Supporting Ambulance Crews Electronically through the Provision of 'On-Demand' Patient Health Information

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How to cite:

ALTUWAIJRI, EMAN,ALI,S (2018) *Supporting Ambulance Crews Electronically through the Provision of 'On-Demand' Patient Health Information*, Durham theses, Durham University. Available at Durham E-Theses Online: http://etheses.dur.ac.uk/12754/

Supporting Ambulance Crews Electronically through the Provision of ‘On-Demand’ Patient Health Information

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A Thesis presented for the degree of
Doctor of Philosophy

Supervised by

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United Kingdom

2018

بِسْمِ اللهِ الرَّحْمنِ الرَّحِيمِ

Dedicated to

My Mother and Father,

My daughters Dana and Lina

Declaration

The work in this thesis is based on research carried out at the Innovative Computing Group, the School of Computer Science, United Kingdom. No part of this thesis has been submitted elsewhere for any other degree or qualification and it is all my own work unless referenced to the contrary in the text.

Acknowledgements

First of all it is Allah, The Most Graceful and the Most Merciful who gave me everything, including the strength and patience to accomplish my dream.

Thank you to every single person I encountered within the North East Ambulance Service NHS Foundation Trust, especially Graham McClelland, Soniay Byres, Marc Birkett and all operational and senior management staff. I sincerely salute the ambulance crews and the supporting staff from the control centre, for their heroic job they do, helping and saving people's lives.

I am grateful to James Cook University Hospital NHS Foundation Trust for giving me this opportunity and support, especially Dr Simon Taggart and the support from Elaine Hall and the ED staff. Cliff Challenger from Epilepsy Action offered great help and support as well as Adam Nobel from the International League Against Epilepsy- Epilepsy Chapter.

Many thanks go to all the people with epilepsy and their carers who shared with me, their personal views, experience and stories. Thank you to Taiib Obadje who helped me tremendously in the IB development. My heartfelt appreciation goes to Durham University and the diverse City of Durham, for giving me a wonderful experience that I will always cherish enabling me to meet wonderful individuals from all walks of life.

Thank you to my precious friends, my extended family, Dr Andrew Crossland, Rukiya Sood, Dr Aswila Sood, Frank Coppuck, Ibrahim and Ijjou Thompson, and Dr Fatima Almazkuri. I cannot adequately express my deep love for you all.

Never will I ever forget the continuous and generous support, discussions, time, advice and efforts of my supervisors Professor David Budgen and Dr Sharyn Maxwell. No words or actions can show how grateful and thankful I am. I have been extremely fortunate to have you as my friends and supervisors. I have love and respect for you both.

Words cannot describe the gratefulness and appreciation I owe to my mother Norah Altuwaijri and my father Professor Ali Altuwaijri, who supported me through thick and thin during this long journey of my PhD. I love you beyond love itself. Thanks to my brother Dr Mohammed Altuwaijri for his support and cooperation, it means a great deal to me.

My endless love and passion goes to my two beautiful smart daughters, Dana and Lina who were patient and always put a smile on my face when things were low. You are the best thing that ever happened in my life. . . .

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Abstract

The North East Ambulance Service (NEAS) does not have direct access to any information regarding patient health history, current medication, allergies, etc. that might assist an ambulance crew when they are dispatched to an emergency incident. Therefore, an ambulance crew responding to a call-out usually travels to the incident 'information blind' regarding the patient's general health status. What makes the ambulance service in general, and the ambulance crew in particular, unique from other healthcare organizations is the spectrum of exposure to a diversity of health organizations (care homes, GPs, hospitals, etc.), and none-health organizations (police, social services, fire forces,etc.).

This thesis describes an investigation into the feasibility of implementing a software Information Broker (IB) prototype, that has the ability to provide 'on-demand' electronic health information to ambulance crews while on scene, by accessing a set of autonomous databases containing patient records. This is to support the ambulance crew with reliable patient information in order to assist their decision-making process, therefore, reduce unnecessary patients' conveyance to the Emergency Department (ED). The thesis also examines the sociotechnical issues surrounding health information transfer between and within the National Health Service (NHS) in the United Kingdom (UK) for patients with epilepsy (PWE), specifically in the North

East region of England.

A case study approach was employed as an overarching framework for the feasibility study of the IB prototype. This case study was centred upon studying the needs of people with epilepsy (PWE), as this group has been identified by NEAS as frequent users of the ambulance service. In many cases, if the ambulance crew are given adequate information to support their decision-making, they do not need to convey patients to a hospital ED unless necessary. Within the case study, a phenomenological approach was employed for the set of perspectives used for investigating the sociotechnical issues surrounding the IB. The three perspectives were the perceptions of NEAS operational and management staff, those of the JCUH staff and PWE/carers, and finally, the perceptions of the ambulance crew.

The prototype IB technology has demonstrated the feasibility of using an information transfer broker to transfer information from autonomous organizations to the ambulance crew on scene. Overcoming technical challenges alone is not sufficient for this success. Stakeholders' requirements, organization collaboration, compliance with national standards and targets, social and technical aspects, and so forth, are other issues that have been considered. Involvement of potential stakeholders in stages of any Health and Information Technology (HIT) development is an essential element to be included, as much as possible, to satisfy those requirements and needs of end-users.

Improving the data availability to the ambulance crews on scene via an IB, means that they can perform better decision-making while on scene with a patient. The demonstration of the IB prototype has shown its potential for transferring patient health information from an autonomous database to ambulance crews. To increase opportunities of success, shared incentives and aims of the intra- and inter-organizational communication and collaboration should facilitate the implementation of HIT. Facilitating incremental improvements of systems and technologies may have an effect on the organization as a whole in terms of robustness of systems and technologies.

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List of Abbreviations

ACSC	**A**mbulatory **C**are **S**ensitive **C**onditions
AEDs	**A**nti **E**pileptic **D**rugs
AJAX	**A**synchronous **J**avaScript **A**nd **X**ML
API	**A**pplication **P**rogramming **I**nterface
AT	**A**cute **T**rusts
CAD	**C**omputer **A**ided **D**ispatch
CCG	**C**linical **C**ommissioning **G**roups
CDD	**C**onceptual **D**atabase **D**esign
CDM	**C**hronic **D**isease **M**anagement
CDS	**C**linical **D**ecision **S**upport
CfH	**C**onnecting for **H**ealth
CFR	**C**ommunity **F**irst **R**esponder
Choose and Book	Electronic Appointment Booking
CORBA	**C**ommon **O**bject **R**equest **B**roker **A**rchitecture
CPOE	**C**omputerized **P**hysician **O**rder **E**ntry
CQC	The **C**are **Q**uality **C**ommission
CSCW	**C**omputer-**S**upported **C**ooperative **W**ork
CSS	**C**ascading **S**tyle**S**heets

DaaS	**D**ata as a **S**ervice
DAS	**D**ata **A**ccess **S**ervice
DB	**D**ata **B**ase
DHE	**D**istributed **H**ealthcare **E**nvironment
DoH	**D**epartment of **H**ealth
DoS	**D**irectory of **S**ervices
DR	**D**esign **R**esearch
DS	**D**esign **S**cience **R**esearch
DSR	**D**esign **S**cience
EAI	**E**nterprise **A**pplication **I**ntegration
ECS	**E**mergency **C**are **S**olution
ED	**E**mergency **D**epartment
EDI	**E**lectronic **D**ata **I**nterchange
EHR	**E**lectronic **H**ealth **R**ecord
EMS	**E**mergency **M**edical **S**ervices
ePCR	**e**lectronic **P**atient **C**linical **R**ecord
ePRF	**e**lectronic **P**atient **R**ecord **F**ile
EPS	**E**lectronic **P**rescription **S**ervice
ER	**E**ntity**R**elationship
GP	**G**eneral **P**ractice
GP2GP	**G**eneral **P**ractice to **G**eneral **P**ractice
GPS	**G**lobal **P**ositioning **S**ystem
HCI	**H**uman-**C**omputer **I**nteraction
HIS	**H**ealth **I**nformation **S**ystems

HIT	**H**ealth **I**nformation **T**echnology
HQ	**H**ead**Q**uarter
HTML	**H**yper**T**ext **M**arkup **L**anguage
HTTP	**H**yper**T**ext **T**ransfer **P**rotocol
IB	**I**nformation **B**roker
IBE	**I**nternational **B**ureau for **E**pilepsy
IBHIS	**I**ntegration **B**oker **H**eterogeneous **I**nformation **S**ources
IBIS	**I**ntelligence **B**ased **I**nformation **S**ystem
ILAE	**I**nternational **L**eague **A**gainst **E**pilepsy
IM&T	**I**nformation **M**anagement and **T**echnology
IS	**I**nformation **S**ystems
IT	**I**nformation **T**echnology
JCUH	**J**ames **C**ook **U**niversity **H**ospital NHS Foundation Trust
JRCALC	**J**oint **R**oyal **C**olleges **A**mbulance Liaison **C**ommittee
JSON	**J**avaScript **O**bject **N**otation
LAS	**L**ondon **A**mbulance **S**ervice
LDD	**L**ogical **D**atabase **D**esign
MDT	**M**obile **D**ata **T**erminal
N3	The **N**ational **N**etwork for the **NHS**
NAO	The **N**ational **A**udit **O**ffice
NASH	The **N**ational **A**udit of **S**eizure Management in **H**ospitals
NEAS	The **N**orth **E**ast **A**mbulance **S**ervice NHS Foundation Trust
NFRs	**N**one-**F**unctional **R**equirements
NHS	**N**ational **H**ealth **S**ervice

NIB	The **N**ational **I**nformation **B**oard
NICE	**N**ational **I**nstitute for Health and **C**are **E**xcellence
NPfIT	**N**ational **P**rogramme for **I**nformation **T**echnology
PCT	**P**rimary **C**are **T**rusts
PD	**P**articipatory **D**esign
PDD	**P**hysical **D**atabase **D**esign
PRF	**P**atient **R**ecord **F**ile
PTS	**P**atient **T**ransport **S**ervice
PWE	**P**eople **W**ith **E**pilepsy
R&D	**R**esearch & **D**evelopment
RBAC	**R**ole-**B**ased **A**ccess **C**ontrol
REST	**RE**presentational **S**tate **T**ransfer
SCR	**S**ummary **C**are **R**ecords
SE	**S**oftware-**E**ngineering
SECAmb	**S**outh **E**ast **C**oast **A**mbulance Service NHS Foundation Trust
SOA	**S**ervice-**O**riented **A**rchitecture
SOAP	**S**imple **O**bject **A**ccess **P**rotocol
STHFT	**S**outh **T**ees **H**ospitals NHS Foundation **T**rust
TBS	**T**echnology-**B**ased **S**olution
TOXBASE	The **N**ational **P**oisons **I**nformation **S**ervice
UAT	**U**ser **A**cceptance **T**esting
UDDI	**U**niversal **D**escription **D**iscovery and **I**ntegration
UK	**U**nited **K**ingdom
US	**U**nited **S**tates

WHO	**W**orld **H**ealth **O**rganization
WS	**W**eb **S**ervice
WWW	**W**orld **W**wde **W**eb
XML	e**X**tensible **M**arkup **L**anguage

Chapter 1

Introduction

This thesis reports on a feasibility study that aims to design and demonstrate a Technology-Based Solution (TBS) system for information transfer. This TBS information transfer system will be able to provide ambulance crews, who already lack reliable patient information while on scene, with 'on-demand' reliable patient information for People with Epilepsy (PWE) during an incident, thus aid them to conduct better health decisions, resulting in providing care on scene without the need to convey patients unnecessarily to an Emergency Department (ED), hence saving ambulance crew time and ambulance service resources.

Additionally, it describes an investigation into some of the sociotechnical issues surrounding health information transfer between and within the National Health Service (NHS) in the United Kingdom (UK) for patients with epilepsy, specifically in the North East region of England.

It is essential to note that members of an ambulance crew are either paramedics, advanced technicians or emergency care support workers (North East Ambulance Service NHS Foundation Trust (NEAS), 2011*a*). The term ambulance crew might be used interchangeably with the word paramedic(s), unless it is stated otherwise.

1.1 Context

The ambulance services play an important role in the community by providing urgent care. The ambulance services have been facing an increasing burden, in recent years, through demand from the public for many reasons (National Ambulance Service Medical Directors (NASMeD), 2014). People who think they require emergency help will be in contact with the service. Depending on the perceived condition of the patient, an ambulance crew will be dispatched to provide on-site medical assistance, or to facilitate transport to hospital or to other supporting facilities. Ambulance services, along with EDs, share an interest in reducing the unnecessary transport of patients by ambulance services to ED, and the aim of this work is to achieve this by identifying factors that lead to this unnecessary conveyance to ED as well as proposing solutions to address them. For example, by developing protocols for paramedics to aid them identifying where the needs of patients can be managed in the community rather taking them to ED unnecessarily (Finn et al., 2013). This may also involve determining the safety of discharging patients at scene by paramedics instead taking them to ED (Tohira et al., 2016).

Depending on the nature of the call, different pathways that are available will be employed for treating the patient. For instance, a call handler may employ the ‘Hear and Treat’ pathway, which involves providing the call maker with suitable telephone advice. If the situation is deemed to require further assistance, then the call handler has other pathways to select among. Additionally, the ambulance crew while on scene also has to choose which pathway is suitable, based on the situation and patient condition they encounter. For instance: ‘See and Treat’ involves seeing the patient and treating them on site, ‘See and Convey Elsewhere’ is transporting them to other supporting facilities like walk-in centres, out of hours service and so forth. The final option, ‘See and Convey’ involves transporting the patient to an ED (National Institute for Health Research, Health Services & Delivery Research Programme, 2015; Tohira et al., 2016).

One must not ignore the fundamental role that the ambulance crew play on site. This role is not just limited to providing medical care to patients. Crews find themselves facing multiple challenges while **on scene** with a patient. Challenges vary between:

- Patient assessment and diagnosis.
- Determining what medication to be administered.
- Making suitable decisions according to a patient's needs.
- Coping with a lack of information about patient's health (patient health history) and health conditions.
- Decisions about whether a patient needs to be taken to ED or not.
- Whether it is safe to release the patient or to refer to other supporting facilities.
- Achieving national targets.
- Considering the patient/carer's desire to be conveyed to ED or not.
- Fear of litigation.
- Lack of protocols and/or of training to be able to leave the patient at the scene, etc. (Porter et al., 2007; National Ambulance Service Medical Directors (NASMeD), 2014; Burrell et al., 2012; NHS England, 2013; Snooks et al., 2005, 2002; Halter et al., 2010; Snooks et al., 2015; O'Hara et al., 2015)

Pressure on the ambulance service to reduce conveyance rate to ED, places a burden on the ambulance crew with regards to making an effective decision about whether there is a need to convey or not. O'Hara et al. (2014) discussed how different factors affect a crew's decision-making and patient safety. They identified seven system influences that affect the ambulance crew's decision-making, these are:

- The lack of patient information when attending a call-out.
- Opportunities for training, development, and skill use are constrained by operational demands.
- The local variations in availability, accessibility, and awareness of alternatives other than ED, which may be used as better options.

- Resources are strained by persistent high demand. Variations in organizational resources of staff, drugs, equipment, and vehicles can participate in inconsistent care.
- Increase in demand in non-emergency cases on the ambulance services.
- Risk tolerance among staff was disproportionate.
- Performance indicators, priorities, and organizational pressure imposed on paramedics.

The National Ambulance Service Medical Directors (National Ambulance Service Medical Directors (NASMeD), 2014) have also published a set of clinical priorities for future development to be applied by the ambulance services in England to enhance the services for the benefit of users. They suggested enabling ambulance clinicians to have access to specific patient notes from across all health agencies. They also suggested that ambulance services need to be able to access specific information about patients as well as patient care plans for those who have a long term condition(s). In their survey study Zorab et al. (2015) provided evidence that front-line ambulance teams are not always able to access health information regarding patients while on scene. This lack of timely access of patient health information while on scene, affected their decision-making to convey to ED, leading to unnecessary conveyance to hospital. Making this information available is likely to lead to better management of the patient and a more appropriate selection of care pathways regarding the patient in need. Generally speaking, ambulance services should promote patient information being stored and shared electronically between organisations by applying improved information transfer technology systems.

In summary, the lack of specific patient health information and/or the availability of patient health plans for those who have long term condition(s) may affect a patient's safety, the crew's decision-making, and involve the unnecessary use of heavily loaded health organisations like an ED. Overcoming this challenge in ambulance services, specifically the North East Ambulance Service NHS Foundation Trust (NEAS), will benefit patients, ambulance crews, the ambulance service, other health organisations and resources. In addition, it will reduce the unnecessary use of ambulance services, as the lack of specific patient health information is one of the main causes of this, leading to an overload of the services, and causing a reduction of the quality of service provided, especially to those who are in a genuine need of it (National Institute for Health Research, Health Services & Delivery Research Programme, 2015).

1.1.1 Why Epilepsy?

During initial meetings with the North East Ambulance Service NHS Foundation Trust (NEAS), Research & Development (R&D) division, it was emphasized that People with Epilepsy (PWE) were heavy users of the service. NEAS has identified groups such as this as a major issue for them, since many would frequently have an ambulance dispatched to them and be either treated on site or taken to the ED unnecessarily. This is because PWE during a fit or when unconscious, share some common symptoms similar to other critical conditions. Conditions commonly misdiagnosed as epilepsy are: cardiac disorders, blackouts (Syncope), Transient Ischemic Attacks (stroke or cardiac arrest), Hypothermia, or Hypoglycemia (Lordeon, 2017). PWE, undergoing their normal pattern of seizure(s), do not usually need a health provider to manage their seizure(s) or to stabilize them, having a carer around, who is aware of their condition, is usually sufficient. Therefore, dispatching an ambulance to them, unnecessarily, will waste ambulance time that could be used for another person who is in a more genuine need of help. Moreover, this comes with various costs: financial, staff time, ambulance use, and the disruption of patient's daily life routine.

Epilepsy is considered as a long term condition, and people who have such a long term condition, or their carers, tend to call the ambulance services for help in non-emergency situations where an ambulance is not required (Kirkby and Roberts, 2011). Booker et al. (2014*a*) investigated the reasons why patients or carers do this. The perception about the community-based doctor and what services they provide was one reason. Their perceptions were centred around accessibility and availability of appointments, waiting times for appointments, limited opening hours, lack of after-hours care, and inconvenience of appointment time (Coster et al., 2017). Some stated that calling the ambulance service will avoid them being admitted to hospital and result in their being treated at home instead. Others stated the reason for contacting the ambulance service is due to previous negative experiences with other urgent care providers, causing them to prefer making contact with the ambulance service for help, whereas others thought seeking urgent care from other providers might result in long waiting times. Patients or carers, out of anxiety, will call the ambulance service for reassurance or immediate access to hospital for confirmed clinical assessment. Finally, the decision to call an ambulance for help, when encountered with an epilepsy incident, may be affected by interpersonal factors of carers.

Additional reasons were also highlighted by Ridsdale et al. (2012) that describes PWE explanations for using emergency medical services. Reasons for PWE to call ambulance services for help were due to the fear of death, the shock of the public and their feelings of social responsibility towards them, absence of a family member, and other individuals, within PWE's social circle, and lack of epilepsy management and support.

Identifying the characteristics of PWE who frequently visit the ED and factors associated with such visits has been investigated by Noble et al. (2012). They found, poor Quality of Life (QoL), anxiety and depression, higher frequency of seizures, the feeling of stigma, a low level of knowledge of epilepsy, and of how to manage their epilepsy were associated more with PWE who frequently visited the ED than with those in the general PWE population (Mameniskiene et al., 2015).

1.2 A Proposed Solution

This thesis focuses on the role of the service providers, to be more specific, the North East Ambulance Service NHS Foundation Trust in England, which will be referred to throughout this thesis as NEAS. It assesses the practicality and feasibility of a proposed Technology-Based Solution (TBS) that can be integrated into NEAS's current systems, and which could provide the ambulance crew, who lack reliable patient information while on scene, with 'on-demand' health information for the chosen group of patients with epilepsy during an incident. This information empowerment will support a crew by enabling better health decision-making, and aid with deciding if the patient needs to be conveyed to ED or not.

First of all, an explanation of the current systems at NEAS alongside the feasibility study will be briefly explained and defined. Figure 1.1 reflects a holistic view

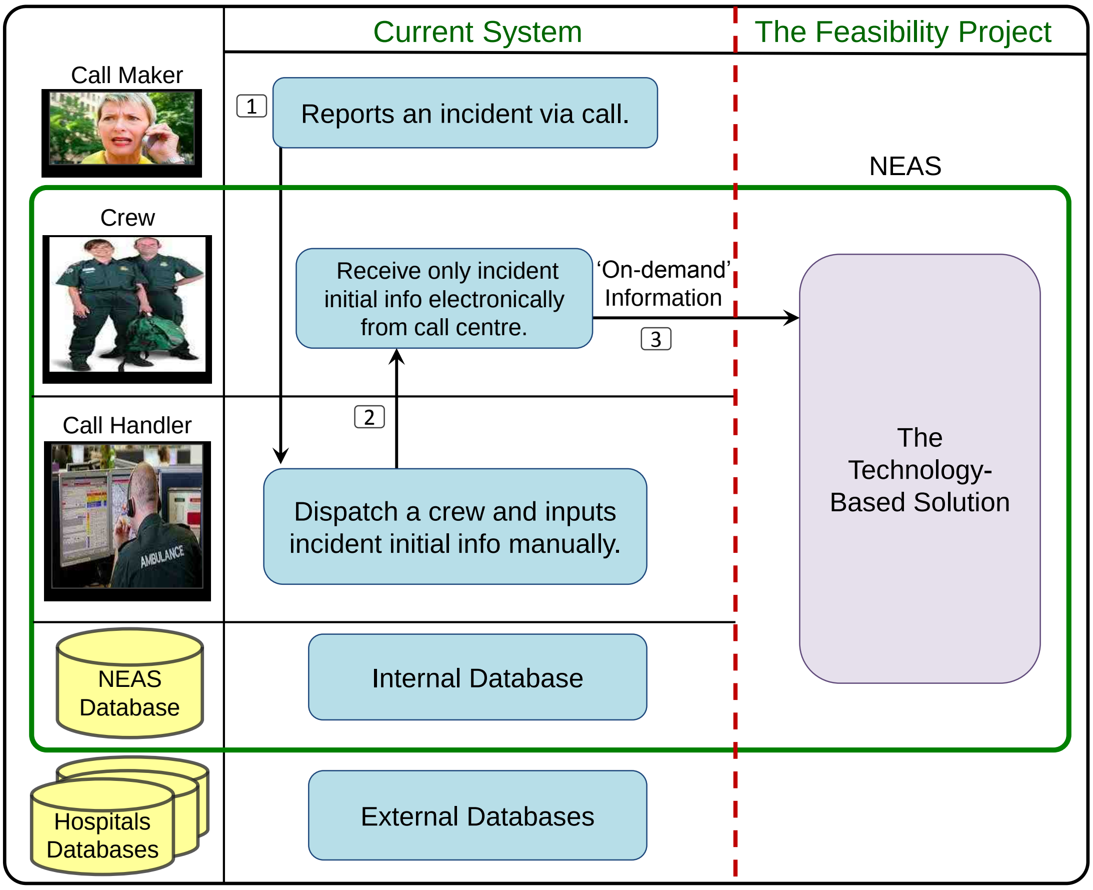


Figure 1.1: A Simple Outline of the Current System and the Feasibility Project

of the current system at NEAS in parallel with the proposed Technology-Based Solution (TBS) that may enhance the performance of an ambulance crew in addition to the ambulance service and other healthcare organisations by supporting them with reliable patient health information which they already lack.

The involvement of the other human subjects, that is the call handler and the crew, in Figure 1.1 will be first triggered by a 999 call to the emergency services placed by a member of the public asking for help (1). Depending on the situation described in the 999 call, the **call maker** will then be connected with a **call handler** based at the **call centre** at NEAS. The call handler will talk to the call maker and ask for details and information regarding the health situation of the person in need, their symptoms and location. Meanwhile, an ambulance will be dispatched to the scene within 60 seconds of receiving the call (2). The call handler will manually input all the information about the person in need, as provided from the perspective of the call maker, into an electronic triage system called NHS Pathways. The triage system, based on the information inserted, will identify a suitable relevant care service (pathway) appropriate to the symptom(s). If the triage system selects a pathway where an ambulance crew is no longer necessary, the crew will be notified via the system to stand down. This chain of decision-making does not cease here, it continues when a crew is on scene, where they are faced with the task of choosing between the different pathways mentioned earlier. The thesis focuses only on that situation where the ambulance crew are on scene and need to make a decision between 'See and Treat' or 'See and Convey' to ED.

A crew on the ambulance vehicle will accept the dispatch instruction from the **dispatch centre**. Immediately after that, they will be able to pin point the location of the incident via the SatNav provided in the ambulance vehicle. Simultaneously, they will be receiving live and updated **incident initial information** regarding the patient on scene, which the call handler will continue to insert into the system, should this become available from the call maker. While travelling to the incident, the crew have limited information about what will be facing them. In complication-free scenarios, the crew will reach the scene with incident initial information about the patient and the incident situation to hand, in addition to having electronic access to databases of the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidelines and the National Poisons Information Service database (TOXBASE) directly available to them if needed.

In 2014 in England, 36% of all incidents were managed on scene and the patients involved did not need to be conveyed to ED (Workforce & Facilities Team Health & Social Care Information Centre (HSCIS), 2014). This proportion has grown to 38.3% in 2016 (NHS England, National Statistics, 2016). While on scene, the crew are usually faced with a complex decision-making situation and a lack of patient health information (patient's health history). This study will try to fill this gap in patient health information, and supply such information 'on-demand' to the on-site crew by electronic means, according to their needs (3), by testing the feasibility of implementing a TBS system that transfers patient information to the crew upon request. Along side this, is an understanding of the other sociotechnical issues surrounding this implementation and most effective use.

Going back to Figure 1.1, the left hand side of the dotted red line is the current process that is employed in NEAS. Usually, the ambulance crew will, at point (2) on the figure, make a decision either to 'See and Treat', 'See and Convey Elsewhere' or 'See and Convey' to ED based on the current health situation gained about the patient in the incident. The right hand side of the dotted red line is what the thesis is seeking to describe, involving the provision of a TBS in addition to existing systems, in order to support the ambulance crew on scene with 'on-demand' health information.

In summary, the ambulance crew who work for NEAS, while on scene, will be able to electronically request additional health information about a patient who has epilepsy from the PWE database at James Cook University Hospital (JCUH) database. Therefore, this thesis will describe the investigation of the provision of 'on-demand' health information to an ambulance crew while on scene, and how this information transfer may assist a crew's decision-making in treating patients locally rather than conveying them to the ED unnecessarily. Doing so involves designing and evaluating a prototype TBS information transfer system and using this to identify sociotechnical issues surrounding this electronic information transfer.

1.3 Information Transfer Systems for Ambulance Related Incidents Involving Epilepsy

Figure 1.2 provides a simple illustration of the information transfer model being proposed. As noted, there are four main elements. These are the NEAS system, the crew in the ambulance vehicle, the JCUH ED, and PWE database. The solid arrows indicate existing information transfer between the components. The dotted arrows, on the other hand, describe the proposed information transfer that will be available

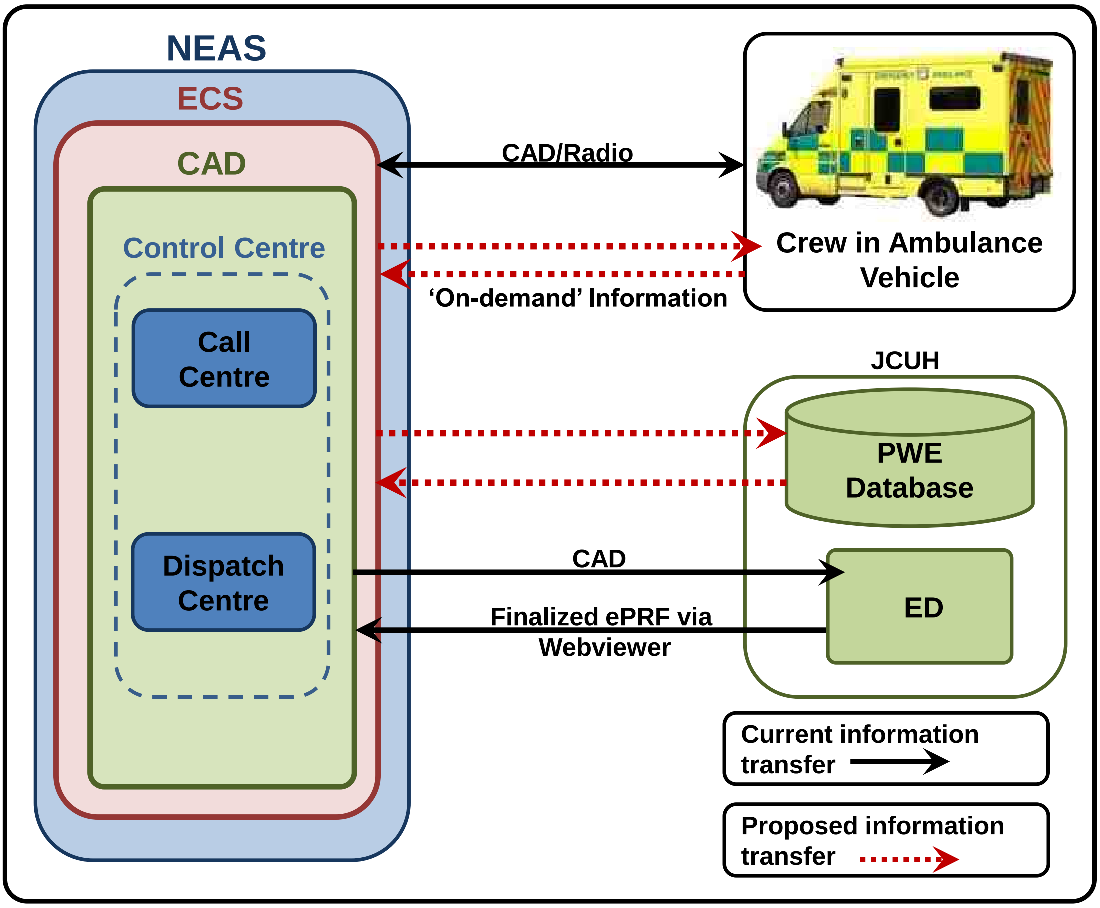


Figure 1.2: Information Transfer Systems Model

to a crew when using the TBS. The NEAS system forms the starting point that will trigger all other actions of information transfer between the other components. It is also the linking point between those involved in the process of this information transfer. At NEAS, the **dispatch centre** is responsible for managing the logistics. The **call handler** based at the **call centre** is in direct contact with the public and is responsible of entering the **incident initial information** into the triage system, i.e. the NHS pathways. The **dispatcher** (also termed communications officer), on the other hand, is located at the dispatch centre and has direct contact with ambulance crew via the Computer Aided Dispatch system (CAD) in addition to radio and telephone. If the patient needs to be conveyed to ED, then the control centre will send the same incident initial information to the designated ED via the CAD prior to patient arrival.

NEAS applies an integrated patient care data management solution called the Emergency Care Solution (ECS) which manages a whole spectrum of processes and actions related to patient care and data. This starts from the point of receiving an emergency call, and involves dispatching a crew, performing data collection of patients and medical equipment devices on scene, patient handover, reporting, auditing and ending at planning as a final point. Other systems within NEAS are integrated with the ECS. For instance: the Computer Aided Dispatch system (CAD), NHS Pathways, the Directory of Services (DoS) as well as other systems that are not relevant to this thesis.

Further, NEAS has adopted the use of electronic information transfer to enable ambulance crews and ED staff to transfer information by moving from use of a paper Patient Report Form (PRF) to an electronic one (the ePRF). Authorized ED staff will be able to view the ePRF only when it is finalised, see Section 9.2 for background information regarding both the PRF and the ePRF.

The idea of transferring information in healthcare systems was previously introduced by Budgen et al. (2007). They have developed a prototype integration broker for healthcare systems called the Information Broker for Heterogeneous Information Sources (IBHIS). The IBHIS is based on software service model which has the ability to collect and integrate data from autonomous and heterogeneous agencies. The prototype TBS described in the thesis does not comply/adhere completely with all of the characteristics of the IBHIS, but it is rather a simplified version of it. The term **Information Broker** (IB) will be applied throughout this thesis as a place holder for such a system on an understanding of that this project will be a complete full one in the long term. Chapter 10 presents an overview on the concept of an IB.

1.4 Aim of the Study

The overall aim of the work described in this thesis is to provide a feasibility study undertaken as a case study, to report how an information transfer system within a wider Health Information Technology (HIT) mechanism in the NEAS context, of an Information Broker (IB), can provide 'on-demand' health information of People with Epilepsy (PWE) to an ambulance crew while on scene, in order to support improved decision-making about patient treatment.

1.4.1 Research Questions

In particular, this study aims to achieve the following:

1. Is it feasible to develop and demonstrate an IB to support an electronic 'on-demand' health information provision system that can convey patient information from health trusts to an ambulance crew on scene?
2. What are the sociotechnical issues which will affect the design, implementation and uptake of this electronic information transfer system?

1.4.2 Expected Benefits

Immediate and long term expected benefits are anticipated from such a development. These include the following:

1. Enabling better-informed ambulance responses to call-outs for people who have had an epileptic seizure, and who have used the services provided by NEAS on at least one previous occasion.
2. Providing an 'on-demand' health information provision system that will save patients and crew's time rather than conveying them unnecessarily to ED.
3. Improving the quality of life and safety of patients who have epilepsy.

1.5 Thesis Structure

The rest of this thesis will be structured as follows:

1. **Chapter 2. Epilepsy:** background information about epilepsy and its effects on people and the ambulance services as well as a view of healthcare systems affecting the care of people with chronic condition(s)/PWE.
2. **Chapter 3. Health Informatics:** this chapter presents the role of health information technology and challenging issues of it.
3. **Chapter 4. Research Methodology:** this chapter presents the methodology that has been adopted to conduct the research.
4. **Chapter 5. NEAS Foundation Trust and its Operations:** this chapter presents contextual background information and description of ambulance services.
5. **Chapter 6. NEAS Operational and Management Staff: Findings:** this chapter is a presentation of the findings regarding NEAS operational and management staff.
6. **Chapter 7. JCUH Staff and PWE/Carers: Findings:** this chapter presents the database that has been built for PWE in JCUH and findings of JCUH staff and PWE/carers.
7. **Chapter 8. The Ambulance Crew: Findings:** this chapter describes

findings related to the ambulance crew and their needs and requirements of the IB presented and the ePRF.

8. **Chapter 9. Lessons from the ePRF as a Current Information Transfer System:** this chapter presents an investigation that has been conducted on a current information transfer system that has been implemented in NEAS, and investigating sociotechnical issues surrounding it in relation to the research questions.
9. **Chapter 10. The Information Broker:** the chapter presents the concept of an IB, the designing blocks used to create it, and finally demonstration of the system.
10. **Chapter 11. Discussion:** this chapter presents an overview of the findings and discussions followed by limitations of the study.
11. **Chapter 12. Conclusion:** the final chapter comprise a summary of the thesis succeeded by research findings, research contributions then recommendations for future work.

Finally, Figure 1.3 illustrates the general process of the research. It highlights the main general steps that were applied in the research. While investigating to answer the research questions and demonstrate the IB, the research drifted slightly from the main course of the study, this was not irrelevant to the research questions, instead, it strengthened the investigation conducted to answer the research questions proposed in this study. The following chapters will discuss those in more detail.

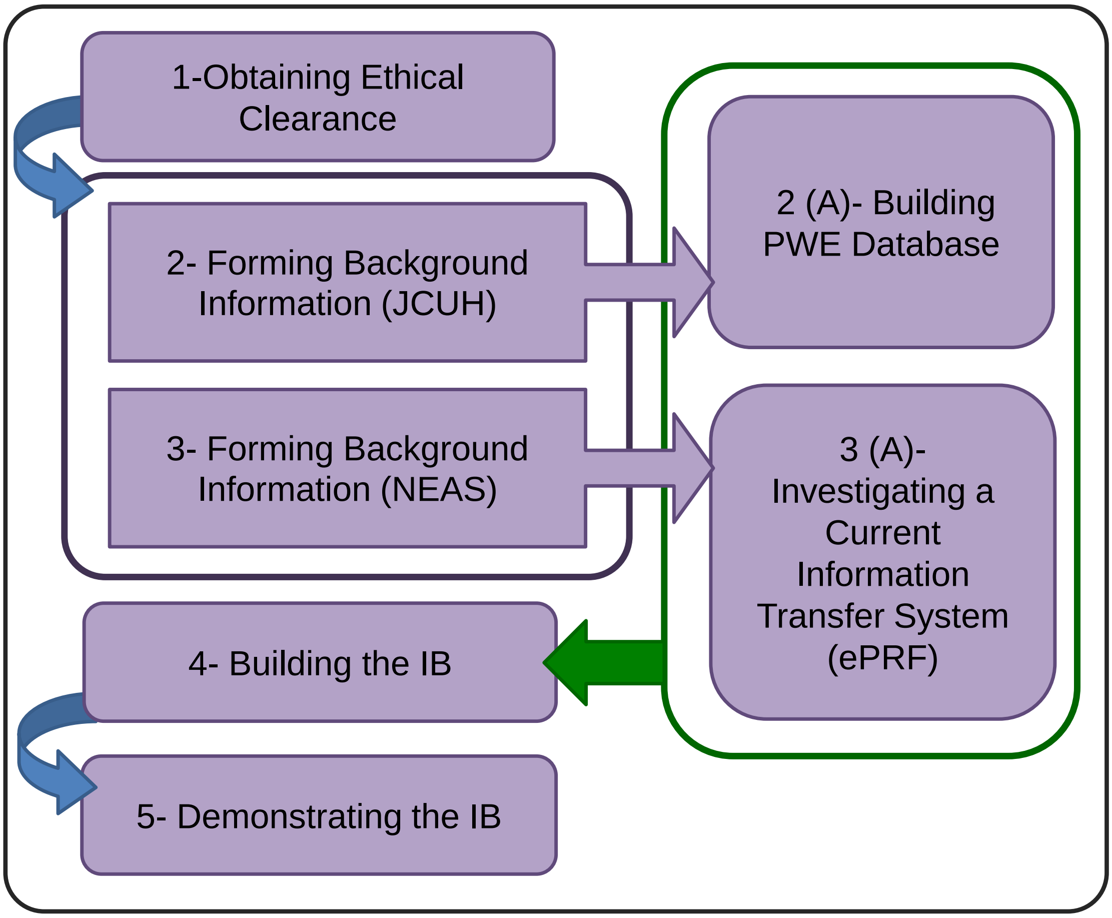


Figure 1.3: Thesis General Process

Chapter 2

Epilepsy

It is widely thought, by others who have little or no contact with anyone who suffers from epilepsy, that epilepsy is a single condition. However, this idea is incorrect. The facts are that more than over 40 different forms of epilepsy have been identified by the medical society.

This chapter will address what epilepsy is and the effect it has on patient/carers' lives. Presenting a holistic view of the issue is essential to form a clear picture in order to understand and identify possible impediments in the system that may impact care provided to PWE/carers. This was first approached by exploring the wider health system view then narrowing it down to reach the patient level with regard to the ambulance services in general.

Specifically, factors affecting healthcare systems for PWE on the policy level (macro), the organization level (meso), and the individual patient level (micro) will be discussed. This is followed by exploring the role of ambulance services in general and NEAS in particular for PWE/carers and their perceptions of the ambulance service. The chapter then concludes with system gaps related to PWE with regard to the ambulance service. NEAS, with other ambulance services, are faced with various challenges relating to diverse stakeholders, system requirements, government targets, and standards of which need to be dealt with.

2.1 What is Epilepsy?

Epilepsy is a common neurological chronic condition that is characterised by the recurrence of provoked or unprovoked seizures. It affects 50 million people worldwide, of different age groups, regardless of racial, social class, national or geographic boundaries (Forsgren et al., 2005; Elger and Schmidt, 2008). Different forms of epilepsy are categorised by: syndrome, seizure type, aetiology (causation or origin of epilepsy), and seizure onset site. Seizures are also classified into at least 40 different types and an individual may experience one or more seizure types (Berg et al., 2010; Shorvon, 2010). Based on the 2010 population, the estimated prevalence of people in England who are diagnosed with epilepsy and take Anti-Epileptic Drugs (AEDs) is approximately 1 in 105 people; and in the UK as a whole the figure is 1 in 103 people (Joint Epilepsy Council, 2011).

Fisher et al. (2005) consider the definition of the terms **epilepsy** and an **epileptic seizure** as proposed by both the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE): "*Epilepsy* is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure. An *epileptic seizure* is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain". The electrical activity in the brain triggers the epileptic seizure causing change in body movement, behaviour, awareness, sensation and function (The World Health Organization (WHO), 2004). However, not all seizures, sometimes called **fits**, are caused by epilepsy; some are caused by other reasons, such as low blood sugar (hypoglycaemia) or a sudden cardiac arrest (Kandula and Harden, 2009).

Epilepsy cannot be cured, but available treatments can help to improve the quality of life of people who have epilepsy, by controlling seizures while having minimal side effects upon the person. Treatments available can vary between medication, surgery, vagus nerve stimulation, and/or a ketogenic diet, however the most common treatment is medication. Treatment with medication makes use of Anti-Epileptic Drugs (AEDs) and is 60-70% effective in individuals (Elger and Schmidt, 2008; Kandula and Harden, 2009). It may take a while for the health provider to find the appropriate type of AED and the correct dose to manage the seizures. Elger and Schmidt (2008) identified some co-morbid conditions that are associated with epilepsy. These include: migraine, anxiety, depression, suicidal thoughts and higher risk for accidents and injuries.

People in the community may therefore associate a person who has epilepsy with mental health disorders. Individuals with epilepsy are not only faced with co-morbidity, they also have increased morbidity, where this could be as a result of seizures, fits or falling down causing physical injuries like fractures, bruising, and so forth. (De Boer et al., 2008). An individual with epilepsy may lead a normal life if seizures are controlled and managed. However, some social aspects need to be managed differently. Selecting an appropriate form of employment, starting a family, or even driving, are matters to be considered in the light of seizure management and control (Dekker et al., 2002; Wilby et al., 2005).

The prevalence of people who have epilepsy who are unemployed is greater than those who do not. Jacoby et al. (1998); Cockerell, Hart, Sander and Shorvon (1994) discuss the uptake of cost in care for epilepsy in the UK, and highlight that individuals with epilepsy are at a higher risk of unemployment than others. Individuals who have epilepsy not only face this disadvantage, but also have to face social stigma, discrimination in the work place and prejudice from other people. They might not want to go out of their households for fear of having a seizure while unaccompanied, or because of what people might think, causing an added psychological burden for them to bear (De Boer et al., 2008).

2.2 The Effects of Epilepsy on Patients' Lives

Moving on from a focus upon epilepsy as a condition, an exploration with regard to the effect upon People with Epilepsy (PWE) and carers, is needed in order to form a better understanding of this complex situation. Epilepsy and seizures not only have an impact on the life of the PWE but also upon their caregivers, family members, relatives, and their wider social circle (Mahrer-Imhof et al., 2013). Many aspects of this situation are discussed in the literature from different angles. As epilepsy is not the main theme of the thesis, only a selection of aspects surrounding the condition will be mentioned here, to indicate the many different perspectives of the situation and condition.

Schachter et al. (1993) have discussed how frequency of seizures affect an individual's life with regard to their employment and the difficulty of affording necessary medical expenses arising from their condition. Their study revealed that PWE who were aware of the effects of their seizures were less satisfied with their medical care than those who were not. PWE who experience frequent seizures are at a higher risk than others of finding themselves in unemployment and underemployment. This risk is increased if seizures are poorly controlled (Jacoby et al., 1998).

Bautista et al. (2014) also highlighted the problem of societal integration of PWE. They focused on examining the factors that continue to impede their integration with society, and how those impediments might be conquered by proposed solutions that might aid them. They discuss in detail, nine factors that influence integration of PWE into society. For example, suffering psychological co-morbidity as depression, anxiety and mood disorders. The ability to drive and the availability of transportation are important factors for PWE, by allowing them to travel to access medical care, to go to work and interact socially. The paper also examined factors that could affect family life, socioeconomic status, social stigma, and racial disparities.

Mortality rates of PWE are increased either from epilepsy itself (uncontrolled, poorly controlled seizures) or from an underlying cause. Mortality in PWE was associated with recorded alcohol problems, having collected the last AED prescription, having an injury in the previous year, and having been treated for depression (Ridsdale et al., 2011; Cockerell, Hart, Sander, Goodridge, Shorvon and Johnson, 1994; Sperling et al., 1999). Holmes and McCagh (2014) also identified other issues regarding PWE who face difficulties managing their seizures, with regard to their social functioning. Cognitive shortfall, impact of stigma, co-morbid depression and anxiety, difficulties in employability and relationships, and social interaction are all factors that influence the psychosocial aspects of PWE.

On the other hand, Jacoby (1992) presented the psychosocial functioning of PWE who are seizure free, or have been for at least two years. This group of participants reported lower levels of distress over epilepsy, they also reported that they were well adjusted to their condition. The employment rate was in accordance with the general population rate. In contrast with those results is the rate of marriage among this group of participants, which revealed that they were slightly less likely to get married than the general population.

Suurmeijer et al. (2001) highlight the psychosocial variables affecting the quality of life of PWE, regardless of the physical status of their condition. The most significant variables were, stigma perception, loneliness, psychological distress, and finally adjustment and coping with epilepsy. Moran et al. (2004) emphasized that participants with severe epilepsy stated that the commonest reported impacts on PWE were: education and work, followed by driving, and then the impact of epilepsy on their psychological and social life (Martin et al., 2005; Hayden et al., 1992).

Sillanpää et al. (2004) have viewed the impact of epilepsy from another angle. They investigated PWE who had the condition from childhood, and asked how it impacted their quality of life as adults. They concluded that the major impact of the condition was upon those still on medication, whether they were in remission or not, compared to the those who are in remission but off medication. The former group had rates of unemployment significantly higher than latter ($p < 0.001$) as well as lower socioeconomic status. All participants showed lower rates of marriage and of having offspring when compared to the control group, regardless of remission or not.

It should also be noted that it is not only PWE who are affected by the condition, it extends to their caregivers. Although studies regarding the effects of the condition on family members are under-researched, some have discussed this issue, and highlighted the effects on them in addition to the emotional burden it imposes (Saada et al., 2015; Saburi et al., 2006). Furthermore, applying interventions regarding PWE should be addressed with consideration of issues regarding the family members associated with their quality of life (Mahrer-Imhof et al., 2013).

A study conducted by Saburi et al. (2006) on the quality of life of adults with epilepsy, and their family's reactions and behaviours that occur due to epilepsy, revealed that some families managed epilepsy negatively by concealment, fear, overprotection, and isolation of the PWE. Thompson et al. (2014) conducted an online survey to examine this issue. Their study revealed that safety and vulnerability concerns, in addition to the unpredictability of seizures, were likely to impose some challenges for the family's day to day life, or even for planning a holiday. The inability to be in places as an entire family, the lack of time to spend with siblings and spouses, social isolation arising from not engaging in public events, frustration by finances, and unhelpful systems, were all examples of such challenges. All can lead to added stress, frustration, and exhaustion for family relationships and life dynamic (Cianchetti et al., 2015).

Saada et al. (2015) have examined the psychological effects of adult epilepsy on family members and caregivers. Negative experiences were not the only thing reported. In contrast, participants reported positive aspects such as the closeness and harmony gained within family members. It also created opportunities to support others and educate them. Family members gained more patience, empathy, and were more open minded about their situation as well as others. A family's perspective about what is important in life may well change their priorities of what is really important.

2.3 Healthcare System Factors Affecting the Care of PWE

Any healthcare system in the world, including the NHS in the UK, is continuously faced with new challenges that need to be addressed (García-Goñi et al., 2012; England et al., 2012; Sheikh et al., 2015). The challenges identify include the following:

- Increasing healthcare expenditure.
- Increasing size of the ageing population.
- Increasing number of people who have chronic condition(s).
- Constant demand in safety and quality of care.
- The lack of health professional boundaries collaboration and partnership leading to healthcare fragmentation.
- The increasing costs of medical and technological innovations.

Trying to manage all of those issues is like juggling several small balls with one hand; especially in as complex a domain as healthcare. Managing and maintaining the population's health is not an easy task, especially for people who have a chronic condition(s). Chronic conditions (e.g. diabetes, epilepsy, asthma, etc.) affect the quality of life of people, their productivity, and functionality (Wallace et al., 2012; Wagner et al., 2001).

Healthcare systems are not usually organised to meet the demands of chronic conditions, but rather focus on providing care for acute illness or injury (Wallace et al., 2012; Wagner et al., 2001; Schoen et al., 2009). The World Health Organization (WHO) has discussed this extensively in their global report: *Innovation Care for Chronic Conditions- Building Blocks for Action, Global Report* (The World Health Organization (WHO), 2002). Their report emphasizes the fact that global healthcare systems were "developed in response to acute problems" therefore causing a notable unevenness in the provision of care to those with chronic conditions. The report identifies that this defect in global healthcare systems has created problems at:

1. The macro-level (relating to policy)
2. The meso-level (concerned with healthcare organization and community).
3. The micro-level (addressing patient interaction).

Problems identified at the macro-level were centred upon policy issues. Some were:

- Fragmentation of the associated financial systems.
- Insufficient monitoring and standards.
- Lack of continuous education for healthcare workers.
- Lack of inter-organizational collaboration.
- Communication between healthcare and non-healthcare sectors and government and non-government organizations.

At the meso-level some problems were:

- The failure to organize care for chronic conditions.
- The lack of tools and support for healthcare workers.
- Failure to use information systems and strategies for monitoring: chronic conditions, prevention, patient self-management, and intra-organization communication.

Finally, at the micro-level problems identified are centred upon the failure to empower patients and to value their interactions with the health providers, whether it be systems or personnel.

2.3.1 The Policy Level

The policy level is concerned with decision making about resource allocation and healthcare development related to principles, organizational collaboration, legislation, leadership, financing, policy integration, values, and strategies (Epping-Jordan et al., 2004; The World Health Organization (WHO), 2002).

The healthcare domain is a dynamic and a complex environment that relies heavily on recording, transferring, and exchanging information. Therefore, establishing effective inter- and intra-organizational communications is an essential element for achieving goals, ensuring effectiveness and achieving success (Yang and Maxwell, 2011; Boyd et al., 2014). In 2000 the NHS set up a reform plan of core principles to tackle existing problems. Calling for a patient-centric approach, as one of its principles, by organising NHS services around the needs and preferences of patients (Department of Health, 2000). This approach requires healthcare organisations to collaborate and communicate effectively both within a given healthcare organization, and between them, by sharing and exchanging health information; leading to success in achieving efficiency and performance (Yang and Maxwell, 2011). Effective communication will pave the path to positive health outcomes, ensuring patient safety, providing a high quality of care, and making responsive treatment decisions (Hasan and Rashid, 2016; Blackstone, 2009; Donaldson et al., 2000).

Policy makers in the NHS gave particular attention to People with Epilepsy (PWE) in 2003 when the Department of Health (DoH) published an Action Plan titled: *Improving Services for People with Epilepsy* (Department of Health, 2003; Besag, 2004; Dickson et al., 2015). This was the first step by policy-makers towards setting up an action plan that would cover service improvements, policies, and initiatives, as well as providing care, management, information, and treatment for PWE (Department of Health, 2003). Although this action plan drew attention to this need, it did not provide any vital steps to be taken or make any firm commitments that are necessary to address shortcomings in the health service as it was then (Besag, 2004). Since then, very little has been added in relation to the care for epilepsy.

In 2009, **Epilepsy Action**, a UK based charity organization, called for the government to take action and leadership by publishing a study which revealed a "worrying variation in service provision, data collection, evaluation and quality of care" for PWE. It was reported that many Primary Care Trusts (PCT) and Acute Trusts (AT), that provided care to PWE, still fell short of the 2004, 2008 guidelines for PWE from the National Institute for Health and Care Excellence (NICE) (Epilepsy Action, 2009).

The WHO global report also cast light on the UK NHS. After the failure of the *Connecting for Health* (CfH) initiative; in 2014, NHS England announced the *Five Year Forward View* which highlights how services need to be changed to fulfil the needs of users. The *Five Year Forward View* focuses on key strategies that require more emphasis to be placed on prevention, patient empowerment, and services integration. In addition to these strategies, "complementary approaches" are essential to achieve them and overcome the challenges. For instance, supporting the workforce skills and education, and applying different approaches to health information sharing and dissemination on different levels, nationally, locally, and individually, in other words supporting the inter- and intra-organizational communication and collaboration.

Finally, the *Five Year Forward View* seeks what is termed the "combinatorial innovation", which involves combining different technologies and ways of working that are already available in the NHS in order to transform the delivery of care to the population (NHS England, 2014). In many ways, the NHS Five Year Forward View initiative can be compared with the WHO global report in identifying the challenges and gaps that need to be tackled and addressed in the macro-level, indicating pitfalls in the current healthcare system. The difference is that the WHO global report was focused on the needs of chronic conditions, whereas the Five Year Forward View was focusing on the system as a whole. Some gaps identified by the Five Year Forward View that need to be addressed are that:

- Increasingly we need to manage systems, networks of care, not just organisations.
- Out-of-hospital care needs to become a much larger part of what the NHS does.
- Services need to be integrated around the patient (NHS England, 2014).

Policy initiatives should be targeting services for this vital, yet neglected, group of people who have chronic conditions. Policy makers should structure integrated care suitable for patients with chronic conditions (Department of Health and Children, 2014). The National Audit of Seizure management in Hospitals (NASH), the first national epilepsy adult audit in the UK that took place in 2011 (NASH1) followed later by another audit in 2013 (NASH2), stated that the linking structures for primary, secondary, and tertiary care services in the NHS are "less well defined and there are many opportunities for patients with epilepsy to be 'lost' or 'ignored' within the system" (The National Audit of Seizure Management in Hospitals (NASH), 2011). This huge gap in the system, which is neglected by policy makers, causes patients to miss out on using the appropriate specialist services available, therefore leading to unjustified ambulance services usage, ED visits, and hospital admissions, resulting in unnecessary financial costs (Dixon et al., 2015).

2.3.2 The Healthcare Organization Level

Sharing patient health information within and among healthcare agencies can help support the best delivery of faster, safer and better care (NHS Englan, Information Governance Alliance, 2016). Disruption of the information flow may lead to substantial problems regarding the health of a patient, that can lead to error regarding medication and/or medical issues, that can cause morbidity and mortality (Coiera, 2000). Coiera (2000) stated that information flow in healthcare is mainly composed of clinical communications. Leape et al. (1995) have identified 16 system failures that underlie errors causing adverse drug events. The most two common defects identified in the study included inadequate dissemination of information about drugs (29%) and the lack of readily accessible patient information (18%), e.g. laboratory test results. All of these errors can potentially be prevented by better information systems.

Difficulties and problems regarding PWE, their treatment, and care have been discussed and identified in the literature (Thapar, 1996). However, little attention is paid to the organizational level of assessment and epilepsy care across the UK (The National Audit of Seizure Management in Hospitals (NASH), 2011). The National Audit of Seizure management in Hospitals (NASH) aims to describe and understand the variations in epilepsy care as currently delivered in the healthcare system. It also outlines options to share and improve care of PWE with hospitals, patients, organizations, and NHS managers in order for all to apply and act on improvements (The National Audit of Seizure Management in Hospitals (NASH), 2011, 2013; Dixon et al., 2015). NASH2 is the audit report that was conducted in 2013 after the first audit report, NASH1. Dixon et al. (2015) have discussed the results from NASH2. They observed that for this group of people, many ED visits can be avoided by improving other channels of access, apart from ED. For example, through the use of outpatient community services and providing better management of the condition in the community and the pre-hospital settings. Marson (2013) observed that the results from the NASH audit reflect inadequate and poor care coordination of services. The lack of engagement between acute medical services and neurology services was a major deficiency identified. Again reflecting the need to establish intra-organizational communications and collaborations.

