

## Main Article

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# Returning to work: a qualitative study of the experiences of head and neck cancer survivors

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## Abstract

**Background.** UK head and neck cancer incidence and prevalence in working-age people are increasing. Work is important for individuals and society. Head and neck cancer survivors return to work less than other cancer survivors. Treatment affects physical and psychological functioning long-term. Evidence is limited, with no UK qualitative studies.

**Methods.** A qualitative study was conducted, underpinned by a critical realism approach, involving semi-structured interviews with working head and neck cancer survivors. Interviews were conducted using the Microsoft Teams communication platform and interpreted using reflexive thematic analysis.

**Results.** Thirteen head and neck cancer survivors participated. Three themes were drawn from the data: changed meaning of work and identity, return-to-work experiences, and the impact of healthcare professionals on returning to work. Physical, speech and psychosocial changes affected workplace interactions, including stigmatising responses by work colleagues.

**Conclusion.** Participants were challenged by returning to work. Work interactions and context influenced return-to-work success. Head and neck cancer survivors want return-to-work conversations within healthcare consultations, but perceived these as absent.

## Introduction

The numbers of working-age head and neck cancer survivors are rapidly increasing in the UK.<sup>1</sup> In the last 30 years, head and neck cancer incidence has increased by 34 per cent, with the largest increase in the age group of 50–59 years for both males and females.<sup>2</sup> Although more people survive head and neck cancer (there has been a 9 per cent decrease in mortality rates since the 1970s), living longer may not equate to living well.<sup>3</sup>

Across cancer types, increased age, lower education and jobs with high levels of physical exertion are negatively associated with returning to work.<sup>4</sup> In the UK, a cancer diagnosis is classed as a disability.<sup>5</sup> Following long-term sickness absence, disabled people are 10 times more likely to leave the workplace than non-disabled people.<sup>6</sup> For the individual, work provides income, social connections and a sense of purpose, and forms part of an individual's identity.<sup>7</sup> For society, work increases economic productivity and reduces public spending on welfare benefits. Not being in work negatively impacts on health.

Head and neck cancer incidence is more common in deprived areas of the UK, and is associated with early retirement and unemployment.<sup>8</sup> The financial costs of head and neck cancer for individuals are also significant. In a survey of 447 UK head and neck cancer survivors, over 20 per cent reported loss of earnings, and increased costs associated with changed food types, heating and transport.<sup>9</sup>

Studies in the UK, Taiwan and America demonstrated that head and neck cancer survivors face significant return-to-work barriers, including fatigue, changed concentration, breathing problems, speaking and eating issues, and appearance alteration.<sup>10–12</sup> Alongside treatment-related factors, returning to work after head and neck cancer can be further complicated by the effects of personal beliefs and feelings, changed life priorities, and work-related issues.<sup>13</sup>

A substantial proportion of head and neck cancer survivors experience changes in mental health. One UK quantitative study reported depression in 39 per cent and anxiety in 43 per cent of survivors.<sup>14</sup> Over half of head and neck cancer survivors surveyed in England reported long-term negative effects on quality of life due to the financial burden of head and neck cancer.<sup>15</sup> Together, these effects have profound consequences for head and neck cancer survivors, affecting relationships, everyday functioning, and capacity to work and remain in work.<sup>16</sup>

For head and neck cancer survivors, returning to work represents normality, and almost three-quarters of all cancer survivors continue to work long-term.<sup>17,18</sup> Evidence suggests that head and neck cancer survivors are less likely to return to work than other cancer survivors, and treatment affects physical, psychological and functioning long-term.<sup>19,20</sup>

Socio-demographic factors, illness perception and mental adjustment also influence likelihood of returning to work in head and neck cancer survivors; for example, people

with higher educational levels were found to be more likely to return to work.<sup>21</sup> However, there is limited evidence in the field of work and head and neck cancer, with no UK qualitative studies to aid understanding regarding the return-to-work experiences of head and neck cancer survivors.<sup>22</sup>

## Materials and methods

In order to investigate head and neck cancer survivors' experiences following a return to work, an exploratory qualitative study, underpinned by critical realism, was carried out. The aim was to understand experiences, establish head and neck cancer survivor priorities for practice, and situate knowledge within context.<sup>23–25</sup>

