

Message to Members

Our first newsletter for 2020 certainly finds us in unprecedented times. On the back of dealing with the aftermath of a series of catastrophic natural disasters over many months and the knock on effects including loss of life, livelihoods and homes, we now find ourselves in the midst of the global COVID-19 pandemic and trying to navigate its impact including all the uncertainties and challenges.

We are awash with information. It is important to take messaging from the official health and government authorities and agencies. These include both the Australian and NSW Government websites which are updated daily. We have provided some links on Page 2.

Despite these circumstances along with the many unknowns, we are doing our best to continue our work in the interests of those affected by cancer albeit in a different manner. Safety and wellbeing are paramount. We are utilizing technology to stay in touch and to continue to address the many issues that are on our agenda. Understandably, decision makers will be consumed by COVID-19 for the foreseeable future and many events are being postponed and/or cancelled (some are trying to go virtual). The recent Survivorship Conference is probably the last conference that we will attend for this year. A full report is on Page 6.

As advised in our previous newsletter, 2020 is a special and significant milestone in the history of Cancer Voices – 20 years / two decades of providing the voice of those affected by cancer. This however, will now take a back seat in light of the current circumstances. We will have opportunities to recognise and celebrate this milestone at another time. We have produced a new poster to celebrate 15 years of our CIR program. A link can be found on Page 7.

We continue to be engaged across a range of issues, many at a national level, details of which appear in this newsletter.

A significant amount of work is currently being done on the development or revision of national strategies, policies and documents that, while covering the wider health spectrum, are relevant to those affected by cancer including: *the National Preventive Health Strategy development; the National Medicines Policy review and the National Health Information Strategy.*

Cancer Voices Australia (CVA) has recently endorsed the Standard for Informed Financial Consent developed by Cancer Council Australia, BCNA, PCFA and Canteen. CVA has also been involved in stakeholder consultation with the Department of Health regarding the federal government initiative to include radiation therapy services in 13 regional and rural cancer centres. Further details on P16.

We have introduced a new Special Report feature which will comprise a series of reports about a wide range of 'other people' involved in helping cancer survivors live well during and after treatment. This first special report is about *Return to Work* for cancer survivors and the important role an occupational therapist can play in this.

Cancer Council has provided details of a range of recently updated and new information resources, those details and links are on Page 8.

We wish you all the best over the coming months. We hope that you, your families and loved ones are safe during this unprecedented coronavirus situation. During these uncertain times look out for those more vulnerable members of the community, and be kind to and patient with others.

We can't forget those on the frontline who are caring for our community in these difficult times. To you all, our sincere thanks. Please do take care and stay safe.

**Elisabeth Kochman (Chair) and
the Cancer Voices Executive Team**

COVID-19 and the cancer community

We would like to hear how COVID-19 is affecting the cancer community - cancer patients, carers and family, and if it has created issues regarding access to medical services. Please contact us at info@cancervoices.org.au

IMPORTANT INFORMATION ON COVID-19 FROM THE DEPARTMENT OF HEALTH

To ensure you have the most up-to-date information, the Department of Health is providing daily updates via their website at www.health.gov.au

Coronavirus (COVID-19) health alert

<https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>

Coronavirus (COVID-19) – frequently asked questions (FAQs)

<https://www.health.gov.au/resources/publications/coronavirus-covid-19-frequently-asked-questions>

Launch of the coronavirus (COVID-19) campaign

The Australian Government has launched a [national communications information campaign](#) to inform all Australians about the coronavirus (COVID-19)

Coronavirus (COVID-19) resources

<https://www.health.gov.au/resources/collections/novel-coronavirus-2019-ncov-resources?fbclid=IwAR1xGyQwOxtwXoEI4xPY-6DnfeZvtITnvcTUN1XenM7xxBJJQyW3b8kzoZ8>

Coronavirus (COVID-19) – identifying the symptoms (symptoms poster)

https://www.health.gov.au/resources/publications/coronavirus-covid-19-identifying-the-symptoms?fbclid=IwAR0yqQPuElwDcYfJah70QjQvk64YuYGdk4jbOI_6xiNGQX-u26-gi5rNfD4

From

Cancer Australia
the lead national cancer control agency

COVID-19 - new website hub

Cancer Australia has launched a [dedicated hub](#) providing coronavirus (COVID-19) information for people affected by cancer, health professionals and researchers.

It is a repository of up-to-date, evidence-based resources and guidance from some of the most trusted sources in Australia and around the world.

NSW Government – Official information

COVID-19 (Coronavirus)

<https://www.health.nsw.gov.au/Infectious/diseases/Pages/coronavirus.aspx>

COVID 19 – Clinical Trial guidance

<https://www.medicalresearch.nsw.gov.au/covid-19-clinical-trial-guidance/>

Phone Services

National Coronavirus Health

Information Line [1800 020 080](tel:1800020080)

General Advice [1800 022 222](tel:1800022222)

Interpreter Service [131 450](tel:131450)

Important message from Cancer Council Australia website Cancer and COVID-19

Cancer Council understands that Australians undergoing cancer treatment, cancer survivors and their families and friends may have questions in relation to the recent outbreak of COVID-19.

To learn more go to <https://www.cancer.org.au/cancer-and-covid-19.html>

Knowledge of coronavirus and the associated illness, covid-19, is changing rapidly as are the public health messages that keep you safe. Keep checking the government website for updated information.

From the Cancer Council Online Community

To support those who have questions or concerns about COVID-19, [we've created a forum](#) specifically for discussions around this topic. Visit now: <http://cancercouncil.com.au/OC>

We invite you to sign up and get chatting. If you need any assistance, please contact our Online Community team [via email](#).

Cancer Council Helpline

Talk to a qualified health professional

Call 13 11 20
Monday to Friday 9am – 5pm



CVN Notice Board

CALL FOR EXPRESSIONS OF INTEREST

Gastro-Intestinal Cancer Research Consumer Advisory Panel

The Australasian Gastro-Intestinal Trials Group (AGITG) / Gastrointestinal (GI) Institute has called for EOI from people affected by gastro-intestinal cancer (survivors /patients /carers /family) to join the Consumer Advisory Panel (CAP).

Further information at: <https://gicancer.org.au/news/consumer-advisory-panel-call-for-expressions-of-interest/>

Consumers in Research Annual Workshop

When: September 2020 – Date TBC

Where: Cancer Council NSW, Woolloomooloo

Duration: Half day

This interactive workshop complements the online training modules and gives participants an opportunity to hear from experienced consumers and researchers. At the end of the course, participants will be ready to work with researchers as community advisors.

