

# Health Data in Practice lecture series

Learning Health Systems:  
a fundamental framework  
for health data in practice

Carol Dezateux

22<sup>nd</sup> September 2020

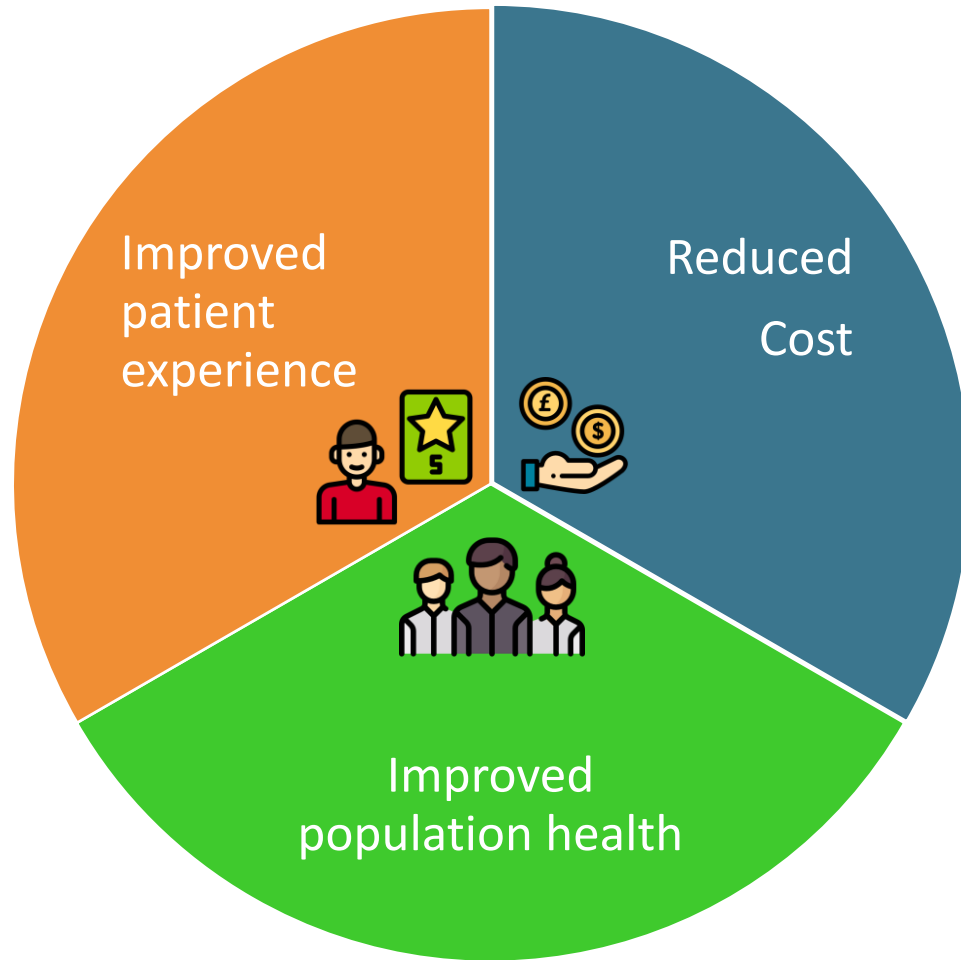


# Learning Objectives

At the end of this lecture you should be able to understand

- The triple aim for health care, opportunities and challenges
- What a learning health system (LHS) is
- Key elements needed for LHS success
- Barriers to achieving LHS success
- Factors influencing success in adopting and sustaining innovation within a LHS using the NASSS framework

# Triple Aim<sup>1</sup>



“We propose that a new shared duty should be introduced that requires those organisations that plan services in a local area ... and NHS providers of care to promote the ‘triple aim’ of better health for everyone, better care for all patients, and efficient use of NHS resources, both for their local system and for the wider NHS. “

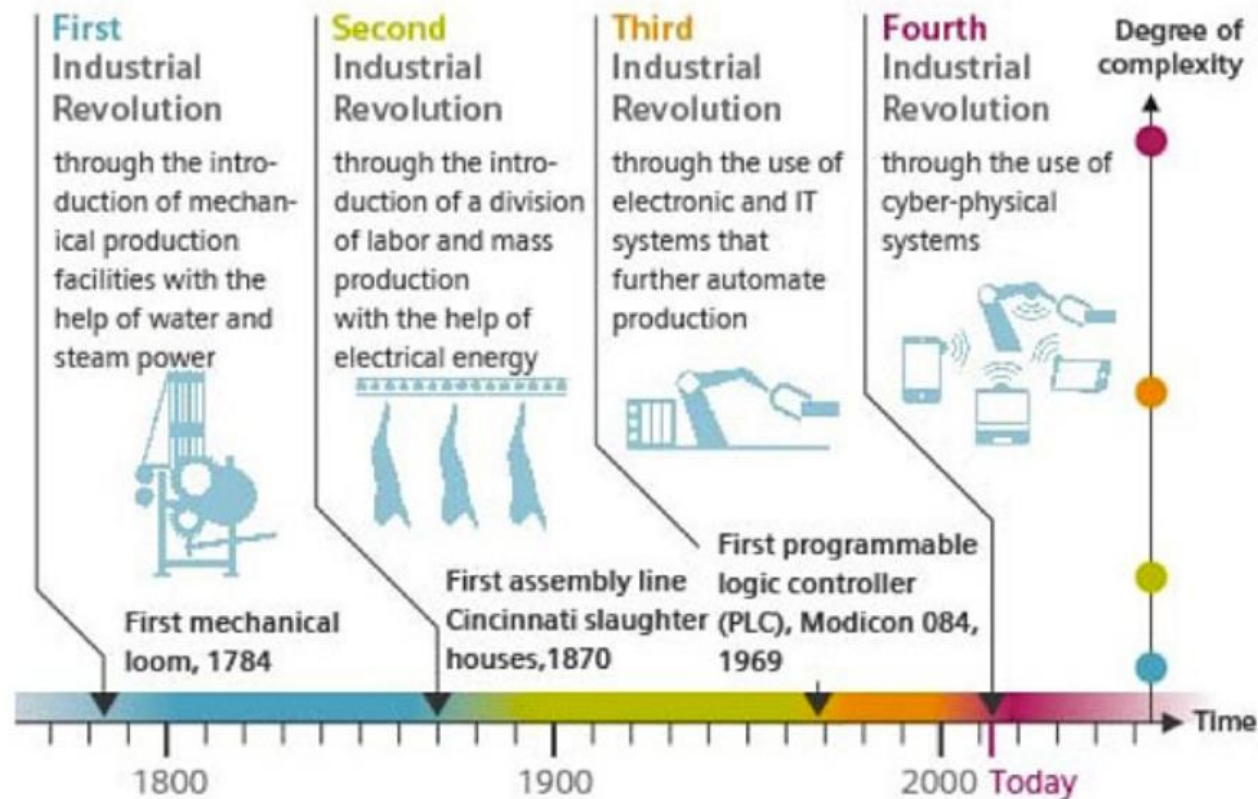
*Implementing the NHS Long Term Plan, NHS England, 2019*

<sup>1</sup> Don Berwick *Health Affairs* 27, no. 3 (2008): 759–769; DOI 10.1377/hlthaff.27.3.759

# The Opportunity

A once in a lifetime opportunity to make game changing improvements in the health of patients and populations through data-intensive research and innovation

