An Assessment of User Needs and Mobile Technology For The Assessment And Treatment Of Patients Presenting With Vaso-Occlusive Crisis

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HCI-E MSc Final Project Report 2018
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ABSTRACT

Patients with Sickle Cell Disease often face delayed or suboptimal treatment when they present to A&E with vaso-occlusive crisis; a painful episode commonly affecting and of the major joints, chest and/or back. Causes of these delays include clinicians having negative attitudes such as patients and poor knowledge of how to treat them. The solution proposed was a mobile app, Sickle Crisis Care, which provides clinicians with a clear personalised care plan on the patient’s phone. Requirements for the app were derived from interviews with Haematologists and a literature review. Through a user-centred, iterative design process, the app was designed and received enthusiastic, optimistic reviews during usability tests. Concept was seen favourable by the NHS Director for Digital Development who encouraged further work be done. Research recommendations for the creation successful digital health information technology solutions include the use of: qualitative research methods, design methods and theory, and behaviour change theory.

Author Keywords
Sickle Cell Disease, Behaviour Change Theory, Design Methods, Research Methods, HCI, Designing Digital Healthcare Solutions

MSc Contribution Type
Empirical, Design,

(conditional) Video Submission

https://vimeo.com/user88369662/review/284680411/b29961de85

1. INTRODUCTION

It has become widely accepted that the use of technology in healthcare is nowhere near as effective or widespread as it should be. Indeed, there are many times that technology in healthcare falls short of expectations [26,51,52,106,114]. With that said, there is great opportunity for health information technology (HIT) to improve healthcare provision [16, 20, 48, 102]. This project looks at this situation in more detail in the context of the assessment and treatment in A&E of the common painful episode suffered by sickle cell patients known as vaso-occlusive crisis (VOC). The intention of the project was to identify whether optimising the use of mobile technology could improve outcomes for patients with VOC seen in A&E. Delayed and suboptimal treatment of pain [50, 121, 69] are common issues VOC patients face in A&E on a global scale [27]; causes are associated with the attitudes and knowledge of A&E doctors and nurses [27, 50, 104] despite the availability of guidelines from respected bodies [78, 104] and personalised care plans being accessible in hospitals. Attending an event in July 2018 run by NHS England who oversee the care of sickle cell disease (SCD) in the UK, provided further insight in to the challenges SCD patients face; SCD patients often receive poor quality of care when attending A&E with a VOC. Initial insight in to the problem situation concluded that further research was required.

Therefore, the objectives of this project were as follows:

- better understand the situation of treating vaso-occlusive crisis in A&E
- understand the use of technology to assess and treat vaso-occlusive crisis in A&E
- discover ways to optimise the treatment of vaso-occlusive crisis in A&E through better use of technology
- design a new technology that would help.

Overwhelming evidence from both primary and secondary research concluded that the current use of technology was not adequately improving the problem situation. A potential solution was therefore proposed of a mobile app, Sickle Crisis Care, on a patient’s phone detailing their personal care plan and medical history could be shown to staff when they present to A&E with a VOC. Interviews were conducted with Haematologists to further understand the problem situation. Then through an iterative, user-centred, design process, the design and functionality of the app’s functionality was tested with the use of both low and high-fidelity prototypes with Emergency Physicians and Haematologists as participants. This included identifying how the mobile app could be successfully deployed in the
NHS, considering existing work processes and potentially new work processes instigated by the mobile app. Finally, the problem situation and potential solution involving a mobile app was reviewed by the Director for Digital Development at NHS England, providing support, feedback and recommendations for the app to be potentially implemented and the project to be continued beyond the research completed in this dissertation.

The dissertation is made up of the following chapters:

2. Background details: background reading and preliminary research to understand SCD and VOC, how well they are treated, and their financial and quality of life costs; the use of technology in hospital settings and in the treatment of SCD and VOC; theory and methodologies for researching and designing digital solutions, including behaviour change theory; and considerations when designing digital solutions for healthcare.

3. Methods explains the methods used in this project to research and design a mobile app to present suitable information to A&E staff when treating VOC. The chapter is divided into three parts which relate to the three phases of the research: discovering information relating to the problem situation; defining the problems that need solving and for whom; and developing a suitable solution.

4. Results details the results of the research of the discovery, defining and development phases. It also explains how findings from interviews and usability tests feed into the design process of the mobile app.

5. Discussion explore the results in more detail, evaluating how well the aims were achieved and the success of the project overall. It also explores the limitations of the project and what further work could be executed.

6. Conclusion ends the dissertation with the author’s final conclusions.

2. BACKGROUND
This chapter outlines findings from background reading and literature review which has shaped this author's understanding of the problem situation and considerations to have when creating potential solutions. There is an explanation of SCD and VOC and the health issues SCD patient face in general and in hospital settings. Then details of the Cost associated with SCD and VOC in the NHS are given. The benefits, risks and opportunities provided by Health Information Technology are explained, later focusing on their use in SCD in the form of mobile apps. Then there is a discussion of behaviour change theory, research methods and design theory and practices. Finally, there is a review of best practice and considerations when designing digital healthcare solutions.

2.1 Sickle Cell Disease and Vaso-Occlusive Crisis
Sickle Cell Disease (SCD) affects between 12,500 and 15,000 people [25, 78, 104] in the UK, although the number could be closer to 20,000 [97]. 2/3rds of patients live in London [78]. Around 80 percent of all people with SCD are born in or originate from Sub-Saharan Africa [78, 104]. Most of the remain are of African-Caribbean descent, but the disease can be found in the Mediterranean, across Asia, and among people who would otherwise appear Caucasian [78, 104].

SCD is an inherited red blood cell disease where haemoglobin, the oxygen carrying component of red blood cells, has an abnormal structure due to a malformation in the proteins used to make haemoglobin in the body [28, 78, 104]. This structural change leads red blood cells to morph in to a crescent moon or sickle shape in response to giving off their oxygen to cells in the body, also known as deoxygenation. Sickled red cells are more prone to get stuck in the smallest of blood vessels known as capillaries. When this happens to enough red blood cells in the same location, it can induce blood clots, cell damage and Vaso-occlusive crisis (VOC). VOC is the most common complaint for people with SCD [28, 78, 104]. It is associated with gradually worsening pain in one or more joints, the chest and/or back [28, 78, 104]. Those who have had sickle cell for several years learn more about their condition, VOC and how best to both prevent and treat it at home [78, 104]. Treatment involves: increasing hydration; taking over the counter analgesics; like paracetamol and ibuprofen [78, 104]; rest; and distraction techniques such as playing a game or watching tv. Complications of VOC include: infection at areas of the pain; neurological symptoms such as weakness or numbness; and rapid breakdown of sickle red cells (haemolysis) [78, 104]. When complications present, or the pain is too extreme, VOC then leads to a hospital admission. VOC is the major cause of hospital admission in patients with sickle cell disease (SCD), accounting for over 90% of all hospital admissions associated with the disease [78, 104]. For some patients, admission could be less than once a year, for others, a monthly occurrence [78, 104]. The broad range in admission is a result of varying: severity of the disease; quality of preventative steps taken; and effectiveness of long term management of the disease [78, 104].
2.2 Issues Affecting People with Sickle Cell Disease

It is during emergency department admissions for VOC where SCD patients have their most significant problems when engaging with healthcare services and getting the pain relief they need [5, 50, 104, 121]. The issues fall within main categories; negative attitude towards sickle cell patients and poor knowledge clinicians have of sickle cell diseases [27, 50, 104]. These include poor pain management [50, 104], patients feeling stigmatised and mistrusted [5, 69], and negative attitudes of hospital staff [27, 50, 104]. SCD patients also report a need to convince clinicians of the legitimacy of their pain [27, 50, 104].

Other studies report: poor quality of emergency care versus planned care [27, 50, 121 104]; low levels of clinical awareness of how to deal with SCD across primary and acute care [27, 50, 104]; significant variation in care quality [27, 50, 104]; and poor management of SCD including coping with pain [27, 50, 104]. These are a result of several issues; racism towards and discrimination of patients [27]; little or no clinical experience and knowledge of SCD [27]; and false perception that SCD patients are drug seekers or drug addicts [27]. These all become barriers to effective pain relief for those in VOC. Many factors affect how patients respond to pain with increased sensitivity to pain noticed in people who have a chronic condition [67], feel stigmatised [5, 69] discriminated [5, 69], or generally have a low mood [5, 69]. These too need to be considered to effectively manage pain [5, 69].

VOC patients can have better outcomes when they attend day units; health centres which provide care delivered by specialist nurses without the need for hospital admission [6]. Swift assessment and treatment in day units result in shorter length of stay (LOS) in hospital [6]. LOS is further reduced by optimising analgesia use [6, 23, 45, 59, 67, 76, 77], improvement of the patient’s mental attitude [6, 23, 69], removing stigma and improving general wellbeing [5, 6, 69]. However, if the VOC is complicated with an infection or another pathology then this can generate an increased LOS. Other proven strategies to combat the issues include training sessions for clinicians and patient [50] to improve understanding of SCD, VOC and how to manage them both. Following medical guidelines can also improve patient care both in and out of hospital. In the UK, the National Institute for Health and Care Excellence (NICE) provide evidence-based guidelines and recommendations on treatment for a large range of medical conditions and treatments. Sickle cell disease - managing acute painful episodes in hospital, are NICE guidelines designed to provide appropriate advice for healthcare professionals treating VOC [78]. However, guidelines are not for mandatory use and professional judgement should be taken with each patient [78].

Like other chronic diseases, SCD can negatively impact an individual's life, pertaining to: education and employment as days to months of sickness absence to treat VOC [69], anxiety or depression resulting in adjusts to both educational [69], and work environments [69], quality of life impairment to prevent triggers of VOC such as swimming or going to holiday destinations where there is extreme temperatures [69], family planning due pregnancy risks [69], miscarriage [69], and probability of children being born with SCD or sickle cell trait [69]. Even high levels of stress can trigger a VOC [5, 69].

2.3 Cost Implications of Vaso-Occlusive Crisis

The annual NHS spend on VOC is approximately £16.2 million [78] to £20.4 million [93], but these can be reduced. Reducing LOS by one day, yielding a cost saving of £589 per day for children and £456 per day for adults [78]. The use of Patient Controlled Analgesia (PCA) can save an estimated £292 per adult and £147 per child admission compared with other forms of pain relief [78]. Day care units can generate cost savings of over £1100 per visit vs hospital admission [77]. Diligent use of NICE guidelines when treating VOC, the NHS could save millions of pounds; reducing average the 3.75 annual admissions for VOC per SCD patient [77] by 1 can save £7 million [77]. Preventing one annual A&E visit can save an additional £350,000 [77]. Optimising the treatment of SCD patients when in hospital and at home can reduce admissions to hospital [23, 28, 45, 59, 67, 77] and can therefore reduce costs associated with the disease.

