

#### Skin Cancer – a supplemental response to the Skin Cancer Inquiry, April 2014

#### lssue:

Despite the high rates of skin cancer in Australia, the general community is hazy about possible skin cancer signs which should trigger a GP consult. Access to GPs and especially to Dermatologists can be difficult. The expertise of staff in Skin Cancer Clinics is assumed but not accredited. Melanoma is feared as a lethal diagnosis, but other forms of skin cancer are less known and seem not to be taken seriously by GPs or the community.

#### Recommendations (as per Inquiry Terms of Reference): Increased awareness in the community and among health professionals-Strategies to enhance early diagnosis:

- -increase community understanding and clarity around what skin cancer is, how to access services and what services are available
- -enhance diagnosis of skin cancer with increased community awareness of signs -use personal scenarios to raise awareness of all types of skin cancer and that non-melanoma skin cancer can still be serious (eg Claire Oliver and the power of one patients story; 5 things I now know about melanoma http://www.oncologynurseadvisor.com/5-thingsi-now-know-about-melanoma/article/319174/); also need to be targeting men and their partners & families, as 68% of melanoma deaths are men, & mostly it's older men who are dying of non-melanoma skin cancers.
- -acknowledge the vital role of partners and carers in shared responsibility for seeing spots eg on the back etc where individuals can't see, in noticing changes and in urging medical checks. Men in particular may need urging from their family to take action.
- -use online technologies that are available 24/7 to enhance broad community awareness eg recent Qld research found videobased education increased mens skin awareness. http://www.scoop.it/t/cancer-advocacy-by-cancer-voices-

sa/p/4019858606/2014/04/18/videobased-education-increases-mens-skin-awareness

-the community is puzzled by the silence and lack of any debate around screening for skin cancer, for such a significant issue.

#### Strategies for prevention:

- -enhanced knowledge and awareness of risk factors for skin cancers. Collate what is already known and present this in a fresh, succinct and engaging way.
- -put statistics about skin cancers in the context of other cancers, for comparison. The extent of skin cancer impact is under acknowledged.

#### Implementation of evidence-based best practice treatment and management

- -triaging mechanism for referral to specialists, so urgent referrals are treated in a timely manner
- -enhance Skin Cancer qualification of GPs and provide accreditation of this training. Clarify the role of Skin Cancer Clinics and qualifications of their staff. More awareness is needed of this resource, especially where access to GPs can be difficult and expensive
- -enhanced access in rural communities to GPs with skin cancer qualifications. Locums and poor continuity of care makes monitoring 'changes' difficult. Many overseas trained doctors working in rural locations were trained in countries where skin cancer is not a big issue -even GPs seem unsure of skin cancer monitoring, as online forums abound with Drs asking other Drs what sort of device/ camera to monitor and document skin cancer lesions -systematically enhance awareness of need for long-term follow-up and risk of local
- -systematically enhance awareness of need for long-term follow-up and risk of local recurrences of skin cancer. Basal Cell Carcinoma BCC diagnosed early in life, eg. by 25yrs age, confers risk of subsequent melanoma.

- -funding for skin cancer research
- -refreshed Australian data about skin cancers. Latest non-melanoma skin cancer data is from Skin Cancer Survey in 2002, or mortality data.
- -more comprehensive national data collection to address the gap in data around cancer stage at diagnosis, time and location of recurrence or development of metastases, and occurrence of second cancer types. We know nothing between date of diagnosis and death for most cancers.

#### Background:

Australia has one of the highest rates of skin cancer in the world. Skin cancer is largely preventable and amenable to good outcomes if detected early. However, beyond the 'Slip, slop, slap' campaign there seems to be limited awareness about skin cancer In the general community. Even amongst 'people affected' by a range of cancer types, and in whom 'sun protection' messages might have been provided during cancer treatment, there is limited awareness.

Cancer Voices SA conducted a short online survey and received 70 responses during one week in April 2014. See Attachment 1 for the questions, and Attachement 2 for full results summary.

We found that 59% of respondents describes themselves as spending a lot of time outdoors and 84% said they usually took precautions against sun exposure when going outdoors. 61% were males. 16% were less than 40yrs of age, 58% were aged 40-59yrs, 17% 60-69yrs. 68% had experience of cancer requiring chemotherapy &/or radiotherapy treatment, either themselves or someone close to them:

