Data Archiving of Genome Sequencing and Medical Records of Radioiodine-Treated Differentiated Thyroid Carcinoma Patients at NINMAS since 1980: A Continuing Initiative

[1]Jasmin Ferdous, [2]Papia Akhter, [3]Md. Sajjad-Al-Mishal, [2]Urnas Islam, [4]A.K.M. Fazlul Bari, [5]Fatima Begum

[1]Associate Professor, National Institute of Nuclear Medicine & Allied Sciences (NINMAS)
[2]Assistant Professor, NINMAS
[3]Medical Officer, NINMAS
[4]Head of Thyroid Division and Director, NINMAS
[5]Senior Consultant & Head, Department of Nuclear Medicine, Continental Hospital PLC

Correspondence Address: Dr Jasmin Ferdous, Associate Professor, NINMAS, Block-D, BMU Campus, Shahbag, Dhaka-1000.
Email: jasmin.ferdous.aelee@gmail.com.

ABSTRACT

Differentiated thyroid carcinoma (DTC) is among the most prevalent endocrine malignancies, with a rising global incidence. Since 1980, the Thyroid Division of the National Institute of Nuclear Medicine and Allied Sciences (NINMAS), Bangladesh Atomic Energy Commission (BAEC), has been treating DTC patients with Radioactive Iodine Therapy (RAIT) following thyroidectomy and maintaining lifelong follow-up. To date, over 9,000 patients have received RAIT, generating a vast volume of medical records that have been preserved exclusively as hardcopies, creating significant space and retrieval challenges. This project aims to digitally archive both medical records and BRAF mutation genomic sequencing data of all radioiodine-treated DTC patients, encompassing records from 1980 to the present. Approximately 4,000 patient records have been digitized so far, using dedicated software, specialized hardware, and individual patient ID systems. Among them, 15 high-risk patients underwent BRAF gene sequencing, of which 10 tested positive. Digital archiving has demonstrably improved clinical efficiency, enabling faster data retrieval, better longitudinal patient management, and a robust foundation for future oncological research. Continuation of this initiative will ensure comprehensive registration of all remaining DTC patients.

Keywords: Differentiated thyroid cancer, Genome sequencing, Medical records, Radioiodine, BRAF gene, NINMAS.

Bangladesh J. Nucl. Med. Vol. 28 No. 2 July 2025

DOI: https://doi.org/10.3329/bjnm.v28i2.89124

INTRODUCTION

Thyroid carcinoma is the most common endocrine malignancy worldwide, with its incidence rising steadily over the past three decades (1). Differentiated Thyroid Carcinoma (DTC), encompassing papillary thyroid carcinoma (PTC) and follicular thyroid carcinoma (FTC), accounts for approximately 90% of all thyroid cancers and is associated with favorable long-term outcomes, with five-year survival rates exceeding 95% (2). However, effective long-term management demands meticulous, longitudinal follow-up spanning decades. In Bangladesh, the National Institute of Nuclear Medicine and Allied Sciences (NINMAS), operating under the Bangladesh Atomic Energy Commission (BAEC), has served as the principal center for radioactive iodine therapy (RAIT) in DTC patients since 1980 (3). Over this period, more than 9,000 new DTC patients have received RAIT following thyroidectomy, generating an extensive corpus of clinical records preserved exclusively in hardcopy format. This analog archiving system, while operationally maintained, has become increasingly unsustainable due to physical space constraints and inefficiencies in data retrieval.

Parallel advances in oncogenomics, particularly the identification of somatic mutations such as BRAF V600E in PTC, have introduced new diagnostic and prognostic dimensions to DTC management (4, 5). BRAF mutation status has been shown to correlate with increased risk of recurrence, extrathyroidal extension, lymph node metastasis, and radioiodine resistance (6). Integrating genomic data with longitudinal clinical records therefore represents a critical advancement in precision oncology for thyroid cancer. This report describes the ongoing project of digital archiving of medical records and BRAF genomic sequencing data at the Thyroid Division, NINMAS, highlighting the outcomes achieved to date,

the clinical and research implications, and the future directions of this initiative.

METHODS

As of April 2024, a total of 9004 new DTC patients have received RAIT. Among them, about 18% of the patients received repeated doses. Huge data of all those patients have been archived as hard copies in the medical records room, and there are overflowing files of patients in the medical records room and no spaces on the shelves.