Further information <https://www.cancer.org.au/about-us/consumertraining.html>

Consumer Review Panel training (held every two years)

When: September 2020 – Date TBC

Where: Cancer Council NSW, Woolloomooloo

Duration: Half day

This training course is for people who would like to help Cancer Council NSW make research funding decisions. You will need to complete the Consumers in Research training (see above) before attending and have had experience as a consumer involved in research. At the end of the training, participants will be skilled in reviewing research grant applications from a community perspective.

Further information:
<https://www.cancercouncil.com.au/research/community-involvement-research/>

PLEASE NOTE THAT DUE TO THE COVID-19 SITUATION EVENTS MAY BE POSTPONED AND OR CANCELLED

Head & Neck Cancer

Patient, Family & Team Forum 2020

Living Well Before, During & After Treatment

Date: Friday 16 October 2020

Time: 8.30am to 3.30pm

Venue: Garvan Institute of Medical Research

Registration: \$25

Free to patients, family & volunteers

Enquiries to MC & Forum Co-ordinator

juliemccrossin@bigpond.com

Full program & registrations at

www.headneckcancerforum.com

All welcome

SAVE THESE DATES



Cancer Council webinar 21 May at 7pm - complementary

Life changes after cancer - When it all falls apart.

For further information and to register

<https://login.redbackconferencing.com.au/landers/page/b17406>

This one hour discussion will be facilitated by **Katie Towers**, Survivorship Lead - Cancer Council NSW.

Please note that we have been advised that this is a tentative date which may be changed due to the current Covid-19 situation.



CVN Committee News

The CVN Executive Committee met on 28 January in the offices of Health Consumers NSW with some members via teleconference.

Cancer Voices NSW Annual General Meeting was held on 21 February in the Woolley / Lawson Rooms, Level 1, SMSA Building, 280 Pitt Street Sydney. Peter Crossing AM also joined us and fulfilled the role of Returning Officer. The CVN 2019 Annual Report was presented and is available on our website at <https://www.cancervoices.org.au/wp-content/uploads/2020/04/Annual-Report-Cancer-Voices-NSW-2019-Final.pdf>

2020 CVN Executive Committee (EC):

Chair: Elisabeth Kochman

Deputy Chairs: Shirley Baxter Murray McLachlan

Hon Sec Minutes: Murray McLachlan

Hon Treasurer: Sandra O'Sullivan

Committee Members: Bev Noble, Lee Hunt, Roberta Higginson, Jan Mumford, Sarah Lukeman, Kathryn Leaney, Lillian Leigh and Dan Kent

Advisor: David Campbell

The new CVN poster *Consumers shaping research – 'Nothing about us without us'* was on display for the first time at the AGM. It celebrates 15 years of our CIR program which is part of the twentieth anniversary of CVN. It was also on display as part of the poster presentation at the recent Survivorship Conference held in Melbourne. A detailed report of the conference by Shirley Baxter is on Page 6.

Following the AGM, Executive Committee members participated in a strategic planning workshop. Focus was on our Consumers Included logo and our Consumer Involvement in Research program. Once again, we were expertly facilitated by EC member Kathryn Leaney. We were fortunate to have marketing and communication consultant, Geoff Michels, present to guide and assist us with our discussions and directions relating to the use of our Consumers Included logo. We are grateful to Geoff for his time and expertise and thank him for his active participation.

The CVN EC meeting scheduled for 24 March was held by teleconference. A very full agenda was addressed.



Advocacy Updates

Lymphoedema Action Alliance (LAA) - plans for 2020

The first meeting of the LAA for 2020 was held on 24 March entirely via teleconference and Zoom, courtesy of Macquarie University Lymphoedema Clinic. The purpose was to provide an update of progress around Australia and within our various member organisations and to discuss the future directions of the LAA in light of current circumstances. Issues associated with garment schemes were also discussed.

Given the ever changing environment that we find ourselves in, government resources are now focused on the COVID-19 pandemic so much will be on hold. The next meeting has been scheduled for September.

Elisabeth Kochman

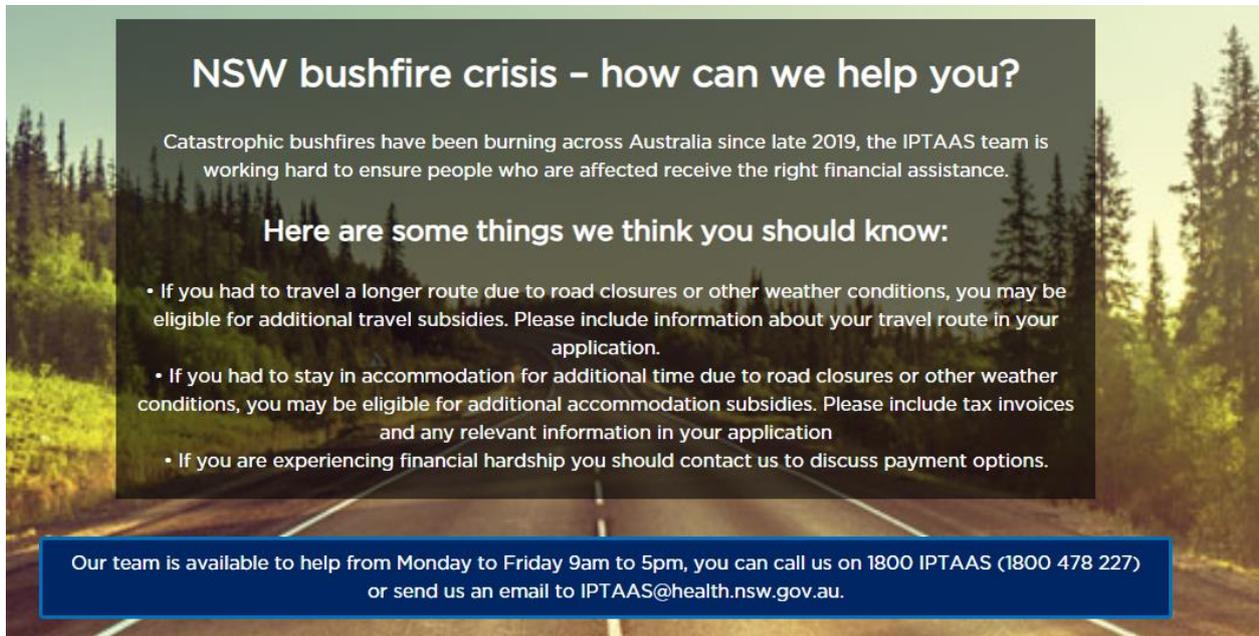
NSW Cancer Plan Governance Committee

As reported in our 2019 October newsletter, Cancer Institute NSW (CINSW) completed an interim evaluation of the current NSW Cancer Plan 2016-2020. One of the recommendations of that review was the setting up of a Governance Committee. This committee met for the first time on 4 March.

