Barriers to Patient Agency in Health Insurer Privacy Policies: A Document Analysis of Readability, Data Sharing, and Consent Mechanics

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Abstract

This study examines how privacy rights are operationalized through member-facing privacy policies from five major private health insurers operating in Georgia: Anthem Blue Cross Blue Shield, UnitedHealthcare, Aetna, Cigna, and Humana. Privacy policies are approached as navigational documents across three dimensions: scope (what information is collected and shared), comprehensibility (whether members can reasonably understand those practices), and actionability (whether members can realistically exercise the rights described).

A systematic document analysis was conducted across ten privacy policies. Readability was evaluated using the Flesch-Kincaid Grade Level, Flesch Reading Ease, and SMOG Index. Opt-out burden was operationalized as the number of documented actions required for a member to exercise a stated privacy right, following a step-count framework adapted from Nouwens et al. (2020). Document coding was supported using a structured codebook informed by the European Data Protection Board Guidelines 03/2022 and the FTC report Bringing Dark Patterns to Light (2022).

All documents exceeded the American Medical Association's recommended readability threshold for patient-facing health materials. Member-facing privacy policies described extensive collection of clinical, behavioral, commercial, and demographic information alongside broad sharing with healthcare providers, research organizations, corporate affiliates, advertising and analytics vendors, law enforcement, and in some cases correctional institutions. Among seventeen documented opt-out pathways, five described no opt-out mechanism, six demonstrated procedural asymmetry between enrollment and withdrawal, and three required written requests that insurers explicitly reserved the right to deny.

These findings suggest that administrative complexity, fragmented privacy notices, and limited transparency may shape patients' ability to understand and exercise available privacy protections. Future community-partnered research is needed to examine how these documented processes align with members' lived experiences.

1. Introduction

Health insurers routinely collect, use, and disclose personal and health information as part of claims processing, care coordination, fraud prevention, marketing, research, and administrative operations. While these practices are governed by federal and state privacy regulations, the mechanisms through which members understand, consent to, or limit these activities are primarily communicated through privacy policies and notices.

Much of the existing literature evaluates privacy regulation from legal or compliance perspectives. Comparatively less attention has been given to how privacy rights are operationalized for members attempting to understand or exercise them. This study approaches insurer privacy policies as navigational documents that shape patient agency across three complementary dimensions.

In this study, patient agency refers to members' practical ability to understand available privacy rights and exercise choices described in insurer privacy documents. This study evaluates document characteristics that may support or constrain that ability; it does not directly measure member experiences. Although these documents primarily serve legal disclosure requirements rather than educational purposes, they remain the primary mechanism through which members are expected to understand available privacy rights.

Scope refers to what information is collected and with whom it may be shared. Understanding the full scope of insurer data practices requires reading multiple documents simultaneously, as the HIPAA notice and non-HIPAA policies govern different categories of data under different regulatory regimes.

Comprehensibility refers to whether members can reasonably understand the practices described. Document readability shapes whether members have the cognitive access required to make informed decisions about their privacy.

Actionability refers to whether members can realistically exercise the privacy rights described. Opt-out friction, absent mechanisms, and insurer discretion to deny requests all bear on whether described rights translate into practical protections.

Together, these dimensions constitute the framework through which this study evaluates patient agency in insurer privacy policies.

1.1 Population of interest

This exploratory analysis is motivated by populations that experience repeated interaction with health and social service systems, including adults living with chronic illness and individuals with intersecting histories of housing instability, incarceration, substance use recovery, or other forms of structural vulnerability. These populations often navigate complex administrative systems while managing ongoing healthcare needs and may experience disproportionate exposure to insurer data practices.

People navigating insurance consent during periods of housing instability, reentry from incarceration, or recovery from substance use disorder face compounded barriers. They are disproportionately likely to have lower health literacy, less stable access to the internet or printing, and less capacity to engage in multi-step bureaucratic opt-out processes. For these populations, a postgraduate-level consent document may represent more than an inconvenience.and can become a structural barrier to meaningful consent.

1.2 Related literature

One in five US adults may find dense consent documents difficult to read, making truly informed consent a challenge (Kutner et al., 2006). Lower health literacy is more prevalent among racial and ethnic minorities, older adults, people with low educational attainment, and people with chronic illness (Berkman et al., 2011). A systematic review of 114 US medical school IRB consent forms found a mean Flesch-Kincaid score of grade 10.6, exceeding AMA readability standards by 4.6 grade levels (Paasche-Orlow et al., 2003).