2.4 Health Information Technology

Although there have many global successes in designing, developing and deploying Health Information Technology (HIT), it has proven difficult to create effective, safe and interoperable HIT [106]. HIT is an all-encompassing term for information technology in healthcare [102] which allows people to use data to improve health or provide healthcare services [106]. Paper can be replaced by using HIT [48, 106], resulting in more complete and accurate data [48, 106], especially when usability is HIT is optimised [74]. Despite this, clinicians are often fearful that the use of HIT will reduce their time with patients [47, 114]. This fear is substantiated as many HIT solutions in general fail [47, 51, 52, 114]. HIT solutions are usually poor because: they are not what was originally designed [47], they negatively change the way people work [47, 52, 106, 114], or they are not user friendly [74, 106]. These failures can be extremely expensive: the British Government’s National Program for IT (NPfIT) spiralled from an initial budget of £2.3 billion in 2004 [11], to £12.4 billion three years later [11], and a final estimated cost of £20 billion [32, 53, 11] in 2011 when the project was shutdown [26, 114]. There were numerous delays throughout the programme’s history as solutions
were deployed late or rejected because they; did not increase productivity of staff; caused loss data; disrupted otherwise good ways of working; unfit for purpose [26, 51 52, 114].

Looking more positively at HIT, many benefits can and are realised. The Electronic Health Record (EHR), is a digital repository of patient data; authorised individuals use it, to create, update and analyse this data [16, 102]. An EHR can increase the time spent with a computer, but the efficiency gains result in more time spent directly with patients [16]. An EHR for individuals to see their own data is Personal Health Record (PHR) [102]. When clean and reliable data is displayed in an easily digestible format, all who use it are offered the opportunity to process more information, quicker and more efficiently [16, 48, 74]. The use of wearable technology, which can collect and upload data to either an EHR or PHR, can be used to provide telemedicine services; medical assessments conducted with audio-visual technology from anywhere in the world [102]. All this data can be used to analyse and manage the health programs on a regional, national and international basis [102] With the addition of artificial intelligence, precision medicine becomes available, where individuals can get treatment that is specific to them at a genetic level [36, 102]. There is also the scope for virtual and augmented reality to be used to visualise the body during surgery [118] or for medical education purposes [19].

Further benefits of HIT can be realised through mobile computing [2], where tasks can be completed using a variety of forms of mobile technology including laptops, tablets, smartphones and smartwatches [2, 102]. These benefits can be realised in hospitals. Take, for example, the case of the A&E department in a hospital; Emergency physicians spend most of their time with activities that indirectly provides patient care [18]. This is due to being interrupted frequently and having to interact with several other professionals to complete their tasks [18]. It is normal for them to care for several patients at the same, with sudden shifts in priorities being common [18]. This observation is twice as notable in teaching hospitals where work pressures are greater [18]. Mobile computing can facilitate effective activity-based computing, allowing people to complete several tasks in quick succession if not in unison whilst being mobile [2, 18].

2.5 Health Information Technology Use for Sickle Cell Patients
An internet search of the term ‘sickle cell app’ will yield pages of results. A noteworthy result described a project researching technology for voice-controlled data collection of pain scores and medication use and biometric readings such as heart rate [10]. At the time of writing this dissertation, preliminary research of the search term ‘sickle cell’ on the Google Play Store found 56 mobile apps which try to solve a problem related to SCD. However, none of them link to or hold a health record created by a clinician as proposed by this dissertation; instead they: provide information about SCD aimed at clinicians or the public; allow someone with SCD to track and monitor their condition; or are of unknown benefit. Often, these apps are no longer being supported or updated; one such app is VOICE Crisis Alert, a tracking and communications app [124]. It allows users to track their pain and medication use and to contact their clinical team, relatives or friends. However, the last update for the app was on September 29th, 2014 and it can no longer be downloaded on Android smartphones. The last update on iOS was on October 8th, 2014; suggesting it is no longer available. The apps can also have large variability in aesthetic quality and general user experience. Some look very dated as they were made several years ago or may not have been designed by professional designers. Others however can have high production value such as Little George and the Dragon [99]. The app teaches children about sickle cell as they help George manage a VOC.

The most app most like the one proposed in this dissertation is SiKI [58] The app was not formally tested as this author does not own an iPhone. However, screenshots of the app demonstrate several functions: an emergency summary; personal details; history of the patient’s sickle cell, health in general and medical use; information about what SCD; the ability to print and email any data from the app. Yet SiKI is not without its limitations: it was only available for iPhone owners; and as a reviewer comments on January 27th 2015, the app looks dated [58] as a it was design to the 2012 iOS 6 design standards [110]. It has been suggested that the app has been downloaded over 300 times [17], but a healthcare app being downloaded does not guarantee its use [54, 68, 92, 107]. It can be concluded that the app has limited to no support and a likely small user base for several reasons: the hyperlink for app support directs to an error page[58]; the copyright was last updated in 2013 [58], there are only two reviews on the app stores page[58]; and a Google search engine search for the term ‘SiKI app’ only found two articles that discusses the app [17, 56], and the iTunes App store page [58]. Although SiKI app can present a health record to clinicians on the patient’s phone, it is suspected that this does not link to any Electronic Health Record system and is most likely inputted by the patient themselves. Therefore, there is a risk of entering the data incorrectly, either by error or deliberately which can negatively impact patient care [74].
2.6 Behaviour Change Theory

New digital solutions can significantly change the way someone performs a task or the environment it exists in, which needs understanding to ensure user needs are still met [20]. This can effectively be achieved through research and design methods [7, 62, 108]. But behaviour change theory also has a role in maximising the success of digital solutions, including healthcare solutions, when implemented [22, 30]. This has been observed in studies of effective telemedicine [100] and the use of medical guidelines by physicians [33]. Telemedicine combined with self-management tools for patients can be an effective way of providing a variety of therapies to patients [100], but a lack of human interaction can lead to high participant attrition [100]. Communicating with a healthcare professional or peer through text, audio or video can benefit [100]. There are many difficulties to overcome for these tools to be successful: a change of environment which changes context [100]; low levels of experience with technology [100]; and digital literacy [100]. Digitally accessible medical guidelines are useful in improving patient care [15, 33] but are not always used [15, 65].

Guidelines have greater chance of being utilised when: they are easy to follow [33], be implemented [33] and only require general resources [33]; professionals know of their existence [33] and are familiar with their content [33]; patients with do not have complex comorbidities [33]; there is support from the colleagues and superiors of those using them [33]; and there is sufficient time and staff to use them [33]. The reasoned action approach, and evolution of theory of reasoned action, aims to identify the few variables that govern the main reasons why a wide variety of behaviours can be exhibited in specific situations [30, 75, 76]. Briefly, it predicts behaviour based on one’s intentions where are a result of one’s: attitudes of how they evaluate how positive a negative the behaviour is; perceived norms, the perception of social pressure to perform a behaviour or not; and perceived behavioural control, the perception of how successful they will be in completing the behaviour [30, 75, 76]. The theory suggests that when attitudes and perceived norms are positive and one’s perceived behavioural control is high, there will be a stronger intention to act [30, 75, 76].

The first step to understand this for a behaviour being analysed is by defining the behaviour with the four elements of action, target, context and time [76]. An example using a current behaviour of Emergency physicians use guidelines to treat VOC which can be explained as follows

Action: Emergency physician uses guidelines to treat VOC

Target: SCD patients

Context: presenting with VOC

Time: all instances a patient presents with vaso-occlusive crisis

Changing one of these elements changes the context which in turn changes behaviour; if the guidelines are not available, the action of treating VOC changes which in turn can beget variation in behaviour of emergency physicians and outcomes for SCD patients.

For this research, the behaviour being proposed is that of Emergency physicians using the Sickle Crisis Care app to treat a patient in VOC whenever a patient in VOC has the app on their phone. This is defined as follows:

Action: Emergency physician uses Sickle Crisis Care app on patient’s phone to treat VOC

Target: SCD patients

Context: presenting with VOC

Time: all instances a patient presents with vaso-occlusive crisis with Sickle Crisis Care app on their phone

The intention of emergency physicians to use the app can increase if their: attitude of using the app is deemed positive behaviour; perception of social pressure from the patient and/or patients to use the app is high; and perception of how successful they could be at using the app to treat the patient.

The Behaviour Change Wheel is a tool for selecting the most appropriate behaviour change interventions [72, 73, 41]. It is dependent on a behaviour system which recognises that the three conditions: capability, physical or psychological; opportunity, social and physical; and motivation, reflective and automatic; lead to behaviour, also known as the COM-B system [73]. Each condition is loosely associated with four intervention functions; groupings of interventions based on their function [73]. These in turn are associated with two policy categories: categories of policies that can influence the use or effectiveness of interventions [73]. One can then look at what behaviours they want to trigger or modify by working at a policy, intervention or condition level. The Behaviour Change Technique Taxonomy (BCTTv1) lists many behaviour change techniques which can be used for coding purposes [41]. Six of these appear to be suitable for this dissertation: 4.1 Instruction on how to perform a behaviour; 6.3 Information about others' approval; 7.1 Prompts/cues; 9.1 Credible source; and 11.3 Conserving mental resources. These relate to the intervention functions of education, training, persuasion and in turn relate to the policy categories of service provision, environmental/social planning, communication/marketing and guidelines.
2.7 Research Methods for Digital Solutions

A combination of qualitative research methods were used during this dissertation which should be easily replicated. But the nature of collecting and analysing qualitative data means it is normal for results not to be exactly replicable [66]. Qualitative research goes against the common practice in medical research such as randomised controlled trials and can be considered weak in its efforts to build an evidence base [7, 34]. Indeed, qualitative research is not as highly regarded as quantitative research [34]. This however does not mean that the results are any less reliable, as the biases and emotions associated with qualitative data capture add to the richness of the data [66, 94]. It is useful in identifying what really matters to individuals, as well as gain insight in problems situations and understand why change improvement techniques succeed or fail [94]. Quantitative data capture can often fail to achieve this [94]. Qualitative data capture is deemed valid if it is the most appropriate way to collect data [66], which was the case for this dissertation, as it used interviews, thematic analysis and think-aloud tests.

The semi-structured interview as a technique of qualitative data capture focuses on the use of open ended questioning as well as being guided by the personal experiences of the participant [8, 35]. The technique encourages the answering of specific questions. But in contrast to structured interviews, it also facilitates learning from opportunistic questioning [8, 35]. There is the additional benefit of building rapport with participants, encouraging participants to provide more detailed answers [35]. To prevent participants providing only general opinions, questions about a specific event in the past should be asked as suggested by Flanagan’s Critical Incident Technique [31].

Unstructured interviews emphasise the use of open ended questions that may not be predetermined [71]. Although there is the risk that some questions do not get asked, it provides the freedom to be led by the participant when conducting exploratory research [71].

A thematic analysis looks for trends and groups the data collected from qualitative research to find meaning and answer a research question [9, 115]. Assigning codes to individual pieces of data aids with this process [9, 115], but one must become familiar with the data first [9, 115]. Sometimes there is no clear distinction between codes and themes as codes are themselves ways of sorting and categorising data [9, 115]. It is best practice to review the codes and themes after the analysis to ensure that they are affective.

Usability testing is a way evaluating whether a solution works participants [116]. Usability tests should involve participants who are representative of the target user [79, 116]. They are asked to complete a variety of tasks which are measured to identify how effective the design and functionality is [16]. Measurement methods include measuring how long it takes a participant to complete a task or recording what they do. The think-loud technique involves participants verbalising what they are thinking and doing as they complete a task with a prototype or deployed technology [55, 80, 101], be them positive or negative thoughts. This elicits information about what is helping or hindering the participant’s ability to perform the task [55, 80, 101]. It is a very simple, low cost and easy to learn technique which can be done remotely with participants [80]. To gain valid results, at least five participants should be used for usability testing [79]. There are some exceptions however: any form of quantitative study requires 20 participants or more so that a statistically significant data set is collected, with more participants providing smaller confidence intervals [79]; 15 participants or more are required for card sorting tests [79]; and at least 39 participants are required when using eye tracking technology to get a reliable heatmap [79].

