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1 **What do young adolescents think about taking part in longitudinal self-harm research? Findings**
2 **from a school-based study.**

3

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31 **Abstract**

32 **Background:** Research about self-harm in adolescence is important given the high incidence in youth,
33 and strong links to suicide and other poor outcomes. Clarifying the impact of involvement in school-
34 based self-harm studies on young adolescents is an ethical priority given heightened risk at this
35 developmental stage. **Methods:** Here, 594 school-based students aged mainly 13-14 years completed a
36 survey on self-harm at baseline and again 12-weeks later. Change in mood following completion of
37 each survey, ratings and thoughts about participation, and responses to a mood-mitigation activity were
38 analysed using a multi-method approach. **Results:** Baseline participation had no overall impact on
39 mood. However, boys and girls reacted differently to the survey depending on self-harm status. Having
40 a history of self-harm had a negative impact on mood for girls, but a positive impact on mood for boys.
41 In addition, participants rated the survey in mainly positive/neutral terms, and cited benefits including
42 personal insight and altruism. At follow-up, there was a negative impact on mood following
43 participation, but no significant effect of gender or self-harm status. Ratings at follow-up were mainly
44 positive/neutral. Those who had self-harmed reported more positive and fewer negative ratings than at
45 baseline: the opposite pattern of response was found for those who had not self-harmed. Mood-
46 mitigation activities were endorsed. **Conclusions:** Self-harm research with youth is feasible in school-
47 settings. Most young people are happy to take part and cite important benefits. However, the impact of
48 participation in research appears to vary according to gender, self-harm risk and method/time of
49 assessment. The impact of repeated assessment requires clarification. Simple mood-elevation
50 techniques may usefully help to mitigate distress.

51

52 *Keywords: self-harm, adolescence, ethics, longitudinal, multi-methods, mood-mitigation*

53

54

55 **Background**

56 Self-harm, here defined as any act of self-poisoning or self-injury irrespective of motivation or suicidal
57 intent [1], is a common and significant health concern in adolescence. Average lifetime prevalence of
58 self-harm in community-based samples of adolescents in Europe and Australia has been estimated at
59 17.8% [2], with rates comparable internationally [3]. While self-harm for many is about preserving
60 rather than ending life [4] it is nonetheless strongly linked to completed suicide, with 40-60% of those

61 who die by suicide having a history of self-harm [5]. Youth who self-harm are also at increased risk of
62 mental health difficulties and multiple life problems such as increased alcohol use and relationship
63 difficulties [6, 7]. Adolescents who self-harm thus represent an extremely vulnerable group.

64

65 Adolescence - the developmental period spanning 12-25 years of age – is an important time to focus
66 research on self-harm as these years are likely to include the onset (12 to 14 years), peak (15-24 years)
67 and start of remittance of the behaviour [8-10]. Rates of self-harm behaviour are three times higher in
68 adolescents than adult populations [11]. Much self-harm research to date has focused on mid to late
69 adolescence. This approach is important given high rates of self-harm in this age group [12], but this
70 focus may also be a consequence of the additional ethical and procedural challenges involved in
71 research with younger age groups, and a reluctance on the part of ethics committees and Institutional
72 Review Boards (IRBs) to sanction self-harm research in those perceived to be at heightened
73 vulnerability. Yet, research at earlier stages of adolescence is important to understand how and why
74 self-harm first develops [13]. Moreover, recent reports suggest that increasing rates of self-harm across
75 adolescence show the steepest rise in girls under 16 years of age [14], suggesting that early adolescence
76 is a period of particular concern in adolescent self-harm. Most young people who self-harm do not seek
77 clinical support [2], and this is particularly the case in young adolescents (aged 12-14 years) where
78 community-based cases of self-harm outnumber hospital presentations by up to 20 times [15] School-
79 based studies thus provide a vital opportunity to engage with an early adolescent population at risk of
80 self-harm who may otherwise remain hidden. Work which strengthens the evidence base for the ethical
81 suitability of self-harm studies in younger age groups in school-based samples can help to reframe the
82 calculation of risk for future research in this critical area.

83

84 **Ethical challenges – overstated risks?**

85 For researchers and regulatory bodies rightfully mindful of the need to balance the delivery of research
86 objectives against ensuring participant wellbeing [16, 17], a key concern is that asking participants
87 about self-harm/suicidality may introduce, reinforce or exacerbate such acts, or cause undue
88 psychological distress [16]. In fact, reviews of the evidence, which have pooled findings across adult
89 and adolescent populations, have suggested that asking about such issues is not associated with

90 negative outcomes [18, 19] and may, in fact, confer benefits for those at most risk [20]. This is
91 important for anonymous survey-based studies where a direct gauging of impact is impossible.

92

93 **Response from school-based youth to self-harm studies**

94 Relatively few studies have sought to understand the impact that being asked specifically about self-
95 harm has on school-based respondents. Hasking and colleagues [21] examined whether completing a
96 survey about non-suicidal self-injury (NSSI), suicidality, and wider psychological constructs was
97 perceived as either enjoyable or upsetting/worrying, in school-based students aged 12-18 years.
98 Overall, the majority of participants enjoyed participation at baseline and at one-year follow-up with
99 only a minority finding participation to be upsetting/worrying, but those who had thought about or
100 experienced self-harm were more likely to have had this response. Notably, Hasking and colleagues
101 found that girls were more likely than boys to find the survey upsetting, but also more likely than boys
102 to report enjoying participation. There may be a nuanced gendered distinction in reactions to sensitive
103 research that warrants further analysis. It is important, given the greater prevalence of self-harm in girls
104 relative to boys [14], to establish further if this gendered distinction is moderated by the likelihood that
105 an individual has a history of self-harm i.e. whether vulnerability is conferred by self-harm status, by
106 gender, or an interaction between the two. Other school-based studies have similarly found that while
107 overall participation in a research survey is viewed positively there are nonetheless links between
108 increased vulnerability and likelihood of reporting distress [22, 23]. Importantly, these studies point to
109 factors such as being “interested” in the topic [22] or finding it “worthwhile” [23] which partially
110 mitigate this distress, and similar findings have been found in a study with young adults [24]. Notably,
111 one of these studies only included boys from a select-entry school [22] which limits how generalisable
112 these findings are to a general school population; the other [21], gathered reactions to questions on
113 suicide, drug use and sexual abuse, issues which could arguably have a different personal resonance
114 than self-harm in a younger population. Nonetheless these studies suggest that there may be an
115 important distinction when making a judgment of impact in self-harm research, between having an
116 emotional response and a cognitive evaluation of that response, and highlight that more evidence,
117 particularly examining gender differences is now needed.