Existing research on digital consent interfaces documents that opt-out processes are systematically more burdensome than opt-in processes, a pattern identified as a dark pattern associated with reduced opt-out rates (Nouwens et al., 2020; EDPB, 2023). This study adapts concepts from dark-pattern literature as an analytic lens for examining friction in privacy decision-making rather than making claims about organizational intent. Research on hospital website privacy policies found that 96% transmitted user information to third parties while only 71% included a publicly accessible privacy policy (McCoy et al., 2024). Privacy policies have doubled in length and increased a full grade level in reading difficulty over two decades (Amos et al., 2021). This study extends these findings to private insurer privacy documents with attention to a population facing compounded barriers.

2. Methods

2.1 Document collection

Privacy documents were collected from the public websites of five major private insurers operating in Georgia: Anthem Blue Cross Blue Shield, UnitedHealthcare, Aetna, Cigna, and Humana. Selection was based on market presence in Georgia and public availability of member-facing documentation.

For each insurer, publicly accessible member-facing privacy documents were collected, including the HIPAA Notice of Privacy Practices, general privacy or web and mobile privacy statement, data sharing notices where available, and financial information privacy notices governed by the Gramm-Leach-Bliley Act. Documents were accessed between June 13 and June 17, 2026. Source URLs and access dates were recorded for each document in a document inventory maintained with the project repository.. Insurers update privacy terms without prior member notice, making timestamped collection a methodological necessity rather than a formality.

Ten documents were collected across the five insurers. Where multiple document versions existed for different plan types or regulatory contexts, the primary English language member-facing document was used. The Spanish language version of the Anthem BCBS HIPAA notice was included as a secondary document to assess language accessibility. Documents were collected as PDFs where available and as Word documents otherwise. Text was extracted from PDFs using pdfplumber and from Word documents using python-docx.

2.2 Readability scoring

Three validated readability metrics were applied to each document. **Flesch-Kincaid Grade Level** translates readability into a US school grade level using average sentence length and

average syllables per word. The American Medical Association recommends patient health materials be written at or below a 6th grade reading level. **Flesch Reading Ease** is a 0–100 scale where higher scores indicate easier reading. **SMOG Index** estimates years of education required to understand a document based on polysyllabic word density and is the metric most commonly used in health literacy research (McLaughlin, 1969).

Readability scores were computed using the textstat Python library. Each document was scored in full without section-level filtering. All runs are timestamped to enable reproducibility and comparison across document versions.

2.3 Data scope and sharing

Document content was coded for data types explicitly described as collected or inferred, and for destinations to which data is described as shared. Coding followed a deductive approach with categories derived from the document text and from prior literature on health data practices. All claims were coded from document text only with no inferences beyond what documents explicitly state.

