NIHR | Yorkshire and Humber Patient Safety Translational Research Centre

Users, reporters, or co-creators? The many roles of patients and families in supporting system safety.

Jane O'Hara

University of Leeds

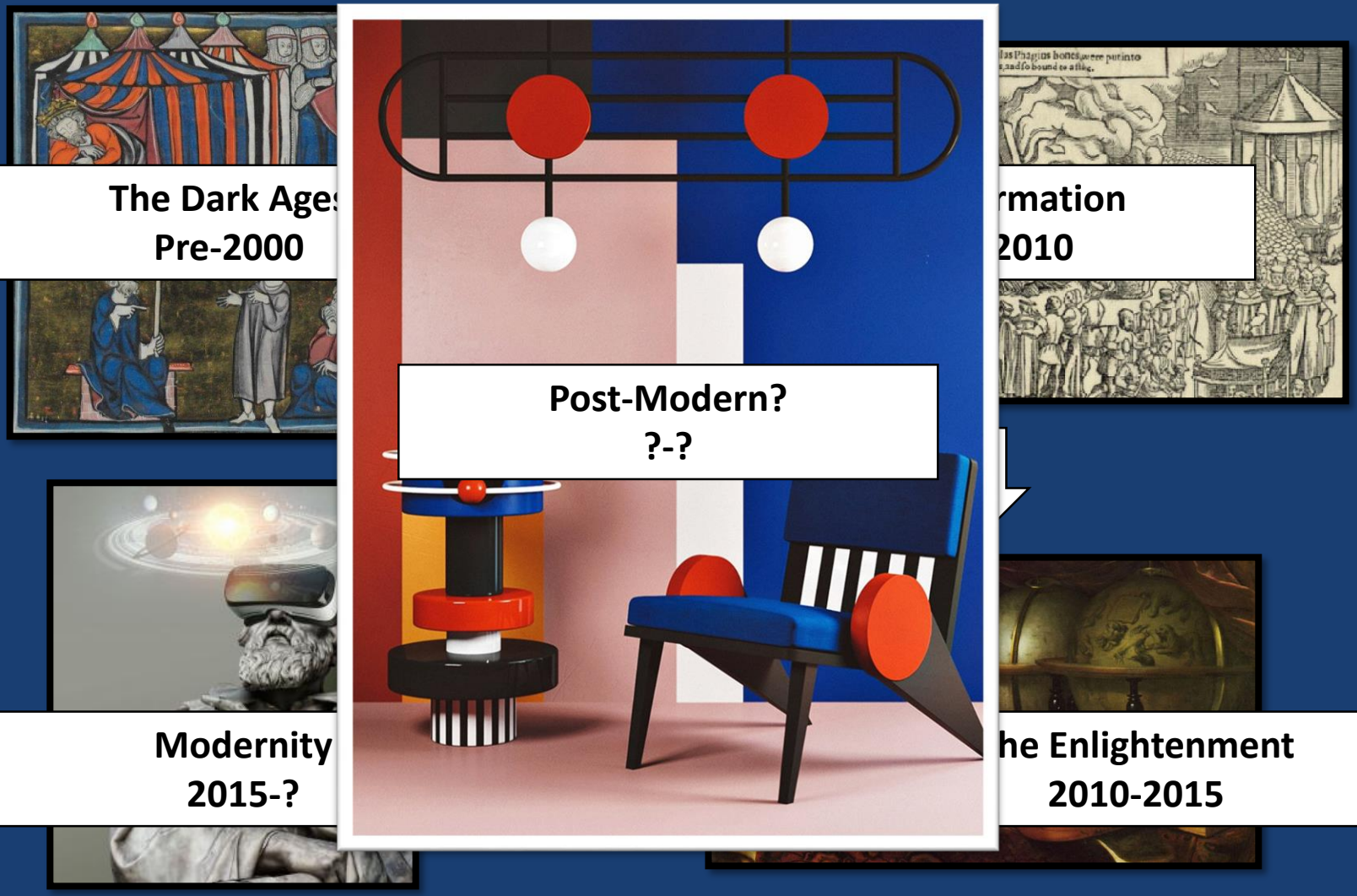

Honesty
Equality
Accountability
Respect
Teamwork
Putting patients
Caring Together
Heard
Valued
Environment
Leadership
Service Delivery
Your Experience
your patients

YQSR

Yorkshire Quality and Safety Research Group

Community of Scholars

A social history of patient involvement



A Social History of Patient Involvement

‘THE DARK AGES’:

Pre-2000

Era of Health & Safety

PATIENTS AS RECIEVERS OF CARE

SPECIAL ARTICLES

INCIDENCE OF ADVERSE EVENTS AND NEGLIGENCE IN HOSPITALIZED PATIENTS

Results of the Harvard Medical Practice Study I

TROYEN A. BRENNAN, M.P.H., M.D., J.D., LUCIAN L. LEAPE, M.D., NAN M. LAIRD, PH.D., LIESI HEBERT, SC.D., A. RUSSELL LOCALIO, J.D., M.S., M.P.H., ANN G. LAWTHERS, SC.D., JOSEPH P. NEWHOUSE, PH.D., PAUL C. WEILER, LL.M., AND HOWARD H. HIATT, M.D.

Abstract *Background.* As part of an interdisciplinary study of medical injury and malpractice litigation, we estimated the incidence of adverse events, defined as injuries caused by medical management, and of the subgroup of such injuries that resulted from negligent or substandard care.

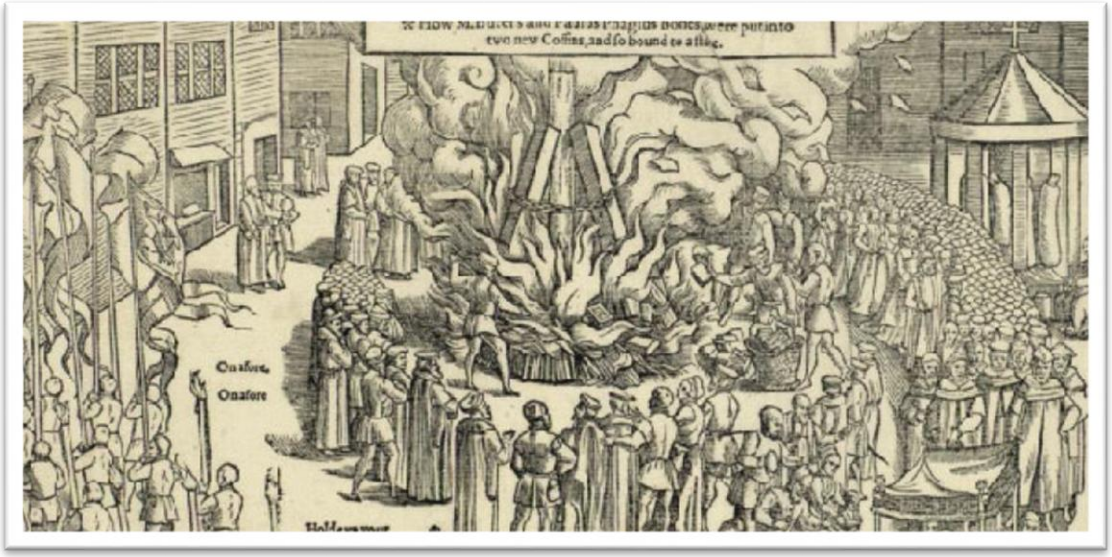
Methods. We reviewed 30,121 randomly selected records from 51 randomly selected acute care, nonpsychiatric hospitals in New York State in 1984. We then devel-

permanently disabling injuries and 13.6 percent led to death. The percentage of adverse events attributable to negligence increased in the categories of more severe injuries (Wald test $\chi^2 = 21.04$, $P<0.0001$). Using weighted totals, we estimated that among the 2,671,863 patients discharged from New York hospitals in 1984 there were 98,609 adverse events and 27,179 adverse events involving negligence. Rates of adverse events rose with age ($P<0.0001$). The percentage of adverse events due

