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OF HEALTH INNOVATION
*Faculty of Medicine
and Human Sciences*

imp

November 29
DSKS DANSK

The Learning Health System— *konsekvenser for kvaliteten af plejen* *i*

QUARIE
sity
TRALIA

Danmark og leveringen af danske sundhedsydelser

Jeffrey Braithwaite, PhD,
FIML, FCHSM, FFPHRCP, FAcSS, Hon FRACMA, FAHMS

Professor and Director

Australian Institute of Health Innovation

Director

Centre for Healthcare Resilience and
Implementation Science

President

International Society for Quality in Health Care
(ISQua)

Tak for Invitationen



National level



Ministry of Health

Regional level

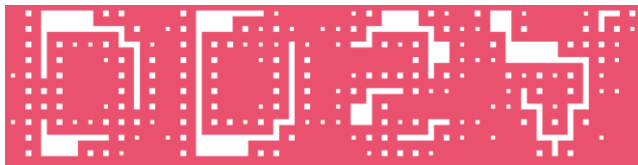
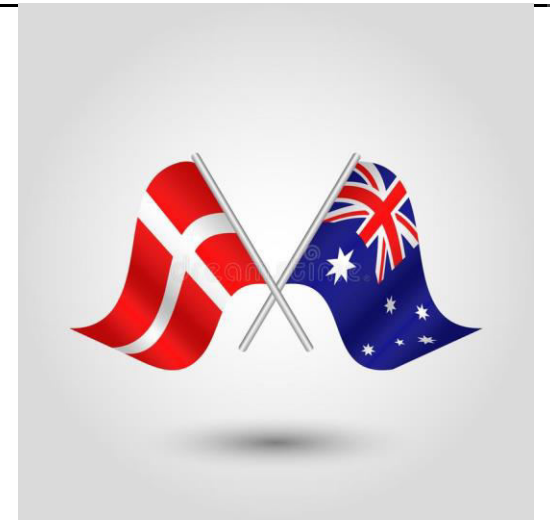


5 Regions

Local level



98 Municipalities



#Kvalitetskonference

@JBraithwaite1

Heal | Learn | Discover





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Australian Institute of Health Innovation



Australian Institute of Health Innovation



Our mission is to enhance local, institutional and international health system decision-making through evidence; and use systems sciences and translational approaches to provide innovative, evidence-based solutions to specified health care delivery problems.



Australian Institute of Health Innovation



AIHI

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OF HEALTH INNOVATION



Professor
**Jeffrey
Braithwaite**

Founding Director,
AIHI

Director, Centre for
Healthcare
Resilience and
Implementation
Science



Professor
**Johanna
Westbrook**

Director, Centre for
Health Systems
and Safety
Research



Professor
**Enrico
Coiera**

Director, Centre for
Health Informatics



Professor
**Henry
Cutler**

Director, Macquarie
University Centre
for the Health
Economy

NHMRC Partnership
Centre for Health
System Sustainability

NHMRC Centre of
Research Excellence
in Implementation
Science in Oncology

NHMRC Centre of
Research Excellence
in Digital Health

AIHI International collaboration

SELECTED SITES



Disclosure

I have no affiliations with any commercial organisations

But I do hold multiple national and international grants to do research, e.g., NHMRC, Government Agencies, etc.

Details are available from:

<https://www.mq.edu.au/research/research-centres-groups-and-facilities/healthy-people/centres/australian-institute-of-health-innovation/our-people/our-people-chris/professor-jeffrey-braithwaite>



Part 1: The problem from a research perspective

Longstanding challenges

The problem

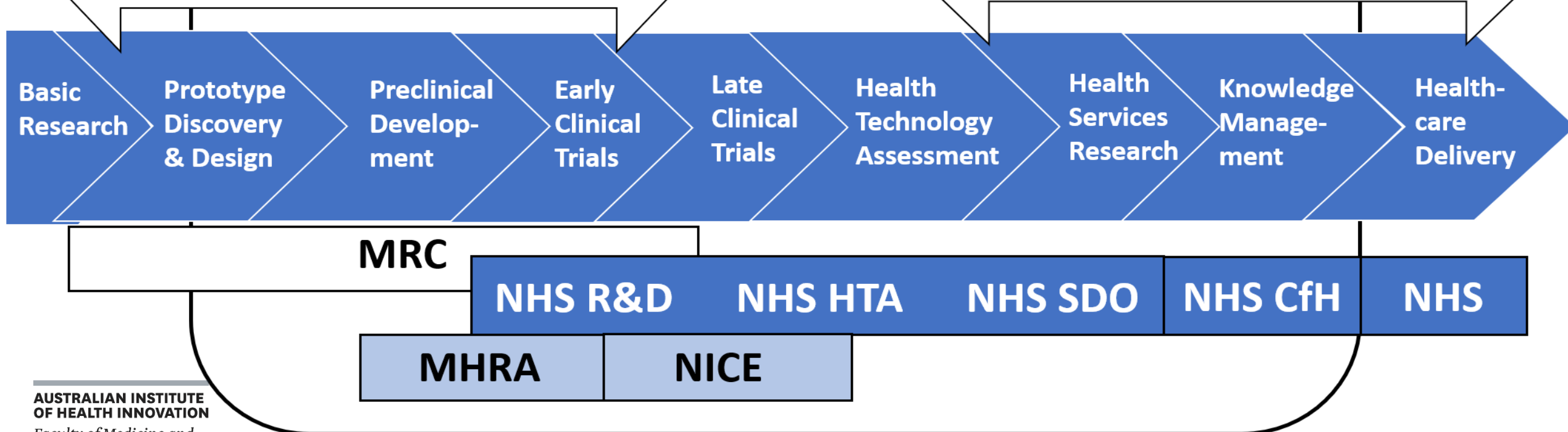
- It takes an average of 17 years for only 14% of new discoveries to enter practice
- Roughly 60% of care is in line with evidence or consensus-based guidelines
- About 30% of health care is waste of some kind
- Around 10% of patients are harmed when receiving care

A “solution” - the knowledge pipeline

Critical Path within UK health research

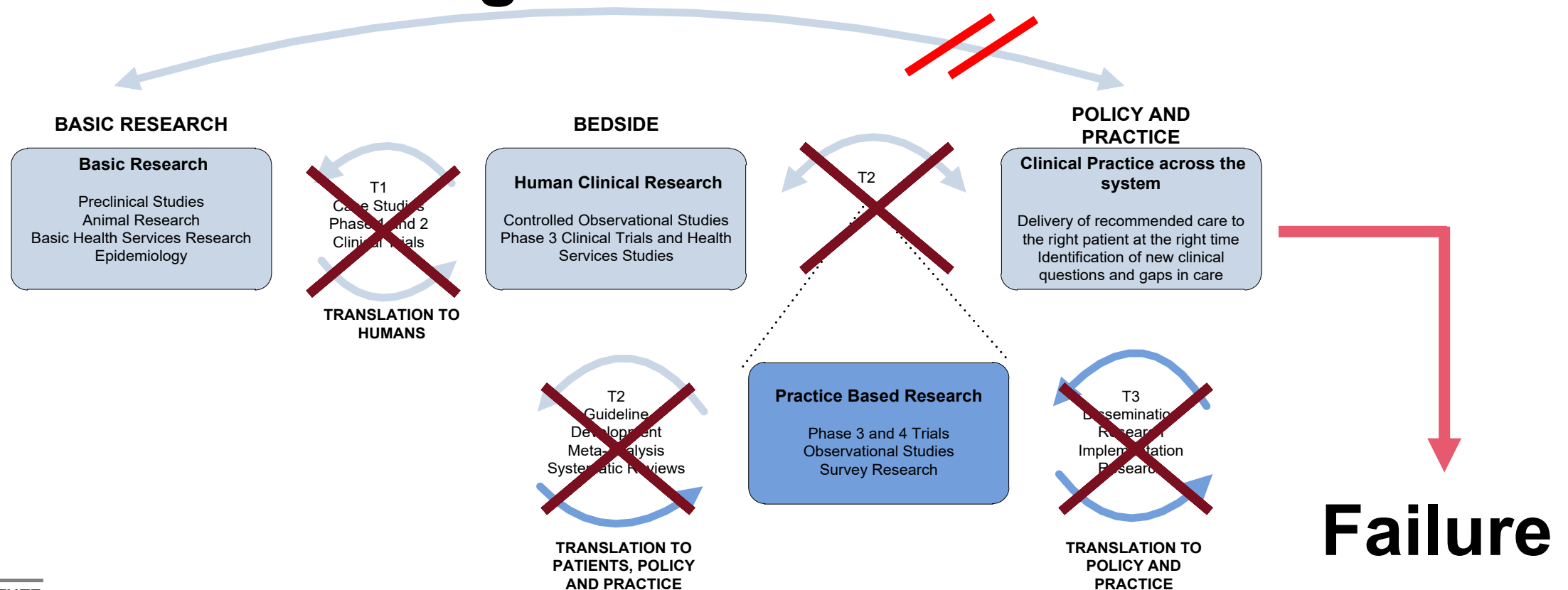
“First Gap in Translation”