2.8 Design Theory and Methodologies for Digital Solutions

The success of products can be improved by design for all three levels of emotional design [64, 87]; visceral design, the aesthetics of a design which are pleasing to the eye and makes someone feel good; behavioural design, the usefulness and functionality of a product; and reflective design, the impact the design has on high thought processes [64, 87]. This can be accomplished by utilising theory and methods outlined in the rest of this section.

Designing a solution should be an iterative process [24, 29, 39] that keeps the needs and limitations of the user at the centre of the design process [24, 29, 39, 86, 89]. Unlike traditional research methods, design methods are a creative process of finding a solution [24]. With that said, design is still a process that can be defined. The methods employed for this research project involved a hybrid version of the Double Diamond Design Process by the Design Council [24]; a process of four phases: discover, define, develop and deploy [24]. The diamonds visually represent the amount information, thinking and options that are discovered during the process of understanding the problem and finding solutions. Divergent thinking to first discover a problem situation is followed by convergent thinking to design the right problem or problems to solve, which makes up the first diamond [24]. The second diamond is created by divergent thinking to develop potential solutions, followed by convergent thinking to deliver the right solution or solutions [24]. Although the phases can happen in sequence, as this is an iterative process, it is normal to
conduct activities from all phases at any time. The end goal is to get to a right solution that solves the right problem by collecting and analysing data to then exploring, testing and refining potential solutions before developing the final solution. This process can technically go on forever as one continues to iterate a solution that has already been deployed.

Personas are fictitious characters which represent a population of real users [40, 60]. Information used to create personas are strictly meant to come from a research phase. However, it can be just as effective and indeed quicker to create proto-personas [40]; personas based on the best knowledge available to designers at the time which are then refined or replaced as necessary based on research findings [40]. The use of personas of any type are an effective way of ensuring everyone working on a project are designing directly for that persona and indirectly design for real end users [40, 60].

User requirements derive from research with users and stakeholders and are a list of what a solution must have or do to satisfy their needs [70]. An example for would be a mobile phone must have the ability to make phone calls. User requirements can be discovered during the development of a potential idea; users themselves may not know what the solution is to their problem, but the well-informed designer may be able to [24]. Referring to the example of a mobile phone, a requirement a user may not suggest but would need is the ability to easily replace the sim card without a pin to release the slot holding it. An extensive list of user requirements can be used to design a user centred solution, but that list may not be enough to design a suitable solution. Again, using the example of a mobile phone, a user requirement to replace a sim card without a pin may not breed a design that satisfies the needs of a potential user who has severe arthritis of the hands. Job stories can support the designing of suitable solutions as they list requirements and valuable information about a potential user’s motivations and emotions and context of the tasks they are completing [1, 111]. Job stories are an evolution of user stories which are usually a single sentence in simple language explaining a specific goal a user wants to achieve when using technology [63, 88]. ‘As a mobile phone user, I want to replace the sim card without using a pin, so I can make international calls’ would be a suitable example of a user story. The job story however would be more like ‘When I am travelling, I want a simple way to remove my sim card without my arthritis holding me back, so I can make international calls.’ This example ensures that accessibility is considered as arthritis is not an issue that affects every mobile phone user. It should also stimulate designing a mobile phone that does not require a pin to remove the slot at all, as suggested by articles on the issue and comments left by their readers [4, 91].

A combination of sketching and prototyping is used to design solutions, with an evaluation of designs being a constant process during the creative process [24]. Low-fidelity mock-ups such as sketches which are rough drawings on paper or created digitally to represent an idea [39, 105]. High-fidelity prototypes which are realistic creations which more accurately simulate what a design would look like if real [39, 105]. Interactive prototypes which can be either low or high in fidelity but have the additional function of allowing a user to manipulate them [39, 105].

Visual design by following the CRAP design principles [120]: contrast, elements in a design that a very different to each other will be recognised as different, which can aid with focusing attention on a specific element that is particularly different to others [120]; repetition, elements that repeat parameters such as font, colour or size will be more pleasing to the eye and ensures elements are associated with each other [120]; alignment, elements placed in relation to each other so as to form an invisible line against one side, or in the middle of all elements creating symmetry on either side [120]; and proximity, elements close together are associated with each other [120].

2.9 Designing Digital Healthcare Solutions
This subsection reviews several considerations when designing for digital solutions for public services in the UK, before focusing more on designing for the NHS.

The Government Digital Service (GDS) is the digital transformation department of the British government. The GDS service manual [42] outlines evidenced based recommendations when creating accessible, user-centred and user-friendly digital solutions [42]; NHS organisations, as a public service provider are encouraged to follow them. The GDS design principles [43] also lists 10 statements which when followed ensure that a high-quality digital product is created. These are as follows:
1. The GDS design principles explain the importance of starting with the needs of users through a period of research and analysis;
2. Appropriate technology should be reused rather than recreated;
3. Data should support design decisions, which may overtime change the design dramatically;
4. Solutions should be kept as simple as possible;
5. Iteration is vital to learn from testing ideas, prompting a better design being created much faster from findings;
6. Accessibility is crucial as public services should be available for use by everyone;
7. Understand the context of what someone is trying to achieve when using a digital solution as context has implications on how best to design the digital solution;
8. Digital solutions should be a service, not simply a website, as they are meant to connect with something happening in to real world;
9. Language and design patterns should be used consistently so users can become familiar with the solution. However, when being uniform prevents innovation or hinders the use of a better solution, changes should be made that can still maintain consistency;
10. The sharing of resources, intentions, successes and failures is an essential part of improving the quality of digital solutions for all

NHS Digital is a national organisation that uses information technology to transform health and social care for the NHS [83]. To improve the quality and use of healthcare apps used in the UK, NHS Digital have created the NHS App Library, which has been reviewed to “meet the high standard of quality, safety and effectiveness people expect from the NHS.” [84]. Anyone who has created or is creating a healthcare app to be used by patients or staff of the NHS can gain advice and guidance from the developer.nhs.uk website. By visiting the website, you can view a list of currently NHS approved apps and apps that meet a quality standard but are currently being tested before formal approval [84]. The website provides links to like-minded communities such as Code4Health which supports the use of technology to maintain high levels of safe and efficient care. Completion of the Digital Assessment Questions allows one to assess whether a satisfactory standard has been achieved with the design of new app [82]. There are 10 sections in total which include assessing clinical effectiveness, security, interoperability and clinical safety [82].

There are strict guidelines on how to use the NHS logo and branding, whether they are for an NHS branded product or service or not [85]. Following these guidelines ensures that the brand is instantly recognisable and that anything carrying the NHS branding gains all the benefits of association with the NHS brand [85]. This is particularly useful for healthcare apps as they can positively influence trust in users simply by the presence of NHS branding [85]. Non-NHS brands are limited to only using the NHS logo in information detailing how they provide an NHS service [85]. Therefore, to use the NHS logo as part of a new brand, said brand needs to be part of the NHS.

3. METHODS

Instead of a 4 step Double Diamond Design process, a three-phase process was used, where the fourth step of deploying a completed solution was not completed; delivering a finished solution was out of scope for this dissertation. This is discussed further in the Chapter 5. Discussion section under Limitations. The first phase involved researching and discovering the problems of VOC having such a varied level of care quality and the factors influencing it. The second phase involved defining the problems that needed to be solved. An iterative design process to rapidly prototype and test a suitable solution was achieved in the third phase, developing solutions. Details of participant recruitment are provided at the end of the chapter.

3.1 Methods of Discovery Phase

Secondary research was undertaken to better understand the problem situation, concluding that to gain further insight, Haematologists needed to be interviewed. The literature provided enough information about SCD patients and their carers as well as A&E staff to support the interviews with haematologists and the defining phase. Semi structured interviews were conducted with five participants; a list of questions used can be found in Appendix 1. A thematic analysis was then completed on all interview findings, with data being analysed for similarities or themes. All interviews were conducted over the phone due to differing geographical location and availability of clinicians. The interviews were audio recorded with consent forms signed in advance, although as a precaution consent was asked for again during all recordings. The audio files were then played back with relevant segments transcribed to identify themes among the interviews and to capture quotes.

3.2 Methods of Defining Phase

A combination of both personas and proto-personas were created. Only after the discovery phase of research did it become clear which personas would be needed to design a user centred solution. A resource that was useful in the creation of the proto-personas was the descriptions of various roles in the NHS from the website https://www.healthcareers.nhs.uk. The personas had the following features: a picture, name, age, occupation, and sentence which summarised: their use of technology, access to patient information, rights to update patient information and clinical responsibilities.

User requirements were created as a list of features that were asked by interview participants. These were recorded in a table and went through a simple assessment to judge whether they would be created; if the requirement could be simulated or created in the prototype, it should be.
Job stories were created to facilitate defining the problem or problems that needed solving. These were statements in the structure of ‘*When I* [a specific user or persona] *am* [in a specific situation], *I want/need* [a feature or functionality] *so I can* [achieve a specific goal].’

3.3 Methods of Development Phase

A high-fidelity, interactive prototype was used so that the design’s visual design, usability and trustworthiness could be tested. Sketches were created before building a high fidelity, interactive prototype using Axure RP 8; a commonly used prototyping tool in industry used to create artefacts across the full spectrum of mock-ups and prototypes. The prototype was made up of 3 pages: The first was a welcome screen with script explaining the project. The other two pages were each for a different patient who had different content specifically for the variables of: first language, allergies and travel history, as they would require slightly different content and layout which needed to be tested. The prototype was then hosted on a secure, cloud-based server provided by Axure RP 8; allowing usability testing to be done remotely with all but one participant due to time constraints and geographical locations of participants. During remote tests, the author used the website [https://appear.in](https://appear.in), a free browser-based video conferencing and screen sharing tool, thus allowing the mouse pointer and current page the participant was on to be viewed.

The design was tested with A&E doctors and Haematologists. There were eight usability tests with seven participants who between them reviewed five iterations. Participant 1 saw iteration 1 during the first usability test, followed by iterations 2, 3 and 5 during their second usability test to test if their needs where still met after all the rounds of iterations. Participant 2 and 3 saw iterations 1-3. Participants 4, 5 and 6 saw iterations 1-4. Participants 7 saw iterations 1, 2, 3 and 5. This way of testing provided opportunity to test if the subsequent participants made comments that supported or countered what previous participants had to say about the design, and test whether the new design was an improvement or not. As inferred, iterations were created after usability tests with Participant 1, 3 and 6. All participants were asked to review the prototype and to think-aloud. It was not practical to define the specific tasks before the define phase or before the prototype was designed as the tasks had to correlate with user requirements and the design itself. It was deemed unnecessary to test a scenario with the patient as the test environment was too relaxed and dissimilar to real life.

A thematic analysis of usability test findings was conducted organically whilst the prototype was iterated.

The final part of the research was an unstructured telephone interview with the NHS Director for Digital Development, who at the time of writing, was Dr Sam Shah. During the interview, Dr Shah was also able to look at the mobile app on his computer during the interview. But this was simply for his reference and not to conduct a usability test of the design, as Dr Shah was not a potential user of the solution. Therefore, his opinion of the apps usability was less valid. His review would have impact on deciding whether the solution designed by this research is suitable or not, and how it could be improved where possible.

