

A CHRISTMAS CAROL

HEALTH DATA RESEARCH EDITION

Bah! Humbug! Information Governance!

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Stochastic Parrot
Publishing

Preface

Marley was dead, to begin with. Or at least, his research project was. It had died in the "Pre-Application Phase," strangled by a loop of emails between three different Information Governance boards who couldn't agree on the definition of "anonymised."

Ebenezer Lock did not mourn it. Ebenezer was a man of principle, and that principle was "No." Ebenezer Lock was the composite embodiment of the Joint GP IT Committee and the spiritual leader of MedConfidential.

He sat in his freezing office—The Counting House of Opt-Outs—guarding the National Data Asset like a dragon sitting on gold that no one was allowed to spend, not even to cure dementia.

"Bah!" said Ebenezer, stamping a **REJECTED** stamp on a proposal to analyse cancer screening outcomes across the UK. "Humbug!"

They say 'Public Benefit,' I say 'Theoretical Re-identification Risk.'

Keep the data in the silo! Keep it safe! Keep it dark!"

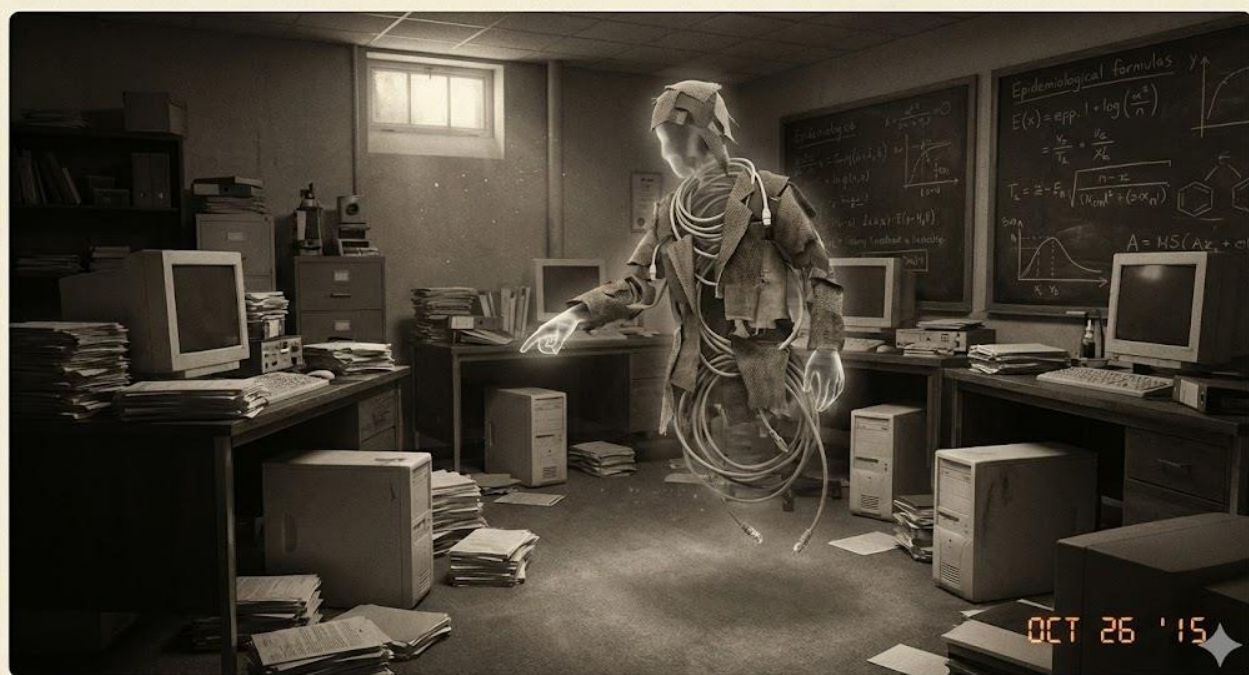
Stave I: The Ghost of Health Data Past

The clock struck one, and the room was filled with the smell of old paper, tweed, and lukewarm instant coffee. The curtains parted to reveal a spectral figure. It looked scholarly, slightly fragmented, and was carrying four different ID badges for four different universities.

"I am the Ghost of Health Data Past," the spirit intoned. "I am the Spirit of the Farr Institute."

"You look... disjointed," Ebenezer remarked.

"We were a federation of the willing!" the Spirit said, waving a hand. The walls dissolved, showing a scene from 2015. "Look, Ebenezer. Real academics. Doing epidemiology on actual servers kept under desks."



Ebenezer looked. It was a simpler time. Researchers in Manchester and London were working hard, but they were shouting at each other down bad phone lines. "Look at that efficiency," Ebenezer sneered. "They can't access each other's datasets." "Precisely," sighed the Farr Ghost. "We built the foundation. We proved you could do big science. But we were silos within silos. We lacked the infrastructure. We lacked the Gateway. But we had heart. But you, Ebenezer... you were already there. Look."

In the corner of the lab stood a younger Ebenezer Lock, holding a clipboard. A young PhD student was begging for a linkage key. "Computer says no," the young Ebenezer said. "Have you filled out the 94-page PIA?"

"I was protecting them from themselves!" old Ebenezer cried.

"You were protecting the spreadsheet until it became obsolete," the Ghost faded away. "Beware the fragmentation..."

Stave II: The Ghost of Health Data Present

The clock struck two. The room was suddenly illuminated by a blinding white light and the whirring sound of a thousand cloud servers.

A giant, jovial spirit appeared. It wore a t-shirt that said “Uniting the UK’s Health Data” and was juggling balls labelled ‘Data Hubs,’ ‘Alliances,’ and ‘Sprint Exemplars.’