Participant recruitment took place between November 2020 and June 2021, during the coronavirus disease 2019 (Covid-19) pandemic. The study was promoted at a head and neck cancer survivor conference, and via peer recommendation, support groups, social media and one National Health Service (NHS) Trust. Patient and public involvement representatives were consulted through head and neck cancer charities about study rationale, recruitment, an interview guide, participant materials and dissemination of findings, to increase head and neck cancer survivor engagement and public trust, and to shape further research.<sup>26</sup>

An interview guide was used, based on Duijts and colleagues' interview questions,<sup>27</sup> one author's (AM) clinical knowledge as a practitioner-researcher and empirical study findings. Each interview iteratively informed subsequent interviews, analysis and theme development. Open questions enabled participants to tell their stories and generate situated knowledge.<sup>28</sup>

One-off semi-structured interviews were conducted by one author (AM) via video platform ( $n = 12$ ) or telephone interviews ( $n = 1$ ) according to participant preference. Interviews were recorded on the Microsoft Teams communication platform and uploaded onto the Microsoft Stream video-sharing service. Video footage collected non-verbal cues indicating emotion and aided understanding of participants with speech intelligibility changes associated with head and neck cancer. Interviews, including the single telephone interview, were also audio-recorded on a portable device for data back-up and transcription purposes.

Interviews were transcribed verbatim; they were anonymised and pseudonyms were allocated. Reflexive thematic analysis was used to explore the data within and between participants, to inductively make sense of head and neck cancer survivor experience, and to contextually locate data in order to facilitate interpretation.<sup>29</sup> Interview transcripts were repeatedly read by one author (AM). Initial codes were identified from the data prior to theme generation. Five transcripts were double-coded and one was triple-coded by two authors (EW and CD) for consistency and agreement. Repeated interaction with the data generated refined higher-level themes and mind maps linked themes.

Ethical approval was granted by West Midlands Research Ethics Committee and Health and Care Research Wales (approval code: 20/WM/0107-20020-276015).

## Results

A projected sample size of at least 12 participants was anticipated, and recruitment took place until data saturation occurred, as determined during interviews and data analysis.<sup>30,31</sup> Interviews lasted between 1 hour and 2.06 hours (mean, 1.5 hours).

Thirteen head and neck cancer survivors who had returned to work participated (five women and eight men) (Table 1). Two participants were recruited from one NHS site and 11 participants self-selected. Participants' ages ranged between 39 years and 63 years (mean, 54 years). Time since diagnosis ranged between 3 months and 20 years (median, 24 months). Participants were employed and/or self-employed, with varied occupations, including academic, managerial, administration, health, sales, marketing, service, factory and trade work.

Data analysis identified three major themes: (1) the changed meaning of work following head and neck cancer and the impact of head and neck cancer on identity; (2) return-to-work experiences, both supportive and challenging; and (3) the impact of healthcare professionals on returning to work. These themes are discussed below.

### Theme one: changed meaning of work and identity

All participants acknowledged the valued role of work, not just to provide income, but also for social interaction and as a basis

**Table 1.** Participant characteristics

Participant (anonymised)	Age (years)	Gender	Head & neck cancer site	Year of diagnosis & treatment	Employed, self-employed or both
Jim	63	Male	Tongue	2013	Self-employed
Ron	56	Male	Undetermined	2018	Employed
Lucy	41	Female	Tongue	2019	Employed
Glenda	63	Female	Tonsil, lung	2019	Employed
Pete	50	Male	Tongue	2020	Both
Mike	55	Male	Larynx	1996, 2001	Employed
Julie	49	Female	Unknown primary	2019	Employed
Patrick	44	Male	Parotid gland	2021	Both
Craig	58	Male	Tonsil	2020	Both
Nancy	39	Female	Hypopharynx	2020	Employed
Colin	62	Male	Tongue base	2012	Self-employed
Vanessa	59	Female	Tongue base, tonsil	2020	Self-employed
Tony	63	Male	Tongue base	2017	Employed

for supporting self-esteem, mental health and well-being. All participants reported a change in their identity and a change in what work meant to them. A loss of confidence in returning to work was common; several participants reported anxiety and depression, and three reported having had suicidal thoughts.

