CENTER FOR DEMOCRACY & TECHNOLOGY

<u>Final Comment:</u>

April 18, 2022

The Center for Democracy & Technology (CDT) respectfully submits this comment in response to the [Request for Information](#) ([RFI](#)) issued by the Centers for Medicare & Medicaid Services (CMS), on the development and implementation of a comprehensive access strategy for Medicaid and the Children's Health Insurance Program (CHIP). CDT applauds CMS's efforts to consider how data and technology can be used responsibly to increase access and help beneficiaries maintain public benefits.

Our comments focus on addressing improvements to enrollment and eligibility determinations, as outlined in Question 2 under Objective 1. Specifically, our comments address the question posed by CMS regarding the role of sharing data across agencies to help individuals access and maintain benefits. Appropriate and timely data sharing can play an important role in better serving individuals and ensuring that benefits determinations are based on necessary, complete, and accurate data. However, there must be procedures and limits around how and when individuals' data is shared to preserve the privacy of applicants and beneficiaries and to increase the likelihood of successful data sharing that is trusted by communities.

As a result, CMS and their state partners should ensure that benefits determinations embrace responsible and equitable data governance practices. To do so, guidance from CMS should support state agencies in taking the following three actions:

- Adopt robust data governance practices and policies
- Engage communities meaningfully and ensure transparency around data sharing
- Mitigate the risks of automated benefits determination

Adopt Robust Data Governance Practices and Policies

Data governance is "the overall management of data, including its availability, usability, integrity, quality, and security,"[1] and includes people, processes, and structures that are responsible for data and technology. To prevent privacy harms that come from inappropriate data sharing, CMS can play an important role in assisting state agencies in their efforts to share limited data across agencies. Specifically, state agencies will benefit the most from CMS providing guidance on how to implement strong data

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[1] Corey Chatis and Kathy Gosa, *Communicating the Value of Data Governance*, SLDS Issue Brief (2017) https://slds.ed.gov/services/PDCService.svc/GetPDCDocumentFile?fileId=28771.

governance policies and practices that preserve privacy and security and support responsible data sharing that engender trust.

Robust data governance practices and policies can help keep beneficiaries' data safe by addressing issues such as ensuring that someone at an agency is explicitly tasked with supporting beneficiaries' privacy, to ensure there is a coherent and strategic approach to data sharing and privacy; developing and enforcing clear policies for when and how to delete data; following best practices when transferring or porting data, to avoid data breaches; and conducting training and regular audits, to ensure that everyone follows the policies and prevent employees from mishandling data. CMS can also highlight that technology, community values, and agency needs evolve over time. As such, data governance should be an active consideration throughout the life of a data-sharing partnership to ensure that policies and practices grow and evolve in parallel.

The following recommendations represent key elements that are important for CMS to address in supporting state agencies in establishing robust data governance in conjunction with their efforts to share data across agencies:

Data Minimization
CMS should develop and provide guidance to the states to limit the amount of data they collect, share, and use to reduce the risk of privacy and security violations as well as irresponsible data use. CMS should advise state agencies to limit data collection and sharing to only what is necessary for a specific Medicaid or CHIP benefits determination. CMS can assist states to determine which data is essential to the correct and equitable administration of benefits. Collecting and sharing only necessary data helps ensure that benefit determinations will not be influenced by unnecessary or inappropriate data and minimize the possibilities for losing trust among beneficiary applicants and recipients. Moreover, the costs and risks associated with data handling and retention are lessened when there is less data to manage and store.

Access to Data
Access limitations work hand-in-hand with minimization principles to ensure that data about individual beneficiaries is only being shared, used, and accessed for appropriate uses by a limited number of authorized users. CMS can develop and provide guidance to states that detail ways in which agencies can appropriately limit access to beneficiary data. Limiting access also reduces the risk of beneficiaries' data being shared or used for inappropriate and unrelated purposes.

Data Retention, Storage, and Deletion Practices
Transparent rules and processes designed to establish secure storage, defined retention periods, and deletion practices for beneficiaries' data reduces risks associated with security failures and data breaches. CMS guidance can help states determine when beneficiary data are no longer necessary for the purpose for which the data was collected, shared, or used to minimize risks like determinations relying upon incorrect, irrelevant, or outdated data.[2] CMS should also make clear that these practices should apply both to the agency that initially collects the data and any agency with which the data is shared.

Engage Communities Meaningfully and Ensure Transparency Around Data Sharing
Community engagement, accompanied by greater transparency, has several benefits that can support individuals accessing and maintaining Medicaid and CHIP. The most important benefit of meaningful community engagement and transparency is increasing trust among community members. Unfortunately, a growing number of stories demonstrate that when public agencies share individual data without community buy-in or knowledge, they experience push back that ultimately undermines their efforts. Additionally, community engagement and transparency ensures that efforts to share data across agencies ultimately meet individuals' needs and address potential barriers, rather than perceived issues that may not actually align with community members' experiences.

