



**Patient experience of the acute post-surgical period following total laryngectomy before and during COVID-19**

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## Background

Total laryngectomy (TL) is a treatment option for some people with advanced laryngeal cancer (Bozec et al. 2020), but it can have devastating consequences to everyday functions including loss of a naturally produced voice, and changes to eating, drinking, swallowing and breathing. People after a TL therefore need to learn a set of complex new skills to adapt to their new communication method, eating and breathing function. A significant portion of this learning takes place in hospital after the surgery, which can often be distressing and traumatic (Perry et al. 2015).

Recently, there has been increasing interest in enhanced recovery after surgery (ERAS) pathways in head and neck cancer (HNC) to facilitate early and safe discharge home. ERAS originated from general and colorectal surgery with pathways in these specialities demonstrating improved long-term patient outcomes (Muller et al. 2009). ERAS pathways in TL have primarily focussed on early oral feeding (Boyce and Meyers 1989; Seven et al. 2003; Prasad et al. 2006; Bannister and Ah-See 2015; Aires et al. 2015) to reduce overall hospital length of stay without adversely impacting on patient outcomes e.g. increased risk of post-operative infection. The positive outcome from these studies has concluded that there is no increased risk of pharyngo-cutaneous fistula formation (Seven et al. 2003; Prasad et al. 2006; Bannister and Ah-See 2015; Aires et al. 2015). However, the quality of the studies conducted is variable, for example, a lack of participant homogeneity and limited use of quality appraisal methods (Watson and Ewers 2020). It is therefore unclear whether the introduction of early oral feeding after TL has the expected impact on hospital length of stay. However, there is potential that these protocols could reduce hospital length of stay, as well as result in cost-savings and positively influence patient recovery.

Consequently there is controversy around the implementation of early oral feeding regimes, (Watson and Ewers 2020) leaving clinicians with unclear guidance for implementation into clinical pathways. Additionally, other elements of care such as early stoma education are not adequately considered in current ERAS laryngectomy literature (Seven et al. 2003; Prasad et al. 2006; Bannister and Ah-See 2015; Aires et al. 2015). As a result, there are significant challenges in successfully implementing ERAS protocols in the acute post laryngectomy period;

1  
2 and it may be that ERAS in laryngectomy care needs to shift focus beyond the medical model  
3 alone. A potential option to consider is a 'multiphasic prehabilitation' model (Santa Mina et al.  
4 2021). Whilst novel in its approach; multiphasic prehabilitation advocates a move beyond the  
5 medical model alone and incorporates principles of survivorship into prehabilitation models of  
6 care i.e. maximising physical, social, psychological and vocational functioning within that  
7 individual's capacity following cancer treatment (Cromes and Fred 1978). In practice, this would  
8 require a multi-disciplinary team (MDT) of professionals working collaboratively with individuals  
9 to assess and implement physical, social, psychological and vocational interventions at  
10 repeated time-points from diagnosis to optimise health, maximise outcomes and achieve rapid  
11 and safe recovery after surgery.  
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21 Whilst 'multiphasic prehabilitation' could be a potential option to consider for TL patients, quick  
22 changes to acute HNC surgical pathways, which includes patients undergoing TL, have been  
23 made due to the COVID-19 pandemic e.g. commencing oral intake earlier, starting stoma care  
24 competencies quicker. Particularly, there has been significant emphasis on reducing hospital  
25 length of stay to facilitate early, safe discharge home to reduce the coronavirus transmission  
26 risks to high-risk HNC patients (Day et al. 2020). Patients undergoing a TL are particularly  
27 vulnerable in the acute phase of treatment due to increased risk of infection and there are  
28 significant threats to HNC services as a result of COVID-19 (Patterson et al. 2020). Head and  
29 neck teams were recommended to avoid primary tracheoesophageal puncture (TEP) to reduce  
30 the risk of post-operative problems (BAHNO 2020) including wound complications (Panwar et  
31 al.2017) which would increase hospital length of stay. Consequently, local service delivery  
32 models have rapidly changed to incorporate these recommendations, with the majority of  
33 patients not being offered primary TEP, the 'gold standard' for communication rehabilitation  
34 (Blom et al.1998; Hutcheson 2012; Sethi 2014). People having a TL during COVID-19 are left  
35 without a voice and therefore dependent on alternative communication methods which can  
36 sound unnatural and are often difficult to learn effectively e.g. electro-larynx, oesophageal  
37 speech.  
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54 It is therefore likely that there has been a possible unanticipated shift towards some principles of  
55 ERAS in laryngectomy care as a result of COVID-19 recommendations. For example patients  
56 may learn stoma care competencies earlier, recommence oral intake earlier or be discharged  
57 sooner. The result of this rapid change in service provision on patient outcome, hospital length  
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2 of stay, patient-reported quality of life, and experience is currently unknown. It is imperative that  
3  
4 the rapid changes to acute laryngectomy service provision is evaluated from the patient's  
5  
6 perspective in order to understand the impact of this change on both the patient experience and  
7  
8 our clinical services offered to TL patients in the COVID-19 era (Patterson et al. 2020).  
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## 10 **Aims**

- 11  
12 1. Explore the acute patient experience following total laryngectomy both before and  
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14 during the COVID-19 pandemic  
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For Peer Review Only

