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Foundation



Patient
Information
Forum

**Better records
for better care**

The future of digital health portals

MAY 2024

Problem statement

- The use of digital health portals has expanded. Portals include websites, apps and online consultations. The pandemic and increasing public acceptance of digital tools has driven change.
- Our research found digital health portals may help people become more active in their care. This could improve health outcomes.
- Increased self care may create capacity for face-to-face care for those who need it most. This could help the NHS meet rising demands for care at a time of workforce and financial shortage.
- The development of portals has been rapid and organic. This has led to inconsistency in definitions, language and terminologies used within them. There is a huge variation in functionality.
- A lack of coordination, oversight and evaluation of portals results in:
 - A complex and confusing environment for both clinicians and patients. They are unsure which portals to use and for what purpose.
 - Difficulty in categorising and comparing portals to assess their relative effectiveness.
 - Difficulties with access, capability and interoperability between digital solutions.

- The Health Foundation funded this PRSB project. The Patient Information Forum acted as partners. We consulted with patients, health professionals, commissioners and suppliers. We aimed to identify what is working well and the barriers to use of portals. We also looked at opportunities to guide further development.
- The project used this definition of portals. "Any digital tool requiring a level of personal information to gain access to health and care related information."
- There are is a huge range of digital health portals. Examples include:
 - Nationwide apps such as NHS App in England and the Welsh GP Record
 - Booking management apps
 - Information portals
 - Condition specific apps, websites and portals
 - Provider organisation developed ('homemade') apps, websites and portals
 - Health and care record apps
- Open websites such as NHS.uk were out of scope.

Key findings

- 1. User feedback is generally positive about digital health tools.** But there are barriers to access and use of portals:
 - Lack of public awareness
 - Clinician uncertainty as to how or what to signpost to patients
 - Lack of proper integration in care pathways
 - People asked to use multiple portals for their care
 - Digital exclusion
 - Lack of translation options for non English speakers
- 2. There is limited evidence showing the effectiveness of portals globally. Evidence is lacking in the UK.**
 - Some American studies have shown digital portals improve health outcomes.
 - UK commissioners and suppliers are beginning see efficiency benefits from appointment portals. These include reducing missed appointments and the cost of printing and postage.
- 3. Clinicians do not see the benefits of portals**
 - Work plans are not adjusted to accommodate the split of face-to-face and digital work. Digital work is perceived as extra workload rather than a change in model.
 - GPs reported a changing relationship with patients. Digital processes can be transactional. This means GPs may not see the whole person.

Summary of recommendations

- A **collaborative approach is necessary to support the design and implementation of portals.** Action in three areas may realise the opportunity presented by digital health portals.
 1. **Strategic development.** A common strategy for digital health portals is needed. It should be created by policy makers, commissioners, suppliers and users.
 2. **Awareness and advocacy.** Clinicians and patients need support to understand how and when to use portals. Clinicians and patients should experience portals as a convenient support to face-to-face care.
 3. **Connectedness.** Strategy should incentivise suppliers to focus on integration and connectedness. This would support care pathways and reduce fragmentation for patients.
- A transformation programme linked to the findings of this report should be adopted.
- These recommendations may apply to other digital solutions. These include digital health accounts and personal passports.

Summary of recommended actions

Opportunity	Action
Policy, strategy and purpose	<ol style="list-style-type: none">1. Develop methods to understand and improve digital inclusion.2. Develop clear and well understood national strategies including:<ul style="list-style-type: none">• Expectations and purpose• Common measures of effectiveness• Support for digital inclusion,3. Creation of portal categories based on functionality. This would support implementation and integration.
Awareness and advocacy	<ol style="list-style-type: none">1. Develop national guidance and support for clinicians on how and when to use digital options.2. Create guidance for campaigns to awareness of portals. This should include case studies, quality standards and how to promote to users3. Consider how metrics can evidence the effectiveness of portals. This will support public messaging and create a factual and trusted narrative.
Connectedness	<ol style="list-style-type: none">1. Clarify the strategic intent of national NHS apps. Identify the opportunity for other portals to integrate or remain separate.2. Develop and communicate a set of requirements for integration to national NHS apps.3. Consider professional and citizen perspectives in plans for portal integration in NHS apps

Methodology

The project included an evidence search and consultation with a wide range of stakeholders.

Evidence search

This process included:

- A literature review of global publications on the effectiveness of digital health portals, with a focus on the four UK nations
- National policies and strategies associated with digital health
- Existing guidance and standards on digital health portals

Consultation

- The consultation ran during March 2024. It included a survey, semi-structured interviews and an expert panel.
- Organisations consulted included the four UK governments and health services, health charities and suppliers of portals.
- The survey was shared with the memberships of the PRSB and PIF and via social media such as LinkedIn.
- The expert panel was attended by representatives of patients, clinicians, suppliers and commissioners.

Evidence search

- There is limited evidence on the effectiveness of portals and their ability to support self-care. But there is emerging evidence on positive health outcomes achieved by digital health portals.
- Many studies report on the US insurance-based health service. These findings may not be relevant to the NHS.
- Clinical endorsement of digital health portals increased uptake by patients in the US.
- European studies were uncertain on the impact of portals on healthcare use and efficiency.
- Research is needed on the effectiveness of digital health portals in use in the NHS.