Dunn et al. (2005) observed that having an emergency clinical pathway of epilepsy management, as well as selecting necessary investigations and hospital admission, would result in avoiding undesirable and unnecessary admissions to hospital. Iyer et al. (2012) also have stated that this lack of an epilepsy care pathway in the ED will lead patients to be admitted and readmitted to hospitals unnecessarily, due to the lack of available epilepsy care support channels for outpatient investigations, leading to an annual structured review and follow up by a specialist. Having such a care pathway, in addition to early specialist follow up, together with advice, patient education and self management tools can improve the quality of epilepsy care. Unfortunately, a clear pathway for PWE for the ambulance crew to follow is absent. As more focused guidelines would mean better compliance by a crew; it is therefore crucial that defined clinical areas be more specifically targeted in guidelines (Gray and Wardrope, 2007).

These gaps in the healthcare system indicates what PWE need from the system and what is lacking. People with chronic conditions, of which PWE form an important group, have no clear care pathway or publicity about available services and supporting services for them to follow. As a result, they use the ambulance services as a clear and correct choice, adding more pressure to the ambulance services and EDs in hospitals with cases that can be managed safely through an alternative suitable care pathway.

2.3.3 The Patient Interaction Level

People with a chronic condition(s), such as epilepsy, widely lack structured care. The literature identifies problems in the care provided to PWE in the community (Goodridge and Shorvon, 2013). Seizures remain uncontrolled for up to half of all people who have epilepsy in the UK, with a significant impact on work, family and social life (Moran et al., 2004).

Problems identified include: lack of follow up and adequate review (Jones, 1980; Minshall and Smith, 2006) lack of intra- and inter-organizational communication, coordination, and shared care between primary care, secondary care, specialist centres, and the voluntary sectors, in addition to lack of shared decision making with healthcare providers (Elwyn et al., 2003; Minshall and Smith, 2008; The Clinical Standards Advisory Group, 2000). They also include: poor appropriate effective management of epilepsy (Jacoby et al., 1996; De Groot, 2013), low patient knowledge about their condition (Nour et al., 2014), and difficulty in accessing services (Heaney et al., 2002; Elwyn et al., 2003).

A person with a chronic condition, like epilepsy, is in need of continuous lifelong healthcare management (England et al., 2012; The World Health Organization (WHO), 2002). Increased attention has been paid to the importance of self-management for chronic conditions by patients themselves, and how this can contribute to fulfilling their needs with healthcare systems capacity (Barlow et al., 2002; Wagner et al., 1996).

Kennedy et al. (2007) in their study examined the reasons why many such initiatives fail to deliver. They suggested that key changes to achieve effective support for people with chronic conditions to be able to self-manage their health were needed. One of their suggestions was to view the healthcare system as a whole. That would involve approaching chronic conditions in the whole context of the healthcare system by empowering patients, opening channels to other sources of help, changing healthcare services organization and empowering professionals with training and tools to manage chronic conditions effectively.

The Chronic Disease Management (CDM) model was set up to improve and manage the quality of chronic condition care. This international move to transform the way that chronic conditions are managed aims to improve the management, quality, and safety of chronic conditions care while controlling healthcare expenditure (Fitzsimons et al., 2012). The CDM model has led to a number of recommendations. These are:

(i) PWE, as one of the stakeholders, should play a vital role in managing their condition, therefore promoting participation in self-management and education of their health.

(ii) There is a need to improve integrated care across healthcare providers and organizations.

(iii) Support for clinical management decisions by applying clinical guidelines is needed.

(iv) Standardized clinical information systems could be used to facilitate exchange and sharing of patient information within and across health organizational boundaries (Fitzsimons et al., 2012).

To consistently deliver high quality, safe, and accessible care to all, there is a need to move from the doctor-centric approach to the patient-centric approach (Cresswell and Sheikh, 2015). This approach to patient care and health management requires different healthcare disciplines from different settings to collaborate with each other (Bell and Liu, 2001).

Disease-centric clinical information systems also need to be developed to support people with chronic condition(s), in other words, applying the patient-centric approach and seeing the patient as a whole. Those clinical information systems developments should first be applied in the primary care level and gradually rolled out to include national systems, taking into account integration with other different systems and conformity with the NHS policies and requirements (Department of Health and Children, 2014).

NASH2 collected data of 4,544 attendances at EDs at a total of 154 sites from 132 NHS trusts/health boards in the UK. Of the attendances, 61% were for patients who were known to have epilepsy, 12% were for patients who have had previous blackouts or seizures with no epilepsy diagnosis, and finally, 22% were for patients having a seizure for the first time (The National Audit of Seizure Management in Hospitals (NASH), 2013). The results from NASH1 showed that 89.3% of these patients were transported to ED via an ambulance (The National Audit of Seizure Management in Hospitals (NASH), 2011).

Every PWE attending the ED represents a "*failure* in control" (The National Audit of Seizure Management in Hospitals (NASH), 2013). It is not surprising to know that 89.3% of patients were transported to ED via the ambulance services, indicating a big gap in the healthcare system of care services provided to such a group.

2.4 Involvement of Ambulance Services and NEAS in Particular

Ambulance services across the UK are faced with multiple challenges imposed by different stakeholders. Not only that, but also the need to focus on a set of strategic priorities, in addition to coping with the increased demand on the service and funding issues, as well as complying with the national standards and targets, clinical care, patient safety and education, workforce, and development (Association of Ambulance Chief Executives, 2016). The demand on the ten English NHS ambulance trusts in England continued to grow in 2015/16. It has increased more than 15% over three years, resulting in almost 30,000 calls a day (Association of Ambulance Chief Executives, 2016). Ambulance trusts are moving towards applying new operating models which are clinically based, in order to alleviate ED attendances. For instance, managing incidents through increasing the rate of 'Hear and Treat' (Section 1.1 explains different pathways) services from 5.9% in 2013/14 to 10.2% in 2015/16 (Association of Ambulance Chief Executives, 2016).

NEAS, among other ambulance services in the England, prefers not to convey a patient to ED unnecessarily, especially where there is no urgent life threatening medical need. Conveying patients to ED unnecessarily poses financial and time burdens to the ambulance services. It also adds more pressure to ED and services provided to patients. That is why treating patients on scene by qualified ambulance crew then discharging them can alleviate the pressure on ED attendances, hospital admissions and conveyance by ambulance services (The House of Commons, 2013). In December 2016, of all 999 calls received to NEAS, 35% were seen by an ambulance crew but not conveyed to ED. On the other hand, 21,364 journeys to ED were made during the same period of time (The Association of Ambulance Chief Executives, 2017).

NEAS is the authority responsible for providing emergency medical service to the population in the North East of England. It is critical when analysing financial costs and performance in ambulance services to be accurate in the matter of distinguishing various courses of action, meaning defining the immediate expenditure of various pathways that can be delivered to the patient in need. For instance, differentiating the immediate costs of calls (when a call handler applies 'Hear and Treat' then discharge), the cost of call-outs (dispatching an ambulance vehicle to an incident and providing care on scene), and the cost of conveyance (when the ambulance crew conveys patients to ED or any other pathway). Data highlighting the expenditure of those different pathways in different time periods, are scant in the literature and government reports. Studies and reports identified in the following paragraphs, are concerned with the impact of time and immediate expenditure. This is merely to accentuate the importance of identifying immediate expenditure and the impact of time with drawing no relation between the two. Also, it is important to note that the study presented here, in the following paragraph, is focused on people aged 65 who had fallen and required assistance or were conveyed to ED. This is to illustrate the immediate costs of different pathways of NEAS.

In 2004, a seven month study period in Newcastle upon Tyne, UK on the elderly population, over the age of 65, was conducted by Newton et al. (2006), which revealed the costs of falls in the community to NEAS. Their study highlighted some interesting results. The cost of a call-out for NEAS was £115. This cost is not the same if the crew were to spend time on scene with the patient for assistance or treatment, the cost in this case would be £123 per hour of crew time spent on scene. The time spent on scene with the faller to be assisted or treated on the spot was significantly longer compared to the time spent on scene for those being conveyed to ED. This resulted in the cost for assistance or treatment on scene being greater, £173.16 per call-out, compared to the cost of conveyance to ED which is £142.40 per call-out. Table 2.1 tabulates this information clearly.

Call-out Status	**Cost**	**Unit**
Call-out only	£115	per call-out
Call-out only	£123	per hour
Call-out with treatment/assistance on site	£173.16	per call-out
Call-out then conveyance to ED	£142.40	per call-out

Table 2.1: Cost of Call-outs in NEAS, 2004

Presenting the immediate cost published by The National Audit Office for the North East region of England can give an idea of expenditure fluctuation, however, they do not present the different expenditure for the various pathways that can be delivered to the patient in need. Table 2.2 tabulates the information clearly. For the year 2007-2008 the cost of a call-out, in the general population, was £171. For year 2008-2009 this was £180, and it was £176 the following year 2009-2010 (The National Audit Office, 2011). Further, for the year 2015-16 the cost per call-out was £235 (National Audit Office (NAO), 2017).

Financial Year	**Immediate Cost of a Call-out**
2007-2008	£171
2008-2009	£180
2009-2010	£176
2015-2016	£235

Table 2.2: Call-outs Expenditure Fluctuation for the North East of England

Regarding the time impact, the average time spent on scene in 2015-16 in the region NEAS covers was 26 minutes 49 seconds, and the average travelling time to a hospital for the same period was 16 minutes 20 seconds (North East Ambulance Service NHS Foundation Trust (NEAS), 2016*a*). In 2015 alone, NEAS received 575,133 calls. Of those, 377,608 calls required an ambulance dispatch, and 295,008 resulted in the patient being conveyed to ED (North East Ambulance Service NHS Foundation Trust (NEAS), 2016*b*). For the group of interest in this thesis, from April 2012 until August 2015, 2483 cases with fits were seen and treated on site, while 6127 cases with fits were taken to ED, so that 0.63% of cases with fits were taken to ED (North East Ambulance Service NHS Foundation Trust (NEAS), 2015*b*).

Tian et al. (2012) observe that 9.5% of emergency admissions in England 2009/10 for Ambulatory Care-Sensitive Conditions (ACSC), were for convulsions and epilepsy, placing this as the fifth leading cause of ED admissions. ACSC are those chronic conditions that can be managed by primary and preventive care centres in order to avoid unnecessarily admissions to hospitals and ED (Purdy et al., 2011; Tian et al., 2012; Purdy et al., 2010).

A study conducted by Dickson et al. (2016) revealed that 3.3% of all emergency incidents for the Yorkshire Ambulance Services (YAS) were incidents of suspected seizures, for which 97% had an emergency vehicle dispatched and 75% of those were taken to hospital. The annual estimated cost of the emergency management of suspected seizures in the English ambulance services is £45.2 million.

Faced with cases of seizures, paramedics find it clinically safer to take patients to ED, due to the lack of guidance, care pathways, lack of experience, anxiety over litigation, and lack of access to patients' medical information (Zorab et al., 2015). Hart and Shorvon (1995) in their study which included only PWE who were receiving treatment for the condition, revealed that the most common reasons for 43% of them to visit the ED were due to an occurrence of an uncomplicated seizure with either clusters of seizures or due to prolonged seizures, or an injury caused by a seizure. Their study suggests providing recommendations regarding care of PWE and their lack of hospital follow ups, direct referral to a consultant neurologist or a specialist epilepsy clinic, and PWE notes that lack information regarding their condition.

What has been highlighted are some of the factors influencing the constant pressure imposed on the ambulance service trusts in England regarding PWE, and how seeking to tackle some of those factors will help ambulance trusts to concentrate on real genuine emergency incidents.

2.4.1 User Perspectives on the Ambulance Service

Ridsdale et al. (2012) in their qualitative study reported PWE's explanations for using the emergency services. PWE did not use the emergency services solely because of a seizure occurrence, as other triggers were associated with this action. The lack of available family members, or of a knowledgeable significant other person, the public's shock when faced with seizures, and fear of sudden unexpected death were reasons identified for using the service. Furthermore, carers would often call the emergency service if they noticed something unusual about the PWE, or if they were uncertain about what actions to carry out (Ridsdale et al., 2012).

There are other factors affecting user's perspectives and their actual needs from the ambulance services. For instance, PWE who experience a seizure do not want to be taken to ED unnecessary by the ambulance, especially if they are undergoing an un-deviated seizure episode of their normal pattern and if they are in the company of someone who is sufficiently informed and confident to support and manage the situation (Ridsdale et al., 2012). In addition, carers would like to be assured that transportation by the crew to the ED will only occur if there is a genuine need for help. The ambulance crew would like to have more information regarding the patient, that would help them assess the patient and support their decision-making while on scene, in order to select the pathway appropriate to the condition and situation (Dickson et al., 2016).

Burrell et al. (2012); Ridsdale et al. (2012) conducted a study regarding on scene decision-making by paramedics when needing to care for patients with epilepsy. Paramedics expressed their desire to have ready access to information about previous seizures in addition to related patient health information. Some expressed the lack of adequate organizational support in the case of litigation, encouraging them to decide to take the patient to ED as a safety net. They also reported insufficient guidance, practice and training when it comes to dealing with PWE on scene.

2.5 Gaps Related to PWE

Although policies and guidelines are being set by the NHS, yet firm actions and commitment to those are still lacking (Besag, 2004; Epilepsy Action, 2009). More emphasis should be focused on prevention, patient empowerment, service interactions, systems and networks of care; supporting end-line workforce skills, education; applying different approaches to health information transfer; expanding out-of-hospital care; and integrating services around the patient. A large proportion of PWE are conveyed to hospital after a seizure unnecessarily, when their need can be managed locally. However, there is little research regarding alternative care pathways or criteria that could assist the ambulance crew to avoid conveyance to hospital. Further, more studies are needed to improve care for such group after a seizure (Osborne et al., 2015).

Alternative pathways and channels of access of support, for PWE should be improved in the community to alleviate the unnecessary usage of the ambulance services and ED in hospitals (Dixon et al., 2015). More attention should be paid to intra-organizational communication and collaboration in regards to services provided to PEW, as available collaborations are poor among services and healthcare providers. Clear guidelines for PWE should be targeted in clinical pathways to be followed by crew on scene (Gray and Wardrope, 2007).

PWE widely lack structured care and poor self-management of their condition. They also lack follow up and adequate review (Jones, 1980; Minshall and Smith, 2006), and there is a lack of intra- and inter-communication between healthcare services and clinical staff (Elwyn et al., 2003; Minshall and Smith, 2008; The Clinical Standards Advisory Group, 2000). PWE lack information about which health service provider to contact for follow up, for urgent help, for guidance and/or support.

There is a need for a patient-centric approach to be applied to the whole system where clinical staff can collaborate and communicate around the patient's health. As noted above, some PWE/carers will call the ambulance service unnecessary even when experiencing their normal pattern of seizures. This results is an ambulance being dispatched to an non-urgent incident, only because they share the same symptoms with life threatening conditions. Therefore the ambulance crew will convey them to ED unnecessarily adding more financial and resource expenditure on the ambulance service.

A study conducted by Stiell et al. (2003) supports the argument about the lack of information (information gaps) for those who are conveyed to the ED. One-third of visits to ED were identified as having information gaps, 34% of those presented to the ED with information gaps were brought by an ambulance. The most common types of gaps identified were medical history accounting for 57.9%, then laboratory information which was 23.3%. People with serious chronic conditions, who arrived by ambulance, the elderly, and those who have been recently hospitalized or visited the ED, were more likely than others to have information gaps. Alleviating a little of this problem could be achieved by supporting the ambulance crew, who lack patients information and find themselves with no choice but to convey to ED, with patients health information provision (i.e. filling the information gap) on scene in order to reduce unnecessary conveyance to ED. As providing information does not just benefit the ambulance crew, but also may offer potential benefit ED staff as well.

Finally, it is important to note that there has been another analysis that was performed while doing this main one, regarding the handover process between the ambulance crew and ED staff. This will be discussed in more detail in the Chapter 9.

2.6 Summary

To sum up, ambulance services are faced with an increasing demand by the public; with an average annual increase rate of 5.2% (National Audit Office (NAO), 2017). This inflicts difficulty and resourcing challenges on them, especially when funding does not keep up with the imposed rising demand. Ambulance services need to identify barriers in the use of Health Information Systems (HIS), Health Information Technology (HIT) and related fields in the sociotechnical aspects etc.; and try to resolve and overcome those impediments to increase benefits and save resources, including designing collaborative systems based on Computer-Supported Cooperative Work (CSCW) in healthcare (Fitzpatrick and Ellingsen, 2013).

Therefore, it is important to develop and implement simple HIT solutions in ambulance services not just to save resources, meet national targets, and support communication and collaboration, but also to meet the requirements of other stakeholders, each with different needs to be met by the ambulance system. For example, one stakeholder, PWE/carers, do not want to be taken to ED unless it is necessary. They would rather be treated on site, then released with minimum disruption to their lifestyle routine and independence. Ambulance crew, another stakeholder, would like to have more reliable patient information, regarding the PWE, while on scene, in order to support them in their decision-making when selecting the most suitable care pathway, therefore saving financial and time resources by reducing unnecessary conveyance to ED and satisfying the preference of the patient. Of course, the lack of information may incur financial cost and total time lost to the ambulance services. Thus, developing a simple Technology Based Solution, like the Information Broker (IB), to meet the demands of stakeholders carries potentials benefits, not just to those directly involved, but also reducing financial costs of unnecessary convenience to ED and time lost on scene due to lack of patient information, and consequently, on the three different healthcare system levels (macro, meso, micro).

Chapter 3

Health Informatics

This chapter will present the role of Health Information Technology (HIT) in regards to the ambulance services. This is important to shift the focus from the system view side as a whole to the information and the technology view side. Identifying possible challenges and issues in different dimensions is a necessary task. For example, issues related to a sociotechnical model, to information security, and to Computer-Supported Cooperative Work (CSCW). This facilitates the chances of new HIT being successfully implemented. A presentation of a case study of the London Ambulance Service (LAS) was appropriate to illustrate some challenging issues in HIT.

Finally, what makes the ambulance services different from other organizations is its functionality. Ambulance services work in a dynamic environment with time constrain situations, and they are in continuous contact with different health and non-health organizations. This makes decision-making a challenging task for the ambulance crew. Decision-making is better performed if it is based on reliable patient information. All these elements are contained in the studies presented in this chapter.

3.1 Health Informatics

Health Informatics (HI) has been defined by the U.S. National Library of Medicine as “the interdisciplinary study of the design, development, adoption and application of IT-based innovations in healthcare services delivery, management and planning.” (U.S. National Library of Medicine, 2012). Additionally, the American Medical Informatics Association (AMIA) has defined HI from two different perspectives as:

- A scientific discipline that is concerned with the cognitive, information-processing, and communication tasks of healthcare practice, education, and research, including the information science and technology to support these tasks.
- A field of information science concerned with the management of all aspects of health data and information through the application of computers and computer technology (The American Medical Informatics Association, 2014).

In this chapter, focus will be only on HI in the context of its role for PWE who need support from an ambulance service.

3.2 The Role of Health Information Technology

Ambulance services do not normally have access to any form of patient record information for the people they are called to, with the result that many people who are not in need of hospital care are unnecessarily transferred to ED (Byers, 2013). This is often the case for people who have had (experienced) blackouts, falls, or a seizure.

Information systems in healthcare are needed to “enable more-effective and efficient care” for people with chronic condition(s). This is essential to improve their health outcomes by patient-centric care approaches, which can be achieved by integrating well coordinated/collaborated care and teams around them (Schoen et al., 2009). PWE are one such group who often become frequent users of ambulance services and EDs. This is undesirable for the patient(s) in many cases, as well as resulting in unnecessary use of ambulance/ED time and resources.

Health professionals and supporting staff, e.g. ambulance crew, call handlers, dispatchers, all work in a dynamic environment that demands the availability of reliable and updated health information about the person in need; and in many situations they may lack even basic information due to the unconscious state of the patient. Health Information Technology (HIT) offers opportunities to improve the quality of care provided to patients and their safety as well as improved medical care costs and efficiency by providing access to relevant information (Chaudhry et al., 2006; Kasemsap, 2016; Buntin et al., 2011).

Within the North East of England, NEAS receives 371,000 emergency and urgent calls per annum (North East Ambulance Service NHS Foundation Trust (NEAS), 2013). This indicates the heavy use of the service, which deals with people experiencing an urgent need for medical healthcare.

Many issues emerge when providing healthcare for a person who is involved in an incident. The condition of the person, the time spent for an ambulance crew to reach and treat the patient, the availability of information about the patient and the location of the incident, are all factors affecting the provision of appropriate urgent care. In emergency situations, the availability of health information is critical and everything happens quickly, therefore the lack of health information may lead to a significant percentage of patients, who do not eventually require any further investigation, being transported to the ED in a hospital (Hjälte et al., 2007*a*; The House of Commons, 2013). Hence the lack of patient health information can lead to precautionary decisions being made by the ambulance crew, that are later shown to be unnecessary. Useful health information which has been gathered by different health organizations or departments, if available to an ambulance crew through the aid of Health Information Technology (HIT), could provide the basis for making better medical decisions (Budgen et al., 2005).

3.3 Some Challenging Issues in Health Information Technology

In this section, three challenges related to HIT are presented, these are Computer-Supported Cooperative Work (CSCW), sociotechnical, and information security challenges. Although there are more challenges identified and of such importance, those were the ones considered to be of critical importance, with great relevance to the feasibility study of the IB.

High quality, cost effective, seamless and shared healthcare delivery is what healthcare organizations aim to provide, and the successful management of a large amount of information must be achieved if they are to fulfil this aim. The integration of health information across heterogeneous, distributed, and autonomous information systems is a major concern (Sabooniha et al., 2012); and healthcare systems struggle with integration challenges (Khoumbati et al., 2005). Other shared aims for healthcare organizations are to ensure protection of patients' information, streamline administrative and clinical tasks, and reduce medical errors, while providing privacy and confidentiality, interoperability, data security, data sharing, consent, and information governance (Wachter, 2016).

Since the introduction of Electronic Records to the healthcare industry, a range of ongoing and incremental developments involving HIT have taken place. The deployment and use of HIT in various healthcare organizations at different levels with specific processes and aims in different departments, has resulted in the development of various Information Systems (IS). Theses distributed and different systems have created "islands of technology" (Sabooniha et al., 2012) that form isolated heterogeneous information systems, with information structures that cannot easily be shared or integrated.

Attempts to improve care by using HIT to resolve the lack of information between different parts of the NHS have been made previously using a number of approaches. The most well-known of these was The National Programme for Information Technology (NPfIT). The NPfIT programme was introduced to the UK in 2002 and shut down in 2011. It was the largest information technology programme in the world (Keen, 2006; Currie and Guah, 2007), and was intended as a strategy that would modernize government services through the integration of information by use of IT in the NHS. In 2005 the Department of Health, established *Connecting for Health*, an agency charged with the delivery of the NPfIT.

The Department of Health stated that the NPfIT aims to “support the delivery of the NHS Plan through the use of modern information technologies”, in order to support services to be quick, convenient, and seamless for the patient; to support integrated care through effective electronic communications, finding essential information in a timely manner, ease of access to specialized expertise, better learning knowledge management to staff; and also, to improve good quality data, clinical audit, management information, and governance in order to improve organizational management (Department of Health, 2002).

The NPfIT was based upon various applications and tools, all aiming to facilitate seamless medical care and information sharing (Cresswell and Sheikh, 2009). The main national systems included patient e-booking, e-prescription, secure email, the summary care record (spine), picture archiving and communications systems, etc. that would improve services and the quality of care provided to patients (Justinia, 2016; Hendy et al., 2005). This “technology-push”, however, (Greenhalgh et al., 2008) actually added more complexity to the NHS.

The NPfIT was a failure (Avison and Young, 2007; Waterson, 2014) due to a number of direct and indirect factors. This large centralized system was **pulling** vast data from other big systems (Randell, 2007; Peltu et al., 2008) rather than using simple solutions to **link** them together. This brought with it problems among users in attaining effective information flow with issues relating to confidentiality, safety, privacy, and security (Hendy et al., 2005; Randell, 2007). The lack of support and fit between HIT applications and work practices, cultural, and environmental, while implementing new IT services with no prior evaluation of pilot studies, and lack of robust cost evaluation methods, were also considered as added factors (Avison and

Young, 2007).

Following the failure of the NPfIT (Shortell et al., 2015; Maughan, 2010; Justinia, 2016; Wachter, 2016), the NHS has shifted its approach to patient information sharing, by finding local solutions to link separate systems together (Shortell et al., 2015). The NHS initiated the Five Year Forward View, published in October 2014, which sets out defined strategies on how services and care need to change over a period of five years (NHS England, 2014). In general, the Five Year Forward View identifies required strategies that need to be applied in the future to reach this change. Some of these are:

(i) Patient and community engagement to be maximized by patient empowerment, prevention programs providing support for carers, and encouraging volunteering.

(ii) New models of care to replace the traditional ones. For example, Multi-speciality Community. Providers (MCPs), Primary and Acute Care Systems (PACS) and urgent and emergency care networks.

(iii) Exploitation of the information revolution.

(iv) Accelerating useful health innovation.

In their article, Shortell et al. (2015) have proposed benefiting from the experiences of the United States (US) in applying the Five Year Forward View. They have emphasized the importance of IT as a powerful tool to integrate care. A further tool that can also be utilized, is to employ predictive methods to identify likely high risk patients or high risk costs in order to initiate early interventions; improve care at the point of service; provide feedback for ongoing improvements of quality; and facilitate information sharing across settings and providers of care. However, this has been difficult to implement successfully, due to the complex technical and expensive financial considerations (Mark, 2007; Brennan, 2007).

Research by Stoll et al. (2010) has demonstrated the importance of collaboration and inter-organizational coordination among organisations. They identified four factors that limit the ability of organizations to work together effectively. These factors are:

(i) **Structural**: concerned with on the organisation itself, e.g. competitiveness due to funding pressures and the inability to plan for sustainability.

(ii) **Technological**: differences in Information and Communication Technology (ICT) access.

(iii) **Organisational**: the lack of strict boundaries between organizations for coordination is found to be of minimal, instead priority was on individuals rather than organizations for coordination purposes.

(iv) **Individual**: depending on personal motivation and trust with the other individual in the other organization.

In the context of this thesis, the result is that ambulance services are still unable to access patient records held elsewhere in the NHS.

3.3.1 Computer-Supported Cooperative Work

Computer-Supported Cooperative Work (CSCW) addresses the use of technology and software tools to support group work on different locations, sites, etc. In other words, how computer systems support collaborative activities and their coordination (Carstensen and Schmidt, 1999). CSCW has contributed to this rich domain in terms of how to design collaborative work and systems, healthcare practices and tools to support those work and systems (Fitzpatrick and Ellingsen, 2013). CSCW is not an isolated field of study, it also interacts with the research fields of Human-Computer Interaction (HCI) and Participatory Design (PD).

The number of NHS trusts seeking to acquire foundation trust status has increased. In the period 2010-2015 £2 billion was allocated to finance only 12 of the 20 merges. The main objective for this merging, in most cases, was to deal with financial challenges, but some also addressed the quality of services (Collins, 2015).

This of course changes the way healthcare providers function. They are loosening the coupling of centralization and gaining a greater degree of autonomy from the Department of Health and NHS England, as foundation trusts have more financial and managerial freedom than trusts. This semi-autonomy, or decentralization, brings more freedom to foundation trusts in terms of standards and work adjustment in their area of expertise with local environment, ambulance services as examples. Nonetheless, this loose coupling approach can limit the information flow between health organizations leading to difficulty in coordinating services. To overcome this challenge, groupware systems have the potential to fill the gap by improving information access and coordination between and among healthcare organizations (Pinelle and Gutwin, 2003; Scott, 1985; Pinelle and Gutwin, 2006). However, it might be challenging when trying to apply a CSCW, or groupware system (Cruz et al., 2012), that spans over multiple organizations or even units in the same place, because the decentralization of authority, regulations and standards might be different in each entity and unit.

Information Technology (IT) in healthcare enhances teamwork among professionals. This is achieved by the improvement of information transfer, communication and workflow, leading to patient safety and quality of care (Chaiken, 2003). An example is research conducted by Lu (2005) that presented the design and development of a CSCW based remote cooperative oral medical diagnosis system in healthcare. This system enabled healthcare professionals to access patient information in a dynamic environment as well as cooperating with other health professionals located in different health organizations.

Hardstone et al. (2004) considered the implications for teamwork and clinical documentations which are distributed and embedded in IT systems. They argue that organizational embedded IT systems, with regard to design and implementation, must support collaborative work in healthcare services; and for collaborative work to be effective, it must be supported by lessons learnt from CSCW studies. As embedded IT systems are poor at supporting collaborative work, adding CSCW applications middleware to existing HIT systems enables it to be part of the inter-organizational system.

When designing systems or technologies for the healthcare domain, employing HCI and CSCW principles should be considered essential. In the ambulance services, where different people work collaboratively, in groups and teams, from different locations, the need to designing systems and technology to support this should be a key goal. Health organisations ought to understand how this heterogeneous environment of field work is conceptualised and how it evolves over time. Understanding what makes work situations complex to actors and how to handle or reduce this complexity by technology is essential to design usable and useful technologies for cooperative work settings (Carstensen and Schmidt, 1999). Furthermore, developers when designing systems for groups and teams need to understand the unique demands that their system will impose on actors (Grudin, 1994). Likewise, attention to individuals who work in those teams are of equal importance, that is starting from the bottom of an organization, as intended by CSCW studies, rather than the top-down approach often advocated by ICT and IT studies (Fitzpatrick and Ellingsen, 2013). Pinelle and Gutwin (2006) have illustrated a case study of CSCW deployment challenges and strategies in a home care setting. Challenges included: perceptions of inequality, role conflicts, difficulties centralizing deployment, and problems achieving critical mass.

The Ambulance service, NEAS in this case, is a dynamic and a varied environment that involves several healthcare actors, coordinating daily activities and documentation practices by using technology. Furthermore, it faces complex sociotechnical challenges based on cooperative work and collaborative systems (Berg, 2003; Pettersson et al., 2004; Fitzpatrick and Ellingsen, 2013). Grudin (1988) stated three reasons why CSCW applications fail. Identifying what causes those problems in NEAS and avoiding them will enhance performance. These are:

- The disparity between who does the work and who gets the benefit.
- The breakdown of intuitive decision-making.
- The underestimated difficulty of evaluating CSCW applications.

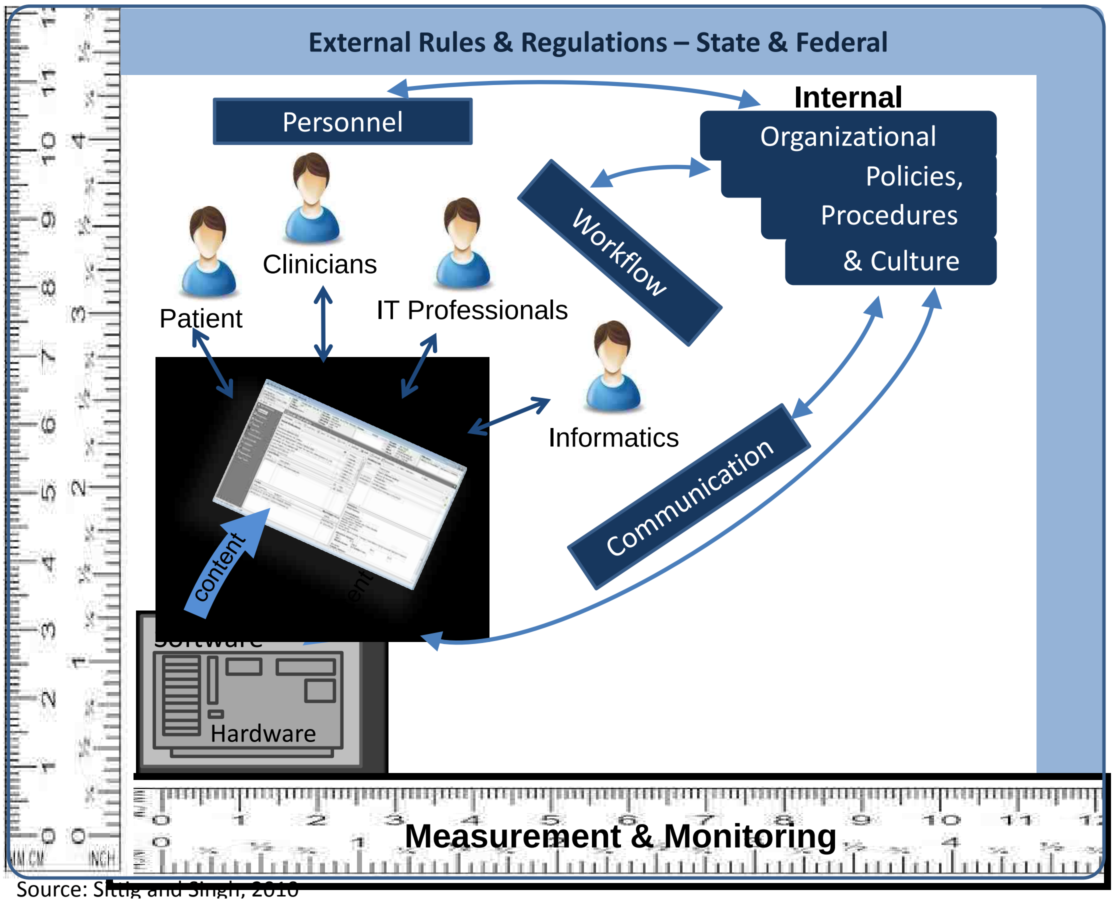
Finally, An important but often neglected concern in HCI is “designing **for** appropriation” (Tchounikine, 2017). Designing for appropriation, as Dix (2007) explains, is when users of this technology improvise and adapt new ways of performing tasks, in ways that the designer had not intended in their initial design. This domestication of the technology reflects how well the user understands and interacts with it but specifically in ways that suits themselves. The importance of this is several-fold. First, situatedness, which means the environment it is in; second, dynamics, meaning that needs and environments change; and finally, ownership, appropriation gives a sense of ownership. However, it may not be suitable to employ this approach in some environments in healthcare where it is often necessary to follow specific medical procedures and pathways. On the other hand design **from** appropriation might be more suitable. Design **from** appropriation is observing the ways users adapt the technology for their use and how it has been appropriated, then redesigning the technology to fulfil those new uses (Carroll et al., 2001; Dix, 2007).

3.3.2 Sociotechnical Issues

Sittig and Singh (2010) proposed a new sociotechnical model for Health Information Technology (HIT). Figure 3.1 represents this model. The foundation of their model was influenced by four previous studies related to sociotechnical models proposed by Henriksen et al. (1993); Vincent et al. (1998); Carayon et al. (2006); and Harrison et al. (2007). Further, the model overcomes the limitations in models previously applied in HIT, for example Rogers (2010); Venkatesh et al. (2003); Hutchins (1995); Reason (2000); and Norman (1988).

They argue that those previous models do not consider and address the full range of factors and dimensions in the design, development, implementation, use, and evaluation of HIT interventions. Furthermore, none included a measurement and a monitoring infrastructure (e.g. methods to routinely collect data, etc.). The aim of this new proposal was to develop a comprehensive model to overcome those limitations; by integrating specific technological and measurement dimensions of

HIT with other sociotechnical dimensions (people, communications, workflow, organizational politics, external rules and regulations). Consequently, they have developed a comprehensive eight-dimensional model that can influence the success of HIT intervention. The eight-dimensional model consists of:



Source: Sittig and Singh, 2010

Figure 3.1: A Sociotechnical Model for HIT and the Intra-relationships between the Eight-Dimensions

(i) **Hardware and Software Computing Infrastructure:** the software and hardware that are essential to run applications.

(ii) **Clinical Content:** the continuum storage of the data, information, knowledge in the system. That is structured and unstructured, numerical, or textual data and images.

(iii) **Human Computer Interface:** an interface, to interact with aspects of the system that users can see, touch, or hear.

(iv) **People:** this represents all the humans involved in all aspects of the design, development, implementation, and use of HIT.

(v) **Workflow and Communication:** this is a two way communication regarding patients care in the system. The steps to ensure that each patient receives the right care in the right time represents the workflow of this communication.

(vi) **Internal Organizational Policies, Procedures, and Culture:** meaning all the organization's internal structures, policies, and procedures that affect every other dimension in the sociotechnical model.

(vii) **External Rules, Regulations, and Pressures:** this accounts for the external forces that facilitate or place constraints on the design, development, implementation, use, and evaluation of HIT in the clinical setting.

(viii) **System Measurement and Monitoring:** the effects of HIT must be measured and monitored on a regular basis. This can be achieved by addressing four key issues related to HIT features and functions. First is the availability issue, meaning the availability and the readiness of the features and functions. Second is determining how clinicians use various features and functions. The third measurement objective is monitoring and measuring the anticipated outcomes of HIT implementation. Finally, the assessment of usability, quality of care, and effectiveness of HIT, not just on the local level, but also at state, regional, and national levels (Sittig and Singh, 2010).

As with any system, components (dimensions) of this complex model must be investigated in relation to each other. They are not independent, hierarchical, or sequential steps; rather, they are interdependent and interrelated concepts. Additionally, the multiple dimensions of the HIT interventions should be considered across the context of their simultaneous effects. This new model can be applied in real world HIT interventions with consideration to various levels of design, development, implementation, use and evaluation (Sittig and Singh, 2010). Aspects of this theoretical sociotechnical model underpins the structure of the IB. Identifying the range of dimensions that added strength or weakness to the IB was essential.

Additionally, not all elements of design, development, implementation, use, and evaluation were considered due to the feasibility nature of the IB. In this thesis, only the three dimensions of the eight (i, iii, iv) were directly relevant to the IB.

This conceptual model takes into account its users and workflow processes, and how those two interface with technology; the work system context, the policy and organizational factors that affect HIT; and the interactions among them (Sittig and Singh, 2011). Another strength to add is this conceptual model addresses limitations identified in previous models, resulting in eight dimensions that address interdependent and interrelated concepts. On the other hand, this model does not completely fit the feasibility study of the IB, reasons for this will be presented at the end of this chapter.

3.3.3 Information Security Issues

One cannot ignore the important role IT plays and the challenges that it brings. The Five Year Forward View describes how the new NHS will be organised around new care models. Achieving this will be accomplished by the aid of digital technology and new innovations (Thomson, 2016). Going digital in all NHS organisations is not an easy task. This overarching aim needs collaboration between all stakeholders and a framework for action where the NHS acts as a single organisation. To satisfy this target, the Department of Health has established a new body called The National Information Board (NIB). The NIB brings different stakeholders together in order to develop the strategic priorities for data and technology.

They have published a report to guide stakeholders that envisages that a collaborative approach must be adopted between stakeholders to facilitate a cooperative approach to information and IT (National Information Board (NIB), 2014). Service needs must be identified by end-users not only by technology. Going digital is underpinned by Information Systems (IS), data, and innovation technology. All organisations, especially health, need to do their best to protect their client's data by applying the most effective information security systems and protocols.

Of course, all these initiatives that need to be delivered are mainly based on patients and their data. Storing information about patients in secure systems requires that the NHS trusts ensure confidentiality and safety for the information that they hold, making sure that only authorised personnel can view the data. Collecting, storing, using, sharing and dealing with sensitive information about patients, and at the same time keeping it safe and available to authorised personnel carries its own challenges.

NEAS, applied NHS requirements and legal obligations regarding the data protection policy like other trusts and foundations in England as they are committed to protecting the rights and privacy of any individual employed, or patients in accordance with the Data Protection Act. Those legal obligations cover all sites and systems operated and utilized by NEAS (North East Ambulance Service NHS Foundation Trust (NEAS), 2014*a*).

The Care Quality Commission (CQC), is the independent regulator of health and adult social care in England. They monitor, inspect, rate services, and take actions to protect service users. The CQC has published a report on how data is securely and safely managed in NHS organisations, and NEAS being one of them. They have found that:

- Even though data security policies and procedures were in place, staff at all levels were challenged in their commitment to these practices.
- The quality of data security training was varied at all levels.
- It was not always evident that security policies were practised on a day-to-day basis.
- There was little inter-organisational benchmarking to enable users to benefit and learn from each other.
- End-users' needs must be met when designing data security systems and protocols. This will ensure that end-users do not develop potentially insecure workaround practices to deliver timely good care.

- Improvements must be continuous regarding the use of technology for recording and storing patient information, otherwise this will increase the risk of data losses on a large scale.
- Improvements regarding integrated patient care must be made to facilitate safety and ease of inter-information sharing (The Care Quality Commission, 2016).

3.4 The London Ambulance Service as a Case Study

Having identified challenging issues in HIT, a similar IT system implemented by the London Ambulance Service (LAS) will be presented as a case study for some lessons.

The LAS Computer Aided Despatch (CAD) project, implemented in 1992, was a failure due to many reasons (Adamu et al., 2010). The LAS CAD was moved from a manual process to total automation of tasks in one phase. Among these tasks were call taking, resource mobilization, resource identification, and ambulance resource management. The LAS CAD suffered from an over-ambitious timetable to complete the project with financial constraints. Furthermore, delays and corruption in the technical communication and transmission of the system, affected the quality and reliability of the system. Analysis revealed various issues including:

- Incomplete status reporting due to inadequate training and communication failures.
- Poor instillation of equipment leading to inaccurate locations.
- Transmission black-spots and software errors.
- Incomplete and insufficiently tested software.
- System inability to cope with specific established working practices.

- Overload of communication channels (e.g failure of some messages to be received).
- Poor interface for the crews to use which lacked robustness.
- Poor project management.
- Slow system operation.
- Ambulance crews' frustration and negativity towards the system (resistance).
- Vehicles being dispatched inappropriately (Finkelstein and Dowell, 1996; Breitman et al., 1999; Finkelstein, 1993).

All this reflects how the technical infrastructure was built and how front-line staff reacted with such a system. The human element and resources are as important as the technical infrastructure of a system. Likewise, cooperation and joint ownership of the ambulance crews with the LAS management with regards to the system were lacking. In addition, ambulance crews were not involved in the development process; and along with insufficient training about the use of the new system, leading to inaccurate information status reports being sent to the control room, because crews were pressing the wrong buttons. As a result, the ambulance crew and staff at control lost confidence in the system (Finkelstein, 1993; Hougham, 1996; Fitzgerald and Russo, 2005).

Zooming out a little from the micro level and moving towards the macro level, it is important to indicate that IT in the NHS is not an easy task to fully investigate. IT is controlled at different levels: regions, trusts, hospitals, departments, and specialities, each with a different perception towards IT. The NHS is composed of multiple networks of autonomous and semi-autonomous groups and entities all of which focus on health. The absence of a clear IT organization in LAS meant a lack of clear strategic vision for IT, as well as conflict on objectives from different stakeholders towards the system. The size, depth of change, and speed of the project were "too aggressive" for the LAS culture and environment (Beynon-Davies, 1999). Furthermore, the system lacked a systematic development methodology, clear project management, and adequate testing. At the implementation stage, front-line users were faced with new patterns of work which resulted in system resistance. System failures are not only due to technical, or management reasons; socio-complexity has a share in this matter as well (Greenwood et al., 2010).

3.5 Identified Gaps

The prevalence of issues identified in the sociotechnical model developed by Sittig and Singh (2010) is clear in the literature. One might question its applicability in a dynamic end-user environment, for example paramedics and ambulance crews where time and reliable decision-making are critical factors. This model, and other studies around it, are more focused on the Electronic Health Records (EHR), Clinical Decision Support (CDS) or Computerized Physician Order Entry (CPOE) as forms of HIT (Brenner et al., 2015; Sittig and Singh, 2012; Kushniruk et al., 2013; Lanham et al., 2013).

Referring back to the sociotechnical model of Sittig and Singh (2010), it is observed that the interaction and flow of communication processes are within the same organization (the intra-organizational communication), and the only external element in the model is in the form of rules and regulations imposed by official bodies. Adding Inter-organizational communication to the model may aid the information transfer, collaboration and communication with other external health organizations, which is a key element for ambulance services.

Most studies regarding HIT are focused on in-patient, out-patient, single-centre settings, and studies on multi-centre settings are scarce. However, research is rapidly expanding in the ambulatory care setting. Research regarding HIT that focused on paramedics and the ambulance crew (ambulance services front-line staff) is also scant (Brenner et al., 2015; Graber et al., 2016; Buntin et al., 2011). Ambulance crews are autonomous, widely dispersed, mobile, and communicate with the ambulance service staff intermittently.

From what has been presented, it was possible to identify a key gap in the literature, which this thesis is trying to address. The lack of reliable patient information to health providers to support decision-making with the aid of HIT. This thesis is one small step, towards improving the working processes of end-line ambulance crews and the lives of PWE. This chapter demonstrates what has been researched in the literature from the policy, and system level leading to the end-users of the system. That is to say, highlighting the gap at the focal point where the exchange of PWE information actually occurs, and the work conditions of the ambulance crew in the ambulance service who are actually trying to meet their needs.

3.6 Summary

The availability of HIT simple solution that transfers reliable patient information to the ambulance crew on scene to support decision-making and the approach of patient-centric care, would provide more-effective and efficient care for PWE. Having reliable patient information during an incident is crucial, especially in such a dynamic environment as an emergency incident. Ambulance crews need to make patient health decisions under pressure for lack of information and time constraints.

Consideration for issues surrounding the development of HIT solution regarding patient information transfer is important, because they increases chances of functionality, usability, and success. Consideration of these issues was challenging in studies in the literature of suitability and appropriateness. Studies are more focused on settings for in-patient, out-patient, and single-centre settings, which do not match ambulance crews work process characteristics. Ambulance crews perform their work in a unique setting from other health providers. In addition to pressure of time and lack of information, there are barriers to communication, constant mobility, geographically scattered yet in constant contact with various health and non-health organizations. Hence, this chapter reported on challenging issues surrounding the development of an IB prototype system appropriate to the nature of ambulance crews' needs on scene. Theses issues are related to CSCW, sociotechnical aspects, information security issues, and lessons from the LAS case study.

Chapter 4

Research Methodology

This chapter provides a description of the research methodologies used in the study and the rationale for applying each method. It addresses the research questions with different research approaches that are appropriate to each. The first research question addressed the IB development and was a case study. The second applied a qualitative phenomenological approach regarding involved stakeholders (NEAS operational and management staff, JCUH staff and PWE/carers, and finally the ambulance crew), these three elements were to investigate sociotechnical issues surrounding this information transfer system. The combined findings of the three elements of phenomenological approach were triangulated to analyse the first research question of the feasibility of an IB prototype. A User Acceptance Testing (UAT) was conducted for the feasibility of the IB. This was essential, in order to identify any errors, gaps and system malfunction of the IB prior to demonstration.

Discussion and rational of each research question are addressed with presentation of the study participants, data collection tools, data analysis, and ethical consideration.

4.1 Introduction

Any researcher must carefully select an appropriate research tool that can answer their research question(s) when deciding to investigate a problem. This is especially so in a complex domain such as the NHS, that involves individuals, systems, entities, processes, interventions, programs, groups, and phenomena, etc. The case study approach and the phenomenological approach have both been applied in this thesis; this is best to describe the phenomenon under investigation. An illustrative overview of the research methods applied in the thesis is presented in Figure 4.1.

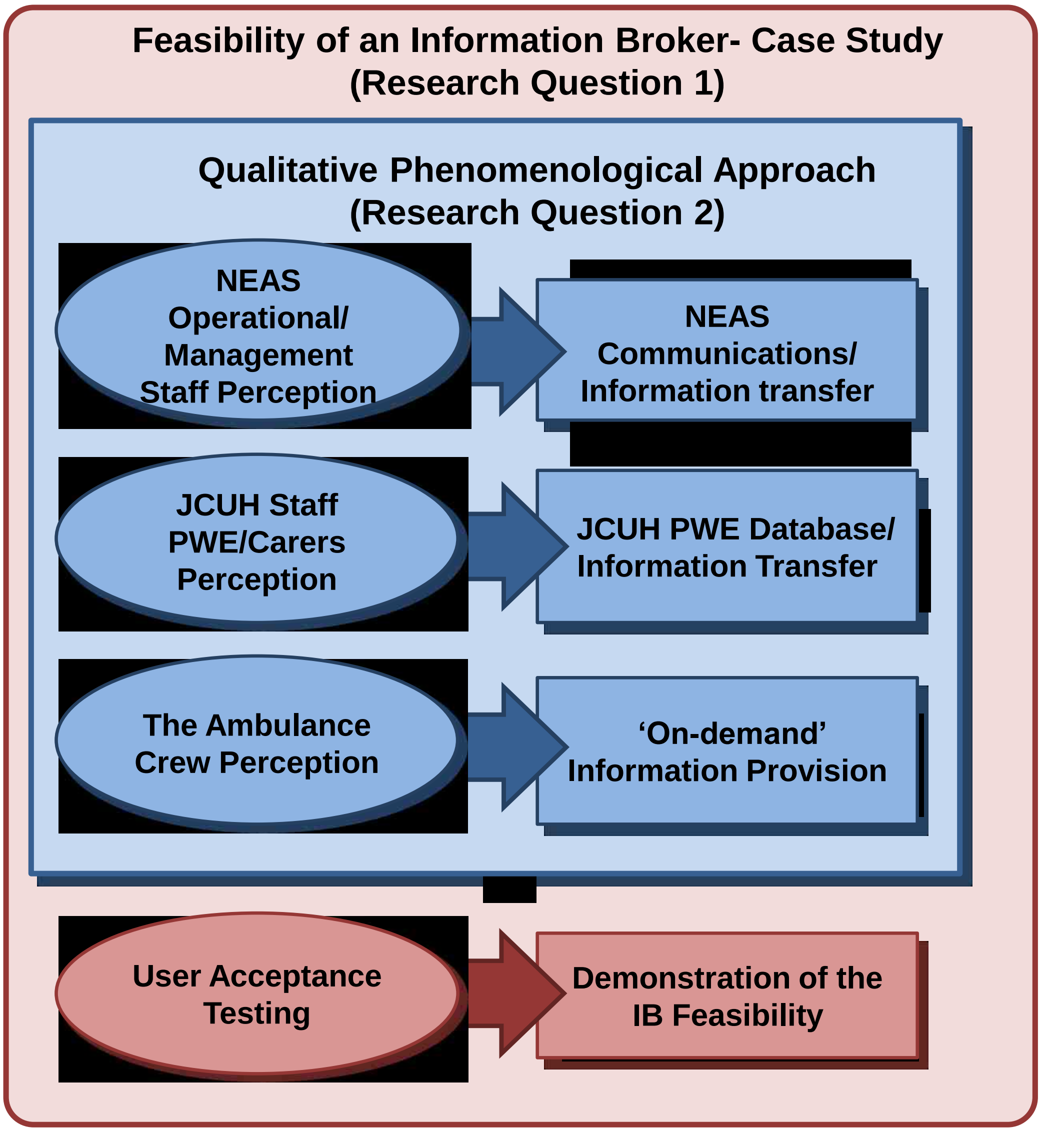


Figure 4.1: Research Methodology Profile

A case study approach was conducted for the first research question regarding the IB development. This study approach is best used for understanding and exploring a "complex social phenomena" (Yin, 2014) within its natural context. Crowe et al. (2011) state that the case study approach allows "in-depth, multi-faceted explorations of complex issues in their real-life settings.".

As Merriam (2001) states, a "case study does not claim any particular methods for data collection or data analysis. *Any* and *all* methods of gathering data,.... can be used". The case study approach provides a valuable tool for health science research to evaluate programs, develop theory and interventions due to its rigour and flexibility for coping with the multiplicity of data sources (Baxter and Jack, 2008). According to Jenkins (1985) this approach is best used to determine the "effects of a prototyping on the information system under development and on the system and user processionals engaged in the process". Therefore, case studies offer understanding and meaning of the phenomena to researchers (Algozzine and Hancock, 2016).

For investigating the sociotechnical issues surrounding the IB, the second research question, a qualitative phenomenological approach was carried out. This approach is well suited for this study as it provides a description (not explanation) of participants' experiences and perceptions regarding a phenomenon, how the phenomenon appears to them and how they experienced (lived) it, therefore formulating themes that represent those experiences (Creswell, 2007; Algozzine and Hancock, 2016). This approach is effective in bringing deep issues to the surface, enabling individuals' voices to be heard, as a result, empowering researchers to support, clarify, inform, or challenge a policy or an action (Lester, 1999; Creswell, 2007).

Murphy et al. (1998) state that for health technology assessments it is useful to apply qualitative methods during the exploratory phase of a project. The strengths of that is it provides descriptive information and better understanding of the context, when compared to quantitative methods in this domain. Not only that, but qualitative research carries more strength when studying the phenomenon holistically in context and the associated social behaviours, paying attention to the process and dynamics of interactions and social events. Kaplan and Maxwell (2005) have observed that qualitative research is widely used in research related to health services where there are many perspectives and organizations.

4.2 Methodology Unfolded

This exploratory study is intended to demonstrate an IB prototype. Specifically, it is a feasibility study of an IB that transfers information, 'on-demand', to the ambulance crew while on scene. Additionally, it investigates the sociotechnical issues surrounding the IB system.

The demonstration of the IB prototype case study acts as the overarching framework of the thesis. In order to analyse the case study overarching framework (the IB prototype), three different perceptions were triangulated by applying a phenomenological approach to each. The three perspectives were perceptions of: NEAS operational and management staff, those of the JCUH staff and PWE/carers, and finally, the perceptions of the ambulance crews. The collection of the three different phenomenological approaches results were able to answer our second research question and, hence the main research question.

4.2.1 Research Paradigm

Developing the IB cannot be isolated from the views and requirements of the end-users if it is to be successful. To achieve this, investigating the sociotechnical issues facilitating the IB utilization was necessary.

The nature of the IB development and understanding the sociotechnical issues surrounding its development is best suited to an interpretive qualitative approach. This approach is suitable when subjective data "of immediate response to a new innovation" is required (Ponelis, 2015). According to Harrison et al. (2017), this approach allows the researcher to view reality as "multiple and subjective, based on meanings and understanding. Knowledge generated from the research process is relative to the time and context of the study and the researcher is interactive and participates in the study."

This approach adds emphasis to human experiences, values and provides a good understanding of surrounding conditions and situations. Additionally, this approach requires the researcher to define meanings of what they see and hear from the observations. The researcher shares with participants in the generation of knowledge, where direct interpretations and thematic grouping of findings are used (Stake, 2010).

4.2.2 Case Study Approach

This approach best suits the purpose as an overarching research framework as it facilitates information gathering from multiple data sources (Yin, 2014; Creswell et al., 2007; Baxter and Jack, 2008). Furthermore, according to Farquhar (2012), a case study is a good tool to study a phenomenon, an intervention in this case, in context. In other words, studying the phenomenon in the situation where it actually occurs. She defines case study research as: "an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident.". A case study is suitable for answering **how** and **why** questions and can be used where manipulation of behavioural events cannot easily be controlled by the researcher. In addition, knowledge and experience are important elements in this approach. According to Oates (2005) a case study enables all the inter-relationships (users, managers, developers, etc.) and factors to be studied. In addition to that, it has the potential to incorporate multiple data collection tools, perspectives and strategies (Marshall and Rossman, 2014).

