Healthcare research data sharing and academic journal: A challenging but fruitful initiative

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Data are the building blocks the researcher uses to find the unknown, validate the hypothetically known or even disapprove of the known. Although data sharing is not new for different businesses and marketing strategies in the corporate world, the recent coronavirus disease 2019 (COVID-19) pandemic has highlighted the value of health-related research data sharing.[1] Healthcare researchers collect data on different trials and clinical studies and use them to find new therapy or effective drug, technique, etc., for better patient care and evidence-based practice. Sharing the data will enable collaborative research, helping reach a common goal earlier and more efficiently. It was evident from the call of the World Health Organization for global data sharing to mitigate COVID-19 outbreak.[2] Therefore, it has considerable potential for building knowledge and benefitting patients by finding precise medicine. For example, although many of the studies published in the current era are powered to find the primary objective with a designated minimum power of 80%, such studies are not powered to assess other objectives like rare side effects or threats to life. The number of participants required to be recruited in a study increases when the incidence or prevalence of the outcome in focus is lower. It leads to continued use of a drug or technique for a long duration despite having a life-threatening consequence before it gets noticed and withdrawn. Easily accessible data might help clinicians in managing patients with unique and rare diseases.

Nevertheless, data are not only generated in research, but also in daily patient care. With the increasing healthcare research and electronic health record (EHR) systems used for daily patient care, vast amounts of data are generated daily. Data sharing will enable us to generate big data that might help a researcher to find a solution for many clinical scenarios early.

While it is said that sharing is caring, sharing such data and building a large data bank is challenging. It is emphasised that data should be 'Findable, Accessible, Interoperable and Reusable' (FAIR) for sharing.[3] It is feasible only if the data are in electronic form. While the continued increase in digitalisation is taking away the challenge, most of the world is still deprived of or lacks proper adoption and implementation of EHR systems, which can help better data capturing, storage, transfer and translation into patient care.[4,5] Data management should have standardisation, and proper classification and coding should be used.[6] Further, vast amounts of data are also available in languages other than English. Another barrier is the proper translation, digitalisation and coding of such data to maintain data integrity.[7] Multiple repositories will be required to store such big data, and knowing which repository to use might be challenging. Further, all repositories may not be open access. Such big data will require colossal infrastructure, human resources and cost. Even if such repositories are made available, misuse of the data by

bad actors, violation of intellectual property rights and possible disclosure of personal information and confidential data cannot be ruled out. Loss of control over data and data theft by hackers for malicious intentions are genuine concerns.[8]

While these data are generated daily, there is also a dilemma on who owns the data. Even for research purposes, the researcher collects the patient's data using the existing institutional infrastructure. Sometimes, the researchers are even funded by institutions, industries and other organisations. There still needs to be more clarity on whether such data belongs to the researcher, institution or industry.[9] Negative results are not infrequent in health research, and such adversarial science data are likely to impact the profit-making industries relying on such products, which get affected by negative results. All these also raise fear of medico-legal issues.

Even obtaining data from patients might be a challenge. While the researcher collects data after informed consent and presents de-identified data, obtaining consent for data sharing might be a hurdle, especially when it is unclear who, when and for what purpose the data will be used. While institutional ethical committees and research boards enquire about the storage and future use of data collected by researchers, such professional committees still need a vigilant eye or proper rules and regulations to monitor data sharing in an open network. The challenge lies with more than administrative regulations, cost and data security. Many times, even researchers are not very keen on sharing the data. Sharing such data will require time and money, but usually for no personal gain. There are also technological challenges for transferring large datasets.[10] Further, they might be subject to institutional policies, sometimes requiring another permission process. Recently, the Indian Journal of Anaesthesia (IJA) enquired authors for data sharing. Most of the authors agreed with it as per their institutional norms. The authors who were keen to share the data published articles in different aspects and designs when seen in one of the IJA issues; five randomised controlled trials (RCTs) – two on regional analgesia for postoperative pain,[11,12] one on non–opioid-based analgesia,[13] one on multimodal drug therapy for haemodynamic stabilisation for laryngoscopy and tracheal intubation[14] and the remaining one on airway management.[15]

