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Care for sexual health in oncology survey: a regression analysis of variables associated with the likelihood of people with cancer having a sexual health discussion with the hospital cancer team

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A R T I C L E I N F O

Keywords:
MESH terms
"Cancer survivors"
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Sex*
"Sexual dysfunction"
"Sexual health"
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Associations
Barriers
Cancer
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Discussion

A B S T R A C T

Purpose: Despite high levels of sexual dysfunction following cancer treatment, people with cancer report that sexual health is infrequently discussed during cancer care. Reasons for this infrequency have been identified in the qualitative literature. The purpose of this paper is to identify statistically significant barriers to, or facilitators of sexual health care identified by people with cancer.

Methods: The care for sexual health in oncology survey (CaSHOS) was a cross-sectional, analytical, retrospective, online survey of people with cancer who had received treatment and follow-up care for any type of cancer in the UK during the previous 10 years. A convenience sample was recruited via UK cancer charities. A minimum sample size of 120 people with cancer was required. Univariate, bivariate and multivariate statistical analyses were conducted. Despite attempts to mitigate recall bias, this remained a limitation of this study.

Results: Sexual activity worsened following cancer treatment for the majority of participants. Sixty-one per cent self-reported never having talked about their sexual health during their cancer care. Univariate analysis found little agreement with proposed barriers to care but more agreement with proposed facilitators of care. Bivariate/multivariate analyses found four statistically significant variables that decreased the likelihood of ever having talked to professionals about sexual health (two related to privacy in the hospital setting) and two that increased the likelihood (one related to being sexually active in the past year).

Conclusions: Although few barriers to care for sexual health were identified, most of these related to organisational aspects of the hospital setting.

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1. Introduction

Although variations in the prevalence of sexual dysfunction following cancer treatment have been reported, Reese et al. (2017) argue that sex-related sequelae are one of the most frequent, distressing, and persistent consequences of cancer treatment. The sex-related sequelae of cancer and its treatment are very varied, and the use of a biopsychosocial lens can help to fully describe the nature of these problems (Bober and Varela, 2012). Despite this, people with cancer continue to report that their sexual concerns are not discussed during cancer care (Sheppard et al., 2024; Zhang et al., 2020), even though much is already known about the barriers to and facilitators of sexual health communication (Canzona et al., 2019; Zhang et al., 2020).

In 2009, Park et al. summarised the literature to date on sexual

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health communication in cancer care and noted many barriers to discussing this issue from the perspectives of both people with cancer (for example patients' need for healthcare professionals to raise this issue, and erroneous beliefs about cancer and sex) and healthcare professionals (for example certain patient characteristics; lack of training; personal discomfort; and systems' issues). The barriers found by Park et al., in 2009 were not dissimilar to those found in a more recent scoping review by Zhang et al. (2020).

Embarrassment and discomfort are psychological barriers that have been frequently cited in past and present literature as barriers to communication, especially in healthcare professionals (Fitch et al., 2013a; O'Connor et al., 2019; Papadopoulou et al., 2019; Ussher et al., 2013). Organisational barriers also continue to be currently cited as important factors that hinder sexual health communication for example, lack of time and sexual health care not being a routine part of care (Canzona et al., 2019; O'Connor et al., 2019; Perz et al., 2013). The literature also suggests broader social barriers have hindered this type of communication e.g. sex/sexuality being seen as a private, taboo topic in many parts of the world, where social norms dictate what can and cannot be discussed (Fitch et al., 2013b; Stewart et al., 2021; Ussher et al., 2013).

Many of the barriers to communicating about sexual health in oncology that are known to date have been found using qualitative methods. Whilst this prior research has enabled in-depth understanding of people's experiences, it does not enable estimation of the proportions of those who are in agreement with different barriers to and facilitators of care. Therefore, a UK, online survey (care for sexual health in oncology survey (CaSHOS)) of people with cancer was designed using quantitative methods to investigate possible associations for a very broad range of previously identified factors that have been purported to hinder or help the provision and receipt of care for sexual health. The hospital cancer team for the purposes of this survey was considered to include the following: surgical oncologists, medical/clinical oncologists, clinical nurse specialists, chemotherapy nurses, radiographers, cancer support workers plus a response option of 'other' was also possible.

This survey was the quantitative phase of a mixed methods study, which had the overall aim to better understand the barriers to and facilitators of care for sexual health in UK cancer services, in order to develop an intervention to improve care for sexual health in oncology. This paper leads on from a previous paper that reported on the survey's results relating to the impact of cancer treatment on sexual health plus the nature of discussions about sexual health in UK cancer care (Sheppard et al., 2024).

2. Objectives

To describe:

1. The proportion of people with cancer who self-reported whether sexual health was discussed with the UK hospital cancer team during their cancer care.
2. The proportions of people with cancer who agreed or disagreed with statements about potential barriers to and facilitators of care for sexual health.
3. To clarify to what extent the barriers to and facilitators of care for sexual health identified by people with cancer, combined with their personal characteristics, affected their likelihood of having a sexual health discussion with the hospital cancer team.

3. Methods

The care for sexual health in oncology survey (CaSHOS) was a cross-sectional, analytical, retrospective, anonymous, online survey with closed question types. The survey was designed to investigate the aforementioned objectives for people with cancer who had received treatment and follow-up care for any type of cancer in the UK during the previous 10 years. A convenience sample was recruited via UK cancer charities with a minimum sample size of 120 required. Other data from this sample have already been reported and full details related to study design, study setting/participants, bias/limitations (recall bias was a limitation, despite attempts to mitigate this), sample size, ethics and reporting can be found in Sheppard et al. (2024). However, pertinent aspects of the methods not described there have been described below.

3.1. *Study design/setting/participants*

No validated questionnaire was available on the topic of care received for sexual health. As a result, questions about care were created by the researcher, as explained in Sheppard et al. (2024). In order to improve the face and content validity of the questionnaire, adaptations were made in relation to good survey design principles with respect to: question order; question wording; threatening questions; knowledge questions; attitude questions; and response format (Sudman and Bradburn, 1982 cited by McColl et al., 2001; Schuman et al., 1986 cited by McColl et al., 2001; Fink, 2017). Further improvements of face and content validity were made via multiple reviews of the survey questionnaire by both the authors and a local PPIE group. This included both review of the questions and questionnaire usability in the online environment. Reliability testing (in terms of measures of consistency) was not considered necessary for this survey questionnaire because a scale was not being developed.

