Changing Cancer Data Collection: The Challenge for Cancer Networks

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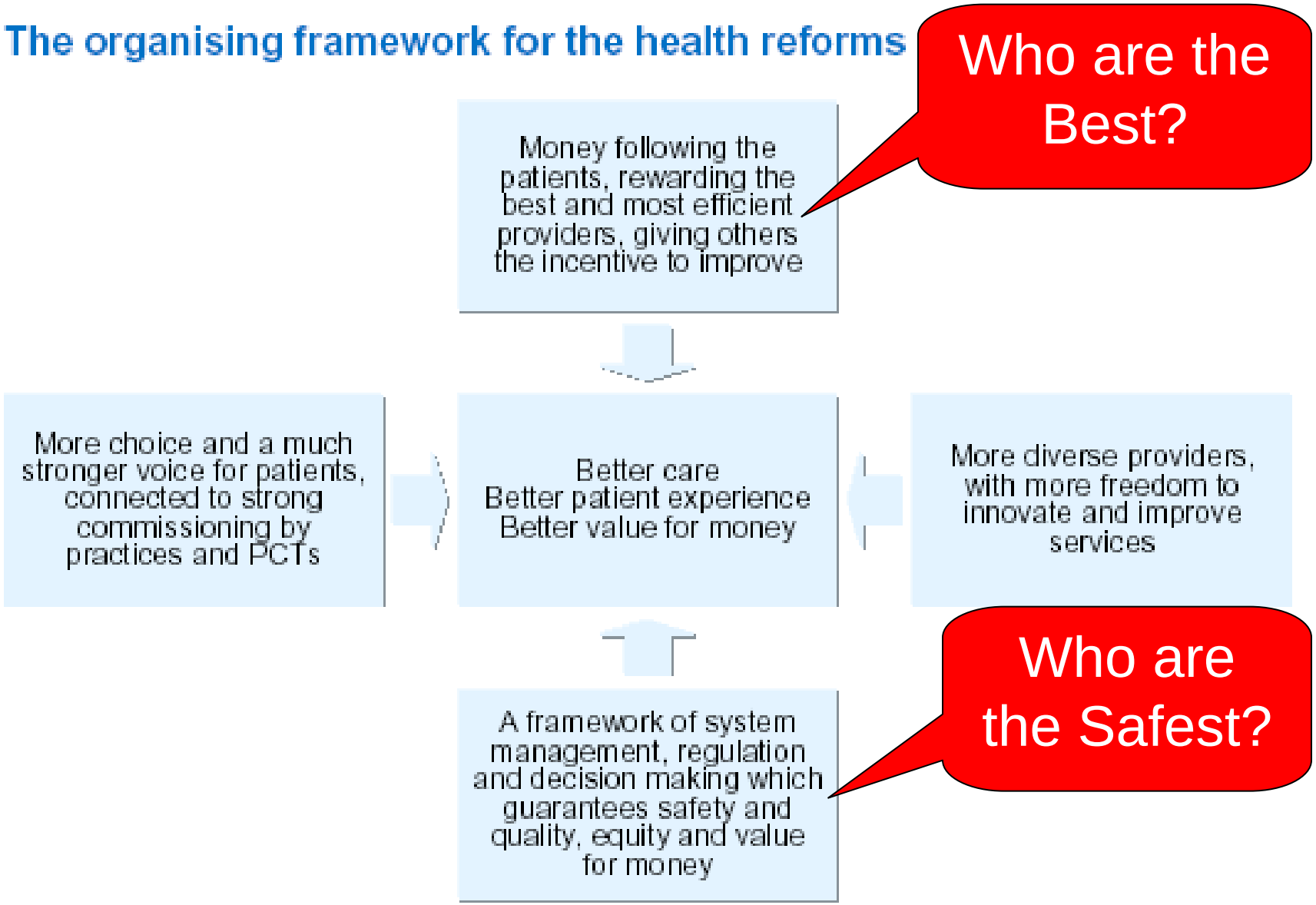
Core Objective #1:
Promoting efficient and effective data collection throughout the cancer journey

The organising framework for the health reforms



Clinical Governance Issues

- Most clinical teams have no idea of the relative quality of their service and outcomes

- PCTs need to develop robust mechanisms to ensure effective clinical governance arrangements for the **services they provide and commission-WCC**

Clinical Governance Framework

- The NTCN clinical governance framework will ensure that:
  - **patients** have access to services that are patient-centered,
  - That any service, **independent of setting**, can demonstrate compliance with quality standards and performance measures defined within the cancer pathways.
  - This approach will ensure that extensive and comparable information on the **quality and safety** of care is made available to the network/commissioners/providers/public.

