Patients' and Clinicians' Perceived Trust in Internet-of-Things Systems to Support Asthma Self-management

Patients and clinicians perceived trust in internet-of-things (IoTs) systems to support asthma self-management: a qualitative study

Chi Yan Hui, Brian McKinstry, Olivia Fulton, Mark Buchner, Hilary Pinnock

Submitted to: JMIR mHealth and uHealth
on: September 04, 2020

Table of Contents

Patients and clinicians perceived trust in internet-of-things (IoTs) systems to support asthma self-management: a qualitative study

Chi Yan Hui[1] BEng, MSc, PhD; Brian McKinstry[2] FRCPE, FRCGP, MD; Olivia Fulton[1] BSc; Mark Buchner[3] BSc; Hilary Pinnock[1] MRCGP, MD

[1]Asthma UK Centre for Applied Research, Usher Institute, University of Edinburgh Edinburgh GB
[2]Usher Institute, The University of Edinburgh Edinburgh GB
[3]Tactuum Ltd 280 St Vincent St Glasgow GB

Corresponding Author:
Hilary Pinnock MRCGP, MD
Asthma UK Centre for Applied Research, Usher Institute, University of Edinburgh
The University of Edinburgh, Doorway 3, Medical School, Teviot Place
Edinburgh
GB

Abstract

Background: Internet-of-things (IoT) systems with artificial intelligence can provide customised support for a range of self-management functions, but trust is vital to encourage patients to adopt such systems.

Objective: We aimed to explore patients/clinicians' trust in IoT systems in the context of asthma self-management (including emergency advice in action plans).

Methods: We interviewed patients recruited from research registers and social media, purposively sampled to include a range of age/sex, action plan ownership, asthma duration, hospital admissions and experience with apps. Clinicians, (primary, secondary, community-based), were recruited from professional networks. We transcribed interviews and used thematic analysis to categorise IoT features with reference to McKnight's trust model.

Results: We interviewed twelve patients and twelve clinicians. Most patients believed an IoT system could help support a broad range of self-management tasks, but wanted the system to provide customised advice. They believed they could rely on the system to log their asthma condition and provide pre-set action plan advice triggered by their logs. However, they were not confident that the system could generate new advice or reach diagnostic conclusions without the interpretation of their trusted clinicians. Clinicians needed clinical evidence before trusting the system.

Conclusions: IoT systems were regarded as offering potentially helpful functionality in mediating the action plans developed with a trusted clinician, but technologically adept participants were not yet ready to trust artificial intelligence to generate novel advice. Research is needed to ensure that technological capability does not outstrip the trust of the individuals using it.

(JMIR Preprints 04/09/2020:24127)
DOI: https://doi.org/10.2196/preprints.24127

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**
Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
Only make the preprint title and abstract visible.
No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**
Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

Original Manuscript

Patients and clinicians perceived trust in internet-of-things (IoTs) systems to support asthma self-management: a qualitative study

Chi Yan Hui io.hui@ed.ac.uk
Research Fellow, Asthma UK Centre for Applied Research, Usher Institute, University of Edinburgh

Brian McKinstry brian.mckinstry@ed.ac.uk
Professor Emeritus of Primary Care eHealth, Usher Institute, The University of Edinburgh

Olivia Fulton olive.fulton@gmail.com
Patient and Public Involvement Lead, Asthma UK Centre for Applied Research

Mark Buchner mbuchner@tactuum.com
Managing Director, Tactuum Ltd

Hilary Pinnock hilary.pinnock@ed.ac.uk
Professor of Primary Care Respiratory Medicine, Asthma UK Centre for Applied Research, Usher Institute, University of Edinburgh

Address for correspondence:
Professor Hilary Pinnock
Asthma UK Centre for Applied Research
Usher Institute, University of Edinburgh
The University of Edinburgh
Doorway 3, Medical School, Teviot Place,
Edinburgh EH8 9AG
Tel: 0131 650 8102
Fax: 0131 650 9119
E-mail: hilary.pinnock@ed.ac.uk

Keywords: Asthma, Self-Management, Telehealth, Internet-of-thing, Trust

ABSTRACT

Background

Asthma affects 235 million people worldwide. Supported self-management, including an action plan agreed with clinicians, improves asthma outcomes. Internet-of-things (IoT) systems with artificial intelligence could provide customised support for a range of self-management functions, but trust is vital to encourage patients to adopt such systems. Many models for understanding trust exist, some explicitly designed for ehealth, but no studies have used these models to explore trust in the context of using IoT systems to support asthma self-management.

Objective

We aimed to use McKnight's model to explore the functionality, helpfulness and reliability domains of patients' and clinicians' trust in IoT systems to deliver the 14 components of self-management support defined by the PRISMS taxonomy.Methods

We used 'think-aloud' techniques in semi-structured interviews to explore views from patients and clinicians. Patients were recruited from research registers and social media, purposively sampled to include a range of age/sex, action plan ownership, asthma duration, hospital admissions and experience with apps. Clinicians (primary, secondary, community-based), were recruited from professional networks. Interviews were transcribed verbatim, and we used thematic analysis to explore perceptions of the functionality, helpfulness and reliability of IoT features to support components of supported self-management.

Results We interviewed twelve patients and twelve clinicians.

- Perceived functionality: Most patients considered that an IoT system had functionality that could support a broad range of self-management tasks. They wanted the system to provide customised advice involving artificial intelligence
- Perceived helpfulness: They considered that IoT systems could usefully provide integrated support for a number of recognised components of self-management support.

- Perceived reliability: They believed they could rely on the system to log their asthma condition and provide pre-set action plan advice triggered by their logs. However, they were less confident that the system could operate continuously and without error in providing advice. They were not confident that artificial intelligence could generate new advice or reach diagnostic conclusions without the interpretation of their trusted clinicians. Clinicians wanted clinical evidence before trusting the system.

Conclusions

IoT systems including artificial intelligence were regarded as offering potentially helpful functionality in mediating the action plans developed with a trusted clinician, though our technologically adept participants were not yet ready to trust artificial intelligence to generate novel advice. Research is needed to ensure that technological capability does not outstrip the trust of the individuals using it.

