
Welcome everyone

Welcome to the July edition of YCS Matters and the halfway point of 2016!

The last few months have seen the continuation of the fantastic work around Australia, with many key service delivery targets met and exceeded, and a number of key initiatives in research, advocacy and service development underway. In this edition we have an important call to action to support reimbursement for critical Oncofertility procedures on the Medicare Benefits Schedule. See over the page for details on what you can do to support this vital fertility preservation initiative for young people living with cancer.

This issue includes an exciting announcement about support for greater access to clinical trials for young people living with cancer, and includes a profile of CanTeen member and clinical trials advocate Joey Lynch. The National Youth Advisory Group met in Sydney at the end of May to discuss ongoing projects and initiatives and provided feedback on AYA-related research, including providing consumer perspective on a study being undertaken at Westmead Children's Hospital. This edition also includes updates on the Phase 2 evaluation, Phase 3 funding process, AYA dataset specification pilot, and a roundup of the comprehensive work taking place amongst the services around the country.

Finally, we'd like to say a fond farewell to Hannah Baird as she leaves the YCS National Team to take up an exciting new role as Lead Supportive Care Manager at Cancer Council NSW. Over the last 3 years Hannah has worked to support the growth and consolidation of YCS Phase 2 services across the country. We wish her every success in the future!

The National Team

Show your support today to help cancer patients' access oncofertility through the MBS

Two new oncofertility Medicare applications are currently open for public comment until midnight Friday **15th July 2016**:

- 1. Application 1434: Pathology: Anti-Müllerian monitoring**
- 2. Application 1435: Processing of gonadal tissue and gametes**

Go to: <http://www.msac.gov.au/internet/msac/publishing.nsf/Content/surveys-lp>

Your support for these initiatives is a vital component of their approved onto the MBS. These applications will not be reviewed again, so we have this one chance to get them through and transform the lives of cancer patients into the future!

Background

Through the FUTuRE Fertility team at Sydney's Children's and Prince of Wales Hospital, the Medicare Oncofertility Advocacy Campaign has focused on the inclusion of new Oncofertility Medicare items on the Medicare Benefits Schedule (MBS) to ensure that cancer patients have equitable access to fertility preservation and fertility-related support.

Four new Medicare applications were submitted to Medicare earlier this year and three of these were approved – with two requiring public comment for them to be approved.

• **Application 1434: Pathology: Anti-Müllerian monitoring**

This application is in support of the Anti-Müllerian Hormone (AMH) test which will provide female cancer patients with the opportunity to determine what their fertility might look like before and after cancer treatment. The AMH test is a simple blood test and is currently the most accurate test for informing a patient as to the number of eggs that exist pre and post treatment. This test may assist female cancer patients who are interested in having a biological family of their own later in life and help patients in considering their fertility preservation options.

• **Application 1435: Processing of gonadal tissue and gametes**

This application details recommendations for the establishment of three new Oncofertility Medicare item numbers:

1. Processing and cryopreservation of ovarian tissue for fertility preservation treatment for female patients.
2. Processing and cryopreservation of semen for fertility preservation treatment.
3. Processing and cryopreservation of testicular tissue for fertility preservation treatment.

• **Application 1436: Ovarian repositioning** (no public comment required)

How to make public comment:

- You can access the applications via the link below, listed under their respective application numbers (1434 & 1435).

<http://www.msac.gov.au/internet/msac/publishing.nsf/Content/surveys-lp>

- Please click on the link to each item number in order to access the 'feedback and survey form' in word and feel free to make your comments of support (note these feedback forms are also attached to this email for your convenience).
- Please email your completed form to **hta@health.gov.au**, and if possible, cc Brigitte Gerstl on **Brigitte.Gerstl@health.nsw.gov.au**.
- The applications are available for public comment until midnight this **Friday 15 July 2016**.

Providing positive feedback on the importance of these applications is vital for their success!

For further information, please contact the FUTuRE Fertility National Manager Brigitte Gerstl on **Brigitte.Gerstl@health.nsw.gov.au**. CanTeen is delighted to have been able to partner and support this very important initiative.

