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Co-Designing a Primary Care Breathlessness Decision Support System: General Practitioners Requirements Analysis, Workflow Assessment and Prototype Development

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Abstract. Clinical decision support systems (CDSS) have been shown in a variety of diseases to lead to improvements in care. The aim of this study is to design a CDSS to assist GPs to assess and manage breathlessness, a highly prevalent symptom in practice. A focus group is conducted to explore the needs of general practitioners (GPs), assess current workflow to identify points for intervention and develop early prototypes for testing. Five GPs took part in the focus group elucidating 248 relevant data points which were then qualitatively analyzed using the Technology Acceptance Model as the theoretical framework. In general, there was a positive attitude towards the use of CDSS for breathlessness with various proposed features from the participants. Twelve high level workflow steps were identified with 5 as key points for intervention. Several proposed features such as reporting likelihood of causes of breathlessness in a patient, link with evidence-based recommendations, integration with clinical notes and patient education materials were translated into a prototype. Mixed-method studies are planned to assess its usability to inform subsequent iterations of the CDSS development.

Keywords. clinical decision support system, primary care, breathlessness

Introduction

Breathlessness defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity"[1] is found in about 11% of Australians.[2] Changes to the biosphere and environment due to climate change[3], sequelae of respiratory infections like coronavirus disease 2019 (COVID-19), all of which negatively affects cardiopulmonary health will likely further increase the burden of breathlessness in Australia and globally. With 87.8% of Australians visiting their primary care physician at least once a year[4], most breathless patients are likely to present to primary care even when it is not their main or only presenting symptom.

The multidimensional aspect and myriad possible causes for chronic breathlessness, ranging from respiratory to cardiac to metabolic diseases, mental health and

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deconditioning, create a major diagnostic challenge for this very common problem. In the primary care setting, a study of patients referred for breathlessness reported that less than 30% had a fully concordant referral diagnosis with the final diagnosis.[1] An analysis of the online British Lung Foundation Breath Test also reported that even after seeking medical advice, 58% stated that their breathlessness had not improved.[5] The researchers hypothesised that this sub-optimal care for breathlessness may be due to the underutilization of effective evidence-based interventions for breathlessness.

Clinical decision support systems (CDSS) have been shown in a variety of diseases to lead to improvements in care. Even so, the systematic review also concluded that among the trials included, usage and compliance was generally low. Furthermore, compliance with CDSS recommendations was also reported to be low.[6]

Hence, while designing a user friendly and validated CDSS is of great importance, its implementation into practice relies on how clinician end users and practices respond to the integration of a CDSS with existing workflows.[6] Understanding the needs of clinicians who will be the end-users and having them participate from the start in a co-design process will improve uptake of digital health interventions.

The aim of this phase in the development of the breathlessness algorithm and CDSS is to explore the needs among general practitioners who care for people with breathlessness. Specific aims were to understand the burden of breathlessness in their practices, current assessment pathways and points for referrals, identify the most challenging point in care, their current use of CDSS, response to using CDSS for breathlessness and development of an early CDSS prototype for further testing.

1. Methods

1.1. Participants and Data Collection

A focus group (FGD) was conducted with five general practitioners (3 males and 2 females) from varying local health districts. Exploratory open-ended questions were used to enquire about the current state and challenges in breathlessness assessment and management. Questions were specifically developed to assess what could help GPs in this field, current use of other CDSS, facilitators and barriers to use, and their openness to using a breathlessness CDSS. The discussion lasted about 90 minutes in length and was conducted in February 2018. Clinicians were invited to participate through the local primary care health network and from doctors that have previously referred patients for breathlessness to the investigator's clinic. Average monthly prevalence of patients identifying breathlessness as a problem was between 5% to 12%. Workflow assessment was conducted using a business processes workflow diagram and prototypes developed using Balsamiq. Ethical approval was granted by the University of Sydney Human Research Ethics Committee. Informed consent forms were sent to participants prior to the FGD.

