



## Original Article

## Beyond Teenage and Young Adult Cancer Care: Care Experiences of Patients Aged 25–39 Years Old in the UK National Health Service



E. Lidington<sup>\*</sup>, A.S. Darlington<sup>†</sup>, C. Vlooswijk<sup>§</sup>, S. Beardsworth<sup>¶</sup>, S. McCaffrey<sup>¶</sup>, S. Tang<sup>\*\*\*\*\*</sup>, K. Stallard<sup>¶</sup>, E. Younger<sup>\*†</sup>, P. Edwards<sup>\*</sup>, A.I. Ali<sup>||</sup>, M. Nandhabalan<sup>\*\*</sup>, A. Din<sup>‡</sup>, N. Starling<sup>\*††</sup>, J. Larkin<sup>\*††</sup>, S. Stanway<sup>\*</sup>, M. Nobbenhuis<sup>\*</sup>, S. Banerjee<sup>\*††</sup>, Z. Szucs<sup>‡‡</sup>, M. Gonzalez<sup>\*\*</sup>, B. Sirohi<sup>§§¶¶</sup>, O. Husson<sup>††|||1</sup>, W.T.A. van der Graaf<sup>\*††|||1</sup>

<sup>\*</sup>Royal Marsden NHS Foundation Trust, London, UK

<sup>†</sup>Radboud University Medical Center, Nijmegen, the Netherlands

<sup>‡</sup>University of Southampton, Southampton, UK

<sup>§</sup>The Netherlands Comprehensive Cancer Organisation, Utrecht, the Netherlands

<sup>¶</sup>London, UK

<sup>||</sup>St George's University Hospital NHS Foundation Trust, London, UK

<sup>\*\*</sup>Imperial College Healthcare NHS Trust, London, UK

<sup>††</sup>Institute of Cancer Research, London, UK

<sup>‡‡</sup>East Suffolk and North Essex NHS Foundation Trust, Ipswich, UK

<sup>§§</sup>Barts Health NHS Trust, London, UK

<sup>¶¶</sup>Apollo Proton Cancer Centre, Chennai, India

<sup>|||</sup>Netherlands Cancer Institute – Antoni van Leeuwenhoek, Amsterdam, the Netherlands

<sup>1</sup>Public Health England, London, UK

## Abstract

**Aims:** Adolescents and young adults aged 15–39 years with cancer face unique medical, practical and psychosocial issues. In the UK, principal treatment centres and programmes have been designed to care for teenage and young adult patients aged 13–24 years in an age-appropriate manner. However, for young adults (YAs) aged 25–39 years with cancer, little access to age-specific support is available. The aim of this study was to examine this possible gap by qualitatively exploring YA care experiences, involving patients as research partners in the analysis to ensure robust results.

**Materials and methods:** We conducted a phenomenological qualitative study with YAs diagnosed with any cancer type between ages 25 and 39 years old in the last 5 years. Participants took part in interviews or focus groups and data were analysed using inductive thematic analysis. Results were shaped in an iterative process with the initial coders and four YA patients who did not participate in the study to improve the rigor of the results.

**Results:** Sixty-five YAs with a range of tumour types participated. We identified seven themes and 13 subthemes. YAs found navigating the healthcare system difficult and commonly experienced prolonged diagnostic pathways. Participants felt under-informed about clinical details and the long-term implications of side-effects on daily life. YAs found online resources overwhelming but also a source of information and treatment support. Some patients regretted not discussing fertility before cancer treatment or felt uninformed or rushed when making fertility preservation decisions. A lack of age-tailored content or age-specific groups deterred YAs from accessing psychological support and rehabilitation services.

**Conclusions:** YAs with cancer may miss some benefits provided to teenagers and young adults in age-tailored cancer services. Improving services for YAs in adult settings should focus on provision of age-specific information and access to existing relevant support.

© 2021 The Royal College of Radiologists. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

**Key words:** Cancer services; health services; oncology; patient involvement; qualitative research; young adult

Author for correspondence: O. Husson, Institute of Cancer Research, 15 Cotswold Road, Sutton, London SM2 5NG, UK.

E-mail address: [Olga.husson@icr.ac.uk](mailto:Olga.husson@icr.ac.uk) (O. Husson).

<sup>1</sup> Joint last authors.

<https://doi.org/10.1016/j.clon.2021.02.010>

0936-6555/© 2021 The Royal College of Radiologists. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

## Introduction

Adolescents and young adults (AYAs) aged 15–39 years with cancer have been described as a distinct group in oncology. AYAs face heightened psychosocial and practical issues compared with paediatric and older adult patients that include the drive to achieve 'normality,' the importance of family and friends, and difficulty balancing school, treatment and family matters [1–4]. Furthermore, tumour biology and incident cancer types differ in AYAs compared with other ages, further highlighting the need for tailored care [5,6].

Although this message of distinction has brought international attention and action, critics have suggested that it fails to appreciate the heterogeneity of AYAs and differences in experience depending on context [7,8]. The 15–39 year age range encompasses a spectrum of life stages, meaning the experiences of patients can vary extensively [9,10]. Younger AYAs tend to develop cancers common in paediatric patients, such as leukaemia which requires inpatient admissions, whereas older AYAs tend to develop adult cancers, such as breast cancer or melanoma which are usually treated in outpatient settings [11,12].

Treatment setting is particularly relevant in the UK, where tailored cancer units and services have been established for teenagers and young adults (TYAs) aged 13–24 [13]. TYAs are routinely referred to these services, which have multidisciplinary input providing age-tailored medical and psychosocial support [14,15]. However, young adults (YAs) aged 25–39 years are treated in general adult settings with minimal provision of age-specific support through hospital services.

Studies that consider the complete AYA age range as a single group may obscure important differences driven by access to relevant services. The 2017 National Cancer Patient Experience Survey reflects these differences in care experience where YA participants between ages 25 and 34 years scored the lowest of all age groups on over half the items, including questions about involvement in treatment decisions and overall ratings of care [16].

Although it is recognised that unique medical, practical and psychosocial issues arise in cancer patients across the AYA age range, previous research and age-specific services have focused primarily on TYAs. To understand whether tailored support is also needed for YAs treated in an adult setting, we aimed to qualitatively explore the healthcare experiences of YAs with cancer treated in UK hospitals.

## Materials and Methods

### Study Design

We aimed to explore the care experiences of YAs in a phenomenological qualitative study and involve patients in the analysis to accurately describe the data and improve the robustness of the results.

### Participants

Eligible patients were diagnosed with any cancer type between ages 25 and 39 years in the previous five years at one of the participating sites, including the Royal Marsden NHS Foundation Trust, Imperial College Healthcare NHS Trust, University Hospital Southampton NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust and Barts Health NHS Trust. Potential participants were identified in clinic lists or local databases and approached in clinic or by telephone by the clinical team. We recruited a convenience sample with a view to including patients with a range of tumour types across hospital sites.