INTRODUCTION

Asthma is a variable long-term condition affecting 235 million people worldwide[1]. In everyday life, patients make decisions on how to maintain control of their asthma and what to do if their condition worsens. When they are not sure what to do, they contact their healthcare advisor; within the UK healthcare system this would normally be the general practitioner or primary care asthma nurse. Supported self-management of asthma has many components[2], but specifically includes provision by the patients' usual healthcare professional of a personalised action plan summarising agreed decisions (e.g. medication adjustment, emergency strategies)[3-5].

With the increasing availability of sensors and improved coverage of wireless networks, an internet-of-things (IoT) system has the capability to observe patients' status and medication use and support self-management. Devices have the intelligence to perform a task on their own or connect to other sensory networks, platforms, and mobile phones to perform multiple tasks. Artificial intelligence (AI) may be 'narrow' (ANI: systems that interact with users based on set of planned rules) or can 'mimic/equal' or ultimately 'surpass' human intelligence to create new ways to interact with users (described as artificial general intelligence (AGI), or artificial super-intelligence (ASI) respectively) [6].

The IoT has been used to support clinical management in a range of contexts (for example, asthma, diabetes, hypertension) with examples including diagnosis, remote monitoring, remote consultation, self-management, emergency care and home rehabilitation[7-13]. The traditional trust between patients and their clinician is associated with improved medication adherence and health outcomes[14-18] and can be harnessed to encourage adoption and continued use of digital health systems[19-21]. Underpinning this is a gradual shift of trust from clinician to technology.

The concept of trust

The concept of trust is 'elusive'[22] but is typically illustrated as a relationship between two agents (a trustor and a trustee)[23]. Terms such as 'confidence', 'have faith in' and 'believe in' are commonly

used, and in the healthcare context multiple attributes have been summarised broadly as ‘The belief that a doctor is working in the patient's best interest’[14]. The term ‘e-Trust’ has been used to describe the trust between a human agent (e.g. patient, clinician, health carer) and a digital artefact agent (e.g whether it can achieve a given goal)[24]. In an IoT system, however, there may also be ‘trust’ between artefact agents, for example, an AI system may rely on (or ‘trust’) the technical specifications of a smart devices and system to collect and transfer accurate data on which to base advice to the user.

In the context of supported self-management, patients are the core users of digital health service such as health information websites, web-based consultations or online support group. Patients adopt telehealth for many reasons such as personal, technological, institutional and legislation but the decision to delegate a specific task to an intelligent system a fundamental factor is whether the patient trusts that the system can fulfil their expectations. Models of e-Trust have defined multiple factors required for the trustor to decide to trust a digital health system broadly classified as [25-30]:

- Personal factors such as altruism, ease of use, self-efficacy, sociodemographic, usefulness, recommendation by others, fair use of data, cost.
- Technological factors such as customisation, interoperability, data privacy.
- Institutional factors such as ability (or not) to improve communication with their clinician, professional training, accuracy of the information provided to the clinical service, service provider’s reputation, the organisation’s nature or business model.
- To these might be added ‘legislative factors’ in the context of healthcare, as (for example) medical device registration requires evidence of technological performance, effectiveness and safety that demonstrates that a product is worthy of trust[31-34].

McKnight’s model[35] in comparison to eTrust models, is based on an interpersonal trust model between human agent and the digital artefact agents and sees trust in technology as task specific

(aligned with the Castelfranchi & Falcone cognitive trust model for human agents[36]). This conceptualises three dimensions of task-specific trust in technology: functionality, helpfulness and reliability. In the context of supporting asthma self-management, ‘Functionality’ is how patients and clinicians believe an IoT system has the features and capability to accomplish a range of self-management tasks. ‘Helpfulness’ is the degree to which patients and clinicians believe an IoT system can provide adequate, responsive and useful aid to support their asthma self-management tasks and decisions. ‘Reliability’ is whether patients and clinicians believe an IoT system can operate continuously and properly to support tasks.

Trust in the context of digital support for self-management

Although there are many trust models[20,37] including some in ehealth[29, 30, 38], no studies have used existing model explicitly to explore trust in using IoT systems to support asthma self-management. McKnight’s trust model is task specific enabling a comprehensive investigation of the application features and various device combinations of the IoT system as opposed to examine the digital health system as a ‘black box’. Therefore, using asthma as an exemplar, we aimed to use McKnight’s trust model to explore the domains of trust beliefs between patients/clinicians and IoT systems in the context of the PRISMS taxonomy, a framework defining components of self-management support in long-term conditions [2].

METHODS

Ethical considerations

The study was conducted between May 2019 and January 2020 with the approval of the London Fulham Research Ethics committee (ref: 19/LO/0703), sponsored by the University of Edinburgh and the NHS Lothian (Academic and Clinical Central Office for Research and Development) and funded by the Chief Scientist Office/Asthma UK Innovation Grant (ref: CSO-AUK-2018-03). All participants provided their informed consent prior to the interviews.

Design

We used semi-structured interviews to explore patients' and clinicians' trust in using IoT systems to support asthma self-management. Purposive sampling (see below) continued until we achieved data saturation with respect to our aim; we estimated from previous studies this would be 12 patients and 12 clinicians [39].

Patient recruitment

We recruited people (16 years or above) with 'active asthma' (defined as a physician diagnosis of asthma and prescribed at least one asthma treatment in the previous year[40]) in the UK. We wanted to explore the perceived trust between patients and technology, so we excluded children and adolescents as the involvement of a parent/guardian would have added an additional person to the interactions. We recruited patients via volunteer databases (Scottish Health Research Register [41], Register for Asthma Research[42], Asthma UK volunteer database, and social media of Asthma UK and Asthma UK for Applied Research.

Potential participants were invited to register their interest on our recruitment webpage which provided an information sheet. They were asked to confirm their eligibility (diagnosed with asthma by their GP; 16 years old or above; living in the UK), provide their demographics and give us consent to contact them to complete registration.

Purposive sampling

From the information provided, we purposively sampled patients to achieve maximum diversity of perceptions about use of technology to support self-management.

