

Scoping the Design Space for Data Supported Decision-Making Tools in Respiratory Care: Needs, Barriers and Future Aspirations

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ABSTRACT

There is an increasing demand from healthcare providers for timely and accurate information about patients' conditions, to support appropriate decision making about their needs. Often, healthcare providers have limited data access due to complex issues surrounding sharing agreements and data recording and storage. Designing data-supported decision making (DSDM) tools in this environment is challenging, as they often fail to fully integrate into practice. Existing work focuses on implementing tools such as dashboards and smartphone apps to support decision making practices. However, these tools often operate independently from main systems, and there is limited HCI research on the challenges of designing and integrating such tools into long-term health-care delivery. We describe our participatory design research with clinical and service management staff on a respiratory care ward. We use the process of designing a DSDM dashboard to explore larger challenges behind designing DSDM tools for healthcare providers.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)**; Interaction design process and methods; *User centered design, Participatory design*

KEYWORDS

Data supported decision making; clinicians; user centered design; respiratory care; health data.

1 INTRODUCTION

Healthcare professionals are responsible for making swift, lifesaving decisions each day to ensure the best quality of

care for patients. Hospitals, clinics and general practitioners encounter a hugely diverse number of patients living with different conditions, including chronic conditions which are long lasting and usually progress with time. Chronic Obstructive Pulmonary Disease (COPD) is an umbrella term encompassing a set of progressive lung conditions, causing narrowing and inflammation of the airways [1]. COPD is estimated to become the third leading cause of death worldwide by 2030 [3], with high rates of emergency hospital admissions in the UK and US [43, 4].

Being admitted to hospital is a highly disruptive experience for patients and their families. Hospital admissions, especially if unplanned, also place a great strain on healthcare services [43, 44]. Data supported decision-making (DSDM) tools can be a vital resource for clinicians who are required to plan for, and continuously evaluate service delivery and patient care; allowing them to plan for potential spikes in admissions by supporting the effective management of resource demand [6, 19].

Existing research has identified different types of DSDM tools, from patient health self-tracking apps that share data with clinicians for personalized care planning [16]; to system dashboards used by clinicians to interlink data from different sources and support decision-making around patient treatment [18]. This paper focuses on data dashboards due to their extensive use in healthcare delivery, including hospital admissions reduction [16], best practice adherence [17], high risk patients' identification [27] and medication monitoring [18]. Related work highlights the challenge of integrating systems into clinical use, due to poor cultural fit or lack of integration and linkage to other key clinical systems [5, 6].

However, there is currently limited HCI research working in partnership with clinicians to understand the complex procedural, cultural and technical challenges that arise behind the scenes when innovating for long-lasting technology in this space. Thieme et al. [33] discuss the difficulties of integrating research into hospital services and the cultural changes needed to accommodate the introduction of research projects onto hospital wards. In addition, Fitzpatrick and Ellingsen [24] discuss the technical complexities of implementing technology in the healthcare

domain, due to diverse requirements attributed to different hospital departments and professions. Existing clinical systems also tend to be poorly integrated [5] and fail to meet the demands of its users [24].

In this paper, we describe an 8-month ongoing research project which involved working in partnership with COPD clinicians and service management staff in a UK hospital. Our work focuses on designing DSDM tools that can integrate into current healthcare practices and facilitate transition to future data supported healthcare delivery. Our paper provides three contributions to the HCI community. First, we outline the complex multi-stakeholder involvement process required to integrate technologies into healthcare systems infrastructure. Second, we introduce an in-depth understanding of technical and cultural barriers, and appropriate design mechanisms that can advance future work in this area. Finally, we offer insights into opportunities within the design space surrounding DSDM technologies. We present perspectives and lessons learnt from our localized case study in a UK hospital that can be translated across to other healthcare contexts [9].

2 BACKGROUND

2.1 Chronic Obstructive Pulmonary Disease (COPD)

Lung diseases, like COPD, account for over 700,000 hospital admissions annually in the UK [4]. COPD primarily affects those over the age of 45 and is often linked to smoking and social deprivation [1]. Symptoms include breathlessness, persistent coughs and frequent chest infections. This can have an impact on multiple activities of daily living, such as climbing stairs or engaging in social activities. Diagnosis usually involves a spirometry test, where a patient will blow into a device to test their lung function [1]. Patients with COPD may be prescribed with inhalers, attend annual check-ups and self-manage their condition. Smoking cessation is seen as the most effective way to prevent the worsening of COPD [1].

