

Consensual, Safe, and Transparent

What do we do:

	Consensual	Safe	Transparent		
GPs - Direct Care	~	~	•		
GPs - local CCGs / councils	•	Varies by recipient	Depends on GP		
GPs - research copies	~	Unknown	×		
Hospital - Direct Care	~	~	✓		
Hospital - local sharing	By 2020	Varies by recipient	By 2020?		
NHS Digital: SCR controls	~	~	In 2018		
NHS Digital: Safe Setting	~	~	~		
NHS Digital: Sale of hospital records	✗ (opt outs ignored)	×	Partial: now; More: late 2017; Full: Late 2018.		
NHS Digital: Commercial reuse of hospital records	✗ (opt outs ignored)	×	×		
NHS England: CSUs / councils / national	Variable	Unlikely	×		
DH family: https://medconfidential.org/for-patients/loopholes/					
PHE disease registries	✗ (no fair processing)	×	✗ (proposed as a postcode lottery)		
	✗ (misleads patients)				
CPRD @ MHRA	✓ (Type 1)	x	Partial (unknown:		

Bad Pharma

Ben Goldacre

Bestselling author of Bad Science

How drug companies mislead doctors and harm patients

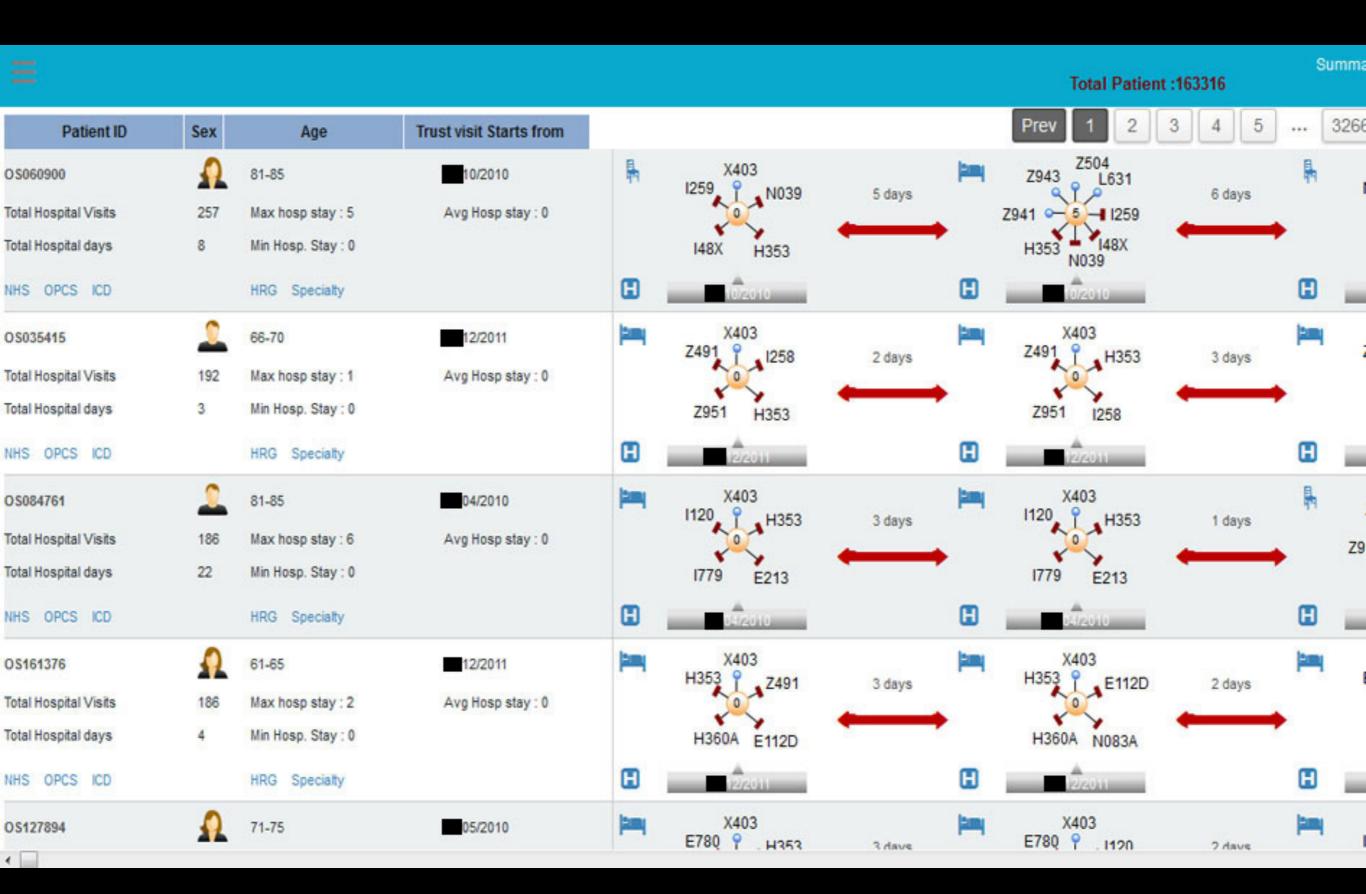
364 pages





Hospital data: case study

2014:

