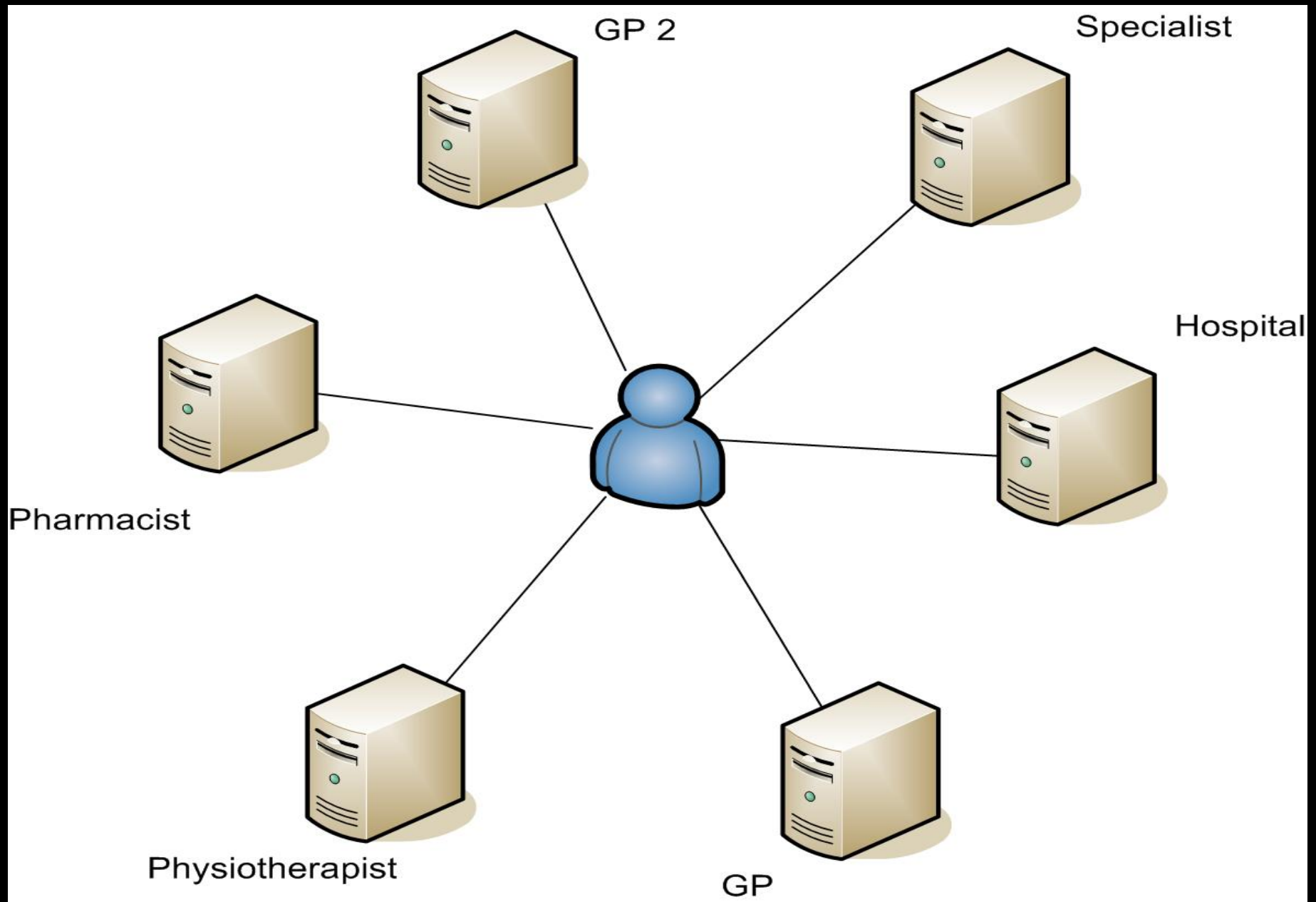# A Case Against Centralised Shared Electronic Health Records

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HIC' 08 - The Person in the Centre

Some Background

- Computer science / software engineering
- Health informatics for 4 years
- Just completing Masters in eLaw at Monash University
- This paper was submitted as part of the assessment for 'Privacy in Cyberspace' course at Monash University
- Thanks to the lecturer Moria Paterson (no relation) for her comments

This Talk

- A legal look at centralised v federated models
- A brief proposal for a possible federated model - if we get time and I doubt we will

What do we mean by 'centralised'?