A Social History of Patient Involvement

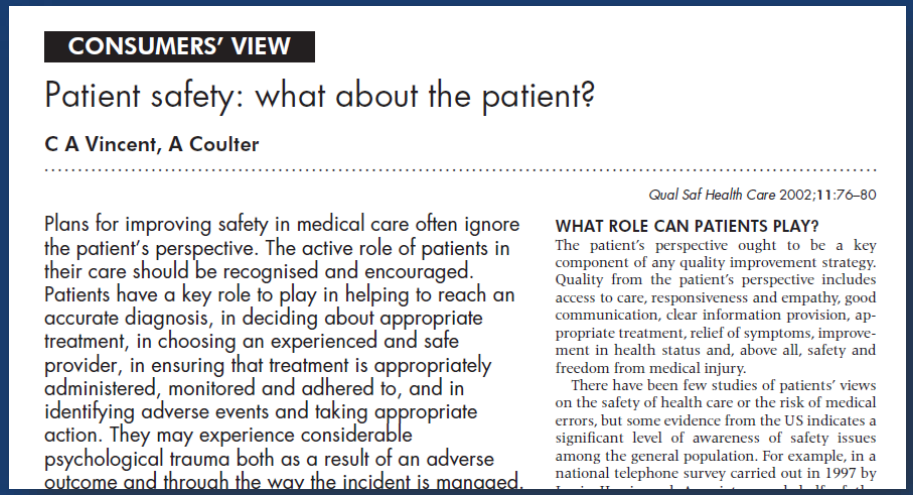
'THE REFORMATION': 2000-2010

Patient safety emerges as a valid concern



PATIENTS AS USERS OF CARE


FIRST, DO NO HARM
TO ERR
BUILDING A SAFER HEALTH SYSTEM
INSTITUTE OF MEDICINE
DH Department of Health
standards
EVALUATE
LEARN
active
CULTURE
hazard
accountability
memory
chaired by the Chief Medical Officer



CONSUMERS' VIEW

Patient safety: what about the patient?

C A Vincent, A Coulter

Qual Saf Health Care 2002;11:76–80

Plans for improving safety in medical care often ignore the patient's perspective. The active role of patients in their care should be recognised and encouraged. Patients have a key role to play in helping to reach an accurate diagnosis, in deciding about appropriate treatment, in choosing an experienced and safe provider, in ensuring that treatment is appropriately administered, monitored and adhered to, and in identifying adverse events and taking appropriate action. They may experience considerable psychological trauma both as a result of an adverse outcome and through the way the incident is managed.

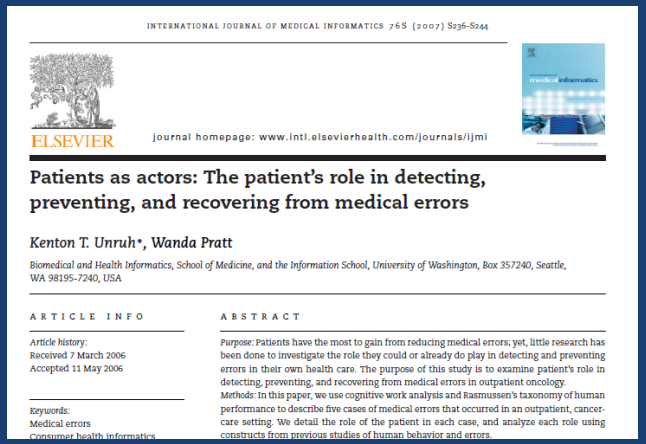
WHAT ROLE CAN PATIENTS PLAY?

The patient's perspective ought to be a key component of any quality improvement strategy. Quality from the patient's perspective includes access to care, responsiveness and empathy, good communication, clear information provision, appropriate treatment, relief of symptoms, improvement in health status and, above all, safety and freedom from medical injury.

There have been few studies of patients' views on the safety of health care or the risk of medical errors, but some evidence from the US indicates a significant level of awareness of safety issues among the general population. For example, in a national telephone survey carried out in 1997 by

"Patients are the only actors physically present during every treatment and consultation event...

Patients are uniquely positioned to observe, understand and monitor their overarching disease trajectory as it unfolds over time…"



INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS 76S (2007) S236–S244

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Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors

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ARTICLE INFO

Article history:
Received 7 March 2006
Accepted 11 May 2006

Keywords:
Medical errors
Consumer health informatics

ABSTRACT

Purpose: Patients have the most to gain from reducing medical errors; yet, little research has been done to investigate the role they could or already do play in detecting and preventing errors in their own health care. The purpose of this study is to examine patient's role in detecting, preventing, and recovering from medical errors in outpatient oncology.
Methods: In this paper, we use cognitive work analysis and Rasmussen's taxonomy of human performance to describe five cases of medical errors that occurred in an outpatient, cancer-care setting. We detail the role of the patient in each case, and analyze each role using constructs from previous studies of human behavior and errors.