“Second Gap in Translation”



But the pipeline is an idealisation

Blockages and fractures





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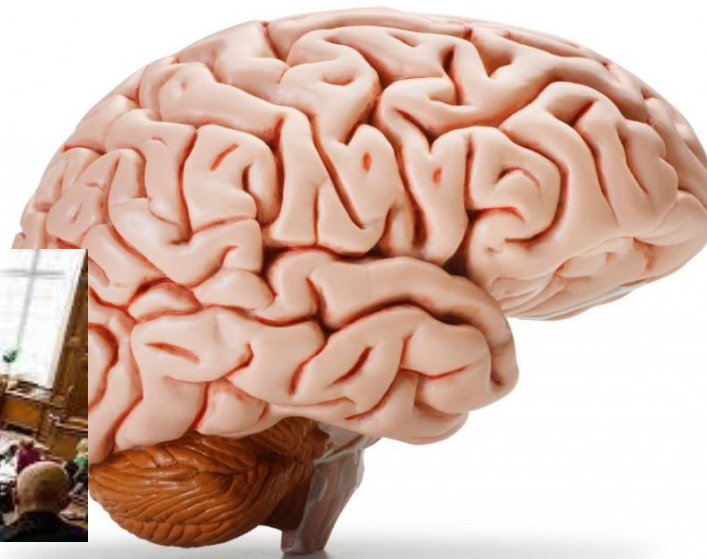
Part 2: It's a complex system

Applications to healthcare

**The pipeline model
suggests solutions
are linear**

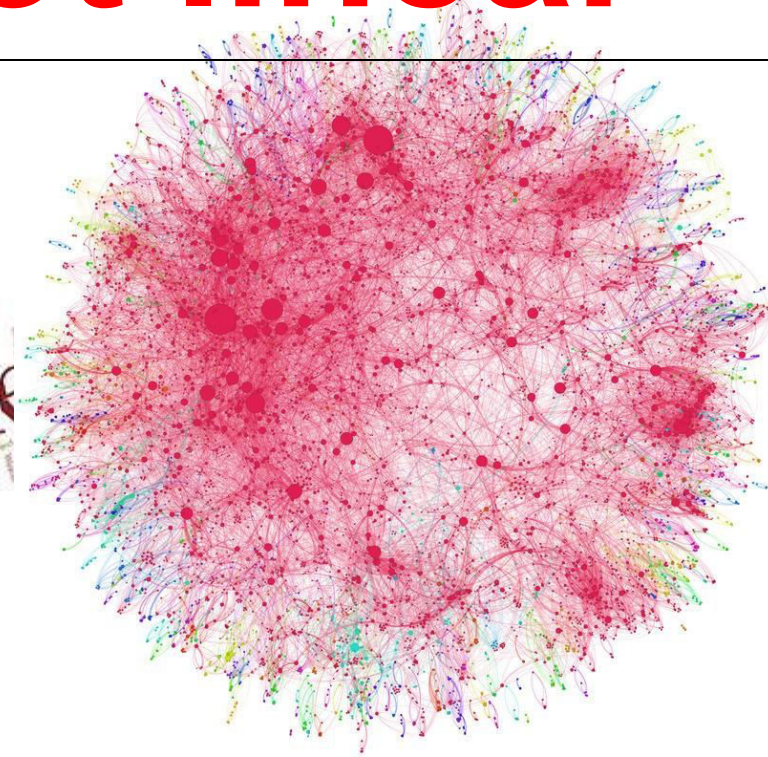
**But the health
system is complex
– incredibly
complex**

Complex systems are everywhere



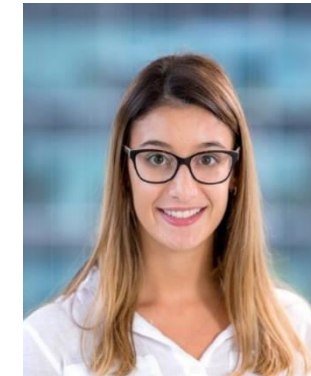
It's rarely simple to solve any health system problem, not just a pandemic

Health systems problems are typically complex, not linear



So: how does care actually work?

Complexity Science in Health Care: *A WHITE PAPER*

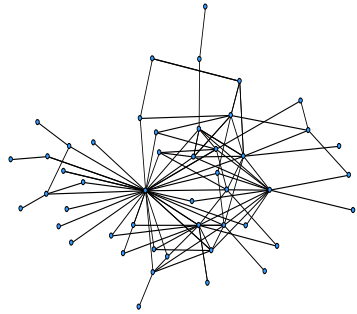


Key features of complexity in health care

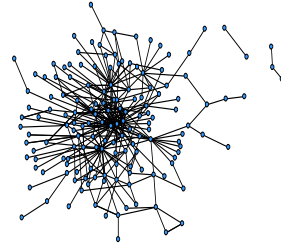
1. Populations of agents + artefacts
2. Interacting
3. Dynamically
4. With emergent rules and governance mechanisms, and bottom-up networks

Collaborations of Translational Cancer Research Network (TCRN)