A PDF copy of the full survey questionnaire, which was composed of seven sections (5 sections are reported herein), can be found in supplementary data file 1.

3.2. *Variables/data sources/measurement*

a) Outcome (dependent) variable

The main outcome variable for this study investigated whether the hospital cancer team ever talked about sexual health from the perspectives of people with cancer. This variable was the first question in the care for sexual health section of the survey and is the only variable from that section reported herein. It was selected as the main outcome variable as it was considered to be an important component of care for sexual health in people with cancer, and all participants answered this question.

b) Explanatory (independent) variables

Five sections of the survey contained explanatory variables. These were variables considered to potentially affect whether a discussion about sexual health with the hospital cancer team happened or not and were identified during a literature review on sexual health communication in oncology. Each of these five sections of the survey are described briefly in Table 1. Four sections related to personal characteristics including sociodemographics, cancer characteristics, sexual activity, and emotional distress. The fifth section related to what participants themselves found to be barriers to and facilitators of care for sexual health. The grouping of these barriers and facilitators was based on a critical realist conceptual model (Porter, 2015) that identifies causal mechanisms embedded in the various strata of the social world that includes people's bodies and bodily activities, their relations with sexual partners and with healthcare professionals, all within an institutional (the hospital organisation) and wider (the society participants live in) social setting.

Table 1
Explanatory variables for a survey of people with cancer about care for sexual health received in the UK.

Survey section	Explanatory variables	Details/rationale/references/permissions to use
Socio-demographics[a]	Age; partnership status; highest level of education achieved Ethnicity; sex; gender; sexual orientation	Rationale: collected due to perceived importance in similar studies Reference: Office for National Statistics (2021)
Cancer characteristics[a]	Cancer type; cancer stage; time since diagnosis; previous cancer treatments; currently on treatment or not	Rationale: collected due to perceived importance in similar studies
Sexual activity[a]	Selected questions from the Sexual Function Questionnaire (SFQ-long; SFQ-Short) and its associated Health Impact Scale version 2017 including: a) Closed-ended questions about:sexual activity status; sexual impact of cancer/cancer treatment; whether participants were bothered by any negative impacts.	Rationale: 1. SFQ can be used by males and females, does not depend on being sexually active and explores treatment impact. 2. Full questionnaires not used to avoid overburdening participants. 3. SFQ instructions used as recommended to improve self-reporting. Reference: Syrjala et al., (2000); Syrjala, SFQ scoring manual, unpublished, 2017. Permissions: Fred Hutchinson Cancer Research Centre in the USA
	Four statements about sexual health generated by the researcher: a) Each variable was measured by level of agreement on a 5-point Likert scale (strongly disagree to strongly agree).	Rationale: items of interest identified during literature review on sexual health communication in oncology
Emotional distress[a]	Emotional distress measured by the Distress Thermometer (DT): A validated one item, 11-point Likert scale represented graphically as a thermometer and has a scale ranging from 0 (no distress) to 10 (extreme distress). Scores related to feelings over the previous week. A cut off score of greater than or equal to 4 is used to identify clinically significant distress	Rationale: literature recommended collecting these data (Zimmaro et al., 2020) References: Cutillo et al., (2017); Riba et al., (2019) Permissions: The US National Comprehensive Cancer Network (NCCN) provided permission to use an adapted form of the DT to enable its use in an online environment.
	Emotional distress & sexual concerns measured by one question: Is any of the reported distress related to sexual concerns?	Researcher generated question
Barriers to & facilitators of care for sexual health[a]	Thirty-seven known barriers to or facilitators of care for sexual health were selected for inclusion in the survey. Barriers to and facilitators of care were grouped according to type by the researcher into 6 subsections: 1 Sexual issues and the hospital setting (4 statements) 2 Sexual issues and me (8 statements) 3 Sexual issues and the hospital cancer team (8 statements) 4 Sexual issues and partners (3 statements) 5 Sexual activity after cancer treatment (6 statements) 6 Sex and the society that I live in (8 statements) Each variable was measured by level of agreement on a 5-point Likert scale (strongly disagree to strongly agree).	Rationale: Identified via a literature review on sexual health communication in oncology. References: Albers et al. (2020); Almont et al. (2019); Annerstedt and Glasdam (2019); Bamgboje-Ayodele et al., 2021; Canzona et al. (2019); Dai et al., (2020); Fitch et al. (2013a); Fitch et al. (2013b); Gong et al. (2021); Heβ et al. (2021); Gong et al. (2021); Katz, 2005; Kristufkova et al., 2018; Krouwel et al. (2016); Krouwel et al. (2020); Lee et al. (2020); Liberacka-Dwojak and Izdebski (2021); McMullen et al. (2017); Maree and Fitch (2019); Masjoudi et al., 2019; O'Connor et al., 2019; Papadopoulou et al. (2019); Penson et al. (2000); Perz et al. (2013); SparkNotes, 2005; Stewart et al. (2021); Traumer et al. (2019); Wazqar (2020); Williams and Addis (2021); Ussher et al. (2013); Zhang et al. (2020); Zhu and Wittmann (2020); Zimmaro et al. (2020).

[a] To minimise missing data participants had to answer all questions in the survey. This was enabled, for most questions, by providing response options of "I prefer not to say" and "I cannot remember". However, "I prefer not to say" options were not possible for 5-point Likert scales and so participants were instructed to select the neither agree nor disagree response option if they preferred not to say, or if they did not feel that the question applied to them in any way.

Table 2
Characteristics of people with cancer participating in a UK survey about care for sexual health in 2022.

