Australian Government
Australian Digital Health Agency

INSPIRE

Interoperability and Standards in Practice:

Innovation, Readiness, Education

Australian Government
Australian Digital Health Agency

Consumer Keynote

with Dave deBronkart

INSPIRE
Interoperability and Standards in Practice: Innovation, Readiness, Education

Interop is vital to achieving healthcare's potential.

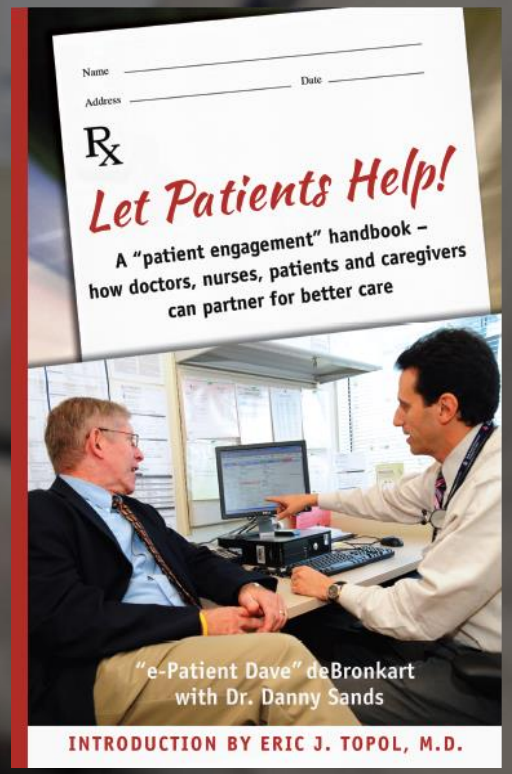
Dave deBronkart

LinkedIn / BlueSky: **ePatientDave**

dave@epatientdave.com

Society for Participatory Medicine

Bringing together e-patients and health care professionals.



"Gimme My Damn Data"
Medicine 2.0
September 18, 2009

Nobody can perform
to the top of their potential
if they don't
have the facts.

Informatics
is the information science aspect
of patients getting
the best possible care.

QUITWORKS
DELL
Healthcare Associates

**Pain, suffering,
and medical errors can happen
when information isn't
at the point of need**

unblock.health/patient-impact-stories/

Unblock Health

Individual Access Services (IAS) are here!

Home About Services Register News Press Events Blog FAQs Patient Impact Stories Resources

Unblock Health

Patient Impact Stories

Stress and Labor

Morgan Gleason's records are scattered across 23 portals; no provider anywhere has the full picture.
"I had to spend hours requesting records from 12 doctors – while unwell."

Delay and Suffering

Amy had kidney stone treatment delayed "three painful days and four sleepless nights" while her doctors tried to retrieve her records.

Delay, Suffering, Death

Stacy is a patient advocate with 20 years of experience as a healthcare executive. She still has trouble obtaining records that her clients are legally entitled to.

Three patients she was assisting have died during delays awaiting records to seek second opinions.

Sharing information safely and securely: the foundation of a modern health care system

Meredith AB Makeham, Angela Ryan

In November 2015, a Coroner's case revealed the details of a patient who died after complications that arose from routine cancer treatment. Four days earlier, a scan showing signs of potentially fatal lung toxicity had been faxed by the hospital to an incorrect number, and neither the treatment team nor the patient were aware of the results — vital information that may have prevented a further fatal dose of chemotherapy.[1] This failure of information sharing resulting in an avoidable death is not an isolated case in our Coroners' courts.[2]

Australian Digital Health Agency, Sydney, NSW.

Sharing information safely and securely: the foundation of a modern health care system

Meredith AB Makeham, Angela Ryan

In November 2015, a Coroner's case revealed the details of a patient who died after complications that arose from routine cancer treatment. Four days earlier, a scan showing signs of potentially fatal lung toxicity had been faxed by the hospital to an incorrect number, and neither the treatment team nor the patient were aware of the results — vital information that may have prevented a further fatal dose of chemotherapy.[1] This failure of information sharing resulting in an avoidable death is not an isolated case in our Coroners' courts.[2]

Australian Digital Health Agency, Sydney, NSW.

