



Australian Evaluation Society August 2012

Evaluating e-Health programmes: the good, the bad and the ugly

Professor Trisha Greenhalgh

Acknowledging critical insights from Jill Russell



Barts and The London
School of Medicine and Dentistry

www.smd.qmul.ac.uk

Senate passes e-Health Bills with amendments

AAP JUNE 19, 2012 8:52PM

THE Senate has passed the government's controversial e-Health Bills but last minute amendments will see them return to the Lower House before becoming law.

The Federal Government says the system will bring the management of health records into the 21st century and provide life saving information in emergencies.

The legislation passed the Senate this evening with the support of the Coalition despite the concerns about privacy from some Opposition senators.

The system aims to reduce the number of hospital admissions because of medication errors which equate to 190,000 a year as well as cutting down on medical errors because of inadequate patient information.

Australians' health records will be available online and protected by encrypted passwords.

The electronic health system will be rolled out over time beginning on July 1.

Liberal senator Concetta Fierravanti-Wells raised concerns about the roll out of the system and sought a launch date from the government, particularly if a planned launch in Sydney on July 2 was still proceeding.

" the aim is that patients and service users will be increasingly active participants in their care and will share decision making with their clinicians.

"[...] Our own research, conducted during 2009, showed that patients were keen to have access to their medical records

as well as available

"The UC rather than HealthSpace those as well as c

Depart

"I'm not sure what is more worrying – the findings reported in our paper or what appears to be the purposive use of the five Ds (deny, denigrate, dismiss, distract and distort) by the Department of Health. We did not set out to present HealthSpace as a failure but to undertake an impartial and rigorous independent evaluation. Given the amount of public money that went into the work reported, it is surely of some public concern that the findings have been put aside so promptly by policymakers."

Prof T Greenhalgh, e-Health Insider 18th November 2010

¹Healthcare Infr Unit, Centre for Barts and the Medicine and E1 2AT, UK

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³Division of M University Col

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Why National eHealth Programs Need Dead Philosophers: Wittgensteinian Reflections on Policymakers' Reluctance to Learn from History

TRISHA GREENHALGH, JILL RUSSELL,
RICHARD E. ASHCROFT, and WAYNE PARSONS

Queen Mary University of London

Context: Policymakers seeking to introduce expensive national eHealth programs would be advised to study lessons from elsewhere. But these lessons are unclear, partly because a paradigm war (controlled experiment versus interpretive case study) is raging. England's \$20.6 billion National Programme for Information Technology (NPfIT) ran from 2003 to 2010, but its overall success was limited. Although case study evaluations were published, policymakers appeared to overlook many of their recommendations and persisted with some of the NPfIT's most criticized components and implementation methods.



House of Commons
Science and Technology
Committee

Scientific Advice, Risk and Evidence Based Policy Making

Seventh Report of Session 2005–06

Volume II

Oral and written evidence

*Ordered by The House of Commons
to be printed 26 October 2006*

guardian.co.uk



Government drug adviser David Nutt sacked

Professor David Nutt asked to resign after his claims that ecstasy and LSD were less dangerous than alcohol

Mark Tran

guardian.co.uk, Friday 30 October 2009 17:54 GMT

A [larger](#) | [smaller](#)

Professor David Nutt, the government's chief drug adviser, has been sacked a day after claiming that ecstasy and LSD were less dangerous than alcohol.



“It is the responsibility of ministers, not advisers, to make policy... but there are clearly implications for all areas of scientific advice to government.

I've served on a lot of advisory committees, and I've never seen anything like this. I'm sure that every independent expert who sits on an advisory committee would now like an assurance that the Government remains committed to proper consideration of the recommendations it receives..”

Colin Blakemore, MRC



House of Commons
Science and Technology
Committee

**The Government's review
of the principles applying
to the treatment of
independent scientific
advice provided to
government: Government
Response to the
Committee's Third Report
of Session 2009–10**

**First Special Report of Session
2009–10**

*Ordered by the House of Commons
to be printed 24 February 2010*

HC 384
Published on 2 March 2010
by authority of the House of Commons
London: The Stationery Office Limited
£0.00

Principles of Scientific Advice to Government

The Principles of Scientific Advice set out the rules of engagement between Government and those who provide independent scientific and engineering advice. They provide a foundation on which independent scientific advisers and government departments should base their operations and interactions.

The Principles apply to Ministers and Government departments, all members of Scientific Advisory Committees and Councils (the membership of which often includes statisticians, social researchers and lay members) and other independent scientific and engineering advice to Government. They do not apply to employed advisers, departmental Chief Scientific Advisers or other civil servants who provide scientific or analytical advice, as other codes of professional conduct apply.

