Preserving Access to CMS Data for Early-Career Researchers

Anna Lewis, MSW, LCSW; Jenny Markell, BA; Robert J. Besaw, MPH

Recently, the Centers for Medicare & Medicaid Services (CMS) announced impending changes to their data access procedures and fees, citing increased health care environment data breaches and data security concerns. Among the proposed changes is the elimination of the ability for nongovernmental researchers or institutions to obtain physical data extracts for new studies. Instead, researchers must purchase individual licenses to obtain access to Medicare or Medicaid data using the Chronic Conditions Warehouse (CCW) Virtual Research Data Center (VRDC). These individual licenses are not only nontransferrable but also cost prohibitive for graduate students and early-career investigators. Project fees would rise from approximately $20,000 per project to between $80,000 and $200,000 per project to accommodate multiple individual licenses or “seats” on the CCW VRDC.

On March 1, 2024, CMS updated its request for feedback on its proposed data access policies to include considerations from graduate students and trainees related to the number of student dissertation projects expected annually and whether lower-cost limited datasets that do not require VRDC access for early-stage researchers would be useful. Graduate students often rely on the data access of their mentors to further their own research agendas, using the scope of existing projects to develop and answer their own research questions. Doing so without full access to data would not allow student researchers to address novel questions that can contribute to enhancing the quality of Medicare and Medicaid.

Prior research by graduate students and early-career investigators using CMS data has had significant effects on health policy. Such work has quantified the effects of price changes from Medicare’s Prospective Payment System on hospital billing behaviors, whereby hospitals largely upcoded beneficiaries to diagnosis codes with the greatest price increases. Researchers have identified racial disparities in hospital readmission rates, finding that Black beneficiaries were at increased odds of hospital readmission for common conditions compared with White beneficiaries. Most recently, an evaluation of the fiscal benefits of fraud monitoring in the Medicare program determined that for each $1 spent on waste monitoring, $24 to $29 in program savings resulted.

Additionally, given the increasing role of Medicare Advantage, limiting access to both Medicare Advantage and fee-for-service Medicare data will hinder future efforts to compare use and outcomes between the programs. If researchers lose access to these data, they lose the potential to improve health care access and quality for populations covered under Medicare and Medicaid, including older adults, individuals with disabilities, unstably housed individuals, socioeconomically disadvantaged households, and other underserved populations.

Under the current system of data access, graduate students and early-career investigators can generate preliminary data to support new project proposals and strengthen the potential impact and feasibility of their applications for funding using data at their institutions. Without funding to purchase the required licenses, researchers will be unable to include power calculations or other estimations of feasibility in grant applications, and they will be less likely to obtain the necessary funding without these supporting figures. Furthermore, dissertation and training grant funds are insufficient to cover the annual fees required to access CMS data. The Agency for Healthcare Research and Quality’s R36 dissertation grants cover student stipends plus an additional $15,000 for direct costs covering up to a 17-month period. Neither this nor other prominent training awards provide the necessary funds to obtain a CCW VRDC seat. Should dissertation and training grant funding be reorganized to accommodate the proposed costs of CMS data access, fewer graduate students and early-career investigators would have access to these valuable datasets.

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students will receive any funding for their research. Discounted seat costs for graduate students could mitigate this barrier but would likely still be cost prohibitive. If price reductions are allocated by program size, this could inhibit graduate program growth. Furthermore, this could still leave early-stage investigators without access to data.

Many graduate students are under tight timelines and budgets within their departments, and new regulations may dissuade graduate students from working with CMS data. This will constrict the development of new researchers who are skilled at analyzing Medicare and Medicaid data. The new fee structure to access the CCW VDRC is likely to worsen already existing disparities between the most well-resourced researchers and those who do not have the additional financing or infrastructure to allow for ongoing access to CMS data. Currently, Black researchers’ applications to the National Institutes of Health (NIH) are less likely to be discussed at study section and receive lower scores when they are discussed. Additionally, there are significant disparities in receipt of multiple NIH grants by race, ethnicity, and gender. Without access to NIH funding, researchers from these groups could lose access to CMS data if it is no longer available institutionally.

Many current graduate students will be required to scramble to finish their research before the new fees go into effect or risk losing their access altogether, potentially derailing years of work and dedication to the evaluation and improvement of CMS programs. With these proposed changes to the CMS fees, academic institutions will be less able to offer competitive salaries and retain researchers skilled in using CMS data, further hindering the ability of graduate students to train with researchers who are familiar with and have access to CMS data. Researchers will not be the only parties affected by these changes; Medicare and Medicaid enrollees will have a less robust network of researchers seeking to provide evidence for potential improvements in health care quality and delivery.

Health care data security concerns should continue to be of paramount importance. There is regular media coverage of data breaches, ransomware attacks, and other technological security risks concerning the safe housing of health care data and research data files. However, limiting access to Medicare and Medicaid data for research has important ramifications that may outweigh the security concerns. Academic institutions currently using CMS data have strict protocols and safeguards in place to protect research data, and users receive required training in maintaining cybersecurity to reduce the possibility of data breaches. Encouraging and supporting universities, health systems, and other health care organizations to continually adapt and enhance cybersecurity training and protections will reduce further the risks of data breaches and ransomware attacks.

As graduate students at universities with strong commitments to health policy and health services research, we encourage CMS to reconsider the proposed data access policy change. Affordable and secure access to CMS data are crucial to fostering the continued development of early-career investigators as future leaders in Medicare and Medicaid research. To ensure ongoing access, we recommend that fees to access the CCW VRDC not drastically increase costs and thus severely limit access to data for emerging researchers. Instead, fees should be comparable to current fees for access to physical CMS data.

Graduate students and early-career investigators will likely be the first ones to have access to data severed due to constraints on existing budgets, and they are also the least able to secure additional funding to support their own research. Additionally, researchers who are already systematically disadvantaged and underfunded are likely to see preexisting gaps in access widen. It is therefore imperative that CMS reconsider its announced plans to restructure data access. Otherwise, the next generation of health services researchers will be left without the ability to access some of the most robust data for improving the health services of millions of Medicare and Medicaid beneficiaries.
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ARTICLE INFORMATION
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Corresponding Author: Anna Lewis, MSW, LCSW, Department of Health Policy and Management, University of Pittsburgh School of Public Health, Public Health Building, 130 De Soto St, Pittsburgh, PA 15261 (anna.lewis@pitt.edu).

Author Affiliations: Department of Health Policy and Management, University of Pittsburgh School of Public Health, Pittsburgh, Pennsylvania (Lewis); Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland (Markell); Department of Health Policy, Vanderbilt University School of Medicine, Nashville, Tennessee (Besaw).

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REFERENCES