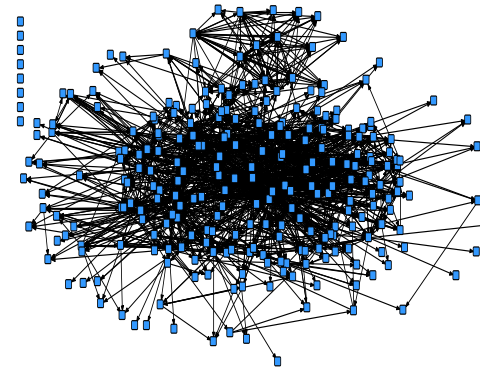
2012



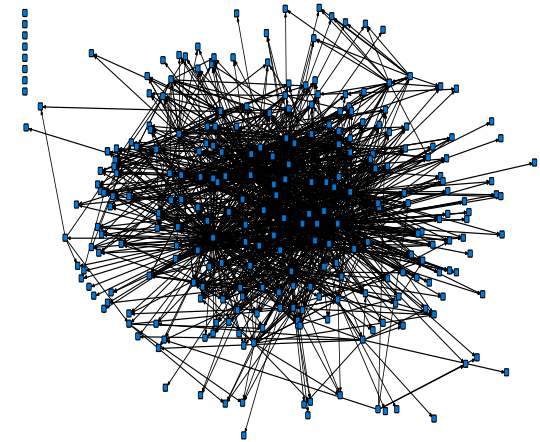
2013



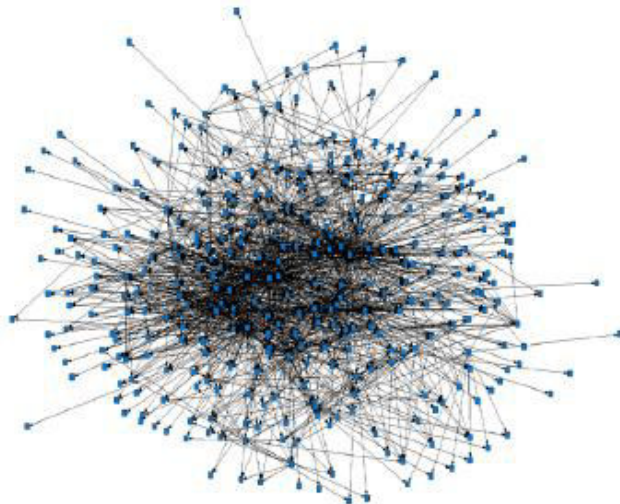
2015



2017

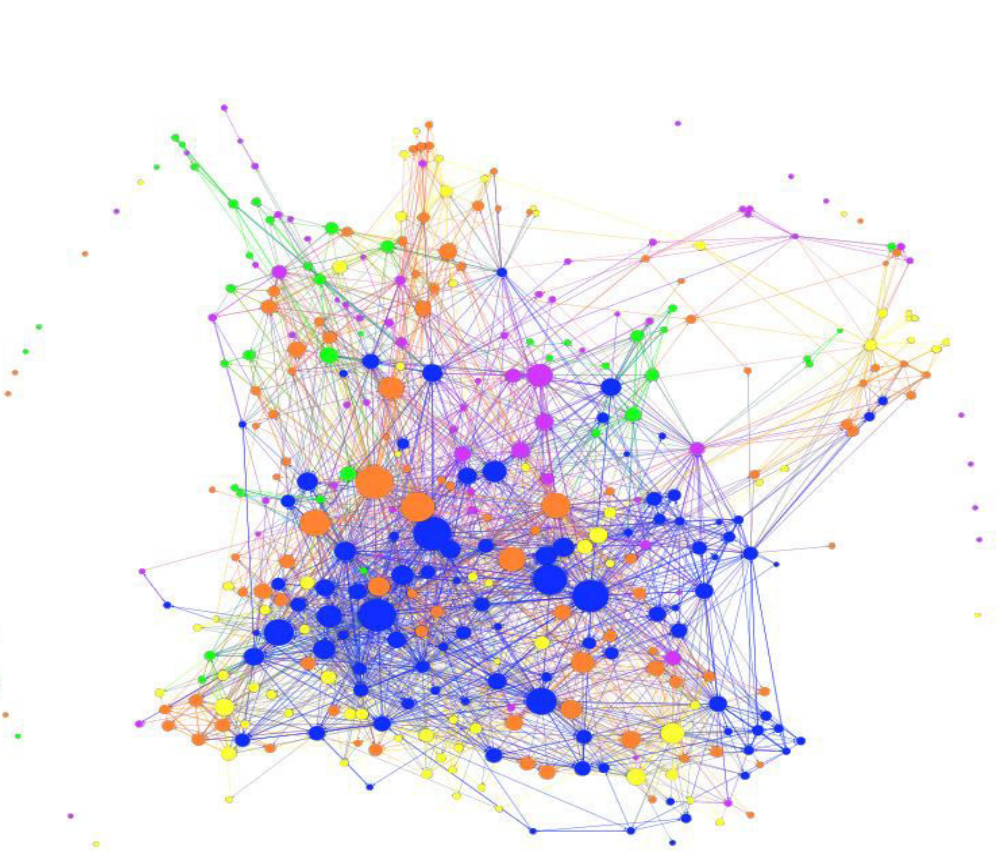


2021



Each dot represents a TCRN member,
each line a collaborative tie.

Creating a learning community with Australian Genomics

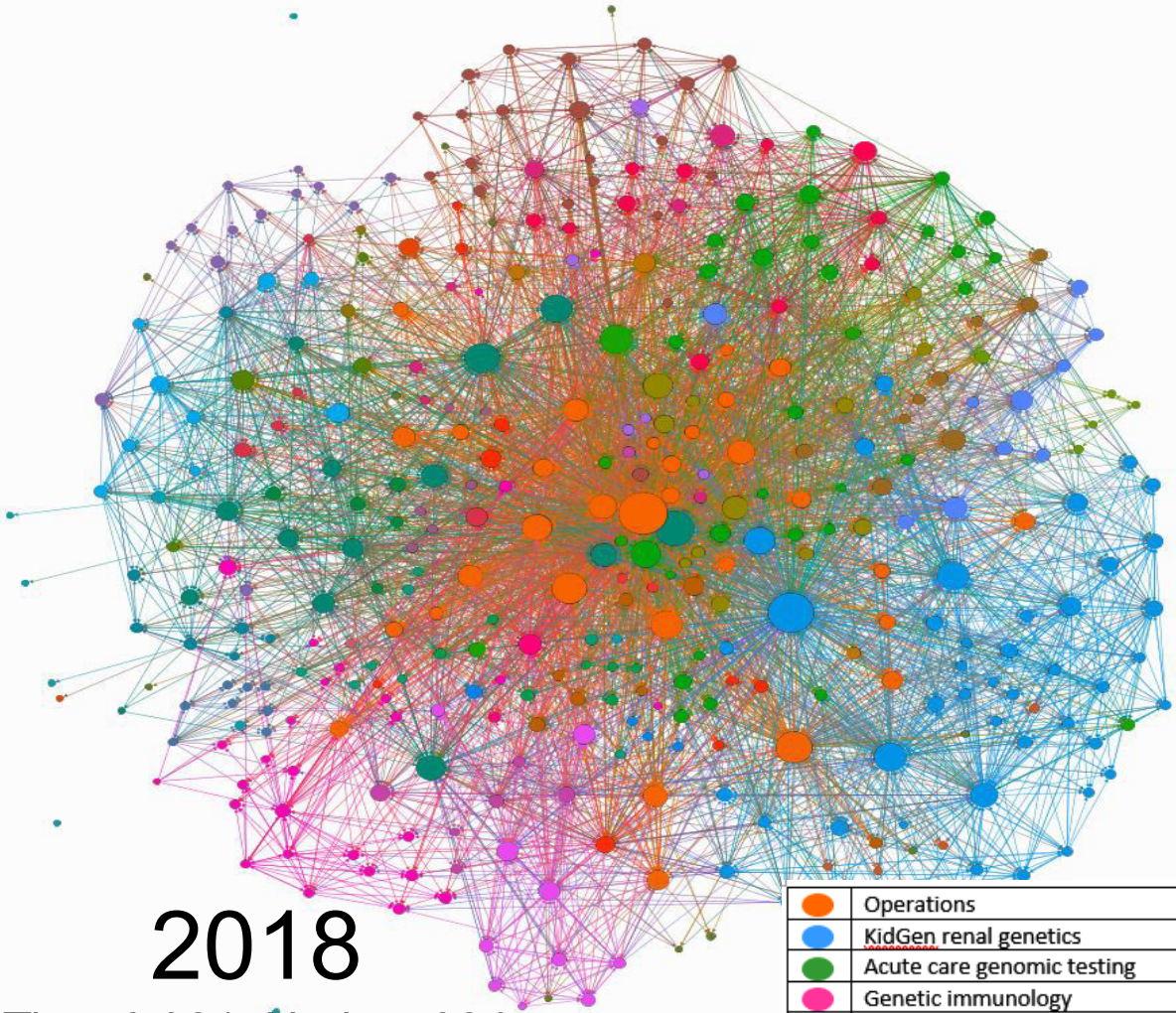


Pre-2016

(before Australian Genomics)

Ties=2,925; Nodes=384

Orange circle	Medical scientist
Blue circle	Genetic specialist
Pink circle	Other
Yellow circle	Medical specialist
Green circle	Researcher



2018

Ties=6,381; Nodes=384

Orange circle	Operations
Blue circle	KidGen renal genetics
Green circle	Acute care genomic testing
Pink circle	Genetic immunology
Brown circle	Cardiovascular genetic disorders
Teal circle	National steering committee
Purple circle	Acute lymphoblastic leukemia



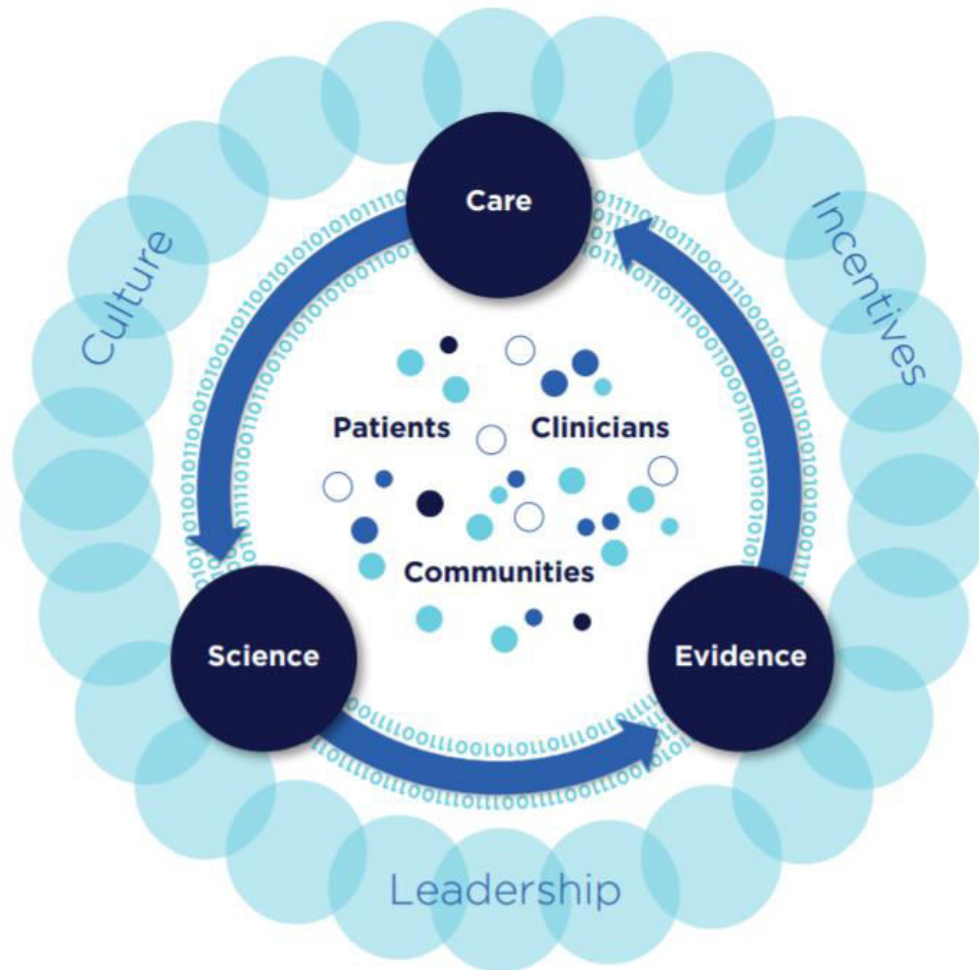
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Part 3: A learning system

