Developing a leaner approach to delivering learning health systems at scale using lessons learned from the North of England's Connected Health Cities Programme

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Summary

The Connected Health Cities (CHC) programme is a Northern Health Science Alliance (NHSA) led programme delivered by a consortium of academia, NHS organisations and industry partners across four regions in the North of England. Each of the four regions has been tasked with establishing a Learning Healthcare System (LHS), using patient data to create and test innovative improvements for a variety of clinical pathways. The programme has demonstrated[ii] that a ground-breaking 'learning health system' with informed consensual use of citizen's health data at its heart can fulfil the IHI Triple Aim[iii] of improving the experience of care, improving the health of populations, and reducing per capita costs of health care.

This paper highlights key lessons learned from this ambitious, complex, real-world Northern Health Science Alliance (NHSA) programme which spanned the whole of northern England and its 15m population. It describes a series of approaches and practical thinking tools that can be used to overcome common stumbling blocks observed when:

- testing the learning health care system methodology for data driven transformation of health and care in the real world;
- developing a social licence for the use of for data driven transformation;
- developing new models of partnership with service providers, academia, industry and citizens.

A key lesson learned is that data driven transformation of health services does not occur simply by making health data available for analytical purposes: it is essential that the people and organisations providing those services and collecting the data are integral to the analytical work. This document proposes a series of approaches and practical thinking tools that, when combined with a truly multi-disciplinary central co-ordinating hub and regional centres for innovation around health and social care, can:

1. deliver large-scale transformation where data is the currency for inclusive economic growth and service improvement;
2. expand the diameter of trust;
3. foster the commitment and collaboration of a critical mass of health and social care stakeholders across organisational boundaries.

The DataSavesLives Lean Stack of tools forms part of the legacy of CHC as a component of its pipeline for scaling innovation and improvement[iv]. It opens the doors to the Civic Data Co-operatives that can build on the CHC programme. These have been calibrated by regular and repeated engagement with academic institutions, health organisations, government bodies and industry across the US, Canada, Australia, Singapore, China, Japan and Europe. Towards the end of the CHC programme, elements of these tools were successfully and effectively prototyped during a half-day workshop for the leaders of the Northern Irish health and social care ecosystem. The DataSavesLives Lean Stack of tools enables front-line innovators to improve care, reduce waste and unlock learning while expanding the diameter of trust.

Overall, the CHC programme has revealed the potential of a systematic approach to scaling innovation and improvement to:

- ✓ Enable front-line innovators to improve care, reduce waste and unlock learning;

- ✓ Shape learning health systems to deliver policy objectives and influence policy;

- ✓ Codify the knowledge and apply the know how to scale what works in different contexts;

- ✓ Curate an online library and community for open sharing of applied resources and best practice;

- ✓ Focus on collaborative approaches with existing projects as well as innovative new initiatives to achieve short-term gains with long-term impact in UK.

Contents

Introduction

The learning health system (LHS) cycle defines the key components for a LHS system (*Figure 1*). These include three key parts: data to knowledge flow, knowledge to practice flow and practice to data flow. Within these parts are specific areas that provide a more detailed nuts-and-bolts theoretical framework that can be used to create a LHS. While the theory of a learning health system is an elegant feedback loop, the reality is messy (*Figure 2*).

Flynn et al., Learn Health Sys. 2018;2:e10054.
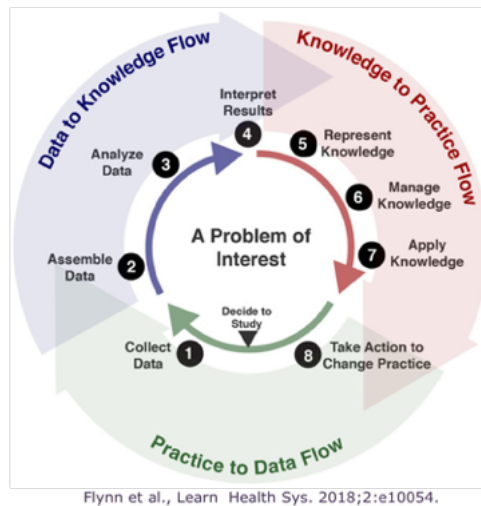
Figure 1: Learning Health Systems Cycle[v]

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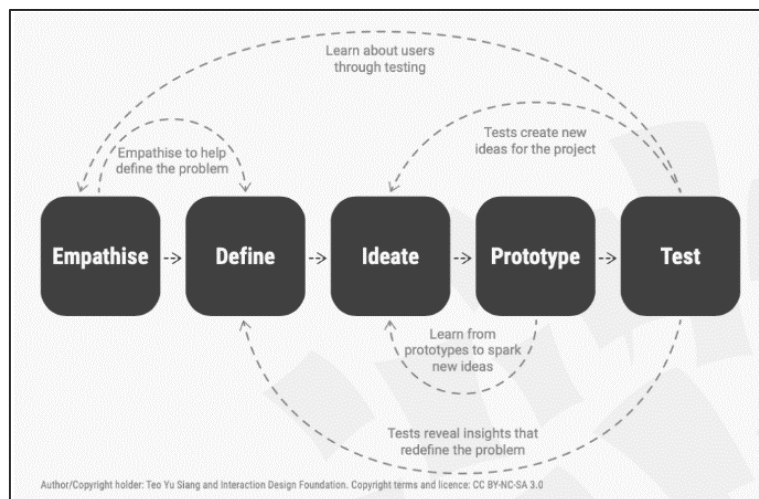
Figure 2: Design Thinking Model from the Interactive Design Foundation[vi]

The CHC programme tested the creation and implementation of LHSs at scale within the "mess" of reality. It revealed generic stumbling blocks that impact the realisation of future value and drivers of systemic waste (*Table 1*). The obvious challenges lay in technical feasibility and achieving a social license[vii]. In hindsight, the critical non-obvious challenge faced was: *"as digital learning systems become technically feasible and embraced by citizens, how*

do you inspire and enable the simultaneous commitment and collaboration of a critical mass of health and social care stakeholders across organisational boundaries people to work together to build the quality foundations required when they habitually focus on the near term, local and urgent?"

Current waste	Stumbling blocks	Future value
Strategy and resource allocation: making planning tractable		
• Wasted investment • Predictable causes of failure • Missed opportunities	• How do I allocate resources? • What do I do next? • Where is the low-hanging fruit?	• Increased return on investment • Reduce time to impact • Build belief and momentum
Feasibility: transforming hard infrastructure		
• Increased costs from re-inventing the wheel • Delay	• What do we need? • What do we have? • How should we proceed?	• Faster, cheaper deployment
Desirability: transforming soft infrastructure		
• De-motivation • Disengaged citizens • Lost learning • Spread challenge: non-adoption and lack of scaling	• How do we inspire patient engagement to achieve the social contract? • How do we forge shared commitment? • How do we build capacity and capability?	• A cultural transformation that inspires a critical mass of health and social care stakeholders to collaborate across boundaries • Citizens embrace liberating data to save lives from an informed perspective

Table 1: Generic stumbling blocks identified while implementing learning health systems at scale

Overall, CHC uncovered nine generic challenges that prevented realising the full potential of learning health systems. In tandem with the year-long evaluation of the programme, CHC inspired a baseline of components and activities that can make it easier for front-line innovators to support successful implementation of the learning health system cycle. These nine approaches are not formal parts of a learning health system, but instead are linked to it. Overcoming the nine challenges is crucial to the success of safely and effectively delivering learning health systems at scale.

