

# What do users want from an e-Referral system? A requirements gathering activity

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## ABSTRACT

Referring a patient from one Health Care Professional (HCP) to another can be a complicated process, and breakdowns in communication can happen. This can often lead to unnecessary delays, slow diagnosis and poor continuity of care for the patient. Research is showing that e-Health tools can offer new ways of delivering healthcare by digitally connecting people. The introduction of e-Referral systems internationally has been shown to lower healthcare costs, reduce waiting times, improve communication between primary and secondary care and allow doctors to offer longitudinal care for a broader range of conditions. However, some barriers to the systems' adoption have been identified, such as inflexibility, inefficiency and failing to accommodate the details of clinical work.

Involving users throughout the design of e-Health tools is essential in realising high adoption rates from both patients and HCPs. This study aimed to address this by taking a qualitative approach to understanding users' needs for an e-Referral system. Thirteen participants who had recently experienced being referred by a HCP were interviewed. During the interviews, participants' experiences of the referral process were explored, as well as their feelings towards interacting with an e-Referral system.

Using thematic analysis three key themes were identified: the role of the patient, the role of the HCP and communication between the two. Mostly, participants were enthusiastic about using an e-Referral system, and identified many situations in which it would be beneficial to them. However, some participants did express a reluctance to take on the additional responsibilities the system would introduce, such as booking a referral online themselves. Accordingly, the analysis also highlighted the importance

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of HCPs feeling confident passing on this responsibility to their patients.

A number of recommendations are made around the system design and implementation. These include features such as offering learning and support to users, orientation with traditional services, providing a guarantee of security of data, as well as simplicity of use. Inclusion of these should support higher adoption rates from all stakeholders of the e-Referral system.

## Author Keywords

Referrals, e-Referrals, e-Health, EHRs, patient engagement, e-Health literacy, resistance.

## ACM Classification Keywords

H.5.m. *Information interfaces and presentation* (e.g., HCI): Miscellaneous; Healthcare information systems; Health information exchanges.

## MSc Contribution Type

Empirical.

## 1. INTRODUCTION

A referral is defined as a *healthcare process that results in the transfer of patient care from a referring provider to a secondary service or provider, and the transfer back when and if appropriate* [13]. For patients, a referral should facilitate a critical transition from one HCP to another. Depending on the context of the referral, a patient could visit any one of the health centres available to them - such as specialists, diagnostic centres, acute care hospitals, emergency departments, or social care agencies. Their referral could involve a single visit to a specialist or a long-term coordinated effort across multiple health teams.

From a HCP's perspective, a referral is important in terms of transferring responsibility of patient care from the referring provider to the appropriate HCP, and in as short a time-frame as possible [30]. Referrals from primary to other health services can be for reasons such as gaining advice on diagnosis or disease management, organising a specialised procedure, or to get a second opinion [13].

During a referral, care must be coordinated across multiple HCPs, for instance from GPs to specialists, specialists to specialists, hospital to specialist, and so on. Breakdowns in communication can often occur during referrals as a result of the diverse teams involved [13].

This can impact on the patient's experience during the referral leaving them with longer waiting times, slow diagnosis and unnecessary duplication of tests [13].

e-Referral systems are now being introduced in many countries including Finland, Denmark, Norway, the Netherlands, New Zealand, the UK, and the US [30]. Such systems are said to automate all or part of the referral workflow [20].

The aim of an e-Referral system is to support the referral process by providing quick, well-documented, reliable and secure communication between all involved. Much of the literature on existing e-Referral systems has described several benefits such as improved communication between primary and secondary care, a reduction in unnecessary referrals, improved continuity of care, and better management of chronic illnesses [46]. However, adoption of these systems can be slow with some HCPs deeming them inefficient, inflexible and overly complicated [19].

The aim of this study was to identify patient and HCP factors which must be taken into consideration in the design and implementation of an e-Referral system in order to encourage and facilitate adoption by the general public. In particular, patient attitudes towards interacting with an e-Referral systems are explored, and how these may impact on the design of an e-Referral system. A qualitative study was conducted by interviewing participants who had recently experienced a referral. The results of the study uncovered three key themes: the role of the patient, the role of the HCP and the communication between the two during the referral process. These themes highlight the necessity of a shift in roles between patients and HCPs, and how this shift is necessary for a successful implementation of the e-Referral system.

## 2. LITERATURE REVIEW

In the UK, GPs make more than nine million referrals to secondary care each year, costing the NHS over £15 billion in healthcare costs [24]. Given the level of complexity involved in a referral, effective coordination of care can be a challenge for providers. Breakdowns in communication can happen - and will often result in poor continuity of care, slow diagnosis for the patient, unnecessary delays, and duplication of tests [13]. Often these issues are a consequence of paper-based referral processes, which can cause difficulties in tracking referrals and results, excessive paper work, insufficient information for the specialist, and a lack of feedback for referring HCPs [26].

### e-Health and e-Referrals

e-Health tools are increasingly being seen as possible solutions to improve the quality of referrals and patient flow [46]. Variations of e-Health tools have been developed over the last decade, for example Electronic Health Records (EHRs), e-Prescribing, e-Consulting, telemedicine, and symptom monitoring tools [49]. e-Referral tools have also been developed with the aim of digitally connecting

referrers with referral providers – and consequently making the referral process less paper dependent. Finland was the first country to introduce an e-Referral system in 1990. As a result of the Finnish initiative, more patients are treated at a lower cost, and continuity of care and chronic disease management have also seen an improvement [46]. Denmark followed in the footsteps of Finland by introducing their e-Referral system in 1994 - which is said to be saving the national economy approximately €3.5 million each year, cutting costs by 25% [9].

In 2005, the introduction of an e-Referral system to San Francisco General Hospital brought with it an improved communication between primary and secondary care [23]. Referring doctors can now send specialists pre-consultation questions regarding patients. Every clinic has a dedicated specialist (a triager) who reviews and responds to each pre-consultation question. The specialist can then ask for clarification, recommend additional tests before scheduling a visit, or refer the patient to self-management strategies without needing a visit. This collaboration has led to a decrease in unnecessary referrals, shorter referral waiting times for patients, and allows GP's to offer longitudinal care for a broader range of conditions. It also lowered the necessity of the GP to act as 'Gatekeeper' between the patient and specialist care [23]. Similar benefits were experienced when an e-Referral system was implemented in New Zealand allowing the use of electronic messaging between referrers. This facilitated more 'advice only' referrals. As a result, referrers came to understand more about referral criteria and management options for patients, and so reducing the number of in-person referrals needed [20].

### Patient engagement

Gu et al [20] discuss the possibility of incorporating patients' health data within the e-Referral system, and the potential benefits this could have for engaging patients with their own health. Additionally, Olayiwola et al [35] presented research at the *45<sup>th</sup> Annual Scientific Meeting (2016)* into increased patient involvement in e-Referral systems. Their work at San Francisco General Hospital is investigating the potential for enhanced patient engagement and reduction of 'no-shows' for specialist consultations.

Previous studies have discovered an increase in patient engagement as a result of interaction with e-Health tools. For instance, in the Netherlands, an e-Health tool was offered to rheumatoid arthritis sufferers giving them access to their diagnosis, current medication, medical history, test results, and possible treatment options. Studies found that patients using the portal commented that they felt more involved and in control of their condition [48].

Public and Patient Involvement (PPI) has become a fundamental part of healthcare - with its focus on including and empowering individuals and communities. Evidence is showing that when patients are more involved in their own healthcare, they often experience improved health outcomes.

Examples of such improvements are a reduction in hospital admissions, a better quality of life - especially for people with chronic conditions - a reduction in doctor surgery visits, and an overall improvement in the patient experience [29]. Further research is showing that an engaged patient can be more advantageous for a patient's recovery than medication or surgery [27].