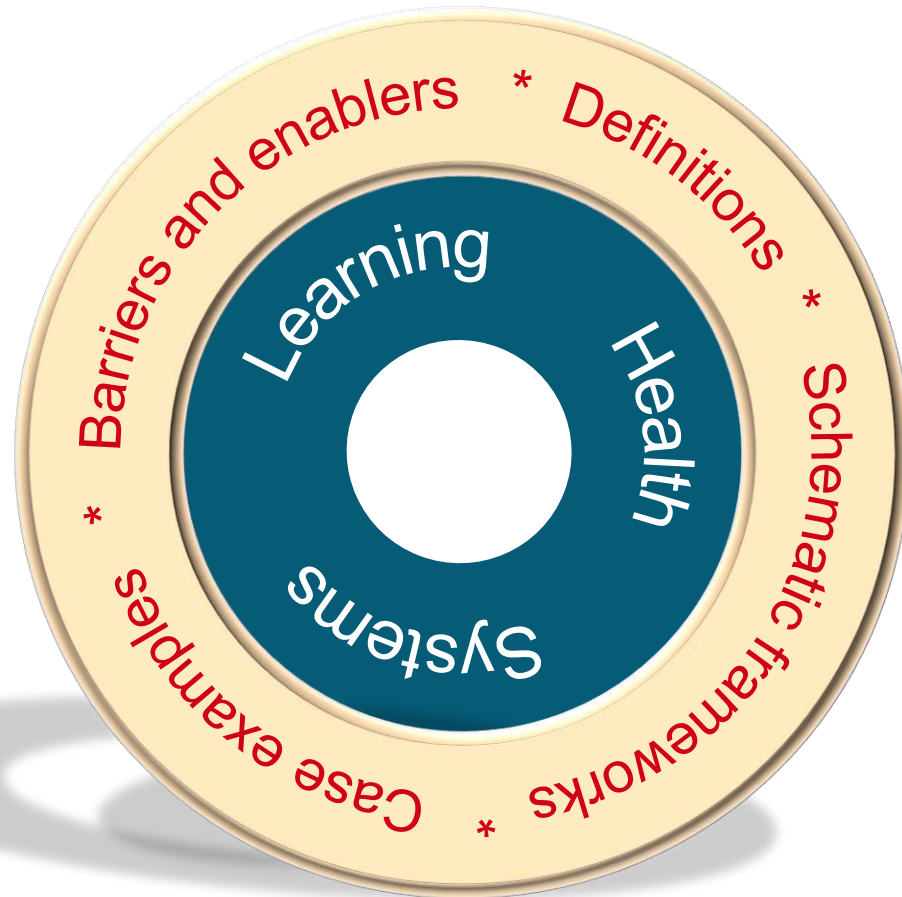
**Complex systems
need to bring
things together**

At the heart of a Learning Health System



A Learning Health System is a system in which *“Science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience”*. (Institute of Medicine, 2007)

Mapping the Learning Health System: a White Paper



Defining a Learning Health System

Evaluating case studies

Assessing barriers and enablers

Evaluating schematic frameworks



New Learning Health System
domain: Structure and Governance

The Learning Health Systems Framework

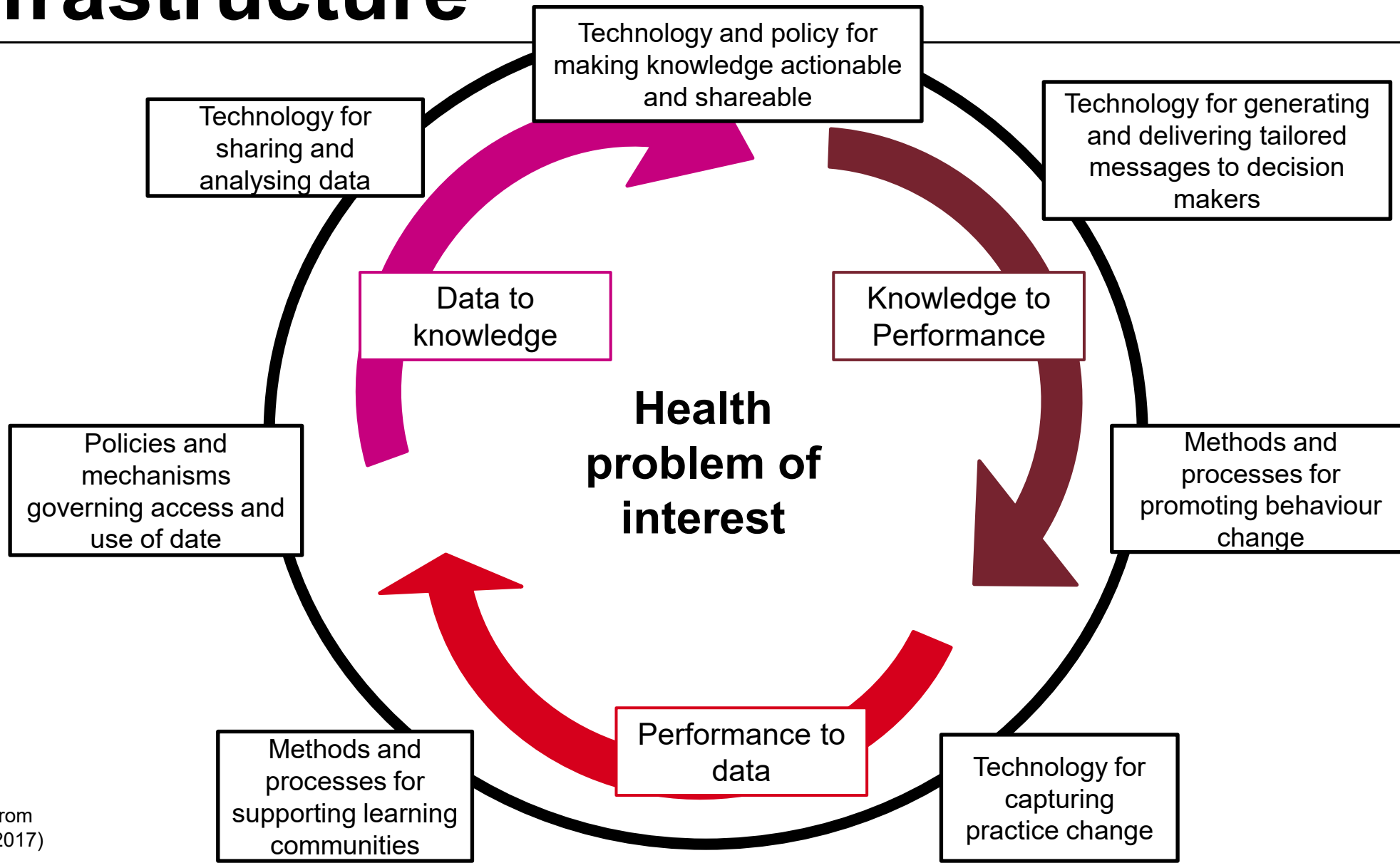
Dimensions	Characteristics	Description
Science and informatics	Real time access to knowledge	Best available evidence incorporated into clinical decision-making processes to improve the quality of care and patient safety.
	Digital capture of the care experience	Digital platforms (e.g., eHRs, disease registries, mobile devices) utilised for the real-time capture, production, and application of knowledge based on best available data
Patient-clinician partnerships	Engaged, empowered patients	Patients, families, and caregivers are full partners in a patient-centred system.
Incentives	Incentives aligned for value	Policies actively encourage ongoing evaluation of care given and improvement of processes and support the provision of high-value care and reduction in wasteful practices.
	Full transparency	All aspects of care, including safety, quality, processes, costs, and outcomes are recorded and available to stakeholders (patients, health professionals, managers) to improve patient care and decision making.
Continuous learning culture	Leadership-instilled culture of learning	Leaders instil a culture of collaboration and adaptability to support the learning process.
	Support system competencies	Staff training, skill building, and support to enable continuous refinement of processes and system improvements is implemented.

The Learning Health Systems Framework

To which we added

Dimensions	Characteristics	Description
Structure and Governance	Organisation	Policies, governance, and regulations aligned to facilitate research, collaboration, and learning

The Learning Health Systems Infrastructure



Learning Health Systems: A review of key topic areas and bibliometric trends (2022)

Received: 8 November 2020 | Revised: 3 March 2021 | Accepted: 4 March 2021
DOI: 10.1002/lrh2.10265

RESEARCH REPORT

Learning Health Systems

Learning health systems: A review of key topic areas and bibliometric trends

Chiara Pomare¹ | Zeyad Mahmoud¹ | Alex Vedovi^{1,2} | Louise A. Ellis^{1,2} |
Gilbert Knaggs^{1,2} |Carolynn L. Smith^{1,2} | Yvonne Zurynski^{1,2} |
Jeffrey Braithwaite^{1,2}

¹Australian Institute of Health Innovation,
Macquarie University, Sydney, Australia
²Partnership Center for Health System
Sustainability, Macquarie University, Sydney,
Australia

Correspondence
Chiara Pomare, Australian Institute of Health
Innovation, Macquarie University, Sydney,
New South Wales 2109, Australia.
Email: chiara.pomare@mq.edu.au

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APP1176620AQ6

Abstract

Introduction: The emergent field of learning health systems (LHSs) has been rapidly evolving as the concept continues to be embraced by researchers, managers, and clinicians. This paper reports on a scoping review and bibliometric analysis of the LHS literature to identify key topic areas and examine the influence and spread of recent research.