## Methods and Procedures

### *Study Recruitment*

Participants were recruited from a single unit in the North-East of England and were eligible for recruitment to the study if they had had a TL within the last two years. Participants were recruited to the study via purposive sampling. Purposive sampling was used to ensure collection of data rich information (Patton 2002) from a group of participants who were knowledgeable about the study question (Cresswell & Plano Clark 2011). The first five participants had their TL during the COVID-19 pandemic, had completed all of their cancer treatment i.e. adjuvant radiotherapy and used any communication method e.g. silent articulation, electro-larynx. The next three participants had had their TL before the COVID-19 pandemic, had completed all their cancer treatment and used any communication method. This allowed comparison of the patient experience before and during COVID-19 which meets the aim of this study. The final two participants had just had their surgery i.e. were within the first two weeks of discharge from hospital and therefore may not have completed all their cancer treatment. These participants were approached to capture the immediate reported inpatient experience to determine whether time had any impact on information recall. Interviews were stopped after this as no new codes or themes were generated.

Patients with active or recurrent disease, receiving palliative care or with cognitive issues making it difficult to recall their experiences, participate in an interview or which would impact on capacity were excluded. Demographic information including age, gender, cancer site/stage/treatment, time post-surgery and social deprivation level using the English Indices of Social Deprivation 2019 ([English indices of deprivation 2019 - GOV.UK \(www.gov.uk\)](http://www.gov.uk)) was collected for all participants. The indices ranks each small area in England from most – least deprived based on the following seven domains: income, employment, education, health, crime, barriers to housing and services, and living environment. Ranking is based on geographical location using a scale of one-ten: those in group one being in the 10% most deprived areas of the UK and those in group ten being in the 10% least deprived areas.

1 All eligible participants were approached by a Speech and Language Therapist, from November  
2 2020 – May 2021 and were given a patient information sheet describing the study and a  
3 consent form (see appendix 1). These were either given in person at an outpatient appointment  
4 or posted to participants with a pre-addressed stamped envelope enclosed to return completed  
5 forms prior to the interview. The lead researcher (LJW) contacted all potential participants to  
6 answer questions about the study and arrange a convenient time for the interview if they wished  
7 to take part. Participants were not obliged to take part in the study and could withdraw at any  
8 time. Some participants had received clinical intervention from the researcher so for the  
9 purpose of the interview, specific information about the researchers' role and interest in the  
10 research area was provided to improve transparency and frankness in participants' responses  
11 (Tong et al. 2007).

### 22 *Data Collection*

23 All participants were offered either face to face interviews alongside a cancer follow-up  
24 appointment or virtual interviews via telephone or NHS-attend, a secure video-conferencing  
25 platform, in a private room at the unit. Participants were invited to bring a partner/friend to the  
26 interview if they wished but results from the partner/friends responses were not included in the  
27 final analysis. Written consent was obtained prior to the interview.

28 Interviews were semi-structured as they allow the researcher to understand an individual's  
29 perspective by exploring their thoughts, feelings and beliefs whilst probing very personal and  
30 sensitive experiences (DeJonckheere and Vaughn 2019). A topic guide (see appendix) was  
31 designed by two of the research team, using the literature base and clinical expertise as the  
32 basis, and reviewed by a patient representative. This topic guide was revised after interim  
33 analyses with the research team. This follows an iterative process (Srivastava and Hopwood  
34 2009) to ensure depth and richness of data collection and analysis based on participants'  
35 responses to ensure the aims of the research were met.

36 Interviews were audio-recorded using Audacity software and written field notes were taken by  
37 the interviewer to support the recording e.g. if participant used silent articulation as their main  
38 communication method. Interview length ranged from 45-80 minutes and on average lasted 60  
39 minutes. All interviews were transcribed verbatim, allocated a number to maintain confidentiality  
40 and stored securely with the audio-recording on an NHS computer in a password protected file.

1  
2 This study was registered and approved as a service evaluation by the research and  
3  
4 development department at the unit in August 2020.

### 6 *Data Analysis*

8  
9 Reflexive thematic analysis as described by Braun & Clarke (2013) was used for interview  
10  
11 analysis. This approach to qualitative data analysis is described as being both accessible and  
12  
13 flexible by understanding, exploring and interpreting individuals' experiences through  
14  
15 organisation of data into a pattern of shared meaning. Braun & Clarke's approach does not fit  
16  
17 data into a pre-existing framework (Fereday and Muir-Cochrane 2006) and themes do not  
18  
19 'organically emerge', nor are identified prior to data collection. Instead, themes are interpreted,  
20  
21 generated and discovered to reflect the active role of the researcher in the analysis (Braun and  
22  
23 Clarke 2020). This acknowledges the importance of the researchers' subjectivity within data  
24  
25 analysis (Braun and Clarke 2019) which in this instance is the researchers' clinical expertise in  
26  
27 TL. In Braun & Clarke's (2020) approach, there are six different orientations which can be used  
28  
29 in thematic analysis: inductive, deductive, semantic, latent, critical and constructionist. For this  
30  
31 research, an inductive, semantic and critical approach was taken. As described by Braun &  
32  
33 Clarke (2020) this approach to thematic analysis is directed by the content of the data with  
34  
35 theme development reflecting the explicit content of the data and reporting focussing on a  
36  
37 reality evident in the data.