Clinical Trials Funding Announcement

It is with great pleasure that we share the announcement made by the Federal Health Minister, the Hon Minister Sussan Ley in May 2016, that the federal government will commit \$7M to improve young cancer patients' access to clinical trials.

This clinical trials proposal evolved over an 18 month period, commencing with the Feb 2015 submission to the Senate Inquiry into the Availability of new, innovative and specialist cancer drugs in Australia. Following on from



this, a formal proposal was developed with input from representatives across the YCS Advisory Groups and YCS clinical leads, as well as senior experts within the clinical trial and cancer research field. Consultations were also conducted with pharmaceutical and clinical trial companies as well as clinical trial specialists across a number of different tumour streams.

The proposal was initially submitted to Government in November 2015, supported by a revised proposal following meetings with senior Departmental executives and the Federal Health Minister. In brief, the proposal highlights the need to streamline trial governance and initiation processes, enhance capacity to conduct trials across both adult and paediatric settings and for building capacity in AYA treatment centres to conduct clinical trials. The proposal outlines the establishment of four early phase clinical trials focussing on high lethality cancers.

Profile: Joey Lynch



Joey Lynch was diagnosed with Stage IIIB Hodgkin's Lymphoma in September of 2008, or as he describes it: "Four days before Adam Cooney won the Brownlow Medal playing for his Bulldogs". Over the past eight years, Joey has been to a vast number of hospitals

in Melbourne and has been able to, in his words, "access fantastic care provided by the Australian Public Health System."

Unfortunately for Joey, in early 2015, he exhausted the last of the potentially curative treatments available at this time in Australia.

Looking overseas, he began to research potential experimental trials in North America and Western Europe, discovering a clinical trial in Philadelphia that not only presented a potential treatment, but a potential cure. This trial uses CD19 immune cells extracted from his body, and modifies them with a virus so that they can recognise and destroy cancer cells. However it came with a catch; which he described in a blog post in September of 2015: "I'm

not ready to give up fighting though, which means that I need to travel to the USA, which comes with the high price tag of \$600,000 USD, to access a potentially curative early stage clinical trial."

Now, in 2016, Joey is travelling to the USA to access this potentially life-saving cancer treatment in a clinical trial run by the Children's Hospital of Philadelphia in partnership with the University of Pennsylvania. This clinical trial represents a new frontier for Joey in his ongoing eight years of treatment.

Representing Joey, who was spending the week in Philadelphia undergoing testing to determine eligibility for the trial (which later showed his full eligibility), his mother, Elizabeth, and brother, Eugene, joined Health Minister Sussan Ley in May to announce that a Coalition Government, if re-elected, would provide significant funding for nationally coordinated clinical trials. It is hoped that this funding will ensure that AYA patients in the future will have access to these clinical trials here in Australia rather than being required to travel overseas, where there are much greater financial burdens.

Introducing Adam Walczak

Following Hannah's departure, Adam Walczak has joined YCS team as Senior Project Officer. Adam has been part of the CanTeen Research, Evaluation and Social Policy team for over a year and may be familiar to some of you from his work on last year's Youth Summit and AYA Oncology Congress. He has a background in psycho-oncology research, having recently submitted a PhD in this area, and has worked in various psychosocial and translational research roles for more than 8 years. Adam will be splitting his time between YCS and his CanTeen research role for the foreseeable future and is excited to work with and support the YCS teams across the country to continue the amazing work being done.

Phase 3 Re-Funding Submission

With about a year of Phase 2 YCS funding remaining, CanTeen is committed to ensuring the continuation of the excellent work being done across the country. To ensure the best possible foundation from which to seek Phase 3 funding from the Federal Government, Peter Orchard and Pandora Patterson have been meeting with representatives from various state governments and senior hospital executives across the country

to shore up broad engagement and a commitment of support for the next phase of funding. These meetings have been very productive and have highlighted the high regard with which the YCSs services are viewed and the importance of seeing them continue into the future.

