



Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Sansom-Daly, UM;Wakefield, CE;Bryant, RA;Patterson, P;Anazodo, A;Butow, P;Sawyer, SM;McGill, BC;Evans, HE;Cohn, RJ

Title:

Feasibility, acceptability, and safety of the Recapture Life videoconferencing intervention for adolescent and young adult cancer survivors

Date:

2019-02-01

Citation:

Sansom-Daly, U. M., Wakefield, C. E., Bryant, R. A., Patterson, P., Anazodo, A., Butow, P., Sawyer, S. M., McGill, B. C., Evans, H. E. & Cohn, R. J. (2019). Feasibility, acceptability, and safety of the Recapture Life videoconferencing intervention for adolescent and young adult cancer survivors. *Psycho Oncology*, 28 (2), pp.284-292. <https://doi.org/10.1002/pon.4938>.

Persistent Link:

<https://hdl.handle.net/11343/284792>

Sansom-Daly Ursula (Orcid ID: 0000-0003-4200-8900)
Butow Phyllis (Orcid ID: 0000-0003-3562-6954)

**Feasibility, acceptability, and safety of the Recapture Life videoconferencing
intervention for adolescent and young adult cancer survivors**

Ursula M.Sansom-Daly,*^{1,2,3}_Claire E.Wakefield,^{1,2}_Richard A.Bryant,⁴_Pandora
Patterson,^{5,6}_Antoinette Anazodo,^{2,3}_Phyllis Butow,⁷_Susan M.Sawyer,^{8,9,10}_Brittany
C.McGill,^{1,2}_Holly E.Evans,^{1,2}_Richard J.Cohn,^{1,2} & *The-Recapture-Life-Working-
Party*

¹School of Women's/Children's Health, UNSW Sydney, Australia.

² Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital,
Australia.

³Nelune Comprehensive Cancer Centre, Prince of Wales Hospital, Australia.

⁴School of Psychology, UNSW Sydney, Australia.

⁵Research, Evaluation and Social Policy Unit, CanTeen, Australia.

⁶Cancer Nursing Research Unit, Sydney Nursing School, The University of Sydney,
Australia.

⁷Centre for Medical Psychology & Evidence-based Decision-making (CeMPED),
School of Psychology, University of Sydney, Australia.

⁸Department of Paediatrics, University of Melbourne, Australia.

⁹Murdoch Children's Research Institute, Australia.

¹⁰Royal Children's Hospital Centre for Adolescent Health, Australia.

***Correspondence:**Dr.-Sansom-Daly._T:+612-9382-3114._E:ursula@unsw.edu.au

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: [10.1002/pon.4938](https://doi.org/10.1002/pon.4938)

KEYWORDS:adolescent;_feasibility;_cancer;_psychological_interventions;_oncology;
_online_video-conferencing;_survivorship;_young_adult.

ABSTRACT

Objective: Online psychological therapies provide a way to connect adolescent and young adult (AYA) cancer survivors to evidence-based support. We aimed to establish the feasibility, acceptability, and safety of *Recapture life*, a six-session group-based online cognitive-behavioural intervention, led by a facilitator, for AYAs in the early post-treatment period.

Methods: A randomised-controlled trial (RCT) compared *Recapture Life* to an online peer-support group control and a waitlist control. Participants could nominate a support person. Acceptability was assessed using study opt-in and retention rates, participant-reported benefits/burdens of participation, and group facilitator burden. We also assessed the feasibility (e.g.,-frequency/impact of technological difficulties) and psychological safety (i.e.,-occurrence of clinically-concerning distress) of the program.

Results: Sixty-one participants took part (45 AYAs, 51.1% female;-19 support people). The opt-in rate was 30%, the enrolment rate was 87%, and 75% of participants took part in $\geq 5/6$ sessions. AYAs reported high benefit and low burden of participation. Overall, 95 online group sessions were conducted; few required rescheduling by group facilitators (3%), but many took place outside of office-hours (~90 hours). It took 40 days on average to create online groups, but established weekly sessions commenced quickly ($M=4.0$ minutes). Technological difficulties were common but had a low impact on intervention delivery. Although 54% of AYAs returned a clinically-concerning distress screen at some point, none reflected acute mental health risks.

Conclusions: The data largely indicates that *Recapture Life* is an acceptable, feasible, and safe model of evidence-based psychological support for AYAs during early survivorship, that nevertheless experienced common challenges in online/AYA intervention delivery.

Background

A cancer diagnosis during the adolescent and young adult (AYA) years compounds the challenges of this already complex developmental period, including mental health risks.^{1,2} Within 12-months of diagnosis of cancer, clinical-level distress is seen in about a quarter of AYAs³ that does not substantively decrease over the next year.⁴ Compared with cancer-free peers, AYAs remain at significantly higher risk for suicidal behaviour in the year post-diagnosis and up to five years later.⁵ Even beyond five years, 25-40% of AYAs experience ongoing unmet needs related to their identity, social isolation, difficult emotions, survivorship, and life direction.⁶ Such unmet supportive-care needs are associated with ongoing psychological distress.^{7,8}

Intervening at earlier points of vulnerability may help to prevent the mental health burden of long-term survivorship. The time of transition ‘off-treatment’ can present a point of psychosocial risk, including a mental health crisis,⁹ as AYAs grapple with the aftermath of their cancer experiences whilst simultaneously attempting to rejoin pre-cancer communities and recommence old routines.¹ AYAs in rural or remote communities can experience particular challenges in accessing specialist psychosocial services close to home once hospital-based support systems are withdrawn post-treatment.¹⁰ AYA survivors may also lack contact with peers who have been through a similar experience,⁷ and can feel disconnected from existing social networks in their home communities.¹¹ Connecting with peer survivors has been highlighted as an important developmental need by AYAs,¹² and is an important focus of distress-reducing interventions in this group.¹³

E-mental health programs have the capacity to remove many barriers to high-quality psychological support for AYA cancer survivors. A large body of evidence supports the feasibility and efficacy of online psychological interventions for depression, anxiety, post-traumatic stress disorder, and addiction among adults without cancer.^{14,15} Online psychological support also appears acceptable and feasible for supporting young people with mental health problems.^{16,17} Considerably less evidence is available regarding videoconferencing-based online programs,^{18,19} although one meta-analysis has suggested that online interventions with more therapist input have greater effects.¹⁷ Videoconferencing-based interventions are also a closer approximation to ‘real life’ clinical interactions,²⁰ and may thus be more appealing to patient users and require less adaptation on the part of the therapist.

