



Our not-so-unique but personal story of Life in the Maze (a.k.a. 'the healthcare system')

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MEDINFO23

8 – 12 JULY 2023 | SYDNEY, AUSTRALIA





3rd December 2019 – Life Changed

Blood tests, scans, x-rays,
continuous monitoring +++



Admitted to Intensive
Care Unit



A&E Physician,
Nephrologist, Cardiologist,
Endocrinologist, Intensivist,
Nurses +++



Acute Renal Failure =>
*Pancreas and Kidney
Organ Transplant*



And it started:



- Test after test
- Waiting for results constantly
- Rounds of assessments, consultations, investigations, procedures
- Growing list of medications with different instructions
- Growing care team – Specialists, Nurses, Pharmacists, Dieticians, Dialysis Team, Transplant Coordinators..
- Increasingly complex care

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A&E

ICU

Ward

Theatre

Dialysis

Ward

Home

(starts with)
Hosp Dialysis
78 x

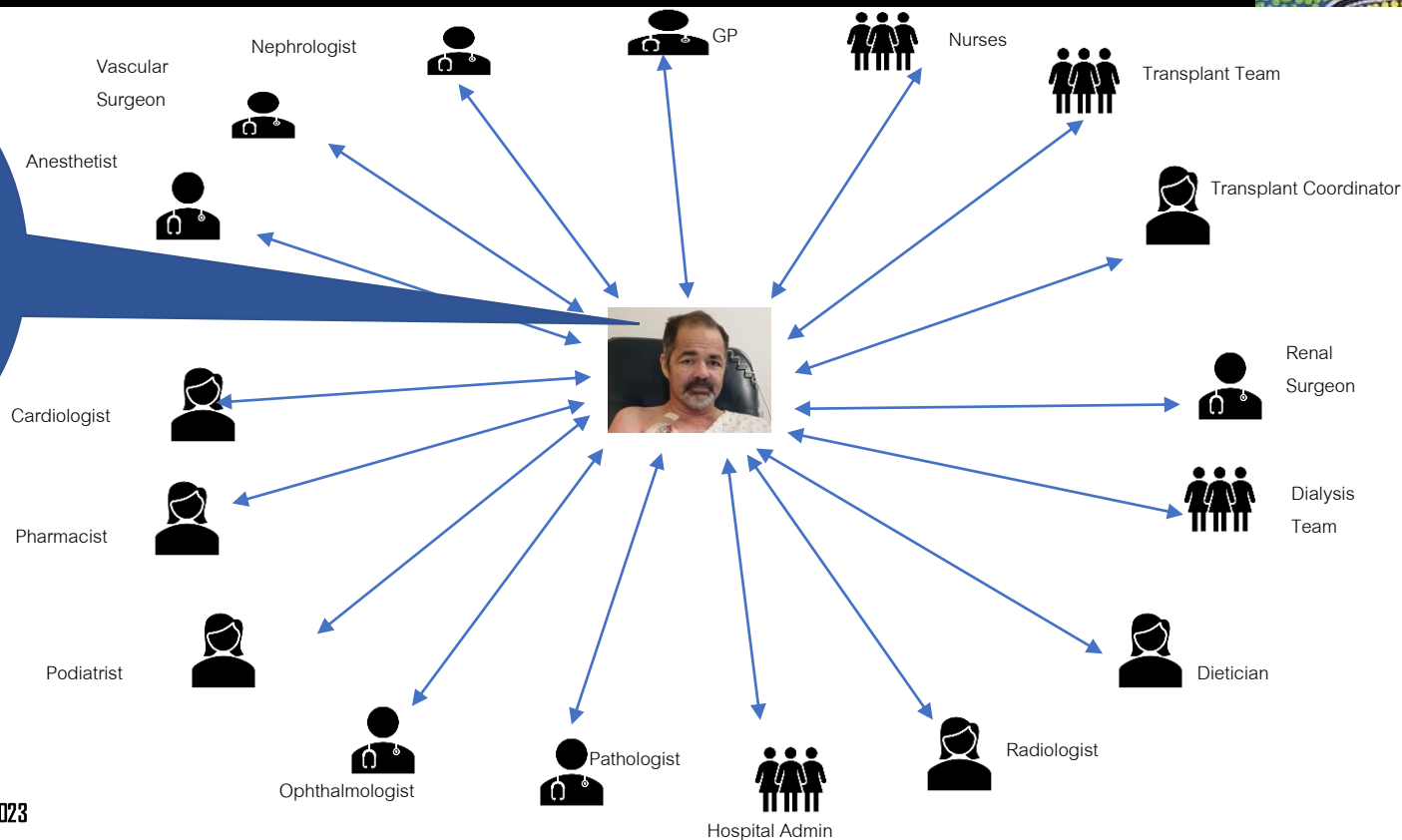
(then) Home
Dialysis

In the first 6 months alone:

- 110+ specialist consults
- 4 operations
- 16+ diagnostic images
- 160+ pathology tests
- 2450+ medication doses