"I am the Ghost of Health Data Present!" the spirit boomed. "I am HDR UK!"

"You seem very busy," Ebenezer grumbled. "And expensive."

"We are building the ecosystem!" The Spirit touched Ebenezer’s robe. "Come! To the Innovation Gateway!"

They flew over the internet. They saw a dashboard—slick, modern, filled with metadata. It was beautiful.

"Look at the metadata!" the Spirit cried. "It is discoverable! It is accessible!"

"Is it?" Ebenezer smirked. "Look closer."

They zoomed in on a researcher clicking "Request Access." The screen turned into a loading bar that stretched out into infinity. Shadows appeared around the edges of the screen—the spectres of Data Controllers.



"Here is where you live, Ebenezer," the Spirit said sorrowfully. "The technology exists. The Trusted Research Environments (TREs) are secure. But look."

They saw a meeting room. The Joint GP IT Committee sat at a long table.

"It's a very nice proposal," said one GP representative.

"But have they considered that if a patient has a rare disease and lives in a village of three people, and walks with a limp, and tweets about it, they might be identified by a supercomputer?"

"Better to block the whole dataset," said the MedConfidential representative.

"Privacy is paramount. Research is a nice-to-have."

The Spirit of HDR UK wept. "These people are dying, Ebenezer. The researchers have the code. They have the TREs. But you hold the keys, and you have swallowed them."

"I am protecting the covenant of trust!" Ebenezer insisted.

"You are protecting a graveyard!" the Spirit thundered. "If you do not solve the governance bottleneck, if you do not streamline the approvals, a darker force will come. Nature abhors a vacuum, Ebenezer. And the market... the market abhors latency."

Stave III: The Ghost of Health Data Future

The last phantom approached slowly, gravely, and silently. It was draped in a long, gold-plated trench coat. It did not speak; it only pointed a finger that looked suspiciously like a branding iron.

"Am I in the presence of the Ghost of Health Data Future?" asked Ebenezer. The Spirit nodded. It pulled out an iPhone 25 and played a pre-recorded message. The voice was unmistakable.

"We have the best data, folks. Everyone says so.

It's tremendous. It's huge."

The scene shifted. It was London, 2029. But the NHS logo was gone. In its place was a neon sign:

The Donald Trump Health Data Research Service for the UK

"What is this?" Ebenezer gasped.

"The Tariff Avoidance Deal," the Spirit's interface text-to-speech replied. "To save the UK export market on artisanal cheese and Jaguar Land Rovers, the Prime Minister agreed to the 'Total Tech Adoption Package.'"

Ebenezer looked around. The Trusted Research Environments were gone. In their place was **Foundry**. Everything was Foundry. Palantir engineers patrolled the streets, optimizing queues for coffee shops in real-time.

"But... where are the Caldicott Guardians?" Ebenezer asked.

The Spirit pointed to a museum exhibit labelled *'Relics of Inefficiency.'* Inside was a wax figure of a Data Protection Officer saying, "I need to check with legal" on a loop.

"You see," the voiceover continued,

"We got rid of the blockers. The Scrooges. The MedConfidentials? Fired. Total losers.

We released the data. All of it. Now, if you want a hip replacement, you agree to the Terms and Conditions. You want to see a GP? That's an in-app purchase. But the research? It's flying. We cured three diseases last week.

Tremendous."

Ebenezer watched in horror. A pharmaceutical company was bidding on a live stream of GP records from Yorkshire. The highest bidder got the phenotypes.

"But the privacy!" Ebenezer cried. "The consent models!"

"Consent is for people who don't want to Make Health Great Again," the voice boomed. *"You blocked the reasonable requests, Ebenezer. You made it so hard for the good guys to do ethical research that the system collapsed. So we bought it. And we don't do 'Governance Boards.' We do Deals."*



The Ghost pointed to a grave. It read: **Here lies the National Health Service. Death by Analysis Paralysis.**

"No!" Ebenezer screamed, clutching the Ghost's gold-plated robe. "I'm not a bad man! I just wanted to be careful! I can change! I can approve the applications! I can distinguish between malicious actors and university researchers! Don't let the tariffs take us! Don't let Palantir become the HDRS!"

Stave IV: The End of It

Ebenezer Lock woke up. He was in his own office. The *REJECTED* stamp was still in his hand.

He looked at the calendar. It was today. The date of the next Joint GP IT Committee meeting.

"I haven't missed it!" he cried. "The Spirits have done it all in one night!"

He rushed to his computer. He opened the backlog of data access requests.

He saw a request from a team looking at long-term cardiovascular outcomes.

"Approved!" he shouted, typing furiously. **"Tier 2 Access! Secure TRE! Linked Data! GOD BLESS US, EVERYONE!"**

He ran to the window and threw it open. A startled data analyst was walking below. "You there! Boy!" Ebenezer shouted.

"Me, sir?" "Yes, you!"

Do you know the MedConfidential office down the street?"

"I do, sir!"

"Run down there and tell them to calm down! Tell them that Safe Data Saves Lives!"

And then go to BHF Data Science Centre and tell them to spin up a docker container, **I'm approving the linked GP dataset!"**

Ebenezer Lock became as good a friend, as good a master, and as good a Data Controller as the good old city knew. He didn't just protect data; *he enabled its use.*

And though some folks laughed to see the alteration in him, and whispered that he'd gone "techno-optimist," he let them laugh. For he knew that it was better to build a secure, functioning highway for research than to wait for the wall to be bought by a tycoon and turned into a toll road.

God bless us, every phenotype.



Merry Christmas!
May 2026 bring you the
Health Data Research Service
you wished for