2.2 Challenges of Working with Health Service Data

Health data can be captured in a diverse number of ways and subject to a complex recording process. This makes extracting data for analysis in new systems challenging, as it can be difficult to correctly identify patients being treated for a certain condition. Free text, such as handwritten notes, is rarely used for secondary analysis due to the difficulty of analyzing such data [11]. For this reason, it is difficult to incorporate such data into DSDM tools.

In addition to the complexities of working with health data, strict data sharing agreements and interoperability issues that exist in many healthcare environments limit clinicians from accessing data they often require to effectively treat a patient (e.g. emergency room staff not having a list of medications prescribed to a patient by their GP) [8, 40]. In a recent mainstream UK newspaper article, it

was reported that UK doctors and nurses have turned to smartphone apps such as *Whatsapp* to share patient information in non-identifiable ways [29]. This was seen as a response to the inadequacy of data sharing in the healthcare environment. In the US, patients may bring print-outs of their health information from one hospital to another due to lack of access by their clinicians [36]. Such challenges in accessing health data calls for more effective data sharing, access and communication tools in the healthcare sector. Exploring the design challenges arising in this space is required to provide knowledge for moving forward.

2.3 Data Supported Decision Making (DSDM)

DSDM is a core topic of HCI and computer science. IBM's Watson, for example, shows potential in offering DSDM in healthcare industries, through assisting physicians in patient treatment and diagnosis by mining medical data to support clinical decision-making [12]. Research into DSDM tools has spanned from healthcare service planning around insurance costings [13], service administration [14] and business intelligence uses [15]; as well as improving the provision of care, such as reducing hospital admissions through patient captured data [16].

Medical research highlights how DSDM dashboards can be implemented to ensure adherence to best practice in clinical settings, and manage a range of medical conditions. McMenamin et al. [17] described a patient dashboard, linked to electronic medical records that provided color coded indicators for health targets agreed between patients and clinicians relating to smoking, alcohol, cervical and breast screening [19]. They report a higher recording of smoking status and alcohol consumption from patients through its use [17, 19]. Similarly, Waitman et al's [18] Adverse Drug Event dashboard combines data from different clinical systems to identify high-risk scenarios with certain medications; an example of the benefits of using DSDM tools to improve healthcare provision [19].

The majority of HCI research within this space has focused on self-care and the use of DSDM technologies to support patients in making sense of their own healthcare needs [20, 13, 16]. For example, Colley et al. [20] discuss the recent drive to empower citizens to monitor and manage their own health in collaboration with medical professionals. They designed and evaluated a personal health monitoring dashboard for citizens, to address challenges with existing personal health data collection (such as paper diaries which can get lost and are difficult to reflect on.) There has also been research around patients collaborating with healthcare professionals for better care planning, through shared visualization tools [13] and shared access to patient collected data through smartphone apps [16].

The literature uncovers multiple challenges around conducting research within healthcare contexts. For example, Zois [22] reviewed Internet of Things (IoT) healthcare applications that utilize sequential decision-

making models to improve patient care, noting that the designers of DSDM tools need to take into account missing data through potential non-compliance of the patient. Challenges around integrating healthcare tools in practice are attributed to healthcare professionals not understanding the purpose of tools [6], prevailing culture against the tools [6], designers failing to consider clinical expertise level when designing systems [25] and tools not being linked to key data or other systems (such as electronic health records) [6]. The challenges around integrating healthcare tools demonstrate a key requirement to work in partnership with healthcare professionals and other stakeholders. This ensures that researchers are designing tools that address current problems in practice, whilst being mindful of clinical culture and ensuring that data needs are understood.

Our study attempts to bridge some of these gaps in the literature by (a) understanding the needs of clinicians that can be supported by a DSDM tool; (b) uncovering the challenges in addressing these needs within current clinical practice and organizational operation; and (c) investigating the complexities of integrating DSDM tools into existing healthcare systems infrastructures.

3 STUDY DESIGN

3.1 Research Context

The National Health Service (NHS) is the UK's publicly funded national healthcare system. In England, many hospitals are managed by NHS 'foundation trusts' (or trusts), which are self-standing, self-governing organizations which provide healthcare services to patients [21]. A foundation trust is made up of primary and secondary care services. Primary care services are the first point of contact for a patient, such as GP practices, pharmacies or dentists. Secondary care services are carried out within hospitals and clinics (such as in-patient care, where a patient is admitted to hospital for a condition). In the US, healthcare is primarily funded through employer-provided insurance [8]. Hospital services are provided by private or government corporations. Similar to the UK, physicians in the US will see patients in their practice and refer them to hospital for further care if necessary. These hospitals can be community hospitals or specialty hospitals (e.g. specializing in an area of care) [8].

