Digital Health Passport

London Pilot Evaluation

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TinyMedicalApps.

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1.0 Executive Summary

Thanks to the investment from Healthy London Partnership, the Digital Health Passport has overcome all of the barriers needed to be ready to scale. Projects are already underway in Manchester and Sheffield capitalising on the work done to date. This report gives some background to the work before the pilot and focuses on the initial evaluation work. Evaluation will be continuous as we gain more data and increase user numbers.

- The Digital Health Passport has been designed for teenagers to take control of their health and has an initial focus on asthma self-management with Asthma UK action plans.
- It enables remote tracking of symptoms and accessing NHS support.
- Addresses key recommendations in: NICE Asthma Quality Standard, BTS/SIGN clinical guideline 153, GINA 2019 and The National Review of Asthma Deaths (NRAD 2014).
- DHP meets all high level NHS assurances and has been accepted into the NHS Apps Library and is assured to use NHS login.
- DHP has been assessed to contain 14 Validated Behaviour Change Techniques
- From the NICE Digital Evidence Standards Framework the DHP demonstrates evidence of effectiveness at Tier 2 and partial evidence for Tier 3a.
- TMA have evaluated the DHP Pilot using the NASSS Framework to inform both future adoption, use and commissioning.
- A total of 20 of an initial target of 36 people have so far been on-boarded to the live version of the DHP.
- A combination of low number of asthma reviews scheduled and high DNA in clinics were major blockers in signing patients up.
- Seven interviews were carried out with users of the DHP and gave overwhelmingly positive feedback and valuable information has

been obtained to influence the design and adoption of the next version.

- Twelve site visits to observe and evaluate use of the portal and seven follow up interviews with clinicians were conducted
- Key technical requirements for scalability within London have been identified with an estimated cost of £25k to integrate with Discovery (One London).
- We advise the STPs to build upon the pilot investment from HLP including setting up of a Project Board, investment in NHS local teams to support workflow changes, integration with Discovery/ One London and support of a new custodian such as Care City.

2.0 Background

The Digital Health Passport has been designed for young people to take control of their health – creating asthma action plans, tracking symptoms and accessing NHS support.

The project has been led and commissioned by the NHS Healthy London Partnership, Children & Young People's team as part of their work to improve asthma standards in London. In the past few years young people in the UK have had worse outcomes from asthma than in most other countries in Europe, and there have been a number of preventable asthma deaths.

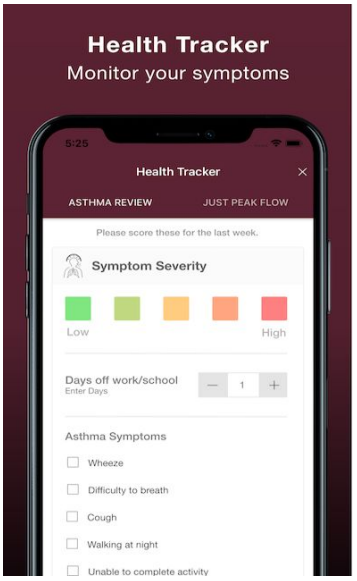
Young people with a personalised asthma action plan are four times less likely to go to A&E - so a key feature of the app is the action plan from Asthma UK which gives instructions and advice of what to do if your asthma is getting worse.

The Digital Health Passport has been co-produced with young people, school nurses, GPs and asthma specialists in east London and is now available in the NHS Apps Library by invite only as it is further refined with the first users. It is being piloted and tested at the Royal London and Barts hospitals and at Chrisp Street GP practice in Tower Hamlets.

This innovative project has been recognised by NHS England and is one of only a handful of 'Personal Health Record' Apps to be evaluated around the country. It is now being rolled out in Greater Manchester and South Yorkshire with additional features planned to support young people with allergies, epilepsy and other long-term conditions.The main features of the Digital Health Passport are

- Asthma UK action plan
- Emergency plan
- Track symptoms on a visual timeline

- NHS health advice and Asthma management educational information
- Air quality levels (pollution, pollen and weather changes)



3.0 National assessment and local assurance

The Digital Health Passport requires a high level of regulatory assurance.

