RISING T1DE ALLIANCE

Making Continuous Glucose Monitoring (CGM) Data Work For People Living with Diabetes

A Cross-Sector Framework for CGM Data Access, Interoperability, And Governance

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About the Rising T1DE Alliance

The Rising T1DE Alliance (RTA) is a multi-institution collaboration working to advance data-driven, patient-centered diabetes care. Founded in 2016, RTA brings together clinicians, researchers, data scientists, health systems, people with diabetes and their families, and other partners to develop, test, and share practical approaches for turning diabetes data into better care. Its work spans data integration and interoperability, population health, remote monitoring, implementation science, evidence generation, and sustainable care models. Across these efforts, RTA's goal is to help make high-quality, proactive, technology-enabled diabetes care more accessible and scalable, so that people with diabetes can benefit from timely, actionable information regardless of where they receive care. Learn more at www.risingt1dealliance.org.

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Introduction

Continuous glucose monitors, or CGMs, have transformed diabetes care. These small wearable sensors measure glucose throughout the day and night, giving people living with diabetes, caregivers, and their care teams more information to help make better decisions about insulin dosing, food, physical activity, and other aspects of daily care. But while CGM technology has advanced rapidly, the systems for using the data have not always kept pace.

Today, CGM data often stays within the app and online platform connected to a person's device. This can make it difficult for the information to be available in a person's electronic health record (EHR), shared when they receive care at another healthcare organization, or easily accessed by members of their care team. Healthcare organizations may also struggle to use CGM data to identify people who could benefit from additional support.

For the Rising T1DE Alliance, making CGM data easier to access and use is an important next step in the evolution of data-driven diabetes care. The challenge is no longer just collecting and analyzing CGM data. It is making sure that data can be accessed, understood, and used wherever a person receives care, while protecting patient choice, privacy, and trust.

The Problem: The Data Does Not Always Follow the Patient

The United States has made progress in helping health information move between healthcare organizations. Policies give patients rights to access their health information, create protections against practices that interfere with health information exchange, and encourage the use of modern interoperability standards. Interoperability refers to the ability of different electronic systems to exchange and use information in a consistent way. However, many of these policies and frameworks were developed around EHRs and other certified health information technology. CGM data often starts somewhere else, such as in a medical device, a manufacturer's cloud platform, or a third-party data service.

This means the rules and expectations for CGM data may not be as clear or consistent before the data reaches a person's EHR. Once CGM data reaches an EHR, many familiar health-information rules apply. Before it gets there, the expectations for access, exchange, and interoperability are less consistent. At the same time, much of the technical foundation needed to solve this problem already exists. Technical standards such as FHIR can support modern data exchange, and iCoDE has established recommendations for integrating CGM data into the EHR. The next step is making these approaches easier and more consistent for healthcare organizations to use.

CGM provides a tangible example of a much broader challenge. As more health information comes from connected devices, wearables, and technologies used outside traditional healthcare settings, the lessons learned from CGM could help inform how other types of health data are accessed, shared, and used.

How We Approached the Problem

These gaps are what led the Rising T1DE Alliance to launch the CGM Data Policy Initiative. We wanted to better understand why CGM data remains difficult to access, share, and use consistently across healthcare, and what practical changes could help. Beginning in 2025, RTA brought together people and organizations with different perspectives to examine these challenges and identify possible solutions. Participants included CGM manufacturers, data aggregators, patient advocacy organizations, people living with diabetes, caregivers, quality organizations, and other partners. The initiative combined a review of the policy and regulatory landscape with five working group meetings, direct stakeholder engagement, three patient and caregiver surveys, and practical work on a shared CGM Data Dictionary and contracting principles.

Patient participation was built into the process from the beginning. Patients, caregivers, and advocacy representatives received a dedicated orientation before joining the larger group discussions, helped review the surveys before they were distributed, and participated in interpreting the findings afterward.

The result is our report, *CGM Data Policy Initiative: A Cross-Sector Framework for CGM Data Access, Interoperability, and Governance*, which describes the current challenges surrounding CGM data access and interoperability and proposes six recommendations for creating a more connected CGM data ecosystem. The initiative also produced practical resources to support implementation, including a shared CGM Data Dictionary and a set of common principles for data-sharing agreements. Together, these outputs are intended to provide both a policy framework and practical tools that organizations can build on. Participation in the initiative does not mean that every participating organization endorsed every recommendation, but the report identifies areas of substantial alignment as well as questions that still require further work.