Members to date include representatives from the Ministry of Health, Cancer Institute NSW, metro and regional Local Health Districts and Primary Health Networks, NSW Health Multicultural Services, the Aboriginal Health and Medical Research Council, Cancer Council NSW and consumer representatives. Elisabeth Kochman was invited to join this committee along with Nyan Thit Tieu who founded Sisters' Cancer Support Group <https://www.scs.org.au/> in 2013, a community based NFP organisation that provides support for women from multicultural communities affected by cancer. **Update:** Work on the Plan has been postponed due to COVID-19.

Additional IPTAAS assistance as circulated in a CVN e-bulletin to members on 13 February 2020

Please circulate to your networks and or to anyone affected



NSW bushfire crisis – how can we help you?

Catastrophic bushfires have been burning across Australia since late 2019, the IPTAAS team is working hard to ensure people who are affected receive the right financial assistance.

Here are some things we think you should know:

- If you had to travel a longer route due to road closures or other weather conditions, you may be eligible for additional travel subsidies. Please include information about your travel route in your application.
- If you had to stay in accommodation for additional time due to road closures or other weather conditions, you may be eligible for additional accommodation subsidies. Please include tax invoices and any relevant information in your application
- If you are experiencing financial hardship you should contact us to discuss payment options.

Our team is available to help from Monday to Friday 9am to 5pm, you can call us on 1800 IPTAAS (1800 478 227) or send us an email to IPTAAS@health.nsw.gov.au.

Source: IPTAAS website <http://www.iptaas.health.nsw.gov.au/>

In response to numerous requests, Cancer Council NSW approached the Minister for Health asking the Government to relax the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) criteria for people in bushfire areas, to help ease the financial burden and emotional stress.

The Minister has announced additional travel and accommodation assistance for people in bushfire areas who must travel for treatment.

Health Minister Brad Hazzard said the criteria for IPTAAS will be broadened so patients impacted by bushfires can access the subsidy to help cover out-of-pocket costs.

To read the **full press release** go to https://www.health.nsw.gov.au/news/Pages/20200204_00.aspx

For more information regarding IPTAAS go to <http://www.iptaas.health.nsw.gov.au/>

Cancer Voices welcomes this initiative and hopes that it provides some much needed relief for those affected by cancer living in bush fire affected areas.

Further to this, Cancer Voices has written to both the federal Minister for Health, Greg Hunt, and the NSW Minister for Health, Brad Hazzard, to draw their attention to issues that must be addressed in relation to the health and cancer consequences of these unprecedented natural disasters. Further details, Page 14

COVID-19 and the cancer community

We would like to hear how COVID-19 is affecting the cancer community - cancer patients, carers and family, and if it has created issues regarding access to medical services.

Please contact us at info@cancervoices.org.au

Conference Report

3rd Victorian Cancer Survivorship Conference – 12-13 March 2020

A 2020 VISION: Building on learnings...partnering for success

On the cusp of tighter restrictions to public gatherings, Prof Michael Jefford, CEO of the Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre, welcomed all to the 3rd Victorian Cancer Survivorship Conference.

Technology came to the fore with dial in being made available for up to 90 registered participants who were unable to travel and several of the guest speakers 'Zooming' in to deliver their presentations with questions online via Slido.

As reflected in the title, the conference most definitely provided an interesting line up of invited international and local speakers as well as rapid fire and oral presentations and posters. Each topic building on research and enablers for survivorship care and programs in relation to many familiar areas. Areas of focus included Patient Reported Outcomes (PRO's), telehealth, shared care, financial burden, living with & beyond cancer, exercise, needs assessment tools and more.

Posters were proudly presented by both Cancer Voices NSW with [Consumers shaping research – 'Nothing about us without us'](#), celebrating 15 years of the Consumers Involvement in Research (CIR) Program, and Cancer Voices SA with their poster titled "*10 years of Advocacy – Building Partnerships and Learning from the Collective Experience*"

<http://www.cancervoicessa.org.au/assets/documents/posters/cvsa-10yrs-advocacy-2019.pdf>

Each of the posters were well received, generating a great deal of interest and discussion.

One standout consumer speaker was Viv Interrigi who gave a compelling story of the importance of community in Survivorship with "*2 years on My Cancer, My Community*".

Viv talked of feeling like a hamster on a wheel during her cancer treatment. Coming off that wheel post treatment to be told "you look great", albeit feeling emotionally and physically the

opposite and in the realisation that cancer had redefined her new normal.

Viv found that solace came in surrounding herself with people with passion in her new community. Drawing support from new friends in community in the new norm varied from the local pharmacy, to the key breast care nurse providing regular injections and so many more. All providing support and friendship, making Viv laugh again and to start the dance of life with no questions asked.

After leaving the medical system and going back into community Viv accepted there could be unexpected ups and downs and that cancer survivorship was not over for the rest of her life. Reaching out to her community in the transition from hospital and embracing the help and friendship in community was essential in the transition to primary care where ongoing support is needed.

The Peter MacCallum Cancer Centre in Victoria continue as leaders in Survivorship Care Plans and Programs to support people living with and beyond cancer year on year. Consumers are front of mind in all, including starting each Board Meeting at Peter Mac with a consumer story.

The robust ongoing government (and philanthropic) financial support in Victoria is a reminder of the need for consistency in government funding across States to ensure equity for all Australians irrespective of where we live.

This is essential to support over 1.1 million cancer survivors in Australia today with expectations that this may double over the next 20 years.

Building on learnings and partnering for success is key in minimising replication and costs of survivorship support solutions by each State.

Looking forward to the next Cancer Survivorship Conference on March 18-19 2021 in Adelaide to be hosted by The Clinical Oncology Society of Australia (COSA) and The Flinders Centre for Innovation in Cancer and even greater advancements in Cancer Survivorship support available to all.

Shirley Baxter – March 2020



Consumers Involved in Research (CIR)

Our Consumers Involvement in Research program continues to grow as a new group of recruits undertook the training program last September at the Cancer Council NSW. Twelve of these enthusiastic members have been added to our data base, which now sits at approximately 130. They bring a wealth of experience and expertise and will provide great insight as they contribute their perspective to research projects and cancer committees.

The training involves completion of the theory component online. The link to the online section of consumer training is available on the Cancer Council Australia website at <https://cancercouncil.litmos.com.au/online-courses/>

It comprises a series of four short online modules, designed to inform and prepare consumers to be involved in health and medical research. Trainees must complete the online modules prior to attending a half-day face to face workshop run by the Cancer Council NSW at their Woolloomooloo offices (for NSW-based consumers). The consumers meet researchers, workshop scenarios and are involved in discussions which prepare them for their contribution to cancer research. We ask that consumers from interstate who would like to be involved with the program to undertake the online modules and then contact us to be added to the CIR database.