### Research Team

The study coordinator, formally trained in qualitative methodology, facilitated the interviews and focus groups. The research team included clinicians, nurses, patients, psychologists and health scientists, providing multidisciplinary perspectives. Additional funding was secured to involve four YA patients who did not participate in the study in data analysis. A YA cancer charity advertised the opportunity by e-mail.

### Data Collection

Each participant provided informed consent before choosing to take part in an individual interview or focus group. Patients reported sociodemographic and clinical information in a structured questionnaire before taking part. The researcher conducted the interviews and focus groups following a semi-structured schedule reviewed by patient representatives and healthcare providers to ensure relevance and comprehensiveness (Table 1). Focus groups were held in hospital meeting rooms or local charities. A clinician was present to answer arising clinical questions. Interviews were conducted in-person at the hospital or by telephone. Focus groups and interviews were audio-recorded and field notes were kept by the facilitator or an observer.

### Data Analysis

Data analysis followed the six phases of inductive thematic analysis described by Braun and Clarke [17]. These phases included: (i) getting to know the data, (ii) initial coding, (iii) generating potential themes and subthemes, (iv) reviewing potential themes and subthemes, (v) defining and naming themes and (vi) report writing.

Audio-recordings were transcribed verbatim and stored and analysed in NVIVO [18]. Two researchers initially open-coded the data and reconciled the codes using field notes to justify decisions. The two researchers used the initial codes to generate potential subthemes and themes. The potential themes and subthemes were then reviewed by the study team in an iterative process.

**Table 1**  
Semi-structured interview and focus group schedule

Questions
1. Could you tell me about your experiences leading up to and in the time since your cancer diagnosis?
2. What has your experience been like receiving healthcare and supportive care services for your cancer?
3. Have you faced any challenges or problems?
4. What are your expectations for age-specific cancer care for young adults?
5. Have you had any particular needs or issues in the following areas as a young adult cancer patient?
<ul style="list-style-type: none"> <li>• Psychological or emotional</li> <li>• Physical</li> <li>• Risk behaviour</li> <li>• Practical</li> <li>• Social</li> <li>• Spiritual</li> <li>• Healthcare</li> </ul>

### Rigor

Potential themes and subthemes with five exemplary quotes from each subtheme were shared with YA patients together with training materials on qualitative methodology. The quote interpretation, theme and subtheme structure and the salience, definition and wording of each theme and subtheme were discussed in-depth across three half-day sessions held in hospital meeting rooms or remotely by video-conference. Suggested changes were evaluated against the full dataset by the researcher. In this iterative process, changes made by the researcher according to patient suggestions were reviewed and agreed at the next session. The patients and study team also reviewed and commented on each manuscript version. Reporting of patient involvement follows GRIPP2 guidelines [19].

### Ethical Approval

The study was reviewed and approved by the Royal Marsden and Institute of Cancer Research Joint Committee on Clinical Research (CCR4648) and received ethical approval from the Research Ethics Committee and Health Research Authority in the UK (17/LO/0219). The study followed the standards of the Declaration of Helsinki. The authors followed the COREQ reporting guidelines in drafting the manuscript [37]. Informed consent was obtained from all individuals included in the study. Informed consent was obtained from all participants to publish anonymous, direct quotations.

## Results

Clinical team members approached 152 patients. Sixty-five (42.8%) patients participated, 50 (76.9%) in interviews and 15 (23.1%) in five focus groups. Three individuals declined because they felt too ill, two felt too distressed, seven were too busy, 45 gave no reason, six did not meet

eligibility criteria after careful review and 24 did not participate after consent. Interviews lasted, on average, 42 min (range 20–88 min), whereas focus groups lasted 117 min on average (range 92–150 min).

Participants, on average, were 33.6 years at participation and 1.9 years from diagnosis (Table 2). Most YAs were female ( $n = 39$ ; 60.0%), White ( $n = 50$ ; 74.6%), married ( $n = 35$ ; 53.8%), university educated ( $n = 45$ ; 69.2%) and did not have children ( $n = 38$ ; 59.4%).

Participants had a range of tumour types; most commonly sarcomas ( $n = 13$ ; 20.0%), breast cancer ( $n = 12$ ; 18.5%) and central nervous system tumours ( $n = 12$ ; 18.5%) (Table 3). Most patients had completed treatment ( $n = 37$ ; 56.9%).

Initial analysis identified five themes (delay in diagnosis, navigating the healthcare system, health information, variability in fertility preservation discussion and sign-posting to relevant resources) with 14 subthemes. YA patient analysis elevated ‘internet double-edged sword’ and ‘psychological and emotional support’ to themes and reshaped subthemes, resulting in seven themes and 13 subthemes. YAs also advocated renaming ‘delay in diagnosis’ to ‘prolonged diagnosis’ to better reflect the diagnostic experience. Patients felt the size of ‘navigating the healthcare system’ appropriately highlighted the salience of the theme.

In-text parentheses refer to the exemplary quotes in Table 4, which presents the coding hierarchy with the final themes, subthemes, codes and quotes. The healthcare experience themes broadly translate to two categories of needs: health system needs and information needs.

### Theme 1: Prolonged Diagnosis

#### Subtheme 1a: Patient interval

Participants recognised personal factors that delayed contact with a clinician about symptoms, including a lack of awareness about cancer symptoms and life circumstances that hindered addressing issues. Many YAs noticed symptoms but assumed they were related to other causes, such as work stress or pregnancy (1a-1). Participants described feeling too busy to visit a general practitioner due to work, childcare and travel plans and often assumed the symptoms were unlikely to be serious (1a-2).

#### Subtheme 1b: Care interval

Participants highlighted a number of disease- and system-related factors that contributed to a prolonged time from first consultation to diagnosis. Patients felt the relative rarity of cancer in the YA age range was partly responsible for the hesitance of healthcare providers to investigate symptoms (1b-1). The symptoms patients experienced were also sometimes non-specific or different from classical cancer presentations (1b-2). As a result, a number of patients were misdiagnosed, lengthening the time to diagnosis. In some cases, patients believed this contributed to severe symptoms and emergency presentation. Some patients felt the reasons for further investigations or potential diagnoses were not communicated clearly, which made the period to diagnosis feel further extended.

