ORIGINAL ARTICLE

Feasibility of Establishing an Artificial Intelligence Based Head and Neck Cancer Registry: Experience from a Tertiary Care Hospital

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Abstract

Introduction Establishing and maintaining a cancer registry in a tertiary high volume centre is fraught with difficulty, inaccuracy and missed data entry. Further, the raw unstructured data must be converted into a structured digital data, so that scientists can identify trends in cancer diagnoses and treatment responses. **Objective** We test the feasibility of establishing a cancer registry of Head and Neck malignancy patients through a research oriented artificial intelligence (AI) enabled data collection platform, using its smartphone application version. **Materials and Methods** This prospective observational study was conducted in the Department of Otolaryngology & Head and Neck Surgery, Post Graduate Institute of Medical Education And Research, Chandigarh in collaboration with Departments of Radiotherapy and Community Medicine. After taking due clearance from the Institute ethical committee, HNC patients, who were biopsy proven, were enrolled from October 2019 up to March 2021. The obtained data was entered, followed up and analysed through Jiyyo Research application which is a commercially available dedicated research oriented AI enabled data collection platform. **Results** The Jiyyo Research site was browsed and after proper registration, the patient data was entered into a proforma/questionnaire. The entered patient details were browsed for review, follow up and addition of new information. The whole process of data capture for each patient, took approximately 5-8 min, while any updates or review for the same patient required less than a minute. Search and data retrieval was very quick, and can be done in 1-2 min. Through this platform, a total of **1214** HNC patients were collected, followed and analysed during the study period. **Conclusion** It was feasible to establish a Head and Neck Cancer Registry using an AI based smartphone app. This AI based tumor registry could benefit in further studies with longer follow up of 5 and 10 years and in future AI studies.

Keywords Head and neck cancer registry · Artificial intelligence · Oral cancer · Indian cancer registry · App. based cancer registry

Introduction

More than 6,00,000 patients worldwide are newly diagnosed with head and neck cancer (HNC) annually (1). As per the Global Cancer Statistics 2018: GLOBOCAN, new cases of Lip and oral cavity cancers in 2018, is 354,864 (2.0% of all sites), with 177,384 (1.9% of all sites) deaths related to this cancer subsites (2). HNC is becoming a major public health problem in India. Overall, 57.5% of the global HNC patients occur in Asia especially in India in both sexes (3).

A cancer registry is an essential part of any rational program of cancer control, benefiting both the individual and society in which he lives. However, establishing and maintaining a cancer registry in a tertiary high volume centre is fraught with difficulty, inaccuracy and missed data entry. Crunched time due to the busy out patient department (OPD) schedule and requirement of extra resources, in the form of manpower and equipments have made it very demanding to set up a registry in the OPD, where the data are available

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from the patient themselves and real time data entry and checking is possible (4,5).

Further, this raw unstructured data must be converted into a structured digital data, so that scientists can identify trends in cancer diagnoses and treatment responses. This may only become possible through manual extraction by clinical teams. However, the amount of human resources consumed by manually abstracting data often results in a cumbersome, costly, and error-prone process, especially as patient data grow exponentially in volume (6).

To address these limitations, organizations are turning to artificial intelligence (AI) to automate data abstraction. Leveraging AI to populate clinical registries can (7):

- **Provide high-quality, accurate, complete data**: AI can handle more unstructured data, from more sources, and translate them quicker, with greater accuracy than humans by using methods such as natural language processing (NLP).
- **Allow better investment of time and resources**: Using human resources for updating registries, clinical abstraction and other related processes put a strain on an organization's resources. Automating data abstraction frees up clinicians' time to focus on caring for their patients and quality initiatives to improve patient care overall.

In a bid to increase the efficiency, reliability and dynamism of registration without the necessity of undue extra resources, several authors have reported on the use of electronic devices including novel mobile based applications for data capture, follow ups and monitoring of patients' outcomes (8–10). However, no literature was found on the use of a smartphone applications for the establishment and maintenance of a Head and Neck cancer registry.

