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Worldwide clinical intensive care registries response to the pandemic: An international survey



## 1. Introduction

The COVID-19 pandemic presented a major challenge to Intensive care units (ICU). ICU registries responded by capturing and reporting findings that guided resource allocation, informed policy, and generated time-critical data via observational and clinical research [1-3]. The LOGIC (Linking of Global Intensive Care) [4] consortium of national ICU Registries conducted an international survey to describe the changes in structure, data, funding as well the role of ICU registries for public reporting, data sharing and research during the pandemic.

#### 2. Material and methods

An electronic questionnaire (online supplementary material) was developed by the authors and iterated by pilot-testing by 4 registry coordinators. IRB approved the study and waived the need for informed consent (CAAE: 44181021.3.0000.5249 - D'Or Institute for Research and Education, Rio de Janeiro, Brazil). An invitation was sent by email to a single member of each national registry. Only registries that were collecting Covid-19 specific data were included. Standard descriptive statistics were used.

## 3. Results

We invited 25 ICU registries, of whom 18 (72%) responded from a total of 21 countries; 8 from Europe, 5 from Asia, 2 from Oceania, 4 from South America,1 from Africa and 1from North America. In 2020, two national registries were not collecting data specifically on Covid-19 patients in the ICU. As a result, we analyzed data from 16 registries (representing 19 countries); ten from high-income countries (HICs) and six from low-and-middle income countries (LMICs) (Table 1-ESM). Two collected data as a response to government requests. Most (55%) registries (6 of 10 from HICs) reported no specific funding and only one received governmental funds. Similarly, 11 out of 16 registries integrated data collection into the existing registry platform. Seven of 16 (5 in LMICs) captured data exclusively relying on manual data entry. Two created independent data capture structures for COVID-19. Intermediate care and high-dependency unit patients were enrolled by nine registries (56%) where of 3 registries also included the wards.

Approval to capture new data was needed by 14 registries. Individual ICUs from all registries had access to reports. Six ICU registries made data publicly available and seven shared data with governmental agencies. Nine of 16 registries shared data with other ICU registries or benchmarking initiatives, and three shared data with international organizations such as ISARIC and WHO. Data from eight registries (80%) from high-income countries were used by scientific societies or government agencies for strategic planning, while only one (16.7%) from LMICs used it.

All registries provided data for research; All 16 registries used data in clinical research, six (three in LMICs) shared data for Randomized Control Trials (RCTs), and two for systematic reviews. A summarized comparison between main responses of LMICs and HICs is provided on Fig. 1.

## 4. Discussion

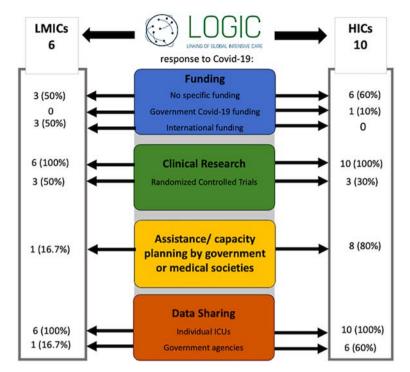
In the context of a pandemic, in which there is a multifactorial overload of health systems and an urgent need for rapid responses, our data shows that registries were able to organize their response providing data for capacity planning, tracking of severity and treatment trends, sharing data with governmental agencies, and contributing to clinical studies [5]. In addition, the previous existence of national registries, facilitated the data collection on ICU COVID-19 patients without the need

#### Table 1

Countries and their respective national registries.