Sampling was based on

- Age (16-25, 26-45, 46-65, 65 or over);
- Ownership of action plan (or not);
- Duration of asthma (diagnosed <6 months, 6-12 months, 1-10 years, >10 years);
- Admission to hospital in the past 12 months (or not);

- App download experience (can download apps by themselves; have asked someone to download apps for them; have never downloaded an app).

Clinicians' recruitment

We recruited primary, secondary and tertiary care clinicians who provide routine care for children or adults with asthma. We posted advertisements in the newsletter and social media of the NHS Research Scotland Primary Care Network and professional bodies such as the Primary Care Respiratory Society [43]. We also invited individual clinicians known to have interest in asthma and technology.

Data collection

We conducted in-depth semi-structured interviews with patients to understand their perceived usage of self-management support features, and specifically to explore their perceived trust in using IoT systems to support their self-management. The potential features we explored were from our previous work, and from scoping commercially available devices. We provided images of smart devices and data (see Appendix 1), and asked patients to design a personalised IoT system incorporating the features they thought would help them live with asthma. We used 'think aloud' techniques to explore their trust (or not) in using the IoT system they had created to support their self-management. Clinicians were asked to formulate IoT systems that would support self-management and the care they provide for people for asthma and explored their trust in the features and the IoT system. See Multimedia Appendix 2 for the topic guide.

Data synthesis and analysis

Interviews were digitally recorded and transcribed, and analysed in the NVivo; version 12[44]. We used McKnight's trust model[35] to categorise patients' and clinician's perceptions about their trust in the functionality, helpfulness and reliability of using IoT systems to support asthma self-management.

We used a framework analysis [45], creating a matrix of self-management support features against

perceptions related to the McKnight's trust model (or not) expressed by patients and clinicians. All interview data related to trust were extracted to the matrix and aligned with the feature(s) to which they referred. To increase applicability to other long-term conditions and because the perceived trust domains (functionality, helpfulness, and reliability) in the McKnight's are task-specific, we mapped the perceptions of trust to components used to support self-management in long-term conditions generally as described in the PRISMS taxonomy (Practical Systematic Review of Self-Management Support for long-term conditions[2]). We were alert to other trust-related themes that did not fit the matrix either because they did not reflect the domains of 'functionality, helpfulness and reliability' or because they were over-arching rather than task-related.

One researcher (CYH) coded one patient and one clinician interview which were then reviewed by another researcher (HP). The two researchers discussed their decisions and standardised the coding for the rest of the transcriptions. CYH then coded all the data related to perceived trust (or not). (HP) reviewed the matrix for quality control.

Reflexivity and interpretation

CYH has research expertise in exploring user preference on asthma apps, and an academic interest in developing IoT systems to support asthma self-management. She discussed the coding and interpretation of results with the study team members from different backgrounds and with different experiences, including GPs, a patient, and a technology developer to ensure a broad interpretation.

Results

Participants

Patients

From 362 expressions of interest (74% female (268/362), we purposively sampled 12 patients with a range of ages, gender and action plan ownership for interview (see table 1). The resultant maximum variation sample included more females - eight females and four males. None had been diagnosed with asthma for less than a year, and all were confident in their ability to download an app without

asking for help.

Clinicians

We recruited 12 UK clinicians (GPs, asthma nurses, pharmacists, consultant chest physicians, respiratory paediatricians) who provided care for people with asthma. Most had experience with using technologies such as smart inhaler, mobile apps and SMS to support respiratory patients in their practices or hospitals.

Table 1 Patients and professionals demographics

12 Patients	**Demographics**
Age	Spread across 4 age groups from teenage/young adults to over 65: 16-25 years (n=3); 26-45 years (n=2); 46-65 years (n=3); 65 or over (n=4)
Gender	8 females; 4 males
Ownership of an asthma action plan?	Only 4 had been given a written action plan. Of the 8 who did not have an action plan, 5 had been 'told what to do'. Of the 5 participants who had been 'told what to do', 2 were 46-65 years old; 3 were 65 or over
Duration of asthma?	8 (4 male) had had asthma for more than 10 years; None were newly diagnosed.
Hospital admissions in previous 12 months?	Only 4 had had a hospital admission in the previous year, 3 of whom were still under a specialist clinic. None of the male participants had had an admission
Experience of using apps	All the participants were confident to download an app by themselves
Clinicians	**Number of participants (n=12)**
4 primary care clinicians	2 GPs; 2 asthma nurses
Gender	1 male, 3 females
Practice experience	GPs: ≥8 years' experience. Asthma nurses: ≥ 20 years' experience.
Technology experience	GPs had research experience in digital health for asthma patients. Asthma nurses had experience in using a remote telemonitoring for hypertension
4 secondary care clinicians	1 respiratory consultant and 3 respiratory paediatricians
Gender	1 male, 3 females
Practice experience	Respiratory consultant: diagnostics; asthma management; severe asthma care.
Technology experience	Respiratory paediatricians: asthma management; range of asthma severities 1 had used an asthma app; 1 uses smart inhalers in their service & research; Two had research experience in asthma technology.
4 pharmacists	1 hospital pharmacist; 3 primary care support pharmacist/prescribing advisor
Gender	1 male, 3 females
Practice experienceTechnology experience	1-14 years' experience in reviewing asthma medications; All used online repeat prescriptions service; 1 developed an asthma app.

Overview of results

Perceptions related to the three domains of McKnight's model of task-specific trust in technology (functionality, helpfulness and reliability[35]) are synthesised below. Multimedia Appendix 3 lists

the perceived trust in functionality, helpfulness, reliability in IoT features related to generic LTC/asthma self-management tasks. Finally, we consider the over-arching domain of trust in data security which was clearly important to our participants, reflecting not only the properties of the technology but also the context within which it was implemented.

Perceived functionality of IoT components to support self-management

Most patients perceived the IoT had the functionality that can well support a range of self-management tasks. (See Multimedia Appendix 3 for examples of tasks that participants trusted IoT to deliver). This belief was often based on past technological experience.

