

Recruiting cancer survivors into research studies using online methods: a secondary analysis from an international cancer survivorship cohort study.

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Abstract

Recruiting participants into cancer survivorship research remains a significant challenge. Few studies have tested and compared the relative use of non-clinical online recruitment methods, especially in samples of adult cancer survivors. This paper reports on the feasibility of recruiting a representative cohort of cancer survivors using online social media. Two-hundred participants with a cancer diagnosis within the past 12 months were recruited via social media (Facebook, Twitter, Reddit) into a longitudinal questionnaire study. Different methods of online recruitment proved to be more effective than others over time. Paid Facebook boosting, Reddit posts, and Twitter adverts placed by existing cancer charities proved most helpful in reaching our recruitment target (contributing 27%, 22% and 32% respectively). Recruiting online achieved a more demographically and clinically representative sample for our study: our sample was younger, less heteronormative, including those with a range of clinical diagnoses, primary and recurrence illness, and patients who had both completed and were still receiving treatment. This was certainly not a quick method of sample recruitment but that could have been optimised by focussing only on the three most effective methods describe earlier. Whilst we found that online recruitment is significantly lower cost than traditional recruitment methods, and can reduce some biases, there still remains the potential for some biases (e.g. excluding much older participants) and ethical/methodological issues (e.g. excluding those without access to the internet). We outline our recruitment strategy, retention rates, and a cost breakdown in order to guide other researchers considering such methods for future research in cancer survivorship.

Keywords: Survivorship, online, recruitment, methodology, psychosocial

Background

Recruiting patients into cancer survivorship research presents a significant challenge, and yet continued research on this growing population is necessary, particularly to address psychological supportive care needs [1]. There remains a lack of awareness of the barriers to recruitment in this population. Failing to address these barriers may increase the risk of publication bias [2], particularly in randomised clinical trials [3]. Psychosocial oncology research often tends towards the quantitative and makes heavy use of inferential statistics, the primary purpose of which "...is to draw inferences about parameters (characteristics of populations) from statistics (characteristics of samples)." [4]. The processes by which participants are recruited are the pillars upon which rests the external validity of research studies. However, the more recruited samples differ from the population of interest, the less confidence we can have in the external validity or generalisability of the findings. In cancer survivorship research, such threats to validity are particularly acute.

Why is recruitment so challenging?

Barriers to recruitment in health research can include: resources (mainly cost and funding restrictions); patient ineligibility (e.g., cancer stage, comorbidities, risk of death); failure to participate due to poor or decreasing health; and, preference for specific treatments and patient characteristics [2,5]. Language barriers, infrastructure (e.g. additional hospital visits/travel time) and participant characteristics (especially altruism) may also be important predictors willingness to participate in research [6], in both patients and caregivers [3]. Emphasising the benefits of research participation, using information technology to create easier routes into participation for those with access issues [6], and allowing self-referral into research [7] may improve recruitment rates and provide information about demand and patient characteristics.

Recruitment rates into trials of interventions are often higher than observational or questionnaire-based studies as the benefits of participation (receiving an intervention) are more explicit. However, longitudinal questionnaire studies have an important place in survivorship research by modelling which variables — demographic, clinical, and psychosocial — predict changes in wellbeing over time. This can be useful for clinical monitoring and risk stratification [8] and to identify potential statistical moderators of patient-reported outcomes [1,9] thus informing data-driven intervention design. Recruiting into these studies is typically even more challenging [10]; perceived burden is high and individual benefit less clear.

Survey studies in cancer survivorship most typically recruit from the clinical setting. Within the UK, however, this is becoming increasingly difficult. Putting aside problems of clinical gatekeeping [6,11], increasingly limited health-care resources may lead to de-prioritisation of research promotion. One potential solution, implemented in the UK in 2004, was the development of the UK Clinical Research Network (UKCRN) which has resulted in better quality and regulated research [12]. Research that is adopted onto the UKCRN Portfolio can use a dedicated team of Research Nurses based usually in the clinical setting to help with recruitment [13]. However, this increases the cost of survivorship research, and limits access to only those studies eligible for portfolio adoption; research funded by non-NIHR affiliated charities, Universities, and the majority of postgraduate research are excluded. Of those adopted, priority is given to treatment trials over survivorship research: only 2.1% of patients entered into UK clinical cancer trials between 2012 and 2014 were recruited to psychosocial oncology and survivorship research [14]. Alternative recruitment methods have included platforms such as local radio, postal invitation or newspaper advertisement with varying success.

