Connected Health Cities – End of Project Report

Workforce Development:

The Role of Data Supported Decision-Making Technology in Respiratory Care

Contents:

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Helena Tendedez

Abstract:

A collage of information is required for effective clinical decision-making around a patient's care. This includes reviewing paper notes, digital documentation, and liaising with other clinicians involved in the patient's care.

Data supported decision-making (DSDM) technology can support clinicians in this process, by connecting them to required data and providing useful visualisations of that data.

However, understanding how to design these technologies and how clinicians will engage with them is crucial to their success in practice.

Moreover, there is potential for clinicians to access health data generated by patients themselves to better manage the patient's care and promote self-management.

To explore this in more detail, we have worked with healthcare professionals and patients to uncover their needs for designing DSDM technologies that aim to support Chronic Obstructive Pulmonary Disease (COPD) care.

COPD is a large challenge both on individual patients and healthcare services in the North of England, which makes it an important point of focus for this research.

We present novel design considerations that can help future work in the area of designing DSDM technologies that aim to improve the care of patients with COPD.

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Introduction:

Healthcare professionals are tasked with making timely, informed decisions to plan a patient's care.

For patients with chronic health conditions, informed clinical decisions often rely on accessing information from a range of different sources including other healthcare professionals involved in a patient's care.

Patient information can be shared between healthcare professionals through multidisciplinary team meetings which bring them together to discuss a patient's care or through technologies such as electronic patient records (EPRs).

However, the heterogeneous, sometimes incomplete, ways that data is collected and presented via these methods can create challenges for information sharing (Swartz et al. 2014; Rowlands and Callen 2013; Vogwill and Reeves 2008).

Moreover, some argue that EPRs do not have sufficient ways of visualising data on chronically ill patients (Christensen and Grimsmo 2008).

This presents an opportunity for digital technologies to better connect, communicate, and visualise data for clinical decision-making. In doing so, technology can better support healthcare professionals and patients alike by using data to provide insights into care management.

In this research, we contribute an understanding of how to design technologies that healthcare professional and patients can use to improve Chronic Obstructive Pulmonary Disease (COPD) care.

COPD is a blanket term that covers chronic lung conditions including emphysema, chronic bronchitis, and chronic asthma (COPD Foundation, 2016). It typically arises due to long-term exposure to airway irritants, such as cigarette smoke or air pollution (National Heart, Lung, and Blood Institute 2019).

It is a prevalent chronic condition that affects 64 million people worldwide (World Health Organisation, 2019). As well as impacting many people across the world, COPD also proves to be a large financial challenge the National Health Service (NHS) in the UK. It generates over

140,000 hospital admissions annually with 97% of these for emergency care reasons (Snell et al. 2016).

We worked with healthcare professionals and patients to understand how we could design technology that would support them in COPD care.

We focused on ensuring that the aims of our project aligned with the Connected Health Cities (CHC) Programme, outlined in Table 1.

This research was made up of three primary research questions:

(1) How can technology support healthcare professionals in their decision-making for COPD care?

(2) How can technology support patients to self-manage their COPD?

(3) How can technology facilitate collaboration between healthcare professionals and COPD patients through the practice of self-monitoring?

To answer these research questions, we conducted three strands of work. The first involved co-designing a DSDM dashboard prototype with respiratory healthcare professionals that would unite them with the data that they need around COPD care.

The second involved working with the respiratory community to understand their self-management needs and opportunities for technology to inform and support their self-management to reduce exacerbations of their condition.

The third took a case study approach where we investigated the role of self-monitoring technology in COPD care. We gave patients an off-the-shelf mobile health app to use for four weeks for symptom monitoring, and the data was sent to community care respiratory nurses. Overall this research seeks to understand how we can *design* technology that meets a real need in COPD care, by working directly with end-users.

