# Welcome.

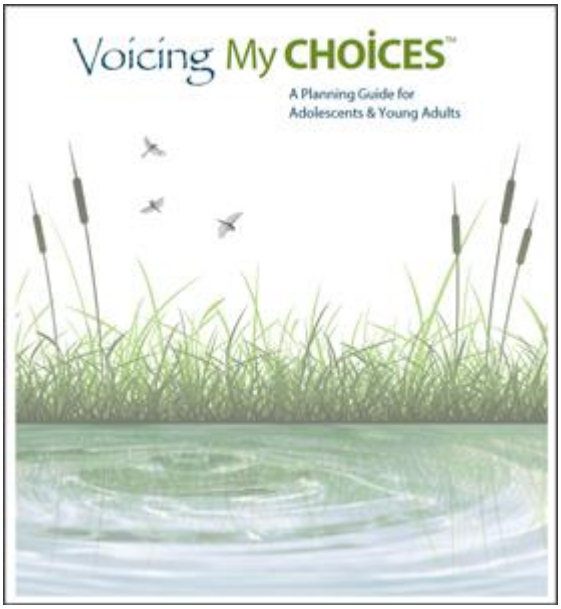
Dear *Difficult Discussions* Team,

Hello and welcome to our study newsletter. It has been a while since we last checked in, and a lot has happened since then! We have had some new team member transitions, advancement in data collection, and have begun to prepare a manuscript based on findings from Stage 1 interviews with healthcare providers.

We are excited to update you on the progress of the Difficult Discussion study ("Difficult Discussions: Helping young people to voice their choices at end-of-life"; funded by the HCF Foundation). Keep reading to learn more about the study activities since our last newsletter!

**Brief recap of the study**

The *Difficult Discussions* study aims to assess the perceived utility and acceptability of the advance care planning tool *Voicing My CHOiCES*™ *(VMC)* with Australian consumer groups, including adolescent and young adult (AYA) cancer survivors, cancer and cystic fibrosis patients, families (including bereaved families) and healthcare professionals. The study involves three stages:




**Stage 1** face-to-face interviews aim to gain feedback from the consumer groups about the utility and acceptability of the current VMC tool in the Australian context.

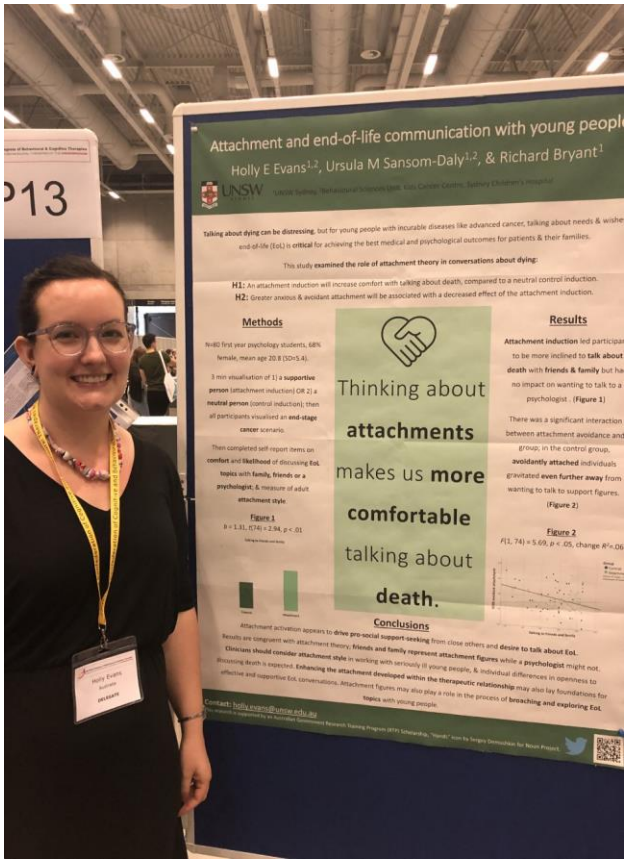
**Stage 2** will take the form of a focus group, exploring the proposed changes to the VMC tool, based on feedback from Stage 1.

**Stage 3** will be a pilot study in which the revised VMC tool will be evaluated by current AYA patients.

# Study Progress.

A lot has happened since our last newsletter! In April of 2019, Ursula returned from parental leave after the birth of her youngest son, Felix, in 2018. Additionally, our Research Assistant, Holly Evans, transitioned to PhD student status in 2018. As a result, we have brought on a new Research Assistant to the team, Stephanie Arteaga (right), who has been with us since January 2019. Stephanie is from San Francisco, California in the United States, and hold a Master's Degree in Public Health. Prior to working at the Behavioural Sciences Unit, Stephanie worked as a Research Associate the University of California, Berkeley, examining contraceptive decision-making and pregnancy intentions among young women and their male partners in the San Francisco Bay Area.

Our team has been very busy during 2019! Ursula recently promoted the study in a number of media features (radio and online; see ***Media*** below). Currently, we are working on recruiting a few more AYA participants for Stage 1 interviews before closing out this phase. Next we will finish synthesising data from Stage 1 and prepare a modified version of the *Voicing My CHOiCES*™ tool based on these data. This will be followed by initiation of recruitment for Stage 2 interviews through our professional networks at Sydney Children's Hospital and CanTeen. These interviews will use the 'think aloud' technique to prompt participants to respond to the proposed changes to the tool.