However, one study examining public involvement in service design, such as healthcare services, discovered that representatives were inclined to be chosen from a narrow group of individuals [3]. Individuals were rarely from older or minority ethnic groups. Moreover, those who do represent, have reported having little say in the organisation and delivery of healthcare [36]. Ocloo and Matthews [36] state that patient input is often represented in the form of patient survey results read out at board meetings. This confined method for gathering patient views fails to truly represent the diversity of patient journeys through the healthcare system. The consequences of this means that groups who may have the most to gain from services such as e-Health tools are excluded from decision-making [3].

### **e-Health Literacy**

An individual's ability to engage with their health data through e-Health tools is often determined by their e-Health literacy [32]. e-Health tools require patients to be able to seek out, evaluate, appraise and apply what is found, in order to help solve a health problem. These tasks require that patients can interact comfortably with a wide range of technology and media [32]. A recent study on e-Health literacy and older adults found that factors such as level of education and electronic device usage, affected participants' e-Health literacy levels [45]. Research into North American adolescents and health literacy discovered that they struggled to find health information online because of challenges such as the spelling of medical conditions, describing symptoms, deciding relevance of information, and knowing which sites to trust [17].

The advantages of a patient-facing element to an e-Referral system are evident. These can be seen in terms of enhancing patient engagement, and the subsequent benefits this can bring for a patients' health outcomes. However, it is important that an inclusive approach is taken in the design and implementation of such a system. A diverse set of groups must be involved in its design, additionally, e-Health literacy should be addressed to ensure it does not act as a barrier to its adoption [46, 48].

### **e-Health Tool Development**

Winkelman and Leonard [50] argue that one reason for poor adoption rates of EHRs amongst patients is the use of challenging medical terms and codes in patient-facing interfaces. They also say that this is often a result of e-Health tools being built from paper-based systems which were traditionally developed for HCPs only. Additionally, e-Health tools are often designed for HCPs first. When patient-facing features are eventually implemented, they often reflect HCPs' workflows and cognitive behaviors.

Understanding who your users are - and how they work - is a central part of establishing requirements for any system. There are a number of characteristics of requirements gathering for e-Health that can present unique challenges. These include: the complexity of health information and it's forever evolving nature, the difficulties in sharing health information relating to security, trust and interoperability, the length of time health information must be stored, the need for traceability, the socio-cultural needs of the patients, clinical guidelines, and the safety-critical aspect of the health care domain [16]. Other challenges during the scoping, design and development of e-Health tools include the cultural and methodical divisions between developers and health service researchers [39]. These divisions can often lead to teams working separately in silos, lacking the cross-disciplinary learning required during development of an e-Health tool. This can lead to e-Health tools that are not clinically appropriate and have poor usability.

Given the critical nature of e-Health tools these challenges highlight the need for joint thinking between developers and health care researchers during the development of the e-Referral system, to ensure a user-informed product with high adoption rates amongst patients and HCPs.

### **Socio-technical considerations**

Eysenbach [14] describes e-Health as *a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare*. This definition emphasises the need to take a holistic approach in the development of e-Health tools. Considering how patients and HCPs think, work and interact across the health care sector is essential. Some early implementations of e-Referral tools have been accused of not taking into consideration the relationship between technology and its social environment [31]. In 2005, the NHS rolled out an e-Health tool called 'Choose and Book', now referred to as the NHS e-Referral Service (ERS) [19]. The initial objective for the introduction of the tool was to fulfil government policy stating that patients should be allowed to choose the hospital, time and date of their referral appointments [19]. During an ethnographical study of 200 GP-patient consultations in 2008, a number of issues relating to the system were observed.

For instance, in order to offer patients *choice at referral*, GPs found it was necessary to guide the patient through choosing a suitable hospital on the e-Referral system. As a result of this process, consultations had doubled in duration. It was also found that patients often preferred to follow their GP's advice as opposed to making their own choices. Technical problems also experienced by GP's included the need for excessive data entry, as well as the system running slowly, or even freezing or crashing.

Indeed, Greenhalgh et al [19] assert that the teams driving the implementation of the system had little understanding of the details of clinical work, or of the knowledge or experience behind organising patient referrals.

It would seem that for an e-Referral system to be effective, a holistic approach to design and implementation must be considered. This should include not only user and technical requirements, but also inter-organisational business processes. Socio-technical approaches to IT projects aim to take these aspects into account [4]. However, integrating the nature of healthcare work with the characteristics of technical tools can be challenging. It is essential that all stakeholders see the value of new tools in order for them to be successful [46].

On the whole, the focus of previous research has been on the HCPs' experiences of using e-Referral systems, as well as on patients' experiences of *choice* using the NHS e-Referral system [19, 18]. The present study hopes to fill a gap by including patients as the primary participants, while gathering qualitative data on their experiences and views, in order to help identify a set of useful requirements for an e-Referral system.

### 3. METHODS

In order to gather a set of stable requirements for an application it is essential to understand how and why it will be used. For example, the tasks the participants perform, the context in which they are performed, and the rationale behind performing them. Semi-structured interviews were chosen as a data gathering method, as they encourage discussion, are exploratory, but are also mostly replicable [41]. This format allowed the researcher to ask open and closed questions - probing when necessary, for example:

- *What are user's experiences of being referred?*
- *Could an e-Referral system improve their experience in any way?*
- *What kind of users would interact with an e-Referral system?*
- *What would users expect from an e-Referral system?*
- *How would patients feel about viewing or editing their data on an e-Referral system?*

### Interview design

Care was taken when selecting questions for the interview to ensure that they explored the research questions, and fitted the participants' experience. First, two pilot interviews were completed to ensure the questions were clear and the interview was natural and fluid. Based on observations made during these the interviews the script was amended before beginning interviews with participants.

Questions relating to the participant's experience with the referral process were asked first. As the interview continued, questions around their feelings about the process, as well as their attitudes towards an online system, were explored. Below is a selection of questions from the interview script used in the first round of interviews:

1. *Can you tell me how many times you have been referred roughly?*
2. *Can you tell me how long ago was the most recent referral you experienced?*
3. *Did you have any questions regarding the referral information you received? If so how did you ask your GP?*
4. *If your GP had informed you of an online system that you could log on to in order to retrieve details of your referral would you have accessed it?*
5. *In your own experience of being referred can you recall an incident that may have triggered you to access an e-Referral system?*
6. *Would you have liked to have seen the information sent between your GP and specialist?*
7. *Would you have liked to have left any notes of your own on your referral or condition?*

### Participants

Before recruiting participants, it is important to consider resources available and potential constraints. Factors such as obtaining ethical clearance, time taken to recruit, the duration of the interview, as well as time required for transcription and analysis, much be taken into consideration [6].

For this project, the sampling strategy used was a combination of convenience sampling and purposive sampling. The former method refers to recruiting participants that are available to you, and the latter involves recruiting participants as they meet the requirements of your study [7]. The latter was the most appropriate approach considering time and resources available to the researcher.

The recruitment methods for prospective patient users of the e-Referral system were direct contact, indirect contact through social media, and mediated contact. An advertisement (Appendix 4) was placed on the UCL HCI student Facebook group, organisations such as Involve.org.uk, Health Watch Haringey, and Nuffield Hospital Oxford, were contacted in order to recruit suitable participants.

No.	GENDER	AGE	LOCATION	NATIONALITY
1	Male	25-34	London	British
2	Male	25-34	London	British
3	Female	25-34	London	Latvian
4	Male	25-34	London	Singaporean
5	Female	25-34	London	Chilean
6	Female	25-34	London	British
7	Female	25-34	London	Irish
8	Female	25-34	Shropshire	British
9	Female	65-74	Dublin	Irish
10	Female	65-74	Oxford	British/Irish
11	Male	65-74	Dublin	Irish
12	Female	55-65	London	Irish
13	Male	65-74	London	British

**Table 1. Participant list**

However, the most fruitful recruitment methods used for this study were recruiting fellow students through Facebook and word-of-mouth. Participants were compensated by entry into a prize draw to win either £50, £25 or £25 Amazon gift vouchers. They were also assured the interview would take no longer than thirty minutes. When using convenience sampling, care must be taken to ensure there are no biases in recruiting participants and the samples are representative of the wider population [7].