This study involves a hospital in the North West of England that is part of a larger NHS foundation trust. At this hospital there are approximately six different digital systems used across primary and secondary care domains. These include a prescription management system, digital document archives (that archive patient documents such as hospital discharge letters) and an electronic medical records system. However, these systems are not linked together and are governed by strict data sharing agreements, meaning that not all healthcare professionals can access required (yet already

digitally captured) data about their patients. For example, a clinician treating a patient who is admitted to hospital for a COPD exacerbation may be unable to see what medication the patient has been taking. This might affect the type of medication a patient may be given to treat their exacerbation. This limited data access means that clinicians must rely on patient and family report to gain needed information, which can be time-consuming for patients and medical staff alike and duplicates data that has already been captured.

3.2 Data Analysis

This was a qualitative study made up of individual interviews, focus groups and workshops, which were audio recorded and then transcribed. Following this, the transcripts were coded using a thematic analysis approach [26]. Two of the authors coded the transcripts which were then discussed with and checked by another author. This involved iteratively creating codes for the data at a sentence level, then comparing codes to form similar groupings. These groupings would then be used to generate broader themes which described key topics that had emerged, resulting in a detailed taxonomy of the data. The findings after each stage were then used to drive the next stages of the research, using the key themes to fuel the next discussion points with the participants. In addition, a one-day observation was conducted at the hospital's IT department to understand how the current clinical systems worked in practice. Field notes were taken and used to augment the interview and focus group data during the analysis stages.

3.3 Dashboard

Our work with participants revolved around understanding clinicians' data needs and the ways in which data could be combined to inform better care planning. The process of requirements gathering and design scoping of the dashboard has uncovered the processes and challenges of system design in healthcare contexts. We engaged a range of stakeholders to understand the complexities and feasibility of implementing a DSDM dashboard that could address the needs of the clinicians within the healthcare infrastructure. Our research is grounded in a complex and multifaceted setting which requires careful research to understand barriers which may be faced when implementing a DSDM in this space. A DSDM dashboard was chosen to achieve these aims as they are familiar to the clinicians and commonly used across hospitals. They are accessed on clinicians' office computers and shared computers across the hospital for specific disease areas, such as cardiac disease.

3.4 Participants

Our research involved 10 stakeholders; 4 clinicians (3 consultants and 1 nurse, all specializing in COPD), 3 business intelligence (BI) representatives, and 3 IT representatives. BI are responsible for the operational service management support of the services within a trust.

IT staff are responsible for the training, development and maintenance of the IT systems within the service. All stakeholders worked for the same organization.

We included different participants groups as this approach supports a more inclusive consideration of different levels of expertise, knowledge and skills [30]. For example, it was necessary to involve BI and IT to better understand the technical and work-flow feasibility of the emerging dashboard designs. BI and IT staff were also able to contribute unique knowledge about the different types of data and systems across various organizational departments; this equipped us with a better understanding of the possibilities of implementing DSDM tools into the broader healthcare infrastructure.

4 FINDINGS

4.1 Stage I: Scoping the Design Space

The first stage of the research focused on working with participants to scope the problem space and discover areas where a COPD dashboard could provide a solution. Three initial one-to-one interviews were conducted with the consultant clinicians (CLIN1, CLIN2, CLIN3). The goal was to gain initial insight into their everyday practices and challenges—and ultimately discuss how they felt a DSDM dashboard could address these challenges—with a focus on the types of data that was either currently available and ready to use, or unavailable but required. Questions surrounding data needs focused on service level decision making relating to the clinicians' entire caseload, and data that was needed to inform better decision-making around individual patients' care. The data needs were then collated and outlined in a requirements document that would be used to probe the rest of the scoping stage. This was followed by a two-hour interview with 2 IT leads (IT1, IT2) to better understand the systems currently used in clinical practice. During this time, IT2 carried out a cognitive walkthrough (a common usability inspection method [31]) of the main system used in practice. The types of data collected and stored in the system were explored, followed by the processes a clinician would go through to access certain data about a patient. The feasibility of addressing the data needs outlined in the requirements document were then discussed with the IT leads, distinguishing the needs that could easily be met from those that would be more challenging to meet.

4.1.1 Lack of Data for Daily Decision-Making. Clinicians were asked to discuss areas in which they felt a clinical dashboard would alleviate some of the challenges they faced during their everyday work. When discussing these challenges, they highlighted that it is often difficult to make informed decisions around individual patients' care as data about their full care journey is captured and stored in different digital systems. Furthering this, they did not have access to every system where this data was held, which made it difficult for clinicians to decide the next steps to take when

planning care for a patient. CLIN2 displayed frustration around not being able to access patients' data history “*you have to be able to compare and contrast in order to make a case for change*”. BI2 explained that they “*use a combination of systems ... so that we are able to capture more detail essentially*” expanding on this by saying “*systems don't necessarily talk that well together ... so, there's a challenge around that in the first instance*”. To which BI1 summarized the overall problem as: “*patients move from one place to another...when they're at the hospital it's the systems the hospital is using and then when they're in community [care] it's the IT systems we use*”.