1.2. Data Analysis

The audio recording of the FGD was transcribed for analysis. Coding was performed using NVivo 12 using an approach as described by Terry et al.[7] With a focus on the intrinsic behavior intention of end users (doctors) to a CDSS, the Technology Acceptance Model (TAM) was used as framework for analysis and not others which has

substantial focus on external influences.[8] Direct quotations from participants were reported between single quotes.

2. Results

A total of 248 relevant data points was collected from the FGD. Data were analyzed into 2 main themes – perceived usefulness and perceived ease of use. We examined these themes from the view of current CDSS usage, related this to proposed features to improve the breathlessness CDSS and in brackets link this to the prototype translation.

2.1. Perceived Usefulness of a CDSS for Breathlessness

To elucidate the usefulness of a CDSS for breathlessness, we aimed to understand the current care pathways and challenges clinicians faced in practice when managing patients with breathlessness. The challenges described by GPs are summarized in Table 1.

Table 1. Current breathlessness care challenges reported by clinicians

Topic	Key points and quotes	Summary
Current practice challenges and tests	'Frustrating' 'moving diagnosis. 'Multifactorial' causes, 'multimorbidity' and 'uncertainty' found especially in the elderly. Common tests in practice are electrocardiography, complete blood count, spirometry and pulse oximetry.	Diagnosis is the most challenging component in the care spectrum and 'most important'. Among common tests spirometry is one which they can do 'okay' but am 'not an expert'.
Points for referral	'Concerned patients', 'personal worries', 'severity' and 'length of time with symptoms'. 'The reward for sending to a specialist is low'. 'Compartmentalized medicine'.	Gut feelings described as 'internal anxiety' and 'litmus test' as driver of deciding on a diagnosis, diagnostic tests done and referral.
Manage-ment	Issue with treatment 'adherence' in some patients including asthmatics. Patients often come with requests for testing after visiting 'naturopaths' and other alternative practitioners.	Once diagnosis is made it becomes possible to 'formulate a management plan'. Time needed to compare the utility of further tests.

Considering diagnosis to be the main challenge, most clinicians proposed a diagnosis focused CDSS, hence our focus on the diagnosis stages in the prototype (Figure 2A-C). The clinicians mention the need of an 'algorithm' for breathlessness. The algorithm should help with 'ruling things in but also ruling things out', importantly to help cast away the organic issues that if missed 'could kill the patient' and lead to determination of inorganic causes like 'deconditioning' and 'anxiety'. GPs could see the utility of a CDSS that can provide the 'percentages e.g. 10% deconditioning, 10% cardiac disease etc' and 'chance' for the causal disease of breathlessness in a patient (Figure 2C top). A CDSS would need to be based on the most recent 'evidence' with quick access to 'guidelines'. (Figure 2D left) Whereas another clinician proposed a CDSS that can recommend the most 'important decisions' early on. This was translated by presenting differentials from page one of the CDSS (Figure 2A). The clinician imagined that knowing these recommendations, he would be more inclined to prioritize them over other tests especially with the time limitation in practice where consults typically last for only '15 minutes'. The CDSS should also guide decisions based on the patient's 'previous results and current results' before recommending a 'referral' e.g. to a cardiologist.

Even so, one clinician pointed out that his problem with 'pathway algorithms is that sometimes it stops you thinking', a solution proposed for this by the group is for a CDSS that is 'simple but takes you down a diagnostic path as opposed to trying to establish a diagnosis'. This is with a note from one clinician that this only stands true 'till you're absolutely certain what it is'. Additionally, when this happens, risk scores and management oriented CDSS' can help to educate patients (Figure 2B – links to validated questionnaires).

One clinician described the usefulness of the cardiovascular (CVD) disease risk score in 'scaring patients' by seeing the impact of their activities on their health. Another possible use is if a CDSS can automatically provide the above 'side-by-side comparison' of the utility of diagnostic tests (Figure 2C). It can also be useful to provide 'management plans' with reference to red flags that patients need to be reminded to 'come back sooner rather than later' if particular symptoms appear. Another use for the CDSS in patients with inorganic causes is to provide guides on 'how fit patients can get' and 'improving their conditioning'. This is currently all done manually.