Objective

Against this background we attempted to test the feasibility of establishing a cancer registry of Head and Neck malignancy patients attending the Otorhinolaryngology and Head & Neck Surgery OPD at PGIMER, Chandigarh, through a research oriented AI enabled data collection platform, using its smartphone app version. The registry would be in the form of a structured, dynamic data and stored in cloud and would be easily accessible.

Materials and Methods

This prospective observational study was conducted in the Department of Otolaryngology & Head and Neck Surgery, Post Graduate Institute of Medical Education And Research, Chandigarh in collaboration with Department of Radiotherapy and Community Medicine. After taking due clearance from the Institute ethical committee, HNC patients, who were biopsy proven, were enrolled from October 2019 up to March 2021. The WHO Guidelines for cancer registration was strictly followed (11). All the selected patients underwent a thorough history and clinical examination. Diagnosis and staging of the disease were made on the basis of the pretreatment his topathological (HPE) reporting of the primary lesion and Fine needle aspiration cytology (FNAC) of neck nodes, along with appropriate imaging, as per the 8th edition AJCC cancer-TNM staging system (12). The patients were planned for the most appropriate management protocol at the multidisciplinary tumour clinic. Patients who received some form of definitive treatment during the study period were followed upto June 2021 at 3, 6 and 9 months, to study the comparative impact of different modalities of therapy provided in various parameters viz., overall survival (OS), primary site and neck node recurrences, distant metastasis, complications and any further treatment given.

The obtained data was entered in Jiyyo Research application(13) which is a commercially available dedicated research oriented artificial intelligence enabled data collection platform. In this system one can:

- create and manage proforma securely.
- Upload Patient's consent form or register a patient's mobile number via OTP.
- Collect data as free text, numbers, dropdown, radio buttons, checkbox and date etc.
- Combine the related questions in group.
- Show/hide questions based on user response, no unnecessary question is shown to the user if not applicable.
- Fill the proforma from www.jiyyo.com or using Jiyyo Android apps.
- The entered data become automatically structured data.
- Easy follow up of patients, through search facility and incorporated linked personalized reminder system.
- Control the access of the proforma.
- Download as PDF and print proforma.
- Download the collected data in excel format anytime with flexibility as per the data.
- Analyse the exported data on laptop.
- It was a complete paperless procedure.

The assessment of completeness was monitored, through comparison with other sources, like the Tumour clinic

Fig. 1 **(a)** Jiyyo application screenshots showing the homepage, with call pending status for follow up. **(b)** Page showing multiple options, which allows a single tick to enter the appropriate data i.e. Presenting complaint
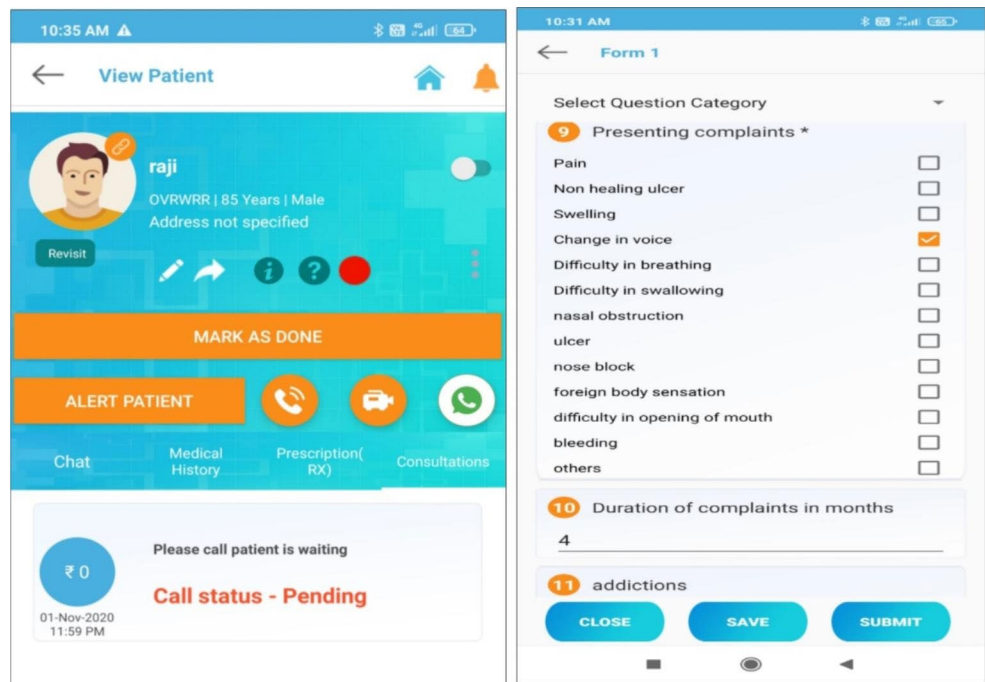
registry, operation theatre register, admission register and registers from the Department of Radiotherapy and oncology. There was regular presentations of the data at the department meetings to assess the completeness and the accuracy of the details. All reports were checked immediately, and any errors were corrected, while the original records were still available to us.

