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# Primary mode of communication for people with total laryngectomy in the UK: a cross-sectional survey

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## Main Article

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## Abstract

**Objective.** This study aimed to report on the UK rate of surgical voice restoration usage and investigate the factors that influence its uptake.

**Method.** A national multicentre audit of people with total laryngectomy was completed over a six-month period (March to September 2020) in response to the coronavirus disease 2019 pandemic. This study is a secondary analysis of the data collected, focusing on the primary communication methods used by people with total laryngectomy.

**Results.** Data on surgical voice restoration were available for 1196 people with total laryngectomy; a total of 852 people with total laryngectomy (71 per cent) used surgical voice restoration. Another type of communication method was used by 344 people. The factors associated with surgical voice restoration in the multiple regression analysis were sex ($p = 0.003$), employment (employed *vs* not employed, $p < 0.001$) and time post-laryngectomy ($p < 0.001$).

**Conclusion.** This study provides an important benchmark for the current status of surgical voice restoration usage across the UK. It found that 71 per cent of people with total laryngectomy used surgical voice restoration as their primary communication method.

## Introduction

People with total laryngectomy are unable to produce laryngeal voice because of removal of the larynx and redirection of the airway to a permanent neck tracheostoma. Total laryngectomy is primarily performed to treat advanced laryngeal or hypopharyngeal cancer. Post-operative communication options include surgical voice restoration, electrolarynx, oesophageal speech, silent articulation, writing and text-to-speech applications.

Loss of laryngeal voice is associated with poorer quality of life,[1] hence, in the UK, it is recommended that surgical voice restoration is offered routinely to all eligible patients as part of laryngectomy rehabilitation.[2] In Australia, a survey suggested 70 per cent of people with total laryngectomy had surgical voice restoration.[3] The rate of surgical voice restoration uptake in the UK is unknown, however, making it difficult to benchmark services.

Surgical voice restoration involves the creation of a tracheoesophageal puncture tract to shunt pulmonary air into the neopharynx, thereby creating vibration of the neopharyngeal walls to produce tracheooesophageal voice. A voice prosthesis (a one-way silicone valve) is inserted into the puncture tract to facilitate airflow while preventing aspiration through the tract. Surgical voice restoration can be performed as a primary procedure (at the time of total laryngectomy) or as a secondary procedure, particularly in salvage surgery, where risk of pharyngocutaneous fistula is higher.[4] Pulmonary airflow enables longer phrase length and fluency.

Surgical voice restoration may also provide better voice quality and intelligibility,[5] patient acceptability[6] and improved quality-of-life outcomes.[1,7] Research suggests that healthcare professionals and untrained listeners prefer surgical voice restoration communication over other methods of voice restoration.[8,9]

Despite these advantages, there are several reasons why surgical voice restoration may not be offered, such as surgical complications preventing functional voice, institutional capacity and patient preference.[10] Surgical voice restoration requires specific maintenance, care and regular voice prosthesis changes, which can involve multiple, and sometimes unplanned, hospital attendances.[11,12] Travelling distance may influence patients in their decision to proceed with surgical voice restoration. Moreover, older adults may struggle with the dexterity required to care for their voice prosthesis.

For the first time, a UK audit of people with total laryngectomy was completed in 2020[13] in response to concerns that people with total laryngectomy may be at high risk of contracting and transmitting coronavirus disease 2019 (Covid-19) infection.[14] The background to the audit has been reported previously.[13,15] Using this data, this study aimed to report on the UK rate of surgical voice restoration usage and investigate the factors that may influence its uptake.

## Materials and methods

This paper used the Strengthening the Reporting of Observational Studies in Epidemiology[16] checklist for reporting cross-sectional studies. The methods and audit data collection have been described in detail in an earlier paper[13] and are summarised below.

### *Ethical considerations*

Data were collected during the timeframe covered by the Control of Patient Information notice issued during Covid-19. The project was approved by the Applied Health in Cancer Governance Group at the lead National Health Service (NHS) site. Individual sites also sought local approval to share data. A data flowchart is attached as supplementary information.

### *Study design and setting*

A national multicentre audit of people with total laryngectomy was completed in response to the Covid-19 pandemic over a six-month period (March to September 2020). This study is a secondary analysis of data collected during the UK audit, focusing on primary communication methods and factors that may have influenced these methods prior to and during the pandemic.

### *Participants*

All people with total laryngectomy under the care of participating centres were eligible for inclusion. Data were collected via case note review or during speech and language therapy consultations, either in person or via telehealth during the period of the first national lockdown.

### *Data collection*

A data capture worksheet (devised in Excel, password protected and encrypted) was used to collect data for the objectives outlined below. Personal identifying information was minimised, as advised by the information governance team. Verbal patient consent was obtained whenever possible.