Following on from this, it was also reported that data was collected in different formats (paper notes, digital notes, Excel spreadsheets). Paper based data was difficult to access due to where it is physically stored after capture, and the mixture of formats made it difficult to make use of such data. CLIN2 discussed the trust's ambition to integrate more data into electronic systems, stating that “*changing the way we work and collected data*” would be “*really important*” to accommodate this desire. They then continued by saying:

“There's a lot of data out there, but it's just not in a useable format at the moment ... it's a mixture of paper and electronic records. We are slightly altering as we move on, trying to build more data into the electronic systems...”

Clinicians were asked if they believed they had access to all the data required to make decisions around a patients' care, to which CLIN3 responded with a degree of frustration stating “*We don't ... I have to physically ask the GP to fax [test results], why can't I see the investigation on my screen if there is one?*”. When prompted further about how they saw a dashboard alleviating this problem, CLIN3 resumed: “*If it's all in the cloud somewhere ... I can tap into those resources and see that information, which will help me make further decisions when it comes to A&E that is not available at the moment.*” It was then revealed that the reason patient data was not shared between primary and secondary care services was due to strict data-sharing agreements. However, clinicians were able to share data verbally through phone calls (such as calling a GP to obtain test results) and letters, but not digitally through the IT systems.

4.1.2 Lack of Data for Strategic Planning. Clinicians mentioned that another key challenge for their service was the lack of data for resource allocation and strategic planning. Service managers often had to make decisions on how to best allocate resources based on anecdotal evidence from clinicians rather than having data supported evidence. For example, clinicians noted that service performance data (such as number of admissions for COPD, performance levels for certain interventions, average length of stay for COPD, etc.) was not visible to them, which affected their ability to work with service managers to forward plan. CLIN3 described how lack of visibility of this data interferes with their ability to plan for spikes in hospital admissions:

“We need to understand what is going on, so we can see how many more COPD nurses we need, or community based COPD services we need and address that”

Having access to service level data would allow the clinicians to address *“that unpredictability [the rise in COPD hospital admissions]”* that *“makes us vulnerable and makes the whole system vulnerable really”* (CLIN2). This could be achieved through using data to identify patterns and *“look at what is causing that pattern”* (CLIN3) and address service vulnerabilities. Clinicians noted that without access to such data, their current strategy to deal with spikes in admissions is simply to work harder. BI1 discussed ways in which visualizing service performance data could serve to improve the performance of their overall service:

“If you suddenly saw an increase in activity from a particular GP practice...then you could go and do some further investigations, there might be that there’s a locum in for 6 months...it’s being able to visualize it and see where the connections might be”.

This simple, but key requirement demonstrated the possibility to benefit services beyond respiratory care, holding the potential to also impact their wider trust. BI1 described how this type of service level data was currently collected and available for use, meaning that it was possible for this data to be used to address these needs.

4.2 Stage II: Understanding Priorities and Implementation Challenges

To further investigate data needs and solutions feasibility, we wanted to observe how the clinical systems were used in practice. For this, a one-day observation was carried out at the hospital with IT3. This began with IT3 carrying out a cognitive walkthrough [31] of the remaining clinical systems used in practice. We then unobtrusively observed clinicians using the different systems on the wards in the hospital. Field notes were later made recalling the experience, as it was not permitted to bring writing materials onto the wards. The final stage of the scoping phase was a focus group with the broader stakeholder team, which included 2 clinicians (CLIN2 and CLIN3) and 3 BI representatives present (BI1, BI2, BI3). The objective was twofold: to update the rest of the stakeholder team about the previous research activities, and to discuss and refine the data needs outlined from the initial one-to-one interviews with the wider group.

The next stage of the research was aimed at understanding and prioritizing the clinicians’ data needs and challenges to implementation that may follow. Two 2-hour workshops were held at a quiet clinical site away from the hospital, with CLIN2 and IT2 in one, and CLIN3, CLIN4, BI1 and BI2 in the other. The reasoning for two separate design workshops was due to clinicians’ availability. Including BI and IT within the workshops was important to utilize their expertise around some of the wider organizational challenges that could affect technology

adoption (not just within clinical practice). During the workshops, clinicians were asked to think about their data priorities for the dashboard that would improve their service. BI and IT were tasked with assessing each of the priorities and deciding whether the data for each priority was readily available, or if there were any challenges or barriers for accessing such data. Collaboratively, we discussed possible solutions and their feasibility, including how they could be integrated into existing infrastructure. Participants were encouraged to think out loud and talk through their ideas when writing their priorities on the post-it notes, sparking discussions between the clinicians and other participants. We focus our stage II findings below on the challenges and opportunities that were raised during these two workshops.