Participants described the effects of changes in their appearance on how they conducted themselves at work or decision-making regarding returning to work:

'Short weird-coloured hair, no side teeth affecting my face...I aged 15 years in seven weeks... I didn't want to talk to people or them to see me [so] I'm emailing' (Vanessa).

'My HR [human resources] director mentioned there might be a concern over customer face-to-face meetings with how I look...[so] my diagnosis, the way I look and felt about returning to the corporate world drove me to want to work for myself again' (Patrick).

Most participants were concerned about speech changes following head and neck cancer, and the effect it might have on their ability to work, communicate with colleagues, and carry out work duties involving telephone calls or public speaking:

'How on earth am I going to do a telephone call when I can barely understand myself? What if I can't do my job?' (Lucy).

Many participants experienced changes in employers and/or job role, with new jobs or job loss, following head and neck cancer, which was also related to living through a pandemic. Head and neck cancer, combined with Covid-19, led to self-reflection, questioning and consideration of alternative versions of themselves, work identity and future job prospects.

Within the workplace, some participants described positive changes following head and neck cancer. Pete felt more 'laid-back', and Ron reported increased confidence managing workplace conflict. A new job, or returning to supportive workplaces, motivated recovery following treatment, for both social and work achievement reasons.

Several participants commented that Covid-19 related job losses led to an appreciation of their own job security and financial stability. Previous ambivalence about work was changed by head and neck cancer and prognostic uncertainty:

'When you are threatened with no longer having [work] ... suddenly makes you want something a lot more' (Glenda).

Following head and neck cancer, some participants wanted to 'give something back', leading to altruistic acts such as peer support activities, fundraising, or pursuing head and neck cancer awareness education opportunities.

### Theme two: return-to-work experiences

A minority of participants described supportive work experiences such as a phased return to work, flexible work schedules, altered work duties and working from home. These strategies appeared to be helpful approaches for anxiety or fatigue management:

'They didn't force me into the office if I didn't want to go because I was still very anxious' (Colin).

A few larger workplaces offered workplace counselling, adjustments such as longer meal breaks, text-to-speech technology,

or a simple but essential solution of providing a hand mirror for laryngectomy care. Some participants described their workplace as compassionate, where individuals were viewed as a person rather than an employee. Regular communication with managers and colleagues enhanced workplace satisfaction.

Self-employed participants, and those with dependents, living alone or on lower incomes, described a pressure to return to work to maintain income.

Nearly all participants also described challenging return-to-work experiences, mainly related to being treated differently by work colleagues, or colleagues not knowing how to respond:

'I was treated like a frail little guy!... like my health was the only thing that I was, so that was a low point' (Ron).

Being treated differently by work colleagues led to participant lack of openness about diagnosis, functional difficulties and potential head and neck cancer recurrence risk, and consequent fears about job security:

'I didn't want to say I've had cancer because I didn't want them to think... she could drop dead in two years or have all these hospital appointments...[head and neck cancer] doesn't affect me from doing the job' (Julie).

Head and neck cancer survivors also perceived that work relationships could be fraught with judgements related to head and neck cancer:

'My throat cancer is HPV [human papillomavirus] related... I don't think I've told anyone at work, there's a stigma around being promiscuous' (Nancy).

Participants had already experienced 'traumatic' feelings related to appearance changes, scarring, feeding tube presence or poorly fitting work clothes. Negative work interactions, and poor communication from managers and colleagues, exacerbated poor mental health and eroded confidence levels on returning to work:

'If my current employer had just cared a little bit more and I wasn't expecting [them] to wrap me up in cotton wool, but I never even got an email or a quick phone call... "Hi, have you settled in ok, is there anything that you need...that we can do for you?" Just a two-minute phone call would have made me feel just that little bit more worth' (Julie).

Some participants reported that rigid interpretation of policy and procedure meant head and neck cancer survivors felt treated as a 'resource, a commodity, not a human being anymore' (Glenda).