- although 68/70 (97%) of respondents recognized melanoma as a skin cancer, only 54% were also aware of squamous and basal cell skin cancer types.
- 66% said they would make an appointment to visit their GP if worried about a skin mark, but 21% would wait and ask the GP during an appointment for another health concern.
- Comments about seeking medical advice about skin marks indicated
  - a number made annual appointments to Skin Cancer Clinics (although feedback from many community members suggest they weren't sure what Skin Cancer Clinics were or the qualifications of their staff. More awareness is needed of this resource.)
  - access to GPs can be difficult and expensive, particularly in rural areas, discouraging people from presenting for skin checks
  - several instances of misdiagnosis were cited, with GPs being relaxed about something that turned out to be serious. The need for 'self responsibility' & persistence was reiterated, in regard to presenting for skin checks. People are puzzled that no skin cancer screening check is offered, or discussion of this issue is heard.
  - Confusing messages about exposure for adequate Vit D and being SunSmart were mentioned in the survey and by community members
- Additional comments covered a range of issues
  - Skin checks need to be more affordable and available, to help identify problems earlier
  - Suggesting 'shopping centre' skin check campaigns
  - Suggesting an imaging system for initial screening. 'People might be more inclined to interact with a machine for the initial diagnosis'.
  - Bad experience using Efudix (topical flurouracil) on the face, due to poor instructions provided
  - Urging ongoing TV commercials warning against over-exposure to the sun to make younger people aware of the danger of long exposure to the sun
- In a series of 5 True/False/ Don't know questions about skin cancer all statements were in fact 'True', 12 of 70 respondents got all correct.

- O 77% thought skin cancers are mostly (95-99%) caused by sun exposure
- O 97% thought Australia has one of the highest rates of skin cancer in the world
- O 62% thought two out of three Australians will be diagnosed with skin cancer by the age of 70yrs. 31% answered 'don't know'.
- 26% thought Skin cancer accounted for almost 80% of all new cancers diagnosed. 54% answered 'don't know'.
- 40% thought that Almost 2,000 Australians die of skin cancer each year.
  51% answered 'don't know'.

While this is a self-selected community sample of respondents, a number of issues and concerns were raised which we trust can contribute to the Senate Inquiry's deliberations.

Cancer Voices SA supports the submissions to the Inquiry from Cancer Voices Australia and Melanoma Patients Australia.

Cancer Voices SA is an independent, not-for-profit, 100% volunteer organisation, formed in 2007. We are 'raising a voice for those affected by cancer' through advocacy, involvement, awareness and information. We cover all types and stage of cancers across all ages, social circumstances, gender and locality. Our focus is on wellness and not just illness.

Membership is free and open to all South Australians eg cancer patients, their partner, carers, family, friends, neighbours, colleagues and supporters because 'Cancer doesn't affect one person, it affects the entire community around them'. Having cancer is not a prerequisite for membership.

The Cancer Voices SA membership continues to grow and has now reached about 800. The organisation is led by a 10 member Executive Team.

We aim to be representative, responsive and respectful of the diversity of our grassroots members background and experiences, and we try hard to hear those views. We have regular engagement and interaction via our websites (<a href="www.cancervoicessa.org.au">www.cancervoicessa.org.au</a> and <a href="www.cvsacyclingteam.org.au">www.cvsacyclingteam.org.au</a> ), events, social media (Twitter <a href="@cvsAinfo">@cvsAinfo</a>, <a href="FaceBook">FaceBook</a> — <a href="CancervoicesSA">CancervoicesSA</a>, <a href="YouTube">YouTube</a>), and physical activity initiatives.

Yours sincerely

Julie Marker

Acting Chair, Cancer Voices SA

Raising a voice for people affected by cancer.

www.cancervoicessa.org.au

27 April 2014

Attachment 1 – Cancer Voices SA online Skin Cancer Survey questions

Attachment 2 – Skin Cancer Survey results, summary from 70 respondents.

## **Skin Cancer Survey - Cancer Voices**

Page One
1. Have you ever been told you had a skin cancer?
© Yes
O No
O Other
2. Do you recognise any of the following as types of skin cancer?: (tick all that apply) *
□ melanoma
□ basal cell carcinoma
squamous cell carcinoma
non-melanoma skin cancer
3. If you were worried that a skin mark could be a skin cancer, please select which of the following actions you'd most likely take.*
make an appointment to visit your GP
wait and ask the GP during an appointment for another health concern
© go along for a GP appointment only if family or friends pressured you to
mention it only if the GP noticed or asked about any worrying skin marks
O Other

4. Any comments you'd like to make about seeking medical advice on skin marks?
5. Do you usually take precautions against sun exposure when you go outdoors?
© Yes
© No
Not sure
6. Would you describe yourself as someone who spends a lot of time outdoors? *
O Yes
C No
C Not sure
7. Do you think the following statements are True or False? 95-99% of skin cancers are caused by exposure to the sun?
C True
© False
C Don't know

8. Australia has one of the highest rates of skin cancer in the world.
O True
© False
C Don't know
9. Two out of three Australians will be diagnosed with skin cancer by the age of 70 years.
C True
C False
C Don't know
10. Skin cancer account for almost 80% of all new cancers diagnosed.*
C True
C False
C Don't know
11. Almost 2,000 Australians die of skin cancer each year (compared to 3,000 breast cancer deaths, 4,000 bowel cancer deaths, 8500 lung cancer deaths) *
C True
© False
C Don't know