**Table 2**  
Self-reported patient demographic information

	Mean (range)
Age at participation	33.6 (25–42) years
	Number (%) (total = 65)
Gender	
Female	39 (60.0)
Male	26 (40.0)
Ethnicity	
White	50 (74.6)
Asian/Asian British	11 (16.4)
Black/African/Caribbean/Black British	2 (3.0)
Mixed/multiple ethnic groups	2 (3.0)
Relationship status	
Married	35 (53.8)
In a relationship	16 (24.6)
Single	13 (20.0)
Divorced	1 (1.5)
Children under 18 years ( <i>n</i> = 64)	
No	38 (59.4)
Yes	26 (40.6)
Current living situation	
Live with spouse/partner	24 (36.9)
Live with spouse/partner and children	20 (30.8)
Live with parents	6 (9.2)
Live with housemate(s)	6 (9.2)
Live alone	6 (9.2)
Live with spouse/partner and parents	2 (3.1)
Live with children	1 (1.5)
Highest level of education	
University or degree	45 (69.2)
College or diploma	11 (16.9)
Secondary school	7 (10.8)
Vocational qualification	2 (3.1)
Current employment status ( <i>n</i> = 64)	
Full-time employed	30 (46.9)
On sick leave	15 (23.4)
Part-time employed	7 (10.9)
Self-employed	5 (7.8)
Unemployed	3 (4.7)
Homemaker and/or caretaker for children	2 (3.1)
Other	2 (3.1)
Experienced financial difficulties ( <i>n</i> = 61)	
Not at all	28 (45.9)
A little	20 (32.8)
Quite a bit	9 (14.8)
Very much	4 (6.6)
If so, why? ( <i>n</i> = 37; non-exclusive)	
Decrease in income	27 (73.0)
Travel costs	8 (21.6)
Childcare	2 (5.4)

### Theme 2: Navigating the Healthcare System

#### Subtheme 2a: First interaction with the healthcare system

Participants often felt overwhelmed by the system and the assumption by healthcare professionals that the process was routine (2a-1). After receiving the cancer diagnosis, many YAs were surprised by how quickly decisions were

**Table 3**  
Self-reported patient clinical information

	Mean (range)
Age at diagnosis	31.7 (25–39) years
Years since diagnosis	1.9 (0–5) years
	Number (%) (total = 65)
Diagnosis	
Sarcomas	13 (20.0)
Breast cancer	12 (18.5)
Central nervous system tumours	12 (18.5)
Gastrointestinal cancer	7 (10.8)
Urological cancers	6 (9.2)
Gynaecological cancers	5 (7.7)
Haematological cancers	5 (7.7)
Lung cancer	3 (4.6)
Melanoma	2 (3.1)
Current treatment status	
In follow-up	37 (56.9)
On treatment	28 (43.1)
Treatments received ( <i>n</i> = 64; non-exclusive)	
Chemotherapy	46 (71.9)
Surgery	38 (59.4)
Radiotherapy	28 (43.8)
Clinical trial	13 (20.3)
Hormone therapy	7 (10.9)
Immunotherapy	7 (10.9)
No treatment	5 (7.8)
Targeted therapy	5 (7.8)
Bone marrow or stem cell transplant	1 (1.6)
Brachytherapy	1 (1.6)
Treatment intent	
Curative	42 (64.6)
Unknown	13 (20.0)
Palliative	10 (15.4)
Disease recurrence ( <i>n</i> = 61)	
No	41 (67.2)
Yes	10 (16.4)
Not applicable	10 (16.4)
Number of comorbidities ( <i>n</i> = 61)	
None	45 (73.8)
1	12 (19.7)
2	1 (1.6)
3	3 (4.9)

made and treatment began. For many participants, this was their first experience with a serious illness and they felt they needed more communication about how the healthcare process worked, including basic information about who to contact for particular issues and how (2a-2). This naivety, in combination with a self-awareness of looking visibly younger than other patients, added to feelings of discomfort in hospital.

#### Subtheme 2b: Need to self-advocate

Participants felt a lack of provider continuity and the need to chase appointment confirmations and results shifted the responsibility of treatment management onto the patient (2b-1). YAs believed that seeing different providers

**Table 4**  
Coding hierarchy

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)	
1. Prolonged diagnosis	1a. Patient interval	Attribute symptoms to something less sinister	1a-1	I was thinking oh loss of energy, bruises but I just thought that was because I've got two young children who jump all over me so everything that was happening I just put it down to something else (female 708, haematological cancer, in curative treatment)	
		Surrounding life circumstances	1a-2	When you're young, you might be starting a new job, you don't want to take time off because you think it's going to be nothing. You move house, and then you're in a different area code so you have to get re-registered (female 919, breast cancer, completed curative treatment)	
	1b. Care interval	Cancer uncommon in young adults	1b-1	They were just calling me unfit and thinking that because I'm a young person, you don't suspect these things (female 709, haematological cancer, in curative treatment)	
		Non-specific or atypical symptom presentation	1b-2	I have been going to my GP for over 5 years for my symptoms, obviously the blood coming out of my, you know, in your stool was the first one, and swollen belly and stuff. But obviously because of my age and because, throughout all of this, I had never really sort of lost my appetite they are kind of thinking it's probably not cancer (male 805, gastrointestinal cancer, in curative treatment)	
2. Navigating the healthcare system	2a. First interaction with the healthcare system	Overwhelmed by practical aspects of healthcare system	2a-1	As a new patient, you haven't got a clue what is happening around you and things are moving at 100mph and it's hard to catch your breath and work out what's going on ... this nurse started talking to us about everything really quite quickly. And you'll do this, and you'll do this, and you'll come into here ... I felt out of control and I felt really scared because she's going through this as if it's nothing. Because she does it every day, she's not realising this is new to me (female 928, breast cancer, in curative treatment)	
		No personal experience of illness	2a-2	The only thing that I felt a little not in the know of is right at the very beginning because that's the time when you're most overwhelmed by it. You're unlikely to have known anybody or very few people who've gone through it (male 816, germ cell tumour, completed curative treatment)	
	2b. Need to self-advocate	Lack of healthcare provider continuity	2b-1	I find it very difficult to communicate with them. Most of the time I don't even see my consultant. I see someone else. I see someone new every day, so I can't even. I feel like I have to start all over again, which is difficult (female 154, sarcoma, in treatment with unknown intent)	
		Need to be proactive	2b-2	It feels like, if you don't take charge of that as a patient, it, then, it doesn't feel like anyone is in charge of it (male 115, sarcoma, in treatment with unknown intent)	
	2c. Appreciation of healthcare professionals	Appreciate familiarity in healthcare staff	Appreciate familiarity in healthcare staff	2c-1	I just feel more cared for ... sometimes I just get a phone call from my nurse and she's saying, just checking to see everything's okay, do you need help with anything in terms of appointments. That makes a huge difference (male 885, central nervous system tumour, completed treatment with unknown intent)
			Reassured by time given for detailed discussions	2c-2	He explained everything that was going to be done. He explained the process, what the suspicions were ... And he did it in quite a lot of detail and I was actually very appreciative of that. In particular he did a lot to try to put me at ease (male 886, central nervous system tumour, completed curative treatment)

