

The Brazilian Data Managers Working Group: a 10-year grassroots initiative for the development of the national hematopoietic cell transplantation and cellular therapy registry

Cinthy Corrêa da Silva^{1*} , Heliz Regina Alves das Neves² , Anderson João Simione³ , Alayne Magalhães Trindade Domingues Yamada⁴ , Antonio Vaz Macedo⁵ , Afonso Celso Vigorito⁶ , Vanessa Aparecida do Nascimento Varjão⁷ , Flavia Ferreira da Costa^{1,8} , Adriana Mendes de Quadros Cavilha² , Monique Ammi⁹ , Nelson Hamerschlak¹ , Vergilio Antonio Rensi Colturato³ , Adriana Seber^{7,10,11} , Carmen Silvia Vieitas Vergueiro¹¹ , Simone Ojima Ferreira⁸ , Andreia Ribeiro de Almeida¹² , Vaneuza Araújo Moreira Funke^{2,13} , Ricardo Pasquini^{2,13} , Carmem Maria Sales Bonfim¹⁴ , Paula Moreira da Silva Sabaini¹⁵ , Rosana Rocha Concilio¹⁶ , Joaquim Gasparini¹⁷ , Bruna Letícia da Silva Santos Geraldo¹⁸ , Leonardo Jun Otuyama¹ , Luiz Carlos da Costa Junior¹⁹ , Eliana Cristina Martins Miranda⁶ , Fernando Barroso Duarte^{20,21} , Beatrice Araújo Duarte²² , Marcelo C. Pasquini²³ 

1. Hospital Israelita Albert Einstein  – São Paulo (SP), Brazil.
2. Universidade Federal do Paraná  – Hospital de Clínicas – Curitiba (PR), Brazil.
3. Hospital Amaral Carvalho  – Jaú (SP), Brazil.
4. Instituto D’Or de Pesquisa e Ensino  – Rio de Janeiro (RJ), Brazil.
5. Hospital da Polícia Militar – Belo Horizonte (MG), Brazil.
6. Universidade Estadual de Campinas  – Campinas (SP), Brazil.
7. Grupo de Apoio ao Adolescente e à Criança com Câncer  – São Paulo (SP), Brazil.
8. Hospital Sírio-Libanês  – São Paulo (SP), Brazil.
9. Center for International Blood and Marrow Transplant Research – Minneapolis (MN), United States.
10. Hospital Samaritano Higienópolis – Rede Americas  – São Paulo (SP), Brazil.
11. Associação da Medula Óssea do Estado de São Paulo – São Paulo (SP), Brazil.
12. Hospital Municipal Souza Aguiar  – Rio de Janeiro (RJ), Brazil.
13. Hospital Nossa Senhora das Graças  – Instituto Pasquini – Curitiba (PR), Brazil.
14. Instituto de Pesquisa Pelé Pequeno Príncipe – Hospital Pequeno Príncipe – Curitiba (PR), Brazil.
15. Hospital de Câncer de Barretos  – Barretos (SP), Brazil.
16. Beneficência Portuguesa de São Paulo  – São Paulo (SP), Brazil.
17. Universidade de São Paulo  – Faculdade de Medicina – Hospital das Clínicas – São Paulo (SP), Brazil.
18. Hospital Moinhos de Vento  – Porto Alegre (RS), Brazil.
19. Instituto Nacional de Câncer  – Rio de Janeiro (RJ), Brazil.
20. Hospital Universitário Walter Cantídio  – Fortaleza (CE), Brazil.
21. Monte Klinikum Hospital – Fortaleza (CE), Brazil.
22. Universidade Federal de São Paulo  – São Paulo (SP), Brazil.
23. Cleveland Clinic  – Cleveland (OH), United States.