Clear roles and responsibilities

- Government should respect and value the academic freedom, professional status and expertise of its independent scientific advisers.
- Scientific advisers should respect the democratic mandate of the Government to take decisions based on a wide range of factors and recognise that science is only part of the evidence that Government must consider in developing policy.
- Government and its scientific advisers should not act to undermine mutual trust.
- Chairs of Scientific Advisory Committees and Councils have a particular responsibility to maintain open lines of communication with their sponsor department and its Ministers.

THREE CRITICAL QUESTIONS

- What is the role of scientists in evaluating government policy?
- What does a “scientific” evaluation of government policy mean?
- What other kinds of policy evaluation are there?



1998

“If I live in Bradford and fall ill in Birmingham, then I want the doctor treating me to have access to the information he needs to treat me.”



2010

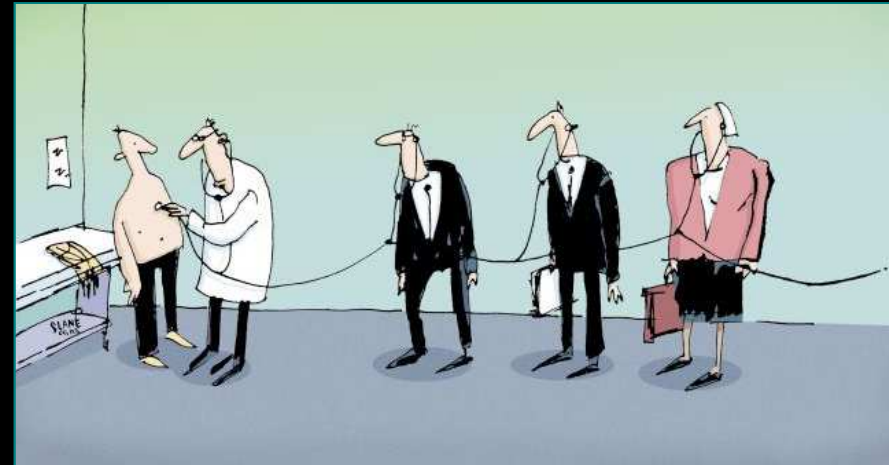
“A computerized medical record for every American within the next five years.....

...could prevent medical error, save lives and create hundreds of thousands of jobs”

SUMMARY CARE RECORD: FINDINGS

- £235 million of a £12.4 billion IT programme
- Began with a politician's promise
- Implementation phase characterised largely by non-adoption, resistance and abandonment
- Numerous delays, technical glitches, unforeseen issues, 'wicked problems'
- Described as "ridiculously over-governed"
- Multiple stakeholders, multiple versions of the story

Summary Care Records



Connecting for Health



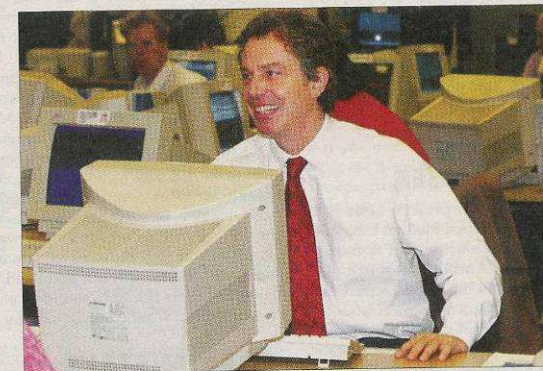
FORMER SHIPMAN PATIENT IN CONTROL

Margaret Rickson 79, retired

SYSTEM FAILURE!

A Private Eye special report by RICHARD BROOKS

How this government is blowing £12.4bn on useless IT for the NHS



CLUELESS: Tony Blair, who can barely use a computer himself, naively believed that a grandiose IT project could transform the NHS

“Waste and inefficiency in the NHS is intolerable”, declared Health Secretary Patricia Hewitt one year ago amid mounting deficits. “A penny wasted is a penny stolen from a patient.” This is the story of the theft of 1,240,000,000,000 pennies from patients through an IT

such was the development of the healthcare IT market that by March 2003 McKinsey’s Bennett reported that there were 27 “entirely viable and interesting vendors” with suitable software packages to sell.

Yet in February 2002 when Pattison crossed

POLITICAL

THE POLITICAL WORLD: SCR is a tool for achieving manifesto promises e.g. greater “transparency”, more efficient public spending