Videoconferencing-based platforms have begun to be used internationally with AYAs with cancer.¹⁸ While early evidence suggests that videoconferencing may be acceptable,¹⁸ very limited data has been published, especially within AYA cancer survivors. Data are also lacking to support the safety of using online platforms for vulnerable groups, including AYA cancer survivors.^{21,22} Given the potentially serious consequences of uncontrolled distress in this population, and mental health providers’ potential concerns about managing patient distress and risk remotely, establishing the safety of videoconferencing interventions is critical to supporting their adoption within clinical practice.^{21,22}

Our group developed the ‘*Recapture Life*’ program²³ to target the vulnerable period soon after the completion of cancer treatment using a secondary prevention

approach.²⁴ Delivered using group-based videoconferencing, *Recapture Life* uses evidence-based cognitive-behavioural therapy (CBT) coping strategies that are tailored to common concerns reported by AYAs in early cancer survivorship.²³ This program aims to improve quality of life and general functioning, and to reduce distress for AYA cancer survivors in the early post-treatment period. We have previously reported that important therapeutic processes translated well online,¹³ and that we were able to manage clinically-challenging incidents (e.g., participants' acute distress) in a timely and appropriate manner throughout the trial.²² With a view to strengthening the broader evidence-base for online interventions in AYA oncology, we aimed to answer the following research questions:

1. How acceptable is a videoconferencing-based group-format intervention (*Recapture Life*) to diverse AYAs in early survivorship?
2. How feasible is *Recapture Life* to deliver?
3. How safe is *Recapture Life* in terms of ensuring participants' wellbeing and psychological safety throughout the intervention and trial?

Methods

The Recapture Life intervention

The development of *Recapture Life* has been previously described in detail.²³ It involves six, weekly, small-group sessions led by a facilitator (two psychologists; USD/BM), during which 3-5 AYAs discuss common challenges of cancer survivorship and learn evidence-based CBT coping strategies. The program is framed as a way for AYAs to learn coping skills applicable to all aspects of life after cancer, regardless of

distress levels. AYAs also receive a workbook containing further psycho-educational information (to reinforce session content) as well as weekly home-practice exercises to help them master the coping strategies learnt in-session.²³ AYAs may also invite a support person (e.g., parent, partner/spouse) to participate, who receive a single telephone consultation with the facilitator before the group commences. The purpose of the support person telephone consultation is to discuss the AYA's and family's experiences in relation to the focus and goals of the program. Support persons then receive weekly psycho-educational emails summarising session content, and tips about how to support and communicate with their participating child/partner.

Study Design

This phase II feasibility RCT used a three-armed design to compare the *Recapture Life* intervention with both an active peer-support group control and a three-month waitlist control.²³ As this paper is interested in assessing the acceptability and feasibility of online therapeutic interventions generally, and not differences between the trial arms, we report all data in the aggregate.

The South Eastern Sydney Local Health District-Northern Sector Human Research Ethics Committee approved the trial (REF#12/008-HREC/12/POWH/14; Australian/New Zealand Clinical Trials Registry number: ACTRN12610000717055) with site-specific approval subsequently received from 11 hospital sites nation-wide.²⁵

Participants

Participants were recruited through 10 Australian paediatric and adult hospitals. Each site's local investigator (oncologist, psychologist, social worker, occupational

therapist or nurse) identified potential participants through clinic lists, who were then mailed a study invitation. We also advertised the study through several community-based cancer support organisations including CanTeen Australia. Eligible participants were aged 15-25 years (the Australian definition of 'AYA' aligning with AYA-specific clinical services) at the end of curative cancer treatment completion, and were within 12-months post-treatment at opt-in/consent. Participants were ineligible if they (i) did not speak English; (ii) demonstrated active suicidality, psychosis, and/or severe depression, or (iii) had incurable cancer with no remission achieved (i.e.,- active/progressing disease). AYAs were eligible to participate regardless of their degree of residential rurality; this was classified according to the Accessibility/Remoteness Index of Australia.²⁶

Measures

Data was collected from both AYA participants and support person participants at four time-points across the course of the trial (see Figure 1).²³

Feasibility. We examined several logistical aspects of delivering *Recapture Life*, including the: (i) recruitment rates across sites; (ii) mean days to group commencement (with a minimum number of participants); (iii) median time for session commencement (the difference between the scheduled session start-time and the time that the last group member 'logged in'); (iv) proportion of eligible, interested AYAs who had the technological equipment and internet access required to participate; (v) number and type of technological difficulties experienced across sessions and described in facilitators' notes (categorized and into audio, visual and/or internet

difficulties, then counted in a content analysis approach), and the perceived impact of these on content delivery (rated on a 10-point scale from 1=*No impact* to 10=*High level of impact*); (vi) time taken to check participants' between-session emotional safety using email/text inquiries; and vii) total number of additional catch up sessions conducted for AYAs who missed their group session, rescheduled group sessions, and group sessions scheduled outside of office hours (beyond 17:00 or on a weekend).

Acceptability. We followed recommendations²⁷ to measure the acceptability of *Recapture Life* from the AYA perspective using several indices. First, we calculated the trial's *opt-in* (total eligible and consenting AYAs/all AYAs approached), *enrolment* (total AYAs who consent/all eligible AYAs) and *retention rates*. We also calculated participant engagement (total group sessions attended), and completion rates for between-session homework. Both AYA and support person participants also responded to two previously used items,²⁸ namely “*Was participation in this study beneficial to you in any way?*” and “*Was participation in this study burdensome for you in any way?*” (0=*Not-at-all*-to-4=*Very-much*). Qualitative analysis of open-ended questionnaire responses was also used to further explore participants' experiences with the program.