Methods: We conducted a scoping review of LHS literature published between January 2016 and May 2020. The authors extracted publication data (eg, journal, country, authors, citation count, keywords) and reviewed full-texts to identify: type of study (empirical, non-empirical, or review), degree of focus (general or specific), and the reference used when defining LHSs.

Results: A total of 272 publications were included in this review. Almost two thirds (65.1%) of the included articles were non-empirical and over two-thirds (68.4%) were from authors in the United States. More than half of the publications focused on specific areas, for example: oncology, cardiovascular care, and genomic medicine. Other key topic areas included: ethics, research, quality improvement, and electronic health records. We identified that definitions of the LHS concept are converging; however, many papers focused on data platforms and analytical processes rather than organisational and behavioural factors to support change and learning activities.

Conclusions: The literature on LHSs remains largely theoretical with definitions of LHSs focusing on technical processes to reuse data collected during the clinical process and embedding analysed data back into the system. A shift in the literature to empirical LHS studies with consideration of organisational and human factors is warranted.

KEYWORDS

bibliometrics, healthcare, learning health systems, learning healthcare systems

1 | INTRODUCTION

Contemporary health systems are not fit for purpose. Even in the most developed countries less than two-thirds of healthcare delivered

is in line with evidence-based guidelines (60%); one third of care is some form of waste (30%) and one tenth (10%) of it is associated with an adverse event.¹ These numbers have persisted for decades despite substantial efforts and resources dedicated to improving the safety

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- We conducted a scoping review of 272 included papers
- 65.1% of articles were non-empirical
- 68.4% from US-based authors
- We found that definitions of the LHS are converging
- Most papers focus on data platforms, rather than organisational and behavioural factors

Learning Health Systems: A review of key topic areas and bibliometric trends (2020)

- LHS generally referred to an LHS as achieving healthcare quality improvement by using big data and embedding data analysis and decision-making into routine care delivery processes.
- This focus on information technology was at the expense of discussions around human and organisational factors.

The Science of Learning Health Systems: Scoping Review of Empirical Research (2022)



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JMIR MEDICAL INFORMATICS

Ellis et al

Review

The Science of Learning Health Systems: Scoping Review of Empirical Research

Louise A Ellis, PhD; Mitchell Sarkies, PhD; Kate Churruca, PhD; Genevieve Dammery, BSc (Hons); Isabelle Meulenbroeks, MRes; Carolyn L Smith, PhD; Chiara Pomare, PhD; Zeyad Mahmoud, PhD; Yvonne Zurynski, PhD; Jeffrey Braithwaite, PhD

Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

Corresponding Author:

Louise A Ellis, PhD
Australian Institute of Health Innovation
Macquarie University
75 Talavera Rd
Sydney, 2113
Australia
Phone: 61 298502484
Fax: 61 298502499
Email: louise.ellis@mq.edu.au

Abstract

Background: The development and adoption of a learning health system (LHS) has been proposed as a means to address key challenges facing current and future health care systems. The first review of the LHS literature was conducted 5 years ago, identifying only a small number of published papers that had empirically examined the implementation or testing of an LHS. It is timely to look more closely at the published empirical research and to ask the question, Where are we now? 5 years on from that early LHS review.

Objective: This study performed a scoping review of empirical research within the LHS domain. Taking an “implementation science” lens, the review aims to map out the empirical research that has been conducted to date, identify limitations, and identify future directions for the field.

Methods: Two academic databases (PubMed and Scopus) were searched using the terms “learning health* system*” for papers published between January 1, 2016, to January 31, 2021, that had an explicit empirical focus on LHSs. Study information was extracted relevant to the review objective, including each study’s publication details; primary concern or focus; context; design; data type; implementation framework, model, or theory used; and implementation determinants or outcomes examined.

Results: A total of 76 studies were included in this review. Over two-thirds of the studies were concerned with implementing a particular program, system, or platform (53/76, 69.7%) designed to contribute to achieving an LHS. Most of these studies focused on a particular clinical context or patient population (37/53, 69.8%), with far fewer studies focusing on whole hospital systems (4/53, 7.5%) or on other broad health care systems encompassing multiple facilities (12/53, 22.6%). Over two-thirds of the program-specific studies utilized quantitative methods (37/53, 69.8%), with a smaller number utilizing qualitative methods (10/53, 18.9%) or mixed-methods designs (6/53, 11.3%). The remaining 23 studies were classified into 1 of 3 key areas: ethics, policies, and governance (10/76, 13.2%); stakeholder perspectives of LHSs (5/76, 6.6%); or LHS-specific research strategies and tools (8/76, 10.5%). Overall, relatively few studies were identified that incorporated an implementation science framework.

Conclusions: Although there has been considerable growth in empirical applications of LHSs within the past 5 years, paralleling the recent emergence of LHS-specific research strategies and tools, there are few high-quality studies. Comprehensive reporting of implementation and evaluation efforts is an important step to moving the LHS field forward. In particular, the routine use of implementation determinant and outcome frameworks will improve the assessment and reporting of barriers, enablers, and implementation outcomes in this field and will enable comparison and identification of trends across studies.

- What empirical work has been conducted?
- What have been the key areas of research?
- By what study designs and research methods?
- Which implementation science frameworks and tools have been used?

The Science of Learning Health Systems: Scoping Review of Empirical Research (2022)

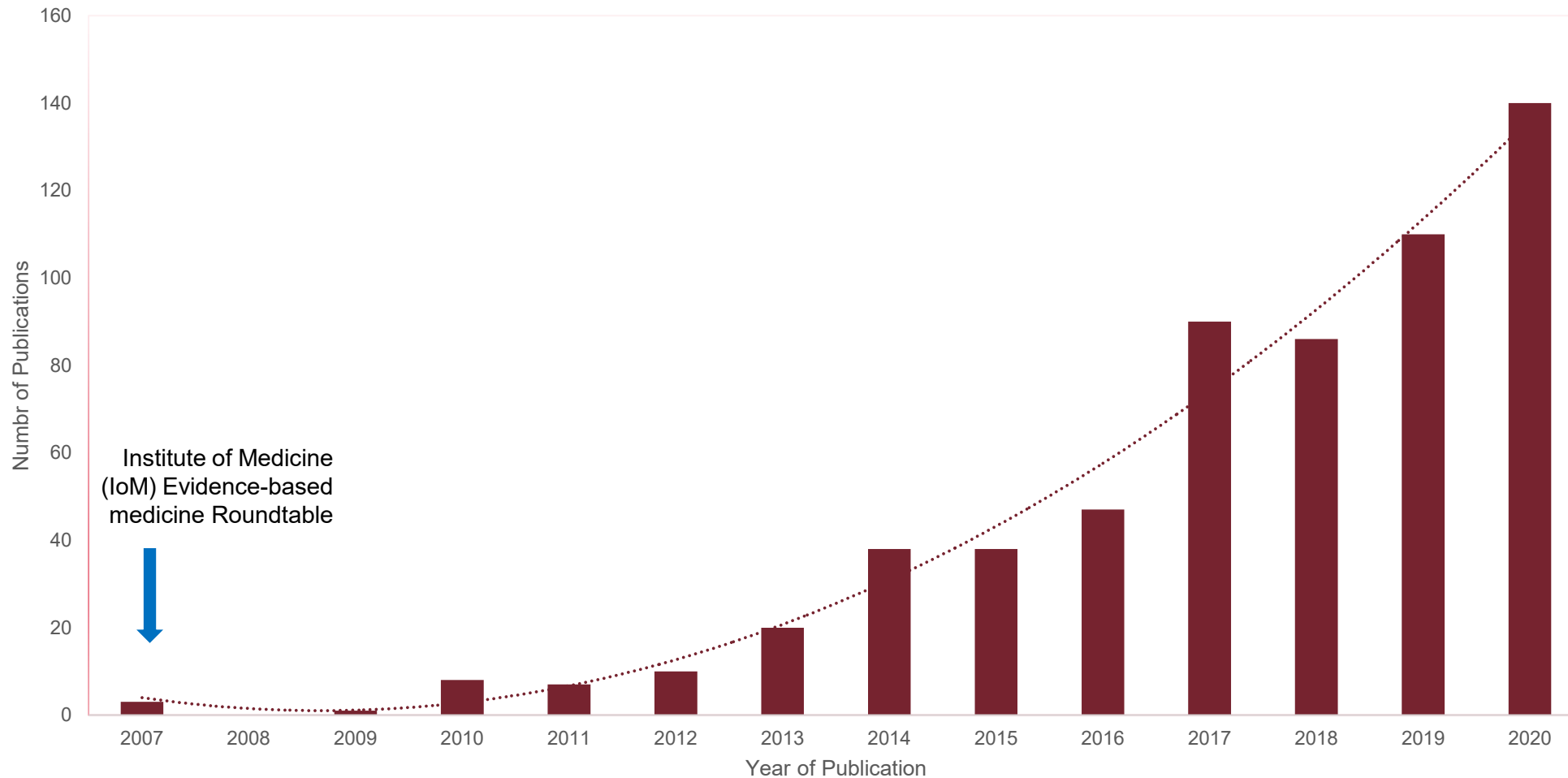


Figure adapted from Ellis et al. The science of learning health systems: A scoping review of the empirical research (2022)