Data analysis were carried out with the help of IBM-SPSS software version 26, after the datas were downloaded in Excel format from the Jiyyo platform. The findings were analyzed with tabulations, graphs, proportions and ratios to see the various associations. Survival analysis was done through Kaplan Meier method.

Results

The Jiyyo Research site was browsed and after proper registration, an account was set up, following which the proforma/questionnaire was made online. The proforma was made in a way that, the collected data can be entered as free text, numbers, dropdown, radio buttons, checkbox and date etc., according to their suitability. These allowed the segregation of the types of data that were entered, viz. single option question like male or female, were just entered with a tick, or multiple options question like types of symptoms or surgeries, could be entered with multiple ticks (Fig 1, Fig 2 and Fig 3). The app also showed us if any essential question had been left unanswered, thus allowing the entry of a complete data (Fig 2b). The data entered through the app became automatically structured, and complete, so further

interpretation and evaluation was easy. Further data capture was done using the Jiyyo Research application available in smartphones.

The entered patient details were browsed for review, follow up and addition of new information. This facility allowed to check whether the same patient had been entered more than once, thus preventing duplication of data (Fig 3a,b). The data entry was done online and got stored in the cloud, from which retrieval was easy and convenient. The use of username and password means that the account and the information can accessed only by authorised persons, thus data security is ensured. The reminder facility included in the system allowed us to keep track of the follow up timeline by reminding the exact date of the patient's appointment (Fig 1a). The duration, it took for the different activities to be carried out viz. data capture, updates and rectification, retrieval and transfer of data were assessed. The whole process of data capture for each patient, took approximately 5-8 min, while any updates or review for the same patient required less than a minute. Search and data retrieval was very quick, and can be done in 1-2 min. Also transfer of data was done online in a matter of seconds.

The patients were demonstrated on how to download the software in their smartphone and how to use it. Once the app is downloaded, they were able to see there appointment dates, and thus plan ahead for visits, do phone calls and messaging via WhatsApp to us. Many patients, however were not able to use the software to its full extent, due to illiteracy and being in lower social economic group. This, however did not hinder the process of follow up as we were