To support meaningful community engagement, CMS should provide state agencies with guidance that addresses topics like identifying clear purposes for community engagement, engaging communities early in the decision-making process, and prioritizing inclusivity within community engagement efforts. CMS guidance should foster robust communication between agencies and the public they serve. Beneficiaries have a vested interest in how their data is shared and used. Engaging beneficiaries along with trusted community members and stakeholders, both when discussing and designing a sharing plan and then throughout any sharing program, can help ensure that community perspectives are understood and that any concerns they might raise can be addressed. To reap the full benefits of this type of engagement, it is important to be transparent and evenhanded. Moreover, CMS guidance should encourage agencies to invest time and resources to build long-lasting relationships of trust as positive and constructive relationships can yield continued and ongoing benefits and allow agencies

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[2] Elizabeth Laird & Hannah Quay-de la Vallee, *Balancing the Scale of Student Data Deletion and Retention in Education*, Center for Democracy & Technology, March 2019, https://cdt.org/wp-content/uploads/2019/03/Student-Privacy-Deletion-Report.pdf.

to benefit from community experience and recommendations on an ongoing basis. Finally, the data governance efforts described above should consider how to involve community members in these decisions.

Additionally, guidance from CMS about greater transparency should include requirements for states to document their policies and procedures for data collection, data use, and data sharing - including with vendors and other third parties. States should also document all decision-making based on the data.[3] CMS guidance should encourage agencies to affirmatively release information about their tools, even if not required to do so.

Mitigate the Risks of Shared Data Use by Automated Benefits Determinations
Tech-assisted and algorithmic benefit determination tools are increasingly being used by government agencies, including those who administer public benefits. Frequently, these tools use beneficiaries' data that has been shared across agencies. States find these tools appealing because that can shorten the timeliness for determinations and improve the enrollment or eligibility processes. Indeed, an increasing number of states are turning to automated algorithm-driven assessment and decision-making, relying on tools that quickly process multiple data inputs to evaluate whether a person needs assistance and how much they should receive.[4] However, to achieve these goals, tools have to produce accurate, equitable outputs, and today, some do not.[5]

CMS can help states identify if and when tech-assisted and algorithmic benefit determination tools are appropriate and when they should not be used. Specifically, CMS guidance can help states evaluate potential tools and ask the necessary questions before they are acquired or deployed. Core to any procurement and implementation decision are considerations and plans for the complete lifecycle of a tool. CMS can help state agencies implement processes through which algorithmic tools are developed, purchased, deployed, and routinely audited in accordance with the law and policy-making best practices.

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[3] Elizabeth Laird & Hugh Grant-Chapman, *Sharing Student Data Across Public Sectors*, December 2021, https://cdt.org/insights/report-sharing-student-data-across-public-sectors-importance-of-community-engagement-to-support-responsible-and-equitable-use/

[4] Lydia X. Z. Brown, Michelle Richardson & Ridhi Shetty, *Challenging the Use of Algorithm-driven Decision-making in Benefits Determinations Affecting People with Disabilities*, October 2020, https://cdt.org/wp-content/uploads/2020/10/2020-10-21-Challenging-the-Use-of-Algorithm-driven-Decision-making-in-Benefits-Determinations-Affecting-People-with-Disabilities.pdf
(See Appendix B for a chart of each state's use of algorithm-informed assessment and decision-making tools in public benefits.)

[5] *Id*.

Automated tools that are trained on biased and unrepresentative data can produce disparate outcomes that result in beneficiaries not receiving the benefits they are entitled to.[6] CMS guidance can help states ensure that any algorithmic tool is built on substantial, reliable, and relevant data. Moreover, CMS guidance can also advise states on ways to test and analyze algorithm-driven assessment and decision-making tools to ensure that they are fit for purpose, and are making benefits determinations that meet individual needs, and do not risk, result in, or perpetuate discriminatory biases or unfair treatment. Formulas, data sets, and their subsequent outputs must be reviewed on a regular basis to ensure they operate fairly, correctly, and as intended. CMS guidance can assist states to audit algorithm-driven assessment and decision-making tools regularly.

Conclusion

Any time data is shared, there is the potential for inadvertent disclosures, violation of expectations, increased administrative burden, and data used in biased manners that can limit access to benefits for eligible individuals. At the same time, data sharing can play an important role in expanding and maintaining access to public benefits like Medicaid and CHIP. The benefits associated with data sharing can only exist within privacy-protective data governance programs, meaningful community engagement, and risk mitigation of inequities in automated benefits determination, all of which build trust. As CMS considers how it can support thoughtful and limited data sharing, it should also exercise its leadership to ensure that state agencies are just as focused on engendering trust and respecting beneficiaries' privacy as they are sharing their data.

Sincerely,

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[6] Eliza Strickland, *Racial Bias Found in Algorithms That Determine Health Care for Millions of Patients*, IEEE Spectrum (Oct. 24, 2019), https://spectrum.ieee.org/racial-bias-found-in-algorithms-that-determine-health-care-for-millions-of-patients