Demographic Characteristics (n = 136)		**People with Cancer**	
		N[e]	%[f]
Age	Under 50 years	30	22.1
	Equal to or over 50 years	106	77.9
Partnership Status PNTS[a]: n = 1 (0.7 %)	Partnered (married/civil partnership/living together)	117	86.0
	Partnered but not living together	7	5.1
	Not partnered	11	8.1
Age achieved highest level of educational attainment PNTS[a]: n = 5 (3.7 %)	Up to 18 Years	58	42.6
	Over 18 years	68	50.0
	Other	5	3.7
Ethnicity PNTS[a]: n = 1 (0.7 %)	White	130	95.6
	Other than White[b]	5	3.6
Sex at birth[c,d] PNTS[a]: n = 1 (0.7 %)	Female	83	61.0
	Male	52	38.2
Sexual orientation PNTS[a]: n = 4 (2.9 %)	Heterosexual	117	86.0
	Non heterosexual	15	11.0
Cancer Characteristics (n = 136)			
Cancer type	Haematology	46	33.8
	Gynaecology	29	21.3
	Genitourinary	24	17.6
	Gastrointestinal	13	9.6
	Breast	11	8.1
	Other (skin/lung/head & neck/brain/musculoskeletal)	13	9.5
Cancer stage at diagnosis	1 & 2	50	36.8
	3 & 4	53	38.9
	Unsure	30	22.1
	Other	3	2
Time since diagnosis PNTS[a]: n = 1 (0.7 %)	≤ 6 months	9	6.6
	> 6 months to < 2 years	37	27.2
	2–5 years	46	33.8
	> 5 to ≤ 10 years	43	31.6
Which type of treatment was ever received (Participants reported yes or no for each treatment type)	Surgery	80	58.8
	Chemotherapy	99	72.8
	Radiotherapy	41	30.1
	Hormone therapy	16	11.8
	Targeted drug therapy	14	10.3
	Immunotherapy	26	19.1
	Stem cell/bone marrow transplant	36	26.5
On treatment currently (for 1st or 2nd cancer)	No	72	52.9
	Yes	64	47.1
Emotional Distress Characteristics (n = 136)			
Distress Thermometer score (Score of ≥ 4 indicates clinically significant distress)	<4	50	36.8
	≥ 4	86	63.2
If distressed (score of 1–10) then did distress relate to sexual concerns	No	50	36.8
	Yes	65	47.8
	N/A	21	15.4
Sexual Activity Characteristics			
Impact of Cancer/Cancer Treatment on Sex life (n = 136)			
	My sex life is: as bad as it could be/a lot worse/a little worse than before cancer	116	85.3
	My sex life is: no different than before cancer/a little/a lot better than before cancer	20	14.7
The changes to my sex life bother me *n = 116* *(only answered if sex life worsened)*	Strongly Disagree/Disagree	5	4.3
	Neither Agree Nor Disagree	8	6.9
	Agree/Strongly Agree	103	88.8
Sexually active in past year (n = 136)			
	No	43	31.6
	Yes	93	68.4
Sexually active in past month *n = 93 (only answered if sexually active in past year)*			
	No	22	23.7
	Yes	71	76.3
Statements about sexual health/wellbeing after cancer/cancer treatment (n = 136)			
Sexual self-confidence worsens			
	Strongly Disagree	4	2.9
	Disagree	10	7.4
	Neither Agree Nor Disagree	9	6.6
	Agree	59	43.4

(*continued on next page*)

Table 2 (*continued*)

Demographic Characteristics (n = 136)		**People with Cancer**	
		N[e]	%[f]
	Strongly Agree	54	39.7
Sexual changes lead to problems in relationships			
	Strongly Disagree	8	5.9
	Disagree	24	17.6
	Neither Agree Nor Disagree	29	21.3
	Agree	46	33.8
	Strongly Agree	29	21.3
Being with a new partner would be difficult			
	Strongly Disagree	2	1.5
	Disagree	5	3.7
	Neither Agree Nor Disagree	19	14
	Agree	35	25.7
	Strongly Agree	75	55.1
Those needing to start new sexual relationships will need extra support from the hospital cancer team			
	Strongly Disagree	3	2.2
	Disagree	5	3.7
	Neither Agree Nor Disagree	24	17.6
	Agree	49	36
	Strongly Agree	55	40.4

a PNTS = prefer not to say; b UK Government recommended description when space is limited.
c zero intersex participants; d all participants reported that their gender was the same as their sex assigned at birth; e N = Number; f % = percentage.

3.3. Analytical methods

All statistical analyses were conducted using SPSS version 29 (IBM Corp, 2021).

Univariate analyses of closed question type variables included calculation of frequencies and percentages.

Bivariate analyses were planned to test the null hypothesis that there was no association between any of the explanatory variables and the outcome variable. The outcome variable was planned to be binary (response: no/yes), once ‘I cannot remember’ responses had been treated as missing data. The explanatory variables were all categorical (including age, which was dichotomised into <50 years and ≥50 years) and included dichotomous, nominal and nominal ordered types (Bland, 2000). Chi-squared tests of independence (± Fisher’s Exact Test) were conducted where the independent variables were dichotomous or nominal. Nominal ordered, explanatory variables (e.g. 5-point Likert scale responses for barrier/facilitator statements) were individually tested for association with the outcome variable using simple binary logistic regression, and each level of agreement was compared with the respective reference category (e.g. strongly disagree).

Multivariate analysis using multiple binary logistic regression (MBLR) was performed for explanatory variables found to be statistically significantly associated with the outcome variable upon individual bivariate analysis. Each such variable was individually entered into an MBLR along with potential confounder variables to provide adjusted estimates of effects. MBLR was not used for prediction purposes but to explore and estimate the effects (associations) of a range of explanatory variables upon the outcome variable.

The significance level for all bivariate and multivariate tests was defined as 0.05.

Missing data were minimised through study design, as all questions required a response in the online survey system with additional options of ‘I prefer not to say’ or ‘I cannot remember’ enabling this (both response types were treated as missing data and removed from the analysis). No attempt was made to impute missing values.

4. Results

4.1. Participants

One hundred and thirty-six people with cancer completed the survey. The JISC survey system only provided the completion rate for the total sample, which was 70%. The total sample was 169 participants, which included 136 people with cancer and 33 partners of people with cancer (data related to partners is unpublished). Reasons for non-completion were not collected by Jisc Online Surveys.