What People Living with Diabetes Told Us

Across three surveys, one message was especially consistent: people want their data to be actionable. Most respondents were already able to see their own CGM data. The harder problem was getting that information to move across the healthcare system. In the first survey, only 29% said all their key providers could see the same data, and only 5% reported that their clinic used CGM data to proactively reach out between visits. The surveys reflect the perspectives of participating respondents and were not designed to represent every person living with diabetes.

Respondents also drew a clear distinction between using data to help them and using data to make decisions that could disadvantage them. In the second survey, 67% considered it acceptable for an insurer to use CGM data to improve coverage for diabetes services and devices, while only 11% accepted its use for eligibility or prior-authorization decisions and 9% for premiums or cost-sharing.

Trust depended strongly on transparency and control. When asked what would make them more comfortable sharing CGM data, 76% said a clear explanation of how their data would be used would increase their comfort, and 74% identified the ability to opt out of specific uses as important. Respondents also wanted more support: 70% wanted personalized recommendations based on their CGM patterns, and 52% wanted proactive outreach when concerning patterns emerged.

Together, these findings suggest that successful interoperability is not simply about moving data from one computer system to another. The goal is to make information available in ways that help people living with diabetes and clinicians act on it.

Six Recommendations for a More Connected CGM Data Ecosystem

The report identifies six interconnected recommendations. Rather than starting from scratch, they build primarily on existing health-information rules, technical standards, industry practices, and consensus processes:

1. **Clarify patient access rights for device data.** Patients should be able to access their CGM data and direct it to the healthcare providers and trusted third parties they choose, with clearer expectations for how existing health-information rights apply when data is held by device platforms.
2. **Use common interoperability standards**. CGM data should increasingly move through modern, standards-based interfaces, with FHIR as the preferred approach and essential CGM information incorporated into national interoperability standards.
3. **Extend information-sharing protections to device platforms.** Existing rules intended to keep health information from being unnecessarily blocked do not consistently apply to the device platforms where CGM

data originates. The report describes a phased approach to extending those protections and to reducing unnecessary contractual, licensing, and operational barriers while preserving appropriate protections for privacy, safety, and intellectual property.

4. **Define baseline capabilities for device-data platforms.** Reliable interoperability requires more than an API. Platforms also need capabilities such as secure authorization, audit logs, standardized data models, data-quality controls, reliable performance, and patient-directed sharing.
5. **Reduce contracting friction.** Even when technology works, progress can be delayed by lengthy and highly individualized agreements. Shared principles around issues such as permissions, consent, data granularity, and downstream sharing could provide a more consistent starting point while allowing organizations to negotiate their own agreements.
6. **Use consistent definitions for CGM data.** A measure such as Time in Range or Glucose Management Indicator should be interpreted consistently regardless of which device or platform produced it. A shared CGM Data Dictionary can help standardize definitions, calculation methods, terminology, and the context that travels with each value.

These recommendations reinforce one another. Patient access is more useful when data can move through common standards. Standards work better when platforms have reliable infrastructure. Comparable data depends on shared definitions. And none of those technical advances scale easily if every organization must create its own agreements and processes for sharing and using CGM data.

Why CGM Matters Beyond Diabetes

CGM is one example of a broader challenge. Wearables, home monitoring technologies, connected medical devices, and patient-facing apps are generating more health information outside traditional care settings, raising questions about how that data can be accessed, shared, protected, and used in care. CGM offers a practical place to work through these questions because the technology is already widely used, the clinical value of the data is well established, and much of the technical infrastructure already exists. Improving how CGM data is shared and used could benefit the diabetes community while also helping inform how other forms of device-generated and patient-generated health information are handled in the future.

What Comes Next

These recommendations are a starting point for improving how CGM data is shared and used in healthcare. More work is needed to give people living with diabetes clear and consistent choices about how their data are used, ensure healthcare organizations have the technology and processes needed to manage CGM data, and determine how CGM information can be used reliably to measure and improve the quality of diabetes care. RTA will continue to share what we learn and work with people living with diabetes, caregivers, healthcare organizations, technology developers, quality organizations, researchers, and other partners interested in improving how diabetes data can support care. Most importantly, people who use CGM should have a voice in decisions about their data. CGM data should be available, understandable, and useful wherever a person receives care, and the people generating that data should remain at the center of how it is shared and used.

Read the Full Report

For additional detail, including the full recommendations, patient survey findings, CGM Data Dictionary, and supporting resources, read CGM Data Policy Initiative: A Cross-Sector Framework for CGM Data Access, Interoperability, and Governance report at: www.risingt1dealliance.org/cgm-data-policy