*Corresponding author: cinthya.silva@einstein.br

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ABSTRACT

Hematopoietic cell transplantation is a data-driven field, and reporting to outcomes registries has become a common practice worldwide. However, comprehensive transplant data collection requires dedicated professionals who can accurately capture data, follow international guidelines, and maintain reliable databases for the evaluation of transplant outcomes. This article describes the development and evolution of the Brazilian Data Managers Working Group (GTGD) and its contributions to professional education, collaborative networking, registry implementation, data quality improvement, and scientific engagement in hematopoietic cell transplantation and cellular therapy in Brazil. The transition from single-center reporting to the establishment of a national transplant registry required collaboration among centers, partnership between the Brazilian Society of Cellular Therapy and Bone Marrow Transplantation (SBTMO) and the Center for International Blood and Marrow Transplant Research (CIBMTR), and the development of the GTGD to ensure the sustainability of this effort. The GTGD originated from a grassroots collaboration among data managers and transplant centers seeking to address limited professional recognition, inconsistent reporting practices, and restricted access to specialized training. Supported by collaboration with the SBTMO and CIBMTR, the initiative evolved into a nationally coordinated network. Over the decade, the GTGD promoted structured education, knowledge sharing, professional development, operational support, standardized data-management practices, quality-improvement initiatives, and scientific collaboration. In parallel, participation in the national multicenter protocol expanded to 95 centers, with 51 centers reporting data to the CIBMTR by 2025. The group also developed educational resources, supported benchmarking and cellular therapy reporting, strengthened national and international collaboration, and increased the visibility and professional identity of data managers within transplant programs. This experience demonstrates how coordinated engagement, continuous education, institutional collaboration, and professional advocacy can contribute to the development of national registry infrastructure and the generation of reliable real-world evidence in hematopoietic cell transplantation and cellular therapy.

Keywords: Hematopoietic cell transplantation; Registries; Data management; Brazil.

INTRODUCTION

Hematopoietic cell transplantation (HCT) is a key therapeutic modality in the management of several malignant and non-malignant disorders, providing potentially curative outcomes and substantial improvements in patients' quality of life¹.

In Brazil, the first HCT was performed in 1979 at Hospital de Clínicas da Universidade Federal do Paraná (HC-UFPR)^{2,3}. In subsequent decades, Brazilian centers began contributing data to the international registry, then known as the International Bone Marrow Transplant Registry (IBMTR)^{4,5}.

Since then, there has been a marked expansion in the number of HCT centers in the country. The use of an international cord blood graft in 1993 and an unrelated donor in 1995 represented important steps in increasing donor availability and enabling transplantation for a broader patient population⁶. The Brazilian Volunteer Unrelated Bone Marrow Donor Registry (Redome) currently ranks among the largest donor registries worldwide⁷. After the consolidation of post-transplant cyclophosphamide for graft-versus-host disease prophylaxis, the increase in haploidentical HCTs has further broadened the donor pool for the Brazilian population⁸.

The CIBMTR was established in 2004 through a formal research collaboration that brought together the IBMTR, the Autologous Blood and Marrow Transplant Registry of the Medical College of Wisconsin, and the National Marrow Donor Program⁴. Its online platform enables participating centers to submit data and supports data-management activities. In Brazil, coordinated initiatives involving experienced centers, data managers, and CIBMTR were developed to expand reporting and training^{5,9}.

A partnership between the SBTMO and the CIBMTR was signed in 2019 and supported the adoption of this internationally standardized and validated system for data capture in Brazil. Data reporting is conducted under a national multicenter research protocol (protocol number CAAE 65575317.5.1001.0071), in accordance with Brazilian regulations. All patients provide informed consent before their personal data are reported to the registry.

The objective of this manuscript is to review how the Brazilian Data Managers Working Group (GTGD) evolved from a grassroots initiative into a national collaborative network supporting education, governance, data quality, and the consolidation of the Brazilian Registry of Hematopoietic Cell Transplantation and Cellular Therapy over the past decade.

THE ORIGINS OF THE BRAZILIAN DATA MANAGERS WORKING GROUP

Data reporting is a long-standing practice in HCT because of the high level of coordination required for successful transplantation and the potential for life-threatening complications. In Brazil, data collection was initially implemented in only a few centers. Maintaining this activity was challenging because it depended on professionals who also performed other functions within transplant programs, resulting in inconsistent reporting and limited follow-up. Few Brazilian centers had dedicated professionals responsible for collecting data and reporting to international registries. According to CIBMTR data, centers with dedicated data-management professionals achieved follow-up reporting comparable to that of centers in the United States. Another challenge was that the data manager role was not well defined in Brazil, and the presence of this professional was not required for the registration of a new transplant center⁴. Several initiatives contributed to the development of the Brazilian Registry and the GTGD.