Fig. 2 a. Screenshots showing the entry of details in multiple options. **b.** The highlighted heading is showing that the answer for this question is pending
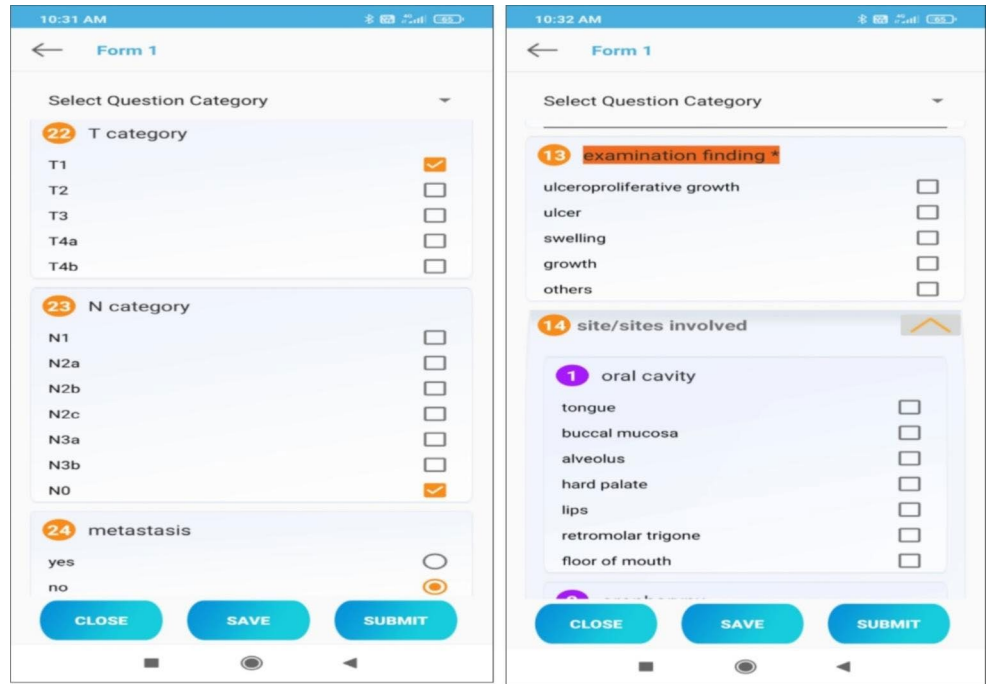

Fig. 3 (a) Screenshot showing the homepage with options to enter a new patient or to see the entered patients' data. **(b)** Patients already entered are shown, and the details of each patient can be seen
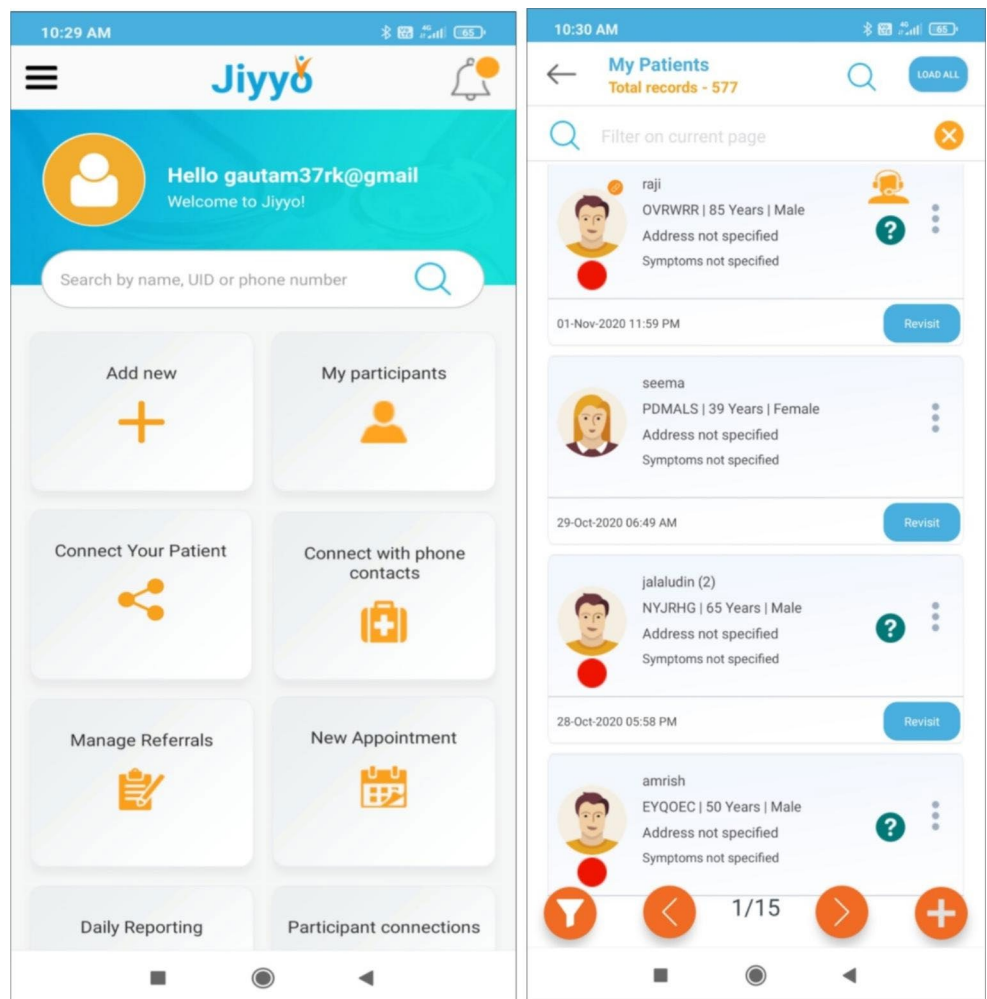
Table 1 WHO classification of patients in cancer registry