## The 4<sup>th</sup> Industrial Revolution



WORLD  
ECONOMIC  
FORUM



With thanks to Andrew Morris for this slide



# The drivers

 Older Population
  Higher Costs
  Inequality of Access

By 2050, 20% of the global population will be aged over 60

By 2040, the world will spend around USD 25 trillion every year on healthcare

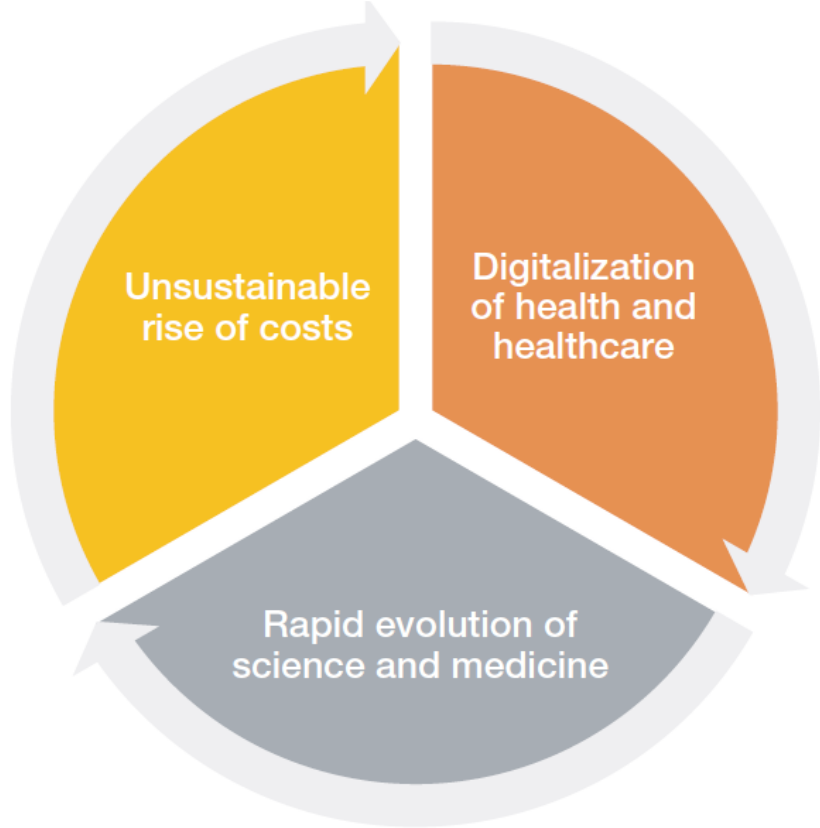
Spending more does not necessarily achieve better health results, or higher life expectancies

For example, the US spends more than five times as much per person as Estonia, yet both countries have similar life expectancies.

Yet, at least half of the world's population cannot obtain essential health services. 800 million people spend at least 10% of their household budgets on health expenses; For almost 100 million people these expenses are high enough to push them into extreme poverty.



Exciting developments in:



- Precision medicine
- Immunotherapy
- Microbiology
- Genetic engineering
- Regenerative medicine



Technological advances being leveraged in health and healthcare

- Artificial Intelligence
- Big Data and Analytics
- Virtual and augmented reality
- Nanotechnologies
- Modern machines (robotics, drones, 3D-printing)

 Apps
  Wearables

 Social Media
  Big data and analytics

By 2020, it is estimated that the volume of medical knowledge will be doubling every 73 days.

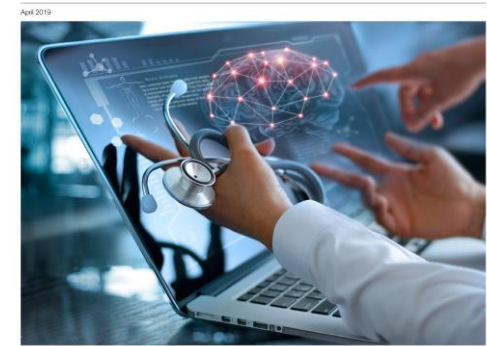
Over 318,000 health apps are now available (double from just two years ago) on top app stores worldwide with more than 200 health apps being added each day.

The integration of data will enable a system biology approach to prevention, disease surveillance, early detection, and intervention

Genome mapping now costs less than USD 1000

More than 15'000 drugs are in the pipeline in 2018, with over a third targeting cancer

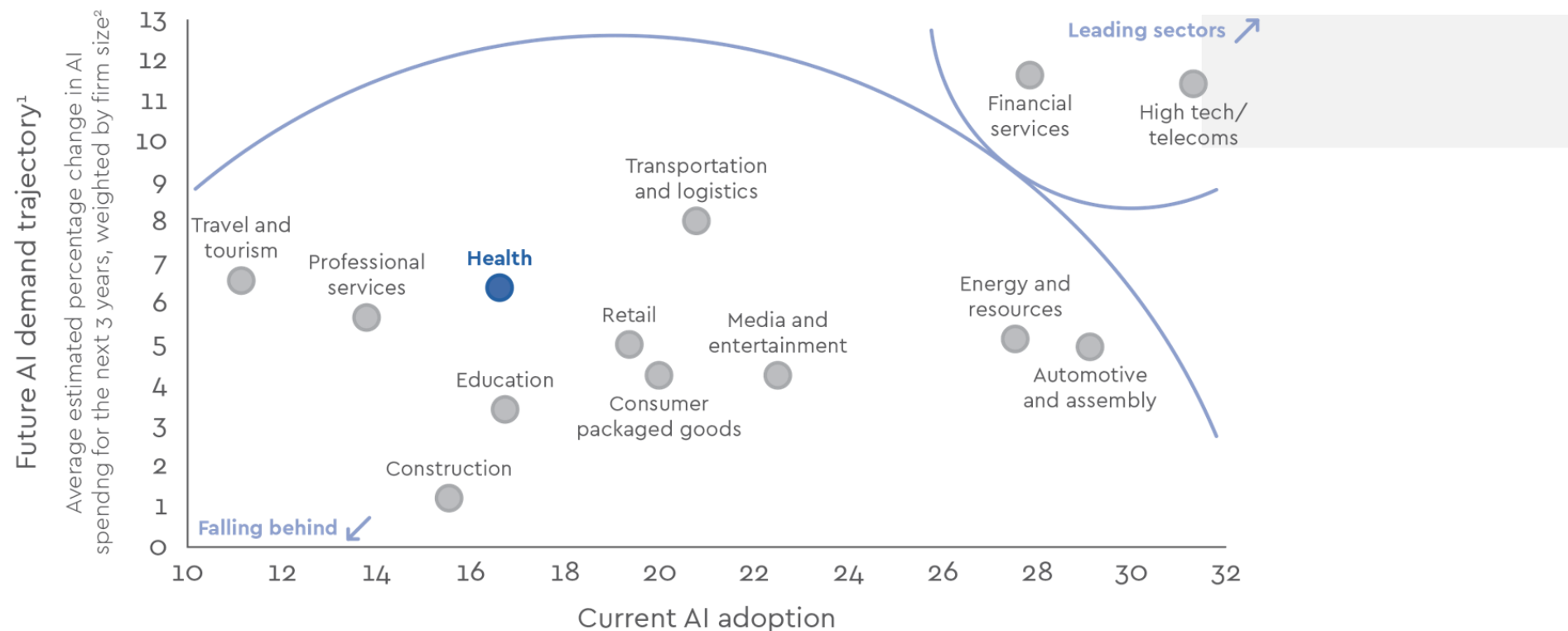
New processes for drug development



<https://www.weforum.org/reports/health-and-healthcare-in-the-fourth-industrial-revolution-global-future-council-on-the-future-of-health-and-healthcare-2016-2018>

# The challenges

## 2. Digital Maturity of NHS Systems



SOURCE: McKinsey Global Institute, AI adoption and use survey.

1 Based on the midpoint of the range selected by the survey respondent

2 Results are weighted by company size.

### Sectors leading in Data Science and AI adoption today

With thanks to Andrew Morris for this slide

# The challenges



FIGURE S-2 Schematic of the health care system today.

Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.  
Washington, DC: The National Academies Press. 2013 <https://doi.org/10.17226/13444>

# Questions???



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[hdip-dtp@qmul.ac.uk](mailto:hdip-dtp@qmul.ac.uk)





# What is a Learning Health System?

## DEFINITION

### A Learning Health Care System

*A learning health care system is one 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. (Roundtable on Value & Science-Driven Health Care, 2012)*

# In a Learning Health System .....

- **Every patient contact** is available to learn from
- Best practice is **immediately available**
- Improvement is **continuous**
- This happens **routinely and efficiently**
- This is part of a **culture**

Friedman 2016



*Friedman CP et al . The science of Learning Health Systems: Foundations for a new journal. Learn Health Syst. 2016 Nov 29;1(1):e10020. doi: 10.1002/lrh2.10020*

# Learning *Health* System or Learning *Healthcare* System?



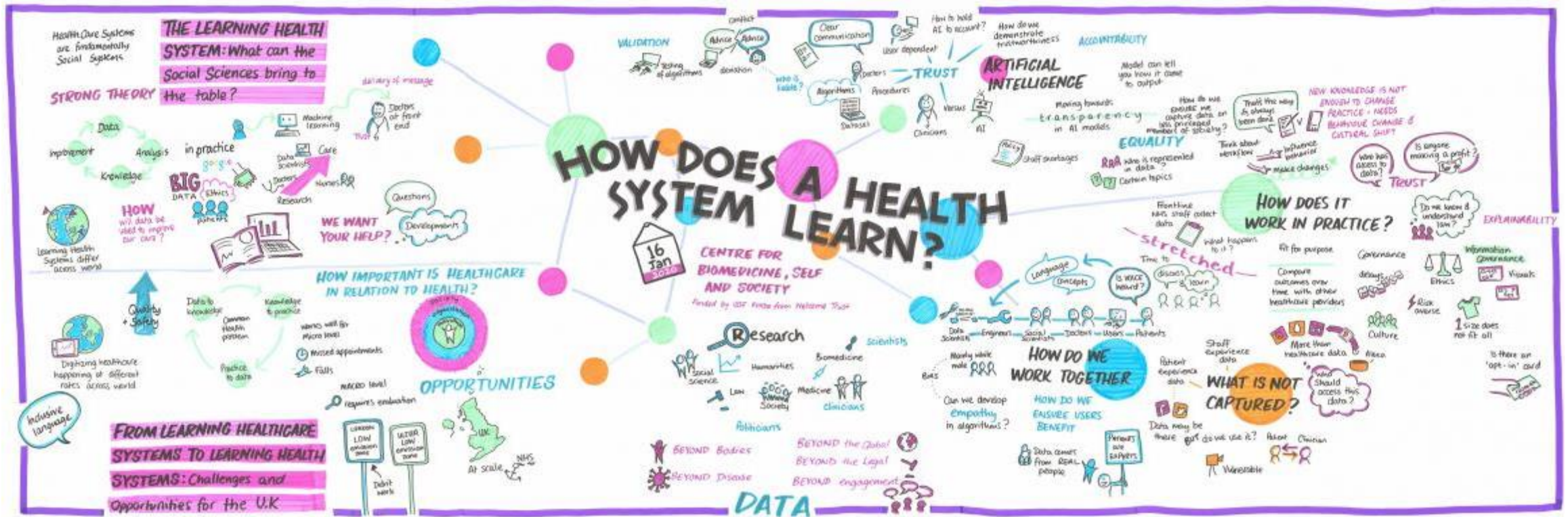
Learning **HEALTH** System because health

- ....is only poorly correlated with healthcare provision or expenditure.  
Healthcare is responsible for only 15 to 40% of population health outcomes.
- ....at the population level ....wider determinants are outside ambit of traditional healthcare provision (eg housing, road traffic, air pollution, violence) need to be addressed
- ....depends on policy decisions made by government (eg taxation on sugary drinks, age limits and minimum pricing for of alcohol, smoke-free legislation)

In UK >90% of all healthcare interactions are in community-based settings, mainly within general practice multidisciplinary teams

Aziz Sheikh *Learn Health Sys.* 2020;4:e10216. <https://doi.org/10.1002/lrh2.10216>

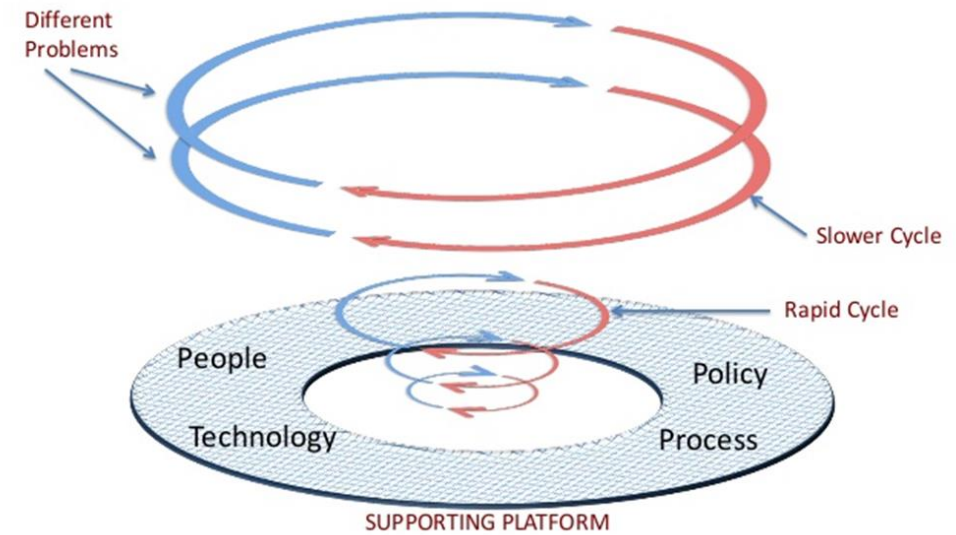
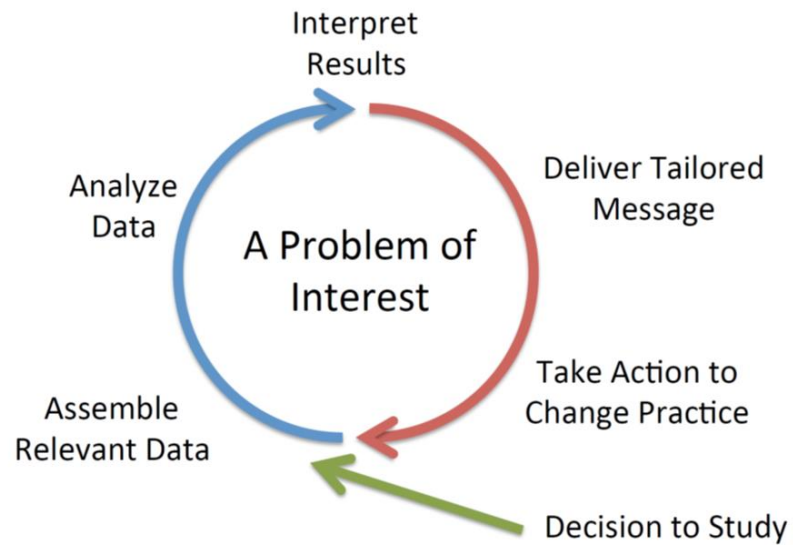
# Complexity



<https://www.ed.ac.uk/usher/biomedicine-self-society/centre-news/how-does-a-health-system-learn>



# A Learning Health System is a platform to support multiple simultaneous learning cycles



Dr. Charles Friedman and Joshua Rubin's 2015 AMIA Symposium



# Characteristics of a Continuously Learning Health System

## Science and Informatics

- *Real-time access to knowledge*
- *Digital capture of the care experience*

## Patient-Clinician Partnerships

- *Engaged, empowered patients*
- *Incentives aligned for value*
- *Full transparency*

## Continuous Learning Culture

- *Leadership-instilled culture of learning*
- *Supportive system competencies*

Taken from Table S2 in Institute of Medicine 2013. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington, DC: The National Academies Press.  
<https://doi.org/10.17226/13444>

# Elements of success: our experience in east London



**Trusted Data  
Access**



**Clinical  
Health  
Data  
Science**



**Clinical  
Utilities**



**Public Health  
Commissioning  
Research**

# Learning Health Systems: not a IT “plug-in”



Practice teams

RAG chart showing practice current performance

Consultant Diabetes

Guideline



## Capability

Evidence  
Stakeholders  
Consensus  
Guidance and KPIs  
Education



## Action

IT support  
Decision support  
Alerts  
Patient recall  
and review lists



## Motivated

Financial targets  
Dashboards  
Peer performance  
Facilitation



# ALIGNING SYSTEMS

# The future LHS Researcher: attributes and skills

- An individual who is embedded within a health system and collaborates with its stakeholders to produce novel insights and evidence that can be rapidly implemented to improve the outcomes of individuals and populations and health system performance.