The Science of Learning Health Systems: Scoping Review of Empirical Research (2022)

- In total, 76 publications were included in the review
- Studies were predominantly from high-income countries
 - United States (n=55, 72.4%)
 - United Kingdom (n=9, 11.8%)
 - Canada (n=3, 3.39%)
- Over half (55.3%) of the studies were quantitative, 35.5% were qualitative, 9.2% were mixed methods study
- All included studies focussed on implementing a program, system or platform
- Very few studies explicitly incorporated an implementation science framework in their implementation efforts.

The Science of Learning Health Systems: Scoping Review of Empirical Research (2022)

- Marked increase of LHS studies
- Research predominantly focusses on implementing programs, systems, or platforms that assist in achieving an LHS
- There is a lack of high quality empirical research, such as randomized controlled trials and implementation evaluations
- Using implementation determinant and outcome frameworks will improve the assessment and implementation outcomes for LHSs.



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Part 4: A learning system

Case studies

Case study: Veterans Health Administration (VHA)

- The VHA provides healthcare to 9 million military veterans each year and is the largest publicly funded healthcare delivery system in the USA.
- It consists of 1,293 healthcare facilities including 171 medical centres and 1,112 outpatient sites



Case study: Veterans Health Administration (VHA)

Science and informatics		Patient-clinician partnerships	Incentives		Culture	
Real time access to knowledge	Digital capture of the care experience	Engaged, empowered patients	Incentives aligned for value	Full transparency	Leadership-instilled culture of learning	Supportive system competencies
National Corporate Data Warehouse enabling performance tracking	Systemwide eHRs Daily processing of more than two million lab results	My HealtheVet web portal allows patients to access and update their health records, schedule appointments, and refill prescriptions	Clinicians are paid a salary so that remuneration is not based on care volume	Public reporting of large amounts of data on quality for both self-auditing purposes and for the benefit of unaffiliated researchers. Providing clinicians with access to multiple dashboards to track quality relative to their peers	Academic affiliations in larger VHA hospitals, with many clinicians holding dual appointments	Diffusion of Excellence Program seeks to discover how VHA facilities are rewarded for sharing their best practices and to what degree such innovations are adopted elsewhere in the system
Providing clinicians with access to multiple dashboards to track quality relative to their peers.	500,000 pharmacy fills, and 400,000 patient encounters					

Geisinger Health System

- Geisinger Health is based in Pennsylvania and services over 3 million patients across the state, predominantly in rural areas
- Geisinger aims to deliver high quality care at a low cost, with a focus on population health.

Geisinger

Geisinger Health System

Science and informatics		Patient-clinician partnerships	Incentives		Culture	
Real time access to knowledge	Digital capture of the care experience	Engaged, empowered patients	Incentives aligned for value	Full transparency	Leadership-instilled culture of learning	Supportive system competencies
Robust eHR system that feeds genomic data back into the sequence and allows for data analysis to improve genetic variant annotation, creating a cycle.	<p>Stable enrolment of patients into eHR system within a robust informatics infrastructure allowing for the tracking patient experiences and outcomes over the long term.</p> <p>Over 180,000 patients had consented to contribute their genomic data.</p>	<p>MyCode Community Health Initiative (biorepository) relies on opt-in consent, and of those approached, 85-90% agree to participate</p> <p>Informatics infrastructure with security requirements and stores patient data behind a system firewall to protect patient information</p>	Paying clinicians a salary so that their remuneration is not based on care volume.	eHR and genomic data variants are reported back to patient participants, while also being deposited into publicly available databases.	The goal of establishing an LHS has been embraced by the organisation's leadership, who have aimed to develop conceptual and business models for moving toward a learning culture.	Emphasis on continual quality improvement and the promotion of best practices checklists for physicians.

The Ottawa Hospital

- The Ottawa Hospital is a three campus acute care facility in Canada and one of the main providers of cancer treatment in the Ottawa region.
- The Ottawa Hospital operates with a transformation model. It aligns several domains: people, processes and technology.



The Ottawa Hospital

Science and informatics		Patient-clinician partnerships	Incentives		Culture	
Real time access to knowledge	Digital capture of the care experience	Engaged, empowered patients	Incentives aligned for value	Full transparency	Leadership-instilled culture of learning	Supportive system competencies
Process monitoring and business intelligence tools allowed for the local generation of dashboards to visualise and track performance metrics at a provincial level, create alerts and queries to monitor individual and clinical team performance.	Process monitoring and business intelligence tools that integrate process-related data were also employed to establish a learning cycle and create insights on system performance.	Patients were among the stakeholder groups engaged – through interviews – in the system redesign.	N/A	Consensus approach to the initiative’s creation led to general buy-in among most relevant stakeholders and their ability to access and benefit from the process monitoring and business intelligence tools implemented in the restructuring.	Reported buy-in from leaders of the academic and community hospitals.	Operating with a conceptual focus of a “health region” as a geographic unit of implementation, the OHTM brought about the establishment of a “regional Community of Practice” to engage stakeholders.

MQ Health General Practice

- MQ Health General Practice operates across two sites and is a department of MQ Health, a not-for-profit health enterprise.
- MQ Health includes a private hospital, specialist clinics, allied health clinics, digital mental health services and an affiliation with the university's medical faculty.



MQ Health
MACQUARIE UNIVERSITY
HEALTH SCIENCES CENTRE

MQ Health General Practice

Science and informatics		Patient-clinician partnerships	Incentives		Culture	
Real time access to knowledge	Digital capture of the care experience	Engaged, empowered patients	Incentives aligned for value	Full transparency	Leadership-instilled culture of learning	Supportive system competencies
<p>Access to subscription only platforms through Macquarie University.</p> <p>Lunchtime teaching sessions on topical health issues.</p> <p>Access to clinical auditing tool to provide practitioners with overview of their patient cohort.</p>	<p>Trialling implementation of 'MyPractice' App which provides patients with access to referrals, prescriptions, certificates.</p> <p>Use of online booking system.</p>	<p>Opportunities for patients to leave Google reviews</p> <p>Patient focus groups to discuss the implementation of 'MyPractice' App</p>	<p>Paying clinicians a salary so that their remuneration is not based on care volume.</p>	<p><i>In progress:</i> the practice is in the process of designing a way to publish metrics on patient health outcomes, centred around the Quadruple Aim.</p>	<p>Affiliation with University medical school providing teaching and learning opportunities for staff.</p> <p>Research opportunities for practice staff.</p> <p>Opportunities for learning through educational sessions and grand rounds.</p>	<p>Regular meetings involving clinical and non clinical staff that address quality improvement.</p>



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Part 5: The missing, best learning system ... ever!