4.2.3 Phenomenological Approach

Identifying the different elements that could be triangulated for the case study was helpful to investigate the sociotechnical issues surrounding the IB. This was conducted by the phenomenological method through investigating the perceptions of:

1. The operational and the management staff in NEAS, towards communications and information transfer.
2. The staff of JCUH and PWE/carers, towards the use of the JCUH PWE database and information transfer; and ED staff at JCUH towards the information transfer of the ePRF.
3. The ambulance crews of NEAS toward the electronic 'on-demand' health information provision and the information transfer of the ePRF.

Silverman (2006) states that "the main strength of qualitative research is its ability to study phenomena which are simply unavailable elsewhere." He adds that using this method adds strength to the research as it uses "naturally occurring data" to provide a deeper understanding of the phenomena. Kaplan and Maxwell (2005) also add that this method is well suited for use in the field of computer information systems development, implementation and evaluation, as it offers better understanding of the system's development, use, and end-users perspectives and process.

Consequently, this approach seemed most suitable for addressing the research questions. Yin (2014) explains that integration of different methods of research approaches permits researchers to "address more complicated research questions and collect a richer and stronger array of evidence than can be accomplished by any single method alone".

Gathering background information was helpful to assist the technical development of a prototype model for an IB intervention. It involved information transfer processes, communications between and within organizations, reviewing the current information needs, identifying what data is required, and how the access can be established using secure communication channels. The methodology, was organized in terms of three different stakeholders: NEAS operational and management staff, JCUH staff and PWE/carers, and the ambulance crew.

What follows is an outline of the role of stakeholders of the proposed IB architecture from the perspective of the research questions. The phenomenological approach that has been applied offers a description of the direct experiences of subjects.

4.2.3.1 NEAS Operational and Management Staff

This part addresses the creation of the background information for the sociotechnical and organizational gaps in health communication and information transfer that are associated with the ambulance crews working in NEAS while on scene during an incident.

To understand how the process of passing information to the ambulance crew while on scene with a patient, interviews with the crew and the staff in the control centre (operational staff) were employed to formulate background information of the system, interactions, people, patients etc. This was supported by multiple observations made in the control centre of the working process of communication and information transfer occurrence with the ambulance crew and other organizations. These examined what procedures were applied to pass information to the crew on scene, how a job was managed, how the crew communicated with the control centre staff etc.

Group meetings with management staff were also beneficial to help understand NEAS requirements and how the broader view of actions were managed and functioned. These addressed how systems were collaborating and how data was stored, accessed, maintained etc.

The aggregation of these sources, consequently, formed useful background information in regards of how NEAS management and operational staff were functioning generally, and in regards to communication and transferring information to the ambulance crew while on scene, or with other organizations.

4.2.3.2 JCUH Staff and PWE/Carers

The initial plan was to gain access to representative samples of the electronic data for PWE who are patients of the Neurophysiology Department, in collaboration with a consultant neurophysiologist at JCUH. Using such information was critical to test the feasibility of the IB. Doing so, however, was not possible as it emerged that the department lacked an electronic database for their patients records and employed a paper-based filing system. As a result, with guidance from JCUH staff, a prototype database for PWE was built, with a front-end interface that enabled end-users to store, manipulate and retrieve electronic patient information from the database. Therefore, the initial plan, which was to gain access of already available electronic patient information was abandoned, and was replaced by the use of a representative database that was built from scratch to facilitate the study.

Staff of JCUH provided useful information regarding building the PWE database, such as what electronic information transfer and communication mechanisms were available within the hospital, database hosting, and patient information transfer and communication with other healthcare organizations. PWE/carers perceptions were helpful in shaping the background picture in regards of what information they would like to share, who can access them, what needs they require from the ambulance service, the IB, the PWE database

Even though the PWE database is controlled and technically owned by the Neurophysiology Department in the hospital, the information in it is owned by the individual PWE not the department or the organization. For the IB to access information from the database, the individual PWE/carers need to give direct consent and permission to share their information with NEAS through the IB to enable the crew to view their data. This presents legal, security, and ownership issues of who owns and access the information etc. which will not be discussed. However, their views on what they would like to have shared were considered.

Furthermore, the interviews of ED staff in JCUH were critical in order to form background information of communication and information transfer occurrence through the ePRF with the ambulance crew form NEAS.

4.2.3.3 The Ambulance Crew

Gaining background information from the ambulance crews experiences was constructive in order to build the IB. The aim of it was to assess the feasibility of providing electronic 'on-demand' patient health information, for the ambulance crew to use while on scene after providing appropriate treatment. This is to assist them in their decision on conveyance of the PWE to ED, home or immediately release.

Furthermore, observing the ambulance crew and ED staff in JCUH added insight into issues the ambulance crew face in regards to communication, information transfer (ePRF) and needs with the ED staff, with the NEAS system, and with patients/carers information.

4.2.4 User Acceptance Testing

The aim from the aggregation of the various approach of research, noted above, was the IB development. Demonstrating the prototype IB software and interface was a necessary step in order to apply any required modifications or changes to it. The development of the IB as a case study provided a valuable tool to demonstrate its feasibility.

Testing software is an essential and integral part of the system development stage; as it carries a number of benefits. It is a very critical stage for finding defects, their root causes and their effects (as early as possible) allowing them to be fixed prior to system deployment. The identification of those deficiencies will then allow to make improvements on the software. As a result quality, decrease in cost, and efficiency of the software product will be improved. Leading to confidence on both the user and the developer sides (Graham et al., 2008; Iacob and Constantinescu, 2008; Jangra et al., 2011; Davis and Venkatesh, 2004).

In software engineering there are different software testing strategies, and the User Acceptance Testing (UAT) is one. UAT is a type of testing that was carried out to verify and validate if the development of the product complies with end-users requirements and needs. This lead to develop confidence of the software product by end-users (Pandit and Tahiliani, 2015; Wallace, 1986). UAT is considered one of the most important testing strategies before the software is finally delivered (Sawant et al., 2012). A one hour meeting with a paramedic from NEAS was set to test the IB interface and interact with it freely. A set of test steps were conducted when testing the IB interface. Each step conducted by the participant was to verify if the end-user requirements were met and performed as desired. The IB feasibility demonstration took place only after all the functional specifications of the IB architecture were in place. Any feedback from the paramedic on the system performance, the interface, requirements, the information displayed etc. was considered for improvements (Sawant et al., 2012).

4.3 Data Collection Tools

Different techniques were employed for collecting the data, these are presented in the same order as the previous groupings of the the stakeholders for simplicity and clearance (NEAS operational and management staff, JCUH staff and PWE/carers, and the ambulance crew). A general presentation of the data collection tools applied in this thesis will be presented first to give a holistic view of tools applied. This is then followed by detailed presentation of the data collection tools for each group individually.

(i) ***Documentation:*** When the forms of data collected through direct means is likely to be insufficient to answer a required question, one may use other kinds of data collecting tools to provide a better understanding of the phenomenon. This can include the use of government papers, formal letters, publicity materials, published research papers, magazines, technical reports, newsletters, etc. (Ritchie et al., 2013*a*; Kaplan and Maxwell, 2005).

Documents were provided by NEAS and Epilepsy Action; while others were extracted from journals. Some documents were management documents describing time frames of implementation, others stated the purpose of the system, and program manuals or software guides. Material also included emails with participants, minutes of meetings, written reports, announcements, administrative documents (progress reports, internal documents) and formal studies. Part of this information was used to understand the background and others were used to prompt reflections about what the respondents were saying.

By and large, this material contributed to forming a better understanding of the relevant processes of communication and information transfer through the ePRF, as well as the context of NEAS and PWE in which the IB prototype is intended to be used as well as to corroborate evidence from other sources (Yin, 2014).

(ii) ***Interviews:*** Interviews as used in qualitative research, offer a “deeper” picture than can be achieved through the use of quantitative studies. This tool of data collection provides in-depth information related to the participants’ viewpoints and their experiences of a specific topic/phenomenon (Silverman, 2006; Turner III, 2010). Prior to the face-to-face interviews, validity checks for the various participants interviews questions were conducted; e.g. see Appendix A in order to refine the questions. These were followed by a pilot semi-structured interview with a representative participant, prior to confirming the final versions of the semi-structured questions. The pilot aimed to identify ambiguities, assess the suitability of questions, time and repetition, as well as identify any irrelevant, repeated or unclear statements/questions; helping with early detection of necessary omissions or additions (Noor, 2008).

Semi-structured questions were carefully designed to provide adequate coverage for the purpose of the research questions. General statements of major questions were developed which was then followed by a sequence of sub-questions for further investigation and assurance; e.g. see Appendices B, C.

Participants who showed interest were asked to select the best time, date and location that suited them. Once this had been defined, an interview was conducted. Prior to the interview, explanation about the research and a walk-through of the project was delivered to participants verbally, explaining the purpose and the aim of the research. Each participant in each group was provided a copy of an information sheet and a copy of walk-through storyboard that was appropriate to the participant (staff, lay people), whether they were paramedics, PWE/carers, NEAS staff, or JCUH staff. The information sheet summarized the research and included contact information of the research group in lay English. An example of a paramedic information sheet and a patients' walk-through can be viewed in Appendices D, E.

All interviews were recorded after obtaining the interviewee's consent. This was to ensure that all information was captured to avoid losing data and to secure accurate records of conversations, since not everything can be written down during an interview. Each interview was indexed by being dated and given an ID number based upon the participant's ID number for later analysis.

Before initiating the interview participants signed a consent form, and retained a copy. Participants were assured of confidentiality, anonymity, ethical approvals and clearance. They were also been made aware that the session would be recorded, and that they had the right to stop/delete the recordings or even withdraw from the interview/research any time they desired without providing any reasons of withdrawal. Some interviews were approximately one hour long e.g. NEAS management staff. Whereas others were interviewed for an approximately 30 minutes e.g. PWE/carers. The location of the face-to-face interview was determined by the preference of the interviewee. Participants were identified by a specific code and were anonymised.

At the end participants were asked if they had any questions, comments, or/and suggestions they would like to add. They were also told that if they had any questions or concerns in the future they could contact any member of the team, and that their contact details were stated in the information sheet.

(iii) ***Observation:*** Observation is another instrument used for data collection in qualitative research. Participant observation allows a phenomenon to be investigated and studied in its natural context (Yin, 2014; Ritchie et al., 2013*b*). It enables the researcher to collect naturally occurring data with respondents having an awareness and knowledge of the researcher's presence (Seaman, 1999). The researcher can engage with the participants by asking questions for clarification and become involved with them in discussions regarding the relevant process (Kaplan and Maxwell, 2005). Observation was, therefore an excellent method to observe how the system is being used by participants in the process of information transfer. In addition, this method is fundamental to " understanding another culture" (Silverman, 2006). Observing their actions in real life situations rather than only hearing what they say, helps capture end-users reactions, usability and implementation of the system (Merriam, 2002).

All observations included note-taking of how participants worked/performed actions and tasks. Approval from NEAS, JCUH and the Directorate Manager of Accident and Emergency, Trauma, Anaesthetics and Theatres Centre was obtained prior to observing the ambulance crew in the ED of JCUH.

The ED receiving bay, was the main location where participant observation took place, the ambulance crews performed their (main) tasks there. Tasks include patient's incident information transfer from the ambulance crew to the ED staff supported by the ambulance crews' actions and processes to complete the success of this handover.

In addition, this location also facilitated the viewing and observing of actions performed with the docking station and the pre-alerting screen (both installed by NEAS). This also included viewing the nursing station where paramedics sometimes would stay to complete finalization of the ePRF. Participants were aware of the researcher's presence, and some (who were not involved/finished with patient care) would approach and ask about the reason for the observation. A quick informal conversation would initiate and some questions from both participants and/or researcher would be answered.

Observation included how participants worked/performed actions and tasks with the aid of software and hardware devices (Toughbook, ePRF, Docking Station), how handover was processed, how responsibility was passed to ED staff, how information was transferred, how long the whole process took, how long finalization of the ePRF took, duration of patient handover, use of PRF/ePRF, and duration of verbal information handover.

Observation of the working process was not limited to the ambulance crew, but also conducted in NEAS headquarters, in both the call centre and the dispatch centre. This included observing participants working processes, management of ambulance vehicles, communicating with the ambulance crews, and dispatching. Asking participants questions was only possible when there was no interruption of their work.

Furthermore, observation of meetings was conducted on an ongoing basis with top management. Participants of meetings included the Information Management & Technology manager (IM&T), Informatics manager, and Research & Development (R&D) manager and staff of which are all based in NEAS headquarters, as well as the JCUH ICT System manager and staff, and the Director of Information. This added a deeper insight of the phenomenon (Yin, 2014).

(iv) ***Focus Groups:*** Focus groups provided another technique for collecting data. They are group discussions and interaction of participants to discuss a topic presented by the facilitator. This technique is used to identify weaknesses and strengths of a program or interpret assessment projects results (Morgan, 1998). This technique is also recommended to generate ideas when action and investigation is required in a new field. Furthermore, using this technique is useful with studies on a wide scale to generate additional information in addition to understanding participants' experiences in a rich context (Freitas et al., 1998; Gill et al., 2008). Focus groups with PWE/carers were held in different locations on different dates and sites.

Semi-structured questions were asked in group meetings. The questions that were asked in group meetings were the same as the questions that were asked in the one-to-one interviews with PWE/carers, see Appendix C.

A storyboard walk-through was delivered to the audience explaining the research in summary, see Appendix E. Appendix G illustrates the information sheets that were also handed to them for additional explanation and research group contact information. Similar to interviews, focus group discussions were recorded and participants were notified of their right to withdraw from the group any time giving no justification. This was also applicable to recording the session or asking to delete it.

(v) ***Questionnaire:*** A questionnaire can be used to collect large amounts of data in a short period of time. It collects participants' present and past behaviour, attitudes, believes and reasons for action towards the investigated research question(s) (Bulmer, 2004; Bird, 2009). An online questionnaire was posted on the Epilepsy Action website (17 July, 2015- 12 Feb, 2016) in order to gather PWE/carers point of views and opinions, see Appendix H. Unfortunately, this method was unsuccessful, as no participation was received.

It is important to emphasize that prior to conducting any data collection tool (interview, group meeting, etc.) that involved a human subject, the research was verbally presented by the researcher with a research protocol to follow, which highlighted their right to withdraw, delete or approve their participation without giving any reason, see Appendix I. A detailed presentation of the data collection tools for each group individually are as following:

4.3.1 NEAS Operational and Management Staff

Interviews, observations, and group meetings were held with staff working under the umbrella of NEAS on different dates and locations. Table 4.1 provides information regarding NEAS participants as some participants participated in multiple forms of data gathering, for instance the one R&D staff.

Participant	**No. Participants**	**Data Collection Method**	**Location**	**Approx Duration**
Control Centre Duty manager	4	Interviews	NEAS HQ	Total of 4 hours
Call Handler	1	Interview then observation	NEAS HQ	1 hour (30 min each)
Dispatchers (Communication Officer)	3	Interviews and observation	NEAS HQ	Observe 8 hours (30 min interview each)
Communication Support Officer	1	Interview	NEAS HQ	1 hour
IM&T manager	1	Group meeting	NEAS HQ	1.5 hour
IM&T staff	1	Group meeting	NEAS HQ	1.5 hour
Informatics manager	1	Group meeting	NEAS HQ	1 hour
Informatics staff	1	Group meeting	NEAS HQ	1 hour
Transformation Program Officer-project manager	1	Interview	NEAS HQ	1 hour
R&D manager	1	Group meetings	NEAS HQ, Durham University	Total of 4 hours
R&D staff	1	Group meetings and interviews	NEAS HQ, Durham University, Newcastle University	Total of 7 hours

Table 4.1: NEAS Participants

Staff of the call and dispatch centre, top management, the research division, and operations support managers were interviewed, observed and/or were part of group meetings. This took place during a period (March 2013- March 2018). Some interviews were approximately one hour long, some were only 30 minutes. Semi structured face-to-face interviews were conducted. Interviews were held in NEAS Headquarters (HQ) and only one interviewee was interviewed in Newcastle University based on their preference. Participants that were interviewed were:

- 4 control centre duty managers (1 hour each) two on 14/11/2014 and two on 17/11/2014.
- a call handler (30 min) on 13/11/2014.
- 3 dispatchers (30 min each) on 13/11/2014, a communication support officer (1 hour) on 13/11/2014.
- Transformation Program Officer- project manager (1 hour) on 29/10/2015.
- One R&D staff (3 divided hours) on 30/10/2017, 21/8/2017 and 23/2/2018.

Interviews involved gathering information from NEAS's senior and operational staff. The research and its development were also discussed. Requirements, ideas, and opinions about the role of a feasibility study of the IB were gathered in addition to the importance of data, data transfer and sharing (communications). Gathering of background information not only assisted the clarification of communications that were accruing on the inter- and intra-organizational level, but also assisted in the technical development of the IB.

Group meeting discussions with NEAS senior staff ranged between an hour or an hour and a half, they have been held in various locations: NEAS HQ and/or Durham University. Senior staff were from a different division in NEAS. Information regarding the group meetings are:

- Four separate one hour long group meetings with two participants, the manager and a member of staff, from the Research & Development (R&D) on 11/3/2013,17/2/2014, 2/5/2014 and 12/12/2014.

- A one group meeting of an hour and a half long with two participants, the manager and a member of staff, from the Information Management & Technology (IM&T) on 4/12/2014.
- One group meeting of an hour long with two participants, the manager and a member of staff, from the Informatics division on 4/6/2015.

Those group meetings were conducted to elicit what systems were available, the mechanism used for storing ePRF data of patients, which users were heavy users of the ambulance service, patient information, information transfer/sharing with other health organizations, collaboration with other organizations, operational staff working processes with each other, the system and the public, interaction of staff with the system, system technicalities, etc.

Observations were conducted in the control centre. This was helpful in forming a holistic view of the working process, the information transfer, the communication that is occurring with the ambulance crew while on scene, and to see how participants interacted with the systems, crews and information flow and management. Observations took place in NEAS HQ on three different days were:

- Day one on 13/11/2014 in the call centre observing the call handler for 30 minutes.
- Day two on 14/11/2014 in the dispatch centre observing the dispatchers (communication officers) for 4 hours.
- Day three on 17/11/2014 in the dispatch centre observing the dispatchers (communication officers) for 4 hours.

4.3.2 JCUH Staff and PWE/Carers

Face-to-face interviews, group meetings and focus groups were the main data collection tools applied. Table 4.2 represents information regarding this matter. A series of group meetings and one-to-one meetings with a consultant neurophysiologist

Participant	**Data Collection Tool**	**No. Participants**	**Approx Duration**	**Location**
The Consultant Neurophysiologist	• Group meetings • Ongoing meetings	1	1 hour	Neurophysiology Department in JCUH
Administration Staff	Group meetings	2	1 hour	Diabetes Care Centre in JCUH
ICT/System Development Department	Group meeting	2	1 hour	JCUH
Director of Information	Group meeting	1	1 hour	JCUH
Epilepsy Specialist Nurse	Interview	1	1 hour	Neurophysiology Department in JCUH
PWE/Carers (Epilepsy Action)	Focus groups	81	1 hour	• Durham City • Middlesbrough • York
PWE/Carers (JCUH)	Interviews	3	30 min approx	Neurophysiology Department in JCUH
ED staff	Interviews	3	30 min approx	ED in JCUH

Table 4.2: Information Regarding Participants

was conducted to elicit the needs of consultants from an electronic database, what they require to be stored in the database, how to navigate this, how to subgroup information, etc. that are necessary and essential for managing patient information. The focus was on information that is considered critical and vital for the consultant to record and store in the database and what needs to be retrieved. What specific data that needed to be included and which ones need to be displayed under specific groupings and sub-tabs in order to make navigation and retrieval easy and fast. The group meetings were held in the office of the consultant neurophysiologist in the Neurophysiology Department in JCUH and were no more than one hour long. Those group meetings were as needed over the course of the project in a period of time from June 2013- Jan 2017.

As the Neurophysiology Department had no electronic forms for storing patients information, it was essential to request assistance from another department in the hospital, which had more experience with dealing with an electronic database in the hospital, and the Diabetes Care Centre did have such experience. The reason for this was that the Diabetes Care Centre was also previously working on a paper based filing system, and their electronic database was created by the individual effort of a physician. Consulting them was initiated, supported and guided by the consultant neurophysiologist. This paved the way to ongoing consultations with the administration staff who were responsible in managing the electronic database for people who have diabetes. Multiple group meetings with two staff from the Diabetes Care Centre administration were held in the hospital in the Diabetes Care Centre. Those group meetings were essential to understand who hosted the database, how the database was created, how the database was constructed, and the management of patient information. It was also necessary to know what systems were available in the hospital, how they stored data, manipulated it, altered it, managed it, etc. The ongoing meetings were spread over a period between 2014- 2017 and no meeting exceeded an hour in length.

A one hour group meeting with the JCUH Director of Information on 18/10/2013 and later on with the ICT/System Development Department on 15/12/2015 were essential prior to building the PWE database and the front-end interface. Likewise, gathering their feedback of the model in order to be consistent with the operational system at JCUH. Discussions included how to host the PWE database and technical, operational, and organizational opportunities. Additionally, explaining the IB system and the role of the database for PWE that is to be built in the Neurophysiology Department. Unfortunately, after a change in South Tees Hospitals NHS Foundation Trust's staff and priorities, the researcher was later informed that JCUH could not host the database.

Meetings, with an epilepsy specialist nurse, were also arranged in order to gather her requirements for the database and the front-end interface, as the information needed by a nurse in order to deliver healthcare for PWE is different from that needed by a physician. What seems critical for a physician may not be as critical to a specialist nurse; so their requirements from the database differ according to their roles. For example, the epilepsy specialist nurse will be more focused on the patient's care plan. The nurse will give instructions to the PWE on safety, indoor and outdoor life skills, and special training if the patient needs it. Information about other people to contact in the case of an emergency, setting appointments, and updating their contact is also needed. These information requirements and usage are different from those of a consultant neurophysiologist. An hour long face-to-face interview with a walk-though of the end-user interface was delivered to the participant in the Neurophysiology Department on 13/2/2017.

Three expert patients, who are heavy users of the JCUH Neurophysiology Department and the ambulance service, were face-to-face interviewed separately in the Neurophysiology Department for 30 minutes. Two expert PWE/carers were interviewed on 28/10/2014 and the other PWE/carer on 20/9/2013. The selection of the participants were made by the consultant neurophysiologist from the patient list in JCUH Neurophysiology Department. Their perspectives provided the focused in-depth knowledge of the concerns of PWE/carers who are heavy users of the ambulance service and frequently transported to ED. They have also shared their views regarding their data and how it is transferred with other health organizations, they also discussed issues regarding the IB and the PWE database.

A number of PWE and/or carers participated in focus groups with the aid of Epilepsy Action, UK. All focus groups were organised by the North England Manager of the Epilepsy Action through which invitations were sent to all participants. The first focus group was held at Middlesbrough on 20/4/2015. Six participants were there, excluding the organiser and the main researcher. The second focus group was held in Durham city on 13/5/2015. Five people attended this focus group, excluding the main researcher. On 13/6/2015, another focus group, organised by the Epilepsy Action in York, was introduced to the researcher to get participants reflections, insight and opinions towards the IB system. A storyboard walk-through was delivered to the audience, which consisted of approximately 70 participants, leading to valuable feedback and opinions. This helped to identify what participants wanted from the IB system, what outcomes they needed from the ambulance service, what they wanted from ambulance trusts, the crew, and whether they be happy to share their information with ambulance trusts, what concerns they have towards data transfer issues, etc., what they would like their physician, epilepsy specialist nurse, the hospital, etc. to know about their health.

Participants in focus groups were all PWE/carers but with less severe needs for the ambulance services. Their perspectives provided a more holistic view of what PWE/carers concerns were, what help was available for them, what information can be shared with the crew if an ambulance was dispatched, and if there is a need to be conveyed to ED even when not necessary. This group gave a better understanding of the wider population of PWE and how needs might vary across degrees of severity and different perspectives of people who have not yet had, or only had little involvement with the ambulance service, and if they had the same kind of views of those who use the service heavily.

ED staff were also interviewed. The interview was approximately 30 minutes long. One interview was held on 14/5/2015 and the two others were on 19/5/2015, which all took place in the ED at JCUH. Due to the busy nature of the ED and the time pressure staff are under, there were only three interviewees, and the duration of the interview did not exceed 30 minutes. The participants were asked about what they thought of the existing information transfer system (ePRF) that was provided to them by NEAS, their views about information transfer and patient data, and about the IB and its role.

4.3.3 The Ambulance Crews

Participants were all ambulance crew working for NEAS. Experience ranged from five to 20 years. All made use of the ePRF and the electronic systems of MDT, CAD and SatNav. An hour-long face-to-face interviews with members of crews were held in Durham University on various dates, and times. The participant was given the choice to select the time and date suitable to their convenience. Interviews were conducted between (24-9-2014 and 30-10-2014). Table 4.3 provides information regarding the ambulance crews and methods of data collection.

Participant	**Data Collection Tool**	**No. Participants**	**Location**	**Approx Duration**
Paramedics	face-to-face Interviews	7	Durham University	One hour/participant
Ambulance Crew	Observation during handover to ED staff	74	JCUH ED	4 days consisting of 2 morning/night shifts and a busy weekend

Table 4.3: Ambulance Crew Participants

Observations of ambulance crews were also performed while they were performing handovers to ED staff in JCUH. In total, 37 handovers were observed on two different night shifts and two different morning shifts, making sure that these included a busy shift and a weekend. Handovers by crews who were not working for NEAS were excluded. Each shift was four hours long, observation took place in the receiving bay at the ED, sitting adjacent to the docking station and the monitoring pre-alerting screen installed by NEAS. The entire handover process and how crews used the PRF/ePRF, the Toughbook and information transfer to ED staff were observed. Sometimes questions were addressed to the crew when a handover had been completed, and after the point it was possible to be sure that no interruption of the process would be caused. Shifts observed were on:

- Tuesday 26/1/2016 from 10am- 2pm.
- Wednesday 27/1/2016 from 7pm- 11pm.
- Thursday 28/1/2016 from 10am- 2pm.
- Saturday 30/1/2016 from 7:30pm- 12am.

4.4 Participants

Participants were staff working in NEAS, JCUH, and PWE/carers. Front-line and operational staff participants working within NEAS contributed to the development of the project, and helped form a holistic view of the communication accruing on the inter-and intra-organizational level. Those participants are relevant to the IB project and the information transfer system of the ePRF. In addition to that, professionals working in NEAS HQ were also approached to contribute in the formation of background information about the current system and work processes.

Similarly, participants included those who were carers and people with pre-existing diagnosis of epilepsy. It was important to extract their requirements, opinions, and views about the current system and available and future services. Staff from different divisions and working in JCUH were also included for their opinions, requirements and feedback which assisted tremendously in the final outcome of the IB. More details of each group is provided in the following sections:

4.4.1 Participants from NEAS

As this thesis mainly focuses on how to provide information to crews, it was necessary to consider their needs apart from other staff in NEAS. Therefore, the two groups working in NEAS are:

(i) **The Ambulance Crews:** Participants included were staff working as either paramedics, advanced technicians or emergency care support workers; who are part of an ambulance crew. Others working in the patient transport service, rapid response and volunteers were excluded. An invitation email was delivered by a NEAS staff member from the R&D division to people identified within the trust as suitable participants. The invitation email included an information sheet and a leaflet about the project encouraging them to participate, they were also provided with the researcher's email for whomever desire to participate. Participants who wanted to be interviewed sent an email directly to the researcher, of which date, time and location of the interview was agreed upon the interviewees desire, see Appendix J.

(ii) **Non-Ambulance Crew:** Participants included the control centre duty manager, call handlers, dispatchers (communication officer), communication support officer, Information Management & Technology (IM&T) manager and a member of staff, Informatics manager and a member of staff, Transformation Program Officer- project manager, Research & Development manager, and Research & Development staff. Participants were selected based on their job roles to help understand the working procedures and communication occurrence internally and externally in NEAS. Participants who did not have a direct role were excluded from the research. A member of staff from the Research & Development division initiated requests with the selected participants to take part in the research. Consent forms for this group were not required, as participants were aware of the researcher's role and the purpose of presence, therefore, participants gave verbal consent to collect data in group meetings, interviews and observations. Participants within NEAS HQ thought it was not required for them to sign individual consent forms. However, verbal permission was sought prior to recording any observation, group meeting or interviews.

4.4.2 Participants from JCUH

This describes participants who are from JCUH either as staff or PWE/carers.

(i) **Physician:** A consultant neurophysiologist working in the Neurophysiology Department. An email invitation had been sent to be part of the research. Only one consultant who provided care to PWE was included. A lead consultant neurophysiologist was involved because he was enthusiastic and had ideas about how to improve the functioning of the department. Because NEAS identified PWE as heavy users of the service, consultants from other specialities were excluded, as their patients are not identified by NEAS as frequent callers/users to the ambulance service.

(ii) **ED Staff:** Participants working in the ED in JCUH were first approached by the help of the directorate manager of Accident and Emergency in the South Tees Hospitals NHS Foundation Trust who initiated the first contact with the ED senior nurse. ED staff participants, therefore, were recruited by the ED senior nurse. Other departments in JCUH that provided emergency care to patients brought by NEAS were excluded, for instance the paediatric ED and the resuscitation unit. Those were excluded because both do not match our criteria. First, PWE must be over the age of 18. Second, PWE who are brought to the hospital are not taken to the resuscitation unit unless they are co-morbid.

(iii) **Administration Staff:** Administration staff managing the electronic database for people with diabetes and who worked in the Diabetes Care Centre were included in the project. The consultant from the Neurophysiology Department invited them to take part in the research. On the other hand, administration staff from the Neurophysiology Department were excluded as they do not manage any electronic information about PWE.

(iv) **ICT/System Development Staff:** ICT and System Development Department staff and manager were included in the research. Their participation in the research was encouraged again by the consultant neurophysiologist. Other departments from the hospital who do not have direct contact regarding systems and databases management and development were not included.

(v) **Epilepsy Specialist Nurse:** A an epilepsy specialist nurse who has direct contact with adult PWE/carers and involved in the management of their care plans, was also recruited and encouraged by the consultant neurophysiologist to take part. Paediatric epilepsy specialist nurses and personnel with no direct contact with PWE or/and their care plan in the department, were not included in the research.

(vi) **PWE/Carers:** A number of PWE and/or carers participated in the research.

> PWE are people with a pre-existing diagnosis of epilepsy and/or currently patients of JCUH or were part of the Epilepsy Action who were 18 and over in age. PWE/carers who took part in the research from the hospital were considered to be expert patients/carers, selected by the consultant neurophysiologist from his patient list according to the criteria in the department. They agreed to take part in the defined time frame, and could provide a defined picture about their own experience and/or the experience of the others they take care of. PWE/carers from the Epilepsy Action who took part were recruited by North of England Division manager of the Epilepsy Action, as they present the general view of PWE.

As noted above, it is important to indicate that the selection of participants was conducted by those who had direct contact with them. This might therefore, not be a comprehensive representative of the PWE/carers, the ambulance crew, the operational staff in NEAS, but it was the best available way for recruiting them. The selection of participants were made by NHS staff representatives (e.g. consultant neurophysiologist), this eliminated NHS breach, none ethical considerations and direct recruitment by the researcher, as only those who attained this ethical clearance conducted recruitment of participants.

Participants who were involved in interviews signed a consent form, of which a copy was given to them. This included paramedics and ED staff only. All other participants were asked for their permission prior to recording of the information and they all verbally gave consent. The reason for this was because recruiting participants was not performed directly by the main researcher, rather they were recruited by an official representative of NHS and the Epilepsy Action.

4.5 Data Analysis

In this study, a qualitative methods design was applied whereby data was thematically analysed. Immersion and familiarizing of the data was done by listening to the recordings of the interviews, meetings and focus groups more than once, which led to identification of patterns and meanings. This was followed by transcribing all recorded materials and observations. The data was represented in a readable format via a word processor. Each individual transcription was then read more than once, providing a deeper insight, understanding of the data and an initial list of codes. Organizing the data in those meaningful groups formed the process of coding them. Codes were then aggregated into themes. Refinement of themes was necessary, as some were part of other themes and some needed to be broken down to smaller ones. Highlighting similar themes with the same colour in the text was also found helpful for identifying repetition within and between participants. This was all done manually on the left-hand margin of every transcription, see Appendices K and L for examples. Computer based analysis tools, such as NVivo, were avoided in order to interact closely with, and be more immersed in, the text and context. This assisted in the understanding and visually observing the data. This process of encoding the qualitative information (thematic coding and analysis) allowed themes to be clearly identified (Boyatzis, 1998; Aronson, 1995).

4.6 Validity

Validity, according to Bannigan and Watson (2009) is "the degree to which a scale measures what it is intended to measure". To test the "trustworthiness" of the findings researchers conducting qualitative methods incorporate some methodological strategies to ensure validity. Data **triangulation** is one strategy that can be applied (Creswell and Miller, 2000; Noble and Smith, 2015; Golafshani, 2003) to achieve this trustworthiness. Triangulation was used to perform validity checking in this research. In other words, using different methods to collect data in order to corroborate findings from different sources (Creswell and Poth, 2017; Healy and Perry, 2000). Interviews, observations, and documentations, as previously mentioned, were facilitated to reach triangulation in order to achieved validity. Creswell and Poth (2017) also suggest the use of member checking, which is the checking of participants' views of the credibility of the findings and interpretations. A paramedic, working in the Research & Development division in NEAS, regularly checked credibility, processes and interpretations of findings. He also revised, provided feedback, information, etc. on the project as a whole.

4.7 Ethical Considerations

In ordered to authorize the research and the researcher, ethical approvals and certificates were obtained from the following bodies:

- A Standard Criminal Records Certificate clearance was issued by the Disclosure and Barring Services on June the 6th, 2013.
- An Occupational Health Evidence Approval was issued on July the 17th, 2013.
- A Research Passport for JCUH and NEAS was issued on July the 30th, 2013.
- A Letter of Access for Research from the Research and Development/Academic Division, Academic Centre at JCUH was obtained on September the 20th, 2013.
- A Good Clinical Practice Certificate was obtained on November the 12th, 2013.
- An approval letter from the School of Medicine, Pharmacy, and Health Ethics Sub-Committee for ethical review from Durham University was obtained on December the 10th, 2013.
- Approval was obtained from the Public Liability Insurance Cover from Durham University on February the 7th, 2014.
- Finally, the NHS Health Research Authority- NHS Research Ethics Committee has awarded the researcher clearance on February the 22nd, 2014. Protocol Number: (ESC2/2013/20).

Appendix M displays the ethical approvals of this study.

(i) ***Consent***: Participants were asked, prior to their involvement in the research, to sign a consent form to participate in the research under no coercion, pressure, or threat, see Appendix F. They were informed of their role in the research and were made aware of the aims and purpose of the IB, who the research team was, how data will be used. Participants were also made aware that their participation is voluntary. Consent was sought from management first then from individual participants later (Ritchie et al., 2013*a*). Two consent forms were signed by the participants, of which one was kept by the participant. It was also emphasized that the participant had the right to withdraw at any time from the study without giving any reason.

(ii) ***Confidentiality***: It is important to ensure confidentiality of data collected (transcripts, recordings of interviews, the identity of participants) and that this is not passed to others than the research team. Strategies to ensure secure storage of information and data; and anonymity of participants are essential (Richards and Schwartz, 2002; Ritchie et al., 2013*a*). Confidentiality was promised to participants and to ensure this, all information gathered from interviews, focus groups, and observations was stored in either locked cupboards or password protected computers, all of which were kept in a password protected room in the Computer Science School buildings of Durham University. Transcripts were all transcribed by the main researcher and no other party was involved. This was to ensure confidentiality of information and anonymity of participants. Every participant, in order to be anonymised, was assigned a unique code for the study.

4.8 Summary

This chapter presented the methodologies that were applied in this study and the rational of their selection. In order to conduct the case study of the IB prototype (the first research question), three phenomenological studies prior to the case study, were necessary (the second research question) to investigate sociotechnical issues surrounding an information transfer system. The results of the three phenomenological studies were triangulated to confirm and contribute to the formation of background information and understanding in relation to the stakeholders involved, for building the IB prototype, and therefore, demonstrating the IB interface by UAT to detect any malfunctions, errors, etc. in the system. All experiences, views and knowledge gained with and from the various people involved (NEAS staff, JCUH staff and PWE/carers, and ambulance crew) helped to determine what should be included in the IB prototype system.

Chapter 5

NEAS Foundation Trust and its Operations

This chapter provides background information about the ambulance trusts in the wider NHS context with regard to collaboration in the inter- and intra-organizational level. Exploration of the current ambulance service in general was vital to understand procedures performed in NEAS of the dispatch mechanism, communication interactions, and patient journey to ED. The background information helped to identify NEAS's intra- and inter-communication challenging issues and gaps. Addressing some of the identified gaps can be done by the application of simple alterations in work performance and/or better utilization of available resources on both the intra- and inter-organizational level.

This chapter and the following Chapter 6 represent the first discussion of the three elements of the phenomenological approach which have been triangulated to form the case study analysis.

5.1 Ambulance Trusts and the Wider Health System

A foundation trust is an independent legal entity of the NHS. Although independent, it is still part of the NHS and follows the NHS principles and quality standards for providing care based on need, not ability to pay. Foundation trusts are not under the control of central government, as part of a decentralization of public services. This means that members of the local community can become members, trustees, and/or governors, where the local community could be patients, staff and partner organisations. This gives the foundation trust the ability and freedom to direct their services and develop new ways of working that address the community's needs and priorities. Furthermore, giving patients, the public and staff more freedom to run the foundation trust according to the needs of the local communities while at the same time being obliged to follow national NHS guidelines that aim to safeguard the quality and interest of the public and the services provided to them. The North East Ambulance Service NHS Foundation Trust (NEAS) is one of ten ambulance trusts in England and one of five ambulance foundation trusts, responsible for providing ambulance services on behalf of the National Health Service (NHS) to the public free of charge (North East Ambulance Service NHS Foundation Trust (NEAS), 2015*d*). The South Tees Hospitals NHS Foundation Trust (STHFT) also provides care to a range of specialist regional services. STHFT is the largest hospital trust in the Tees Valley with two acute hospitals of which JCUH is one (The South Tees Hospitals NHS Foundation Trust (STHFT), 2018).

A foundation trust is controlled, run and managed locally, not nationally, underpinned by NHS principles and national healthcare standards of providing care to patients. Not only that, but they have greater freedom over their finances, investments and organizing their resources (Department of Health, 2005; NHS Choices, 2015*a*). NHS trusts and foundation trusts, such as NEAS, are overseen by the *NHS Improvement* that was established in 2016 as a result of the Five Year Forward View (NHS Improvement, 2016). The NHS Five Year Forward View has set new strategies for the NHS organizations to follow in a span of five years. One strategy proposed new care models for the urgent and emergency care networks; where this new care model will focus on simplifying and organizing the urgent and emergency care system (NHS England, 2014).

An ambulance trust is an entity that is in constant contact with many other health and non-health organizations, as it needs to collaborate and work within complex health and social care systems. An ambulance trust interacts with the police forces, fire and rescue service, social services, mental health services, hospital trusts, GPs, urgent care centres, charities and community groups as well as the public (National Audit Office (NAO), 2017; Association of Ambulance Chief Executives, 2016). Although all of these health and non-health organizations are essential external interactions with the ambulance services, they will not be discussed here as they fall out of the scope of the thesis. Focus will only be on examining the interaction and collaboration that the ambulance service has with one external organization which is JCUH.

At the ambulance trust level, attention should be given to pathways that are frequently used, and any reasons for overuse should be identified. Once identified, solutions should be initiated to overcome those challenges, and as ambulance services do not work in isolation, this identification of challenges and initiation of solutions should not be isolated either. This means including other organizations that are involved in this pathway (Dunn et al., 2005; Iyer et al., 2012; Gray and Wardrope, 2007). For instance, the ambulance crew, will sometimes choose to take a patient to ED even if this is not necessary, for reasons discussed in Chapter 2. Therefore, collaboration between the ambulance trust and the EDs in various hospitals should be an ongoing process that sets clear boundaries of responsibilities, priorities, and communications, including identifying frequent users and proposing shared goals, solutions, etc.

Ideally, management staff from both the ambulance service and EDs in hospitals need to collaborate together to identify frequent users. Doing so will enable them to identify alternative channels for providing care, other than calling the ambulance service or unnecessarily going directly to ED. Ambulance service management may work in partnership with EDs in trusts to identify frequent users of the service.

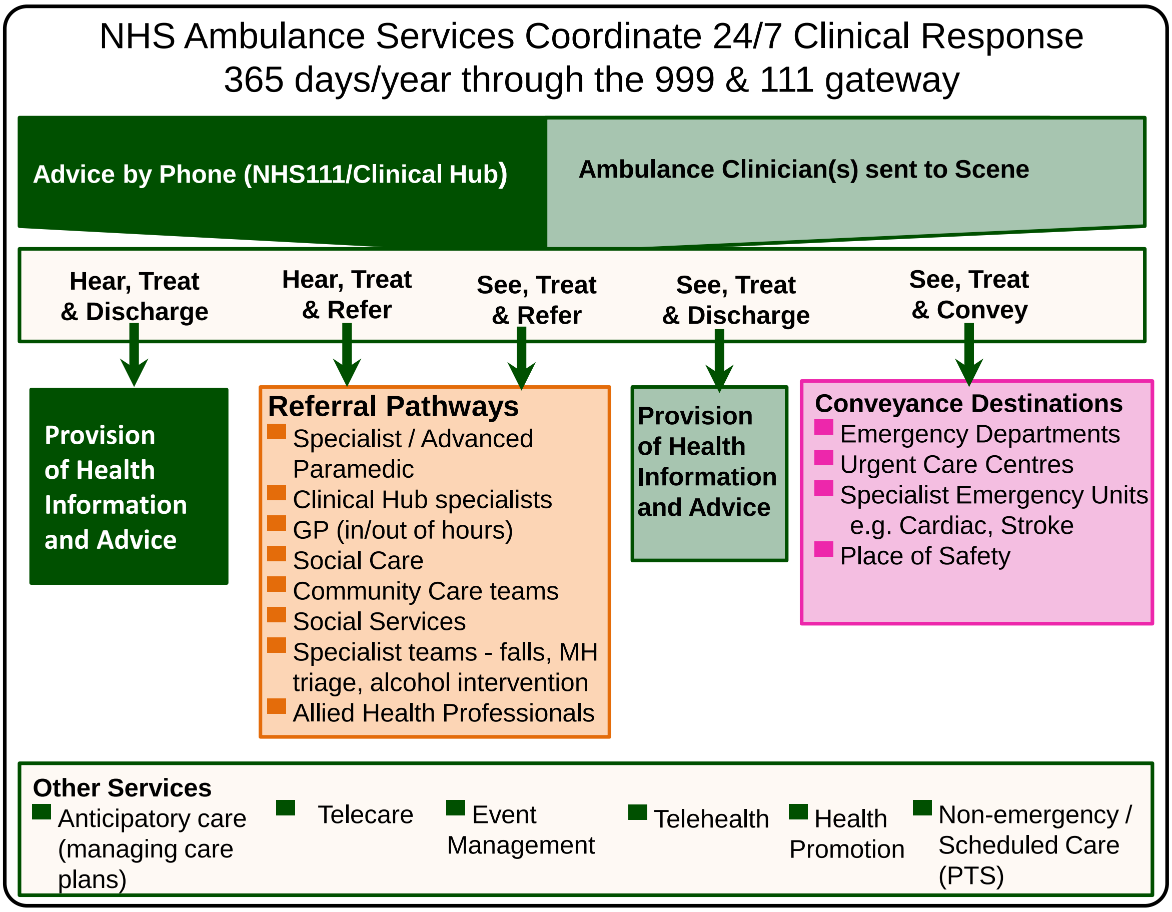
On the national level, collaboration should not be limited to hospitals only, but should also include other diverse organizations in the wider health system. In 2017, the National Audit Office reported that, with regard to ambulance services, the wider health system is not always fully utilising the knowledge and experiences of most ambulance trusts. However, some stakeholders, e.g. hospital EDs, also reported that some ambulance trusts chose not to engage fully with them (National Audit Office (NAO), 2017). It is suggested that joint observational audits of handover delays, as an example, should be undertaken in a timely manner (NHS Interim Management and Support (IMAS), Emergency Care Intensive Support Team, 2013; Association of Ambulance Chief Executives, 2015). This would be to identify gaps in the system and to propose appropriate solutions and improvement plans for addressing this issue. Management staff from the ambulance service alongside GPs, EDs in hospital trusts and Clinical Commissioning Groups (CCG) should all work as one team and agree on comprehensive shared strategies to improve performance.

5.2 Description of the Current Ambulance Services

Ambulance services in England are designed to provide people with either an Emergency Care Medical Service such as a rapid response vehicle or a Patient Transport Service (PTS). The former provides help to people who are seriously hurt or ill and need urgent medical care. The latter is for people who have a medical condition and cannot travel to/back from their appointment, or who require special skilled assistance while being transported (North East Ambulance Service NHS Foundation Trust (NEAS), 2011*b*). The ambulance service, depending on their assessment of the patient's condition, can dispatch a selection from the following:

- A rapid response vehicle.
- An ambulance crew.

- A doctor.
- An air ambulance.
- Patient Transport Service (PTS).
- A Community First Responder (CFR) or volunteers (NHS Choices, 2015*b*).



Source: AACE Annual Report 2015-2016

Figure 5.1: 999 and 111 Call Response Pathways

Calling 999 should be reserved for life-threatening emergencies where immediate medical help is necessary, that is, when someone is seriously injured or ill and their life is at risk. If the situation is not life-threatening and does not require immediate medical help, there are other options that can be used to provide medical assistance, such as calling NHS 111, calling/visiting the GP, going to a local NHS walk-in centre, a minor injuries unit, an urgent care centre, or going directly to an ED.

Figure 5.1 displays the available various pathways of care which are available for call centre staff to select from when receiving a 111 or a 999 call in the NHS (NHS Choices, 2015*b*). The appropriate pathway is determined by the nature of the call received. The diagram shows how diverse those pathways are and the spectrum of services available for staff to select, in order to provide suitable care to patients.

5.2.1 The Dispatch Procedure at NEAS

The dispatch procedure employed by NEAS is not a simple process, it involves multiple systems, divisions, personnel etc. A holistic, yet brief, description is essential to understand this process. Expanding on Figure 1.2 from Chapter 1, Figure 5.2 provides this information in more detail. The CAD system automatically records

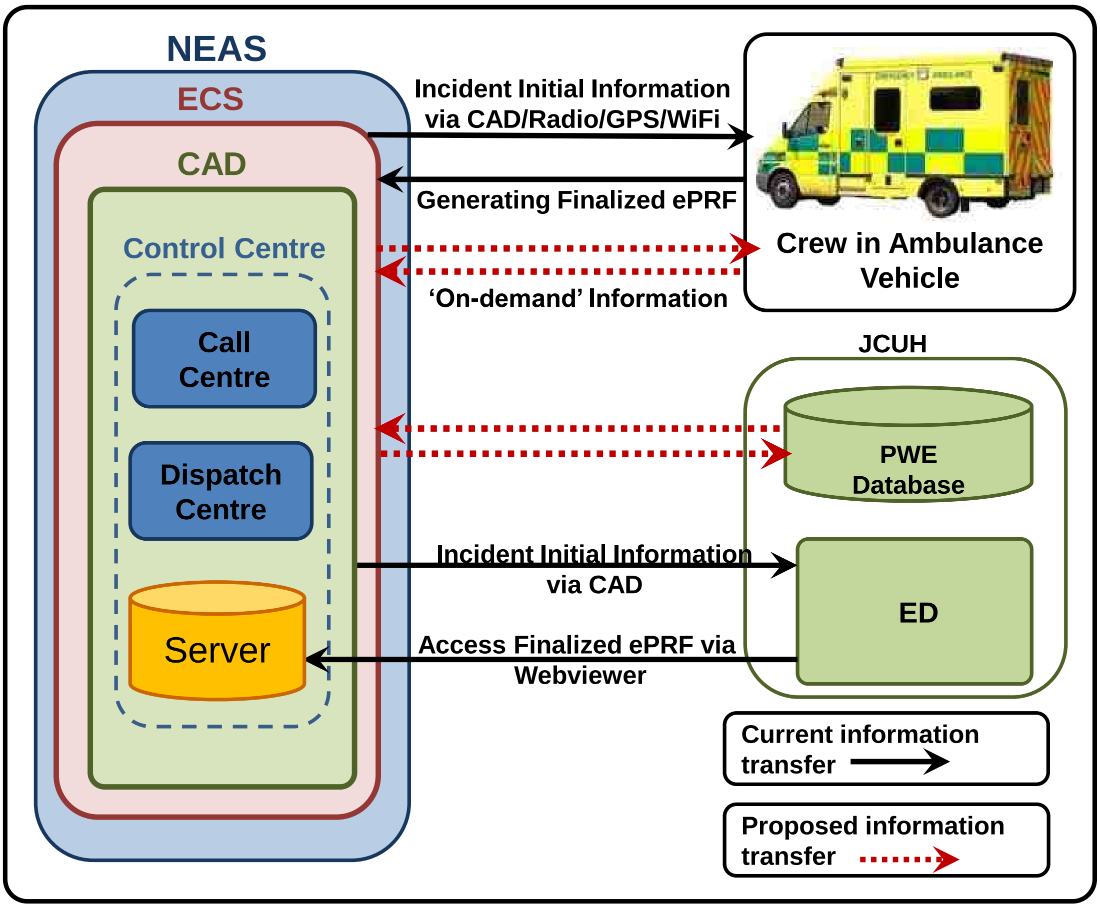


Figure 5.2: Information Transfer Systems Model

details about all actions and processes occurring within and between the control centre and the ambulance crew. More specifically, the system allows location information and patient details of the **(incident initial information)** to be recorded and transferred from the control centre to the ambulance crew, and if needed, to the selected ED. The CAD system provides the means of sending live incident initial information **on the go** to crew who are en-route to an incident. It also receives details from the crew about their choices of action and any decisions made regarding the job. Every operating vehicle is fitted with a telematic system which has its own GPS antenna that enables connection to the CAD, in addition to WiFi and radio. The CAD system also displays the vehicle's mobility position, enabling control centre staff to view mobile vehicles on a map that is updated every fifteen seconds.

For a given incident involving the dispatch of an ambulance, where a decision has been made by the ambulance crew to convey the patient to ED, the CAD system, via the Emergency Care Solution (ECS), will send the incident initial information to the designated ED before the arrival of the crew. This means that ED staff will view the same incident initial information that was sent to the crew and will know what to expect.

Once the crew has arrived at the ED and completed the handover to the ED staff, they need to finalize the electronic Patient Report Form (ePRF). This will only be achieved when both a member of the crew and the ED staff sign the ePRF electronically, indicating the completion of mandatory data fields and the transfer of patient responsibility. The ePRF finalization by the crew will then allow authorised ED staff to access the finalized ePRF through the **Webviewer** system even after the ambulance crew has left the ED. The online Webviewer, provided by NEAS, will prompt authorized ED staff to authenticate their access by entering their user name and password. This action allows them to access the ECS server and view a copy of a finalized ePRF that holds the patient incident information, the crew's observations of the patient on scene, and other details about the incident (North East Ambulance Service NHS Foundation Trust (NEAS), 2011*c*, 2015*a*, 2014*b*; Williams, 2009).

The following sections will generally describe the interactions of communications within NEAS from placing of a 999 call untill discharge from the system of NEAS.

5.2.2 Control Centre Communication Interactions (999 Call)

When a call handler based at NEAS call centre receives a 999 call from the public, where appropriate, they will notify a dispatcher who will use the CAD to assign a suitable ambulance vehicle to be sent to the location. These actions occur within 60 seconds of taking the call about the incident. Figure 5.3 illustrates the communication interactions in the **control centre** during a 999 call.

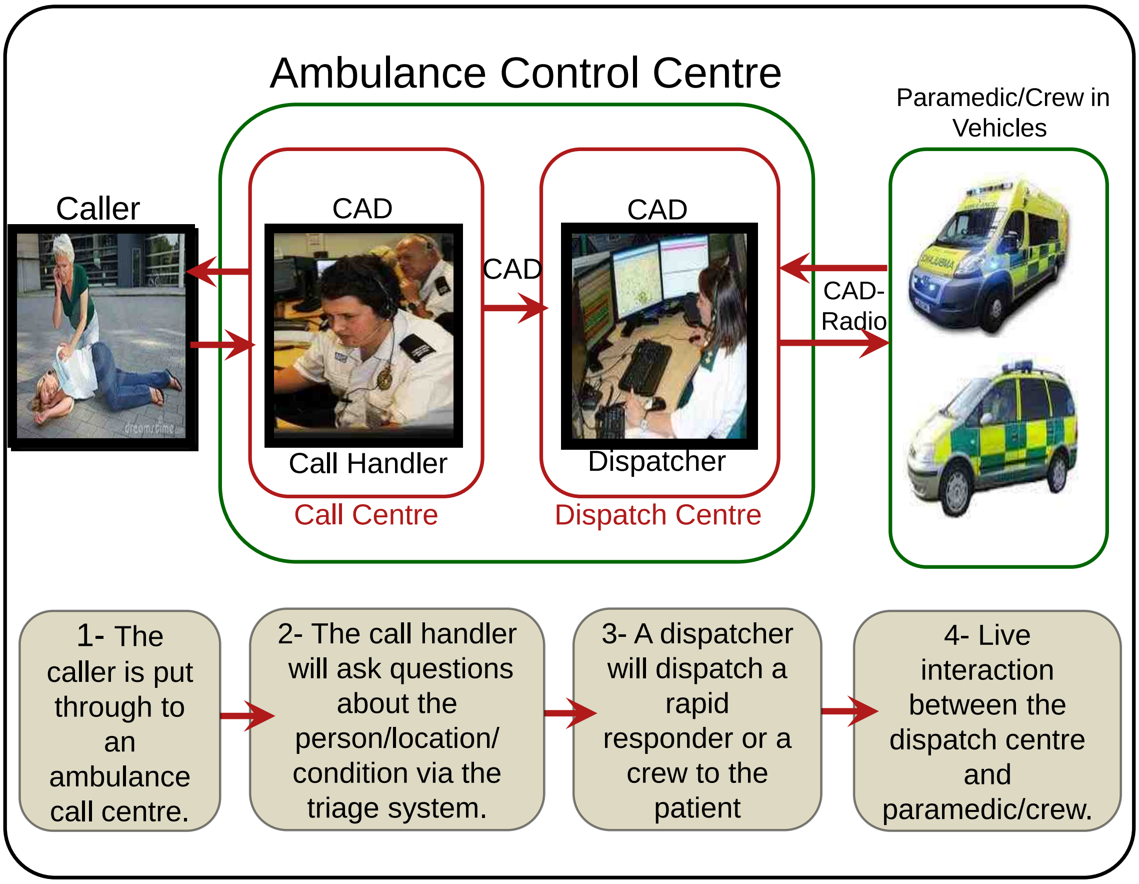


Figure 5.3: Communication Interactions in the Control Centre

Simultaneously, the call handler is talking to the person placing the call for help, and inserting the incident information in the NHS Pathways triage system, which is a medical assessment tool. The NHS Pathways, based on the patient's symptoms will be used to establish if this call is a **red** or **green** category call, i.e. the level of medical assistance that is relevant to the patient's need is selected. If the call is determined to be a green category call, then the NHS Pathways which is linked to the Directory of Services (DoS), displays details of services available to send the patient to that are appropriate for their symptoms. In the meantime a message will be sent via the CAD to the ambulance crew to step down.