118

119 **Establishing short-term risk**

120 Not all studies have found that those at highest risk are more likely to experience distress. In suicide
121 research [20], high risk students with raised depressive symptomatology who answered survey
122 questions about suicide were less likely to report distress or suicidality immediately afterwards and two
123 days later than high risk participants in a control group who were not asked these questions. Hence,
124 asking about suicidality apparently conferred short-term benefits to those at most risk. In support,
125 Mathias and colleagues [25] in a sample of mainly 14 year olds with experience of in-patient
126 psychiatric care reported a dose-response effect where adolescents with greater severity of suicidal
127 ideation reported greatest reduction in ideation in repeated assessments over 6-month intervals [25].
128 These studies are important in establishing the impact of participation in research over time for young
129 samples, albeit in research focused on suicide or with clinical groups. Notably, within self-harm
130 research, the potential salutary effects of study participation over time for the most vulnerable was
131 supported in a University-based sample over a three week period [24], but not in a school-based sample
132 over a one-year period [20]. Hasking and colleagues [20] demonstrated that a deterioration in
133 psychological functioning over time (i.e. increased vulnerability) was associated with a change in
134 evaluation of study participation from a positive to a negative valence at one-year follow-up. Given
135 that clinical decisions may often be based on short-term assessment of risk – hours, days, weeks, rather
136 than years – short-term follow-up studies may improve the clinical relevance of study data [26, 27]. It
137 is therefore important to test the impact of participation in a self-harm study with a school-based
138 population using a short-term prospective design. Such prospective examination will also be important
139 in establishing if school-based youth with and without self-harm experience differ in their response to
140 repeated assessment. Of note, Muehlenkamp and colleagues [28] found that University participants
141 without self-harm experience were less amenable to repeat participation.

142

143 **Current study**

144 The current study sought further understanding of how school-based adolescents with and without
145 experience of self-harm felt about taking part in a longitudinal study about self-harm. Specifically, the
146 impact of study participation on early adolescents (aged 15 years and under) was sought. Other self-
147 harm/suicide studies that have included youth of this age have predominantly targeted participants
148 across a broader span of adolescence [19, 20, 21, 25]. Given evidence that the pattern of risk for
149 adolescent self-harm may differ in early, mid and late adolescence it is important to distinguish

150 between these developmental stages [14, 15]. As male and female respondents have been shown to
 151 differ in response to research participation [21], and are known to differ in prevalence of self-harm [15]
 152 a nuanced examination of responses to participation based on gender and self-harm status was also
 153 sought. Given that prospective studies with short follow-up phases are recommended for clinically
 154 relevant research [26, 27], this study seeks to evaluate the impact of asking young people to take part in
 155 a longitudinal study over a short time period (10-12 weeks) and strike a balance between being
 156 sufficiently short-term to enable clinical relevance, but also sufficiently spaced in time to be
 157 accommodated within a dense school timetable. Recent research has recommended taking steps to
 158 reduce any potential negative impact of study involvement on youth [21]. Mood elevation techniques
 159 have been employed following lab-based self-harm research [28, 29] and studies using other methods
 160 [7, 30] and are also recommended in online settings [24, 31]. An additional aim of the present study
 161 was to evaluate the use of a simple mood elevation tool that can easily be incorporated into a paper-
 162 based survey. A multi-method exploratory approach combined quantitative and qualitative analysis to
 163 augment understanding and maximise interpretation of findings [32]. Specifically the present research
 164 asked (1) Does participation in a longitudinal self-harm survey have an impact on participant mood?
 165 (2) How do young people rate and describe their experience of participation? (3) Do young people
 166 engage with a simple mood elevation device following participation in a self-harm survey? As our
 167 multi-method examination is largely exploratory no testable predictions were made. Responses across
 168 these outcomes (mood impact / survey rating / survey description / engagement with a mood elevation
 169 device) were compared for the sample overall and according to self-harm status and gender.

170

171 **Methods**

172 **Participants**

173 Participants were recruited from three secondary schools in the East Midlands of England to a broader
 174 study on impulsivity and self-harm. The study ran from October 2016 until February 2017. Parents of
 175 students in Years 9 and 10 (aged 13-15 years) were sent an Information Sheet and opt-out Consent
 176 form via electronic parent mail and asked to discuss the study with their child. School assemblies and
 177 tutor sessions, held before data collection, reinforced information and participant rights. Reminder
 178 messages were sent to parents one week before data collection.

179 A total of 710 students were invited to take part. Parental consent was withdrawn from n=18 (2.5%). In
180 addition, 46 students (6.5%) did not take part due to withdrawing assent (n=11), other school
181 commitments, or absence. The total number of participants completing the survey at baseline was thus
182 646. Recruitment was spread across schools (198:218:230). The mean age of participants was 13.5
183 years, (SD= 0.61) and 94% of the sample were aged 13 -14 years. The sample was 51% male, 46%
184 female, with 3% not stating a gender. The majority (81%) identified their ethnicity as white. Of the
185 baseline participants, 594 completed the follow-up survey. Average follow-up time was *12.1 weeks*,
186 *SD=1.15*. The retention rate of 92% compares favourably with other school-based longitudinal studies
187 [21]. Reasons for attrition (n=52) at follow-up included spoiled or missing codes from completed
188 papers n=27 (52%); parent removed consent for follow-up n=3 (5.7%); and unspecified absence n=22
189 (42%). Distributions of gender (male 50%, female 47%, 3% unspecified) and ethnicity (white 84%)
190 were similar at follow-up. Main analysis focuses on those who participated at both time points.