3.4 Participant Recruitment

Social media was used to advertise for participants. Facebook was the primary social network used, with posts left on several groups where UK based doctors were members of; the Doctors’ Digital Collective and Doctors’ Digital Forum. Participants would then either respond to the post by leaving a comment or sending a private message to the author. Sample adverts can be found in Appendix 2. Twitter was also used to send adverts. Participants were successfully recruited through Facebook posts, recommendations from recruited participants and word of mouth.

Six haematologists and five emergency physicians were recruited. Of the haematologists, one a Speciality Trainee (ST) completing their third year (ST3), one ST4, two were ST6, one ST7 and one was a consultant. One ST6 participant had been on maternity leave for the past 8 months and the other ST6 participant was completing a PhD and did not have regular clinical duties for over a year. All others were full time practicing haematologists. The ST3 participant was based outside of London, all other participants worked inside London but all at different hospitals. One ST6 haematologist participant was involved in the discovery and development phase. The ST4 haematologist was involved in the development phase. All other haematologists were only worked with in the discovery phase. Of the emergency physicians, one was a junior locum, three were middle grade locums and one was a consultant. The consultant was based outside of London, all others were based in London. All emergency physicians were involved in the development phase.

NHS Director of Digital Development, Dr Sam Sha, was recruited by contacting him directly.

4. RESULTS

This chapter details the results of the research, presented as sections divided by the three phases research: the discovery, defining and development phases. There was over 11 hours
and 18 minutes of audio recordings from the discovery and development phases. The design and development phases were spread over a three-week period.

4.1 Discovery Phase Results
This subsection outlines the results of the different tasks completed during the discovery phase: an analysis of findings from secondary research; and details from a thematic analysis of participant interviews.

4.1.1 Secondary Research
The bulk of secondary research findings can be found in chapter 2. However, there was further research in to medical guidelines. There are guidelines for a variety of conditions which hospitals provide for their staff, but also guidelines from national bodies such as the Royal College of Haematologists, Royal College of Emergency Medicine and the National Institute for Health and Care Excellence (NICE). The NICE guidelines, *Sickle cell disease: managing acute painful episodes in hospital*, consist of 15 pages and over 3200 words. There is free access to these guidelines, but it is not practical to consult such a lengthy text in an emergency. A much smaller alternative document is a summary of the guidelines published by the British Medical Journal (BMJ), which are only two pages [37]. This would theoretically be a much easier document to read. However, access to the summary is limited to members of the British Medical Association (BMA), subscribers to the BMJ and those with extensive access to journals, such as academics. Not all doctors are members of the BMA as membership is voluntary. Therefore, access to this summary is significantly more limited and one would need to know to look for it, further reducing the occurrence of its use.

After completing the secondary research, however, what was not fully understood were strategies taking place in the NHS to rectify the issues of negative attitudes and poor knowledge among A&E staff nor how successful these strategies were. It was therefore concluded that speaking to haematologists exclusively about their experiences would provide this insight; very little insight could be gained by interview SCD patients and A&E staff at this stage.

4.1.2 Participant Interviews
Six themes emerged from the interviews which are outlined below.

4.1.2.1 Clinical Knowledge of Sickle Cell Disease and Vaso-occlusive crisis
All the participants gave details of how VOC patients present in general, how the condition should be treated as an emergency and the most suitable treatment that should be offered. Participant 4 mentioned the NICE guidelines, quoting that patients should receive pain relief within 30mins of attending the hospital. The participants also suggested that both stroke and acute chest syndrome were conditions that A&E staff should be aware of and should inform a haematologist about immediately if there are signs of either.

4.1.2.2 Problem Situation and Efforts to Improve Patient Care
The participants collectively described a similar problem situation of VOC patients regularly facing suboptimal care. Causes mentioned included: racism, clinicians having negative views of SCD patients, lack of understanding of sickle cell or guidelines to treat VOC, and failure of A&E staff to utilise care plans for the patients. Participant 1 explained that there is a “delay for an hour, over an hour to get analgesia” which was a claim supported by all other participants. Regarding the causes for these problems, Participant 1 said they “...think its racism ... Most of my sickle patients, although not all of them...I do have sickle cell patients who appear Caucasian ... are of African heritage”. Furthermore, they detailed that “because sickle cell ... [is a] relapsing remitting condition, unpredictable in nature and associated with severe pain, patients do come to hospital asking for painkillers. They are not opiate seeking, they are asking for the only treatment we have for their painful episode”. Participants consistently made similar points, concluding that patients were being unfairly labelled as “drug seekers”. With that said, Participant 2 disclosed an experience with a patient that lied about their needs for medication and abused the system. “we have got one patient who goes from hospital to hospital and takes her protocol on a piece of paper. But what she has done is, she has crossed out the drug dose and changed the drug dose on it and then signed it and presented to people saying, ‘this is my protocol, my consultant has changed it’ even though he hasn’t.” All other participants explained that there is a risk of a patient being a drug seeker or otherwise abuser of the medical service, but this was rare; “Less than 1%” according to Participant 3. Participant 5 said that when patients explain their situation or needs with very specific or medical language they would “take [it] as true until proven false” and would “always try to prove it true if it is going to influence [their] treatment”. This contrasts with what the participants and primary research suggested A&E staff do.

Participant 1 discussed how the medical team can negatively influence how patients are treated. “It’s the nurses who have all that contact with the patient, far more than the doctors”. They suggested that the doctors can be influenced by nurses. If stuff
are speaking ill of patients, it can lead to those opinions being considered fact. This “bad habit” can breed further bad habits in others. Participants 1 and 2 revealed that patients who are unhappy with the care they receive can lead to “patients presenting late” resulting in a much worse condition having to be treated by the medical team. However, all participants explained that it was easier to deal with patients who were seen in A&E previously, and such patients generally had better outcomes and quality of care.

Participant 1 and 3 alluded that efforts to train A&E staff was almost futile. Participant 1 explained that “...with staff turnover and shift pattern, [training staff is] like a constant battle.” Patient 3 took this further stating that training “...could never be done frequently enough, it would have to be done daily which is just not possible.”

4.1.2.3 Guidelines and Care Plan Use

Universally participants indicated the importance of guidelines and care plans to optimise the treatment of VOC and that “every patient has a care plan”. Participant 2 referred to these as “care protocols”. However, they pointed out that there are great variety in the way clinicians created, stored and accessed guidelines across the NHS. Patient 3 highlighted that there were in fact only three care plans that were assigned to SCD patients in their hospital. The exception was if a patient was in a clinical trial, then a new care plan would be made for them. Participant 2 described four care plans, where the two variants of both dose and route were changed, “oral and sub cut morphine and oral and sub cut oxynorm.” However, the care plans only provided details of pain relief and no further guidance. Participant 1 explained that there were two processes used to create and store guidelines that they were involved with as they worked between two London hospital sites. In one hospital, the care plans were in the EHR and were discovered by going to the documents section in a patient’s record followed by manual searching of documents within the Patient Team Records folder. In the second hospital, the care plan was not within the EHR record at all. Instead, staff would have to manually search a list of approximately 350 pdf documents in a shared folder. The documents are labelled with the patient’s name. Participant 1 highlighted that “it’s not ideal” storing the information this way as if there are spelling mistakes in the document labels, it would be easy to not find a patient’s care plan at all, and that manually searching so many names is time consuming. Participant 4, who works in a hospital outside of London and has a small SCD population, highlighted a scenario where a patient’s care plan was emailed to all doctors who may see the patient in A&E as well as it being printed and pinned to a notice board in the office of the A&E department. They explained that this worked for a time, until the notice board version fell off and was not replaced, and furthermore, that the emails were not being actioned. A physical folder that had been used in one hospital that Participant 2 had worked in, caused several problems including the care plans not being put back in the folder, or replaced in the wrong section, thus making it difficult if not impossible to retrieve them for future use. Additionally, they detailed that “In [business] hours, if they can’t find a care plan, they can call the [Haematology team]. In the middle of the night, people often don’t ring us and don’t try very hard to find it.”

Guidelines in general were being used by clinicians in A&E, but not as often as all the participants would prefer. A reason presented by Participant 3 is that the guidelines were often very difficult to find on a hospital’s intranet. They later highlighted that getting to a free computer to access guidelines was also a problem. When a clinician did access a computer and went on the patient’s EHR, they would have to conduct a manual search for the care plan in the documents section. Participant 2 said that believed an appropriate guideline or care plan was being used “80-90% of the time”, but ideally this should be “100%”. They also felt that the NICE guidelines were more accessible as A&E doctors can simply find them on their phone and would not need a computer.

All participants mentioned that information for care plans can be, and mostly are, written during outpatient clinic appointments with SCD patients. Participant 3 mentioned this can also happen during Multi-disciplinary meetings. Although the participants stated that haematologists, including haematology specialist nurses should be able to create or update a care plan, Participant 1 further detailed that data managers and potentially GPs should be able to do the same. They explained that a data manager ensures data is kept accurate, including patient records. However, they also indicated that care plans were not standardised across the country and they wanted to have one in the hospitals they worked at so there were more prompts for clinicians. “I’m trying to get it as an electronic form, but that is proving to be challenging ...[because] of current limitations of the IT system.”

4.1.2.4 Trust

Security and validity were significant concerns, specifically how data could be secure on the mobile phone and what clinicians might need to do to verify the information was correct. Four participants said that if the app was trusted fully, they expect clinicians would also trust information about the patient, thus not needing to devote time to verify the information. In contrast, Participant 5 suggested that if they trusted the information, it would then trigger them to
verify it. For example, if the app told them the patient had a complex blood transfusion history, it would then “prompt [them] to make that phone call to get that information in advance [of prescribing a blood transfusion]”. They also believed they would still want to call the patient’s regular haematologist and suggested a number to call them should be provided on the app. Participant 3 was concerned that “[Unless this is] a nationally implemented, NHS secure app, [clinicians] would not necessarily trust it. If you go to hospital and you have donated blood and you come with a card... we would still check your blood group before giving blood... we would not trust it.” The app would not be trusted, according to the participants, if the patient could update information themselves, most specifically what drug and dose they should take as this could be abused by patients. The participants also explained the importance of knowing who wrote the record and when. Furthermore, anything accessed from the EHR or hospital intranet is considered trustworthy.

4.1.2.5 Functionality
Patients recording details of pain and medication use was suggested by all participants without prompting. Participant 4 discussed the use of a pain diary which would be particularly useful if there was a language barrier. Participant 3 also mentioned the use of wearable technology which could automatically upload data about the patient. They further suggested that a patient tracking functionality could be more useful than a patient summary, but later concluded that they would rather both.

Integration is important as specified by Participant 3 “Any form of app that [is] developed must integrate with existing healthcare information systems to be effective. It cannot be another app where patients simply record things. There are plenty of these apps around, if they do not integrate with our systems...then I’m not going to use it”.

Participant 1 explained that since care plans are made during clinic, time could be spent to create one in the patient app as well. The participants in general supported this, explaining that it was not an unreasonable request because of the health benefits. Further questioning explored the need of a system that standardised and automate this process. Participant 5 engaged in a discussion about the desirability and feasibility of an online proforma for seeing patients in clinic, suggesting it could “can this review template...be used to generate customisable outputs for the trust... a trust letter for example.” They highlighted it can also be used for audit purposes.

Several participants gave reference to a potential database to access health summaries of SCD patient, which after further secondary research was discovered to be the National Haemoglobinopathy Register NHR.