Is online recruitment a potential solution?

There is a growing interest in the use of online social media in research [15], but currently this is rare in cancer survivorship. This may be a demographic issue that will resolve over time. Compared to other research where online recruitment is common, the cancer survivor population is older [16]; however, social media use is increasing in older populations [17] and 71% of the 55-75 year age group in the UK now own a smartphone [18]. In one acceptability study, 79% of childhood cancer survivors (18-48 years of age) reported positive attitudes towards the use of social media in research study recruitment, with 80% reporting at least weekly use of social media [19]. As cultures become increasingly digital, these methods of recruitment become more possible in cancer survivorship research.

Facebook currently has 2.23 billion users worldwide [20] and provides a platform in which to post to specific groups, or pay to advertise to the whole Facebook community. Whitaker et al systematically reviewed the use of Facebook for healthcare research recruitment concluding several benefits: reduced cost; quicker recruitment; and more representative samples, particularly for hard to reach demographics [21]. Only one of the included studies was in cancer (recruiting parents of children with cancer) [22]. In 10.5 weeks, the advert generated 3,897,981 impressions (views) and 1050 clicks, with an average cost-per-click estimated at \$1.08. Forty-five of 300 people who went on to view the survey fully participated; at a total recruitment cost of \$1129.88, this study demonstrated the potential cost-effectiveness of this recruitment method for this population. Elsewhere, there are cautions: self-screening methods assume participant honesty, and recruitment rates in some studies are as low as 1% because advertisements are shown to millions of Facebook users worldwide [23].

Reddit is a free, forum-based platform, which tends towards more interactive discussion amongst community users than Facebook. Organized into a number of different discussion forums ('sub-reddits') organized around topic areas, posts can be commented on (as with Facebook), and can be 'up-' or 'down-voted' by group members as a way of indicating post priority (similar to a Facebook 'like'). Data from January 2019 indicated that 1.65 billion people had used Reddit in the preceding 12 months [24]. Reddit may enable the targeting of more specific populations than Facebook [25]. To our knowledge, no studies have reported on the efficacy of Reddit as an online source for recruiting cancer survivors.

There are on average 321 million monthly active Twitter users worldwide [26]; taking just three UK-based cancer charities as examples, Macmillan Cancer Supports has 674,200 followers, Breast Cancer Care has 159,800 followers, and the Teenage Cancer Trust has 105,600 followers. There are just two studies reporting on the use of Twitter for recruitment into cancer survivorship research. Rabin et al [27] reached 11 potential participants through social media (no data were provided on comparisons between Twitter and other platforms) though none were actually eligible to participate, highlighting potential self-screening issues. Keaver et al [28] recruited through Twitter for a cross-sectional study on willingness to participate in nutrition and web-based intervention research. They concluded that whilst Twitter is a feasible recruitment method, samples might be biased towards younger, female, more educated, and less ethnically diverse participants.

Study aim

This paper reports on a secondary analysis of data collected in a longitudinal study exploring predictors of patient-reported outcomes in cancer survivors over a two-year period: this was an early phase study to inform the development of tailored ACT-based interventions [29] for cancer survivors based on our previous conceptual and pilot cross-sectional research

[30-32]. The main study is still ongoing. As a secondary aim of that study we trialed the feasibility of recruiting cancer survivors through online recruitment, comparing the relative use of different social media platforms. These secondary analyses are reported and discussed in this paper.

Method

Ethical approval for this study was provided by the University of Chester, UK (Ref: 2001316) and the University of Sydney, Australia (Ref: 2016/752).

