Connected Health Cities

End of Project Report

WP1: Industry Engagement

Digital Think Tanks

April 2019

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ABSTRACT

The benefits of sharing patient data within data management systems are beginning to be well understood. However, it is also recognised that there are many barriers, particularly related to human factors, workforce issues and service contextual obstacles.

Furthermore, the burden of proof of value for innovative data sharing systems lies with technology developers. This can cause problems for entrepreneurial small and medium-sized enterprises (SMEs) in digital health, who do not have sufficient resource to undertake a robust evaluation.

This project explored these issues. Stage 1 of the project was to explore perspectives of healthcare practitioners to understand how human factors can influence (negatively or positively) the adoption of data management innovations. Structured interviews were held with 15 practitioners across Lancashire and South Cumbria and within a number of professions.

In Stage 2, the findings from Stage 1 were discussed with representatives of digital health SMEs to consider the impact on the sector and propose actions to address issues identified.

INTRODUCTION

The digital revolution in healthcare offers a diverse range of consumer apps, mobile devices and application of the latest technology.

The ‘Connected Health Cities’ (CHC) initiative aims to improve health services in the North of England by applying the latest technology to make better use of data. By changing the way we use information and technology and interact with data, services will become more joined-up and consequently, the health of patients can be improved.

The purpose of the CHC initiative is to carry out relevant and effective research with health practitioners, experts and service users. Smart and efficient use of data and new technology are at the heart of the initiative.

Despite the uses and benefits of digital technologies, the presence of barriers that impede their successful implementation is widely acknowledged. Whilst complications often pertain to technological or infrastructural challenges, more fundamental factors such as human and contextual obstacles need to be considered.

Some researchers claim that most digital health literature has a techno-centric orientation and that the impact of circumstantial complications as determinants of success/failure is often underestimated. These include factors such as; confidentiality issues, poor motivation, high work pressure, failure to integrate new technology within existing systems of care. There is a need for more research to look at the problems of technological implementation, specifically for more pragmatic qualitative and participatory explorations of local opportunities, and threats to digital health technology.

A further related issue is that within the framework of evidence-based practice used by our health service, technology developers are required to find ways to pilot their innovations with health and care providers and then to provide a robust evaluation, normally undertaken by an academic partner. This causes problems for entrepreneurial small and medium-sized enterprises (SMEs) in digital health. The cost of such a robust evaluation may be a significant proportion of the development costs. Further, the elapsed time to undertake data collection, analysis and reporting may be incommensurate with the speed of development with such agile, fast-moving technologies. Finally, due to the emphasis on impartiality, the evidence provided is not always what is required by decision makers.

STUDY AIMS

This two-stage project explored the issues raised above.

Stage 1 investigated the potential barriers to, and facilitators of, the implementation of digital technologies within health services, from the perspectives of health care practitioners. Specifically, an exploration was undertaken on how human factors can influence (negatively or positively) the adoption of data management innovations. The objective was to identify factors that could assist in the successful design, implementation and utilisation of digital technologies for data management. This was achieved through individual interviews, followed by thematic analysis.

Stage 2 involved dissemination of the findings of stage 1 to companies that specialise in the development of digital health innovations (for example, health-based apps). These two workshops explored the potential for enhancing the design, implementation and utilisation of their products.

Workshop one was held in January 2019, with three companies which were selected as experts in the field. The specific aim was to discuss preliminary findings and share case studies around perceived benefits and perceived barriers to the use of data management systems. Finally, participants reviewed and summarised recommendations for further actions and opportunities.

Workshop two took place in March 2019 with six company participants. A similar format was adopted, with the discussion carried out in two facilitated groups, before the final plenary session.

PROGRAMME RECRUITMENT AND DELIVERY

PARTICIPANTS

The initial intention was for the sample to include between 20 to 30 students from the University of Cumbria, who were undertaking programmes relating to health or social care and had current or previous experience of working in healthcare settings. Recruitment was carried out via email through the University of Cumbria's email system. Email invitations were sent out to students who were undertaking programmes relating to health or social care at the University of Cumbria. Individuals were asked to indicate their interest in participating via email to the lead researcher within two weeks of the email being sent out. However, due to the subsequent mismatch between the geographical locations of many of the students who volunteered to participate and the eligible CHC areas, the pool was expanded to include practitioners working in health and social care services.