Descriptive statistics for people with cancer relating to characteristics for socio-demographics, cancer, sexual activity and emotional distress are reported in Table 2 (presented as binary categories when possible due to space limitations but can be found in full in supplementary data file 2). In summary, the socio-demographic characteristics of the participants were majority ≥50 years old (77.9 %), partnered (91.1 %), white (95.6 %), female (61 %), cis-gendered (100 %), and heterosexual (86 %). The largest category for age at which the highest level of educational attainment had been achieved was over 18 years old (50 %). Cancer characteristics provided a sample that was evenly distributed with respect to cancer stage, time since diagnosis (with the exception of the ≤6 months category) and whether on or off treatment currently. Haematology was the most common cancer type (33.8 %), followed by gynaecology (21.3 %), genitourinary (17.6 %), gastrointestinal (9.6 %) and breast (8.1 %) cancers. The majority of participants had experienced chemotherapy (72.8 %) and/or surgery (58.8 %) with fewer participants having received other treatments. Responses related to sexual activity characteristics showed that the overwhelming majority of people reported that their sex lives had worsened following cancer treatment (85.3 %) and that they were bothered by this deterioration (88.8 %). Furthermore, the majority (63.2 %) also reported being clinically significantly distressed (Distress Thermometer (DT) score ≥4) with 47.8 % of those participants having agreed that any reported distress (where DT score was 1–10) was related to their sexual concerns.

Table 3
Level of agreement reported by people with cancer for statements about potential barriers to and facilitators of care for sexual health in a UK survey in 2022 (n = 136).

	PWC[a] % agreement				
	SD[b]	D[c]	N[d]	A[e]	SA[f]
1. STATEMENTS RELATED TO THE HOSPITAL SETTING					
B[g]: There is not enough privacy to talk about sexual issues	8.8	24.3	25.0	**27.9**	**14.0**
B[g]: There are usually too many people in the room to talk about sexual issues	8.1	26.5	27.2	**27.2**	**11.0**
B[g]: There isn't enough time during consultations to talk about sexual issue	4.4	15.4	16.2	**39.7**[j]	**24.3**[j]
B[g]: Sexual issues are not a priority in cancer care	3.7	5.9	11.8	**33.1**[j]	**45.6**[j]
2. STATEMENTS RELATED TO SEXUAL ISSUES AND ME					
B[g]: Sex is a difficult topic for me to talk about	**16.2**	**27.2**	17.6	27.2	11.8
B[g]: Me or my partner should be the first to bring up the topic of sexual issues during hospital appointments (not the hospital cancer team)	**14.7**	**40.4**	27.2	14.0	3.7
B[g]: I might become embarrassed talking about sexual issues to the hospital cancer team	**16.9**	**27.2**	21.3	25.7	8.8
B[g]: I would feel uncomfortable talking about sexual issues to the hospital cancer team	**19.9**	**29.4**	19.1	26.5	5.1
F[h]: I feel confident talking about sexual issues to the hospital cancer team	11.0	27.2	22.8	25.7	13.2
B[g]: I feel ashamed about my/our sexual issues (or would if I/we had sexual issues)	**27.9**	**28.7**	15.4	20.6	7.4
F[h]: I want to talk to the hospital cancer team about my/our sexual issues (or would if I had sexual issues)	5.1	9.6	27.2	**45.6**	**12.5**
B[g]: Sexual issues are only important if you have a partner	**39.7**[j]	**33.1**[j]	14.7	9.6	2.9
3. STATEMENTS RELATED TO SEXUAL ISSUES AND THE HOSPITAL CANCER TEAM					
F[h]: The hospital cancer team should be the first to mention the topic of sex (not me/us)	2.9	13.2	27.2	**41.9**	**14.7**
F[h]: The hospital cancer team should ask if I/we are having sexual issues	2.2	6.6	15.4	**61.0**[j]	**14.7**[j]
B[g]: The hospital cancer team might become embarrassed if I/we talk about sexual issues	**16.2**	**36.8**	30.1	15.4	1.5
B[g]: The hospital cancer team will not be comfortable talking about sexual issues	**14.0**	**35.3**	33.8	14.7	2.2
B[g]: The hospital cancer team will negatively judge those who talk about sexual issues	**22.8**[j]	**45.6**[j]	25.7	5.1	0.7
B[g]: Mentioning sexual issues will offend the hospital cancer team	**29.4**[j]	**45.6**[j]	20.6	4.4	0.0
B[g]: The hospital cancer team don't have the knowledge and training to talk about sexual issues	11.8	20.6	**39.7**	17.6	10.3
F[h]: I would prefer to talk about sexual issues to a healthcare professional who was the same gender as me	12.5	20.6	27.2	**25.7**	**14.0**
4. STATEMENTS RELATED TO SEXUAL ISSUES AND MY PARTNER					
F[h]: I am comfortable talking to my partner about sexual issues (or would be if I had a partner)	2.9	15.4	9.6	**47.1**[j]	**25.0**[j]
F[h]: Partners of cancer survivors should take part in discussions about sexual issues during hospital cancer appointments	0.7	3.7	30.1	**44.9**[j]	**20.6**[j]
B[g]: I worry that talking about my sexual issues may upset my partner (or would do if I had a partner)	**19.1**	**33.1**	15.4	26.5	5.9
5. STATEMENTS RELATED TO SEXUAL ACTIVITY AFTER CANCER TREATMENT					
B[g]: Only patients with reproductive cancers (such as breast, ovarian, womb, cervix, prostate, testicular or penis) need to talk about sexual issues	**47.1**[k]	**47.8**[k]	2.2	2.2	0.7
B[g]: Sexual activity is frightening after cancer treatment because of changes to the body	2.9	14.0	20.6	**35.3**[j]	**27.2**[j]
B[g]: I feel embarrassed to have sexual activity after my/my partner's cancer treatment	**11.8**	**30.1**	26.5	22.8	8.8
F[h]: I think that there are treatments available to help most sexual difficulties[i]	4.4	10.3	38.2	**41.9**	**5.1**
B[g]: I worry that sexual activity might make cancer treatment less effective	**47.1**[k]	**34.6**[k]	11.8	1.5	5.1
B[g]: I worry that sexual activity might make cancer come back	**55.9**[k]	**32.4**[k]	6.6	0.7	4.4
6. STATEMENTS RELATED TO SEX AND SOCIETY					
B[g]: Sex is a private matter	4.4	21.3	25.0	**41.2**	**8.1**
B[g]: Sex is a taboo topic for me	**27.2**[j]	**51.5**[j]	14.0	6.6	0.7
B[g]: Sex is a taboo topic for people in my culture	**29.4**[j]	**44.1**[j]	19.9	5.1	1.5
F[h]: Sex is important to disabled people	0.0	0.7	15.4	**49.3**[k]	**34.6**[k]
F[h]: Sex is important to older people	0.0	2.9	7.4	**53.7**[k]	**36.0**[k]
F[h]: Sex is important to people with advanced cancer[i]	0.7	7.4	21.3	**44.9**[j]	**25.7**[j]
B[g]: Sex is only important for reproduction	**66.9**[k]	**26.5**[k]	2.2	2.2	2.2
F[h]: My own cultural/religious beliefs make talking about sexual issues difficult for me but I still want the hospital cancer team to talk to me about these things	**30.9**	**25.0**	33.1	7.4	3.7