Participants used various coping strategies to help recovery and aid returning to work after head and neck cancer, including regular annual leave from work. Exercise, workplace gyms and counselling services benefitted some participants, whilst others focused on activities like reading or cooking, which promoted mindfulness. Several participants reported continued use of anti-depressant medication, and one participant used alcohol and cannabis. One participant reported leaving her workplace to seek alternative employment following a difficult return to work after head and neck cancer, exacerbated by pre-existing poor work conditions. Others discussed their perception of how a cohesive and functional healthcare treatment

journey or wider contextual factors had influenced their experience:

'If I didn't have a happy, stable home life or a good employer or if I didn't feel well supported by other people...if you took away any one of those elements, I'm sure that my experience of cancer treatment and recovery would have been different' (Nancy).

### Theme three: impact of healthcare professionals

All head and neck cancer survivors bar one stated that interactions with healthcare professionals about returning to work would have been useful. The one participant who was an exception did not think discussion with healthcare professionals about returning to work would have helped because 'I know my body and when it's ready to go back to work' (Craig).

Nearly all participants reported that conversations about work and the psychosocial aspects of life were either not included in healthcare consultations or were covered in a cursory way:

'I haven't spoken to anyone. The only conversations about work were "you'll be off work for six months. Here's a sick note"... No one's asking "When would you like to come back to work or how are you feeling [about] coming back to work?"' (Patrick).

One participant (Glenda) felt she was 'not allowed' to discuss her fears with healthcare professionals and had to 'stay upbeat' because of healthcare professionals' prevailing positive attitudes; her sense of being 'silenced' was compounded by limited healthcare consultation time.

For one participant and her employer, helpful e-mail communication from healthcare professionals determined realistic return-to-work expectations. This information included expected timings for recovery, projected physical and psychological effects of treatment, and likely body image changes.

The majority of participants wanted more holistic conversations within healthcare consultations in order to understand the wider context of head and neck cancer survivors' lives outside the healthcare setting: 'listen to me before I listen to you [to understand] you not your illness' (Mike).

One participant explained how she was 'impressed' by a healthcare professional who enabled her to tell her story and outline experiences, meaning the healthcare professional understood 'who I was, she got a sense of me as a person, what I did' (Nancy).

Some participants suggested that peer support buoyed recovery and complemented healthcare professional advice: 'I can look across at the person who's terrified and say, "look at me I'm working!"' (Ron).

Several participants were unable to disclose return-to-work struggles with work colleagues; instead, peer support groups, social media networks or websites had helped them to manage return-to-work expectations, and workplace communication about head and neck cancer and returning to work. Some participants found useful information on websites, which allayed fears about returning to work. A minority expressed a desire to 'move on' and so resisted formal peer support, whereas others had 'buddied' peers through treatment; one participant even set up a local head and neck cancer peer support group.

## Discussion

This exploratory study aimed to investigate the return-to-work experiences of head and neck cancer survivors. Theme

commonality occurred irrespective of head and neck cancer type, treatment regimen, job, sick leave duration, support available or financial pressures. The main findings of this study highlighted work and identity changes, return-to-work experiences, and the impact of healthcare professionals on returning to work.

As in other studies of head and neck cancer survivors, in our study returning to work signified recovery, and the resumption of 'normality' and pre-diagnosis life.<sup>27,32,33</sup> However, many participants acknowledged that living with impairment meant that resuming full health was impossible.<sup>34</sup> Coping with chronic illness may involve the negotiation of a new normal, which can result in identity reconstruction.<sup>35-37</sup> In our study, head and neck cancer survivors experienced deep thinking and identity reconstruction<sup>27,32</sup> Some even described experiences akin to post-traumatic growth.<sup>38</sup> For the participants in our study, overcoming trauma or stigma appeared to lead to high levels of empathy and altruism for head and neck cancer peers, channelled into peer support or charitable acts. This seemed to assist participants' positive identity reconstruction, and gave head and neck cancer survivors a sense of renewed life purpose.<sup>39</sup>

A minority of participants in our study were reluctant to disclose their head and neck cancer experience, and feared being treated differently by work colleagues.<sup>13,32</sup> Appearance, physical and psychosocial changes affected communication, relationships and workplace interactions. This led to unwelcome attention or stigmatising responses, which further compounded body image and self-identity, and may have resulted in a possible job change. These experiences echo those reported in head and neck cancer studies investigating facial disfigurement, body image and effects of appearance on work status.<sup>11,40,41</sup>