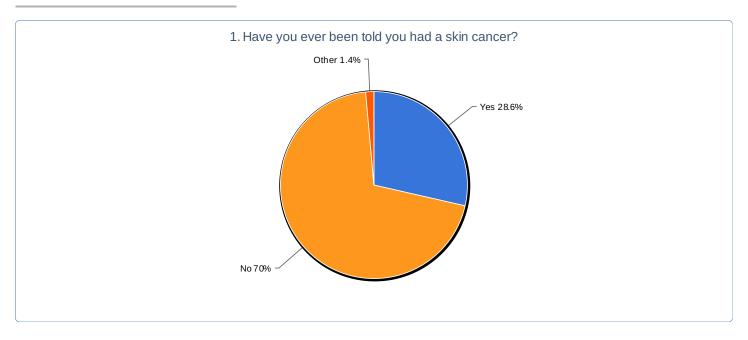
12. A couple of demographic questions follow: Your age (in years)
O 0-19 years
© 20-29 years
© 30-39 years
O 40-49 years
© 50-59 years
© 60-69 years
O 70-79 years
© 80+ years
13. Your gender is
• Male
© Female
14. Please answer the following questions (Q14-17) if you or someone close to you has undergone cancer treatment with chemotherapy and/or radiotherapy. What type(s) of cancer did you/ they have?

15. Were you/ they advised to take extra skin cancer precautions during this cancer treatment period?
O Yes
C No
O Don't know
O Other
16. Did you/ they take precautions to be 'sun-smart' during cancer treatment?
O Yes
O No
O Don't know
Other Other
17. Do you understand why this would have been recommended?
O Yes
© No
C Other

18. Any final comments you would like to make about skin enhance early diagnosis, effective strategies for prevention the community and among healthcare professionals, or opposed best practice treatment and management?	n, the need to increase awareness in
based best practice treatment and management:	



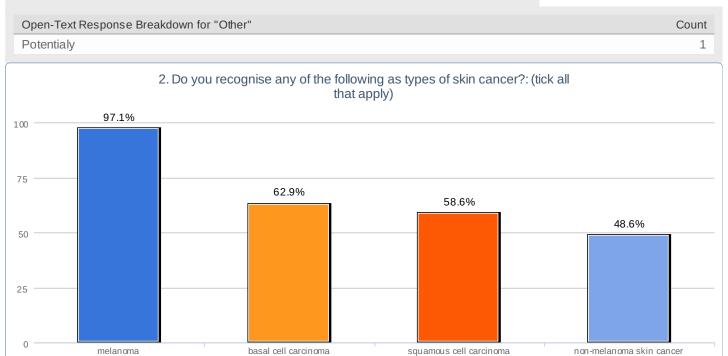
## Summary Report - Apr 13, 2014 Survey: Skin Cancer Survey - Cancer Voices



### 1. Have you ever been told you had a skin cancer?

Value	Count	Percent %
Yes	20	28.6%
No	49	70.0%
Other	1	1.4%

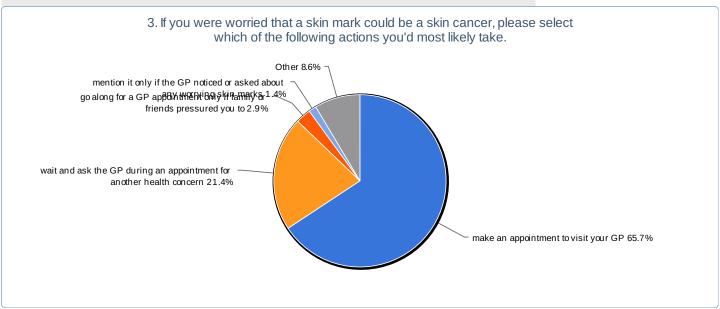
Statistics	
Total Responses	70



### 2. Do you recognise any of the following as types of skin cancer?: (tick all that apply)

Value	Count	Percent %
melanoma	68	97.1%
basal cell carcinoma	44	62.9%
squamous cell carcinoma	41	58.6%
non-melanoma skin cancer	34	48.6%





# 3. If you were worried that a skin mark could be a skin cancer, please select which of the following actions you'd most likely take.