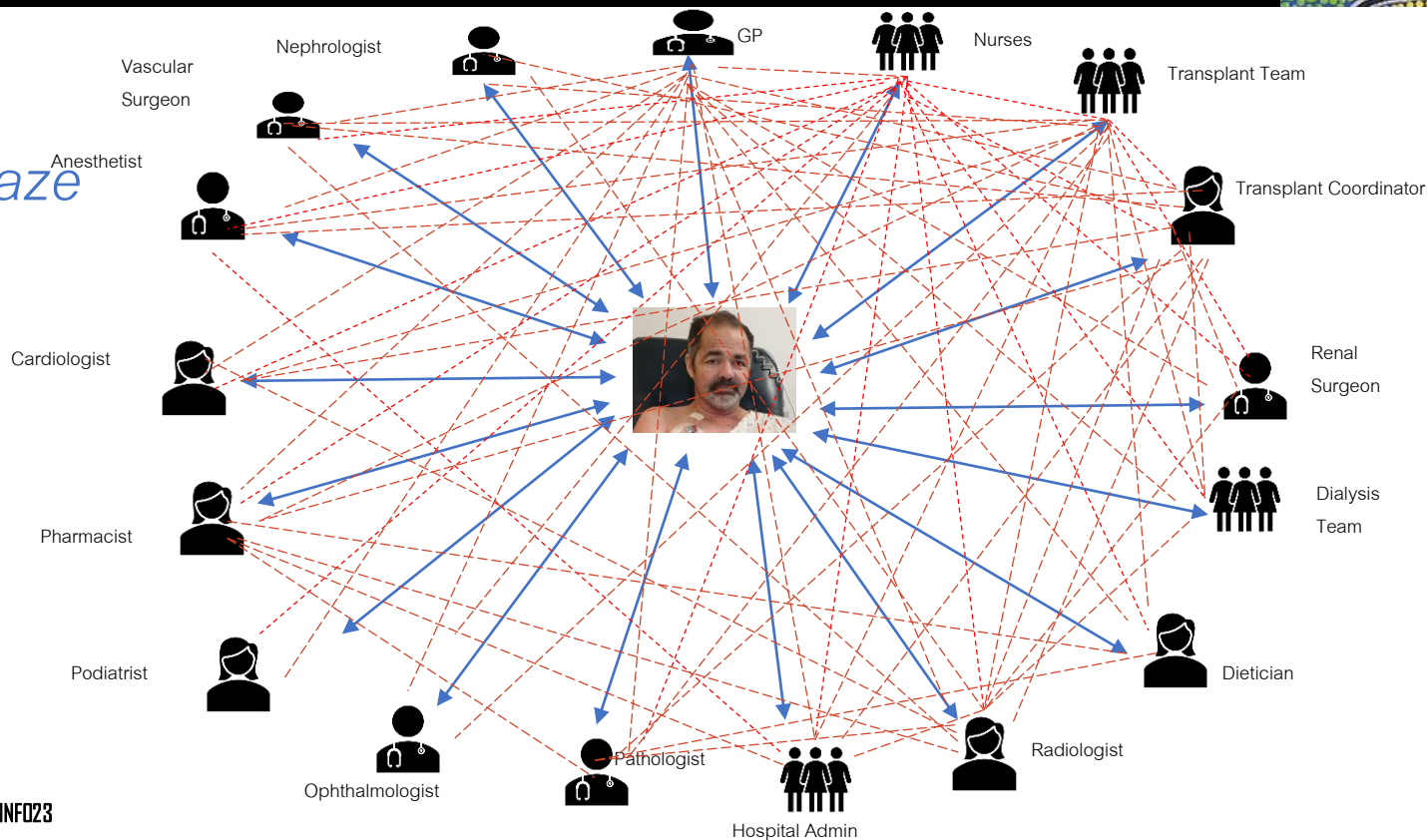


The only
consistent point
of coordination –
The Patient.





*And the maze
grows
and
grows...*





'SMSs are great as reminders, but they come from so many different places, in different formats, with different information and sometimes it's wrong or hasn't been updated'

'I have another appointment for surgery, but I don't know if I am supposed to do anything to prepare for it, I start ringing the Specialist's office and hospital to find out'

'I sometimes forget to take one of my medications, the instructions vary so much – in the morning, at lunch, in the evening, before food, after food, on an empty stomach, just take it if and when you really need it'

'When I see my Specialists, it's often impossible to find the latest lab and radiology results to share with them'

'Why do I have to tell my GP that I've just been in hospital again for surgery, they should have been told'

'Why can't my specialists and care team access my latest orders and test results, so that I don't have to repeat tests that have just been done'

'I have so many appointments - I try to keep track of them on my phone, but I often call Specialist's offices to confirm dates and times'

*And it goes on.... and on ...
and on...*



THEN – THE CALL CAME!
AMAZING CARE EVERYWHERE BUT..



What do "I" want ?



Access to my clinical information
– in one place –
so that I and those caring
for me can see it



The potential of digital

**We can
make it
easier**

- Follow clinical care / workflow
- Enter data once, use many times
- Connect healthcare systems
- Digital technology already out there
- *Share*
- *Communicate*



Agreement – “Hearts and Minds”



**And it can get
complicated
but....
It doesn't have to**

- User friendly access
- Consistent, standards-based data
- Trust the data and the care
- Connect and share



18 months on: Personally, the future is bright



However, the challenge to
share and communicate
continues –
for all of us.