Huge data of all the registered DTC patients had been archived as hard copies in the medical records room. The old data is required to follow up with the patients. All we have been doing is pulling files manually for the benefit of the patients and maintaining the legacy of old data. We physicians are facing huge pressure to treat and archive the data in hard copies. There is also scarcity of spaces. Software data storage of genetic information and other medical information of any cancer is the time-demanding issue. This data archiving is of immense help in retrieving data for the patient for routine consultation. Patients' past history could be judged easily, and clinical correlation would be easier and faster. Genetic analysis is a recent advancement in the diagnosis of cancer and has an impact on treatment strategy, especially in thyroid carcinoma. It has been available in the private sector of Bangladesh for the last 5-6 years on a small scale. By this project, genetic information and medical records are preserved digitally for long-term use, facilitating smarter patient management and further research purposes.

Figure 1: Current Archive room; where blue files are for thyrotoxic and red files are for DTC patients. Files are arranged according to date, month and year sequentially. Each file has definite code number.

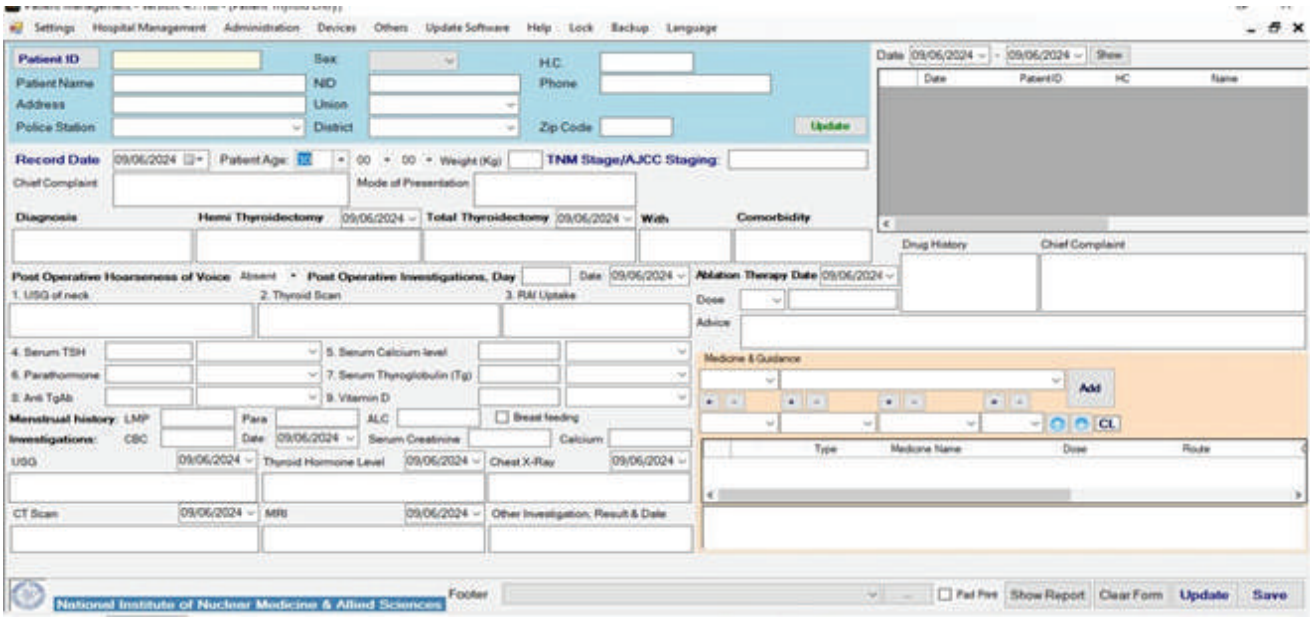

Figure 2: Software interface history documents that track the evolution and updates of software applications, detailing changes in functionality, user interface improvements and system integration over time.

