

PATIENT PERSPECTIVES ON DATA USE AND REUSE

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An Implanted Cardiac Device (ICD)

The Upside

- Constant Monitoring.
- Informed care.
- Minimally invasive surgery.
- Long battery life.


...quicker through airports.

... I am a 'dumb node' in the data flow

The Downside

- I don't know what data is collected.
- I cannot access the data.
- I cannot supplement the data.
- I am not informed about how the data are used.

What could the ICD do

- **Engage** - *me in my healthcare journey.*
 - **Empower** - *me to play a key role in my health and wellness.*
 - **Educate** - *me, my the provider, the system and the community.*
 - **Evaluate** - *the learnings for me, my providers, the system and the community.*
 - **Evolve** - *the system to better meet my and its demands.*
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The 5 'E's' need

A network of partners to collaborate to facilitate a journey through a complex landscape using a variety of vehicles, passing through a web of nodes.

They are the key components of a safe patient journey.



What do we need for the patient journey

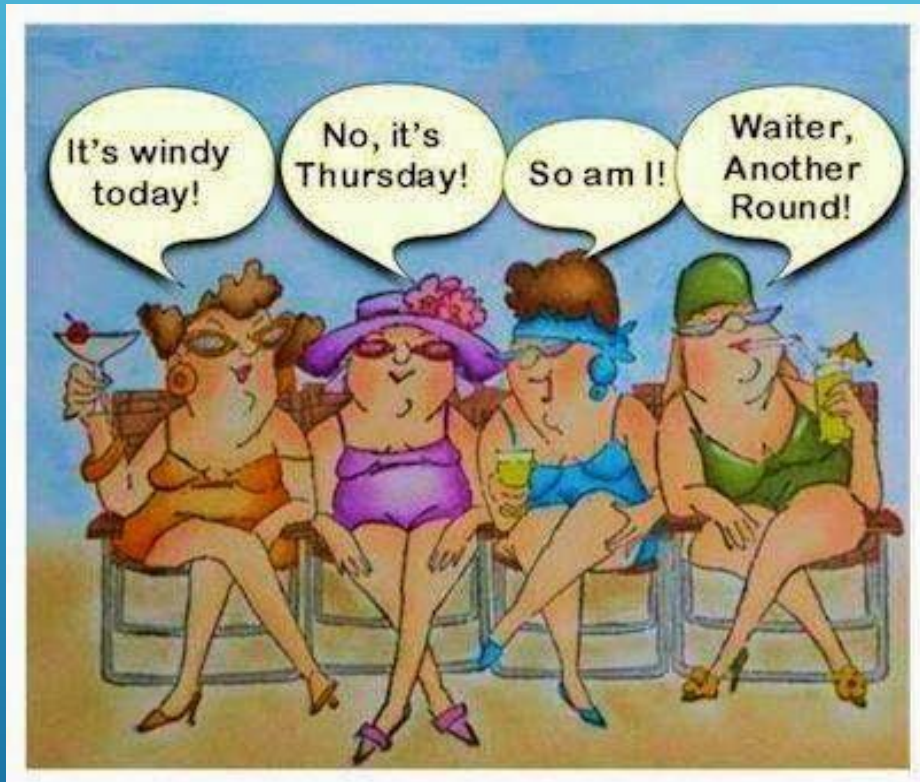
- **Roads** - *the network of players - patients, doctors, nurses, AND social carers, informal carers, schools, workplaces*
 - **Vehicles** - *EHRs, eRX, images, reports, results....*
 - **Collection points** - *doctors, nurses, patients, family, schools, work places, leisure, sport, retail*
 - **Fuel** - *data.*
 - **Ignition** - *interoperability.*
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- **Data standards**
Terms , images, labs
- **Interoperability**
Data, transit, security
- **Governance framework**
access, control, audit
- **Legal codes**
Privacy, penalty, payment

WITHOUT STANDARDS AND INTEROPERABILITY WE MIGHT



Misunderstand the message

WITHOUT GOVERNANCE AND LEGAL CODES WE MIGHT



End up in court !

WITHOUT PROPERLY SHARED DATA WE WILL



Miss the opportunity

With good collection, use and reuse of patient data we can ...

Engage



Empower



Educate



Evaluate



Evolve



THANK YOU