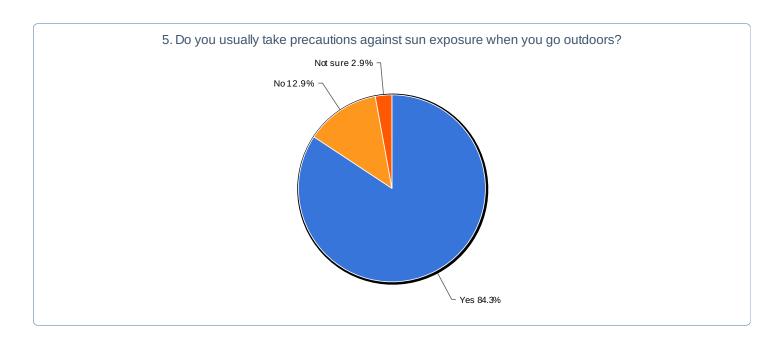
Value	Count	Percent %
make an appointment to visit your GP	46	65.7%
wait and ask the GP during an appointment for another health concern	15	21.4%
go along for a GP appointment only if family or friends pressured you to	2	2.9%
mention it only if the GP noticed or asked about any worrying skin marks	1	1.4%
Other	6	8.6%

Statistics	
Total Responses	70

Open-Text Response Breakdown for "Other"	Count
Annual skin cancer check through workplace health programme	1
Vist skin cancer screening specialist	1
ask family member	1
point out to my dermatologist on my next visit	1
see dermatologist	1
see dermatologist previously referred by GP	1

## 4. Any comments you'd like to make about seeking medical advice on skin marks?

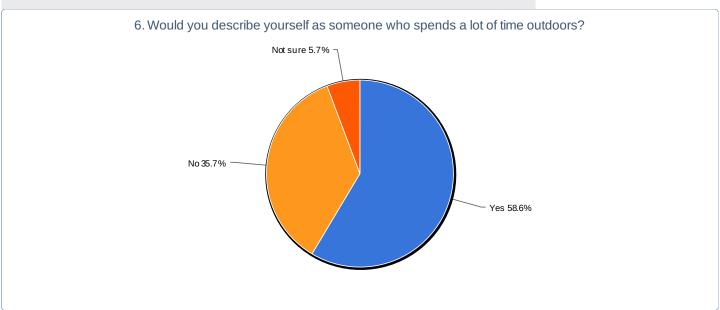
Count	Response
1	Dont waste any time
1	Have gone to a skin cancer clinic to be checked out
1	Have had a full bidy check for skin cancer with my GP
1	Have periodic body checks for skin cancer at a skin cancer clinic (at least yearly)
1	I see a skin specialist on a regular basis and mention any new or usual skin marks.
1	I would visit a GP as a matter of course.
1	Id like to have much less expense and greater availability of dermatology
1	Medical advice is not including the beneficial role f fresh vegetable diet
1	No
1	Nope
1	They have been reassuring. Even the first one when it turned out to be basal cell carcinoma.
1	If you're worried be persistent. Even the experts can't always determine a melanoma until a biopsy is performed. My recurrent melanoma was initially dismissed even though it was adjacent to the first surgery.
1	This is an absolute must. Don't put referral to a specialist off. If unhappy with one response, seek another. My misdiagnosed "cyst" was actually an aggressive SCC. Radiotherapy destroyed the cancer but my body's response to it has destroyed my life. I am in severe pain 24/7 and suffer many side effects. I am about to register my 500th medical appointment in 8 years. I was rarely outside as a teenager yet I regulalry have to have BCCs and SCCs removed in day surgery. JUST DO IT!
1	I have been seeing a dermatologist regularly since returning from living in Papua New Guinea in 1974, and have an ongoing referral from my GP
1	Cancer council do a lot of promotion about the types of established cancers, but it appears that little is offered towards education on prevention, identification or treatment of BCC, SCC and Melanoma. We have Pink ribbon, Yellow ribbon days etc, with a STRONG focus on cancers effecting women. Where is the green ribbon for Testcular or Brown ribbon for Bowel Cancers and equality in promoting cancer that effects men.
1	I'd look at the pictures of skin marks that you see as posters in GP clinics and online to give me some ideas.
1	My GP would never notice or ask about worrying skin marks. I have to ask for anything to be checked, otherwise it is not considered.
1	The cost of GP appointments makes it too expensive to check out every spot that I wonder about. The messages about Vit D and being SunSmart are confusing.
1	I have usually received good advice from GP. Had one spot I was concerned about. Biopsy was taken. Negative result
1	I am not certain that all GP's would know what to look out for and I thought skin had to be mapped for changes?
1	I have spoken to my Dr about a couple of spots, have to wait 3 months to see specialist. Meanwhile a spot on my nose has got worse and darkened. Feel concerned but feel like I have to wait.
1	Don't put it off, I did & it was melanoma. Fortunately my daughter made a Dr's appointment for me & pressured me to go. I was in denial.