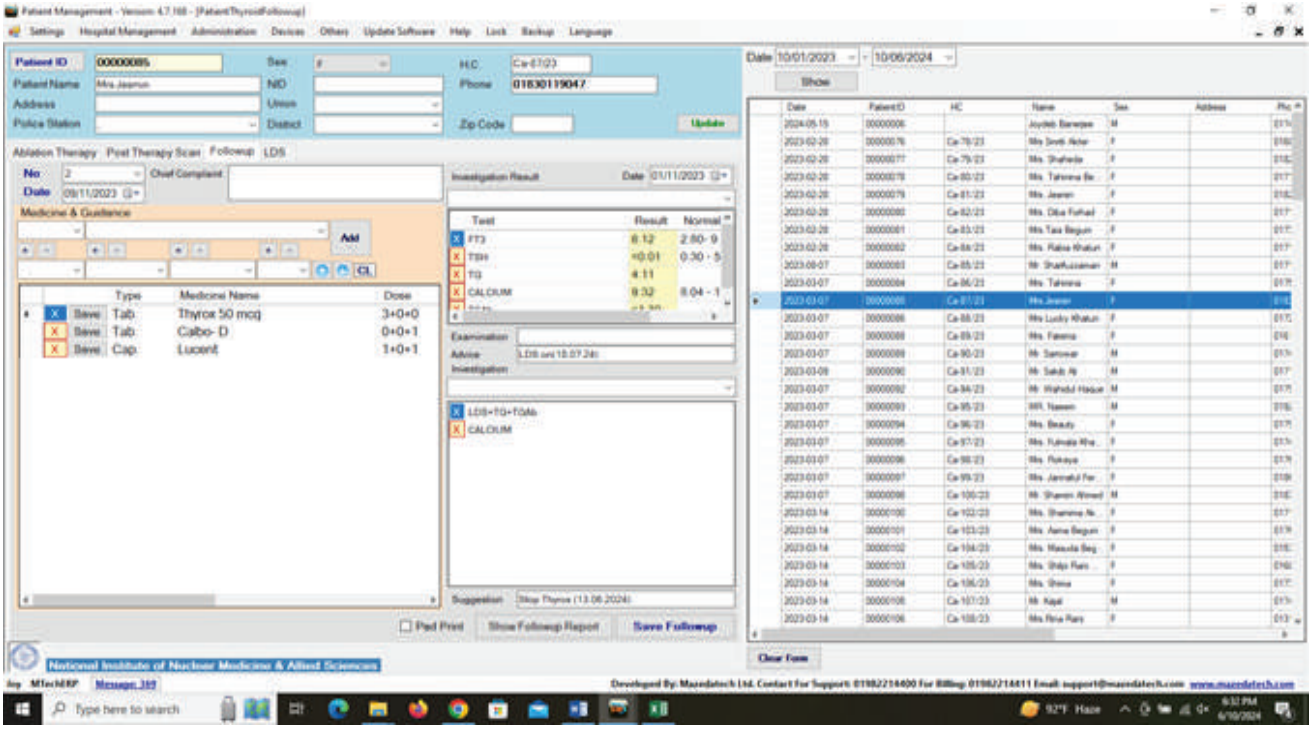

Figure 3: Software interface- Follow up form.

OUTCOME

1. Infrastructure and Software Development

The procurement and installation of two dedicated PCs, a high-resolution scanner, a laser printer, and a UPS at the Thyroid Division, NINMAS, established the foundational hardware infrastructure for this archiving initiative. A bespoke relational database software was developed and deployed, capable of accommodating multi-layered clinical, biochemical, radiological, histopathological, and genomic data fields (7). The software was designed with a modular architecture, allowing IT personnel to continuously update and expand data fields in response to evolving clinical needs. The user interface was tailored to the workflow of nuclear medicine physicians, minimizing data entry time while maximizing data completeness.

2. Patient Registration and Data Entry

As of the reporting period, data entry has been successfully completed for approximately 4,000 DTC patients. Each patient record contains a comprehensive clinical dossier, including demographic identifiers; complete surgical history with dates and operative findings; histopathological reports with tumor staging (TNM classification); pre- and post-operative thyroid function tests, including TSH, free thyroxine (FT4), free triiodothyronine (FT3), serum thyroglobulin (Tg), and TgAb levels at each follow-up interval; radioiodine dose administered (MBq/mCi); post-therapy whole-body radioiodine scan (WBS); diagnostic WBS; neck ultrasonography reports; all relevant cross-sectional imaging (CT, MRI, PET CT); and other relevant medical investigations and procedures. Each entry is time-stamped and linked to the patient's unique ID, enabling longitudinal tracking of disease status across decades of follow-up. This individual-level longitudinal data architecture mirrors internationally recommended standards for thyroid cancer registries, as advocated by the American Thyroid Association (ATA) and the European Thyroid Association (ETA) (8, 9).

