

Newsletter Issue 12, November 2020

10 Year Celebration For Melanoma Research Victoria

MRV is celebrating its 10th year as a research collaboration resource.

A collaboration of Victoria's leading melanoma clinician-researchers and a proactive melanoma survivor started Melanoma Research Victoria in 2010. The Victorian Cancer Agency funded the project, which setup a multisite recruitment program and the MRV consumer reference group (CRG), to facilitate more melanoma research for all Victorian melanoma patients.

MRV initially focused on early stage melanoma lesions and almost every MRV participant's primary melanoma was screened for BRAF, NRAS, CKIT and some novel mutations. Tissue samples became more readily available after the CRG's advocacy forum, aptly named 'Tissue is the Issue'. The use of the tissue samples in molecular pathology studies led to several publications on targeted mutations and assisted Victorian patients gain access to new therapies earlier.

In 2014 MRV changed direction to align with the advancement of the exciting new Immunotherapies. It recruited later stage patients for whom the drugs were more relevant and looked to understand more about their action by comparing tissue samples from the same participant and between similar participants.

Technologies also advanced and the circulating tumor DNA or 'liquid biopsy' idea was floated by MRV participants, adopted by our researchers and announced as a success by the Health

Minister, Jill Hennessy, in 2016. Validation

studies are ongoing with some

encouraging results being presented at international conferences in 2019.

Quality of Life (QOL) questionnaires and a Medicare/Prescription Benefit Scheme (PBS) consent were added to the MRV participant recruitment packs in late 2014. The former, often considered burdensome to participants, is actually very valuable for well-being, survivorship and health economic studies. MRV hopes to convert the QOL questionnaire to an email survey in the near future. The Medicare/PBS consent is of great interest to MRV researchers modelling Victoria's melanoma health decisions and outcomes.

The MRV Governance Committee has approved 66 collaborative research projects in multiple disciplines over the past 10 years. One of the most significant approvals was the decision to provide de-identified MRV patient information to the international review of the AJCC staging system. MRV participants should be pleased to know that their contribution has improved the way melanoma patients are staged across the world.

Consumer engagement in MRV has continued to evolve over the last 10 years. The CRG are now having zoom meetings with individual researchers to discuss project proposals. Many have attended the McArthur/Sheppard laboratory meetings. In line with the new funding requirements the CRG has expanded its capacity to review research project/protocols by creating a new subcommittee, known as the Project Reviewer Group (PRG), who are very keen to help melanoma researchers.

Happy 10th Anniversary to all, and a special thank you to our participants.

INVITATION 2020 Scientific Exchange Meeting

Our 2020 meeting is a Webinar and although we will miss seeing everyone in person this is a great opportunity for our rural members to join in.

We have some excellent speakers: Grant McArthur – MRV Update

Alex Chamberlain – Impact of Covid-19 and the future of teledermatology

Alison Button-Sloan – Patient experiences of Telehealth

David Gyorki – Neo-adjuvant Therapy

Mark Shackleton - the Morgan Mansell: Young Victorian Melanoma Researcher of the Year award.

When:

Thursday 26th November 2020

Time:

6:00-8:30pm

Where:

Zoom Webinar

Please register via the link below:

https://unimelb.zoom.us/webinar/re gister/WN Ztblh9u1QhyOqlOGDNq1 WQ

After registering, you will receive a confirmation email containing information about joining the webinar.

This is a free event.

MRV Database A treasure trove of data

Ten years of melanoma health data is a fantastic resource for MRV researchers to investigate. Here we showcase some alternative data queries, which might inspire some new projects, but also interest our MRV participants.

Australia is divided into 5 classes of remoteness¹. These classes relate to the road distance from where you live to the nearest urban centre or locality. As expected the majority of MRV participants come from metropolitan Melbourne. The next

Row Labels	# MRV patients	%
Inner Regional Australia	823	27%
Major Cities of Australia	1933	64%
Outer Regional and Remote Australia	275	9%
Grand Total	3031	100%

Table 1: Summary of MRV participants by remoteness

highest group are from Inner Regional Australia which includes cities such as Bendigo and Ballarat. The Regional and Remote participants are of particular interest to a MASC² study known as 'Improving Melanoma and Skin Cancer awareness in Regional and Rural Australia'. If you have time to help with the online survey it would be much appreciated.

The link to the online patient survey is:

https://www.surveymonkey.com/r/CR

JWDF7

Interestingly the percentage of rural and metro participants in MRV has changed little since the original postcode analysis in 2014 where there were 70% metro and 30% rural MRV participants.

In Table 2 the Socio-Economic Index for Australia (SEIFA)³: Victorian code, was applied to the Victorian MRV participant postcodes of the MRV cohort.

	SEIFA Description	# MRV patients	%
1	Least Disadvantaged	610	21%
2		522	18%
3		593	21%
4		597	21%
5	Most Disadvantaged	549	19%
		2871	100 %

Table 2: SEIFA analysis of MRV participant postcodes.

170 participants were excluded as they reside outside of Victoria. The remaining 2871 participants were very evenly spread across the five socio- economic categories. These results indicate that there is no bias at the academic centres of excellence, better known as your melanoma treatment hospitals, and no discrimination by MRV recruitment staff or from the disease itself, within the MRV cohort.

Another area of interest to MRV researchers is patients that have a

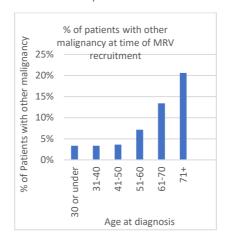


Figure 1: Percentage of patients with another malignancy (cancer) at the time of recruitment to MRV

second cancer around the time of their melanoma diagnosis. As shown in Figure 1 the possibility of developing multiple cancers increases as we age. 20% of patients over the age of 71 may present with two cancers.

Large cohorts of participants make it possible for researchers to investigate these and other observations. So again, thank you to all of the MRV participants for contributing to melanoma research. Your generousity makes so much more possible.

1. Australian Bureau of Statistics, Remoteness Structure

https://www.abs.gov.au/websitedbs/d3310 114.nsf/home/remoteness+structure

2. MASC

https://www.masc.org.au/content.aspx?pa ge=about

3. SEIFA

https://www.abs.gov.au/AUSSTATS/abs@.n sf/DetailsPage/2033.0.55.0012016?OpenDo cument

Acknowledgement: Thank you to Karen Winch for the data analyses and graphs

Reminder

All melanoma services are operating as normal. Please don't delay your skin checks or follow up appointments.

Virtual Meetings

have kept melanoma research going during Covid-19. Looking forward to sharing some of our insights with you at the virtual 2020 Scientific Exchange meeting on the 26th November.





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