191

192 **Materials and Measures**

193 *Questions about self-harm behaviour*

194 Participants were provided with a definition of self-harm based on NICE (National Institute for Health
195 and Clinical Excellence) guidelines [33]: “Self-harm is hurting yourself on purpose such as cutting,
196 hitting, biting, burning or self-poisoning (such as swallowing too many pills or other dangerous
197 substances), *no matter what the reason*. Self-harm is not hurting yourself by accident.” This definition
198 reflects a lack of categorical distinction between self-harmful behaviour with or without suicidal intent
199 [34]. Participants were asked two questions modified from the Lifestyle and Coping Questionnaire
200 [LCQ: 2]: “Have you ever seriously *thought* about trying to harm yourself on purpose in some way but
201 *not* actually done so?” and “Have you ever on purpose harmed yourself in some way?” A modified
202 version of the LCQ has been used in other school-based studies [35]. Analyses for the present study are
203 based on answers to the two self-harm questions indicated above. However, the full survey included a
204 number of additional questions relating to self-harm which asked participants for information about
205 how recently and frequently they self-harm; to provide a description and reason for their most recent
206 episode; and to quantify the typical length of time between first having the urge to self-harm and
207 completing the act. Participants were also asked two questions about help-seeking behaviour in school.
208 All participants were asked to provide an answer to the self-harm questions, even if this was to write

209 “not relevant”. This ensured that all participants completed each section and sought to reduce the
210 visible distinction between those with and without experience of self-harm during testing.

211

212 *Current mood rating scale*

213 Participants were asked to rate current mood state on a visual analogue scale (VAS) at the start and end
214 of the survey. This approach has been used in qualitative self-harm research with adolescents [36]. The
215 VAS had response options ranging from 0 (illustrated by a sad face and additional text “I feel really sad
216 and down in the dumps”) to 10 (illustrated by a happy face and “I feel really happy”). At the midpoint
217 a neutral face and the words “I’m not feeling happy or sad” represented a score of 5. Participants were
218 asked to mark their current mood on the scale. Comparison of pre- and post-survey VAS ratings
219 provided an estimate of the immediate emotional impact of participation.

220

221 *Survey rating*

222 Participants were asked to rate their experience of taking part in the survey by selecting from provided
223 response options, which were positively-valenced (Interesting, Enjoyable); negatively-valenced
224 (Upsetting, Annoying); or neutral (Fine), or by supplying their own term of reference in an open-
225 response section. Multiple response choices were not prohibited.

226

227 *Open questions about the survey*

228 An open response question asked participants to “Describe your thoughts about taking part in the
229 survey and any feelings the content may have raised”.

230

231 *Doodle Activity page*

232 The final survey page contained cute animal images, cartoons, exam howlers, jokes, a space to write a
233 joke, and doodle/colour-in spaces. New doodles and imagery were included at follow-up to maintain
234 interest and novelty. Participants were invited to engage with this page once they had completed the
235 survey, or wished to withdraw, with the following invitation: “The survey has now finished. Thanks for
236 taking part! Time to chill... Check out the following page.” “Engagement” was defined as a
237 demonstrable sign of actively engaging with the activities and spaces on the doodle page by
238 drawing/doodling/colouring in/writing on the page etc. This page aimed to recalibrate mood, which

239 may have been lowered through participation. Evidence suggests that looking at cute images of
240 animals, cartoons and emotive texts are effective at eliciting positive mood [37, 38].

241

242 **Procedure**

243 Ethical approval was obtained from the Division of Psychiatry and Applied Psychology Research
244 Ethics sub-committee at The University of Nottingham. All survey materials were trialled, piloted and
245 modified with a youth advisory panel with lived experience of self-harm. On the day of the baseline
246 study consented students were provided with an Information Sheet, Assent form and envelope. Study
247 procedures, rights of withdrawal and limits of confidentiality and anonymity were explained by the
248 researcher (in person or by video) or by individual tutors according to a set script. Participants
249 generated a unique identification (ID) code and wrote this on their survey. In order that surveys could
250 be linked to a student if responses indicated concern for safety, students were asked to include their ID
251 code on a signed assent form and envelope, and to seal the form inside the envelope. Sealed envelopes
252 and surveys were collected and stored separately. Procedures were repeated at follow-up. Data
253 collection took place during designated lesson time. Students sat individually within class groups and
254 were instructed not to discuss answers. All students received a resource sheet detailing sources of
255 support in school and appropriate outside agencies. Survey responses were screened within 24 hours of
256 data collection for safeguarding reasons.

257

258 **Analysis approach**

259 Data were analysed using SPSS v24 for Windows. Paired sample T-tests were used to examine
260 differences in mood scores pre- to post- survey at baseline and at follow-up for the sample overall.
261 Between-subjects ANOVAs were used to examine effects of self-harm status (yes – a reported history
262 of self-harm vs. no – no reported history of self-harm) and gender (Boys vs. Girls), and the
263 gender*self-harm status interaction, for influence on mood-change scores (post VAS score – pre VAS
264 score) at baseline and follow-up. For statistically significant interactions, simple main effects and
265 pairwise comparisons were examined using a corrected p-value to control for multiple comparisons
266 ($p=.025$). For non-significant interactions, main effects analyses were performed. Chi-square analysis
267 was used to compare distributions of categorical ratings of the survey (positive / negative / neutral) –
268 these were compared for those with and without lived experience of self-harm at baseline and follow-

269 up. Analysis of standardised residuals identified where observed ratings in each category differed from
270 those expected by chance (positive or negative residuals > 1.96). Qualitative responses were coded
271 using Thematic Analysis [39]. Thematic Analysis is a flexible form of pattern recognition which allows
272 themes to be derived inductively (from the data) and deductively (from past literature and theory) in
273 order to best capture and summarise a phenomenon of interest. A sample of transcribed responses were
274 independently read and coded inductively by JL and LR. A coding frame that integrated inductively-
275 and deductively-derived codes was then developed by JL, verified via discussion, and applied to the
276 full data set. The coding frame contained labels, descriptions and examples of codes and themes [40].
277 Themes were identified and refined into main themes and sub-themes. A third researcher blind to study
278 aims independently tested the applicability of data-to-theme allocation from randomly selected extracts
279 with percentage consensus agreement of 83%. Consensus of 70% or above is deemed necessary for
280 themes to be judged as coherent and valid [40].