- We don't necessarily mean one single big server

- Could be a cluster

- Could be a geographically distributed system

- Managed by a central organisation

- Think hotmail.com - is actually hosted on many machines around the globe but appears as one centralised 'service'

GP 2

Specialist

Hospital

Pharmacist

Physiotherapist

GP
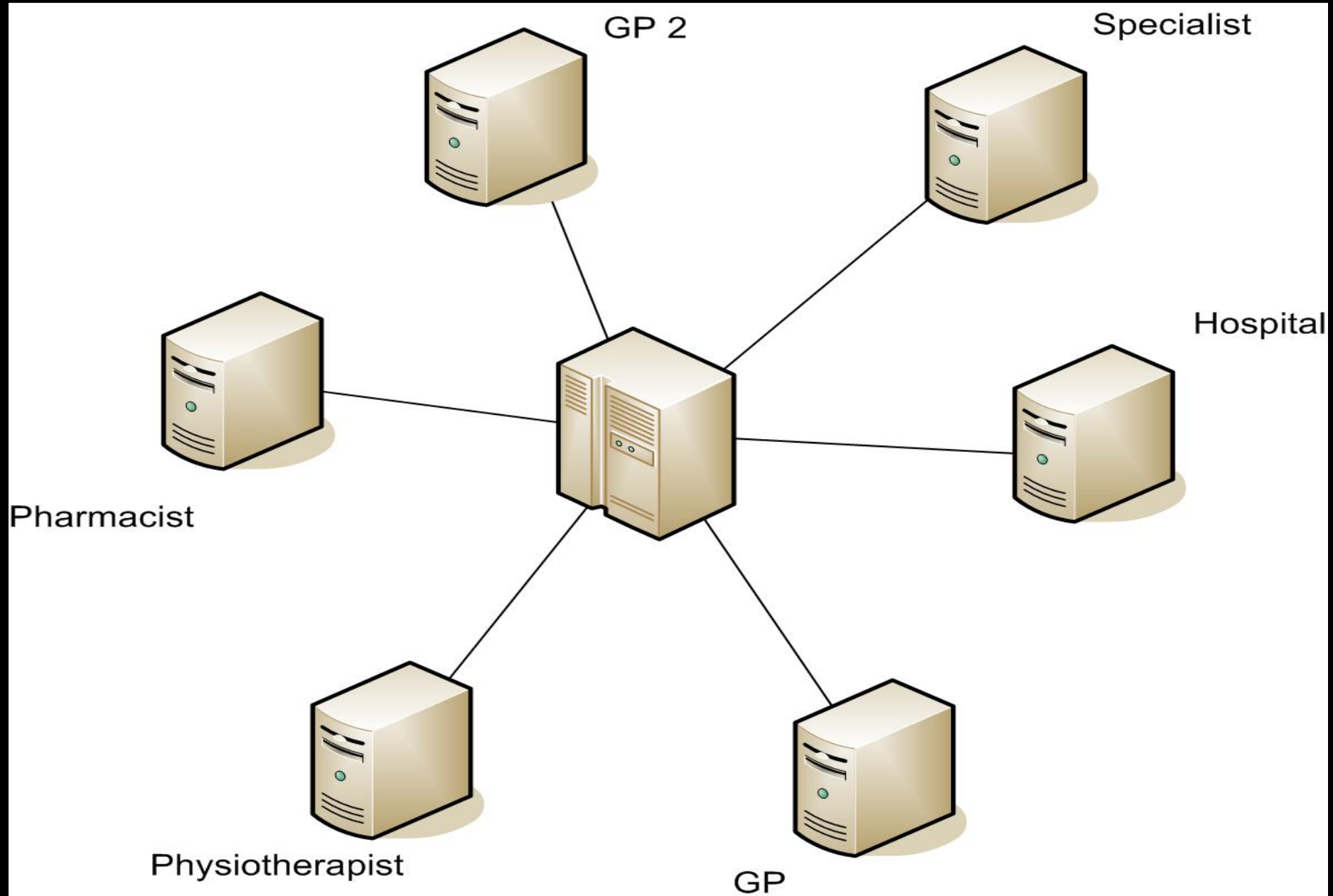
HIC' 02 - The Computer in the Centre

What do we mean by 'federated'?