Table 5.1 displays the type of response for each category which have been prioritized into nationally agreed categories according to the situation (North East Ambulance Service NHS Foundation Trust (NEAS), 2015*c*).

Current Priority	Definition	Target
Red 1	Potentially life-threatening condition (cardiac or respiratory arrest)	To achieve %75 of all Red incidents within 8 minutes (national standard)
Red 2	Potentially life-threatening condition	
Green 1	Not presently used in normal operations, would only use G1 when a G2 had waited too long and the patient does not fit the Red criteria but their condition was worsening, it pushes them to the front of the Green queue	Attempt to respond in 20 minutes to these calls (no national standard set)
Green 2	Serious but not life-threatening condition	Attempt to respond in 30 minutes to these calls (no national standard set)
Green 3	Neither Serious nor life-threatening	Attempt to respond in 60 minutes to these calls (no national standard set)
Green 4	This is Hear and Treat, the call is handled on the telephone and no ambulance response is necessary	

Table 5.1: NEAS Incident Categories

Red category calls are life-threatening calls, whereas green category calls, can be either serious but not life-threatening or neither serious nor life-threatening. For the purpose of this thesis, the focus will be on describing a red category call communication interactions only; as PWE and other patients who share same symptoms, fall in this category.

If an ambulance crew is to be dispatched to an incident, any available updated incident initial information (e.g. patient is bleeding, the location is considered unsafe, the patient is violent etc.) will be sent to the ambulance vehicle via the CAD system. The dispatcher will also notify the crew about the incident over the radio. The crew will hit 'Accept' on the system and then proceed to the location; once there, they will hit 'Arrive Scene' to notify the control centre (North East Ambulance Service NHS Foundation Trust (NEAS), 2014*c*,*b*, 2011*c*).

While en-route to the incident the crew will be receiving updated incident initial information and can view it through the Mobile Data Terminal (MDT). The MDT is a screen fitted in ambulance vehicles that is connected to the control centre; it displays the patient's incident initial information and any updates. Other systems that have been previously mentioned, are also available on the vehicle, for example the radio, CAD, WiFi, GPS etc.

All the incident initial information is sent to the crew from the server, therefore, a connection via WiFi or GPS must be available for them in order to receive live CAD information. When the crew complete their call-out, they will hit 'Available' on the CAD system indicating their availability to accept another job (North East Ambulance Service NHS Foundation Trust (NEAS), 2011*c*, 2015*a*, 2014*b*; Williams, 2009).

The dispatcher is able to view the ambulance vehicle location and should be able to make contact with the crew via radio if a connection is down, or if necessary information needs to be immediately transferred. The ambulance crew can also contact the dispatcher via radio if additional information or clarification is needed regarding the patient, or the location etc.

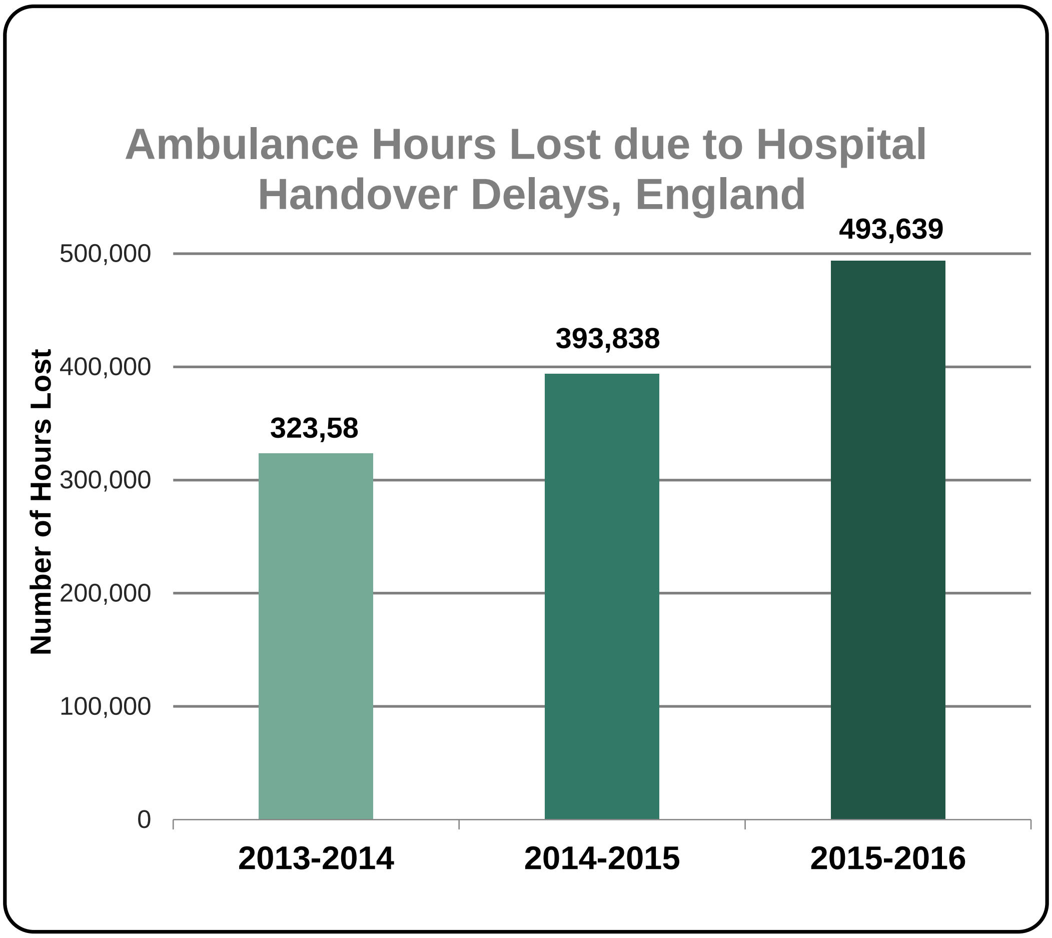
5.2.3 Patient Journey to ED

The ambulance crew will hit ‘Arrive Scene’ on the Mobile Data Terminal (MDT), when they reach the incident location in order to notify the control centre of their arrival. Crew, as noted earlier, are required to make a decision between ‘See and Treat’, ‘See and Convey Elsewhere’ or ‘See and Convey’ to ED (National Institute for Health Research, Health Services & Delivery Research Programme, 2015; Tohira et al., 2016).

5.2.3.1 Patient Handover by Ambulance Crew to ED Staff

The decision to take a patient to ED is not the final action for the ambulance crew. The crew with the patient will wait in the ED bay until an ED staff member assigns a cubicle for them. Once in the cubicle, the crew member will hand over responsibility of the patient and their incident information to the ED staff. After the handover, the ED staff will electronically sign off the ePRF indicating responsibility and information transition. Handover to ED does not cease at this stage, it also involves other issues that the ambulance crew need to manage. Issues that occur that are associated with handover of the patient from the ambulance crew to ED staff include, but are not limited to, problems with clinical communication, knowledge and communication gaps between the crew and ED staff, the lack of a structured form of verbal and written information exchange in handovers and the lack of team work, education and shared common language (Bost et al., 2010; Jenkin et al., 2007; O’Connor, 2002; Dawson et al., 2013).

In addition, the time duration of handover should not be ignored. Sometimes the ambulance crew will need to wait for a long time in the ED to transfer responsibility for the patient. This time delay is a big problem for ambulance services as it ties up their resources. Having an ambulance crew queuing, for hours in some situations, in the ED to handover responsibility to ED staff means that they are unavailable for another call-out. In 2015/16 of all ambulance journeys to ED in England, 49% experienced delays in handover queueing in hospitals with patients waiting to be handed to an ED staff longer than 30 minutes. That represents some 493,639 ambulance hours lost, see Figure 5.4 (Association of Ambulance Chief Executives, 2016; University of Sheffield, The Centre for Urgent and Emergency Care Research, 2016). The Annual Report of the Association of Ambulance Chief Executives (AACE) for 2015-16 has identified this wastage of resources. It points out how this delay in handover can have a significant effect on operational performance, time targets, shortage in available crew, and means that resources are being directed away from increased demand. Furthermore, this time delay not only poses risks to patients with life-threatening conditions who are waiting with an ambulance crew to be seen by an ED clinician, but also a risk to all of those people in the community who are in an urgent need of urgent medical assistance.



Source: AACE Annual Report 2015-2016

Figure 5.4: Ambulance Hours Lost due to Handover Delays to ED Staff in England

5.3 Intra- and Inter-Organizational Communication Issues in NEAS

Healthcare is a complicated environment, and one that involves many aspects of human activity, organisational, political, ethical, technological, financial, structural, infrastructural, sociotechnical, etc. Many studies in the literature have discussed those intra- and inter-organizational communications challenges and proposed solutions for these different aspects, for example Pirnejad et al. (2008, 2007); Sicotte and Paré (2010); Barson et al. (2000); Battiston et al. (2017). The following discusses some intra- and inter-organizational communications gaps.

5.3.1 Intra-Organizational Communication

Details of the systems, technologies, databases, etc. employed by NEAS are scant in the literature. Insight of the available systems employed was gained through organizational documentations, website information, interviews, annual reports, etc. Therefore, information regarding the existence of other hidden systems in NEAS was possible.

Intra-organisational communication is concerned with communication that occur within the same organisational unit. That is, communications that happen within and among individuals and divisions/management that come under the same umbrella. For example, NEAS in general and the ambulance crew in particular.

The front-line ambulance crew (paramedics, advanced technicians and emergency care support workers) work in a dynamic environment where they are operating under pressure, and often with inefficient and ineffective communication practices (Carriere and Bourque, 2009). Crews, most of the time, are mobile during their shifts and geographically distributed. They rely on synchronous communication (where two parties exchange messages at the same time (Coiera, 2015) conducted via any available communication system (Kumar et al., 2010)). Both the crew and the control centre share the same goals but perform their tasks differently. They communicate with each other via several different communication systems, rather than by a face-to face interaction which is considered as a disadvantage (Cascio, 2000).

5.3.2 Gaps in NEAS Intra-Organizational Communication

In the interviews, crews from NEAS indicated their desire to have reliable and stable up-to-date information from the control centre. They reported that issues with connectivity can cause delays in information transfer. The crew then find themselves needing to use other forms of communication that are not intended to be used as the main approach to electronic information transfer, such as using radio for communication. Alternatively, a crew may ring the dispatch centre for additional information regarding the patient, location, etc.

Another problem of this intra-organization communication occurs when the ambulance crew want to download the incident initial information from the CAD system in to the ePRF. When there is a lack of connectivity, this task might be delayed, forcing the member of crew to postpone this step until connection is available. The same problem occurred when the ePRF is finalized and a crew need a connection to upload it to a NEAS server. If a connection cannot be found, the crew will try other ways to upload the ePRF. For instance, connecting the Toughbook laptop onto the Docking Station installed at every ED. The Docking Station is a connectivity source provided by NEAS and is only used by the crew when the Toughbook laptop lacks connectivity, needs battery recharging and/or when downloading incident initial information failed. Those connectivity issues causes the crew to be delayed in attending their next job.

NEAS ambulance crews, do not face intra-communication issues with the system alone, they also face communication gaps with the control centre, for example, in the form of feedback. Feedback is a one way only direction from the ambulance crew to control centre therefore, feedback from the control centre to the ambulance crew is unavailable.

In terms of feedback, the crew, after every job, will provide some information to the control centre about the call category. This feedback is to validate the job rating assigned (red or green jobs) to the incident, see Table 5.1 for call categorization. The feedback from the crew on the suitability of the call categorization of the system carries benefits for management in measuring the system performance.

However, feedback to front-line staff is missing. The ambulance crew in NEAS not only lack feedback about the results of an incident, but also lack routine feedback on their performance. Morrison et al. (2017) found that paramedics have a positive perception towards feedback systems. In addition, they also identified limitations that reduce the practical application of current feedback systems. For example, lack of a feedback structure, integration of feedback and disciplinary action, lack of routine feedback and bias in the feedback received. They have also identified the factors that restrict the feedback delivery to paramedics. There were three barriers: confidentiality regarding patients information; social or cultural barriers includes personal discomfort about criticism, etc.; and finally, practical barriers referring to additional workload, including lack of a feedback provider.

Lindström (2012) has discussed this issue. She has implemented and evaluated a feedback system between the ambulance service dispatch centre and paramedics. She emphasises the importance of the availability of a feedback system and identified how it can help to increase patient safety as well as to evaluate organisational changes. Moreover, it can increase the ability to identify any systematic or individual errors in the ambulance service.

O'Connor and Megargel (1994) have studied the impact of a quality improvement feedback loop on group performance addressing (paramedics) skills, behaviour and the patient report documentation. They have found that providing paramedics with feedback regarding their quality improvement had a dramatic effect on the patient report documentation, and deficiencies had dramatically dropped when documenting patient's reports of an incident. This positive effect was also found in behaviour, as noticed by the reduction in time spent on scene. All of these features seem to be missing from the NEAS feedback mechanisms to the ambulance crew.

First-line crew are different from other staff in NEAS. They are on call 24/7 during their 12 hour shifts, with non-specific working hours. On the other hand, top and middle management in the same organisation work regular office hours. This mismatch of scheduling gives rise to the opportunity for a communication gap between them, leading crews to feel isolated. Not only that, but due to the active nature of the ambulance crew, this makes it hard for management to communicate directly with them when they are busy delivering urgent care to those who are in need (Carriere and Bourque, 2009; Cascio, 2000).

NEAS holds large amounts of incident information about patients. NEAS, like any other health organization, was influenced by HIT, ICT, IS, etc. They moved from a paper based PRF to ePRF1 in October 2010. In June 2016 ePRF1 was replaced with an electronic Patient Clinical Record (ePCR)- this will be referred to as ePRF2 for simplicity. This transition in systems brought with it challenges to NEAS. Each individual system has its own individual database, and each database is isolated from the others; creating fragmented patient information. These fragmented databases are, unfortunately, not suitably structured for integration either.

All of this rich data about patients NEAS has collected, and still collects, is held in different databases and only occasionally accessed. Even when NEAS holds this information in the form of PRFs/ePRFs, it is still generally underutilized. If utilization of the PRF/ePRF does occur, then it would be occasionally on a narrow level for managerial purposes to improve the allocation of resource usage, decision making, complaints, and research purposes. Those databases which are holding this data are largely used as storage facilities; they are not systematically and strategically analysed for incorporation in the data management reviews and quality improvement mechanisms.

The huge amount of fragmented data in the distributed systems NEAS already has, holds great potential for NEAS management if utilized accordingly. This missed opportunity (utilizing already available data) is unused by NEAS management and is just limited to direct managerial purposes as already observed.

In some situations, different ambulance crews will be dispatched to the same address on the same day at different times. Crews will not be notified (flagged) about earlier same day call-outs. This example shows how NEAS management do not share (but isolates) this critical information, even though it is available and stored in the database; it also highlights the lack of established information sharing systems. More details will be presented in the following chapter regarding this matter.

The management of NEAS do not only isolate front-line staff from information already stored in the database, but also from system development and building. NEAS did not consult front-line staff, when developing ePRF1 and ePRF2. The ePRF2 was rolled out by NEAS as a new software and hardware device in June 2016. This new ePRF2, was developed by Safe Triage Ltd, and the project team includes members of the clinical, operations and IM&T departments. 1,300 staff members of the front-line ambulance crews were trained in the run up to implementation. They were not, unfortunately, involved in designing the structure of the ePRF (North East Ambulance Service NHS Foundation Trust (NEAS), 2016*c*).

NEAS management does not appear to be aware of this unintentional isolation of staff. Tackling such issues could improve efficiency for staff and services. Management should extend their strategies to invest and make decisions to further their benefits and work performance. This reinforces the idea that challenges arise more from the sociotechnical aspects than the technical side of things.

Intra-organizational communication within JCUH was also identified as a gap. Information exchange between the ED and the Neurophysiology Department was missing. The fact that the Neurophysiology Department is still storing their data on a paper filing system shows how the department is isolated internally and externally.

5.3.3 Inter-Organizational Communication

These problems in communication do not just occur within the organization, but also outside the organization. It can happen between the foundation trust and other health and non-health organisations, and on the individual level, between front-line individuals from different organisations, such as the ambulance crew and the ED staff. There appear to be few interactions at the management level that should occur between ambulance trusts. For instance, interactions between NEAS management level and another ambulance trust management level in England. These other levels of inter-organisational communication will not be addressed in this thesis.

The National Audit Office (2011) (NAO) in their study have examined the cost-effectiveness of ambulance services in the NHS. They have highlighted some aspects that are relevant to this study. Some of their key findings are that although collaboration in some key areas between ambulance services has improved, e.g emergency planning, there are inconsistent performance measurement criteria used between them. Also there is a lack of consensus on the best way to measure resource utilization to help facilitate the Department of Health in benchmarking performance, and to compare outcomes in order to evaluate the overall system. The NAO have recommended that to measure performance effectively, ambulance services should develop appropriate procedures for sharing and collecting information on an inter-organisational level. A key component to achieve this is by enabling the systems of different organisations to link smoothly.

Moreover, clinical information integration, based on consent, should be established, with other services in local and regional health communities. This could be achieved by overcoming traditional system boundaries, awareness of staff overlap skills and established sharing models. Integration and cross-boundary work with other services that require consideration includes: General Practitioners (GPs), primary care professionals, mental health provision, hospitals and their internal departments, social care and community health services (NHS England, 2015).

At the individual level, the interest here is on the communication aspects and information transfer between ambulance crew and ED staff who are involved in the handover process. This information transfer occurs in a short period of time and under stressful conditions, and has been extensively discussed in the literature from different aspects (Bruce and Suserud, 2005; Bost et al., 2010; Jenkin et al., 2007; O'Connor, 2002). The handover process is essential between two different organisations, with both trying to provide the best care available to the patient, in order to ensure patient safety. This care cannot be fully appropriate if information about the patient is lacking or inadequate. This issue also arises when the ambulance crew travel to the scene with no information.

5.3.4 Gaps in NEAS Inter-Organizational Communication

When the ambulance crew travel to the scene, they can only view the incident initial information that has been provided by the call handler via the MDT. However, the information inserted by the call handler, is as received by the call maker who is describing the incident from their point of view, which might not always represent the actual situation. Therefore, when the ambulance crew reach the scene, they might find a different situation to the one that has been reported. Being in an emergency incident, the crew will act according to the situation, as urgent responses are essential. All of these actions related to the patient will later be recorded in the ePRF, once the condition of the patient is stabilized.

This delayed act of recording information in the ePRF may cause problems (Pirnejad et al., 2008), as an ambulance crew may forget to report some information to ED staff during handover. That is why some crews will jot down essential information on their gloves or on a piece of paper. After the patient is transferred to the care of ED, a member of crew will insert the incident information into the ePRF to record it. This delayed action of completing the ePRF later in the process prevents the ED staff accessing the finalized ePRF instantly if needed. This leaves them with no choice but to rely heavily on the ambulance crew verbal handover or upon information from the patient directly if their health permits. This is not always a smooth and problem free process (Manser and Foster, 2011). See Section 9.2.

As mentioned previously, feedback to NEAS front-line operational roles by management is essential. Equal importance is also laid on the inter-organisation feedback to NEAS front-line operational roles, for example, feedback to crew by ED staff. Feedback to the ambulance crew can improve their performance (Levick and Swanson, 2005; Kramer-Johansen et al., 2006), the quality of pre-hospital care to patients on scene (Lyon et al., 2012), and increase paramedics confidence (Thakore and Morrison, 2001). Mock et al. (1997) have noted the importance of providing feedback from ED staff and patients to ambulance services. The authors have discussed whether formal regular and constructive feedback channels should be open between ED and ambulance services. As feedback provides both a learning process and also a sense of satisfaction to the ambulance crew. Delayed feedback is better than none, as feedback provides information to ambulance services that can aid the provision of care by applying constructive changes to the system for the benefit of all. Gränsevik (2015) also supports the idea of the importance of feedback to ambulance services and emphasises that the lack of feedback to ambulance service staff could have negative psychological effects on crews. In contrast, the availability of feedback can have positive effects on quality improvements, individual development and increased knowledge within the ambulance service. NEAS ambulance crews do not receive any feedback from external organizations on their work performance.

Each organization has different priorities and agendas and this leads working processes to be interdependent on the intra-organizational level, but independent on the inter-organizational level. Establishing regular meetings between NEAS and the trusts they serve (JCUH ED) is essential to open those communication channels between organizations. This can be achieved by setting shared goals, providing financial support for joint projects to increase ownership, incentives, involving front-line end-users to maximise benefits, etc.

NEAS did not consult JCUH or ED staff when designing or implementing the ePRF system. Once the system was rolled out, authorized ED staff were informed of it and trained on how to access the online ePRF. Although the ePRF is available to specific ED staff 24/7, it is only accessed on limited occasions. ED staff reported that they prefer to spend time providing care for emergency patients rather than accessing the online form that consumes their time. Although NEAS has provided this system to support the inter-organizational communication aspect, ED staff do not appear to be utilizing it, for reasons mentioned earlier.

Similarly, this problem in the ED of JCUH happened again with another system NEAS installed in the ED. Those are the Docking Stations and the patients arrival alerting screens. Docking Stations, in addition to alerting screens, were installed in every ED that NEAS serves. They do not provide any benefit to the ED staff or their work process. Docking Stations are for the sole use of the ambulance crew. The alerting screens installed in the nurse station, receive update information of the incident initial information. Even when the alerting screen displays live information with the job category, it appears that ED staff seldom pay attention to it for various reasons. For example, ED staff cannot make any preparation based on incident initial information that may not be clinically accurate, simply because this information is from the call maker's perspective and so may not present the actual clinical situation. This "technology-push" (Greenhalgh et al., 2008) to ED staff has created a sense of a lack of ownership and has some resistance to its use. Again, not involving ED staff on the development of the system has created this gap. Unfortunately, all of this technology NEAS is providing and the resources spent is not enhancing this aspect of inter-organizational communications.

5.4 Summary

This chapter, with the following Chapter 6, represent the first phenomenological study. Providing background information and a description about NEAS Foundation Trust in the wider health context, followed by the communication procedures applied by NEAS control centre with ambulance crews. This includes the dispatch mechanism of crews, communication interactions occurrence between control centre and crews, and the patient handover to ED staff if a patient is conveyed to the ED. This was helpful in identifying the intra-organizational communications gaps within NEAS with reference to the ambulance crews. These were the lack of reliable information, connectivity and feedback. The nature of the ambulance crew working process was an added challenge to the communication process, as the ambulance crew work a 24/7 on demand service, always mobile and geographically scattered.

This communication gap in NEAS is not on the front-line crew operational level only, but it also extends to the management level. NEAS management does not utilize the vast information they already hold in their PRF/ePRF databases with crews . For example, they do not inform the crew of multiple same day dispatches to the same patient. NEAS did not even involve the ambulance crews in the development and implementation process before the ePRF system was live.

The gap is not only on the intra-organizational communication level, but it also occurs on the inter-organizational level. The ambulance crew while on scene, do not have any access to any external database for the patient to support them in their decision-making. Additionally, the ePRF systems lack a seamless mechanism to record on scene patient information. This lack of support caused out-of-system workarounds to be applied, causing delays in accessing the finalized ePRF by ED staff. Ambulance crews not only lack feedback from NEAS management, but they also lack feedback on their performance from external organizations like the ED. Further, NEAS should collaborate more with other ambulance trusts, hospitals, and other health and non-health providers when introducing new HIT to set goals, share aims, identify incentives, and facilitate communication channels. Collectively, this helped to shape background information of the other non-technical (sociotechnical) aspects that may surround the development of the IB.

Chapter 6

NEAS Operational and Management Staff: Findings

This chapter with the previous Chapter 5 form the first phenomenological approach (perceptions of the operational and management staff in NEAS), to describe the communication and information transfer in NEAS. Findings from this chapter will triangulate with the other two phenomenological approaches from Chapter 7 and Chapter 8 to analyse the case study of the IB prototype.

There were various issues regarding communication and information transfer in NEAS's internal/external operations and interaction with technology. Communications with external organizations, access to patient health information, and external information flagging were also issues that emerged from the inter-organization level operations. The communication occurrence between ambulance crews and the control centre was one of the issues that emerged from the intra-communication level within the same organization. Furthermore, information flagging to the ambulance crews, was another emerging theme. Findings were helpful to form a better understanding of background participants experiences of the phenomenon within NEAS and other organizations with respect to communication and information transfer.

6.1 Introduction

Little was known at the beginning of this project regarding communications occurring in NEAS associated with the ambulance crews working for NEAS and when they are on scene during an incident. Findings concerning the management staff at NEAS, were incorporated with the operational staff, as they were essential to complete the background understanding of the communication and information transfer process.

6.2 Findings

Findings regarding NEAS communications emerged by using thematic analysis of the interview transcripts and the observational data that were collected from the ambulance crew at JCUH ED and the operational staff in NEAS HQ.

6.2.1 Presentation of Themes

Themes emerged from coding of the data. After identifying those themes, they were then organized as groups under meta themes. Meta themes were used to provide a description of the emergent themes. Table 6.1 gives a summary of them.

Emergent Themes	**Meta Themes**
• Communications with External Organizations • Access to Patient Health Information • External Information Flagging	External Operations
• Communication with Ambulance Crews • Internal Information Flagging	Internal Operations
• Interaction with Technology	Interaction with Technology

Table 6.1: Emerging Themes

The following first sections discuss each individual meta theme and then its corresponding emergent themes. This is to provide a description of those themes in more detail:

6.2.1.1 External Operations

This meta theme describes the external operations and communications that exist between NEAS and external bodies. It is essential to indicate that this part focuses more on the control centre side, due to the fact that staff can contact eternal organizations. Other divisions in NEAS, like Logistics, Information Management & Technology (IM&T) and duty managers were also included but with less focus compared to the control centre side. Although those divisions are critical to the process of external operations, they are less critical when compared to the call centre due to the direct interaction with the public and the ambulance crew and the provision of information to them while on scene with a patient. This is helpful to understand the full picture of communications occurring on the ambulance crew side.

(i) **Communications with External Organizations:** Communication with other external organizations was limited, and when it did occur, it would not be via the electronic system available to the ambulance crew or the dispatch centre staff. As mentioned previously, there is a pre-alerting system that notifies the designated ED via the CAD system, prior to a patient's arrival. In some situations this pathway is not followed, and channels of communication will deviate according to the patient's health condition. For instance, communication with external organizations will be instigated by either the crew themselves or the dispatcher/communication support officers. A member of the crew addressing a life threatening condition will either radio or call by mobile the dispatch centre to notify them about the patient's condition, so they can check for the nearest available help (ED, ward, resuscitation unit, etc.). Consequently, the dispatcher or the communication support officer will directly call, for example, the ED and ask if they can receive this patient immediately or not. If not, they need to call a different trauma centre and notify them about the patient. Once approval is obtained, it will be passed on to the ambulance crew either by radio or a NEAS mobile for them to execute.

Additionally, sometimes when crew arrive on scene they discover that the situation is dangerous for them to proceed alone. In such a case, they will radio/call the dispatch centre and request for additional support for their safety. Hence, the dispatcher or the communication support officer will contact the police to provide support for the crew. While instances of communication with external organizations regarding the ambulance crew is available, these are not, unfortunately, aided by any current electronic system that is provided to the crews.

(ii) **Access to Patient Health Information:** Both the call centre and the dispatch centre have no means of access to any patient's health information or to databases of external health and/or social organizations. The call centre is the side dealing with the public, and the person who placed the call is the only source for them that can describe the patient's current situation, although this might not match the actual patient's health condition.

It is important to note that the finalized ePRF, cannot be accessed by external health agencies, such as GPs, hospital wards, social health, etc. The only agency that can access the finalized ePRF is the ED via specific authorized personnel. The ePRF carries important patient incident information, which in this case is underutilized. NEAS should consider opening more communication channels with external health organizations to utilize this vital information with consideration to national data protection procedures and security and privacy regulations and standards.

(iii) **External Information Flagging:** An address will be flagged on the NEAS system, if the crew were faced with any safety or medical problems during the incident. When anyone from the same address calls for help again the flag that has been inserted previously will appear, alert the call handler, and it will be passed on to the ambulance crew to act accordingly. The crew will be alerted regarding whether it is a safety or a medical flag in order to perform the appropriate action. The flagging of information is connected to an address, not a patient, which can result in flagging information being lost. For instance, if the patient who is connected to a flagged address has an ambulance crew dispatched but to a different address other than the one in the system. The same thing will occur if the patient changes their address.

Another challenge is that the flagging duration of an address is set for a period of time, which is not more than three months. However, this can be updated if another flagged incident occurs and the same problem persists. This though might not be practical, especially if the flagging is for medical reasons and is connected to a patient living in a care home, as in care homes many different patients live under the same address. This flagging of information with external operations might cause additional support to be provided that is not needed for one patient but is critical for another. It would be desirable to connect the flagging to a patient not to an address, and doing so might reduce some of the problems associated with address flagging.

6.2.1.2 Internal Operations

This is mainly focused on the dispatch centre, as they are the only division that has direct contact with the ambulance crew. Staff working in the control centre are divided into two divisions: the call centre and the dispatch centre. The former contains the call handlers and their duty managers. Staff working in the latter are: the dispatcher, communication officer, communication support officer, and their duty managers. Themes that emerged from data coding were:

(i) **Communications with the Ambulance Crew:** The dispatcher, when notified of an ambulance needing to be dispatched to a location, will select the most appropriate ambulance crew for the call category and location. Information transfer to the crew from the dispatch centre is meant to be via the CAD system and displayed to them on the vehicle on the small screen of the MDT. Radio and mobile phones are other mediums of communication channels that are available to support and backup if the electronic system is not functioning as intended. When a crew is dispatched, and for any reason needs additional information regarding the patient, location, and/or other information they will radio or ring the communication officer or the communication support officer to ask for further guidance or information. The system will sometimes lose connectivity, especially when in remote places, leaving them with no choice but to contact via radio or mobile phones. Furthermore, a crew will, in some scenarios, ring the dispatch centre to get the incident initial information read out to them. This could be because the MDT is not functioning for any reason, the information that is displayed on the MDT is difficult to read due to constant updates, or because driving the vehicle in speed makes it hard to focus on the MDT and the road at the same time.

(ii) **Internal Information Flagging:** As noted above, the flagging system is used for safety and medical reasons. It is therefore, essential for crew to know if additional support is needed or not. But, in some conditions, different ambulances may be dispatched to the same patient more than once on the same day on different time periods. The challenge here is that crew might not be aware that a previous crew visited the patient at a different time on the same day. The only way they might be informed is either by patients themselves or if a copy of the paper PRF (if an ePRF was not used for any reason) is spotted by a member of the crew. It would be useful if the number and dates of previous visits could be flagged, so that paramedics would be aware of previous visits this patient has during a day/week and act accordingly.

The final theme that emerged from coding was:

(i) **Interaction with Technology:** The call centre staff interact constantly with dynamic systems that feed live information simultaneously to different divisions of the dispatch centre and the ambulance crew. For example, the NHS

> Pathways triage system guides the call handler through predetermined pathways according to what information the call maker has provided, and will help them decide what category the incident is, and therefore, dispatch the appropriate resource. When a crew completes a job (goes clear), meaning they have finished dealing with an incident, they need to give feedback to the dispatch centre about the appropriateness of the call category with the actual incident.
>
> In many cases, according to participants, the assignment of incident categories does not match the actual ones when crew arrive to the scene. This is due to the use of the fixed categories in NHS Pathways for assessing an incident. The NHS Pathways scheme is designed in a rigid way. This is to assure both patient and staff safety. However, this rigidity in the system does not allow call handlers to use their experience to interpret a received call, leading to full reliance on the system to make decisions on selected care provided based on symptoms. One participant observed that the triage system is *"too safe, too rigid"*. Another stated that: *"it is better to rate the call higher than the actual situation and step the category down as a safety net to patients health"*.
>
> A communication support officer, who supports the activities of the communication officers, deals with the ambulance crew verbal communication via radio or mobile phones, instead of the system. For instance, they would ask the crew to step down from a call-out, upgrade to a higher level call category, give permission to the crew to fuel the vehicle etc. This reflects how inflexible and rigid the system is.

All themes were strongly based upon the experiences of participants in NEAS and ambulance crews observations in JCUH ED. Formulation of the background and occurring communications was helpful in understanding and investigating the surrounding sociotechnical issues when developing the IB system.

6.3 Summary

This chapter formed with the previous one, the first of three phenomenological study approaches in the thesis, in order to form the case study of the IB. Eliciting end-users requirements from the IB system and involving them in the development process is critical to meet elements of success. This chapter presented what NEAS staff require form the IB, on the external and internal operational level and their interaction with an information transfer system. Requirements with external operations included accessing external patient health information, establishing communication channels with them, and using the information transfer system to notify the external organization of the emergency incident. Furthermore, requirements of internal operations included communication enhancement with the ambulance crew and more utilizing the flagging system to support the information transfer process. Findings also suggest that end-users would like any system they interact with directly to be easy, simple to use, and not rigid.

Chapter 7

JCUH Staff and PWE/Carers: Findings

This chapter will discuss the second element of the phenomenological approach, that was triangulated to analyse the case study of the IB system. It represents what was done in collaboration with James Cook University Hospital (JCUH).

Before presenting the building blocks of the PWE database and the user interface, it was necessary to determine JCUH staff and PWE/carers' requirements of the information transfer system (ePRF), the database, and the IB. Drawing from their experience and identifying their needs was an important step not just to build the PWE database, but also to form vital background information from their perspectives based on their experience with the ambulance service.

7.1 Introduction

As explained in Section 4.2.3.2, the Neurophysiology Department in the hospital is still functioning by keeping its records in a paper based file system. As part of the PhD plan was to work with an electronic database (unavailable in this case), some form of an electronic database system was needed in order for the Information Broker

(IB) to be demonstrated effectively. Therefore, it was decided to build a database based upon specifications from JCUH, and to populate it with representative patient information. The following sections describe the outcomes from this.

7.2 Findings

The original intention is to approach staff and patients listed in the Neuroscience Department PWE pre-existing electronic database to ask permission to use their data in the prototype. It was replaced with building an electronic database together with an end-user interface for the Neuroscience Department in the hospital. When building a database, one must look for a model that best represents the world view. According to Chen (1976) the Entity-Relation (ER) model "adopts the more natural view (of) the real world". This technique has been widely adopted for data modelling in order to represent the conceptual model of the data (Chen, 1976). Interviewing and eliciting users' needs and their overall requirements specification is essential in the process of building the database. Those specifications included data required for data relationships, data processing and the choice of software platform for implementing the database (Teorey et al., 2011). The following sections will highlight key elements of the development processes for the PWE database as well as how this relates to the needs of the staff from the ambulance service and PWE/carers.

7.2.1 PWE Database Development Process

Building an electronic database for the department seemed at that time, most appropriate to overcome this dilemma, as it would have been time consuming to collaborate with a different health body or a department (obtaining organizational and NHS approvals had already taken a year's time). Benefiting from the experience of an existing database system within other departments in the same hospital was an appropriate and a suitable starting point for the development process of the electronic system of PWE database. Therefore, advice was sought from the Diabetes Care Centre, which was located opposite the Neurophysiology Department.

Working with staff from the Diabetes Care Centre was beneficial in forming a comprehensive idea of how database systems are hosted, function, collaborate, maintain etc. in the hospital. Also, it was important to know how the diabetes database was managed and maintained. The Diabetes Care Centre staff provided guidance, using their long experience of working with the diabetes database, to help determine needs and requirements.

7.2.2 Participants' Needs

It was important to meet user's requirements and elicit their perspectives towards the information transfer system (ePRF), the electronic database, and the IB. Requirements and perspectives were elicited from three groups. The first group was staff in JCUH (excluding ED staff), the second was PWE/carers, and finally the third group was ED staff only in JCUH. The reason for having the last group separately was because authorized staff in the department can access the finalized ePRF. Data gathered from all groups were analysed thematically to extract themes. Table 7.1 represents information regarding these.

Participants	**Identified Needs**
JCUH Staff (excluding ED staff)	• Database creation and management • Operational requirements from PWE database and interfacer • Internal/external information access
PWE/Carers	• Avoiding conveyance to ED • Information access/sharing • Information storage • Data protection • Stable lifestyle
ED staff only	• Rapid Access to Patient Information • Information Availability • Accessibility

Table 7.1: Participants' Needs

7.2.2.1 JCUH Staff Needs

The consultant neurophysiologist initiated linkage with the Diabetes Care Centre staff. Referral to them by the consultant was helpful in gaining more information of JCUH staff requirements from the database and the IB system. Additionally, their requirements were also helpful in regards to building the PWE database.

(i) **Database Creation and Management:** The diabetes database was first initiated by an individual effort 20 year ago by a consultant at the same hospital, and since then it has been functioning to serve their needs. Management of the database is run by two staff. They stated their desire to update the database and have connections with other external organizations like ambulance services and GPs. It was essential when intending to build a database to consider all the technical, software, hardware and system aspects. Not only that but incorporating end-users needs and requirements from the database. For instance, staff who will maintain and interact with the database directly prefer a robust system with no glitches. Staff indicated how important it should be to create a database that has the capacity to expand in the future to add more patients. Also compliance with the JCUH regulations and other system as well as the NHS standards in regards to security requirements, privacy, access and so on to patient data is critical.

(ii) **Operational Requirements from PWE Database and Interface:** Ongoing exchanges with the consultant neurophysiologist and the epilepsy specialist nurse, before and during building the PWE database was constructive in meeting their requirements and needs. Each one of them had a different requirement from the end-result interface. What information to insert, alter and access are main requirements for each although realized differently. For instance, the nurse wanted to be able to create care plans for patients she follows up with, whereas the consultant, on the other hand, did not get involved in changing a care plan. Medication dosage, frequency, generic and brand names were among the requirements the consultant neurophysiologist wanted to view and change. Both wanted the view layout and display of the interface to be simple. They wanted related information to be grouped separately in single tabs and displayed in one single view (less navigation).

(iii) **Internal/External Information Access:** The Diabetes Care Centre lacked access to external organizations like the GP, for instance, but were connected internally to the system within the hospital.

A limitation of using a paper database of patient information in the Neurophysiology Department is that this can create isolation of information and lack of communication and information transfer between other departments that are relevant to a patient's health within the same hospital. For example, getting blood test results from the laboratory or the haematology department. This may lead to data redundancy, loss, and fragmentation. The consultant neurophysiologist and the epilepsy specialist nurse expressed their desire to have access to external key information of patients from their GPs and the ambulance service. They also wanted to be linked internally to other departments in the hospital such as the laboratory, ED, etc.

7.2.2.2 PWE/Carers Needs

This section presents both PWE and carers requirements from the database, the IB and the ambulance service. Requirements were extracted from both interviews and focus groups then analysed thematically as described in Section 4.3.

(i) **Avoiding Conveyance To ED:** Participants have expressed their desire to be taken home by the ambulance crew after their normal pattern of seizure(s) if an ambulance was dispatched to them. One interviewee stated that, because the member of crew did not have any information regarding her daughter's condition during a call-out, she had to persuade him to treat her daughter locally and not convey to ED. Being taken to the ED or hospital and staying overnight is viewed as an undesirable outcome for them. She stated:

> *"I persuaded the paramedics not to take her to hospital, ...but I had to sign all sort of forms, but at least she didn't have to go, because she gets distressed if she has to go to hospital."*

Another interviewee said that her daughter should *"be treated (locally) then brought home"* by the ambulance service. A participant from the first focus group stated that after a seizure:

> *"The ambulance gets called-out, by the time the ambulance has arrived, they already have recovered, because some stranger or some helpful person has called it (the ambulance), and then, they maybe are confused afterwards, they are not able to persuade the ambulance to say, I don't want to go to hospital."*

Transportation from the ED or from hospital to back home was considered a challenge to a PWE, as after a seizure the person may be confused and unable to make decisions. Another participant from the first focus group stated that:

> *"Two people were taken in to hospital, and then they've been told, you don't need to stay in and then discharged....they were just left, no ambulance to take them back, they don't got money for a taxi."*

There were times when it was appropriate to transfer the PWE to the ED, however PWE/carers concern were about the times they did not feel they needed to be conveyed. A participant from the second focus group said:

> *"There is nothing worse than going to A&E and had to sit there, and you just sit there, you know, wasting time. You are taking someone's space."*

(ii) **Information Access/Sharing:** All interviewed participants stated a desire for the PWE information to be stored in the PWE database at JCUH. All PWE/carers from the interviews and focus groups were also willing to give their approval for NEAS or the ambulance service to access their information that is stored in a database to help facilitate the ambulance crew with their situation if on scenes during an incident.

All participants agreed that it would be beneficial to share medical history, medication, long term conditions, allergies, and next of kin. They are particularly in favour of this, as doing so enables them to avoid unnecessary conveyance to ED or hospital admission. A participant stated that: *"limited epilepsy information"* is sufficient for paramedics to access. Another commented:

> *"I'm 38 years old. I need to be independent. I want them to know what type of seizure, my medication.."*

The availability of information needed to inform next of kin was one of the things PWE wanted both the hospital and the ambulance system to gain access to, in order to inform them immediately if an incident occurs. If this information was not available to ambulance crews and ED staff, the PWE might cause family/carers etc. to panic because no one informed them of what has happened to them. Sometimes in outdoor situations an individual PWE might get an ambulance called-out during a seizure, and because the ambulance crew lacked reliable information about them, they will convey the patient to ED. Once released by ED, a person may not return to their normal condition immediately especially after a seizure. If next of kin was informed, they would be able to support them afterwards. A participant from the first focus group stated:

> *"I would wonder if this sort (IB) would pick up more of these incidents, when people need to be admitted, or else get sort of left at the hospital, nobody knows where they are...... can this (IB) inform next of ken?"*

Patterns of seizures of PWE are not being reported immediately to the the consultant neurophysiologist or the epilepsy specials nurse. The consultant would only know about an episode if the PWE/carer remembers to inform them and then only after a possibly long period of time, because some PWE are seen by the consultant or nurse twice a year for follow up. On the other hand, those patterns are reported to the GP if an appointment was scheduled. A participant stated:

> *"When it comes to see (the consultant or) the epilepsy nurse, its all reported then, or discussed, because I have a chart and everything, so I record them and bring my chart with me. Then they go through it and see what needs to be done if anything."*

The same participant stated that she does not report any seizure incidents or call-outs to the GP. Also, when an ambulance is dispatched to a patient, the consultant or the nurse in the hospital are not notified officially. One participant said: *"I just assume that they'll (the ambulance crew) do it."* The GP might be notified after a member of crew gets a patient's consent to send an email to their GP regarding the incident.

When attending a clinic in the hospital, a patient sometimes would forget to mention to the consultant some specific incidents that occurred (e.g. an ambulance call-out) because of the long time period between appointments, or because their condition at that time meant that they did not adequately remember the incident. They wanted to be assured that the person who was providing healthcare to them had a complete picture of their health status as much as possible, whether it be a consultant, specialist nurse, a paramedic, a GP etc. As an interviewee commented:

> *"I report them to the GP, oh yes. No, I wouldn't report them immediately (consultant neurophysiologist) I'd only show them this (manual recordings of seizure patterns). I would not report them immediately."*

PWE/carers expressed that they want bystanders to call the ambulance service for help during a seizure when they are outdoors alone. Again, a participant from the first focus group said: *"I would think I've want anybody to call ambulance."*

Wearing wrist bands or jewellery with information on is a good idea, which not everybody likes. Assigning specific vivid colours to specific conditions, like purple for epilepsy, might make it easier to be spotted and identified by the ambulance crew and/or people. Some participants also commented that the reason they wear wrist bands is to identify them and alert the ambulance service that they have this condition and that there is potentially information that crew need to know before treating them. One carer commented that her daughter is *"wearing a purple wrist band with her information on."* Another participant also said:

> *"I always have worn it in black, and people just assume it's a pouch. I changed the colour, and my friend told me now that's more noticeable."*

Another person from the second focus group commented that she keeps her bracelet always on her: *"I have a little bracelet as well. I have a little bracelet on me."*

Contacting the ambulance service was not always a negative experience to participants, as some had a positive encounter with them. For example, a PWE from the second focus group said:

> *"The ambulance service came to me when I was having a seizure and they sort of came checked me out and say, well you are ok, where do you live? I told him and I was actually near the ambulance station, so they said, jump in the back we will give you a lift home, so you know, that was the plus side of it."*

Carers will also call the ambulance service for support if they feel panicked or do not know what to do if the person they are caring for is experiencing a seizure. For instance, a carer commented:

> *"I went upstairs and she was having a seizure. Just quietly, just lying there and I couldn't rouse her; I just couldn't get her to respond in any way at all. So I panicked and called the ambulance and the following day they kept her in hospital."*

(iii) **Information Storage:** All participants interviewed in JCUH were happy to have their information stored in the PWE database as long as security and data protection procedures are applied. A participant stated *"as long as it is secure, you know, and there is only access for people who are allowed to access it really"* regarding the information stored in the database. One participant thought the ambulance service already had access to their information from the hospital database. He said: *"I would've thought it was accessible."* Another showed her agreement to store her information in the electronic database, *"the more information they have, the more benefit it is for the carer."*

(iv) **Data protection:** Again, the only concern participants showed regarding their information being stored in a database and accessed by the ambulance service was third party access; that is accessed by people who are not authorized to view their health information. A participant from the first focus group stated: *"its just if it goes to the database, not given out to other third parties or other organizations."* Another from the second focus group said: *"yes, I would like them to access it, but just health bodies, just health."*

(v) **Stable Lifestyle:** The availability of their information to be accessed by ambulance crew may increase PWE/carers confidence and independency. Participants commented on that saying: *"yes, I think it would"*, another said:

> *"Yes, absolutely, definitely. I live a very independent lifestyle, I live on my own and I'm prone to seizures in the mornings. There is a 15 minute gap where I go from home to work, I worry about that people don't know me. But as soon as I get work, all my colleagues know that I'm epileptic ....(and if this system is available it would give me confidence) absolutely yeah, yeah."*

Additionally, a PWE commented saying:

> *"I mean any help at all is good. And I would be more independent....my husband get worrying about me all the time. I would like to have as much as I can, get on the bus..."*

7.2.2.3 JCUH ED Staff Needs

This section presents staff working in the ED at JCUH needs from NEAS ambulance service, the information transfer system (ePRF), and the IB. Those were elicited from their interviews, which were thematically analysed as previously mentioned in Section 4.3.

(i) **Rapid Access to Patient Information:** The ePRF is not accessible to all ED staff, as only authorized staff have permission to view the finalized ePRF from NEAS's server. Not only that, but accessing the electronic form is not immediately available after the patient handover, it might take 20 minutes on average to finalize the ePRF. This may put the ED staff in a critical situation, especially when they are with the patient and need to confirm facts. Authorized ED staff, may be faced with other issues regarding rapid access to the ePRF. Some issues are: time consumed accessing the electronic form, viewing it or even printing it off.

(ii) **Information Availability:** Accessing the ePRF is also time consuming and sometimes it is not immediately available on the system because it has not been finalised yet due to connectivity issues or a complicated job, etc. Staff therefore rely heavily upon verbal information from paramedics, and/or from the patient, if their condition permits. Those sources of information help them to decide on what they think is suitable for the patient.

Furthermore, patient information generated in ED often does not get integrated with their existing hospital records. This puts responsibility for data integration across health professionals and/or hospital units on to patients rather than the hospital system.

Although the ePRF is available online via the Webviewer, no other personnel or departments, in the same hospital, have access rights to view it, which makes the ePRF underutilized. In contrast, the ready availability of the PRF allows the paramedics' notes to be attached to the front sheet of the ED patient records which facilitates access by all ED staff to the data. Again, this is a contrast to the ePRF which restricts access to patient data and stores information independently, thereby causing information fragmentation. Giving similar access to ePRF forms for specific personnel in all wards and departments in the hospital could help to reduce this fragmentation.

(iii) **Accessibility:** With the PRF, ownership of both the form and the data is shared between NEAS and ED. Also, the clinical staff providing care to the patient can easily read the form, adding assurance and confidence to their actions. This is not the case for the ePRF, as not everyone has access rights to enter the system, thus many ED staff lack ways to obtain information regarding a patient who arrives by ambulance. Of the three interviewees, two stated that they had never seen an ePRF before.

7.3 Building the Database

Consulting the Diabetes Care Centre staff has played an essential role in building the electronic database system for PWE. It provided important elements of what platforms to use and interface to apply, as well as the effect upon what are the requirements if the number of patients were to increase etc.

7.3.1 The Database Design Life Cycle

The life cycle of database system development requires three main phases, namely: the Conceptual Database Design (CDD), the Logical Database Design

(LDD), and the Physical Database Design (PDD). The CDD phase commences with the creation of the conceptual data model from the organization, which is independent of all physical implementation details such as application programs, programming languages, performance issues, hardware platform or any other physical considerations. This stage requires a clear understanding of the organization and its functional area, and includes determining end-users needs, requirements, and views. This is then followed by defining entities, attributes, and relationships then defining relationships among them. After that, defining the primary keys and foreign keys of each entity. This is then followed by normalization of entities, leading to the creation of the Entity Relationship (ER) diagram.

The second stage is the LDD and this provides information to the following stage PDD, it also drives a set of relations from the CDD to produce a model. That is, it translates the CDD into an internal model for the database that has been selected. All objects in the model are to be mapped in specific constructs which the selected database can use. Thus, the LDD is software dependent.

The final phase, which is the PDD, is dependent on the previous modelling and it is not an isolated activity. The LDD defines the PDD requirements that allow the system to function within the selected hardware environment. There is constant feedback between the logical and the physical design activities (Gupta et al., 2011; Teorey et al., 2011; Coronel and Morris, 2016). The following highlights some of those steps, noted above, applied to the design of the PWE database. Fuller details are provided in Appendix N:

7.3.2 The Data Model

All requirements were summarized in a document form that grouped relevant data items together to determine what needs to be included or removed. This was followed by finding a relation between various data items that are related to each other. See Figure 7.1. Further analysis was applied by defining the entities, attributes, relationships, primary keys, etc. The result was organized as groupings

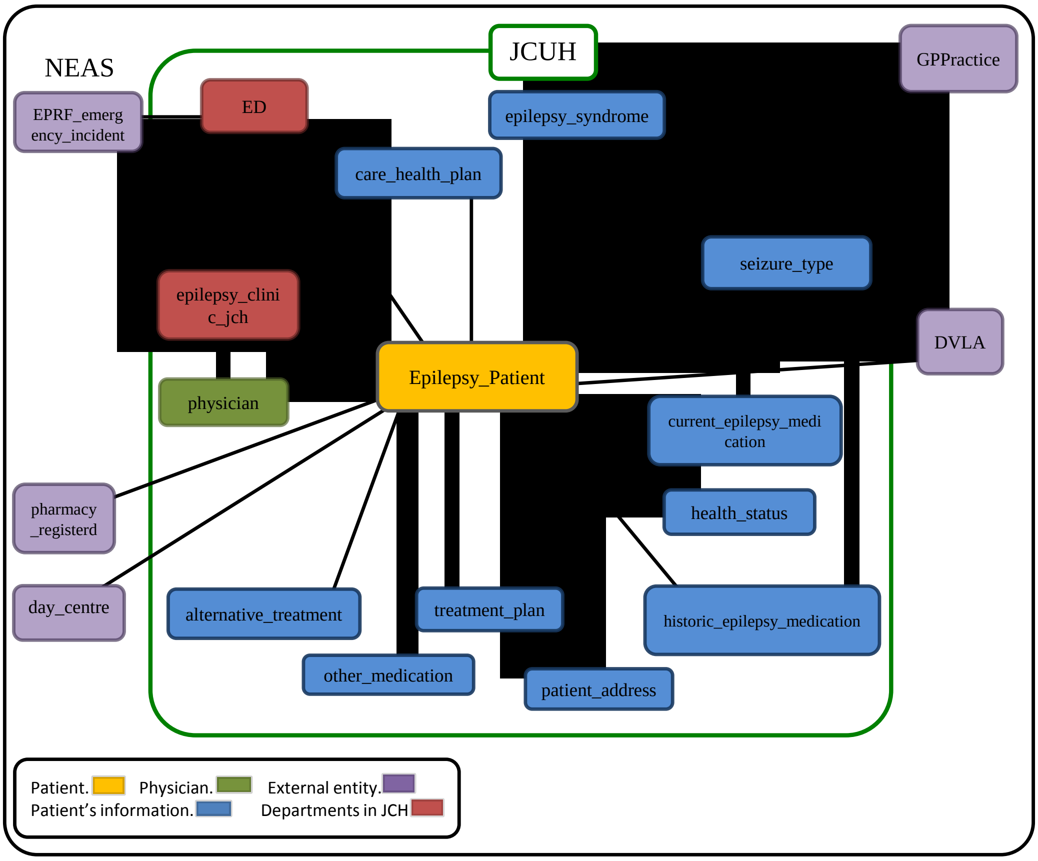


Figure 7.1: Database Model

in logical tables, (Appendix O that displays details of this). This helped create a diagrammatical view of the database in the form of an Entity-Relationship (ER) diagram as shown in Figure 7.2, which was then used for designing the database. This data modelling technique, i.e. the Relational Model, aims to show relationships between entities (people, objects, places, events, etc.) by applying Chen's "crow's-foot" approach to emphasize the relationships between the entities (Chen, 1976).

What fields to include in the database, and what should appear at the user front-end was agreed by all potential end-users (physicians, epilepsy specialist nurse, administration staff, IT staff, and PWE/carers). All of the information stored that is related to one PWE, must be connected and related to the same person in the database. (Epilepsy_Patient) was therefore the main entity in the database, and then other related entities were connected to it. Those other related entities carried

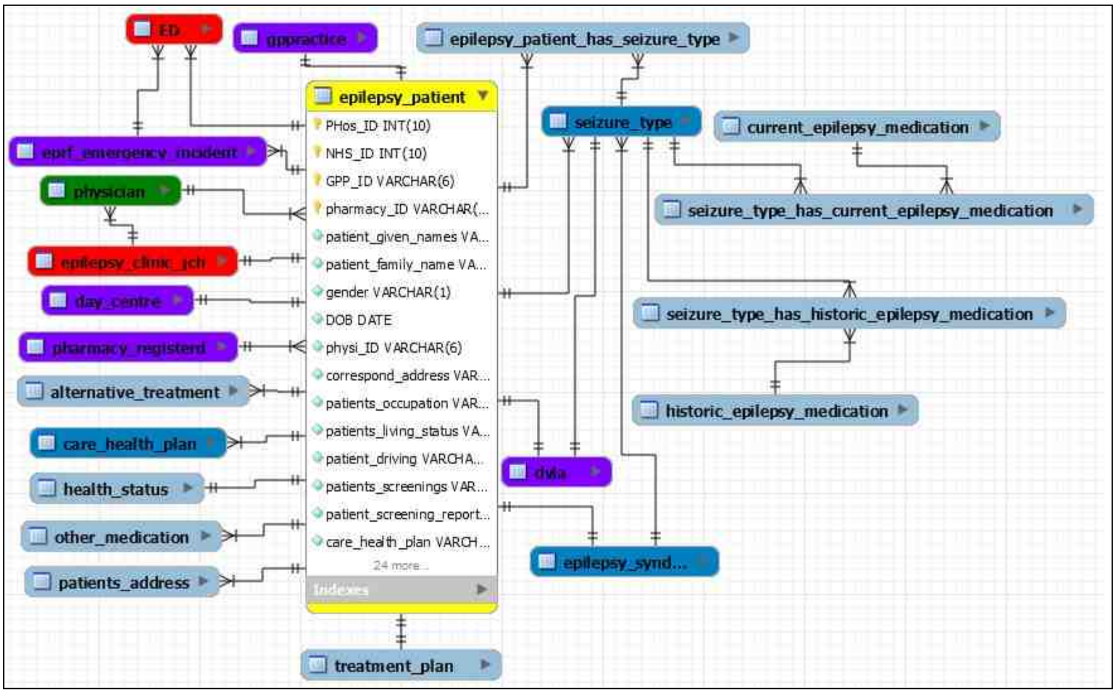


Figure 7.2: The Entity-Relational Diagram

additional information about the (Epilepsy_Patient), see Figure 7.1. For instance, GPPractice in the database will display information regarding the GP Practice's ID (GPP_ID), GP Practice name (GPP_name), GP Practice address (GPP_address), GP Practice email (GPP_email), GP Practice contact (GPP_contact), and GP Practice notes (GPP_notes) associated with the PWE. Appendix O provides an example of records (tables) of the database and categories of datasets assigned to each field.