Data were collected on the primary mode of communication used by people with total laryngectomy before and after the onset of the Covid-19 pandemic. Data on the type of humidification used and the incidence of Covid-19 infection were also collected and are reported independently of this paper.[13,15] Information on living circumstances was also collected to indicate opportunities for communication on a regular basis and during the lockdown period. Information on distance from the centre was collected because this may have an impact on the opportunity for speech and language therapy-led voice prosthesis management. Information on time since surgery was collected because available communication options have changed over time.

### *Data analysis*

Data were analysed using SPSS version 24 for Microsoft Windows. Continuous data were summarised as medians and interquartile ranges, and categorical data were described as frequencies of counts and percentages. A univariable analysis was initially performed to see how each of the explanatory variables was associated with surgical voice restoration using Pearson's chi-square test for categorical explanatory variables and the two-sample *t*-test or Mann–Whitney *U*-test for continuous variables. Potential explanatory variables included sex, age, living circumstances, employment, distance from treatment centre and time elapsed since laryngectomy.

Correlations between continuous explanatory variables were assessed using either Pearson's or Spearman's rank correlation depending on the distribution of the variables. A backwards selection procedure was used to determine the final model (criteria for entry $p < 0.05$ and for removal $p > 0.1$). The overall fit of the model was ascertained using the Hosmer and Lemeshow goodness-of-fit test.

## Results

Twenty-six centres across the UK submitted data for analysis. Data were collected on a total of 1216 people with total laryngectomy. The details of the participating centres and patient demographics are described in previous work[13] and are summarised in Table 1.

Data on surgical voice restoration use were available for 1196 people with total laryngectomy (Table 1). Twenty people with total laryngectomy (2 per cent of the entire cohort) were excluded as 16 had a tracheoesophageal occluder in situ and there were missing data for four patients. The cohort consisted of 970 males and 226 females, with a mean age of 69.6 years (range 28–97 years); the median number of months post-laryngectomy was 71. A total of 852 people with total laryngectomy (71 per cent) used surgical voice restoration and 344 people used an alternative communication method (silent articulation, communication aid, electrolarynx or oesophageal speech), although specific details were not collected.

### *Factors associated with surgical voice restoration*

In univariate analysis, sex was a significant factor for surgical voice restoration use, with 63 per cent of females using surgical voice restoration compared with 73 per cent of males ($p = 0.01$) (Table 1). There were similar proportions for living circumstances, i.e. people with total laryngectomy living alone, with others or in a care facility, across surgical voice restoration and non-surgical voice restoration. There was no significant difference between surgical voice restoration versus no surgical voice restoration for distance travelled or age. Nineteen per cent of people with total laryngectomy with surgical voice restoration lived over 20 miles from their treatment centre. Date on the mode of transport and the time taken to travel to the treatment centre were not collected. Only 127 patients (11 per cent) were employed at the time of data collection and 78 per cent of these were surgical voice restoration users. The largest subgroup was retired surgical voice restoration users (71 per cent). However, time post-laryngectomy was found to be significant, with a difference of 19 months between surgical voice restoration users (98 months) versus non-surgical voice restoration users (79 months).


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**Table 1.** Patient characteristics grouped by SVR *vs* non-SVR usage

| Characteristic | Cases* | SVR | No SVR | *p* value |
|---|---|---|---|---|
| Sex (*n* (%))† | | | | **0.01** |
| – Male | 970 (81) | 709 (73) | 261 (27) | |
| – Female | 226 (19) | 143 (63) | 83 (37) | |
| Living circumstance (*n* (%))† | | | | 0.07 |
| – Living with someone | 763 (64) | 548 (72) | 215 (28) | |
| – Lives alone | 385 (32) | 278 (72) | 107 (28) | |
| – In care facility | 26 (2) | 11 (42) | 15 (58) | |
| – Missing/other | 22 (2) | 12 | 10 | |
| Distance from centre (*n* (%))† | | | | 0.82 |
| – <5miles | 315 (26) | 230 (73) | 85 (27) | |
| – 5–10 miles | 367 (31) | 264 (72) | 103 (28) | |
| – 11–20 miles | 280 (23) | 194 (69) | 86 (31) | |
| – >20 miles | 228 (19) | 161 (71) | 67 (29) | |
| – Missing | 6 (1) | 3 | 3 | |
| Employment (*n* (%))† | | | | **<0.001** |
| – Employed | 127 (11) | 111 (78) | 16 (22) | |
| – Retired | 820 (68) | 580 (71) | 240 (29) | |
| – Sick leave | 21 (2) | 13 (62) | 8 (38) | |
| – Unemployed | 83 (7) | 54 (65) | 29 (35) | |
| – Missing and/or other | 145 (12) | 94 | 51 | |
| Age‡ (mean (SD), years) | 69.6 (10.1) | 69.6 (10.1) | 69.4 (10.8) | 0.40 |
| Time post-laryngectomy (months)** | 71 (28–140) | 98 (31–144) | 79 (15–113) | **0.001** |