Group 1 (Diagnosed and treated at PGI)	190
Group 2 (Diagnosed at PGI but some treatment outside)	421
Group 3 (Diagnosed outside but treatment at PGI)	218
Group 4 (Only supportive care at PGI)	12
Group 5 (Registered before the study period)	373
Total	1214

Table 2 Patient Characteristics

Characteristics	Overall n = 1214	Male n = 935	Female n = 279
1. Age			
Median (SD)	55 (13.6)	55 (13.4)	50 (14.8)
Range	3–94	5–94	3–85

Table 3 State wise distribution of the patients

State	No. of Patients	Percentage
Chandigarh	89	7.33
Haryana	296	24.38
Himachal Pradesh	153	12.60
Punjab	267	21.99
Uttar Pradesh	113	9.31
Not available	220	18.12
Others	76	6.26
Total	1214	

able to call and remind them for requisite visits as well as do teleconsultation during the Covid-19 pandemic lockdowns.

Through this data mobile collection platform, a total of **1214** participants were collected during the study period. the HNC patients were categorized into WHO groups 1,2,3,4 and 5. The patients in group 1,2 and 3 i.e. 829 patients were followed up and included in the analytical studies as per WHO registry guidelines(11). Group 4 and 5 i.e. 385 patients were included to see the disease burden at the institute. (Tab 1)

Out of the total Head and Neck cancer patients of 1214, maximum number were in the age group 55-65 years, with male to female ratio of 3.35:1 (Tab 2). The maximum number of patients hailed from Haryana state with 296 patients, followed by Punjab with 267 patients and Himachal Pradesh with 153 patients (Tab 3).

Discussion

Machine Learning and its subfield Deep Learning which are concerned with algorithms along with the increasing availability of health related data is improving the impact of AI on health care. Gupta et al. (14) applied machine learning techniques on information from a cancer database and the electronic data can be used to predict outcomes. Most importantly, the approach described makes use of digital data that is already routinely collected but underexploited by clinical health systems.

However, much of the raw data obtained from medical reports such as pathology, imaging, and genetic reports are trapped in unstructured text. Only through making this unstructured data into a structured digital cancer registry, scientists can use AI to identify trends in cancer diagnoses and treatment responses, which in turn can help guide research and public resources(6).

In this study, we used the Jiyyo research application, an AI based Mobile research platform to establish a HNC Registry. Through this platform, participants were enrolled and data entered in a paperless mode using a smartphone. During the busy OPD schedule, use of the smartphone for data capture was convenient, handy and time saving and data entry could be done on the go. The process of data capture for each patient took approximately 5-8 min, while any updates, follow up and review for the same patient required less than a minute. The patient follow up was also helped by the inbuilt reminder system. In comparison, manual entry of this data and manual search of each patient for review and follow up, was cumbersome, time consuming, error prone and required much more resources, both logistics and manpower.