4.1.2.6 Usefulness and Overall Verdict
Unanimously, the participants agreed that a mobile app with a personalised care plan and summary of the patient’s medical history would help in A&E settings. Participant 5 believed that it would “absolutely” help as providing the guidelines and patient details on the patient’s phone is much quicker than going to a computer. They believed that following the guidelines should lead to patients being discharged sooner and having a better experience. Improving this was “number one, that’s what we are in this job for”.

Participant 3 detailed that “Taking a [medical] history ...[is] the single most important step in any kind of patient’s treatment ... but it’s the most time consuming and annoying and difficult one, especially if it is a repeated history. So, any form of concise, informative, and useful summary of their medical history ... which is immediately available to me... would speed up the process. It’s all about speed, you want things to happen quick, quick, quick.”

Participant 1 said “I think it would... empower the patient... it means the patient can have their blood results right there and things like that, all useful stuff for them.”

Participant 4 affirmed “I think that would be really, really good.” They recited a time when working in London before becoming a haematologist, that they had heard of plans for “a London wide database of patients’ care plans and what their complications of sickle cell disease have been...and frequency of admissions so you can gauge how severe their sickle cell disease is.” But they did not know any more details of it. They were not convinced this was happening any time soon and felt that this app would likely be more successful. They also explained that information on past complications of VOC can increase the risk of those complications in the future. Therefore, a record of this would be useful, an opinion echoed by the other participants.

Participant 2 admitted “Personally, I think that’s a great idea. They can take it with them on holiday, to uni, to visit friends.” highlighting the value in having the record anywhere in the country and abroad.

4.2 Defining Phase Results
This section outlines the results of different tasks completed during the defining phase: the creation of personas; writing a list of user requirements; and generation of job stories.
4.2.1 Personas
Six proto-personas were created based on findings from both secondary research of papers and articles, and primary research from interviews. The proto-personas created were: A&E Receptionist, Tracy; Accountant and SCD patient, Nathan; Triage Nurse, Justin; Staff Nurse, Stephanie; Emergency Physician, Dr Jones; and Haematology Consultant, Dr Tidus. The personas can be found in Appendix 3.

4.2.2 User Requirements
A list of 12 user requirements were created which can be seen in Table 1. The recommendations for the app included: a clear summary of recommendations to assess and treat VOC; information to be provided by a respected source; be available on the patient’s mobile phone; details of the patient’s long term and acute pain management plans; and details of the patient’s medical history including comorbidities, allergies and recent blood test results.

Five of these requirements, 5, 6, 7, 10 and 11, were not able to be designed fully as they did not provide any functionality that needed to be tested with A&E doctors. These included: having the care plan written in outpatients by haematologists or other qualified staff; the ability for patients to track their condition and data from wearable technology; an online form to create or update care plans. Requirement 4, which was to have content available on the patient’s EHR, was out of scope as it would not be possible to test a prototype in a clinical environment, and there was insufficient research of all possible EHRs used by A&E doctors in the UK.

The requirement for patients to have read only access to all their clinical information was partially designed for, as it was out of scope to define exactly what all this information could be, rather only some of the information, such as details of the patient’s medical history.

4.2.3 Job stories
Four job stories were created. Two were for the Accountant Nathan: ‘When I go to hospital in a pain crisis, I expect to be given an appropriate dose of painkillers quickly, so I can get better and get back home as soon as possible.’ and
<table>
<thead>
<tr>
<th>Requirement</th>
<th>Reason for requirement</th>
<th>For Prototype?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Instructions and recommendation for clinicians on how to assess and treat the patient suffering vaso-occlusive crisis</td>
<td>So clinicians can quickly respond to the recommendations on what to do for their patient.</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Information is from a respected and recognisable source.</td>
<td>So clinicians trust to use the app if this is their first exposure to it.</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Content should be provided on the patient’s mobile phone</td>
<td>So clinicians can access the information with the patient as soon as they arrive at the hospital.</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Content should be available the patient’s EHR</td>
<td>So clinicians can access content even if the patient does not have their phone or the app</td>
<td>No</td>
</tr>
<tr>
<td>5. Care plan should be written during outpatient’s haematology clinic</td>
<td>So haematologists can control the data, ensuring it is correct and up-to-date at a scheduled and convenient time with the patient.</td>
<td>No</td>
</tr>
<tr>
<td>6. Patient can log their pain and medication use</td>
<td>So additional information can be stored in real time and not be reliant on patient memory.</td>
<td>No</td>
</tr>
<tr>
<td>7. Using wearable technology, patient can track biometric readings including blood pressure, HR, O2 saturations on air, sleep, temperature and hydration.</td>
<td>So additional information can be stored in real time and not be reliant on patient memory.</td>
<td>No</td>
</tr>
<tr>
<td>8. Patient has read only access to all their clinical notes, pending investigations and investigation results</td>
<td>So the patient can be informed about their health but also lacks the ability to maliciously or accidently edit their record</td>
<td>Partially</td>
</tr>
<tr>
<td>9. Patient can have read only access to both long term and acute pain management plans</td>
<td>So the patient can be informed about their health but also lacks the ability to maliciously or accidently edit their record</td>
<td>Yes</td>
</tr>
<tr>
<td>10. Care plan created and updated by all those with authority which should include the Haematologist and Specialist nurses who see the patient.</td>
<td>So clinicians with expert knowledge and appropriate experience can control the data, ensuring it is correct and up-to-date at a.</td>
<td>No</td>
</tr>
<tr>
<td>11. Care plans can be completed or updated on a web application that updates the EHR and mobile app.</td>
<td>So authorised clinicians can update the EHR and mobile app at the same time, and to standardise the process for all</td>
<td>No</td>
</tr>
<tr>
<td>12. Summary record should include baseline observations, past VOC episode details, comorbidities, allergies, contraindications</td>
<td>So clinicians seeing the patient have additional information which may be of benefit to them.</td>
<td>Yes</td>
</tr>
</tbody>
</table>
to medication, transfusion history and details, baseline blood test (FBC, U&Es, phenotype of SCD

| Table 1. Table listing 12 requirements gathered from interviews. |

‘When I am sick and see a doctor in A&E, I expect them to know how best to treat me even if they have not seen me before, so I can be treated quickly and get back home.’ Two job stories were for Emergency Physician Dr Jones: ‘When faced with a sickle cell patient in pain crisis, I need to know how best to treat them so I can give optimal care.’ and ‘When on a busy shift in A&E, I want to use as few different computer systems as possible so I don’t have to remember too many passwords or be slowed down at work.’

4.3 Development Phase Results
This section outlines the results of different tasks completed during the development phase: initial design work including building a high-fidelity prototype, usability testing and iterating the prototype based on feedback until a final design was reached, and the interview findings with the NHS Director of Digital Development.

4.3.1 Initial Design and Prototyping
Sketches were made of possible layout options for different types of content which is shown in Figure 1. Whilst sketching, a checklist of steps was explored which would have had the doctor mark a box every time a task was completed but on the patient’s phone. There was also an exploration of how a list of instructions could be displayed in an easy to read fashion, including the use of medical shorthand. It was important to highlight to users that VOC should be treated as a medical emergency as the literature and interview participants explained. A photograph of the patient and the clinician who wrote their record was added as it was theorised that the photographs would build trust and act as an additional proof of identity for the patient; as would the inclusion of the patient’s full name, date of birth and NHS number. Content should be directed at the clinician as the user and always give reference to the patient by name, to make it clear that the patient is recognised as a human, not just another patient.

Figure 1. Sketches during the early stage of designing, taken by author.

Figure 2. shows screens from the first iteration of the high-fidelity prototype. NHS brand guidelines were used to design an app that looked like it was built by the NHS. The prototype is made up of 4 clickable pages; three are accessible from the navigation section at the bottom of the phone; he fourth, a recreation of the NICE guidelines for treating VOC, was accessible when hyperlinks of the guidelines were clicked. Each of the navigation section pages had the patient’s details at the top and details of who wrote the record at the bottom. The first was the Emergency page listing the recommended medication the patient needed, and a call to action to read the patient's care plan. The Care Plan page provided patient information and more
recommendations for ongoing assessment and treatment of the patient, including prompts for when care must be escalated. The third page was the Health Summary which detailed the patient’s medical history, including transfusions and episodes of VOC at home or in hospital, allergies, medications and baseline observations and blood tests.

4.3.2 Usability Testing

The final iteration of the prototype is shown in Figure 3. The main findings of all the usability tests are summarised below, grouped into categories pertaining to what aspect of the design they relate to and provides details of how the findings evolved the design.

4.3.2.1 Building Trust

Generally, the participants much preferred the use of the NHS logo than a generic Crisis Care logo. Participant 1 suggested the logo for the Royal College of Emergency Medicine be used to increase trust as most Emergency physicians are members of it. Subsequent participants agreed with this and approved of its inclusion when they saw it. Participant 3 felt it makes a “massive difference”.

Figure 2. Screenshots of iteration 1, taken by author.
Nathan believes he is in Sickle Crisis. He needs 30mg morphine to control his pain. Treat as a medical emergency.

Nathan Ambrose
1234567890
NHS 043 476 5619

Nathan has no known allergies

Pain relief: Morphine 30mg sc 87.5 ml
Although not commonly prescribed in A&E, morphine sc is very effective treatment and is recommended in NICE guidelines.

Review pain management every 30mins until under control.

If pain persists, consider a Patient Controlled Analgesia (PCA) if available.

For more detailed recommendations, access Nathan’s Care Plan.

These recommendations are based on NICE guidelines and personalised for Nathan. This record was written by:
Dr Anna Tomlinson MBBS, FRCP
Consultant Haematologist
North East Thames
Oncology
OIC 324789
ally.tomlinson@ntcu.nhs.uk

For side effects, prescribe:
Ondansetron 4mg 3 hourly or on demand.

Do you need a haematologist? Performing your assessment, if you observe:
• Oxygen saturations on < 90% or < 91% lower than Nathan’s baseline (75-77% v/o)
• Neurological symptoms, e.g. headache or weakness contact your local haematologist on call immediately.

For more detailed recommendations, access Nathan’s Care Plan.

If pain persists, consider a Patient Controlled Analgesia (PCA) if available. Effective for uncontrolled pain if the first four attempts of injectable analgesia are not enough.

Start with immediate pain relief

Nathan has no known allergies

Morphine 20mg sc 87.5 ml
Although not always prescribed in A&E, morphine sc is very effective treatment and is evidenced based.

Review pain management every 30mins until under control.

Initial assessment

Always keep an open mind that anything else could be wrong with the patient in addition, or instead of a pain crisis.

After giving immediate pain relief, examine the patient and make the following observations:
• Oxygen saturations on %:
  If oxygen saturations are less than 91%, provide oxygen and investigate for a cause such as acute anaemia or PE.

• Temperature:
  If temperature greater than 39°C, take blood cultures, order a Chest X-ray, perform antibiotics and investigate source of infection.

• Clinical:
  This could be a sign of lodging inside the artery, but could also be a coronary, respiratory, or infective event.

• Hydration:
  For more detailed recommendations, access Nathan’s Care Plan.
Figure 3. Screenshots from iteration 5 of the prototype. Screenshots taken by author.
Participant 2 stated “I can see the NHS logo, so it looks genuine. The colours point to the logo as well, so it gives it an NHS feel, like this must be [an] NHS endorsed app or an NHS app.” Participant 4 was convinced that Crisis Care was a real brand.