The bold font was to highlight the three factors which were significant
*Total *n* = 1196. Summary statistics are †counts (%), ‡mean (standard deviation), and **median (interquartile range). SVR = surgical voice restoration

Factors associated with surgical voice restoration in the multiple regression analysis (Table 2) were sex ($p = 0.003$), employment (employed *vs* not employed $p < 0.001$) and time post-laryngectomy ($p < 0.001$).

## Discussion

Our data collection highlights a comparable percentage of surgical voice restoration users within the cohort to that reported in the Australian literature.[3] In this large UK cohort of people with total laryngectomy, sex, employment status and time post-laryngectomy surgery were all found to be statistically significant factors in surgical voice restoration usage. None of the other variables (age, living circumstances and distance from the treatment centre) were predictive.

Previous smaller studies have failed to determine whether sex is of significance.[17,18] Some studies have only included male participants.[19] Given the greater prevalence of head and neck cancer in males, this large sample was able to identify that females were less likely to have surgical voice restoration: 63 per cent of females in contrast to 73 per cent of males. A recent qualitative study highlighted that females dislike their post-laryngectomy vocal quality, feel more vulnerable and are more reluctant to be perceived as different than male counterparts.[5]

Head and neck cancer survivors have a higher unemployment rate than survivors of other cancers.[20] Notably, a low percentage of people with total laryngectomy have been reported to return to work,[21] particularly females.[18] Occupation type has previously been reported to influence this, with those in manual jobs less likely to return to work.[22] Most of our cohort (69 per cent) were of retirement age at the point of surgery. However, in the group who returned to work, 78 per cent used surgical voice restoration as their primary communication method.

Return to work following head and neck cancer is rarely addressed in depth by healthcare professionals,[23] but there is an argument that people with total laryngectomy should be supported to maintain employment post-surgery, as employment is associated with lower levels of anxiety and depression.[24] One enabling factor appears to be successful communication,[25] which is confirmed in our findings. It is also noteworthy that higher levels of general activity are reported by surgical voice restoration users than by those relying on other forms of communication.[26]

Our results show that time post-laryngectomy was a significant factor for surgical voice restoration use: people with total laryngectomy who had their surgery most recently are less likely to use surgical voice restoration. Conversely, our previously published research[15] analysed the same sample and found that the longer the time elapsed post-surgery, the less likelihood of a heat moisture exchange device being used. At a time when organ preservation is the recommended primary treatment of choice,[2] laryngectomy surgeries are becoming increasingly complex in nature. When performed as a secondary, salvage procedure they often require the use of a 'flap' to close the pharyngeal defect. We hypothesise, therefore, that people with total laryngectomy whose surgery took place many years ago were more likely to have had a standard total laryngectomy. There is likely to be a greater number of 'salvage' laryngectomies over more recent years.


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**Table 2.** Variables associated with surgical voice restoration from multivariable logistic regression*

| Variable | $\beta$ | Standard error | Odds ratio | 95% confidence interval | $p$ value |
|---|---|---|---|---|---|
| Sex | 0.55 | 0.18 | 1.7 | 1.2–2.5 | 0.003 |
| Months post-laryngectomy | 0.004 | 0.001 | 1.0 | 1.0–1.0 | <0.001 |
| Employment status | 1.19 | 0.29 | 2.9 | 1.7–5.2 | <0.001 |

*Hosmer and Lemeshow goodness-of-fit test, $p > 0.05$. The employment variable is dichotomised into employed and not employed as a result of small numbers in some cells. $\beta$ = beta coefficient

Debate is ongoing over whether performing a primary puncture in salvage laryngectomy surgery increases the risk of complications.[27,28] Surgeons who believe this to be the case are more likely to avoid a primary puncture. This may also have been an influencing factor in our results. Furthermore, national guidelines do not currently state a recommended time for secondary puncture placement. With reference to our current study, we recognise that 25 per cent of our cohort had surgery fewer than 15 months prior to the data collection period (the interquartile range for non-surgical voice restoration users was 15–113 months). Hence, those people with total laryngectomy have been classed as non-surgical voice restoration users, but may have been awaiting a secondary puncture at the time of data collection.

