

October 12, 2026

Feedback I received and the changes I made

DBbun Invisible Illness Burden Simulator. Uri Kartoun, DBbun LLC.

Since the August 13 kickoff I have shown the work at the sprint demos and office hours and changed the product after each round. I held 8 interviews. Six were with patient advocates from the list the sprint organizers provided for user research; I arranged the other two myself, with a Long COVID patient and with a deputy director at a Massachusetts government agency. I also asked 17 people with Lyme on the LymeX Healthathon board a question each; 15 replied. People are described by role, not name. Feedback received does not imply that anyone endorses the product. People who gave feedback are not authors, co-developers or sponsors of the product.

When (2026)	Who	What I heard	What I changed	Where to see it
Aug 13	Federal lead, cost-of-illness track	Which federal resources matter most, and why?	Added a ranked list of the federal sources, each with the reason it ranks where it does (what it lets the tool check or add), not just how often it appears.	FAQ: "Which federal resources are the most valuable, and why?"
Aug 13, Sep 10	Federal leads	Show a variety of what-if scenarios and how much results vary, not one answer.	Named scenarios with a stated goal, sensitivity charts, and (Oct 5), on the five simulators with a forecast, a band showing the middle 80% of 500 random draws, labeled as illustrative.	Explore, Sensitivity and Forecast tabs
Aug 21	Federal lead	Comparing Lyme disease and Long COVID could teach each field something ("cross-pollination").	Built the cross-pollination analysis. Since Oct 5 it is a side-by-side comparison: findings with cited simulators, which burdens have tagged results in each simulator, key figures from each. Thirteen saved comparisons.	Library > Cross-pollination analysis
Aug 31, Sep 3, Sep 9	Long COVID patient; patient advocates	Participants reported that counts based on claims and diagnosis codes miss many real cases and may omit costs patients pay directly.	Added a guardrail that flags figures sourced from claims or ICD-10 codes as likely undercounts.	Overview, limitations
Sep 4, Sep 10	Patient-advocate network leader; federal lead	Be clear what is measured, assumed or modeled; show which assumptions drive which numbers; let the reader change them.	Every input is labeled observed, assumed or projected; a "what you changed" panel lists each changed input and the results it feeds; a panel ranks the assumptions that move each result most.	Explore and Overview tabs
Sep 10	Federal leads	Be intentional about sex and gender differences.	The tool discloses sex- or gender-specific findings instead of silently pooling them, in every analysis.	Overview, limitations
Sep 8, Sep 10	Patient advocate; federal lead	Patients fear sharing medical data because of coverage consequences. Review the CMS interoperability framework; how will you handle data governance?	Plain statements of what leaves the machine (a document's text, never the file, reaches the model); every model call recorded in each download; a FAQ answer on federal data standards.	FAQ, NOTICE file in each download
Sep 11	State health-policy official	Needs structured data to feed their own budget forecasting.	Added an Excel export with parameters, formula text, saved values and sources (no recalculation).	Export tab
Sep 20-23	People with Lyme on the LymeX Healthathon board (15 of the 17 I asked replied)	Care split across five or more clinics; a diagnosis delay that turns into years of downstream cost; co-infection costs; years of remote schooling for a child.	The replies were consistent with the uncoordinated-care burden category I had added on Sept 22 from a published paper; I wrote these mechanisms and the schooling example into the generation instructions.	Burden map, burden categories
Sep 24	Federal data stewards, cross-track office hours	The Medical Expenditure Panel Survey withholds three-digit condition codes with fewer than 30 cases and advises caution on Lyme costs.	Evidence cards now say "withheld", not "zero"; the limit is stated in the tool; no Lyme-cost simulator was built from that survey.	Evidence & Sources tab
Sep	AI model reviews of generated bundles	About half of ten review points held up on checking.	Fixed the points that held up in the generation instructions and checks, each with a regression test.	Automated tests (233 passing)
Oct 1	Federal lead, Beta Demo	Label time periods and real versus nominal dollars, break cost out by who pays, and signal where data are incomplete.	Added price-year and data-period labels, a "who bears the cost" table, and a burden map showing which of 16 categories have tagged results in each simulator and which do not.	Explore and Overview tabs
Oct 1	Patient advocates, Beta Demo	Make the choice of audience easier to see.	Moved the audience choice above the tabs.	Results page
Oct 8	Federal statistics experts	Long COVID "ever" and "currently" are different measures and surveys differ; the public 2022 to 2025 adult codebooks of the National Health Interview Survey contain no Lyme question.	The submission states there is no Lyme question in the survey codebooks. Planned after Oct 15: refresh the Long COVID evidence cards and label "ever" and "currently".	Submission text; planned
Oct 8	Federal regulator expert; insurance-program data staff	Software that organizes information should be labeled as an aid for human review, give no medical advice and recommend no treatment.	Removed "decision-support" wording from the product text; stated it gives no medical advice and recommends no treatment; Blue Button 2.0 is shown only against the federal sandbox.	FAQ, limits, standards answer
Sep 8, Oct 8-10	Patient advocate; community members reviewing the public demo	"Simulator" meant nothing; the page is too complicated and text-heavy; wanted a one-line summary per study, a condition filter and a picture of how it works.	Added a "what this is and is not" banner, one-line study summaries, a Lyme / Long COVID filter, a collapsed coverage map, FAQ step graphics and pictures of the interactive tool.	Library, FAQ, banner
Sep 3 to Oct 8	Advocates; federal leads (heard, not built yet)	Household income hides individual access; mold and air-quality costs; caregiver substitution; a "who loses coverage" scenario; a two-way process for flagging assumptions that do not match reality.	Not built. The household-income caveat is deliberately left open. Unmeasured burdens are shown as gaps on the burden map, not estimated.	Burden map