Making learning health systems feasible pathway by pathway	
Challenge	**Proposed approach**

1	Complexity can be overwhelming	Assemble a multi-disciplinary team
2	Every context is unique	Deliberately diagnose before treating
3	Perceiving reality in a complex system	Systematically reveal ground truths
Making learning health systems desirable		
4	Building and sustaining citizen trust	Innovate to expand the diameter of trust
5	Absence of end to end quality foundations	A hub focused on "doing the unsexy bit"
6	Inconsistent levels of stakeholder support	Inspire a critical mass of shared commitment
Scaling evidence-based policy by making it easier to safely use data to save lives		
7	Lack of replication, scaling and spread	Make LHS scaling tractable by using lean tools
8	Avoiding re-inventing the wheel	Library of blueprints, resources & know-how
9	Accelerating learning and improvement	Found a global community of practice

Table 2: Summary of proposed approaches to overcome challenges identified to implementing learning health systems at scale

Inspired by the lessons learned during the CHC programme, external consultants have worked with the CHC team to prototype practical thinking tools that combine system thinking, human centred design, behavioural psychology and strategic thinking to make it easier for front-line innovators and health system leaders to plan learning health systems, translate that strategy into action and extract lessons learned. The prototype tools and models outlined in this paper are an attempt to make the process of designing and implementing learning health systems at scale tractable. Together, these form the **DataSavesLives Lean Stack** of tools (Figure 3).

Scaling a global learning health system: CHC International

The range of organisations who have invited the CHC programme for further meetings to explore collaboration include: the Singapore Ministry of Health; New South Wales Ministry of Health; South Australia Health and Medical Research Institute; Beijing University (PKU) National Institute for Health Data Science; China National Health Development Research Centre; Institute for Global Health Policy Research, and World Economic Forum (WEF) Centre for the Fourth Industrial Revolution, Japan.
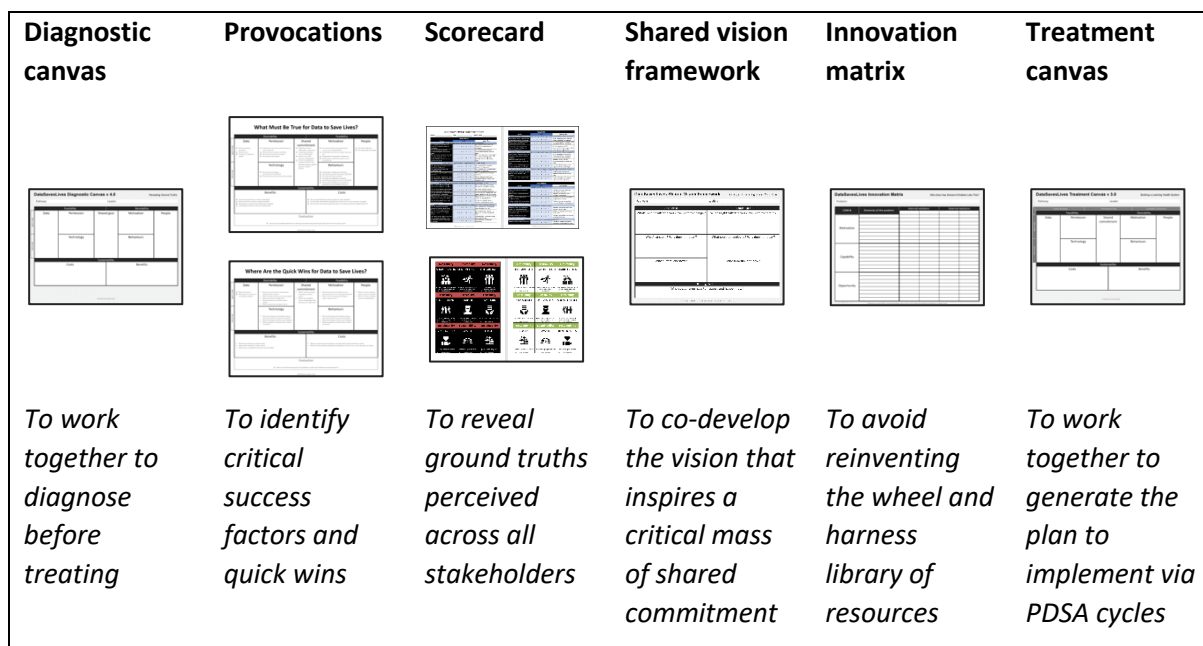
Diagnostic canvas	Provocations	Scorecard	Shared vision framework	Innovation matrix	Treatment canvas
To work together to diagnose before treating	To identify critical success factors and quick wins	To reveal ground truths perceived across all stakeholders	To co-develop the vision that inspires a critical mass of shared commitment	To avoid reinventing the wheel and harness library of resources	To work together to generate the plan to implement via PDSA cycles

Figure 3: DataSavesLives Lean Stack of tools

This report and the DataSavesLives Lean Stack forms part of the community of practice that is being developed to promote sharing and access to a suite of online tools and software because of this successful international relations programme. This report is divided into three sections: first section describes the three key challenges to making learning health systems feasible and proposes approaches that can be used to overcome these challenges. The second section discuss the challenges and approaches to making learning health systems desirable to both the public and other stakeholders. The third section outlines the key challenges and approaches for scaling evidence-based policy by making it easier to safely use data to save lives. Finally, this report closes with our conclusions.

Section 1: Making learning health systems feasible pathway by pathway

This first section describes the three key challenges to making learning health systems (LHS) feasible and proposes approaches that can ensure:

- Context can always be diagnosed before acting
- Strategy and planning are driven by a shared perception of ground truths
- Quick wins are identified so time to impact reduced and return on investment increased
- Belief and commitment can be built from the planning stage to deliver momentum for the messier stages still to come

Table 3 provides a summary of the proposed approaches to overcome challenges identified to make implement a LHS at scale feasible.

	Challenge	Proposed approach
1	Complexity can be overwhelming	Assemble a multi-disciplinary team
2	Every context is unique	Deliberately diagnose before treating
3	Perceiving reality in a complex system	Systematically reveal ground truths

Table 3: Summary of proposed approaches to overcome challenges identified to making learning health systems feasible at scale

In addition to the challenges and waste identified in the summary below (Table 4), strategy and planning may be influenced by unchecked assumptions.

Current waste	Stumbling blocks	Future value
Strategy and resource allocation: making planning tractable		
- Wasted investment - Predictable causes of failure - Missed opportunities	- How do I allocate resources? - What do I do next? - Where is the low-hanging fruit?	- Increased return on investment - Reduce time to impact - Build belief and momentum
Feasibility: transforming hard infrastructure		
- Increased costs from re-inventing the wheel - Delay	- What do we need? - What do we have? - How should we proceed?	Faster, cheaper deployment

Table 4: Generic feasibility stumbling blocks identified while implementing learning health systems at scale

The first three elements of the DataSavesLives Lean Stack are most relevant to making learning health systems feasible pathway by pathway. These enable stakeholders to: 1) work together to diagnose before treating; 2) identify critical success factors and quick wins; and 3) reveal ground truths perceived across all stakeholders.

Challenge #1: Complexity can be overwhelming

Proposed approach: Assemble a multi-disciplinary team

A LHS is a powerful, high-leverage approach to improving care. However, most LHSs are cross-cutting projects that are highly complex. It was reported during the CHC programme that this complexity can feel overwhelming.

"As the scale of the LHS increases, its characteristics approach those of an ultra–large-scale system that exhibits unique characteristics, behaves in ways fundamentally different from systems at smaller scale, and requires new approaches"[viii]

Consequently, the following questions may be difficult for front-line innovators and health system leaders to address:

- How do I allocate resources?
- What do I do next?
- Where is the low-hanging fruit?

Stakeholders may have followed approaches that served them well on other projects, but find these approaches counterproductive in developing a LHS, particularly in trying to apply technical solutions to adaptive challenges within highly complex situations.[ix] Approaches that feature domain experts making their own judgement of a situation, then deciding on the correct course of action often break down in the face of complexity.

Highly complex situations are intrinsically hard to understand. They typically require multiple vantage points simply to make sense of a situation. The many individual parts of a complex system interact as a network via feedback loops, thresholds and tipping points. Small variations can produce large changes. Unlike simple situations, a common starting point would give rise to vastly different outcomes because of the interaction of the parts of the system. Consequently, complex systems are hard to learn from, making it almost impossible to make predictions in a complex system. Learning health systems are just such complex systems.

"The system as a whole—not just the digital infrastructure, but also networks of people and institutions—will have to be understood not just as users of a technological infrastructure, but also as parts of the information system itself." [x]

Therefore, applying traditional approaches in implementing a LHS can lead to waste. Specifically, these are:

1. Wasted investment
2. Predictable failure
3. Missed opportunities

Supporting front-line innovators and health system leaders with a multi-disciplinary team familiar with working in highly complex situations can avoid this waste.