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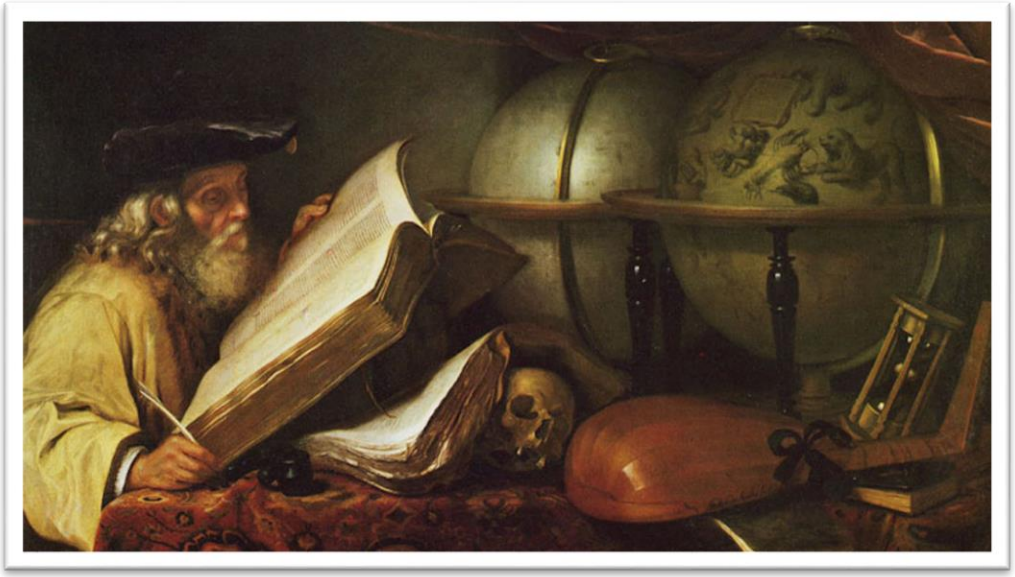
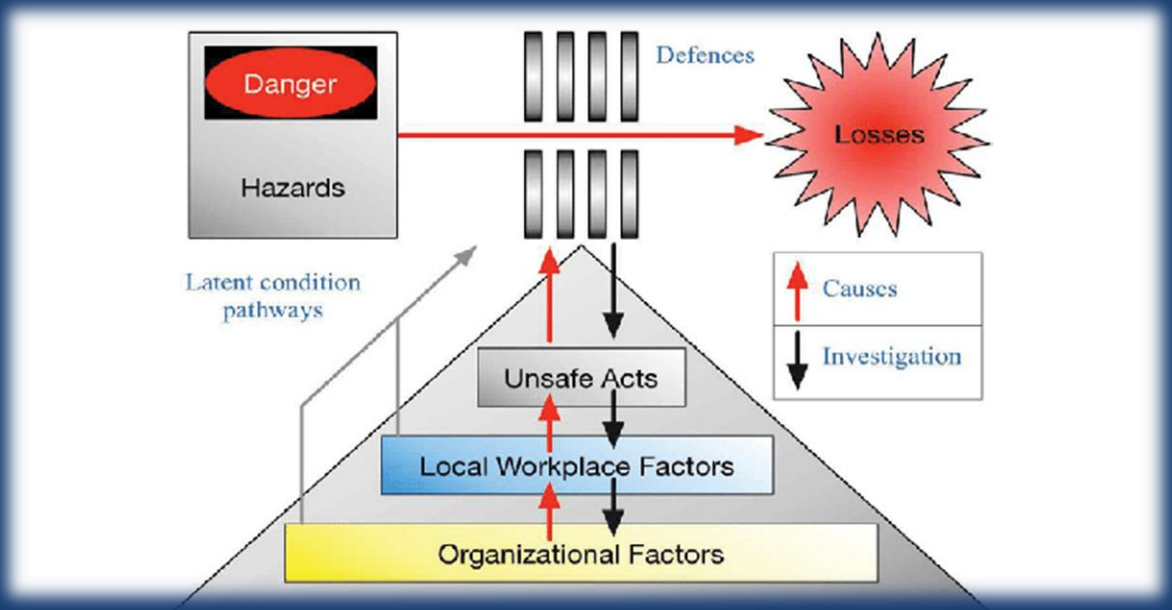
‘THE ENLIGHTENMENT’: 2010-2015

Patient safety comes of age



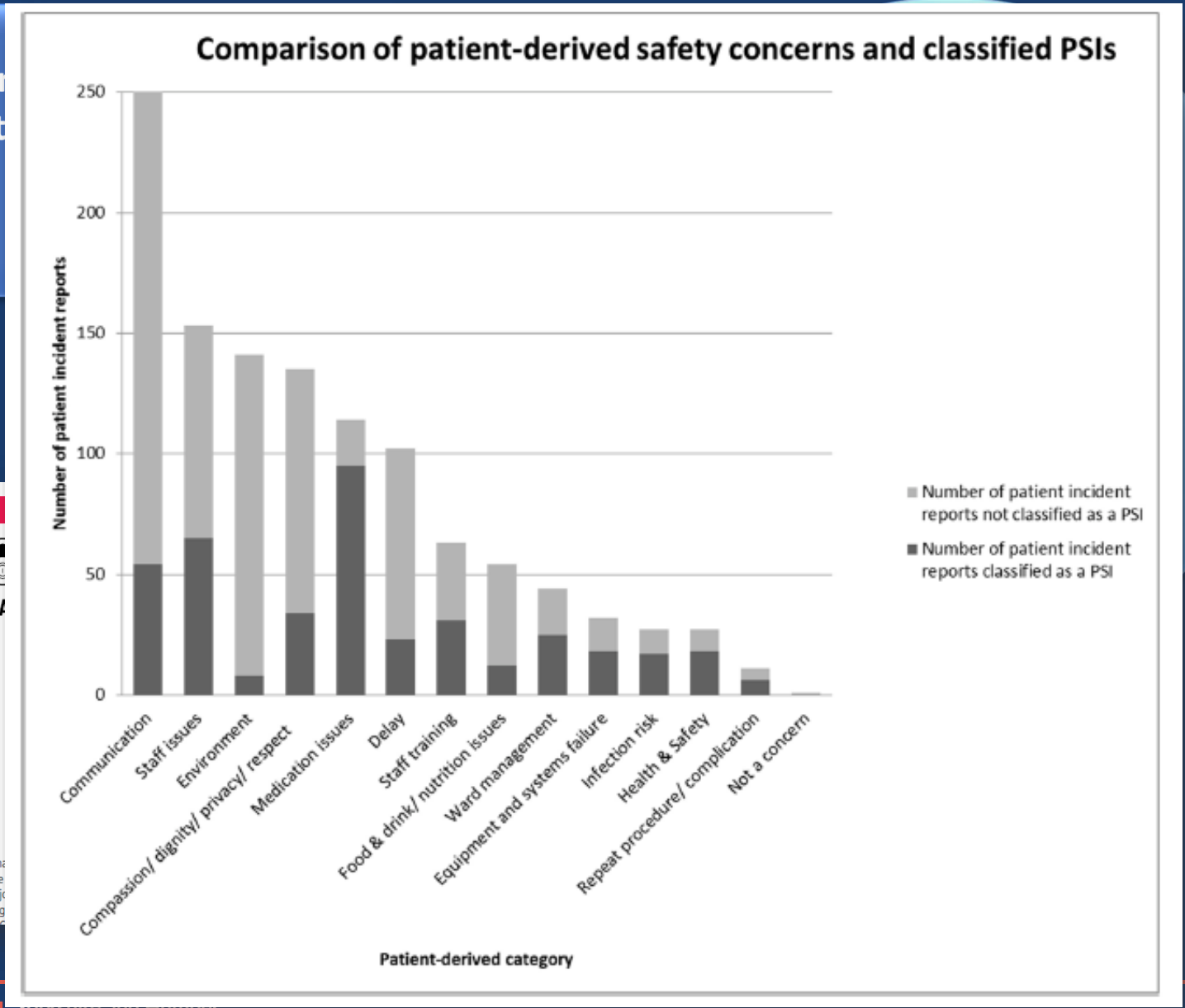
PATIENTS AS REPORTERS OF SAFETY


Danger
Hazards
Defences
Losses
Latent condition pathways
Causes
Investigation
Unsafe Acts
Local Workplace Factors
Organizational Factors

Can patients tell us things that can help us understand how safe we are?