4.2.1 Integrating New Systems into Workflow. During the observation of the systems used on the wards, a clinician mentioned that during the integration of a new system for prescriptions, many nurses and clinicians were heavily against the technology, but had then become more receptive to it after time had passed and the benefits were realized. The initial rejection was due to having to change their work flow (recording paper based data in a digital format instead), their lack of perceived technical competence, and the commitment required to being trained to use the system. Training was identified as a huge challenge area for nurses and clinicians, due to time constraints. IT3 described how the training of staff was attempted gradually, as clinicians and nurses could not be away from clinical practice all at once for long periods of time. This led to some nurses and clinicians being trained on the system, while others were not. Inconsistency of training then meant that data was being incorrectly input into the system, such as entering different units of measurements for medicine. IT3 expanded on the negative effects of lack of training as clinicians relied on their, often fallible, ‘intuition’ to use the system. This also led to data entry errors, which were not immediately flagged due to the way the systems had been designed, again causing errors further down the process.

In order to support a DSDM tool, it was acknowledged that some paper based data would need to be collected digitally for use on the dashboard. The organizational change from collecting paper based data to digital data was another challenge area identified. IT1 discussed the challenges with marrying paper and digital notes and the effect that this would have on current systems:

“You’re actually taking that paper assessment and saying we need it to go into a live system ... it does change the way that the current data is held in there ... that’s a little bit of time and constraint [to change and adapt]”.

How to act upon data visualized on the dashboard was another area that was described as a change to current workflow. CLIN2 highlighted that there would need to be a clinical and business protocol in place in preparation for responding to data projected from the dashboard (i.e. how to

collectively respond once the dashboard demonstrates there is an increase in admissions for example). CLIN2 expanded:

“What leads on from that, really, is a bit more complex I guess, is how we have agreements with other trusts about how we respond to these spikes in admissions as well. Although we need to re-deploy staff and stuff, how we actually go about doing that is going to be [difficult] ... Understanding the agreed resources needed to be able to respond to that, and how that will look, so some kind of plans as to what will happen if we get spikes in admissions”

The concern that staff might be unwilling to use a new system was also raised. CLIN2 raised questions around *“how to get people to use it and to be able to educate them [on using it]”* once it became available. They noted further that it would require *“transforming people’s ideas about how they put information in [to a digital system].”*

4.2.2 Trust in Data Sources. The reliability, consistency and trustworthiness of some of the data captured was also identified as a challenge. For example, the clinicians spoke of the *“issues around diagnosis at the moment, around spirometry”* (CLIN2) stating that incorrect readings lead to patients being misdiagnosed with COPD and referred into hospital. Spirometer tests are routinely used to test for COPD. Being misdiagnosed with a condition puts patients on the wrong care pathway, and introduces increased demand on services. CLIN2 raised the concern that *“there’s been a big change in the way people are trained to deliver spirometry and we don’t really have any idea about the quality of spirometry across the patch”* and expanded further by saying that they *“can’t really be sure that it is correct [the quality of the spirometry reading]”*. Clinicians noted having to *“beg, borrow and ask somebody”* (CLIN3) for patients’ test results, but once obtaining the result, being unsure if they are able to trust the quality of the test undertaken.

“[A] patient is referred into chest clinic, the GP might do some spirometry, they might not ... I would repeat it anyway because I wouldn’t be sure [of the quality], so they get done often more than once” – CLIN2

CLIN3 vented their frustration in having to repeat these tests by saying: *“it’s duplication for the patient, I kind of feel like I’m forgetting the patient in the middle of doing all these things”*. BI1 also acknowledged that there was some *“consensus”* that *“the quality of spirometry depends on where the patient has attended that test, it’s higher in some areas than others”*. This led to a higher likelihood of patients being misdiagnosed and admitted into hospital depending on the place they had attended for diagnosis. BI1 discussed the benefits of accessing this data on a dashboard:

“If we could just look at that, that in itself would make a massive difference, not just to the number of inappropriate referrals that we’d have to accept anyway because technically they’ve been diagnosed with COPD, but also from the patient perspective as well because it then puts the patient on the pathway that they might not need to be on.”