3. BRAF Genomic Sequencing Results

Among the 4,000 registered patients, 15 individuals classified as high-risk DTC (based on ATA risk stratification criteria including extrathyroidal extension, lymph node metastasis, vascular invasion, or aggressive histological variants) were selected for BRAF V600E mutation analysis (10). Histopathological tissue samples were submitted for sequencing, and results revealed that 10 out of 15 patients (66.7%) were BRAF V600E-positive.

OUTCOME

1. Infrastructure and Software Development

The procurement and installation of two dedicated PCs, a high-resolution scanner, a laser printer, and a UPS at the Thyroid Division, NINMAS, established the foundational hardware infrastructure for this archiving initiative. A bespoke relational database software was developed and deployed, capable of accommodating multi-layered clinical, biochemical, radiological, histopathological, and genomic data fields (7). The software was designed with a modular architecture, allowing IT personnel to continuously update and expand data fields in response to evolving clinical needs. The user interface was tailored to the workflow of nuclear medicine physicians, minimizing data entry time while maximizing data completeness.

2. Patient Registration and Data Entry

As of the reporting period, data entry has been successfully completed for approximately 4,000 DTC patients. Each patient record contains a comprehensive clinical dossier, including demographic identifiers; complete surgical history with dates and operative findings; histopathological reports with tumor staging (TNM classification); pre- and post-operative thyroid function tests, including TSH, free thyroxine (FT4), free triiodothyronine (FT3), serum thyroglobulin (Tg), and TgAb levels at each follow-up interval; radioiodine dose administered (MBq/mCi); post-therapy whole-body radioiodine scan (WBS); diagnostic WBS; neck ultrasonography reports; all relevant cross-sectional imaging (CT, MRI, PET CT); and other relevant medical investigations and procedures. Each entry is time-stamped and linked to the patient's unique ID, enabling longitudinal tracking of disease status across decades of follow-up. This individual-level longitudinal data architecture mirrors internationally recommended standards for thyroid cancer registries, as advocated by the American Thyroid Association (ATA) and the European Thyroid Association (ETA) (8, 9).

3. BRAF Genomic Sequencing Results

Among the 4,000 registered patients, 15 individuals classified as high-risk DTC (based on ATA risk stratification criteria including extrathyroidal extension, lymph node metastasis, vascular invasion, or aggressive histological variants) were selected for BRAF V600E mutation analysis (10). Histopathological tissue samples were submitted for sequencing, and results revealed that 10 out of 15 patients (66.7%) were BRAF V600E-positive.

This positivity rate is consistent with published global data, where BRAF V600E mutation prevalence in PTC ranges from 29% to 83%, with higher rates observed in populations with aggressive or advanced-stage disease (11, 12). The identification of BRAF mutation in these high-risk patients has direct implications for: (a) prognostic stratification, that is, BRAF-positive patients carry a higher risk of disease recurrence, distant metastasis, and cancer-related mortality; (b) therapeutic decision-making, like BRAF mutation status may guide selection of patients for adjuvant therapies, including tyrosine kinase inhibitors (TKIs) such as vemurafenib or dabrafenib in refractory or metastatic settings; and (c) surveillance intensity, such that BRAF-positive patients may benefit from more frequent Tg monitoring and earlier cross-sectional imaging.

4. Clinical Benefits of Digital Archiving

The digitization of patient records has yielded measurable improvements in clinical workflow at the Thyroid Division. Physicians can now retrieve complete patient histories within seconds, compared to the several minutes previously required to manually locate and review hardcopy files. This has been particularly impactful during outpatient consultations, where time efficiency directly affects patient throughput and satisfaction (13). Furthermore, the digital system has enabled more accurate and timely clinical correlation. Physicians can simultaneously view serial Tg levels, radioiodine dose history, WBS reports, and genomic data, facilitating holistic assessment of disease trajectory. This integrated view supports risk-adapted management, where treatment intensity is tailored to individual patient risk profiles rather than uniform protocols.

5. Research and Epidemiological Value

The assembled digital dataset represents a unique and historically rich resource for thyroid cancer research in Bangladesh and South Asia. With records spanning over four decades (1980 to present), the database is uniquely positioned to support long-term epidemiological analyses of DTC

incidence trends, evaluation of RAIT efficacy across different histological subtypes and risk groups, pharmacovigilance studies examining late effects of high-cumulative-dose radioiodine, and genetic epidemiology studies exploring the relationship between BRAF mutation status and clinical outcomes in the Bangladeshi population (14,15). Such a dataset, once fully populated and validated, may also serve as a platform for multicenter collaborations with other INMASs under BAEC, enabling national-level thyroid cancer registry development, a priority highlighted by global cancer surveillance organizations such as the International Agency for Research on Cancer (IARC).

