

People Powered Records





Lloyd George

...the Glorious Social Reformer

- ▶ 1911 - founded a national health record for a small number of male workers
- ▶ Since - patients couldn't access records, let alone contribute to them
- ▶ Today - health records are based on decades and decades of work exploring what clinicians need from them



Michael Young

...champion of the people, inspiring rebel

Down with paternalism!

Today's World...



Current Purpose of the Core Record

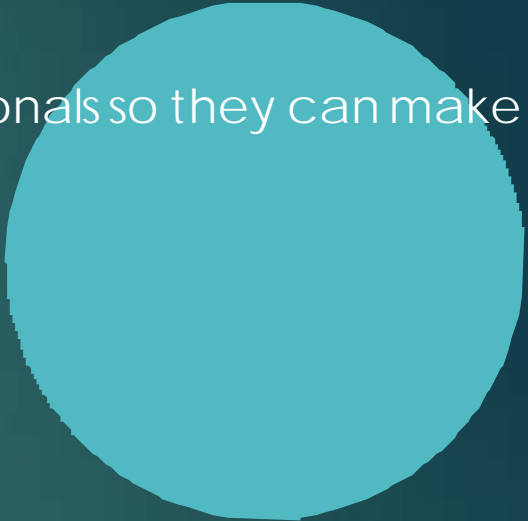
- ▶ To provide the necessary information for health & care professionals so they can make the right decisions to care for patients

Questions in the Ten Minute Window of Interaction:

Driven by logic:

- ▶ What is wrong with this patient & how can I fix it?
- ▶ How do I best care for them?

And me? Not only can I not access information... but none of the data helps me make decisions for myself...



WHERE AM I GOING?

WILL I SURVIVE?

IS THIS MY FAULT?

IS THIS MY LIFE NOW?

WHAT'S NEXT?

WHO DO I CONTACT ABOUT A NEW LUMP?

WHAT DO I DO IF SYMPTOMS DON'T CLEAR UP?

WHY WILL NO ONE BELIEVE ME?

WHAT IS THIS APPOINTMENT FOR?

WHEN WILL I GET BETTER?

WHEN CAN I GO BACK TO WORK?

I CAN'T COPE – WHO DO I TELL?

WHAT IS MY ROLE IN ALL THIS?

IS THIS NORMAL?

WHO AM I BECOMING?

IS IT OK TO ASK TO SPEAK TO A SPECIALIST?

I NEED TO MOVE – BUT WILL I END UP HOMELESS?

WHY DO I FEEL SO POWERLESS?

HOW DO I RETURN TO THE LIFE I ONCE LED?

HAS MY REFERRAL BEEN LOST? HOW HAS THIS HAPPENED?

WHERE DO I GO FOR HELP?

THIS SHOULD NEVER HAPPEN TO OTHERS – BUT WHY WILL NO ONE LISTEN & LEARN?

MY NURSE SPECIALIST HAS LEFT, WHO DO I SPEAK TO NOW?

Clinical Outcomes vs. Individual Outcomes

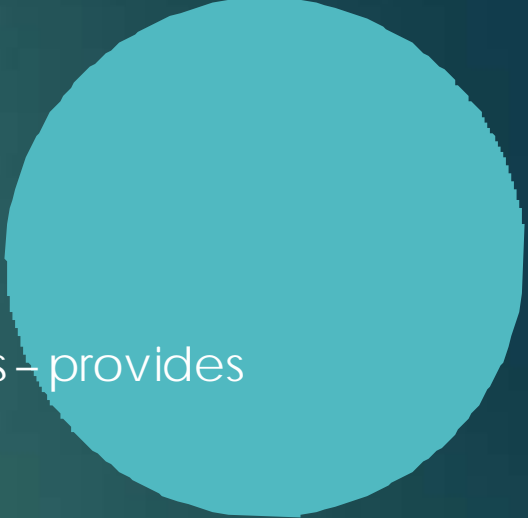
- ▶ **Themes for individuals:**

- ▶ Access & Rights
- ▶ Communication & Voice
- ▶ Empathy – Fear, Anxiety
- ▶ Confidentiality
- ▶ Control & Autonomy, not Lost in the System
- ▶ Burden
- ▶ Hopes & Dreams – Reach my Full Potential, not care
- ▶ Learning from education – teaching vs. learning
- ▶ Starting from scratch, not engaging patients on clinical outcomes



Opportunities - About Me?



- ▶ Empty Bucket – boo!!
 - ▶ Never once have I been asked what I want to achieve.
 - ▶ This is not just about pets... it's about goals and concerns – provides a means to communicate ahead of appointment
 - ▶ I want to think of the FUTURE, getting better, or managing health conditions as well as possible
 - ▶ Patients aren't limited to a 10-minute window.
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Opportunities – Challenge the 'Get Back in Your Box' mentality

- ▶ The challenge that data is created by patriarchy – based on algorithms chosen by men
- ▶ But what about people & patients?
- ▶ Core record is facilitating the NHS as a firefighter – it's stuck in the 'now'
- ▶ Wide consultation – outcomes moving away from care and on to us all living full and fantastic lives
- ▶ Wide issues - 'Care Plans' – who gets one? Shouldn't this be about empowerment, not care?

Opportunities – THE OATH for People Champions

- Time to empower the public meaningfully
- All decision-making groups/ boards/ committees should have a patient champion – people trained to champion the outcomes important to us as patients.
- Clinicians & managers – support this by pledging an oath
 - Not to sit on a board without patient champion and ask before agreeing to be involved.
- This includes NHSE/ NHSX/ and all programme boards – strategy needs to move away from focus on care
- Need for Patient Community - <https://www.hsj.co.uk/patient-and-public-involvement/a-royal-community-of-advocates-can-help-the-nhs-engage-with-the-public-/7025127.article>