## Seven Domains

- Systems Science
- Research Questions and Standards of Scientific Evidence
- Research Methods
- Informatics
- Ethics of Research and Implementation in Health Systems
- Improvement and Implementation Science
- Engagement, Leadership, and Research Management

*Forrest et al Health Research and Educational Trust DOI: 10.1111/1475-6773.12751*



# Questions???



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[hdip-dtp@qmul.ac.uk](mailto:hdip-dtp@qmul.ac.uk)



# Barriers

Scobie et al grouped barriers to LHS under 5 main themes

- 1) research versus innovation and implementation
- 2) analytical capacity and capability in the workforce
- 3) ethical issues and LHS
- 4) robust data access and governance arrangements
- 5) high quality data

*Scobie S, Castle-Clarke S. Implementing learning health systems in the UK NHS*

*Learn Health Sys. 2020;4:e10209 <https://doi.org/10.1002/lrh2.10209>*

# Some solutions to these barriers emerging.....

- 1) research versus innovation and implementation: *NHS Long Term Plan 2019, Team Science AMS 2016*
- 2) analytical capacity and capability in the workforce: *Wachter review 2016; Topol review 2019*
- 3) ethical issues and LHS: *Centre for Data Ethics & Innovation, Ada Lovelace Institute*
- 4) robust data access and governance arrangements: public and clinician trust:  
*Understanding Patient Data, DHSC code of conduct; National data opt out; Trusted Research Environments*
- 5) high quality data:  
*International data standards: SnoMed; HL7 FHIR (Fast Healthcare Interoperability Resources)*



## Making *IT* Work: Harnessing the Power of Health Information Technology to Improve Care in England

1. **Boost 'out-of-hospital' care:** unite primary and community services.
2. **Redesign** to reduce emergency hospital service use.
3. **Personalised care** when patients need it.
4. **Digitally-enabled** primary and outpatient care
5. **Focus on population health** and partnerships with local authority through new Integrated Care Systems (ICSSs)

“...trying to achieve the aims of the Five Year Forward View without giving highest priority to digitisation would be a costly and painful mistake”

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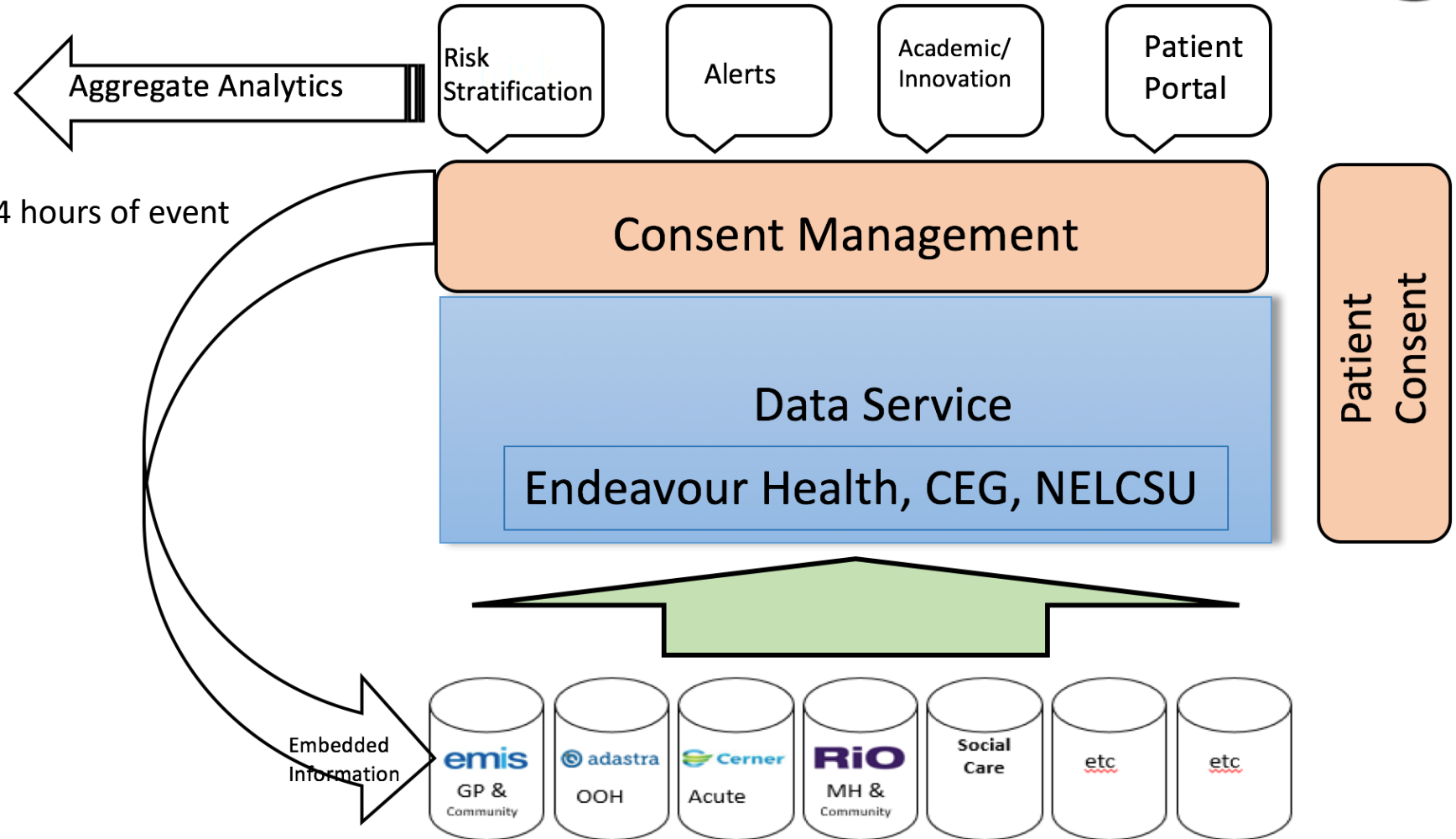