281

282 **Results**

283 **Initial analysis**

284 *Completers v non-completers*

285 Initial analysis compared the 594 participants who completed both the baseline and follow-up surveys
286 (completers) with the 52 who only provided baseline data (non-completers). Chi-square tests revealed
287 that groups did not differ by gender ($p=.287$) or ethnicity ($p=.497$). However, groups differed
288 according to school ($p<.001$). Groups did not differ in terms of self-harm incidence ($p=.313$); or
289 thoughts ($p=.121$). Nor were they more likely to have rated the survey at baseline as a negative rather
290 than a positive experience ($p=.734$). Mann-Whitney U tests revealed no difference between groups in
291 the distribution of mood-change scores pre- to post-survey ($p=.367$).

292

293 *Incidence of self-harm thoughts and behaviour*

294 At baseline, 30.4% of participants indicated having had thoughts of self-harm and 23.6% indicated
295 lifetime self-harm. At follow-up, rates of self-harm thoughts were similar to baseline (30.6%), and
296 reported incidence of lifetime self-harm was 27.6%. Of the additional 29 respondents indicating self-
297 harm behaviour at follow-up, 25 reported first onset of behaviour between the baseline and follow-up
298 assessment.

299 **Did current emotional rating scores change following completion of the survey?**

300 A 2 X 2 between subjects ANOVA revealed a statistically significant interaction between gender and
 301 self-harm status on mood-change score from pre to post survey completion at baseline $F(1,$
 302 $467)=4.673, p=.031, \text{partial } \eta^2 = .010$. Simple main effects analysis revealed there was no significant
 303 overall effect for self-harm status ($p=.755$); however, there was an overall statistically significant
 304 difference in mean mood change scores by gender. Specifically, mood change scores differed between
 305 boys with a self-harm history and girls with a self-harm history, $F(1,467) = 8.189, p = .004, \eta^2 = .017$
 306 (Bonferroni corrected). There was no significant difference between boys and girls who had not self-
 307 harmed ($p=.447$). Table 1 presents mean VAS scores at both baseline and follow-up for boys and girls
 308 with and without self-harm, and the complete sample. Findings suggest that completing the survey had
 309 a negative impact on mood for girls who had self-harmed (post-survey mood scores were lower than
 310 pre-survey scores), but conversely a positive impact on mood for boys who had self-harmed (post-
 311 survey scores were higher than pre-survey scores). A second ANOVA compared mood change scores
 312 pre-to-post survey for boys and girls across levels of self-harm status at follow-up. This time there was
 313 no statistically significant interaction between gender and self-harm status $F(1,427) = .379, p=.538,$
 314 $\text{partial } \eta^2 = .001$. Main effects analysis revealed no statistically significant main effect of gender F
 315 $(1,427)=1.278, p=.259, \text{partial } \eta^2 = .003$; or main effect of self-harm status $F(1, 427)=.021, p=.884,$
 316 $\text{partial } \eta^2 = .000$. Hence, neither gender nor self-harm status influenced mood change scores at the
 317 follow-up timepoint. (See table 1.)

318

319 *[Table 1 about here]*

320

321 **How did participants rate the survey?**

322 Table 2 presents proportions of participants rating each survey in positive (“interesting”, or
 323 “enjoyable”), neutral (“fine”), and negative (“annoying” or “upsetting”) terms. Most participants at
 324 baseline rated the survey in positive/neutral terms overall (79.7%) and across gender and self-harm
 325 status. However, comparing groups by self-harm status: Chi square analysis revealed that the ratings
 326 differed between those with and without self-harm $\chi^2(2) = 37.606, p < .001$. Inspection of standardised
 327 residuals revealed that those who did not endorse self-harm had lower levels of negative ratings than
 328 would be expected by chance; while those with self-harm experience had higher levels of negative

329 ratings, and lower levels of positive ratings than would be expected by chance. The most common
330 negative responses cited by those without lived experience of self-harm were “annoyance” (n=17,
331 4.3%) and “boring/pointless” (n=13, 3.3%). By contrast, the most common response for those
332 endorsing self-harm was feeling “upset” (n= 23, 16%) with a few respondents reporting finding the
333 survey annoying (n=9, 6.3%) or “boring/pointless” (n=4, 2.8%). However, it is important to note that
334 most participants did not report negative responses. Comparing ratings by gender did not reveal a
335 significant difference in response ($p=0.184$).

336
337 At follow-up, the survey was again rated in positive/neutral terms by the majority overall (73.5%) and
338 across self-harm status and gender. However, an increased percentage of respondents gave the survey a
339 negative response at follow-up, compared to baseline, and this was driven in part by an increase in
340 those finding the survey “boring” or “pointless” (8.7% v. 3.1% at baseline). Chi-square analysis
341 revealed that the distribution of positive, negative and neutral ratings did not differ according to self-
342 harm status ($p = 0.071$). The most common negative response cited by those without self-harm was
343 “boring” (increased to 10.4% from 3.3%) with “annoying” selected by an increased 6.9% compared to
344 4.3% at baseline. Similarly, the most common response for those with self-harm was now “annoying”
345 (14.2%) with feeling “upset” reduced from 16% to 10.3%. Notably, for those endorsing self-harm the
346 percentage of negative evaluations was lower at follow-up than at baseline while positive evaluations
347 were proportionally higher at follow-up; the opposite pattern of response was reported in those without
348 self-harm experience for whom positive ratings decreased and negative ratings increased in comparison
349 to baseline. Of the 25 participants who revealed a first incidence of self-harm between assessments,
350 most rated the survey as a positive/neutral experience at baseline (83%) and follow-up (60%), although
351 again the response pattern reflected an increase in negative ratings by follow-up, and the highest
352 proportion of negative response for any category of respondent. Again, when comparing ratings by
353 gender, no significant difference in response was observed at follow-up ($p=0.545$).