> *"I do use technology to control my asthma, so I keep copies of my peak flows and I can do charts on my laptop so, when I am deteriorating and I end up in hospital, I can take this with me and show them that obviously it's happened over a period of days. And I use alarms on my phone as well so I can wake up and have my medication because I have to have four-hourly nebulisers as well at the minute to control it.*"[P6, 16-25 years old, Female]

> "*I tend to put a reminder on my phone so I can have the one (asthma review) in a year's time, but it is a bit of effort*"[P10, 16-25 years old, Female]

Some patients perceived the IoT system could have functionality to support how they lived with asthma though those features were not yet available in the market.

> "*I think if there was something similar* [to energy saving tips in a smart home] *on the app where you're using the app but it gives you a tip each day that you know, 'air pollution could be a trigger for your asthma' or 'washing can be a trigger for asthma', then that might give you some additional information*."[P7, 46-65 years old, Male]

> "*I think kind of mindfulness breathing exercises you can find on, like, YouTube. If it was, like, breathing exercises to assess the asthma, it might be the sort of thing I might try once and see what I thought of it and if I thought it was useful I might try it again.*"[P10, 16-25 years old, Female]

Some clinicians perceived IoT had the functionality to well engage patients to look after their asthma and to support self-management. They believed(in the future) systems could transfer patients' manual/auto logs to a healthcare professional for review, or to flag up

when inhaler medication needed to be replenished. In contrast, others doubted if technology could change patients' behaviour.

> *"There isn't an app that I'm aware of that can link with the GP systems. So if that is possible from a technology perspective, inputting how much they're using and there's a log then of when they have their new prescription, and then that app then talks to the GP system it can flag when they get to a certain level and order a repeat, I think that's perfectly feasible."*[HCP2, Pharmacist in hospital, Female]
>
> *"I think patients either are physically active or they're not, and the app's not going to make them physically active if they're not."*[HCP5, Consultant Chest Physician, Female]
>
> *"In the last few months in my pharmacy we've introduced…well, we always had online ordering but there wasn't huge engagement with it but we've introduced an app-based system for ordering. And a younger population who are ordering things like asthma inhalers and contraceptive pills and so on have really engaged with that actually quite well."* [HCP7, Pharmacist in Practice, Male]

Perceived helpfulness of supporting components of self-management

Most patients had a perception that in IoT systems could provide a useful service to provide integrated support for a number of recognised components of self-management support[39]. (See Multimedia Appendix 3 for some examples of tasks that participants thought it would be helpful for IoT to provide).

They wanted IoT systems to log data about their asthma symptoms, peak flow, medication use, inhaler technique, indoor/outdoor environmental data, activity intensity and weight and perceived it would be helpful if these could be collected effortlessly, such as a voice assistant asking about their asthma (e.g. 'Good morning! Did your asthma disturb your sleep last night?') or automatically collecting data from wearable devices or environmental sensors in their living area. Some specific ways in which they thought an IoT system would be useful if that can help them to look after their asthma by providing customised alerts and advice, such as,

- Identifying unusual asthma symptoms or peak flows and automatically providing customised information about their asthma and advice on medication adjustment and follow up actions (suggesting and counting number of rescue puffs to be taken in an emergency, calling medical help);
- Alerting them if their inhaler technique was incorrect;
- Detecting unusual use of their rescue inhaler to help them identify what was triggering their

asthma;

- Reminding them to comply with their preventer inhaler.

In addition, they thought an IoT system would be helpful to support their communication with clinicians. Most participants believed it is helpful to be able to ask quick questions or arrange follow up consultations with clinicians via Text/Whatsapp/email and then to be able to share their data with clinicians to inform assessment of their asthma status. Some patients thought objective evidence from logs would help explain their asthma to their friend or senior colleague at work.

> *"I've missed so many events in my life because of my asthma and I think it's difficult to say to someone. I think if you had this medical evidence behind you, they'd understand without you having to explain it."*[P6, 16-25 years old, Female]

> "*I think particularly my parents. I live in a flat on my own and if for whatever reason during the night I was suddenly puffing my blue inhaler multiple times, I'd almost want a warning siren to be sent to my parents just in case I'm really struggling.*"[P12, 26-45 years old, Female]

A patient who had had a recent hospital admission thought it would be helpful to share their asthma logs automatically with the emergency department, and to share test reports between different hospitals to prevent treatment delay. Some patients described how they panicked when they were very short of breath and could lose track of how many puffs of their reliever inhaler they had taken over a short space of time. A system that counted the doses of reliever inhaler they had taken and warned them in real-time about over-dosage would be a helpful safety net. Patients with multimorbidity wanted the system to integrate information from different healthcare specialists about all their treatments and provide medication advice to reduce side-effects from different drugs.

Most clinicians agreed that receiving data about peak flow and symptoms would help them assess asthma status in reviews, but also highlighted the benefits of an IoT system that could transfer objective data on (in)correct inhaler technique, and medication usage to help assessment of adherence and suitability of the inhaler device.

> *"Because very often patients don't remember to bring their inhaler with them so it's difficult to always test when they're in the clinic. So if you're being alerted to that, when they're doing it at home, then that's perfect, because if you ask a patient are you doing it right, they always say 'yes'."*[HCP1, GP, Female]

> *"If I've got some hard data on their peak flow and their symptoms over the last couple of months, and their adherence, that gives me a much better idea of what I need to do with them, so that's incredibly helpful for me."*[HCP5, Consultant Chest Physician, Female]

Perceived reliability

Patients and clinicians discussed reliability – whether they trusted the IoT system would operate continuously and without error - in two contexts: logging data and providing advice.

Logging data

Some patients observed that a system that logged data (such as coughing, sleep disturbance, and medication use) automatically 'in the background' would reduce missing data. They believed smart peak flow meters and smart inhalers could reliably capture data, though there were caveats. Some patients did not always carry these devices with them or had more than one reliever inhaler in use (at home, at work, in the car) and a reliable system would need to accommodate these behaviours. Some patients suggested a voice assistant was easier to use but others raised concerns about its accuracy. Most clinicians agreed that automatic logs were more accurate as they reduced human error.