Researchers have been sending requests for consumers as they prepare their projects for the 2020 funding cycle. I ask that you check your emails daily and respond to any emails from Cancer Voices as soon as possible, so that matching can be undertaken within a short time frame. Please notify us if your contact details have changed. Presently, for the 2020 funding cycle, there have been 25 requests for consumers to be involved with research projects and cancer committees, with 47 of our consumers undertaking this important role. Thank you to all our consumers for their willingness to undertake this vital role in cancer research.

At times Cancer Voices is asked to assist with recruiting participants for cancer research studies. We only assist once a study has ethics approval. Your support by participation ensures that the studies reflect the expertise and knowledge of those with a lived experience of cancer.
Lee Hunt

Impact of COVID-19 on research funding

The NHMRC, one of the main funding bodies of cancer research in Australia, has recently decided to curtail some of its funding streams, which is likely to have an effect on requests by researchers for consumers to contribute to their grant applications. More detail is available <https://www.nhmrc.gov.au/about-us/news-centre/update-changes-nhmrc-2020-funding-schemes>.

Cancer Voices will continue to monitor the impact of COVID-19 on the CIR Program.

Cancer Voices has produced a new poster to celebrate 15 years of our CIR program, 2005-2020. [Consumers shaping research – ‘Nothing about us without us’](#) an updated summary of its history, process and achievements

University of Sydney Pacer Network

The PACER Network is a joint initiative of The University of Sydney, and the Kids Research at The Children’s Hospital at Westmead, Westmead Hospital, and the Westmead Institute for Medical Research. The network was established in 2018. Its aim is to facilitate knowledge exchange, cross-disciplinary collaboration, and innovation in conducting and implementing patient-centred outcomes research and patient involvement in research’ – (<http://pacernetwork.org.au/about/>)

PACER run webinars and workshops around patient-centred research – see <http://pacernetwork.org.au/events/>

All webinars are recorded and can be accessed at <http://pacernetwork.org.au/webinars/>

In order to view the webinars you need to be a member of PACER. This can be easily done via the above link. Once you have registered as a member, you will be able to access the links to the webinars (scroll down the list) and download. The 10 March 2020 webinar “***Appreciating the patient journey when involving consumers in research***” is now available.

This may be of interest. From Pacer: Have your say on what outcomes are important for research in COVID-19 – a global initiative. Input sought from patients with confirmed/suspected COVID-19, family members, community members and health professionals [please complete the survey](#)

The Voices being heard

(Please note: many events are being cancelled and/or postponed due to current COVID-19 circumstances)

Meetings

- Prostate Cancer Foundation Australia (PCFA) Resources Update Expert Oversight Panel meeting, 21 January
- CCA, Rare and Less Common Cancer Resource Project Teleconference, 22 January
- CCNSW, 23 January (three meetings)
- Dying with Dignity NSW, 23 January
- RANZCR Interventional Radiology Committee teleconferences, 28 January and 2 April
- Health Consumers NSW, 28 January
- CVN EC, 28 January
- Sydney Cancer Conference organising committee teleconference, 3 February
- CCNSW Advocacy Working Group, 10 February, 23 March
- Consumers Health Forum, Research Special Interest Group, 13 February
- Australian Patient Organisation Network PEEK Briefing, 14 February
- PCFA Prostate Cancer Survivorship Essentials Expert Panel meeting, 20 February
- CVN AGM, 21 February
- COSA Teletrials Consortium, Teleconference, 18 February
- COSA Teletrials Consortium (F2F), 24 February

- Health Infrastructure Branch, Portfolio Strategies Division, Australian Government Department of Health, 27 February, teleconference
- NSW Cancer Plan Governance Committee, 4 March
- Cancer Australia, Teleconference, 19 March,

Conferences / Events / Forums

- Lung Cancer Conference, Melbourne, 20-21 February
- CVN EC Strategic Planning Workshop, 21 February
- Patient Voice Initiative Workshop, 4 March
- MHCS / CONCERT Ingham Inst / SEaRCH UNSW; Multicultural co design workshop, 6 March
- Consumer-Pharmaceutical Industry Relationships Workshop: Building Trust and Transparency, 11 March
- CCNSW Research Awards, 12 March (postponed)
- Peter Mac Survivorship Conference, Melbourne, 12-13 March

Submissions / Correspondence

- Medicinal Cannabis Inquiry, February
- Letter of support: MRFF grant application for implementation of the Australasian Teletrial Model, Feb
- Correspondence Dept of Health; NSW Health, March
- NSW Independent Bushfire Enquiry, March

Recently updated information resources at Cancer Council (CC)

[Understanding Cervical Cancer](#) (Sept 2019)

[Understanding Head and Neck Cancers](#) (Sept 2019)

[Understanding Stomach and Oesophageal Cancers](#) (Oct 2019)

[Understanding Non-Hodgkin Lymphoma](#) Nov 2019

[Understanding Radiation Therapy](#) (Dec 2019)

[Understanding Skin Cancer](#) (Jan 2020)

[Understanding Thyroid Cancer](#) (Jan 2020)

[Cancer, Work & You](#) – Cancer and Work package of resources (Nov 2019)

This booklet (and online resource) for people with cancer has been revised and updated, and additionally CC has also revised its 10 x [Workplace factsheets](#) (Jan 2020) for employers and human resource managers. These are workplace guides for creating a supportive and fair work environment for people with a cancer diagnosis. They have current information and list practical suggestions for workplaces and are now live on our website.

[Understanding Peripheral Neuropathy](#) (Jan 2020)

This new information resource has just been added to the website. The fact sheet has been prepared to help people affected by cancer understand more about the nerve condition known as peripheral neuropathy.

The condition can be caused by certain chemotherapy drugs, other cancer treatments or the cancer itself. It is a digital only resource and provides easy-to-read information about: what peripheral neuropathy is; its causes and the importance of early reporting; symptoms and diagnosis; how it is treated; self-care tips and ways to manage symptoms; and questions for your doctor.

It was reviewed by a national panel of clinicians, researchers and consumers.

[Facing End of Life](#) (Feb 2020)

This booklet aims to help people dying with cancer. There is also information for carers, family and friends.

[Understanding Bladder Cancer](#) (Feb 2020)

This booklet aims to help people affected by a diagnosis of bladder cancer. There are substantial changes to the previous edition.

