


# Data Points

*A Newsletter Update from the Data Equity Coalition*

## Q4 Highlights: Readiness, Mobilization & 2026 Momentum

A defining quarter for the Data Equity Coalition (DEC), shaped by key federal action on SPD 15 implementation timelines and DEC’s continued focus on readiness, education, and state-level mobilization. While OMB timelines shifted, DEC remained aligned and clear: **the 2024 updated SPD 15 standards are active** — and the work to ensure communities are visible, protected, and accurately reflected in data must continue to advance.

1	2	3
<p><b>SPD 15 Implementation Timeline Extended — Standards Remain in Effect</b></p> <p>In October, OMB announced extensions to key SPD 15 implementation deadlines, while confirming the <b>2024 SPD 15 standards remain in effect</b>.</p> <p><b>Key timeline updates:</b></p> <ul style="list-style-type: none"> <li>▪ <b>Agency CFO + EEOC action plans:</b> Sept. 28, 2025 → March 28, 2026</li> <li>▪ <b>Federal collections alignment:</b> March 28, 2029 → Sept. 28, 2029</li> </ul> <p><b>DEC interpretation:</b> The extension provides agencies additional implementation time; however, it also introduces political risk by pushing key compliance windows beyond the 2026 midterm cycle and into the next presidential window. DEC reiterated that this moment calls for <b>readiness and accountability</b> — not retreat.</p> <p><b>Recommendation:</b></p> <ul style="list-style-type: none"> <li>▪ <b>SPD 15 readiness dashboards</b></li> <li>▪ Encourage private-sector systems (vendors, EHRs, and data dashboards)</li> <li>▪ Include preservation of <b>MENA</b> and expanded disaggregation</li> </ul>	<p><b>Interoperability Reinforced as the “Engine” for Data Equity and Visibility</b></p> <p><b>Data equity requires connected data.</b></p> <p>Standards translate into real-world outcomes:</p> <ul style="list-style-type: none"> <li>▪ <b>SPD 15</b> establishes demographic standards</li> <li>▪ <b>USCDI</b> advances required health data elements (demographics, clinical, SDOH)</li> <li>▪ <b>ONC/ASTP certification + FHIR-based APIs</b> help operationalize standards across health IT</li> </ul> <p><b>Why It Matters:</b> Interoperability enables demographic data to move across payers, providers, and public health systems — supporting more complete population visibility, accountability, and equity measurement.</p> <p><b>For additional information</b>, the webinar session can be found here:</p> 	<p><b>DEC Commitment to Practical Tools Explaining SPD 15</b></p> <ul style="list-style-type: none"> <li>▪ Clear, plain-language <b>talking points</b> for non-technical audiences</li> <li>▪ <b>Infographics</b> that demystify SPD 15 and connect it to lived impact</li> <li>▪ Support expanding awareness beyond current DEC stakeholders, including language that answers:                     <p><i>“How do we elevate the importance of SPD 15 in this moment?”</i></p> </li> </ul> <p><b>DEC key message:</b> SPD 15 is foundational to our federal infrastructure—now revised to ensure more communities are accurately represented. When identity data is collected and used responsibly, it <b>enables</b> progress tracking, accountability, and more equitable representation and investment.</p>

## Webinars & Visibility Opportunities

Refreshing visibility to: *Beyond the Aggregate webinar*:

<https://www.youtube.com/watch?v=i1ozNgxH4Is>

- Identification of expanded amplification pathways across **podcasts, LinkedIn Lives, and member networks**
- Planning to improve webinar distribution and accessibility for broader audiences



**Upcoming:** DEC will host a **LinkedIn Live on TBD - January 2026** focused on data disaggregation and SPD 15 readiness.

## State Strategy Accelerated: Toolkit + Model Legislation Development

**11 states** expressed interest in state data disaggregation bills for the 2026 legislative session with direct alignment and coordination.

**Toolkit development advanced toward:**

- Simplified messaging resources and downloadable tools
- Advocacy talking points and use case framing
- **Model legislative text**
- Stronger state/federal alignment narrative in support of interoperability



**Goal: Toolkit publication in Q1 2026, beginning with Phase 1 resources and advancing toward Phase 2 state-focused mobilization.**

## Research Reinforces Trust

Data collection is relational — and identity disclosure decisions are shaped by social context, lived experience, and trust.

**Core research insights elevated:**

- **Identity is complex**
- **Trust is earned through identity alignment**
- **Disclosure in health care is conditional** — it can be built and broken, and is not static

These findings reinforce DEC’s ongoing focus on privacy, trust-building, and respectful engagement — particularly as sensitive identity data becomes increasingly contested.



## Looking Ahead: DEC 2026 Priorities

As DEC enters 2026, the Coalition remains aligned around three priorities:

1. **SPD 15 Accountability and monitoring federal oversight**
2. **State alignment and data modernization**
3. **Private-sector implementation and partnership**



## Closing Reflection

Data equity is the foundation for the health equity movement. As timelines shift and narratives become contested, DEC will remain steadfast in its role:

**Ensuring communities are seen in data, that data standards are protected in the process, and data disaggregation remains a priority to drive accurate and equitable outcomes.**