July 31st, 2026

The Honorable Dr. Mehmet Oz
Administrator
Center for Medicare and Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: CMS-2454-IFC; Medicaid Program; Community Engagement Requirement for Certain Individuals

Dear Administrator Oz,

On behalf of the EveryLife Foundation for Rare Diseases, we write to share recommendations and concerns regarding the Interim Final Rule on Community Engagement Requirement for Certain Individuals. The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community. These comments reflect the engagement of our coalition of rare disease stakeholders around our community's shared priorities to ensure that rare disease patients and families have access to affordable health insurance coverage and the care they need to manage their rare disease.

More than 30 million Americans currently live with one of the more than 10,000 rare diseases.[1] Rare disease patients often have highly complex, chronic health conditions that can require around-the-clock care. The rare disease community relies on Medicaid for access to coverage for diagnosis, treatment, medical equipment, home healthcare, and caregiving services. In many cases, Medicaid is the only insurance program that provides the comprehensive care that rare disease patients need

Implementing Community Engagement requirements is an administratively complex process that will significantly impact Medicaid beneficiaries. Our analysis of Medicaid TMSIS data using 1,465 known rare disease diagnosis codes identified over 6 million Medicaid beneficiaries who live with one or more rare diseases in the United States.[2] While Public Law 119-21 mandated community engagement requirements, **we urge the Agency to consider a series of recommended changes before finalizing the IFR to minimize coverage loss and ensure that rare disease patients and caregivers who should be eligible for exclusions are identified. The**

[1]National Human Genome Research Institute. (2019, March 9). *Rare Diseases FAQ.* Genome.gov. https://www.genome.gov/FAQ/Rare-Diseases
[2] Ramani, S., McDannell, B., Sullivan, J., Kennedy, A., Trent, J.& Lewandowski, L. (2026). Medicaid Service Utilization by Beneficiaries with Rare Diseases. Zenodo. https://doi.org/10.5281/zenodo.20819134

rare disease-specific information provided below should be considered, in addition to the overall recommendations regarding the definition of medically frail contained in comments submitted by the Partnership to Protect Care.

Take Action to Account for the Rare Disease Coding Gap

Ex Parte Verification

As noted in the comment submitted by the Partnership to Protect Coverage (PPC), the addition of criteria requiring states to verify that one's condition significantly impairs their ability to comply conflicts with the instruction to states to rely primarily on a healthcare data-driven strategy to verify exclusions from community engagement requirements. This complication notwithstanding, the requirement for states to attempt ex parte verification can minimize the need for additional beneficiary or healthcare provider action and coverage losses for eligible beneficiaries. However, for individuals living with, and caring for those with rare diseases, an automated, code-driven process alone will systematically miss the very patients the statute was written to protect unless it is built around the coding gap and includes clear alternative verification processes.

For the vast majority of rare diseases, diagnosis codes simply do not exist. Approximately 97% of the >16,000 rare diseases in the Mondo disease terminology, an open-source medical vocabulary, have no specific ICD-10-CM code[3]. Patients without a specific code are recorded under nonspecific parent terms ("other specified," "unspecified," NOS) or symptom-only R-series codes, where they are indistinguishable from the far larger, able-bodied populations the requirement is meant to reach.

A rare disease diagnosis takes, on average, more than six years and roughly 17 health-care encounters after symptoms begin.[4] During that time, there is no specific disease code to flag, yet these patients are among the sickest and least able to sustain 80 hours per month of work[5]. Patients without a diagnosis, despite years of specialist care, carry the strongest evidence of medical severity and should be presumptively excluded pending confirmation.

The EveryLife Foundation, along with experts in rare disease informatics, developed suggestions to support states' *ex parte* processes in the short-term, and we are eager to engage with CMS to advance medium-term opportunities to leverage federally supported informatics infrastructure like Mondo to ensure states have the information they need to best understand and support beneficiaries with rare diseases. A full explanation and examples of the rare disease coding gap are included as an appendix to these comments. Suggestions include:

- **Do not rely solely on dedicated rare disease codes.** Build a proxy or composite flag to catch people on the diagnostic odyssey or those likely to have complex, genetic, and

[3] McMurry J, Matentzoglu N, Bailey K, Berg J, Jason C, Chute C, et al. Which rare diseases are best suited to diagnostic AI? A systematic selection framework. Zenodo; 2026. doi:10.5281/ZENODO.20520796

[4] Yang G, Cintina I, Pariser A, Oehrlein E, Sullivan J, Kennedy A. The national economic burden of rare disease in the United States in 2019. Orphanet J Rare Dis. 2022 Apr 12;17(1):163. doi: 10.1186/s13023-022-02299-5.