Over the coming months, feedback will be sought from AYA cancer care stakeholders, including YCS jurisdictional representatives, to ensure a compelling case for continued funding is put forward. The final proposal will be submitted to the Federal Government for consideration later this year. We will keep you posted as developments arise.

The Australian Youth Cancer Framework

Work is progressing well on the development of the Australian Youth Cancer Framework (AYCF). Moving into the third phase of the Youth Cancer Services, the AYCF aims update the 2008 National Service Delivery Framework for Adolescents and Young Adults with Cancer and provide an aspirational five year national vision for evidence-based treatment and care for young cancer patients. It will be broader in scope than the original Framework, with a strong system focus, together with an ongoing emphasis on service delivery and patients unmet needs. Primary care, survivorship, personalised medicine and greater AYA access to clinical trials have all emerged as key priorities for the updated version.

Following a comprehensive literature review by the Behavioural Sciences Unit at the University of NSW, ZEST Health Strategies has developed a draft Framework and undertaken jurisdictional and national consultations to further develop the content. The AYCF Reference Group of health professionals and young cancer patients are providing advice and expertise on this initiative, and met earlier this year to consider the findings of this review and their implications for the vision, scope and priorities of the framework.

To date, consultations have been held with five key informants and three jurisdictional NCERG representatives along with four jurisdictional governance groups. An additional jurisdictional consultation is currently being planned.

Following this, feedback from a broad network of AYA stakeholders will be sought via an online consultation, with the final AYCF to be widely circulated towards the end of 2016.

For further information, please contact Adam Walczak on adam.walczak@canteen.org.au

AYA Dataset Specification Pilot Project

As part of a series of national initiatives to improve data on AYA cancer in Australia, the YCS lead site teams are currently taking part in an outline pilot project to determine the potential for collecting a commonly defined national dataset specification through the YCS services, and to consider options to progress the pilot project into implementation. Under the guidance of Professor David Roder at the University of South Australia, the overarching aim of the project is to improve the consistent collection of national dataset items on adolescents and young adults with cancer in Australia to guide service planning, service evaluation and quality improvement. It will also inform and develop aspects of treatment and care. The pilot project is taking place over a 10 week period between the beginning of May and mid July 2016.

For further information, please contact Allison Warr on allison.warr@canteen.org.au

RESEARCH PARTICIPATION OPPORTUNITY: Understanding the impact of transitioning AYAs to Palliative Care on Healthcare Professionals

In collaboration with Cardiff University, CanTeen and the Cancer Nursing Research Unit at the University of Sydney are conducting a study to better understand the practical and emotional implications of end of life service provision for AYAs in Australia and the UK.

The study is particularly focussed on understanding the process of transitioning young people from care with curative intent to palliative intent and what impact that has on individual healthcare professionals and the teams they work in.

We are seeking healthcare professionals (incl. doctors, nurses and allied health professionals) who have some experience of caring for young people prior to, during or after the transition to palliative care and who would be willing to participate in a 30-40 minute semi-structured interview about their experiences. Interviews can be completed over the phone or in person if you are based in the greater Sydney area.

Participation is completely voluntary and no individuals will be identified in any publication or presentation of the findings. If you are interested in hearing more about this study, please contact Adam Walczak on 1800 243 007 or adam.walczak@canteen.org.au.

YCS Phase 2 Evaluation

Nous Evaluation

In recent months, as part of the Phase 2 evaluation, The Nous Group has undertaken several nationwide consultations across key stakeholder groups, including the YCS Advisory Groups, federal and state health departments, operational and executive hospital staff and broader groups such as private hospitals, other NGOs and Cancer Services. Consultations with YCS adolescents and young adults and parents have commenced and are ongoing in some jurisdictions. Quantitative data is also being collected via online surveys which will be analysed by Nous and tracked against last year's results.

Thank you to all readers involved in these evaluation activities. The mid-term report, due later this year, will synthesise all of the data sources, consisting of key source documents, YCS activity data, qualitative (i.e. consultations) and quantitative data sources.