Participants were concerned that patients could be lying with the app so ensuring the app could be trusted was important to them. Participant 6 elaborated on this further; “My worry would be here’s somebody angling for a hit of morphine… As soon as they say they have sickle cell anaemia, I actually wouldn’t care. It’s far worse to let someone suffer a sickle cell crisis than give someone a hit of something that quite frankly isn’t that psycho active.”, highlighting that if someone really wanted to satisfy a drug habit, they would ask for a different drug. This supported the design decision to ensure the diagnosis of the patient was made clear at the top of the app.

4.3.2.2 Respect and Professionalism

Several participants were concerned about the recommended analgesia dose because they felt that some of their colleagues may be reluctant to provide it. Participant 1 mentioned they would be suspicious if a patient asked for opiate pain relief, but the app could help remove that suspicion. They also suggested it would be useful to give additional information about why the medication is safe to prescribe. This was reflected in iteration 2 and 3 where light blue coloured boxes with additional information were placed under instructions. All participants who saw iteration 2 and 3 had a generally negative response to the Emergency page. Participant 2 said “I don’t like it, I don’t know where to look, it feels heavy, takes a lot more mental effort to process it... blah, blah, blah, made by haematologists... NICE guidelines... nice to know but I don’t really care...If it’s to build trust, I am not really that fussed.” It was generally considered “wordy”, “blocky” and generally “harder to read”. This is particularly after looking at the first iteration, as several participants who only saw iterations 1-3 of the prototype concluded they preferred the layout of the emergency and care plan pages from the first iteration. The use of coloured backgrounds broke up the text too much, making it more confusing when reading the content.

Participants explained that information was needed, but they did not want to feel patronised, or to feel robbed of their ability to use their training and experience to do their job. Participant 2 felt that some of the language was a little irritating such as ‘immediate pain relief required’; “I decide whether immediate pain relief is required... [doctors] don’t just follow decisions blindly. We generally want to make decisions ourselves.” This conflicted with Participant 5 who said “Are we trying to teach people or are we trying to get them to do the right thing... When you are in the midst of A&E... it’s pretty crazy. You just want to be told what to do.... You can go home and read up about [Sickle Cell] later.” Participant 3 admitted that there was often too much content “everyone knows that giving a PCA is useful...it’s not controversial.... You can trust doctors more than this to know what they are doing. The main benefit of this is easy access to a personalised plan... As an educational tool, there might be scope for that, but I wouldn’t confuse the messages too much ‘cause there is a lot of stuff in there explaining why you are doing stuff and I think a lot of people would know already and it’s just adding to the words.” With that said, Participant 3 was the first to mention that there would be a need for clear next steps for severe complications of VOC as not all A&E staff would be aware of these. All other participants felt the information was optimised in iteration 4 when the information was made clearer with prompts placed after all the instructions are provided.

Participant 1 said that the photographs did not make a difference but “if the doctor was famous, it might make a difference”. All other participants considered the photographs important and were not pleased to see the photos removed. Participant 2 stated that “It’s funny that the picture makes a big different...makes it easier on the eye.”, a point echoed by Participant 4, although they expressed that it might be “purely an aesthetics thing”. Participant 5 and 6 were particularly fond of the photographs. Participant 5 stated “I think the photo should be there. Because it’s important that you know that the patient who’s got the phone in front of you is the patient you are treating. So, I like the photo.” They further elaborated on the benefit of mentioning the patient’s occupation; “acknowledge that these people have lives outside of their disease”. During their second usability test, Participant 1 reversed their suggestion; “keep the photo because...we are going to be in a place where asking the patient for photo ID is not farfetched...If you need to make way for space then I can understand why you would want to drop it, but there should be enough space for it there.”

4.3.2.3 Getting the language right

Participants collectively explained that although the allergies are shown, they should be in red and either in bold or capital letters, so they stand out more. Specifically, for Patient Nyala, the example for allergy status was confusing for participants because the example recommended medication was also in the allergy section and it was not clear to them if this was a contradiction or not. It became clear that the
The first attempt at drawing attention to recommendations for serious complications and presentation of VOC received mixed opinions. Three Call to Actions were made with information inside a dark blue box with an exclamation mark icon at the front and the headline ‘Caution’. Participant 4 said “I like the prompts for...chest crisis, giving oxygen and hydration, if people are somewhere there is not much of an awareness [of sickle cell]...this would be a good prompt.” But Participant 3 mentioned that although the Call to Actions looked different to the rest of the text, they were not grabbing their attention enough considering how important they were. Iteration 4 resolved this by placing the information inside one light blue box, with one clear headline “Do you need a haematologist?” next to an exclamation mark icon. This received very positive responses from all subsequent participants, particularly from Participant 5; “From a haematology point of view, we love to be contacted early so that’s excellent, I love that.”

All participants noticed that iteration 1-3 of the app did not say that the patient had SCD. Participant 2 said “Sickle Crisis should be up front and centre...then I would understand why the word emergency is there.” Changing this to include the diagnosis was favoured by all subsequent participants.

The use of medical shorthand was favoured, as detailed by Participant 1 who revealed that it “works as it’s speaking my language...it increases my trust in the app.” Participant 3 said the use of shorthand was a good thing and “probably better than what you get from other sources.”

Highlighting the patient’s first language when it is not English was supported by test participants; Participant 5 said “It’s brilliant, I like that. I like that her first language is highlighted. When you get a patient ..., and they don’t speak English, you can’t always ask them what language they speak, so that’s useful.”

4.3.2.4 Useful Content
The participants unanimously praised the inclusion of the NICE guidelines in the app; Participant 5 said “I like that, a link to the Nice Guidelines”. Participant had a clear opinion of this “This is way, way better than what we’ve currently got which is basically the NICE guidelines. The problem with these bloody guidelines ... is that you have to drill down to find the salient information... And I’ve said it time and time again about some of the hospitals policies, ‘don’t bury the ‘need to know’ stuff in a forest of bollocks’. They all liked that details of the clinician who wrote the patient’s record were included. Several participants highlighted that they would also like contact details in the form of a telephone number and email address, although Participant 7 felt that a generic one would be good enough as the staff member may not be on shift at the time they were contacted.

Participant 1 suggested it might be useful to have a simple bullet point summary of what Sickle Cell Disease is.” This led to the creation of a fourth button in the navigation bar labelled Sickle Cell with a question mark icon. It was planned that this button would lead to a page that held information of what SCD and VOC is. Iteration 3 had a disabled version of the Sickle Cell button which Participant 4 queried. They guessed it should have information on SCD and VOC, which validated the suggestion from Participant 1. Subsequent participants liked the feature and felt it would be particularly useful for junior doctors.

The inclusion of personal and summarised medical information was favoured. Quoting Participant 2, “It’s also got the NHS number, gives more reassurance that it’s genuine... The medications ... look reasonable. There is a recommendation when I scroll down, which makes me reassured that this plan was made by another doctor.” They further stated “this is really good. It’s the type of information you could spend a lot of time looking around for. If I saw this, I would be quite relieved and quite appreciative that this exists.” When directly asked if anything was missing for them to use the app they responded, “I guess the answer is no, as an instinctive answer, but I would still be questioning where did this app come from, who made it...those questions might run in the back of my head.” They pointed out that “all the doses look correct and the names of the medication and the past medical history sort of is the icing on the cake, if I look at that I say this is legit as it is very hard to fake this” which reinforced trust.

Feedback from several participants led to a change in iteration 4 which had the inclusion of a date when Health Summary and all blood tests and observations were last updated. This was well received by all subsequent participants.

4.3.2.5 Additional Functionality
Participant 1 recommended that the content of the app could be printed or be accessible through a website not on the patient’s phone, suggesting a solution like Toxbase, a clinical toxicology database, could be useful. They explained that the hospital will have a username and password that all the clinicians can use and is changed regularly to prevent abuse. When discussed with other participants, they thought it was a good idea, but generally
preferred being able to use the patient’s phone first and foremost.

4.3.2.6 Overall Verdict
The participants were all very happy with the general concept of the app and believed it could make a difference. Praise was given for the time that could be saved with it, and with subsequent iterations, the ease of use. Participant 1 believed the app was good as “it tells me what exactly I need to do… that’s a strength”. Participant 2 felt the app had a “nice, simple presentation… Overall I like it, I think it’s really good, intuitive instant piece of information that would be useful in real life. My feeling is that it would be quicker than medical records, because it always takes time to look those things up… you have to log in… you have to find the patient...all the consoles are constantly busy... As soon as I see the patient I can see the records”. Instead of having to log in to another computer to access the information, they would like to be able to access it on their own phones, “if the patient could Bluetooth it, that would be amazing”. They explained “The way I would behave in a busy A&E department is that I’d give it a few seconds to pull out all the relevant information that I need, then I wouldn’t look at it again.” They felt that the design could support such behaviour. Participant 3 said “The concept is good.” Referencing their personal experience, they highlighted the importance; during one medical job it took them two weeks to know where to find care plans for SCD patients. They elaborated saying that “Another advantage you’ve got with this is that most sickle cell patients are pretty young, so they would probably go for this kind of thing.” Participant 4 stated “we would always have the local records anyway” but admitted that it would be good to have it on the patient’s phone as well, especially when travelling. Participant 5 admitted “I’d love for a patient to come up with one of these”. Participant 7 was happy to see that “the whole approach here is [your] distilling this down to the concise stuff that you need to know, and if you do want to drill down in more detail then hey, this is where you go...Compared to the status quo, this is already light years ahead and if only more people thought this way, it would be great.”

4.3.3 Interview with NHS Director of Digital Development
Dr. Shah’s responsibilities at NHS England includes developing digital system and services aimed at patients, digitalisation of health provider environments, and the digitalisation of urgent care and emergency services for patients and clinicians and NHS in England. After hearing an explanation of the solution and viewing the prototype, he affirmed that “The content itself is useful in two ways, for the patient to give them some degree of confidence… and the second… it would be impossible to say it wouldn’t be useful [for clinicians]. Some of the things I would be thinking about…how to do you iterate this to make this useful knowing some of the challenges we have already come across with other similar types of products…so one difficulty is the single product, single app idea”. He highlighted that “people have more and more apps” and that the app will likely need to connect to another application. “To make this useful and usable is how can you migrate... this to WebRTC”. Briefly, WebRTC is a technology used for high quality audio and visual communication on the web [119]. He also talked about data quality, “If there are multiple sources of data for the same field from different clinicians, what is the rules-based mechanism in deciding which one of those is taken as the source of the truth and how is that conflict dealt with?.... These are things that need to be thought about over time.”

“This is clearly useful for this group of services users in whatever setting they go to...” explained Dr Shah “…and I think that is important, and I can see its application is wider than the emergency care setting.” He added “This could be used as a form of blueprint for lots of patient held records.”, identifying that the app could be used for other medical conditions other than sickle cell disease.

Supporting a root cause analysis was discussed, which is important as there are times when something can go wrong during a patient’s care. “What mechanism would there be...to send this content in to the EHR of the person that is treating [the patient] so that it is evident to someone else looking at this [can determine]...what was it that they could see at that point of time that they made the decision that they did? Is there something you have to work out how you overcome to make this useful beyond the first case this becomes an incident”. He also detailed the importance of sharing the information with all healthcare professionals involved with the patient’s care, including their haematologist and GP. “this is a good concept”.