### 5. Do you usually take precautions against sun exposure when you go outdoors?

Value	Count	Percent %
Yes	59	84.3%
No	9	12.9%
Not sure	2	2.9%

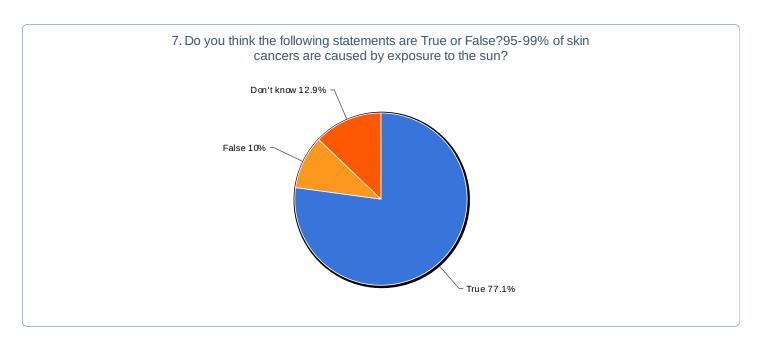




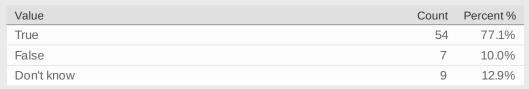
## 6. Would you describe yourself as someone who spends a lot of time outdoors?

Yes    41    58.6%      No    25    35.7%      Not sure    4    5.7%	Value	Count	Percent %
	Yes	41	58.6%
Not sure 4 5.7%	No	25	35.7%
	Not sure	4	5.7%

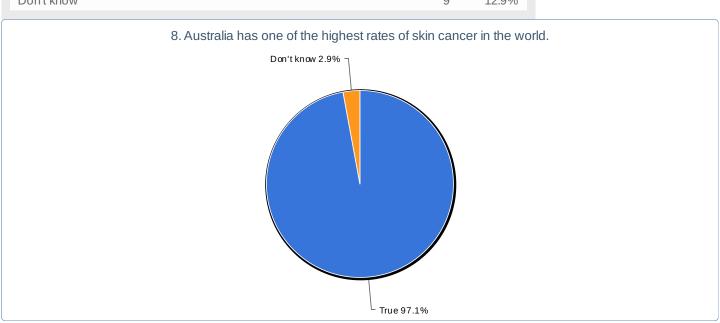
Total Responses	70



# 7. Do you think the following statements are True or False? 95-99% of skin cancers are caused by exposure to the sun?



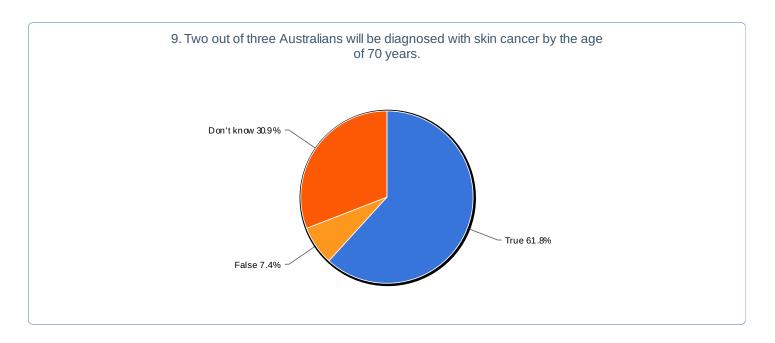




## 8. Australia has one of the highest rates of skin cancer in the world.

Value	Count	Percent %
True	67	97.1%
False	0	0.0%
Don't know	2	2.9%

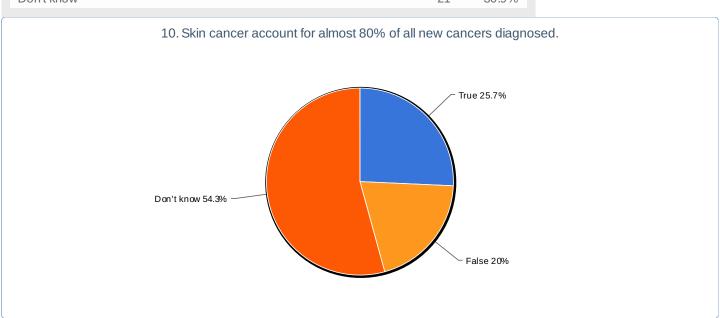
Statistics	
Total Responses	69



9. Two out of three Australians will be diagnosed with skin cancer by the age of 70 years.

Value	Count	Percent %
True	42	61.8%
False	5	7.4%
Don't know	21	30.9%

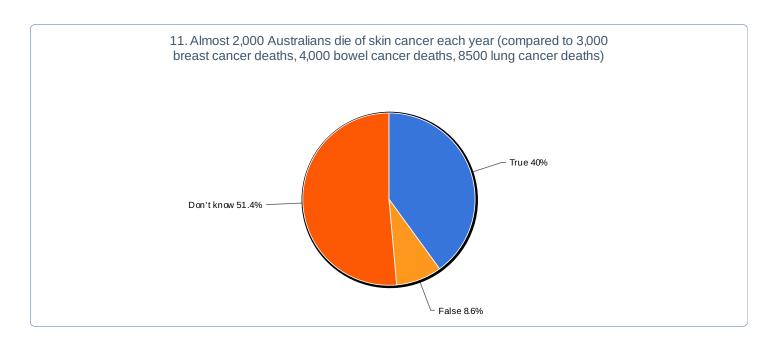
Statistics	
Total Responses	68



### 10. Skin cancer account for almost 80% of all new cancers diagnosed.

False 14 2	Value	Count	Percent %
	True	18	25.7%
Don't know 38 5	False	14	20.0%
	Don't know	38	54.3%