Safety. Participants' psychological safety during the intervention was ascertained using the validated Emotion Thermometers Tool.²⁹ Previously used in a range of oncology settings,^{29,30} the Emotion Thermometers Tool uses five images of thermometers to gauge the extent to which participants experienced distress, anxiety, depression, anger, and need for help in the past week, on a self-report scale ranging

from 0 (no distress) to 10 (high/extreme distress). This tool was sent to participants by email between sessions or by SMS text messages sent by the trial research officer. These emails/messages also asked about participants' engagement with the weekly homework to practise CBT skills.

For the *Recapture Life* trial, we prospectively applied a risk-management approach;^{22,23} any participant who scored $\geq 7/10$ or recorded an increase of >3 points in any emotional domain was telephoned by their group facilitator who conducted a more in-depth assessment of the participants' distress and level of risk (e.g., suicide/self-harm). Any psychological risk was managed using pre-determined as well as case-specific management protocols.²² We examined the safety of *Recapture Life* by assessing the proportion of participants who: (i) returned clinically-concerning distress scores at any point; (ii) had distress scores which increased by a clinically-concerning amount (>3 points), and the proportion of these whose distress remained at this higher level at the following assessment; and (iii) were judged by the psychologist to be in a state of actual, immediate risk of harm upon further assessment. We also examined the trajectory of participant distress over the course of the online intervention, and whether this differed between *Recapture Life* and the peer-support control.

In the results, continuous variables are summarised by their mean and standard deviation or median and inter-quartile range as appropriate, while categorical variables are presented as frequencies and proportions.

Procedure

Figure 1 shows all participant contacts across the trial.

Results

Participants

Out of 148 eligible AYAs who were approached to participate, 52 were reached via phone or responded to study information received via mail (96 were uncontactable, either due to lack of interest, or incorrect contact details). Overall, 45 of the 148 (30%) chose to participate in the trial and progressed to the study baseline (23 female, 51.1%), with a mean age of 20.6 years ($SD=2.91$). Almost half had a support person take part (19, 45.2%; 13 were mothers, 68.4%, M_{age} : 44.4 years, $SD=11.7$; four spouses/partners, 21%, M_{age} : 22 years, $SD=1.5$; one father, 5%, aged 49 years; and one sibling, 5%, aged 31 years). Blood cancers were the most common diagnosis ($n=21$, 47%), followed by solid tumours ($n=18$, 40%) and brain/central nervous-system cancers ($n=3$, 6.7%). AYAs had on average completed treatment eight months previously ($M=8.0$, $SD=4.6$, range: 1-19). Participants resided in five Australian states, an average of 86 kilometres from their nearest capital city ($SD=128$, range: 4-429 km). Most resided in areas classified as metropolitan ($n=30$, 67%), with nine in regional (20%) and three in remote (6.7%) communities.

Feasibility

Figure 2 depicts recruitment variability across sites, with each site recruiting an average of 4.1 participants (range 0-12). Table 1 outlines *Recapture Life's* feasibility end-points. Most participants (32/40, 80% [23/28, 82% metro; 9/12, 75% regional]) had access to all the required technology. Individuals waited on average 40 days (range: 5-107) from completing the baseline questionnaire until they could commence

their online group with a sufficient number of peers. Sessions took a median of four minutes to commence; 74% of sessions had all participants log-on within five minutes of the scheduled start time.

The two psychologists facilitating *Recapture Life* conducted a total of 95 online sessions overall, totaling >104 hours. Six additional ‘catch up’ sessions were delivered for participants who were unable to attend their scheduled group session. One group required an entire session to be rescheduled twice due to multiple members being unable to attend the original time (3% of all sessions). Overall, 10/12 groups required sessions to be scheduled out-of-hours, representing 60 online sessions across the trial (~90 hours).

Technological difficulties were common, being experienced at least once in 51/72 (71%) sessions, and two or more times in 27/72 (38%) total sessions within the trial. Content analysis of the post-session facilitator notes indicated that the most common type of technological difficulty was poor-quality audio and ‘drop-outs’ ($n=31$ sessions, 43%) and webcam images ‘freezing’ ($n=31$ sessions, 43%). Overall difficulties were rated as having a relatively low impact on facilitators’ delivery of session content ($M=2.1$, $SD=1.2$, Range 1-6).

Acceptability

Recruitment for the *Recapture Life* trial took place from April 2012-August 2015. Of the 45 baseline participants, there was an enrolment rate of 87% (39) who began an intervention; 36/39 completed the online program/waitlist (92%) and 24/36 completed the 12-month follow-up (67%). This represents an overall attrition of 47%

($n=21$). Participants' engagement with both online programs was high: 29 (21 participants in metropolitan areas; 8 participants in regional areas) attended at least 5/6 online sessions (74% [70% metro; 67% regional]) and only four (4 metro; 0 regional) participants missed ≥ 3 sessions (no differences between *Recapture Life* and peer-support groups). Figure 1 depicts recruitment and retention across all trial stages.

Most AYAs reported receiving significant benefit from the intervention 12-months later with few burdens reported (Table 1). No support persons reported any personal burden, however only some reported personal benefits for themselves (Table 1). Several themes emerged from participants' free-text responses regarding the program's benefits and burdens (Online Materials 1). Some noted that *Recapture Life* supported self-reflection, "*This program helped me pick apart the confusing feelings I was having and sorting them out in my mind into what I felt was normal, abnormal, positive, negative, helpful or unhelpful.*" (23-year-old female) and the development of coping skills, "*[It] gave me confidence to approach difficult aspects of my life, for example, telling new friends that I've had cancer, without getting upset whilst telling them about my experience.*" (20-year-old male). *Recapture Life's* normalising effects were powerful for many: "*It was a free space and I felt very open, cancer was normal in that space, which is rare in my day-to-day life, where I feel like I walk around with a heavy little secret sometimes.*" (26-year-old female) and, "*The smaller intimate groups were very helpful and allowed [us] to talk more about personal experience[s].*" (18-year-old female)

The burden perceived by AYAs included logistical elements (e.g., “...*time commitment during university, its emotional effects during a stressful time, and homework completion...*”; 20-year-old male) but also reflected participants’ sense of treading a fine-line between re-experiencing distressing cancer-related topics whilst also trying to return to ‘normality’ (e.g., “...*at the stage of testing my boundaries with new activities, e.g. work, at a fairly stressful time trying to balance new things.*”; 22-year-old female).