Design

The study from which these recruitment data are drawn uses a longitudinal, cohort design. Participants complete online, self-report questionnaires at baseline, and then at three-monthly intervals thereafter, for up to two years. One UK-based participant requested a traditional paper-and-post questionnaire which was sent at equivalent timepoints to the online sample. Participants are entered into a prize-draw to win a £50 Amazon shopping voucher at each time-point as an incentive; those who complete all nine questionnaires will be entered into a further prize-draw to win an iPad Mini. At each timepoint, participants completed a batch of repeated-measures questionnaires, including: the revised Acceptance and Action Questionnaire (AAQ-II) [33]; the Brief Experiential Avoidance Questionnaire (BEAQ) [34]; the Cognitive Fusion Questionnaire (CFQ) [35]; the Mindful Awareness and Attention Scale (MAAS) [36]; the Engaged Living Scale (ELS) [37]; the short Depression, Anxiety and Stress Scale (DASS-21) [38]; the EQ-5D [39]; the Assessment of Survivor Concerns Scales (ASC) [38]; and, a revised version of the Benefit Finding for Breast Cancer Scale [40], with reference to breast cancer omitted for broader applicability (as previously published) [31]. Participants also completed a demographic and clinical questionnaire at baseline, and were

asked to report on changes to the clinical nature of their cancer and/or treatment at each follow-up phase. To reduce participant burden, we selected the shortest, psychometrically sound scales for each variable available at the time of study initiation. In total, questionnaire length was 112 items at baseline, and 100 items at follow-up. Completion was estimated to take between 30 and 45 minutes, dependent on reading speed. Online questionnaires were administered using the LimeSurvey platform, which presents the questions in the form of a webpage which formats itself appropriately for screen and device type.

Participants: eligibility and target sample size

Participants confirm that they met the following eligibility criteria at consent:

1. Over the age of 16 years at the time of consent;
2. Received a cancer diagnosis (including recurrence) within the past twelve months;
3. Good comprehension of written English (translation into other languages was not possible within our study budget).

As our recruitment design was relatively novel, there was very little on which to base an estimated likely response rate. Our sample size calculation was based on the assumption that between 10 and 15% of participants would be lost to attrition at each follow-up stage. We thus aimed to recruit in excess of 500 participants, to ensure a final follow-up sample of at least 150 participants to adequately power multivariate regression modelling [42].

Procedure

Study advertisements were distributed through a variety of online, social media platforms. Where necessary, permission was granted by the moderators or administrators beforehand. Advertisements contained a web-link to a longer study invitation letter which then linked to the online participant information sheet, followed by an online consent form, and then the questionnaire itself.

Our initial recruitment took place from March (month 1) to November 2016 (month 7), with study advertisements placed on a dedicated Twitter account and Facebook page (see Figure 1). Throughout this period, a member of our research team actively used those accounts to ‘retweet’ and ‘like’ content provided by other social media users to boost the number of followers to those study-specific accounts, as a means to maximizing reach through ‘retweets’ and ‘likes’ of our own content. During month six, a number of UK cancer charities retweeted posts, and placed dedicated advertisements on their own Facebook pages.

After a short break to review our strategy we recommenced recruitment in April 2017 (month 13) for a further 18 months through to September 2018 (month 30). We continued advertisements from our own dedicated Twitter and Facebook accounts, though with a greater emphasis on members of the research team re-tweeting and sharing (via Facebook) to maximise circulation within personal social media networks. We requested two further waves of charity re-tweeting. In months 20, 22 and 27, we paid for Facebook ‘boosts’. We began posting advertisements to Reddit online community groups from month 21, continuing for nine months until the close of recruitment in August 2018. Follow-up data collection will continue until September 2020.

Over a three-month period in Spring 2018, we attempted to supplement recruitment using a local distribution newspaper advert (total readership estimate: 10,000 readers across one single print-copy and associated online presence) and by attending local community interest (four in total) and cancer support groups (six in total). We were able to analyse recruitment rates from these sources separately because participants were required to contact the research team directly to request a link to the survey website.