Can it help improve system safety?

Ca
that


Comparison of patient-derived safety concerns and classified PSIs
Number of patient incident reports
250
200
150
100
50
0
Communication
Staff issues
Environment
Compassion/ dignity/ privacy/ respect
Medication issues
Delay
Staff training
Food & drink/ nutrition issues
Ward management
Equipment and systems failure
Infection risk
Health & Safety
Repeat procedure/ complication
Not a concern
Patient-derived category
Number of patient incident reports not classified as a PSI
Number of patient incident reports classified as a PSI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Can we use that information to ***improve system safety***?

Intervention found *NO EFFECT* on either outcome


OPEN ACCES

Can patient involvement improve

Rebecca Lawton,[1,2] Jane Kathryn O'Hara,[3] Laura Sheard,[4] Gerry Armitage,[5] Kim Cocks,[6] Hannah Buckley,[7] Belen Corbacho,[7] Caroline Reynolds,[8] Claire Marsh,[8] Sally Moore,[2] Ian Watt,[9] John Wright[10]

BUT:

Patients can and did provide feedback and staff valued that feedback for improvement…

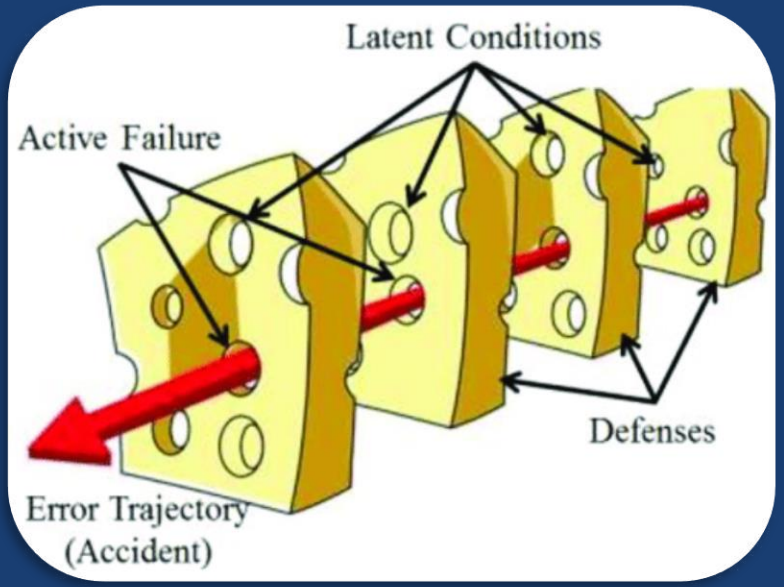
Patient reported safety

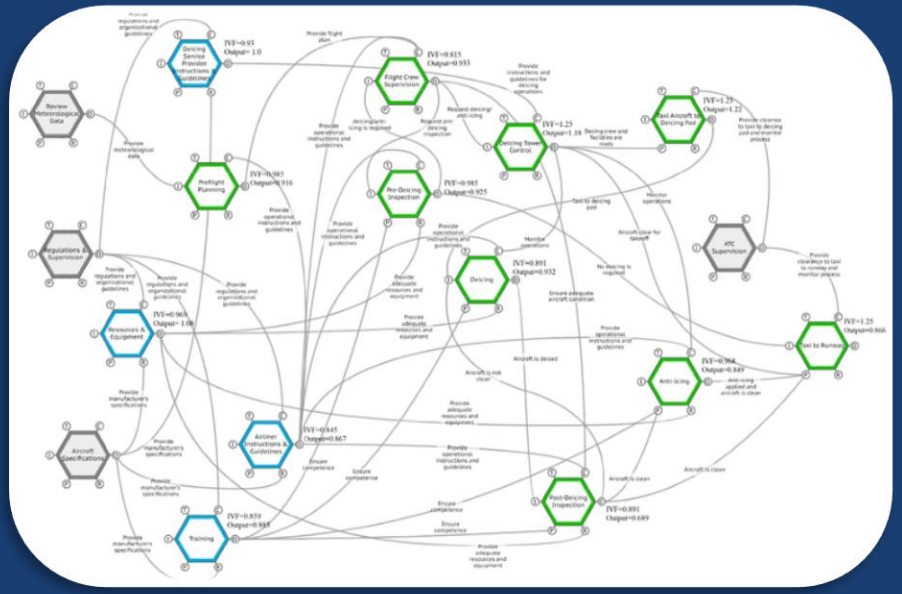
A Social History of Patient Involvement

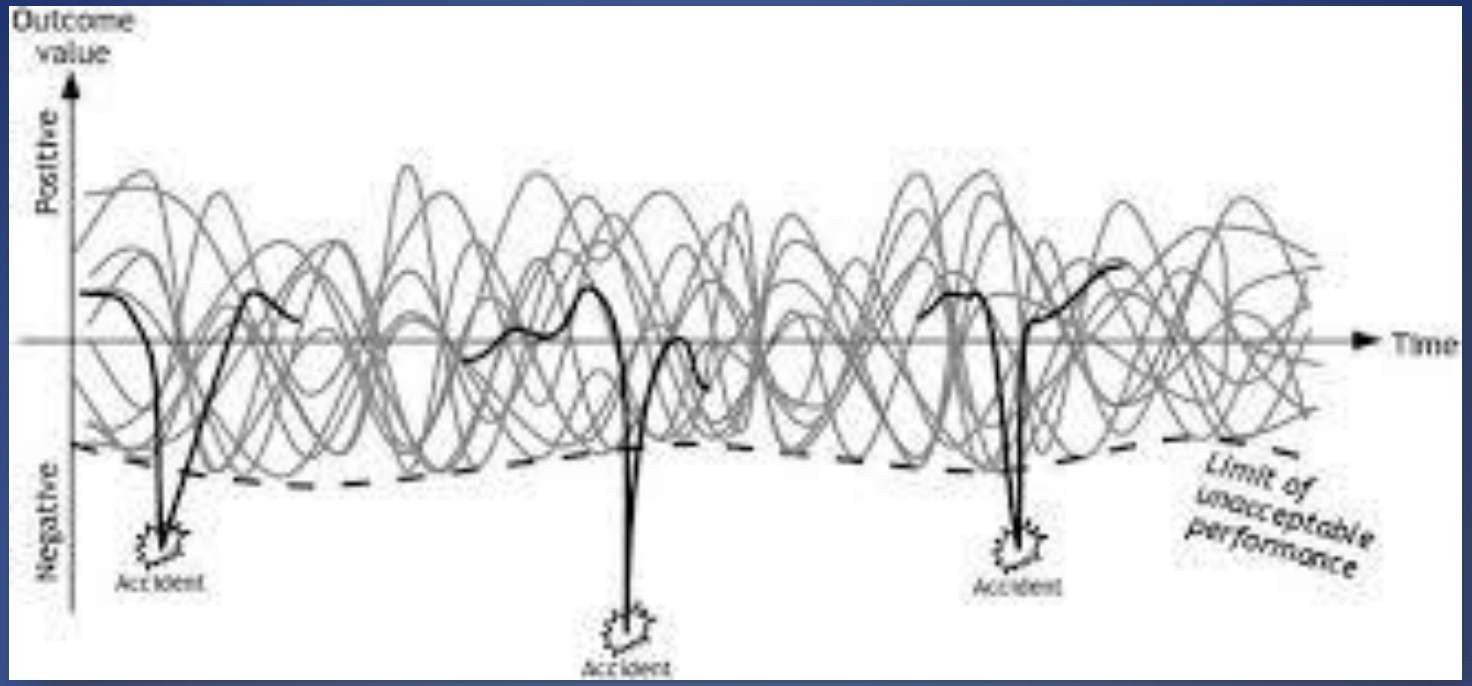
‘MODERNITY’: 2015-?