Case study

Study at 12:34pm on 29 November 2022

- Searched the terms “Learning health system” and “Denmark”
- “Learning health system” – 735 hits
- “Denmark” – 279,438 hits
- Found only two studies mapped to these two terms
- None were led by Danes



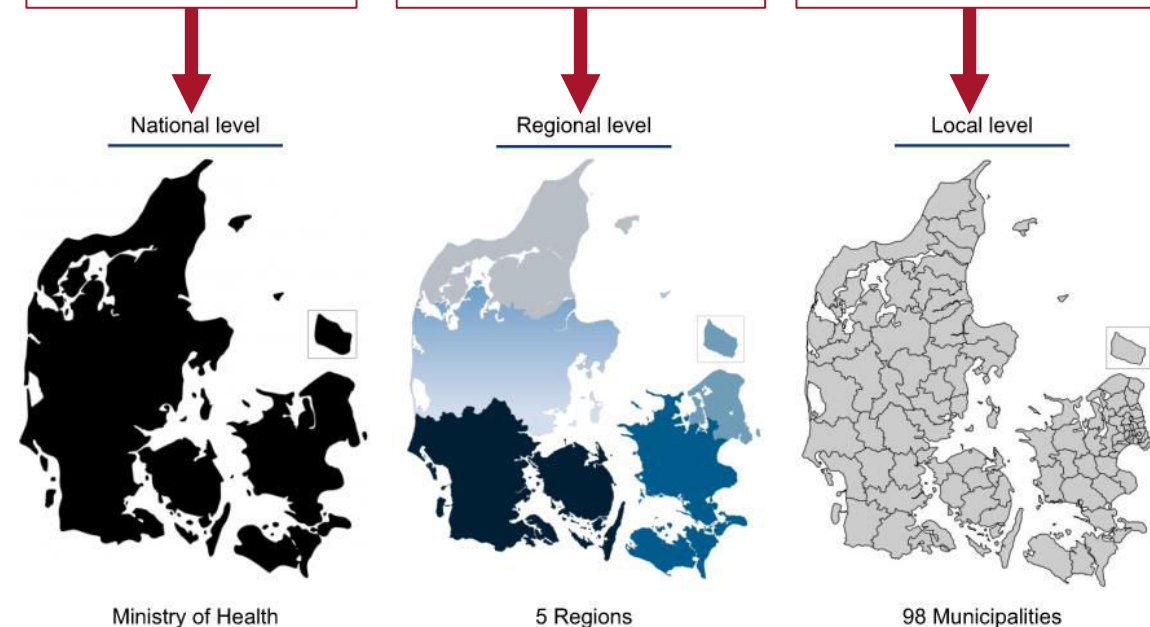
Denmark

- Advanced health care system
- Better data than most comparative systems, e.g., clinical registries, information on citizens
- Unique electronic personal identifier
- National patient registry (DNPR) > world's oldest
- Sundhed.dk

Danish
LHS at
the
National
level

Danish
LHS at
the
Regional
level

Danish
LHS at
the
Municipal
level



The Learning Health System for Denmark

Dimensions	Characteristics	Description
Science and informatics	Real time access to knowledge	Best available evidence incorporated into clinical decision-making to improve the care quality and patient safety.
	Digital capture of the care experience	Digital platforms (e.g., eHRs, disease registries, mobile devices) utilised for best available data
Patient-clinician partnerships	Engaged, empowered patients	Patients, families, and caregivers are full partners in a patient-centred system.
Incentives	Incentives aligned for value	Policies actively encourage ongoing evaluation of care given and improvement of processes and support high-value care.
	Full transparency	All aspects of care, including safety, quality, processes, costs, and outcomes are recorded and available to stakeholders.
Continuous learning culture	Leadership-instilled culture of learning	Leaders instil a culture of collaboration and adaptability to support the learning process.
	Support system competencies	Staff training, skill building, and support to enable refinement of processes and systems improvements.

The Learning Health Systems Framework

Don't forget

Dimensions	Characteristics	Description
Structure and Governance	Organisation	Policies, governance, and regulations aligned to facilitate research, collaboration, and learning



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Part 6: Six suggestions

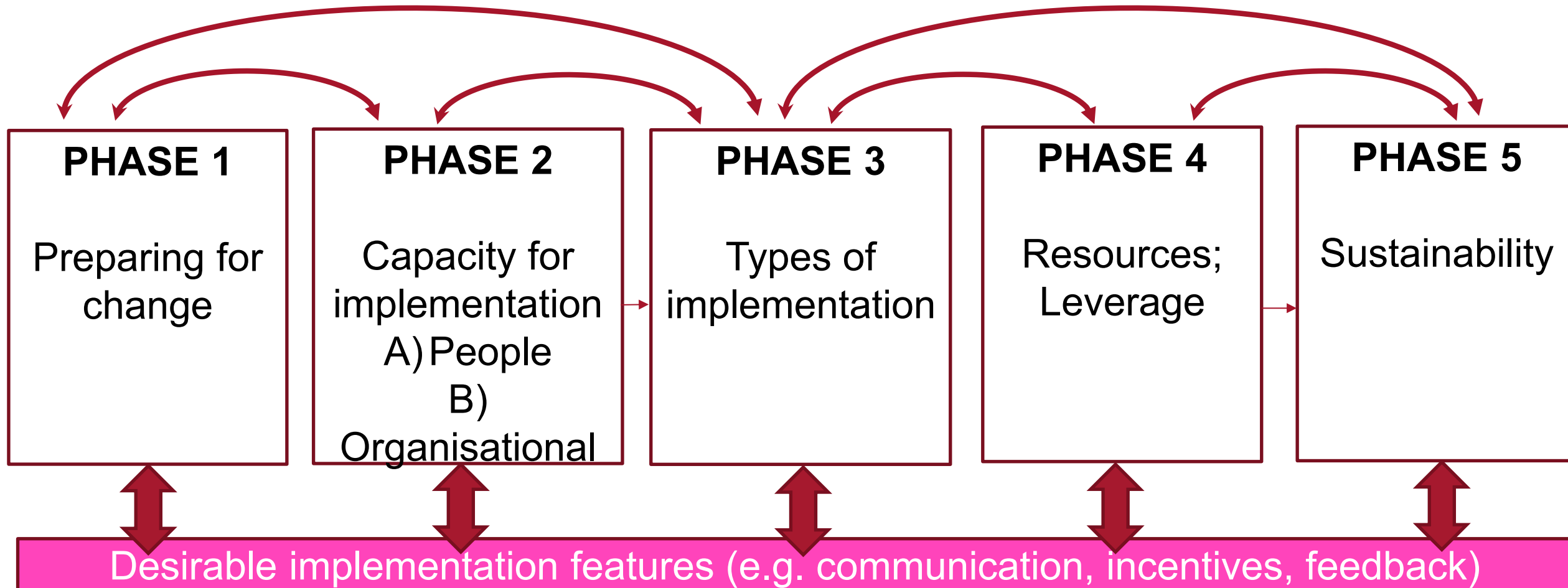
A way forward ...

1. The inside and outside world— everyone is in their own box



**So get out of
your box,
embrace the
complexity,
and lead your
bit of the
needed
transformation**

2. Have a plan based on implementation science



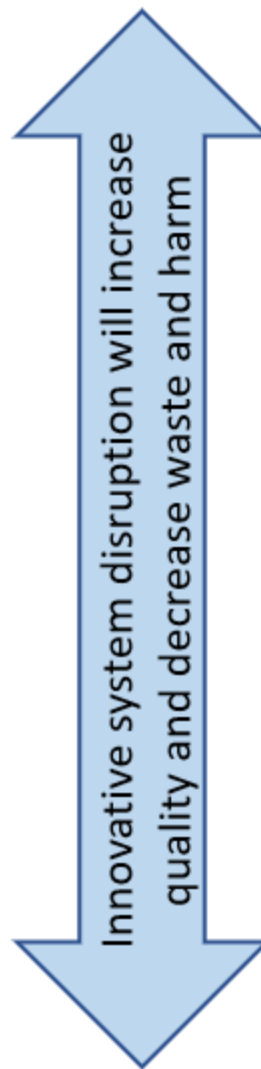
[Braithwaite J, Marks D, and Taylor N. (2014) Harnessing implementation science to improve care quality and patient safety: a systematic review of targeted literature. *International Journal for Quality in Health Care*, 26:3]