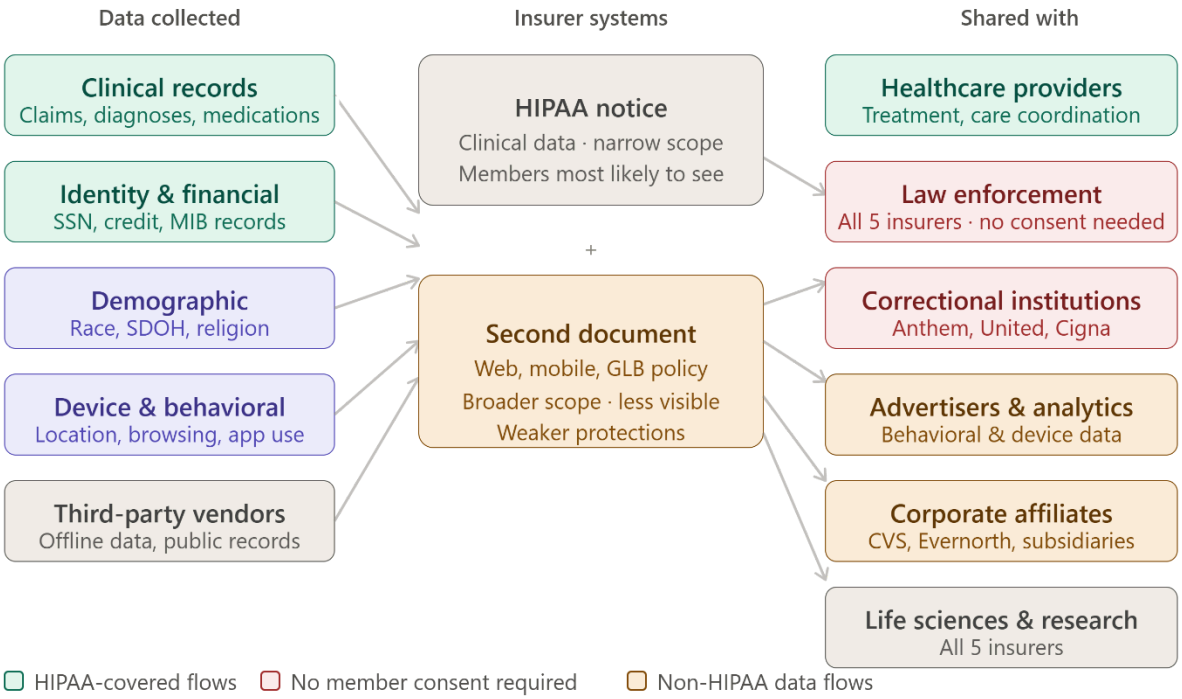


Figure 1.
Health insurer data ecosystem. Member data flows from five collection categories (left) through insurer systems operating under two parallel privacy regimes (center) to downstream destinations (right). All five insurers describe

circumstances in which member data may be disclosed to law enforcement without member authorization, consistent with applicable legal requirements. The full scope of collection and sharing is only apparent when the HIPAA notice and secondary documents are read together.

2.4 Opt-out step coding

The codebook operationalizes consent friction measurement for insurance privacy documents. Step counting follows the approach established by Nouwens et al. (2020) in their analysis of GDPR consent interfaces, extended to cover non-digital opt-out pathways predominant in health insurance documents. Friction categories align with the European Data Protection Board's deceptive design patterns taxonomy (EDPB Guidelines 03/2022, version 2.0) and the FTC's 2022 Staff Report *Bringing Dark Patterns to Light*. The step count estimates documented procedural complexity and should not be interpreted as a direct measure of cognitive effort, time burden, or user experience.

A step is any discrete action a member must take to exercise a single privacy right, counted from the moment a member decides to act to the moment the request is submitted. Steps are classified as Locate (finding information needed to act), Act (taking an action such as calling, navigating, or mailing), or Verify (providing identity confirmation). Waiting periods and system limitations are recorded separately as flags. Asymmetry is recorded when opt-out requires more steps than opt-in, a documented dark pattern per Nouwens et al. (2020) and EDPB Guidelines 03/2022.

This codebook measures described friction — what the document instructs members to do — rather than experienced friction. Described friction is a conservative measure. Actual burden may exceed what documents describe due to navigation difficulty, unclear instructions, and interface design not captured in text (Habib et al., 2020). AI-assisted coding was applied using a structured prompt administered through the Anthropic API (claude-sonnet-4-6). All coding decisions were reviewed against source documents. The full codebook, prompt, and raw coded outputs are available in the project repository.

3. Results

3.1 Readability

All ten documents exceeded the American Medical Association's recommended 6th grade readability threshold for patient-facing health materials. Flesch-Kincaid grade level scores ranged from 6.7 (UnitedHealthcare HIPAA Notice) to 18.4 (UnitedHealthcare Online Privacy Policy).

The documents governing the broadest data collection and offering the least member control were consistently the hardest to read. The two most extreme examples belong to the same insurer. UnitedHealthcare's HIPAA notice is the most readable document in the dataset at grade 6.7 while its online privacy policy is the hardest at grade 18.4. The HIPAA notice covers the narrowest data practices. The online privacy policy covers location data, behavioral tracking, device identifiers, and third-party data combining with no unified opt-out.

The Cigna Gramm-Leach-Bliley notice scores grade 16.5. It is the only document in the dataset that explicitly states members cannot limit data sharing, citing federal law as the basis. The documents describing the broadest data collection practices and the fewest member controls also exhibited the highest readability burden.

The Anthem BCBS Spanish notice scores grade 12.4, harder than the English version at grade 9.9. Spanish-speaking members receive a harder document than English-speaking members governed by identical terms.