2.2. Perceived Ease of Use

Individuals' past actions have been shown to be a good reflection of their future behaviour.[9] Considering this, perceived ease of use is elucidated based on how easy or challenging it is to use current systems. Furthermore, as with usefulness, we will relate this with clinicians' proposed features to improve ease of use.

The clinicians reported current use of a variety of CDSS tools namely the 'CHAD score', 'AUSDRISK', 'MMSE score', 'DASS-21', 'Cervical screening flowchart', 'Health Tracker', 'FRAX score' and 'CVD risk calculators'. 'Embedded' or 'integration' with current electronic medical records system (EMR) is a feature reported to improve ease of use. One clinician described how she calculates CVD risk on the 'background' for all patients of appropriate age. Another describes CDSS automatically incorporating available data such as blood pressure and smoking to the score. Even so, integration with family history remains a caveat.

Others reported the use of more basic CDSS being 'a set of questions you answer and get the score'. On the other hand, another clinician reported some algorithms being more 'complicated than what he can handle', all clinicians did concur that the CDSS must be 'simple' and 'short' to fit with practice timing constraints. CDSS use is expected to 'save energy' through communicating ideas simply and providing only 'the most important points' in an algorithm.

The clinicians proposed something 'smaller than an algorithm' presented on screen that 'sums up the recommendation' based on the history and previous results. However, it should also provide the option of seeing the 'more complex' 'main algorithm' either by 'right clicking for further details' or through other buttons where they can bounce between the algorithms (Figure 2D). This also addresses the need of some of the clinicians to know 'how did they get there (the recommendation)' before deciding whether they are to agree or disagree. Especially one of them who preferred to have 'the computer pop the algorithm in from of me' and make their own decisions.

In addition, information from the EMR, integration with results from equipment (e.g. spirometry) was proposed. Furthermore, all clinicians concur that ease of use would be improved if the result of the CDSS could be directly 'incorporated into clinical notes' and even replace 'some of the history'. (Translated into ability to copy summary of CDSS recommendation into notes) Another idea was to incorporate patient's self-reported

history before 'actually going to the doctor' as part of the system. Lastly, one clinician suggested the analogy that the CDSS should be as easy to use as 'Google' where asking a specific question would lead you the most relevant guidelines and answers.

2.3. Attitude and Acceptance of CDSS for Breathlessness

In general, there was a positive attitude towards the use of CDSS for breathlessness. This is especially true when a 'diagnostic quandary' is reached or in providing help in deciding to send patients for 'something simple or should I escalate'. The clinicians find CDSS acts as a 'question channel', help 'validate my decision' and 'builds confidence I am in the right ballpark' for diagnoses that is at times made based on gut feelings.

Another aspect is the current 'swarm' of decision support tools, one clinician noted 'there's so many tools, there's so many things' that even when CDSS exist they are often forgotten and remain unutilized. The group suggest the use of appropriate reminders to remind clinicians that the CDSS exists.

An important aspect brought forward was whether the interventions including CDSS for breathlessness are positively affecting patients' 'quality of life' and their 'life expectancy'. Only when this is expected would one clinician said they "be open to expanding the number of patients with breathlessness they see", translating to screening more patients for breathlessness and routine CDSS use for this diagnosis purpose.

2.4. Clinical Workflow Assessment

Using a business-processes-workflow diagram, twelve high-level steps were identified in the process of assessment and management of breathlessness by GPs based on the results of the FGD question on how breathlessness patients are currently managed in practice and reflection from the clinician members of the team. Several points for intervention identified were at history taking, reviewing patient medical records, formulating a differential and personalized management plans, patient education and reporting into clinical notes as shown in Figure 1. Currently most of the steps in the workflow are undertaken manually by clinicians and involves their own clinical judgement based on varying levels of education and personal experience.