Table 1. The studies within this doctoral research and which Connected Health Cities aim they align with

Study	Alignment with aims of Connected Health Cities
Understanding Data Supported Decision-Making in Respiratory Care	• Develop ways health professionals can use their expertise to turn data into knowledge • Put in place the consent and systems needed to enable health professionals to use data to improve care • Support front line staff to develop and monitor new and more effective pathways (programmes of care) for patients with Chronic Obstructive Pulmonary Disease (COPD).
The Role of Technology in Supporting Self-Management of Chronic Respiratory Conditions	• Create a culture that enlists the trust and active involvement of residents in the North West Coast • Put in place the consent and systems needed to enable health professionals to use data to improve care
Understanding the Role of Patient-Reported Data in Respiratory Care	• Create a culture that enlists the trust and active involvement of residents in the North West Coast • Put in place the consent and systems needed to enable health professionals to use data to improve care • Develop ways health professionals can use their expertise to turn data into knowledge • Support industry, academia and others in using data that both improves understanding of health care efficiency and effectiveness and also enables new techniques, ideas and organisational systems to be tested

Methods:

The research carried out within this doctoral research primarily utilises a user-centred design (UCD) approach. User-centred design is a common framework in human-computer interaction research that emphasises the importance of focusing on the target user's needs at each stage of the design process.

In the context of this work, the design process refers to the design of technology that can help with the care of people with COPD.

The principles of UCD are drawn from numerous diverse fields, including computer science, engineering, psychology, anthropology, and sociology (Ritter et al. 2014).

The methods used in this work are mainly qualitative, drawing on individual people’s rich experiences of working within, and receiving care from, various healthcare services. I worked closely with both patients and healthcare professionals through three chapters of research to uncover how data supported technology could help support the care of people with COPD.

All research presented here had the necessary ethical approvals from the Health Research Authority and Lancaster University.

Understanding Data Supported Decision-Making in Respiratory Care

While conducting the research for this chapter, we carried out a series of focus groups, one to one interviews, design workshops, and surveys with healthcare professionals working within two collaborating NHS trusts.

There was a total of 11 healthcare professionals involved in this work, three business intelligence representatives, and three IT representatives from both NHS trusts.

Including different participants groups in this study supports a more inclusive consideration of different levels of expertise, knowledge and skills, which are valuable to understanding how such technology could be integrated within the NHS trusts (Bowen et al. 2011).

For example, involving BI and IT staff provided an insight into the technical and work-flow feasibility of emerging dashboard designs. They could also contribute unique knowledge about the different types of data and systems across the organisation.

This information could not have been effectively obtained through solely involving the HCPs. Therefore, the involvement of a diverse group of participants equipped us with a better understanding of the possibilities and challenges involved with designing and implementing a DSDM dashboard into a broader healthcare infrastructure.

During this study, we worked to understand why healthcare professionals believed a DSDM dashboard could support their decision-making around COPD care and their service. We then used this understanding to co-design, with healthcare professionals, a DSDM dashboard that would meet their data access needs.

To do this, we conducted a series of design workshops where we focused on healthcare professionals' data needs and paper prototyped the ways in which they would require the data to be visualised.

Once this iterative process was concluded, we decided to focus on five key areas which the dashboard could best support the work of the healthcare professionals that we could explore in more detail.

We worked with a research associate to develop the paper prototypes into a professional digital dashboard. Once the digital dashboard was prototyped, we conducted 11 one to one qualitative evaluations with the healthcare professionals to gather their feedback.

The Role of Technology in Supporting Self-Management of Chronic Respiratory Conditions

This work focused on exploring the potential role of technology in the management of COPD to overcome the challenges and needs faced by people with the condition.

Particularly, this chapter takes the mix-methods approach to understand how technology can support people with the management of their CRC.

We explore ways in which people with COPD can start collecting health data of their own to share with their healthcare professionals for decision making.