[Understanding Pancreatic Cancer](#) (Feb 2020)

This booklet aims to help people diagnosed with pancreatic cancer, including early pancreatic cancer, advanced pancreatic cancer, and pancreatic neuroendocrine tumours (NETs).

SPECIAL REPORT - CANCER SURVIVORSHIP AND RETURN TO WORK

Cancer diagnosis and treatment often focusses on the researchers and doctors who specialize in cancer. But there are a wide range of other people involved in helping cancer survivors live well during and after treatment. In this series of special reports, we will introduce you to these people – those who are working to support cancer survivors in other ways. This first special report is about Return to Work for cancer survivors and the important role an occupational therapist can play in this.

RETURNING TO WORK AFTER CANCER

An estimated 150,000 new cases of cancer will be diagnosed in Australia this year. More than 40 per cent of these new cancer cases will occur in people of working age, so the question of returning to work during and after cancer treatment is significant for these people. But how easy is it for cancer survivors to do this and how well do organisations cope with someone returning to work after cancer treatment?

In Australia today, there are about 1.2 million people living with a history of cancer diagnosis. Cancer changes lives. With more effective treatments, there are more Australians than ever living longer with—and after—cancer. And these people want, not only to live, but to live *well*. This means preventing and reducing side effects of cancer treatment as well as being emotionally and psychologically supported. And the financial implications of cancer treatment can take a heavy toll on this.

Survivorship care should be provided to people both *during* and *after* cancer. People need support as they go through a cancer diagnosis and subsequent treatment. But they also need support afterwards as they readjust to normal life, when so much has changed – emotionally and physically, and as their family and friends grapple with their diagnosis. Some people recover physically but experience substantial emotional or psychological issues. Others cope well mentally but are left with physical side effects, new conditions or disability caused by cancer or cancer treatments.

Support can't begin only after a patient is cured. Support needs to start from the moment a person is diagnosed.

Returning to work

Cancer has a negative impact on employment patterns with studies estimating between 10% and 38% of employees do not return to work following treatment for cancer.

During consultation for Working with Cancer⁽¹⁾, comments made by HR managers suggest that a formal return-to-work program contributes to a supportive workplace environment for all employees and not just those people returning to work after cancer diagnosis or treatment.

To try to return their life to 'normal', many people consider returning to work as early as possible and this can present challenges, not only for the individual, but also for the employers and the work colleagues.

Cancer Council Australia CEO Sanchia Aranda says: *"While there is no law requiring you to share a cancer diagnosis with your employer, you do have some obligations"*.

Aranda suggests that employees consider changing their work patterns while recovering, and to go easy on themselves. *"There is no rulebook, so don't feel obliged to be upbeat every day"*, she says.

For a successful return to work (RTW) after cancer, it is important to recognise that RTW is a positive clinical health outcome for patients and their families, from a physical, cognitive, psychological and financial perspective. For this to be achievable and sustainable for the survivor, there must be collaboration, coordination and resources between the employer and the survivor, with the help of a qualified third party such as an occupational therapist.

Alice Fung (pictured right) is a qualified Occupational Therapist, with a Master of Occupational Therapy and Graduate Certificate in Pain Management from University of Sydney. She has over 19 years' experience as a rehabilitation consultant in disability employment, mental health, non-communicable diseases and brain injuries. She specializes in rehabilitation strategies advising on cancer and return to work.



Alice has a mission. Following the loss of the entire maternal side of her family with familial cancer, Alice wants to help reduce the stigma of cancer and return to work by promoting recovery through purposeful activities and employment in workplaces in Australia.

I caught up with Alice recently and asked her a number of questions about her work.

Are RTW strategies for cancer patients different from other RTW strategies?

Return to work after a personal non-cancer illness or injury share a lot of common challenges and solutions to someone returning to work after cancer.

What are some techniques you use to better equip cancer patient to return to work?

Some of the RTW management strategies that are **commonly applied** by allied health professionals such as Occupational Therapists include:

- **RTW Readiness:** Patients and treating doctors would normally consider return to work only when the person is “100% fit and ready”. This common challenge is not helpful - it stops the dialogue from happening between the survivor, the GP and the employer at the earliest possible stage. Allied health professionals can assist with identifying and assessing what minimum functional requirements need to be met for the survivor to be gradually returning to the “job” and the workplace and provide this benchmark for both the survivor and the GP to consider. The employer can also objectively consider a safe minimum requirement for the survivor to start a gradual return to work at the workplace or work from home.
- **RTW Planning:** Occupational Therapists are often called upon to conduct workplace assessment and job task analysis to help understand and bridge the gap between the job demands and what the

survivor can do functionally. By identifying the gap, a return to work plan can be drawn up, including how to start and what a return to work scenario would look like, as a proposal for everyone to consider. Such a proposed strategy allows the GP to review and provide medical advice on what a safe return to work might look like AND allows the employer to plan what resources the survivor needs to make this plan successful. It is essential that the survivor is also involved in this plan design and implementation.

- **Physical/Cognitive/Psychological functional upgrading plan:** As we know, like with any other chronic illness, returning to work after an extended period of time off plus the impact of treatment and ongoing side effects can affect a person’s capability to function to capacity. To ensure a successful a return to work, preparation is the key. It is important to stage the return to work so that the survivor is not overwhelmed in the early stages and can take on more responsibilities as their strength builds. Some of the common tools we can use include:

1. **Goals planning:** for some survivors, returning to work may not be the most important priority. However, as we all know, having a meaningful and purposeful “job” extends beyond “paid work”. Having a clear goal of what they want to achieve helps the survivor focus on what is meaningful to them.
2. **Exercise program:** this focuses initially on managing fatigue and on matching job demands such as lifting/carrying or endurance with the survivor’s physical abilities.
3. **Cognitive and psychological recovery:** this focuses on improving nutrition and sleep, and on improved mood and focus/concentration. These solutions can be provided through health coaching, structured activities planning and web-based programs that aim to improve cognitive loading and processing speed for thinking.
4. **Community re-engagement:** this is focused on helping the survivor feel comfortable about re-entering the workplace after an absence. Some people will be open about their situation, while others will be more private.

What are the main differences when considering RTW after cancer?

The key important difference is that, unlike a work-related injury, an employer has no legal obligation to support or offer graduated return to work for someone suffering a personal illness or injury. They do however, have a duty of care to support an employee to work in a safe work environment. This is why having earlier dialogue with the employer about return to work is crucial. Most employers have limited exposure and experience to support employees return to work after cancer so they often need just as much guidance from a health professional as does the employee.

What support/information can employers provide to the cancer patient's work colleagues to help them deal with their returning colleague?