Some participants in our study were further down their cancer journey, and described longer-term challenging and supportive work experiences, expanding on those described at diagnosis, and during and after treatment.<sup>32</sup> Personal factors (e.g. sense of control, attitude), environmental factors (e.g. workplace interactions) or organisational factors (e.g. job demands, workplace support, culture, relationship with line managers) appear to make a difference. As factors interact, it is difficult to define 'support', which may vary depending on the inter-relationship of these factors. Returning to work following head and neck cancer is a complex phenomenon, and is likely to be a 'situational context process'.<sup>21</sup>

Studies acknowledge (but may not describe) the role of healthcare professionals in supporting a return to work after head and neck cancer. Vocational rehabilitation may help self-efficacy beliefs.<sup>27</sup> Dewa *et al.*<sup>32</sup> suggest that healthcare professionals could assist recovery, and support head and neck cancer survivors' return to work and their development of a new normal, and facilitate supportive workplace interactions; however, healthcare professionals require appropriate training.<sup>17</sup>

Our study suggests that healthcare professional support was either lacking or unhelpful. Our findings indicate that although anxiety, depression or stigma were invisible, they affected head and neck cancer survivors' behaviour, minimising open workplace communication. Whilst head and neck cancer survivors acknowledged that positive thinking was helpful, one participant reported being silenced by healthcare professionals' positivity, which induced shame, a phenomenon also seen in other cancer survivors.<sup>42</sup>



The wider cancer literature stresses the importance of cancer survivors talking openly about the impact of cancer, to minimise being ignored or trivialised by others.<sup>43</sup> Whilst previous studies have touched on this issue, our findings begin to explore the potential role for healthcare professionals in talking with head and neck cancer survivors about returning to work. It remains unclear how healthcare professionals can best help head and neck cancer survivors successfully return to work and this requires further research.

## Conclusion

This is a small exploratory study; to our knowledge, it is the first UK study to investigate head and neck cancer survivors' return-to-work experience. Our study provides qualitative context, and begins to develop knowledge for healthcare professionals and employers.

The study took place during the Covid-19 pandemic, and interviews had to be carried out virtually. Concerns over the challenges of conducting remote virtual interviews with a population who had communication difficulties or facial disfigurement were not realised. Participation occurred over a wide geographical area. Virtual interviews appeared to work well for head and neck cancer survivors. Rapport was quickly established, facilitating emotional disclosure and in-depth discussion. In addition, the remote interviews were convenient to conduct within a working day, and negated travel costs. Video recordings helped intelligibility for transcription and analysis. Remote interviewing thus became a strength of our study. It is an appropriate data collection method for head and neck cancer survivors, and can be used in future studies.

- UK head and neck cancer incidence in the working-age population is increasing
- Head and neck cancer is more common in deprived UK areas, with greater suffering and worse treatment outcomes, and is associated with early retirement and unemployment
- Many head and neck cancer survivors have a negative quality of life, affecting their capacity to work and remain in work
- Work benefits individuals by providing income, and a sense of purpose and identity; work is also critical for the nation's health and wealth
- No previous UK studies explored return-to-work experiences after head and neck cancer, including stigmatising responses by work colleagues
- Head and neck cancer survivors highlighted current care gaps; survivors want, but did not get, return-to-work conversations with healthcare professionals

Limitations include that most participants self-selected into the study, so there may be a degree of selection bias. One participant was an academic in the USA, affecting transferability, but qualitative research seeks understanding of a range of perspectives, and not to generalise results based on representative samples of the general population. All participants were white, and future studies would need to seek to include a more ethnically diverse sample of head and neck cancer survivors, as well as those who were working at the time of diagnosis and who stopped work or did not return to work. The experiences of employers and healthcare professionals in supporting head and neck cancer survivors in their return to work would also be useful additions to the evidence base in this area.