Challenge #2: Every Context is Unique

Proposed approach: Deliberately Diagnose Before Treating

"The success of a complex intervention is likely to depend heavily on its context" [xi]

Deeply understanding all critical aspects of a context before acting runs counter to the human bias to action. It requires the deliberate collation of multiple perspectives which are often ignored.[xii] Wasted investment, predictable failure and missed opportunities also arise from failing to take the time to make an accurate "diagnosis" of a complex situation before deciding what "treatment" is appropriate to build a successful learning health system. A deliberate focus on "diagnosing" a complex context before planning "treatment" may mitigate elements of current waste, especially when the dynamic interaction between individual factors and technological innovations influence the success of technology implementation. [xiii]
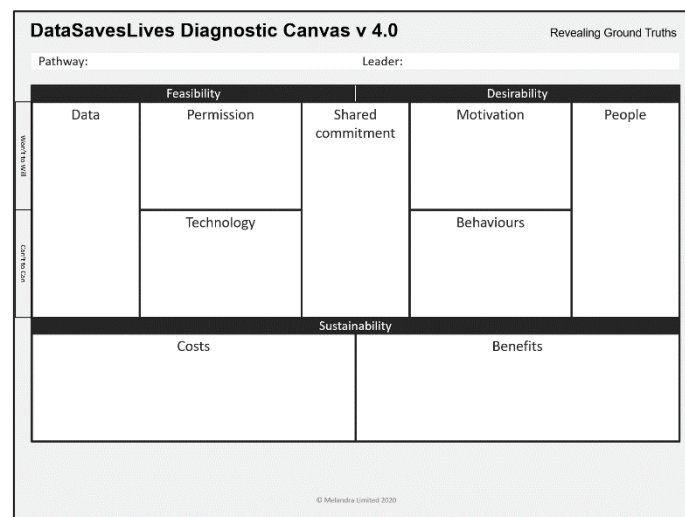

Figure 4: DataSavesLives Diagnostic Canvas

It would be heroic to expect each front-line innovator or health system leadership team to invent their own strategic methodology for building learning health systems. To expect every member of the team to diligently apply the approach while simultaneously developing and internalizing it would seem optimistic. Practical thinking tools such as the Business Model Canvas[xiv] have been developed to make complex situations tractable, i.e. capable of having logic applied.

At the core of the CHC **DataSavesLives Lean Stack** lies the prototype **DataSavesLives Canvas** (**Error! Reference source not found.**) which has been designed to:

- Make planning learning health systems easier and tractable (capable of having logic applied)

- Help teams assemble all components necessary for success

- Achieve focus on non-obvious potential causes of failure and de-risk them

- Enable collaboration across organisational boundaries

- Act as the springboard for scaling future NHS improvement and by international partners such as Beijing University (PKU)

- Act as a lingua franca to support the ad hoc conversations that can be the spark to inspire front-line innovators to launch the successful pathway projects that translate policy into better care, cheaper care and better outcomes.

In this way, the doors may be opened to more reliably diagnosing the complex contexts in which learning health systems are to be deployed before action is taken, reducing waste and enhancing the return on investment of learning health systems. Furthermore, the process may feel uplifting for the participating stakeholders.

Challenge #3: Perceiving Reality in a Complex System

Proposed approach: Systematically Reveal Ground Truths

The context specificity of learning health systems opens the door to biases arising from the mental behaviour summarised by Daniel Kahneman in Thinking Fast and Slow. Kahneman refers to his long-time collaborator Amos Tverky's observation regarding the *"asymmetry between the way our minds treat information that is currently available and information we do not have."*[xv] Kahneman refers to the human trait of jumping to conclusions on the basis of limited information as "what you see is all there is" (WYSIATI). Therefore, no single person is deeply familiar with every part of the system in which the learning health system will be developed. Each person will, without realising it, engage in WYSIATI and snap to a rapid judgement regarding aspects of the context of the learning health system. Consequently, no two people see the same complex situation the same way. This provides fertile ground for errors of perception. It has been said that 90% of decision errors are errors of perception and not reason.[xvi]

An obvious example may be the difference in perception between senior health system personnel who "know" that an electronic system has been deployed system-wide because they were part of the team that approved its roll-out and front-line health workers who still see paper records being wheeled along a corridor in the department where domain specific reasons have delayed the electronic system. While that is a crude example, subtle differences in understanding about the availability and quality of data were a common occurrence for CHC pathways. Without deliberate action, strategy and planning may be influenced by unchecked assumptions.

Example: SILVER - Smart Interventions for Local Vulnerable Families[xvii]

The SILVER CHC pathway project tackled the challenge that high-risk user groups, such as adults and young people out of work or at risk of financial exclusion, as well as vulnerable families, are often affected by a range of social and health problems. These persons are often in the care of multiple agencies such as healthcare professionals, the criminal justice system and social services.

The project sought to provide social workers with the latest up to date information on their service users to enable better support. This necessitated creating a secure corridor for data to flow from different agencies via a single platform.

GPs initially declined to share data with this platform in the belief that protecting the privacy of the vulnerable individuals was in the best interest of these high-risk user groups. The multi-disciplinary SILVER team built a programme of work around gaining the trust and deeply understanding the vulnerable families. This work challenged the well-intentioned assumption by GPs. It revealed the vulnerable families specifically wished their data to be shared by GPs in order to provide social workers with up to date information.

It is all too easy to misallocate resources as a consequence: to invest where conditions are not conducive or to ignore a potentially impactful project. Therefore, the antidote to all these errors of perception is to deliberately reveal ground truths through the following essential elements:

1. Ask "whose perspectives do we need?"
2. Bring those perspectives together, preferably face to face
3. Use tools such as the prototype **DataSavesLives Diagnostic Canvas** to make it easier to direct attention, section by section, to every element essential to the success of a learning health system
4. Use provocations such as **What Must be True for Data to Save Lives?** to build a shared understanding of the critical success factors of a learning health system
5. Use provocations such as **Where Are the Quick Wins for Data to Save Lives?** to build a shared understanding of the potential pilot learning health system projects
6. Use tools such as the prototype **DataSavesLives Diagnostic Scorecard** to evaluate one or more potential learning health systems, either as an individual or by compiling the absolute scores

Facilitation by a multi-disciplinary team is likely to add value to the use of these tools. Going further, one may deliberately reveal differences in perception. Here, one could distribute the **DataSavesLives Diagnostic Scorecard** to reveal differences in perception between groups of stakeholders. One may reveal differences in perception between those working on the project and those whose external opinions are valued. These learning health system specific tools can be used in conjunction with generic behaviour tools, for example COM-B[xviii] and APEASE[xix]

These prototype tools are intended to help focus attention on non-obvious potential causes of failure. They provide the focus to seek to de-risk the potential causes of failure. Crucially, they have been designed using approaches that have been shown to harness collective intelligence and build psychological safety (*"the belief that the work environment is safe for interpersonal risk taking"*[xx]) thereby building engagement and motivation.

Section 2: Making Learning Health Systems Desirable

*"There's a real passion and drive to develop something to make a difference...
to really make a difference to quite a complex system..."*

The CHC programme was launched at a time when public trust in the reuse of health and care data was at its lowest. The approach developed in CHC for public engagement was innovative and set a new benchmark that has been adopted widely. We have learned that data driven transformation of health services does not occur simply by making health data available for analytical purposes: It is essential that the people and organisations providing those services and collecting the data are integral to the analytical work. Therefore, a holistic approach is required that brings together all stakeholders including patients, public, providers, industry and academia.

	Making learning health systems desirable	
	Challenge	**Proposed approach**
4	Building and sustaining citizen trust	Innovate to expand the diameter of trust
5	Absence of end to end quality foundations	A hub focused on "doing the unsexy bit"
6	Inconsistent levels of stakeholder support	Inspire a critical mass of shared commitment

Table 5: Summary of proposed approaches to overcome challenges identified to making learning health systems desirable at scale

Table 5 provides a summary of the proposed approaches to overcome challenges identified to making learning health systems at scale desirable. In addition to the challenges identified in the summary above, Table 6 shows the generic desirability stumbling blocks identified while implementing learning health systems at scale.