Patient safety widens its lens

PATIENTS AS CO-CREATORS OF SAFETY

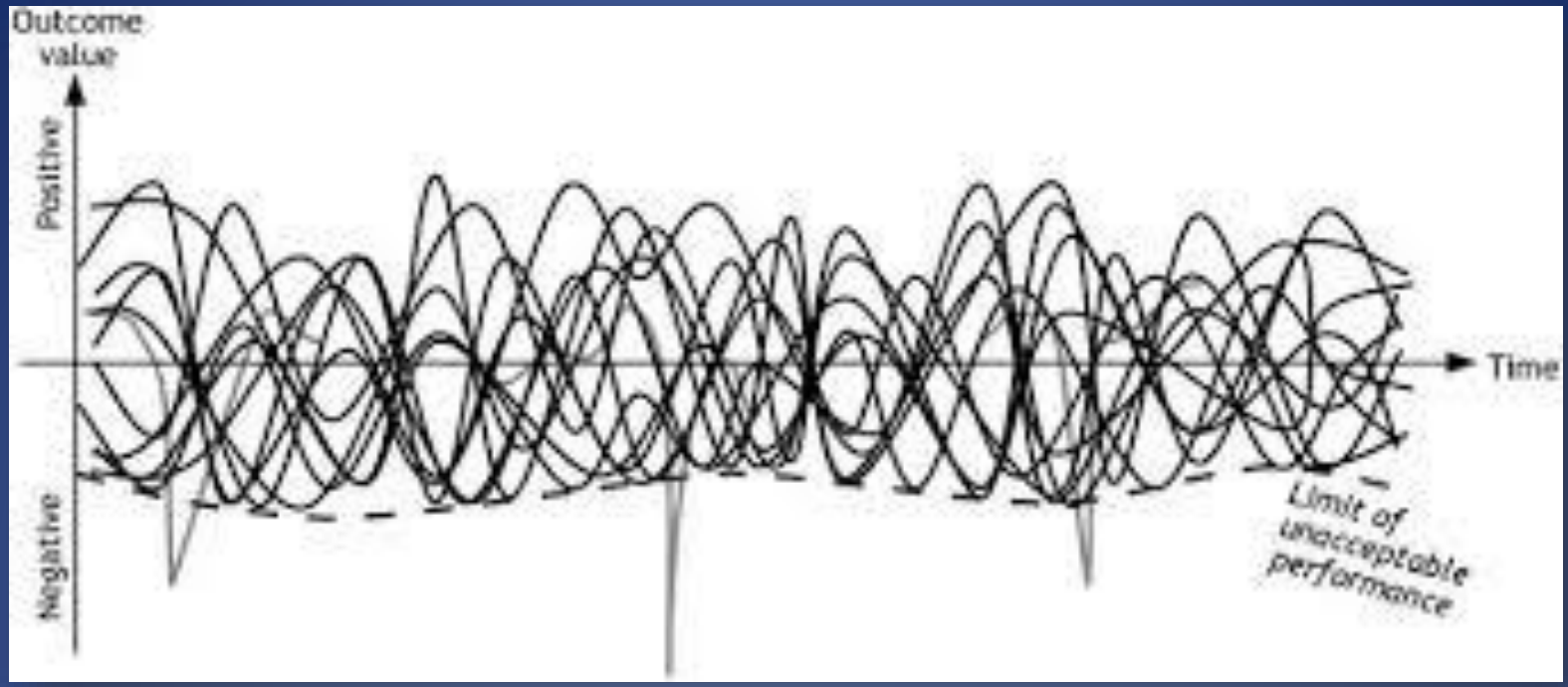

Latent Conditions
Active Failure
Defenses
Error Trajectory
(Accident)





'Safety I'

Managing safety by 'snapshots'



'Safety II'

Managing safety by supporting continuous performance within acceptable boundaries

EDITORIAL

Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience.

Jane K O'Hara,[1,2] Karina Aase,[3] Justin Waring[4]

[1]Leeds Institute of Medical Education, University of Leeds, Leeds, UK
[2]Yorkshire Quality and Safety Research Group, Bradford Institute of Health Research,

Redley and colleagues' study[1] suggests that involving patients in their care can be challenging, even when patients express a preference for involvement. Their paper examines a key opportunity for patient

… the intrinsic ability of a system to adjust its functioning prior to, during or following changes/disturbances in order to sustain required operations under expected or unexpected conditions.[6]

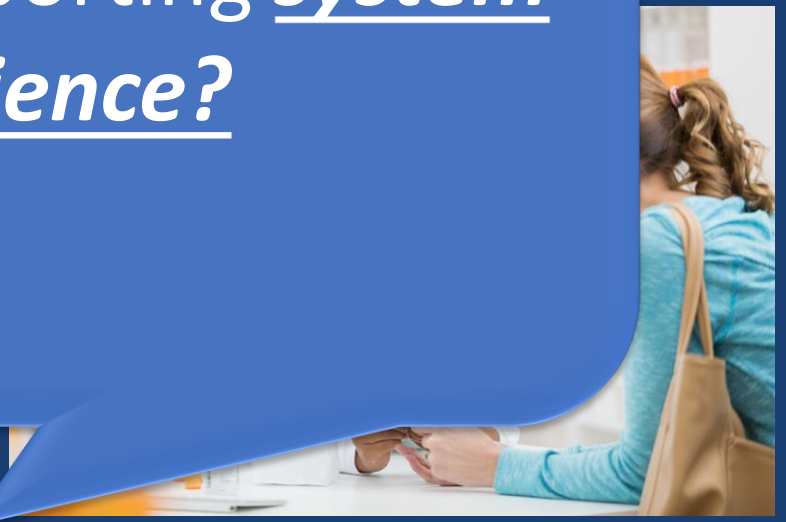
Patients and families have long been seen as a source of unwanted variability in treatment outcomes (eg, medication adherence), but patients and families may also be a unique source of insight and resilience in supporting the quality and safety of our healthcare processes. The key to harnessing this role more fully is

Do patients and their families have a role in supporting their safety?