> *"If it can capture most things, like obviously in the air it's cold or there's pollen or there's pollution, I could probably trust it quite a bit, that, because it's solid data that's already captured in other places."* [P1, 46-65 years old, Female]

> "*I think it (an IoT system) might be more accurate as well than say if I did it (logging) myself*" [P11, 16-25 years old, Female]

> "*I know some people say that sometimes they [patients] come in and they sit in the waiting room and they're filling in the results "*[HCP4, Prescribing Support Pharmacist in practice, Female]

> *"I suppose adding technology in to it might make it more accurate and take out the human error and that."*[HCP10, GP, Male]

Providing advice

Most patients believed the system could accurately highlight the advice on an agreed action plan when their condition was getting worse but were sceptical that the system could safely generate new advice. They would trust the system to reliably prompt an alarm when their condition worsened or if they took their inhaler incorrectly, to identify environmental triggers and recommend avoidance, and to remind them of the actions suggested on an agreed action plan. In contrast, all the patients preferred their clinician to interpret data and decide on new advice. Similarly, patients did not believe the system could take 'human factors' (such as the impact of psychological or emotional context) into account when reaching a diagnosis. Clinicians were also comfortable with an IoT-based early warning system to alert patients to seek further assistance when their condition worsened, but considered automatic generation of new advice as an '*unproven route*'. They also cited the importance of personal relationships. They accepted that AI may be used to generate new intelligent advice to patients in the future but would need evidence to prove clinical accuracy before trust in its reliability.

> *"Well, again it goes through two stages, so if I'm really bad, maybe a message to say I'm really bad and…probably notice my wife first (to make decisions) and then the healthcare professional (to arrange follow up actions)… I wouldn't want that to trigger an appointment with a healthcare professional*." [P4, 26-45 years old, Male]

> "*Like if it was suggesting changes to me, that feels more like the time that I would actually have to have a conversation with the GP or nurse rather than my phone triggering stuff like that.*"[P12, 26-45 years old, Female]

> *"So if there's some sort of really intelligent system that can work out how to do an asthma action plan for somebody based on intelligent peak flow monitoring and intelligent looking at the symptoms and all of that, great, but until we've got that we need a human being I think to sit with the patient and make an asthma action plan. Because even as an experienced clinician it can be quite challenging sometimes because you have to know quite a lot about asthma to do them."*[HCP5, Consultant Chest Physician, Female]

> "*I don't think we're at a stage where a system can advise patients. I would be a little bit nervous about it. I'd have to have proof that that actually works because I think I would recognise that in my practice I establish a relationship*

with a patient. A machine advice, automated advice doesn't necessarily understand that."[HCP11, Paediatrician, Male]

Trust in data security

Privacy of personal data was a strong over-arching theme that emerged in the interviews. Whilst clearly relevant to trust, but was not task specific (as in McKnight's trust model) Patients were found to accept the health services to implement IoT systems, if they knew how their data would be used. Attitudes varied, with one patient suggesting they were not concerned about data security, whilst another explained they were not happy to use a voice assistant as because it was connected to the cloud service. Most patients and clinicians wanted to use text message or email for follow up questions, though both suggested the General Data Protection Regulation (GDPR) was a barrier to adopting these services in the NHS. Clinicians balanced the data privacy risk and the helpfulness of the services, and thought that explaining to patients about the use of their data and having their consent was a pragmatic approach, as opposed to blocking the service completely.

"*That (Email communication) would be useful sometimes, but they (healthcare professionals) wouldn't do it, so I don't really know…(the clinicians) they'd be worried about that (spam in email), same with text messages and WhatsApp…It might work from my side, but I don't think it would work from their side."*[P5, > 65 years old, Male]

"*The NHS contract can be difficult, with regards GDPR and so on, so nearly everything is done via phone, and if you can't speak to an actual person, we don't routinely leave messages and so on."*[HCP7, Pharmacist in Practice, Male]

"*This is personal data but it's only about your health condition. So in one way I wouldn't be that worried about that so much because actually that's just about one condition that actually you want to make sure that people know about so that you actually get treated properly."*[HCP4, Prescribing Support Pharmacist in practice, Female]

DISCUSSION

Summary of findings

Most of the patients believed IoT systems to be functional and helpful to support a broad range of

self-management tasks, but they raised some concerns about the reliability. They believed IoT systems could collect their data accurately from devices, check for incorrect inhaler technique and advise them on treatment options based on the thresholds and actions agreed with clinicians (e.g. in an action plan) and customised to their situation. However, they doubted if the system could interpret their data to generate novel advice or reach diagnostic conclusions. They would want to check with a healthcare professional for reassurance and 'human' advice before acting on AI-determined actions. Most of the patients' beliefs resonated with those of the clinicians. Before trusting and adopting AI-developed advice clinicians wanted evidence to reassure them about accuracy. Pragmatic approaches were required to deliver services under the requirements of the GDPR. Our study did not find diversity of views between different ages and gender, possibly because all participants had experience on technology and were the end users of similar NHS asthma care services in the UK. Racial biases, social-cultural norms and understanding of AI are other potential factors that need to be considered when developing IoT supported services applicable to diverse communities.

Strength and limitations

We explored perceived trust in IoT systems from the perspective of patients and clinicians; however, there are some limitations. Firstly, patients' and clinicians based their opinions on their past experience of existing technologies and arrangements within current healthcare services. Our clinician participants were interested in technology and asthma, which will have affected opinions based on their experience, personal interest, age and gender. The views from these group of participants may not be applicable to users with limited access to technology, or lacking experience with digital options. Real-life experience with an IoT system might have generated new themes. However, our findings represent the current perceived expectations from patients and clinicians and can therefore inform future IoT system design and underpin further investigation. Secondly, due to time and resource limitations, we did not interview children (patients under 16 years old) and their parents though we included experienced paediatricians to explore some of the issues from their

perspective. Thirdly, we could not recruit patients who were newly diagnosed (0-1 year) with asthma who may have had specific requirements, though our experienced asthma patients provided some feedback on their needs/expectations when they were newly diagnosed. Fourthly, all of our participants were confident in using technology such as social media, web information, voice assistant, activity tracker, and hence participants may have bias in assessing perceived functionality, helpfulness, and reliability because of their past use experience on technologies. However, their real-life experience enabled them to give examples of IoT features that they considered to be trustworthy (or not) from personal experience. Lastly, the McKnight domains used in this study were limited to perceived functionality, helpfulness and reliability, other domains such as perceived ease to use, the perceived value and the recommend body (e.g. recommended by the clinician who his/her patient believe the clinician understands their asthma may gain patient's trust on the technology than it is recommended by a general clinician who the patient doesn't believe in him/her or know who the clinician is)[21,46] may also important to the perceived trust in asthma self-management IoT system.