Experience of Care Study

In the past few months, work on the patient and carer experiences of care study has continued apace. These surveys will provide incredibly

valuable insight into AYA patients' and their carers' experiences of receiving treatment at YCS-affiliated hospitals across the country. These surveys will help us to understand the vital consumer perspective of the successes of YCS to date and identify areas for development into the future.

We are delighted to have received overarching ethics approval for NSW, Qld, Vic and SA. We are also progressing local approvals to begin recruitment in YCS-affiliated hospitals in these states and will continue to seek approvals to conduct the study in other states in the near future. We anticipate that the staggered roll out of the surveys will begin in July.

The survey will be open to all eligible AYA patients who received treatment through a YCS-affiliated hospital between January 2015 and December 2016 and their carers. It will involve completing a questionnaire at the end of active treatment and will take roughly 20 minutes to complete. Options are available to complete the survey on paper, online or over the phone.

For more information on this study, please contact: Adam Walczak adam.walczak@canteen.org.au, Liz King liz.king@canteen.org.au or call 1800 243 007.

YCS Matters Survey Feedback

A big thank you to everyone who completed the survey included in the April 2016 edition of YCS Matters. We are currently reviewing the feedback you provided and will be using this to inform the content and direction of future editions of YCS Matters. We want to make sure that the newsletter is as engaging and relevant as it can be to all of our readers, so your input is appreciated.

Themes that have emerged from the survey feedback, so far, include interest in seeing: more research developments and initiatives, including international coverage; detailed snapshots of jurisdictional work and projects; greater coverage of collaborative opportunities; continued national project updates; and clinical focus areas. We will be trying to incorporate these themes in to the editions going forward in an effort to improve the content of the newsletter.

While the survey is now finished, we do appreciate any feedback you'd like to provide. Should you have any questions or suggestions, please don't hesitate to contact Thomas Brown on thomas.brown@canteen.org.au

Service Updates

YCS QLD Update

The second Qld Clinical Leadership Workshop was held on Thursday, 26 May. The workshops bring key medical, nursing and psychosocial team members together to collaboratively plan service, education and research initiatives. Participant involvement provides an excellent opportunity for networking with all the partner teams and to share local experiences.

The Central team has bid a sad farewell to our Senior Social Worker, Belinda Matigian, who has been welcomed back to the Princess Alexandra Hospital (PAH) AYA cancer team. Belinda replaces Kim Sutherland who has been appointed into a full-time role. Kim will be sadly missed from her direct involvement in AYA care but her experience will continue to support oncology patients at PAH.

We are delighted to congratulate:

- Natalie Bradford, and two of our paediatric colleagues, Katrina Anderson and Rachel Edwards, whose paper Improving the management of the febrile child with cancer across Queensland, was awarded 'Best Scientific Research Paper' at the recent Cancer Nurses Society Australia annual congress.
- Anita Cox, who was the 2016 winner of the \$5,000 Adem Crosby Haematology Nursing Award from The Leukaemia Foundation and Sunshine Coast charity Team Adem.
- Jane Roach, who has been awarded an adjunct lecturer position with the University of Sydney, School of Nursing under the leadership of Professor Kate White.
- The AYA team, who were finalists in the PAH International Nurses Day 'Team of the Year' category.

Our Youth Advisory Group has had a busy few months. Chris Timoney has joined the Qld Steering Committee as a consumer representative and we have welcomed three new members to the YAG, Michael Lo (Milo), Cody-Leigh Ammenhauser, both from Townsville, and Frazer Baker. Frazer has recently replaced Jenna Maloney on the National YAG. A big thank you to Jenna, who has contributed significantly over the past 3 years.

Milo and Frazer have generously shared their reasons for joining the YAG;



Anita Cox and Team Adem



Michael Lo (Milo)

Milo joined the YAG as it provided 'A chance to help out where I can as throughout my treatment many doctors and nurses helped me and by joining YAG, I have the chance to help improve the hospital system in Far North Queensland for youth cancer patients.'