Survey findings

The survey gathered views, experiences and comments from patient, clinician, commissioner and supplier groups. The majority of responses were from patients and carers.



118 people responded to the survey

■ Patient or carer ■ Clinician
■ Commissioner ■ Supplier



Lack of awareness was the main reason people had not used a portal. 7 people did not want to use portals for health and care needs.

Reasons patients or carers used portals:

- Viewing and requesting repeat prescriptions
- Make, amend or cancel appointments
- View records, care plans and treatments
- Information about my condition



15% had downloaded a portal but never or only used once or twice



84% of patients and carers were neutral or found portals easy or very easy to use

Type of use	No. patients or carers
Short term care	27
Long term care	18
Maternity	3
I have downloaded a portal but do not use it	12
I have not used a portal	20

What did people say: the patient perspective (survey)



118 people responded to the survey

- 66% of responders were patients or carers
- 66% had used portals.
- **54% of those using portals found them easy to use.**
- A range of portals were used including hospital specific, condition specific and general health information.



“You can refer back to it, at a time that suits you”

“Confusing log-in steps and nobody to ask for help”



“It was easy to download and access letters and appointments”

“I had not received any communication on how to use it”



“Quick access to medication (information) saves time”



“Test results are sent through without explanation. There should be some interpretation”

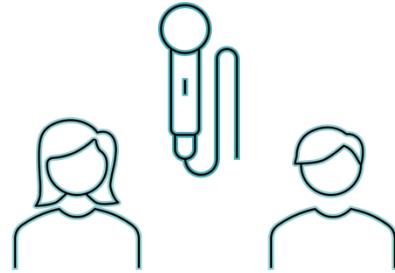


“I feel better informed but not necessarily more in control”

“It would be helpful if I had access to my health record for all care settings and so I can share it with all of my clinicians”

Semi-structured interviews

14 semi structured interviews took place with patients, clinicians, commissioners and suppliers. Most were from commissioner and supplier groups



Respondents gave different definitions and examples of portals including:

- Websites
- Apps
- Clinic portal
- Information sharing; one way and two way
- Communication tool
- Education
- Admin management tool
- Enhancement to face-to-face care

A variety of terminology was used for similar tools:

- Patient Empowerment Portals (PEPs)
- Digital health technology
- Citizen portals
- Personal health records

Commissioners and suppliers of appointment portals are starting to see efficiency benefits including:

- Reduction in missed appointments
- Some reduction in costs of printing and postage

Clinicians noted work plans had not been adjusted to accommodate the split of face to face and digital work. Digital work seemed additional.

What did people say: perspective from interviews



The 14 semi-structured interviews identified clear themes in the feedback and experiences of stakeholders



“I have too many systems open on my desktop, very few are integrated – this causes safety and human error issues”



“Digital should be an enhancement to face to face care not a replacement”



“Evidence suggests we are reaching the older populations. It is the younger people who are becoming digitally averse”



“The benefit to the user needs to be clear to maintain engagement”



“Are we clear on the objective we are trying to meet? The tech is the enabler not the objective”

“As a charity, we can often adapt quicker than other companies but how can we ensure we have a place in a market of private and NHS funded portals”

Expert panel key messages

The expert panel reviewed the findings and identified three opportunity areas: **policy, strategy and purpose, awareness & advocacy and connectedness.**

Promoting digital inclusion should be embedded within digital strategies. There is a need to understand the current exclusions and access challenges of the population.

The expert group recommended stakeholders work together to realise the potential of digital health portals. Co-design and co-production was felt to be key in achieving this.



Artificial intelligence present opportunities but further guidance and regulation is needed to ensure its safety in the health space.

People do not always perceive themselves as patients when accessing health and care services. Care needs to be taken with terminology. Discussions with Scottish participants referred to using citizen as possible alternative.

Potential opportunities

Opportunity A: Policy, strategy & purpose

Clarity of purpose and direction enables a shared journey to success.

Supplier: *“I am unclear on the ultimate goal we are aiming to achieve across the industry”*

Commissioner: *“We haven’t commissioned a portal due to a lack of funding but can see the potential for more personalised care”*

Opportunity B: Awareness & advocacy

Raising awareness is key to implementation

Patient: *“I wasn’t told about the portal by my clinician”*

Clinician: *“How do I know which portal to recommend to my patient, there are so many to choose from”*



Opportunity C: Connectedness

Reducing fragmentation makes it easier for people to manage their health and for clinicians to deliver care. It would support suppliers developing solutions.

Patient: *“I am using 5 different apps for each of my health needs”*

Supplier: *“If my app isn’t integrated with the NHS App will it still be supported by clinicians?”*

Opportunity A: Policy, strategy and purpose



Strategy

England, Wales, Scotland and Northern Ireland have digital health policies in place.

There are differences in approach in the four nations. Digital first operates in England with digital becoming the default. Digital choice operates in Scotland where digital is an option.

Our work struggled to identify clear strategies describing purpose, definition or goals associated with digital health portals.