[5] McMurry J, Sizer A, Allaway R, Boerkoel C, Chen AJ, Colquitt J, et al. Critical bottlenecks in Rare Disease research and care: A community perspective. Zenodo; 2025. doi:10.5281/ZENODO.14907384

multi-system diseases without specific codes. For example, an exome or genome sequencing claim (CPT 81415-81417 or 81425-81427) combined with a threshold of specialist visits, hospitalizations, or clustered nonspecific and symptom codes (including R69, "illness, unspecified") over a defined period can trigger a presumptive exclusion or manual review.

- **Accept high-signal qualifying indicators,** such as involvement of a rare disease specialty center, genetics clinic, or Undiagnosed Diseases Network site where diagnosis codes are unavailable.
- **Use the Mondo-in-Epic and IMO crosswalk[6]** where available to identify rare disease patients and verify medical-frailty determinations, rather than making patients provide additional documentation. Mondo's hierarchical structure allows states to make policy determinations at intermediate, high-level nodes. This enables states to group related conditions based on shared, high-impact phenotypic evidence, simplifying the burden of building the exclusion list while maintaining clinical precision.
- **Do not limit claims and encounter data to the prior 12 months,** a timeline not specified in statute and not appropriate for adequately capturing all relevant data for determining medically frail status. Given long wait times for clinical specialists, extended diagnostic odysseys faced by rare disease patients, and up to a year-long lag in populating many sources of healthcare data that states can access, the allowable period should be extended to at least five years with exceptions for longer periods that are considered clinically appropriate.
- **CMS should require Mondo** rare disease codes to support deterministic analysis of exclusion eligibility in systems such as T-MSIS, so that rare disease patients are countable and verifiable using ex parte strategies. **CMS should support the urgency of CDC and NCHS' efforts to reform the ICD-10-CM coding process, including support for the coordinated bulk-request framework proposed by Mondo[7] and use of code R69 ("illness, unspecified").[8]** NCHS has paused new ultra-rare and genetic-condition code proposals through spring 2027 because genetic conditions are scattered across ICD-10-CM chapters and lack an organizing structure. Moving quickly to enable the addition of codes in large, coordinated batches rather than one at a time (each of which often takes years) will reduce the number of rare disease patients missed by data-driven verification processes.

<u>Expand the Use of Sworn Self-Attestation</u>

PL 119-21 specifically gave states the ability to use sworn attestation to verify compliance and exclusions and exceptions. The IFR requirements limiting self-attestation, in particular for

[6] Bookner M. Operationalizing rare disease knowledge in clinical workflows. In: IMO Health [Internet]. 25 Feb 2026 [cited 23 Jun 2026]. Available: https://www.imohealth.com/resources/operationalizing-rare-disease-knowledge-in-clinical-workflows/

[7] MONDO CDC COORDINATION https://form.fillout.com/t/fcP2cRCG13us

[8] Hernandez HW. Improving Diagnostic Uncertainty Coding in ICD-10-CM and ICD-11. In: R69 Initiative [Internet]. Available: https://www.r69initiative.org

medical frailty starting in 2028, contradict the statute's intent and will be harmful to rare disease beneficiaries.

CMS should revert to the statute's direction and allow states to permit beneficiaries whose medically frail or caregiver status cannot be verified using existing data, and in some cases, documentation, to continue to provide sworn self-attestation.

For patients with rare diseases, this required documentation combined with the inability to self-attest will create barriers to coverage. Given the long diagnostic odyssey, very limited availability of specialists overseeing their care, the high numbers of undiagnosed patients, and frequent use of out-of-state care, sworn self-attestation will minimize unworkable burdens on already strained healthcare practitioners and aid in ensuring those who remain unseen in healthcare data will not lose coverage they are eligible for.