BI1 discussed the benefits of making data on the source of where tests are undertaken available, for example, when and where tests are taken followed by misdiagnosis rates at these locations. They mentioned:

“If there are misdiagnosed patients, if we have the data to see where they are, where the initial assessment took place, then technically if it’s one clinician somewhere who is not particularly good at carrying out that test then we might be able to track it back” – BI1

However, BI1 was careful to identify that this type of data could be considered *“political”* and a thorough consideration of the granularity of the data and *“who has visibility of that”* would be necessary.

4.2.3 Patient Reported Data. Clinicians also stressed the importance of encouraging patients to record qualitative health data in the future. Clinicians were especially excited for patient generated data to be captured and shared with them *“either electronically or using [an] app”* (CLIN2). They felt this could help with early identification of higher risk patients and predict increases in admissions rates. CLIN4 expressed the importance of gathering qualitative data for COPD as *“two people with the same spirometry might show quite different levels of symptoms”*, demonstrating that quantitative tests in hospitals do not fully capture how a patient is feeling. CLIN4 discussed how paper based self-management booklets are provided to COPD patients, but have a poor compliance rate:

“They are provided with a self-management booklet which looks at and monitors their symptoms...I would say the level of compliance with it, again this is anecdotal, it’s quite poor, lots of colors and lots of ticks and people just look at them and go I’ll never be able to do that...”

CLIN4 further highlighted the need for simple tools to support these kinds of patient driven activities.

4.2.4 Technical and Implementation Barriers. There were several technical barriers raised regarding the implementation of a new DSDM. One of the most prominent challenges identified by BI2 was that the main system at the hospital, used to collect and store the majority of patient data is *“a very old system”* and that they hold a contract with and *“it’s essentially is as it is”* which meant that *“our hands are kind of tied in terms of what we can do”*. This made it difficult to address the additional data requirements that clinicians raised, since the current system was incapable of recording certain types of additional data that a DSDM could utilize. For example, data around clinical outcomes were noted as being *“not really something at the moment that current system are able to record ... if they were, it would be dead easy”* (BI1). This highlighted the need for clinical systems to be flexible to adapt to evolving needs.

Clinicians discussed that in order to overcome the limitations of current clinical systems, they had to create their own solutions such as using Excel spreadsheets. However, this approach did not work particularly well due

to the vast amount of data to be recorded, as CLIN4 reported: *“I’m just waiting on the spreadsheet we have at the moment, we are inputting the data onto it but it doesn’t work properly.”* They stated that capturing and maintaining data in this way was very *“manual”*, to which BI2 explained why approaches such as spreadsheets are used in the first place:

“Having a system across the trust that fulfils everyone’s demand in services that operate very differently across the trust is very challenging and this is why you have these things like spreadsheets and recording things in this way because there’s no alternative bespoke system” ... it’s basically because we can’t, let’s say, have the flexibility to have it in the main system.”

The process of viewing certain data on the main clinical system was highlighted as a challenge by clinicians. Clinicians used the example of accessing a list of patients who are in hospital with an admission relating to their COPD. This is something that the clinicians said they would do daily by logging on to a system that would: *“bring up a list of patients who have got this flag [a COPD flag] but it won’t say whether the particular admission is because of their COPD, they could have come in with, you know, a nose bleed”* (CLIN2). This meant that clinicians would either have to *“ring the ward”* (CLIN2) or physically click into each individual patient profile on the list to clarify their admission, which CLIN2 stated was *“a waste of time, unfortunately I don’t have the capacity to do this for every COPD patient”*. CLIN2 and IT1 both agreed there was a need for these data flags to be more *“meaningful”*. Data flags referred to tags that linked a patient to a certain condition or code (for example, a ‘Do Not Resuscitate’ code), where each patient diagnosed with COPD would be flagged with what was known as a ‘COPD flag’. This made COPD patients easily identifiable on the system. IT1 and described their ideas of what a meaningful flag would be:

“A meaningful COPD flag would say ‘yes, this patient is in’, but on the problem that they’ve come in for, it would say broken leg, therefore the system will say they’re in for a broken leg, and the specialist nurse will go, hmmm, might pop and see and see if they’re okay, haven’t seen them for a while, or might go, you know what, I really need to see the other 5 that have come in which says ‘COPD patient’ problem ‘COPD related’- that’s meaningful” – IT1

Along with the inflexibility of current systems, time and resources were highlighted as a barrier to preparing data to feed into a DSDM tool from current clinical systems. IT1 mentioned that it was not necessarily the technical complexity of integrating a DSDM into existing infrastructure that would cause the main problem, but the management and operational aspects of such a large project:

“It’s not the ability, because we could do it, but again it is down to time and resource, we need someone gluing it all together and being able to communicate it all ... it’s like

what we are doing now ... it’s that constant keeping it flowing, otherwise stuff gets butted in, I end up behind”.