Current waste	Stumbling blocks	Future value
Desirability: transforming soft infrastructure		
• De-motivation • Disengaged citizens	• How do we inspire patient engagement to achieve the social contract? • How do we forge shared commitment? • How do we build capacity and capability?	• A cultural transformation that inspires a critical mass of health and social care stakeholders to collaborate across boundaries • Citizens embrace liberating data to save lives from an informed perspective

Table 6: Generic desirability stumbling blocks identified while implementing learning health systems at scale

The first four elements of the **DataSavesLives Lean Stack** are most relevant to making learning health systems feasible pathway by pathway. These enable stakeholders to: 1) work together to diagnose before treating; 2) identify critical success factors and quick wins; 3) reveal ground truths perceived across all stakeholders; and 4) to co-develop the vision that inspires a critical mass of shared commitment.

Challenge #4: Building and Sustaining Citizen Trust

Proposed approach: Innovate to Expand the Diameter of Trust

Citizen engagement and approval for working with health data has often been neglected in the health data space, and yet without the conscious and consistent building of citizen trust, the potential for health data to improve lives will not be realised. CHC worked throughout the project to build connections with citizens, gain informed consent on the use of data, provide full transparency on the use of data and prioritise improvements in the health and welfare of NHS patients in line with the principles.

It is typical for people to be cautious when change is imposed on them, when they do not feel in control, when the benefits are hard to quantify while the perceived risks are salient. For these and other behavioural reasons, prior initiatives which adopted a 'top-down' approach to obtaining the social contract encountered resistance. They were frequently unable to achieve the critical mass of public trust necessary for success. As described above, we tend to be loss averse, to prefer the familiar to the unfamiliar and to prefer to maintain the status quo. The reporting of data breaches, irrespective of whether in the commercial or public sector, create and reinforce the belief that there is risk associated with sharing one's data with a large data set. We trust people we know and those who we perceive to have something in common with us.

To transform beliefs, the CHC programme conceived a new approach centred on building civic data clusters with clear local benefits. The goal was to expand the diameter of trust to achieve a critical mass of support and engagement. As well as creating public trust, this approach was designed to create professional trust so that teams felt they were operating in the right environment for data to be used safely to save lives.

A key piece of learning has been that working with a population size of 3-5m and then scaling up supra-regionally has, undoubtedly, been a success factor by demonstrating reciprocity to our citizens on how their data improves care within their communities. Across over 3,000 conversations with citizens on principles that should apply to the use of their data, five clear expectations emerged around:

- Agency
- Reciprocity
- Fairness and lack of exploitation
- Privacy
- Transparency and trust

In hindsight, the effective principles were:
- Involve citizens in decision making and conversations to ensure transparency
- Acknowledge that this is a complex problem, so the CHC teams could not forecast which approaches would be effective, but instead they would need to experiment and learn their way to success

- Appreciate that there is diversity in the contexts in which citizens operate, in their existing beliefs and hence in their perception of the merits of providing the social licence for their data to be shared

- Operate under a principle of no surprises, i.e. engage in dialogue with citizens to ensure they remain informed about how data is used so that they are never surprised because surprise is likely to trigger an understandably strong, adverse emotional response.

Many approaches were taken, with the principal ones being 1) to adopt and develop the #DataSavesLives brand which was developed by the communications team at the Centre for Health Informatics during their work for the Farr Institute, and 2) run citizen juries with the aims of understanding the drivers of citizen beliefs and behaviours. Figure 5 and Figure 6 show the range of initiatives taken to create a diameter of trust analysed by:

- Inputs: the cost and time to develop the initiatives

- Outputs: the impact the CHC team perceive was delivered by the initiative and the longevity of the initiative's benefits
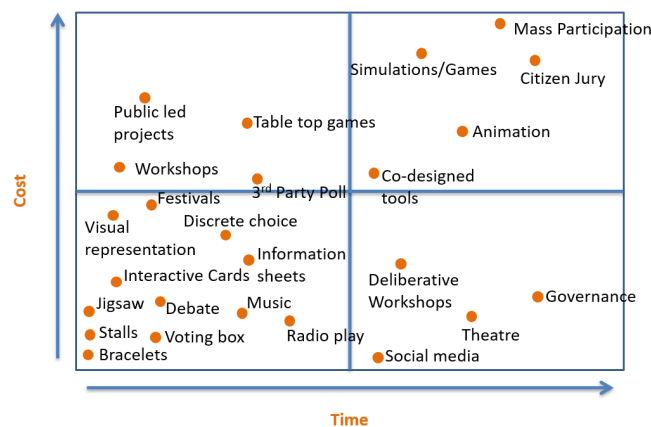
Figure 5: Comparison of the inputs (the cost of and time required by) of a range of initiatives taken by the Connected Health Cities programme to expand the diameter of trust
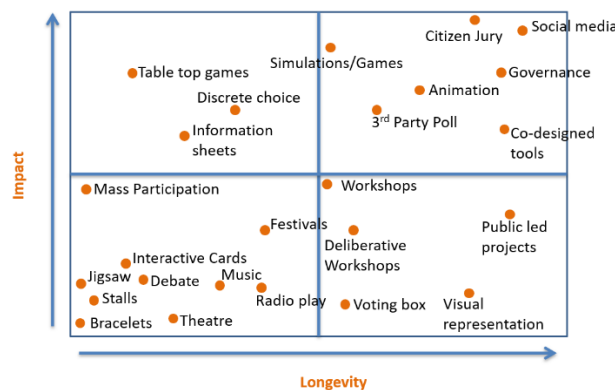
Figure 6: Comparison of outputs (the impact and longevity of benefits) of a range of initiatives taken by the Connected Health Cities programme to expand the diameter of trust

There is no one-size-fits-all approach to achieving the social contract by inspiring and sustaining citizen trust. Each context is complex and unique so a solution whereby a multi-disciplinary team follows principles similar to the ones outlined above and iteratively develops a portfolio of citizen engagement initiatives is likely to be more successful than one that follows a rules-based approach, faithfully replicating exactly what worked in a different context.

In this regard, the library of resources and global community of practice (see proposed approaches 8 and 9) will increase the range of options, provocations and lessons learned for all who are seeking to build and sustain citizen trust. Extending the use of #DataSavesLives and championing examples where care was enhanced because citizens embraced sharing data will contribute to a snowball effect.

Challenge #5: Absence of End to End Quality Foundations

Proposed Approach: A Hub Focused on "Doing the Unsexy Bit"

"CHC has been able to bring data together and sort out all those horrendous data sharing agreements…just being able to do that is such an amazing feat…I know a lot of other projects that have not been able to progress just because of that"

Learning health systems are created by front-line innovators. The learning health systems of individual pathways translate policy into reality, moving the health system from one characterised by inequality, waste and predictable failure to better care, cheaper care and better outcomes. One could picture each pathway project travelling along a road between these two states. To achieve the policy aims, the journey must be made successfully, i.e. for a learning health system to function it must be unbroken from end to end.

Unbroken, quality foundations for the whole journey are essential because a gap in the road runs the risk of foregoing the benefits of the pathway project and wasting the investment. It would be easy for foundations to merely be perceived in terms of hard infrastructure. When this is the case, teams focus on the feasibility and sustainability of that hard infrastructure.

This perspective may overlook that all stakeholders require the confidence to invest their discretionary effort without fear that something vital to the project is missing. If there are quality foundations for most, but not all, of the journey then the project will stall, draining momentum, sapping morale and triggering collaborators to return to their habitual behaviour of focusing on the "day job". Furthermore, delay or failure implants a belief that cross-cutting projects do not work, adversely impacting the desirability of participation in the many future projects that will be necessary to deliver evidence-based policy using learning health systems.

Neither the front-line innovators, nor those to whom they turn for advice, can perceive the totality of each part of the health and social care system that will form eventually come together to form the learning health system. As several pathway projects reported during CHC, it is only when one starts to build out the LHS that one discovers that vital foundational aspects of hard infrastructure are missing. For example, the stroke app for paramedics filled a need to detail specific and bespoke treatment pathway information and acts as a replacement for a telephone support service that can could not respond in a timely way.