354

355 *[Table 2 about here]*

356

357 **What did participants think about taking part in the survey?**

358 Responses to the item “Please share your thoughts about taking part in the survey, and any feelings the
 359 context may have raised” were refined into six themes (three positive, two negative and one neutral)
 360 using Thematic Analysis [39]. No main thematic differences emerged between time-points. Main
 361 themes, subthemes, and frequencies of endorsement are shown in Figure 1.

362

363 *[Figure 1 about here]*

364 **Fig.1** Thematic map showing six main themes (circled) and subthemes reflecting participant views on
 365 taking part in the research.

366

367 *Theme: Understanding and reflection*

368 Young people valued the greater self-awareness and understanding gained from participation: “*It’s a*
 369 *really good and interesting way to gain information and think about your life.*” (F, aged 14, SH).

370 Participants felt that they “knew themselves better” from the experience and enjoyed the opportunity
 371 for self-reflection: “*I think it [taking part] brings you more in touch with your feelings and allows you*

372 *to get presence and really think.*” (M, aged 13, no SH). For some it was greater understanding of others

373 that was important: “*It makes me more aware of the emotional health of my peers.*” (F, aged 13, no

374 SH.) Taking part was a chance to offload and also provided relief: “*It’s made me feel relieved that I*

375 *have let out how I feel*” (F, aged 13, SH). Some found value in realising they were in a good place: “*I*

376 *realise now that I enjoy lots of things and I am a better and happier person that I used to be.*” (F, aged

377 13, SH); “*It’s just reminded me how much happier I am now than when I was so sad, so that’s good.*”

378 (F, aged 15, SH). This theme was the most consistently endorsed overall with endorsement from 50

379 participants at baseline (28% of responses) and 30 participants at follow-up (18% of responses).

380 Overall, a slightly higher numbers of girls (n=44) than boys (n=36) endorsed this theme.

381

382 *Theme: Altruism and helping others*

383 Being able to help others was a source of value: “*I hope my input will help people for the better.*” (F,

384 aged 13, no SH); “*It’s ok, and didn’t upset me and I’m happy to help.*” (M, aged 13, SH). The benefits

385 were often linked to contributing to research: “*I feel happy I have taken part in some useful research.*”

386 (F, aged 13, no SH). Students felt it was important to raise awareness of mental health: “*I think that it*

387 *is good that people are recognising that mental health in young teenagers, especially students, is a big*

388 *deal.*” (F, aged 14, SH). Some wanted further opportunities and support to discuss such issues: “*I think*
389 *we should get lessons in PSHE [Personal, Social and Health Education] about self-harm and*
390 *depression and suicide as it is a bit of a stigma topic and it shouldn't be.*” (F, aged 14, no SH). A
391 number of students felt that schools could do more to facilitate peer support: “*I don't know how to help*
392 *people who self-harm and feel that this is something that schools should teach.*” (F, aged 13, no SH).
393 This was the second most consistently endorsed theme overall, endorsed by 33 participants at baseline
394 (18.5% of responses) and 28 participants at follow-up (17% of responses). Endorsement was similar
395 overall between boys (n=31) and girls (n=30).

396

397 *Theme: Enjoyable and interesting – a positive experience*

398 For some participants the process of taking part in the research was enjoyable in itself: “*I thought it*
399 *was quite fun, like Christmas!*” (F, aged 13, no SH). “*It was good, I would do it anytime*” (M, aged 13,
400 SH). For others there were additional perceived benefits, like missing class: “*Don't mind, gets us out of*
401 *lessons.*” (M, aged 13, no SH). Students felt happy to have been asked their opinions: “*I think it is*
402 *good that people are researching our age group and giving us a say.*” (F, aged 14, SH). Some were
403 pleased to be involved with a University study: “*I think it is cool that the University is asking us.*” (F,
404 aged 13, no SH). Participants reported enjoying the survey in similar numbers at baseline (n=26, 15%)
405 and follow-up (n= 27, 16%). More girls than boys endorsed this theme at baseline (n=17 vs n=9), a
406 pattern reversed at follow-up (n=12 girls vs. n=15 boys).

407

408 *Theme: Provoked negative emotions*

409 Some students indicated that thinking about self-harm in others made them feel sad: “*I find it quite*
410 *upsetting to know that people can feel some of the options.*” (F, aged 15, no SH). For some, the survey
411 was a difficult reminder of past actions: “*It made me feel upset, because I remembered that time.*” (F,
412 aged 13, SH). However, this was often a mixed emotional response: “*I felt upset because it reminded*
413 *me of what I used to do, but happy because I have passed that stage in my life.*” (F, aged 13, SH).
414 Some voiced feelings of anxiety, particularly about anonymity and confidentiality: “*I feel really*
415 *anxious and in a panic because anyone could read this.*” (F, aged 13, SH). This theme was endorsed
416 by similar numbers at baseline (n= 24, 13 % of responses) and follow-up (n=23, 14% of responses).

417 Notably, at both time points, more girls than boys endorsed this theme - (n=22 vs n=2) at baseline and
418 (n=17 vs n=6) at follow-up.

419

420 *Theme: Boring or irrelevant*

421 Some participants simply found the survey to be “pointless” or a “waste of their time”. Feelings that
422 the survey was “boring”, or “repetitive” were increasingly cited at the follow-up assessment: “*Boring*
423 *because we have already done it.*” (M, aged 13, no SH). For some, the lack of personal relevance was a
424 source of annoyance: “*It’s annoying as it is not relevant and depressing.*” (F, aged 14, no SH). A small
425 number of participants endorsed this theme, with 6 participants at baseline (3% of responses) and 12
426 participants at follow-up (7% of responses). This response was predominantly a male phenomenon
427 with all but two references to boredom or irrelevance coming from boys.