4. Understand deeply that our problems and solutions are not linear

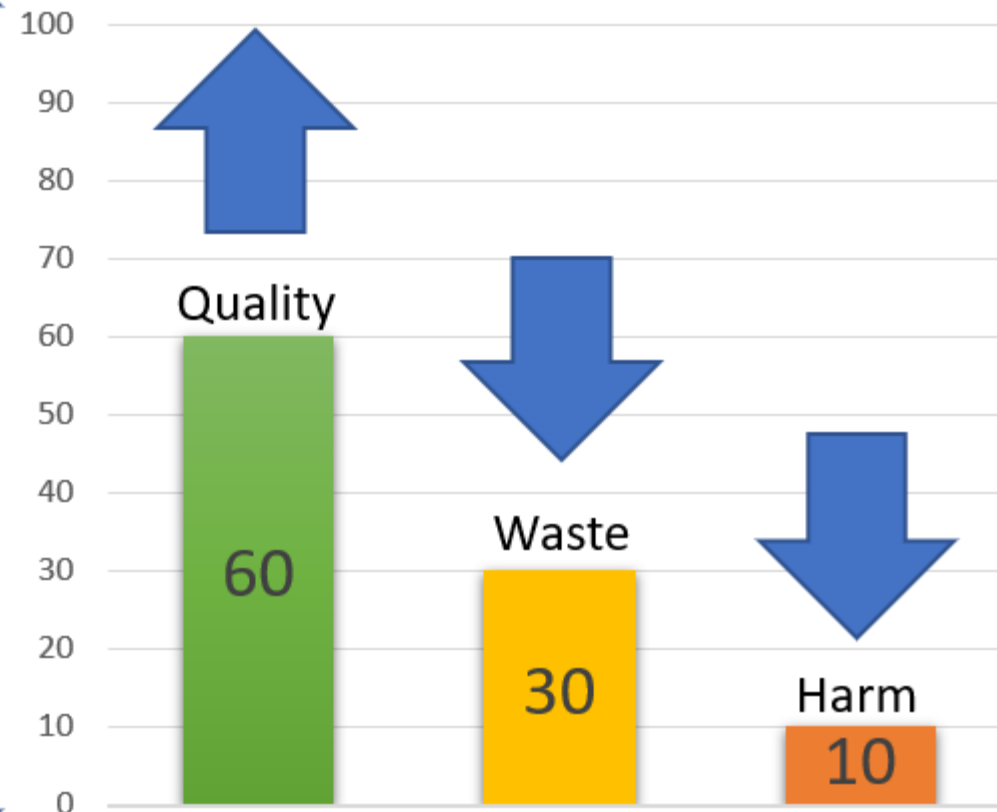


5. Focus on the important

Just three numbers – 60:30:10



Moving the indicators of health system performance in the right direction



60:30:10 has been static for 25 years

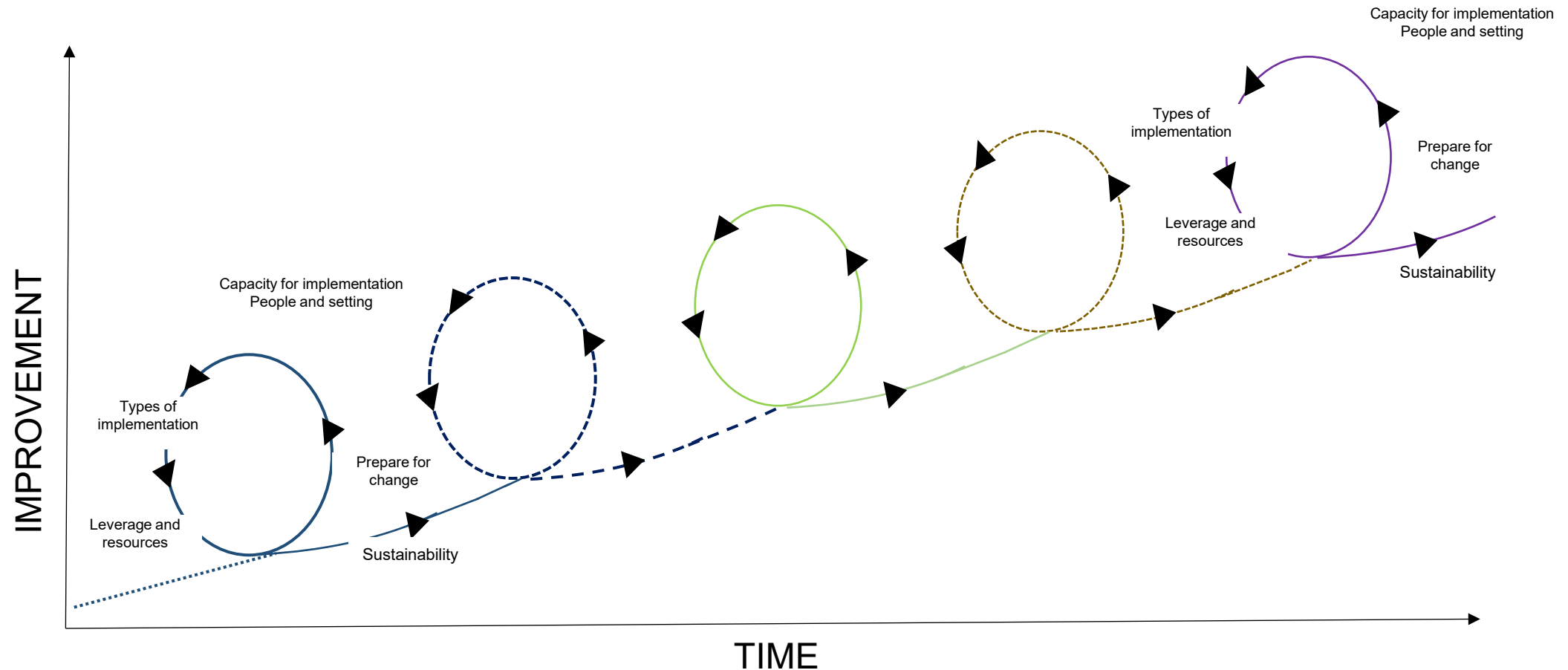
In 6 out of 10 encounters, patients receive care according to best practice guidelines

In 3 out of 10 encounters, patients receive ineffective or low-value care

In 1 out of 10 encounters, patients are harmed

[Braithwaite, J., Glasziou, P. & Westbrook, J. The three numbers you need to know about healthcare: the 60-30-10 Challenge. *BMC Med* 18, 102 (2020). <https://doi.org/10.1186/s12916-020-01563-4>]

6. End project-itis



[Adapted from Braithwaite et al. 2014. Harnessing implementation science to improve care quality and patient safety: a systematic review of targeted literature. *Int J Qual Health Car*; Braithwaite et al. 2007. An action research protocol to strengthen system-wide inter-professional learning and practice. *BMC Health Serv Res*]



Discussion

Q&A

Comments

Australian Institute of Health Innovation



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Dr Elizabeth Austin
Diana Fajardo Pulido

Health Outcomes

A/Prof Rebecca Mitchell
Dr Reidar Lystad
Dr Virginia Mumford
Dr Vu Do
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Nicole Halim

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Prof Frances Rapport
Mia Bierbaum
Dr Andrea Smith
Dr Karen Hutchinson
Lieke van Baar

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A/Prof Peter Hibbert
Dr Louise Wiles
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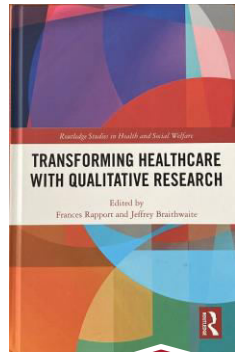
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Kelly Nguyen
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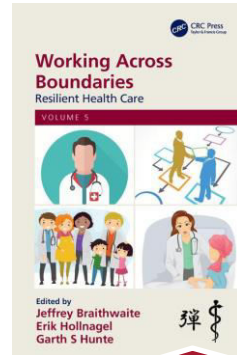
Current Research Candidates

Hossai Gul
Sheila Pham
Luke Testa
Renuka Chittajallu
Faran Naru

Recently published books



2020 – Transforming Healthcare with Qualitative Research



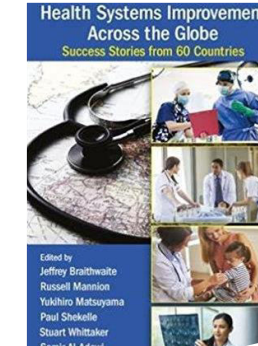
2019 – Working Across Boundaries



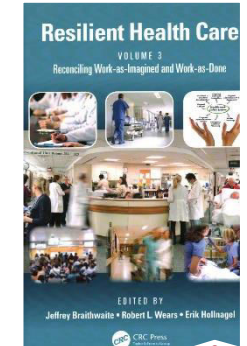
2018 – Delivering Resilient Health Care



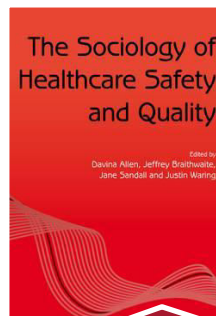
2018 - Healthcare Systems: Future Predictions for Global Care



2017 - Health Systems Improvement Across the Globe: Success Stories from 60 Countries



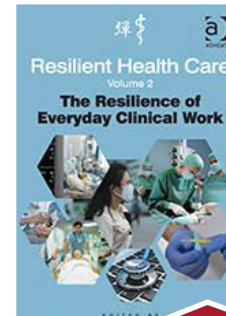
2017 - Reconciling Work-as-imagined and Work-as-done



2016 – The Sociology of Healthcare Safety and Quality



2015 - Healthcare Reform, Quality and Safety: Perspectives, Participants, Partnerships and Prospects in 30 Countries



2015 - The Resilience of Everyday Clinical Work



2013 - Resilient Health Care



2010 - Culture and Climate in Health Care Organizations

Forthcoming books



Gaps: the Surprising Truth
Hiding in the In-between



Surviving the Anthropocene



Counterintuitivity: How your
brain defies logic



Muddling Through With
Purpose

Jeffrey Braithwaite PhD

CONTACT DETAILS

Founding Director

Australian Institute of Health Innovation

Director

Centre for Healthcare Resilience and Implementation Science

Professor





Faculty of Medicine, Health and Human Sciences, Macquarie
University

Sydney, Australia

President

International Society for Quality in Health Care (ISQua)



	Email:	jeffrey.braithwaite@mq.edu.au
	AIHI website:	http://aihi.mq.edu.au
	Twitter:	@JBraithwaite1
	Wikipedia:	http://en.wikipedia.org/wiki/Jeffrey_Braithwaite