Significant effort has gone into delivering a safe and assured platform.

NHS Apps Library

Gaining acceptance to the NHS Apps Library has been time consuming, but is a huge assurance hurdle that has been overcome. The bedrock of the process is the Digital Assessment Questionnaire (DAQ) which requires passing assurance in seven domains from clinical need, evidence to information governance and security.

NHS Login

The developers Tiny Medical Apps were invited to be in the first wave of companies allowed to use NHS login. We have invested in attaining all of the additional assurance requirements to enable rapid integration with regional Local Health & Care Records such as One London.

Clinical Safety DCB 0129, DCB 0160:

These standards provide a set of requirements suitably structured to promote and ensure the effective application of clinical risk management by those health organisations that are responsible for the deployment, use, maintenance or decommissioning of Health IT Systems within the health and care environment.

ISO/IEC 27001

ISO/IEC 27001 Information Security Management system is designed to help organisations manage their information security processes in line with international best practice

Our certification is externally audited by BSI and our scope specifically covers the Digital Health Passport platform.

Cyber Essentials +

Cyber Essentials helps us to guard against the most common cyber threats and demonstrates our commitment to cyber security. We are Cyber Essentials + certified which means we are also externally audited.

SCAL

The Supplier Conformance Assessment List (SCAL) is a technical document which details the consumer supplier approach to information governance, clinical safety, functional testing and SMSP-PDS requirements.

As part of our compliance and conformance assessment for NHS Login we successfully completed the requirements of the SCAL.

Data Security and Protection Toolkit

The Data Security and Protection Toolkit is an online self-assessment tool that allows organisations to measure their performance against the National Data Guardian's 10 data security standards.

All organisations that have access to NHS patient data and systems must use this toolkit to provide assurance that they are practising good data security and that personal information is handled correctly.

4.0 Pilot assessment

4.1 Content evaluation and evidence base

The content of the Digital Health Passport is consistent with the best evidence for reducing asthma exacerbations and reducing unplanned hospital attendances as part of a supported case management approach.

The asthma plan and the educational content is provided by Asthma UK and the NHS

Having a personalised asthma action plan is a NICE quality standard.

Improving outcomes will come from behaviour change and patient activation. From the first pilot we are introducing behaviour change techniques that will expand, test and refine in future iterations. A Queen Mary's University study demonstrated 14 behaviour change techniques within the Health Passport app.

Evidence for asthma plans and self-management education reducing hospital attendances

The evidence in favour of supported self-management for asthma is overwhelming. Self-management including provision of a written asthma action plan and supported by regular medical review, almost halves the risk of hospitalisation, significantly reduces emergency department attendances and unscheduled consultations, and improves markers of asthma control and quality of life (Pinnock, Breathe 2015).

The British Thoracic Society/Scottish Intercollegiate Guideline Network (BTS/SIGN) asthma guideline cites 261 randomised controlled trials reported in 22 systematic reviews in support of its grade A recommendation that "all people with asthma (and/or their parents or carers) should be offered self-management education which should include a written personalised asthma action plan and be supported by regular professional review"

NICE Asthma Quality Standard (QS25) Sept 2018

NICE Quality Statement 1

"People (5 years old and over) with asthma discuss and agree a written personalised action plan."

https://www.nice.org.uk/guidance/qs25/chapter/Quality-statements

What the quality statement means for each audience:

- Service providers ensure systems are in place for people with asthma to receive a written personalised action plan.
- Healthcare professionals ensure they give people with asthma a written personalised action plan.
- Commissioners ensure they commission services that give people with asthma a written personalised action plan.
- People with asthma receive a written plan with details of how their asthma will be managed.

A written personalised action plan (such as Asthma UK's asthma action plan) should be tailored to the person with asthma, enabling them to recognise when symptoms are worse. The plan should set out actions to be taken if asthma control deteriorates and who to contact.