3. Healthcare patient communication	3a. More clinical detail	Want full and accurate information	3a-1	Initially I was drip-fed information and I suppose a lot of people probably couldn't handle it. Maybe I couldn't have handled it, I don't know at the time. But now, I still feel like I don't know enough ... I know it's spread to the bones in my back, but I need to know which bones. I don't know (female 503, lung cancer, in palliative treatment)
		Information gives agency	3a-2	You do get this sort of information in the letters ... but actually having some sort of agency, and a bit more detailed knowledge on the options, the pathway itself, would be incredibly helpful. Because you're very much directed when you're diagnosed, and I think there's sort of an assumption that when you're diagnosed you're a bit too blinded by the diagnosis to be able to make some sort of, you know, a judgement (female 970, breast cancer, in curative treatment)
		Access to medical records	3a-3	It's nice that I know that I could just go back to that [scan] and look at it again. I haven't bothered to, but it was a question that popped into my head and the fact that I had at my fingertips, the answer—somewhere, my filing's not that good—that is nice. You feel much more empowered (female 222, gastrointestinal cancer, completed curative treatment)
	3b. Impact of side-effects	Impact on daily life	3b-1	Yes, information about how you're likely to feel, how tired you're likely to feel, how spaced out you are. I was very spaced out on some of the tablets. Yes, things like that because that's quite surprising. Left looking after a baby and a 3.5-year-old and you're not quite there because you're sort of floating around a bit (female 200, gastrointestinal cancer, completed curative treatment)
		Experience of side-effects	3b-2	With the side-effects thing as well, you go for chemo and then you like go home, and you have got like your thermometer, you are ready, but you don't really know what is a side-effect, and what isn't (female 801, gynaecological cancer, in curative treatment)
		Long-term effects	3b-3	Being younger, we probably do want to be able to fix things or feel a bit more in control of recovery. Just don't want to feel like you're going to have these problems for 40 years. So those are the things that I actually worry about a bit. So the effects, the late effects, of having radiotherapy (female 603, gynaecological cancer, completed curative treatment)
4. Internet double-edged sword	4a. Overwhelming	Information not relevant to individual clinical situations	4a-1	Pieces of information we get online are not necessarily accurate. And they might just give you a general look, but in your own case they become suddenly imprecise and scary (male 138, sarcoma, completed curative treatment)
		'Funnel of negativity'	4a-2	A lot of people do sometimes just go on because you have had a shit day and whereas people won't go on and say yes today was brilliant and I have had no side-effects. So, you can get a lot more of a funnel of negativity (female 919, breast cancer, completed curative treatment)
	4b. Source of information and support	Information about treatment options and experiences from peers	4b-1	I read a lot on that forum about treatment options and all those things. So that's what helped me, actually, quite a lot ... and also a little bit of – how do you say it – psychological ... Yes, you know, there are a lot of people who are about the same age as you, and who also have that problem, so I think that also helps (male 149, sarcoma, in curative treatment)
		Peer support	4b-2	When it's online, you feel like you can connect any time. So, I think that's what I find with the forum. At any time that I need some support or advice I can literally just ask there and then, and there's always somebody that's there. And the same if other people have got a problem, it's nice that I can share my experience with them, as well (female 652, breast cancer, completed palliative treatment)

(continued on next page)

**Table 4** (continued)

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
5. Fertility preservation	5a. Variability in discussions	Not fully informed	5a-1	He kind of just sat down and broached the subject of getting pregnant, which caught me off guard a lot because it wasn't something I was ... well, am considering at this point in my life, not for a few years but he then was like, just to let you know, we highly recommend that someone in your position does not think about getting pregnant for at least the first three years .... It might have been something I wanted to think about prior to that. I guess that kind of choice is then taken away from me, which is something I wasn't expecting at all (female 402, melanoma, completed curative treatment)
		Rushed	5a-2	It felt really like rushed and a bit like I didn't really have a choice as well. It's hard to make decisions when you're swamped with information and they just want to get you under treatment (female 605, gynaecological cancer, completed treatment with unknown intent)
6. Psychological and emotional support	6a. Need for formal psychological support	Formal counselling	6a-1	I was referred to a psychologist ... That actually really helped to just let it all out and I think that's the most I've ever cried, got really emotional about the prospect of losing my job, not having kids, not being in a relationship, not getting married, not having a husband and not owning a house and all of that stuff (female 883, central nervous system tumour, in treatment with unknown intent)
		Coping strategies	6a-2	I really wanted something like CBT and I just didn't know where to get it ... They said, oh, why don't you try psychology and I did that, but I didn't feel I really needed psychology. It was more I, kind of, wanted someone to say right, here are some strategies to deal with this particular period, how it might take your mind off the pain or whatever, but I never managed to find it (female 202, gastrointestinal cancer, completed curative treatment)
		Relationship and family support	6a-3	The only thing that might have been nice was, sort of, the support for your spouse and family and, you know, talking to kids about it and stuff. That would probably be the only thing that was slightly difficult (female 200, gastrointestinal cancer, completed curative treatment)
		Barriers	6a-4	It would've been really beneficial if it had just been a default practice that you have an appointment with someone to talk to ... To actually go and sort that out independently, myself, is quite a big thing when you're going through a traumatic time (female 813, urological cancer, in curative treatment)
	6b. Peer support	Reduce isolation	6b-1	I would like to know how many people is of my age at the hospital being treated because it would be nice to meet them ... I have no idea if there is anyone else (female 126, sarcoma, in treatment with unknown intent)
		Want to avoid cancer	6b-2	I didn't really want to speak to anyone who had the same thing because I just wanted to block the whole situation out ... I didn't want to go to any support groups. I didn't want counselling. I just wanted my life to get back to normal, like it's never happened. But looking back on it now, I guess I just didn't want to be weak (male 872, central nervous system tumour, completed curative treatment)
		Barriers	6b-3	There's a support group for women who had cervical cancer and I went last year I think. I just ... I didn't really like it. I went to go and I looked into the window, and everybody in there was at least 70 or older. And I was just like: I'm so much younger. I just didn't go in. I just thought: I can't. I've got nothing to relate to about this (female 603, gynaecological cancer, completed curative treatment)