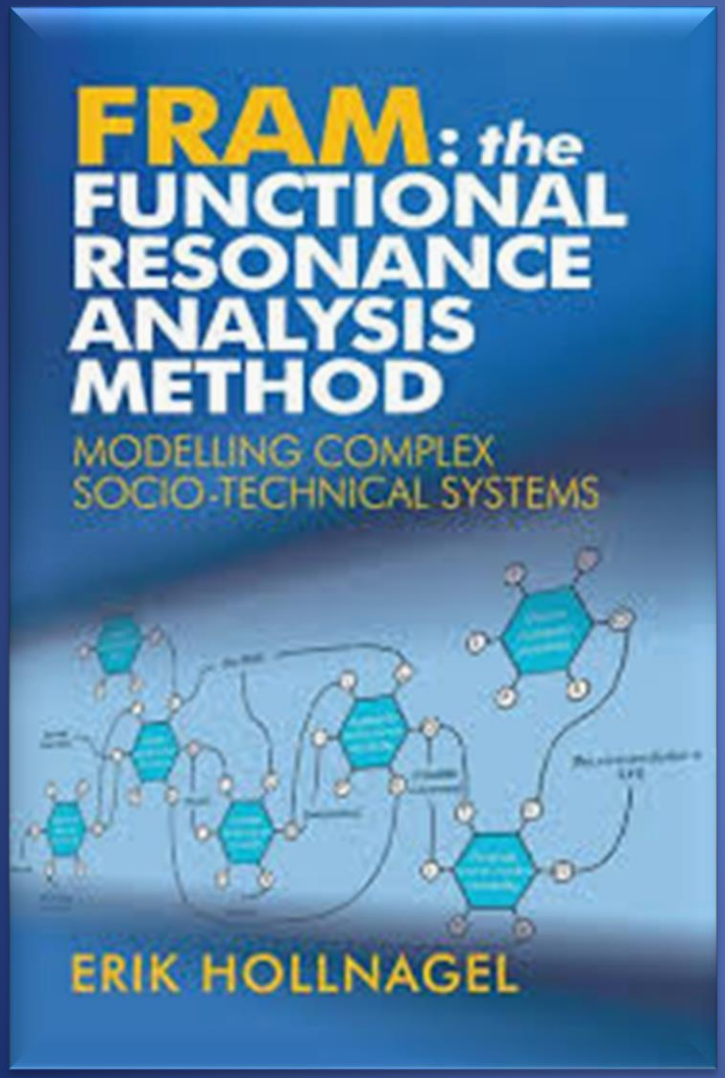
Do patients and their families have a role in supporting ***system level resilience?***

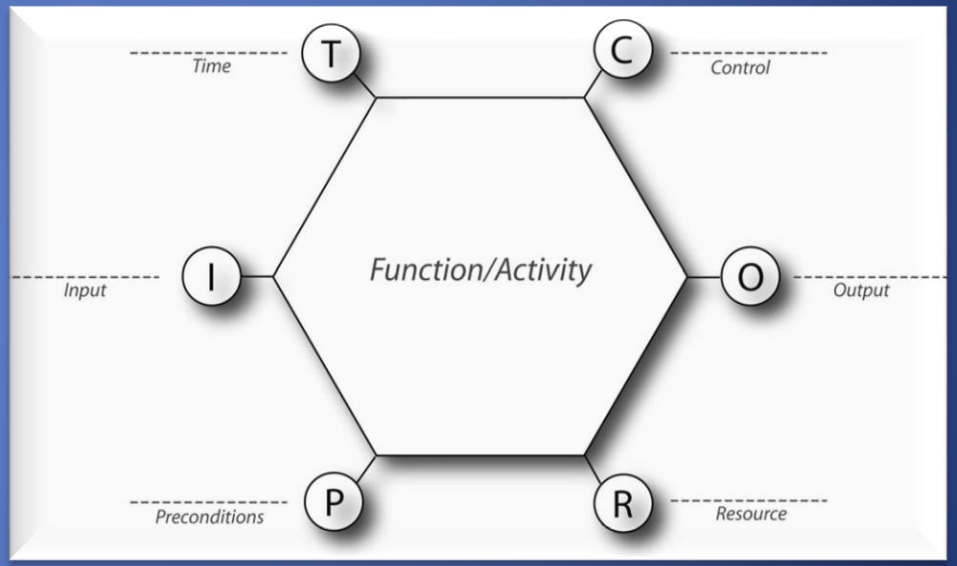
Do patients and their families have

Do patients and their families have a role in supporting ***system level resilience?***

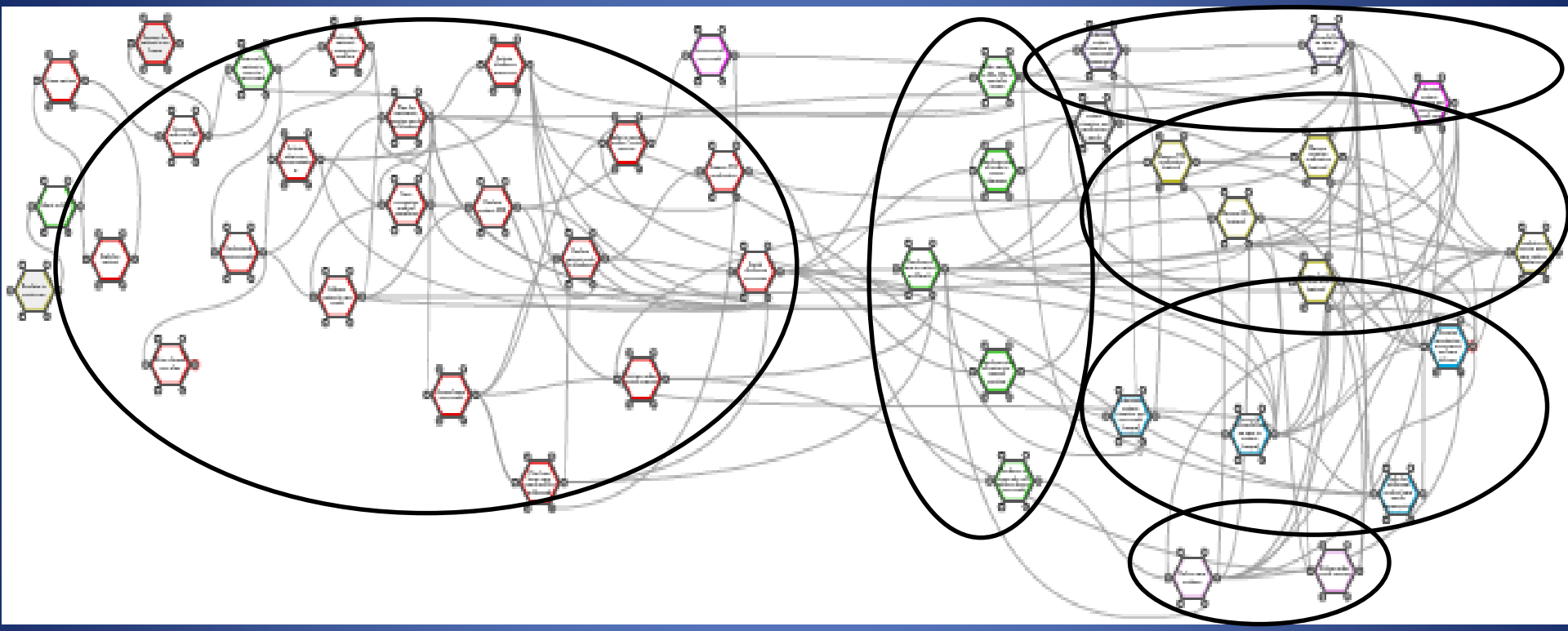


- Older patients (75yrs +) and their carers
- Multidisciplinary hospital, general practice, and community staff
- Focused observation of transitions and discharge processes


FRAM: the FUNCTIONAL RESONANCE ANALYSIS METHOD
MODELLING COMPLEX SOCIO-TECHNICAL SYSTEMS
ERIK HOLLNAGEL


Time
T
C
Control
Input
I
Function/Activity
O
Output
Preconditions
P
R
Resource

What does transition look like?



