

# Development of a data manager support manual for hematopoietic cell transplantation and cellular therapy for Latin America: an innovative approach to data reporting to the Center for International Blood & Marrow Transplant Research

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## ABSTRACT

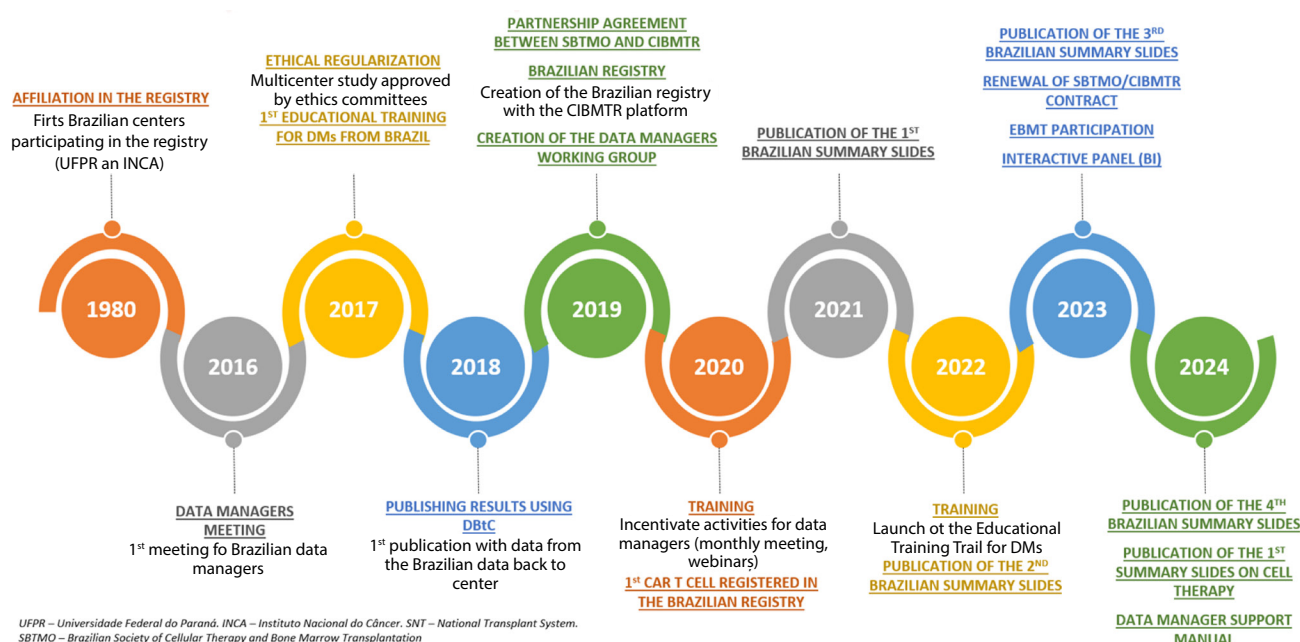
The Brazilian Hematopoietic Cell Transplantation and Cellular Therapy (HCT-CT/BR) Registry depends on data manager (DM) training to ensure sustainability, for which it is essential to standardize processes. The objectives of this study were

to describe the development of a support manual for Brazilian DMs reporting to the Center for International Blood and Marrow Transplant Research and to present quality assessment results. The descriptive study (Feb–Aug 2024) included structuring, content creation, and dissemination of the manual. Survey assessed satisfaction. The manual was launched at the XXVIII Brazilian Society of Cellular Therapy and Bone Marrow Transplantation Congress. Thirty-nine professionals rated it 9.3/10 for satisfaction and 9.4/10 for recommendation. A manual is crucial for standardizing processes and ensuring data quality, offering clear and up-to-date guidance.

**Keywords:** Hematopoietic Stem Cell Transplantation. Health Information Management. Education. Data Accuracy. Data Collection.

## INTRODUCTION

Since 2016, efforts have been made to consolidate the Brazilian Hematopoietic Cell Transplantation and Cellular Therapy (HCT-CT/BR) Registry (Fig. 1), established in 2019, by the collaboration between the Brazilian Society of Cellular Therapy and Bone Marrow Transplantation (SBTMO) and the Center for International Blood and Marrow Transplant Research (CIBMTR)<sup>1</sup>.



Source: Elaborated by the authors. DM: data manager; CIBMTR: Center for International Blood and Marrow Transplant Research; EBMT: European Society for Blood and Marrow Transplantation; DBtC: Data Back to Centers.

**Figure 1.** Brazilian hematopoietic cell transplantation and cellular therapy data management path.

One of the first initiatives was the creation of a FormsNet3 filling out tutorial that addressed the basic forms (transplant essential data) pre- and post-transplant (2016–2017). It was the first Brazilian data manager (DM) training developed via the collaboration of three institutions (Universidade Federal do Paraná, Hospital Amaral Carvalho, and Hospital Israelita Albert Einstein<sup>2</sup>.