# Tackling the barriers in east London: real world data



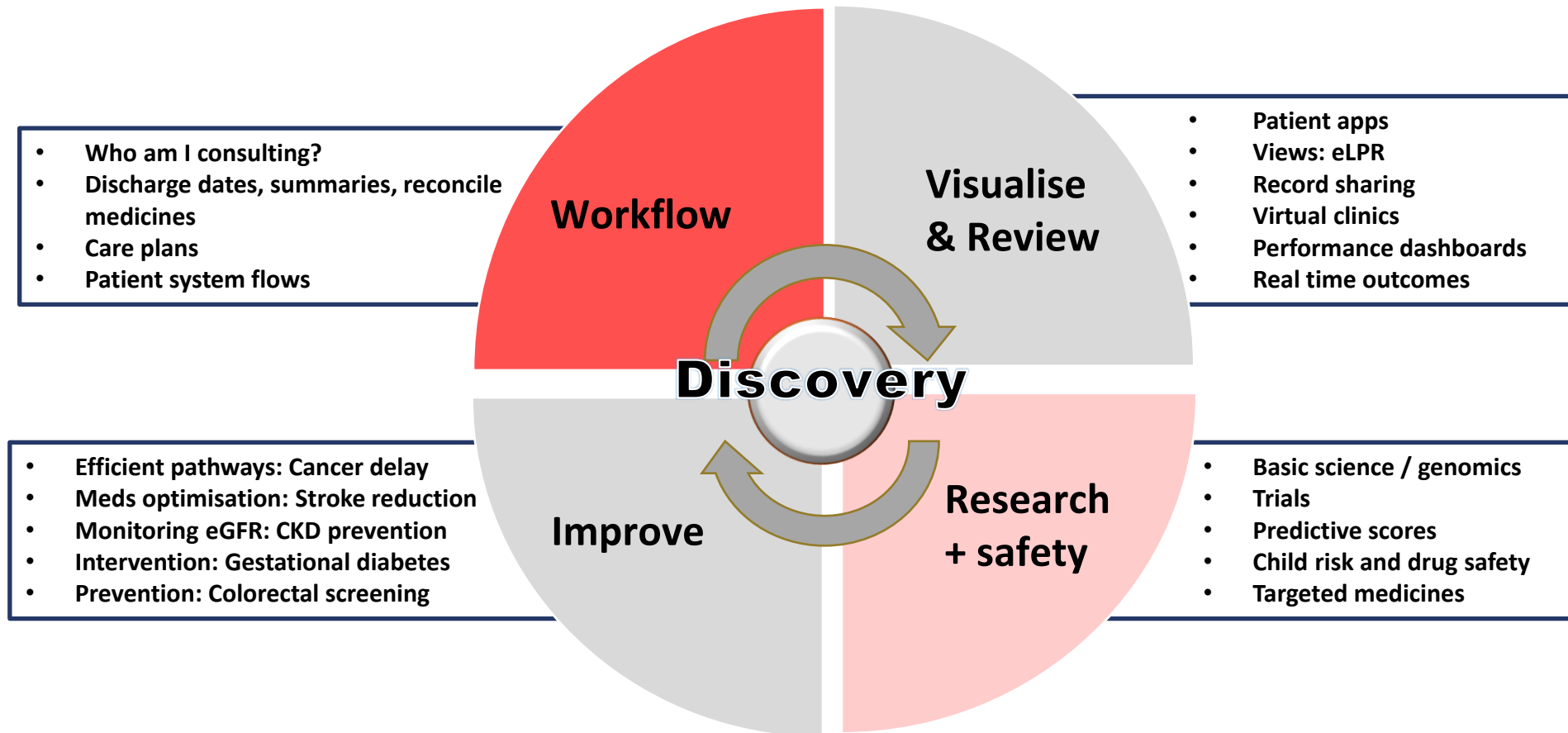
# Discovery Architecture

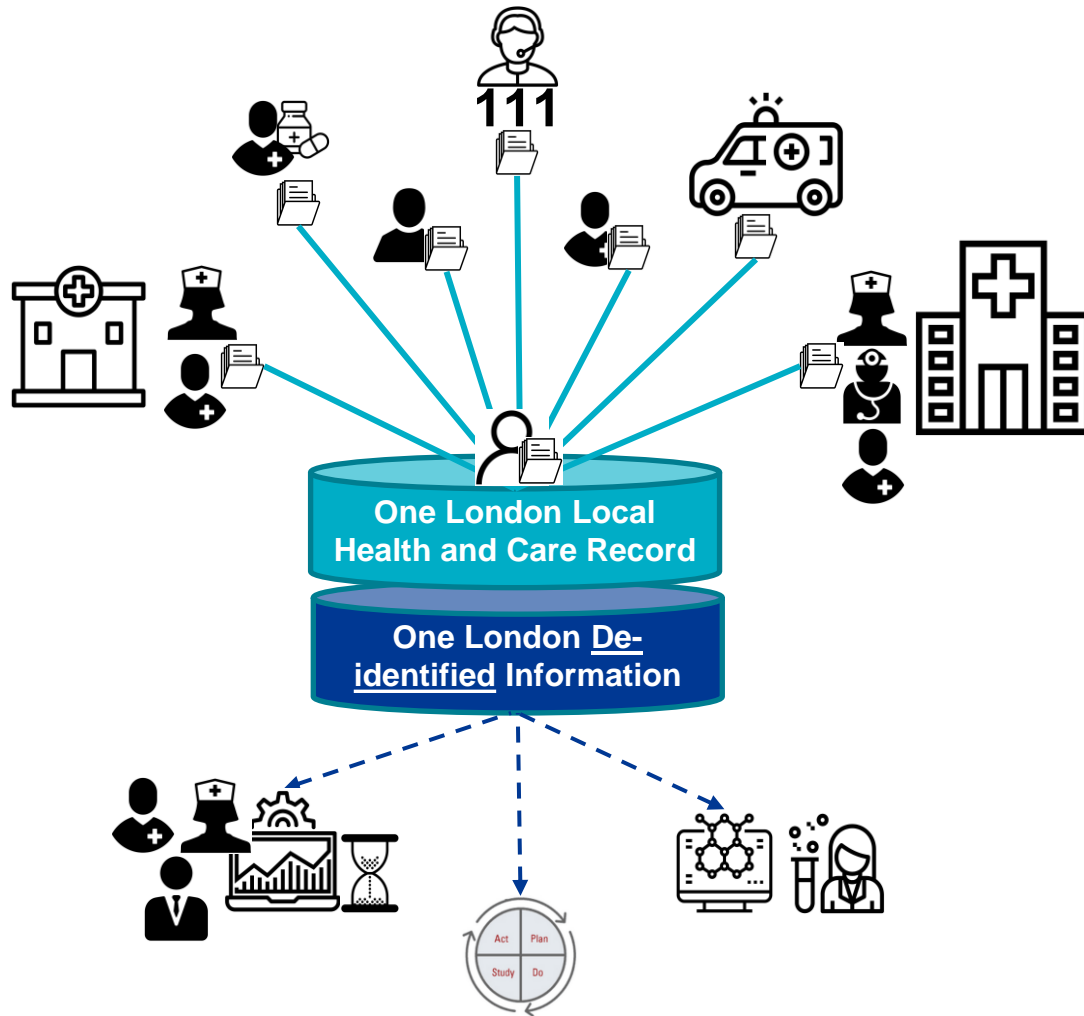
- Real-time reporting – within 12-24 hours of event
- Efficiency – no duplicate tests
- Efficiency – admission avoidance
- Predictive scores
- Decision support
- Research
- Patient connection
- Social services, OOH, 111 etc. ...



# A Learning Health System

Informed by the learning cycle, as described in 'Toward Complete & Sustainable Learning Systems' by Professor Charles Friedman (2014)





- Information, influence and services focused on service users and service providers
- Use all available information and new methods to create new healthcare knowledge for patient and public benefit
- Scale innovation to 9 million Londoners



## INDIVIDUALS NEED ACCESS TO THEIR FULL HEALTH RECORDS TO ADDRESS INFORMATION GAPS

**1/3** who have seen a health care provider in the last year experienced at least one of the following gaps in information exchange.<sup>1</sup>



Had to bring an X-ray, MRI, or other type of test result with them to the appointment



Had to wait for test results longer than they thought reasonable



Had to redo a test or procedure because the earlier test results were not available



Had to provide their medical history again because their chart could not be found



Had to tell a health care provider about their medical history because they had not gotten their records from another health care provider



74% stated patient experience improved with regards to accessing history



80% stated patients were pleased clinicians can access information such as blood test results, hospital appointments, etc., saving DNAs



Ward pharmacists no longer phone practices to reconcile medicines on admission, saving an hour a day EACH



74% stated their confidence in patient safety increased; 63% saying patients felt more confident





# One London

02 19/20

**9.2m** population



**1,437** statutory health and care provider organisations

**39%** of statutory health and care provider organisations have access to shared care records



**1,369** systems that could provide health and care information to the local health and care record



**40%** of these systems are connected to a shared care record

**55%** of systems are accessed via single sign on or within 5 mouse clicks



**206,736** health and care professionals targeted to have authorised access to local health and care records



**16%** already have access to shared records\*

8,720 Clinical Practitioners\*  
21,545 GPs\*  
1,901 Social Care Professionals\*  
467 Administrative / Clinical Support Staff\*