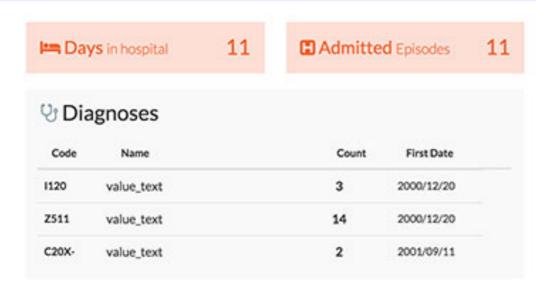


Omega solver — shut down after attention was paid to them

HES Viewer Load ► Open III Dashboard S Timeline

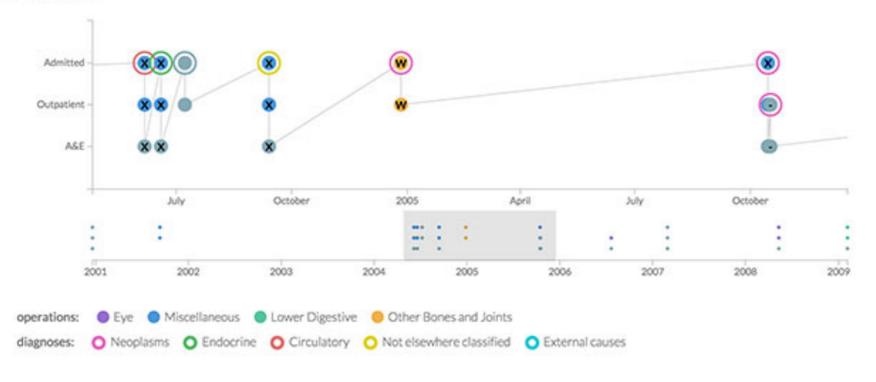


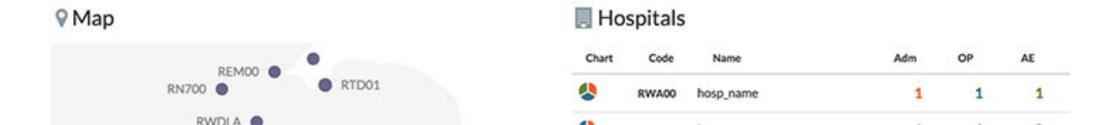
Postcode:





Timeline 2





Market Access is Evolving

AXON now holds over I billion LINKED patient HES records

Big Data... extraordinary insights

Contact us to find out how we can transform your patient pathways

T: 01928 515215

E: support@harveywalsh.co.uk

www.harveywalsh.co.uk





Harvey Walsh

Audit source: http://content.digital.nhs.uk/dsa

"In September 2016, Harvey Walsh was found to have breached its Data Sharing Agreement"... "NHS Digital found that the AXON system backend database held record level data that was not aggregated or small numbers suppressed."... "no secondary suppression was being applied"

Commercial secrecy

Cancer Data: case study



"HDI is an Information Broker

Sometimes called an information intermediary, HDI will act to facilitate access to healthcare data and information. Those we work with use our expertise and knowledge of the UK healthcare system to help identify and gain access to the specific data they require."

https://healthdatainsight.co.uk/about-hdi/

Where are we going?

	Consensual	Safe	Transparent		
GPs - Direct Care	~	•	·		
GPs - local CCGs / councils	•	Varies by recipient	Depends on GP		
GPs - research copies	~	Unknown	×		
Hospital - Direct Care	~	~	✓		
Hospital - local sharing	By 2020	Varies by recipient	By 2020?		
NHS Digital: SCR controls	~	~	In 2018		
NHS Digital: Safe Setting	~	~	~		
NHS Digital: Sale of hospital records	✗ (opt outs ignored)	×	Partial: now; More: late 2017; Full: Late 2018.		
NHS Digital: Commercial reuse of hospital records	✗ (opt outs ignored)	×	×		
NHS England: CSUs / councils / national	Variable	Unlikely	×		
DH family: https://medconfidential.org/for-patients/loopholes/					
PHE disease registries	✗ (no fair processing)	×	✗ (proposed as a postcode lottery)		
	✗ (misleads patients)				
CPRD @ MHRA	✓ (Type 1)	x	Partial (unknown:		

Why?

100% PROMs for Cancer

 Would you like a detailed patient outcome measure for 100% of cancer pathways, linked to the cancer registry and medical history, with informed consent for future research?

 A 100% online PROM allows for additional collections via explicit informed consent, without additional NHS resources.

 This is a key benefit from an NHS cancer registry (ie, the move from PHE to NHS Digital)



www.medConfidential.org

@medConfidential