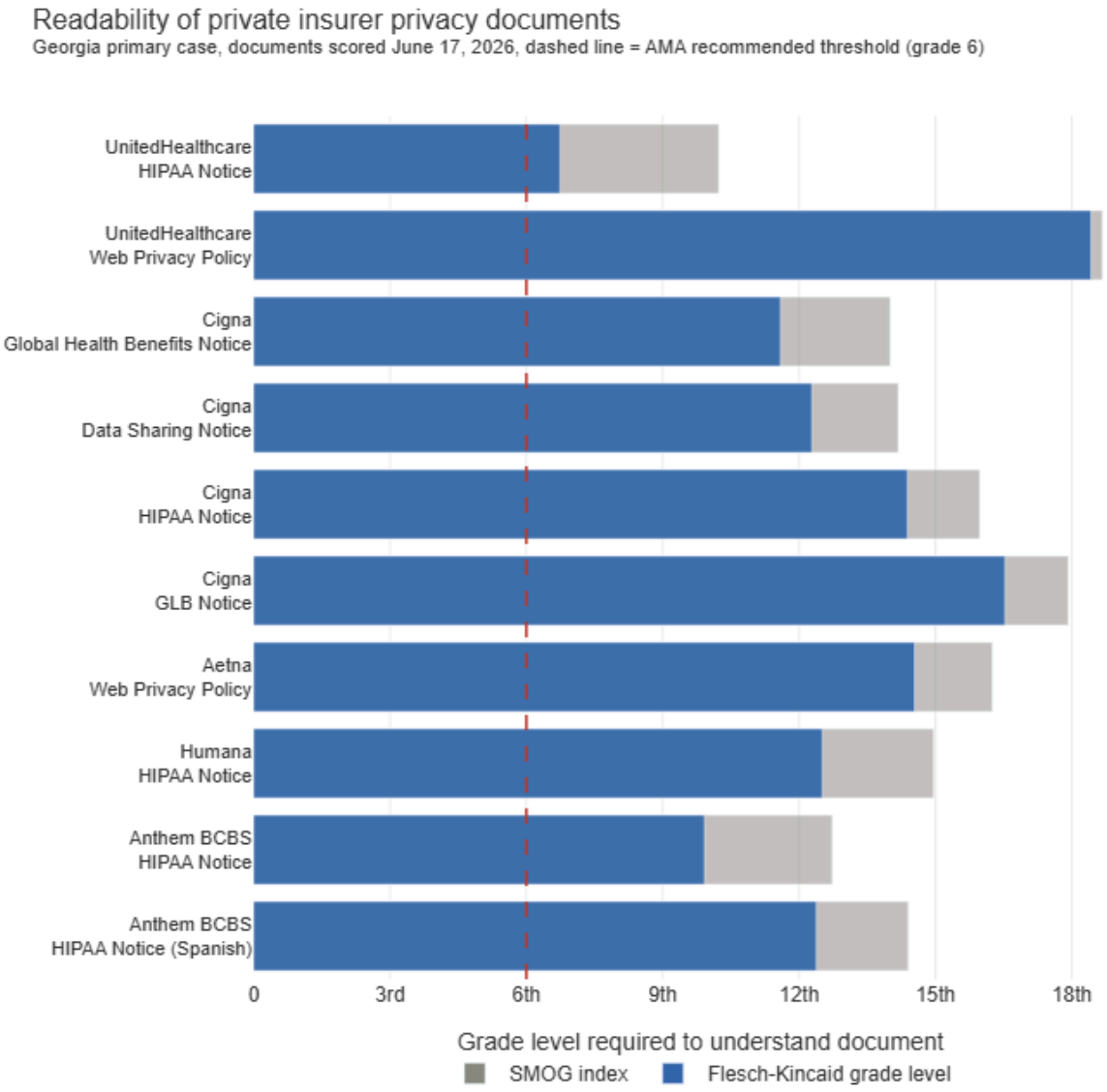


Figure 2.
Readability of member-facing privacy documents across five Georgia insurers (n = 10). Flesch-Kincaid Grade Level (blue) and SMOG Index (gray) are shown for each document. The dashed red line indicates the American Medical

Association's recommended readability threshold for patient-facing health materials (grade 6). All documents exceed this threshold. Documents are sorted by Flesch-Kincaid Grade Level descending.