The Data Managers Working Group (DMWG) of SBTMO was also established in 2019 and has sought over the years to develop strategies to help other DMs to understand the CIBMTR data reporting process, improve data management skills, and standardize processes<sup>3</sup>. Based on these objectives, the Data Manager Support Manual for Hematopoietic Cell Transplantation and Cellular Therapy was designed, developed and published<sup>4</sup>.

The main objectives of this short communication were to describe the development of a support manual for Brazilian DMs who report data to the CIBMTR and to present the results of a material quality assessment.

## METHODS

This is a descriptive, methodological study, focused on the development of educational material with practical application in Hematopoietic Cell Transplantation and Cellular Therapy DM training and support. The project was developed between February and August 2024 and counted with the voluntary collaboration of different experts. The completed process included three stages:

- Structuring of topics on data reporting to the CIBMTR;
- Content creation;
- Dissemination.

To assess user engagement and satisfaction, a REDCap<sup>5</sup> survey was conducted, addressing content access, satisfaction level (0–10), clarity of topics, format suitability, and likelihood of recommendation. The research was made available in the Hematopoietic Cell Transplantation (HCT) and Cellular Therapy (CT) teams' communication groups.

## RESULTS

Given the rapid increase in the number of Brazilian centers affiliated to the CIBMTR, the DMWG of SBTMO envisioned the need to develop a material that could be readily accessible to guide professionals regarding the main steps of the process, as a handy means of supporting HCT and CT teams on their daily activities, considering the complexity of the field.

The first stage of the process began as a scoping review of the literature on the main needs related to the field, by reviewing official CIBMTR resources, meeting minutes and records of previous DM calls including various institutions, as well as by defining the target audience. Next, the educational objectives were defined, followed by the topics that would be covered in the manual and the professionals who could potentially collaborate in their respective areas of expertise. These specialists (physicians, nurses, data managers, and analysts) were then formally invited via a letter signed by the DMWG and the SBTMO president.

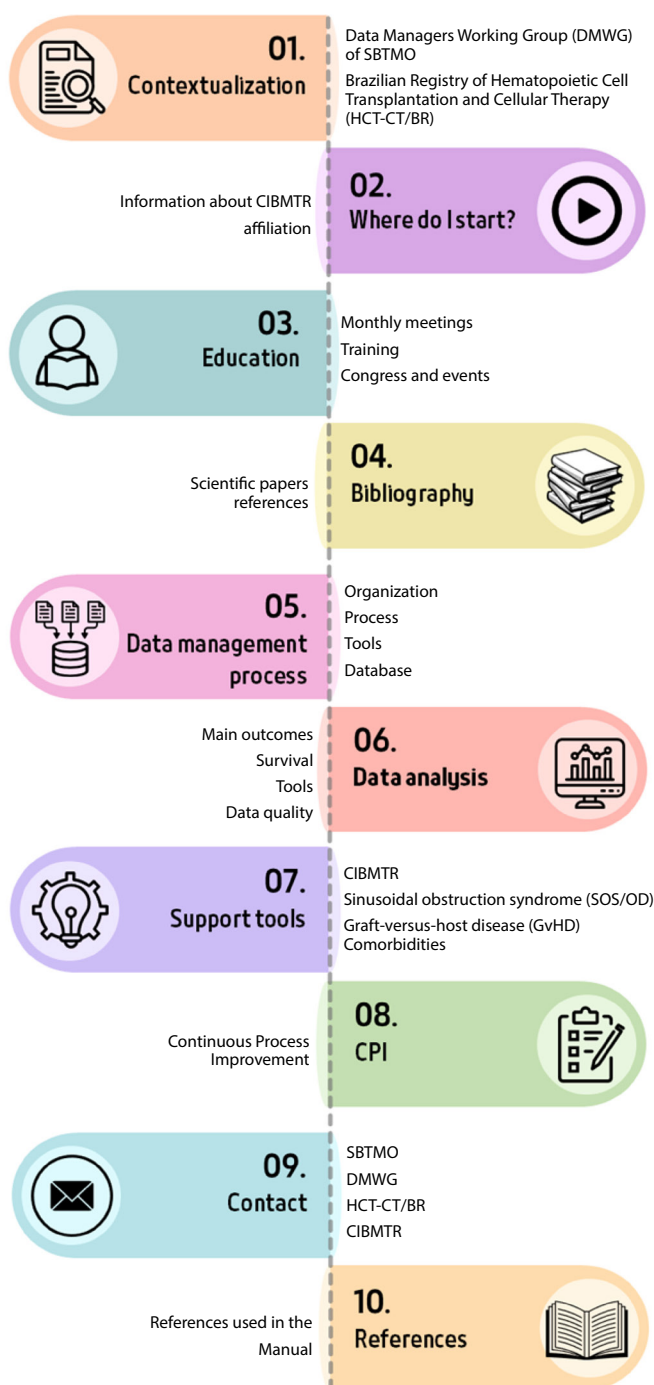
The second stage involved content creation. Experts were instructed to use clear and instructional language and to add illustrations, practical examples, flowcharts, and CIBMTR system screenshots, in order to produce a handy and user-friendly material. The manual was divided into 10 modules, with the aim of encompassing all the stages of CIBMTR data management and reporting, starting with basic concepts and guiding through each of the steps to be followed during the data management process, including highlights on educational and training opportunities and useful and freely available tools (Fig. 2). All the content produced was subjected to an orthographic and instructional design review and was subsequently validated by key professionals in the DM group.