Source guidance:

- NICE guideline NG80, (2017) Asthma: diagnosis, monitoring and chronic asthma management, recommendations 1.10.1 and 1.10.2
- BTS/SIGN clinical guideline 153(2016) British guideline on the management of asthma, recommendation 5.2.2
- GINA 2019 Global Initiative for Asthma Ch 3, pg69
- The National Review of Asthma Deaths (NRAD 2014) recommended the use of Personalised Asthma Action Plans as have multiple Coroners' reports into avoidable deaths from asthma.

Validated Behaviour Change Techniques

The provision of an agreed self-management plan and educational materials are core features of the Digital Health Passport, however in order to maximise the potential of the tool we are including validated behaviour

change techniques and plan to test their effectiveness in a large randomized controlled trial in east London in the coming years.

An analysis by Dr Samaresh Mazumdar and Dr Liz Edwards, under supervision of Prof Chris Griffiths and Dr Anna De Simoni of Queen Mary's University London identified the 14 BCT's in use in the app and recommended further we could introduce based on analysis of 50 asthma apps used internationally. We jointly identified the Australian app 'Kiss My Asthma' as the leader in the field and worth emulating in many respects. Future versions will incorporate and evaluate further BCTs based upon the recommendations from QMUL researchers, particularly with greater ability to contribute to the care plan from patients with regard to goal setting, action planning and thus increased status within the team. Features such as medication reminders and 'gamification' have been planned for the next version.

From the BCT taxonomy we can demonstrate the use of the following techniques:

1.2 - Problem Solving - with the use of information provided in videos about avoiding triggers

1.4 - Action Planning - in the action plan/emergency

2.3 - Self Monitoring of behaviour - logging of peak flows

2.4 - Self monitoring of outcomes of behaviour - symptom logging

3.1 - Social support unspecified - 'my team' section

4.1 - Instruction on how to perform behaviour - video instructions on PEFR/spacer use

5.1 - Information about health consequences - outlined in videos

5.4 - Monitoring of emotional consequences - mood log

6.1 - Demonstration of behaviour - video instructions on PEFR/spacer use

8.1 - Behavioural Practice - videos and encouraging daily peak flows/preventer use

8.3 - Habit Formation - encouraging daily use through the timeline/ calendar homepage

9.1 - Credible Source - Asthma UK/NHS branding

11.1 - Pharmacological Support - encouraging the use of inhalers

15.3 - Focus on past success - calendar homepage showing previous good days

Full taxonomy by Michie et al

It contains 93 techniques to change behavior that are hierarchically clustered into 16 groups.

Comparator analysis

A Queen Mary's University study in 2018 analysed 50 international mobile phone apps for behaviour change techniques from which we were able to see the leading apps being used.

We jointly identified the leader to be the 'Kiss my Asthma' app from Australia with over 30 BCTs including goal setting, action planning and medication reminders. The following versions of the Health Passport will incorporate many of these features, together with other recommendations from the researchers.

4.2 NICE Digital Evidence Standards Framework Evaluation

NICE Digital Evidence Framework Intent

"The aim of the standards is to make it easier for innovators and commissioners to understand what good levels of evidence for digital healthcare technologies look like. Digital healthcare technologies must also meet the needs of the health and care system, patients, and users."

https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies

Framework Partners

The evidence standards framework is made up of:

- effectiveness standards
- economic impact standards.