The data was downloaded in excel format and analysis work was done. The captured data could be accessed and retrieved from anywhere anytime, through a username and password with encrypted security. Search and data retrieval was very quick, and can be done in 1-2 min. Also transfer of data was done online in a matter of seconds. All of these activities were done through the smartphone app. Otherwise, the same process, if done manually would require a visit to the Medical records department followed by a search for the desired file and transfer to an appropriate device, all of which took several minutes to hours.

Hambek et al. had developed a computer based oncology database of head and neck cancers, allowing the entry of 410 patients. He mentioned that, this allowed for an accurate and time efficient follow up and care of patients(8).

Two other studies were found, where smartphone apps were used to study patient self reporting and monitoring in cancers other than head and neck sites. Egbring et al. (9) used a novel electronic device, with both mobile and Web-based app versions to study the patients' own recording of disease- and medication-related symptoms in breast cancer patients undergoing chemotherapy. Trojan et al. (10) studied the use of a smartphone app called Consillium for monitoring patients of lung, prostate and urinary bladder carcinoma

and stated that it was convenient, with great patient participation. However, we did not come across any literature using such smartphone based research platform for establishing a Head and Neck Cancer Registry.

In our study, the established cancer registry showed great concordance with previous other larger registries, both at national and international level.

A Hospital Based Cancer Registry (HBCR) was started in our Institute from 1st January, 2011, and the data from this registry reflected similar findings with our registry. In contrast to our data, it had shown the most common HNC as Laryngeal Ca. (15) The more recent, population based National Cancer Registry Programme (NCRP) report, 2020, however showed that oral cavity was the commonest site of HNC, thus relating to our findings (16).

There was great similarities with other Indian HNC registries like the study on South Indian registry by Francis (17), Shenoi et al. (18), and Jaganath et al. (19) from Dr. B Borooah Cancer Institute, Guwahati.

The Head and Neck Cancer Registry of Japan Clinical Statistics of Registered Patients(20), 2016, showed many similar findings with our data, though there were some reflections of the differences in regional demography and epidemiology, as well as the differences in nomenclatures and practices. Similar observations were seen with the First Comprehensive Report of the Longitudinal Oncology Registry of Head and Neck Carcinoma (LORHAN), United States, for the year 2012 (21).

The number of HNC patients attending our OPD was affected by the Covid pandemic and complete lockdown. Physical OPD was shut down in March 2020, with no patients registered in OPD in April 2020. This were also experienced by several other HNC centres as published in two studies by Yuen et al. (22) and Tevetoglu et al. (23).

Our study was able to demonstrate the feasibility of establishing a Head and Neck Cancer registry of our institute through an Artificial Intelligence enabled smartphone research app. Through this registry we demonstrated a detailed demographic and epidemiological profile of the Head and Neck Cancer patients coming to our OPD.

Conclusion

Using an Artificial intelligence based Jiyyo research smartphone app, we were able to establish a Head and Neck Cancer Registry. Data capture was done easily in a paperless manner as well as the patient follow up could be done easily through the reminder system of this app. The data we obtained was found authentic, reliable and concurred with several reputed registries and was available for access and retrieval from anywhere anytime from the cloud. This AI based tumor registry can benefit in further studies with longer follow up of 5 and 10 years survival and mortality rates and also in future AI studies.

The limitations of our study was the lesser number of patients attending our OPD during the period of Covid-19 pandemic and lockdowns, due to which we were not able to assess the app in the normal precovid scenario for a few months. Furthermore, the annual existing tumour burden of the Institute varied due to the Covid-19 pandemic. Another limitation was that this AI based app could not be used by many patients due to illiteracy and poverty, depriving us of testing the full potential of this novel data collecting platform.

Declarations