7. Sign-posting to relevant resources	7a. Financial information and support	Lack of information	7a-1	It was also quite difficult financially ... and I don't feel there was any support there available, I didn't find any support. I did look and I asked people for help but no, there was nothing forthcoming (male 705, haematological cancer, completed palliative treatment)
		Burdensome applications	7a-2	Access to Work alone took me and my previous boss almost 2 weeks to prepare. It's a 40 odd pages thing, I had to count the steps I have to make and achieve to come out to explain why they took a tangerine out of your leg and still you're not able to walk very well. It's just ridiculous. Calculate alternative routes on a GPS (male 138, sarcoma, completed curative treatment)
	7b. Diet and exercise	Appetite for tailored dietary advice	7b-1	I spoke to the dietician and they were able to sort of talk through what sort of lower fibre food, soluble fibre and all that kind of stuff which was helpful. But I do think ... I did feel a bit, you know, they want to be helpful and they're lovely. Their primary concern is that you're not losing weight (female 672, lung cancer, in palliative treatment)
		Need for age-appropriate rehabilitation	7b-2	It was geared towards post-menopausal women in their 60s. It was not geared towards younger women who have been more active, and want to continue being active, and for people who have children, and needing a coping strategy for lifting, bathing, changing children (female 970, breast cancer, in curative treatment)

meant the clinician lacked an understanding of their medical and personal condition. Many told stories of missing appointments due to receiving letters after the date, miscommunication between treating teams and delays to treatment due to clerical errors. Delays in hospital were particularly frustrating as they clashed with work and childcare. YAs often also felt burdened by needing to research relevant resources such as financial advice, access to charities or complementary services (2b-2).

#### *Subtheme 2c: Appreciation of care*

Patients were largely happy with the care they received and praised individual efforts of the treating doctors, nurses and staff (2c-1). YAs were particularly appreciative of the support that seemed to go beyond the staff role, coordinating care and answering questions (2c-2). YAs rejected the need for age-specific care compared to older adults other than the opportunity to meet other YAs in hospital. In particular, a few participants who experienced inpatient stays suffered severe emotional distress when exposed to other patients with advanced disease or very elderly patients. Seeing other patients with advanced disease or dementia confronted the YAs with their own mortality or added to feelings of discomfort.

### *Theme 3: Health Information*

#### *Subtheme 3a: Level of clinical detail*

As with any age of patient, participants varied in the amount of information they needed regarding clinical details, prognosis, possible side-effects, etc. However, around a quarter of participants in this study felt they lacked full and accurate information about their own disease and treatment or the reasons for certain tests and investigations, particularly in the time soon after diagnosis (3a-1). Participants who wanted further details felt this would give them a greater sense of control and comfort, allowing them to actively engage in decision-making (3a-2). Patients wanted to have access to their electronic medical records to see their own blood results, scans and treatments and to have access to accurate, personal clinical details (3a-3).

#### *Subtheme 3b: Impact of side-effects*

Beyond clinical details, many YAs wanted a deeper understanding of how potential side-effects and treatment recovery could physically and practically impact their lives (3b-1). As busy YAs, participants felt information was lacking to indicate recovery timelines to manage caring for children and returning to work. Many YAs felt the list of side-effects was available but it was difficult to distinguish between worrying side-effects and normal side-effects (3b-2). In addition, patients wanted much more information about how the cancer and treatment may impact them physically and cognitively in the long term (3b-3). YAs prioritised recovery of function and wanted information about how to mitigate long-term effects by potentially making adjustments to treatment and changing their behaviour along the treatment pathway.



#### *Theme 4: Internet Double-edged Sword*

##### *Subtheme 4a: Overwhelming*

As young people, the internet was a common source of information about the cancer diagnosis, clinical details and treatment options. However, most patients were overwhelmed by the large amounts of information found online not specific to their disease characteristics or treatment. This was particularly the case for YAs with rare cancer types. Encountering information about prognosis often caused distress. Patients also found it difficult to identify trustworthy and up-to-date information (4a-1). When exploring sites with patient discussions such as forums, YAs were also worried about encountering stories of patients with poor prognoses (4a-2).

##### *Subtheme 4b: Source of information and support*

Despite hesitancy towards searching online, many YAs found the internet an instrumental source of information and support. YAs felt the internet empowered them as they were able to research their condition independently and bring information to the table, particularly for rare cancers (4b-1). This helped enable shared decision-making. Online support groups and forums were vital in providing patients with vivid examples of other patients' experiences, particularly regarding side-effects and strategies for dealing with them. Peer forums, especially those that were age-specific, went beyond information and provided a platform for YAs to connect and relate to one another (4b-2).

#### *Theme 5: Variability in Fertility Preservation Discussions*

Discussions around fertility and fertility preservation varied widely among participants. Although for many patients fertility was brought up soon after diagnosis and options to preserve fertility discussed as a matter of urgency, eight patients described being uninformed about the consequences and options available (5a-1). With a number of patients, both men and women, fertility was not discussed before starting treatment. In a few cases, patients felt they had to push the clinical team to discuss fertility and consider treatment options. Among those who did discuss fertility, quite a few felt the decision was rushed and made without a full understanding of the consequences (5a-2). Most YAs who felt they were not fully informed about potential fertility preservation options and wanted children in the future felt a sense of regret after treatment.

#### *Theme 6: Psychological and Emotional Support*

##### *Subtheme 6a: Need for formal psychological support*

Most participants described an unmet need for access to formal psychological support (6a-1). Although this varied with regards to the timing and type of support needed, many patients felt that psychological support should be offered routinely by the clinical team. Although many YAs felt the need for one-to-one counselling, they also wanted access to therapy that could help them cope during treatment, such as cognitive behavioural therapy, relationship

counselling, family support, including advice around talking to children, and psychological support for loved ones (6a-2; 6a-3). Participants struggled to access services due to long waiting times, a lack of cancer-specific therapists and a lack of awareness of how and where to access services (6a-4).

##### *Subtheme 6b: Peer support*

YAs had mixed interest in peer support from other young cancer patients. As mentioned above, YAs appreciated online forums for the opportunity to learn from the experiences of others and share their own experiences. Age-specific peer support, particularly from local charities and informal meetings in hospital, also reduced feelings of isolation (6b-1). However, many YAs were uninterested in formal peer support groups. Participants felt they lacked the time with young families and jobs and received adequate support from friends and family. Some YAs felt that attending a support group was daunting or an admission of illness (6b-2). YAs also found that many hospital support groups included mostly older patients where the experiences and challenges were too dissimilar (6b-3).

#### *Theme 7: Sign-posting to Relevant Resources*

##### *Subtheme 7a: Financial information and support*

Many patients found a lack of information about sources of financial advice and support (7a-1). As patients incurred large travel costs, paid high mortgages and experienced a decrease in income, this was a source of distress for YAs. Participants found financial advice difficult to navigate and often needed support from charities to complete applications. YAs felt cancer-specific details, such as the exemption from prescription charges as a cancer patient, should be shared routinely by the clinical team.