CLINICAL

THE CLINICAL WORLD: SCR will improve patient care BUT privacy is an issue

TECHNICAL

THE TECHNICAL WORLD: SCR must be innovative, elegant, fit for purpose etc

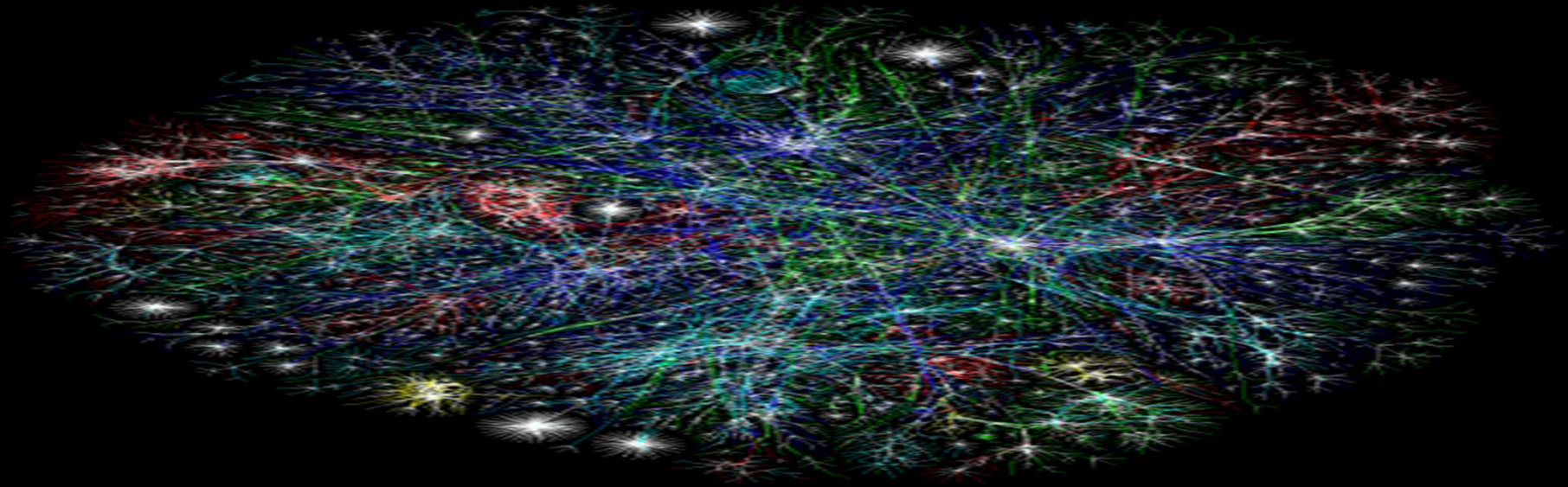
COMMERCIAL

THE COMMERCIAL WORLD: SCR must bring return on investment for shareholders

PERSONAL

THE PERSONAL WORLD: Will the SCR help my doctor provide personal care for me (and what about my privacy)?

10 BOTTOM-LINE LESSONS



1. The bigger is the harder it gets

10 BOTTOM-LINE LESSONS



2. Different stakeholders see things differently

10 BOTTOM-LINE LESSONS



3. Insoluble tensions and paradoxes are a fact of life

10 BOTTOM-LINE LESSONS



4. Knowledge is more than what gets passed up the line in accrual reports

10 BOTTOM-LINE LESSONS



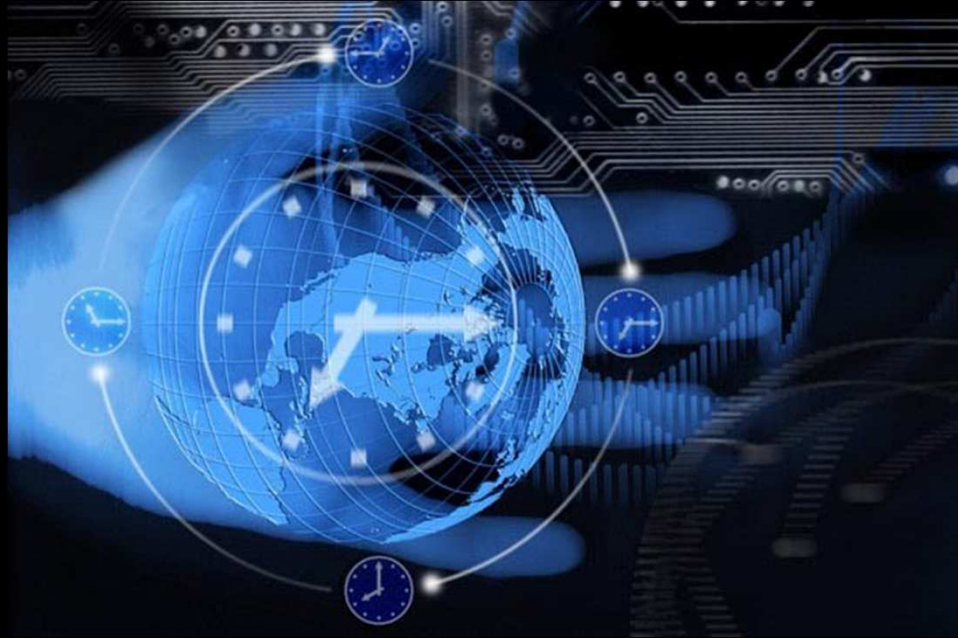
5. The preferred change model is organic rather than mechanistic