Sharing information safely and securely: the foundation of a modern health care system

Meredith AB Makeham, Angela Ryan

In November 2015, a Coroner's case revealed the details of a patient who died after complications that arose from routine cancer treatment. Four days earlier, a scan showing signs of potentially fatal lung toxicity had been faxed by the hospital to an incorrect number, and neither the treatment team nor the patient were aware of the results — vital information that may have prevented a further fatal dose of chemotherapy.[1] This failure of information sharing resulting in an avoidable death is not an isolated case in our Coroners' courts.[2]

Australian Digital Health Agency, Sydney, NSW.

Standardisation isn't bureaucracy.

It's compassion for the suffering, at scale.

I didn’t know.

Nobody can perform
to the top of their potential
if they don't
have the facts.

Not even AI.

Field note: Using AI in Healthcare

Dad James Cummings on using AI to help his rare-disease kids' doctors

JUL 24 · DAVE DEBRONKART

Priority need: Complete and organized personal longitudinal health records

The best way I can contribute to our highly-trained doctors is to organize all available facts. There is no better utilization of patient energy than aggregating their entire and accurate health data, which includes electronic health records (EHR) from all the various providers, genomic data, and all their contributed data such as wearables, social, family history, and tracking and monitoring devices.

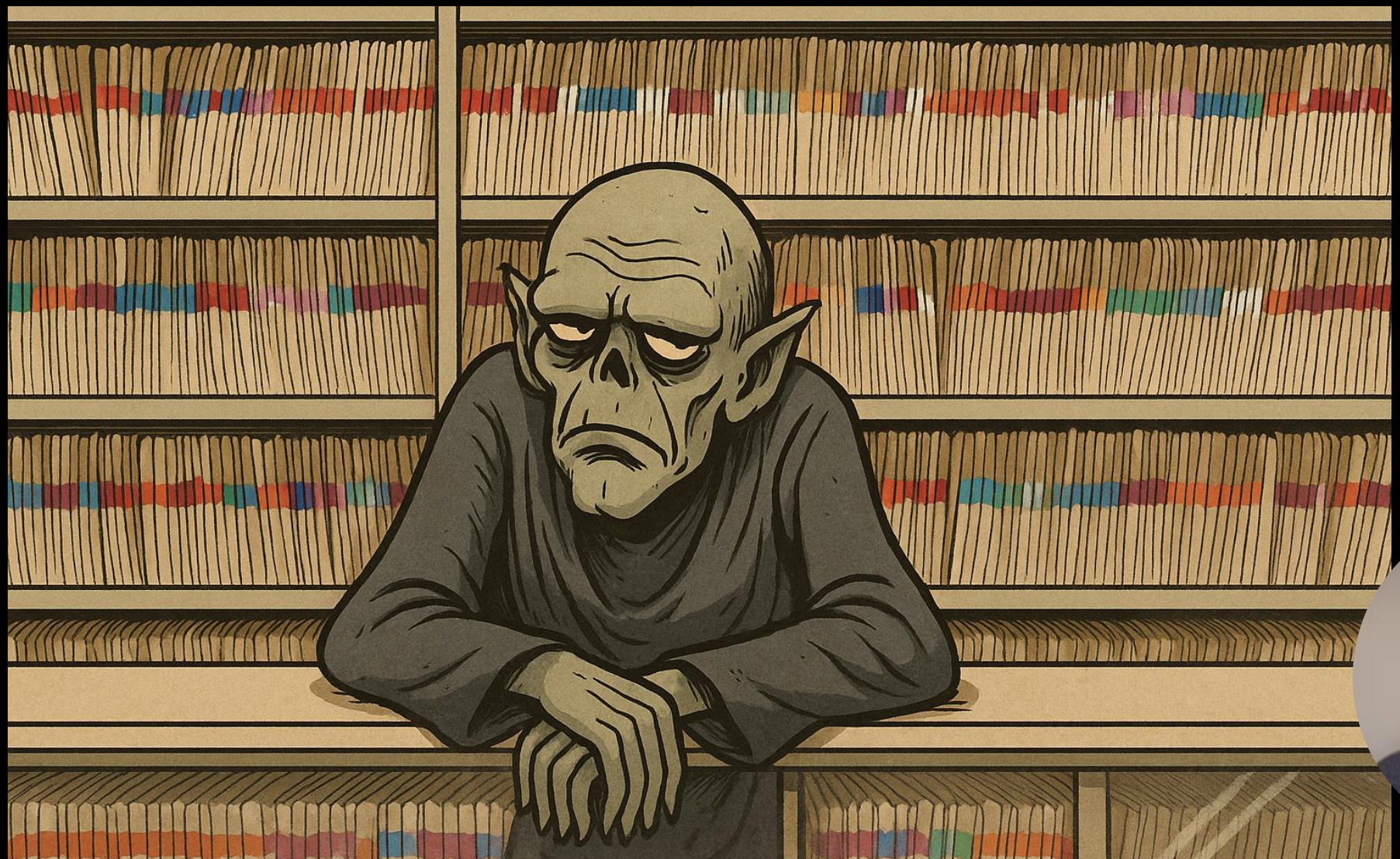
Having such so-called longitudinal health records (LHR) for both my sons has made provider encounters much more productive. LHRs help clinicians get a clear understanding of my sons' health profiles and history to diagnose and prescribe treatment sooner.