##### *Subtheme 7b: Diet and exercise*

Individually tailored diet and exercise advice was a priority for YAs. Patients wanted to take action to help them recover from treatment. Many patients were disappointed by the dietary advice from doctors to maintain weight rather than specific recommendations related to their disease (7b-1). YAs often felt courses on physical exercise were not vigorous enough, geared towards much older, less active patients (7b-2). Some participants were nervous that physical activity could cause damage and wanted tailored advice. Again, recovery and regaining function was paramount to YAs to move forward from the cancer diagnosis.

## **Discussion**

YAs lacked guidance in navigating health and supportive care services and had an appetite for more clinical information and health behaviour advice. Most challenges broadly relate to health information needs, suggesting that services for YAs may be initially improved by providing timely, age-tailored information. This is the first study to explore healthcare experiences specifically in YAs treated in adult cancer services in the UK.

Participants highlighted issues coordinating their care and navigating the healthcare system. This is not surprising given that cancer services are designed for older adults with previous illness experience. Although third sector organisations fill local gaps in practical and emotional support for YAs, the health system and information needs shared across institutions suggest that YAs would benefit from support integrated into clinical services. This may require increasing capacity in psychological services or developing stronger links with external organisations. The National Institute for Health and Care Excellence (NICE) recommends identifying a skilled key worker to support TYAs in coordinating their care, providing information and assessing and meeting holistic needs [20]. This recommendation could be extended to YAs in adult services to ensure provision of age-specific information and access to relevant support. TYAs who choose to undertake cancer treatment in adult services are still reviewed by TYA-specific multidisciplinary teams [21]. Similar joint care could provide a model for providing specialist input to YAs in an adult setting.

This specialist input may be particularly important for addressing the variability seen in discussing fertility. Previous research has found that failure to discuss fertility risks before anti-cancer treatment can be associated with poor mental health [22,23]. The variability contrasts a UK survey in which most oncologists reported discussing fertility risks with all patients, suggesting patient–clinician communication may be an issue [24]. Alternatively, perceived lack of knowledge about resources and referrals, patient characteristics, such as poor prognosis or prior children, and time constraints may result in inconsistent discussions by clinicians [25]. These barriers may be exacerbated in adult settings where clinicians have high caseloads and rarely treat young patients, with most new patients over age 60 years [26]. Discussing potential fertility loss and fertility preservation is important for any YA where the cancer or treatment may affect fertility to improve post-treatment quality of life, particularly with a fertility specialist where possible [27]. Instating interventions such as quality indicators, resources and education may improve the consistency of fertility discussions where appropriate by encouraging the conversations to become routine practice [28].

There was also a clear need for tailored information about diet and exercise. Consumer trends suggest that young people are increasingly concerned with health and well-being. This may translate to a greater interest in tailored advice for health behaviours. Recent surveys have shown that few clinicians are aware of nutritional guidance or provide tailored advice [30,31]. Given emerging evidence that physical exercise can reduce mortality, recurrence and adverse side-effects, physical activity advice should also be shared as standard care, particularly with YAs who are likely to have been active before diagnosis [32]. Third-party organisations, such as Macmillan Cancer Support or SHINE Cancer Support, often provide relevant supportive care information and services for YAs, such as age-tailored exercise classes. New patients may benefit from the clinical team actively sign-posting to these organisations. An YA-

specialist key worker may again be helpful in filling this role.

The emphasis on the need for information by YAs may be driven by a desire for control. Information is seen as a form of cognitive control and information-seeking a type of problem-focused coping [33]. Previous research has found that perceived control may mediate active coping and improve well-being in some circumstances, suggesting that enabling YAs to access information may promote quality of life [34]. Providing access to medical records may increase one's sense of control and has been shown not to increase anxiety [35]. Guidance about trusted online sources should be provided soon after diagnosis, highlighting that prognosis and potential symptoms may vary greatly from what is presented online depending on an individual's clinical circumstances.

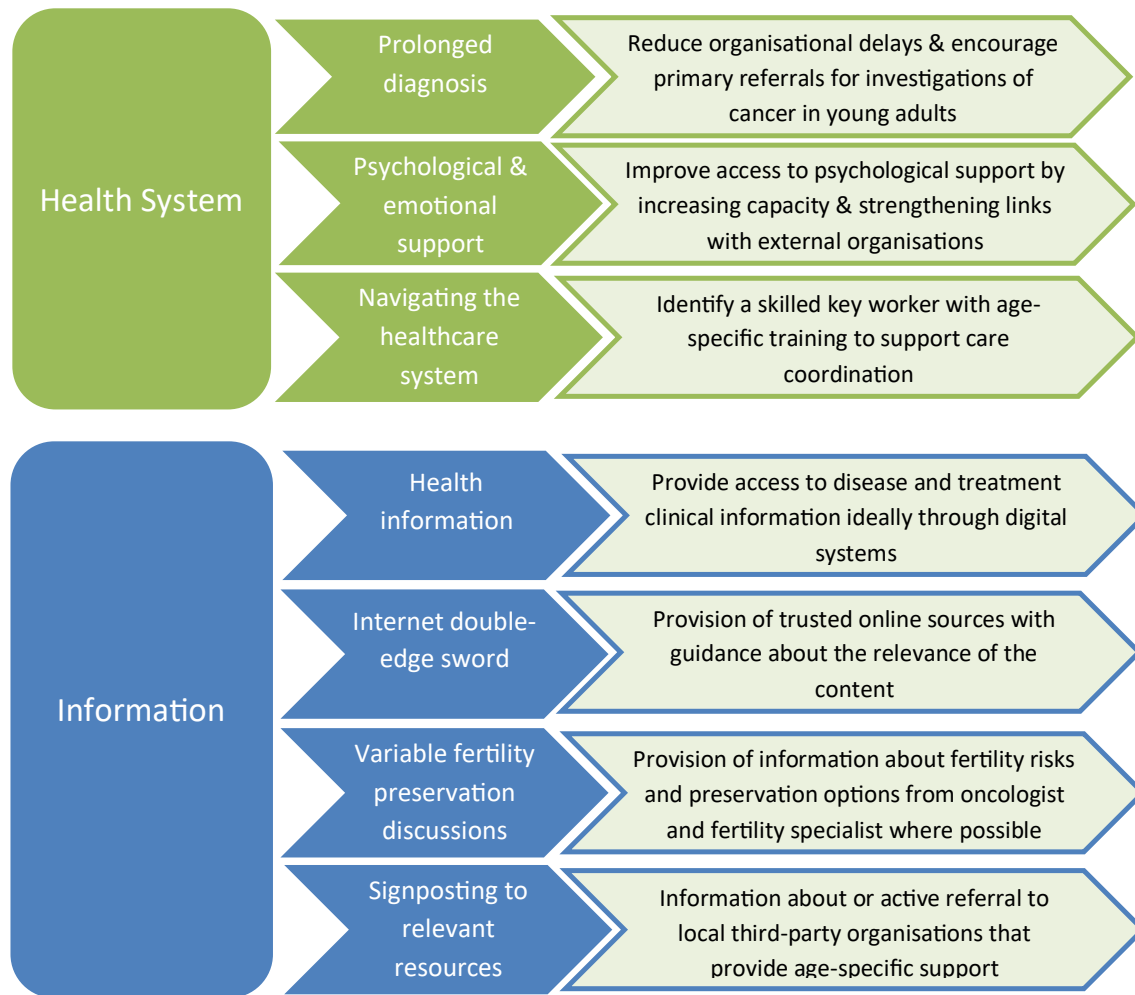
Although this explorative analysis exposes the need for additional age-tailored support, we could not determine the prevalence of the issues due to the semi-structured nature of the interviews and focus groups. The sample also over-represented less common cancers with poor prognoses, which may have over-emphasised certain topics such as the overwhelming nature of online information or the need for psychological support.