Regarding branding, Dr Shah indicated that the NHS is “very protective of the logo”, stating that this would need to be looked in to if the app was to become an official NHS product. But the process to do this, in his opinion, is “fairly straightforward”. He also gave reference to the Digital Assessment Questionnaire and clinical safety compliance. This is important as “technically it becomes a health IT product” if clinicians are to use it.

I discussed two potential solutions that haematologists had suggested they wanted from primary and secondary research. The first was to utilise the National Haemoglobinopathy Register as a database to also include care plans and not just research data. The second was “The solution for that requirement is probably not the one they
Dr Shah discussed that cost savings suggested in reports detailing potential transformations can be misleading. He explained that “in the NHS there is very rarely ever any cash savings. Generally speaking...we have efficiency gains”, where the money can be used elsewhere to provide care to patients. Additionally, transformations often require an absolute uptake of the recommendations to achieve the savings they suggest which is not always possible. Age of the user, digital literacy, and uptake of users were also considerations which could affect the success of the app.

An overall verdict of the app and where Dr Shah believed it could go in the future ended the discussion. “Principally, the concept of making clinical information, in context, available to clinicians which is owned by the patient is an incredibly positive thing and a useful thing first and foremost to the citizen... as it allows empowerment of the citizen... The second part of it is, if we can make it really easy to use for the clinicians and make their work flow easier it will have benefits to the health system and to the patient.” He explained that by evolving it further to collect data from other sources, the app can be used to prevent a crisis from happening, “that's the win in this, it suddenly takes this from a being something used in a reactive setting to something that becomes a proactive, wellbeing management tool.”

5. DISCUSSION
This chapter discusses: the achievement of research objectives, summarising the main details from the results; evaluates the research and design methods; reflects on the impact of behaviour change theory and how accurate their predictions have been; the practicality of designing for several different types of users; the limitations and future work of the project.

5.1 Achievement of Research Objectives
The research successfully gained a deeper understanding of the problems faced by SCD patients, especially in the context of when they are treated for VOC in A&E. The main issues identified were negative attitudes towards SCD patients by clinicians and the poor knowledge clinicians had of SCD and VOC. There was also clarity of the financial and quality of life implications of treating such patients optimally. Better treatment of VOC and management of SCD in general could save the NHS £7 million a year, further enhanced through using day units, and reduce the LOS for VOC hospital admissions. This in turn would lead to less absence from school or work and help combat some cases of anxiety and depression experienced by SCD patients.

A review of technology aimed at SCD patients showed a clear opportunity to provide a new and more successful solution, using lessons learned from previous efforts to design HIT in general, not just HIT aimed at SCD patients. It was also important to make clinicians complete tasks quicker and more effectively. This can be achieved by: considering the current ways healthcare staff worked, including the context of the tasks they completed; asking clinicians about their specific needs; observing behaviours to identify opportunities to change behaviour without disrupting workflow.

Interviewing Haematologists provided great insight into the problem situation, supporting findings from secondary research and offered several ideas and suggestions to create a useful mobile app on patient phones. The app would require: personalised recommendations of what to do for patients presenting with VOC known as a care plan, including an escalation plan if the patient’s situation got worse; details of the patient’s medical history, and other information that would be useful for a clinician treating them; clear guidance of what to do immediately for the patient as VOC should be treated as an emergency. Participants were enthusiastic about the possibility of using such an app, and scope to improve other aspects of a patient’s care and a clinician’s workflow were highlighted. Patients and clinicians could benefit from patients recording the use health experiences, including medical use, directly in to the app, since most episodes of VOC are experienced by SCD patients at home. Clinicians could significantly reduce their workload if they could automatically create an entry in the EHR and this app whilst documenting details from an outpatient’s clinic appointment with a SCD patient. It should also be able to help with audit purposes. The system used to do this should be standardised and guide users so that no section was left missing as data gaps could have a negative impact on patient care.

Through a user-centred design approach, a high-fidelity prototype of a mobile app was created; supported by using: proto-personas, user requirements, job stories, sketching, prototyping, and usability testing. Observing participants whilst conducting think-aloud tests with them lead to the
app being iterated and redesigned five times. The app design in general was praised by all participants of usability testing, especially the final iteration. The app has four pages; the emergency page which explains to treating clinicians the most important information on treating the immediate pain symptoms of their patient; the care plan page which provides more detailed instructions in a systematic way on how best to treat the patients pain and make a final diagnosis; the health summary page outlines the patient's medical history, SCD history, allergy status, medication use, and the most recent blood tests and observations; the Sickle Cell page provides a summary of SCD and VOC. The mobile app designed was particularly suitable as a solution as it successfully makes mobile computing more available for clinicians without relying on new technology being procured by the NHS, or existing computers being utilised which are not always available for use.

The app designed still requires further work which is discussed later in this chapter, however it was deemed significantly better than current alternatives for clinicians accessing guidelines and patient care plans. It also provided significantly more useful information in one location than available alternatives. Successful implementation of the app is completely dependent on a suitable method for haematologists to add patient care plans to the app. Without it, the app would be useless.

NHS Director for Digital Development, Dr Sam Shah, provided valuable feedback on the usefulness for SCD patients and A&E staff conceptualised in the prototype; the app could empower patients and speed up the workflow of clinicians in hospital. He supplied considerations and suggestions for extending the benefits of the app to more stakeholders and beyond the use of just SCD patients: patients could record data about their health manually or by using wearable technology; other healthcare professionals could receive reports about the patient from the app and have appointments automatically booked with them when necessary.

5.2 Reflections on Research Methods

Secondary research findings were comprehensive and saved this author considerable time in getting insight about SCD patients and A&E staff. A user centred design approach would normally insist that all stakeholders be consulted, however secondary research findings were triangulated with the results of interviews with Haematologists, validating that conclusions drawn from secondary research were valid and reliable. Semi-structured interviews encouraged longer discussions beyond questions needed for the study, and participants were keen to follow up. This made the interview process longer but had positive impact on rapport with participants; they are all willing to be a part of future work. This could of course have been because they were already very interested in the topic. Remote usability tests worked extremely well; they were easy to organise and conduct and facilitated very rapid prototyping.

5.3 Reflections on Design Methods

The Double Diamond Design Process was effectively used to continually explore potential solutions by theorising, sketching, prototyping and testing. The use of proto-personas was very effective at speeding up the design process whilst still maintaining a user-centred design process. It allowed stakeholders to be considered quickly without investing time interviewing them when it became clear that they were not influential over what was being tested; interviewing an A&E receptionist and Staff Nurse would not have impacted the design that much, if at all. With that said, further work would include interview and observing these professionals as they could impact other aspects of the patient journey and potentially generate beneficial functionality in the app.

5.4 Reflections on Behaviour Change Theory

The Behaviour Change Wheel suggests that work relating to guidelines at a policy level can impact education, and in turn impact one’s capability. This ultimately should lead to a change in both psychological and physical behaviour, which is what was proposed by research for this dissertation as a desired behaviour change for A&E staff.

By changing the action of how the clinician could access information they would need to treat VOC, could change how successful they were at treating VOC. Using the Reasoned Action Approach, it was predicted that clinicians may use the information more if the it was presented on the patient’s phone rather than a computer hospital or their own phone. This could not be completely proven as the mobile app was not used in real life. However, it was highly suggested by all participants, both interviewees and those who tested the app, that it would improve access, and therefore speed.

The BCTTv1 coded techniques correlated to those designed in the app: 4.1 Instruction on how to perform a behaviour was satisfied by providing clear medical guidelines; 6.3 Information about others’ approval was provided by showing that several respected bodies trusted the information such as NICE, the Royal College of Emergency Medicine and a GMC registered Haematologists; 7.1 Prompts/cues were provided throughout the app about what to do if specific signs and symptoms were identified in the patient; 9.1 Credible source, was achieved with logos of respected sources and details of a GMC Haematologist; and
11.3 Conserving mental resources by providing most of the important information a clinician would otherwise need in a single location, without the need of memorising the information.

5.5 Satisfying All Participants
There were occasions where participants gave very contradictory opinions and suggestions. For example, Participant 5 from the interviews said that they would still validate information provided to them, whether the source be a patient or a trusted app. Participant 1 from the usability tests reversed their opinion that photographs in the app were not necessary, but their reason was not the same as all other participants; Participant 1 just felt it was going to happen anyway, whereas others believed it was necessary to make it more trustworthy. In the end, the most important task was to ensure that as many possible needs were met to ensure maximum use by users. Therefore, if one uses gave a convincing argument for a feature, negative opinions from others would not lead to the favourable arguments being dismissed; additional features can be ignored by those who do not need them. The noteworthy exception for this can be demonstrated by the suggestion of information about SCD and VOC for junior doctors. By providing information about sickle cell above emergency information, it would be useful for users unfamiliar with SCD and VOC, but significantly less useful for those who are. An alternative of this suggestion was made in iteration 2 and 3 where additional was provided in between important points and participants did not like this very much. But placing the information on another page was useful for both types of users. This further supported the claim that designs need to be iterated, as the best design was only reached after previous designs were reviewed.

5.6 Transferability and Relevance for Other Research
Although the project was based in the UK reviewing the situation in the NHS, findings are generally transferable to other healthcare settings around the world as it is a worldwide phenomenon. Furthermore, it has successfully used a user-centred approach and followed a Double Diamond Design Process to design a desirable, feasible and viable solution to the research problem. It therefore adds to the body of literature and anecdotes that listening to the user and adopting an iterative design approach really does lead to better designed solutions. Additionally, it supports the use of behaviour change theory to ensure digital solutions are useful and implemented.

5.7 Limitations
The prototype does not explicitly mention the NICE recommendation that pain relief be provided to the patient within 30mins of arriving at a hospital. It is quite possible that if the design was used in real hospital setting and clinicians trusted the app, then this objective would be achieved anyway, as the clinicians would already be trying to get the patients pain under control; hopefully they will do this quicker by being prompted by the app. This of course requires testing. It would be interesting to test this prediction. Although the app is designed to be used by clinicians, the fact it is to be used on a patient’s phone means they have needs to be considered and designed for too. Patients were not formally interviewed for the research. A patient may want to use their phone themselves or could be getting calls and messages which disturb the user of the application. However it is theorised, with reference to the reasoned action approach, that patients would be willing to use: the app can be considered to have clear health benefits when used which is a positive attitude; patients may want to prevent bad past experiences being repeated, leading to an attitude that favours the use of the app; clinicians want to use an app like this so there is positive perceived norms; other patients will likely see benefit in the app, improving perceived norms; patients simply need to open the app and show it to the patient which is a very achievable tasks. This would need to be tested in future work.

Testing the accuracy and validity of clinical information was out of scope of the research for four main reasons. The first is that there will be need for the information to be personalised, which for a fictitious patient used in a prototype would also be fictitious. Therefore, the information at least needs to make sense and be believable. Secondly, the information is primarily being provided by NICE guidelines which outline the best way to treat VOC. It provides evidence-based recommendations which are peer reviewed so copying and pasting information and taking care not to alter context should maintain its accuracy and validity. The third reason, if new types of recommendations would be required that are not found in guidelines from NICE or another respected body, a new peer review process would be needed as well as a new ethical clearance for the study. And finally, the research was specifically investigating whether personalised recommendations could result in a behaviour change in A&E, not how accurate or valid the clinical information is. That would require a test with real data, which again would have required different ethical clearance.
The app was not tested in a real hospital environment due to time and resource restrictions. The research findings are valid, reliable, and can be used as the foundation for future work. But real-life text would have evaluated how successful the behaviour change was rather than suggest how successful it could be. With that said, the solution has been considered much better than current solutions by a reliable sample of the target population of users which highly suggests it would be used.
Axure RP has been used by this author professionally for several years, making it an ideal tool to use for this research. However, other researchers may find it difficult to create as detailed a prototype in the short period of time used by this author. There are several other tools available though, albeit tools requiring some time to learn to use them, including InVision and Omnigraffle which can also create high fidelity prototypes.