**39%** of citizen records are currently available to authorised health and care professionals via shared care records

**8,638** health and care professionals utilised shared care records in the reporting month





Date from 01/01/2020

Date to 22/09/2020

Filter series Suspected, Confirmed

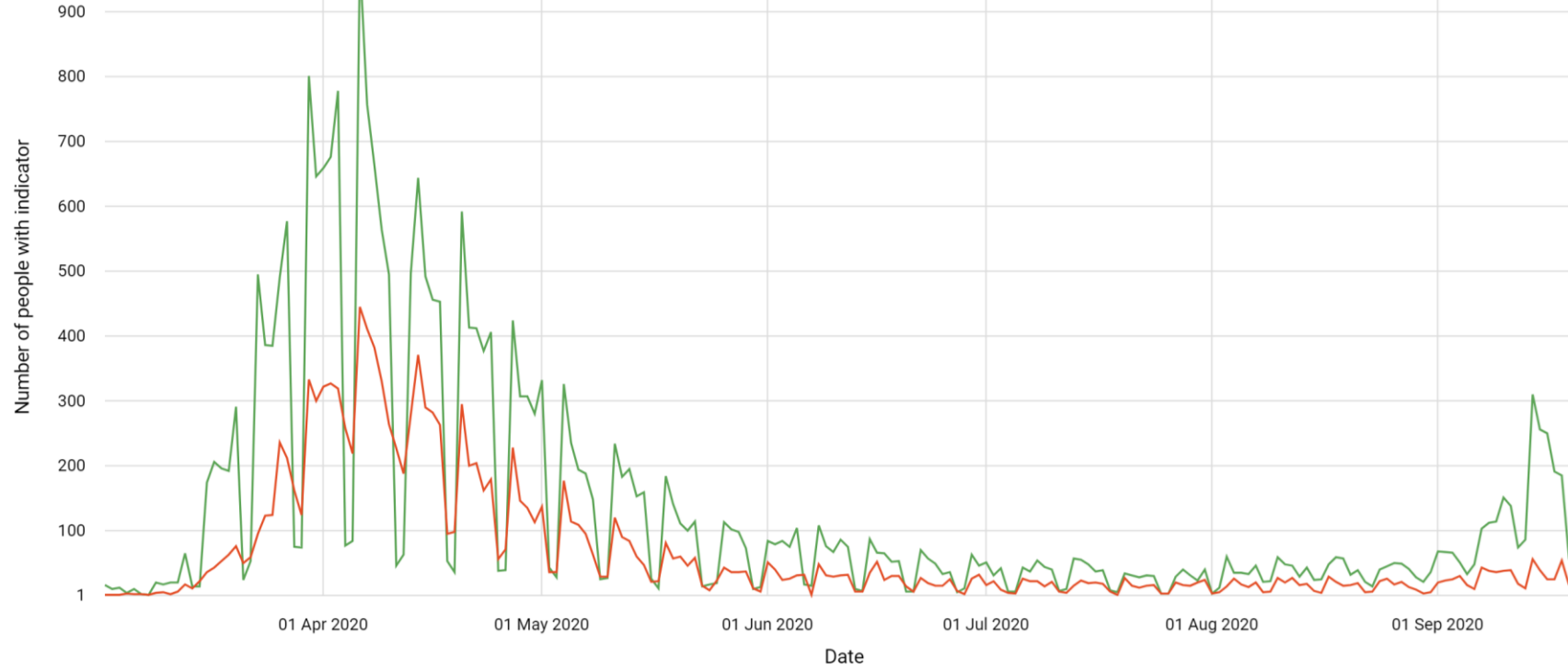
Filter CCG/TRUST NHS BARKING AND DAGENHAM CCG, N...

Download CSV

- Show gridlines
- Show area chart
- Gradient fill
- Logarithmic
- Cumulative
- Weekly

**Legend**

- Suspected
- Confirmed





Population Health Information for Integrated Care

GP consultation types

Date from 01/01/2020

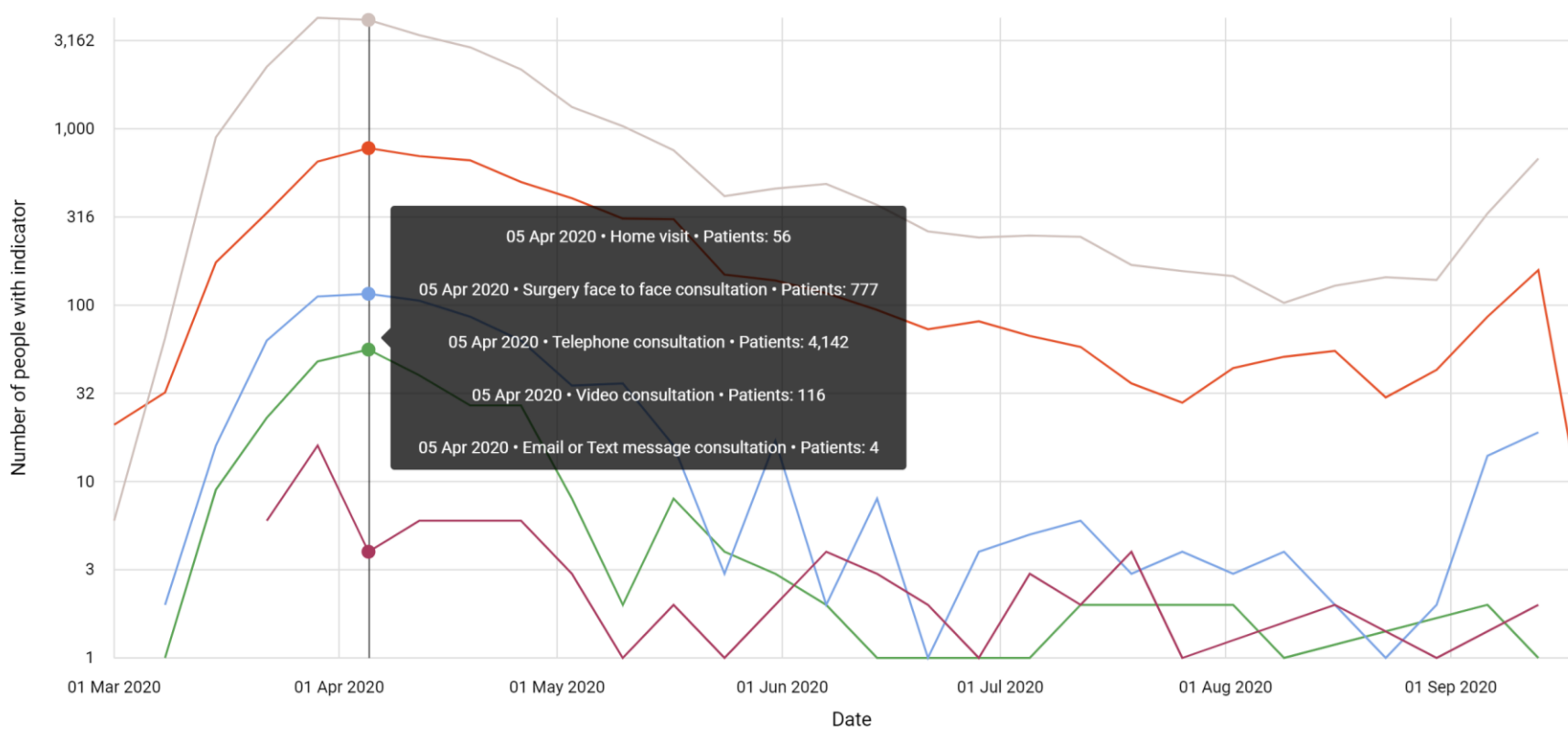
Date to 22/09/2020

Filter series Home visit, Surgery face to face consult...

Filter CCG/TRUST Barts Health Community Services, BART...