38  
39 Following decision regarding data orientation, the recursive six step framework as described by  
40  
41 Braun & Clarke (2013) was used as follows: data familiarisation, generating initial codes,  
42  
43 searching for themes, reviewing themes, defining themes, writing up. All interview transcripts  
44  
45 were read multiple times by the lead researcher (LJW) to generate initial conceptual codes. A  
46  
47 list of codes was developed which were then grouped together to search for initial themes. This  
48  
49 was done on an interim basis after every 2-3 interviews. Initial themes were discussed virtually  
50  
51 on multiple occasions with the research team; and re- reviewed alongside the transcripts to  
52  
53 explore whether any detail was missing and ensure rigor, reliability and validity in data analysis.  
54  
55 Final themes were established following this process and defined using a pattern of shared  
56  
57 meaning (Braun and Clarke 2013). Themes were then defined and named to shape the focus of  
58  
59 each theme and 'tell the story' (Braun and Clarke 2013). A copy of the interview findings were  
60

sent to all participants for feedback. Seven participants returned this feedback and agreed with the interpretation of the interview data.

## Outcomes & Results

A total of 17 patients underwent TL at the unit within the two year inclusion period. Six participants were ineligible due to either palliative disease status or being under active investigation for other health conditions. All eligible participants were approached and ten consented to participate; five participants had a partner present for the interview. One participant did not respond to the study invitation.

Table 1 summarises participants' characteristics. The sample consisted of seven males and three females, with a median age of 63. Participants used a range of communication methods including writing, silent articulation, electro-larynx, oesophageal speech and tracheoesophageal voice. Five participants had a glottis cancer site. Five participants had a cancer stage of T1-II and five had a staging of TIII-IV. Four out of five participants in the T1-II cancer staging group had residual or recurrent disease. Over half the participants received combined modality treatment: six having surgery followed by chemo/radiotherapy and three needing salvage surgery for recurrent/residual disease. All participants who had salvage surgery had a flap reconstruction as part of their surgery. Six participants were within their first year post-TL. Seven participants lived within the top four most deprived areas in the UK.

Table 1: Participant characteristics

Variable	N	%
Sex		
Male	VII	70
Female	III	30
Age at interview		
<50	II	20



50-59	I	10
60-69	III	30
70+	IIII	40
<b>Cancer site</b>		
Larynx	V	50
Supraglottis	III	30
Pyriform Fossae	II	20
<b>Cancer stage</b>		
I	I	10
II	IIII	40
III	I	10
IV	IIII	40
<b>Time since surgery</b>		
<1 month	II	20
2-3months	I	10
4-6 months	I	10
7-12months	II	20
13 months+	IIII	40
<b>Treatment received</b>		
Primary surgery alone	I	10
Primary surgery + adjuvant chemo/radiotherapy	VI	60
Salvage surgery	III	30
<b>Free flap</b>		
Yes	IIII	40
No	VI	60
<b>Length of stay</b>		
1-7 days	0	0
8-14 days	V	50
15 days +	V	50

Level of social deprivation		
1	II	20
2	IIII	40
3	0	0
4	I	10
5	II	20
6	0	0
7	0	0
8	I	10

Four equally important, interrelated themes were generated from the analysis. These describe significant factors and principles which influence the post-operative inpatient acute experience following TL. Two themes highlighted patients early decision making processes about TL based on their own personal values and the information they were provided with; and the other two themes demonstrated how both internal and external factors shaped early post-operative recovery and initial coping to life with a TL. Themes included: (1) pre-operative information giving "it was just words"; (2) decision-making influences: "I just wanted them to get it all out and get it over with"; (3) coping with adjustment to the new normal "this is part of me now"; and (4) the importance of relationship building "when you've had something like this, you need some care and understanding". There was little difference between participant responses when comparing those who had their surgery before COVID-19 to those who had their surgery during COVID-19; therefore limited weight was given to this area in the final thematic framework.

Figure 1 demonstrates the thematic framework developed from analysis, representing the four key themes and their sub-themes.



Figure 1: Thematic framework

*Theme 1: Pre-operative information giving: "it was just words"*

All participants discussed the information they were provided with before their surgery, which they mainly recall being delivered verbally by their Consultant Surgeon,

*"I was told about the operation and that was all" (P8, M).*

Only a few participants could remember meeting other members of the MDT e.g. Clinical Nurse Specialist, Speech & Language Therapist; at this stage. Participants recalled a lot of verbal information provided about surgical details, immediate post-operative changes to communication, breathing and swallowing, and options for communication after their surgery. However, some participants were overloaded with information before their operation,

*"Mrs. X says that they didn't know whether I'd have a voice box put straight in erm...it all depended on when they got further down and you know they could see what was*

1  
2 *what and whether they needed to take any tissue from either the top of me leg or me*  
3  
4 *arm” (P4, F).*

5 Other forms of information were provided e.g. written and video,

6  
7 *“I got a CD... well I knew what I was going in for put it that way” (P1, M).*

8  
9 However, participants did not talk about anything other than the key surgical information being  
10 provided in these forms. When written information was provided, most participants said they  
11 either did not read it or found the language too complex to process the information,  
12  
13

14  
15 *“In some parts they explained it okay but in other parts there were some words...bigger*  
16 *words I couldn't understand so I had to ask about them” (P7, F).*

