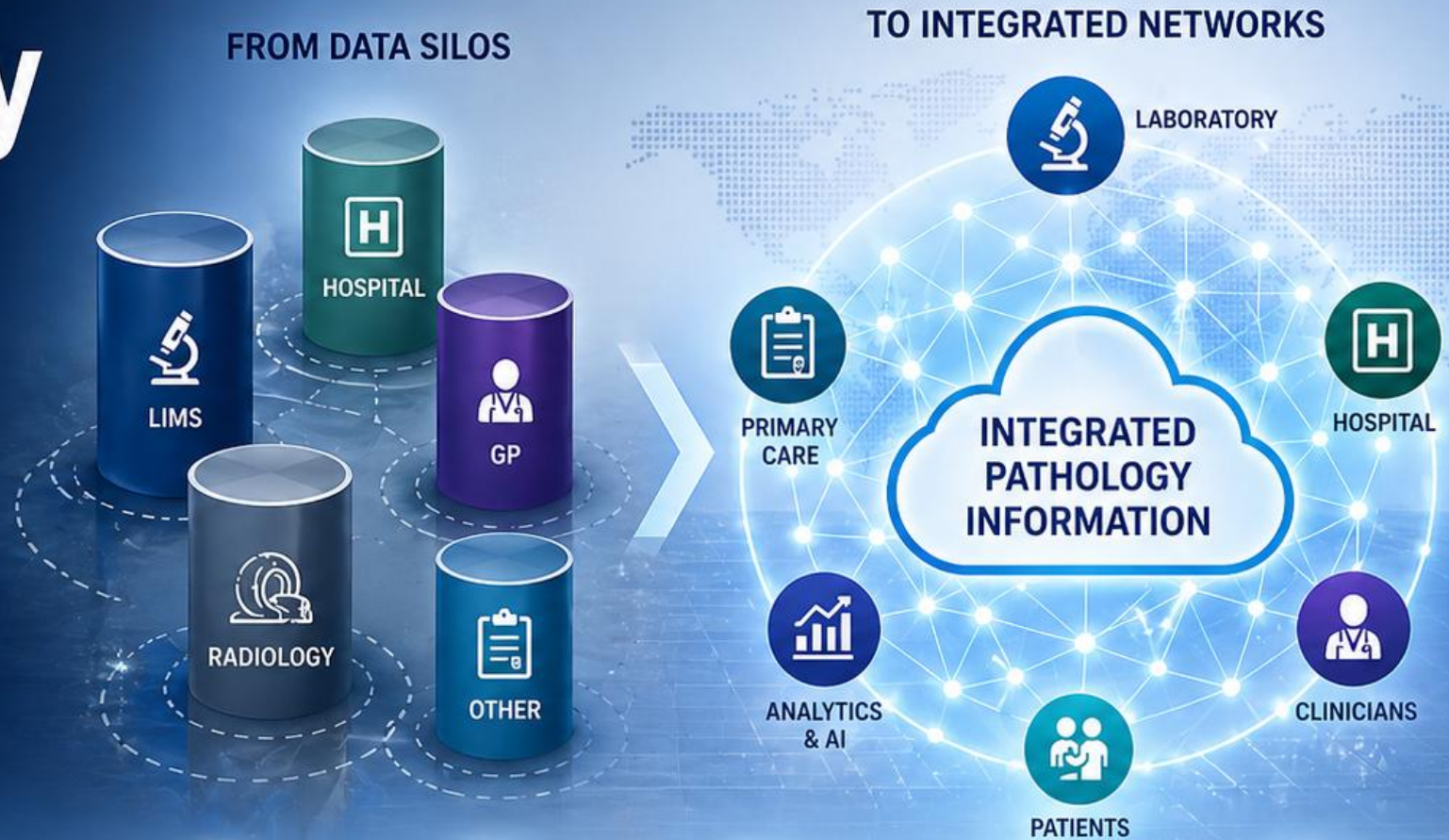


# The pathology information lifecycle: from data silos to integrated networks

**Craig Webster**  
Consultant Clinical Scientist  
Director of Pathology,  
University Hospitals Birmingham



“The only product of the Clinical Laboratory is information.”