At the third and last stage, the manual was prepared in both print and digital versions for dissemination. Two hundred copies of the first edition were printed for publicity and commercialization during the XXVIII SBTMO Congress in Fortaleza, Ceará, Brazil, in August 2024. The e-book version was made available at the same time through direct downloading from the SBTMO<sup>4</sup>, CIBMTR<sup>6</sup>, and HEMATOLOG<sup>7</sup> websites. The digital version aims to democratize access, since it is freely available, and allows for timely updates and incorporation of interactive elements.

Key metrics were used to evaluate sales of the printed version, and publications regarding the manual on social media, including the websites providing the download of the e-book, were also assessed. Among the copies printed, 52% (103) were sold at a cost of US\$ 11. Two units were purchased by two other Latin American countries. All the funds raised will be used for future DM educational activities promoted by the SBTMO. Among the 44 HCT/CT centers that contributed to the 2024 Brazilian summary, 50% (22) purchased the printed manual.

# 10 MODULES

## Data Manager Support Manual

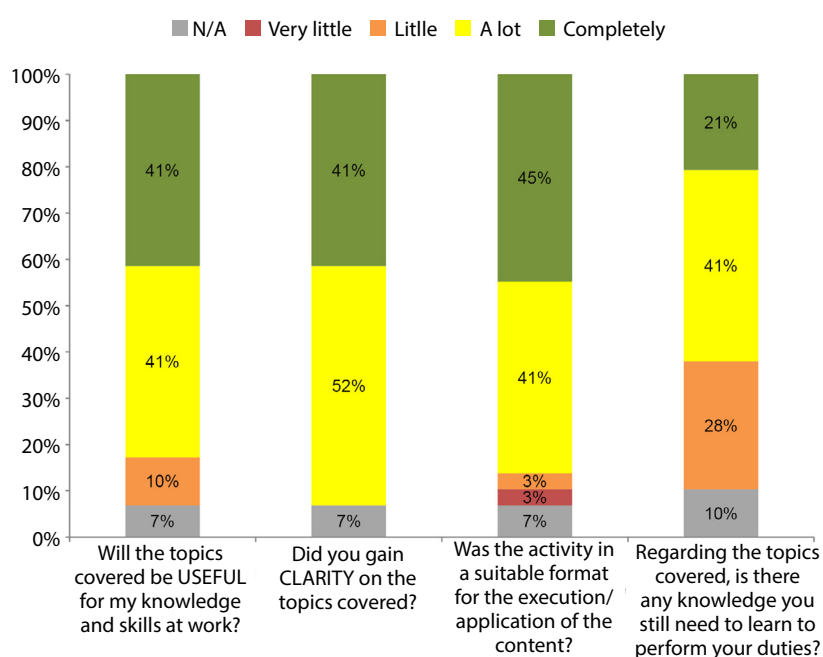


Source: Elaborated by the authors. SBTMO: Brazilian Society of Cellular Therapy and Bone Marrow Transplantation; CIBMTR: Center for International Blood and Marrow Transplant Research; CPI: continuous process improvement.

**Figure 2.** Data manager support manual for hematopoietic cell transplantation and cellular therapy contents.

Regarding the digital version of the manual, between August 2024 and May 2025, the SBTMO website identified 220 visits to the e-book page. During the same period, the HEMATOLOG website identified an average of 3.2 views per user, 26 views in total. The publication on the HEMATOLOG Instagram account had 753 views, and 42 impressions published on LinkedIn. The Spanish version of the material was released in May 2025<sup>8</sup>, and a few metrics were extracted soon after from HEMATOLOG. The website identified 24 views, an average of three views per user. The HEMATOLOG Instagram computed 595 views, and 180 impressions were identified on LinkedIn. The Portuguese version is currently being translated to English.

Regarding material adherence and satisfaction, a survey consisting of five multiple choice questions was completed by 39 professionals, some of whose answers can be viewed in Fig. 3. Among those, 29 (74%) purchased the manual, 26 in its printed form, two in its digital version, and one did not respond, with an average satisfaction rate of 9.3/10 and recommendation rate of 9.4/10.