17  
18 Two participants looked for information themselves online,

19  
20  
21 *“I looked on YouTube...I wanted to know what to expect” (P10, F).*

22  
23 No participants discussed information about what life might be like for them in the longer-term  
24 after TL when revisiting the information provided to them pre-operatively.  
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30 *Theme 2: Decision-making influences: “I just wanted them to get it all out and get it over with”*

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32 All participants discussed the influences which played a role in enabling them to make their  
33 decision about proceeding with a TL. This consisted of participants weighing up what was  
34 important for their life after surgery; with all participants talking about their personal preferences  
35 in their life, for example, the importance of family. All participants talked about the need to  
36 survive and as a consequence, the need for survival was often the main priority for participants  
37 when making decisions about their treatment,  
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43  
44 *“I wanted to be here for V (husband)...it wasn't my time to go yet” (P7, F).*

45  
46 For some participants, this decision-making process was based around both survival and  
47 getting back to 'normal' life as quickly as possible after the operation,  
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50  
51 *“Beforehand I was worried about the cancer, I just wanted it cut...I thought I was going*  
52 *to go back to normal...I just wanted to be back home, to get back with my son and*  
53 *family. I just wanted to get it out of the way” (P2, M).*

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56  
57 Participants also talked about what was going to be an acceptable trade-off for their life after  
58 surgery, for example, a willingness to accept losing their voice permanently in order to survive,  
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1  
2 *"I was saying to Y (wife), I've still got me good health, I can see, I'm fit, I can walk, it's*  
3 *only going to be the voice"* (P5, M).

4  
5  
6 However, the majority of participants had not considered the reality about how life would be  
7  
8 from a practical, physical and emotional perspective in the longer-term following their discharge  
9  
10 from hospital. Participants mainly talked about how they got to grips with key skills after their  
11  
12 operation so that they could get home quickly; they did not think about their life beyond this  
13  
14 period of time.

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16  
17 *Interviewer: 'Did you want to know what life would be like after?'*

18  
19 *Participant: 'It didn't really cross me mind...I just wanted to get out of hospital as quickly*  
20 *as possible' (P9, M)*

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23 This theme is strongly linked with 'Theme 1' as participants seemed to use the information  
24  
25 provided from their Consultant surgeon to help inform their decision about survival:  
26  
27

28 *"I think I did ask which was erm best for the success thing...wey how many average out*  
29 *of a hundred sorta thing survive and sorta thing... he didn't say how may out of a*  
30 *hundred, he just said there's more success with the one I've got so that's what I opted*  
31 *for"* (P5, M).

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39 *Theme 3: Coping with adjustment to the new normal: "this is part of me now"*

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41 When talking about their time in hospital after the operation, participants described how they  
42  
43 started to adjust to their 'new normal':  
44  
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46 *"I was a bit shocked at first, then I learnt to live with it"* (P9, M).

47  
48 Whilst within this 'new normal' participants talked about the anticipated changes in  
49  
50 communication, swallowing and breathing that they were prepared for; they also talked about  
51  
52 their practical adjustment, such as how they began to prepare for the transition from hospital to  
53  
54 home,  
55

56  
57 *"You got into a routine and you realise that routine, if it wasn't here, it would be very*  
58 *difficult at home."* (P3, M).

1  
2 Participants described how they learnt to communicate, look after their stoma, and swallow  
3 again; with an overall feeling that they knew they would have to do this. Adjusting to  
4 communication was described as being most difficult by the majority of participants, followed by  
5 stoma management with swallowing being of lesser need.  
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9  
10 There was a wide range in experiences, particularly in how participants learnt to communicate  
11 again, with some participants finding the experience challenging,  
12  
13

14 *"I was using a board to write things on and that, that was very stressful...it was more*  
15 *stressful than I thought it was going to be"* (P1, M).  
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18  
19 Others found this experience more rewarding,  
20

21 *"I was over the moon with that...very excited about it...actually being able to speak to*  
22 *somebody rather than writing notes down"* (P3, M talking about electrolarynx use).  
23  
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25  
26 The way in which participants coped with these changes was individualised, for example, some  
27 participants took photographs of their stoma as a way to initially look at themselves post-  
28 operatively. How participants coped was affected greatly by their mood, as some participants  
29 reported that they did not have the motivation to engage in learning these new skills in the early  
30 days after their operation,  
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33

34 *"first week I just couldn't be chewed...I mean I did get up and get washed but it was like*  
35 *'agh'"* (P2, M).  
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40  
41 All participants said that they needed some support to develop these skills, with the level of  
42 support varying dependent on their level of adjustment to the 'new normal',  
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44