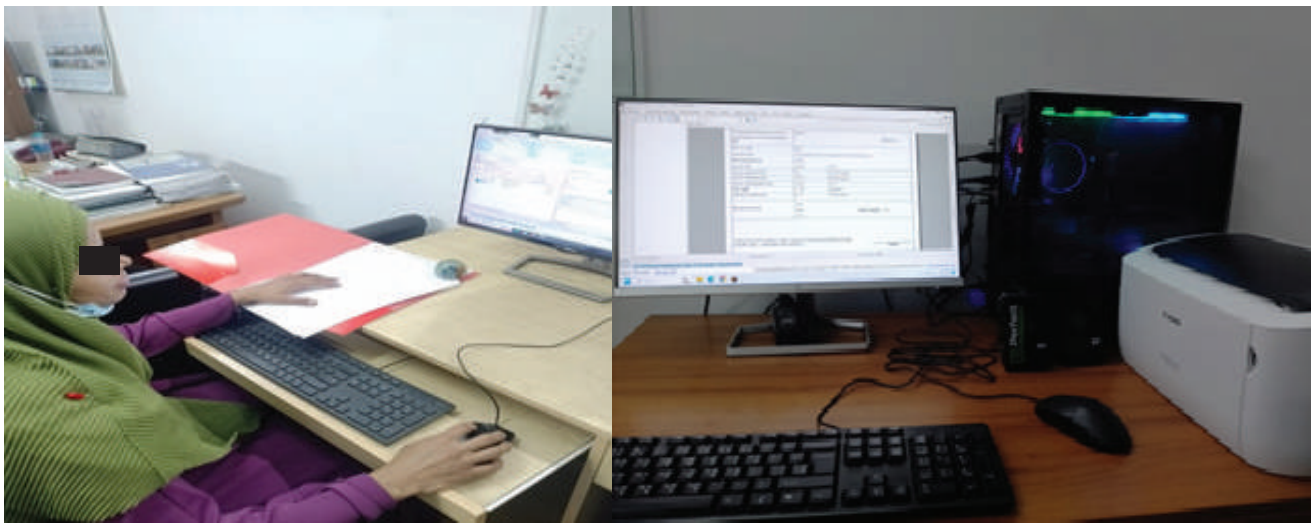

Figure 4: Thyroid division staff are responsible for entering data related to differentiated thyroid carcinoma patients

This initiative at NINMAS represents a landmark step in the modernization of oncology data management in Bangladesh and underscores the increasing recognition of electronic health records (EHRs) as indispensable tools in cancer care. The challenges faced are a backlog of over 40 years of hardcopy records, limited digital infrastructure, and the nascent availability of genomic testing, which are not unique to NINMAS but reflect systemic realities encountered by cancer centers in low- and middle-income countries (LMICs) worldwide (1, 7).

The Global Burden of DTC and the Importance of Long-Term Follow-Up

The incidence of DTC has increased globally by approximately 3% per annum over the past three decades, driven partly by advances in diagnostic imaging facilitating the detection of subclinical tumors and partly by a genuine rise in disease burden (2). DTC, despite its overall favorable prognosis, demands lifelong surveillance because recurrence can occur decades after initial treatment (3). The 2015 ATA Guidelines and the ETA Guidelines both emphasize risk-adapted, long-term follow-up as the cornerstone of DTC management, necessitating longitudinal data systems capable of tracking patients across extended time horizons (8, 9). Manually maintained records, as previously employed at NINMAS, are inherently vulnerable to physical deterioration, misplacement, and loss of risks that are entirely eliminated through digital archiving.

Electronic Health Records in Oncology: Evidence and Impact

The transition from paper-based to electronic record systems in oncology has been associated with significant improvements in clinical efficiency, data accuracy, and patient safety (13). Studies from resource-limited settings comparable to Bangladesh have demonstrated that EHR implementation reduces documentation errors by up to 60%, decreases time-to-treatment decisions, and enhances multidisciplinary communication (7). In the context of thyroid cancer, where management decisions hinge on precise serial measurements of FT3, TSH, Tg, and TgAb often across years of follow-up, the availability of structured, easily retrievable longitudinal data is not

This initiative at NINMAS represents a landmark step in the modernization of oncology data management in Bangladesh and underscores the increasing recognition of electronic health records (EHRs) as indispensable tools in cancer care. The challenges faced are a backlog of over 40 years of hardcopy records, limited digital infrastructure, and the nascent availability of genomic testing, which are not unique to NINMAS but reflect systemic realities encountered by cancer centers in low- and middle-income countries (LMICs) worldwide (1, 7).