Holly Evans recently attended the World Congress of Behavioural and Cognitive Therapies in Berlin (left). She presented a poster on her PhD research which has focused on experimental studies exploring how young people approach conversations about death, using a sample of healthy first-year psychology students. Her first experiment has found that an attachment induction (which involved participants thinking about a close supportive person) increased participants' willingness to have end-of-life conversations. We look forward to seeing what else comes from Holly's PhD research!

Additionally, we are working on our first manuscript from study findings, a paper documenting healthcare professional's perceptions about barriers and facilitators to engaging in end-of-life discussions with AYA patients. Stay tuned for more information on this, and be sure to let us know if you'd like to be a part of the active writing group!

# Presentations.

Evans H.E., Sansom-Daly U.M., Wakefield C.E., Wiener L., Girgis A., Patterson P., Anazodo A., Sanson-Fisher R., Donovan L., Lindsay T., O'Dwyer C., Maguire F., Drew D., Jaffe A., Hetherington K., Baenziger J., Cohn R. Difficult discussions about end of life with adolescents and young adults. Invited presentation for the Cancer Counselling Professionals Psycho-oncology Conference, August 2018, Sydney Australia.

Sansom-Daly U.M., Wakefield C.E., Wiener L., Anazodo A., Cohn R.J., Patterson P., Girgis A., Sanson-Fisher R., Donovan L., Drew D. Bridging the gap between standards and 'standard-practice' using advance-care planning tools: The Difficult Discussions study. Oral presentation delivered at the 20th World Congress of Psycho-Oncology and Psychosocial Academy, October 2018, Hong Kong China.

Sansom-Daly U.M., Wakefield C.E., Wiener L., Anazodo A., Cohn R.J., Patterson P., Girgis A., Sanson-Fisher R., Donovan L., Drew D., O'Dwyer C., Maguire F., Matigian B., Lindsay T., Evans, H. How to talk about death when life is just beginning: Evaluating an advance-care planning tool for adolescents and young adults with cancer. Oral presentation delivered at the Global AYA Cancer Congress, December 2018, Sydney Australia.

Evans H.E., Sansom-Daly U.M., Bryant R.A., "It's a topic that everyone needs to encounter": What young adults think about care and conversations at end-of-life. Poster accepted for the Global AYA Cancer Congress, December 2018, Sydney Australia.

Sansom-Daly, U.M. (2019). Strategies for effective communication in caring for children with cancer. Invited oral presentation as part of a symposium entitled, Communication matters: conquering stigma, marginalisation and fear, as the Cancer Survivorship Conference, 29th March 2019, Sydney, Australia.

Sansom-Daly, U.M. (2019). *Distress, dignity & difficult discussions: Psychological interventions to support young people at end-of-life.* Invited half-day workshop at the Australian Psychological Society's College of Clinical Psychologists Annual Conference, 26th May, 2019, Melbourne, Australia.

Evans, H.E., Sansom-Daly U.M., Bryant, R. Attachment and end-of-life communication with young people. Poster accepted for the World Congress of Behavioural and Cognitive Therapies, July 2019, Berlin, Germany.

Evans, H.E., Sansom-Daly U.M., Bryant, R. Activating Attachment Impacts Young People's Approach to Conversations About Death. Talk accepted for the Australasian Conference of Traumatic Stress, September 2019, Sydney, Australia.

Evans, H.E., Sansom-Daly U.M., Bryant, R. Tackling taboos with young people: The role of attachment in end-of-life conversations with adolescents and young adults. Poster accepted for the Public Health Palliative Care International Conference, October 2019, Leura, Blue Mountains, Australia.

Sansom-Daly, U.M., Wakefield, C.E., Cohn, R.J., Girgis, A., Anazodo, A., Patterson, P., Darlington, A-S., Poort, H., Rosenberg, A., Weaver, M., Mack, J., Haase, J., Phillips-Salimi, C., Wernli, K., Fernando, R., Donovan, L., Trethewie, S., Herbert, A., Fair, D., Kirchhoff, A., Lindsay, T., Schulte, F., Mosher, P.,[26] Al-Awamer, A., Sue, L., Evans, H., Wiener, L.. (2019) *Opening the door: Equipping and empowering healthcare professionals to engage young people in gold-standard end-of-life communication.* Accepted for an oral presentation at the Public Health Palliative Care International Conference, 13-16th October 2019, Leura, Blue Mountains, Australia.

# Media.

Interviewed (live) on ABC Newcastle's Mornings program with Kia Handley. Segment entitled *'Why we need to talk about the end of our lives more.'* https://www.abc.net.au/radio/newcastle/programs/mornings/end-of-life-convesations/11152256

Interviewed on Sunday Nights with Rev. Bill Crews show, 2GB. Segment entitled *'Planning for your death.'* https://www.2gb.com/podcast/planning-for-your-death/

Interview on ABC Triple J Hack with Nkayla Afshariyan. Segment entitled *'End-of-life conversations are hard, but they can empower young people.'* https://www.abc.net.au/triplej/programs/hack/end-of-life-conversations-aid-better-death-for-young-people/11293128

# The Team.

We would like to extend our appreciation to all our national and international collaborators, for your continuing assistance, guidance and invaluable contribution to the study:

**University of New South Wales / Kids Cancer Centre, Sydney Children's Hospital**

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**University of Newcastle**

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**National Cancer Institute, USA**

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Ms Lyndal Gray

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Ms Toni Lindsay