10 BOTTOM-LINE LESSONS



6. The programme should therefore include ‘soft’ elements....
- space to reflect and talk
 - someone who can tell us what’s going on *and* hard elements...
 - competent project management
 - reliable performance data fed back locally

10 BOTTOM-LINE LESSONS



7. Technical development should be alert to the subtleties of clinical work and the realities of the NHS

10 BOTTOM-LINE LESSONS



8. 'Clinical engagement' is more about being listened to than being written to

10 BOTTOM-LINE LESSONS



9. A great deal depends on front-line staff, who usually want to do a good job

10 BOTTOM-LINE LESSONS



10. Government is respectfully reminded that...

- you can't contract for innovation
- privacy isn't a footnote
- civil servants don't always have to drive the boat

Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study

Trisha Greenhalgh, director,¹ Katja Stramer, senior research fellow,² Tanja Bratan, research fellow,² Emma Byrne, research fellow,³ Jill Russell, senior lecturer,² Henry W W Potts, lecturer³

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ABSTRACT

Objective To evaluate the adoption and implementation of a shared electronic summary record in patients' medical practices.

Design Mixed-method case study.

Setting English general practices. **Setting** English summary care records. **Setting** National Programme for Information Systems. **Setting** evaluation of national policy.

THE DEVIL'S IN THE DETAIL

Final report of the independent evaluation of the Summary Care Record and HealthSpace programmes

Trisha Greenhalgh, Katja Stramer, Tanja Bratan, Emma Byrne, Jill Russell, Susan Hinder, Henry Potts

7th May 2010

*From Simon Burns MP Minister of State
for Health*

POC4_511760



Dr Hamish Meldrum, Chair of Council
Dr Laurence Buckman, Chair of GP Committee
British Medical Association
BMA House
Tavistock Square
London
WC1H 9JP

*Richmond House
79 Whitehall
LONDON
SW1A 2NL*

*Tel: 020 7210 3000
Direct Line: 020 7210*

10 JUN 2010

Dear Drs Meldrum and Buckman

We have noted that the BMA is discussing the issue of the Summary Care Record in the LMC afternoon session on Friday and will be interested to learn the outcome of these discussions. To help inform your thinking, we thought it would be useful if you knew the Government position on the issue.

Broadly, our view is that we see a need for both patients and clinicians to be able to access patient records in an electronic form. This is part of our thinking about making information transparent and available, while involving patients in decisions about their healthcare.



 [Newsletter](#)  [RSS](#)  [Twitter](#)

04 September 2010 | 19:44 GMT

Greenhalgh slams Burns SCR review

Tags: [BMA](#) [Burns](#)

15 Jun 2010

The leader of the independent Summary Care Record review has described the government's promise to doctors to conduct another review as an "absolute disgrace."

Health minister Simon Burns wrote to the British Medical Association promising a review last week, and his letter was read out at the Local Medical Committees' conference as it debated the SCR.

In an interview with E-Health Insider, Trisha Greenhalgh, professor of primary healthcare and director of the Centre for Life Sciences at Barts and The London School of Medicine and Dentistry, said the review would be a "cosmetic consultation" and "like shifting the chairs on the Titanic."

7th October

Dear Minister

Reviews into the Summary Care Record

You asked us to conduct two reviews of the Summary Care Record: the first into the content of the Record and the second into the information that patients receive regarding the Record and the process by which they can opt out. This letter summarises the reviews and key recommendations.

A wide range of patient and clinical groups participated in the reviews and it is clear that an overwhelming consensus exists for change.

Professor Sir Bruce Keogh KBE



Medical Director of the National
Health Service in England

Joan Sandler OBE



National Director Patient and Public
Affairs, Department of Health

MENU OF SCR REVIEWS

Greenhalgh et al (independent)

- Content of the SCR
 - Opt-out process
1. Scale & complexity of NPfIT
 2. Multiple stakeholders
 3. Insoluble tensions & paradoxes
 4. Complex nature of knowledge
 5. Inappropriate change model
 6. Balance between 'hard' & 'soft'
 7. Technical development
 8. Clinical engagement
 9. What happens at the front line
 10. Role of government

Keogh / Sadler (civil servants)

- Content of the SCR
- Opt-out process

Essay

Evaluating eHealth Interventions: The Need for Continuous Systemic Evaluation

Lorraine Catwell, Aziz Sheikh*

Centre for

This
article

Essay

Evaluating eHealth: Undertaking Robust International Cross-Cultural eHealth Research

David W. Bates^{1,2,3,4*}, Adam Wright^{1,3,4}

¹Division of General Internal Medicine, Brigham and Women's Hospital, Boston, Massachusetts, United States of America, ²Department of Health Policy and Management, Harvard School of Public Health, Boston, Massachusetts, United States of America, ³Harvard Medical School, Boston, Massachusetts, United States of America,