DATA COLLECTION AND ANALYSIS

The original proposal for the method was to collect data through the use of digital think tanks. These were planned to start with presentations by two PhD students, who were undertaking research that was related to the 'Connected Health Cities' initiative. Following the presentations, structured discussions would be facilitated using four key questions:

- What do you currently use data for?
- What could you use data for?
- What are the problems and risks associated with data management systems and digital technologies?
- What could be the potential problems, and solutions associated with the problems and risks?

Due to the wide geographical spread of participants however, the logistics of conducting such workshops was not feasible. Therefore, individual and small group interviews were conducted but using the same questions. The two PhD students recorded short presentations of their research which were shown to participants immediately prior to the interviews taking place.

ETHICAL ISSUES

Ethical approval was granted by the University of Cumbria Ethics Committee (Ref 17/34 Dated 28th February 2019).

Participant information sheets providing details about the purpose of the study, participants' rights and management of the research data were attached to the invitation emails in order that individuals were able to make an informed decision about whether or not they wished to participate in the study. Additionally, the researcher's contact details were provided in the event that potential participants had any questions relating to the study. Prior to commencement of the interviews, a verbal explanation of the study was given and participants had the opportunity to ask further questions. After any questions had been addressed and participants had indicated that they were willing to continue and participate, they were asked to sign the consent form.

Audio data was transcribed and any identifying information was removed and anonymised on production of the transcripts. Electronic data was saved onto a password-protected server at the University of Cumbria. Data collected during the study will be held securely for five years then will be confidentially destroyed.

RESULTS

Stage 1 participants identified a range of benefits:

- Benefits of data management systems for clinicians and service users at an individual level
    - Support for clinical interventions and quality of care
    - Ease of communication
    - Time efficiency
- Benefits of data management systems for clinicians and service users at a population level
    - Predictive analytics
    - Diagnostic and clinical decision support tool
- Benefits of data management systems for service quality and development
    - Operational management
    - Information access.

A number of examples and case studies were also described and discussed, particularly relating to improvement of care at an individual level. Barriers were also discussed and identified:

- Security and confidentiality
    - Access barriers
    - Service user confidence
    - Inappropriate use of data
- Knowledge and understanding
    - Training
    - Functionality gap
    - Lack of interest
    - Lack of trust
- Technical infrastructure

Stage 2 participants, SME representatives, related similar experiences from their own side. A lack of time for training and implementation was a frequent issue that they faced.

They were also concerned with difficulties around interoperability of their software with other systems. There was a general view that NHS organisations should take a lead in specifying frameworks or standards. However, concerns were also expressed about trying to control too much. There was a view that very large scale implementation is doomed to failure and a better approach is to encourage smaller scope implementation, but with clear standards.

Full results from this work have been attached as Appendix 1 and Appendix 2.

IMPACT

It is anticipated that interview participants will have found that the opportunity for structured reflection has influenced their practice. This is informally found in such situations and could be documented by a round of follow up calls or emails.

Companies participating in workshops will benefit through the shared findings, which describe views, perceptions and suggestions from potential customers.

A specific outcome is that one of the researchers on this project was invited to take part in a Round Table on ‘Innovating for an Ageing Society’, supported by the Economic and Social Science Research Council, in May 2019. The findings of this project will form the content of her presentation.

FUTURE PLANS/SUSTAINABILITY

The industry participants were particularly keen for this work to be continued and used as a basis to develop a framework and standards for industry. The suggested approach was to develop a 'blueprint' from the workshop discussions and then take this forward into an influencing document with politicians and health leaders.

In addition, there should be further work to develop appropriate training for health professionals. This should be embedded in undergraduate study and in continuing professional development (CPD). Both partner universities (Cumbria and Lancaster) are already working in this area and will continue to do so.

The partners intend to explore funding opportunities to continue the work.

CONCLUSION/DISCUSSION

The project aimed to investigate perceptions and attitudes to shared data systems, within Lancashire and South Cumbria NHS organisations, followed by review and discussion of the findings with companies in the sector. In total 15 interviews were held, with a range of health professionals engaged in sharing patient data within data management systems. Two workshops were held, firstly an 'expert panel' with three companies and a further larger workshop with six companies.

The findings from both stages were largely related to individual patient benefits and clinical practice. In general, participants in the study perceived many benefits to having full patient history shared across different services. A number of specific examples were provided. However, the participants also raised concerns and described difficulties. Although data security and confidentiality was raised as a possible concern, generally those interviewed were more concerned with how these perceived issues constrained data sharing. Many were frustrated that colleague health professionals were reluctant to share data, particularly GPs, and described a number of examples where they felt this had impeded care. However, it was also generally thought that good guidelines for security were paramount.