The arrangement of the records within the database was a result of all agreement between end-users, suiting each of their needs and requirements. For example, if the physician would like to prescribe new medication for the PWE, he/she would access tables (historic_epilepsy_medication and current_epilepsy_medication). Accessing this information will display the full information about past and current medication prescribed to the patient and still prescribed . This will display generic and brand names of medication, dosage, frequency, side effects, start/end date, etc. Having all this information displayed in front of the physician will give a full picture to help determine what medication to administer, discontinue, alter, and/or keep.

7.3.2.1 MySQL Database System

MySQL is an open-source relational database management system (RDBMS) based on Structured Query Language (SQL). It enables users to add, access, and process data that are stored in separate multiple tables in the database. Each table (rows and columns) holds a specific type of information (World Wide Web Consortium (W3C), 2018*b*; MySQL, 2018).

MySQL database server is very fast, reliable, robust, and easy to use because it was originally developed to handle large databases. Other features include security, reliability, scalability, and compliance with existing standards (Vaswani, 2005). Additionally, the MySQL server works in client/server or embedded systems, it supports different back-ends, several different client programs and libraries, and a wide range of Application Programming Interfaces (APIs) (MySQL, 2018).

Prerequisite system requirements were necessary to install prior to demonstrating the IB prototype and its access to the PWE MySQL database, these are Apache and Hypertext Preprocessor (PHP). Each is presented briefly:

- **Apache:** is a web server that "intercepts HyperText Transfer Protocol (HTTP) requests and either serves them directly or passes them on to the PHP interpreter for execution". Apache web server was used because of its wide spread and popularity. It is also lightweight, robust, open source and cross-platform (Ljubuncic, 2011).

- **PHP:** is a scripting language that is "widely-used open source general-purpose.... that is especially suited for web development and can be embedded into HTML". PHP scripts are executed on the server side, and the result is returned to the browser as plain HyperText Markup Language (HTML), more details of HTML is discussed in Section 10.5.2. Additionally, PHP can access a variety of databases and it is available in most operating systems and web servers (Bakken et al., 1997; Vaswani, 2005).

Both the Apache web server and PHP were essentially installed, this is to prepare the PWE database to be accessed by the IB. What makes MySQL, Apache, and PHP popular is not only that they are open-source, but also their availability for different platforms and architectures (Vaswani, 2005).

All these features in MySQL made it the best available database system to use for the PWE database in JCUH. MySQL was applied as the back-end data repository, Microsoft Access was used for end-users interface in JCUH to manipulate the data (Delisle, 2006).

Data inserted in MySQL database was dummy information of PWE. What information to include in tables is discussed in Section 7.3.2 of this chapter.

7.3.2.2 Structured Query Language (SQL)

Structured Query Language (SQL) is a standard computer sub-language "for access to relational databases that are managed by relational database management systems (RDBMS)" (Melton and Simon, 1993). SQL is the standard database query language and using SQL not only fulfils the requirement for data manipulation and the management of data and data structures, but also enables interaction with the database. SQL can be used to retrieve large amounts of records from the database in a quick and efficient manner, which appears a suitable reason to use for patients' information stored in databases. SQL statements in Data Manipulation Language are (SELECT, INSERT, UPDATE, DELETE) are used to add and update the data within the database. Statements in the Data Definition Language are (CREATE, ALTER, DROP) are used to define the structure of the database.

SQL is an easy language to learn and use, also it is widely implemented in the NHS and other organizations. It is a simple and a powerful language (Atzeni et al., 2013). Being a database sub-language set can be embedded into other languages such as C, Java, C++. Other strengths include, portability across computer systems, compatibility with a client-server architecture, and internet database access. Theses are all important for both building the database for the hospital and for linking it to demonstrate it with the IB. Further, SQL-based database applications can be implemented on personal computers as prototype applications before moving to upgrade it to a multi-user system. It also allows personal computers to function as front-ends to network servers. Finally, SQL is a common gateway widely used to retrieve and represent database information on web pages (Groff et al., 2002).

After deciding on the technical part of the system, the end-users requirements needed to be provided. Therefore, a database system requirements analysis was conducted in order to define the objective of the database and to gather end-users' requirements and needs.

7.3.3 Building the Interface

After building the database, it was necessary to provide a set of interfaces for use by end-users. This front-end user interface is based on the different needs and requirements of the end-users. Furthermore, they need to be able to add, edit, delete and modify data located in the database, which can be achieved by using queries based on the Structured Query Language (SQL). Fields in tables were created corresponding to what was required by end-users to manipulate. Multiple visits and meetings with the consultant neurophysiologist, epilepsy specialist nurse, and the administration staff were involved to ensure that all tables and fields in the database contained the exact needs for each group. This was accompanied by multiple revisions of the database tables/fields in order to finally capture the exact requirements.

Later on, this was followed by the need to present the database through a front-end user interface. For this, Microsoft Access was to create a front-end user interface. Steps suggested by Rogers et al. (2011), in their book *Interaction Design: Beyond Human-Computer Interaction* were employed in its design. They state four activities for successful interaction design, these are:

1. Establishing requirements.
2. Developing alternative designs that meet those requirements.
3. Building interactive versions so that they can be communicated and assessed.

4. Evaluating them, i.e. measuring their acceptability.

Those four activities were involved when building the PWE database and the front-end interface.

1. ***Identifying needs and requirements:*** After identifying users benefiting from PWE database and front-end user interface, their needs and requirements needed to be identified. Understanding their work and the context they work at is essential in order to develop a system that supports their activities and achieve their goals. It is more likely that the end result will satisfy users' requirements if end-users needs and requirements were considered and satisfied. The consultant neurophysiologist, epilepsy specialist nurse, and the administration staff each had their own different needs from the database and from the front-user interface. For instance, the consultant neurophysiologist, wanted specific information regarding seizures, seizure types, current medication, and past medication to be in the database.

2. ***Developing alternative designs:*** This is the core activity of design. It is based on two sub-activities: the conceptual design and the physical design. The conceptual design is producing a conceptual model for the product. This describes what the interface should do, look like and behave. This was discussed with the potential end-users based on their requirements. The physical design, on the other hand, considers the details of the interface: colours, images, menu design, and icon design, see Appendix P. At every stage, alternatives proposed by the end-users were considered and were modified to meet their needs.

3. ***Building interactive versions:*** The most suitable way for users to evaluate the design involves interacting with the interface. An interactive version of the front-user interface was built. This was very useful in observing how end-users interacted with the interface and how they engaged with it. Such practice using dummy data enabled the end users to assess, communicate and evaluate the interface. End-users were able to give feedback into further design changes.

For instance, the epilepsy specialist nurse wanted to combine two tabs (current epilepsy medication and historic epilepsy medication) under one tab named (epilepsy medication) of which it consists of both tabs combined. She also wanted information in the medication fields to be arranged and displayed in a table format instead. Further, the consultant neurophysiologist, for example, wanted the patients demography tab to be removed and to have the patients demography display on the top, even when navigation takes place between different tabs. Appendix Q represents both the first version interface and the final version interface after end-users feedback have been applied.

4. ***Measuring their acceptability:*** This involves evaluating the final interface by end-users. It is to determine the usability and acceptability of the interface. The number of errors users make using the interface, how well the interface matches the requirements, how appealing is it, etc. are different criteria to measure the interface.

Collection of all these activities led to the creation of the front-end user interface. Figure 7.3 represents the general view of PWE database interface and Figure 7.4 illustrates the end-user view to the interface, that displays the stored information in the database about a person with epilepsy.

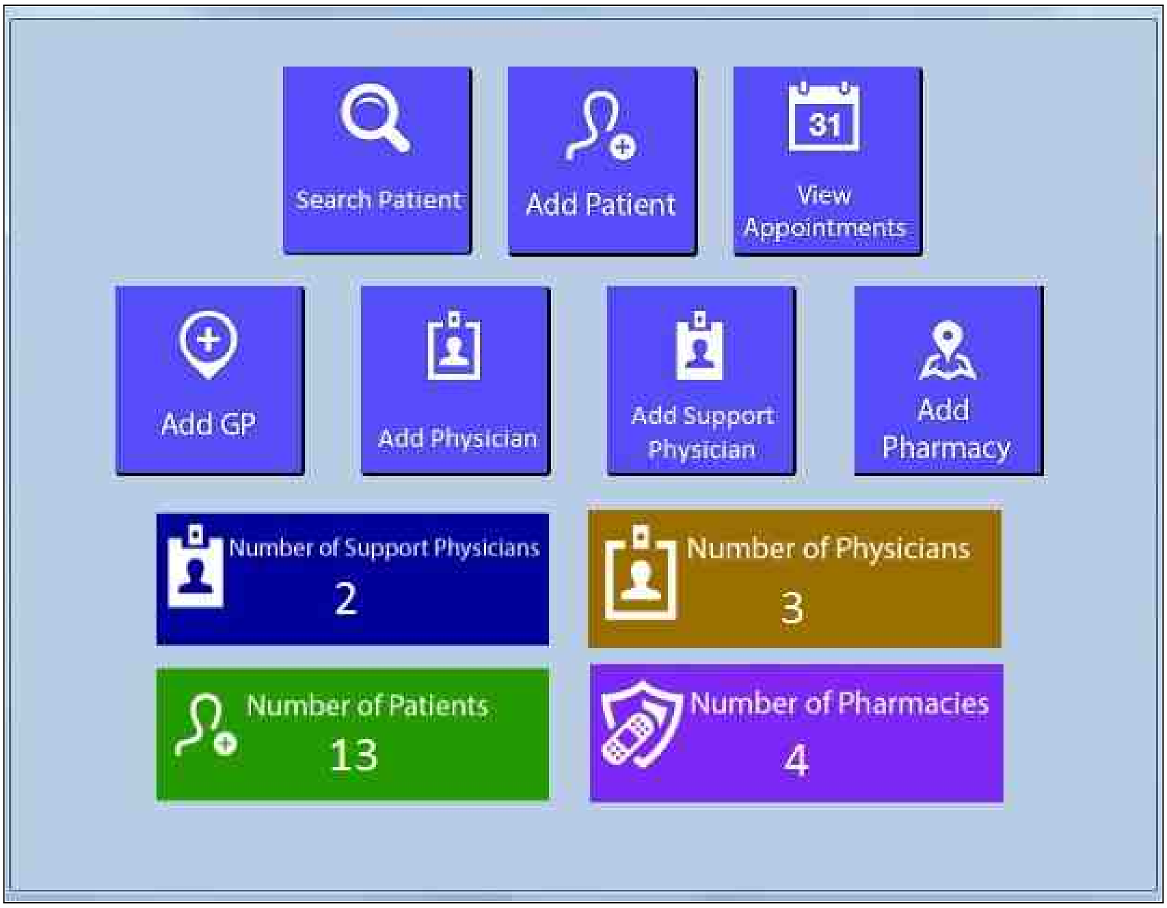
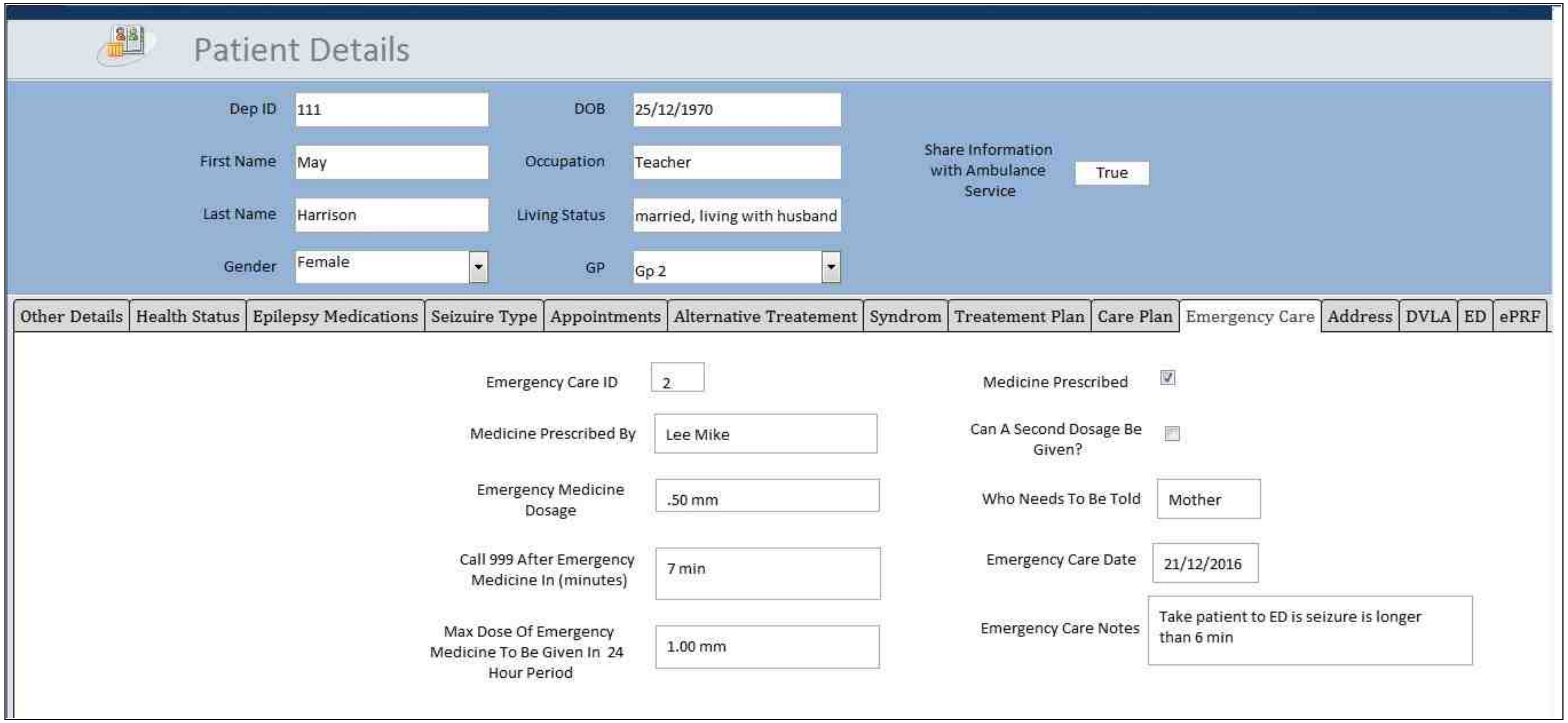


Figure 7.3: The Epilepsy Database Interface- General View



Dep ID: 111
First Name: May
Last Name: Harrison
Gender: Female
DOB: 25/12/1970
Occupation: Teacher
Living Status: married, living with husband
GP: Gp 2
Share Information with Ambulance Service: True

Emergency Care ID: 2
Medicine Prescribed By: Lee Mike
Emergency Medicine Dosage: .50 mm
Call 999 After Emergency Medicine In (minutes): 7 min
Max Dose Of Emergency Medicine To Be Given In 24 Hour Period: 1.00 mm
Medicine Prescribed: ☑
Can A Second Dosage Be Given?: ☐
Who Needs To Be Told: Mother
Emergency Care Date: 21/12/2016
Emergency Care Notes: Take patient to ED is seizure is longer than 6 min

Figure 7.4: The Epilepsy Database Interface- Patient Details

7.4 Summary

Here presentation of the second phenomenological study was presented. Findings were related to JCUH staff and PWE/carers. This was important to form background information not just for developing the IB and building the PWE database, but also to elicit end-users opinions and requirements from an existing information transfer system (ePRF). Requirements varied according to end-users status. JCUH staff (excluding ED staff) were more focused on the system data management, presentation, manipulation, internal/external integration, and information access. ED staff wanted the ePRF to be rapidly accessed, available and accessible. Finally, PWE/carers requirements were focused on their lifestyle routine, the unnecessary conveyance to ED, data access, protection and information security.

Chapter 8

The Ambulance Crew: Findings

This chapter will describe the third element of the phenomenological approach, i.e. the perceptions of the ambulance crews working for NEAS towards the IB, and the information transfer system of the ePRF. Eliciting what ambulance crews required from this information transfer system in general, and what specific information was needed to support their decision-making in particular, was necessary for building the Information Broker (IB) prototype and the ambulance crew user interface.

8.1 Introduction

Gaining background information from the ambulance crew was essential in order to build the IB prototype as a feasibility study on providing electronic 'on-demand' health information. This required an understanding of what members of a crew wanted to be able to use while on scene after providing appropriate treatment. This is to assist them in their decision on conveyance to the appropriate location for a given patient condition. This also included the ambulance crew's opinions and experiences towards the ePRF as well as their opinions toward the information transfer and communications occurrence in the NEAS system. Data collection tools applied were previously discussed in Section 4.3. Participants involved were also presented in Table 4.3 and discussed in Section 4.3.3.

Both interviews and observations of the ambulance crew were critical in obtaining their experience in order to understand how the current system worked and what problems were facing them. Not only that, their feedback was essential in eliciting their information requirements of the IB and their perceptions towards the information transfer process in the ePRF system.

8.2 Findings

The outcomes of the thematic analysis are the presentations and description of the ambulance crews' opinions about what was lacking in the current system, their perceptions towards the ePRF system, and what 'on-demand' health information they wished to have from the IB. As mentioned previously in the data analysis in Section 4.6, codes were identified from the transcripts of the interviews, leading to grouping of themes. Observations included note taking and then later on were analysed. As observing participants in the field is the best way to determine their requirements and form background information of the system process. The following presents identified emerging themes regarding the IB, then those regarding the ePRF:

8.2.1 Emerging Themes regarding the IB

Two themes emerged from the thematic analysis of the interviews and observations which are related to the research questions. Appendix R represents a sample analysis of the observations that occurred at ED. Presentation of emerging themes and the ambulance crew requirements from the IB are highlighted in Table 8.1.

1. ***Information Regarding Patient Health:*** The ambulance crews stated that if additional information regarding patient's health was available, this would aid them in providing treatment suitable to the patient's health condition.

Theme	**Crews' Requirements from IB**
Information Regarding Patient Health	• Current Medication • Allergies • Known Conditions • Attempt Resuscitation • Next of Kin • Care Plan
Information Regarding Patient Encounter with other Organizations including the Ambulance Service	• GP Latest Notes & Contact Information • Previous Encounter with the Ambulance Service • Recent Contact with Health Services

Table 8.1: Ambulance Crew Requirements and Emerged Themes from the IB

The lack of information results in undesirable actions like unnecessary ED conveyance. The ambulance crew would make the decision to convey the patient to ED if information was lacking. One participant gave a reason to that saying:

> *"(If) feedback information (was lacking) they would be transported to hospital to place a safety for their own."*

Another paramedic stated that having additional information of the patient on scene:

> *"Will give me the chance to get ensured that the patient gets the right treatment at the right time."*

Additional information regarding patients health would also assist them in deciding the most suitable care pathway to follow. For example, if the crew knew what long-term condition(s) that patient had, they would be able to manage the patient appropriately and may be able to quickly determine whether this unconscious patient, for instance, is in this health state because of hypoglycaemia or due to an epileptic fit. Once determined, the ambulance crew will be more confident to choose a suitable care pathway, 'See and Treat', 'See and Convey Elsewhere', or 'See and Convey'.

The ambulance crew, because they are in time critical situations, do not require detailed information if they are to have any sort. Basic information regarding the patient's current medication, known condition(s), allergies, next of kin, and care plan were identified as being sufficient. Table 8.1 represents those requirements. A paramedic interviewee stated:

> *"When you go into the room you solely concentrate on the patient for the first 5-10 minutes."*

Some patients will not inform the ambulance crew of their medical history due to various reasons. Confusion, tiredness, forgetfulness, etc. are reasons that might cause such action. Therefore, transferring health information of patients, to the ambulance crew while on scene, through electronic information transfer means are more reliable and accurate. In an interview a paramedic stated that:

> *"Sometimes you spend two hours with the patient and you think you have everything, and then you walk into A&E and he turns around and say something totally different to the A&E staff or to the doctor. And it's like, you never told me you had that. Oh, did I not mention that one? Did I forget to tell you of the five heart attacks and a triple bypass?.....even things as big as that. Not just little things, you know, you think you've got everything out of them, and then suddenly they will pop out just a little bomb in there."*

2. ***Information Regarding Patient Encounter with other Organizations including the Ambulance Service:*** the ambulance crew also expressed their desire to have additional information regarding encounters the patient has made with other external organizations and with the ambulance service as well. Knowing this kind of information might alert them about the patients' health status, or lead them to seek more detailed additional health information from the health provider. For instance, knowing that a patient has had an ambulance dispatched to them several times on the same day might enable a crew to foresee a medical alert, a need to visit their GP, or to be taken to an

ED. Table 8.1 again represents the ambulance crew requirements of patients information access of the IB related to other organizations.

In addition, there are cases where the patient is not conveyed to ED. This could be due to patient's health stabilization, therefore, the need to convey to ED is not necessary any more; the patient has deceased, or simply because the patient refused conveyance to ED. In those situations, the member of crew will need to give a paper form to the patient stating the care that was provided on scene (patient information leaflet), patient has refused conveyance (capacity form), or patient has deceased (roll form). A paramedic will decide on what form(s) to be given based on the situation, as one commented:

> *"It might be a capacity form, a patient information leaflet, it could be a roll form if they've died. It depends.."*

The patient information leaflet and the roll form are kept with either the patient/career or the carer if the patient is deceased. The capacity form will be signed by the patient and kept with the ambulance crew. The ePRF will be created as well, and permission to send a copy of the incident to the patient's GP electronically needs to be approved by the patient's signature, as a paramedic has stated: *"... GPs can get a form of it, if the patient agrees to share data."*

The challenge here is leaving the incident information with the patient/carer in a paper format. This places the responsibility of passing information on the patient not the system if the patient decides to share their information with a health provider. This creates an increased possibility of the paper format being lost, not conveyed to the relevant health provider for any reason, or even damaged. Although this thesis focuses on the ambulance crew side of providing them with the patient information, it is important to indicate the other side of the process. As this challenge has an indirect effect on the chain of information passing and transfer by being fragmented in regards to format, storage, access and flow. Leaving the responsibility of critical information transfer to the patient rather than the system just adds more complexity to the process of information transfer, loss, storage, and sharing.

8.2.2 Emerging Themes regarding the ePRF

Data from the handover observation of the ambulance crew to ED staff revealed that (42/74) 56.7%, preferred the electronic handover of patients information on the paper one, in other words, preferred using the ePRF on the PRF, for more detail see Section 9.2. Yet still ambulance crew had mixed views about the benefits from using the ePRF. In particular:

1. All participants think it is time consuming and it takes a long time to complete. Five participants stated that it is comprehensive and covers everything.
2. Some consider the ePRF as a detailed legal medical document, and some view it as a sophisticated system that is too detailed, which can then lead to information overload.
3. The ePRF has more fields than the paper PRF, however, some of these require information that is beyond the crews' training and ability to assess.
4. The format of the PRF ensures the included data is concise and that the most important information needed is highlighted, whereas the volume of information requested by the ePRF on multiplicity of 'pages' on the screen can cause important information to be lost in the details.

Four themes emerged from the thematic analysis of the combined interviews and observations of the ambulance crew regarding communication and information transfer of the ePRF system. The thematic analysis of the data revealed:

1. ***Connection Availability:*** If connectivity is not available, the ambulance crew face the challenge of finding a way to connect their Toughbook (that holds the ePRF) to the system to download a patient's incident initial information and/or upload the finalised ePRF. Finding workarounds to overcome those

obstacles adds more time and stress to the job. For instance, after completing a handover in ED, paramedics sometimes need to connect the Toughbook to the Docking Station in order to download the patient's incident initial information, where this has failed to download previously due to connection failure. They will also try to reboot the system if the screen freezes or the system does not respond. They will even go outside the ED in order to make a connection. All that might happen more than once in a 12-hour shift. The need to reboot the system, attach the Toughbook to the Docking Station at the ED, and enter the patient's information manually increase the delay in making the ambulance crew available for the next job. A interviewee paramedic stated that one of the problems they face is:

> *"Connectivity sometimes with the Toughbook, because if you are in a bad communication area, or for whatever reason it's not downloading the information, sometimes we end up having to manually put all the information in, which is time consuming..... Sometimes if you've got either connectivity issues, where the Toughbook got more than 500 packets a day waiting to be sent or received, and you've get two little red balls on it, and it's got no internet, no connectivity, you've either got to wait till you get to the hospital, they have a database station (Docking Station) where you can log it in, and hopefully it should download the information, but if the system is down totally, which frequently happens, then the only way to do it is manually."*

Another interviewee paramedic stated that she downloads information from the Docking Stations installed in EDs if connectivity was lost:

> *"....and we just put it (Toughbook) in there (Docking Station) and it downloads all the information."*

2. ***Job Type:*** The two job categories are **red** jobs, which are life threatening incidents requiring an eight minute response rate, or **green** jobs, which are not

deemed to be life threatening, and for which the response rate can be between 20 minutes to 60 minutes depending on the patient's condition. Table 5.1 displays the type of response for each category which have been prioritized into nationally agreed categories according to the situation. The job category also affects the crews' availability to be assigned to another incident and a call-out, and hence can reduce the numbers of ambulance crews available for other incidents. It seems more reasonable to have two different ePRF formats compatible with the incident category, complex for **red** jobs, and simple for **green** jobs. In an interview, the paramedic's reply to the question 'how long do you typically spend entering all the information about the patient into the ePRF?' was:

> *"It totally depends on the sort of incidence it is, if it is a straight forward incident and depending on the individual paramedic, ... If it's a major job i.e. uses a resuscitation, or a major trauma incident, or a major medical emergency if we take them in through resuscitation they will may probably take a lot longer "*

3. ***Ease of Data Entry:*** Entering the data in the ePRF while travelling to ED might also distract a paramedic from observing the patient or providing care. This is due to the fact that doing such a job requires attention and focus because different tabs and boxes may have to be filled or chosen, involving scrolling up and down and clicking on other tabs with different information requirements.

   Two factors that affect patient data entry time were identified. The first is the type of format being used whether electronic (ePRF) or paper (PRF). According to the interviewees the ePRF takes at least 20 minutes to complete on average; one paramedic reported that in complex 'outlier' cases completion can take up to three hours. In contrast, the PRF takes on average five to ten minutes to complete, depending on how complicated the job is. As a consequence, the PRF has sometimes been used by paramedics to buy time by claiming that the ePRF is not working. However, although the time spent completing the PRF is less than that needed for the electronic one, it might not ensure legibility as the ePRF does.

The second factor that affect patent data entry is the job category. If the job is a **green** incident (not life threatening), then the paramedic can complete entering the data en-route, but if it is a trauma or a complicated **red** job (life threatening), where time is needed to provide care to the patient, then entering the data may not be possible until the patient is handed over to ED care. A paramedic in an interview stated that entering data in the ePRF is not as easy compared to the paper format:

> *"In the sense of inputting data in the ePRF, that is time consuming compared to a soft format (PRF) where you just write it yourself. (The PRF) is free flow you could just write it.... but most of us finds it time consuming to complete it......compared to the paper"*

4. ***Technical Issues:*** Ambulance crews also have identified other technical issues related to hardware, software, and/or malfunctions. The problems encountered while using the Toughbook may be either technical, physical, and/or personal. Technical and/or physical problems include: running out of battery charge, Toughbook damage, software updates, data insertion to ePRF, navigation issues and rigidity with the ePRF system, dropping it, facing a technical glitch, unresponsive system and out of date devices that are more than four years old. The personal issues are reflected thorough the threat to data accuracy when spelling errors occur. Data accuracy can be a problem when spelling errors mislead readers and potentially contribute to treatment error (though this is not unique to the ePRF). Medication error may lead to disability, death, and unnecessary health processes (Courtenay and Griffiths, 2009). One paramedic interviewee stated that she once broke her Toughbook unintentionally, she said:

> *"In an ambulance they (Toughbook) are stored in the back, on a secure house and then in a car, this is stored on the floor on the passenger seat, so that they do not move around. Because I forgot*

> *last week and left it on the seat and went, weeeeee, straight to the floor when I hit the brakes"*

Another paramedic stated the technical difficulties he faces with the Toughbook:

> *"We are only supposed to use the PRF if the ePRF is not working, but then it's only if it's (Toughbook) actually physically broken. Frequently what happens is they don't charge up enough on the vehicles and we don't have the cables to do it when we are back on base during a break to give it a boost, so eventually if you're on it too long the batteries die."*

8.3 Summary

The final phenomenological approach was focused on the ambulance crew. Eliciting their requirements were in two sets. The first set was regarding an existing information transfer system of the ePRF. The second was their requirements from the IB interface. Ambulance crew wanted the IB interface to be simple, easy to navigate, view, and use. They also required specific patient information to be displayed to support their decision-making while on scene. Other information they required were patients' previous encounters with external healthcare providers and/or the the ambulance service. Findings from the ambulance crew from the ePRF study were issues related to connection, job type, easy of data entry, and technology.

Findings from this chapter and the previous three, Chapters 5, 6, and 7, were to answer the second research question, which is investigating issues of the sociotechnical aspects surrounding the information transfer system. The three approaches were triangulated in order to form background basis for the study of the IB prototype, and therefore assisted in answering the first research question.

Chapter 9

Lessons from the ePRF as a Current Information Transfer System

This chapter examines the electronic Patient Report Form (ePRF) which is an existing information transfer system being employed by NEAS for mainly management purposes. There are various factors that impede the electronic handover process of the ePRF from the ambulance crew working in NEAS to ED staff at JCUH. Front-line ambulance crews perceived using the ePRF in handover as time consuming. Some perceived the insertion of patient information into the ePRF as beyond their knowledge to assess. Other issues regarding the ePRF were related to the unease of system navigation, data entry, connection availability, incident job type (red or green), and technical issues.

9.1 Introduction

A study of describing how a current technology is being used as a learning exercise by extracting related issues of its implementation and effective use, was undertaken by investigating the view of operational staff about the ePRF. The ePRF system is a good match for the feasibility study.

The current system is used by NEAS as a means of transferring, storing and recording a patient's incident information when a vehicle is dispatched to them.

9.2 Background of the ePRF/PRF

The Patient Report Form, or PRF, which has now been largely replaced by the ePRF, is an A3 sheet of paper with sections for entering information about the incident's date, number, patient information, observations, location, diagnoses, medication administered, patient's final destination and care providers' information. The PRF could be completed manually by a paramedic on the spot or while on the way to ED. After verbal handover, an ED staff would sign the PRF indicating the acceptance of responsibility for that patient. The PRF, has not been completely discarded in the new system, it is still available to be used as a backup mechanism in some situations as mentioned in Section 8.2.2.

An ePRF, in contrast, cannot be finalized until all mandatory sections have been completed and it has been signed by both the member of the crew and the receiving ED staff. After it has been finalized, the crew member will upload the ePRF to the server using wireless connection if available, or by physically attaching the Toughbook to one of the Docking Stations that have been installed by NEAS in every ED. The data will be stored in NEAS's database, making it accessible to personnel who have been granted access rights by NEAS. Authorised ED staff are among those who can view the ePRF via the Webviewer if needed.

The ePRF/PRF form the ambulance crews' official record for an incident. It is a report from their point of view and conveys their observations about the incident. It is their version of clinical notes, and the only way to evidence the incident officially should there be a complaint or an investigation. The PRF gives ED staff immediate assurance of what the crew have said verbally after they have left the ED, since the PRF does not require any finalisation and a paper copy will be available to them. On the other hand, the ePRF can only be accessed by authorised ED personnel and only after it is uploaded to NEAS's server by the crew. The ePRF is not immediately accessible after the patient handover, it might take 20 minutes on average to finalize the ePRF. This may put the ED staff in a critical situation, especially when they are with the patient and need to confirm facts.

The ambulance crew sometimes find themselves lacking a connection and will not be able either to insert patient information, download the incident initial information of the patient, or upload the finalized ePRF. They might suddenly find the screen frozen or the system responding slowly or not responding at all. Finding workarounds to overcome those obstacles adds more time and stress to the job. Data from the 37 handover observations of the ambulance crew to ED staff that were described earlier in Sections 4.3.2 and 4.4.2, revealed that more than half of the handovers involved one or more kind of workaround. There were 20 occurrences of workarounds in the 37 handovers observed, with some involving more than one form of workaround. Table 9.1 summarizes how often each type of workaround was observed.

Workaround Type	**No. of Occurrence**
Writing on small pieces of paper	7 occasions
Writing on the back of a printed ECG	7 occasions
Writing on a glove	5 occasions
Using a PRF	3 occasions
Writing on a napkin	1 occasion

Table 9.1: Occurrence of Workarounds Employed during Handover to ED

Data collection as reported in this chapter were from documentation, interviews, and observations. Although the data collection tools applied were the same as the ones previously discussed in Section 4.3, the information extracted for the analysis underpinning this chapter was limited to those only relevant to the ePRF. Interviews involved members of the ambulance crew working in NEAS and staff working in JCUH ED. Table 9.2 describes the participants involved and the forms of data collection employed.

Participant	**No. Participants**	**Research Tool**
Ambulance Crew	74	Observation
Ambulance Crew	7	Interview
ED Staff	3	Interview

Table 9.2: Participants in the ePRF Study

9.3 Analysis of the ePRF Study

Thematic analysis was employed to extract issues related to the ePRF for both the ambulance crews and the ED staff. The emerging themes from the ambulance crews were connection availability, job type, easy of data entry, and finally technical issues. The emerging themes from the ED staff in regards to the ePRF were: rapid access to patient information, information availability, and accessibility. Discussion of the findings related to the ambulance crew and the ED staff towards the ePRF can also be found in Sections 7.2.2.3 and 8.2.2. The findings were further analysed in terms of the three perspectives of **cause**, **consequence**, and **potential amelioration** where these can be interpreted as follows. The cause identifies why these concerns arise (the underpinning mechanisms). Each cause can be viewed as arising as a consequence of specific design choices or decisions. The third element, amelioration, suggests possible ways of removing or reducing the effects of the issue. Those are presented in separate tables for simplicity. Table 9.1 represents the analysis of findings related to the ambulance crew. Table 9.2 represents the analysis of the findings related to the ED staff.

The factor	The cause of concern	As a consequence of	Potential ways to ameliorate
Connection Availability	• (Non-technical) connectivity problem. • Toughbook is connected to the remote NEAS server rather than directly to an ED. • Data flows from the ambulance to NEAS HQ, and only then is it available to ED staff access.	• Focusing upon NEAS management needs, therefore treating this as a database system rather than an information transfer system. • A 'compatibility' barrier for end-users who are concerned with the needs of patients at ED, not completeness of ePRFs in NEAS database.	• The information flow should start from the ambulance directly to the ED and then to the NEAS database. This would improve connections and be simpler to use.
Job Type	• The design of the ePRF focuses upon its role (means of collecting and recording data), rather than the role of the data itself. • The way that the end-user interacts with the system.	• Focus placed upon recording data rather than upon its operational use.	• Allowing crew greater freedom to organise data entry in a more task-related manner to fit the needs of different job categories.
Easy of Data Entry	• Navigational challenge from the limited size screen of Toughbook. • The ePRF layout has a set of tabs, each with two further levels of sub-tab. • The introduction of the ePRF introduced new fields in the ePRF (requiring more tabs), some of which are mandatory.	• Additional time required for data entry in the ePRF compared to the PRF. • Increased 'complexity' arising from additional navigation.	• Provide users with a choice of navigational models. • Introduce different navigation structures for red/green jobs, e.g. by providing a different set of tabs.
Technical Issues	• The use of a commercial operating system (Windows) that was designed for general office and home use. Therefore, system housekeeping may not be under the control of the users.	• NHS procurement processes. • Probably available developer skills.	• A robust platform (e.g. Linux) might address this problem, but would require quite extensive re-development.

Figure 9.1: Analysis of Findings Relevant to the Ambulance Crew Regarding the ePRF

The factor	The cause of concern	As a consequence of	Potential ways to ameliorate
Rapid Access to Patient Information	• The cause of this is the same as that discussed in (Connection Availability) for crew. These are: • (Non-technical) connectivity problem. • Toughbook is connected to the remote NEAS server rather than directly to an ED. • Data flows from the ambulance to NEAS HQ, and then it's availability to ED access.	• Designing the ePRF system as a Database Management System (DBMS) rather than a 'command and control' situation to handle operational data resulted in, both priorities and system architecture are unsuitable to the sets of roles the ePRF has.	• To upload the data directly to the ED as suggested for (Connection Availability). Suggestions from ED staff of a printout of the ePRF available may help reduce the risk of errors arising from verbal handover.
Information Availability	• ED staff do not wish to perform potentially inappropriate preparations or treatments based upon the incident initial information (i.e. the original call). • Information is currently being routed to NEAS before it is provided to the ED.	• Added complication by the verbal interaction between the caller and NEAS call handler, which involves providing information within a stressful situation and the various issues identified in Section 5.3.4.	• Streaming live key fields information from the ePRF to the ED.
Accessibility	• The addition of a Role-Based Access Control (RBAC) model to the system as a mechanism to ensure data confidentiality in NEAS database.	• System and information governance and data protection became NEAS's rather than being under the control of the ED.	• The use of RBAC may be unsuitable within an ED context, where focus is upon the patient rather than on the data. Decisions about patient data protection and access should be the responsibility of the ED, not of other organizations.

Figure 9.2: Analysis of Findings Relevant to the ED Staff Regarding the ePRF

In the analysis, the **consequences** identify the reason why **causes** arise. Therefore, elucidating key factors that emerge from them was essential to form a better view of the ePRF system utilization. Table 9.3 summarizes the three key factors that were considered to emerge from these.

Factor	**Elucidation**	**Supporting Issues**
System architecture	The system architecture is designed around a central database model which makes it unsuited to the purpose, it needs to support operational decisions instead (e.g. made by ED staff).	• Connection availability • Job type • Rapid access to patient information • Information availability
User interface	In relation to the elucidation above, the database context is constraining system usability (e.g. data entry, clinical use of the information in ED). Ensuring data integrity as a major goal rather than ensuring data availability	• Ease of data entry • Job type • Information availability • Accessibility
System procurement	Based on requirements of one group stakeholders (NEAS management), rather than shared aims of different and potential stakeholders (e.g. other hospital departments), therefore affecting the centralized database architecture.	• Ease of data entry • Job type • Connection availability • Technical issues • Rapid access to patient information • Information availability • Accessibility

Table 9.3: Elucidating Key Factors Emerging from Consequences

9.4 Lessons from the ePRF Study

The combined data collection tools of interviews and observations resulted in identifying some issues shared among participants that were associated with information transfer via the ePRF system. Themes identified that resulted from analysis were:

- Information about the patient during a call-out.
- Patent's data.
- Patient-centric approach.
- Technical issues.
- The sociotechnical aspect.
- Organizational issues.

The following section discuss each theme separately.

9.4.1 Information about the Patient during a Call-out.

This concerns a patient's data from the moment of dispatch until they are conveyed to ED or treated locally, and how information is transferred between different people. This transfer of information can be categorised in five stages. Figure 9.3 illustrates the five stages visually.

(i) The first stage is when the ambulance crew **receives** this information from the call handler during the first few minutes when accepting a job on the MDT and going mobile to the scene. The information received via the MDT might not represent the actual patient incident information, as this information was delivered to the call handler from the perspective of the call maker who will usually be a lay person and may also be under stress.

(ii) The second stage is when reaching the scene, with information being **formulated** directly from the process of providing care to the patient during the incident. Formulation of information means that when the crew are at scene, they can start to observe and assess the actual condition of the patient then administer medication to stabilize them, if necessary, in order to convey to ED. As a result, information during this stage is formulated by the actions conducted by the ambulance crew.

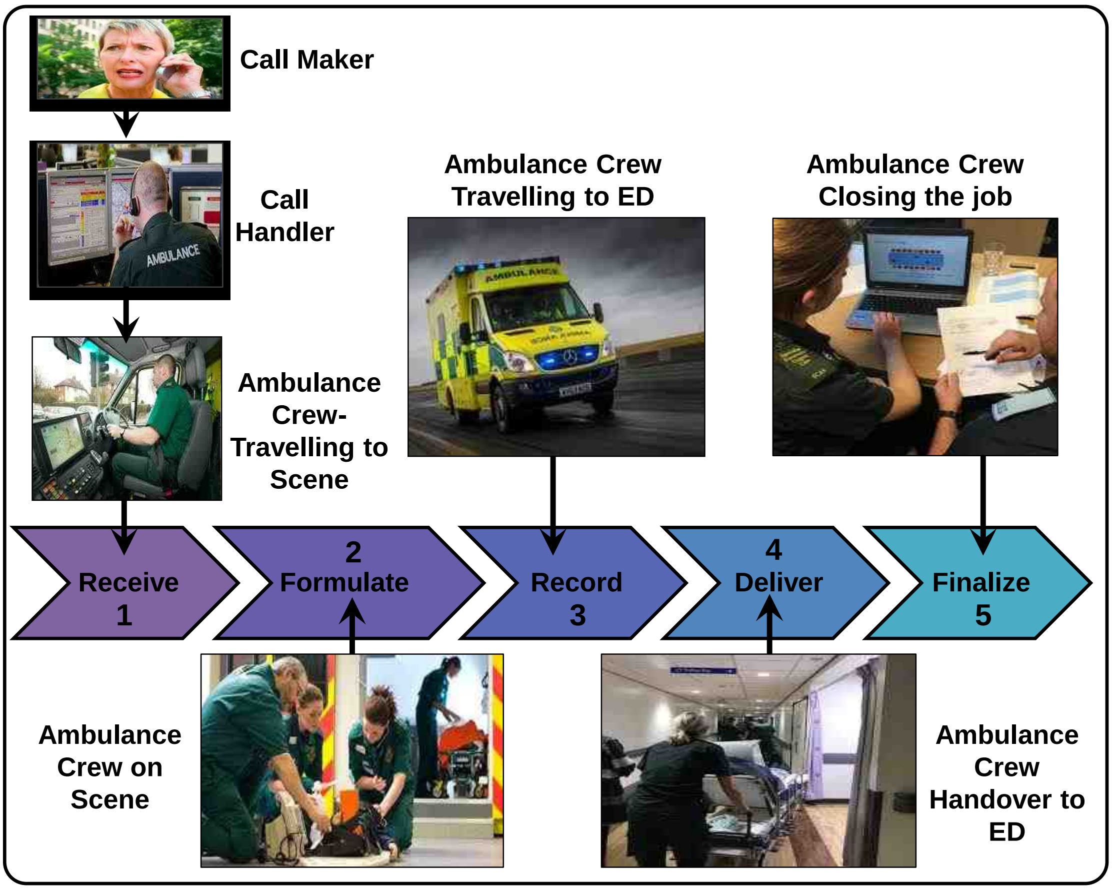


Figure 9.3: Overview of Information Transfer Stages to ED for Ambulance Crew

(iii) The third stage is to **record** the incident information about the patient in the ePRF form. This is meant to occur during en-route conveyance to ED. Sometimes crew will not able to perform this action en-route to ED, due to either the journey being too short, allowing little time to insert data, or due to the condition of the patient, as time needs to be given to providing care to the patient rather than recording data in the ePRF. Entering the data in the ePRF while travelling to ED might distract a paramedic from observing the patient from providing care. This is due to the fact that doing such a job requires attention and focus. The different navigation activities of choosing and filling in tabs and boxes, scrolling up and down and clicking on other tabs with different information requirements consumes time and requires focused attention. As a consequence, recording of incident information may be delayed until after the patient has been transferred to ED staff care.

(iv) The fourth stage is to **deliver** the information about the patient as collected from the incident to the ED staff. From the observations, information transfer was in two phases. The verbal transfer of information was made immediately to ED staff, and the electronic transfer of information only occurred after the ePRF was finalized which then enables authorized ED staff to access it.

(v) Finally, the fifth stage involves **finalizing** the information about the job and leaving. The finalization of the ePRF is an important stage, as an unfinalized ePRF will not allow authorized ED staff to access the incident information of the patient, making them dependent mostly on the information that has been passed to them verbally by a crew member, or from asking the patient if their condition allows. The finalization of the ePRF needs to be completed when all the data of the incident is recorded and delivered as planned in stages three and four. This completion is made official by the signature of both a paramedic and an ED staff member, after which the finalized ePRF is ready to be uploaded to the system and can then be accessed by ED staff. In many cases, stage three does not go as desired, since crew sometimes cannot record the information in this stage while en-route, resulting in delay in recording the data until after handover is completed (stage four). As a consequence, stage four, the ePRF finalization, will be delayed as well, resulting in time delays in the process chain of the electronic transfer of information.

It is clear that the creation of an ePRF goes through multiple stages that are interrelated and dependent on the previous stage. The multiplicity of stages just adds complexity to the information transfer. This domino effect, where one stage will cease if the proceeding stage was distorted or ceased for any reason, is considered as an added challenge to the process. The number of actions to perform and stages to apply become a problem in a time tight situation when a patient is in more need of the crew's time. This challenge presented here, was considered when building the IB, by making it comprised of one single stage of requesting (demanding) patient data, and only if needed. Reception, formulation, recording, delivering, and finalizing data are irrelevant components in the information transfer process. As the IB had an aim to suitably be appropriate in time constrain situations and making the stages of an information query and information presentation simple and direct.

9.4.2 Patients' Data

Issues of confidentiality, security, data protection, standers and terminology are aspects that are critical when considering health information transfer system (Lorenzi and Riley, 2004; Deutsch et al., 2010). In the case of the ePRF, NEAS grant accessibility rights to specific personnel in the ED to view the finalized ePRF; as this was a result of data ownership NEAS established. It is essential for any health organization, as NEAS, to ensure that patients' information is secure and protected.

Although PWE/carers expressed their acceptance of the IB to access their information, they showed concerns towards health information privacy and security. They have been assured that the ambulance crew will not insert any data when using the IB nor store data. The ambulance crew will view their data only after their approval to share. Ambulance crew accessing the IB are to comply with Role Based Access Control (RBAC) regulations imposed by the organization holding the database, as only authorized crew will be granted access based on their roles. The IB will be accommodating the policy of each organization that exist within, prior to data access. There is the possible potential of the IB to share incident information with participating health organizations after patients consent, however, this aspect could be applied in advanced stages of IB development if necessary.

9.4.3 Patient-Centric Approach

Electronic information transfer, involves a sender and a receiver of information together with a medium for this information to be transmitted. Transfer of information can occur within the same organization (intra-organizational), or it can happen in a network with other organizations (inter-organizational) (Coiera, 2015).

Those two forms of information transfer occurrence are found extensively in a domain such as health. As health organizations nowadays are employing a patient-centric approach, which encourages multidisciplinary health teams to work together (Parry et al., 2003). Figure 9.4 illustrates the lack and/or gaps of information transfer occurring within and among health organizations, thereafter, isolating the patient-centric care approach.

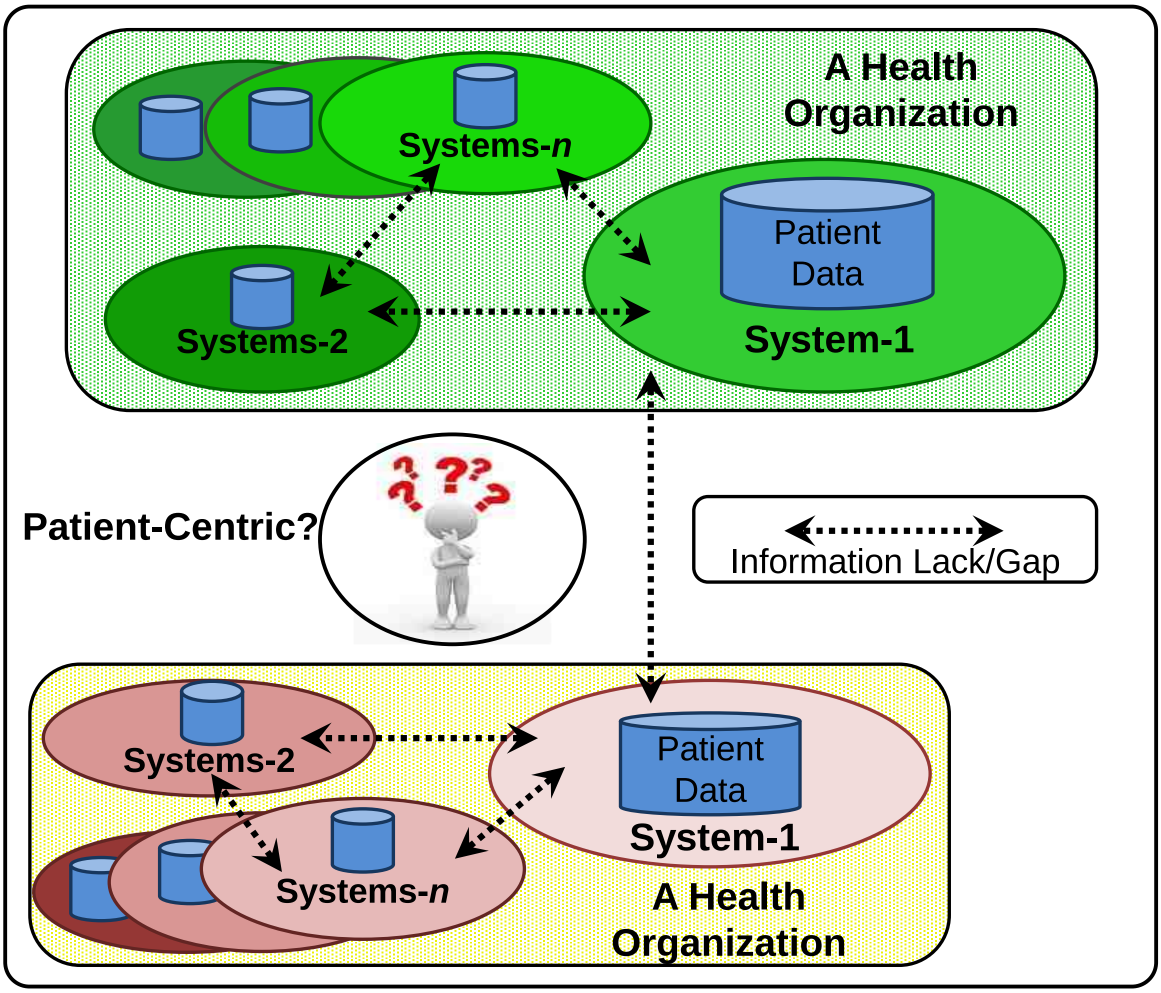


Figure 9.4: Patient Information Gaps in and among Health Organizations

Both the academic literature and the recorded experiences of paramedics have identified that the handover process can be problematic. Paramedics stated that their verbal handover with ED staff could be brief, detailed or even ignored, depending on many factors. Bost et al. (2010); Aase et al. (2011); Institute for Healthcare Improvement (IHI) (2005) have discussed this issue. They observed that the people involved in the verbal handover process, paramedics and ED staff, may react differently and have different perspectives towards this process due to cultural issues, organizational issues and individual issues. Consequently, information gaps, lacks and/or interruption of this transfer leads to fragmented care and fragmented patients' information; contributing to a direct impact on the patient-centric approach in terms of patient safety and may lead to clinical errors, inappropriate or conflicting care recommendations, medication errors, duplication of services, patient/carer distress, and higher expenditures of care (Westbrook et al., 2010; Apker et al., 2007; Parry et al., 2003; Stiell et al., 2003).

The IB, will act as an agent that enables the ambulance crew to view key patient information as a whole. It will gather information from different sources then display what is relevant to the ambulance crew, in order to support them in making the most appropriate decisions, therefore support the approach of a patient-centric care.

9.4.4 Technical Issues

The most obvious and critical issue identified by the ambulance was connectivity. System connectivity availability is the core bone of any information transfer that takes place via an electronic system. Losing connectivity caused problems and delays for a crew. Issues identified as being related to unavailable connectivity were: downloading the incident initial information from the CAD system, downloading the information from the CAD system to the ePRF, accessing the JRCALC and TOXBASE online resources databases via the Toughbook, and uploading the finalized ePRF to NEAS' server.

Indeed, those technical issues are relevant to any hardware and software issues of technology, and the IB is not an exception. There is the possibility of the IB losing connectivity, system halt, updates, system malfunctions, etc., but what makes the IB unique is that it is a lightweight system. As for the current time, the IB prototype will just be displaying the patients information and nothing else. Other feature can be added to enhance the information transfer, but only if end-users require such an addition.

9.4.5 The Sociotechnical Issues

Interaction between the social aspects and the technical aspects is complicated, especially in health. Hence the literature has tackled this complex relationship in various dimensions. For instance, Human-Computer Interaction (HCI) and Computer Supported Cooperative Working (CSCW), each contributing to various components and interconnected within each other.

When reflecting back to the sociotechnical issues identified by the ambulance crews, most can be managed, avoided or/and overcome. When building the ePRF system, it would have been more suitable if input from key stakeholders using the system, the ambulance crew as an example, have been considered. Their input in the development, testing, implementation stages would have meant that the system would satisfy their requirements. Unfortunately, NEAS did not include ambulance crew views when building the system. They were only asked to try the system prior to implementation. As a consequence, when the system went live, ambulance crews adopted various workarounds to record information in a non electronic manner to preserve key information about patients. This was achieved by writing on their gloves, napkins, or/and pieces of paper; alleviating the jeopardy of losing or forgetting to record some information of the incident. This reflects a critical issue to considerer in order to contribute in information transfer system implementation and success.

When developing the IB prototype, the sociotechnical aspects needed to be considered. Those who will be using the IB and their interactions with objects were identified. Ultimately, the IB is not just adding a technology to an existing system with no consideration of other aspects that use it and interact with it. It is not uncommon to focus on the technology side of a system and somehow ignoring the requirements of those who will most benefit from it. As a result, all potential end-users (ambulance crew, PWE/carers, JCUH and NEAS staff) were consulted in a way that meets their requirements. In a period of five years, their involvement and feedback in the development, interface design, and appearance offered satisfaction with the final outcome of the prototype IB.

9.4.6 Organizational Issues

Understanding the communication patterns and the needs of the different clinical roles is an important prerequisite for any attempt to improve communication processes and practices (Spencer et al., 2004). For instance, understanding patterns and needs of those working in a dynamic environment as in an ED when the ambulance crew bring in a patient to the clinical staff.

To mention some of NEAS's vision briefly would be fair. Their expected effect of adopting the ePRF is the electronic capture of the incident data, improving communications between NEAS and receiving locations, aiding with selection of the appropriate health service pathway which will alleviate the pressure on acute resources and improving the reporting of the information management of patients outcomes.