Hospital functions

Prescribed functions for all patients

General practice functions

Community functions

Patient functions

Patient functional activity

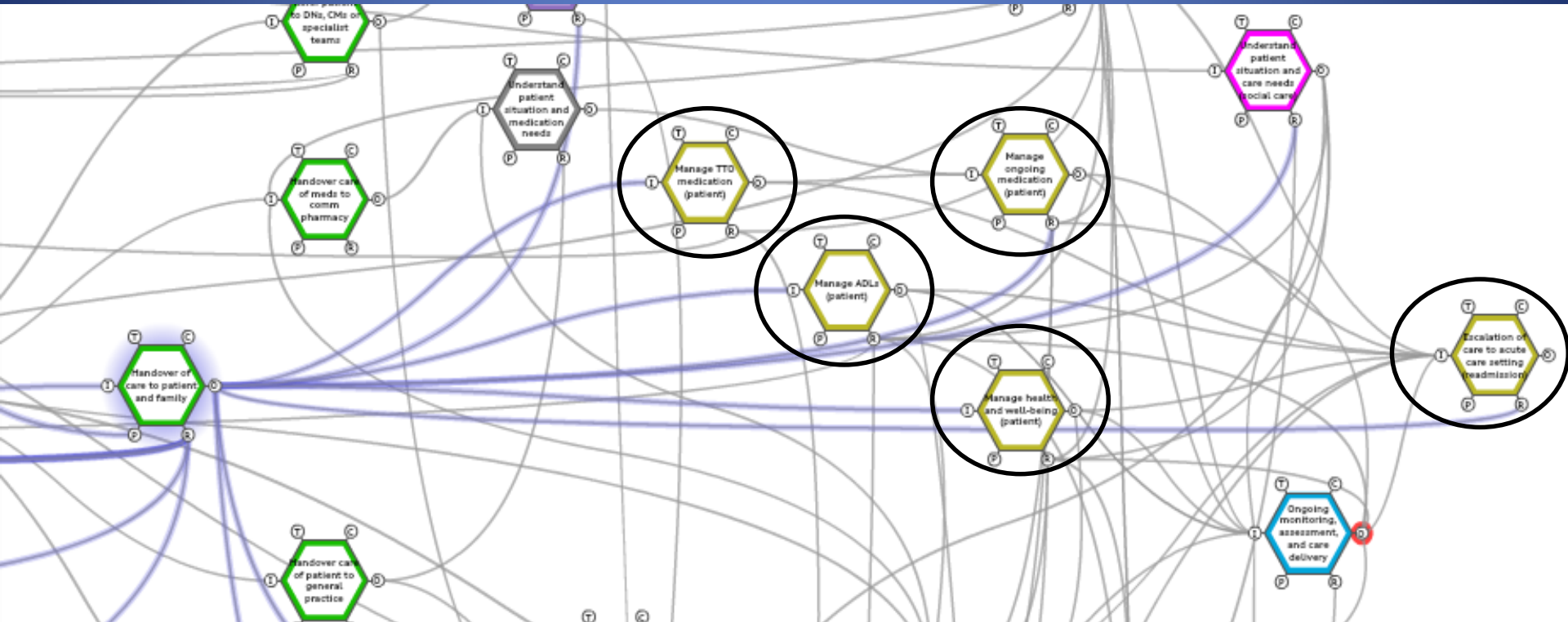
Manage take home medications

Manage ongoing medications

Manage health and wellbeing

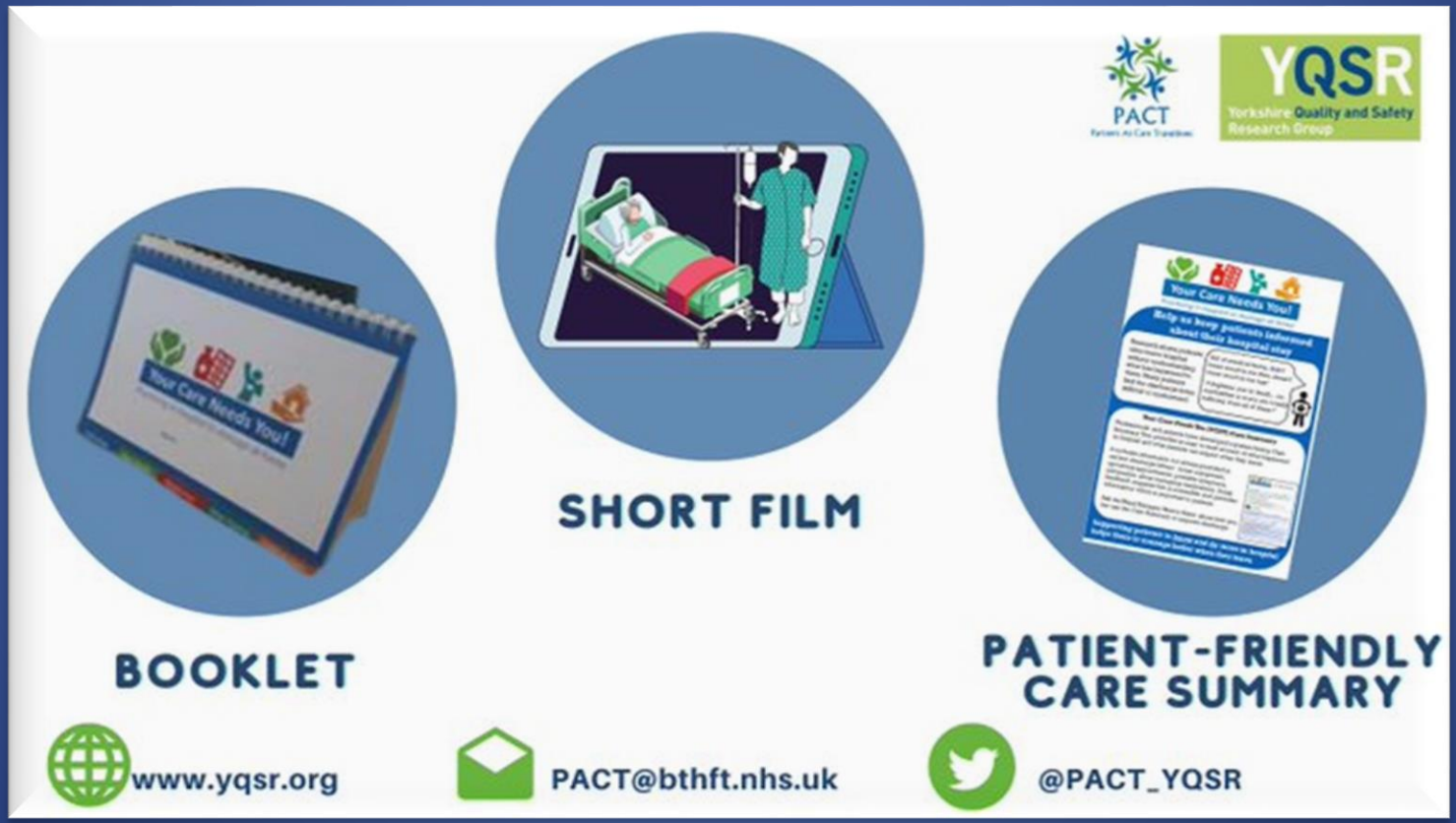
Manage activities of daily living

Escalate care



Handing over to the patient

Supporting patient functional activity

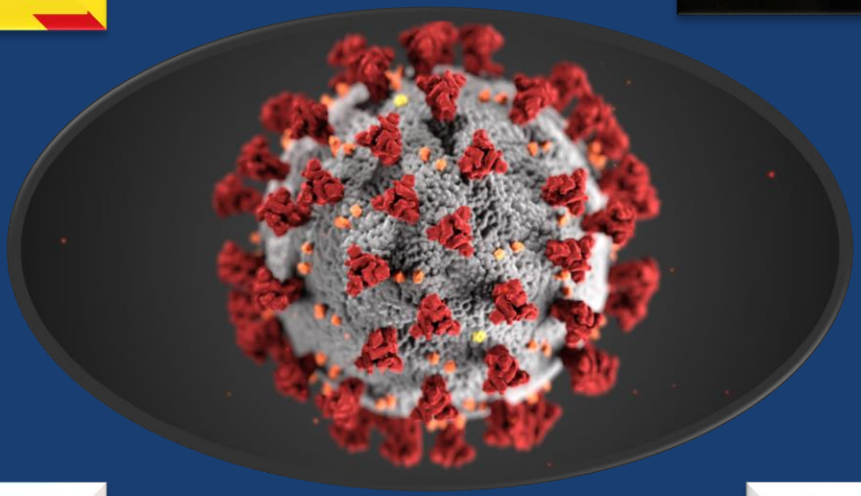


A Social History of Patient Involvement

‘POST-MODERN’: ?-?

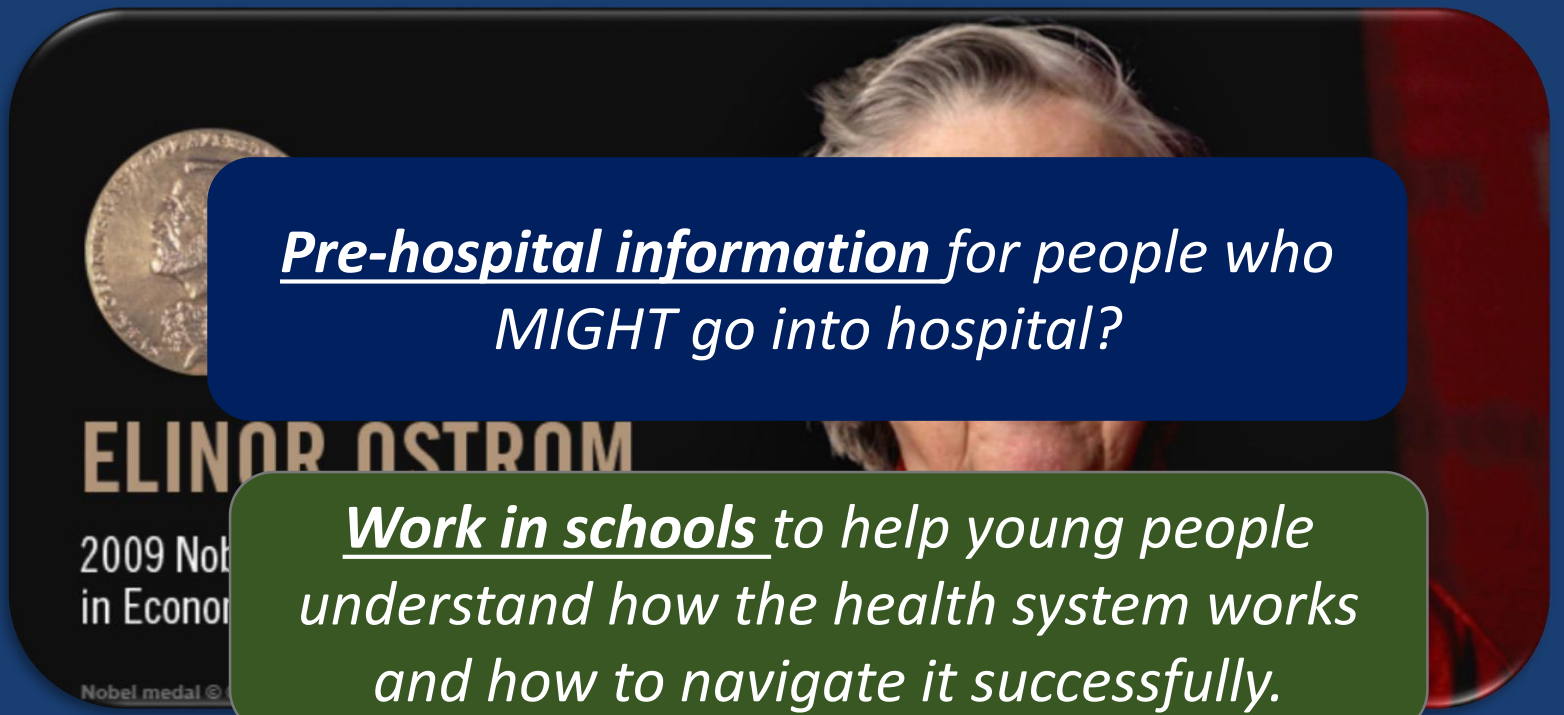
The future of patient involvement

PUBLIC AS CO-CREATORS OF SAFE HEALTHCARE SYSTEMS?



Covid pandemic has added almost 1.5 million people to the NHS waiting list in England

Even without the impact of Covid, the NHS in England would have expected to see a waiting list of around 5.3m people at the end of May 2022, health experts said



Pre-hospital information *for people who MIGHT go into hospital?*

Work in schools *to help young people understand how the health system works and how to navigate it successfully.*

A focus on ***how people enter INTO the healthcare system****, not just on services.*

Citizen act … es of
public ager … k their
doors, whil … itizens
may affect victimization rates and, thus, objective outcomes.

1. Stories are powerful, but *not the only thing* that can contribute to safety improvement or safe performance

2. Admitting patients and families (and the public) contribute to system performance is not a failing, *it is a necessary reality*

3. Patients and families help keep the system within the boundary of acceptable performance

4. Patients and families are part of the 'buffer zone' or redundancy in systems

5. This role needs to be supported if it is to be useful to the system, and less burdensome for patients and the public

6. ***Don't forget to look back and don't reinvent the wheel***


THANK
YOU