When planning a return to work, the OT can discuss with the survivor how and to whom they are comfortable disclosing their cancer and their ongoing capacity for work. Some survivors are quite open about their illness whilst others may choose not to disclose their illness. It is important to support the survivor to make that decision.

It's natural for the co-workers to feel a range of emotions in response to the survivor's return to work. They may experience a variety of emotions including disbelief, fear, anxiety, concern and sadness. It may be particularly confronting for co-workers who have experienced cancer in someone close to them or had cancer themselves.

Research led by Dr Kirsten Petersen and published in the Journal of Occupational Rehabilitation⁽²⁾ last year following extensive interviews with managers and their teams from a number of European workplaces found that the cancer survivors were "welcomed and encouraged [in] the workplace" while simultaneously encountering "negative attitudes regarding [their ability] to engage in work and meet employment demands".

That's why management training must incorporate insights and guidelines on how to balance the needs of an unwell team member with the needs of the business to continue functioning efficiently, while the team itself needs greater support so that resentment is kept at bay and warmth is left to stay.

To support co-workers, communications about the

survivor's return to work plan and their workload should be clear and well managed. Those organisations that have employee health benefits such as an Employee Assistance Program (EAP) can encourage the survivor and co-workers to utilize this service. This service can also be utilized by line managers as well to help them access support and resources whilst managing a survivor returning to work.

Are family members involved in the strategies in any way? If so, how?

A family member can support a survivor by providing insights around their day-to-day routine at home and help identify any barriers that need to be addressed before a return to work plan can be developed. For example, transportation/access to the workplace, current routine at home and other relevant information that would help prepare the survivor to return to work successfully. It is important that the survivor has provided consent and agreement for the family member to be involved in this discussion.

More resources

Cancer Council has a range of booklets and Fact Sheets⁽³⁾ for employers and employees including:

- Talking to your employee about cancer
- Managing the effects of treatment
- Supporting a colleague with cancer
- Supporting working carers
- Creating cancer-friendly workplaces
- Cancer in the workplace: other support
- Cancer, Work & You

- (1) https://www.cancer.org.au/content/pdf/AboutCancer/support/workingwithcancer_sect2.pdf
- (2) <https://www.ncbi.nlm.nih.gov/pubmed/31056724>
- (3) <https://www.cancercouncil.com.au/cancer-information/legal-work-and-financial-issues/work-and-cancer-for-workplaces-employers/>

Kathryn Leaney

Note: 1: Alice presented at the 2019 CINSW Innovations Conference. See her abstract, *It takes a village: collaboration can achieve return to life and employment in the community* at <https://www.cancer.nsw.gov.au/getattachment/about-us/events/innovations-in-cancer-treatment-and-care/2019-innovations-conference/Abstract-It-takes-a-village-collaboration-can-achieve.pdf?lang=en-AU>

2: This issue will be further exacerbated by the RTW issues of the broader community due to COVID-19.



National issues

There is a significant amount of work currently being done on the development or revision of national strategies, policies and documents that, while covering the wider health spectrum, are relevant to those affected by cancer. These include:

► ***The National Preventive Health Strategy development***

As a consequence of pressures on the federal health department resulting from the September 2019 to February 2020 bushfires and other weather events, the federal health minister, Greg Hunt, has agreed to extend the delivery of the National Preventive Health Strategy to September 2020. This revised delivery timeframe will align with the delivery of the Primary Health Care Ten Year Plan.

It is not known at this stage what the impact of the COVID-19 pandemic will be on these and other projects of work that the health department is undertaking.

► ***The National Medicines Policy review***

The National Medicines Policy (the NMP) was launched in December 1999. It is a well-established endorsed framework based on partnerships between Governments (Commonwealth, States and Territories) health educators, health practitioners, and other healthcare providers and suppliers, the medicines industry, healthcare consumers, and the media working together to promote:

- quality care responsive to people's needs
- incentives for preventive health and cost effective care
- better value for taxpayers' dollars
- more clearly defined roles and responsibilities, and
- continued universal access to basic health services through Medicare.

A meeting of stakeholders in February identified a range of issues regarding the review of the NMP, including:

- ensuring the current principles of the NMP are fit for purpose and incorporate monitoring and accountability processes to evaluate the implementation of these principles
- broadening the definition of medicines within the scope of the NMP
- the NMP needs to be written in a way that it resonates with all Australians, not just bureaucracy
- the NMP should provide integrated processes that give patients a seamless pathway
- the review process, including the outcomes and consultation process, must be patient centric
- transparency, collaboration and accountability should be central to the NMP
- the NMP must make sure jurisdictions and geographical locations are not a barrier to access, and ensure greater harmonisation between states and territories
- conflict of interests with stakeholders can affect how the principles are applied.

Public consultation on the review of the policy was expected to begin in March, with the review process to be completed by June 2020, which is a very tight timeframe.

It is expected that a further stakeholder meeting will be held, while the Australian Patient Advocacy Alliance (of which Cancer Voices Australia is a member) has requested an additional meeting solely for consumers.

► ***The National Health Information Strategy***

Work by the Australian Institute of Health and Welfare (AIHW) is continuing on the development of the National Health Information Strategy (NHIS). The Strategy will deliver a coordinated national health information system that is unified in purpose and addresses intersecting aspects of health and wellbeing, including the social determinants of health, over the life course of individuals. It will bring together comprehensive data and information from private and public sources and relevant sectors.

The challenges of disparate legislative, regulatory, and technical arrangements must be overcome to ensure that health data are high-quality, and shared and used in timely ways for the benefit of all.

It is expected that the Strategy will include broad priorities such as:

- Governance: Privacy and confidentiality, Social licence, Data liberalisation, Data access and sharing
- Infrastructure: Secure remote access facilities, Cyber security, Digital health systems and tools
- National health data: Indicators of health status, Information on health determinants, Health policy information requirements
- Analysis, insights and reporting for: Governments and private sector, Consumers and citizens, Clinicians, Researchers.

The NHIS will aim to overcome information gaps and barriers and drive prioritised investments in health information to ensure that national health information assets and infrastructures are fit-for-purpose into the future. It will also provide an overarching framework which will assist in the coordination of jurisdiction and non-government priorities so that activities undertaken do not duplicate effort across jurisdictions and lead to better, more effective use of resources which in turn will assist in improving health outcomes.

A NHIS will provide a framework which will address interoperability issues and think ‘beyond health’ to domains such as aged care, disability, participation in sport and workers’ compensation. The development of the NHIS will take into account but not duplicate other strategies and initiatives such as the National Health Reform Agreement, the implementation of Australian Health Performance Framework, the National Health Information Agreement, the National Digital Health Strategy, My Health Record, and the National Genomics Strategy.