William Dito (1979)



BETTER DATA FLOW



BETTER INFORMATION



BETTER DECISIONS



BETTER OUTCOMES



# Laboratory information

"The only product of the Clinical Laboratory is **information**. The generation of that information is the **end product** of appropriate test selection, specimen collection, analysis, result reporting and interpretation.

To achieve this sequence requires the harmonized interaction of a variety of personnel with a spectrum of expertise. Such is the domain of Medical Informatics."

- *William Dito (1979)*



**Each step generates and transforms data.**  
Failure anywhere in this chain degrades clinical value.

# Historical Origins of IT Systems

- The Six Labs Project - 1960s
  - Data processing
  - Demands of early automation
  - Data reduction
  - Laboratory management control as by-product
  - We optimised laboratories, not information flow.

# Historical Origins of IT Systems

- 1960s–80s:
  - Focus: data processing + automation
  - Outcome: local optimisation
- Systems built:
  - Lab-centric
  - Not patient-centric

# The Problem: Data Silos

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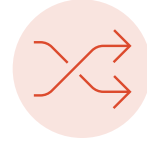
**LIMS**



**GP Systems**



**Hospital Systems**



**Coding Differences**

## Impact

### Delays

Slow turnaround from fragmented workflows

### Duplication

Repeated tests and redundant data entry

### Incomplete Picture

Gaps in the clinical record across care settings

# The Present

- **Drivers of integration:**
  - Intelligent instrumentation
  - Robotics
  - Clinical networks integration
  - Laboratory consolidation
  - Service realignments
  - Testing Outside of the Laboratory
  - Cloud
  - AI is both a driver and a consequence of integration

# Key Points

- Linking it all together is the key
- The value of joined up data sources is synergistic
  - Faster decisions
  - Fewer duplicate tests
  - Better patient pathways
- User satisfaction is higher
- Key shift:
- From **lab system** → **networked information system**

# The Present

- Technology is not the limiting factor
- Trust is
  - Patient trust
  - Organisational trust
  - Security
- The rate limiting step won't be technology but privacy / data sharing concerns and security.

# Security / Privacy

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Protecting trust in integrated pathology systems





# Quantified Toilets

Every day. Every time.

## Continuous capture of physiological data outside traditional clinical settings

Behaviour at the toilets is recorded anonymously for real-time data and health analysis.



Behaviour



Data



Insight

### Real-time anonymized data feed (CHI2014 deployment)

Time	Volume (ml)	Odor	Blood alcohol	Drugs detected	Pregnancy	Infections
10:26:52 AM	270	neutral	0.064%	no	no	none
10:26:48 AM	220	nutty	0.001%	no	no	none
10:26:41 AM	220	acidic	0.001%	no	no	none
10:25:52 AM	145	acidic	0.051%	no	no	none
10:25:41 AM	225	neutral	0.000%	yes	no	none
10:19:58 AM	250	neutral	0.000%	yes	no	none

### Why it matters



#### Passive, real-time data capture

Non-invasive and anonymous collection in everyday settings.



#### Multi-parameter physiological insight

Captures volume, odor, alcohol, drugs, pregnancy and infection indicators.



#### Potential for early detection & monitoring

Enables timely intervention and population health monitoring at scale.



Access live data  
[quantifiedtoilets.com](https://quantifiedtoilets.com)



Turning everyday behaviour into actionable health intelligence. From data to better outcomes.

## Public attitudes to health data sharing

- This is the constraint. Even when the technology exists, its use depends on what patients are willing to share
  - and that varies with trust, context, and perceived benefit.



# The consequences of security & privacy failures

Breaches cause real harm — and carry significant financial and reputational costs

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## Your confidential medical records for sale at just £1: Hunt insists plan to sell details to private firms is vital to combat epidemics – but critics fear ‘unprecedented’ privacy threat



- Campaigners describe plan as ‘unprecedented threat’ to confidentiality
- Health Secretary Jeremy Hunt says it will be a ‘boon to research’



A profound betrayal of trust... patients expect their data to be handled with the utmost care and confidentiality.