Download CSV

- Show gridlines
- Show area chart
- Gradient fill
- Logarithmic
- Cumulative
- Weekly



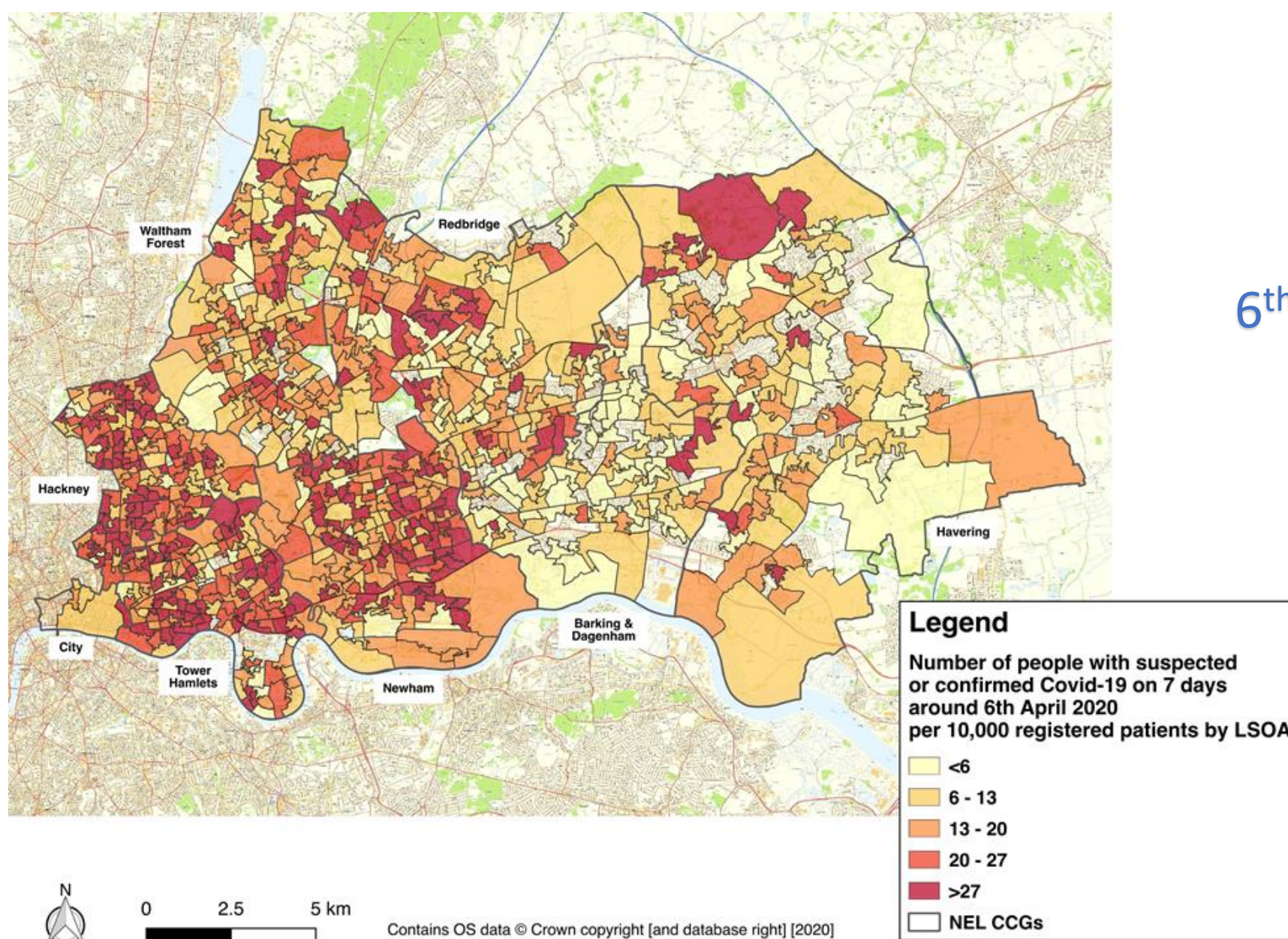
Legend

- Home visit
- Surgery face to face consultation
- Telephone consultation
- Video consultation
- Email or Text message consultation





6<sup>th</sup> April 2020



# Questions???



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@hdip\_dtp



[hdip-dtp@qmul.ac.uk](mailto:hdip-dtp@qmul.ac.uk)





# Learning Objectives

At the end of this lecture you should be able to understand

- The triple aim for health care, opportunities and challenges
- What a learning health system (LHS) is
- Key elements needed for LHS success
- Barriers to and enablers of LHS success
- **Factors influencing success in adopting and sustaining innovation within a LHS using the NASSS framework**

# Developing and scaling innovation and improvement in using health data in practice

- Turning data into knowledge (eg through risk stratification) often involves an intervention (eg an alert, dashboard) to support clinical care or shared decision making
- It is usually developed and evaluated in a single area or site initially but then implemented more widely
- However many interventions with evidence of effectiveness do not get scaled
- This is because replicating and scaling to support full scale implementation is difficult
- Understanding how to avoid non-adoption or abandonment of technologies at the design stage can increase success of LHS
- The nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) framework has been developed to identify complexity and potential points of failure
- It draws on implementation, complexity and social science theories and methods which are used in combination to tackle this issue

*Greenhalgh et al J Med Internet Res 2017 19 (11) e367*

# The NASSS framework 7 domains

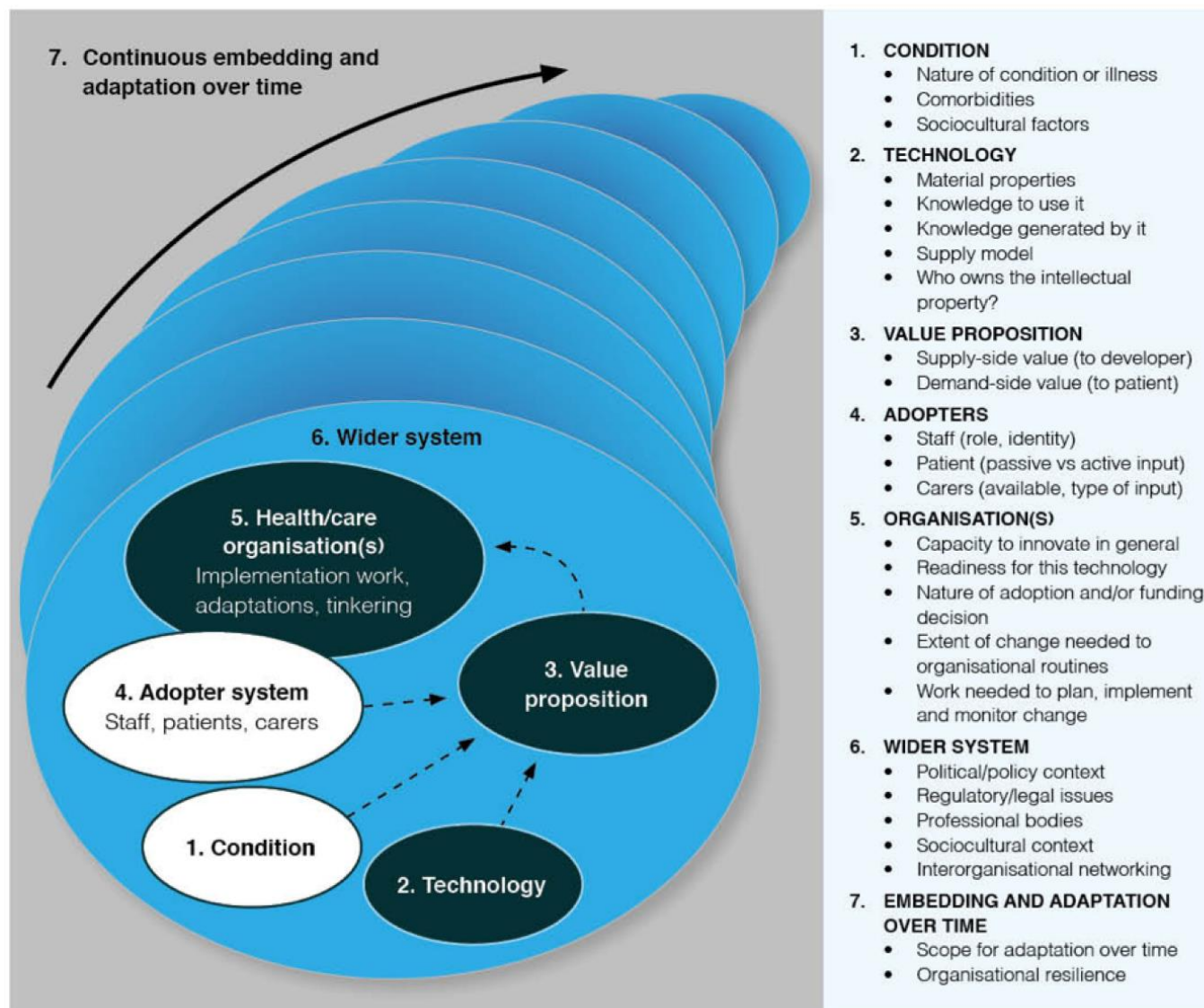
- condition or illness
- technology
- value proposition
- adopter system (comprising professional staff, patient, and lay caregivers)
- organisation(s)
- wider (institutional and societal) context,
- interaction and mutual adaptation between all these domains over time
  