Effectiveness standards

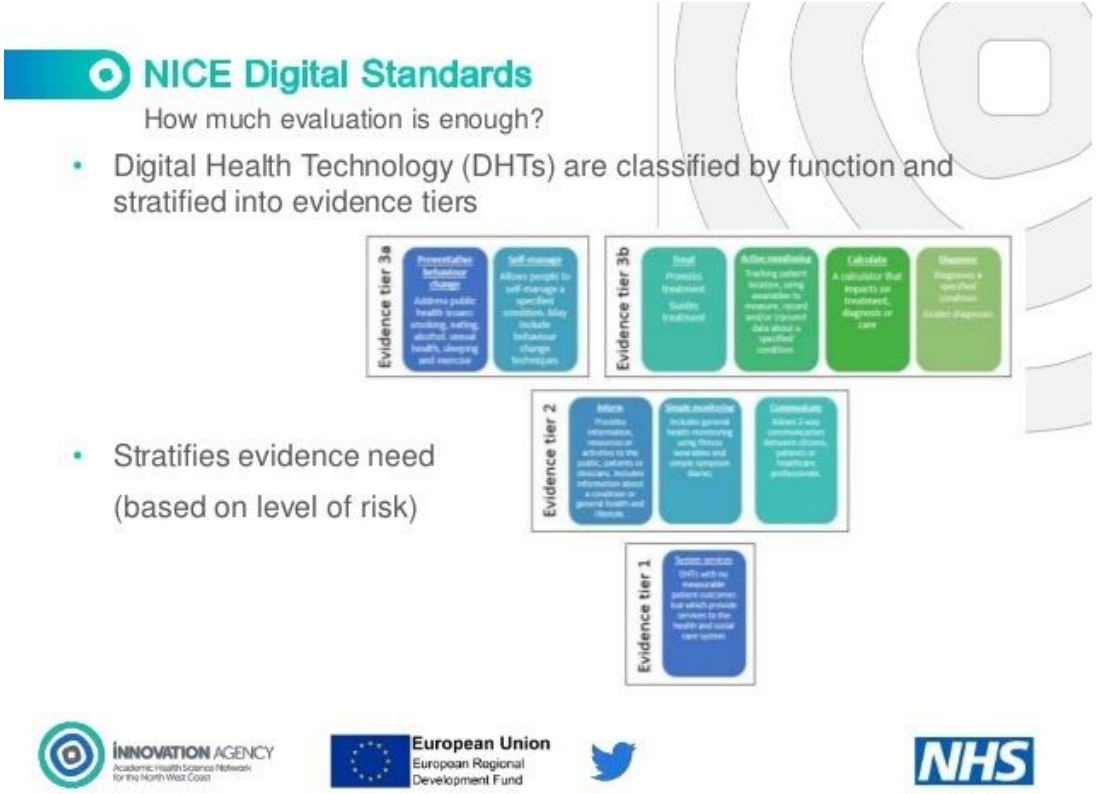


Image credit: Laura Boland - Excel in Health, Innovation Agency

The NICE DHT tiers

- Digital Health Technology (DHTs) are classified by function and stratified into evidence tiers
- Stratifies evidence needed (based on level of risk)

Tier 1

DHTs with potential system benefits but no direct user benefits

Tier 2

DHTs which help users to understand healthy living and illnesses but are unlikely to have measurable user outcomes.

- Inform
- Simple monitoring
- Communication

Tier 3a

DHTs for preventing and managing diseases. They may be used alongside treatment and will likely have measurable user benefits.

- Preventative behaviour change
- Self-manage

Tier 3b

DHTs with measurable user benefits, including tools used for treatment and diagnosis, as well as those influencing clinical management through active monitoring or calculation. It is possible DHTs in this tier will qualify as medical devices.

- Treat
- Active monitoring
- Calculate
- Diagnose

DHP NICE Standards Assessment Overview

The Digital Health Passport can now demonstrate evidence of effectiveness at Tier 2 and partial evidence for Tier 3a (Behaviour change techniques) We aim to demonstrate complete evidence of effectiveness at Tier 3a in the next 12 months by evaluating with licensed Patient Activation Measure scores (skills, knowledge and confidence to self-manage).

Higher-risk DHTs - require a higher level of evidence for the Tier. Children and vulnerable groups are at higher risk. This means a higher level of evidence is required for the Digital Health Passport than if it was only for adults.

Tier 1 and Tier 2 (cumulative evidence)

Credibility with UK health and social care professionals (tier 1)

"Has a plausible mode of action and reflects current standard/best practice in the UK health and social care system or provides an alternative to standard/best practice that is beneficial to users and the health and social care system"

A large number of asthma specialists, adult and paediatric have been involved in the co-design of this product from inception including Prof Chris Griffiths, (Deputy Director Asthma UK, Centre for Applied Research, Dr Chinedu Nwokoro (Children's Asthma Lead, Royal London), Dr Paul Pfeffer (Severe Asthma Lead Adult, Bart's Hospital), Tori Hadaway (Community Asthma Nurse), Dr Richard Iles (Paed Resp Cnslt Evelina), The Tower Hamlets School nurse team and multiple other stakeholders.