There were further reflections on how system design could be improved and the need for better support for users of data management systems. Many participants had specific issues to raise and were clearly keen to engage with technology designers to improve their systems. This may not be a typical view of healthcare professionals, as those participating were volunteers who had an interest in the subject.

Discussions with companies have enabled the researchers to embed the findings of the project within design practice. A number of suggestions were made for taking forward this work, including leadership of an industry movement to develop standards and regulatory frameworks. The need for training of healthcare professionals in digital and technology selection skills was also noted. This should be included in undergraduate education, as well as postgraduate professional development.

The discussion has focused specifically on delivery of individual patient care. Few of the participants had the breadth of view to be able to contribute any helpful thoughts on data sharing for planning and research. In general, it seems that this is a much ‘easier sell.’ There remain many problems in understanding the wider societal benefits of sharing personal data and major concerns about security, which are difficult to surmount. Consequently, this issue was not explored in this research.

Overall, there is enthusiasm for improving systems for sharing data, but a need for system-wide approaches and leadership.

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APPENDIX

APPENDIX 1: RESULTS: STAGE 1

Participant Demographics

Role/Profession	Locality	Interview Date
Occupational Therapy	Preston	01/05/18
Occupational Therapy	Lancaster	01/05/18
Health visitor	Morecambe	03/05/18
Physiotherapy	Preston	03/05/18
Commissioner	Liverpool	11/05/18
Occupational Therapy	Lancaster	14/05/18
Occupational Therapy	Lancaster	14/05/18
Nursing	Preston	23/05/18
Nursing	Lancaster	25/05/18
Occupational Therapy	Rawtenstall	01/06/18
Occupational Therapy	Liverpool	01/06/18
Physiotherapy	Blackburn	28/06/18
Physiotherapy	Rossendale	04/07/18
Physiotherapy	Rossendale	04/07/18
Equipment provider	Bromborough	25/09/18

Benefits of Data Management Systems

Table 1 below illustrates the range of benefits of data management systems as discussed by participants. These are sub-divided into benefits for clinicians and service users at individual and population levels and for service quality and development. The most commonly cited benefit of data management systems was focused around the value of having shared access to records (particularly GP records) for community services. This was considered to be greatly beneficial in enabling practitioners to provide more effective interventions for their service users, as illustrated in this quote from a physiotherapist;

> *"It might be they've had a scan in the past but it's been done elsewhere so it's absolutely fantastic I find, because it just means we can see things we couldn't once see, find out information we wouldn't have known, so manage the patient more effectively because it's all about getting all the information and then deciding where to go from there and that's what I think we've got now with EMIS and with the sharing agreement we've got through EMIS*[1]*."*

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[1] Egton Medical Information Systems – a market leading software package for managing patient records.

Furthermore, shared records were considered to be particularly advantageous in providing access to more accurate information which can then help in terms of risk management, as this physiotherapist describes;

> *"You can ask patients about their past medical history. Some patients are fantastic; they can remember everything. Some patients, you'll say as an example, 'have you had any serious illnesses in the past?' And they'll say, 'no I never have', and a bit later, 'oh I remember I had an operation for lung cancer', and you know, you do forget the past don't you? Or maybe the way you term it, so serious illnesses to some people would just mean cancer or a massive operation but like if they've had septicaemia, they might not remember it because it's been, it's gone, and they've recovered fully from it, but it's always very useful to know so yeah, basically, if the patient's then given consent, we can click on all records which allows you then to view the GP record which has all their past medical history."*

The ability to download GP summaries prior to going out to service users helped practitioners to feel more prepared. Furthermore, information management and security was considered another benefit to record sharing. Participants spoke of the ease with which they are able to upload documents such as discharge summaries, without having to rely on more time-consuming communication systems such as fax, post, email or telephone. Participants also spoke of having greater confidence in the security of the data management systems that they were using. Other specific advantages include preparation for patient consultations, enhanced communication between practitioners and also between practitioners and service users, safeguarding and time efficiency for practitioners and administration teams. This quote from another physiotherapist illustrates how interoperability between two systems improves efficiency as well as communication between practitioners and service users.