428

429 *Theme: Critical engagement with the research process*

430 Participants offered thoughts on how the research could be improved. Some suggested that the survey
431 did not go far enough: “*The questions were very clear, but needed more depth.*” (M, aged 14, no SH),
432 or had, “*surprisingly little content about self-harm*” (M, aged 13, no SH). Others felt the survey should
433 have included broader questions on “drugs and alcohol” or “sexuality”. Some queried what would
434 happen with their data: “*It would be interesting to see what research you would do with the results, or*
435 *what solutions you would have to problems.*” (M, aged 13, no SH). Some questioned the validity of a
436 survey: “*I think that people who have self-harmed wouldn’t say it on a survey because if you self-harm*
437 *you don’t tell anyone.*” (F, aged 13, no SH). Others wondered whether participants would be able to
438 adequately assess their responses: “*People may not be able to evaluate what they think.*” (F, aged 13,
439 SH). This final theme was the most commonly identified response at follow-up, with endorsement
440 rising from 17 participants (10% of responses) at baseline to 34 participants (21% of responses) at
441 follow-up. More boys endorsed this theme than girls overall, although proportions were similar at each
442 time point (n=10 boys and n=7 girls at baseline; n=19 boys and n=15 girls at follow-up).

443

444 **Did participants engage with the final doodle page?**

445 Just over half of the participants (55% baseline and 60% follow-up) chose to tangibly engage with the
446 doodle page (e.g. doodled, filled in speech bubbles, offered a joke). At baseline a higher proportion of

447 participants with self-harm engaged (76%) than those without (55%), but this was not a significant
448 difference $\chi^2(2)=2.303, p=.129$. At follow-up by contrast, a significantly higher proportion of those
449 without self-harm (63% v 50%) tangibly engaged with this page, $\chi^2(1)=8.045, p=.005$. There were no
450 differences in proportions of interactions with the doodle page between boys and girls. The distribution
451 of mood-change scores (pre- to post-survey) differed between those who did and did not complete the
452 final activity page at baseline (Mann-Whitney $U=26139.5, z=-2.570, p=.010$). Those engaging with the
453 page reported a small decrease in emotional rating (mean change in score -0.19), while those not
454 engaging reported a small increase in emotional rating (mean change in score $+0.05$). However,
455 distributions did not differ at follow-up ($p=.294$). Students commented on the final doodle page in the
456 open response section: *"I'm rating the survey a 10 because of the cats"* (Did not say, aged 13, no SH).
457 *"I love doing these surveys. I feel relieved to write down how I feel and I love the doodle page at the*
458 *end!"* (F, aged 13, SH thoughts). A number of young people suggested that the final page had made
459 them feel better: *"I feel strange, nervous, also confused and hurt, but relieved. Thanks for the doodles*
460 *– it helped calm me down"* (F, aged 13, SH).

461

462 Discussion

463 Overall, the present findings suggest, that for the majority, participation in research on self-harm was
464 not perceived as a negative experience by young adolescents and did not impact negatively on mood.
465 Participants described important benefits such as increased self-awareness, a chance to off-load, and
466 helping others. However, subtle differences were observed according to gender, self-harm status and
467 across time-points. Firstly, emotional rating (VAS) scores indicated that, following participation,
468 respondents largely rated their mood at the positive (happy) end of the scale. But there were notable
469 differences between the most vulnerable boys and the most vulnerable girls in their immediate
470 emotional reaction to participation, as indicated by the VAS. For boys with self-harm, participation led
471 to an improvement in mood; whereas for girls with self-harm, participation led to a deterioration in
472 mood. The finding that high-risk boys found a mood-based benefit from involvement resonates with
473 some previous studies [19, 24, 25] which indicate that participation can confer benefit for those at
474 greatest risk. Although notably, this pattern of findings was not supported at follow-up. These findings
475 suggest however, that in terms of immediate emotional reaction, conferred benefits are less likely to be

476 found for girls who self-harm. As such, studies may need to be particularly alert to the immediate
477 emotional impact of research participation on vulnerable girls.

478

479 The survey rating data revealed that the majority of participants judged taking part as a positive/neutral
480 experience at both baseline and follow-up. Positive/Neutral evaluations far outweighed negative
481 evaluations for boys and girls and those with and without self-harm at both time points. Closer analysis
482 at baseline revealed significant differences in the pattern of emotional responses felt between those
483 with and without self-harm experience: a higher proportion of those endorsing self-harm found
484 participation to be a negative experience and a smaller proportion rated the survey positively compared
485 with those who did not self-harm. This suggests an increased vulnerability in response for those with
486 lived experience of self-harm. However, differences in response distributions between these groups
487 were not observed at follow-up. In most cases, at the second assessment, participants reported fewer
488 positive/neutral evaluations and more negative reactions to the survey (which may be in line with the
489 overall VAS follow-up findings) but there was one notable exception. For those endorsing self-harm, a
490 larger proportion found the survey to be a positive or neutral experience at the second compared to first
491 time of assessment, and negative reactions to the survey for this subset actually decreased over time.
492 This resulted in a smaller percentage point difference in positive/neutral ratings and negative ratings
493 between those who had and had not self-harmed. The finding of an increased positive outcome over
494 time for those at higher risk of self-harm again chimes with previous research [25, 28] suggesting that
495 those at greatest vulnerability may gain greatest long-term benefit from on-going participation.