This
three

Essay

Evaluating eHealth: How to Make Evaluation More Methodologically Robust

Richard James Lilford^{1*}, Jo Foster¹, Mike Pringle²

¹Division of Primary Care, School of Health and Population Sciences, University of Birmingham, Birmingham, United Kingdom, ²School of Community Health Sciences, University of Nottingham, Nottingham, United Kingdom

Essay

Evaluating eHealth Interventions: The Need for Continuous Systemic Evaluation

Lorraine Catwell, Aziz Sheikh*

Centre for Population Health Sciences, The University of Edinburgh, Edinburgh, Scotland

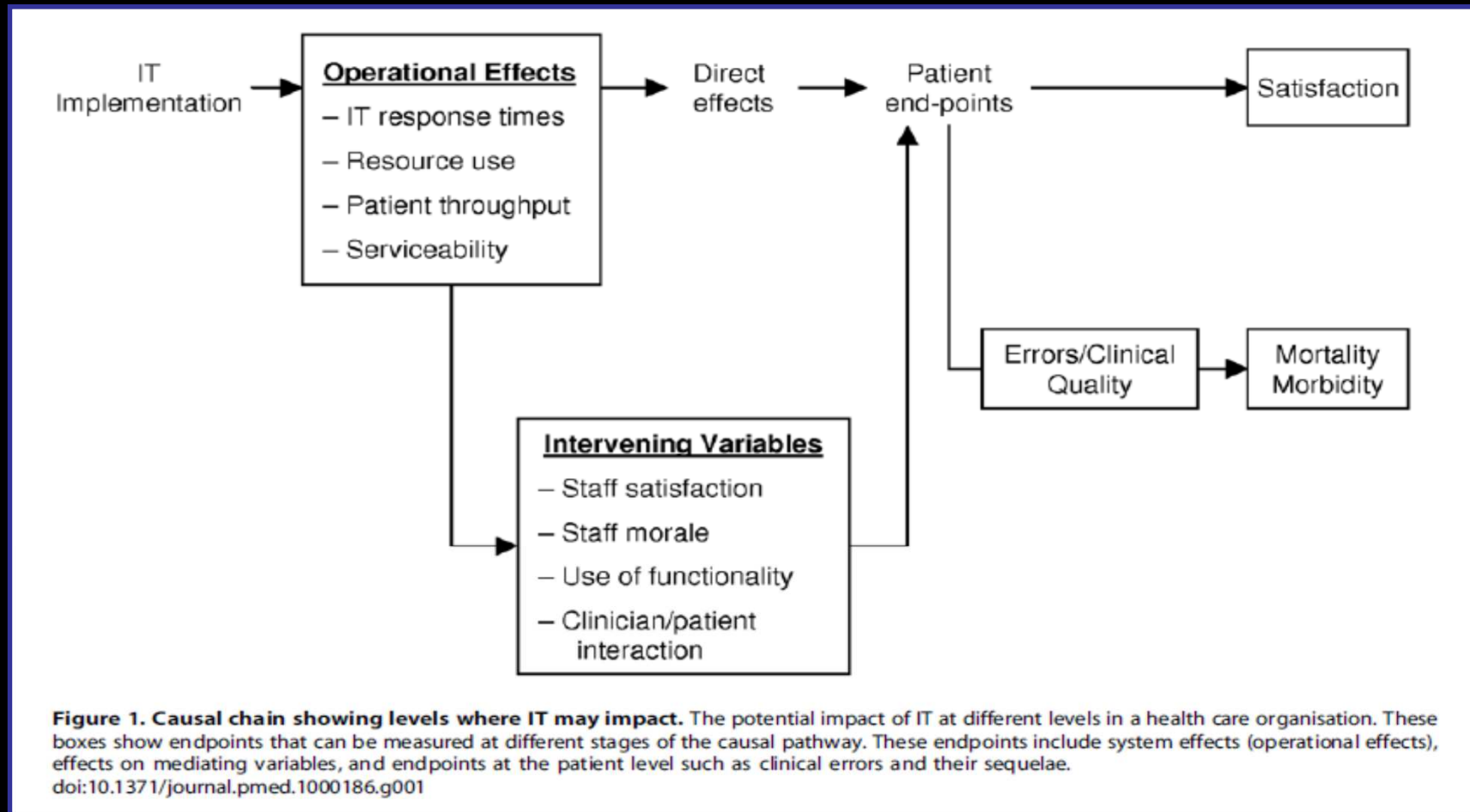
This is the first in a monthly series of three articles on evaluating eHealth

Summary Points

ably, reluctant to adopt these new technologies. The paradox is that unless we have