> *"We also have linked EMIS in with ICE[2], so our investigation requesting permission, so the benefits to the physiotherapists are, within two clicks they're into ICE without having to open ICE, login, put the patient's NHS number in and find the details. They can click in from within that patient's record and view all investigation results and that can be whoever it had been requested by. From my point of view, I used to have to go into the filing cabinet and get out an MRI[3] request form and fill all that in, now it's two clicks for me and I can be requesting things. The results ping straight back to me rather than a letter in the post that takes several days. The download from the Trust happens every 60 minutes and that's weekends, every day, all night. You can be ringing a patient back with their*

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[2] Integrated Clinical Environment – a suite of technologies that enables different patient care units to communicate with a wider range of ancillary and clinical departments such as laboratory and radiology.

[3] Magnetic Resonance Imaging – a type of scan that produces detailed images of inside the body.

> *investigation result on the same day that they've had the test, and that would never happen in the old way of working."*

Benefits of data management systems to address health promotion and the prevention of ill health at a population level was also discussed by some of the participants. This quote by a physiotherapist provides one example of how information from data management systems can be analysed for this purpose;

> *"There's the operational productivity and reducing those instances of people slipping through the net or failed encounters, and so managing things on a productivity level really. I was talking to somebody today who was analysing their DNA*[4] *rates so they could identify whether there was a postcode match to rates of DNAs, so is there an issue amongst a certain population group who don't tend to attend for their appointments, and again if we haven't got the information in and don't think to analyse then we can't pull that sort of stuff out so I think that whole productivity and operational side is one benefit"*

Barriers to the use of data management systems

All participants discussed the existence of various barriers to the effective use of data management systems. Thematic analysis of the interview data led to grouping into themes. As indicated in Table 2, barriers are categorised into three themes: Security and Confidentiality, Knowledge and Understanding and Technical Infrastructure.

In relation to the first, the issue of access restrictions arising from concerns around security and confidentiality, was a frequently cited problem. The most common issue tended to relate to the difficulties accessing GP records which was sometimes due to certain practices not signing up to sharing agreements. Some of the consequences in terms of the impact on efficiency are illustrated in this quote by a physiotherapist:

> *"Some of the local GPs haven't signed up to the sharing agreement so we would still have to work in the way I mentioned before in terms of, if we need information, telephone contact to get it but like I said it does take longer. Often, say if you were the patient, if you were with me now, 'can I look at your GP records?', you say 'yeah', I can access your GP records there and then so I can formulate that plan while the patient's still here rather than saying 'oh I need that information, I need*

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[4] Did not attend.

> *to contact your GP for it, so go away, I'll contact you', so it's more time for the admin staff, it's also a telephone consultation or a review if you need to discuss things in a bit more detail."*

Furthermore, a Health Visitor discussed how lack of access to GP records can restrict valuable opportunities to identify issues in relation to safeguarding in children's services:

> *"Sometimes, especially in areas of safeguarding, we may need to complete referrals to children's social care but it's very difficult if we only have the parents' history of how well the child is using medication, is attending GP appointments, is up to date with things that aren't necessarily in our roles. So you might have multiple referrals to the GP for uncontrolled asthma and it's why is the asthma uncontrolled? Is the medication being used correctly? Are the parents ringing up at the last minute for things constantly and are they taking due care of the child's needs? That's probably what frustrates me the most is not being able to readily access that information because it would be really relevant, but I can only see what speech therapists and audiologists have put on. I can't readily see the GP information."*

The same participant went on to consider how data management systems could offer effective means of providing valuable data without the need to compromise patient confidentiality:

> *"Some information could be just summarised so like a list of missed appointments, not the details of the appointments but a general appraisal that comes up on our information system so, even if it's just a tag line that says GP appointment missed, no reason given, or GP appointment missed, cancelled by mum, then we know that that's happening and we could observe a pattern, it wouldn't breach confidentiality."*

This participant discussed how she perceived hierarchical differences between professionals to be a factor that impacted on the sharing of records. Additionally, a number of participants spoke of the lack of data sharing between health and social care as being a substantial barrier to effective communication between services.

Another issue relating to confidentiality and security was in relation to inappropriate/unnecessary access to data by practitioners, often due to general curiosity. Participants spoke of the need to have measures in place that could restrict practitioners accessing records that are not relevant to them, or monitoring procedures such as random audits.

In relation to knowledge and understanding, several of the participants who were in roles where they acted as 'technology champions', spoke of how there was often a big divide between the functionality of the technology and clinicians' and managers' understanding of it. Consequently, they felt that data management systems were often not being utilised to their full potential. There was a perception that this was due to fear of overwhelming people but these participants called for greater involvement of clinicians in the design and development of systems as well as in their adoption and roll out. This quote from a physiotherapist illustrates her frustration that clinicians are not empowered to be able to use data in ways which could assist them with quality improvement and professional development despite the fact that the system has the ability to provide the data in the required format.