Recapture Life participants reported on average completing 51% (54% metro; 48% regional) of the set homework. Thirteen (65%; [8 (53%) metro; 6 (86%) regional]) participants reported completing at least ‘some’ of the homework following three or more of the *Recapture Life* sessions.

Safety

AYAs responded to between-session safety checks (Emotion Thermometers Tool) 81% of the time. Twenty-one AYAs (54% [15 (54%) metro; 6 (50%) regional]) returned a combined total of 40 clinically-concerning distress scores ($\geq 7/10$, or >3 -point increase since last screen) between sessions, across the course of the trial.. Of these, nine (22.5% [6 (19%) metro; 3 (33%) regional]) were for a score of 5-6/10, 18 (45% [14 (45%) metro; 4 (44%) regional]) for a score of 7/10, and 13 (32.5% [11 (35%) metro; 2 (22%) regional]) for a score $\geq 8/10$ on at least one domain. Of participants whose scores triggered a between-session telephone call, all were telephoned within 48 hours. An average of 1.8 (range: 1-4) email, text and/or phone calls was required to confirm safety. Upon further assessment, none were assessed to

be at immediate mental health risk. The majority (24/40, 60%) of the clinically-concerning distress scores over the course of the trial returned to a level of non-clinical concern at the next week's assessment. Average scores for each domain tended to decrease linearly over time with no meaningful distress increase evident in the average scores across the six weekly session (Figures, Online Materials 2).

Discussion

This evidence from multiple indices supports the acceptability, feasibility, and psychological safety of the *Recapture Life* program, but also illuminates the challenges of recruitment and online intervention delivery in this population. We successfully delivered the program to AYAs of different ages and genders, across metropolitan, regional and remote areas, and across five states in Australia. The relative gender balance of our participants differs from previous videoconferencing interventions with AYA survivors which have reflected the female predominance typically seen in psycho-oncology studies more broadly.^{18,31} While to some extent this reflects the extent that emotional distress is gendered, it also highlights the potential for online programs to overcome the barriers that prevent young men from accessing mental health support.³²

The *Recapture Life* trial opt-in rate was lower than expected. Challenges related to multi-site recruitment likely played a role.²⁵ Following delays in receiving ethical approval across different sites, recruitment varied considerably.²⁵ Four sites recruited no participants, and the remaining sites recruited between 1-18 AYAs each. It is plausible that investigators at different sites were differentially engaged in promoting

the study. Reviews suggest that in-person approaches from a nurse (rather than other disciplines) are most likely to lead to successful engagement of patients in research studies.³¹ Importantly, if on-the-ground, in-person, recruitment strategies are most effective, then steps need to be taken to ensure that local champions are well-supported; for example, by an on-site funded study officer.

Additionally, although cancer treatment-completion is a time of risk for increased distress,² AYAs are also known to be vulnerable to perceived stigma around mental health issues and help-seeking.³⁶ These developmental issues may have played a role in our lower than expected opt-in rates, notwithstanding that our enrolment and participation rates mirror that seen in other online interventions with AYA survivors. For example, Campo and colleagues reported an 'enrolment' rate of 64% consenting AYAs (compared to our 87%) and high program completion rates (as with our trial, 92%).¹⁸ These figures suggest that while accessing and recruiting AYAs to research may be challenging,^{37,38} online interventions may be a highly engaging way for a subset of AYAs to access support.

It took longer to form online groups than anticipated. While not ideal that AYAs waited just over a month for their group to start, this is comparable to average wait-times for community-based child/adolescent mental health services which range from 60 to >120 days.^{33,34} Once involved, AYAs were highly engaged, with an intervention enrolment rate of 87%, low attrition and excellent session attendance. *Recapture Life* participants also reported completing over half of the home-practice activities. Although there is little comparison data available among AYAs, these rates

appear comparable to homework compliance in adult psychological intervention trials.³⁵

We reported evidence that the Recapture Life program was highly acceptable to AYA participants, who commonly reported high levels of benefit and low levels of burden in participation. Although support persons also reported low levels of burden, the personal benefit derived appeared limited. The inclusion of the support person in the trial was designed to up-skill the AYAs' family/support system, and thus we may not necessarily expect that the support person would report personal benefit.²³ Future efficacy analyses will be able to yield the effect of support person participation on AYAs' mental health outcomes.

In support of the feasibility of the online model, our facilitators reported reasonably low impact of technological difficulties. The frequency of technological challenges, however, highlights that online programs involving 'live', synchronous therapeutic content need to proactively plan for this in their delivery. Mental health professionals often report hesitation in delivering treatments online due to the potential for technological difficulties.²¹ Our trial highlights that addressing and/or planning for this is essential.

However, the primary source of these difficulties was internet quality, rather than difficulties navigating the online software,¹⁸ which speaks to the utility of using online formats for young people. *Recapture Life* was delivered in Australia during a period when high-speed broadband Internet networks were largely unavailable and the quality of internet connections lagged behind other developed countries.³⁹ Estimated

rates of internet access in Australian households are currently 86%, however only 57% have access to high-speed/4G networks.⁴⁰ The fact that we delivered *Recapture Life* in the context of these local challenges is a testament to its feasibility; as Wi-Fi access and speeds improve internationally, videoconferencing programs will experience fewer challenges.

If the hallmarks of online interventions are reach and flexible service provision, then the mental health professionals who deliver these interventions need to have similarly flexible working arrangements. Given the high number of out-of-hours sessions delivered and the rescheduling/additional scheduling required in the *Recapture Life* trial, flexible working hours and job-sharing arrangements may be necessary to alleviate any potential burden on the professionals who deliver these services. We acknowledge that this may be difficult in tertiary healthcare settings, but may be better aligned with the strategic priorities of other organizations.