Minimize Unnecessary Reverification Requirements

The IFR requires that states verify a beneficiary's medical frailty exclusion at least every 12 months but allows states to require more frequent verification. Requiring reverification every 12 months when scientific and clinical evidence suggests that a beneficiary's condition is chronic, progressive, or unlikely to change creates unnecessary administrative hurdles and risks unwarranted coverage and care interruptions.

The EveryLife Foundation's analysis of Medicaid beneficiaries with documented rare diseases mapped known ICD-10-CM codes for rare diseases to the AHRQ HCUP Chronic Condition Indicator, finding that 69% of rare disease ICD-10-CM codes (1,014 of 1,465) map to chronic conditions.[9] Additionally, about 70% of rare diseases are genetic in origin, and many of these result in conditions that will never improve.[10]

Beneficiaries with rare diseases and those who care for them are more likely to experience inconsistent work patterns, especially those with episodic conditions that involve periods of worsening health that disrupt work history. Verifying the impact of a diagnosis on a patient's ability to work will require additional effort from clinicians already strained by administrative burden and limited supply for most rare diseases.

To account for the complex, episodic nature of rare diseases and the limited availability of experts, states should limit reverification to once per 12 months and allow states to determine that beneficiaries with chronic, lifelong, and progressive diseases are permanently excluded from community engagement requirements, with no repeat verification requirements.

Provide States with Universal and Clear Language Describing Specified Excluded Populations and Who are and are not Required to Verify Compliance or Exclusions and Exemptions

[9] Footnote 2.

[10] Nguengang Wakap S, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet. 2020;28: 165–173. doi:10.1038/s41431-019-0508-0

Congress purposely included several populations that are not subject to community engagement requirements and for which states can't evaluate compliance or exclusion status. There is broad confusion among beneficiaries and families of those with rare diseases and the organizations that represent them regarding the verification requirements for different populations.

For example, patients who are enrolled in Medicaid through a Home and Community Based Services (HCBS) waiver pathway should automatically be a specified excluded group due to their previously verified disability status and high-need, complex care, as are beneficiaries who also have Medicare, yet our community expressed confusion when HCBS recipients or caregivers would be required to go through verification, in particular if they receive benefits under an 1115 waiver. Nearly one-third of the over 6 million beneficiaries with a rare disease in our analysis were dually eligible for Medicare and Medicaid, and 44.7% qualified through home- and community-based services (HCBS) waivers, underscoring the importance of these pathways for access to care.[11]

Additionally, the IFR takes a commendable approach to defining the specified excluded caregiver population, but the community expressed confusion about allowable criteria when caregivers are siblings and grandparents, foster parents, kinship caregivers, or close family friends who support a patient's ability to secure health care, in addition to expressing confusion about when and how verification is needed.

Serving as a caregiver to patients with rare diseases is a substantial time commitment that often requires family caregivers and family friends. Rare caregivers of adults spend about 37 hours a week providing care on average – about 12 more hours a week than general caregivers. Even more striking is the amount of care provided by rare caregivers of a child: 53 hours a week, on average, compared to 30 hours for general child caregivers.[12]

CMS should support beneficiary and family understanding of, and ability to comply with, requirements by providing clear explanations of specified excluded populations and making it clear when no action on the part of the individual is required. This explanation should be universal and not left to the states to create, enabling the rapid deployment of easy to understand and consistent messages across the country.

Collaborating with Rare Disease Patient Communities and Patient Advocacy Organizations

A recent survey found that about 55% of Medicaid enrollees are completely unaware that work requirements will become a condition of eligibility in January 2027. An additional 27% said that they have heard something but are unsure of the details.[13] Without strong patient engagement and notification, many enrollees will be unaware of requirements until it's too late.

---

[11] Ramani, S., McDannell, B., Sullivan, J., Kennedy, A., Trent, J., & Lewandowski, L. (2026). Medicaid Service Utilization by Beneficiaries with Rare Diseases. *Zenodo*. https://doi.org/10.5281/zenodo.20819134.