These findings are consistent with prior research demonstrating that health consent documents routinely exceed recommended readability thresholds (Paasche-Orlow et al., 2003) and that lower health literacy is disproportionately concentrated among populations most affected by insurer data practices (Berkman et al., 2011; Kutner et al., 2006).

Table 1. Readability scores for all ten documents, sorted by Flesch-Kincaid Grade Level descending.

Insurer	Document	FK Grade	Reading Ease	SMOG	Word Count
UnitedHealthcare	Online Privacy Policy	18.42	19.92	18.67	5,050
Cigna	GLB Notice	16.53	26.19	17.92	1,115
Aetna	Web Privacy Policy	14.54	32.57	16.25	2,650
Cigna	HIPAA Notice	14.38	35.48	15.97	3,151
Humana	HIPAA Notice	12.51	40.88	14.96	2,014
Anthem BCBS	HIPAA Notice (Spanish)	12.38	39.93	14.40	3,867
Cigna	Data Sharing Notice	12.28	41.95	14.18	2,060
Cigna	Global Health Benefits Notice	11.59	44.16	14.00	2,674
Anthem BCBS	HIPAA Notice	9.92	55.09	12.73	3,621
UnitedHealthcare	HIPAA Notice	6.74	67.39	10.23	2,578

3.2 Data scope and sharing

Member-facing privacy documents described extensive collection across five categories: clinical and medical records (all five insurers), identity and financial information (all five insurers), demographic and identity characteristics (Anthem BCBS, UnitedHealthcare, Aetna, Cigna), device and behavioral data (UnitedHealthcare, Aetna), and third-party and commercial data (Anthem BCBS, Aetna, Cigna).

Notable insurer-specific findings include: Anthem BCBS explicitly collects and infers race, ethnicity, language, sexual orientation, and gender identity. UnitedHealthcare collects GPS and real-time location, screen touch patterns and frequency, camera access, and combines online data with offline vendor sources. Humana is the only insurer to explicitly name the Medical Information Bureau, an industry-wide data sharing consortium, as a data source. Cigna is the only insurer to explicitly acknowledge receiving payment for data disclosures and selling aggregate data to third parties.

Regarding destinations, all five insurers share member data with law enforcement without requiring member consent and with life sciences and research organizations. Three insurers

explicitly list correctional institutions as disclosure recipients. Commercial destinations include third-party advertisers (UnitedHealthcare, Aetna), analytics vendors (UnitedHealthcare, Aetna), credit bureaus (Cigna, Humana), corporate affiliates including CVS Health for Aetna and Evernorth for Cigna, and acquiring entities in mergers and acquisitions without member consent (Aetna, Cigna).

Table 2. Data types collected by insurer. ✓ = explicitly described. ◐ = partial or conditional. — = not described in available documents.

Data type	**Anthem**	**United**	**Aetna**	**Cigna**	**Humana**
Claims & treatment history	✓	✓	✓	✓	✓
Medication & prescription data	✓	✓	✓	✓	✓
Social Security number	✓	✓	✓	✓	✓
Race, ethnicity, language (inferred)	✓	—	—	—	—
Sexual orientation & gender identity	✓	—	—	—	—
Demographic data (third-party sourced)	—	✓	✓	—	—
Religious affiliation	—	—	—	✓	—
Occupation	—	—	—	✓	—
Credit bureau data	—	—	—	✓	✓
Medical Information Bureau data	—	—	—	—	✓
GPS & real-time location	—	✓	◐	—	—
Browsing behavior across websites	—	✓	✓	—	—
Screen touch patterns & frequency	—	✓	—	—	—
App usage patterns	—	✓	✓	—	—
Device identifiers (UDID, IP)	—	✓	✓	—	—
Publicly/commercially available data	✓	—	✓	✓	—
Offline vendor data combined with online	—	✓	✓	—	—
Aggregate data sold to third parties	—	—	—	✓	—

Data type	Anthem	United	Aetna	Cigna	Humana
Payment received for data disclosures	—	—	—	✓	—