Data analysis

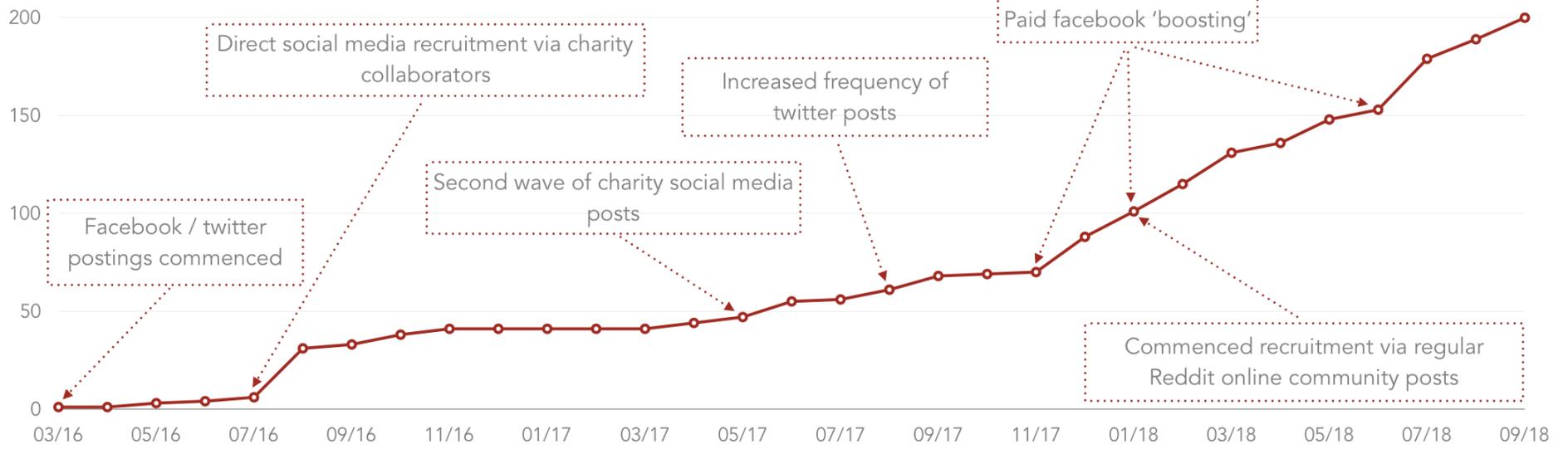
We analyse data on online recruitment feasibility according to three key metrics:

1. Comparative speed and success of recruiting cancer survivors through Twitter, Facebook and Reddit;
2. Representativeness of the recruited sample; and,
3. Cost-considerations of employing online recruitment methods.

Our results are analysed and presented descriptively only, given the scope of these study aims.

1 **Figure 1. Cumulative recruitment and notable changes in recruitment strategy over time.**

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Results

6 Overview

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8 Two hundred and ninety-four individuals consented and accessed the questionnaire,
9 but only 202 submitted a complete data set (68.7% completion rate). Two were excluded as
10 they did not meet study inclusion criteria and 19 (8% of the recruited sample) did not provide
11 valid email addresses for follow-up. The majority were recruited online, with just one
12 participant recruited through the newspaper advert, and one recruited through a community
13 group (1% of our total sample collectively). No participants were recruited through local
14 cancer support groups; with few exceptions this was because most of the support group
15 attendees exceeded the time-since-diagnosis eligibility criteria. Forty-one participants were
16 recruited across the first wave of recruitment; at least 28 of these coincided with a retweet or
17 a post from a charity collaborator highlighting the importance of partnering with other online
18 organisations with an established social media following. The most effective sources of
19 recruitment over the second wave of recruitment were paid Facebook ‘boosts’ and Reddit
20 posts (see Figure 1).

20 Speed and success of recruitment through various social media platforms

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22 *Twitter.* During the first five months of recruitment, six participants were recruited
23 through posts from our study-specific account. This recruitment rate was replicated at other
24 times where no other specific recruitment activities were taking place, providing a baseline of
25 one participant recruited per month (23 in total). During recruitment month 15 we increased
26 the tweet frequency per week contributing six additional participants recruited (14.5% of the
27 total sample recruited through direct twitter adverts). During months six to nine, 18-20, and
29, we engaged with cancer charities through Twitter, encouraging them to re-tweet our

28 advert, or to directly tweet a study invitation. This was more successful during the first time-
29 period, but in total we estimate that charity engagement online resulted in recruitment of 64
30 participants (32.0% of our total sample).

31 We undertook two detailed audits of twitter activity, first in January 2018, and again
32 updated in March 2019. Each Twitter advert was viewed a median number of 313 times
33 (range=19 to 34,084; mean=904), with between zero and 86 people clicking the embedded
34 web-link per tweet ('clicks': median=1; mean=4.15). These data are not appropriate for
35 inferential statistical analysis, but our audit suggests that tweets placed between 23:00 and
36 09:00hrs GMT were most effectively distributed; our most successful tweet—which was
37 viewed 34,084 times and was retweeted 65 times—was placed at 01:02hrs (GMT). Whilst
38 these tentative findings might not generalize, it is probable that timing is an important
39 consideration for online recruitment. It is impossible for us to calculate a definitive number of
40 independent Twitter users reached given overlap between followers of the various re-
41 tweeting accounts, and fluctuations in twitter account followings over time.