Interpretation in relation to published literature

Our findings show that patients and clinicians both recognised the potential of IoT systems to provide a range of customised support for self-management which they believed would help them look after their asthma. They trusted smart devices to observe their status accurately and had confidence that the system could trigger advice previously agreed with the clinician when they experienced unusual asthma symptoms or reduced peak flows. They found it acceptable for systems to detect errors and correct inhaler technique and address non-compliance to medication. These functions implied that IoT systems could be trusted to include artificial intelligence that could learn about an individuals' asthma over time and provide advice based on a set of rules. However, neither patients nor clinicians trusted the IoT system to mimic clinicians' intelligence and create new self-management advice, preferring a human check to reassure that the AI advice was applicable to the individual before deciding what to do. This resonates with the findings of a recent review on AI

clinical interventions in the context of other LTCs such as depression, weight, nutrition, limb pain and smoking cessation management[47]. People trusted a customised system which included elements that imitated human-human (patient-clinician) interaction and provided easy communication channels between patient and clinician. Furthermore, the involvement of clinicians was pivotal to encourage patients' adoption and adherence to digitised self-management[21].

Technically, patients and clinicians are reluctant to move from using 'narrow' intelligence that follows pre-set rules (ANI) to general (AGI) or super-intelligence (ASI) in which the system initiates rules. While there are high-level guiding principles[48,49] and governance recommendations[50] to ensure that future AI designs are ethically and technically trustworthy[51] (e.g to ensure the use of AI is fair, transparent and meets universal human values), they focus on the trust between AI and the community. Few have explicitly considered the trust between AI and the individual patient in the context of supported self-management.

Patients are not yet ready to transfer their trust from the clinician (a human) they know to an IoT system (a machine) generating self-management advice by artificial intelligence. In the traditional self-management model, the GP or asthma nurse assesses the patients' condition and agrees self-management advice in a (face-to-face) consultation. In the new IoT self-management model, the app interface, the smart devices or a lifelike robot (in the near future) has the responsibility to sense the patients' condition, the AI replaces the clinicians' intelligence to give self-management advice to patients. The decision process is an impenetrable 'black box' to patients and clinicians. In contrast, clinicians in the traditional model can discuss options with the patient and is able to consider aspects such as patients' mood, personality, self-management habits and experiences so that the final decision is (relatively) transparent. This may be one reason why many patients trust that AI-based IoT systems can record their asthma condition better than themselves but none have shifted their trust from clinician to the AI in terms of issuing new advice.

From e-commercial literature, we know that it is possible to shift peoples' trust from a known

person/organisation/shop to an electronic service that is related to the known entity[30, 52, 53] or if it is recommended by the known person/organisation/shop[54]. Iterative interaction with an automated system or lifelike robot can build up trust for first-time users who are curious about new systems and robots, but struggle to use them in their daily lives[55,56]. In the healthcare context, studies of apps and electronic consultations have suggested the potential to transfer trust from a physical healthcare service (appointment booking, monitoring physiological parameters, or activity after discharge from hospital) to an app[57-59]. However, to encourage clinicians to recommend an AI system to patients, strong clinical evidence is required to earn their trust. Currently there is little evidence in the context of asthma self-management to reassure clinicians or patients.

CONCLUSIONS

Introducing IoT systems involving advice from artificial intelligence to support self-management requires more than just functionality able to deliver tasks that users regard as helpful. There is a need to increase the trust of users in the reliability of systems as AI moves from the currently acceptable ‘narrow’ intelligence directed by clinician-determined action plans, to a future in which advice is generated by the IoT system. Our technologically adept participants were not yet ready for this step: research is needed to ensure that technological capability does not outstrip the trust of the individuals using it.

Acknowledgments

We are grateful to patient and professional participants for taking part in this study; Asthma UK and the Asthma UK Centre for Applied Research (AUKCAR), the Scottish Health Research Register (SHARE) and REgister for Asthma researCH (REACH) for help on patient recruitment; the NHS Research Scotland Primary Care Network, the Primary Care Respiratory Society (PCRS) and the NHS Lothian Respiratory Managed Clinical Network (MCN) for help on professional recruitment; the AUKCAR Patient Public Involvement (PPI) group members for advice on the interview materials.

Funding

This work was funded by the Chief Scientist Office/ Asthma UK Innovation Grant (ref: CSO-AUK-2018-03). The views expressed in this publication are those of the authors and not necessarily those of the Chief Scientist Office (Scotland) or the Asthma UK.

Contributors

CyH and HP designed the study. CyH undertook the data extraction and synthesised the data with HP. HP is the study guarantor. CyH with HP wrote the initial draft and final version of the manuscript. BM reviewed the final manuscript. OF commented on the findings from patient prospective and MB commented on implications from technology prospective. All authors approved the final version.

Conflict of Interest statement

CyH has received grant funding from the Chief Scientist Office/ Asthma UK Innovation Grant (ref: CSO-AUK-2018-03) to plan and carry out the study works. BM and HP have received grant funding from Philips NV. MB is Managing Director of Tactuum Ltd. OF contributes in a lay capacity to Teva Pharmaceuticals, AstraZeneca and WEGOHealth.