- Many distinct organisations each running (or contracting to run!) their own clinical record system

- Communication between nodes through some mechanism

- Messages may traverse central infrastructure but never stored long term (> weeks)
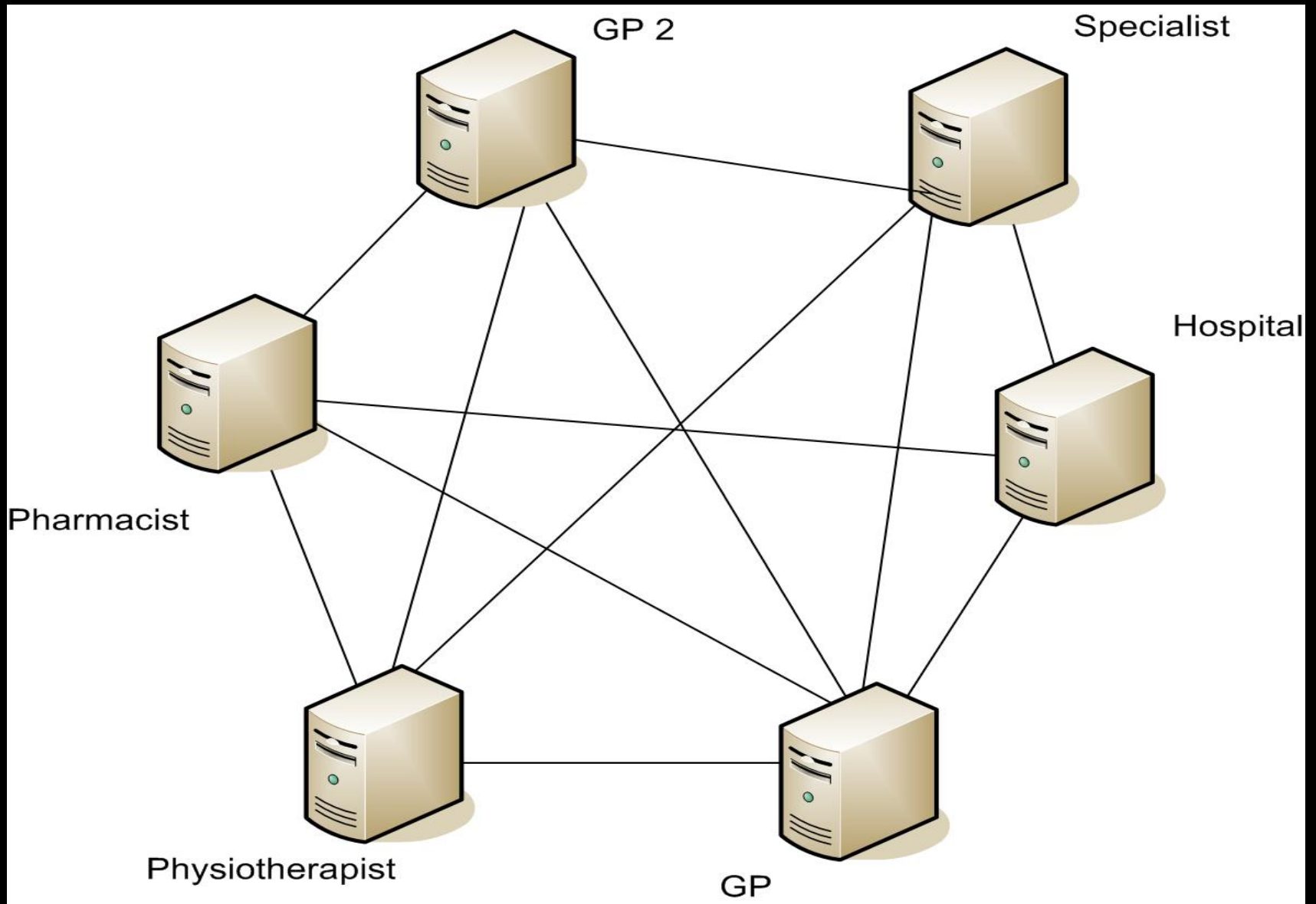
HIC '09 - Nothing in the Centre