| Country             | Name of National Registry   | Website                                       |
|---------------------|---|---|
| Argentina           | SATI-Q  | www.satiq.net.ar                              |
| Australia           | ANZICS CORE   | www.anzics.com.au                             |
| Brazil              | UTIs Brasileiras  | utisbrasileiras.com                           |
| Canada              | iCORE   | NA  |
| England             | ICNARC case-mix program   | https://www.icnarc.org                        |
| Finland             | Finnish Intensive Care Consortium                                     | NA  |
| Iceland             | Icelandic ICU registry  | NA  |
| India               | IRIS  | www.irisicuregistry.org                       |
| Japan               | JIPAD   | https://www.jipad.org/                        |
| Kenya               | Kenya Critical Care Registry, CCAA<br>(Critical Care Asia and Africa) | NA  |
| Nepal               | NICRF, CCAA (Critical Care Asia and Africa)                           | NA  |
| Netherlands         | NICE  | https://www.stichting-nice.<br>nl             |
| New<br>Zealand      | ANZICS CORE   | www.anzics.com.au                             |
| Northern<br>Ireland | ICNARC case-mix program   | https://www.icnarc.org                        |
| Norway              | Norwegian intensive care and  | https://helse-bergen.                         |
|                     | pandemic registry   | no/norsk-intensivregister-nir                 |
| Pakistan            | PRICE, CCAA (Critical Care Asia and Africa)                           | https://searchpk.org.pk/                      |
| Scotland            | SIGSAC  | https://www.sicsag.scot.nhs.<br>uk/index.html |
| Umanau              |   |   |
| Uruguay<br>Wales    | UCIs Uruguayas<br>ICNARC case-mix program                             | ucisuruguayas.com<br>https://www.icnarc.org   |

<sup>&</sup>lt;sup>1</sup>On behalf of JIPAD Working Group.



**Fig. 1.** LOGIC (Linking of Global Intensive Care) response to Covid-19 pandemic in low-middle-income countries (LMICs) and high-income countries (HICs). The figure shows the number of positive responses to questions related to national registries funding during the pandemic, and the use of these registries in clinical research, assistance/capacity planning and data sharing. ICU = Intensive Care Unit.

for specific funding. It is noteworthy that only one national registry had government investment specifically in the fight against Covid-19. Our data showed that manual data entry was more frequent in LMICs. This should alert need for funding and capacity to allow better data integration and sustainability of such projects. We have no detailed information on how data was used by ICUs and its effectiveness to build capacity or improve outcomes. Discussions about the importance of international benchmarking as a way of contributing to improve the delivery of care of critically ill patients are growing, with national registries having a fundamental role to increase the transparency of case-mix and outcomes as well us to improve structural organization, research, and processes.

## 5. Conclusion

The response of existing quality registries during the pandemic shows their potential value in times of crisis. Funding, legal aspects, transparency use of data for research purposes and governmental use, varied, with even greater variation when LMICs and HICs are compared. Global initiatives such as this survey can help registers to learn and show possibilities for the use of their data in the post-pandemic to support the worldwide critical care community.

## **Authors' contributions**

The writing committee designed, drafted, and revised the present manuscript.

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## Availability of data and materials

Not applicable.

## Ethical approval and consent to participate

IRB approved the study and waived the need for informed consent (CAAE: 44181021.3.0000.5249 - D'Or Institute for Research and Education, Rio de Janeiro, Brazil).

## **Consent for publication**

All authors reviewed and approved the final version of the manuscript.

#### **Declaration of Competing Interest**

Drs Salluh and Soares are co-founders and shareholders of Epimed Solutions, a cloud-based analytics company. Dr. D.A. Dongelmans is unpaid chair of NICE foundation.

The other authors declare that they have no conflicts of interest.

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#### Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi. org/10.1016/j.jcrc.2022.154111.

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Dave A. Dongelmans

Amsterdam UMC location University of Amsterdam, Department of Intensive Care Medicine, Meibergdreef 9, Amsterdam, the Netherlands National Intensive Care Evaluation (NICE) foundation, Amsterdam, the Netherlands

Amanda Quintairos

D'OR Institute for research and Education, Rio de janeiro, Brazil Department of Critical and Intensive Care Medicine, Academic Hospital Fundación Santa Fe de Bogota, Bogota, Colombia

\*Corresponding author at: D'Or Institute for Research and Education, Rua Diniz Cordeiro, 30 – 3° andar; Rio de Janeiro, RJ CEP 22281-100, Brazil.

