Randomised Control Trial
- Timed for important markers in the progress of treatment.

The Project Plan (ctd)

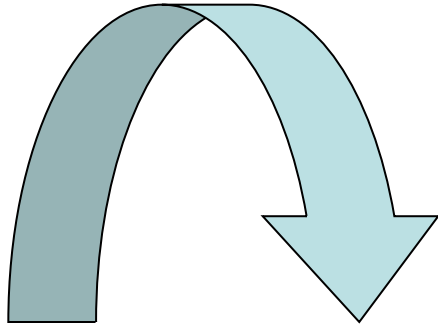
- Manual produced
- How can I help?
- Personal journey details
- Pre-emptive strike

Significant Others

- Reviewers – include them
- Problems with some topics?
- Sexual subjects
- Participants agreed on exclusion

Stage 3 of Research Cycle

Doing it



Group Sessions:

- Start of treatment
- Midway through treatment
- End of treatment
- Three months after treatment

Topics for Discussion

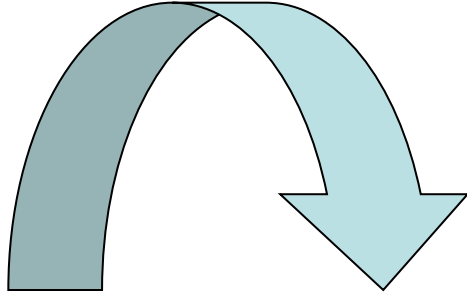
- Stress and Emotions
- Bowel Problems
- Future incontinence and/or impotence
- Fatigue
- Sexuality & impotence
- Life after Treatment

Life After Treatment

- Incurable?
- Curative Intent treatment
- Power of positive thinking?
- Delayed side effects
- Radiation Proctitis and Radiation Cystitis

Stage 4 of Research Cycle

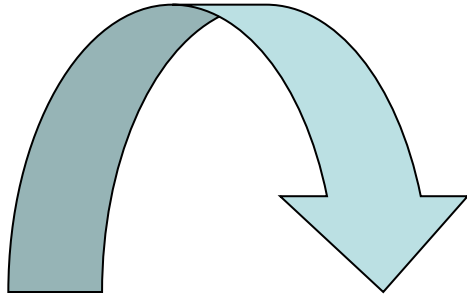
Letting people know the results



- Publications
- Conferences
- Discussion Groups

Stage 5 of Research Cycle

Deciding what to research next



- Stress and depression
- Is QOL related to treatment method?
- Delayed Side Effects
- Cost effectiveness of group sessions compared with one on one
- Effects of impotence and incontinence

Finally - Translation

- Original funding application:
 - Can improve men's quality of Life?
 - If so, what about other serious illnesses?
 - Can we change health care practices?
- Positive feedback from participants

Acknowledgments

- Doreen Akkerman - Cancer Council Vic
- A/Prof Penelope Schofield - Principle Investigator
- Professor Sanchia Aranda –Peter Mac
- All other members of the project team
- Peter Mac and NHMRC - encouragement for consumer involvement