496

497 The contrasting responses found from those with and without self-harm experience across VAS and
498 survey ratings may relate to the perceived relevance of the survey for individual respondents. At
499 follow-up, an increased number of negative reactions to participation for those not endorsing self-harm
500 related to boredom, a lack of personal bearing and annoyance at being asked to complete a survey
501 twice - findings which were supported in the qualitative analysis. These reactions featured far less for
502 those with lived experience of self-harm. Relevance may drive the benefit gained from longitudinal
503 engagement with this topic, although this does not rule out finding the survey emotionally impactful (as
504 demonstrated by lower VAS scores). Qualitative findings suggest the increase in positive ratings at
505 follow-up in part may relate to a possible therapeutic benefit derived from an on-going opportunity to

506 “offload” and self-reflect. This may be particularly important for groups typically unlikely to have
507 disclosed their behaviour [2] or lacking opportunity to discuss and describe it. It could also be argued
508 that exposure to the topic at baseline may have desensitised participants for the follow-up assessment.
509 The effects of this could be greatest for those with lived experience who may have felt a greater
510 emotional response to the topic at the outset. The sharp increase in negative evaluations of the survey
511 for those without lived experience at follow-up suggests it will be important for future research to
512 explore the impact of research participation for those who are psychologically healthy, as well as those
513 at greater risk, over repeated assessment, particularly where follow-up is relatively short. In particular,
514 increased rates of annoyance mainly for those not endorsing self-harm behaviour (see also[28] , but
515 also across the sample overall, should be recognised and mitigated where possible.

516

517 The findings also highlight the varied nature of individual response to participation. Engaging with a
518 sensitive topic may cause understandable distress for some (such as the lowering of mood found for
519 girls with self-harm), but it does not necessarily follow that this is evaluated as a “negative” outcome.
520 Markedly, many participants coupled positive and negative ratings, separating emotional responses
521 from a cognitive evaluation (e.g. *nervous yet interesting; uncomfortable, but fine; difficult yet*
522 *worthwhile*). Given the complexity of the behaviour, it is not surprising that respondents selected
523 multiple categories to describe their response. This suggests that it is important for ethical guidelines
524 around self-harm research to recognise that potential benefits and potential risks from involvement are
525 not necessarily mutually exclusive.

526

527 Although there was no statistical distinction between boys and girls when comparing survey ratings,
528 analyses indicated differences in emotional response to survey participation according to both VAS
529 scores and thematic analysis, where a qualitatively different reaction to survey participation from girls,
530 who did describe feeling upset, was found to boys, who broadly did not. Further qualitative research
531 may help to clarify these gender differences in response to participation. The qualitative findings
532 largely support those found by Hasking and colleagues [20] in their school-based sample. A novel
533 thematic finding in this study was the large endorsement for a critical engagement in the research
534 process indicating that many young people are not only supportive of research endeavour but are keen
535 to reflect on, question and challenge the process.

536 This study also provides insight into the use of a simple mood recalibration doodle page. A small
537 majority of participants chose to engage with this page, though rates of engagement varied across
538 groups. At baseline, those whose mood decreased the most (participants endorsing self-harm) had a
539 higher rate of engagement with the page. At follow-up, those who reported an increase in negative
540 survey ratings (participants not endorsing self-harm) were more likely to demonstrably engage. It could
541 be argued that those feeling the greatest negative impact from participation may more readily seek out
542 recalibration, but more work should seek to evaluate the impact of such mitigation tools in community
543 samples using longitudinal designs. The present study did not provide an experimental test of
544 mitigation or specifically elicit participants' reactions to the doodle page. We can not know to what
545 extent the page was helpful for those who nonetheless left no physical indication of engagement.
546 However, large numbers of participants did demonstrably engage and many chose to reference this in
547 open responses. Undoubtedly for some, the page helped to calm emotions. Moreover, the study's
548 advisory youth panel strongly endorsed the doodle page. Importantly, the page brought an additional
549 and unexpected ethical advantage. The self-penned jokes, doodles, or direct comments written directly
550 on the survey script by participants who also used the page to offer reassurance to the research team
551 that they were feeling all right, had a positive impact on researcher wellbeing. Collecting data on self-
552 harm has an inevitable impact on researchers but the evaluation of this impact is under-researched. The
553 need to better document and discuss harm minimisation for researchers has been discussed elsewhere
554 [31, 41] and sharing potential practical solutions is advocated.

555

556 Key strengths of this study include the focus on a community-based sample of early adolescents (aged
557 13-14) for whom self-harm risk is heightened [15] and the additional insight offered on how both male
558 and female participants, with and without self-harm experience, respond differentially to study
559 involvement. Given recommendations for short-term prospective examinations of self-harm risk in
560 youth [26, 27] this study provides important ethical encouragement, via multiple and converging
561 methods, that short-term assessment (at least in terms of weeks) does not confer added risk to the
562 majority of participants. In addition, novel insight is provided into the role of a simple mood
563 enhancement tool. The low attrition (8%) compares favourably with previous school-based research
564 [21]. High willingness to complete a follow-up survey may be seen as an additional marker of a study's
565 acceptability. Nonetheless, the influence of the school-based setting must be recognised. Schools, as an

566 “adult-owned territory” [42] hold an inherent power asymmetry within which children generally
 567 participate in compulsory activities [43]. Thus, despite clear efforts to emphasise participant rights to
 568 withdraw, a learned compliance can compromise the voluntary principles of participation [44]. There
 569 are limitations to the conclusions that can be reached from this study. We did not explicitly ask
 570 participants at follow-up how they felt after completing the baseline assessment and we can not
 571 examine if reported reactions were transitory. Neither did we explicitly ask participants if they found
 572 the research to be worthwhile. A small number of students (4%) indicated initiating self-harm
 573 behaviour between assessment points. This compares with rates reported in other prospective school-
 574 based studies of 2.6% and 6.0% [13, 45]. While the development of self-harm observed here may
 575 follow the natural trajectory of self-harm, the design of the study does not allow us to rule out any
 576 causal iatrogenic link. These questions would be usefully addressed in future studies. The present study
 577 largely assesses self-harm in terms of a lifetime presence of behaviour. While this broad indicator of
 578 self-harm status was adequate in distinguishing differences in response, meaningful information about
 579 the impact of study involvement is likely to be gained from a finer grained analysis of self-harm status
 580 in which the recency or frequency of behaviour is accounted for. Notably, those indicating the most
 581 recent onset of self-harm (i.e. first time behaviour occurring between assessment points) recorded a
 582 high proportion of negative responses at the follow-up assessment (40%). Those with current versus
 583 historical self-harm may differ in both emotional response and cognitive appraisal of that response.
 584 Further research should explore these ideas.