What laws are we looking at?

- Privacy Principles - Privacy Act 1988 (Cth), Health Records Act 2001 (Vic), Health Records and Information Privacy Act 2004 (NSW) etc

- Copyright Act 1968 (Cth)

- Contract law

- I covered all the legal issue topics addressed by the Clayton Utz "HealthConnect Legal Issues Report" from 2005

NPP 4 – Data security

Centralised

- Easier to resource with adequate security staff
- More resources in general to devote to layers of security
- More serious consequences for a breach

Federated

- Harder to get adequate staff x number of sites
- Less resources at each site
- Balanced by more localised data loss in case of a breach

NPP 5 – Data availability

Centralised

- More resources available to keeping the damn thing running

- More resources available for fail over scenarios

- Things can still go wrong though (eg Optus and the Gold Coast)

Federated

- Perhaps harder to fund the resources to keep things working 24/7

- What level of availability is actually required (open question?)

- Currently people survive with zero data availability so is it really a concern at this point?

NPP 3 - Data quality

'steps must be taken to make sure information is accurate, complete and up to date'

Centralised

- Everyone responsible for their contribution to the central store
- Noone responsible for the overall picture
- Primary care is always a battle against missing, incomplete and out of date material

Federated

- Provider takes responsibility for the *organisation* of data stored in their system, **though this data may be attributable to other providers**

Liability and indemnity

- Similar to data quality argument
- Noone is responsible for ongoing accuracy of the central records. Would the court find that noone is liable?
- Provider who accepts data into their system must not be legally liable for not taking action, or for held liable for content they didn't author

Custodianship and control

Centralised

- A completely new ball game legally
- Who actually owns the records in the central repository?
- Australian copyright in databases may give additional copyright protection to the information as a collection – but to who?

Federated

- Legally quite neutral Breen v Williams etc
- Implied copyright license to the material put into someone else's system

Privacy and consent

Centralised

- Still a large concern to the general population regarding clinical details held on a big "government" database
- "How can I to trust some people who I don't know at all to hold my very private medical data"?

Federated

- Patients are still concerned about their data being 'on the internet', even though it might be stored by their health provider
- I believe they are unconcerned about the sharing of information between their providers

Competition

Centralised

- Intense competition to win a big tender to run the system, but then where does the innovation come from?

Federated

- Harder to get written in the first place but assuming you can get multiple implementations, you then get competition between implementations
- Purchasing power is in the hands of the users of the software – best way to keep vendors on their toes

Score card

- Some **big** wins for federated models regarding data quality, custodianship, privacy and competition
- Security and availability probably should be awarded to the centralised model
- At the end of the day – an engineering trade off
- These trade offs need to be analysed more

How would I do a federated model..