AI tools used. In the product: Claude Sonnet 5 (model ID claude-sonnet-5, Anthropic) reads uploaded papers and writes each simulator's specification and wording; code checks the generated specification against defined rules and performs the simulator arithmetic, and those checks do not establish that extraction or tagging is correct. To build and test the software: Claude Code with Claude Sonnet 5.5 (claude-sonnet-5-5). AI reviews of generated simulators and code: GPT and GPT-5 Codex (OpenAI; exact builds not exposed), Grok 4.5 (xAI), Gemini 3.5 (Google) and Claude Sonnet 5.5 (Anthropic). Audio overviews: scripts written with Claude Code; voice by Kokoro-82M, an open-source text-to-speech model run locally.

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DBbun Invisible Illness Burden Simulator: quality assurance log

Uri Kartoun, DBbun LLC. Covers work through October 11, 2026. Independent entry, not endorsed by HHS or NIH.

How quality was checked

Check	Who or what did it	What it found	What changed
Automated tests	Python test suite (unittest)	233 automated tests pass. Five tests for a retired two-model workflow are intentionally skipped; they are not failures.	Every defect fixed gets a regression test.
Own five-part audit	Author-directed audit using Claude Code with Claude Sonnet 5.5; read-only first, reports kept	Accuracy, function, federal-resource, interface and wording problems.	Fixed in batches, then re-tested.
AI model critiques of earlier versions of every simulator PDF (25) and comparison PDF (13)	Claude Sonnet 5.5, Grok 4.5, Gemini 3.5 (Google), GPT (OpenAI; exact build not exposed) and GPT-5 Codex, given one rubric-based prompt	Reviewers rated the comparison PDFs 3 to 4 of 5 and raised the same themes across simulators: price-year and currency labels, non-U.S. data compared with U.S. figures, text that broke the PDF layout, over-confident model wording.	Fixed once in the code and prompts, not simulator by simulator. All 25 simulators were then regenerated and the 13 comparisons rebuilt (about \$21 in model calls).
AI code review	GPT-5 Codex; report only, it changed no code	Ten findings.	Nine fixed with regression tests; one documented (the browser token is a single-user limit).
Federal cross-checks	Code, not the AI model	Twelve of 25 simulators have at least one computed federal operation; ten compare a figure with federal data. Other figures may receive context only.	The tool distinguishes computed comparisons from context-only figures and states limits on comparability.
FHIR export	Official HL7 FHIR validator, R4 4.0.1, terminology checking off. The check covered structure only; codes were not looked up in an online code library, because they are DBbun's own labels, which no standard library contains.	26 files (25 simulators and one reuse demonstration; the second reuse demonstration was not validated): 0 errors. 40 to 74 best-practice warnings each: no patient, no performer or time, no narrative text, DBbun-defined codes.	First run gave 28 errors per file (undefined DBbun extensions); fixed by shipping their definitions with each bundle.
Public demo	Rebuilt from the same code and opened live	The 25 library simulators and 13 comparisons load; FAQ and downloads match the local tool.	Rebuilt with the audio overviews, simulator numbering, the feedback log and the accuracy fixes.
Generated Python check	check_generated_python.py, run locally October 10, 2026	The downloadable Python file in each of the 25 library bundles reproduced the app's numbers: 593 results (107 at default assumptions, 486 across 115 named scenarios) and 12 forecast series (only 5 simulators have a forecast). All 605 were identical.	New simulators' files are not run automatically.