42 **Facebook.** At the time of writing this manuscript (April 2019), our study-specific
43 Facebook group had 859 subscribed followers though this has increased slowly through the
44 recruitment period. We were cautious not to post too frequently so as not to appear that we
45 were 'spamming' followers' timelines. Six free-of-charge study adverts were posted during
46 the first eighteen months of recruitment: collectively, these attracted eight 'likes', 13 'shares'
47 and seven 'comments', indicating low-level engagement. We do not believe that any of our
48 recruited sample were recruited through these posts. During month 22, free-of-charge
49 advertisements were placed directly on 17 other cancer-specific Facebook pages; this was
50 more successful, resulting in seven participants recruited (3.5% of the total sample).

51 Facebook allows users to pay for post ‘boosting’ which prioritises posts to targeted
52 users online feeds. We paid for three separate ‘boosted’ recruitment adverts in total, targeting
53 both male and female users, over 16 years of age, concentrated on England, Scotland, Wales,
54 Northern Ireland, Canada, Australia and New Zealand as geographical locations. Each ‘boost’
55 was designed to spread the advert over seven days. These ‘boosted’ adverts reached 10,623,
56 13,142, and 204,609 respectively (‘reach’ is defined by Facebook as the number of unique
57 users to whom the advert was targeted), making 185,724 impressions (advert views or reads),
58 and recorded 120,445 direct engagements (active ‘clicks’, ‘likes’, ‘shares’ or ‘comments’).
59 Despite increased engagement there was continued passivity of interaction– most of the
60 ‘comments’ focused on disclosure of diagnosis or the seeking of peer support, rather than
61 comments about the study specifically. We estimate that 54 participants (27.0% of the total
62 sample), were recruited through this boosted Facebook advertising.

63 **Reddit.** During the final eight months of recruitment we advertised on 10 cancer-
64 specific sub-reddits, five health-related sub-reddits, and two research-participation oriented
65 sub-reddits. Membership of these sub-reddits ranged from just ten (‘psychooncology’ sub-
66 reddit) to 563,000 (‘health’ sub-reddit), with an average of 73,816 members per group. We
67 posted to each between one and ten times dependent on engagement to early postings. Forty-
68 nine adverts were placed in total, which were up-voted between zero and fifteen times; ten
69 were commented on by community members showing higher engagement. We estimate that
70 44 participants were recruited through Reddit posts (22% of the total sample) but over a
71 considerably shorter period of time than other methods.

72 **Representativeness of the recruited sample**

73 Table 1 (below) summarises the demographic and clinical characteristics of our
74 sample. As we would often see in cancer survivorship research there was a female bias,

75 though the mean age is slightly younger, and the range greater, than we might otherwise
76 expect. Wakefield et al [43], for example, report that across 155 international surveys of adult
77 cancer patients, the overall mean age of participants is 53.39 years (SD=14.5; Range=24-64),
78 though in a recent survey of UK cancer survivors recruited through clinical services (with
79 similar inclusion criteria and aims to the current study) we recruited a sample with a mean
80 age of 61.4 (SD=16.8, Range=32.90) [31]. The proportion of participants disclosing as non-
81 heterosexual is higher than we often see in this kind of research study; a recent secondary
82 analysis of the UK Cancer Patient Experience Survey (which recruited through the NHS), for
83 example reported that less than 1% identified as lesbian, gay or bisexual [44]. The majority of
84 our participants were recruited from the UK, which is not surprising as we recruited for
85 longer in this country, and we partnered with a greater proportion of UK charities than those
86 in other countries. We were able to recruit cancer survivors from twelve countries in total,
87 including those less represented in the literature: for example, Turkey, Central and South
88 America, The Philippines and South Africa.