The content evaluation demonstrates use of asthma care plans that are the recommended best practice with a strong evidence base for the paper equivalent. The content and behaviour change techniques provide a plausible mode of action.

Relevance to current care pathways in the UK health and social care system (tier 1)

"For the best practice standard, evidence could include published or unpublished reports describing the successful implementation of the DHT showing benefits to users in the UK health and social care system."

Having an asthma action plan, receiving advice on inhaler technique and completing symptom diaries are fundamental parts of asthma care pathways. We can demonstrate some benefits in process to care pathways for clinical and patient users (eg, the ability to generate completed pdf that can be uploaded without scanning, ability to send asthma action plan directly to a patient's mobile phone, the ability for a patient to record a symptom diary on their phone and easily access educational resources).

Acceptability with users (tier 1)

"Some evidence to show that potential users of the DHT have tested it and found it to be usable and useful will help to show that implementing the DHT may be successful. Evidence could include reports from user or user group testing, or showing that users have been consulted in the design and development process."

Equalities considerations (tier 1)

"Consider whether the DHT helps to reduce any existing inequalities within the health and social care system. This could include factors such as digital exclusion, or use by hard-to-reach populations."

"Indicate any equalities considerations needed when commissioning, adopting or implementing the DHT, particularly in reference to the Equality Act 2010."

Digital Health Technology may have unforeseen consequences such as creating a two-tier system through digital exclusion - this may become more of a risk with the introduction of NHS login to access some services. The Digital Health Passport is an alternative to current paper based pathways which should remain in place.

Reliable information content (tier 2)

"Any information or advice to users concerning health, healthy living, lifestyle, diseases, illnesses or conditions must be correct and relevant."

The content for the Digital Health Passport comes from trusted and reliable sources: Asthma UK and NHSgo.

Ongoing data collection to show usage of the DHT (tier 2)

"To ensure value for money to the health and social care system, the DHT owner must commit to providing data showing that the DHT is used as expected by the intended user group after adoption."

Used 'as expected' defined as one of the following:

- view their care plan
- view their emergency plan
- complete a symptom tracker form (asthma review)
- watch a video, or link out to NHS go
- check an air quality or pollen level

For some people to do 2 or more of the following:

- view their care plan
- view their emergency plan
- complete a symptom tracker form (asthma review)
- watch a video, or link out to NHS go

- check an air quality or pollen level

For some people to do any of the following, on multiple occasions:

- view their care plan

- view their emergency plan

- complete a symptom tracker form (asthma review)

- watch a video, or link out to NHS go

- check an air quality or pollen level

Evidence of patient usage demonstrating that users have met these requirements is available in the attached Appendix.

Ongoing data collection to show value of the DHT (tier 2)

"To ensure value for money to the health and social care system, the DHT owner must commit to providing data demonstrating that people using the DHT are showing the expected benefits from its use. This could include improvements in symptoms or general health measures."

It is too early to show any improvements in symptoms or general health measures. This will require a much more robust evaluation. Over the next 12 months, whilst demonstrating Tier 3a evidence we will use the validated Patient Activation Measure score. This is a 13 question system to assess an improvement in skills, knowledge and confidence to self-manage.

Quality and safeguarding (tier 2)

"Some DHTs provide chat platforms or peer-to-peer communication, or link the user to support from third-party organisations. The DHT owner

should be able to clearly identify who the user can interact with, describe why these interactions are appropriate, any risks in those interactions, and what safeguarding measures have been put in place."

