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How to Unleash the Potential of the Portuguese Registry of Intensive Care Medicine?

Como Libertar o Potencial do Registo Nacional de Medicina Intensiva?

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INTRODUCTION

Intensive Care Medicine has undergone profound transformations in recent years. Although reliable data specific to Portugal is unavailable, it is estimated that Intensive Care Departments (ICD) account for approximately 13.4% of total hospital costs, 4.1% of national healthcare spending, and nearly 0.6% of the gross national product globally.[1] Given the rapid pace of development in this field, ensuring safe, effective and equitable care depends on solid metrics and high-quality research as the cornerstones for continuous improvement.[2]

National registries, developed over 30 years ago as part of quality improvement programs, have become indispensable data sources globally, providing valuable insights into the epidemiology of critically ill patients.[3] The success of

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these pioneering initiatives, coupled with advancements in information technology and recognition of their potential to support a broad range of observational and interventional research, has driven their geographic expansion.[2]

The Portuguese Registry of Intensive Care Medicine (RNMI, Registo Nacional de Medicina Intensiva) was established within this global movement, with the goal of supporting research and quality improvement in national intensive care. By offering a robust, data-driven foundation, the RNMI enables meaningful national and international comparisons, fostering evidence-based practices and enhancing patient outcomes in intensive care settings. Furthermore, in 2012, Portugal had only 6.4 ICU beds per 100 000 inhabitants, and while the latest national census reports an increase to 9.5 active beds per 100 000 inhabitants, this figure remains significantly below the European average, highlighting the need for better resource planning.[4]

Project overview

The RNMI is based on an idea introduced over 20 years ago by Professor Rui Moreno to establish a National Center for Intensive Care Data Management. This initiative was formally implemented in 2022 through a consortium comprising the Portuguese Society of Intensive Care Medicine (SPCI), the College of Intensive Care Medicine of the Portuguese Medical Association (CEMIOM), and the Association of Intensive Care Medicine Trainees (AIMINT).

The primary goal of the RNMI is to improve the quality of intensive care by generating and advancing knowledge in this field and promoting its implementation and dissemination (Fig. 1).

The RNMI operates within a structured regulatory framework, accessible at https://www.spci.pt/rnmi.

Digital platform

Content structure

The content structure of RNMI was developed through a collaborative process led by a multiprofessional task force. This task force employed a modified Delphi methodology to reach a consensus, with all discussions conducted online.

The platform's design is based on a flexible modular system referred to as 'cassettes', with each cassette containing datasets specific to key aspects of intensive care (e.g., ventilation), thereby supporting a wide range of research studies within intensive care medicine. Furthermore, the platform was structured to automate calculations for essential clinical scores, including health-related quality-of-life metrics adapted for the Portuguese population.[5]

Technical specifications

Development and security guarantees

The digital platform was developed with rigorous standards to ensure data privacy and security. Hosted on European Microsoft Azure servers, the platform ensures data privacy and security through strict firewall policies, advanced encryption for data transfer and storage, and a multi-layered security approach to protect against external threats.

Anonymization and data security

The platform anonymizes patient data using a 'hash with salt' security technique (that transforms data into a fixed-length string using a unique random value) and assigns unique identifiers (UUIDs) to ensure data remains non-identifiable while enabling secure tracking and correlation throughout a study, even in the event of a breach.

Data management and research ethics principles

Compliance with General Data Protection Regulation

The RNMI ensures that data is collected and processed in strict compliance with data privacy laws, notably the General Data Protection Regulation (GDPR). The GDPR compliance for RNMI is further assured through oversight by a designated data protection officer, who is responsible for implementing the data protection strategy and ensuring adherence to regulatory standards.

Coordination with competent ethics committees

The RNMI's data collection and processing protocols adhere to high ethical standards, with data collection initiated only after approval from each institution's Ethics Committee. Data collected through the RNMI is anonymized, exempting it from informed consent requirements under the GDPR. However, the concept of anonymization is fluid, particularly in studies beyond the basic data package that handle a large volume of variables, where the data might be considered pseudo-anonymized. In such instances, informed consent may still be waived under national data protection regulations, as RNMI data is recognized as serving public interest by facilitating quality management and critical care coordination. Additionally, ethics committees may waive consent when it is impractical or impossible to obtain. For instance, in studies on cardiorespiratory arrest, excluding individuals unable to provide consent would undermine the research's validity.[6]

Data collection

The RNMI supports manual and automated data collection aligned with European interoperability standards (HL7). Currently, data is entered manually by supervised trainees, with automation requiring stakeholder agreements and application programming interface (API) development for hospital system integration.