3.3 Consent mechanics

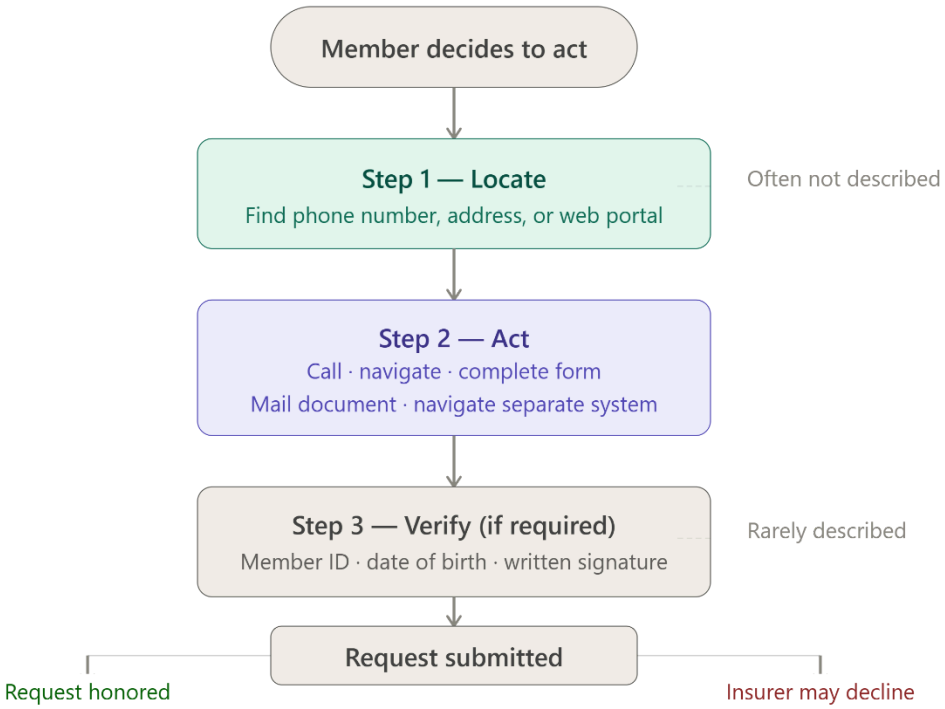
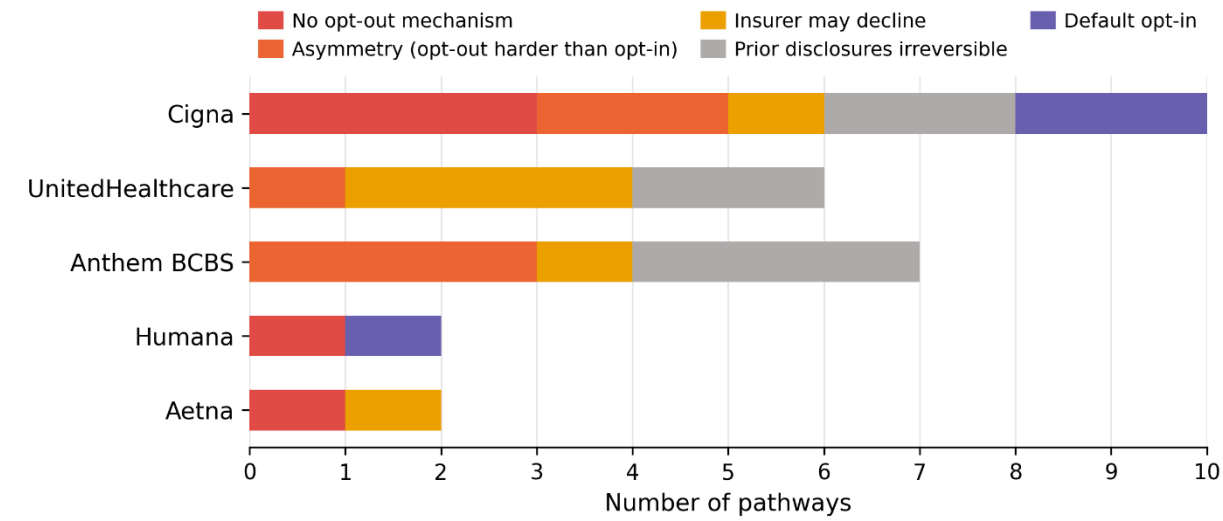


Figure 3.
Consent friction framework. Steps required to exercise a single privacy right are classified as Locate, Act, or Verify, counted from the moment a member decides to act to the moment the request is submitted. Flags are recorded separately and are not counted as steps. Three United Healthcare HIPAA pathways required three steps and carried an explicit flag that the insurer may decline the request.