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91 **Table 1: Clinical and demographic sample characteristics**

Gender	Female (<i>n</i> =170)	85%
	Male (<i>n</i> =30)	15%
Age	Mean= 47.5 years (SD=13.42 years; Range = 16 – 79 years)	
	16 to 30 years (<i>n</i> =26)	13%
	31 to 65 years (<i>n</i> =160)	80%
	65 years or over (<i>n</i> =14)	7%
Relationship status	Married/De Facto (<i>n</i> =106)	53%
	Single (<i>n</i> =58)	29%
	Divorced/separated (<i>n</i> =36)	18%
Sexual orientation	Heterosexual (<i>n</i> =174)	87%
	LGB+ (<i>n</i> =26)	13%
Location	Europe (<i>n</i> =106)	53%
	North America (<i>n</i> =72)	36%
	Australia (<i>n</i> =14)	7%
	Other (<i>n</i> =8)	4%
Cancer	Breast (<i>n</i> =74)	37%
	Other (<i>n</i> =70)	35%
	Colorectal (<i>n</i> =30)	15%
	Gynaecological (<i>n</i> =26)	13%
Diagnosis	Primary (<i>n</i> =148)	74%
	Recurrent (<i>n</i> =54)	26%
Treatment	Ongoing (<i>n</i> =120)	60%
	Completed (<i>n</i> =80)	40%

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93

94 Clinically, we recruited cancer survivors of those diagnoses corresponding to the
95 focus of charities that were more willing to engage with our study; as a result, we have a
96 breast cancer bias, though this is far reduced in comparison to other published research with
97 mixed diagnosis samples. We were able to recruit a good mix of participants who had
98 received both primary and recurrent diagnoses, and who, at the time of consent, were still
99 undergoing or had completed their active cancer treatments.

100 **Cost considerations**

101 Recruiting participants into this study has taken approximately one hour per week for
102 the 30-month duration. This includes the placement of all online materials, regular
103 monitoring of (and responding to) comments and interactions, liaising with charity partners,
104 and managing the recruitment queries email address. A significant portion of time
105 (approximately 40 hours) was spent over a two-month period where we attempted, somewhat
106 unsuccessfully, face-to-face recruitment at community and cancer support groups. Given that
107 the researcher undertaking recruitment activities was doing much of this activity either
108 virtually (online) or in general population samples rather than in clinical settings, it was
109 possible to appoint a more junior member of staff with less relevant cancer-related expertise.
110 Excluding study-set up activities (e.g. ethical approvals) and costs associated with data
111 collection, the direct staffing costs of this recruitment activity equate to approximately £2000.
112 This is substantially cheaper than clinic-based recruitment which often necessitates: (i) higher
113 grade and more experienced research staff, (ii) travel costs and unproductive time waiting for
114 referrals in clinics, and (iii) in some cases in the UK, additional Research Support costs to
115 access the UKCRN. To formulate a cost-comparison for just this latter point, we modelled
116 Research Support costs for recruitment had we used the UKCRN; allocating time for study
117 set-up meetings and clinical staff briefings (90 minutes), regular study monitoring meetings
118 with recruiting nurse teams (60 minutes, every 3 months, for 30 months), eligibility screening
119 (one hour per week for 30 months), and study introduction/informed consent meetings with
120 each participant ($N=200$), this cost alone would be £9,708 (calculation correct as of August
121 2019), and that would be in addition to staff employed at the university to undertake all other
122 research-related activities. Online recruitment also enabled a more time-flexible working
123 pattern which would not have been possible had the research been recruiting directly from
124 clinics.

125 Regarding other recruitment costs, we paid a total of £625 for Facebook ‘boosting’,
126 £380 for the newspaper advertisement, and approximately £50 for travel and printing costs
127 related to the face-to-face recruitment attempts. If we exclude the latter two of these, the
128 combination of Facebook charges and staffing required to recruit the 198 participants
129 recruited through electronic methods equates to a cost of £13.25 per participant recruited.

130 Moving forward with our study, 199 of our participants (99.5%) have agreed to
131 complete our surveys using electronic methods, which enables further cost-savings.
132 LimeSurvey is open source software which can be installed on an institution’s web-server for
133 free. In most cases, the only costs associated with data collection are, again, time of survey
134 administration. This could be further reduced by using a survey distribution platform that
135 enables automated follow-up administration, but this was not possible in our case.
136 Nonetheless, the cost-saving of using online questionnaires compares favourably with the £15
137 printing and postage costs (not to mention staff time for data input) for the participant
138 completing questionnaire through paper means. Had our full sample participated in a paper
139 and post format this would have added a further £3000 to our study cost. Online data
140 collection also has the added benefits for the environment, of course.