The Global Burden of DTC and the Importance of Long-Term Follow-Up

The incidence of DTC has increased globally by approximately 3% per annum over the past three decades, driven partly by advances in diagnostic imaging facilitating the detection of subclinical tumors and partly by a genuine rise in disease burden (2). DTC, despite its overall favorable prognosis, demands lifelong surveillance because recurrence can occur decades after initial treatment (3). The 2015 ATA Guidelines and the ETA Guidelines both emphasize risk-adapted, long-term follow-up as the cornerstone of DTC management, necessitating longitudinal data systems capable of tracking patients across extended time horizons (8, 9). Manually maintained records, as previously employed at NINMAS, are inherently vulnerable to physical deterioration, misplacement, and loss of risks that are entirely eliminated through digital archiving.

Electronic Health Records in Oncology: Evidence and Impact

The transition from paper-based to electronic record systems in oncology has been associated with significant improvements in clinical efficiency, data accuracy, and patient safety (13). Studies from resource-limited settings comparable to Bangladesh have demonstrated that EHR implementation reduces documentation errors by up to 60%, decreases time-to-treatment decisions, and enhances multidisciplinary communication (7). In the context of thyroid cancer, where management decisions hinge on precise serial measurements of FT3, TSH, Tg, and TgAb often across years of follow-up, the availability of structured, easily retrievable longitudinal data is not merely a convenience but a clinical necessity.

The NINMAS digital archiving system, with its individual patient ID structure and multi-domain data fields, aligns with the architecture of validated oncology electronic registries such as the Surveillance, Epidemiology, and End Results (SEER) database in the United States and the Thames Cancer Registry in the United Kingdom (14). While the current system remains in its developmental phase, the framework established here can serve as a prototype for broader national adoption across all INMASs under BAEC.

BRAF Mutation in DTC: Clinical and Prognostic Implications

The BRAF V600E mutation is the most identified somatic mutation in PTC, identified in approximately 29–83% of cases depending on the population studied and the methodology employed (4,11). It results from a thymine-to-adenine transversion at nucleotide 1799 of the BRAF gene, producing a constitutively active kinase that drives tumour proliferation through the MAPK/ERK signalling pathway (5). In the present cohort, the BRAF positivity rate of 66.7% among high-risk DTC patients is broadly concordant with data from Asian populations, where BRAF mutation prevalence in PTC is generally reported to be higher (50–80%) compared to Western cohorts (40–60%) (12). This elevated prevalence in Asian populations may reflect both biological differences and referral bias toward higher-risk cases. The clinical significance of BRAF mutation identification at NINMAS extends across multiple dimensions:

First, prognostically, BRAF V600E-positive PTC has been associated with significantly higher rates of extrathyroidal extension, lymph node and distant metastasis, and cancer-related mortality. A large meta-analysis by Xing et al. involving over 2,000 PTC patients demonstrated that BRAF mutation was an independent predictor of recurrence (OR 1.93, 95% CI 1.37–2.71) (6). In a resource-constrained setting such as NINMAS, where post-treatment surveillance resources may be limited, BRAF status can serve as a rational triage tool to intensify monitoring in high-risk, mutation-positive individuals.

Second, therapeutically, BRAF V600E status has emerged as a predictive biomarker for response to targeted therapies.

Vemurafenib and dabrafenib, selective BRAF inhibitors, have demonstrated clinical activity in BRAF-mutated, radioiodine-refractory DTC in phase II and III trials (10). As access to targeted oncological therapies gradually expands in Bangladesh, the availability of prospectively collected BRAF mutation data will be essential for identifying patients who may benefit from these agents.

Third, from a public health perspective, the accumulation of BRAF data across a large, ethnically homogeneous Bangladeshi DTC cohort will contribute meaningfully to understanding the genetic epidemiology of thyroid cancer in South Asia, a region underrepresented in global genomic databases such as The Cancer Genome Atlas (TCGA) (15).