This analysis identified 17 opt-out or consent-revocation pathways across privacy notices from all five insurers. Across the 17 coded pathways, documented procedural burden was generally low (0–3 steps). The most common forms of friction were absent mechanisms, insurer discretion to deny requests, inability to reverse prior disclosures, and potential asymmetries between consent and withdrawal processes.



Note. Pathways may carry multiple friction flags. Zero-step pathways indicate absence of opt-out mechanism, not frictionless access.

Figure 4.
Distribution of consent friction types across 17 coded opt-out pathways by insurer. Pathways may carry multiple friction flags. Zero-step pathways indicate absence of any opt-out mechanism, not frictionless access. Asymmetry = opt-out requires more steps than opt-in, a documented dark pattern (Nouwens et al., 2020).

Table 3. Summary of consent friction findings across 17 coded pathways.

Finding	**Pathways affected**	**Insurers**
No opt-out mechanism exists	5	Cigna (3), Aetna (1), Humana (1)
Asymmetry confirmed	6	Anthem (2), Cigna (2), United (2)
Steps present but insurer may decline	3	UnitedHealthcare (3)
Right named, mechanism not described	2	Humana (1), Aetna (1)

Five pathways did not describe any opt-out mechanism. This does not indicate frictionless access; it indicates the absence of any opt-out right. The Cigna Gramm-Leach-Bliley Notice explicitly states that federal law does not allow members to limit sharing. The Humana HIPAA notice acknowledges an opt-out right exists but provides no instructions for exercising it. The Aetna web privacy policy references consent without providing a withdrawal mechanism.

Six of 17 pathways were flagged for potential consent asymmetry, a documented dark pattern in which opt-out requires more steps than opt-in (Nouwens et al., 2020; EDPB, 2023). Because opt-in procedures were often not fully described in source documents, these flags should be interpreted as indicators for further review rather than definitive evidence of asymmetry.

All three UnitedHealthcare HIPAA pathways required three steps and carried a flag that the insurer may decline the request. The document states explicitly that it will try to honor restriction requests but is not required to do so. No recourse pathway is described for declined requests.

4. Discussion

4.1 Administrative complexity

Across seventeen coded pathways, the most common forms of friction were absent opt-out mechanisms, insurer discretion to deny requests, inability to reverse prior disclosures, and incomplete procedural disclosure. These patterns appeared more frequently than extensive step requirements. The documents place substantial responsibility on members to identify, interpret, and act on available privacy options.

4.2 Transparency and fragmentation

All five insurers maintain at least two separate privacy documents governing different categories of data under different legal regimes. The HIPAA notice is the document members are most likely to encounter. The web, mobile, or financial privacy policy governs substantially broader data practices with weaker protections and less visibility. The full scope of data collection and sharing is only apparent when all documents are read together. Members must integrate information across multiple documents to reconstruct insurer data practices.

Readability findings compound this pattern. Documents governing the broadest data collection and offering the least member control scored consistently higher on all three readability metrics. The Cigna Gramm-Leach-Bliley Notice, which explicitly prohibits member opt-out under federal law, scored grade 16.5. The UnitedHealthcare online privacy policy, which governs location, behavioral, and third-party data practices, scored grade 18.4. The UnitedHealthcare HIPAA notice, the most accessible document in the dataset, scored grade 6.7 and covers the narrowest data practices.

4.3 Patient agency

These findings have particular relevance for populations with lower health literacy, reduced digital access, or limited capacity for multi-step administrative processes. For these members, document complexity functions as a structural barrier to meaningful consent rather than an inconvenience. The combination of broad data scope, fragmented documentation, high readability demands, and restricted opt-out mechanisms suggests that privacy rights as described in these documents may not translate into practical protections for the populations most exposed to insurer data practices.

4.4 Limitations

This analysis is limited to described friction in ten documents from five insurers in a single state. Experienced friction may exceed what documents describe. Cross-state comparison and community-partnered validation are planned as next phases. The sample is limited to five

insurers selected by market presence in Georgia and document availability; findings may not generalize to other insurers or markets. AI-assisted coding introduces a single-coder limitation; human review of flagged and ambiguous pathways is recommended before publication.