CHC stakeholders shared the following observations as to why quality foundations are frequently lacking:

- It is nobody's job to improve the foundations
- People are understandably focused on just getting through the day. They may be focusing all their attention on the urgent, rather than the strategically important

- The relevant departmental budget is already exhausted meeting day to day service demands so there is no scope for one-off capital expenditure
- The value to a single department of improving infrastructure is lower than the value to the whole system of a fully functioning learning health system. From the perspective of that department, the investment cannot be justified, yet across the whole system the return on investment is compelling.

This was best summarised by one CHC stakeholder as "*nobody wants to do the unsexy bit".*

A key lesson learned during the CHC project was the importance of stepping in to ensure that there are the quality foundations in place necessary for the front-line innovator to lead the creation of a learning health system unbroken from end to end. The unusual and flexible funding available to the CHC project was vital as it enabled such mundane matters as phone lines to be installed (other examples) that were the difference between success and failure and where for the want of a few thousand pounds, several hundred thousand pounds of investment would otherwise have been wasted.

Front-line innovators require quality foundations, much of which take material time to build. Quality foundations reduce time to impact, reduce waste and increase return on investment. Crucially, they sustain the commitment of the stakeholders. The experience of the CHC programme is that a central hub dedicated to "doing the unsexy bit" sustains momentum and belief, contributing to safeguarding a return on the investment in a pathway project.

Challenge #6: Inconsistent Levels of Stakeholder Support

Proposed approach: Inspire a Critical Mass of Shared Commitment

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"One of our main initial challenges was to unite disparate groups around a common vision…and that took a while I have to say…about a year, but now we're in a good place."

"Acceptance by professional staff may be the single most important determinant of whether a new technology-supported service succeeds or fails at a local level."[xxi]

As discussed, digital LHSs are highly complex projects that cut across traditional organisational boundaries and which require the co-ordination of many diverse stakeholders. Typically, it is impossible for front-line innovators to anticipate at the conception of a project all the people and roles who will be affected. These may well be discovered along the way. Examples of roles that may be touched by a LHS project:

- Care service analysts
- "C-suite" executives
- Communications
- Data guardians
- Data managers
- Data scientists
- Domain experts
- General Practitioners (GP)
- Guideline developers
- Health economists

- Health IT vendors
- Health service
- Hospital staff
- Industry partners
- Informaticians
- Involved citizens
- Nurses
- Patients and families
- Physicians
- Policy makers

- Problem owners
- Public health analysts
- Researchers
- Risk managers
- Social care staff
- Social scientists
- Social workers
- Statisticians
- SME partners
- Software developers

To the front-line innovator or health system leader, with rich domain knowledge and having immersed themselves in the project, the value of the change may well be obvious. It is human nature to assume that others perceive what we do. However, we perceive through the lens of our existing beliefs, values and loyalties so that in a complex situation no two people see the same thing the same way. This 'curse of knowledge effect' can lead front-line innovators to assume that all stakeholders will view the personal effort and interpersonal risk required to introduce a learning health system as a price worth paying given the force of logic regarding its merits that they present.

This assumption does not resonate with models of behaviour such as the COM-B model. The COM-B model recognises that behaviour is part of an interacting system of involving 'capability', 'opportunity' and 'motivation'. It is vital to find an approach that unlocks the motivation of stakeholders before investing in developing their capability and opportunity to act.

The CHC team has come to refer to this as helping people move from 'won't' to 'will' prior to helping them to move from 'can't' to 'can'. Each is essential, but unlocking willingness has to come first. As innovative cross-cutting projects, helping to develop a learning health system is not part of the formal job description for the majority of stakeholders. The stakeholders are being asked to provide their discretionary effort against competition from the demands that their 'day job' places on them. *"A [person's] emotional commitment is the ultimate trigger for their discretionary effort."[xxii]*

"There is no evidence in the large-scale change literature that any healthcare system has ever delivered sustained transformational change through compliance, rather than commitment."[xxiii]

The NHS England report Leading Large-Scale Change distinguishes between compliance, *"if I don't deliver this, I fail to meet my performance objectives"*, and commitment, *"if I don't deliver this, I let down the group and our shared purpose."* Front-line innovators are typically not the managers of the majority of the stakeholders whose effort is essential to the development of the learning health system. They do not have the authority to give orders and make all the decisions. However, they are leaders with the capacity to influence and hence the ability to affect ideas and actions.

To achieve the vision that typically initially exists in the mind of a front-line innovator requires the simultaneous commitment and collaboration of a critical mass of health and social care stakeholders across organisational boundaries. People generally adopt a behaviour when they discover the reason for themselves. One approach would be for the front-line innovator to describe their objective, the problem they wish to solve and to say to each stakeholder, "to achieve my goal, what I need you to do is ...". This does not correlate with success, especially where stakeholders are contributing their discretionary effort.

As Theodore Levitt wrote in his seminal paper on marketing, *"People don't want a quarter inch drill, they want a quarter inch hole."[xxiv]* Stakeholders do not want a learning health system; they seek the impact of a learning health system that helps them to achieve their personal goals.

An alternative approach is therefore for the front-line innovator to be curious, to seek to understand each stakeholder's current situation, the objectives they have and what is holding them back from achieving those objectives, as perceived by the stakeholder. They may then ask themselves what common enemy the front-line

innovator has with the stakeholder. This enables the articulation of the front-line innovator's vision in such a way that a stakeholder immediately sees how supporting the front-line innovator is a valuable step towards achieving their own goals.

This is a powerful approach, but one that does not always scale, because the messaging may differ for each stakeholder. An even more effective approach is to develop and articulate a vision that is compelling for all stakeholders. This is best co-developed by all stakeholders since learning health systems are complex, no single person understands the whole domain and no two people see the same complex situation the same way.

In hindsight, providing the soft infrastructure to make it easier for front-line innovators to unlock and sustain this commitment is crucial to the success. The **DataSavesLives Shared Vision Framework** is an attempt to provide a simple tool and provocation questions that a front-line innovator may use to co-develop a shared vision. Developing this compelling shared vision, around which a front-line innovator builds commitment, is an essential milestone for the project. From the experience of the CHC programme, a project leader should not progress further until this vision has been co-developed.

A compelling shared vision is required to unlock shared commitment. For stakeholders to feel compelled to act, there must be an acute sense of urgency so that stakeholders are motivated to devote their discretionary effort to deliberately setting aside their habitual actions, to not focus their attention on the urgent matters that help them feel a sense of progress through the day, but instead find the motivation to tackle a novel challenge with potentially new teammates. For this reason, building and sustaining a reason to act is designed into all the components of the **DataSavesLives Lean Stack**. Wherever possible, the leader should translate the shared vision and reason to act into simple mantras which are repeated at every opportunity.

The journey to the successful creation and embracing of a learning health system will be arduous and uncertain for all stakeholders. To sustain emotional commitment, front-line innovators should champion and communicate all indications of progress and achievement to build trust that the goals of the stakeholders will be realised.

> *"There is almost a sense of almost a commanding control structure where people are told what to do and generally, with professionals in particular, I find they don't like to be told what to do, there's this almost herding cat problem, so I think if something has been co-created, and in addition, where we don't have the answers and they don't have the answers…it creates a space for us both to test out answers, and that seems to me a better way of getting research done which will be used on the ground in a concrete way."*

Achieving and sustaining a critical mass of support from stakeholders requires relationship building. This may be seen as a distraction for those who have not previously led a cross-cutting project. It may also not play to the strengths of all front-line innovators. However, within a healthcare system where there is competition for scarce resources, building and sustaining trust is crucial to effective collaboration. Specific issues that came to the surface

during the CHC programme including distrust of those who sought to extract resources rather and not give back to the system. The evidence from projects such as predictive modelling for unplanned care in the North East and Cumbria[xxv] is that while this takes time, once there is a high level of trust among all the professionals on the project, the team is able to progress rapidly and effectively, providing a compelling return on the time invested in relationship building.