For this study, the researcher endeavored to ensure participant characteristics were balanced as much as possible in order to achieve generalisability of the data gathered to the population [21]. In total, thirteen participants were recruited ranging in age from twenty-five to seventy-four. Out of the thirteen, eleven had experience of being referred through the NHS (NHS Participants), while two shared their experience of being referred through the Health Service Executive (HSE) in Ireland. In order to keep the HSE Participants' interviews comparable to the NHS Participants, the focus of questioning remained on their experience of being referred, and on their expectations of an online system - without concentrating on any NHS-specific components.

Attempts were also made to recruit HCPs through word-of-mouth and Facebook. However, these were unfortunately unsuccessful. The researcher had also hoped to recruit hospital patients and individuals suffering from chronic illness. However, obtaining the necessary ethical clearance was not possible within the given time frame for this study.

## Ethics

The researcher operated under Ann Blandford's Non-Invasive Research on Healthy Adults and ethical clearance, and was approved by UCLIC Research Ethics Committee as Project ID Number: UCLIC/1213/015.

## Procedure

Interviewees were given an information sheet containing details about the project and interview, and asked to complete a consent form which requested the use of audio recording during the interview.

Given the sensitive nature of the topic, care was taken to ensure participants felt comfortable throughout the interview. At the start, participants were informed that they could stop the interview at any point without having to give a reason. They were assured that their experiences of the referral process were the researcher's area of interest, rather than the reason for referral. Participants seemed comfortable knowing this, and the majority only spoke of the process. Participants were also informed that all their data would be anonymised throughout the entire process.

## Apparatus and materials

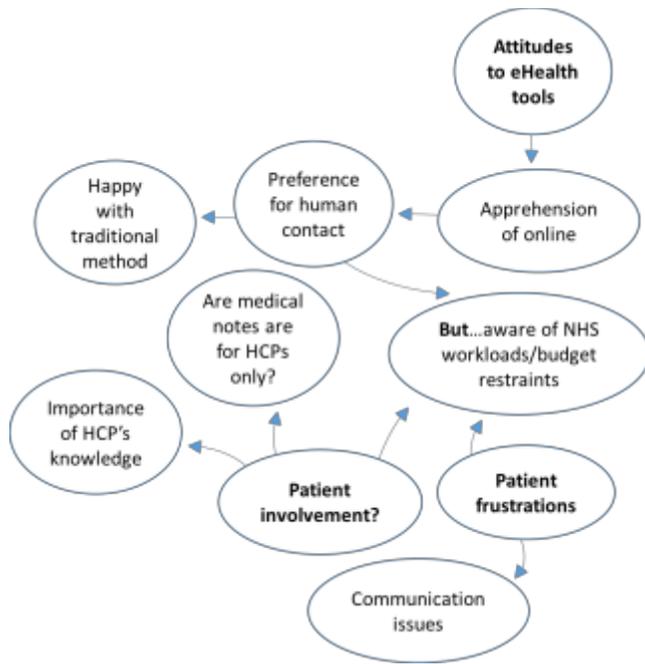
Interviews took place either in a private room booked at UCL, a quiet café, or by Skype. As all interviewees agreed to be recorded, audio for all interviews was recorded on an iPhone 5c. Recording the interview allowed the researcher to focus on building a rapport with the participant by listening carefully and making steady eye contact, rather than focusing on writing notes [10]. The researcher used a Mac Book Pro, with the interview script open in Word to be used as a reference to ensure the interview remained on topic throughout. Mac's Notes application was used to make note of points of interest during the interview, with the intention of returning to the point later in the interview.

## Analysis

Between five and six hours of audio was recorded for the thirteen interviews. Many researchers believe the act of transcribing is an important step in the analysis of data [38]. For this study, the researcher transcribed each conversation as close to the conversation as possible, ensuring each participant's views were being represented accurately.

Patterns in the data were identified and analysed using a thematic analysis method. This method was chosen for its ability to organise a data-set in rich detail, allowing an in-depth interpretation of the research topic, while at the same time remaining flexible [8].

Patterns can be identified in two ways in thematic analysis – either an inductive or bottom up approach, or a deductive or top down approach [8]. The former method stays as close to the data as possible, ignoring existing theory or literature on the research topic, and allowing the data to speak for itself. The latter is concerned with staying close to the research question, and focusing on how it is answered by the collected data.



**Figure 1. Initial set of themes**

In the present study, it was necessary to stay as close to the research question as possible in order to form some useful requirements for an e-Referral system. Consequently, a deductive approach was taken while still trying to remain close to the data.

The researcher aimed to perform the analysis at a semantic level initially, in order to organise explicit themes, finally digging deeper to the latent meanings behind themes and how they relate to previous literature.

The analysis began by reading each transcript and taking notes in order to become familiar with the data. Next, using Nvivo<sup>1</sup> software, the researcher commenced coding the transcripts line by line, looking for issues or areas of interest, again making notes along the way. At this point, the researcher remained open, giving equal attention to each item. By the end of this stage of analysis, 67 codes were identified in the dataset (Appendix 3).

The next stage involved reviewing the codes and discovering some over-arching themes. This was done firstly using post-it notes to organise themes and sub-themes. Themes that overlapped were grouped together or merged if possible. Themes that had little significance to the research question were disregarded and relationships between remaining themes were identified. Using the resulting themes and sub-themes a mind-map was created in PowerPoint (Figure 1).

Initial themes such as attitudes to e-Health, frustrations over patient-doctor communications, and patient involvement in

their health, had begun to emerge during the analysis (Figure 1). However, as the investigation progressed to a more latent level of analysis, it became apparent that these themes related to the *roles of patients, the roles of HCPs, and their relationship to each other*, and how these could be altered by the introduction of an e-Health system. Each of these themes is discussed in detail in the Results and Discussion sections that follow.

#### 4. RESULTS

The results are based on thirteen semi-structured interviews with participants who have experienced being referred from one HCP to another. These findings show the results of a thematic analysis that was conducted on the transcribed data. The themes are intended to help inform the initial research question:

What do users want from an online NHS referral system? A requirements gathering activity.

The majority of participants in this study were referred by their GP to a specialist. However, in order to account for the variety of potential referrers in healthcare the non-specific terms doctor and HCP are used when discussing the referral throughout the analysis and discussion.

##### Role of HCP

When discussing the role of the HCP here it is important to emphasise that this is the patient view of the HCPs' role during the referral process. This theme relates to how the participants feel the role of the HCP may change if an e-Referral system was introduced to the process.

When participants were asked how they would feel about booking the referral themselves using an e-Referral system, many expressed a sense of apprehension at the prospect. Although the reasons for this concern varied considerably amongst participants, there was a consistent thread throughout which suggested the importance of the role of the HCP in their referral, and the expertise they brought to the process as a whole.

##### Speaking to a human

Some participants felt a key part of the referral process lay in their interaction with their doctor, which an electronic system could potentially jeopardise. This group in particular had often developed a strong relationship and sense of trust, both with their doctor and the healthcare system. Participant 10 emphasised how they would have more confidence in a person organising the entire referral for them.

*"The thing is the referral process has never bothered me it's the illness that bothers me. I think that having the doctor and speaking to somebody gives you that confidence rather than going through a system..." (P10)*

##### Expert knowledge

When participants were asked about the prospect of selecting a hospital or specialist themselves through an e-Referral system, participants provided mixed responses.