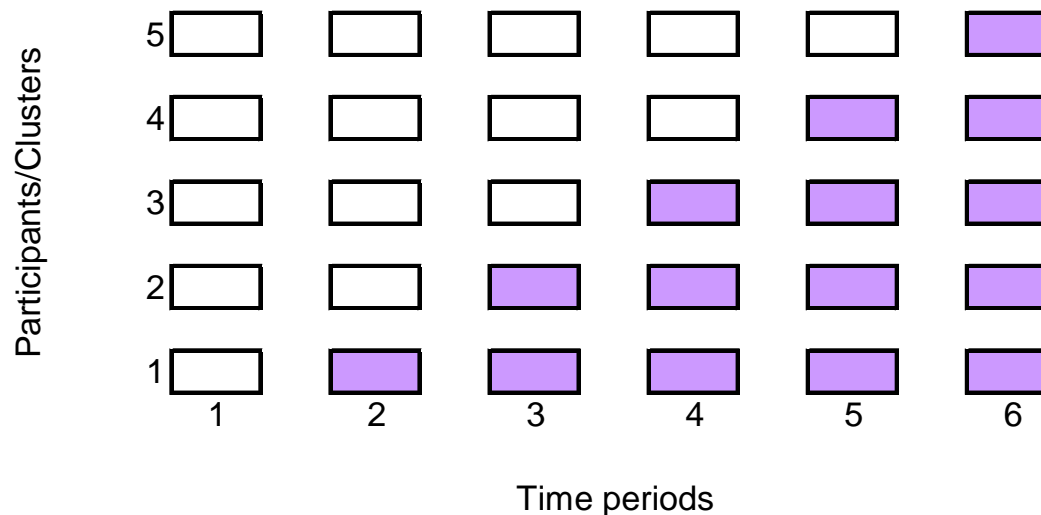
“Health information systems should be evaluated with the same rigour as a new drug or treatment programme, otherwise decisions about future deployments of ICT in the health sector may be determined by social, economic, and/or political circumstances, rather than by robust scientific evidence.”

Catwell & Sheikh 2009



“...systematically address each part of a chain of reasoning, at the centre of which are a programme’s goals.”

Lilford, Foster & Pringle 2009



Shaded cells represent intervention periods
 Blank cells represent control periods
 Each cell represents a data collection point

“The step-wedge design appears to have particular promise in the evaluation of eHealth systems. The largest project commissioned under the NPfIT follows the step-wedge design.”

Lilford, Foster & Pringle 2009

Essay

Why Do Evaluations of eHealth Programs Fail? An Alternative Set of Guiding Principles

Trisha Greenhalgh^{1*}, Jill Russell²

¹ Healthcare Innovation and Policy Unit, Centre for Health Sciences, Barts and The London School of Medicine and Dentistry, London, United Kingdom, ² Division of Medical Education, University College London, London, United Kingdom

Introduction

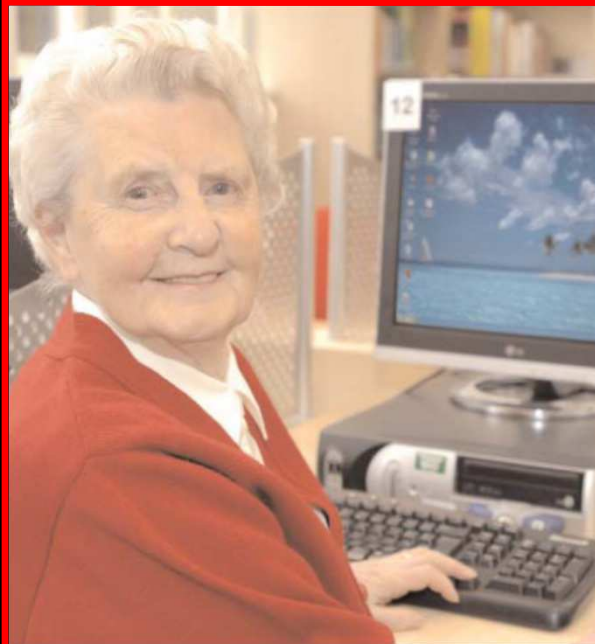
Much has been written about why

to facts)—hence, reality is never objectively or unproblematically knowable—and that the identity and values

These traditions reject the assumption that a rigorous evaluation can be exclusively scientific. Rather, they hold that as well as