The role of the front-line innovator is one of *"listen, learn, then lead"*[xxvi]. The front-line innovator must harness the power granted by the stakeholders who are trusting the leader to deliver the outcomes they seek. A central hub can help with the soft infrastructure that enables these passionate individuals to inspire the shared commitment of a critical mass of stakeholders throughout the project as they work together for a time-bound effort to fulfil a purpose bigger than any one of them.

Section 3: Scaling Evidence-based Policy by Making it Easier to Safely Use Data to Save Lives

"Me and [name] presented, and it was all about innovation and how long it takes to roll it out, and it's something like 17 years from starting a project to rollout…compared to 18 months on this CHC pathway."

The CHC programme sought to deploy learning health systems at scale. Additional challenges became apparent as pathway programmes were encouraged to expand beyond their initial localities. Generic challenges also became apparent to the co-ordinating CHC Hub which were not apparent to the individual pathway projects. This final section of the paper sets out approaches which have the potential to mitigate some of the effects of these challenges.

	Scaling evidence-based policy by making it easier to safely use data to save lives	
	Challenge	**Proposed approach**
7	Lack of replication, scaling and spread	Make LHS scaling tractable by using lean tools
8	Avoiding re-inventing the wheel	Library of blueprints, resources & know-how
9	Accelerating learning and improvement	Found a global community of practice

Table 7: Summary of proposed approaches to overcome challenges to making it easier to scale learning health systems

As one looks beyond the initial deployment of a learning health system to one that is scaled up, one encounters some variations on the stumbling blocks set out in Table 7 above, as well as a set of generic scaling stumbling blocks identified while implementing learning health systems at scale Table 8.

Current waste	Stumbling blocks	Future value
Strategy and resource allocation: making planning tractable		
• Wasted investment • Predictable causes of failure • Missed opportunities	• How do we accelerate introducing evidence-based policy?	• Increased return on investment • Reduce time to impact • Build belief and momentum
Feasibility: transforming hard infrastructure		
• Increased costs from re-inventing the wheel • Delay	• What do we need <u>here</u>? • What do we have <u>here</u>? • How should we proceed <u>here</u>?	• Faster, cheaper deployment • Systematic scaling of pilot projects
Desirability: transforming soft infrastructure		
• Lost learning • Spread challenge: non-adoption and lack of scaling	• How do we extract and share learning? • How do we work with international partners? • How do we work together to "lift and shift?"	• Habitual extraction and sharing of lessons learned • New global relationships drive innovation • Exemplars of successful scaling inspire replication

Table 8: Generic scaling stumbling blocks identified while implementing learning health systems at scale

Thus, we can use the whole DataSavesLives Lean Stack of tools to scale learning health systems (Figure 7)

Diagnostic canvas	Provocations	Scorecard	Shared vision framework	Innovation matrix	Treatment canvas
To work together to diagnose before treating	To identify critical success factors and quick wins	To reveal ground truths perceived across all stakeholders	To co-develop the vision that inspires a critical mass of shared commitment	To avoid reinventing the wheel and harness library of resources	To work together to generate the plan to implement via PDSA cycles

Figure 7: The whole DataSavesLives Lean Stack of tools is relevant to scaling learning health systems

Challenge #7: Lack of Replication, Scaling and Spread

Proposed Approach: Make LHS Scaling Tractable by Using Tools

During the latter stages of the CHC programme as pipeline projects have developed, the most common request we have heard from leaders of other health systems is "what can we 'lift and shift'?". To maximize the probability of success, one must acknowledge that *"when an individual, team or organisation does take up a new innovation it may not work as well as it did first time round – something we see particularly with complex health care interventions that seek to make improvements in clinical processes or pathways."*[xxvii] Furthermore, *"The more complex an innovation or the setting in which it is introduced, the less likely it is to be successfully adopted, scaled up, spread, and sustained"*[xxviii] Without successful replication:

- There is an opportunity cost from failing to realise the potential of successful learning health systems
- There is waste from investing in projects that fail to scale successful initiatives
- There can be a loss of motivation as stakeholders see promising projects fail and develop a belief that innovation is not possible where they work

The Health Foundation report, The Spread Challenge[xxix], set out to investigate the factors affecting the successful uptake of innovations in healthcare and the 'replicability problem'. The report highlights that complex interventions are:

- Social
- Context-embedded
- Dynamic

The challenges listed in this report are rooted in these three elements. Therefore, if the success of scaling a learning health system depends on understanding context in which it is deployed, then it is only by making the diagnosis of that context easier and appealing that we may start to tackle the spread challenge.

We suggest that a combination of lessons learned during the CHC programme, codified into the practical thinking tools described in this report may help enable spread by making the scaling of learning health system tractable, i.e. capable of having logic applied to each element of the situation.

Challenge #8: Avoiding Re-inventing the Wheel

Proposed approach: Library of Blueprints, Resources and Know-how

During the evaluation of the CHC programme, it became apparent that front-line innovators and their teams typically face many generic problems that have been solved elsewhere. Being front-line innovators, they are focused on delivering great care in one part of a health system and do not habitually search across the whole health system and beyond for a solution. In hindsight, the teams working on pathway projects would repeatedly invest their scarce energy and resources to solving problems which had already been addressed elsewhere within the health system or even outside it. This understandable approach led to waste, suboptimal solutions and lack of scaling the learning and improvement.

We propose three that may help mitigate this waste:

a) A library of learning health system blueprints and resources

b) The **DataSavesLives Innovation Matrix** is a first attempt at a practical thinking tool to avoid re-inventing wheel

c) Deliberately harnessing the know-how of multi-disciplinary teams with experience scaling learning health systems

Library of blueprints and resources

To assist other teams developing learning health systems, the CHC team has shared a library of blueprints and resources at https://connectedhealthcities.github.io

Know-how

"It is possible, but not accurate, to view the achievement of an LHS at any level of scale, as an exercise in construction from a blueprint. This conceptualization belongs to an earlier era. It fails to recognize that the LHS is a new and fundamentally different type of system"[xxx]

Blueprints for learning health system are important, but not sufficient. Know-how is also essential. We suggest that tapping into the perspectives of those who have built learning health systems at scale may be a valuable potential solution for many situations where the **DataSavesLives Innovation Matrix** is applied. A multi-disciplinary team with such experience can create value by asking questions, coaching, synthesizing and problem solving, as well as offering broad perspectives that may extend the team's portfolio of potential solutions.

Challenge #9: Accelerating learning and improvement

Proposed approach: Found a Global Community of Practice

There were many components required by the CHC programme that did not exist at its outset and which had to be invented along the way. The CHC programme was also fortunate to have been able to invest in a year-long evaluation and to translate the lessons learned into the library of blueprints, resources and know-how. The range of organisations who have invited CHC for further meetings to explore collaboration include: the Singapore Ministry of Health; New South Wales Ministry of Health; South Australia Health and Medical Research Institute; Beijing University (PKU) National Institute for Health Data Science; China National Health Development Research Centre; Institute for Global Health Policy Research, and World Economic Forum (WEF) Centre for the Fourth Industrial Revolution, Japan.

It has become apparent that a new type of organisation is required that does not fit into the existing structures. Only a trusted, independent body with a noble mission, independent of any vested interest is able to avoid the turf wars and organisational antibodies that are natural when seeking to develop innovative cross-cutting projects. As a high-leverage legacy of the CHC programme, the Northern Health Science Alliance wishes to share these lessons learned to make it easier for learning health systems to be embraced at scale by inviting likeminded teams and individuals.

Going further, an intra-disciplinary global community of practice would combine the lessons learned from the Connected Health Cities programme with other initiatives around the world. It would act as a platform to build trust by role modelling the benefits of sharing resources and know-how in the spirit of an honest broker and good neighbour. To expand the diameter of trust through a sense of reciprocity, wherever possible, resources will be released as open source projects or under creative commons licenses. The mission of the community of practice will be to make it easier for front-line innovators and health service leaders to safely transform:

1. Strategy and resource allocation
2. Feasibility: hard infrastructure
3. Desirability: soft infrastructure
4. Sustainability: economics

It will champion diverse exemplars from around the world that build belief that learning health systems may be embraced at scale such that data can save lives.