<sup>1</sup> Nvivo – Software for Qualitative Data Analysis

Some participants relied on their doctors' knowledge to help them choose the most appropriate hospital for them. Participant 11 stated that they would not feel confident in choosing a specialist themselves - and relied on their doctor's expertise to make this decision for them.

*"I wouldn't have been able to make that decision [chose the specialist], the GP would know who the specialists are and he recommended this one and I was happy with that..." (P11)*

Similarly, Participant 7 said they had more confidence in their doctor's knowledge regarding which hospital to choose over their own ability to research information on hospitals online.

*"I think I'd prefer the GP to do that [choose hospital] ... so her experience is definitely gonna outweigh anything I find online... you know... so I think I'd prefer her to do that..." (P7)*

#### **Shouldn't my doctor do that?**

Other participants felt that having to go online and use the e-Referral system to book a referral after visiting their doctor would add an additional step to the referral process for them. These participants wanted the process to be as quick and uncomplicated as possible.

Participant 6 said they would prefer their doctor to book the referral during their visit. It was important to them that their doctor played a primary role in their referral, given that they were their first point of contact for a referral. For this participant, having the doctor make the referral offered a sense of reassurance that they were being assisted by their doctor, and their visit to the surgery essentially triggered the referral process itself.

*"I think if he was to say to me you have to go online and book this... that could be a bit frustrating if I'm honest ... cause to see the doctor is a headache in itself... so the fact that he made that appointment made me feel that they were doing some kind of work." (P6)*

Participant 4 stated that although the process had felt very 'low technology', they were happy with the experience, and in particular the fact that it had been a quick one. This participant again felt that having to go online after their doctors' appointment, to organise the referral themselves, would introduce another step, and possibly delay their journey through the healthcare system.

*"The way that I went through even though it was very low technology it got the task done really fast. If I had to go through a system, it feels like I would have to get the log in again. I would prefer the paper one to be honest and getting someone to do it for me." (P4)*

These themes would suggest that the role of their doctor in the referral process is an important one to most participants. The act of the doctor booking the referral and choosing the hospital is central in helping participants feel that not only

was their visit to their doctor worthwhile, but the right choices were made in terms of hospitals and specialists. Participants in the 55-74 age group showed they were inclined to value face-to-face contact with their doctor more than the younger cohort aged between 25-34. However, both groups did hold their doctors' knowledge in high regard, which is also discussed later in relation to the role of the patient.

#### **Role of Patient**

When participants were asked about how they would feel about engaging with their own health information on the e-Referral system - such as reading the doctors' or specialists' notes regarding their referral, or leaving notes of their own - they gave mixed responses. Most participants spoke about seeing their referral notes, and leaving their own notes on their referral, as two separate activities, and applied different values to each.

#### **Viewing notes**

Many participants felt that the referral notes were for doctors only, and not intended to be read by patients. Participant 7 felt that they would not understand the medical terms or shorthand. They felt that their notes were easily accessible within the doctor's office, as their doctor sits beside them allowing them see what they are typing.

*"It probably wouldn't have made a lot of sense to me, because they tend to use a lot of short hand. No I don't think I'd need to see those, anyway in the doctors' office she kind of sits beside... so if you want to you can see what she's typing..." (P7)*

Participant 8 shared a view similar to most other participants, feeling that if they needed to see the referral notes they could just ask their doctor.

*"I'm not overly fussed about that if I want to see [GP notes] I can just ask my GP..." (P8)*

Participant 13 felt that if they had questions regarding their referral, they would prefer discussing this openly with the doctor, rather than seeing the notes independently.

*"Definitely, definitely someone to talk to about it... [instead of reading it themselves]" (P13)*

Participant 2 felt that seeing these notes could potentially threaten a level of confidentiality that doctors are entitled to between themselves.

*"So they are professionals so you gotta give them a degree of confidentiality between themselves as professionals so..." (P2)*

However, some participants did show some curiosity in seeing their medical notes online and identified some potential advantages in being able to do so. Participant 12, for example, expressed a curiosity to see their notes feeling that as the information was about them they were entitled to see it.

They also felt that they would be interested in checking the facts of their notes to ensure the correct interpretation would be made by anyone reading them.

*“I suppose I would because after all it's something he's writing about me... and you don't want it to be seen as... if someone else had seen it with a completely different meaning behind it.” (P12)*

Participant 5 was one of the three participants who managed to recall a specific incident where seeing their notes could have prevented an error caused during their own referral. Again this participant was expressing a need to check that the correct information was being passed between doctors.

*“Yeah. I have a medical condition and there's another one with a similar name so the first doctor put the wrong name, so then when I went to the cardiologist he thought that I had a totally different condition. So I would like to see that.” (P5)*

### Leaving notes

When participants were asked how they would feel about leaving their own notes regarding their referral on the e-Referral system they were more receptive. Overall the majority of participants wanted to leave notes for HCPs. Participants frequently mentioned how useful this could be for clarifying details around their complaint. For instance, Participant 5 mentioned how they felt their doctor may not always get every detail relating to their condition taken down. They saw leaving their own notes as an opportunity to ensure all their information was added to their referral.

*“Yeah maybe, sometimes doctors don't listen to you very well so yeah I think it's good to put some notes [online]. Because they may forget to write something.” (P5)*

Participant 2 felt it would be a useful way for them to communicate more about their activities as a sportsman, and what that meant for their physical health requirements. They believed being given the opportunity to express how important their flexibility is to this part of their life could add some context to their health data, and perhaps to the next HCP reading it.

*“So I think to be able to communicate what I needed as a sportsman what I needed to do [such as backflip] I think that would have been useful...” (P2)*

Participant 6 again felt they would like to ensure all the details of their condition were covered. They also showed an interest in adding their own notes in a format that suited them. They felt they could choose the format in which to write the notes, and perhaps refer back to it later for reference.

*“Well yeah because did he really get down everything... so yeah ... even if I hadn't seen his notes ... I could be as clear as I want to and write my own notes...” (P6)*

Some participants began to explore the concept further by imagining this feature as a means of keeping track of their own health information over time. Participant 3 was experiencing an ongoing health issue, which had also been investigated in their home country. Although they kept track of all documents themselves, they expressed an interest in having this information online and in one place.

*“Yes [would like to leave own notes] because I actually also have material because I did the ultrasound somewhere here, I've got the scans from the clinic in another country. So I'd have all that on hand...” (P3)*

Participant 4 was one of a number of participants who felt this could be a useful medium for asking their doctor questions regarding their health.

*“I think I would be interested in having it online [e-Referral system to leave referral notes] and of course if you had the chance to interact with him [their GP] more that would be nice but I think that's the issue of his time.” (P4)*

When describing their potential interactions with the e-Referral system many participants discussed it in relation to other applications they used to manage their life. For example, Participant 6 suggested the system allow them to add their specialist appointments to their calendar as they can do with the EventBrite<sup>2</sup> application.

*“Email [reminder email], then I can add it to my calendar. Kind of like EventBrite tickets that appear in your calendar...yeah” (P6)*

When discussing information that could be useful to see on the e-Referral system, two participants were interested in seeing details of the specialist or team they would meet prior to the consultation. Participant 8 suggested that having more information about the specialist before the consultation, such as photographs, might help prepare them for what to expect during the referral consultation.

*“It would be nice also to know who you're gonna see ... so it's nice to know what to expect... even if it's these are the four people who are members of this clinic with a photo just something to make it a bit more human.” (P8)*

Similarly, Participant 12 stressed how some patients can feel a sense of anxiety or anticipation at the thought of meeting a new HCP. Having some background information on the individual could potentially make the consultation more personable and less daunting for the patient.