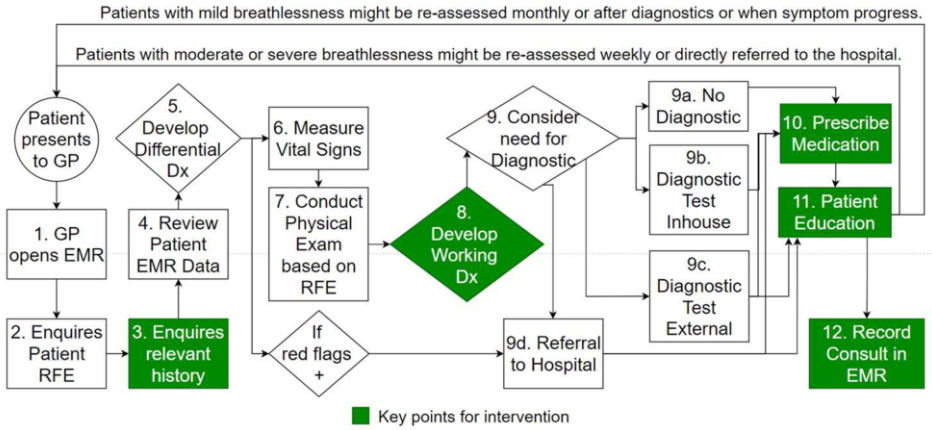

Figure 1. High level workflow overview and key points for CDSS intervention (green)
Dx – Diagnosis, EMR – Electronic Medical Record, RFE – Reason for Encounter

2.5. CDSS Prototype based on Clinician Requirement and Proposed Features

Based on the focus group and recent review on developing successful CDSS interfaces[10], we proposed the development of an expert system with integrated information display, order facilitators and documentation support which was then prototyped. Several screens from the prototype can be viewed in Figure 2.