Hashtag
#73cents

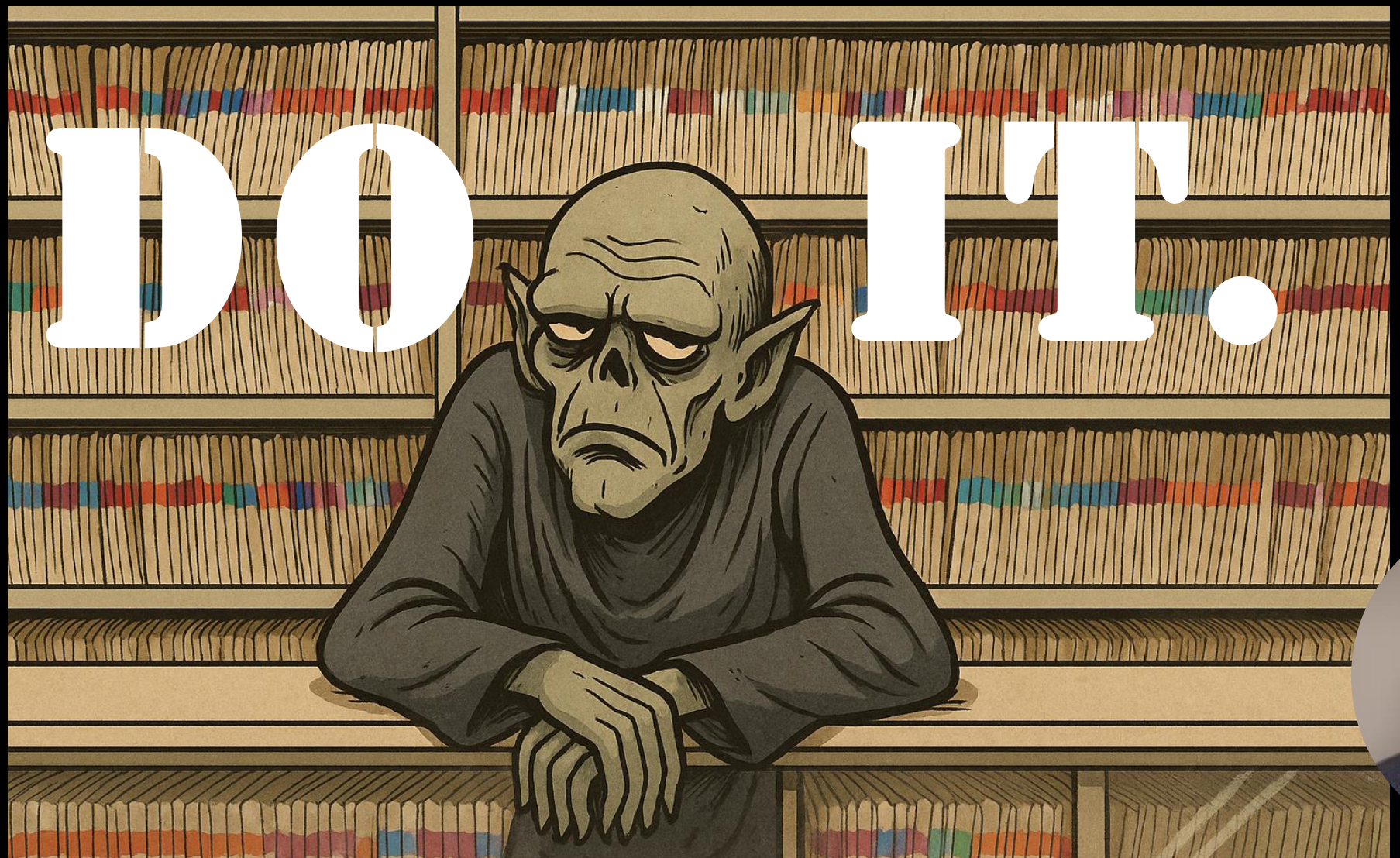
From #73cents to FHIR

**Pain, suffering,
and medical errors can happen
when information isn't
at the point of need**

It's *ghoulish* not to *help* health data get to the point of care.



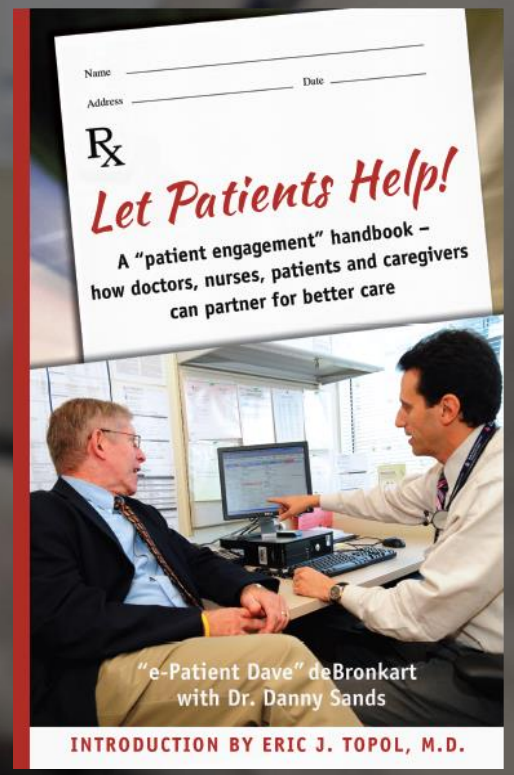
It's *ghoulish* not to *help* health data get to the point of care. It *causes harm*.



When the facts flow, care's potential improves.

Sick people & staff need your nerdy expertise.

Thank you for having the skills!



dave@epatientdave.com

Australian Government
Australian Digital Health Agency

Follow Dave's story

www.epatientdave.com

INSPIRE Interoperability and Standards in Practice: Innovation, Readiness, Education

Australian Government
Australian Digital Health Agency

INSPIRE

Interoperability and Standards in Practice:

Innovation, Readiness, Education