*“Yes I would em...that would be useful [seeing information about the HCP] because when you see someone for the first time you're a little bit like... you're full of anticipation you're not quite sure whether you'll get on with them, so I think it's terribly important to do that...” (P12)*

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<sup>2</sup> EventBrite.com –Event Organisation Application

### **Trust and Security**

When discussing the viewing and editing of health data, some participants expressed concerns over the security of their information

Participant 7 expressed concern over third parties accessing their health data. They were particularly concerned over the possibility of insurance companies having access to their data.

*“I definitely don't want anyone else accessing my health record... you know just for insurance companies; you've got to be careful...” (P7)*

Participant 10 expressed similar concerns around insurance companies accessing people's health data. They mentioned the possibility that people who were ill might be charged higher premiums for private health insurance if their data was easily accessible.

*“...people feel they will be penalised by certain conditions if they wanted private health insurance...” (P10)*

Initially many participants were reluctant to view their referral notes using the e-Referral system. Yet, when discussing scenarios such as changing appointments, tracking their own health data, or confirming their information was correct, they began to explore the idea further. As mentioned earlier, some participants began to make comparisons of the proposed application to other applications they use in daily life, for example booking holidays on Expedia<sup>3</sup>, keeping track of dates in Outlook<sup>4</sup>, or renewing their driver's license online. These types of comparisons would suggest that participants may adjust to managing their health information online, as they may have already done so with many other areas of their lives. However, participants' initial concerns around security, and reluctance to viewing notes, suggests this shift in thinking may not take place immediately - and could perhaps only take place gradually over time.

### **HCP / Patient Communication**

When discussing their experiences of being referred, many participants mentioned times when they felt either lost in the referral process, or uncertain of their referral status. Participant 2 complained of leaving their doctor's surgery unsure of what the next steps were in the process.

*“I left without any further information. I had no indication of the amount of time I had to wait, I had no communication, I didn't even know who to call if I wanted to find out when or where the appointment was gonna be.” (P2)*

This was a recurring remark, not only in relation to the status of referrals, but also in terms of test results - such as

<sup>3</sup> Expedia.co.uk – Trip planning application

<sup>4</sup> Microsoft Outlook – Email software

blood work or scans. Participant 7 expressed anxiety over waiting for bloodwork results. The fact that they would only be contacted if their results were not OK left them to interpret a void of no information.

They wondered if the time period in which they should receive their results had passed, or if they had missed the call giving them bad news.

*“Ehh waiting for results... definitely...that would be the number one...just good or bad...cause you're not contacted when they're OK and you're like...has two weeks passed I don't know did I miss a call so yeah it would be good double check and just know yeah it's ok...” (P7)*

When participants were asked if they used the existing NHS e-Referral system, only two out of the eleven NHS Participants had heard of it. These two participants had been made aware of the system through the media and word of mouth. Participant 2 mentioned that they were aware of the e-Referral system from talking to other NHS patients in their doctor's surgery reception area. However, when being referred for physiotherapy on numerous occasions, they were never offered this option by their GP.

*“I did [know there was an e-Referral system], I didn't do this but I'm aware from talking in the waiting room that other people do... so there's supposedly an online system... but of all the people I've spoken to in all the times I've gone back to the physio [referred by GP to the physio] no one mentioned it and that's always puzzled me.” (P2)*

Some participants also expressed an acute awareness of the pressures facing the NHS, and felt apprehension over how this additional interaction on an e-Referral system could impact on HCPs' time. When Participant 1 was asked if they would like to leave notes for the specialist relating to their scans, they felt that this would place extra pressure on the individual to read them, potentially increasing their workload. This participant expressed a sense of duty towards keeping their interactions with HCPs quick so as to save them time.

*“I always imagine doctors are really, really busy people and you just wanna tick certain boxes for them, give them the basic information...” (P1)*

In the same way, Participant 8 doubted whether or not the consultant would read their notes given the time pressures they were under.

*“Well what benefit has it? [leaving notes] Also they're busy...so there's just...just no point.” (P8)*

Patient frustrations over communication with HCPs - or the lack of it - is an issue that the e-Referral system could certainly address. For example, information such as a patient's referral status, their bloodwork results, or referral times, could all be available to them in one place.

This should also have the effect of lowering the number of patients phoning doctors' surgeries and hospitals to get such information. Participant concerns over whether or not their notes would be read, or taken onboard, by HCP, must also be addressed – perhaps by incorporating a 'has read' functionality in the system, which the patient can access prior to a new consultation. HCPs' schedules and work practices must also be considered to ensure they are afforded adequate time to review patients' notes.

## 5. DISCUSSION

The aim of this study was to understand what people expect from an e-Referral system, and to identify key factors for its design and implementation. The study has identified three key themes in relation to patient requirements for an e-Referral system. These cover the role of the HCP, the role of the patient, and communication between the two.

Other factors addressed by the study included what kind of concerns patients might have over the introduction of this system, and what barriers to its usage must be considered during its design and implementation.

Some participants indicated that they would favour face-to-face communication over digital in relation to their health. These respondents felt that their doctor's knowledge could not be substituted by an online system. For these participants, it seemed the trust and rapport between the doctor and patient played a major role in their GP visits. This theme is supported by research which has shown that there are many positive effects of patient-doctor communication. This communication needs to not only include physical examinations, but also sharing medical information and listening carefully to patients [28]. Psychosocial interventions such as offering patients information, emotional support, and educating patients, have helped people with ailments such as chronic pain and chronic disease become more independent in their own care [44]. Comparably, it has been argued that when measuring a patient's level of engagement, in cases where e-Health tools form part of their care, a patient's emotional needs are often overlooked [2]. Barelo et al [2] believe a more holistic approach needs to be taken to understand the patient's experience of e-Health tools during their care. This suggests that the empathy and emotional support a HCP can offer during face-to-face interactions cannot be replaced by an e-Health system, and must remain a strong element of all patients' care.

In the present study, some participants expressed a reluctance to booking the referral themselves online, preferring the HCP to do it for them. This could stem from a belief that their doctor should be the only manager of booking their referrals, or perhaps an unwillingness to take on responsibility for this new task themselves. In order for a successful implementation of the e-Referral system, a shift in responsibilities for both patients and HCPs would need to take place.

As discussed in the literature review, evidence has shown that patients who are more engaged in their own healthcare can experience better health outcomes [29]. For this shift in responsibility to happen, the patient must be willing to use their time to contribute to their care in different ways than they have in the past [29].

For patients to accept their new role as active players in their own healthcare, they need to be given confidence in their own knowledge and abilities to do so. Another theme identified in the present study was participants' reluctance to view patient records independently. Some concerns around this were related to not understanding medical terms, or a preference to discuss their record with their doctor. A patient's self-perceived health literacy could be a potential barrier to using the e-Referral system. Their ability to take a more active role in their healthcare can be defined as their level of activation, and can be measured using the Patient Activation Measure (PAM). A study into patient uptake of an e-Health system in the US discovered that patients with a higher level of activation were more likely to use the e-Health system than those with lower levels of activation [22].

This highlights the need to encourage and educate patients in the use of the e-Referral system, and to identify those who might need more support than others, to ensure a universal adoption of its use. Additionally, knowing the population's level of activation will be essential when deciding what kinds of support are required.

Also noted during interviews was NHS participants' lack of knowledge around existing NHS e-Health tools. For example, the majority of these participants were unaware that there was an e-Referral system, and summary EHR, available to them [33]. This supports the findings from the study by Green et al [18] into patients' experiences of booking referrals at their doctor's surgery. From 104 patient responses, less than a half were offered the 'Choose and Book' option for their referral. Doctors' reluctance to use the system was discussed earlier in the Greenhalgh et al [19] study into GP attitudes towards the system. This study found a number of reasons for low adoption, such as inefficiency, inflexibility, and doubling of consultation time due to the need to guide the patient through their choices on the system.