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Discussion

143 Longitudinal ‘cohort’ studies of adjustment to cancer survivorship are a crucial part of
144 the ongoing psychosocial oncology and supportive cancer care research effort. They help
145 researchers and clinical teams alike to better understand the prevalence of longer-term
146 consequences of cancer treatment [8], including the enduring psychological impact [45,46],
147 and they provide important data on which to build effective interventions to improve
148 survivorship care [1,9]. Whilst there are some excellent examples of cohort studies of cancer
149 survivors [46-49], ours is the first to explore third-wave, ACT-based, psychological processes

150 as predictors of patient reported psychosocial outcomes. Many of these other cohort studies
151 represent incredibly expensive and logistically complex research projects. The CREW Cohort
152 Study, for example, recruited nationally using UK CRN nurses across 30 UK cancer centres
153 [50] for 17 months to achieve their sample of 1056 colorectal cancer survivors (Fenlon et al,
154 [51]. As detailed in our background section to this paper, the high cost of these traditional
155 recruitment methods limits the number of these types of studies that can be undertaken.

156 A secondary aim of our research, as reported in this paper, was to explore whether a
157 sample of cancer survivors could be recruited using more cost-effective, online methods. We
158 aimed also to explore whether these methods might enable us to recruit a demographically
159 and clinical representative sample to improve on some of the age, gender, sexuality, and
160 clinical biases commonly reported in cancer survivorship research [2,31,43, 44,52-56].

161 Regarding recruitment feasibility, our analysis focused on the speed and success of
162 recruitment, and the cost-considerations of online recruitment methods. After a period of 30
163 months, we closed recruitment with a total sample size considerably smaller than we had
164 anticipated. Our decision to close recruitment was made pragmatically because of the time
165 that recruitment had already taken. The data from this study highlight three particularly
166 effective methods of online recruitment (established charity Twitter posts; Facebook boosts
167 and Reddit posts); were we to have had this knowledge prior to this study, and implemented
168 these methods from the start of recruitment, we believe we would have reached our full
169 sample in approximately the same length of time (estimated 16 participant recruits per month
170 for 31 months).

171 One important limitation from our study is that we did not include a question on the
172 survey about where the participant was recruited from. This means that (a) we cannot
173 compare sample characteristics between different social media platforms, and (b) we cannot

174 be absolutely certain how each participant was recruited. We are, however, able to make
175 inferences about where participants were recruited from in various months of the study, given
176 that we altered focus throughout the study and kept systematic records of differential
177 responses per month following a shift in recruitment focus. A future study which better
178 captures this data would be a helpful methodological contribution to the cancer survivorship
179 literature.

180 Comparing different online recruitment methods, there were distinct limitations to
181 using both Twitter and Facebook on an *ad-hoc* basis, from study-specific platform accounts:
182 recruitment, we conclude, was slow and unfeasible for studies that require a large sample
183 size, which most cohort studies often do. Recruitment through both of these methods was
184 considerably improved when the advert: (a) was posted by a collaborating charity with an
185 existing social media following; or (b) used targeted Facebook postings incurring a minimal
186 advertising cost (Facebook ‘boosts’). An audit of the reach of our study advertisements
187 demonstrates that in both cases, Twitter and Facebook are inefficient sources of identifying
188 cancer survivors: as reported elsewhere too [57,58], there was very low pull-through
189 recruitment rate from the total population reached, despite high (and increasing) population-
190 level prevalence of cancer. It is interesting that our Twitter recruitment was so much poorer
191 than reported by Keaver et al [28], however, there are two important differences between that
192 publication and our own work. First, our work recruited directly into a comparatively high-
193 burden research study rather than exploring (in a cross-sectional survey) willingness to
194 participate in future studies. Second, all of their Twitter recruitment was via established
195 collaborator accounts, whereas here we attempted (with little success) to recruit using a
196 study-specific Twitter account. In this regard, our data agree with Rabin et al [27] that these
197 strategies are probably most effective when partnerships are made with existing organisations
198 with established social media followings. Recruitment through Reddit was reasonably

199 successful, approximately equivalent to that of paid Facebook advertisements, though
200 obviously without the cost implications. In all cases, online recruitment was more effective
201 than either general population community recruitment and a print newspaper advertisement in
202 our study.