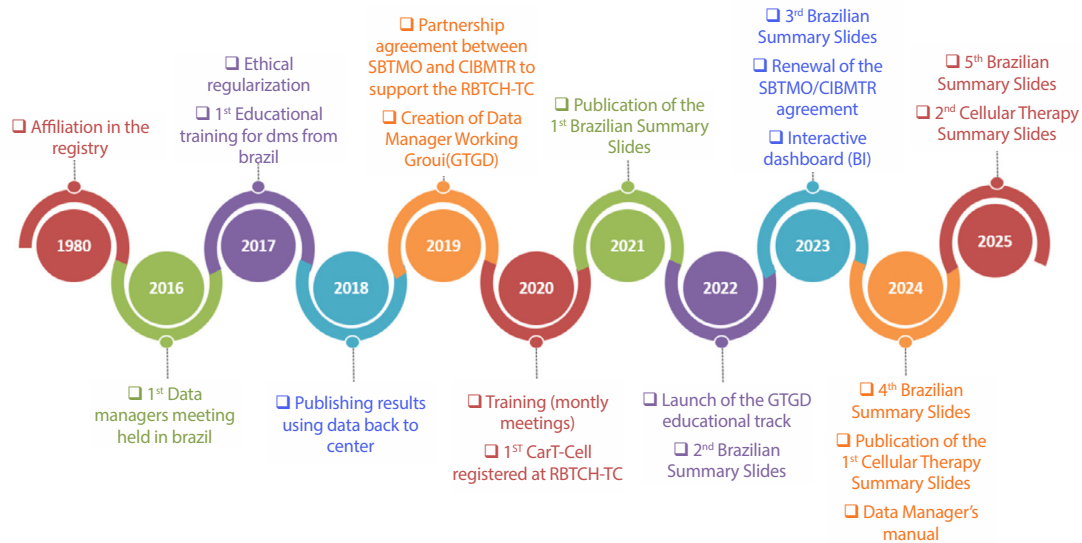
Three data managers received training at the CIBMTR at different time points and subsequently became a source of training for other Brazilian centers. Another important initiative was the development of a centralized protocol for collecting and sharing HCT data, which was approved by the Brazilian National Research Ethics Commission (CONEP). This protocol enabled participating centers to obtain patient consent for data collection and research use.

A third initiative was a Brazilian government-funded project supported through PRONON (no. 25000.001178/2017-55) and conducted by the Associação da Medula Óssea do Estado de São Paulo (AMEO). Beginning in 2018, the project included the training of two nurses at the CIBMTR. This intensive initiative trained 144 data managers from 36 centers and was followed by weekly meetings designed to maintain and improve data-management skills, address questions, and strengthen cooperation among centers⁵. Periodic in-person audits were planned but were interrupted by the COVID-19 pandemic, during which many data managers were reassigned to direct patient care⁵. These successive initiatives were aligned by a group of data managers who led this grassroots effort and supported its dissemination throughout the country.

In 2016, during the SBTMO Annual Meeting, data managers and CIBMTR discussed the challenges and opportunities of registry development in Brazil. This meeting became the foundation for what would later evolve into the GTGD and led to the establishment of annual data managers' meetings within the SBTMO congress.

Integration into the Brazilian Society of Cellular Therapy and Bone Marrow Transplantation

The origins of the GTGD date back to 2016, when data managers from different Brazilian transplant centers began collaborating through educational and registry-development initiatives promoted during the SBTMO Annual Meeting. Following its formal incorporation into the SBTMO in 2019, this collaborative movement evolved into the Brazilian Data Managers Working Group (GTGD), which subsequently expanded into a national network integrating professionals from transplant centers across Brazil (Fig. 1).