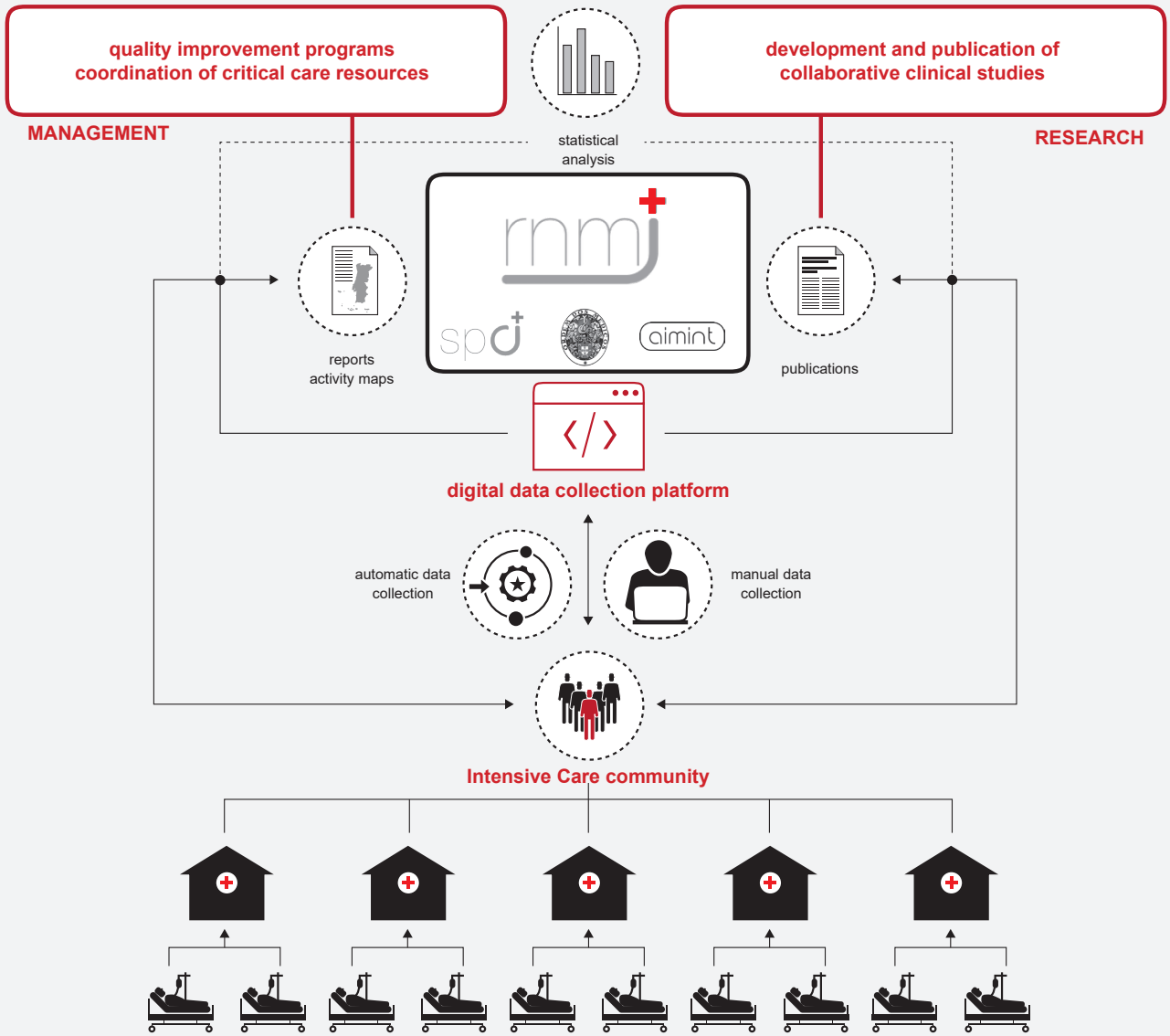

Figure 1 – Structure and functions of the Portuguese Registry of Intensive Care Medicine. The RNMI is built on a collaborative network linked to a digital data collection platform that supports both manual and automated data entry. This platform is designed to collect data for clinical research aimed at improving patient-centered outcomes. Additionally, it provides management tools at both local and national levels, enabling: (1) the creation of reports to support quality improvement initiatives and foster a collaborative quality improvement system, and (2) the development of activity maps to facilitate real-time and long-term coordination of critical care resources.

Seminal studies

RNMI-BACKEND, RNMI-TRAUMA and RNMI-PCR

To demonstrate the potential of the RNMI, three seminal studies were designed in key areas of Intensive Care Medicine: cardiac arrest (RNMI-PCR), trauma (RNMI-TRAUMA), and general supportive care (RNMI-BACKEND), each targeting essential areas for enhancing patient outcomes in intensive care.