Second AI review of the whole package	GPT (OpenAI; exact build not exposed), October 10, 2026; report only	Excel exports hold saved values and formula text, with no working formulas or recalculation; one comparison said figures were "not provided" while citing them; some cost ranges and PDF text were stale.	Wording corrected, that comparison regenerated with a code check, stale text fixed.

How reviewer advice was handled

I fixed only problems that were real and systematic, checking each against the paper or the data first. Wording that claimed more than the evidence showed was not used. The reviewers are tools, not authorities: I decided what to adopt.

What this log does not show

- The AI critiques covered earlier versions. The regenerated outputs received automated checks and my own spot checks, without a second full AI critique.
- No independent person has yet completed a documented, uncoached task in the public demo. Two outside readers (a neighborhood-group member and a person with lived experience of Lyme disease and a research background) gave written feedback without doing the tasks: the first screen was too dense, the page text-heavy and my time estimate too short. I added a skip-the-grid note, a collapsed coverage map, one-line study summaries, a Lyme / Long COVID filter, a "what this is and is not" banner and FAQ pictures, and shortened my request.
- The 41 spoken overviews (25 simulator, 13 comparison, 3 about the tool) use a synthetic voice. Of the 38 simulator and comparison scripts, three received an additional paragraph-by-paragraph review using Claude Code; the other 35 received automated rule checks only. The three tool overviews were written with Claude Code and revised to my wording rules. The FHIR export is a prototype: not clinical data, not profiled to US Core or USCDI+, not certified; terminology checking was off.
- The two demonstrations on other conditions (a paper on post-surgical chronic pain and an emergency-care cost paper) used the general pipeline only. The cost paper's dollar amounts were restated in current prices by the price-index check; neither has curated federal evidence for its condition or outside validation.

AI tools and model IDs

Inside the product: Claude Sonnet 5 (claude-sonnet-5, Anthropic) reads the papers and writes each specification and its wording; code checks the generated specification against defined rules and performs the simulator arithmetic, and those checks do not establish that extraction or tagging is correct. Building and testing: Claude Code (Anthropic) with Claude Sonnet 5.5 (claude-sonnet-5-5). Audio overviews: scripts written with Claude Code; voice by Kokoro-82M, an open-source text-to-speech model run locally. Reviews: Claude Sonnet 5.5, Grok 4.5 (xAI), Gemini 3.5 (Google), GPT and GPT-5 Codex (OpenAI; exact builds not exposed). I designed and directed the simulator. AI tools wrote code and text under my continuous review, feedback and modification; people who gave feedback are not authors, co-developers or sponsors. Interviewees, forum respondents and outside testers are described by role only.

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DBbun Invisible Illness Burden Simulator: interoperability status

Uri Kartoun, PhD, DBbun LLC. As of October 11, 2026. Independent entry, not endorsed by HHS or NIH. Each row says what exists, what does not, and what is next.