To achieve the aims of this work, we conducted a survey of 147 participants, one-to-one interviews with 13 participants, workshop findings from 11 participants, and a number of engagements with the Breath Easy groups across the North West of England.

The first phase on data collection was a survey. The survey was hosted on Qualtrics and consisted of 17 core questions, ranging from free-text responses to selection lists for user input. It was advertised primarily through a snowball sampling approach (Johnson 2014).

We distributed the survey link online through email and social networking websites such as Facebook, Reddit, and HealthUnlocked. We used the COPD community forums on HealthUnlocked and Reddit to ensure we were reaching the relevant audience.

I also sent paper versions of the survey to four respiratory support groups in the UK (who then distributed these to their members and posted responses back to us), to reduce the chance of technology literacy bias in the results and ensure the responses reflected both online and offline communities.

Once the survey had closed, responses were collated and analysed using NVivo software to better organize, manage and code the number of survey responses (Welsh, 2002).

We analysed the survey responses using an inductive content analysis approach by hand (Hsieh and Shannon 2005).

The second phase of the study was conducting 13 one-to-one interviews with people with CRCs. Most participants were recruited through the support groups, but interview recruitment was also advertised online.

We set out to recruit participants that varied in their age, length of time having been diagnosed with a CRC and their experience of using self-management tools for their condition. This would help to ensure that diverse and rich perspectives were captured.

Before finalising the interview schedule, which would be used to guide each one-to-one interview, we provided the proposed schedule to an experienced Patient and Public Involvement lead, Debbie Parkinson, who provided feedback on the questions.

Debbie Parkinson also provided the interview schedule to a COPD patient champion whom she worked with, who additionally provided feedback on the wording of the questions.

It was important to gain feedback on the questions so that we could ensure that our language and wording of questions was sensitive and inclusive to participants.

Interviews were then conducted using a semi-structured exploratory approach, which allowed the questions to change direction (to an extent) to explore interesting ideas and insights provided by participants. Each interview was audio-recorded with participants' permission and transcribed verbatim for analysis. Each interview transcript was coded using a bottom-up thematic analysis approach, conducted by hand (Braun and Clarke, 2006). We stopped recruiting participants for interviews once we felt that no new themes were emerging from the interviews, which indicated data saturation (Fusch and Ness, 2015).

The third and final phase of the study was a participatory design workshop held at one of the support groups that we had been engaging with throughout this research.

The aim of the workshop was to explore one of the key findings from the interviews in more detail, through detailed discussions with the respiratory community.

We decided to explore the importance of support networks and information needs within the respiratory community, which we would then consider in the design of future self-management technologies for COPD.

The workshop was structured as a series of activities that were designed to draw out discussions with participants, in a way which was hands-on and allowed participants to feel empowered. The workshop was audio-recorded and analysed in the same way as the interview data.

Understanding the Role of Patient-Reported Data in Respiratory Care

The final strand of work in this doctoral research employs a case study approach to understand how technology can facilitate collaboration between healthcare professionals and COPD patients through the use of self-monitoring technologies.

We worked with an NHS Trust, and issued patients with a COPD self-monitoring app called 'How Are You Today', which allows patients to monitor their daily symptoms. The reports of their symptoms are then sent to the respiratory clinicians in the Trust.

We used a publicly available mobile health app instead of creating our own as the purpose of the study was to understand the potentials that technology could hold in this context.

We were not looking to design and evaluate our own mobile health app. Instead, through understanding the patient and healthcare professional experience of generating and receiving self-monitoring data, we could provide insights into how design technology that can best facilitate this collaboration.

We provided patients with the How Are You App to use for a period of four weeks. We recruited four patients with COPD for the study, which is an adequate sample size for investigating patient experience.

Before the patients used the app, we interviewed them for an hour to learn about their experiences living with COPD and their perceptions of technology to self-manage their condition. We then proceeded to enrol each patient on the study for four weeks, where they were tasked with monitoring their symptoms every day.