N/A - There is no 2 way communication from within the DHP

Tier 3a (partially complete)

Use of appropriate behaviour change techniques (tier 3a)

"DHTs that aim to change the behaviour of the users should be consistent with accepted and effective behaviour change techniques. The DHT owner should be able to describe which behaviour change techniques are used and provide references to these"

See content evaluation

From the BCT taxonomy we can demonstrate the use of 14 BCTs

Demonstrating effectiveness (tier 3a, best practice standard)

"A high quality intervention study using a quasi-experimental or experimental design would compare the effect of the DHT on a group of users with 1 or more groups having a different (or no) intervention. The study would report the difference between the groups. It would include statistical considerations such as sample size and statistical testing, report outcomes that are relevant to the condition, and be clear on reporting the outcomes of every person in the group testing the DHT. Ideally, the comparator group would be people having current standard care, but it could also be a before-and-after study (measuring people's symptoms over a period of time before they use the DHT then comparing this with while they are using the DHT)."

Evidence plan - Use of PAMs with a larger number of users as a before and after study.

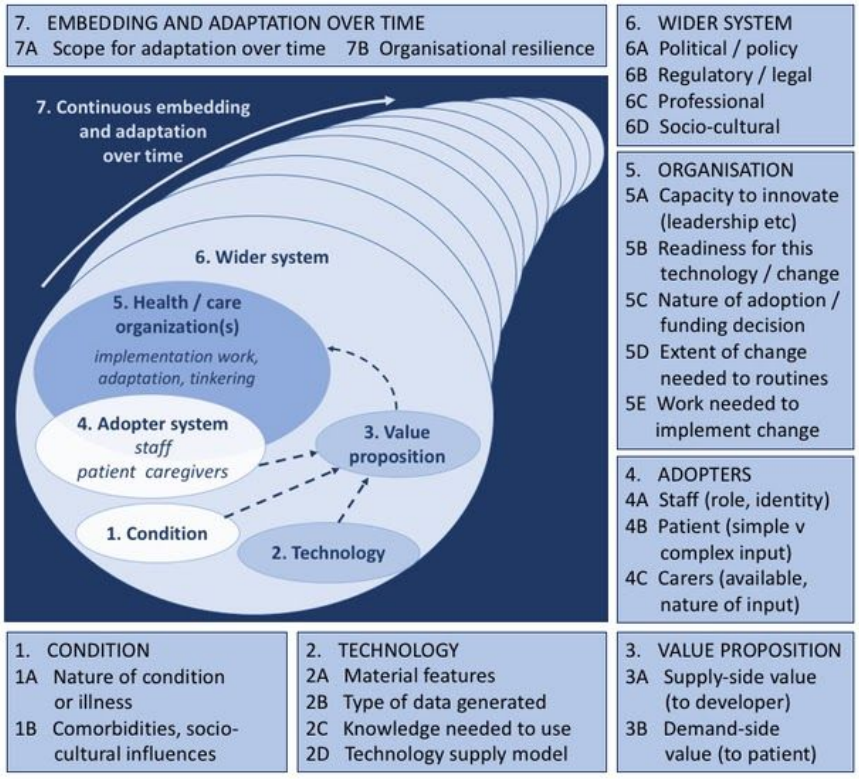
4.3 NASSS Framework Evaluation

Many promising technological innovations in health and social care are characterized by non adoption or abandonment by individuals or by failed attempts to scale up locally, spread distantly, or sustain the innovation long term at the organization or system level.

The NASSS framework has been developed by Trish Greenhalgh and others to be used at any time in a project lifestyle

Projects with too many domains in the complex/complicated zones will fail to achieve scale and sustainability.