> *"I would say that's a frustration because, with a clinical hat on, I would like to be able to look at how many lumbar spine patients I saw in the last 12 months and how many of them I ended up scanning and of the ones I scanned, how many went to surgery, and of the ones that I didn't scan, what was different about them, so trying to understand better why I've done what I've done, whether it was the right thing to do. I'd like to be able to access that information on my own. I don't want to have to go to a data inputter or the data team and ask them to pull me that information because I don't want to add to their workload. I'd like a system where, as a clinician, it's either presented in a dashboard format so I can see it visually and I can monitor in sort of a live situation how I'm progressing or if there's specific things where I think, I don't feel that I'm managing my shoulder rotator cuff patients as well as I could, and I could retrospectively look back over what I've done and try and work out for myself what I might have done better."*

In relation to the third theme, lack of interoperability of different systems was regarded as a barrier to efficiency by many of the participants as illustrated by this physiotherapist:

> *"We use EMIS, we use something called BADGER, we use this, we use that, but they don't talk to each other, but even if they don't talk to each other, they don't have a window in to each other so you have to go and log into this system and do that piece of work, and then when you're ready to do the other thing, you turn around over there and do this on the other thing and you can't put that into there at all easily. It can't see it, they don't talk to each other so you create quite a convoluted method of working to try and bring the two together because you have to try and meet the standards of documentation."*

Desired opportunities for shared data management systems

Table 3 illustrates some participants' ideas for how digital technologies could be developed to assist them in their practice. These include improved accessibility of systems for use in the community and by service users; greater interoperability between different systems, consideration of the different formats in which data can be retrieved and manipulated by practitioners and the use of technology for interventions. This occupational therapist discussed how a portable device with an accessible and easy to use system might increase efficiency of assessment and intervention as well as empowering service users;

> *"If you're working in falls you could pull in a FRAX5 assessment, look at educating people around falls and fear of falls but you could pull in all those different things and not have to keep going back for repeated visits to go through that. So you've got all that intervention information at your fingertips. We always do the FRAX assessment to see if people are at risk of refracturing, but you need to go back to the office and do that on the computer and it will calculate the percentage risk of a fracture in the future, which is annoying when you could do it there on site and then tell the patient the result. It would just definitely speed things up and I think it would help educate patients and families better and help them feel more in control"*

In relation to the previous issue that was discussed about the lack of interoperability of different systems, participants spoke of their hopes that the needs of community services might be addressed more in the future by integrating data management systems with intervention tools. This physiotherapist discusses how she would like to see a data management system integrated with an exercise platform;

> *"So I'm looking at, what does EMIS work with in terms of online exercise platforms. But they don't really have that facility set up with any company yet and it's gone from primary care to community care bumph, like the district nurses might need a wound care thing or physios might need exercise tools and it's a real battle to try and find, how can I go from EMIS into an exercise platform? And when I've chosen one I want to do, how do I get that saved in there without having to do a real convoluted, print things off and then it goes in a pile for scanning for admin, 2 or 3 days later. So it needs to represent its customers as the customer base expands and it needs to link in with other systems better. And I'm sure every service will have a similar thing really. Now if there was*

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[5] Fracture Risk Assessment Tool

> *something, I don't know if this is pie in the sky but if there was something linked in to the system whereas whilst we're on EMIS we could find different exercises then that would be fabulous."*

Another physiotherapist, whilst speaking of how data management systems are underused as clinical decision support tools, expressed how she would like to see data about individual patients collated for use in population analysis and resource planning;

> *"I think taking that individual-level idea and sort of modelling that on a larger scale. I'd love to see all the data that we do collect about patients in a pot where we can then start to look at population trends and then start to identify what, and I guess use predictive analytics to work towards what areas do we need at a larger population scale, need to focus our intentions on and our resources on."*

Related feedback on other technologies and issues

It is not unusual in interview situations for participants to raise issues that are not directly related to the objectives of the study. In our case, the objectives were to discuss patient data management systems, but many participants wanted to discuss other types of digital health technologies (such as use of video-conferencing, telehealth and telecare, mobile apps). There was also often a tendency to reflect on very specific design features of the software they were using. This feedback is collated in Tables 4-6.