IT1 also expressed that they would feel guilty working too closely with the clinicians stating: *“I know we can do this, but I don’t want to take any of CLIN2’s time working”.*

5 DISCUSSION

The following synthesizes the findings from our study. We discuss considerations for the design and implementation of future DSDM tools in healthcare contexts.

5.1 Inflexibility of Current Systems

We learnt that there was considerable variety of clinical systems used within and between health trusts. It was not uncommon for clinicians to switch between the different systems in place to gather the patient data that they needed. Payne et al. [23] note the challenges around access to patient data when organizations implement multiple clinical systems. Existing systems were bought in and contracted, confined to settings offered by the suppliers until the end of the contract. Therefore, in practice it may not be feasible to suggest creating completely new systems to replace existing systems. Within this limitation, we recommend taking advantage of the configuration and customization options offered by suppliers to address data challenges and functionality within existing systems. Further, researchers should look to create bespoke DSDM tools that layer on top of existing systems that provide additional functionality and improved design.

We found that clinicians required data to be more *“meaningful”*. That is, data that is more useful by being *“pertinent to that particular patient on that particular admission”* (CLIN2). This would allow clinicians to pinpoint exactly which patients to prioritize in pressured situations. Existing systems required clinicians to manually click through lists of admitted patients flagged with having COPD to find the true reason for their admission—or even phone the wards to ask for this information. This was frustrating for the clinicians, as they were not presented with the relevant data, instead having to manually search through the system to find information. However, during discussions with IT, it was discovered that data flags could be modified, allowing for more meaningful connections between the data. In this instance, flags could be modified to show patients *who were admitted to hospital for an event relating to their COPD* rather than patients *who had COPD and were in hospital*, providing a more intelligent view on the data. This simple modification would save time and allow clinicians to better prioritize which patients require specialist care.

5.2 Trust in Data Sources

While trust and health data has been documented in areas such as patient trust in health information [35] and trust in use of patient data and systems [28, 37, 38], we uncovered clinicians’ trust concerns around certain medical data. This

stemmed from not having access to both the source of the data and meta-data (i.e. who collected and recorded the data and how), which they felt they needed in order to ‘trust’ certain data and act on it.

For example, it was reported that there was a consensus that certain practices had higher rates of misdiagnosis due to lack of training. We found that clinicians were reluctant to trust the quality of the spirometry tests undertaken at different practices. As a result, they often duplicated spirometry tests to avoid acting on results that they could not trust. There lacked a way for clinicians who encounter a misdiagnosed patient to report this back to the referring primary care physician. This made it difficult for struggling practices to be identified and targeted for extra support. A system feature that can support a feedback process to inform practices of their misdiagnosis statistics could allow them to be targeted for support. This could be a simple check-box approach that verifies that the test results (taken in hospital) correspond with the original diagnosis (taken by the primary care physician). This would reduce the number of patients who are put on the wrong care pathway and would support and strengthen struggling services.

Designers of future DSDM systems should be mindful of the potential trust issues around the quality of test results, which may make clinicians hesitant to act on presented data. Considering that clinical data can be input into systems from different locations and healthcare professionals, accompanying this data with information on its source may allow service managers to identify struggling practices to instigate training. However, BI highlighted that identifying struggling practices and less trained healthcare staff could be considered political, and to alleviate this potential tension, systems could provide an option for clinicians to provide feedback without disclosing the origin of the initial test.

We further found that clinicians were keen for a DSDM tool to support integration of *qualitative* self-management data collected by patients through a smartphone app. This would aid patient-personalized care planning. Qualitative symptom data was said to be important for clinicians to understand a patient’s quality of life. App prescribing mechanisms are on the rise [7, 39]. However, it has been noted that self-care apps selected by patients are not always certified [2], do not always support collaborative review in clinic [2] and lack standardized format which effects how well they integrate into existing health provider tools [10]. Clinicians may be hesitant to prescribe or advise apps that are not certified as being safe and relevant [40, 45]. In order for patient reported data to effectively integrate with DSDM tools, self-management apps must integrate within the patient care pathway to ensure patients and clinicians can benefit from the collected data as part of their care planning. It is also important for apps to gain the trust of clinicians and patients alike through app validation processes [45], such as the through the FDA [46] in the US or ORCHA in the UK

[42]. App validation processes utilize clinically validated frameworks to assess health apps on the market. This provides reassurance to clinicians that the apps they prescribe are safe and clinically validated, and provides assurance to patients that the apps are effective for self-care.