Challenges and Future Directions

Despite significant accomplishments, challenges remain in the digitisation of over 9,000 patient records, necessitating ongoing human resources, training, and quality assurance. Current throughput of about 4,000 entries underscores the ongoing effort. Expanding genomic testing to include additional mutations could enhance the dataset's scientific value. Furthermore, ensuring patient data anonymisation and compliance with data protection laws is crucial for confidentiality. Future integration with a national thyroid cancer registry could facilitate multi-institutional research and improve epidemiological studies; while linking to national mortality databases would address current gaps in literature regarding cause-specific survival outcomes in Bangladesh.

CONCLUSION

The ongoing digital archiving of medical records and BRAF genomic sequencing data at the Thyroid Division, NINMAS, represents a transformative initiative in the management and research of differentiated thyroid carcinoma in Bangladesh. With over 4,000 patient records successfully digitized and a BRAF V600E positivity rate of 66.7% identified among high-risk patients, the project has already demonstrated its clinical utility and research potential. Continued investment in this initiative through expanded genomic testing, enhanced software capabilities, and inter-institutional collaboration will establish NINMAS as a center of excellence in the data of thyroid oncology, ultimately improving patient outcomes and advancing scientific knowledge in this field.

CONFLICT OF INTEREST

Authors have no financial, personal, or professional conflicts that could inappropriately bias this work.

REFERENCES

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2021;71(3):209–249.

2. Lim H, Devesa SS, Sosa JA, Check D, Kitahara CM. Trends in thyroid cancer incidence and mortality in the United States, 1974–2013. JAMA. 2017;317(13):1338–1348.

3. Islam N, Hossain S, Rahman A, Begum R. Pattern of differentiated thyroid carcinoma and its management at NINMAS, Dhaka, Bangladesh: a retrospective study. Bangladesh J Nucl Med. 2015;18(1):14–19.

4. Xing M. BRAF mutation in thyroid cancer. Endocr Relat Cancer. 2005;12(2):245–262.

5. Nikiforov YE, Nikiforova MN. Molecular genetics and diagnosis of thyroid cancer. Nat Rev Endocrinol. 2011;7(10):569–580.

6. Xing M, Alzahrani AS, Carson KA, Viola D, Elisei R, Bendlova B, et al. Association between BRAF V600E mutation and mortality in patients with papillary thyroid cancer. JAMA. 2013;309(14):1493–1501.

7. Fraser HS, Blaya J. Implementing electronic medical record systems in developing countries. J Innov Health Inform. 2010;18(2):83–88.

8. Haugen BR, Alexander EK, Bible KC, Doherty GM, Mandel SJ, Nikiforov YE, et al. 2015 American Thyroid Association management guidelines for adult patients with thyroid nodules and differentiated thyroid cancer. Thyroid. 2016;26(1):1–133.

9. Filetti S, Durante C, Hartl D, Leboulleux S, Locati LD, Newbold K, et al. Thyroid cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. Ann Oncol. 2019;30(12):1856–1883.

10. Brose MS, Nutting CM, Jarzab B, Elisei R, Siena S, Bastholt L, et al. Sorafenib in radioactive iodine-refractory, locally advanced or metastatic differentiated thyroid cancer: a randomised, double-blind, phase 3 trial. Lancet. 2014;384(9940):319–328.

11. Li C, Lee KC, Schneider EB, Zeiger MA. BRAF V600E mutation and its association with clinicopathological features of papillary thyroid cancer: a meta-analysis. J Clin Endocrinol Metab. 2012;97(12):4559–4570.

12. Kim TH, Park YJ, Lim JA, Ahn HY, Lee EK, Lee YJ, et al. The association of the BRAF(V600E) mutation with prognostic factors and poor clinical outcome in papillary thyroid cancer: a meta-analysis. Cancer. 2012;118(7):1764–1773.

13. Campanella P, Lovato E, Marone C, Ricciardi W, Specchia ML. The impact of electronic health records on healthcare quality: a systematic review and meta-analysis. Eur J Public Health. 2016;26(1):60–64.

14. Dasgupta P, Baade PD, Aitken JF, Ralph N, Chambers SK, Dunn J. Geographical variations in prostate cancer outcomes: a systematic review of international evidence. Front Oncol. 2019;9:238.

15. Cancer Genome Atlas Research Network. Integrated genomic characterization of papillary thyroid carcinoma. Cell. 2014;159(3):676–690.