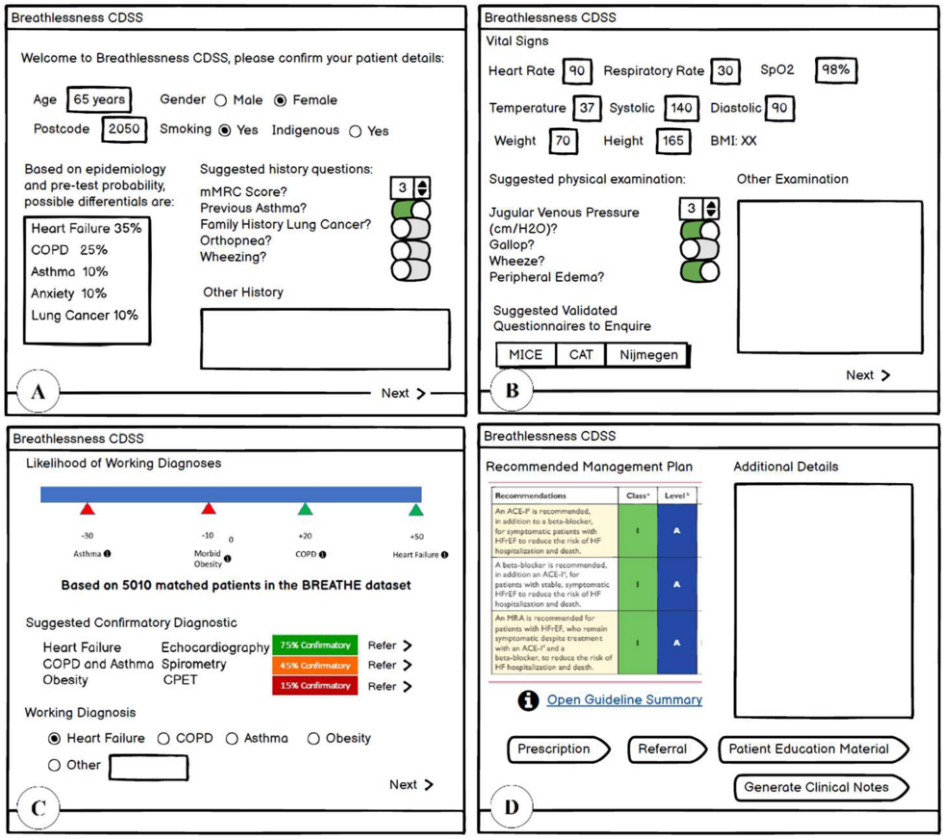

Figure 2. Breathlessness CDSS screen prototypes based on features proposed.
A: High yield history suggestions; B: Prioritising key physical exams; C: Diagnosis likelihoods, diagnostic utility of tests; D: Evidence based management suggestions

3. Discussion

This early co-design with general practitioners who will be end users of the future breathlessness CDSS has provided a reflection of the current reality of breathlessness care, workflow and CDSS use in primary practice. It has also provided inputs for design of the CDSS prototype which will be tested in future mixed methods studies.

Some of the findings elucidated were similar to a recent focus group discussion conducted by Trinkley and colleagues among general practitioners to explore physicians preferred features of a CDSS. Features proposed included being clinically relevant and

providing customisable support, presentation of pertinent clinical information e.g. labs and vitals, and improving their workflow as proposed by our focus group participants.[11] Reminders to use the CDSS were another point proposed by our participants and previous studies have also reported interruptive alerts may be more effective if well-designed.[11]

The barriers to current CDSS use do not seem to be as extensive as reported from another focus group in the Netherlands among 24 primary care physicians which reported insufficient knowledge of the CDSS, irrelevant and high intensity alerts, lack of flexibility and CDSS update, effects on patient communication and additional time as well as effort to utilise it.[12] This will be further explored in our subsequent focus groups.

The utility of CDSS for educating patients on CVD risk described by clinicians is one that is also supported by existing international literature. In another study on the use of CDSS in primary care for cardiovascular disease, 18 months after CDSS implementation 98% of physicians reported the CDSS improved cardiovascular risk factor control in their patients and helped initiate cardiovascular risk discussion.[13] These results demonstrate that when doctors have tackled the learning curve post CDSS implementation, these tools can provide benefits to the patient-doctor consultation.

With 96% of general practitioners[14] in Australia using computer for clinical purposes, the use of CDSS for managing breathlessness has potential to bring great improvements in care. However, as a recent systematic review on identification and assessment of breathlessness in clinical practice which included 97 studies showed a lack of study in primary care.[15]

Previous studies on CDSSs' effectiveness related to breathlessness have been on disease oriented systems once a diagnosis has been reached such as in patients with asthma, COPD[16] and heart failure[17] which reported improvements in outcomes and even reduce costs. However, as the focus group has shown, the clinicians want to have a precursor to such systems, one that helps in guiding them to an appropriate diagnosis before moving to more specific disease oriented CDSS.

Furthermore, the group recognised the potential benefit of a CDSS to support interpretation of simple tests – such as spirometry, where typically they report greatest difficulty. This is in line with a study which reported only 57.8% of COPD patients diagnosed in primary care having post-bronchodilator spirometry results consistent with COPD or asthma.[18] These suggest lack of confidence in interpretation although it might also relate to the recording quality, both of which can be supported by CDSS.

There were mixed views among participants on when CDSS recommendations should be provided. Previous studies by Kostopoulou et al. has shown that physicians have an emerging judgement early in the consult and that 56% of physicians remained committed to initial diagnostic leaning even after receiving conflicting cues.[19] Therefore an early CDSS as proposed by a participant might be an option to counter this diagnostic inertia and make clinicians more open to new differentials.

While this study is limited to the contexts of the participating clinicians, in general it suggests a positive attitude towards use of a breathlessness CDSS system by general practitioners. Five key points for intervention were identified and with clinician proposed features were translated into a prototype. This first iteration of the co-design process would support planning of future mixed-method studies to assess its usability to inform subsequent iterations of the CDSS development. Further studies are also planned to assess the accuracy of the expert system.

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