5. Conclusion

This study provides a preliminary examination of how privacy rights are communicated through member-facing health insurer privacy documents. Across five major insurers operating in Georgia, privacy policies described extensive data collection and sharing practices, consistently exceeded recommended readability thresholds, and frequently presented limitations or ambiguities in the exercise of privacy rights. While this analysis evaluates document-described rather than experienced barriers, the findings suggest that administrative complexity, fragmented privacy notices, and limited transparency may shape patients' ability to understand and exercise available privacy protections. Future community-partnered research is needed to examine how these documented processes align with members' lived experiences and to identify opportunities for improving transparency and patient agency.

6. Future directions

Future work will expand this analysis in four directions:

- Comparative analyses across additional states including Massachusetts and Florida.
- Community-partnered interviews examining how members interpret privacy policies and navigate opt-out procedures, requiring IRB coverage and institutional partnership.
- Computational analyses of privacy policy language and consent architecture at scale.
- Development of publicly available tools that improve transparency around insurer data practices and support patient agency.

Community engagement

Preliminary findings were shared with organizations working in health privacy, digital rights, and patient advocacy to assess interest in future collaborative research. At the time of writing, three organizations responded. While all expressed interest in the topic, each noted limited organizational capacity to provide direct support. These conversations reinforced the importance of community-partnered validation and interdisciplinary collaboration as next steps.

Generative AI statement

Portions of this analysis were developed with assistance from Claude (Anthropic, claude-sonnet-4-6). AI assistance was used for code generation, literature identification, and methodological scaffolding. All citations were independently verified against primary sources. Coding decisions, interpretive judgments, and research conclusions are the author's own.

Data Availability

All documents analyzed, extraction scripts, coded outputs, and analysis notebooks are available at https://github.com/victoriamccray/mccr/tree/main/research/insurance-privacy.

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Appendix A. Complete opt-out coding table

Table A1. Opt-out step counts and flags across 17 coded pathways. 0 steps = no opt-out mechanism described, not frictionless access. Asymmetry = opt-out requires more steps than opt-in, a documented dark pattern (Nouwens et al., 2020). Asym. = Asymmetry.

Insurer	Document	Pathway	Steps	Flags	Asym.
Aetna	Web Privacy Policy	Email contact for privacy inquiries	2	Insurer may decline	No
Anthem BCBS	HIPAA Notice	Opt-out of PHI sharing with HIEs	2	Prior disclosures cannot be undone	No
Anthem BCBS	HIPAA Notice	Opt-out of unspecified PI sharing	2	Opt-out not available for this data type	No
Anthem BCBS	HIPAA Notice	Cancel written authorization for PHI use	1	Prior disclosures cannot be undone	Yes
Anthem BCBS	HIPAA Notice (Spanish)	Opt-out of PHI disclosure to HIEs	2	Insurer may decline	No
Anthem BCBS	HIPAA Notice (Spanish)	Opt-out of PI use for certain activities	2	Insurer may decline	No
Anthem BCBS	HIPAA Notice (Spanish)	Revoke written authorization for PHI use	1	Prior disclosures cannot be undone	Yes
Cigna	Data Sharing Notice	Provider Access Data Sharing Opt-Out	2	Default opt-in; prior disclosures cannot be undone	Yes
Cigna	Data Sharing Notice	Third-Party App Data Authorization	0	No opt-out available; prior disclosures cannot be undone; insurer may decline	No
Cigna	Global Health Benefits Notice	Marketing use of PHI	0	No opt-out available; default opt-in	Yes
Cigna	HIPAA Notice	Opt-out of disclosure to individuals in care	2	Default opt-in	Yes
Cigna	GLB Notice	No opt-out pathway described	0	No opt-out available — federal law cited	No
Humana	HIPAA Notice	Opt-out of health-related benefit contacts	1	Default opt-in; mechanism not described	No
UnitedHealthcare	Web Privacy Policy	Location Data Opt-Out (Mobile Device)	1	Prior disclosures cannot be undone; loss of functionality	No

Insurer	Document	Pathway	Steps	Flags	Asym.
UnitedHealthcare	HIPAA Notice	Revoke written permission for special uses	3	Prior disclosures cannot be undone; insurer may decline	Yes
UnitedHealthcare	HIPAA Notice	Request limit on use or sharing of HI	3	Insurer may decline	No
UnitedHealthcare	HIPAA Notice	Request confidential communications change	3	None	No