Clinical Governance Framework

The information requirements will be based on:

- Patient Experience- dignity, satisfaction surveys
- Peer review standards
- Key Clinical outcome information
- Entry into clinical trials
- Compliance with NICE guidance / IOG Implementation / Guideline implementation
- Sustaining waiting times including implementation of good practice

Clinical Governance Framework - Wins

- Patients- explicit evidence of qu
  outcomes
- Providers- inform internal clini
  governance processes
- Clinical teams - have evidence of quality and outcomes. Any performance issues can be addressed
- PCT's- evidence of quality commissioning and enhance internal governance arrangements

All along the patient pathway

Data Pathways

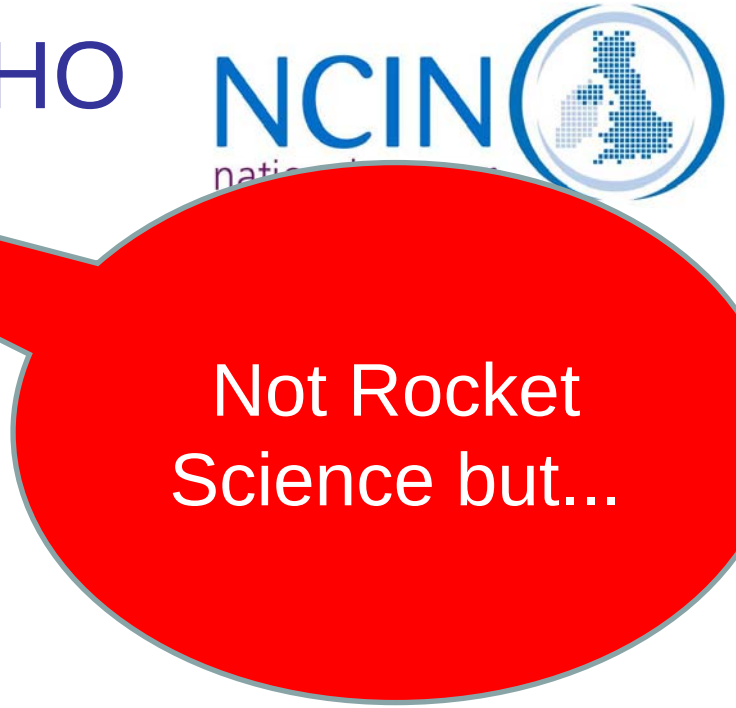
- NHSIA- pilots
- Sheffield
  - Clinicians and admin team looked at the dataset items
  - Where we could collect the data
  - What could not be collected

Outcome

- 90% could be collected at the MDTM
- Surgeons could record procedure codes!
- Modifying the presentation of the patient at the MDTM helped

- Chemotherapy/Radiotherapy data and follow up status could not collected
- Performance status could not be determined

Performance status - WHO



0 Normal

1 Capable of light work

2 Up > 50% of day, self-caring

3 Up <50% of day, not self caring

4 In bed

We also found…

- MDTM must be very well structured, with adequate admin support
- A senior clinical lead within the team is needed
- It takes a bit more time
  - but is worth it **if** data returns to the team

Progress needed

- Integrated whole-system solution needed
- Links to **all** providers
  - including primary care/ Independent sector
- Some electronic solutions on the market

- Cancer Networks need to lead and facilitate a network solution

- Look to link with:
  - Sir Bruce Keoghs work-surgical procedures
  - NPSA- Patient safety campaign
  - Primary care
  - EOLC
  - NHS Reform Bill

Clinical engagement

- Vital
- Data must be analysed and returned
- Useful for
  - Clinical governance
  - Job planning
  - Service planning
  - Re-validation of staff
  - Reconfiguration of services

How?

- Nominated Clinical lead(s) for each network
- In secondary care
- In primary care
  - Future proof

Follow up

- Much routine cancer follow up has no evidence base
- Could be undertaken in the community (if at all)

How can we deliver **quality** cancer care in primary care?