Our data also highlighted the psychological safety of *Recapture Life*, as participants' mean distress declined over the course of the intervention. Only a small proportion reported clinically-concerning increases in distress, and none reflected safety issues. We have previously described the comprehensive risk management procedures within the *Recapture Life* trial;²² the data here provide further support for the safety of online models among potentially vulnerable populations. Although international best-practice guidance for videoconferencing-based mental health treatments do not agree whether online models are clinically-appropriate for more high-risk groups,²¹ these data and our previously reported results²² strongly suggest

that videoconferencing interventions can be safely undertaken with AYA survivors. Indeed, it may be appropriate for future AYA survivorship interventions (that are not focused on providing support to AYAs with severe depression or who are at risk of harm) to adopt less intensive risk-screening procedures. Specifically, occasional spikes in distress may be interpreted as normative in the context of post-cancer adjustment, rather than assuming increased mental health risks requiring prompt facilitator follow-up. Overall, our data suggests that mental health providers can be further assured that participant distress and safety can be contained and effectively managed in an online intervention.

Study limitations

We have reported several process aspects of acceptability, feasibility, and psychological safety that have been rarely documented in the literature. These kinds of process indices are critical to enable other researchers and clinicians to develop and implement online interventions, with their ‘eyes wide open’ to potential challenges and trade-offs. Our safety data are particularly novel, and provide confidence around broadening access to online videoconferencing interventions to a range of diverse AYA survivors.

Nevertheless, our findings should be considered in the light of several limitations. The sample size was modest, and lower than our projected target; this may limit the generalisability of our findings to broader clinical populations. This is compounded by the difficulties we encountered in collecting research data from this population, with 47% attrition (missing data) up to the last questionnaire. Due to

limited resources across multiple recruiting sites, we do not know the exact denominator of AYAs approached and successfully reached, and also could not collect data on the AYAs who declined to participate. Consequently, we cannot know whether these AYAs differed systematically to our final sample in terms of demographics, rurality, or distress. Further, we acknowledge that in the context of a funded research trial, we were able to provide AYAs with the resources (e.g. internet dongles), to allow participation in *Recapture Life*, if required. We suggest that some funding for internet and technology resources for consumers should be factored in to estimates of the overall cost of delivering online programs, and otherwise may limited the accessibility of the program.

Clinical implications

These acceptability and safety data suggest that within the context of appropriate safety frameworks, clinicians working with AYAs should feel comfortable to extend their repertoire of services to include online videoconferencing programs. Such programs may be considered an adjunct as well as an alternative to face-to-face support.^{21,22} Future research, including future *Recapture Life* data, will clarify whether such programs achieve clinically-significant impacts on AYAs' mental health and quality of life. Analysis of efficacy data will also allow us to explore 'why' and 'how' online programs may work, in particular, by exploring differences between the *Recapture Life* intervention, peer-support control, and waitlist control groups. One unanswered question is whether online programs attract participants who would not otherwise participate in face-to-face interventions. Future research examining the

impact of online interventions on AYAs' use of other mental health services is also needed; positive experiences of online support may provide a gateway to AYAs accessing other professional supports, further mitigating mental health risks.

Conclusions

Recapture Life appears acceptable, feasible and safe for AYAs across several important participant- and facilitator-rated indices. Nevertheless, challenges remain, unique to AYA interventions and online programs. Examining future efficacy data of such online programs that take these feasibility challenges into account will be critical for the field.

References

1. Sansom-Daly UM, Wakefield CE. Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Translational Pediatrics*. 2013;2(4):167-97.
2. Merikangas KR, He J-p, Burstein M, Swanson SA, Avenevoli S, Cui L, et al. Lifetime Prevalence of Mental Disorders in U.S. Adolescents: Results from the National Comorbidity Survey Replication–Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry*. 2010;49(10):980-9.
3. Kwak M, Zebrack BJ, Meeske KA, Embry L, Aguilar C, Block R, et al. Trajectories of psychological distress in adolescent and young adult patients with cancer: a 1-year longitudinal study. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2013;31(17):2160-6.
4. Kwak M, Zebrack BJ, Meeske KA, Embry L, Aguilar C, Block R, et al. Prevalence and predictors of post-traumatic stress symptoms in adolescent and young adult cancer survivors: a 1-year follow-up study. *Psychooncology*. 2013;22(8):1798-806.
5. Lu D, Fall K, Sparen P, Ye W, Adami HO, Valdimarsdottir U, et al. Suicide and suicide attempt after a cancer diagnosis among young individuals. *Ann Oncol*. 2013;24:3112–7.
6. Millar B, Patterson P, Desille N. Emerging adulthood and cancer: how unmet needs vary with time-since-treatment. *Palliative & supportive care*. 2010;8(2):151-8.
7. Sawyer SM, McNeil R, McCarthy M, Orme L, Thompson K, Drew S, et al. Unmet need for healthcare services in adolescents and young adults with cancer and their parent carers. *Support Care Cancer*. 2017;25(7):2229-39.
8. McCarthy MC, McNeil R, Drew S, Orme O, 2, Sawyer SM. Information needs of adolescent and young adult cancer patients and their parent-carers. *Support Care Cancer*. 2018;26:1655–64.
9. Wakefield C, McLoone J, Butow P, Lenthen K, Cohn R. Support after the completion of cancer treatment: Perspectives of Australian adolescents and their families. *European journal of cancer care*. 2013;22(4):530-9.
10. Meadows GN, Enticott JC, Inder B, Russell GM, Gurr R. Better access to mental health care and the failure of the Medicare principle of universality. *Med J Aust*. 2015;202(4):190-4.
11. Choquette A, Rennick J, Lee V. Back to school after cancer treatment: Making sense of the adolescent experience. *Cancer Nurs*. 2016;39(5):393-401.
12. Olsson CA, Boyce MF, Toumbourou JW, Sawyer SM. The role of peer support in facilitating psychosocial adjustment to chronic illness in adolescence. *Clin Child Psychol Psychiatry*. 2005;10(1):78-87.
13. McGill BC, Sansom-Daly UM, Wakefield CE, Ellis SJ, Robertson EG, Cohn RJ. Therapeutic Alliance and Group Cohesion in an Online Support Program for