45 *"the nurses showed iz...they used to take it out on a morning and a night and then I*  
46 *would do it four or five times a day"* (P8, M explaining laryngectomy tube removal/stoma  
47 care).  
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51  
52 Participants said they also had a strong focus on trying to cope with the adjustment to their 'new  
53 normal' so that they could get home, usually to their families, and often had a specific and  
54 individual goal for their length of hospital stay. Some participants were able to have a staged  
55 return to home e.g. day leave from hospital,  
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1  
2 *“they started letting ‘iz go out for a couple of hours a day, maybe once or twice a week*  
3 *and then stayed over home for a night and that was absolutely great ‘coz I missed me*  
4 *family” (P4, F).*  
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8 These participants reported that this helped them consider what life would be like beyond  
9 hospital, for example doing their stoma care at home. However; the majority of participants said  
10 that they had given little thought to their return to home, i.e., how this ‘new normal’ would be  
11 integrated into what their everyday life looked like pre-operatively. Some participants who had  
12 surgery in the COVID-19 era commented on the lack of face-to-face visiting during their post-  
13 operative inpatient stay, but this was more from a lack of interaction perspective rather than an  
14 adjustment issue.  
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22 *“I like meeting people, I like talking to people and I like socialising. So to lie there and sit*  
23 *there with nobody there it’s bound to affect you in some way and it affected me so*  
24 *visitors would’ve been fantastic” (P3, M).*  
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31 *Theme 4: The importance of relationship building “when you’ve had something like this, you*  
32 *need some care and understanding”*  
33  
34

35 The importance of relationships was discussed extensively by all participants, specifically those  
36 relationships with healthcare professionals, peers and family,  
37  
38  
39

40 *“You need family to talk too...it’s a big operation” (P10, F).*  
41  
42

43 Participants described the positive therapeutic relationships formed with healthcare  
44 professionals and how these relationships made them feel as a person. This relationship and  
45 interactions between healthcare professionals and participants helped participants to feel  
46 normal, not just another patient who was going to have or had had a TL,  
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51 *“there was some nice characters of the nurses...funny...make a joke with iz...just didn’t*  
52 *look at iz any different to any other patient which was really good...It made iz feel*  
53 *normal...it made iz forget” (P2, M).*  
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2 Pertinent to this relationship was the level of expertise that healthcare professionals displayed,  
3  
4 with some participants feeling negative about the lack of specialist support once they were at  
5  
6 home,

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8 *“I have rang her once when I needed some things for the nebuliser...that was a waste*  
9  
10 *of time because they haven't even got them, they sent iz an spacer wey I says 'that's no*  
11  
12 *good, I've got a stoma I cannit even put it over me mouth”* (P4, F talking about  
13  
14 community support).

15  
16 Some participants described the relationships that they formed with other patients on the ward,  
17  
18 and the positive impact this had on their recovery by facilitating the adjustment to their new-  
19  
20 normal,

21  
22  
23 *“You know X she would say 'are you alright Y?' and you know I would try and I would*  
24  
25 *say 'I'm, I'm a-a-a-alright X' you know that's the way I was sounding. She says 'Y it's*  
26  
27 *great to hear you flower' and erm I really took to her well you know X”* (P4, F).

28  
29 A sense of togetherness and connection came through strongly for those participants who found  
30  
31 these relationships helpful; and having a natural environment for this to happen in seemed to  
32  
33 help e.g. swapping newspapers in the day room. All participants were beyond grateful for the  
34  
35 relationships they had with their families which supported them through all time points in their  
36  
37 journey pre-and post-TL,

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39  
40 *“Me Mam and Dad were watching the bairns... I knew I had good family support”* (P6,  
41  
42 M).

43  
44 Family relationships were described as being important for all participants, whether that be a  
45  
46 spouse/partner, parent or child.  
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## Conclusions & Implications

This study provided a unique insight into the early post-operative phase following TL from the patient's perspective. Four equally weighted themes were generated from qualitative data analysis, with the key points from these being: information provision, decision-making influences, coping with adjustment to the new normal and relationships with family, friends, healthcare professionals and other patients. The key message between these themes from participants was the need for a person-centred approach to both the practical and psycho-social needs as a TL, particularly at the pre-operative and early discharge home phase. Qualitative information about information provision at the pre-operative stage was an incidental finding from this study. However, this does have direct implications on how people are prepared for what will happen during the acute inpatient period after TL; and from the experiences described, participants were on the most part, adequately prepared for their post-operative time in hospital. As well as being adequately prepared for their post-operative time in hospital; the majority of participants were prepared for the anticipated changes to communication, swallowing and breathing. Participants were given practical and functional verbal information during their pre-operative preparation which fits with standard practice in UK clinical services (NICE Improving Outcomes Guidance 2004). However, for some participant's complex information provided appeared to overload them, which questions how useful this information has been in supporting them beyond the surgical details, acute rehabilitation and potentially their understanding of life-long changes following a TL. This finding has been explored in other qualitative literature (Llewellyn et al 2006 and Brockbank et al 2015) which advocates for personalised pre-treatment information delivered at an individual's own pace and which incorporates information about longer-term outcomes and support; for example, how the long-term effects of treatment will impact an individual's work ability and quality of life.

This level of information overload reported by participants is likely due to the multitude of complex information provided verbally at a highly stressful time. Although written information was provided, the majority of participants either did not read this or found the information too complex to process. A potential reason for this could be linked to low health literacy levels which are reported to be prevalent in 14% of HNC survivors (Nilsen et al 2020) and also in areas with high levels of social deprivation (Simpson et al 2020). Seven of the ten participants in this study

1  
2 lived in the top four most socially deprived areas in the UK, hence it is possible that issues with  
3  
4 health literacy have contributed to information overload for these participants. It is also possible  
5  
6 that a reduced capacity to process information at a highly stressful time has contributed to this  
7  
8 information overload; a concept which has been highlighted in qualitative work by Govender  
9  
10 (2019) whilst investigating the use of video-animation in patients with dysphagia following HNC.  
11  
12 Participants in Govender's study (2019) also experienced information burden and cognitive  
13  
14 overload, with findings recommending the use of multi-modal, personalised information to meet  
15  
16 the individual needs of each patient. Although this has not been tested, this concept could be  
17  
18 considered in information-provision, particularly at the pre-operative stage, for people having a  
19  
20 TL.