– Information Commissioner's Office

## Potential penalties for organisations (UK GDPR / DPA 2018)



### Organisations

Up to the greater of:

**£17.5 million**

or

**4%**

of total global annual turnover

Recent examples:

British Airways: £20 million (2020)

Marriott International: £18.4 million (2020)



### Senior managers

May be held personally liable where there is negligence or failure to comply with data protection law.

Fines up to

**£17.5 million**

and/or disqualification from acting as a director



### Individuals responsible (e.g. unlawful disclosure)

Could face criminal prosecution for serious breaches.

Fines up to

**£5,000**

and/or imprisonment for up to 2 years

## The wider impact



### Loss of trust

Patients lose confidence in organisations and systems.



### Financial damage

Fines, legal costs, compensation and remediation.



### Reputational harm

Negative media, public scrutiny and long-term brand impact.



### Operational disruption

Investigations, service disruption and diversion of resources.



## Protecting data protects people

Strong security and privacy are fundamental to safe, trusted healthcare.



Fines shown are maximums under UK GDPR / DPA 2018. ICO has the power to issue monetary penalties up to these limits.

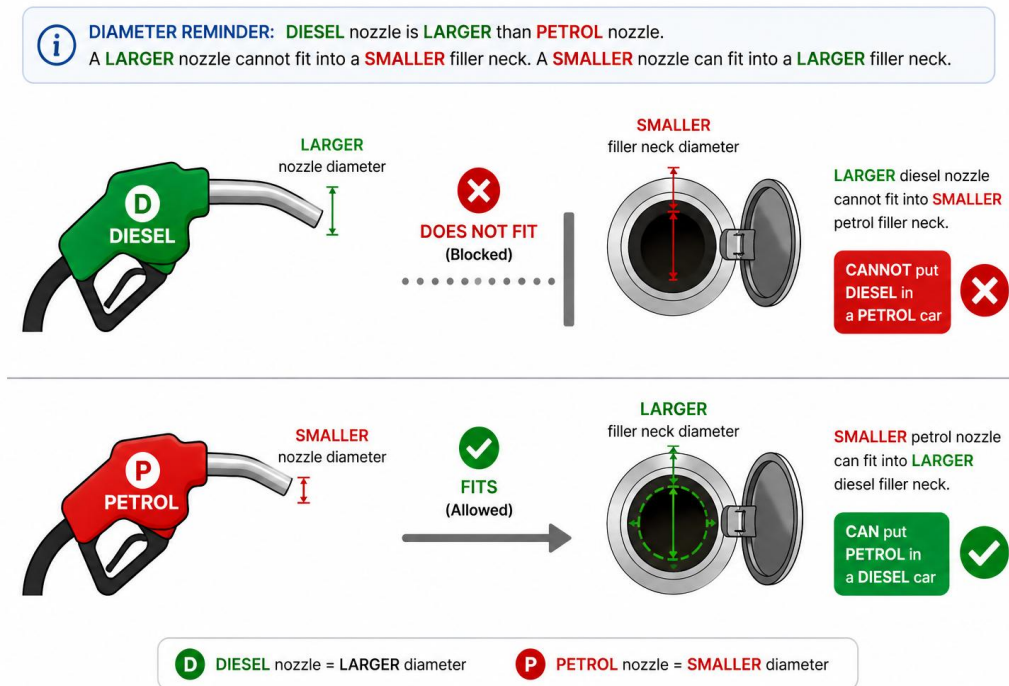
Source: ICO, 2024; Recent enforcement actions.



# Data Standards

# Standardized Work : Poke Yoke

- Prevent error at source
- Enforce standards
- Eliminate downstream impacts
  - In pathology, this means designing systems where incorrect data simply cannot enter or propagate.