YA patient involvement in data analysis was integral to accurately interpreting and presenting the results, particularly with the large and diverse sample. Adequate funding for time and travel, authorship and training materials helped to promote active and successful involvement. The dataset size and limited availability of qualitative software due to licence costs restricted the point at which we could involve patients. Future projects should involve patients throughout the full research cycle.

### *Clinical Implications*

Like the prolonged periods to diagnosis described in this study, previous research has found that TYAs similarly deal with extended times to diagnosis potentially contributing to unnecessary emergency presentations [36]. Evidence from this study and the paper by Dommett *et al.* [36] suggests that referrals from primary care for suspected cancers in young people should be encouraged and organisational delays, such as errors in referrals, must be reduced for timely investigations.

Efforts need to identify optimal pathways for provision of age-tailored information and access to relevant services for YAs in adult cancer settings. NICE guidelines provide excellent recommendations for age-specific multidisciplinary care for children and TYAs [14]. Patients and providers should review these guidelines to determine whether they should apply to YAs. Although dedicated inpatient units may not be necessary for YAs as most are treated in outpatient settings, YAs are faced with similar challenges as TYAs and would likely benefit from elements of the national TYA network of cancer services. Practical recommendations discussed in this paper for the challenging experiences identified are presented in [Figure 1](#).



**Fig 1.** Practical recommendations to improve care experiences for young adults with cancer.

## Conclusions

YAs with cancer lack guidance in navigating health and supportive care services and access to some relevant age-specific information and support. YAs would probably benefit from elements of the TYA cancer services focusing on providing tailored information and access to age-relevant services.

## Conflicts of Interest

S. Banerjee reports personal fees from Amgen, Astrazeneca, Clovis, Pfizer, GSK, Genmab, Immunogen, Tesaro, MSD, Mersana, Roche and Merck and Sereno and grants from Astrazeneca, Tesaro and GSK outside the submitted work. J. Larkin reports grants and personal fees from Achilles Therapeutics, AstraZeneca, BMS, MSD, Nektar, Novartis, Pfizer, Roche/Genentech and Immunocore, personal fees from Boston Biomedical, Eisai, EUSA Pharma, GSK, Ipsen, Imugene, Incyte, iOnctura, Kymab, Merck Sorono, Pierre Fabre, Secarna, Vitaccess, Covance and grants from Aveo and Pharmacyclics outside the submitted work. S. Stanway reports personal fees

from Clinigen, Roche, Eli Lilly and Novartis outside the submitted work. N. Starling reports grants from AstraZeneca, BMS and Pfizer, personal fees from AstraZeneca, BMS, Eli Lilly, Merck, Roche, MSD Oncology, Merck and Sereno, Pierre Fabre, Servier and Pfizer outside the submitted work. Z. Szucs reports salary from AstraZeneca outside the submitted work. W.T.A. van der Graaf reports grants and personal fees from Novartis, grants from Consultancy Springworks and personal fees from GSK outside the submitted work. All other authors declare no conflicts of interest.

## Acknowledgements

The authors would like to thank all the patients who took part in interviews and focus groups and in the analysis of the study. We would also like to thank Ceinwen Giles and SHINE Cancer Support for helping share the patient involvement opportunity. We would like to acknowledge the support from NIHR Biomedical Research Centre at The Royal Marsden and The Institute of Cancer Research, London (NIHR RM/ICR BRC) and the National Institute for Health Research Clinical Research Network (NIHR CRN) for the study and funding of the patient recruitment. Dr Olga Husson and the

data collection were supported by a Social Psychology Fellowship from the Dutch Cancer Society [grant number #KUN2015-7527]. Patient involvement in data analysis was funded by the Patient and Public Involvement and Engagement Grants from the NIHR RM/ICR BRC [grant number B079]. The Royal Marsden NHS Foundation Trust sponsored the study and had sole responsibility for the study design, data collection, analysis and interpretation, report writing and the decision to submit the article for publication. Funders had no involvement in such activities.