Innovation is fast moving. Progress may be hindered by disjointed approaches to integration and interoperability.

Patients and the public need to be aware of portals, their purpose and how they support health and care.



Digital exclusion

Digital inclusion is often a separate area of work and not a force to support improving access.

Data and device poverty are an increasing barrier. Some people prefer to avoid digital solutions for managing health and care.

People who do not speak English well or at all face additional barriers.

Some regions have digital skills workshops and community digital hubs to support access.



Measuring success

We found limited evidence of effectiveness of portals in the UK. There are differing views on what to measure

- Usage rates and uptake
- Health and care outcomes
- Efficiency in administration
- Health economics including productivity and prevention measures.

Opportunity A: what next?

The opportunity: A common strategy would ensure successful delivery of policy goals. This should bring stakeholder expertise together to deliver the benefits of digital health.

The strategy should bring digital inclusion to the forefront. This focus will drive innovation. It limits the potential for exclusion becoming an unintended consequence of digital health.

A conversation with the public is needed on why portals are being introduced and how they will support their care needs

Portals should be categorised based on their type. Operational and technical guidelines should be developed for each category.

This would support consistency in information, integration and functionality but allow innovation.

Actions

1. Develop methods to better understand and improve digital inclusions
2. Develop clear and well understood national strategies on portals including:
 - Expectations and purpose
 - Common measures of effectiveness
 - Digital inclusion
 - Creation of clear digital health portal product description categories, based on functionality. This would support implementation and integration.

Opportunity B: Awareness and advocacy

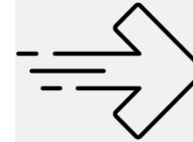


Clarity

Public awareness and understanding of the role of portals is required. People need to identify trusted portals and how to access them. They need to recognise how these support their health and care needs.

Clinicians need evidence of what works for their patients and what is available to recommend or prescribe. Time is limited for clinicians during a consultation so easy to reach, trusted solutions are required.

Positive experiences and outcomes should be shared. This will build trust in digital health for both user groups.



Signposting

Public awareness is based on personal experience rather than signposting or promotion to support the implementation of a portal.

Clinicians are uncertain how to signpost patients to trusted portals. There is no approved portal pathway for specific conditions.

Clinicians need confidence that portals can complement care models and maintain effective patient relationships.

Evidence from the US suggests people are most likely to use portals recommended by health professionals.

Opportunity B: what next?

The opportunity: Raise awareness of digital health portals. Support clinicians to use digital solutions safely in a changing and challenged sector. Support patients to take charge of their own health and support self care. **Inform users of industry standards including**

- NHS Digital Technology Assessment Criteria (DTAC),
- Organisation for Review of Care and Health Apps (ORCHA)
- Patient Information Forum (PIF) TICK. The independently-assessed quality mark for health information, providing reassurance to users.

Portals should be easy to use and understand. Patients in the survey reported difficulty in understanding blood test results. If results are not clear it can cause concern to patients and additional calls to GPs.

Actions

1. National guidance and support for clinicians on how and when to use digital options.
2. The creation of campaigns to raise awareness of portals. These should include to include case studies and the quality standards portals should meet.
3. Set metrics to evidence the effectiveness of portals. Identify good practice to support public messaging. Data helps create a factual and trusted narrative.

Opportunity C: Connectedness



Market fragmentation

We heard many examples of fragmentation across the health sector and NHS.

In the same hospital patients are using different portals for different services. This leads to separate sets of patient data held in portals.

Fragmentation limits the opportunities for integration with other portals. It causes confusion and frustration for patients and clinicians. It is a barrier to use.

Fragmentation limits opportunities for learning and sharing good practice. It makes the sector less efficient.

This appears to stem from a lack of strategy at national and local level.



Who is the integrator?

People responding to our survey used multiple portals for their care. **One patient used five different portals for their needs.** This creates frustration and leaves important information in silos.

Clinicians, particularly GPs, saw some digital processes as transactional. This stopped them seeing the whole person. It limits their ability to be the integrator across the patient's needs.

It is not clear if patients want to be the integrator of the information held in the portals they use. It requires time and skill to do this.

Clinicians noted disengagement when another non-integrated portal landed on their desktop.

Market fragmentation is not meeting the needs of patients or clinical services

Opportunity C: what next?

The opportunity: A clear strategy would allow suppliers to focus on integration and connectedness.

Local and national fragmentation is a barrier to efficiencies presented by portals. Use of multiple portals by clinicians is time consuming. And people's opportunities for self care reduce if their records are not connected.

The opportunities and criteria for integration into national NHS Apps should be clear to suppliers. This will support private and third sector suppliers to see their place in the market.

There are real opportunities for digital health to improve health outcomes and the care of patients. A connected approach will make this easier to achieve.

Actions

1. Clarify the strategy of national NHS apps. Identify the opportunity for other portals to integrate or remain distinct.
2. Develop and communicate a set of requirements for integration to national NHS apps
3. Consider professional and citizen perspectives in plans for portal integration in NHS apps

Acknowledgements

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Appendices

Examples of portals used or produced by survey participants and interviewees