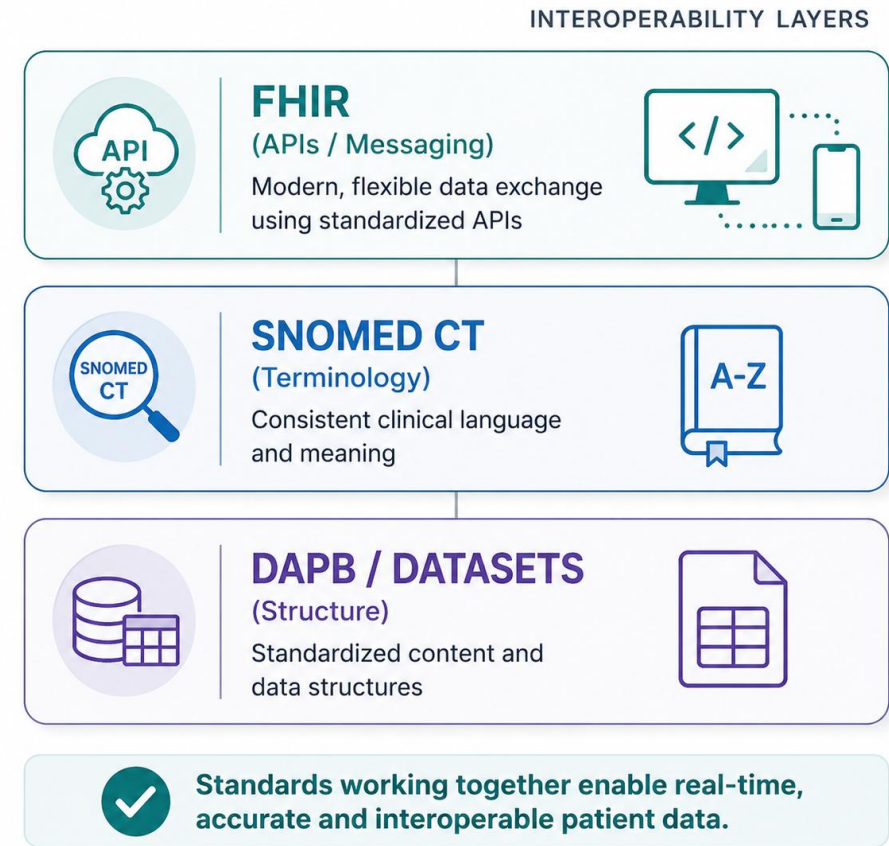
# Standardized Work : Poke Yoke

- Standardisation ensures data “fits” everywhere
  - Electronic requesting
  - Coding (SNOMED CT / NLMC)
  - Structured reporting
  - Consistent test definitions

*“If data isn’t standardised, it isn’t interoperable.”*

# Data Standards

- **Past**
  - HL7 v2 / EDIFACT
  - Message-based, system-centric
- **Transition**
  - DAPB4017 (pathology workflows)
  - CareConnect (FHIR STU3 – now deprecated)
- **Current direction**
  - **UK Core FHIR (R4)**
  - API-first, patient-centred
- **FHIR is not just a format — it is the architecture for interoperability**



# What is FHIR?

FHIR is a **standard** for sharing healthcare data via **APIs** in **real time**.

It enables systems to access the right data, about the right patient, at the right time.

## THE OLD WAY: MESSAGE-BASED



- ✗ Fixed, rigid message formats
- ✗ Built for system-to-system communication
- ✗ Data sent in batches, not in real time
- ✗ Hard to get just the data you need
- ✗ Creates silos and delays



Like sending a whole file or letter.

## THE NEW WAY: FHIR (API-BASED)



- ✓ Flexible, standards-based (resources + APIs)
- ✓ Built for data access, not just data exchange
- ✓ Real-time access to the data you need
- ✓ Granular, reusable data components
- ✓ Breaks down silos and enables interoperability



Like querying a live system for exactly what you need.



FHIR enables data to be use, d, not just moved.



Patient centred



Real-time insight



Better decisions, safer care



Foundation for AI and innovation



# Shared Care Record

Making a joined-up approach to health and care much more possible

You are here: [Home](#) > [Our initiatives](#) > Shared Care Record

Ever wondered why, when you visit your GP or hospital, they can't see all your health and care information?

And why you find yourself having to answer the same old questions over and over – about things like the medicines you take, the treatment you've had, and whether you have any allergies?