Above all, it is intended that the NHIS will provide assurance to the community and health information stakeholders of the competence of the system and key information organisations in managing data with a strong and respectful focus on privacy and data security.

(Information from the AIHW website at www.aihw.gov.au/)

Murray McLachlan

Building trust and transparency: relationships between consumers, consumer groups and the pharmaceutical industry

Cancer Voices NSW was well represented at the ‘Consumer-Pharmaceutical Industry Relationships: Building trust and transparency’ workshop held at the Charles Perkins Centre at Sydney University on 11 March 2020. Organised by Health



Trust and Transparency Workshop.
L-R: Elisabeth Kochman, Bev Noble, Jan Mumford, Murray McLachlan, Sarah Lukeman

Consumers NSW and Consumers Health Forum Australia, the day brought together a range of representatives of consumer and stakeholder individuals and groups who are interested in the issue of relationships between consumer groups and the pharmaceutical industry as a whole, and with individual pharmaceutical companies.

The workshop program included presentations by researchers and academics, consumer group representatives (both paid positions and



Panel: Independence, risk & benefits of industry funding

volunteers) across a range of health and disease types, panel sessions, and group work.

I represented Cancer Voices NSW in the ‘Independence, risk and benefits of industry funding’ session, where I spoke about Cancer Voices’ position statement

on relationships with the pharmaceutical industry

<https://www.cancervoices.org.au/wp-content/uploads/2019/01/CVN-2019-Position-Statement-Pharmaceutical-companies-relationships-January-2019.pdf> and was part of the panel session that followed.

From the range of other speakers, it is clear that CVN sits at the ‘minimalist’ end of a ‘funding continuum’, which acknowledges the realities of needing to ‘be at the table’ but which allows us to maintain a crucial level of independence which is central to our credibility as a voice of those affected by cancer.

The results of the workshop, including the work done in small groups to develop both principles and practices for building trust and transparency with the

pharmaceutical industry, will be prepared as a report by the workshop organisers.

Further information about this will be provided in a future newsletter.

Murray McLachlan

Bushfires and cancer letters

Following the devastating bushfire season between September 2019 and February 2020, Cancer Voices Australia and Cancer Voices NSW have written to their respective health ministers to draw their attention to issues that must be addressed in relation to the health and cancer consequences of these unprecedented natural disasters.

The CVA letter to the Federal Health Minister, Greg Hunt, stated that:

The impacts of the bushfires are far-reaching and include all first responders, those at the scene of fires (families and workers who live there), and the general public. Everyone has seen and felt the effects of smoke with days when it was not advisable to go outside and the smoke crept inside, such was its density. This effect was felt in both rural, regional and metropolitan areas. Public health processes need to be widely implemented to ensure that people who have been exposed are not only treated but monitored on an ongoing basis at the local level.

The letter then:

- emphasised the need for Australian-specific research on the health and cancer consequences of prolonged exposure to toxic, particularly carcinogenic, substances
- proposed the establishment of a properly-funded centre of excellence to perform this research
- indicated that funding of such research from the National Health and Medical Research Council, and the Medical Research Future Fund, should 'not impinge on the funding that currently, and into the future, needs to be directed towards other cancer-related research'
- expressed CVA's concerns about 'the variability between, and within, states in the extent and efficacy of the personal protective equipment (PPE) that firefighters are provided with and, in the most disturbing of cases, have had to provide for themselves'
- referred to the lack of PPE available to the general public living in bushfire areas.

The drafting of this letter benefitted from the input of a number of people, including members of the CVN Executive Committee, and some of our colleagues from Cancer Voices South Australia.

The CVN letter to the NSW health minister, Brad Hazzard, raised similar issues at the state level, including urging the Minister to 'work with the Cancer Institute of NSW so that it, as a matter of priority, allocates (or reallocates) a significant proportion of its funding programs on a sustained (that is multi-year) basis to research the health and cancer effects of bushfire fighting, and of exposure to bushfire smoke more broadly in the community'.

In relation to bushfire fighters, the letter said that the Government should also give serious consideration to implementing a program of health testing of bushfire fighters (whether professional or volunteer) to provide base measures for ongoing health surveillance in the same way as is done for workers exposed to dust disease, through the NSW Lung Bus. CVN believes that the Lung Bus resources should not be diluted, given the urgent need for ongoing testing and surveillance of workers, including those groups who have been exposed to silica in the engineered stone benchtop industry. Rather, for a modest financial investment, the Government should implement a parallel 'lung bus' service that is dedicated to the health monitoring of fire fighters.

While congratulating the Government for its health and cancer-related actions during the bushfires, particularly in broadening the access criteria for the Isolated Patients Travel and Accommodation Scheme (IPTAAS), the CVN letter proposed that the NSW Government consider the continuation of these provisions, and a permanent change to IPTAAS policy, to remove the inequities of access, such as restrictions on travel distances, that still exist in the scheme.

Replies to the letters have not been received from either minister, but the details of any responses will be included in a future newsletter.

Murray McLachlan

Working on prostate cancer issues

The Prostate Cancer Foundation of Australia (PCFA) is currently working, with the involvement of consumer representatives, on the development of a consensus approach to change the face of prostate cancer survivorship care in Australia.

The Prostate Cancer Survivorship Essentials Expert Panel has completed three separate online surveys to develop a sense of how a range of people involved in prostate cancer, as patients, carers, researchers and treatment specialists (such as exercise physiologists) see the essentials of prostate cancer survivorship. The panel has identified these as being:

- Health Promotion and Advocacy
- Shared Management
- Vigilance
- Personal Agency
- Care Coordination, and
- Evidence-based Survivorship Interventions.

The Expert Panel met on 20 February to further consider the development of the Survivorship Essentials, which included receiving presentations on the following:

- clinical context
- National Position Statement on Screening for Distress and Psychological Care for Men with Prostate Cancer

- Position Statement on Exercise, Medicine and Prostate Cancer.

A workshop component focused on the implementation of the Survivorship Essentials, with the work to be further developed by PCFA for finalisation and release.

Separately, an Expert Oversight Panel is involved in PCFA's Resources Update project, which has as its goal the support of Australians affected by prostate cancer by providing updated information and advice. The project's objectives are to:

- consult with the prostate cancer community, identifying their needs and preferences for information
- optimise the provision of information, reducing repetition and the total number of resources
- produce new resources as recommended by the Expert Committee
- bring PCFA's resources up-to-date with current knowledge and recommendations.

It is likely that a major component of the new resources approach will be app based.

The project is due to be completed by 30 June 2020.