- Adolescent and Young Adult Cancer Survivors: Lessons from "Recapture Life". *J Adolesc Young Adult Oncol*. 2017;6(4):568-72.
14. Christensen H, Hickie IB. Using e-health applications to deliver new mental health services. *The Medical journal of Australia*. 2010;192(11 Suppl):S53-6.
 15. Gainsbury S, Blaszczyński A. A systematic review of Internet-based therapy for the treatment of addictions. *Clin Psychol Rev*. 2011;31(3):490-8.
 16. Ye X, Bapuji SB, Winters SE, Struthers A, Raynard M, Metge C, et al. Effectiveness of internet-based interventions for children, youth, and young adults with anxiety and/or depression: a systematic review and meta-analysis. *BMC Health Serv Res*. 2014;14:313.
 17. Hollis C, Falconer CJ, Martin JL, Whittington C, Stockton S, Glazebrook C, et al. Annual Research Review: Digital health interventions for children and young people with mental health problems - a systematic and meta-review. *J Child Psychol Psychiatry*. 2017;58(4):474-503.
 18. Campo RA, Bluth K, Santacroce SJ, Knapik S, Tan J, Gold S, et al. A mindful self-compassion videoconference intervention for nationally recruited posttreatment young adult cancer survivors: feasibility, acceptability, and psychosocial outcomes. *Support Care Cancer*. 2017;25(6):1759-68.
 19. Zhou E, Partridge A, Blackmon J, Morgan E, Recklitis C. A pilot videoconference group stress management program in cancer survivors: lessons learned. *Rural and remote health*. 2016;16(3863).
 20. Freeman LW, White R, Ratcliff CG, Sutton S, Stewart M, Palmer JL, et al. A randomized trial comparing live and telemedicine deliveries of an imagery-based behavioral intervention for breast cancer survivors: reducing symptoms and barriers to care. *Psychooncology*. 2015;24(8):910-8.
 21. Sansom-Daly UM, Wakefield CE, McGill BC, Wilson HL, Patterson P. Consensus Among International Ethical Guidelines for the Provision of Videoconferencing-Based Mental Health Treatments. *JMIR Ment Health*. 2016;3(2):e17.
 22. Sansom-Daly UM, Wakefield CE, McGill BC, Patterson P. Ethical and Clinical Challenges Delivering Group-based Cognitive-Behavioural Therapy to Adolescents and Young Adults with Cancer Using Videoconferencing Technology. *Aust Psychol*. 2015;50(4):271-8.
 23. Sansom-Daly UM, Wakefield CE, Bryant RA, Butow P, Sawyer S, Patterson P, et al. Online group-based cognitive-behavioural therapy for adolescents and young adults after cancer treatment: a multicenter randomised controlled trial of Recapture Life-AYA. *BMC Cancer*. 2012;12:339.
 24. Durlak JA, Wells AM. Evaluation of indicated preventive intervention (secondary prevention) mental health programs for children and adolescents. *American journal of community psychology*. 1998;26(5):775-802.
 25. Sansom-Daly UM, Evans HE, Ellis SJ, McGill BC, Hetherington K, Wakefield CE. Something's got to give: time-cost trade-offs in site-specific research approval

can negatively impact patient recruitment in multi-institutional studies. *Intern Med J.* 2017;47(9):1088-9.

26. Dunne L, Hugo G, Bamford E. Measuring remoteness: accessibility/remoteness index of Australia (ARIA). Canberra: Commonwealth Department of Health and Aged Care, 2001: 1-25.
27. Kazak AE. Evidence-based interventions for survivors of childhood cancer and their families. *Journal of pediatric psychology.* 2005;30(1):29-39.
28. Wiener L, Battles H, Zadeh S, Pao M. Assessing the Experience of Medically Ill Youth Participating in Psychological Research: Benefit, Burden, or Both? *IRB.* 2015;37(6):1-8.
29. Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol.* 2007;25(29):4670-81.
30. Pepin AJ, Lippe S, Krajcinovic M, Laverdiere C, Michon B, Sinnett D, et al. How to interpret high levels of distress when using the Distress Thermometer in the long-term follow-up clinic? A study with Acute Lymphoblastic Leukemia survivors. *Pediatr Hematol Oncol.* 2017;34(3):133-7.
31. Wakefield CE, Fardell JE, Doolan EL, Aaronson NK, Jacobsen PB, Cohn RJ, et al. Participation in psychosocial oncology and quality-of-life research: a systematic review. *The Lancet Oncology.* 2017;18(3):e153-e65.
32. Doherty DT, Kartalova - O'Doherty Y. Gender and self - reported mental health problems: predictors of help seeking from a general practitioner. *Br J Health Psychol.* 2010;15(1):213-28.
33. Naughton J, Basu S, O'Dowd F, Carroll M, Maybery D. Improving quality of a rural CAMHS service using the Choice and Partnership Approach. *Australasian Psychiatry.* 2015;23(5):561-5.
34. Smith J, Kyle R, Daniel B, Hubbard G. Patterns of referral and waiting times for specialist Child and Adolescent Mental Health Services. *Child And Adolescent Mental Health.* 2017;23(1):41-9.
35. Scott TG, Lawrence PS, Rosemary ON-G. Measuring Homework Compliance in Cognitive-Behavioral Therapy for Adolescent Depression: Review, Preliminary Findings, and Implications for Theory and Practice. *Behav Modif.* 2006;30(5):647-72.
36. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychol Med.* 2015;45(1):11-27.
37. Cantrell MA, Conte T, Hudson M, Shad A, Ruble K, Herth K, et al. Recruitment and retention of older adolescent and young adult female survivors of childhood cancer in longitudinal research. *Oncol Nurs Forum.* 2012;39:483-90.
38. Tonorezos ES, Oeffinger KC. Research challenges in adolescent and young adult cancer survivor research. *Cancer.* 2011;117:2295- 300.

39. Tucker R. The Tragedy of Australia's National Broadband Network. *Australian Journal of Telecommunications and the Digital Economy*. 2017;5(1):116.
40. Australian Bureau of Statistics. Internet activity, Australia, December 2017 (Catalogue No. 8153.0). 2018.

