

Strengthening survivor's roles in cancer trials advisory groups

Joint Community Advisory Group (JCAG)

of the Psycho-Oncology Cooperative Research Group (PoCoG) & Primary Care Collaborative Cancer Clinical (PC4) Trials Group



Introduction

Cancer survivors and carers play a vital advisory role in all 14 Australian cancer clinical trials groups.

For volunteers who join these Consumer Advisory Groups, the language and processes of research and clinical trials can be bewildering, as well as the uncertainty about expectations of us.

A 'peer-support-pairs' program for sharing ideas and to strengthen the collaboration, capability and confidence of group members to operate in this unfamiliar role has been implemented by the Joint Community Advisory Group (JCAG) for the Psycho-Oncology Cooperative Research (PoCoG) and Primary Care Collaborative Cancer Clinical (PC4) Trials Groups.

Our advisory input can include commenting on the

- potential challenges for trial participants eg. burden of filling in questionnaires; inequity or access barriers to involvement,
- suggestions for improving recruitment,
- research-study design,
- suitability of outcome measures,
- refining study and information materials
- general 'consumer perspectives' of the importance or priorities for research or study directions.



About JCAG

The JCAG was established in mid 2010 with **10 members**. The peer-support program was initiated by the PoCoG and PC4 Executive Officers.

JCAG members are **located across Australia**, so regular contact between peer-support pairs is generally by **email, skype or phone**. Discussions can be general and/ or focussed on specific proposals that we are reviewing.

A second round of JCAG recruitment took place in mid 2013 to renew the group to 12 members. Pairing 'old' with 'new' members aided the orientation, in addition to our formal training sessions.

JCAG is unique:

- as a **collaboration** between two cancer trials groups
- having a broad remit across **any cancer type**,
- with some '**community members**' who are at average risk of developing cancer for their primary care perspectives around **cancer prevention, early detection and screening**.
- focusing on **non pharmaceutical interventions** that are often complex psycho-social or primary care interventions
- and in having a **peer-support program!**



JCAG members Don & Julie skyping about development of this poster!



JCAG team at a Training Workshop:

Front row, left to right – Don (SA), Elizabeth (Qld), Julie (SA),
Back, left to right – Joanne Shaw(PoCoG Research Manager),
Briony Williams (PC4 Project Officer), Heinz (NSW), Robyn (SA), Nikki (Vic),
Julia Fallon-Ferguson (PC4 National Manager), Max (Vic), Associate Prof
Lyndal Trevena (PC4 Operation Team member) and missing from photo:
Elle (Qld), Claire (Vic), Celia (NSW), George (NSW), Rachel (Qld).