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# LIMS

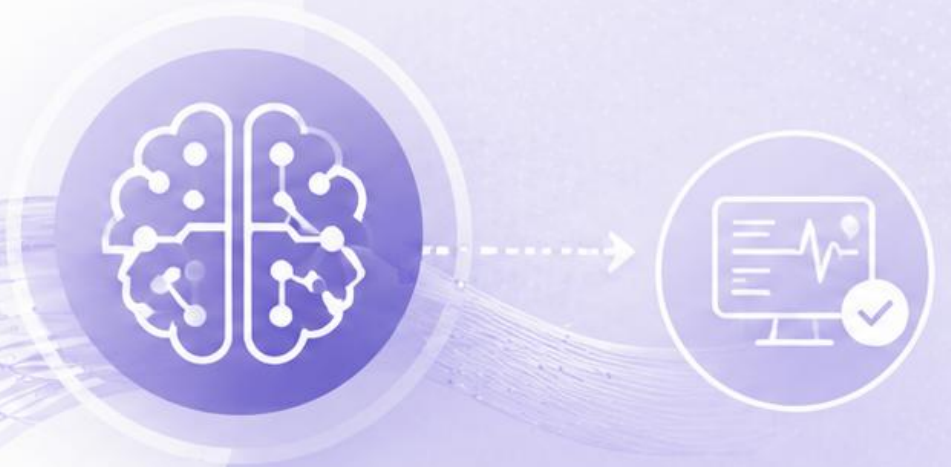
- Patient centred
  - Real-time access to a more complete and accurate patient record, including instant referral and letter communications, helps clinical decision making and allows fast responses to patient queries.
- Operational
  - Workload visibility, prioritisation
- Safety
  - Accurate, up-to-date data

# From integrated data to intelligent systems

- Integrated data enables:
  - Longitudinal patient records
  - Structured, coded results
  - Real-time availability
- Then:
- This creates the conditions for:
  - Clinical Decision Support (CDS)
  - Machine Learning (ML)
  - Predictive analytics
- “AI is not a technology layer—it is a function of data quality, structure, and flow.”

# Expansion into machine learning and clinical decision support

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# Clinical Decision Support

- Basic (rules-based)
  - Reference ranges
  - Alerts (critical values)
- Intermediate
  - Reflex testing
  - Guideline-driven prompts
- Advanced (AI-enabled)
  - Predictive models
  - Pattern recognition across datasets
  - Personalised thresholds

# AI in pathology information systems

- Pattern recognition in results over time
- Risk stratification (e.g. deterioration signals)
- Reflex and cascade testing optimisation
- Demand management and test stewardship

“This is not replacing clinicians—it is augmenting interpretation.”

# AI in pathology information systems

- AI supports:
  - Decision-making
  - Prioritisation
  - Pattern recognition
- Clinicians remain responsible for:
  - Interpretation
  - Contextual judgement
  - Final decisions

# What AI depends on

- Standardised data (NLMC, SNOMED CT)
- Interoperability (FHIR)
- Complete patient records
- Data quality and governance
- Without these → AI is unsafe or ineffective
- With these → AI becomes clinically meaningful

# The world is complicated



It's **really hard** to create expert systems to do difficult tasks, i.e. to create detailed descriptions of the world that machines can follow in order to act intelligently.



Expert rules and detailed descriptions don't scale.  
**Machines can't follow them reliably.**



Capturing all relevant possibilities is very, **very complex / impossible**. Such systems were expensive / slow / didn't work!



Exhaustive rule-based systems are not feasible.  
**Too expensive, too slow, too brittle.**



Instead, we want to **embrace uncertainty** and improve performance by **learning from data/experience**.