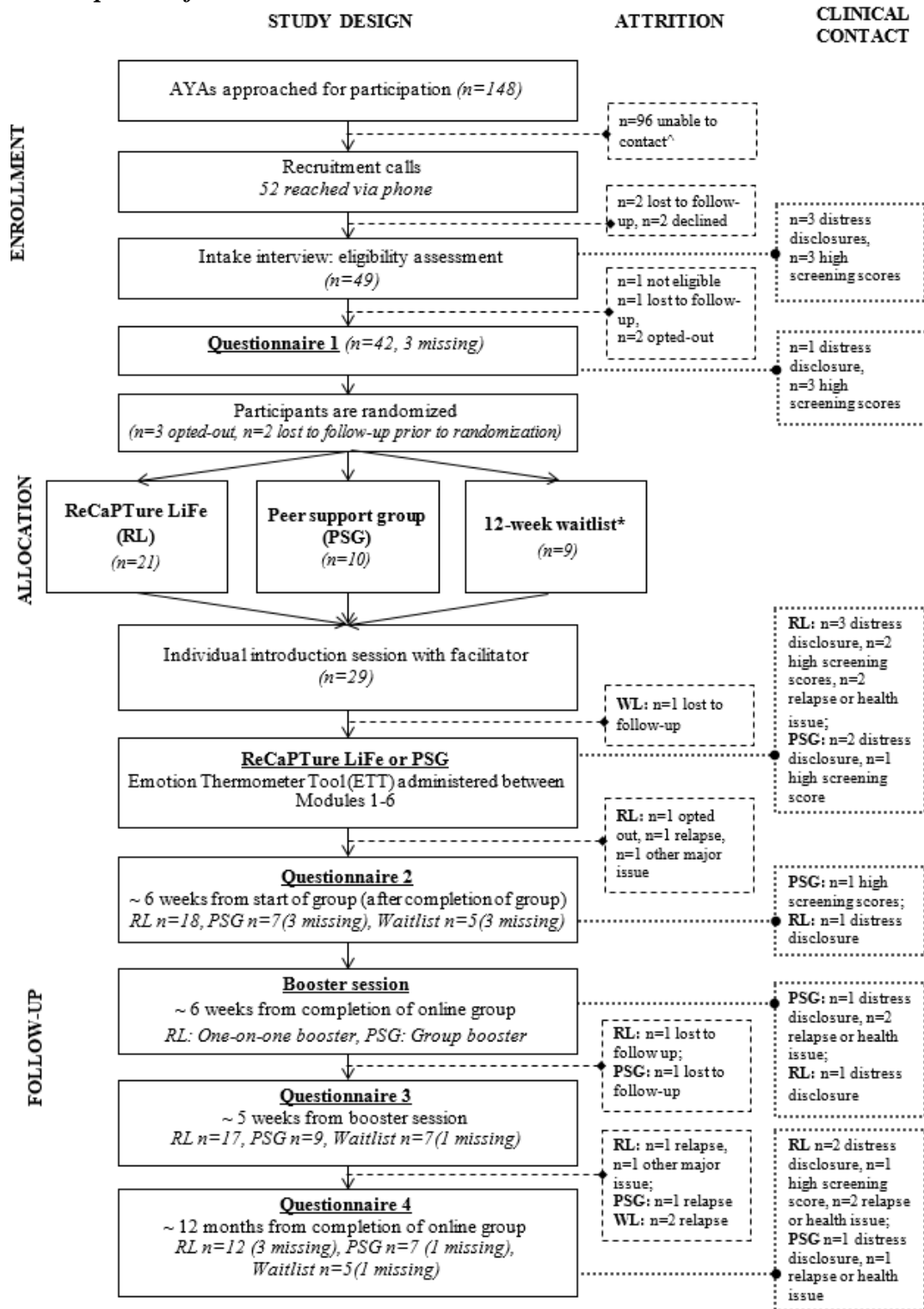
Table 1. Feasibility indices within the *Recapture Life* trial

			Metropolitan; Regional
Access	Number-of-AYAs-with-required-technological-equipment_(%)	32_(80%)	23 (82%); 9 (75%)
Timing	Time-to-form-groups_(Mean-days_[range],_SD)	83_[5-280],_60.5	NA
	Time-to-start-of-session_(Median-minutes_[range],_IQR)	4_[0-30],_6	NA
Technological difficulties	Number-of-sessions_(%)	51_(71%)	NA
	Resulting-time-lost-in-session_(Mean-minutes_[range],_SD)	6.7_[0-30],_8.8	NA
	Facilitator-rated-impact-on-content-delivery,_1-10_scale_(Mean_[range],_SD)	2.1_[1-6],_1.2	NA
Engagement	Between-session-homework-completion_(Mean_%_[range],_SD)	51_[0-100],_45	54, 44; 48, 46
<i>AYAs</i>	High-perceived-benefit [†] Post-booster-session_/_12m-FU_[N_(%)]	20_(61%)/_16_(70%)	13 (59%) / 12 (75%); 7 (64%) / 4 (57%)
	Low-perceived-burden [‡] Post-booster-session_/_12m-FU_[N_(%)]	30_(91%)/_20_(87%)	20 (91%) / 14 (88%); 10 (91%) / 6 (86%)
<i>Support persons</i>	High-perceived-benefit [†] Post-booster-session_/_12m-FU_[N_(%)]	3_(25%)/_1_(11%)	1 (11%) / 1 (13%); 2 (67%) / 0 (0%);

	Low-perceived-burden [‡] Post-booster-session_/_12m-FU_[N_(%)]	12_(100%)/_9_(100%)	9 (100%) / 8 (100%); 3 (100%) / 1 (100%)
--	--	---------------------	---