Results

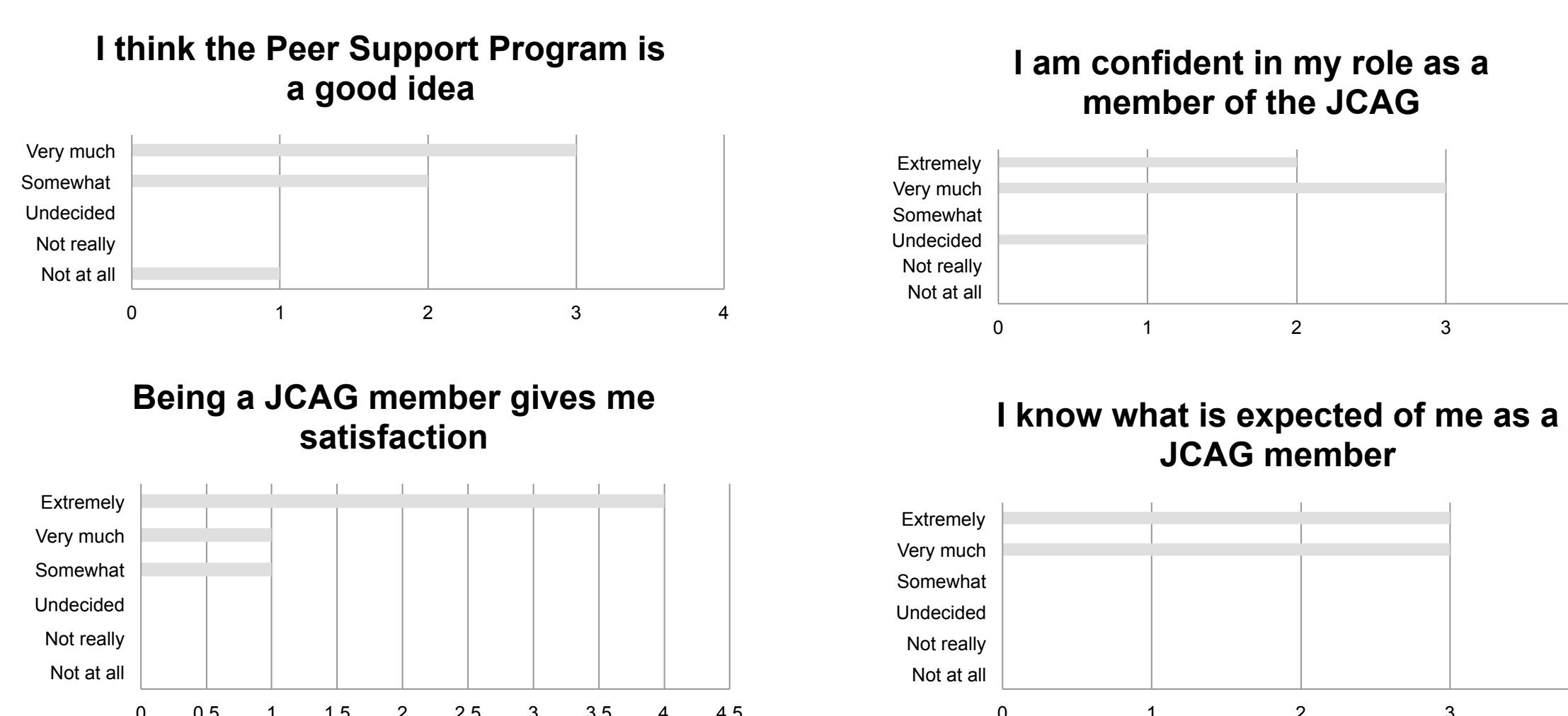
We are cancer survivors, carers or community members interested in clinical trials to improve cancer detection, treatments, survivorship, care and quality-of-life outcomes.

JCAG members generally value and strongly support the formal peer-support process to assist us to grow in this role.

In addition to our diverse personal experiences of cancer, JCAG members all come from very different walks of life. We have learnt a lot from each other's life experiences. This has helped **broaden our understanding of various social circumstances, attitudes, values, habits and behaviours** to consider when reviewing trial concepts and proposals.

We also value this opportunity for **building on experience** from successive rounds of trial reviews, **strengthening capability**.

Recent evaluation of the Peer Support Program by JCAG members is shown below.



Feedback from researchers indicates they **greatly appreciate the JCAG input**, and increasingly involve us at the early 'concept development' stage of studies.

Results (continued)

Feedback from JCAG members

"The peer support program has helped me to get to know other JCAG members better, and has given me an understanding of the pool of experiences and knowledge that the group has to offer."

"Peer support conversations have given me confidence to put forward some suggestions that I might not otherwise have done, and prompted thoughts and memories that were relevant to these tasks"

"I enjoy being involved with this group. It gives me a lot of satisfaction & reward for being involved and contributing to the discussions."

Conclusions

Participation in clinical trial advisory groups is a steep learning curve for most new-comers.

Supporting cancer survivors to share their experience and contribute most effectively in this research environment is a means to improving the quality and focus of cancer clinical trials.

We feel the quality of feedback we provide in our advisory roles, is enhanced by this collaborative peer-team approach.



JCAG members leading discussions at an Information Workshop to recruit more cancer survivor, carer and community members in 2013.

Contact information

PoCoG www.pocog.org.au
PC4 www.pc4.org.au

Cancer survivors, carers or community members interested to be involved in the JCAG?
please email info@pc4.org.au or ph: Briony on **08 9346 4439**

Primary Care Collaborative Cancer Clinical Trials Group
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