NCIN national cancer intelligence network

- Not like this:

"None of us can have failed to notice that clinics are not being filled to capacity. I am sure this is in part due to a move by PCTs for GPs to undertake more community based management of patients. Indeed, a GP rang me this morning "offering" to undertake the sole management of a man with hormone resistant prostate cancer to "save him from coming to the hospital". This man may well have required some palliative intervention such as bisphos, RT, 2nd line hormones, Taxotere etc, all of which I have pointed out in writing.

At the end of the conversation, almost as an afterthought, the GP asked whether this man would need to stay on his Zoladex!"

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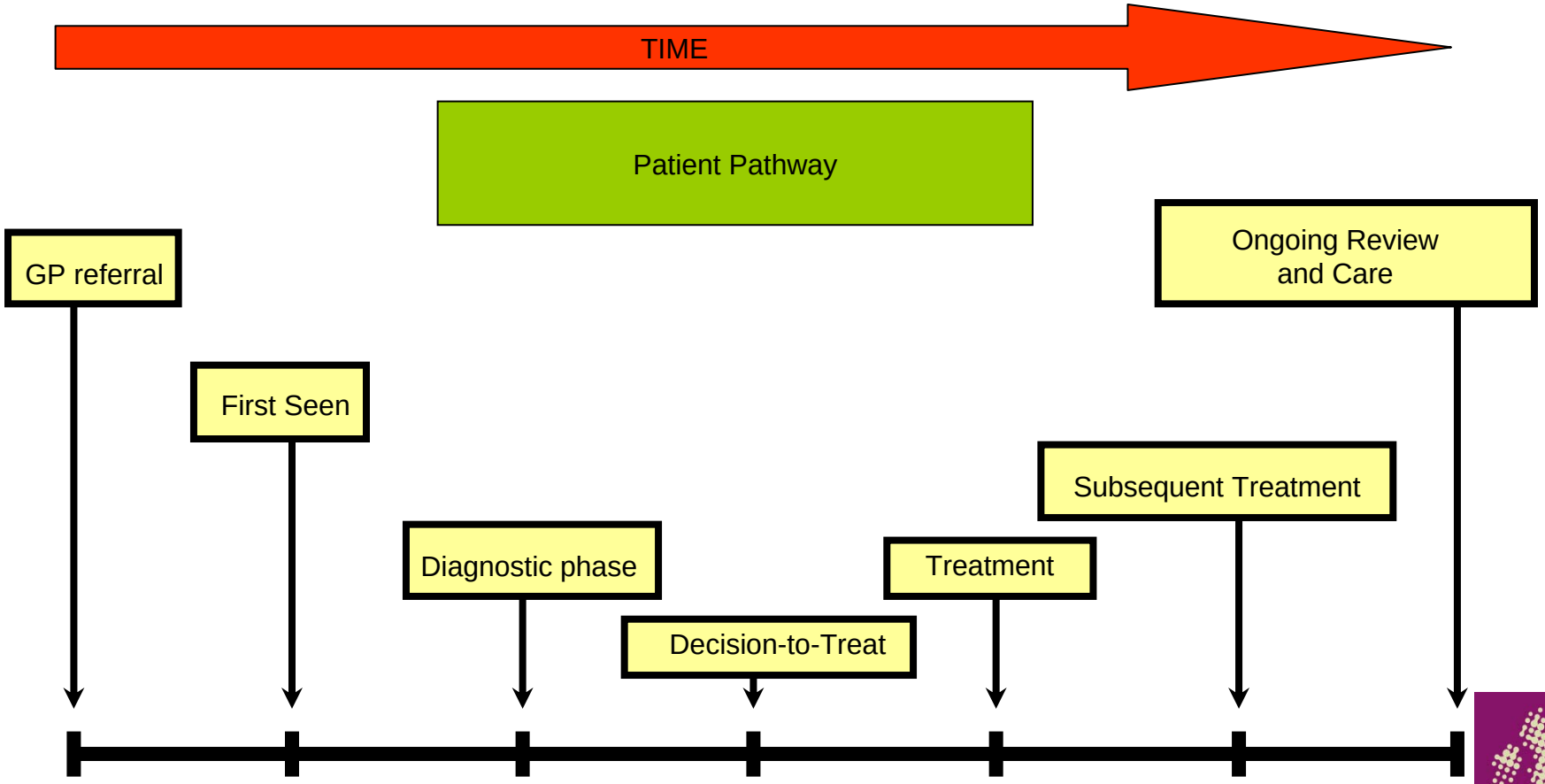
