



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

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# MEDINFO 23

8 - 12 JULY 2023 | SYDNEY, AUSTRALIA





## 3rd December 2019 - Life Changed

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

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

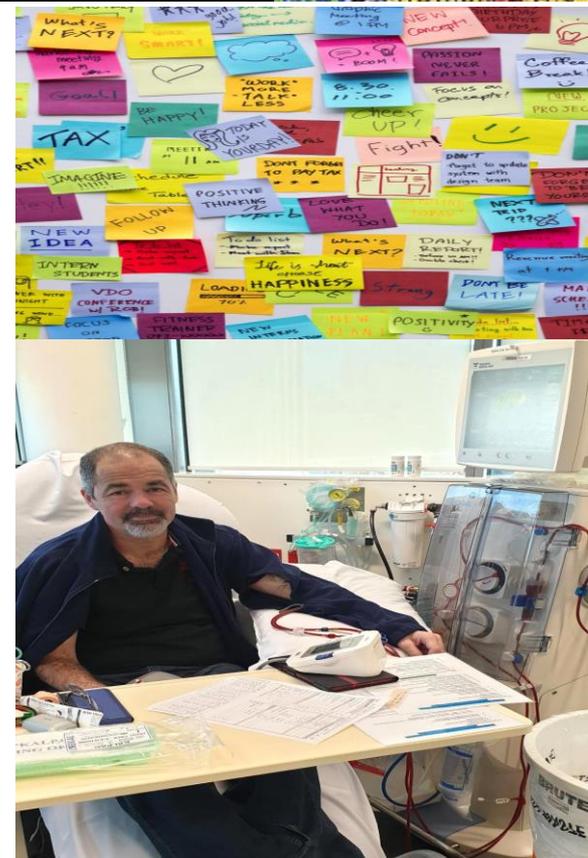


## *Data Collected At Every Turn – but where is it?*

- Devices and monitoring at every level
- Complex information systems, staff entering data
- Paper records everywhere, at bedside, at handover
- Home based care – dialysis every second day

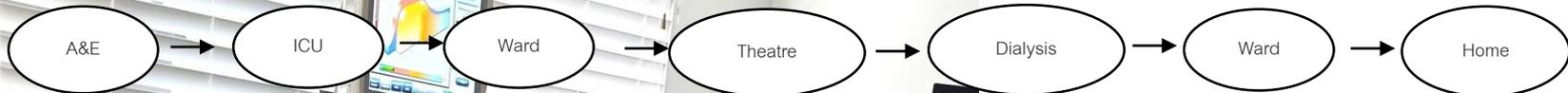
### *As a patient ?*

- Why do I need to repeat myself over and over?
- Why can't they share what they have?
- Why is it so hard to communicate?



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(starts with)  
Hosp Dialysis  
78 x

(then) Home  
Dialysis

## In the first 6 months alone:

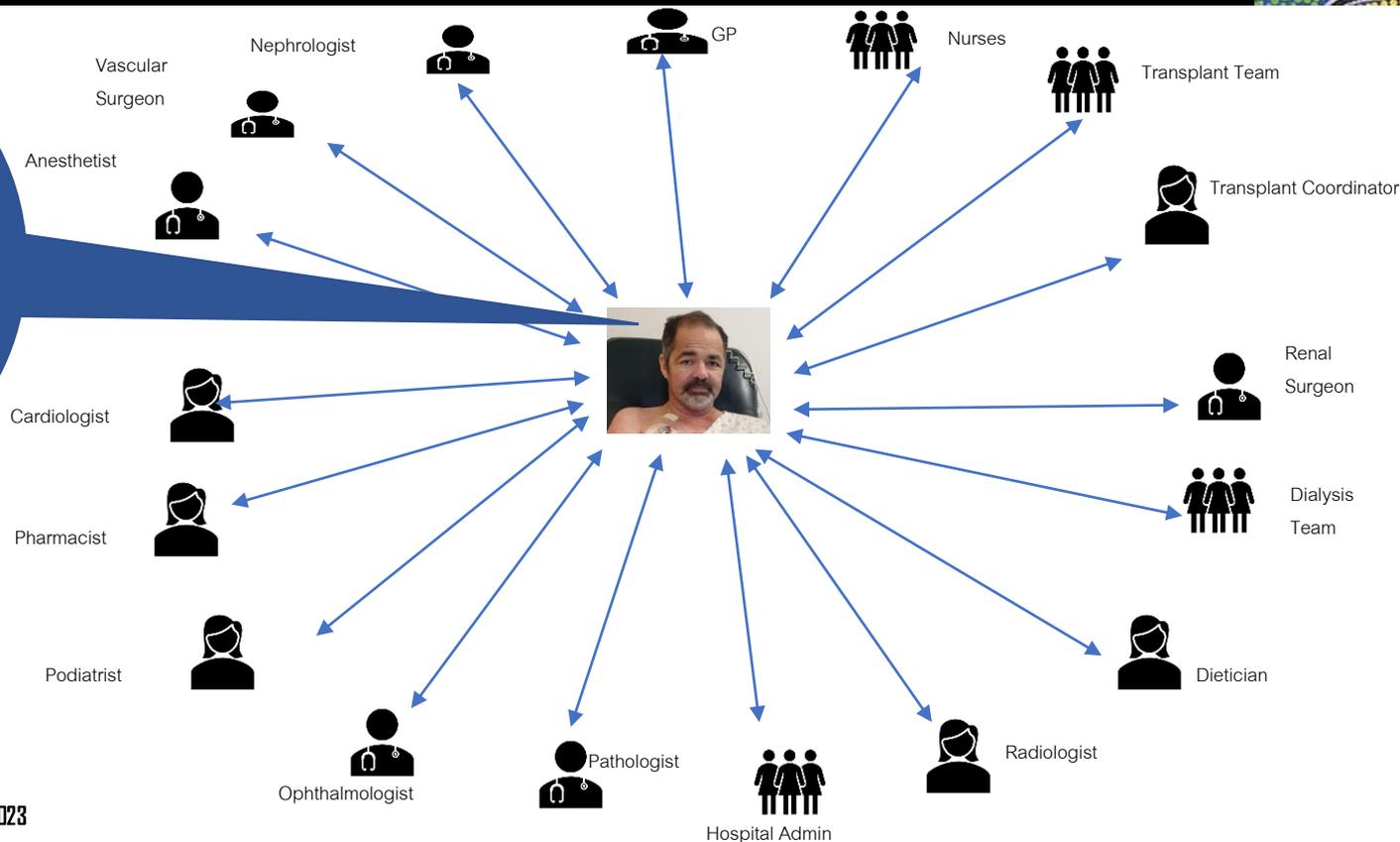
- 110+ specialist consults
- 4 operations
- 16+ diagnostic images
- 160+ pathology tests
- 2450+ medication doses