Standard or framework	What DBbun does today	What it does not do	Evidence	Next step
HL7 FHIR R4	Every simulator exports its inputs and default results as FHIR R4 Observation resources, with a DocumentReference for the source paper and a Provenance resource. DBbun-defined extensions and code systems ship with the file.	No patient. Not clinical data, not profiled to US Core, not certified. The check covered structure only; codes were not looked up in an online code library, because they are DBbun's own labels, which no standard library contains.	All 26 files (25 simulators and one reuse demonstration; the second reuse demonstration has no validator record) pass the official HL7 validator (R4 4.0.1) with 0 errors, terminology checking off; 40 to 74 best-practice warnings each. Record: FHIR_VALIDATION.md.	Profile to US Core where it fits; run with terminology checking on.
CMS Interoperability Framework	Echoes its consent and transparency principles at DBbun's own scale: a document's text reaches the model but never the original file; every model call is recorded in the download. The app performs simulator arithmetic in ordinary code; generated Python downloads were run separately during the local reproduction check.	Does not claim formal alignment.	App FAQ ("What happens to my uploaded document?") and the notice file in each bundle.	Review the framework's patient-access requirements when a claims input is built.
Blue Button 2.0	Demonstrated against the CMS sandbox with synthetic test beneficiaries: an OAuth 2.0 sign-in with PKCE, Coverage and ExplanationOfBenefit read as FHIR R4, reduced in memory to yearly totals and shown beside a simulator.	No real Medicare data; sandbox only. No CMS production review. Not endorsed or certified by CMS.	A real run on October 7, 2026 read 155 synthetic claims for 2015 to 2025; a saved example is in the public demo (Evidence tab); README section; tests.	Apply for CMS production access; add consent and data-retention controls for real beneficiaries.
USCDI+	Not implemented.	At the last check (August 2026) USCDI+ had no cost-of-illness domain.	App FAQ.	Tag extracted diagnoses with ICD-10-CM codes so exports map to existing data classes.
TEFCA	Not implemented, by design.	TEFCA exchanges identified clinical records between institutions. DBbun does not implement TEFCA exchange. The local upload workflow rejects documents with Social Security numbers or medical-record-number and date-of-birth labels; this is not a guarantee that every identifier is detected.	App FAQ.	None planned.
DBbun programming interface (REST, OpenAPI)	Submit a paper, collect the result later, call a finished simulator with your own inputs; API keys and a queue.	Not a public self-service upload service; it runs on Dr. Kartoun's computer and answers only there by default.	API.md (public); exercised in the full tool.	Hosted deployment with rate limits.
Reuse for other conditions	The extraction, labeling and checking pipeline runs unchanged apart from a label and a scope sentence. Two demonstrations on other conditions (one without costs, one cost-effectiveness paper) are kept apart from the 25 simulators. The cost paper's 2022 dollar amounts are restated in 2025 prices by the code-side price-index check.	No curated condition-specific federal evidence and no outside validation. The price index is general inflation, not medical-care inflation.	Library section "Reuse demonstrations"; FAQ entry.	Curate federal evidence, comparable definitions and source review for a new condition.

Why it matters for adaptation

Bundles keep each number tied to its source, its label (observed, assumed or projected) and its model call. These links support inspection and reuse by another system; they do not establish that extraction or tagging is correct. That is the reuse case: the pipeline, the evidence labels and the guardrails are not specific to Lyme disease or Long COVID; the curated federal evidence is, and curating it is the work needed for a new condition.

Six burdens with no tagged result in a library of 25 Lyme disease and Long COVID simulators

Policy brief. Uri Kartoun, PhD, DBbun LLC. Counts rechecked October 11, 2026. Independent entry in the TOPx HHS Tech Sprint; not endorsed by HHS or NIH. Built from the 25 simulators in the DBbun library (12 Lyme disease, 13 Long COVID), derived from 23 papers and two reports.