- In my view, storing an authoritative, longitudinal record that allows coordination of activity is inherently asymmetric – someone needs to be in charge
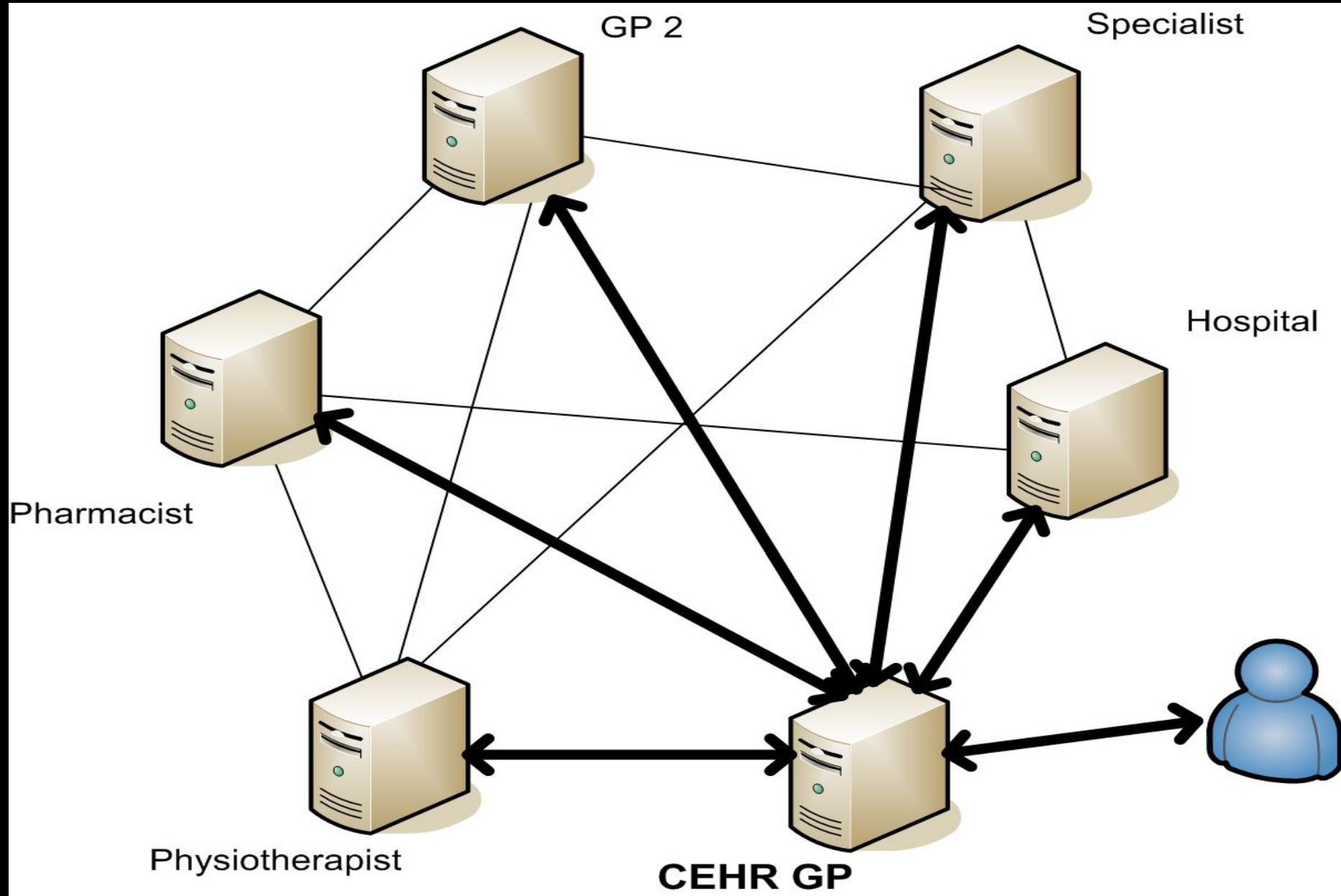
HIC 2020 - The GP near the Centre

'Collaborative GP' Index

- GP consents to holding my longitudinal, coordinated record
- Central index (patient id -> GP clinic id)
- Doesn't force exclusive use of that GP by the patient
- Doesn't require each encounter to be documented in the shared EHR (can consent per encounter, though assumption might be to send report unless told otherwise)

Problems

- Change in mindset by GPs - to allow others to read from and contribute to their electronic record systems

- Change in mindset by GPs - to take provision of IT services seriously

- All the associated security, standardisation, governance issues

An opportunity for GPs?

- If GPs are the gatekeepers to the Australian health care system

  Does this mean they need to be the electronic information gatekeepers in the Australia health care system?