Source: Elaborated by the authors.

**Figure 3.** Hematopoietic cell transplantation and cellular therapy responses to the questionnaire on satisfaction and adherence regarding the data manager support manual.

## DISCUSSION

The creation of a structured support manual is a crucial tool for standardizing processes and ensuring data quality, offering clear and up-to-date guidance on best practices for experienced and novice professionals. The guide helps to comprehend the processes and identify critical stages. Furthermore, its flexibility will allow for frequent updates and will strengthen the educational process.

The increasing number of Brazilian centers affiliated with the CIBMTR underscores the urgent need for structured educational materials to support professionals responsible for data management and reporting. The current support manual represents an initiative aligned with this demand, providing a tool that standardizes processes and strengthens professional training in a practical and accessible manner.

To support Brazilian educational initiatives, the CIBMTR offers a dedicated page in its portal. Through the CIBMTR portal, users can access a range of center-focused applications, including Data Operations Education & Training, which provides comprehensive information and training materials for data management

professionals, covering both field-specific knowledge and CIBMTR data submission requirements. One of the dropdown menus leads to the Data Manager Training Offerings, in which the “SBTMO Curso Brasil” page is located. This page features the “Educational Track for Data Managers in Cell Therapy” and provides access to both digital versions of the manual—Portuguese and Spanish<sup>6</sup>.

The multidisciplinary involvement that was needed for content development, including that of physicians, nurses, analysts, and data managers, ensured the material’s comprehensiveness and relevance to the specific needs of the hematopoietic cell transplantation and cellular therapy fields. The modular structure, combined with the use of visual aids and practical examples, facilitated the complex processes understanding, as demonstrated by the high user satisfaction.

The strategy of offering the manual in both print and digital formats was essential to broadening access and enabling dynamic updates of its content. The significant uptake of the printed material, along with the digital content engagement shown, attests to the material’s relevance in the professional community. Additionally, the positive feedback, with average satisfaction and recommendation scores exceeding<sup>9</sup>, reinforces the effectiveness of the manual in meeting user expectations.

The Spanish version release of the manual, along with its ongoing translation to English, indicate a potential for internationalization, which may enhance integration and knowledge exchange among Latin American countries and the global hematopoietic transplantation and cellular therapy community.

## CONCLUSION

The Data Manager Support Manual constitutes an innovative and necessary educational resource for the qualification of Brazilian professionals reporting data to the CIBMTR. This initiative has promoted process standardization, contributed to the improvement of data managing skills, and facilitated access to essential information for high-quality reporting.

The results demonstrate strong acceptance and a positive impact, reflected in its broad dissemination, team engagement, and high user ratings. The continuation of translations into other languages and the reinvestment of proceeds in future educational activities ensure the project’s sustainability and expansion.

In summary, the DM support manual strengthens the technical and educational infrastructure for data reporting in HCT and CT in Brazil, fostering significant advancements in clinical data quality and professional integration.

## CONFLICT OF INTEREST

Nothing to declare.

## DATA AVAILABILITY STATEMENT

All data sets were generated or analyzed in the current study.

## AUTHORS’ CONTRIBUTIONS

**Substantive scientific and intellectual contributions to the study:** Costa FF, PSabaini PMS, Silva CMCR, Simione AJ, Neves HRA, Ammi M, Concilio RRB, Vigorito AC, Miranda ECM, Otuyama LJ, Santos JG, Cavilha AMQ, Salgado JDC, Toledo M, Melo E, Ferreira SO, Macedo AV, Seber A, Bonfim CMS, Funke VAM, Pasquini M, Flowers ME, Hamerschlak N, Duarte FB; **Conception and design:** Costa FF; **Analysis and interpretation of data:** Simione AJ; **Technical procedures:** Silva CMCR; **Statistics analysis:** Simione AJ; **Manuscript writing:** Sabaini PMS; **Final approval:** Duarte FB.



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The progress of hematopoietic cell transplantation (HCT) in Brazil has been driven by dedicated leaders and collaborators who have catalyzed major advances in the field since 2016. Ongoing partnerships with the CIBMTR ensure that the latest research findings and best practices are continuously disseminated throughout the community. Efforts to affiliate Brazilian centers with the CIBMTR, as well as to educate and support data managers involved in national initiatives, have been essential for strengthening the country's HCT network. Multidisciplinary HCT teams across Brazil, through their commitment and expertise, make direct and meaningful contributions to the continued growth and success of this specialized field of medicine. Finally, the invaluable contributions of patients who have undergone HCT cannot be overstated; their willingness to share data and participate in scientific research is fundamental to advancing knowledge and improving outcomes in this vital area of healthcare.

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