Learn from data.  
Improve over time.  
**Smarter, faster, more adaptable.**

# What good data enables: a simple example



## Predictive modelling depends on data quality

- Structured, consistent inputs
- Clear definitions (what does “form” mean?)
- Sufficient volume over time



## Performance improves with:

- Feature engineering (derived variables)
- Clean, comparable datasets

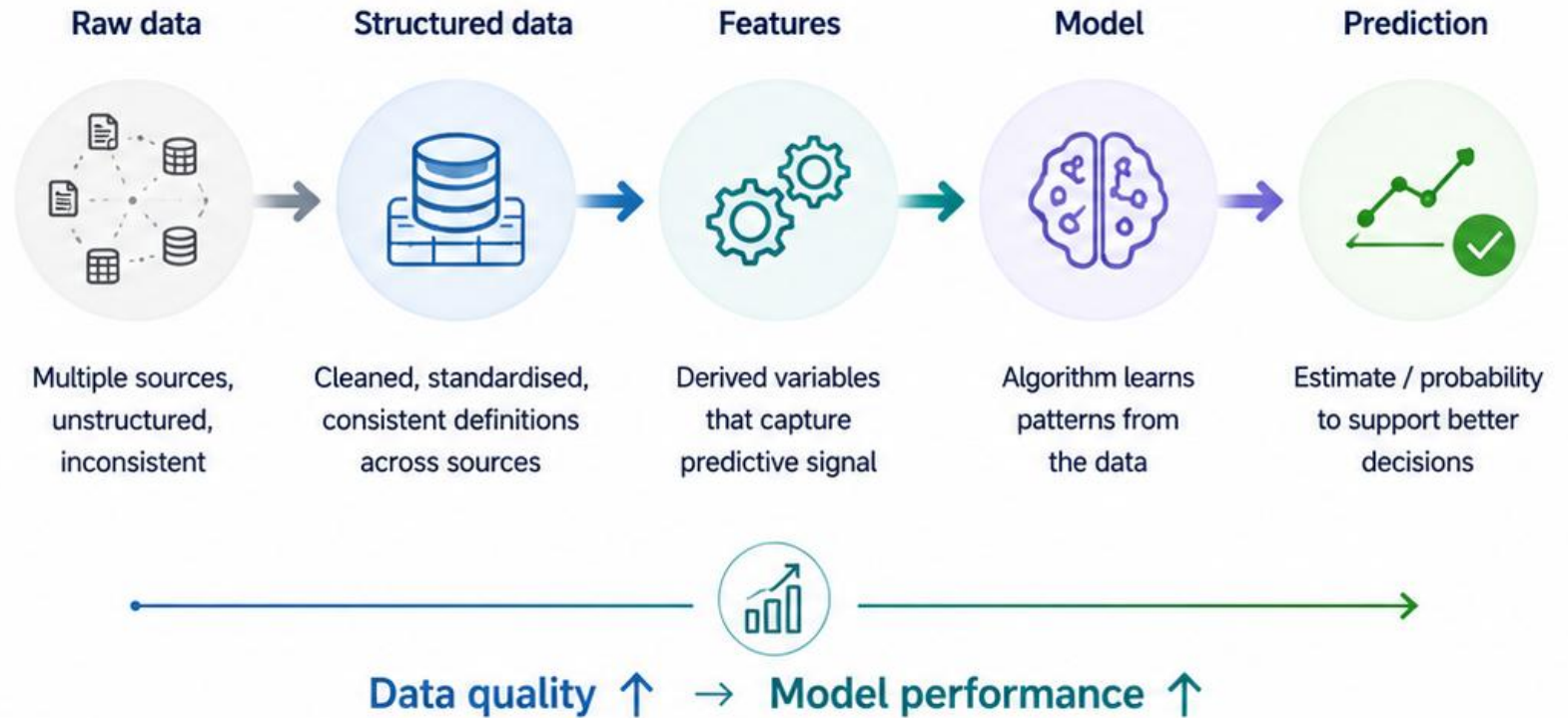


## Failure mode:

- Poor data → **confident** but **wrong** predictions



This is true in many domains—such as horse race prediction—and it is **equally true in healthcare.**



**The model is the easy part.**  
The challenge is the data.

# Clinical risks of AI in CDS

- Opaqueness (“black box” models)
- Bias from training data
- Over-reliance by clinicians
- Loss of local context

# Professional responsibilities

- Define acceptable performance standards
- Lead validation and governance
- Ensure explainability where required
- Retain clinical accountability

# Pathology is a clinical information system



**Integration creates value**  
(not data volume)



**Standards enable trust**  
(not just connectivity)



**Clinical leadership is essential**  
(not optional)



AI is not the transformation. **Data is.**