REFERENCES

1. World Health Organization. Asthma. 2020. Available from https://www.who.int/news-room/q-a-detail/asthma (accessed date 28 February 2021)
2. Pearce G, Parke H, Pinnock H et al. The PRISMS Taxonomy of Self-Management Support: Derivation of a Novel Taxonomy and Initial Testing of Utility. *J Health Serv Res Policy.* 2016 21: 73-82. PMID: 26377727
3. Pinnock H, Parke HL, Panagioti M et al. Systematic meta-review of supported self-management for asthma: a healthcare service perspective. *BMC Med 2017*;15:64. PMID: 28302126
4. British Thoracic Society/Scottish Intercollegiate Guideline Network. British Guideline on the Management of Asthma (SIGN 153). 2019. Available from https://brit-thoracic.org.uk/quality-improvement/guidelines/asthma/ (accessed date 28 February 2021)
5. Global Initiative for Asthma. The Global Strategy for Asthma Management and Prevention (GINA). 2020. Available from https://ginasthma.org/reports/ (accessed date 28 February 2021)
6. Kaplan A, Haenlein M. Siri, Siri, in my hand: Who's the fairest in the land? On the interpretations, illustrations, and implications of artificial intelligence. *Business Horizons.* 1 Jan;62(1):15-25.
7. Saheb T, Izadi L. Paradigm of IoT big data analytics in the healthcare industry: A review of scientific literature and mapping of research trends. *Telematics and Informatics.* August 2019; 1;41:70-85.
8. Thilakarathne NN, Kagita MK, Gadekallu DT. The Role of the Internet of Things in Health Care: A Systematic and Comprehensive Study. *International Journal of Engineering and Management Research.* 2020;10(4):145-59.
9. Deshkar S, Thanseeh RA, Menon VG. A review on IoT based m-Health systems for diabetes. *International Journal of Computer Science and Telecommunications.* January 2017;8(1):13-8.
10. Baali H, Djelouat H, Amira A et al. Empowering technology enabled care using IoT and smart devices: A review. *IEEE Sensors Journal*. December 2017; 22;18(5):1790-809.
11. MyAirCoach. 2015. Available from https://www.myaircoach.eu/content/what-myaircoach-project (accessed date 28 February 2021)
12. Bui AA, Hosseini A, Gilliland F et al. Biomedical REAL-Time Health Evaluation (BREATHE): toward an mHealth informatics platform. *JAMIA Open*. 7 May 2020 ;3(2):190-200. doi: 10.1093/jamiaopen/ooaa011. PMID: 32734159
13. Hui CY, McKinstry B, Pinnock H et al. The use of mobile applications to support self-management for people with asthma: a systematic review of controlled studies to identify features associated with clinical effectiveness and adherence. *JAMIA*. 1 May 2017;24(3):619-32.
14. Rolfe A, Sheikh A, McKinstry B. Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Syst Rev*. 4 Mar 2014;2014(3):CD004134. doi: 10.1002/14651858.CD004134.pub3. PMID: 24590693; PMCID: PMC7386923
15. Bending ZJ. Reconceptualising the doctor–patient relationship: recognising the role of trust in contemporary health care. *J Bioeth Inq*. Jun 2015;12(2):189-202.
16. O'neill O. Autonomy and trust in bioethics. Cambridge University Press xi, p.213; 18 April 2002. Available from http://locatorplus.gov/cgi-bin/Pwebrecon.cgi?DB=local&v1=1&ti=1,1&Search_Arg=101149509&Search_Code=0359&CNT=20&SID=1(accessed date 28 February 2021)
17. Birkhäuer J, Gaab J, Gerger H et al. Trust in the health care professional and health outcome:

A meta-analysis. *PLoS One*. 7 Feb 2017;12(2):e0170988. PMID: 28170443; PMCID: PMC5295692
18. Gille F, Smith S, Mays N. Why public trust in health care systems matters and deserves greater research attention. *Journal of health services research & policy*. Jan 2015;20(1):62-4.
19. Hoque R, Sorwar G. Understanding factors influencing the adoption of mHealth by the elderly: An extension of the UTAUT model. *International journal of medical informatics*. 1 May 2017;101:75-84. PMID: 28347450
20. Sabater J, Sierra C. Review on computational trust and reputation models. *Artif. Intell. Rev.* 1 Sept 2005;24(1):33-60.
21. Hui CY, McKinstry B, Pinnock H et al. A mixed method observational study of strategies to promote adoption and usage of an application to support asthma self-management. *J Innov Health Inform.* 9 Jan 2019;25(4):243-53. doi: 10.1371/journal.pone.0170988; PMID: 30672405
22. Corritore CL, Kracher B, Wiedenbeck S. On-line trust: concepts, evolving themes, a model. *Int J Hum Comput Stud*. 1 Jun 2003;58(6):737-58.
23. Castelfranchi C, Falcone R. Trust theory: A socio-cognitive and computational model. John Wiley & Sons; 20 Apr 2010. ISBN: 978-0-470-02875-9.
24. Taddeo M. The role of e-Trust in distributed artificial systems. *Trust and Virtual Worlds.* 2011:75-88.
25. Wang YD, Emurian HH. An overview of online trust: Concepts, elements, and implications. *Computers in human behavior*. 1 Jan 2005;21(1):105-25.
26. Corritore CL, Kracher B, Wiedenbeck S. On-line trust: concepts, evolving themes, a model. *Int J Hum Comput Stud*. 1 Jun 2003;58(6):737-58.
27. Sillence E, Briggs P, Fishwick L et al. A framework for understanding trust factors in web-based health advice. Int J Hum Comput Stud. 1 Aug 2006;64(8):697-713.
28. Briggs P, Burford B, Lynch P et al. Trust in online advice. *Social science computer review*. Aug 2002;20(3):321-32.
29. Harris PR, Sillence E, Briggs P. Perceived threat and corroboration: key factors that improve a predictive model of trust in internet-based health information and advice. *JMIR.* 2011;13(3):e51.
30. Adjekum A, Blasimme A, Vayena E. Elements of trust in digital health systems: scoping review. *JMIR*. 2018;20(12):e11254. PMID: 30545807
31. NHS. Digital, data and technology standards. Jan 2020. Available from https://digital.nhs.uk/about-nhs-digital/our-work/nhs-digital-data-and-technology-standards/framework (accessed date 28 February 2021)
32. International Organization for Standardization.. ISO 14971 Application to risk management. 2019. Available from https://www.iso.org/obp/ui/#iso:std:iso:14971:ed-3:v1:en (accessed date 28 February 2021)
33. International Organization for Standardization. ISO 13485:2016 Quality management systems. 2016. Available from https://www.iso.org/standard/59752.html (accessed date 28 February 2021)
34. International Organization for Standardization. IEC 62304 Medical device software. 2006. Software life-cycle processes. Available from https://www.iso.org/standard/38421.html (accessed date 28 February 2021)
35. Mcknight DH, Carter M, Thatcher JB et al. Trust in a specific technology: An investigation of its components and measures. *ACM Trans Manag Inf Syst*. 1 Jun 2011;2(2):12.
36. Castelfranchi C, Falcone R. Principles of trust for MAS: Cognitive anatomy, social importance, and quantification. In proceedings International Conference on Multi Agent Systems (Cat. No. 98EX160) 1998 Jul 3 (pp. 72-79). IEEE.
37. Ferrario A, Loi M, Viganò E. In AI We Trust Incrementally: a Multi-layer Model of Trust to