Distance from centre was not a significant variable for predicting surgical voice restoration use. We hypothesise that this might be an important factor given the unpredictable frequency of voice prosthesis changes required and the requirement for potentially unplanned hospital visits, often at short notice.[29] It is unknown whether mode of transport and time taken to travel to the treatment centre may be more important than distance. Previously surgical voice restoration changes have generally required people with total laryngectomy to travel to a specialist NHS hospital for voice prostheses changes, the frequency of which is unpredictable.[12] However, there has been some evidence to suggest that community services can be cost-effective following the need to trial these during the Covid-19 pandemic.[30] Given the increased use of telemedicine within the NHS, it may be possible to implement models of care in the UK that provide remote support to individuals without the need for travel into tertiary centres. These pathways already work well in countries such as Australia.[31]

Eleven (42 per cent) of the people with total laryngectomy living in a care facility used surgical voice restoration. This correlates with the figures relating to heat moisture exchange device use in this population and is a much lower proportion than for those living independently.[15] As far as we are aware, published work does not exist focusing on the care or lived experience of people with an altered airway (laryngectomy or tracheostomy) living in a residential or nursing home. Anecdotally, very few care homes in the UK are prepared to accept residents with an altered airway and may not be adequately equipped to look after this population.[32] There is an identified lack of altered airway knowledge in the community,[33,34] with training directed more towards staff in hospital settings[35] or self-care.[36] More training and support in community settings may enable safer altered airways care and thus maximise residents' quality of life.

## Limitations

The current study was a secondary data analysis from a convenience sample collected during the Covid-19 pandemic. Information was not collected on protected characteristics such as ethnicity or socioeconomic status due to governance restrictions. Despite these limitations, the study offers the first, and largest, exploration of alaryngeal communication method used by people with total laryngectomy in the UK and represents a benchmark for further work. Surgical voice restoration is funded by the NHS in the UK; it is noteworthy that is not the same in all countries and this may influence the rate of uptake outside the UK.

## Clinical implications and future research

Surgical voice restoration has always been presented as the 'gold standard' of communication rehabilitation, but with the increasing age of the population, the accumulative prevalence of co-morbidities and the growing proportion of previous cancer treatments requiring more complex laryngectomy surgical procedures, should this claim be maintained? Advances in telemedicine and the potential to develop community services offer new ways for clinicians in the UK to work with people with total laryngectomy in the future.

In reference to our previous paper,[15] it is possible that the use of surgical voice restoration has a positive impact on heat moisture exchange device use. In comparison, where time elapsed post-surgery was negatively correlated with heat moisture exchange device usage, the current paper reports an increase in surgical voice restoration use for those patients who are longer post-surgery.

- SVR has been long been recommended as the 'gold standard' for communication rehabilitation after TL
- The nature of TL surgery has changed significantly in light of recommendations to provide organ-preservation treatment, where feasible
- Prior to this audit, the number of patients using SVR was unknown across the UK
- SVR currently remains the preferred method of communication post-laryngectomy with 71% of PTL in this UK audit known to be SVR users - this is similar to other countries
- Males, PTL who are employed and individuals who were longer post-surgery are more likely to be SVR users

Further investigation is required to detail information regarding laryngectomy surgical procedures, including the reconstruction method, and primary versus secondary tracheoesophageal puncture status. Data on average time delay to secondary puncture would be useful to inform national standards. More in-depth studies around voice prosthesis type, commonly experienced tracheoesophageal puncture complications and frequency of voice prosthesis changes, including the number of people with total laryngectomy trained to self-change their voice prosthesis, would be useful to underpin service planning across the UK. It would also be beneficial to explore factors that might enable greater acceptance of tracheoesophageal voice, particularly for females.


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Additionally, it would be worthwhile investigating facilitators to greater engagement in general activity in people with total laryngectomy who use other forms of communication . Ongoing training and support are required to for those with altered airways in supported living settings.

## Conclusion

This paper provides an important benchmark for the current status of surgical voice restoration usage across the UK. Seventy-one per cent of people with total laryngectomy use surgical voice restoration as their primary communication method, which is comparable to data reported in other countries, for example Australia. Sex, employment status and time post-laryngectomy were significant factors in surgical voice restoration use. Males and people with total laryngectomy who were employed were more likely to use surgical voice restoration. Moreover, people with total laryngectomy who were further post-laryngectomy were more likely to have surgical voice restoration, and we hypothesise this is due to the increasingly complex nature of total laryngectomy surgical procedures being performed, often following organ preservation attempts. In comparison, our previous work with the same cohort highlights that those who were further post-operative were less likely to use a heat moisture exchange device. Age, distance from the treatment centre and living circumstances did not show any statistical significance with regards to surgical voice restoration use in this cohort.

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