At the end of the study, we interviewed patients again to understand their experience of using the app to self-monitor.

We also interviewed the community care respiratory clinicians at the start of the study to understand their motivations around introducing self-monitoring technology in their service and their expectations.

At the end of the study, we interviewed them again to understand their experiences.

Results:

The sections below provide a *summary* of the findings from this doctoral research. A full breakdown of the findings from each section can be found in the relevant publications and doctoral thesis produced from this work (Tendedez et al. 2018, Tendedez et al. 2019a, Tendedez et al. 2019b).

Understanding Data Supported Decision-Making in Respiratory Care

Through undertaking a series of interviews, observations, and workshops, we managed to uncover requirements for a DSDM dashboard for COPD that would support clinical work.

Using these requirements, we designed a prototype dashboard, which we evaluated qualitatively with clinicians.

Evaluations showed that DSDM dashboards have the potential to support clinical decisions around COPD care, by being able to better understand the patients' severity and condition journey through the collation of relevant data.

A node of caution arising from the research relates to how clinicians may trust data that is visualised on a dashboard, as it was revealed that some data sources are considered more reliable than others.

In summary, we believe that the collation and visualisation of data around COPD can support clinicians in their decision making, but how it is visualised and where it is sourced from are important contenders in how the information can form part of clinical decision making. We have published part of these findings and are continuing to publish this work.

The Role of Technology in Supporting Self-Management of Chronic Respiratory Conditions

Through involving a total of 167 participants from the respiratory community, our findings reveal the self-care challenges of COPD and other chronic respiratory conditions.

Key findings include a lack of information received at diagnosis from healthcare professionals, uncertainty around the diagnosis of the condition, the stigmatisation of the condition faced by participants, and the reactive management approaches that some take to manage their condition.

Overall, we believe there are opportunities for technology to better support these challenges living with chronic respiratory conditions. For example: through better connecting people to information on how to manage their condition at the point of diagnosis and how to identify their personal triggers in their condition.

We also identified that technology, such as mobile health apps, needs to cater to the evolving needs of the condition. This means that people may outgrow certain self-care practices and require different types of support as their condition progresses.

Moreover, technology should be designed to ensure that it has the potential to reach everyone. That includes people who do not have access to the latest technologies (such as wearables), and those who may be hesitant to seek help due to stigmatisation and concerns around using healthcare services as an older adult.

Understanding the Role of Patient-Reported Data in Respiratory Care

Although clinicians did feel that there was a valuable place for self-monitoring in the care of people with COPD, the findings from our small-scale study revealed three key accountability concerns that clinicians faced when supporting patients' use of the self-monitoring app as part of their service during the study.

These accountability concerns arose from:

(1) the need to verify daily recommendations that the app produced with the patient

(2) account for concerns about patients who may over-report their symptoms

(3) account for concerns that patients may depend on them to immediately detect and subsequently act on any signs of health decline surfacing from the data.

This created unforeseen strains on the clinicians' daily work, as they had to correct or clarify aspects of the patient-generated data and the daily recommendations with the patient.

As clinicians could not rely on these recommendations being appropriate, they became accountable to correct them for patients.

We argue there is a need to better recognise potential accountability concerns and factor in contextual differences within local services when designing self-monitoring technologies (such as considering the advice they give to their patients that may align with local guidelines).

Conclusion:

DSDM technologies have the potential to support and enhance the care of COPD.

By working closely with healthcare professionals and patients, we have uncovered a number of designs considerations that impact how future technologies for COPD care should be created.

Our user-centred approach to this research has additionally helped us to cover complex socio-technical considerations that must be addressed to successfully support DSDM technologies in the healthcare space.

Author/Main Contact:

Doctoral Research by Helena Tendedez

Supervised by Dr Maria-Angela Ferrario, Dr Roisin McNaney, and Professor Jon Whittle

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Helena Tendedez

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Helena Tendedez