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The only  
consistent point  
of coordination –  
The Patient.

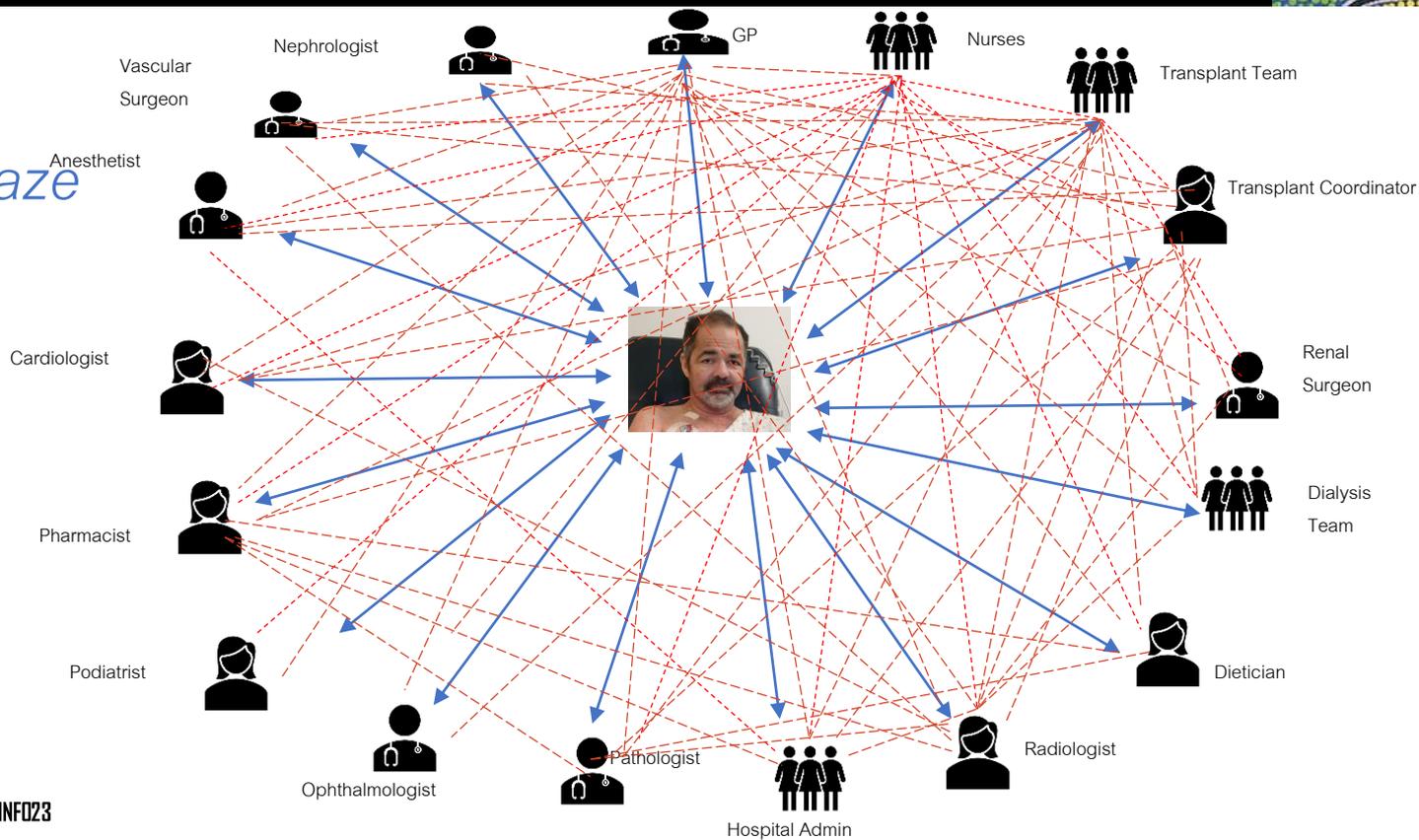


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*And the maze  
grows  
and  
grows...*





*'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...*

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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.