## References

- [1] Miedema B, Hamilton R, Easley J. From “invincibility” to “normalcy”: coping strategies of young adults during the cancer journey. *Palliat Support Care* 2007;5:41–49. <https://doi.org/10.1017/s147895150707006x>.
- [2] Gibson F, Hibbins S, Grew T, Morgan S, Pearce S, Stark D, et al. How young people describe the impact of living with and beyond a cancer diagnosis: feasibility of using social media as a research method. *Psychooncology* 2016;25:1317–1323. <https://doi.org/10.1002/pon.4061>.
- [3] David CL, Williamson K, Tilsley DWO. A small scale, qualitative focus group to investigate the psychosocial support needs of teenage young adult cancer patients undergoing radiotherapy in Wales. *Eur J Oncol Nurs* 2012;16:375–379. <https://doi.org/10.1016/j.ejon.2011.08.002>.
- [4] Zebrack B, Kent EE, Keegan THM, Kato I, Smith AW. “Cancer sucks,” and other ponderings by adolescent and young adult cancer survivors. *J Psychosoc Oncol* 2014;32:1–15. <https://doi.org/10.1080/07347332.2013.855959>.
- [5] Barr RD, Ferrari A, Ries L, Whelan J, Bleyer WA. Cancer in adolescents and young adults: a narrative review of the current status and a view of the future. *JAMA Pediatr* 2016;170:495–501. <https://doi.org/10.1001/jamapediatrics.2015.4689>.
- [6] Bleyer A, Barr R, Hayes-lattin B, Thomas D. The distinctive biology of cancer in adolescents and young adults. *Nat Rev Canc* 2008;8:288–298. <https://doi.org/10.1038/nrc2349>.
- [7] Hammond C. Against a singular message of distinctness: challenging dominant representations of adolescents and young adults in oncology. *J Adolesc Young Adult Oncol* 2017;6:45–49. <https://doi.org/10.1089/jayao.2016.0018>.
- [8] Levin NJ, Zebrack B, Cole SW. Psychosocial issues for adolescent and young adult cancer patients in a global context: a forward-looking approach. *Pediatr Blood Canc* 2019;66:e27789. <https://doi.org/10.1002/pbc.27789>.
- [9] Warner EL, Kent EE, Trevino KM, Parsons HM, Zebrack BJ, Kirchoff AC. Social well-being among adolescents and young adults with cancer: a systematic review. *Cancer* 2016;122:1029–1037. <https://doi.org/10.1002/cncr.29866>.
- [10] Sodergren SC, Husson O, Rohde GE, Tomaszewska IM, Griffiths H, Pessing A, et al. Does age matter? A comparison of health-related quality of life issues of adolescents and young adults with cancer. *Eur J Canc Care* 2018;27:e12980. <https://doi.org/10.1111/ecc.12980>.
- [11] Close AG, Dreyzin A, Miller KD, Seynaeve BKN, Rapkin LB. Adolescent and young adult oncology—past, present, and future. *CACanc J Clin* 2019;69:1–12. <https://doi.org/10.3322/caac.21585>.
- [12] Fidler MM, Gupta S, Soerjomataram I, Ferlay J, Steliarova-Foucher E, Bray F. Cancer incidence and mortality among young adults aged 20–39 years worldwide in 2012: a population-based study. *Lancet Oncol* 2017;18:1579–1589. [https://doi.org/10.1016/S1470-2045\(17\)30677-0](https://doi.org/10.1016/S1470-2045(17)30677-0).
- [13] Carr R, Whiteson M, Edwards M, Morgan S. Young adult cancer services in the UK: the journey to a national network. *Clin Med* 2013;13:258–262. <https://doi.org/10.7861/clinmedicine.13-3-258>.
- [14] National Institute for Health and Care Excellence. *Quality Standard: Cancer services for children and young people*. NICE; 2014. <https://www.nice.org.uk/guidance/qs55>. [Accessed 16 December 2019].
- [15] Teenage Cancer Trust. <https://www.teenagecancertrust.org/> [Accessed 7 August 2019].
- [16] Quality Health. *National cancer patient experience survey: National results summary 2017*. <http://www.ncpes.co.uk/>. [Accessed 17 June 2020].
- [17] Braun V, Clarke V. Thematic analysis. In: Cooper H, editor. *APA handbook of research methods in Psychology*. American Psychological Association; 2012. p. 57–71.
- [18] NVIVO qualitative data analysis software 2015 <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
- [19] Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engagem* 2017;3:1–11. <https://doi.org/10.1186/s40900-017-0062-2>.
- [20] National Institute of Health and Clinical Excellence. *Guidance on cancer services improving outcomes in children and young people with cancer*. Available at: 2005. p. 198 <https://www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-children-and-young-people-with-cancer-update-pdf-773378893>. [Accessed 18 June 2020].
- [21] NHS Commissioning Board. *NHS Standard contract for cancer: teenagers & young adults 2013*. NHS England; 2013. p. 31. Available at: <https://www.england.nhs.uk/specialised-commissioning-document-library/service-specifications/>. [Accessed 17 June 2020].
- [22] Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, et al. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol* 2004;22:4174–4183. <https://doi.org/10.1200/JCO.2004.01.159>.
- [23] Griggs JJ, Sorbero MES, Mallinger JB, Quinn M, Waterman M, Brooks B, et al. Vitality, mental health, and satisfaction with information after breast cancer. *Patient Educ Couns* 2007;66:58–66. <https://doi.org/10.1016/j.pec.2006.10.008>.
- [24] Adams E, Hill E, Watson E. Fertility preservation in cancer survivors: a national survey of oncologists’ current knowledge, practice and attitudes. *Br J Canc* 2013;108:1602–1615. <https://doi.org/10.1038/bjc.2013.139>.
- [25] King L, Quinn GP, Vadaparampil ST, Gwede CK, Miree CA, Wilson C, et al. Oncology nurses’ perceptions of barriers to discussion of fertility preservation with patients with cancer. *Clin J Oncol Nurs* 2008;12:467–476. <https://doi.org/10.1188/08.CJON.467-476>.
- [26] Cancer Research UK. Cancer incidence by age. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age#heading=Zero>. [Accessed 7 September 2020].
- [27] Letourneau JM, Ebbel EE, Katz PP, Katz A, Ai WZ, Chien AJ, et al. Pretreatment fertility counseling and fertility preservation improve quality of life in reproductive age women with cancer. *Cancer* 2012;118:1710–1717. <https://doi.org/10.1002/cncr.26459>.
- [28] Bradford NK, Walker R, Henney R, Inglis P, Chan RJ. Improvements in clinical practice for fertility preservation amongst young cancer patients: results from bundled interventions. *J Adolesc Young Adult Oncol* 2018;7:37–45.

- [30] Williams K, Beeken RJ, Fisher A, Wardle J. Health professionals' provision of lifestyle advice in the oncology context in the United Kingdom. *Eur J Canc Care* 2015;24: 522–530. <https://doi.org/10.1111/ecc.12305>.
- [31] Hardcastle SJ, Maxwell-Smith C, Hagger MS, O'Connor M, Platell C. Exploration of information and support needs in relation to health concerns, diet and physical activity in colorectal cancer survivors. *Eur J Canc Care* 2018;27:1–9. <https://doi.org/10.1111/ecc.12679>.
- [32] Cormie P, Zopf EM, Zhang X, Schmitz KH. The impact of exercise on cancer mortality, recurrence, and treatment-related adverse effects. *Epidemiol Rev* 2017;39:71–92. <https://doi.org/10.1093/epirev/mxx007>.
- [33] Van Der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *Eur J Canc Care* 1999;8:238–244. <https://doi.org/10.1046/j.1365-2354.1999.00176.x>.
- [34] Dijkstra MTM, Homan AC. Engaging in rather than disengaging from stress: effective coping and perceived control. *Front Psychol* 2016;7:1–12. <https://doi.org/10.3389/fpsyg.2016.01415>.
- [35] Giardina TD, Menon S, Parrish DE, Sittig DF, Singh H. Patient access to medical records and healthcare outcomes: a systematic review. *J Am Med Inform Assoc* 2014;21:737–741. <https://doi.org/10.1136/amiajnl-2013-002239>.
- [36] Dommert RM, Pring H, Cargill J, Beynon P, Cameron A, Cox R, et al. Achieving a timely diagnosis for teenagers and young adults with cancer: the ACE “too young to get cancer?” study. *BMC Cancer* 2019;19:1–15. <https://doi.org/10.1186/s12885-019-5776-0>.
- [37] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6): 349–357.