Further research would need to be conducted in order to obtain HCPs' perspectives on the existing NHS e-Referral system. However, the present study reveals that for the e-Referral system to be adopted by patients, there will also need to be a level of doctor activation [5]. In order for patients to become active in their own health care, HCPs will need to modify their approach from being an expert instructor to a collaborator or partner with their patients. This shift in roles for HCPs must be supported by ensuring their work practices and routines are considered carefully during the design and implementation of the e-Referral system.

Little research has been undertaken into what patient perceptions are in regards to reading and interacting with their own health data. In this study participants were found to differentiate between viewing their referral information and adding notes of their own.

Interestingly, participants showed an initial reluctance to view medical notes on their referral. However, when asked if they would like to leave notes on their referral, participants were generally enthusiastic. A reason for participants' initial reluctance could be their automatic response to doing something they are not accustomed to. Also a concern voiced by some participants was the fear of not understanding their medical notes.

However, when discussing leaving their own notes, participants described situations where this would have been an opportunity to correct or verify information their HCP had added, or to provide further information regarding tests or scans they may have had.

Some participants referred to applications they currently used when describing their expectations of interacting with the e-Referral system. Personal management tools were described such as Expedia for booking their trips, EventBrite for adding events to their calendar, or Outlook for arranging meetings with others. Mentions of such applications highlight how patients may view referrals as something they need to fit into their life, and how important it is for them to be able to do this effectively.

Patients' initial reluctance to view their referral notes, which then turned to enthusiasm when useful scenarios were considered, could be an indication of the need to change mind-sets about healthcare, and what patients' roles could be. Once the advantages of using the e-Referral system are made immediately apparent, the public may be more inclined to adopt its use.

When discussing viewing and editing their referral data, some NHS participants expressed an awareness of, not only the potential this has of putting more pressure on an already burdened NHS, but also a skepticism over whether their input would be read, or even taken seriously. Although collaborative care has been shown to be beneficial to both patients and doctors, studies have uncovered potential barriers to this partnership [25]. In one study involving patients and HCPs, doctors felt that patients should take on a consultative role, as opposed to being involved in decision making. One doctor commented that often the onus was on them to educate the patients in order for them to make useful contributions to their health care decisions [15].

This again goes back to a shift in roles and responsibilities where patients willingly take on more responsibility for managing their health, and doctors feel confident passing some responsibility on to their patients. It highlights the need to move away from a paternalist approach to healthcare and recognise the value that all patients can bring to a collaborative relationship.

### **Implications for design**

Many implications for design can be derived from analysis of the results of this study. However, one central theme that stands out from the others is the necessity to change the mind-sets of both doctors and patients as to what their roles are in health care.

Changing peoples' attitudes or behaviors, or requesting that people behave in a manner they are not accustomed to, even when there are obvious advantages for them, can be difficult to achieve and does not happen immediately. In his book 'Diffusion of Innovation', Rogers [42] states that public acceptance of a new technology, or new approach to doing things, has four main elements: (1) the innovation itself, (2) which is communicated through certain channels, (3) over time, (4) among members of a social system. In the present study, the innovation is an e-Referral system, its use needs to be communicated across multiple channels, prior to the project rollout and beyond, to both the public and to healthcare professionals. Rogers [42] also observes that characteristics of the innovation, such as relative advantage for the user, complexity of innovation, compatibility with existing beliefs and values, trialability (option to try first) and observability (observe the benefits) can determine its rate of adoption. When developing an e-Referral system, these characteristics must be considered in terms of the system design, the process changes required to support its use, and the implications it will have on both patients and HCPs. The characteristics identified by Rogers [42] are reflected in many of the design recommendation discussed below.

### ***Trust and security***

e-Referral system users must feel that their data is in safe hands. One concern voiced by three participants during interviews was the security of their data. Participants wanted to know that their data would not be passed on to any third parties which might have an impact on their access to insurance policies, or on existing premiums. Others expressed concern over their data being "on the Internet".

Concerns over security were discovered in a number of other studies into patient attitudes to EHR adoption [1, 40, 43]. Rigorous and continuing safety procedures must be put in place in order to secure patients' data.

Clear messages conveying the robust safety measures taken to secure the privacy of their referral data must be communicated when introducing the system and across the system itself.

Participants also expressed a sense of trust in their doctors choosing hospitals for them, that they did not want to lose to an e-Referral system. This was also discovered in Greenhalgh et al's [19] study on the 'Choose and book' system. It was found that patients preferred their doctor to choose the hospital rather than choose it themselves. This demonstrates that patients must feel a sense of empowerment and trust in their own decision-making skills when selecting hospitals and specialists on the e-Referral system. One way to achieve this is by providing them with comprehensive and understandable information regarding the hospitals, specialists and teams available to them. They must have easy access to both patients' reviews and Care Quality Commission (CQC)<sup>5</sup> evaluations of hospitals and specialists.

### *Usefulness*

One of Rogers' [42] characteristics for a successful adoption of an innovation was relative advantage for the user. For both patients and doctors to adopt use of the e-Referral system, it is important that they can clearly see the benefits it holds for them. Lack of understanding of system features, or their importance, have been cited as major reasons for patients not to use EHRs [15].

Some participants in the present study mentioned the importance of fitting their referral into their lives and schedules. Others compared it to applications such as Expedia - which provided a straightforward booking flow - or to EventBrite - which conveniently adds the date to your calendar. These kinds of features could make the application useful for patients and encourage its use over traditional methods. Below are some proposed features for an e-Referral system based on user feedback collected during the interviews:

### *Hospital*

- View most recent hospital CQC results.
- View hospital location on map.
- Select hospital.

### *Specialist*

- View specialist profiles for hospital and area selected (picture, qualifications, specialist areas, research interests, certifying bodies).
- View specialist availability.
- Select specialist for date required.

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<sup>5</sup> Care Quality Commission (CQC), the independent regulator of health and social care in England.

### *Referral information*

- View status of referral (pending confirmation, confirmed, completed).
- View notes sent from referrer to specialist.
- Leave notes for any extra clarification needed.

### *Results & Scans*

- View list of tests relating to referral and due dates.
- View results of tests completed.

### *Manage alerts & communication*

- Select preferred contact method (text message, email, post, phone).
- Select frequency of reminder information.

In order for adoption of the e-Referral system to be successful it will be essential that patients are informed of its value at various stages of their care - allowing them multiple opportunities to begin using it. Highlighting the importance of features such as viewing referral status, and receiving test results online, should help patients to see how using the system could prevent the need to call their HCP or referral management centres.

HCPs should also be made aware of the benefits they can experience from the implementation of the e-Referral system. For example, if patients can view their referral data online they will be less likely to make calls to the doctors' surgery requesting a status update. Furthermore, seeing results from tests relating to their referral will also reduce patient phone calls to the surgery.

Another advantage for HCPs is the opportunity for primary and secondary care specialists to communicate electronically via the e-Referral system. The use of 'advice only' referrals, as discussed earlier, allows doctors to ask specialists questions regarding patients prior to referring them. An advantage of this feature has been to reduce the number of unnecessary referrals, and to allow doctors to provide longitudinal care for a wider variety of illnesses (SFGH). To ensure HCP uptake of the system, they should be made aware of the benefits an e-Referral system can have for them, such as a reduction in paper work, improved communication and access to specialists, a simpler and more efficient access to referral systems, and fewer patient phone calls.

### *Simplicity*

Another characteristic Rogers' [42] recommends for a successful innovation was to minimize complexity. The innovation must not be perceived as being overly complex. Doctors and patients must find the system easy to use. To achieve this, an inclusive approach must be taken when designing the system, and during its implementation.