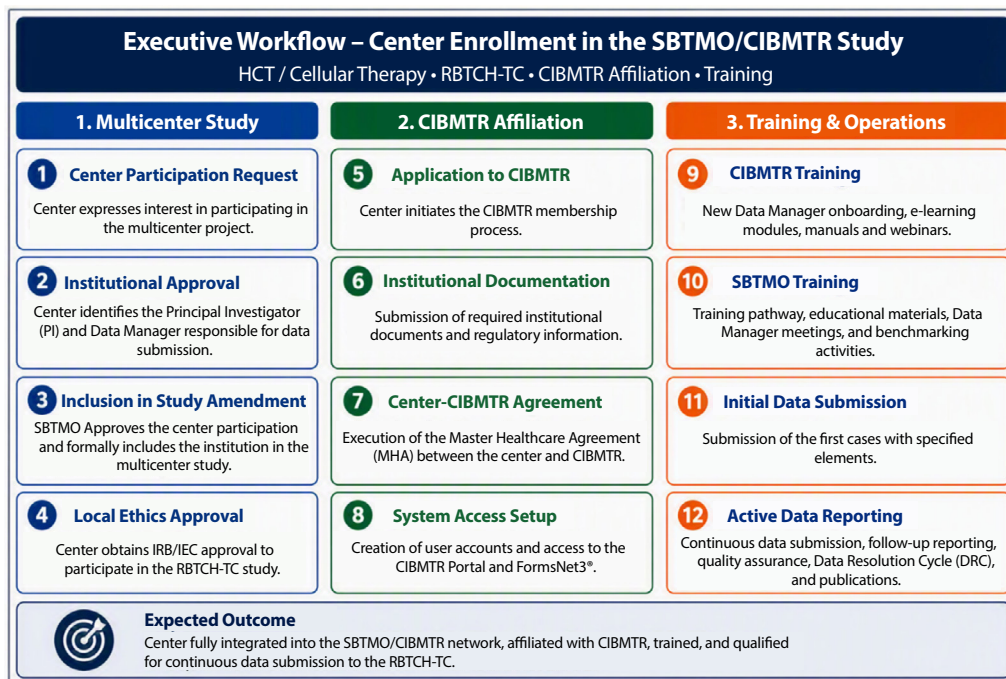


DMs: Data managers; SBTMO: Brazilian Society of Cellular Therapy and Bone Marrow Transplantation; CIBMTR: Center for International Blood and Marrow Transplant Research. Source: Elaborated by the authors.

Figure 1. Key milestones in the development of the Brazilian Hematopoietic Cell Transplantation and Cellular Therapy Registry (RBTC-TC) and the Brazilian Data Managers Working Group (GTGD) over the past decade.

Center affiliation

The expansion of the registry required a structured process for incorporating new transplant centers, including regulatory approval, training, and integration with the CIBMTR platform (Fig. 2).



SBTMO: Brazilian Society of Cellular Therapy and Bone Marrow Transplantation; CIBMTR: Center for International Blood and Marrow Transplant Research; HCT: hematopoietic cell transplantation; RBTC-TC: Brazilian Registry of Hematopoietic Cell Transplantation and Cellular Therapy; IRB: Institutional Review Board; IEC: Independent Ethics Committee. Source: Elaborated by the authors.

Figure 2. Center affiliation workflow for participation in the SBTMO/CIBMTR initiative, illustrating the sequential process of inclusion in the national multicenter protocol, CIBMTR affiliation, training, and operational activation of transplant centers within the RBTC-TC.

Following approval of the national multicenter research protocol in 2017, 10 CIBMTR-reporting centers were initially incorporated into the initiative coordinated by SBTMO. Over time, nationwide efforts to expand the network resulted in 95 centers being approved by the Brazilian National Research Ethics Commission to participate in the RBTCH-TC. As of December 31, 2025, 51 of these centers had reported data to the CIBMTR, contributing to the consolidation of the national registry.

Participation in the registry involved implementation of standardized reporting levels, including Transplant Essential Data (TED) and Comprehensive Report Forms (CRF). TED reporting captures essential transplant and follow-up information, whereas CRF reporting collects more detailed clinical data and long-term outcomes for selected patients. Because CRF participation requires a substantially greater level of data collection and sustained reporting activities, it represents an important step in the maturation of transplant centers and supports broader participation in registry-based scientific research.¹⁰

TRAINING

Training programs have been a central component of GTGD activities since its early development.

The first distance-learning (e-learning) program in Portuguese focused on TED was developed in 2017 through collaboration among HC-UFPR, Hospital Amaral Carvalho, and Hospital Israelita Albert Einstein. The program was later incorporated into the CIBMTR platform, facilitating dissemination and access by Brazilian transplant centers^{11,12}.

In 2022, the training program underwent substantial revision with participation from national and international experts. English and Spanish subtitles were incorporated, expanding accessibility throughout Latin America.