5.3 Building on Current Practices

Time and effort required to train and *convince* clinicians to use a DSDM tool was identified as a major challenge. System training was not only identified as a time-consuming, but unnecessary by medical professionals who often thought they had the knowledge and skills to quickly master the use of new tools themselves. We found that, despite efforts, not all medical staff were trained on systems that were used, which led to human errors in the use of the system, which then affected work flow and on occasions caused disruption to patients. These findings place great emphasis on the importance of creating sensitively designed tools [34] which are mindful of the cultural differences between health practices and practitioners. We found that current technology used in the hospital had failed to keep up with the expectations from users. Clinicians expected to be faced with intuitive systems that did not require extensive, time consuming training for their use. It has been noted that lack of training can prohibit healthcare professionals from supporting certain clinical interventions [33]. This puts clinicians who lack the time to spend on extensive system training at a disadvantage. This stresses the importance of ensuring that healthcare professionals can be efficiently trained in system use, in order to fully support the use of DSDM tools and their intended benefits for care planning and service management.

Systems designed for clinical environments should consider the culturally diverse users while designing the system, instead of attempting to *convince* resistant users after implementation. Flexible training approaches should be considered, for example, visual tutorials that use step-by-step guidance, so users can learn ‘on the go’. It is also important to understand that changing current practices, such as computerizing documents extends beyond simply transitioning across media [32]. A slow participatory approach must be used to understand different clinical users. It is also vital to understand the unique data collection and workflow processes that revolve around obtaining and documenting data. This will enable design of DSDM tools that integrate well into clinical practice. The result of intuitive system design that supports familiar practice will ultimately minimize the time taken for staff to be trained on new system and promote system adoption.

Participants discussed the lack of data collation and visualization. They found it particularly frustrating that much of the digital data they required for resource allocation and strategic planning was already being collected, however it required a way to be assembled and visualized to support decision making in the fast-paced clinical settings. This data

included numbers on hospital admissions, available beds and average patient length of stay. Marrying these existing data sources on a DSDM dashboard and creating intuitive data visualization was noted as a ‘quick win’ – a task which could support current data collection processes and make use of pre-existing data sources.

5.4 Lessons for Future Research and Conclusions

Through our IT stakeholder involvement, we found that there are challenges around capturing a clinician’s expert knowledge when designing a new system. Capturing clinical expert knowledge and requirements for a new system involves clinicians spending time outside of clinical practice to liaise with IT staff, a prospect which gave IT1 a sense of guilt. This sense of responsibility, followed by time and resources, was voiced as a larger challenge than the implementation of a DSDM dashboard. In our study, we found that clinicians often made the time to attend sessions due to strong personal interest in the topic. However, there were periods where despite strong interest, clinicians had limited availability for session involvement. It was difficult on occasions to bring participants together. Therefore, we put forward the need for recognition within the HCI/design community around understanding more efficient ways of capturing expert knowledge from time-starved clinicians. We also believe it is important for health trusts to be exposed to HCI approaches and practices through research partnerships during their in-house design and development of systems.

We found the lack of data sharing between primary and secondary care services particularly challenging. It was interesting that clinicians share patient data verbally and through letters – but cannot share and access that same data on existing clinical systems. The difficulties of sharing patient data across services is also evident in the US [36]. In our study, this made obtaining some patient data difficult and time-consuming for clinicians, who had to phone and write to one another to obtain needed data. Providing a way to record how often these verbal and written requests for data occurred between clinicians would provide an evidence backed case for better sharing agreements across services.

In addition to the difficulties of data sharing, the differing of data formats (paper based, spreadsheets, and digital notes) made it challenging to design a DSDM tool that utilized all the data that clinicians needed. The challenges around multiple data formats in clinical settings is well documented [5, 11, 24, 32]. Future work must focus on designing and building flexible systems that support the slow integration of digital data in clinical settings that still use paper-based records. In real world clinical contexts, there may not be scope to implement perfect high-tech solutions. Solutions must strive to provide minimum disturbance and integrate well into current work practices and culture.

6 CONCLUSION

Understanding clinical data needs and the way that healthcare systems are integrated in clinical practice is essential for designing useful DSDM tools that can integrate into existing technical infrastructure. Previous research demonstrates several DSDM tools designed for the healthcare domain, however little is explored around the current challenges faced when integrating DSDM tools into clinical practice. Our study identifies cultural and technical challenges when designing a DSDM tool to integrate into a hospital setting, which can be translated across different to clinical contexts. We provide design implications which map from findings that emerged from our two-stage study process. We believe the findings from our work will help to advance HCI research around designing DSDM tools with clinicians that can positively impact clinical practice and fulfill healthcare professionals’ genuine desire to improve patient care.

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