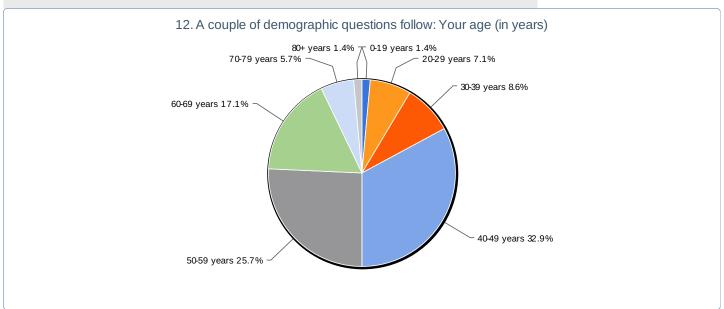
Statistics	
Total Responses	70



# 11. Almost 2,000 Australians die of skin cancer each year (compared to 3,000 breast cancer deaths, 4,000 bowel cancer deaths, 8500 lung cancer deaths)

Value	Count	Percent %
True	28	40.0%
False	6	8.6%
Don't know	36	51.4%

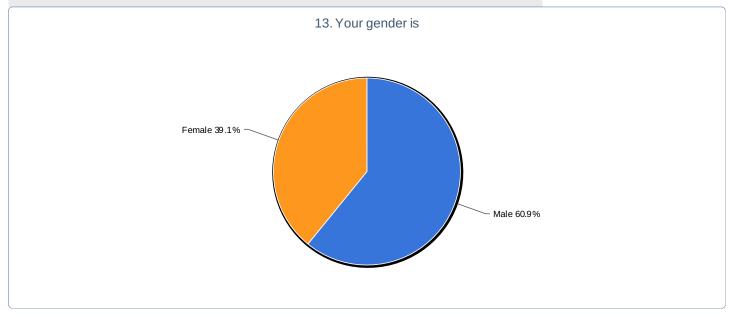




## 12. A couple of demographic questions follow: Your age (in years)

Value	Count	Percent %
0-19 years	1	1.4%
20-29 years	5	7.1%
30-39 years	6	8.6%
40-49 years	23	32.9%
50-59 years	18	25.7%
60-69 years	12	17.1%
70-79 years	4	5.7%
80+ years	1	1.4%

Statistics	
Total Responses	70
Sum	3,180.0
Avg.	46.1
StdDev	13.1
Max	0.08



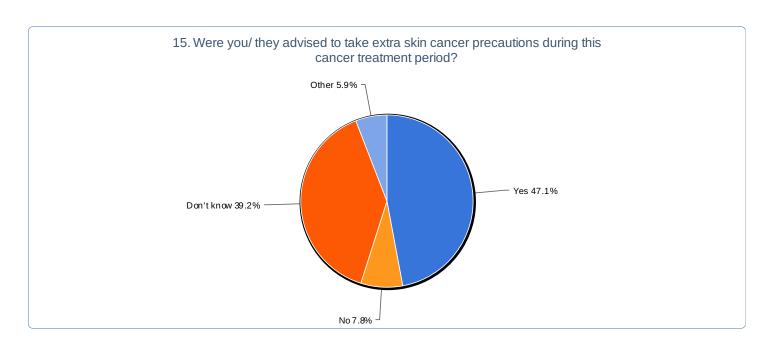
### 13. Your gender is

Value	Count	Percent %
Male	42	60.9%
Female	27	39.1%

Statistics	
Total Responses	69

14. Please answer the following questions (Q14-17) if you or someone close to you has undergone cancer treatment with chemotherapy and/or radiotherapy. What type(s) of cancer did you/ they have?

Count	Response
4	Bowel
1	Bowel and testicular
3	Bowel cancer
1	Bowel cancer, liver cancer, breast cancer
1	Bowel, Lung, Non-Hodgskins, Brain, Prostate
1	Brain Tumour, breast cancer, bowel cancer
1	Brain tumor
1	Breast cancer
1	Dad/Bowel/Chemo/Radio
1	Head and Neck
1	I have Cronic lymphatic leukaemia
1	Inner ear
1	Lung Cancer
1	Lung Cancer, Breast Cancer, Non-Hodgkins Lymphoma
1	Lung cacer
1	Lymphoma
1	Non Hodgkins Lymphoma
1	Non hodgkins lymphoma
1	Ovarian Cancer
1	Overian
1	PROSTATE
1	Peritoneal
1	Prostate
2	SCC
1	Small cell Lung cancer
1	Throat
1	Type 3 meningioma
1	bone cancer
1	bowel
1	brain primary
1	breast
1	breast cancer
1	chemo
1	leukemia
1	nasal pharangial
2	nodular melanoma
1	oral cancer
1	prostate
1	squamous cell carcinoma
1	my father just died from mesothelioma? lung cancer due to asbestos exposure in navy service duting the 60's
1	Father, Multiple Skin Cancers - Removed and OK. Aunty, Cancer of everything - Chemo, radio but passed away at 43