It is clear that some of these developments as proposed by NEAS are aimed at a management perspective rather than the operational aspects. The system appears to have been designed more as a NEAS management tool than as a clinical aid. The ePRF has made the finalization process for the ambulance crew longer when handing over patients to ED, whereas the previous paper form facilitated this same process quicker. This is evident from the participants responses who were interviewed stating that using the ePRF is time consuming compared to the paper form. Ambulance crew and ED staff are not utilizing the ePRF fully. For example, two of the ED nursing staff interviewed never have seen an ePRF. Only specific personnel in the ED are granted this access making the availability of the ePRF to other staff time consuming, therefore relying mostly on the verbal handover.

Also, paramedics stated that finalizing an ePRF takes longer than when using the paper form. The PRF is concise and takes approximately five minutes to complete as one paramedic stated. Whereas the ePRF cannot be finalized unless all data from the control centre has been uploaded (assuming no connection difficulty), mandatory fields filled in, and signature of the paramedic and ED staff. These are all factors that has to be met in order to establish a seamless finalization of the ePRF, which is not always the case as interviews revealed. These problems could be reduced by:

1. Using a different mechanism other than signing the ePRF to shift responsibility to the ED.
2. Removing joint signing as a mandatory action prior to finalisation.
3. Providing a printed copy immediately to the ED clinical staff may be another way to assist the process of patient and information transfer.

Holding a joint improvement session between the ambulance crews and ED staff might identify further ways in which fine tuning the electronic data transfer procedures could reduce the time and job stress associated with the ED patient and information handover.

The only time NEAS shares patient incident information with external organizations is with the GP. The ambulance crew will send an incident report to the patient's GP, but only after the patient has provided consent. Other health providers would also like to have access of their patients incident information, if for any reason they have used the ambulance service. Some patients would not inform their health care providers, of an ambulance call-out, due to forgetfulness or unawareness of importance. The following conversation occurred in one of the focus groups in regards to informing their healthcare provider (the GP, the consultant, etc.) of the ambulance call-out:

> Participant 2: *"I forget sometimes."*
> Participant 1 *"Yeah."*

> Participant 3*“Do you need to tell them you think?”*
>
> Participant 2 *“Well, I don’t.”*
>
> Participant 1 *“I think they know anyway...”*
>
> Participant 2 *“I thought the hospital would let them know that you’ve been took in.”*

If access to incident information is not possible, healthcare organizations would like to be informed, at least, of any incident call-out of patients they provide care for. Some incidents may alert or foreshadow a critical health problem that can be avoided if treatment and help was introduced early. This was also true in the case of wards within the same hospital of the ED. Health professionals in wards cannot access the incident information of a call-out of their patient who was brought to the ED by the ambulance service.

Further, the limitation in the ePRF system through which it does not alert a crew about previous call-outs on the same day regarding a patient, as previously discussed, was avoided when building the IB. A tab that displays the last date/time the ambulance crew was dispatched to the patient was inserted in the IB end-user interface for the crew to view if required. The IB might be a joint ownership between NEAS and the participating organization, leading to supporting shared goals, collaboration and communication, resource management, etc.

Even-though the system is not designed for the purpose of which it is used for, the ambulance crew yet can be more functional by adding a few small changes, rather than big ones. For instance, if the ambulance crew could print off a paper copy of the finalized ePRF and hand it to the ED staff, then rapid access to patient information by ED staff is ensured.

9.5 Summary

Transferring information to ED staff is an important part in the process of handing over a patient to the ED, and both electronic and paper formats are used to support this action. It is necessary first to consider the factors that affect the ePRF finalization, in order to make it available in the system immediately after verbal handover. Some of these factors are sociotechnical in nature because they are about not involving the ambulance crews in redesign and implementation of the ePRF. Some of these are technical, especially the influences of journey time, job type, and connection availability. The health organization in the wider context of NHS standards and regulations have an impact on patient health data ownership, sharing and transfer on the inter- and intra-organizational levels.

The focus of any solution should be on how to facilitate effective communication during verbal handover, using advance HIT to overcome the problems identified in this chapter. If all health organisations (including GP practices) that routinely provide healthcare to the patient who is the subject of an ambulance services' call-out could be granted ownership of the ePRF content, it would reinforce the idea of the patient-centric approach to healthcare. Both inter- and intra-communication among and between health organizations must be well established and organised effectively. Most importantly, there is a need to overcome current problems with information transfer while causing minimal disruption to work, involving minimum financial cost and providing maximum benefit to users.

Adding some relatively small technical features to the system can potentially provide a substantial benefit to ambulance crews in terms of improving usability. For example, applying auto-spell checks to free text boxes for common words and medication names. Another suggestion would be tailoring different interfaces appropriate for each job type, i.e. an interface suitable for complex **red** jobs and another different interface suitable for simple **green** jobs, that matches the nature of the incident.

The way that the ePRF is used also highlights some of the challenges that arise from software procurement practices in a federated system of organizations such as the NHS. Ideally, the development of an information transfer mechanism, such as the ePRF, should involve an exercise in co-design, with participation from and consultation with all of the other organizations and stakeholders involved in its use, in whatever form. However, because funding is organised through the individual organization, this is unlikely to occur, which then leads to lost opportunities to make better use of electronic information transfer. Indeed, both co-design and sharing of information is not only failing to occur between organizations, but may also be lacking within an organization.

There are two examples of this. Regarding co-design, the NEAS did not involve either the ambulance crew nor other organizations in the design of the ePRF; and for sharing of information- within the hospital there are no mechanisms for information transfer related to the ePRF between the JCUH ED and the other departments of the hospital, as each department functions individually.

These are essentially organisational issues, rather than technological ones, and given that they stem from the fundamental nature of health, especially at the inter-organizational level, they are ones that could potentially have wider benefits if it could be addressed more effectively.

To conclude, this chapter was helpful in extracting lesson from an existing information transfer system (ePRF) that is employed by NEAS for the ambulance crew use, hence helped understand other issues that need to be considered when developing a HIT as the IB.

Chapter 10

The Information Broker: Findings

This chapter makes use of the three phenomenological studies discussed in previous chapters: NEAS operations and staff (Chapters 5 and 6), JCUH staff and PWE/carers (Chapter 7), and the ambulance crew (Chapter 8). The result of the three phenomenological studies triangulated to form a solid knowledge base about PWE and the requirements of an ambulance crew needed for building the IB, and therefore, demonstrating the feasibility of the concept and answering the first research question.

All experiences collected helped to determine what should be included in the end-user IB interface for an ambulance crew. The Broker architecture and the concept behind it will be presented, followed by a presentation of the prerequisite essentials that are considered prior of the IB development. This leads to the design process of the IB and the technology employed in building the IB system prototype on both the server-side and the client-side. The chapter will then conclude with a use case scenario, IB demonstration, then findings from the IB prototype.

10.1 System Requirements

When building any system intervention, it is essential to understand what requirements the system need in order to minimise any conflicts with other systems and platforms; specifically speaking, interoperability. The ambulance crew need to access patient health information, this could be through accessing one or more database(s) from heterogeneous and autonomous health organizations. The challenge here comes from finding a way to overcome the diverse systems, platforms and languages each health organization applies. Other considerations also need to be included, especially when dealing with patient information, as different organizations apply different security frameworks to protect their patient information. The ambulance crew need to be provided with information from a range of health organizations each with their own set of frameworks and access rules. Building a new system, by NEAS, that access all involved databases of other systems just adds more complexity and ethical issues. To avoid those challenges, applying the idea of an Information Broker (IB) offers the best solution to overcome these impediments. The IB, does not store data, it is based on the the idea of Web Services, that enables the exchange of data between different applications, systems, languages and platforms over the internet. Web Services rely on a set of open standards (e.g. eXtensible Markup Language (XML) and HTTP) which supports interoperability (Chen et al., 2003). More details about this will be presented in Section 10.4.1

The association between roles and permissions, where users are assigned appropriate roles, is named Role Based Access Control (RBAC). In health organizations patients data privacy and security are paramount, therefore enforcing access permissions to users based on their roles was a necessity. Access to patient information is based on the role of the person, what qualifications and responsibilities the role holder possess in the health organization (Sandhu et al., 1996). Applying RBAC becomes more of a priority when it involves inter- and intra-organizational communication and distributed health information systems (Blobel, 2004; Fernández-Alemán et al., 2013). RBAC should be assigned by the organization that created or holds the data, in this case, JCUH. Logically, organizations that hold data ownership of their patients information should retain the right to establish their RBAC policies, standards, ways of access, etc. JCUH should grant access rights to their patients data, based on the ambulance crew role working in NEAS. RBAC should be implemented by the database owner, as the IB system will only access the information and will not own it. In addition, Web Services do not offer any security or firewalls methods because it works on the internet. All this makes it essential for health organizations to apply their own data protection strategies. Table 10.1 highlights key ways in which the broker architecture matches the needs of the IB.

Characteristic of a Broker Architecture	**Role of the IB**
Providing expert knowledge about where things to be found.	Information in the health domain is complex, dynamic and is constantly being updated and extended, with the broker being delegated the task of keeping up to date with the availability of relevant sources of data.
New sources can be added without the need to configure the software system.	Within the NHS, new GP practices, hospital departments, health organizations etc. may be created. Also, the structure may change within part of a health organization in a department, in an organization as a whole or in a system nationally. Knowledge about such changes only affects the broker.
Isolation from changes.	Data owners may change the rules regarding data access, security access, protocols, etc. However, the knowledge incorporated in the IB will not be affected by such changes and it does not need to be notified of those changes occurrence as well, as long as the access agreements are in place.

Table 10.1: Reasons for using a Broker Architecture for the IB

10.2 The Broker Architecture

Schmidt et al. (2000) define a Broker architecture as one that “can be used to structure distributed software systems with decoupled components that interact by remote service invocations. A Broker component is responsible for coordinating communication, such as forwarding requests. As well as for transmitting results and exceptions."

A direct query interface enables users to enter queries and then send it to the Broker. The Broker, after receiving the query, sends it to other applications, determined by rules defined in query flows and query sets. It also transforms the data into the structures required by the receiving application.The Broker obtains and integrates the responses from autonomous sources then send it back as a response to the requester (client) that sent the original query (Sadtler et al., 2004; Martin et al., 1997). Schmidt et al. (2000) have identified six components for a Broker architecture, these are:

1. ***Servers:*** can either implement specific functionality for a single application, domain or task, or can offer common services to many applications. For instance, World Wide Web (WWW) servers that provide access to HyperText Markup Language (HTML) pages.
2. ***Clients:*** are applications that access the services of at least one server.
3. ***Broker:*** is the messenger that is responsible for the relaying of the request from clients to servers, as well as conveying responses back to the client.
4. ***Client-side:*** is the layer between clients and the broker.
5. ***Server-side:*** is the layer between servers and the broker, this is responsible for receiving requests, unpacking incoming messages, and calling the appropriate service.
6. ***Bridges:*** are optional components used for hiding implementation details when two brokers interoperate.

A client will only be able to use the IB to access information that is provided by those entities that have registered with the broker (hospitals, GPs, Care Homes etc.) and/or departments/wards (ED, Paediatric, neurophysiology, etc.). For every new request a client places through the IB new mappings of data/information will be generated. A key characteristic of the server-side is that it is constantly changing (new patients, new patient data, new health and non-health outcomes, test results, medication, etc.) because patients' health needs and interaction with health providers are usually in constant update and change, therefore, data and information is updated accordingly. The IB therefore acts as a mediator between the client seeking access to patient information and the sources of information on the server-side that are constantly changing. As the IB has expert knowledge of the information/data available in registered parties and will only access that information that it has been granted to access, it offers decoupling of knowledge about information provision from the user.

10.3 The Concept of an Information Broker

The concept of an Information Broker (IB) is not a new one. The IB in this project is based on the concept of the Integration Broker for Heterogeneous Information Sources (IBHIS) presented in Budgen et al. (2007). In their study, the IBHIS was based on software services. The IBHIS was an element in a service model that provided information as a service and was designed to gather data from distributed autonomous sources, each with different technologies.

The IB created for this project is based on the same concept, collecting data from autonomous organizations, for the ambulance crew to use. The data provided to paramedics is based on Web Services, where the ambulance crew will enter a request to 'on-demand' patient health information by using a dynamic web interface. As this project was tied to a PhD, it was necessary to demonstrate the IB in the laboratory. The database created for PWE was hosted by an external server, and access to it was through the IB Web Service that was hosted by Durham University. Demonstrating of the IB interface and of access to the PWE database was undertaken repeatedly within and outside the university.

10.3.1 Prerequisite Essentials

The following highlights considerations that were identified as being essential prior to building the prototype:

(i) ***Ambulance Crew Requirements:*** As the IB will be used mainly by the ambulance crew, determining their needs and requirements was essential. Details of how this was conducted are given in Chapter 8. Table 10.2 from Chapter 8 is reproduced as a reminder.

Emerging Theme	**Crews' Requirements from IB**
Information Regarding Patient Health	• Current Medication • Allergies • Known Conditions • Next of Kin • Care Plan
Information Regarding Patient Encounter with other Organizations	• GP Latest Notes & Contact Information • Previous Encounter with Ambulance • Attempt Resuscitation • Recent Contact with Health Services

Table 10.2: Ambulance Crew Requirements and Emerging Themes

Those emergent requirements identified by the ambulance crew were later used to guide how the IB end-user interface was organized. Members of an ambulance crew can then select the information they require from the database by checking the box(es) for the data they need to access about the patient on scene.

(ii) ***Other Considerations:*** Although the IB is mainly for the use of ambulance crew, it was essential to present this technology solution to as many indirect users as possible. Discussion of indirect users will not be presented in this section, as it has been previously discussed in Section 7.2.2. However, some issues that emerged will only be presented briefly, as this chapter is mainly for discussing the IB implementation and demonstration. Indirect users that were considered were:

- PWE/carers from JCUH.
- JCUH IT department staff.
- JCUH ED staff.
- A consultant neurophysiologist.
- An epilepsy specialist nurse.
- NEAS management (Information Management &Technology manager and Informatics manager).
- The Epilepsy Action groups,
- NEAS Research & Development division staff.
- Transformation Program officer (project manager).
- Control centre staff in NEAS.

The IB system needs to let health organizations set their own data control regulations, privacy, security policies and grant access rights to their patient's information based on roles and responsibilities. This will give the health organization the freedom to use their own data syntax, policies, etc. The reason for that is because Web Services technology do not provide direct support for encryption, security features, and session management.

10.4 The Design

Budgen et al. (2007) demonstrated the concept of an IB, in the Integration Broker for Heterogeneous Information Sources (IBHIS). The IBHIS project investigated how health and social care data could be obtained and integrated using a Broker architecture to gather and integrate diverse patient information from autonomous and heterogeneous healthcare organisations. The Broker does not store any data, it collects the data, passes it on leaving the data ownership to the organisation that created it. Data-providing organisations can create their own access policies. The IBHIS uses a software service technology; meaning that the service is not owned rather it is being used.

This 'on-demand' electronic health information provision is not unique in the NHS. In 2011/12 The South East Coast Ambulance Service NHS Foundation Trust (SECAmb), developed a system called The Intelligence Based Information System (IBIS) for storing care plans for people with long term conditions in their database. This database can be accessed by paramedics and community specialist clinicians where they can upload and view patient data, needs and wishes as well as specific care instructions. IBIS allows paramedics to view patient's information while en-route and at the same time notify the patient's community specialist clinician of the ambulance call-out (Collen, 2012; South East Coast Ambulance Service NHS Foundation Trust (SECAmb), 2012).

The IB prototype, in this research, is a simpler version of the IBHIS as both are based on a Broker architecture. Yet what makes the IB prototype different from the IBHIS is basically because the technology has evolved since 2007, and to apply the technology of that time now is infeasible, as some technology used in the IBHIS is no longer supported (such as the IBM platform). For instance, the IBHIS has various searching mechanisms which are not needed in the IB prototype. It is also easier to build ones own code and building blocks of their system than adopting other complex systems codes, especially when building a simple version. When building systems it is more efficient to start with simple solutions and extend it later on by adding new functionalities tailored to needs. This mechanism helps to identify any errors or challenges that might hinder upgrading.

The IB prototype system is different to SECAmb IBIS in that it does not store any information. The IB created in this project just accesses information from an autonomous database, after obtaining a patient's consent, and provides this information to the paramedic on scene. The IB acts as a trusted agent with the ability to provide reliable up-to-date patient health information from different sources and displays them to the ambulance crew on scene if requested.

10.4.1 An Overview of the IB Design

Figure 10.1 is an extended version of the figure shown in Chapter 1, it includes details of current system and the IB. The prototype IB demonstrated in this thesis will create the other part (on the right) of this information transfer. The ambulance crew gets dispatched by the control centre (2) as a result of call received by a member of the public for help (1). While on scene the crew demand additional information of the patient (3), a request will be placed by a member of the crew using the IB interface. This request will be passed on to the IB by the ECS system (in the call centre) (4). The IB then will search for patient information internally, within the NEAS database and externally within JCUH PWE database after access rights have

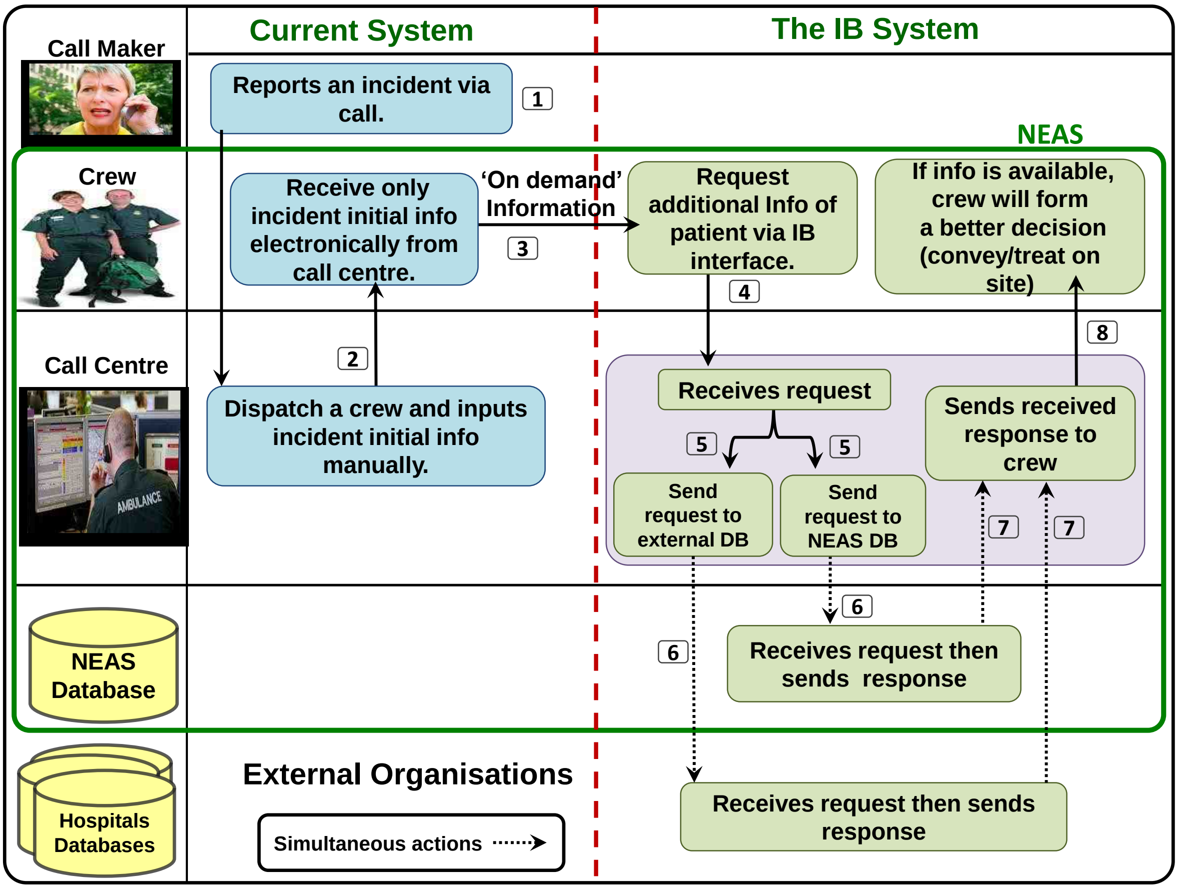


Figure 10.1: Outline of the Current System and the IB

been checked (5, 6). The PWE database in JCUH will return up-to-date data to the IB about the person for whom the ambulance has been called-out (7). The IB through the ECS will pass the response to the IB interface for the ambulance crew to view (8).

If the PWE database does not provide any additional information about that specific patient, the crew might still need to take the patient to the ED. Appendix S represents the information flow between the ambulance vehicle, NEAS and JCUH. Appendix T represents the IB process between the call centre and the ambulance crew on scene. Appendix U provides how the database(s) are updated by the IB.

It is essential to note that all of these actions cannot be performed without obtaining the patient's consent to share their information among participating services.

10.5 Implementing the Information Broker

A major goal is to design the end-user interface to be easy, simple and informative. Meaning, easy to navigate, simple design of the interface and at the same time providing only the requested information. The purpose of the IB was not only to provide a simple end-user interface, but also to display clearly 'on-demand' vital health information regarding the patient on scene, especially in situations when decisions need to be made in a timely manner. This in turn carries benefits to other participating stakeholders (NEAS, JCUH, crews and patients).

This section will highlight the main building blocks needed for the IB implementation, followed by a use case scenario of the IB technical walk-through.

10.5.1 IB Server-Side

This represents the server-side of the IB prototype, in this case JCUH, or any other heterogeneous autonomous organization. The following technologies were employed:

(i) **Web Services:** The IB is based on Web Services (WS). The World Wide Web Consortium (W3C) (2004) defined WS as "a software system designed to support interoperable machine-to-machine interaction over a network...". The main goal of WS is to exchange information in a standard way among applications on the internet seamlessly. WS offers several features, that match the needs of many users, for example, they are language and platform independent, interoperable and more used among heterogeneous platforms (interoperability feature) (Endrei et al., 2004; Feng et al., 2009).

These features of the WS seem most suitable to the IB prototype, especially in a domain that is system diverse and autonomous as health. The use of WS also makes access to the PWE database available on the internet, which means it can be remotely accessed by the ambulance crew any time a connection is available (reusability feature).

WS are based on a client-server architecture. This approach provides a solution on how to handle centralized data control and widespread data accessibility (Papazoglou, 2008). WS communicate using (XML, HTTP, and Uniform Resource Locators (URIs)) which are standard web protocols that are widely used and work across the web (standardized protocol feature) (Mumbaikar et al., 2013). Additionally, Web Services support loosely coupled connections, meaning that there is no direct connection between the Web Service and the user. For instance, a user's capability to interact with the service will not deteriorate if alterations were made to the WS. This feature minimizes the impact of change and facilitates software system management and different system integration (flexibility feature).

Understanding the role of a **web server** is important to understand Web Services. A web server is a software or a hardware that provides services to other programs or clients. A web server uses HTTP to communicate with a web browser over the internet. Its basic objective is to process, store, and deliver web pages to the user. The most popular web server is Apache. For more details of Apache see Section 7.3.2.1 (Ljubuncic, 2011).

(ii) **REST or SOAP:** The communication that occurs among those applications is based on Simple Object Access Protocol (SOAP) or Representational State Transfer (REST) principles. Both SOAP and REST are kinds of Web Services. SOAP communications causes processing delays, higher latency and network traffic (Mumbaikar et al., 2013). Therefore, REST was selected as an Application Programming Interface (API) over SOAP. On the other hand, REST API is easy to understand and design, and compared to SOAP, it is lightweight and simple (Al-Zoubi and Wainer, 2009), most businesses are heading towards applying RESTful API architecture, and the NHS is one. In addition, REST API is designed to integrate with standard web protocols, meaning that REST API services can be called with standard web verbs (GET, POST, DELETE, and PUT) and URLs. REST API also allows discovering of web resources without any registry repository or discovery (automatic discovery feature).

Furthermore, REST API offers scalability, coupling and performance (Feng et al., 2009), it is a simple alternative to SOAP (Rodriguez, 2008). Other added benefits are that it uses Hypertext Transfer Protocol (HTTP) methods explicitly to transfer XML or JavaScript Object Notation (JSON), or both. More details of these technologies are presented in the following Subsection 10.5.2. The REST API architecture is based on a client-server style, where the client sends the request to the web server and the server receives the request, processes it then return a response (Mumbaikar et al., 2013).

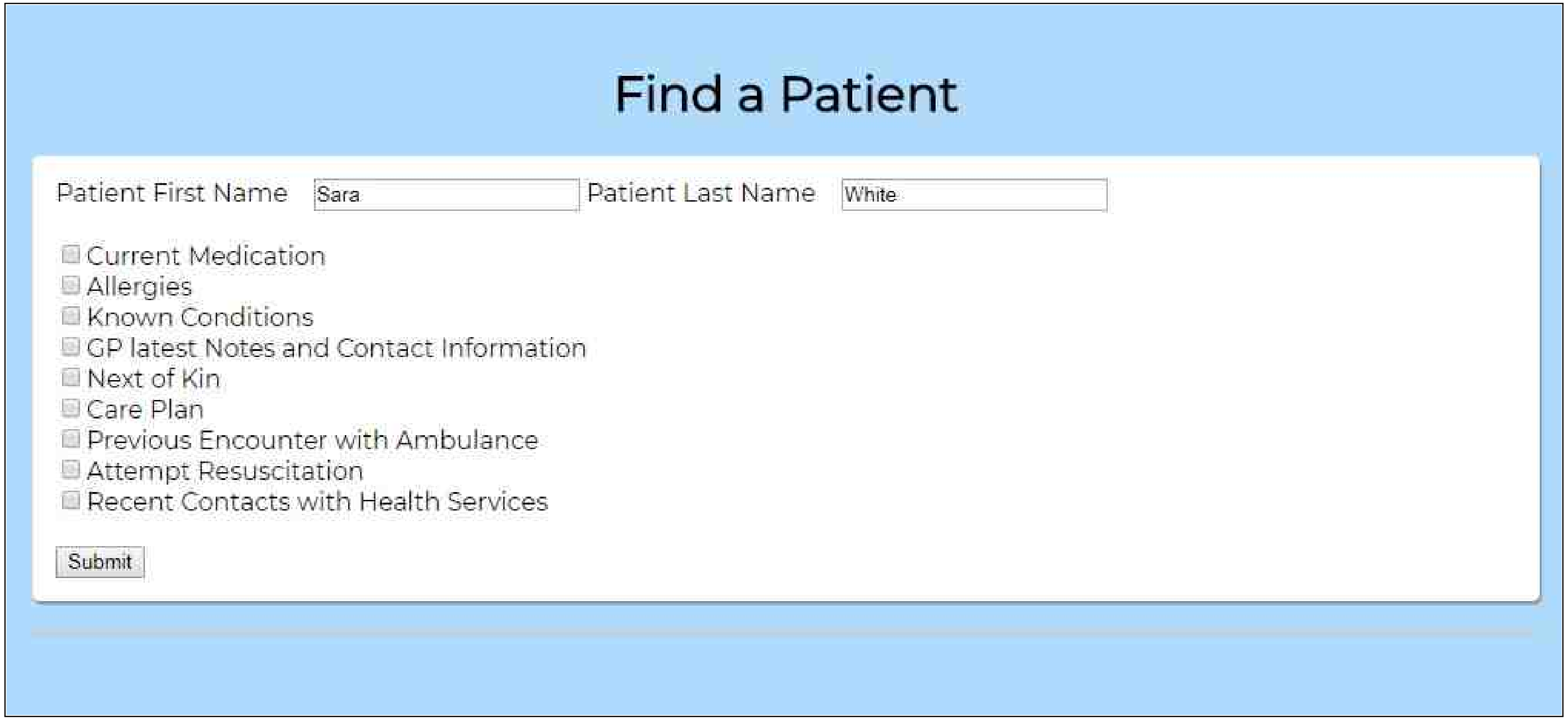
REST API allows the ambulance crew to interact with external databases, in this case the database for PWE in the Neurophysiology Department at JCUH. A member of the crew (the client) will initiate the request to the JCUH web server requesting a service, this service is the provision of the patient health information. The web server will receive the request from the client and process it and will respond appropriately. This communication of course is happening over the internet via the Web Service (REST API).

The other components of the sever-side (Apache, PHP, MySQL, SQL) were discussed in Section 7.3.

10.5.2 IB Client-Side

What matters is the output of the previous building blocks; that is, how crew request electronic ‘on-demand’ health information and how a database(s) will respond to the request(s) placed by the crew through the IB user interface.

The User Interface: The IB user interface enables the ambulance crew to place queries to request patient health information from the databases. The aim was to build a simple user interface that is easy to use, form queries, navigate and display data precisely in a timely manner. If the ambulance crew during an incident require additional health information regarding the identified patient, they will need to demand it via the IB interface. When utilizing the IB user interface the ambulance crew will view a window exactly like Figure 10.2. This window contains check boxes that the authorized member of crew can choose among, based on what the crew needs during the incident. Once the choice of boxes (requests) has been checked, the crew member will press the **submit** button. This action will generate a response of the selected items, and the information will be displayed under the list of the checked boxes. Later on, the crew may also request additional information if needed. A member of the crew will check the designated box and hit **submit** again and the information will appear under the list checked boxes next to the previous requested ones. Figure 10.3 represents how the ‘on-demand’ health information appears to crew after response formulation.



Find a Patient

Patient First Name Sara Patient Last Name White

☐ Current Medication
☐ Allergies
☐ Known Conditions
☐ GP latest Notes and Contact Information
☐ Next of Kin
☐ Care Plan
☐ Previous Encounter with Ambulance
☐ Attempt Resuscitation
☐ Recent Contacts with Health Services

Figure 10.2: The IB End-User Interface- ‘On-Demand’ Health Information Selection View

Find a Patient

Patient First Name: Sara
Patient Last Name: White

☑ Current Medication
☐ Allergies
☐ Known Conditions
☐ GP latest Notes and Contact Information
☑ Next of Kin
☐ Care Plan
☑ Previous Encounter with Ambulance
☐ Attempt Resuscitation
☐ Recent Contacts with Health Services

Next of kin	Mr Sam Green
Next of kin number	07538456215
Next of kin relationship	Brother

Figure 10.3: The IB End-User Interface- Next of Kin View

The client-side user interface browser employs web technology techniques. Web programming technologies have three basic layers: HTML, CSS, and JavaScript. Those techniques are employed to access resources on the web. Each resource on the web has a particular URL (Uniform Resource Locator). The URL, which is typed in the user interface browser, tells the browser which server to access. Before proceeding to the use case scenario of the technical walk-through of the IB, some important components are explained briefly, this is to give a good understanding of the IB system. The following will give a brief description of each:

(i) **HTML:** stands for HyperText Markup Language which is an open source language. HTML is designed to be a simple tagging language for displaying text in a web browser, therefore it is the foundation of any web page which is used to write them. It tells the browser what to display on the page, the visual appearance of the web page, in terms of colour, font, etc. HTML **defines the content of web pages** (World Wide Web Consortium (W3C), 2018*e*; Shuler, 2002; North, 1999).

(ii) **CSS:** is Cascading Style Sheets, which is a language that expends on HTML, and it controls the style, text size, colour, font, etc. of the web page. CSS are used to **specify the layout** of, how to display, the HTML elements of the web page (World Wide Web Consortium (W3C), 2018*d*).

(iii) **JavaScript:** is a client-side default scripting language for use in HTML and web browsers in order to make the web page more dynamic. JavaScript is used to **program the behaviour of web pages**. JavaScript can open a connection to the server and download data from the server by a code that uses a special object built into the browser (XMLHttpRequest object) (Holzner, 2009). JavaScript can convert a JSON format into JavaScript objects through a built in function (Holzner, 2009).

(iv) **AJAX:** stands for Asynchronous JavaScript And XML, they are browser and platform independent. It enables **web pages to be updated asynchronously** by allowing small amounts of data to be exchanged with the server behind the scenes. This means only part(s) of the web page is updated, instead of updating (reloading) the full web page. Further, AJAX requests/receives data from the server after the page has loaded, it also sends data to the server in the background. Classical web pages, which are in contrast to AJAX, are based on three basic layers (HTML, CSS, and JavaScript) and must reload all the entire web page if the content was changed. AJAX uses the JSON format to send data from the server back and forth over HTTP, but it can also transport data as plain text or XML (Holzner, 2009; World Wide Web Consortium (W3C), 2018*c*; Holzner, 2009).

(v) **JSON:** stands for JavaScript Object Notation which is a lightweight data-interchange independent language. JSON uses **JavaScript syntax for storing and exchanging data**. The format used for JSON is text only, but it can be used and read as a data format by any programming language, meaning they can be processed by Java, PHP, JavaScript, etc. Because JSON is a text format only, this gives it the ability to be sent to and from a web server easily. JSON can be loaded into the JavaScript object by a function (World Wide Web Consortium (W3C), 2018*a*; JavaScript Object Notation Organization, 2018).

(vi) **XML:** stands for eXtensible Markup Language. XML is an independent tool for **storing and transporting data** and it is machine- and human-readable. XML can be used with web protocols like HTTP which is often used for distributing data over the Internet. XML is a Markup language similar to HTML, but each has different goals. XML focuses on what data is, and was designed to describe the structure of data. On the other hand, HTML focuses on how data will appear, and was designed to display data on web pages (North, 1999; World Wide Web Consortium (W3C), 2018*f*).

(vii) **HTTP:** stands for HyperText Transfer Protocol. HTTP is the underlying protocol used by the World Wide Web (WWW). HTTP is a stateless protocol, meaning that each connection is independent of each other. This protocol defines **how messages are transmitted and formatted over the internet.** It also defines what actions browser and web servers should perform in response to requests. The client sends an HTTP request from the web browser to the web server for web elements (images, web pages, etc.). When the web server receives the HTTP request it will search to find the requested data. After a request is responded by the web server, the connection between the client and the web server across the internet is disconnected. For each request a new connection is established (Shuler, 2002).

10.5.3 A Use Case Scenario Technical Walk-through

Figure 10.4 demonstrates a use case scenario of the IB technical walk-through system. While the crew are on scene and they decide they need more information about the patient, they open their laptop Toughbook and open the browser with the IB interface (1). Using the IB user interface, they will check the relevant box(es) to

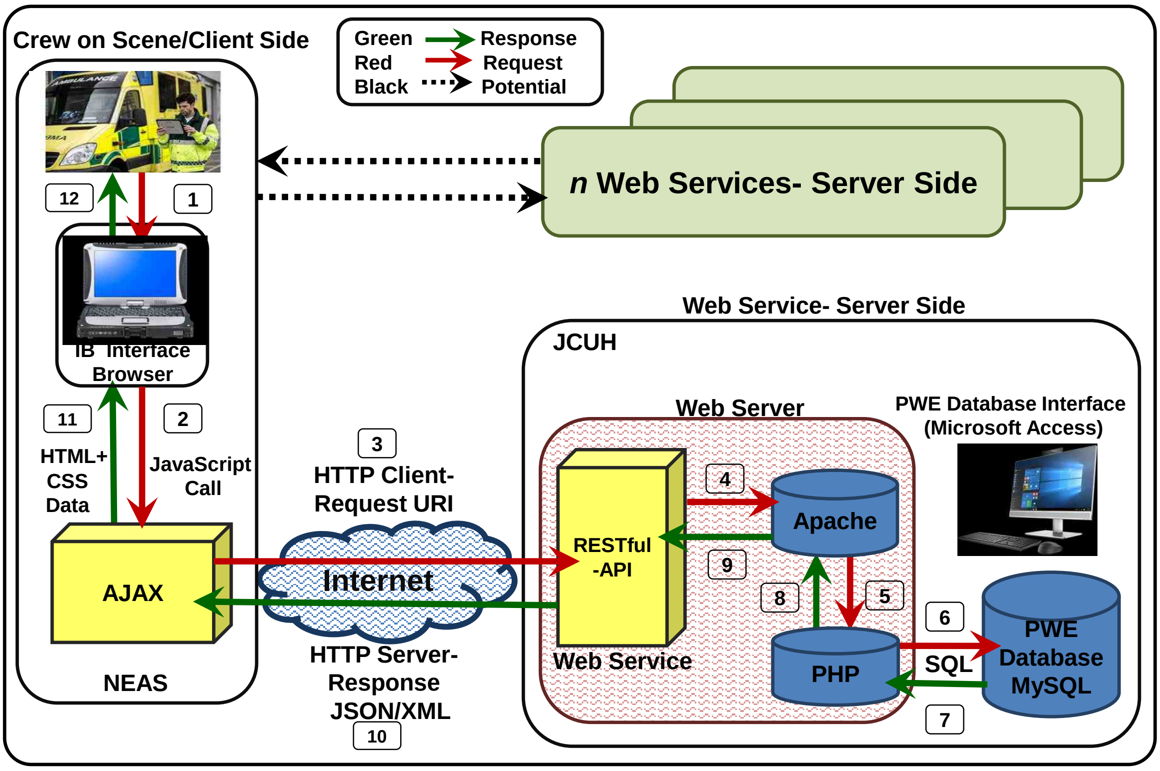


Figure 10.4: IB Technical Walk-through

place a query for the additional information they would like to view. Afterwards, the submit button will be clicked to start sending the request.

The browser which is an HTML page will send a JavaScript call to the AJAX engine (2). The AJAX engine will transfer this JavaScript call as an HTTP request URL over the internet to a specific resource(s) (3), in this case the PWE database which resides in the Neurophysiology Department at JCUH. This request will go through the REST API (Web Service) which runs on the web server, which in turn sends it to the web server Apache (4). Apache will pass the request on to the PHP interpreter for execution (5). PHP, will then send an SQL query to the PWE database (6) and search to see if there is any information regarding this patient. A response from the PWE database will be sent back to PHP (7), with additional information about the patient, or with a message to say that there is no information available. The PHP will send back the response to the web server Apache (8), in which it will pass it on to the RESTful API (9). The REST API via the internet will return the response over HTTP in JASON/XML (10). The AJAX engine will, therefore, return the response to the browser in an HTML/CSS data (11) enabling the crew member to view the response on their IB user interface on the Toughbook (12).

10.6 IB Demonstration

After completing the development of the IB, it was then necessary to demonstrate the final end result of the interface. Contact with the Research & Development (R&D) manager to recruiter paramedics to try the IB was unsuccessful. Only one paramedic from the R&D division participated in demonstrating the IB. This took place on February 2018 for an hour long in Newcastle University. The IB interface that appeared to the paramedic was exactly as it is shown in Figure 10.3.

The paramedic tested the IB interface multiple times by inserting different patient names and selecting various check boxes (formulation of the query) which resulted in the information to be displayed (response of query). The paramedic examined all the information displayed after placing the query to make sure if this information is suitable, relevant, detailed or not.

After a demonstration of the IB end-user side interface, the paramedic expressed his desire to see this go live. Regarding the output of the 'on-demand' health information. He stated:

> *"Yeah, this is the sort of stuff that are really useful and we don't have access to it. It would influence your decision-making at scene.....I would like to see how this works in practice."*

He added:

> *"This is so useful, if that's how fast and easy it is to access the information, ...that's brilliant. I think this is very useful. I think that's quite neat. It's fast, its got the information that's relevant to what you've doing... You've build something that is actually useful for patients, for us, for the health service, for the hospital."*

He also added:

> *"that is really useful (IB), if that's how fast and easy it is to access the information, and that's just working over a normal wifi connection, that's that's brilliant."*

The participant have made a comment about paramedics using information regarding (attempt resuscitation tab) in the interface. He said:

> *"It is useful in the wider patient context and probably useful for trigging conversations, perhaps, outside of the context of epilepsy; but in that, that is useful information. Because you might get called to an*

> *epileptic patient who's had cardiac arrest. If you know they are an epileptic patient, this is something you can look at to support the decision-making. But because the way you set it up, you don't have to go to it. You don't have to look at it (attempt resuscitation tab). It's not extra information that you are gonna get without wanting it. You only get it if you want it. I don't think it a downside to keep it (attempt resuscitation tab), because you only will go to it if you want it."*

The participant also asked if the IB interface can be implemented on smart phones and tablets for the ambulance crew use. He stated:

> *" Could that work on a phone? You know that all the vehicles will get the tablets on, or whatever they will end-up going to, I don't know if they will change them to sort of iPads or something like that. They might be moving toward a tablet, but we still got the Toughbooks at the minute."*

This User Acceptance Testing (UAT) by the paramedic gave a chance to observe how the paramedic used the interface, how he navigated between the tab buttons, and how he interacted with the interface. The features and functions of the interface were accepted by the participant and he did not find any difficulty in navigation or demanding information. A simple explanation of how the interface worked and how would it function was verbally delivered to him prior to paramedic use. After that, the paramedic felt comfortable in navigation and reading under the tabs he selected. It was essential to consider and apply the appropriate relevant dimensions from Sittig and Singh (2010) eight-dimensions, as mentioned in Section 3.3.2 in regards to the IB interface. As the IB is a feasibility study, only three dimensions were applicable which are: (i) the hardware and software computing infrastructure dimension, (iii) the human computer interface dimension, and (iv) people.

10.7 Findings

The prototype, so far has demonstrated that the idea of using the IB for this purpose is feasible. Yet, other elements need to be investigated if it is to be applied on a wider health context and scale.

Building the IB itself was relatively straightforward. As languages, functionalities and programs that has been adopted are already robust, easy to use and free sourced. Facilitating those in the IB architecture added robustness and simplicity to the system. All this collectively contributed in a less challenging construction process and demonstration of such a system.

The IB system does not store any information, it passes the query from the client-side (the crew) to the server-side (database) and sends the response back to the client-side via the interface to view it only. This quality is desirable for healthcare organizations when considering data protection policies and information access rights. As the healthcare organization will be responsible of dictating such rules and access rights on whomever accesses their database(s). The IB will be connecting already existing systems, thus no high cost systems will be built; the idea is to join them together each with their own data protection protocols and security mechanisms.

Furthermore, utilization of the IB system, that is the use of the IB interface by a member of crew, will only be after patient stabilization. Sometimes, the crew, might not be able to consult the IB interface for more information, and decide to take the patient directly to ED.

Although the requirements that ambulance crews have for patient health information needs across different health scenarios and conditions are the same, this prototype was only demonstrated with PWE database. If other chronic and non-chronic conditions databases need to be included, the IB system then might need to be adjusted to comply with the needs of other databases. Investigating other chronic and non-chronic conditions database needs and information requirements might reveal different challenges.

Finally, the IB system has been demonstrated with a small database and in the laboratory, where time and data security were not of a big issue. Applying the prototype as a pilot investigation in real case scenarios will bring to the surface other issues and challenges that need to be understood and tackled.

10.8 Summary

This chapter presented the first research question of this study, i.e. developing, then demonstrating the feasibility of an IB that provides ambulance crew while on scene with an 'on-demand' patient information of PWE from an external database. The IB is to support ambulance crews' decision-making therefore reducing unnecessary conveyance to ED offering potential benefits, not just on a patient level, but also on an organizational and a policy level. Considerations of the sociotechnical aspects and end-users requirements were helpful in developing the IB prototype. Considerations of the technical aspects of the IB was also essential prior to the technical development phase. This included applying well established and wide spread technologies on both the server-side and the client-side, for example, Web Services, REST APIs, JSON, MySQL, etc. Findings from the demonstration of the IB shown its feasibility to access information form an autonomous database and deliver to the ambulance crew while on scene when requested. More research ought to be conducted in order to identify other potential benefits and challenges of implementing a HIT in the ambulance service domain.

Chapter 11

Discussion

This chapter considers all the various elements of what have been done in this study and assesses the successes and the potential complexities involved in bringing the IB beyond the feasibility stage into full implementation and development.

Chapter 10 reflected upon how the first research question was demonstrated and showed that an effective IB architecture has been developed. The development and demonstration of the IB architecture enabled an electronic presentation of health information needed 'on-demand' to the ambulance crew in this specific case study, supporting crews by providing reliable health information through accessing JCUH PWE database.

The feasibility of the prototype IB case study acts as an overarching framework of the thesis. To understand this case study, three different phenomenological studies were triangulated to formulate a solid background to the IB case study, Figure 11.1, reproduced from Chapter 4 presents an overview of the research methodology. Those research methods were applied to answer the research questions, which were:

1. Is it feasible to develop and demonstrate an IB to support electronic 'on-demand' health information provision system that can convey patient information from health trusts to an ambulance crew on scene?
2. What are the sociotechnical issues which will affect the design, implementation

and uptake of this electronic information transfer system?

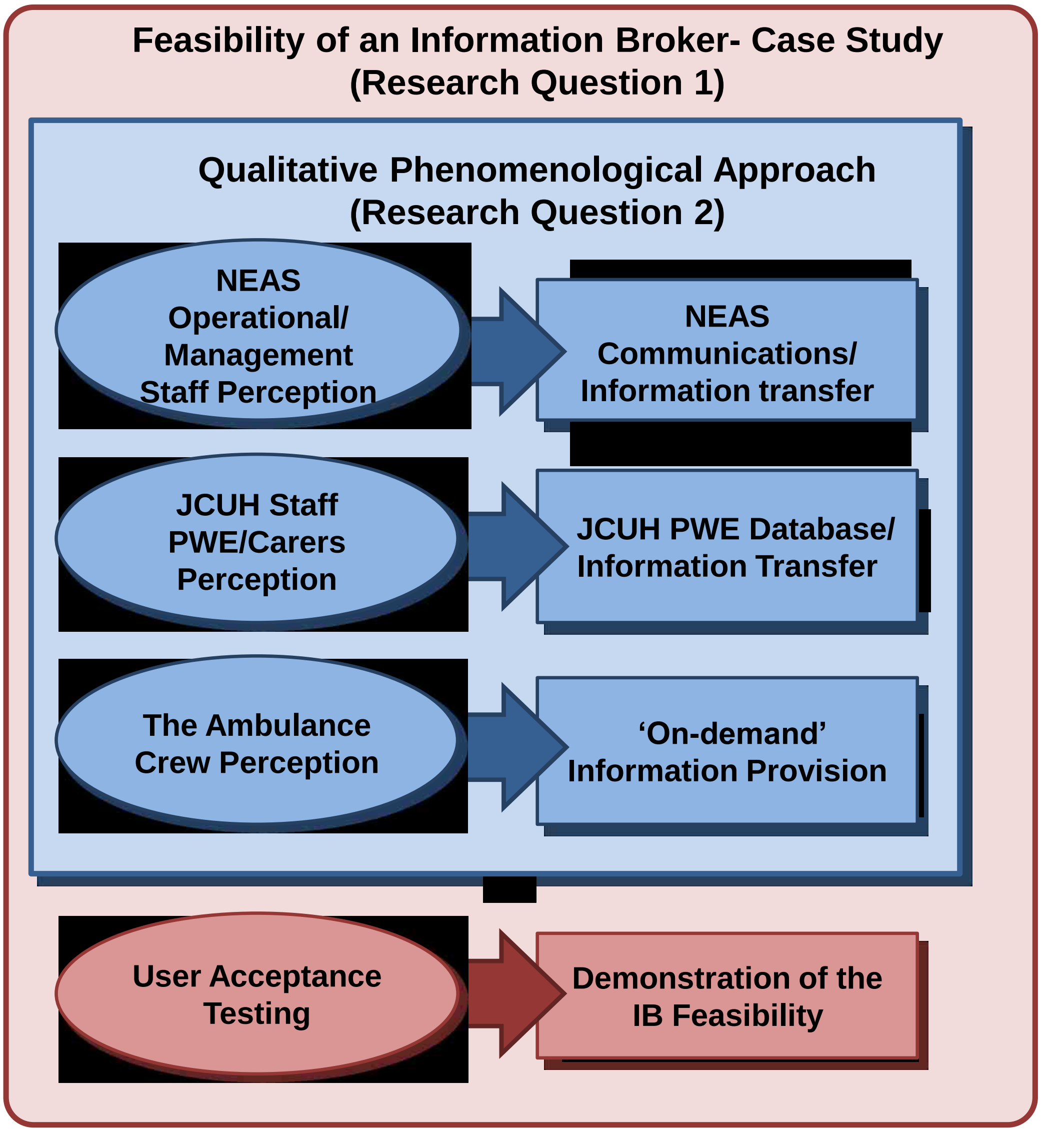


Figure 11.1: Research Methodology Overview

11.1 Discussion Related to the Feasibility of the IB

This section discusses the case study findings related to the IB prototype. The IB prototype supported feasibility and indicated how front-line end-users would value this as a tool. The IB prototype utilized widely common building elements in the IB architecture like Web Services, REST APIs, HTTP, PHP, Relational Database

Management Systems (RDMS), and so forth. These are languages and functionalities which are well known and have widespread acceptance as well as being robust. All of them are open source which would not impose any financial burdens on organizations. They are easy to learn and widely used by individuals, government and commercial organizations. This therefore reduces the chance of system isolation and increases interoperability and compatibility.

The IB could potentially increase collaboration and interoperability of systems between organizations and the ambulance service by applying simple solutions that join existing systems instead of building new expensive ones to connect them. The IB will only be granted access rights to databases and will not store data. It will not **pull** data from a single centralized database, rather it will **link** to different databases supporting the approach of information decentralization. This is important, as the concept of data centralization was one of the reasons for the failure of the NPfIT programme (Hendy et al., 2005; Randell, 2007). The fact that the IB could utilize existing but isolated information database(s) can help with better decision-making by ambulance crews and reducing the number of information gaps regarding the patient on scene (Stiell et al., 2003; Hjälte et al., 2007*a*; The House of Commons, 2013).

The improvement in decision-making is not limited to PWE. The design is simple enough to extend the IB for use with other frequent users of ambulance services. However, although a crew would have similar requirements regarding patient health information for other chronic conditions, whether the patient has epilepsy or another condition, it is possible that adding other chronic and non-chronic condition databases to be accessed might reveal other challenges that need to addressed.

The demonstration of accessing the IB, via a laptop Toughbook hardware, by an experienced paramedic suggested, even at this prototype stage, other potential ways of hardware adoption and extension such as using smart phones and tablets. Any IB extension and full implementation will also need to apply additional software designs and principles about appropriation, HCI, and CSCW. The enthusiasm and the rethinking of the paramedic during the IB demonstration, with regard to the potential forms of interaction and the possibilities presented by a full implementation of the IB, suggests how the ambulance crew may view the possibility of extending the IB in a way that supports their working process.

For extension to be possible, small single steps in different time frames are essential. Figure 11.2 illustrates possible extensions to increase the sources of information - horizontally by clinical condition and vertically by adding in of multiple different health and non-health organizations. As the IB system does not store any copies of information, there is the willingness that healthcare organizations will be more willing to share their database information (after patient consent). As they can set their data protection rules, functionality and protocols to determine who may be allowed to accesses their patient information.

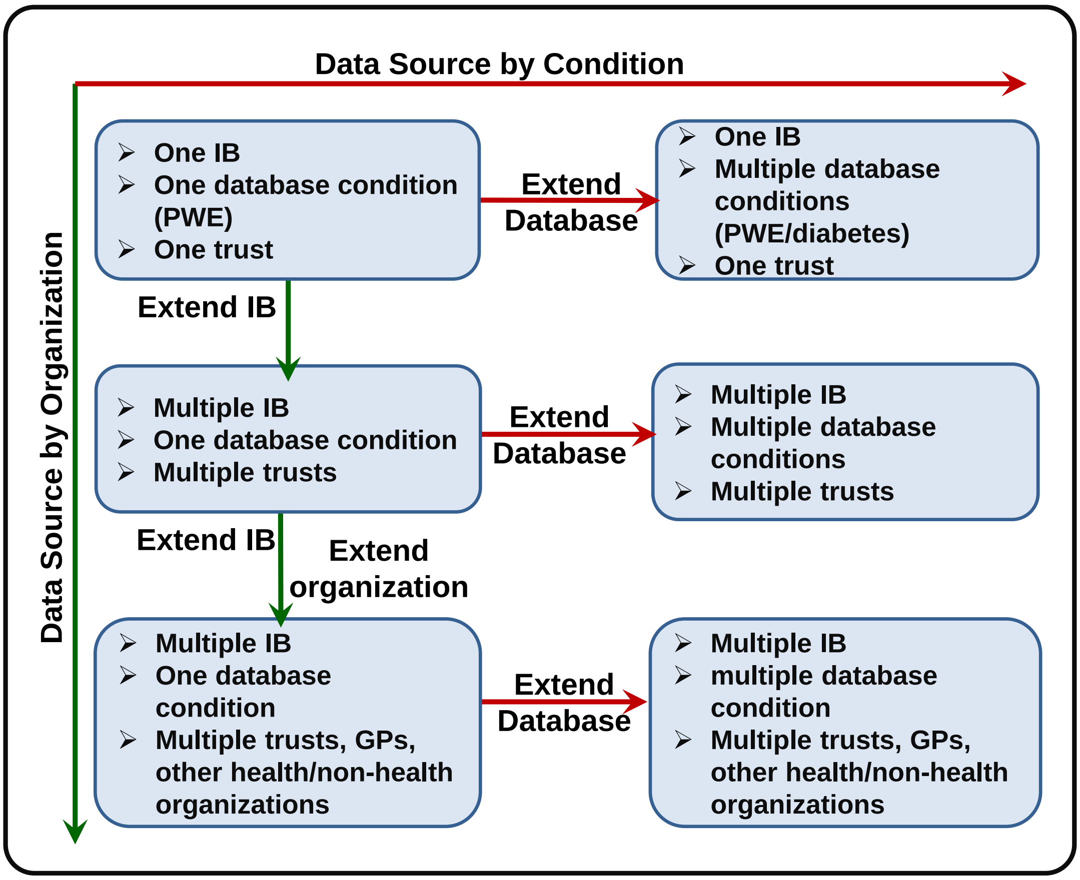


Figure 11.2: The IB Potential to Extend

Although the demonstration of the IB prototype has shown the feasibility of such an idea applying it in the wider ambulance service context will inevitably reveal different challenges needing to be investigated, including the need to manage the process of searching for information where there are multiple possible sources, as well as coping with more challenging forms of patient identification.

If the IB prototype is to be implemented and upgraded to a live system with new functionalities, stakeholders (especially patients and carers) may wish to alter the nature of the IB somewhat, to remove some data gaps between what NEAS, GPs and consultants know about PWE's ambulance use in line with their current expectations, see Chapter 7. This would potentially mean giving the IB a capacity to input certain limited data or giving consent to organizations to save data shared with them. Doing this however would significantly change the nature of the IB and would create a need for additional consents for information sharing. The technical and organizational challenges in this have not been considered in this thesis.

Observing the ways the ambulance crews adapt existing HIT was critical in designing the IB by using CSCW and HCI approaches and principles through facilitating the principles of designing **from** appropriation (Carroll et al., 2001; Dix, 2007).

Continuing the CSCW principles should ensure the design of the IB system, if adopted, will not be imposed by the ambulance crew but co-designed with them. As a result, the ambulance crews should have a sense of ownership towards the IB, perceiving it as their own initiative rather than a "technology-push" towards them (Greenhalgh et al., 2008). The ambulance crew will have the freedom of choice to use the IB system based on patient needs.

A possible (likely) limitation regarding the operational use of the IB is that only a proportion of PWE data will be available for use. As PWE care management is not limited to a specific health setting, a variety of health providers are involved in providing support for PWE. Not all PWE are managed in hospitals, some are managed and monitored by their GPs, and some are seen by an epilepsy specialist nurse annually or semi-annually in a hospital under the oversight of a consultant.

If the related records and databases are not linked to the IB then that will limit the usefulness of the IB, since the data available to the user will be incomplete, and hence possibly inaccurate.