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22 Strongly linked to information overload was the participants' ability to navigate through the  
23  
24 information in order to make decisions about their treatment and care. Often treatment decision  
25  
26 was centred on survival, with participants not fully considering the practical, physical and  
27  
28 emotional perspective following discharge from hospital. Some of this could be linked to the  
29  
30 clinician voice being strongly conveyed during this time due to the level of verbal information  
31  
32 provided, and therefore, there is the possibility that the participants' voice was not heard as  
33  
34 equally. This concept has been explored in previous research studies (Val Linden et al 2017  
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36 and Hamilton et al 2016) which recommend a shift in HNC consultations so that the patients'  
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38 voice is heard just as much as the clinicians, to ensure that patients' values and preferences are  
39  
40 incorporated into treatment decision-making. A shift to using this approach in TL care could help  
41  
42 future patients to fully consider their practical, physical and emotional needs in the longer-term  
43  
44 during this stressful and life-changing time.

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46 The majority of participants in this study were prepared for the practical and functional changes  
47  
48 post-operatively due to the practical information they were provided with pre-operatively.  
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50 However, some participants found it difficult to navigate their early adjustment to what 'normal'  
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52 was for them post-TL. This finding is supported by other qualitative research (Dawson et al  
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54 2019) which describes how surgical HNC patients feel adequately prepared for the 'physical'  
55  
56 changes following their surgery but found it challenging to navigate through the more emotional  
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58 and psycho-social adjustments to life after their surgery. This again links directly to the level and  
59  
60 mode of pre-operative information provision and decision-making process; highlighting the need  
to re-evaluate the structure and format of this intervention.

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2 For participants who found it challenging to navigate the adjustment to the 'new normal', the  
3 motivation levels that they described during this time were low. Their ability to engage in  
4 activities such as stoma care competencies was often limited, so problem-solving and  
5 navigating to a 'new normal' with this was difficult. Other research studies discuss issues with  
6 engagement (Neilson et al 2013) and suggest that inpatient length of stay can increase as a  
7 result of low mood. This could be linked to those individuals ability to problem solve and adjust  
8 to their post-treatment functional changes; particularly as the rates of psychological distress in  
9 people who have HNC are reported as being as high as 50% (Lydiatt et al 2009). It is therefore  
10 possible that low levels of motivation reported by participants in this study could be similar to  
11 other research in HNC looking at mood. Early identification of people who experience low levels  
12 of motivation in the early post-operative period could help to provide those individuals with  
13 increased support. This could help them to navigate more readily through their early post-  
14 operative adjustment to the 'new normal'.  
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27 This period of adjustment to the 'new normal' extended to participants first few weeks at home  
28 following hospital discharge. All participants highlighted the need for ongoing support at this  
29 stage to help with their transition home and coping with the life-long adjustment to having a TL.  
30 This finding is supported by other qualitative work (Dunne et al 2019 and Nund et al 2014)  
31 which highlighted the need for structured, individualised support from professionals, including  
32 emotional and psychosocial support in addition to support with physical changes. Participants in  
33 Nund's study (2014) talked about ongoing support coming from their own support networks of  
34 family and friends; whilst also raising the need for more specialist clinical support in the long-  
35 term to help with their adjustment to life post-treatment. This finding is similar to what  
36 participants in this study discussed as family support was key for them, but participants also  
37 highlighted the importance of ongoing specialist clinical support, with some participants  
38 discussing the disparity in community service provision. This potentially impacted on their  
39 coping and adjustment to life at home following TL and could be linked to a lack of experience,  
40 knowledge or time that community services have available. This is an area which should be  
41 explored in future research to deepen understanding of how services can be delivered to  
42 provide patients with optimum support at this time.  
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58 For participants in this study, the COVID-19 era did not appear to have any influence to any of  
59 the four themes despite changes to the patient pathway. One small difference was described  
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1 with regards to COVID-19 in the 'coping with adjustment to the new normal' theme. Participants  
2 who had their surgery during COVID-19 talked about the lack of face-to-face interaction with  
3 their family during their post-operative hospital stay. Whilst participants commented on this  
4 being difficult from a lack of interaction perspective, the lack of visiting did not adversely impact  
5 on their adjustment to the 'new normal' when compared to participants who had their surgery  
6 out-with COVID-19. Therefore, there is the possibility that changes to service provision due to  
7 COVID-19 has impacted on clinician experiences and perspectives more than the patients; and  
8 this is something which could be explored in future studies investigating the impact of COVID-  
9 19 on clinical services.