Frazer is 24, from Rockhampton and was treated for an osteoblastic osteosarcoma left thigh at the PAH in Brisbane "I joined YCS because I want to turn this horrible thing that happened to me into good and to also give back for all the support that I received."

YCS WA Update

The WA YCS has had some staff changes in the first half of 2016. We said a sad farewell to Todd Dennis, our admin and project officer, as he commences post-grad medicine studies and welcomed Helen Henderson to fill Todd's shoes for a few months. Daniel Berk has quickly settled into the role of CNS replacing Nic Hedley who left us in May 2015 to have her first baby. Meg Plaster also resumes responsibilities as Service Manager alongside her CNC role.

The rest of the WA team have been working hard developing our local research agenda, with our Exercise Physiologist Claire Munsie successfully gaining ethics approval for her Life Now for AYAs study, which she is working on in conjunction with Cancer Council WA and Prof Rob Newton from Edith Cowan University. Claire will commence recruitment this month.

Kendall Stratton and Meg have been participating in the YCS Nursing Research Mentorship Program and are developing their respective research proposals. Kendall is also working with Rachel Hughes to progress our End of Treatment project being piloted with sarcoma patients.

Claire presented her Masters work exploring the long term functional outcomes of sarcoma patients at the recent Exercise & Sports Science Australia conference in Melbourne and was awarded best oral presentation. Well done, Claire!

Our counsellor, Julie Sparrow, is developing a proposal to run a Drumbeat program in the second half of 2016. Early interest from young patients is very enthusiastic and we're bracing ourselves for the sounds of drums emanating from the You Can Centre!

The team is also eagerly anticipating and working hard towards the implementation of MOSAIQ, to improve out interdisciplinary communication, data collection and reporting processes. The oncology information management system has been rolled out in most departments in the SCGH Cancer Centre through this year and the WA YCS will soon be well integrated when we go live with the system in the second half of this year.

Lastly, the You Can Centre hosted another extremely successful Look Good Feel Better workshop for young women in May, facilitated by Geanette, our



John Sutton and young patients at the WA You Can centre

counselling intern. In June we also welcomed South Sydney Rabbitohs NRL player John Sutton to the You Can Centre to spend some time with a few of our young patients. One of our patients, James Marquet, a former New South Welshman and keen NRL follower, was given the honour of tossing the coin for their match against the Gold Coast Titans that weekend. Part proceeds of the game went towards You Can, supporting the development of Centres around Australia.

YCS VIC/TAS Update

Across Victoria & Tasmania work continues on a range of initiatives aimed at strengthening relationships between health services delivering care to young people and their families. As part of evaluating this work, we have recently completed a series of focus groups with young people, their carers, members of the VIC/TAS YCS team, and

health directors/executives across partner sites. Ethics has been approved for the patient and carer experience of care study and recruitment will commence shortly.

This quarter saw a number of team members invited to present at conferences and forums on a range of topics associated with AYA cancer. These included: The Australian Society of Head & Neck Surgery ASM; The Melbourne Fertility Preservation Summit; and The Northern Hospital Cancer Seminar Series. In Tasmania, Victoria Jayde AYA CNC, alongside local CanTeen staff, presented to over 100 healthcare professionals in Launceston on the Youth Cancer Service initiative and the role of the AYA CNC in Tasmania. The visit continues to support the development of inter hospital collegial relations, and has resulted in an increase in young Tasmanians being referred though for support from the YCS.

We have continued to build our collaboration with the University of Melbourne through our student program with four post graduate students currently undertaking research placements. Areas of interest include youth participation in the oncology sector, primary care engagement amongst AYA cancer survivors, and clinical data mining in the area of sarcoma. This collaboration has also seen a number of staff appointed through the Faculty of Medicine, Dentistry and Health Sciences in teaching positions.

This will be our last contribution to YCS Matters from our home in East Melbourne as we prepare for the move to the new Peter Mac located within the Victorian Comprehensive Cancer Centre (VCCC). The VCCC will see the largest providers of AYA cancer care come together, where young people will have access to the Sony Youth Cancer Centre and treating teams which combine tumour expertise and developmentally appropriate healthcare.