Educational infrastructure

The development of a national support manual in Portuguese in 2024 represented another milestone in the standardization of data management practices. The manual was subsequently translated into Spanish and English, expanding its reach and promoting collaboration throughout Latin America.¹³

Towards continuous professional development

To address educational disparities, staff turnover, and regional differences in access to specialized training, SBTMO implemented a national digital learning strategy. Launched in 2025, the platform provides structured educational pathways, multilingual resources, and automated certification processes.

In parallel with educational and professional development initiatives, increasing attention was given to data quality monitoring and compliance with international standards. The adoption of principles aligned with the continuous process improvement (CPI) program of the CIBMTR reinforced the importance of timely, complete, and accurate data submission¹⁴.

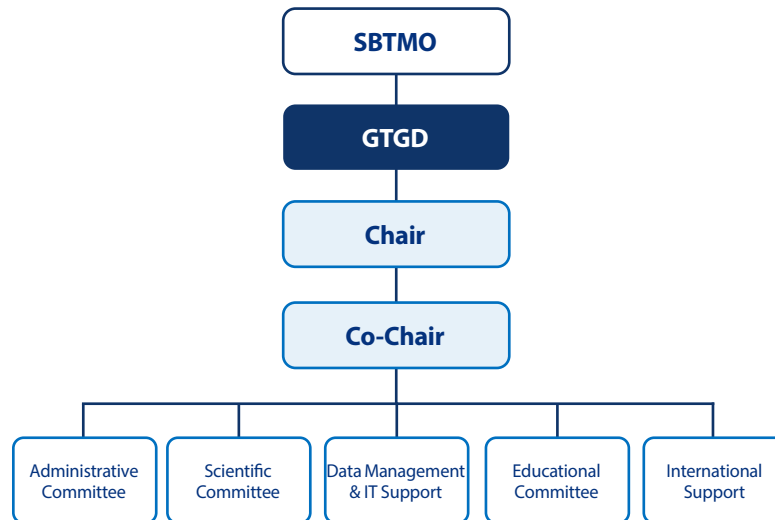
BUILDING GOVERNANCE AND PROCESSES

Establishing a governance structure for the group

Creating a formal structure within the SBTMO to support the development of Brazilian data managers was an important step in recognizing the contribution of these professionals to the field.

The GTGD was created as a formal working group within SBTMO and is responsible for education, scientific activities, international collaboration, and coordination of national initiatives (Fig. 3).

This organizational structure enabled multidisciplinary collaboration among physicians, data managers, analysts, and other professionals involved in registry-related activities. The organogram outlines leadership



SBTMO: Brazilian Society of Cellular Therapy and Bone Marrow Transplantation; GTGD: Brazilian Data Managers Working Group; IT: information technology. Source: Elaborated by the authors.

Figure 3. Functional structure of the GTGD within the broader governance framework of the SBTMO, illustrating the group's operational, educational, scientific, and technical contributions to registry-related activities.

transitions, responsibilities, key operational roles within the GTGD, and representation from the RBTCH-TC through ex officio members.

As the GTGD expanded, processes were progressively formalized to define leadership roles, representation of participating centers, and continuity of activities. Early governance discussions within the group contributed to subsequent institutional initiatives within the SBTMO, which established a formal regulatory framework for all working groups¹⁵.

The GTGD serves as the central operational, educational, and technical group supporting registry-related activities in Brazil. Registry governance, scientific oversight, and strategic decisions regarding data utilization remain embedded within the broader institutional framework of the SBTMO, which includes the RBTCH-TC Committee, the Scientific Committee, and other governance bodies.