203 In light of these data we would recommend that a combination of (a) targeted Reddit
204 community postings, (b) fee-payable Facebook ‘boosting’, and (c) recruitment via existing
205 cancer-related Twitter accounts, is likely to be the most effective online combination strategy.
206 Due to limited turnover of membership of each of these online communities, we remain
207 unconvinced as to how effective multiple repeated recruitment drives would be over time: our
208 second wave of Twitter posts through charity partners, for example, resulted in far reduced
209 recruitment than the first of these attempts. The total sample size achievable may, therefore,
210 have a ceiling effect. Notwithstanding these limitations, and despite some published evidence
211 to the contrary [15], we have clearly demonstrated the cost-effectiveness of these recruitment
212 methods in comparison to clinic-based recruitment, though this will be tempered by the need,
213 in many cases, for recruitment to be completed over a shorter-time frame than we were able
214 to achieve. As a result, our conclusion is that whilst appropriate for some studies, recruitment
215 through online social media is certainly not a feasible replacement for more traditional
216 methods of recruiting patients in the clinical setting for all types of cancer survivorship
217 research.

218 In this study we recruited a sample of cancer survivors which was more heterogenous
219 than we often otherwise see in psychosocial oncology research. Some research questions
220 might well require a more homogenous sample construction, but where there are no
221 fundamental theoretical or conceptual reasons to do so, limiting the generalisability of
222 findings through non-representative recruitment is problematic [4]. We have demonstrated
223 that where the goal is to maximise representability, online recruitment methods successfully

224 identify younger participants, presumably because social media usage—whilst increasing in
225 older populations [17]—remains higher in younger age groups. In this context, however, it is
226 understandable why recruitment was slow: cancer diagnosis is far rarer in these younger age
227 groups and so recruitment methods focussed here miss higher-prevalence demographic
228 groups. There may well be a case to be made for a recruitment strategy with mixed traditional
229 and online recruitment until generational issues in social media usage become less
230 pronounced. As in the Keaver et al [28] study, we were also not able to demonstrate that
231 online recruitment can overcome the gender-bias of participants in cancer survivorship
232 research; this is a considerable problem for our field and there are clearly other reasons why
233 men do not participate in our research than need to be further explored. We were interested to
234 see that we recruited a larger sub-sample of participants who identified as non-heterosexual
235 than in other survivorship research [44,59]; we suspect that the anonymity of our recruitment
236 and data collection methods may have led to a higher rate of disclosure of non-
237 heterosexuality. This is aligned with systematic review evidence that suggests that online
238 recruitment may be more effective for “hard-to-reach” target populations [15]. Although we
239 recruited from a larger range of geographic regions than we might otherwise have achieved,
240 our sample was still biased towards English-speaking, developed nations; online
241 advertisements and availability of the questionnaire in alternative language formats may have
242 countered this, though there would have been additional study set-up costs in doing so.

243 One final limitation that we must highlight here is that there may be a confounding
244 effect of multiple online components of this study: online recruitment rates may well have
245 been limited, for example, because participants did not wish to complete data collection
246 online too. Similarly, it is reasonable to assume that the longitudinal nature of our study, and
247 the perceived participation burden inherent in it, may have been off-putting. It is possible that
248 online recruitment may well be more successful with less complex study designs.

249 **Conclusions**

250 In their own conclusions, Whitaker et al and Kapp et al [21,57], suggest that whilst
251 there is potential for online recruitment in this kind of research study, there is still much to
252 learn about how to optimise the method. We are inclined to agree: the decision to recruit
253 online is complex and whilst it may overcome cost limitations, and may protect against some
254 sample biases, other biases and unanticipated methodological limitations may also be
255 introduced [58]. Our experiences were somewhat positive, but we by no means recommend
256 this as a panacea to sampling and recruitment issues in cancer survivorship research. Since
257 we initiated recruitment into our study, ethical recommendations for the use of social media
258 as a research recruitment tool have been published [60] and we encourage other researchers
259 considering using these methods to consult these guidelines to build sustainable and ethical
260 research practice.

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267 **List of abbreviations used**

268 UKCRN UK Clinical Research Network

269 NIHR National Institute for Health Research

270 ACT Acceptance and Commitment Therapy

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274

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