https://www.ncbi.nlm.nih.gov/pubmed/29092808



Assessment overview

Current assessment position of DHP is highlighted in bold

Domain/question		Simple	Complicated	Complex
Domain 1: The condition or illness				
	1A. What is the nature of the condition or illness?	Well-characterized, well-understood, predictable	Not fully characterized, understood, or predictable	Poorly characterized, poorly understood, unpredictable, or high risk
	1B. What are the relevant sociocultural factors and comorbidities?	Unlikely to affect care significantly	Must be factored into care plan and service model	Pose significant challenges to care planning and service provision
Domain 2: The technology				
	2A. What are the key features of the technology?	Off-the-shelf or already installed, freestanding, dependable	Not yet developed or fully interoperable; not 100% dependable	Requires close embedding in complex technical systems; significant

				dependability issues
	2B. What kind of knowledge does the technology bring into play?	Directly and transparently measures [changes in] the condition	Partially and indirectly measures [changes in] the condition	Link between data generated and [changes in] the condition is currently unpredictable or contested
	2C. What knowledge and/or support is required to use the technology?	None or a simple set of instructions	Detailed instruction and training needed, perhaps with ongoing helpdesk support	Effective use of technology requires advanced training and/or support to adjust to new identity or organizational role
	2D. What is the technology supply model?	Generic, "plug and play," or COTS solutions requiring minimal customization; easily substitutable if supplier withdraws COTS: customizable, off-the-shelf.	COTS solutions requiring significant customization or bespoke solutions; substitution difficult if supplier withdraws	Solutions requiring significant organizational reconfiguration or medium- to large scale-bespoke solutions; highly vulnerable to supplier withdrawal
Domain 3: The value proposition				
	3A. What is the developer's business case for the technology (supply-side value)?	Clear business case with strong chance of return on investment	Business case underdeveloped; potential risk to investors	Business case implausible; significant risk to investors
	3B. What is its desirability, efficacy,	Technology is desirable for patients,	Technology's desirability, efficacy,	Significant possibility that technology is

	safety, and cost effectiveness (demand-side value)?	effective, safe, and cost effective	safety, or cost effectiveness is unknown or contested	undesirable, unsafe, ineffective, or unaffordable
Domain 4: The adopter system				
	4A. What changes in staff roles, practices, and identities are implied?	None	Existing staff must learn new skills and/or new staff be appointed	Threat to professional identity, values, or scope of practice; risk of job loss
	4B. What is expected of the patient (and/or immediate caregiver)—and is this achievable by, and acceptable to, them?	Nothing	Routine tasks, eg, log on, enter data, converse	Complex tasks, eg, initiate changes in therapy, make judgments, organize
	4C. What is assumed about the extended network of lay caregivers?	None	Assumes a caregiver will be available when needed	Assumes a network of caregivers with ability to coordinate their input
Domain 5: The organization				
	5A. What is the organization's capacity to innovate?	Well-led organization with slack resources and good managerial relations; risk taking encouraged	Limited slack resources; suboptimal leadership and managerial relations; risk taking not encouraged	Severe resource pressures (eg, frozen posts); weak leadership and managerial relations; risk taking may be punished
	5B. How ready is the organization for this technology-su	High tension for change, good innovation-system fit,	Little tension for change; moderate innovation-system fit; some	No tension for change; poor innovation-system fit; many opponents,

	pported change?	widespread support	powerful opponents	some with wrecking power
	5C. How easy will the adoption and funding decision be?	Single organization with sufficient resources; anticipated cost savings; no new infrastructure or recurrent costs required	Multiple organizations with partnership relationship; cost-benefit balance favorable or neutral; new infrastructure (eg, staff roles, training, kit) can mostly be found from repurposing	Multiple organizations with no formal links and/or conflicting agendas; funding depends on cost savings across system; costs and benefits unclear; new infrastructure conflicts with existing; significant budget implications
	5D. What changes will be needed in team interactions and routines?	No new team routines or care pathways needed	New team routines or care pathways that align readily with established ones	New team routines or care pathways that conflict with established ones
	5E. What work is involved in implementatio n and who will do it?	Established shared vision; few simple tasks, uncontested and easily monitored	Some work needed to build shared vision, engage staff, enact new practices, and monitor impact	Significant work needed to build shared vision, engage staff, enact new practices, and monitor impact
Domain 6: The wider context				
	6A. What is the political, economic, regulatory, professional (eg, medicolegal), and	Financial and regulatory requirements already in place nationally; professional bodies and	Financial and regulatory requirements being negotiated nationally; professional and lay	Financial and regulatory requirements raise tricky legal or other challenges; professional bodies and lay