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## References

- 1 Mehanna H, Evans M, Beasley M, Chatterjee S, Dilkes M, Homer J *et al*. Oropharyngeal cancer: United Kingdom National Multidisciplinary Guidelines. *J Laryngol Otol* 2016;**130**:S90–6
- 2 Cancer Research UK. Head and neck cancer statistics. In: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/head-and-neck-cancers> [31 January 2021]
- 3 Macmillan Cancer Support. After cancer treatment. In: <https://www.macmillan.org.uk/get-involved/campaigns/life-after-cancertreatment> [31 January 2021]
- 4 Van Muijen P, Weevers NLEC, Snels IAK, Duijts SFA, Bruinvels DJ, Schellart AJM *et al*. Predictors of return to work and employment in cancer survivors: a systematic review. *Eur J Cancer Care (Engl)* 2013;**22**:144–60
- 5 Equality Act UK 2010. In: <https://www.legislation.gov.uk/ukpga/2010/15/contents> [24 January 2023]
- 6 Adelman L. *Health and work policy research and analysis: our agenda. Presented at NIHR PRP Working Age Consultation Event*, [24 October 2019], London, UK.
- 7 HM Government. Advancing our health: prevention in the 2020s - consultation document. In: <https://www.gov.uk/government/consultations/advancing-our-health-prevention-in-the-2020s/advancing-our-health-prevention-in-the-2020s-consultation-document> [24 January 2023]
- 8 Purkayastha M, McMahon AD, Gibson J, Conway DI. Trends of oral cavity, oropharyngeal and laryngeal cancer incidence in Scotland (1975–2012) – a socioeconomic perspective. *Oral Oncol* 2016;**61**:70–5
- 9 Rogers SN, Harvey-Woodworth CN, Hare J, Leong P, Lowe D. Patients' perception of the financial impact of head and neck cancer and the relationship to health related quality of life. *Br J Oral Maxillofac Surg* 2012;**50**:410–16
- 10 Wells M, Cunningham M, Lang H, Swartzman S, Philp J, Taylor L *et al*. Distress, concerns and unmet needs in survivors of head and neck cancer: a cross-sectional survey. *Eur J Cancer Care (Engl)* 2015;**24**:748–60
- 11 Liu HE. Changes of satisfaction with appearance and working status for head and neck tumour patients. *J Clin Nurs* 2008;**17**:1930–8
- 12 Buckwalter AE, Karnell LH, Smith RB, Christensen AJ, Funk GF. Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Arch Otolaryngol Head Neck Surg* 2007;**133**:464–70
- 13 Rangabashyam M, Koh SQ, Sultana R, Tan NC, Iyer NG, Soo KC *et al*. Factors associated with returning to work in head and neck cancer survivors in Singapore: a preliminary exploratory mixed-methods approach study. *Head Neck* 2021;**43**:1451–64
- 14 Shiraz F, Rahtz E, Bhui K, Hutchison I, Korszun A. Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients. *Br J Oral Maxillofac Surg* 2014;**52**:513–17
- 15 Rogers SN, Harvey-Woodworth CN, Lowe D. Patients' perspective of financial benefits following head and neck cancer in Merseyside and Cheshire. *Br J Oral Maxillofac Surg* 2012;**50**:404–9
- 16 Bristol-Myers Squibb. *Beyond Clinical Outcomes: UK Patient Experience in Head and Neck Cancers*. New York: Bristol-Myers Squibb, 2019
- 17 Giuliani M, Papadakis J, Broadhurst M, Jones J, McQuestion M, Le LW *et al*. The prevalence and determinants of return to work in head and neck cancer survivors. *Support Care Cancer* 2019;**27**:539–46
- 18 de Boer AG, Torp S, Popa A, Horsboel T, Zadnik V, Rottenberg Y *et al*. Long-term work retention after treatment for cancer: a systematic review and meta-analysis. *J Cancer Surviv* 2020;**14**:135–50
- 19 Broemer L, Friedrich M, Wichmann G, Müller J, Neumuth T, Dietz A *et al*. Exploratory study of functional and psychological factors associated with employment status in patients with head and neck cancer. *Head Neck* 2021;**43**:1229–41
- 20 Ross L, Petersen MA, Johnsen AT, Lundstroem LH, Carlsen K, Groenvold M. Factors associated with Danish cancer patients' return to work. A report from the population-based study "The Cancer Patient's World". *Cancer Epidemiol* 2012;**36**:222–9
- 21 Chen YJ, Lai YH, Lee YH, Tsai KY, Chen MK, Hsieh MY. Impact of illness perception, mental adjustment, and sociodemographic characteristics on