Finding

Across the 25 simulators, 67 numeric results were tagged with one of 16 burden categories. 49 of those results (73%) fall in just three categories: work and income, direct costs of care, undercounted by official surveillance. Six categories have no tagged result in any simulator, for either condition: care continuity risk, caregiving and household labor, cognitive impact, congenital/parent-to-child transmission, longer-term opportunity costs, psychological burden. That shows where this library's numbers are thin. It does not show that these burdens are small, or that they were never studied elsewhere.

Burden category	Lyme	Long COVID	Total
Work and income	2	15	17
Direct costs of care	13	3	16
Undercounted by official surveillance	3	13	16
Diagnostic delay	6	none	6
Barriers to reaching care	4	none	4
Overall quality of life	none	3	3
Administrative burden	2	none	2
Harm from misdiagnosis-driven treatment	1	none	1
Medical disbelief and dismissal	1	none	1
Uncoordinated, fragmented care	none	1	1
Care continuity risk	none	none	none
Caregiving and household labor	none	none	none
Cognitive impact	none	none	none
Congenital/parent-to-child transmission	none	none	none
Longer-term opportunity costs	none	none	none
Psychological burden	none	none	none

Numbers are results per burden category (each result has at most one tag). Bold rows have none. Counts are tagged numeric results, not numbers of simulators.

Why it matters

- **Claims and codes miss it.** In 14 of 25 simulators the saved record flags a source warning that claims data or ICD-10 codes undercount the condition; in 20 of 25 it flags a gap in the care or evidence system.
- **What is counted is lopsided.** In this library, work and income, direct costs of care, and undercounting account for 49 of 67 tagged numeric results (73%). The six categories listed above have no tagged numeric result in these 25 simulators.

What measuring the six would look like

- **Care continuity risk:** Share of care that depends on one person.
- **Caregiving and household labor:** Caregiver hours per week.
- **Cognitive impact:** Task completion time; share needing help.
- **Congenital/parent-to-child transmission:** Transmission rate; number of children affected.
- **Longer-term opportunity costs:** Years of schooling disrupted; tutoring hours; projected career earnings lost.
- **Psychological burden:** Anxiety or depression prevalence.

Suggested next steps (the author's suggestions, not findings)

- Ask whether an existing federal survey could add an item on caregiver hours per week and one on years of schooling disrupted. The other four would need a review of clinical relevance and feasibility first.

How far to trust this

Dr. Kartoun chose the papers, not through a systematic review, so the counts describe this library, not all Lyme disease or Long COVID research. An AI model (Claude Sonnet 5, claude-sonnet-5) assigned each tag; code checked them against a fixed list. "None" means no numeric result in the saved simulator outputs was assigned that category. It does not mean the burden is absent or unstudied elsewhere. This brief summarizes published sources and saved simulator outputs; it does not analyze individual patient records. I directed this brief's preparation and reviewed and modified AI-generated text produced with Claude Code (Claude Sonnet 5.5, claude-sonnet-5-5). Live counts: public demo, Simulation library.

References

DBbun Invisible Illness Burden Simulator. Uri Kartoun, PhD, DBbun LLC. Independent entry; not endorsed by HHS or NIH.

A. The source of each of the 25 simulators (library number first). Every simulator is built from one published paper or report (23 papers and two reports). † marks the ten references on the reference slide of the organizers' August 13, 2026 kickoff presentation. All ten have a simulator in this library; inclusion does not imply endorsement.

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- Household Pulse Survey, Long COVID prevalence, 2022 to 2024 (U.S. Census Bureau with the National Center for Health Statistics).
- Medical Expenditure Panel Survey (Agency for Healthcare Research and Quality).
- National Health Interview Survey, adult codebooks 2022 to 2025 (National Center for Health Statistics).
- HL7 FHIR Release 4, version 4.0.1 (HL7 International).
- Blue Button 2.0 sandbox and the CMS Interoperability Framework (Centers for Medicare & Medicaid Services).
- USCDI+ and TEFCA (Office of the National Coordinator for Health Information Technology), named as not implemented.