Analyze Human-Artificial Intelligence Interactions. *Philosophy & Technology*. Oct 2019; 23:1-7. Available from https://doi.org/10.1007/s13347-019-00378-3 (accessed date 28 February 2021)
38. Schnall R, Higgins T, Brown W et al. Trust, perceived risk, perceived ease of use and perceived usefulness as factors related to mHealth technology use. *Studies in health technology and informatics*. 2015;216:467. PMID: 26262094
39. Hui CY, McKinstry B, Pinnock H et al. Time to change the paradigm? A mixed method study of the preferred and potential features of an asthma self-management app. Health Informatics J. Jun 2020;26(2):862-79. doi: 10.1177/1460458219853338. PMID: 31195877
40. NHS employers. Quality and outcomes framework guideline. 2019. Available from https://www.england.nhs.uk/wp-content/uploads/2019/05/gms-contract-qof-guidance-april-2019.pdf (accessed date 28 February 2021)
41. NHS. Scottish Health Research Register. Available from https://www.registerforshare.org/ (accessed date 28 February 2021)
42. AUKCAR. Register for Asthma Research. Available from https://www.aukcar.ac.uk/reach (accessed date 28 February 2021)
43. Primary Care Respiratory Society. Available from https://www.pcrs-uk.org/ (accessed date 28 February 2021)
44. NVivo version 12. Available from https://www.qsrinternational.com/nvivo/support-overview/downloads (accessed date 28 February 2021)
45. Gale NK, Heath G, Redwood S et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Method*. Dec 2013 Dec;13(1):1-8.
46. Gordon WJ, Landman A, Bates DW et al. Beyond validation: getting health apps into clinical practice. *NPJ Digit Med*. 3 Feb 2020;3(1):1-6.
47. Triantafyllidis AK, Tsanas A. Applications of machine learning in real-life digital health interventions: Review of the literature. *JMIR*. 2019;21(4):e12286. PMID: 30950797
48. IBM. Trusted AI. 2018 Available from https://www.research.ibm.com/artificial-intelligence/trusted-ai/. (accessed date 28 February 2021)
49. IEEE. Ethically Aligned Design, A Vision for Prioritizing Human Well-being with Autonomous and Intelligent Systems. 2019. Available from https://standards.ieee.org/content/dam/ieee-standards/standards/web/documents/other/ead1e.pdf?utm_medium=undefined&utm_source=undefined&utm_campaign=undefined&utm_content=undefined&utm_term=undefined (accessed date 28 February 2021)
50. AI4People's Scientific Committee. Good AI Governance. 2019. Available from https://www.eismd.eu/wp-content/uploads/2019/11/AI4Peoples-Report-on-Good-AI-Governance_compressed.pdf (accessed date 28 February 2021)
51. Rossi F. Building trust in artificial intelligence. *J of International Affairs*. 1 Oct 2019;72(1):127-34.
52. Belanche D, Casaló LV, Flavián et al. Trust transfer in the continued usage of public e-services. Information & Management. 1 Sept 2014;51(6):627-40.
53. Dong C, Russello G, Dulay N. Trust transfer in distributed systems. Conference proceeding: Joint iTrust and PST Conferences on Privacy, Trust Management and Security.Volume 238 of IFIP., Springer (2007) 17–30.
54. Stewart KJ. Trust transfer on the world wide web. *Organization science*. 2003 Feb;14(1):5-17.
55. Lee JD, See KA. Trust in automation: Designing for appropriate reliance. *Human factors*. Mar 2004;46(1):50-80. PMID: 15151155

56. Haring KS, Matsumoto Y, Watanabe K. How do people perceive and trust a lifelike robot. Conference proceeding: world congress on engineering and computer science 2013 (Vol. 1).
57. Meng F, Guo X, Peng Z et al. Investigating the adoption of mobile health services by elderly users: trust transfer model and survey study. *JMIR mHealth and uHealth.* 2019;7(1):e12269. PMID: 30622092
58. Ackerman SL, Gleason N, Shipman SA. Comparing Patients' Experiences with Electronic and Traditional Consultation: Results from a Multisite Survey. *J Gen Intern Med*. Feb 2020; 19:1-8. PMID: 32076987
59. Lin YH, Huang GS, Ho YL et al. Patient willingness to undergo a two-week free trial of a telemedicine service for coronary artery disease after coronary intervention: A mixed-methods study. *J of Nurs Manag*. Mar 2020;28(2):407-16.

Supplementary Files

Multimedia Appendixes

Images of smart devices and data.
URL: http://asset.jmir.pub/assets/4cccad0f84759d60a1a6aa97e8643acb.pdf

Topic Guide.
URL: http://asset.jmir.pub/assets/6b44d00ae18b99f5d70c8fff03cc05a6.pdf

Perceived Trust Table.
URL: http://asset.jmir.pub/assets/a9766eabfbd32084b3cb5044d8de3647.pdf