5.8 Future Work
A companion web app for haematologists and haematology specialist nurses to use during outpatient’s clinic or day units needs to be researched and designed. As is tracking functionality so patient users can record details about VOC they experience at home. Geolocation can track where the patient is and recognise if the patient has been inside the hospital for more than 30mins. This could then be used for auditing how well VOC is treated at a hospital, region, national and international level. Decisions can be made on analysis of these findings too. However, a privacy issues is introduced here; if the app is always tracking where a patient is, it could provide the wrong person with information about where the patient is.

6. Conclusion
SCD patients often receive delayed or suboptimal treatment of VOC in A&E settings. This dissertation has discovered that negative attitudes towards SCD patients by clinicians and the poor knowledge clinicians have of SCD and VOC, can be removed through better use of guidelines and personalised care plans. Their use can also improve a SCD patient’s: quality of life, general health, and reduced LOS in hospital for VOC. This in turn can reduce the costs associated with treating and managing SCD and VOC.

Few technologies were found that can support SCD, and none have been found that specific provides a personalised care plan with a patient history that is solely aimed at clinicians on a patient’s phone. Interviews with Haematologists supported the notion that such an app, named I, would be of great benefit.

Using the Double Diamond Design Process, a high-fidelity prototype of the app was created. Subsequent usability tests with Emergency Physicians supported a user-centred, iterative design process, resulting a high rated final design. This was supported by the NHS Director for Digital Development, who suggested was to further the work and support patients beyond the target SCD population.

When designing digital solutions in healthcare, this dissertation supports the use of: qualitative research methods such as semi-structured and unstructured interviews, usability studies and think-loud tests; design methods and theory including the Double Diamond Design Process, using personas, user requirements, job stories, sketching, prototyping, and the 3 levels of emotional design; and behaviour change theory including the Behaviour Change Wheel, Reasoned Action Approach and The Behaviour Change Technique Taxonomy

Limitations included the lack of interviewing SCD patients, although behaviour change theory suggests that SCD patients would most likely use it if they find the app useful, easy to use and its use encouraged by clinicians.

Future work includes: designing a companion tool to upload care plans to the app, created by haematologists in outpatient’s appointments, geolocation functionality to track how long a patient has been in hospital; and the ability for SCD patients to track and monitor their health experiences.

ACKNOWLEDGMENTS
I’d like to thank my supervisor, Prof Ann Blandford, for many words of wisdom, patience and, more importantly, supporting me throughout the research. I also thank all the participants who happily volunteered to support me and my research. Your enthusiasm and confidence have been a great motivator. I also thank the Sickle Cell Society for inviting me to their event in July 2018; I learned a great deal and made some amazing connections. To Dr Sam Shah, thank you for the early morning interview and providing such great insight and advice. I also acknowledge everyone who has, has ever had, and are destined to have Sickle Cell Disease, and all the friends, family and healthcare professionals, scientists, social workers and other professionals who strive to improve their health and wellbeing. And finally, I give thanks to my wife, who has been the biggest motivator of them all. It has been my honour, privilege, and pleasure to use my love of UX and healthcare and this dissertation to help improve your health.

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APPENDIX 1 - SAMPLE INTERVIEW QUESTIONS

Can you explain for the recording who you are, and what you do on a day to day basis?

How do patients present with Sickle Crisis?

What are the steps one must take to assess and start initial treatment?

In your experience, what has made assessing and treating sickle crisis difficult or easy?

Are there any tools or formal guidance you feel are effective in assessing and treating sickle crisis?

Do you believe a personalised health record with information about a sickle patient, held by the patient, would help with the assessment and treatment of sickle crisis? If so, what information would you need?

What would make you or your colleagues trust a personalised health record for sickle cell patients?
APPENDIX 2 - Advert for Participants

Call for Haematologists

Any Haematologists in the group?

I'm doing some research for my MSc in Human Computer Interaction and want to talk to some haematologists about treating patients with sickle crisis. My project is about whether technology can help create better outcomes for such patients when they are first admitted to hospital and started on treatment.

If you, a colleague or friend, are willing to talk to for about 30 mins on the phone, please reply to this message or message me privately.

Thanks in advance.

Call for A&E doctors

Hi everyone.

I'm in need of A&E doctors to help me with my MSc dissertation. I'm exploring how new uses of technology can improve the assessment and treatment of sickle crisis. I've already had some great insight from haematologists and patients.

I want to speak to 5 A&E doctors of any level of experience and show them some designs of new ways to access patient information to evaluate if they would be useful or not. It shouldn't take more than 30mins. It can be done over a web based video tool like Skype, or in person depending on where you live in the UK. I am based in Leicester but will be in London next week.

I hope to hear from you soon.
APPENDIX 3 - PERSONAS

Tracey, 29yrs
A&E Receptionist

“I’m the first person a patient usually sees when coming to A&E. I ensure they are booked on the system to be seen by the clinical team.”

Technology use at work: Desktop computer, landline telephone, general admin technology.

Access to patient information: limited to that found on Patient Admission System

Rights to update patient health record: limited to demographic data, although a new record is also created at times.

Clinical Responsibilities: Rarely any clinical qualifications. Often limited to basic first aid, and not usually the first responder if clinicians are around.

Nathan, 28yrs
Accountant

“I try to avoid coming in to as much as possible the nurses take so long to give me strong painkillers. But the pain gets so bad that I have no choice”

Technology use: Laptop computer, mobile phone

Access to patient information: limited to that provided when applying to view

Rights to update patient health record: limited to demographic data when in contact with a health provider.

Clinical Responsibilities: Manage health needs, seeking a clinician when unable to do so on their own. Also attend appointments in accordance to Consultant’s plan.
Dr Jones, 32yrs
Emergency Physician

“I conduct immediate assessment and treatment of patients with a serious or life-threatening issue. This is a specialty in itself, but I have general knowledge of diseases of all organ systems.”

Technology use: Laptop computer, mobile phone, general admin technology

Access to patient information: unrestricted, but most often limited to information owned by the hospital, or accessed via hospital software.

Rights to update patient health record: can update EHR and send instructions to GP. Cannot delete someone else’s data.

Clinical Responsibilities: Main responsibility over patient’s care when seeing them.

Justin, 31
Triage Nurse

“I am the first clinician a patient sees when they come to A&E and I ensure that patients are prioritised based on their presenting complaint.”

Technology use: Desktop/Laptop computer, mobile phone/handsfree phone

Access to patient information: limited to what is provided by the patient unless involved in clinical responsibilities in emergency situation when access to EHR and/or paper records are expected

Rights to update patient health record: limited to demographic data unless involved in clinical responsibilities in emergency situation when access to EHR and/or paper records are expected

Clinical Responsibilities: Limited unless in clinical responsibilities in emergency situation or protocol dictates they act.

Stephanie, 24
A&E Nurse

“I am the first point of call for a patient in need. I collect observations, administer medication and ensure patients are prepared for the different points of their journey in the department. I also provide life saving treatment when necessary.”

Technology use: Desktop/Laptop computer, telephone, rarely general admin technology

Access to patient information: virtually unlimited, although often only includes demographic data, patient history, allergies, medications investigation results

Rights to update patient health record: can create new entries based on work completed and updating observations

Clinical Responsibilities: Trained nurse, can conduct simple procedures, administer medication, and offer advanced life support
Dr Tidus, 60
Haematology Consultant

“I have a special interest in Red Cell disease and considered one of the main authority figures in the hospital on treating Sickle Cell disease in its most severe forms”

Roles/responsibilities associated with VOC: create and update care plans, review patients with VOC, audit VOC data in the trust regularly.

Technology use: Desktop/Laptop computer, mobile phone

Access to patient information: unrestricted

Rights to update patient health record: unlimited, and can influence what is held in the GP record

Clinical Responsibilities: Clinical assessment and treatment of patients, including requesting advanced and expensive procedures, investigations and treatments

APPENDIX 3- COPY OF CONSENT FORMS

For Interview Participants
Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: An assessment of user needs and mobile technology for the assessment and treatment of patients presenting with vaso-occlusive crisis.

This study has been approved by UCLIC Research Department’s Ethics Chair
[Project ID No]: UCLIC/16117/004/Staff Blandford HFDH

Name, Address and Contact Details of Investigators:

UCL Gower Street
London WC1E 6BT
United Kingdom
+44 (0)794947559

Principal Investigator:
Professor Ann Blandford
UCL Gower Street
London WC1E 6BT
United Kingdom
+44 (0)20 3108 7049

We would like to invite you to participate in this MSc Dissertation project overseen by researchers at UCL. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

We are investigating the assessment and initial treatment of patients admitted to hospital with sickle crisis. We then aim to design a prototype of a web app that can improve the assessment and treatment process of sickle crisis in a hospital setting. We are interested to know what challenges both clinicians and patients face during this type of hospital admission, as well as suggestions for improvements. This includes better understanding what tools and formal guidance clinicians use, as well as the experiences patients have when they go the hospital and the treatment they receive until they leave.

You will not be asked personally sensitive information and can refuse to answer any questions that you do not wish to answer.

Interviews are audio recorded. This data will be stored on an encrypted drive. Data will be anonymised as it is transcribed, and the anonymised transcriptions will also be stored securely. All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only the two investigators will have access to your anonymised data. With your permission, anonymised quotations from your interview may be used in reports about the study.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.
For Usability Test Participants

Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: An assessment of user needs and mobile technology for the assessment and treatment of patients presenting with vaso-occlusive crisis.

This study has been approved by UCLIC Research Department's Ethics Chair
[Project ID No]: UCLIC/1617/004/Staff Blandford HFDH

Name, Address and Contact Details of Investigators:

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After an initial period of research, we have designed a prototype of a web app that can improve the assessment and treatment process of sickle crisis in a hospital setting. We are interested to know what your views are of the solution, including anything you identify as strengths and weaknesses of the design and functionality. This includes visual design, ease of use and practical benefit in a clinical setting. All your feedback will be considered in order to further improve the solution.

You will not be asked personally sensitive information and can refuse to answer any questions that you do not wish to answer.

Interviews are audio recorded. This data will be stored on an encrypted drive. Data will be anonymised as it is transcribed, and the anonymised transcriptions will also be stored securely. All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only the two investigators will have access to your anonymised data. With your permission, anonymised quotations from your interview may be used in reports about the study.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.
Informed Consent Form for Participants in Research Studies
(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)

Title of Project:
An assessment of user needs and mobile technology for the assessment and treatment of patients presenting with vaso-occlusive crisis.

This study has been approved by UCLIC Research Department's Ethics Chair [Project ID No]: UCLIC/1617/004/Staff Blandford HFDH

Participant’s Statement

I agree that I have

•  read the information sheet;
•  had the opportunity to ask questions and discuss the study;
•  received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact if I have any concerns.
•  I understand that my participation will be audio recorded and I am aware of and consent to the analysis of the recordings.

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed: ___________________________ Date: ___________________________

Investigator’s Statement

I confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: ___________________________ Date: ___________________________