E-mail address: amandaqsilva@gmail.com

Eirik Alnes Buanes Norwegian Intensive Care and Pandemic Registry, Helse Bergen Health Trust, Bergen, Norway

> Diptesh Aryal Nepal Intensive Care Research Foundation, Kathmandu, Nepal

# Sean Bagshaw

Department of Medicine, Faculty of Medicine and Dentistry (Ling, Bagshaw), University of Alberta and Alberta Health Services; Department of Critical Care Medicine, Faculty of Medicine and Dentistry and School of Public Health, Division of Internal Medicine (Villeneuve), University of Alberta and Grey Nuns Hospitals, Edmonton, Alta, Canada

> Stepani Bendel Dept. of intensive care, Univ. hospital Kuopio, Finland

Joe Bonney Komfo Anokye Teaching Hospital, Ghana Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

> Gaston Burghi Hospital Maciel, Montevideo, Uruguay

> > Eddy Fan

Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, Canada

## Bertrand Guidet

Sorbonne Université, INSERM, Institut Pierre Louis d'Epidémiologie et de Santé Publique, AP-HP, Hôpital Saint-Antoine, service de réanimation, Paris, France Rashan Haniffa Crit Care Asia, Network for Improving Critical Care Systems and Training, Colombo, Sri Lanka Centre for Tropical Medicine and Global Health, University of Oxford, UK University College Hospital, London, UK

> Madiha Hashimi Ziauddin University, Sindh, Pakistan

Satoru Hashimoto Division of Intensive Care, Department of Anesthesiology & Intensive Care Medicine, Kyoto Prefectural University of Medicine, Kyoto, Japan

Nao Ichihara Department of Healthcare Quality Assessment, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

Bharath Kumar Tirupakuzhi Vijayaraghavan Department of Critical Care Medicine, Apollo Main Hospital, Chennai, India The George Institute for Global Health, New Delhi, India

> Nazir Lone Usher Institute, University of Edinburgh, UK Scottish Intensive Care Society Audit Group, UK

Maria del Pilar Arias Lopez Argentine Society of Intensive Care (SATI). SATI-Q Program Buenos Aires, Argentina Hospital de Niños Ricardo Gutierrez, Intermediate Care Unit, Argentina

> Mohd Zulfakar Mazlam Department Anaesthesiology and Intensive Care, School of Medical Sciences, Kelantan, Malaysia

Hiroshi Okamoto Department of Critical Care Medicine, St. Luke's International Hospital, Tokyo, Japan

Andreas Perren

Intensive Care Unit, Department of Intensive Care Medicine – Ente Ospedaliero Cantonale, Ospedale Regionale Bellinzona e Valli, Bellinzona, Switzerland Faculty of Medicine, University of Geneva, Geneva, Switzerland Faculty of Biomedical Sciences, Università Svizzera Italiana, Lugano, Switzerland

> Kathy Rowan Intensive Care National Audit and Research Centre, London, UK

Martin Sigurdsson University of Iceland, Faculty of Medicine, Department of Anesthesia and Critical Care, Landspitali University Hospital, Reykjavik, Iceland

Wangari Silka Dr Wangari Silka, Intensive Care Unit at Aga Khan Hospital, Nairobi, Kenya

> Marcio Soares D'OR Institute for research and Education, Rio de janeiro, Brazil Post Graduation Program, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil

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D.A. Dongelmans, A. Quintairos, E.A. Buanes et al.

Abigail Beane Critical Care, Mahidol Oxford Tropical Medicine Research Unit, Bangkok, Thailand Nuffield Department of Clinical Medicine, University of Oxford, Oxford, UK

> Jorge I.F. Salluh D'OR Institute for research and Education, Rio de janeiro, Brazil Post Graduation Program, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil

Grazielle Viana D'OR Institute for research and Education, Rio de janeiro, Brazil

David Pilcher

Department of Intensive Care, Alfred Health, Commercial Road, Prahran, VIC 3004, Australia

The Australian and New Zealand Intensive Care Society (ANZICS) Centre for Outcome and Resource Evaluation, Camberwell, Australia