Conclusion and next steps

This report and the **DataSavesLives Lean Stack** will form part of the community of practice that is being developed to promote sharing and access to a suite of online tools and software as a result of this successful international relations programme.

The CHC programme has revealed the potential of a systematic approach to scaling innovation and improvement to:

- ✓ Enable front-line innovators to improve care, reduce waste and unlock learning;
- ✓ Shape learning health systems to deliver policy objectives and influence policy;
- ✓ Codify the knowledge and apply the know how to scale what works in different contexts;
- ✓ Curate an online library and community for open sharing of applied resources and best practice;
- ✓ Focus on collaborative approaches with existing projects as well as innovative new initiatives to achieve short-term gains with long-term impact in UK

Just as the Connected Health Cities programme sought to expand the diameter of trust across the north of England, so the legacy community of practice will seek to expand the diameter of trust around the globe.

Join the #DataSavesLives movement.

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Appendix: the DataSavesLives Lean Stack

Using a combination of system thinking, behavioural psychology and user-centred design (human centred design (IDEO)) principles, along with concepts that have helped industry scale innovation, such as the Business Model Canvas, CHC has developed tools that are a first attempt to enable other health systems to be able to effectively plan for implementation of learning health systems.

Diagnostic canvas	Provocations	Scorecard	Shared vision framework	Innovation matrix
To work together to diagnose before treating	*To identify critical success factors and quick wins*	*To reveal ground truths perceived across all stakeholders*	*To co-develop the vision that inspires a critical mass of shared commitment*	*To avoid reinventing the wheel and harness library of resources*

Figure 8: DataSavesLives Lean Stack of tools

The **DataSavesLives Lean Stack** is merely a first attempt to make planning, deploying and scaling learning health systems easier by enabling a multi-disciplinary team to deliberately diagnose before treating and systematically reveal ground truths.

These prototype tools are intended to help focus attention on non-obvious potential causes of failure. They provide the focus to seek to de-risk the potential causes of failure.

Crucially, they have been designed using approaches that have been shown to harness collective intelligence and build psychological safety (*"the belief that the work environment is safe for interpersonal risk taking"*[xxxi]) thereby building engagement and motivation.

These learning health system specific tools can be used in conjunction with generic behaviour tools, for example COM-B[xxxii] and APEASE[xxxiii]

Facilitation by a multi-disciplinary team is likely to add value to the use of these tools.

The DataSavesLives Diagnostic Canvas

At the core of these stack lies the prototype **DataSavesLives Canvas** which has been designed to:
- Make planning learning health systems easier and tractable (capable of having logic applied)
- Help teams assemble all components necessary for success
- Achieve focus on non-obvious potential causes of failure and de-risk them
- Enable collaboration across organisational boundaries
- Act as the springboard for scaling future NHS improvement and by international partners such as Beijing University (PKU)
- Act as a lingua franca to support the ad hoc conversations that can be the spark to inspire front-line innovators to launch the successful pathway projects that translate policy into better care, cheaper care and better outcomes.
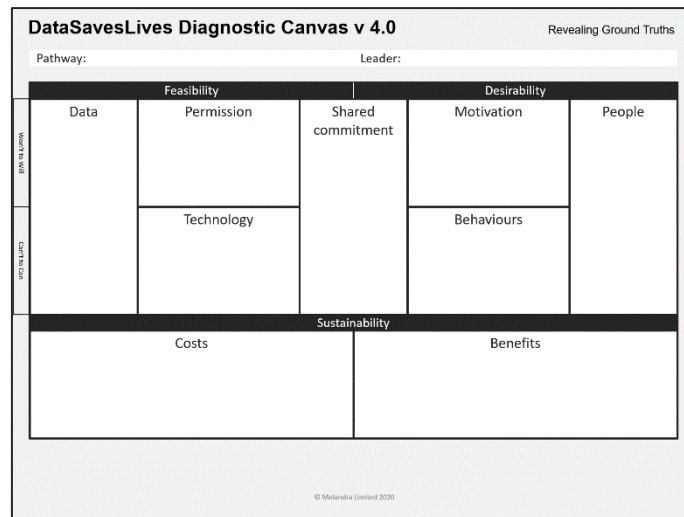
The **DataSavesLives Diagnostic Canvas** encourages a team to always consider the *technical safety*, *behavioural safety* and *economic safety* of a learning health system
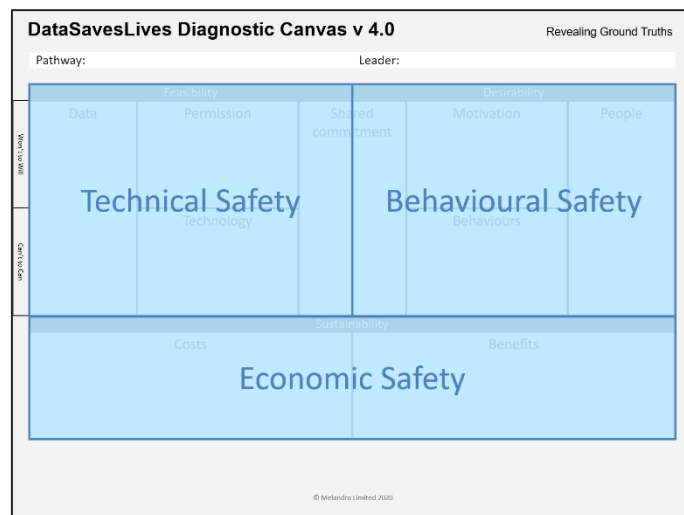
Provocation: What Must be True for Data to Save Lives?

During the CHC programme it became apparent that no team had experience in all domains required to build a successful learning health system. To help teams include all essential areas in their planning, key lessons learned during the CHC programme have been compiled into a set of provocation questions under the heading **What Must be True for Data to Save Lives?**

Figure: What Must Be True for Data to Save Lives?
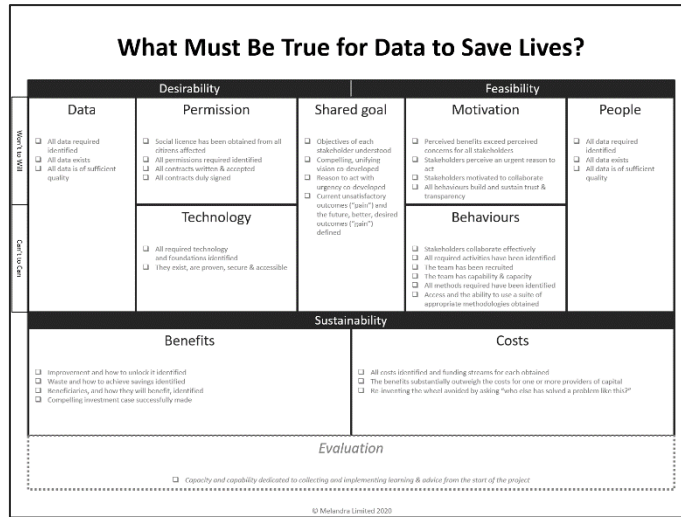
Provocation: Where Are the Quick Wins for Data to Save Lives?

Similarly, to health system leaders focus effort, key lessons learned during the CHC programme have been compiled into a set of provocation questions under the heading **Where are the Quick Wins for Data to Save Lives?**

Figure: Where Are the Quick Wins for Data to Save Lives?
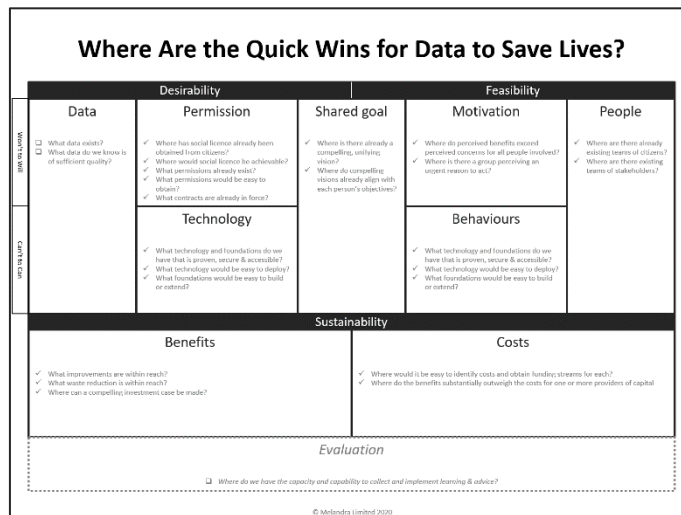
The DataSavesLives Diagnostic Scorecard

The **DataSavesLives Diagnostic Scorecard** contains a set of questions, inspired by the experience of the CHC pathway projects and other complex situations, designed to ensure all critical success factors are considered.