Table 1: Perceived benefits of data management systems

Benefits of data management systems for clinicians and service users at an individual level	**Benefits of data management systems for clinicians and service users at a population level**
Support for clinical interventions and quality of care • Information from other disciplines feeds into profession specific assessments. • Greater access to information enables greater preparedness when meeting service users and therefore improves decision making. • Access to medical records (overview of previous hospital admissions, medical history, medication and risk factors) enables immediate formulation of treatment plans rather than having to arrange further review or telephone contact (physiotherapy). • Greater access to GP records can assist with safeguarding – e.g. assess parents concordance with treatment regimens for children. **Ease of communication** • More systematic and streamlined recording of information than paper-based systems. • Ease of electronic referrals to other services. • Generation of letter to GPs. • Use of templates. • Ability to send tasks to colleagues. • Continuity of care from hospital to community and vice versa. • Used for discharge summaries and discharge planning. • Some systems can link with other systems e.g. investigation requests. • Immediate access to investigation results. • Ease of access to relatives contact details. **Time efficiency** • Remote authorisation (e.g. MHA section 17 forms). • Automatic population of individual identifiers on each page.	**Predictive analytics** • Collection, analysis and formulation of data with speed and at scale to identify population trends and plan services to respond to need. • Identification of people at risk of ill health in order to shift from reactive to proactive services to focus on ill health prevention at a population level. • Assists with resource planning, managing services and requesting additional services. **Diagnostic and clinical decision support tool** • Technology can do this quicker and reduce error.
	Benefits of data management systems for service quality and development **Operational management** • Management of referrals and waiting lists. • Management of reminders to ensure service users don't slip through the net (e.g. breast screening scandal). • Analysis of DNA rates to identify trends/characteristics. • Can combine patient record systems with clinical management systems to record contact etc – improved accuracy and saves time. • Avoids duplication of data and minimises error. • Greater data security than email. **Information access** • Ability to retrieve information in formats that support (longitudinal) research. • Information can support quality improvement e.g. audit. • Information for professional development.

Table 2: Perceived barriers to the use of data management systems

Security and confidentiality	**Knowledge and understanding**
Access barriers • Complexity of rules around sharing of information (need for more mandatory sharing of information). • Lack of sharing between the NHS and Social Care. • Some professions do not share records. • Reluctance of some GPs to sign up to sharing agreements. • Perceived hierarchical issues in data sharing – having to justify reasons for gaining access (solution – summary information could automatically be shared without the need to access the whole record e.g. missed appointments and reasons rather than current 'all or nothing'). • Some service users don't give permission for GP records to be accessed. • Lack of empowerment of practitioners to retrieve data in formats that support audit, research and quality improvement. ***Service user confidence*** • Suspicion amongst the public re. how their data are used. Need to educate the public and have bigger conversations about 'big data' (generally a sense however that younger generations are less concerned about security).	***Training*** • Lack of formal training from people with experience of using the system. Training from IT is often quite basic. Can lead to incorrect use e.g. with filing of information. ***Functionality gap*** • Often a big gap between practitioners' knowledge of the systems and the actual potential of their functionality. This is often due to fear of overwhelming practitioners. Need for 'clinical champions' or 'clinical information officers' who understand the needs of services to get maximum potential out of systems' functionality. Involved interested practitioners to form working parties to evolve systems. ***Lack of interest*** • Need to educate practitioners about how systems and 'big data' can help them to do their jobs more effectively. ***Lack of trust*** • Systems are underused as diagnostic and clinical decision support tools as practitioners do not always trust tech to do this better than humans.

Inappropriate use of data	**Technical infrastructure**
• Misuse by staff (nosiness). Practitioners shouldn't be able to open records that aren't of relevance to them (should be prompts asking if they really need access). • Some systems automatically connect to relative records which is inappropriate. Practitioners divulging passwords and leaving smartcards in computers (solution – biometrics).	• Slow systems • Systems crashing and not saving data. • Lack of interoperability across different systems. • Not all systems permit effective data mining and searching.

Table 3: Desired opportunities for digital technologies

For service users

- Opportunities for service users and carers to be able to input information directly into data management systems (in order to increase sense of responsibility, empowerment, person-centred care, reduce 'them and us' perceptions.

For practitioners

- Greater use of teleconferencing for meetings.
- Teleconferencing of consultations would save time (in terms of travel and recording of notes).
- Access to a dashboard that would allow practitioners to monitor own performance in terms of service user management.
- Portable devices and technology for use during community visits (to record information, access assessment tools and calculate results, access records). Would need to be accessible with data management systems so that information can be accessed and uploaded. This would save time and repeat visits, increase collaboration.