[a] PWC: people with cancer.
[b] SD: strongly disagree.
[c] D: disagree.
[d] N: neither agree nor disagree.
[e] A: agree.
[f] SA: strongly agree.
[g] B barrier statement.
[h] F facilitator statement.
[i] 2 statements were noted as barriers in the literature review but were phrased as facilitators in this survey for balance.
[j] Results show ≥ 60 % to <80 % of participants either agreeing/strongly agreeing or disagreeing/strongly disagreeing.
[k] Results that show ≥ 80 % agreement/strong agreement or disagreement/strong disagreement.
Bold text reveals the highest percentage of responses for disagree/strongly disagree, neither agree nor disagree, or agree/strongly agree.

4.2. *Results related to objective 1 (main outcome variable): to describe the proportion of people with cancer who self-reported whether sexual health was discussed with the UK hospital cancer team during their cancer care*

This data was reported in Sheppard et al. (2024) but has been reported again here, as it was required for the MBLR analysis. Outcome data related to this objective showed that the proportion of people with cancer who ever discussed sexual health with the hospital cancer team was:

- 61.0 % (n = 83): No, never talked about sexual health
- 30.9 % (n = 42): Yes, did talk at some point about sexual health
- 5.1 % (n = 7) could not remember (these participants were removed from the analysis)
- 2.9 % (n = 4) were excluded from the analysis because despite having responded no to the outcome variable, they had contradictory data elsewhere in the survey with regards to talking about sexual health with the hospital cancer team

As a result, there were 125 participants with valid responses to the outcome variable that could be tested in the planned bivariate and multivariate analyses.

4.3. Results related to objective 2: univariate analysis of the proportions of people with cancer who agreed or disagreed with statements about potential barriers to and facilitators of care for sexual health

Table 3 shows the level of agreement/disagreement (as percentages) with a broad variety of statements related to possible barriers to and facilitators of care for sexual health that were reported by people with cancer in this survey (see supplementary data file 3 for full descriptive statistics). Due to the number of statements in Table 3 and to help with interpretation, the response option with the largest combined percentage of agreement/disagreement with each statement has been highlighted in bold. In addition, statements that produced a discernible pattern of agreement or disagreement have also been shown with a superscript (i.e. those with $\geq$60 % - <80 % (j) or $\geq$80 % (k) agreement/disagreement with a statement). Furthermore, each statement is identified as either a barrier (B) or a facilitator (F).

Of the 25 statements related to barriers to care for sexual health, the largest percentage of participants were found to disagree/strongly disagree with 18 of these. More participants disagreed/strongly disagreed with all or all but one of the barrier statements in each section, except for in the hospital setting section.

Participants agreed/strongly agreed with only 6 of the barrier statements that they were presented with and four of these were in the “hospital setting” section of statements. The first related to a lack of time in consultations (64 % agreed/strongly agreed) and the second to sexual issues not being a priority in cancer care (78.7 % agreed/strongly agreed). The other two statements about lack of privacy in the hospital setting achieved the most responses but did so at a lower level of agreement for both variables (approximately 40 %). The “sexual activity after cancer treatment” section also contained a barrier statement that participants were in agreement/strong agreement with, which was that sexual activity was considered to be frightening after cancer treatment because of changes to the body (62.5 %). The final barrier statement that participants agreed with was from the sex and society section of statements in which 49.3 % of participants agreed/strongly agreed that sex is a private matter.

Of the 12 facilitator statements that participants were presented with, the largest percentage of participants agreed/strongly agreed with 10 of these statements, disagreed/strongly disagreed with 1, and produced no overall majority for one further statement.

The sexual issues and me section of statements found the greatest percentage of participants to be in agreement/strong agreement with the statement ‘I want to talk to the hospital cancer team about my sexual issues (or would if I had sexual issues)’ (58.1 %). However, the statement ‘I feel confident talking about sexual issues to the hospital cancer team’, found very similar percentages of participants disagreeing/strongly disagreeing (38.2 %) and agreeing/strongly agreeing (38.9 %). Moreover, in the sexual issues and the hospital cancer team section, 75.7 % of people with cancer agreed/strongly agreed that the hospital cancer team should ask if people are having sexual issues. As to who should bring the topic up first, 56.6 % agreed/strongly agreed that it should be the hospital cancer team (whereas 17.7 % agreed/strongly agreed that the patient/partner should be the first to raise the topic), and 39.7 % agreed/strongly agreed that they would prefer to talk to a healthcare professional of the same gender as themselves. Two statements from the sexual issues and my partner section showed that 72.1 % of people with cancer agreed/strongly agreed that they were comfortable talking to their partners about sexual issues, and 65.5 % agreed/strongly agreed that partners should be included in consultations. Notwithstanding this finding, 72.8 % of people with cancer disagreed/strongly disagreed that sexual issues were only important if you have a partner. Finally, more participants were in agreement with a variety of facilitator statements in the section about “sex and society”. Here, people with cancer believed that sex is important to both older people (89.7 % agreed/strongly agreed) and to people with a disability (83.9 % agreed/strongly agreed). Additionally, 70.6 % agreed/strongly agreed that sex is important to people with advanced cancer.