In the present study, participants who were aware they had access to a summary EHR on the NHS stated that they had not used it yet as it involved visiting their doctor's surgery in order to set it up. Similarly, complications around setting up an account were cited as reasons for low adoption rates of EHRs in studies in the Netherlands and Australia [15, 1]. All patients using the portal must find the registration process smooth and uncomplicated to ensure that they can see the advantage using it has for them, and to ensure they will continue using it in the future.

Participants should also be offered access to the system via multiple mediums, for instance desktop, smartphone or tablet. During interviews, participant's views on which medium they preferred were varied. This finding is an indication of the diverse needs of a heterogeneous user group which must be met.

Lack of efficiency, inflexibility and being overly complex were some of the reasons for HCPs not using previous e-Health tools [1, 19, 40]. Therefore, it is essential the system meets the needs of HCPs - and that their work practices are considered carefully during the design and implementation.

#### *Learning and Support*

As discussed earlier an individuals' e-Health literacy can be a potential barrier to engagement with their health and e-Health tools [17, 45]. To ensure that an e-Referral system is a universally accessible scheme, learning and support must be provided at every stage of the rollout to patients and doctors. Studies have shown that life expectancy varies across people from different socio-economic backgrounds [34]. In the UK, 10.5 million people have no basic digital skills, half of whom have never been online [47]. A strong relationship between those with poor digital literacy, and those who risk health complications, has also been discovered. When learning and support initiatives are put in place to support the rollout of such a system, they must be designed to reach people from all groups. Activities such as running community outreach events, digital surgeries to engage and train patients, and embedding digital health with existing digital training workshops, have all been found to be effective in taking an inclusive approach to empowering all patients to use e-Health services [47]. There should also be clear and direct online and physical guides about the e-Referral system which give the patient guidance around choosing hospitals and specialists. These should include both comprehensive and easy-read guides, which are easily accessible to all.

Effective provision of training and information for patients should remove the need for doctors to spend time during consultations having to educate patients on its use. Patients should be encouraged to practice autonomy in their use of the system, without relying on their HCPs' assistance.

HCPs must also receive training and support in the use and promotion of the e-Referral system. According to Dunn et al [12], managers in social care settings felt that some staff

lacked the digital skills needed to support patients' e-Health literacy. They also commented that technology was changing so quickly it was difficult to maintain staff skills. Some suggestions for training healthcare staff could include shadowing, peer learning, supervisory support, and supervisor-led formative assessment.

#### *Traditional service*

Rogers [42] also stated the importance of the innovation being compatible with the users' existing beliefs and values. In the case of an e-Referral system, it is important that its features are as similar to the existing service as possible. For example, once a patient has booked a referral using the system, they should be sent a confirmation letter in the post by default. Information regarding their referral should not only be available on the system, but should also be provided on their letter, as is the case with the traditional referral process. Patients should also have the option to change their appointments online, or by phone, as is the case now. Patients who are comfortable using the online system should have the option to opt-out of mail correspondence.

Matching the e-Referral system to the existing service, while also keeping the traditional procedures in place, will mean a smaller learning curve for users, and a smoother transition during its implementation. This will be particularly important for those who have become accustomed to the traditional method over time. Some of the older participants in this study commented that they liked the process the way it is, and were reluctant to see it change. It is essential that patients do not feel pressured into changing their habits, and that all users' needs are being supported during its implementation and subsequent use.

#### *Opt-out option*

Finally, Rogers [42] mentions the importance of trialability, i.e. by offering users the option to try first. Giving patients the option to try the e-Referral system, without needing to commit longer term, could reduce the feelings of uncertainty around its use. This method is currently being implemented in parts of Australia, where residents were automatically given an EHR which they could access online immediately [1]. They were given a time frame of five months from when it was introduced in which they could opt-out [37].

This approach has also been taken by a US corporation, where they switched new employee pension status to automatic enrollment with an opt-out option. This change saw pension uptake increase significantly, when compared with employees hired prior to the introduction of automatic enrollment. As a consequence, the Pension Act 2008 now requires employers to automatically enroll all eligible employees [11]. This auto-enrollment method could also by-pass the need for a complicated registration processes, which has previously been identified as a barrier to e-Health adoption [1].

Patients who prefer not to use the e-Referral system should be given multiple options for opting out, for instance by phone, online or at their doctors' surgery.

### **Limitations and Future Work**

Attempts were made to recruit HCPs to interview as part of this study. Indeed, as the major themes identified related to the roles of patients, HCPs, and how they communicated, future work involving HCPs would be particularly useful. Certainly, as it became apparent that only two participants were aware of the NHS e-Referral system, it would have been useful to discuss the system with HCPs, and discover what their attitudes were towards it.

This feedback would also be a useful source of information for possible improvements to the existing system, and how it's use could complement their work existing practices. Another theme discovered, that could warrant further exploration, was HCP's views on patients becoming more involved in their own healthcare - and how this may impact on the patient-doctor relationship.

While participants in this study represented a diverse set of nationalities, were balanced in gender, and had varied experiences with the referral process, it was not possible to gain ethical clearance to interview participants with ill-health in the time available. Future work should include participants suffering from chronic or serious ailments, and who may have had frequent contact with various HCPs over a long period of time. This work should explore the context around the patients' illness, be it acute or chronic, and how it may impact on their expectations for the system. Additionally, much of the literature pointed to the fact that people with chronic illness tend to experience improved health outcomes from using e-Health applications [48]. It would also be of interest to the researcher to validate this finding in the use of e-Referral systems also.

### **6. CONCLUSION**

This study took a qualitative approach to understanding what the user requirements are for an e-Referral system.

Thematic analysis from thirteen interviews uncovered three over-arching themes; the role of the patient, the role of the HCP and the communication between the two.

When discussing the use of an e-Referral system to book referrals, participants gave mixed responses. Some participants expressed a preference for their doctor to do this for them, trusting the expert knowledge of the HCP and preferring human interaction over electronic.

Other participants were reluctant to take on the task of booking the referral, feeling that their visit to their doctor should essentially start the process.

On the topic of viewing their referral notes, participants were initially skeptical. However, when the discussion moved on to leaving notes of their own many participants were eager to have this feature, and often described

scenarios where this would have improved their referral experience.

When discussing communication between HCPs and patients, participants expressed frustration over lack of information during the referral process. Participants saw advantages the system could bring - such as the status of referrals, and pre- or post-referral test or scan results, with some citing it as an additional opportunity to communicate with HCPs.

Discussion around these themes highlighted some contextual shifts that need to take place for successful adoption of the e-Referral system.

The relationship between patients and HCPs must change from one that is primarily a patient consultation with an expert, to one that is more of a collaboration, or partnership between the two.

These findings share similarities with previous research, particularly into the use of EHRs [1, 19, 40]. However, there has been little research on patient use of e-Referral systems. The present study has explored patients' attitudes towards using an e-Referral system, moving beyond their perceptions of being offered choice, to also investigating their interest in interacting with their referral data on the system.

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## APPENDIX 1: SEMI-STRUCTURED INTERVIEW SCRIPT

### Topic Guide

- Feelings about referral process
- Thoughts about being involved more in referral process
- Thoughts about this involvement being online
- What participants do when having no information or not fully understanding the information they have
- Patient aware of HCP's workload

### Introduction

Firstly, thanks for agreeing to take part in this study. As it states in the consent

form you're free to stop the interview at any point without reason, also I can assure you all your data will be anonymised throughout. Also as the information form states, what I'm researching is your experience with a recent referral and how you would feel about changing the way you receive information about the referral. You do not have to disclose the reason for referral if you prefer not to.