The scorecard is intended to:

1. Provide an absolute measure of the preparedness of a system for a prospective project;
2. Capture diverse perspectives;
3. Reveal whether differences in perception relate to different groups of stakeholders.

To achieve this, different stakeholders on a project are encouraged to answer it independently. They may focus on a single section of the scorecard or complete it all.

It not only identifies differences in perception, it identifies whether those differences correlate with different groups of stakeholders

Going further, one may deliberately reveal differences in perception. Here, one could distribute the **DataSavesLives Diagnostic Scorecard** to reveal differences in perception between groups of stakeholders. One may reveal differences in perception between those working on the project and those whose external opinions are valued.

The scorecard may be delivered in all or in part:

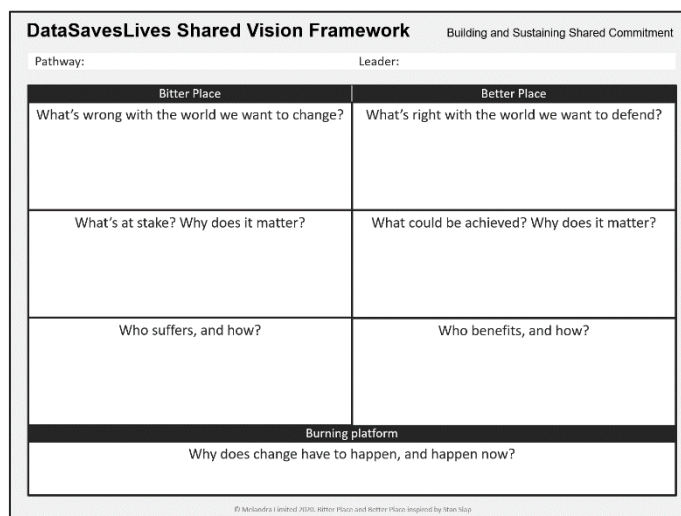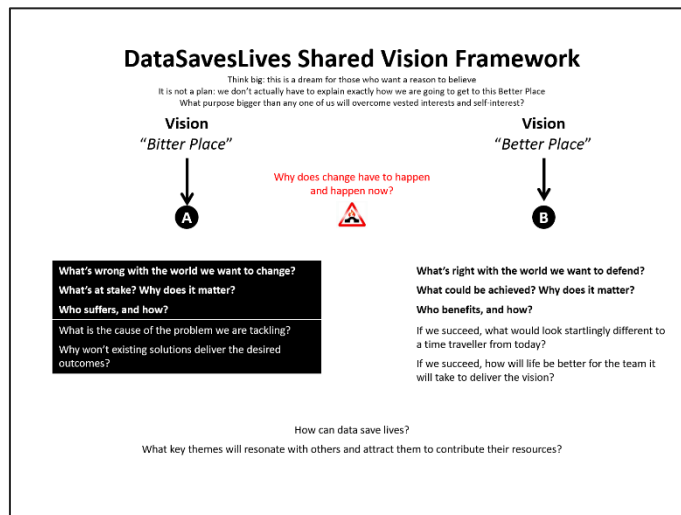- As part of a workshop
- Using an online survey platform

Preserving anonymity of results sustains a spirit of "what is right, not who is right".

Provocation cards to be used face to face or remotely could be developed using the dimensions of the scorecard

The DataSavesLives Shared Vision Framework

The DataSavesLives Shared Vision Framework has been designed to make it easier to co-develop the shared vision that is critical to building and sustaining the motivation that enables all stakeholders' commitment

DataSavesLives Shared Vision Framework

Think big: this is a dream for those who want a reason to believe
It is not a plan: we don't actually have to explain exactly how we are going to get to this Better Place
What purpose bigger than any one of us will overcome vested interests and self-interest?

Vision
"Bitter Place"

Vision
"Better Place"

Why does change have to happen and happen now?

A

B

What's wrong with the world we want to change?
What's at stake? Why does it matter?
Who suffers, and how?
What is the cause of the problem we are tackling?
Why won't existing solutions deliver the desired outcomes?

What's right with the world we want to defend?
What could be achieved? Why does it matter?
Who benefits, and how?
If we succeed, what would look startlingly different to a time traveller from today?
If we succeed, how will life be better for the team it will take to deliver the vision?

How can data save lives?
What key themes will resonate with others and attract them to contribute their resources?

DataSavesLives Shared Vision Framework

Building and Sustaining Shared Commitment

Pathway: Leader:

Bitter Place	Better Place
What's wrong with the world we want to change?	What's right with the world we want to defend?
What's at stake? Why does it matter?	What could be achieved? Why does it matter?
Who suffers, and how?	Who benefits, and how?

Burning platform

Why does change have to happen, and happen now?

© Melandra Limited 2020. Bitter Place and Better Place inspired by Stan Slap

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DataSavesLives Shared Vision Drill-down — Building and Sustaining Shared Commitment

The DataSavesLives Shared Innovation Matrix

DataSavesLives Innovation Matrix — Who Else Has Solved A Problem Like This?

It is natural that these talented, motivated teams that habitually rise to whatever clinical challenge presents itself, exhibit the same behaviour of looking to solve the complex problems of creating a learning health system.

In Strategic Intuition[xxxiv], William Duggan describes how General Electric in the 1990s faced a similar situation. Duggan explains that CEO Jack Welch wanted to tackle exactly this issue by developing a way to look across the whole company to find and combine what works. He championed the resulting 'what-works matrix' which GE's training center at Crotonville, New York, under chief learning officer Steve Kerr, embedded. Welch said, "The operative assumption is that someone, somewhere, has a better idea; and the operative compulsion is to find out who has that better idea, learn it, and put it into action—fast."[xxxv]

In the what-works matrix, a problem is firstly defined, then broken down into its component elements as rows in a table. The team asks itself, "has anyone ever made any progress solving pieces of this puzzle?" If so, the source of the potential solution is noted at the top of the column and the potentially effective approach they took is recorded in the cell that is the intersection of that source with the relevant element of the problem. In this way, a team can build up inspiration for solutions piece by piece, working not until the matrix is full but merely until they have candidate ideas sufficiently promising to explore.

The team can therefore develop a new habit of asking itself "who else has solved a problem like this?" whenever a novel, complex challenge is encountered.

The authors of The Spread Challenge observe that, *"insufficient appreciation of complexity can lead to mistakes and misconceptions in attempts to codify and spread interventions. These can include failing to consider the social as well*

as technical components of the intervention."[xxxvi] The COM-B model which is a helpful tool for overcoming this human nature whereby teams to focus on the technical elements of any complex challenge in front of them. It recognises that behaviour is part of an interacting system of involving 'capability', 'opportunity' and 'motivation'.

The **DataSavesLives Innovation Matrix** simply combines Duggan's description of the GE what-works matrix with the COM-B model so that teams are prompted to consider 'capability', 'opportunity' and 'motivation' when identifying elements of a problem. It also divides sources of potential solutions between 'internal' sources native to the group and 'external' sources perceived to be outside the group.

Early prototyping of this tool has been encouraging with teams developing a learning health system across multiple sites in the UK where each site features a context with both generic elements common to all sites and elements specific to the site. The innovation leaders of the teams report that it feels easier to diagnose these generic and specific elements of the problem at each site, ensure that the 'capability', 'opportunity' and 'motivational' elements of the context are considered and hence accelerate the translation of the appropriate elements of what works at other sites to system improvement.

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