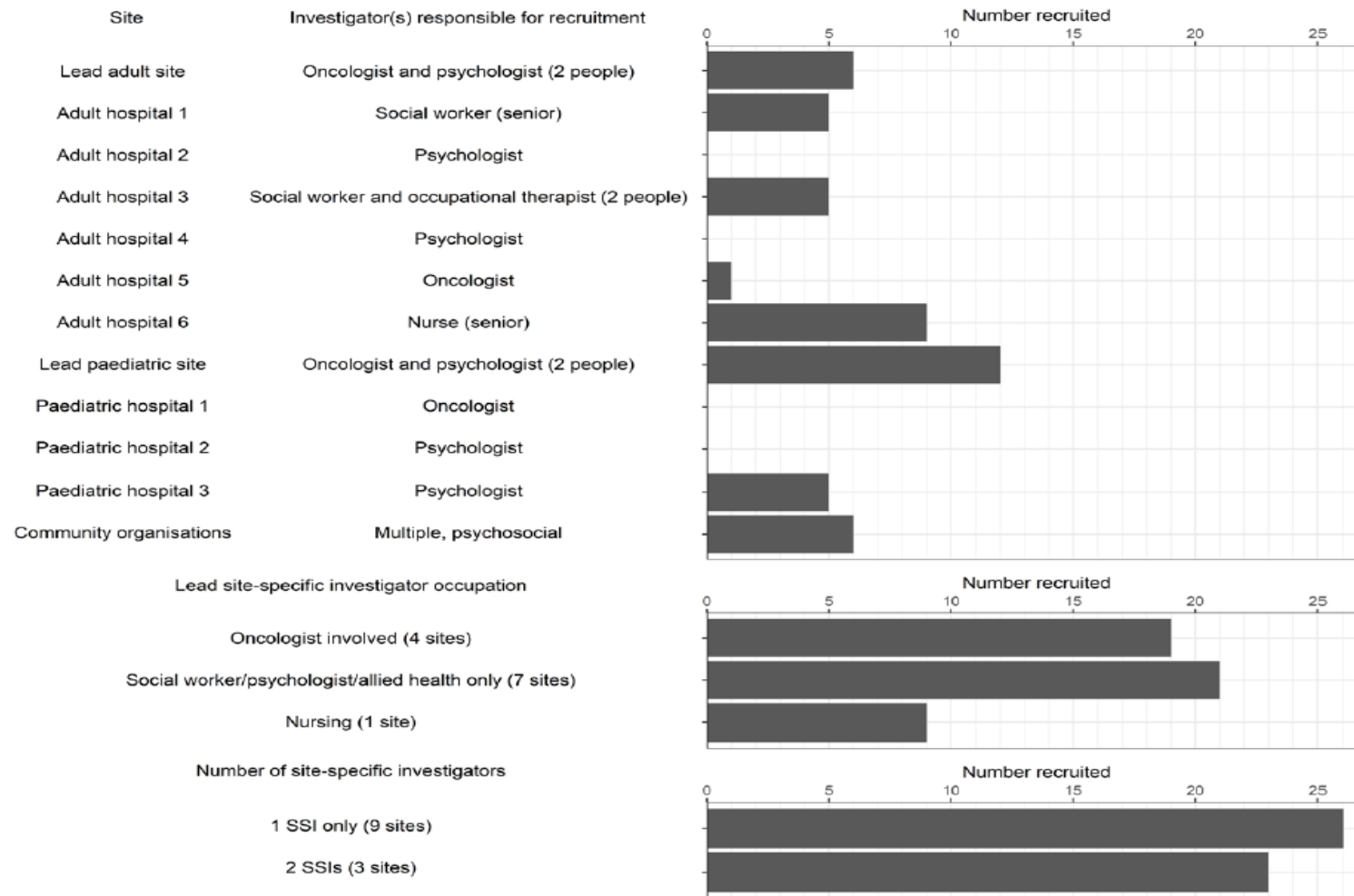
Note: Statistics represent summary statistics across all trial arms, with the exception of homework completion. AYA=adolescent and young adult; FU=follow-up; U(x,y)=Mann-Whitney U test statistic, with n₁=x, n₂=y observations in each group. †comprised 'quite a bit' and 'very much' benefit ratings; ‡comprised 'not at all' and 'a little bit' burden ratings.

Figure 1. Rates of recruitment, retention and clinical contacts over the course of the *Recapture Life* trial



^ Study team attempted contact but received no response, unclear whether due to incorrect contact information or disinterest in participation. *Followed by repeat of questionnaire 1 and re-randomisation to PSG or RL. **Notes.** 'Distress disclosure': participant requiring follow-up contact following disclosure of distress to Recapture Life team (during/outside of session), or facilitator clinical-judgment (e.g. flat affect observed in-session). 'High screening scores': scores above cut-offs on either the Emotion Thermometers Tool or DASS21. Abbreviations: RL: ReCaPTure LiFe, PSG: Peer support group.

Figure 2. Recruitment variability by hospital site and site-specific investigator (SSI) attributes



Acknowledgements

In addition to the named authors, the wider *Recapture Life Working Party* includes Ms Kate Thompson, Ms Lucy Holland, Dr Belinda Barton, Ms Belinda Matigian, Ms Lyndal Gray, Dr Michael Osborn, Ms Meg Plaster, and Dr Marianne Phillips. We would also like to thank Lauren Carlson, Emma Doolan, Sarah Ellis, Fiona Maguire, Kate Marshall, Sanaa Mathur, Catherine O'Dwyer, Eden Robertson, and Helen Wilson for their contributions to this study. The *Recapture Life* study was co-funded by a *beyond blue* and Cancer Australia project grant (ID: 1022868). It was also endorsed by the Psycho-Oncology Cooperative Research Group (PoCoG), Australia. Ursula Sansom-Daly is supported by an Early Career Fellowship from the Cancer Institute of New South Wales (ID: 14/ECF/1-11) and an Early Career Fellowship from the National Health and Medical Research Council of Australia (APP1111800). Claire Wakefield is supported by a Career Development Fellowship from the National Health and Medical Research Council of Australia (APP1143767) and an Early Career Development fellowship from the Cancer Institute of NSW (ID:11/ECF/3-43). The Behavioural Sciences Unit is proudly supported by the Kids with Cancer Foundation, by the Kids Cancer Alliance, as well as a Cancer Council New South Wales Program Grant (PG16-02) with the support of the Estate of the Late Harry McPaul.