The International Committee of Medical Journal Editors prepares some guidelines and recommendations, and their recommendation on the trial data availability for sharing is praiseworthy and the need of the hour.[16] This recommendation can even be followed for non-trial clinical studies. A few observational, pre- and post-interventional studies and surveys were also published in IJA in August 2023. The pre-and post-intervention study analysed the phantom-based needling training for regional anaesthesia training,[17] another observational study evaluated postoperative cognitive dysfunctions in the elderly after spinal anaesthesia,[18] and a survey assessed thromboprophylaxis in neurocritical care patients.[19] Like the authors of RCTs, the authors of these studies were also keen to share their data. Sharing such practice-related data or adverse clinical outcomes, even from observational studies or non-RCTs, will help the researchers, the public and enterprises. While non-trial–related data can be shared even before publishing, research-related data are nearly always shared after the study's completion or publication, causing a significant delay. Although published research or trial-related data are the tip of iceberg, such data are still helpful for secondary analysis and *post hoc* analysis for other objectives.

The challenges are multidimensional; a systematic review found 20 barriers to data sharing. The authors categorised them into six domains, namely, technical, motivational, economic, political, legal and ethical.[20] Although deep-rooted, they could be more solid; the collaborative efforts of individuals, health institutions, healthcare enterprises and international healthcare-related organisations can overcome them. Political, legal and ethical aspects will require international collaboration and interventions from governments of different countries for dialogue and consensus. Regulations are necessary for high transparency regarding data use – especially for external data sharing. We must define the scope of shared data use and confidentiality agreements. Deploying technical information technology solutions for high-level security will also prevent data theft. A dialogue system for adversarial data, diplomatic solutions for each party's wants and needs and employing a liaison, if necessary, might also be helpful. Finally, the reluctance of the researchers to data sharing can also be reduced by providing incentives and/or academic benefits for their extra time and efforts.

Data sharing for the research already performed a few years back might still be helpful, especially when the studies were on a hot topic, recent

instrument and techniques. For example, using a high-flow nasal cannula (HFNC), ultrasound use for different perioperative producers and simulation or mannequin-based training studies can help the researchers find better, efficacious and evidence-based use of such technologies for patient care. The previous IJA issues also have published some articles on these hot areas. Abdel Twab *et al.*[21] evaluated the efficacy of HFNC during apnoeic oxygenation for foreign body removal. Thota *et al.*[22] compared HFNC with non-rebreathing facemask oxygenation in acute hypoxaemic respiratory failure. Many studies used ultrasound for perioperative pain management and evaluated the serratus anterior plane, erector spinae plane, transversalis fascia plane and thoracolumbar interfascial plane blocks.[23-25] Mounika *et al.*[26] evaluated the double-lumen tube placement in a simulated difficult airway using two advanced airway equipment. There were some practice-related articles exploring relatively less-explored horizons like the use of 6% hydroxyethyl starch to reduce propofol injection-related pain,[27] patient position for performing spinal anaesthesia and its relation with post-dura puncture headache[28] and finding the optimal position for internal jugular vein catheterisation.[29] Journals can even approach the authors of all such studies to deposit their data retrospectively to build data repositories of the journal and/or affiliated societies, which can be further used for pooled data analysis, *post hoc* analysis, secondary analysis, meta-analysis, etc.

To conclude, healthcare data are vast. Even though healthcare research data of published articles are minuscules, sharing such data can be helpful to develop evidence-based medicine early and efficiently. Academic journals can contribute to such a noble cause. Nevertheless, data sharing has a diverse pathway to travel and overcome geopolitical and ethical barriers beyond the technicality and intention of the researchers.

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