YCS SA/NT Update

Our Service Manager, Allan Hayward, visited the Northern Territory in March, meeting with clinicians in Darwin and Alice Springs. An education day was held for health professionals in Darwin, with a focus on paediatric and AYA cancer care. Topics included types of paediatric/AYA malignancies, nursing care, social media/professional boundaries, communicating with young people, palliative care, sexual health, fertility preservation, as well as specific supports available in the Northern Territory.

The day also featured a moderated consumer panel of two young people who have now completed treatment as well as the parent of a young person. This session was extremely well received as the panel spoke very openly and honestly about their

experiences, particularly around the impact of having to relocate for treatment and being far away from family support.

Speakers included Dr Michael Osborn and RN Julie Duffield who presented via videolink from Adelaide. Shandelle Hill (Women's and Children's Hospital, SA), Allan Hayward (YCS SA/NT), Shirelle O'Halloran (Acting YCS Cancer Care Coordinator, Royal Darwin Hospital) and Rachel Buckley from Royal Darwin Hospital presented in person on the day.

We will be heading back to Darwin in August and will be teaming up with the Leukaemia Foundation, CanTeen, Redkite and other NGO's to provide two education days; one for health professionals and the other for consumers and their families.

In April, we had an invited guest to our local Youth Advisory Group (YAG) in Adelaide. Natalie Meti is the National Leadership Coordinator for CanTeen and works very closely with the National YCS Youth Advisory Group and CanTeen's Member Advisory Council. Natalie presented some of the great feedback from the inaugural AYA Summit and Congress held last December in Sydney. We were also able to discuss ways that we can work with Natalie in the future. Our YAG members really valued the opportunity to hear about both conferences and are excited to explore ways that they can work with Natalie in the future.

YCS NSW/ACT Update

Royal Prince Alfred Hospital (RPA) welcomes back Kristyn Schilling (CNC) from maternity leave. A big thank you to Tanya Haynes for her efforts over the last 12 months covering the position.

Sydney YCS Social Worker, Michael Hopkins, recently submitted a poster on the NSW/ACT YCS YAG for the Bright Spots Program, focusing on using consumer engagement to improve service delivery and growth. It is hoped this will increase awareness across the network around the Youth Cancer Services.

The Western Sydney YCS (WSYCS) team is in the process of wrapping up a pilot study examining sleep disturbance among AYA oncology patients. A key outcome of the study was evidence of at least mild sleep quality disturbance in the entire group of participants and severe disturbance present in



Left: NSW/ACT YCS Youth Advisory Group
Right: Lyndal Moore (CNC)

approximately half of the sample. The WSYCS team are in the process of designing a follow up study to address this issue.

Lyndal Moore (CNC) recently graduated from the University of Newcastle with a Masters of Nursing (Advanced Practice). Lyndal is also taking part in the YCS Nursing Research Mentorship Program supported by CanTeen and has submitted her first ethics application on the topic: Investigating the proportion of AYA cancer patients in the Hunter New England Local Health District who are presented at MDT meetings and the associated clinical outcomes.

The "Link to Ink" tattoo project, covered in the April 2016 issue of YCS Matters, is currently on exhibition at the Calvary Mater Newcastle, and has received great interest from local media and the community. Julia Drake, Social worker for Hunter & Northern NSW YCS, is championing the initiative. Julia will be submitting an abstract to present this project at the Global AYA Cancer Congress in Edinburgh, December 2016. This will be a great opportunity to present the project to an international audience showcasing and acknowledging each cancer patient who exhibited their tattoo as an inspiring record of their survivorship.

Julia Drake also presented a case study at the recent Social Work Grief and Loss Professional Development Group for the Hunter and Northern NSW area, in May on the topic When a young person dies and the intervention of the YCS social worker. There were five rural sites who were involved with the presentation, which resulted in discussions centred around the importance and value of YCS teams, YCS intervention and support.



Youth Cancer Services are funded by the Australian Government and State / Territory health departments.

Youth Cancer Service Connecting young people living with cancer to specialist care and support