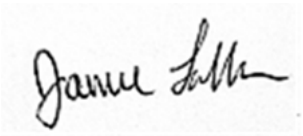
[12] National Alliance of Caregiving (2018). Rare disease caregiving in America. Can be found at: NAC-RareDiseaseReport_February-2018_WEB.pdf

[13] The Health Management Academy. (n.d.). *What 70 million Medicaid recipients don't know about their coverage*. https://hmacademy.com/blog/medicaid-enrollee-awareness-survey-2026

Patient advocacy organizations are a valuable resource. Engaging community members, especially those living with or providing caregiving for complex, high-need conditions, is essential to designing programs that reflect real-world experiences and maximize the benefits of the therapy. Patient advocacy organizations bring important disease-specific expertise that is often difficult to find elsewhere. We recommend that the final rule specifically include patients, their families, caregivers, and the advocacy organizations as interested parties to develop and disseminate resources to the rare disease community. Their support in developing community outreach plans and educational content will improve the success of the outreach to the rare disease community.

Medicaid is an essential, life-saving program for many in the rare disease community, and the EveryLife Foundation for Rare Diseases remains committed to working with CMS and state officials to protect the coverage and care that they are eligible for. Thank you for the opportunity to provide comments. If you have questions or would like to discuss opportunities to address the rare disease coding gap in community engagement implementation, please reach out to EveryLife Foundation for Rare Diseases' policy team at Jamie Sullivan, SVP of Policy and Advocacy, jsullivan@everylifefoundation.org

Sincerely,



Jamie Sullivan, MPH
Senior Vice President of Policy and Advocacy
EveryLife Foundation for Rare Diseases

Dylan Simon
Senior Director of Policy
EveryLife Foundation for Rare Diseases

CC:
Annie Kennedy, Chief Mission Officer, EveryLife Foundation for Rare Diseases
Michael Pearlmutter, Chief Executive Officer, EveryLife Foundation for Rare Diseases
Amy Gaviglio, Chair, Board of Directors, EveryLife Foundation for Rare Diseases

A Roadmap for States: Data-Driven Work Requirement Exemptions for Rare Disease Patients and Caregivers

Why a claims-based approach alone misses the rare disease patients who most need an exemption, and what states can do about it

Context. To remain eligible for Medicaid after January 2027, most adults ages 19–64 who enrolled through the ACA expansion must complete 80 hours per month of qualifying activity or qualify for an exclusion or exception[1]. Congress wrote the requirement to apply to able-bodied adults who can work, and deliberately excluded nine populations, including the **medically frail** and certain **caregivers**. On June 1, CMS released an Interim Final Rule (IFR) to provide implementation guidance to states. To limit documentation burden, states were directed to first rely on automated healthcare data-based screening to flag exclusions at scale, without requiring patients to submit documentation. While not specified in statute, CMS is also requiring that states verify the condition qualifying a patient as medically frail significantly impairs their ability to work, adding a significant complication to data-based verification strategies. Prior to the release of the June 1st IFR, most states expected to rely on lists of diagnosis and procedure codes to confirm the population considered medically frail. For individuals living with and caring for those with rare diseases, an automated, code-driven process alone will systematically miss the very patients the statute was written to protect unless it is built around the coding gap and includes clear alternative verification processes.

Why a claims-based screen cannot capture all rare disease patients

The codes mostly do not exist. Approximately **97% of the >16,000 rare diseases in the Mondo terminology have no specific ICD-10-CM code**[2]. Patients without a specific code are recorded under nonspecific parent terms (“other specified,” “unspecified,” NOS) or symptom-only R-series codes, where they are indistinguishable from the far larger, able-bodied populations the requirement is meant to reach.

The diagnostic odyssey makes them invisible in coding. A rare disease diagnosis takes, on