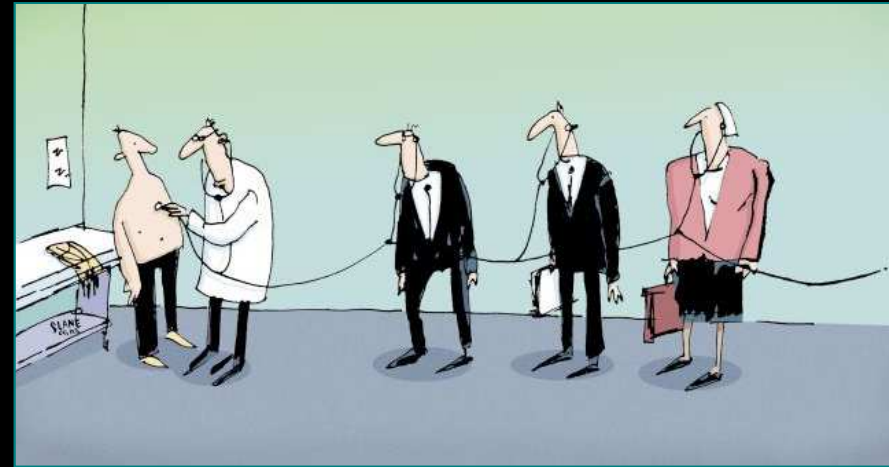
“...the authors of the empirical study flagged as an exemplary illustration of the step-wedge design abandoned it in favour of a largely qualitative case study because they found it impossible to establish anything approaching a controlled experiment in the complex, fast-moving and politicised context in which their study was conducted”.

Greenhalgh & Russell 2010



FORMER SHIPMAN PATIENT IN CONTROL

Margaret Rickson 79, retired



“eHealth ‘interventions’ may lie in the technical and scientific world, but eHealth dreams, visions, policies and programmes have personal, social, political and ideological components, hence typically prove fuzzy, slippery and unstable when we seek to define and control them”

Greenhalgh and Russell 2010



Professor Saville Kushner

“The [positivist evaluation] model is elegant in its simplicity, appealing for its rationality, reasonable in asking little more than that people do what they say they will do, and it is efficient in its economical definition of what data count....”

BUT.....



Professor Saville Kushner

- Programmes have multiple and contested goals, so no single goal can be a fixed referent for “success”
- Outcomes are not stable: they erode and morph over time and in different contexts
- The causal link between input and outcome is interrupted by numerous intervening variables
- Programme learning which leads away from initial objectives threatens failure against outcome criteria



“Expressing findings as statistical relationships between variables may draw attention away from people taking action.”

People exhibit particular personality traits, express emotions, enact power relationships and generate and deal with conflict.

Technologies also ‘act’ in their own non-human way: for example, they boot up, crash, transmit, compute, aggregate and permit or deny access.”

Greenhalgh & Russell 2010

“RIGOROUS” EVALUATION

Positivist

- Quasi-experimental
- Methodologically robust
- Values objectivity and disengagement
- Seeks to determine causal relationship between abstracted variables
- Takes reality as a given
- Seeks to resolve ambiguity/contestation

Critical-interpretivist

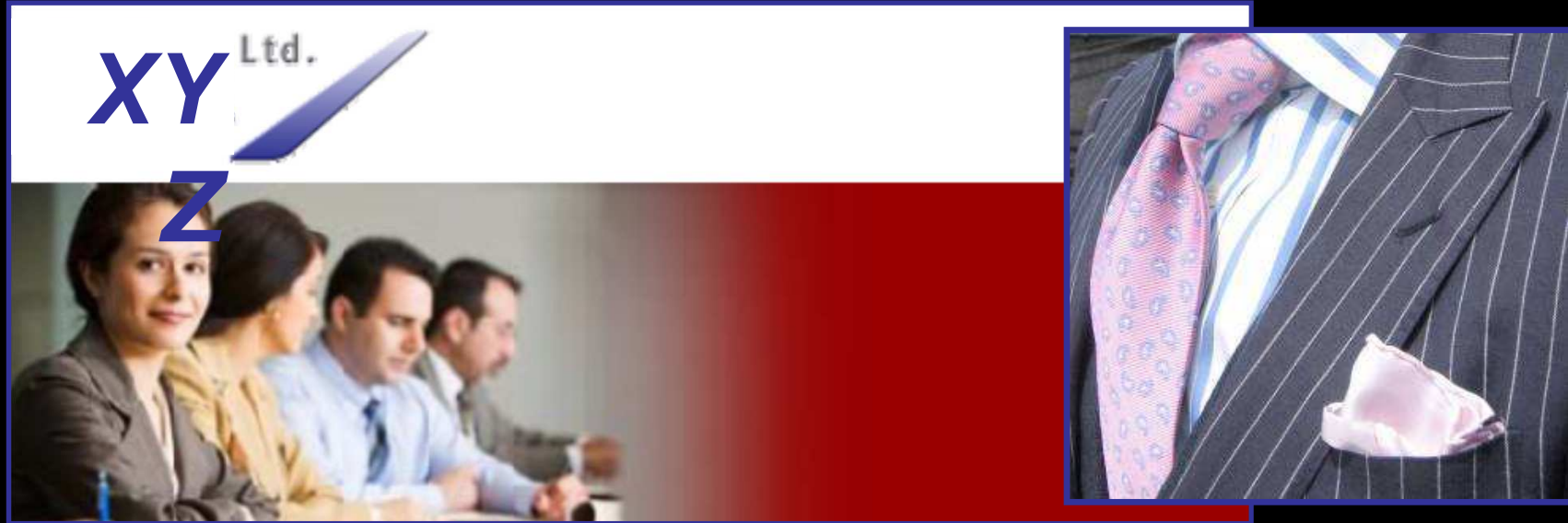
- Naturalistic
- Theoretically robust
- Values reflexivity and engagement
- Seeks to produce a meaningful account of *these* actors in *this* context
- Questions reality, especially power relationships and taken-for-granted assumptions
- Views ambiguity and contestation as data