For interventions

- Greater use of teleconferencing for consultations (easier for service users with mobility problems and lack of access to transport).
- Use of teleconferencing or other platforms that permit two way communication by physiotherapists to demonstrate exercises and check that service users are performing these correctly.
- Data management systems that can link to apps e.g. to automatically recommend exercises for physiotherapy.

Table 4: Perceived benefits of other digital technologies

Health interventions	**Service organisation and management**
Current treatment • Information provision, general advice and education ('virtual crutch'). • Ability of apps to provide video instruction rather than written instructions (useful for physiotherapy exercises). • Visual information for people with poor literacy skills. • Simulators to minimise risk and enable practising of skills. • Apps for cognitive remediation and mood diaries – more accessible, easier to engage with and more fun, less stigmatising and less like a therapy session, particularly useful when dealing with difficult situations. • Apps with reminders to carry out interventions can be very motivating. • Use for first line management whilst users are on waiting lists. • Continuity of intervention – tech can be used to take service users beyond the level that is sometimes achieved by face to face services. ***Upstream health promotion and early intervention*** • Use of devices to track and monitor own health – increases user responsibility, sense of control, empowerment and collaboration, potential reduction of appointments and prevention of admissions.	• Automatic text reminder services. • Digital appointments sent out via text with links to the letters (system prompts postal letter to be sent if the electronic copy is not opened). Gives users option to rebook or cancel. • E-learning for practitioners.

Table 5: Perceived barriers to the use of other digital technologies

Resources and management	**Service users access**
Funding • Large scale deployment of tech requires funding for service redesign (deployment is typically on a small scale). Limited capacity within health and social care for R&D and for trying new things. **Time** • Lack of time and support for practitioners to innovate. Current services are reactive. Practitioners are faced with large caseloads and meeting targets with little capacity for training and time out (focus on the gadgetry is not sufficient). • Lack of time to review apps in order to confidently recommend them (not all participants aware of ORCHA). **Support** • Lack of sharing of information and lack of ‘permission to get things wrong’. Cultural shift is needed. • Lack of communication and engagement from management. Staff need to feel that they are valued. • Need for greater academic partnerships - ‘AHSN and universities are too far removed to understand the challenges that are faced on the front line. • Need for more robust evaluations – ‘poor quality research around the lack of tech deployment’ that blames practitioners and gadgetry itself.	• Relies on users having up to date technology. Social and financial deprivation are barriers for some. • Fear of technology. • Lack of knowledge of how to use technology.
	Design • Insufficient attention to the psychology of how apps are used e.g. what makes people choose particular products over others.
	Ethical issues • Ethical issues of technology that attempts to replicate real life. • Deskilling e.g. use of robots.

Table 6: Specific design issues *(most of these relate to data management systems and are followed by DMS)*

Likes	Negative aspects of design	Recommendations
• Ability of systems to 'lock down' and restrict access to specific information e.g. psychology reports, addresses of domestic refuges (DMS) • Visual systems with images of bed layouts (DMS) • Ability to upload photographs of service users (DMS) • Symbols to highlight specific alerts (DMS) • Predictive typing for conditions (DMS) • Audio alerts that interface with calendars (DMS) • Ability to send messages within the data management system (DMS) • Bright and colourful interface rather than grey (DMS) • Colour coded task bars (DMS) • Rounded fonts • Large icons	• Format is too GP focused – doesn't allow for larger amounts of information and free text appears cluttered (DMS) • Limited wordage capacity (DMS) • Data management systems that print out information in reverse chronology (DMS) • Only being able to have two consultations or one document open simultaneously (DMS) • Systems allows a second document to be opened (in the event of forgetting to close the first one) but then will not let the second document be saved (DMS) • Drop down menu does not allow for multiple options to be selected simultaneously. Having to reopen the menu is time consuming (DMS) • Multiple areas for the same information (DMS) • Having different ways to perform the same task (DMS) • Lack of formatting options – cannot embolden, italicise, underline, insert headings/subheadings or add circles or asterisks (DMS) • Doesn't allow for reporting of negative findings e.g. strikethroughs (DMS) • Doesn't allow for annotations (DMS) • Images can be scanned but show up as paperclips that are buried within the text (DMS) • Bombardment of information and notifications on apps can be overwhelming • Systems/apps that require multiple clicks • Systems that do not auto check for spelling errors • Flashing icons • Overload of options on menu bars • Too many sub menus	• Systems should be able to track who has logged into a record in order to ensure appropriate use. Ability to audit time of access, pages viewed, amendments made in order to facilitate random checks to be carried out (DMS) • Systems that can permit diagrams that can be annotated (DMS) • To be able to scan and upload documents (DMS) • Systems to be able to replicate information in several places (DMS) • Search and find tool (DMS) • Tools to filter information by discipline (DMS) • Systems should have a 'back' function which allows for exploration, trial and error and self-teaching (DMS) • Pre-set input options to save time, e.g. attempted telephone call, assessment completed (DMS) • Customisable tabs (DMS) • Need for a balance of information and support on apps