4.4. Results related to objective 3: to clarify to what extent the barriers to and facilitators of care for sexual health identified by people with cancer combined with their personal characteristics affected their likelihood of having a sexual health discussion with the hospital cancer team

a) Bivariate analysis (unadjusted estimates of associations)

The majority of bivariate analyses performed showed no statistically significant association between the explanatory variables and the main outcome variable, and therefore the null hypotheses could not be rejected. However, for the 6 variables described below, a statistically significant association was found (comparisons were with the respective reference categories - further details can be found in Table 4). Decreases or increases in the likelihood of talking about sexual health are described below as 1/odds ratio (OR) (for simple binary logistic regression) or as an effect size (Phi values calculated for chi-square tests (Davis, 2013)).

Decreased likelihood of ever having talked about sexual health with the hospital cancer team (all statistical tests used simple binary logistic regression):

1. Sexual activity characteristics section: participants in strong agreement with the statement, ‘sexual changes lead to problems in relationships’ were 14 times less likely to have ever talked about sexual health (OR 0.07, 95 % CI 0.009 to 0.469, p = 0.007)
2. Cancer characteristics section: participants diagnosed more than 5 years but less than 10 years ago were almost 6 times less likely to have ever talked about sexual health (OR 0.18, 95 % CI: 0.04 to 0.85, p = 0.03)
3. Barrier/facilitator statements from the “hospital setting” subsection produced 2 variables that were associated with a decreased likelihood of talking about sexual health for those who were in some level of agreement:
   a. There was a lack of privacy to discuss sexual issues:
      i. Neither agree nor disagree: 7 times less likely to talk (OR 0.14, 95 % CI 0.03 to 0.66, p = 0.01)
      ii. Agree: 9 times less likely to talk (OR 0.11, 95 % CI 0.02 to 0.52, p = 0.006)
      iii. Strongly agree: 8 times less likely to talk (OR 0.13, 95 % CI 0.02 to 0.76, p = 0.02)
   b. There were usually too many people in the room to talk about sexual issues:
      i. Neither agree nor disagree: almost 6 times less likely to talk (OR 0.18, 95 % CI 0.04 to 0.78, p = 0.02)

Increased likelihood of ever having talked about sexual health with the hospital cancer team:

1. Sexual activity section: being sexually active in the past year was associated with talking about sexual concerns (p = 0.01) with a moderate effect size ($phi^2 = 0.05$) (chi-square test)
2. Barrier/facilitator statements from the “sexual issues and the hospital cancer team” subsection produced 1 statement that showed an increase in the likelihood of talking if agreement was reported (simple binary logistic regression):
   a. The hospital cancer team might become embarrassed if I/we talk about sexual issues:
      i. Agree: 5.9 times more likely to talk (OR 5.93, 95 % CI 1.29 to 27.28, p = 0.02).

It was not possible to obtain a result for certain explanatory variables

Table 4
Statistically significant associations ($p < 0.05$) for bivariate and multivariate analyses of explanatory variables with the outcome variable (did you ever talk about sexual health) from a UK survey on care for sexual health in people with cancer in 2022.

Explanatory Variable/Level of Agreement	PWC[a]		Bivariate: $\chi 2$ [c]				PWC[a]	Multivariate: MBLR[d]			
	N[e]	M[b]	$\chi 2$[c]	Df[f]	P (2-S)[g]	Phi	N[e]	p[h]	OR[i]	95 % CI[j] (OR[i])	
										Low[k]	Upp[l]
Sexual Activity Characteristics Section: Have you been sexually active in the past year (alone or with a partner)?											
	125	11					115				
No			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
Yes			6.22	1	**0.01**	0.23		**0.01**	3.72	1.28	10.73
Explanatory Variable/Level of Agreement	PWC[a]		Bivariate: SBLR[n]				PWC[a]	Multivariate: MBLR[d]			
	N[e]	M[b]	p[h]	OR[i]	95 % CI[j] (OR[i])		N[e]	p[h]	OR[i]	95 % CI[j] (OR[i])	
					Low[k]	Upp[l]				Low[k]	Upp[l]
Sexual Activity Characteristics Section: Sexual Changes lead to problems in relationships											
	125	11					115				
SD[q]			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
D[r]			0.14	0.25	0.04	1.58		0.06	0.09	0.01	1.06
NAND[s]			0.22	0.33	0.05	1.96		0.12	0.16	0.02	1.61
A[t]			0.05	0.17	0.03	1.01		0.02	0.06	0.01	0.68
SA[u]			0.007	0.07	0.01	0.47		0.007	0.03	0.003	0.4
Cancer Characteristics Section: How long ago were you first diagnosed?											
	124	12					114				
< 6 months			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
>6 months - < 2 years			0.25	0.4	0.09	1.85		0.26	0.39	0.07	1.99
2 years–5 years			0.49	0.6	0.14	2.56		0.5	0.55	0.09	3.06
>5 years to <10 years			**0.03**	0.18	0.04	0.85		**0.03**	0.13	0.02	0.8
B/F[p] Statement: There is not enough privacy to talk about sexual issues											
	125	11					115				
SD[q]			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
D[r]			0.36	0.49	0.11	2.26		0.34	0.46	0.09	2.3
NAND[s]			**0.01**	0.14	0.03	0.66		**0.02**	0.13	0.02	0.67
A[t]			**0.006**	0.11	0.02	0.52		**0.004**	0.08	0.01	0.45
SA[u]			**0.02**	0.13	0.02	0.76		0.04	0.14	0.02	0.88
B/F[p] Statement: There are usually too many people in the room to talk about sexual issues											
	125	11					115				
SD[q]			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
D[r]			0.86	0.89	0.23	3.48		0.62	0.68	0.15	3.09
NAND[s]			**0.02**	0.18	0.04	0.73		**0.02**	0.15	0.03	0.74
A[t]			0.11	0.31	0.08	1.28		0.04	0.18	0.04	0.9
SA[u]			0.19	0.33	0.06	1.75		0.19	0.31	0.05	1.81
B/F[p] Statement: The hospital cancer team might become embarrassed if I talk about sexual issues											
	125	11					115				
SD[q]			RC[m]	RC[m]	RC[m]	RC[m]		RC[m]	RC[m]	RC[m]	RC[m]
D[r]			0.07	3.49	0.9	13.6		0.09	3.5	0.83	14.71
NAND[s]			0.46	1.71	0.41	7.26		0.47	1.75	0.38	8.0
A[t]			**0.02**	5.93	1.29	27.3		**0.02**	6.86	1.35	35.05
SA[u]			0.28	5.33	0.26	110.8		0.42	3.59	0.16	82.02