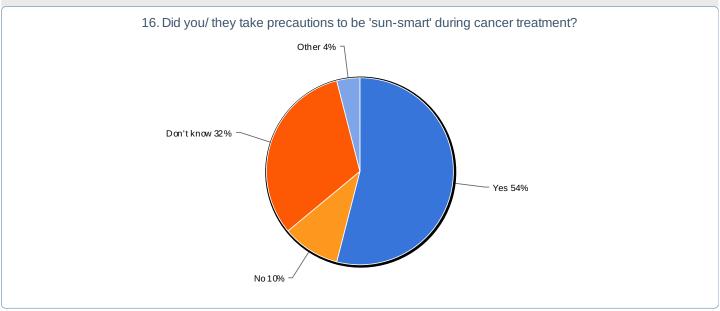


# 15. Were you! they advised to take extra skin cancer precautions during this cancer treatment period?

Value	Count	Percent %
Yes	24	47.1%
No	4	7.8%
Don't know	20	39.2%
Other	3	5.9%

Statistics	
Total Responses	51

Open-Text Response Breakdown for "Other"	Count
Because of my lengthy experience with skin cancers it was just expected that I would.	1
Yes, but screening specialist advised I inherited my Mums mediterranean skin and risk very low	1
yes and for the rest of my life	1

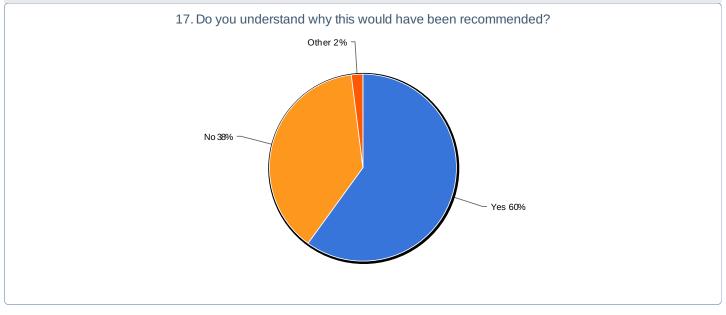


## 16. Did you! they take precautions to be 'sun-smart' during cancer treatment?

Value	Count	Percent %
Yes	27	54.0%
No	5	10.0%
Don't know	16	32.0%
Other	2	4.0%
Open-Text Response Breakdown for "Other"		

Statistics	
Total Responses	50

Open-Text Response Breakdown for "Other"	Count
NA	1
Yes, but the damage had already been done and because of my treatment more was about to be done.	1



### 17. Do you understand why this would have been recommended?

Value	Count	Percent %
Yes	30	60.0%
No	19	38.0%
Other	1	2.0%

Statistics	
Total Responses	50

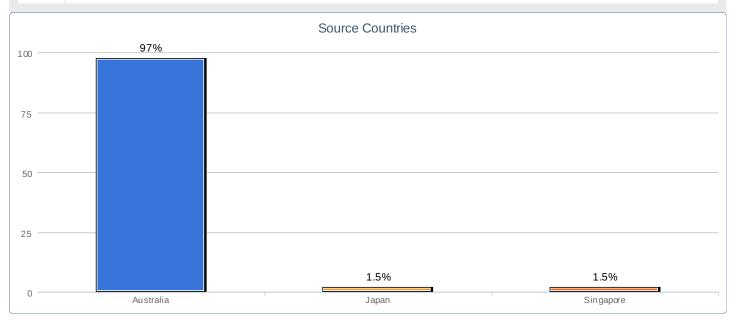
Open-Text Response Breakdown for "Other"	Count
I don't know the exact science but I'm aware that your body's ability to combat skin cancer.	1

18. Any final comments you would like to make about skin cancer? eg in terms of strategies to enhance early diagnosis, effective strategies for prevention, the need to increase awareness in the community and among healthcare professionals, or options to increase uptake of evidence-based best practice treatment and management?