	sociocultural context for program rollout?	civil society supportive	stakeholders not yet committed	stakeholders unsupportive or opposed
Domain 7: Embedding and adaptation over time				
	7A. How much scope is there for adapting and coevolving the technology and the service over time?	Strong scope for adapting and embedding the technology as local need or context changes	Potential for adapting and coevolving the technology and service is limited or uncertain	Significant barriers to further adaptation and/or coevolution of the technology or service
	7B. How resilient is the organization to handling critical events and adapting to unforeseen eventualities?	Sense making, collective reflection, and adaptive action are ongoing and encouraged	Sense making, collective reflection, and adaptive action are difficult and viewed as low priority	Sense making, collective reflection, and adaptive action are discouraged in a rigid, inflexible implementation model

NASSS assessment discussion

The condition or illness (simple, with complicated social factors)

The intervention has been focused on simple asthma (excluding young people with anaphylaxis, or difficult to treat asthma). Teenagers are defined here as 'complicated' and the social status in Tower Hamlets also cannot be considered simple. In other areas of the NASSS framework the ideal is to move towards simple - however in this domain of 'Condition or illness' we want to prevent digital exclusion - this means proactively looking to work with the more complex cases. In order to make that possible we need to make changes in the other domains (moving them all from complex or complicated).

The technology (mainly complicated)

The Digital Health Passport app is simple to use, however overall the platform is assessed as complicated. A lack of interoperability, not using native GP or EPR software (resulting in double entry, poor workflows) and on-going changes as part of the agile co-design process means that several improvements need to be made in the future version. The use of NHS login has the potential to both improve some aspects (eg authentication) but in the short term may increase complexity (extra stage of verification needed - potentially difficult for our population group without photo ID). This assessment supports the need for care plans to be entered via native software, uploaded to a Local Health & Care Record and made accessible to multiple users (including PHR apps such as the DHP).

The value proposition (complicated)

Currently there is no strong business case for either vendor or purchaser. There is no market for vendors to develop solutions without demand from commissioners (unless selling data or advertising), and there is not yet evidence of cost saving or clinical effectiveness in order for commissioners to purchase with demonstrable in-year savings. This chicken and egg conundrum has been recognised as a hurdle to the take up of innovation by NHSx and others. The proposed Innovation & Technology Payment mechanism offers a short term solution, enabling reimbursement for commissioners whilst evidence is generated. A clarification of the longer term tariff proposition would be welcome and evidence generation will require scale and time.

The adopter system (complicated)

New skills are required (eg data entry) but they are fairly routine and there are no complex steps. There is overlap with the technology assessment as by having care plans entered into native software workflows would be

improved and this would lead to a more simple system. There are clear improvements that can be made.

The organisation (complicated and complex)

We feel there is widespread support for change amongst clinicians and most commissioners, but the complicated organisational structures and on-going transformational changes lead to complexity that is difficult to manage. During the project we have struggled for example with school nurse groups being disbanded, frequent staff changes, changes in management roles and funding bodies and a lack of communication regarding future plans. There is little information provided to SMEs regarding the future funding and management which makes planning difficult.

The wider context (complicated and complex)

There is a national drive to make the regulatory environment more simple, but presently the information governance and technical assurance pathways are complicated and complex. Many of the things we are trying to accomplish have not been done before - for example interoperable care plans. Developing a standard and getting this high on the national agenda is not easy amongst their other competing priorities. There is no guidance, for example, on parents having access to PHRs for adolescents or what the criteria should be for CYP to take ownership of their own digital record. Despite many years of effort multiple data sharing agreements are still needed to implement a solution across a region. The assurance work is expensive and time consuming, however we note that solving these problems is high on the national agenda.

Embedding and adapting over time (simple/complicated)

There is strong scope for embedding and adapting the technology over time if there is enough commitment and a long term vision. It is accepted

that young people want to use digital tools and that those tools will be constantly changing. Any digital solution will need to be adaptable. The Digital Health Passport should be seen as one of a number of front ends, built onto a long term integrated and interoperable system.

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