a PWC: people with cancer; b M: missing data (Outcome variable: 7 cannot remember if talked about sexual health and 4 were excluded; Explanatory variables: 1 preferred not to say about time since diagnosis); c *$\chi 2$: chi-square;* d MBLR: multiple binary logistic regression with following confounders adjusted for age, sex, education level, impact of cancer treatment on sex life, currently on cancer treatment (all collapsed into 2 categories); e N: number; f df: degrees of freedom; g 2-S: 2 sided significance; h p: p value; i OR: odds ratio; j CI: confidence interval; k Low: lower; l Upp: upper; m RC: reference category; n SLBR: simple binary logistic regression*;* p B/F: barrier/facilitator; q SD: strongly disagree; r D: disagree; s NAND: neither agree nor disagree; t A: agree; u SA: strongly agree.

that underwent bivariate analysis with the outcome variable for two main reasons including 1) test assumptions were not met; 2) it was not possible to collapse the variable into 2 categories, if test assumptions were not met. No results were obtained for the following explanatory variables: partnership status; ethnicity; whether sex life changes bothered people; cancer type; or those variables for which multiple response options were allowed (e.g. type of treatment). The proportions of people with different types of cancer who talked/did not talk about sexual health during their cancer care has been reported in other studies and may be considered a valuable metric. These descriptive frequencies can be found in Sheppard et al. (2024).

b) Multivariate Analyses (adjusted estimates of associations)

The 6 explanatory variables found to be statistically significantly associated with the outcome variable at bivariate analysis were further tested individually using MBLR. The sample size was either 114 or 115 for all regression tests and degrees of freedom ranged from 6 to 9 depending upon the number of categories in the variable being tested. Assumptions for MBLR were met and included: the outcome variable was binary; all observations were independent; no extreme outliers were present (all variables were categorical); sample size was sufficient (Field, 2018 p. 914; Statology, 2022). Extent of multicollinearity, interactions and residual analyses were not performed.

Adjustment variables (confounders) included in the MBLR included some variables commonly known as standard epidemiological parameters i.e. age, sex and education level (McNamee, 2005), whilst others were included for their considered relevance to the outcome variable including: 1) the impact of cancer treatment on sex life; 2) whether currently on cancer treatment (no other variable from the cancer characteristics section was structured in a way suitable to be included in the MBLR). All adjustment variables were collapsed into two categories. No other variable selection process was applied.

Table 4 shows that all six variables maintained their statistically significant association with the outcome variable upon multivariate analysis. Furthermore, two of the six variables further strengthened their p values and/or odds ratios in the adjusted regressions at either all or some levels of agreement. These included the sexual activity section statement about sexual changes leading to problems in relationships with those agreeing/strongly agreeing being 17 (OR 0.06) to 33 (OR 0.03) times statistically significantly associated with a reduced likelihood of talking about their sexual health. Additionally, those who neither agreed nor disagreed or those who agreed with the barrier/facilitator statement, ‘there are usually too many people in the room to talk about sexual issues’ were statistically significantly associated with a reduced likelihood of talking about their sexual health being approximately 6 times less likely (OR 0.15 and 0.18 respectively) to have talked about sexual health.

The overall model fit for the MBLR models was not statistically significant for any of the regression models shown in Table 4, but this was not considered important because regressions were performed for effect estimation across a range of interesting variables rather than for prediction. With the strength of the associations (as p values), their magnitudes (as odds ratios (OR)) and their precisions (as confidence intervals (CI)) having been reported as the more valuable metrics.

5. Discussion

5.1. Key results

The proportions of people with cancer who self-reported having discussed sexual health with the hospital cancer team was found to be low in this sample. Univariate analyses of a wide range of barrier/facilitator statements related to the provision and receipt of care for sexual health revealed that participants agreed/strongly agreed with only 6 of the 25 barrier statements. Of these 6 barriers, 4 related to the hospital setting, one to sexual activity after cancer treatment and one to a broader social barrier - sex is a private matter. However, participants agreed/strongly agreed with 10 of the 12 facilitator statements.

Testing for associations between a broad range of variables related to people with cancer and their likelihood of talking about sexual health with the UK hospital cancer team showed that the majority of these variables were not statistically significantly associated with ever having talked. However, bivariate and multivariate analysis did find six explanatory variables that were statistically significantly associated with the likelihood of ever having discussed sexual health. Four variables decreased the likelihood and two increased the likelihood of ever having talked about sexual health.

Whilst the overall sample size for this survey was relatively low for a quantitative study, the required minimum sample size was achieved as planned.

5.2. Interpretation

Objective 1: the proportion of people with cancer who self-reported whether sexual health was discussed with the UK hospital cancer team during their cancer care.

The proportion of people with cancer in this survey who self-reported that sexual health was discussed during their cancer journey was low, which was consistent with recent reports from the perspectives of both people with breast cancer (Aupomerol et al., 2022) and healthcare professionals (McGrath et al., 2021). This finding has been discussed in more detail in Sheppard et al. (2024).

Objective 2: to describe proportions of people with cancer who agreed or disagreed with statements about potential barriers to and facilitators of care for sexual health.

In relation to statements outlining a wide range of previously known barriers to and facilitators of care for sexual health in oncology, participants in this sample were found to disagree/strongly disagree with more barrier statements than they agreed with. Whereas they agreed with more of the facilitator statements than they disagreed with. Some of these findings were consistent with the wider literature but others were not.

Consistent with the wider literature, participants from this survey were found to agree with the following statements: people with cancer believed that the hospital cancer team should be the first to mention the topic of sex (Traa et al., 2014; Chow et al., 2021); and that partners should be included in discussions about sexual issues (McCaughan et al., 2020). Those with both reproductive and non-reproductive cancers have also been found to need to discuss sexual health (Perz et al., 2014). Finally, findings in the broader literature also supported the idea that sexual health matters regardless of age or disability (Perz et al., 2014; Lee et al., 2020).