10 The aim of this study was to explore pre and during COVID-19 inpatient experiences of having a  
11 TL. Some ERAS principles were incorporated into the pathway for participants who had their  
12 surgery during COVID-19, for example, earlier contrast swallows post-operatively to get back to  
13 eating and drinking sooner. However, information from participants in this study did not highlight  
14 any significant differences to experiences from pre-operative preparation through to the early  
15 weeks at home following hospital discharge when compared to those who had surgery out-with  
16 COVID-19. Although the current literature in ERAS advocates that early oral feeding positively  
17 influences patient recovery and outcomes (Seven et al. 2003; Prasad et al. 2006; Bannister and  
18 Ah-See 2015; Aires et al. 2015); participants in this study focussed more broadly, rather than  
19 focussing on specific time-points, such as the timing of re-starting oral intake. Participants talked  
20 more about how they were prepared for and adjusted to their functional changes post-  
21 operatively, who supported them during this time and how this experience made them feel as a  
22 person. This feeling described by participants is supported by other research (Dawson et al  
23 2019 and Santa Mina et al 2020) in which physical, social, functional and psychological  
24 principles of care can maximise function; with people remembering how interactions made them  
25 feel rather than the details of the clinical interventions provided. This aligns more closely to what  
26 the participants in this study see as important in their TL pathway and could be considered for  
27 integration in future ERAS laryngectomy models of care.

28 Whilst this study generally reported positive experiences, there are limitations which should be  
29 considered. The participants in this study were recruited from a single centre. Experiences are  
30 therefore from one UK surgical centre and there may be subtle differences in service provision  
31 dependent on geographical location; for example, provision of community services available

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2 and individual centre care pathways. This was an exploratory study and results cannot be  
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4 generalised widely and should be interpreted carefully. However, the demographics of the  
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6 participants in this study are similar to the national demographic for HNC (NICE Improving  
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8 Outcomes Guidance 2014).  
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10 Findings from this preliminary study have highlighted potential avenues for further research.  
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12 Participants in this study have talked about the need for specialist support beyond the hospital  
13  
14 stay to support their longer-term adjustment to the 'new normal'. Future research could explore  
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16 what these service models should look like in collaboration with patients, community service  
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18 providers i.e. GP's and District Nurses; and specialist hospital staff to shape future services for  
19  
20 the benefit of the patient. There is also potential from this to re-evaluate what ERAS services  
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22 should look like for TL, extending to the pre-treatment phase. Further work should be done to  
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24 provide a patient-centred ERAS model of care. There is potential that a model similar to the  
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26 'multiphasic prehabilitation' care package as described by Santa-Mina (2020) would provide  
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28 more than just information giving, and may help to prepare individuals for the longer term  
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30 psycho-social adjustment to life following TL. Future models of care should therefore consider  
31  
32 both the format and content of information delivered to patients to maximise their outcomes.  
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34 Tools to measure readability scores e.g. Fog Index and co-designing information packages with  
35  
36 patients are potential options to improve future TL services.

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38 This exploratory study has explored the acute experiences of patients undergoing a TL both  
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40 before and during the COVID-19 pandemic. There was no difference in experience reported by  
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42 participants in this study who had their surgery either before or during COVID-19 despite rapid  
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44 service changes at their unit. Overall, people are adequately prepared for the functional  
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46 changes they will face immediately following their surgery; however, there needs to be  
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48 enhanced services provided to people having a TL both at the pre-operative and early home  
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50 discharge period.

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52 Going forward, this study has shown how enhanced recovery could be instigated in clinical  
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54 practice, and also demonstrated the need to shift enhanced recovery models of care away from  
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56 the medical model alone. By making this shift there is potential to improve patient-reported  
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58 outcomes and achieve individualised care.  
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**Appendix 1 (patient information sheet and consent form; topic guide)****Information about the research****Study Title**

Patient experience of the acute post-surgical period following total laryngectomy during the COVID-19 era

**Invitation and brief summary:**

You have been invited to take part in this study as you have had surgery to remove your voice box within the last two years.

Joining this study is completely voluntary. We would like to give you some more information about the research.

A member of our team will go through this information sheet with you. They can answer any questions you may have. We expect this will take around 5-10 minutes. You can then decide whether or not you would like to take part.

Please feel free to ask questions at any time.

**1. What is the purpose and background to the research?**

This study is aiming to explore people's experience of their time in hospital following surgery to remove their voice box both before and during COVID-19. We know that there have been major changes to the way we run our clinical services due to COVID-19 and would like to understand the impact that this has had on you. This will help us to know which part of our inpatient services are helpful, and allow us to make improvements to the service in the future.

**2. What would taking part involve?**

You will be invited to take part in an interview with us at XX Hospital. We aim to do this on a day that you are at the hospital for a clinic appointment. The interview will last between 30 – 45 minutes and will be audio-recorded.

**3. Why have I been invited to take part?**

You have been invited to take part because you had surgery to remove your voice-box within the last two years.

**4. What are the possible benefits of taking part?**

We do not expect that the study will directly benefit you; however, some people do find it helpful to talk about their experience in hospital. The information you provide in the interview about your experience will likely benefit the service we provide and our future patients.

**5. What are the possible disadvantages and risks of taking part?**

We do not expect there to be any disadvantages to taking part in the study. However, some people can find some topics difficult to talk about and may become emotional during the interview. If this was to happen, we will support you through this and can also offer further support from our Psychology service or signpost you to other avenues of support.

**6. How will my information be used?**

All information about participants will be handled in confidence. Completed interviews will be stored securely on an NHS computer in a password protected file that only XX can access.

Names and addresses will not appear on any of our data. You will be given a unique number for identification and only XX will be able to link this number to your name and details.