Disease (example and exemption type)	Current coding status	Why a codes-only screen misses
SLC6A8 creatine transporter deficiency (MONDO:0010305) Exclusion: Caregiver for child likely disabled	No dedicated ICD-10-CM code; captured only under nonspecific intellectual disability categories (e.g., F70-F79 "unspecified intellectual disabilities") and epilepsy codes (G40)	Severe intellectual disability, profound speech delay, and intractable seizures require intensive parental care, but nonspecific codes reading "unspecified intellectual disability" and "seizures" leave this invisible to claims.
POLG-related mitochondrial disease (MONDO:0008199) Exclusion: Patient (adult); highly likely medically frail	No specific ICD-10-CM code; typically coded under nonspecific categories (G11.9 ataxia, R26.9 gait disorder, E88.9 metabolic disorder)	Progressive ataxia, neuropathy, cognitive decline, and seizures make work impossible, yet in claims the patient is indistinguishable from a large population with general ataxia or metabolic issues, many of whom are able-bodied.
Undiagnosed patient on the diagnostic odyssey Exclusion: Patient; highly likely medically frail or caregiver for disabled child	Often only R69 (“illness, unspecified”) or scattered symptom (R-series) codes across encounters and specialties; or no code	Among the sickest and least able to sustain 80 hours per month, yet entirely unreachable by any disease-code screen.

average, more than six years and roughly 17 health-care encounters after symptoms begin[3]. During that time, there is no specific disease code to flag[4], yet these patients are among the sickest and least able to sustain 80 hours per month of work. Patients without a diagnosis despite years of specialist care carry the strongest evidence of medical severity and should be presumptively excluded pending confirmation.

The undercount is very large, and the data back this up. A 2023 Medicaid analysis using a crosswalk of 1,465 rare disease ICD-10-CM codes identified approximately **6.1 million** beneficiaries with a rare disease nationwide[5]. Because that crosswalk can only see the small fraction of rare diseases that have any usable ICD-10-CM code, **6.1 million is an undercount**. The true number, including everyone still on the diagnostic odyssey, is substantially higher.

How the IMO Health, Mondo, and Epic integration changes verification

The Mondo disease ontology exists to reconcile rare disease definitions across communities and knowledge sources, the fragmentation of which has historically hindered diagnostics and care. Mondo provides a rigorous, computational framework that fills the extraordinary gap of 97% of rare disease codes not available in health systems. Because of this capability, in Epic's February 2026 update, health systems using IMO Core can now apply Mondo Disease Ontology codes directly in the EHR, where more than 5,000 new rare disease codes have already been added, with thousands more being added in the next release. This changes the exclusion verification process in two ways:

- For the **state** (data-driven screening): a Mondo code is a specific, machine-readable rare disease code, whereas in non-IMO systems, there was only a nonspecific code or none. It makes automated (ex parte) identification feasible, and its built-in crosswalks (to ICD, Orphanet, OMIM) let states map a diagnosis to disabling or chronic categories automatically.
- For **providers** and patients (documentation burden): a single Mondo code consolidates evidence that would otherwise be scattered across years of records, making an exclusion or short-term exception far easier to substantiate and serving as durable proof across reverifications.

Recommendations to States

Auto-identification reduces the state's administrative overhead and reduces burdens on many patients, but a clear, comprehensive solution is needed for rare disease patients and caregivers who will be missed. A system that misses eligible patients isn't just harmful to patients; it is a budget failure for the state.

The Mondo team comprises informatics experts with deep expertise in healthcare data systems. The EveryLife Foundation for Rare Diseases, a national, non-profit patient advocacy organization focused on ensuring our healthcare systems account for the unique complexities inherent in rare diseases, is pleased to work closely with the Mondo team to offer insights to states seeking to make their ex parte verification strategies as comprehensive as possible. The Mondo team has generously offered to hold an informational session for state Medicaid teams and CMS officials to discuss practical solutions.

Short-term: what states can do now with existing systems

- **Do not rely on dedicated rare disease codes alone.** Build a proxy or composite flag to catch people on the diagnostic odyssey or those likely to have complex, genetic, and multi-system diseases without specific codes. For example, an exome or genome sequencing claim (CPT 81415-81417 or 81425-81427) combined with a threshold of specialist visits, hospitalizations, or clustered nonspecific and

symptom codes (including R69, “illness, unspecified”) over a defined period can trigger a presumptive exclusion or manual review.