Murray McLachlan

From PCFA: Coronavirus FAQs

<https://www.prostate.org.au/media/790412/coronavirus-consumer-qa-2.pdf>

Rural and Regional access to new treatments - Clinical Oncology Society Australia (COSA) Teletrials Consortium

In 2016, COSA developed the [Australasian Tele-trial Model](#) and a national guide to implementation. The Model uses tele-oncology and tele-health to enable clinicians from larger centres (primary sites) to enrol, consent and treat patients on clinical trials at regional and rural centres (satellite sites), thereby providing patients with access to clinical trials closer to home.

Access for people with cancer to clinical trials is a core component of providing optimal cancer care. Rural and regional patients have, in the past, been denied access to these trials and this is without doubt, a contributing factor to the poorer survival outcomes we see for rural Australians when compared to those in metropolitan areas.

In June 2017, COSA was successful in securing competitive grant funding, via MTPConnect to pilot

the implementation of the Australasian Tele-trial Model. This project, due for completion in September 2020, is co-chaired by Professors Sabe Sabesan from Townsville Hospital and John Zalcborg of Monash University. Cancer Voices NSW and Rare Cancer Australia are members of the funding consortium for the project and represents consumers on the Steering Committee.

This project has already achieved many of its milestones. There are currently 75 cancer patients participating in tele-trials across Australia in Queensland, NSW, ACT, Victoria and South Australia. 10 tele-trials are open and two are now closed to recruitment with a further nine pending. Earlier trials focused on oral medications (due to being pilots) and the new ones now include intravenous medications.

For additional information

https://www.mtpconnect.org.au/Category?Action=View&Category_id=130

Podcast available : To hear more about this tele trials project, listen to the recently released (12 March) MTPConnect podcast interview with Prof Sabe Sebesan, Director of Medical Oncology at Townsville Hospital, and Marie Malica, CEO COSA via the following link

<https://podcasts.apple.com/au/podcast/spotlight-how-tele-trials-are-giving-rural-cancer-patients/id1453637211?i=1000468270951>

Elisabeth Kochman

Cancer Voices Australia endorses the Standard for Informed Financial Consent

Cancer Council Australia in partnership with Breast Cancer Network of Australia, CanTeen and Prostate Cancer Foundation of Australia developed this Standard for Informed Financial Consent in response to patient's experience of unexpected out-of-pocket costs related to their diagnosis, treatment and ongoing care, contributing to financial burden or poorer health decisions. The Standard for Informed Financial Consent aims to guide discussions to include cost of care between patients and healthcare professionals to help make informed decisions about treatment and care.

Cancer Voices participated in the consultation process throughout the development of the Standard and was one of several organisations invited to endorse it in March this year.

The Standard for Informed Financial Consent has been finalised and is now available on [Cancer Council's website](#). It also includes *The financial cost of health care*, information for people with cancer and for those caring for someone with cancer.

Elisabeth Kochman

Regional and Rural Cancer Centres Update

Regional Cancer Treatment Centres for Radiation Therapy

The Regional Cancer Treatment Centres for Radiation Therapy initiative was announced by Minister Hunt in April 2019. The federally funded initiative will provide greater access, help and support for cancer patients in regional Australia. \$63.4 million will be invested in expansion of cancer treatment capacity through new radiation therapy services in 13 regional locations. A key barrier to radiation therapy in Australia is a lack of access because patients live too far from their nearest centre.

The Australian Government Department of Health is working with key stakeholders to ensure that the investment is well targeted to support regional population centres that can service their surrounding areas. Three of the sites are being built in partnership with state governments and 10 sites will be built through a tender process.

As part of the stakeholder consultations, Cancer Voices Australia was invited to comment and discuss the initiative with staff from Health Infrastructure Branch, Portfolio Strategies Division. Four Cancer Voices members who have a lived experience of

cancer and experience of cancer health services in regional and rural Australia were able to discuss potential issues so that these issues are addressed in the tender process.

Cancer Voices appreciated being included in the stakeholder consultations and being able to provide advice to better ensure that the new radiation therapy cancer centres will support the nominated regional communities.

Dubbo Cancer Centre

Work has commenced on the building of the new Western Cancer Centre located in the Dubbo Hospital precinct. The centre is being built on the footprint of the hospital's old renal unit, which has now been demolished. The centre will provide critical services and care to patients and families, much closer to home.

Cancer Voices NSW supported the community campaign led by the Jimmy Little Foundation and Dubbo West Rotary Club to secure the long-awaited facility. The doors of the cancer centre will open in 2021. Having comprehensive facilities such as 16 new chemotherapy chairs, a linear accelerator, PET-CT scans and a wellness space for support services will

increase the likelihood that patients will choose curative, life-extending or potentially symptom-helping treatments for their cancers. Previously, patients had to travel to Orange or Sydney for radiation therapy treatment.

The Western Cancer Centre will be the hub for new remote video-assisted chemotherapy unit and the clinical trials unit in western NSW. The centre has addressed many issues such as patient travel, accommodation for patients near the centre and the provision of allied health services through their community consultations with patients, health workers and stakeholders. There has been continuous

stakeholder engagement and collaboration in the planning and development of the centre. Cancer Council NSW have organised their Transport to Treatment services. This service is for cancer patients and their carers residing within a 200km/2 hour radius of Dubbo who have no viable transport options to get to their cancer-related appointments and treatment.

This free service, undertaken by volunteers, works with community transport and referring medical professionals to remove barriers to treatment for rural cancer patients and provide support for their families and carers.

Lee Hunt



My Health Record Consumer Experience Survey

Consumers Health Forum of Australia (CHF) and the Australian Digital Health Agency (the Agency) invites you to participate in this survey to share your experience using My Health Record.

The overall purpose of the survey is to better understand consumer experiences of using My Health Record in real life situations. An additional aim is to develop a series of case studies to capture opportunities for improvement and highlighted what is working well with My Health Record, from a consumer perspective.

If you are interested in completing the survey, please read the [Information Sheet](#).

[Click here](#) to complete the survey. The survey will close **COB Tuesday, 14 April 2020**.

If you have any questions, please contact Project Lead, Leanne Kelly on 02 6273 5444 or send her an email to l.kelly@chf.org.au

THANKS to the Team who bring you this Newsletter:

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Special thanks to Geoff Vass for his ongoing pro bono technical support.

We hope you find it interesting, even inspiring! Let us know about any other advocacy issues you think we should feature and/or work on, and if you would like to help.

Info@cancervoices.org.au

REMEMBER the full archive of previous newsletters is available at:

<https://www.cancervoices.org.au/newsupdates/>



Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the estimated nearly 48,000 people who are diagnosed in our state each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this, we work in partnership with providers of these services, ensuring the patient perspective is heard.