THREE TYPES OF EVALUATION OF GOVERNMENT PROGRAMMES

- Bureaucratic evaluation
- Autocratic evaluation
- Democratic evaluation

Macdonald (1970s)

BUREAUCRATIC EVALUATION



- Evaluators are there to *serve* the government
- Evaluation = *management consultancy*
- Evaluator *does not question* the values or goals of the client
- Recommendations take the form of *endorsement*
- Quality judged in terms of *client satisfaction*
- Published by *government*

AUTOCRATIC EVALUATION



- Evaluators provide a *conditional service* to government: non-endorsement of policy is a possibility
- Evaluation = *scientific enquiry*
- Evaluator is an *independent academic* who demands non-interference by client
- Recommendations take the form of *scientific findings*
- Quality judged in terms of *objectivity* and *scientific rigour*
- Published by *government* and in *academic journals*

DEMOCRATIC /DELIBERATIVE EVALUATION

OPEN ACCESS Freely available online

PLoS MEDICINE

Essay

Why Do Evaluations of eHealth Programs Fail? An Alternative Set of Guiding Principles

Trisha Greenhalgh^{1*}, Jill Russell²

¹Healthcare Innovation and Policy Unit, Centre for Health Sciences, Barts and The London School of Medicine and Dentistry, London, United Kingdom, ²Division of Medical Education, University College London, London, United Kingdom

- Evaluators provide a *service to society*
- Evaluation = *informed citizenry*
- Evaluator is a *broker* in the exchange of information between groups (some of whose voices are seldom heard)
- Recommendations take the form of *illumination*
- Quality judged in terms of *inclusivity, fair representation, confidentiality, dialogue*
- Published in *multiple formats* for different audiences

AN ALTERNATIVE SET OF GUIDING PRINCIPLES FOR eHEALTH EVALUATION

1. Reflect on your own role as an evaluator and the expectations placed on you.
2. Formally acknowledge that there are multiple stakeholders.
3. Promote dialogue between stakeholders.
4. Take an emergent approach.
5. Consider the macro level of the socio-political context in which the programme is being introduced

AN ALTERNATIVE SET OF GUIDING PRINCIPLES FOR eHEALTH EVALUATION

6. Consider the meso level of the different organisations.
7. Consider the micro level of the front-line staff.
8. Consider the technologies e.g. their inbuilt constraints and assumptions.
9. Use narrative as a sensemaking tool to produce meaningful accounts of actions in context.
10. Capture attempts by stakeholders to redraw the boundaries of the evaluation or contest its findings.

THREE CRITICAL QUESTIONS

- What is the role of scientists in evaluating government policy?
 - Scientists may contribute evidence but they cannot and should not control the deliberative process by which society decides what is right and reasonable
- What does a “scientific” evaluation of government policy mean?
 - It means that evaluators are limited to producing objective reports on questions defined by powerful stakeholders and must not ask upstream questions like “who sets these questions - and why *these* questions?”
- What other kinds of policy evaluation are there?
 - Bureaucratic ☹ and democratic 😊

Essay

Why Do Evaluations of eHealth Programs Fail? Principles and Alternatives

**“I don’t agree with what you say but will defend your right to say it”
Richard Lilford, head of CFEP**

**“I think this provokes a very good debate which we need to have. I can see considerable strengths in your arguments!!”
Mike Pringle, chair of CFHEP steering group**

Introduction

Much has been written about why electronic health (eHealth) initiatives fail [1–4]. Less attention has been paid to why *evaluations* of such initiatives fail to deliver the insights expected of them. *PLoS Medicine* has published three papers offering a “robust” and “scientific” approach

Health Sciences, Barts and
on, London, United Kingdom

• “c... that crit-
ical... generate insights
about... relationships and interests

the assumption that
evaluation can be exclusively
... Rather, they hold that as well as
the scientific agenda of factors, variables,
and causal relationships, the evaluation
must also embrace the emotions, values,
and conflicts associated with a program
[19]. eHealth “interventions” may lie in



**Thank you for
your attention**

*Trisha
Greenhalgh*

*Acknowledging
critical insights from
Jill Russell*