- **Use the Mondo-in-Epic and IMO crosswalk**[6] where available to identify rare disease patients and verify medical-frailty determinations, rather than making patients provide additional documentation. Mondo’s hierarchical structure allows states to make policy determinations at intermediate, high-level nodes. This enables states to group related conditions based on shared, high-impact phenotypic evidence, simplifying the burden of building the exclusion list while maintaining clinical precision.
- **Accept high-signal qualifying indicators,** such as involvement of a rare disease specialty center, genetics clinic, or Undiagnosed Diseases Network site where diagnosis codes are unavailable.
- **Minimize unnecessary reverification requirements using the data.** In our crosswalk, **69% of rare disease ICD-10-CM codes (1,014 of 1,465) map to chronic conditions**[5,7] under the AHRQ HCUP Chronic Condition Indicator. Additionally, about 70% of rare diseases are genetic in origin, and many of these result in conditions that will never improve[8]. States should designate the chronic, lifelong, and progressive diseases permanently excluded, with no repeat documentation.
- **Default to the least burdensome path** when data are insufficient: presumptive eligibility for exclusion plus a simple pathway to submit documentation. States should be careful to avoid documentation requirements that necessitate new in-person encounters or impose administrative burdens on physicians, especially given the extremely limited availability of rare disease specialists.
- **Create well-vetted, easy-to-follow instructions.** Rare disease patients and caregivers should be able to easily understand if they are subject to community engagement requirements, if they qualify for an exclusion or short-term exception, and what action they must take to verify their status. Materials should reflect the complexities highlighted above and engagement with the community in their design.

Long-term: CMS, CDC, and Congress can embrace structural fixes to ensure rare disease patients are visible in healthcare data.

- **CMS should require Mondo** rare disease codes to support deterministic analysis of exclusion eligibility in systems such as T-MSIS, so that rare disease patients are countable and verifiable using ex parte strategies. **CDC and NCHS should move quickly to reform the ICD-10-CM coding process, including support for the coordinated bulk-request framework proposed by Mondo** [9] **and use of code R69 (“illness, unspecified”)** [10]. NCHS has paused new ultra-rare and genetic-condition code proposals through spring 2027 because genetic conditions are scattered across ICD-10-CM chapters and lack an organizing structure. Moving quickly to enable the addition of codes iin large, coordinated batches rather than one at a time (each of which often takes years) will reduce the number of rare disease patients missed by data-driven verification processes.
- **Support progress towards ICD-11 adoption.** ICD-11 is integrating Mondo directly, and will give rare diseases the native, granular representation that ICD-10-CM lacks today.

Sources

1. Arrington, [r-Tx-19] JC. An act to provide for reconciliation pursuant to title II of H. Con. Res. 14. 1 Jul 4, 2025. Available: https://www.congress.gov/bill/119th-congress/house-bill/1/text
2. McMurry J, Matentzoglu N, Bailey K, Berg J, Jason C, Chute C, et al. Which rare diseases are best suited to diagnostic AI? A systematic selection framework. Zenodo; 2026. doi:10.5281/ZENODO.20520796
3. EveryLife Foundation for Rare Diseases / Lewin Group. The National Economic Burden of Rare Disease Study. 2021. Available: https://www.burdenstudy.org
4. McMurry J, Sizer A, Allaway R, Boerkoel C, Chen AJ, Colquitt J, et al. Critical bottlenecks in Rare Disease research and care: A community perspective. Zenodo; 2025. doi:10.5281/ZENODO.14907384
5. Ramani S, McDannell B, Sullivan J, Kennedy A, Trent J, Lewandowski L. Medicaid service utilization by beneficiaries with rare diseases. Zenodo; 2026. doi:10.5281/ZENODO.20819133
6. Bookner M. Operationalizing rare disease knowledge in clinical workflows. In: IMO Health [Internet]. 25 Feb 2026 [cited 23 Jun 2026]. Available:

https://www.imohealth.com/resources/operationalizing-rare-disease-knowledge-in-clinical-workflows/
7. Chronic Condition Indicator Refined (CCIR) for ICD-10-CM. [cited 23 Jun 2026]. Available: https://hcup-us.ahrq.gov/toolssoftware/chronic_icd10/chronic_icd10.jsp
8. Nguengang Wakap S, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet. 2020;28: 165–173. doi:10.1038/s41431-019-0508-0
9. MONDO CDC COORDINATION https://form.fillout.com/t/fcP2cRCG13us
10. Hernandez HW. Improving Diagnostic Uncertainty Coding in ICD-10-CM and ICD-11. In: R69 Initiative [Internet]. Available: https://www.r69initiative.org