

WHAT IS IMPORTANT TO RESEARCH: THE CANCER SURVIVORS' VOICE

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WHY THIS ISSUE?

- Research shows that cancer survivors have many unmet needs (Burg et al, 2015)
- Service user involvement in research enhances its quality and appropriateness at all stages of the research process (Williamson, 2014)
- Greater feelings of empowerment, value, insight and rapport for all concerned (Brett, 2014)
- A national framework for consumer involvement in cancer control (Cancer Voices Australia, 2011).
- FCN - 18 focus group participants, Sept 2014.

INFORMATION (ACCESS, HEALTH LITERACY, COMMUNICATION/SHARING, OWNERSHIP)

- How information is packaged for cancer survivors
- A mechanism to identify where a person is at in their information gathering?
- What approaches specialists use and why, what they think works and doesn't work, and the patients' perspective on this?
- What lessons health professionals have gained from their patients?
- The general community's literacy regarding cancer survivorship?
- Stigma

PEER SUPPORT

- Benefits
- The role of health professionals
- The need for specialists to be educated
- Health professionals' perceptions

PSYCHOLOGICAL NEEDS

- Holistic treatment options
- Picking up our lives again

OTHER TOPICS

- Comorbidity
- Referral and linkage, transitions, system coordination
- The role of family
- Carers' issues
- Survivorship care plans
- Surveillance, Remission and re-occurrence
- Resilience, disability

WHAT THIS ALL MEANS?

- Finding cures / effective treatments for cancer, essential, but only one aspect of the picture of cancer survivorship.
- Valid forms of knowledge to bring to the research process; an expertise inherent in experience.
- Survivors increasingly likely to prioritise physical, social and emotional impacts of their care and in research.
- Implications for researchers, types of data collected, and the cancer workforce.

REFERENCES

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