The only other people allowed to know about who is in the study will be staff from the Research and Development Department of the hospital. They help to ensure that the research is being done properly. They will not disclose your identity to anyone else. We will keep the data from the study for ten years. Any identifiable data will be destroyed as soon as possible after the end of the study. All study records and participants' rights to them will be protected in accordance with the UK data protection laws.

#### **7. What if something goes wrong?**

If you have any concerns about the study you can contact XX (contact details at the bottom of this Information Sheet) and she will do her best to answer your issue. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital. If you would like to talk to someone not involved in the study, please contact the NHS Patient Advisory Liaison Service (PALS) Tel 0800 5876513. In the event that something goes wrong and you are harmed during the research due to someone's negligence then you may have grounds for legal action for compensation but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

#### **8. What to expect during the consent process?**

After reading the study information, you will provide written consent to participate in the study. You will be given a copy of the consent form and information sheet to take home with you.

#### **9. What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at any time. Coming out of the study will not change your future care in any way.

#### **10. What will happen to the results of the study?**

The results of the study will be written up for a Masters research Dissertation submitted to XX. They may also be shared at national and international research conferences and submitted to an academic journal for publication.

A summary of the study will be available to research participants. You will not be identified by name in any reports or publications.

#### **11. Who is organising and funding the study?**

The study is being led by XX. XX's research time is being funded by the XX. The XX have no role in the study design, data collection/analysis/interpretation or report writing.

#### **12. Who has reviewed the study?**

This study has been reviewed by the Research Design Service at XX

#### **Further information and contact details**

For further information regarding the study, please contact:

XXX

Thank you for taking the time to read this information sheet.

**CONSENT FORM**

Centre: XX

Participant Identification Number for this trial:

Title of Project: Patient experience of the acute post-surgical period following total laryngectomy during the COVID-19 era

Name of Researcher: XX

Please initial box

1. I confirm that I have read the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from XX, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers.
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature  
taking consent

**Topic guide**

## Introduction

1. Introduce self and thank for agreeing to participate
2. Participation is optional and you can stop the interview or decline to answer specific questions if you wish. It should last no longer than an hour.

## Confidentiality and consent

1. The findings may be written up in the service evaluation but you will remain anonymous
2. I would prefer to record the interview to help capture everything you say and also to evaluate the questions that I use. I may repeat some of your answers to make sure I have understood you. Everything you say will remain on a device that can only be accessed by password and transcribed on a password protected NHS computer. Is this okay with you?
3. Clarify that they understand the purpose and confidentiality of the service evaluation and that they are happy to partake. Consent form signed.
4. Any questions.

These questions are about general information, giving me an idea of the background of your laryngectomy.

This is about your experience when you were in hospital having your laryngectomy – what jumps out for you? What were the low points? Was there anything that particularly went well?

Probe further dependent on participant response

Before you came in to hospital for your operation – what was that like for you? (probe for level of preparation e.g. pre-treatment information, including setting; materials to support info; meeting another patient)

Why did you feel like that? Is this the information that you wanted to know? (probe dependent on response)

How did you think you would cope with the surgery and life afterwards? Why?

## Communication

1  
2 Tell us about how you communicated after your surgery ... what was that like for you and  
3 others?

4  
5 What helped / what hindered

6  
7 Why?...

8  
9  
10 Socialising with others

11  
12 What was it like talking to other people on the ward?

13  
14 What was it like talking to staff?

15  
16 How did you communicate with your family? (may need to probe around lack of visitors)

17  
18 (If you can, get them to describe an experience of trying this out – anything that helped or  
19 hindered?)

20  
21 Why?....

22  
23  
24  
25 Eating and drinking

26  
27 Tell us about your experiences of eating and drinking after your operation?

28  
29 (probe whatever they come up with .. if not very much, ask about having a tube in .. can they  
30 recall the first attempt at eating; how long after their surgery was this – try to get some detail,  
31 how did it feel?)

32  
33 Why?....

34  
35  
36  
37 Stoma care

38  
39 Tell us about your stoma – what was your experience of it in hospital? How did you get to learn  
40 to look after it – what helped? What hindered? Probe whatever they come up with – try to get  
41 some info on timings

42  
43 Why?....

44  
45  
46  
47 Mobility / dressing

48  
49 Can you tell us a bit more about getting back to doing everyday things like dressing and  
50 washing, moving around? How was this for you – any problems? Anything that went better  
51 than expected?

52  
53 Why did you/did you not do that? Why did you feel like that?

54  
55  
56  
57 Discharge

58  
59 Can you tell us a bit more about your discharge from hospital – anything that particularly  
60 bothered you about going home? How did this actually go? How many days were you in  
hospital?

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2  
3  
4 What was it like for you in the first few days/weeks at home?  
5  
6

7 Why???

8  
9  
10  
11 Experience

- 12  
13 1. How would you describe your overall experience? Specifically of having a  
14 laryngectomy during covid-19 pandemic (if during this timeframe)?  
15  
16 2. Was there anything that could be done differently? Why?  
17  
18 3. How did it make you feel? Why?  
19  
20 4. What went well for you? Why?  
21  
22 5. How did it make you feel? Why?  
23  
24

25 Summarising and reflecting

26 Just thinking about your hospital stay after you lary – is there anything else you want to talk  
27 about?  
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31  
32 Is there anything else you would like to add?  
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