- Within each domain challenges are classified as
  - simple (straightforward, predictable, few components)
  - complicated (multiple interacting components or issues)
  - complex (dynamic, unpredictable, not easily disaggregated into constituent components)

# The NASSS framework incorporates 7 domains

These are

- condition or illness
- technology
- value proposition
- adopter system (comprising professional staff, patient, and lay caregivers)
- organisation(s)
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**Figure 1.** The nonadoption, abandonment, scale-up, spread, and sustainability framework for studying nonadoption and abandonment of technologies by individuals and the challenges to scale-up, spread, and sustainability of such technologies in health and care organizations.



The NASSS CAT is a structured appraisal tool published in a variety of formats

- Short: taster, semiquantitative
- Long: workshop, planning stage
- Project: for monitoring complexity
- Interview: semi-structured interview

*Greenhalgh et al*  
*JMIR Res Protoc 2020;9(5):e16861* doi: 10.2196/16861

*BMJ 2019;365:l2068* doi: 10.1136/bmj.l2068



# 1. THE ILLNESS OR CONDITION



*Think about the illness or other condition that the technology is designed for – and what sort of person has that condition.*

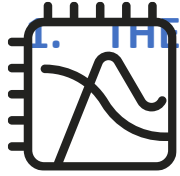
|  | Agree                        | Disagree                    | Not applicable or don't know |
|--|------------------------------|-----------------------------|------------------------------|
| There are significant uncertainties about the condition e.g. poorly-defined, variable manifestations, uncertain course                       |                              |                             |                              |
| Many people with the condition have other co-existing illnesses or impairments that could affect their ability to benefit from this solution |                              |                             |                              |
| Many people with the condition have social or cultural factors that could affect their ability to benefit from the technology or service     |                              |                             |                              |
| The population with the condition, and/or how the condition is treated, is likely to change significantly over the next 3-5 years            |                              |                             |                              |
| <b>SUMMARY: The condition has significant complexity which is likely to affect the project's success</b>                                     | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                              |

## 1. THE TECHNOLOGY



Think about the technology (e.g. a tool or piece of software), and how it might affect care.

|   | Agree                        | Disagree                    | Not applicable or don't know |
|---|------------------------------|-----------------------------|------------------------------|
| There are significant uncertainties in what the technology is (e.g. it hasn't been fully developed yet)                                   |                              |                             |                              |
| There are significant uncertainties in where the technology will come from (e.g. supply chain issues, substitutability)                   |                              |                             |                              |
| There are significant uncertainties about the technology's performance and dependability (e.g. bugs, crashing, cutting out)               |                              |                             |                              |
| There are significant uncertainties about the technology's usability and acceptability (e.g. key people don't trust the data it provides) |                              |                             |                              |
| There are significant technical interdependencies   |                              |                             |                              |
| The technology is likely to require major changes to organisational tasks and routines  |                              |                             |                              |
| The technology (and/or the service model it supports) is likely to change significantly within the next 3-5 years                         |                              |                             |                              |
| <b>SUMMARY: The technology has significant complexity which is likely to affect the project's success</b>                                 | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                              |

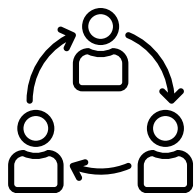


## 1. THE VALUE PROPOSITION

Think about what kind of value the technology might generate for different groups of people. ('Value' can be financial, such as profit, or non-financial, such as control of symptoms)

|  | Agree                        | Disagree                    | Not applicable or don't know |
|--|------------------------------|-----------------------------|------------------------------|
| The commercial value of the technology is uncertain  |                              |                             |                              |
| The value to the intended users (e.g. patients, clinicians) is uncertain   |                              |                             |                              |
| The value to the healthcare system (e.g. from efficacy and cost-effectiveness studies) is uncertain              |                              |                             |                              |
| The value to this particular healthcare organisation, given the current situation locally, is uncertain          |                              |                             |                              |
| The technology could generate a negative value (costs are likely to outweigh benefits) for some stakeholders     |                              |                             |                              |
| The value proposition is likely to change significantly over the next 3-5 years                                  |                              |                             |                              |
| <b>SUMMARY: The value proposition has significant complexity which is likely to affect the project's success</b> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                              |

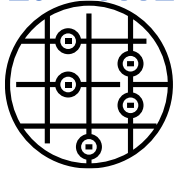
## 1. THE INTENDED ADOPTERS



*Think about who is intended to use the technology and what changes it will bring for them.*

|   | <i>Agree</i>                 | <i>Disagree</i>             | <i>Not applica<br/>or don't kno</i> |
|---|------------------------------|-----------------------------|-------------------------------------|
| There is uncertainty about whether and how patients/citizens will adopt the technology [if applicable]                        |                              |                             |                                     |
| There is uncertainty about whether and how front-line staff will adopt the technology   |                              |                             |                                     |
| There is uncertainty about the implications for people who might be indirectly affected by the technology                     |                              |                             |                                     |
| There will be significant changes to individual users' perceptions of the technology over the next 3-5 years                  |                              |                             |                                     |
| <b>SUMMARY:</b> There is significant complexity relating to intended adopters which is likely to affect the project's success | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                                     |

# 1. THE ORGANISATION(S) IMPLEMENTING THE TECHNOLOGY



*Some organisations are better at taking up innovations than others. What about yours?*

|   | Agree                        | Disagree                    | Not applica<br>or don't kno |
|---|------------------------------|-----------------------------|-----------------------------|
| The organisation's capacity to take on technological innovations is limited   |                              |                             |                             |
| The organisation is not ready for this particular innovation  |                              |                             |                             |
| The organisation would find it hard to commission/purchase the innovation   |                              |                             |                             |
| The work needed to introduce and routinise the innovation has been underestimated and/or inadequately resourced                                     |                              |                             |                             |
| The organisation(s) involved are likely to have significant restructurings or changes in leadership, mission or strategy over the next 3-5 years    |                              |                             |                             |
| <b>SUMMARY:</b> There is significant complexity relating to one or more participating organisations which is likely to affect the project's success | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                             |



# 1. THE EXTERNAL CONTEXT FOR INNOVATION



Think about external conditions that could complicate adoption and spread of the innovation.

|  | Agree                        | Disagree                    | Not applica<br>or don't kno |
|--|------------------------------|-----------------------------|-----------------------------|
| The political and/or policy climate is adverse   |                              |                             |                             |
| Professional bodies are opposed to the innovation or don't actively support it   |                              |                             |                             |
| Patient organisations and lobbying groups are opposed to the innovation or don't actively support it                             |                              |                             |                             |
| The regulatory context is adverse  |                              |                             |                             |
| The commercial context is adverse  |                              |                             |                             |
| Opportunities for learning from other (similar) organisations are limited  |                              |                             |                             |
| Introduction of the technology/innovation could be threatened by external changes that impact on the organisation                |                              |                             |                             |
| The policy, regulatory and economic context for this innovation is likely to be turbulent over the next 3-5 years                |                              |                             |                             |
| <b>SUMMARY: There is significant complexity relating to the external context which is likely to affect the project's success</b> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |                             |

# Questions???



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@hdip\_dtp



[hdip-dtp@qmul.ac.uk](mailto:hdip-dtp@qmul.ac.uk)



# Seminar topic/related tutorial

We will work through a case study of health data in practice together using the NASSS framework tool

You will be assigned an exercise to bring for discussion at next week's seminar

This slide set will be made available to you on QMPlus together with a reading list