1. Can you tell me how many times you have been referred roughly?
2. Can you tell me how long ago the most recent referral was experienced?
3. Were you referred by a GP or from one specialist doctor to another?
4. Can you remember what information was given to you about the referral and how you received that information?
5. Did you have any questions regarding this information? If so how did you ask your referrer?
6. Did your referrer inform you of any further steps you needed to take next regarding your referral times/dates etc? If so, did you carry out these steps? [Were they informed of e-Referral system]
7. After your visit to the referring doctor did you follow up on any information provided? If so how?
8. If your referrer had informed you of an online system that you could log on to retrieve details of your referral would you have accessed it?
9. In your own experience of being referred can you recall an incident that may have triggered you to access an online referral like this?
10. Would you like the option on this system to choose the hospital you are referred to?
11. Would you like information on the hospitals available to you? For example, their location, times available, reviews from other patients?
12. Would you like the option on this system to choose the specialist in the hospital you're referred to?
13. Would you be interested in knowing more about the specialist you're being referred to? For example, their specialties, number of times performing a procedure (i.e. surgical procedure), reviews from other patients.
14. What would be the most important factor for you in choosing a hospital, specialist etc. time, location, reputation?
15. If there was some information about your health condition would you find this useful? Would you be interested in reading it on the referral system, or perhaps shown useful links to the NHS Choices website?
16. What kind of health information would you have found useful? For example, details of symptoms suffered, description of discussion with referrer, notes to the specialist you're being referred to, prescriptions offered, recommendations of life style changes.
17. Would you have liked to leave any notes of your own?
18. If you were to make use of this system, where would you most likely access it? For example, at home, at work, anywhere? Would you expect to see different information depending on where or when you were accessing it?
19. What type of device would you expect to use such a system? For example, a laptop, a tablet or a mobile phone?
20. Would like to receive further information about your referral other ways. For example, information about hospital location or appointment reminders. If so, which medium would you prefer. For example, by text message, by post or included online? And why?
21. Have you ever accessed your EHR?
22. Can I ask what prompted you to? For example, your GP, NHS advertisements or just curiosity?
23. How did you find the process of accessing it? Did you find the information useful?
24. Do you have access to the internet? If so, how often do you use it and on what type of device?
25. Do you own a smart phone? Could you imagine yourself accessing either your EHR or details on a referral on your phone?
26. Can I ask what age range you're in?  
18 – 25, 26 – 35, 36 – 45, 46 – 55, 56 – 65, 66 – 75, 75 +2-6-

**APPENDIX 2: INTERVIEW PARTICIPANT INFORMATION SHEET AND ETHICS FORM**

**Information sheet**



*This MSc project is jointly supervised by researchers at University of Oxford and University College London.*

**Barbara Collery**

**Tel: 074 932 17669**

**Email: [barbara.collery.15@ucl.ac.uk](mailto:barbara.collery.15@ucl.ac.uk)**

***You can withdraw from this study at any time. In order to do so contact me on the details above.***

\*\*\*\*\*

***Information Sheet for Participants in Research Studies***

You will be given a copy of this information sheet.

Title of Project: ***What do patients expect from an online NHS referral system: A requirements gathering activity***

This study has been approved by the UCL Research Ethics Committee as Project ID Number: UCLIC/1213/015

***UCL Interaction Centre (UCLIC) - University College London, 2nd floor 66-72 Gower Street, London, WC1E 6BT Tel: +44 (0) 20 3108 7050***

I would like to invite you to participate in this research project. 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, please read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information.

**Study Details**

The purpose of this interview is to understand more about a recent experience you had while being referred to a specialist clinician. In particular, I am interested to know if you used any technology or websites for additional information during the referral process. If you did I would like to know which aspects you found useful, which you did not find useful and any further information you feel would have been beneficial to you. If you did not use any websites during the referral, I would like to know your level of interest in viewing your referral details online and in particular what kinds of information you would find useful to have access to.

It is up to you to decide whether or not to take part. If you choose not to participate, you won't incur any penalties or lose any benefits to which you might have been entitled. However, if you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. Even after agreeing to take part, you can still withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

**Ethics form**

*Informed Consent Form for Participants in Research Studies*

Title of Project: *What do patients expect from an online NHS referral system: A requirements gathering activity.*

This study has been approved by the UCL Research Ethics Committee as Project ID Number: UCLIC/1213/015

Participant's Statement

I \_\_\_\_\_ agree that I have read the information sheet and/or the project has been explained to me orally; had the opportunity to ask questions and discuss the study; and 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 in the event of a research-related injury.

I understand that I am free to withdraw from the study without penalty if I so wish, and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

I understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained, and it will not be possible to identify me from any publications.

Would you also be happy for me to record audio during the interview? This would be to ensure I do not miss any important points you have made during the interview while note taking.

Yes  No

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: \_\_\_\_\_

### APPENDIX 3: INITIAL CODES DISCOVERED IN INTERVIEW TRANSCRIPT

Accessing EHR	Lack of trust in specialist
Accessing notes passed between GP & specialist	Lack of trust or frustration over NHS postal correspondence
Apprehensive of online system	Loss of control or voice
Assessing own health	NHS-Patient communication
Belief that medical notes are for HCPs only	Onus on patient to track their information
Booking referral with GP	Organising a self-referral
Communication of results	Patient anxiety over condition
Confusion over medical terms	Patient deciphering information or no information
Confusion over RP	Patient expectation of online system
Consultant meeting expectations	Patient feeling like needs not met
Criteria for hospital selection	Patient preparations before visits
Degree of patient involvement in health	Patient reluctance to add to NHS employee workload
Duration of wait time	Patient understanding of RP
Disappointment at QoS	Patients leaving notes on system regarding health or consultation
Expectations of online system	Positive experience with referral
Expectations of the NHS	Positive feelings towards online system
Feeling healthcare professional is apathetic	Preferable context for system use
Feeling time pressure during appointment	Preference for online comm.
Feeling unqualified to write notes on referral	Preference for reminder information
Finding information on specialists	Preferring independent search for info on illness
Fitting treatment into my life	Private vs Public service
Frustration over duplication of tests	Referral letter details
Frustration over inflexibility of appointment booking	Risks associated with exposing data to patients
Frustration over lack of continuity between parts of NHS	Role of doctor
Frustration over lack of feedback or reassurance	Role of patient
Frustration over lack of information from GP	Salience of hospital feedback to patients
GP conducts selection of hospital	Sense of security around health information
GP surgery comm. of NHS online tools	Triggers for using system
GPs trust in patient knowledge	Trust or confidence in GPs
Happy with online service	Trust or confidence in specialists
Importance of timing for patient	Uncomfortable around GP
Knowledge of existing NHS online tools	Use of and storage of information in physical form
Lack of communication between GP & specialist	Using online booking system for booking GP appointments
Lack of trust in GP	Using technology to find more information
Lack of trust in process	

## APPENDIX 4: ADVERTISEMENTS SEEKING PATIENT AND HCP PARTICIPANTS

### Advertisement seeking patient participants for interview

I'm looking to interview some participants for my project on e-Health and patient referrals. I'd like to speak with people who have experience of being referred from either a GP to a specialist or a hospital to a specialist on the NHS. I'm interested in your experience of the referral process rather than the reason for referral. The interview would not take longer than 30 mins and you will be entered into a draw to receive one of three prizes; £50, £25 or £25 Amazon voucher.

If you're interested or know someone who might be please PM me. Many thanks!

### Advertisement seeking HCP participants for interview

As part of my MSc final project in Human Computer Interaction at UCL I'm researching into NHS referrals and what kind of digital information might be useful to patients and doctors during the referral process. I would like to speak with GPs and specialists who have experience referring patients on the NHS. The interview would not take longer than 20 mins and you will be entered into a draw to receive one of three prizes; £50, £25 or £25 Amazon voucher.

Interviews will take place this week and next. If you are interested in taking part please contact me at [barbara.collery.15@ucl.ac.uk](mailto:barbara.collery.15@ucl.ac.uk), or call me on 074 932 17669 and we can arrange a time and place that suits you. Thank you!