Expansion of the registry activity

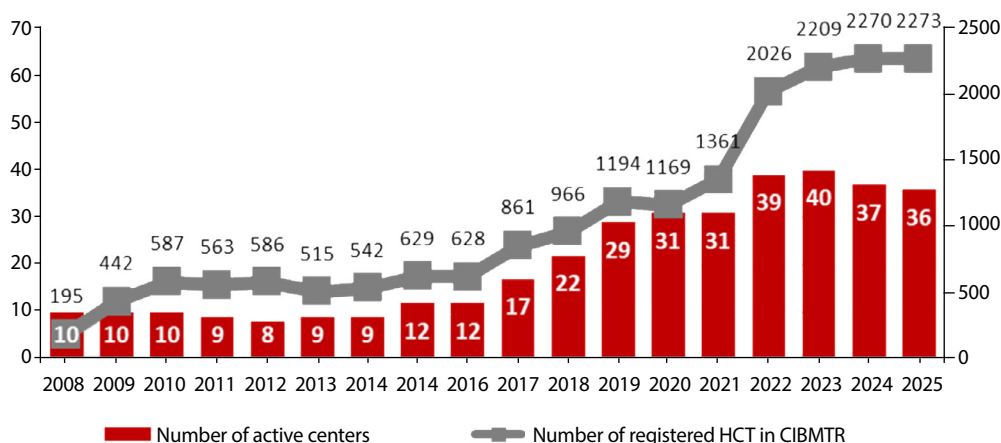
The increase in participating institutions was also accompanied by a steady growth in the number of reported procedures, as documented in the most recent national RBTCH-TC report. In addition to the expansion in the number of participating centers, the average number of reported transplant procedures per center also increased over time, reflecting the consolidation of transplant programs and greater engagement in registry activities¹⁶.

Although the COVID-19 pandemic impacted HCT activities worldwide, registry data from the Brazilian registry did not demonstrate a marked reduction in participating centers or transplant activity during this period. Following years of steady growth, transplant activity remained relatively stable throughout the most recent reporting periods¹⁶.

Between 2023 and 2025, the number of centers actively reporting new transplant procedures decreased from 40 to 36, while the total number of registered procedures remained relatively stable. This change may partly reflect the implementation of the CIBMTR Continuous Process Improvement program and its reporting-compliance requirements, including timelines for form completion and the resolution of data

queries; however, the available descriptive data do not allow a causal relationship to be established. Centers experiencing reporting delays may have their active reporting status affected. Despite these fluctuations, centers that discontinued reporting represented only a limited proportion of the overall transplant activity, while procedure volumes increased among centers that remained actively engaged in reporting.

Trends in transplant activity reported through the Brazilian registry are presented in Fig. 4.



HCT: hematopoietic cell transplantation; CIBMTR: Center for International Blood and Marrow Transplant Research. Source: Elaborated by the authors.
Figure 4. Number of centers actively reporting data and annual number of hematopoietic cell transplantation procedures registered from 2008 through December 31, 2025.

National and international scientific engagement

The expansion of registry-related activities was accompanied by a progressive increase in participation at national and international scientific meetings. Between 2017 and 2026, scientific dissemination expanded considerably in parallel with the growth of the Brazilian registry and the increasing number of trained data managers. International visibility was primarily driven by participation in the Tandem Meetings of the CIBMTR and the American Society for Transplantation and Cellular Therapy, with 16 abstracts presented between 2017 and 2026. As registry activities matured, scientific contributions expanded to other major international forums, including six abstracts presented at the European Society for Blood and Marrow Transplantation (EBMT) Annual Congress between 2023 and 2026 and two abstracts presented at the American Society of Hematology (ASH) Annual Meeting in 2025.

At the national level, 21 abstracts were presented at SBTMO congresses and subsequently published in the JBMTCT between 2020 and 2026. Additionally, one abstract was presented at HEMO 2025 and published in Hematology, Transfusion, and Cell Therapy (HTCT). Over time, the thematic focus evolved from educational initiatives and strategies to enhance CIBMTR data reporting toward more advanced topics, including registry implementation, business intelligence applications, data quality improvement, workforce development, digital education platforms, and cellular therapy research.

International collaborative networks

The collaboration between the GTGD and the Worldwide Network for Blood and Marrow Transplantation (WBMT)/Latin American Bone Marrow Transplantation Group (LABMT) has played a critical role in strengthening transplantation data reporting across Latin America. Brazilian data managers have actively participated in data collection activities and have been instrumental in raising awareness among and engaging transplant centers to contribute data to the WBMT/LABMT registry.

The consolidation of this collaborative network and the progressive expansion of the regional database subsequently enabled participation in international multicenter research initiatives. Through LABMT, Brazilian professionals contributed to studies evaluating transplantation activity across Latin America, including analyses of access to transplantation, regional activity trends, impact of the COVID-19 pandemic on transplant practices, and the increasing utilization of haploidentical donors^{17,18}.

LESSONS LEARNED AND FUTURE PERSPECTIVES

Beyond scientific productivity and institutional recognition, one of the most important outcomes of the GTGD initiative was the development of a collaborative national community dedicated to data quality, education, registry development, and continuous professional growth.