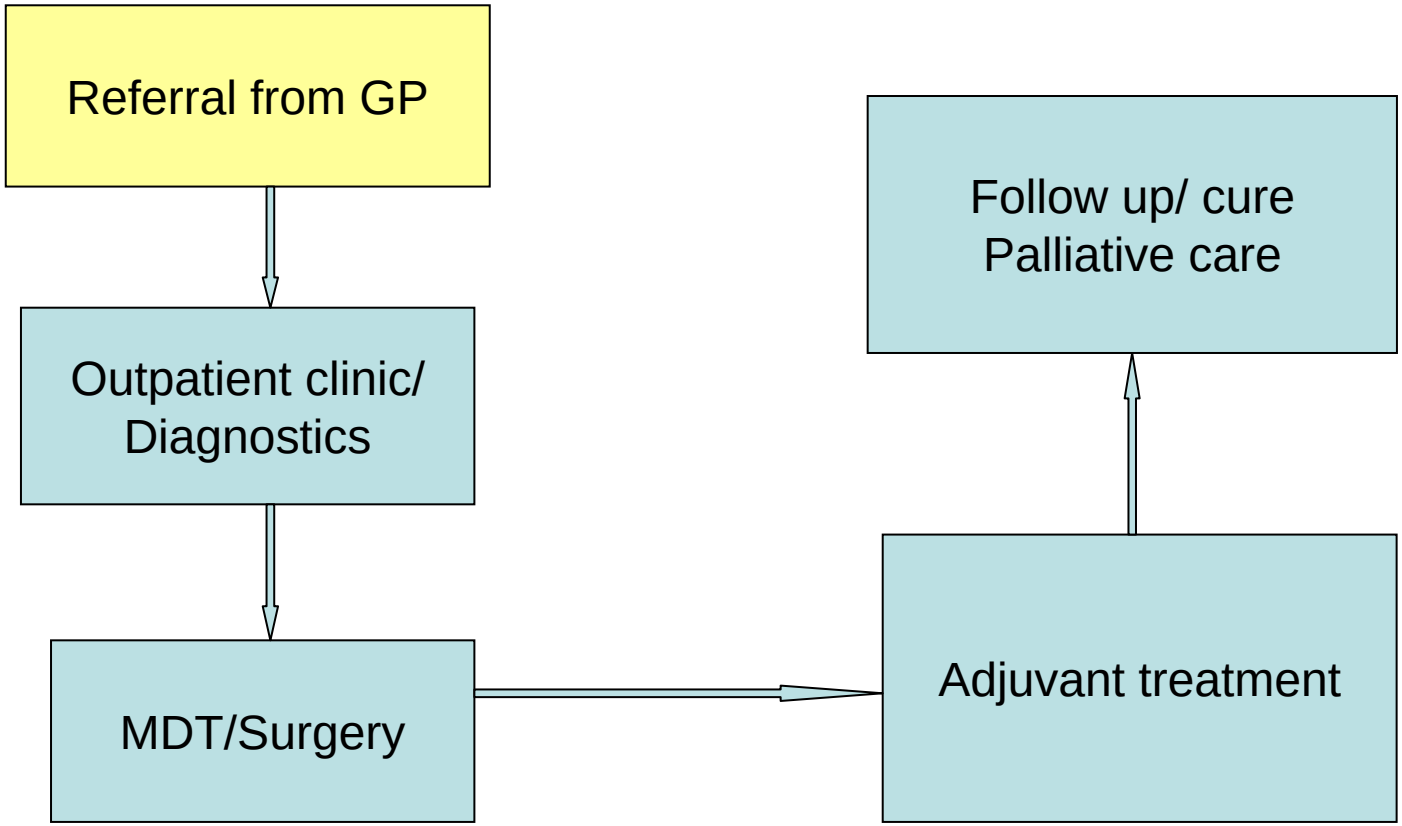
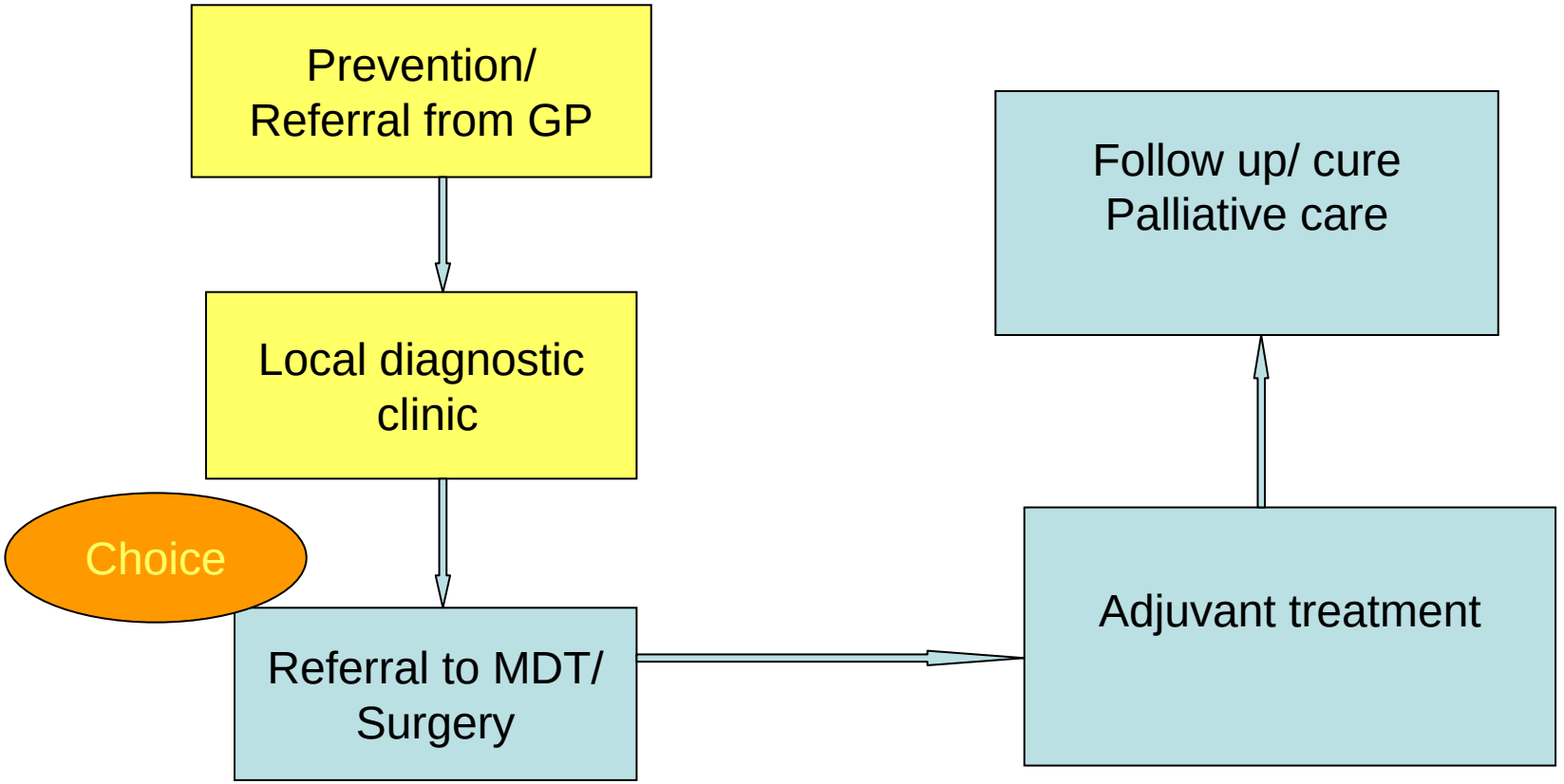

TIME
Patient Pathway
GP referral
First Seen
Diagnostic phase
Decision-to-Treat
Treatment
Subsequent Treatment
Ongoing Review
and Care

Patient journey- Now



Patient journey- Future



Using information to improve quality & choice

David Levy

Patient journey- 2012