Count	Response
1	A diet of fresh vegetables is protective against cancer.
1	GPs lack of awareness on this different type of melanoma
1	I have had surgery for BCC, SCQ and pre melanoma lesion.
1	I've had a couple of suspicious lesions removed - all good though!
1	Slip slop slap
1	There is no substitute for attention by a qualified dematologist
1	Wish I hadn't had so much sun exposure in my younger years
1	skin cancer clinic was good didn't feel like I was wasting the doctors time with one small lump
1	thanks
1	too often hear of cancers being missed, ignored or misdiagnosed by doctors.
1	Maybe a free quick check at Big shopping centres like Westfield.Somewhere you don't have to book. You could just stop when you saw it if you had time. People are so time poor these days.
1	I am concerned about the conflicting information around Vit D deficiencies and being sun smart - I grew up with 'slip slop slap' - but should we still be doing this? I am confused?
1	There needs to be greater awareness of treatment and what it can lead to. For example there should be increased awareness of how to use Efudix (active ingredient - fluoracil). Used inappropriately it can make a mess of your face. Recent experience confirms this. I accidently smeared the Efudix across my face while sleeping. I know of someone else who covered his whole face (the result of poor instruction). Get your partner to help keep a track of suspicious skin marks and be safe not sorry. Refer to a doctor asap.
1	Any doubtscheck it out. Don't delay another day. If you don't look after yourself first how will you look after your family.
1	The GP did not think it was a skin cancer as it didn't fit the typical melanoma signs. My husband only got it checked as I had made him an appointment as he'd had it for about 6 months or so. Luckily it was removed just in time. I believe that there is not enough knowledge of skin cancers. Awareness is there but understanding is lacking in the community. Skin checks need to be made more affordable and available, helping to identify any problems earlier.
1	The ongoing tv commercials warning against over-exposure to the sun is essential to make younger people aware of the danger of long exposure to the sun.
1	i had cancer of the womb but i didnt need chemoor radiotherpy. the rah womans hearth service doctors were able to get it all out with surgery
1	I've heard that rural people often have so much trouble getting an appointment to see a GP that 'early diagnosis' is hampered. Melanoma is feared and thought as 'life threatening', but other types of skin cancer are often treated with a much more cavalier attitude. Even though I'm a cancer survivor, I don't feel I know enough about skin cancer and whether cancer survivors are at increased risk.
1	More info required. More specialists available for screening or advertised if there are more than public aware of.
1	More awareness needed about the Skin cancer clinics that are around, like the Ibis Clinic that I attend in Adelaide. Most people don't know they exist
1	The public is getting tired of the long winded messages from Cancer Council. The original add was fine. How can one really be active in Australia's climate if one has to seek shade? We are not living in England!
1	If we are serious about skin cancer and need to notice change, then I believe a medical specialist needs to record and review changes! I can't see whats on my neck, shoulders or back!
1	There should be an 24/7 expert system that diagnoses people based on imaging and visual cues and refers them to a specialist. People might be more inclined to interact with a machine for the initial diagnosis.
1	Unless a specific screening program is introduced as for breast and bowel cancer, skin cancer will always be at risk of flying under the radar. Any GP i have seen has never suggested having skin cancer checks and from my experience despite asking about individual spots and having a few spots frozen and one biopsy done (which was negative) the GP has never done a full body check or suggested I have one. They are always running late and do not want to take the extra time to do a thorough examination. I booked in for a full check up 2 years ago and just came out with a pathology form for some blood tests. Paying gaps for every individual request to have something checked and time off work to get

into appointments is becoming increasingly difficult as GP's are always booked weeks in advance, so it all becomes to hard and to expensive when they do not actually suggest that a skin check is required.

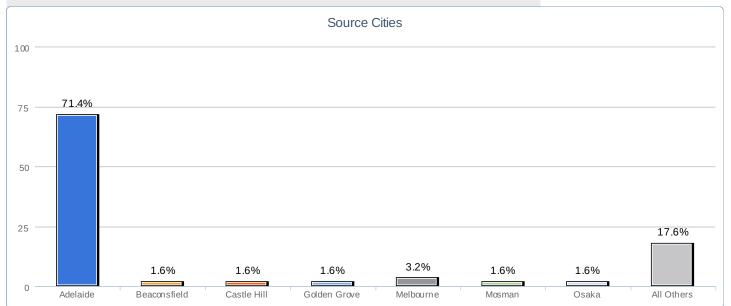
I have had 5 operations for skin cancer the last one took 5 hours under a local anesthetic i was opened up from the bottom eye lid down the nose to the top lip on my mouth "so scarey listening to all the conversations the doctors were having...



#### **Source Countries**

Value	Count	Percent %
Australia	65	97.0%
Japan	1	1.5%
Singapore	1	1.5%





### **Source Cities**

Value	Count	Percent %
Adelaide	45	71.4%
Beaconsfield	1	1.6%
Castle Hill	1	1.6%
Golden Grove	1	1.6%
Melbourne	2	3.2%
Mosman	1	1.6%
Osaka	1	1.6%
Perth	2	3.2%
Plympton	1	1.6%
Prospect	1	1.6%
Seacliff	1	1.6%
Singapore	1	1.6%
Smithfield	1	1.6%
South Morang	1	1.6%
Sydney	2	3.2%
Unley	1	1.6%

Statistics	
Total Responses	63