585

586 **Conclusions**

587 This study contributes important information on the impact of research participation on young
 588 adolescents using quantitative and qualitative data to augment understanding. Participation was, for the
 589 most part, reported to have been a positive and beneficial experience, and many valued the chance to
 590 critically engage with the research process. Those with self-harm experience, and in particular girls
 591 who self-harm, displayed an increased vulnerability compared to those who did not self-harm (lower
 592 mood ratings following participation, a larger proportion of negative ratings) but, nonetheless, most
 593 evaluated their participation in positive or at least neutral terms. However, further work is needed to
 594 understand the impact of repeated assessment on those with and without lived experience for whom
 595 research reactions qualitatively differ. Many young people felt that having an opportunity to discuss

596 mental health in school was important and may confer unique benefits for those who self-harm. School
597 settings are potentially well placed to accommodate appropriate response to risk and provide support.
598 Ensuring that any school-based support is appropriate and effective is critical however. Evidence-based
599 school programmes such as the Signs of Self-Injury Programme [46], for example, which are designed
600 to educate about self-harm and offer skills to staff and students to respond to self-harm may offer a
601 promising and systematic way forward [47]. Prospective research on adolescent self-harm is ethically
602 viable in schools, but the inclusion of a simple mood-elevating tool may be an additional and easily
603 incorporated means of mood elevation, and beneficial to participants and researchers.

604

605 **List of abbreviations**

606 NICE (National Institute for Health and Clinical Excellence)

607 LCQ (Lifestyle and Coping Questionnaire)

608 VAS (Visual Analogue Scale)

609 F (Female) M (Male)

610 SH (self-harm)

611 PSHE (Personal, Social and Health Education)

612 IRB (Institutional Review Board)

613

614

615

616 **Declarations**

617

618 **Ethics approval and consent to participate:**

619 Ethical approval was obtained from the Division of Psychiatry and Applied Psychology Research

620 Ethics sub-committee at The University of Nottingham (Ethics Reference No. 202). Informed parental

621 consent (opt-out) and informed student assent was obtained for all individual participants included in

622 the study.

623

624 **Consent for publication:**

625 Not applicable

626 **Availability of data and materials:** Datasets used during the current study are available from the
627 corresponding author on reasonable request.

628

629 **Competing interests:** The authors declare that they have no competing interests.

630

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632 The funding body was not involved in the design of the study, the collection, analysis or interpretation

633 of data, or the writing or approval of the manuscript.

634

635 **Authors' contributions**

636 JL conceptualised the study, performed the analysis, and drafted the initial manuscript. LR provided

637 additional qualitative analysis. ET KS, and DD were involved in designing the study and editing the

638 manuscript. JL ET KS and DD approved the final version.

639

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643

644

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769

Table 1. Mean pre-survey and post-survey mood scores at baseline and follow-up

<i>Self-harm status</i>	<i>Gender</i>	Baseline			Follow-up		
		<i>N</i>	<i>VAS pre-</i>	<i>VAS post-</i>	<i>N</i>	<i>VAS pre-</i>	<i>VAS post-</i>
SH no	Boys	199	7.09(1.82)	7.21(1.99)	176	7.03(1.89)	6.72(2.24)
	Girls	164	6.72(1.86)	6.68(2.15)	138	6.67(1.76)	6.67(2.01)
SH yes	Boys	43	5.93(2.29)	6.35(2.28) ^a	45	6.12(2.22)	5.48(2.44)
	Girls	65	4.97(1.77)	4.79(1.85) ^a	72	5.33(2.13)	4.58(2.24)
Overall		491	6.60(1.97)	6.54(2.18)	489	6.49(1.9)	6.22(2.3) ^b

Note: The table presents means for the VAS (visual analogue scale) ratings provided at the start (VAS pre-) and at the end (VAS post-) of each survey assessment for the sample overall, and by self-harm Status and Gender. Standard deviations are shown in parentheses.

“SH yes” denotes lifetime incidence of self-harm. “SH no” denotes no reported history of self-harm.

a. A significant interaction between mean mood-change score for boys and girls at the level of SH yes $F(1,467)=8.189, p=.004, \eta^2=.017$ which survives Bonferroni correction at $p=.025$,

b. A statistically significant difference between VAS pre- and VAS post- survey scores, $t=3.807, p<.0001$.

Table 2. Proportions of participant ratings for Positive, Neutral and Negative evaluation of the survey at baseline and follow-up

	Baseline					Follow-up				
	<i>N</i>	<i>Positive (%)</i>	<i>Neutral (%)</i>	<i>Positive/Neutral(%)</i>	<i>Negative (%)</i>	<i>N</i>	<i>Positive (%)</i>	<i>Neutral (%)</i>	<i>Positive/Neutral (%)</i>	<i>Negative (%)</i>
Overall	582	170 (28.6)	309 (52.0)	479 (79.7)	103 (17.3)	578	136(23.5)	300 (51.9)	436 (73.5)	142 (23.9)
SH yes	119	25 (18.5) –	64 (47.4)	183 (60.6)	46 (34.8) +++	155	30 (19.4)	77 (46.5)	107 (69.0)	48 (31.0)
SH no	439	145 (32.6)	240 (55.3)	391 (86.1)	54 (12.1) – –	423	106 (25.1)	223 (51.3)	329 (77.7)	94 (22.2)
Girls	273	73 (26.7)	147 (49.0)	220 (76.2)	53 (19.4)	270	60 (22.2)	148 (54.8)	208 (77.0)	62 (23)
Boys	293	96 (32.8)	153 (52.2)	249 (84.3)	44 (15.0)	292	74 (25.3)	147 (50.3)	221 (76.0)	71 (24.3)

Note: – / + Standardised residual score of >1.96; – – / ++ standardised residual score of >2.58; – – – / +++ standardised residual score of >3.29 at $p < 0.01$ (0.05/5).

“SH yes” denotes lifetime incidence of self-harm, “SH no” denotes no reported history of self-harm.

What do young people think about taking part?

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