APPENDIX 2: RESULTS: STAGE 2

Initial workshop

A workshop was held on 11th January with three companies, selected to represent 'opinion leaders' in the digital health sector. This was effectively an 'expert panel' to discuss the results of the clinical interviews and gain input to plan the larger workshop event.

The discussion focused in three main areas:

- Review of the findings, particularly those related to barriers and opportunities to use shared data systems;
- Discussion of how the findings could be used most effectively;
- Proposals for further work.

Review of Findings (Barriers and Opportunities)

There was a discussion about standards and the limitations that this implies. Companies are not able to gain large scale traction, as each organisation requires a slightly different approach. There is a need for standards and frameworks that might include how data should be used, how consent should be taken, as well as the existing Information Governance (IG) systems. This is required at a national level, but should also be co-ordinated at an international level.

The panel noted also that training needs should be more effectively addressed. All clinical professions need digital skills and this should be included within their basic education programmes. They need to be able to use digital systems, but also to select and assess them. Such training would enable clinicians to prescribe and coach patients to use IT effectively, as well as empowering them to work more closely with technology developers.

There was an impression that acute services are more concerned about data security than community services, and that allied health professions (AHPs) were less concerned than medics or physicians. The panel discussed whether this could be part of the power imbalance in the structure and a perception that control of data (knowledge) is correlated with control. It was noted that AHPs' work is often less 'black and white' and requires an ability to seek a wider range of information than an acute surgeon or physician. Hence, the use of shared data fits more naturally. There is also a tendency for community services to work across different professions and with organisations outside the NHS, again requiring a pragmatic approach to data sharing.

There was a further discussion about culture. Medical specialists operate in a highly competitive framework and the funding framework can further reinforce this, as they may perceive that collaborative practice could lead to 'losing their patients' to another service or colleague.

The researchers reported that it had been difficult to in many cases to get interviewees to think conceptually, with a tendency to want to discuss very specific software issues. For instance, many used EMIS and wanted to focus on its features and design, rather than being able to reflect more generically on patient data management principles. The panel advised that, conversely, the findings were rich and the individual professionals' stories could be powerful. There is a need to 'evangelise' still within the NHS and to promote these experiences.

It was also noted that poor design can lead to software being used in unintended ways. If people cannot get the system to do what they want it to do, they find ways around. Sometimes these new ideas can be helpful to developers and managers, but more often they are indicative of a design problem.

Many interviewees had noted problems working with GPs. The panel observed that many GPs disliked data sharing, but as patients or citizens, we should be pressurising them to share our data. The data should legally belong to the patient, although this is by no means clear under present frameworks.

Using the findings

The format for the larger workshop was discussed and planned. The panel then made suggestions for some specific dissemination.

Some of the findings are useful to the software development community. However, companies need to understand that in healthcare it is not enough to have good products. They need to engage with users, understand processes, workflows and services. The most successful systems have ‘role specific’ user profiles, that are well tested and designed.

There is also a major need to influence NHS decision makers, who need to show leadership in the field. This needs to include setting standards, training and skills development, regulating and maintaining frameworks. The IG framework has started the process but does not go far enough.

Royal Colleges are very influential. Many health professionals identify as much with their professional institutions than with their organisations. Clinical ‘evangelists’ can be helpful, but in some cases, they alienate their colleagues and need to be supported to avoid them working in silos. Our findings should also be shared with politicians at a national and regional level.

Proposals for further work

There is a need for a ‘blueprint for change’ which could later become the basis of standards and regulatory systems. This should be academically led, but could be supported by industry. A starting point would be an academically led working group, with representation from the clinical professions. The panel suggested various sources of funding, but was particularly interested in a model that could involve industry subscriptions and hence would not have to be run on a time-limited ‘project’ basis.