Other studies have reported findings for people with cancer that contrasted with those of this survey, examples are provided next. The hospital cancer team would negatively judge or be offended by those talking about sexual health (Canzona et al., 2019). Additionally, the topic of sex has been perceived to be a taboo for some participants in some studies (Fitch et al., 2013b; Canzona et al., 2019; Traumer et al., 2019).

These data could serve to reassure the UK hospital cancer team that people with cancer in the UK do think that the hospital cancer team should ask if people are having sexual issues, and that they do not see the topic as a taboo. Moreover, participants believed that the hospital cancer team should be the first to bring the topic up, and that sex is something that is important to everyone regardless of age, cancer type, cancer stage, or disability. Proactivity on the part of the hospital cancer team is even more imperative given that the majority of participants do not believe that there is enough time to talk about sexual issues and that the topic is not a priority in cancer care. Others have also reported on organisational barriers perceived by people with cancer, which have impacted the occurrence of sexual health discussions - these have included a lack of time (Canzona et al., 2019; Traumer et al., 2019; Zhu and Wittmann, 2020) and a lack of privacy (Fitch et al., 2013b; Gong et al., 2021).

Objective 3: to clarify to what extent the barriers to and facilitators of care for sexual health identified by people with cancer combined with their personal characteristics affected their likelihood of having a sexual health discussion with the hospital cancer team.

The barrier and facilitator statements used in this survey questionnaire were largely based on previous findings from qualitative studies. However, very few of these previously identified factors were found to be statistically significantly associated with the occurrence of a discussion about sexual health, as reported by people with cancer in this survey. This may be related to the limitations of this survey’s design. The discussion will now focus on the variables that did show a statistically significant association with talking about sexual health.

Barriers and facilitators related to the internal aspects of an organisational setting (such as a hospital) can be categorised into structural, cultural and resource-related factors (Porter, 2015; Greenhalgh et al., 2017). Discussions about sexual health were found to be statistically significantly associated with structural aspects of the organisational setting. Those who were in some form of agreement about there not being enough privacy or that there were too many people in the room to talk about sexual issues were found to be less likely to discuss their sexual health with the hospital cancer team. Lack of privacy as a barrier to care has also been found in qualitative studies of people with cancer (Fitch et al., 2013b; Gong et al., 2021) and also in studies with healthcare professionals (Fitch et al., 2013a; Ussher et al., 2013; Wazqar, 2020). Results of the multivariate analysis from this survey add to the current literature by providing an effect size of the impact of beliefs about lack of privacy and their association with talking about sexual health.

Two variables in the sexual activity characteristics section were found to be statistically significantly associated with the occurrence of a discussion about sexual health. Firstly, participants who had had sexual activity in the past year were found to be statistically significantly associated with an increased likelihood of talking about their sexual health when compared to those who had not been sexually active in the past year. Viewing this finding in the context of other data from this survey, which showed that the majority of participants reported a deterioration in their sex lives which bothered them, may suggest that those who are so impacted that they no longer have a sex life are getting the least help. Additionally, those who agreed/strongly agreed with the statement, 'sexual changes lead to problems in relationships' were also less likely to have had a discussion. The reason for this is unclear but speculatively may relate to people not wanting to bring something up that may subsequently cause problems. Therefore, need for care may not be related to provision of care, suggesting personalised care is not taking place, which is inconsistent with UK cancer plans (Department of Health and Social Care, 2022).

People with cancer who were diagnosed 5–10 years ago were also found to be less likely to have discussed their sexual health during their cancer care. These people will not benefit from future improvements in hospital care, as they are likely to have already been discharged in the UK. Finding a way to reach these people and offer retrospective information and advice would be challenging but may not only be beneficial but also ethically imperative.

5.3. Limitations

Limitations (and generalisability) have been described in Sheppard et al. (2024) but additional pertinent points have been described below. As previously noted, although the sample size was met within the planned recruitment period, the achieved sample size was small for a quantitative research study.

With a relatively small sample size, the regression analysis may have been underpowered to detect subtle relationships between discussions about sexual health and possible barriers to and facilitators of care. This may have been responsible, in part, for the finding that there were few variables that were statistically significantly associated with discussing sexual health in this sample. Due to this limitation, a descriptive look at the data was undertaken for any suggestions that certain variables might have an effect if the survey was repeated with a larger sample size. The following three variables were found to be just outside the pre-specified level of significance for bivariate analysis (if participants agreed/strongly agreed then a decreased likelihood of talking about sexual health was found): 'I worry that talking about my sexual issues may upset my partner (or would do if I had a partner)'; 'sexual activity is frightening after cancer treatment because of changes to the body'; and 'I feel embarrassed to have sexual activity after my/my partner's cancer treatment'.

6. Conclusions

Univariate analysis found that the majority of participants disagreed with many previously identified barriers to care for sexual health. However, there was majority agreement with one personal (sexual activity is frightening because of changes to the body) and one societal (sex is a private matter) barrier. Whereas majority agreement with other barriers only pertained to the hospital setting (lack of time/privacy/priority for sexual issues). Furthermore, multivariate analysis found two of the four statistically significantly associated variables that hindered discussions about sexual health were related to the hospital setting (both to a lack of privacy).

Although discussions about sexual health were found to be less frequent in this sample, the majority of participants agreed with many facilitator statements about care for sexual health. The majority agreed that the hospital cancer team should ask if people are having sexual issues and also be the first to bring the topic up - regardless of people's age, disability or cancer stage.

Taken together the above suggests that whilst participants appeared willing to receive care for their sexual health, organisational barriers (collectively) appeared the most salient. Healthcare professionals raising the topic of sexual health (regardless of age, disability or cancer stage) may counter the barriers reported by people with cancer that sexual health is not a priority in oncology or that there is a lack of time to discuss the topic.

Further qualitative research into the barriers to and facilitators of the provision of care for sexual health in oncology has been planned using the critical realism paradigm.

CRediT authorship contribution statement

Suzanne Sheppard: Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **David Culliford:** Writing – review & editing, Methodology, Formal analysis. **Tracy Glen:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Sally Lee:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Zoë A. Sheppard:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Sam Porter:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

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Declaration of competing interest

None declared.

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Appendix A. Supplementary data

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