This wide distribution of information related to individuals with PWE within the health system may form a barrier when seeking to encourage them to enrol in the IB, since consent forms sent by post may be ignored, missed, lost, etc. Obtaining data about PWE from different health sources may also require the ambulance service to negotiate with a large number of GPs, hospital departments, care homes, etc., both to help with gaining patient consent and also to encourage them to grant the IB access to their data. For instance, NEAS may approach an ED and ask them to provide information access, as this can provide benefits to both the ED and the patient, including reducing the number of occasions involving the unnecessary conveyance of patients to ED by the ambulance. Patients experiencing a seizure would also like to maintain their normal daily life routine with minimal disruption as possible by being provided with care on the spot and reducing their unnecessary conveyance to ED. However, even if patient consent was sought from all healthcare organizations, there will be the need to consider organizational and national requirements of data information transfer schemes, and those issues need to be addressed by the organizations owning the information itself, not the IB, so as to be compliant with the NHS standards and protocols. On the other hand, there is the possibility that not all patients/health organizations and/or providers want their information to be accessed by the IB and the ambulance service.

Even if the IB is not to be used and/or patients do not give consent for their information to be accessed, the ambulance service (NEAS) may still be able to provide better support for PWE in the community simply by utilizing and making more use of the data they have already collected from the ePRFs related to previous call-outs, and which is stored in NEAS's file store. This was apparent when examining the use of the PRF and the ePRF 1 and 2. Unfortunately, although NEAS currently holds those records, they are not integrated nor organised in a form in which they could be used to provide useful information to their own employees when needed.

NEAS is simply not utilizing the data that is already available in their databases from previous call-outs. The records available in NEAS that are based on call-outs could be set up as an additional source for the IB to access, providing 'historical' data of previous support provided to a patient.

11.2 Discussion Related to Sociotechnical Factors

Following are discussions related to the sociotechnical issues surrounding the IB.

11.2.1 Information Isolation

The combined findings from the results chapters were helpful to form a background understanding of stakeholders' working routines and needs as well as indicating where there seems to be some gaps in best practice in making use of HIT capabilities. There is a lack of full utilization of already available HIT within NEAS, at both the intra- and inter-organizational communication level. Intra-organizationally, this is evident in the isolation of the various NEAS PRF, ePRF1 and ePRF2 data storage systems and the lack of integration and sharing of the data within the ambulance crew at an incident to support their decision-making while on scene. Each one of the three incident information documents are stored in different data silos and offered in a different state of format. Utilizing the data already stored in the NEAS databases, such as reasons for call-outs, diagnoses of the patients, and the care pathway utilized by the last attendance may be sufficient to improve ambulance crews' decision-making without accessing any information held by JCUH or other healthcare organizations. The information improvement challenge here is not limited only to the format of the document, whether it is a paper or an electronic form, but also the three different system for working with each one of them the PRF, the ePRF1, and the ePRF2.

Poor intra-organizational use of HIT capacities is also evident within JCUH in the lack of an electronic database for PWE in the Neurophysiology Department. The paper filing system the department utilizes is an obvious indication of information isolation, fragmentation, and redundancy. For instance, the physician may request a PWE to have a specific blood test, which has already been done previously, but because the department is not linked to either the electronic system of the Haematology Department or the hospital's electronic patient records, the physician will not know that an earlier test has been done and may request another blood test.

An electronic database with connection capabilities will increase potential intra-organizational data flow within JCUH. Facilitate inter-organizational information flows between front-line staff especially ambulance crews and clinical staff in the Neurophysiology Department. This assumes, of course, that, at a future date, the JCUH IT department agrees to both hosting the new database and JCUH management agrees to become an enrolled information-sharing health provider with NEAS. This database access offered via the IB is not necessarily limited to NEAS and the Neurophysiology Department in JCUH but could also include other departments within and between JCUH and NEAS as well as GP patients records. Many factors may generate end-users resistance and/or integration with new systems and technologies including the IB. For instance, the rigidity of the system due to required standards and the none involvement of end-users in the designing, developing and testing phases. Efforts to introduce new technologies to organizations should therefore simultaneously apply national standards and policies with organizational requirements and information protocols. They should also simultaneously seek to discover and include end-users working practices, requirements and needs.

11.2.2 Different Benefits for Stakeholders

In this study, all stakeholders expressed the desire to convey patients to ED only when necessary. Designing and using an IB architecture to support this however must be a collaborative activity. NEAS needs the collaboration and involvement of patients, carers, their own staff especially ambulance crew, and JCUH staff to ensure further development and implementation of the IB. It also needs to work with stakeholders to ensure the incentives in the current system of funding and assessing care quality are aligned coherently to promote exchange of patients data.

The ambulance crew are faced with various challenges when making suitable decisions according to each patient current condition and personal preference. These include coping with a lack of information about the patient health history and current health condition; decisions about whether it is safe to release the patient or to refer to other supporting facilities; the challenge to make performance indicators, priorities, and organizational concerns, fear of litigation, lack of protocols and/or training to be able to leave the patient at the scene or take the patient home (Zorab et al., 2015; Porter et al., 2007; National Ambulance Service Medical Directors (NASMeD), 2014; O'Hara et al., 2014; Burrell et al., 2012; NHS England, 2013; Snooks et al., 2005, 2002; Halter et al., 2010; Snooks et al., 2015; O'Hara et al., 2015).

The availability of additional health data should assist the crew to juggle these various concerns. They should be more confident in deciding on medication to administer, what care to provide, what chronic condition this patient has, and how to deal with the presenting incident in ways that enable them to be sure that the pathway they are following is best for the person with epilepsy being treated.

This improved decision-making by paramedics however would carry benefits not just to the ambulance crew but also to other stakeholders involved. The ambulance crew will demand information only if they think they need more support which regards their decision-making and affirmation of the appropriate care pathway to follow. This will potentially save time spent on scene with a patient and therefore increase the possibility of accepting other jobs or call-outs (North East Ambulance Service NHS Foundation Trust (NEAS), 2016*a*,*b*); this also provides benefits to other patients with medical emergencies who need ambulance assistance.

Additionally, patients and their carers do not always want the PWE to be conveyed to ED at JCUH or wait in the ED for hours unnecessarily, but equally patients and their carers do not want somebody to be returned home if they do need to go the ED. Patients taken to ED for treatment and released without being admitted can find it challenging to return home again after they have received their treatment. They would rather to be treated on site by the ambulance crew and released or taken home if their condition permits it. If the IB made this possible, patients would feel more confident about going about their ordinary lives and experience less disruption to their daily routine.

Pursuing patient-centric care in this way start to raise issues about patient rights and powers and how they are exercised. One question that needs to be addressed in adopting this system is how patients' consent for data sharing can be gained, held and shared appropriately within all relevant health organizations, in this case NEAS, JCUH Neurophysiology Department, and the wider South Tees Hospitals NHS Foundation Trust (STHFT). There are also questions about the status of the next of kin data held in the PWE database. Do the next of kin need to give their permission for their personal data to be shared between JCUH and NEAS? Does NEAS need a next of kin's permission to keep and/or reuse their personal data if a PWE provides it when at a call-out?

Even if patients support and promote the use of the IB and data exchange, in the current way the NHS is structured, patients are relatively powerless to achieve change in operational systems despite their inclusion as trustees on local foundation Trust Boards. Furthermore, PWE are dependent on others especially if they are unconscious or still confused upon regaining consciousness. They may not be willing to suggest or insist upon changes in information storage and/or sharing in any one health organization because of their vulnerability and dependency on health professionals. Finally, when developing the ePRF systems, NEAS demonstrated a propensity not to consult with its own staff or key organizations (e.g. JCUH). There are limited indications that managers in NEAS would be willing to implement system changes in response to not alone individual patients or organized patient support groups.

The IB can meet some aims of the NEAS management expressed in their initial research discussion but it cannot solve all their issues. Some problems with providing best service utilization and appropriate care seem to be generated internally by NEAS management, through an overemphasis on management own IT needs and limited appreciation of the needs of their front-line staff when at an incident. Inability to manage service demands and usage is also a result of not fully utilizing patient information they already have in their database. If NEAS discussed with ambulance crews the advantages and the disadvantages of the various PRF and ePRF systems, what works, what does not work, and how the stored information in the ePRF is used, they and the ambulance crews would receive feedback essential to enhance working processes, individual performance, and organizational performance. Equally, ambulance crews would like to get feedback externally from the ED about their performance as this would allow both the crews and NEAS to monitor crew performance, identify gaps particularly at patient handover, and devise appropriate solutions.

When developing a new system, it is wise to involve all possible stakeholders in various stages of system or intervention development and implementation. Limiting involvement to the management level does not ensure success of systems or technology. Chances of success may increase if all levels (top, middle, and bottom) in the organization are included.

Even so, this may create a sense of ownership towards the system which may help reduce reluctance to change, unwillingness to share the benefits of change and therefore increase the likelihood that the IB would be adopted. If this is the case, implementation of a full IB will require further consultation with PWE, their carers, the management of JCUH and NEAS, front-line and other operational staff to ensure the IB meets the needs of all stakeholders.

Unfortunately, even if NEAS does consult with JCUH, there is no guarantee that improvements and/or collaborative design of the IB would be easily achieved. This is partially because STHFT also has its IT shortcomings. Even if the PWE database created in this project is adopted by STHFT, we do not know how many other patient records are also not held electronically but remain paper based. The priorities of and pressures upon the JCUH management in updating its patient data systems have not been examined in this thesis. Making the changes the IB system needs to be fully operational may not be high on JCUH management's priority list. This situation may also be replicated in other trusts NEAS may wish to include in an expanded IB system.

The IB may offer financial incentives by saving resources, cost and time. The financial incentives for using the IB are quite complex. This thesis looks primarily at the technical challenges and the organizational issues of getting people to engage appropriately at every level, but the economic factors are also important because all health organizations have to manage their finances efficiently, and so this introduces a further level of complexity about whether the IB is going to be beneficial or not. The IB might be beneficial to paramedics by providing additional patient information, might be beneficial to the life style of patients, and might be beneficial to the hospital by reducing unnecessary attendances. This does not necessarily mean that this will save money for NEAS or the NHS as a whole. Therefore, in any detailed consideration about whether to develop the IB, the cost of developing the IB itself and the cost of maintaining that system from the revenue that flows in and out of NEAS forms an important factor that must be considered.

11.2.3 Patient Related Factors

People will call for ambulance help for both clinical and non-clinical reasons. The following are some examples of non-clinical reasons for calling an ambulance:

- Lack of knowledge about the system. Paramedics report that patients lack knowledge about the health system. Patients, who are experiencing a health or a social need and are unsure from whom to seek help, will call the ambulance service. In such situations, paramedics are required to offer reassurance to patients and to act as "information providers" (Dejean et al., 2016). Patients will also call the ambulance if they perceive that there is a gap in the health system that means that it does not meet their needs. For instance, when encountering long waiting times for appointments and if they are experiencing difficulty in accessing appropriate health services (Dejean et al., 2016; Booker et al., 2014*b*).

- Social support availability, perceived need for attention, unmet social/personal care needs, and the patient's age (elderly). This may arise from the lack of an available family member who can provide support, or of a knowledgeable significant other person. For instance, an elderly woman may call the ambulance service to lift her husband from the house to the car in order to go to an appointment, if she is unable to perform such task (Dejean et al., 2016; Knowlton et al., 2013; Edwards et al., 2014; Durant and Fahimi, 2012; Ahl et al., 2006; Richards and Ferrall, 1999).

- Need for transportation. Some patients think that the ambulance service can provide transportation to enable them to visit health providers, even if the patient is able to drive themselves (Hjälte et al., 2007*b*; Khorram-Manesh et al., 2011; Durant and Fahimi, 2012; Ahl et al., 2006; Richards and Ferrall, 1999).

- Substance abuse of alcohol and drugs. This may be a psychosocial cofactor, whether arising from psychiatric causes or social causes such as homelessness. Acute or chronic mental illness, suicidal intentions, self-harm, high level of anxiety are all factors that may arise from such causes (Knowlton et al., 2013; Edwards et al., 2014; Durant and Fahimi, 2012; Booker et al., 2014*b*; Snooks et al., 2004).

Edwards et al. (2014) in their study of frequent callers to the London Ambulance Service (LAS) reported that "the majority of frequent callers (86%) had multiple and complex reasons for calling, including frequent medical need, acute or chronic mental health condition, older age and unmet personal or social care needs". The most frequently occurring category of frequent callers to the LAS were frequent clinical/medical need (64%), followed by acute or chronic mental illness (40%), elderly (38%) and unmet social/personal care needs (28%). Furthermore, (16.4%) of frequent callers had suicidal intentions/self-harm. Many calls were categorized against more than one profile category applied to each patient.

Selden et al. (1991) reported demographics, disposition, and reason for non-conveyance to hospital. There was no gender difference between patients conveyed to hospital or treated on site. On the other hand, non-conveyed patients were significantly younger than those conveyed to hospital ($p<.001$). The most frequent conditions among the on site assessment were minor trauma (25%), blunt head trauma (19%), and no injury or illness (16%). 47% of patients were treated and released at scene by paramedics, while 23% sought medical care or went to ED by private vehicle, and 24% refused treatment. Thirty nine per cent of the conditions that resulted in patient refusal to travel were due to an epileptic seizure. Patient disposition was: thirty nine per cent left with friends or relatives, 35% were left alone, 18% left with the police, 7% taken to other medical care (mental health facility, "detoxification unit") or prison (Selden et al., 1991).

When a crew is dispatched to an incident, they may find themselves faced with both clinical and non-clinical situations, and so the potential benefits of using an IB may not always be achievable. An example is the situation when an ambulance crew is dispatched to an incident and find out that the patient has consumed/misused alcohol or drugs, resulting in the presence of an ambulance being thought of as necessary (some turn out to be genuine) (Osborne et al., 2015; Snooks et al., 2004). The different reasons for call-outs occur across the general population, of which PWE are part. Therefore, some call-outs may not be triggered by epilepsy itself, but by something else. Thus, many call-outs are not strictly associated with epilepsy but are generated by a mixture of social conditions, some of these are within a patient's control and some of them may not be. Without change in individuals' social context, lifestyle and/or their way of thinking, then no matter how effective the IB is and the amount of information it can provide to paramedics it will still not reduce the individual's use of the ambulance service, as the reasons they are using the ambulance service are not strictly related to their epilepsy. For instance, a co-morbid person's health condition might be exacerbated by the use of alcohol or drugs etc., meaning that this social action increases their vulnerability to any health crisis. However, the IB may still assist a crew with determining if this person is co-morbid, has a long term condition(s), what medication they are under, if they hold any criminal or mental health records (police, mental health database) etc. and therefore they can still be supported with information that will guide them in their decision-making regarding to convey or not. Thus, the potential role of the IB in such call-outs would be one of providing the crew with contextual information that will help them to deal appropriately with the conditions encountered.

11.2.4 The Wider NHS Structure

At a more macro level perspective, adoption of the IB would help to fulfil the Five Year Forward View desire for "combinatorial innovation" (NHS England, 2014). It should also be minimumly disruptive because using the IB will preserve each organization's database integrity, data ownership, security protocols, and Role Based Access Controls (RBAC) all of which should ensure the autonomy of each health organization. Cooperation and agreement between different trust and health providers would still be essential in order to grant NEAS access to their relevant databases. This might be challenging to achieve since the introduction of Foundation Trusts within the NHS was designed to make each organization more independent and financially responsible.

Assuming each of these issues could be resolved, there are currently unanswered questions about how the benefits and costs of introducing the IB will be shared among the stakeholders. Under the existing system, the cost of introducing the IB would be born by the NEAS but the majority of benefits will likely accrue to patients and to the hospital trusts. For both JCUH and NEAS, achieving a high degree of compliance to arrange NHS standards may also be a strong incentive to them to adopt the IB and associated new ways of working. This is particularly so as the IB should allow them to highlight their interest in the provision of patient-centric care.

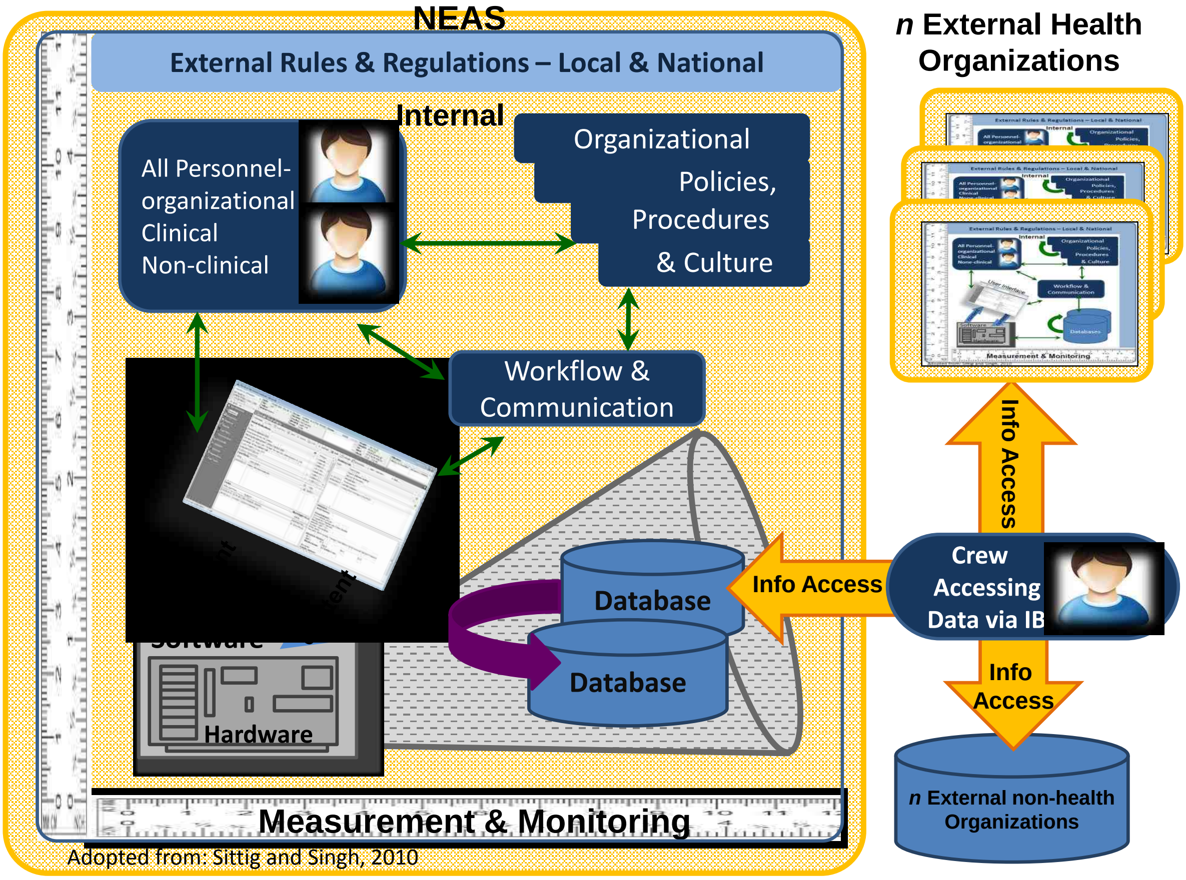
The cost estimates, provided in Section 2.4, exhibit the fact it is currently less costly, in terms of time and money, for NEAS to transfer patients quickly to ED

(Newton et al., 2006; National Audit Office (NAO), 2017; The National Audit Office, 2011). Unfortunately, as Section 2.4 demonstrated, currently NEAS is likely to become financially worse off, if it adopts the IB and the proportion of PWE it transports to the ED falls, because it is cheaper not to 'See and Treat', but to 'See and Convey' to ED. Changing the operational patterns with PWE (and/or other conditions) will potentially affect NEAS' financial position negatively by a greater amount than the cost of the development and implementation of the IB. From JCUH perspective the Neurophysiology Department may not have a direct financial benefit in allowing NEAS access to PWE database, as the financial benefits of reduced admissions (to ED or hospital) may go to the trust as the whole and not the clinical department concerned. Despite this both may benefit from reduced patient pressure and workload as well as potentially providing better care to PWE during a call-out. Therefore, identifying direct and indirect incentives for each stakeholder that would appear as a result of the use of the IB is essential to understanding how each organization might respond to the initiative to design and implement a full IB.

This study also highlights some of the challenges that arise from software procurement practices in a federated system of organizations such as the NHS. Ideally, the development of an information transfer mechanism such as the ePRF should have been an exercise in co-design, with participation from and consultation with all of the other organizations and stakeholders, both internally and externally. In this research project examples of the lack of co-design was evident within and between both organizations. For example, NEAS did not involve either the ambulance crew nor JCUH when designing either version of the ePRF; and JCUH management appeared that it did not consider whether information contained within the ePRF could be shared between the ED and other departments for the hospital. Finally, there appears to be little cooperative design between NEAS and JCUH in the sharing of information within ED both before and during handover. These are essentially organisational issues, rather than technological ones, and given that they stem from the fundamental nature of health care in the NHS, especially at the inter-organization level, they are ones that could have potential benefits system wide if addressed more effectively.

11.2.5 The Theoretical Model

All of the discussion to this stage reflects the interdependence which is critical to the NHS function, however this interdependence is not reflected in the theoretical model of the sociotechnical issues put forward by Sittig and Singh (2010). This is primarily because Sittig and Singh (2010) model assumes that successful information transfer occurs within a closed system of a single organization. The model is an oversimplification assuming there is no flow of operational information between organizations. This is clearly not true, especially for health care organizations in general and NHS organizations in particular. The model also greatly oversimplifies the complexity, intricacy and sensitivity of the components of the personnel and organizational policies, procedures and culture elements of NHS organizations.



Adopted from: Sittig and Singh, 2010

Figure 11.3: An Adapted Sociotechnical Model for Ambulance Services Incorporating Inter-organizational Communications

Nonetheless, Sittig and Singh (2010) do provide insight into the range of internal organizational factors necessary for efficient and effective management of information. The insight the model provides, however, can be expanded to make a better application to ambulance trusts via some modification as illustrated in Figure 11.3. Figure 11.3 includes communication flows among and between health and non-health organizations such as the trust itself (NEAS) and other healthcare providing organizations such as foundation trusts, GPs, care homes, etc. and non-health organizations such as police and social services. The figure also demonstrates the intermediary function that the IB plays in making data available between those organization. Referring to the original Sittig and Singh (2010) model, in Section 3.3.2, emphasizes that organizational policies, procedure and culture facilitate individual work conduct, work flows between individuals and organizational functions, and information communication necessary for organization effectiveness and efficiency. This thesis has shown that the organizational policies, procedure and culture in NEAS are insufficiently developed to make best use of information already held within NEAS, thus it is not available internally to resolve some of the ambulance crew work pressures and communication issues. This is also evident in the example presented previously in Chapter 5 regarding, feedback , ePRF development, isolation of staff, and information by management. Although NEAS has both an Informatics manager and an IM&T manager, better use of NEAS' internal data was overlooked by both managements in discussion with the researcher about how to achieve improved care for PWE. This gap in the distribution and the **recycling** of organizational policies, procedures, and data throughout the whole organization (indicated by the purple arrow in Figure 11.3 of the modified model) could be overcome with effort to change management and organizational culture towards capitalizing on NEAS existing holding of patient data while still maintaining patient confidentiality, system security, adherence to government protocols, etc.

Most existing studies regarding HIT development are not applicable to the ambulance crew environment. Perhaps following the Sittig and Singh (2010) model, most of those studies were conducted solely in out-patient, in-patient and/or single-centred settings within individual organizations. The ambulance crew are mobile, autonomous, widely dispersed, and in constant contact and communication with numerous healthcare and non-healthcare organizations and staff. More studies focusing on this unique environment are needed to fully elucidate and address the sociotechnical factors and dynamics identified by this research (Brenner et al., 2015; Graber et al., 2016; Buntin et al., 2011).

This thesis demonstrated found that research in this complex environment is difficult to undertake and the complexities of inter-organizational working are time consuming to resolve. It is possible that resolving these hindrances to the real world adoption of the IB may prove elusive. At the organizational level anticipated key difficulties are the apparent lack of motivation to fully understand front-line staffs' working practices, information needs and a possible (but temporary) increase in both managerial and front-line staff workloads, as IT developers work with the front-line staff to design and adapt both hardware and software to their needs. Other significant challenges include differences between stakeholders in the financial and quality assessment incentives for adopting IB technology. At the more macro-level, key challenges include the challenge of prioritising IT development by organizations in a time of financial austerity and against a background of large HIT project failures, ensuring the costs and benefits of that investment are borne equitably by the various stakeholders, and the power differentials that inhibit NHS services being truly patient-centric and patient-led.

11.3 Limitations of the Study

For this particular case, the feasibility of the IB has been demonstrated, while recognising that a broader application of this would be more complex and will require further work. What was not anticipated when the project has first started, was the extent to which degree the social and organizational factors are critical to the successful design, development and implementation of the IB.

Although the IB provides promising results, a number of drawbacks were present during the research. The lack of a current electronic database in the Neurophysiology Department in JCUH, was not expected, therefore it was necessary to create a database in order to complete the chain of demonstrations and to fill this gap. Another drawback was the long time that took to get ethical clearance and research governance from Durham University, NHS Research Ethics, NEAS and JCUH. Furthermore, the system was demonstrated with a database that was implicitly designed to meet the needs of the IB. Accessing existing databases might reveal different challenges.

This study offers a small snapshot of what can be done on a wider scale. Other issues might appear if other organizations are included such as GPs, wards in different hospital, mental health services, etc. Demonstration of the IB in the laboratory only will not predict all issues if it is to be applied on a local or wider scale. As the prototype does not replicate the true conditions under which the IB would operate within the NHS. For instance, query formulation from the IB interface was sent directly to the PWE database. The request was not directed by the NEAS ECS system. Also, the PWE database was accessed directly; fully application of Role Based Access Control (RBAC) functionality was not possible, as the database was not part of a functioning system, and RBAC protocols are applied by the organization that is holding the data. Receiving the response from the PWE database was the same, it was sent directly to the IB then displayed on the interface in front of the paramedic. The lack of this step was due to organizational changes within the South Tees Hospitals NHS Foundation Trust and consequent changes in its priorities which led to JCUH withdrawing permission to host the PWE database.

Furthermore, participants from ED were limited in numbers. It was hard to recruit more, due to the fact that ED is a dynamic place where providing patients with care as soon as possible is a major principle. Additional research around this domain is needed to identify more missed factors or new emerging needs.

When demonstrating the IB, only one paramedic conducted the process of demonstrating the IB in a remote location in Newcastle University. Getting more experienced crew members to test the system would add more value and provide more extensive end-user feedback.

A major limitation to the study arose from the need to involve and work with a large and distributed set of stakeholders for this research. Getting hold of participants, collaborators, and other members in the study was a major obstacle. Managing three different entities (Durham University, JCUH, and NEAS) required new skills for the researcher to learn. Setting appointments, interviews, or meetings were challenging. As both health organizations, the ambulance service and the Neurophysiology Department in JCUH, are dynamic and short in time, and individuals were extremely engaged with their work.

Chapter 12

Conclusion

This final chapter presents a summary of the thesis and findings of the research. Findings are provided to reflect how an HIT, the IB, can support the work of ambulance crews while on scene with reliable information in order to help them in their decision-making. These are followed by reflections on how the sociotechnical issues surrounding the presentation of an IB system may affect development of such a system or other similar HIT systems. Contributions from this study to the literature on health informatics will then be presented. Finally, some recommendations are made for future work.

12.1 Thesis Summary

This thesis describes a feasibility study of an Information Broker (IB) as a health information transfer mechanism that provides an ambulance crew, who lack reliable patient information during an incident, with electronic 'on-demand' health information about PWE. It also examined the sociotechnical factors which will facilitate its implementation and its most effective use. Understanding the sociotechnical issues surrounding was derived from lessons learnt from a current HIT system, the ePRF, which supports information transfers during patient handovers from ambulance crews to ED staff.

People with Epilepsy, were identified by NEAS as heavy users of the ambulance service. Many PWE experiencing their normal pattern of seizure, and only need stabilization, have an ambulance dispatched unnecessarily. Often these people are transported to ED unwillingly, placing an unnecessary burden on NEAS, the ambulance crew, resources, and patients convenience. Many incidents of this type could be managed locally without the need to convey them to the ED if additional health information was available to the crew while on scene. For that reason, this feasibility study of the IB was developed in collaboration with NEAS. People around a PWE (family, friends, social circle, bystanders) will call an ambulance for help if seeing the person in a fit due to many reasons. For instance, fear, overprotection, lack of clear pathways for support when in need, (other than ambulance services), lack of structured care, etc., as previously discussed in Sections 2.2 and 2.3.3.

This case study employed a qualitative phenomenological approach to understand the context of the ambulance crew receiving health information during a call-out in NEAS. Examining elements of the context was crucial to understand experiences of the current system by PWE, their carers and NHS staff so that the IB system reflected the needs of each.

It was necessary to divide the research to a series of small steps to understand the context, and reach the ultimate result of the IB. This was only possible by following the phenomenological approach of the different stakeholders perspectives: NEAS operational and management staff, JCUH staff, PWE/carers, and especially the ambulance crew. These steps, collectively, shaped and identified the context of the current situation of what is provided to support the crew while on scene. This knowledge was deepened by extracting technical, sociotechnical and organisational lessons from a current system that is already in use (ePRF), to help avoid obstacles to this information transfer.

The importance of this feasibility study is to determine what should be considered and avoided when introducing a technology based solution in a health context where time and reliable key patient information are critical. Reliable up-to-date key information should be summoned instantly from various enrolled databases for the ambulance crew while on scene. This additional information will support them in suitable decision-making in order to avoid unnecessary patient conveyance to ED. The lessons from this study should be transferable to ambulance services in other health systems.

12.2 Research Findings

The feasibility of using an IB system has been demonstrated at a basic level. Providing ‘on-demand’ health information to the ambulance crew while on scene is feasible and applying such a system will contribute to the intra- and inter-organizational communications relevant to healthcare organizations. This presents potential benefits for patients, healthcare staff, organizations on the macro, meso, and micro levels and is not necessarily limited to PWE but can also be employed for those people who have other chronic conditions. The reason for this is that ambulance crews require much the same set of patient health information regardless of the condition of the patient.

12.2.1 NEAS Operational and Management Staff Findings

As indicated in Chapter 6, the management staff findings were incorporated with the operational staff as part of the background context of the the operations, communications, information transfer, and elements related to the IB system. Themes emerging from the analysis included communications with external organizations, access to patient health information, external and internal information flagging, communication with ambulance crews, and finally interaction with technology. The focus was largely on the inter- and intra-organizational communication relevant to treating patients on scene and/or transferring them into the care of an ED. The literature has stated that lack of information at either or both operational and management levels can lead to system failures (Leape et al., 1995), error regarding medication and/or medical issues leading to morbidity and mortality (Coiera, 2000).

In this particular research project, the inter-organizational transfers of patient information at operational levels is currently limited to specific personnel in the ED viewing the finalized ePRF via the Webviewer, or is performed via other communication channels other than the CAD system, for example, the verbal handover of patients information from the ambulance crew to ED staff.

Access to patient health information held in external databases is currently not available to the dispatch centre personnel or ambulance crew. The only information that can be sought is through an unreliable medium, which is the person who made the call to NEAS asking for help. On the other hand, NEAS do not share the incident information (the finalized ePRF) with other external bodies that provide subsequent care to the patient who used the service. Specific personnel in the ED are the only ones who can be granted authorization to view the ePRF. Furthermore, the information flagging in the system is tied to an address, not a patient. This might cause misjudgement of the person in need, especially if the patient who is tied to specific address moves to another address or lives in a care home, causing active flagging to be misjudged and the inappropriate support wasted.

Intra-organizational communication links, on the other hand, that emerged from the analysis are equally important. These focus on communication in the dispatch centre with the ambulance crew. Communication with the ambulance crew occurs via the electronic system of CAD and the MDT. Crew sometimes find themselves forced to use backup channels of communication (radio/mobile phones) instead of the CAD system, for further information regarding the incident. Utilizing non-standard means of communications is due to various reasons like connection poverty, delayed information streaming, information overload etc. Moreover, the information flagging is to do with crew being dispatched to the same address on different occasions on the same day. Yet, crews mostly will not be aware of a previous dispatch on the same day, causing duplication or redundancy of health provision or misjudgement of foreshadowing health alerts.

The last emergent theme was the interaction with technology. The system in the call centre is rigid and inflexibility in decision making. The NHS pathways triage system will make decisions on behalf of the call handler. This action is enforced by the system as a safety net to patients and personnel. However, this results, in some cases of an inappropriate category being assigned to an incident. An experienced call handler can often identify unsuitability of decisions made by the NHS pathways with regard to the actual patient situation, but due to the rigidity of the system, they are unable to change, alter, or overwrite the algorithm of the selected job category made by the system.

12.2.2 JCUH Staff, PWE/Carers Findings

The analysis revealed various outcomes when building an electronic database and eliciting the requirements from JCUH staff and PWE/carers. Doing such an important activity, is vital to consider the logical beneficial steps and processes of the development stage of the database. Gaining end-users requirements, feedback and opinions are critical backbones when building an electronic database. It was necessary to achieve this in order to form the data model that is necessary to complete the database. This led to the development process of the actual building of the database and presentation of the application interface of the database.

Additionally, JCUH staff (excluding ED staff) had needs from the information transfer different from the ED staff, therefore, it was decided to elicit their needs separately. Needs identified by JCUH staff were: PWE database creation and management, operational requirements from PWE database and interfacer, and finally internal/external information access. These findings were helpful in building the PWE database and forming background information of information transfer internally and externally. Additionally, information regarding database development, management, requirements, and access was also helpful in contributing to the final development of the IB. On the PWE/carers level, their needs were: avoiding conveyance to ED unless necessary, information access and sharing, information storage, data protection, and maintaining a stable lifestyle. PWE/carers all agreed their information to be accessed by ambulance crew only if done in conjunction with data protection policies and regulations by health personnel who are in their healthcare circle. They support the idea of an information transfer system broker that will provide ambulance crew to make suitable health decisions and reduce their conveyance to ED unnecessarily so that they resume with their normal life routine with minimal disruption and more independence.

ED staff differ from other JCUH staff due to the fact that they are in direct contact with an existing information transfer system employed by NEAS, the ePRF. Issues revealed from the ePRF study were the lack of rapid access to patient information, information availability, and accessibility. These issues were considered to be met when building the IB prototype.

An important point that needs to be emphasised is the limitations created by the paper based filing system in the Neurophysiology Department. This paper-based system perpetuates inadequate and poor care coordination, service isolation and information fragmentation and redundancy.

12.2.3 Ambulance Crew Findings

The IB user interface and the IB as a system is mainly to be used by an ambulance crew who are on scene providing care to a patient and who need additional health information to support their decision-making about whether to convey to ED or not. Therefore, it was important to analyse what the ambulance crew needed from the IB and what precise information would help them in this process of decision-making. The analysis of the data revealed two emergent themes. The first was information regarding patient health, and what kind of information crew would like to obtain. 'On-demand' health information that they would like to see in the interface were current medication, allergies, known conditions, next of kin, and a care plan. Information regarding patient encounter with other organizations, formed a second emergent theme. This included recent GP notes and their contact information, previous encounters with the ambulance service, whether a resuscitation attempt is to be permitted or not, and finally details of any recent contact with other health services. Ultimately, what ambulance crew need is a tool to support the multiple challenges they encounter while on scene.

Findings related to the ePRF, an existing information transfer system employed by NEAS and used mainly by the ambulance crew, was helpful in terms of the IB development process. Connection availability is poor, detail of information inserted in the ePRF is dependent on job type (complicated, non-complicated), any problems with data entry to the system, and technical issues when dealing with the ePRF were taken into account when development of the IB was in process.

12.2.4 ePRF System Findings

The current ePRF system is still in use by the ambulance crew working in NEAS. Investigation of this system was crucial to extract lessons to apply and/or avoid when building the prototype IB. This was helpful in elucidating key factors related to system architecture, user interface, and system procurement.

Patient based, technical, sociotechnical, and organizational issues were considered when developing the IB. The patients data journey from the moment of dispatch until reaching the final destination and going clear in the ED included five stages which began with receiving information, formulating it, recording, delivering, then finalizing it. When building the IB, it was essential to keep process steps, for crews who might use it, simple and involve as minimal working stages especially in time pressure situations during incidents.

Issues regarding patients' data are critical to consider. For instance, the ePRF is created and stored by NEAS, and therefore ownership is vested in NEAS. Sharing this information externally is limited. Only specific personnel in ED are granted access to view the finalized ePRF. Health providers, GPs, hospital wards etc. cannot access the ePRF system or the data within it. Not only that, but they are not even notified if an ambulance was dispatched to their patient. On the other hand, once the ePRF is finalized, the ambulance crew lose their access to it. To re-access the ePRF again, for any reason, crew need to submit an official request justifying the reason(s) of access. This will not be the case with the IB, as any decisions about data ownership and Role Based Access Controls (RBAC) are left with the organization holding the database.

The sociotechnical aspects should be given due consideration. Fulfilling this aim will assist shape a better system that meets end-users requirements through improving the system design, development, evaluation and implementation (Berg et al., 2003). Systems are not just limited to technology by itself; when designing such systems one must include those using the system and consider the interactions of people with objects and systems.

The influence of the sociotechnical issues is evident in the ePRF in terms of the exclusion of any end-users from the HIT development phase. Although this seems fairly simple and clear, it is just the tip of the iceberg. When bringing forward the two elements (social and technical), a lot of important considerations must be accounted for. It is widely recognized, in the literature, that HIT and people interaction in systems are inseparable, in other words, the social (human) and the technical aspects go hand in hand as interaction and the interrelation between technology and its social environment is critical in understanding and supporting health information systems (Berg et al., 2003; Lorenzi et al., 1997; Bostrom and Heinen, 1977).

Despite this knowledge, the operational staff and front-line crew in NEAS were excluded from various stages of the ePRF development, resulting in the need to find workarounds when using the ePRF system. Writing on gloves, pieces of paper, etc. in order to preserve incident information are indicators of undesirable working processes that have been adopted as a consequence of not meeting users' IT requirements. The need to use workarounds reflects the system builders lack of knowledge about end-users requirements from a system that can impact information transfer implementation and success.

Establishing inter- and intra-organizational communications feedback is also an issue that was overlooked by NEAS. Front-line crews had a positive perception towards receiving feedback, from NEAS and ED, in regard to their working performance. Within NEAS, crews would like feedback from management on performance. From JCUH, crews would like feedback from ED staff about the handover, the patient care and work performance.

12.2.5 IB Findings

Providing an ambulance crew with additional information while they are on scene has been identified as a necessity (National Ambulance Service Medical Directors (NASMeD), 2014; Zorab et al., 2015). The simple prototype developed for the IB has demonstrated the feasibility of providing additional information. Development of the technical IB system was relatively straightforward, as languages, functionalities and system requirements were technologies that were readily available and used, for instance, instance, REST APIs, PHP, MySQL, SQL, etc. They are robust, well established, and used in different health and non-health organizations. Components that were utilized were also open-source, lightweight, and easy to install and work with. The IB will not store data, it will only pass information from the database and display it to the ambulance crew on scene. This is an aspect that is desirable by organizations and patients equally. Tailoring of the IB system to fit other types of patients, different job categories, ambulance crew needs and multiple organizations' requirements is a possibility that can be added incrementally after implementation. The demonstration of the IB in supporting the needs of PWE showed this is feasible, applying it to the wider health context with diverse stakeholders will no doubt reveal other challenges and requirements that need to be met.

12.3 Research Contributions

Ambulance crew lack reliable patient information while on scene, therefore supporting their decision-making process for PWE during an incident with reliable patient information has been demonstrated as feasible through the IB prototype. This contribution to knowledge, working process, patient quality of care, organizations will clear the path to identify more issues, challenges, and research.

That said, the issue is: *can organizations internally and between themselves agree to do what is required to facilitate the work of the IB or a new HIT?* The challenge here is the incentives that are causing such separation and autonomy. For instance, even if NEAS did not apply a new HIT, integrating its own databases and making their own information available to crews would help crews' decision-making. Small incremental steps such as this may have a big affect on the organization by better utilizing its available resources. NEAS can make the whole system better without the IB at this stage, just by making small incremental changes and fuller use of their own data.

On comparing the cost of 'See and Convey' to ED and the cost of 'See and Treat', it appears that the cost of the former is less than the latter for NEAS. Hence there is an incentive to convey patients to ED, as it reduces the immediate costs to NEAS. NEAS is therefore faced with conflicting incentives, incentives about both reducing cost and alleviating pressure at different points in the ambulance system by reducing the time that an ambulance needs to spend at the ED.

The application of the IB brings forward potential immediate benefits to NEAS regarding cost and patients satisfaction. The availability of 'on-demand' patient information to the crew on scene by the IB, will not only decrease unnecessary conveyance rate to ED, but also increase fast reliable decision-making time on the spot. This of course carries benefits to NEAS, as it should lead to decreased treatment time on scene which will decrease the cost of on spot treatment and the cost of unnecessary ED conveyance. In addition, patients desire not to be taken to ED unnecessarily will be met, therefore increasing patients satisfaction. Thus, increased patient information on scene by the IB, should reduce on spot treatment cost and unnecessary conveyance costs, bringing together NEAS incentives with reduced conflict.

Healthcare organizations need to look deeply into their existing resources and utilize them effectively. In the example provided by NEAS, the records that NEAS holds of call-out data could usefully be expanded from its management role to provide operational support for ambulance crews, operational staff and patients. Repurposing and utilizing existing data for use by different levels in the organizations carries potential benefits in planning, resource utilization, information management and patient care.

However, the introduction of new technology solutions is not an easy process; it starts at the procurement stage and involves identifying the suitability of the technology according to use, work environment, users and organizational specific and general needs. This process should involve meeting the requirements of not only top management, but also the different direct and indirect needs of the users of IT.

The technical aspects of developing the IB were relatively straightforward when compared to the sociotechnical aspect surrounding this technical intervention. It particularly demonstrated the benefits of using a broker architecture and involved applying widely used system principles, programming languages, protocols etc. The real challenge is likely to be the introduction of the IB to a busy organization, as the ambulance service needs to communicate with different external health and non-health organization on top of managing the sociotechnical and organizational challenges imposed by protocols, standards, regulations, management, individuals, employees, etc.

Finally, the aim of this thesis is to provide a feasibility case study that investigates how an information transfer system can provide paramedics on scene with ‘on-demand’ patient health information about PWE in order to facilitate their decision-making about patient treatment. As such, it has largely focused upon investigating related sociotechnical issues that will affect this information transfer.

12.4 Recommendations for Further Work

This thesis has also identified some weaknesses in Sittig and Singh (2010) theoretical model for organizations in complex environments such as healthcare. The first weakness is the oversimplification of the internal social and cultural facets of intra-organizational communication. The second weakness is the assumption that health care organizations are largely self-contained. The model was therefore extended to highlight the multiplicity of stakeholders involved in efforts to improve the transfer of information between organizations for ambulance crews. This theoretical extension is quite basic and could be much more developed but is still useful for highlighting additional sources of challenge when trying to improve inter-organisational information flows for ambulance crews.

Further research is needed to study applying the IB to facilitate information transfer to the ambulance crew. An earlier study conducted by Budgen et al. (2007) introduced the idea of an information broker to healthcare systems that accessed databases owned by different agencies. Findings provided by this study, opens the door to other research of how simple technology based solutions can carry benefits to various stakeholders, save resources, increase the quality of life for patients, improve information transfer on an inter- and intra- organizational levels, save time, and financial resources. Other benefits and/or impediments might emerge if implemented within a health organization. Consideration of the findings identified in this study should also be incorporated, though it is recognised that facilitating patient-based information sharing in such complex environments will always be challenging.

The IB has a potential for future development of an added functionality in providing a copy of the ePRF via the IB to enrolled databases. For instance, during the IB access of PWE database, authorised staff at the Neurophysiology Department will be notified that a participating patient has used the ambulance service, consequently placing a flagged message in the JCUH PWE database. Neurophysiology staff could potentially then view a copy of the ePRF, for the information within the ePRF to always be easily available to JCUH staff. NEAS need to agree with the patient that a copy of the ePRF can be exported and saved to the Neurophysiology Department database or any other database are to be enrolled. Part of the agreement of this information sharing (IB accessing external databases) could be allowing a two way information sharing process, i.e. information exchange. This could happen if NEAS access the database for patient data via the IB and in return provides the database with a copy of the ePRF, but such an extension would need further agreement, research and be subject to conditions.

Potential extensions to the IB in the wider context is a bigger challenge that needs to be addressed gradually to meet elements of success. Figure 11.2 displays the potential IB extension that could occur. The additional complexity involved in moving to the use of multiple data sources by organizations (vertically) and/or by clinical conditions (horizontally) should be added incrementally. The breakdown of complex steps into small incremental ones is helpful in identifying challenges prior to any further vertical and/or horizontal extension. For example, the NEAS IB can access more than one database in JCUH, e.g PWE database, cardiac patients database, ED database, and so forth. This horizontal extension by NEAS can be further extended vertically, by accessing multiple databases (PWE, ED, etc.) from another organization, such as JCUH, the Royal Victoria Infirmary, etc. More databases and more organizations can be added gradually. The success the IB potential extension is not solely dependant on incremental technical development of the system; stakeholders need to collaborate and set shared aims, incentives and open feedback channels to contribute to this potential.

Additionally, the IB demonstrates the idea that effective systems do not need to be complex and sophisticated. Adding simple technology inexpensive solutions to existing functional systems can enhance performance, facilitate processes and meet aims. Not only that, but it can lighten the burden of financial expenses, save resources, increase employee satisfaction, and increase patients' quality of life.

Obviously, investigating more deeply in the findings of this study regarding organizational, system and technological, and human issues indicates how dynamic the domain is. Future researchers should account for those different aspects and call for collaboration of interdisciplinary research. That said, applying models suggested by research to new systems carries considerable amount of benefits as the model suggested by Sittig and Singh (2010). Furthermore, policymakers should extract lessons and learn from others', detailed analysis and deep thinking which offer important and unique insight. This is especially important in complex domains such as health care, particularly the NHS, with multiple and various stakeholders and large technology initiatives, which as Greenhalgh et al. (2011) note, is unusually prone to *reluctance to learn from history.*

Policymakers, software engineers, end-users, top management, health informaticians, etc. from different organizations should all meet and discuss requirements when a new system is to be introduced, especially when it transfers patients health information within and between organizations. They need to jointly identify impediments in the current system, how to overcome them, propose solutions that meet the aims, purposes, incentives and goals at all levels of the health; including national policy settings, organizational goals, management responsibilities, front-line staff working environments and processes, and patient needs and desires. Having done this, they need to identify the challenges that might appear when such a new system is implemented and formulate contingency plans that suit all stakeholders. Additionally, they need to examine currently available resources and fully utilize them as simply as possible. This should strengthen the IT development and operational processes and therefore produce robust health and organisational outcomes. It is not necessary to have a large and expensive system IT that promises a lot. Adding a simple system to an existing one can produce unexpected benefits if all elements of success are considered and applied.

The health domain is unique in the way that it involves various stakeholders, different needs, sensitive information, service provision, organizational, national and government legislation and policies. This unique diversity and complexity imposes challenges for new HIT to be implemented. It is better to develop, implement HIT incrementally, and roll it out gradually. It is easier and more manageable to identify errors and obstacles on a local scale, and overcome them with solutions suitable to this stage. Once success has been achieved in small local services, extending the technology to include other potential beneficiaries may be desirable and encouraged.

Finally, extending this feasibility study into a real live system, and including different active databases of various organizations should enhance the communication channels between and among health organizations and reinforce the approach of patient-centric care. It should also promote system collaboration and interoperability. This feasibility study of IB provides a strong indication that future development of this information transfer system carries potential benefits not just to individual UK patients, carers and NHS organizations but to similar stakeholders with similar goals facing similar challenges in other health systems.

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Appendices

Appendix A

Validity Check Sample- Patients

Validity Checks (Patients' interviews):

Section / **Question**	**Sec (1)** **Engagement/Process**	**Sec (2)** **Database/Current System**	**Sec (3)** **Information**	**Sec (4)** **Requirements/needs**
1.1 How long have you been diagnosed with epilepsy?	√			
1.2 How frequently do you get a seizure?	√			
1.3 Do you always/ occasionally need assistance to do your daily life routines? If yes, who?	Altered to: Do you always (or occasionally) need assistance to do your daily life routines or accompany you every time you go out? Add (1.4) If yes, who accompanies you? And when?			
1.4 How do you manage your epilepsy?	(1.4) altered to (1.5)			
1.5 What do you do if you have a seizure? Do you record seizures?	1.6 What do you do if you have a seizure while alone? If accompanied?			
1.6 Can you go out alone? Or do you need someone to always/ occasionally accompany you every time you go out?	Redundant/ has been deleted then emerged with Q 1.3			

Appendix B

Interview Booklet Sample- Patients

INTERVIEW NOTE-TAKING BOOKLET

(Patients at JCH Interview)

Lead Interviewer Position Title: Ms. Eman Altuwaijri, PhD researcher, the principal researcher at Durham University.

Interview Number: …………………………………………………..

Interviewee's ID #: Pti….

Interview Date: ……/……. / 201

Interview Time: from (:) am/pm till (:) am/pm

Interview Place: …………………………………………………...

Gender: M/ F

Age: …………years old

Carer of Person with Epilepsy: Yes/ NO

V.5. July 4, 2014

Opening the interview – 3-5 minutes

Part. 1: (Engagement/Process) 8-13 minutes

Process sub-questions:

1.1 How long have you (the person you are taking care of) been diagnosed with epilepsy?

…………………………………………………………………………
…………………………………………………………………………

1.2 How frequent do you (he/she) get a seizure?

…………………………………………………………………………
…………………………………………………………………………

1.3 How often do you (he/she) need assistance to do your (his/her) daily life routines?

- Always
- Occasionally
- Never

1.4 Does anyone accompany you (him/her) every time you (he/she) go out?

- Always
- Occasionally
- Never

1.5 If you (he/she) are accompanied, **who** accompanies you (him/her) and **when**?

……………………………………………………………………
……………………………………………………………………

1.6 How do you (he/she) manage your (his/her) epilepsy?

……………………………………………………………………
……………………………………………………………………

1.7 What do you (he/she) do if you (he/she) have a seizure while alone? If accompanied?

……………………………………………………………………

1.8 How long and frequent have you (he/she) been followed up at JCH?

……………………………………………………………………
……………………………………………………………………

1.9 Have you (he/she) ever been hospitalized due to a seizure?

- Yes
- No

1.10 If yes, how many times?

……………………………………………………………………
……………………………………………………………………

1.11 What are the means of your (his/her) hospitalization:

- After a doctor’s appointment
- From the A&E via self
- From the A&E via ambulance
- From GP

1.12 If more than one, which is the most common means by which you (he/she) are hospitalised?

……………………………………………………………………
……………………………………………………………………

1.13 If you recall, how many times has an ambulance been dispatched to you (him/her)?

……………………………………………………………………

Appendix C

Interview Booklet Sample-Paramedics

INTERVIEW NOTE-TAKING BOOKLET

(Paramedic's Interview)

Lead Interviewer Position Title: Ms. Eman Altuwaijri, PhD researcher, the principal researcher at Durham University.

Interview Number: ………………………………………………..

Interviewee's ID #: Par……

Interviewee's current role/ job title: ………………………………………….

Interview Date: ……/……. / 201

Interview Time: from (:) am/pm till (:) am/pm

Interview Place: …………………………………………………...

Gender: M/ F

Age: …………years old

Total years of experience: ………………………

How long have you worked with NEAS: …………………….

Opening the interview – 3-5 minutes

Part. 1: (Engagement/Process) 8-13 minutes

1.1 How are you informed by a controller about an incident?

…………………………………………………………………………………
…………………………..…………………………………………………………

1.2 Can you accept or refuse a dispatch request from the controller? Or is it mandatory to accept all calls if not engaged?

- Yes
- No
- Mandatory

1.3 When is the final contact with the controller during the incident?

…………………………………………………………………………………

1.4 When and how do you input the information of an incident and patients' treatment?

When:
…………………………………………………………………………………

How:
…………………………………………………………………………………

1.5 How long do you typically spend to entering all the information about the patient from the incident each time?

…………………………………………………………………………………

Appendix D

Paramedics' Information Sheet Sample

Supporting Ambulance Crews through Electronic Information Provision

1. *Invitation paragraph:*

I would like to invite you to take part in our research study. The study is a feasibility study of an information brokering system which has the ability to gather information from separate and independent health organisations (e.g. the North East Ambulance Service and James Cook Hospital) and pass it to paramedics who are attending a callout.

Before you decide to whether to take part we would like you to understand why the research is being done and what it would involve for you. If you would prefer, I will go through this information sheet with you and answer any questions that you might have. This would take about 3-5 minutes of your time. If you wish to take others' advice about participating please feel free to talk to others before you make a decision.

2. *The purpose of the study:*

The ultimate aim of our study is to improve services for people with epilepsy who, at some point of time, have had used the services provided by the North East Ambulance Service (NEAS).

We are seeking to achieve this by improving the information flow to paramedics called to help people with epilepsy who have had a blackout. Our study will create a database in South Tees Hospitals NHS Trust (James Cook Hospital) that will be connected to an Information Broker. The Broker will send up-to-date data about the person for whom an ambulance has been called to NEAS ambulance controllers. The controllers will collate this information and pass this information to the paramedics in the ambulance. It is expected that paramedics will then be able to stabilise more patients in the community and decrease the likelihood that the person will be admitted to hospital, enabling participants to continue with their daily routine with minimal disruption as possible.

3. *Why have you been chosen?*

We are looking for people who can help us with their experience and knowledge. As a paramedic you can give us a valuable perspective on what is already done, what could done better and how any changes might affect you.

4. *Do you have to take part?*

Your participation in the research is voluntary. We invite you to participate in the study as we believe that you can make an important contribution to the research. You are free to withdraw from the study anytime you wish without giving any reason.

Appendix E

Patients' Walktrough Sample

Supporting Ambulance Crew through Electronic Information Provision

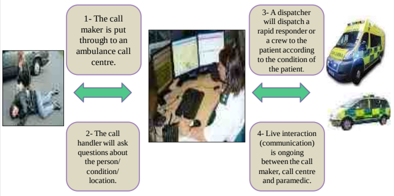
Presented by: Eman Altuwaijri – Durham University
Supervised by: Prof David Budgen/ Dr Sharyn Maxwell

V.S. Date June 3, 2015

The following is a scenario that explains the project

The Person With Epilepsy Has a Seizure

Calling For Help



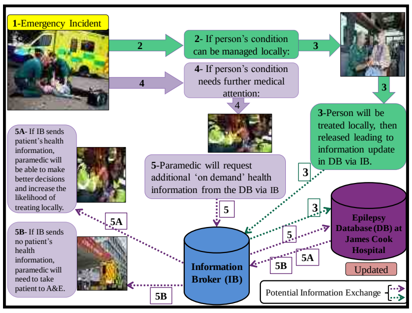
1- The call maker is put through to an ambulance call centre.

2- The call handler will ask questions about the person/ condition/ location.

3- A dispatcher will dispatch a rapid responder or a crew to the patient according to the condition of the patient.

4- Live interaction (communication) is ongoing between the call maker, call centre and paramedic.

The Project



1-Emergency Incident

2- If person's condition can be managed locally:

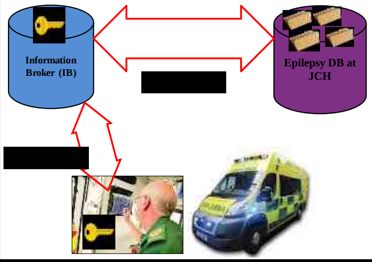
3-Person will be treated locally, then released leading to information update in DB via IB.

4- If person's condition needs further medical attention:

5-Paramedic will request additional 'on demand' health information from the DB via IB

5A- If IB sends patient's health information, paramedic will be able to make better decisions and increase the likelihood of treating locally.