RNMI-BACKEND studies the epidemiology of ICD patients and evaluates the prevalence and impact of supportive measures on patient outcomes, providing insight into general national intensive care practices. Both RNMI-TRAUMA and RNMI-PCR adopt standardized Utstein templates[7,8] (standardized reporting frameworks for collecting and comparing data on trauma and cardiac arrest) to ensure consistent, high-quality data collection, offering valuable insights into these two areas that currently lack comprehensive and up-to-date national data.

Dissemination of results

The findings from these seminal studies will be shared through publications in high-impact, peer-reviewed journals. Rigorous authorship standards that allow for large-scale contributions (e.g., CRediT system)[9] along with transparent data-sharing frameworks (e.g., FAIR principles),[10] will guide these efforts. On the other hand, by deepening the understanding of critical care in key areas in Portugal, these studies support quality improvement initiatives that drive data-informed protocols and eventually improve patient outcomes.

Participating intensive care units

As of the latest data, the RNMI has achieved an 80% participation rate across Portuguese ICDs, representing 90% of ICD beds in the country (Table 1). Such broad participation ensures the RNMI's capacity to generate high-quality, representative data, essential for scientific publications and for collaborative quality improvement programs at the national level.

Future prospects and conclusions

The RNMI has already achieved considerable success in developing a secure, scalable digital platform with a collaborative design, built around content created by intensivists. This initiative has launched seminal studies in critical areas of intensive care medicine and has gained participation from the vast majority of Portugal's ICDs, thereby creating a robust foundation for representative, large-scale data collection.

Despite these achievements, the RNMI still faces barriers to further development. These challenges include legislative and governance inconsistencies, particularly concerning data sharing and patient confidentiality, as well as technical issues related to system integration and interoperability.[2]

Strategically, the RNMI holds significant potential to evolve into a Center of Excellence for Intensive Care Medicine in Portugal. By fostering continuous high-quality data collection and maintaining an engaged professional network, the RNMI can position Portugal as a leader in intensive care research and quality improvement, enhancing resilience in healthcare and contributing meaningfully to international advancements in critical care. Moreover, the RNMI embraces interoperability at the European level, enabling connections to initiatives such as the European Health Data Space (https://www.european-health-data-space.com/). This integration underscores its commitment to international cooperation, fostering collaboration and innovation across borders while serving as a data-driven tool for optimal resource allocation.

Table 1 – Participation Rate of Intensive Care Units in the Portuguese Registry of Intensive Care Medicine

	Public system								Private system								National total							
	National			ICD		RNMI		beds	National			ICD		RNMI		beds	National			ICD		RNMI		beds
	ICD n	beds N		n	%	n	%		ICD n	beds n		n	%	n	%		ICD n	beds n		n	%	n	%	
Northern Region	12	277		12	100%	277	100%		3	26		2	67%	20	77%		15	303		14	93%	297	98%	
Central Region	7	135		7	100%	135	100%		0	0		0	–	0	–		7	135		7	100%	135	100%	
Lisbon and Tagus Valley Region	13	299		11	85%	267	89%		5	59		2	40%	35	59%		18	358		13	72%	302	84%	
Alentejo and Algarve Region	5	84		4	80%	74	88%		0	0		0	–	0	–		5	84		4	80%	74	88%	
Autonomous Regions of the Azores and Madeira	4	47		2	50%	35	74%		1	7		0	0%	0	0%		5	54		2	40%	35	65%	
Total	41	842		36	88%	788	94%		9	92		4	44%	55	60%		50	934		40	80%	843	90%	

ICD: intensive care departments; RNMI: Portuguese Registry of Intensive Care Medicine (*Registo Nacional de Medicina Intensiva*)

AUTHOR CONTRIBUTIONS

All authors contributed equally to the conceptualization, organization, writing, revision and approval of the final version of the manuscript.

COMPETING INTERESTS

JGP received honoraria for lectures from Biomerieux, Thermofisher, Gilead and MSD; is the president of Grupo de Infeção e Sépsis (unpaid role).

PM received an unrestricted research grant from AstraZeneca; received consulting fees from Chiesi; received payment or honoraria from AOP, MSD, Pfizer, Biomérieux, Shionoggi, Thermofisher, Cepheid, GSK and Chiesi; received support from MSD for attending the 2022 International Symposium on Intensive Care & Emergency Medicine (ISICEM); is the president of the Portuguese Society of Intensive Care.

PP received consulting fees from MSD, BioCodex and Gilead; received payment or honoraria from Gilead, Abionic and Mundipharma for lectures, presentations, speakers' bureaus, manuscript writing or educational events.

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