- return to work in patients with head and neck cancer. *Support Care Cancer* 2021;**29**:1519–26
- 22 Miller A. Returning to work after head and neck cancer. *Curr Opin Otolaryngol Head Neck Surg* 2020;**28**:155–60
  - 23 Miller J, Glassner B. The “inside” and the “outside”: finding realities in interviews. In: Silverman D, ed. *Qualitative Research*, 3rd edn. London: Sage Publications, 2011;131–48
  - 24 Bloor M. Addressing social problems through qualitative research. In: Silverman D, ed. *Qualitative Research*, 3rd edn. London: Sage Publications, 2011;399–415
  - 25 Scotland J. Exploring the philosophical underpinnings of research: relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *Engl Lang Teach* 2012;**5**:9–16
  - 26 National Data Guardian. National Data Guardian for Health and Care 2017 report: Impact and influence for patients and service users. In: <https://www.gov.uk/government/publications/national-data-guardian-2017-report> [24 January 2023]
  - 27 Duijts SFA, van Egmond MP, Gits M, van der Beek AJ, Bleiker EM. Cancer survivors’ perspectives and experiences regarding behavioural determinants of return to work and continuation of work. *Disabil Rehabil* 2017;**39**:2164–72
  - 28 Mason J. *Qualitative Researching*, 3rd edn. London: Sage Publications, 2018;117
  - 29 Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health* 2019;**11**:589–97
  - 30 Guest G, Bunce A, Johnson L. How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* 2006;**18**:59–82
  - 31 Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B *et al*. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;**52**:1893–907
  - 32 Dewa CS, Trojanowski L, Tamminga SJ, Ringash J, McQuestion M, Hoch JS *et al*. Work-related experiences of head and neck cancer survivors: an exploratory and descriptive qualitative study. *Disabil Rehabil* 2018;**40**:1252–8
  - 33 Handschel J, Gellrich NC, Bremerich A, KrüSkemper G. Return to work and quality of life after therapy and rehabilitation in oral cancer. *In Vivo* 2013;**27**:401–7
  - 34 Dewa CS, Trojanowski L, Tamminga SJ, Ringash J, McQuestion M, Hoch J. Advice about work-related issues to peers and employers from head and neck cancer survivors. *PLoS One* 2016;**11**:e0152944
  - 35 Rennie C, Stoddart K, Hubbard G. A new normal: reconciling change in appearance and function for men with head and neck cancer. *Cancer Nurs Pract* 2018;**17**:20–8
  - 36 Robinson C. Managing life with a chronic condition: the story of normalization. *Qual Health Res* 1993;**3**:6–28
  - 37 Trusson D, Pilnick A, Roy S. A new normal?: Women’s experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Soc Sci Med* 2016;**151**:121–9
  - 38 Menger F, Patterson J, O’Hara J, Sharp L. Research priorities on post-traumatic growth: where next for the benefit of cancer survivors? *Psychooncology* 2020;**29**:1968–70
  - 39 Threader J, McCormack L. Cancer-related trauma, stigma and growth: the “lived” experience of head and neck cancer. *Eur J Cancer Care (Engl)* 2016;**25**:157–69
  - 40 Yaron G, Meershoek A, Widdershoven G, van den Brekel M, Slatman J. Facing a disruptive face: embodiment in the everyday experiences of “disfigured” individuals. *Hum Stud* 2017;**40**:285–307
  - 41 Fingeret MC, Yuan Y, Urbauer D, Weston J, Nipomnick S, Weber R. The nature and extent of body image concerns among surgically treated patients with head and neck cancer. *Psychooncology* 2012;**21**:836–44
  - 42 Ellingson LL, Borofka KGE. Long-term cancer survivors’ everyday embodiment. *Health Commun* 2020;**35**:180–91
  - 43 Hubbard G, Forbat L. Cancer as biographical disruption: constructions of living with cancer. *Support Care Cancer* 2012;**20**:2033–40