5B- If IB sends no patient's health information, paramedic will need to take patient to A&E.



[redacted]

[redacted]

How Do You Benefit From All That?

- Ensuring that you are to get the most appropriate treatment since the paramedics will have additional information to assist decision-making.
- At the incident, the paramedics can decide:
  1. To manage your condition locally (take you back home/ relative /neighbour etc.)
  2. To take you to the A & E department.
  3. That no further treatment is necessary.
- So you can be more confident that you will be treated according to the best available information and may be able to avoid unnecessary inconvenience and/or medical treatment

---

This Will Make it Possible to:

1. Provide treatment locally wherever possible.
2. Enable you to carry on with your daily routine after reassurance from the paramedics.
3. Avoid attendance at the A&E unless absolutely necessary.
4. Add to the information stored in the Epilepsy Database which will help health professionals to monitor your health.
5. Alert medical staff to investigate further suitable medical action if necessary.

Appendix F

Participants' Consent Form

Participant Identification Number for this study………………………

CONSENT FORM

Full Title of Project: Supporting Ambulance Crews through Electronic Information Provision.

Name of Researcher: Eman Altuwaijri

Please initial the boxes to confirm
you agree with each statement

1. I confirm that I have read and understand the information sheet dated. June, 2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my legal rights being affected. I understand that any information collected up until the point of my withdrawal will be kept and used as part of the research. ☐

3. I understand that my details will be added to the patient's database as a third party contact. ☐

4. I understand that my contact details will be used by authorised personnel in the case of an emergency and that I will be contacted when needed. ☐

5. I agree to take part in the above study. ☐

Name of Participant…………………………………………………………

Date ……/……/ 201….　　　Signature……………………………………

Name of Person taking consent (Researcher): Eman Altuwaijri

Date...…/……/ 201….　　　Signature…………………………………….

When completed: 1 for participant; 1 for researcher study file

Appendix G

Patients' Information Sheet Sample

Durham University

Patient Information Sheet

Version 3, Jan 2015 Protocol Number: ESC2/2013/20

1- Study Title:

Supporting Ambulance Crews through Electronic Information Provision.

2- Invitation Paragraph:

I would like to invite you to take part in our research study, and granting us a few minutes of your valuable time to read this information sheet before making up your mind about whether or not you would like to help us with our research in which we are conducting a feasibility study of an Information Broker (IB) that has the ability to get 'on demand' health information from James Cook Hospital (JCH) and providing this information to the controller who will pass it on to paramedics attending an incident of a frequent faller who had a blackout, and be more able to make better decisions regarding the health of the person in need and trying as much as possible to not disrupt their daily routine and at the same time would save ambulance resources.

3- The purpose of the study:

The aim of our study is to improve services for paramedics and people who are frequent fallers and diagnosed with Epilepsy and have had used at some point of time the services provided by the North East Ambulance Services NEAS. We aim to create a database in South Tees Hospitals, NHS Trust (James Cook Hospital) which will be connected to an Information Broker (IB). The IB will be able to improve data availability to ambulance controllers who will pass this information to paramedics in the ambulance so that they can stabilise more patients in the community and potentially decrease the likelihood that people who have had a seizure requiring ambulance assistance will be admitted to hospital, enabling participants to continue with their daily routine with minimal disruption as possible.

4- Why have you been chosen?

We are inviting people who are frequent fallers and have been diagnosed with Epilepsy and have had used the ambulance services at some point to take part in our study, and we hope to have around 50 people to participate.

Appendix H

Online Questionnaire Sample

Epilepsy Database Questionnaire

About the study:

This project seeks to improve information flow to the paramedics who are heading to an incident in an ambulance. This health information will be available on demand from an Information Broker (IB) using a Database at James Cook Hospital (JCH). This Database will store your information and share it with the North East Ambulance Service (NEAS), this includes: medical history, medication, history of seizures, contact details, etc.

Currently, I'm at the early stages of developing this project. And I would really like your opinion and insight about what personal information you would like the IB to be able to access and share.

Your opinion, experiences and what information that might be shared to make a better outcome is very important. All your input is valuable. It will help us shape the functions of the system based on your needs and requirements.

What is the aim of the questionnaire?

To obtain:

- The views of the people with Epilepsy about the establishment of an Epilepsy Database at JCH.
- What information you would like to have stored in such a database.
- What kind of information from the database are you willing to share with the North East Ambulance Service (NEAS).
- What outcome(s) would you prefer from encounters with paramedics.
- What concerns you have about your information being stored in the database.
- What suggestions would you like to be considered

What will participants are asked to do?

Answer a 6-15 min questionnaire

Who can take part?

Any of the following criteria:

1. If you have Epilepsy.
2. If you provide support, help and/ or care to a person with Epilepsy.
3. if you are of age of 18+

Appendix I

Interview Protocol Sample

INTERVIEW PROTOCOL

(Patients at JCH Interview)

Lead Interviewer Position Title: Ms. Eman Altuwaijri, PhD researcher, the principal researcher at Durham University.

Interview Number: ………………………………………………..
Interviewee's ID #: Pti….
Interview Date: ……/……. / 201
Interview Time: from (:) am/pm till (:) am/pm
Interview Place: …………………………………………………...
Gender: M/ F
Age: …………years old
Carer of Person with Epilepsy: Yes/ NO

Opening the interview – 3-5 minutes

A. Before commencing the interview:

1. Introduce myself, welcoming and thanking the participant (be friendly).
2. Seat in good place, offer refreshments.
3. Check if participant is comfortable and ready to start.

B. On commencing the Interview:

1. Make an **introductory statement.**
2. **Purpose** of interview.
3. Explicate the importance of **their views** and experience.
4. Assurance of **confidentiality/ ethics and clearance.**
5. Ask permission **to record.**
6. Clarify the following:
    - "You will have less than 60 minutes for this interview."
    - "Providing detailed responses is important."
    - "I will be taking notes throughout the interview, so I may not be able to maintain eye contact with you, but I am listening."
    - "You may ask to repeat the questions, but we must respect the 60-minute interview duration."
    - "Do you have any questions before I begin?

C. During the interview:

1. 1st question should be planned
2. Ask questions about their experience, needs, requirements and suggestions.
3. Occasionally reflect back on what they say.
4. Do not rush the interviewee/ interview and allow silence.

Closing the interview – 3-5 minutes

Closing remarks - points to be covered:

1. Thank the applicant for participating in the interview.
2. End the interview with warmth and thanks
3. Ask if they have any questions regarding the interview or the process.

V.5. July 4, 2014

Appendix J

Leaflet

Durham University

Can you give us around 20 min to help our researc[redacted]

We are investigating a way to improve experiences for people with epilepsy, by enabling better-informed ambulance responses to callouts for people who have had an epileptic seizure, and who have used at some point of time the services provided by the North East Ambulance Service (NEAS) or have attended the epilepsy clinic at James Cook Hospital (JCH).

Our aims are to:

- Improve the data available to the paramedics, via an electronic Information Broker (IB), so that they can perform better informed decisions and diagnosis.
- Save ambulance and paramedics' time when it is possible to treat a person locally, rather than taking them to A&E.
- Make relevant health information available to the Epilepsy Clinic. People with epilepsy will then benefit from the health information generated during an incident as this can assist with formulating a holistic view of your health status, and therefore providing the most suitable level of healthcare.

What are we seeking?

We are looking for people who can help us with their experience and knowledge. We only want to know what you already know. That's it.

We will have a little chat (interview) around 30 minutes in a friendly relaxing atmosphere, with a complementary cup of coffee. We only need to ask you simple direct questions. There are no right or wrong answers, and if you feel you want to stop at any time, then that's fine with us.

Thanks a lot in advance, looking forward to meeting you.

Eman Altuwaijri (Chief investigatior),

Professor David Budgen & Dr Sharyn Maxwell

V.4.August 18, 2014

Appendix K

Transcription Colours Coding Sample

Transcription Colours Coding

1. For Paramedics' Interviews:

Process/ Engagement of the current system

What paramedics can do/ don't

Suggestions to improve

Paramedics' Opinions- Likes/ dislikes about a system

Information about Database

Information Regarding patients' (Health)

Requirements/ Needs

If word id written with this COLOUR (Green), it means that it can be quoted or a Key Word. Words written in (Red) are the words of the interviewer to the participant.

2. For Patients' Interviews:

Process/ Engagement of the current system.

What patient (carer) can do/ don't.

Suggestions to improve.

Patent's (carer's) Opinions- Likes/ dislikes about a system.

Information about Database

Patient's health Information (can be in the database).

General Information about the patient. (Reflects daily routine and/ or life activities of the patient)

Requirements/ Needs.

If word id written with this COLOUR (Green), it means that it can be quoted or is a Key Word. Words written in (Red) are the words of the interviewer to the participant.

3. For A&E Staff's Interviews:

The process

The ePRF

Information/ Information transfer

Information Sharing

Requirements, Needs and Opinions.

The handover

The PRF

If word id written with this COLOUR (Green), it means that it can be quoted or is a Key Word. Words written in (Red) are the words of the interviewer to the participant.

Appendix L

Paramedics' Interviews Meta-Analysis Sample

Meta-Analysis for Paramedics

Theme	Par-1	Par-2	Par-3	Par-4	Par-5	Par-6	Par-7
Process/ engagement of the current system	Time spent entering data in ePRF depends on incident(normal job 20min- trauma 1hr) ------------------ Start with verbal handover to ED then read-only ePRF after finalising ----------------- Every ED with a docking station will be able to view the ePRF in PDF format --------------- No available handover protocols/guidelines to ED (only 1- care pathways for specific conditions. 2- basic life support protocol. 3- assess patient &treat accordingly	P do not categorise the incident, they will only give feedback if the category selected by OC was appropriate or not. ----------------- When P is on scene they go through 1- basic assessment. 2- Initial treatment starts. 3- Based on those, p steps back and think (how to treat-what to decide) according to condition. --------------- P has to fill other paper work, if patient does not need to be taken to ED. 1- mental capacity form. 2- Roll form. 3- Patient leaflet. ------------------- ePRF are used to monitor P's performances and work process, to check targets. And document the incident officially.	Ps use the ATMIST guidelines while handing over to ED. ----------------- Pre-alert to ED. of patient arrival is electronic, which allows time to make a cubicle available for immediate access. ----------------- All ED in hospitals in the NE have the Terrafix system, but not all departments. ----------------- Address flagging is set for 3 months.	Average time entering data in ePRF is 20 min approx. ----------------- ED staff rely or verbal handover. It is easier for A&E staff to use the PRF. It is immediate to use, see and take. Unlike the ePRF where you have to access it electronically. -------------------- Verbal handover takes approx. 5 min to do. ED staff sometimes will record this verbal handover if the EPRF is used. ----------------- ED staff find it hard to access the finalised	Ps spend 20 min in average filling in an ePRF.	There is no formal protocol to handing over patients to A&E staff, there are only trauma guidelines. Ps use standard ways of passing information, but depending on the nurse and hospital this might not apply.	Ps can enter the Obs of the patient on the ePRF after dealing with the patient immediately, but the actual ePRf will not be finalized by then, it has to wait for a signature of the ED staff, which is at the end of the incident. This is not like the PRF where information is inputted immediately after dealing with the patient, since the paper form does not need any finalising.

Appendix M

Study Ethical Approvals

NHS
Health Research Authority

NRES Committee East Midlands - Northampton
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839521

21 April 2015

Ms Eman Altuwaijri
PhD student
Durham University
School of Engineering & Computing Sciences
Durham University
South Road
DH1 3LE

Dear Ms Altuwaijri

Study Title:	**Supporting Ambulance Crews through Electronic Information Provision-Phase 1**
REC reference:	**14/EM/0095**
Protocol number:	**ESC2/2013/20**
IRAS project ID:	**135720**

Thank you for sending the progress report for the above study dated 16 April 2015. The report will be reviewed by the Chair of the Research Ethics Committee, and I will let you know if any further information is requested.

The favourable ethical opinion for the study continues to apply for the duration of the research as agreed by the REC.

14/EM/0095: **Please quote this number on all correspondence**

Yours sincerely

Vic Strutt
REC Assistant

E-mail: NRESCommittee.EastMidlands-Northampton@nhs.net

Copy to: *Professor David Budgen,*
Miss Sonia Byers, North East Ambulance Services

Durham University
School of Medicine, Pharmacy and Health

Shaped by the past, creating the future

Rebecca Maier
Research, Development and Trials Manager
Chair, School of Medicine, Pharmacy and Health Ethics Sub-Committee

Eman Altuwaijri
PhD Student
School of Medicine, Pharmacy and Health
Durham University

20th November 2013, re-issued 10th December 2013

Dear Eman,

Re: Ethics Application ESC2/2013/20
Supporting Ambulance Crews through Electronic Information Provision
Phase 1, Feasibility study

Thank you for sending the above application to the School of Medicine, Pharmacy and Health Ethics Sub-Committee for ethical review. The committee requested some changes to the application, and these have now been reviewed by me. I am satisfied that all of the comments made by the committee have been addressed and I am therefore pleased to confirm Durham University ethical approval for the study.

This approval is given on the following basis:

- Please ensure that data generated for this study is maintained and destroyed as outlined in this proposal and in keeping with the Data Protection Act.
- If you make any amendments to your study, these must be approved by the School committee prior to implementation.
- At the end of the study, please submit a short end of study report (ESC3 form) to the School ethics committee.

Please do not hesitate to contact me should you have any questions. Good luck, I hope that the study goes well.

With best wishes,

RHMaier

Rebecca Maier

South Tees Hospitals NHS
NHS Foundation Trust

Research & Development / Academic Division
Academic Centre
The James Cook University Hospital
Marton Road
Middlesbrough
TS4 3BW

www.southtees.nhs.uk

Tel: 01642 282585
Email: julie.rowbotham@stees.nhs.uk

20th September 2013

Eman Al-tuwaijri
PhD Student
Durham University
Department of Engineering and Computer Sciences
Stockton-on-Tees

Dear Eman

Letter of access for research

Supporting Ambulance Crews through electronic information provision

This letter confirms your right of access to conduct research through South Tees Hospitals NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **20th September 2013** and ends on **19th September 2016** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at South Tees Hospitals NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to South Tees Hospitals NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through South Tees Hospitals NHS Foundation Trust, you will remain accountable to your employer **University of Durham** but you are required to follow the reasonable instructions of **Dr Simon Taggart** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with South Tees Hospitals NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with South Tees Hospitals NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on South Tees Hospitals NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

South Tees Hospitals NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Julie Rowbotham
R&D Manager, South Tees Hospitals NHS Foundation Trust

Cc: **Kirsten Shale**
HR Assistant
Durham University
Rowan House
Mountjoy Centre
Stockton
DH1 3LE

Durham
University
Procurement Service

Shaped by the past, creating the future

Ms Eman Altuwaijri
School of Medicine, Pharmacy and Health
Durham University

7 February 2014

To Whom It May Concern:

Dear Sirs

Public Liability Insurance Cover – Ms Eman Altuwaijri

I am pleased to confirm that Ms Eman Altuwaijri, as a registered postgraduate student in the School of Medicine, Pharmacy and Health at Durham University, will be covered by the University's Public Liability policy during her period of research on her project "Supporting Ambulance Crews through Electronic Information Provision", as approved by the University's Research, Development and Trials Manager in writing on 20 November 2013.

I am pleased to confirm that the University's Limit of Liability in respect of Public Liability is £25,000,000 any one event and unlimited in the aggregate.

Yours faithfully,

Barbara Dick

Barbara Dick ACII
Insurance Assistant
Telephone 0191 334 9267
Fax 0191 334 4539
Email b.k.dick@durham.ac.uk
www.durham.ac.uk

Finance and Estates Division Mountjoy Research Centre Block 4
Stockton Road Durham DH1 3UZ

Telephone +44 (0) 191 334 4531 Fax +44 (0) 191 334 4539
Email procurement.office@durham.ac.uk www.durham.ac.uk

Durham University is the trading name of University of Durham

Appendix N

The Conceptual Database Design CDD Stages

Epileptic Patient Database Design

1. The CCD Phase:

In order to achieve this phase sequential steps must be undergone.

1.1 Identifying the entities:

The following entities have been defined and are displayed in the data dictionary

Entity name	Description	Aliases	Occurrence
EpilepticPatient	General term describing all people diagnosed as having epilepsy and attending JCH.	Epileptic.	Each epileptic patient is registered with the JCH and seen by the health providers.
MedicalHistory	General term describing detailed information regarding any non-epileptic medication.	Medication.	Each medical history displays details of medication that have been dispensed to the person and are not epileptic medicine.
Physician	Describes all consultants/ physicians seeing a person with epilepsy and working in JCH.	Consultant.	Each member of the set of physicians who work at JCH as a consultant.

Table 1: data dictionary

1.2 Identify relationship types:

After identifying the entities, the following step would be to identify all the relationships that exist between these entities. The available entities and the relation among them are as follow:

- EpilepticPatient *has* MedicalHistory
- EpilepticPatient *has* HealthStatus
- EpilepticPatient *experiences* SeizureIncidnet
- EpilepticPatient *takes* Medication
- Medication *undergoes* AlternativeTreatment
- EpilepticPatient *has* EmergencyIncident

An easier way to display those relationships is by using the Entity-Relationship Diagram (ERD) the ERD helps build up a visualization of the model for both the NEAS and JCH:

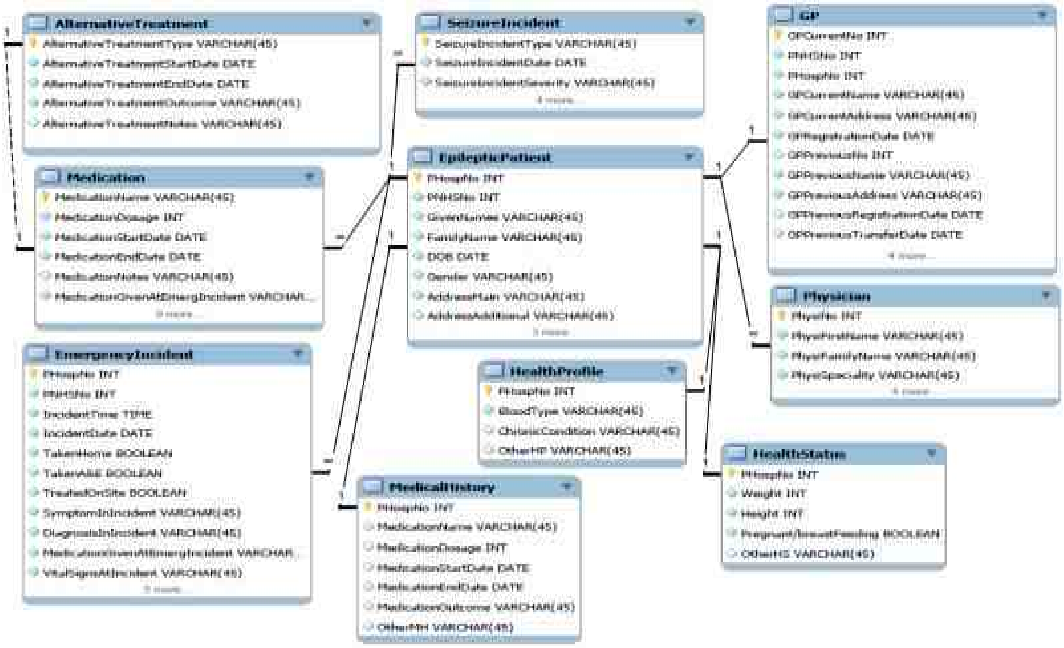


Figure 1: ERD displaying entities and relationships

After identifying all the relationships to model, we then determine the multiplicity of each relationship. Multiplicity is used to check and maintain data quality. In other words, when data is updated in the database, multiplicity constraints make sure that the applied updates do not violate the rules of NEAS and KCH, allowing updated entity occurrence to be applied. The following ERD displays the multiplicity constrains of relationship types:

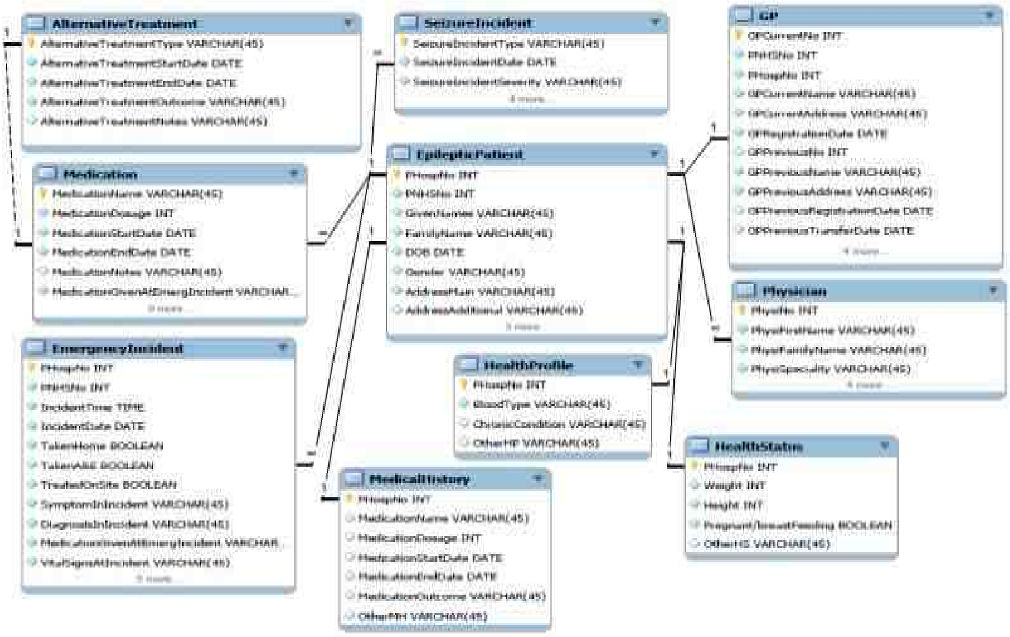


Figure 2: ERD showing multiplicity constraints of relationships

In addition, recording the relationships descriptions and the multiplicity constrains in the data dictionary can be conducted as well. The following table illustrates it:

Entity name	Multiplicity	Relationship	Multiplicity	Entity name
EpilepticPatient	1..1	Has	1..1	MedicalHistory
EpilepticPatient	1..1	Has	1..1	HealthProfile
EpilepticPatient	1..1	Visits	1..*	Physician
EpilepticPatient	1..1	Experience	1..*	SeizureIncident
EpilepticPatient	1..1	Takes	1..*	Medication

Table 2: data dictionary showing description of relationships

1.3 identifying and associating attributes with entity or relationship types:

In this step we should identify the attributes about the entity and relationships that we have chosen to represent in the database. It is important to identify if the attribute is simple or composite. Composite attributes are made of simple attributes. We also identify single attributes, multi-valued attributes and derived attributes in the conceptual database model. These attributes can be encountered while modelling the DB which most of will be single valued. Occasionally an attribute that holds multiple values for a single entity occurrence might be encountered. The derived attribute whose values are based on the values of other attributes. Often, these attributes are not represented in the conceptual data modelling. The representation of the derived attributes will be considered during physical DB design. We display the associate attributes with entities as follows:

A- Attributes with entities:

EpilepticPatient	PHospNo, PNHSNo, GivenNames, FamilyName,DOB,Gender,AddressMain (Composit: houseNo,St,PostCode,City), AddressAdditional (Composit: houseNo1,St1,PostCode1,City1)
Physician	PhysiNo, PhysiFirstName, PhysiFamilyName, PhysiSpeciality
GP	PHospNo, PNHSNo,GPCurrentNo, GPCurrentName, GPCurrentAddress (Composite: GPcSt, GPcPostC, GPcCity) GPRegistrationDated, GPPreviousNo, GPPreviousName, GPPreviousAddress (Composite: GPpSt, GPpPostC, GPpCity), GPPreviousRegistrationDate, GPPreviousTransferDate

B- Attributes for relationships:

Visits	GPVisitDate, GPVisitOutcome
Visits	PhyVisitDate,PhyVisitOutcome

The description of the attributes is displayed in the following table:

Entity name	Attribute	Description	Data type	Nulls	Multi-valued	Single-valued	Composite Attri	Simple Attri	Derive Attri
EpilepticPatient	PHospNo	Uniquely identifies a member of the epileptic patients in JCH	Int	No	No	Yes	No	Yes	No
	PNHSNo	The person’s NHS number	Int	No	No	Yes	No	Yes	No
	GivenNames FamilyName	First name(s) of person	Varch	No	No	Yes	No	Yes	No
	DOB	Date of birth of person	Date	No	No	Yes	No	Yes	No
	AddressMain houseNo	Current house number of the person	Varchar	No	No	Yes	Yes	No	No

Table 3: data dictionary (description of attributes)

1.4 determining the attribute domain:

The objective of this step is to determine the domains for all the attributes in the model.

The importance of a domain as a powerful tool appears by giving the user to define in a central place (domain) the meaning and source of values that attributes can hold. Every attribute in a relation is defined in a domain. Information can be specified for the domain, from which other attributes draw their values, that allowable operations that can be applied on those attribute and attributes that can be compared with other attributes or used in combination with others. A domain may be specific to an attribute; moreover two or more attributes may as well be defined on the same domain. The following table highlights the attribute domains:

Attribute	Domain name	Meaning	Domain definition
PHospNo	PatientHospitolNumbers	The set of all possible patient hospital numbers	Characters: size 7, range A000001- Z999999
PNHSNo	PatientNHSNumbers	The set of all possible patient NHS numbers	Character: size 10
GivenNames	GivenNames	The set of all possible given names	Character: size 20

Table 4: domains for the attributes

1.5 determining candidate, primary and alternate key attributes:

This step is to define the candidate key(s) (CK) for each entity type. If there is more than one candidate key, we must choose one as the primary key (PK) and the others as alternate keys (AK).

Appendix O

Logical Tables of the Database Model Sample

ERD-V.16. Date 15 June, 2016

a_and_e

A&E_ID varchar(12) pk nn

PHos_ID int(10) n

EPRF_ID int(10) n

NHS_ID int(10)n

A&E_visit_method varchar(60) nn

A&E_visit_time time nn

A&E_visit_date date nn

A&E_visit_reason text nn

A&E_treatment text nn

A&E_diagnosis text nn

A&E_discharge_to varchar(100) nn

A&E_medication text nn

A&E_notes text n

seizure_type

seizure_type_No int (11) pk nn

PHos_ID int(10) nn

seizure_type_ID varchar(7) nn

seizure_type varchar(100) nn

seizure_type _status varchar (75) nn

seizure_type _approx_count varchar (100) nn

seizure_type_approx_date date nn

seizure_type_approx_time text nn

seizure_type_approx_frequency text nn

seizure_type_approx_duration text nn

seizure_type_sevirity varchar(200) nn

seizure_type _outcome text nn

seizure_ type _informed_by varchar(50) n

current_epilepsy_medication_ID varchar(100) nn

historic_epilepsy_medication_ID varchar(150) n

seizure_type _notes text nn

generated_pdf_pattern_chart varchar(4) n
Attachments

epilepsy_syndrome

epilepsy_syndrom_No int(11) pk nn

PHos_ID int(10) nn

epilepsy_syndrom_ID varchar(10) nn

seizure_type_ID_ varchar(10) nn

epilepsy_syndrome_name text nn

epilepsy_cause text nn

patient_screenings varchar (100) nn

patient_screening_reports text nn

seizure_type_approx_time text nn

seizure_type_approx_duration text nn

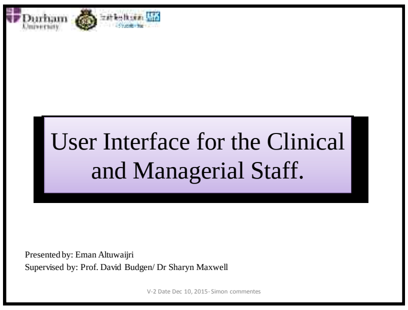
seizure_type_approx_frequency text nn

current_epilepsy_medication_ID varchar(100) nn
historic_epilepsy_medication_ID varchar (150)nn

epilepsy_syndrom_physi_notes text nn

Appendix P

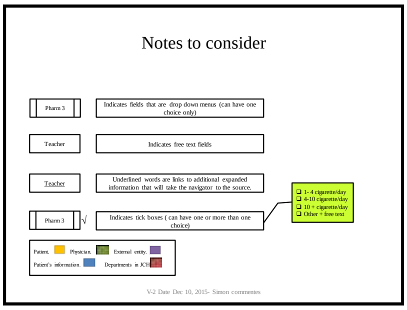
The Conceptual Model of the End-user Interface PWE Database Sample



User Interface for the Clinical and Managerial Staff.

Presented by: Eman Altuwaijri
Supervised by: Prof. David Budgen/ Dr Sharyn Maxwell

V-2 Date Dec 10, 2015-Simon commentes



Notes to consider

Pharm 3	Indicates fields that are drop down menus (can have one choice only)
Teacher	Indicates free text fields
Teacher	Underlined words are links to additional expanded information that will take the navigator to the source.
Pharm 3 √	Indicates tick boxes (can have one or more than one choice)

❑ 1- 4 cigarette/day
❑ 4-10 cigarette/day
❑ 10 + cigarette/day
❑ Other + free text

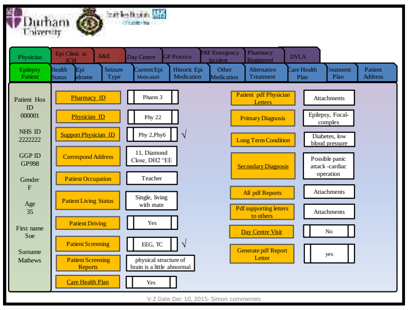
Patient. 🟨 Physician. 🟩 External entity. 🟪
Patient's information. 🟦 Departments in JCH 🟥

V-2 Date Dec 10, 2015- Simon commentes

Username
Password

Login

V-2 Date Dec 10, 2015-Simon commentes



Physician | Epi Clinic at JCH | A&E | Day Centre | GP Practice | PRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi drome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

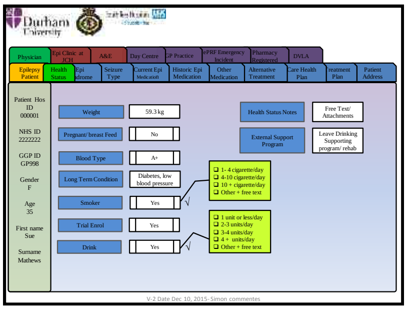
Age
35

First name
Sue

Surname
Mathews

Pharmacy ID	Pharm 3
Physician ID	Phy 22
Support Physician ID	Phy 2,Phy6 √
Correspond Address	11, Diamond Close, DH2 "EE
Patient Occupation	Teacher
Patient Living Status	Single, living with mate
Patient Driving	Yes
Patient Screening	EEG, TC √
Patient Screening Reports	physical structure of brain is a little abnormal
Care Health Plan	Yes
Patient pdf Physician Letters	Attachments
Primary Diagnosis	Epilepsy, Focal-complex
Long Term Condition	Diabetes, low blood pressure
Secondary Diagnosis	Possible panic attack -cardiac operation
All pdf Reports	Attachments
Pdf supporting letters to others	Attachments
Day Centre Visit	No
Generate pdf Report Letter	yes

V-2 Date Dec 10, 2015-Simon commentes



Physician | Epi Clinic at JCH | A&E | Day Centre | GP Practice | ePRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi drome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

Age
35

First name
Sue

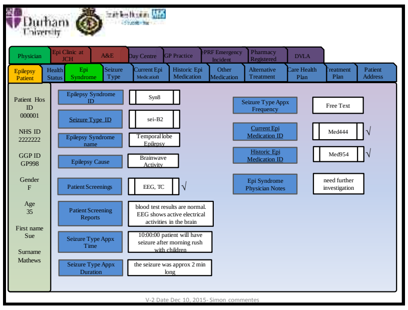
Surname
Mathews

Weight	59.3 kg
Pregnant/ breast Feed	No
Blood Type	A+
Long Term Condition	Diabetes, low blood pressure
Smoker	Yes √
Trial Enrol	Yes
Drink	Yes √
Health Status Notes	Free Text/ Attachments
External Support Program	Leave Drinking Supporting program/ rehab

❑ 1- 4 cigarette/day
❑ 4-10 cigarette/day
❑ 10 + cigarette/day
❑ Other + free text

❑ 1 unit or less/day
❑ 2-3 units/day
❑ 3-4 units/day
❑ 4 + units/day
❑ Other + free text

V-2 Date Dec 10, 2015-Simon commentes



Physician | Epi Clinic at JCH | A&E | Day Centre | GP Practice | ePRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi Syndrome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

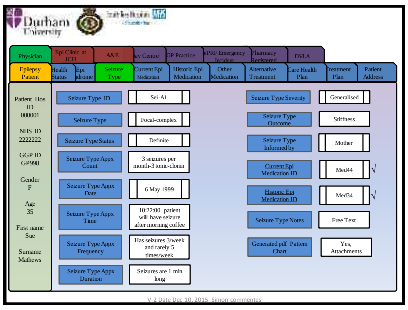
Age
35

First name
Sue

Surname
Mathews

Epilepsy Syndrome ID	Syn8
Seizure Type ID	sei-B2
Epilepsy Syndrome name	Temporal lobe Epilepsy
Epilepsy Cause	Brainwave Activity
Patient Screenings	EEG, TC √
Patient Screening Reports	blood test results are normal. EEG shows active electrical activities in the brain
Seizure Type Appx Time	10:00:00 patient will have seizure after morning rush with children
Seizure Type Appx Duration	the seizure was approx 2 min long
Seizure Type Appx Frequency	Free Text
Current Epi Medication ID	Med444 √
Historic Epi Medication ID	Med954 √
Epi Syndrome Physician Notes	need further investigation

V-2 Date Dec 10, 2015- Simon commentes



Physician | Epi Clinic at JCH | A&E | ay Centre | GP Practice | ePRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi drome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

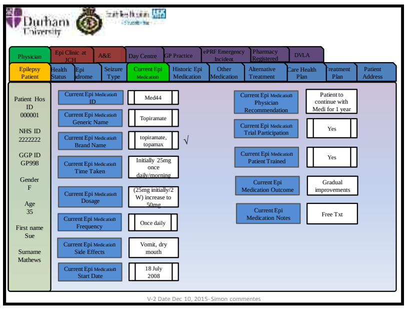
Age
35

First name
Sue

Surname
Mathews

Seizure Type ID	Sei-A1
Seizure Type	Focal-complex
Seizure Type Status	Definite
Seizure Type Appx Count	3 seizures per month-3 tonic-clonin
Seizure Type Appx Date	6 May 1999
Seizure Type Appx Time	10:22:00 patient will have seizure after morning coffee
Seizure Type Appx Frequency	Has seizures 3/week and rarely 5 times/week
Seizure Type Appx Duration	Seizures are 1 min long
Seizure Type Severity	Generalised
Seizure Type Outcome	Stiffness
Seizure Type Informed by	Mother
Current Epi Medication ID	Med44 √
Historic Epi Medication ID	Med34 √
Seizure Type Notes	Free Text
Generated pdf Pattern Chart	Yes, Attachments

V-2 Date Dec 10, 2015-Simon commentes



Physician | Epi Clinic at JCH | A&E | Day Centre | GP Practice | ePRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi drome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

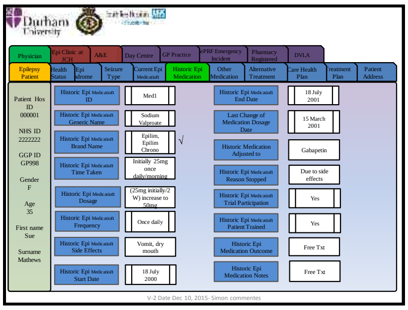
Age
35

First name
Sue

Surname
Mathews

Current Epi Medication ID	Med44
Current Epi Medication Generic Name	Topiramate
Current Epi Medication Brand Name	topiramate, topamax √
Current Epi Medication Time Taken	Initially 25mg once daily/morning
Current Epi Medication Dosage	(25mg initially/2 W) increase to 50mg
Current Epi Medication Frequency	Once daily
Current Epi Medication Side Effects	Vomit, dry mouth
Current Epi Medication Start Date	18 July 2008
Current Epi Medication Physician Recommendation	Patient to continue with Medi for 1 year
Current Epi Medication Trial Participation	Yes
Current Epi Medication Patient Trained	Yes
Current Epi Medication Outcome	Gradual improvements
Current Epi Medication Notes	Free Txt

V-2 Date Dec 10, 2015-Simon commentes



Physician | Epi Clinic at JCH | A&E | Day Centre | GP Practice | ePRF Emergency Incident | Pharmacy Registered | DVLA

Epilepsy Patient | Health Status | Epi drome | Seizure Type | Current Epi Medication | Historic Epi Medication | Other Medication | Alternative Treatment | Care Health Plan | reatment Plan | Patient Address

Patient Hos ID
000001

NHS ID
2222222

GGP ID
GP998

Gender
F

Age
35

First name
Sue

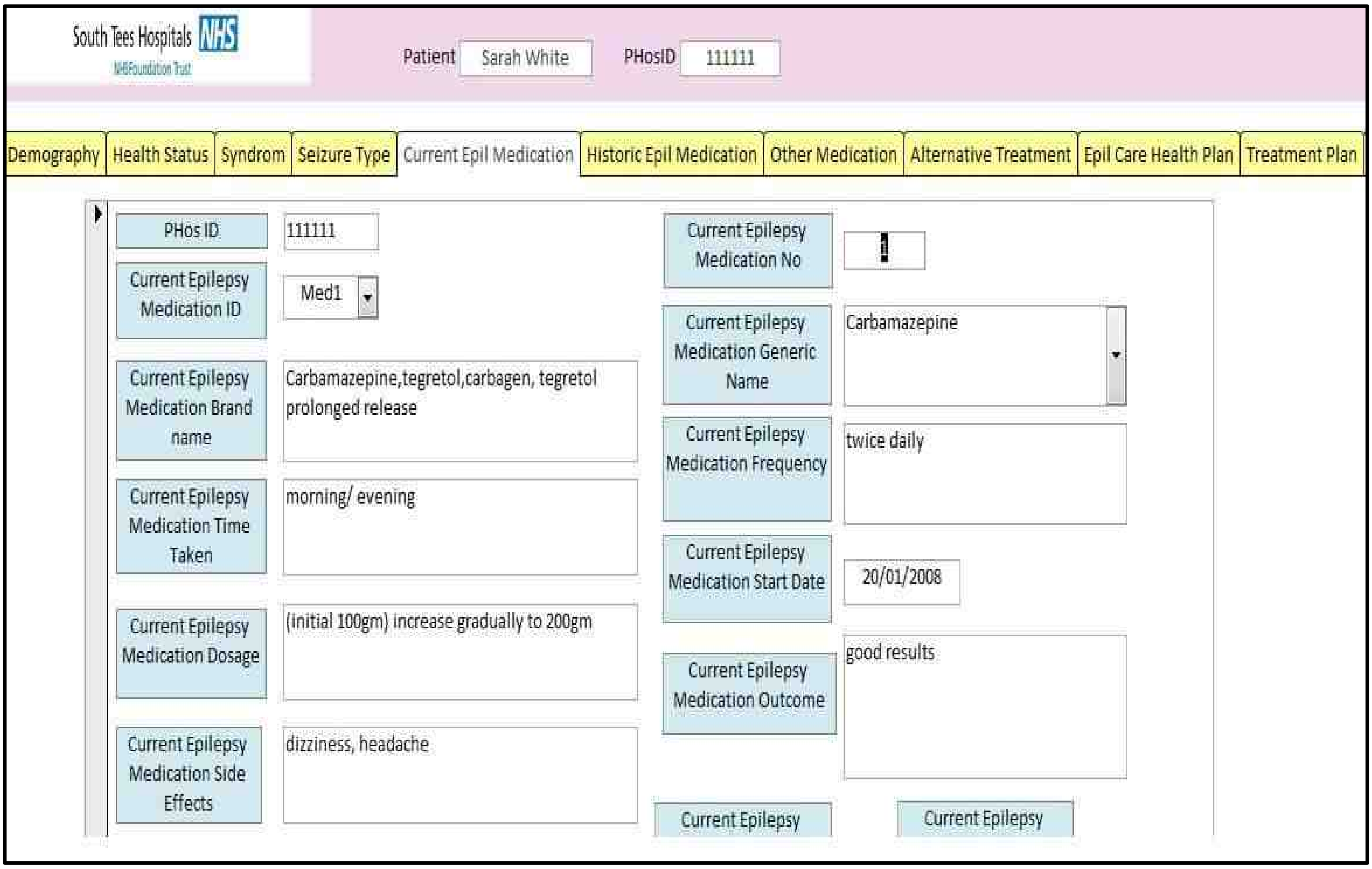
Surname
Mathews

Historic Epi Medication ID	Med1
Historic Epi Medication Generic Name	Sodium Valproate
Historic Epi Medication Brand Name	Epilim, Epilim Chrono √
Historic Epi Medication Time Taken	Initially 25mg once daily/morning
Historic Epi Medication Dosage	(25mg initially/2 W) increase to 50mg
Historic Epi Medication Frequency	Once daily
Historic Epi Medication Side Effects	Vomit, dry mouth
Historic Epi Medication Start Date	18 July 2000
Historic Epi Medication End Date	18 July 2001
Last Change of Medication Dosage Date	15 March 2001
Historic Medication Adjusted to	Gabapetin
Historic Epi Medication Reason Stopped	Due to side effects
Historic Epi Medication Trial Participation	Yes
Historic Epi Medication Patient Trained	Yes
Historic Epi Medication Outcome	Free Txt
Historic Epi Medication Notes	Free Txt

V-2 Date Dec 10, 2015- Simon commentes

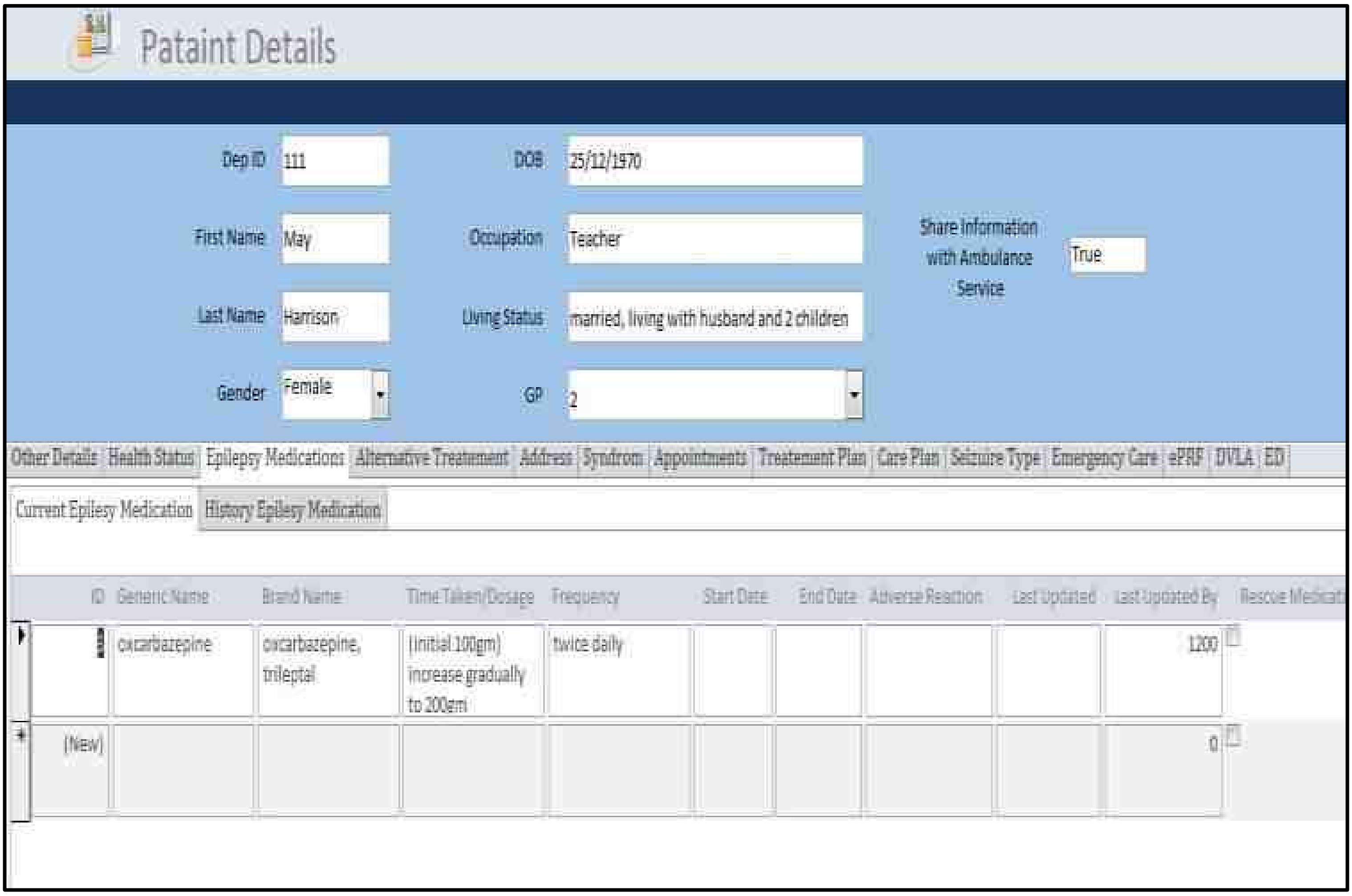
Appendix Q

The First Version Interface Vs. the Final Version Interface



Patient	Sarah White
PHosID	111111

PHos ID	111111
Current Epilepsy Medication ID	Med1
Current Epilepsy Medication Brand name	Carbamazepine,tegretol,carbagen, tegretol prolonged release
Current Epilepsy Medication Time Taken	morning/ evening
Current Epilepsy Medication Dosage	(initial 100gm) increase gradually to 200gm
Current Epilepsy Medication Side Effects	dizziness, headache
Current Epilepsy Medication No	1
Current Epilepsy Medication Generic Name	Carbamazepine
Current Epilepsy Medication Frequency	twice daily
Current Epilepsy Medication Start Date	20/01/2008
Current Epilepsy Medication Outcome	good results
Current Epilepsy	
Current Epilepsy	



Dep ID	111
First Name	May
Last Name	Harrison
Gender	Female
DOB	25/12/1970
Occupation	Teacher
Living Status	married, living with husband and 2 children
GP	2
Share Information with Ambulance Service	True

ID	Generic Name	Brand Name	Time Taken/Dosage	Frequency	Start Date	End Date	Adverse Reaction	Last Updated	Last Updated By	Rescue Medicat
1	oxcarbazepine	oxcarbazepine, trileptal	(initial 100gm) increase gradually to 200gm	twice daily					1200	☐
(New)									0	☐

The Interactive Version Interface (top) Vs. The Final Version Interface (bottom)

Appendix R

Analysis of Handover Observation at ED Sample

V-1-dated 5, Feb 2016

Analysing paramedics and ED staff handover observation and ePRF- PRF

P= paramedic/ N= nurse/ VH= verbal handover/ DS= docking station

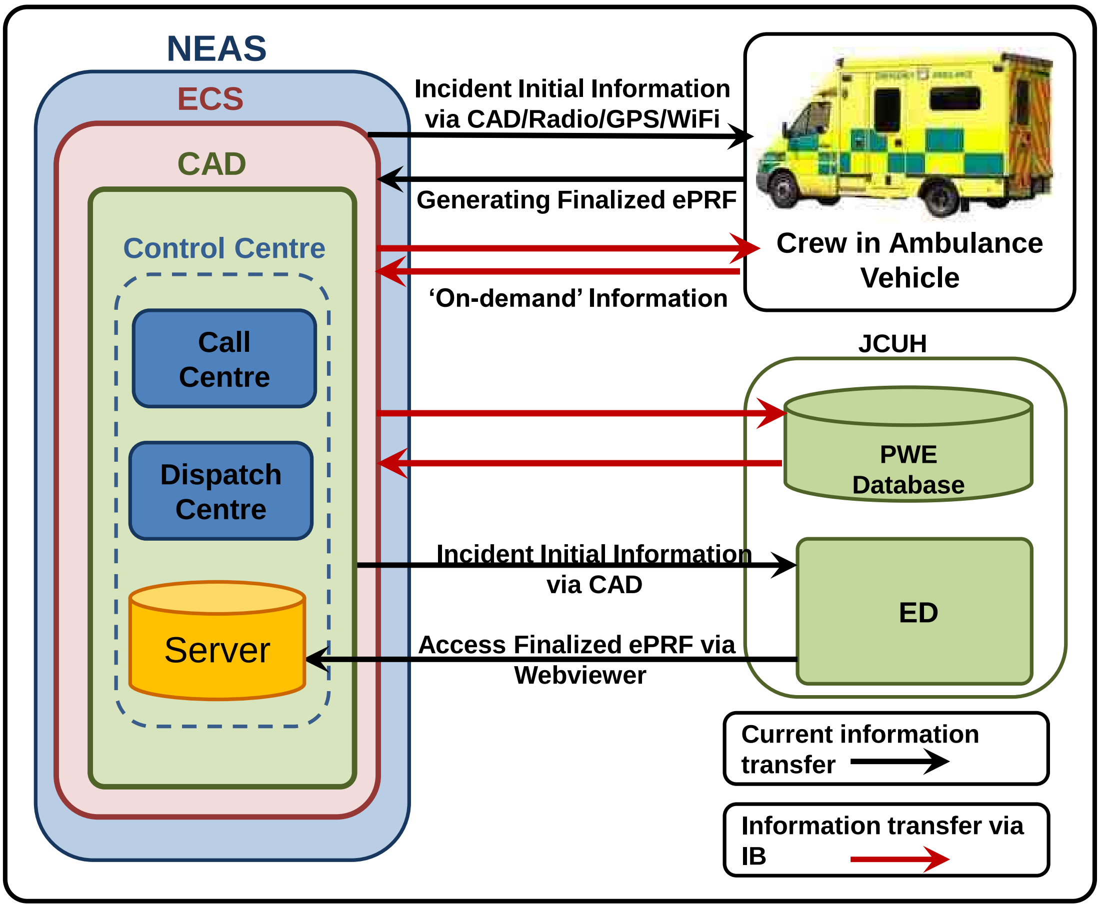
Handover #	P Arrival Time to ED	P time left ED	P time spent in ED	P finalising after HV	Time spent to finalise- out ED	Used DS	ePRF/ PRF	External papers to write on	P preference	problems
H1	10:27am	10:36am	9 min	No/ finalised outside ED	N/A	No	ePRF	No	N/A	
H2	10:39am	10:46am	7 min	No/PRF	0	No	PRF	No	N/A	
H3	11:29am	11:38am	9 min	No/ finalised outside ED	More than 10m	Yes	ePRF	Glove	Paper	• Lost connectivity
H4	11:41am	11:48am	7 min	Trying to connect to finalise	Approx. 10 min	Yes	ePRF	Random paper	Electronic	Problem downloading initial information

Reflections:

- The N’s signing to the ePRF is not the final stage, the P can let the N sign even before completing the ePRF
- The job’s category is not a mandatory field to finalise the ePRF
- P should book the patient before entering the ED
- Some N have good personal relations with P
- Detailed VH happens in the cubicle usually.
- P may have entered all the patient’s data, have the N signed, but the initial information of the job from (HQ) was not downloaded to the system due to lost connectively, causing obstacles to finalise the ePRF, and making Ps look for other ways to connect which waste more of their time.
- ePRF is comprehensive, detailed, clear but the PRF is fast and can visualise all fields easily and you see everything in front of you.
- ePRF is good, but might distract the P from giving care to the patient. When entering the data, the P is disconnected from the patient because entering data needs more attention, and different views and boxes might appear that needs the P’s focus, unlike the PRF, which is simple and boxes information needed is defined and specific.
- The Ps will go to the DS to find connectivity, to download initial information.
- Constant updates is needed/ or not?
- After a certain number of years, the Toughbooks will go out of date and need replacing, therefore, adding more financial burdens to the NHS
- Some ED staff have good social relations with Ps, especially if working for a long time
- The system is good, only if there were no connectivity problems.

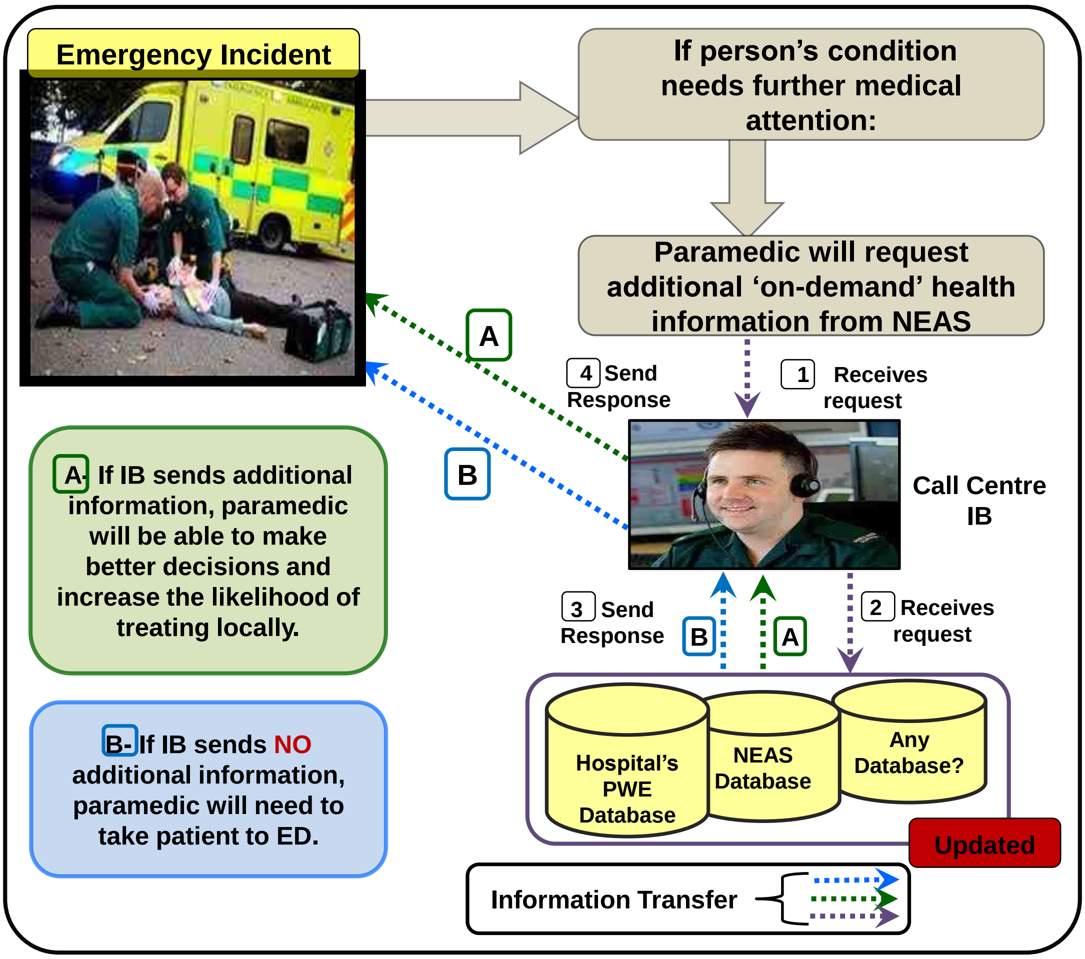
Appendix S

IB Overview Model



Appendix T

IB ‘On-demand’ Health Information Provision



Appendix U

Database(s) Updated via the IB