The Brazilian experience has demonstrated that developing a national registry requires more than a data-collection platform; it also requires community mobilization through grassroots initiatives. Registry consolidation depends on coordinated efforts involving professional training, governance structures, institutional engagement, and sustained collaboration among participating centers, SBTMO, and CIBMTR. Throughout the development of the GTGD, several factors proved essential for success, including continuous educational initiatives, standardized data-management practices, structured governance mechanisms, and international collaboration.

An important outcome of this process was the consolidation of the professional identity of data managers within the HCT and cellular therapy community in Brazil. The establishment of the GTGD provided a national framework for professional development, knowledge sharing, and advocacy, increasing the visibility of data managers as essential members of transplant programs. This evolution occurred in parallel with the strengthening of the Brazilian regulatory framework for transplantation, which increasingly emphasizes the importance of structured processes for data collection, monitoring, quality management, and program governance within the national transplant system¹⁹.

Current challenges

Despite important advances, significant challenges remain. Sustaining registry activities depends on continued investment in trained personnel, institutional support, and stable data management structures across participating centers. One of the most critical barriers is the shortage of qualified data managers with expertise in HCT and cellular therapy, particularly in the context of increasingly complex conventional and advanced cellular therapies. In addition, the lack of standardized career pathways and sustainable funding mechanisms for data management roles poses a substantial challenge to workforce retention and long-term program sustainability.

Additional challenges include staff turnover, long-term maintenance of educational initiatives, increasing procedural complexity, and the continuous need to adapt data collection systems to evolving clinical and regulatory requirements. The ongoing expansion of cellular therapy programs, particularly CAR-T programs, requires further investment in specialized training, professional recognition, governance frameworks, and quality assurance processes to ensure accurate and timely data reporting.

Future perspectives

Future priorities include expanding registry participation to all HCT and cellular therapy centers in Brazil, including centers involved in academic initiatives, strengthening national and international collaborations, and increasing the use of registry-derived data for quality improvement and scientific research.

CONCLUSION

The GTGD evolved from a grassroots initiative comprising a small number of professionals into a national collaborative network that contributed to education, governance, registry development, and scientific production in HCT and cellular therapy in Brazil.

Beyond the consolidation of the registry itself, the initiative helped establish a sustainable national culture of data management and collaboration, providing a model that may be adopted by other countries seeking to strengthen registry-based activities.

CONFLICT OF INTEREST

Nothing to declare.

DATA AVAILABILITY STATEMENT

The information supporting this descriptive article is provided within the manuscript and its cited sources.

AUTHORS' CONTRIBUTIONS

Conception and design: Silva CC, Neves HRA, Simione AJ, Seber A, Hamerschlak N, Pasquini R, Yamada AMTD, Macedo AV, Duarte FB and Pasquini M. **Analysis and interpretation of data:** Silva CC, Neves HRA, Simione AJ, Yamada AMTD, Macedo AV, Vigorito AC, Varjão VAN, Costa FF, Cavilha AMQ, Ammi M, Hamerschlak N, Colturato VAR, Seber A, Vergueiro CSV, Ferreira SO, Almeida AR, Funke VAM, Pasquini R, Bonfim CMS, Sabaini PMS, Concilio RR, Gasparini J, Geraldo BLSS, Otuyama LJ, Costa Junior LC, Miranda ECM, Duarte FB, Duarte BA and Pasquini M. **Technical procedures:** Silva CC, Neves HRA, Simione AJ, Seber A, Hamerschlak N, Macedo AV, Duarte FB and Pasquini M. **Manuscript writing:** Silva CC, Neves HRA, Simione AJ, Seber A, Yamada AMTD, Duarte BA, Macedo AV and Pasquini M. **Critical revision:** Seber A, Duarte BA, Neves HRA, Simione AJ and Pasquini M. **Final approval:** Silva CC, Neves HRA and Simione AJ.

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DECLARATION OF USE OF ARTIFICIAL INTELLIGENCE TOOLS

The authors declare that artificial intelligence (AI) tools were used solely to assist with language editing, grammar refinement, and clarity of expression during manuscript preparation. No AI tools were used for data analysis, interpretation of results, or generation of scientific content. The authors retain full responsibility for the content of this manuscript.

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